INCREASING THE RATE OF LIVING DONOR KIDNEY TRANSPLANTATION IN NEW ZEALAND: DEVELOPING AN EVIDENCE BASE

BY

PAULA MARIE MARTIN

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Abstract

Increasing numbers of New Zealanders are experiencing end-stage renal failure, requiring kidney transplantation or dialysis. A transplant from a living kidney donor is the preferred treatment, offering better quality of life than dialysis, and greater life expectancy and cost-effectiveness than dialysis and deceased donor transplantation. Living donor transplant rates in New Zealand have plateaued and may even be declining at a time when many comparable countries are experiencing sustained increases. Viewing this issue as a complex policy problem, this research aimed to identify how rates of living donor kidney transplantation could be increased in New Zealand. Based on Walt and Gilson’s health policy triangle, which suggests that understanding policy issues requires attention not only to content (policy options) but also processes, contextual issues and actors, this research asked firstly, what the barriers are for patients in the journey to living donor transplantation, and secondly, why greater attention has not been paid to how to increase current rates, given evidence of better outcomes for patients and cost-effectiveness.

The research took a patient-centred, systems perspective and used a pragmatic, interdisciplinary, mixed-methods research design. Methods included a survey of kidney transplant waiting-list patients; interviews with patients, renal health professionals and key informants; document analysis; and a survey of health managers. A Five-Stage Model of the living donor kidney transplant process was developed to map specific barriers in the journey to transplantation and Kingdon’s multiple streams agenda-setting model was used to examine the issue of why so little attention had been paid to living donor kidney transplantation in New Zealand.

The research found that, in common with patients elsewhere, New Zealand patients are not systematically informed about living donor transplantation, would like to receive a transplant but have concerns about health and financial impacts on donors, and face challenges in approaching people in their networks about living donation. Incompatibility and medical unsuitability are major barriers for potential donors who do come forward. Issues with existing service models, configuration of key roles in transplant services, and delays in donor work-up processes are all evident. Perceived ethical constraints may limit how willing health professionals are to promote living donation, requiring both potential
recipients and donors to be very proactive to successfully navigate the living donation process.

There has been political will to address organ shortages in the past but there has been little focus specifically on live donation. An absence of feasible and acceptable options for decision-makers to consider, crowding-out by demand for dialysis services, lack of leadership, absence of an effective advocate, and issues in funding and accountability arrangements may all have contributed to why live kidney transplantation has not had more prominence on the policy agenda in New Zealand in recent years.

Overall, the research concludes that policy and practice in the wider system are not adequately oriented to supporting living donor kidney transplantation as the preferred treatment for end-stage renal failure. A comprehensive national strategy for increasing New Zealand’s rate is recommended.
Preface and acknowledgements

The motivation for this research came from two main sources. Firstly, my professional experience as a policy manager in the Ministry of Health with oversight of the Vote: Health Budget process from 2008-2010, which increasingly came to mean focusing on how to improve value for money, as we sought to “live within our means” in the face of a reducing rate of growth of health expenditure. Secondly, my personal experience as a living kidney donor for my husband in 2006, and subsequent involvement in the renal community, for example, as a Board member of Kidney Health New Zealand for two years.

It is fair to say that it was only after the transplant that I truly appreciated the tremendous benefits of transplantation for someone with end-stage renal failure in comparison to dialysis. When I realised how few renal transplants are done each year in NZ I began to wonder why this was. I could find little previous research and the explanations I heard, for example, that certain groups have cultural objections to organ donation, did not seem entirely satisfactory (particularly given I am of Māori descent). As a health policy manager, I was aware of how frequently concerns about rising dialysis expenditure were raised in the context of needing to find savings. As I learned more about the costs of transplantation compared to dialysis, I started to wonder why more was not being done to increase transplant rates, given the potential benefits for patients and for the health system. The combination of these factors led to this research.

Two articles based on this research have been published to date (1-2) and the material is included in this thesis.

Many people supported me to make this research possible. My deepest thanks go to all the patients who filled in the survey and were willing to share their experiences during interviews. I am also grateful to the many health professionals and key informants who made time for interviews and were willing to talk so openly.

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List of Abbreviations Used

ABOi-transplant ABO incompatible transplant
ANZDATA Australia and New Zealand Dialysis and Transplant Registry
BMI Body Mass Index
CE Chief Executive
CKD Chronic kidney disease
CMO Chief Medical Officer
DDKT Deceased donor kidney transplantation
DHB District Health Board
DHBNZ District Health Board New Zealand
ESRF End-stage renal failure
GFR Glomerular filtration rate
GM General Manager
GP General Practitioner
HD Hemodialysis
HEHA Healthy Eating Healthy Action
HLA Human Leukocyte Antigen
HTA Human Tissue Act
IDF Inter-District Flow
IHI Institute for Healthcare Improvement
KAS Kidney Allocation Scheme
KHNZ Kidney Health New Zealand
KPE Kidney paired exchange
LDKT Living donor kidney transplantation
MOH Ministry of Health
MP Member of Parliament
MRG Ministerial Review Group
MSD Ministry of Social Development
NHB National Health Board
NHC National Health Committee
NHS National Health Service
NHSBT National Health Service Blood and Transplant
NRAB National Renal Advisory Board
NSTR National Service and Technology Review Advisory Committee
NTA National Travel Assistance
NZ New Zealand
NZPHDA New Zealand Public Health and Disability Act
ODNZ Organ Donation New Zealand
OIA Official Information Act
PD Peritoneal dialysis
PMP Per million population
RRT Renal replacement therapy
SPNIA Service Planning and New Interventions Assessment
TSANZ The Transplantation Society of Australia and New Zealand
UK United Kingdom
USA United States of America
VFM Value for money
WHO World Health Organisation
Chapter One: Introduction

1.1 The issue

This research addresses the question of how to increase the rate of living donor kidney transplantation (LDKT) in New Zealand. Transplantation, from a living or deceased donor, is one of the treatments available for someone with end-stage renal failure (ESRF); the other is dialysis\(^1\). Without one of these treatments, death is inevitable, usually within days or weeks (4-5).

Internationally, demand for renal replacement therapy (RRT) is increasing (6) driven by increases in chronic conditions (especially Type 2 diabetes), aging populations, and increased survival rates of people with chronic kidney disease (CKD) and ESRF. International expenditure on RRT is increasing and absorbing sizeable proportions of health-care budgets in high-income countries (7).

Kidney transplantation has been available since the 1950s (8) and has evolved from an experimental, risky treatment option to standard clinical practice in more than 80 countries (6) with 73,179 kidney transplants in 2010, of which 32,194 were from living donors (9). Transplantation offers ESRF patients better outcomes than dialysis in terms of both quality of life (10-12) and survival (12-14). Overall, successful transplantation triples the life-expectancy of a waitlisted ESRF patient (Figure 1) (14).

RRTs are amongst the most commonly studied treatments in health economics, and transplantation is consistently demonstrated to be much more cost-effective than dialysis (15-17). The relative survival benefits of transplantation appear to be increasing over time with improvements to immunosuppressant medications (12). Cost-effectiveness has also increased (17). Transplantation from a living donor (either genetically related or unrelated\(^2\)) offers even better survival outcomes than from a deceased donor (19-20), making it the preferred treatment for most people with ESRF (21). The ideal is a pre-emptive LDKT which is performed before the patient has had to commence dialysis (22).

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\(^1\) There are two main forms of dialysis: hemodialysis (HD) and peritoneal dialysis (PD). PD is performed at home, while HD is performed at home, in hospital or in a dialysis centre (3).

\(^2\) The risk of rejection meant that LDKT was originally restricted to identical twins. Advances in immunosuppressant medication, particularly cyclosporine in the 1980s, have enabled transplants between genetically unrelated people, greatly expanding the potential of living donation (18).
Chapter One: Introduction

The short- and long-term risks to healthy donors who are properly screened and monitored are considered to be low. The mortality risk within 90 days of the surgery is 0.02-0.03% (23-24). Longer-term, there is some risk of slightly increased blood pressure (25) and loss of protein in the urine (26). Available evidence suggests no impact on long-term survival in healthy donors (26-31) and studies of psychosocial outcomes are overwhelmingly positive (32-34). The low risks to donors give LDKT its legitimacy (20, 35-36).

In all countries with transplant programmes there is a significant and growing gap between the demand for transplantation and the number performed, due primarily to the shortage of available kidneys, resulting in increased mortality rates on transplant waiting lists and rising costs to health systems from dialysis.

There is considerable variation in transplant rates between countries, both from living and deceased donors. Spain and Croatia have the highest rates of deceased donation in the world at over 30 donors per million population (pmp) (9). Variation also exists in rates of LDKT (Annex 1) which may in part be due to whether payments for donors exist (37-38). However, many countries without payment systems have experienced significant increases.

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3 Per-patient costs vary between different dialysis modalities, with home-based haemodialysis and peritoneal dialysis being less expensive than hospital-based or in-centre haemodialysis in all countries (7).

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in rates of LDKT, particularly the Netherlands which has a rate approaching 30pmp. Abramowicz (as cited by Watson (39)) notes this is “proof that living donations can be increased”.

Most countries are now attempting to expand both living and deceased donation, but rates in some countries have plateaued (40). There are also considerable disparities within countries with minority and other disadvantaged populations less likely to receive transplants (6).

The World Health Organization (WHO) (41-42) has called for countries to strive for self-sufficiency in meeting the organ donation needs of their populations, with strategies to reduce demand and increase supply. It is recognised that living donation now plays a critical role in the ability of countries to achieve self-sufficiency (6) since even if deceased donation was maximised, it would never be enough to meet demand for kidneys (43-44), even in countries with very high rates of deceased donation such as Spain (45-46). Increasing attention is therefore being given to LDKT.

1.2 New Zealand situation
New Zealand (NZ) faces similar challenges to other countries with projections of rising demand for RRT (47), and an actual average increase of 5.4% per annum from 2000-2011.4 In 2011, 3834 people were receiving some kind of RRT in NZ, representing a total prevalence rate of 0.08%. Of these, 1453 people were living with a functioning transplant, and 2381 were on dialysis. There were 477 new patients in 2011 (48). RRT is thought to account for around 1-2% of health expenditure (49).

Waiting lists for deceased donor kidneys have increased to nearly 7005 (55). Total transplant numbers, however, have changed little over this period and the gap between supply and demand is increasing (Figure 2).

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4 Annual increase calculated from data from ANZDATA Registry Reports, Appendix III.
5 Waiting lists are frequently used to indicate demand for transplantation. However, waiting lists often do not represent the true demand for transplants as access to lists is typically restricted due to the scarcity of deceased donors. Many people who might benefit from transplantation are therefore excluded from waiting lists (50). The key challenge in determining access to waiting lists is balancing the principles of utility (getting the greatest benefit from a kidney by ensuring only those who have
Transplantation rates vary between population catchment areas in NZ (69) and there are also variations between ethnic groups. Māori and Pacific populations have higher rates of CKD and ESRF than the NZ European/Pākehā population. This is mostly associated with higher rates of diabetes and obesity within those populations but also greater susceptibility to renal disease deriving from glomerulonephritis and lupus nephritis (70). Transplant rates for Māori and Pacific patients are lower than for NZ European/Pākehā, due in part to less likelihood of being waitlisted for transplant and also because of a lower likelihood of receiving a transplant, particularly from a living donor (70-71).

NZ’s deceased donor rate is one of the lowest in the world at around 8.6 pmp (9). In 2012, there were 38 deceased donors resulting in 54 deceased donor kidney transplants (67). LDKT now makes up around half of all renal transplants in NZ, with 54 transplants from living donors in 2012 but any growth in numbers has only just compensated for the declining numbers of deceased donor kidney transplants (DDKT) (Figure 3).
In terms of rate, LDKT rates in NZ have plateaued and appear to now be declining, from a high of 16 pmp in 2008 to 12.2 pmp in 2012 (Figure 4).

There has been little prior research on how to increase rates of organ transplantation in NZ (74-75) and none that focuses specifically on LDKT or incorporates patient perspectives. The main purpose of this research is to fill that evidence gap.
1.3 Framing the problem

The consequences of the growing gap between those who might benefit from a transplant and those who receive one include poorer outcomes for patients and higher than necessary costs to the health system. A comprehensive strategy to address this problem would be multi-faceted and would include measures to reduce demand for RRT, such as through prevention (e.g. to reduce rates of obesity) and early detection to minimise (or at least slow the progression towards) ESRF, (4, 6) as well as maximising deceased donation. However, prevention and early detection will never prevent ESRF in all cases, either because prevention initiatives requiring behavioural change can be difficult (76) or because some causes of ESRF are simply not amenable to prevention. The potential number of deceased donors is declining in all countries due to factors such as greater use of seat belts and improvements in critical care (15) (although NZ’s rate is particularly low) (see Chapter Six). For those people who do develop ESRF, therefore, LDKT currently offers the best outcomes and is the most cost-effective treatment option.

International comparisons suggest that, prima facie, the overall rate of LDKT in NZ is not as high as it could be. There are also ethnic disparities in transplant rates, particularly from living donors (70, 77).

It might be expected that policy-makers, health managers and health professionals would take a greater interest in increasing rates of LDKT given the potential benefits to patients and healthcare budgets. The goals of NZ’s health system have at different times emphasised equity of access, quality of services, and cost-containment (78), with increasing attention to questions of cost-effectiveness of health services (79). The aims of the NZ Public Health and Disability Act (2000) (80) are to provide the best care for those in need of services and to reduce disparities (s3). District Health Boards (DHBs) are required to deliver services in the most efficient and effective way (s22(1)(a)(ba)). In common with virtually all OECD countries, growth in Crown spending on health in NZ has outstripped national income over the last 15 years (76), with forecasts that health expenditure will take up an increasing proportion of all public expenditure (81). The rate of growth is considered to be unsustainable and there has been renewed emphasis on improving value for money (VFM), in order to avoid the need for a reduction in service coverage and/or quality.
However, despite the goals of the health system, and the growing imperative to improve VFM, until very recently there has been virtually no policy focus in NZ on LDKT.

Governments might also wish to encourage LDKT (and DDKT) further to reduce the demand for organs acquired through organ trafficking (82) or pressure to utilise living donors who would previously have been declined on health grounds and for whom the risks of donation are higher than in healthy donors (83-84).

A variety of factors influences variation in transplant rates (between and within countries), such as social norms, cultural values and health system resourcing. However, it is now well established that a significant factor influencing deceased donation rates is the organisation of services (e.g. processes in intensive care units for identifying potential donors) and various institutional arrangements (42, 46, 85). There are many significant differences between deceased and living donation (and they need to be considered separately) but the lessons from deceased donation suggest strongly that rates of living donation can be influenced by changes in policy and practice.

In considering this issue as a policy problem, this research has taken a broad view of what policy is. There are many definitions of public policy (86-87). At its simplest, Dye (88) suggests public policy can be defined as “whatever governments choose to do or not to do” (p.2). Policy includes not only government action, but also inaction (89), and includes bundles of decisions over time that are not intended or recognised as policy (90).

Solutions to policy problems are not limited to formal rules or legislation. Governments have a variety of levers available to address problems, including legislative/regulatory, information, education, bureaucratic reforms, and service provision (91). In addition, government agencies no longer have a monopoly on policy analysis and policy solutions and a range of stakeholders inside and outside government can be properly thought of as part of the policy process (92). In a largely devolved health system such as NZ’s, DHBs have an important role in policy processes, given their significant responsibility for decisions about funding and provision of services. Clinicians also have considerable influence over health policy (79, 90, 93).
The issue of how to increase rates of organ donation is unique in health policy because the rate-limiting factor is not the usual problem of the level of resource allocation but the more fundamental problem of how to increase the supply of donors (94). Wilkinson (95) notes that “the public policy problem is not a shortage of money but a shortage of the vital raw material” (p.1). In LDKT, the requirement for a healthy person to undergo medically unnecessary surgery to enable the intervention is at the heart of the complexity of the problem and gives rise to a number of ethical issues which must be considered in any debate about how to increase rates.

1.4 Ethical issues in LDKT

The field of organ transplantation, from both living and deceased donors, has always had to deal with significant ethical issues. Price (96) notes:

\[\text{It has been observed that... what is truly distinctive about transplantation is not technology or cost, but ethics, emphasising the unique and (virtually) utter dependence upon the participation of the public for its continued viability as a therapeutic option at all....In short, the fundamental nature of transplantation in clinical, physiological and biological terms is entirely matched by its significance in legal, ethical, theological and cultural terms (p.2).}\]

Concepts such as patient choice and informed consent, autonomy and dignity are fundamental in all medical ethics (97) but have added complexity in organ donation. Coercion and altruism are further key principles that must be addressed.

Sharp (98), however, argues that it is necessary to be very clear in the distinction between living and deceased donation:

\[\text{Key to understanding cadaveric organ donation is that it relies overwhelmingly on donors who have sustained sudden, unexpected head traumas who are declared brain dead within hospital settings....Because the shadow of death pervades this form of organ transfer, I argue that very particular and peculiar responses emerge that stand in contrast to those associated with living donation (p.6).}\]

Issues such as universal taboos on the desecration of bodies after death (18), an historical backdrop of the practices of post-mortem dissection and autopsy (18, 99-100), challenges in
defining death (97-99), and the knowledge for recipients that somebody has had to die in order for them to live (101-102) have all shaped deceased donor transplant legislation, policy and practice.

In LDKT, the primary ethical issue, however, is the risk to the donor (40). Unnecessary surgery on a healthy person for the benefit of someone else can be seen as violating the fundamental medical ethic of *primum, non nocere* (first do no harm) (100, 103) and this has been the paramount concern since the first LDKT in 1954 (8). Spital (104) notes that “few issues in medicine have generated as much controversy as has living organ donation” (p.89).

Weighing risks and benefits is necessary in all clinical practice (103) but the risk/benefit equation in LDKT is unique because the risks and benefits fall on different people (96). LDKT, therefore involves a complex balancing of risks to donors, benefits to recipients and respect for donor autonomy (40, 96). Health professionals are active participants in the process since they are necessary to facilitate the transplant (105) and are thus “moral agents” who must decide what they believe is ethically appropriate (106). They must balance respect for donor autonomy with their professional duty to do the best for their patients, one of whom is the donor (103).

Overall, a consensus has emerged over 50 years that risks and benefits can be balanced in such a way that LDKT is ethically acceptable. This is because risks to healthy donors are low when performed in the right conditions; in particular, when careful screening, professional care and follow-up of donors are in place (107).

The main issues now regarding donor wellbeing are: the increasing trend to accepting medically complex donors (108); variability in ongoing follow-up of donors (109); protection of donors involved in organ trafficking (110); and the need for more research on long-term outcomes, especially for those groups where outcomes are less well-understood (108-109, 111). It is widely recommended that clear and transparent guidelines for living donation are in place (24, 40, 112-113); that donor registries should be established; and that all transplant programmes should regularly submit data on donor outcomes (112, 114-115).

Informed and voluntary consent and, in particular, the absence of coercion are the other ethical conditions that must be met. Pressure to donate may be internal or external, e.g.
from other family members or health professionals (96). From the earliest days of transplantation, there have been concerns that potential donors may be pressured into donating by other family members. Pressure to accept a kidney may also arise along with obligations (real or perceived) to reciprocate. Fox and Swazey (102) suggest that “the giver, the receiver, and their families, may find themselves locked in a creditor-debtor vise that binds them one to another in a mutually fettering way. We have called these aspects of the gift-exchange dimensions of transplantation ‘the tyranny of the gift’” (p.40).

Protocols are often put in place to minimise the risks of coercion, e.g. psychosocial counselling, confidential consultations with a physician who is not also treating the recipient, and the offer of a “medical alibi” for people who do not wish their families to know about their reluctance to donate (96, 116). Possibly as a result of such protocols, external pressure has been found to affect only a small minority of donors (116).

The principle of altruism underpins organ transplantation. Titmuss’ (117) work on blood donation, and his arguments that blood donors should not be paid for donating, heavily influenced organ donation policy (118). Boas (119) suggests that in the 1980-90s altruism was “codified as the ‘default method’ of organ supply around the world” (p.1379). This is reflected in WHO Guiding Principles (107) and a recent report by the Nuffield Council on Bioethics (105). There is considerable debate about the definition of altruism, its role in organ donation, whether altruism is possible when living donors derive emotional benefits from donation, and whether it matters (34, 85, 96, 105, 120).

In practice, altruism in organ donation is usually seen to mean that there is an absence of any form of remuneration (121-122). A significant debate in LDKT now is the failure of reliance on altruism alone to ensure an adequate supply of organs, leading to suggestions to consider incentives for living donors (106, 123-126).

Incentives might be financial or in-kind (e.g. college scholarships (124)) and systems can be regulated or unregulated. Matas and Delmonico (40) note the transplant community has “taken a unified stand against... underground unregulated markets” (p.274). However, fierce debate continues about the role of incentives, dominating debate about how to increase rates of LDKT for a number of years (98) (to the point of “saturation” according to some (127)).
Some transplant professionals believe that there are other options that can, and should, be tried before turning to financial incentives (128), while others suggest that the time has come for trials of regulated schemes (129). Others remain firmly opposed to any move towards incentives (130).

Politically, incentives are generally seen as an unpalatable option. Mendoza (131) notes that the significant ethical and moral challenges inherent in such proposals “outweigh the benefits of a legalized kidney market from the standpoint of most governments” (p.264). Iran is currently the only country in the world with a regulated payment system for living donors although the possibility for donors and recipients to negotiate additional payment means it is not completely regulated (132-133).

Suggestions for incentives to living donors appear occasionally in NZ, (95, 134-135). In the past there has been little public support for such a proposal (136) and there is no evidence that this has changed. The Minister of Health’s response in 2010 to a suggestion to pay donors was, “We are not going to create a market for human organs by paying people to donate. To do so would create significant ethical issues” (134).

This research deliberately excluded examining financial incentives on pragmatic grounds: NZ cannot be said to have yet tried all other options; there is no evidence of widespread political or public appetite to introduce incentives; and paying donors is a controversial and polarising proposal that shows no sign of resolution internationally and risks diverting attention from other, more acceptable, options. These other options are the subject of this research.

1.5 The research questions

The overall aim of this research was to identify how rates of LDKT in NZ could be increased. There were two main research questions:

1. **What are the barriers to LDKT for patients in NZ?**
   - What does the international literature suggest about the barriers at each stage of the journey to LDKT and what interventions are possible to reduce barriers?
   - What are the barriers for NZ patients and what could be done to address barriers to LDKT?
The second research question arose from the observation that it is rare in health policy to come across an intervention (transplantation), which is so unequivocally more effective and more cost-effective than the alternative (dialysis) (16). This raises the question of why, given the goals of the health system, there has not been greater attention given to how to increase rates of LDKT in NZ (although this began to change after this research began). The second research question asked:

2. **Why hasn’t more been done in NZ to try to increase rates of LDKT given evidence of better outcomes for patients and greater cost-effectiveness compared to dialysis?**

- What developments have there been between 2000 and 2012 in LDKT policy?
- Why had more not been done to try to increase rates until 2011?
- Why has LDKT had more attention during 2011 and 2012?

These questions reflect different aspects of the overall aim and are based on Walt and Gilson’s (137) model that understanding health policy issues requires attention not only to policy content (e.g. the options), but also to processes, context and actors, as encapsulated in the health policy triangle (Figure 5). The components of the triangle include:

*Context* – these might include situational, structural, international or cultural factors, e.g. issues in the wider health system or attitudes and beliefs about organ donation. While all policy has a normative dimension (138), some policy problems have inherent moral issues that cannot be avoided (139). In LDKT, a key contextual factor is the ethical issues discussed above that stem from the reliance on medically unnecessary surgery on a healthy person;

*Process* – refers to the ways in which issues come on to the agenda, and how decisions are made, implemented and evaluated. The lack of

![Figure 5: The health policy triangle (adapted from Walt and Gilson, 1994 (139))](image-url)
attention to the issue until very recently forms part of the challenge to increasing rates of LDKT;

_Actors_ – includes a wide range of individuals, groups, and organisations both inside and outside government. This research also explicitly included institutional arrangements which may empower and constrain actors (140-141). These overlap with other parts of the triangle and may include formal structures (86) as well as rules, incentives, accountability arrangements, norms and culture, decision-making systems and processes (142);

_Content_ – these are the options available to decision-makers to address a problem. For a complex problem like this, a range of solutions is needed, rather than relying on a single option.

The triangle is a conceptual model only, and in reality the components overlap and interact, but it is useful as an organising framework for systematically considering a policy issue (90). Framing the issue of how to increase rates of LDKT as a policy question meant attention was needed to all aspects of the triangle. Question One related primarily to the content corner of the triangle while Question Two related mostly to processes. Actors, institutions and other contextual issues were incorporated into both.

### 1.6 Overview of the NZ environment

#### 1.6.1 Legislative and policy framework

NZ adheres to the WHO’s Guiding Principles on Human Cell, Tissue and Organ Transplantation in its broad approach to living organ donation (personal communication, email from the Ministry of Health (MOH), November 2010). The Human Tissue Act (2008) is the primary legislation relating to organ donation in NZ regulating the collection and use of tissue (which includes organs), and providing a framework for informed consent for human tissue collection and use. Its purpose (s3) is to ensure that such collection takes into account autonomy and dignity of individuals before and after death, the cultural and spiritual values of those individuals’ family members, and the public good associated with collection of human tissue (143).
The Act is primarily focused on the collection of human tissue following death, with a particular emphasis on clarifying consent provisions, and is relatively silent on living donation as this is covered under “existing legislation and common law” (144). Provisions prohibiting the exchange of organs for “financial or other consideration” (sections 56, 58, 59, 61) are aimed at preventing the sale of organs from living or deceased donors.

When the Act was updated in 2008, a clause was included (s91) to amend the Health and Disability Commissioner Act to explicitly cover living donors under the Code of Health and Disability Services Consumers’ Rights (145).

Other explicit policy provisions relating to living organ donors include a Live Donor Organ Assistance programme introduced in 2005 under the Social Security Act (1964) which provides some financial support to living donors for childcare costs and for lost income up to the level of the Sickness Benefit ($204.96 per week for a single person aged 25+) (146). Accommodation and travel assistance for living donors are explicitly included in the MOH’s National Travel Assistance Policy (147).

There has been no other legislation specific to living donation (personal communication, email from the MOH, November 2010) until 2012 when legislative restrictions on Kidney Paired Exchange (KPE) were removed (see Chapters Four and Five). Unlike many countries, there have been no legislative restrictions on practices such as non-directed (stranger) donation which began in 1998 at the Christchurch Renal Transplant Unit (65).

1.6.2 Organisation of services
LDKT is provided only in the tax-funded health system in NZ. In this system, DHBs are allocated funding from government on a weighted capitation basis with which they must purchase or provide services for the population within their geographical area. People with chronic kidney disease and end-stage renal failure in NZ receive services, including LDKT, within this public system. Services provided directly by DHBs (including hospital services and home or community-based dialysis) are free of charge to patients while primary care services and pharmaceuticals incur a co-payment. Services are available to all citizens or permanent residents of NZ, as well as people from NZ’s dependencies - Niue, the Cook Islands and Tokelau (148).
Renal services are provided by renal units in 11 of the 20 DHBs (personal communication, MOH, 21 March 2012). Adult LDKTs are performed in hospitals in three DHBs – Auckland, Capital and Coast (Wellington) and Canterbury (Christchurch). The first organ transplant in NZ was of a kidney in 1965, a living donation between identical twin sisters, and the first DDKT took place in 1966 (66). Unlike other solid organ transplants which are organised as a national service and all performed at Auckland City Hospital, LDKT has developed as three regional services organised around the three transplanting DHBs.

When transplants are performed on donor-recipients from non-transplanting DHBs, the DHB normally responsible for the donor and recipient (DHB of domicile) pays the provider DHB via an Inter-District Flow (IDF). The MOH develops national guidelines for IDF but prices may be negotiated between individual DHBs.

There are teams of people with roles in the transplant process (both before and after the actual transplant), including nephrologists, transplant surgeons, specialist renal nursing staff, transplant coordinators, social workers and psychologists or counsellors. Potential recipients are assessed for suitability for a transplant and potential donors are also evaluated for medical and psychosocial suitability to be a donor.

Diagnostic tests for recipients and donors are performed by the relevant service in the hospital such as Cardiology or Radiology. Compatibility testing for living donations is performed by the Tissue Typing Laboratory of the National Blood Service.

There is an Australian and NZ Dialysis and Transplant Registry (ANZDATA) which records data on the incidence, prevalence and outcome of dialysis and transplantation for patients with ESRF in both countries as well as data on living and deceased donors. ANZDATA is funded by the Australian Commonwealth, the NZ Government and Kidney Health Australia. It is responsible jointly to the Australia and New Zealand Society of Nephrology and to Kidney Health Australia (http://www.anzdata.org.au/v1/index.html).

There is a national clinical body, the National Renal Advisory Board (NRAB) which was established in the 1990s by senior clinicians “to address significant issues in renal service provision that require a consistent national approach” (149). It formulates advice for DHBs, the MOH and the Minister. There is a Renal Transplantation Subcommittee of the NRAB.
Organ Donation New Zealand (ODNZ) (the National Donor Coordination Agency prior to 2005) is responsible for coordination of the national deceased donor organ programme. This includes developing nationally consistent processes for deceased organ donation in NZ, information and follow-up for families of deceased organ donors, and public information about organ donation (150). ODNZ has no role in LDKT and there is no equivalent national body with responsibility for LDKT.

Kidney Health New Zealand (KHNZ) (formerly the New Zealand Kidney Foundation) was founded in 1979 as a non-profit organisation to provide information and education services relating to renal disease. It also funds research and promotes kidney donation for transplantation. Increasing the rate of LDKT has been identified as a strategic priority in KHNZ’s strategic plan (151).

Overall regulatory and policy responsibility for renal services and organ transplantation sits with the MOH.

1.7 Organisation of the thesis

Chapter Two sets out the theoretical framework that underpins the research as well as the overall research design. The complexity of the topic and the public policy focus of research leads me to a multidisciplinary, pragmatic approach that takes an overall systems perspective. In particular, I develop a theoretical framework that takes into account the multiple interacting systems that impact on a patient’s opportunity for LDKT, similar to a social-ecological transplant model that has previously been suggested as suitable for research in this area (152). The framework includes patients’ family and wider social networks, multiple levels of the health system, and wider socio-cultural and community factors, all of which influence access to LDKT. To provide a structured way of identifying and discussing barriers to LDKT, a five-stage conceptual model of the patient journey is also developed in Chapter Two. A brief outline of issues at each stage is presented in this chapter, with a fuller review of existing literature provided in subsequent chapters. I then set out the research design which uses mixed methods, incorporating both quantitative and qualitative methods that gather data from patients, health professionals and managers, key informants and official documents. Ethical considerations and issues in relation to “insider research” are also discussed briefly in this chapter.
Chapters Three and Four focus primarily on the content corner of the policy triangle introduced above and present the literature and results relevant to the first research question – the barriers to LDKT and what might be done about them. The material is structured around the stages in the patient journey introduced in Chapter Two. Chapter Three focuses on Stages 1-3, while Chapter Four focuses on Stages 4-5. Literature and results are presented together for each stage. The emphasis of these chapters is on the inner circles of the social-ecological transplant model, namely issues for patients in their interactions with their families and social networks, as well as with health providers. Other issues, such as the role of the media as well as specific government policies (e.g. the reimbursement of donors for lost income) are also covered. Chapter Four concludes by discussing critical cross-cutting issues that impact on opportunities for transplantation.

Chapter Five turns to the processes corner of the policy triangle and examines the second research question of why so little attention has been paid to how to increase rates of LDKT given clear evidence of its superior outcomes for patients and cost-effectiveness, relative to dialysis. This chapter moves from a focus on patients and their interactions with their networks and health providers, to wider policy and decision-making and agenda-setting processes at different levels of the health system. The chapter begins with an overview of the agenda-setting literature and describes Kingdon’s multiple streams model, which is used to guide this part of my research. Issues at macro, meso and micro levels of the health system are then explored in terms of Kingdon’s model. Supplementing the multiple streams model, institutional arrangements that have a bearing on the overall question of the lack of focus on LDKT are also discussed.

The results from Chapters Three to Five are synthesised, and key themes relating to each of the two research questions are discussed in more depth, in Chapter Six. In relation to the specific barriers in the patient journey to LDKT, overarching themes are identified and initiatives that may address the availability of suitable donors are summarised. Findings from Chapter Five are contextualised within the wider NZ health system. The findings are also considered in the broader context of organ donation policy, specifically deceased organ donation. NZ’s very low rate of deceased organ donation by international standards also provides critical context. The chapter concludes by discussing how ethical issues faced by health professionals impact on the design and delivery of LDKT services.
Chapter Seven brings together all the findings to present the overarching conclusions of the thesis. A national strategy to increase rates of LDKT in NZ is proposed, incorporating seven integrated components based on the evidence and analysis from the previous chapters.

Finally, Annex 1 presents rates of LDKT internationally, while survey instruments and interview schedules are included in Annexes 2-6.
2 Chapter Two: Theoretical framework and research design

2.1 Introduction
This chapter describes the overall research approach, setting out first a framework that informed the research and an overview of the stages of the LDKT process. The research design is then described encompassing three components: philosophical world view or paradigm; strategy of enquiry or research methodology; and specific methods (153).

2.2 Theoretical framework – a systems perspective
This research aimed to contribute to resolving a complex policy problem and took a pragmatic, problem-solving, multidisciplinary approach. The research questions required an approach that could take into account all aspects of the health policy triangle.

Boston et al (154) note that “drawing on different disciplinary perspectives is not without its challenges, but...can enrich our understanding and deepen our appreciation of the complexity and gravity of the issues at stake” (p.12). Contributions to our understanding of organ donation and transplantation have been made from many different disciplines and fields of study, in addition to medicine, for example: sociology (85, 101-102, 155-156), anthropology (98); psychology and behavioural sciences (34, 157-158); economics (159-160); bioethics, policy and the law (96, 161-162); and history (18). For the research questions here, public policy and political science also contribute (86, 142, 163-164).

In keeping with the framing of the issue as a policy problem, no single discipline or framework was sufficient to address the research questions. Scott and Baehler (92) suggest that “the hallmark of a discipline is a distinctive and defining theoretical framework” (p.22) but that there has been a longstanding debate about whether public policy as a discipline does in fact have such a defining theoretical framework. They argue (92) that “rather than starting from a particular disciplinary framework... policy analysis moves from a presenting problem or issue to select frameworks and disciplines that are likely to help devise a solution” (p.23). This research, therefore, drew on a range of disciplines and theoretical perspectives to take a systems perspective on the question of how rates of LDKT in NZ might be increased.
Scott and Baehler (92) suggest a systems perspective is “necessary for approaching complex problems or those where there is uncertainty about cause and effect, so a wide net must be cast to capture all the influences that should be taken into account” (p.57). They note that one advantage of this approach is that it focuses on “understanding what is going on” (p.233) and developing solutions to the range of issues associated with a particular problem, rather than starting with the question of what government can or should do, potentially limiting the options available. It can also enable consideration of the full range of factors from the different disciplines as described above, from the individual to the socio-cultural, to the organisational and institutional.

Systems perspectives when applied to public policy problems may suffer from problems such as unmanageable scope or excessive data needs (165). Likewise, Scott and Baehler (92) caution against “being buried alive by complexity and creating a false sense of completeness” and advocate for “a delicate balance between wallowing in endless details and prematurely closing the system” (p.187).

They suggest there is no one way to map a system, and advocate developing hybrid approaches that are fit for purpose given the situation. A system model was developed for this research (Figure 6). It is similar to Rodrigue’s (152) Social-Ecological Transplant Model (which was adapted from Bronfenbrenner’s 1998 Ecological Systems Theory). Rodrigue’s (152) model provides a framework within which:

... to develop, implement and evaluate programmes to promote LDKT....This model proposes that patients’ decision making about LDKT is influenced by multiple systems, including their personal values, their core family, their extended social network, the health care system at large, and their community or culture. Each system, represented graphically as a series of concentric rings, represents a type of influence with the rings closest to the patient indicating systems in which the patient most directly interacts (e.g. family). What successful interventions highlight is the need to promote LDKT both at the individual level and within other systems in which the patient is embedded (p.299).

The model developed for this research incorporates actors and institutions specific to NZ as well as multiple levels of decision-making in the health system. The levels of the model are:
• The patient, as the potential end-recipient of a transplant, is at the centre of the framework. Similar to Rodrigue’s model, how patients think, feel and make decisions about their treatment options, whether and how they decide to pursue LDKT, and the information and knowledge they have to do that, are critical factors;

• The patient’s family and social networks, both immediate and more distant, are the usual source of potential donors for a given patient as non-directed donation is rare. Their knowledge, motivation and opportunity for donation are central. These people may also be a prime source of support for patients in managing their own health, navigating through the health-care system, and deciding whether or not to pursue LDKT;

• The NZ health system has three levels: micro, health-care providers who make decisions about treatment for patients; meso, decision-makers who determine priorities and allocate resources at a district and regional level; and macro, national decision-makers and advisors, as well as non-government groups (166);

• Wider community and societal factors, such as ethics, beliefs, norms, culture, the media and public awareness and preferences, influence all other parts of the system. Legislative frameworks that reflect societal norms are also relevant. Global developments, such as the need to respond to the rise of organ trafficking, or technological advancements in surgical techniques, also affect the opportunities for LDKT.

Many actors have roles in more than one part of the model, e.g. clinicians are involved in micro-level decision-making about individual patients but frequently participate in leadership and governance groups at both meso and macro levels and play a significant role in central government policy processes. Roles are not static, e.g. patients and their networks may be part of “the general public” with little awareness of, or interest in, kidney disease until they are personally affected.
Figure 6: A social-ecological model for living donor kidney transplantation in New Zealand
2.3 Stages in the Living Donor Kidney Transplant Process

2.3.1 Five-stage model of LDKT

In addition to the overall system framework described above, it is important to understand the stages a patient must pass through in order to receive a transplant. This enables barriers at each step to be identified and interventions targeted. Models for describing the steps involved in accessing a DDKT have existed for some time (167). For example, Devitt et al (168) suggest that patients must: be deemed medically suitable; become informed and make appropriate decisions; complete the work-up for transplant; be placed on the waiting list; and receive a transplant.

More recently, the stages in the LDKT process have also been described by Purnell et al (169) who developed a four-stage model comprising: 1) donor identification, 2) transplant evaluation, 3) kidney transplant, 4) post-transplant, and identified potential barriers at each stage at multiple levels.

A five-stage model was developed for this research (Figure 7). Patients do not necessarily progress through the stages in a linear fashion, e.g. steps are sometimes repeated, or occur in parallel. Patients may begin the process of moving towards transplantation before they reach the stage of needing dialysis, or may have been on dialysis for many years before being offered transplantation as an option. They will also be involved in other “journeys” simultaneously, such as adjusting to living with ESRF and dialysis. Most patients will not make it to the final step and will remain on dialysis or will become too ill to be a candidate for any kind of transplant. This model was used as the basis for addressing the first research question of identifying barriers to LDKT for patients. Although the focus in this research is on NZ patients, the general stages are the same for any patient and the model is thus applicable in any LDKT programme.

2.3.2 Overview of barriers at each stage

The key barriers at each stage identified from the international literature are briefly summarised here.

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A version of this model has been previously published (2).
Figure 7: Stages in the LDKT process

**Description**

1. **Transplantation is an option**
   - Stage 1: Patient is referred for transplant assessment
   - Patient completes evaluation
   - Patient meets clinical and psychosocial criteria

2. **LDKT is offered and patient decides to pursue/accept**
   - Stage 2: Patient is told about LDKT
   - Patient decides to pursue LDKT and accept offers from donors

3. **Someone is willing to be a donor**
   - Stage 3: Someone offers to donate e.g. family or friend
   - Patient accepts the offer
   - Donor goes forward for work-up

4. **Potential donor is suitable**
   - Stage 4: Donor and recipient are compatible
   - Donor meets clinical and psychosocial criteria
   - Donor completes work-up and decides to continue

5. **Receive transplant**
   - Stage 5: Patient is still healthy, donor still willing
   - Final compatibility test
   - Have the transplant

**Stage 1: Transplantation is an option**

There is variation between clinicians and centre practices in whether and how patients are referred for transplant assessment. Patients from certain groups (age, gender, ethnicity) are often less likely to be referred for assessment, to complete the evaluation and/or be listed for transplantation (50, 170-173).
Stage 2: Patient decides to pursue LDKT

Patients may not necessarily be told about LDKT as one of their options or LDKT may not be covered adequately in patient education (174-176). Attitudes of clinicians to LDKT and centre practices can make a difference to the types of discussions held with patients (177-179). Who provides information to patients (180), the timing of discussions (181), ongoing engagement with patients about LDKT (182), and the type of information provided (183-184) are all factors influencing patient decision-making.

Patients may lack knowledge about LDKT, including risks and benefits for themselves (180, 185), and are likely to overestimate the risks to donors and underestimate the positive feelings donors typically have about donation (186). Even patients who would like a LDKT may have concerns about it and may not necessarily be willing to accept a kidney if offered (187-189). Patient knowledge, concerns and preferences are not homogenous and may change over time (182).

Stage 3: Find a willing donor

Health professionals are typically unwilling to approach potential donors so it is up to patients to find a donor themselves (74, 190). Patients consistently report extreme difficulty in approaching potential donors and often wait for donors to come to them (157, 182, 186). Patient concerns or misinformation may result in them turning down offers from potential donors (187). Overall, relying on patients to find donors is a significant barrier to LDKT (185).

Potential donors may have concerns about donation on their own health (157, 191), lack accurate knowledge about risks to donors (192), have personal or cultural beliefs against donation (193) and/or face financial barriers (194). Potential donors may not be aware of the need for donation and many may be willing to consider donation but have never been asked (157).

Stage 4: Donor is suitable

Even when potential donors are willing, many are excluded due to incompatibility with the intended recipient (195-196) or because they are medically unsuitable. Medical
unsuitability is a particular barrier in ethnic groups with high rates of obesity, hypertension, and diabetes (197-198).

**Stage 5: Receive the transplant**

To receive the transplant, the patient must remain well enough, a final test must confirm compatibility with the donor, and adequate health service capacity must be in place to carry out the transplant (e.g. workforce or theatre capacity (148)).

### 2.4 Research design (1): Paradigm – a pragmatic, mixed-methods approach

This research used a mixed-methods approach with a pragmatic philosophical world view. Mixed-methods research (sometimes known as a multi-strategy research (199)) is defined by Tashakkori and Creswell (200) as “research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches in a single study or program of inquiry” (p.4). Mixed-methods research is not new although it has evolved as a specific field only relatively recently (200-201).

Mixed methods are an alternative to the so-called “paradigm wars” between quantitative and qualitative research (199) and an attempt to move beyond polarising arguments, to recognise the usefulness of both types of research (202). These “wars” have been characterised by purists on both sides arguing for the superiority of their ideological paradigm and methodological tools. Johnson and Onwuegbuzie (202) note that the focus has been on the differences between the two paradigms, citing Sieber who says this has resulted in two distinct research cultures “one professing the superiority of ‘deep rich observational data’ and the other the virtues of ‘hard, generalizable’ data” (ibid, p.14). The debate has often led to commitment to an ideological paradigm dictating methods, rather than the research question itself (203).

Issues that have needed to be resolved in the mixed-methods field have included philosophical positions, designs, data analysis, validity strategies, mixing and integration procedures, and rationales (202), and whether fundamentally different paradigms can truly be mixed (200). Proponents (202) argue for a focus on pragmatism as an alternative to otherwise interminable “metaphysical disputes” (p.17), which allows researchers to choose methods that are best suited to answering questions about complex, dynamic,
interdisciplinary, real world problems (153, 202, 204). While debate continues about whether true integration of quantitative and qualitative approaches is really possible (199), Johnson and Onwuegbuzie (202) argue that pragmatism and mixed methods offer “an immediate and useful middle position philosophically and methodologically” (p.17).

The advantages of mixed-methods research are generally considered to be: allowing triangulation (or testing of data from several angles) and corroboration to provide a stronger evidence base for conclusions; addressing different but complementary questions within the same research study; and enhancing meaning, precision, completeness and generalisability (202, 205).

The main disadvantages of mixed-methods research are the additional time and resources needed for data collection and analysis, and the requirement for the researcher to be familiar with both quantitative and qualitative methods (153, 202).

Key criteria for selecting a research design include the research problem itself and the intended audience (153). My research problem was framed as a complex, multidisciplinary one with an emphasis on providing evidence that can help address a real world problem. In this context, it was considered that neither a purely qualitative nor a purely quantitative approach would be adequate to answer the questions or be credible with diverse audiences. A pragmatic mixed-methods approach was therefore considered most appropriate.

2.5 Research design (2): Methodology

The second component of a research design is the overall strategy of enquiry, or research methodology (Figure 8). In this research, there were two paths of data collection and analysis. Path One focused primarily on answering the first research question about specific barriers to LDKT while Path Two focused on the second research question, about why more attention had not been given to how to increase rates of LDKT.

Both began with a review of the existing literature which continued to be updated throughout the research. In the first path, literature about barriers to LDKT and options was used to inform the development of a survey of current waiting-list patients in NZ. The survey was structured around the stages in the process and generated quantitative data about the experiences of patients in NZ who had been so far unable to receive a LDKT. The
survey was followed by in-depth semi-structured interviews with a small number of patients who had completed the survey. This enabled further exploration of the issues identified in the survey as well as allowing new themes to emerge. Transplantation health professionals were also interviewed about the barriers to LDKT. Many of these people occupied roles that enabled them to also comment on issues relevant to the second research question.

In the second path, analysis of official documents relating to LDKT policy was undertaken along with interviews with key informants who occupied decision-making or other key roles in the LDKT system. A short survey of DHB managers was also carried out.

Data from each source were analysed separately and then integrated firstly within each stream, and then finally between the two paths, with conclusions and recommendations developed.

Some elements of the methodology were sequential (e.g. patient interviews followed the patient survey; key informant interviews followed document analysis) while other aspects were concurrent (e.g. interviews with patients, health professionals, and key informants were conducted within the same time frame) (153).
Chapter Two: Theoretical framework and research design

A senior renal clinician was available for advice and clarification on clinical matters throughout the research, and many other clinicians also provided assistance on clinical issues, processes and procedures.

Time, resources and the need to keep the scope manageable meant that greater attention was given to some parts of the system than others. Key actors have therefore been excluded, including donors and potential donors, and LDKT recipients. Much of the research concentrated on the first research question with a focus on patients on the waiting list who have not been able to overcome the barriers to LDKT, and health professionals. Given the absence of almost any NZ-based research and the centrality of patients in the system model, it was decided this was the most appropriate place to begin to fill the gap in knowledge.

2.6 Research design (3): Specific data collection methods and analysis

2.6.1 Path 1: Barriers to LDKT

2.6.1.1 Survey of people on the waiting list for a kidney transplant

2.6.1.1.1 Rationale

A nationwide postal survey was undertaken of everyone aged 16 and over on the waiting list for a DDKT as at October 2011. Quantitative, generalisable data was considered necessary to be of maximum use to decision-makers. Originally it was intended to carry out secondary data analysis of transplant unit data but this was too logistically and ethically difficult and would have required considerable work from the transplant units. A patient survey was more feasible and enabled a wider set of questions to be asked, e.g. on patient experiences and preferences.

The survey population was restricted to people on the waiting list for a DDKT. These people are by definition also eligible for LDKT as they have been assessed as suitable for a transplant. As noted in Chapter One, the waiting list does not necessarily reflect the true level of demand for kidney transplants and others may also be suitable for, and offered the option of, LDKT. Surveying this wider group (e.g. everyone on dialysis), about barriers to LDKT, however, would have been inappropriate as it would include people who are clinically unsuitable for a transplant, or who do not want a transplant of any kind. Restricting the
population to the waiting list ensured that all those surveyed were both clinically suitable and were willing to accept at least a deceased donor kidney.

People under 16 were excluded, as additional issues are raised in relation to children and transplantation which were not the focus of this research. People waiting for a combined kidney-pancreas transplant were also excluded, as these people are not eligible for LDKT but must wait for a deceased donor.

2.6.1.2 Topics and analysis

The survey consisted primarily of closed questions with room for written comments. Respondents willing to participate in a more in-depth interview provided a name and contact phone number or email address.

The questionnaire (Annex 2) was structured around the stages in the LDKT process. Clinicians in transplant units provided feedback on early drafts and it was piloted with a small number of renal patients. Topics included:

- renal unit discussions with patients about LDKT;
- patients’ preferences and willingness to accept offers from living donors;
- donor recruitment activity (e.g. discussing living donation with others or asking them directly to consider it);
- the existence of any willing potential living donors, with two measures of willingness: any offer to consider donating (“offers”), and anyone who had begun the work-up process with an initial blood test (“tests”);7
- outcomes for donors who began the work-up process.

Numeric responses were coded and entered into an Excel spreadsheet. Codes were checked twice by the researcher and an assistant helped to check data entry accuracy. SPSS was used to generate descriptive statistics. Further statistical analysis to identify relationships between variables was undertaken with the assistance of Victoria University’s

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7 Often, but not always, the first step in the work-up process is a blood test to determine compatibility of ABO-blood type. Compatibility testing is complex but typically includes ABO-blood type, tissue-typing, and cross-matching (206). Cross-matching is necessary to determine if the recipient has specific antibodies to the potential donor that could cause rejection – a positive cross-match means there would be a rejection and the transplant should not proceed.
consultant statistician. Results of Chi-square and Analysis of Variance were deemed to be statistically significant at $p<0.05$.

Presentation of survey results to clinical transplant groups in the three regions and the NRAB provided an opportunity for testing results, e.g. discussion at these presentations provided a means of checking how results accorded with clinical experiences. Other comments suggested areas for further follow-up in the patient interviews to clarify survey results.

2.6.1.1.3 Distribution of surveys

The three transplant units, plus the Mid-Central DHB renal unit, distributed surveys to everyone over the age of 16 on the waiting list for a deceased donor kidney transplant in mid October 2011. A total of 510 surveys were posted and five were returned marked “addressee unknown”, bringing the total number of surveys received to 505.

2.6.1.1.4 Characteristics of survey sample

One hundred and ninety-three completed surveys were returned, representing a response rate of 38.2%\(^9\). Two additional surveys arrived too late to be able to be incorporated into the quantitative analysis, although were included in the qualitative analysis. Response rate alone is not necessarily a good proxy for validity and other factors such as representativeness of the sample may provide more important information (207). The demographic characteristics of survey respondents compared to the total waiting list population are shown in Table 1 (missing respondents for each variable are excluded; thus totals are sometimes less than 193).

The sample was reasonably representative of the waiting-list population, with a slight over-representation of respondents from the Southern region. NZ European/Pākehā respondents were overrepresented in the sample while Māori and Pacific people were slightly underrepresented, although still making up sizeable proportions of the sample (13.5% and 15.5% respectively). Because numbers of Asians, Indians and “Other” were

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\(^8\) The total waiting list for 2011 was over 600 (55). However, this includes people who received a transplant during the year, were permanently removed from the list, or were listed after October. Thus the number on the list as at October 2011 was 510.

\(^9\) Based on a final distribution of 505 surveys.
Table 1: Characteristics of survey respondents and total waiting list population (waiting-list characteristics provided by transplant units)

<table>
<thead>
<tr>
<th></th>
<th>Number of survey respondents (%)</th>
<th>Number on total waiting-list (%)</th>
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<tbody>
<tr>
<td><strong>Region</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Northern</td>
<td>111 (58.4)</td>
<td>302 (59.8)</td>
</tr>
<tr>
<td>Central</td>
<td>56 (29.5)</td>
<td>161 (31.9)</td>
</tr>
<tr>
<td>Southern</td>
<td>23 (12.1)</td>
<td>42 (8.3)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>190 (100)</td>
<td>505 (100)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>104 (54.5)</td>
<td>288 (56.5)</td>
</tr>
<tr>
<td>Female</td>
<td>87 (45.5)</td>
<td>222 (43.5)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>191 (100)</td>
<td>510 (100)</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pākehā/NZ European</td>
<td>111 (57.8)</td>
<td>234 (45.9)</td>
</tr>
<tr>
<td>NZ Māori</td>
<td>26 (13.5)</td>
<td>90 (17.6)</td>
</tr>
<tr>
<td>Pacific</td>
<td>30 (15.5)</td>
<td>92 (18.0)</td>
</tr>
<tr>
<td>Asian</td>
<td>11 (5.7)</td>
<td>37 (7.25)</td>
</tr>
<tr>
<td>Indian</td>
<td>9 (4.7)</td>
<td>21 (4.1)</td>
</tr>
<tr>
<td>Other</td>
<td>5 (2.6)</td>
<td>36 (7.1)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>192 (100)</td>
<td>510 (100)</td>
</tr>
<tr>
<td><strong>Age group (years)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(average = 53.63, range 19-77)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16-46</td>
<td>46 (25.1)</td>
<td></td>
</tr>
<tr>
<td>47-56</td>
<td>49 (26.8)</td>
<td></td>
</tr>
<tr>
<td>57-63</td>
<td>43 (22.3)</td>
<td></td>
</tr>
<tr>
<td>64+</td>
<td>45 (23.3)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>183 (100)</td>
<td></td>
</tr>
<tr>
<td><strong>Partner/spouse</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>56 (29.0)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>130 (67.4)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>186 (100)</td>
<td></td>
</tr>
<tr>
<td><strong>Dialysis time (months)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(median = 30 months)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-12</td>
<td>47 (26.3)</td>
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</tr>
<tr>
<td>13-30</td>
<td>50 (27.9)</td>
<td></td>
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<tr>
<td>31-48</td>
<td>42 (23.5)</td>
<td></td>
</tr>
<tr>
<td>49+</td>
<td>40 (20.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>179 (100)</td>
<td></td>
</tr>
<tr>
<td><strong>Previous kidney transplant</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>156 (81.3)</td>
<td></td>
</tr>
<tr>
<td>Yes, living donor</td>
<td>15 (7.8)</td>
<td></td>
</tr>
<tr>
<td>Yes, deceased donor</td>
<td>21 (10.9)</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>192 (100)</td>
<td></td>
</tr>
</tbody>
</table>
small, these respondents were grouped into a single “Other” group for the purpose of analysis.

There were a large number of missing responses to the question on time on dialysis (n=179). This was largely due to the exclusion of responses where it could not be certain that respondents had counted current time on dialysis, rather than total time they had ever been on dialysis, e.g. some people who had had previous transplants appeared to have counted total time.

Most people had never had any previous kidney transplant. Where people reported having had previous transplants from both living and deceased donors, this was coded only as “living”.

2.6.1.2 Interviews with waiting-list patients
A larger than expected number of people indicated on the survey they would be willing to be interviewed (n=138). As many people as possible were contacted by phone or email and thanked for their offer to participate and advised that, because of the overwhelming response, a selection of interviewees would be made and these people would be contacted again. Responses (email and in personal phone calls) suggested that people were comfortable with this approach. Several people commented that they were pleased the research was being done and were not surprised at the level of patient motivation to help improve transplant policy and services.

Semi-structured, in-depth interviews took place with 17 patients. At this point, saturation was reached and no new themes emerged. Interviewees were purposefully selected (153). Following analysis of the survey, it was decided that one of the main issues to explore further in interviews would be donor recruitment, and interviewees were selected according to their responses on these questions. The process followed was that survey respondents were first sorted by region to ensure a geographical spread, given different populations and potential variation in service delivery and practice. Within each region, potential interviewees were sorted according to their survey responses about donor recruitment. Three groups were identified: those who had never discussed living donation with any family or friends, those who had discussed living donation but not asked anyone directly to consider donation, and those who had both discussed with and asked others
about donation. A mix of genders and ethnicities was selected as far as possible in each of these groups, with emphasis given to selecting Māori and Pacific patients because of their underrepresentation amongst transplant recipients.

The characteristics of the patient interviewees are shown in Table 2.

<table>
<thead>
<tr>
<th>Table 2: Characteristics of patient interviewees (n=17)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
</tr>
<tr>
<td>Male 8</td>
</tr>
<tr>
<td>Female 9</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
</tr>
<tr>
<td>Pākehā/ NZ European 9</td>
</tr>
<tr>
<td>NZ Māori 4</td>
</tr>
<tr>
<td>Pacific 4</td>
</tr>
<tr>
<td><strong>Type of dialysis</strong></td>
</tr>
<tr>
<td>Peritoneal 5</td>
</tr>
<tr>
<td>Home haemodialysis 7</td>
</tr>
<tr>
<td>In-centre dialysis 5</td>
</tr>
<tr>
<td><strong>Years on dialysis</strong></td>
</tr>
<tr>
<td>1 to 3 8</td>
</tr>
<tr>
<td>4 to 9 7</td>
</tr>
<tr>
<td>10+ 2</td>
</tr>
<tr>
<td><strong>Cause of ESRF</strong></td>
</tr>
<tr>
<td>Polycystic 3</td>
</tr>
<tr>
<td>Diabetes 3</td>
</tr>
<tr>
<td>Glomerulonephritis 2</td>
</tr>
<tr>
<td>Other 7</td>
</tr>
<tr>
<td>Unexplained or patient does not know 2</td>
</tr>
</tbody>
</table>

Building on the results from the survey and the literature review, a semi-structured interview guide was developed covering the following topics (Annex 3):

- discussions with the renal unit about LDKT;
- patient preferences, concerns and attitudes about LDKT;
- donor recruitment issues;
- barriers to LDKT;
- any suggestions for improvement.
Potential interviewees were contacted by phone or email and a time was arranged. The face-to-face interviews lasted one hour on average. Sixteen took place in the interviewee’s own home, and one at their workplace. The patient’s spouse participated in three of the interviews. Interviews were taped and transcribed and a copy of the transcript provided to the person for factual checking and the opportunity for additional comment if desired.

### 2.6.1.3 Interviews with health professionals

Health professionals have an important role in policy and practice relating to transplantation and are instrumental in developing the system response and organising health services. They are also the key interface with patients and are critical for providing support and information in the donor recruitment process and in ensuring that patients understand the advantages of transplantation over dialysis.

Purposive sampling was used to select health professional interviewees. Twelve health professionals currently involved in renal transplantation were interviewed including nephrologists/renal physicians, pre-dialysis nurses, transplant coordinators and surgeons. Interviewees came from five DHBs, including the three DHBs providing transplants and two non-transplanting DHBs.

A semi-structured interview guide was developed (Annex 4). Topics were broadly based on the five stages of the LDKT process but focused more on service delivery and wider system issues. Interviews were tailored slightly differently for people in different roles. Educational booklets or DVDs used by the unit were also collected. Interviews took place at the person’s workplace and lasted for about one hour. Interviews were taped and transcribed and transcripts returned for checking if requested. In addition, several preliminary interviews with health professionals were also carried out by phone to gather background information.

### 2.6.2 Path 2: Attention to LDKT

Kingdon’s (164) multiple streams model of agenda-setting was used to examine the second research question. This model suggests that issues come on to the policy agenda when there is an alignment of “streams”: the problem is recognised, there is political willingness or interest in addressing it, solutions are available, and a policy entrepreneur is able to bring them together to advance the issue on to the agenda. Path 2 included key informant
interviews with decision-makers at different levels in the health system, analysis of official documents, and a short survey of DHB managers.

2.6.2.1 Key informant interviews
Fourteen key informant interviews were carried out with a range of decision-makers, managers and advisors at different levels of the health system. Key informants included current and past Ministers of Health, other politicians, members of the NRAB and regional clinical networks, DHB managers, the National Health Committee, patient groups, KHNZ and MOH/National Health Board advisors. Some had previously worked in renal medicine and others had worked in other areas of medicine. Many of the health professionals interviewed also answered questions as key informants.

Semi-structured interview schedules were developed and tailored to each individual. The main focus of these interviews was agenda-setting and factors affecting the level of attention given towards the issue of increasing rates of LDKT (see Annex 5). Other relevant or role-specific topics were explored.

Most interviews lasted about one hour, although two were as short as 20 minutes. All interviews were taped and transcribed and transcripts returned if requested for checking and additional comment if desired.

2.6.2.2 Official documents
Analysis of official documents was carried out to identify the key events in policy relating to LDKT and issues relating to agenda-setting. This was restricted largely to documents relating to central government processes but also included material from the NRAB. Documents were obtained via a search of the New Zealand Parliament website and the NRAB website. An Official Information Act (OIA) request was made to the MOH and the Ministry of Social Development (MSD) for any material relating to LDKT within the decade prior to 30 May 2011. MSD was also asked for information about how many people had accessed the Ministerial Welfare Programme for Live Organ Donors and annual financial expenditure since the programme began.
A second OIA request was made to the MOH approximately one year later asking for any relevant information from the period since the last request. The scope of this second request was expanded to include information relating to deceased donation as well as living.

A total of 76 documents were obtained from the first search, which included 46 documents from the MOH OIA request. Documents included: transcripts of Parliamentary debates; reports from Health Select Committees; reports to Ministers from government agencies; Ministerial correspondence to members of the public, non-government organisations and other MPs; emails between government agencies and transplant unit staff; and internal agency reports, minutes of meetings and emails. Some documents, e.g. the transcripts of Parliamentary debates, were primarily about deceased organ donation, but these were important for understanding the broader context about public policy processes relating to organ donation.

The second OIA request to the MOH resulted in 90 documents, most of which related to LDKT. The high number of documents compared to the first OIA request is in part due to the expanded scope of the request (deceased as well as living donation) but also to an increased level of activity during the year relating to LDKT (see Chapter Five).

2.6.2.3 DHB managers

Key decision-makers in DHBs were also given an opportunity to comment. An email was sent to General Managers (GM) (Planning and Funding), Chief Operating Officers, and Chief Medical Officers (CMO) in all 20 DHBs. Questions focused on the priority of LDKT in the wider health system and within individual DHBs, and any barriers to doing more transplants from their perspective (Annex 6). The CMO email was sent via the lead CMO in the MOH.

Responses were received from seven DHBs. Some GMs provided significant detail while others sought input from, or simply forwarded the email to, the renal unit in their DHB. Some responded that they had no comments but that the regional renal service or transplant unit would be better placed to reply.

2.6.3 Qualitative analysis

2.6.3.1 Interviews (patients, health professionals, key informants), documents, DHB survey, comments in patient survey
Ryan and Barnard (208) note that themes in qualitative analysis can come from both the data itself (inductive) and from the investigator’s prior understanding of the phenomenon (a priori), such as from existing literature. Data was initially coded according to a priori themes from the literature review that informed the selection of topics in the interview guides, with an inductive approach to identify new themes that emerged in the interviews (153).

In total, 43 people were interviewed (two more than once): 17 patients, 12 health professionals currently working in renal transplantation and 14 key informants. Analysis of all interviews followed a similar approach.

Interview tapes were listened to and transcripts checked. Initial high-level themes and categories were identified. For patients and health professionals, these themes were based broadly around the five stages in the model of the LDKT process. Cross-cutting themes and issues that could not initially be categorised were also identified. These initial themes became high level nodes in NVivo which was then used to code the transcripts.

For key informant interviews, a similar process was followed but using the multiple streams model for the initial themes (problem recognition, political interest, the availability of policy options, and policy entrepreneur) (164). Other issues that could not be coded using these streams were coded separately. Codes for specific actors and institutions were also used.

Patient, health professional and key informant interviews were coded separately. Interviews from health professionals who were also key informants were added to the other key informants so that all issues relating to the second research question could be coded together.

Once high-level coding was completed, nodes were printed and further detailed reading identified sub-themes (through an inductive approach). These were then sorted further with a mind-map drawn for each main node, with relevant sub-themes or nodes. Nodes were combined at this stage as linkages and overlaps were identified. The mind-maps were used as the basis for an initial write-up of the themes, with all relevant quotes included. Further sorting and condensing then took place, e.g. representative quotes were selected for each issue or theme. Write-ups of the results of each set of interviews were prepared as a base document from which integrated results could then be developed.
A variety of techniques for establishing trustworthiness and credibility of qualitative research was used here. These included triangulation of methods, checking with respondents (particularly health professionals), a systematic and documented approach to data analysis, checking and rechecking of raw data for different issues and interpretations, and checking consistency with previous research (205, 209).

2.6.3.1.2 Documents

Documents were analysed for descriptive information about the key events in organ donation policy since 2000. A timeline and summary of events was developed in an Excel spreadsheet. This included both living and deceased organ donation and was organised according to level of the health system.

Thematic analysis was then carried out to identify issues relating to LDKT agenda-setting at different levels of the health system. As with the key informant interviews, the multiple streams model was used as an initial organising framework to manually code the documents. Other themes that did not fit into this framework were also identified and coded separately.

2.7 Research design issues

2.7.1 Insider research

My own background - kidney donor, spouse of a renal patient, former MOH policy manager, former KHNZ Board member - meant that issues of being an insider needed to be considered. Insider research, where the researcher has a direct involvement with the research topic, contrasts with positivist notions of the researcher as the objective outsider, who is both detached and neutral (210-211). The possibility of bias and risks to validity are often raised as issues in insider research (212-213).

There are also potential advantages to insider research and ways in which validity may be enhanced as a result of a researcher having insider knowledge, e.g. gaining access to hard-to-reach respondents may be easier; knowledge of the subject can facilitate data collection and analysis, e.g. understanding internal jargon, technical matters, internal politics; rapport may be easier to establish and people may feel more comfortable opening up to someone who has a greater understanding of their world view (213). Being an insider also provides motivation to undertake and persevere with research (205).
Brannick and Coghlan (211) note that reflexivity enables “the relationship between the researcher and the object of research” to be examined (p. 60) and is useful for mitigating potential bias or threats to validity. A checklist developed by Robson (205) was used as a basis for reflexive practice throughout this research. This included: clarifying personal motivations and values for doing the research and acknowledging areas of subjectivity; being aware of where I sit in the system and how this influences choices about who to approach or not, and the potential impact on how results are reported; recognising feelings that indicate a lack of neutrality; dealing with findings that were surprising, including standing back and asking “am I being captured” by a particular group of respondents; considering whether some respondents are being used in the write-up more than others and why; and reanalysing data or re-interviewing/checking with respondents if the initial analysis seems to show signs of bias.

My multiple insider roles are one of the strengths of the research. I was able to view the issues from many different perspectives, establish rapport with very diverse interviewees, and take a whole-system view. I was open with all respondents about my roles. In addition, my husband is active in many renal networks as a patient representative. I ensured that this was made known to key informants and health professionals interviewed. We were careful to maintain boundaries between the work we were involved in, such as maintaining confidentiality of information. Although we inevitably discussed our work, the results reported in this research reflect only material gained through the methods described above, not any insider knowledge stemming from the various networks he is involved in.

2.7.2 Ethics of the research

Ethical approval was granted by the Health and Disability Multi-Region Ethics Committee on 21 June 2011 (MEC/11/04/048). The ethics application included written support for the research from the NRAB.

The main ethical issues related to confidentiality of respondents, particularly patients, and ensuring that patients did not feel any pressure to participate in the research, e.g. by thinking their access to treatment might be affected in some way. Transplant units were asked to mail the questionnaire to patients, and then questionnaires were returned directly to me. This ensured I did not have access to patient details and that transplant units did not
know who completed the survey. Patients’ names and contact details were only made available by patients themselves if they indicated they wished to participate in a follow-up interview. The cover letter made these arrangements clear and also noted there would be no impact on treatment (Annex 2).

Respondents are not identified in the write-up of the research. Where quotes have been used that might identify someone, some details were changed and/or composite quotes used. Permission was sought from key informants who are public figures to use certain quotes that would identify them.

Details of local patient support groups were provided to patient interviewees, as is commonly required by ethics committees. Like Shaw (214), I also took the approach that ethically it was necessary to “respond with understanding and compassion” (p.67). Thus, I answered any questions about my husband’s and my experiences of dialysis and transplant. Knowing how isolated dialysis patients often are, I decided at times to reassure people that their experiences and beliefs were not unusual.

Care was taken not to provide advice to patients. The research was not being used as an opportunity to educate about or encourage patients to pursue LDKT. I therefore talked only about my personal experiences and encouraged interviewees to speak to their own health professionals for information about their own situation. Information sheets about LDKT from the KHNZ website (206, 215) were printed out and offered to interviewees at the end of the interviews. In some cases, an explanation of Kidney Paired Exchange (KPE) (see Chapter Four) was provided if patients had not heard of this and interviewees were advised to speak to their transplant coordinator if they wanted more information.
Chapter Three: Barriers to LDKT – Stages 1-3

3.1 Introduction
This chapter focuses primarily on the content corner of the policy triangle and covers the first research question: what are the barriers to LDKT and what can be done about them? It covers Stages 1-3 of the five-stage patient journey model presented in Chapter Two and is based primarily on the patient survey and interviews with patients and health professionals. Each stage begins with an overview of the international literature, identifying key issues within each step, and then presents NZ results. Stages 4-5 of the patient journey are examined in Chapter Four.

3.2 Stage 1: Transplantation is an option
3.2.1 Overview
The first step towards transplantation (from either a living or deceased donor) is that a patient with, or approaching ESRF, is referred for evaluation and assessed as being medically and psychologically suitable for transplantation. This is a key gateway to transplantation. The general process is typically that patients are identified as potential transplant candidates, are referred for evaluation, complete the medical and psychological tests required, and a decision is made about whether the person is suitable for transplant (216). There are several possible outcomes of this process including that the person: is not suitable for any transplant; meets the criteria for being placed on the waiting list for a deceased donor kidney; receives a pre-emptive LDKT before dialysis has begun, if the process has begun early enough (217); or does not meet the criteria for waitlisting but is eligible for transplantation if they can find a suitable living donor (218). As noted in Chapter Two, everyone on the waiting list for a DDKT is also eligible to receive a LDKT if they can find a suitable donor.

There is considerable focus in the literature on access to waiting lists since formal processes are often oriented around deciding who will have access to deceased donor organs (see Chapter Six for further discussion). However, issues relating to referral and evaluation for
transplantation are also relevant to LDKT, and the timing of these processes has significant implications for whether pre-emptive transplantation is possible.

The initial process of referring, evaluating and deciding on transplantation suitability is usually carried out at a local clinic level or by individual clinicians (although once listed, access to organs is usually through transparent national allocation systems) (219). Deciding who is suitable requires an individualised assessment of the likely risks and benefits of transplantation (170) and is not always straightforward as many patients fall into a “grey area” and judgements are needed about their suitability (220). Criteria for assessing suitability for transplantation usually include life expectancy post-transplant, co-morbidities, lifestyle and psychosocial factors. Older age per se is not usually an exclusion criterion, although age-related co-morbidities may mean older people are less likely to be accepted (54).

International evidence shows there is considerable variation in access to transplant waiting lists (50, 53, 170, 172-173), e.g. criteria for accepting patients vary between countries (173). In addition, there are patient factors associated with lower likelihood of being assessed and/or listed, including older age and the presence of Type 2 diabetes, obesity and hypertension (171-172, 220). None of these factors is an absolute contraindication for transplantation but some studies suggest that older patients or those with diabetes are more likely to be excluded from waiting lists than younger or non-diabetic patients with equal co-morbidities (172). Obese patients are also more likely to be unassessed after adjusting for demographic and co-morbidity factors (220). This is despite evidence that older people and those with co-morbidities may benefit considerably from transplantation and that transplantation would often be a cost-effective option (53, 221).

Ethnic minorities are frequently found to have lower rates of referral, longer evaluation times and be less likely to be waitlisted for transplantation, independent of co-morbidities (167, 222-224). Female gender is also associated with less likelihood of referral for assessment (167, 220, 225-226).

Lack of insurance, being a Medicare patient (in the USA), and economic deprivation have been found to be barriers to referral and listing (220, 227). The greater presence of co-morbidities in disadvantaged populations may in part explain this, but not entirely (227).
The lack of Medicare funding for immunosuppressant medication beyond the first three years is likely to be a factor in the USA (175), leading to a higher transplant failure rate in this population (228) and thus possible reluctance to refer these patients for transplant.

Higher health literacy and patient education levels are associated with being more likely to be referred and listed (229-230). Patients who have demonstrated willingness and ability to comply with medical treatment may also be more likely to be offered transplantation as an option (226, 230-231).

As well as patient characteristics, clinic systems, processes and practices also have a significant influence on whether, and how early, patients are placed on the waiting list (170, 172). Variations in practice may include whether referral and assessment is up to a patient’s own physician or whether processes are in place for regular and systematic review of all ESRF patients (172). Being treated in a renal unit that is also a transplant unit may lead to an increased likelihood of being listed for transplant (170) although this finding is not universal (227).

There may also be variations between centres in the thresholds set for accepting patients for transplantation, with patients being accepted in some centres who would be declined in others (227). This may be on the grounds of making the best use of scarce resources, although it is possible that some centres concerned about achieving the optimal outcomes for their programme may “cherry pick” the best candidates and deny opportunities to others who would also benefit significantly from transplantation (53).

Increasingly, national guidelines for waitlisting are being developed in order to reduce the inequities that can arise from localised or individual clinician decision-making (54). However, even if national criteria for deciding suitability for transplantation are available, there is potential for differences in interpretation by individual clinicians or centres (170). As Batabyal et al note (54) “decisions to wait-list patients for kidney transplantation... are ultimately at the discretion of the nephrologist and the transplant surgeon” (p.711). Clinic systems and processes, e.g. whether all patients are regularly and systematically reviewed by a committee or whether this is left to the discretion of individual clinicians, may also influence a patient’s chances of access to transplantation (172).
3.2.2 Results

3.2.2.1 Referral, evaluation and acceptance for transplantation

Patients did not discuss this stage in detail since all, by definition, had been assessed as suitable for transplantation. However, health professionals reported that there has been ongoing concern amongst NZ transplant professionals about variation between renal units in how patients are referred and assessed for transplantation, including access to the waiting list itself, similar to overseas reports. This included both processes for referral as well as application of criteria, particularly those relating to non-compliance\(^{10}\).

One of the main issues raised by health professionals was variation in how patients are put forward for consideration for transplant and accepted for transplantation, from either a deceased or a living donor. Most people mentioned that, ideally, patients would start being considered for transplantation well before needing RRT to allow adequate time to consider options and make decisions, and, in particular, to allow the possibility of a pre-emptive transplant.

In some centres, systems were in place to ensure that all patients approaching ESRF were considered for transplant:

*We have a database for all our patients who we’ve ever seen and the software selects out patients with low GFR\(^{11}\)....Each month we meet. We have a systematic approach to the population of people we are seeing so we identify people whose GFR’s becoming low....the transplant coordinators look at all the patients moving into that low GFR group and we make a decision about transplantation for them... they can be listed on the transplant list at the point when their renal function has declined to 15 mls/minute, so we can list patients pre-emptively or we can plan live donor*

---

\(^{10}\) Once on the list, NZ has a national Kidney Allocation System which determines how deceased donor kidneys are allocated and aims to ensure all waitlisted patients are considered equally (232). Points are assigned primarily on the basis of closeness of tissue-type match and time spent waiting (233).

\(^{11}\) Glomerular filtration rate (GFR) provides a measure of kidney function. ESRF is diagnosed when GFR is less than 15mL/min/1.73\(^2\) (234).
transplants pre-emptively because we’ve got a good handle on that group of patients.

The role here is to make sure that every patient with end-stage renal failure who’s going to lose their kidney function is actually assessed, even if it is deemed that they’re medically unsuitable.

In other centres, individual clinicians played a greater role in deciding on referral and suitability for transplantation:

Whilst we try to bring up transplantation issues early, it depends on the individual clinician with that patient as to how aggressively it’s sought....it’s up to the individual as to how to approach it really and the individual rapport with that patient. So the only agreements we have are what our criteria are to get on the list, from the medical/social aspect. Are they fit enough to receive a transplant? So if they fulfil those criteria then the rest of the discussions are up to the individual.

Some people felt that sometimes too much of the decision-making about who would be referred for assessment was left to individual clinicians. Variation in referral practices was felt to be an issue, with the decision about being referred being up to individual clinicians in many units:

The thing is that we have a pretty strict protocol about who gets on [the list] so that’s quite transparent, but we don’t have the protocol for how you get discussed or presented. That’s very, very variable all round the place, as it is all round the world.... My way of doing it would be that everybody who had renal failure got seen by their pre-dialysis nurse, specialist, coordinator and got worked up for transplant and live donor transplant. It wouldn’t be left to physician vagaries (and people don’t see physicians long enough anyway and the time you’ve got allocated in clinic’s just not long enough to do all that). So I would just have everybody worked-up and then they’d all be discussed....I think you just have it where everybody gets worked up and you’ve actually got to present a reason why not and they have to be honest about that.
Different transplant units may also take different philosophical approaches to transplantation in general:

There was a recognition that dialysis was difficult and patients didn’t do well on it, and indeed died despite it, so this unit was more willing to take a risk on transplanting people because they could see the patients weren’t doing too well… whereas another unit saw transplants as a limited resource and so therefore said it should go to those who will most benefit from it… and that’s overlaid with a philosophy that they set quite a high standard for people to go on the list.

Ability to comply with medical treatment often forms part of the assessment for transplant acceptance. Australasian guidelines (218) specify an exclusion criterion of “inability to comply with complex medical therapy” (p.9). Previous NZ research (74) has suggested that there may be a form of “subtle bias” in the approach of some transplant staff; for example, “an attitude wherein some patients have to ‘prove’ they are worthy of a transplant and the concomitant belief that patients who demonstrate non-compliance are less likely to get a transplant” (p.5).

A few respondents discussed the issue of “non-compliance” which requires more subjective judgments and is therefore a source of variation in who is presented for assessment or accepted on to the list:

The other major variability is about compliance and about how it’s assessed or judged, judged being a better word than assessed. I don’t think that any one doctor or nurse should be making that decision and I think that anybody who is fit for assessment or fit for transplant should be presented to a group for assessment of compliance….You can get bees in your bonnet about things like how someone’s doing their dialysis or not. I think there’s no great hardship about discussing it in the meeting….We have transplanted some real ratbags and they’ve been fine after transplant. So there is wide variation about compliance.

Overall, there was some concern about equity of access to transplantation:

There are some very vague rules in different DHBs about who is entitled to give and who is entitled to get.
Chapter Three: Barriers to LDKT – Stages 1-3

The debate is that people are happy to accept some limitations on the list, so long as they are convinced that everybody in the country is following the same limitation – so equity from the point of view of the whole country getting it….so I think everybody agrees there should probably be some sort of good use of the kidneys… but it’s not consistent [getting on the list] so [having national guidelines] will help, will make it more uniform.

Health professionals reported that issues of variability in referral and acceptance for transplantation were being addressed by the NRAB and NZ Renal Transplant Subcommittee and national criteria were in the process of being agreed.

3.2.2.2 Recipient evaluation

Some centres report that there can be delays in completing recipient assessments because of the need to access tests by other hospital departments, particularly cardiac assessments:

If they just need a basic assessment without any extra bits and pieces, it probably takes two to three months. If they need anything additional, one of the hold-ups we have... is that we get everybody to have a cardiac evaluation... and depending on where they are, sometimes there is a bit of a hold-up.

One of the issues for recipient evaluations is that appointments are usually prioritised on the basis of need or urgency and people being assessed for transplant may not have high immediate need (see also Stage 4):

I think one of the biggest delays is actually accessing cardiology services as an outpatient to do that...if we really need something done, I really have to go to Cardiology and really make my case and push people forward for it... because if they’re already on a dialysis programme or they’re well managed at the moment, they tend to be pushed back.

Difficulty getting work-ups done not only slows the process down but can potentially mean a patient misses out on a transplant altogether:

We can’t get our patients worked up in a timely fashion. In deceased donation, you’ve got that window of a year or so to get someone worked-up and on the list. You’d like to get it done as quickly as possible but there’s no actual penalty for being
slow other than the patient dies, which may not be a penalty – death is cheap. With live donation you’ve gotta get them quickly before people have babies, change their mind, do other stuff or someone gets settled on dialysis and thinks, “Oh well I might as well stay here now”. So I think you need to get it done very quickly - a short, sharp shock.

3.2.2.3 Reassessment
Transplantation Society of Australia and New Zealand (TSANZ) guidelines specify that patients on the waiting list should be formally reassessed annually to ensure ongoing suitability (218). However, several people also mentioned the issue of reassessing patients who are not on the waiting list, either because they were initially declined or because they have been temporarily suspended. In some centres, reassessing non-listed or suspended patients was carried out systematically:

We have a database and once they’re on dialysis, every patient who’s not on the transplant list is considered again every month; why isn’t this patient on? We have a large group of medically unfit patients here because they’re in an elderly group with a lot of co-morbidities, but everybody’s who’s on dialysis who’s not on the list is considered. That’s [transplant coordinator]’s role, once a month to look at why they aren’t being assessed.

In other centres, however, reassessment processes were less systematic:

People get suspended, particularly young people, for non-compliance. And they just get suspended for ages and so periodically I’ll go through the list of everybody who has been off for more than 18 months to find out why, and ask that those people get formally presented again… there’s no process for being automatically re-assessed if you’re suspended.

Patients who had been suspended from the list for medical reasons felt they had to actively pursue reassessment:

Yeah, I pushed it. That was one of the questions that I kept on asking the doctor, “What’s the story?” Blood pressure was the main concern, I had high blood pressure... but then the blood pressure come down and the first thing I said is, “I
want back on the list.”...Possibly they would have suggested it but I think even if they suggest it, they don’t sort of push the paperwork through that quickly.

One health professional commented on the importance of reassessing patients because circumstances can change:

I always think that even if someone isn’t suitable for transplant they should still know what’s available because their circumstances might change and it might be available in a year or two years or five years....We went through every single patient in our service, working out who was listed [and who wasn’t]...and what the reason for that was and then the next step was to go back and say, “Okay, did you know the reason why?” because some of the reasons are changeable. Medication adherence for one, that’s such a subjective thing that can make a big difference to people and if they don’t understand that’s the reason that they’re not being listed, that can make people change completely....I think it is a problem because sometimes it doesn’t get revisited and then, potentially, unless someone’s thinking, “Are you now suitable for transplant?” you’re missing a very good opportunity.

Being assessed, and reassessed, as suitable for transplantation is the first step in the process but several steps remain before LDKT is achieved, including whether patients are told about LDKT and patients themselves deciding to pursue LDKT.

3.3 Stage 2: Patient is told about, and decides to pursue, LDKT

3.3.1 Overview (2a): Discussions with patients about LDKT
In many disease areas, the discussions clinicians have with patients are strong predictors of the treatments patients choose (235), and the effectiveness of communication between health professionals and patients has long been known to influence patient understanding of their disease, feelings about the disease, choice of treatment, and outcomes of chronic disease (236-238).

Several studies have found that renal patients are not always provided with comprehensive information about RRT options, and that many patients are not fully informed about transplantation (217, 220, 238-239). In particular, pre-emptive transplantation, which
typically involves a living donor, may not be adequately covered in patient education (178, 240).

Being informed about transplantation options is significantly associated with access to transplantation (either being listed or receiving a transplant) (220) and transplant recipients have been found to be more likely to be able to recall a conversation with their physician about transplantation, than patients who had not received a transplant, with recipients of a transplant from a living donor the most likely to recall a conversation (175).

Clinician attitudes may be important. The options presented to patients typically reflect the attitudes of clinicians (177) which may also affect outcomes. For example, positive opinions about transplantation are related to fewer encounters being needed to motivate patients to have a transplant evaluation (178) and, as suggested by Sofaer et al (cited in Gordon (187)), to higher transplant rates, although the possibility remains that attitudes do not always reflect actual practice (178).

Nephrologists’ attitudes towards transplantation are generally reported to be very positive with the majority agreeing that transplantation is the treatment of choice for most ESRF patients (although some groups, such as older people, may be less likely to be encouraged to seek transplantation) (52, 177, 235, 241-242). Around 70% of nephrologists agree that pre-emptive transplantation (which is more commonly from a living donor) is the best treatment for ESRF (177-178). Transplant centres have also become more willing over time to allow friends and non-directed donors to donate (243).

Positive attitudes are more likely in nephrologists who are younger, have been in practice for less than 10 years, work in transplantation rather than dialysis, and work in larger urban renal centres (177-178).

Patient factors may affect who is specifically offered the option of LDKT. Health status, compliance, age, lack of insurance were associated in one study (178) with delayed discussion about pre-emptive transplant. Many Australian nephrologists were found (242) to be unwilling to refer a patient with Type 2 diabetes for LDKT and far less likely to recommend living donation to a potential donor if the patient’s ESRF was due to diabetes.
The approaches and practices of transplant units are thought to be associated with variation in LDKT rates (more so than DDKT) in both Australia (179) and the UK (170). Walker et al (179) note “it is important that patients understand that differences in approaches and/or providing access to live donor transplantation do exist among professionals and that different patients at different institutions are likely to be offered different ESKD treatment options” (p.3).

Variation in the way clinics introduce and discuss the topic of LDKT with patients may therefore be a factor in which patients choose to pursue LDKT and is a potentially modifiable barrier in transplantation pathways (174, 176, 179).

Information about RRT options may come from many different sources including multidisciplinary teams (175), social workers (181) and pre-dialysis nurses (244), as well as patient groups, websites and online social media (245). Previous donors and recipients can be important sources of information about LDKT for transplant candidates, with one Canadian study reporting that this was the most highly desired source of information, followed by transplant surgeons or nephrologists (180). The opportunity to meet with previous donors and recipients may therefore form an important part of any formal education process (180, 192).

The health professional’s role in discussion of treatment options, however, is critical. Kaplan et al (236) note that:

*the physician may be in a unique position not only to influence the patient’s technical care and to persuade the patient to follow the dictates of that care, but also to change the patient’s perceptions of their health status and beliefs and self-confidence regarding their ability to influence their health status and to provide motivation and incentives for engaging in health promotion (p.112).*

Renal health professionals may also be the preferred source of information for patients. A European survey found that this was the most important and helpful source of information for renal patients (245) while a USA survey found that the most preferred way to learn about treatment options and issues was one-on-one with a physician (43% of respondents
compared to the next most preferred option of a class or seminar at 7%) (175). Family doctors, however, may not be a desirable source of information for patients (180).

Overall, the European Kidney Patients’ Foundation (245) comments that “doctors and nurses should not be thought of as replaceable by online guidelines or patient communities and forums….patients’ views on their disease is still shaped by and largely dependent on the information given to them by healthcare professionals” (p.15).

Early consideration of LDKT may facilitate pre-emptive transplantation or at least give patients and families adequate time to fully consider the risks and benefits of LDKT (175, 181). However, transplantation may often be mentioned too late to enable pre-emptive LDKT, and education may initially emphasise dialysis, on the basis that patients cannot cope with too much information at once and, since most are likely to end up on dialysis, this is what needs to be discussed most (235).

Where discussion about LDKT does occur, it is most likely to be around the time when RRT is first needed. Thus, patients who do not initially indicate interest in transplantation may not have further formal opportunities for discussion and education (180). However, patient preferences may change over time, e.g. as their health deteriorates they may become more open to the idea of LDKT (182). This suggests that treatment options should be discussed regularly and systematically, including with patients who have previously indicated no interest in transplantation or who have said there are no likely donors amongst their networks (180, 182, 192, 235).

Comprehensive and accurate information about all RRT options is necessary for informed patient choice and decision-making (220, 245-248). There is increasing concern, however, about an emphasis on “modality neutrality” in RRT education when presenting different treatment options because some choices are clearly better than others in terms of both survival and quality of life. Different forms of dialysis may have different implications for patients (246-247) while transplantation is the preferred option above dialysis in terms of morbidity and mortality, but many patients may not even be told about it (175).

Transplantation may not be presented as an option at all, or as only one of several equivalent options, because it is not perceived as being practically available to most patients.
The European Kidney Patients’ Federation (245) points out that “these alternatives are not neutral choices, either for individual patients and their quality of life, or for health systems and their overall budgets” (p.9) and argues that the shortage of donors should not be accepted as a reason not to inform patients about their options.

Prognostic or life expectancy data, in particular, may not be clearly communicated to patients (183-184, 235, 240, 246-247). One survey found that, while nephrologists are willing to tell patients that without dialysis they will die within weeks or months, they are far less willing to reveal the mortality data relating to dialysis itself unless a patient specifically asks for it (240). A survey of patients in Canada (183), however, found that 97% wanted to know about life expectancy on dialysis, and almost all said that the information should be volunteered without having to be requested by the patient. Similar debates have occurred in other areas of medicine and are not restricted to renal (183, 235, 247, 250).

Information about life expectancy may be withheld because of a view that disclosure of distressing information that a patient has not specifically requested may breach the principle of “do no harm” (184) or from a desire to maintain patients’ hope (235).

These conversations may be challenging for health professionals. Mendelssohn et al (240) comment that “disclosure of end-of-life information inherently is a complex and ambivalent task for [physicians]” (p.283). Abbott and Gaston (249) note that it is perhaps “not... so surprising that such potentially awkward conversations are often avoided” (p.273).

Other challenges to effective discussions may include time constraints, complexity of the information, patient characteristics such as educational background or level of worry (238, 248), health literacy (251), and power imbalances between clinicians and patients (252).

Dimensions of patient-provider communication that may be particularly important in LDKT decision-making include education and knowledge for patients, families and providers; availability of culturally sensitive and language/health literacy-appropriate information; and provider trustworthiness (253).

Mendelssohn (184) concludes that, although there are many challenges to having these awkward conversations, health professionals should “not actively or passively create an illusion about health and quality of life on dialysis” (p.239). Furthermore, he notes that an
important flow-on effect from greater openness about the risks and benefits of different treatment options is that it may “stimulate renewed efforts to enhance the pool of transplant donors (live and cadaveric)” (p.239).

3.3.2 Results (2a): Discussions with patients about LDKT

3.3.2.1 Is there a discussion about LDKT with the patient?

Despite being on the waiting list, more than a fifth of survey respondents said either no one from the renal unit had ever discussed LDKT with them or that they did not know (Table 3).

<table>
<thead>
<tr>
<th>Table 3: Number of waiting-list patients who reported someone from the renal unit discussing LDKT with them</th>
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<tr>
<td><strong>Number (%)</strong></td>
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<tr>
<td>No discussion</td>
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<tr>
<td>Discussion held</td>
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<tr>
<td>Don't know</td>
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<td><strong>Total</strong></td>
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People in older age groups were less likely to report someone discussing LDKT, compared to people in younger age groups ($p=0.042$) – 89.1% of people under the age of 46 had had a discussion compared to 64.4% of people over the age of 64. People with a partner were also significantly more likely to report a discussion than people without a partner ($p=0.005$): of the people with a partner, 83.1% (108) said they had had a discussion with the renal unit compared to 64.3% (36) of people without a partner. There were no statistically significant differences in this research in terms of region, ethnicity, gender, time on dialysis or being a previous transplant recipient.

Follow-up interviews with patients explored in more depth patient perceptions of the discussions the renal unit had with them about LDKT. Consistent with the survey, most people said that LDKT had definitely been mentioned at some stage. Discussions took place in a variety of settings and with a range of different health professionals, including one-on-one discussions with nephrologists or transplant coordinators, or group education sessions. Some patients reported being approached about LDKT during dialysis training sessions. Casual conversations about LDKT with other health professionals such as dialysis nurses, technicians or social workers were also mentioned.
An important theme was patients’ perception of how in-depth the discussion had been, or even whether there had been a discussion at all. Of particular interest were the interviewees who had said on their survey that there had never been a discussion with them about LDKT. Interviews suggested that in all cases there had in fact been a discussion of some kind. However, these patients felt the discussion had been superficial or something mentioned only in passing. Even where the discussion had been part of a formal or planned education programme, it had not necessarily registered as being a specific discussion about LDKT, as being particularly significant or as being about them directly:

No, not specifically. I have had a general discussion with the transplant coordinator and they put on a mini-seminar prior to actually going on dialysis about the different options. And they explained things like the anti-rejection drugs that you’d be on and some of the side-effects and things like that.

No, we haven’t had a chance to really do that. We’ve discussed it to the point like, “Is there anyone in the family that’s available?” and as it turns out there were two or three but no, we haven’t really gone into it, really sat down and talked about it....I don’t believe we talked about it as such. We just touched the subject of, “Okay, well, we’ll investigate that”;

I am aware of a live transplant. There is no obvious person [donor]. They [renal unit] haven’t said much to me about it. Well, he may have done but it’s not something that is uppermost in my mind that I can remember quite distinctly and got terribly excited about. I think it was a bit vague, a bit out there, a bit general and I thought, “Oh, yeah,” and I would just go home and forget about it. My wife would ask how it was and I wouldn’t even mention it, it wasn’t a big deal. But I just thought it was a bit blasé, a pretty laid-back approach to the whole thing. From both parties really.

3.3.2.2 Changes in discussions over time about LDKT
A consistent finding was that patients reported the main discussions about LDKT seemed to occur at about the time RRT was first needed, either before dialysis commenced or shortly after, with respondents in both the survey and interviews commenting that discussions were “one-off” or “only at the beginning”. In general, it seemed there was a change of focus over time and it was less likely that LDKT would be discussed as time went on. Regular
patient clinic reviews became more about discussing dialysis management than transplantation:

> I feel that even now when I go for my appointments, there’s no urgency...I mean, I understand where they are. They can’t get me a kidney. But they’re like, “Oh, you’re fine, you’re happy, you’re dialysing, you’re on medication, see you later.” Like it’s nothing.

> When I go for my check-ups they don’t talk about transplantation, no, I mean they mention it, saying, “Still waiting” or “Still on the list”.

Patients in some regions continued to be seen by the same nephrologists throughout the course of their illness. Others, however, reported that while initially they had been seen by nephrologists actively involved in transplantation, this ceased to be the case over time, particularly once there were no longer any potential living donors being tested:

> Once you start dialysis you get a whole new team, and since I’ve been going there, I think I’ve had three different [specialists] that I see....As soon as you start dialysing, the transplant tends to drop off the radar. There’s no follow-up, nobody’s come and said, “Have you still got anyone else that you think might be considered?” or even an email, or phone call, nothing. There’s been no follow-up from the transplant coordinators since I’ve started dialysis.

Many described a feeling of isolation on dialysis:

> You just feel like you’re on your own really. I know they’re only at the end of the phone and they’re here the next morning if something goes wrong, but we’re just sort of autonomous.

### 3.3.2.3 Health professional perspectives on discussions about LDKT

#### 3.3.2.3.1 Health professional attitudes to LDKT

Like many of their overseas counterparts (177, 242), NZ health professionals were overwhelmingly positive about LDKT and clearly stated that it was by far the preferred treatment for most ESRF patients:
I’m a renal physician and I think there is no doubt the most rewarding aspect of my work is dealing with transplantation and if I have a patient coming through for dialysis who has a live donor and we can get it all sorted and avoid dialysis completely – then that gives me a real buzz.

Generally, everything with donation is such a feel-good thing, you’re making lives better....And if you ever go on the ward, if we’re doing a transplant, everyone feels upbeat about things. It’s a positive thing; dialysis is not.

There was acknowledgement that attitudes in the past had often not been as positive amongst renal physicians but that this had gradually changed. It was felt, however, that there was still some variation amongst health professionals:

I think that there is an increasing awareness. In certain centres there’s always been people that are passionate about transplantation but there are people who...have been primarily dialysis people, who have not got in the way but have not pushed it along. Times are changing.

I think there’s some variation. I think people are pretty keen on it now...but people worry. For instance, there’s been two reported donor deaths in Australia in the last 10 years and whenever they come to the press, I can see people worrying. But the trend is for them to become more advocates, particularly the younger nephrologists.

Consistent with patient perceptions that the focus on transplantation reduced over time, most health professionals confirmed that there was typically significant emphasis on discussing LDKT when a patient was approaching ESRF or had just started dialysis. They described a “window of opportunity” to get someone transplanted while family and friends are most likely to be motivated to donate and before patients have become used to being on dialysis.

Overall, LDKT was seen as the preferred option and it was felt very strongly that ESRF patients should focus on finding a living donor if they wanted a transplant:

If you’re going to have a transplant, you’ve got to get a live donor transplant; there’s no point going on the waiting list. If you’re trying to manage your patient with end-
stage renal failure by putting them on the deceased donor list, it’s just a nonsense because you can’t. You’ve got to get a live donor transplant, otherwise you’re probably more likely going to die or become medically unfit on the list than actually get one.

Live transplantation is certainly the way to go as the deceased rates seem to be staying pretty static. The only way really to get more transplants done is to have living transplants and they’ve proven to be so successful that it’s obviously the best way to go.

3.3.2.3.2 What health professionals say to patients about LDKT

Education about transplantation can cover a range of topics about risks and benefits, the process of transplantation, and criteria for recipients and donors. Two significant themes discussed in the interviews were whether LDKT was encouraged or promoted as the best treatment option and why; and what patients were told about the deceased donor waiting list.

3.3.2.3.2.1 Is LDKT clearly promoted as the best treatment option?

Health professionals all said that their renal service told patients that LDKT was the “best treatment option” for most people with ESRF:

We tell them that it’s considered the best treatment option. I always say to them, I don’t think you’ll find a physician or surgeon who works in the area who won’t tell you it’s the best option.

Unless there are obvious contra-indications or they are too unwell, or the prognosis is so poor, I will always talk about live donation as they are approaching dialysis and I stress that every time.

It is difficult to know how consistently or how effectively these discussions are done, considering the findings from the patient survey and interviews. Patients and health professionals appeared to have different views about what constitutes a discussion about LDKT and how this should be done. Some health professionals recognised that more could be done:
I think there’s obviously work to do within renal services to promote transplantation more with patients than we currently do; I’m sure there’s room there. Because we tend to fall back on dialysis all the time.

Some health professionals talked about the difficulty of getting the “right balance” when giving patients information about transplantation. Some felt there was no point or it was unfair to “talk up” transplantation for people who were unsuitable for transplantation, and did not want to make dialysis seem “hopeless”:

My job is to say that transplantation is considered the best renal replacement therapy option for failing kidneys and these are the two types of transplant. There’s no point in making someone on dialysis who hasn’t got a live donor and who’s blood group O feel miserable about the fact that they may never get a transplant…you have to keep that balance. And there are patients who have survived on dialysis for 20 years so you cannot say that they may not have a reasonable life expectancy.

The main reason for not consistently “talking up” transplantation, however, was the low chances most people had of ever getting a transplant:

It would depend… I mean there’s no doubt that if you have a transplant, on average you’re going to live longer, the difficulty is that if you sit there and hype up all the transplant stuff too much and then they’re not going to get a transplant, then I think that’s a bit miserable. And if you are young, well, young people in general are going to live for a reasonable time, although a lot less if they stay on dialysis. But I think you have to be a bit careful about making the dialysis thing too bleak so it’s going to depend on when I see them and whether it looks like they’re going to be suitable for a transplant.

However, there is a risk this simply becomes a self-fulfilling prophecy:

If live donation is the best option, we should be promoting it. How well do we as health professionals know what their family circumstances are or who in their lives are prepared to give them a kidney?
Respondents commented on a debate about what information to give patients regarding the risks and benefits of different RRT options. Although some people will live for a long time on dialysis, it is accepted overall that a transplant increases life expectancy. Some respondents commented, however, that there are many renal health professionals reluctant to highlight that to patients:

There’s a bit of not quite telling the full story. We’re just rewriting our information booklet and we’ve decided that we’re going to be more honest about the life expectancy outcomes for people with kidney failure, particularly for dialysis, because we think that’s really important. We can’t just paint it to be a pretty picture, we have to be honest and I think that’s becoming a lot more accepted now as well.

The only way to motivate a patient to get a transplant is to tell them death is coming. It’s extremely hard to get my colleagues to tell patients that death is coming....Our pre-dialysis education is on the benefits of dialysis and is generally encouraging and optimistic and I agree that you have to do that. But it doesn’t say that in three and a half to five years you have a 50 percent chance of pushing up daisies and the only way to motivate transplantation really is to tell them that. I think that doctors’ attitudes are critical in this process actually.

Respondents acknowledged that these were potentially difficult discussions:

We draw them a graph to show them life expectancy of the different options so they can actually see...whether it’s just that some people don’t want to be the bad news bearer, I don’t know.

Health professionals recognised that discussions about transplantation could vary between patients. A few people commented that they were more likely to actively encourage certain people to seek LDKT than others, particularly younger people. This is consistent with the finding from the survey that older people were less likely to report anyone having a discussion with them about LDKT:

I probably focus very much on our young people on dialysis too. I talk to them about what their options are going forward, and how much quality of life they can gain back, and how long they can live as well because the longer they’re on a dialysis
programme the more complications can develop…I think it’s probably just me, my personal view that I want to see a young person off dialysis. I get really concerned about them.

With some people you might say, “Well, we don’t have to think about it now, we can think about that later.” If it’s a young person, 20s, 30s, 40s, you’ll say, “Look, really the only option we should be trying to get is a pre-emptive transplant.”

3.3.2.3.2.2 The deceased donor waiting list
Some clinicians thought that the chances of getting a transplant from a deceased donor were so small that patients were much better off finding a living donor, or risk dying or being taken off the list:

I tell them at the moment the average waiting time is five years so they could be lucky and win Lotto next week as soon as they go on the list. But I see the flip side as that’s the average and many people wait a long time and then get too unwell to ever receive one.

When I’ve seen people in the nephrology clinic, I’ve told them they should be having a live donor kidney….I say to the ones I’m looking after, “You’re not going to get a transplant; you’re going to end up on dialysis for ages and eventually you might get one if you’re lucky, but if you actually want to have a transplant, find someone.”

Some health professionals were concerned about patients’ understanding of their chances of receiving a deceased donor kidney. “Waiting time” refers not to how long people will wait until they get a transplant, but rather to how long people who did get a transplant had actually waited. Most people who are listed, however, do not get a transplant and die or are removed from the list because they have become too unwell:

Patients get the idea that they’ll get a transplant in four and a half years. It’s an incorrect perception and it’s quite difficult to explain… I’m not sure that it’s only patients that don’t understand that, many physicians don’t get it…It’s a problem worldwide. The waiting time can only ever be the time that it takes before people get transplanted. No one presents their data in terms of the people that drop off and
never get one... I think it is a big problem that people just don’t understand that about the list.

Combined with not understanding the risks and benefits of dialysis and transplantation, it was felt that patients may not have a sense of urgency about LDKT, e.g. may be less motivated to look for a living donor, or may turn down offers from potential donors (see Stage 3):

*Being on the list gives people hope, but it’s also a bit of a false hope... [they might not be very active about looking for a live donor] because they think, “Well, I’m on the list...”*

[Patients will turn offers down] and that might be a misunderstanding about how long it’s going to be before they get a kidney... [there’s also not that urgency about getting a live donor]. It’s partly that dichotomy of how much you play up having the transplant and how much you talk about dialysis being a misery.

3.3.2.3.3 Challenges to effective discussions about LDKT

Health professionals discussed the barriers to effective communication with patients about what is a complex and highly emotional topic. Several health professionals described their patients as being in a state of shock when they were told they were approaching ESRF and were not ready, or were unable, to hear the messages they were given. Information about RRT options often had to be repeated many times or when the patient was ready to hear it:

*There’ll be patients who have been told things and don’t recall or don’t hear... particularly in those early days with their developing kidney failure, I encourage them to bring other people in because too many times people don’t quite hear what you’re saying, especially in the important conversations about dialysis and transplant....In some appointments you have a lot of information to give out... so four ears are better than two.*

*When they’ve first been told [about their renal failure] and the nephrologist asks me to do some education, I take them next door and say, “Are you ok?” and generally they burst into tears....People just can’t hear; they hear “dialysis” or “transplant” and they just stop hearing... and the next time I see them I say, “What do you*
remember?” Most of the time they don’t remember anything, it’s just gone over their head.

Some patients were also aware of the difficulty of remembering or taking in information:

I probably did ask and I probably was told but it never really registered when I asked. ‘Cause you always come back from those things and think, “Now, what did I hear?”

Patients also talked in their interviews about their reactions to being told they had CKD or ESRF. For people who presented late, dialysis sometimes had to start immediately:

It was a shock! It was a shock to the system...the diagnosis was Sunday and by Monday I was dialysed.

Even those who had known for some time that they had CKD described their reactions most commonly as shock and denial:

They were trying to show me the machine, this lady, she was showing me all these lines and things. I just couldn’t take it in, I really couldn’t. And the bag thing, that came later but by that time I didn’t want to know. I thought, “I can’t deal with this”.

Another of the difficulties cited by health professionals was the lack of time in clinic appointments with nephrologists to really talk about all the treatment options. Effective discussions often needed to happen over many sessions.

Some people acknowledged that these were difficult conversations to have and that health professionals rarely received any training or advice on how to carry out such conversations:

You don’t really learn how to have those conversations...well, you do a little bit, as a registrar you learn from talking to your seniors about how to do those things when they come up but a lot of it comes down to the individual personalities and how people do that. There’s a lot of that in medicine, I think it’s a poorly taught area of medicine. I think the medical schools are slowly doing more of that communication skills stuff but when I went through there was very little on that.

How to communicate clearly to laypeople was identified as an issue:
I guess as health professionals we’re used to talking about it and in some ways we normalise the way we’re educating people and we get used to the terms and it’s our expectations of what they are getting from us. Unless you go and sit on the consumer side of things, you don’t understand what someone without medical knowledge is actually taking in. Like [regarding peritoneal dialysis] people often say, “Well what do you do with the plastic inside you?” because we talk about, “the bag going in” so that’s what they imagine.

One of the challenges for health professionals is how far to push patients about their attitudes and beliefs about transplantation, even when these are based on misinformation. Some people said it was not their role to challenge patient beliefs while others took a more active approach:

You get all sorts of reasons like, “I couldn’t ask my daughter because she’s got two little children.”…There’s two sides to it, one is I think you have to respect their view and secondly you can say, “Well, we may be able to look at support for them.” But they’re worried about their own child and I think you can’t tell people how to feel about their own child and grandchildren, I think that’s not appropriate. I think you can say, “Well, it may be in time you might feel differently about that.”…I’m not sure exactly what they’re worrying about because I don’t think it’s my place to push at that. If they say, “I don’t want to ask my daughter because she’s got two little children,” I think you respect that really.

Some others felt they should challenge a bit harder or try to find out what patients were really worried about so that concerns could be addressed:

So we talked about the possibility of a transplant and whether he had talked to anyone in his family and he told me that no, he couldn’t. He didn’t want to ask anybody. I said to him, “But you would like a transplant?” and he agreed that he did want a transplant. I said, “If somebody could ask for you, how would you feel about that?” So he thought that that was a good idea. He said, “Yeah, I do want one but I don’t want to be the one that asks”.

65
Discussing with patients what is involved in donor evaluation can give reassurance that people would not be accepted as donors if they did not meet the medical criteria:

> For parents who won’t take one from their child, you have to accept their point of view and then I try to deconstruct a few myths really and say, “Well, here are the issues. We have to consider genetic diseases and things like that.” I do talk about the risks that we know about for young people in terms of lack of risk if they are fit and healthy. Because a parent’s concern is normally that they would develop kidney failure later and you have to say, “We would do all the tests and only accept them if they fit our criteria as suitable donor.” Sometimes that works, but most times it doesn’t.

Even though discussions with patients can be difficult and require challenging patient beliefs, some health professionals felt this was an important part of their role:

> As long as you make it very clear exactly where they’re at and where their options are, I don’t know how far you can push that because you still have to maintain a rapport with that person as well. You have to look for your opportunities to bring it [potential donors] up, but sometimes we just have to raise it. It’s not up to us to be reserved in what we say to the patients unless we think it’s going to be offensive to them at the time. You just have to bring up the difficult bits for them and you just have to say, “Look, this is going to be difficult”.

### 3.3.3 Overview (2b): Patient willingness to pursue LDKT and accept offers

The benefits of transplantation are so great that it might be expected that any ESRF patient with the opportunity for a transplant would gladly accept it, but patient decision-making is more complex than this (187-188). Patients may decide they are not interested in any transplant (live or deceased) (254) or may be willing to accept a transplant from a deceased but not a living donor (187).

People on waiting lists are by definition willing to accept a DDKT. Around 90% of waiting-list patients in both Canada (180) and the Netherlands (188) say they would also accept an offer from a living donor. Many patients say they actively prefer LDKT to DDKT, primarily for the better quality of a living donor kidney (188). However, even those who want a LDKT may
have concerns about it which affect how actively they pursue LDKT or whether they will accept offers from potential donors (189).

Patient knowledge is a critical factor influencing a patient’s approach to LDKT, hence the importance of effective discussions about RRT options (above). Levey et al (255) note that “sound information of the benefits and risks to donors and recipients is the underpinning of kidney transplantation from living donors” (p.343). Preferences for LDKT and willingness to accept an offer of a kidney do not appear to be related to ethnicity or gender but have been shown to be related to the perception of the risks and benefits of LDKT, including patient longevity. Patients with misperceptions about the risks associated with long-term dialysis and who lack understanding of the benefits to themselves of LDKT are more likely to say they are unwilling to accept a kidney if offered (185).

Studies suggest that knowledge of CKD is low in the general population, relative to other common chronic diseases (256) and there may be significant variation even within renal patients in their level of knowledge (257). Patients may underestimate the risks of ESRF, especially cardiovascular disease, the primary cause of death in patients with ESRF (185). Lack of awareness of survival rates of different treatments (as discussed above) may have a direct influence on the choices that patients make about pursuing transplantation or remaining on dialysis (235).

For example, Murray and Conrad (189) found that patients said they would consider accepting a transplant from a living donor when they became “really sick”, noting that patients “did not view themselves as currently in a life or death situation [as] in their minds, being on dialysis was a successful treatment for ESRD” (p.482). Another study (175) found that 60% of renal patients viewed transplantation as a “last resort” which is to be pursued once all other treatment options have been exhausted, rather than as the preferred RRT option. Many transplant recipients also said that if they had had a better understanding about the benefits of LDKT, they would have pursued it sooner.

Optimism about receiving a DDKT may also be related to being more likely to decline offers from living donors or preferring to wait for a deceased donor (258-259).
As noted above, patient preferences may change over time, and those who are unwilling to accept a donor initially may consider it after being on dialysis for some time or experiencing medical complications (187, 197).

Worries about the health impacts on donors (both short- and long-term), financial burdens for donors (especially loss of income during the recovery period), and fear about impacts on relationships with donors, e.g. being worried about being obligated to the donor, are widely reported (175, 185, 187-189, 258, 260).

Concerns about health risks to donors are found to be greater amongst patients who have not previously undergone a transplant (175). While many patients have a generalised fear of what living with one kidney might mean for a donor, other fears are based on a specific knowledge that many of the causes of ESRF have a genetic basis, in which case a related donor might be at risk themselves (185, 187). Some patients are concerned specifically about peri-operative complications for the donor and about the appearance of the scar, a concern which may be reduced if laparoscopic nephrectomy is an option (185, 260).

Unwillingness to accept a kidney from one’s own adult child is common, e.g. because of a parent’s desire to protect their child from harm or because the patient’s grandchildren might need a kidney in the future (180, 187). Fear of rejection, including worry about how the donor would feel if the transplant failed, is also reported (189). Uninsured patients in the USA may be reluctant to pursue transplantation because of the Medicare policy of only funding immunosuppressant medication for three years (175).

Patients’ social networks may motivate them to pursue transplantation, or discourage them from doing so. Patients with people in their social networks who are knowledgeable about transplantation, including people who are a previous recipient or donor, were more likely to want a transplant (261). Negative experiences, on the other hand, such as knowing of someone with a failed transplant, may influence patients not to pursue transplantation (254). Amongst Gordon’s (254) sample, there was a view that “most” transplants failed and some patients had been actively dissuaded by recipients of failed transplants from seeking one.
Gaps in knowledge and concerns about LDKT impact on a patient’s approach to LDKT. Patients typically overestimate the risks to donors which may affect their willingness to ask others about donation or accept an offer (128, 176, 185) and they may decline offers without full consideration of the risks and benefits (182, 187). High patient knowledge and positive beliefs about LDKT may be related to having someone interested in donation or being evaluated. People in one study who had actually received a transplant had the highest knowledge and belief scores, while those with the lowest scores had no one interested or evaluated (180).

Rodrigue et al (182) note that patients’ attitudes and concerns about LDKT are not homogenous, suggesting that patients need both general information about the risks and benefits of both dialysis and transplantation, but also “a more detailed discussion that specifically addresses their unique concerns about LDKT and living donation” (p.30).

Coorey et al (175) note that “fears and emotions are subjective; they are not easy to quantify or alleviate. In the absence of appropriate education, patients learn myths instead of facts and will fail to grasp the consequences of inaction as their CKD progresses” (p.36), while Hilhorst et al (262) note that for patients, “medical, psychological and ethical considerations...are intertwined in a complex way” (p.83). Murray and Conrad (189) also argue that health professionals must spend time addressing the individual concerns and fears of patients and their families and suggest that “changing one’s perceptions about receiving a transplant requires more than just education” (p.483).

3.3.4 Results (2b): Patient willingness to pursue LDKT and accept offers

3.3.4.1 Preference and willingness to accept LDKT
Like patients overseas (180, 188), NZ patients were very keen to get a transplant with high levels of support for LDKT and the vast majority (164 or 85%) said they agreed or strongly agreed that they would accept a kidney from a living donor if offered (Table 4).

Preferences for a live or deceased donor transplant did not differ by ethnicity, gender, age, having a partner or spouse, length of time on dialysis, or whether the person had had a previous transplant (data not shown). A typical comment from the survey was:
I would be happy to accept a kidney from anyone, dead or alive; as long as it gets me off dialysis, I’ll be very happy.

Table 4: Patient preferences and willingness to accept a kidney if offered (number and percentage)

<table>
<thead>
<tr>
<th>Prefer live donor to deceased donor transplant (n= 190)</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 (5.3)</td>
<td>14 (7.4)</td>
<td>101 (53.2)</td>
<td>29 (15.3)</td>
<td>36 (18.9)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Willing to accept a live donor kidney if offered (n= 192)</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 (5.2)</td>
<td>3 (1.6)</td>
<td>15 (7.8)</td>
<td>51 (26.6)</td>
<td>113 (58.9)</td>
<td></td>
</tr>
</tbody>
</table>

Some people commented that they could see potential advantages for either deceased or living donation. A deceased donor would avoid potentially complicated relationships with a living donor or alleviate guilt should anything go wrong with a living donor. Others thought a living donor kidney sounded “stronger” than a deceased donor kidney or were nervous about whether a kidney from a deceased donor “would start working again”. On the whole, however, people would take either:

I’ve been on this far too long and it’s wearing a bit thin, so I need to get a kidney.

Patients were surprised that more was not being done to increase transplant rates and reduce reliance on dialysis, given the wider benefits:

I think if they could clean up their act with organ donation, it’s got to be cheaper in the long run.

That’s what I think they should look at, okay, it’s x number of dollars to have a patient [dialysing] in the hospital, it’s x number of dollars to have a patient at home, it’s x amount of dollars for a transplant. So there needs to be most probably more transplants or time or budget for transplants.

3.3.4.1.1 Changes in preferences over time

While for many people the decision to accept a transplant was a straightforward one, for others, it was more of a journey and not everyone was initially willing to consider
transplantation, either deceased or live. Feelings about transplantation sometimes changed as patients’ circumstances changed, as the reality of being on dialysis struck them or as they learned more about transplants. Some patients specifically mentioned how a health professional had motivated them:

> When he mentioned it to me last year, he actually sounded quite keen. I thought, “If you’re keen, I can get keen”. I came home and searched it up.

Hearing from previous recipients could also affect how motivated people felt:

> I remember doing my [dialysis] training and from up on the renal ward, two of the patients came down who’d just had transplants, so yeah, wow! Which was a bonus as well. They were quite fit and healthy. You ask some questions and it’s, “Oh a bit sore, a bit tender, a bit slow walking but other than that everything’s working.” And it spurs you on, you think, “Oh well, if it’s happened to them, there’s a good chance it will happen to us.”

Some people said they had initially refused to be put on the waiting list because of a general discomfort at the idea of transplantation or because they were overwhelmed with coping with dialysis and could not also cope with thinking about the work-up for a transplant. However, family or friends with experience of CKD persuaded them to change their minds:

> The specialist said to me, “If a kidney comes and it’s one from a dead person, would you take it?” First of all I said, nah, because, you know….But then talking to [my mates] they said, “Oh no, mate, grab a kidney, as soon as it comes say yes.” So that changed everything around. I didn’t really want to listen to other people but when I saw that fella who’d had a transplant, I looked at him and said, “How long you had your kidney?” He said, “Eight years,” and he’s still going so that made me think again.

> My cousin said, “Put yourself back on the list.” I said, “Really?” He said, “Yeah, put yourself back on because this dialysis will probably eat you up in the end”….Now, I’d like to have the transplant. I know things could happen but that’s just the way it is, I guess, so I’m quite happy to try.
Many people talked about feeling neutral or even negative about transplantation in the early stages of their illness or dialysis but now, having experienced time on dialysis, were more eager for a transplant and less likely to turn down offers from family and friends. People who had been on dialysis for longer periods of time (more than five years) talked about turning offers down early on which they now wish they had accepted, or accepting offers now that they might previously have declined:

*If someone offers, I’d certainly run with it, especially after being on dialysis for the time I’ve been on now.... At the time I wouldn’t take one off that person because they’re a pain in the arse but it’s got to the stage now where there was that discussion [in the media] about the paedophile or some guy that was going to donate. Someone asked me, “Would you take it?” In a flash, yeah. They said, “Oh wouldn’t you feel...?” I said, “You haven’t been on dialysis for day after day, month after month, year after year. Because if you had, you wouldn’t think twice.”*

### 3.3.4.2 Patient concerns about LDKT
Respondents expressed the highest level of concern about donor loss of income and donors being upset if the transplant failed through rejection, with the lowest level of concern being about the donor having a painful recovery after surgery (Table 5). The average rating for this item, 3.25, was significantly lower than all the other items ($p<0.005$), which were not significantly different from each other.

<table>
<thead>
<tr>
<th>Concern</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Donor health problems ($n= 189$)</td>
<td>3.46 (1.205)</td>
</tr>
<tr>
<td>Painful donor recovery ($n= 188$)</td>
<td>3.25 (1.027)</td>
</tr>
<tr>
<td>Loss of donor income ($n= 189$)</td>
<td>3.66 (1.053)</td>
</tr>
<tr>
<td>Donor upset if rejection ($n= 189$)</td>
<td>3.66 (1.058)</td>
</tr>
</tbody>
</table>

There was no significant relationship between patient preferences and willingness to accept an offer: people who were more worried about the impacts on donors were just as likely to
prefer LDKT or say they would accept a kidney if offered one. However, the comments in both the survey and the interviews suggested a more complex picture.

Most people interviewed were concerned about one or more specific aspects of LDKT or had more general concerns that could not be easily articulated. Most of the concerns were related to the donors and it was clear that, regardless of how the person felt about accepting a kidney, the wellbeing of donors was of paramount importance to everyone. As in the survey, the main issues identified in the interviews were impacts on donor health, and financial and practical issues for donors. Fear of rejection was mentioned by only a few people in the interviews, although the survey suggested this was something many people were worried about. Potentially difficult relationships with living donors also emerged as a theme in the interviews.

3.3.4.2.1 Impacts on donor health

People in the survey who said they would not accept a kidney if offered typically commented that they were afraid of what would happen to the donor or would feel responsible if anything happened to them:

I won’t ask because I couldn’t stand it if the donor ended up like me because they gave me a kidney.

Many people in both the survey and interviews who were willing in general to accept a kidney from a living donor had turned down, or would not accept, an offer from certain people because of fears about impacts on the donor’s health, most often their own adult children or someone else they perceived as “too young”:

My 30-year-old son offered but I declined as I felt that he still had many years ahead of him with a young family.

Our daughter offered but I won’t consider her as she is only 24 years old.

I’d be worried my son mightn’t see his children grow up....My grandchildren need a father....He might have one kidney and then something might happen to him and then they’ve got no father. That’s how I looked at it.
Health professionals also commented on the concerns patients have about donors and how this influenced their willingness to accept a kidney if offered. Again, unwillingness to accept a kidney from an adult child was common:

You get people who already come with ideas of who they would and wouldn’t take a transplant from. Usually they say they wouldn’t take one from very close family members, particularly their adult children. That’s the most common one they’ll say they wouldn’t take one from.

Patients who said they would “love” a LDKT often said they also had some concerns about impacts on donor health and were often uncertain about the impact of living with one kidney:

My daughter’s saying, “You can have one of my kidneys,” but I don’t know what that means for her. Does that mean that she doesn’t cope just as well without her kidney, with her other kidney gone?

I’m worried about them. I’m not worried about myself. I’m more worried about them having to give me one and then something just pops up and then, you know, if they’ve only got the one kidney...when I think about it, I guess the one kidney does the function of the two kidneys but with not the same power sort of thing, not the same strength I mean....I guess it’s getting my head around that, that they will be fine! I’ve got one, I’ll be ok. Will they be ok?

Others described their concerns as “the normal concerns anyone would have” and said it would not stop them accepting an offer from a suitable donor:

I know that it’s probably going to go ok. There’s one in so many people that don’t make it, but that’s pretty small; and one in something will get a side effect or something but that’s pretty small. So I don’t really dwell on that. It’s all well worth going for....I mean I’d have the usual concerns but no, my sons want to see me off dialysis and enjoying life.
I wouldn’t feel guilty [if anything happened to donor] but I wouldn’t want it to happen. It’s just how we are as mums, you don’t want bad things to happen to your kids.

For these people accurate knowledge about the risks of transplantation as well as insistence by their children that they be allowed to donate appeared to be important factors.

Knowledge of, and trust, in the work-up process for donors were also important factors for alleviating patients’ concerns:

I think the process that the living donors go through really covers it. And if we get to that stage where they’re saying, “Yes”, I feel quite comfortable that things are going to progress well for both parties.

Many people were also concerned about a potential donor’s current state of health, or perceived risk of ill health (e.g. a family history of diabetes or concern that donors might not look after themselves in the future), which was a barrier to either approaching people or accepting offers:

My brother’s had so many things wrong with him, I’m very reluctant to ask him.

But again, our daughter is 23; it’s the history in it. [My husband’s] family’s diabetic, my family’s diabetic, so she would have a full blown history of it, you know. And she’s terrible at eating. We keep telling her, “Stop doing those things, otherwise you’ll end up being a diabetic”.

My 20-year-old son had agreed to donate one of his kidneys for me but I was very reluctant to accept his offer because of fear that he might have kidney failure like me since diabetes is our family curse.

The possibility of donors wanting to get pregnant made some patients unwilling to consider them, sometimes on the advice of the renal unit (some units have until recently declined female donors for this reason).

3.3.4.2.2 Financial and other practical issues
Donors being financially out-of-pocket was a significant concern for patients in the survey and in the interviews. This was sometimes described as an overall family problem as people
grappled with financial interdependencies between donors and recipients, and the need for wider family members to also take time off work to care for donors and/or recipients after the transplant. Other costs for donors were mentioned such as travel and accommodation, hospital parking fees, time off work for appointments, with particular issues when a donor would need to come from overseas. Many people had strong concerns and several patients commented that this made it hard for them to approach others or accept offers:

_Certainly the financial thing would have to be overcome, because they _all_ work. They won’t be able to take two months off for anybody. So that has to be addressed._

_And there’s not a lot of money around… Economically, people are just existing; I’m talking about my family. So I guess at that time that’s why I didn’t want to encroach I suppose or ask… all of that travelling, accommodation. We just don’t have the means, if you like, as a family… yeah, I wouldn’t ask any of the family because of [their poor health] and because of the economic thing. They struggle even now just to keep on board with just normal living._

Practical issues, such as how donors and their families would manage after the surgery, were also a concern. Whole families could be affected:

_I guess that’s part of the reason why I haven’t pushed as far as my daughter’s concerned because I’m her support with her kids…[her husband] was a bit reluctant even for her to go and do anything like that and financially they’re pretty strapped because they’ve got a mortgage and everything else. So if he had to take time off work to care for her, and I wasn’t there, his mother doesn’t drive. She’s got a couple of sisters-in-law but they’ve all got young children and families so it was a case of well, who’s going to look after my daughter? And that concerned me… it was most probably a major concern for me._

Patients were not always aware of what financial support was available for donors but everyone who commented on this thought that the current amount available (Chapter One) was too low to remove financial barriers or avoid hardship.
3.3.4.3 Relationships with donors
A few people mentioned aspects of relationships with donors, e.g. feeling obligated or beholden in some way, sometimes in a general sense because donation was viewed by the patient as “a big thing” that they could never reciprocate. In other cases, people did not like the idea that they would be connected to a particular person forever or even feared that the donor might ask for something in return:

*He’s the sort of guy that would possibly want something out of it....I could see him hitting me up later on, “Give us a backhand because I helped you out” sort of thing.*

*I just know that it means they’re kind of connected to me now, and I don’t want that... physically I would want them... but just the whole shebang afterwards....I just know they’ll hold me to ransom and by that point there’d be nothing I could do.*

Others talked about relationships with potential donors in more positive terms, mentioning the disappointment felt by those who were unable to donate. Several mentioned their acknowledgement, and acceptance, of what it would mean for a donor to be able to help someone and how it would have benefits for them as well as the recipient:

*They’ve seen me on it for all of their lives, that thing’s [dialysis machine] been sitting beside my bed and it’s really gotten to them over the years.*

*When I had to go onto dialysis, the first thing my husband said was, “I will give you a kidney.” Without any issue he said, “I will give you a kidney” and both my boys turned round and said, “Mum, we want to do this, can we do this?”....They have both made me promise that I would take it, they have both said to me, “Mum, this is what we want to do, it’s not what you want to do, it’s what we want to do and you have to allow us that”.*

3.3.4.3 Patient knowledge
Patient knowledge was not measured directly in the research but patients commented on what information they had been given and what they would like to know more about. Renal units were a major source of information for patients about LDKT but there were also several other sources of information, including the media, particularly coverage of Jonah
Lomu’s\(^\text{12}\) situation. A few people mentioned they had sought information on the internet. As discussed above, other patients, particularly previous transplant recipients, were also a source of information.

Several patients commented that, like the rest of the general population, they had known very little about renal disease – until it affected them personally. This also presents challenges for health professionals in their discussions with patients:

> People just don’t know about it and that makes it very hard. How many people don’t even know that you’ve got two kidneys? There’s just such a general lack of knowledge. And patients say, “Oh, I didn’t know anything about this until it happened to me.”

Patients who had had a previous successful transplant were more likely to feel well-informed:

> I believe they have seminars that they put on for people....I haven’t been to any...They wouldn’t really be telling me much that I didn’t already know.

Previous LDKT recipients also had first-hand knowledge of the impacts on donors:

> Well, I know it just didn’t affect him, I mean he was back at work in two or three weeks....Having seen him go through it, he was fine.

Health professionals mentioned that a patient’s approach to LDKT could be influenced by their knowledge. A common problem was patients saying they would delay seeking a transplant until things got “rocky with dialysis”, suggesting they did not fully appreciate the seriousness of being on dialysis and the risk of being unsuitable for transplant if they waited until their situation had deteriorated further. Overcoming this was not necessarily just a matter of being given information:

\(^\text{12}\) Jonah Lomu is a former All Black rugby player whose diagnosis with nephrotic syndrome in 1995, and subsequent transplant in 2004 from friend and radio host Grant Kereama, was highly publicised in NZ. Around time the interviews for this research were carried out (early 2012), the transplant failed and Lomu returned to dialysis (http://www.donor.co.nz/index.php/newsroom/125-jonah-lomu-needs-another-transplant).
I had one patient say to me, this is a very clever man, and he said, “Oh, I think I’ll just wait, I think my family’s just waiting till it all turns to custard,” and I said to him, “But look, look at the graph [of outcomes]. If you wait until you’re on dialysis, this is what your life is,” and we drew it again. I said, “You’ve got little kids, you need to keep your life as good as you can...” and he said, “That’s my denial talking.” So how do we expect people who are in denial to try and get the best options for them?

Health professionals also reported that patients often made incorrect assumptions about who could be a donor, e.g. someone not being genetically related, of a different ethnic group, or that they presumed would not meet medical criteria:

*People rule out their own people because they think they can’t donate. They’ve got their own list of exclusions which might not be valid.*

Most patients felt they had very little information about the waiting list and wanted more information about how many transplants are done in NZ each year, how the list works, criteria for allocating kidneys, waiting times and “where they are on the list”. Patients often said they knew the wait for a DDKT could be long:

*They told me that if I could find a donor, that would be the quickest way to get a transplant. Failing that, then you go onto the public waiting list.*

*And he did explain that [the waiting list] is a long process and that it would be good to try if your family members wanted to; yes that it would be good for them to give it a go and let’s see because that would be the quickest way of doing it and if not, then to see if there was family or friends or whatever, somebody else. If it was a live donor, it would be a lot quicker.*

However, some people seemed to believe that the average waiting time did in fact give them an indication of how long they could expect to wait to get a kidney, supporting the health professionals’ concern about possible misunderstandings of the likelihood of a DDKT, although it may also be possible this was an attempt to “stay positive”: 
I get down about it occasionally. I sort of slap myself and I get a bit more philosophical and say, well, “Every year you wait, it’s a year closer to getting it,” because sooner or later my name’s gonna come out of the hat.

The waiting list is about five years, so I just figure hang in there and maybe after about five years I might be getting to the top of the list – you just don’t know when it happens or if it does.

Some health professionals commented that what patients wanted to know more about was often the practicalities of transplantation and the risks for the donor, and questions were not always what health professionals expected:

[At a group session with previous donors and recipients] they asked very specific things about the actual process of transplantation like, “When you got home, how did you cope when you’d both been in hospital?” Just little things like, “How did you get home from the hospital?”....So some things that I guess we kind of gloss over whereas they wanted to know the gritty detail of everything.

In the interviews, patients took the opportunity to ask me about these same practicalities, such as pre- and post-transplant logistics, how much time off work donors have and the remuneration available for donors. Several people were particularly interested in the impact receiving a transplant had had on my husband’s life:

And the water-works, does that work as well as everything? Does everything come back to normal?

Well, what exactly is involved with a live donor? What are the logistics of it? What happens? Do I pack a bag? Do I have a bag ready to go into the hospital and what happens? Just some of the basic practical things and what you can expect. How long are you in hospital for approximately?....And your husband, he got better and better and stronger?....Wow, and you know when you say he’s fit, he’s strong, he can work? He’s just a normal person?....And these anti-rejection drugs, are they steroids, are there quite a lot?....And you’re right, with a live donor you can plan it. See, I haven’t been told about that kind of thing....We haven’t been stepped through that.
The quality and consistency of health professional discussions with patients, and patients’ own concerns, influence how willing patients are to pursue LDKT. Although 85% say they would accept a kidney from a living donor, they may not always do so in practice. This in turn impacts on the major challenge in the journey to LDKT: to find a willing donor. The issues involved in finding donors are presented in Stage 3.

3.4 Stage 3: Find a willing donor

3.4.1 Overview

In many other areas of blood and tissue donation (e.g. blood, bone marrow or deceased donation), third party organisations have the responsibility for donor recruitment through promotional efforts, establishing and maintaining registers of potential donors, and approaching family members about donation when someone has died. In LDKT, however, patients themselves must find a potential donor from their own networks, unless a non-directed donor comes forward. This stage covers how patients inform potential donors, getting offers from people willing to consider donation, and options for addressing barriers in donor recruitment.

3.4.1.1 Health professionals

There has been longstanding reluctance amongst health professionals to play a direct role in donor recruitment because of fears about coercion of potential donors. There has been concern that health professionals’ own enthusiasm for LDKT might place pressure on potential donors, or reinforce pressure from other family members (101).

Most transplant centres internationally, therefore, have reasonably conservative donor recruitment policies. Stothers et al (192) outline a typical approach:

The policy at our center regarding recruitment of live kidney donors is to initially provide information to the potential recipient. Potential donors are given information only if they personally make contact with the transplant program, and medical evaluation is carried out only if that individual expresses a strong desire to proceed. This policy reflects our concern for potential coercion and solicitation of live donors (p.1105).

However, clinicians in Norway take an active part in donor recruitment. Physicians there will ask a patient’s permission to contact potential donors and then approach them directly.
to ask if they would be willing to discuss live donation. This has the advantages of removing the difficulty patients have in asking donors directly and allows potential donors to speak freely to a doctor (or refuse) without having to speak to the patient (263). This is an approach that many health professionals, and others, in other countries would regard as undue pressure (or coercion) on the potential donor (157).

Previous NZ research (74) found that health professionals here also generally take a conservative approach to donor recruitment, similar to those in many other countries:

Most members of the transplant teams were adamant that it was not their role to seek out donors, and many felt that any behaviour that might lead to the perception that they were “chasing” a donor would be at best unprofessional and at worst unethical. This led to the widespread practice of leaving donor recruitment squarely in the hands of the patient and whānau [family] many of whom... were uncertain or apprehensive about initiating such discussions (p.27).

Studies suggest patients may be more comfortable with the idea of health professionals being directly involved in approaching donors than health professionals are (157, 264-265). One survey of patients found that 30% thought the potential recipient should be the one to first approach potential donors while more than half thought the initial approach should be made by a health professional of some kind (e.g. the patient’s doctor, the transplant team, or an independent clinical party) (265). Another found that more than 50% of patients and their relatives thought doctors should address relatives directly, with the patient’s consent (262).

However, the appropriate role of health professionals in donor recruitment remains the subject of debate internationally and views amongst health professionals are not unanimous (266-267). One survey of health professionals found that the highest number of respondents felt that recipients should make the initial request of a potential donor (43.5%), although younger professionals were more likely to agree that the approach should be made by the transplant team (264).

Overall, although patients may wish health professionals to take a more active role in donor recruitment, many health professionals remain reluctant. Mazaris et al (265) cite the need
to “remain neutral, acting both for the benefit of the recipient and the donor” (p.5).
Massey et al (268) also argue that “it is not the responsibility of [the health care provider] to find a donor for the patient; however we do believe that is the responsibility of the [health care provider] to remove barriers for living donation” (p.681), e.g. by providing information to patients and their social networks.

3.4.1.2 Patients
Factors influencing patient approaches to donor recruitment include their preferences, beliefs, knowledge of transplant procedures, understanding of risks and benefits to donors and recipients, willingness to ask for help and fear or anxiety about live donation (36, 176, 182, 191-192).

Siegel et al (186) note that the difficulty for patients in asking people to consider donation has been known for many years. The proportion of patients who report being willing to ask others to consider live donation varies between studies. Siegel et al (186) suggest rates typically vary from about 0-20%, although one study (185) found that 41% of patients felt it was appropriate or completely appropriate to ask a family member to donate a kidney and 35.6% had done so.

Patients may be more willing to discuss donation with others than to ask directly. One American study found 78% reported discussing donation and 51% reported initiating that discussion (269). Even discussing can be difficult with one study (182) reporting more than half the patients surveyed were either not willing to consider discussing live donation with others or were ambivalent about it. According to Rodrigue et al (182), raising the issue “may seem like an insurmountable emotional hurdle for some patients” (p.29).

Consistent with concerns reported in Stage 2, barriers to recruitment include concern for the donor’s wellbeing, not wanting to pressure someone, embarrassment if they said no, not wanting to owe someone, guilt about the pain and costs involved for the donor, worry that the donor would later regret the decision, concern about the impact on the relationship and worry about how the donor would feel if the transplant was unsuccessful (157, 176, 187, 269-272).

Not knowing how to ask or not having the skills to initiate a discussion is a significant barrier for many patients. One survey found that 71% of patients cited it most frequently as a
barrier to LDKT (272). Other specific areas of knowledge associated with willingness to discuss donation include knowing that live donation does not result in a higher risk of kidney disease, that it is not restricted to those under 50 and that risks for donors are small and manageable (182), as well as knowing the risks to donors and knowing how and why to begin the LDKT process (272).

Patients also report concern about donors being pressured, with 85% of patients in one study saying they would not allow a donor volunteer to be evaluated if they thought the person was being pressured into it (271). Even those willing to accept a kidney from a living donor or with a strong preference for LDKT can find it difficult to discuss donation with others (273). Kranenburg et al (157) note that "patients may feel that even sharing information or inviting their potential donors to an information meeting on live kidney donation, is a veiled way of asking for a kidney....The majority of patients on the waiting list are willing to accept a living kidney donor but are reluctant to discuss the issue of living donation with their potential donors" (pp.970-1).

As a result of these difficulties, many patients never ask anyone (or only speak to a few people) and instead wait for someone to volunteer (157, 176, 271, 273). This is reflected in surveys of actual donors and recipients. One study (36) found that in 66% of LDKTs, potential donors had initiated the recruitment, with recipients asking in only 21% of cases. Another reported that 90% of donors said they had initiated the idea of donation themselves (274).

Patients often appear to see a difference between the acceptability of asking someone directly and accepting a kidney if offered, with asking being perceived as difficult to do and as undermining the voluntary nature of donation, because it implicitly puts pressure on a potential donor. Patients are often concerned with protecting potential donors (187) “from the psychological discomfort of being thrust into an unwanted gift-giving relationship” (p.259).

Patients may also turn down offers from potential donors, even if they have a strong preference for LDKT. One study found that 81% of patients had actually been offered a kidney but only 39% said they would accept it (187). Believing it is not acceptable to ask
family members to donate is associated with being less willing to accept a kidney when offered (185).

Some patients are now turning to the internet or mainstream media to appeal to a wider group of potential donors, e.g. through websites such as MatchingDonors.com, media appeals (275), or Facebook (276). Some success has been reported for patients using Facebook (277-278) although concerns have been raised that online recruitment may introduce greater risks of donors seeking or receiving payments (278-279).

3.4.1.3 Potential donors
Potential donors were not included in this research but a brief summary of donor-related factors is provided. A complex mix of factors influences donor decision-making (193). An important point, however, is that most research is with actual donors. Issues reported by donors may tell us little about potential donors and people who refrain from donation (280).

Directed donors are typically motivated by love or concern, a desire to help someone, and wanting to improve someone’s health (281). Wanting to improve one’s own quality of life (e.g. in cases of spouses or parents), a sense of moral duty, and in a minority of cases feeling that relations with family members would be damaged if they refused to donate, may also be motivations (265, 282-283). Non-directed donors report similar motivations such as the desire to offer someone the chance of a normal life, without expectations of reciprocity. Triggers may include knowing someone on dialysis or another donor, media stories, and gaining awareness that living non-related donation is possible (284).

Accurate knowledge about the potential risks of donation is associated with hypothetical willingness to donate to a family member (191) and differences have been found (192) in the knowledge of donors and non-donors on basic questions such as “a person cannot spare a kidney because they are vital organs required for a healthy life” and “long-term health problems in live donors are very rare after kidney donation” (p.1109). Potential donor concerns can be exacerbated by others in their social networks who may express negative (and misinformed) views about LDKT (282). Potential donors may fear the consequences of donating a kidney and overestimate the risks of donation (157, 191), the time needed to recover in hospital and the size of the scar (191). Personal, religious and cultural beliefs about organ donation may also have a role (98-99, 193, 239, 285-287).
Awareness of ESRF and LDKT is low in the general population (256) and may influence the perceived need for donation. Patients typically interpret the absence of an unsolicited offer as lack of interest. However, in one of the few studies with potential donors, it was found that more than one-third of potential donors were, in fact, willing to consider donation (157). A key issue, therefore, is whether potential donors are approached about donation.

Many people who do donate report that they found out about the possibility of donation because of their everyday involvement with the recipient, in particular going to clinic appointments and hearing about the person’s illness and treatment options (282), but few people typically attend clinics with patients and there is no guarantee of patients passing on information (270, 288).

Financial barriers may deter an unknown number of potential donors because living donors can incur significant direct and indirect economic costs, including travel, accommodation, meals, incidental medical costs post-discharge, time required for work-up procedures, parking costs, care required after discharge (e.g. personal care, shopping, childcare), lost productivity around the home or at work, and other miscellaneous expenses. The most significant cost for many donors is lost income during the recovery period (usually 4-6 weeks) (194).

In a publicly-funded health system, such as New Zealand’s, costs related to the surgery itself and pre-surgery tests are covered. In insurance-based systems, the recipient’s insurance may cover the direct costs of evaluation and surgery as well as immediate post-operative costs, but longer-term follow-up is often not included and there is no guarantee that a donor’s health insurance will be maintained (128, 289-290).

The prevalence of economic hardship for donors is well recognised in the transplantation field (194). The extent to which people are actually deterred from donation because of it is less clear. Living donation is less common in those with lower income and inadequate medical insurance which might suggest that economic burdens are a barrier (255, 291) and donation rates appear to have declined during the recent global recession, particularly amongst low-income people (255). Potential donors who are close relatives may already be suffering from the economic hardship caused by having a family member with a chronic illness and donation may impose an additional burden (291).
In summary, health professionals are reluctant to be actively involved in donor recruitment; patients find approaching potential donors difficult and most simply wait for someone to offer; but potential donors may be unaware of the need for donation, who can be a donor, or what is involved. Thus, Zimmerman (185) notes that “the reliance on the patient to identify a living kidney donor...probably represents a significant barrier to living donor transplantation” (p.2575).

### 3.4.2 Results

Some of the results in this section have been reported previously (2).

#### 3.4.2.1 Donor recruitment – letting people know about the need for a donor

Most patients surveyed had at least had a discussion with family about live donation and/or with friends but few people had asked someone directly to consider live donation (Table 6).

| Number (%) | Discussed living donation with family (n= 193) | 160 (82.9) |
| Number (%) | Discussed living donation with friends (n= 190) | 118 (62.1) |
| Number (%) | Asked family to consider living donation (n= 190) | 57 (30.0) |
| Number (%) | Asked friends to consider living donation (n= 191) | 21 (11.0) |

Note: Some people who had not discussed with/asked family members, had discussed with/asked friends

Respondents were grouped into three categories for further analysis:

- those who neither discussed with NOR asked their family/friends;
- those who discussed with but did NOT ask their family/friends;
- those who both discussed with AND asked their family/friends.

There were no differences in donor recruitment activity by age, gender, ethnicity, region or being partnered. However, previous LDKT recipients were significantly ($p=0.016$) more likely to have discussed/asked both family and friends, compared to people with no previous transplant or a DDKT only.
Follow-up interviews explored in more depth how patients went about letting other people know about the need for a living donor. As in the survey, only a few of the interviewees said they had asked another individual directly. Some had asked in a more general way, such as via Facebook. Only one person interviewed had actively gone out with a strategy:

“I’m very proactive as far as spreading the word….I said, “I’ve got a major health issue as far as my kidney function. I’m losing it and I’m going to need a transplant and if you’re the right blood type, would you be prepared to get tested to look at doing one for me?” And people were great. I also used emails – I did a generic email and sent it to everyone on my contact list and said, “Don’t take this the wrong way... but this is my situation and if you could help me out it would be really great.” And then I put a little notice up at my class with a little kidney on it and said, “I’m in trouble, can you please help me?”...And I continually put it on Facebook and everything I see about kidney research, I’ll share it and say, “If you feel like offering, this is the number to ring at the hospital”.

This person reported receiving a large number of offers, none of whom were suitable.

Some people had asked someone very close to them but said they would not ask more widely:

I asked them all [siblings]. I said, “I want to get this out of the way just so that when people ask me, I can say that I did ask.” They all said no.

I think it was on Skype or something, I said, “Well, Mum’s been checked, are you going to get checked when you come back?” He said, “Yeah, sure.”

3.4.2.1.2 Types of discussions patients have with others
Amongst people who had discussed living donation with others, the types of discussions varied considerably from very direct, to indirect, to little or no discussion at all. The categories are not necessarily mutually exclusive, e.g. people might have in-depth direct discussions with close family but not mention it to anyone else at all.
• Direct discussions

Some patients were quite direct in their discussions with family and friends while emphasising that they would not ask an individual directly. Some people reported that they initiated such discussions, e.g. on returning from a visit to the renal specialist and reporting to family what had been said; or that discussions came about in response to questions from others about how things were going. These patients often felt that their family and friends were clear about the need for a donor as a result of these types of discussions:

*Everybody knows, I talk to everybody about my situation; I don’t keep it a secret....All my work colleagues, all friends, all family, everybody knows because I do speak about it. It’s not something that I feel I have to keep a secret or that people shouldn’t know that I have a kidney problem or that I need a kidney....I just tell them, “I have kidney failure, I am waiting for a kidney, I am on dialysis... if there’s anybody out there who wants to give me a kidney, you’re welcome to come along.” That’s sort of how I put it out there....I don’t feel I can go to somebody and say, “Hey, do you want to give me a kidney?” It’s like saying to somebody, “Hey, give me some money.” I can’t do that, maybe I should, but I can’t do that. I’m not scared to talk about it. I feel from that that they know I need a kidney. If it’s something they feel they would like to do, they will do it.*

• Indirect discussions

Patients might talk indirectly about living donation, e.g. about being on dialysis or mention that they were on the waiting list. This might lead to a discussion about LDKT but not always, depending primarily on what the other person already knew about LDKT. These patients said that their family and/or friends may or may not be clear about the need for a donor:

*Just the ladies in our church group know that I do dialysis but that’s about all....I think they know I need a transplant but they don’t talk about it. Some people do but not many; I don’t talk about it much... I usually tell people I’m on dialysis but I never say I need a kidney.*
• Little or no discussion

Others said that they really had no discussion with anyone, or only superficial discussions about their illness, being on dialysis or living donation. Some spoke with immediate family but sometimes not even with them. These patients were less likely to say their family and friends were clear about the need for a donor:

*Family and friends know I’m on dialysis... My brother, we may have fringed on [transplantation] at some stage. I don’t raise it with him. I don’t think they’re really that interested;*

3.4.2.1.3 Not a one-off event

Donor recruitment can sometimes be portrayed as a one-off event such as “initiating a discussion” or “asking someone”, with the next step being that a person willing to consider donation contacts a transplant coordinator. In reality, the process is far more complex. Patients often had discussions with many different people over significant periods of time and found themselves having to answer questions or having in-depth discussions for some time before a health professional became involved:

*I discussed it reasonably fully with my work colleague who offered to give me a kidney and he discussed it in great detail with his wife. We discussed it actually for quite a while before he made the approach to the transplant coordinator.*

When a potential donor made an offer but did not immediately contact a transplant coordinator, patients were not always sure how to follow up or find out if the person might still be interested, and consequently said nothing. Thus, both parties may assume the other is not interested in continuing:

*She emailed and offered and then we saw each other again; I didn’t bring it up. I was too embarrassed to bring it up so I just thought, “Oh, I’ll leave it because if she’s not going to say anything, then I’m guessing she’s changed her mind or forgotten about it.”*

3.4.2.1.4 Changes over time

Often there were many discussions with family and friends when a person was approaching ESRF or first went on dialysis but this lessened over time, perhaps because patients
themselves became tired of talking about it, because people became accustomed to the person being on dialysis, or because the patient had already had several offers who were unsuitable and did not think there were any more potential donors:

When the subject’s brought up, I don’t really like talking about it because it frustrates me, I think. I’m at that point where I’m like, “You’ve got kidney failure?” “Yes.” “So you’re waiting for a transplant?” “Yes.” They go, “Are you on the list? What number on the list are you?” I say, “No, we’re in a pool and have blood tests.” I’m just over repeating myself. That’s what I feel I’m doing all the time, repeating myself….I don’t initiate anything. But if someone asked me, I’d definitely take the time to talk to them. But it frustrates me now, I think.

For some people there was a period of adjustment to being on dialysis which meant they were not ready to talk to others immediately:

It’s only been six months since I’ve been in the position where I can [receive a transplant]. So it’s kind of like I’m working towards there I think, and I’ll get a little bit more serious and when I do, I think I’ll be ready to make decisions or ready to talk to people myself.

Patients sometimes thought about revisiting discussions many months or years later, especially if they were not ready to consider transplantation or accept an offer early on. This was particularly difficult:

It would be hard for me to go back and ask her again...though if she came back and offered again, I could probably, I should probably say yes, but I don’t know.

3.4.2.1.5 Patient views about approaching others
Consistent with previous research (182, 269), survey and interview respondents commented frequently on the difficulty of approaching others about live donation. For some people, there was a clear distinction between asking and discussing, with discussing being somewhat easier, while for others the distinction was less clear - simply raising the topic could feel like they were making a request. Many, however, were comfortable talking about LDKT especially if someone else raised it first.
Most said they felt kidney donation was a “big thing” to ask of anyone or said simply that they felt “uncomfortable” or “rude” in asking. One person, on being asked by her specialist if she had anyone to give her a kidney, felt like she had been asked, “Have you got anybody to give you the moon?” Typical comments were:

*I don’t feel I have the right to ask. I think it’s a big sacrifice to ask for someone to donate a live kidney to you. It’s a huge decision and one that I’m not able to ask of someone.*

*I don’t ask anybody, nah. It’s not something you do, “Hey, can I have a body organ?”*  

*It’s no light matter donating a kidney. It’s not only are you asking for a piece of them, but it’s also the discomfort and the time off that goes with it, and the cost.*

A number of people mentioned a sense of personal embarrassment, pride or not wanting to push themselves forward:

*I don’t bring it up because there’s more interesting things to talk about...and I don’t want to sound like a person that’s always going on about my issues or my condition. But I’m the opposite. I don’t talk about it at all.*

Some patients felt they were in the position of “selling something” that they themselves have a strong vested interest in:

*I just tell them, because they do ask, what happens. I say, “Well, you need to find out your blood-type first off.” I go through the whole thing. I mean I don’t really know myself. I don’t really know the pros and cons of them either....And of course I want the kidney so I’m not going to try and tell someone the bad sides of things or it’s worse for you than me, type of thing. I mean I do say that....[but] I feel [awkward] because I need the kidney, and I’m trying to talk to them [about kidney donations].*

Others were worried about a negative reaction, e.g. the other person feeling awkward, not being able to say no, or feeling pressured in some way. Far from pushing or pressuring people to consider donation, patients were at pains to make sure they never made anyone feel like this:
If they said no, you know, the position it puts them in… I certainly don’t want to put them in a position whether they felt awkward.

Many people said they would prefer it if someone offered to donate without being asked which would also indicate that the potential donor “really” wanted to do it and had not been pressured or talked into it:

I am uncomfortable about asking anyone to consider donation. If the offer is made, then I am happy to accept it.

I could not ask anyone…. I couldn’t say, “Have you ever thought of maybe being a donor?” I would prefer it came from them.

Many people believed that if people wanted to donate, they would offer and therefore did not need to be asked:

No, they know what I’m doing, and if they feel this is what they’d like to offer, that’d be fine… if they want to come forward they will.

I feel that, as far as I know, everybody who’s connected to me knows that I’m on dialysis and waiting for a transplant and if they felt the need to, they would have offered.

One interviewee had a different perspective from most others, saying that, while it would be easier just to have people offer, it was acceptable to ask. Simply asking other people to consider donation did not in itself constitute pressuring them or talking them into it. Her feeling was, “It’s your life that you’re talking about and if I’m not going to do it, nobody else is going to.” Her approach was that:

I don’t put any pressure on people because we were told it had to be altruistic and it’s like there’s no point if you try and blackmail someone or pressure them into doing it and they’re not happy…. [I don’t feel like I’m pressuring people] because I’ve always been pretty outgoing and talk about whatever’s on my mind and I just tend to back off if people really don’t want to talk about it…. I didn’t really find anything wrong with [asking people] because people have the right to say no, and also knowing that they had to go through a different transplant coordinator as well.
3.4.2.1.6 Advice and support given to patients to find donors

Most patients understood that it was up to them to find a donor, although one person asked during the interview:

*Are we expected to find our own donor?*

Most people said that the only advice they had been given about finding donors was to go and ask people if they would consider being a donor, usually family members. In some cases, they had been encouraged to ask more widely and use a range of different approaches such as email and Facebook. A few people commented that they had been given information about transplantation (written or DVDs) that they were able to share with their family but had not been given anything specifically to give to potential donors. Lectures, seminars or group meetings to which they could take family were also mentioned.

No one could recall being given advice about how to actually approach other people and have a conversation about kidney donation:

*No, of course not. All they do is say, “This is this, this is that, out you go, have a look.”*

*I think I might have said to him, “How do I go about it?” and he said, “Ask everyone you know, anyone you come across,” which is… yeah.*

Health professionals did not feel it was appropriate for them to ask potential donors directly to consider donation. Approaching potential donors directly was described as unethical and coercive:

*I don’t think anybody considers it’s appropriate to have a role in donor recruitment. I don’t think in this country that it’s considered acceptable to approach people and say, “I hear you might be a potential donor for John Smith.” I don’t think that’s acceptable… I’ve had some recipients say, “I should be able to give you a list of names and you should ring them,” but that’s not considered ethically appropriate. They’re not our patients, these people, we don’t have a mandate to contact them, like countries like Norway.*
If people contact us, that’s absolutely fine, but if someone just gives us somebody’s name and says, “Well, my Aunt Sally says she wants to be a donor,” we wouldn’t follow that up. To us that would be coercion.

Nephrologists were very happy to raise the topic of living donation with family members present, e.g. in a clinic setting, with some saying they actively encouraged family members to come to clinics so that they could hear information firsthand. However, they would never suggest donation directly:

I certainly raise it if the patient comes in with other people. So if they come in with a spouse or other family member or friend sometimes, I raise the conversation about transplantation with that other person there. I wouldn’t suggest it but I would raise it as a conversation point....but unless the conversation steers to that person, I would feel uncomfortable asking that person to be the donor....I’ve never said to someone, “Why aren’t you coming forward?” because I think that person’s not my patient, they’ve got to make their own mind up and come forward. I’m more than happy to give them the information. I don’t think it’s my role to ask that person to step forward.

Many health professionals acknowledged, however, how difficult it was for patients to approach potential donors and that there was little support to do this. Some spoke about indirect ways of letting family and friends know about LDKT:

There were other tools we could use so I used to talk at patient meetings that the local patient support group would put on, educational meetings, and that would be an opportunity for patients to bring along their whānau and get them exposed to it.

There are also sessions for potential donors, individually or as part of a group, but these are for people who have already expressed some interest in donation:

I do these education sessions for the patient group where people who are thinking about being live donors can come along and ask questions. That’s quite good and usually a pretty good number of the people who come turn out to be live donors...so it’s for people already thinking about it. People do come, but, yeah, obviously it’s still a problem, how do people get asked [in the first place]?
Many patients were reported as asking for help with donor recruitment, often saying, “How do I ask?” or, less frequently, wanting someone to ask on their behalf:

*It’s not an uncommon question. It’s not something that absolutely everybody asks but it’s quite a common question that people are not sure how to broach the subject.*

The main advice health professionals reported giving was to tell patients that they didn’t need to ask potential donors directly but rather to look for opportunities to start a conversation about transplantation and donation:

*I say to them, “Look, I know it’s a really awkward thing to do because you can’t be out there asking for someone’s kidney.” I try and encourage them to let it be known, I say, “If it comes up in conversation, mention it. If someone comes back to you asking what can they do, point them at us.” Try and make it simple and not threatening and unlikely to damage their relationships with their friends and family. I think it’s pretty difficult.*

*If people say, “I can’t ask for it,” I say, “Don’t then. Go home and say, ‘I’ve just had this education, my kidneys are poked, will you watch this DVD with me?’ And talk about what we’ve told you, that you’ve been told transplants are best.” I tell them to do it that way.*

Health professionals in many different roles may give patients advice about how to approach potential donors, but support for donor recruitment was not specifically part of anyone’s role, and nor was there any training for staff in how to advise patients:

*If a patient asked for help with, “How do I find a donor?” I would discuss that to a certain level, beyond that we would get the transplant coordinators or the pre-dialysis nurse involved. But none of them have had any specific training in providing that support. That’s what’s lacking, I think....It’s role delineation. That’s not part of the transplant coordinator’s role here at the moment. The people involved in that area are pre-dialysis but our pre-dialysis nurses very much focus on preparing people for dialysis, not preparing them for transplantation. So there is a bit of work around that role delineation, education of the workforce, and thinking about how you best deliver that information.*
3.4.2.2 Willingness of potential donors to consider donation

3.4.2.2.1 Offers and tests
Willingness to consider donation was measured in two ways in the survey: any offer to consider donation (“offers”) and taking an initial step towards the donor evaluation process by having a blood test for compatibility (“tests”).

Most patients reported that at least one person amongst their family and friends had said they would consider live kidney donation, while over half said they knew of at least one person who had been tested for compatibility with them (Table 7). During the interviews people often recalled additional offers so there may be some underreporting on this item. The number of compatibility tests carried out per patient ranged from 0-10. The average number of offers per patient amongst those who had had any offer was 2.67, and the average number of compatibility tests per patient amongst those who had had at least one person tested was 2.43.

| Number (%)
Anyone ever offered to consider living donation n= 192 | 155 (80.7) |
| Anyone ever been tested for compatibility with you n= 189 | 107 (55.7) |

There were few significant differences between different groups in terms of who received an offer and who had had someone tested (region, gender, age, time on dialysis). Significant differences were seen between ethnic groups, however, in terms of both offers and tests (Table 8).
### Table 8: Number of patients with any offer from a potential donor and any potential donor tested for compatibility, by ethnic group (number and percentage)

<table>
<thead>
<tr>
<th>Ethnicity of patient</th>
<th>Offers (p=0.001*)</th>
<th>Tests (p&lt;0.0005*)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pākehā/NZ European</td>
<td>99 (89.2)</td>
<td>78 (70.3)</td>
</tr>
<tr>
<td>Māori</td>
<td>21 (80.8)</td>
<td>15 (57.7)</td>
</tr>
<tr>
<td>Pacific</td>
<td>19 (65.5)</td>
<td>6 (20.0)</td>
</tr>
<tr>
<td>Other</td>
<td>15 (60.0)</td>
<td>8 (32.0)</td>
</tr>
</tbody>
</table>

In total, patients reported that 415 people indicated to them that they would consider live donation, and 261 of these went as far as an initial test (Table 9).

### Table 9: Sources of offers to consider living donation, and of people tested for compatibility

<table>
<thead>
<tr>
<th></th>
<th>Partner/spouse</th>
<th>Close family</th>
<th>Other family</th>
<th>Friend or other</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of offers to consider living donation from:</td>
<td>57</td>
<td>184</td>
<td>42</td>
<td>132</td>
<td>415</td>
</tr>
<tr>
<td>Number of compatibility tests from:</td>
<td>33</td>
<td>129</td>
<td>28</td>
<td>71</td>
<td>261</td>
</tr>
<tr>
<td>Proportion of offers converted to tests</td>
<td>57.8%</td>
<td>70.1%</td>
<td>66.7%</td>
<td>53.8%</td>
<td>62.9%</td>
</tr>
</tbody>
</table>

The rate at which offers are converted into tests varied between ethnic groups with offers to Pacific and Other patients much less likely to convert to a test (Table 10).

### Table 10: Conversion rate of offers to tests, by ethnic group

<table>
<thead>
<tr>
<th></th>
<th>Number of patients with an offer who also reported a compatibility test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pākehā/NZ European offered a kidney (n= 99)</td>
<td>78 (78.8%)</td>
</tr>
<tr>
<td>Māori offered a kidney (n= 21)</td>
<td>15 (71.4%)</td>
</tr>
<tr>
<td>Pacific offered a kidney (n= 19)</td>
<td>6 (31.6%)</td>
</tr>
<tr>
<td>Other offered a kidney (n= 15)</td>
<td>8 (53.3%)</td>
</tr>
</tbody>
</table>
Overall, Pacific people were less likely to have any offers, and it was less likely that offers they did get converted into potential donors going forward to start the work-up process.

3.4.2.2 Relationship between donor recruitment and receiving offers

There was a significant relationship between the type of donor recruitment activity reported and whether a patient had received an offer from either family or friends (Table 11). Patients who reported not discussing live donation with anyone were significantly less likely to receive an offer to consider donation than people who either discussed or asked about live donation. Asking someone directly to consider donation, however, was not associated with a higher likelihood of receiving an offer than simply discussing it.

<table>
<thead>
<tr>
<th>Table 11: Number of patients who had had at least one offer, by donor recruitment activity</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Been offered a kidney (%)</strong></td>
</tr>
<tr>
<td><strong>Family:</strong></td>
</tr>
<tr>
<td>Not discussed (n= 32)</td>
</tr>
<tr>
<td>Discussed, not asked (n= 100)</td>
</tr>
<tr>
<td>Discussed and asked (n= 57)</td>
</tr>
<tr>
<td><strong>Friends:</strong></td>
</tr>
<tr>
<td>Not discussed (n= 71)</td>
</tr>
<tr>
<td>Discussed, not asked (n= 97)</td>
</tr>
<tr>
<td>Discussed and asked (n= 21)</td>
</tr>
</tbody>
</table>

The relationship between donor recruitment and having someone proceed to testing was not as clear, with some associations between asking/discussing and having someone proceed to testing but not significantly ($p=0.070$). Interviews explored these issues in more depth, as reported below.

3.4.2.2.3 Not getting offers

There may be many reasons people do not get any offers, or do not get more offers, from potential donors. Notably, people who do not discuss living donation with others are significantly less likely to get an offer. Indirect or superficial discussions seem less likely to result in offers than discussions where patients clearly talked about their situation and the
need for a donor. Thus, potential donors simply may not know that a donor is needed or that they themselves could be a donor.

It was clear from patient interviews that potential donors often had concerns about donation or other reasons that meant they were not willing to consider it. These concerns were present in all ethnic groups:

My son said that he didn’t think he could because he wanted to be there for his kids.

Some kind of shudder and turn around and say, “Oh no, I couldn’t do that, no way could I do that.”

I think my family’s in shock. They don’t know how to take it, they don’t know how to deal with it and don’t really want to speak about it….If I try to talk to them about it, they kind of go into a depression, they really do!

A lot of persons know I’m on dialysis, they say, “Eee, yuk” like that... dialysis, that name “dialysis”.... Once they hear dialysis, they reckon that’s your last legs.

Several patients mentioned that family and friends often thought they “didn’t really look sick”, and perhaps therefore did not appreciate the importance of getting a transplant:

To most people, they look at me, they’re kind of, “he’s doing all right.” And even for a dialysis patient I do well and I don’t really look like a dialysis patient. Most days I think I don’t....so people probably don’t really get it, sort of, how it affects my life and how it [transplant] would change my life.

And you don’t know what normal is because I’ve been living with it for so long. I don’t even know what it’s like to wake up in the morning and feel great. Then trying to explain to family and friends that you’re having a bad day. They just don’t see it. I wear make-up, I try to look nice and I get on with it. I mean, you can’t change it, so I just get on with it. Everyone’s like, “Oh, she’s not sick.” They don’t believe me.

Health professionals were unable to identify particular characteristics of patients that they thought prevented them from getting offers. The general impression was everyone found
approaching potential donors difficult. People who had large and/or strong networks of family and friends were thought to be more likely to get offers:

\[
I \text{ think it’s those people who aren’t in a close sort of family network. There’s some people who live by themselves and then you say you’re going to have to come to [transplant centre] for six weeks for the transplant and you need a support person – those sorts of people who don’t have that support around them often find it difficult...I think a lot of people have family members who discuss it straight away but there’s also a large number of people who don’t have anybody, they don’t have a close-knit family.}
\]

3.4.2.2.4 Getting offers without any discussion

While discussion or asking about living donation is more likely to be associated with receiving an offer, a substantial proportion of the people who said they did not discuss it had received an offer (Table 11). Interviews suggested several possible explanations, e.g. someone else may ask/discuss on the patient’s behalf:

\[
My \text{ sister, she kind of rallied everyone up. She was the elder sister and, “Right, you’re all going to get tested.” And a brother had to fly in from Australia and all that.}
\]

\[
I \text{ only asked my immediate family....It’s so hard. I asked my brother, “Can you ask your wife what blood type she is?” and he said, “You are the same blood type as my wife, I’ll ask her if she can donate to you, I’ll talk to her.”}
\]

Indirect discussions, as described above, e.g. about being on dialysis, or being on the waiting list, may trigger questions about LDKT or even offers:

\[
[\text{At our prayer group}] \text{ somebody said, “All right, now get into twos and threes and share about something that’s on your mind.” I got to share about how I’m a bit scared to go on dialysis....This girl just sat there and she said, “I’ll give you a kidney.” Just like that. I was so blown away. I was just so grateful, what a tremendous thing to do without even thinking of herself.}
\]

\[
\text{He raised it with me, he offered....He asked me about it, he said, “What does it involve, what you’re doing [dialysis]?” and I told him and he could see. I think what did it was that he could see how crook I was, when I was turning up to work and I}
\]
was just very ill. He thought, yeah, maybe he could do something. Initially I was a little taken aback. I wasn’t quite sure where to go from there... because although I’d known the guy a long time, it was a surprise.

With my nephew, it was when I said I’ve got to take my husband to dialysis, that’s when he said, “Oh, does he need a kidney?” That’s how it started with him.

Thus even indirect, or no, discussions about donation can lead to an offer, although a direct discussion or request appears more likely to be effective. Relying on indirect discussions to trigger offers is dependent on the prior knowledge that potential donors may have about LDKT, such as who can be a donor, and, as a strategy, is therefore more “hit and miss”:

One or two come here and they see that thing [dialysis machine] and they don’t really want talk about it. If they ask I’ll say, “Well, I have to go on it three nights a week, I stick needles in my arm.” Once you start telling them the ins and outs of it, they sort of realise, “Blimey, is that what you have to do three nights a week?” That does concern them a bit, but it hasn’t pushed anybody over the edge to say, “Well, what can I do?” They’re probably not sure there is anything they can do.

3.4.2.2.5 Conversion of initial offers to testing
Converting potential donors to actual donors is one of the key challenges in LDKT and there are many reasons this does not occur. The survey suggested that on average more than 60% of people who made an offer to consider donation went on to at least have an initial blood test, although this rate was far lower for Pacific and Other patients. This should be treated as indicative only, given that it is based on patient reports and also that there may have been some underreporting of offers. Patient interviews and survey comments suggested a number of reasons why an initial offer may not lead to a potential donor starting the work-up process:

- There may be practical reasons, e.g. the donor being overseas or financial barriers:

  My husband offered but we own our own business so this would be almost impossible for us both to be away at the same time, both financially and time.
• Potential donors may change their mind:

My brother was keen until he realised what was involved. I fully understand him changing his mind as it’s a big thing to do.

• Offers may not be serious or genuine:

Some of them I know have been very serious, but others you can’t really tell.

It’s easy enough to say, isn’t it, when you meet someone maybe, sitting around having a drink or out at a barbeque or something and they’re like, “Oh, I’d give you one.” The thought is nice, that’s great. I think now I’ve got to the point where I’m a little bit sick of hearing it. If I was a good friend and I want to give one, I wouldn’t even tell that person until I knew if I could if I was serious about it. I’d just go and have a test done.

• Potential donors may rule themselves self out, e.g. for pre-existing health reasons:

Most answers are, “Mine are too rotten” or “I’m an alcoholic” or I guess they don’t think they’re healthy enough. I guess because they know themselves. They just think, “Oh no, my kidney’s no good” so most replies are “Oh no, my kidneys aren’t good for you.” So I think they just know their own health or their own background or family health.

He had a lot of heart problems and that and he probably thought, “How am I going to look after myself?”

• The potential donor’s family may not be keen:

My older sister, she said she was going to give me a kidney. My brother-in-law said, “No she’s not, you can get one off your kids.” Like he butted in when she said to me, “I’ll give you a kidney”....She didn’t have good health anyway but I thought that was really nice and then he poked his nose in.

My friend’s son contacted me and said, “I would like to do this, I would like to give you a kidney” and I said to him, “Have you spoken to Mum and Dad about it?” and he said, “No, and I don’t want to....Please don’t tell Mum and Dad”... and that was really
hard for me because we are friends….And I think what happened there is then he spoke to his parents and I don’t think they were very happy at that stage and it never happened and I’ve never questioned it and as friends we’ve never spoken about it.

• Occasionally, health professionals are unwilling to start testing a potential donor:

She hasn’t decided whether she wants any more [children] yet, and if she goes ahead basically that’s what they said, they wouldn’t touch her until she’s decided she’s done with her children.

Comments suggested that one of the most common reasons for a potential donor who has offered not proceeding further is that patients themselves turn down offers. Even patients who said they would “love” to have a live donor transplant had turned people down. Again, there are several reasons for this which relate to the concerns patients have about live donors or misinformation about aspects of the process:

• Many people had concerns about a specific potential donor:

Two of my daughters have investigated the live donor process. One had blood pressure problems and the other is a solo parent running her own business and raising a child so this was not acceptable. I could not agree to it.

At the time, an 18- or 19-year-old niece wanted to be a donor, and I immediately said no to that because I think she’s too young.

• Some had more general concerns about LDKT such as the health impacts on donors:

Have had an offer from one close friend but said no. I cannot bring myself to let someone do that for me.

• There were also concerns about the potential relationship with donors:

I don’t let them get as far as [ringing the coordinator]. I go, “Hang on, this is where the line stops here. We don’t need to talk about this anymore.” Some people want to go further. I go, “No, no, no.” A couple of girls wanted to offer, I go, “Hang on, I barely know you and you want to give me a body organ?” You know what I mean?
It’s not like something where you just go get another one, you know, that sort of stuff. I don’t know if people understand that.

He wanted to take me out, I thought, no, you know. I don’t want to have no connection with him because he’s a friend of my brother’s. I thought, “No, stay away from there,” so I just said to him, “No, don’t worry about it.”

 Patients often assumed the person would be unsuitable due to health, age or incompatibility:

My father offered....I assume he would have been too old at that stage anyway....I don’t know whether there is an age limit for donors....I mean he was very fit and healthy but, I mean, we didn’t really think of that seriously, because we just said no, you’re older and you deserve to live the rest of your life without complications (spouse of patient).

At that time I didn’t think about transplant because I knew all my family are different [blood types], my brothers and sisters. Because I only have one sister and two brothers and my sister, she had hepatitis B and my two brothers they’ve got A-blood type. We are all different so I knew that no one can donate to me; same as my children, all my children are like my husband. They’ve all got A-positive blood.

 Patients sometimes refused an offer or did not respond initially and then did not know how to raise it again in the future:

I don’t think I said “no”, I just said we’d have to do all sorts of tests and I guess it’s finding the time and all that sort of thing to do that, and that was it....I don’t think I’d raise it with her again. It’s not something we talk about when we come together.

Health professionals are generally not involved in this part of the process and may often only become involved once a potential donor steps forward. They could not, therefore, say why potential donors may not be willing to consider donation:

I don’t think anyone knows about that group where the recipients talk to a group of people and they don’t come forward. I think that’s a whole different issue.
Several people, however, commented on the issue of patients turning down potential donors often due to misunderstanding about who can be a donor. Transplant coordinators, in particular, tried to emphasise to patients that they should let the renal unit assess donors, rather than patients or donors making assumptions about who might be suitable:

*It’s just education, education, isn’t it? Patients have some very different ideas they’ve picked up about who can have a transplant and who can’t.*

*There was a chap who’d had a number of people who’d said they wanted to be a donor and he’d said to them all, “Oh no, you wouldn’t be able to because your mum had diabetes” or whatever and he was turning people down. I said to him, “If somebody has got diabetes or are on blood pressure medicines, we wouldn’t accept them but just because somebody’s got a family history of something it doesn’t necessarily mean they’ve got it…. You could be turning someone down who might actually be able to do it… so let those people approach us and we’ll assess whether or not they can be a donor.”* He hadn’t really thought about that, he’d just made this decision that they weren’t going to be suitable because they had a family history of diabetes or whatever.

### 3.4.3 Addressing barriers to finding willing donors

A variety of options are possible for addressing barriers to finding donors and expanding the pool of potential donors. One approach has been to loosen restrictions on who is eligible to donate by permitting unrelated and non-directed donation. Many countries have had legislation prohibiting these types of donors which has now been amended (although some have not) (292) and many transplant units are reportedly becoming more positive about non-directed donation (243). Ethical concerns, particularly in relation to non-directed donors, have had to be addressed (190, 293-294) and suspicion about motives and psychological stability may also exist (284, 295).

NZ has never had legal restrictions on unrelated and non-directed donors. Unrelated donors (e.g. spouses, friends) made up more than one-third of all living kidney donors in 2010 (55). There are few non-directed donors (with 36 non-directed donors between 1998 and 2010 (65)) but no legal barriers to this form of donation.
Increasingly, attention has been given to improving the education, information and support available for patients and their networks about LDKT, as well as raising general awareness of living donation. The other main option identified is reimbursement for donors of costs associated with donation.

3.4.3.1 Providing information, education and support for patients and their networks

3.4.3.1.1 Overview

Improving the information, education and support for patients and their networks about LDKT includes the quality and timing of discussions about ESRF and RRT options (Stage 2), which can shape patients’ perceptions of their illness, decision-making, and their willingness to approach potential donors and accept offers. The wide range of concerns that different patients have, and the fact that preferences can change over time, suggest that individualised, ongoing discussions with patients are necessary. Approaches can include allowing patients who are ambivalent about LDKT to meet with a transplant psychologist who provides general information as well as identifying the patient’s specific concerns. They then collaboratively develop an LDKT action plan to support the patient in the LDKT process (182). More recently, the Talking About Live Kidney Donation (TALK) study has developed protocols for trained social workers to engage with patients and their families about pre-emptive LDKT and is being trialled to test its acceptability and feasibility in clinical practice (296).

It has been argued that attention is also needed to specific initiatives aimed at donor recruitment, similar to the investment that has been made in developing recruitment strategies for deceased organ donation (157, 271). Healy (85) notes that the most common reason for not donating blood is that people have not been asked. He comments on the importance of “the ask” stating that “altruistic action often happens in response to a direct request” (p.60).

Many patients have asked for advice and support in how to approach potential donors (36, 271) and suggestions have included structured training for patients in how to initiate a conversation with potential donors, ideas for wording of letters or emails, or role playing different ways to have a conversation (182, 271).
Hearing from previous recipients and donors may be useful for both potential recipients and donors (176), including balancing out negative stories about failed transplants (254). Hearing about donors’ positive experiences and about the safeguards that are in place for protecting donors’ wellbeing, may help alleviate potential recipients’ concerns about LDKT (176). These encounters may be through individual or group meetings, written or DVD material with donor and recipient stories (297), or self-initiated donor groups (e.g. www.nierdonoren.nl.).

Information for patients is usually provided during clinic appointments but this has limitations because it will typically only reach patients and whoever happens to come to a clinic with them; may not address a patient’s primary concern of how to actually discuss the issue with others; and requires the patient to have a high level of health literacy so that they can accurately pass the information on to others (270). Information for potential donors is usually only provided once they have approached the transplant clinic and expressed interest in donation (192). Thus, methods are needed to convey information directly to a patient’s networks rather than relying solely on patients to be responsible for informing others about donation or waiting for potential donors to approach the clinic.

At a minimum, this might involve consistently and systematically encouraging others to attend clinic appointments with a patient (128). Formal family education programmes, traditionally held in a clinic setting, have been shown to increase the numbers of people who offer consider donation and the actual number of transplants performed, particularly amongst African-American and elderly patients (298).

Another approach for involving a patient’s networks is facilitated home-based education sessions (268, 270, 299). Trained educators (e.g. nurses or social workers) present information about renal disease and RRT options in a patient’s own home, rather than in a clinic setting, with family and friends invited to attend. At follow-up in one trial, 41% of patients whose family had participated in the information session had received a LDKT compared to a rate of 30% amongst patients in the preceding three years at the same clinic, with a four-fold increase in transplant rates for African-American patients (270). In a similar trial in the Netherlands, someone from all 10 meetings held came forward within three months offering to be a living donor (299). Nearly 90% of patients in one study were very
supportive of such an approach (300). This approach allows accurate information about all aspects of ESRF and RRT to be provided to a wider group of people without relying on patients to convey the information. Importantly, no direct requests for potential donors were made, yet many people were willing to step forward.

The Norwegian approach of health professionals approaching family members is considered unacceptable by many clinicians (157) but many patients would like someone else to make the initial approach on their behalf. A recent initiative has trialled the use of trained advocates or champions who can speak on behalf of the patient to potential donors (301). Arguing that simply providing education does not reduce patient anxiety sufficiently to enable them to approach potential donors, this programme provides training to a family member or friend in how to initiate a conversation with a potential donor. By the end of the trial, champions reported becoming more comfortable initiating conversations and there were significantly more donor enquiries and transplants for patients with a trained champion, compared to a group of matched controls.

Finally, some clinics have begun using an on-line form to carry out preliminary screening of potential donors (302). A short questionnaire enables potential donors to answer a range of questions about their health status which can quickly determine whether they are definitely ineligible to be donors (e.g. having hepatitis C or HIV or diabetes) or relatively ineligible (e.g. being obese or a smoker). Clinicians at these units have found that they can screen large numbers of people very quickly, productivity of transplant nurse coordinators increased by 50%, and that multiple potential donors are now stepping forward for initial screening. The on-line approach also provides another donor recruitment strategy for patients, because “the paperless format makes it easy...for people needing kidneys to pass word on to friends and family, by simply emailing the screening website’s URL” (302). This avoids the difficult task of patients having to have individual face-to-face conversations with potential donors. It is also possible that the immediacy and simplicity of the approach makes it easier for potential donors to respond, rather than, for example, having to contact a transplant coordinator by phone.
3.4.3.1.2 Results

Many respondents felt that improved communication with and information for patients and their networks was the key to increasing the number of people willing to consider living donation. One clinician noted:

*I guess just looking at the literature reviews that we’ve done, I think probably the biggest bang for your buck is going to be putting in place strategies that raise awareness of outcomes of live donations much higher in people’s consciousness and that’s at recipient level but particularly family level. So putting in place a strategy to get more visibility around that in the chronic kidney disease and pre-dialysis assessments that we do. I think there’s quite a lot of stuff you can do in that area. A lot of it is just communication, taking the opportunities when they arise.*

There are already many ways to inform families about LDKT but these are often opportunistic (e.g. if a family member happens to come to a clinic), likely to involve people who have already expressed some interest in donation (e.g. seminars for potential donors), and may not provide comprehensive information about all possible RRT options (see Stage 2). Given the significant role that patients themselves must play, support for patients in donor recruitment is a current gap in services.

Patients had a variety of views about what they thought might help them. It was clear that there is no “one size fits all” approach. Some people thought they would like someone else to approach potential donors for them:

*I suppose I need somebody to come along and do it for me because... I’m just a bit scared to do it....I’d like somebody else to mention it, that would be good.*

*I find it really hard to talk to family and friends about donating a kidney...I would much prefer it if there was a go-between to talk to them on my behalf.*

Many patients would welcome training in how to approach others or ideas from other patients who have tried different approaches. Patients often did not want to learn how to ask someone else, but they were interested in learning about ways to let their networks know in a way that would not be seen as offensive:
I would like any help at all on how to approach friends. Letter suggestions, anything. Because I’ve got quite a few friends who really value me as a friend and I think with the right kind of prompting they would say, “Yeah, I’ll do that. And I don’t think it will take much in a lot of cases... how to approach them, how to just flick that switch, yeah....I’d like to know how other people have done it in New Zealand, how do they actually ask friends, how do they actually put it out there to start with?

I couldn’t just walk up to somebody and ask them for a kidney. So if there’s another way of doing it that’s a bit more subtle, it might be all right.

I guess having more information and being taught how to ask, not just blurt it out. When I blurt it out, it’s just as a joke, but I’ve never, I haven’t really approached someone and said, “Excuse me, I’m just looking for an O positive match to be a possible kidney donor. Would you be willing to go through some tests?”

Facilitated home-based education sessions were described to patients in interviews and many thought that such an approach would be very helpful:

I think that would be a good thing...for people that can’t speak or even to have, like, an information evening type of thing where a person could just invite their friends along and say, “I’m a kidney patient, we’re having a kidney evening and they’re going to talk about live donation and things like that, do you guys want to come along?” and get a group of people to come along.

I think that would be great if they had sessions like that...then they would have the proper information and answers. That would be a good idea. I never thought of it that way, but with my family having hypertension and diabetes, I would be more open to inviting friends over to do that.

Others had some reservations and worried that it would still be seen as just another way of asking people for a kidney:

I would be a bit nervous to do that....I don’t know. If there was more than just me wanting a kidney, but if it’s just me and she’s talking to a group of people, it looks
rather pointed that I’m the one that would be wanting the kidney, it would look a bit... it would be okay if there was more than just me.

If you had the right people there, that were genuinely interested in doing it, yes, it would be ideal. But if you open it up, I can see people thinking, “Oh god, this is like some member of our family trying to sell Amway or something.... The only reason we’re getting the invite is because they want one of us,” you know. I sort of like the one-on-one basis, more so than like a family group.... Maybe back at the beginning.

Others thought it would be helpful in certain circumstances, particularly early on in the process when the need for a transplant was first known. Some people felt a session predialysis would allow for wider education session about ESRF and RRT options rather than a more obvious focus on transplantation:

Once upon a time maybe but not now, definitely not now, I’m too long in the tooth now and I can’t be bothered and neither can they.... But yes, I think that definitely could work, but not in my case now.

3.4.3.2 Raising general awareness about LDKT

3.4.3.2.1 Overview

In addition to targeting patients and their networks, strategies may also seek to raise general awareness about organ donation. Public education and raising awareness are often key planks of strategies to increase organ donation (303) and organ donation campaigns have been seen in many countries (304). The focus has historically been on deceased rather than living donation (298). Campaign goals may include encouraging people to register as a deceased organ donor or discuss donation with their families, creating perceptions of normative behaviour, or simply maintaining salience of the issue (304-305). A deliberate media strategy has been part of the Spanish model for some time, which incorporates: regular engagement with the media; providing clear, positive and accurate messages; informed spokespeople; and consistency of messages by all those involved in transplantation (306).

Creating positive perceptions may be important because media representations of organ donation are often sensationalist, highlight fears about organ donation (e.g. that doctors
will hasten a person’s death in order to obtain their organs), and involve false information (307-308). These portrayals have been associated with negative opinions about organ donation (309) and with declines in actual deceased donation rates over long periods (306, 310). Positive media stories may have the opposite effect in the short-term but evidence of long-term impacts is less clear (306). Transplant professionals have little control over these stories and may be wary about the media as a result (308).

As noted, public awareness efforts often emphasise deceased rather than living donation and less is known about whether publicity campaigns would be effective in increasing rates of living donation. Media stories may have prompted some people to consider non-directed donation (284) and the internet may also be raising awareness and resulting in increasing numbers of non-directed donors coming forward (293). Positive media stories about LDKT have been correlated with spikes in enquiries from potential living donors (311).

Sound formative research is essential to any campaign to increase organ donation rates along with consideration of target groups and messages (304), including whether investment in media campaigns is cost-effective compared to other possible interventions (306).

3.4.3.2.2 Results

Both health professionals and patients thought that awareness about renal disease and transplantation was generally very low in the wider community. Health professionals commented that:

*Some people just have to experience something in their family and a lot of people have experienced people with strokes and heart attack, and they know people with diabetes. It's a bit harder for us... That's an international thing.*

*Most people don’t know how serious kidney disease is, not until they're right involved in it they don’t understand. I don’t think the public understand how intensive dialysis is for a patient and how much it impacts on their lives, because it’s not something that’s visible.*

Patients (other than those with a family history of kidney disease) said it was something they had never thought about until it happened to them:
I didn’t know anything about it until I had my kidney problems. To me, a kidney was a kidney, and I’ve learnt since being a kidney patient that your kidneys mean so much to the rest of your body.

Most people thought there would be a benefit to increasing general awareness about LDKT:

If someone actually did a campaign towards it or there was some media exposure on all of this….I think at the moment it’s such an invisible problem and an invisible altruistic opportunity. I think many more people would donate (health professional).

Jonah’s brought it out in the open….A lot of people didn’t really know about donating and stuff like that until the first time Jonah did it. That sort of made everybody aware of it and now that he needs another one it’s sort of realising, “Gee, maybe I need to do something about that as well.” So Jonah is doing a very good advertising thing (patient).

The benefits of raising awareness might include:

- Making it easier for patients to talk to their networks about living donation or providing opportunities to talk about it:

  So the more publicity you get around things, the more it makes people think about it and hopefully the more it would make people with a kidney disease able to talk about it as well.

  That documentary last year, it was incredibly interesting….A lot of my walking group know about [husband], and after that, quite a few people said to me, “Oh, that was really interesting.” And they were interested in it, about how it related to him….I thought, well that’s really good because a lot of them probably didn’t know anything about it before then (spouse of patient).

- Potential donors may be more open to considering donation when a patient raises it, if they have already heard of it:

  Having some knowledge is critical... because people are human. If you’re not sure and it’s sprung on you, well, you’re going to say no.
• The networks of potential donors may have a more positive view:

I sometimes get calls from people who are concerned about their loved ones being donors [it’s understandable]. If your husband suddenly came home and said, “Right, I’m going to give my kidney to somebody...” Of course you’ll be thinking, “Oh hang on a minute, is that safe?” And you won’t have any of that information unless you know a bit about it.

• Key people in potential donor networks can have a significant influence on decision-making and must be well-informed:

Educating health professionals, that’s something I should emphasise.... Say you went to your GP and said, “I was thinking of being a donor.” “Oh, I don’t think they’re doing people like you”, say if you haven’t had a family or something like that and they think it could put you at risk. We know those things aren’t a risk but inevitably GPs can’t be up to date on everything and unless they’ve had experience with someone who’s been a donor...so we need to focus on educating them as well (health professional).

• Misperceptions about living donation, such as who can be a donor, can be addressed:

People don’t know that they can be live donors. It’s amazing, we think they do, but they don’t....I’m always surprised by the conversations I have in general with people and when they find out about my job, often they’ll say, “Oh I didn’t know I could give a kidney.” That always surprises me because, being in my role, I think surely everyone must know you can do it, but they don’t....Mostly they think you have to be related and a certain age; they’re probably the two main things, particularly being related... but it’s only because we’re in this field that we know, otherwise, how else would you?

• There may be direct impacts on people’s willingness to consider donation and act on it. Transplant coordinators commented:

You can tell when there’s been something in the newspaper because suddenly we’ll have five brand new donors ring us in one day and we always go, “Right, what’s
happened, there’s been a story somewhere.” I do think it does have an influence on people contacting us. We do have people ring us and say, “I saw an article a couple of months ago and I’ve been thinking about it....”

While some health professionals thought that “any publicity is good publicity”, there may be challenges in raising awareness through the media. Some commented that the media may perpetuate misinformation or only be interested in sensationalist stories, rather than positive stories about LDKT:

To get the information out there we rely on patient’s stories to be perfectly honest, good stories that people are interested in, people like those stories... the smaller papers usually like those. The bigger papers want something more sensational....Trying to get anything on TV is really hard....I don’t know, we’ve tried everything ....We ring them up if we think we’ve got an interesting story but more often than not they don’t take it up.

Negative stories could put people off transplantation:

I’m not sure that all media stories are helpful in promoting transplantation. I have had a number of patients who don’t want to have a transplant because they have seen what has happened to famous people who have had transplants and they have failed. And the media can be particularly unhelpful around those times....Some media are really good and some are really bad and you have got no control over what they put in.

While there may be benefits to raising general awareness of LDKT, further formative research is necessary about messages, target groups and useful strategies for disseminating information (e.g. relying on the media to print positive stories or developing campaigns such as those for blood donors) and likely cost-effectiveness compared to other strategies. One clinician noted:

Whether there is a need for a bigger, global sort of education, I’m not really sure. You can spend a lot of money on those things without it being particularly well targeted.
3.4.3.3 Removing financial barriers for donors

3.4.3.3.1 Overview

As noted above, donors may suffer financial hardship as a result of donation. It is not clear to what extent this actually deters people from donation although there is some evidence of economic barriers. Many jurisdictions have introduced schemes to reimburse some or all of the costs incurred by donors. Reimbursement for actual costs can be clearly differentiated from that of financial incentives and the sale of organs and is widely recognised as ethically acceptable (107, 312). The Nuffield Council on Bioethics (105) concluded that while some people find the “image of money” in any part of the organ donation process to be unpalatable, “the simple presence of money in the transaction (for example in the form of reimbursed expenses) does not in itself imply a ‘purchase model’” (p.153).

A cross-country review (313) found that of 40 countries from which data could be collected (out of 72 that practised LDKT at that time), reimbursement of some form existed in 21. Of the major types of costs (travel, accommodation, meals, lost income and childcare), 10 countries had comprehensive programmes covering all of these. Others reimbursed only some of these costs or only partially. Many programmes have been introduced only in the last five years and some countries are experimenting with pilot projects. The authors note that the review provides an indication of the moves being made internationally to support LDKT although it remains to be seen what impact they have on transplant rates. Klarenbach et al (291) suggest that it should be entirely possible to eliminate economic barriers for living donors and argue that “not only is implementation of such a strategy just, but the removal of this barrier is an obvious step to encourage and recognize living donation” (p.798).

3.4.3.3.2 Results

Concerns about donors being out-of-pocket rated highly in the patient survey and interviewees confirmed that this contributed to the sense of difficulty patients felt about approaching potential donors and accepting offers. Everyone who commented on this thought the current level of payment in NZ was too low and should be increased to at least cover actual costs.
Health professionals were also concerned that many donors were out-of-pocket and suffered financial hardship as a result of donating, including having to use up sick or annual leave:

*Donors can be out-of-pocket by being donors and they’re doing an altruistic, a good thing. They certainly shouldn’t be out-of-pocket. They need to be reimbursed for travel and accommodation and loss of income and things like that….We don’t say, “Look, we don’t want you to be any worse off so we’ll make sure that you have enough money to tide you over or keep your job or whatever.” That’s one thing we won’t do and that’s not right.*

Potential donors were not included in this research so it is not known to what extent financial issues act as a barrier. Some health professionals thought financial barriers were likely to exist for low-income people, anyone with a mortgage, self-employed people, or in situations where a couple were a donor-recipient pair. However, transplant coordinators generally felt that by the time people made it as far as starting the work-up process, they had worked through such barriers and/or were committed to carrying on regardless of the hardship they might suffer. The number of people who never made it that far in the process, however, was unknown and coordinators thought that people for whom it was a barrier probably did not contact them:

*I think the financial barriers are still there. I think that the WINZ benefit doesn’t really cover it for people who are anxious about their financial situation….but you don’t know why people don’t come forward so you’re not sure [if it’s a barrier].*

*That’s very seldom brought up by donors so I’d have to say I don’t usually find it’s financial at that point for donors [when they approach the coordinator]….If it’s a problem, they might not even bother. No, we might never see them….I guess you’re committed at that point, you’re going to continue.*

Most donors do not utilise the support available under the current scheme which has been consistently underspent since it was introduced. Between 2005 and 2010, there were 380 living donors (347 kidney and 33 partial liver) with 130 receiving a payment under the programme, at a total cost of $220,928, or an average of $1699 each (personal
communication, letter from MSD, 28 July 2011). It is likely that for some people the amount offered is not sufficient to overcome the financial barriers and so they choose not to donate at all. Some coordinators thought the effort of completing the paperwork may be too much:

*A lot of donors don’t apply for it….It’s a hassle, you can’t really apply for it until you’ve had the operation and the social worker has to be quite proactive to help them get it….Self-employed people don’t apply for it because it costs them more to get the accountant’s information than it’s worth and people with good incomes who are being covered by their employers don’t apply.*

While it is currently unclear what impact increasing the level of reimbursement for donors might have on its own, it might be a tangible initiative that could be used as a focal point to raise awareness about LDKT:

*For my money, the [proposal to increase reimbursement to live donors] is small chickens but it would go very nicely with a government campaign.*

Furthermore, it is likely to make an important difference to patients who feel uncomfortable about approaching potential donors or accepting offers knowing that donors will be out-of-pocket.

### 3.5 Summary: Stages 1-3

The research suggests that there is inconsistency in how patients are referred and assessed for transplantation (Stage 1). Even amongst waitlisted patients, there is variation in the discussions health professionals have with patients about LDKT – with a fifth of the sample not being able to recall a conversation about LDKT despite having been assessed as suitable for transplantation. These discussions may influence how willing patients are to pursue LDKT (Stage 2a). While patients on the waiting list were generally very positive about LDKT, they reported a number of concerns about it, especially impacts on donor health and donors being out-of-pocket financially, and they wanted more information about both living and deceased donor transplantation (Stage 2b).

Most patients found approaching potential donors very difficult and some found even discussing it challenging. Most people would rather somebody offered to donate, and many
thought that if people wanted to offer, they would do so without being asked. Patients received very little support from renal units for donor recruitment. Health professionals did not see it as their role to suggest the idea directly to potential donors, although were happy to discuss donation with interested people. Many patients said nothing to their networks or talked about the need for a donor in an indirect way. The main “strategy” employed by patients, and in fact suggested by health professionals, was to try to raise the topic in conversation and hope that this prompted somebody to come forward (Stage 3).

Most patients reported at least one person was willing to consider living donation and over half said someone had had an initial blood test. Discussing living donation with others was positively related to receiving an offer although not discussing, or discussing only indirectly, could generate an offer if potential donors had some level of awareness about LDKT already. Asking potential donors directly was no more likely to result in an offer than discussing living donation. Several factors influenced whether potential donors who made an initial offer went on to start the work-up process, in particular patients declining offers because of concerns about living donation or misinformation (Stage 3).

For NZ patients, as elsewhere, key issues at these stages included patients not being encouraged to pursue LDKT, patients turning down offers from potential donors, and insufficient potential donors who were willing to consider donation and start the work-up process. This may have been influenced by patient concerns about LDKT, knowledge/awareness, and not informing their networks about the need for donation.

Based on the international literature and the results of this research, several initiatives may address barriers to finding a donor, many of which involve improving the timing, quality and consistency of discussions with patients and their networks about LDKT, addressing individual concerns, and providing greater support for donor recruitment. Raising general awareness of LDKT and removing financial barriers are further options (Stage 3).

This chapter has focused on issues leading up to the identification of potential willing donors. Once a potential donor has come forward to signal their interest, they must complete an extensive evaluation to determine their suitability to be a donor (Stage 4) so the transplant can be carried out (Stage 5). These stages of the patient journey are discussed in Chapter Four.
Chapter Four: Barriers to LDKT – Stages 4-5 and cross-cutting issues

This chapter continues the analysis for the first research question - what are the barriers to LDKT and what can be done about them? The previous chapter has discussed Stages 1-3 of the patient journey and this chapter examines barriers in Stages 4 and 5 of the patient journey: for those potential donors starting the work-up process, including issues in the work-up process itself (Stage 4), and issues in receiving the actual transplant (Stage 5). This chapter also considers cross-cutting issues, particularly around the organisation of services.

4.1 Stage 4: Donor is worked up and suitable

The evaluation of a potential donor must determine compatibility with the intended recipient, the medical and psychosocial suitability of the donor, that they are fully informed of risks, and acting voluntarily (and, in particular, not accepting any form of payment for donating). In NZ, tests include blood tests, a check of general health (such as Body Mass Index (BMI) and blood pressure), chest x-rays, an ECG, a CT angiogram, a psychosocial assessment (in some cases) and other tests as necessary (206).

Not everyone who makes an initial approach to a transplant coordinator, or does an initial blood test, continues further with the process. Many donors are excluded due to incompatibility or medical unsuitability.

4.1.1 Overview

4.1.1.1 Kidney Paired Exchange

Estimates suggest that as many as 30% of willing and otherwise suitable donor-recipient pairs are biologically incompatible and do not proceed to transplantation (195)\(^\text{13}\).

Incompatibility barriers may be overcome using clinical protocols which use advanced

\(^\text{13}\) Some patients face particular challenges to finding a compatible donor due to the presence of high levels of preformed anti-HLA antibodies (known as being sensitised), usually as a result of pregnancy, blood transfusion or previous transplants. There are some estimates are that up to 30% of patients on waiting lists may be sensitised (314).
immunosuppressive techniques\textsuperscript{14} or systems in which an incompatible donor-recipient pair is matched with another incompatible pair to “swap” kidneys, known as Kidney Paired Exchange (KPE). Since it was first suggested in 1986 (318), KPE has become the fastest growing source of transplantable kidneys in the last decade (319) and is now established in a number of countries (196).

The simplest variation is a two-way exchange (Figure 9), in which the donor in each pair gives their kidney to the recipient in the other pair. Other variations include three-way exchanges and chains which begin with a non-directed (altruistic) donor and can extend over time (196, 319-322). Chains offer significant potential to increase transplant numbers, with the largest chain ever performed involving 60 donors and recipients in the United States of America (USA), and resulting in 30 transplants (323).

It is estimated that routine two-way or three-way KPE and altruistic donor chains could increase transplant rates by between 7% and 10% (195). The Netherlands was the first country to introduce a national KPE scheme in 2004 (319, 324) and KPE may be one reason for its high rates of LDKT (38, 325).

The critical issue in any KPE scheme is to maximise the number of donor-recipient pairs in the pool (326-328). While there is no “right number”, pools of 15 donor-recipient pairs frequently have no matches with other pairs at all (196), and it has been suggested that at least 100 pairs are required for a sustainable matching programme (319). National programmes are therefore preferable (319, 324, 329) with international schemes being the next step (330).

Successful matching also depends on the types of matches performed and the algorithms used to identify potential matches, with matching software allowing more complex

\textsuperscript{14} Immunosuppressive techniques may be used in cases of ABO blood group incompatibility or where there is a positive cross-match. These are becoming more routine (315) with recent evidence of high graft survival rates (316) although there is a greater risk to recipients of complications from the higher immunosuppressive dosages needed (317).
exchanges than the standard two-way ones (327, 331-332). Matching algorithms, well established in deceased donation, have been unnecessary in living donation previously (319).

Legislative and logistical issues must also be addressed (324, 333). Regulation that prohibits the transfer of organs for “financial or other consideration” in order to prevent the sale of organs, has also prohibited KPE schemes and many countries have amended legislation to specifically exclude KPE (195-196). Prohibitions on living unrelated donation and non-directed donation have also presented barriers, and again a number of countries have amended laws to allow KPE to proceed (324, 334).

Logistical and coordination issues include: performing transplants simultaneously to reduce risks of reneging (196); determining whether donors should travel or kidneys should be transported (with possible impacts on quality of the kidney and risks of delays or missed connections in transport arrangements (315, 335)); and agreement between different centres on minimum criteria for accepting donors (336). Simultaneity requirements may have limited many KPE programmes to two- or three-way exchanges (327) and relaxing simultaneity requirements increases the potential of KPE as longer chains are possible (196, 337). Adequate infrastructure and funding (325), appropriate independent governance and oversight of the matching procedures, and a national coordinator are recommended (338).

KPE has raised a number of ethical issues, e.g. anonymity and privacy protocols (319); and the potential for an increased risk of coercion because donors can no longer use incompatibility as an excuse not to donate (161). Empirical research can explore the extent to which these possible concerns are true in reality (339-341).

Overall, KPE is considered to have significant potential for increasing the number of LDKTs although it does not offer a complete solution to the incompatibility barrier15, and other strategies are necessary to increase the chance of transplantation, such as continuing the search for other living donors, remaining on the waiting list (314, 333) or pursuing ABO-incompatible transplants. Montgomery (343) argues techniques such as ABO-incompatible

15 For example, O-blood type patients may be unlikely to benefit because they can only receive a transplant from an O-donor but these donors may donate to any blood group, reducing the likelihood they would need to enter a KPE scheme (196, 342).
transplants should be seen as “complementary modalities” to KPE (p.455) while Yabu et al (344) suggest combining them with KPE to offer further options. Although these protocols require higher levels of immunosuppressive medication and a subsequent higher risk of complications, this needs to be weighed against the risks of remaining on dialysis (315). Furthermore, many patients themselves may be willing to tolerate a higher level of immunosuppression than is often assumed because the prospect of returning to dialysis is so feared (345).

Although the logistical challenges in KPE are considerable, Connolly et al (330) state that “these can be overcome, much as the co-operating national registries have done for bone marrow [and] these challenges are inconsequential next to the potential benefits for patients who might receive transplants as a result of internationally broadened KPE+” (p.869).

4.1.1.2 Donor medical and psychosocial suitability

4.1.1.2.1 Guidelines for living donation

A recent systematic review of clinical practice guidelines for living donation (112) found that guidelines are generally comprehensive, covering: psychosocial assessments (including informed voluntary consent, motivation, payment, mental illness and support); assessment of kidney function; co-morbidities (especially obesity, glucose tolerance, hypertension, cardiovascular disease and malignancy); and short- and long-term follow-up care. However, scope varied and many lacked methodological rigour. Important differences were seen particularly in the thresholds for co-morbidities which preclude donation. The authors recommend international cooperation in guidelines development to reduce unnecessary duplication and contradictory advice especially in relation to exclusion thresholds. Individualised assessments of all potential donors are necessary and there is a need for agreement between all team members about whether a transplant should proceed and independent assessments where there is disagreement (20).

4.1.1.2.2 Medical barriers

Medical unsuitability of donors is a significant reason for failing to convert offers from potential donors to transplants (84). Hypertension and obesity are amongst the most common medical barriers for potential donors (197, 346).
Most patients look to their immediate family or other close networks in the first instance to find a donor which may restrict the possibilities for patients from populations with poor overall health outcomes. Ladin and Hanto (347) found that similar proportions of White and African-American patients had at least one person offer to be evaluated to be a donor, but African-Americans were less likely to go on to receive a transplant. The authors hypothesise that African-American patients are more likely to belong to a “risky network” with, among other things, higher rates of obesity, diabetes and hypertension: “Belonging to a risky network might impart disadvantage beyond the individual level by decreasing the patient’s number of eligible potential donors” (p.475). Research with potential donors suggests that obesity and hypertension amongst African-Americans are significant barriers to becoming living donors (197-198). Contrary to popular assumptions about the lack of willingness to donate amongst these populations as the reason for lower rates of transplantation, medical barriers may be a significant factor in inequalities in transplant outcomes (197).

These factors may not be amenable to intervention (198), e.g. weight loss efforts may be unsuccessful (346), while many people regain the lost weight and some have suggested it may not be in the best interest of donors to accept them at what may be a temporarily low weight (197, 348).

### 4.1.1.2.3 Marginal or medically complex donors

The growing demand for transplantation means that donors who do not met the usual criteria (known as marginal or medically complex) are increasingly being accepted in some centres (349-351). Lentine et al (352) note that “the stringency of living-donor selection has inherent tensions with the goal of increasing organ supply” (p.731). One survey of USA transplant centres found that 24% of living donors could be defined as medically complex (351).

Outcomes for medically complex donors are not well understood (108, 112) and studies showing good long-term outcomes for living donors cannot be generalised to medically complex donors (28). This raises significant ethical issues (84, 350).

Some argue that it is ethically unacceptable to accept medically complex donors, and that while living donation in general may be justified, the desire to meet the growing demand for
kidneys should not lead to the use of donors for whom there is a potentially greater level of risk (114, 350).

It might be possible to argue that donors should be able to choose to take a higher level of risk but the absence of outcome data makes informed consent difficult. Some studies are emerging that suggest medically complex donors such as obese and elderly people do not appear to be at greater risk than non-obese and younger donors (353). However, many commentators believe that caution is needed before accepting them and transplant professionals need to highlight the lack of data about long-term outcomes (108, 351).

In addition, potential donors may minimise risk to themselves (191). Reese et al (351) found that spouses were more likely to be medically complex donors and suggest this may be because they are likely to accept a greater level of risk due to their relationship with the recipient. It may be questionable whether donor autonomy and informed consent can adequately balance risks, especially in the absence of data about outcomes for these donors.

A further concern relates to the impact on the quality of transplants (84), although again the evidence is inconclusive (353). O’Brien et al (353) suggest that, given the risks of dying on the waiting list before receiving a deceased donor transplant, “perhaps it might be said that a marginal graft is better than no graft at all” (p.1164). This may need to be weighed against the possibility of shorter graft survival and faster return to dialysis.

4.1.2 Results

4.1.2.1 Outcomes for donors who were tested
Survey respondents identified what had happened to the people who had started the work-up process (some of these results have been reported previously (2)). This information should be treated as indicative only since it relies solely on patient reports. More accurate information may be available from renal unit records (although it should be noted that some potential donors will go to their own GP for a blood test and may not approach the renal unit at all).

Of the 242 potential donors for whom results were reported, incompatibility was the most common outcome followed by medical unsuitability (Table 12). Further analysis of these
results showed that 28% of patients reported at least one incompatible potential donor and 27% reported at least one potential donor turned down for medical unsuitability. Only 13.5% of patients said they still had someone being tested. Although indicative, this may give some idea of what the major barriers are likely to be for patients and potential donors at this stage.

In a very few cases, patients had turned the person down or the potential donor had changed their mind once the work-up had begun. These outcomes appeared to be more common earlier on in the process (Stage 3).

One patient reported changing his mind about a potential donor who had already started the evaluation process, saying:

_She was just really worked up about it, if it failed. She kept on and I says, “Well, these things do happen you know”….And it was for those reasons and her reaction to that and how worked up she was, I just didn’t think it would be good….I didn’t divulge that to her. I just went to my nephrologist and told him._

Occasionally patients were aware that potential donors had decided not to proceed further:

_I had a friend and she offered to donate and she went part-way through the process and then she decided that it wasn’t for her, again, that’s fine. I think she was talking to other people at work, and they were telling her all the bad points about donating a

| Table 12: Outcomes for potential donors who started the work-up process (as reported by patients) |
|--------------------------------------------------|----------------------------------|
| Number (%):                                       | Number (%)                      |
| Potential donor incompatible                      | 112 (46.28)                     |
| Potential donor medically unsuitable               | 73 (30.17)                      |
| Potential donor still being tested                 | 30 (12.4)                       |
| Potential donor changed their mind                 | 11 (4.55)                       |
| Patient turned the potential donor down            | 10 (4.13)                       |
| Donor suitable and waiting for transplant          | 2 (0.83)                        |
| Other                                             | 4 (1.65)                        |
| Total                                             | 242 (100)                       |
kidney, that she has to think about family and all that sort of thing and got into her head a bit and she backed out.

My nephew couldn’t take the tests and he pulled out....He didn’t say exactly what but that’s supposed to be confidential between him and the transplant coordinator, and I told him, “You don’t have to tell me anything. If you want to pull out, that’s all you need to tell me and no reason at all.” He didn’t actually tell me, his mum, my sister, told me. He couldn’t handle the tests.

Health professionals commented that in their experience, while it was common for many potential donors to make initial contact with the renal unit and then not proceed further, they were unlikely to withdraw from the process once making the commitment to start:

We don’t get a big drop-out rate once they’ve started because we make sure they’re well educated here.

Transplant coordinators did not have data about the number of people who make contact and then do not continue and estimates varied in different centres:

When they contact me, I send them a copy of the booklet and a blood group form and ask them to re-contact if they wish to continue. I would say that of every 100 books I send out, only a third come back and re-contact.

Most people do contact us back. Of all the people that phone us as donors, I would say that 75% of them do phone us back.

Only 4.55% of potential donors were reported by patients as changing their mind after the initial blood test which may conflict with the experiences of transplant coordinators who sometimes report that many people do not continue after an initial blood test. This apparent discrepancy may be due to interpretation of the question, such as when the work-up is thought to have started, patients not having accurate information about donor decision-making, or a bias in the sample in that people who had a more serious or committed potential donor were more likely to respond to the survey.
4.1.2.2 Kidney Paired Exchange in NZ

Auckland City Hospital began ABOi-transplants in 2008 (64) and a KPE scheme was established in 2009 (354). It operates out of Auckland DHB with nationally agreed criteria for potential donors and transportation of kidneys is coordinated by ODNZ when necessary (355). According to interviewees, each centre is responsible for working up its own donor-recipient pairs and files are reviewed by the Auckland transplant unit. Suitable pairs are then entered into the database. In 2012, an exemption to the Human Tissue Act regarding financial or other consideration removed legal barriers to KPE (356).

There were reportedly 19 pairs in the scheme at the time of the research. By the end of 2012, two exchanges had been performed since the scheme began – both were a domino paired exchange, each beginning with a non-directed donor and ending with someone on the list without a potential donor. Each resulted in two transplants (354, 357).

Two-thirds of survey respondents said they would definitely consider KPE (Table 13). People who had had a previous LDKT were significantly more likely to say they would definitely consider KPE than people with a previous DDKT or no previous transplant (93% compared to 67% and 63%, respectively, \( p=0.029 \)). Māori and Pacific patients were significantly \( p=0.017 \) more likely to answer “don’t know” to this question than NZ European/Pākehā patients (38.5% of Māori and 43.3% of Pacific, compared to 17% of NZ European/Pākehā).

<table>
<thead>
<tr>
<th>Table 13: Number of patients willing to consider Kidney Paired Exchange</th>
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<tbody>
<tr>
<td><strong>Number (%)</strong></td>
</tr>
<tr>
<td>Would consider paired exchange</td>
</tr>
<tr>
<td>Would not consider paired exchange</td>
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<tr>
<td>Don’t know</td>
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<tr>
<td><strong>Total</strong></td>
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</table>

Most patients felt that, as long as their donor was comfortable, they would most definitely take the option of KPE if offered. Most felt that their potential donors would be happy to participate although one person interviewed said that her potential donor was not comfortable with KPE and had refused to participate.
The critical problem in NZ’s scheme is the small number of pairs in the pool. As such, some patients reported that health professionals were careful not to raise their hopes about the likelihood of getting a transplant from the scheme:

I spoke to my specialist and he said, “Yeah, it can take a long time because it’s not the best situation and it’s not something you should be holding on to saying, ‘Yeah, my kidney’s going to come from there’” because there’s so few people on that list so it could take forever. He said, “Your best chance at this stage would still be another live donor and then your deceased donor list”.

Health professionals confirmed this approach:

It depends on their situation. If a patient comes forward and they’ve got three potential donors, they get tested one at a time. They start off with who they think is the best donor and the most willing and if it’s a positive cross-match, you move on to the next one. If they’re all incompatible, then you might say, we need to look at this a little differently and we’ll offer the paired exchange. But I won’t immediately go to paired exchange if someone’s got a number of different donors, because if they’ve got another compatible donor, it’s a far easier, quicker route for them to get their transplant.

Several key issues emerged:

- **Lack of promotion with, and awareness amongst, patients**

The fact that a quarter of survey respondents said they did not know if they would consider KPE, may reflect the novelty of the scheme in NZ and lack of awareness amongst some patients. Amongst the interviewees, six people, five of whom were Māori or Pacific, were unaware of KPE or unaware that it existed in NZ as an option. The interview was the first time they had heard of the concept:

What do you call that? Paired exchange, first time I heard of that….I would do that, yeah….Gee I didn’t realise. Maybe we need to have a little bit more of a talk to [incompatible potential donor]….Oh gosh, that’s good, that’s excellent.
While some people had first heard about KPE from the renal unit, patients were just as likely to have become aware of it through media stories or patient support group newsletters. In some cases, patients had been the ones to raise it with the renal unit after hearing about it in the media.

Patients frequently commented on the lack of information about the NZ scheme or whether it existed:

> Paired exchange is in its infant stages and I believe is not yet happening. If it is, let me know.

> It was mentioned because it was done in either the US or Australia and they say it hadn’t come here yet. Is it here? [Yes] Oh, wow, oh, that’s neat.

Several health professionals mentioned that there was not enough general publicity and promotion of the scheme and that it did not have a high enough profile:

> I think we need to be doing more on paired exchange. There’s some information on the [KHNZ] website but I think we should be advertising it more to be perfectly honest....There was one story in the Australian Women’s Weekly last year, quite a good article about it and I didn’t even know there’d been one [exchange]. So I think in the kidney community we need to communicate a lot better about progress that’s been made about these really significant events...you’d think we’d want to share the good news more....People take interest in things like that, if they don’t know that they can do it, they’re not going to put their hand up if there’s no information out there or stories about it....Even we don’t get told, we’ve got to seek the information and even then it’s not that easy.

> So if you’re going to have it, then you should promote it as best you can. And if you promote it, you may find you get a lot more people coming out of the woodwork to act as donors, so I think it’s a spin-off if you promote it.

Some people felt that there was variation in whether or how KPE was presented to patients and it seemed that it was not always being actively promoted with patients.
• **People previously declined for incompatibility**

Newer patients may be more likely to have been told about KPE. Patients who were listed further in the past, however, may not necessarily have been told that KPE now exists. Several patients raised the question of how previously willing incompatible donors should be contacted:

> My potential donor was not compatible. I have probably missed an opportunity for paired exchange. Whose responsibility should it be to approach a donor about a paired exchange? I would think transplant coordinators or renal practitioners would want to grab any opportunity to transplant!

> I’m not going and tapping on my donors’ shoulders and saying, “Hey look, they’ve got this going now.”...It’d be good if my own doctor would kind of review where my donors were then and what the possibilities are now... and say, “Hey you should go and talk to this donor that you talked to previously. We’ve looked at their results and where they were at that time; it could be a good idea to have another chat to them, to see whether they’re willing to come in and get re-tested.”...As a recipient, you’re not sure what’s going on with your donor and they’re not, generally, medically savvy enough to tell you exactly why they might have been turned down....[I’d be comfortable going back to them if the doctors said] “Hey, the way the technology’s moved, you could approach this person.”

Health professionals recognised that previously-declined donors may not have been revisited. Some centres commented that they had attempted to identify patients with incompatible potential donors, while others had not:

> There are some people who, when they went on the list, didn’t have the opportunity to have an ABOi-transplant or a paired kidney exchange. So some donors were potentially turned down because they were incompatible, so we’ve contacted all those patients... but some of them may not have been badgered in the right way to see if their donors would pop out of the woodwork again.

> I think a lot of people know about it now who were in that situation [had an incompatible potential donor] but from a resource perspective, we haven’t gone out
there looking for people. I’m sure that probably if we went through the list there might be other people that are potential candidates for it….If we had a positive cross-match come back this week, the first thing we would do is talk to them about paired exchange… but I think there may be some people who we’ve previously turned down that may not know about it.

A further problem, however, is that patients frequently decline offers from potential donors due to blood group incompatibility and transplant coordinators may not be aware of this (Stage 3). KPE must therefore be raised with all patients who are suitable for transplantation, not only those who have had a donor previously declined by the renal unit.

- **Difficulties accessing the scheme**

Some patients who were aware of KPE were finding it difficult to access the scheme and commented that they had to be proactive about getting enrolled:

> And every time I mentioned it, they used to just tell me the same story, “Oh yeah, there’s a paired exchange available and what happens is…” I know the story, I know how it works. Where’s the list? How do I get on it?….We were expecting them [renal unit] to do it. You should just be able to tell them, “We want to go on the paired exchange list,” and then it’s like “Ok, well, write your name down.” But no, you’ve got to physically chase it and make sure it’s happening.

> They just told us what they do and everything but I don’t think they had many people signed up at that stage either….I think I asked [renal unit] to send the papers out… and I don’t know that we ever got them, so, yeah, I guess it’s something I should actually go back into.

- **Donor work-ups for KPE**

Donor work-ups, as described below, are complex, resource-intensive and require considerable coordinator time, and, in particular, for KPE (358). Health professionals commented that there was a need for transplant coordinators in each centre to actively promote and pursue KPE in order to get people into the scheme, but this was not always easy:
We’ve got a few in the paired kidney exchange programme and quite a few with multiple donors, so multiple donors for the one individual. It’s quite resource-intensive to do that because you’ve got to work up multiple donors... but each donor is effectively another potential match so I think it’s worthwhile, but it’s a bit of a hurdle getting enough people in the paired exchange.

There aren’t more in there because we might not have been quite as organised as we could have been....Sometimes people won’t have had their donor angiogram and things like that so they need one significant thing to get onto the list and you can’t be listed until it’s done. You need the whole donor work-up so sometimes people haven’t done that last thing...it does take a fair bit of coordinating to get all those things sorted out.

Some coordinators viewed working up donors for KPE as being of low priority:

From the perspective of evaluating live donors, it kind of seems like a bit of a waste of time. I don’t mean that in a bad way, but we’re doing a lot of work to get live donors ready and there’s nobody for them to donate to so it seems like you’re doing all this work for nothing because you’ve got to have so many pairs in it to make it work....I had so many other potential live donors that actually had somebody to donate to, that the PE donors were a lower priority for me because I kept thinking, “Well, I’m going to do all this work and actually nothing’s going to come of it anyway,” which could contribute to why there’s so few pairs in the programme - because there’s a lot to do to work up the donor... which sounds terrible, I know.

- Interface with other options

While the best option for a transplant is with an ABO-compatible, negative cross-matched donor, many clinicians would argue that an ABOi-transplant is preferable to years on dialysis waiting for a possible KPE. One physician said:

So, I reckon if it was me and I was going to be the donor or I was getting the kidney, I would say, “We’re up for the paired kidney or the ABO-incompatible,” and so I’d put my name into the paired kidney thing and see whether I was going to get a kidney. And this is what I would say to my patients, “So, put your name up, we can run it
through to see whether you’re going to get a kidney out of the paired kidney exchange; if you’re not, forget it and do an ABO-incompatible.”….So we can look to see if they’re going to come up in the PE, and if they’re not, I wouldn’t do it.

Some patients, however, may be overly optimistic about their chances of a KPE and were not pursuing alternative options such as ABOi-transplant. One person who had already been on dialysis for several years said:

My wife said that she’d rather go for the paired exchange if she’s going to give a kidney and I’m going to get one. If we could get as close a match as possible, that would be the way to go as opposed to mickeying with your drug intake just to try to use something that’s not really compatible.

- **Hard-to-transplant recipients**

Highly sensitised or O-type patients may have extra difficulty finding a match in a KPE scheme, which is compounded when there are few pairs in the pool as in NZ. These patients may already be overrepresented in the NZ pool:

One of the problems is that a lot of people are going onto that scheme because they have a lot of cross-match issues, they have a lot of antibodies. So they’re still going to have a lot of cross-match issues because they have a lot of antibodies to everybody. So the paired exchange might increase the option of a number of donors but it’s not any easier for them to be cross-matched.

- **NZ’s population size**

Several people felt that NZ’s relatively small population base was a significant constraint on developing an effective KPE scheme and that NZ should develop a partnership with Australia which already has a KPE scheme in operation ([http://www.donatelife.gov.au/the-authority/the-australian-paired-kidney-exchange-program](http://www.donatelife.gov.au/the-authority/the-australian-paired-kidney-exchange-program)). This would require resolving some crucial issues around agreed donor criteria, logistics and funding:

The NZ market is so small that PE is never going to have a big impact...there’s talk of joining with Australia. That does raise some considerable logistical issues, funding issues.
I think the biggest boost it would get would be if we joined the Australian scheme because you suddenly increase the pool a whole lot more. But then there’s a whole other level of logistics with regards to shipment of kidneys from Australia. Initially when we set it up, we said that all the transplants would be done on the same day, ideally at the same time, so no one would back out of it but I don’t think that’s really an issue these days. There’s enough experience around the world with these things to show that people don’t pull out of them.

While most people thought joining with Australia was in principle a good idea, it was also noted that any barriers in the NZ programme needed to be resolved first. Even with NZ’s relatively small population base, it might be expected that more pairs would have entered the scheme given the number of people on the waiting list. Discussions with Australia about a joint scheme were apparently put on hold during the period of this research (359).

- **Ownership within the renal community**

There seemed to be relatively little sense of ownership of the KPE scheme within the renal community, with mixed views about its potential to make a difference to LDKT rates in NZ. Some health professionals thought that, while not the sole answer to increasing transplant rates, it was essential that NZ was able to offer KPE:

> It’s not going to transplant everybody; no one measure is ever going to transplant everybody and so if you do five extra transplants in NZ, that’s a five percent increase so that’s worthwhile doing.

> Dialysis is way increasing, so if it increases, you’ve got to look at new ways of doing things and paired exchange is another system to do that.

Others were less convinced of its potential:

> I’m lukewarm about some of the proposals to increase transplant numbers... particularly the thing on tandem, what’s it called, paired donation which I think is probably redundant these days....With ABO-incompatible transplants, I don’t know why you’d ever do a paired transplant. I’m not sure it’s cheaper; I haven’t seen any maths on it at all. The logistics of doing it might actually increase the costs
alarmingly...I guess where the problem is positive cross-matches rather than ABO, it might be useful but I think it’s very small chickens really.

The USA 30-transplant chain mentioned above (see page 122) had happened just before the interviews and raised awareness and enthusiasm amongst a number of people:

_That was an enormous undertaking, it was like going to war really, and the resources required. I mean, it’s a bit over the top in a way, but what it does show you is that it can be done._

Even many of those who support KPE and were putting forward donor-recipient pairs, seemed disconnected from it, had little information about it, and described it as “Auckland’s scheme”. Few health professionals were aware of how many pairs were in the scheme and were often unsure of how many exchanges there had been:

_As far as I know there has only been one exchange actually happened so far....I don’t know how many people we’ve got in the scheme or what our local number is either._

_Auckland are the ones in the know with all this and also with the incompatible transplants so they need to let us know what’s happening, because it’s really exciting._

4.1.2.3 Donor medical and psychosocial suitability

4.1.2.3.1 NZ criteria for donors

Health professionals reported that individual transplant units use international guidelines to determine criteria for their own region but that there are no national guidelines for donor evaluation, selection and follow-up. In practice, there are reportedly relatively few variations between regions – these relate to BMI thresholds, acceptance of hypertensive donors, and thresholds for kidney function (GFR). If the transplant is being performed outside the donor’s own region (e.g. if the recipient is from a different region), the criteria of the transplanting DHB are followed.

4.1.2.3.2 Medical suitability in NZ

The survey suggested that medical unsuitability of donors was the second most common reason for potential donors not to proceed (30%) and 27% of patients reported at least one potential donor declined for this reason. Data was not available from renal units on exactly how many potential donors do not meet medical criteria although comments from health
professionals suggested that many potential donors are discovered to have medical issues that preclude them from donation. For some groups this is a major problem.

Obesity may be a significant barrier to LDKT in NZ given that one in four adults is obese, the third highest rate in the OECD (360). Amongst Māori, 41.7% of adults are obese and amongst Pacific adults this figure is 63.7% (361). The prevalence of diabetes in the adult population is estimated at 7.1%. Rates for Māori and Pacific people are estimated to be higher at around 10% and 15%, respectively, although in some age groups this may be significantly higher (362).

Obesity, hypertension and risk of diabetes have previously been identified as a barrier for many potential Māori and Pacific donors (74). As in international studies of barriers for ethnic minorities (197), health professionals in this research thought that lack of donor willingness was less of a problem than finding someone who met the medical criteria for donors:

My perception is that one of the barriers for Māori and Pacific people is that a lot of them have got diabetic nephropathy and a very strong history of diabetes and obesity. I’m not saying it’s everyone but that’s a more predominant issue for those cultures and that can exclude donors....For Māori and Pacific people it’s often that their family are medically unsuitable as opposed to not willing.

There are challenges for Māori and Pacific groups. I think there are less healthy donors available to that person than some other less deprived patient groups.

Patients with a family history of kidney disease can also be said to have “risky networks”. One NZ European/Pākehā patient interviewed also commented that it was harder to find a healthy donor from people within her age group despite receiving a large number of offers:

There’s been umpteen....I’ve had two or three friends that have had chemo. One’s got a kidney problem. You know, just the age, any of my friends from sort of mid-forties up. Another one’s had a heart condition, one’s got a pacemaker, and it’s just, realistically for me unless a deceased one comes up, that’s the end of the road.

As in the international literature, there were some comments about whether criteria should
be relaxed to allow more medically complex donors and how much donor autonomy to allow. Some health professionals thought that donors themselves should decide what risks they are prepared to take:

There is evidence that if you are obese, you have an increased chance of problems but we decided that’s up to you. You get warned about it. If you’re obese, you’ve got more chance of getting diabetes, hypertension, renal disease but that’s up to you and, for us, to stop being so paternalistic.

I’m not sure there should be any rules for live donation whatsoever. I think you should be able to donate to your neighbour’s cat if you want to. I think it’s a contract between two consenting adults.

Others, however, thought there were wider issues such as the need to retain trust in the transplant system by protecting donors:

That’s really important for the service as well as for the individuals being the donors. You don’t want to have problems with donors and it’s a disaster if you start having donor fatalities or donor complications or donors on dialysis and stuff. That’s really bad for the whole service.

Many patients also wanted assurance that their donor would not be accepted if donation was not safe for them. Relaxing criteria for donors too much may result in patients losing confidence about how well donors are looked after.

A particular issue raised was whether BMI thresholds create an unfair disadvantage for populations that are “naturally bigger”. Several participants mentioned that thresholds have been increased at some transplant units to take account of this:

If people are just marginally over the limit and not hugely centrally obese, like some people are just really big people anyway and especially when you’re dealing with Pacific or Māori people who might not necessarily be particularly overweight but they’re heavy boned, or people who go to the gym are well muscled, they can often have bigger BMIs anyway.
The limit of 35 is related to immediate operative mortality and morbidity....We decided to make it 35 because there’s problems with different racial groups and so on – although it has to be said with anyone, if your BMI is 35 then you are still fat.

It was noted that potential donors and recipients may not always be aware that the criteria for accepting donors have changed, e.g. changes in BMI thresholds may be publicised in patient newsletters but this may not reach everyone.

4.1.2.4 Donor work-up process
Donor work-ups in NZ often take up to a year or longer. The NRAB (4) notes that long work-up times are frustrating and stressful for both donor and recipient, requiring donors to “put their lives on hold” (p.16). It is not uncommon for a potential donor to be rejected on clinical grounds after a year of testing which then requires the patient to start the process of finding a donor again (74). Another factor is that usually only one donor at a time is worked up, and it is only once a potential donor has been excluded that the next one will start the work-up process (74).

Complaints about the donor work-up process have been reported occasionally in the media and in patient support group (363) newsletters: “Donor assessments in [region] frequently take much more than six months – and sometimes, as people have told us, as much as a year” (p.5, emphasis in original).

4.1.2.4.1 Patient views on the donor work-up process
Survey respondents and patient interviewees who had had potential donors evaluated frequently mentioned issues in the work-up process that they and their potential donor were unhappy about. This was one of the few areas of complaint with the overall renal service:

I felt the time taken for testing (almost 12 months) was too drawn-out for both parties. The initial response to a phone call from a donor was very poor. Two donors left voice messages on the coordinator’s phone and neither got calls back. It is hard enough to make that first phone call without not getting a response.

The testing takes too long and the not knowing is very stressful for all parties. There is also a low communication rate between health professionals which is frustrating.
Confidentiality requirements mean that potential recipients are not allowed to be given information about donor work-ups. The sometimes poor communication with potential donors put patients in a difficult situation:

It was difficult because my donors would express that to me, that they’d been trying to get in contact with their coordinators, and they would never get answers, and they’d want to know how things were progressing as far as the tissue-typing and so forth. And they weren’t getting back and then I would tell my doctor but because it’s all separated because of the ethics it was very difficult. And I would phone up my coordinator to tell the other coordinator to, “come on, my donor is in my ear”.

Patients, therefore, do not know how work-ups are proceeding or sometimes even whether someone has come forward to start the work-up. This may mean they do not know whether to continue looking for potential donors and do not know how effective their donor recruitment discussions are:

I’ve told so many people [about needing a donor] and it’s there on Facebook. So for all I know I could have had a dozen people in there testing but I have got no idea. I’m not saying they have to tell you who it is, but it would be nice to know if someone’s come forward. I mean the only time I’m going to find out that someone’s come forward is if I get asked for a blood test.

Patients already have significant levels of concern for potential donors and were concerned that the work-up process was a burden for many people, requiring time off work, multiple trips to hospital and for people to “put their lives on hold” while waiting to see if they would be suitable donors:

Three trips to hospital so far. It’s been quite drawn-out actually. I’m not exactly sure, but it seems to be a few weeks between each, like an x-ray, blood tests… a few weeks between everything. Surely they can get some things done the same day? I mean they’re nothing really and yet it takes her to drive to town, find a car park, all that messing around, blood tests; then do it again in two weeks, then a chest x-ray.

Patients recognised that it was important that potential donors were not “rushed” in the work-up process but felt the time taken was unreasonable and the lack of communication
very stressful. Overall, it was unclear to patients why this part of the process should be so difficult:

I don’t know whether it’s their workload or whatever….I don’t know how many people they’ve got coming forward….You just wonder what they’re doing, you know, if they can’t get back to you, it’s only an email or a quick phone call….A phone call doesn’t take much. When you’re in that type of job, you need to be communicating with people, especially the donors. Because they’re uninitiated to the health system and what’s going on, so to me I feel they need more guidance….I think there should be a lot more support to the donors to school them through what they’re going through and what’s going to happen.

4.1.2.4.2 Health professional views on barriers to donor work-ups

Many health professionals acknowledged that donor work-ups often took longer than ideal. As LDKT has grown both in absolute terms and as a proportion of the number of renal transplants performed, there has been greater reliance on the transplant coordination function:

Transplant coordinators certainly weren’t there for a long time. Of course, initially there was only a limited number of people [in the transplant programme]. I think it was initially done by the physician working with the renal clinic nurses. They had these specialised renal clinic nurses who have really evolved into transplant coordinators. They were probably doing so few and it was being done in such a considered way, that there was no huge list of people waiting….In the earlier times the work was nothing like the pressure on resources. So usually if the doc wanted something done, he just wandered down to the Radiology Department and they organised it for him. It just doesn’t happen like that anymore. A lot of it was almost run by the physicians themselves.

Most centres said they aimed to have a donor work-up completed in 3-6 months but said that it frequently takes longer and can be a year or more. Health professionals identified several barriers to getting work-ups done in a timely manner.
• **Some work-ups are more complicated than others**

Unexpected medical issues may arise that need to be worked through and may require additional tests to be undertaken and some situations require more coordination:

> Some people are easier to work up in a timely fashion than others. . . . Some of them are complicated to arrange like ABOs and Paired Exchanges and people from out of the area [or overseas] – that sort of stuff can get coordinators bogged down so they can’t get on with the routine ones.

• **Access to other specialist services**

Donor work-ups require referral for tests to other specialist services (as do recipient work-ups). In some regions, many specialties are already very stretched, e.g. cardiology and psychiatric services. This has been identified by the NRAB as a significant barrier in the LDKT process (see Chapter Five).

One of the issues when referring potential donors for tests in other departments is that they may have a low priority:

> I tell them it’s at least six months for an assessment. I explain to them that you’re fitting a well person into a system designed to treat sick people so we have to wait our turn for some appointments.

> Cardiology see the donors as healthy and their waiting lists are so big, so they get pushed back. . . . people in the DHB work so separately. I’m not saying that they don’t understand that getting people off dialysis is an important thing, but I think Cardiology has come under its own pressures.

> Another caveat is that the well donor donating to a patient who is coping with their chronic disease is pitted against a patient who may be at risk of dying in the prioritisation slots and it is quite difficult in the case of limited resources.

Coordinators said that they often relied on personal contacts and relationships with staff in other departments to facilitate getting tests done:
If we really need something done I have to go to Cardiology and really make my case and push people forward for it.

One potential barrier to improvement is the lack of robust data in some centres about how long referrals to other departments are actually taking:

We don’t have the data because we haven’t really put a lot of resource into collecting that data very well. That’s one of the problems we’ve identified in our region....Someone needs to be driving it a bit more closely.

- Coordinator time

In some centres, the main barrier identified was the number of coordinators available. LDKT is a labour-intensive service and this needs to be factored into capacity and workforce planning (364). It requires significant coordination effort:

The more people that you have coming forward and the more work-ups you have, the greater the demand on the transplant coordinators. So those roles become quite key in trying to keep it on track and so forth, it’s a matter of trying to put sufficient resource in place there. They, I think, are the key people really. Because they keep nagging away at the physicians to make sure things are done. The physicians often don’t have a great handle on where things are at, what stage it’s up to, what needs to be done next. They often need to be told what to do next, and that is where the coordinators come into it. There are issues around the logistics of some of the tests but I have to say they are not major barriers to us here...coordinators not having enough time is probably the biggest problem.

It’s a resource-related issue because it’s not a one-to-one process – for every donor work-up, you don’t get a donor, it’s several-fold higher than that. We have to get notified about three, four, five people before we actually get a donor for a recipient and so you need quite a bit of manpower to do live donor work-ups especially if we’re going to try and get ahead.
• **Deliberate slowing down of the process**

Donor work-ups may be deliberately slowed down to avoid “rushing donors”. This was regarded as positive by some people:

> I think there’s a right amount of time for it to take...some of the delay is actually good because you want patients, donors, particularly to have a good chance to think it through to be really well prepared for it mentally, what they’re getting themselves in for. And to be sure that your doctors have had a good chance to consider things from all angles, seek advice if need be, and that you’re not rushing into something that you’re going to regret or have a problem with a donor.

Others, however, felt that deliberately slowing down the process was wrong:

> Overseas clinics can do the work-up for a donor in a week. Here it takes a long time. Yeah, there are some inefficiencies in a socialised medical system, but some of that length is almost put there on purpose because people think, “Oh they need a lot of time to think about this”. Maybe giving them a bit of extra time will help. My view is that mostly they’ve made up their mind before they come in so we should just provide a service and we should do the work-up as quickly as possible and get the transplant done as quickly as possible.

• **Practical issues for donors**

Few health professionals mentioned financial issues for potential donors in completing work-ups, stating that if this was to be a barrier they probably would not have proceeded as far. One coordinator, however, mentioned that she had found that some people were struggling to get time off work, pay for travel, and attend appointments during work:

> He actually didn’t have any transport, he couldn’t get in to get the tests done...he had some financial issues and he’d lost his car so he couldn’t get in to the hospital...the DHB can’t help him with that because he doesn’t qualify for National Travel Assistance funding – he’s well, he hasn’t got anything wrong with him. But I did say to him, “Look, if you are having some real trouble give me a ring and I’ll come out and get you.”
Financial assistance for donors only covers the time off work after the transplant, not any time needed before that so some people may struggle with the demands of the tests that need to be carried out. There are special provisions to help living organ donors with transport for specialist tests (147) so there may be some support for donors for this. This requires a recommendation from a specialist and may cover mileage but not taxis or parking costs (personal communication, email from MOH, 26 July 2012). Thus there may still be some barriers for donors, e.g. those without cars or access to public transport.

4.1.2.4.3 Risks of inefficient donor work-ups

There were different views amongst health professionals about how long work-ups should take and to what extent long work-up times are a problem. Some health professionals did not think they really had any major problems in their centre with getting work-ups done, while others felt it was a significant barrier. There is no data on whether inefficient donor work-ups actually prevent transplants occurring or whether they simply slow the process down. In particular, it should not be assumed that the difficulties reported by actual donors are the same reasons other potential donors do not proceed further.

Some health professionals had a view that being able to process potential donors more quickly would increase transplant numbers, although it was not clear how this would result in an ongoing increase in transplant rates (once any backlog was cleared) without a simultaneous increase in donors. Nevertheless, there are several possible impacts of slow or inefficient work-ups:

- People may miss out on transplant altogether:

  *If you slow it down, people miss out. They miss out because their live donors expire, their goodwill expires or time or whatever. They miss out because they die on dialysis or develop a co-morbidity as a result of dialysis. Absolutely.*

- People may miss out on pre-emptive transplant and/or spend longer on dialysis than necessary. One patient said:

  *I found it extremely frustrating. Like, I was hanging in by not dialysing thinking if we can work up some of the donors, then I won’t have to go on dialysis, and this was going on and on and on and on and on….It was all up in the air.*
Chapter Four: Barriers to LDKT – Stages 4-5 and cross-cutting issues

(Rates of pre-emptive transplants have declined in recent years from 43% in 2007 to 25% in 2010 (57) although reasons for this are not known.)

- There is unnecessary stress for donors and recipients:

  I imagine it’s incredibly frustrating for donors....When there’s been a delay in getting back to people, it’s frustrating because you can tell when you’re speaking to people (transplant coordinator);

  Some of [my donors] were getting stressed out about it. And to me, you want to make the path as easy as possible for donors....People most probably pull out because, you know, this is just way too hard. So I think there should be more emphasis on the donor side and support that goes into them and letting them know what they’re up for, timeframes, so people can organise things. My donors were saying, “I don’t know when I’m going to have to be off work,” and all that kind of thing, trying to juggle all that (patient).

Finally, slow or disorganised donor work-ups may have a larger negative effect on commitment and goodwill towards LDKT, particularly if there is negative publicity from potential donors who have experienced difficulties. Some people commented the system cannot cope with those donors coming forward now:

  This is limiting the rate of transplants. If you were to increase the supply of donors, it would fall upon a sea wall and disappear back into the sea.

One patient group (363) has publicly questioned whether NZ should even be trying to increase the number of living donors:

  We need more donors! – Or do we? If we had another 100 people come forward to donate a kidney to a friend, relative or total stranger today, would the transplant service cope? We don’t think so....There is no point in recruiting more donors if there is no money to employ the staff to manage the assessments so the transplants can be done (pp.5-6).

Such negative publicity could well cause people thinking about living donation to decide there is no point coming forward. In addition, anything that makes the process harder for
donors is likely to make it harder for patients to feel confident about approaching potential donors and accepting offers from them. The patient survey and interviews suggest that patients have significant concerns about donors and need to feel confident that donors are being looked after properly. A difficult and slow work-up process where donors feel frustrated and undervalued may add to the already considerable sense of guilt that many patients feel towards live donors.

4.1.2.4.4 “Coercion” in donor work-ups

Part of the donor work-up process is to ensure that potential donors are acting voluntarily, e.g. psychosocial counselling may explore whether potential donors have been offered financial inducements or are under pressure from family members.

Protocols are also in place to prevent any perception of pressure by the transplant service itself. The ability to withdraw at any point is emphasised and potential donors are given plenty of time to change their mind. Several transplant coordinators said that they would not contact someone who did not complete work-up tests or attend appointments, stating quite clearly that this would constitute coercion:

*I don’t follow up the ones that don’t come back to me, I don’t think that’s appropriate….I think you have to be very careful that you’re not showing any evidence of coercion.*

*We don’t follow them up because to us that would be coercion.*

Often potential donors needed to demonstrate that they really were acting voluntarily by continuing to be proactive and “driving the process” themselves:

*I think it’s important that donors feel that they are in control of the process...so I’ll put the ball back in their court and say, “You’re cross-match compatible and if you’re ready to move on for medical assessment, please contact me and make a time to come in.”*  

*We say at every phone conversation or email, “As part of this process, we’ll send you out the information; if you want to go ahead, it’s really important that you phone us back because we don’t phone you or follow you up. It’s really important that this is driven by you so that you don’t feel like we’re trying to push you into doing this.”*
There was some disagreement about whether it was ever appropriate to follow up donors who appeared to have decided not to continue with the work-up process. Some simply said it was never ethical. One coordinator talked about the dilemma of wanting more donors but of not wanting to be seen to be coercing them:

> It’s a fine line that you walk between wanting to get donors and not being able to have it said that, “Well, you know, I actually only did it because they used to phone me up and hassle me.”

Other units had started contacting these people by letter:

> There’s been suggestions that we should ring and chase those people because I think some people are concerned that we’re losing people who might actually want to do it, but then you’re kind of stuck from an ethical perspective because it’s got to be a voluntary thing and we don’t want to put any pressure on anybody. So what we were doing, if people hadn’t been back to us in three months, we were just sending them a letter saying this is where you’re up to and if you want to proceed any further, then please get in touch with us.

One of the issues with not following up with potential donors is that neither patients nor transplant coordinators really know why a person does not continue and may make assumptions about the reasons. Sometimes when coordinators did follow up, e.g. by letter, they found that there were practical reasons a potential donor has not completed tests:

> With a couple of donors, we didn’t get their results in and I initially thought, “Maybe this person is a little reluctant,” but then I delved into it and found they were having transport problems. I sent a letter to one of them to say, “Look if you’ve changed your mind, just let us know,” and he was actually really angry and he rang me and said, “What’s this letter you’ve sent?”....He was really angry because he took it that I thought he wasn’t interested. But he actually didn’t have any transport, he couldn’t get the test done....So I think that is interesting because I had assumed he didn’t want to and didn’t know how to say he didn’t want to do it, but he just didn’t have the money to come and get his tests done.

One person disagreed that contacting potential donors constituted coercion:
I have this debate all the time. Transplant coordinators say, “No, I’m not doing that because that’s coercing the patient,” or “I’m not going to chase donors.” But sometimes someone comes forward and is a potential donor and they don’t get their bloods done and then they don’t follow them up because that would be coercion, whereas they might have lost the form, or the number, there’s a whole series of things that might have happened. People’s lives are complex. But if you just follow up and say, “You haven’t had your bloods done, are you not interested in doing it? Is there a barrier to you getting it done or is there any other information I can provide?”, and some people would see that as coercion. I just don’t.

This person also noted that it might be unethical not to follow up with potential donors, e.g. to offer support to people who feel guilty for having decided not to proceed:

I don’t see how it’s unethical if you’re ringing and saying, “Are you no longer interested?” and then offering them support if they’re not because they might be going through a whole lot of stuff internally that they need to discuss and then potentially you’re putting them at more harm because it’s been raised with them and then you’re just leaving them to it.

If all of the issues in determining compatibility, medical suitability and the work-up process itself can be overcome, the final stage is to schedule and carry out the transplant itself.

4.2 Stage 5: Receive the transplant

4.2.1 Overview

The main issues at Stage 5 are a final compatibility test, the recipient still being well enough for a transplant, and the donor still being willing. Delays at earlier stages or unresolved barriers for potential donors may affect whether the recipient is still suitable for transplantation and the donor still willing. The capacity of the system to actually carry out the transplant is the other major potential barrier, including the availability of theatres and surgical staff. In all three transplanting hospitals in New Zealand, the number of theatre slots available each month for LDKT sets a maximum constraint on how many transplants can be performed. Theatre slots and work-up times are matters for internal prioritisation by individual DHBs (4) and not subject to any national guidelines or policy. LDKTs may also be rescheduled at short notice should there be a more urgent requirement for surgery.
Theatre capacity is closely related to workforce issues, particularly as LDKT requires not only two theatres to be available on the same day (one for the donor and one for the recipient) but also two sets of surgical teams. Ashton and Marshall (148) have commented that workforce capacity and capability are not yet barriers to New Zealand’s transplant programme, because “the number of physicians available to treat ESR[F] is probably sufficient” (p.237). However, they note that fewer surgeons are now being trained to do transplants so this could be a problem in increasing the numbers of transplants. KHNZ (365) has also commented on the need to maintain a skilled workforce of transplant coordinators, surgeons and nursing staff in the context of a global market for transplant staff.

Theatre and surgical workforce requirements would need to be addressed should there be any significant increase in the supply of suitable donors. An expanded KPE programme might also place significant demands on the system, particularly given the logistics involved of coordinating simultaneous transplants.

4.2.2 Results

4.2.2.1 Theatre capacity
Theatre capacity was the main issue raised by health professionals in relation to actually carrying out the transplant. Each of the three transplanting DHBs allocates a certain number of theatre lists (or slots) each month to enable LDKTs to take place. At the time of the research the number of slots available was three per month in Auckland, two in Wellington and two in Christchurch, giving a total of 84 per annum potential slots for LDKT.

In the past, lack of theatre adequate theatre time was reported as a barrier but was no longer thought to be a problem in any of the transplant units:

One of our complaints was always that we don’t have enough access to the operating rooms and that’s no longer true.

We usually have enough theatre slots….We just have agreed operating days where the donor surgeon and the recipient surgeon are operating in the hospital on the same day, so those are available for living donor transplants.

Furthermore, several respondents said it was usually possible to negotiate for additional theatre time if needed, particularly given the excess theatre capacity in the overall system:
If we do have a backlog of people ready, we can approach theatres and ask for another all-day theatre list and often it might not be next week but it might be within a couple weeks’ time. We usually can get an extra list. We just contact the surgical schedulers and say have you got any lists that we can have and they’ll say, “Oh yeah, there’s Tuesday morning in this theatre and Tuesday afternoon in another theatre,” so we can get a live donor transplant done.

Theatres have innumerable days when they don’t actually do anything, there’s an appalling waste of theatre time so we have come to an agreement with them that we can use that time too.

In 2012, while there was capacity for 84 LDKTs nationally, only 54 were performed. While some slots may be lost due to falling on public holidays or surgeons being on leave, these figures would suggest the bigger problem is having sufficient donor-recipient pairs for transplantation:

Sometimes we’ve had to cancel at the last minute because the recipient’s ill or something and then we don’t have anybody to replace them. It’s a tragedy. Because we’ve got all these surgeons, we’ve got the bed booked, we’ve got the list booked which often isn’t used and if we can’t replace it with another transplant, then that’s one less person that’s done.

A few people thought that work-up delays meant some current potential donors and recipients were “stuck” in the system. Once they are through all the final tests, however, there seemed to be no current difficulties in being transplanted within a three-month period.

If work-up delays have caused a backlog, the more fundamental issue once this is cleared will be the ongoing supply of suitable donors coming forward to enable available theatre slots to be filled:

Could we fill all the slots if we could get the surgeons? It varies. Sometimes we might have up to six or eight people that are waiting for a surgical date. Then at other times we’ll be down to two people who are completely worked-up and could go tomorrow. There’s a whole bunch of other people at various stages of work-up. So
we don’t necessarily feel there’s great pressure to get someone ready and race them through just to get those dates. There’s enough people to fill the slots, but [only] just, at the moment.

If significantly more donors are found, expanding the transplant service would require extra theatre capacity and may become a barrier at some point if not addressed:

One year we managed to do about double our normal number of transplants and that was within the same resource. It was quite hard, we burned a few bridges and we had to cancel a few other operations on the side to get things done….It would be good to futureproof our ability to do that in case we find we’re running up against constraints in the future.

Theatre time is not a problem at the moment but it clearly would be if we went much further.

4.2.2.2 Travel assistance
Travel assistance in relation to the transplant itself for both donors and recipients was also mentioned in a few cases. Travel and accommodation assistance for donors who must travel is explicitly provided for under MOH policy (147) but the exact provisions of the policy may not always be suitable for living donors. In one DHB, for example, despite donors not being able to drive immediately following the transplant, donors were reported as being given petrol vouchers to get to the transplanting DHB which was less than 350km away, because, under the policy, air travel is not normally funded for distances of less than that. This is at the discretion of the DHB (personal communication, Ministry of Health, email 26 July 2012). One coordinator said:

We’ve been able to make a couple of cases in the past for airfares but that was for special circumstances….It seems a little rough for someone who’s voluntarily going there to get a kidney removed and then they have to face a four-hour trip home in the car afterwards and find somebody to drive them. So that’s a problem.

4.3 Cross-cutting issues
As well as the issues arising in each of the five stages, there were cross-cutting issues relating to overall service models and organisation of services in different centres. This
includes not only models of care and configuration of roles but the fundamental philosophy and approach to the delivery of RRT services, including the orientation of services towards LDKT.

4.3.1 Organisation of services

4.3.1.1 Overview

Increasing attention is being given in health-care improvement literature to the role of systems, processes and organisational performance. Bohmer (366) notes that “medical outcomes have become as much a function of organisational performance as of individual doctors’ skill” (p.265).

As noted in Chapter One, it is widely recognised that the way services are organised and delivered impacts on deceased donation rates. Delmonico (41) comments that “deceased donation is hard work and it requires an efficient organization”, noting that the “Spanish model” is the “premier effort of the world in the coordination of [deceased] donation activities” (p.315), resulting in donation rates well above the rest of the world. Key to this model has been a concerted focus on developing an organised, coordinated network of transplant programmes, including coordinators trained in asking potential deceased donor families (310). Variability in rates of blood donation and deceased organ donation between different USA centres has been linked to organisational and institutional settings (85), and commentators (367) note that most European countries now reportedly view the “professionalization of donor identification and management including the establishment of in-house transplant coordinators” to be the most promising means of enhancing organ donation efforts (p.362).

The Nuffield Council on Bioethics (105) has commented:

*Discussions around how best to increase supply of bodily material often focus on questions of donor motivation: how individuals may best be encouraged to donate different forms of bodily material. Considerable effort is put into coordinated advertising campaigns to recruit blood and organ donors, and proposals to incentivize potential donors through benefits in money or in kind regularly emerge in academic circles. However, individual motivation and choice is only one part of the picture: the central role of organisations, organisational procedure and intermediary roles.*
professionals in facilitating donation is becoming better understood, as is the importance of trust in these systems (p.84).

Similarly, Healy (85) has argued that relying on altruism alone, or the motivations of donors, to increase blood and organ donation rates is insufficient, noting that “without the logistical effort that makes it possible to donate, possessing the necessary willingness to give would not have any practical consequences” (p.69).

As noted in Stage 2, there is also emerging evidence that transplant centre practices are strongly related to LDKT rates (170, 179).

4.3.1.2 Results
In NZ, there are differences in rates of LDKT between different centres (69). This research also found some differences between regions – e.g. patient preferences varied significantly, with 52.2% of patients in one region actively preferring LDKT to DDKT, compared to 36.7% and 20% in the other regions (p=0.044).

Some regional differences may be attributable to factors such as the size and composition of the client populations. However, some health professionals mentioned that there may be differences in the way services are organised and delivered that influence outcomes. In the absence of a more comprehensive review, it is not possible to say definitively how differences in services relate to LDKT outcomes. At least one person thought this type of analysis was needed:

I don’t think anybody’s looked at the proper processes of care and where the process of care in different centres results in better outcomes when you adjust for other confounders.

There was some comment from health professionals about the variation in approaches:

I guess it’s the same with health everywhere. I saw much wider disparity overseas, transplanting was incredibly variable over there as well, incredibly variable. It’d be much more uniform here but the point is, in a small country like this, we should be able to get our shit together.
I was a little surprised by the variation. I thought we would have had national criteria that all the three units worked to. I didn’t think there would be even little variances between the three transplant units….I just assumed that it was a national programme with national criteria but there are subtle differences....I wonder why we don’t have a national programme?

Some of the differences between services included:

- **Systems to identify and review patients for transplantation**
  As discussed in Stage 1, only some centres could clearly articulate processes for early identification of patients approaching ESRF and how they were referred for transplant assessment. Computer systems were in place to support these processes and monitoring patients’ kidney function was the clear responsibility of the transplant coordinators. This ensured all patients were assessed for transplant in a timely fashion and facilitated a high rate of pre-emptive LDKT. In these centres, regular, systematic review of dialysis patients’ suitability for transplantation was also a feature:

  We have a system for all our patients coming thorough; it’s thought about early on. Our transplant coordinator is like a dog with a bone; she’s incredibly dedicated and has a rigorous approach and chases everyone down.

- **The type of pre-dialysis education provided and how it is delivered**
  Early education for patients approaching ESRF is variable, with an apparent focus on either education about dialysis options (pre-dialysis) or education about transplantation for people referred for transplant, rather than comprehensive, systematic education about all RRT options for all patients. Some pre-dialysis nurses are reportedly moving more into this latter role:

  I know some of the pre-dialysis nurses are really happy to talk about transplant, and some of them are happy to tell people but not go through whether they’re the ideal transplant person or whether they see that as their role; whereas other pre-dialysis nurses will talk to the families about the pros and cons of transplants. So there is a big variation in that... it seems a little bit more consistent now but it still varies and it probably varies because of the time people have.
• **How the transplant coordinator role is configured**

Transplant coordinator roles are configured slightly differently in different renal units, although generally their involvement begins when patients are identified as potentially being suitable for transplantation. Some people thought that there was sometimes misunderstanding about the transplant coordinator role:

> I think that sometimes there’s a bit of a misconception about what the transplant coordinator’s role is. People think that they’re the ones giving the initial education but, really, the patients don’t get to see the transplant coordinator unless they’re referred there, either through the pre-dialysis nurse or the nephrologist.

Coordinators may focus primarily on LDKT or play other roles in the transplant service as well:

> I work with patients really up to the time the last cross-match is done and all the paperwork’s signed off....Some people say it must be awful not working with patients after transplant, but that’s not my focus. My role is to get them transplanted, move on to the next group and work efficiently with live donors.

> Our role is to facilitate transplantation for patients, so that means getting people on the deceased donor list and doing live donor work-ups, but also when we have a transplant, that we look after that patient on the ward and do the education, and we follow up all those patients in various ways....Of the existing recipients, the more stable ones, probably at any given time there might be 10 percent of them that have got issues going on that we follow quite closely as well. The others tend to just tick along there quite nicely, we look at their results, make sure they’ve got their appointments and so on.

Some individuals are only part-time coordinators and have other roles, e.g. looking after dialysis patients:

> I work half-time as a transplant coordinator. I try and devote equal amounts of time to both roles but I know there are certain things I struggle to do, like I’m struggling to keep the potential donors who are in work-up at the moment in the top of my head.
Coordinators whose role encompassed multiple functions, or who were part-time, spoke of being pulled in several directions and, in particular, that living donor work-up issues were often of lower priority than many other things they were dealing with:

*We have a big hold-up because we’ve got such a lot of patients. It’s not just the patients who are being assessed and the donors. We have long-term patients who come to see our nephrologists anywhere from one month to three monthly and their blood results come to us as well.*

When transplant coordinators are also responsible for monitoring existing transplant recipients or have a role in dialysis nursing, there will always be a risk that “the urgent will crowd out the important”. For example, live donor work-ups may be crowded out by urgent problems with an existing transplant recipient or a crisis with a dialysis patient:

*The donor work-up is only one part of the role and that’s what a lot of donors don’t understand and why should they? They’re not interested in what else we have to do; they just want to get through their process quickly, but we’re always having to say, it’s just a small part of the job and I’m trying to do all these other things as well and we’re trying to get you through the process as quickly as we can.*

Coordinators with a narrower range of roles did not experience this conflict and felt that they were able to manage the LDKT process more efficiently as a result

- **Scope of the service**

A transplant unit may be responsible only for recipients-donors who are covered by their own DHB or may have a significant role with recipients-donors from other DHBs in the wider region, e.g. if there is no transplant coordinator in the other DHBs or only one renal physician - since donors and recipients must see different clinicians.

The more regional work is managed through the coordinators of a transplanting DHB, the greater their workload will be, with a risk of slowing down the process. Interviewees in some non-transplanting DHB felt they could take a greater role than currently:

*See, the problem is we can work it up. We’re motivated to work up our patients, we really are, but we’re not allowed to….There’s a rule that they have to work up their...*
patients. For instance, the donor has to ring their coordinator to volunteer to be a donor. Ringing us isn’t good enough.

- **The components of donor and recipient work-ups**

There is some variation between regions in terms of which range of tests donors (and recipients) are required to undergo. In some centres, certain parts of the assessment may be discretionary while in other centres they may be required for everyone. The more the renal service must depend on other (already stretched) departments for testing, the greater the risk of potential delays:

> One of the things that we’re experiencing at the moment is that we’ve got a bit of a blockage with regards to our liaison psychiatry department. We get everybody to see the liaison psychiatrist regardless, every potential donor and their recipient.

- **The orientation of the service, philosophy and approach**

Some respondents said that their centre had a clear goal of maximising pre-emptive LDKT for as many people as possible, and that this was reflected in how the services were organised. In other centres, there did not seem to be an agreed unit approach or philosophy and it was up to individual clinicians to decide how to promote it with their patients:

> We don’t have a separate transplant programme from the Nephrology Department so everyone is involved in transplantation....Also we generally don’t have our own patients, we work as a collective....There are some plusses and minuses to that approach but one of the plusses, I think, is that we do have uniform views about things....An upside would be that most people would have the view that living donor transplantation is best.

The orientation of services is a key cross-cutting issue for service improvement, as discussed below.

4.3.2 **Orienting services towards LDKT**

Having a clear goal to drive improvements in services is fundamental. Don Berwick (368), founder of the Institute for Healthcare Improvement (IHI) argues that change in health-care
systems starts with the will to do something, noting that “improvement must be intended” (p.620).

Increasingly in the field of deceased organ donation, there is recognition that reducing the gap between supply and demand for transplantation requires an explicit focus on the goal of increasing rates of transplantation, with policies and organisational and institutional settings aligned with this goal. The Nuffield Council on Bioethics (105) argues this will mean changing the default settings in policy and practice “to make organ donation a usual rather than unusual event” (p.102).

Historically within renal services, the default RRT option has been dialysis. It has been noted that, although LDKT is now widely regarded as the preferred treatment for ESRF, renal service policies and practices are still oriented towards the provision of dialysis, with access to DDKT as the next option, rather than LDKT. Changing the model of care may require willingness to reassign personnel from dialysis to transplantation (179). Gaston (369) suggests that the problem “rests with an ESR[F] program that evolved at a time when dialysis was the only viable option for the vast majority of patients, with transplantation, thought to “cure” ESRF, almost an afterthought” (p.16). He goes on to argue that introducing specific initiatives to increase LDKT rates without a more fundamental paradigm shift will be inadequate:

*Why is transplantation not the default position in RRT? Changing the current paradigm is one of the major challenges facing the transplant community. Our ability to deliver the promise of kidney transplantation to all those who would clearly benefit will require a multifaceted effort (ibid, p.17).*

In the USA, the Organ Donation Breakthrough Collaborative was launched in 2003 by the federal government and the Organ Transplantation Breakthrough Collaborative was launched in 2005 in response to the shortage of deceased organ donors (83). These initiatives were based on the “collaborative method” devised by the IHI (370), which sets out a systematic methodology for achieving “breakthrough improvements” in health-care services. The initiative established goals to increase transplant volumes by 20% by 2012 (371) and achieved increases by identifying and sharing best practices in high-performing centres and rolling this out elsewhere (372).
An evaluation of the initiative (372) commented on the critical success factors, noting that:

A factor that is fundamental to the success of a transplant center [is] vision and commitment from the institution. Hospitals cannot dabble in organ transplantation; they must commit to it fully and provide the resources and support necessary for the transplant programs to be successful (p.v).

The success of concerted efforts to increase rates of deceased organ donation has prompted a number of suggestions to apply a similar focus to LDKT (255, 259, 325). Davis (128) has also commented on the importance of “focusing a transplant center’s mission on living donation” (p.345).

In NZ, a similar lack of focus on LDKT compared to dialysis has previously been noted (74):

Many [health professionals]... do not seem to be focused on pre-emptive transplants. Instead, they seem to spend more time discussing dialysis and “how to make it work for you”. This appeared to be part of the renal clinical culture...[reflecting a time when] dialysis was the standard, most widely available treatment (p.18).

Some key informants commented on the lack of a clear goal to increase rates of LDKT and noted that neither renal services nor the wider health system was aligned to a commitment to LDKT. The variation in discussions with patients about LDKT, messages given, and how actively it is promoted also raise questions about whether LDKT is really treated as the preferred RRT option:

My impression is that there’s significant variation in the commitment to transplantation for whatever reason....So maybe there’s a little bit of everyone agrees in theory, but how much do they want to do, how orientated are they in their practice to actually make that happen?

Systems and things aren’t in place; there’s still frustration, huger frustrations within the system; so waiting six months for a cardiology review for someone who has got a live donor. You know, that’s just rubbish. And then, we wait for 24-hour blood pressures and just really simple things that hold it up. So our whole system isn’t attuned to the whole transplant thing.
The variation in LDKT rates between NZ renal units suggests there is scope for improvement by learning from the practices of higher performing units, e.g. by using the types of Breakthrough approaches discussed above. However, increases in LDKT require more than just changes in individual renal units. A wider system approach, involving a range of actors and institutions, is likely to be necessary to bring about change. Lotjonen and Persson (263) note:

In general, the [Nordic] population trust their healthcare staff more than their politicians, and hence it has been possible to draft legislation that has been rather broadly formulated and leaves a good deal of discretion to the healthcare professionals working in the field. This has resulted in the advantage of healthcare professionals being able to develop new strategies more quickly than the legislative process can, but this approach will only take matters so far. When considerable changes in the system are required, which must be supported with public funds, governmental involvement is essential (p.183).

4.4 Summary: Stages 4-5 and cross-cutting issues
Incompatibility and medical unsuitability were major barriers for potential donors who began the work-up process (Stage 4). Once the work-up began, few donors were reported as changing their minds and few patients turned donors down. This appeared to happen more often earlier in the process. Most patients were positive about the opportunity for KPE, but many were not aware of it, former potential incompatible donors were not necessarily being recontacted, access to the scheme was difficult, and health professionals were not always fully supportive of it. As a result, there were very few pairs in the pool and only two exchanges had been carried out since the scheme began.

Medical unsuitability was the second most common outcome reported. NZ has high rates of obesity and diabetes, which may be a particular barrier for Māori and Pacific patients looking for donors amongst their family networks. However, there are ethical challenges in relaxing criteria for accepting living donors and this barrier is therefore less amenable to direct intervention.
There can be significant delays in donor work-up processes, resulting from prioritisation policies, service-capacity issues and deliberately slowing down work-ups. Negative consequences include unnecessary stress, lost opportunities for pre-emptive transplantation and/or spending longer on dialysis than necessary. Delays in work-ups not only compromise patient outcomes but risk the loss of public goodwill towards LDKT.

Ethical concerns mean there is a significant focus on ensuring donors are not coerced in any way. The impacts of this are discussed further in Chapter Six. Theatre capacity has been a barrier in the past but there are currently sufficient theatre slots across the country for LDKT given the current number of suitable donor-recipient pairs (Stage 5). Around 30 available slots were not utilised in 2012. There were variations in models of care, configuration of key roles, and the philosophy or approach of the centre, all of which may influence transplant outcomes.

This completes the analysis of the first research question - what are the barriers to LDKT and what can be done about them? - which concerns the content component of the policy triangle. The issues raised at the end of this chapter regarding the organisation of services lead into broader issues of the orientation of the wider system towards supporting LDKT. This is consistent with the increasing recognition internationally that increases in transplant rates do not “just happen” but must be facilitated by an explicit goal and orientation of policy and practice towards this objective. Chapter Five looks further at this issue of the orientation of the wider system towards LDKT, turning to the second research question (with its focus on the processes corner of the triangle) of why more has not been done in NZ to increase rates of LDKT given evidence of better clinical outcomes and greater cost-effectiveness.
5 Chapter Five: Attention to LDKT: Getting on the agenda

5.1 Introduction
While Chapters Three and Four examined issues relating to the content corner of the policy triangle, this chapter considers the second research question, with its primary focus on processes. Decision-makers at all levels of the health system – policy-makers, health-care managers and health-care professionals - should all have good reasons to maximise rates of LDKT. Given the advantages of LDKT over all other forms of RRT, it is necessary to examine why in NZ there has not been more attention paid to the question of how to increase rates.

This chapter begins with a brief overview of how issues come to the attention of decision-makers (agenda-setting); provides an overview of developments in organ donation policy between 2000-2012; and presents and discusses the results from this research, based on data from key informant and health professional interviews, analysis of official documents and a survey of DHBs. Results are presented using Kingdon’s multiple streams model of agenda setting, and institutional arrangements which emerged as themes are also highlighted.

When the research began in 2010, there had been very little attention paid by policy-makers in central government, and DHBs, to strategies for increasing LDKT. During the course of the research, however, greater attention began to be given to LDKT by the Minister of Health and clinical networks such as the NRAB. This occurred for a variety of reasons (including this research), which are discussed later in the chapter.

5.2 Getting on the agenda

5.2.1 Agenda-setting in the policy process
Theories of how policy happens were dominated until the mid-1980s by stages models, which depicted the policy process as a rational linear one, progressing through discrete stages (usually agenda-setting, policy formulation, decision-making, implementation and
evaluation). Criticism that the model did not reflect “real world” policy-making led to the development of many new frameworks that attempted to capture the complexity of policy-making, including institutional rational choice, punctuated-equilibrium, and multiple streams models (373).

Stages models retained usefulness as an analytical tool for breaking down the process into component parts allowing them to be more easily studied (86, 90) and, in particular, facilitated the development of theories of agenda-setting (373).

Kingdon (164) notes that issues to which government, and people around government, are paying serious attention to at a given time are said to be “on the agenda”. According to Jones and Baumgartner (163), the policy world is an information-rich environment which requires decision-makers to sort between competing streams of information to decide which issues they will attend to:

*The process by which information is prioritized for action, and attention allocated to some problems rather than others, is called agenda setting. Agenda setting can be viewed as a process by which a political system processes diverse incoming information streams. Somehow these diverse streams must be attended to, interpreted and prioritized (p.viii-ix).*

Theories of agenda-setting seek to explain why some issues come to the attention of governments, particularly when there has been no apparent crisis to motivate their interest. Agenda-setting theories have shifted from viewing problem recognition as a mechanical process to a more complex sociological process (86). Buse et al note (90):

*Early explanations of what constituted a public problem... assumed that problems existed purely in objective terms and were simply waiting to be recognized by government acting in a rational manner....According to this explanation, governments would actively scan the horizon and the most “important” issues would become the subject of policy attention (pp.65-6).*

Later theories suggested that how an issue comes to be defined as a problem is a matter of interpretation, rather than objective reality. Jones and Baumgartner (163) comment: “While a situation can be described objectively, a problem is essentially subjective. People
translate ‘situations’ into ‘problems’ when they think the situation is relevant to their wellbeing” (p.12). Several factors can cause an issue to be seen as a problem requiring government intervention. A change in indicators can prompt decision-makers to perceive a problem, while a “steady state” may not signal there is an issue requiring attention.

Decision-makers can ignore changes until a crisis or series of disasters highlight the changes, or until policy entrepreneurs or advocates bring it to their attention, their own personal experience makes it more salient, or they perceive it is something citizens are concerned about (163-164).

Theories of agenda-setting have become more complex, less high-level and more able to be applied to specific examples (86). Rather than assuming that agenda-setting precedes the other stages in the policy process, later models posited that stages operate in parallel and interact with each other in less linear ways (90).

5.2.2 The multiple streams model

Kingdon’s (164) multiple streams model, first introduced in 1984, attempts to capture the complexity of agenda-setting. In this model, issues come onto the agenda when three parallel processes, or streams, align, namely:

- problem recognition – an issue captures the attention of people in government and is perceived as a problem requiring government intervention;
- policy solutions – policy advisors or other specialists analyse problems and generate solutions. Solutions need to be both technically feasible and acceptable to decision-makers; and
- politics – this stream comprises things such as lobbying by interest groups, changes in the national mood or changes in government, all of which may impact on the attention given to particular problems by political leaders.

Kingdon suggests that these three streams develop and operate largely independently of each other, and that the key to understanding agenda-setting and policy change is the alignment of the three streams – a problem is recognised, a solution exists and political circumstances are favourable. This creates a policy window, or an opportunity for change. During these windows, when the streams are aligned, they must be brought together, or coupled, by a policy entrepreneur.
Kingdon (164) describes entrepreneurs as people who are “willing to invest their resources – time, energy, reputation, money – to promote a position” (p.179). He says they lie in wait for a window to open:

In the process of leaping at their opportunity, they play a central role coupling the streams at the window....Without the presence of an entrepreneur, the linking of the streams may not take place. Good ideas lie fallow for lack of an advocate. Problems are unsolved for lack of a solution. Political events are not capitalised on for lack of inventive and developed proposals (ibid, pp181-2).

The model highlights the importance of individuals in policy-making with Kingdon suggesting that in most case studies of policy change, a particular person can be identified who was instrumental in moving the issue along.

He argues that windows open due largely to changes in the problems and political streams, but are typically only open for a short time and that, to take advantage of a window, feasible and acceptable solutions or policy options need to be “ready to go”. This differs from stages models of policy processes that posit problems are first identified and put on the agenda, and options then developed. While political will or interest in a problem may be enough to open a policy window, all streams are needed to keep the window open long enough for change to occur.

Policy windows close for a range of reasons:

- participants may feel they have addressed the problem, especially if legislation has been passed;
- participants may fail to get action and lose interest;
- events that prompted the window to open, e.g. a crisis, may pass;
- if a change in personnel has opened the window, a change in personnel can close it;
- there is no available alternative or worked up proposal so the opportunity passes.

Mucciaroni (374) praised the model for capturing “much of the complexity, fluidity, and unpredictability of agenda-setting and highlights the important role of chance, innovation and human agency in policy making” (p.482) although criticised the emphasis on the independence of the three streams rather than the linkages between them. Schlager (141)
also suggests the model pays little attention to the institutional context of decision-making, focusing more on “individual behaviour and the behavioural factors that affect individual choice” (p.306).

Kingdon’s multiple streams model was used as the starting point for analysing the question of why so little attention had been given to the problem of how to increase rates of LDKT in NZ but was adapted as necessary. Analysis captured issues at all levels of the health system - macro (central government), meso (DHB) and micro (clinician) – as described in the system framework (Chapter Two).

5.3 Results

5.3.1 Overview of the main developments in NZ organ donation policy 2000-2012

Table 14 shows the key events relevant to organ donation policy in NZ from 2000-2012.

A key event was a petition in 2002 from organ donor advocate Andy Tookey, calling for Parliament to take action to address the organ donor shortage in NZ. Tookey’s petition called for wide-ranging initiatives (including activity to increase living organ donation) but attention was eventually focused on establishing an organ donor register for potential deceased organ donors. This proposal was ultimately rejected although the Labour-led Government agreed to provide additional resources to organ donation and established Organ Donation New Zealand in 2005 “to give a national focus to organ donation” (375).

Two years later, lobbying by Tookey led to a further proposal to establish an organ donor register which would be legally binding and would not allow family members to override the deceased’s wishes. This was introduced as a Private Member’s Bill by opposition MP Jackie Blue in 2006. While initially receiving considerable support, this proposal was also eventually rejected.

Beginning in 2004, the MOH also carried out a review of the regulatory framework for human tissue and tissue-based therapies to bring together regulations in a comprehensive framework and to take account of technological and societal changes (376). One of the main outcomes of this review was an updated Human Tissue Act, passed in 2008. The
<table>
<thead>
<tr>
<th>Year</th>
<th>Event</th>
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<tbody>
<tr>
<td>2002</td>
<td>Andy Tookey presents a petition to the Health Select Committee requesting Parliament to take action to address the organ donor shortage</td>
</tr>
<tr>
<td>2003</td>
<td>MOH rejects any form of reimbursement to living donors</td>
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| 2004 | Government rejects Health Select Committee's recommendation to establish a national organ donor register  
Ministry of Health begins review of the regulatory framework of human tissue and tissue-based therapies  
National Travel and Accommodation Assistance Policy amended to include living donors |
| 2005 | Organ Donation New Zealand established to replace National Office of Transplant Coordination and provided with increased resources to provide a national focus to deceased organ donation  
Financial assistance to living organ donors introduced |
| 2006 | Human Tissue (Organ Donation) Amendment Bill introduced by Jackie Blue  
Government's Human Tissue Bill is introduced  
NRAB commissions a scoping paper for a National Strategic Plan for Renal Services |
| 2007 | Human Tissue (Organ Donation) Amendment Bill defeated on second reading  
Proposals to increase reimbursement to living donors are rejected |
| 2008 | Human Tissue Act 2008 passed (replaces HTA 1964)  
MOH recommends increasing the level of reimbursement for living organ donors |
| 2009 | Kidney Paired Exchange scheme established, run by Auckland Renal Transplant Group |
| 2010 | Michael Woodhouse drafts "Financial Assistance for Live Organ Donors" Bill to increase support to living organ donors to 80% of lost income |
| 2011 | Central Region Renal Network sets goal to increase LDKT from 20 to 30 per annum  
NRAB requests a review of the funding model for renal transplantation. NHB agrees to a review.  
Minister of Health seeks advice on increasing rates of LDKT in NZ. NRAB submits a Five Point Plan to Increase Rates of LDKT to Minister of Health |
| 2012 | Budget 2012 includes funding for initiatives to increase living and deceased organ transplantation |
Health Select Committee decided to consider the Human Tissue Bill and Blue’s organ register Bill together, given the similarity of subject area.

The main focus in relation to living organ donation was the question of reimbursement for donors. This included introducing financial assistance for living donors in 2005 (Chapter One) and various subsequent proposals to increase the level of reimbursement, by members of the public, the New Zealand Kidney Foundation (now KHNZ), the MOH itself, and National list MP Michael Woodhouse, who has drafted a Private Member’s Bill that has not yet been drawn from the ballot box.

In 2006, the NRAB developed a scoping paper calling for the MOH to develop a national strategic plan for NZ renal services, which would have included LDKT. In 2009, clinicians established a national KPE scheme (Chapter Four). Individual clinicians and the Renal Transplant Subcommittee have also advocated for a different funding model for renal transplantation over a number of years.

Attention to LDKT at regional and national levels began to increase markedly around 2011. The Central Region Renal Network, for example, decided to set an explicit target to increase the number of LKDTs in the region from 20 to 30 per annum, and began a programme of work dedicated to this goal. At a national level, the NRAB submitted a proposal to the National Health Board (NHB) proposing a national funding model for renal transplantation, which aimed to ensure adequate capacity for the transplant service and remove certain barriers, such as access to work-up services (Chapters Three and Four) and other disincentives (as discussed below) (49). The NHB agreed to review the funding model.

Also at a national level, the Minister of Health became interested in LDKT for the first time, prompted in part when he was interviewed for this research. As a result, he requested advice from the MOH on how to increase rates of LDKT. This advice was subsequently provided by the NRAB which submitted a *Five Point Plan to Increase Live Donor Renal Transplantation in New Zealand* to him in August 2011 (377). In Budget 2012, the Minister provided $4 million over a four-year period for organ donation, half of which was directed to living organ donation: one-off funding to develop and formally establish a national KPE Scheme, and funding for demonstration projects to trial specific initiatives for supporting patients in donor recruitment (378) (both of which had appeared in the Five Point Plan).
Overall, between 2000 and 2010 most organ donation policy activity, especially at the macro level, had focused on deceased organ donation. Reasons for the lack of attention to LDKT, and the increase in interest in 2011-12, are discussed below.

5.3.2 2000-2010: Why hadn’t more been done to try to increase rates of LDKT in NZ?
The results are discussed in relation to each of the three streams of the multiple streams model and the various institutional arrangements that also emerged as issues.

5.3.2.1 Interest in, and willingness to address, the issue (politics stream)

5.3.2.1.1 Macro level: Ministers and politicians
Key informants thought that Ministerial interest was critical if further progress was to be made on increasing rates of LDKT:

- I think the Minister’s involvement is key. I think it won’t fly without it.

Records of Parliamentary debates and Health Select Committee reports on both Tookey’s petition and the two pieces of proposed legislation in the mid-2000s make it clear that politicians from all parties had a strong desire to address the organ donor shortage in NZ, and looked to the HTA review to facilitate this (although this was not, in fact, its purpose).

Comments included:

- We share the petitioner’s concern at the current level of organ donation in New Zealand and the inadequacies of the current system for recording donor preferences (Health Select Committee (379)).

- The Green Party is absolutely delighted to be supporting this bill [review of Human Tissue Act]. We have wanted New Zealand and our Parliament to look at this issue for many years…. We really believe that it is long, long overdue for us, once and for all, to resolve this issue and, hopefully, to improve significantly the organ donation rates in New Zealand (Sue Kedgley, Green Party (380)).

- The [Labour-led] Government joins with the member – and I am sure any other member of this House – in saying that anything that can be reasonably done to improve the organ donation rate of this country across a variety of organs… is to be supported and we certainly support it strongly (Pete Hodgson, Labour Party (381)).
For reasons that are not clear, living donation was ruled out of scope very early on in the organ donation debates of the 2000s, with the Health Select Committee (379) considering the 2002 petition deciding to focus on “donation of organs from brain dead persons, rather than on donation from live donors” (p.2). This restricted focus continued through the following years (other than the issue of reimbursement for living donors), despite the point often being made by officials and politicians that there would only ever be limited numbers of deceased donors and that, for kidneys, deceased donation would never be able to meet demand (382). There appears to have been no advice suggesting that this narrow focus should be reconsidered.

Only one political party appears to have raised LDKT during the debates over the proposed organ donation legislation. The Māori Party had consulted extensively with its constituents and found strong opposition to Blue’s Bill to establish an organ donor register. It is not clear whether this was because those consulted were generally uncomfortable with the idea of deceased organ donation, or with the idea of next of kin’s wishes being overridden, as was being proposed. However, given the overrepresentation of Māori amongst ESRF statistics, the Māori Party mentioned living donation as an alternative option. This is the only time this seems to have been raised throughout these debates:

"I raise another way of looking at this issue. It is one that the Māori Party has been talking about in our communities given that people spoke so strongly against the Bill when we presented it to them. We raised the issue of live transplants between whānau members. That actually seemed to catch on with our people. They were quite accepting of the idea that it is really important that we take responsibility within our whānau to ensure the wellness of our whānau and that we give life back to our own (Tariana Turia, Māori Party (381))."

Interviews with key informants confirmed that there had been widespread political support to address the organ donor shortage:

"Everyone said we must do something about organ donor rates...the fact that one person’s body can save the lives and improve quality of life of so many people...I think there was an economic argument and obviously a human argument too."
Proposals for a binding register were eventually rejected, largely due to objections by intensive-care specialists who had said in their submissions that they would refuse to override the wishes of bereaved families. Evidence was also presented that a register was unlikely to increase donation rates. The whole issue eventually went off the agenda.

One previous Minister of Health interviewed suggested, however, that this was not because Ministers were not interested in increasing organ donation rates. In fact, their role in the system may mean that organ donation issues have particular salience with Ministers of Health:

    We all know people who’ve been hanging around waiting for a kidney. Some make it, some don’t. And the awfulness when Ministers have to get involved with sending the good people from Tuvalu back home to die [due to ineligibility for dialysis in NZ]. These are bloody awful situations. So I think Ministers yet to be born are going to be well attuned to the idea of having more live kidney transplants. But they need someone to give them some more ideas as to where the live kidneys are coming from.

This was echoed by a senior clinician who thought LDKT was something that politicians might easily be interested in:

    I think they should take a role. I mean, gosh, it’s a win for them, it’s a feel-good story for them. Things go wrong with transplants occasionally…but generally everything with donation is such a feel-good thing; you’re making lives better and saving money for the government.

The reason LDKT had not been on the political agenda was summed up by the current Minister of Health:

    Well, it’s like so many things. To get onto the public agenda you need a protagonist and an agitator. And I don’t think there’s been a protagonist or an agitator for live organ donation that I’m aware of. There’s never been any profile around it. There’s never been anybody that’s really said, “You need to rark it up”…I don’t think I’ve ever had a proposal cross my desk for it [LDKT]. And I don’t think that anyone has really drawn it to my attention before today, this issue of live donors.
At the time of the interviews, only one politician had shown any explicit interest in LDKT (although others such as Jackie Blue had promoted deceased organ donation). Michael Woodhouse’s proposed Bill to increase the level of reimbursement to living organ donors was sparked by representations from a local renal patient support group. Woodhouse reported that he already had some personal knowledge of renal issues because a friend had previously received a kidney transplant. These two events were instrumental in him deciding to draft a proposal to increase reimbursement.

Thus, while deceased organ donation is an issue that has had considerable political focus in the past, LDKT has not had similar attention. Rather than being the result of a deliberate decision, however, or lack of interest by Ministers, this appears to be largely due to the lack of an advocate to raise its profile and the lack of proposals for how LDKT rates could be increased (discussed below).

5.3.2.1.1 Awareness, advocacy, entrepreneurship
There is generally a low level of awareness about renal disease. Its seriousness is not appreciated and renal transplantation is usually portrayed as being about quality of life, rather than extending life. In terms of the numbers of people affected, it is much smaller than some other service areas. As one senior renal physician commented:

Renal is not nearly as emotive or as in your face as cancer....Cancer, cardiac, kids are the three buzz words, the big ticket items for public awareness and Ministry involvement. It’s not as visible and the perception is that it’s not as lethal as cancer, although in some ways it is actually.

In this environment, something or someone is needed to raise the profile of the issue with politicians. The importance of an effective advocate to bring issues to the attention of Ministers was highlighted in several interviews and in the document analysis. Deceased organ donation came onto the agenda in the early 2000s and remained under consideration for several years due largely to lobbying by a single individual, Andy Tookey, who is still strongly associated with this issue.

Kingdon’s model highlights the importance of individuals, or policy entrepreneurs, in the agenda-setting process. Mintrom and Norman (383) note that entrepreneurs can play a variety of roles; for example, drawing attention to policy problems, identifying solutions,
building coalitions and bringing about policy action. They suggest that there are four common elements in policy entrepreneurship:

- Displaying social acuity – successfully taking advantage of windows of opportunity requires social acuity and perceptiveness; in particular, through making good use of policy networks (often using knowledge acquired from elsewhere) and also by having a good understanding of the ideas, motives and concerns of others and responding effectively;
- Defining problems – problems do not exist objectively, but are interpreted as such, and policy entrepreneurs pay close attention to this issue, using a variety of techniques to present issues as problems requiring attention;
- Building teams – individuals may be able to instigate change but it is their ability to work effectively with others and build coalitions that contributes to their success; and
- Leading by example – policy entrepreneurs pay attention to managing the perception of risk by highlighting the feasibility and workability of a policy proposal.

Mintrom and Vegari (384) note that policy entrepreneurs are often embedded in social networks rather than being “atomised, instrumental individuals” (p.422).

Interest groups are also an integral part of the policy process and often form part of the policy community or policy subsystem (86, 385). In health-related issues, patients or their families may form interest groups and take a lead role in raising issues with decision-makers.

Advocacy or lobbying can be a key part of the policy entrepreneur role. Advocacy is sometimes viewed with concern in health policy because it brings the risk of “squeaky wheel” decision-making (386) rather than a more “rational” approach. The breadth of issues in health may make an entirely rational approach impractical, however, and several interviewees commented that advocacy by interested parties outside government was a legitimate way for issues to be brought to the attention of decision-makers in a democratic system. As one politician said:
That’s one of the many ways in which health policy gets influenced, as you know. We don’t sit in hermetically sealed rooms, coming up with mad schemes and then deciding to pass laws….People come and go all the time….We have to engage with the sector.

The question is what other analysis, evidence or advice is brought to bear to support decision-making processes:

That’s a way things get elevated up the agenda, and it is a game, an established game that some groups play. So the squeaky wheel gets listened to, and that squeaky wheel often uses the media. Sometimes the margins between what is sensible and what is evidence and wise judgment-based get blurred. Then politicians are pushed in different directions which is really hard because they’re lay people and they’re entirely dependent upon the advice they get....So I think there are lots of groups of people. That’s how it should be in a democracy and that creates tensions. The trouble is how do you put a framework around the tensions that lets us manage them without constraining the whole system in such a way that you lose the value of the tensions?

Respondents referred to a number of influential individuals and interest groups in other areas of health including cancer, cardiac, and arthritis. While Andy Tookey can be clearly identified as an advocate for deceased organ donation over most of the period, it is not possible to identify a protagonist in relation to LDKT, whether it be an advocate acting alone, a policy entrepreneur or an interest group.

KHNZ plays a role in education and community awareness about LDKT and has in the past raised the issue of reimbursement of donors, but it has not otherwise been active in promoting the issue of LDKT with Ministers. Local patient support groups generally focus on supporting patients in their daily lives, e.g. managing dialysis, rather than advocacy.

In summary, it is not that NZ politicians are not interested in organ donation issues but rather that viable solutions have not been presented and there has not been a protagonist, advocate or interest group to raise the issue of living organ donation with them.
5.3.2.1.2 Meso level: DHBs

DHBs seem to have considered issues regarding LDKT on a case-by-case basis for additional resourcing as demand has increased, but have not taken a more strategic approach to increasing LDKT numbers. For example, 10 renal units have appointed transplant coordinators, while in 2008 Capital and Coast DHB doubled the number of theatre slots available for LDKT from one to two per month to cope with the number of donors coming forward. Requests for additional resources must be weighed up against other priorities, however, and have reportedly not always been successful.

Some key informants interviewed were puzzled as to why there did not seem to have been greater attention to LDKT by DHBs. One senior politician commented:

> It’s interesting because it’s such a saving if you can give someone a new kidney but I don’t know why the DHBs don’t fund that stuff as a priority. The payback seems pretty quick.

The research suggested there were several possible reasons LDKT was not more of a priority for DHBs.

One key informant felt that LDKT may not be recognised as a problem by DHBs because the logic of the arguments, such as the cost-effectiveness of transplantation compared to dialysis, is not well understood by many Boards, CEs and other DHB managers:

> I don’t think that argument is well understood....If we had a single piece of paper: here’s the demand, here’s the future cost profile, and here is an alternative. I’d use the value for money lens and then the whole quality of life thing is really, really important.

The salience of the transplant issue was found to vary between and within DHBs. Some managers from DHBs with large numbers of ESRF patients, particularly with a high proportion of Māori or Pacific patients, expressed concern about low transplant rates within their populations and at different times had tried to address the problem in their communities:

> We frequently debate the issues around the increasing cost of hemo and peritoneal dialysis in this DHB. The numbers have risen exponentially....We frequently observe there
should be a national promotion initiative and some of this money [dialysis] would be better spent on promoting the live donor solution.

Respondents noted that only three DHBs provide renal transplantation and many DHBs will have very few patients, if any, who are transplanted each year. It may not, therefore, have a high profile relative to other DHB activity:

It’s not a priority at present in our DHB as the number of people who may qualify are small and the focus is on improved efficiency and productivity across the sector.

A key theme was the difference between the three transplanting DHBs (provider DHBs) and non-transplanting DHBs, which play different roles in planning and providing transplant services. Despite a greater emphasis on regional service planning since the Ministerial Review Group (387), provider DHBs may still be seen as largely responsible for transplant services in each region:

I think because very few DHBs do transplants, so [they’re] not having to worry about the capacity and the workforce changes....The ones that do transplants will want to know what the future volumes look like, so they can gear up capacity-wise, workforce-wise and so on. Because volumes are still relatively small, they would be wanting early signals around future volumes and capacity for that to be as firmed-up as best you can possibly do.

Non-transplanting DHBs could often look to transplanting DHBs for leadership of LDKT, rather than sharing the responsibility:

Of course, part of that was that it was a service provided by X DHB so it came up in the context of inter-district flow [funding] but it was not a kind of planning focus that was in front of us....So it meant that it was X DHB that had the transplant focus and I suspect that will be the case with almost all DHBs: that tertiary service stuff will belong with the tertiary service provider and it won’t be inside the frame of reference of the DHBs of domicile.

The perception that it is transplanting DHBs that are responsible for transplantation was a widespread one. In fact, other than the surgery itself, most of the service is provided by a
patient’s own renal unit, as they are responsible for pre- and post-transplant care and, importantly, are likely to have a far greater influence on donor supply (Chapters Three and Four). One clinician from a non-transplanting DHB commented:

There’s no one more motivated to work up their own patients than their own DHB....In fact, that physician [at the transplanting DHB] only has clinical responsibility for them for six weeks and then they’re handed back to us. Personally, I think the professional responsibility lies with us and not that team; they’re just doing a technical service and they’re a subbie and I think they should behave themselves like a subbie.

A perception that they are unable to influence donor supply, may result in DHBs focusing their attention on aspects of the renal service that they have greater control over:

When we were thinking about the whole renal mix, we did have these discussions about transplants and two things came up. One, that this is X DHB’s business, but the second thing that came up was the terrible shortage of donors. So, therefore, we thought we can’t rely on that, therefore, we’ve got to focus on this other stuff [dialysis modality].

One DHB manager said it was not that LDKT had been actively deprioritised by DHBs. Again, it was the lack of donors that was thought to be the main reason it had not had more attention:

If the transplant group came to us and said we want to do an extra 50 transplants a year, we’d probably say, “Yeah, that seems like a good idea,” but it’s whether you’ve got the extra 50 donors. My understanding is that’s always been the bigger constraint rather than any sort of hospital constraint.

Theatre capacity has been a barrier in the past but, as reported in Chapter Four, is not at present because DHBs have increased slots available when the number of donor-recipient pairs has exceeded capacity. Some people spoke of the issues associated with making a business case for additional theatre capacity:
In the past, when there has been the pressure to provide more [theatre] resource, then you develop the case around that. You put the case, you argue it and you develop the service. We’re wanting to increase our number of transplants but at the moment there hasn’t been the need to go cap-in-hand to my managers or funders because we haven’t got the extra donors. We haven’t got a burgeoning waiting list; as they come through we are dealing with them. We are not having people waiting an enormous amount of time in a queue to have transplants and, therefore, it is very difficult for me as a clinical manager to go to people and say we need more theatres, we need more surgeons….Until we’ve got that waiting list, we won’t get traction at that end….So you have to create the demand before you find the solution….In an ideal world you would have a very robust plan around all these things but, in fact, the worst thing you can do is say there is demand, put the infrastructure in place and then find that you are giving away theatre slots….It’s hard to get the two in sync.

In fact, the greater problem now is that the shortage of donors means available theatre slots are not being filled.

An important factor influencing where DHBs focus their attention is Ministerial priorities (388). This was reiterated by several respondents in this research, and is another reason that Ministerial awareness and willingness to address the problem were considered critical:

Ministerial priorities and targets certainly make a difference at DHB level because they’re driven through DHB KPIs and so there’s an expectation that you will deliver on them.

Think about the Government priorities. We spent years focusing on joints and cataracts. The volumes here [transplants] would be less but we did tens of thousands of those operations because it was a Government priority.

Overall, DHBs appear to have responded when donor numbers have required additional resources (e.g. theatre slots). However, they have apparently shown little further interest in increasing the rate of LDKT. Lack of visibility of the problem, competing priorities, the lack of obvious solutions to increasing donor supply, and the lack of Ministerial attention may all be factors.
5.3.2.1.3 Micro level: renal health professionals

Chapter Three has described the increasingly positive approach to LDKT of many renal health professionals who now widely regard it as the preferred treatment for ESRF, although with some variation in attitudes and approaches of different units. Interviews and document analysis suggest that at the micro level there have been several efforts to improve the LDKT service, such as quality, efficiency and capacity of the transplant service (e.g. donor work-up times, theatre capacity), but little explicit focus on the question of donor supply and no overall strategy to increase LDKT rates.

Although LDKT is widely regarded as the preferred treatment for ESRF, renal services may be dominated by dialysis services which can crowd out a focus on transplantation:

_I don’t think that our services and policies entirely reflect the fact that LDKT is the preferred treatment. I think partly we’re overwhelmed by dialysis, depending on where you are in the country....When you look at some places, they’re probably just struggling to get through all the dialysis patients let alone anything else. Hence the result is they don’t proactively focus on transplantation._

There have been concerns about the quality and safety of dialysis services in the past, leading both MOH and nephrologists to the view that the service was in crisis (148). A national multidisciplinary committee working with the MOH was established to develop national standards and audit processes covering all aspects of the dialysis service. There has been no similar crisis in transplantation.

Moreover, LDKT is classified as an elective procedure. This is defined as a service that “will improve the quality of life for someone suffering from a significant medical condition, but that can be delayed because it is not required immediately” (389).

Although LDKT is likely to also significantly increase survival, dialysis is life-sustaining in a far more immediate sense; that is, dialysis must be available or people with ESRF will die within days or weeks. This was described by interviewees as creating a situation where “the urgent crowds out the important”. As a result, LDKT could be seen as “value-add”:

_Although it’s big for individuals who get there, only about 6.5 per cent of people get transplanted so 95 per cent of the souls live and die on dialysis which for my money is_
core business. This is nice, and it might become greater, but I think most people will still live and die on dialysis.

One key informant also questioned whether there might be a sense of “fatalism” amongst renal professionals or being overwhelmed by increasing demand:

Renal professionals see people in end-stage renal failure for a reasonably short period of time and then they’re replaced by another one. I’ve watched renal professionals and I just wonder whether there’s a sort of learned response of, “there’ll be another one along soon; this one will go.” And that given the increasing numbers of people with end-stage renal failure, that they become passive in this.

Thus, despite positive attitudes towards LDKT at an individual level and a desire to see the rate of LDKT increase, crowding out by dialysis, being overwhelmed by the level of demand and the complexity of the problem may have contributed to the renal community as a whole not being as proactive about trying to increase rates of LDKT as might have been expected.

5.3.2.2 Recognising and defining the problem (problem stream)

The need to increase LDKT has not been widely recognised as a problem in NZ outside the renal community itself. Problems do not exist in isolation waiting to be discovered but instead are socially constructed (163). Bardach (91) notes they also require analysis beyond the raw material of “issue rhetoric” (p.4) to get below the presenting problem. Clear problem definition is therefore an integral part of problem recognition.

Lack of clear problem definition has meant the LDKT problem is largely invisible. A key issue that emerged in the research is that several related issues may be recognised, but LDKT is often not recognised in its own right. LDKT may be located and discussed within several different policy contexts, including organ donation policy generally, as part of chronic diseases policy and/or as part of renal services policy.

Organ donation policy incorporates all types of organs and both deceased and living donation. Policy may focus on deceased donation because most types of organ transplant can only come from deceased donors or simply because of lack of awareness. As discussed above, there have been times when organ donation was clearly on the political agenda but
living donation was out of scope. Although internationally and in NZ, the vast majority of people waiting for organ transplants are waiting for kidneys, kidney transplants may be seen simply as another type of transplant. Furthermore, although it had been noted that deceased donation would never be sufficient to meet demand for kidneys, living donation was never raised by officials during the legislative debates in the mid-2000s. The 2004 regulatory review understated the significance of living donation in NZ’s transplant service with consultation documents (376) stating that “organ and tissue donors are largely deceased donors” and a footnote that “a limited amount of live organ donation occurs in New Zealand” (p.63). This was at a time when well over 40% of renal transplants came from living donors.

According to key informants LDKT was “just never on the work programme”:

_Andy Tookey had been very successful in terms of deceased donation and a lot of energy and an awful lot of time went into that but it hadn’t translated across into doing something about live donation._

LDKT may also fall within the general area of chronic conditions which is a significant issue facing all health systems (76). Again, lack of profile and problem definition may act as a barrier to problem recognition. Chronic kidney disease is often not discussed in its own right as a chronic condition despite its increasing prevalence and frequent co-location and interaction with cardiovascular disease (390). Instead, it may be seen as one of the outcomes of other chronic conditions, such as Type 2 diabetes or obesity. Thus, strategies may focus more directly on those issues. To the extent that anyone in the Ministry thought about renal transplantation, it was likely to be in the context of obesity and diabetes:

_I think HEHA [Healthy Eating, Healthy Action] was around at that stage. It was the big push and end-stage renal failure was just one of the problems from obesity... So it was thought that going back to the start of the problem would be where the best action could be taken._

Finally, LDKT is part of the continuum of renal services. Informants mentioned that renal issues are of concern to health managers and several interviewees described them as a “hot topic”: 
Renal is a huge spend. It’s a big burden of disease coming down the track at all of us….I can sit at two or three Boards in the country and hear them constantly talk at Board level about the cost of renal services, the growing problem with diabetes, and what we’re looking at coming down the pipeline….You hear them talk about all sorts of changes in dialysis, home dialysis, changes in machines, whether or not DHBs are going to build new expensive renal units, the fact that we don’t have very many nephrologists in New Zealand and what are we going to do about that. I think renal diseases are a really hot topic.

Several informants commented that when LDKT is raised, however, discussion especially with non-renal managers frequently turns to other issues:

And then they go into, “Why do we have end-stage renal dialysis for all these oldies?” And then it’s, “Is there equitable access to dialysis across the country?” They go off on tangents and it depends on who they are, where they’re from and what their knowledge of the sector is.

As noted above, issues relating to dialysis services have been recognised over many years such as rationing and access (391) and quality and safety (148). Transplantation has not been recognised as a problem:

The main focus has been primarily on the dialysis side. Especially on the issue of restricting dialysis, especially people from the Pacific Islands. That’s been the big one. Transplantation hasn’t featured very heavily anywhere.

A theme that emerged was that LDKT is not seen as part of the solution to rising demand for RRT. Thus, while DHBs are concerned about rising expenditure on dialysis, the solutions are often seen as either prevention or making greater use of home dialysis:

Inside a hospital budget, renal is certainly an area that’s going up. But the solutions are generally, “Good lord, we’ve got to do something about diabetes, we’ve got to make people skinnier and get them to eat well and exercise more and get better primary care treatment.” What you’re talking about [transplants] is kind of at the end of a pathway and the numbers that hit it, in the great scheme of things, if you were really going to address that, you’d be looking upstream…..Keeping up
forecasting and keeping up with demand for dialysis and looking at cost-effective methods of dialysis and the mix between various modalities and the mix of in-home, in the community, in-centre dialysis – that kind of consumed everybody’s thinking space.

A change in indicators such as expenditure on dialysis might be thought of as indicating a problem exists. However, LDKT is rarely raised as at least a partial solution to the rising demand for RRT and seems to almost be “decoupled” from the problem. Greater rationing of dialysis (such as to older people, as in the comment above) is more likely to be put forward as a “solution” to rising demand for RRT, than increasing the rate of LDKT.

Official documents suggest there has been little analysis of the problem and respondents also suggested that there had been a failure in the past to develop and present ideas about LDKT coherently:

Nobody has crunched NZ data to any degree from either registries or the operational side. There is a giant void….I think there’s a lack of evidence on which to make the argument; it’s there but it needs to be pulled out and cohesed together….So I think in some ways the barriers to transplantation are that people haven’t made their arguments well, haven’t seen it as their obligation to go around and get all the information and knit it together and come to some sensible conclusions which are genuinely agreed upon. It’s really hard to talk about things without any solid evidence behind you.

Another clinician commented on the lack of understanding of the cost-effectiveness of transplantation compared to dialysis:

People have a perception, I think, of transplant being an expensive business. Dialysis is way more expensive.

Official documents suggest there have been some changes over time within the MOH as to whether the problem is recognised. There was a marked change in the advice given by the MOH in 2008 (392) when, for the first time, it started to recommend that increasing rates of LDKT was something that government ought to be interested in:
The State has an interest in the person who is a potential donor actually making the choice to give up an organ in order to enable a renal patient to move from the expensive therapy of dialysis. In this view the State could provide a higher level of financial support for organ donors than in other circumstances in order to maximise organ transplants, specifically as part of a strategy for managing the continuing growth in demand for RRT in New Zealand (p.2).

This was the first mention of an explicit objective to increase organ transplant numbers by utilising living donors, and recognition of the link between LDKT and the problem of rising dialysis expenditure. Despite this, recognition of the problem has remained low.

The complexity of the problem was a recurring issue. As interviewees pointed out, “it’s not like doing more knee operations”:

You have to talk about the whole thing. You can’t just say, “OK, so we’ll just throw some more money at it and get more people.” But where are we getting the people from and how are we having those conversations and who’s giving the education and everything else? Are we looking at people who need it the most, and are we looking at how well we’re doing for different cultures or what the barriers there are?…Is it that someone’s GP says, “You shouldn’t be a donor” or is it the cardiology work-up that holds it up? There are just so many factors which influence it. It’s just huge.

The lack of analysis and clear problem definition are likely to have hampered progress because barriers, and therefore solutions, are not well understood. One senior clinician commented:

I think the main problem is that people sit there and think, “Oh, here’s something that causes a barrier,” without actually really thinking quite clearly about whether it is or not and what the solutions might be, and so people keep coming up with reasons people aren’t being transplanted and they’re not true….The barrier to being transplanted in New Zealand is the fact that there’s only 80 donors.

Lack of agreement about problem definition and multi-causality are hallmarks of complex or wicked policy problems (393-394). Clear problem definition and agreement between stakeholders about the issues appear to be missing in LDKT.
In summary, the problem of how to increase LDKT rates has not had significant recognition. Related problems are, or have been, recognised, including how to increase deceased donor rates, how to prevent diabetes and obesity, the rising costs of dialysis, dialysis modality, and quality and safety of dialysis services. However, increasing the rate of LDKT has generally not been seen as a problem in its own right and, outside the renal community, has not been widely seen as a more cost-effective form of RRT that might contribute to addressing the problem of how to slow the rate of growth of ESRF expenditure.

5.3.2.3 Solutions to the problem of how to increase rates of LDKT (policy stream)

5.3.2.3.1 The importance of having solutions

Kingdon’s model highlights the importance of having solutions ready to go in order for issues to get on to the agenda. When respondents in his original research (164) were asked why seemingly important issues were not more prominent on the government agenda, they said, “because we don’t know what to do about them” and “it’s difficult to get mileage out of something that we don’t have any approach to solving” (p.143).

A review of policy advice in NZ also noted that deciding what gets on to the policy agenda and what Ministers commission departments to work on often involves a series of discussions, including about what options are likely to emerge (395). The review noted that Chief Executives (CEs) were sometimes reluctant to initiate work on big or difficult policy issues “because the intractability of the issues means that governments are typically reluctant to see issues opened up without being able to see where the exploration might lead” (p.28).

In this research, the lack of feasible and acceptable options for how to actually increase rates of LDKT emerged time and again as not only a barrier to LDKT rates being higher, but also as a reason for why the issue as a whole has not been more of a priority for decision-makers.

Much is known about LDKT, particularly about clinical aspects. LDKT is not an experimental procedure, with recent developments such as laparoscopic surgery making the process even less burdensome for donors (396). Advancements in immunosuppressive medication mean many more people may now benefit from the treatment and clear evidence of cost-effectiveness and patient outcomes exists. However, less is known about how to increase
utilisation of the therapy. The limited knowledge about barriers and solutions for increasing the rate is a gap in the evidence base.

Arguably one of the reasons the deceased donor issue made it on to the agenda in the 2000s was that there was a tangible option put forward: an organ donor register. This acted as a focal point and gave decision-makers something on which to base the subsequent debate. However, politicians gradually came to view this as an unacceptable option because of clinician concerns and poor evidence of effectiveness. The absence of alternative options became a frustration to politicians who had repeatedly signalled their wish to address the problem. One former Minister said:

> What matters in setting priorities? What works. My recollection of the transplant debate was that it was a great deal about what didn’t work. The register didn’t work. The driver’s licence didn’t work. Compelling families to pass over their dead didn’t work. So a lot of things didn’t work – anything that does work, folks?

Alternative advice was eventually provided to Ministers about processes within intensive care units and training for health professionals (although decision-makers recalled that this did not come from the MOH but rather from clinicians).

In general, giving problems to Ministers without solutions is unhelpful. As one commented:

> It was a mantra in my office: I’ve got enough problems so don’t make an appointment to give me another one.

This was confirmed by senior advisors who thought that decision-makers were more likely to be interested in addressing a problem if they thought there was something they could do about it:

> On this issue, my sense is he [Minister] would make it a priority, but this brings us right back to, “Where are the donors going to come from?” doesn’t it? Otherwise, you’re just handing him a problem; you’re not handing him a solution....If he gets a united voice from the profession, telling him something and giving him an answer at the same time, he’s likely to listen.
Commenting on the fact that cost-effectiveness evidence may exist but that this is only part of the information needed, one person said:

> It’s no use the National Health Committee telling the Minister that we should do this if everyone comes along and says, “Yes, but there’s no way of getting the donors” and tells us that we can’t get the donors. So part of assessing whether it will work or not is “Can you get the donors?” If you can’t, what levers do we have to get them? How likely are they to work? If we all say, “Well, they’re not really likely to work,” then regardless of how good [cost-effective] it is, it’s not a goer.

The lack of available options and not knowing what to do to get more donors, were identified by numerous key informants as a significant reason for not prioritising this issue more highly.

The fact that feasible solutions could generate interest in a problem was demonstrated in the interviews with politicians who took the opportunity to ask me a range of questions about different aspects of LDKT, including what could be done about it. Towards the end of one interview, a former Minister said:

> Well, the thing that’s interested me about our conversation today is that I think I’ve learnt for the first time about this idea of paired donors [KPE]....Of course, I could have worked that out for myself, and should have, but I think I’m hearing it for the first time....I mean, I just said to you, “Give us a for-instance,” and you came up with that. And I’m thinking, “Jeez, why didn’t we think of that?”

Kingdon suggests that options in the policy stream must be technically feasible and acceptable to decision-makers. The unacceptability of the proposal for a register which would allow the wishes of bereaved family members to be overridden indicates what happens when options do not meet these criteria. As discussed above, both politicians and DHB managers mentioned not knowing what to do about getting more donors as one of the reasons for not doing more to try to increase rates of LDKT.
Publicly, the most commonly-heard solution in NZ to the supply of living donors has been financial incentives (134-135). None of the politicians interviewed were willing to consider financial incentives for live organ donors:

_No, I’m quite a rational person but I’ve got repugnance written all over me._

Prior to 2011, there were two main sets of proposals put forward for increasing LDKT rates:

1. Reimbursement of costs, especially lost income, for living donors – this is the most frequent suggestion made by members of the public, as reflected in the volume of Ministerial correspondence on the issue, and has been raised by KHNZ and more recently by the MOH and now Michael Woodhouse;

2. Suggestions to address service capacity barriers such as theatre capacity, work-up times and numbers of transplant coordinators – this has been raised with the MOH at various times by individual transplant clinicians and more recently taken up by the Renal Transplant Subcommittee. Service capacity issues have now been subsumed, along with concerns about pricing disincentives (see below), into a single proposal for a national funding model for renal transplantation.

Reimbursement for donors has had a long history of ambivalence and opposition from officials for a variety of reasons, until about 2008 when MOH (but not MSD) advice became more supportive. Reasons for opposing proposals included concerns about undermining altruistic motives for donating, the possibility of setting a precedent for the State paying other groups in society who give up work to perform an altruistic act, the lack of off-setting savings and questions about whether removing financial barriers would have any impact on LDKT rates (397).

Internationally, reimbursement of costs incurred by donors is generally regarded as ethically unproblematic (105, 107). The more significant problem may be that its likely impact on donor supply is unknown and it may not be significant without other interventions also being introduced (Chapter Three), something that seems well understood by decision-makers. Woodhouse himself describes his Bill as just “a piece of the jigsaw” and another senior politician said of the Bill:
Oh, yes, we’re going to support it. But it’s probably not necessarily the one thing that’s a game-changer.

Key informants noted that, because the likely impact of reimbursement for donors could not be quantified, the MOH did not support proposals to increase the amount paid. However, files suggest that officials did not carry out further research or review international literature to identify alternative solutions. Instead, the MOH accepted transplant unit advice that service capacity issues (rather than donor supply) were the more important problem:

My recollection of the major thing was that if increasing transplants is the issue, payment for donation isn’t the bottleneck. The bottleneck is capacity in DHBs and you need to look at the payment systems between DHBs and that’s what we were hearing from our people….That was the key issue.

The main focus of the renal community itself has, until recently, been on the funding proposal to address service capacity issues:

The recent work around transplantation from a national perspective is more around funding. People have been grappling with a way of dealing with the funding and sorting that out rather than a specific strategy around live donation.

Reimbursement for donors and funding models were therefore the sole solutions put forward until 2011 when the NRAB submitted its Five Point Plan to the Minister of Health.

One former Minister commented that options for increasing LDKT had not been raised with him but that if tangible options had been presented, interest in trialling something would have been high:

I don’t ever remember, for example, a budget bid for a study to fund the feasibility of a paired donor scheme, say. That would have been an easy decision, I think. I mean, my instinct was that the payback time was bugger all. I mean, this would be stuff that you really would do if you could.

Overall, the solutions proposed up until 2011 were relatively limited in their scope with a lack of evidence about what might really make a difference, particularly to the critical
problem of donor supply. The lack of feasible and acceptable solutions for both Ministers and DHBs to consider are major reasons preventing traction on the LDKT issue.

In terms of the multiple streams model, therefore, there seems to have been critical gaps in all three streams, and no advocate or policy entrepreneur. In addition, however, and consistent with previous critiques of multiple streams models (141), the results suggested there were several issues in relevant institutional arrangements.

5.3.2.4 Institutional arrangements
Gaps in institutional arrangements around LDKT may explain some of the lack of attention to, and traction on, the question of how to increase rates of LDKT. There are three interrelated issues:

a. Capacity and capability for analysing the problem and developing options;
b. Leadership;
c. Funding arrangements, savings and incentives.

5.3.2.4.1 Capacity and capability for analysing the problem and developing options
The shortage of analysis and solutions raises the question of where ideas might come from. Kingdon (164) suggests that policy options and solutions float around within policy communities in the same way that molecules floated around in the “primeval soup” before life (p.116). Policy communities are composed of specialists in a given policy area and include researchers, academics, local and central government officials, and interest groups. “But they have in common their concern with one area of policy problems. They also have in common their interactions with each other. People in the health community know each other’s ideas, proposals and research and often know each other very well personally” (ibid, p.117). He comments that this community “hums along on its own, independent of such political events as changes of administration and pressure from legislators’ constituencies” (ibid, p.117). Ideas grow, develop, are discarded or change within this community, ready to be put forward for consideration when the window of opportunity opens.

The questions of who is involved in the policy formulation process and their qualifications for involvement are important ones for understanding how policy happens, and the concept of the policy subsystem has received significant attention in the literature (86). In theories of policy processes, the origin of ideas may be less important than what happens to them.
In Kingdon’s (164) model, “ideas can come from anywhere….[t]he key to understanding policy change is not where the idea came from but what made it take hold and grow” (pp.71-2).

An issue that emerged in this research, however, was that there is no obvious policy community doing the necessary research and developing ideas about how to increase rates of LDKT.

It is now generally accepted that policy advisors in government departments do not have a monopoly on providing advice to Ministers, and there are many potential sources of advice both inside and outside government including interest groups, academics, researchers, service providers and consultants (398). Thus, any or all of these actors could theoretically contribute advice about LDKT but this does not seem to have happened to any great extent.

This is not unique to LDKT, and several informants commented in general on the longstanding difficulties of ensuring a robust evidence base to improve decision-making in many parts of the NZ health system, in comparison to international arrangements (e.g. NICE\(^{16}\)):

> But it does require resource. I mean, the SPNIA\(^{17}\) process really fell over because there just wasn’t the resource to do the grunt work….But the amount of work that needs to go into that is huge, because you can’t make a decision without the evidence. And the minute you don’t have the facts and the evidence, which is a whole lot more than the literature, you’ve lost all your credibility and the system won’t work.

> I think we are challenged on the evidence base and I compare where we’re at in New Zealand to, for example, such places as Australia, Canada or the UK and we’re a bit like a number-eight wire approach.

In relation to organ transplantation, the development of an evidence base and options has been piecemeal. The MOH has commissioned some research about organ donation in the

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\(^{16}\) National Institute for Health and Clinical Excellence http://www.nice.org.uk/  
\(^{17}\) The Service Planning and New Interventions Assessment process was designed to improve prioritisation and decision-making across the 21 DHBs. It was disbanded following the Ministerial Review Group (387) report and replaced with a reconfigured National Health Committee.
past (74-75) although this did not seem to be in the context of a wider strategy and it is not clear how or if it was used.

Research by DHB staff is another source but, again, may be ad hoc and opportunistic, rather than being aligned with any particular strategic objectives. One clinician noted that:

*People at DHB level do come up with some really fantastic stuff but it’s quite hard, and often they seek some innovation funding from somewhere or someone does some research as part of a course they’re doing. So you do it in those sorts of ways but it is fairly piecemeal; it’s not linked particularly well.*

The clinical community, both individuals and groups such as the NRAB, is another important source of evidence and advice about how to increase rates of LDKT. Clinical involvement in finding solutions was seen as critical:

*I think doing the analysis is actually a collective responsibility. I don’t think it’s just the Ministry; I think they’ll get it wrong. I would have thought it’s for the NRAB or the Transplant Subcommittee. It has to be clinical.*

Clinicians, however, may face barriers to doing this kind of work, such as getting the time to research and write papers to support initiatives to increase transplant rates, and effectively have to do this “on top of their day jobs”:

*There is generally a release of time to attend meetings and so forth. What there isn’t generally much assessment of is the background time to invest in those sort of projects [how to increase LDKT rates]. That’s why it is hard very often between meetings to really get much done and much momentum and it often relies on one or two keen people. From a physician point of view, our contracts are supposed to include a certain amount of what is called “non-clinical work”, which for some people is teaching, for others it’s research or service development – stuff like that. So the DHB would argue that that is the sort of thing that time is used for….Most physicians would say it doesn’t work in practice, that they don’t have that amount of time.*

One informant commented that DHBs were unlikely to lead the necessary research analysis and that it would need the Minister to direct the MOH to take responsibility:
And the answer really is that it’s going to take a top-down direction from the Minister. You can’t get 20 DHBs to spontaneously decide this because they won’t. You could drive it through the National Health Committee but then that would go up to the Minister, so it’s going to require the Minister. And so that’s the question, isn’t it, which is where we started from, which is what would it take for the Minister to get interested in this?

Research funding may be limited. Mulgan (398) notes that NZ does not have “a strong philanthropic tradition of privately funding public-interest research” (p.10). There are some sources of research funding. KHNZ, for example, has some research funding available which has recently begun to be targeted towards non-clinical research. Beyond this, its capacity to contribute to the evidence base and development of options may be as constrained as it is for many not-for-profit interest groups. Policy formulation models of “co-production”, where government advisors work with people outside of government to develop advice (395), are one model, but this relies on non-government organisations possessing the necessary knowledge, expertise and capacity to contribute meaningfully.

The developing infrastructure to support the greater focus on regionalisation may be another source of analytical capacity. The Central Region’s Technical Advisory Support group, for example, was reported as having provided some project management resource for the central region’s project to increase the number of LDKTs. More generally, regional approaches were thought to be an opportunity for greater collaboration in many ways:

You need a critical mass of people, analysts, smart planning and funding people, to actually think at the greater-good level, rather than individual DHBs approaching issues from a self-interest perspective. Not till you’ve created clinical leadership and management people thinking at the greater-good level do you ever get any change….We need to start regionalising some of these services so you stop being a club in which people meet and the clinical people sitting in X DHB actually come to understand that other DHBs are their responsibility; they can’t just regard it as a bloody nuisance, they’ve actually got to sort it out.

The National Health Committee which has replaced the SPNIA/NSTR process may be another source of advice, and several respondents suggested this was the type of issue that
it should be addressing. Whether its role would be to provide the type of analysis that goes
beyond whether or not LDKT is cost-effective and should be increased is unknown.

Given these constraints, the MOH, is therefore a critical institution in the policy advice
process. The MOH’s role in LDKT, however, has been limited. Its main role until around
2008 has been a reactive one, focused on responding to requests for advice on
reimbursement of donor costs, rather than initiating advice itself.

Respondents raised issues of both capacity and capability in MOH’s role in LDKT advice. In
terms of capacity, it was reported that LDKT had never been on the Ministry’s work
programme; that for many years no one had been responsible for renal issues and that renal
issues had not had a “home” within the MOH; and that teams that might have paid
attention to LDKT had been focused on other priorities.

Most of the organ donation focus during this period was on deceased donation. One group
within the Ministry was described as being consumed by the “juggernaut of the legislation
[Human Tissue Bill]” while other parts of the Ministry that might have had some
involvement were busy on other government priorities:

*They were busy elsewhere, [another] strategy was the big area that was absorbing
most of the energy of that team, so this was probably one that just was not being
picked up.*

In terms of capability, it was reported that until recently, the “wrong” people had been
given responsibility for providing advice on LDKT. Teams working on related issues, such as
the legislation, were reporting as finding themselves responding to anything else that came
up in the general area of organ donation, such as reimbursement for living donors. They did
not necessarily have any knowledge of LDKT and some people felt that issues “were dealt
with by the wrong part of the Ministry” simply because there was nowhere else for them to
go.

One of the issues with renal services advice in the MOH has been a lack of continuity and
thus a lack of opportunity for staff to build up adequate subject knowledge:
Historically, there’s been different people involved in different things, depending on what’s come up. I would say that’s the whole way it’s been managed actually.

A lot of these things come down to who was sitting in what job at what time, what other things were on the agenda, how big they were. It’s timing and all these things which are really frustrating, particularly for dedicated clinicians. Once they’re a renal physician or whatever, that’s their career for the next 30 years. Whereas some of the Ministry guys pop in and out and can make calls which frustrate the hell out of them.

There were also examples of Ministry staff apparently misunderstanding some of the clinical aspects of ESRF and RRT, e.g. advice has implied that people with ESRF queue for dialysis until a machine becomes available. This view is not uncommon outside the renal community:

They don’t really understand that [dialysis isn’t an elective procedure]. The other thing you get all the time with managers is, “Why don’t we just restrict access to dialysis?”…The analogy they’re using is they think of it like hip replacements, they tend to think well, you can wait for it. Of course, what happens is you inevitably die and obviously that really galvanises health professionals because our job is to save lives… I think they realise that people will die but they think of it like heart disease, “Oh, you might die eventually.” What they don’t realise is that when you get to the point of needing dialysis, that that’s what will happen.

How much expertise to have internally versus accessing it from outside as issues arise is one of the challenges for the Ministry:

I think there needs to be a way to access that expertise, I don’t think you can rely on it being in the Ministry because, actually it won’t be….The challenge is how much do you need in the Ministry to be able to engage effectively….When someone rings up and wants something now or today, you need to know who to contact in the sector to find out. But if no one even knows who to ring, they’re just going to look it up on Google and give their best view. I personally think they should have someone who’s got the renal portfolio and that person will develop some expertise if you keep them on it for a period of time.
There is increasing discussion about responsiveness to Ministerial priorities determining departmental work programmes (395). The fact that LDKT has not been an explicit Ministerial priority is likely to have shaped MOH’s largely reactive approach to the issue but does not entirely explain it in a context of widespread political concern about how to increase organ donation rates during much of this same period, the fact that it was widely agreed that deceased donation would never meet demand for kidneys, and that living donation already accounted for around half of all renal transplants at this time.

Document analysis and interviews suggested that options, such as reimbursement for living donors, were rejected by the MOH but no alternative solutions suggested; and that there was no assistance for many years to resolve apparent service capacity and pricing issues despite repeated requests for assistance from clinicians. Analysis of proposals to increase reimbursement for donors did not seem to include any reviews of literature but was instead based largely on comments from transplant units who are not necessarily well-placed to know the barriers to donation, since by definition they deal only with those who choose to donate. These issues are discussed further in Chapter Six.

In summary, while there may be a number of actors and institutions with an interest in increasing rates of LDKT, there is no obvious “policy community” generating the research and ideas needed. There is a lack of philanthropically-funded research centres, or “think tanks”, general constraints on research funding in NZ, barriers for DHBs and clinicians, and the MOH has had little role in analysis and options development.

Rather than there being a “primeval soup” of ideas, these gaps in institutional arrangements have led directly to a lack of feasible and acceptable options. Developing an evidence base and generating ideas has thus far been ad hoc and tended to rely on “keen individuals” either in the clinical community or in the wider renal community. If getting on the agenda requires robust solutions for decision-makers to consider, these gaps in capacity and capability are one reason decision-makers have not given more attention to the problem of how to increase rates of LDKT.

5.3.2.4.2 Leadership
The NRAB’s Five Point Plan (377) notes that there is no single body that “owns” the problem of how to increase LDKT and that “national leadership, political commitment and resourcing
to make it happen” (p.13) are required. It recommended that the MOH, supported by the NRAB, be mandated to lead this issue.

The lack of ownership or leadership of the problem was raised by a number of respondents. One senior politician noted that:

*We don’t have any manager in the public health service whose sole responsibility is to drive up organ donation rates; it’s quite dispersed. This group here has got one part of it, the providers of the transplants are another group…. We should have someone who is responsible for this.*

ODNZ has no mandate over living donation (Chapter One), and the MOH has had little involvement in LDKT, as discussed above. Until the Five Point Plan, it has been largely up to individual transplant units to consider whether or how to increase rates of LDKT:

*I think it would be fair to say that increasing live donation rates was not really seen as a major national initiative. I think it was left to the individual units to look at their processes and what they were doing from a local perspective…. I think there was probably a lack of vision as to what could be done from a national perspective. It was very much seen as: live donors come to us, we deal with them. We [NRAB] would only want to develop a national strategy, I guess, if there were issues about the way units dealt with their live donors…. If they weren’t coming across our desk, then we didn’t get too involved, it would be fair to say.*

The lack of leadership is a significant gap in the system. With LDKT now accounting for half of all renal transplants, several respondents thought that some kind of greater national leadership, at least of some aspects of the service, was necessary:

*It’s a problem that there’s no one in a leadership role…. Previously I think we’ve been small enough that everything’s been able to be discussed just within everybody but, it’s getting slightly bigger now.*

*There’s no oversight for transplantation and it’s kind of ungoverned really in the three centres…. I don’t think there’s any oversight of transplantation in NZ and I think*
there probably should be...there should be something that has a mandate for live donation [similar to ODNZ].

The MOH is expected to play a leadership role in the health sector, as noted in a recent Central Agencies review (399) of the Ministry:

The Ministry’s role is to provide stewardship over the performance of the New Zealand health system. This leadership and stewardship role is the Ministry’s niche; the place where it must add value to New Zealand (p.5).

There are many ways to show leadership even when an issue is not formally on the work programme, including taking responsibility for solving problems raised by the sector or being proactive about providing advice. However, the MOH’s general approach to LDKT over many years has been largely passive or “hands-off” (a description key informants agreed with), and at times unsupportive, until 2008 when its stance towards LDKT began to change.

The MOH’s “hand- off” approach to organ donation and LDKT could be seen in its original response to the Tookey petition (400):

The Ministry considers that the National Transplant Donor Coordination Office and the health professionals working in this area are best placed to consider the ethical and clinical issues and to provide advice on how to ensure a quality organ donation process is in place throughout the country (p.5).

Later MOH advice (397) when transplant units raised concerns about barriers to LDKT such as work-up processes, theatre capacity, pricing, and coordinator numbers was that this was up to DHBs to address. One key informant reflected:

I can remember going to talk to the Ministry about it. They just weren’t really interested. I’m not criticising them personally but I think at that point it was, “Well, you’re the DHBs, you do it.”

Many of the issues identified above in relation to the problem and solution streams can also be viewed as symptomatic of the MOH’s lack of leadership, including the failure to take up opportunities to solve problems, recognise living donation as part of the solution to the
organ shortage, provide alternative advice when proposals for reimbursement were rejected, or carry out its own analysis rather than simply accepting provider views of the problem.

The MOH also seemed to accept an MSD concern about donor reimbursement that a precedent would be set for the wider income support system (although notably the Ministry of Justice disagreed with this view (401)). It might be expected that MSD would raise this issue given its lead role in the income support system. Buse et al (90) note it is not unusual for other ministries involved in health-related policy, to “be absorbed in their own sectoral policy issues rather than concerned to contribute to a government-wide set of health policies” (p.92). It is not clear, however, why this should also have been such a significant concern for the MOH. Interviewees commented on the MOH approach:

I was surprised…There was advice also coming from MSD and they were clearly quite opposed to it. The Health people didn’t seem to want to go in to bat against them.

There was that MSD concern: if we do this, where will it stop? That was one of the points they raised. Not very convincing from a health perspective.

The change in the MOH approach to LDKT in 2008 appears to be due to renal issues being assigned to a particular team in the Ministry which included someone who had knowledge of, and interest in, the area. One clinician commented:

I think to be honest, having someone in the Ministry who actually cares about renal medicine makes a big difference. That was always the difficulty because if you wanted something done, you’d ring someone at the Ministry and it would be a different person every time who’d been dumped with renal.

The role of individuals, both inside and outside organisations, in progressing policy issues is highlighted in Kingdon’s model. However, relying too much on individuals to bring about change can also leave a portfolio vulnerable. Kingdon (164) notes, “people in key positions come and go, and so do the opportunities that their presence furnishes” (p.169). Reliance on individuals is not unique to LDKT, with the recent review of the MOH (399) noting a broader tendency towards it being “‘person dependent’, that is, key individuals have considerable knowledge and expertise which can be lost when individuals move on” (p.28).
Chapter Five: Attention to LDKT: Getting on the agenda

The history of general organisational ambivalence towards LDKT reflected in official documents means it is not necessarily the case that there has been an organisational shift or greater commitment to a leadership role, but rather is reliant on individuals.

The NRAB’s Five Point Plan signalled its own willingness to provide greater leadership on LDKT. There has been a resurgence of interest in the concept of clinical leadership internationally, driven by concern about divisions between management and clinicians and the desire to re-engage clinicians in the running of health systems to improve quality, safety and overall performance (402-403). This has also been seen in NZ (404), and enhancing clinical leadership is now a key policy goal (403).

There are many definitions of clinical leadership (or governance). Gauld and Horsburgh (403) suggest that “at the heart of clinical governance is the idea that doctors, nurses and other health professionals are best placed to encourage performance improvement amongst peers and should be involved in leadership” (p.10).

Clinical leadership can take a variety of forms, including: the general influence of clinicians on health policy as a result of their status as professionals (90, 93, 402); small “l” or dispersed leadership which operates at the level of a ward, clinic or practice (366, 402); formal clinical leadership/management positions within organisations (e.g. DHBs) (403); and regional or national clinical networks focused on specific clinical areas which may be initiated by clinicians (natural) or instituted externally (mandated) (405).

Clinical leadership of LDKT at local and national levels in NZ has focused mostly on aspects of service delivery. The NRAB and Transplant Subcommittee, for example, have focused on clinical standards, consistent criteria, and quality of aspects of the renal service. Consistent with the discussion above about the “crisis in dialysis services”, much of the NRAB’s focus has been on dialysis, and many of its published reports are about dialysis standards and audits.

Issues relating to transplantation services were reported as being largely devolved to the Transplant Subcommittee which, again, has focused on developing clinical standards and consistent processes, such as the deceased donor allocation system, protocols for the ABOi-transplant and KPE schemes, and cross-match procedures.
However, there has been little strategic leadership specifically aimed at the question of how to increase rates of LDKT:

There has always been transplantation issues dealt with through the NRAB but I think it would be fair to say that was predominantly around the allocation system, annual reports of the national allocation system, tissue-typing issues and so forth rather than a specific strategy around live transplantation.

At times, the NRAB has attempted to take a more strategic leadership role in renal services, e.g. its 2006 paper on a national strategic plan for renal services - which did not progress – and, more recently, its Five Point Plan and championing of the revised funding model for renal transplantation.

Key informants felt that clinical leadership on the specific question of increasing rates of LDKT was critical:

I think we do debate quite a few issues in society - alcohol springs to mind in recent times and we've made some good headway around smoking - but one of the key issues for me we're still pretty quiet on is organ donation and the benefits. And so I think it does require leadership and it would be great to hear the clinical voice, you know our top clinicians talking.

What interests the Minister? What doctors tell him. He really relates to that; clinical networks and clinical engagement are big deals for him. And if he gets a united voice from the profession, telling him something and giving him an answer at the same time, he’s likely to listen....If a case was put to the Minister in a unified way that said, “We the NRAB, with the backing of all the renal specialists in the country, say the following: this makes sense clinically, in equity terms, in financial terms, in every way,” he’ll listen and, “Minister, this is what we’re looking for from you and if you do this for us, this is what we guarantee to deliver for you,” of course he’ll do it.

Many respondents thought that the NRAB and/or the Transplant Subcommittee could, and should, take a greater role but noted several challenges facing these groups (as are commonly reported regarding clinical leadership (403)):
• As a “natural” rather than “mandated” network, there is a lack of connection with wider decision-making structures and processes:

> It seemed to be an organisation that had been established but it was just sort of waving around in the ether. There were some really good, committed people on it – clinicians – but their purpose wasn’t well understood....They would sort of circulate papers amongst themselves but they didn’t know where they should connect with the system.

• There has been little support from the MOH, and the NRAB has struggled to have wider influence or as one clinician said, “to get on and do things”:

> The relationship between the NRAB and the Ministry has been variable. We had a Ministry person who supported us in the sense of some infrastructure and for a while attended meetings, but it quickly became that we’d go off and meet as our own little group and just report to the Ministry, but we never really had a strong advocate within the Ministry. It’s fair to say that only since X has come on board as a Ministry person that we have been able to push things a bit more.

> It’s always been a bone of contention [Ministry support for NRAB]. It is extremely hard to be heard at a Ministerial level and there are a lot of people...who have demanded Ministry support. I think that would be optimal but it’s clearly not going to happen. I think that the payback for the NRAB is really just an ability to be heard and if there’s no actual facilitation of the process and it doesn’t go anywhere, it will fall down.

• Administrative and analytical support for the NRAB has been limited:

> It’s impressive how long the NRAB has gone on for actually, with and without Ministry support....Other clinical networks, for example, the Ministry funds a person’s DHB for one day a week to work on the network and there’s also secretariat support that the Ministry pays for.
It isn’t going to work is the bottom line. Those committees don’t get the support they want. They just don’t get the grunt they need to do the work – clinicians can make the decisions but they have to have the evidence put in front of them.

- The role and mandate of the Renal Transplant Subcommittee are unclear, there are no Terms of Reference and, although it is technically a subcommittee of the NRAB, very few of its members are also members of the NRAB, weakening the connection between the groups:

  Its relationship with the actual NRAB has been a little bit obscure. It’s tended to operate almost simultaneously; maybe that’s to do with its origin, I’m not sure. Then again, it hasn’t done very much either... and it’s a different group of people [from the NRAB]....They don’t really show much leadership....I think transplantation has suffered a bit because we have had the transplant subcommittee but its linkage with the NRAB has been quite vague.

- Both regional and national groups seemed to rely on “keen” people to get things done, often in their own time. Chairs of clinical networks, who are expected to drive agendas forward, were reported as “burning out” or making other sacrifices:

  The challenges are the same as for a clinical head really. It’s not a paid position, it’s done out of your own time....It’s at the expense of your personal life; it’s not done through the DHB because it’s never core business. The NRAB is probably more important than a lot of things we do but less urgent. Unfortunately, the way score cards are tallied, you actually have to do some of the urgent yet less important things. So the NRAB, unfortunately, is not a sustainable long-term thing.

Gauld and Horsburgh (403) suggest that one of the rationales for enhanced clinical leadership is that health professionals should lead improvements to services because they are “most closely involved in their design and delivery and have the best knowledge of where weaknesses lie, have the most control over resource use, and knowledge of which initiatives are likely to provide best value and improve health care delivery and options”
Thus, the fundamental premise is that clinicians know what to do, and have the levers to do it. This was echoed by one key informant:

*Actually it’s the clinicians who know, who are the most informed of what the needs of their patients are, and what is possible…. We are looking to clinicians to lead this stuff.*

This raises questions about the challenges for clinical leadership for resolving complex issues without adequate support and where the evidence base is missing. Where there are also difficult ethical issues that directly influence what clinicians feel they can and should be responsible for (see Chapter Six), there may be limits to what clinical leadership alone can accomplish.

Finally, views were mixed about whether ODNZ’s current role should be extended to living donation:

*I’d worry about why ODNZ is only involved when someone dies. Isn’t the outcome you want more organs donated? And so for me, I’d question why someone is being funded just to focus on deceased.*

*I think they focus on the deceased and I think it would be hard to do both…. It’s different, you’re not dealing with bereaved relatives so it’s quite different. They’re quite separate [live and deceased donation]… and I think they should be kept quite separate.*

ODNZ was thought to run an efficient service and work well with bereaved families but some respondents thought it had not done enough to promote organ donation. There was concern that living donation would also suffer if responsibility for it was given to ODNZ:

*ODNZ are doing a tremendous job, particularly when it comes to the donation side of things and dealing with the families, they do an incredible job… [but] I feel that what they’ve done with the deceased side, the funding, there’s not a lot of public information or education out there. I’d be worried that might happen if living donation went to ODNZ. With another organisation, hopefully, they’d be a lot more proactive and focused in a different area, rather than the hospitals…. I don’t know,*
there may be reasons I don’t know about as to why there’s not a public education programme.

In summary, there are, in theory, a number of actors who could take on national leadership or ownership of the problem of how to increase rates of LDKT, but who had not done so during the period 2000-2010, at least. ODNZ has no mandate to address living donation and arguably would need substantial reconfiguration and specific expertise in LDKT if it were to take on such a role. The MOH has been largely absent on LDKT issues, despite opportunities to step up, and much of its advice until 2008 has appeared ambivalent. The NRAB and Transplant Subcommittee have been largely focused on clinical standards and processes rather than strategic leadership to increase LDKT (until relatively recently). There are challenges to be resolved if existing clinical networks are to provide a greater level of leadership, including administrative and analytical support, and formal connections to wider decision-making processes.

5.3.2.4.3 Funding arrangements, savings and incentives
Financing arrangements in health-care systems can create different barriers and perverse incentives in the LDKT process that may partially explain why LDKT is not carried out on a larger scale. The USA Medicare policy of only funding immunosuppressant drugs for three years, yet funding dialysis for as long as it is needed, means many uninsured patients do not pursue LDKT or are not offered the option. Those that do receive a transplant return to dialysis after three years at much higher rates than insured patients (228).

In the UK, the Organ Donation Taskforce identified disincentives to deceased donation because hospitals managing deceased donors were not compensated for the costs they incurred and recommended that these be removed (406). Disincentives to living donation were also identified, again because the price paid to hospitals did not reflect the cost of transplantation, resulting in a situation where it was cheaper to keep patients on dialysis than transplant them. Resolving this has been a priority for the UK Strategy for Living Donor Kidney Transplantation (364, 407).

A cluster of issues relating to funding arrangements, savings and incentives was identified by a number of informants as possible reasons for not giving greater attention to increasing to LDKT rates, particularly by DHBs. The financial (and clinical) incentives should, in theory, be
strong enough to encourage DHBs to increase transplant rates even if it is not an explicit priority of central government. One senior health manager commented:

_If it’s not a Government priority and you’re going to get Boards to take a leadership role, then you’ve got to have a compelling argument for them to use their core PBFF [base annual funding] and know it’s going to save them over time...two years is a pretty powerful payback time....You should be delighted if you can reduce your dialysis costs and pay for some one-off stuff, it would be hugely attractive...you’d love to be able to take another 10 or 20 or 30 people off dialysis with access to some one-off organ donation. That would be absolutely wonderful._

However, it appears that a variety of factors in the funding arrangements may have weakened or negated the strong incentives that should exist to seek to increase rates of LDKT.

- **The price and where costs and benefits accrue**

While at an overall system level there should be financial incentives to make greater use of transplantation, this incentive may be undermined by a combination of two factors. Firstly, the price paid to provider DHBs by non-transplanting DHBs is reported to be lower than the true cost so that transplanting DHBs are in effect subsidising other DHBs whose patients they treat (148, 365). This may act as a barrier to carrying out greater numbers of transplants and constrain the application of new technologies, such as ABOI-transplants which are more costly than standard transplants (148).

Secondly, the costs and benefits of transplantation accrue in different parts of the system. DHBs of domicile reap the benefits of transplantation because fewer of their ESRF patients require dialysis than otherwise would. For provider DHBs, transplantation should be at least cost neutral, but in fact they may lose money if the IDF price paid for transplantation does not cover the costs to transplanting DHBs. This is reported as creating an actual disincentive for provider DHBs:

_There is no doubt that a transplanting DHB loses money every time they transplant an out-of-town patient. That’s not hugely high in people’s consciousness but it is_
certainly no incentive to be working to increase rates or for that DHB to be putting in resource.

It is difficult to quantify the effect this has on transplant rates. It did not seem that transplant units were refusing to take patients from other DHBs, but rather that there was a general “brake” on expanding the service beyond what it was already doing:

People aren’t being turned away or refused a transplant. It’s just that the unit isn’t being funded for their transplant, therefore it can’t grow.

Some units that had attempted to expand their service had found it difficult to make a compelling financial argument to the wider DHB:

We can’t just go and say, “If we did more transplants, it would all be better” because you’ve got to come up with a business case and the business case is only for patients from our DHB because obviously it doesn’t save us any money if we transplant people from somewhere else. So if it was clear that if we did more transplants we would bring more money in, that might make a difference.

Solutions for addressing this problem might include changing the price to reflect actual costs and thus remove the disincentive for provider DHBs to expand the service. Several people interviewed asked why this had not already been done, as it seemed to be the obvious solution:

To me, that’s not an argument for changing the funding model; it’s an argument for changing the IDF, isn’t it? Or is that too simplistic?

Key informants suggested that there had been attempts to do this in the past, which had been unsuccessful, possibly because of the general lack of engagement by the MOH on addressing issues relating to LDKT.

- Savings are not perceived as “real”

LDKT is more cost-effective than the alternative, dialysis, but a common theme throughout the interviews was what the concept of “savings” actually means. Respondents distinguished between different forms of savings, using terms such as “paper savings” or
“notional savings” to describe a situation where health expenditure continues to increase (e.g. because of increasing demand) but at a lower rate of growth than previously:

I think the DHBs used the phrase “dark green or light green dollars”. So one is genuine things you can bank and one is avoided costs.

It’s controlling cost. It’s not saving money.

Because demand for RRT is projected to continue to increase, transplanting more patients is unlikely to result in an actual reduction in expenditure for renal services, but will allow more new patients to be treated for less than would otherwise be the case. This is the difference between reducing costs (or creating bottom line savings) and creating capacity (408).

Several interviewees also expressed general scepticism about proposals to reduce the rate of growth of health expenditure over time (known as “bending the curve”) (409)) in part because there is often very little follow-up or evaluation of such initiatives intended to do this. Nor is there usually an agreed way to measure the impacts because there is no counterfactual about what expenditure would otherwise look like without the intervention:

What I’ve observed, not just in terms of renal, but just generally is that we’re attempting to make what I call paper savings or notional savings….In terms of actual expenditure, it’s still going up and then we rationalise by saying, “Oh but we’ve stopped the curve going up.” There’s no actual causal evidence that we’ve done that but we always project and it’s quite easy to do estimates that way.

Most cost-benefit analyses that are done, most business cases that are done, are in the avoided, downstream costs domain so you never see the money. Pharmac analysis is just absolutely classic. “If we invest in this drug, it’s going to keep these people out of hospital, therefore we’ll save this amount of money.” Well, it never saves that money. Pharmac spends the money but there are never any savings that one sees, because the bed’s filled up by somebody else….You hope you see the curve bending over time but that connection’s never made.
An example of this can already be seen in renal services which by international standards are very cost-effective because of NZ’s high rate of home dialysis (7), as noted by one clinician:

*The way we provide dialysis in New Zealand is very cost-effective internationally. We save a lot with the amount of home dialysis that we do. And we don’t get enough recognition for that because that saving’s always been there. But it’s about $30,000 a year for each person doing home dialysis, so it’s quite big numbers.*

Effectively, the curve has already been bent but there is no way to recognise this.

Many interviewees, however, were not so dismissive of so-called “notional” or “light green” savings and regarded this as a legitimate form of savings that should be pursued. One key informant felt there was a sense of overstating the “notional” nature of the potential savings from increasing transplant rates, commenting that the costs of dialysis are very real for the health system and that transplanting more people would help avoid costs such as building more dialysis facilities:

*Once upon a time people would say, “Well, we don’t actually save money; you take a patient off dialysis you don’t really save money because there’s always another patient coming on, blah, blah, blah,” but now it’s not like that because everybody’s building these little satellite units for dialysis to give better access to dialysis patients and everything. So there’s an ongoing incremental cost and if you don’t transplant the people who are transplantable, who are younger and actually live longer than the average dialysis patient, you’re going to incur enormous costs and you can measure those because even in this city, we’re building new dialysis centres, so it’s no longer a marginal cost, it’s a real cost. It is truly about the cost of dialysis so it’s an ongoing cost of $50 or $70,000 a year so we should transplant every person who’s transplantable and we should do it as soon as we possibly can.*

This distinction between initiatives that are more cost-effective and those that reduce total expenditure is not a new phenomenon (and, as noted above, previous MOH advice has been that there are no offsetting savings from transplantation) but may have particular salience
for respondents in the context of the overall fiscal situation and subsequent tightening of health funding.

- **VFM has not been a significant driver of decision-making**

Chapter One noted that the goals of health policy have shifted over time with an increasing focus on attempts to improve the health and welfare of the population within the resources available, that is to maximise value for money.

Despite this goal, arguably VFM has not been a significant driver of decision-making. During the 2000s, policies of a relatively generous funding environment in health (386), along with a failure to hold DHBs to a tight deficit track and what was colloquially known as “the second cheque book”, may have reduced the imperative to look for ways to improve VFM. The financial incentives to increase LDKT rates would thus have been weakened since it may not have been perceived there was a burning platform to increase VFM, despite concern about the rising costs of dialysis expressed by DHBs.

The international financial crisis has sharpened the focus on VFM in health systems everywhere (76). NZ has not seen the reductions in health expenditure experienced in some other countries although the funding environment has become more restrictive. The rate of growth of public health expenditure has slowed since 2009 (personal communication, Ministry of Health), and DHBs have had to make significant efficiency gains (410). New initiatives are now funded from reprioritisation within Vote Health, rather than new funding from the Crown Budget. There has been strong signalling from the centre on management of DHB deficits and wage growth (399). This should, in theory, encourage DHBs to look for more cost-effective ways of delivering services to their populations, such as increasing rates of transplantation.

It is not clear yet how much of an imperative for change there is. The recent review of the MOH (399) noted that the more restrictive financial environment has largely been managed through incremental changes and requiring DHBs to make efficiency gains, rather than genuine VFM improvements, and “this approach has been effective to date, but without business process changes, service performance will be impacted at some point” (p.22).
• Short- and medium-term perspectives

A final issue that may affect the incentives to increase LDKT rates is the time horizon. While the payback period is only two-to-three years, transplantation requires up-front funding in the first year. In times of generous base funding growth or when there is an external source of new initiatives funding (e.g. the annual Budget), it may be more feasible for DHBs (particularly larger ones) to consider these types of “invest-to-save” options, although the issues mentioned above may have reduced the incentive to increase transplants.

In tight financial periods, such as since 2009, invest-to-save may be even more difficult as DHBs look to short-term cost-containment initiatives, or “real savings”, rather than VFM:

*A lot of DHBs when they think about value for money and prioritisation, are increasingly thinking about, “What the hell can we disinvest from?”*

For DHBs to decide to invest in additional transplantation in the current environment, the up-front funding must be found from reprioritisation which is notoriously difficult at the best of times (388, 411-412):

*There’d have to be extra money in finding donors and getting the surgery done and all the follow-up costs that go with a lifetime of immunosuppressant medication. So all the money’s got to be found for that, and there isn’t any money in the system; nobody’s putting new money into the system....That money’s got to come from somewhere and, in this sort of environment, where would a DHB get the money from when they’re battling for survival?....And yes, it will in time reduce dialysis costs but with what’s forecast for the growth in dialysis, it’s not going to be real savings. It’s just flattening the growth rate for dialysis a bit.*

A short-term horizon may be reinforced by the annual basis of the DHB planning and funding cycle. The review of MOH (399) noted that “an annualised planning cycle is highly inefficient given that delivery of interventions is over a much longer cycle” (p.27). This cycle, however, is necessitated by macro level Budget settings. Although there is an indicative funding path setting out what the annual increases to Vote Health will be for the next four years (410), the sector is still operating on annual budgets which requires a balancing of the books each year. This reduces the opportunity to manage budgets across
years (i.e. balancing the savings in outyears against the initial investment) and thus makes
invest-to-save options much more difficult. Multi-year funding paths may alleviate this and
give the sector tools to retain a longer-term focus on VFM, rather than encouraging a short-
term focus on cost containment. There have been anecdotal reports of DHB CEs being
concerned about proposals to increase donor numbers without funding being available to
do extra transplants.

5.3.3 2011-2012: The policy window starts to open
While the period 2000-2010 saw relatively little attention being given to how to increase
LDKT, during 2011-12, it appeared that for the first time a policy window started to open.

Several factors aligned during this period including: interest in LDKT by the Minister of
Health in Budget 2012; a generally greater level of interest in LDKT as the treatment of
choice in a wider context of rising dialysis costs; the development of a wider range of
options for decision-makers to consider; the emergence of a policy entrepreneur; and some
changes in institutional arrangements such as the establishment of the National Health
Board.

The Minister’s attention was reportedly prompted by several factors: political colleagues
who had raised organ transplantation with him over a period of time; a general growing
awareness about renal issues through being asked to open new dialysis facilities (with the
chance to speak directly with patients); and the initial interview for this research during
which he became sufficiently interested in the issue to seek advice from the MOH:

   Oh, well, it’s a no brainer. So why has it not happened?....I’ll ask for a report on it:
   [writing] “Live organ donations and what can be done to improve this, based on
   international experience – and provide a cost benefit analysis.” That might set the
   ball rolling.

The Minister’s interest in the issue was seen by people in the sector as a definite
opportunity:

   I think that the fact that the Minister appears to be very interested in solving a lot of
   the renal problems and it’s not just transplant, but it’s dialysis as well, and the closer
to home philosophy that they’re working under at the moment. I think, given enough time, this could actually give us some progress; I think it can go somewhere.

It was also seen as important for giving it a focus within the MOH which it had not previously had:

There’s no doubt the Minister showing an interest helps...he decided to put some funding in and that will mean there’s a recognition [in the Ministry].

Wider interest in LDKT could be seen both within the MOH and the wider renal community, driven by rising demand for RRT, the ongoing shortage of deceased donors and more research about the low risks for living donors which has contributed to more positive attitudes about LDKT amongst health professionals.

The growth in RRT expenditure reportedly influenced renal units to take a greater focus on VFM “to demonstrate that we are doing everything within our sphere to control costs”:

Internationally, I guess there’s a lot of interest in live transplantation. I guess the reason is that the number of patients who are developing end-stage renal failure is just getting so big and all of the units are at capacity and the expected growth isn’t slowing down and we know that we need to have an alternative. The spotlight’s on how much it’s costing with the current financial situation that we’re in so I guess that we’re looking at different options....I think a lot of it has to do with cost because everything’s about cost really now.

The challenge of sorting out dialysis services, such as quality and equity of access, had “crowded out” a focus on LDKT for some time with a prevailing sense that dialysis was “core business”. Some respondents felt that with many of the problems around dialysis resolved, attention could now be freed up to focus more on transplantation:

I suppose most nephrologists have been dealing with the urgent day-to-day stuff of dialysis and now I guess one of the reasons why transplant has some attention and traction at the moment is because that sort of drama is over now and people can think about this.
The newly-formed NHB also took an interest because officials started to observe a wider problem around renal issues:

> And renal has come up from several perspectives: obviously the work that the Ministry was doing with the NRAB and the Five Point Plan that was recognised and the opportunity that came from there. But also from the sector itself, in terms of discussions with the GMs Planning and Funding and the access problems to dialysis in some places. But also the NHC had a view that if we don’t get a grip on this now, it’s going to come back and bite us. So it’s interesting because sometimes issues bubble up because of a disgruntled clinician or a disgruntled service, so when it comes at me from three different angles, I’m thinking, “Yeah, there’s definitely something here.”

This attention is significant given the almost complete lack of recognition by the MOH previously of the issue. A number of people commented on the importance of having an identified person with ongoing responsibility for renal issues. This was thought to have made a difference, particularly in terms of the issues that clinicians had attempted to raise in the past:

> I think having someone in the Ministry who focused on it and carried through on things has gradually over time had some effect….It’s partly about having someone to talk to instead of just sending stuff in.

The establishment of the NHB, with a business unit in the MOH, was an important development in institutional arrangements. One of its roles is to review services that require a national focus, acknowledging that issues may not always be able to be resolved amongst DHBs. This more centralised approach provides a new avenue for issues to be addressed at national level. Thus, the NRAB was able to make its submission on a national funding model for renal transplantation after many years of unsuccessfully attempting to raise issues with the MOH:

> I don’t think [the NHB’s] perfect, far from it, but I think there’s the opportunity to flag issues and look at them from a national lens where that isn’t politically mandated down; it’s gives the sector a bit of an opportunity to say, “Hey, there’s a bit of an issue here”….I think some of the Ministry’s previous approach was a bit hands-off and DHBs had to sort
things out. They had a national body, DHBNZ, that would look at some of this and then step back, “Ok, you guys will sort this out”. So apart from the things which were politically driven, like the cancer strategy and other bits and pieces, it’s been a bit haphazard. I’m not saying that the MRG changes solved it all but it’s a recognition that, for whatever reason, the model we had for the last nine, 10 years didn’t quite pick this up as well as it could…Sometimes things can’t all be sorted out at local or regional level… and there needs to be a call made on behalf of the country when you’ve got 20 people in the room from 20 different DHBs who are on opposite ends of the spectrum.

It probably makes a difference having the NHB and that’s why it got invented, isn’t it?

However, clinicians also mentioned that they would not have known about this route if it had not been raised by the person in the Ministry with responsibility for renal issues, again highlighting the importance of having someone in MOH with an ongoing role who is able to work with the sector:

So we’ve been trying to get it funded through various ways for ages and then X said that would be the best way of doing it and so that’s why it went that way.

A significant factor in the window opening was the appearance of two sets of proposals which aimed to increase rates of LDKT (the proposal for a national funding model and the Five Point Plan), providing a significantly wider range of options for decision-makers to consider than at any time previously.

The Five Point Plan for LDKT was developed in response to the request from the Minister to the MOH for advice following the interview for this research. The Ministry consulted the NRAB which then decided to take the opportunity to put some advice directly to the Minister. The plan was described in the sector as a significant step forward:

The fact that the Renal Advisory Board have got their paper to the Minister, which I think is a really good thing….It’s always been talked about in circles and then it’s not actually got anywhere. I think this is an opportunity to give some concrete suggestions as to how it can be fixed and I do like the plan…for once it’s all come together and it’s clear in one plan.
The importance of tangible suggestions in advancing the overall issue was reinforced in a follow-up interview with the Minister who emphasised that “practical, discrete, affordable ideas that will make a difference” were the most helpful.

Finally, for the first time, key informants identified the appearance of an advocate within the renal community. This may be the closest to a policy entrepreneur yet seen on this issue:

*I think having X on the network has provided a strong advocacy around transplantation in general, and particularly live donation....That stuff does percolate up to the NRAB and it’s changed because I think X is on the NRAB and is raising it a bit more. Usually it takes an advocate to really push these things along and I think that’s what has helped.*

*Maybe that’s just the change of the NRAB, too; different people coming through with different objectives that are pushing that along.*

For wicked problems, one of the key risks is that decision-makers believe a problem has been “solved” with a one-off initiative that tackles only one part of the problem (393). Nor do policy windows remain open indefinitely (164). The 2011-12 window could easily close again if underlying institutional problems are not resolved, there is little demonstrable progress, and/or there are changes in key personnel.

5.4 Summary: Attention to LDKT

Factors in each of the three streams of the multiple streams model, as well as gaps in certain institutional arrangements, have all contributed to the lack of attention to how to increase rates of LDKT in NZ.

In particular, lack of problem recognition and clear problem definition, as well as a shortage of options for how to address the fundamental problem of donor supply, were critical. Political willingness to address organ shortages had been evident in the past but living donation had had little saliency primarily because of the shortage of options about what to do, suggesting considerable interdependencies between the politics and policy streams. There had also been a lack of an advocate or entrepreneur to raise the issue and a lack of leadership or ownership of the problem, that is, no one in the system is responsible for trying to increase rates of LDKT. The MOH has taken a largely passive approach to the issue,
ODNZ has responsibility only for deceased donation, and there are challenges to effective clinical leadership.

Further interdependence could be seen between the problem recognition and policy streams. The problem was not recognised or clearly defined – LDKT was crowded out by related issues or “decoupled” from dialysis so was not clearly seen as part of the solution to rising demand for dialysis. Poor (or lack of) problem definition meant solutions had often not focused clearly on the fundamental importance of donor supply but instead focused on service capacity issues. There was no obvious policy community and this lack of analytical capacity means the active process of recognising and defining problems, identifying options and joining them together had not happened. Moreover, these processes are ongoing and iterative, requiring evidence, intervention logic, and constant refinement of the problem definition (91-92). This had not happened in the case of LDKT.

The alignment of several factors that had not existed previously, in particular some tangible solutions being put forward to the Minister, the emergence of a policy entrepreneur, and the NHB’s new role in reviewing services requiring a national approach, seemed to have resulted in a policy window opening in 2011-2012, including funding in Budget 2012 for LDKT. Gaps in institutional arrangements still exist, however, particularly analytical capacity, leadership and ownership of the problem.

This completes the initial analysis of the key findings from my research data. These findings, from Chapters Three, Four and Five covering both the key barriers in the LDKT journey (content) and issues in processes and institutional arrangements, are synthesised and discussed in more depth in the following chapter.
Chapter Six: Discussion

6 Chapter Six: Discussion

6.1 Introduction

This chapter discusses the overall themes arising from the results presented in Chapters Three, Four and Five. This research suggests a complex mix of barriers to increasing the rate of LDKT in NZ, many of which are consistent with findings from elsewhere. The quality, timing and consistency of discussions with patients about their illness and treatment options are major issues and patients require much greater support to raise the issue of living donation with their networks. Incompatibility and medical unsuitability are major barriers for potential donors who start the work-up process, but NZ’s KPE scheme is yet to have any significant impact.

Inefficiencies in parts of the process, particularly evaluations of potential donors, can slow the process down and have several possible negative consequences, including undermining goodwill towards LDKT. These need to be addressed although it is unlikely that there is a large “backlog” of potential donors in the system – in this research, only 13.5% of patients reported a potential donor was still being evaluated.

As in all transplant programmes, the main barrier to LDKT for NZ waiting-list patients is not yet having a willing and suitable donor. The question of how to increase the supply of donors requires a direct and specific focus, which goes beyond the usual health policy question of whether or not to allocate more resources.

LDKT has not been on the policy agenda until relatively recently and this lack of attention itself constitutes one of the barriers to increasing the rate of LDKT since, as noted previously, improvement in health services does not just happen but must be intended (368). Issues in each of the three streams of the multiple streams model may have contributed to the issue not having been on the agenda in NZ. These issues included: decision-makers at all levels not being interested in or aware of the issue, or having other priorities; lack of recognition and clear problem definition; a shortage of feasible and acceptable solutions for decision-makers to consider; and the absence of a policy entrepreneur or protagonist. Lack of leadership or ownership of the issue is a significant gap in institutional arrangements.
The remainder of this chapter discusses some of the key findings relating to each of the research questions in more depth and reflects on a number of issues arising from the research, placing these in a wider context. Although there was no specific research question relating to ethical issues (the key contextual issue in the health policy triangle), important ethical issues emerged that impact on LDKT policy and practice. These are discussed also.

6.2 Key issues

6.2.1 Research Question 1: Barriers to LDKT in the patient journey

6.2.1.1 Sense of urgency
Change happens when there is a perception of a problem that needs to be fixed. This research shows there is little problem recognition or sense of urgency about LDKT anywhere in the system. Renal disease is not widely understood compared to some other diseases and renal transplantation may not have the same sense of urgency as many other types of organ transplantation, despite the well-established findings that transplantation can extend survival significantly compared to remaining on dialysis. Richards (413) suggests diseases such as cancer and AIDS “carry an entirely different symbolic significance to kidney failure, although all are fatal if left untreated” (p.1718).

In the transplantation field itself, the lack of a sense of urgency around renal disease has often been reinforced with heart, lung and liver transplants being referred to as “life saving” while kidney transplants are referred to as being about improving “quality of life” (414-415). ODNZ’s website currently states that “people waiting for a heart, lungs or liver will die without a successful transplant while those waiting for a kidney transplant lead lives restricted by long-term dialysis treatment” (416). Within the NZ health system, LDKT is regarded as an elective procedure that can be delayed. This is not unusual internationally because, according to Varekamp (417), the availability of dialysis means that patients “are seldom urgently in need of transplantation” (p.141).

A lack of urgency may also be reinforced within the renal service, with accurate information about the risks and benefits of different options not always provided, because these conversations are difficult and/or because health professionals do not want to make patients feel “hopeless” about dialysis. This may well affect patients’ approach to seeking LDKT. Oniscu et al (14) have suggested previously that accurate information about survival
could be a “powerful clinical tool” (p.1865) to use in discussions with patients about RRT options and knowledge of the risks and benefits of different RRT options has been shown previously to be associated with willingness to accept offers from potential donors (185). Not presenting accurate information to patients about risks and benefits of different treatment options is clearly in contravention of their rights under the Code of Health and Disability Services Consumers’ Rights (145) which requires that consumers should be fully informed about the risks and benefits of all the options available. Lack of accurate information about the outcomes for the patient may also reduce the motivation of family and friends to consider donation. Similarly, Oniscu et al (14) suggest that emphasising the life-saving benefits of renal transplantation to the public may have a positive effect on donation rates.

Accurate understanding about the chances of receiving a DDKT, and misunderstanding about what “waiting time” means, may also influence how actively patients pursue LDKT. Previous research has found an association between waiting times and rates of LDKT. Segev et al (418) found that patients at centres with longer waiting times for DDKT were more likely to receive a LDKT suggesting that, “this could indicate that the perception or knowledge of long waiting times for a DD kidney…encourages the search for a live donation and inspires the participation of potential live donors even before long waits ensue” (p.2412). In my research, health professionals noted that patients may lack a clear understanding about what waiting times actually mean and the low chances of a DDKT. Combined with incomplete knowledge about the survival advantages of LDKT, this may reduce the sense of urgency for them, and for their potential donors, in pursuing LDKT.

A lack of urgency is also reflected in the often long work-up processes for potential recipients and donors. People being considered to be potential recipients or donors are, by definition, likely to be relatively well – extremely well in the case of donors. Even the potential recipient is unlikely to be “acutely unwell” and thus neither is of “high priority” which may delay work-up processes. International guidelines for living donation generally give little attention to the efficiency of health service delivery, despite the consequences of unnecessary delays which Tong et al (112) note can cause “undue stress and worry for donors, particularly if their recipient’s kidney function is deteriorating” (p.970). The drawn-out nature of the work-up and reported difficulty donors have in contacting coordinators in
some centres, may also give the impression that receiving an LDKT is not necessarily critical for a patient. Whether this has any impact on attrition of potential donors is unknown.

LDKT is unusual in elective services because it is clearly about life expectancy as well as quality of life, but the availability of dialysis reduces the sense of urgency. Delays are also due to whether or not there is a suitable donor, which is traditionally regarded as being outside the control of the health system, and standard elective waiting-time targets cannot be easily applied. However, this does not explain why donor work-ups themselves are often so drawn out.

Health professionals being overwhelmed by demand for dialysis may also result in the “sense of fatalism” referred to by one key informant, rather than imbuing a sense of urgency around LDKT.

6.2.1.2 Patient and donor activation

The increasing trend in renal transplantation from deceased to living donation as the predominant source of organs has been described by Hilhorst (419) as representing “a shift in attitudes from passive expectation to active participation” (p.487). Hilhorst (419) notes that rather than waiting, passively, for a deceased donor transplant which in all likelihood will never happen, LDKT represents an opportunity for “many patients and their relatives...[to] take their precarious fate into their own hands” (p.485).

LDKT is, therefore, by definition an active process, since it is about bypassing the waiting list. However, this represents not only an opportunity for patients, but a potential barrier because of what is required of patients themselves in order to get through the process. In deceased donor programmes, patients’ main role is to complete the evaluation and then remain healthy enough to receive a transplant. The process of acquiring (and allocating) organs is the responsibility of the transplant system.

In LDKT, patients must complete all necessary steps in the transplant evaluation process and successfully manage a chronic and life-threatening illness to remain healthy enough for transplantation – described by Mauri Ora Associates (74) as being a “professional patient” (p.28). In addition, they have the primary responsibility for the critical step in the whole process: finding a willing donor. Difficulties accessing the KPE scheme, with patients
reporting they had to “chase” coordinators to get into it, suggest this may be the latest example of patients having to be very active to access the service.

Potential donors, in turn, are also expected to be proactive in the LDKT process. Health professionals will not ask potential donors, and many patients would rather wait for someone to offer than approach them directly. Previous NZ research (74) notes: “to be a live donor you need to be quite proactive and put your hand up. If you are waiting for people to come to you, it won’t happen” (p.27).

As one patient noted in this research, many donors will be novices in dealing with the health system, because donors must be healthier than the general population, and they must persevere through the work-up process over many months. The research found that transplant coordinators often take a “hands-off” approach in order to avoid perceptions that they are “chasing” or coercing donors, and may require donors to “drive the process” to demonstrate their commitment. There were reports of no response to phone calls and emails by potential donors, who had to persist in trying to contact transplant units. Some transplant coordinators acknowledged that people who were proactive in driving the process had a greater chance of getting through more quickly, raising questions about what happens to people who are more reticent:

*Those donors who ring are the ones that get through in a timely manner which is wrong; I don’t think that’s a good way for things to be, but the donors who ring and are quite pushy get through the process in a reasonably quick manner and the ones who sort of sit back, don’t and, unfortunately, they take a bit longer.*

The critical role of patients in achieving health outcomes is well understood in chronic conditions, with patient engagement and active participation in their own health-care being linked to better outcomes (420). “Patient activation” refers to patients having the skills, knowledge, beliefs and motivation to participate in the management of their own condition. Domains of patient activation include believing an active role is important, confidence and knowledge to take action, taking action, and staying the course under stress (421).

Patient activation was not measured in this research but it is plausible to suggest that the current policy settings, the organisation of services, and the way ethical concerns are
managed require an especially high level of patient and donor activation to successfully receive a LDKT. Interacting with health systems requires a high degree of confidence and potential donors may interpret lack of contact from the transplant coordinator as them not being wanted.

Activation is not simply a characteristic inherent to patients, but something that health-care providers can develop in their patients (421). This might include interventions to inform and educate patients as well as actively addressing belief systems that make them feel it is unacceptable to discuss living donation with others or accept offers of kidneys. However, even highly activated patients may continue to feel a level of embarrassment about approaching someone about living donation and other forms of support to find donors will often be needed.

6.2.1.3 Ethnic issues
Previous research suggests several factors affecting ethnic variation in access to transplantation including: late referral from primary care services (148); issues in processes for referral and evaluation for transplantation (see Chapter Three); patient preferences (422); health practitioner attitudes (74, 422); communication barriers (422-423); community attitudes (423); geographical isolation (423); and difficulty in finding a medically suitable donor (74, 197-198, 347).

Consistent with previous NZ research (74), health professionals in this research commented that their impressions were that one of the main issues for Māori and Pacific patients was the difficulty of finding a medically suitable donor rather than cultural barriers or patient preferences:

*I haven’t ever come across any cultural barriers. Māori and Pacific people usually turn up with more potential live donors than other people do I think. It’s just that they get ruled out for medical reasons. I remember one poor woman who had 13 brothers and sisters and the half that were still alive had all been ruled out as live donors. So, no, I don’t think so.*

The Māori and Pacific patients in this research, by definition, had all made it through the evaluation process and wanted a transplant. They were similar to Pākehā/European patients in terms of preferences for LDKT and the donor recruitment activity they had
engaged in. Patients of all ethnic groups were more likely to discuss donation with others
than ask directly and to comment that approaching others about donation was very difficult.
Māori were nearly as likely to have received at least one offer to donate as
Pākehā/Europeans, but Pacific people less likely to have, and less likely again to have
anyone go on to start the work-up process.

Māori and Pacific patients discussed a similar range of issues as other patients: not
approaching potential donors and/or turning down offers out of concerns for donors;
incompatibility problems; and medical unsuitability. Pacific interviewees seemed especially
likely to have turned down offers, and Māori and Pacific patients were less likely to have
heard of KPE and had turned down offers from people from the “wrong” blood group.

The requirement for high levels of patient activation and possibly health literacy may be
issues in LDKT, given findings that on average Māori have lower levels of health literacy than
non-Māori (424). This has also been identified as an issue for indigenous Australian dialysis
patients who often wait for information rather than actively seeking it out, which is wrongly
interpreted by health professionals as lack of interest by patients about treatment options
(425).

Barriers to transplantation are often thought to be linked to cultural values. Previous NZ
research cautions against assuming homogeneity of views about transplantation within
Māori and Pacific populations (74, 426) and of assuming that attitudes to living and
deceased donation are necessarily the same (427). It is also important not to assume that
the factors affecting transplant rates are necessarily the same for Māori and Pacific patients.
The patterns in this research, especially the very low conversion rate from offers to tests
reported by Pacific patients, suggest that there may be different factors affecting how
successful these two groups are at finding willing donors and emphasise the need for
approaches which are tailored to the situations, knowledge and concerns of individual
patients and their families.

6.2.1.4 Ongoing engagement about LDKT
Timing was a significant theme. Some patients had not been ready to consider
transplantation early on, particularly Māori and Pacific patients (similarly to African-
American patients (226)). Patients reported being overwhelmed by their diagnosis of ESRF
and starting dialysis. Sometimes chance discussions with family, friends or other recipients caused them to change their minds about pursuing a transplant and being waitlisted, rather than systematic reassessment by the renal unit.

Patients reported a common pattern of significant engagement by the renal unit as they were approaching ESRF or just starting dialysis but often little further mention of LDKT after these initial discussions. Some health professionals referred to a “window of opportunity” for getting a LDKT, because of the higher salience of the need for transplant amongst family. Motivation to consider donation at this time was thought to be particularly high.

If no donor is found early on, it may be assumed by health professionals that no one is interested in donating, with people on the list being described as “not having a donor”. After this initial period of activity, therefore, many patients reported being left to “get on with dialysis” and wait for a DDKT. Many described a sense of isolation and abandonment and a definite reduction in focus on LDKT.

It is true that some people are harder to transplant than others, for example, highly sensitised patients face additional compatibility barriers and those with genetic forms of kidney disease will find it more difficult to find a medically suitable donor amongst their family. However, “not having a donor” should not be regarded as a fixed state that cannot be altered.

Patient preferences, attitudes and willingness to accept an offer often changed over time. People talked about turning down potential donors earlier on that they might now consider, having realised what life on dialysis was like, or accepting donors they would previously not have considered. Many of those interviewed were still talking to people about donation (although this reduced over time), thought they might still have potential donors, were still getting offers, and were thinking about how to revisit earlier offers. Most people were very interested in learning about alternative ways to approach potential donors indicating that they did not feel they had exhausted their options and had not given up hope of LDKT.

The so-called “window of opportunity” may in part be a construct of the way the service is delivered – it is health professionals, rather than patients and their families, who seem to give up on LDKT as an option for patients after a certain point. If providers are no longer
encouraging or mentioning LDKT, patients may well lose motivation as well. Ongoing and active engagement with patients about LDKT is recommended by a number of researchers internationally (180, 182, 192, 235, 428) and the research here suggests that many NZ patients may also benefit from such an approach.

6.2.1.5 Lost opportunities and points of intervention

In deceased donation processes, it has been estimated that there are nine decision points for donation, with a range of different types of interventions that might minimise the “lost opportunities” at these critical points (292). There is a more clearly defined window of opportunity in deceased donation, and the steps in the process are more uniform. In LDKT, identification and recruitment of donors can take place over a long period of time, occurs largely outside health-care settings and may be subject to multiple influences. Nevertheless, there are several steps where opportunities may be lost, and where interventions may be possible including: patients not being ready to consider transplantation early on but limited opportunities later for revisiting it; inconsistent systems for reviewing dialysis patients or suspended patients for suitability; patients not having the right information to give them the motivation, skills or knowledge to pursue LDKT effectively; failure to consistently and systematically inform patients’ networks; offers to donate being made but not converted to tests; potential donors making contact with transplant coordinators but not proceeding; and donors being ruled out for incompatibility but not being offered KPE.

The process of finding a willing donor (Stage 3), in particular, involves several sub-steps rather than being a one-off event:

- Potential donors who have never considered LDKT or are not aware of the need for donation – how to make potential donors aware of the need for donation is the key issue, with the current system relying almost entirely on patients themselves to raise LDKT with their networks;
- Potential donors who may be considering living donation, including making an offer, but have not yet contacted at transplant coordinator – many potential donors spend considerable time discussing living donation with others or reading about it prior to contact with transplant programmes (281). Information comes from patients, their
own family and friends, GPs, the internet, and mass media. Patients may turn down people for many reasons and financial barriers may deter both patients and donors;

c) **Potential donors who contact a transplant coordinator** – it appears that many potential donors may make initial contact with a transplant coordinator and then decide not to proceed. There is no NZ data on how often this happens or, critically, why, because of a common policy of not following up with people who do not continue the process for fear of being seen to “chase donors”;

d) **Potential donor who begins the work-up process** – this research, and previous research suggests that, beyond a certain point, donors who start the work-up tend not to drop out (281). Both potential recipients and donors have overcome major concerns by this point and incompatibility or medical unsuitability may be more significant barriers.

Conversion of potential donors into transplants is a critical issue in LDKT and identifying possible improvements in services, policy or wider system settings is necessary. Further research with potential donors would be beneficial. Those who make contact with a transplant coordinator or start the work-up process could be asked what is the quality of the initial contact like? How easy is it to contact a transplant coordinator, are messages returned, what sort of information is given, do potential donors feel welcomed and encouraged or that they are getting in the way; is a sense of the importance of LDKT conveyed, are there language barriers? How easy is it for potential donors to get to appointments (time off work, travel costs), are they experiencing pressure from their own networks not to proceed?

Although there is still more research to be done, it is possible to suggest some options for improvements, particularly in the key area of how to widen the pool of potential donors, the most significant constraint in any transplant programme.

6.2.1.6 **Widening the pool of potential donors**

Even with very little support for the donor recruitment task, most listed patients reported receiving at least one offer from someone willing to consider donation, and many had received more than one offer. For a range of reasons, none of these offers had resulted in a successful transplant and few patients reported anyone still being worked-up.
Some people are lucky enough to find a suitable donor immediately; others have multiple people tested without finding anyone suitable. However, there is currently an overreliance on luck and approaches to donor recruitment are somewhat “hit and miss”.

It is often assumed that the main barrier to LDKT is that patients have no one willing to donate to them. The finding that most waiting-list patients had had at least one offer, and more than half had had someone tested, tends to not support that argument. However, the key issue for all potential recipients is how to widen the pool of potential donors.

There may a number of explanations for why more people do not come forward to consider donation, including that potential donors are not always aware of the need for a donor and/or are not aware that they themselves could donate because no one has discussed it with them; that patients have turned down offers through misinformation or unaddressed concerns; or that willing but unsuitable donors (e.g. incompatible) have not been able to be utilised. Previous research (157) has found that assumptions that the absence of an unsolicited offer from a potential donor implies lack of willingness to consider donation, may be incorrect. Thus, Gourlay et al (180) comment:

> An enormous pool of potential live kidney donors exists for patients who are currently waiting for a cadaver kidney transplant. Educational strategies designed for wait-list patients may correct knowledge deficits and alter unfavourable beliefs about LDKT which, in turn, may increase their willingness to seek and accept an offer of live kidney donation (p.2511).

Getting an offer appears to be related to whether patients had talked about living donation with their networks, how widely they had discussed it, and the quality of the conversation. For many people, knowing how to initiate, respond to, or follow-up a discussion was a barrier. There may be two critical factors interacting: how direct the discussion about living donation is; and the level of prior knowledge of LDKT amongst the patient’s networks. As Siegel et al (429) note, interventions are needed to make the possibility of living donation more salient to people because “even with a friend on dialysis, the possibility of living donation may not be explicitly evident to individuals (p.95).
The difficulty most patients report in even having a direct discussion with their networks is, therefore, a significant barrier to LDKT. Little support is available for patients and many said they would welcome ideas about how to raise the subject. There is significant pressure on patients to be well-informed about living donation, and to be able to answer questions over a long period of time before transplant coordinators become involved. Many felt embarrassed about being in the position of having to “sell” the idea of living donation.

There is no single solution to how to widen the pool of potential donors and a package of initiatives is needed that can address diverse situations. Leichtman et al (83) suggest:

*Small increments in several or all of the potential donor sources...have the capacity when considered collectively to markedly increase kidney availability for transplantation (p.954).*

Options for widening the pool of donors are summarised in Figure 10.

### Figure 10: Options to widen the pool of donors

- Allow unrelated/non-directed donors - already permissible in NZ
- Remove financial barriers for donors
- Greater use of medically-complex donors - not recommended
- Information, education and support for patients and their networks
- Raise general awareness about LDKT
- Improve access to KPE to enable greater utilisation of incompatible donors

#### 6.2.1.6.1 Removing financial barriers for donors

Internationally there seems to be some correlation between the global financial crisis and lower rates of donation amongst lower-income people, although there is little direct evidence because people who decide not to donate are rarely known to transplant centres. NZ’s universal publicly-funded health system removes many of the barriers seen in insurance-based systems since direct costs of the treatment plus travel and accommodation are covered. However, lost income is only partially reimbursed. Potential donors were not
included in this research but financial issues for donors create significant barriers for patients, affecting both their willingness to approach others about donation or accept offers. Transplantation may also be delayed while families save to cover the donor’s lost income, which may affect transplant outcomes. Donor hardship as a result of transplantation is not uncommon and governments must consider whether it is feasible or justifiable to have policies to increase rates of LDKT without protection from financial harm, which is now considered to be part of donor protection (45). Policies of reimbursement for donors should be considered within a wider LDKT policy, rather than simply being added to existing income-support frameworks (e.g. the benefit system or accident compensation system) which were not designed with living organ donors in mind.

6.2.1.6.2 Information, education and support for patients and their networks
Interventions with patients and their networks currently appear amongst the most promising initiatives. These encompass two broad inter-related aspects: improving the consistency, quality, content and timing of discussions with patients about ESRF and RRT options; and initiatives aimed at supporting donor recruitment activity.

a) Discussions with patients about ESRF and RRT

Increasing recognition is being given to improving the education patients receive about their illness and their RRT options, including comprehensive information about all options with clear information about risks and benefits. Accurate knowledge and positive beliefs have been found to be progressively associated with getting offers from potential donors, having someone evaluated and actually receiving a transplant. For example, in comparison to transplant recipients, waitlisted patients are more likely to believe that offers are made out of guilt or family pressure, that parents should not receive kidneys from their adult children, that recipients should not ask for a kidney, and that donors experience long-term health problems as a result of donation (180).

There has been a history of role segmentation, with pre-dialysis nurses educating patients about dialysis and transplant coordinators educating people about transplantation. Emphasis is now turning to comprehensive education about all options and involvement of patient networks. Pre-dialysis nurses, in particular, may be reshaping their traditional role of dialysis education and taking a greater role in transplant education (244).
The timing and quality of discussions health professionals have with their patients, especially as they are approaching ESRF, are critical for shaping patients’ decision-making and approach to LDKT. The consistency and quality of patient-provider discussions seemed variable, with many people listed for transplanting reporting that LDKT had not been discussed with them. Even where a discussion had taken place, it was often felt that discussion was superficial, not really relevant to them or that they did not have a chance to really talk about the issues concerning them. Previous research suggests that just being given information about transplantation is not effective education, with the quality and content of communication being critical (425).

Understanding what patients are concerned about is important so that their specific concerns can be addressed. Patients reported wanting more information about LDKT, often about matters that the renal unit had not anticipated, such as the practicalities of donation. Many patients were worried about how donors would feel if the transplant failed. In some senses, this is a realistic fear since previous research suggests that in the small number of cases where donors report regretting donation, this is typically linked to the failure of the transplant or death of the recipient (33). However, in NZ, the risk of transplant failure is in fact very low, with outcomes of around 95% graft survival rate at year one and 90% at year five (20). This needs to be emphasised to patients.

Providing accurate, objective information does not mean portraying all options as equally good if they are not (262), but outcomes of different treatment options may not always be made clear to patients. These conversations can be challenging, and respondents noted that clinical training did not always include communication skills for difficult conversations.

As well as factual information, education must address patients’ beliefs about living donation and their specific concerns. This research suggests that one size does not fit all and that approaches need to be tailored to individual patients to take into account their particular gaps in knowledge, beliefs, concerns and where they are in the process. Standardised group education sessions may have an important role but cannot substitute for in-depth, one-on-one discussions.

Health professionals appeared equivocal on how actively they would challenge a patient’s beliefs about living donation, e.g. the acceptability of approaching potential donors or of
accepting offers from certain people. Hilhorst et al (262) argue that “active interference in people’s personal lives is justified – if not obligatory” (p.81). They suggest that counselling of patients might include challenging beliefs by asking questions such as, “How can you be so sure that he doesn’t want to donate if you haven’t discussed it?” or “Why don’t you give your friends the chance to decide for themselves whether they wish to become donors?” or “Why don’t you give your son the opportunity to help you?” (ibid, p.85).

Consideration is needed of how ongoing, active engagement of dialysis patients (on or off the waiting list) is achieved and who else needs to be involved, such as patient groups, previous donors and recipients, and other health professionals involved with the patient who need to provide consistent messages about LDKT.

b) Interventions to support donor recruitment

Closely related to the discussions with patients about ESRF and RRT, are interventions that are aimed at supporting patients in the donor recruitment process. A key message for patients should be that asking people directly to consider donation is not necessary. The survey suggests that there was about the same likelihood of receiving an offer if patients had asked directly as if they had had a discussion. Although both approaches appear equally effective, the reluctance of most patients to ask suggests that advising them to do this may deter them from any action at all. Emphasising that asking directly is not necessary may alleviate the concern patients have (430).

There is no single answer to how best to support the donor recruitment process. Evaluative information is relatively scarce and many initiatives are still being trialled. Patient circumstances and preferences vary and change over time suggesting tailored, flexible approaches are necessary.

The approaches discussed in Chapter Three included:

- Systematically and consistently encouraging patient networks to attend clinics with patients;
- Training of patients in how to initiate discussions, write emails or letters, role-playing;
- Training donor champions to act on behalf of patients;
• Opportunities for group and one-on-one discussions;
• Family meetings;
• Home-based facilitated education sessions;
• Using Facebook;
• Opportunities to hear from previous donors and recipients – individual and group meetings, written information, DVDs, online resources, donor associations;
• Having on-line forms for potential donors to register their interest, which patients can send to their networks;
• Designated staff to work with patients to develop LDKT action plans and monitor over time;
• High-quality, accessible on-line information.

A key challenge is how to convey information to patient networks where there has not already been an approach to a transplant coordinator by potential donors. Facilitated home-based education sessions about renal disease and treatment options appear to be a promising mechanism for informing networks without relying primarily on patients. Research suggesting many potential donors search for information themselves on the internet and spend on average six hours reading about and 32 hours discussing LDKT before contacting a transplant coordinator (281) highlights the need for easily accessible, high quality on-line information (431).

6.2.1.6.3 Raising general awareness about LDKT
Promotion and public awareness are usually key planks of strategies to increase organ donation. An assumption that increased education or knowledge of the general public will result in specific desired actions may be too simplistic (303) but raising awareness may have more indirect benefits. Public education is regarded as part of the Spanish success story by raising awareness and contributing to positive discussions within families so that the death of a loved one is not the first time families have heard about or thought about organ donation (432).

General education about LDKT could have multiple purposes, including: prompting people to consider non-directed donation; prompting someone to consider donation to someone they know who already needs a transplant; or creating positive public attitudes and
maintaining a level of salience should someone they know need a transplant in the future. This may extend to the networks of people considering donation, since they can often be an important influence on potential donors, whether friends, family or other health professionals (e.g. GPs). This research suggests that some prior awareness facilitates discussions about donation amongst patients and their networks.

Relying on the media to “tell stories” may be ineffective given a tendency to sensationalise stories about organ donation. Simply telling stories about previous donors and recipients may also not necessarily address myths and misconceptions about LDKT. Widespread publicity about NZ’s most famous donor-recipient pair, Jonah Lomu and friend Grant Kereama, does not seem to have been sufficient to dispel the common view that donors must be genetically related. Any promotion and education campaigns, therefore, should be underpinned by careful research about messages, target groups and effective methods of imparting information.

6.2.1.6.4 Improve access to KPE to enable greater utilisation of incompatible donors
Chapter Four notes that NZ’s KPE scheme has been slow to develop, with few pairs in the pool and only two exchanges so far. The programme in place has been a “bottom-up” initiative without the necessary support from central government for infrastructure and funding. Legal barriers were only removed in 2012, despite the scheme existing since 2009. Population size may be a barrier to an effective scheme (but also an advantage because national coordination should be easier) but does not entirely explain the very small number of patients in the scheme after three years. There are logistical challenges in all KPE schemes but it is likely that many of the barriers in the NZ scheme are simply extensions of wider barriers to LDKT.

The low chance of achieving a transplant through the KPE scheme may be causing some health professionals not to promote KPE or deprioritise donors being worked up for it. This creates a vicious circle because the fewer pairs in the scheme, the less it is promoted.

How much of an impact a KPE scheme might have in NZ is unknown and part of the funding announced in Budget 2012 (Chapter Five) is to be used to model what might be possible in NZ. There is no suggestion that it is the total answer to the problem of low rates of LDKT. However, failure to maximise the potential of such a scheme not only represents a missed
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opportunity but may also carry other risks by creating false hope for patients in the scheme, or those trying to get into it, and cause them to stop exploring other options for LDKT.

6.2.1.6.5 Using medically complex donors
There are always complex clinical judgements about the application of general guidelines to individuals. However, widespread use of marginal or medically complex donors because of organ shortages raises ethical concerns, especially given the shortage of evidence about long-term outcomes for these donors. Supporting patients to recruit from a wider pool, especially patients from risky networks, is an ethically less challenging approach (347).

6.2.2 Research Question 2: Attention to LDKT: Getting on the agenda
Chapter Five suggested a number of factors that may have influenced the relative lack of attention to how to increase rates of LDKT, at least up until 2011. These findings, however, must be considered in a broader context. For example, many of the challenges identified may not be unique to LDKT but may apply more broadly to other parts of the health system. LDKT also needs to be seen in the wider context of other forms of human tissue donation, particularly the predominance of deceased organ donation in policy discussions. This requires consideration of both international and historical factors, as well as NZ’s approach to organ donation more generally. These contextual factors are discussed in more detail below.

6.2.2.1 Findings in the context of the wider health system

6.2.2.1.1 Where to focus efforts
Both the MOH and DHBs face a constant challenge about where to focus their efforts. They are expected to focus on certain priorities, such as Ministerial targets, yet are responsible for delivering the full range of expected health and disability services. There may be a tension between exhortations (399) for the MOH to identify “the vital few priorities or changes that will create most value for the future of New Zealand’s public health” (p.35), and the sheer breadth of health issues.

Consistent with previous research (388), this research suggests that Ministerial priorities are a significant driver of DHB decision-making. For government departments, there has also been an increasing trend towards policy advice being focused on responding to Ministerial priorities rather than being more proactive or strategic about raising issues that are not already on the agenda (395).
Issues not on the agenda are unlikely to have anyone responsible for doing analysis and advice in departments, as reflected in comments from several respondents that LDKT “just wasn’t on the work programme”. There is an element of “Catch 22” here: policy resources may not be assigned to an issue unless it is already a Ministerial priority; but Ministers require at least an indication of options (which require analytical capacity) before they put an issue on the agenda. It may be difficult to break this cycle and it is unlikely to be unique to either LDKT or the MOH.

The MOH faces the problem of how to maintain capability on issues that are not on the agenda, as well as whether it is feasible to maintain ongoing in-house expertise on every subject in health. A lack of clear responsibility and subject expertise may not be unique to renal issues or transplantation. Respondents noted that with such a vast range of issues, it was difficult for MOH to maintain adequate capability on everything and there were other disease or service areas that had no “home”:

An analogy is respiratory now or frankly arthritis; we get stuff coming in all the time. Where does it sit? It’s a ping-pong game because there isn’t any obvious place for it to go to.

More broadly, a focus on the “vital few” by both MOH and DHBs may lead to a situation where large portions of the health system (representing significant expenditure) end up being largely ignored. Continuous improvement in all services, improving clinical outcomes and enhanced cost-effectiveness should be goals in all parts of the health system but there are risks if efforts to improve VFM are limited to “the big issues”.

6.2.2.1.2 Adding value
The MOH approach to LDKT has been largely passive but this cannot be explained entirely by it not being a Ministerial priority. Officials did not raise the issue even when organ donation was on the political agenda; for many years there seems to have been little assistance to resolve problems when requested by clinicians; options such as reimbursement for donors were rejected largely because of concerns raised by another agency but no other options were put forward by the MOH; and when advice has been given, it seems that presenting problems and solutions were simply accepted.
There is a significant body of literature which espouses the view that public services should be actively aimed at creating “public value” (433-434). Value-adding policy advice requires an approach to policy that is generally proactive, seeks opportunities and does not simply accept presenting problems or solutions (92).

The recent review of the MOH (399) commented that it was important that the Ministry “inculcates a proactive culture in which staff look for innovation in provider sectors, support it by quality analysis and systematise it as appropriate” (p.23).

This may relate to long-standing concerns about MOH’s policy leadership role in the health system. Gauld (79) notes concerns about gaps in strategic policy and leadership from the MOH in the late 1990s. A theoretical distinction between policy and implementation was introduced in the 2001 health sector reforms, with government as policy developers and DHBs as implementers. A review of the reforms (435), however, found “a significant gap between general policy frameworks and implementation detail with DHB staff asking for more detail rather than less” (p.51). More recently, the MOH review (399) noted that the agency needed to become “an enabling agency with a well-informed policy ‘brain’ and a willingness to lead the sector on complex and controversial issues” (p.9).

The purpose of policy analysis is to support decision-makers (138) which, in a devolved system, includes DHBs as well as Government. MOH analytical support for DHBs has been identified as an issue because DHBs had limited capacity to carry out Health Needs Assessments (388, 436) or robust prioritisation processes once these functions were dispersed from the Health Funding Authority to the DHBs (437).

The MOH remains the key policy advisor in the health system. The review (399) suggests it should be seen as “the first, best source of advice on health policy and performance” (p.10). Without the MOH taking an active role in providing analytical support or leadership on complex problems, there is a gap in the system. In the case of LDKT, this has contributed to the absence of leadership and lack of ideas in the “primeval soup”. However, this is likely to reflect a wider issue about the role of the MOH in adding value in the health system.
6.2.2.1.3 Funding arrangements

It is difficult to know exactly what impact funding and pricing arrangements have on the willingness of DHBs to address the question of how to increase rates of LDKT. It seems that the inherent financial incentive to increase LDKT rates is not able to be realised and there may even be disincentives in the system. These stem from a mix of pricing issues, the short-term horizon of health planning and funding, and a lack of clarity about how rhetoric such as “bending the curve” can be achieved and measured. All these issues are now exacerbated in the current financial environment as DHBs grapple with the requirements to make efficiency gains. There is a risk that rather than providing a burning platform for increased VFM, the health system will turn towards short-term, cost-containment measures.

A further reason to properly address any funding and pricing arrangements is that they have been identified as a major barrier by clinicians, many of whom have devoted considerable time and energy trying to resolve the problems. Ensuring the right incentives in these arrangements should be core business for the MOH/NHB to resolve and would free up clinicians to focus on other aspects of the problem of how to increase rates of LDKT.

Although a national funding model has been proposed, consideration could also be given to regional funding and accountability arrangements for renal services so that costs and benefits for dialysis and transplantation are not separated across DHBs. This would not only remove the current financial disincentive but actually allow the incentive to be realised. Importantly, dialysis and transplantation would not be “decoupled” and the financial benefits of transplantation would be more transparent. Budget settings that encourage a longer-term perspective and a more sophisticated discourse about “bending the curve”, including modelling that would enable assessment of the counterfactual, would also be beneficial. These issues have relevance beyond the issues of LDKT alone.

6.2.2.2 Findings in the context of organ donation policy

6.2.2.2.1 The predominance of deceased donation in organ donation policy

One of the issues raised in Chapter Five was that attention to LDKT, especially amongst central government policy-makers, could be “crowded out” by deceased organ donation. This greater attention to deceased donation is not necessarily unusual in organ donation policy internationally. National organ donation organisations often have no mandate over
living donation and are typically established to address deceased donation (179, 438). Organ donation taskforces, legislation and policy documents are often focused almost entirely on deceased donation.

In NZ, there are more forms of central oversight of deceased than living donation. ODNZ has formal responsibility for national coordination of the deceased donor organ system, and has formal accountability arrangements with the MOH (150). The NZ Kidney Allocation Scheme also has formal arrangements with the MOH including a funded Medical Director (232). In contrast, ODNZ has no mandate over LDKT and there are no other equivalent arrangements for living kidney donation. Human tissue legislation is focused almost entirely on deceased donation, but there is very little regulation which relates to living donation.

There are several reasons for the generally greater level of attention to deceased, rather than living, donation in organ donation policy, e.g. that for many types of organs, a deceased donor is the only possible source for a transplant.

Deceased donation systems in general have a more public foundation than living, with longstanding and distinct normative, ethical and legal foundations (18). Although there are differences between countries in the details of how procurement and allocation are organised, Boas (119) suggests that all legislation is based on the notion that deceased donor organs are seen as “social goods which are held by the medical team ‘in trust for society’ and are allocated objectively to patients in need” (p.1379).

Living donation is a more private matter, since, historically, living donors have only donated to a particular individual with whom they were already in a close relationship. Hilhorst (419) comments that there are effectively two transplant systems in place: a public deceased donor system based on the principle of impartiality in both the acquisition and allocation of organs and a private, living donor system. “Living transplants are, strictly speaking, carried out within a private context: living programmes facilitate, support and effectuate private organ transactions between individuals” (p.484).

The acquisition and allocation of organs in these two systems are also handled quite differently. Living donation programmes have historically had no role in “acquisition” since for many years, the donor pool for a given patient has been restricted to immediate family.
There was no need to put in place measures to identify and inform other potential donors or “motivate” them in any way because the few people who were eligible were assumed to already know about it and be sufficiently motivated to donate. Thus, transplant services simply waited for potential donors to come to them with the patient (439).

Nor is there a need for the fair and transparent allocation algorithms and protocols required by deceased donor programmes, again because living donation is generally directed towards a specific recipient. Acquisition and allocation policies and protocols may be developed by national organ donation organisations as in the USA (438) or delegated to health professional groups as in NZ. Either way, they have historically demanded more oversight and governance than living donation.

At a practical level, deceased donation has also required institutional arrangements to deal with logistical and coordination issues such as matching donors and recipients, or transporting organs between transplant centres (18, 119).

The introduction of KPE has, for the first time, required similar logistical, allocation and ethical arrangements as for DDKT, and it is therefore often through KPE that existing organ donation organisations first become involved in living donation. Successful national KPE programmes will require a paradigm shift in LDKT (319). As Segev (cited in Sack (440)) argues, “this is organ allocation….They’re deciding who lives and who dies”.

It is also no longer possible to ignore the fact that in many countries LDKT makes up an increasing proportion of all renal transplants, leading, as Glazier (441) says, to an “increased legal and regulatory focus on living organ donation” (p.209). Hilhorst (419) notes that private, living donation may be seen as “merely” supplementing the public deceased donor scheme, but the scarcity of deceased donors means that, for kidneys, DDKT “is losing its once-obvious predominance” (p.485), requiring a shift in policy thinking.

Overall, LDKT is moving from being seen as primarily a private matter between family members to a legitimate area of public policy interest, both to ensure quality and safety but also as part of the mainstream response to the demand for kidneys (292). This may result in a greater focus in NZ, possibly already reflected in the developments in 2011-12.
6.2.2.2 NZ’s general approach to organ donation

LDKT must be seen in the wider context of NZ’s approach to organ donation. The high proportion of renal transplants that come from living donors could be regarded as indicating a highly successful LDKT programme, but needs to be seen alongside the fact that NZ’s deceased donation rate is one of the lowest in the world. Any increases in LDKT have barely been enough to compensate for the decline in DDKT numbers. While deceased donation alone is unlikely to be sufficient to meet demand, a rate of 8.6 pmp raises questions about whether this is the maximum that can be achieved.

It is unclear why NZ’s rate of deceased organ donation is so low or what the potential to increase the current rate might be (e.g. how many families refuse donation (442)). While cultural attitudes may play a role in rates of deceased donation (e.g. Japan’s low rate is generally associated with widespread cultural attitudes towards death (15, 18)), international experience consistently points to deceased donation rates being strongly related to policies, systems, processes and practices. Commenting on the variation in rates in Europe, Farrell (443) notes that, “such variability cannot be easily explained in terms of general or specific mortality rates or religious and/or sociocultural differences” (p.230).

Thus, while NZ, like many other countries, has paid less attention to living donation than deceased in its policy processes, the very low rates of deceased donation may suggest a wider issue in the overall approach to organ donation policy and practice which cannot be ignored. It can be argued that it is unethical to rely more on living donors without seeking to maximise deceased donation as well. International guidelines (107) often stress that, while living donation is ethical, the priority should be to maximise deceased donation. It may, therefore, be considered problematic to ask living donors to make up an increasing shortfall in supply if deceased donation is not being optimised.

This research did not include a systematic analysis of the policies of other countries so it is not certain whether NZ has paid less attention to organ donation than other comparable countries. There do, however, seem to be many more examples of initiatives funded and mandated by governments aimed at increasing organ donation numbers (deceased and living) in other countries than in NZ. There have been organ donation taskforces in the UK (406), Australia (444) and the Netherlands (43); Breakthrough Collaboratives to increase deceased organ donation in the USA (372) and Australia (444); the WHO Madrid Resolution
on self-sufficiency; and an EU directive on organ donation (443), which includes deceased donation led by Spain and living donation initiatives led by the Netherlands.

There is some evidence of generally greater regulatory oversight of LDKT in other countries. In 2000 and 2004, it was noted that NZ was one of the few countries with a LDKT programme without specific legislation (96, 294), while regulation to ensure assessment and care of donors is in place in several countries (e.g. the UK (292), Finland (263) and recently, the USA (445)). In terms of actively promoting LDKT, governments in many countries have removed legislative barriers to KPE and invested in the necessary infrastructure to support these programmes, something the NZ Government only started to consider in 2012. The UK Government has had a campaign to promote LDKT since 2005 (446) and in 2010 appointed a lead clinician with specific responsibility for developing and implementing a strategy to increase LDKT rates there (364).

Overall, NZ seems to have given less attention to LDKT than have many other countries. Whether this reflects the highly devolved nature of our health system, general approach to organ donation or something else is not known. While there may be advantages to this lack of attention (e.g. that clinicians have been able to get on and establish an LDKT programme without excessive interference), it is possible that, as in other countries, this approach has reached its limits. The low rate of deceased organ donation raises wider questions. Without wider concerted effort, NZ’s rate of LDKT may continue to decline, in contrast to other countries that are seeing sustained increases.

6.2.3 Ethical issues

6.2.3.1 The role of ethics in policy and practice

This research did not set out to answer a specific question about the role of ethics. However, this issue emerged as a significant issue in shaping policy and practice.

As noted in Chapter One, there are many ethical issues in LDKT but the key concerns are the safety of donors and the possibility of coercion. Ethical issues in LDKT have always had to be considered at two levels. Firstly, the unique role of medical professionals meant they needed to ask themselves whether it was permissible to perform such surgery, even with the donor’s consent, and secondly, society needed to decide whether consent could ever legitimatis living donation (18).
Attitudes at both these levels have become more positive, particularly as more evidence about outcomes for donors has emerged. LDKT is now widely agreed to be ethically acceptable in the right conditions. Commentators suggest that LDKT is now part of the mainstream response to the organ shortage (292, 447). Price (292) notes, for example,:

_The contemporary era of LDT in the UK is one characterised by explicit endorsement and direct regulation....Rather than mere grudging tolerance of it as a “necessary evil”, LDT is now one of the main planks of official transplant policy, supported by discrete funding for dedicated personnel at identified health-provider locations. The UK and many other European nations are actively promoting living organ donation to help boost transplant rates (p.256)._

Ethical issues, nevertheless, remain a critical part of the LDKT environment (31), with new issues arising every time a new class of donors or innovation are considered (295), such as non-directed donors, KPE, and medically complex donors.

It is also necessary to consider how ethical concerns shape existing services. Often the detail of how to protect donors on a day-to-day basis is up to health professionals to resolve. Price (292) suggests that clinicians’ sensitivity to ethical issues “have proved effective against over-zealousness” (p.259), building services that are both safe and trustworthy, e.g. through clinical guidelines for the assessment, selection and follow-up of living donors (112) and protocols to prevent pressure or coercion (104).

However, there is a possibility that this sensitivity to ethical issues has resulted in elements of passivity in services, particularly in relation to the appropriate role of transplant programmes in addressing the issue of donor supply and interactions with potential donors, summed up by one clinician in this research as “live donors come to us; we deal with them”.

Examples in this research included the reluctance of health professionals to suggest living donation to potential donors; a view that information about living donation should be provided to potential donors who had approached a transplant coordinator or expressed interest in donation but not before; a reluctance to follow-up potential donors who do not complete blood tests or miss appointments, because this would be “chasing” donors and a form of “coercion”; deliberate slowing down of work-ups; and an expectation that potential
donors should “drive the process” as a way of demonstrating their commitment to donation.

There are difficult judgements on many of these issues. Perceptions of coercion are subjective and vary between individuals. Some transplant coordinators in this research felt they were walking a “fine line” and thus tended to err on the side of caution. Others thought concerns were overstated and disagreed that giving people opportunities to donate or following-up potential donors was coercive.

However, what seems like caution from a health professional’s perspective may send mixed messages to potential donors (who may perceive a lack of interest in their offer), requires high levels of activation from both patients and their networks, and may miss opportunities to provide support to willing donors who are facing barriers. Protocols to avoid coercion such as continually telling potential donors that they may withdraw at any time, while reassuring, can also be off-putting, with one study of donors (280) finding that “the repeated information that they could withdraw was sometimes annoying and regarded as a doubt about the decision” (p.1710).

This caution might also be interpreted as representing some ongoing ambivalence about LDKT. Sanner (280) argues that the delays in donor work-ups, constant questioning of a donor’s decision, lack of support for donors during the work-up and after the transplant, could be seen as indicative of health professionals’ “ambivalence toward the whole idea of living donation” (p.1712).

Transplant health professionals are in a difficult position. Not only do they have a duty of care to donors, but there is a long history associating transplanters with resurrectionists or body snatchers (18, 99). Any perception of taking organs, living or deceased, against someone’s will can undermine trust and confidence in the transplant system.

However, passive or ambivalent approaches to services are inconsistent with the need for vision and commitment to a goal of increasing rates of LDKT. The impact of health professionals’ ethical concerns on transplantation practice was highlighted by the UK Organ Donation Taskforce (406) which included a recommendation “that all clinicians are
supported and are able to work within a clear and unambiguous framework of good practice” (Rec.3). Farsides (448), a member of the Taskforce, notes:

...in order to understand fully the obstacles to delivering a good service in any sphere, it is important to understand the motivations and impediments of those who carry out the labour required to make it happen. Either explicitly and consciously, or implicitly and subconsciously, the moral attitudes of healthcare professionals can shape the service they provide both locally and nationally....It is therefore extremely important to remember...that in the context of organ donation and transplantation there is the potential for those involved to feel conflicted over a number of different complex moral issues relating to the recruitment and treatment of donors (pp.216-7).

The Taskforce’s recommendation was specifically in relation to aspects of deceased donation, but this research suggests that similar support on living donation would also be beneficial.

The UK has established a Donation Ethics Committee, which includes health professionals, ethicists, living donors and recipients, to provide independent advice and guidance on ethical aspects of organ donation and transplantation (449). In NZ, resolving organ donation ethical issues has been primarily up to health professionals (and this has been the MOH’s previous advice (400)). It is questionable, however, whether it is reasonable to expect health professionals to drive service change without support for resolving ethical issues, when their unique and pivotal role in the process constrains what they feel they can ethically do to promote LDKT.

One senior clinician interviewed suggested:

If I had a budget and time to set out to change this, I would probably run some kind of session and I would line up some good, hot ethicists....I think the right kind of ethicist is really valuable to clinicians... because what you’re doing is saying, “we understand that you unconsciously have some ethical issues here, so here’s somebody that’s going to make that conscious and talk about it”....Most clinicians are not equipped to make ethical decisions; they don’t understand the science of it
and they know that and they’re nervous about it, so they default to erring on the side of caution.

Mechanisms for advising on ethical issues would be beneficial for clarifying what is ethically acceptable practice. This would also benefit the MOH which has in the past suggested that reimbursement for donors would undermine the principle of altruism, a position not supported by ethicists (105).

Guidance on ethical issues requires analytical frameworks so that specific issues can be identified and discussed. For example, the Nuffield Council of Bioethics (105) developed an intervention ladder (Table 15) to help assess the ethics of different interventions for promoting donation of bodily material.

| Table 15: Nuffield Council of Bioethics "Intervention Ladder" for promoting donation |
|---|---|
| 6 | Financial incentives that leave the donor in a better financial position as a result of donating |
| 5 | Interventions offering associated benefits in kind to encourage those who would not otherwise have contemplated donating to consider doing so |
| 4 | Interventions as an extra prompt or encouragement for those already disposed to donate for altruistic reasons |
| 3 | Interventions to remove barriers and disincentives to donation experienced by those disposed to donate |
| 2 | Recognition or gratitude for altruistic donation, through whatever methods are appropriate both to the form of donation and the donor concerned |
| 1 | Information about the need for the donation of bodily material for others’ treatment or for medical research |

Source: Nuffield Council of Bioethics (105)

Similar frameworks may assist in discussing issues such as what constitutes coercion, which is heavily debated in LDKT (96, 450-451), including how best to raise living donation with a patient’s networks or how to follow-up with potential donors in ways that do not place undue pressure on people.
Options for alternative ways to support donor recruitment (as discussed above), other than health professionals having to ask potential donors directly, might also reduce ethical concerns. Involving non-health professionals in donor recruitment initiatives may be helpful, such as trained social workers or educators to work with patients on LDKT action plans; facilitators for home-based education sessions; training family members as donor champions; and greater roles for KHNZ or previous donors/recipient.

There is a passivity and even ambivalence in some aspects of current practice and in the MOH approach that are in stark contrast to the high levels of activation required of potential recipients and donors to access LDKT. Support to resolve ethical issues may go some way to alleviating this.

6.2.3.2 Protection of donors
Specific processes relating to the care of donors were also not a focus of the research but, as a key ethical underpinning of the LDKT service, require some comment. Internationally, as LDKT has grown to become an increasing proportion of all renal transplants, there has been ever greater attention to quality and donor safety (31). Improved reporting and communication of Serious Adverse Events in LDKT have also been suggested (364). Some governments (e.g. in the UK and Finland) have introduced regulatory requirements regarding assessments of donors, which require all proposed living donations to be reviewed and approved by an independent assessor (263, 292).

The MOH has not been closely involved in protection of donors and has previously taken the view (376) that “the key to managing the live donation process is ensuring that good informed consent procedures are followed” (p.74). Existing consent provisions under the Code of Health and Disability Services Consumers’ Rights were deemed to be adequate in the 2004 regulatory review and, other than specifying that donors are covered under this Code, no further provisions were thought necessary.

Informed consent, however, is only one aspect of protecting the wellbeing of donors, internationally, it is increasingly recommended that transparent and accessible guidelines for living donation be developed covering selection criteria, screening processes and monitoring/follow-up. It has also been suggested that living donors should be involved in developing such guidelines (112).
There is no suggestion that NZ donors are not well cared for. However, each transplant unit has its own criteria and processes rather than there being a single transparent set of national guidelines. Australasian guidelines (452) are aimed at a clinical audience and not easily accessible by potential donors.

Interviews suggested some variance in follow-up practice of donors. Some centres offer lifelong follow-up, while others refer donors to their own GP after a certain period. This may not be ideal, particularly as it has recently been suggested that long-term monitoring may contribute to the positive outcomes observed in donors by allowing any changes to be detected and managed (28).

LDKT is a core component of the renal transplantation service in NZ. If government/society wishes to encourage more of this activity, transparent national guidelines about living donation are warranted.

6.2.3.3 A word on incentives
Chapter One noted that, for pragmatic reasons, the research excluded consideration of incentives to donors. There are many both in NZ and internationally who argue that financial incentives are needed because nothing else will have a great enough impact on donor numbers. Matas (cited in Coleman (453)) comments:

*I’ve been listening to arguments over the last 30 years of “let’s just try one more thing” and it’s not that little bits and pieces haven’t helped, but I’m worried that the lack of donors will just get that much worse* (p.12).

However, it is hard to argue that NZ has exhausted all other options and pragmatically, if nothing else, policy-makers are likely to need evidence that nothing else can be done before considering more controversial approaches. As one key informant said:

*Probably what we’ll need to do on a practical level, is exhaust the volunteer donors first, so if we make it a lot more efficient than what we do now and we’re still not doing nearly enough, there’s still a lot of people out there waiting, then you could say, “Well, the next practical step is to see what an incentive does in this environment”.*
There are also many health professionals in NZ who are opposed to incentives which would potentially make implementation difficult. The question of whether NZ needs to go as far as financial incentives remains open and may need to be addressed at some point in the future but this should not be at the expense of some immediate improvements in policy and practice that could benefit current patients waiting for a transplant.

6.2.3.4 Conclusion
Responsibility for advancing the issue of how to increase rates of LDKT has rested almost entirely with individual clinicians and transplant units. Such an approach has the advantage of allowing innovation and the ability to move more quickly than centralised processes might allow, but will only go so far, given the complexity of the issue and possible ethical constraints on health professionals. A national, societal-wide strategy, supported by government, is now required if further progress is to be made. The final chapter brings all the elements of the research together to propose such a strategy.
7 Chapter Seven: Conclusions

7.1 A strategy to increase LDKT in NZ
The aim of this research was to identify how to increase rates of LDKT in NZ, taking a system perspective and addressing issues relating to content, process, context, actors and institutions. A lack of NZ-based evidence and restricted options for addressing the unique and wicked problem of how to ethically increase donor supply have been major impediments in the past. This research has provided new evidence and canvassed a range of options to increase donor supply and to increase the rates of LDKT in NZ. Wider system issues, e.g. funding arrangements and challenges for clinical leadership, are also present and have also been considered in this research. This chapter draws final conclusions arising from the research.

A key conclusion of the research is that LDKT is widely regarded as the treatment of choice for most people with ESRF, but this is not adequately reflected in policy, practice and the system overall. There are always elements of luck in organ donation. However, many of the barriers identified in this research are amenable to intervention. While debate about financial incentives rages, there are numerous steps that can be taken immediately. Access to LDKT relies too heavily on whether individual patients acting alone have the skills, personality or luck to find willing and suitable living donors, who are themselves able to successfully navigate the system and overcome the barriers to donation.

The VFM case for LDKT is compelling and ethically there is no reason not to seek to increase current rates, as long as donor wellbeing remains the paramount concern. LDKT is not an experimental treatment and is already funded and provided in the public health system. If the service is to be offered, there is an obligation to ensure there is a high-quality and accessible service. If there is ambivalence about more actively encouraging it, this must be addressed directly.

A more active, less ambivalent approach to LDKT does not mean persuading or pressuring individuals to donate. It means creating an environment where LDKT is publicly acknowledged as a positive activity that government, society and the health system wants more of. It also means ensuring that everyone who might be willing to consider donation –
whether close family, wider networks or strangers – has the opportunity and the means to do so. This requires proactively and systematically providing information, removing barriers and no longer relying solely on patients to find donors, with little or no support. Government needs to clearly support efforts to increase rates of LDKT.

There are some signs that this shift is starting to occur. The Budget 2012 funding for trials of initiatives to support donor recruitment and KPE is an important signal that it is acceptable and desirable for the transplant community to tackle this problem and that government (society) is prepared to see the LDKT service taking a more active approach to the question of where donors come from.

NZ’s rate of LDKT peaked at a high of 16.1 pmp in 2008, but was down to 12.2 pmp by 2012. The number of people on dialysis has increased by 5.4% per annum over the last decade and the official waiting list has expanded to around 700. This strongly suggests that current approaches to the problem are not working. Despite some recent interest in the problem, there is still no sense of a comprehensive strategy and there is a strong risk that current activity will be piecemeal, “one-off”, and too slow to demonstrate results.

A comprehensive strategy is needed that can take into account all aspects of the health policy triangle and bring about the necessary service improvement for the benefit of patients and the health system. The complexity of the problem and the ethical issues involved suggest that, regardless of where leadership sits, the development and implementation of a strategy require input from a range of sources, transparency, and debate across communities to both raise awareness and foster support for a goal to increase rates of LDKT in NZ.

The components of a possible strategy, bringing together the findings of this research, are shown in Figure 11. The components do not need to be introduced sequentially, although there are some fundamentals, such as establishing a shared goal. There is no single answer to the problem and it is likely that a combination of incremental changes will have the most impact. Many specific actions are likely to be at provider level, including reorienting services and systems to LDKT, trialling new approaches, and sharing best practice. However, these need to be supported by the MOH, Ministers and the wider community.
Component One: Agreement on a clear goal, vision and commitment to increasing rates of LDKT in ethically acceptable, cost-effective and equitable ways

Component Two: Strengthened leadership, institutions, evidence and analysis: strategic leadership; national/regional planning, funding and accountability arrangements; capacity and capability for research and analysis; robust evidence base

Component Three: New mechanisms to address ethical issues in policy and practice

Component Four: Increased protection of donors - national, transparent guidelines for living donation; financial protection of donors

Component Five: Enhanced infrastructure and capacity - adequate capacity to ensure a responsive, safe and efficient LDKT

Component Six: Identify and roll out current best practices - benchmark systems and practices from high-performing centres to raise overall performance

Component Seven: Introduce initiatives to widen the pool of potential donors - multi-pronged strategies to remove barriers, raise awareness and enhance utilisation

Component Eight: Consideration of incentives for donors once other options are exhausted

Figure 11: Components of a strategy to increase rates of LDKT in NZ
Chapter Seven: Conclusions

Component One: Clear goal and vision

A common barrier to resolving wicked problems is lack of agreement on the problem or the preferred solutions (393). Kania and Kramer (394) suggest one of the requirements for collective success is a common agenda, including “a shared vision for change, one that includes a common understanding of the problem and a joint approach to solving it through agreed upon actions”.

It has been noted that vision and commitment, rather than “dabbling” are necessary for improvements in transplantation rates (372). It is also difficult to measure progress without a goal. Benchmarking against another country is one option for setting an appropriate goal. The Netherlands has the highest LDKT rate of Western countries (28 pmp) but it may be unrealistic to expect this can be matched in the short- to medium-term. A cluster of European countries have sustained rates of around 16-18 pmp and this would be a reasonable rate to aim for initially, equating to 71-79 LDKT per annum in NZ.

There are risks of perverse incentives when targets are set and increasing rates of LDKT should not compromise donor safety, e.g. accepting medically complex donors who would otherwise be declined. Equity issues are also important given the overrepresentation of Māori and Pacific populations amongst ESRF patients and lower rates of transplantation.

Component Two: Leadership, institutions, evidence and analysis

Critical issues in information and institutions have acted as barriers to making more progress. Key issues include leadership or ownership of the problem; appropriate regional/national planning, funding and accountability arrangements; and capacity and capability for analysis, research and evaluation.

Leadership or ownership of the problem is critical. As noted in Chapter Five, leadership or governance arrangements of the transplant service are not necessarily the same as leadership of a specific strategy to increase rates of LDKT. It is essential that someone “owns” the problem of how to increase LDKT rates.

The nature of the problem may mean that it lends itself to what one respondent called a “leadership coalition” with a range of stakeholders coming together to address the problem,
rather than relying on a single group or body (such as a clinical network). This is similar to the concept of “collective impact” described by Kania and Kramer (394) as a systemic approach to resolving certain types of social problems that require collaboration between stakeholders involving a common agenda, shared measurement, continuous communication and mutually reinforcing activities among participants. They note that:

*Some social problems are technical in that the problem is well defined, the answer is known in advance, and one or a few organizations have the ability to implement the solution... Adaptive problems, by contrast, are complex, the answer is not known, and even if it were, no single entity has the resources or authority to bring about the necessary change.*

Such a coalition might involve clinicians, the MOH, an effective patient interest group, a donor association and legal/ethical experts. The current roles, responsibilities, mandate and configuration of key institutions, such as the NRAB and Transplant Subcommittee, and ODNZ, all need to be reviewed. Any leadership coalition must be supported by dedicated resource and a clearly identified individual with responsibility for the strategy. The UK, for example, has appointed a lead nurse to the NHSBT whose sole focus is to develop and implement the strategy for LDKT.

Funding arrangements for renal transplantation are already being reviewed by the MOH/NHB which should resolve long-standing issues relating to pricing disincentives. Issues in macro-Budget settings that may prevent DHBs taking a longer-term view also need to be addressed.

**Component Three: Mechanisms to address ethical issues**

Ethical issues influence policy and practice in both positive and negative ways – donors are well cared for but there may be ambivalence or passivity in services arising from ethical concerns about coercion of donors. Health professionals have had little support to resolve these issues. Mechanisms to provide guidance on ethical issues in policy and practice are required, e.g. by involving ethicists and previous donors (449). Clear analytical frameworks for examining ethical issues would be beneficial as would approaches to donor recruitment
that do not compromise health professionals’ ethical standards. These mechanisms can also address ethical issues in new proposals to increase donor supply (Component 7).

**Component Four: Protection of donors**

Closely related to Component 3, is transparency about protection of donors. Donor safety in LDKT is paramount, and vital to the success of LDKT programmes (454), particularly in an international environment of increasing acceptance of medically complex donors. Davis (109) notes that “robust quality assurance and improvement programs that enhance donor outcomes and stimulate safe innovations in LD care might actually increase living donation” (p.208). Potential donors and recipients, policy-makers, those involved in providing transplant services and the public need to trust that the LDKT programme is committed to ensuring the wellbeing of donors through appropriate screening, selection and follow-up.

Transparency about how this is achieved is desirable, and national, accessible guidelines for living donation should be developed in NZ, with the participation of living donors (112). As noted in Chapter Six, protection of donors is now widely regarded as including protection from financial harm. NZ should introduce greater financial protection for living donors since lost income is not currently fully reimbursed. This could be on a trial basis initially, similar to pilots being carried out in some others countries (313, 455).

There is reportedly variation in how donors are followed up, with some being referred to GPs. The costs of donor follow-up should be factored into pricing models because cost is reportedly a reason for not offering lifelong follow-up in some centres. Primary care is not fully subsidised in NZ and this may be a barrier for donors. Data about donors is already submitted to the Australia and New Zealand Organ Donation (ANZOD) Registry, but variation in follow-up practices may mean this does not happen consistently. If follow-up is being carried out by GPs, arrangements for submitting data to ANZOD are required.

**Component Five: Infrastructure and capacity**

Although the primary problem in LDKT is not the traditional policy issue of lack of resources, adequate infrastructure and capacity to support LDKT are necessary, including workforce, theatre/surgical capacity, and access to services needed for recipient and donor work-ups.
Chapter Seven: Conclusions

Aspects of current infrastructure may be acting as a brake on the overall LDKT process. Work-up processes for both potential recipients and donors are not as efficient as they could be in many areas. This creates risks for patient outcomes (especially as they are likely to miss out on opportunities for pre-emptive transplantation), causes unnecessary stress for donors, may reduce goodwill towards the LDKT programme, and leads to a view that there is no point in trying to attract more donors until the system is able to deal with them more efficiently.

There appears to be adequate theatre capacity currently with insufficient suitable donors coming through the system to utilise available theatre slots. However, if more donors come forward, infrastructure is likely to be stretched. Future workforce and other capacity planning is necessary. The ability of DHBs to pay the upfront costs of additional transplants may also be an issue (unless this is addressed in the NHB funding review).

Infrastructure and capacity constraints can be a distraction for clinicians, who become focused on trying to resolve these issues, rather than on service improvement, and need to be addressed.

**Component Six: Benchmarking best practice**

The importance of practice, systems and services are well understood in deceased donation. Breakthrough Collaborative initiatives, which involve identifying and sharing best practice from high-performing centres, have been used in the USA and Australia with apparent success in increasing deceased donation rates (441, 444).

Less attention has been given to these issues in LDKT although some research has started to identify a link between centre practices and access. Recently, the Living Organ Donation in Europe project has taken on the task of identifying and exchanging best practice across Europe in living donation as part of wider work stemming from the EU Directive to increase organ donation (456). Danovitch et al (325) suggest collaborative approaches could be extended to LDKT:

*Living donation could well benefit from the application of the best practices principles that have been developed by the National Organ Donor Collaborative for deceased*
donation. The 30% increase in donation that followed is a first target that would seem to be eminently achievable in living donation: we have no time to lose (p.1346).

In NZ there is variation in transplant rates between the 11 renal units (including rates of pre-emptive transplantation), and Chapter Four suggested some potential differences in service design and delivery that may be important. A more comprehensive review of approaches and services across all the units to identify and share current best practices in NZ (possibly using similar methodologies to the Breakthrough approach) may go some way to lifting the overall rate of LDKT.

**Component Seven: Initiatives to widen the pool of potential donors**

For a sustainable step-change, specific attention is also needed to increasing the supply of donors. Commentators on the Transplant Growth and Management Collaborative (371) suggest that benchmarking and rolling out best practice has been important but that now it is necessary to consider the next steps:

*Despite all of these process improvements, increasing transplant volume remains solely dependent on increasing organ availability....Attention to transplant center performance through the TGMC, organ allocation via a web-based system and improved preservation techniques has led us as a community to perform more transplants....However, we have reached a plateau in conversion rates, organs transplanted per donor and organs from DCD (pp.884-892).*

Identifying and learning from best practice is an important component of improvement. However, a sustainable improvement also needs an explicit focus on donor recruitment and donor supply. A number of initiatives and incremental changes are possible. Interventions that focus on information, education and support for patients and their networks appear likely to show the most promise. Financial and other practical barriers to donation need to be removed and an effective KPE scheme is necessary to enable utilisation of willing but incompatible donors.
Component Eight: Incentives for donors

Consideration of incentives for donors is included here for completeness. However, it is necessary to demonstrate to decision-makers that other options have been exhausted before this option is considered. Debate about incentives also risks diverting attention from other options, and could result in no action at all given this debate shows no signs of being resolved internationally. For these reasons, initial effort needs to go on Components One to Seven.

7.2 Future research

This research has filled part of the evidence gap in NZ, particularly in relation to patients and health professionals. Future research should focus on trialling and evaluating a range of new initiatives in different areas to increase donor supply. The National Health Committee could play a role in considering the cost-effectiveness of different options for increasing LDKT rates, bearing in mind that no single intervention will be sufficient. The NRAB could undertake analysis of secondary data from renal units to produce basic information about transplantation, similar to its successful dialysis standards and audits reports. Some of this has already begun but this could be expanded.

Formative research to support the development of public awareness strategies is needed to identify appropriate messages, target groups and delivery methods. Further information about barriers for Māori and Pacific patients would be useful, e.g. the extent to which medical unsuitability of potential living donors affects transplant rates as opposed to unwillingness amongst networks to donate, and understanding why Pacific patients are less likely to receive offers despite being just as likely to discuss living donation as other groups. The low conversion rate of offers to starting the work-up reported by Pacific patients also requires further exploration. Research with potential donors and analysis of secondary data is needed to understand why some people do not offer, offer then do not proceed to testing, or contact a transplant coordinator but do not continue.

Empirical evidence about ethical aspects of service delivery would support guidance to health professionals, e.g. how do potential donors who miss appointments feel about being contacted by a transplant coordinator – is it “coercion” or are they pleased someone is showing an interest in them; how could this be done in a way that does not make people
feel like they are being “chased”; how can information be provided so that all those who might want the opportunity to donate are fully informed, but others do not feel pressured?

7.3 Final word

The failure to adequately address the organ shortage results in unnecessary loss of human life, vast public expenditure on a suboptimal therapy (dialysis), desperation amongst patients and their families, a thriving organ trafficking trade (106) and pressure to accept medically complex living donors (350). For LDKT not to be treated as the preferred RRT in policy and practice contradicts the goals of the NZ health system to provide the best care possible in an efficient and effective way and can be considered unethical.

Berwick describes the duty to improve the health-care system as a moral imperative, because the failure to improve services forces choices that can be avoided through better care: “The choice is stark: chop or improve” (457). Failing to improve the overall cost-effectiveness of RRT will continue to lead to calls for further rationing of access to dialysis. When there is a more cost-effective treatment available, as well as possibilities to reduce demand (through prevention and early detection and management of CKD), such a response to the rising expenditure on dialysis represents not only a policy failure, but an ethical and moral failure.

Further restricting access to dialysis as the solution to rising RRT expenditure, rather than seeking to increase transplant rates, is a doubly-flawed strategy. This approach would affect not only the group who would no longer be eligible to receive treatment (probably those least likely to benefit from therapy), but also those who stand to gain many additional life years if transplantation was more widely available, and for whom the government will continue to incur considerable costs while they are kept alive on dialysis.

“Tough choices” rhetoric is now common in health policy and goes well beyond the field of organ transplantation. Improving health services is challenging, but the danger is that it becomes easier to talk about cutting services than doing something to improve them. This is the real policy failure and the policy challenge.
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9 Annexes
9.1 Annex 1: Rates of LDKT internationally, 2010

Source: Global Observatory on Donation and Transplantation (9)
9.2 Annex 2: Patient survey

14 October 2011

Dear Kidney Transplant Waiting List Candidate

Survey about living donor kidney transplantation in New Zealand

I am doing research into living donor kidney transplantation in New Zealand and have asked the [city] renal unit to send you this letter. It is being sent to everyone who is currently on the waiting list for a kidney transplant (including people temporarily suspended from the list). I am hoping you will be willing to fill in the survey attached to this letter.

The aim of my research is to find out more about the barriers to live kidney transplantation and whether there are ways to help more people who want a live transplant to get one. I am doing this research as part of my PhD studies at Victoria University. I have been a live donor myself and have firsthand experience of the transplant process. This survey will help to build understanding about live transplantation from the point of view of renal patients and it is hoped it will provide useful information that can be used in planning renal services.

The survey will only take about 15-20 minutes of your time to complete. There are no right or wrong answers. I am interested in your views and in any experiences you may have had to do with live transplantation. You do not have to fill in the questionnaire but it would be a great help if you were able to.

I am also hoping to speak to a range of people who are waiting for a kidney transplant. If you are interested in being interviewed, please put your name and contact details at the end of form so I can contact you later. An interview would take about an hour and would be completely confidential.

The survey is completely anonymous so, unless you decide you want to be interviewed, neither I nor anyone else (including the transplant unit) will know if you’ve filled it in.

If you decide to complete the survey, I would appreciate it if you could return it to me in the enclosed stamped addressed envelope as soon as possible, preferably by the beginning of November. I look forward to hearing from you.

Best wishes

Paula Martin
PhD Candidate
Survey about living donor kidney transplantation

This is a survey of people waiting for a kidney transplant. It is about your experiences and what opportunities you have had for a transplant from a living donor and possible barriers to getting a live transplant. There are no right or wrong answers. The questionnaire should take no more than 15 minutes to complete. For most of the questions you just need to tick the box or circle the number that applies to you. There is room at the end for you to write comments if you wish to. Thank you for your time.

1. How long have you currently been on dialysis for? ________

2. Has someone from the renal (nephrology) unit discussed transplantation from a living donor with you? (Please tick)
   - [ ] Yes
   - [ ] No
   - [ ] Don’t know

3. For each of the following statements, please circle the number to show how much you agree or disagree:

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I would prefer a transplant from a living kidney donor rather than a transplant from someone who has died</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>If a living donor offered to donate a kidney to me, I would accept the offer.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

4. Please tick yes or no for each of the following statements:

   I have discussed living kidney donation with my family  [ ] Yes  [ ] No
   I have discussed living kidney donation with my friends [ ] Yes  [ ] No
   I have asked someone in my family to be a donor for me  [ ] Yes  [ ] No
   I have asked a friend to be a donor for me            [ ] Yes  [ ] No

Please comment:
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

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5. People who need a kidney transplant sometimes have concerns about a transplant from a live donor. For each of the following statements, please circle the number to show how much you agree or disagree:

<table>
<thead>
<tr>
<th>I am worried that:</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>A living person who donated a kidney to me would develop health problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The donor surgery and recovery will be too painful for the donor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The out of pocket expenses (e.g. lost income) for the donor will be too high</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>The donor will feel upset if my body rejects the donated kidney</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

6. Has anyone ever said they would consider donating a kidney to you, for example, said they would think about it or would like to do it? (Please tick)

☐ No  ✧ Go to question 9.

☐ Yes  If yes, please who and how many of each:

- Your partner/spouse  ☐
- A close family member ☐
- Other relative     ☐
- A friend or someone else ☐
- outside your family ☐
7. Has anyone ever been tested to see if they would be a compatible donor for you (blood group and/or tissue type)? (Please tick)

☐ No  Go to question 9.

☐ Yes  If yes, please indicate who was tested and how many of each:

- Your partner/spouse  ☐
- A close family member  ☐
- Other relative  ☐
- A friend or someone else outside your family  ☐

8. For each person in Question 7 who was tested for compatibility with you, please indicate with a tick what happened:

<table>
<thead>
<tr>
<th></th>
<th>Person 1</th>
<th>Person 2</th>
<th>Person 3</th>
<th>Person 4</th>
<th>Person 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I turned the person down</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The person decided not to go ahead with being a donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The person wasn’t compatible with me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The person wasn’t medically suitable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The person is still being tested to see if they are medically suitable to be a donor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The person is medically suitable and we are waiting for a date for the transplant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None of the above (please explain)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
9. Sometimes if two people each have a willing donor who is incompatible with them, it is possible to “swap” donors so that both people can receive a transplant. This is called a paired exchange. Would you be interested in paired exchange if you had a willing donor who wasn’t compatible with you?

☐ Yes  ☐ No  ☐ Don’t know

10. Sometimes people come forward to a transplant unit and offer to donate a kidney to someone who they don’t know. Would you be willing to accept a kidney from a stranger who wants to donate a kidney?

☐ Yes  ☐ No  ☐ Don’t know

11. Please add any other comments you would like to make about any of these questions or other issues about your experiences of living donor transplantation.

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Some final questions about you:

12. Have you ever had a kidney transplant before? (Please tick)

☐ No
☐ Yes, from a living donor.
☐ Yes, from a deceased donor.

13. Are you male or female? (please tick)  ☐ Male  ☐ Female

14. What year were you born? __________
15. Which ethnic groups do you belong to? (Tick all that apply to you)

☐ Pakeha/NZ European
☐ NZ Māori
☐ Pacific Island
☐ Asian
☐ Indian
☐ Other (please specify) __________

16. Do you currently have a partner or spouse? (Please tick)  ☐ Yes  ☐ No

17. Which renal unit do you usually attend?

☐ Auckland  ☐ Wellington  ☐ Hawkes Bay  ☐ Palmerston North
☐ Christchurch  ☐ Dunedin  ☐ Other ______________________

Thank you very much for your time. Your answers will be very useful in helping to build better understanding of the situation for people waiting for a kidney transplant.

Please return your completed form in the stamped addressed envelope by the beginning of November 2011.

Follow up interview

I would like to interview a number of people to find out more about their experiences. If you would be interested in being interviewed, please fill in your name and contact details below.

Name: ______________________
Home phone number: ______________________
Mobile phone number: ______________________
Email: ______________________

Best time to ring: weekdays  week nights  weekends  any time (please circle)
9.3 Annex 3: Patient interview guide

Main themes: finding a donor, interaction with renal/transplant services, what would improve the current situation

Introduction: general introduction, explanation of research, consent, any questions

Background

- History of respondent’s end stage renal failure – causes, progression, timing
- Any previous transplant- if yes, when and who (if living donor)
- Type of dialysis, time on dialysis (current)
- Time on waiting list (current)
- Family situation, working/not working
- Renal unit

Information and concerns about transplantation

- If discussion with renal unit re live transplantation:
  o Who from the renal unit has talked to you about live Tx?
  o When (e.g. pre dialysis, after dialysis started)?
  o Is this something they discuss regularly with you?
  o What did they say (e.g. live transplant is the best option, encourage you to find a live donor)?
  o How helpful was the information?
  o How well informed do you feel about all your treatment options?
  o Where else have you got information about live transplantation from e.g. other patients, internet, media stories?

- If no discussion with renal unit:
  o How did you find about live transplantation? e.g. other patients, internet, media stories?
  o How well informed do you feel about all your treatment options?

- All What are the benefits of a live transplant from your point of view? What concerns do you have about live transplantation compared to deceased donor transplantation?
  o Shorter waiting times, better outcomes
  o Risks to donors, financial loss for donors, don’t want to be obligated to anyone
  o Cultural issues

Potential donors

- Recruitment activity (discuss/discuss and ask)
  o Who have you discussed live donation with? Who initiated the discussion?
    What did you say? What sort of reaction did you get?
  o Have you asked anyone directly to be a donor? Who? What did you say?
    What response did you get?
  o What difficulties are there for you in talking to others/asking others? E.g. guilt, fear, embarrassment, financial barriers, don’t know how to ask, cultural issues
o What approaches have you tried to find a donor? (e.g. face to face, letter, email, someone else asked for you, family meeting, Facebook). What has worked, what hasn’t worked?

o What kind of information or support did you have from the renal team for this? (Probe for: written information, discussions with specialist/transplant coordinator/pre-dialysis nurse). Was this helpful?

- Recruitment activity (no discussion)
  o What kind of information or support did you have from the renal team for this? (Probe for: written information, discussions with specialist/transplant coordinator/pre-dialysis nurse). Was this helpful?
  o What are the difficulties for you in talking to others about live transplantation? (Probe for: no family or friends, family not suitable, guilt, fear, embarrassment, financial barriers, don’t know how to ask, cultural issues embarrassed, guilty, afraid for donors)

- Offers
  o Has anyone volunteered or offered to be a donor? Who?
  o How did the person know you needed a donor? Was this someone you discussed with or asked/they attended clinic with you/someone else told them?
  o What was your response? What happened?

- Work up
  o Has anyone started the work up process to be a donor for you?
  o Have they said anything to you about their experiences?
  o What has it been like for you e.g. sequential testing, time taken, feedback to you on progress, concern for the donor?

- Paired exchange
  o Are you aware of the paired exchange scheme? Who told you about it? What do you know about it?
  o Have you been given the option of paired exchange for incompatible donors?

Options for improvement

- What else would be helpful to support you to find a donor?
  o Training in how to approach potential donors
  o Someone from the renal team approaching potential donors for you
  o Home-based education session for family and friends with a trained facilitator
  o On-line forms that donors could complete

- What else would help increase the number of transplants or improve live transplant processes for patients and donors?
  o Compensation for donors
  o Financial incentives for donors
  o More general awareness about live donation e.g. media campaigns
  o Faster work ups
  o Other
9.4 Annex 4: Health professionals’ interview guide

**Introduction:** general introduction, explanation of research, consent, questions

**Background:** your role, time working in renal transplantation, relevant transplant unit

**Donor recruitment**
- What support is there for patients to recruit donors? What information, training, other support is given to patients?
- How does your programme approach donor recruitment? What is your role in donor recruitment? What are the ethical issues for health professionals in donor recruitment?
- Views about others being involved in donor recruitment?

**Utilisation**
- How does the paired exchange scheme work now? What is the potential for increasing the number of transplants via this? What would it take?
- ABO-incompatible scheme – how does this work? What is the potential for increasing the number of transplants via this? What would it take?

**Increasing supply**
- Widening clinical criteria for donors – how widely is this happening, issues in doing this?
- Encouraging altruistic donation – is this worthwhile, concerns about altruistic donation, how could this be done?

**Removing barriers**
- Compensation
- Allowing non-waitlisted patients to have a live transplant

**Capacity and resourcing issues**
- Could transplant services be organised more efficiently to maximise numbers of transplants? Would a national service help? Why/why not?
- What are the barriers/incentives for DHBs or individual transplant programmes to do more? (pricing, funding, need to constrain costs)
- Are there resourcing barriers e.g. theatre slots, numbers of coordinators, work up times, access to donor evaluation services by other specialties?
- How significant are these issues compared to the overall supply of kidneys?

**Options for improvement**
- What are the most important barriers and options for increasing rates of LRT?
- Should incentives for donors be on the agenda?
9.5 Annex 5: Topics covered in key informant interviews

Questions for each key informant varied depending on their particular role and individual interview guides were developed for each. Generic issues covered in interviews included:

**Prioritisation and decision-making in health:**

- Influences on decision-makers, what determines what gets on the agenda at national and DHB level
- How prioritisation is supposed to work, how it works in practice, challenges to robust decision-making

**History/context:**

- Organ donation legislative processes and Parliamentary debates
- Origin of the welfare programme for living organ donors
- History of the establishment of key institutions e.g. NRAB, ODNZ
- History of clinician concerns regarding funding and pricing

**Attention to LDKT:**

- Why increasing rates of LDKT has not had more attention in the past/ not been more of a priority – macro, meso, micro levels
- Lack of focus on LDKT during organ donation policy processes
- Why more attention started being paid to LDKT during 2011-12

**Roles of actors and institutions:**

- Roles of different organisations regarding LDKT, who does what, mandate, where are the gaps, how they work together
- Changes in approach by key organisations e.g. MoH, NHB

**Leadership:**

- Where should leadership of this issue sit?
- Issues/challenges for clinical leadership
9.6 Annex 6: Email survey questions to DHB managers

1. Why do you think LDKT has not been more of a priority in the health system generally, despite research suggesting it is better for patients and more cost effective than dialysis?

2. Is increasing the number of live renal transplants a priority for your DHB? Please comment.

3. What, if any, discussions has your DHB had about trying to increase the numbers of renal patients who receive a live renal transplant?

4. Are there any policy, operational or resourcing issues that act as a barrier to doing more live renal transplants e.g. number of transplant coordinators, availability of theatre slots, service planning issues, funding and pricing arrangements for renal transplantation?