

**Scoping paper**

**New Zealand's Renal Services:  
Towards a national strategic plan**

**National Renal Advisory Board**

**14 September 2006**

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## Executive Summary

Renal services comprise a relatively small but steadily growing and expensive area of the health sector. This scoping paper, prepared by the National Renal Advisory Board, highlights for DHB CEOs' attention a range of key issues facing the renal sector in New Zealand, and presents the case for developing a national strategic plan for renal services.

If a person develops diabetes, hypertension, or glomerulonephritis (an immunological disease of the kidneys) he or she is at risk of kidney damage leading to interference in these functions. Where chronic kidney disease (CKD) develops, treatment can help reduce complications and slow the progress of the disease. However, in many patients, when CKD occurs it can progress to end stage kidney disease (ESKD). The treatment of ESKD with dialysis and/or transplantation (together termed renal replacement therapy, or RRT) is life sustaining. Without such treatment death is inevitable in days, weeks, or months.

Over the decade from 1995 to 2004, the number of renal dialysis patients (per million population) in New Zealand grew by 7.2 percent per annum on average, while the number of people with functioning transplants grew by only 3.9 percent. The number of transplants performed in New Zealand remained constant at approximately 28 per million from 1998 to 2003, declining to 26 in 2004.

The key drivers of the growth in dialysis patient numbers are an increasing incidence of CKD either presenting or being referred for dialysis, as a result of:

- Improved survival (especially cardiovascular) of the general population
- Type II diabetes epidemic
- Greater acceptance of and demand for dialysis services from Maori and Pacific Island peoples
- Greater acceptance of and demand for dialysis services from elderly patients
- Greater expectation for dialysis services from the medically frail, who previously would either not have been offered, or would not have taken up an offer of dialysis.

Projections undertaken by the Public Health Intelligence group of the Ministry of Health indicate that RRT in the 15-69 year age group is expected to grow by 57 percent between 2005 and 2015, at an annual rate of 4.6 percent per year. PHI conservatively suggests that the same growth rates could be applied to those aged over 70 years. Furthermore, only approximately one-third of the projected growth in RRT is expected as a result of demographic factors, the remaining two-thirds are due to non-demographic factors; up to half of the total projected growth in RRT demand would be due to the impact of type II diabetes.

A range of critical issues facing the renal sector are highlighted, existing within and across the three branches of renal services:

- **CKD management:** Public education and prevention; screening; primary-secondary interface;
- **Dialysis:** Late referrals; innovation constraints; appropriate mix of modalities
- **Transplantation:** Kidney donation; accessing transplant services

- **System-wide issues:** Growing demand for renal services; inequality of provision; workforce shortages; patient perspectives; information infrastructure; clinical knowledge base.

With some exceptions, there is a lack of regional and national planning in New Zealand. Establishing a national framework for renal services would provide guidance to DHBs to plan services, with the aim to prevent, delay onset and better manage CKD. In the long term this should reduce the burden of CKD to the health sector and society.

Such a framework should take a whole system perspective, integrating renal services with other services across the spectrum of prevention, management, treatment and palliative care. Benefits of such a framework include:

- Foundation for improved interface with primary care
- Transparency of service provision and access
- Establishment of high level principles for regional service planning
- Guidance for planning and service provision as demand escalates
- Responding to CKD in Maori and Pacific populations.

If not confronted through a national framework working to a five to ten year horizon, this could lead to significant shortfalls in service provision in many areas, poorer patient outcomes and potentially less cost-effective responses.

The National Renal Advisory Board proposes that the Ministry of Health is best placed to lead work in this arena, and seeks support from DHB CEOs for such a work programme.

## Recommendations

It is recommended that DHB CEOs:

- a) **note** the ongoing growth in renal replacement therapy, particularly dialysis;
- b) **note** the projected growth of at least 5 percent per annum over the next decade;
- c) **note** that only one-third of the projected growth is due to demographic factors;
- d) **note** the key issues facing the renal sector in areas of CKD management, dialysis, transplantation, as well as system-wide issues;
- e) **note** the potential for improved patient-centred management with cost savings to the sector through an enhanced primary-secondary interface;
- f) **endorse** the proposal of the National Renal Advisory Board that the Ministry of Health should take a lead role in developing a national strategic framework to guide local planning for renal services;
- g) **endorse** the establishment of an agreed funding stream for renal services through a national strategic framework.

## Introduction

This scoping paper from the National Renal Advisory Board highlights for DHB CEOs' attention a range of key issues facing the renal sector in New Zealand, and presents the case for developing a national strategic framework for renal services.

Stephen McKernan, in his former capacity as CEO Counties Manukau District Health Board (CMDHB), provided initial sponsorship of this project. Following Stephen's appointment to Director-General of Health, Ron Dunham (Acting CEO CMDHB) has taken on the role of sponsor.

This paper was prepared against a backdrop of growing demand for renal services nationally, a trend which given the type II diabetes mellitus epidemic, appears set to continue for decades to come. With some exceptions, there is a lack of regional and national planning in New Zealand. If not confronted through a national framework working to a five to ten year horizon, this could lead to significant shortfalls in service provision in many areas, poorer patient outcomes and potentially less cost-effective responses.

The paper was developed by Dr Adrian Field (Planning and Funding Division, CMDHB) for the National Renal Advisory Board, with significant input from the following people involved in the renal sector:

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- Associate Professor John Collins, Auckland District Health Board (ADHB)
- Dr Ian Dittmer, ADHB
- Dr Maggie Fisher, Waikato DHB
- Pauline Hanna, CMDHB
- Debbie Keys, CMDHB
- Associate Professor Kelvin Lynn, CDHB and New Zealand Kidney Foundation (NZKF)
- Dr Mark Marshall, CMDHB
- Professor John Morton, NZKF
- Dr Brandon Orr Walker, CMDHB
- Justine Patterson, CMDHB
- Dr Grant Pidgeon, Chair National Renal Advisory Board (NRAB), and Capital Coast DHB (CCDHB)
- Associate Professor Johan Rosman, CMDHB
- Dr Gary Sinclair, CMDHB
- Dr Stephen Streat, Organ Donation New Zealand
- Miranda Walker, CCDHB

This work has been informed by regional planning initiatives in the Auckland<sup>1</sup> and Midland<sup>2</sup> regions, renal service data from the ANZDATA and USRDS data warehouses, as well as related published and unpublished documentation, including information provided by the people consulted above.

## Scope of publicly-provided renal services in New Zealand

The main function of the kidneys is to clear the blood of waste products and maintain fluid and mineral balance in the body. If a person develops diabetes, hypertension, or glomerulonephritis (an immunological disease of the kidneys), he or she is at risk of kidney damage leading to interference in these functions. Where chronic kidney disease (CKD) develops, treatment can help reduce complications and slow the progress of the disease. However, in many patients when CKD occurs it can progress to end stage kidney disease (ESKD).<sup>1</sup>

There are five stages of CKD (defined by the Kidney Disease Outcomes Quality Initiative<sup>3 4</sup>) and these are defined by the level of kidney function or glomerular filtration rate (GFR). Measuring GFR was until very recently an intensive process, but the introduction in 2005 of the eGFR test provides an estimate of GFR, using a combination of simple serum biochemistry results and demographic factors. GFR testing enables informed doctors in primary and secondary care to determine what treatments are required to delay progression of renal disease and when referral to a renal unit is required.

In New Zealand, there are five broad categories of renal services:

1. Diagnostic and treatment service for patients with kidney diseases.
2. Management of patients with chronic kidney disease (CKD).
3. Dialysis programmes (Haemodialysis and Peritoneal Dialysis).  
*Haemodialysis* (HD) uses a proportioning machine connected via tubing to the patient's circulation to deliver blood to a filter and return it to the patient once cleared of waste products and freed of excessive fluid. Haemodialysis services are provided either:
  - o incentre (hospital based with nurse and/or technician assistance, for people unable to manage dialysis independently)
  - o satellite bases (closer to patients' homes, for people who can manage dialysis with varying degrees of independence, with some nursing or technician support).
  - o home settings or community bases, where no staff are present and dialysis is managed either independently or with family support.*Peritoneal dialysis* (PD) is a further self-care option undertaken by patients using a permanent catheter implanted in the peritoneal cavity. Blood is filtered using the network of fine blood vessels in the peritoneal lining of the abdominal cavity, and a daily process of 'fluid exchanges' allows for infusion of PD fluid and removal of waste products and fluid. A problem for all PD patients is the development of peritonitis.
4. Renal transplantation (offered in three centres in New Zealand), where the patient's kidney function is replaced by a donor kidney via surgery. Patients receiving transplantation tend to have an improved quality of life and greater life expectancy than those receiving dialysis modalities. Transplants can occur using kidneys from either living or deceased donors; each form of transplantation raises different issues (discussed later in this report).
5. Palliative care, or 'conservative management': Not all patients are clinically suitable for transplantation or dialysis treatment, or they may choose to live with their progressive disease, managing their kidney failure with the support of their family, GP and other health professionals. This conservative approach recognises that many of these patients will die of other co-morbid conditions

before requiring RRT. Likewise a patient undergoing RRT has the option of withdrawing from continued dialysis treatments and it is important that the patient and their family is linked into the appropriate palliative care networks and support at this time. End of life planning is an important component of the renal care continuum and health professionals should ensure that there are regular opportunities provided for patient review and discussion of management plans.

The treatment of ESKD with dialysis and/or transplantation is life sustaining. Without such treatment death is inevitable in days, weeks, or months.<sup>5</sup> The significance of CKD is not only its impact in and of itself, but also its co-location with other diseases. Where CKD is present alongside other diseases, such as cardiovascular disease, there is a multiplier (rather than additive) effect of premature mortality.

Renal replacement therapy (RRT, which covers all forms of dialysis and transplantation) should ideally have a significant preparation period before being commenced. This allows:

- Education regarding CKD and associated dialysis therapies in the six to twelve months prior to need
- Assessment for pre-emptive transplant
- Surgical placement of AV fistula for HD access undertaken at least three months prior to first planned use, or alternatively placement of peritoneal catheter undertaken at least two weeks prior to first planned use
- Frequent lab and clinical monitoring
- Nutritional advice and support
- Planning of palliative care services, if required
- Social work assessment and management.<sup>6</sup>

## Location of renal services within national strategies

The *New Zealand Health Strategy* (2000)<sup>7</sup> is based on seven underlying principles, which apply across the health sector. The seven principles are:

- Good health and wellbeing for all New Zealanders throughout their lives
- An improvement in health status of those currently disadvantaged
- Collaborative health promotion and disease and injury prevention by all sectors
- Acknowledging the special relationship between Maori and the Crown under the Treaty of Waitangi
- Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay
- A high-performing system in which people have confidence
- Active involvement of consumers and communities at all levels.

Although the delivery of renal services is concentrated in secondary care, renal services have relevance to all seven principles of the strategy. This is because of the importance of an approach to CKD which draws in the prevention, management and treatment branches of the health sector to reduce the long-term burden of CKD; the impact of CKD among disadvantaged populations, particularly Maori and Pacific peoples; the current inequities in provision of renal services; and the need to develop local solutions within a national framework.

Renal services are also highly relevant to the key directions of the *Primary Health Care Strategy* (2001):

- Work with local communities and enrolled populations
- Identify and remove health inequalities
- Offer access to comprehensive services to improve, maintain and restore people's health
- Co-ordinate care across service areas
- Develop the primary health care workforce
- Continuously improve quality using good information.<sup>8</sup>

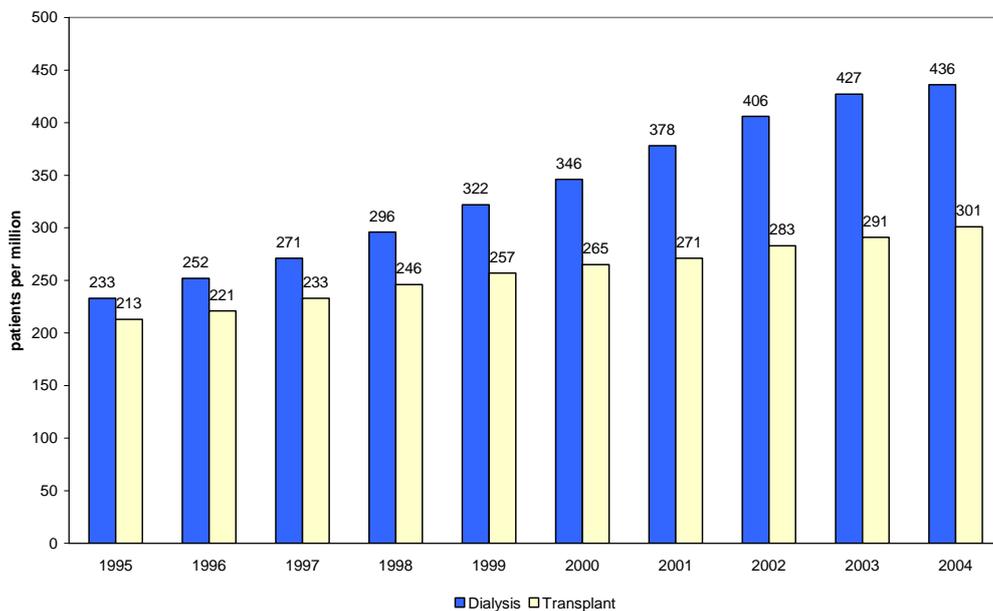
These objectives resonate strongly with the key issues facing renal services, particularly the need for greater involvement of primary care in CKD management, linkages with secondary care, and a more integrated information infrastructure.

*He Korowai Oranga*, the Maori Health Strategy, is a further key strategic document.<sup>9</sup> Central to He Korowai Oranga is whanau ora, whereby Maori families are supported to achieve their maximum health and wellbeing. Within the strategy, the pathway of 'effective service delivery' aims to ensure that whanau receive timely, high-quality, effective and culturally appropriate health and disability services to improve whanau ora and reduce inequalities.

## Provision of renal services

Figure 1 below displays the growth in dialysis patients and functioning kidney transplant patients in New Zealand over the decade from 1995 to 2004.\* Over this period, the number of renal dialysis patients (per million population) grew by 7.2 percent per annum on average, while the number of people with functioning transplants grew by only 3.9 percent. The number of transplants performed in New Zealand remained constant at approximately 28 per million from 1998 to 2003, declining to 26 in 2004.<sup>10 11</sup>

**Figure 1: Dialysis dependent patients and functioning transplant patients per million population, New Zealand 1995-2004**



Source: Australia and New Zealand Dialysis and Transplant Registry Reports 2000 and 2005

Dialysis patient numbers are growing due to increasing incidence of CKD either presenting or being referred for dialysis, combined with improved survival rates. The key drivers of growth are:

- Improved survival (especially cardiovascular) of the general population, including the sub-population with CKD
- Type II diabetes epidemic - in 2004, type II diabetes was the primary renal disease of 36 percent of New Zealand dialysis patients, compared to 21 percent in Australia<sup>11</sup>
- Greater acceptance of and demand for dialysis services from Maori and Pacific Island peoples who have high rates of CKD and ESKD
- Greater acceptance of and demand for dialysis services from elderly patients who have the highest rates of CKD and ESKD

\* Note that functioning transplant patients are all transplant patients with functioning kidneys, not just those who had a transplant operation in each year.

- Greater expectation for dialysis services from the medically frail, who previously would either not have been offered (or alternatively would not have engaged an offer of) dialysis. <sup>12 13</sup>

The growth in dialysis patients began to plateau between 2002 and 2004, after sustained growth over previous years of 8.3 percent. The changing incidence of dialysis could be due to a number of factors, including therapies for management of pre-dialysis patients (such as EPO); changes in referral patterns; and a slowdown in supply of dialysis services (rather than a reduction in demand for dialysis). Given the continued growth of the obesity and type II diabetes epidemics it is questionable if CKD rates are slowing. <sup>14</sup>

At present, there are no reliable prevalence estimates of the number of people in New Zealand with chronic kidney disease. US data from K/DOQI indicates CKD affects 11 percent of the national population.<sup>1</sup> Applying these data to the New Zealand population would suggest the following levels of CKD prevalence at stages 3 to 5:

- CKD 3 with GFR 30-59mls/min - 178,000
- CKD 4 with GFR 15-29mls/min - 8300
- CKD5 with <15 mls/min or RRT - 4200 <sup>15</sup>

CKD 4 represents advanced kidney disease not requiring dialysis, and CKD 5 represents ESKD, most of whom require dialysis or transplantation.

In New Zealand, there were 2,994 patients (737 per million) receiving renal replacement therapy (RRT) as at 31 December 2004. Of these, 1,224 (301 per million) had a functioning kidney transplant<sup>†</sup>, and 1,770 (436 per million) received dialysis treatment. Among those receiving dialysis treatment, 34 percent were Maori and 19 percent were Pacific peoples.<sup>11</sup>

If the US prevalence estimates apply to New Zealand (although such an assumption is fraught with difficulty), service provision is not meeting potential demand. It should be noted that the higher prevalence of type II diabetes and its impact at an earlier age in Maori (many of whom live in rural area without access to renal services) and Pacific people contributes to even higher rates of ESKD in these populations. Furthermore, the number of patients entering RRT programs in New Zealand is generally lower than for other developed countries such as the US and most members of the European Union, although the New Zealand rate is slightly higher than that of Australia.<sup>16</sup> The incidence of dialysis commencement in elderly populations (greater than 75 years) is considerably lower than most other developed countries.<sup>5 12</sup>

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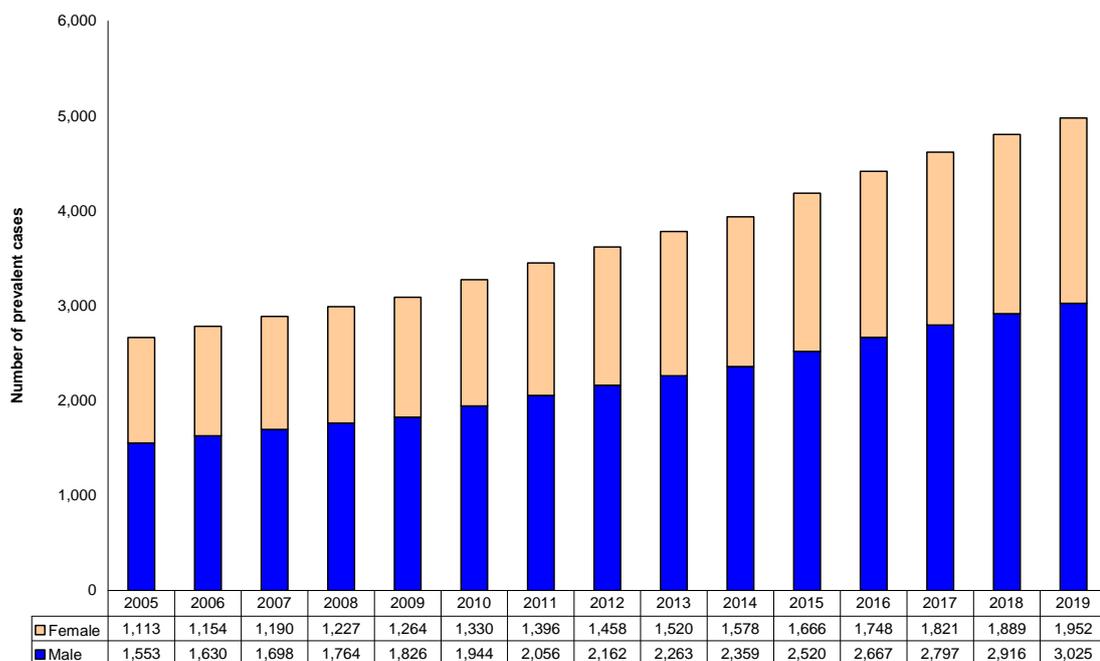
<sup>†</sup> Note that those with functioning transplants move from CKD 5 category to CKD 2 or 3, as a direct result of their improved kidney function.

## RRT demand projections

To support this work, the NRAB asked the Public Health Intelligence (PHI) group of the Ministry of Health to prepare 10 to 15 year projections of RRT demand. Using available ANZDATA, PHI combined dialysis and transplantation into one set of projections. Because of time and data limitations, the analysis was restricted to the 15-69 year age group, and did not examine ethnic-specific projections.<sup>17</sup>

Even within these limitations, the projections indicate growth in RRT exceeding population growth and funding paths over the next decade. The number of new cases of RRT is projected to increase from 2,377 in 2005-2009 to 3,837 in 2015-2019. As a result of increasing new cases, and improvement in survival for RRT patients, prevalence of RRT is also forecast to continue. Figure 2 below shows the projected increase in RRT prevalence from 2005 to 2019. The authors indicate the data is robust to 2015. RRT is expected to grow by 57 percent between 2005 and 2015, at an annual rate of 4.6 percent per year. The increase is steepest among males at 5 percent per year, compared to 4 percent per year for females.

Figure 2: Projected number of prevalent RRT cases by gender, 2005-2019 (age 15-69 years)



PHI conservatively suggests that the same growth rates could be applied to those aged over 70 years. Furthermore, only approximately one-third of the projected growth in RRT is expected as a result of demographic factors, the remaining two-thirds are due to non-demographic factors. The authors suggest that up to half of the total projected growth in RRT demand would be due to the impact of type II diabetes. The authors note that if increasing access to RRT (as pictured in figure 1) is approaching saturation, then growth in demand will be over-estimated. However, PHI concludes that “both incident and prevalent burdens are unlikely to grow at less than 4 percent per year, or much more than 6 percent per year, over the next decade.”<sup>17</sup>

## Cost modelling of RRT interventions

Estimates of the cost of various RRT interventions were undertaken to inform renal service planning in the Auckland region.<sup>1</sup> Based on 2003/04 CMDHB data, the comparative costs of dialysis modalities were (including all hospital costs):

	Average cost per Patient Treatment Year
Incentre dialysis	\$64,318
Satellite haemodialysis	\$48,172
Home haemodialysis	\$33,585
Peritoneal dialysis	\$36,614

The authors of the report stressed the key feature is the magnitude of the differences in costs. Of note is the higher costs of incentre dialysis compared to all other treatments. Peritoneal dialysis was 8 percent higher than home HD, after taking into account the additional costs of inpatient admissions, and reflecting the high incidence of peritonitis in CMDHB. It is possible that the high incidence of peritonitis in CMDHB distorts the costs of PD in this analysis. It is also worth noting that the report did not consider or adjust for differences in baseline co-morbidities between the groups treated with different modalities. These cost estimates therefore should not be for cost-minimisation analyses as it is unproven that the same clinical outcomes could be achieved if, for instance, peritoneal dialysis was applied to all patients currently treated with incentre dialysis.

More recently, CMDHB have compared the three-year costs of each dialysis modality against renal transplant costs, to incorporate post discharge care costs for transplant care services. These are detailed below, and indicate lower costs for transplantation compared to most other services over a three year period. Over a four-year period, transplantation costs would be lower than all other services (based on an estimate of \$85,000 cost for the first year, including surgery, and \$10,000 for each subsequent year).<sup>18</sup>

	Average three year costs per patient	Difference from transplant costs
Renal transplant	\$105,000	
Incentre dialysis	\$192,954	87%
Satellite haemodialysis	\$144,516	38%
Home haemodialysis	\$100,755	-4%
Peritoneal dialysis	\$109,842	5%

The lower long-term cost of transplantation is consistent with an economic analysis of ESKD in Australia, which concluded that increasing the transplant rate would result in considerable health sector savings and also significantly improve health outcomes for people with ESKD.<sup>19</sup>

## Critical national issues

### Overview

This section explores key issues facing renal services in New Zealand. There are specific challenges facing each arm of renal services: CKD management, dialysis and transplantation. There are also critical issues that span all three branches of renal services. These are all summarised in the table below

CKD management	Dialysis	Transplantation
Public education and prevention	Late referrals	Kidney donation
Screening	Innovation constraints	Accessing transplant services
Primary-secondary interface	Appropriate mix of modalities	
<b>System-wide issues</b>		
Growing demand for renal services		
Inequality of provision		
Workforce shortages		
Patient perspectives		
Information infrastructure		
Clinical knowledge base - New Zealand's specific circumstances		

### Public education and CKD prevention

In the long-term, reducing the burden of CKD and ESKD requires attention to preventing its causes alongside managing its prevalence, linking with population health strategies such as *Healthy Eating, Healthy Action*. With type II diabetes now the leading cause of ESKD, there are potentially significant gains to be made from population-level improvements in nutrition and physical activity, and reductions in obesity. Achieving these changes in population health requires action on a broad range of fronts, including public awareness of and motivation for adopting healthy lifestyles, changes to the environments that influence nutrition and physical activity, and improvements in health service responsiveness to at-risk populations. Gains can also be made through heightened public motivation to find out about CKD or to identify at an early stage if they have the disease.

### Screening

Screening in primary care can be an effective means of identifying the presence of disease in an individual. There is currently no systematic screening of the New Zealand population for kidney disease. Opportunistic screening is undertaken through primary care, using the eGFR test. The recent introduction of eGFR testing in the Auckland region has initially led to a surge in referrals; some of these are in advanced stages of CKD requiring intensive treatment within timeframes that are far from ideal. Others are complex with multiple medical needs but at a stage where primary care could potentially manage better with appropriate guidance.

Nationally, more systematic targeted screening of high-risk patients through primary care has the potential to identify a greater number of patients with kidney disease,

and to treat these people at an earlier stage, preventing or delaying the need for intensive treatments such as dialysis.

There are currently no New Zealand guidelines for the management of CKD, despite increasing evidence of a role for primary care in early stages of CKD, such as aggressive management of blood pressure. There are however Australian guidelines that are potentially of use to managing CKD through primary care.<sup>20 21</sup> Any development of disease management support or decision tools in primary care will require a foundation of guidelines that are relevant to New Zealand's circumstances.

### **Primary and secondary interface**

A key issue is the interface between primary and secondary care. Secondary services are currently stretched to absorb a substantial number of people who are referred with advanced kidney disease. It is critical that people with CKD are referred for assessment at an early stage when their conditions can be managed effectively and independence maintained.

In 2004, 22 percent of patients starting dialysis were first referred to a renal service within 3 months of the start of dialysis, many more within a year of commencing dialysis.<sup>11</sup> This is too late for strategies to delay commencement of dialysis, let alone properly assess and prepare the patient and their families for therapy.<sup>6</sup> Late referrals are strongly associated with greater co-morbidity, longer initial hospitalisation and higher mortality.<sup>22</sup> Moreover, 80 percent of late referrals are treated in NZ with peritoneal dialysis, although after a 90 day period only 53 percent of late referrals remain on this modality. The large cost of initiating and training patients onto peritoneal dialysis who then fail rapidly onto haemodialysis is potentially avoidable.<sup>11</sup>

An appropriately enabled and multidisciplinary primary care workforce should be able to deal with CKD in its earlier stages, supported by detailed guidance from secondary care or readily available information tools to support primary care management. This would be assisted by more innovative approaches to primary/secondary consultation, such as greater ability of GPs to discuss issues with consultants. Other options in this area include enhanced capacity of nurse specialists and general practitioners working across the interface with secondary care; guidelines for managing people in this pre-RRT stage through primary care; and enhanced support services. Currently however GPs are disconnected from secondary care without a strong interface between the sectors. There is also a shortage of GPs and practice nurses which form the bulk of the primary care workforce.

### **Innovation constraints**

Following referral, a patient receives the first specialist assessment (FSA). FSA, and subsequent follow-up may not in all cases be the best way of seeing a patient. Many issues can be dealt with directly between specialist and GP, but funding is not structured for this approach. Funding in some DHBs is structured around FSAs, DRGs and follow-ups, and does not encourage innovative use of specialist capacity.

Under current models of care the specialist capacity for such roles is also constrained. Development of different models of care, such as around more intensive use of nurse specialists and increasing doctor/consultant discussion, could encourage more innovative practice.

### **Appropriate mix of treatment modalities**

Whilst offering the full range of treatment modalities, New Zealand has among the highest proportions of ESKD patients treated with home dialysis (both PD and HD) in the world.<sup>16</sup> This has emerged from a mixture of philosophical position favouring this form of treatment, evidence of better patient outcomes and quality of life, and lower costs of such treatments.<sup>23</sup> There is significant variation across New Zealand DHBs in the mix of dialysis modalities that are offered. These include application of home therapies and approaches to satellite care, reflecting different population needs and differences in how services have developed.

Where dialysis is indicated, a continued focus on home/community or self care dialysis treatment is favoured, where patients have sufficient independence and where such services are available. It is also clear that kidney transplantation is a cost-effective intervention delivering improved quality of life and life expectancy.<sup>1 19</sup> However, the National Renal Advisory Board advises that not all patients can have a kidney transplant and not all dialysis patients can be treated in the community. Unfavourable community circumstances, lack of family support, other medical problems and complications of treatment, require that full care dependent haemodialysis facilities are available.<sup>5</sup>

### **Kidney donation and transplantation rates**

For health planners and policy-makers, kidney transplantation offers a rare combination of markedly improved health outcomes and relatively lower long-term costs. Transplantation is the treatment of choice for all medically suitable kidney failure patients, and offers significantly improved quality of life and long-term survival. However, compared to renal dialysis, transplantation numbers are quite low. The number of kidney transplants performed nationally in 2005 was 93 (in 46 of whom the kidney came from a live donor, and in 47 from a deceased donor), a decrease from 111 in 2003 and 105 in 2004, and the lowest since 1994.<sup>11 24 25</sup> There is a trend towards greater reliance on live kidney donors, which doubled between 1995 (24) and 2005 (47).<sup>10 11 24</sup>

New Zealand's kidney transplantation rate is relatively low compared to the United States and European nations, although similar to Australia.<sup>16</sup> This is primarily due to a low donation rate (for reasons discussed below).<sup>23</sup> The shortage of kidney donors is likely to continue, although efforts should focus on increasing the number of potential donors. However, given that the limited supply is likely to continue, a continued emphasis is needed to ensure that the patients offered transplantation are the ones most likely to benefit.

Improving the rate of live donation will require increased public awareness of how to donate a kidney, what living with one kidney means, what is involved in donation and transplantation, and the benefits of donating a kidney.<sup>1</sup> Recently, live kidney donors became eligible to receive the sickness benefit in the recovery period following surgery, which gives some recognition of the impact that such surgery has on donors. There are also models from overseas for paying donors, which warrant consideration, although this is likely to be an area of considerable public debate.

Continued use of deceased donors is also supported, although this source of supply has declined over the past decade. This is due to a number of factors, including an ongoing decline in strokes and road traffic fatalities; implementation of evidence-

based guidelines for management of severe traumatic brain injury; and improvements in technologies and treatments for subarachnoid haemorrhages. Organ Donation New Zealand has initiated a multi-faceted programme to ensure that every opportunity for organ donation is recognised and the opportunity to donate is offered to all families of suitable potential donors. This will be achieved through developing 'link teams' in intensive care units across New Zealand to coordinate organ and tissue donation and retrieval from brain-dead patients; provision of liaison, support and advice to link teams; and training programmes for intensive care doctors and nurses in organ and tissue donation.

### **Availability of transplantation services**

A further issue is the ability of the three New Zealand transplant centres to offer transplant operations, and internal barriers to carrying out transplants. Approximately 400 New Zealanders are currently on the kidney transplant waiting list, and most can expect to wait three to four years.<sup>26</sup> Assessment processes for recipients can take six to nine months in some DHBs. There are few parameters within DHBs on referrals and timeframes, and potential donors are often required to put their lives on hold until surgery can occur. Access to operating theatres for live donor transplants, which are treated as scheduled procedures, can pose further delays, as DHBs frequently struggle with prioritising transplants over other procedures.

### **Growing demand for renal services**

As indicated above, provision of renal services in New Zealand has consistently grown above the change in demographic growth and the cost therefore has exceeded the rate of inflation for the past decade. Given the obesity epidemic, the ageing population and the relatively young Maori and Pacific populations, we can expect a continued growing need for renal services. Although previously the Ministry of Health recognised growth of at least seven percent and budgeted accordingly, there is no such recognition of increased costs under population-based funding. An agreed funding stream is required within which renal services can be planned.

The steady increase in demand for dialysis treatment requires additional operational costs associated with increases in staff such as nurses, technicians, pharmacists, social workers, dieticians, occupational therapists, nephrologists, radiologists and other medical staff, surgical and vascular expertise.

The growing demand also requires additional capital funding of backup facilities such as in-centre and satellite facilities, inpatient beds, radiological facilities, and operating room time.

Current trends in renal services reveal a disproportionate increase in the number of new patients aged 65 years and over, with accompanying expectations of availability of dialysis support. As the age of patients increases, issues that will need to be addressed include the practicalities of treating older patients who may be less mobile and require greater personal support, the social and ethical implications of increasing access for older people to limited resources (especially donor organs), and the higher cost of providing services to elderly patients.<sup>23</sup>

## **Inequality of service distribution and unmet need**

The DHBs that operate as centres for renal services are Northland, Waitemata, Auckland, Counties Manukau, Taranaki, MidCentral, Waikato, Canterbury, Capital and Coast, and Otago. Many DHBs have developed 'hub and spoke' arrangements with neighbouring DHBs for the provision of renal services.<sup>2</sup> These are intended to improve access to renal services at a regional level, to effectively utilise capital resources and to minimise duplication of services.

Nevertheless, where services are not provided in situ, there tends to be unequal provision of renal services. As a result, there is likely to be some unmet need in many rural areas, which is as yet unidentified. For example, when renal services were provided in Northland, demand for service quickly grew, meeting needs which had previously been unidentified. Funding and workforce constraints limit the extent to which incentre and satellite dialysis can be provided. Improving access is therefore also an issue of how different modalities can be appropriately provided and how other assistance, such as transport and accommodation, can be made available.

A further constraint that could compound service inequality is that despite the facility-intensive nature of renal services, DHBs are only funded through IDF funding for services rather than capital development. This funding arrangement, unless factored into regional planning between DHBs, places additional pressures on renal centres. In the population-based funding formula environment there is a need to refine prices for services through the national pricing programme, to ensure appropriate transfer of IDF funding.

## **Workforce**

There are currently 37 adult nephrologists and three paediatric nephrologists nationally, of whom 11 are part-time. At present there are at least three vacant positions and more nephrologists will be required in coming years. Although there are currently a number of advanced trainees it is not expected that they will be able to fill all the expected positions. Other key workforce shortages are in the areas of dialysis nurses, dialysis technicians, dieticians, health psychologists and social workers. There is a need for timely building of staff and capacity in the renal workforce to keep pace with growing demand for services.

Renal providers need to think creatively about the skills their workers will need in the future, and create roles and training to reflect those needs. Trends in similar services in NZ (such as diabetes), and renal services internationally, indicate that an effective way to respond to the growing demand for renal services lies in the development of new roles within the renal workforce, such as nurse practitioner. There may also be benefits in developing links to these new roles within the primary health sector, dealing with the early stages of CKD as part of a comprehensive package addressing chronic disease in general (incorporating cardiac and diabetes in particular).

This could be an attractive field of work for renal nurse specialists, offering flexibility and a community base. Such working conditions are likely to promote workforce retention. However, training for specialty nephrology nursing is currently provided on an ad hoc basis from within renal services, and there is no nationally agreed clinically-based curriculum for this training. Consequently, the quality and quantity of training is variable between centres. This exacerbates the problem of

shortages of skilled nurses. An agreed strategy is required for training skilled nephrology nurse specialists/practitioners for the future. The New Zealand Board of Nephrology Practice has recently developed such a curriculum for the training of dialysis technicians with the first two trainees recently starting in Auckland Hospital

### **Patient perspectives**

The experience of the patient in renal services is a perspective that should not be ignored in strategic planning in the sector. For example, home-based treatments afford substantial efficiency gains for the health system, and maintain the independence of the patient. Effectively dealing with CKD can in many respects enhance the patient's sense of self-worth. Yet patients are also expected to bear many basic costs, such as pharmaceutical part-charges, and electricity and water services, which are associated with either treatment or necessary equipment. Arguably, the savings that these patients are affording the system deserves some recognition to meet the additional costs that their treatments bring.

Those who manage their own dialysis independently develop a significant set of knowledge of their self care. This form of learning has parallels with 'expert patient' models of self care that have been developed in the UK. The approach helps people to learn more about their own illness, and how to manage it effectively without always depending on professionals for support.<sup>27</sup> Such models have applicability in the renal sector in New Zealand, and potentially could be extended to bring renal patients in as part of the health team, drawing on their skills as people who know intimately the detail of their care and the impact that treatment options have had.

### **Information infrastructure**

Interventions for CKD and related co-morbidities for individual patients occur across geographical boundaries, as well as across the entire care spectrum from primary to tertiary care, including community settings. Each of these points of intervention occurs as one component of the chronic patient care continuum.<sup>6</sup> Together they generate significant quantities of data, but these are generally disparate and not integrated into a single information system. Without an information infrastructure, it is impossible to track the progress of patients along the primary and secondary care pathways, and to ensure that they are receiving the appropriate treatments. There is currently considerable variability in the quality of information systems to support this level of integrated care.

The NRAB favours development of an integrated national information system that is able to receive, organise and manage large amounts of data in order to optimise patient care. Such an information system should interface with existing hospital, general practitioner, lab and pharmacy databases to streamline patient care across geographic boundaries, and monitor dialysis and transplant therapies and outcomes. If implemented, this would provide a systematic approach to new patient referral, monitoring and management; enhance the ability to predict volumes and resource requirements; improve clinical outcomes (including reducing progression rates towards ESKD); and reduce cost in some areas of renal service provision through delayed onset of chronic renal disease, improved drug utilization and workforce management practices.<sup>28</sup>

The NRAB has sought funding for a scoping and establishment project to assess feasibility of such a system; to date this has not been forthcoming. The problem of

information integration is not confined to CKD however; action on improving the information environment for chronic disease management in general could offer significant gains for management of many chronic conditions, including CKD. Action in this area would be consistent with the key directions identified for the information environment in the next phase of the Primary Health Care Strategy.

### **Clinical research knowledge base**

There is a lack of clinical research in New Zealand, particularly in terms of how the factors that make New Zealand unique in provision of renal services, such as CKD among Maori and Pacific populations and effective interventions to reach these groups; the actual prevalence of CKD 3, 4 and 5 in NZ (including causes, co-morbidity, progression rates, survival to ESKD); outcomes from PD versus HD in the elderly in NZ; and regional incidence of CKD and access to renal care.<sup>14</sup>

### **Regional responses**

Although there is clear evidence of growing demand for renal services, there has been no national coordination of planning in this area. Significant work has been undertaken in the Auckland and Midland regions. Work is also underway in Canterbury, MidCentral and Wellington to develop regional plans.

In 2005, the three Auckland DHBs collaborated to develop the *Auckland Regional Renal Project*.<sup>1</sup> The objective was to produce a document that reflected the views and expectations of renal clinicians in the three DHBs, and to have a common and planned approach to the development of renal services across the region. The report identified recommendations around eight themes:

1. Choice of renal replacement therapy
2. Transplantation
3. Quality of patient care
4. Access to renal care
5. Promote new knowledge/practice in primary care
6. Workforce: Renal technician training
7. Information Infrastructure
8. Facilitation of renal care

The Midland group of DHBs, comprising the Bay of Plenty, Lakes, Tairāwhiti, Taranaki and Waikato DHBs, together commissioned the *Renal Service Plan for the Midland Region* in 2004.<sup>2</sup> The plan's objective was to ensure a planned approach to prevention, treatment services, workforce development and data management. Recommendations from the plan encompassed:

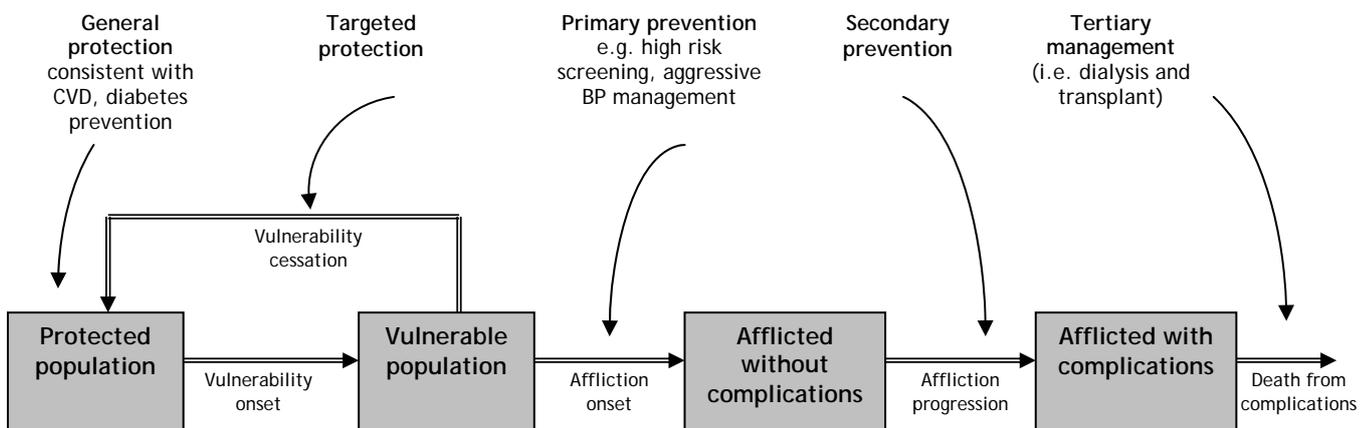
1. Changing practice, particularly a shift from PD towards greater use of HD
2. Workforce retention and recruitment
3. Development of a chronic renal failure programme at primary care
4. Information management
5. Support for patients through the continuum of care
6. Transplantation
7. Equity of access across the region using a hub and spoke model
8. Systems development around FSAs and Subsequent Attendance volumes

## The case for a national strategic plan

Renal services comprise a small but expensive and steadily growing area of DHB services, a trend which is likely to continue. Dealing with the growth of renal services requires a strategic solution, which takes into account the complex factors at play. Beyond the regional initiatives discussed above, there are few examples of coordinated efforts to develop renal services with a view to meeting long-term demands. There is a need to develop a national framework within which regional services can be planned to meet local needs and conditions, working to a five to ten year timeframe. The aim of such a framework should be to prevent, delay onset and better manage CKD so that in the long term, its burden to the health sector and society is reduced.

Such a framework should take whole system perspective, integrating renal services with other services across the spectrum of prevention, management, treatment and palliative care. A possible approach is presented diagrammatically in figure 3 below (adapted from concepts developed by USCDC and which underpin CMDHB's *Let's Beat Diabetes Strategy*<sup>29 30</sup>). This approach places CKD within a continuum of care that tackles its causes, better manages prevalence, and in the long term reduces incidence.

Figure 3: A system-wide approach to CKD



The major contributions that a national strategic framework could add are in the following areas:

- **Planning across spectrum of prevention, management and RRT:** Renal services are part of the continuum of care from prevention activities through to end stage treatment. Actions at earlier stages of the continuum can fundamentally affect outcomes in renal services. A system orientation, as depicted above, is needed that emphasises CKD prevention and management as key partners with renal services and provides a model to deliver patient-oriented care.
- **Foundation for improved interface with primary care:** A national framework could establish a basis for facilitating innovation, information infrastructure and stronger linkages between primary and secondary care, to promote better patient management and prevent or delay onset of ESKD. Supporting this approach could

be assessment of CKD burden of disease to better identify the target groups for screening/intervention, and developing information tools or guidelines for primary care management of CKD (consistent with, and building on, existing guidelines for type II diabetes and cardiovascular disease).

- **Transparency of service provision:** At the present time there is no transparency as to what is provided in different areas of the country. There are some patient level KPIs which are set out as standards and audited nationally on an annual basis, but there are no such standards or audits of service provision. A national framework, with an agreed funding stream, would assist with identifying what constitutes a minimum standard of clinical service in terms of renal replacement therapy and workforce requirements. DHBs could then plan accordingly, in line with identified local needs.
- **Establish high level principles for regional service planning:** A national framework would set the overarching objectives for regional renal services. These could include ensuring access for patients, providing the right treatments to the right people at the right time, ensuring funding for services tracks growth in demand, providing locally-appropriate solutions.
- **Responding to CKD in Maori and Pacific populations:** The continued increase in rates of obesity and type II diabetes in Maori and Pacific populations is likely to place increased pressure in future years on CKD management programmes and RRT services. A national framework should give attention to the particular needs of these populations and support ongoing development of approaches to improve CKD prevention and management, and access to appropriate RRT.
- **Guidance for planning and service provision as demand escalates:** The lack of forward planning in many DHBs leads to frequent crisis management around increasing dialysis volumes. DHBs need to develop a five to ten year plan for renal services based on accurate modelling of demand for dialysis. This should include planning for dialysis facilities and staffing levels. A national framework would provide a basis from which such planning could be initiated.
- **Establishing access criteria:** To date, renal services have expanded to meet demand but without clear and systematic criteria to ensure transparency of service delivery and that treatment is provided to those with greatest ability to benefit. A national framework has the potential to provide guidance to DHBs to promote the best use of resources in this area.
- **Workforce planning:** A national framework would assist with identifying the key renal workforce needs and roles over the coming decade and promote DHB-level planning to meet these needs, focusing on training, recruitment and retention. This should include developing a nationally agreed renal nursing curriculum and a strategy to enhance local training of nephrologists and general practice.
- **Provide a focus for public and professional attention to CKD:** Establishing a national framework could assist in raising the profile of CKD, and means of prevention and management, across the public, health professions and government. It also provides an opportunity to showcase the benefits of transplantation and improved systems of management and service integration to a wide audience.

- **Improving CKD knowledge base:** A national framework could provide direction around improving national-level data collection and the introduction of new technologies, and could also provide a foundation to support the development of New Zealand-based research in this area.
- **Better mechanisms for capturing cost:** Robust cost-minimisation models to identify the least expensive model for dialysis provision for the same clinical outcomes could inform development of a national framework.

This paper has drawn attention to the significant growth in demand for renal services, a trend which is forecast to continue into the next decade and beyond. Although a large number of complex issues face renal services, the sector has to date succeeded in delivering a comprehensive range of services to New Zealanders.

What is now needed is a strategic approach that confronts the complexities of the issues, develops systems to optimise patient centred-treatment in a cost-effective manner, and takes a long-term outlook whilst taking action in the near to medium term. Such an approach would be consistent with the directions of overarching strategies for the New Zealand health sector.

The National Renal Advisory Board proposes that the Ministry of Health is best placed to lead work in this arena, and seeks support from DHB CEOs for such a work programme.

In promoting the advantages of developing a national framework, it should be recognised that there are consequences of not developing such a framework. These include piecemeal responses to service shortages, continued fragmentation of prevention and care, failure to meet growing service demand, and ongoing workforce retention and recruitment problems.

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