Renal disease is one of the few sectors in the health system where better services can be achieved at lower cost.

It is estimated that more than 400,000 New Zealanders live with Chronic Kidney Disease (CKD). That is more than the number diagnosed with diabetes. Some 4,500 New Zealanders have end-stage kidney disease (ESKD), and this number is increasing by 5% each year. The prevalence of treated dialysis and transplanted patients (forms of Renal Replacement Therapy – ‘RRT’) has risen by 250% over the last 15 years.

The cost of RRT accounts for 1 to 2 percent of total public health expenditure. Dialysis alone costs New Zealand over $150 million each year, and is approximately 3 times more expensive than transplantation on a per patient per year basis.

Prior to the last General Election, Kidney Health New Zealand (KHNZ) offered an initial Blueprint for better and lower cost services to renal patients in New Zealand, highlighting seven priority areas for improvement:

1. Addressing New Zealand’s internationally low rate of deceased renal transplantation.
2. Facilitating pre-emptive live kidney transplants.
3. Increased reimbursement of lost income for live donors.
4. Reducing barriers to home dialysis.
5. Improving support for home dialysis patients.
6. Improving access to ‘away from home’ dialysis for haemodialysis for patients needing to travel for work or family reasons.
7. Improving General Practitioners’ knowledge of how to identify and best manage Chronic Kidney Disease in the primary healthcare setting.

Significant progress that has been made against four of these priorities – as a result of ongoing lobbying by Kidney Health New Zealand, and cross-party Parliamentary support over the past three years to a number of initiatives. These include:

1. A Ministerial review of deceased organ donation practice in New Zealand and the subsequent development of a national strategy for increasing New Zealand’s rate of deceased organ donation.
2. Through the dedicated work of the National Renal Transplant Service, the achievement of an increase in both the overall number of kidney transplants and those pre-emptively offered (i.e. patients receiving a kidney transplant before needing to go onto dialysis).
3. The passing into legislation of the Compensation for Live Organ Donors Act late last year, proving 100% reimbursement of lost income for live organ donors – the result of unanimous cross-party support.
4. The rollout across New Zealand of the Government’s initiative to prioritise early identification and intervention for CKD in the primary healthcare setting – benefitting the more than 400,000 New Zealanders with CKD.

But we’re not there yet. There are still significant opportunities to increase the quality of services to renal patients, while reducing costs to the health sector.

**Blueprint II: Improving Renal Services in New Zealand** sets out a further two priorities that KHNZ believes are fundamental to continuing the progress already made in improving the health and wellbeing of the growing number of renal patients in New Zealand, and ensuring that New Zealand offers world class renal services:

1. **Ensuring that the implementation of the Government’s Strategy for Increasing Deceased Organ Donation is sector-driven and adequately funded**
2. **Ensuring timely, equitable and nationally consistent delivery of dialysis treatment**

The rationale underpinning these two priorities follows.
Ensuring the implementation of the Government’s Strategy for Increasing Deceased Organ Donation is sector-driven and adequately funded

What is the issue?
Organ transplantation is a life-saving treatment that is often the best, or only, option for people with organ failure. A transplant can improve a person’s quality of life, their life expectancy, and therefore their ability to contribute both socially and economically as full and active members of society.

While New Zealand’s rate of deceased organ donation is increasing, it is still relatively low compared to rates in other countries.

In early 2015 the Minister of Health initiated a review of deceased organ donation and transplantation in New Zealand. A sector-wide Expert Advisory Group was established to support this task, with a subsequent Sector Working Group tasked with developing a National Strategy for increasing deceased organ donation in New Zealand. Assisted by the Ministry of Health, the Sector Working Group included a broad range of specialists working in this area, including intensive care and emergency department specialists and DHB management representation. Kidney Health New Zealand was represented on both the initial Expert Advisory Group and the subsequent Sector Working Group (SWG). A draft National Strategy was delivered to the Minister in May of this year, and KHNZ understands that a formal launch of the Strategy is scheduled for late July.

Recommended action
Whether or not the Government has accepted all of the recommendations of the SWG, it is critical to the success of New Zealand’s National Strategy for Deceased Organ Donation that it is

a. fully owned by the sector that will be responsible for its implementation, and
b. adequately funded.

Throughout the review process and the development of the Strategy, it has been clear, for example, that the role and support of Intensive Care Unit (ICU) physicians and nursing staff will be critical to the Strategy’s success. While international evidence shows that it is the implementation of a comprehensive and integrated national strategy (as proposed by the SWG), rather than any single initiative, that is essential to increasing deceased organ donation rates, so too does research show that any such strategy needs to be championed by those holding day-to-day responsibility for its implementation.

The Strategy will need to place greater emphasis upon the role that ICU staff across the country have to play in the organ donation process, and provide those staff with adequate training and ongoing support. Other changes to the current processes for coordinating deceased organ donation can also be expected to feature in the Strategy. It is therefore equally vital to the Strategy’s success that it is appropriately and adequately funded. Funding will need to be made available for any increase in the responsibilities carried by ICU staff, for example, as will additional funding to cover the cost of any increase in ICU and transplant unit workload as a result of anticipated increases in deceased organ
donation rates. Again, both sector input and a strong governmental lead will be needed to ensure this funding is delivered.

What will it cost?
As with the rationale for increasing the level of financial support available to live organ donors, the savings to the health budget from increasing organ transplantations through increasing deceased donation rates will far outweigh the additional costs incurred. It is estimated that that each donor transplant saves the health budget at least $125,000 over the course of that patient’s lifetime, excluding any additional private financial benefits such as the increased earning capacity of patients who are able to return to the workforce after receiving a transplant.\footnote{Compensation for Live Organ Donors, Elisabeth Prasad, NZ Initiative, 2015} As the following table demonstrates, not only is there a significant cost saving from a patient on dialysis receiving a kidney transplant, their active life expectancy – and therefore their ability to contribute to both the economy and their community - also dramatically increases.

\begin{table}[h]
\centering
\begin{tabular}{|l|c|c|c|c|}
\hline
Treatment & Life expectancy (years) & QALYs & Lifetime costs (7% discount rate) & $/QALY \\
\hline
Dialysis & 55.00 & 3.4 & $280,811.84 & $82,529.09 \\
Transplant & 63.11 & 11.0 & $157,459.16 & $14,299.34 \\
\hline
\end{tabular}
\caption{Comparison for RRT for a 50 year old male\footnote{Ibid.}}
\end{table}

2. Ensuring timely, equitable and nationally consistent delivery of dialysis treatment

What is the issue?
Renal replacement therapy (RRT) is treatment to replace kidney function when a patient reaches end-stage kidney disease and includes either dialysis or a kidney transplant. In 2015 (the latest data available)\footnote{New Zealand Nephrology, Annual Data Report 2015} over 500 adults and children started RRT – the majority commencing dialysis. Overall, nearly 2,700 New Zealanders were being treated with dialysis by the end of that year – continuing the year on year increase that the graph overleaf highlights.

While the rate of starting dialysis or kidney transplant treatment for European New Zealanders seems to be trending downwards, the equivalent rate for Māori and Pacific patients is substantially higher; nor is it decreasing. Overall, 156 patients starting dialysis treatment in 2015 were Māori (30% of all patients) and 104 (20%) were of Pacific ethnicity. Inequities in the incidence of end-stage kidney disease based on ethnicity have persisted over time.\footnote{Ibid.}
Nearly half (47%) of all patients starting renal replacement therapy in 2015 had kidney disease caused by diabetes. This rate was substantially higher than the comparable rate in Australia (37%) and is indicative of the complexity of end-stage kidney disease care in New Zealand and the consequences of diabetes on the health of New Zealanders. Over half of all patients (54%) treated with dialysis have diabetes, and this rate has increased from 45% in 2006. As is well-recognised, the prevalence of diabetes amongst those of Māori and Pacific ethnicity is considerably higher than that of the general population, further compounding this inequality.

The 2015 New Zealand Nephrology Annual Data Report (already cited) draws upon clinical and demographic data from the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry, as well as information provided by the National Renal Transplant Service. A number of areas for further investigation and action are identified in the report, adding further weight to KHNZ’s own concern to see more timely, equitable and nationally consistent treatment available to dialysis patients. These include:

- Low permanent vascular access rates for haemodialysis patients
- Disparities in RRT treatment rates among Māori and Pacific patients and younger patients
- Issues of access to Home Dialysis

### Permanent vascular access:

Over 60% of patients commencing haemodialysis started treatment with a temporary dialysis catheter. This is a sign of a system failure to engage the patient in timely planning for dialysis. Starting dialysis on this “temporary” access is associated with worse patient outcomes (higher risk of procedures, serious infections, and hospitalisation). Additionally it creates a barrier to earlier transition from in-centre dialysis to home dialysis – representing a saving of some $25,000 per new dialysis patient per annum. Currently none of New Zealand’s renal units achieved the national standard of 50% of patients commencing haemodialysis with permanent
vascular access. KHNZ suggests that, given the clear patient and economic benefits of prioritising permanent vascular access, much greater emphasis – and, where necessary, funding – needs to be directed towards improving the levels and consistency of pre-dialysis training, and to ensuring surgical waiting lists have the capacity to prioritise vascular access procedures.

Disparities in Renal Replacement Therapy treatment rates across age and ethnicity:
While the number of NZ European patients commencing dialysis has remained relatively stable, the number of Māori and Pacific patients receiving dialysis continues to increase.

Similarly, there is persistent inequity in access to transplantation based on both ethnicity and age. In 2015, no Māori patients and only 2 Pacific patients received pre-emptive kidney transplantation compared with 21 New Zealand European patients. In the last 5 years since 2011, 3 Māori patients had pre-emptive transplantation compared with 82 New Zealand European patients – a 27-fold difference. Only one child (aged below 15 years) received a pre-emptive transplant in 2015.

Children and young adults also have the highest rate of starting dialysis care after late referral – a figure that has remained static at 25-30% of children starting dialysis. This compares with an overall late referral rate of 8.5% of patients. Late referral reduces the opportunities for patients to start dialysis care with permanent vascular access, with their preferred dialysis modality, or a kidney transplant as first treatment for kidney failure.

Issues of access to Home Dialysis:
International evidence consistently supports the benefits of home dialysis as opposed to facility-based (i.e. in a hospital or satellite renal unit) dialysis – both in terms of patients’ health outcomes and in terms of reduced cost. It is estimated that the cost of supporting a patient on home-based haemodialysis is up to $25,000 per annum less than were that same patient to receive facility-based dialysis. Despite this, less than half of patients on dialysis in New Zealand are dialysing at home.

There is also considerable variability in terms of home dialysis rates across the 11 renal units in New Zealand. In fact, most renal units sit well below the national average of 48% noted above. Both KHNZ and the authors of the 2015 New Zealand Nephrology Annual Data Report are particularly concerned that the proportion of patients on home-based dialysis is falling – with a growing proportion of haemodialysis patients dialysing within a hospital centre or satellite unit.

Recommended action:
With such variability in terms of RRT treatment provision across the country – in terms of ethnicity, age and clinical performance – there is a clear and pressing need for the development of key
performance indicators (KPIs) to ensure equitable access to the most appropriate renal replacement therapies for patients and clinical best practice.

While KHNZ is contributing to the Ministry of Health’s current development of a new Long Term Conditions Strategy – and, as part of that process, is strongly advocating for the inclusion of appropriate chronic kidney disease KPIs (see Appendix 1) – KHNZ believes that this is an issue of such importance that it requires a level of Government direction. KHNZ recommends that:

- The Government launch an investigation into age and ethnicity access to transplantation (especially pre-emptive transplantation) and access to dialysis (including the impact of late referral dialysis and variability of home dialysis rates)
- Irrespective of the findings of the investigation, the Government ensure that appropriate chronic kidney disease KPIs are developed for both primary and secondary care renal services, and that these are incorporated into both the Ministry of Health’s Long Term Conditions Strategy and the Tier Two Renal Service Specifications contained in the National Service Framework that District Health Boards are required to report against.

What will it cost?
The cost of an investigation would be about $150,000, the cost of which could be met by reprioritising existing Ministry of Health baselines. Any ongoing costs associated with ensuring equity of access to RRT and national consistency will only be known once the recommended stocktake has been completed. A business case for any funding requirements would need to be prepared once these costs are known.

Conclusion
The past parliamentary term has demonstrated the value of the growing working relationship between Kidney Health New Zealand and government. Much has been achieved; but there is more still to be done to address growing rates of chronic kidney disease in New Zealand and growing disparities. To reiterate: kidney disease is one of the few sectors in the health system where better services can be achieved at lower cost.

Kidney Health New Zealand looks forward to continuing to work with both Government and Opposition parties to ensure that the voice of the 400,000 kidney patients in New Zealand continues to be heard, and that New Zealand continues to develop and deliver world class kidney health services.

Dave Henderson
Board Chairman
Kidney Health New Zealand

Max Reid
Chief Executive Officer
Kidney Health New Zealand
Appendix 1

Key Performance Indicators for the care of patients with Chronic Kidney Disease in New Zealand
(Primary and Secondary Care)

Rationale:

Kidney Health New Zealand has commissioned the development of chronic kidney disease (CKD) Key Performance Indicators (KPI), with the purpose of developing and implementing indicators to measure the performance of Primary and Secondary Care teams for the management of CKD in New Zealand.

The aim of these indicators is to drive service improvement and increase efficiency and consistency of patient centered care through the transparent comparison of DHB performances.

These KPIs are focused on the patient journey through the renal unit. They are independent of, and are not designed to replace, any current or future targets of clinical care used by the renal teams of New Zealand.

Executive Summary of Proposed KPIs:

The KPIs are divided into two broad groups to reflect the patient’s journey within primary and secondary care.

<table>
<thead>
<tr>
<th>Primary Care KPIs:</th>
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<tbody>
<tr>
<td>1. All GP practices will develop and maintain a registry of patients with CKD</td>
</tr>
<tr>
<td>2. GP practices will undertake targeted and screening and monitoring of groups at high risk of CKD</td>
</tr>
<tr>
<td>3. Eighty percent of patients with CKD will have blood pressure within target range: blood pressure is 140/90 or less without proteinuria or 130/80 or less with proteinuria.</td>
</tr>
<tr>
<td>4. Ninety percent of patients will have their kidney risk explained</td>
</tr>
<tr>
<td>5. Patients with advanced CKD (stages 4+5) within New Zealand will have timely access to specialist care at a local renal unit</td>
</tr>
</tbody>
</table>

Secondary Care (Renal Unit) KPIs:

1. Greater than 90% of patients starting a renal replacement therapy, from Chronic Kidney Disease, will have been referred to a renal service at least 3 months before treatment is commenced.
2. All patients with advanced CKD, stage 4 and 5, known to a renal service will be cared for by a renal Multi-Disciplinary Team
3. Within 90 days of first specialist appointment with the renal service all patients, under 75 years of age, with Chronic Kidney Disease stage 4 or 5 will have a decision made as suitable for transplant assessment or not.
4. Greater than 80% of patients starting planned dialysis for progressive Chronic Kidney Disease will start dialysis with definitive access (either a catheter for those commencing on peritoneal dialysis, or permanent vascular access for those commencing on haemodialysis)
5. All patients receiving dialysis will be offered Advanced Care Planning
Appendix 2

STRATEGIC OBJECTIVES

Kidney Health NZ is a primary source of reliable & relevant information on the prevention and management of kidney disease

- Continuously review our resources to identify gaps/opportunities
- Intentionally promote prevention, early detection and management of kidney disease
- Strengthen links with Organ Donation NZ, Kidney Donor Action, National Renal Advisory Board, National Renal Transplant Service, Diabetes New Zealand, the Heart Foundation of NZ, and other allied organisations

Kidney Health NZ is the national voice for people with kidney disease and their families

- Promote changes to policy & service delivery models to improve both live & deceased kidney transplant rates
- Promote improved access to dialysis & greater use of home/community dialysis in particular
- Promote improved support for patients/families in the community, with a particular emphasis on improved home & social work support
- Promote early risk identification and early detection in line with the Ministry of Health's Chronic Kidney Disease Consensus Statement
- Following consultation, represent kidney patient support organisations on national or regional issues
- Develop a structured and deliberate programme of engagement with decision-makers on both the issues and the practical actions that can be taken

Kidney Health NZ is a leading advocate for world class kidney health care in NZ

- Advocate for the development and implementation of targeted CKD screening programmes
- Support & contribute to the development and delivery of CKD education in primary care
- Promote timely referral of advanced CKD patients to renal services
- Promote transplantation as the 'gold standard' Renal Replacement Therapy
- Promote home dialysis as a first option for patients
- Promote and support the adoption of best practice guidelines for all renal patients

Kidney Health NZ commissions research to support the organisation's objectives

- Develop & implement a policy on research funding (including annual priorities) enabling the commissioning, funding and dissemination of high quality ethical research that is closely aligned to its strategic priorities

OUR VISION

Better Kidney Health for all New Zealanders

GUIDING PRINCIPLES

KHZ is committed to maximising the wellbeing of people affected by kidney disease by

- Prevention and early detection of kidney disease in people at high risk of kidney disease
- Promotion of best practice in the management of people with kidney disease
- Maximising kidney transplantation

VALUES

- The pursuit of the highest standards of professionalism, quality and ethics
- The diversity and the independent roles of support organisations
- Collaboration through working with staff, volunteers, kidney support organisations, health professionals and the public
- The human rights and autonomy of patients with kidney disease and their families.