



Prevention • Support • Research

STRATEGIC PLAN

2014 to 2017

September 2014

KHNZ's STRATEGIC PLAN

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1. INTRODUCTION TO THE STRATEGIC PLAN

This document sets out the strategic intent of Kidney Health New Zealand (KHNZ) for the three years 2014 to 2017.

This Strategic Plan has been developed by the Board of KHNZ following extensive consultation with regional patient support groups. The detailed focus and priorities of the Plan will be reviewed annually in consultation with the Consumer Council – a group of representatives of regional kidney (renal) patient support groups.

This Strategic Plan sets out KHNZ's intent to:

1. Be the national voice for people with kidney disease and their families.
2. Be the primary source of reliable and relevant information on the prevention and management of kidney disease.
3. Commission research to support KHNZ's objectives.

In fulfilling this intent, KHNZ plans to be an organisation focused on kidney health and addressing:

- Diseases of the urinary tract and their impact on the whole person, their family and the social environment;
- Early detection in people at high risk of kidney disease and promotion of best practice in the management of people with kidney disease;
- Advocacy and support for those with kidney disease;
- Community education about prevention and treatment, and minimising the impact of kidney disease;
- Kidney transplantation.

2. ABOUT KIDNEY HEALTH NEW ZEALAND

History

The Kidney Foundation of New Zealand was established in 1979 to increase the rates of kidney transplantation and raise funds for research into the understanding, prevention and cure of kidney diseases.

Until recently, relatively little attention has been paid to the early detection of kidney disease in the community because of concerns about the effectiveness of such measures.

In 2007 different challenges meant that we needed to:

- Establish a single body representing the needs of all kidney patients
- Work with other NGOs e.g. Diabetes New Zealand
- Increase the rate of kidney donation in NZ
- Undertake research into the prevention of kidney diseases
- Ensure early detection and treatment
- Identify high risk individuals with early kidney disease who would benefit from intensive treatment
- Ensure access to effective treatment
- Increase the rates of home dialysis.

In response, the Kidney Foundation launched its new name in February 2008 as Kidney Health New Zealand, a Charitable Trust registered with the Charities Commission.

This strategic plan continues to address these issues, but with the added focus of KHNZ being the national voice for people with kidney disease and their families. This shift will sharpen the role of KHNZ, relative to other stakeholders in the prevention and management of kidney disease, and is intended to lift the role of patients in decision-making.

About KHNZ

KHNZ is an independent national organisation with a Board consisting of the Chair, and up to 6 Board members, elected by the Board and approved at the AGM.

Stakeholders include people with kidney disease, their families and supporters; kidney health professionals; researchers and 18 independent kidney patient support organisations.

Location and Access

Kidney Health New Zealand's national office is in Christchurch

KHNZ can be contacted at:

Phone: 0800 543 639 (0800 KIDNEYS)

Email: info@kidneys.co.nz

Web: www.kidneys.co.nz

3. THE CHALLENGES

Context

Kidney Health New Zealand exists within the wider New Zealand society and global context. As such, the implementation of the strategic plan will be affected both directly and indirectly by factors such as government funding priorities, growth in the number of people with kidney disease and changes in the design and delivery of services to patients.

The environment within which we operate is changing and thus KHNZ must accept the challenge to adapt and grow if we want to maintain our reputation and achieve our mission.

Future Growth in Kidney Disease

Predicting future growth in the number of people with kidney disease is a complex task due to the many variables and the level of uncertainty regarding factors which may lead to both increases and decreases in kidney disease.

Some of the factors driving change at a population level include aging, obesity, diabetes, heart disease, the changing ethnic mix and health technologies. The diabetes epidemic and the aging population are, and will continue to be, important but not the sole factors driving increases in the number of people with kidney disease.

The means of identifying high risk individuals with early kidney disease are still rudimentary. Early detection and treatment, particularly of hypertension and diabetes, is more cost effective than dialysis or transplantation.

Number of patients on dialysis

About 2,500 people are currently on dialysis. The number of people on dialysis in New Zealand is predicted to increase by 4-6 % annually. Nearly half of all patients are on hospital dialysis, despite the desire to increase community based dialysis.

Kidney Transplantation

Kidney transplantation rates are low by international standards, and have remained unchanged over the past ten years. This has led to an increased focus by both KHNZ and the Government on strategies to improve the rate of kidney transplantation, in particular live kidney transplantation. This increased focus is welcome. However, much needs to be done to ensure that the resulting changes are sufficiently comprehensive and effective, and are workable from a patient perspective.

Government

Other than the current focus on kidney transplantation, compared to other chronic diseases kidney disease is not seen as a priority. KHNZ will need to work with other NGOs such as Diabetes NZ and the Heart Foundation to obtain government support.

Population Profile

The population profile is also changing: Maori, Pacific and people of Asian descent (to a lesser degree) are more likely to be affected by kidney disease. These population groups are projected to make up a greater proportion of the New Zealand population over time.

Financial Challenge

KHNZ faces a significant financial challenge as we rely heavily on voluntary giving to achieve our goals. A number of other charities and worthy organisations compete for funding on a daily basis; thus our income remains uncertain. We must ensure KHNZ's long term sustainability by strengthening our revenue base.

KHNZ'S Board has approved this 3 year strategic plan to address these challenges and guide the development of priorities within the resources available.

4. STRATEGIC CONTEXT

1. VISION

Better Kidney Health for all New Zealanders

2. GUIDING PRINCIPLES

KHNZ 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;

3. VALUES

KHNZ 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.

4. MISSION

1. The national voice for people with kidney disease and their families

Being the national voice for people with kidney disease and their families involves advocating on such matters as:

- Strategies for improving the prevention of kidney disease
- Strategies for improving the management and outcomes of kidney disease, including:
 - Promoting transplantation
 - Promoting new models of care and service delivery
 - Promoting the adoption of consistent, best practice models of care and service delivery across New Zealand
 - Ensuring appropriate and consistent access to care.

KHNZ will:

- Outline key priorities to decision-makers, and work with them to improve outcomes for renal patients and their families
- Work with decision-makers to ensure that the identified priorities translate into tangible actions.

We have identified four goals if we are to be the national voice for people with chronic kidney disease and their families.

1.a Lead advocacy on national issues related to kidney health from the perspective of patients and their families

Objective 1

We will, following consultation, represent kidney patient support organisations on national issues either alone or in partnership with them.

Between 2014 and 2017, our focus will be on:

- Promoting changes to policy and service delivery models to improve rates of kidney transplantation in New Zealand – both live and deceased;

- Promoting improved access to dialysis, and greater use of home or community dialysis in particular;
- Improving the support for patients and their families in the community, with a particular emphasis on improved home and social work support.

Objective 2

We will develop and annually update a national advocacy plan to maximise our advocacy impact with decision-makers.

1.b Strong working relationships with kidney patient support organisations

Objective 1

To develop mechanisms to ensure that we are truly representative of the perspectives of patients and their families, we will:

- Advocate with, consult with and collaborate on behalf of kidney support organisations
- Meet annually with the Consumer Council

Objective 2

To support kidney patient support organisations, we will:

- Assist with publicity and media articles
- Provide speakers on education and other relevant topics as requested.

1.c Working with Ministers and Government Agencies

Objective 1

Ministers and Government agencies are critical decision-makers in the design and delivery of services to kidney patients and their families. We need to successfully

engage with Ministers and Government agencies not only on the challenges, but also the practical solutions that decision-makers can readily implement.

Under our annual advocacy plan (Objective 1), we will develop a structured and deliberate programme of engagement with decision-makers on both the issues and the practical actions that can be taken.

To progress this between 2014 and 2017 this we will:

- Develop, by mid-2014, a “manifesto” to political parties on ways to improve outcomes for renal patients, as expressed through KHNZ’s goals. The “manifesto” will help set a basis for engaging with Ministers and Government in the later years covered by this plan
- Advocate on other issues with, or on behalf of, kidney support organisations, following consultation or as requested.

1.d Promote kidney transplantation as the most effective treatment for kidney failure

Objective 1

We will work with decision-makers to improve the rate of live kidney transplantation in New Zealand.

Between 2014-2017 our points of focus will be:

- Support the development of a national kidney transplantation service by providing a patient perspective to its design and implementation
- Develop and promote a policy on reimbursement of costs (including lost income) for live kidney donors
- Identify and promote potential improvements in service design and delivery to improve live kidney transplantation rates
- Develop and promote a policy for better support for live kidney donors, including annual follow up medical checks for all live donors in New Zealand.

Objective 2

We will work with decision-makers to increase the number of deceased kidney transplantations.

Between 2014-2017 our points of focus will be:

- Identify the underlying causes for New Zealand's low rate of deceased kidney transplantation, and the strategies successfully used internationally to improve deceased kidney transplantation rates
- Develop and promote a strategy for improving deceased kidney transplantation rates in New Zealand.

2. THE PRIMARY SOURCE OF RELIABLE AND RELEVANT INFORMATION ON THE PREVENTION AND MANAGEMENT OF KIDNEY DISEASE

This will be achieved by being recognised as a credible source of information on kidney health and in creating greater awareness of the prevention, management and early detection of kidney disease.

We will be the primary source of information on both clinical and non-clinical information relating to the prevention and management of kidney disease.

To achieve this part of our mission, KHNZ has identified the following two goals.

2.a A credible source of information on kidney health

Objective 1

We will update our website and other sources of information to ensure that it includes the best current professional understanding and recommendations regarding the prevention and management of kidney disease, and present the information in a way that is relevant to NZ users including people with low health literacy.

We will:

- Continually review our website and address any gaps in content or content requiring updating
- Publish information and guidelines to patients, health professionals and other relevant bodies, on our website and by other means
- Provide information to kidney patient support groups on a regular basis
- Maintain regular newsletters to ensure patient organisations are kept well informed.

Between 2014-2017 our points of focus will be:

- Review and update the ***Non Clinical Support resources for Renal Patients and their Families*** information resource
- Develop resources for the caregivers of kidney patients on the supports available for them, including self support
- Fund and produce an educational DVD on treatment choices, for use by pre-dialysis educators

- Develop information for live kidney donors and provide support for a “Donor Association”
- Develop patient resources on:
 - Urinary tract infection
 - Kidney stones
 - How to find a kidney donor
- Develop and market test a concept of a consolidated “information pack” for new renal patients and their families.

2.b Greater awareness of the prevention, management and early detection of kidney disease

Objective 1

We will raise awareness of the significance of all types of kidney disease and seek to improve early detection and diagnosis.

We will do this by:

- actively promoting awareness and raising the profile of kidney disease and the role of KHNZ throughout New Zealand through websites, publications and media articles
- facilitating the development of coordinated national public relations and marketing strategies, particularly through the annual World Kidney Day
- building strong links with Diabetes New Zealand, and the Heart Foundation of NZ.

Between 2014-2017 our points of focus will be:

- Complete revision of the General Practitioner Chronic Kidney Disease (CKD) management guide to harmonise with KHA-CARI and KDIGO guidelines
- Contribute to further assessment of CKD pilots assessing the effectiveness of nurse led CKD clinics and electronic support packages for GP practices
- Prepare detailed plans for each World Kidney Day
- Promote KHNZ staff as speakers to community and health professional groups

- Review “value for money” of our current Grant-in-Aid programme with a view to improving support for kidney health professional education.

3. TO COMMISSION RESEARCH TO SUPPORT KHNZ'S OBJECTIVES

We will only be successful in our goals if our advocacy and information is underpinned by credible research. We will therefore commission and sponsor research to inform issues critical to patients and their families, with an emphasis on public/social policy.

To achieve this part of our mission, KHNZ has identified the following:

Implement a policy on research funding whereby we will fund and disseminate high quality ethical research that is closely aligned to our other priorities for 2014-2017.

For 2014-2017, this means priority will be given to ethical research that focuses on:

- Identifying the underlying causes for New Zealand's low rate of deceased kidney transplantation and how to address this
- Identifying changes to policy and service delivery models to improve rates of live renal transplantation in New Zealand
- Improving the support for patients and their families in the community, with a particular emphasis on improved home and social work support
- Improving the early detection of kidney disease
- The better management of chronic kidney disease, for example to delay or prevent the progression of the disease to end-stage kidney failure.