

ANZDATA Registry

Annual Data Report

For Patients, Families, Whānau, and Supporters.

2015

Treating People with Kidney Disease
in New Zealand



Report on behalf of the
Australia and New Zealand Society of Nephrology



National Renal Advisory Board



The ANZDATA Registry is funded and supported in part by the Ministry of Health of the New Zealand Government.

To the Dialysis and Transplant Communities in New Zealand,

Each year, the 4500 patients who are treated with dialysis or a kidney transplant in New Zealand share their information about the care they receive at one of 11 hospital units around the country. This information is shared with the ANZDATA Registry, which has worked to improve dialysis and transplant care for 40 years. ANZDATA is funded in part by the New Zealand government.

The information shared by patients with ANZDATA is released in reports to hospitals and health professionals to highlight progress in dialysis and transplant care and identify ways that dialysis and transplant care can and should be improved. Based on the most up-to-date information shared by patients in 2015, the highlights of care include:

- Access to a kidney transplant as *first* treatment for kidney failure is rare but increasing.
- 147 patients received a kidney transplant in 2015 – the highest number of kidney transplants in any single year in New Zealand.
- New transplant processes are increasing access to kidney transplantation for many patients and families.
- The chances of being referred to specialist services too late to prepare well for dialysis or transplant treatment is decreasing.
- Access to home haemodialysis therapy is staying steady.

The ways kidney care could be improved include:

- There are big differences in access to kidney transplantation between hospitals and patients.
- More patients are receiving hospital-based haemodialysis and fewer are doing peritoneal dialysis every year.
- Māori and Pacific patients experience a much higher need for dialysis therapy.
- Children are referred late for kidney specialist assessment more often than older people.

We hope the information in this report helps as a tool to strengthen kidney care by increasing shared understanding about the quality of hospital-based kidney care that New Zealand patients receive. We encourage you to use this report as a way to talk about kidney care and ways to improve treatments in New Zealand. We are deeply grateful to people with advanced kidney disease and their families who generously agree to share their treatment information to improve kidney care in the future.

Dr Suetonia Palmer and Dr Tonya Kara (on behalf of kidney specialists in New Zealand)

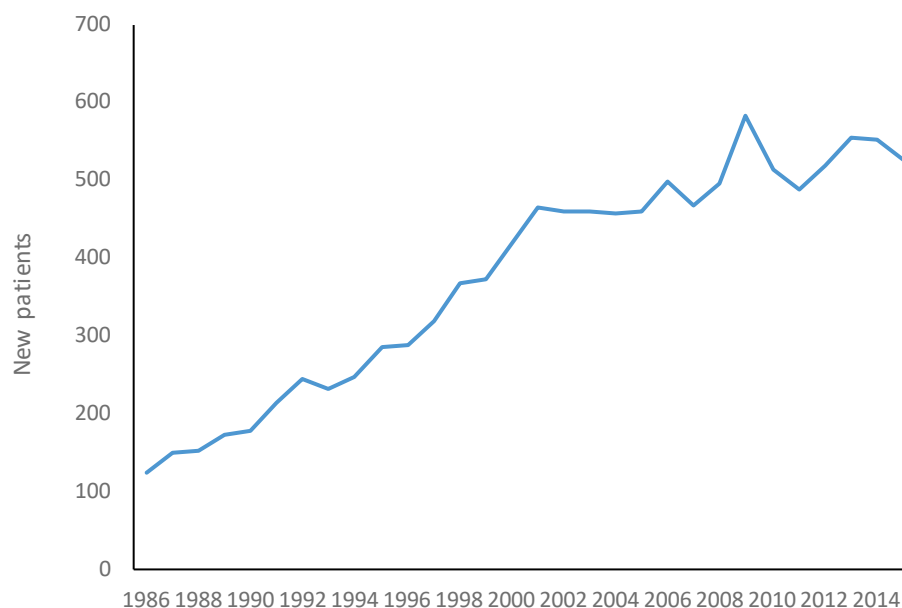
OVERVIEW OF ADVANCED KIDNEY DISEASE IN NEW ZEALAND

The ANZDATA Registry is a way to measure and monitor the number of people who need treatment for advanced kidney disease in New Zealand each year. As the natural population of New Zealand grows each year, the number of people who need a kidney transplant or dialysis increases too. Because of this, the number of people needing treatment is measured per every million New Zealanders. This can then be compared with previous years and other countries.

In 2015, 503 New Zealanders started dialysis and 24 people received a kidney transplant as their first treatment for kidney failure. This meant that 115 New Zealanders needed to start therapy for kidney failure for every 1 million New Zealanders (which is the same as about 1 in a 1000 people). This number is about the same as for Australia.

Based on the chart below, the number of people who needed to start dialysis treatment in New Zealand increased dramatically between the years of 1986 and 2006, but this increase has been much slower (and a bit more variable) in the last 10 years. The reason for this slower increase in the number of people needing to start dialysis in New Zealand might be due to better medical and lifestyle care for diabetes and blood pressure.

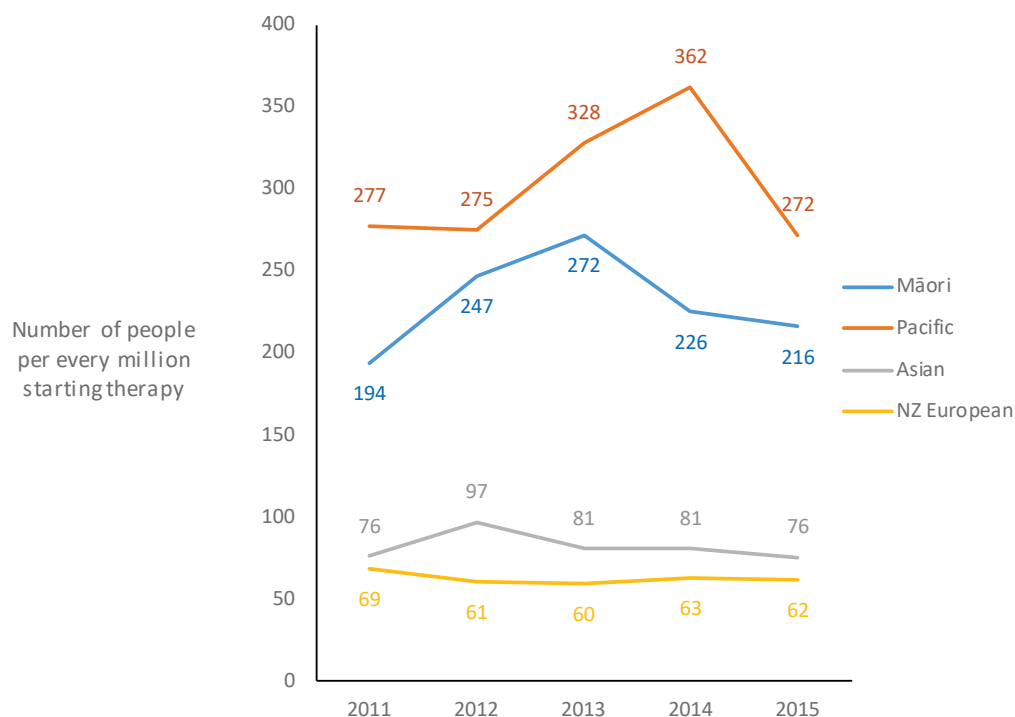
Number of people starting treatment for advanced kidney disease in New Zealand between 1986 and 2015



It is important to know whether particular communities are more at risk of starting dialysis than others. This helps to plan care services and identify when services are not working as well for some communities. It is likely that differences between communities in the number of people starting dialysis or transplant therapy are explained by life events that have occurred at a younger age including poverty and long-term health conditions such as diabetes.

It is noticeable that Māori and Pacific patients start dialysis treatment much more often than New Zealand European patients and those of Asian descent. The chart below shows that 62 people who were New Zealand European started treatment per every 1 million people in New Zealand, compared with 272 people who were of Pacific descent, and 216 who were Māori out of every million people. The chart also shows that this difference has not changed in the last 5 years. We need to learn more about why this is continuing to happen for some communities so that we can learn how to reduce the risk of dialysis treatment for *all* people in New Zealand.

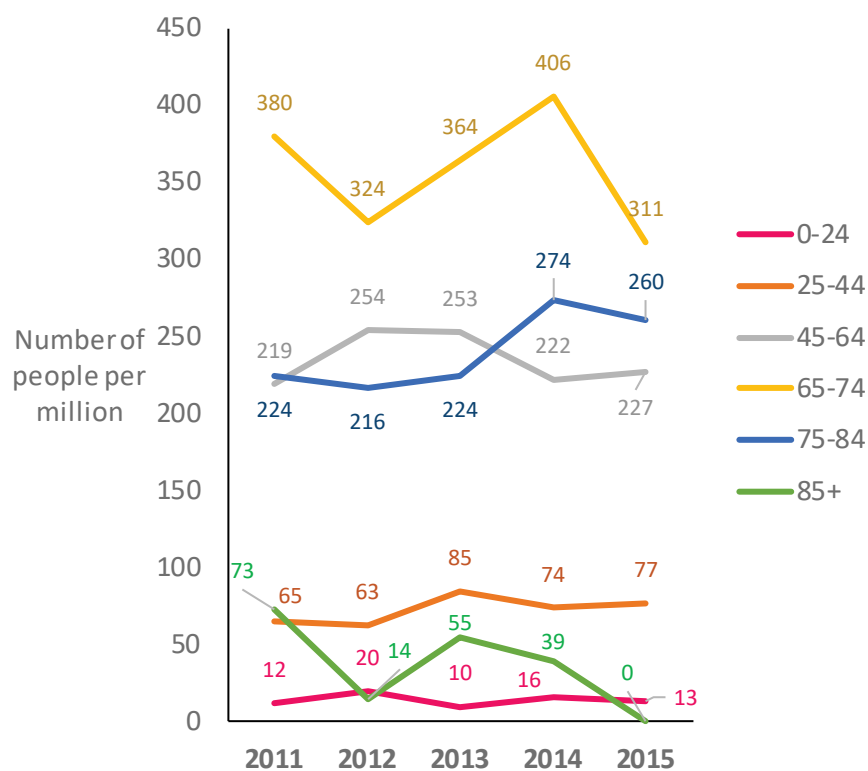
Number of people starting therapy related to ethnicity in New Zealand, over the last 5 years



It is also important to know whether age is a factor that predicts whether people will start dialysis or transplant care. Dialysis or transplant is recommended when people can expect to have better life quality and to live longer with therapy.

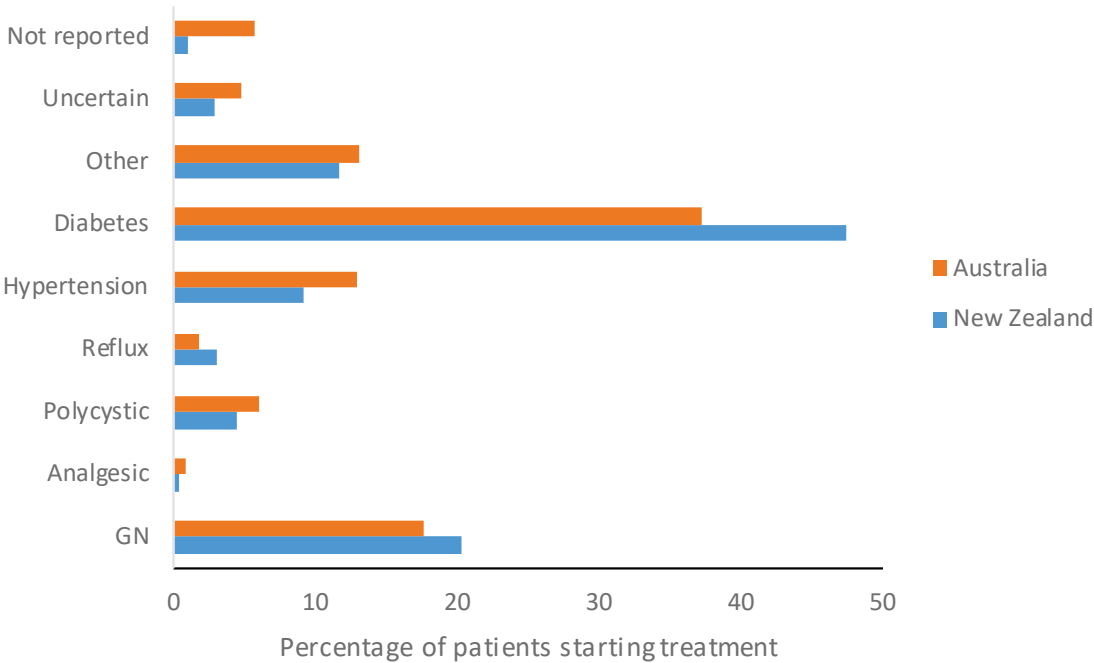
The chart below shows that people in New Zealand most commonly start dialysis treatment when they are older. The group of people with the highest chance of starting dialysis is those adults who are aged between 65 and 74 years old. The next most common group is people who are aged between 75 and 84 years of age. In 2015, no patient over the age of 85 years started dialysis care. This shows that with the aging population, it is likely that more people overall will be likely to start dialysis treatment over the next decade or more in New Zealand.

Number of people starting dialysis or transplant therapy based on their age group in New Zealand



The most common disease that causes the need for dialysis in New Zealand is diabetes. Nearly half of people starting dialysis care in 2015 had diabetes. This shows the burden that this disease is placing on communities and health systems. The number of people who start dialysis in New Zealand with diabetes is higher than in Australia, and this statistic is a cause for concern. It is likely that ways to reduce diabetes in communities might reduce the burden of dialysis in the years to come. New ways to prevent the complications of diabetes in children and younger adults are needed.

The diseases leading to people starting dialysis or transplant care in 2015 in both New Zealand and Australia



GOALS OF CARE

The ANZDATA registry exists to improve kidney care. The information in the ANZDATA Registry can help doctors, nurses, communities, and the government to measure the quality of the care being provided at the 11 hospital regions that provide transplant and dialysis care in New Zealand. This information can be used to improve health services and the lives of patients and families.

In this report, we have identified 8 specific aspects of care for dialysis and transplantation that could be measured to start a conversation about how treatments could be improved.

Goal 1: Starting therapy whenever possible with a kidney transplant

Children, adolescents, and adults can benefit from starting therapy for advanced kidney disease with a kidney transplant whenever this is medically suitable.

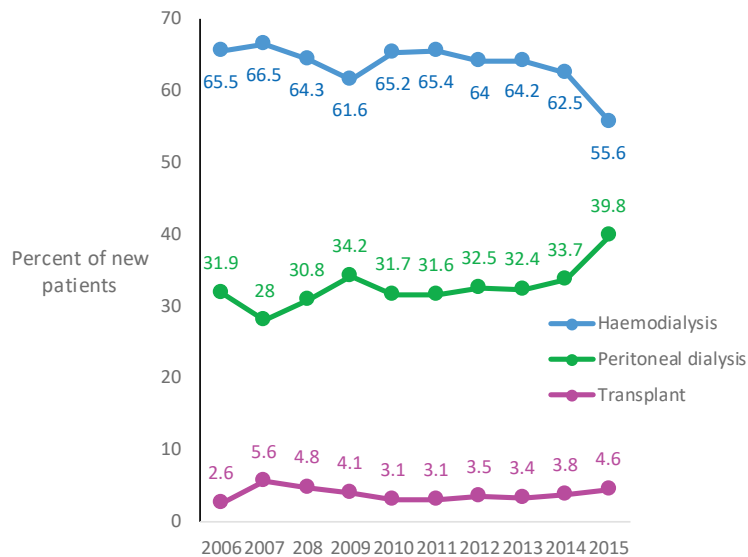
A kidney transplant -- receiving a kidney from another person -- is the best treatment for advanced kidney disease for many people. A kidney transplant leads to a much better quality of life and a longer life compared with dialysis treatment for many people. Receiving a kidney transplant requires complex assessment to know whether a patient will benefit from a transplant. This process can take many months.

Receiving a kidney transplant from a living person (such as a husband or wife, sister or brother, or friend) increases the chances of having a kidney transplant sooner than waiting for a kidney transplant from a deceased person. Many patients do not have the option of a living kidney transplant and can wait for many years to receive one.

Because of the complexity of finding a possible kidney donor and having medical assessment before being accepted to have a kidney transplant, most people start dialysis as first treatment for kidney failure.

The chart below shows that about 5 in every 100 patients who start treatment for kidney failure get a kidney transplant instead of starting with dialysis first. This number hasn't changed very much over the last ten years. The new National Renal Transplant Service (known as the NRTS) -- which was started by the government in 2014 -- is working to increase the number of people in New Zealand who get a kidney transplant. It will be important to check whether this new service can increase the number of people who have a kidney transplant as their first treatment (known as a *pre-emptive* transplant). The National Renal Transplant Service is now measuring how many transplants from living donors occur before a patient starts dialysis or soon afterward (within about 3 months) as a way to check on the quality of transplant care in New Zealand -- called a quality improvement metric.

The types of treatment started for severe kidney failure in New Zealand over the last 10 years



Goal 2: Access to kidney transplantation

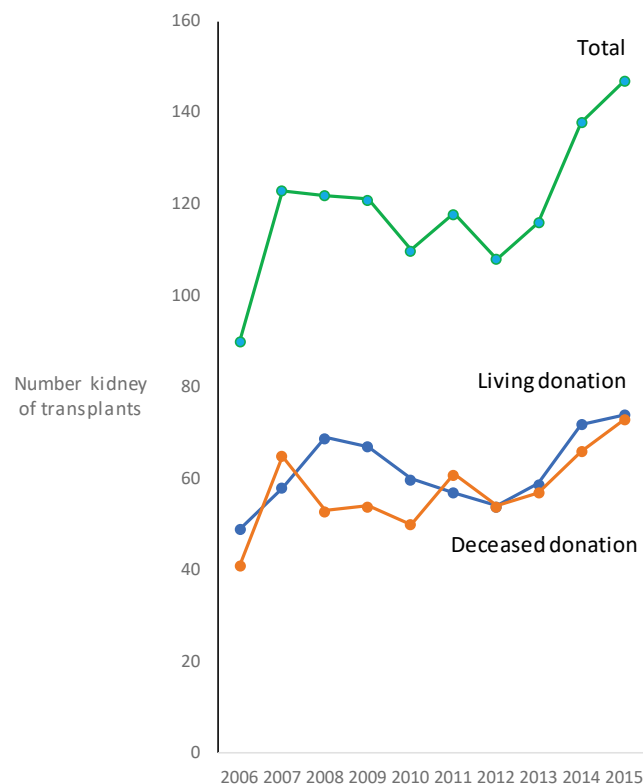
All patients who are medically suitable should have access to kidney transplantation.

As mentioned above, having a kidney transplant gives people a better quality of life and a longer life expectancy than many dialysis treatments. The number of people who receive a kidney transplant each year in New Zealand is an important measure of the quality of kidney transplant care in the country. In New Zealand, about 30 patients out of every 100 patients who are on the waiting list for a kidney transplant receive a transplant every year. This number is increasing: in 2011, only about 25 patients out of every 100 on the waiting list received a kidney transplant.

The total number of kidney transplants done in New Zealand each year is another way to measure the quality of care. In 2015, there were 147 kidney transplants in New Zealand. This is a large increase compared with 10 years earlier, when there were 90 in 2006. The increase in the number of transplants appears to have started in the last 2 years and is probably related to kidney teams and national services planning and developing services that help people get better access to kidney transplantation. It will be important to monitor this increase to see if it is sustained. About half of new transplants are from living donors and half are from deceased donors.

New ways to deliver kidney transplants such as the kidney exchange program and the ABO incompatible program are increasing so that New Zealanders can have better access to kidney transplants.

The number of new kidney transplants in New Zealand each year over the last 10 years



Goal 3: Starting haemodialysis with a fistula

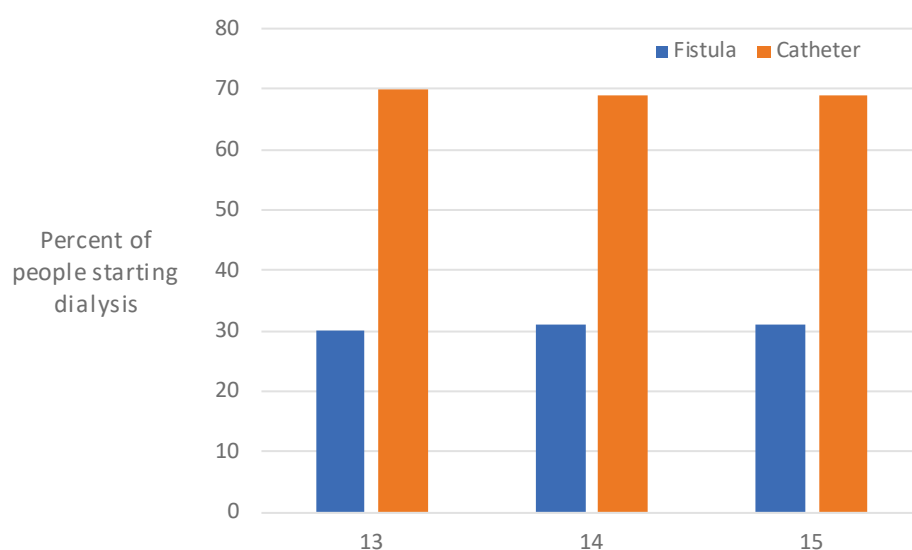
People starting haemodialysis will ideally start treatment with a fistula rather than a dialysis catheter.

Haemodialysis requires a connection with the patient's blood stream to clean the blood. This can be done using a large plastic tube that is placed in a large vein in the upper chest (catheter) or through a fistula (a connection made by a surgeon in the blood vessels in the arm under the skin). Using a fistula rather than a catheter is linked to better patient survival and a lower risk of needing hospital

admission. A fistula operation is needed at least a couple of months before starting dialysis so that the fistula can grow enough to support dialysis. The percentage of people who start dialysis with a fistula rather than a catheter is an important measure of the quality of dialysis care. Currently, the New Zealand nephrology standard is that 80% of patients who start dialysis in a planned way should start with a fistula.

In New Zealand, the use of catheters continues to be a concern. In 2015, 69 out of every 100 people who started haemodialysis started with a catheter. At some hospitals in New Zealand, only 10-20 patients out of every 100 who started dialysis had a fistula ready to use at their first treatment. This statistic has not improved and is likely related to access and coordination with surgical services. In New Zealand, many surgical teams that operate to make a fistula are located in another city or region and have other pressures on their service. This quality measure will be important to continue monitoring and better understand.

The percentage of people who start dialysis with a catheter or fistula over the last three years



Goal 4: Early kidney specialist assessment

People should receive a kidney specialist assessment at least 3 months before they require treatment with a transplant or dialysis.

Preparing for dialysis and a kidney transplant takes time and can be complex. Seeing a kidney specialist at least 3 months before treatment starts is the best way to make sure people have plenty of time to consider their treatment options and start dialysis well-prepared. Being seen by a kidney

specialist early helps to increase the chances of having a kidney transplant instead of starting with dialysis. Early assessment relies on general practice teams referring a patient to hospital services on time and for hospital teams to have available services to see the patient in the right time frame.

Delays in assessment can lead to lower chances of patients getting a fistula, having an early transplant, and choosing the best dialysis treatment for their needs.

In 2015, about one in every 8 patients saw a kidney specialist for the first time less than 3 months before they needed dialysis. This statistic is improving for patients who are aged between 25 and 44 years – five years ago, one in every 4 patients in this age group had a delayed first assessment.

The chart below shows that younger people in New Zealand have the highest risk of seeing a kidney specialist too late to plan for treatment. The purple line in the chart is for children and young adults who are younger than 25 years old. Over half of these younger patients saw a kidney specialist very late in 2011. This statistic has improved a bit, but is still much higher than for older people. This is most likely because it can be more difficult to notice kidney disease in younger people.

Improvements in blood testing systems and general practice care to increase awareness of kidney disease in children may help to improve care.

The percentage of people who have their first assessment by a kidney specialist within 3 months of starting dialysis treatment



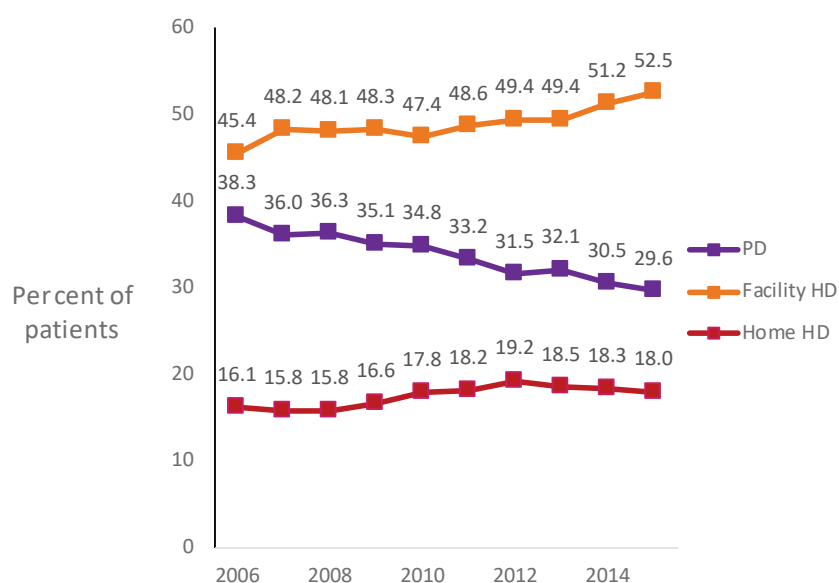
Goal 5: Access to home-based dialysis therapy

People should be supported to access home-based dialysis therapy whenever possible and preferred.

Home-based dialysis therapy can be linked to better quality of life and longer survival for some patients and can increase opportunities for patients to continue working and participate in schooling/training. New Zealand is the international leader in home-based dialysis care, with the highest proportion of home-based care in the world. The per cent of people in New Zealand who have home-based dialysis treatment may be decreasing because of the increased medical needs of people with advanced kidney disease. Home-based care is also dependent on a strong culture within kidney units to maintain home therapies.

In New Zealand, most people living with kidney failure have a kidney transplant. The chart below shows that about 1 in every 5 people who do dialysis are on haemodialysis at home (red line). This number is remaining reasonably steady over time. The number of people doing peritoneal dialysis is falling sharply and seems to be because more people are having haemodialysis in a hospital facility. This change may be due to increasing numbers of more frail patients accessing dialysis care, a change in the ways hospitals deliver dialysis care, or patient preferences (or a combination). It appears home dialysis based therapy may be decreasing in New Zealand due to fewer patients starting peritoneal dialysis.

The number of dialysis patients in New Zealand who do home haemodialysis, peritoneal dialysis, or dialysis at a hospital unit (facility)



Goal 6: Freedom from infection (peritonitis) with peritoneal dialysis

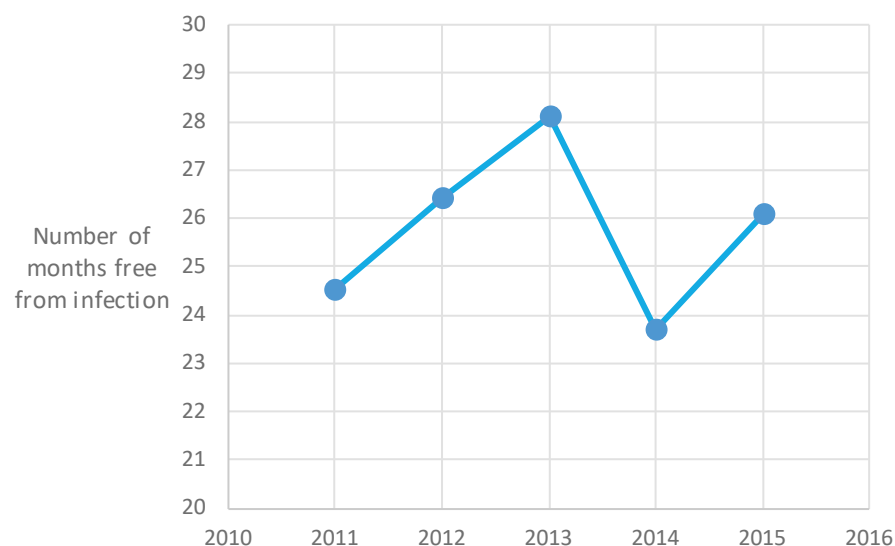
People treated with peritoneal dialysis can access care that decreases their risk of infection related to dialysis treatment.

Peritoneal dialysis involves exchanging about 2 litres of fluid in and out of the abdomen either 4 times a day or using an automatic machine at night time. Infection in the abdomen (peritonitis) can lead to hospital admission and failure of peritoneal dialysis. It is important to be well trained to do peritoneal dialysis by dialysis staff and to have a careful technique to reduce the chances of peritonitis. Measuring how long people doing peritoneal dialysis are free from peritonitis is an important way to monitor the quality of care. Usually, this statistic is measured as the number of months a person is living free from having a peritonitis infection.

The risk of peritonitis infection is related to several factors including the quality of training that patients receive to learn how to do dialysis, and the use of guidelines and protocols to prevent infection. In Australia, the number of patients having peritonitis has decreased dramatically in the last 5 years, following a big campaign to improve care. In Australia, patients can have about 30 months of dialysis treatment without having a single peritonitis infection (this was only about 20 months free from infection five years ago in 2010).

The chart below shows that in New Zealand, patients have about 26 months without peritonitis infection. This statistic is not quite as good as Australia and is currently not improving. It will be important to continue monitoring this statistic.

The number of months free from peritonitis infection for people treated with peritoneal dialysis in New Zealand.



Goal 7: Looking at the underlying variation in specialist kidney care in New Zealand

People treated with dialysis or a kidney transplant can access optimal care wherever they live in New Zealand.

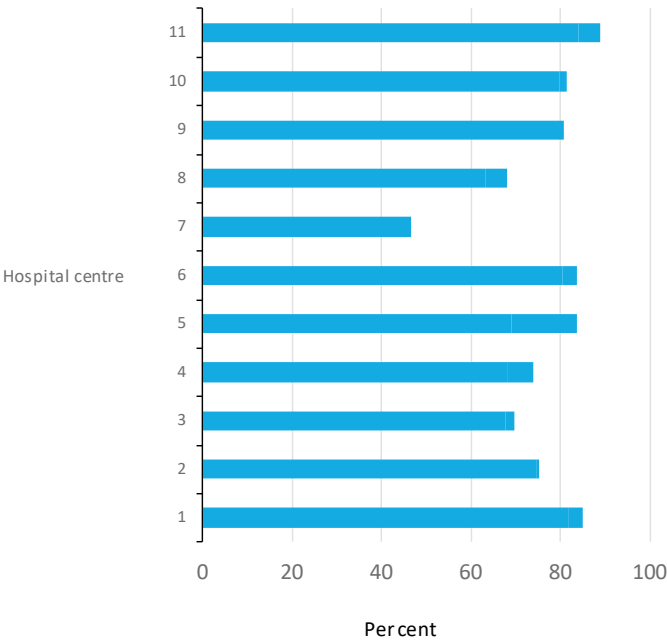
There is still wide variation in specialist treatments at different hospitals across New Zealand. Some examples include access to a fistula, delays in timely access to the first kidney specialist assessment, transplantation rate, home dialysis use, and the risk of needing dialysis therapy in each region.

These reasons for differences in the care provided at different hospital centres are complex and relate to the organization of services in each region, the health needs of the population being served, the access of specialist services in more rural areas, and the development of transplantation care. These differences in hospital access to access need to be monitored as a measure of care quality across the whole of New Zealand.

The chart below shows one example of the differences between hospitals for one quality measure: the percentage of patients using a fistula for haemodialysis (ranging from 45% to 89% across New Zealand).

Variation (fluctuation) in clinical care is normal but may be indicative of different practices at hospitals and may be linked to worse outcomes for some patients.

Variation in the number of patients using a fistula for haemodialysis at different hospital centres in New Zealand in 2015



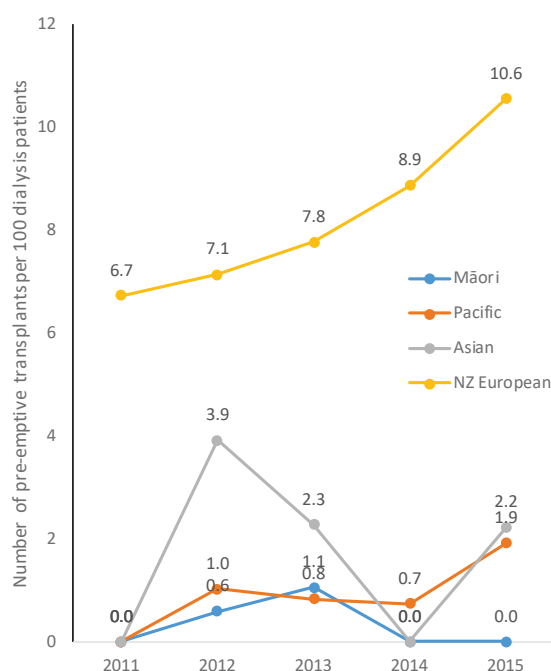
Goal 8: Equal access to treatment

People in New Zealand should receive equal access to dialysis or kidney transplant care.

It is important that kidney specialist services work to make sure all New Zealanders can access similar quality of care. At present, not all New Zealanders can access timely transplantation care equally and some New Zealanders are at much higher risk of kidney failure than others. These differences are likely to be caused by health services in New Zealand not being designed to protect against kidney failure for all patients and supporting patients to access kidney transplantation equally. Differences in access to care is an important measure of care quality that can be monitored.

The chart below shows that receiving a kidney as first treatment for kidney failure (*pre-emptive*) is increasing for New Zealand European patients (yellow line), but is much lower for Māori (blue line), Pacific (orange line), and Asian New Zealanders (grey line), and is not improving. In 2015, 10 New Zealand European patients had a kidney transplant for every 100 who started therapy for kidney failure, while no Māori patients accessed *pre-emptive* kidney transplantation. Access to pre-emptive transplantation is steadily increasing for New Zealand European patients but is not clearly increasing for other New Zealand communities. New healthcare developments need to consider this unequal access when designing healthcare innovations.

Access to pre-emptive kidney transplantation in New Zealand over the last 5 years



POTENTIAL ACTION POINTS TO IMPROVE RENAL SERVICES IN NEW ZEALAND

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The sharing of health information by patients in New Zealand can help to tell us a lot about the quality of that care.

The following points are potential ways to improve and monitor the quality of renal care in New Zealand:

- Increase access to kidney transplantation as **first** treatment for kidney failure.
- Increase equal access to kidney transplantation for **all** communities including Māori, Pacific, and Asian New Zealanders.
- Reduce late assessment by a kidney specialist for children and young adults.
- Reduce the frequency of peritonitis for peritoneal dialysis patients through quality improvement programs.
- Reduce variation in access to care between different New Zealand regions.
- Support patients to access peritoneal dialysis as first treatment for kidney failure.
- Improve services to increase access to a fistula for use at the start of dialysis care.

SUMMARY TABLE OF ANZDATA INFORMATION FOR 2015

Summary of the Data: New Zealand people in the ANZDATA Registry		
Characteristic	2011	2015
People with treated kidney failure	3893	4368
People with treated kidney failure (for every million people)	(888)	(950)
Newly starting therapy (dialysis or transplant)	488	527
Transplant (<i>pre-emptive</i>)	15	24
Peritoneal dialysis	154	210
Haemodialysis	319	293
Age of starting treatment (for every million people)		
0-24 years	12	13
45-64 years	219	227
65-74 years	380	311
75-84 years	224	260
85+ years	73	0
Ethnicity of starting therapy (for every million people)		
Māori	194	216
Pacific	277	272
Asian	76	76
New Zealand European	69	62
Home therapy		
Transplant	38.3%	38.8%
Home dialysis	31.7%	29.1%
Home dialysis, % of all dialysis	51.4%	47.5%
Kidney transplants	118	147
Living donor	57	74
Deceased donor	61	73
ABO incompatible kidney transplants	0	9
Kidney exchange transplants	0	4
People active on transplant waiting list	446	472
Months free from peritonitis	24.5	26.1
Starting dialysis with fistula (%)	30%	31%
Late referral to specialist services (%)	22%	13%
Automated peritoneal dialysis	315	416