Transforming Lives and Saving Money:

An Integrated Strategy to Address Kidney Transplant Equity and Increase Kidney Transplantation in New Zealand

Kidney Health New Zealand

November 2021

Executive Summary

Context

The Covid-19 pandemic has caused a significant disruption to health services in New Zealand, notwithstanding New Zealand's exemplary approach to managing the health system impacts of the pandemic. Renal transplantation in New Zealand has been impacted, with lower transplant activity in 2020 and 2021 than in the preceding years, and with disruptions to both Intensive Care Unit processes and patients' preparation for transplantation. We expect this disruption to continue for the next 6-12 months.

This report, backed by research from NZIER, looks beyond the immediate management of the Covid-19 pandemic, and outlines the opportunities and benefits of making changes now that would address transplant inequity and low rates of transplantation once New Zealand has reached a 90% vaccination level.

Overview

Over the past decade Parliament and successive governments have made policy and legislative changes aimed at boosting New Zealand's overall low rate of organ transplantation. Reflecting in part the impact of these changes, the rate of deceased donor kidney transplantation in 2019 (the last year before the impacts of the Covid-19 pandemic) was the highest ever.

Despite the improvements, in many cases New Zealand started from a position of being well behind best practice in the world in transplantation rates and practice. It means that in New Zealand today, we still have three inter-related challenges with kidney transplantation:

1. **Transplant inequity: Māori and Pasifika dialysis patients have low rates of kidney transplantation compared to non-Māori/non-Pasifika.**

    - In 2019, 14 out of every 100 non-Māori/non-Pasifika dialysis patients secured a transplant.
    - For Māori, the equivalent figure was just under 4 transplants for every 100 Māori dialysis patients in 2019.
    - For Pasifika, it was 3½ transplants for every 100 Pasifika dialysis patients in 2019.
    - These inequities grew between 2015 and 2019.

2. **Continuing low rates of kidney transplantation in New Zealand compared to the rest of the world, especially for deceased donor kidney transplantation.**

    - In 2019, New Zealand achieved its highest rate of deceased donor kidney transplantation ever, and the highest ever number of deceased donor kidney transplants (133).
    - 23 other countries exceeded New Zealand's rate in 2019, including Australia, UK, USA and Canada.
    - Had New Zealand matched the deceased donor transplantation rate per million of population of the 2nd highest country in the world (France) in 2019, an extra 144 deceased donor kidney transplants would have been performed in New Zealand.

3. **The official deceased donor waitlist significantly understates the demand for kidney transplants in New Zealand. In addition, Māori and Pasifika are less likely to be waitlisted than non-Māori/non-Pasifika.**

   - The current active waitlist for kidneys is about 460 patients.
   - The waitlist is a means of trying to balance demand with the currently limited supply. To do so, the waitlist sets criteria about who would benefit from a transplant <u>the most</u>; this means that some patients who are medically suitable and would benefit from having a transplant are not waitlisted. Studies suggest that Māori and Pasifika are less likely to be waitlisted than non-Māori/non-Pasifika, even after differences in co-morbidities are taken into account.
   - If the waitlist was expanded to include everyone who is medically suitable and could benefit from a transplant, we expect that it would approximately double the number on the active waitlist to a minimum of 900-1,000 patients.

The opportunity: addressing kidney transplant inequity and increasing transplantation is the right thing to do for patients, will save the health system money and support the economy

Kidney transplant inequity is not fair or just to Māori and Pasifika patients and their whānau, and is affecting their life chances. Improving health equity is a key driver for system change in New Zealand – from the upcoming health reforms through more technical changes such as the recently updated Health and Disability Standards. It needs to extend to renal services too.

Increasing deceased donor kidney transplantation will have a significant impact on transplant inequity. Māori and Pasifika represent about 60 percent of those on dialysis and the majority receive transplants from deceased donors. But there are also ways to improve their opportunities to secure a live kidney donor.

Increasing kidney transplantation saves lives, extends life and improves lives.

The median number of years that a patient lives on dialysis is 5-6 years; for transplant recipients the median life of a transplant is 15-20 years. Outcomes on dialysis are worse than for many cancers: the five-year survival on dialysis is 59%, compared to survival of all cancers of 69%. And studies have shown that the symptom burden for dialysis is as severe or worse for half of dialysis patients as they are for cancer patients. Transplant inequity means that the burden of these outcomes falls disproportionately on Māori and Pasifika. Annual mortality for Māori and Pasifika patients is 3-5 times higher per million of population than that of non-Māori, non-Pasifika patients, reflecting the much higher incidence and prevalence of kidney failure, and relatively lower prevalence of transplants in these populations.

Kidney Health New Zealand (KHNZ) appreciates that the fiscal demands on the health sector are severe at present. But increasing kidney transplantation is an investment that more than pays for itself – it saves the health system money compared to the alternative life-extending treatment, dialysis, by reducing current and future treatment costs.

KHNZ has commissioned the New Zealand Institute of Economic Research (NZIER) to complete a fiscal and economic analysis of increasing kidney transplantation in New Zealand. Its analysis shows:

- There are significant cost savings to the health system from kidney transplantation. Over 6 years – the median life expectancy for a person on dialysis – on average a kidney transplant is cheaper by $389,000 per patient. Over 20 years – the median life expectancy with a live donor transplant - on average a kidney transplant is cheaper by $503,000 per patient.

- For every person gives up employment on account of dialysis, and is able to return to full-time employment post-transplant, the additional benefits of transplantation amount to up to $53,831 in lost employment income and productivity, $8,815 in wellbeing directly related to labour force status, and up to $47,026 in welfare savings.

- In the absence of any action to limit growth rates, the number of patients on dialysis will grow by about 30 percent over the next 10 years, mostly centred in Auckland and in Māori and Pasifika communities. The cost of dialysis services will be about $150 million higher in 2031/32 than it is now.

Based on the fiscal costs and benefits alone (ie: before taking into account the health and wider economic gains), the NZIER estimates that an investment of at least $4 million to $5.5 million in the first year, rising to $6 million to $9 million in 2031, would be justified if it lifted the combined renal transplant rate by 5 percent year on year.

Improving patient outcomes – the steps to take now

The good news is that there are immediate, low-cost actions that could made significant in-roads into improving transplant equity and increasing kidney transplantation rates . Some of these actions have already been agreed by the Government – but have not been funded or implemented. Others have been implemented, but in a piecemeal way, and without an enduring and sustainable funding base that gives continuity and confidence to build service models that would make a lasting difference, particularly for Māori and Pasifika. This report sets out several examples, including:

- In 2017 the Government released *Increasing Deceased Organ Donation and Transplantation: A National Strategy* and in 2019 Parliament unanimously passed legislation to give the New Zealand Blood Service a leadership role to implement the strategy.

  But since 2017 no extra funding has been set aside to implement the *Strategy*. Out of six strategic priorities in the Strategy, only one substantive action (the transfer of Organ Donation NZ (ODNZ) to the now NZ Blood and Organ Service) has been completed (and even that transfer was underfunded).

  The commitment made to the Health Select Committee in 2019 to work out detailed roles, functions and responsibilities of the NZ Blood and Organ Service (NZBOS) has not been completed.

  More than four years after the launch of the *Strategy*, no significant progress has been made to implement or fund it. This failure hurts Māori and Pasifika patients disproportionately, as these patients receive most of their transplants from deceased donors. We also suggest modifying the *Strategy* by including an objective to address deceased donor equity.

- Extra LINK[1] nurses were placed in Intensive Care Units from 2012. These have undoubtedly made a difference to deceased donor transplantation rates, but have never had a secure and enduring funding base, with funding provided by the Ministry of Health on time-limited funding arrangements that are extended every couple of years. As the health system moves towards restructuring in 2022, there is considerable uncertainty how these important roles will be funded.

- In 2013, the Government conducted a four-year project, the *Live Kidney Donation Aotearoa* project in Counties Manukau DHB, with a focus on increasing live donation kidney transplantation amongst Māori and Pasifika in that DHB. The project saw offers of live donor kidneys increase from an average of 10/year before the project, to 80/year during the project. Live donor kidney transplants in Counties Manukau increased from an average of 2/year prior to 2013, to over 10/year from 2014. For Māori and Pasifika, the number of live donor transplants rose from an average of 0.7 a year (a total of five in the preceding 7 years to 2013), to an average of 4¼ a year (a total of 17 from 2013-mid-2017). This is a six-fold increase in live donor transplant rates for Māori and Pasifika in a single DHB.

  This project demonstrates that there are approaches that could make a difference for Māori and Pasifika patients in an area where their rate of kidney transplantation is very low.

  The project wound up in 2017. Small elements of the project have continued in Counties Manukau and other DHBs offering renal services through "Donor Liaison Co-ordinator" roles. But these roles are funded only part time, the number of positions across DHBs is not linked to caseloads, and funding is provided in short term, time-limited blocks (which are due to expire in 2022). In some DHBs there has been no programme to expand and continue the whole-of-service philosophy and service re-design that realises the benefits that resulted from the *Live Kidney Donation Aotearoa* programme.

Fully implementing these already designed and agreed policies and giving them a multi-year sustainable funding path, are immediate and practical actions that would address transplant equity in New Zealand and increase kidney transplant rates. We are not starting from a blank slate.

It's also an integrated approach; the actions to increase transplantation rates would reduce transplant inequities and vice versa. For example, increasing deceased donor kidney transplantation rates will disproportionately benefit Māori and Pasifika as this is the main source of their kidney transplants.

Addressing transplant inequity will be immediately helped by the actions outlined in this report, but fully meeting the needs of Māori and Pasifika dialysis patients wanting a transplant will require specific, targeted actions and underlying system change. To this end, we call for an explicit target to reduce transplant inequity in New Zealand and targeted actions to engage with Māori and Pasifika to support access to kidney transplantation. We propose a Renal Transplant Equity Taskforce to shape and drive these actions, while also looking at the underlying systems and structures that need to be changed to address transplant inequity in New Zealand. We see this as a specific example of

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[1] Each ICU has a "LINK Team" that is a senior ICU nurse, an ICU doctor, and an operating room nurse – who has a "link" role with ODNZ. The LINK team undertakes deceased donation quality assurance and education work.

achieving system change that the Government is looking for through the establishment of Health New Zealand and the Māori Health Authority.

We propose that the Taskforce get underway in advance of the new management and governance structures for renal services under the Health New Zealand and Māori Health Authority, so that immediate progress is made while those new structures are established.

The actions outlined in this report have a cost, but in the context of the $20.7 billion of public funding of health each year, the sums involved are minute. While we don't have all the details from the NZBOS, we understand that they have costed the full implementation of the 2017 *Strategy* at between $3-$5 million per annum. We have not costed a full and sustainable funding path for *Live Kidney Donation Aotearoa*, but the initial project in Counties Manukau was $1.5 million over 4 years and the annual cost of donor liaison co-ordinators is about $1 million per annum. An Australian equivalent to the proposed Renal Transplant Equity Taskforce, that runs pilot projects, data management and governance, cost A$2.6 million in its first year.

Since increasing transplantation more than pays for itself financially, we asked the NZIER to investigate why the health system in general and DHBs in particular have not funded pro-transplant initiatives themselves. The answer is the current health system does not facilitate funding across "time" (making operational investments now that reduce operational costs later) or "space" (between DHBs or between departments *within* DHBs). This is the result of the current siloed and year-by-year funding model, and that DHBs cannot individually manage the financial risks and uncertainty in the transplantation pathway. The NZIER has recommended a "National Renal Service" model within the new Health New Zealand, with a more flexible funding model across "time and space". We recommend that the Government investigate this as part of the upcoming health reforms.

The structure of our recommendations

Addressing kidney transplant equity and increasing transplant rates in New Zealand requires a shift in approach and mindset across the health system in general and the renal community in particular. This report outlines a range of actions and strategies to make that shift. Some are for the Government in the first instance, but others are for the health system and the renal community to own and drive.

We have not recommended legislative change, or changes to the nature and type of consent (deemed consent, opt in/opt out). This reflects (a) the uncertainty whether legislative change would make a (significant) difference[2], (b) the long lead times for legislative reform (at least 3-5 years) and (c) there is an opportunity to make more significant and more immediate progress by fully implementing and funding approved policies such as the 2017 *Increasing Deceased Organ Donation and Transplantation: A National Strategy,* which to date has had a high measure of political support.

In going through this report, readers should be aware that the latest data used is from 2019, to avoid the impact that Covid-19 has had on transplantation activity in both NZ and worldwide from 2020, which will make inter-year and international comparisons difficult.

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[2] All countries, whether they have opt-in or opt-out/presumed consent approaches, still require family consent (the so-called "family veto") in the ICU for a donation to occur. What seems to be more important is that the family has some evidence available to them about the intent of the deceased patient with respect to donation. Having reliable evidence about the patient's wishes in the ICU setting was a key part of the 2017 *Strategy.*

Recommendations

For Immediate Action by the Government:

1. **Set an explicit goal to address transplant equity.**

   To help drive action on transplant equity in New Zealand KHNZ believes the Government, the incoming Health New Zealand and the Māori Health Authority, should commit to an overarching goal of addressing transplant equity. Our suggested goal is:

   > *To achieve kidney transplant equity by 2030, by identifying and addressing the causes of kidney transplant inequity in New Zealand, so that everyone who is medically suitable and would benefit from a transplant has a fair and just chance of getting one.*

   While an analysis of the impact of this goal for New Zealand has yet to be done, we expect it could double the number on the active waitlist to a minimum of 900-1,000 patients.

2. **Increase number of transplants for Māori and Pasifika people in particular.**

   Improving transplant equity means finding ways to increase the overall levels of kidney transplantation, for Māori and Pasifika in particular. Specific proposals to increase both deceased donor and live donor kidney transplantation rates are in (3) to (5) below.

3. **Apply equity lens to current system by establishing a Renal Transplant Equity Taskforce.**

   The Renal Transplant Equity Taskforce would report to the Māori Health Authority and Health New Zealand. It would develop a national strategy for improving transplant equity, including defining, measuring and monitoring transplant inequity, community and iwi engagement, funding pilot studies and rolling out new approaches to address transplant equity, and provide an equity lens on kidney transplant activities in New Zealand. Australia's *National Indigenous Kidney Transplantation Taskforce* – established in July 2019 - is a potential model for the Renal Transplant Equity Taskforce.

4. **The Renal Transplant Equity Taskforce to revitalize and extend approaches such as *Live Kidney Donation Aotearoa* and donor liaison co-ordinators across all renal services, to support increased live donor kidney transplantation, especially for Māori and Pasifika.**

   This will require a sustainable, multi-year finding model for relevant renal unit staff to enable transplant listing and support for underserved communities through the transplantation pathway.

5. **Increase the rate of deceased donor transplants by providing a multi-year, sustainable funding path for the New Zealand Blood and Organ Service to implement the 2017 *Increasing Deceased Organ Donation and Transplantation: A National Strategy.***

   Specifically, KHNZ calls for:

   - Fully fund a forthcoming investment request from the NZBOS of between $3-$5 million per annum to build the national agency and to implement the 2017 *Strategy.*
   - A sustainable, multi-year funding path for LINK teams in ICUs.
   - The Government to finalise the specific roles, functions and responsibilities of the NZBOS, in line with its undertaking to the Health Select Committee in 2019.
   - Fully fund NZBOS for transfer of functions from Auckland DHB.

NZIER's financial analysis shows that this level of investment will more than pay for itself if there is an 5% increase year on year in deceased donor kidney transplants – or about an extra 10-12 deceased donor kidney transplants per annum.

If, for whatever reason, additional Government funding is not able to be provided in Budget 2022, the Government allow these functions to be cost recovered from the rest of the health system, in the same way that the costs of traditional blood and plasma products are met through a cost recovery process.

6. **The Government investigate, as part of the upcoming health reforms, the establishment of renal and kidney transplantation services as a "National Renal Service" within Health New Zealand, with funding mechanisms that allow for funding flexibility across "time and space".**

For action by relevant agencies in the health system:

7. **Increase access to the waitlist for deceased donor transplants for underserved communities in NZ.**

   (For Health New Zealand, the Māori Health Authority, and the renal community, working with KHNZ)

   Achieving transplant equity for deceased donor transplantation would ensure that everyone who meets legitimate clinical criteria is (1) waitlisted and (2) have a fair and just opportunity to receive the next available deceased donor kidney. Actions that could be taken to improve access to the deceased donor waitlist for underserved communities will require change to the systems and processes within the health system itself, including:

   - Fund transplant assessment teams, networks and engagement activities at the front line so that individuals can access transplantation with the support of well-equipped local teams.
   - Publishing aggregate data on the deceased donor waitlist annually, and generating robust data on access to the waitlist through analysis of the Transplant Survival Score.
   - Review the on-going suitability of the waitlist criteria, such as BMI thresholds and the 5-year survival score.

8. **Include a strategic objective to address deceased donor equity in the 2017 *Strategy.***

   (For the NZBOS working with Health New Zealand, the Māori Health Authority and KHNZ)

   A strategic priority of addressing deceased donor equity would require the NZBOS:

   - To tailor their public awareness and media engagement in ways that specifically supports engagement with Māori and Pasifika communities.
   - To identify and deliver specific strategies for Māori and Pasifika families and whānau in ICUs, as part of their overall strategy to increase deceased organ donation rates overall.

   This additional strategic priority should not be used as a reason to further delay the implementation of the remainder of the *Strategy.* Rather, this new strategic priority would be included in the NZBOS's detailed implementation plan for the 2017 *Strategy.*

Abbreviations used in this report

BMI	Body Mass Index
DHB	District Health Board
EHR	Electronic Health Record
ESRF	End Stage Renal Failure
ICU	Intensive Care Unit
KHNZ	Kidney Health New Zealand
KPI	Key Performance Indicator
NRS	National Renal Service
NRTS	National Renal Transplant Service
NRTLT	National Renal Transplant Leadership Team
NZ	New Zealand
NZBS/NZBOS	New Zealand Blood Service (pre-November 2019)/ New Zealand Blood and Organ Service (post-November 2019)
ODNZ	Organ Donation New Zealand
PBFF	Population Based Funding Formula
pmp	per million population
RRT	Renal Replacement Therapy

Kidney Transplantation in New Zealand: Context

Some background on kidney transplantation ….

Patients with kidney failure (“end stage renal failure” – referred to as “ESRF” in this paper) need a form of renal replacement therapy (RRT) - either a kidney transplant or receive dialysis, or will die from kidney failure.

Some patients will have no choice of RRT other than dialysis, because they are not medically suitable for a transplant – for example because of severe heart disease or diseased blood vessels.

Some patients will not be suitable for a transplant and will also choose not to continue with, or start, dialysis. Patients who choose “conservative care” will usually pass away within a few weeks.

Most patients commence dialysis while being considered for a transplant because it takes a long time to complete transplant assessments and then wait for an available kidney. However some patients receive a pre-emptive transplant (ie: that is, a transplant that happens before dialysis starts). A pre-emptive kidney transplant is the optimal treatment, since it avoids all the negative effects of dialysis treatment. A pre-emptive transplant uses a kidney from a live donor.

There are two distinct, but inter-connected, parts to a ESRF patient getting a transplant. The first is for any patient to be assessed as being suitable for a transplant.

The second part is finding a donated organ, either from a live or deceased donor. Without organs, there are no transplants.

There are two possible sources of kidneys for a transplant:

- A deceased donor – a person who has passed away in an Intensive Care Unit (ICU).
- A donor from a living person – a live donor – usually but not always known by the person requiring the transplant.

If a patient is suitable, and if an immediate pre-emptive/live donor transplant is not possible, the patient is put on the deceased donor “waitlist”. Once a donor is found, the transplant surgery is arranged.

Responsibilities across organ donation and kidney transplantation have been split:

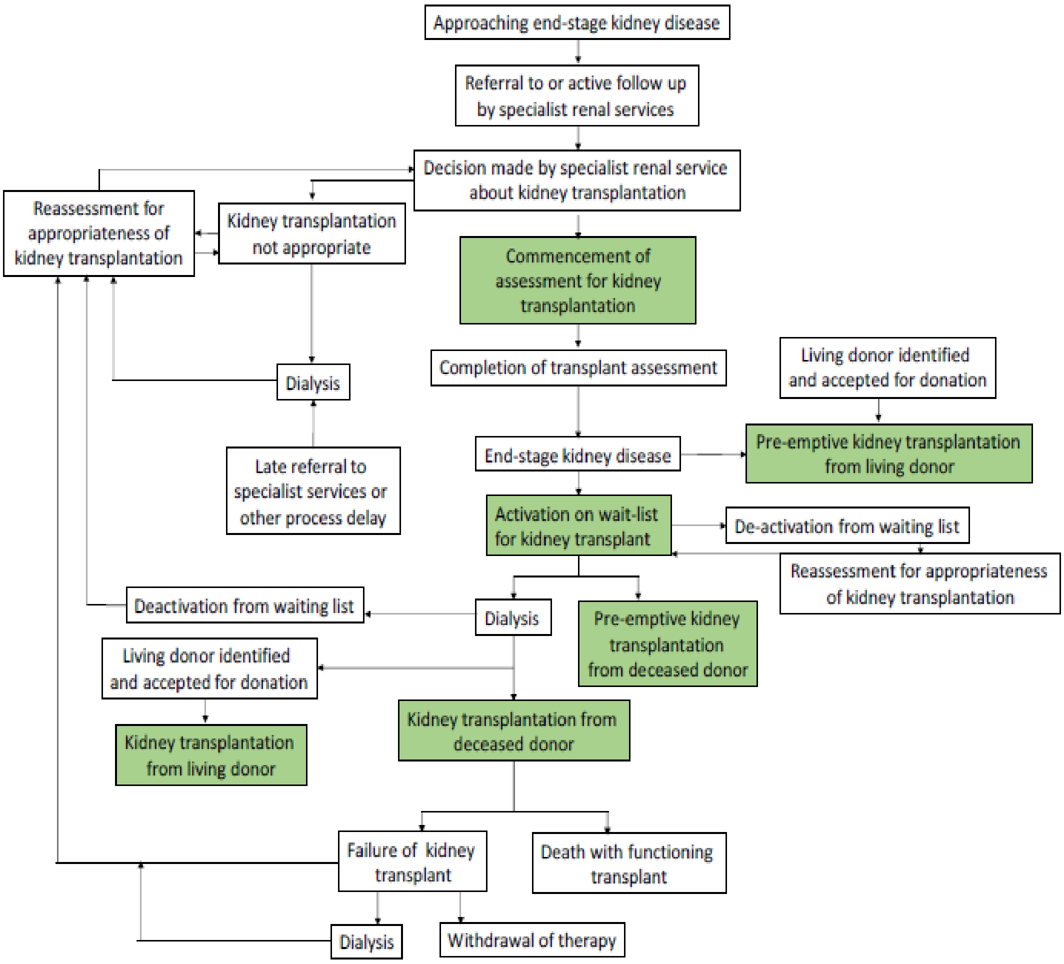
- Care of ESRF patients is undertaken by specialist renal units in 13 District Health Boards (DHBs) in New Zealand. These units are responsible for ensuring that people with kidney failure who are potentially suitable transplant recipients are assessed and waitlisted for transplantation.
- Transplant operations themselves are undertaken in three DHBs: Auckland, Capital and Coast and Canterbury District Health Boards (DHBs).
- Organ Donation New Zealand (ODNZ) plays a critical role in the deceased organ donation and transplantation process, especially arranging the matching of organs to people on the deceased donor waitlist, and organising the resulting deceased donor transplant logistics. In November 2020, ODNZ was transferred from Auckland DHB to the New Zealand Blood and Organ Service (NZBOS) as part of the process of establishing a national agency to address

deceased organ donation in New Zealand. Note that NZBOS has responsibilities for deceased donation only.

- A leadership body of renal specialists - the “National Renal Transplant Service” (NRTS) - has been tasked by the Ministry of Health with oversight of kidney transplantation. In practice this includes oversight of practices and policies associated with live kidney donation.
- With respect to live kidney transplantation, the management of this at a day-to-day level is through the individual renal units, working with their patients.
- Patients are however responsible for finding their own live donors; with some support (ie: without coercion) from their local renal team. Once a prospective donor is found, the local renal unit arranges for the assessment (“work-up”) of the prospective donor to establish whether or not they are a suitable candidate and can proceed to transplantation.

The processes for the assessment of, and possible transplant for, a ESRF patient are complex…

The following diagram provides an overview of the transplantation pathway in New Zealand:



Source: Tania Huria (2021) *Created Equal: A Kaupapa Māori Analysis of Research and Health System Perspectives of Inequity in Chronic Kidney Disease in Aotearoa* PhD Thesis, page 80

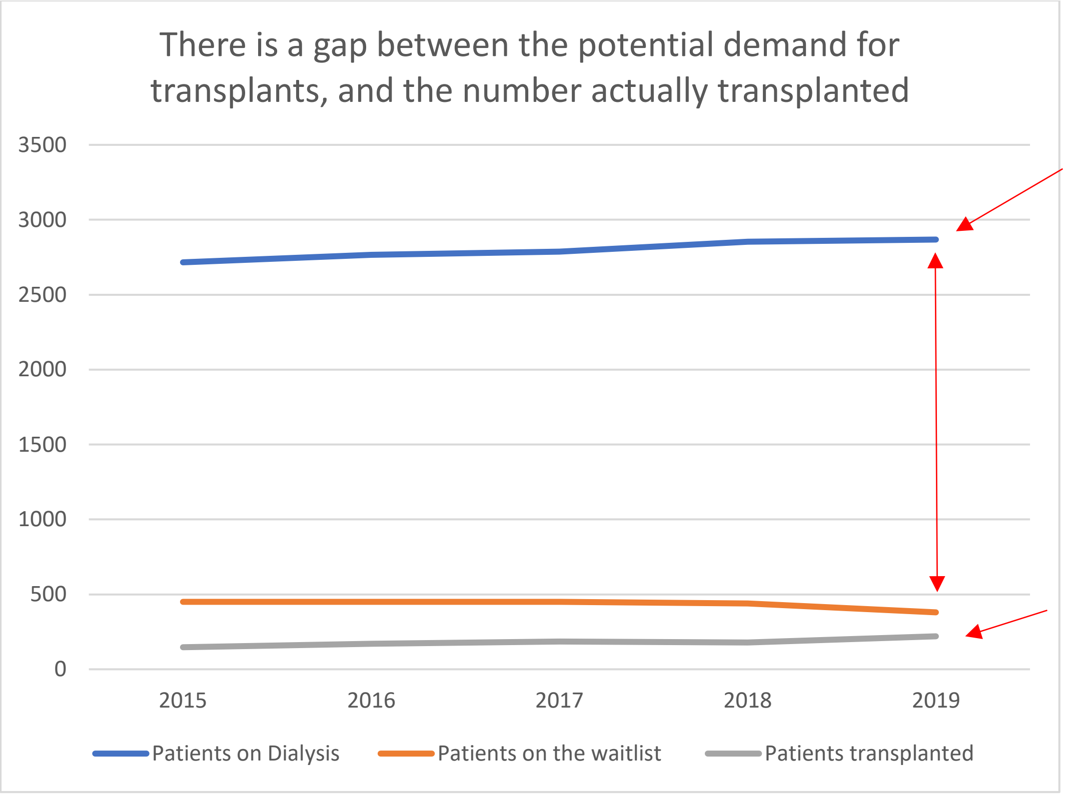
As can be seen, the pathway for any one patient to a transplant is complex and non-linear - it involves many steps and processes, and there are many ways that a patient can find themselves back at the start of the process. For live transplantation in particular, the patient and the potential live donor have to be proactive in working their way through the system. This stems in part because renal units want live donors to come forward, and complete assessments, without any sense of coercion or pressure being applied.

This pathway can also be very slow to complete from initiation to a successful transplant. We are aware of cases where it has taken a patient two years to complete the step of "completion of transplant assessment" (in the top centre of the above pathway). The work up of a potential live donor can typically take a year to complete, even when there are no complications with the prospective donor.

We will come back to the complexity of this system from a patient point of view later in this report as one of the key challenges in increasing live donor transplantation in particular, and for addressing transplant equity.

The demand for kidneys outstrips supply by a large margin….

A key feature of the kidney transplantation process is that the demand for kidneys outstrips supply, and that the official waitlist is not a true reflection of the actual demand for kidneys.



While not all patients on dialysis would be medically suitable for a transplant, the official waitlist significantly understates the demand for a transplant

While the number of kidney transplants in 2019 was the highest on record, less than 8% of all dialysis patients received a transplant in that year

Source: ANZDATA

… and this means that rationing processes have been put in place.

To help manage demand, patients are assessed and those who are medically suitable and would benefit <u>the most</u> from a transplant are "waitlisted". The waitlisting criteria are:

- At least an 80% chance of living for more than 5 years after a deceased donor transplant.
- Overall health of a person – including such matters as Body Mass Index (BMI) and the other health conditions that they have.

- How their kidney disease has affected the rest of their body.
- Any other surgery that a person might need at the time of their transplant.

These criteria mean that some people who are otherwise medically suitable and could benefit from having a transplant – but do not meet the criteria - will not be waitlisted. To illustrate, a young patient with kidney failure who has a BMI of 41 may be otherwise healthy and expected to survive more than 5 years after transplant and would be expected to benefit from transplantation, will not be waitlisted for a transplant because their BMI is above the eligibility threshold (BMI ‹ 40). Or a patient who is assessed as having "only" a 75% chance of living for more than 5 years would similarly be excluded from the waitlist.

These criteria matter because an ESRF patient needs to be on the waitlist to be eligible for a deceased donor transplant.

Once a deceased donor kidney becomes available, it is allocated to a patient on the waitlist according to (1) waiting time on the list and (2) best match. Note that this means, for example, that a deceased donor kidney from a NZ European patient can be transplanted into a Māori or Pasifika patient, or a kidney from a Māori or Pasifika deceased donor could the transplanted into a NZ European patient. Deceased donor organs are not allocated to ensure an ethnicity match between the deceased donor and the recipient.

If a patient finds a live donor (eg: a family member, friend or relative), that kidney will be transplanted to the specific patient who found the donor.

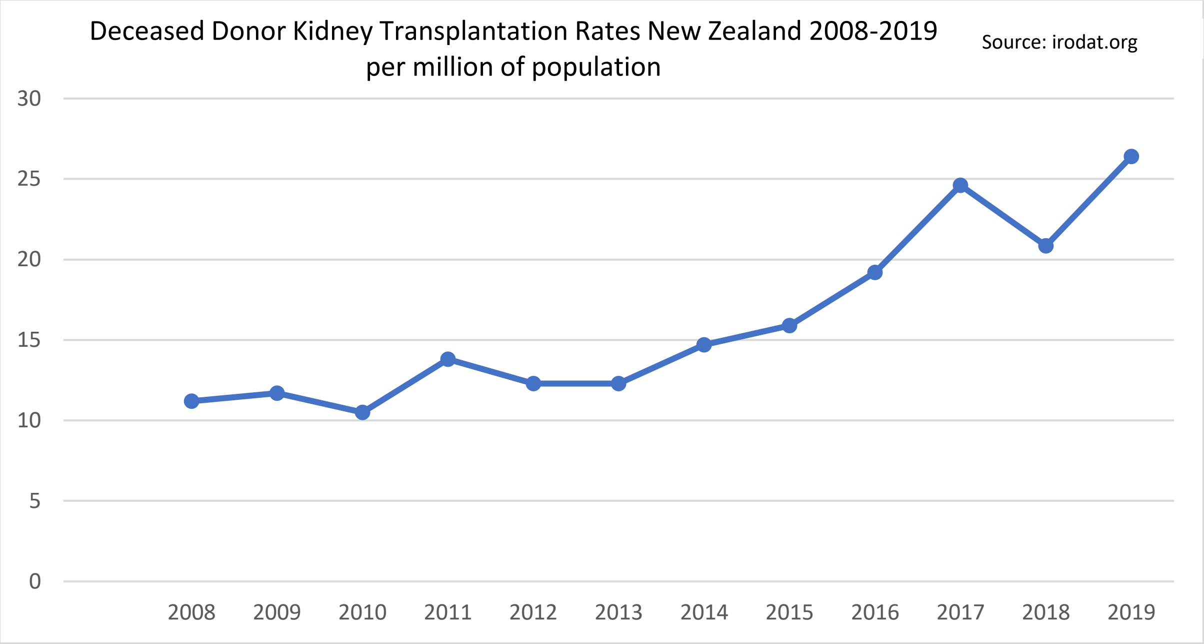
New Zealand has also established a "paired kidney exchange" scheme, where a live donor and recipient pair who cannot proceed with direct live donor kidney transplant (usually because of an unexpected tissue match issue between donor and recipient) can exchange kidneys with another live donor and recipient pair in a similar predicament. This scheme has more recently been expanded to included live donor and recipient pairs in Australia, although the benefits of this scheme have been harder to realise since the travel restrictions related to the Covid-19 pandemic have been in place.

There are a small number of voluntary live kidney donors come forward each year, who do not have a specific patient that they wish to give a kidney to. Such "non-directed" live donors are allocated as if the donor kidney was derived from a deceased person.

Deceased donor kidney transplantation rates have improved since 2013 …

Internationally, comparisons between countries are made on the basis of kidney transplantation rates per million of population (pmp), according to whether the kidney was sourced from a deceased or a live donor.

In terms of deceased donor kidney transplantation, since about 2013 New Zealand's rate of kidney transplantation from deceased donors has improved, as seen below:

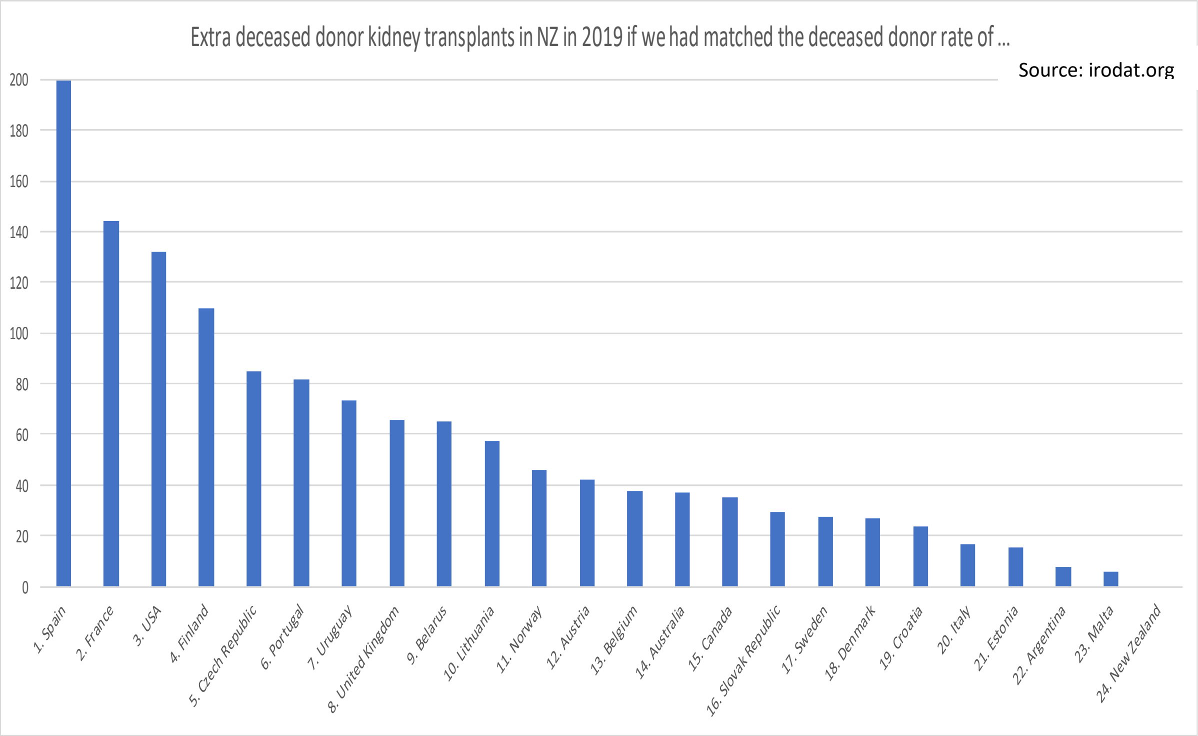


There has been no empirical research on what has driven the uplift of deceased donor transplantation rates from 2013. Anecdotal evidence suggests that increased resourcing to support transplantation in ICUs from 2012 played a role. Further, as the Government started the process for what became the deceased organ donation strategy (discussed below), this created greater awareness of the issues and opportunities for organ donation, and immediate changes in approach and practice, across the system.

… but New Zealand still lags behind the rest of the world …

Despite these improvements, we need to acknowledge that these gains were off a very low base. In 2008 Spain was the country with the highest rate of deceased donor kidney transplantation at 44.9 transplants pmp whereas New Zealand's rate in 2008 was 11.2pmp - a fourfold gap. In 2019, the gap between the country with the highest deceased donor kidney transplantation rate (still Spain, at 66.55pmp) had narrowed but was still 2½ times New Zealand's rate that year (26.4pmp).

The extent of the gap existing in deceased donor kidney transplantation in 2019 is shown in the graph below. This graph shows the 23 countries with a higher deceased donor kidney transplant rate than NZ in 2019, and how many extra deceased donor transplants would have been performed in NZ had we matched that country's rate in 2019 (NZ had 133 deceased donor kidney transplants in 2019):


Extra deceased donor kidney transplants in NZ in 2019 if we had matched the deceased donor rate of ...

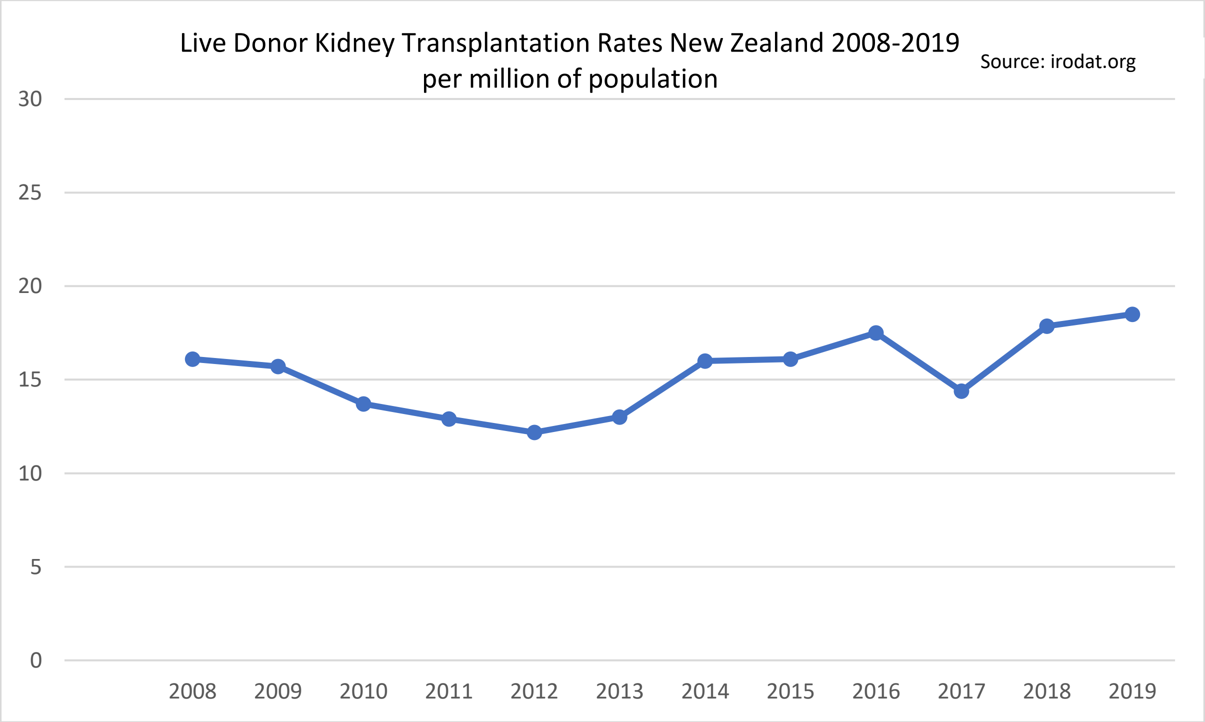
Source: irodat.org

For example, if NZ had matched the rate of the second ranked country in the world in 2019 (France), an extra 144 deceased donor kidney transplants would have occurred in NZ in 2019.

While NZ has improved since 2013, we are still a long way behind many of the countries we like to compare ourselves to.

Live donor kidney transplantation rates have not changed much over the last ten years…

Live donor kidney transplantation rates have varied up and down over the past ten years, with the 2019 rate pmp slightly better than the 2008 rate.


Live Donor Kidney Transplantation Rates New Zealand 2008-2019 per million of population

Source: irodat.org

While the overall rate of live donor kidney transplantation has not shifted much over the past 10 years, at 9th in the world New Zealand has one of the higher rates of live donor kidney transplantation.

The countries with the highest rates of live donor kidney transplantation – Turkey, Saudi Arabia, the Netherlands, South Korea and Israel – have rates of live donor kidney transplants between 27-36 pmp. With New Zealand's rate in 2019 at 18.5pmp, the top rates in the world were between 50% and 100% higher than New Zealand's in 2019.

In the past decade, successive Governments have sought to improve transplant rates in NZ …

Between 2012 and 2019 successive Governments have launched a number of initiatives to help improve organ donation and transplantation rates in New Zealand, including:

- Extra LINK nurses in ICUs from 2012. (Each ICU has a "LINK Team" that is a senior ICU nurse, an ICU doctor, and an operating room nurse – who has a "link" role with ODNZ. The LINK team undertakes deceased donation quality assurance and education work).
- The *Live Kidney Donation Aotearoa project* in Counties Manukau DHB (2013-2017) with a focus on increasing live donor kidney transplantation amongst Māori and Pasifika in that DHB.
- Budget 2014 created "donor liaison coordinators", which are positions established at each the three transplanting centres and in the seven larger renal units in NZ. These coordinators support donors and recipients throughout the transplantation process, from providing education to interested potential donors to organising blood tests and carrying out pre-surgery preparation.
- A 2017 Government Strategy: *Increasing Deceased Organ Donation and Transplantation: A National Strategy* and the subsequent transfer of ODNZ to the NZBOS in 2019. Note that this *Strategy* covers all deceased donor organs, not just kidneys.

In addition, the Compensation for Live Donors Act 2016 made important changes to the way, and the level, to which live donors were compensated for lost earnings as a result of their organ donation.

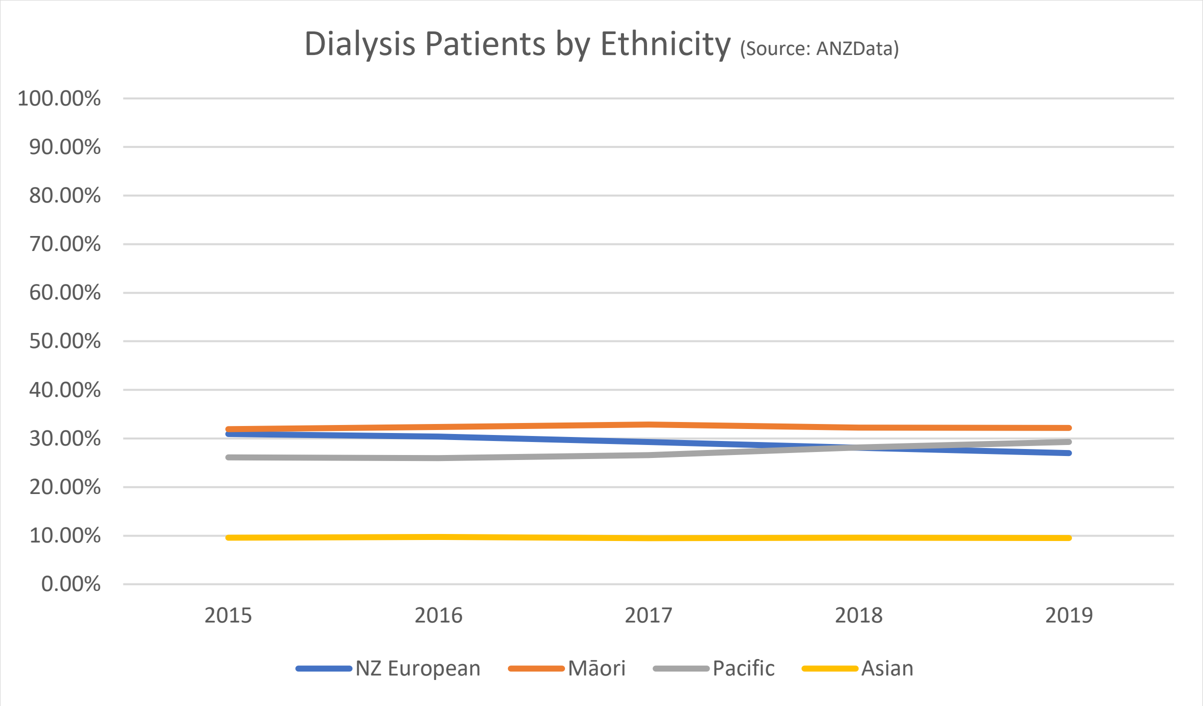
In this report, we identify that some of these initiatives not been followed through, some have not been funded and some have been followed through in a way that limits their impact.

None of these initiatives have specifically looked at issue of transplant equity in New Zealand, even though this is a significant challenge for kidney transplantation in New Zealand.

What does transplant inequity look like in New Zealand?

In 2019, there were 2,868 dialysis patients in New Zealand. While, as noted earlier, not all dialysis patients will be suitable for a transplant in this report we use the number of dialysis patients for whom transplantation is a potential therapy. (This is a simplification, as some ESRF patients are suitable, and receive, transplants before dialysis starts).

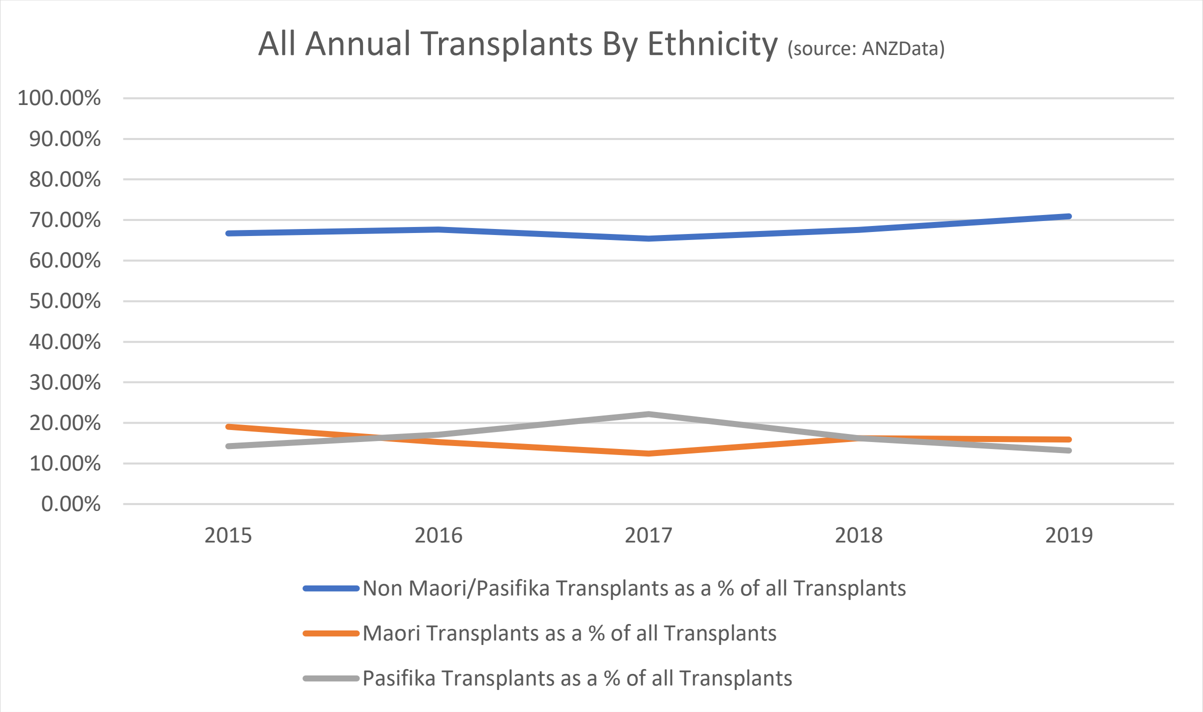
The next graph shows the ethnic breakdown of dialysis patients between 2015-2019. It shows that Māori, Pasifika and NZ European each made up about 30% of the patients on dialysis (with people of Asian descent making up the remaining 10%) between 2015-2019. The overall proportion of patients who were NZ European patients was gradually falling, with the overall proportion of dialysis patients who were Pasifika gradually increasing over this period.



The upshot of these trends is that the total number of Māori and Pasifika patients receiving dialysis has grown between 2015-2019, whereas the total number of non-Māori/non-Pasifika patients receiving dialysis has fallen.

There is a big discrepancy between the ethnic make-up of dialysis patients, and the make-up of who is transplanted in New Zealand each year….

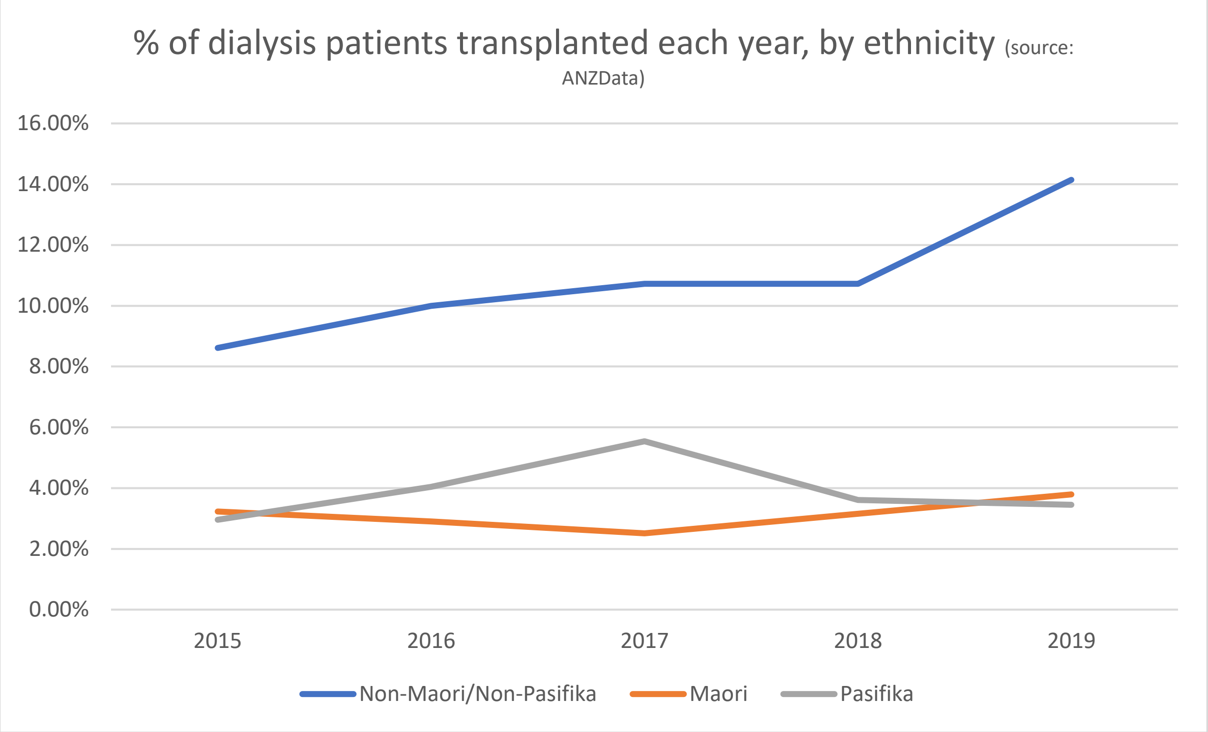
This graph shows the breakdown of all kidney transplants – both deceased donor and live donor transplants – between 2015-2019:



It shows that while non-Māori/non-Pasifika (ie: NZ European and Asian peoples) made up about 40% of patients on dialysis in 2019, they received over 70% of all kidney transplants in 2019. In contrast, Māori made up over 32% of dialysis patients in 2019, but received less than 16% of all kidney transplants that year. Similarly, Pasifika made up over 29% of dialysis patients in 2019, but received only 13% of all kidney transplants that year.

Another way to look at transplant inequity is to look at the proportion of dialysis patients who receive a transplant in each year.

In 2019, about 8% of all dialysis patients received a transplant. What this graph shows is a large majority of those transplants went to non-Māori/non-Pasifika dialysis patients.



Just over 14% of non-Māori/non-Pasifika dialysis patients received a transplant in 2019. In contrast, just under 4% of Māori dialysis patients received a transplant in 2019, and about 3½% of Pasifika dialysis patients received a transplant in 2019.

In terms of total numbers of kidney transplants, compared with 2015, this corresponds to an extra 58 transplants in 2019 for non-Māori/non-Pasifika people; the additional number of transplants performed in 2019 for Māori was 7, and the additional number for Pasifika was 8. Clearly, the increase in transplants between 2015 and 2019 has not been distributed equitably.

This graph shows that this "transplant equity" gap has existed for many years, and has got worse with unequal distribution of additional transplants in recent years.

We discuss what we know, and don't know, about the causes of transplant inequity in New Zealand, and what could be done now to start to address it, in the next section of this report.

Addressing kidney transplant equity in New Zealand requires both targeted strategies to improve transplant rates for Māori and Pasifika, as well as increasing overall rates of kidney transplantation

The actions outlined in this report to address kidney transplant equity, and to increase overall kidney transplant numbers, are inter-dependent:

- Addressing transplant equity requires increasing overall transplant numbers: increasing deceased donor kidney transplant numbers will disproportionately benefit Māori and Pasifika as this is where they currently receive the majority of their transplants from.
- Increasing overall transplant numbers requires addressing transplant equity. Later in this report we will see that the rates of live donor kidney transplantation for Māori and Pasifika are low. Reducing the live donor transplantation gap between non-Māori/non-Pasifika and Māori and Pasifika will automatically reduce transplant inequity.

Addressing kidney transplant equity in New Zealand

What do we mean by "transplant equity"?

Internationally "transplant equity" refers to the ability for patients to have a fair and just opportunity to access a transplant, irrespective of:

- Social position (which covers such variables as age, gender, ethnicity, income level, education, citizenship status, place of residence (urban vs rural), the centre where a patient is treated).
- Some clinical factors such as blood type and cause of organ failure.

Enabling transplantation for everyone who is medically suitable and who would benefit from a transplant would provide a framework to address current transplant inequities. Internationally, efforts to achieve transplant equity are focused on specific and targeted activities to address transplant inequity together with actions to increase the total number of available transplants.

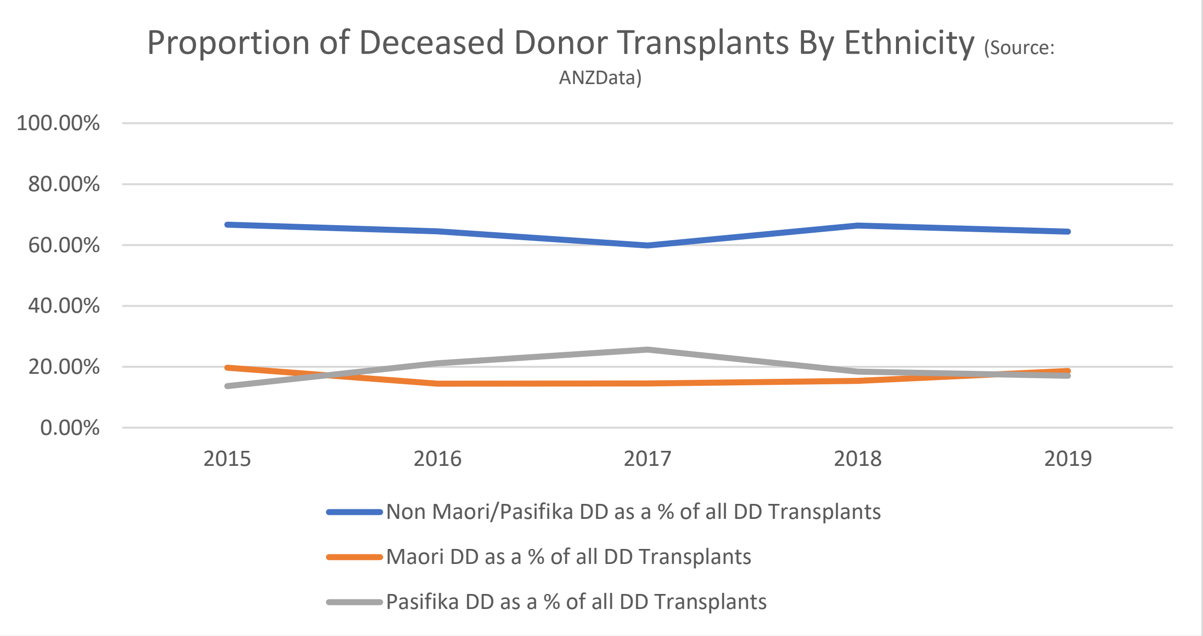
In terms of the live donor transplant system, implementing specific, tailored and targeted supports are required to enable people from different groups to achieve a live donor kidney transplant; different people need different supports to realise the same health outcome.

In terms of the deceased donor transplantation system, (1) the criteria for accessing the kidney transplant waitlist should not unfairly discriminate against groups of patients on the basis of medical or social determinants of health and (2) all patients should have an opportunity to receive the next available deceased donor kidney according to fair and just allocation criteria.

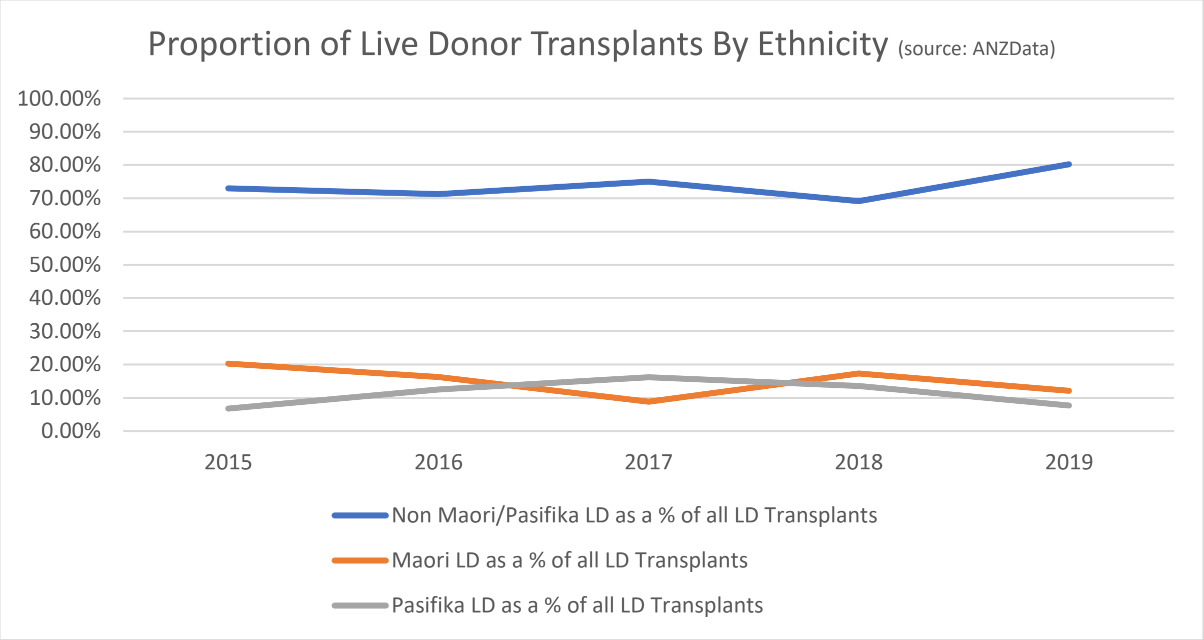
Do we have transplant equity in New Zealand?

There is strong evidence to suggest that there are inequities in access to transplantation in New Zealand.

Earlier in this report we identified the differences between (1) the ethnic composition of dialysis patients, and (2) the make-up of those receiving a transplant. We see these differences in transplantation rates in both deceased donor transplantation:

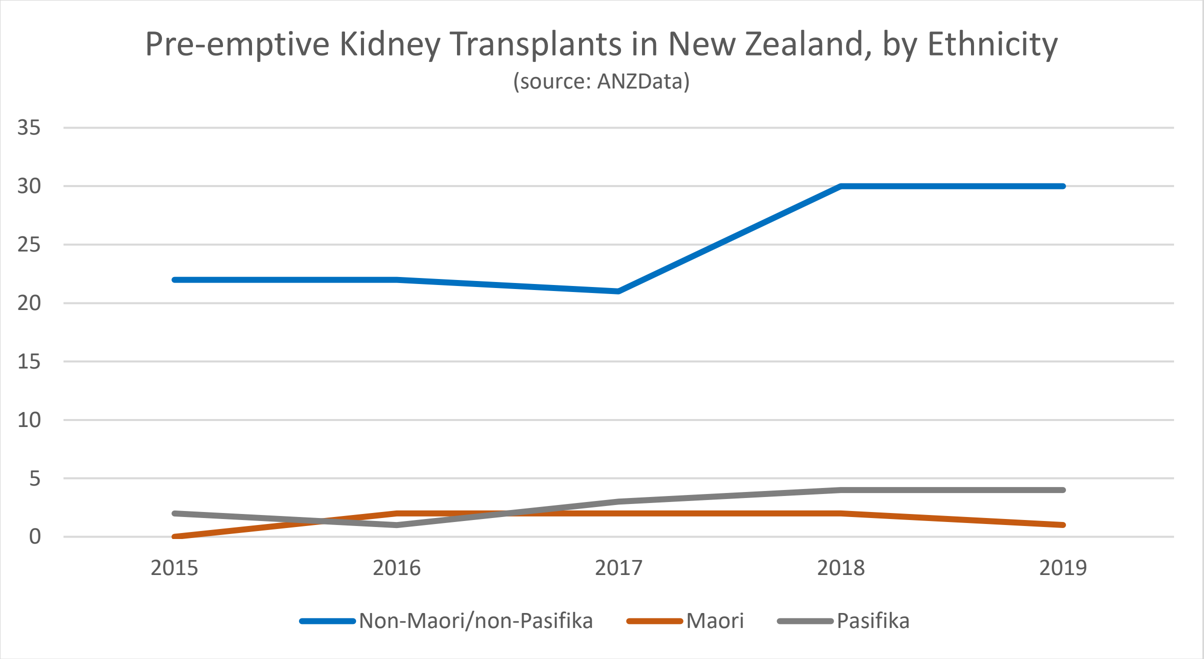


and live donor transplantation:



We also see differences in terms of the timing of kidney transplantation.

Pre-emptive transplantation – that is, before dialysis starts – is considered the gold standard treatment for kidney failure. In the last 5 years, non-Māori/non-Pasifika patients were 18 times more likely to receive this gold-standard treatment than Māori patients:



In the five years between 2015-2019, 7 Māori and 14 Pasifika patients have been provided with a pre-emptive transplant compared to 125 non-Māori/non-Pasifika patients over the same period.

Whichever way we look at the data, transplantation rates by ethnicity are not aligned to the ethnicity of dialysis patients.

We now turn to what we don’t, and do, know about what causes this inequity.

What we currently <u>don't</u> know about transplant inequity in New Zealand….

…lack of information about the make-up of the deceased donor waitlist …

International studies into transplant inequities suggest a key factor is timely access to the deceased donor transplant waitlist. But the demographic breakdown of the waitlist in New Zealand has not been publicly available in recent years, although it is expected to be publicly available from late 2021 or early 2022.

This matters because, and as discussed earlier, to get a deceased donor transplant, a patient must be placed on the waitlist (which itself is a way of rationing access to a scare resource – kidneys).

As waitlist data has not been publicly available in New Zealand we do not know:

- Who is, and is not, being waitlisted, and why.
- If Māori and Pasifika patients are not being waitlisted, whether this is because of legitimate issues with comorbidities, or for other reasons.
- Are Māori and Pasifika patients waiting the same length of time, once on the waitlist.
- Are waitlisted Māori and Pasifika patients being disadvantaged by the amount of time the patients are inactive on (ie: cycling on/off) the waitlist.

The National Renal Transplantation Service is currently commissioning an AcceSS and Equity in Transplantation (or ASSET) study which will include an analysis of the dynamics and flow of people with ESRF or advanced chronic kidney disease who were referred for a kidney transplant (living or deceased) in New Zealand. Specifically, it will explore whether inequities exist in getting a referral, remaining active on the waitlist and receiving a kidney transplant. This study is due to be completed in late 2023.

This is a crucial piece for understanding the transplantation picture in New Zealand and KHNZ fully supports the expeditious completion of this work.

… as well as a lack of information on specific barriers to accessing the waitlist…

In addition to our incomplete understanding of the make-up of the kidney transplant waitlist, we also do not know about the specific barriers that patients face before they are accepted onto the deceased donor kidney transplant waitlist.

In New Zealand, all patients are required to go through a stringent set of assessments to ensure that they would not be at undue risk from a kidney transplant operation and the medications used to support a kidney transplant. This assessment includes a review of heart, lung, and dental health, and previous history of cancer, as well as time that they joined the kidney transplant waitlist. This information is collated to produce a "transplant survival score": those with a predicted 80% chance of survival 5 years after transplantation are eligible for ongoing assessments for the kidney transplant waitlist.

We do not know:

- Whether all people with kidney failure who might benefit from a transplant are being assessed.
- How long it takes for these assessments.
- Whether there are specific barriers in this assessment process that unduly affects specific groups of patients.

- If Māori and Pasifika patients are not being waitlisted, what role do social determinants of health play?
- Which renal centres are good at enabling patients to access the kidney transplant waitlist, and what features of their service could be reproduced in other centres?

One of the challenges in the New Zealand context is understanding how much of the difference in kidney transplant rates can be accounted for by differences in the prevalence of co-morbidities such as diabetes, heart disease and lung disease. International studies tend to stress these issues as explanatory factors, but they also indicate that socio-economic determinants of health, and differing levels of health literacy (especially given the complex pathway to a transplant), also play a role in explaining the differences in access to transplantation between groups of patients.

What we do know about transplant inequity in New Zealand at this time

Notwithstanding the absence of data about the make-up of the deceased donor waitlist and the pathway to waitlisting, a number of studies have been completed about the nature of transplant inequity in New Zealand and/or for indigenous peoples across a range of countries.

It is often assumed that differences in the prevalence of co-morbidities play a significant role in accounting for differences in transplant rates between patient groups. Some studies have taken the presence of co-morbidities in New Zealand populations into account[3]. These find that co-morbidities (such as the higher incidence of diabetes and obesity) explain only half the variation in observed transplantation rates in the 1990's[4].

Other studies have sought to provide a rich picture of the nature of the differences in transplantation outcomes and explore what might sit behind them. They find:

- Indigenous peoples in New Zealand have a strong desire for a kidney transplant. While traditional cultural values may impinge upon decisions regarding kidney transplantation, patients are able to reconcile traditional beliefs with their pragmatic need. This leads to Indigenous patients having an "openness towards and indeed a strong desire for transplantation."[5]
- In the 1990's, Māori and Pasifika patients were less likely to be waitlisted for a kidney transplant.[6]
- More recent studies show the same issues persist in New Zealand. Data from 2004-2015 shows that Māori patients are less likely to receive a pre-emptive transplant than non-Māori, and were more likely to be waitlisted later than non-Māori. For those Māori who were waitlisted, the time to waitlisting was longer than for non-Māori. Māori patients are less likely

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[3] For example, Tania Huria, *"Created Equal" – A Kaupapa Māori Analysis of Research and Health System Perspectives of Inequity in Chronic kidney disease in Aotearoa*; PhD thesis, 2021 and Stephen P McDonald and Graeme R Russ*, Burden of end-stage renal disease among indigenous peoples in Australia and New Zealand*, Kidney International, Volume 63, Supplement 83 (2003), pages S123-S127

[4] Stephen P McDonald and Graeme R Russ*, Burden of end-stage renal disease among indigenous peoples in Australia and New Zealand*, Kidney International, Volume 63, Supplement 83 (2003), pages S123-S127

[5] Rachael C Walker, Sally Abel, Annie Reynolds, Suetonia C Palmer, Curtis Walker and David C Tipene-Leach, *Experiences, perspectives and Values of Indigenous peoples regarding kidney transplantation: systemic review and thematic synthesis of qualitative studies, International Journal for Equity in Health*, 18:204, 2019

[6] Stephen P. McDonald and Graeme Russ, *Burden of end-stage renal disease among indigenous peoples in Australia and New Zealand*, Kidney International, Volume 63, Supplement 83, 2003, pages S123-S127

to receive either a deceased or live donor transplant, and were more likely to die prior to waitlisting, or while on the waitlist.[7]

- Formal studies of the indigenous (including Māori and Pasifika) patient experience highlight the key challenges patients have in accessing transplantation. They mirror the findings of the *Live Kidney Donation Aotearoa* project (discussed later in this report, on pages 48-52), including[8]:
    - Receiving inadequate information about kidney transplantation and the transplantation pathway that would enable confident decision-making at both community and individual levels.
    - Not being told early about their eligibility for a transplant as a treatment option, which meant that assessments for transplant eligibility were delayed.
    - Ineffective communication by health professionals, with patients often feeling intimidated to ask for clarification.
    - The difficulty that ESRF patients have in asking potential donors …. especially a concern that making a request to a potential donor was "too big" a request to make of others – especially as many patients have (unfounded) concerns about the impact of donation on a donor's own health. Many patients wait to see if others will approach them with offers.
    - The lack of culturally sensitive resources and education about kidney transplants.
    - An overall lack of trust and confidence in clinicians and the health system, both as a cumulative effect of the above and a sense that some information was being withheld from them (such as the patient's status on the waitlist).

- Later diagnosis of ESRF for Māori compared to non-Māori patients.[9] For a patient presenting late, the discussion on options for transplantation occurs relatively late and at a time when the patient is also learning how to do dialysis. It is difficult for any patient to start the transplantation pathway at the same time they are learning how to do a complex treatment such as dialysis. This burden falls disproportionately on Māori patients.

What does this tell us about what we can do now to address transplant inequity – and where to start?

In this context, KHNZ believes the key enablers for addressing transplant inequity include:

1. **Create focus on kidney transplant inequity by setting an explicit goal to address transplant equity in New Zealand**

2. **Increase number of transplants for Māori and Pasifika people in particular**

    - By supporting new approaches that would increase both deceased and live donor kidney transplantation.

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[7] Tania Huria, *"Created Equal" – A Kaupapa Māori Analysis of Research and Health System Perspectives of Inequity in Chronic kidney disease in Aotearoa*; PhD thesis, 2021

[8] As summarised in Rachael C Walker, Sally Abel, Annie Reynolds, Suetonia C Palmer, Curtis Walker and David C Tipene-Leach, *Experiences, perspectives and Values of Indigenous peoples regarding kidney transplantation: systemic review and thematic synthesis of qualitative studies, International Journal for Equity in Health*, 18:204, 2019

[9] Rachael C Walker, Shayne Walker, Rachael L Morton, Allison Tong, Kirsten Howard, Suetonia C Palmer*, Māori patients' perspectives of chronic kidney disease: a New Zealand qualitative interview study*, BMJ Open, 7, 2017

3. Apply equity lens to current transplant system

- To ensure all aspects of the transplant pathway works equitably for all patients.

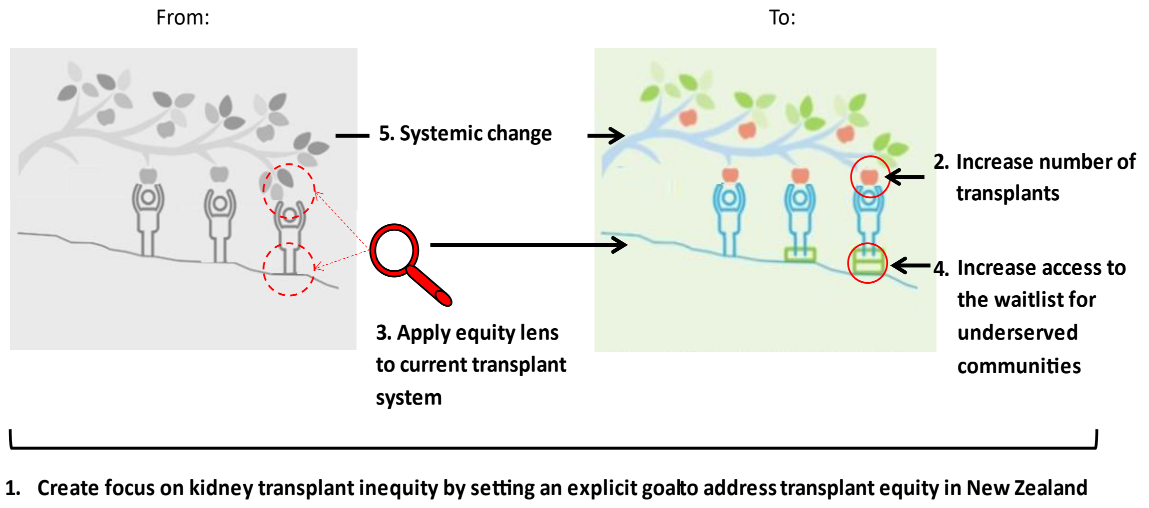
4. Increase access to the waitlist for deceased donor transplants for underserved communities in NZ

- To ensure that the waitlist structures and processes do not inappropriately exclude Māori and Pasifika.

5. Systemic change in the Health System

- While outside the scope of this report, system change as outlined in strategies such as *Whakamaua: Māori Health Action Plan 2020-2025*, the *Ola Manuia: Pacific Health and Wellbeing Action Plan 2020-2025*, and the establishment of the Māori Health Authority through the upcoming health reforms.

We see this as an integrated and interconnected approach, as shown in the diagram below. The diagram uses the imagery of how to shift a system from one where not everyone is able to reach the apple on the tree (in the kidney context, get a kidney transplant) to a system where everyone can reach the apple (transplant)…



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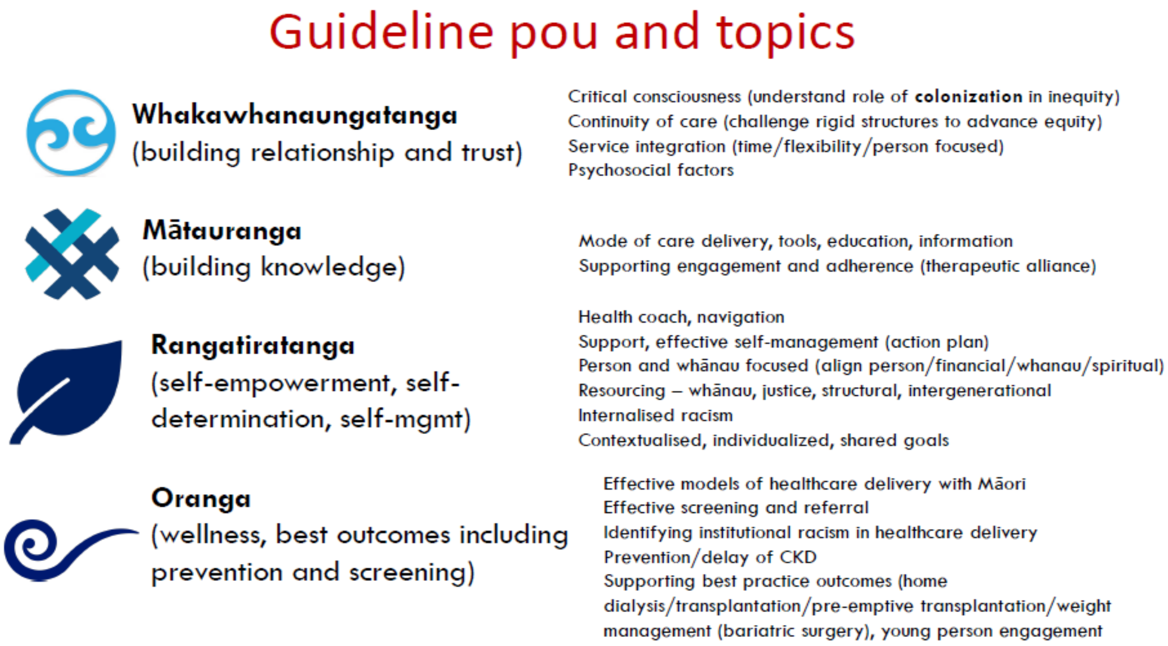
…with these shifts underpinned by:



Guideline pou and topics

Whakawhanaungatanga (building relationship and trust)	Critical consciousness (understand role of **colonization** in inequity) Continuity of care (challenge rigid structures to advance equity) Service integration (time/flexibility/person focused) Psychosocial factors
Mātauranga (building knowledge)	Mode of care delivery, tools, education, information Supporting engagement and adherence (therapeutic alliance)
Rangatiratanga (self-empowerment, self-determination, self-mgmt)	Health coach, navigation Support, effective self-management (action plan) Person and whānau focused (align person/financial/whanau/spiritual) Resourcing – whānau, justice, structural, intergenerational Internalised racism Contextualised, individualized, shared goals
Oranga (wellness, best outcomes including prevention and screening)	Effective models of healthcare delivery with Māori Effective screening and referral Identifying institutional racism in healthcare delivery Prevention/delay of CKD Supporting best practice outcomes (home dialysis/transplantation/pre-emptive transplantation/weight management (bariatric surgery), young person engagement

Source: Curtis Walker, *Te Wero, Te Taiaha: Equity in Kidney Transplantation*, 2019

What practical actions can be taken now to address kidney transplant equity in New Zealand?

In practice, these enablers and frameworks lead to the following recommendations for immediate action to start addressing kidney transplant inequity in New Zealand.

1. Set an explicit goal to address transplant equity.

To help drive and shape action on transplant equity in New Zealand, KHNZ believes the Government, the incoming Health New Zealand and the Māori Health Authority, should commit to an overarching goal of addressing transplant equity in New Zealand. Our suggested goal is:

> *To achieve kidney transplant equity by 2030, by identifying and addressing the causes of kidney transplant inequity in New Zealand, so that everyone who is medically suitable and would benefit from a transplant has a fair and just chance of getting one.*

While in principle this is what the health system seeks to achieve now, the fact that the waitlist is a rationing mechanism means that not everyone who is medically suitable and could benefit from a transplant is waitlisted. While an analysis of the impact of this goal for NZ has yet to be done, we expect that it could approximately double the number on the active waitlist to a minimum of 900-1,000 patients.

And there are barriers and impediments in the transplant pathway and the wider health system that means that patients - particularly Māori and Pasifika - who would be otherwise suitable for a transplant are currently unable to access one.

Achieving this goal means that we need to lift kidney transplantation rates in New Zealand because at current transplantation levels, not everyone on the waitlist – let alone a waitlist of 900-1,000 patients – would receive a transplant.

Our ambition to address transplant equity in New Zealand would be further supported by the 2017 *Strategy* for deceased organ donation to include a goal to address equity in deceased organ donation. We outline our proposals on this later in this report.

2. Increase number of transplants for Māori and Pasifika people in particular.

Addressing transplant equity means finding ways to increase the overall level of kidney transplantation, for Māori and Pasifika in particular.

The later sections of this report outline the actions and opportunities for further increases in deceased donor and live kidney donor transplantation in New Zealand through:

- a full and sustainable funding path to fully implement the 2017 *Strategy.*
- addressing the disadvantages that Māori and Pasifika in particular face in relation to live kidney transplantation through approaches such as the *Live Kidney Donation Aotearoa* project in the Counties-Manukau DHB and donor liaison co-ordinators in other renal units. Such tailored approaches recognise that different people with different levels of advantage require different approaches and resources to get equitable transplant outcomes.

These actions would either involve fully implementing and funding strategies the Government has already announced, and/or and addressing issues with the implementation of existing strategies, which are currently limiting their impact. This includes improving the overall level of resources to support kidney transplantation, in the renal units across New Zealand.

We expect that the strategies outlined in this report to increase Māori and Pasifika transplantation will also benefit and support increased transplantation rates amongst non-Māori and non-Pasifika who experience similar challenges.

3. Apply equity lens to current transplant system by establishing a Renal Transplant Equity Taskforce.

The Renal Transplant Equity Taskforce, reporting to Health NZ and the Māori Health Authority, would develop a national strategy for addressing transplant equity, including:

- Defining, measuring and monitoring transplant inequity.
- Ensuring that appropriate data is available for analysis of transplant inequity and underlying causes.
- Providing an equity lens on kidney transplant (and other renal) activities in NZ (*eg: NRTS, National Renal Advisory Board, ANZData*).
- Coordinating and supporting community and iwi engagement with Māori and Pacific peoples (*e.g. regional hui & talanoa; accessible resources*).
- Funding pilot studies and innovative approaches, together with research for addressing transplant inequity (*e.g. whānau ora approach; Mana Tū model).*
- Identifying barriers and supporting continuous improvement / implementation of solutions to transplant inequity.

Australia's *National Indigenous Kidney Transplantation Taskforce*[10] – established in July 2019 - is a potential model for the Renal Transplant Equity Taskforce.

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[10] In June 2019, the Australian Commonwealth Government committed $2.3 million to establish the National Indigenous Kidney Transplantation Taskforce (NIKTT). It followed a report from an Expert Panel of the Transplantation Society of Australia and New Zealand which made 36 recommendations to improve access to and outcomes of kidney transplantation among Aboriginal and Torres Strait Islander people. The NIKTT comprises of a secretariat that is housed within the South Australian Health and Medical Research Institute, a steering committee, a national consumer board, and several working groups. The steering committee includes

As part of its role in supporting innovative approaches to improve transplant rates for Māori and Pasifika in particular, we propose that the Renal Transplant Equity Taskforce leads the work to revitalise and extend existing approaches such as the *Live Kidney Donation Aotearoa* and the donor liaison co-ordinator approaches across New Zealand. (This is discussed more fully later in this report).

4. Increase access to the waitlist for deceased donor transplants for underserved communities in NZ.

We recommend above a goal to achieve kidney transplant equity that everyone who is medically suitable and would benefit from a transplant has a fair and just chance of getting one. We noted that this could approximately double the number of people on the waitlist.

Actions that could be taken to improve access to the waitlist for underserviced communities will require change to the systems and processes within the health system itself – including:

- Funding transplant assessment teams, networks and engagement activities at the front line so that individuals can access transplantation with the support of well-equipped local teams.
- Publishing aggregate data on the New Zealand's deceased donor waitlist annually, and generating robust data on access to the waitlist through analysis of the New Zealand Transplant Survival Score.
- Review the on-going suitability of the waitlist criteria, such as BMI thresholds and the 5-year survival score.

One of the key actions the Government can support and fund are the opportunities to further increase both deceased donor and live donor kidney transplantation in New Zealand. The next sections of this report outline how this could be done in practice.

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members from the clinical, academic, government and non-government sectors. The NIKTT will be responsible for implementing and evaluating the following key objectives:

- Establish the NIKTT,
- Enhance data collection and reporting,
- Pilot initiatives to improve patient equity and access, and
- Evaluate cultural bias interventions.

Why Addressing Transplant Equity and Increasing Kidney Transplantation in NZ Matters

The existence of transplant inequity is not fair nor just, and is affecting the life chances of Māori and Pasifika renal patients

In discussing equity in healthcare in New Zealand, the Ministry of Health defines health inequity as:

> *"in Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust.*
>
> *Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes."*

The international concept of transplant equity outlined in the previous section of this report closely mirrors the Ministry of Health's definition of equity in health care.

Unjustified differences in access to kidney transplantation in New Zealand meets this definition of health inequity in New Zealand. This matters because the differences in years lived, and the quality of life, is markedly different between dialysis patients and transplant recipients.

Transplantation saves lives and extends life

The choice between dialysis and transplantation is sometimes seen as simply a matter of improving the quality of life. For example, from the Hansard debate on the 2019 Organ Donors and Related Matters Bill:

> *" … [transplantation] just transforms their life because they're not having to rely on dialysis or other things like that, basically, limit their quality of life".*

However, it is much more than that: access to transplantation is the difference between life and death. The outcomes for dialysis patients are worse than for many other diseases, including some cancers, as summarised below (*Source references can be found in the endnotes to this report):*

	Dialysis	Kidney transplant
Median survival	5-6 years	15-20 years (>20 years with live donor transplant)
Average life expectancy gain	-	~10 years
5yr survival **(compared with other diseases / interventions)**	59% (All cancers: 69%)	91% (live donor transplant: 96%) (Coronary Artery Bypass Graft: 75%) (Planned aortic aneurysm repair: 70%)
Quality of life	Reduced in ⅔ cases - Common reason for stopping treatment - Worse than paralysis due to spinal cord injury	Significant reduction in - disease-specific symptoms, - effects and burden of kidney disease, <u>and</u> significant improvements in the ability to work
Symptom burden	symptoms as severe or worse than for cancer patients in ½ of patients 50% pain, 40% anxiety/depression, 35% mobility issues	Significantly improved
Hauora Māori	whakamā and whakamana - disempowerment - stigmatising - importance of family/whānau - importance of maintaining cultural identity	strong desire for a kidney transplant - recognise need for more kidney transplants - lack of partnership in shared decision-making - lack of cultural competence - barriers to live kidney donation

The renal community does not often talk about the poor outcomes for dialysis patients in such stark terms. Sometimes this is motivated by wanting to give dialysis patients a sense of hope, particularly for those for whom transplantation is not an option. However, the reluctance to talk about dialysis outcomes in such frank terms means that the urgency for increasing kidney transplantation is sometimes lost, sometimes even for individual patients themselves.

Transplantation costs less over its lifetime than dialysis …

Kidney transplantation is internationally recognised as not only the best treatment for ESRF, but also the cheapest. For example, a study of comparative costs in Finland between 2009-2014 concluded that after the first transplant year, the cost of the kidney transplant to the health system was less than ⅓ of the cost of dialysis treatment[11]. This study reported a comparable Swedish analysis which showed cost savings of €380,000 per patient from transplantation over a 10 year period.

KHNZ commissioned the New Zealand Institute of Economic Research (NZIER) to complete a comparable analysis for New Zealand. The intention of this analysis was to indicate the level of extra cost, and thus waste occurring in New Zealand health system, of a failure to maximise kidney transplantation in New Zealand.

The NZIER's full report *Transforming Lives and Saving Money: The Golden Opportunity of Kidney Transplants and the System Changes Needed to Lift Numbers*[12] has been published separately and can be accessed on the KHNZ website. This section of this report summarises the NZIER's conclusions of the comparative costs of dialysis and kidney transplantation; later parts of this report will come back to underlying system changes identified by the NZIER that are needed to support increased transplantation in New Zealand.

The NZIER's analysis is based on a "cohort analysis" which compares patients who had a transplant in 2015/16 with patients who started dialysis in 2015/16. This involved following a cohort of:

- 760 people who started dialysis in 2015/16 (determined by the National Health Index number for these individuals not appearing in any dialysis service anywhere in New Zealand in 2014/15).
- 150 people who obtained a transplant in New Zealand in 2015/16 (identified through renal transplant diagnosis-related groups in inpatient data).

The 760 individuals who started dialysis, and the 150 individuals who had a renal transplant, were tracked over the first year in dialysis or the year of the transplant (2015/16) through to 2020/2021 – six full financial years. Over six years, the NZIER identified and compared:

- The number and rate of emergency department presentations.
- The number and rate of outpatient attendances.
- The number and rate of acute and arranged admissions.
- The number and rate of elective admissions.
- The average length of stay in inpatient admissions.

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[11] Ilkka Helantra, Timo Isola, Taru K Lehtonen, Fredrik Aberg, Marko Lempinen, Helen Isoiemi, *Association of Clinical Factors with the Costs of Kidney Transplantation in the Current Era*, Annals of Transplantation, 2019, 34, pages 393-400

[12] NZIER, *Transforming Lives and Saving Money: The Golden Opportunity of Kidney Transplants and the System Changes Needed to Lift Numbers*, NZIER Report to Kidney Health NZ, 5 November 2021

- The weighted average annual cost of dialysis.
- The cost of transplantation, follow up care and post-transplant medication.

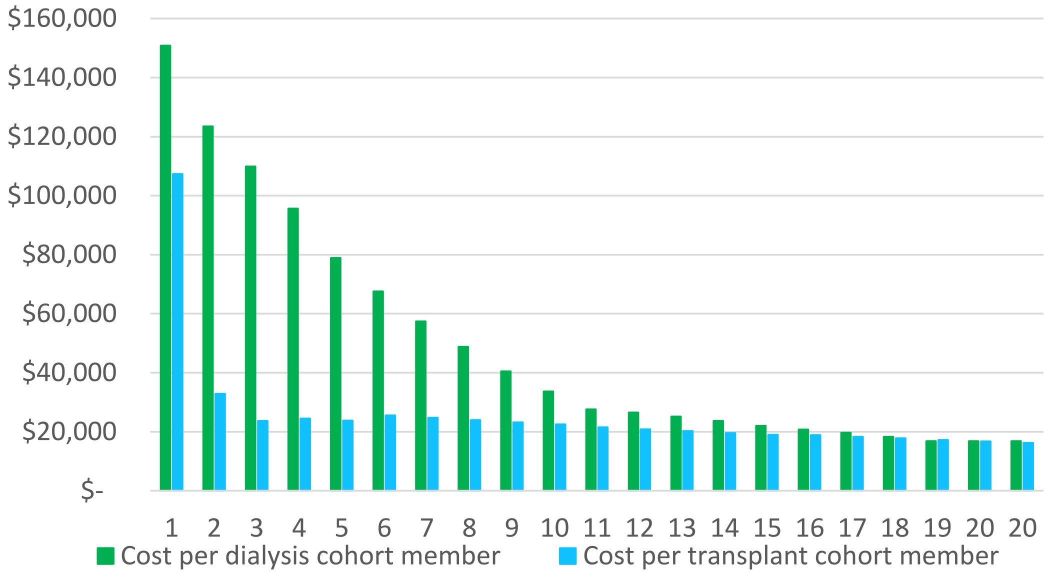
To calculate the full value of a transplant beyond the initial 6 years, the NZIER estimated 20 year comparative costs based on expected survival on either dialysis or transplantation, and a simple assumption that year 6 costs for each surviving member of each cohort continue to be incurred in every year that they remain alive (with the exception of transplant patients who survive graft failure and return to dialysis; those patients are assumed to incur the same costs as a dialysis patient).

The expected cost also reflects the expected survival of dialysis and transplant patients (and for transplant patients, the expected graft loss and return to dialysis). This method of analysis means that the expected (average) cost of both dialysis and transplantation *decreases* for a patient in a cohort – recognising the simple fact that on average some dialysis/transplant patients die each year. The analysis takes into account, however, the different rate at which dialysis and transplant patients die.

…with a transplant costing on average about $389,000 less than dialysis per patient over a 6 year period, and an average $503,000 less per patient over a 20 year period …

Using this approach, the NZIER's "base case" analysis concludes that

- The 6 year total costs of a person in the dialysis cohort amounted to $626,443 while the 6 year costs of a person in transplant cohort amounted to $237,508 – a cost difference of $388,935 per patient in favour of transplantation
- Over 20 years, the expected costs of a dialysis patient amount to $1,040,927 while the expected costs of a transplant patient amount to $538,074 - a saving of $502,854 per patient – even though on average a patient in the transplant cohort outlives the dialysis cohort by a wide margin. The profile of these savings is seen in the graph below:



A sensitivity analysis, assuming a higher cost of the initial transplant operation, reduces the 20 year cost advantage of a transplant to $354,280.

The NZIER goes further, to estimate what level of upfront investment would be justified to achieve this reduction in health system costs. They conclude:

> *In 2019, there were 221 renal transplants in New Zealand, against a demand of nearly 600 (the active deceased donor waitlist plus approximately 50 percent more who are not waitlisted but who could benefit from transplantation). Assuming a similar level of kidney transplantation has occurred in 2021, based on our estimated health system cost savings,* ***we estimate that for an achievable goal of lifting the combined renal transplant rate by 5 percent year on year, an investment of at least $4 million to $5.5 million in the first year, rising to $6 million to $9 million in 2031 would be financially justifiable****, purely from a health system perspective. If a societal perspective were used, the justifiable investment would be even higher.*[13] (emphasis added)

Transplantation supports increased economic productivity and reduced income support costs

An additional of benefit of transplantation over dialysis is the ability for some patients to return to full time employment. Some dialysis patients have to travel to an in-centre unit to obtain care three to four times per week for several hours each time. This can make balancing dialysis, family life and employment impossible for some people.

A major systematic review and meta-analysis[14] found that employment rates are not high for dialysis patients or transplant patients, and that employment did not always increase post-transplantation, depending on context, patient variables (such as age and previous employment status) and study follow-up time. However, dialysis patients experienced a significant drop in employment after the initiation of dialysis, whereas transplant patients sometimes experienced an increase in employment post-transplant.

New Zealand based research is needed to identify the employment and income impacts of dialysis and transplantation. Without such research the true benefit of transplantation cannot be known. However, the NZIER notes that every person who gives up full-time employment and becomes unemployed due to their need for dialysis is expected to incur the following costs[15]:

- $53,831 in lost employment income and associated productivity.
- $13,988 in lost income tax and ACC levy.
- $8,815 in lost wellbeing from withdrawing from the labour force.
- $19,097 to $25,220 in supported living payments.
- $7,818 in accommodation supplements.

That is, for every person gives up employment on account of dialysis and is able to return to full-time employment post-transplant, the additional benefits of transplantation amount to up to $53,831 in productivity, $8,815 in wellbeing directly related to labour force status, and up to $47,026 in additional fiscal savings (over and above health system savings)[16].

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[13] NZIER, *Transforming Lives and Saving Money: The Golden Opportunity of Kidney Transplants and the System Changes Needed to Lift the Numbers*, page 69.

[14] Lilli Kirkeskov, Rasmus K. Carlsen, Thomas Lund, Niels Henrik Buus, *Employment of patients with kidney failure treated with dialysis or kidney transplantation—a systematic review and meta-analysis*, BMC Nephrology, Volume 22, Article number: 348 (2021)

[15] Values obtained from the Treasury CBAx Impacts Database

[16] NZIER, *Transforming Lives and Saving Money: The Golden Opportunity of Kidney Transplants and the System Changes Needed to Lift the Numbers*, page 72.

There is significant pressure on dialysis resources, especially in the upper North Island

A number of DHBs in the upper North Island are already hitting capacity constraints in their in-centre haemodialysis facilities with capital investments already planned for extra dialysis capacity in Counties-Manukau and Waikato, within looming capacity issues in Bay of Plenty and Auckland. As well as the up-front financial investment involved, this extra capacity creates further workforce issues on top on those currently existing.

To get a picture of what might happen to dialysis numbers in the absence of any improvement to transplantation rates, we asked the NZIER to model several scenarios. The NZIER projected the population using dialysis to 2031/2032 using three slightly different assumptions in the rate of growth in dialysis patients. (All scenarios project recent growth rates across DHB areas, by age and ethnicity).

The NZIER's three scenarios indicate that the population using dialysis is expected to increase to over 5,700 (5,727 to 5,792) by 2031/32 – about a 30 percent increase in dialysis patients over the next ten years, or a 60 to 61 percent increase since 2014/15[17]:

Projections of dialysis patients

Financial year	Actual dialysis patients (all types)	Projection A	Projection B	Projection C
2014/2015	3,590			
2015/2016	3,758			
2016/2017	3,918			
2017/2018	4,088			
2018/2019	*			
2019/2020	4,331			
2020/2021	4,440			
2021/2022		4,538	4,580	4,558
2022/2023		4,656	4,700	4,675
2023/2024		4,777	4,824	4,799
2024/2025		4,896	4,948	4,923
2025/2026		5,014	5,069	5,043
2026/2027		5,132	5,191	5,164
2027/2028		5,252	5,312	5,284
2028/2029		5,375	5,436	5,405
2029/2030		5,494	5,556	5,524
2030/2031		5,611	5,675	5,640
2031/2032		5,727	5,792	5,754

* Excluded due to incomplete data

In terms of the type of dialysis, the NZIER's projections indicate that in centre haemodialysis will continue to be used by the majority of dialysis patients:

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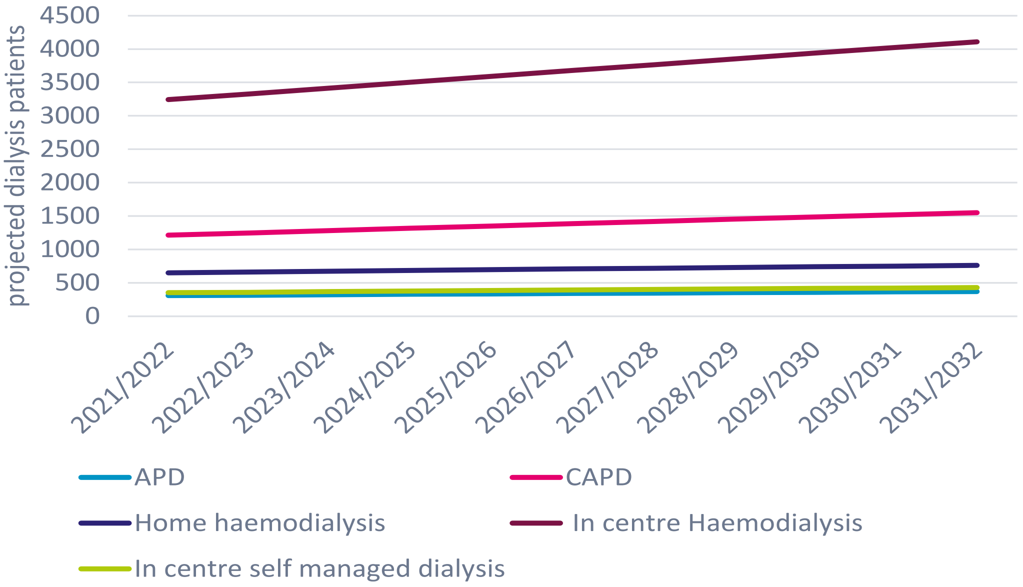
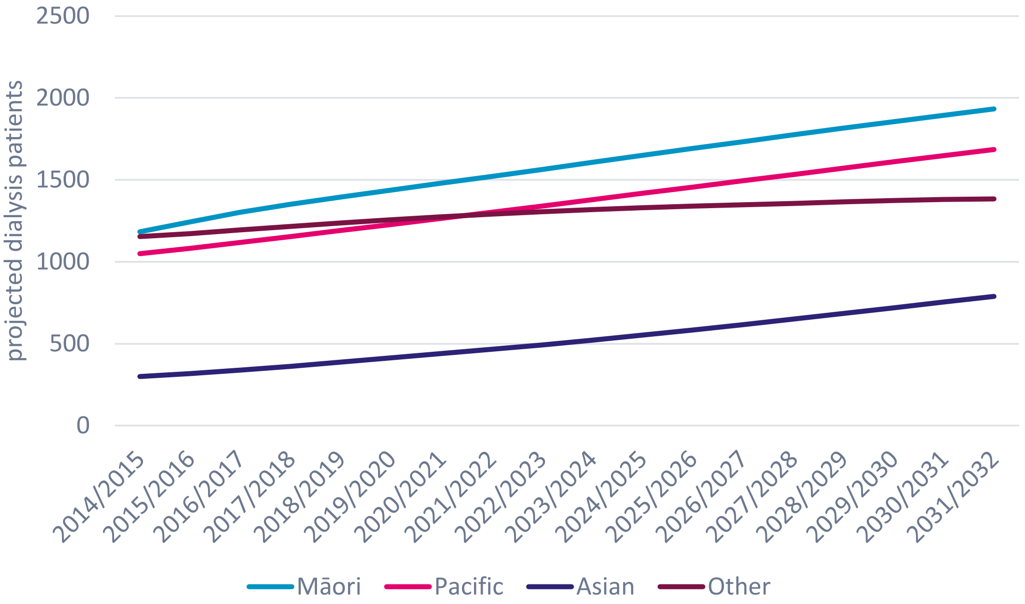
[17] NZIER, *Transforming Lives and Saving Money: The Golden Opportunity of Kidney Transplants and the System Changes Needed to Lift the Numbers*, page 15.



with the majority of this growth centred in the three Auckland DHBs.

As a result of this growth, the cost of dialysis services will be about $150 million higher in 2031/32 than it is now.

The NZIER's analysis highlights that the number of Māori and Pasifika users of dialysis will grow quickly and is expected outnumber other ethnicities on dialysis by a wide margin by 2031/32:



In the absence of any change to transplant rates, dialysis - with its limited life expectancy and quality of life - is and will continue to be experienced predominantly by Māori and Pasifika.[18].

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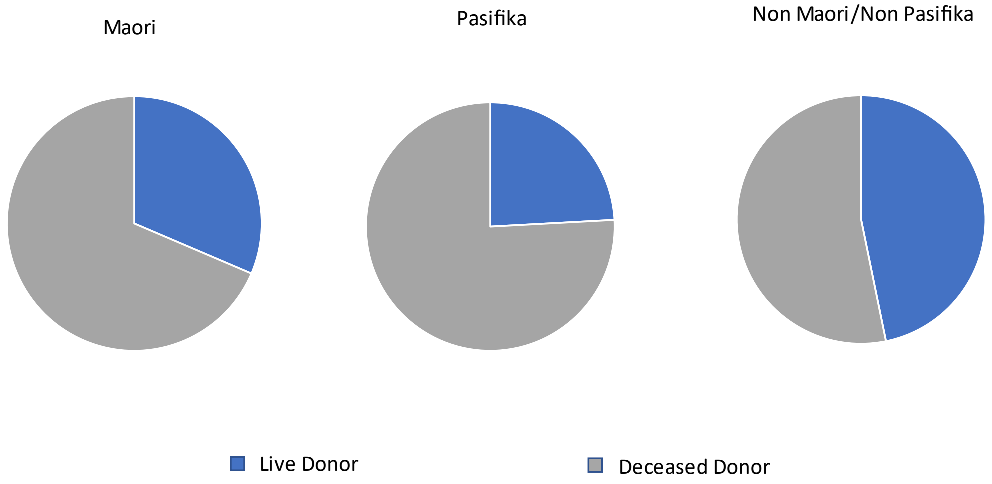
[18] NZIER, *Transforming Lives and Saving Money: The Golden Opportunity of Kidney Transplants and the System Changes Needed to Lift the Numbers*, pages 16-21.

Increasing Deceased Donor Kidney Transplantation

Increasing the rate of deceased donor kidney transplantation is critical to addressing transplant equity in New Zealand. Currently, transplant operations for Māori and Pasifika more frequently involve transplants from deceased donors, as highlighted in the chart below:

Source of Transplants, by ethnicity, 2019 (source:ANZData)



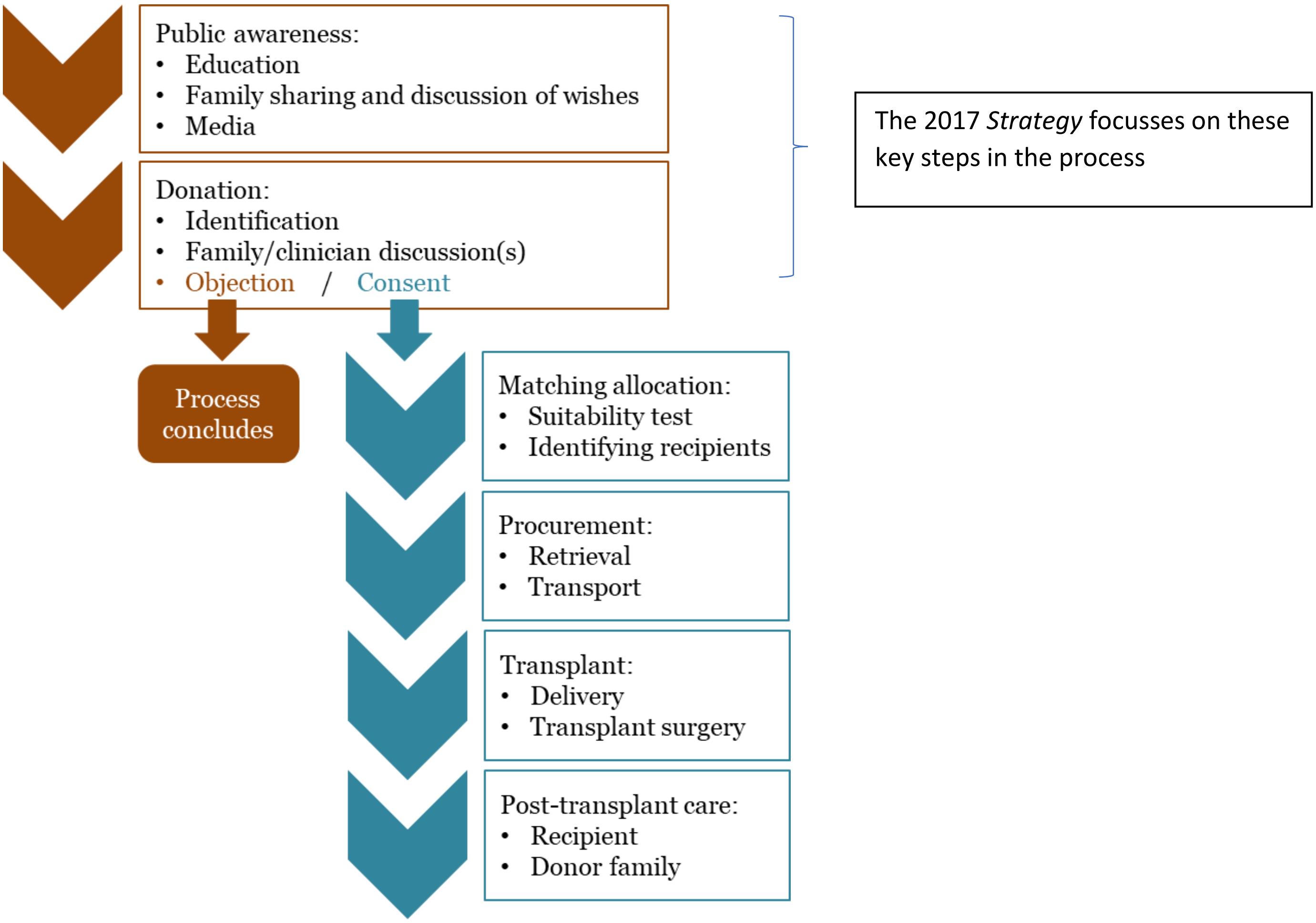
3

This section of this report outlines the progress made in implementing and funding the 2017 Government Strategy: *Increasing Deceased Organ Donation and Transplantation: A National Strategy* – as this is the cornerstone of New Zealand's approach to increasing deceased organ transplantation, for all organs (not just kidneys).

An overview of the 2017 "Increasing Deceased Organ Donation and Transplantation: Towards a National Strategy"…

In recognition of the opportunities inherent in higher transplantation rates for all organs (not just kidneys), in 2016 the Government established an expert advisory group and a sector working group (including KHNZ) to advise of increasing deceased organ donation rates. The resulting *Increased Deceased Organ Donation and Transplantation Strategy: Towards a National Strategy* was released in June 2017.

The focus of the 2017 *Strategy* was on increasing the number of donated organs, as shown in the stylised model of the donation and transplantation process below:



The *Strategy* has six major elements, summarised below. A key element of the *Strategy* was the establishment of a "national agency" to lead and drive increasing deceased organ donation in New Zealand:

Strategic priority one: Improving public awareness and media engagement about organ donation and transplantation	**Responsibility**
The national agency will be responsible for developing a national public awareness and media engagement plan that will be based on sound research and will be monitored and evaluated regularly.	
Priority actions • Raise public awareness and understanding of organ donation and transplantation. • Proactively engage a wide range of media. This will include support for the sector around communication planning.	National Agency

Strategic priority two: Improving New Zealand's system of registering and sharing donor intent for individuals, families/ whānau and clinicians New Zealand has a sound legal consent framework for organ donation that will be retained. It is expected that the electronic health record will become the primary record of donor intent over time to better communicate an individual's wishes to families/whānau and clinicians **Priority actions** • Explore other effective systems, including the EHR (under development), to allow people to record and manage their wishes to be an organ donor more efficiently. • Provide families/whānau and clinicians in ICUs with improved access to accurate donor intent records and encourage them to consult this information. • Enable New Zealanders to record, change and access their donor status more easily. • Promote communication of organ donation wishes to families/whānau and friends through public awareness campaign and social media. • Explore options to expand the list of donor choices from 'Yes', and 'No', to include further options.	The Ministry of Health, and the National Agency upon establishment The National Agency, the Ministty of Transport and the NZTA
Strategic priority three: Enhancing capability and consistency through improved training The importance of organ donation training is well recognised in New Zealand: ODNZ currently provides a range of education and training, including workshops for clinicians, organ donation study days, Link team nurse induction days and Link team workshops. **Priority actions** • Coordinate training in organ donation conversations for clinicians and work with DHBs and professional organisations to promote and improve the uptake of training opportunities. • Provide training to intensive care doctors, Link nurses, emergency department staff, anaesthetists, and other staff involved in the organ donation process. • Develop educational material on cultural awareness as applied to organ donation conversations with Māori and Pasifika. • Collect data on the uptake of organ donation conversation training and its impact on service providers and consumers.	National Agency
Strategic priority four: Increasing hospital-based capacity for deceased organ donation Our health system needs to be able to support increasing numbers of deceased organ donations. **Priority actions** • Continue to support the expanded Link nurse roles across the deceased organ donation environment, as appropriate to regions. • Resource specialist medical and nursing organ donation roles within ICU's as appropriate to enable them to champion and advocate for deceased organ donation within the DHB. • Expand the clinical practice framework specific to organ donation following circulatory death. • Increase knowledge-sharing around the opportunity for deceased organ donation and the organ donation system through the more effective use of Morbidity and Mortality meetings, and wider alignment with Donation Audit data. • Develop sustainable capacity for increased organ donation, retrieval, transplantation, and follow-up care, within national DHB planning and funding processes.	National Agency

Strategic priority five: Establishing a national agency to lead the implementation of the strategy A national agency with overall responsibility for deceased organ (and tissue) donation will implement key elements of the strategy and will have a clear mandate to increase rates of deceased donation. **Priority actions** • Establish a national agency to lead the implementation of the strategy with a role to: – raise the profile of deceased organ donation in the health sector and in the community – support effective clinical governance – work with the sector to coordinate donation and transplantation processes – provide expert advice and information on deceased organ and tissue donation to the sector, government, media, and public	Not stated, but in practice the Ministry of Health
Strategic priority six: Measuring progress An overarching high-level monitoring and evaluation framework will support delivery of the strategy by gathering information on the strategy's priorities for action, measuring core process improvements and improving performance reporting. **Priority action** • Develop and implement a measurement and reporting framework.	Perfromance reporting: National Agency Monitoring the overall strategy: Ministry of Health

Source: *Increased Deceased Organ Donation and Transplantation Strategy: Towards a National Strategy*

The immediate priority was to identify location of, and establish, the national agency…

A key implementation action was to identify which agency would be the national agency – should it be a new entity in its own right, or be part of an existing entity? The Organ Donors and Related Matters Bill, introduced into Parliament in March 2019, proposed that the national agency be located in the New Zealand Blood Service. The Bill, when passed in November 2019, changed the name of the Blood Service to the New Zealand Blood *and Organ* Service (NZBOS) in recognition of its new responsibilities.

The Bill gave the NZBOS the following new functions:

- To provide oversight and clinical governance of the organ donation and transplantation system.
- To manage any related or incidental matters.

The Ministry of Health's initial briefing to the Health Select Committee in April 2019 noted that the Bill was intended to allow the NZBOS to fulfil a national leadership role which could include:

- Raising the profile of organ donation.
- Providing expert advice and information to the sector, government, media and the public.
- Supporting effective clinical governance.
- Working with the health sector to co-ordinate donation and transplantation processes.

Later in its initial briefing, the Ministry noted that the Bill would enable the transfer of ODNZ from the Auckland DHB to the NZBOS. It also noted that this transfer, along with the establishment of a wider national organ donation leadership role, was subject to matters such as:

- Contract and staffing arrangements.
- Operational continuity.

- Governance and advisory arrangements.
- ***Additional funding*** (emphasis added).

The Ministry concluded by saying that if implemented these changes would support strategic priorities under the 2017 *Strategy*.

The 2019 Bill did not outline specific roles, functions and accountabilities of the new national agency, with the Ministry of Health recommending that this gets sorted out later …

The Bill was widely supported by submitters to the Health Select Committee, including KHNZ. Some proposals were put forward by submitters to strengthen NZBOS in fulfilling its new functions. In particular, a number of submitters (including the New Zealand Blood Service itself) requested that the Bill should include greater clarity of role, functions and responsibilities for the new NZBOS in respect of organ donation.

In its June 2019 Departmental Report to the Health Select Committee, the Ministry of Health did not support these suggestions. It advised the Health Select Committee:

> *It is intended that this Bill simply enables the NZBS [New Zealand Blood Service, as it was then known] to deliver the functions of a national agency, and does not oblige them to implement aspects of the National Strategy that may require additional funding. Further specificity of functions and objectives in the Bill, as suggested by submitters, may be too restrictive to be helpful and enduring over time ….*
>
> *… We note that further work is needed to ensure that the NZBS is well supported to enable its broadened functions. This includes identification of the role, scope, objectives and functions of the new agency …*
>
> *… We consider that it would be more suitable to formalise these matters in the annual accountability process including the statement of intent of a Crown Entity, rather than being included in primary legislation….*
>
> *… A phased implementation approach to establishing the role of a national organ donation and transplantation strategy is anticipated and will be subject to funding arrangements being confirmed.* (Ministry of Health, *Organ Donation and Related Matters Bill: Departmental report,* June 2019, pages 7-8)

The Health Select Committee accepted the officials' advice and undertakings.

There was unanimous support for the drive to increase organ donation, and for the NZBOS to be the new national agency, in the Parliamentary Debates. Parliament had high hopes …

All political parties represented in the Parliament supported the 2019 Bill, all supported the goal of increasing transplantation, and all expressed high ambitions (but also some concerns) for the new national agency:

… there was really good cross-party support on this Bill because of the importance that organ donation means to people's lives.

Dr Liz Craig, Labour, Third Reading

… This is a good Bill. I'm thankful to supporters [of the Bill] across the House, and I look forward to the work to be done by this organization [the NZBOS] as it moves into the future.

Hon Peeni Henare, Labour, Third Reading

… The next step is the funding… so my plea to Minister Henare over there, who's an Associate Minister of Health, is: you have got to come up with the dough in the next Budget, my friend, because the Blood Service is going to require an infusion – not a blood infusion – of cash to get on with the job …. We're not talking about a huge sum of money; we're only talking a few million…

Chris Bishop, National, Third Reading

… this [Bill} appears to be one of those cases where we've got bipartisan support … we have got the general direction of the legislation right and people agree with it.

Hon James Shaw, Green Party, Second Reading

… where is the funding? Because, yep, we're going to get the New Zealand Blood Service in charge of organ donation and transplantation. That's all well and good, but I know for a fact that there is no increased funding for the New Zealand Blood Service out there to actually implement the changes that Parliament wants them to do. So where is the extra money?

Chris Bishop, National Party, Second reading

… having a national agency that has a clear responsibility for raising the profile of organ donation and supporting clinical governance and coordinating that whole donation and transplantation process is a really good step forward.

Hon Eugene Sage, Green Party, Third Reading

… [a submitter] recommended that the Committee consider substantial increases in funding towards the New Zealand Blood Service that will be dedicated to this new planned organ donation agency, and suggested that this funding would idealistically be specifically used towards public messaging around live and deceased donations in Aotearoa New Zealand. That's a really great suggestion…

Jenny Marcroft, NZ First, Second Reading

… I think the submitters had valid points in their submissions about whether or not the role [of the NZBOS] should be strengthened legislatively. But I'm relaxed that we have the right balance but also the right oversight to make sure that they are given the tools that they need to deliver what we all want to see, and that is an increase in the rate of organ donation in New Zealand.

Michael Woodhouse, National, Second Reading

> … an important part [of setting up the national agency is] to allow this organization, the New Zealand Blood and Organ Service, to carve its path as it moves forward…. I'm really looking for some innovation in how we are to increase those [donation] numbers, how we're able to encourage more people – in particular Māori and Pacific peoples – to consider themselves for this great cause…
>
> *Hon Peeni Henare, Labour, Committee Stage*

… but since 2017, other than the 2019 legislation and subsequent transfer of the ODNZ functions into the NZBOS, there has been no progress in implementing the Strategy….

The strong and unanimous Parliamentary support for the 2017 *Strategy*, the establishment of the NZBOS as the national agency, and the passage of the 2019 Bill has not translated into action nor full funding for the *Strategy*. Based on official documents from the Ministry of Health obtained under an Official Information Act request[19], the actual amount of progress can be summarised in the table below.

The only substantive action completed since 2019 has been the transfer of ODNZ from Auckland DHB to the NZBOS – although as noted below the funding transferred with ODNZ was insufficient to run the current functions of ODNZ. But transferring an existing set of operational functions and responsibilities does not of itself create a new national agency, enabled to provide strategic and national leadership in the area of organ donation. Nor does it progress the other elements of the *Strategy*. It simply transfers an existing set of functions to a new management structure.

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[19] From an analysis of the papers released by the Ministry of Health under OIA request H202110445 of 11 October 2021, which was for "all reports, memoranda, aide memoirs and any other documents produced by or form the Ministry of Health since June 2017 regarding the implementation of the 2017 *Increasing Deceased Organ Donation and Transplantation: A National Strategy*"

What has happened since 2017 to implement the *Strategy*?

Strategic Priority	Scorecard	Actions Completed or Substantially Completed	Comment
Improving public awareness and media engagement about organ donation and transplantation	✘	None `	Current activity is limited to reactive responses to media enquiries, and organising memorial services.
Improving New Zealand's system of registering and sharing donation intent for individuals, families and clinicians	✘	None	
Enhancing capability and consistency through improved training	✘	None	NZBOS have advised that funding for the training they organise is sourced from an independent charitable trust, not Government funding.
Increasing hospital-based capacity for deceased organ donation	✘	None	
Establish a national agency to lead the deceased organ donation and transplantation	~	2019 *Organ Donors and Related Matters Bill* to make the then NZ Blood Service the home of the national agency. Functions of ODNZ transferred from Auckland DHB to NZBOS in November 2020.	Simply transferring ODNZ to NZBOS does not give NZBOS the capacity to play a national leadership role or to implement the 2017 *Strategy*. NZBOS have advised that the funding transferred from Auckland DHB to the NZBOS was insufficient by about $500,000 per annum to safely run the ODNZ operation**.** We understand that there are also significant issues with the current databases, and with data integrity.
Measuring progress	✘	None	No updates on the *Strategy* on the Ministry of Health website since January 2018. The 2020 Budget bid for the *Strategy* (see below) anticipated the NZBOS would report quarterly, with a three-year review of the performance of the national agency itself.

Source: The analysis of actions completed or substantially completed above has been prepared from the documents provided by the Ministry of Health in response to an OIA request that asked for all document from June 2017 relating to the implementation of the 2017 Strategy.

Essentially the approach taken by the Government has been to devolve any progression of the 2017 *Strategy* to the NZBOS, and for action to be subject to funding. Any actions that could have been taken in the interim – such as improving the system of registering and sharing donor intent for individuals, families/whānau and clinicians – was parked from the outset of the implementation process, even though it could have been progressed in the meantime.

What has happened since 2017 to fund the national agency and the *Strategy*?

Funding for the NZBOS and the Implementation of the 2017 Strategy

In May 2018, in seeking Cabinet's agreement to establish the NZBOS as the national agency, the then Minister of Health advised the Cabinet that: "the establishment of significant additional functions, such as public awareness, will need to be postponed until funding arrangements have been confirmed …. I expect that implementation will be phased gradually as funding becomes available."

In May 2018, Cabinet asked for further information on the cost implications of establishing the new national agency. In his response in November 2018, the Minister of Health advised Cabinet that the NZBOS would receive fiscally neutral funding for the transfer of the ODNZ functions of $1.7 million ongoing (with $0.325 million of one-off transition costs). There would be additional, on-going funding of $0.250 million for the NZBOS to cover the costs of clinical governance of organ donation services ($0.075 million), and marginal increases in the NZBOS overheads from its expanded range of functions ($0.175 million). Cabinet was advised that the full implementation of the 2017 *Strategy* would cost an estimated $2 million per annum. In November 2018, Cabinet agreed to fund $1.325 million over four years (through a "pre-Budget approval") for the $0.325 million one-off transition costs, and the $0.250 million extra costs faced by the NZBOS (which over four years adds to $1 million).

A bid was prepared for Budget 2019 to progress the *Strategy*, covering:

- $2 million per annum on-going for the implementation of the *Strategy*, or $8 million over four years.
- $0.7 million per annum on-going to support expended "LINK team" roles (see below) - $2.8 million over 4 years.
- $25 million over 4 years to meet an expected annual compound increase of 10 percent in the volume of heart, lung and liver transplants conducted in Auckland DHB. This equates to a cumulative increase in such transplants of 10 per annum, or 100 extra such transplants over 4 years. No additional funding was requested for increased kidney transplants, even though this would normally follow from extra heart, lung and liver donation. This omission was justified in the bid on account of renal transplants being provided by three DHBs (not just Auckland DHB) and renal transplants being funded via Inter-District Flows. (The costs of retrieving deceased donor kidneys were however covered by the bid).

A very similar bid was submitted for Budget 2020, which indicates that the 2019 Budget bid was unsuccessful. The traditional Budget process for 2020 was understandably suspended due to the Covid-19 outbreak, and the Government's budget process in 2020 was orientated to funding, and managing the consequences of, the pandemic.

Based on the papers provided by the Ministry of Health, no bid was submitted in Budget 2021, even though the NZBOS wrote to the Ministry of Health in November 2020 advising that the funding provided to date was insufficient to implement the Strategy and that a funding path of $4-5 million per annum on-going would be required to develop a "credible and effective national leadership function". The NZBOS also wrote to the incoming Associate Minister of Health in November 2020 along similar lines, and advised that the continuation of past ad-hoc funding arrangements would lead to the continuation of "the very piecemeal approach towards organ donation and transplantation of the past that the development of the strategy and national agency were explicitly designed to overcome."

Notwithstanding the advice to the Associate Minister of Health, based on the documents provided by the Ministry of Health, no Budget bid was prepared for Budget 2021.

The NZBOS was advised in April 2021 that no new funding would be provided.

The NZBOS itself has been transparent in its annual accountability documents that progressing the Strategy is contingent on funding being available. The NZBOS's Statement of Intent 1 July 2020 to 30 June 2024 notes under the section "Measures of Success" that it would "Implement ***funded*** actions set out in "increasing Deceased Organ Donation and Transplantation: a National Strategy (2017)[20]" (emphasis added).

Funding for the Transferred ODNZ Functions

Notwithstanding the funding top-up for the NZBOS of $0.175 million per annum to recognise the increase in NZBOS overheads from its expanded range of functions, in November 2020 the NZBOS advised the Associate Minister of Health of a funding gap of $0.200 million per annum for the transfer of ODNZ staff to NZBOS (attributed to extra overhead costs) plus under-resourcing of the existing ODNZ function itself. NZBOS advised that the operating and staffing model inherited from Auckland DHB was "shaped by a plan to meet a fixed budget rather than by clinical need and workforce safety". The NZBOS estimated that it needed to boost staffing levels by 4 donor co-ordinator FTEs and 0.8 doctor FTEs to address risks to staff wellbeing and risks to service continuity. We understand that this outstanding funding shortfall is now about $0.500 million per annum. This is currently being funded by running down the NZBOS's reserves on its balance sheet. This can only be a short-term measure and is not a sustainable funding position.

Funding for LINK team capacity

As part of the deceased organ donor process, New Zealand has established a "LINK Team" in each ICU. This is a team of a senior ICU nurse, an ICU doctor, and an operating room nurse – who has a "link" role with ODNZ and undertake donation quality assurance and education work. An expansion of the LINK team approach was trialled from 2012. The 2017 *Strategy* said that these expanded roles were (a) successful in increasing deceased donation rates and (b) would be made permanent, with LINK nurse roles expanded with "protected time provided where appropriate".

The November 2018 Cabinet paper mentioned above confirmed that some of the LINK team funding was "provided from within Vote: Health baselines" but this funding source was only until July 2019. Cabinet was advised that $0.700 million per annum would be required to provide an on-going and stable funding base for the LINK teams.

Continuation of the funding for the LINK teams was included in the unsuccessful 2019 and 2020 Budget bids discussed above. The LINK teams continue to be funded on a periodic, ad-hoc basis by the Ministry of Health. This provides no certainty for LINK nurse management and staff, and makes

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[20] NZBOS Statement of Intent 1 July 2020 to 30 June 2024, page 16

it impossible to build and develop the teams. A new, sustainable, funding arrangement will be required in the transition to the Health New Zealand structure**.**

What has happened since the undertakings given to the Health Select Committee in 2019 to further define and clarify the role, functions and responsibilities of the national agency?

From mid-2020, the NZBOS started consulting on a more detailed set of proposed roles and functions for the national agency, given the lack of specificity in the 2019 legislation.

In its consultation documents, the NZBOS assumed that it would have a role to play in respect of live organ donation and transplantation, as well as the mandate it had for oversight of deceased organ donation, and support for deceased organ transplantation. Proposals on roles and functions resulting from the consultation were put to the Ministry of Health in October 2020, with the Director General of Health replying a month later. In his reply, the Director General stated that the NZBOS's proposals with respect to organ donation were supported, but that "more work needs to be done in defining what 'support for transplantation' by the new agency would mean in practice…". This included the NZBOS's role in respect of live organ donation and transplantation. Further consultation within the sector was advised.

At the same time that the NZBOS wrote to the incoming Associate Minister of Health in November 2020 on its funding issues, it also asked the Minister to agree to a set of specific roles and functions, that would be enduring, rather than re-negotiated each year. We understand that this is outstanding, although the 2021/22 Statement of Performance Expectations for the NZBOS has yet to be tabled in Parliament.

In the meantime, and in the absence of a sustainable multi-year funding path for the national agency and the implementation of the 2017 *Strategy*, the position of the NZBOS has consistently been that the NZBOS is not funded at this time to do anything other than continue the on-going work of ODNZ as transferred from Auckland DHB.

Notwithstanding the lack of progress across the 2017 Strategy, Kidney Health supports the direction of the 2017 Strategy ….

Kidney Health NZ was part of the sector group that helped develop the 2017 *Strategy*, and gave its endorsement to the *Strategy* at the time.

Kidney Health NZ believes the principles and priorities identified in the 2017 *Strategy*, and the decision to give the NZBOS the leadership role, continue to provide the best opportunity to increase deceased donor kidney transplant rates in New Zealand. The 2017 *Strategy* does not need to be reviewed, or refreshed, or updated – it just needs to be implemented.

In developing this report, Kidney Health NZ reviewed the practices of the five countries that have the highest deceased donor transplant rates in the world, and reached out to organ donation and transplantation experts in these countries. Our high level findings are attached as Appendix 1.

Our scan of international best practice highlighted that high rates of deceased organ donation stem from how services are organised and co-ordinated across hospitals to support transplantation. Other jurisdictions organise in-hospital services in such a way that patients with a very low or nil chance of survival are identified early, and sensitive and respectful discussions are held with families at an early stage about the possibility of donation, as a way of securing something good from the family's impending tragedy. If family approval is given, patients in general wards will be moved to an ICU for a 1-2 day stay for the purposes of organ retrieval, once nature has taken its course and the expected death has actually occurred. Family consent is required at all stages, and organ donation does not proceed if the family objects at any time.

The international experience supports the direction of the 2017 *Strategy*. However it also highlights that once the essential building blocks are put in place in New Zealand, there will be further opportunities in New Zealand to support deceased organ donation by looking at the support for donation across the whole of a hospital's processes and infrastructure.

… but the NZBOS needs a sustainable multi-year investment path to enable it to provide national leadership and to fully implement the 2017 Strategy…

Kidney Health NZ calls upon the Government to provide a secure and sustainable multi-year investment path to enable the NZBOS to provide national leadership and to fully implement the 2017 *Strategy.* Specifically, KHNZ calls for:

- Fully funding a forthcoming investment request from the NZBOS of between $3-$5 million per annum to build the national agency and to implement the 2017 *Strategy*.
- A sustainable, multi-year funding path for LINK teams in ICUs.
- The Government to finalise the specific roles, functions and responsibilities of the NZBOS, in line with its undertaking to the Health Select Committee in 2019.
- Fully fund the NZBOS to be fully funded for the transfer of functions from Auckland DHB (about $0.5 million per annum).

The fiscal and economic analysis completed by the NZIER, cited earlier this report, shows that this level of investment will more than pay for itself if there is a 5% increase year on year in deceased donor kidney transplants – or about an extra 10-12 deceased donor kidney transplants per annum.

… this investment path should be included in the Government's 2022 Budget decisions or found within the funding envelope provided to Health New Zealand.

While KHNZ proposes that the full investment for the national agency and the 2017 *Strategy* should be included in the Government's 2022 Budget decisions, if for whatever reason this is not possible then an alternative is for the investment to come from within the health sector.

Under the current DHB model, the NZBOS funds the costs of providing its traditional blood and plasma products from DHBs through a cost recovery process. Currently, the underfunding of the ODNZ functions is being carried within the NZBOS; if the DHB model had continued, and the Government had not met these costs, these costs would ultimately have had to be recovered from DHBs.

It is currently unclear what the funding model will be under the Health New Zealand reforms for traditional blood and plasma products. Whatever that model is, KHNZ believes that extending this cost recovery model to include organ donation services should be implemented if new Government funding cannot be provided in Budget 2022.

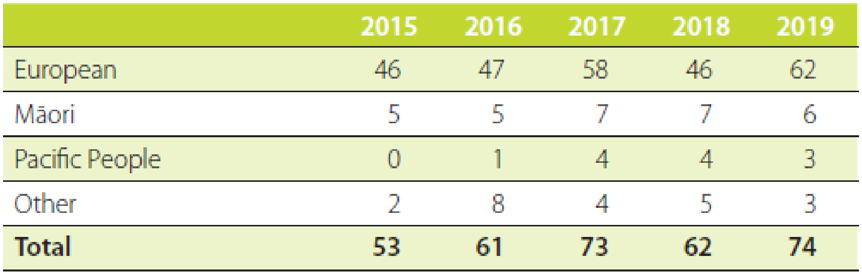
Fully implementing the 2017 Strategy and increasing rates of deceased organ transplantation would make an immediate impact on the current low rate of Māori and Pasifika kidney transplantation…

An immediate benefit of fully funding the NZBOS as a national agency, and the implementation of the 2017 *Strategy,* will be the impact on Māori and Pasifika kidney transplantation rates.

… but the 2017 Strategy can be strengthened by bringing equity objectives into it…

At present, deceased organ donation is predominately from European patients who have passed away in an ICU:

Ethnicity of Deceased Donors, by Year (source: ODNZ Annual Report, 2019)



	2015	2016	2017	2018	2019
European	46	47	58	46	62
Māori	5	5	7	7	6
Pacific People	0	1	4	4	3
Other	2	8	4	5	3
Total	**53**	**61**	**73**	**62**	**74**

KHNZ proposes that a new strategic priority be added, to bring an explicit equity objective into the 2017 *Strategy*. A strategic priority of addressing deceased donor equity would require the NZBOS:

- To tailor their public awareness and media engagement in ways that specifically supports engagement with Māori and Pasifika communities.
- To identify and deliver specific strategies for Māori and Pasifika families and whānau in ICUs, as part of their overall strategy to increase deceased organ donation rates overall.

It is important to stress that KHNZ does not propose that any extra deceased donor kidneys from Māori or Pasifika would automatically be allocated to Māori or Pasifika patients on the waitlist; the kidneys would go to the next person on the waitlist, as determined by the waitlist algorithm (which, as noted above, should be reviewed to address transplant inequity).

Given the delay in the implementation of the 2017 *Strategy* to date; KHNZ does not want to see this extra strategic priority to be used as a reason to further delay the implementation of the *Strategy.* Rather, this new strategic priority would be included in the NZBOS's detailed implementation plans for the 2017 *Strategy* and as it rolls those plans out.

Increasing Live Donor Kidney Transplantation

Improving transplant equity in New Zealand will require specific approaches to support increased live kidney transplantation for Māori and Pasifika – because different people with different levels of advantage require different approaches and resources to get equitable transplant outcomes.

Over the past decade, there have a been a range of initiatives designed to increase live donor kidney transplantation in general, including (in 2014):

- The establishment of the National Renal Transplant Service.
- Increased support for the Paired Kidney Exchange initiative, which allows donor and recipient pairs who are not compatible with each other to be listed for possible swap with other pairs.
- The creation of "donor liaison coordinators" who (in the words of the press release at the time) "will work at each the three transplanting centres and in the seven larger renal services in the country. These coordinators will support donors and recipients throughout the transplantation process, from providing education to interested potential donors to organising blood tests and carrying out pre-surgery preparation".

A further important initiative was the passage of the Compensation for Live Organ Donors Act 2016.

However, there has been only one major initiative targeted at increasing Māori and Pasifika live kidney transplantation. This section of this report focuses on this initiative, and what has (or hasn't) happened to it.

The Live Kidney Donation Aotearoa Project specifically aimed to increase live kidney donation for Māori and Pasifika in Counties-Manukau …

The *Live Kidney Donation Aotearoa* project was established in 2013, with initially three (and then a further year) of time limited funding totalling $1½ million, in the Counties-Manukau DHB to increase the number of live donor kidney transplants by 20 per year by the end of the project. The focus of the project was on Māori and Pasifika live donor transplantation, although transplants of other ethnicities were also accepted.

To achieve this, the *Live Kidney Donation Aotearoa* project needed a way to increase the number of potential donors offering live kidneys to Counties-Manukau Pasifika and Māori patients. This led to a range of supporting objectives for the *Live Kidney Donation Aotearoa* project, including:

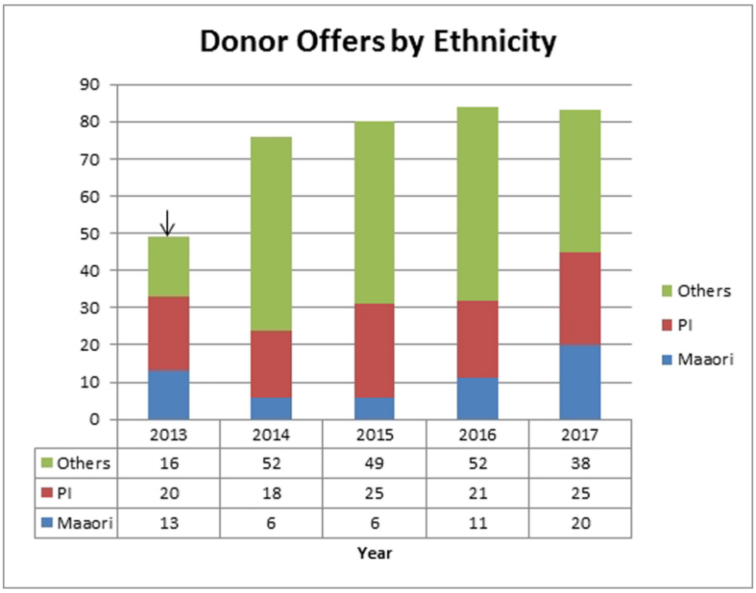
- To develop and trial culturally sensitive and health literacy appropriate educational resources for live kidney donation in Pasifika and Māori.
- To develop an inclusive Home-Based Live Kidney Donor Education Programme using ethnically based health educators trained to build patients' and families' health literacy skills, provided for every clinically appropriate Pasifika and Māori patient.
- To identify and educate lay volunteers within patients' social networks who can provide information on end-stage kidney disease and live kidney donation, and build patients' and families' health literacy around the process and outcomes of offering.
- To improve patients' health literacy and understanding of the benefits and process of pursuing live kidney donor transplantation in the pre-dialysis setting.
- To increase the understanding and knowledge of Primary Care Providers around live kidney donation, to enable them to support and share appropriate information and build health literacy with patients and their families/whānau/friends/associates at the most appropriate and earliest time.

- To develop a community engagement framework for Pasifika and Māori communities, resulting in an average of quarterly large scale community engagement sessions which build health literacy at culturally appropriate venues (churches, Marae, non-healthcare support groups).
- To develop a community-leader engagement framework including health literacy for Pasifika and Māori community leaders.

… with very good results …

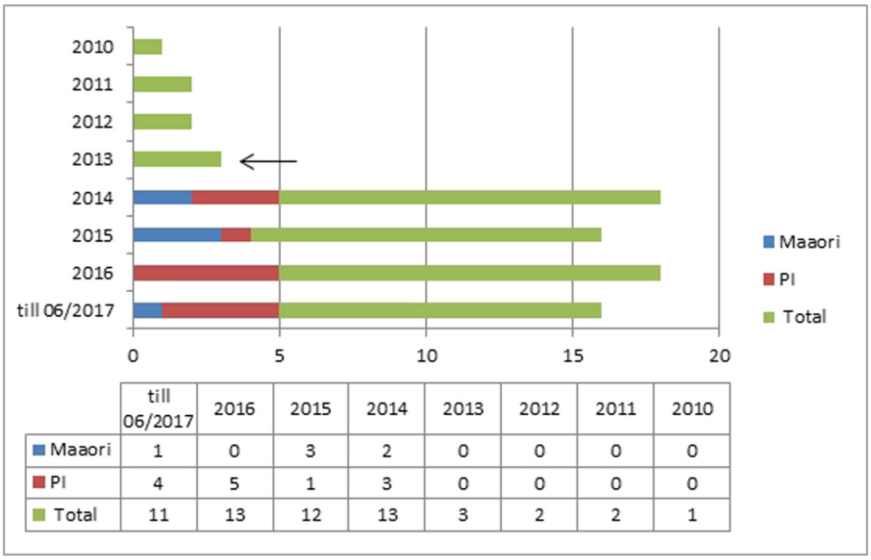
Under the *Live Kidney Donation Aotearoa* project:

- Live kidney donor offers increased from an estimated 10 per year, prior to 2013, to over 80 per year from 2014-2017:



	2013	2014	2015	2016	2017
🟩 Others	16	52	49	52	38
🟥 PI	20	18	25	21	25
🟦 Maaori	13	6	6	11	20

- Live kidney donation transplants increased from an average of 2 per year, prior to 2013, to over 10 a year from 2014:



	till 06/2017	2016	2015	2014	2013	2012	2011	2010
🟦 Maaori	1	0	3	2	0	0	0	0
🟥 PI	4	5	1	3	0	0	0	0
🟩 Total	11	13	12	13	3	2	2	1

- Number of living donor renal transplants increased in the Māori and Pasifika groups from a total of 5 (2 and 3 respectively) for the preceding seven-year period (2006-2013) to a total of 17 transplants (6 and 11 respectively) for the 4½ years from 2013 to mid-2017, and

- Patient referral rates for renal transplant assessment and Live Kidney Donation increased from 39.4% to 59%.[21]

A 2016 evaluation report of the *Live Kidney Donation Aotearoa* project found that while the project did not achieve its stated aim of an additional 20 live donor transplants per annum, there had been a significant increase in transplant numbers, and the number of live kidney donor offers received throughout the term of the project far exceeded the target set[22]. That said, the project was not successful in its objectives of engaging with primary care or the wider community.

Notwithstanding this success, since 2017 only elements of this approach have been continued since 2017….

In 2017 the Counties-Manukau project ceased and was handed (together with the resources developed) back to the Ministry of Health as a completed project. The Ministry subsequently handed any follow up actions to the National Renal Transplantation Service. The NRTS distributed the copies of the *Live Kidney Donation Aotearoa* resources at hand, together with the project reports, to the heads of renal units in DHBs, and the results of the project were communicated to transplant co-ordinators in the respective units. It was then up to individual units to decide whether, or the extent to which, the approaches in the *Live Kidney Donation Aotearoa* approach would be taken forward.

Some DHBs[23] have carried on elements of the *Live Kidney Donation Aotearoa* approach through the donor liaison coordinator roles established in 2014. However, the *Live Kidney Donation Aotearoa* approach was a whole of service approach aimed at supporting patients through the transplantation pathway and in finding potential donors; DHBs have been limited in their ability to replicate this approach across the country because:

- In many centres, the donor liaison co-ordinator role is funded only part time.
- The level of funded resources in each DHB is not necessarily related to caseload of each renal unit/donor liaison co-ordinator – we have been told of two units having widely differing caseloads but being resourced at the same level.
- Funding has been provided in time-limited blocks (two to three years at a time, with no certainty beyond that). Some staff have left these positions because of the job insecurity inherent in this funding arrangement. The latest funding block expiries in 2022.
- In some cases, the units have not entirely embraced the whole-of-service philosophy and service re-design that *Live Kidney Donation Aotearoa* requires.

This points to a wider set of resourcing issues in renal units across the country, where staff at all levels are struggling with increasing caseloads, whether in pre-dialysis, dialysis and transplantation. There is a sense across renal units that they are busy enough with current caseloads and transplant

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[21] All results and graphs sourced from Beechy, D; Marshall, M and Talreja, H; *Live Kidney Donation Aotearoa – Improving Live Kidney Donation in Indigenous and Migrant Populations in South Auckland, New Zealand*, Kidney International Reports, Volume 4, Issue 7 Supplement, July 2019.

[22] *Live Kidney Donation Aotearoa: Evaluation report for the Ministry of Health*, September 2016.

[23] The Live Kidney Donation Aotearoa website lists eight DHBs as having Live Kidney Donor Co-ordination roles as at 15 October 2021.

numbers, before any attempt is made to increase transplant rates or address transplant equity even further.

While the project focussed on Māori and Pasifika patients in Counties-Manukau, the themes identified in the project are relevant for all ESRF patients facing disadvantage, no matter their ethnicity or where they live...

The 2016 evaluation report of *Live Kidney Donation Aotearoa* highlighted a number of issues and challenges facing ESRF patients, and potential donors, in progressing a live donor kidney transplant. Amongst those highlighted in the report were:

- The importance of having educational resources, but that on their own these do not always build the skills and knowledge of donors, recipients or their whānau. They needed to be used as part of an ongoing dialogue that required conversations with good enquiry and excellent listening skills to establish the issues and challenges facing patients, potential donors and their families. This did not always happen – and there was poor uptake amongst renal service staff on how to use the resources appropriately.
- The home-based education support and peer support programmes were very useful as a way of increasing knowledge, increasing the willingness of patients to discuss live donor transplantation with others, and to quell fears about donation/transplantation.
- The donation and transplantation process requires a high level of proactivity of the part of patients and their families. Donors were surprised to learn that it is up to them to make contact and to move things along in the process. They are often unaware of the supports and services available to support them along the way if they do not know what are the right questions to ask.
- The process for "working up" donors (and recipients) takes too long and imposes costs on patients (such as travelling to appointments, time off work, and even car parking costs at the hospitals).
- It is important to discuss transplantation before a patient reaches the stage that s/he requires dialysis. Otherwise, there is a high risk of the patient becomes overloaded with both adjusting to dialysis, as well as simultaneously initiating the process to find a donor. Many patients can only focus on one aspect as a time.
- It is extremely difficult for patients to approach and ask prospective donors – either because of one or more of:
  - not being confident about their level of health knowledge/understanding.
  - concerns about the risk of the transplant procedure for donors (even though it is very small).
  - fear of the recipient's body rejecting a donated kidney, and concerns that the impact this would have on the donor.
  - financial impacts for donors – both through a prolonged work-up process but also time off work recovering (note that this project preceded the changes for compensating live donors in 2016).
  - a patient not knowing how to ask a potential donor, including how to ask in a way that the person being asked can say "no" without embarrassment or awkwardness on either side.
- The high health literacy demands that the donation/transplantation processes implicitly require, especially on donors.

- The need to upskill primary care providers on the donation and transplantation process, so that donors are given consistent advice from both their primary care physician and the renal unit.

While the *Live Kidney Donation Aotearoa* project focussed on Māori and Pasifika patients in Counties-Manukau, patients of any ethnicity who face disadvantage (be it income, education level, health literacy, and/or geographic isolation) in any part of the country will identify the same issues and challenges. These are not just issues in Counties-Manukau, that arose just because of the way that the Counties-Manukau DHB had previously chosen to organise its services. Rather, other research in New Zealand has identified these as issues across the board.

… but the Live Kidney Donation Aotearoa project had identified ways to start to address these issues, and the evaluation report has identified ways to build upon the lessons learnt that could rolled out more widely …

The *Live Kidney Donation Aotearoa* project evaluation report includes a clear outline of the issues and challenges faced by patients and potential donors, where they had been addressed in the project and where improvements could be made. Even with the challenges identified, the project still enabled an 8-fold annual increase in offers of live donors. This is critical result – because if there are no live donor offers, there are no live donor transplants.

KHNZ recommends the wider rollout of a fully funded and resourced approaches such as Live Kidney Donation Aotearoa and donor liaison co-ordinators across all renal units in New Zealand.

Addressing transplant inequity in New Zealand requires action to improve the opportunities for Māori and Pasifika patients to better access live donor transplantation. The gap in the rates of transplantation between Māori/Pasifika on the one hand, and non-Māori/non-Pasifika on the other, is greatest in the area of live donor kidney transplantation. And the gap, if anything, has been getting larger. The *Live Kidney Donation Aotearoa* project in Counties-Manukau and donor liaison co-ordinators elsewhere have identified ways to make a difference for Māori and Pasifika in particular.

KHNZ therefore recommends that the Government task the proposed Renal Transplant Equity Taskforce with revitalising and extending approaches such as the *Live Kidney Donation Aotearoa* and donor liaison co-ordinators across New Zealand, to support increased live donor kidney transplantation, especially for Māori and Pasifika.

This will require a sustainable, multi-year finding model for relevant renal unit staff to enable transplant listing and support for underserved communities through the transplantation pathway.

Funding and Institutional Arrangements

A question that might be asked at this point is why the health system itself has not been incentivised to self-fund initiatives that would deliver more kidney transplants, given that it extends life and is much cheaper than dialysis. The arguments in this report would suggest that it is in a DHB's/the health system's own interest to actively search out new initiatives that would transplant as many extra people as possible, without waiting for new Government investment.

Yet this has not been our experience over the past few years. Robust cases for the opportunities for increasing transplantation have almost always been met by the "there is no money" response, even though it would take very few extra transplants for the up-front investment to more than pay for itself.

KHNZ asked the NZIER for its analysis of the barriers to self-funding of pro-transplant initiatives in New Zealand, and what changes could be made in the upcoming health reforms to address these barriers. This section of this report draws heavily on the NZIER's analysis.

The financing model for the health system determines what and how much is done ….

Health care financing determines what choices are available, what outcomes are easier to achieve, and what behaviours are rewarded. It is critical, therefore, that health care financing is designed deliberately to achieve envisaged results.

The financing-related challenges for renal transplantation include:

- The system-wide involvement of services and providers.
- Geographic distribution of dialysis and transplant services that mean:
  - DHBs that invest in increasing transplant capacity will often generate savings for the patient's home DHB and a revenue decrease for the DHB providing dialysis, requiring multi-DHB planning and financial arrangements that may not always be agreed
  - Patients must often travel and incur high private costs
- The high need for coordination services across the transplant pathway and beyond and across DHB boundaries.
- The high cost of transplantation in the short term with the potential only to generate savings later.

These issues currently create insurmountable barriers in self-funding pro-transplant initiatives due health care financing based on:

- Siloed funding arrangements.
- Short term planning and funding.
- Inadequate consideration of private costs.
- Uncertainty and risk.

The key change needed is to remove barriers that currently make it difficult for DHBs to "borrow across time and space" – the ability to access funding now to enable investment in increased transplantation as a means of reducing the need for costly dialysis services in the future. This section of the report summarises the current challenges, but also sets out an option to allow for funding across time and space.

Siloed Funding Arrangements

Currently, DHBs purchase services for their own populations using the funding they each receive for this purpose, calculated using the population-based funding formula (PBFF). The aim of the PBFF is to equitably distribute available funding between DHBs according to the relative needs of their populations and the cost of providing health and disability support services to meet those needs. But how the funding flows from there is where the silos begin to have an impact.

Delivering a transplant can involves a deep interconnection and reliance on many or all of the following health services and/or departments in a DHB: renal units, primary care, outpatient services, inpatient services, ICUs, ODNZ (through the NZBOS), diagnostic services, and hospital-based specialists. These services have their own budgets, funding drivers, performance metrics and accountabilities that do not immediately support transplantation; what is striking is how often renal staff talk about timely access to these services being provided on a goodwill or an “above-and-beyond-the-call-of-duty” basis.

The impact of siloed funding is heightened by the cross-DHB, regional basis for renal services and for kidney transplantation. There have been long-standing issues in co-ordinating service design and delivery across DHB boundaries; regional service planning was introduced in the early 2010’s as a way to address this, while avoiding structural change. But regional planning has struggled in New Zealand and is often little more than the aggregation of individual DHB plans (rather than a coordinated plan to make best use of services and resources across the region) and takes place with little attention to the connection between plans.

Short term Funding and Planning

The way that health services are funded at present make it extremely difficult to make an investment in treatments that cost extra money now, but will save money in the future.

DHB budgets are announced each year, for the following year, and are intended to support DHBs to provide services for their resident populations over the course of that year. Multi-year funding – an identified amount of funding for each of a number of years that would allow DHBs to plan over a longer timeframe and potentially reallocate funds between time periods – is not a feature of current funding arrangements. This means it is not possible for DHBs to undertake a major investment today that will be funded through the savings it generates next year and the year after that.

Due to the absence of multi-year funding, the options available to DHBs to fund major increases in operating expenses in specific services have required one of three options:

- Cutting back services in other areas.
- Re-directing capital funding.
- Working with the Ministry of Health to develop a budget initiative for additional funding.

Even when a new investment is expected to generate cost-savings in the *same* year (let alone in future years), DHBs struggle to shift expenditure between uses. This is not unique to transplantation; this has been observed as primary care funding has failed to grow despite widespread recognition that increased investment is warranted.

Occasionally, opportunities arise to deliver significant improvements in outcomes and value for money that require substantial operating expenditure. In general, if a DHB needs to make major expenditure shifts, that cannot be achieved by cutting back services in other areas, the DHB would need to work with the Ministry of Health to gain the Ministry’s support and the Ministry would then put forward a budget bid for additional funding. For the Ministry of Health, supporting such requests would open it up to pressure from every DHB for any cost pressure or service change that increases costs in the short run. Therefore, such funding requests are tightly controlled. Moreover, in the case of increasing kidney transplantation, it seems that such opportunities are seen as a net *cost* rather than as a means to reduce upcoming financial pressures on the health system (for example, by reducing otherwise expected increases in dialysis costs).

Inadequate consideration of private costs

The private financial costs of the live kidney donor process for patients and donors have been recognised previously – for example, the Compensation for Live Organ Donors Act 2016 recognised the impact of the loss of income then faced by live donors on their potential to donate. But some barriers continue today.

Due to the regional nature of renal and transplantation services, for many patients there are no local services to support recipient and donor work-up, let alone organ retrieval and transplantation. In many areas, many New Zealanders who could donate a kidney, or could benefit from transplantation, incur significant costs associated with travel and accommodation to access the necessary services.

The National Travel Assistance policy is provided by the Ministry of Health to assist people who must incur travel costs in order to obtain health services. Patients who have travelled can claim for kilometres travelled by car, public transport, accommodation, and specialised transport, including taxis and air travel. However the National Travel Assistance rates have not been reviewed since 2009 – the "mileage" rate in the policy is now about ⅓ of the mileage rate that Inland Revenue allows for business travel in private vehicles. Furthermore, the requirement to incur the cost first and then to provide receipts for reimbursement means that for some patients, there remains an upfront travel cost barrier.

Uncertainty and risk

Uncertainty exists at almost every decision across the patient pathway from primary care to live donor transplantation:

- When to refer the patient to specialist care?
- Will be patient be eligible for transplantation?
- Will the patient be able to find a live donor?
- Will the donor be compatible or assessed as otherwise suitable as a donor? If not, how many other potential donors will need to be assessed?
- Will the patient still be healthy enough to have the transplant by the time the donor work-up is completed?

At every stage, there is potential for a kidney transplant to be delayed or stop. This uncertainty results in a significant financial risk for funders: despite investing in improvements across the system, there may still be a significant risk that many patients end up having dialysis anyway, so the path to a potential transplant represents a potential additional cost for potentially no gain.

In the current health system, there are few ways to manage this risk and uncertainty. The health budget has been split across 20 DHBs – so there is no way to manage or pool this risk across "space" (DHB boundaries). Given the other financial pressures within DHB budgets, any DHB finds it hard to manage these risks easily within their own financial constraints. And, as noted earlier, the current one-year-at-a-time funding arrangements means that these risks cannot be managed across time.

Leadership and Governance

A key role for leadership and governance in the kidney transplant landscape is identifying how to deal with the level of risk and uncertainty that may hinder investment and perpetuate the status of dialysis as the default option for ESRF patients.

The presence of 20 DHBs and 13 independent renal units means that the leadership and governance required is, by design, split. Instead the renal community have established a range of mechanisms to help address the co-ordination challenges they face but this itself can lead to a fragmented system. This report highlighted earlier that responsibilities across organ donation and kidney transplantation have been split:

- Care of ESRF patients is undertaken by specialist renal units in 13 DHBs in New Zealand.
- Transplant operations themselves are undertaken in the Auckland, Capital and Coast and Canterbury DHBs.
- ODNZ arranges the matching of organs to people on the waitlist, and organises the resulting deceased donor transplant logistics. In November 2020, ODNZ was transferred from Auckland DHB to the NZBOS.
- While the NZBOS itself is the national agency with responsibility to improve deceased organ donation in New Zealand, as demonstrated earlier in this report there has been no agreement on the specific role, functions and accountabilities of the NZBOS.
- With respect to live kidney transplantation, the management of this at a day-to-day level is through the individual renal units, working with their patients.
- The National Renal Transplantation Service has an oversight of kidney transplantation, which includes oversight of practices and policies associated with live kidney donation.
- The head of the NRTS leads a National Leadership Transplant Leadership Team (NRTLT).
- A National Renal Advisory Board seeks to provide national leadership on renal issues, advising the Ministry of Health directly.

The Heather Simpson-led Health and Disability System Review noted that the current health system is characterised by “multiple barriers to the shift to a more population health-focused system”. Two specific barriers related to health system leadership and governance were identified by that review:

- Excessive focus on measuring short-term impacts or throughput (such as elective surgery targets) rather than long-term population health gains.
- A lack of long-term planning and forecasting.

The split and multiple leadership and governance arrangements for renal services in general and kidney transplantation in particular – combined with short term and inflexible funding arrangements – leads to this service being an absolute case study for the problems that the Health and Disability System Review was trying to fix.

This is not the fault of the individual specialists and leaders within the renal and transplantation system. They are doing the best that they can, within the confines of the system that they are working within. But the system itself is working against them.

A Reform Model: a National Renal Service within Health NZ

The nexus of:

- Funding arrangements that in many ways work against increased transplantation

- The difficulty in managing transplantation risk and uncertainty in an atomised health system, and
- Split leadership and governance

all work against the health system internally managing and funding investments across time and space in transplantation that could repay themselves many times over.

The upcoming health reforms and the establishment of Health New Zealand and the Māori Health Authority provide an opportunity to put in place institutional and funding arrangements to address the above barriers in current health system settings. The NZIER have recommended to us, and KHNZ supports investigating, the option of a National Renal Service (NRS) within Health NZ, with responsibility for the development and implementation of a renal services strategy, including central and consolidated leadership for the organisation and delivery of renal services across the country and across the spectrum of care. The NZIER recommend that the NRS be charged with:

- A planning horizon of 20 years to support national commissioning of renal services across the spectrum of care.
- An adequate budget allocated to the National Renal Service to:
    - Develop and support the implementation of a national strategy to increase renal transplantation rates, including research to inform strategy with a focus on equity.
    - Develop a national strategy and framework for integrated renal services.
    - Develop integrated models of care that support access to pre-emptive and early transplantation.
    - Build capability across renal services, including increased clinical governance, training and funding of more ICU coordinators to improve the rate of deceased organ donation, increasing the capacity of the donor coordination team at ODNZ to support increased transplantation, and improving GP knowledge of how to identify and best manage CKD in primary care.
    - Improve coordination of renal services.
    - Define good practice and how best to achieve it across the care spectrum, including supporting consensus building towards the development of a national health pathway to support timely referrals to secondary care.
    - Develop renal Key Performance Indicators (KPIs) across the spectrum of care, including KPIs with an equity focus, to drive service improvement and track progress.
    - Inform the service planning and decision-making regarding allocation of resources for Renal Services across the spectrum of care and over time and space.

    to which KHNZ would add:

    - Data infrastructure to support early identification and optimal management of early chronic kidney disease at the point-of-care through existing health records monitoring and coordination between primary and secondary care.
    - A national quality improvement programme to enable hospital renal services to learn from and implement best practice from around the country.

The NZIER report also sets out how the NRS would work within Health New Zealand and alongside the Māori Health Authority.

A NRS would be consistent with the proposal in the Health and Disability System Review for a small number of specialist services not being funded by a PBFF-based formula, but by a specific Health New Zealand service agreement negotiated on a 3-5 year basis.

In such a model, the NRS would pick up the work of the NRTS. We would see the role of the NZBOS as continuing to be the national agency for deceased organ donation, maximising the rate of deceased organ donation through, in the first instance, implementing the 2017 *Strategy*. This separation recognises that the NZBOS's brief is and should be wider than organ donation for kidney transplantation.

Over time, a NRS could pick up the mandate of the proposed Renal Transplant Equity Taskforce but, as outlined earlier in this report, to make immediate progress we propose the Taskforce get underway while the new health system structures are being designed and embedded.

KHNZ recommends that the Government investigate, as part of the upcoming health reforms, the establishment of renal and kidney transplantation services as a "National Renal Service" within Health New Zealand, with funding mechanisms that allow for funding flexibility across "time and space".

Appendix 1: International Best Practice for Deceased Kidney Donation: A Review of The Top 5 Countries and Their Comparison with New Zealand

In developing this report, KHNZ reviewed the practices of the five countries that have the highest deceased donor kidney transplant rates in the world, and reached out to organ donation and transplantation experts in these countries. While the 2017 Strategy reflected best international practice at the time, we were looking to see if best practice had shifted in the intervening 4½ years, and if a different approach was now warranted in New Zealand.

Our review included a literature review, but also discussions with leaders from these best practice jurisdictions, when this could be arranged. We held direct discussions with transplantation leaders from Finland, Spain and France. We would like to acknowledge their generosity in sharing their time and expertise with us.

Our scan of international best practice highlighted that high rates of deceased organ donation stem from how services are organised and co-ordinated across hospitals to support transplantation. Other jurisdictions organise in-hospital services in such a way that patients with a very low or nil chance of survival are identified early, and sensitive and respectful discussions are held with families at an early stage about the possibility of donation, as a way of securing something good from the family's impending tragedy. If family approval is given, patients in general wards will be moved to an ICU for a 1-2 day stay for the purposes of organ retrieval once nature has taken its course and the expected death has actually occurred. Family consent is required at all stages, and organ donation does not proceed if the family objects at any time.

The international experience supports the direction of the 2017 *Strategy*. However, it also highlights that once the essential building blocks are put in place in New Zealand, there will be further opportunities in New Zealand to support deceased organ donation by looking at the support for donation across the whole of a hospital's processes and infrastructure.

We also researched specific aspects of policy and institutional settings that were identified in the 2017 *Strategy* as key to increased organ donation. Our high-level findings on these aspects are set out in tabular form below.

Issue	Context	Experience in:				
		Spain	France	USA	Finland	Czech Republic
Policy towards Donation after Circulatory Death (DCD) donation	The 2017 Strategy suggested that this was an area for potential growth in NZ's donation rates. NZ has relied on Donation after Brain Death (DBD)	Allow donations from both DBD & DCD. Between 20-25% of organs comes from DCD. Spain changed in policy in 2012 to allow DCD.	Allow donations from both DBD & DCD. Among donors who have had at least one kidney removed in 2020, 88.5% were DBD and 11.1% were DCD.	Allow donations from both DBD & DCD. 17.7% of kidney donations were from DCD in 2015 (Gill et al. 2017).	Were one of the first countries to consider DBD, almost never do DCD due to disagreements between hospitals about the ethics of DCD.	Allow donations from both DBD & DCD. All centres have started a DCD program. (Wiess et al. 2018)
Balance between deceased donor and live donor kidney donation	It is often stated in New Zealand that countries can be strong on deceased donation or live donation, but not both. These countries have relatively low live donation rates, and we sought to understand why.	Have consciously chosen to focus on achieving high rates of deceased donations and to keep their status as world leading as a source of national pride. In this context, any live donors are seen as additional rather than central to transplantation.	Have had a focus on deceased donation, until the past few years as live donors had to be close family, and assessment for live donors takes many weeks and sometimes months.		Previously had no need for significant numbers of live donors as deceased donation was sufficient. Preferred deceased donation to avoid surgery on otherwise well people, However, now looking to increase living donation as deceased donation increasingly insufficient.	

Issue	Context	Experience in:				
		Spain	France	USA	Finland	Czech Republic
Transplant Inequity	Given the centrality of this issue for New Zealand, we wanted to understand the known inequities in other countries, especially known ethnic inequities.	No ethnic inequity reported.	Do not collect ethnicity data, and so the extent of any ethnicity inequities are unknown, Geographical inequities are known: there are differences in your chance of getting a transplant depending on where you live as donated deceased organs allocated on complex criteria that includes a regional factor.		No ethnic inequity reported. A risk of geographical inequities for patients in rural/remote locations as transplants undertaken at one hospital (Helsinki) but believe that this risk is currently managed well.	
Access to the waiting list	Waitlist criteria – such as the 80% survival probability after 5 years – exclude some patients who would benefit from a transplant and may disadvantage some patients in NZ from being waitlisted	Do not have an 80% survival probability criterion. Have a scoring system based on blood group, tissue type, time in dialysis and if they haven't been admitted to dialysis yet.	Do not have an 80% survival probability criterion. Have a complex scoring system however ultimately the decision to waitlist comes down to the nephrologist and the medical team.	Waitlist is organised by the united network for organ sharing. Criteria for distribution of kidneys is based on bloody-type and antibody matching, time with kidney failure/time on dialysis, age and if the person has been a previous live donor (National Kidney Foundation, 2021).	Do not have an 80% survival probability criterion. Access to the waitlist is based on co-morbidities and contra-indications, and an assessment whether the transplant would survive > 2 years.	Introduction of extended criteria for all organs. Use of perfusion machine for kidney transplant. (Wiess et al. 2018)

Issue	Context	Experience in:				
		Spain	France	USA	Finland	Czech Republic
Public awareness campaigns	The 2017 Strategy highlighted the opportunities in awareness campaigns.	Do not have any major publicity campaigns as such but Spain takes pride in being number #1 in deceased donation and it is very normal there to talk about organ donation. The national transplant organisation and journalists gather annually for two days, to teach journalists about organ donation and how they should produce and manage news about it			Annual organ transplant week where there is a public campaign in newspapers, public events and posters with celebrities to promote organ donation. €130,000 spent annually through Finland's patient support group.	Public campaigns in regional media. KST organised a national press conference (Valentine´s Day) (Wiess et al. 2018)
Leadership		National agency to co-ordinate national consistency across hospitals across the country.	National agency to co-ordinate national consistency across hospitals across the country.		National agency to co-ordinate national consistency across hospitals across the country, although the transplants themselves are undertaken in Helsinki.	Transplant coordinators in some hospitals. (Wiess et al. 2018)

Issue	Context	Experience in:				
		Spain	France	USA	Finland	Czech Republic
In hospital and ICU arrangements	How services are arranged in hospital and ICU are critical. Given pressures on ICU capacity in New Zealand, we researched capacity and organisational issues in ICUs.	Families are approached upon death in an ICU to discuss organ donation. Families can also be approached when death is expected but has not yet occurred, for patients both in ICU and in general ward (if the family agrees, the patient can then be moved to an ICU for a short stay. Patient must however die of natural causes. Have a very good training system to enable these delicate and sensitive conversations. If the family is approached first by a specialist donor coordinator, the donation rate is much higher than if they were initially approached by a doctor.	Train local hospital teams to talk to families as well as coordination teams. Patients will be transferred from other parts of the hospital to ICU, if possible, to enable organ donation.		Every donor hospital has to offer education at least once a year to their staff. Staff in critical units re-trained at least 2-3 times a year. People can indicate their willingness to donate by telling their next of kin, through a will or on a register (national electronic health record). Neurologists help with family discussions.	Health insurance pays hospitals for donor identification. Contribution to funeral costs of deceased donors. Education and training of health professionals: regular staff training, organised by individual centres. ICU doctor contacts family before brain death. (Wiess et al. 2018)

Issue	Context	Experience in:				
		Spain	France	USA	Finland	Czech Republic
Patient & family consent and registers of donor status	In New Zealand, different consent frameworks are often portrayed as overcoming the situation of a family over-riding a patient's wishes.	Spain has presumed consent however if family do not consent the donation will not go through.	France has presumed consent however if family do not consent the donation will not go through. There is a national database that is accessible to see the wishes of the deceased.	Informed consent (Ahmad et al, 2019), Families must give consent.	Finland has presumed consent however if family do not consent the donation will not go through.	They have presumed consent (Bilgel, 2012) Non-donor register since 2002; optional (Wiess et al. 2018)

References:

Ahmad, M. U., Hanna, A., Mohamed, A. Z., Schlindwein, A., Pley, C., Bahner, I., ... & Jarmi, T. (2019). A systematic review of opt-out versus opt-in consent on deceased organ donation and transplantation (2006–2016). *World journal of surgery*, *43*(12), 3161-3171

Bilgel, F. (2012). The impact of presumed consent laws and institutions on deceased organ donation. *The European Journal of Health Economics*, *13*(1), 29-38.

Gill, John, Caren Rose, Julie Lesage, Yayuk Joffres, Jagbir Gill, & Kevin O'Connor, 2017. "Use and Outcomes of Kidneys from Donation after Circulatory Death Donors in the United States". *Journal of the American Society of Nephrology*. Vol. 28, Issue 12.

International registry of organ donation and transplantation data (IRODaT, 2019)

National Kidney Foundation, (2021) "The Kidney Transplant Waitlist - What you need to know" https://www.kidney.org/atoz/content/transplant-waitlist

Weiss J, Elmer A, Mahíllo B, Domínguez-Gil B, Avsec D, Costa AN, Haase-Kromwijk BJJM, Laouabdia K, Immer FF, on behalf of the Council of Europe European Committee on Organ Transplantation (CD-P-TO). Evolution of deceased organ donation activity vs. efficiency over a 15 year period: an international comparison. Transplantation. 2018;102(10):1768–78 [Figure 2].

Endnotes

The following references support the information in the table on page 31 of this report.

Dialysis

Survival

- the median survival for someone between the age of 45 and 64 on dialysis in New Zealand is 5.3 years (ANZData 43rd report 2020: Ch3, Table 3.3), with 10-15% of patients dying each year on dialysis. (Median survival is the time to which 50% of people can expect to survive).
- for those aged 25-44, median survival on dialysis in New Zealand is 7.6 years (ANZData 43rd report 2020: Ch3, Table 3.3)
- for those aged 65-74, median survival on dialysis in New Zealand is 3.6 years (ANZData 43rd report 2020: Ch3, Table 3.3)

Symptoms & Life impact

- About 2/3rds of people living with dialysis report reduced quality of life. Key domains that are commonly affected are pain (~50% reported moderate to severe pain), anxiety/depression (~40% reported moderate to severe symptoms), and mobility (~35% reported moderate to severe problems), with dialysis patients reporting more problems in almost all domains (Krishnan et al, Health-Related Quality of Life in People Across the Spectrum of CKD. Kidney Int Rep (2020) 5, 2264–2274; https://doi.org/10.1016/j.ekir.2020.09.028)
- Symptom burden and poor QOL are commonly cited reasons for patients stopping dialysis treatment. (Findlay M, Donaldson K, Doyle A, et al. Factors influencing withdrawal from dialysis: a national registry study. Nephrol Dial Transplant. 2016;31:2041-8.)

Hauora Māori

- Māori concepts of whakamā (disempowerment and embarrassment) and whakamana (sense of self-esteem and self-determination) provided an overarching framework for interpreting the themes identified: disempowered by delayed CKD diagnosis (resentment of late diagnosis; missed opportunities for preventive care; regret and self-blame); confronting the stigma of kidney disease (multigenerational trepidation; shame and embarrassment; fear and denial); developing and sustaining relationships to support treatment decision-making (importance of family/whānau; valuing peer support; building clinician-patient trust); and maintaining cultural identity (spiritual connection to land; and upholding inner strength/mana). (Walker RC et al. Māori patients' experiences and perspectives of chronic kidney disease: a New Zealand qualitative interview study. BMJ Open. 2017 Jan 19;7(1):e013829. doi: 10.1136/bmjopen-2016-013829.)

Dialysis compared with other diseases:

- Dialysis has poorer survival than advanced cancers, and lower survival than all cancers combined (Australia and New Zealand Dialysis and Transplant Registry. 42nd Annual Report 2019. Summary Activity for 2018 v1.0. Available at https://www.anzdata.org.au/report/anzdata-42ndannual-report-2019/.; Australian Institute of Health and Welfare. Cancer in Australia 2017. Cancer series no.101. Cat no CAN 100 Canberra: AIHW. 2017:44.)
- 59% 5yr survival on dialysis for 45-64year old (ANZData 43rd report 2020: Ch3, Table 3.1); 69% 5-year relative survival for all cancers combined (Australian Institute of Health and Welfare. Cancer in Australia 2017. Cancer series no.101. Cat no CAN 100 Canberra: AIHW. 2017:44, chapter 7)
- Over half of dialysis patients are affected by symptoms as severe or worse than for cancer patients (Murtagh FE, Addington-Hall J and Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. Adv Chronic Kidney Dis. 2007;14(1):82-99.)
- QoL is frequently low for patients with end-stage kidney disease, with estimates even lower than in patients with metastatic prostate cancer and with paralysis due to spinal cord injury. (*Morton R and

Webster A. Quality of life in Chronic Kidney Disease. In: Management of Chronic Kidney Disease. M Arici (ed.). Springer-Verlag Berlin Heidelberg. 2014;)

Transplant

Survival

- median survival for someone living with a deceased donor kidney transplant in New Zealand is between 15 and 20 years (ANZData 43rd report 2020: Ch7, Table 7.21 Primary Deceased Donor Grafts - Australia and New Zealand 1990-2019; Table 7.23 Second and Subsequent Deceased Donor Grafts - Australia and New Zealand 1990-2019)
- median survival for someone living with a living donor kidney transplant in New Zealand is above 20 years (ANZData 43rd report 2020: Ch7, Table 7.26 Primary Living Donor Grafts - Australia and New Zealand 1990-2019; Table 7.27 Second and Subsequent Living Donor Grafts - Australia and New Zealand 1990-2019)
- even for those over age 60, kidney transplantation offers longer life expectancy than dialysis (8.17 vs 4.32 years) (How great is the survival advantage of transplantation over dialysis in elderly patients? Gabriel C. Oniscu, Helen Brown, John L. R. Forsythe. Nephrology Dialysis Transplantation, Volume 19, Issue 4, April 2004, Pages 945–951, https://doi.org/10.1093/ndt/gfh022)
- across all groups and all comorbid illnesses, the survival advantage conferred by a deceased donor kidney transplant is ~10 years (Wolfe et al. COMPARISON OF MORTALITY IN ALL PATIENTS ON DIALYSIS, PATIENTS ON DIALYSIS AWAITING TRANSPLANTATION, AND RECIPIENTS OF A FIRST CADAVERIC TRANSPLANT. N Engl J Med 1999; 341:1725-30.). In specific groups, this survival advantage is even greater (e.g. for people with diabetes aged 40-59, the survival advantage is 14 years; for people with diabetes aged 20-39, the survival advantage is 17 years)

Symptoms & Life impact

- Kidney transplant recipients experience improved QoL compared with those on dialysis (Krishnan et al, Health-Related Quality of Life in People Across the Spectrum of CKD. Kidney Int Rep (2020) 5, 2264–2274; https://doi.org/10.1016/j.ekir.2020.09.028) (Kovacs et al. Sleep disorders, depressive symptoms and health-related quality of life—a cross-sectional comparison between kidney transplant recipients and waitlisted patients on maintenance dialysis. Nephrol Dial Transplant (2011) 26: 1058–1065. doi: 10.1093/ndt/gfq476)
- Transplantation resulted in significant improvements in disease-specific symptoms, effects and burden of kidney disease, and ability to work (Painter et al. Effects of Modality Change on Health Related Quality of Life. Hemodial Int. 2012 July ; 16(3): 377–386. doi:10.1111/j.1542-4758.2012.00676.x)
- Factoring in individual's preference for health-related outcomes, renal transplantation is the best treatment option to improve quality of life in people with chronic kidney disease (Wyld et al. A Systematic Review and Meta-Analysis of Utility-Based Quality of Life in Chronic Kidney Disease Treatments. PLoS Med 9(9): e1001307. https://doi.org/10.1371/journal.pmed.1001307)

Hauora Māori

- Indigenous participants had a strong desire for a kidney transplant and recognised the need for more readily available kidney transplants for others in their communities with ESKD. However, they faced prejudice and a lack of cultural competence by health workers as well as wider barriers to transplantation in systems that did not support effective and culturally appropriate delivery of information and care (Walker RC et al. Experiences, perspectives and values of Indigenous peoples regarding kidney transplantation: systematic review and thematic synthesis of qualitative studies. Int J Equity Health. 2019 Dec 30;18(1):204. DOI: 10.1186/s12939-019-1115-y)

Transplant compared with other interventions:

- survival after transplantation is ~90% at 5 years (ANZData 43rd report 2020: Ch7, Table 7.19), compared with...

- survival after CABG is 75% at 5 years (https://www-uptodate-com.waitematadhb.idm.oclc.org/contents/coronary-artery-bypass-graft-surgery-long-term-clinical-outcomes?search=survival%20advantage%20CABG&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1#H14980244; PMID 22547673)
- survival after elective repair of asymptomatic abdominal aortic aneurysm is ~70% at 6 years (De Bruin et al. Long-term outcome of open or endovascular repair of abdominal aortic aneurysm. N Engl J Med. 2010 May;362(20):1881-9. PMID 20484396)