November 2021

Transforming lives and saving money: an integrated strategy to address kidney transplant equity and increase transplantation

Executive overview

The Covid-19 pandemic has caused a significant disruption to health services in New Zealand, including renal transplantation. We expect this disruption to continue for the next 6-12 months. This report, backed by research from NZIER, looks beyond Covid-19, and outlines the significant opportunities and benefits of making changes now that would address transplant inequity and low rates of transplantation.

Key points

- **New Zealand's deceased donor kidney transplantation rates have been improving, but in 2019 23 countries still outperformed our rate including Australia, UK, Canada and USA.**

- **New Zealand has high rates of transplant inequity. In 2019 the proportion of non-Māori/non-Pasifika dialysis patients who received a transplant was 3½ times higher than the proportion of Māori dialysis patients, and 4 times higher than Pasifika.**

- **Reducing kidney transplant inequity and increasing kidney transplantation is the right thing to do for patients, will save the health system money and will support the economy.**

- **Increasing kidney transplantation is an investment that more than pays for itself – it saves significant money compared to the alternative life-extending treatment, dialysis, by reducing current and future treatment costs.**

- **NZIER says opportunities like this to invest in a way that improves outcomes and saves money are "rare."**

    - **It estimates an average savings of $389,000 over six years for every patient on dialysis who receives a kidney transplant. Over 20 years the average savings to the health system are $503,000 per patient.**

- **NZIER states that "along with improved quality of life, extended life and the potential of additional fiscal savings should make increasing the rate of renal transplantation a national priority".**

- **If nothing is done now to improve outcomes, NZIER estimates patient numbers will grow by 30 percent, particularly Māori and Pasifika patients, and the cost of renal dialysis services will grow by $150m per annum within 10 years.**

- **This report sets out the low cost, practical actions and strategies that could be put in place now to address transplant inequities and improve transplantation rates. The Government has already designed several critical actions – but it hasn't fully implemented or funded them. We urge progress on:**

    - **Increasing the rate of deceased donor transplants by funding the New Zealand Blood and Organ Service as the national body to fully implement the Government's 2017 *Increasing Deceased Organ Donation and Transplantation: A National Strategy***
    - **Revitalising and extending programmes such as *Live Kidney Donation Aotearoa* and donor liaison co-ordinator positions across all of New Zealand to support increased live donor kidney transplantation, especially for Māori and Pasifika.**

- **We propose setting a target for addressing transplant equity that would increase patient access to the waitlist and establishing a Renal Transplant Equity Taskforce, to lead and drive wider system change to address transplant equity.**

- **We also propose creating new institutional and funding arrangements for renal and kidney transplantation within the Health New Zealand reforms that will incentivise the health system to itself invest in cost-saving transplants.**

The challenges today

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 today, we still have three inter-related challenges with regard to 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 the most; 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 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 transplant form a living 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 six 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 who gives up employment on account of dialysis and can 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), 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 make 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 New Zealand (ODNZ) to the now New Zealand 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 New Zealand 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 uncertainty how these 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 two/year before 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 seven 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; these 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.

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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.

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 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 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 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. 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 require a shift in approach and mindset across the health system in general and the renal community in particular. Our 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 5 years) and (c) there is an opportunity to make more significant and more immediate progress by fully

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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.*

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.

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, supporting 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 funding 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:

   - 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 allows 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 investigates, 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".**

Recommendations for action by relevant agencies in the health system:

7. **Increase access to the waitlist for deceased donor transplants for underserved communities** *(For Health NZ, 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 NZ, 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 plans for the 2017 *Strategy.*