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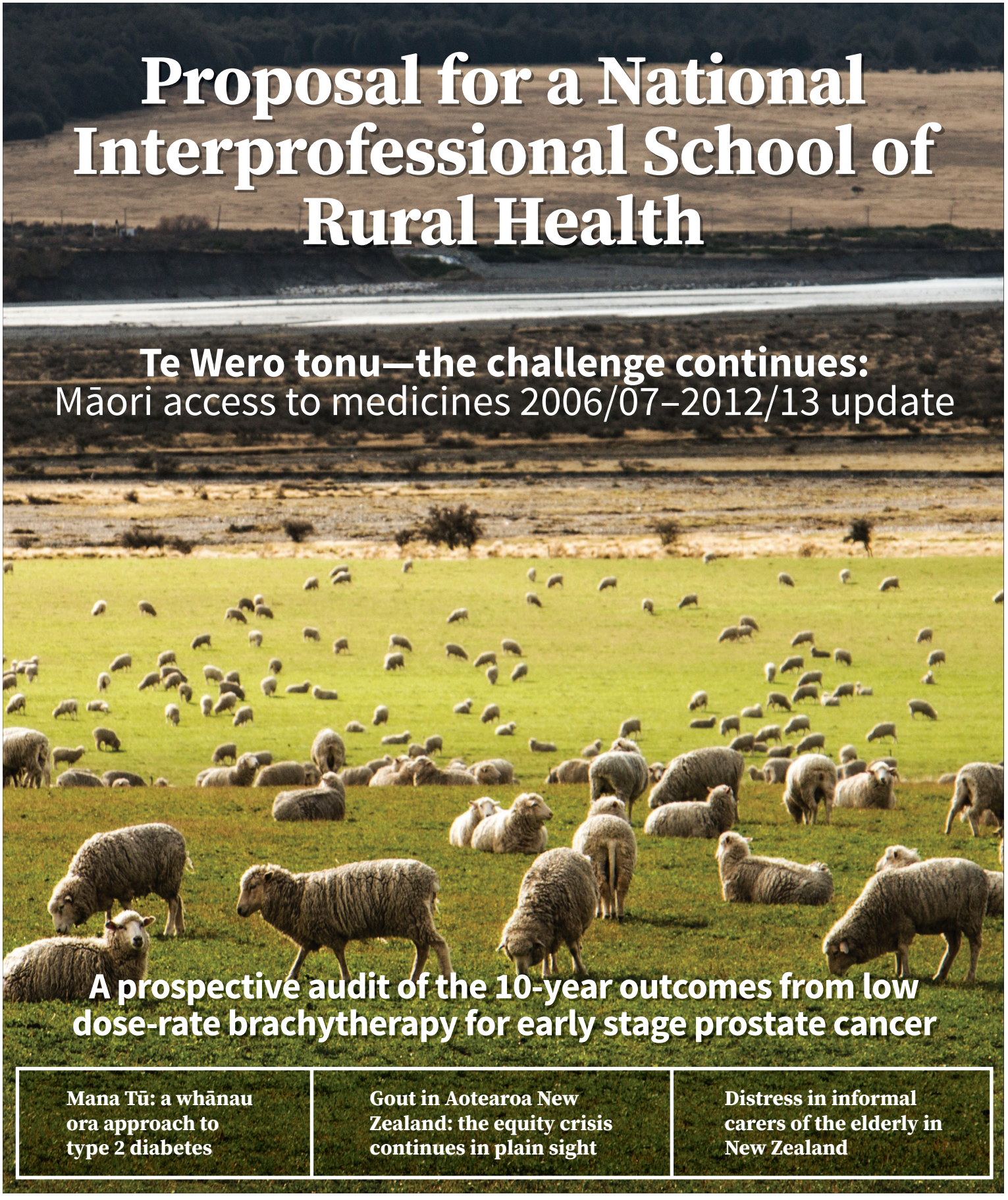

# Proposal for a National Interprofessional School of Rural Health

## Te Wero tonu—the challenge continues: Māori access to medicines 2006/07–2012/13 update

## A prospective audit of the 10-year outcomes from low dose-rate brachytherapy for early stage prostate cancer

Mana Tū: a whānau ora approach to type 2 diabetes

Gout in Aotearoa New Zealand: the equity crisis continues in plain sight

Distress in informal carers of the elderly in New Zealand

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## A prospective audit of the 10-year outcomes from low dose-rate brachytherapy for early stage prostate cancer

David S Lamb, Lynne Greig, Grant Russell, John N Nacey, Kim Broome, Mohua Jain, Judith Murray, Peter J Lamb, Lisa Woods

This is one of the largest series of men with early stage prostate cancer treated with radioactive seed implantation reported anywhere in the world. The treatment has been shown to cure most men with only minor side effects, confirming its position as a front line treatment option for men with such cancers. The results also confirm that the use of complex modern technology can sometimes lead to remarkable medical outcomes.

## Privacy protection for health information research in New Zealand district health boards

Vithya Yogarajan, Michael Mayo, Bernhard Pfahringer

All DHBs that provided patient data for research self-reported that their practices met New Zealand standards. This was done through a combination of individual patient consent, research approval and data de-identification. However, not all the de-identified data was de-identified to the full extent considered best practice internationally. DHBs also lacked standard operating procedures specifically for de-identification of patient data.

## Te Wero tonu—the challenge continues: Māori access to medicines 2006/07–2012/13 update

Scott Metcalfe, Kebede Beyene, Jude Urlich, Rhys Jones, Catherine Proffitt, Jeff Harrison, Ātene Andrews

This paper summarises a commissioned update, by the University of Auckland for 2012/13, of previous research on the shortfall in community medicines dispensed for Māori compared with non-Māori, adjusting for age, population and burden of disease—and what PHARMAC and the health sector needs to do about it. Although complexities and limitations affect interpretation, substantial and unacceptable inequities in medicines access for Māori remain, and are unchanged six years on. Their causes are likely many, complex and entrenched, needing an all-of-sector approach and beyond to address. Deeper understanding of systems and barriers is required, as well as pragmatic ways to monitor outcomes. PHARMAC is committed to eliminating inequities in access to medicines as one of its key priorities; everyone in the health sector has a role.

## Incidence of motor neurone disease within MidCentral Region, New Zealand

Alexandra Caulfield, Pietro Cariga

Motor neuron disease is one of the most devastating pathologies and can affect people seemingly at random with severe disability, rapid unstoppable progression and short survival. Despite extensive research efforts, it remains essentially untreatable. Previous studies suggested that New Zealand has an unusually high number of subjects affected by motor neuron disease. This study, looking at all new cases of motor neuron disease in the Midcentral DHB region in the last five years, corroborates the suspicion of a high rate compared to other areas of the world, and could contribute to the understanding of potential environmental or genetic factors linked with the disease.

## Antidepressant prescribing in New Zealand between 2008 and 2015

Sam Wilkinson, Roger T Mulder

New Zealand has accurate data on prescriptions. In 2018, 12.6% of all New Zealanders were prescribed an antidepressant, an increase of 21% from 2008. Women are more likely to receive antidepressants than men, especially European women. The majority of antidepressants prescribed are SSRIs.

## Distress in informal carers of the elderly in New Zealand

Nicola Swain

For most elderly people in New Zealand, care is provided by a family member. These carers, who are unpaid, can find the job tough. As well as economic costs they have high rates of anxiety and depression. We also found caring restricted their personal and social lives and compromised their physical and emotional health. Most people in the survey said the reason they cared for their relative was love. The health system needs to offer more support for these people to continue this extremely valuable service.

## Proposal for a National Interprofessional School of Rural Health

Garry H Nixon, Ngaire M Kerse, Warwick Bagg, Margot A Skinner, Peter J Larmer, Peter Crampton

Shortages of health professionals persist in much of rural New Zealand despite a range of initiatives. The proposed National Interprofessional School of Rural Health is not a separate education provider, but rather an 'enabling body' that would lever off the expertise and resources of the existing tertiary institutions, colleges and rural communities. Sharing human, physical and other resources would permit these institutions to educate students and undertake research in rural communities in ways currently not possible. It would create a community of health professional teachers and researchers in rural areas. The NISRU would help lift the profile and status and support standards of practice for a range of rural health professional groups.

## Mana Tū: a whānau ora approach to type 2 diabetes

Matire Harwood, Taria Tane, Laura Broome, Peter Carswell, Vanessa Selak, Jennifer Reid, Phil Light, Tereki Stewart

This paper describes the rationale behind the development of the Mana Tū programme. Mana Tū is a unique Māori-lead programme developed and led by the National Hauora Coalition that supports people with poorly controlled type 2 diabetes to successfully self-manage with their condition. The programme was developed alongside patients with type 2 diabetes, as well as doctors, and aims to address both health barriers (things like lack of knowledge around healthy eating, what medications do and physical activity) and social barriers (things like financial, housing and transport issues) that can stop people from living well with their condition.

# Rural matters

Peter Crampton, Jo Baxter

In this edition of the *Journal*, Nixon and colleagues provide a glimpse of an innovative version of the future in their paper *Proposal for a National Interprofessional School of Rural Health*.[1] Both authors of this editorial have a vested interest in this proposal, and one of us is a co-author of the paper.

Attracting and retaining health professionals in rural communities is a pressing issue for health policy in New Zealand and internationally. We believe the proposed School of Rural Health would contribute meaningfully to addressing this issue. Partnerships with rural communities are integral and the paper reinforces the need for rural communities to be woven into the fabric of health workforce production and deployment. Successful rural health workforce solutions must be contextualised within the challenges that rural communities face, and to the strengths that rural communities possess. In so doing, we can ensure that the solutions are fit for purpose and responsive to the diverse needs and aspirations of the communities that they are part of. The paper reminds us that we are not starting from scratch and can embrace the best evidence from New Zealand and overseas to inform rural health workforce production.

Nixon and colleagues also remind us that the context underpinning the state of the rural health workforce has a complex jigsaw of components, all of which fit together to play a part in either attracting and retaining, or repelling and losing rural health professionals. Some of these components are hard to address, for example employment opportunities for partners. Other components are amenable to smart solutions, for example more attractive workforce options and working conditions. They remind us as well that a preoccupation with the production of more doctors—which is in itself a necessary objective—can distract us from wider matters for rural health provision.

Because of the relative isolation of the rural workforce and the range of challenges and opportunities that exist, new, innovative and responsive approaches are needed and welcomed. The School of Rural Health proposal provides an opportunity to contribute not only to rural health workforce development but also to research and knowledge that provides solutions to rural health challenges, wider aspirations for community development, career pathways for young people and equity within a rural space.

Nixon and colleagues further encourage us to focus on the opportunities inherent in rural practice, training and healthcare provision, including, among other things, effective multidisciplinary teams, excellent inter-professional skills, innovative use of technology and rurally-based academic careers. To that end, rural communities could and should be the place of new knowledge production, including vigorous application of research and evaluation. They should be home to health professionals who have academic careers that are integrated into their professional lives. The benefits of having health academics based in rural communities are potentially wide reaching. Not least is the opportunity to have rurally-centred university research, formulated through the lens of rural realities, that supports effective strategies and solutions for meeting the needs of rural communities.

A School of Rural Health brings with it wider community development benefits over and above health provision. We have seen many times the wider benefits of having health professional students embedded within communities. The presence and energetic engagement of health professional students, including students who are themselves from rural areas, provides role modelling and inspiration to young people growing up in rural areas.

Health inequities between Māori and non-Māori in rural areas are stark and are a critical priority for the proposed School. Health professional programmes need to produce graduates who are not only culturally competent but who also have an understanding of the history and dynamics

of rural communities, and a commitment to those communities. This requires understanding of the health of rural Māori and the contexts underpinning Māori health and wellbeing within rural communities. Caution must be exercised in relation to strategies that focus solely on rural needs without consideration of equity and impacts on Māori.

The 2012 Ministry of Health Report *Mātātuhi Tuawhenua: Health of Rural Māori*[2] provides a comprehensive analysis of the inequities that exist between the health of Māori and non-Māori who live rurally. Not only do a higher proportion of Māori live in rural areas, rural Māori are more likely to live with financial and material hardship than rural non-Māori. Across age groups and health conditions, rural Māori have higher mortality and morbidity and lower life expectancy. The gap between life expectancy of rural Māori and rural non-Māori is greater than the gap between urban Māori and non-Māori life expectancy. The School of Rural Health has an important opportunity to support effective strategies that engage with positive health production in rural areas while at the same time addressing the stark and pervasive Māori/non-Māori inequities that exist. The proposed School of Rural health will work in close partnership with rural iwi and hapū and commit to ensuring the School contributes in a meaningful way to elimination of health inequities. This includes a commitment to meeting the health workforce and research needs of Māori communities.

The proposed School is a national collaborative approach including multiple tertiary providers and other organisations and, at its heart, partnerships with rural communities. Rural communities are diverse—if you are familiar with one rural community then you are familiar with one rural community, but not all rural communities. We believe that the significance of the proposed School extends beyond the health workforce needs of rural communities. New Zealand, in common with many other countries, faces serious challenges in achieving a distribution of its health workforce commensurate with population health need. The proposal, with its emphasis on community embeddedness, interprofessional learning and partnerships, will hopefully provide broader learnings about how to encourage health professionals to align their career choices with population need.

Ultimately it is a matter for government to decide whether to adopt the proposal for a national interprofessional school of rural health. New Zealand relies on the rural sector, and rural communities in turn depend so much on attracting and retaining health professionals that we can't as a country afford to sit on our hands.

**Competing interests:**
Peter Crampton is a co-author of the Nixon paper that is the main focus of this editorial.

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# Gout in Aotearoa New Zealand: the equity crisis continues in plain sight

Nicola Dalbeth, Tony Dowell, Catherine Gerard, Peter Gow, Gary Jackson, Carl Shuker, Leanne Te Karu

In January 2016 we reported growing prevalence of identified gout in the general population, while the numbers of those regularly receiving appropriate long-term preventive treatment (urate-lowering therapy such as allopurinol) had remained low and static for three years.[1]

Data to 2014 from the New Zealand Atlas of Healthcare Variation by the Health Quality & Safety Commission (the Commission) showed not only were Māori and Pacific populations with greater gout prevalence being treated least appropriately compared to other ethnicities, but large numbers were being treated with repeated prescriptions of non-steroidal anti-inflammatory drugs (NSAIDs), a poor and potentially dangerous stopgap.

Gout in Aotearoa New Zealand was growing and being mismanaged with differential prevalence and treatment by ethnicity.

We asked the question: "Gout in Aotearoa New Zealand: are we going to ignore this for another three years?"[1]

## New data for 2018—and the answer is "yes"

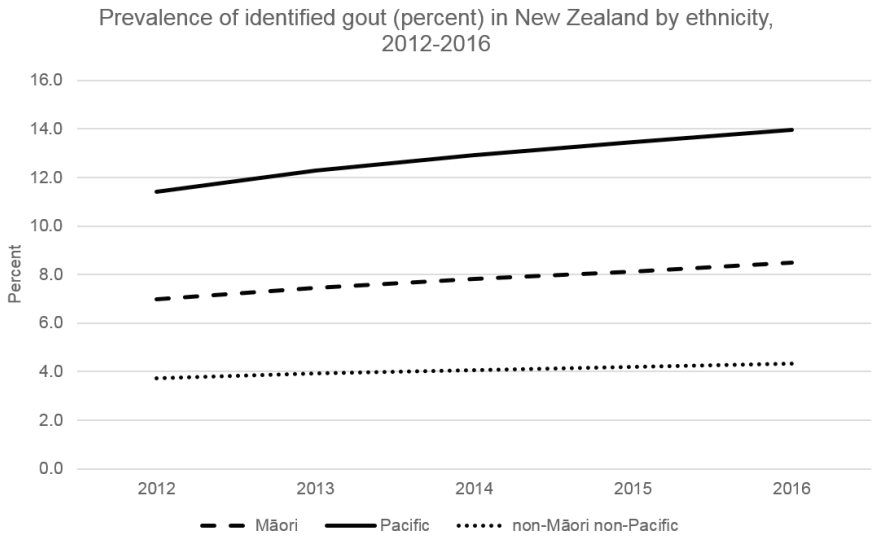
Gout is the most common form of inflammatory arthritis affecting adults. It is a chronic disease of monosodium urate (MSU) crystal deposition, typically presenting as recurrent attacks of severe joint inflammation. Gout causes severe joint pain, work disability and reduced social participation. Untreated, tophi can develop, leading to joint damage. Gout is independently associated with cardiovascular disease, diabetes, kidney disease and overall mortality.[2,3] Gout can be effectively managed with long-term urate-lowering therapy such as allopurinol. Colchicine, often used to treat gout flares, still has a role, particularly to prevent gout flares during initiation of long-term urate lowering therapy. Oral steroids are increasingly used to manage acute flares, to limit use of NSAIDs. Rheumatology guidelines recommend that urate-lowering therapy be continued long-term to reduce serum urate levels to <0.36mmol/L, at which point MSU crystals dissolve.

The gout domain of the Atlas of Healthcare Variation publishes data by district health board (DHB) on six indicators of gout prevalence and treatment. Data including 2016 just published show an escalating crisis in inequity: there is more gout nationwide, and worse and less treatment for Māori.[4] A similar picture exists in terms of inequity for Pacific peoples. As partners under the Treaty of Waitangi, there is a governmental obligation to ensure Māori have at least the same level of health as non-Māori.[5] Under Article 24 of the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP),[6] to which New Zealand became a signatory in 2010, Māori, as the indigenous people of Aotearoa New Zealand, "have an equal right to the enjoyment of the highest attainable standard of physical and mental health".

## New data from the atlas: increasing prevalence, worse treatment, more hospitalisations

Prevalence of identified gout in Pacific peoples across New Zealand continues to climb more steeply than other ethnicities and remains more than three times higher than European/other ethnicities. Prevalence of gout in Māori is twice as high as European/other, and still climbing. Administrative health data suggest at least 182,000 people across the country now struggle with the condition, up from 145,443 in 2012, from 4.5% to 5.35% of the population (Figure 1).

**Figure 1:** Prevalence of identified gout in New Zealand, by ethnicity, 2012–2016.




Gout treatment is inequitable. Though Māori and Pacific peoples were more affected by gout, the new Atlas data show Māori and Pacific peoples continue to be less likely to receive regular urate-lowering therapy such as allopurinol. While by count the number of people with gout regularly receiving allopurinol has increased by 16,435 people since 2012, more people have been identified with gout. Rates of this best treatment have effectively remained static over time, and by ethnicity are inversely proportional for those most affected (Figure 2).

NSAIDs can improve the symptoms of the gout flare, but repeated courses of NSAIDs without urate-lowering therapy represent poor care, due to the risk of kidney disease and other complications. It is thus striking to see 37% of people identified as having gout were dispensed an NSAID compared with 23% for the resident adult population in 2016. Māori and Pacific people aged 20–44 with gout were dispensed NSAIDs more than other ethnic groups. Forty-seven percent of Pacific peoples and 41% of Māori with gout were dispensed an NSAID in 2016, compared with 34% of those identifying as European/Other ethnicities.

The cumulative effect of increased prevalence and differential poor treatment appears as presentation to acute services—in 2016, Māori and Pacific peoples had four to nine times as many hospital admissions due to gout than those of European/other ethnicities. Furthermore, the rate of hospitalisation of Pacific people for gout continues to climb in the new data, while the rate of European/other admissions remains low and static (Figure 3).

**Figure 2:** Regularly receiving urate-lowering therapy in New Zealand, by ethnicity, 2012–2016.

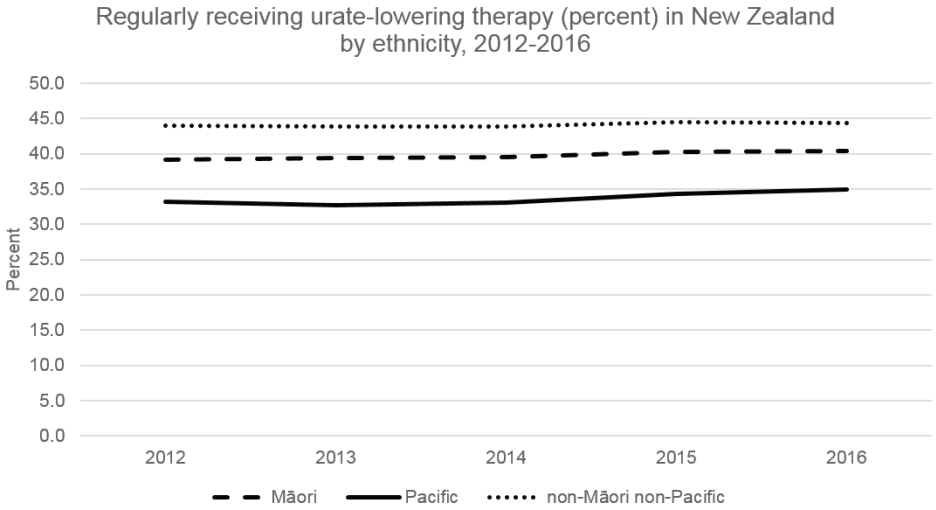
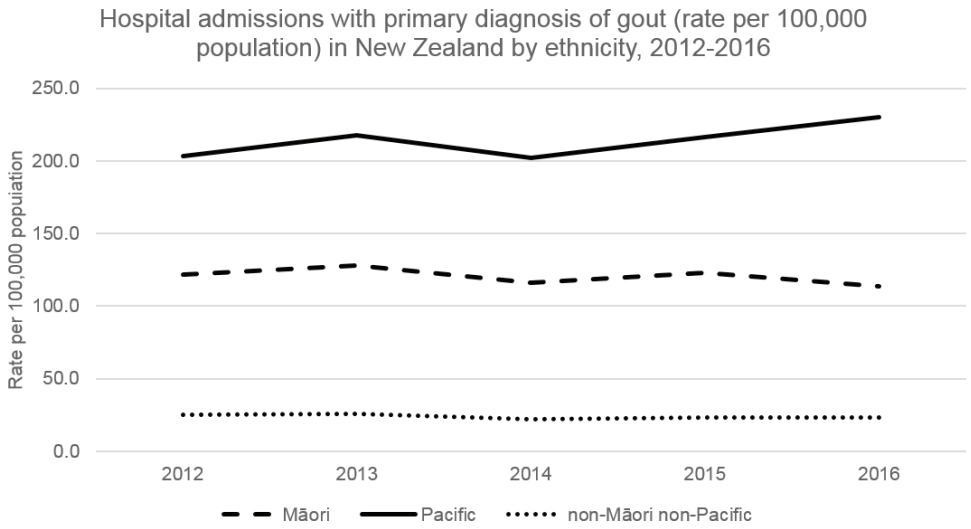


**Figure 3:** Hospital admissions with primary diagnosis of gout, by ethnicity, per 100,000 population.




Estimates using PHARMAC methodology costing ($730 for a day stay or emergency department admission and $1,000 for a medical ward bed night) suggest avoidable gout admissions and hospital length of stay cost the health system more than $3.8m in 2016.[7,8]

## What's driving these poor results?

Gout prevalence, inequity and failures in treatment that further differentiate and exacerbate inequitable outcomes appear to be the product of barriers to access to primary care and health literacy dynamics, including professional failure to build comprehension and awareness of the condition and its treatment in people with gout.[9,10]

Structural barriers to proper diagnosis, treatment and adherence appear in part to be financial. Allopurinol requires a three-monthly co-payment from the patient of $5. Each quarter, the patient must incur further costs including GP or prescriber appointment fees, transport and time off work.

New Zealand Health Survey data have long shown cost barriers to primary care and prescription medicines vary by ethnicity.[11] The 2016/17 survey found 22.2% of Māori adults and 17.8% of Pacific adults did not visit a GP because of cost. Further, 13.8% of Māori adults and 15.5% of Pacific adults failed to pick up prescriptions due to cost. These latter proportions dropped in the latest year after increasing three years in a row.

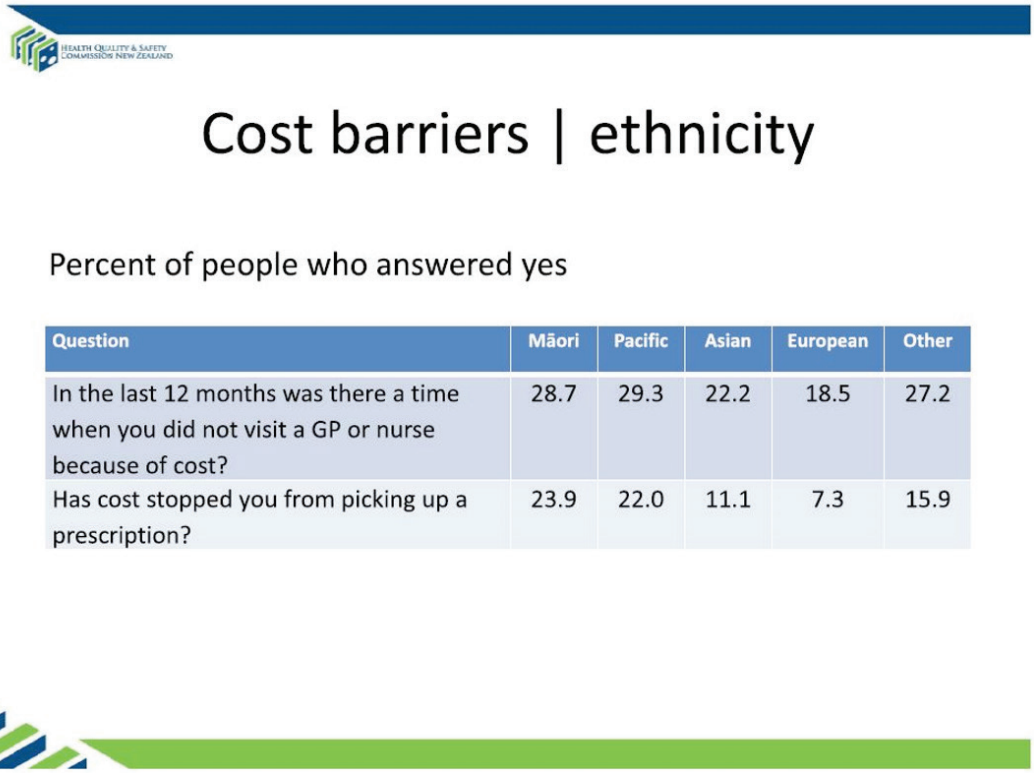
However, recent patient experience data from the Ministry of Health and the Commission's Primary Care Patient Experience Survey seem to suggest greater inequities than previously identified in the Health Survey data. The Patient Experience Survey found nearly a quarter of Māori and 22% of Pacific patients identified cost as a barrier to picking up a prescription, compared with only 7% of Europeans and 15% of other ethnicities. 28.7% of Māori patients and 29.3% of Pacific patients identified that cost was a barrier to visiting a GP or nurse, compared with 18.5% in European patients.[12] Māori adults were, furthermore, less likely than Europeans to answer yes to the question "Was the purpose of the medication properly explained to you?"

Effective treatment of gout requires continuous allopurinol prescription, regular laboratory monitoring of urate levels, and allopurinol dose titration and treatment to serum urate targets. This in turn requires long-term medication adherence, patient understanding of the condition and of the different roles of their medications, and under current conditions, a co-pay and repeated presentations to a GP or prescriber for new prescriptions and monitoring.

## What can be done about it? Culturally competent primary care, pharmacy and whānau empowerment programmes

Successful primary care approaches are available. A recent UK randomised controlled trial of nurse-led care using a treat-to-serum urate target approach showed major benefits in gout flare frequency, tophi and health-related quality of life compared to standard GP care.[13] In the US, a community-based personalised pharmacist

**Figure 4:** Primary Care Patient Experience Survey: cost barriers to primary care by ethnicity.




| Question | Māori | Pacific | Asian | European | Other |
|---|---|---|---|---|---|
| In the last 12 months was there a time when you did not visit a GP or nurse because of cost? | 28.7 | 29.3 | 22.2 | 18.5 | 27.2 |
| Has cost stopped you from picking up a prescription? | 23.9 | 22.0 | 11.1 | 7.3 | 15.9 |

programme, which included pharmacists contacting patients by phone and use of a protocol-based structured approach to urate-lowering therapy dosing, led to maintenance of low serum urate levels in most participants in the programme.[14]

In Aotearoa New Zealand projects with a specific equity focus, with pharmacy and nursing input, that pursue direct engagement and empowerment of communities, have had positive effects. These include the 'Gout Stop' programme in Northland, a collaborative, equity-focused primary care initiative across 36 practices designed to break down barriers to primary care in Northland. 'Oranga Rongoā', initiated at Papakura Marae Health Clinic, is a multi-dimensional care approach to gout management. It is premised on a culturally competent and culturally safe interaction for whānau utilising a multidisciplinary team approach of GPs, nurses, prescribing pharmacist, community health workers and community champions. A decision support tool has been developed for prompting and guiding prescribers with the opportunity for direct rheumatology specialist review. Whānau empowerment-weighted approaches seem promising and acceptable to local iwi. In Opotiki direct iwi involvement was solicited to design multiple hui with pharmacists in attendance to build local champions and upskill local GPs simultaneously. Funding for such approaches, despite available and forthcoming evidence of positive effects, remains fragmented and inconsistent.

## Conclusion

The new data from the gout domain of the Atlas of Healthcare Variation show a problem that is far from stabilising, let alone waning. Biased prescribing exists throughout Aotearoa New Zealand, creating inequities in health, defined as "differences which are unnecessary and avoidable, but in addition are considered unfair and unjust".[15]

Our current healthcare system contains financial and other structural barriers that restrict the number of those on effective urate-lowering therapy, diminishing the productivity and quality of life of people with gout, while increasing the costs to patients and the system through the burden on acute care services. Despite the established benefits of long-term urate lowering therapy such as allopurinol, the situation is worsening, and the health system is falling short of its obligations under the Treaty principles and the United Nations Declaration. Successful gout management takes time and effort. Barriers to effective care for patients must be addressed, including the cost of accessing long-term medications, and the necessary funding, support and training provided to clinicians in both primary and secondary care. It is long past time for effective programmes to be implemented before the next atlas update arrives.

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Nil.

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# A prospective audit of the 10-year outcomes from low dose-rate brachytherapy for early stage prostate cancer

David S Lamb, Lynne Greig, Grant Russell, John N Nacey, Kim Broome, Mohua Jain, Judith Murray, Peter J Lamb, Lisa Woods


## ABSTRACT

**AIM:** New Zealand men diagnosed with early stage prostate cancer need to know what outcomes to expect from management options.

**METHODS:** Between 2001 and 2016, 951 men were treated with low dose-rate brachytherapy (permanent iodine-125 seed implantation) by the Wellington Prostate Brachytherapy Group based at Southern Cross Hospital, Wellington. At follow up after treatment, men had their PSA measured and were scored for urinary, bowel and sexual side effects.

**RESULTS:** Median follow-up of men was 7.9 years (range 2.0–16.3 years). Ten-year PSA control was 95% for the 551 men with low-risk prostate cancer and 82% for the 400 men with intermediate-risk prostate cancer. Adverse effects were generally minor and short-term only. Temporary urinary obstruction developed soon after the implant in 2.6% men, and the 10-year cumulative risk of urethral stricture was 2.6%. Erectile dysfunction developed in 29% men, two-thirds of whom had a good response to a PDE5 inhibitor. Most men returned to a normal routine within four days of the implant.

**CONCLUSION:** LDR brachytherapy is a highly effective low-impact treatment option for New Zealand men with early stage prostate cancer.


PSA testing of asymptomatic men has led to prostate cancer becoming the most commonly diagnosed cancer in New Zealand men, with 3,068 new cases registered in 2015.[1] Many men currently being diagnosed have early stage disease, making them eligible for a number of different management options.

Because PSA-detected cancers generally progress slowly over many years,[2] some men will be offered Active Surveillance, a management option that involves withholding active treatment at the point of diagnosis, and only intervening when either the PSA rises more rapidly than anticipated, repeat biopsies show progression of the histological grade (Gleason score), or the man decides he wants his cancer treated. However, not all men feel comfortable about delaying treatment, and the ProtecT trial[3] showed that major cancer progression occurred 2.4 times more frequently on Active Surveillance than after immediate surgery or external beam radiotherapy (EBRT).

Early stage cancers can be treated by surgery, EBRT or low dose-rate (LDR) brachytherapy. There is evidence that these three treatments achieve comparable results in terms of cancer control,[4–6] so other factors become important for men selecting their preferred treatment. These include treatment convenience, the expected recovery time, and the risk of long-term sexual and urinary side effects.

LDR brachytherapy involves the permanent implantation of radioactive seeds into the prostate. Since the Seattle Prostate Institute published the 10-year outcomes it achieved with the treatment,[7] many other centres in North America and Europe have reported their results.[5,6,8–10]

We report the 10-year outcomes from LDR prostate brachytherapy delivered in a New Zealand centre.


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# Methods

From 2001 to 2016, the Wellington Prostate Brachytherapy Group (WPBG) treated 951 men with permanent iodine-125 seed implants at Southern Cross Hospital, Wellington.

Men were eligible for an implant if they had low-risk or intermediate-risk prostate cancer as defined by D'Amico.[11] Low-risk cancers were those that were less than 20mm in diameter clinically, had a Gleason pathological score of ≤6, and a presenting PSA <10mcg/L. Intermediate-risk cancers were those with a Gleason pathological score of 7 and/or a presenting PSA 10–20mcg/L, and in addition had low-volume cancers no more than 20mm in diameter clinically or on MRI scanning. If the volume of the prostate gland was more than 60cc, hormone treatment was used before the implant to reduce its size. At the start of the programme, men with intermediate-risk prostate cancer were first treated with 45Gy external beam radiotherapy (EBRT), a practice that ceased after four years when the implant team felt confident that an implant on its own consistently delivered sufficient radiation to the entire prostate.

Implants were performed using the same methods as originally described by the Seattle Prostate Institute.[12] The implant team comprised a urologist, a radiation oncologist and a medical physicist, and implants were pre-planned in order to determine the precise number and position of seeds needed for the implant. For the majority of men in this series, pre-planning used ultrasound images collected at a separate procedure called a Volume Study, but the more latterly treated men were pre-planned using MRI images collected routinely at the same time as their diagnostic MRI scan. These men were able to proceed directly to an implant once they decided this was their preferred treatment option.

The seed supplier was a British company (*BXT-Accelyon*) that sourced the iodine-125 seeds from the US. The seeds were delivered preloaded into sterile needles as determined by the pre-plan, so were ready to be implanted without any additional processing.

The prescribed radiation dose for implants was 145Gy, or 110Gy if the implant was preceded by EBRT. Post-implant, men had a CT scan to allow the radiation dose distribution achieved to be calculated. The parameters D90 (percentage of prescribed radiation dose received by 90% of the prostate volume) and V150 (percentage of prostate volume receiving 150% of prescribed radiation dose) were calculated as measures of the implant quality.[13,14]

The importance of long-term follow up by the WPBG was stressed to all treated men. At each follow-up appointment with a WPBG clinician (co-authors DSL, GR, JNN and KB), men had their PSA measured, and urinary and bowel side effects were scored using a scale 0–3 on which a score 3 meant that a medical intervention was undertaken for the side effect. Erectile dysfunction (ED) was scored as being a side effect of the implant if the man required a PDE5 inhibitor during the first three years after the implant, but not before. Direct follow up by a WPBG clinician continued for a minimum of five years, and often for 10 years or more, but those men whose PSA had fallen to low levels were permitted to continue their follow up with their general practitioner, who was instructed to refer the man back if the PSA rose by ≥2.0mcg/L or he developed troublesome urinary symptoms.

A small number of men whose place of domicile made it difficult to attend a clinic serviced by a WPBG clinician were followed up remotely by WPBG using clinic letters from supervising medical practitioners and email communications with the patient. Presenting cancer characteristics, post-implant dosimetry and follow-up data were entered onto a database which was established by the first author in the second year of the programme, and thereafter was updated and checked for completeness on an annual basis. In statistical analyses of the database, survival and cumulative probability of an event figures were derived using the Kaplan-Meier method.

# Results

Table 1 shows the patient and tumour characteristics of the 951 treated men. The median age of treated men was 62.7 years, with a range 39.3–75.7 years.

The median follow up after treatment was 7.9 years, with a range 2.0–16.3 years. Follow up of 933 men was performed by a

**Table 1:**

| | | | | |
|---|---|---|---|---|
| **Patient age (years)** | **<50**<br>31 | **50–59**<br>298 | **60–69**<br>546 | **≥70**<br>76 |
| **Tumour stage** | **T1c**<br>841 | | **T2a**<br>110 | |
| **Tumour Gleason score** | **≤6**<br>620 | | **7**<br>331 | |
| **Presenting PSA (mcg/L)** | **<10**<br>833 | | **≥10**<br>118 | |
| **Risk category** | **Low**<br>551 | | **Intermediate**<br>400 | |

WPBG clinician, and these men had full PSA and toxicity data collected. The remaining 18 men were unable to attend WPBG clinics for geographical reasons, and were followed up remotely.

The implant was preceded by hormone treatment in 128 men, and by EBRT in 48 men. Thirteen men had both hormone treatment and EBRT before their implant.

Post-implant radiation dosimetry demonstrated that the mean D90 for all treated men was 99% (desirable range for an implant 90–125%), and the mean V150 was 50% (desirable range 40–65%).

Biochemical failure (BF) occurred in 73 men. Eighteen BFs occurred in men with low-risk cancers (rate 3.3%), and 55 in men with intermediate-risk cancers (rate 13.7%). BF was called if there was a rise in PSA of ≥2.0mcg/L above the post-treatment nadir PSA value[15] followed by two further rises in the PSA at six-monthly intervals, or alternatively if the PSA value never fell to low levels after the implant. One hundred and seventy-one men (18%) experienced a temporary spike in PSA of ≥2.0mcg/L after their implant known as PSA 'bounce'.[16]

Figure 1 shows that 10-year PSA control was 90% for all treated men, 95% for men with low-risk cancer and 82% for men with intermediate-risk cancer. Numbers of men at risk at 60, 120, and 180 months are provided.

**Figure 1:**

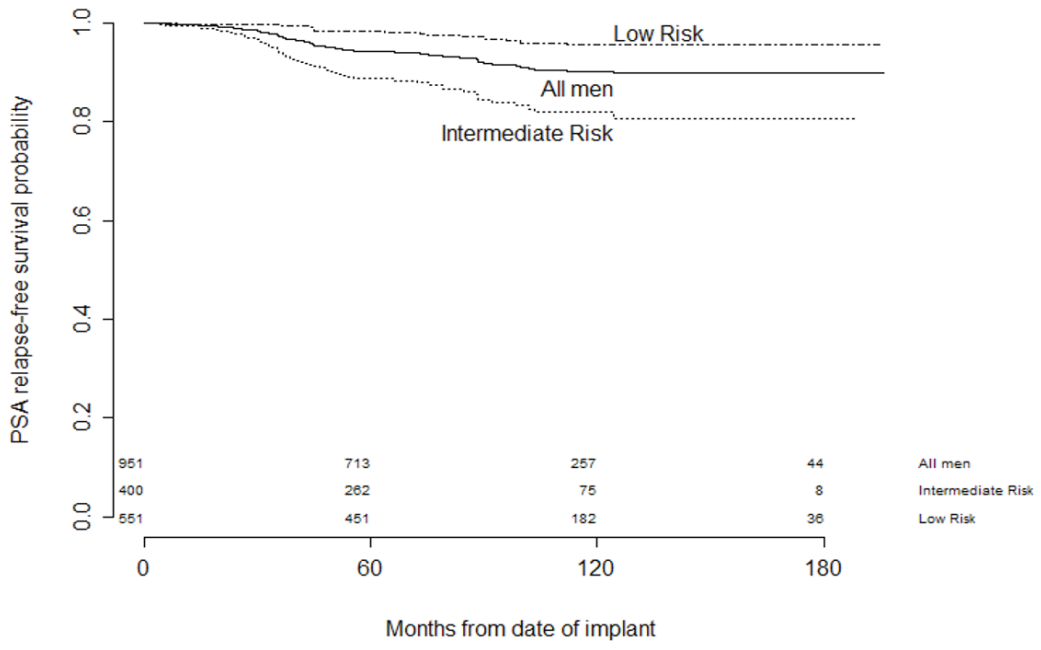




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**Table 2:**

| Acute side effect score | Urinary | Bowel |
|---|---|---|
| 0 (none) | 567 (59.62%) | 856 (90.01%) |
| 1 (minor bother) | 346 (36.38%) | 87 (9.15%) |
| 2 (major bother) | 13 (1.37%) | 7 (0.74%) |
| 3 (intervention required) | 25 (2.63%) | 1 (0.11%) |

There were six deaths from prostate cancer, two in men with low-risk prostate cancer and four in men with intermediate-risk cancer.

Table 2 shows the acute urinary and bowel side effects, defined as those occurring within six months of the implant. No side effects or ones causing minor bother only were experienced by 96% men for urinary symptoms, and by 99% men for bowel symptoms. Twenty-five men (2.6%) developed a grade 3 acute urinary side effect (outflow obstruction requiring temporary catheterisation), and one man a grade 3 acute bowel side effect (rectal ulceration).

Late urinary and bowel side effects were defined as those occurring more than six months after the implant. For both systems, all men scored 0 or 1 except for the 23 men who developed a score 3 late side effect. Seventeen men developed a urethral stricture, and the cumulative risk of this complication was 2.6% at 10 years. Five men developed rectal bleeding and one man rectal ulceration.

Two hundred and seventy-six men (29.0%) required a PDE5 inhibitor after their implant, but not before. Of these, two-thirds (192 men) reported that the PDE5 inhibitor restored satisfactory sexual function.

# Discussion

The most important measure of any cancer treatment is its ability to permanently control (or cure) the cancer. For prostate cancers suitable for LDR brachytherapy, 10-year PSA control rates are considered to equate to cure rates because PSA relapse after 10 years is very uncommon,[17] and our results are supportive of this.

The 10-year PSA control rates we achieved are similar to those reported by LDR centres in North America and Europe treating large numbers of cases[5–10] and at least match control rates achieved by other treatments for similar prostate cancers.[4–6] The high PSA control rates achieved by the WPBG can be attributed in part to the routine measurement of the implant D90 and V150. The radiation physicist monitored these values and informed the implant clinicians if trends became evident that indicated adjustments in implant pre-planning or delivery were advisable. This feedback was especially valuable at the beginning of the programme when the learning curve for the implant team was steepest, and ultimately was responsible for the mean values of D90 and V150 for all treated men sitting comfortably within the desirable range.

The 10-year PSA control rates we achieved are almost identical to those recently reported on a series of 207 men treated with LDR brachytherapy in Western Australia.[16] This provides additional evidence that groups in New Zealand and Australia can produce results equal to those achieved in the Northern Hemisphere.

Analysis of the PSA changes occurring after implants demonstrated that the Phoenix definition of BF after EBRT,[15] a rise in PSA of ≥2.0mcg/L above the post-treatment nadir value, overstates BF after LDR brachytherapy. We found that a PSA bounce[16] of ≥2.0mcg/L occurred in 18% men after their implant, and that this non-prognostic rise in PSA due to radiation effects on the normal prostate could only be distinguished from BF by the PSA falling again within 12 months rather than continuing to rise.

Factors such as convenience, time off work and possible side effects are also important to men making decisions about how they wish to be treated. LDR brachytherapy delivered by the WPBG was easy for men to schedule into their lives, especially once men needed to put aside only a single day for the treatment. Nearly all men were able to return to work or to a normal routine within four days of the implant. Adverse effects were generally minor and short-term only, with the main exceptions being ED, temporary urinary obstruction soon after the implant, and late onset of urethral stricture.

ED is a difficult side effect to quantify after any treatment for prostate cancer because a degree of dysfunction is common as part of the normal aging process in men passing through the seventh decade of life, and not all men are sexually active when treated. Also, ED is variable in severity, with some cases responding better to a PDE5 inhibitor than others. Our 29% rate of ED was similar to the 25% rate in a recently reported series of men aged 60 years or younger.[19] Our results suggest that approximately two-thirds of men experiencing ED as a side effect of an implant will have a good response to medication.

The 2.6% rate of men requiring temporary catheterisation after their implant is similar to the 3.2% rate reported in another large series,[20] when the risk of catheterisation was found to be higher in men with bigger prostates and more baseline lower urinary tract symptoms. We found that catheterisation was less often required as the implant team became more adept at correctly positioning needles in the prostate at the first attempt, and later men in our series rarely needed this intervention.

The 2.6% cumulative risk of a urethral stricture at 10 years is similar to the 3.2% absolute rate recently reported in another large series.[19] Both these rates are considerably lower than the 15.7% risk of a serious urinary adverse event reported in a recent overview of nearly 13,000 LDR brachytherapy cases,[21] in which a serious urinary adverse event included urethral stricture, urinary incontinence and radiation cystitis. These latter two side effects were not seen in men we treated.

# Conclusion

LDR brachytherapy is a highly effective low-impact treatment option for New Zealand men with early stage prostate cancer.

**Competing interests:**
Nil.

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# Privacy protection for health information research in New Zealand district health boards

Vithya Yogarajan, Michael Mayo, Bernhard Pfahringer


## ABSTRACT

**AIM:** To examine the practices used by New Zealand's 20 district health boards (DHBs) to protect patient privacy when patient information is used for research, and particularly practices for de-identifying information.

**METHOD:** An e-mailed questionnaire survey, using New Zealand's Official Information Act to request information on the policies and practices of each DHB.

**RESULTS:** 19/20 DHBs (95%) responded to the survey, one of which reported that it did not provide patient information for research. 18/18 (100%) of the DHBs that reported providing patient information for research required the project to have ethics approval. 18/18 (100%) of the DHBs that offered patient data for research also required individual patient consent and/or de-identification of the information before it was used for research. 14/18 DHBs (78%) deidentified data before releasing it for research, 8/18 DHBs (48%) sought individual patient consent before releasing data for research, and 5/18 (28%) used both methods. Other measures to protect privacy included confidentiality agreements, encryption and cybersecurity procedures.

**CONCLUSION:** Our findings show DHBs self-report that they have sufficient measures in place to protect privacy when patient information is used for research. However, these measures need to be continuously evaluated against rapidly evolving international practices and technological developments.


New Zealand's 20 district health boards (DHBs) potentially hold a large volume of health information about the over 4.5 million New Zealanders eligible for publicly funded health services, including medical notes, prescription records, medical images and laboratory test results. These records are potentially an invaluable resource for secondary data analysis (henceforth referred to as health information research).

There are several legal and ethical codes designed to protect the safety and privacy of patients involved in health information research. The Health and Disability Commissioner's *Code of Health and Disability Services Consumers' Rights* Regulations 1996 guarantees the rights of anyone receiving health and disability services in New Zealand. These rights include the right to have privacy respected, and the code specifically states that it also applies to those involved in research and teaching.[1]

The Health Information Privacy Code 1994 (HPIC) governs how any agency that uses health information—such as a DHB—collects, stores and uses that information, among other things.[2] The Health Research Council's *Health research and privacy: Guidance notes for health researchers and ethics committees* gives detailed guidance on how the provisions of the HPIC apply to health research in New Zealand.[3]

The National Ethics Advisory Committee's *Ethical Guidelines for Observational Studies* provides guidance on the design and conduct of health information research projects, as well as other types of observational studies.[4] This includes guidance on when an individual patient consent should be sought, and which projects have risks

that require ethics approval from the Health and Disability Ethics Committee (HDEC). The guidelines also recommend a set of controls for projects which only use anonymous or de-identified patient information, ie, information from which individual patient identity cannot be reconstructed. There is a different—much stricter—set of controls for projects that use identified or potentially re-identifiable patient information. The guidelines note that de-identification requires the *irreversible* removal of all information that could be used to identify the patient, such as name, date of birth, address and postcode.

The United States Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule goes much further and lists 18 categories of protected health information (PHI) that must be removed for health records to be considered de-identified.[5] These requirements are arguably the worldwide gold standard in de-identification and could be regarded as equivalent to the New Zealand HPIC requirement that the individual cannot be identified.[6] A key component of the present study was determining how de-identification practices used by New Zealand DHBs compare with this gold standard.

We therefore set out to identify the methods used by DHBs to protect individual patient privacy when providing information for health information research. We particularly focused on current DHB practices in de-identifying data provided for health information research, as this is a rapidly evolving field internationally.[7]

# Methods

The study design was an e-mailed questionnaire survey. Information was requested from each DHB under the Official Information Act 1982 (OIA).[8] A standard letter was emailed to the appropriate contact address at each DHB, which were identified via the Ministry of Health website and individual DHB websites. If no response was received within the timeframe of 20 working days required by the OIA, a standard reminder letter was also sent. Copies of the standard letters are available from the authors on request.

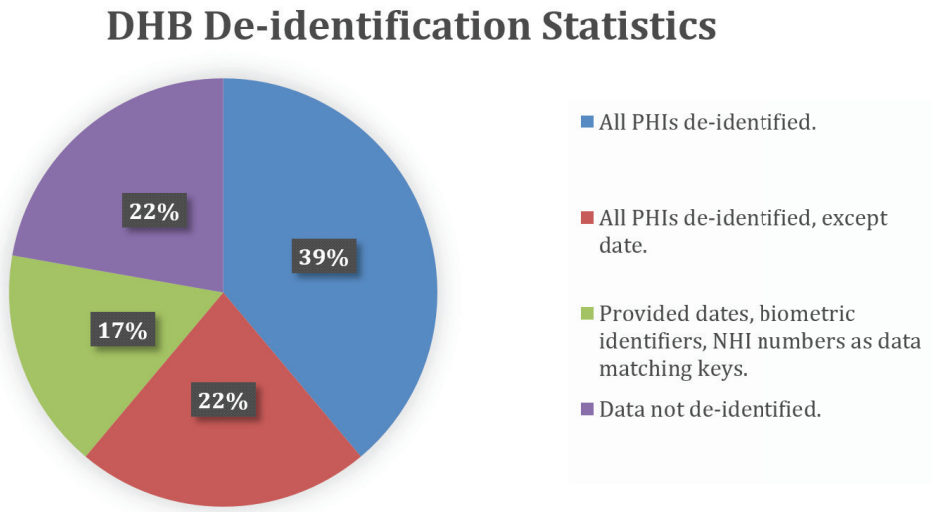
A standard set of questions were asked of each DHB, based on the 18 categories of protected health information that must be removed before health records are considered de-identified under the HIPPA Privacy Rule. Certain US-specific elements such as ZIP code and social security number were changed to their New Zealand equivalents. The full list of questions is available in the Appendix, and from the authors on request. The responses were analysed via descriptive statistics (frequencies).
Ethics approval was not required as the Official Information Act gives all New Zealand citizens the right to request information held by official bodies, including DHBs. Copies of policies, procedures and rules for decision-making by official bodies are specifically included under the remit of the OIA.[8]

# Results

Out of 20 DHBs in New Zealand, 19 of them responded to the request (95% response rate). We opted not to exercise the right under the Official Information Act to appeal the one non-response to the Office of the Ombudsman, as we could not exclude the possibility that our request had not been received. To ensure that the requests and responses were as standardised as possible, we decided not to initiate verbal or written communication with the DHBs other than the two letters, although we did respond to requests for clarifications. One of the DHBs responded that it did not provide patient data for research and was excluded from further analysis.

All 18 of the remaining DHBs (100%) required research projects to go through their internal research approval processes, with referral to the Health and Disability Ethics Committee (HDEC) as needed. Interestingly, all 18 DHBs (100%) also combined ethics approval with individual patient consent and/or de-identification of the data provided, using more than one type of privacy protection.

**Figure 1:** Frequency distribution of the data de-identified by the DHBs.




Of the 18 DHBs, 14 (78%) provided de-identified data, either routinely, or if this was a condition specified in the research approval. The other four DHBs did not de-identify data. Among these DHBs, 7 of the 18 DHBs (39%) either de-identified all 18 categories of protected health information or did not collect them in the first place. A further four of the 18 DHBs (22%) de-identified all elements *except* dates (including dates of birth), which were supplied in the full day/month/year format. The remaining three of the 18 DHBs (17%) provided dates, biometric identifiers such as height and weight, and NHI numbers as data matching keys. Figure 1 provides the breakdown of how DHBs de-identify data.

None of the DHBs that de-identified data had policies or standard processes explicitly related to the de-identification of data. Instead, they relied on combinations of their general research policies, the requirements specified in research approvals, the Health Information Privacy Code and institutional knowledge among their staff.

Out of the 18 DHBs, eight (48%) used individual patient consents before releasing data for research, either routinely or as a condition of the research approval. All three of the precautions—research approval, de-identification and individual consent—were used by 5 of the 18 DHBs (28%). Other privacy measures named by the DHBs included staff and researcher confidentiality agreements, encrypted and password protected files, and cybersecurity procedures.

# Discussion

## Summary of findings

Our findings show New Zealand DHBs self-report that they have sufficient processes in place to protect patient privacy in health information research. All 18 (100%) of the DHBs that confirmed they provide patient data for research use at least two of the following three precautions: research approval, de-identification of patient data and individual consent. By doing so, they facilitate potentially valuable research while complying with relevant legal and ethical codes.

## Strengths and limitations of the present study

To the best of our knowledge, the present study is the first to examine health information privacy protections across New Zealand DHBs, and particularly practices related to de-identification. A key strength is the 95% response rate. The high response rate—perhaps aided by the requirement for DHBs to answer OIA requests—minimises the possibility of response bias. Using a standard set of questions allows relatively objective comparison across DHBs.

However, a potential limitation is that the findings are based on the responses given by DHBs themselves, which may be affected by legal and reputational concerns. In addition, while a standard set of questions allows objective comparison, it limits the scope for an in-depth exploration of differences between DHBs.

The present findings could be validated by future case studies that directly observe the health information research process at individual DHBs, though gaining such direct access could be difficult for security and confidentiality reasons. A potential alternative are follow-up studies that interview key informants at each DHB about how they manage privacy requirements, potentially supplementing the descriptive findings presented here with in-depth qualitative analysis.

## Comparison with existing literature

The HPIC places restrictions on collecting research information from sources other than the individual concerned, such as through health records. The HPIC also restricts the use of information collected to provide healthcare for an unrelated purpose such as research.[2,3] It similarly restricts the disclosure of health information held by the DHB to other parties such as researchers from outside the DHB.[2,3] However, there are several exceptions to these restrictions.

Among these exceptions are:

i) where the individual concerned—or an authorised representative if applicable—has authorised the collection, use or disclosure of the information;

OR

ii) where the information will only be used in a form in which the individual concerned cannot be identified;

OR

iii) where the information is to be used for research purposes (for which approval by an ethics committee has been given if applicable) **and** the information will not be published in a form that could reasonably be expected to identify the individual concerned.[2,3]

These exceptions give researchers and institutions a degree of flexibility, allowing the controls placed on each project to be tailored to the risks of that project, rather than enforcing a 'one-size-fits-all' approach. The multi-pronged approach used by DHBs fits this model, with those that use individual consent in combination with research approval leaning towards the first exception, and those who use de-identification in combination with research approval towards the latter two exceptions.

The cornerstone of the approach used by the DHBs is the ethics approval process. Other authors have noted that New Zealand's ethics approval pathways need to be strengthened to meet the challenges of evaluating health information research, which has different risks to interventional research.[9] These could include stereotyping of and discrimination against individuals or communities, heightened and self-reinforcing surveillance of those perceived to be a threat, and opportunities for financial exploitation.[9–12] It is also essential to consider the emerging risks created by powerful modern algorithmic or artificial intelligence-driven data analysis techniques, so-called 'big data'. Individuals' health information could be exposed by inference, linkage with other publicly available datasets such as voter rolls and postal address data, or information that patients have shared with commercial entities to access goods and services.[9–11,13,14] Information in the modern world is also, once publicly available, essentially 'immortal', and challenging to redact.[10,15] Such information could potentially compromise the privacy not just of the patients concerned, but also their family members and descendants.[15] Many authors have argued for new models of data research oversight that take these risks into account and are soundly based on human rights principles and international law.[9,12,16] We support these approaches, which will inevitably take time to mature. In the meantime, more widespread use of individual consent for health information research and routine de-identification could support the approval process and mitigate the risks. These approaches are complementary, but each comes with its own challenges.

Individual patient consent can increase public support, as even members of the public who are not concerned with privacy are more comfortable with their data being used for research if their consent has been sought first.[17] However, individual consent can be impractical where large numbers of patients are involved, in some cases can affect the validity of the data collected, or even be harmful to patients themselves.[5] It was also important to note that the very definition of consent is affected by how data research differs from interventional or clinical observation research. For instance, can consent be given on behalf of family members or descendants whose privacy may also be affected? Are participants

comfortable with the data being reused for other purposes, even in anonymous or aggregated form, which they may not be aware of? Are they comfortable with commercial entities having access to their records, and possibly linking this with other data those entities may have collected separately?[11,15 17] Are patients even aware of the possibility of any of these things happening?

Greater use of routine de-identification can increase rates of patient consent and public support. Members of the public are more supportive of researchers having access to their health information if the information has been de-identified.[17] Routine de-identification to the standards of the HIPAA Privacy Rule also increases the possibility of collaborations with health systems, academic institutions and public agencies that follow HIPAA or equivalent standards. However, manual de-identification of large volumes of health information is extremely challenging. Specially trained personnel who are familiar with both medical data and de-identification techniques are needed. Also, the process is time-consuming and therefore expensive. Automated de-identification of medical data via machine learning (artificial intelligence) is a rapidly developing field but has not yet reached the stage where all 18 categories of information specified in the HIPAA Privacy Rule can be consistently de-identified to 95% or greater accuracy.[18,19] Given that it is still possible to re-identify individuals from 'de-identified' data, it is also important to debate whether some level of individual consent is still needed for the collection of de-identified data, or whether there is a social consensus that the risks are acceptable when weighed against the potential gains.[20,21]

## Policy implications

Individual DHBs also listed other strategies for protecting research information such as confidentiality agreements, file encryption and cybersecurity measures. Future work could include evaluating how these complement the combination of research approval, individual consent and de-identification in protecting patient privacy. A possible model for a multi-layered system to protect patient privacy in health information research has been proposed previously.[22] This applies the Reason model of error prevention—widely used in patient safety initiatives—to protecting patient privacy in health information research.[23] It also adapts the 'five safes' approach used by Statistics New Zealand to protect information in the Integrated Data Infrastructure to health records.[24]

Such a nationally standardised system could benefit DHBs by reducing legal and reputational risks. It could also address public concerns that individual DHBs take varying approaches to privacy protection, potentially giving patients living in one area protections that patients living in another area may lack ('postcode privacy', if you will). The current varying approach could be considered a natural consequence of the flexibility offered by New Zealand law and the DHB model itself, which decentralises health service provision and delegates most operational decisions to locally based and (partly locally elected) DHB boards.[25] There are also currently no authoritative national guidelines on data sharing and the use of data in health information research for DHBs to draw upon.[26] Organisations such as the Data Futures Partnership are working to develop such guidelines, and such efforts should be supported.[26]

It is important that such guidelines consider the values of the New Zealand public, and thereby build social consent for the use of health records in secondary research.[26] It is also crucial that such guidelines incorporate Māori perspectives on consent, autonomy and the rights of—and obligations to—extended family (whanau).[27] Such differences may be subtle and will naturally vary between generations and individuals. However, guidelines drawn solely from the dominant Western paradigm (which places a premium on the individual as an autonomous unit) may be too restrictive for the needs of Māori, especially considering the health disparities between Māori and non-Māori.[27]

Given the international nature of healthcare, research and information flow, New Zealand's evolving health information research guidelines and research approval processes also need to be acceptable to potential international research partners and overseas regulators. However, variances in national laws and industry codes mean there is no one universally accepted set of best practices to set future standards against, or indeed for DHBs to

measure their current practices against. For example, New Zealand's HPIC, HIPAA in the US, Australia's Federal and State privacy laws and the European Union's General Data Protection Regulation each have their unique requirements.[2,5,6,28,29] While a full comparative analysis of these laws is beyond the scope of this article, all set the most stringent requirements on the protection of identifiable individuals.[2,5,6,28,29] It stands to reason that developing and implementing routine and user-friendly de-identification practices would help ensure New Zealand's health information research is internationally accepted.

# Conclusion

Our findings show that DHBs self-report they have systems in place for protecting patient privacy that meet legal and ethical standards. However, these can be strengthened further to meet the challenges posed by increasingly powerful data analysis techniques. The lack of standardised policies and procedures for de-identification increases the risk that de-identification may be of variable quality. This could be addressed either by policies at the individual DHB level, or New Zealand-wide standards equivalent to the HIPAA Privacy Rule.[5]

# Appendix

## Survey questions

1. Does [X District Health Board] supply patient data for research?
2. Does [X District Health Board] de-identify patient data before the data are supplied for research? If yes, which of the following elements are de-identified? (Please circle all that apply).

   a) Names

   b) All geographic subdivisions smaller than DHB catchment area (eg, postal code, street address, city)

   c) All elements of date (except year)

   d) Telephone numbers

   e) Fax numbers

   f) Electronic mail (E-mail) addresses

   g) Identifiers issued by any other Government agency, such as Inland Revenue Department (IRD) numbers

   h) National Health Index (NHI) numbers or any other medical record numbers

   i) Health insurance plan beneficiary numbers

   j) Account numbers (including patient bank account or DHB client account numbers)

   k) Certificate/license numbers

   l) Vehicle identification and serial numbers, including license plate numbers

   m) Medical device identifier and serial numbers

   n) Web Universal Resource Locators (URLs)

   o) Biometric identifiers

   p) Full face photographic images and any comparable images

   q) Any other unique identifying numbers, characteristics or codes
3. Does [X District Health Board] have a written policy or policies for de-identification of patient data before the data are supplied for research? If yes, please provide one copy of each policy, or a summary of the policy or policies [maximum one page].
4. Does [X District Health Board] have a standard process (separate from that contained in a written policy or policies) that must be followed for de-identification of patient data before the data are supplied for research? If yes, please provide a description of this process [maximum one page].
5. If [X District Health Board] has neither a written policy (or policies) **or** a standard process for de-identification of patient data before the data are supplied for research, please provide a summary of the steps that are taken to protect patient confidentiality before the data are supplied for research [maximum one page].

**Competing interests:**
All three authors work in and research the field of automated de-identification of health records.

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# Te Wero tonu—the challenge continues: Māori access to medicines 2006/07–2012/13 update

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## ABSTRACT

**AIM:** Analysis of dispensings of prescription medicines in New Zealand in 2006/07 reported large inequities between Māori and non-Māori. This present study has now updated the earlier work by describing variations in disease burden-adjusted medicines access by ethnicity in 2012/13, and changes over time.

**METHOD:** The update has linked prescription medicine data with burden of disease estimates by ethnicity for 2012/13 and comparing with 2006/07. This has re-examined the shortfall in prescriptions for Māori vs non-Māori adjusting for age, population and burden of disease (ie, health loss, in disability-adjusted life years (DALYs)).

**RESULTS:** Aft er adjusting for age, population and burden of disease, large inequalities still existed for Māori compared with non-Māori, with generally no improvement over the six years. In 2012/13, Māori had 41% lower dispensings overall than non-Māori; this was nominally worse compared with the 37% relative gap in 2006/07, but the trend was not statistically significant. Many complexities and limitations hamper valid interpretation, but large inequities in access and persistence, across many therapeutic groups, remain. The full University of Auckland report details these inequities.

**CONCLUSION:** Large inequities in medicines access for Māori continue. Inequities in access are unacceptable, their causes likely complex and entrenched; we believe they need deeper understanding of systems and barriers, pragmatic ways to monitor outcomes, and an all-of-sector approach and beyond. PHARMAC has committed to strategic action to eliminate inequities in access to medicines by 2025, recognising it needs partners to drive the necessary change. Kei a tātou tonu katoa te wero kia mahikaha, kia mahi tino mōhio, me te mahitahi (The challenge continues for us to work harder, work smarter, and work together); everyone in the health sector has a role.


## He Karakia Whakatipuranga—A Blessing for Growth and Wellbeing

Manawa mai te mauri nuku
Manawa mai te mauri rangi
Ko te mauri kai au. He mauri tipua
Ka pakaru mai te Pō
Tau mai te mauri
Haumie!
Hui e Taiki e!![endnote A]

Tēnā Koutou ngā mātāwaka o Aotearoa. PHARMAC is the New Zealand government agency that decides which pharmaceuticals to publicly fund.[1,endnote B] Under its Statement of Intent,[2,endnote C] PHARMAC has set three new strategic bold goals—with the first goal "to eliminate inequities in access to medicines by 2025".

This article highlights PHARMAC's updated information[3] on Māori:non-Māori inequities in medicines access[4,5] and how these inequities have changed over time. This is key data that will help the health sector prioritise, drive and monitor progress towards achieving this bold goal.[2]

## Context

PHARMAC's objective is to secure for eligible people[endnote D(i)] the best health outcomes reasonably achievable from pharmaceutical treatment and from within the funding provided.[6] Its functions include engaging in research to meet its objective,[6] which can include monitoring progress towards best outcomes.

Among eligible people in New Zealand, significant negative health disparities[7] (ie, inequities[8,9]) exist, with Māori and Pacific peoples in particular experiencing poorer health outcomes than non-Māori/non-Pacific populations (see though endnote D(ii)). (Endnotes E[10,11] and F[7–9] further define and differentiate 'equality', 'equity' and 'disparity', and their uses.)

PHARMAC's funding decisions assume people access funded treatments when prescribed and dispensed (according to the Pharmaceutical Schedule rules). PHARMAC takes a range of actions to support responsible and optimal use of funded treatments. Where evidence signals that people are missing out on benefitting from funded pharmaceuticals, PHARMAC can vary those actions for better access.

For better access for populations experiencing poor access/health outcomes, PHARMAC has developed its Māori Responsiveness Strategy, Te Whaioranga[13] (which also helps meet Tiriti o Waitangi (Treaty of Waitangi) obligations[endnote G]) and Pacific Responsiveness Strategy.[14] Each strategy has community-based actions to improve access to medicines.

PHARMAC has committed to eliminate inequities in access to medicines by 2025;[2] a dedicated team is driving the workplan to reach this access equity goal.

## Medicines access inequities

Inequalities[10,11,endnote E] in health risks, disease rates, medication access and usage, and health outcomes between ethnic groups are well-described.[16] While some of these inequalities are due in part to population characteristics and are unavoidable, they are also inequitable when associated with social, economic or health-system related factors that are unfair and avoidable.[7–9,17] Inequity (unfair and avoidable difference) is the focus of this updated analysis.[18]

The evidence of inequities in health outcomes[10,11,endnote E] between ethnic groups in New Zealand is clear (see endnote H).[19–23] Excess disease burden in Māori compared with non-Māori has been the leading cause of health loss in New Zealand, more than any disease or risk factor.[24,endnote I] Investing in the latest, sometimes very expensive, medicines and medical devices will not necessarily secure the best health (which includes equitable) outcomes at a population level.[25] Social values[26] and other issues[7,27,28] such as clinical severity[29] and health equity[10,30] remain important. Better outcomes arise from continuing with important public health actions[32–34]—and having better access to, and uptake of, good healthcare. This means that everyone who needs care can and does get it[35–37,endnote J]—including medicines.

## Previous analysis, and update

PHARMAC's focus on best health outcomes including equity has led to developing ways to identify whether access to medicines use varies by ethnicity. In 2013 PHARMAC staff and others published a preliminary analysis,[4] with an overview of medicines dispensed by prescription volumes, category and population dispensing rates for the financial year 2006/07 in Māori, Pacific peoples and non-Māori/non-Pacific peoples' populations.[endnote K] The approach accounted for (i) age differences within each ethnic group, (ii) indicators of health need that combine morbidity and mortality (ie, health loss, in disability-adjusted life years (DALYs)), and (iii) breakdowns by patient numbers vs proxies for adherence. Adjusted for need, there was variable but sizeable differences in medicines dispensed to Māori compared with non-Māori, with Māori, eg, having 19–37% lower dispensings overall than non-Māori. There were however important limitations to what was preliminary analysis.

The preliminary study[4] used the Ministry of Health's New Zealand Burden of Disease Study (NZBDS) 2001,[38,39] which quantified years of life lost by the New Zealand population from premature mortality and disability across many individual diseases. The NZBDS 2001 included some ethnic-specific data, using prioritised ethnicity.[40] Disease burden estimates were for the year 1996. The NZBDS has been updated since (becoming the New Zealand Burden of Disease, Injury and Risk Factors Study (NZBDIRFS)).[21,41,42]

The earlier analysis[4] has helped inform PHARMAC's policy development for medicines funding and access. However, that analysis was preliminary and relied on disease burden estimates that had become

especially outdated.[38,39] To further its access equity goal, in 2015 PHARMAC commissioned UniServices (University of Auckland) to update the preliminary analysis. This present article describes the update, which extends the earlier analysis and aims for faster, more efficient routine future updates. The update used 2006/2007 and 2012/2013 dispensing claims data for publicly funded medicines and updated disease burden estimates from 2006 onwards.[21] The full report is available on PHARMAC's website (http://www.pharmac.govt.nz/tools-resources/research/maori-uptake-of-medicines/).[3]

The full UniServices update report[3] again[4] describes inequities in subsidised medicines access and persistence between Māori and non-Māori populations, and changes in access and persistence rates over time. The update also includes an overview of crude and age-standardised script rates for publicly funded medicines for key ethnic groups in New Zealand.

# Methods

As with Metcalfe et al 2013,[4] the UniServices update was an observational secondary analysis of medicines access and persistence (defined later) at a population level. It linked community prescription medicines dispensing claims data with primary health care organisation (PHO) enrolment data and burden of disease estimates (linking with anonymised person codes).

Data were obtained from prescription medicine dispensing claims for the financial years 2006/07 and 2012/13 in the New Zealand Pharmaceuticals Collection (patient-level dispensing of medicines listed on the New Zealand Pharmaceutical Schedule with demographic data).

The UniServices updated analyses[3] included two analytical cohorts of medicines/people of most direct policy relevance:

X. medicines/people for people alive[endnote L] on 30 June 2013 who were dispensed 1+ subsidised medicine between 1 July 2012 and 30 June 2013;

Y. medicines/people for people alive during all the seven years 1 July 2006 to 30 June 2013 who were dispensed 1+ subsidised medicine during both the 12-month period 1 July 2006 to 30 June 2007 AND the 12 months 1 July 2012 to 30 June 2013 (thus alive at the end of the two time periods, and restricted to the medicines/people cohort of existing medicines that were subsidised both between 1 July 2006 and 30 June 2007 and that continued to be subsidised at 1 July 2012). Medicines/people Cohort Y represents people dispensed medicines that were listed in both time periods but whose subsidy status or funding rules may have changed.

Endnote M provides more detail on the medicines/people cohorts.

Obtained medicines dispensing data (see endnote N) were linked, via ICD10 codes of relevant presumed/known medical condition(s), with data on disease burden for Māori and non-Māori populations obtained from the NZBDIRFS 2006–2016 report (published in 2013).[21,endnote O] Disease burden in NZBDIRFS is total population DALY losses, which combine incidence/prevalence and case severity (morbidity and years lost from premature death).

Outcome measures involved transformations of ratios of rate ratios for the medicines use and burden of disease data respectively, applying to incidences and denominating populations to derive counts of excess and deficit age/disease burden-adjusted scripts (Cohort X above).[3,4,endnotes P,Q]

Analysis over time in the UniServices update transformed rate ratios by time (Cohort Y above), using Keppel et al's methodology for measuring change in absolute and relative disparities[44] comparing 2012/13 with 2006/07.[3] For this article, subsequent analysis was undertaken for statistical significance between the two time periods, using the Bucher method.[45,46]

Analysis then further disaggregated script excesses/deficits by access and persistence (*access* defined as a person being dispensed their first prescription for each item in the 12-month year; and *persistence* defined as a person continuing treatment with receiving subsequent dispensings in the year—see endnote R for further information); the further calculations are described in Metcalfe et al[4] and the UniServices update.[3]

Please refer to the full UniServices report[3] for further methodological detail, including relevant burden of disease data,

data linking, and calculations. Subsequent analysis for statistical significance between the two time periods is in the Statistical Appendix to this article.

## Key findings

The key findings of both sets of analyses are summarised below (noting these results are but part of the full UniServices analysis,[3] which should be referred to at www.pharmac.govt.nz/tools-resources/research/maori-uptake-of-medicines). After adjusting for age and burden of disease, pervasive inequalities remained:

- For 2012/13, translating the relative dispensing rates to a deficit or excess of dispensing, there was a shortfall of 1,126,300 pharmaceutical treatments for Māori—ie, treatments that Māori did not receive. This shortfall comprised 41% of the treatments that could be expected to be dispensed to Māori had they been dispensed at rates equitable to non-Māori, when accounting for relative burden of disease data.
- Of the 1,126,300 shortfall in 2012/13 for Māori, approximately 608,800 (54%) represented lost opportunities for Māori to access treatment (ie, be dispensed a first prescription for that item in the 12-month year, 'access'), and the remaining 46% represented unexpected gaps in ongoing treatment, with people not getting continued medicine they'd previously accessed ('persistence').[endnote R]
- Over time, inequalities had continued. For the cohort of medicines available in 2006/2007, between 2006/2007 and 2012/2013 the overall disease burden-adjusted inequalities in medicine dispensings between Māori and non-Māori for Cohort Y nominally widened by 6%, but this trend was not statistically significant (comparing the Māori vs non-Māori age/disease burden-adjusted standardised rate ratio (RR) overall in 2012/2013 against that in 2006/2007, ie, 0.594/0.629=0.944=-6% relative change, 95% uncertainty interval (UI) 0.552–1.615).[endnote S] Realistically, certain inequity in access to medicines for Māori, however, remained (2012/13 Māori vs non-Māori age/disease burden-adjusted standardised RR 0.594, 95% UI 0.407–0.867). See the Statistical Appendix to this article for details on the uncertainty estimations.

Figure 1 shows trends and large variability in the rate ratios for individual therapeutic groups over time.

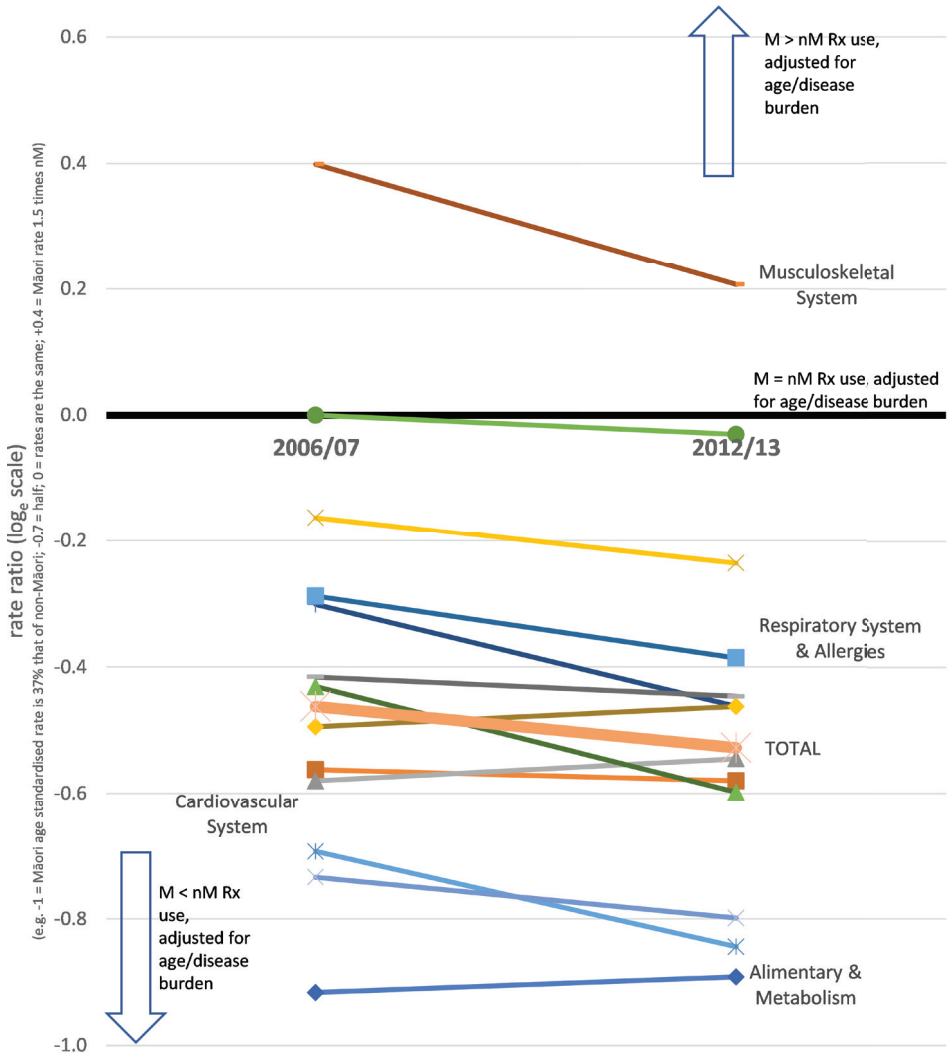
- The overall increase in the apparent gap seemed due to a further deterioration in 'access', while relative persistence had improved—so in 2012/2013 the proportion of Māori receiving their first prescription (compared with expected had they received prescriptions at the same rate as non-Māori) had decreased compared with in 2006/2007, but those who did so were staying on their medicines for perhaps a little longer (relative to non-Māori) compared with in 2006/2007;[endnote T] however, confirmatory statistical testing awaits (adapting the methods in Statistical Appendix).
- Much caution is needed interpreting these results, due to many complexities, caveats and limitations[3]—and further uncertainty calculations are awaited (ie, uncertainty limits around multiple point estimates and rate ratios, see Statistical Appendix). Nevertheless, important apparent inequities in disease burden-adjusted script rates continue to exist for cardiovascular disease, asthma and COPD, mental health (particularly the management of anxiety and depression), diabetes, cancer and bacterial infections.

Please refer to the full report including its online appendices and to the Statistical Appendix to this article for further detail.

# Discussion

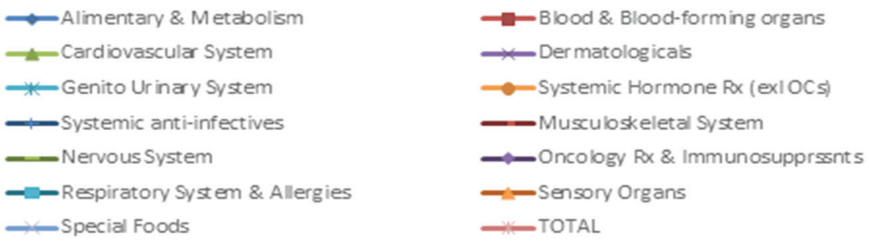
Tēnā rā Koutou. E toru ngā tino mātāpono o Te Tiriti o Waitangi. Ko te noho rangapū-partnership. Ko te mea whakaurunga-participation. Ko te whakamaru-protection. Kei a tātou tonu katoa te wero kia mahikaha, kia mahi tino mōhio, me te mahitahi. (Greetings. The three key principles of te Tiriti o Waitangi—partnership, participation and protection—help guide all of our work. The challenge continues for us to work harder, work smarter, and work together.)

**Figure 1:** Change and variability in rate ratios for Māori:non-Māori age/disease burden-adjusted script rates, Cohort Y, 2006/07 and 2012/13 ($log_e$ scale).




source: UniServices report[3] Table 6.

Key:




Interpretation:

- At a rate ratio of 1.0 (depicted as $log_e(1.0)=0.0$), Māori and non-Māori have equal rates of medicines use (ie, scripts received), after adjusting for population, age and disease burden.
- The higher the rate ratio (towards the top of the graph), the greater the extent that medicines use in Māori exceeds that of non-Māori after adjusting for population, age and disease burden.
- The lower the rate ratio (towards the bottom of the graph), the greater the extent that medicines use in Māori trails that of non-Māori, adjusted for population, age and disease burden.
- Rate ratios are depicted logarithmically, ie, on a natural logarithm ($log_e$) scale, where, eg, -1 = Māori age standardised/disease burden-adjusted rate is 37% that of non-Māori (depicted $log_e$ (RR 0.37)=-1.0), -0.7 = Māori rate is half that of non-Māori ($log_e$ (RR 0.50)=-0.69), 0.4 = Māori rate is two-thirds non-Māori ($log_e$ (RR 0.67)=-0.41), 0.0 = Māori rate equals non-Māori ($log_e$ (RR 1.0)=0.0), +0.4 = Māori rate is 50% higher than non-Māori ($log_e$ (RR 1.5)=+0.41), etc.

Hence, eg:

- Total medicines – M:nM age/disease-adjusted script rate ratio RR 0.63 in 2006/07=37% shortfall for Māori overall; RR 0.59 in 2012/13=41% shortfall; thus a small worsening of the already sizeable shortfall, but numerical counts only of medicines and not tested for statistical certainty; depicted as $log_e(0.63)=-0.462$, $log_e(0.59)=-0.528$.
- Cardiovascular medicines – 2006/07 adjusted RR 0.56=44% shortfall, 2012/13 RR 0.58=42%, thus a small improvement in the still sizeable shortfall, but numerical counts only of medicines and not tested for statistical certainty; depicted as $log_e(0.56)=-0.579$, $log_e(0.58)=-0.545$.
- Respiratory medicines – 2006/07 adjusted RR 0.75=25% shortfall, 2012/13 RR 0.68=32%, thus a worsening in the shortfall, but numerical counts only of medicines and not tested for statistical certainty; depicted as $log_e(0.75)=-0.288$, $log_e(0.68)=-0.386$.
- etc.

## Caveats

As stated in the UniServices update report, there are many important complexities, caveats and limitations to the analysis, and caution is needed interpreting its results. At least 29 of these limitations are outlined in depth over 10 pages (pages 55 to 64 of the update report itself). These include major influencers such as:[endnote U]

- the standard population age structure used (technical but important);
- diluted gaps by including other groups with high disease burden and low access in the non-Māori comparator (eg, Pacific peoples);
- use of prioritised ethnicity;
- how to interpret gaps themselves (unnecessary overuse with wastage by the non-Māori comparator? true under-use by Māori? Māori experiencing harm from over-use of suboptimal regimens?); and
- at a medicine-specific level, how changes in persistence relate to optimal treatment durations, and how changes in prescribing relate to changes in standard treatment pathways;

alongside many other caveats. Further caveats (not stated in the UniServices update) include:

- ageing of cohort Y (by excluding patients who die);
- possible bias from numerator/denominator mismatch using PHO populations as numerators but Statistics New Zealand census population denominators—affecting pharmaceutical estimates and age-specific ethnic proportions.

As well, although the UniServices update is mainly based on Metcalfe et al's[4] methodology, direct comparison of findings from the Metcalfe et al publication and the updated analysis is invalid for several reasons, including different populations, different burden of disease methods, different age standards and different medicine-disease linkages.[endnote V] Cohort Y in the updated analysis instead provides valid internally-consistent comparison over time.

More detailed level analysis at an individual medicine level provides some evidence of both good and relatively less good access to some more commonly prescribed medicines. With individual medicines and therapeutic subgroups (many hundreds), there is much subtlety and variation in the gaps and their changes by time. These data are available in the full report and its associated data tables online,[3] and deserve further investigation, including pharmacoepidemiological research incorporating clinical event data and discussion with relevant parts of the health sector.

The research cannot provide disease-burden adjusted information for other ethnic groups and others, as burden of disease data is unavailable for ethnicities other than Māori, nor other groups, eg, those suffering socioeconomic deprivation. This misses likely large inequities in other groups beyond Māori, while diluting the true extent of Māori medicines inequities compared with, say, New Zealand European people. For example, Pacific peoples are recorded as non-Māori, which means the comparison between Māori and non-Māori would most likely show greater gaps if Pacific peoples' data were excludable from the non-Māori data.

## Implications

The overall burden-adjusted approach[3,4] therefore complements and adds to, rather than replaces, other research into disparities in prescription medicines access.[5] Nonetheless, these updated apparent inequities in medicines access and use were linked to chronic conditions responsible for ~88% of the burden of disease in New Zealand; and given the magnitude and extent of the observed inequities (and lack of countervailing evidence, with consistency with other datasets and studies), plausibly, apparent inequities have not only existed but also persisted for government-funded pharmaceuticals in New Zealand.

PHARMAC's funding decisions should not create or worsen barriers to people accessing medicines, and PHARMAC acts to support optimal and equitable prescribing and uptake (part of PHARMAC's responsible use of medicines statutory function). However, the causes of these apparent inequities are likely to be complex and systemic.[47] Addressing the complex barriers to accessing medicines and optimising their use requires a whole of sector approach.[47]

Once adjusted for burden of disease, inequalities become one (or a combination) of three factors:

1. true disparities (inequity in access or persistence, ie, Māori not receiving sufficient of a medicine if at all compared with non-Māori, thus lost health gain opportunities);
2. wastage (the non-Māori comparator group is receiving excess medicines, unnecessarily, without real gains but with near-inevitable side effects); or
3. harm (Māori receiving excess medicines of lesser benefit and/or greater adverse effects, and thus experience harm, ie, net health loss via opportunities foregone, compared with the non-Māori comparator group receiving better or 'gold standard' treatments; eg, Māori receiving more of older antipsychotics and/or depot antipsychotics, but less of newer antipsychotics and/or oral antipsychotics, than non-Māori, or higher rates of inhaled beta-agonist asthma asthma relievers but lower rates of inhaled corticosteroid preventers[4]).

Inequities in healthcare and outcomes[endnote W] borne by Māori and other New Zealanders, including medicines access, are unacceptable (Martin Luther King Jr saying "Of all the forms of inequality, injustice in health is the most shocking and inhuman…"[48]). Health inequities are inconsistent with principles of social justice and human rights, including indigenous rights as reaffirmed by te Tiriti o Waitangi[49] and the United Nations Declaration on the Rights of Indigenous People (UNDRIP).[50–52] This is where the lack of improvement in top-line medicines access for Māori signals that the broader health system[endnote X] as a whole has yet to take all the "necessary steps" for indigenous people to attain equal standards of health (as per UNDRIP article 24(2),[50,51] supported by New Zealand[52]) (see endnote Y).

Human life and potential is wasted when not everyone gets the healthcare they are entitled to—when every person in New Zealand should have the same access to the funded medicines they need; as a society, we lose opportunities when people don't get to live, thrive and participate.[53]

Future directions for PHARMAC with this work will be:

(a) *Further quantitative research and tools development*

The multi-factorial nature of medicines access inequities suggests that we will need multi-agency approaches to provide the range of solutions and interventions to improve equity of access. Recognising this, in addition to the report, PHARMAC has commissioned UniServices to develop two additional tools of use to funders, policymakers and others within the health sector. These are:

- an updateable process using the New Zealand Universal List of Medicines (NZULM) to link community, cancer and hospital medicines listed on the Pharmaceutical Schedule (Sections B and Section H Part II) to the NZBDIRFS data through the Anatomical Therapeutic Chemical (ATC) classification system; and
- a geospatial analysis of variation in access to pharmaceuticals, adjusted for disease burden, by DHB areas, including the creation of an interactive map to visualise this data.

Other research activities PHARMAC is considering include:

- improving the validity and reliability of DALY-adjusted dispensing measurement, ie, the epidemiology/pharmacoepidemiology (see section 9 of the full UniServices report[3]);
- commissioning or otherwise securing more comprehensive burden of disease data for New Zealand tailored to PHARMAC's needs, eg, including Pacific and perhaps Asian peoples as discrete ethnic populations; using updated prescription data to 2017/18; and using varying standard populations[54] for age-standardisation;
- working with PHARMAC therapeutic group managers for individual medicines within individual therapeutic group levels, to identify particular gaps and needs for future research;
- seeking objective advice from PHARMAC's clinical advisers for specific areas;

- as above, pharmacoepidemiological research at individual medicine level, incorporating clinical event data and discussion with relevant parts of the health sector.

*(b) Behavioural and health systems research*

The causes of inequities are complex, and solutions lie beyond simply the funding of medicines or simply the health system. There are likely barriers to equity at multiple levels,[5,47] including:

- patient/population factors as access barriers to healthcare (including accessing appointments, delayed access), related to costs, transport, family structure, expectations, beliefs, etc;
- health system factors with structural barriers such as how care is organised (eg, accessing appointments, wait times, after-hours advice and access, completing referrals); and
- health professional factors leading to differential treatment, with inability of providers and health systems to address all groups' needs equitably (institutional and professional bias, cultural competency,[55] health literacy involving health professionals (ie, beyond patients/whānau),[56] knowledge and skills, adherence, etc.)

—all in the context of inequities in wider underlying structural and systems[57] (including institutional and professional bias), social and economic determinants of health.[10,16–18,22,30,47,55,57–70]

More broadly, PHARMAC's newly established Access Equity team will lead further work better understanding what barriers Māori, and other under-served groups including those with relatively poor health outcomes,[7–9] face in accessing and using medicines, including down to the level of particular medicines or therapeutic groups. Such work could include how population factors, health professional factors and health system factors interact to produce inequities,[65–70] alongside a behavioural science with medicines/health system focus. This work would aim beyond simply patient and whānau behaviours; it would extend to, importantly, prescriber and other health sector provider behaviours and systems effects[47] too, and their interactions[65–70]—where such research remains comparatively sparse, and yet has great potential to advance Māori health.

*c) Implementing PHARMAC's equity bold goal*

The aim is a robust evidence-base and policy work programme that will focus on:

- Identifying key points of intervention and prioritising these by their amenability and potential to address inequities;
- Reviewing programmes that have successfully reduced health inequities and identify why;
- Opportunities to work with PHARMAC's partners (Whānau Ora collectives and other sector partners) to develop locally-based programmes to reduce inequities;
- Working with system-level partners (clinical, consumer, Māori, other groups experiencing disparities, national health bodies) to identify gaps and influence policy and practice barriers;
- Better understanding the barriers to funded medicines being prescribed and used optimally, eg, commissioning further research; and

Better ways to monitor and evaluate PHARMAC's progress over time.

PHARMAC will also continue to implement Te Whaioranga, its Māori responsiveness strategy,[13] and its Pacific Responsiveness Strategy,[14] both having access equity at their heart.

*(d) Implications for the wider health sector and beyond*

Although this analysis is about access inequities for medicines, these inequities' causes and responses will be those that apply to generic healthcare inequities—to solve medicines access inequities, alongside the other healthcare inequities. Healthcare disparities comprise health system factors, health professional factors and patient/population factors—so that any inequity in healthcare access, quality or outcomes is ultimately the result of a complex interaction of factors.[47] These factors are themselves complex and entrenched—as a result of historical and contemporary social,

political, cultural and economic processes. Hence we need a systemic (and in fact multi-sectoral) approach.[47]

Eliminating inequities, in access to/use of medicines or health inequities more broadly, will therefore require efforts and partnerships beyond accessing and use of medicines alone, covering wider aspects across the whole health sector and afar.[71,72] This includes public policy, regulators and professional quality assurance organisations, universities and other training providers, personal skills and engaging patients and whānau, community action, and health services themselves.[10,47]

Leadership and commitment by the health system, health organisations and health practitioners is required, with the expectation that all New Zealanders will have equity of health outcomes.[73]

Everyone working in the health system—government agencies like PHARMAC,[74] the Ministry of Health,[73] district health boards[75] and primary health organisations, the Health Quality & Safety Commission (HQSC), doctors, nurses, pharmacists, public health, pharmaceutical suppliers, others—has a role to play to reduce these inequities and make sure funded medicines reach all the people who need them. Good engagement and partnership is essential with tāngata whenua[13,22] and other populations experiencing poor health outcomes[7] and variations in medicine use.

Policymakers and funders need to look for ways to allocate Vote Health funds so that population groups are not unduly burdened by pharmaceutical co-payments[5] or access to primary care itself due to cost (eg, 15% Pacific and 14% Māori adults reporting they're unable to pick up prescriptions due to cost, 22% Māori adults at times not visiting a GP due to cost) or other factors.[76]

Organisations should commit to, fund and be accountable for[63,73,74,75] medicines equity targets. This will need expertise, support, guidance, collaboration and engagement with affected communities and others in the health system. Setting systems and organisational performance indicators and targets[73] may substantially improve equity of access, as with, eg, the Health Targets for childhood immunisation.[77]

Health services must make sure primary care and pharmacy services are redesigned and set up in ways accessible, available and acceptable to all. This may include rethinking the physical location of pharmacies and primary care services and considering alternative ways for patients to receive both medicines and advice about taking the medicine in ways that work for them.

Interventions to help achieve medicines access equity should partner with those most affected. Cultural competence for both prescribers and pharmacists needs to continue to improve,[55,78] alongside ensuring people's experience of the health system overall is culturally safe.[79,endnote Z] Unwarranted variation in medicines prescribing and access should be routinely reported on at the DHB level, as a quality improvement concern.

System wise, there are good frameworks for how the medicines access equity bold goal could be achieved. These include the Ministry of Health's Equity of Healthcare for Māori framework,[73] and others including a Māori implementation framework (He Pikinga Waiora).[80]

There is also participatory/co-design actively involving all stakeholders (eg, end users/customers/patients and whānau, citizens, partners, iwi/hapū/marae, health providers, funders and agencies),[81,82] and the importance of Māori leadership.[73,83]

Information underpins all of this.[5] For tāngata whenua, health service and outcomes data are taonga, and Māori researchers and health providers can be kaitiaki in partnership, with good data governance including dissemination and accountability for progress[84–87] within kaupapa Māori research principles.[88–93]

For the health sector, high-quality ethnicity data is needed to measure and monitor healthcare and outcomes for ethnic groups and identify health inequities; implementing the revised Ethnicity Data Protocols—collecting ethnicity data accurately, appropriately, and often—will be crucial for everyone.[94]

For researchers, issues of age standards need to be promoted both in the New Zealand health sector and wider, including using the age structure of the groups experiencing the greatest disadvantage.[54] Using equal explanatory power study designs (ie, sampling equal number of participants from groups experiencing poorer health outcomes

and the comparator population)[95,96] and equal explanatory analysis and equity focus reporting (which involves reporting on the equity gap as well as by ethnicity)[97] can help gain at least the same depth and breadth of information for smaller disadvantaged groups—for fairer comparisons in policy and funding decisions.

Finally, the current analyses derive from an administrative dataset (the New Zealand Pharmaceuticals collection) and therefore have limited ability to capture relevant clinical variables and system-related barriers. For example, the evolution of data repositories generated by electronic transmission of prescriptions and eDispensing would allow, via anonymised data linkage, better understanding of primary and secondary non-adherence. Linking clinical encounters, or indeed prescriptions, to SNOMED/Read codes would provide more accurate mapping of dispensings to NZBDIRFS categories.

# Conclusion

Inequities in access to medicines are unacceptable, and PHARMAC is committed to eliminating these inequities, as a priority. The findings in the Updated Variation in Medicines Use by Ethnicity report[3] provide a good evidence-base[5] to inform PHARMAC's access equity activity and commitment for 2025, and people and the health sector in general.

PHARMAC will be working with its partners in the health sector, tāngata whenua and others to better identify barriers and underlying causes of these inequities and act to improve use of medicines—narrowing and eliminating the gaps.

Nō reira!! Kei te mau tonu tātou i te wero, kei a tātou ngā kaimahi hauora katoa. Ko te wero tonu, kia hikina te hauora Māori kia tae orite ki te Hauora-a-tauiwi i te tuatahi. Kei te werohia tonu te wero nei mo ake tonu atu!! Kia mau!! (Therefore!! The challenge remains for all of us in the health system. The challenge of equitable health outcomes of Māori with non-Māori is the first challenge. The challenge is ever-present. Seize the opportunity!!) Everyone in the health sector has a role.

**Note:** The full Auckland UniServices update report is available at http://www.pharmac.govt.nz/tools-resources/research/maori-uptake-of-medicines/

Endnotes are available here.

# Statistical Appendix

## Calculating 95% uncertainty limits for Māori and non-Māori age/disease burden/population-adjusted script rates and rate ratios

### Context and overall method

The UniServices analysis on Variation in medicines use by ethnicity: a comparison between 2006/7 and 2012/13 (http://www.pharmac.govt.nz/tools-resources/research/maori-uptake-of-medicines/)[3] provided point estimates of inequities in Māori:non-Māori script rates, adjusted for age, population and disease burden, but did not calculate uncertainty. It is thus limited by not assessing for random error (chance) and other uncertainty; such was not required in PHARMAC's commissioning of the research in 2015. The following supplementary analysis retrofits and retrospectively calculates confidence limits and uncertainty limits (akin to confidence intervals) for overall age standardised rates and year-specific rate ratios for Cohort Y, and relative change over time.

In particular, the UniServices analysis reported a nominal 6% change in relative uptake (Māori:non-Māori script rates, adjusted for age, population and disease burden) for Cohort Y overall over the six years 2012/13 vs 2006/07. This is from the calculated ratio of rate ratio (RR) of 0.944 when comparing the 2012/13 rate ratio (RR 0.594 overall M:nM age standardised disease burden-adjusted scripts) with the 2006/07 rate ratio (RR 0.629), where 0.594/0.629 = the 0.944 RR = the 6% relative reduction (1 (ie, equipoise) minus 0.944). The following analysis thus includes retrospectively calculating uncertainty limits for that 0.944 ratio of rate ratios, to examine chance or non-sampling error as a possible likely reason for the 6% change.

To assess uncertainty, the datasets in the analysis (scripts, burden of disease DALYs) were treated as distinct entities otherwise not directly comparable, and were thus combined using methods for indirect comparison.[98] This approach is common to economic analysis, with the use of model simulation etc. to assess uncertainty.

So separate to the UniServices report,[3] we have calculated 95% confidence or uncertainty limits for age-standardised rates,[99] and used the Bucher method[98,100] to calculate 95% uncertainty limits (ULs), using the following three steps:

1. Firstly, extracting or calculating standard errors for both Māori and non-Māori age-standardised rates for overall scripts and for overall disease burden for each time period;
2. Then for each time period, calculating and combining rate ratios (RRs) for Māori:non-Māori (M:nM) age-standardised rates for overall scripts and for overall disease burden (disability-adjusted life years lost (DALYs)), with sample-based confidence limits (CLs) and ULs for scripts and disease burden respectively;
3. Then calculating and combining the M:nM script:disease burden RR and confidence/uncertainty intervals comparing the 2012/13 period with 2006/07, using standard errors.

The use of uncertainty limits for disease burden (rather than simple sample-based confidence limits) was as used in the Global Burden of Disease Study (GBDS),[101] to account for added uncertainty from modelling—ie, accounting for additional non-sampling error, with both measurement error from model instability in the input non-fatal health loss (YLD) component of disease burden inputs, and model specification error from Rx/disease mapping.

(This is where, internationally (including for New Zealand), the GBDS[42,101,102] now reports 95% uncertainty intervals (UIs) rather than confidence intervals (CIs). Unlike confidence intervals, UIs capture uncertainty from multiple modelling steps, as well as from sources such as model estimation and model specification, rather than simply from sampling error alone. Uncertainty associated with estimation of mortality and years of life lost (YLLs) due to premature mortality reflects sample sizes of data sources, adjustment and standardisation methods applied to data, parameter uncertainty in model estimation, and uncertainty

within all-cause and cause-specific mortality models. For estimation of prevalence, incidence, and years of life lived with disability (YLDs), UIs incorporate variability from sample sizes within data sources, adjustments to data to account for non-reference definitions, parameter uncertainty in model estimation, and uncertainty associated with establishment of disability weights. The GBDS assumes that because direct information about the correlation between uncertainty in YLLs and YLDs has been scarce, uncertainty in age-specific YLDs is assumed independent of age-specific YLLs or death rates.[101])

## Equations

Direct age-standardised rate ratios (RRs) and their standard errors calculated as:[99]

$RR = (ASR_1)/(ASR_2)$,

95% CI for RR = $((ARS_1)/(ASR_2))^{1\pm Z/\chi}$, where

Z is standardised normal deviate (1.96 for 95% CIs),

$\chi$ (ie, variance) = $(ASR_1 - ASR_2)/\sqrt{((_{SE}ASR_1)^2 + (_{SE}ASR_2)^2)}$;

$_{SE}ASR$ is the standard error for an age-standardised rate;

algebraically, SE = (95% CI or UI) / Z

Bucher method RR for indirect comparison,[98,100]

| Measure of Association | Indirect Estimator | Indirect 100(1-α)% Confidence Interval Estimator | |
|---|---|---|---|
| | | In Terms of Variance | In Terms of Confidence Limits* |
| Relative risk | $\prod_{i=1}^{k-1} RR_{A_iA_{i+1}}$ | $\exp\left(\sum_{i=1}^{k-1}\ln(RR_{A_iA_{i+1}}) \pm Z_{\alpha/2}\sqrt{\sum_{i=1}^{k-1}Var(\ln(RR_{A_iA_{i+1}}))}\right)$ | $\exp\left(\sum_{i=1}^{k-1}\ln(RR_{A_iA_{i+1}}) \pm \frac{1}{2}\sqrt{\sum_{i=1}^{k-1}(\ln(ucl_{A_iA_{i+1}}) - \ln(lcl_{A_iA_{i+1}}))^2}\right)$ |

where

$RR_c = RR_a \times RR_b$ (= $\exp^{((\ln(RRa)+\ln(RRb))}$):

95% CI or UI = $\exp^{(\Sigma((\ln RRa, \ln RRb,..) \pm Z\sqrt{(\Sigma(var(\ln(RRa)), var(\ln(RRb)), var...))}}$

= $\exp^{(\Sigma((\ln RRa, \ln RRb,..) \pm Z\sqrt{(\Sigma(SERRa2, SERRb2, ...))}}$

where

ln is natural logarithm $\log_e$, exp is natural exponential base e, var(ln(RR)) = SE, var(RR) = $SE^2$, Z = 1.96

## Calculations

The above three steps were calculated and combined as follows:

*1. Age-standardised rates with standard errors*

Using standard methods for direct age standardisation,[99]

- $ASR_{M,s,1}$ Māori direct age-standardised overall scripts in 2006/07
  = 7154.9 per 1000 population age-standardised scripts,
  standard error (SE) ±273.6:1,000
- $ASR_{nM,s,1}$ non-Māori age-standardised overall scripts in 2006/07
  = 6057.5:1,000 age-standardised scripts, SE ±116.7:1,000
- $ASR_{M,s,2}$ non-Māori age-standardised overall scripts in 2012/13
  = 8517.8:1,000 age-standardised scripts, SE ±299.7:1,000
- $ASR_{nM,s,2}$ non-Māori age-standardised overall scripts in 2012/13
  = 7685.2:1,000 age-standardised scripts, SE ±140.1:1,000

*2. Rate ratios with standard errors and uncertainty limits*

Using the Bucher method RR for indirect comparison,[98,100] and age-standardised rates data from Appendices F and G of the UniServices analysis (at http://www.pharmac.govt.nz/assets/2018-02-26-Maori-uptake-of-medicines-appendices.xlsx),

- $s_1$ rate ratio (RR) Māori:non-Māori (M:nM) overall age-standardised scripts in 2006/07

  $s_1$ = $ASR_{M,s,1}/ASR_{nM,s,1}$
  = 7,154.9/6,057.5 per 1,000

  RR = 1.1812, 95% CI 1.1809–1.1814, standard error (SE) ±0.00011626

- $s_2$ RR M:nM overall age-standardised scripts in 2012/13

  $s_2$ = $ASR_{M,s,2}/ASR_{nM,s,2}$

  = 8,517.8/7,685.2 per 1,000

  RR = 1.1083 (1.1082–1.1085), SE ±0.00005646

- $d_1$ RR M:nM overall age-standardised DALYs in 2006/07,

  d1 = $ASR_{M,d,1}/ASR_{nM,d,1}$

  RR = 1.741, 95% UI 1.300–2.331, SE ±0.1938;

  (where sample error-only 95% CI is 1.7017–1.7811, SE ±0.0148)

- $d_2$ RR M:nM overall age-standardised DALYs in 2012/13,

  $d^2$ = $ASR_{M,d,2}/ASR_{nM,d,2,}$

  RR = 1.741, 95% UI 1.301–2.329, SE ±0.1931;

  (where sample error-only 95% CI is 1.7018–1.7810, SE ±0.0116)

where:

- $s_2$'s age distribution is proxied by 2006/07 age distribution
- $d_1$'s by 2013 New Zealand Burden of Disease, Injury and Risk Factors Study (NZBDIRFS)[42,102] standard errors (proportional to point estimates) to total disease then calculated for Māori and non-Māori
- $d_2$'s proportional standard errors for calculating 95% confidence limits are proxied by 2006 NZBDIS[21,41,103] standard errors (proportionate to point estimates) for total disease for Māori and non-Māori (adjusted for RR 1.754), where Māori in 2006 experienced 207,150 DALYs (sample error-only SE 2,323), non-Māori 747,426 (sample error-only SE 5,320).

Note that the standard errors for the 2006 NZBDIS DALY estimates,[21,41,103] for total disease for Māori and non-Māori, are based solely on sampling error-derived 95% confidence intervals. By contrast, the standard errors for the 2013 NZBDIRFS DALY estimates,[42,102] for total disease for total population (ie, not stratified by ethnicity for Māori and non-Māori), are based in sampling and nonsampling error-derived uncertainty intervals. This means that available standard errors for DALYs in 2006 are necessarily smaller than available standard errors for DALYs in 2013; standard errors in the 2006 NZBDIS relate to 95% confidence limits, whereas the bigger standard errors in the 2013 NZBDIRFS related to less confident uncertainty limits.

*3. Ratio of rate ratios, with 95% uncertainty limits*

Using the Bucher method again,[98,100]

*Calculation 1*: rate ratio for M:nM disease burden-adjusted age-standardised scripts in 2006/07:

$RR_1 = s_1/d_1 = 1.18/1.74 = 0.629$

95% UI = $\exp(\ln(RR_1) \pm Z\sqrt{(\Sigma(_{SE}(s_1)^2,(_{SE}(d_1)^2)))}$

= $\exp(\ln(0.629) \pm 1.96\sqrt{((00011626)^2+(0.1938)^2)))}$

= **0.430 to 0.920**

(And where corresponding 95% CI (ie, sample error only) is similarly calculated substituting new SEs in the above equation, ie 95% CI = 0.611 to 0.648)

*Calculation 2*: rate ratio for M:nM disease burden-adjusted age-standardised scripts in 2012/13:

$RR_2 = s_2/d_2 = 1.083/1.74 = 0.594$

95% UI = $\exp(\ln(RR_2) \pm Z\sqrt{(\Sigma(_{SE}(s_2)^2,(_{SE}(d_2)^2)))}$

= $\exp(\ln(0.594) \pm 1.96\sqrt{((00005646)^2+(0.1931)^2)))}$

= **0.407 to 0.867**

(With corresponding sample error-only 95% CI = 0.518 to 0.608)

*Calculation 3*: rate ratio 2012/13 vs. 2006/07 for M:nM disease burden-adjusted age-standardised scripts:

$RR_3 = RR_2/RR_1$ (= $(s_2/d_2)/(s_1/d_1)$) = 0.594/0.629 = 0.944,

95% UI = $\exp(\ln(RR_3) \pm Z\sqrt{(\Sigma(_{SE}(s_1)^2,(_{SE}(d_1)^2,(_{SE}(s_2)^2,(_{SE}(d_2)^2)))}$

= $\exp(\ln(0.944) \pm 1.96\sqrt{((00011626)^2+(0.1938)^2)+(00005646)^2+(0.1931)^2)))}$

= **0.552 to 1.615**

(With corresponding sample error-only 95% CI = 0.910 to 0.980)

## Interpretation and extended use

For each of the individual years 2006/07 and 2012/13, Cohort Y's rate ratios for M:nM disease burden-adjusted age-standardised scripts were statistically significant.

- For 2006/07, with the rate ratio for M:nM disease burden-adjusted age-standardised scripts of 0.63, 95% UI 0.43 to 0.92, the overall adjusted rate in Māori was 37% less than expected vs. non-Māori (calculated from 1 minus 0.63).
- For 2012/13, with the rate ratio for M:nM disease burden-adjusted age-standardised scripts of 0.59, 95% UI 0.43 to 0.92, the overall adjusted rate in Māori was 41% less than expected vs. non-Māori (calculated from 1 minus 0.59)

However, Cohort Y's relative differences in overall adjusted scripts over time were not statistically significant.

- With the ratio of rate ratios 2012/13 vs 2006/07 for M:nM disease burden-adjusted age-standardised scripts of 0.944, 95% UI 0.552 to 1.615, the relative change over the 6 years was -5.6%, with a plausible range (95% UI) of -61.5% to +44.8% (calculated from 1 minus 0.944, 1 minus 1.615, 1 minus 0.552)

Hence, although Cohort Y's overall differences were significant for individual years, the magnitude of the overall difference did not change significantly over the six years. We were unable to exclude chance and accepted modelling artefacts, with uncertainty limits, causing any nominal 6% "deterioration" in Cohort Y's M:nM inequity over time. The 6% gap could have plausibly improved by half, or deteriorated by 3/5$^{ths}$. Simply, there was no improvement in the overall pattern over the six years, but likewise no good evidence that any "deterioration" was real and overt.

(Confining analysis to sampling error, ie, just confidence limits, did provide statistically significant deterioration, with a range around the 6% relative worsening of 2 to 10%, but this excluded additional nonsampling modelling error, so is not reasonably valid.)

The above approaches can be used to assess uncertainty in PHARMAC's and others' future monitoring of disease burden-adjusted script inequities, including one-year prevalence by therapeutic subgroup and major pharmaceuticals, access vs persistence, etc.

Because of the suitability of sampling-only error-derived standard errors for pharmaceutical usage (with 95% confidence limits), but not for burden disease (which require additional nonsampling error, to derive 95% uncertainty limits), note we would be more confident of detecting changes in pharmaceutical usage over time, but less so detecting changes in disease burden and consequent DALY-adjusted pharmaceutical usage.

**Competing interests:**
KB, JH, RJ were the members of the Auckland UniServices team contracted by PHARMAC to update the original PHARMAC analysis. SM, JU, CP, ĀA are or were PHARMAC staff. JU was PHARMAC's Director Engagement and Implementation; SM, JU, ĀA commissioned the Auckland UniServices update and reviewed its earlier drafts.

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# Incidence of motor neurone disease within MidCentral Region, New Zealand

Alexandra Caulfield, Pietro Cariga


## ABSTRACT

**AIM:** The aims of this observational study were firstly to calculate annual incidence of motor neurone disease (MND) within the midcentral region of New Zealand and secondly to characterise the demographics of this patient group, including age, sex, ethnicity and geographical distribution within the region.

**METHOD:** Patients with a new diagnosis of MND over a five-year period (1 February 2013–31 January 2018) were identified via a clinical coding search of all outpatient and inpatient encounters. Records were then individually screened to confirm a new diagnosis of MND via both clinical (confirmation by a neurologist) and neurophysiological (needle electromyography) criteria.

**RESULTS:** Twenty-five new diagnoses of MND were identified. The incidence was 2.9 per 100,000/year. Mean and median age at diagnosis were 69 and 72 respectively (range 38–84), and the male:female ratio was 13:12. Of the 25 identified cases, 21 (84%) were of European descent, two (8%) of Māori descent, and two of undetermined ethnicity.

**DISCUSSION:** The findings from this study (incidence of 2.9/100,000) are in concordance with the higher incidence of MND found in other regions of New Zealand compared with other areas of the world. Further studies are warranted to investigate incidence in other regions, thereby building the foundations for the study of genetic and environmental factors.


In 2016, neurological disease was responsible for the death of almost three million people globally.[1] Its impact will continue to grow as countries become more socio-economically developed and reduce preventable deaths from infectious disease, malnutrition and pregnancy-related causes.

New Zealand already shoulders a heavy burden in this respect; neurological disease is now the 3rd highest cause of death behind cardiovascular disease and cancer, and has overtaken chronic respiratory disease as a cause of death among New Zealanders.[1] In addition, the impact on patients cannot be overemphasised; many neurological diseases are lifelong and degenerative, with a catastrophic personal impact on patients' lives, and economic implications for the individual and wider society. In New Zealand, they are the 4th highest cause of years of life lost to disability.[1]

Motor neuron disease (MND) is one such group of neurodegenerative diseases, characterised by progressive deterioration of upper and lower motor neurons. MND is more common in men, with a peak incidence in the 7th decade.[2] Some MNDs are inherited, but in most cases the causes are not known. In sporadic MNDs, environmental, toxic, viral or genetic factors may be implicated. Recent studies have suggested that the incidence of MND in New Zealand may be higher than in Europe and North America.[3–6] The purpose of this observational study was to calculate the incidence and characterise the demographics of MND within the MidCentral District Health Board region, which provides care for 174,340 people living in the southern region of North Island.

This study is in response to recent calls for further data on the regional incidence of MND within New Zealand,[3] and complements previous studies on incidence in the Hawke's Bay[4] and Canterbury[5] regions, and prevalence in the Wellington[6] region. It is also in line with the World Health Organization's Sustainable Development Goals for 2030,[7] which call for further research into non-communicable disease, aiming to reduce premature mortality from such

causes by one-third through prevention and treatment. It is hoped that further epidemiological data on MND will provide the necessary background for future studies into potential environmental risk factors.

# Method

Patients with a new diagnosis of motor neurone disease between 1 February 2013 and 31 January 2018 were identified using clinical coding data at Palmerston North Hospital. All outpatient visits and inpatient encounters containing the codes 'MND', 'Motor Neurone Disease', 'ALS,' or 'Amyotrophic Lateral Sclerosis' were individually screened to confirm a new diagnosis of MND received during the above period via both clinical (confirmation by a neurologist) and neurophysiological (needle electromyography) criteria. All cases had to meet the Awaji criteria for ALS.[8] The following data were collected: gender, age at diagnosis, date of diagnosis and ethnicity. In addition, we collected data on residential address to identify potential geographical clusters of MND.

DHB protocol for ethical approval was followed; no ethics committee approval was required for this study as it involved analysis of pre-existing data, with no patient contact or interventions carried out. Incidence was calculated as new cases/100,000 per year for the census-derived total population and then separately for the population aged 65 and over, to account for the strong association between MND and age groups.

# Results

Twenty-five patients with a new diagnosis of MND were identified during the five-year study period. The male:female ratio was 13:12, in keeping with existing studies. Mean and median age at diagnosis were 69 and 72 respectively (range 38–84). Of the 25 patients, 21 (84%) were of European descent and two (8%) of Māori descent. Ethnicity could not be determined for two patients. Incidence was 2.9 per 100,000/year for the total population, and 12.7 per 100,000/year for the population aged 65 and over (which accounts for 18% of the total population). No geographical clusters emerged accounting for population density by visual evaluation using clustering of cases on 2013 census map for population and dwellings (no formal analysis was undertaken due to the low number of cases). Individual data for all study subjects is shown in Table 1.

**Figure 1:** Search strategy flow diagram of included cases.

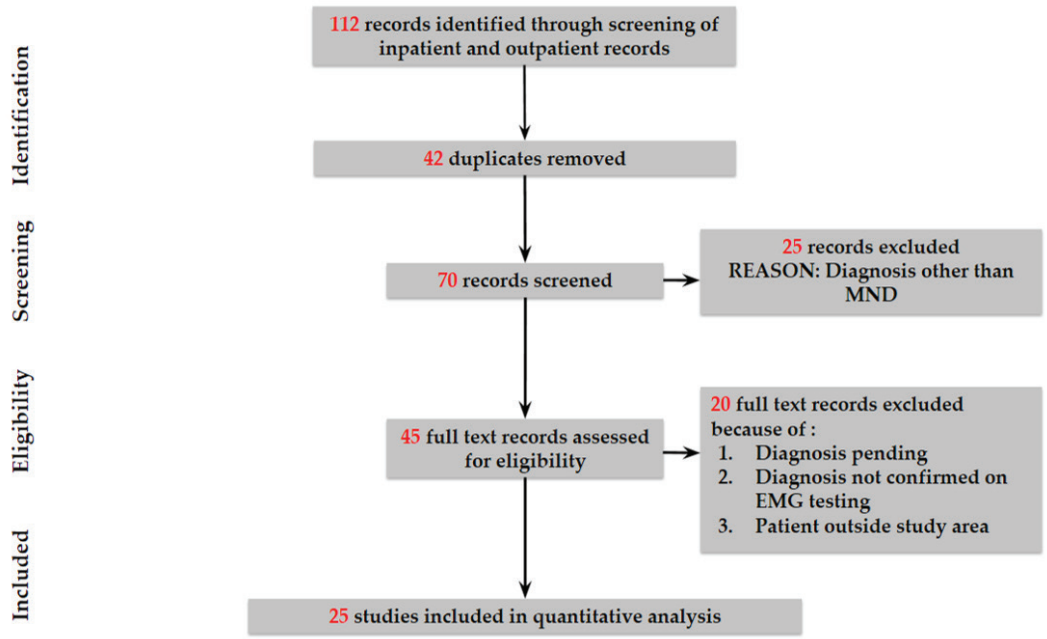

**Table 1:** Individual characteristics of confirmed cases.

| Case number | Gender | Year of diagnosis | Age at diagnosis | Ethnicity | Residential category |
|---|---|---|---|---|---|
| 1 | F | 2013 | 81 | NZ European | Semi-rural |
| 2 | M | 2013 | 84 | Other European | Semi-rural |
| 3 | F | 2013 | 73 | NZ European | Urban |
| 4 | F | 2013 | 74 | NZ European | Urban |
| 5 | M | 2013 | 75 | Other European | Urban |
| 6 | F | 2013 | 80 | NZ European | Urban |
| 7 | F | 2014 | 73 | NZ European | Urban |
| 8 | F | 2014 | 38 | NZ European | Urban |
| 9 | M | 2015 | 76 | NZ European | Semi-rural |
| 10 | F | 2015 | 70 | NZ European | Semi-rural |
| 11 | F | 2015 | 61 | Other European | Urban |
| 12 | M | 2016 | 78 | NZ European | Semi-rural |
| 13 | F | 2016 | 72 | NZ European | Urban |
| 14 | M | 2016 | 65 | Not known | Semi-rural |
| 15 | M | 2017 | 72 | NZ European | Urban |
| 16 | M | 2017 | 55 | Other European | Urban |
| 17 | M | 2017 | 46 | Māori | Urban |
| 18 | M | 2017 | 74 | NZ European | Urban |
| 19 | M | 2017 | 70 | Not known | Semi-rural |
| 20 | M | 2017 | 73 | Māori | Urban |
| 21 | M | 2017 | 65 | Other European | Semi-rural |
| 22 | F | 2018 | 70 | NZ European | Semi-rural |
| 23 | F | 2018 | 69 | NZ European | Urban |
| 24 | F | 2018 | 58 | NZ European | Semi-rural |
| 25 | M | 2018 | 70 | NZ European | Urban |

# Discussion

This study is the first to examine incidence of MND within MidCentral Region, and thus provides important epidemiological data for future research on MND within New Zealand. It does however have several limitations. First, 'borderline' cases with symptoms or EMG results which were suggestive of potential MND (but not yet definitive) may later prove to have had the disease in early stages, with the result that several early cases of MND were excluded from the study. Second, our chosen search terms were 'MND' and its most common subtype 'ALS' (and their unabbreviated forms), which may have excluded patients with less common subtypes of the disease from the study. This illustrates a relevant point for future studies; the disease includes a broad spectrum of different conditions, and the link with 'MND' is not yet fully understood for many of these.

This study answers recent calls to improve epidemiological data on MND in New Zealand, in light of earlier regional studies suggesting a higher incidence than in similarly developed countries; this data may underlie specific genetic and environmental risk factors, as suggested by Scotter.[3] A recent systematic analysis for the Global Burden of Disease Study 2015[9] found geographical variation in the distribution of MND, with highest rates in highest income areas. Reviews of epidemiological studies in Europe and North America have suggested a regional incidence between 1.89[10] and

2.08[2] per 100,000/year. Studies within New Zealand have found an incidence of 2.5 per 100,000/year and 3.3 per 100,000/year in Hawke's Bay[4] and Canterbury[5] regions respectively. Our calculated incidence of 2.9/100,000 (in a population with median age of 37 years) corroborates the higher incidence of MND found in other regions of New Zealand compared with other areas of the world, including studies evaluated in a previous systematic review, in similar populations with median age between 36 and 38 years.[2] Further, incidence of MND within New Zealand appears to be increasing in recent decades,[5] and a recent study by Cao et al[11] found the New Zealand mortality rate was higher than comparable international studies, postulating a potential association with caucasian genetics but also the possibility of additional genetic factors specific to the New Zealand population. Further analysis of the MND burden in New Zealand is necessary in the light of these findings, specifically identifying incidence in other regions and potential geographical clusters. This will lay the groundwork for the identification of reasons behind the apparent high and increasing incidence of the disease within New Zealand.

**Competing interests:**
Nil.

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# Antidepressant prescribing in New Zealand between 2008 and 2015

Sam Wilkinson, Roger T Mulder


## ABSTRACT

**AIM:** To examine antidepressant prescribing trends in New Zealand adults from 2008–2015.

**METHODS:** Antidepressant prescribing data was sourced via the Ministry of Health. Data were examined by year, type of drug, ethnicity, gender, age and location of district health board.

**RESULTS:** All individuals dispensed an antidepressant in New Zealand were included. In 2015, 12.6% of all New Zealanders were prescribed an antidepressant (16% of females and 9% of males) an increase of 21% from 2008. The largest increase in drug classes were venlafaxine and tetracyclic antidepressants. The largest class of drugs prescribed were SSRIs, which made up 57% of the total. Europeans were the most likely to receive antidepressants at 15.7%, but increases were seen across all ethnic categories. The highest users were older European females at 22.8%.

**CONCLUSIONS:** Antidepressant prescribing rates continue to increase in New Zealand although this rate of increase is slowing. The highest users were European women, particularly those age 65 and older.


In New Zealand, antidepressant prescribing has increased substantially over the past two decades. Similar increases have been reported in other Organisation of Economic Co-operation and Development (OECD) countries. New Zealand is now the 8th highest consumer of antidepressants per person in the OECD.[1] Read et al 2014[2] reported that one in nine (11.1%) New Zealand adults received antidepressant medication in 2011/12. This corresponds to 412,631 people and was a 35% increase in users over the previous five years. Exeter et al 2009[3] also reported an increase in antidepressant dispensing in New Zealand adults of 28% between 2004/05 (7.36%) and 2006/07 (9.39%). Since this study there has been no comprehensive study of antidepressant prescribing in New Zealand.

There are a number of potential explanations for this rise, including improved recognition of depression, changes in patient/doctor attitudes and a broadening range of indications treated with antidepressants. Whether this rise in prescribing is a good or bad thing is increasingly subject to debate.[4] Regardless it is important to continue to monitor antidepressant prescribing trends to help inform health policy.

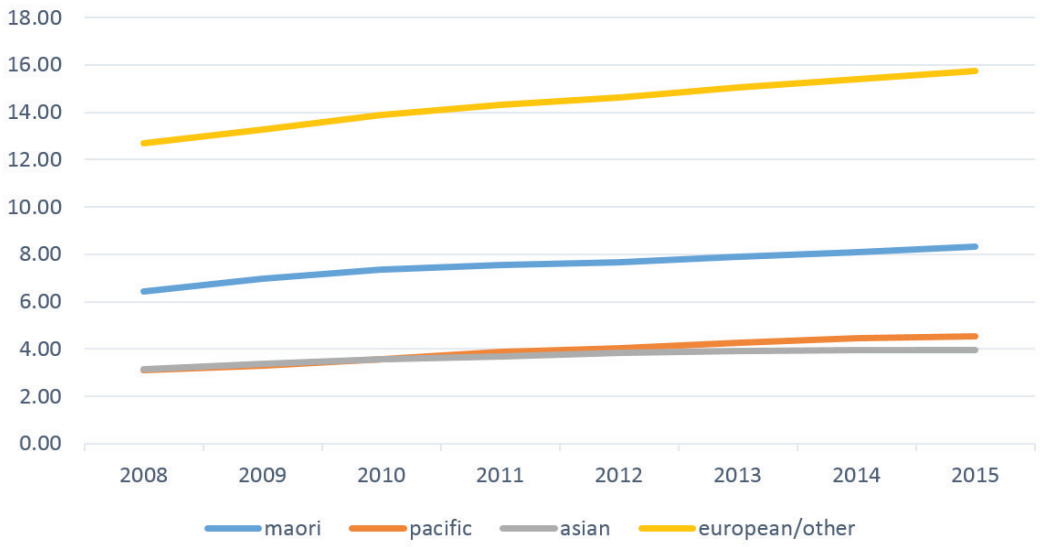
## Objectives

The objectives of this study were to examine antidepressant prescribing trends in New Zealand adults from 2008 to 2015, by antidepressant type, age, ethnicity, gender and district health board location. Our hypothesis was that antidepressant prescribing rates in New Zealand are continuing to increase in the period studied.

## Method

Antidepressant prescribing data was sourced via the Ministry of Health. The dataset contains every person in New Zealand who had been prescribed antidepressant medication.[5] This data is collected by The Pharmaceutical Management Agency of New Zealand (PHARMAC), via the National Health Index (NHI) number—a unique identifier assigned to every person who uses health services in New Zealand. The number

**Figure 1:** Percentage of New Zealand adults dispensed antidepressants over time, by ethnicity.




of prescriptions with an NHI number rose to 97% in 2008 and to 100% in 2015.

The dataset lists the number of patients collecting prescriptions for antidepressant medication within each district health board (DHB), five-year age bracket, gender and ethnicity (Māori, Pacific, Asian and 'Other'). The 'Other' category includes the following ethnic groups: European, Middle Eastern, Latin American, African and 'Other Ethnicity'. For simplicity we named this category 'European/other'. Data for eight consecutive years—2008 to 2015—was examined by ethnicity.

The prescription rates were broken down by antidepressant class, and into individual drugs within each class. The antidepressant class data were further broken down into individual drugs within each class. The data is presented over the four-year period from 2012 to 2015 because this data is more complete.

For the national prescribing rates, four age brackets were created (15–24, 25–44, 45–64 and 65+). The exception was individual DHB populations, where all ages were included, as only the *total* DHB populations were available.

Population data were obtained from the Ministry of Health to calculate dispensing rates.[6] As age group data was available for each ethnicity, the population aged fifteen and over could be calculated. The ethnic groups used are based on the ethnic groups from the PHARMAC database.[5]

### Bias

This is a census of all New Zealand prescribing data so there is minimal bias.

### Statistics

Microsoft Excel was used to analyse the data. Data are descriptive and presented as population prevalence.

## Results

### National rates (2008–2015)

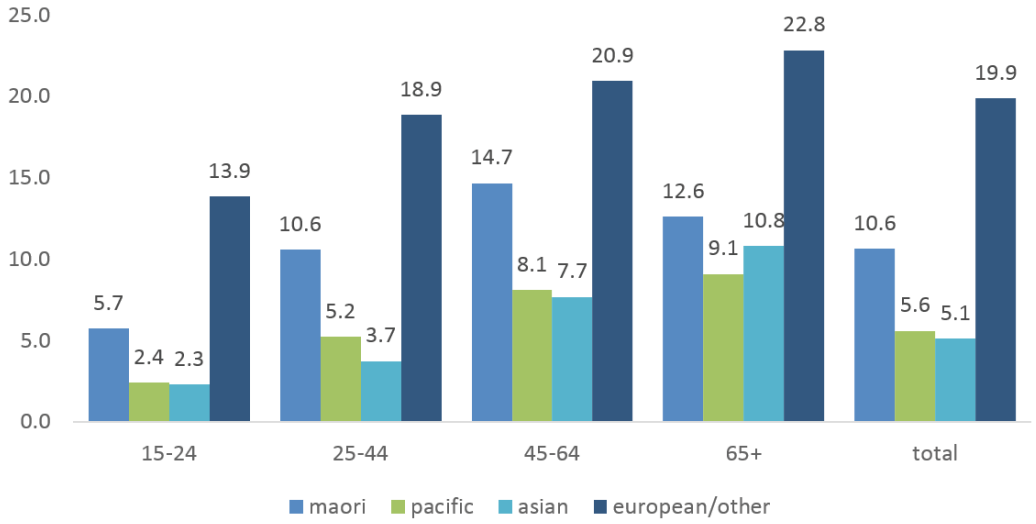
In 2015, 12.6% of all New Zealanders aged 15 and over were prescribed antidepressants (16% of females and 9% of males), an increase of 21% from the 2008 rate of 10.4%.

### Ethnicity

Figure 1 shows the distribution of antidepressant prescribing by ethnicity. 15.7% of the European/other category were prescribed antidepressants in 2015, compared with 8.3% of Māori, 4.5% of Pacific Islanders and 4.0% of Asians.

Since 2008, adult antidepressant prescribing has increased across all ethnicities. Māori rates increased 29%, Pacific rates increased by 46%, Asian rates increased by 25% and European/other rates increased by 24%.

**Figure 2:** Percentage of females dispensed antidepressants in 2015, by age bracket and ethnicity.




## Gender

Figures 2 and 3 show the distribution of antidepressant prescribing by gender, ethnicity and age. Females had higher antidepressants usage than males across all ethnicities. 19.9% of European/other females, 10.6% of Māori females, 5.6% of Pacific females and 5.1% of Asian females were prescribed antidepressants in 2015.

Between 2008 and 2015, dispensing increased 45% for Pacific females, 25% for Māori females and 23% for Asian and European/other females. The total male rate increased 24%, compared to a 19% female rate increase.

## Age

The use of antidepressants rises with age, with the exception of Māori females, where rates decrease in the 65+ age group. Females receive more antidepressants than males in all age groups.

The highest user of antidepressants in 2015 was European/other females aged 65+, at 22.8% (compared to 13.9% of males). This was 1.8, 2.5 and 2.1 times the Māori, Pacific and Asian 65+ female rates, respectively. The next highest user-group was European/other females aged 45–64, with 20.9% receiving scripts in 2015.

**Figure 3:** Percentage of males dispensed antidepressants in 2015, by age bracket and ethnicity.

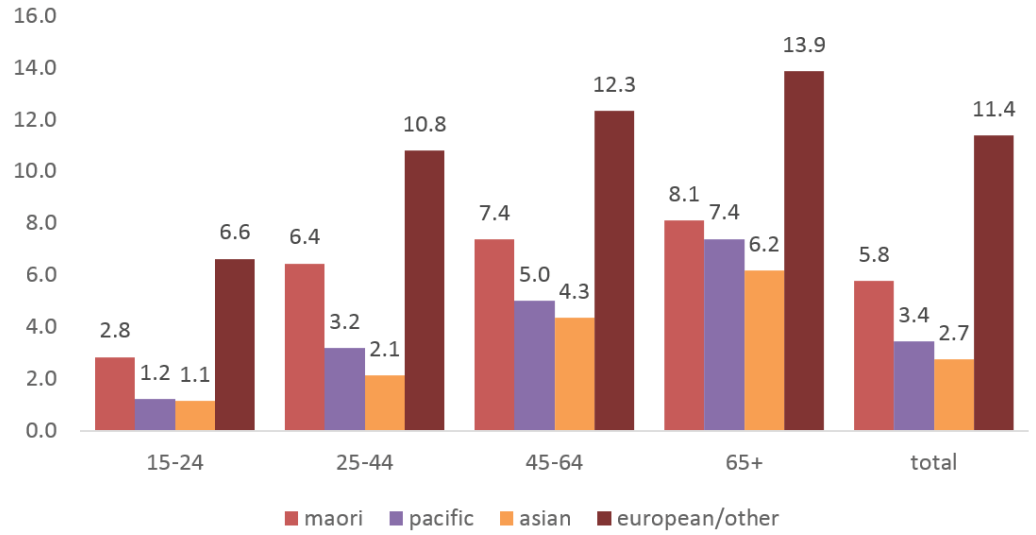
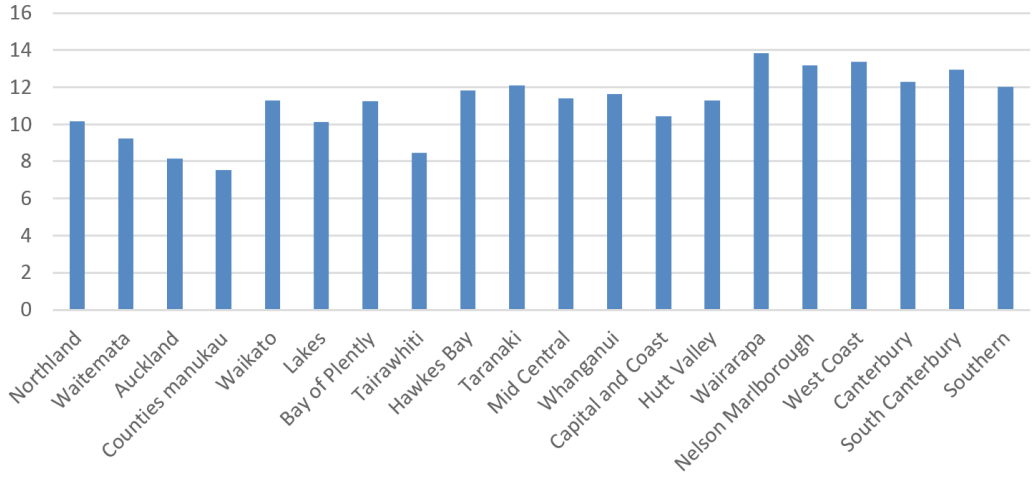


**Figure 4:** Antidepressant use by DHB in 2015.




Note the all-ages DHB populations were used instead of the 15+ population, so rates are lower.

In 2015, the greatest ethnic differences in dispensing were in the 15–24 age range. European females and males received antidepressants at 6.0 times that of Asian females and males. European/other were prescribed at 5.8 and 5.5 times that of Pacific females and males, respectively, and 2.4 times that of Māori females and males. In the 25–44 age bracket, the European/other dispensing rate was 5.1 times that of Asian females and males.

### Geographic distribution

Figure 4 shows the distribution of antidepressant prescribing by DHB in 2015. Significant geographic differences were found. The highest dispensing rate (in Wairarapa) was 1.83 times the lowest rate (in Counties Manukau).

### Drug classes

Figure 5 shows the total prescriptions by antidepressant class in New Zealand over the years 2012 to 2015. The total number of antidepressant prescriptions increased 11.6%, from 1.46 million in 2012 to 1.63 million in 2015. There was a 3.7% increase in tricyclic antidepressants (TCAs), 11% increase in selective serotonin reuptake inhibitors (SSRIs), 41% increase in Venlafaxine and a 45% increase in tetracyclic antidepressant (TeCA) prescriptions (Figure 1). Monoamine oxidase inhibitors (MAOIs) decreased by 17%; this was the only drug class to decrease. Escitalopram and sertraline are the drugs that largely accounted for the rising prescription of SSRIs; they increased by 260% and 300%, respectively.

Most antidepressant prescriptions were for SSRIs, TCAs and venlafaxine; accounting for 97% of the 2015 total (57%, 29% and 11%, respectively). Since 2012, TCAs dropped from 31.6% to 29.4% of total scripts, while SSRIs remained relatively constant around 57%. Venlafaxine prescriptions rose from 8.8% to 11.1%, TeCA's from 1.9% to 2.5%, while MAOI prescriptions dropped from 0.7% to 0.6% of the total.

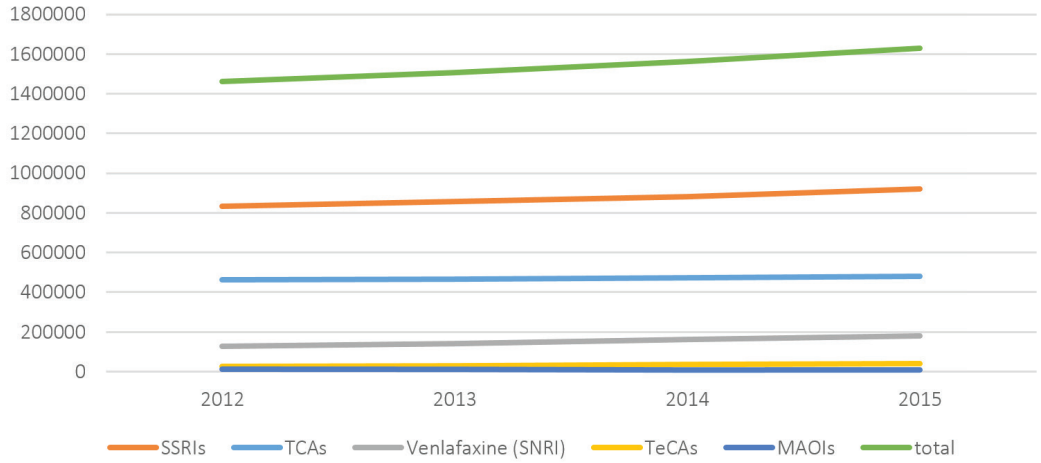
## Discussion

### National rates

This study examined antidepressant use in all adult New Zealanders between 2008 and 2015. One in eight New Zealand adults (12.6%) were dispensed an antidepressant in 2015. There are no directly comparable figures for other countries.

Kantor et al 2015[7] reported a 13% prevalence of antidepressant use from a cross-sectional survey of US adults in 2011–12. The OECD reported pharmaceutical consumption using 'defined daily dose' per 1,000 people (ddd). The highest four countries were Iceland (118), Australia (96), Portugal (88) and Canada (85). New Zealand was 8th—at 73 ddds per 1,000 adults per day in 2014[1] (the only year the OECD provided data for New Zealand).

**Figure 5:** Total prescriptions by antidepressant class in New Zealand.




Antidepressant medication included: selective serotonin reuptake inhibitors (SSRIs), tricyclic antidepressants (TCAs), monoamine oxidase inhibitors (MAOIs), tetracyclic antidepressants (TeCAs) and venlafaxine (a serotonin-norepinephrine reuptake inhibitor (SNRI)). SSRIs: citalopram hydrobromide, fluoxetine hydrochloride, escitalopram, sertraline, paroxetine hydrochloride. TCAs: amitriptyline, nortriptyline hydrochloride, clomipramine hydrochloride, dothiepin hydrochloride, doxepin hydrochloride, Imipramine hydrochloride. MAOIs: phenelzine sulphate, tranylcypromine sulphate, moclobemide. TeCAs: maprotiline hydrochloride, mianserin hydrochloride and Mirtazapine. SNRI: venlafaxine.

## Change in rates

The number of New Zealanders taking antidepressant medication has risen 21% since 2008 to 12.6% in 2015. This is 34% higher than Exeter et al's 2009[3] 2006/07 New Zealand rate of 9.39%. Rates increased in all OECD countries over the past 10 years. Between 2011 and 2014, Belgium (7.0%) and Canada (5.7%) had similar rate increases to that of New Zealand (6% from 2011–2014). The countries with the highest defined daily doses were increasing at the highest rates (11.5% increase for Iceland, 13.3% for Australia and 17.6% increase for Portugal, from 2011–2014).

Although antidepressant use continues to rise each year, the *rate* of increase has decreased. From 2004/05–2006/07, the increase was 12–14% per year.[3] In the present study (2008–2015) the rate of increase gradually falls: from 4.6% between 2008 and 2009, to 1.5% between 2014 and 2015. This is consistent with results from Kantor et al's 20157 US study which reported that while the use of antidepressants increased from 6.8% in 1999/2000 to 13% in 2011/12, the *rate* of increase slowed after 2004. From 2007–2011 the US prescribing rate increases by around 4% per year—similar to the average annual increase (of 3%) in our study. This may represent a 'ceiling effect' in populations where antidepressant use is already relatively high.

## Ethnicity

Significant ethnic differences were evident. Māori received fewer antidepressants than European/other (8.3% vs 15.7%), though the rate of prescribing for Māori is increasing faster than for the European/other group. 4.5% of Pacific people received antidepressants in 2015, although this was 46% higher than the 2008 rate—the greatest increase in any ethnic group. Asian New Zealanders had the lowest antidepressant use, at 4.0% in 2015.

Similar trends have been documented in other studies. In 2007, in the only other systematic review of New Zealand prescribing patterns, New Zealand European/other people were prescribed antidepressants at between 1.5 and 2.3 times that for Māori, depending on age and gender, and Pacific people received significantly less antidepressants than Māori.[3] Ethnic differences in antidepressant prescribing have been consistently reported in other countries. For example, Olfson et al 2009[8] reported that African Americans had lower rates of antidepressant use: 4.51% compared to 11.96% of 'white' Americans in 2005.

## Gender

Females receive more antidepressant medication than males. 19.9% of European/other females aged 15 and over (one in five) were prescribed an antidepressant in 2015. Females received antidepressants at 1.9, 1.6, 1.8 and 1.9 times that of males in Māori, Pacific, European/other and Asian populations, respectively. This gender ratio has been reported consistently. In 2005, US females had a rate more than double that of males (13.42% vs 6.68%).[8] Spence et al 2014[9] reported that women had heavier antidepressant use than men in England.

## Age

The use of antidepressants rises with age, with the exception of Māori females aged 65+. In Exeter et al's 2009[3] report, rates increased with age for *all* ethnicities, and was highest in European/other females aged 65+ (18%). The highest users of antidepressants in 2015 were European/other females aged 65+, at 22.8%. The next highest user-group was European/other females aged 45–64, with 20.9% receiving scripts. High antidepressant usage in older people was also reported by Spence et al 2014,[9] who found that areas of England with a greater number of people aged over 65 had higher antidepressant dispensing.

The highest female to male ratios were seen in the 15–24 age group: 2.09 for European/other, 2.02 for Asians, 2.01 for Māori and 2.00 for Pacific people.

Young adults have the greatest ethnic differences in dispensing, with Europeans/other aged 15–24 receiving antidepressants at 6.0 and 5.8 times that of Asian females and males, respectively.

## Geographic distribution

Prescribing trends differed geographically. Similar trends are reported in the few studies that have examined prescribing rates. In 2015 the Australian Commission on Safety and Quality in Health Care reported that the number of antidepressant prescriptions was 11.7 times higher in the area with the highest rate compared to the area with the lowest rate.[10] Spence et al 2014[9] examined trends in antidepressant prescribing in England from 1998–2012 and reported large geographical variations in the rates of prescribing. Rates varied from 71 to 331 prescriptions per 1,000 people. They also reported that areas with more white people, more women and more people over the age of 65 had the heaviest use of antidepressants.

## Antidepressant drug classes

The absolute number of prescriptions in New Zealand increased from 1.46 million in 2012 to 1.63 million in 2015, an 11.6% increase in three years.

The proportion of the total prescriptions made up by each drug class is slowly changing. SSRIs have increased from approximately 53% of all antidepressant prescriptions between 2004 and 2007,[3] to 57% in 2015. Escitalopram and sertraline are the two SSRIs that largely account for the increasing numbers, with 260% and 300% increases from 2012–2015, respectively. TCAs have continued to drop, from 42.8% in 2004/05 to 29.4% of the total prescriptions in 2015. Venlafaxine's proportionate share increased from 2.43% in 2004/05 to 11.1% in 2015.

In 2006/07 SSRIs, TCAs and venlafaxine accounted for 98.6% of all antidepressants.[3] In 2015 they accounted for 97% of antidepressants. This change can be accounted for by a 32% increased use of TeCA's; from 1.9% to 2.5%.

## Generalisability

The results of this study are generalisable to New Zealand and most other developed countries, especially those with a colonised native population and other diverse ethnic populations.

## Limitations

Although a patient is prescribed a medication, they may not have ingested it. Some patients may have been prescribed a medication once; not for the entire calendar year. Some of the antidepressants are prescribed for non-psychological reasons such as pain and sleep (eg, TCAs), although this should not significantly affect the results.

# Conclusion

The rate of prescribing antidepressants in New Zealand continues to slowly rise. The overall prevalence and distribution among gender, ethnicity and age of prescribing is similar to other OECD countries. Whether this increase is a good thing is open to

debate. There is no evidence that increased use of antidepressants has been associated with any improvement in community mental health measures such as admissions, reduction in disability benefits, reduction in suicide rates or better mental health in community surveys.[11] This is similar to findings in other English-speaking countries.[12] Antidepressants have significant side effects and we have limited evidence for long-term efficacy. Perhaps it is time to switch emphasis from a 'treatment gap' to a 'quality gap' so that antidepressant use is targeted more optimally at those who are most likely to benefit. Simply giving more people more antidepressants does not seem to be working.

**Competing interests:**
Nil.

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# Distress in informal carers of the elderly in New Zealand

Nicola Swain


## ABSTRACT

**AIMS:** Informal care, which is unpaid and often provided by family and friends, is the primary source of aged care in New Zealand. In addition to financial costs there are known psychological costs of being a carer, including poor mental health.

**METHODS:** This research aimed to interview a group of New Zealand carers and describe their rates of depression and anxiety, their motivations for providing care, costs of care and their experience of aggression. Interviews used standardised questions and were conducted over the phone.

**RESULTS:** Results are reported from interviews of 48 carers and suggest this group have elevated symptoms of depression and anxiety. Most of the carers are partners or children of the carees and likely do the caring out of love. Unpaid family carers experience low levels of aggression. Carers reported personal and social restriction, and physical and emotional health the most burdensome aspect of being a carer.

**CONCLUSIONS:** Carers of the elderly in New Zealand show elevated levels of distress. Higher levels of emotional support are needed for New Zealand carers. If the health system continues to rely on unpaid carers more should be done to support them.


In New Zealand, it is estimated that 480,000 people provide regular care for someone who is ill or disabled.[1] While this statistic recognises support for people across the whole lifespan, an increasing number of older people require care. Most older people with disabilities and high dependency on others in New Zealand are known to live in private households within the community rather than in specialised facilities.[2] Thus, care for the aging population becomes an increasingly important topic.

This paper focuses on informal unpaid carers; they will be referred to as carers throughout. Informal care provides many benefits, including improved patient outcomes and reduced unnecessary re-hospitalisations and residential care placements.[3–5] There are also considerable financial benefits to society. Unpaid caring is an essential part of the health system and saves a large amount of money that would otherwise need to be provided by other parts of the health system and would be increasing each year.[6] A large proportion of people providing informal care in New Zealand are also in paid employment (65%).[7]

In addition to financial issues, there is also a psychological cost to informal care. Previous studies report poorer mental health of informal carers.[1,8] While depression and anxiety are known to be prevalent in community samples (14% depression and 6% anxiety lifetime diagnosis in New Zealand)[9], carers are thought to be at increased risk. Family carers of COPD patients reported 34% had depression and 64% had anxiety.[10] Similarly, 30% of carers of cancer patients were reported to have depression.[11] Of pancreatic cancer carers, 15% had depression and 39% had anxiety.[12] In a review of dementia assessment and management it was reported that dementia carers had 23–85% incidence of depression and 16–45% have anxiety.[13] This wide range of findings represents a lack of consistency of measurement, each study using different criteria and scales, and carer burden being highly variable. A sense of carer burden was considered as a possible influence on the

dementia patient. They also noted carers are likely to have low self-efficacy and poor physical health and wellbeing. In a recent review of carer burden in aged care it was concluded that the interventions had little effect as it is difficult to change carer burden in real life, as caring will always involve burden, stress and negative consequences.[14]

A carer's ability to cope does not directly relate to their demographics characteristics or the patients physical or psychological health status.[15] Therefore, without prior knowledge of the people involved, it is difficult for clinicians to make assumptions about the ability of a caregiver to cope with their patient or indeed know what the personal costs might be. Even with information available there may be few options available for clinicians to consider. Typically the available options would be to move the caree to residential care or provide paid caregivers rather than specific support for the carer. This may be difficult, as carers may be motivated to provide care themselves for a wide range of reasons, including religion, traditions, duty, guilt, social pressure[16] or finances.[15] Further data are needed on whether aged care family carers in New Zealand are experiencing wellbeing issues as a result of caring, and if so the extent of these issues.

Although there is some research on health outcomes of caring, little is known about the experience of aggression among carers. A recent study of paid caregivers in New Zealand used the POPAS-NZ scale to investigate aggression towards care workers. These authors reported high rates of aggression towards paid carers in New Zealand.[17] Aggression in this research includes measures of verbal aggression, physical aggression, sexual aggression and threats. This is of potential interest as a further possible risk to the wellbeing of carers.

The objectives of this research were to quantify the burden of care for a sample of people providing informal aged care in New Zealand. Specifically, this research had four aims: firstly it aimed to document motivations to care. Secondly to examine the rates of anxiety and depression in this group. Third, report on the psychosocial cost to care, and fourth, describe the experience of aggression towards carers. The aim of this research was to examine New Zealand-specific data and broaden the measures from typical mental health focus to include aggression and burden.

# Method

## Design

This study was observational using a single interview method and standardised questionnaires.

## Participants and recruitment

The inclusion criteria were: a person who considered themselves to be providing care for another person over 60; 16 years or older; and able to understand and converse in English. Opportunity to participate was advertised on Carers New Zealand Facebook site and a Carers Otago Newsletter. People interested in participating contacted the research assistant for more information. Carers Otago also contacted people directly to ask for their details to be passed on to the researcher. In addition, the research assistant contacted a local organisation (Carers Otago) who had agreed to contact carers from their client list. They passed on contact details of those who have agreed to participate.

## Measures

Data were collected via phone interviews and began with a list of demographics questions including age and disability of carees.

A short checklist of depression and anxiety symptoms was used, known as the Hospital Anxiety and Depression Scale (HADS).[18] It consists of 14 questions, with responses rated from 0–3, giving a possible score of 0–42, with higher scores representing greater impairments.

All of the carers reported on motives for helping using a standardised questionnaire called the Caregiver Appraisal Measure.[19] This is a four-item questionnaire which examines the values base of the carer on a four-point scale. It examines whether the caring experience is shaped by family or religious tradition, self-esteem or modelling for others. Its reliability and validity are unknown. This was followed by a qualitative question: "why do you care for this person?".

The Cost of Care Index was used to examine caregiver burden.[20] This is a 20-item

scale developed for identifying potential and existing adverse consequences for caregivers of elderly people. The measure contains five sub-scales: personal and social restrictions, physical and emotional health, economic costs, value investment in caregiving and the perception of the care recipient as inflaming the situation. Items are scored on a four-point scale (strongly agree, agree, disagree, strongly disagree), giving a possible range of 20 to 80. A mean of 56 would be considered high cost. The authors of the index suggest that the sub-scores will identify specific problem areas.

The POPAS-NZ is used to measure aggression and violence experienced in the previous 12 months from the person that they care for. The POPAS-NZ questionnaire is a brief outcome scale consisting of 12 questions related to the experience of aggression. For each type of aggression people score: 0, never; 1, rarely; 2, sometimes; 3, often; or, 4, very often. To score all of these numbers are added. The lowest category is verbal anger rising up to physical assault and making formal complaints. Previously a test of the psychometric properties of this measurement instrument was conducted. The POPAS-NZ scale has high internal validity, with Cronbach's alpha of 0.89.[17]

## Procedure

Participants contacted the researcher or had agreed to her contacting them. Information and consent forms were posted before interviews. Consent was either posted back in or recorded verbally. Phone surveys were conducted with participants at a time that suited them. The interviewer for most participants was a registered clinical psychologist (n=36), for the remainder was a trained research assistant (n=12). Interviews took around an hour.

Ethical approval was gained from the University of Otago Ethics Committee (Health) - D15/405.

## Data analysis

Data were recorded and then entered onto a spreadsheet for analysis. Planned analyses were descriptive statistics of demographic data, HADS depression and anxiety sub-scores, Cost of Care Index mean scores and sub-scores and Caregiver Appraisal Questionnaire. There was a qualitative question asked "why do you care for this person", this would be analysed by creating an online wordcloud app (http://word-itout.com/word-cloud/create) which would produce a visual representation of the range and frequency of responses.

# Results

This study reports data from 48 people who were interviewed over the phone or in person. All volunteers met inclusion criteria. Participants median age was 67 years (range 41 to 92). There were 13 men and 35 women carers. The average hours care per day was 17, with a mode of 24 hours. The caree ages ranged from 60 to 96, with a median of 81 years. The caree was most often a spouse (54%) or parent (42%). Of the remaining three carers, two cared for their brother and one cared for a non-relative. Thirty-eight percent of the carees had dementia, as reported by their carers. Two people reported being Māori, 37 New Zealand European and 12 other ethnicities. Ethnicity was not diverse enough to allow sub-group analyses.

## Motivation to care

Carers largely disagree with the statements that they provide care "to be a good model for others to follow", and as "a way to

**Table 1:** Responses to Caregiver Appraisal Questionnaire in percentages (numbers) n=47.

| | Strongly disagree | Disagree | Agree | Strongly agree |
|---|---|---|---|---|
| To provide a good model for others to follow | 28(13) | **42(20)** | 15(7) | 19(9) |
| A way for me to live up to religious principles | **43(20)** | 28(13) | 21(10) | 13(6) |
| Gives my self-esteem a boost | 19(9) | 34(16) | **43(20)** | 9(4) |
| True to family traditions | 9(4) | 21(10) | **43(20)** | 28(13) |

The modal response is in bold.

**Figure 1:** A word cloud of responses to the open question of "why do you care for this person".


The more often a response is mentioned the larger it becomes. N=48

live up to religious principles" (see Table 1). There was somewhat more agreement with the statement, "I do it to give my self-esteem a boost". Clearly the highest agreement was for the statement "I care because caring is true to family traditions". The caregiver Appraisal Questionnaire included a fifth open question "what other reason do you have for caring for this person". Responses are collated and presented in Figure 1. This shows a wide range of responses with "Love" being the most often reported.

## Depression and anxiety

Using a standard cut-off of 8+ for caseness on the HADS, 34% (16 people) of this sample have depression and 36% (17 people) of this sample have anxiety. For anxiety, scores range from 0 to 17 with a median of 7. For depression, scores range from 0 to 13 with a median of 6.

## Cost of care index

The mean score reported was 56 with a range of 39–77. Sub-scores for this sample are: personal and social restrictions 6.3, physical and emotional health 6.4, value 1.9, care recipient as provocateur 4.5 and economic costs 4.6. This indicates that the carers found personal and social restriction, and physical and emotional health most burdensome.

## Experienced aggression

Reported aggression was low. When summed the mode of the POPAS-NZ was 0, with 17 people reporting no aggressive behaviour. The remaining 32 carers scores ranged from 1 to 17. The median score across the sample was 2.5. This would indicate responding "sometimes" to just one question, like verbal aggression, or "rarely" to two types of aggression.

# Discussion

This study reports findings of a descriptive study examining motivations to care, cost of care, depression and anxiety in carers and carers experience of aggression.

Of the statements offered in the Caregiver Appraisal Questionnaire, the highest endorsement was for the statement, "A strong reason for taking care of this individual is to be true to family traditions". The Cost of Care index was used to examine the aspects of caring that the respondents found to be most burdensome. Results showed that personal and social restrictions, and physical and emotional health were comparatively more of a burden that the financial costs, the value of the activity of caring and the demands of the caree.

Respondents indicated elevated levels of depression and anxiety. Thirty-four percent of this sample reported symptoms of depression that reached a standard clinical cut-off. Using the same measure (HADS), previous research has cited a population norm of 23% in Germany[21] or 4% in the UK.[22] Similarly, the participants in this study reported anxiety symptoms which led 36% to be above the cut-off for likely clinical diagnosis. The population norm reported was 21% in Germany[21] and 13% in the UK.[22] A British study reviewed norms by age and gender using HADs and for the average participant in this study we might expect depression rates of 15% and anxiety rate of 33%.[23] Using these data our sample seem to have increased rates of depression but close to normal rates of anxiety. There are no norms in New Zealand for the HADs scale, however the rates found in the present study are higher than those reported for people who have had a stroke[24] and pacemakers.[25] While population norms remain problematic for the HADs, we conclude that this sample of carers have elevated rates of depression and anxiety.

This study shows less aggression than a previous New Zealand study on paid care workers. The previous study reported a median score of 5, and mode of 0 and a range of 0–26.[17] This compares to a median of 2.5, a mode of 0 and range of 0–17 in the present study. This shows that family carers experience less aggression from their carees than paid caregivers. This is an interesting finding and may reflect severity of illness, as people often move into care when their family are no longer able to take care of them at home. It might also suggest that carees are more compliant at home and for family carers.

A limitation of this study is that ethnicities in this study do not match the population. Māori were under-represented and New Zealand Europeans over-represented. This is of concern and future studies might consider other ways of recruiting Māori participants. Specific recruitment strategies might be needed. A recent study of older Māori people reported that social support was important for quality of life.[26] Another limitation is the small sample size, these self-selected carers may not be representative of the population of carers in New Zealand.

It is clear that more support needs to be offered to support people to ameliorate these elevated levels of depression and anxiety. Our data also suggests that financial help is not what is most required but support around physical and emotional health, and personal and social restrictions. This was supported by a previous New Zealand study that reported 96% of carers were not satisfied with the support they received.[6] Jorgenson et al (2010) conclude that: "There does seem to be a contradiction between the value we place on caregivers and what we provide to support them, both materially and psychosocially." The intervening years between these two studies do not seem to see any progress made in supporting these people essential to our health system.

However, another possibility is that improved care for carees would also improve things for carers. This has been suggested by other researchers for example, Janda et al (2017) suggest reducing patients' distress would be helpful.[12] Thus, the care job would become easier if there was more support for the carees in their home.

Mittelman et al (2006) reported that psychosocial interventions, including support groups, can improve outcomes for carers.[27] A meta-analysis of interventions found that those most likely to succeed in improving carer wellbeing included both the carer and the caree in structured programmes.[28] In a recent Australian study, a single session of behavioural activation, which involved a 90-minute appointment with a clinician, improved measures of stress and valued living two weeks after the intervention in a small community sample of carers.[29]

In conclusion, this research suggests that in New Zealand Carers experience elevated levels of anxiety and depression and at significant personal cost are motivated to care for their family member out of love. They are an essential part of our healthcare system and further support is needed. Future research trialling methods of support in New Zealand would be helpful.

**Competing interests:**
Nil.

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# Proposal for a National Interprofessional School of Rural Health

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## ABSTRACT

Shortages of health professionals persist in much of rural New Zealand despite a range of targeted university and professional college initiatives. In response to this a collective of universities, professional colleges and sector groups have put a proposal to Government for a National Interprofessional School of Rural Health. If adopted, this proposal would embed rural health professional education and research in rural communities around New Zealand, empowering them to organise the education that occurs in their community, in a coherent and coordinated way. What is being proposed is not a new or separate education provider but rather an 'enabling body' that would lever off the expertise and resources of the existing tertiary institutions, colleges and rural communities. It calls for an 'all of systems' approach that encompasses all the health professions that practise in rural areas, undergraduate education and postgraduate training, and rural health research. Although modelled on successful Australian rural clinical schools, it is a uniquely New Zealand solution that is cognisant of the New Zealand context and resources.


The longstanding geographic maldistribution of the New Zealand medical workforce has resulted in chronic shortages of doctors in rural areas.[1–2] Similarly, the pattern of geographic maldistribution with rural shortages is repeated across a range of health professions.[3–6]

The research needed to quantify the impact that these shortages is having on health outcomes has not been undertaken in New Zealand.[7–8] International evidence suggests that poor access to health services in rural areas accentuates the health disadvantage associated with ethnicity and socioeconomic deprivation.[9] New Zealand rural towns (collectively described by Statistics New Zealand (SNZ) as 'independent urban areas') have overall the lowest socioeconomic status of any of the SNZ geographic categories.[10] Rural towns also have the highest proportion of people specifying Māori ethnicity, 20% overall and 40% in Northland, Bay of Plenty and Hawkes Bay.[11] Data available are limited but research suggests it is likely that the poor access to healthcare as a consequence of workforce shortages is contributing to significant pockets of health disadvantage in these communities. Residents of rural towns have consistently poorer health outcomes, including lower life expectancy, than those living in cities or surrounding rural areas, an effect that is accentuated for rural Māori.[12]

Multiple health service and wider societal factors impact on the recruitment and retention of rural health professionals. Although many of these are outside universities' sphere of influence there are three evidence-based university education strategies that increase the uptake of rural careers. The first is selecting students from rural origin to enrol in health professional programmes; the second is providing quality rural exposure throughout the undergraduate years; and the third is targeted rural postgraduate pathways.[13] The University of Otago (Otago) and the University of Auckland (Auckland) have adopted all three of these strategies.


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## Existing rural programmes

Both Otago and Auckland have admission targets for students of rural origin for medical education (Otago has a similar scheme for dentistry and will for other programmes by 2020), that have lifted the proportion of rural students enrolled in these programmes.[14–15] Attachments in rural general practice have formed part of both the undergraduate medical programmes for more than 25 years.[16] All Auckland medical students undertake compulsory rural placements in 4th year and in 6th year. Rural clinical attachments are also commonplace in other health professional schools. In 2015 almost 1,000 Otago health professional students, in medicine, dentistry, oral health, physiotherapy, pharmacy, nursing and dietetics undertook clinical placements in rural communities. Similarly, Auckland University of Technology (AUT) offers rural clinical attachments for physiotherapy, occupational therapy and paramedicine students in the Bay of Plenty and a distance taught midwifery programme in collaboration with local midwives in Northland and Taranaki.

In 2007 Otago introduced a year-long rural medical immersion programme (RMIP).[17] RMIP is modelled on the longitudinal integrated clerkships (LICs) that evolved in Australia and are most likely to influence the student's future choice of a rural career.[18] Students spend a year based in rural general practice and a rural hospital, and the curriculum topics are taught concurrently rather than in the traditional specialist blocks. Currently 6% of the Otago 5th year medical class undertake RMIP. Auckland established a similar regional and rural programme in 2008. Called 'Pūkawakawa', the programme places medical students for their 5th year in Whangarei, including substantial time in small rural Northland communities.[19] The rural regional model has also been extended to Taranaki and the Bay of Plenty. Both Otago and Auckland teach a range of health professional groups and specialties in eight regional centres that cover provincial New Zealand and their surrounding rural communities.

The rural context lends itself to interprofessional education (IPE) and Otago and Auckland have located their flagship undergraduate IPE programmes in Tairāwhiti and the Western Bay of Plenty respectively. These programmes bring final year nursing, medical, dentistry, oral health, pharmacy, physiotherapy, dietetics, social work and occupational therapy students together for a five-week interprofessional learning attachment.[20]

In recent years Otago and Auckland have seen considerable growth in the number of Māori and Pacific students enrolled on health professional programmes. The intake of Māori students into the Otago MBChB programme this year was about 21% of the total domestic intake, a higher proportion than in the New Zealand population, and the proportion of Māori in the programme increased by 179% between 2010 and 2016.[16] This is the result of partnerships with Iwi (and Pacific) communities, promotion through high schools around New Zealand and foundation entry programmes.

Postgraduate (vocational) education in New Zealand is primarily the responsibility of the professional colleges. Otago is however an active partner with the Royal New Zealand College of General Practitioners (RNZCGP) in the delivery of New Zealand's one rurally-targeted vocational training programme, rural hospital medicine training. The academic component of the training (Postgraduate Diploma in Rural Hospital Practice) is delivered by a dispersed faculty embedded in rural communities across the country.[21]

## Rural health as an academic discipline

What has not evolved in New Zealand in the way that it has in Australia is the development of rural health as an academic discipline. Academic posts and infrastructure have not been established in rural communities nor been brought together under the umbrella of a rural clinical school. By way of contrast there are 17 rural clinical schools[22] and 12 university departments of rural health[23] (the interprofessional equivalents), and numerous senior academic university posts, in rural Australia.

Currently New Zealand rural communities have multiple points of contact with different health professional education and training programmes run by different tertiary institutions and colleges. We are missing the opportunity for a coherent and efficient approach to health professional education in these communities; including the sharing of teaching, administrative

and IT resources and interprofessional education. Importantly, rural health also misses out on the leadership provided by senior academic posts in other branches of health; and rural health research remains 'undeveloped'.[8] Furthermore, there is no formal mechanism for the community engagement needed to feed a rural perspective back into the universities and their curricula.

There is another consequence that goes beyond rural New Zealand. Rural healthcare is more than simply the practice of healthcare in another location. Rural healthcare is more generalist, less resource intense and more engaged with the community; the boundaries between primary and secondary care and between professional groups are more blurred.[24] Generalism is developing as an epistemology and rural generalism as a scope of rural practice.[24] The importance of generalism would be explicitly emphasised if New Zealand had a School of Rural Health. The current low profile of rural health in our universities means we lose an important foil to the specialisation and compartmentalisation that is a feature of modern healthcare,[25–26] impacting students' views of ways to practise.[27] The arguments for undertaking health education in rural communities are not just about generating an equitable workforce. They are also about the value and quality of the educational experience students receive when undertaking rural attachments and the benefits to patients.[28–29]

These issues are not new and have been at the forefront of the minds of New Zealand rural health professionals and educators for more than two decades.[30–32] But perhaps it is not surprising that New Zealand's universities have not made the progress we see across the Tasman: Australian rural clinical schools and university departments of rural health are the result of targeted and substantial Commonwealth Government investment.[22]

## The proposal for a National Interprofessional School of Rural Health

Otago adopted a strategic Rural Health Plan[33] in 2015 in response to reviews of its rural programmes that had recommended a department of rural health and eventually that a rural clinical school be established. When consulted on this plan the rural health sector expressed a preference for an 'all of systems approach', a national and cooperative solution that included the existing medical schools and tertiary training providers, the professional colleges, rural communities and healthcare providers. This feedback resulted in intensifying existing discussions with the University of Auckland, the Royal New Zealand College of GPs and the Rural GP Network (which represents all rural health professionals) and resulted in the current proposal for a National Interprofessional School of Rural Health (NISRH). The collaboration has grown to include AUT and will include other tertiary institutions, including those in regional centres, as it evolves.

Up until now most rural health workforce initiatives have come out of individual urban tertiary institutions and are aimed at single professional groups. The NISRH proposal is fundamentally different in that it calls for an 'all of systems approach' that is embedded in rural New Zealand, is interprofessional and multi-institutional. Key features of this proposal, which is currently sitting with government, are outlined below.

## Interprofessional education

The NISRH is first and foremost a rural health initiative, aimed at improving health services and health outcomes for rural New Zealanders. The overarching educational model is an interprofessional one. The Tairāwhiti (Otago) and the Western Bay of Plenty (Auckland) programmes have each established IPE as a successful model of undergraduate health professional education in rural New Zealand that a NISRH would build on.[20] IPE is not only an educationally sound model in the rural context, it also involves sharing of teaching, administration and physical resources, and is thus efficient and sustainable.

## Community and iwi engagement

The activities of the NISRH would be based around nodes located in rural towns and integrated with the local health services. Rural communities can make a significant contribution to the educational experience of students, especially when they have the opportunity to develop an ongoing relationship with trainee health professionals and can see the potential to secure their future health workforce.[34] Community

engagement occurs at three levels: student immersion in the community, community input into the curriculum and members of the community being involved in programme delivery. It creates a unique opportunity for students to understand the 'health of the community' and the social determinants of health for that community.

It is proposed that a local governance group would be established in each node in order to facilitate this community and iwi engagement. In many rural areas there are already community-owned health service organisations that would be the natural local NISRH partners. Engagement with local rural Māori within the framework of the universities' iwi partnerships will be an essential function of these local governance groups.

Local governance will also enable the NISRH to target the different health needs of individual communities. Mental health is an example of a high-needs area that is often under resourced in many rural communities.[35]

## Distributed rural academic capacity

The core of this proposal is an interprofessional community of rural health academics, dispersed across rural New Zealand and bought together on a 'virtual campus' with the aid of modern IT. The academic posts would be taken up by rural healthcare professionals who would combine academic roles with active rural clinical practice. The resulting academic community would teach the future rural workforce, undertake relevant research and develop, deliver and evaluate services to improve rural health service provision and rural health outcomes. Rural health professionals would have the opportunity to engage in an academic career, without leaving rural clinical practice. This would bring rural health in to line with other specialist- and urban-based branches of practice.

## Education

The LIC rural immersion year would be expanded and offered to a greater proportion of medical students and to other professional groups as evidence and infrastructure for this becomes available. For non-LIC medical and other health professional students, rotational rural clinical attachments will be coordinated. The range of disciplines would be increased to include several where rural placements are currently not an option because of inadequate clinical supervision. The discipline of the local lead academic might be medical, nursing, pharmacy or physiotherapy or another health professional. Lead academic positions would have the responsibility, along with the local administrators and tutors, for coordinating the equitable delivery of education to all the health professional students in that community, including the delivery of an interprofessional education programme.

Student assessment, curricula and qualification completion responsibilities would sit with the parent institutions as they currently do and a small NISRH presence would be maintained on the main campuses to ensure coordination and curriculum alignment. The NISRH would be responsible for delivering the curricula at each rural node, coordinating local clinical placements, ensuring interprofessional education is effective and providing accommodation and pastoral support for all student/trainees. Although the educational outcomes of prolonged rural attachments are well established, even the LIC students undertaking the year-long rural attachment would still receive the majority of their undergraduate education in urban teaching hospitals.

Infrastructure, including consulting and teaching space, student/trainee accommodation and IT would be shared by all health professional students, and with local healthcare providers such as GP clinics, contributing to their sustainability. The NISRH proposal includes funding for health provider facility extensions/utilisation for teaching space, administration and accommodation, as well as the IT infrastructure to support communication across the NISRH and with the main campuses. This would represent a significant investment in rural communities as all funds would be expended locally.

Australian Universities offer a rural LIC year to 25% of each of their medical class intakes. A NISRH could aim for a similar target and offer all health professional students enrolled in the partner institutions a shorter rural clinical attachment. The proposal is however scalable, with the number of nodes dependent on initial resourcing and the potential to increase in the future.

## Vertical integration

Education would also be integrated across the years. For example, GP, rural hospital medicine registrars and postgraduate year 1 and 2 placements would be coordinated through the NISRH who would in turn contribute to the teaching of interprofessional undergraduate students, with all trainee levels involved in the continuing medical education programme for local doctors. This would contribute to the 'rural pipeline', the concept of supporting those with an interest in rural health in a coordinated fashion throughout their undergraduate education, postgraduate training and their years of rural practice (Figure 1).

## Research development

The NISRH would add to existing efforts to develop a rurally-based research programme that responds to the needs of the sector and informs rural clinical practice and rural health policy. It would be well placed to trial new and innovative ways of delivering healthcare. Connections to a number of tertiary institutions would provide access to research expertise and resources.

## Governance

Governance would be provided collectively by all the partners, tertiary institutions, professional colleges (including the RNZCGP), the Rural GP Network (representing rural health professionals) and rural communities.

## Funding

Although draft costings have been provided to government, a full funding model has yet to be finalised. A strength of the proposal is its ability to draw together existing funding streams including Tertiary Education Commission (TEC) equivalent full-time students (EFTS) and Health Workforce New Zealand funding for medical postgraduate (year 1 and 2) and vocational training. Moreover, the NISRH will leverage existing educational and IT infrastructure of collaborating tertiary institutions. Rural communities are supportive of local health service and health professional education initiatives—for example, providing material support—when they can see the long-term benefits. Sharing infrastructure with local healthcare providers will generate additional efficiencies. It is however appreciated that distributed, community-based education is expensive, at least initially, and additional government funding will be needed for new infrastructure, academic posts and student travel and accommodation.

## Benefits of the NISRH

An immediate benefit of a NISRH would be greater capacity for community-based student placements through better coordination and expansion of capacity and capability, at a time when these are in short supply. More students would benefit from exposure to rural programmes. Interprofessional education would become a standard part of health professional learning in the rural context, breaking down the barriers between the professions and improving efficiency and collaborative practice.[36]

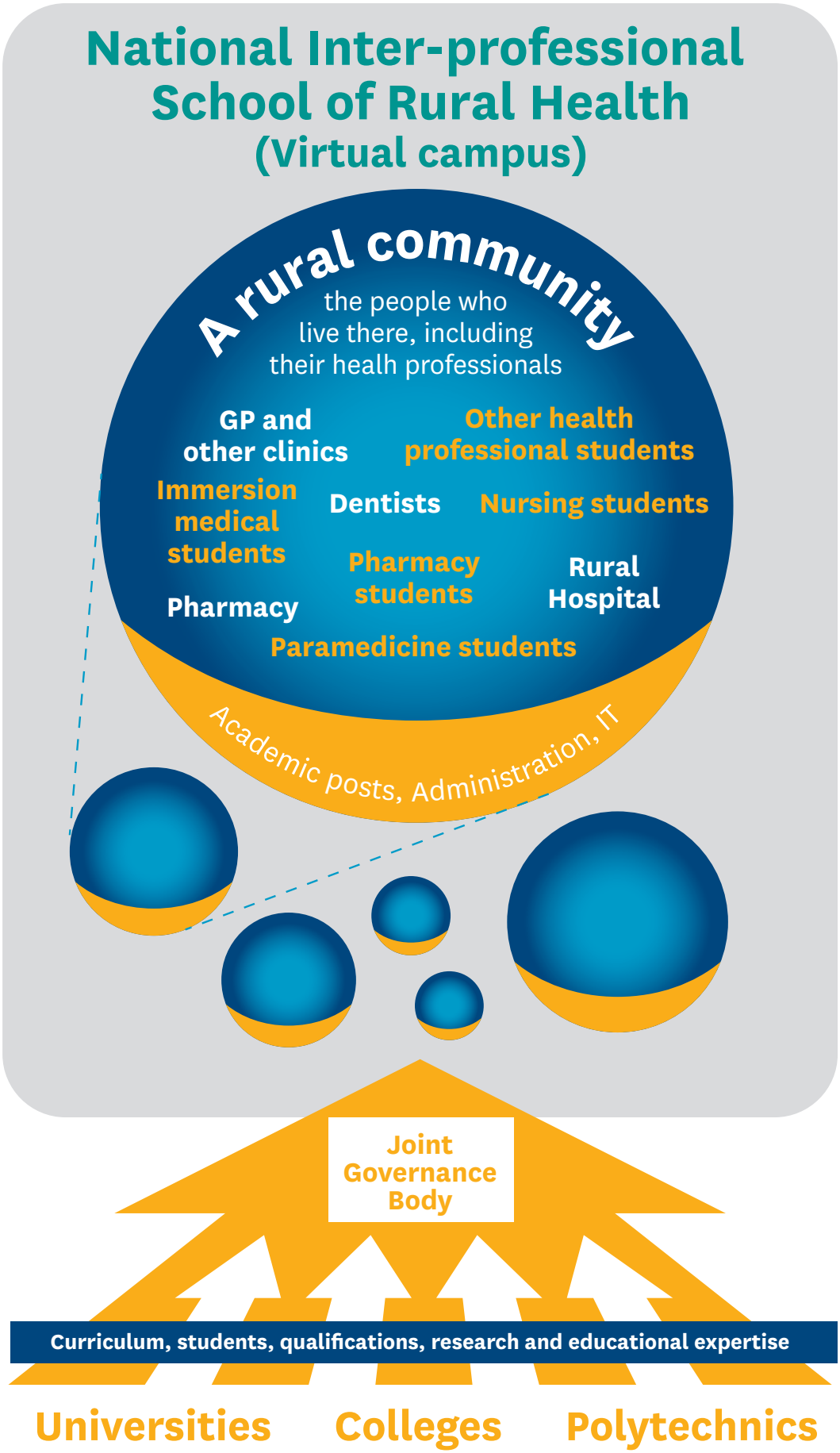
Furthermore, the NISRH would raise the profile, status and standards of generalist practice in health professional education and health service provision, maximising the potential role of generalist and community-based practice in the health services of the future. It would provide a structure that can feed a rural and generalist perspective back into the tertiary institutions, including their curricula. A NISRH would move the focus beyond workforce recruitment to workforce retention, research and leadership.

A NISRH would be a significant investment in the social fabric, institutions and economies of small town New Zealand.

**Figure 1:**

"The key seems to be the creation of a pipeline that reaches out to rural communities to encourage selection and success of rural students, gives them opportunities throughout medical school and residency to work in rural settings, and supports them in practice after they do settle in rural areas. This coupled with a medical school and residency training environment that values generalism, community responsive practice and rural life is a recipe for improving the flow of medical practitioners to underserved rural areas"[37]

**Figure 2:**


National Inter-professional School of Rural Health
(Virtual campus)
A rural community
the people who live there, including their healh professionals
GP and other clinics
Other health professional students
Immersion medical students
Dentists
Nursing students
Pharmacy students
Rural Hospital
Pharmacy
Paramedicine students
Academic posts, Administration, IT
Joint Governance Body
Curriculum, students, qualifications, research and educational expertise
Universities
Colleges
Polytechnics

As indicated above, any new resource and, as more teaching and research are undertaken rurally, more of the existing funding will be spent directly in the nodes in rural New Zealand. This is an important aspect of the proposed NISRH in terms of counteracting migration, as loss of professionals and their families has far reaching effects on rural towns. Experienced rural health professionals would be given opportunities to advance their careers without having to shift back to the city, often at a time when secondary schooling for their children is pushing them in that direction. The potential benefits of this proposal are as much about sustaining rural towns as about stemming the loss of experience and leadership from the local health services.

# Conclusion

The NISRH proposal leverages existing tertiary institutions, avoiding the need to duplicate infrastructure that exists on the main campuses. It focuses on workforce redistribution without increasing the overall size of the workforce. It is not an additional tertiary education provider but an 'enabling body' collectively owned by the existing institutions that, by sharing human, physical and other resources, would permit them to educate students in rural communities in ways currently not possible. It links rural health professionals into the educational, research and clinical expertise already contained in urban institutions.

The model is based on Australian cooperative models, involving two or more universities, which successfully deliver high-quality health professional education and research across multiple rural sites.[22–23] It is however a uniquely New Zealand model that is cognisant of our small size, resources, unique geography and already crowded opportunities for clinical attachments. The need here is for a cooperative and integrated solution. The national whole-system approach incorporating undergraduate and postgraduate education for a range of health professional groups and institutions is a significant innovation.

**Competing interests:**
Nil.

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# Mana Tū: a whānau ora approach to type 2 diabetes

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## ABSTRACT

In 2017, the National Hauora Coalition, a Māori-led Primary Health Organisation (PHO), was awarded a Long-Term Conditions Partnership Research grant to test the effectiveness of Mana Tū: a whānau ora approach to type 2 diabetes. With moves to replicate aspects of it in programmes around New Zealand, it is timely to describe the rationale for Mana Tū and the key components of its unique model of care. Mana Tū was developed in response to current ethnic and social inequities in type 2 diabetes rates, outcomes and wider determinants. It attempts to address various system, service and patient factors that impact on the whānau's ability to 'mana tū' or 'stand with authority' when living with a long-term condition. Results, including clinical, implementation and cost-effectiveness data, will be collected and analysed over the next two years.


Type 2 diabetes is a major long-term condition in New Zealand. Importantly, for every type 2 diabetes indicator, there are significant ethnic inequities with Māori, the indigenous people of New Zealand, and Pacific and Indian peoples, most affected.[1] Type 2 diabetes incidence, hospitalisation and mortality rates are increasing in New Zealand,[2] as are ethnic disparities.[1] Of note, Māori, Pacific peoples and people living in areas of high deprivation are at increased risk for poorly controlled type 2 diabetes (defined here as HbA1c >65), have higher hospital admission rates with diabetes complications and have more severe diabetes-related illnesses.[1,3]

Achieving equity in Type 2 diabetes outcomes requires a comprehensive and determined approach to ensure we "measure it, understand its risk factors, develop valid and efficient approaches to screening and diagnosis, and develop and implement culturally specific interventions for prevention and treatment".[2] Primary healthcare is key but to date much of the focus for primary care funders, planners and providers has been on doctor and nurse-led prevention, screening and diagnosis, education and starting medical management including initiation of insulin.[4] Importantly, there are few proven effective interventions in the community for managing poorly controlled type 2 diabetes.[5] Most research to date has focused on tailoring the medical management model[6] with mixed results for Māori and Pacific peoples.[1,2]

## Development of an evidence-based kaupapa Māori programme for diabetes in primary care—Mana Tū

In 2010 the National Hauora Coalition (NHC), a Māori-led Primary Health Organisation (PHO) based in Auckland, convened an expert advisory group including consumers to develop an evidence-based kaupapa Māori programme for people and their whānau living with complex LTCs—the Oranga ki Tua (OKT) Advisory Roopu. Members included primary and secondary clinicians, rehabilitation and kaupapa Māori researchers and providers, health literacy experts and people living with long-term conditions including diabetes. Their remit was to design a primary care programme to support Māori and their whānau to 'live well' with a long-term condition.

Given the burden, and what appeared to be inertia in service development, a kaupapa Māori programme for type 2 diabetes—Mana Tū—was prioritised by the group. Mana Tū, meaning 'to stand with authority', is a mana-enhancing programme that supports people with poorly controlled type 2 diabetes to 'take charge' of it and its associated conditions. The OKT group designed a programme that aligned with recommendations in the *Equity of Health Care for*

*Māori: A Framework*.[7] Based upon literature in the field of quality improvement and research on improving access to health services for Māori, indigenous peoples and minority ethnic groups, the Framework provides guidance on key actions to be taken at health system and health service levels to achieve equitable healthcare for Māori. It is focused on long-term conditions including diabetes. Mana Tū was further informed by He Korowai Oranga's aspiration for 'Rangatiratanga' or people's right to participate in making decisions about their health and to have meaningful ways to decide how health services might be provided for their benefit.[8]

Mana Tū is based in primary care and has three major components: a Network Hub, Kai Manaaki (skilled case managers who work with whānau with poorly controlled diabetes) and a cross-sector network of services to whom whānau can be referred to address the wider determinants of health. The Network Hub supports the delivery of the intervention through training of Kai Manaaki, referrals management, cross-sector network development and quality improvement of the programme. Mana Tū works across the three—system, service and individual/whānau—levels described above. More detail about the specific elements for each of the three levels is provided below and although we have attempted to ascribe elements to one level, as set out in the Framework[7] and He Korowai Oranga[8], many will sit across two or three system level elements, including Māori leadership, a focus on health equity and addressing wider determinants including discrimination. Service level features for Mana Tū are the Network Hub, its workforce of Kai Manaaki, integrated primary care and information management. Individuals and whānau are empowered in the 'taking charge', whānau ora and 'the journey' factors of Mana Tū that impact on the whānau's ability to 'mana tū'.

## System level

*Māori leadership*, defined as "championing the provision of high-quality healthcare that delivers equity of health outcomes for Māori",[7] is a key factor in successful health programmes.[9,10] At the system level, Mana Tū has demonstrated Māori leadership by engaging Māori governors, developers and providers; setting health equity as a clear expectation; putting in place monitoring and evaluation mechanisms[7] including kaupapa Māori research methodologies,[11] and training its workforce to be responsive to the needs and aspirations of Māori.[7] Importantly, optimal health outcomes will not be achieved unless there is a system-wide commitment to supporting it. Therefore, Mana Tū promotes Māori leadership and system responsibility.[7]

Mana Tū also aligns with the Government's priorities for health research and service development that contributes to Māori health and eliminates health inequities.[12] Achieving *health equity* requires a primary healthcare system that is committed to mitigating rather than extending diabetes inequities.[11] Evidence suggests that health interventions designed specifically for those 'currently missing out' will ultimately achieve health gain and equitable outcomes for all.[13] Those currently 'missing out' in terms of receiving quality type 2 diabetes care that achieves equitable outcomes are Māori, Pacific peoples and people living in communities with markers of socio-economic disadvantage; and people with pre-diabetes.[1] Therefore, Mana Tū was designed by and for these people. The potential benefits of achieving health equity, when realised by our people, our health system and our society, are clear.

However, achieving health equity requires more than just addressing the immediate cause of disease. A focus on the socially determined conditions in which people grow, live, work and age,[14] also known as the *wider determinants* for health, is required. All societies have social hierarchies in which resources, power and privilege are distributed unequally. However, the idea that this is inevitable or immutable not only harms the nation's population and its economy,[14] but is unjust and discriminatory. Mana Tū specifically asks people about the wider determinants that impact on their wellbeing, and provides a Network Hub for relevant sectors (eg, education, housing, justice) to engage with people and their whānau. In doing so it attempts to address the wider determinants in ways that support people's freedom to lead lives in which they feel valued.[14]

In hui held with whānau, clinicians, funders, researchers and policy makers during the development and implementation of Mana Tū, stakeholders were clear that improved outcomes for Māori

and Pacific people require identifying and addressing *discrimination* in the health and social care system. Stakeholders' reports align with the literature: discrimination occurs at policy, funding and service levels in both health and social settings.[15,16] This creates a context in which the social issues are often not addressed, where Māori and Pacific peoples do not feel safe when engaging with the health or social services, further compounded by a system with no clear commitment to sustainable funding for approaches to LTC management that target these issues. Mana Tū seeks to tackle discrimination by working with decision-makers and providers at regular and formal meetings, building evidence, providing ongoing education and working through examples of better practice.

## Service level

Mana Tū's *Network Hub* stemmed from previous NHC experience leading and implementing successful large-scale whānau ora programmes and initiatives such as Mana Kidz and AWHI.[17] In these programmes, care is delivered by a diverse range of providers within a network of contributing stakeholders and the Hub's role is to provide equal access to quality clinical care, population health activity and services that address social determinants in a connected way.[18] The Mana Tū Hub has a critical organising function which supports the delivery of the intervention across multiple providers, including general practice clinics and district health boards, education, housing and social programmes. It also operationally supports Mana Tū delivery through the provision of Kai Manaaki workforce training and development, programme design and implementation, clinical leadership, project management, service quality improvement and data management. The Hub is supported by a network lead manager along with information management and analytical support.

The evidence for case managers or community health workers working with individuals on clinical indicators and in geographically isolated areas to improve health outcomes is well established.[19–21] Mana Tū has engaged *Kai Manaaki* to provide case management via the person's GP clinic. Kai Manaaki are unique in that they also undertake case management with family/whānau; and in ways that support people to take charge of the clinical conditions and the social determinants of wellbeing.[22] The six Kai Manaaki have a range of diabetes-related backgrounds including nursing, social work, educators and community workers. In addition to the 'usual' training about diabetes and its management, KM are trained in motivational interviewing, cultural safety and health literacy. Kai Manaaki live and contribute in the local communities with whom they are working, currently across metro-Auckland and in Whangaroa in Te Tai Tokerau. Importantly, they meet regularly for peer support and review,[23] quality improvement activities and mentorship with qualified health professionals[24,25] and are provided with other capacity building opportunities (ie, conferences, report writing).

Patients receive regular home visits from Kai Manaaki over a period of 12 months. During these visits, patients have ample time and support by Kai Manaaki to express any clinical issues related to their condition, as well as social or psychological issues. This information informs the next steps in which the Kai Manaaki work with the person's primary care clinician to refer onto appropriate services. The Kai Manaaki manages the referral process, supporting the patient into and through it. The patient receives both clinical and social support that otherwise may not have been identified or offered in standard care.[22]

Key to the success of Mana Tū is its *integration in primary care clinics* rather than being co-located or coordinated.[26] Although studies have shown that a greater degree of integration between primary and secondary healthcare improves patient outcomes,[26] evidence has also highlighted issues with, and therefore lack of, integration of horizontal care necessary to manage the spectrum of clinical, psychological and social determinants of LTCs with patients and their families.[27] The whānau ora approach in the title speaks to Mana Tū's role in cutting across multiple sectors, services, providers and settings to enhance quality of care and quality of life for people with complex, long-term health issues and their whānau/families.[28] Integration of the Kai Manaaki into GP clinics has the added benefit of ensuring that the relationships between Kai Manaaki and health and social care professionals are maintained and nurtured.[29]

Mana Tū utilises *a sophisticated information platform* to allow innovative data capture in general practice and patient home visits. Mōhio is a clinical platform developed by the NHC and is designed to support general practice and PHO information management, claims, referrals, compliance reporting, budget management and clinical decision support and analysis. The Mōhio system has been further developed specifically for the Mana Tū programme to allow Kai Manaaki to regularly capture patient progress on a mobile tablet device. All data is stored in a secure server, with live reporting enabled to feedback to practices. Mōhio is efficient and innovative in the way it collects, analyses and views patients' data and progress.

## Individual and whānau

Self-management or *taking charge* is fundamental to supporting people live well with diabetes;[1] yet SM is difficult for people with type 2 diabetes to sustain. Successful self management programmes with indigenous people are culturally safe, relevant, community-based and focused on small changes over longer periods of time.[5] Previous research with Māori and Pacific peoples living with another long-term condition (stroke) tested the effectiveness of a programme with these elements and found that the ability to direct aspects of one's life with a long-term condition or to 'take charge' was highly valued and associated with a better quality of life.[22] Mana Tū has incorporated features of the Taking Charge intervention, including a full initial assessment and prioritised self-directed goal setting based on the assessment. The assessment includes clinical, social, health literacy and whānau-wellbeing related questions that are validated and reliable; and specifically seek whānau participation.[30] Importantly, by going through a checklist, listening and facilitating the process where the person and their whānau identify opportunities to take charge, people take ownership and are more engaged about living with their long-term condition.[22] Feedback on goals is provided at regular, agreed-to intervals including blood test results, which are reported back to patients and their clinician every three months in keeping with best practice.[5]

'Patient' factors include *family/whānau and community engagement,* as the evidence is overwhelming that this will enhance diabetes outcomes.[31] As a result, there are calls to introduce interventions that address family support and functioning in diabetes management plans.[1] Involving whānau is also a great opportunity to engage others, particularly those at risk, in activities to prevent type 2 diabetes, including slowing the progression of pre-diabetes to diabetes.

**Figure 1:** The Mana Tū Journey.

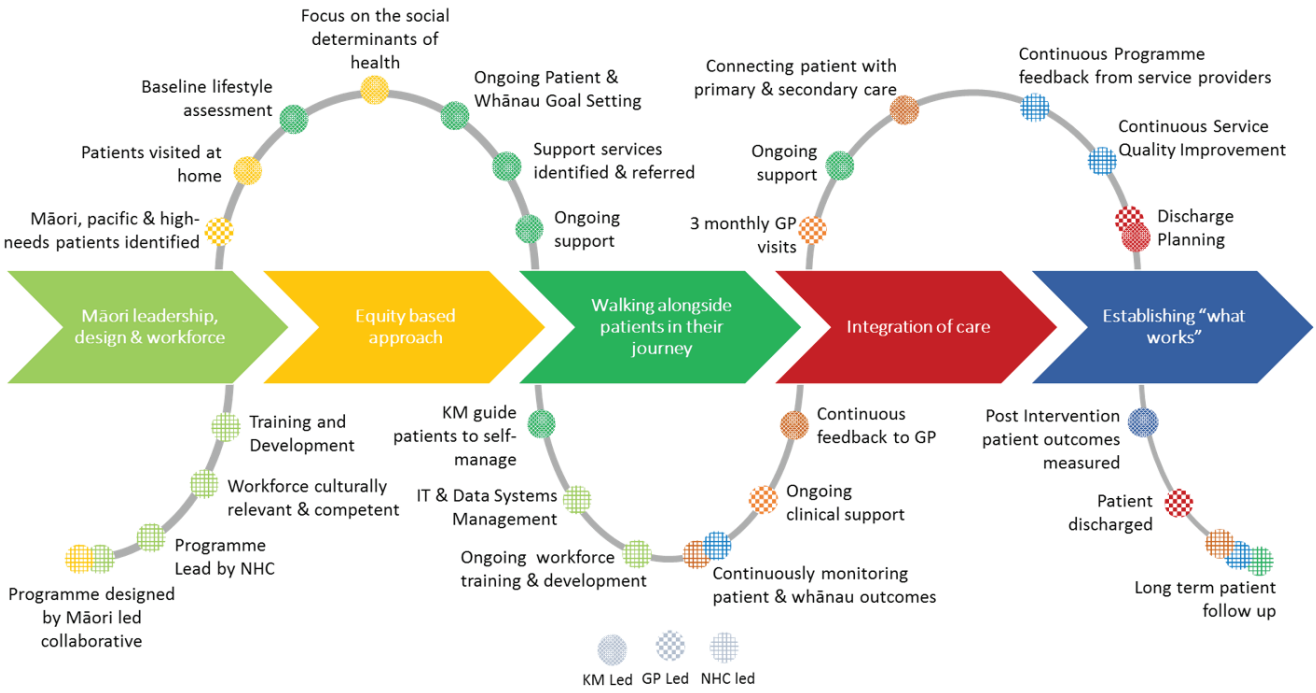




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**Table 1:** Mana Tū framework for change.

**Programme goal:** To support general practice to establish an environment in which discrimination is addressed in order for patients and whānau engage in improving their health and social outcomes.

**Theory of change:**

- The Kai Manaaki will support the patients and whānau to determine goals and access services to achieve those goals
- Addressing institutional discrimination within the health system will help improve patient engagement and trust in the practice
- Support is required to help general practices support their patients in improving social outcomes
- Improving engagement with the practice will improve diabetes self-management
- Building linkages across health and social agencies will support patient engagement
- Building an evidence base for Mana Tū will support sustainable funding

| Context and need | Inputs | Activities | Outputs |
|---|---|---|---|
| • There are poor outcomes for Māori and Pacific peoples<br>• There is a variable quality of care, with social issues often not addressed<br>• There is systemic institutional racism within the health system<br>• Many Māori and Pacific peoples distrust the health system<br>• There is a mismatch between clinical services and the person's needs<br>• There is not a commitment to sustainable funding for innovative approaches to LTC management | • 5 FTE of Kai Manaaki<br>• 1 FTE network manager<br>• .5 FTE research manager<br>• Central IT hub<br>• General practices and patients and whānau<br>• Tablets for collection of patient information<br>• Programme team support for resource development and administration for Kai Manaaki | • Referrals from general practices to programme<br>• Promotion of the programme on brochures, videos, website, and patient information sheet<br>• Patients enrol in programme<br>• Kai Manaaki visits the patient to start working on goals<br>• Goals are identified and Kai Manaaki accesses services and resources to support goals<br>• Kai Manaaki visits patient six times over a 12-month period<br>• Patient receives health literacy training<br>• General practices receive decolonisation training workshops<br>• Kai Manaaki meet quarterly to discuss programme outcomes and area for quality improvement<br>• Promotion of Mana Tū success stories on NHC communications and media | • General Practices enrolled in programme<br>• Patient goals developed<br>• Action plan implemented<br>• Central hub established and functioning<br>• Network of social agencies established<br>• General Practice staff engaged in programme<br>• Kai Manaaki visit both patient and whānau |

**Outcomes**

**Short-term outcomes**

- General practice commitment to enrolling and participating in programme
- Increased awareness and understanding among general practice teams about identifying and addressing social needs
- Improved feedback into practices on patient outcomes
- Improved patient clinical outcomes
- Increased sense of understanding and feeling heard by the patient
- An improved experience of the clinical engagement
- An improved treatment and management plan
- Kai Manaaki principally responsible for the LTC management
- General practices better able to support whānau/patients to better enable the management of diabetes

**Medium/longer-term**

- Patients have improved literacy
- Whānau are thriving as a result of meeting goals
- Patients are self-managing increased multi-disciplinary team practice within the general practice setting
- Increased trust among whānau of the general practice environment
- Patients lead healthier lifestyles
- Improvements in social determinants, eg, employment, education, housing
- There is stable and secure funding for Mana Tū
- Reduced hospitalisations
- Social issues are identified and addressed
- Changes in attitudes and behaviours within the general practice setting in regard to the needs of Māori and Pacific people and their families
- Reduced intergenerational diabetes

| Enablers | Challenges |
|---|---|
| • Clinical champion in practices<br>• Whānau champions<br>• There is a number of funding channels available<br>• NHC has a track record of designing programmes that are effective<br>• A focus on whānau moko | • There is an obesogenic environment<br>• There is a near total reliance on Kai Manaaki as relationship brokers<br>• A need to address the wider social determinants of health<br>• Patient can be hard to reach and engage<br>• Limited understanding on what drives the range of social agencies that Mana Tū needs to work with<br>• There is turnover of staff in social agencies, which creates a need to be renewing relationships<br>• A focus on mental health is currently lacking in the Mana Tū design |

Finally living well with a long-term condition such as type 2 diabetes is *a journey*[1] over time. The duration of navigator-type interventions for long-term conditions reported in the literature ranges from 1–18 months.[32] Careful consideration was given to the duration of Mana Tū and 12 months was deemed suitable to see changes in clinical indicators.[29] Mana Tū seeks to commence discharge planning at nine months, well within the 12-month limit. It also provides for patient-led exits at any point in the 12-month programme and possible re-entry and/or support to access other services. Therefore, it is important that all (patient, whānau, Kai Manaaki and health and social providers) have a clear expectation of Mana Tū and its role in setting people up with tools and skills for life. As Figure 1 shows, Mana Tū is a series of pragmatic steps to support the person's journey across all three levels.

## A framework for change

Notably, the overarching programme goal for Mana Tū is *change*. A Mana Tū framework for change was developed which brings all three levels (individual/whānau, service, system) together (Table 1) to improve a set of short- and longer-term outcomes. In the short term (12 months), improved engagement from general practice with Mana Tū will improve their understanding about addressing the wider determinants. This leads to the patient feeling they are understood better, leading to an improved experience of their clinical engagement and subsequently improved clinical outcomes.In the longer term (1–3 years) Mana Tū is designed to have impacts for the whānau of the patient, with increasing levels of trust of the general practice environment, and improvements in social determinants (eg, employment, education, housing). The programme aims to have broadened attitudes and understanding in general practice, particularly with regard to its responsibilities to meet the rights of Māori and Pacific peoples to excellent healthcare and outcomes. Finally, as a result of whānau meeting goals there will be a reduction in hospital resource utilisation.

## Evaluation and next steps

In 2017 the NHC was awarded a Long-Term Conditions Partnership Research grant (Healthier Lives National Science Challenge Health Research Council and Ministry of Health[33]) to test the effectiveness of Mana Tū. The study is registered with the Australia and New Zealand Clinical Trials Register (ANZCTR registration number 12617001276347) and has ethical approval (HDEC 17/NTB/249). The research is part-way through—recruitment commenced in March 2018 and full results will not be available until 2020.

The funded research project is also distinctive and has four separate studies: (1) a cluster randomised controlled trial with 400 participants across 10 GP clinics, the primary clinical outcome being a reduction in HbA1c at 12 months; (2) qualitative research that explores the implementation process from an indigenous perspective,[34] including acceptability, adoption, fidelity, penetration and sustainability; (3) an investigation of the efficiency and cost effectiveness of Mana Tū; (4) qualitative interviews with clients and their whānau regarding their aspirations and how well Mana Tū met them. Each study is conducted over the programme's timeframe of 12 months, and outputs from each inform the other. Additional research regarding the Kai Manaaki, to be undertaken by a PhD student, will provide important information about how they work. With multiple requests to replicate aspects of Mana Tū in other services and programmes around New Zealand, it seemed timely to describe Mana Tū including its rationale and the key components of its unique model of care. However, the implementation of Mana Tū elsewhere is not recommended until the findings from its evaluation are available. The potential to report on wider benefits including a focus on the health of the population, enhanced patient experience and control of rising costs is worth noting. The tensions associated with these principles have been raised in a number of programmes for the management of long-term conditions and diabetes across New Zealand and with other indigenous populations,[35,36] and though many pilots are successful,[37] challenges are faced in scaling them up or transferring them to other contexts. The researchers plan to contribute to these critical knowledge gaps by gaining a better understanding of the features that make Mana Tū successful; and leading the development of strategies for scaling them up. We look forward to reporting the outcomes in 2020.

**Competing interests:**
Mana Tū is a foundation project of the Long-Term Conditions research funding partnership between Healthier Lives - National Science Challenge, Health Research Council of NZ and the Ministry of Health. Dr Matire Harwood's salary as principal investigator for Mana Tū is funded by this grant.

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# Surgical management of self-inflicted facial gunshot wounds

Katie Goad, Thasvir Singh

A 49-year-old male sustained a self-inflicted low-velocity gunshot wound to his mid and lower face. He had extensive hard- and soft-tissue injuries, including significant cervico-facial lacerations and comminuted fractures of his mandible and midface.

The relative rarity and complexity of this facial ballistic injury in New Zealand emphasises the importance of treatment protocols and early intervention, especially for those health practitioners working in rural or trauma centres.[1] An established treatment algorithm has been revisited for easy reference, which includes immediate lifesaving procedures as well as surgical management.[2]

## Case report

### Clinical presentation

Mr SW is a 49-year-old male who was transferred to Waikato Hospital Emergency Department with a self-inflicted gunshot wound to his mid and lower face after an attempted suicide. He was GCS 15 with signs of hypovolaemic shock that improved after medical management, but he had difficulty maintaining his own airway. He had a 2cm submandibular entry wound with a large midface laceration and exit wound. Mr SW had extensive loss of his left hemi-maxilla, comminuted fractures of the midface and mandible, as well as extensive soft tissue injuries to the floor of mouth, tongue and midface (Figure 1). He had a medical history

**Figure 1:** Intraoperative photos from initial injury.

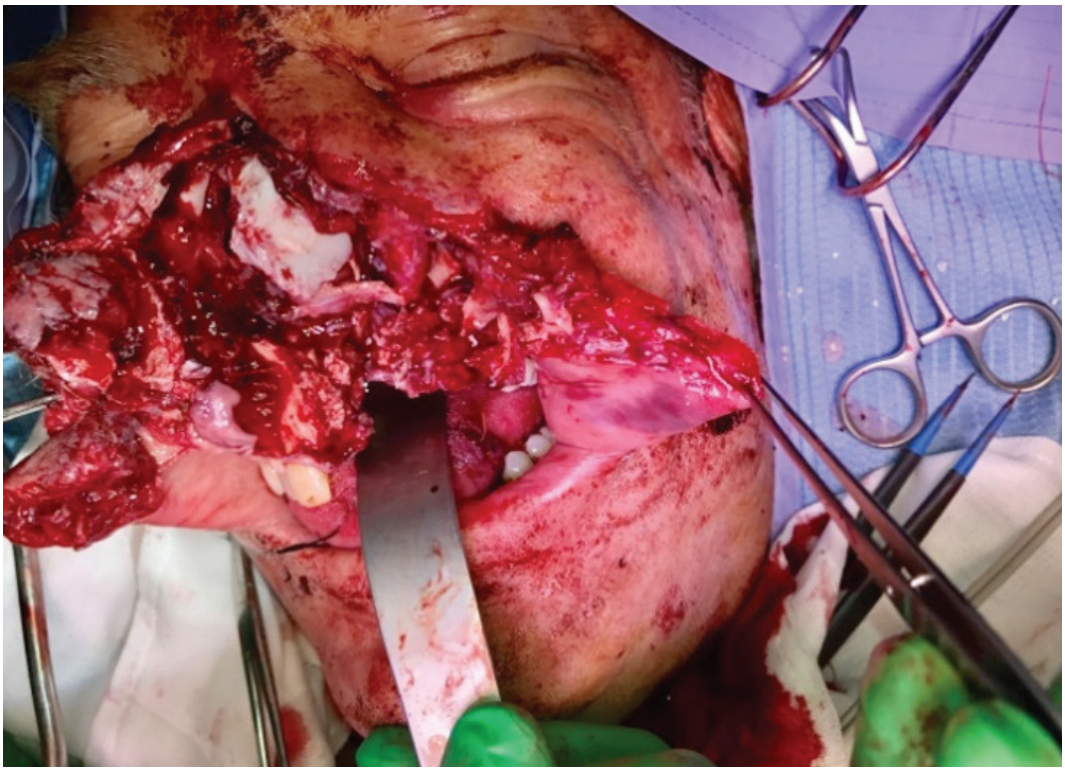


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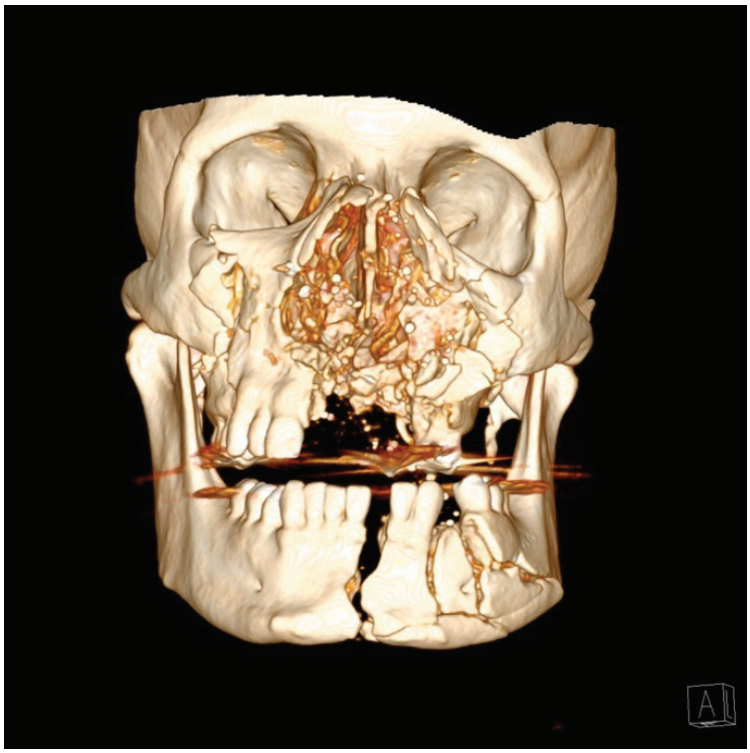
**Figure 2:** 3D Computed Tomography scan showing comminuted fractures of both mid and lower face with extensive shrapnel throughout.



of epilepsy, undiagnosed/non-medicated depression and excessive alcohol intake.

## Management

Ongoing blood loss and developing swelling compromised his airway, so he underwent a cricothyroidotomy. His facial wound was packed and tacking sutures placed to achieve haemostasis, while receiving a concurrent a blood transfusion. CT showed comminuted fractures of the midface and mandible (Figure 2) with extensive shrapnel throughout the wound.

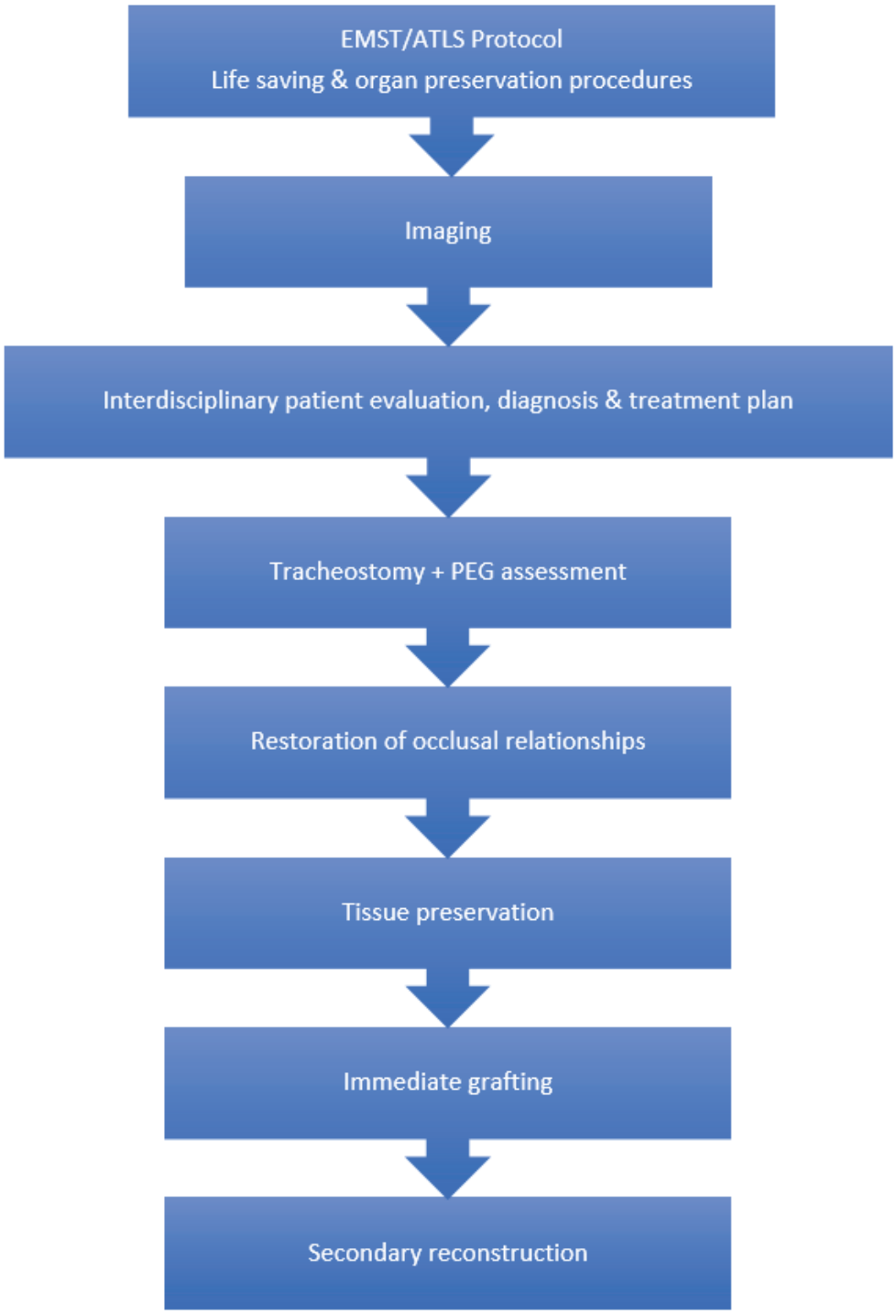
Mr SW immediately attended emergency theatre with the maxillofacial surgery service for haemorrhage control, initial debridement, fracture stabilisation and a surgical tracheostomy. Mucosal and tongue lacerations were closed and haemostasis achieved.

Four days later he underwent definitive and early open reduction and internal fixation of his mandible, with subsequent fixation of his midface fractures six days later. He underwent four further operations resulting in a six-week hospital admission. At each procedure he required ongoing debridement of developing necrotic tissue with antiseptic packing to ensure health of the surrounding tissue. Nutrition was provided via nasogastric tube initially, which was converted to a radiologically inserted gastrostomy prior to discharge. The mental health team was heavily involved and he remains under close follow up in the community where he is well supported and no longer has suicidal ideation. Mr SW currently has satisfactory facial form and function with the aid of a maxillary denture. This will be drastically improved once he undergoes the final stages of his facial reconstruction, which will aim to close his oro-nasal defect prior to a post-traumatic rhinoplasty.

# Discussion

In New Zealand in 2016, there were 168 head and facial gunshot ACC claims approved.[1] These generally require extensive treatment, involving multiple specialties.[3] Countries, such as America, have such a high gunshot injury rate that they have developed specific protocols for their management. Peled[2] designed a treatment protocol for high-velocity facial injuries (which incorporates the advanced trauma life support[4]), and gives an overall protocol for patient management. This was demonstrated in our management of Mr SW (Figure 3).

**Figure 3:**




Definitive management of facial gunshot wounds is still controversial, treatment is moving away from a conservative approach with delayed hard tissue reconstruction, to primary fixation of the hard and soft tissues completed at the time of debridement.[5] The theory behind allowing soft tissues to heal before hard tissue reconstruction is that the chance of postoperative infection is lower, but it does risk long-term tissue contraction, complicating definitive reconstruction. Recent studies have been advocating for single stage management with successful results, which was proven in this case.[5–7] Hopefully these injuries continue to remain uncommon in New Zealand, however health professionals working in either Trauma or rural centres should be familiar with initial inter-disciplinary treatment and long-term management.

**Competing interests:**
Nil.

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# A population-based study of the diabetes paradox in stress cardiomyopathy

George M Watson, Christina W Chan, Kit Doudney, Paul G Bridgman

Three reports have suggested that there is a decreased rate of stress cardiomyopathy (broken heart syndrome) in patients with diabetes.[1–3] There is speculation that early diabetic autonomic neuropathy could protect against stress cardiomyopathy by impairing the autonomic nervous system that links the brain and the heart. This possible protective effect of diabetes in the face of its many negative effects has been termed the diabetes paradox. We undertook a New Zealand population-based study exploring the incidence of stress cardiomyopathy in diabetics and non-diabetics.

All patients aged >40 years registered in the Canterbury, Pegasus and Rural Canterbury Primary Health Organisations (PHOs) are invited for a cardiovascular health check that includes diabetes screening. From this screening a central registry of incident diabetes is maintained. Diabetes is defined as HbA1c of >50mmol/mol. Three major earthquakes have precipitated case clusters of stress cardiomyopathy in Christchurch.[4,5] Since 2010 we have prospectively maintained a registry of earthquake and sporadic cases meeting modified Mayo diagnostic criteria.[6] We cross-referenced the two databases, restricting to women aged >65 years as stress cardiomyopathy predominantly occurs in post-menopausal women.[6] Approval was obtained from the Health and Disability Commission Ethics Committee, reference number URA/11/07/033/AM03.

From our registry of 160 cases of stress cardiomyopathy, 26 women were excluded for being too young and 35 were excluded as they had not undergone the primary care diabetes screening. Ninety of 39,402 non-diabetic patients had stress cardiomyopathy, a rate of 0.0023. Nine of 5,093 diabetics had a stress cardiomyopathy, a rate of 0.0018. The p value for rejecting the null hypothesis of a 20% difference was 0.51. Thus the rates of stress cardiomyopathy among non-diabetics and diabetics were similar.

The previous studies were retrospective and had no formal or consistent definition of diabetes. Additionally, in the earlier studies the background population diabetes rates used were not specific or age matched to the case population. For instance, one publication has compared the rate of diabetes in a collection of global cases reports of takotsubo patients with the rate in an unmatched United States National Health and Nutrition Examination Survey.[7] Such a comparison is almost meaningless. In our study we applied prospective definitions for diabetes and stress cardiomyopathy to a defined population of over 44,000 women. The rates of stress cardiomyopathy in diabetics and non-diabetics were very similar, but with wide confidence intervals. In our New Zealand data we have found no evidence for the diabetes paradox, but note that our data does not disprove the hypothesis. A limitation of our work is that we have no data on the type and severity of the diabetes, nor knowledge of any therapy or presence of neuropathy. This weakness arises by nature of the study design that uses the available prospective community diabetes database. That same design gives the study a unique strength in this area of research, prospective and uniform classification of diabetic status. This highlights the difficulty of this type of research and that further study will be required to determine if the paradox is indeed real.

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# Do interns publish findings of their scholarly research projects?

Yassar Alamri

Studies addressing junior medical staff involvement in research have been a focus of investigation for upwards of two decades;[1] has the new generation of young medical practitioners come any closer to a satisfactory level of research engagement?

The Accreditation Council for Graduate Medical Education in the US requires active participation in "a scholarly activity" by residents.[1] Similarly, Guidance by the UK's General Medical Council stipulates that it is unethical to forego the dissemination of findings of well-conducted research.[2] Scholarly research projects may encompass quality-improvement audits as well as hypothesis-driven research. Dissemination of research findings thereof can take the form of a conference presentation or peer-reviewed publication.

While departmental and conference presentations of results from research projects serve as acceptable means of conveying findings to colleagues and interested audiences,[3] their scope remains limited—both temporally (ie, time of presentation) and spatially (ie, location of presentation). Publishing research findings remains the quintessential method by which scientific findings are communicated[4] and may reflect a higher degree of academic rigour.[5]

There exists a plethora of data on resident (or registrar) involvement in research activities. Data on intern involvement, on the other hand, are relatively sparse. Internship remains a steep learning curve for most newly qualified doctors.[6] Stretching over one to two years, these inexperienced doctors are expected to participate in educational activities including independent study, acquire new clinical skills as well as undertake scholarly research.[7]

## Current state of intern research

Several studies have repeatedly shown that a majority of medical students are eager to be involved in research.[8] Data on research involvement and dissemination by interns, however, are lacking. In one of the very few studies on intern research, Fancher et al found that engaging interns in a research rotation significantly increased published articles, conference presentations and research awards.[7]

We recently examined research output by interns in two cohorts: one from New Zealand and the other from Saudi Arabia. In brief, an investigation of publication output of a required research component (mandatory audit or research project during a general medicine rotation) by interns from a single-centre in New Zealand uncovered only two publications over a five-year study period. Surveys of self-selecting 56 interns from Saudi Arabia yielded 10 publications over a two-year period. Although useful rough estimates, the results of these studies should be interpreted with caution as the two studies differ in several significant ways.

First, New Zealand interns were required to complete a mandatory research component during a limited time-frame (13–14 weeks). Research by Saudi interns, on the other hand, was self-initiated and spanned over a longer period (up to two years). In addition, whereas the study of New Zealand interns was a systematic review of an available database, interns from Saudi Arabia were invited to participate in the study survey. It is possible that interns with the most research experience (56 out of a possible 400) self-selected to participate in our study.

## Barriers and solutions

Previous studies have identified several barriers to research involvement by residents/registrars—these can also be extrapolated to apply to interns. A useful framework to think about such barriers is whether they are modifiable (and may therefore be solved) or non-modifiable (eg, lack of pre-internship research experience[5]). The focus below is on modifiable barriers.

Lack of time is one of the most commonly cited reasons to conducting research by medical trainees.[5] How this affects the quality and 'publishability' of research is unknown. However, provision on protected research time has failed in and of itself to produce an appreciable increase in research productivity in several studies.[9] Lack of intellectual (eg, statistics), mentoring and financial support also represents a significant barrier to many.[3,9] Finally, lack of interest in or loss of motivation towards research can be obstacles to intern research. One of the main motives of medical students to engage in research is career progression and enhancing chances to get into residency.[8] It is conceivable that once medical students attain a position in their training of choice (ie, become interns), the drive is lost.

Addressing these barriers requires an orchestrated approach involving multiple parties. Medical educators ought to instil the passion for research from the early phases of a medical student's career. Certainly, intrinsic interest in research has been shown to be one of the most powerful predictors of continued research involvement as medical trainees progress through their careers.[8] In addition, instituting purpose-designed research programmes with the required supports to lessen intellectual and financial barriers can go a long way in helping junior trainees carry and publish high-quality research.[5] Finally, providing interns with protected research time, with adequate infrastructure and support in place, may circumvent problematic time limits and clashes identified in earlier studies.[7]

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# Failure to refer

## Charge

The Health Practitioners Disciplinary Tribunal considered a charge of professional misconduct laid by the Director of Proceedings against Dr H, registered medical practitioner (The Doctor).

Particular 1 of the charge alleged that on four separate occasions when the patient who was over 50 years of age presented with dysphagia and or continuing weight loss, the Doctor failed to refer the patient for an endoscopy and/or to a specialist. Particular 2 of the charge alleged that the Doctor failed to communicate adequately with the patient to clarify his symptoms.

The Doctor accepted she failed to properly refer the patient to a specialist or for an endoscopy. She believed she was blinkered by her initial diagnosis of gastritis. However, she accepted that by the third consultation a referral for gastroscopy should have been done. There was no admission that this was professional misconduct, simply, that it was negligence at that point not to have made the referral.

## Finding

The Tribunal found that Particular 1 of the charge was established as professional misconduct, warranting disciplinary sanction. It was satisfied that the failure to refer was negligent from the outset at the first consultation and remained so at each of the successive consultations.

The Tribunal found Particular 2 of the charge not established and that the Doctor had not failed to communicate as charged.

## Penalty

The Tribunal censured the Doctor and order her to pay 30% costs of an incidental to the costs of the Tribunal and the Director of Proceedings amounting to $21,636.

The Tribunal ordered permanent suppression of the Doctor's name and directed publication of its decision and a summary.

The Doctor appealed the decision of the Tribunal to the High Court. The appeal was dismissed *H v Director of Proceedings* [2018] NZHC 2175

The full decision of the Tribunal can be found at

http://www.hpdt.org.nz/ChargeDetails.aspx?file=Med17/378D

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# Risks and benefits of direct oral anticoagulants versus warfarin

The objective of this prospective cohort study was to investigate the associations between direct oral anticoagulants and risks of bleeding, ischaemic stroke, venous thromboembolism, and all-cause mortality compared with warfarin.

The participants were recruited from UK general practices and included 132,231 warfarin, 7,744 dabigatran, 37,863 rivaroxaban and 18,223 apixaban users. The main outcome measures sought were major bleeding leading to hospital admission or death.

Overall, apixaban was found to be the safest drug, with reduced risks of major, intracranial and gastrointestinal bleeding compared with warfarin. Rivaroxaban and low-dose apixaban were, however, associated with increased risks of all-cause mortality compared with warfarin.

***BMJ* 2018; 362:k2505**

# Vitamin D supplementation in pregnancy and lactation and infant growth

It is unclear whether maternal vitamin D supplementation during pregnancy and lactation improves fetal and infant growth in regions where vitamin D deficiency is common.

Bangladesh is a country where such a deficiency is common. This report is of a trial which randomised over 1,000 pregnant women into five different groups. One group received neither prenatal nor postpartum vitamin D. Three groups received prenatal supplements only—oral vitamin D 4,200IU/week or 16,800IU/week or 28,000IU/week. The fifth group received prenatal as well as 26 weeks of postpartum supplements at a dosage of 28,000IU/week.

It was concluded that in a population with widespread prenatal vitamin D deficiency and fetal and infant growth restriction, maternal vitamin D supplementation from midpregnancy until birth or until six months postpartum did not improve fetal or infant growth.

**N Engl J Med 2018; 379:535–46**

# Excess mortality and cardiovascular disease in young adults with type 1 diabetes in relation to age at onset

People with type 1 diabetes are at elevated risk of mortality and cardiovascular disease, yet current guidelines do not consider age of onset as an important risk stratifier.

These researchers aimed to examine how age at diagnosis of type 1 diabetes relates to excess mortality and cardiovascular risk. 27,195 individuals with type 1 diabetes and 135,178 matched controls were selected for this study. They report that patients with type 1 diabetes with onset before 10 years of age had a 30-times increased risk of coronary heart disease and acute myocardial infarction compared with matched controls. Women with onset before 10 years of age had a 60-times increased risk of coronary heart disease and 90-times increased risk of acute myocardial infarction.

Age at onset of type 1 diabetes is an important determinant of survival, as well as all cardiovascular outcomes, with highest excess risk in women. Greater focus on cardioprotection might be warranted in people with early-onset type 1 diabetes.

***Lancet* 2018; 392:477–86**

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# Nervous Debility

October 1918

Classroom of school children. Ref: MNZ-2816-1/4-F. Alexander Turnbull Library, Wellington, New Zealand. / records/22735320

It is no exaggeration to state that the majority of professional and business men in this country are neurasthenic. Manual workers are not driven at the same pace, and have abundant opportunity for recreation, but "class-consciousness" and dissatisfaction with their lot in life has caused widespread nervous disorder amongst working-men. The American maxim of "Push or be pushed" is so generally observed that there is insufficient time for rest and repair. It is worthy of note that our New Zealand soldiers are as liable to nervous disorders as British troops; the conditions of life in this country are in many ways less pressing and irksome, and the comparison ought to be altogether in our favour. Worry and nerve strain are the principal causes of insomnia and indigestion and unhappiness generally. We need to learn the truth of the words of Othello, "Poor and content is rich, and rich enough." If we cannot bring our circumstances to our minds we should bring our minds to our circumstances, and this is the root of all philosophy. Our standards and ideals are wrong. Our minds run on "the plumed troop and the big wars that make ambition virtue," and deeds to be admired must be vigorous and prominent and public, and the more private virtues, more feminine than masculine, are held in little esteem. The common round and trivial task, devoid of

excitement and the public applause, does not furnish all we ought to ask, and many a stout fellow the pride of his platoon has not the character in civil life to attend diligently to his vocation or to avoid the ordinary temptations of life: he lacks tenacity, resource, self-control, patience, contentment, evenness of temper, a sense of responsibility to others, and is restless, nervous, and dissatisfied.

Neurasthenia and the like are sometimes acquired but more often hereditary. What can be done by way of prevention? First of all, proper care of the infant is necessary, and this is being well attended to by the Plunket Society. During school age little is being done that should be done in New Zealand. Children are sent to school too early. They are crowded together and often burdened with home lessons which are unnecessary and harmful during the primary stage of education. The Greek method of physical development during that stage is almost neglected. Tuition in good weather should be in the open air. The children, generally speaking, have insufficient sleep, and the daily expenditure of energy is not balanced by sufficient rest. Children, too, should have more intellectual and moral training. It is poor State economy not to provide enough teachers in the State schools to give the scholars individual attention and eradicate shyness or precocity, self-consciousness, introspection, and excessive emotionalism. Are the children in the schools taught that life is a hard task and not a playground or a dormitory, that (duty must not be avoided and conscience must be obeyed, that strength lies in quietness and in confidence? The cares and restiveness of the day should go down with the sunset, so that we may bring a fresh mind to the claims of the morrow.

It is very important that the pre-neurasthenic state should be recognised and treated, and it is very easily overlooked but much more amenable to treatment than when the disease is definitely and obviously established. Various pains, especially in the back, and headache, constipation, blushing, self-consciousness, irritability of temper, fatigue after slight exertion, are the main premonitory symptoms, and the treatment is at first rest at home for a week or two and then a holiday, and the demeanour and "atmosphere" of the physician is of more importance than the pharmacopeia. A patient afflicted in this way should be told how to order his occupation and his recreation and to take a good annual holiday for the rest of his working life, and sufficient time for sleep and for rest. It is sad to think that the doctor himself, more often than not, from the pressing claims of his vocation, cannot put into practice for himself his own advice, and is chained like Prometheus to the rock. It may be that this form of self-sacrifice has won for us such a tribute as Robert Louis Stevenson penned—and he had many dealings with doctors—"The physician is the flower (such as it is) of our civilisation; and when that stage of man is done with, and only remembered to be marvelled at in history, he will be thought to have shared as little as any in the defects of the period, and most notably exhibited the virtues of the race."

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