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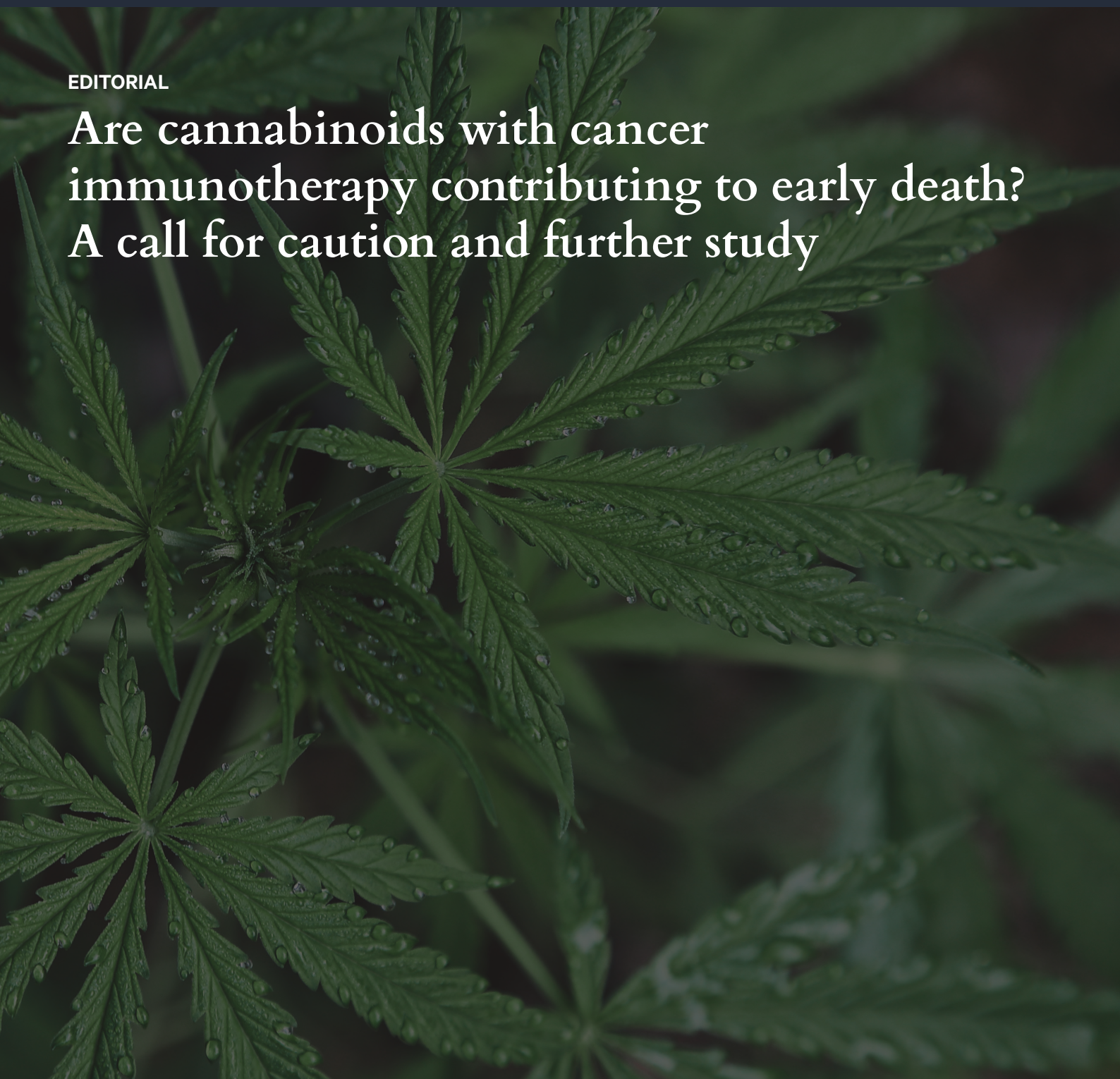

EDITORIAL

Are cannabinoids with cancer immunotherapy contributing to early death? A call for caution and further study

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Are cannabinoids with cancer immunotherapy contributing to early death? A call for caution and further study

Ben Jansen

Some cancer patients use medicinal cannabis to help with symptoms like pain, nausea or poor appetite. However, early studies suggest that using cannabis during immunotherapy—a type of treatment that helps the immune system fight cancer—might make the treatment less effective. These studies showed that patients who used cannabis had poorer responses to treatment and shorter survival times, but the research has several limitations, such as small sample sizes and other lifestyle differences like smoking. Most Australian patients take cannabis by mouth, unlike the inhaled forms used in these studies, so the results may not apply to everyone. More high-quality research is needed, and doctors should talk to their patients about the possible risks before combining cannabis with immunotherapy.

The need for palliative care in Aotearoa New Zealand

Catherine D'Souza

We are all going to die, but we might not be able to get the services we need to die peacefully. There are more older people in Aotearoa New Zealand, and so the number of people dying each year is going up, so we need more help looking after them. Good care at the end of your life is a human right, but in Aotearoa New Zealand not everyone can get what they need. What is available depends on where you live. We know that if you are able to see a team who are specialists in end-of-life care, it can increase the length of your life, plus the quality of your life—as well as that, it saves money as there are fewer unnecessary medical treatments that you might not want.

Acceptability of "The Hui Process" at the Faculty of Dentistry

Te Rauhina Jackson, Ieremia Tuivaiti, Esther Willing, Kuramaiki Lacey

This exploratory study investigated the acceptability of "The Hui Process", a Kaupapa Māori clinical framework, in final-year undergraduate dental clinics at the Faculty of Dentistry in Aotearoa New Zealand. A total of 47 participants completed the survey. Results showed that most dental students incorporated The Hui Process in their clinical consultations, and that this was important to participants. Most participants were satisfied that their needs were met by their dental students, and all participants felt culturally safe. To our knowledge, this was the first study to assess the use of The Hui Process in a dental setting.

Barriers to entry for keratoconus patients to corneal cross-linking services in provincial New Zealand: a patient and family qualitative research project

Colin Parsloe, Malcolm Naude, Joshua Read

This study looked at why people in New Zealand, especially Māori and Pacific people, often face long delays getting diagnosed and treated. Keratoconus is an eye disease that makes the clear front part of the eye (the cornea) thin and change shape, leading to blurry vision that can get worse over time. Even though there is a treatment called corneal cross-linking that can stop the disease from getting worse, many people are diagnosed too late to benefit fully from it. The study found that delays happen because people don't know about the disease, put off eye checks, struggle getting to specialist appointments (due to travel costs/time) or are afraid of the surgery. These delays lead to worse vision, impacting daily life,

work and mental health. The participants suggested solutions like eye screening in schools and better community education to help spot keratoconus earlier.

Whānau-reported experiences of safety netting discharge advice in a paediatric context: a quality improvement project for Kaitaia Hospital

Nicola-Mary Geraghty

This research was conducted at Kaitaia Hospital to examine the effectiveness of discharge information given to paediatric (child) patients and their whānau/families by hospital staff. Questions about discharge information, content and delivery were asked to the primary caregivers of the patients discharged from hospital to identify areas of improvement for discharge information. In doing so, the discharge information was redefined as safety netting information for secondary care hospital services. There were five areas of improvement identified through whānau feedback under the central theme of communication. The results of this project point to the idea that Aotearoa New Zealand should have standardised discharge guidelines to provide optimal information for patient safety and whānau confidence.

Making healthcare SWEET2er: reframing clinical governance to support its operationalisation in Aotearoa New Zealand

Jerome Ng, Marama Tauranga, Linda Chalmers, Graham Bidois Cameron, Tim Antric, Marianne Dowsett

To make clinical governance more accessible, culturally appropriate and actionable in the New Zealand context, we propose explaining the concept as simply as being about 1) knowing how SWEET^2 care is, and 2) making it SWEET^{2}er. The SWEET^2 (Safe, Whānau-centred, Effective, Equitable, Te Tiriti- and Tikanga-based) framework represents a practical step forward in supporting the conceptualisation and operationalisation of clinical governance by clinicians, managers and the general public.

Giant cell tumour of the temporal bone vs atypical meningioma

Joseph N M Luna, Tony Goh, Aditya P Jayawant, Hayleigh Miller, Philip Bird

This paper describes the case of a 51-year-old woman who experienced worsening dizziness, ringing in the ear and nausea. Doctors discovered a rare tumour in her skull, specifically in the temporal bone, called a giant cell tumour (GCT). Although GCT is usually a non-cancerous (benign) tumour, it can be aggressive, damaging surrounding bones. Advanced imaging methods (computed tomography and magnetic resonance imaging) were used to diagnose this tumour, and the patient underwent surgery to remove it. After the surgery, she lost hearing in one ear and had some trouble balancing, but her condition improved over time. The paper emphasises the importance of distinguishing GCT from other similar conditions, like meningioma, for proper treatment.

Are cannabinoids with cancer immunotherapy contributing to early death? A call for caution and further study

Ben Jansen

ABSTRACT

Cannabis use in cancer care is increasingly common for symptom management, but emerging studies suggest potential interactions with immunotherapy that may reduce treatment efficacy. This review explores findings from recent studies, highlights the need for cautious interpretation and discusses the appropriateness of medicinal cannabis use during cancer immunotherapy. While three key studies (Taha et al., 2019; Bar-Sela et al., 2020; Hadid et al., 2024) observed lower response rates and reduced survival in patients using cannabis alongside immunotherapy, methodological concerns and demographic differences raise questions about their findings. Critiques by Piper et al. emphasise the need for larger, more rigorous trials with demographic controls—particularly regarding smoking status. Until stronger evidence is available, clinicians should weigh the benefits of symptom relief against potential treatment risks and ensure patients are fully informed about possible interactions.

In recent years, cannabis has increasingly been integrated into medical treatments including cancer care due to its potential benefits in symptom management. However, concerns are emerging regarding cannabis' interaction with cancer immunotherapy, specifically its impact on treatment response rates (RRs).

As both a physician involved in the medicinal cannabis industry and an advocate for patient care, I find the discussion and patient informed consent around this interaction critical. Three key studies on this topic offer preliminary data suggesting a potential reduction in immunotherapy efficacy from cannabis use, though the results remain limited and controversial, warranting caution and additional research.

Objective

This article aims to raise the question of appropriateness of medicinal cannabis during cancer-related immunotherapy.

Discussion

Study overview and findings

The first study, published in 2019 by Taha et al.,[1] examined the immunotherapy radiological RR, progression-free survival (PFS) or overall survival (OS) in patients receiving nivolumab, an anti-PD-1 (programmed cell death-protein 1) immunotherapy, for advanced cancer, including lung cancer, renal cell carcinoma and melanoma. This retrospective analysis compared two groups: those on nivolumab alone (89 patients) and those on nivolumab with concurrent cannabis use (51 patients).

Findings showed a significantly lower RR in patients using cannabis (15.9%) than in those on nivolumab alone (37.5%), with a statistically significant odds ratio of 3.13 (see Figure 1). RR was measured using radiological evaluation of tumours and analysis excluded patients with advanced disease with survival less than 2 months. This suggests that patients using cannabis were approximately three times more likely to have a poor response to immunotherapy. Notably, cannabis use did not significantly impact PFS or OS.

The second study, published in 2020 by Bar-Sela et al.,[2] which was prospective, aimed to validate and expand on the Taha et al. study findings with a separate cohort of patients. This study compared 34 patients receiving immunotherapy and using cannabis with 68 patients receiving immunotherapy but not using cannabis. All patients were either receiving immunotherapy as either first- or second-line treatment, either anti-PD-1—pembrolizumab or nivolumab, or ipilimumab

Figure 1: Graph of response rate to immunotherapy in patients using cannabis compared with those on nivolumab alone in the Taha et al. (2019) study.

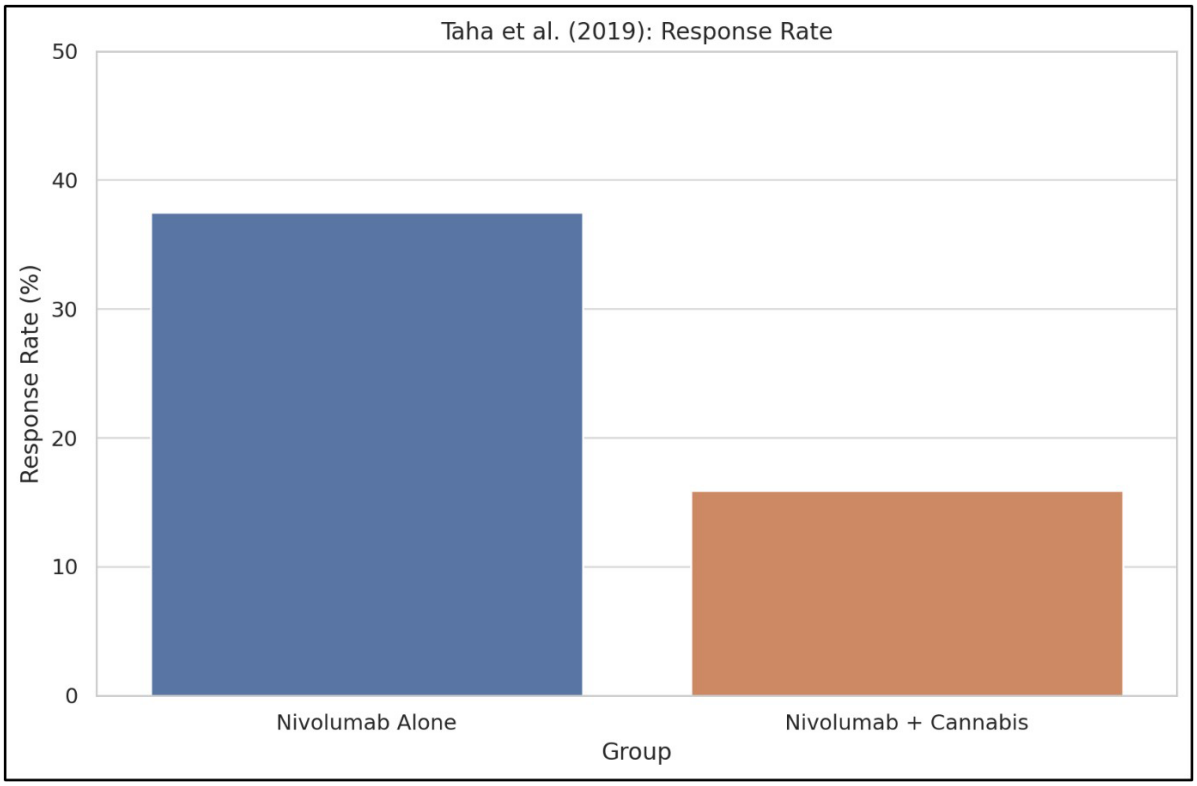
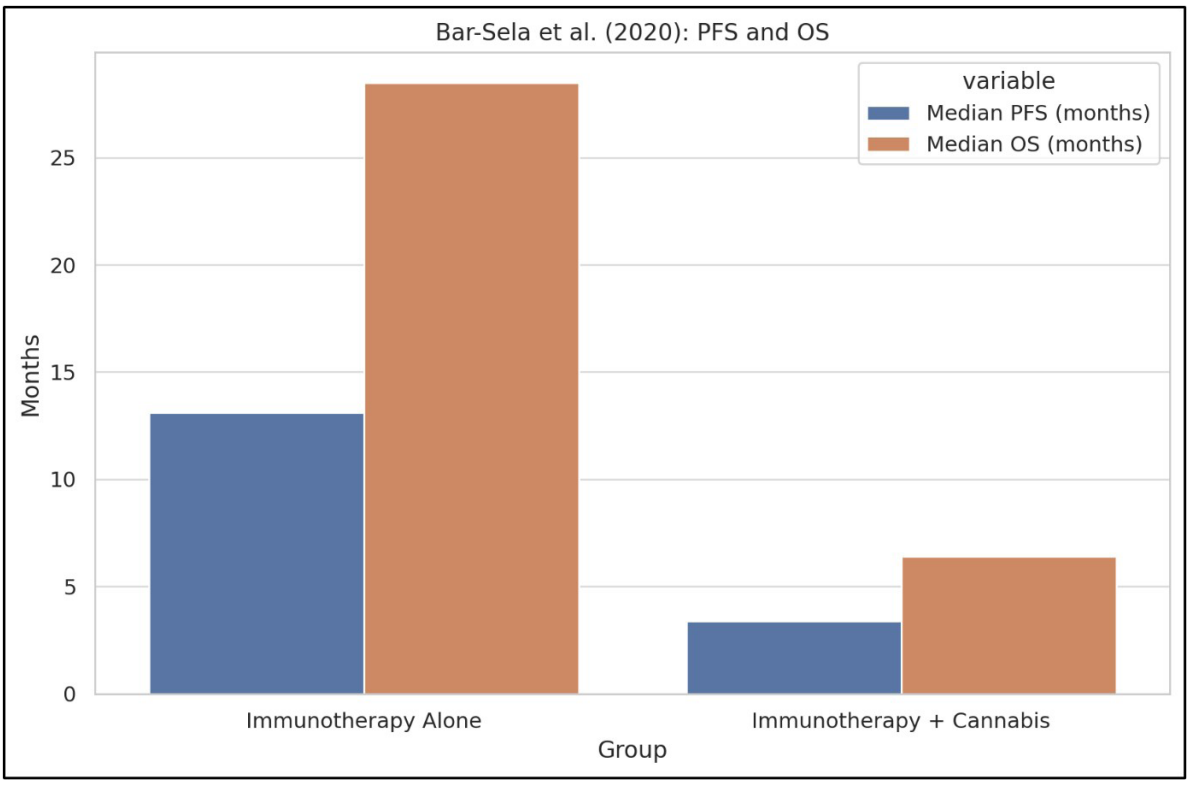


Figure 2: Graph of median progression-free survival and median overall survival (in months) in patients using immunotherapy alone compared with those also using cannabis in the Bar-Sela et al. (2020) study.



and nivolumab—or anti-PD-L1 (programmed cell death-ligand 1)—durvalumab or atezolizumab—without reporting on each immunotherapy treatment per se. The cannabis patients were mostly using inhaled cannabis.

The study reported showing that the median time to tumour progression on radiological imaging for cannabis users was only 3.4 months versus 13.1 months for non-users (95% confidence interval [CI] 1.8–6.0 vs 95% CI 6.0–N/A). Furthermore, the study also reported the median OS for cannabis users was 6.4 months vs a much longer 28.5 months for non-users, with significant Log-Rank tests p=0.0025 and p=0.0009, respectively (95% CI 3.2–9.7 vs 95% CI 15.6–N/A) (see Figure 2). To assess whether ectopic phytocannabinoids in cannabis users affect the endocannabinoid (eCB) system, researchers analysed 28 serum eCB and eCB-like lipids in a smaller cohort of 19 non-users and 17 cannabis users. Only one lipid, 2-oleoyl glycerol, showed a significant difference between users and non-users (p<0.04), suggesting minimal or no lasting impact of cannabis on eCB levels before immunotherapy. In contrast, immunotherapy itself significantly altered several eCB and eCB-like levels, regardless of cannabis use. The study did not demonstrate how serum eCB levels are correlated with local cellular or tissue eCB levels or effects. This study additionally faced critique for data accuracy and methodological transparency, as did the 2019 Taha et al. study.

Comparative analysis and interpretation

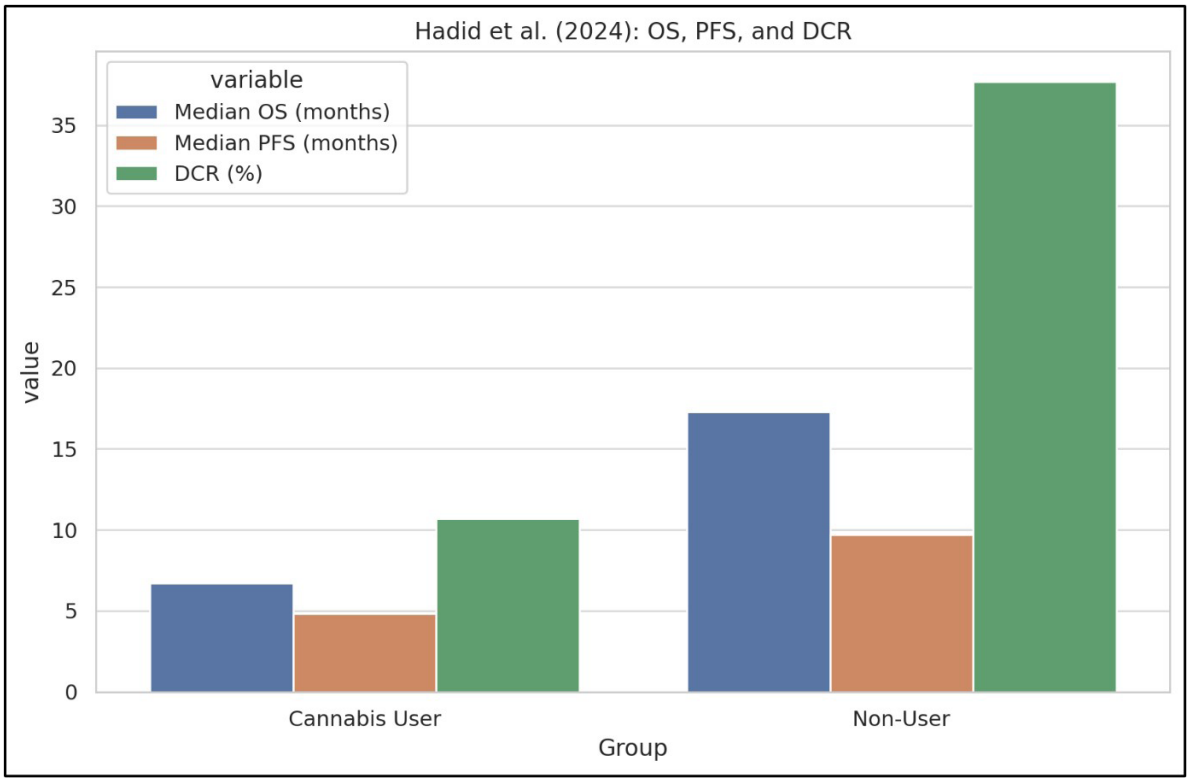
Concerns raised by Piper et al.[3] in their 2024 publication in the medical journal *Cancers* identified inconsistencies in data reporting and statistical discrepancies, undermining confidence in both studies' findings. Re-analyses questioned whether baseline demographic differences between groups could account for the observed outcomes. Piper et al. reported identifying statistically significant differences for the Taha study: between cannabis users and non-users in age (62 years vs 67.7 years), smoking status (56.9% vs 40%), liver metastasis (65% vs 19%) and immunotherapy as a second-line therapy (85% vs 55%). Of the Bar-Sela study, Piper et al. also found that "*of 22 statistics in the prospective report, four could not be repeated using the same statistics*", and that there were multiple instances of misreporting or analytical errors and significant differences in cohort demographics.

Despite both the Taha and Bar-Sela studies suggesting a possible negative interaction between cannabis and immunotherapy, their methodologies and findings have invited scrutiny. Factors such as smoking and other lifestyle elements, which heavily influence cancer risk and treatment outcomes, should be carefully considered when assessing cannabis' role in immunotherapy efficacy and cancer progression, and when interpreting the studies. Piper et al. do not dismiss a possible negative interaction between cannabis and immunotherapy but point towards these as possible confounding factors in both of the small studies.

A third study supporting caution

A recent third study by Hadid et al.,[4] published in 2024, provides further support for the hypothesis that cannabis may antagonise the effects of immunotherapy. In this Detroit (United States of America) single-institution retrospective cohort study of 105 patients with solid malignancies receiving immune checkpoint inhibitors, cannabis use was primarily in the form of prescribed dronabinol (oral synthetic delta-9-tetrahydrocannabinol). In the Hadid et al. study, cannabis use was associated with significantly worse outcomes in patients receiving immunotherapy, including lower median OS (6.7 vs 17.3 months), reduced PFS (4.8 vs 9.7 months) and a markedly lower disease control rate (10.7% vs 37.7%) compared with non-users (see Figure 3). Cannabis use was reported as mostly 5–10mg oral dronabinol per day (82%), versus recreational or smoked cannabis (14%) and cannabidiol (CBD) use (4%). Patients received a range of immune checkpoint inhibitors, primarily nivolumab (60%) and pembrolizumab (25.7%), with smaller proportions receiving combination nivolumab–ipilimumab (5.7%), atezolizumab (5.7%), durvalumab (1.9%) or avelumab (1.0%). Notably, these negative outcomes were most evident in white patients, raising the possibility of ethnicity-related pharmacogenetic variability in cannabinoid metabolism or immune response. Potentially important confounders—such as performance status, comorbidities and socio-economic status—may have been unaccounted for, and although tobacco use was more common among cannabis users (96% vs 74%) and was included as a covariate, it may still have influenced outcomes. This study reinforces prior findings by Bar-Sela et al. and Taha et al. and further underscores the need for prospective clinical trials to determine whether cannabis use should be contraindicated during immunotherapy.

Figure 3: Graph of median overall survival, median progression-free survival and disease control rate in patients using cannabis compared with those using immunotherapy alone in the Hadid et al. (2024) study.



Interpreting the information

One of the challenges in interpreting these studies is the inherent complexity of cannabis as a therapeutic agent. A variety of studies over the years have shown that cannabis affects the immune system through its active compounds, tetrahydrocannabinol (THC), CBD and the minor cannabinoids, which are known to modulate immune cell functions. Interestingly, in contrast, in some *in vitro* and *in vivo* studies cannabinoids are shown to inhibit cancer cell proliferation and metastasis, while also promoting apoptosis and suppressing cancer-related angiogenesis.[5] However, cannabinoids may interfere with anti-tumour immunotherapy responses through several immunomodulatory mechanisms. Klein reported that THC and CBD can suppress pro-inflammatory cytokines such as IL-2 and IFN-γ while increasing anti-inflammatory cytokines like IL-10, potentially dampening immune activity against tumours.[6] Cencioni et al. showed that anandamide, an endogenous cannabinoid, has been shown to suppress both the proliferation and the release of pro-inflammatory cytokines from human T cells, primarily through the CB_2 receptor.[7] Simard et al. highlighted that CB_2 receptors are notably expressed in various immune cells, including eosinophils, B lymphocytes, monocytes and T lymphocytes, and the activation of these receptors has been shown to modulate immune responses, suggesting potential interaction with immunotherapy.[8] Additionally, Hegde et al. found that THC promotes the expansion of myeloid-derived suppressor cells, which inhibit T cell responses and may support tumour immune evasion.[9] These examples of immune modulation may theoretically counteract immunotherapy, but definitive conclusions are premature given these studies' limitations, such as the sample sizes, infancy of the research and potential demographic imbalances.

Conclusion

Caution in clinical practice

These findings hold particular relevance for patients considering, or currently using, medicinal cannabis during immunotherapy. As medical practitioners, we must weigh the benefits of cannabis in managing cancer-related symptoms (such as pain, nausea and anorexia) against its

potential to compromise treatment efficacy. While cannabis has a promising role in supportive cancer care, these early findings support careful consideration when patients are concurrently undergoing immunotherapy.

As someone engaged in the medicinal cannabis industry, it is crucial to approach the results of these studies with an open mind. The therapeutic potential of cannabis in oncology is still developing, and its integration with immunotherapy may carry unintended risks. Therefore, clinicians are advised to exercise caution—ensuring patients are well informed of potential interactions is essential until further research provides clear guidance.

My experience with Australian oncology patients using medicinal cannabis is that the majority will use oral medication rather than inhaled cannabis, where inhaled cannabis was predominant in the Taha and Bar-Sela studies. A significant consideration for patients is the link between smoking tobacco and metastatic disease progression and cancer survival.

Future directions and need for rigorous research

The discrepancies in the studies discussed highlight a need for rigorous, well-designed prospective trials. Future studies should aim to control for variables such as cancer type, cannabis dosage, socio-economic status and patient lifestyle factors, particularly tobacco use, which may confound results.

Data transparency is vital to facilitate independent verification and bolster public and scientific trust in the findings. Additionally, larger studies should be commissioned to improve statistical power, and, considering the New Zealand and Australian governments currently fund immunotherapy, regulatory bodies such as Medsafe and the Therapeutic Goods Administration should require pharmaceutical companies to make their findings publicly available.

COMPETING INTERESTS
Director—Vivienne Jansen Brains Research Pty Ltd.
Director—Australani Health Pty Ltd.
Director—Queensland Health Education, Medicine and Pharmaceuticals.
Committee Member—Vitura Health Limited – Specialty Clinics Clinical Excellence.
Committee Member—Gold Coast Primary Health Network – The Way Back Support Service Steering Committee.
Patents: AU2019902462A0—Pain Relieving Medication, AU2019902162A0—A Cannabinoid Treatment For Ischaemia.

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The need for palliative care in Aotearoa New Zealand

Catherine D'Souza

ABSTRACT

Death is inevitable. Dying is a whānau/family, social, spiritual and cultural experience, not just a medical event. A lack of access to holistic palliative care services in Aotearoa New Zealand means a good death may be out of reach for some.

The population in Aotearoa New Zealand is ageing and the number of deaths is set to roughly double in the next 30 years. The current stretched resources to care for people who are dying are not sufficient to meet this increase in need.[1]

Palliative care is a human right, with laws in many European countries ensuring comprehensive delivery.[2,3] Despite palliative care teams offering high levels of knowledge, skills and expertise, limited access to both generalist and specialist services undermines the overall care available. In particular, crisis support is limited.[4]

Comprehensive research shows that specialist palliative care not only improves quality of life but makes significant savings in health-care spending by reducing unwanted and inappropriate medical treatments.[5]

This paper outlines the current challenges in palliative care provision in Aotearoa New Zealand and key reasons why it is imperative that palliative care delivery is appropriately resourced and developed to ensure everyone in Aotearoa New Zealand has access to quality care at the end of their lives.

What constitutes good palliative care

Health New Zealand – Te Whatu Ora describes palliative and end-of-life care as providing "*people facing life-limiting conditions with holistic support and services based on the needs of the person and their family*", stating, "*this care is essential*" and "*it is appropriate at any age and at any stage in a serious illness, and it can be provided alongside curative treatment*."[6]

Palliative care in Aotearoa New Zealand aims to:

- optimise peoples' quality of life until death by addressing their physical, psychosocial, spiritual and cultural needs
- support the individual's family, whānau and other caregivers where needed into bereavement[6]

Specialist palliative care has consistently shown benefits in improving quality of life, being cared for in the person's place of choice[7] and extending life.[8] The research is so comprehensive that researchers have asked: what more information do funders need in order to properly resource palliative care?[9]

The core minimum for a specialist palliative care team is a specialist doctor, registered nurse and social worker (all with specialist training in palliative care).[10] Good-quality community palliative care requires properly trained staff and 24/7 availability.[11] Neither trained staff nor 24/7 availability are comprehensively provided in Aotearoa New Zealand.[12,13]

Good palliative care provision requires collaborative work between specialist palliative care and generalist providers including hospital staff, general practitioners (GPs), community nurses, allied health, paramedics, community groups and volunteers. These services are under intense pressure, meaning access to generalist palliative care is becoming increasingly limited.[4]

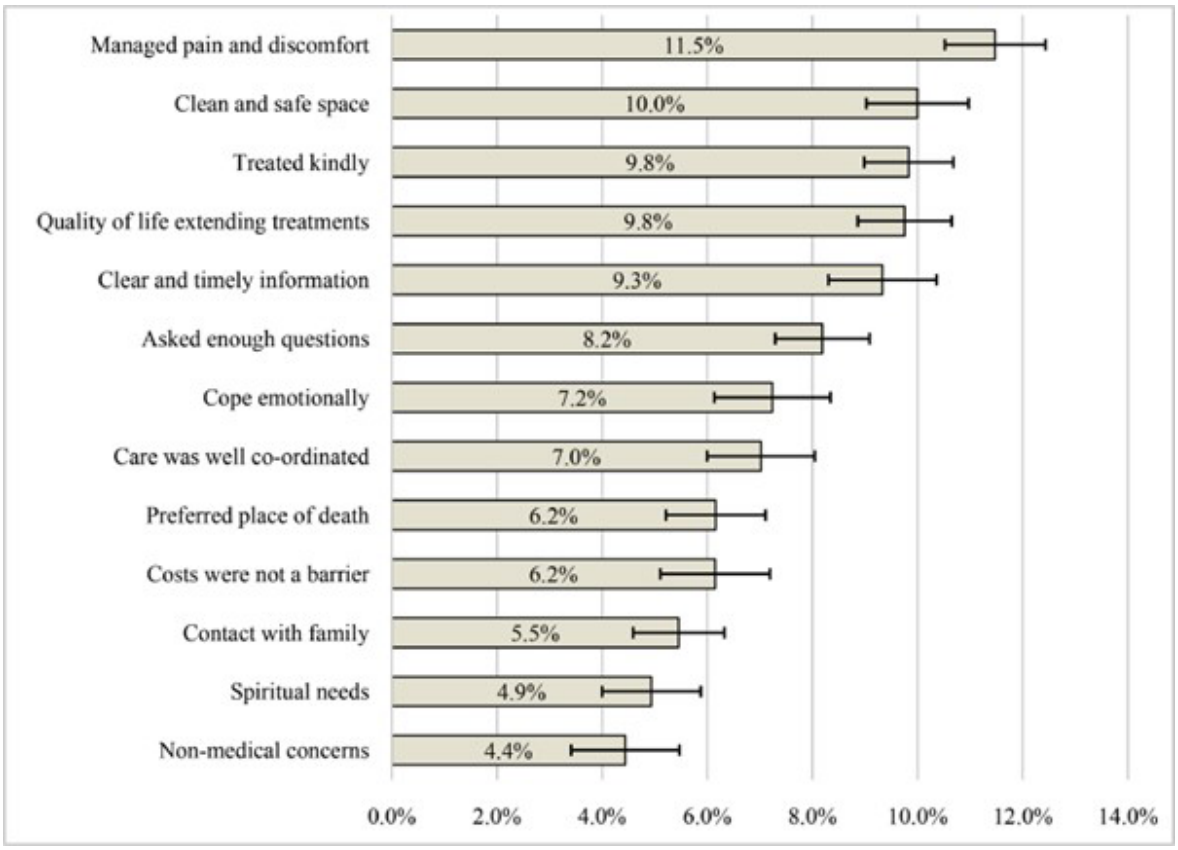
The minimum standards of provision for specialist and generalist palliative care are not being met in Aotearoa New Zealand.

What's important to people at the end of their lives

International research showed that managed pain and discomfort was rated as most important by bereaved families, closely followed by clean and safe spaces and being treated kindly.

Similarly, in an Aotearoa New Zealand survey, experiencing suffering, family/whānau concerns and symptom management were among the top

Figure 1: An international study showing what bereaved families rated as the most important factor when their relative was dying.[14]



five considerations. The least worrying aspects were funeral/care costs, place of death, cultural, religious and spiritual values and equipment.[4]

Evidence has shown that the top-rated concern at end-of-life is physical suffering. Access to services to relieve this are not available equitably across Aotearoa New Zealand.

The human rights imperative

In 2022, the World Health Organization Director-General Dr Tedros Ghebreyesus formally urged heads of state to integrate palliative care into their health systems and "*face this global challenge on palliative care with collective compassion.*"[15]

Aotearoa New Zealand is a signatory to numerous international treaties that recognise the right to health. Obligations include respecting the right to health and to not deny or limit equal access to preventive, curative or palliative health services. These obligations include providing non-discriminatory access to essential medicines and health facilities, especially for vulnerable or marginalised groups.[16]

Palliative care is particularly crucial for marginalised groups, including those in rural locations. These groups often face significant barriers to accessing high-quality care, such as cultural misunderstandings, financial constraints and a lack of localised services.[17] Ensuring equal access to palliative care is not just a matter of healthcare policy but one of social justice.

Ensuring paediatric palliative care is a human rights obligation. The United Nations Committee on the Rights of the Child states, "*children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services*."[18] The one fully funded government specialist paediatric palliative care unit is in Auckland and is insufficient to meet the needs of all of Aotearoa New Zealand.[19]

Palliative care is a human right to which Aotearoa New Zealand is a signatory. Aotearoa New Zealand is not currently fulfilling those requirements.

International legislative progress

As an international example, while Portugal and the United Kingdom (UK) made significant strides in legislating palliative care as a human right, Aotearoa New Zealand is experiencing a lack of resources and infrastructure. Portuguese legislation led to the creation of the National Network for Palliative Care to provide active and comprehensive care to patients and their families.[2]

In the UK, the *Health and Care Act 2022* placed a duty on integrated care boards to commission and oversee palliative care services. The National Health Service England has funded the development of seven regional palliative and end-of-life care strategic clinical networks to support commissioners. A national call for change in palliative and end-of-life care came from academic and industry stakeholders, patients and carers. Considered essential were: the provision of 24-hour, 7-days-a-week specialist community palliative care support; education and communication skills training for health and social care professionals; and investment in community care to reduce unnecessary hospital admissions.[20]

In Aotearoa New Zealand, multiple private members' bills to improve access to palliative care have been submitted to the ballot, with the most recent being in October 2024. However, none of these have ever been selected to be debated in Parliament.

While international progress has been made by legislating for palliative care provision, Aotearoa New Zealand has lagged behind and has not legislated for this essential service.

The economic case for palliative care

In addition to the ethical imperative, there is a strong economic case for investing in palliative care. A multitude of studies have shown that specialist palliative care is not only high value and cost effective, but it is in fact cost saving, reducing overall expenses in healthcare. The savings have been shown in communities and hospitals for cancer and non-cancer diagnoses. Healthcare costs for people with metastatic cancer were found to be 25% less if they had specialist palliative care consultation and 32% less in those with the highest level of comorbidity.[21]

Palliative care is an essential service that not only improves quality and potentially length of life but also saves money from the overall healthcare budget. Aotearoa New Zealand would benefit from similar cost-saving measures, particularly as the population continues to age and the demand for palliative care services increases.

Who needs palliative care?

Expected deaths are those with a predictable trajectory through a chronic disease process, requiring a palliative approach to their care. It is estimated that 90% of deaths are predictable. One-fifth of hospitalised inpatients in Aotearoa New Zealand have been shown to meet criteria for palliative care input.[22]

There were 37,884 deaths in Aotearoa New Zealand in 2023: 34,096 of these required a palliative approach to their care. The number of people requiring palliative care is increasing rapidly each year as age and complexity increase.

Of those requiring a palliative approach, 63.03–81.87% need specialist palliative care.[23] This need is variable in nature, from non-contact advice to comprehensive and intense care. Therefore, between **21,490 and 27,914** people required specialist palliative care in 2023 in Aotearoa New Zealand. Hospices in Aotearoa New Zealand were involved with **10,800** people, less than half of the required number to cover this need.

Specialist palliative care services were originally cancer orientated; however, the paradigm has now shifted to provide care based on need rather than prognosis or diagnosis. Palliative care services look after people with a range of diagnoses, including organ failure and frailty. Increasingly, people with dementia are receiving and will increasingly require palliative care.

Palliative care services should be available to people of all ages, with specialist services being available to all ages, including children and young people.[19]

Despite extensive work by non-governmental organisations, currently Aotearoa New Zealand specialist palliative care services are reaching less than half of those that need it.

How is Aotearoa New Zealand doing?

The international rating of palliative care in Aotearoa New Zealand has slipped from third in 2015 to 12th in 2021.[14] Our rating lies below those of Costa Rica, Lithuania, Mexico and Slovenia.

Palliative care initiatives have often been grassroots led and locally driven. This has led to geographical inequities in funding and service delivery.

In contrast to other health services, only half of the funding for hospice services is provided by the government, while the rest is funded through fundraising and donations.

The only fully government-funded specialist services for children are offered at Starship Hospital in Auckland. Other partial services have been set up in other geographical areas, but they are not fully government funded, nor do they contain the full multidisciplinary team.[18]

The 2024 Health New Zealand – Te Whatu Ora Palliative Care National Survey showed specialist palliative care was highly rated by responders, with hospice as the highest rated provider of good or excellent care overall (94.8%). Access to GPs was limited and costly, with strong feedback on lack of available services in a crisis, particularly after-hours.[4]

It has been reported that clinicians in Aotearoa New Zealand treat people with dignity and respect while they are dying all, or most, of the time in the majority of cases, ranging from 88% for GPs to 99% for hospice doctors.[4] Similarly, in a 2020 survey of bereaved people in the South Island, hospice care was rated most highly for overall quality of care, with GP and urgent care scoring lowest. Pain relief was also more effective as rated by bereaved relatives in hospice inpatient units compared with hospital, aged residential care and home.[24]

Although specialist palliative care services are highly rated, they are inequitably available, understaffed and underfunded. Aotearoa New Zealand has slipped in international comparisons and will continue to do so unless palliative care is properly funded and staffed.

Challenges in palliative care delivery in Aotearoa New Zealand

Workforce and training

A critical issue in providing palliative care in Aotearoa New Zealand is the workforce shortages. The continuing shortages in staff with specialised palliative care training and expertise is a barrier to high-quality provision.

Aotearoa New Zealand minimum standards state that every hospital must have access to a specialist palliative medicine doctor, with Category 1 hospitals having a minimum of one FTE on-site specialist nurse with postgraduate training in palliative care. Every Category 2 hospital should employ a minimum of one part-time nurse with palliative care as at least part of their designated role.[25] A 2016 survey showed specialist nurses were available in **less than half** of hospitals in the South Island, with specialist doctors available in **less than a third**.[25]

International recommendations for numbers of specialist palliative medicine doctors range from FTE **2.0 to 4.4** per 100,000 population.[26] In 2024, the author surveyed the number of FTE for the specialist doctors in Aotearoa New Zealand and found it was currently 44.78. Unfilled vacancies stood at around 25%. This gives a population ratio of FTE **0.84** per 100,000, less than a half to a quarter of the international recommended level.

It should be noted that over 25% of this FTE is provided by doctors over 60 years of age, who can be predicted to retire within the next 5–10 years. Workforce predictions show that the number of specialist doctors will continue at the current numbers over the next 10 years unless action is taken to increase numbers. As the population ages and the death rate increases, the recommended workforce will be expected to rise as the intensity of need for palliative care services increases.

A 2019 Canadian model of specialist palliative care staffing uses a multidisciplinary approach to care, presuming that 15% of deaths require no palliative care and that GPs will lead on 65% of community palliative care.[10] Using this model, Aotearoa New Zealand requires 150 FTE specialist palliative care doctors, 378 specialist palliative clinical nurse specialists and 78 social workers. The current Aotearoa New Zealand FTE equivalent of specialist palliative care doctors is **less than a third** of the required number.

Generalist palliative care providers are under increasing pressure. It is estimated that the number of GPs per 100,000 New Zealanders

Figure 2: Current senior medical officer (SMO) workforce in palliative medicine.

	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total
Full Time Equivalent (FTE)	3.90	6.10	10.30	9.20	3.50	9.38	2.40	0.00	0.00	44.78
Head Count, Practitioners with an APC, inc. Retired	7	11	15	12	8	14	8	1	2	78

is projected to fall from 74 in 2021 to 70 by 2031, and with a higher pace of population growth could potentially fall to below 66. In comparison, the Australian Government Department of Health reported a national 2020 GP rate of 116 per 100,000.

Core competencies in generalist palliative care have not been developed in all healthcare specialities; therefore, capability and confidence in delivering generalist care in Aotearoa New Zealand are limited.

Specialist and generalist staffing in Aotearoa New Zealand is well below minimum international recommendations.

There is a pressing need for the government to invest in education and training programmes that will produce more specialists and upskill generalist providers to increase the overall capacity of the palliative care workforce. This is a high-quality investment and a potential cost-saving measure, and it promotes the long-term stability of the wider health system.

Urgent action to increase training and capacity is required.

Inequity in palliative care services

There is considerable evidence that access to palliative and end-of-life care is not equal. Reduced access is related to ethnicity, socio-economic deprivation, homelessness, imprisonment, learning disability, sexual orientation, age, gender identity, diagnosis, geographic location and socio-economic status.[27]

In Aotearoa New Zealand, there is geographical inequity. Hospice services have grown up outside of government healthcare services, with government funding inequitably distributed across the country. Despite the 2013 Resource and Capability Framework setting out minimum standards for service delivery, this has not been implemented and minimum standards are not met nationally.

Populations with structural inequities face unique challenges in accessing palliative care. It is essential that services are particularly sensitive to those needs and that they are culturally sensitive and responsive to different traditions and values. Although a high-quality framework for delivery of culturally appropriate care for Māori, Mauri Mate, has been developed and utilised by hospices, this has yet to be rolled out by generalist palliative care providers.

There continue to be inequities in generalist and specialist palliative care delivery dependent on who you are and where you live. Although actions are being taken by hospices to address this, continued and sustained effort is required to break down inequities of service delivery.

How our population changes will affect the need for palliative care

The number of deaths per year is predicted to increase by 148% in the next 20 years as the Baby Boomer generation ages. The number of deaths will overtake the number of births in the 2050s. This varies by region: the Northern Region will have the highest increase in deaths in the next 20 years, up 160%, and Te Manawa Taki will increase by 148%, Central by 138% and Te Waipounamu by 143%.[1]

Deaths are rising faster than the population, with the population predicted to increase by 129% by 2073 and deaths by 182%. Commissioning for palliative care must be based on deaths and not population, because deaths are projected to increase much faster than the population.[1]

Deaths of Māori as a percentage of total deaths are projected to increase from 12.6% in 2023 to 13.5% in 2043. The proportion of deaths of people of Asian heritage will more than double over the same period. Equity of palliative care delivery needs to be measured against the ethnicity of deaths and not the ethnicity of the population.[1]

The number of deaths of people over 90 will double in the next 20 years, with a reduction of deaths in the under-69s. This is particularly noticeable in the Māori age groups, with numbers of deaths more than doubling in each category over the age of 75. In the very old (95+), the number will more than triple.[1]

The causes of death are changing as people live longer. Cancer deaths peak around 65 years of age, with organ failures at 75. For those who live over mid-80s, frailty and dementia become the prominent cause of death.[1]

The number of deaths in Aotearoa New Zealand will increase rapidly in the next 20 years. Unless dedicated resources are increased, the already stretched health and social services will not cope with the increasing need.

Crisis management

The availability of appropriately resourced generalist services with access to specialist advice is essential for good palliative and end-of-life care. Twenty-four-hour care as a minimum standard for people with palliative needs is widely recognised in policy documents within Aotearoa

New Zealand and has been a minimum requirement in UK since 2014. However, this is not available across Aotearoa New Zealand.

Where models of 24-hour, 7-day access to care have been implemented, evaluation reveals:

- improved outcomes and experiences for patients and their families and increased quality and standards of care
- improved access to hospice inpatient admission for patients requiring urgent transfer into a specialist palliative care bed on weekends and public holidays
- prevention of unscheduled, avoidable acute hospital admissions and emergency department attendance
- improved support for providers of general palliative care throughout primary and secondary care[28]
- staff working out-of-hours may work in isolation and therefore require a greater level of competency than those working in teams during the week with greater support and supervision[29]

Out-of-hours palliative care provision is vital but often unavailable. Specialist palliative care staff are not available in sufficient numbers; meeting current and future needs requires increasing the numbers of specialist palliative care staff while increasing the support of generalists.

Urgent attention is required to ensure 24/7 palliative crisis management is available to those who need it. Where GPs and community nurses are not available, plans should be put in place to formally collaborate with other services such as paramedics, hospices and neighbouring services to ensure this care is provided.

Conclusion

In conclusion, the need for palliative care in Aotearoa New Zealand is urgent. The growing demand due to an ageing population, coupled with insufficient resources and workforce shortages, requires immediate action. To honour the dignity and rights of all New Zealanders, it is essential that the government invest in expanding and resourcing palliative care services to ensure equitable, high-quality care for everyone, regardless of location, ethnicity or socio-economic status.

By resourcing palliative care services, Aotearoa New Zealand can ensure that its citizens receive the compassionate, holistic care they deserve in their final days, respecting their dignity and improving the quality of life for individuals and their whānau. Palliative care is not only a medical need but a fundamental human right that must be available to all.

COMPETING INTERESTS
Author is Chair of Palliative Care Collaborative Aotearoa. Author is Chair of the Australia and New Zealand Society of Palliative Care, Aotearoa branch.

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Acceptability of "The Hui Process" at the Faculty of Dentistry

Te Rauhina Jackson, Ieremia Tuivaiti, Esther Willing, Kuramaiki Lacey

ABSTRACT

AIM: In Aotearoa New Zealand, Kaupapa Māori health models have been introduced into the dental curricula to provide students with the skills and knowledge to engage meaningfully with Māori patients. This exploratory study investigated the acceptability of "The Hui Process", a Kaupapa Māori clinical framework, in final-year undergraduate dental clinics at the Faculty of Dentistry (FoD) in Aotearoa New Zealand.

METHODS: A cross-sectional study was conducted. Participants were adult patients who attended final-year dentistry clinics at the FoD. The questionnaire asked about three of the four components of the Hui Process (mihimihi, whakawhanaungatanga and poroaki), patient satisfaction, cultural safety and demographic variables. Data were cross tabulated to identify participants' experiences of the Hui Process.

RESULTS: A total of 47 participants completed the survey. Results show that most dental students incorporated the Hui Process in their clinical consultations, and that this was important to participants. Most participants were satisfied that their needs were met by their dental students, and all participants felt culturally safe.

CONCLUSION: The Hui Process was well received by participants in the dental setting, highlighting the benefit of Hauora Māori curricula in dental education. This research can inform curriculum development to further promote Hauora Māori in the dental profession.

The ongoing impacts of colonisation on Indigenous people's oral health have and continue to be detrimental to health and wellbeing.[1,2] In the context of Aotearoa New Zealand, colonisation is understood to be a fundamental driver of Māori health inequities, the social determinants of health and access to healthcare.[3] Academic discourse and national oral health data describe oral health inequities between Māori and non-Māori, whereby Māori suffer the poorest oral health across many indicators throughout the life-course, including dental caries, periodontal disease and missing teeth.[4,5] Māori also experience barriers to accessing oral healthcare due to cost,[6] poorer oral health–related quality of life[7] and a greater exposure to racism in healthcare.[8] Māori experiences of the public health system in Aotearoa New Zealand have been characterised by culturally unsafe interactions with healthcare providers, impacting the quality of care that they have received.[9] This emphasises the urgent need to address the way in which health services are delivered to Māori patients and whānau (see Appendix for te reo Māori glossary).[10]

Whānau Māori want health services that are responsive to their needs and expectations and are acceptable from a Te Ao Māori perspective. This includes access to Kaupapa Māori services as a normal part of health and wellbeing, and culturally and clinically safe services.[11] With the current under-representation of Māori dentists in the dental workforce,[12] it is important that all dentists are trained to provide equitable and culturally safe care that upholds Māori rights as tangata whenua under Te Tiriti o Waitangi.[7] Following the success in medical education,[13,14] one proposal to provide quality care to Māori has been to introduce Māori models of health into the dental curricula to ensure that the values and tikanga that resonate with Māori are upheld by the dental profession. This includes having an understanding of tikanga Māori and mātauranga Māori to improve health outcomes for Māori and improve equity.[10] Since the University of Otago is home to the only Faculty of Dentistry (FoD) in Aotearoa New Zealand, workforce training to address Māori oral health and inequities is important.

In the context of clinical consultation, "The Hui Process"[13] is a framework that integrates Hauora Māori into the clinician–patient interaction. It has been well received in medical education,[13] and the nursing curriculum,[15] and delivered through both simulated and case-based activities. More recently, the Hui Process has been proposed to be integrated into the practice of paramedics.[16] It was introduced into the dental curricula in 2020 to provide dental students with consultation skills

that embed mātauranga Māori and tikanga Māori.

Briefly, the steps of the framework are: mihimihi, whakawhanaungatanga, kaupapa and poroaki/whakamutunga. Mihimihi involves greetings and the initial engagement with the patient. This requires a clear introduction from all clinical staff and their roles. The health professional should explain the purpose of the appointment to the patient and include any whānau present. The use of te reo Māori is encouraged. Whakawhanaungatanga focusses on making connections and developing an authentic relationship with the patient and their whānau. This is beyond building rapport and requires the clinician to have an understanding of Te Ao Māori, Māori beliefs and experiences of the patient and their whānau. Clinical staff are encouraged to share about themselves through shared experiences to foster a meaningful connection on a personal level.[13] Whakawhanaungatanga should occur continuously throughout the appointment and is further developed at subsequent appointments. Whakawhanaungatanga is highly valued by Māori patients and whānau in clinician–patient interactions,[17] and in dentistry, cultural connectedness and whakawhanaungatanga have been shown to have a positive impact on the oral health and overall wellbeing of Māori tamariki and whānau.[18] The kaupapa stage is attending to the main purpose of the appointment. In dentistry, this would be the history and examination during the initial consultation. The use of Māori health models such as the Meihana Model[14] or Te Whare Tapa Whā[19] allow for a broader understanding of the presentations of Māori patients in the history-taking process. The Meihana Model enables the clinician to consider the historical and societal determinants of health, and other aspects of Te Ao Māori that may influence the presentation of Māori participants in the clinical setting.[14] Practitioners should have a thorough understanding of the health context of their Māori patients to improve history taking, and broaden their range of assessment to identify hauora-related issues that should be prioritised. The final stage, the poroaki/whakamutunga, is the closing of the encounter. This involves ensuring that the patient understands all aspects of their treatment, including how the treatment will be done, and the next steps for them and their whānau. It is important that patients are given the space, time and resources to provide informed consent to the treatment plan moving forward, and this includes opportunities for the patient and whānau to ask questions.

This study was exploratory and aimed to investigate, from a patient perspective, the acceptability of the Hui Process model at the FoD. The objectives of the study were to investigate whether the Hui Process was implemented during clinical consultations and whether the elements of the model were important from a patient perspective.

Methods

Ethical approval was granted by the University of Otago Human Ethics Committee (H03/006) and the Ngāi Tahu Research Unit. The study design was a cross-sectional survey. Participants came from a convenience sample of adults who attended general dental practice (GDP) clinics as part of the 5-year dentistry programme at the FoD, University of Otago. Participants were patients who presented for a single clinical session and were identified and recruited by their respective dental student. Eligible participants were provided with an information sheet and a questionnaire following their initial appointment. Eligible participants included adult patients (18 years or older) who could provide informed consent, who attended final-year dental clinics and who presented for the first time for an examination. Anyone who did not meet these criteria were excluded.

Participants were recruited during the first 6 weeks that clinical appointments were available at the FoD for the 2023 calendar year. Participants had the option to complete their survey in the waiting room, away from the dental students and tutors, and surveys were returned to the receptionist and kept in an enclosed box. Participants were provided with the researchers' contact details if they wished to take the time to discuss their appointment with friends and whānau and return the survey at a later date. The questionnaire asked participants about three of the four components of the Hui Process. For the mihimihi, participants were asked whether their dental student introduced themselves, whether participants had the opportunity to introduce themselves to the student and their perceived importance of the mihimihi step. For whakawhanaungatanga, participants were asked whether they felt their student attempted to build a meaningful connection with them, whether they felt comfortable sharing a bit about themselves with their student and their perception of the importance of developing an authentic relationship prior to commencing dental treatment. For the poroaki/whakamutunga,

participants were asked whether they felt informed following their consultation, understood their treatment plan moving forward and whether they had the opportunity to ask questions. Additional questions were asked about patient satisfaction, cultural safety and demographic variables (gender, ethnicity). A definition of cultural safety was provided to participants to support the question related to cultural safety.

Statistical methods

The statistical program SPSS (version 18) for Mac was used to analyse the data. Responses to ethnicity questions were categorised to give a single prioritised response, according to standard health sector protocols. This prioritised ethnic groups in the following order: Māori, Pacific peoples, Asian and European/Other.[20] Data were cross tabulated to identify patient experiences of the Hui Process relative to the independent variables of interest, which were gender and ethnicity. Importance was determined by considering "very important" and "important" to mean important, while "impartial", "not important" and "not sure" were considered "not important". Levels of satisfaction were identified by recoding "very satisfied" and "satisfied" to mean satisfied, while "unsatisfied" and "unsure" were considered not satisfied. One patient did not respond to two questions (item non-response); therefore, some data were analysed according to 46 responses.

Results

A total of 47 surveys were collected throughout the 6-week data collection period. The proportion of females to males was similar, with 51.1% of participants identifying as male and 48.9% identifying as female. The largest ethnic group was comprised of participants who identified as NZ European (83%), while very few identified as Māori, Pacific peoples, Asian or Other (<5% in each ethnic group).

Table 1 presents participant responses to the mihimihi component of the Hui Process. The data showed that all students introduced themselves to the participants, and most participants (95.7%) had the opportunity to introduce themselves. Approximately half of the participants thought that it was important to know where their dental student was from (53.2%).

Table 2 presents participant responses to the whakawhanaungatanga component of the Hui Process. The data showed that most participants (95.7%) felt that their dental student attempted to build a meaningful connection with them. Most participants (97.9%) were comfortable in sharing a bit about themselves with their dental student. Three-quarters of participants thought that it was important to develop an authentic relationship with their dental student before commencing dental treatment.

Table 1: Mihimihi elements by socio-demographic characteristics.

	Participants (n, %)	Student introduction completed (n, %)	Patient introduction enabled (n, %)	Importance of process (n, %)
Sex				
Male	24 (51.1)	24 (100)	22 (91.7)	13 (54.2)
Female	23 (48.9)	23 (100)	23 (100)	12 (52.2)
Ethnicity				
Pākehā	39 (83.0)	39 (100)	38 (97.4)	20 (51.3)
Māori	<5 (4.3)	<5 (100)	<5 (100)	<5 (100)
Pacific peoples	<5 (2.1)	<5 (100)	<5 (100)	<5 (0)
Asian	<5 (4.3)	<5 (100)	<5 (100)	<5 (100)
Other	<5 (6.4)	<5 (100)	<5 (66.7)	<5 (33.3)
Total	47 (100)	47 (100)	45 (95.7)	25 (53.2)

Table 2: Whakawhanaungatanga elements by socio-demographic characteristics.

	Meaningful connection (n, %)	Comfort in sharing (n, %)	Authentic relationship (n, %)
Sex			
Male	22 (91.7)	24 (100)	19 (79.2)
Female	23 (100)	22 (95.7)	16 (69.6)
Ethnicity			
Pākehā	39 (100)	39 (100)	31 (79.5)
Māori	<5 (100)	<5 (100)	<5 (100)
Pacific peoples	<5 (100)	<5 (100)	<5 (0)
Asian	<5 (50)	<5 (50)	<5 (50)
Other	<5 (66.7)	<5 (100)	<5 (33.3)
Total	45 (95.7)	46 (97.9)	35 (74.5)

Table 3: Whakamutunga elements by socio-demographic characteristics.

	Informed (n, %)	Understand treatment plan (n, %)	Questions (n, %)	Needs met (n, %)	Cultural safety (n, %)
Sex					
Male	24 (100)	21 (87.5)	24 (100)	24 (100)	24 (100)
Female	23 (100)	23 (100)	22 (100)[a]	21 (95.4)[a]	23 (100)
Ethnicity					
Pākehā	39 (100)	36 (92.3)	38 (100)[a]	38 (100)[a]	39 (100)
Māori	<5 (100)	<5 (100)	<5 (100)	<5 (50)	<5 (100)
Pacific peoples	<5 (100)	<5 (100)	<5 (100)	<5 (100)	<5 (100)
Asian	<5 (100)	<5 (100)	<5 (100)	<5 (100)	<5 (100)
Other	<5 (100)	<5 (100)	<5 (100)	<5 (100)	<5 (100)
Total combined	47 (100)	44 (93.6)	46 (100)[a]	45 (97.8)[a]	47(100)

[a] Missing data from one participant; only 46 responses.

Table 3 presents participant responses to the poroaki/whakamutunga component of the Hui Process. The data showed that all participants felt informed about their consultation, and most participants (93.6%) understood their treatment plan moving forward. All participants had opportunities to ask questions. The majority of participants were satisfied that their needs were met (97.8%) and all participants (100%) felt that the dental school environment was culturally safe.

Discussion

The results show that over 90% of patient interaction components that were examined fulfilled the expectations of the Hui Process, with 96% of patients having the opportunity to introduce themselves, 96% feeling that the dental student attempted to build a meaningful connection with them and 94% understanding their treatment plan going forward. This research therefore showed that final-year dental students were incorporating elements of the Hui Process into their clinical consultations at the FoD.

Of the participants in the study, three-quarters reported that it was important to develop an authentic relationship with the dental student treating them, prior to treatment commencing. While other aspects of the Hui Process that were examined could arguably be considered to be "good care" in a Western model, developing an authentic relationship is a significant element of the Hui Process that is not emphasised in Western teaching models. This suggests that patients value this model over and above "best care" provided under a Western framework. The positive results in the poroaki/whakamutunga section indicate that the dental students concluded their clinical consultations well. This is in contrast to reports in the medical curriculum, where the poroaki/whakamutunga process was seen as lacking and incomplete in the clinician–patient interaction by Māori participants and their whānau.[13] The poroaki/whakamutunga process derives from the final step of the traditional pōwhiri process and has a traditional role in ensuring that all "business" has been completed, a relationship has been established and next steps are understood by both parties.[13] An important aspect of the poroaki/whakamutunga process is ensuring that the patient and their whānau are well informed about their oral health. This is also integral in the informed consent process, which is a practice standard set by the Dental Council of New Zealand (DCNZ).[21]

All participants reported that the consultation felt culturally safe, suggesting that for the student–patient interactions in the study, all students demonstrated a sufficient level of cultural competence. Despite the Hui Process drawing on Kaupapa Māori methods of clinical engagement, this study showed clear benefits of utilising Māori models of health in clinical practice for all participants, regardless of ethnicity. Culturally safe care is determined by the patient, as a recipient of care, and not by the healthcare professional.[22] This study took a patient-centred approach to understand patient perspectives of their clinical interaction and found that all participants felt culturally safe at the FoD. This is important from a DCNZ regulatory perspective, as they consider cultural safety a minimum competency to be registered in the scope of general dental practice.[23]

Limitations

The participants were drawn from a convenience sample, and participant recruitment relied on dental students to distribute the questionnaires to participants they were seeing for the first time. Therefore, it was not possible to determine a response rate or identify whether all eligible participants were included. It is possible that students were familiar with the nature of the study and changed the way they treated their participants, which could have resulted in an over-estimation of the use of the Hui Process.

This mahi was carried out as part of a final-year dental student research elective, which imposed an 8-month timeline for the project to align with the academic year of the students. This limited the scope of the research, as well as the period of recruitment. The authors acknowledge that a longer recruitment period may have allowed for a larger sampling size. The small sample size overall and small number of Māori participants limited our ability to make wider generalisations about the acceptability of the Hui Process to patients and, in particular, to Māori patients. Furthermore, it was not known whether the study participants represented a true profile of patients attending the student clinics.

Strengths and recommendations

To our knowledge, this was the first study to assess the use of the Hui Process in a dental setting. The study showed that participants seen in final-year dental clinics felt culturally safe and that the Hui Process was being used during

clinical consultation by final-year dental students. This suggests that students are embracing the Hauora Māori curriculum and providing culturally competent and culturally safe care. To build on the strengths of the Hauora Māori curriculum and this study, the authors recommend further consolidating the Hui Process teaching into clinical training, as well as Electronic Oral Health Records. The History and Examination Form at the FoD is completed by all dental students during initial appointments with participants and, if modified to include the components of the Hui Process, would prompt students to use the Hui Process during their clinical consultations.

Conclusion

This study was the first to investigate the use of the Hui Process in final-year student clinics at the FoD. The results suggest that dental students are using the Hui Process during clinical consultation, and that this was seen as important by participants. From a regulatory perspective, providing culturally safe care is a competency requirement, meaning that the adoption of the Hui Process could assist dental students and dentists to meet regulatory standards. However, a larger study is required to capture the perspectives of more people who identify as Māori, Pacific peoples, Asian and Other ethnic categories. The results from this study can be used to inform and further develop the dental curriculum at the FoD in their cultural competency and cultural safety teaching to further facilitate the provision of high-quality care.

COMPETING INTERESTS
KL: Executive member of Te Ao Mārama Aotearoa Māori Dental Association; board member of the National Oral Health Clinical Advisory Network.

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Appendix: glossary

Hauora—health
Hauora Māori—Māori Health
Kaupapa—purpose
Kaupapa Māori—Māori approach
Mahi—work, activity, exercise, operation, function
Mātauranga Māori—Māori knowledge
Mihimihi—greetings
Pākehā—NZ European
Poroaki/whakamutunga—conclusion/farewell
Pōwhiri—welcome ceremony
Tamariki—children
Te Tiriti o Waitangi—the te reo Māori text of The Treaty of Waitangi
Tikanga Māori—Māori customs and protocols
Whakawhanaungatanga—making authentic connections and relationships
Whānau—family

Barriers to entry for keratoconus patients to corneal cross-linking services in provincial New Zealand: a patient and family qualitative research project

Colin Parsloe, Malcolm Naude, Joshua Read

ABSTRACT

AIM: Keratoconus is characterised by progressive corneal thinning and protrusion, leading to vision loss. Despite the availability of treatments to arrest its progression, patient outcomes in New Zealand are limited by delayed diagnosis and treatment. This study aimed to identify barriers to early diagnosis and treatment of keratoconus among patients in New Zealand, focussing on improving outcomes and reducing health disparities, particularly among Māori and Pacific populations.

METHODS: A focus group was conducted with 11 participants, including whānau and patients with serious or progressive keratoconus who underwent corneal cross-linking at Rotorua Eye Clinic. Participants shared their experiences navigating the keratoconus care pathway from initial symptoms to treatment. Grounded theory and thematic analysis were employed to identify key barriers and suggestions for improving care delivery.

RESULTS: Four themes emerged. Firstly, there were barriers to initial diagnosis. The main challenges included a lack of awareness of keratoconus and delays in referral to ophthalmology. Secondly, participants discussed challenges faced in accessing ophthalmology services, including lack of communication and financial and logistical issues. Thirdly, keratoconus significantly impacted their quality of life. Patients and whānau reported emotional, social and occupational burdens. Participants emphasised timely diagnosis and consistent referral pathways to avoid the morbidity they experience. Finally, we discussed suggestions for improving the keratoconus patient pathway. Suggestions included community education, school-based screening programmes and clearer patient education at the point-of-care.

CONCLUSION: Significant barriers hinder early diagnosis and treatment of keratoconus, exacerbating its impact on quality of life. School-based screening and targeted education campaigns could expedite diagnosis and intervention.

Keratoconus is a corneal ectasia that causes progressive thinning and protrusion of the cornea.[1] The resulting irregular astigmatism leads to vision loss.[1] Recent studies indicate that the prevalence of keratoconus in the general population is fivefold to tenfold higher than previously reported.[2] This rise is likely due to increased awareness and the growing use of corneal topography in routine optometric practice. In a 2017 study from the Netherlands, the prevalence of keratoconus in the general population was 1:375,[2] while in 2019 in the Māori high school population of New Zealand, it was found to be significantly higher at 1:45.[3] Additionally, epidemiological data found Māori were 2.25 times as likely to have keratoconus than New Zealand Europeans.[4] The cause of this is likely multifactorial, including Māori having higher rates and more severe atopy, obstructive sleep apnoea and genetic differences.[5]

Advances in treatment

Recent advancements in the treatment of keratoconus, including simplified corneal cross-linking procedures and improved post-operative care protocols, have significantly enhanced our ability to retard or arrest keratoconus progression.[6] Despite these advances, anecdotally we find that most of our referrals continue to present with advanced keratoconus.

Importance of early intervention

Early intervention is crucial in the management of keratoconus to help preserve functional vision. Patients diagnosed at an early stage

can often maintain vision with glasses alone. Delayed diagnosis typically necessitates the use of contact lenses, progressing from soft to hard contact lenses or scleral lenses as the disease advances. Advanced keratoconus can result in rapid corneal opacification, requiring corneal transplants, and rarer complications can be blinding.[1]

Objective

This study aimed to identify the barriers preventing patients from being diagnosed and treated with early-stage keratoconus. By understanding these barriers, we aimed to develop strategies to expedite diagnosis and intervention, leading to improved patient outcomes.

Methods

The focus group consisted of 11 whānau members and patients who had undergone corneal cross-linking at the Rotorua Eye Clinic. All participants resided within a 1-hour drive from the clinic.

Ethical approval for this study was obtained from Health New Zealand – Te Whatu Ora Lakes Research and Ethics Committee (REC #20241001). All participants provided informed consent, and our study complied with all the ethical standards of the *Code of Health and Disability Services Consumers' Rights 1996*.

The moderator of the focus group was one of the treating clinicians, and two other treating clinicians participated and observed the focus group. This was recognised to be a potential source of bias. As a result, it was explained to participants that the moderator was not providing their opinions, and all feedback was welcome. As the topic for discussion was primarily the experiences before treatment in our clinic, we did not think that the presence of the treating clinicians significantly affected the data collected.

Participants received two emails outlining the research aims prior to the focus group. At the start of the meeting, participants were invited to share their experiences as experts, having navigated the process from diagnosis to referral.

The audio recordings were transcribed, and grounded theory, a qualitative research method that systematically develops theories based on patterns emerging from the data, was applied to identify themes within the data.[7] The data were coded using the Delve qualitative research coding software.[8] All three researchers participated in coding the transcribed documents. Through thematic analysis coding we identified three key themes across our qualitative dataset. This methodology ensured that the themes presented in this paper accurately represent the participants' experiences.

Participant selection

We identified participants by reviewing the records of patients who had undergone corneal cross-linking at the Rotorua Eye Clinic over the past 23 months. During this period, 233 corneal cross-linking procedures were performed on 171 patients. The clinic's catchment includes the Bay of Plenty, south-eastern Waikato and, previously, Gisborne. Referrals were made by optometrists, general practitioners (GPs) and ophthalmologists. We excluded patients who had travelled from Gisborne for treatment (as this is a 4-hour drive away) and eight who had previously been involved in a focus group, and we removed duplicate names from the list. We then invited the remaining 124 patients to attend. This was done with a series of emails and follow-up telephone calls.

The mean distance travelled for these procedures was 54km, compared with 12.5km in a recent city-based study in Auckland.[9] The demographic breakdown of our patient population was as follows: Pacific peoples 7%, Māori 61%, Europeans 27%, Asian 3%, Middle Eastern, Latin American and African (MELAA) <1% and not declared 1%. The mean age of our cohort at the time of our focus group was 25.24 years, range 13–61 years.

Pilot focus group

We previously conducted a pilot focus group. An initial attempt to run the pilot focus group included only those with a Rotorua postal address to ease travel. Despite 12 agreeing to participate, only one attended. To improve participation in this focus group, we invited 124 patients and offered $50 remuneration per participant. Twenty-two agreed to attend and 11 attended. No reason for non-attendance was supplied.

Focus group composition

In addition to the 11 participants and three researchers, there was a representative from our local iwi who left after the mihi (traditional welcome).

Participant demographics with self-reported ethnicity and their visual acuities are presented in

Table 1: Demographics of focus group participants who had undergone corneal cross-linking.

Participant number	Ethnicity	Age	Sex	Visual acuity			
				Unaided right	Unaided left	Best corrected right eye	Best corrected left eye
1	Asian	16	Male	6/76-1	6/95-1	6/7.6-1 scleral contact lens	6/9.5-1 scleral contact lens
2	Māori	33	Male			6/15+2 glasses	6/48-2 glasses
3	European	29	Male	6/9.5-2	6/60-1	6/7.5 glasses	6/24+2 glasses
4	Māori	21	Male	6/7.6+2	6/19-2	6/4.8 glasses	6/12-1 glasses pinhole 6/6-2
5	Māori	30	Male	6/12-1	6/60-1	6/6+2 contact lens	6/7.6 contact lens
6	Māori	23	Female	6/19-1	6/12-2	6/6 glasses	6/7.5+1 glasses
7	Māori	62	Female	N/A	N/A	N/A	N/A
8	Mauritian	28	Female	N/A	N/A	N/A	N/A
9	Asian	54	Female	N/A	N/A	N/A	N/A
10	Māori	15	Female	N/A	N/A	N/A	N/A
11	Māori	13	Female	N/A	N/A	N/A	N/A

Visual acuities were measured using a Snellen acuity chart at 6 metres.
(Participants 7–11 were whānau members, so visual acuity was not measured.)

Table 1. The 11 participants included six patients who had undergone cross-linking, two participants' mothers, a participant's partner and a participant's two daughters. The youngest participant who had been cross-linked was still in high school. The mean age of those who had undergone cross-linking was 25.3. Ages ranged from 16 to 33 years and 71.4% were male. Sixty-six point seven percent of our participants were Māori,16.7% were NZ European and 16.7% were Asian.

Data collection

Interview guide

The focus group commenced with a traditional karakia (prayer) led by the representative of the local iwi, who then facilitated the formal introduction of the participants and researchers. After the introductions, the iwi representative left the focus group.

The moderator then outlined the ground rules, emphasising voluntary participation, confidentiality, sensitivity to personal rights, dignity and diversity, and the goal of advancing and protecting society through the knowledge gained. Wall posters highlighted the following guidelines: respect others' opinions; everyone has a chance to speak with no side discussions or interruptions; there is no single correct answer; all ideas, experiences and

opinions are valuable; we need to know both the good and bad of your experiences. Opinions of both children and adults were deemed equally important. Results would be anonymised, with participant numbers allocated to each participant.

All participants provided written consent, and we adhered to strict data protection principles. The meeting was audio-recorded, and three researchers took notes during the focus group. The karakia and introductions took 20 minutes, and the focus group discussion lasted just over 60 minutes. An immediate post-group discussion was held by the researchers, culminating in a final summary of our findings. All documents were handed to the moderator and stored in a locked cupboard. Transcripts were not returned to participants for review as the audio recording was transcribed verbatim. A pilot focus group had previously been held, and no follow-up interviews were conducted

Results

Our analysis of the data pointed to four major themes:

1. Barriers to initial diagnosis
2. Reasons for delayed cross-linking
3. Impact of keratoconus on their lives
4. Suggestions to overcome some of these barriers

Theme 1: barriers to initial diagnosis

The first significant theme that emerged was the barriers to timely diagnosis of keratoconus. Many participants shared that a lack of awareness about keratoconus was a critical issue. They often rationalised their symptoms or attributed them to less-serious causes. A trigger event often pushed them to consult their optometrist. Some participants then required several optometry appointments before they were referred to ophthalmology.

Neither the participants nor their whānau were aware of keratoconus prior to their diagnosis. They frequently attributed their symptoms to other causes—for instance, one participant said, "*I played* [video games] *every day after work for about 2 years, and I thought it was my vision got bad because of that*", and another said, "*Thought it was just a genetic thing, my grandmother and my great grandmother had to wear glasses.*"

Interestingly, teachers and GPs were not involved in our participants' referrals or diagnoses. All participants went to an optometrist.

Keratoconus has an asymmetrical presentation; the participants were able to adjust to the gradual unilateral change until the fellow eye deteriorated. The incipient nature of the onset of keratoconus in the teenage years occurred along with many other body changes. As a result, participants were less aware of their symptoms developing. For many, the age of onset was hard to pinpoint. All participants reported rubbing their eyes. Squinting or frowning along with elongation of lights were common early symptoms. Surprisingly, family history was rare in our cohort. Four participants used computer screens 5–10 hours per day but two did not have significant screen time exposure.

Additionally, part of the delay in going to optometrists included avoiding the stigma of having a condition: "*It got to a point where I couldn't see the white board, but I didn't want to say that I was blind because I would have to wear glasses, and I didn't want to have to wear them.*" Another reported being "*quite introverted, didn't want to go anywhere, super shy, so I never wanted to go to any appointments. Yeah, I'm better now, but I think it is kind of intimidating, not for everyone but for me it was.*" Parents' tight schedules delayed one high school participant's presentation to optometry.

Participants often only attended their optometrist once the vision in their better seeing eye deteriorated. There tended to be an external event, a common one being failing their driver's licence eye test. Driving is one of the most impacted activities. One participant remarked, "*With driving the lights are just blurry. They fill up my whole vision and I can't see. I'm blinded by the light*." (His corrected vision is 6/9.5 right and 6/24 left.)

Theme 2: barriers to ophthalmology appointment and surgery

Barriers to attending ophthalmology appointments and surgeries emerged as a significant challenge. Participants frequently reported a lack of urgency to pursue treatment, often stemming from inadequate communication about the seriousness and progressive nature of the disease. One participant had been given information by their optometrist, who said, "*It is a big cost, so it is not something that most people can afford.*"

One participant explained, "*I think there was no sense of urgency, or it didn't seem that serious at the time, so I didn't really take it seriously, but I think that if I'd known, yeah I definitely would have been more careful.*" Another added, "*I just couldn't be bothered. I'd prefer to just stay in bed instead of*

Table 2: The age of onset of patients' symptoms and the age they were referred to ophthalmology.

Participant number and current age	Age when first aware of visual problems	Age of diagnosis and referral to ophthalmology
1) 16 years old	First symptoms "*when I was 13 or 14, so now I'm 16, turning 17 this December. The eye rubbing started from earlier, around 8.*"	**Referred age 15** to clinic immediately after first optometrist visit.
2) 33 years old	Started wearing glasses in primary school after his school nurse took him to the optometrist. Vision worsened rapidly from age 26. Prescription increased from −1.00 to −9.00 over 5 years.	**Referred to clinic age 31.**
3) 29 years old	At age 18 was still able to pass driver's test. At age 26 he failed renewal of driver's licence and referred to optician, initially no clinic referral made.	Rapid progression when optician saw him for his 2-year review. He was **referred age 28**.
4) 21 years old	Started wearing glasses in Year 10–11 (age 13–14) after his grandmother noticed him rubbing his eyes all the time.	Had noted marked loss of vision in left eye in Year 13 (age 17), only **referred age 20**.
5) 30 years old	Had blurry vision for 20 years—started around age 10, bad at age 18 through to early 20s. He delayed optician visit until he failed driver's vision test age 25.	**Referred age 27** after 2-year optometry review showed marked increasing cylinder in his prescription.
6) 23 years old	Started seeing an optometrist at age 11, who told her that she had keratoconus but had to pay privately for treatment. She has had 2-yearly prescription reviews with new glasses issued at each visit. Her vision has become significantly worse since age 20.	After seeking second opinion from new optometrist, she was immediately **referred age 22**.

travelling an hour to get here, but if I knew about the severity and the urgency of getting it done before it got any worse, then I probably would have come. I would have just got it over and done with."

As mentioned above, inconsistent referral patterns among optometrists also delayed some patients' access to surgery. While some participants were referred promptly at their first appointment, others experienced delays of many years. One participant recounted visiting the same optometry practice since the age of 11, only to finally receive a referral after switching to a new optometry practice at the age of 22. She shared that "*I was told* [that I had keratoconus] *when I was younger, I knew I had it, but up until just last year, every time I went there it was never brought up, and they didn't really tell me much about it either, so I kind of forgot that I had it until they referred me here.*"

The average distance covered by our patients to attend the 233 corneal cross-linking procedures was 54km. This is significantly further to attend appointments than in other settings, such as in Auckland.[9] One participant noted, "*I notice that the lower socio-economic class tends to be affected, and I wonder whether the Māori out of town might have difficulty finding assistance to come over, or whether they have approached WINZ* [Work and Income New Zealand] *for petrol vouchers but have been declined for one reason or another.*" These financial and time requirements have an impact on the whānau. One mother shared that "*I take*

turns with my husband. We share responsibility. I can't just take all my sick leave, so we take turns." Another participant said, "*I am lucky enough because my manager is supportive. For one appointment I took my annual leave*", but then her area manager said, "*No, for this one you can use your sick leave.*" The cost of fuel and taking time off work or depending on others all add to the difficulties of attending ophthalmology clinics.

Finally, fear of surgery also presented a significant barrier. One participant shared, "*When I read about the surgery, I was terrified. It was nerve-racking to think about the risks afterward.*" Another echoed this sentiment, stating, "*The unknown was so scary. Seeing my grandson in pain was hard, and I didn't know how to manage it.*" The post-surgical recovery process was particularly challenging, with some participants resorting to double doses of painkillers or using a whānau member's tramadol. These difficulties discouraged them from undergoing cross-linking for their second eye.

Theme 3: the effect of keratoconus on quality of life

Using qualitative research gave a unique perspective into the profound impact that keratoconus has on the quality of life of patients and their whānau. Many parents expressed guilt about delayed diagnoses. As a nurse, the mother of the 16-year-old participant (with uncorrected vision of 6/76-1 right and 6/95-1 left) was brought to tears as she shared her feelings: "*I felt guilty because if I caught it a bit earlier, maybe it wouldn't have been so bad, but now it is so bad that glasses do not work. Maybe the glasses would work if we got it earlier.*" Another parent echoed, "*I think mum and I both had a bit of guilt about having left it to that degree.*"

Participants often expressed frustration that their keratoconus was too advanced for glasses and required contact lenses instead. One participant noted, "*I don't like contacts sometimes because I wish I had had glasses. One time when I had RGPs* [rigid gas permeable contact lenses] *they were grinding against my eyes, so I went to the car to take them out, and it fell down in the car seat… but yeah, but my eyesight got so bad to the point where I couldn't get glasses. With the contacts I've had to get additional products like saline, cleaner. It's really expensive too.*" Intolerance to contact lenses and the associated costs, such as contact lens resizing and cleaning solutions, were frequent complaints.

The condition also affected participants' daily lives, education and employment. One participant, a painter, shared that he misses fine details and his boss may fire him soon. Another participant, working in hospitality, explained that she must ask colleagues to read the orders because she cannot read fine print.

The emotional toll of keratoconus was significant. The 16-year-old participant, whose ambition it had been to study medicine, was clearly very saddened as he shared: "*I just think about, how am I going to deal with this for the rest of my life, with keratoconus, this chronic condition, you know. I'm going to have this every single day of my life* [long pause]. *It's a lot and sometimes I don't want to do this anymore* [long pause]. *Why do I have this condition? Why can't, it sounds a little selfish, but why can't I just be normal. So, it does get tiring. I think sometimes about jobs and stuff I want to do, it's like, I can't do that because of my eyes, or how am I going to do this, because of my eyes. It has had a big impact on me.*"

Theme 4: suggestions for improving the ease and speed of diagnosis and treatment

Participants provided several suggestions to improve the keratoconus pathway. They stressed education of students, parents, schools and the wider community. One participant stated that they "*only know about keratoconus because it has affected us, or it has affected ones we love. So, I think if we want to raise awareness, we have to raise awareness to everybody.*"

School-based screening programmes were a common recommendation. One participant proposed that "*a mobile optometrist, like the mobile dentist at school*" could help detect keratoconus early. Intermediate schools were suggested for initial screening. Educating teachers and having information in school newsletters and school intranets was suggested.

In addition, educating parents was highlighted, as one participant said, "*If your kids are squinting or rubbing your eyes, don't take it too lightly.*" They suggested that GPs should be aware of the condition so that when patients present with atopic-related complaints their GP should have a discussion around keratoconus.

Community education was another critical focus. A mother emphasised, "*Parents need to know the signs. A video showing how rubbing your eyes can damage them would really help.*" Social media campaigns were also suggested, with a

student participant advocating for videos on YouTube to raise awareness.

Better information at the point-of-care was also seen as essential. Pamphlets from optometrists provided valuable insights for some participants, while others relied on online resources to learn more about their condition. Participants highlighted the need for accessible and clear educational materials to help families understand keratoconus and its implications, advising that there was a lot of misinformation on social media.

With raised community awareness, this will help those currently with keratoconus. One participant suggested, "*I feel that us as keratoconus patients we don't have a voice, sometimes. People just don't know what it is, don't know what we are suffering from. You can't really say without going down this whole tangent and explaining it. It just becomes tiring.*"

Discussion

Keratoconus is a common cause of progressive vision loss in adolescents and adults. The advent of cross-linking has revolutionised the treatment paradigm, proving a safe method of reducing keratoconus progression.[6] A major challenge with management of keratoconus in a population is that the best opportunity for cross-linking treatment is in the early stages of progressive disease. Detecting early cases can be challenging as they may appear to have uncomplicated myopia. Detecting progressive cases can be challenging as it requires continuity of care and regular follow-up. Special attention must be paid to Māori and Pacific populations as they experience higher rates and greater severity of keratoconus.[3,5,9] Unfortunately, these groups also have lower ophthalmology clinic attendance.[9–11] To achieve equitable outcomes, we must understand the reasons for this, then develop strategies to address them.

This study identified several major barriers to the diagnosis and treatment of keratoconus. The main barriers mentioned were a lack of awareness of keratoconus, difficulties travelling to appointments, variable optometry referral patterns, the lack of a sense of urgency regarding treatment and fears of surgery. In addition to affecting the participants' quality of life, delayed diagnosis and treatment of keratoconus was a source of guilt for parents and loss of opportunities for those with the disease. Participants suggested improving community awareness of keratoconus and implementing screening in schools would have expedited their journeys.

While this is the first focus group exploring barriers encountered by patients on their keratoconus journey, prior research has suggested similar themes. Surveys of optometrists highlighted the lack of standardised referral criteria and patient education material as a hindrance to the diagnosis and management of keratoconus.[12,13]

Additional research echoes insufficient communication and costs as reasons for Māori patients' disengagement with healthcare.[14] These themes are not unique to ophthalmology, with lower rheumatology clinic attendance being associated with younger patients, Māori or Pacific ethnicity, longer waiting times and living further from the clinic.[15]

This study identifies key areas where efforts should be made to improve the keratoconus pathway. A national screening campaign presents an elegant solution, as it would tackle both major themes. Implementing a school screening programme would educate parents through parental information packs for informed consent, increase teacher awareness of the disease and remove the need for students to take the initiative to be tested at an optometrist. Upon diagnosis, patients could receive information about the progressive, irreversible nature of the disease and details on free eye tests and financial support for contact lens costs. A similar model has been implemented for dental care in schools throughout New Zealand.[16]

This study has several limitations, most notably our sample's susceptibility to survivorship bias and small sample size. We only contacted patients who had undergone cross-linking, thereby only including those who were already engaged with ophthalmic care. Despite contacting 124 patients and 22 agreeing to participate, only 11 attended. It is possible that those who attended tended to be more satisfied or dissatisfied with their journey. Strengths of our study include the high proportion of Māori participants. Sixty-one percent of our participants identified as Māori despite Māori only making up 24.7% of keratoconus cases in New Zealand.[4] Secondly, the nature of our meeting meant that the participants all had the opportunity to share their own unique barriers on their journey. Despite this, common themes became apparent.

In conclusion, this study provides several targets for optimising the patient journey for those with keratoconus in New Zealand. Further research is required to determine what strategies are most efficacious.

COMPETING INTERESTS
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Whānau-reported experiences of safety netting discharge advice in a paediatric context: a quality improvement project for Kaitaia Hospital

Nicola-Mary Geraghty

ABSTRACT

AIM: The aim was to identify the strengths and weaknesses of safety netting advice given on discharge received by whānau for Kaitaia-domiciled paediatric patients in Aotearoa.

METHODS: Semi-structured phone interviews were conducted with whānau of Kaitaia-domiciled paediatric patients who were discharged from either the Kaitaia or Whangārei Hospitals from March 2023 to August 2023. Whānau were primary caregivers of the paediatric patients and were asked 11 questions about different aspects of discharge advice, content and delivery.

RESULTS: Code saturation revealed five themes under the central theme of communication: 1) mode of communication, 2) opportunity to ask questions, 3) diagnostic and prognostic uncertainty, 4) confidence to manage at home, and 5) red flag recognition.

CONCLUSIONS: Discharge advice given to paediatric patients' whānau was not consistently given in a standardised way from the Kaitaia and Whangārei Hospitals, suggesting that this could be a nationwide service issue. Therefore, this project suggests that a standardised discharge advice guideline may be an optimal way to ensure consistent advice for patient safety and whānau confidence.

Rural communities often have limited resources and tend to be the farthest away from base hospitals despite experiencing poorer health outcomes than their urban counterparts.[1] Kaitaia is one such rural town that shares these health characteristics, serving a dispersed population of 21,000 with only a 28-bed hospital.[1,2] The entire population in Kaitaia is located over 100 minutes from the nearest base hospital in Whangārei, a 246-bed secondary hospital.[3,4] While less ethnically diverse than urban regions, rural areas have a higher proportion of Māori residents.[4,5] Te Tai Tokerau (Northland) reflects this demographic pattern, with Māori tamariki (children) comprising 65% of the region's child and youth population.[1,5–7]

Effective discharge advice for tamariki and their whānau can improve post-hospital outcomes, particularly in rural settings.[8–11] However, there is no nationwide standard for how this advice is communicated or documented, likely leading to inconsistencies across hospitals and clinicians.[11–15] One key component is safety netting, which was first formally described in primary care as a method of communicating diagnostic uncertainty.[10] In secondary care it appears less clearly defined and is often used synonymously with red flag advice.[10] Patients and whānau may not recognise it as a distinct practice either, and, when poorly implemented, it can leave them feeling dismissed.[1,4]

This project proposes that all hospital discharge information—both verbal and written—should be formally conceptualised under the broader framework of safety netting. This approach recognises safety netting as a scaffold for conveying the full context of a hospital admission, helping patients and their whānau understand and manage their care.[10,11,14,15] To support this project, the author independently conceptualised and illustrated an original visual metaphor to redefine paediatric safety netting as follows: see Figure 1, Table 1.

This conceptual framework underpins the investigation into how effective current discharge practices are for Kaitaia-domiciled paediatric patients. The interview questions used in this project explore whether whānau received key elements of safety netting, recognised as essential components of hospital discharge advice.[16,17] By assessing the completeness of these practices, this project aims to identify areas for improvement and ultimately enhance post-discharge outcomes for tamariki and whānau.

Figure 1: Safety netting depicted as a metaphor of fishing with a net. Original contribution of an iPad drawing created personally by the author in this quality improvement project.

Table 1: Description of the aspects of the safety netting picture extended as a metaphor.

Aspects of safety netting picture	Meaning
Stream/awa	The stream/awa represents the hospital journey/admission. Like the hospital, water is healing in nature. Water is also transparent, representing accessibility and transparency of information.
Fisher person and fish/ika	A fisher person represents a healthcare clinician, either doctor or nurse. The fisherperson aims to catch the seven fish/ika (seven key concepts) in their net or to harness the information. The fisher person is going to *share* the fish with the child and their whānau. The fish will satiate the child and their whānau, representing being *filled* with knowledge. The fisher person is responsible for pulling out fish that people will know how to cook—in other words getting information that will be digestible. From this metaphor, it also becomes more obvious that the fisher people do require a certain level of competence at "fishing".
Fishing net/kupenga	The net represents the delivery of information including the communication style and format of advice (verbal or written). The more effective the communication, and the more forms of advice given, the more robust the net and the smaller the holes in the net.
Meaning of the fishing net metaphor	The fishing net metaphor gives autonomy and agency back to the patient and their whānau. The language used in the metaphor implies *nourishment* of people so that they have enough information and whānau and their children are empowered to have autonomy of their health.

Methods

Study design

A qualitative study method was used to focus on the phenomena of safety netting advice given upon discharge. The study design was semi-structured phone interviews, with participants also offered the option of in-person meetings at the hospital.

Study setting

The quality improvement project was conducted at Kaitaia Hospital in Te Tai Tokerau, Northland, Aotearoa, over a 9-week period.

Participants

Eligibility criteria: The project included Kaitaia-domiciled paediatric patients (aged 0–16 years) discharged from either the Kaitaia paediatric inpatient service or the Whangārei paediatric inpatient service between March 2023 and August 2023.

Exclusion criteria:

The following exclusion criteria were applied:

1. Paediatric patients who had self-discharged or departed without formal notification
2. Cases where patient caregivers who were not contactable via the Regional Clinical Portal details
3. Patients not domiciled in the Kaitaia area
4. Patients transferred back for 1-day multidisciplinary team input following admission at Starship Hospital
5. Length of stay of 0 days (admitted and discharged on the same day)
6. Patients admitted to the emergency department only (and not transferred to an inpatient ward)
7. Cases with no existing electronic records in the Regional Clinical Portal, even if alluded to in the original dataset

Reasoning for exclusion criteria is that for many of these cases, contact details of the caregivers would not have been able to be found and/or no formal discharge summary would have been available for these cases.

Sample size

The final project sample comprised 23 whānau participants, all of whom were primary caregivers of the eligible paediatric patients.

Recruitment method

Participants were recruited by phone call if they had been listed on clinical records as “Emergency Contact 1”. During this initial contact, potential participants could consent to a phone interview, reschedule for an alternative time they could consent to a phone interview, reschedule to an alternative time or decline participation (see Table 2). If the first call to whānau went to

Figure 2: Paediatric patients included in quality improvement project by discharge hospital service.

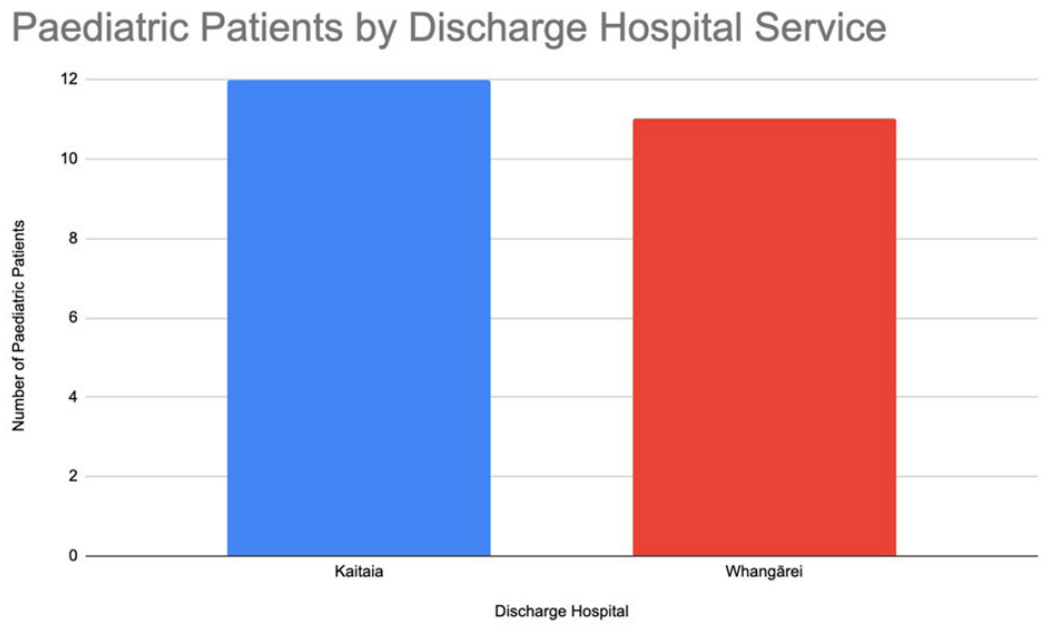


Figure 3: Paediatric patients included in quality improvement project by ethnicity.

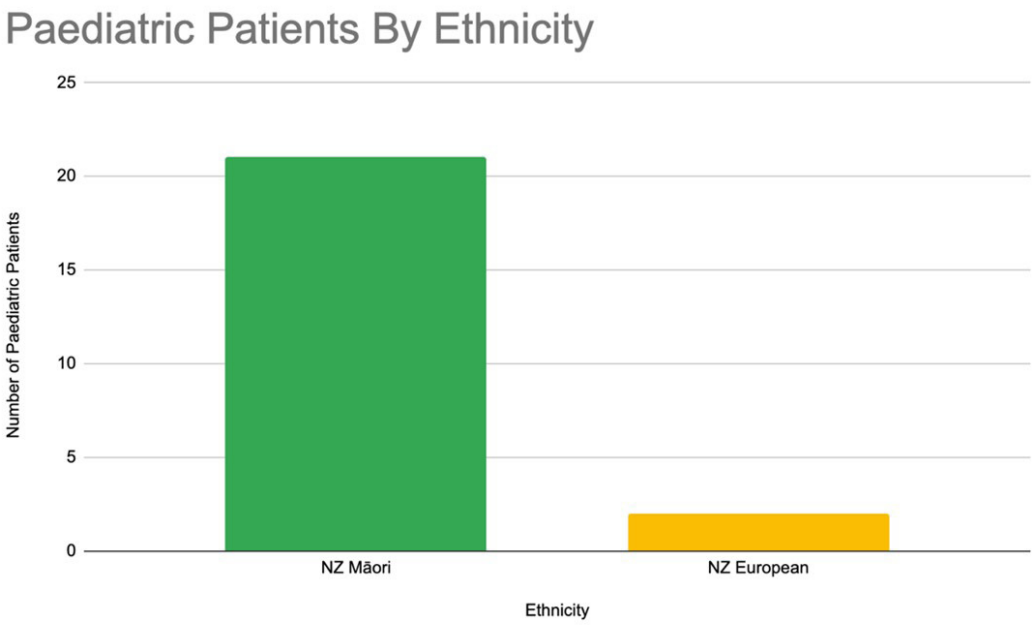
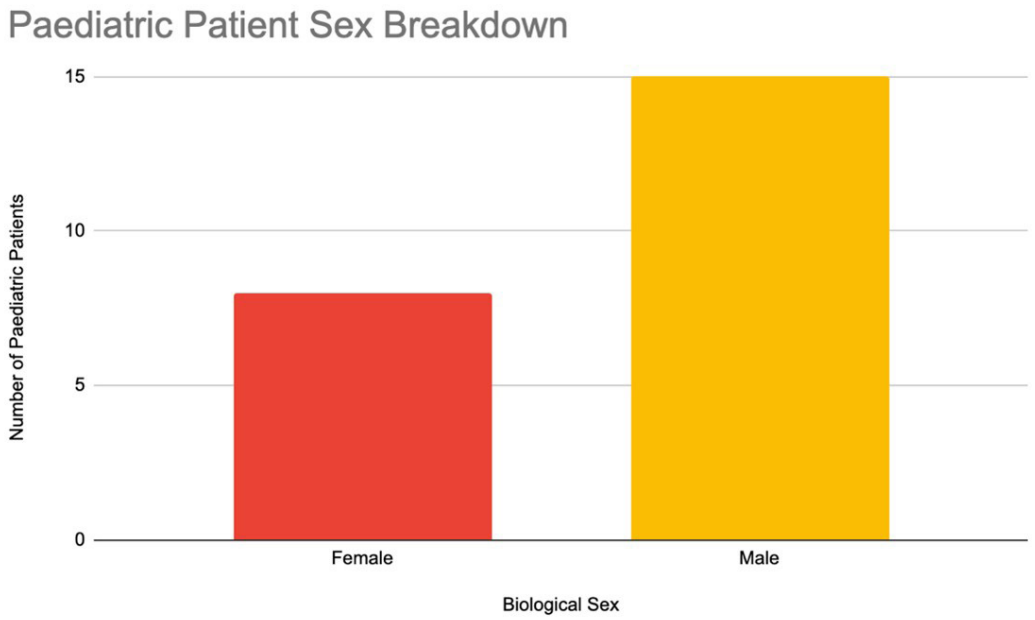


Figure 4: Paediatric patients included in quality improvement project by sex.



voicemail, a text message was sent using the "mtxt" email extension service (see Table 3). This service allowed participants to respond free of charge to reschedule or to request further information.

Data collection

If participants agreed to participate, they were informed about the confidentiality process (see Table 4) and then they were asked 11 questions designed to address the study objectives as outlined in Table 5. Interviews lasted approximately 15 minutes each.

Data analysis

Data were transcribed in real-time onto a password-protected Excel sheet during the interviews.

Table 2: Obtaining verbal consent.

Obtaining consent
I have 11 questions and it should all take about 15 minutes. All your answers will be confidential and answering these questions is voluntary. If you'd like to give us your feedback, is now a good time?
Based on feedback would then prompt: • Would you like to arrange another time? OR • Would you prefer to arrange to meet in person at the hospital? OR • If you would prefer not to be involved, that is okay. Thank you for your time.

Table 3: Email mtxt script that was sent to participants ,with 160-character limit.

Email mtxt script
Kia ora, I'm a student doctor at Kaitaia Hospital. Could we arrange a time to talk about your experience of your child's discharge with us? +Nicola-Mary

Table 4: How confidentiality was explained to participants.

Notes and confidentiality
Before we start, I'd like to let you know that I will be typing down notes as we speak. Your name is never attached to your comments, and in the write-up there are no identifying features. All notes will be securely disposed of. Is that okay?

Table 5: Interview questions participants were asked and their associated objectives.

Interview questions	**What question is trying to ascertain**
1. Did you receive enough information to understand what was going on for X when they were in hospital?	Diagnosis, progress in hospital
2. Were you given information when X was leaving from Kaitaia/Whangārei Hospital? Was this verbal, written or electronic? If you received more than one, was one more helpful than the other?	Importance of verbal and/or written information
3. Who gave this information to you? Do you remember if this was a doctor or nurse or another member of staff? (If answer receptionist, ask did the member of staff talk about what was going to be in the letter?)	Delivering of information

Table 5 (continued): Interview questions participants were asked and their associated objectives.

4. Was the way you received your child's/moko information helpful?	Information tailoring to individual, relevant to family
5. Were you given the opportunity to ask questions about discharge advice for your child/moko? If yes, did you get the answers that you needed?	Opportunity to ask questions, comfortability with staff
6. Were you given enough information about how to look after X at home in the days after leaving hospital?	Information about pain relief/management at home
7. Based on the advice you received, would you have known how to look after X at home if things got worse?	How to manage at home if things get worse, time course of illness
8. What information were you given about what to look out for in case X needed to go back to hospital, or you needed to call an ambulance?	Specific red flags/return advice
9. Were you given advice on who to contact if you had any questions?	Information about how to seek help or ask follow-up questions
10. Was there anything about the information you got before leaving hospital that you found helpful or not helpful?	Ability to discuss general feedback around discharge advice
11. Is there anything else you'd like to tell me about X's discharge?	Ability to discuss any compliments or complaints

The collected data were subsequently analysed using the principles of thematic analysis by the author (one person). Code saturation was achieved during the analysis process.[18]

Results

The main hierarchical theme that emerged from this project is communication, with the following subthemes identified falling under this broader category.

Theme 1: mode of communication—verbal vs written

Participants recalled which staff provided verbal discharge advice, often identifying staff by their role as nurses or doctors. Aria (pseudonyms used) noted that the "*doctors were very good*" and described the "*nurses* [as] *lovely*", indicating that friendly communication improved rapport. The language used by respondents suggests that perception of communication was closely linked to perception of clinician knowledge.

Discharge information varied in consistency, sometimes being verbal, written or not received at all. This variability highlights the need for consistent discharge advice, crucial for patient safety. Ruby remarked that the "*pamphlet that had all the information was easier to follow, rather than the doctor's notes … because they had their lingo in* [the] *doctor's notes*", suggesting that medical jargon can hinder understanding.

Participants who received both verbal and written discharge information found it beneficial. Keira said, "*Verbal and written was good together and needed each other*", while Hannah noted, "*Both were helpful. Hearing it, I would have forgot information without the letter*." Aurora added that it was useful to "*hear it because we were able to process it at the time*" and refer back later. This indicates that having both modes of communication helps in retaining and understanding information.

Participants varied in their preferred method of communication, often favouring one mode of information. Some expressed a desire for the communication method they did not receive. These preferences emphasise the importance of providing both verbal and written discharge information to accommodate individual needs and maximise information retention.

Non-verbal communication also impacted par-

ticipants' experiences. Some felt staff were vague in their choice of language, interpreting this as unprofessional. Some participants' comments highlighted that whānau interpret indirect encounters, leading to misinterpretations of staff actions. Mila recounted that "*the bone surgeon came into the room and bypassed us*", highlighting how staff behaviour affects whānau perceptions of staff. That comment also shows a lack of understanding of the discharge process as it is often the house officer who is responsible for collating information on discharge, as opposed to the consultant. This quote suggests that clear communication about discharge procedures and staff roles is necessary.

Theme 2: opportunity to ask questions and gain meaningful answers

Most participants felt they had the opportunity to ask questions and receive answers. For instance, Hannah appreciated a staff member who, if unsure, would find out answers, saying, "*Got the answers I wanted. If the nurse didn't know, she would find out*." George felt satisfied with the information he received about his daughter, stating, "*I'm no doctor but I understood what she was going through and how I as a dad can help her*." This suggests that these participants were generally pleased with the clarity and appropriateness of the communication.

However, some participants had different experiences. A few were not given the chance to ask questions or did not get satisfactory answers. It appeared that some chose not to pursue answers further once their child began to recover, possibly due to perceived staff stress or discomfort. One participant expressed confusion about the management plan even after leaving the hospital, highlighting the need for clearer communication. Willow felt frustrated when advised to buy a "*heart machine at the Baby Factory for $500*", noting, "*I thought where the f*** am I going to get that money*." This comment suggests that staff may not have fully considered the financial constraints of patients and their families.

Another participant, Tui, mentioned how external stressors, like being a single parent, can impact the ability to ask questions. Tui said, "*If it's the first time, I don't know what to ask. I'm very panicky about it because I'm a single mum with … children. I'm at home by myself and I don't do well with things like that*." This highlights the need for additional support and clear communication for caregivers facing significant personal challenges.

Theme 3: uncertainty about diagnosis and prognosis

Some participants felt the diagnosis was communicated effectively, which helped reassure them about their child's care. For example, Tiana appreciated that staff "*took the time to sit down and make me feel comfortable and give me enough advice to stay the second night*", indicating that clear information about the illness and its course helped her feel more at ease with the extended hospital stay.

However, some participants sensed diagnostic uncertainty and felt it was not always openly addressed. Manaia expressed a desire for more communication about management and noted "*side eyes between doctors*" when suggesting antibiotics. She later observed that the doctors seemed "*surprised it worked*", suggesting that the diagnosis and management plan were not fully communicated, leading to feelings of disrespect and confusion.

Willow's comment highlights issues with communicating uncertainty: "*You can't tell me what's wrong with her, except for the murmur but you don't know why she's stopped breathing*." This underscores the need for clear communication about uncertainties in diagnosis.

Participants also valued information about the illness' time course and expected recovery. Some were surprised by the actual recovery time, indicating that this aspect is not always well communicated. When provided with clear information about the illness and its expected course, participants felt more positive about the care received.

Theme 4: confidence to manage at home

Participants varied in their confidence about managing their child's illness at home. Some felt confident due to factors like adequate information, hospital proximity, having a contact number and previous experience. Amaia noted, "*What made it easier is that my daughter had something similar*", suggesting prior experience helped her feel more prepared.

Interestingly, not all participants attributed their confidence to staff communication. Kaia said she "*felt like it was more instinct*", implying she relied on her own judgment rather than staff advice. Niko also mentioned he would care for his grandchild "*totally on instinct*", indicating a reliance on personal instinct or a lack of home management advice.

Participants preferred being informed about

future care plans and often compared their current experience with past hospital admissions. Aria noted that the "*asthma plan was better in Melbourne Hospital*", suggesting she felt that the expertise there led to quicker recovery.

Pain management was a significant concern for caregivers. Anahera found staff "*very clear on pain relief*", and many participants focussed on pain relief when discussing home management. Moana mentioned that staff "*gave* [her a] *prescription and what to do with it*", indicating that pain relief was well communicated but other aspects of home care may not have been fully covered.

Theme 5: red flag recognition and returning to hospital

Red flag recognition helped some participants feel comfortable going home, as long as they knew what symptoms would necessitate a return to the hospital. For example, Tiana mentioned that staff "*gave advice about breathing … and for fever but reassured that tired would be normal. If he can't be woken and not responding, this might indicate that he can't get enough oxygen*", showing good understanding of when to seek further care.

One participant, Tui, did not receive red flag advice but did not find it crucial, stating, "*Not getting this information was not a big deal with me because I'm used to dealing with two boys with autism*." Tui appears to take personal responsibility for managing symptoms and preventing issues.

Some participants received advice on who to contact with questions while others did not. For example, Naomi said, "*I was not given advice on who to contact for questions*" but added that she thought, "*This is because they made sure I understood everything*." Ava also noted, "*We weren't given advice for if it was worse. I think it was because we were already at the worse point*." This suggests that participants often justify missing information rather than attributing fault to the hospital. Despite this, they sought additional information from family or friends.

Discussion

Although a small-scale project, this study highlights the need for further work on discharge safety netting across Aotearoa. It identifies key components of effective discharge communication and reveals gaps in how whānau receive and interpret information. While the findings are specific to a rural context, many of the themes are likely generalisable to regions with similar population dynamics or resource constraints. This project provides a foundation that can be adapted to audit discharge practices elsewhere in the country.

One key limitation is that the primary investigator is the sole researcher. As a Pākehā woman interpreting the experiences of predominantly Māori participants, the researcher may have encountered cultural blind spots. The researcher's positionality and the historical power imbalance between researchers and Indigenous participants in healthcare remain an important consideration.[6,19] To address these concerns, the researcher sought advice from Kaitaia Hospital colleagues including emergency department doctors, nurses, outreach services, social workers, physiotherapists and the hospital takawaenga (liaison support). This was to review and adapt interview questions for cultural relevance. From these discussions, the importance of the tuakana-teina dynamic (denoting senior and junior relationships) emerged. In response the researcher incorporated respectful language such as whaea (denotes respect for older woman) and matua (denotes respect for older man) into her vernacular, and used inclusive terms when referring to the hospital to reduce hierarchical or Westernised connotations.

Time constraints by concurrent student placement responsibilities for the researcher may have limited participant recruitment. However, the impact of this limitation is likely minimal, as code saturation was reached during data analysis. Thematic analysis was also conducted solely by the author, which may have limited interpretive depth compared to multi-author qualitative studies.

Conclusion

This quality improvement project explores paediatric caregivers' experiences with both written discharge summaries and verbal discharge advice. Thematic analysis reveals five key themes, with communication emerging as a central factor influencing caregiver satisfaction and patient safety after discharge. The findings highlight that caregivers have varied experiences with discharge advice, pointing to the need for clearer, more standardised discharge processes. These experiences could inform the development of regional or national guidelines for discharge procedures. Given the high concern for vulnerable children, whānau are eager for clear information from clinicians. This underscores the importance of implementing clear safety netting and discharge

advice guidelines, particularly when junior staff are responsible for compiling discharge documentation.

Note: The use of the country name Aotearoa to describe New Zealand has been popularised within the lexicon of New Zealanders as a demonstration of commitment to equity under Te Tiriti o Waitangi (The Treaty of Waitangi).[5] For this reason, Aotearoa has been used in place of New Zealand, whānau has been used interchangeably with family and te reo Māori nouns have not been italicised in this quality improvement project.

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Making healthcare SWEET2er: reframing clinical governance to support its operationalisation in Aotearoa New Zealand

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ABSTRACT

Despite national initiatives and resources, the clinical governance movement appears to have stalled both in Aotearoa New Zealand and abroad. Notwithstanding capacity challenges, an important known barrier to operationalising clinical governance is that healthcare staff do not understand what it is about. In this paper, we propose a reframing of clinical governance using the SWEET^2 (Safe, Whānau-centred, Effective, Equitable, Te Tiriti- and Tikanga-based) framework. Applied in practice, we propose that clinical governance can be conceptualised as simply as 1) *knowing how SWEET^2 is care* and 2) *making it SWEET^{2}er.* As part of this reframing, we propose building on and modifying the dimensions of quality dimensions so that it specifically articulates and brings to attention the importance of giving effect to Te Tiriti and tikanga as part of high-quality care. The SWEET^2 framework represents a practical step forward in making clinical governance more accessible, culturally appropriate and actionable in the Aotearoa New Zealand context, and contributes to the global discourse on the operationalisation of effective clinical governance.

Most of the time, healthcare, when it is accessed, is safe and of high quality—delivering good health outcomes and positive patient experiences.[1] However, many patients are also harmed by the medical care intended to help them. Approximately 12% of all patients (higher for Māori) cared for in hospital, ambulatory and primary care settings experience adverse events, with half of these caused by medical errors such as the wrong medication being given.[2–8] Patient harm rates in Aotearoa New Zealand are similar to those found internationally and conservative estimates suggest that at least NZ$800 million is spent annually on their management.[5,9–11] When adjusted for inflation and if indirect costs and other components of poor-quality care such as overuse, underuse and misuse of medical care are included, the cost is likely much higher.

In response, the discipline of healthcare quality improvement (QI) has consequently and incrementally grown over the past 30 years.[12,13] A plethora of concepts, strategies, models and tools to support patient safety and QI have been developed.[14] In the United Kingdom and many Commonwealth countries, including Aotearoa New Zealand, a key enabler for healthcare improvement is clinical governance.[15–17] In this paper, we provide:

1. an outline of clinical governance: its history, purpose, focus, and mechanisms;
2. an overview of the key challenges to operationalising clinical governance in practice;
3. suggestions to support clinical governance in practice and our lessons learned in practice—including a proposal to reframe the concept so it resonates better with healthcare staff.

Clinical governance

Precursors to the evolution of clinical governance were the catalyst Bristol Royal Infirmary Inquiry and the case of Dr Harold Shipman. Both are seminal events and records of avoidable harm in healthcare. Both drew systematic attention to the need for stronger regulation and accountability for the quality and safety of clinical practice and practitioners. First introduced in the 1990s by Scally and Donaldson and remaining largely unchanged since, clinical governance is described as "*a framework*

through which organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish."[15,16]

While the origins of clinical governance were in safeguarding patients, it has evolved in terms of what it addresses and how it is used. For example, clinical governance is used to respond to the substantial evidence of persistent inequities in access, experience and outcomes of healthcare for disabled, Māori and Pacific populations.[1,18] Clinical governance is also commonly employed as a public management tool to improve healthcare quality to that which is safe, timely, effective, equitable, efficient and person-centred (STEEEP, as per Institute of Medicine's definition) at individual, organisation, population and health system–wide levels.[19–21]

Research suggests there is an association between clinical governance maturity and the quality of care and health outcomes. Those with immature-quality infrastructure and poor organisational culture are associated with lower-quality care and health outcomes.[22] Conversely, healthcare organisations with mature-quality governance, strong clinical leaders, patient engagement and co-development, cultural safety, along with strong-quality measurement and improvement infrastructure, operating systems, expertise and cultures, are associated with higher-quality care, outcomes and patient experiences.[23–31] Yet, despite the benefits of clinical governance, there are challenges in terms of its interpretation, implementation and impact.

Challenges to operationalising clinical governance in practice

Most developed nations have national or regional clinical governance frameworks and quality standards. In Aotearoa New Zealand, organisations such as Te Tāhū Hauora – Health Quality & Safety Commission (HQSC) have developed an extensive catalogue of national frameworks, evidence and guidance tools to improve the safety and quality of healthcare.[15,18] The *Collaborating for quality: A framework for clinical governance* publication is a tangible example of system-level attention to clinical governance. It usefully provides both strategic and operational examples of what clinical governance looks like in reality with tangible illustrative examples (e.g., *organisations have clinical supervision and credentialling processes*) and vignettes.

Despite its importance and a range of actions to enable it, the clinical governance movement appears to have stalled.[32,33] For example, national surveys in 2012 and 2017 suggest relatively little progress in the understanding of clinical governance by clinicians. Professionals working in the clinical quality and risk field commonly report the general state of clinical governance in their organisations as immature, not routinely embedded in practice and in need of further improvement. So why is this?

Some of the challenges to operationalising clinical governance in practice, especially in the post-COVID pandemic period, are sustained health system pressures that are evident internationally. In Aotearoa New Zealand, health system pressure has deepened to profound crises in its health workforce, acute, emergency, primary and planned care services. Efforts to comprehensively undertake once-in-a-generation whole-of-health-system transformation (reform) in Aotearoa New Zealand commenced in 2022 and continue today but have become tenuous and fraught with conflicts and constraints, including substantial fiscal austerity across publicly funded services. When healthcare systems and organisations are under sustained and, indeed, elevated pressure, clinical governance may not be prioritised despite harm for both patients and staff, at patient and population levels, being at extreme risk.

Notwithstanding capacity and operational challenges, an important barrier to operationalising clinical governance, in our experience, is that healthcare staff do not understand what it is about. For example, when engaging clinicians, policymakers, managers and consumers on clinical governance, it is not uncommon to hear statements such as "*What's it all about?*" or "*How does it matter to me in practice?*" This observation is consistent with research findings that suggest it is one of the main reasons why clinical governance has stalled.[32–38] The original definition of clinical governance by Scally and Donaldson does not appear to lend itself to being easily remembered, applied or understood by people that are not subject matter experts in the field. In our opinion, the clinical governance concept has been not been framed or promoted well to its intended audience and, not surprisingly, it remains "amorphous", resulting in the why and how of clinical governance not resonating with people.[37] So how might we reframe the clinical governance concept so it is more easily understood for translation into practice?

Reframing clinical governance for operationalisation in practice

Faced with the challenge of reframing clinical governance so it resonates better with people, a small, diverse and multidisciplinary group came together to brainstorm potential solutions. This group comprised senior clinicians and healthcare leaders with expertise in clinical governance, healthcare quality, improvement science, social marketing, mātauranga Māori (see Glossary for definitions), tikanga and kawa, health equity, commissioning and public health. The group considered how clinical governance can be explained in a way that resonates with people. The group also considered how the concept can be customised for local settings so that it better supports anti-racism and pro-equity actions and gives effect to Te Tiriti o Waitangi—Aotearoa New Zealand's constitutional document, which commits to actively protect Māori health/hauora and wellbeing.[39]

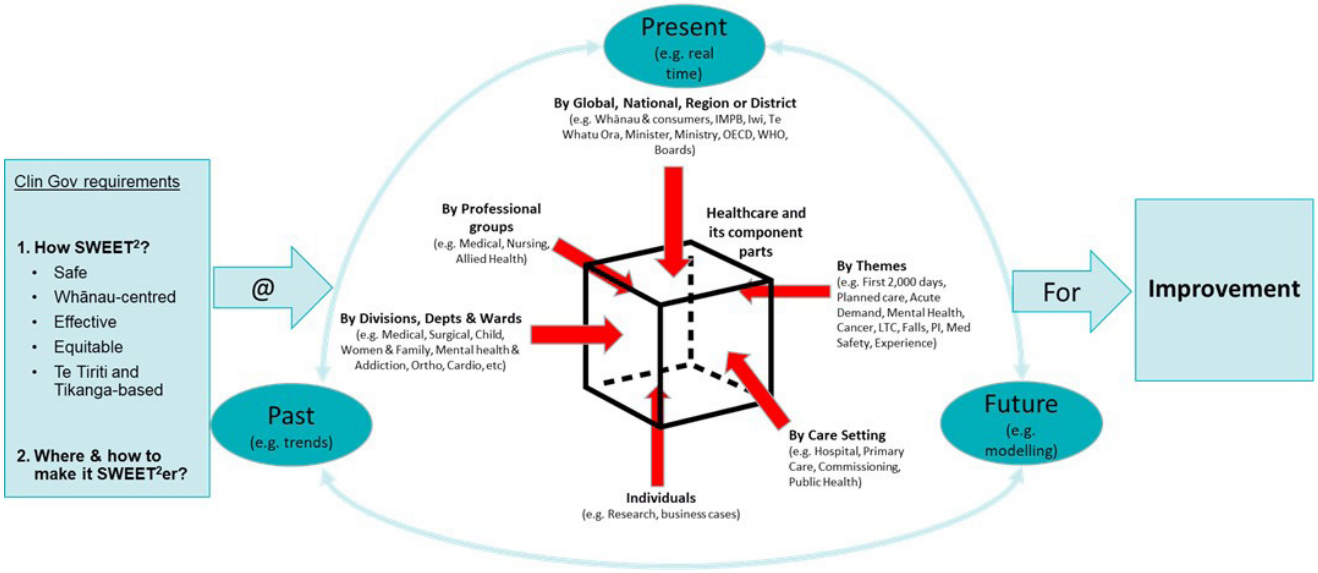
Building on existing research and knowledge, the clinical governance reframing was co-developed via kōrero across several wānanga among the authors and clinicians, managers, consumers and mana whenua, such as with members of the Te Amorangi Kāhui Kaumātua group and the Iwi Māori Partnership Board (IMPB). And finally, through various iterative refinements and testing across different districts and settings, we propose the conceptualisation of clinical governance to be as simple as being about:

1. knowing how SWEET^2 (Safe, Whānau-centred, Effective, Equitable, Te Tiriti- and Tikanga-based) care is in a particular setting and context,* i.e., quality measurement and monitoring;
2. making care SWEET^{2}er in a particular setting or context,* i.e., QI to achieve better health outcomes and experiences for people.

*Setting is used as a catch-all term and can be care in a ward, division, hospital, general practice, commissioning (e.g., healthcare contracts), public health, community care, professional discipline (e.g., medical, nursing, allied health), particular theme (e.g., falls management, medicines management), entire nation and/or time period—see Figure 1.

Our proposed use of SWEET^2—see Table 1—retains the underlying core components as outlined in the Institute of Medicine's (IOM) definition of care quality but further expands on it to take into account important cultural and socio-political considerations and requirements relevant for the Aotearoa New Zealand context. There are six key differences between the two frameworks. Firstly, the safety dimension is expanded to include not only patient but also staff safety, which is consistent with the shift to the quadruple aim focussed on staff wellbeing. Harm includes not just physical but also psychological harm and trauma. Secondly, the safety component is also widened to include cultural safety, which is in line with the need to expand beyond cultural competency.[40,41] Thirdly, instead of "patient-centred", we use instead the term "whānau-centred" because harm to the individual impacts whānau both directly

Figure 1: Application of the proposed reframed SWEET^2 clinical governance framework for different settings.



and indirectly via loss of trust, which may lead to future non-access to care—further perpetuating and causing potential harm. And thus, quality care needs to not only take into account the person being treated but also consider the implications for the wider family and community.[42]

Fourthly, we consolidated the dimensions of timeliness and efficiency of the STEEEP framework into the effectiveness dimension as we were of the view that these are inter-related and should be considered as a whole. For instance, and especially for time-critical illnesses such as stroke and myocardial infarction, care cannot be deemed of high quality if it was effective but cannot be accessed or delivered in a timely manner, is inefficient or has long wait times. Fifthly, we added to STEEEP the dimensions of Te Tiriti and tikanga to recognise the need for the Crown to fulfil its obligations as outlined in Te Tiriti o Waitangi. This is particularly in relation to Article Two, which commits the Crown to protecting taonga (treasured possession) of Māori, including their practice of local customs and processes—which is important if the Health Sector Principles set out in the *Pae Ora (Healthy Futures) Act 2024* legislation are to be realised. Sixthly, our addition of tikanga is used in a broad sense to refer to customs and traditional values—not just in relation to a Māori context (e.g., care of placenta/whenua, Māori data sovereignty) but also non-Māori context (e.g., organisational rules, customs and values).

Our proposed conceptualisation of clinical governance into two key parts in *knowing how SWEET² care* is and *making care SWEET²er* aligns with and distils the core components of the original definition by Scally and Donaldson. For example, the proposed first part of knowing how SWEET² healthcare is promotes and underpins the systems, mechanisms and tools needed to measure and monitor quality. This aligns with the underlying intent of the original definition, which highlights "*the framework for which organisations are accountable … and safeguarding high standards of care*",[16] which requires quality measurement and monitoring mechanisms to know whether standards are being achieved and the state of quality to inform improvement and monitor QI progress.

The second part of our proposed reframing of clinical governance relating to *making healthcare SWEET²er* aligns with and distils the second core component of original definition focussing on "*continuously improving the quality of their services … environment in which excellence in clinical care will flourish*."[16] This focusses on QI activity required to innovate and/or continuously improve the quality of care for better health outcomes and experiences for people. For example, to close the loop on key quality gaps (e.g., Safety I) and/or redesigning care models and learning from clinically excellent care (e.g., Safety II) to make care better.

Application and experiences in practice

Over the past 5 years since our proposed reframing of clinical governance was first introduced, we have tested and applied it in different geographical locations and healthcare settings.

For example, in the Bay of Plenty, we applied our proposed reframing of clinical governance as a framework to develop a Māori health equity scorecard for IMPB use. Using the first part of the reframed conceptualisation *How SWEET² is…* as a framework, an equity scorecard containing quality metrics was developed to assess the quality of hospital and specialist services and commissioned care for Māori. For instance, to assess *How Safe is care for Māori*, data for commonly used patient safety metrics such as hospital-acquired complications and risk-adjusted ratios for hospital-acquired sepsis were analysed to compare the safety of care for Māori vs non-Māori to highlight any clinically significant equity gaps and monitor improvement progress.

To understand *how Te Tiriti- and Tikanga-based care* was, we leveraged existing tools such as Te Arawhiti's *Māori Relations Organisational Capability Framework*, critical Te Tiriti analysis and the He Ritenga tools to self-assess the organisation's maturity and commitment in giving effect to Te Tiriti and adhering to local customs and processes.[43,44] Feedback from IMPB members was that the simple framing of clinical governance helped them in understanding how to assess care quality as part of discharging their duties as governors—especially for laypersons who may not necessarily understand technical clinical jargon and nuances.

The proposed reframing of clinical governance into its two key components has also been used to support a consistent messaging of what clinical governance is and setting the organisation's expectations for its implementation. For example, to support clinical governance in one large metropolitan hospital, the quality governance group regularly asked senior leaders of wards, departments and services: 1) *how SWEET² care is in*

Table 1: Dimensions of quality using SWEET[2] and their description and illustrative metric examples.

Quality dimensions	Description	Potential quality metrics
Safe	No avoidable injury or harm; safe and appropriate care environment, systems and processes (including staff safety and cultural safety—to refer to pro-equity and anti-racist thoughts and actions).	• Adverse events • Mortality rates • Hospital-acquired complications score • Wellbeing index and surveys • Certification requirements relating to cultural safety • Patient views on extent they feel culturally safe in their interactions
Whānau-centred	Shared decision making between patients, whānau and staff; caring and respectful interactions and communication.	• Patient-reported experience metrics • Patient-reported outcomes • Patient and staff satisfaction • Net promoter scores
Effective	Appropriate treatments and services provided at the right time for the right person(s); wasteful or harmful variation eliminated.	• Ambulatory-sensitive hospitalisation • 5-year survival rates • % adherence to good practice • Unplanned readmission rate • Emergency department: seen within 6 hours of admission • First specialist appointment seen by time
Equitable	Equity of health outcomes and care—especially for Māori and Pacific peoples.	• Equity gap scores between different ethnicities, genders or other factors
Te Tiriti and tikanga	Culturally safe environment and mechanisms that give effect to Te Tiriti o Waitangi to enable the achievement of health equity. Tikanga is used in a broad sense to refer to customs and traditional values—not just in relation to a Māori context (e.g., care of placenta/whenua, Māori data sovereignty) but also non-Māori context (e.g., organisational customs and values).	• He Ritenga scores • Te Arawhiti's *Māori Relations Organisational Capability Framework* • Adherence against *Te Mauri o Rongo* (Aotearoa New Zealand Health Charter) • Critical Te Tiriti analysis

their area? and 2) *what is being done to make care SWEET[2]er*? These two core questions were applied at multiple levels—for example, vertically within the organisation such as by division (e.g., medicine, surgery), service (e.g., respiratory, orthopaedics) and ward. In parallel, the same questions were also asked at a horizontal level across the organisation—for instance, to ensure and support clinical governance in falls management, leaders would ask to see evidence for "*How SWEET[2] is Falls management in the organisation? What is being done to make falls prevention and management SWEET[2]er?*" The routine use of the two core questions generated a consistent organisational

Figure 2: Illustrative example of applying the proposed reframed SWEET² clinical governance framework for considering and selecting quality metrics.

Dimensions	Hospital & Specialist Services	Commissioning (and Primary Care)	Public Health	Whole-of-system	Kahu Taurima (1st 2,000 days)	Mate pukupuku (People with cancer)	Māuiuitanga taumaha | People living with chronic health conditions	Oranga hinengaro | People living with mental distress, illness and addictions	Pae ora | Better health and wellbeing in our communities
How Safe?	HDxSMR HAC/CHADx SAB rates	PM&M Hospitalisation	Transmissible disease/ health protection						
How Whānau-centred?	HQSC Inpatient Experience PREMS/PROMS % with advanced care plans Self-reported racial discrimination	HQSC primary care experience survey % with advanced care plans Self-reported racial discrimination	?	QALYs and PROMS	Self-reported experience (ratio) of unfair treatment on the basis of ethnicity 15+	Self-reported experience (ratio) of unfair treatment on the basis of ethnicity 15+	Self-reported experience (ratio) of unfair treatment on the basis of ethnicity 15+	Self-reported experience (ratio) of unfair treatment on the basis of ethnicity 15+	Self-reported experience (ratio) of unfair treatment on the basis of ethnicity 15+
How Effective?	Unplanned readmission ESPI 2&5 (FSAs) ED6h target	ED 6h target ASH % of pts who can access GPs when needed (e.g. NZ Health survey)	Life expectancy % of smokers able to access smoking cessation when needed	Rate of death within one year of ACS	Children aged 5-9 not dispensed ICS regularly one year after hospital admission	FCT	Rate of receiving angiography Kidney replacement therapy patients with diabetes		
How Equitable? (ethnicity > Dep etc etc)	Equity gap – slice/dice by variable DNW rates in ED HEAT assessment	Equity gap – slice/dice by variable	Equity gap – slice/dice by variable	Equity gap – slice/dice by variable	Equity gap – slice/dice by variable	Equity gap – slice/dice by variable	Equity gap – slice/dice by variable	Equity gap – slice/dice by variable	Equity gap – slice/dice by variable
How Te Tiriti and Tikanga based?	He Ritenga Te Arawhiti maturity score Critical Te Tiriti Analysis (CTA)	?	?						
Enabling services key priorities for QI: **•Data and Digital – e.g. HiRA** **•People & Communication – e.g. immigration, international recruitment, culturally safe and competent workforce, 2024-25 Workforce Plan in development , etc** **•Office of the CE – Harmonisation of documents**									

ACS = acute coronary syndrome; DNW = did not waits; ED = emergency department; ESPI = elective services patient flow indicators; FCT = faster cancer treatment; GPs = general practitioners; HDxSMR = hospital standardised mortality ratio; HQSC = Health Quality & Safety Commission; PM&M = preventable morbidity and mortality; PREMs = patient-reported experience measures; PROMS = patient-reported outcome measures; QALYs = quality-adjusted life years.

rhetoric that supported a shared understanding of clinical governance.

So far, positive feedback received from various groups and the fact that our work is being adopted by Health New Zealand – Te Whatu Ora for use in the development of its national clinical governance framework suggests there is utility in our proposed reframing. In another example, the SWEET² framework was used as a broad frame to support the development of national quality metrics—see Figure 2.

We believe that our simple reframing of clinical governance makes it more tangible and easy to apply the concept in practice. Our proposed reframing adds to the existing body of knowledge on clinical governance. It strips the concept of clinical governance into its most fundamental parts yet delivers it in a way that more easily resonates with people so they understand the concept and can apply it in practice. Clinical governance framed as being about *how SWEET² is…* and *making it SWEET²er* is applicable in multiple contexts and makes sense to the layperson compared to, for example, asking "*How STEEEP is care? How can we make care STEEEPer?*" It plays on the commonly used phrase "sweet as" to indicate that something is rather good instead of just "good" or "ok", making it more memorable and

accessible.[45] Further, by customising and expanding the concept of quality care to one that is also Te Tiriti- and tikanga-based, we are supporting pro-equity and anti-racist efforts. This aligns with the growing body of research emphasising the importance of culturally safe and whānau-centred care in improving health outcomes for Māori and other Indigenous populations.

Limitations

The proposed framing of clinical governance and the use of SWEET^2 was developed empirically with no formal content or construct validation undertaken. Consequently, there is potential that it does not cover all relevant parts of the clinical governance concept as per its original intention. The fact that the proposed framework covers Te Tiriti and tikanga, which is specifically aimed for the Aotearoa New Zealand context, means that it is not easily generalisable to other countries. Our proposed SWEET^2 framework includes within the "effective" dimension the "timely" and "efficient" dimensions included in the original IOM's definition. Not explicitly including the timely and efficient dimensions may mean they are unintentionally missed when measuring and considering the quality of care. On the other hand, one could also argue that nearly all of the dimensions could fit within the effective dimension and so reducing the total number of dimensions to one or two may be desirable. For example, care is not effective if it is unsafe, non-whānau-centred and so on. While there is potential merit in this logic, we believe that reducing the dimensions to only one or two may unintentionally miss key dimensions when care quality is measured and considered. In our opinion, the proposed dimensions in SWEET^2 strike a reasonable balance in ensuring key dimensions are visible and explicitly considered yet are arranged in such a way to be accessible and memorable to clinicians, managers and the public.

Implications for policy, practice and research

Our proposed reframing of clinical governance can potentially be adopted by policymakers as a way to help people understand what clinical governance is and why it is important. We understand the HQSC has recently published its national clinical governance framework. We suggest the HQSC consider adopting and/or customising our proposed reframing of clinical governance so it is more easily understandable for people, with a view to increase its likelihood of use in practice.

The use of *how SWEET^2* and *making it SWEET^{2}er* has already been demonstrated in practice to be readily applicable, relevant and useful. It is simple to understand and may be useful in supporting educational and training purposes. The proposed reframed approach can also be used to support comprehensive and balanced quality measurement, monitoring and improvement efforts.

While seemingly face valid, no formal content or construct validation has been undertaken so future research may be warranted to do this. Further, there is the opportunity to better understand the generalisability and reliability of the reframed concept in settings outside of Aotearoa New Zealand. There is clearly significant evidence to show the positive association between mature clinical governance systems and care quality and health outcomes. However, it is unclear whether such positive associations continue to hold in our proposed reframing of the clinical governance concept, and this will be worthwhile to better understand.

Conclusion

In this paper, we propose the reframing of clinical governance to be as simple as *knowing how SWEET^2* is care and *making it SWEET^{2}er*. We also propose building on and modifying the quality dimensions of STEEEP to SWEET2 so that it specifically articulates and brings attention to the importance of giving effect to Te Tiriti and tikanga as part of high-quality care. We believe that our simple reframing of clinical governance represents a significant step forward in making the concept more accessible, culturally appropriate and actionable in the Aotearoa New Zealand context. As healthcare systems worldwide grapple with issues of quality, safety and cultural responsiveness, the SWEET^2 framework offers a model that could be adapted and applied in various settings, contributing to the global discourse on effective clinical governance.

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Appendix: Glossary

Mātauranga Māori—forms of knowledge grounded in a Māori worldview
Tikanga—cultural practices that are responsive to context and relationship
Kawa—ceremonies, foundational protocols
Kōrero—to speak, discussion, speech
Wānanga—to deliberate, a collective learning forum, a collective approach to revealing knowledge
Mana whenua—people who hold authority over an area or territory

Giant cell tumour of the temporal bone vs atypical meningioma

Joseph N M Luna, Tony Goh, Aditya P Jayawant, Hayleigh Miller, Philip Bird

Giant cell tumour (GCT) is a rare benign intraosseous neoplasm that can affect any bone or joint, although it most commonly occurs in long bones and large joints. GCTs are classified into two main subtypes: GCT—GCT of the bone (GCTB) and GCT of the soft-tissue.[1] GCTB of the temporal bone is a rare occurrence, accounting for only 2% of all GCTs arising from the skull base.[1] The condition has a slight female predominance, with a ratio of 1.2:1, and is most commonly diagnosed in individuals during the third and fourth decades of life. While metastases occur in approximately 2% of cases, recurrence rates after surgical resection can range from 40–60%.[1] Other differential diagnoses for the radiological appearances of GCTB would include aneurysmal bone cyst, chordoma, chondrosarcoma, haemorrhagic malignancy, brown tumour of hyperparathyroidism, fibrous dysplasia, cherubism, plasmacytoma, multiple myeloma and cholesteatoma.

Case report

A 51-year-old woman presented to the emergency department with a 6-week history of gradually worsening nausea, vertigo and a mild to moderate right conductive hearing loss with mild tinnitus on the same side. She denied headaches and vomiting but had a 2-year history of right temporomandibular joint (TMJ) disorder. She had an unsteady gait but an unremarkable neurologic examination apart from the hearing loss. An initial computed tomography (CT) scan of the head showed a right temporal bone lesion. A magnetic resonance imaging (MRI) scan was performed for further imaging characterisation of the lesion. She underwent an initial biopsy from which histology was consistent with a diagnosis of GCT.

To remove the tumour a labyrinthectomy, condylectomy, TMJ resection, subtotal petrosectomy and subtemporal craniotomy were performed. The tumour was completely resected. The patient recovered well, the major post-operative deficits being loss of hearing and reduced balance. Her balance function improved over time. She will require ongoing radiologic surveillance for potential recurrence. Microscopic sections of the middle ear taken during surgery showed fibrous joint capsule and synovium with papillary architecture (Figure 1A) containing a proliferation of pigmented mononuclear histiocytoid cells (Figure 1C) and admixed multinucleated giant cells (Figure 1D) extending into the surrounding fibroadipose tissue. These tumour cells form solid sheets consistent with diffuse-type GCT with no malignancy. Normal synovium consists of a thin intima layer of synoviocytes directly supported by vascular subintimal layer of loose connective tissue.[2]

Discussion

This case demonstrates a classic presentation of GCT of the temporal bone. She had common symptoms of hearing loss, tinnitus and vertigo for several months. The symptoms gradually worsened, reflecting the slow progression but local aggressiveness of GCT. This was consistent with the radiological findings and pathology.

Radiological imaging features

CT head (Figure 2A) showed a partially calcified rounded hyperdense extra-axial mass (measuring 31mm x 34mm x 32mm) at the posterolateral floor of the right middle cranial fossa centred within the right temporal bone.

CT demonstrated bony scalloping, thinning, erosion and sclerosis of the adjacent squamous, mastoid and petrous portions of the right temporal bone, as well as the greater wing of the sphenoid bone (Figure 2B). There was bony erosion of the floor of the right middle cranial fossa with lesion extension into the right temporomandibular joint (Figure 2C) and right infratemporal fossa adjacent to the right lateral pterygoid muscle. There was also bony erosion and extension into the right middle ear cavity with bony erosion of the tegmen tympani, otic capsule and facial nerve canal.

MRI head demonstrated a minimally enhancing predominantly low T1W, markedly low T2 signal intensity extra-axial mass posterolateral

Figure 1: Microscopy of diffuse-type GCT.

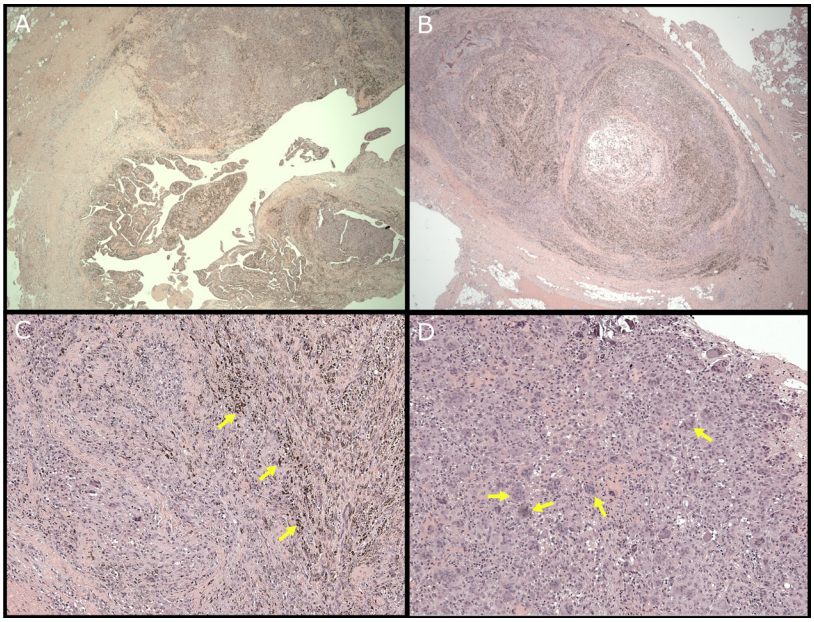

Figure 1A is a low-power view (x2) showing abnormal papillary structure of the TMJ synovium that occurs alongside abnormal nodular architecture in Figure 1B.
Figure 1C is a x10 magnification showing pigmented mononuclear histiocytoid cells.
Figure 1D is a x10 magnification showing numerous multinucleated giant cells.

Figure 2: CT imaging.

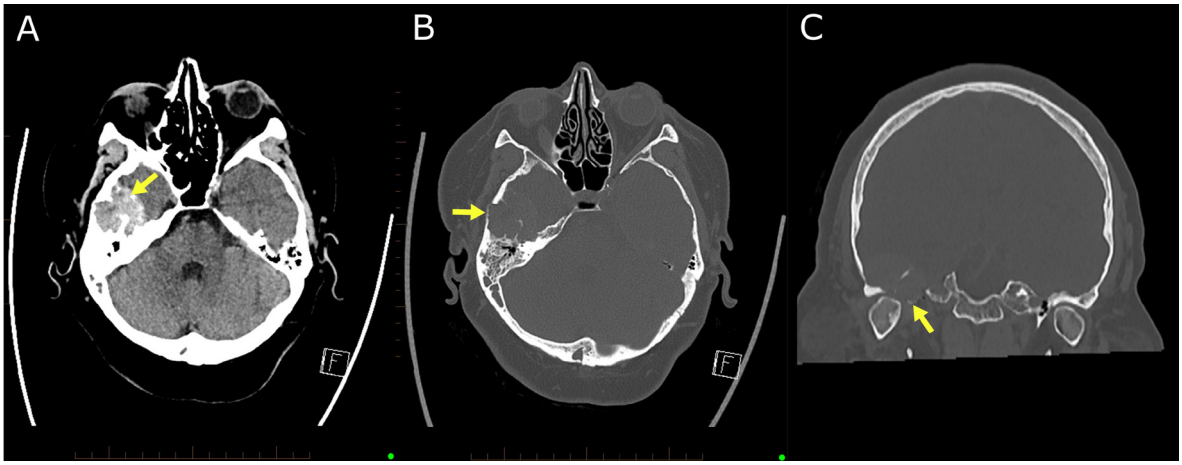

Figure 2A: CT axial—partially calcified rounded hyperdense extra-axial mass posterolateral floor of the right middle cranial fossa.
Figure 2B: CT axial—adjacent scalloping, bony thinning, bony erosion and sclerosis of the squamous, mastoid and petrous portions of the right temporal bone.
Figure 2C: CT coronal—bony erosion of the floor of the middle cranial fossa into the temporomandibular joint.
CT = computed tomography.

Figure 3: MRI imaging.

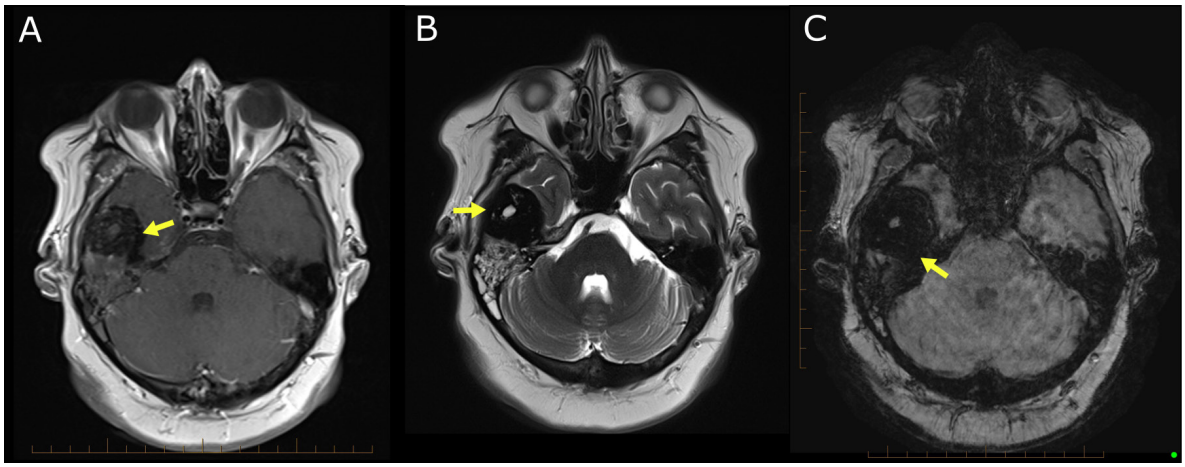

Figure 3A: Post-contrast axial T1-weighted MRI—low T1 signal intensity mass.
Figure 3B: Axial T2-weighted MRI—low T2 signal intensity mass.
Figure 3C: Axial gradient echo sequence—lesional susceptibility artifact consistent with blood products.
MRI = magnetic resonance imaging.

floor of the right middle cranial fossa with adjacent bony erosion (Figure 3A and B). The T2 signal hypointensity and marked susceptibility artifact on the gradient echo sequence are consistent with blood products and haemorrhage within the lesion (Figure 3C). The combination of CT and MRI imaging findings with extensive blood products, bony expansion, erosion and cortical thinning are consistent with GCT of the temporal bone.

CT and MRI are the optimal imaging modalities for demonstrating GCTB. CT would usually be the first imaging investigation and best demonstrates the associated bony changes, while MRI is best for lesion imaging characterisation and defining lesion extent.

Atypical meningioma vs GCTB

Atypical meningioma was considered as the main differential diagnosis due to its similarities with GCTB, both presenting as an extra-axial lesion with associated bony erosion. On CT, atypical meningiomas demonstrate bone destruction without bony expansion, cortical thinning or neocortical involvement that is characteristic of GCTB. In contrast to GCTB, atypical meningiomas are usually isointense to mildly hypointense on T1-weighted MRI, and mildly hyperintense on T2-weighted MRI with areas of marked T2 hyperintensity due to necrosis or cystic change. Atypical meningiomas also commonly demonstrate heterogeneous contrast enhancement with necrosis, calcification, irregular tumour margins, indistinct tumour brain interface, invasion of brain parenchyma and extensive peritumoural cerebral oedema.[3]

In this case, typical meningioma (World Health Organization [WHO] grade I) is unlikely because it usually appears as a well-defined, homogenously enhancing, extra-axial mass based on the dura with associated hyperostosis but no bony erosion. This contrasts with atypical meningioma (WHO grade II), which has more aggressive imaging appearances.[4]

Conclusion

This case illustrates the challenges in radiological diagnosis and assessment of lesion extent of GCT of the temporal bone. Despite its benign histology, the tumour's aggressive local invasion requires thorough imaging with CT and MRI.

COMPETING INTERESTS
There were no conflicts of interest or funding sources. Patient consent was obtained to publish this report.

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Dr Tony Goh helped in drafting the manuscript and deciding radiological images to include.
Dr Hayleigh Miller and Philip Bird helped in drafting the manuscript.
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Response to: "Urgency vs triage prioritisation: appropriateness of referrer-rated urgency of referrals to a public dermatology service"

Dirk Venter

To the Editor,

The recent article on referral urgency in dermatology and the proposed role of artificial intelligence (AI), "Urgency vs triage prioritisation: appropriateness of referrer-rated urgency of referrals to a public dermatology service" (*New Zealand Medical Journal*, June 2025),[1] offers valuable insight into triage patterns in a constrained system. However, the findings raise several questions that warrant further discussion.

First, I would urge the authors to reflect more critically on the underlying assumption that better triage—whether human- or AI-assisted—will meaningfully resolve the systemic issue at hand. In a setting where fewer than 10% of dermatology referrals result in a face-to-face appointment, triaging non-melanoma skin cancers (NMSCs) like basal cell carcinomas (BCCs) and squamous cell carcinomas (SCCs) into "low" priority categories risks exacerbating the very problem the system seeks to solve. If wait times are already prohibitive and capacity insufficient, then down-triaged lesions may simply grow until they qualify as "urgent", at which point they require more complex, resource-intensive interventions—or in some cases, become inoperable. Triage, in this context, risks becoming a form of passive rationing. Without expanding capacity, shifting the order in which patients wait does not resolve the bottleneck—it just delays necessary care for those who present early and appropriately.

Second, the article notes that Māori and Pacific patients are under-represented in referral data, and attributes this disparity, in part, to systemic racism—a claim increasingly common in contemporary discourse. As a vocationally registered general practitioner with 25 years of practice in New Zealand, I must question whether this framing is the most accurate or constructive. In my personal experience across multiple regions and practices, I have never encountered a clinician who would consciously offer different care or referral options to a patient based on ethnicity. To the contrary, there is widespread awareness of health inequities and a strong commitment to equitable care among my colleagues.

More plausible and often overlooked contributors to reduced hospital access for Māori and Pacific peoples include socio-economic disadvantage, transportation barriers, lower trust in or familiarity with institutional processes and mismatches between cultural expectations and the often rigid, impersonal structure of the public health system. These are serious, complex issues that demand attention, but they should not be simplistically reduced to racism. Doing so risks alienating clinicians and detracting from targeted, structural solutions.

Lastly, the article rightly highlights the clinical importance of timely diagnosis in dermatology. Early detection and treatment of skin cancers significantly improve prognosis and reduce morbidity. Triaging must not be used to manage scarcity in a way that allows slow-growing but ultimately harmful lesions to accumulate until they meet high-urgency thresholds. Instead, resourcing must match the disease burden—including investment in surgical, dermatologic and community-based treatment options—or we risk institutionalising delay as a standard of care.

Sincerely,

Dirk Venter

COMPETING INTERESTS
DV: Chair of the New Zealand Advisory Panel for Skin Cancer College Australasia (SCCA); Member of MelNet's panel reviewing Quality Statements to Guide Melanoma Diagnosis and Treatment in New Zealand.

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Response to "Response to: Urgency vs triage prioritisation: appropriateness of referrer-rated urgency of referrals to a public dermatology service"

Amanda Oakley

We write to thank the correspondent for their interest in our paper published in the *New Zealand Medical Journal* (*NZMJ*) in June 2025.[1] We are pleased to respond to their three comments,[2] with which we agree.

First

Non-melanoma skin cancers (NMSC) should be a priority for referral triage, and we share the author's dismay at current public hospital waiting lists for assessment and treatment. Our intention in harnessing artificial intelligence (AI) is to assist workflow and speed up the evaluation of skin lesions. We plan to prioritise by malignant diagnosis (assessed by AI from submitted images) and metadata: lesion location (e.g., central face), size (denoting high-risk NMSC), rapid growth and presence of ulceration or bleeding. Our existing triage teledermatology template for suspected skin cancers includes check boxes for these characteristics, but no means to prioritise lesions in which they are recorded.

Second

Our study evaluated patients referred to the dermatology service in March 2023. Rates of referral for Māori and Pacific patients were lower than average for suspected skin cancer (8% of referrals), which is not unexpected as skin cancers are uncommon in patients with skin of colour, but not for general dermatology referrals (22.3%; 21% of our local population is Māori according to census data[3]), and we found no ethnic disparities in referral urgency. We did not intend to infer that the overall lower rates were due to racism and apologise if this was unclear in our paper. We cited an *NZMJ* publication of 2021 in which racism was listed as one of the five themes that captured the barriers for Māori accessing hospital services.[4] We are not experts in this topic, but we agree with your conclusions that referring to racism is not constructive.

Third

Timely diagnosis is essential in dermatology as in other specialities. We support your call for investment in surgical, dermatologic and community-based treatment options. In the Waikato district, teledermatology confirmation of cutaneous malignancy leads to Health New Zealand–funded surgery in the community for priority groups.[5]

Sincerely,

Hon. Professor Amanda Oakley, dermatologist, Health New Zealand Waikato, on behalf of the authors

COMPETING INTERESTS
Nil.

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A memorable political episode in the history of the Otago Medical School

Paul Oestreicher

Perhaps in this 150th anniversary year, this short episode in the history of the University of Otago Medical School deserves to be remembered. In the late 1930s, Hitler's persecution of the Jews was gathering momentum. By September 1938, Jewish medical doctors were no longer permitted to treat Germans, only their fellow Jews who were no longer regarded as truly German.[1] My father, a Christian with Jewish parents, was one of many. We fled from a provincial town to Berlin to seek asylum from any foreign consulate, as far away from Hitler as possible.

In our case, only two countries agreed to accept us: Venezuela and New Zealand. New Zealand was reluctant, as the government's reply said, because as Jews, they felt we were not likely to assimilate well. Yet, preferring New Zealand, we persisted and were among the mere 1,100 who were given visas under pressure from the British government.[2] Among the 1,100 were 17 medical doctors.

The New Zealand branch of the British Medical Association (BMA), the medics' trade union, was not pleased. Foreign competition was not welcomed. A high hurdle was created by the BMA. A licence to practice should be conditional on retaking the 3 clinical years of medical study.[3]

In fact, the New Zealand branch of the BMA was following the example of its British parent body. The British parent body became alarmed at the number of refugee doctors arriving as early as 1933 and immediately recommended the alteration of the requirements for requalification from 1 year to 3. Scotland provided an exception, with only a 1-year retraining requirement.[4]

All but one of the refugee doctors bit the bullet and went back to university, taking the exams in a foreign language. That one, who had been a professor, accepted a research job. It was up to their partner to finance life for 3 years. My father, a paediatric specialist in his mid-40s, sometimes spoke of this as his mental concentration camp. Even so, we were grateful to be where we were. Even during the war, now classed as enemy aliens, life in New Zealand was a good life.

What was the impact of these mostly middle-aged German and Austrian refugees on the Medical School? Professor Dudley Carmalt-Jones, acting dean 1939–1940, recorded in his memoir that the unplanned sudden arrival of 16 refugee doctors put a great strain on the system.[5] The Medical School had not been consulted. Neither the Medical Council, a statutory body that decides who may or may not practice, nor the Department of Health, chose to challenge the BMA's lobbying. Public opinion was, in any case, not in the mood to support German-Jewish refugees.

By 1942, all of these doctors had graduated and, as the Department of Health made plain, were much needed, with many local doctors now in the armed forces. They opened practices, some in the main centres, some in rural areas. Within a short time, they were in high demand. My parents, already having made a circle of friends, decided to stay in Dunedin, my home since the age of 7. My father was, into his 75th year, a much-appreciated Dunedin GP.

Straight out of school, he had made it to first lieutenant in World War I. With the war lost in 1918, he fled from the French to avoid being captured. In 1938 he fled from the Germans to avoid a Nazi concentration camp—this time, all the way to New Zealand.

It was an irony of history that a stranger, the Frenchman Jean Carette, mayor of the municipality of Rieux, Oise, hearing through distant relatives of our desperate need, offered us the money (NZ$15,000 at today's values, for three people) on which the visa to New Zealand depended. Germany had blocked my father's bank account. He owed his survival to this unknown individual. This was humanity in inhumane times. Every refugee family has its own story. The great majority had no successful story and nowhere to flee, hence were murdered in the Holocaust.

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Measuring low-density lipoprotein cholesterol

Ben Gray

He et al.'s paper[1] on low-density lipoprotein cholesterol (LDL-C) management gives clear evidence of the benefits of LDL measurement in patients on statins to determine whether they are adherent to their medication. It is flawed in arguing that serial LDL-C measurements are useful in titrating statin dose or adding ezetimibe as they take no account of the biological variation in individual LDL-C test results. McCormack et al.[2] describe the reference change value—the percentage change required for two serial measurements to be considered different. For LDL-C this is between 21 and 30%. They demonstrate that an LDL-C test can validly measure the change in LDL-C with the initiation of statins because initiating a statin dose of 10–20mg will lower LDL-C by 30–35%. However, increasing the statin dose from 10 to 20mg to 40 or 80mg only lowers LDL-C by a further 10%, a change that is smaller than the reference change value: "*Repeat measurements after a statin dose change therefore of limited or no benefit and can be misleading.*"[2]

He et al. argue that guidelines unanimously recommend initiation and maintenance of the highest tolerated dose of statins. In addition to guidelines cited it aligns with the *PEER simplified lipid guideline 2023*.[3] However, that guideline states that "*Attainment of lipid targets is not recommended. Statins remain first-line therapy for primary cardiovascular disease prevention based on a patient's estimated cardiovascular risk and shared decision making*."[3]

Initiating and maintaining the highest tolerated statin dose is valuable. Repeated measurement of LDL-C has no value other than checking whether the patient is taking their medication, which is surely better discovered by a good shared decision-making process.

COMPETING INTERESTS
None.

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Response to: "Measuring low-density lipoprotein cholesterol"

Andrew J Kerr

We would like to thank Associate Professor Gray for his very reasonable comments.[1] Our main recommendation, which is aligned with international guidelines,[2–4] is that repeat lipid testing should be performed post-discharge to guide medication and lifestyle optimisation. In our study this was not done in 22% of patients. Of those with a repeat low-density lipoprotein cholesterol (LDL) estimation the mean achieved LDL was 1.9mmol/L, which is well above the internationally endorsed target of <1.4mmol/L. We demonstrated that there were opportunities for further medication up-titration and improved medication adherence. We have argued in our paper that patients should, where possible, be commenced on the highest doses of available medication, but in many cases this is not possible in hospital. Some patients are reluctant to start optimal doses or combinations of therapies. Initial use of rosuvastatin is limited by special authority requirements. The first post-discharge lipid measurement combined with a target level is therefore valuable for guiding and motivating the optimisation of lipid management—both dietary and pharmaceutical. The European Society of Cardiology recommends then repeating the LDL again until the target is met or optimal therapy reached.[4] In Europe, patients are likely to have more repeat LDL testing in this up-titration phase due to the availability of the more potent PCSK9 inhibitors, which are not publicly funded in Aotearoa New Zealand.

We agree with Associate Professor Gray that subsequent LDL estimations will be less useful to assess the effect of changes in statin dosage or addition of ezetimibe, which would be expected to produce smaller changes in LDL. Nevertheless, based on our clinical experience, we believe that serial LDL estimations can be an important tool as part of the shared decision-making process: both to identify patients not consistently meeting treatment targets for review regarding whether medication can be further intensified, and for review of adherence to lifestyle and medications.

We note that in contrast to the Canadian PEER guideline[5] for prevention of cardiovascular disease, which doesn't endorse the use of lipid targets in primary care, the contemporary post-acute coronary syndrome–specific guidelines in Europe, the United States and Australasia all endorse an LDL cholesterol target of <1.4mmol/L.[2–4] We have discussed the advantages and disadvantages of having a dichotomous LDL target in our paper.

Professor Andrew J Kerr, Department of Medicine, The University of Auckland; Cardiologist, Middlemore Hospital, on behalf of my co-authors

COMPETING INTERESTS
AK: Co-chair ANZACS-QI governance group.

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Haematuria.

NZMJ, 1925

By R. Campbell Begg, M.D., F.R.C.S.E., *Wellington*. (*A paper read before the Hawke's Bay Division.*)

Technically the term "hæmaturia" denotes the presence in the voided urine of microscopic or macroscopic blood, including corpuscles. The blood may arise at any point of the urinary tract from glomerus to external meatus or be poured into it from any of the structures which communicate, such as the seminal vesicles, prostate, Cowper's glands, sinus pocularis, etc., or it may burst into the urinary system from without as in cases of aneurysm of the renal artery or new growths primarily in other structures. The bleeding is usually from a localised area, but may be from the greater part of the mucus or epithelial surfaces in such conditions as arterial degeneration, purpura, scurvy or the anæmias where generalised hæmorrhage is liable to occur throughout the whole body.

While a very large number of both local and general conditions may cause blood to appear in the urine at some stage or other, the most important form is that in which without warning obvious bleeding occurs in a person otherwise well and presenting no other symptoms or signs. It is with these cases that it is proposed to deal in this paper. No graver responsibility faces the physician than the management of patients who come to him with the sole complaint that they have passed blood in the urine. The personal and family history give no help. The patient feels perfectly well and strong. He may have no pain, inconvenience or difficulty in passing water. The kidneys are neither palpable or tender. The urine clears after a few days' rest in bed with or without medication, and may not reappear for months or years. It is attributed to a strain or a cold in the bladder or kidneys, and is soon forgotten. It requires all the fortitude, tact, persuasion and, above all, the assurance begotten of accurate knowledge on the part of the doctor to persuade the unwilling patient to undergo the inconvenience, expense, and, it may be journey away from home in order to undergo special examination, and it is only too easy for him to allow himself to be influenced and to treat the case expectantly. In this way the golden opportunity is lost, for in the large majority of cases this quiet bleeding is the only sign of a pathological condition already well advanced in kidneys, ureter or bladder, where delay will prejudice, if not destroy, the chance of cure.

It may be useful to review all the personal cases encountered in the last twelve months (January to December, 1924) of urological practice as a fair average of the distribution of cases of this type. Only those are included where silent hæmaturia was the sole initial symptom, and where on purely clinical grounds there was no clue to the site of the hæmorrhage. In some of these it is true the taking of a careful case history and an exhaustive examination of the whole body elicited small signs and symptoms that had passed unnoticed, and hinted at possible causes, but in every instance it was the occurrence of bleeding, as it were like a bolt from the blue, that first induced the patient to seek medical advice.

While one is chiefly concerned with surgical conditions, the medical causes of hæmaturia require passing notice. The presence of copious bleeding as the first symptom of an acute nephritis is rare but does occur. The same may be said for the blood diseases where coagulation time is lengthened, and where the history of present condition elucidates the real trouble. Such are scurvy, purpura, the leukæmias and anæmias and severe general sepsis. Pyemic and other conditions producing infarction in the kidneys must also be mentioned. Parasitical conditions, of which schistostomiasis is the chief, do not occur in this country.

There is one systemic condition, however, in which the patient's first definite complaint may be hæmaturia and for which the practitioner should be on his guard. I refer to arteriosclerosis, whether accompanied by hyperpiesis or not. The presence of this disease may first declare itself to the patient by hæmorrhage, and this may occur in the urinary tract alone. In this connection it must be remembered that tuberculous or other surgical infection in one kidney, with or without accompanying changes in the other, may of itself produce arterial changes and high blood pressure. In such instances removal of the affected kidney as the toxic focus not only improves the function of the remaining organ, but often reduces the blood pressure. It can be assumed only rarely in these cases, that

hæmaturia when it occurs as the sole symptom is necessarily the sequel to the arterial condition, and full examination and functional testing of each kidney is required in order to exclude a surgical condition. When, however, hæmoptysis or other forms of bleeding occur simultaneously in a patient with thickened arteries and high blood pressure, there is a reasonable presumption especially when the function of the kidneys is approximately equal, that the cause is systemic and the treatment medical.

Proceedings of the New Zealand Society for the Study of Diabetes Annual Scientific Meeting 14–16 May 2025, Kirikiriroa, Hamilton

ORA AI NGĀ MOKOPUNA: EXPLORING MĀORI PATIENT EXPERIENCES OF TYPE 2 DIABETES EDUCATION

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INTRODUCTION/OBJECTIVES

Type 2 diabetes (T2D) inequitably impacts Māori. The cornerstone of managing T2D is education to empower whānau to self-manage their food (kai), medication (rongoā) and movement (korikori tinana). This study explores perspectives of Māori with T2D on the effectiveness and cultural appropriateness of current diabetes rauemi (educational resources).

METHODS

Qualitative methodologies were utilised, with two focus groups recruited through snowball sampling from a diabetes hapōri (community) group in a semi-rural Waikato town. Participants were Māori (n=6) and Cook Island Māori (n=1), aged 35–44 years, two males, five females. Discussions involved a critical analysis of existing rauemi (print, video, websites) in Aotearoa. Participants engaged in open discussion and provided suggestions on how to improve the rauemi. Data analysis utilised Kaupapa Māori inductive thematic analysis applying a strength-based approach.

RESULTS/OUTCOMES

Two overarching themes emerged: mātauranga (knowledge) and whānau aspirations. Mātauranga emphasised the demand for improved diabetes education, highlighting perceived gaps in patient and whānau knowledge, accessibility to resources and the importance of pono (honesty) in the design and delivery of educational materials. Whānau aspirations underscored the significance of inter-generational knowledge transfer, cultural identity expression and a whānau-centred approach to care.

CONCLUSIONS

This study highlights the importance of incorporating mātauranga and whānau in rauemi for Māori with T2D. This approach will likely improve outcomes for Māori with T2D and aligns with the values of whakapapa (relationality) and kaitiakitanga (guardianship), ensuring that current health interventions contribute to the long-term wellbeing of future generations.

HE ARA TIKA: A QUALITATIVE EXPLORATION OF CLINICAL PERSPECTIVES OF TYPE 2 DIABETES CARE IN MĀORI COMMUNITIES

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INTRODUCTION/OBJECTIVES

Type 2 diabetes (T2D) is a global epidemic, with Māori disproportionately impacted. Māori experience higher rates of diagnosis, complications and mortality compared to non-Māori, influenced by historical trauma, systemic racism, socio-economic inequities, limited healthcare access and ineffective communication. Communication and education grounded in cultural sensitivity are fundamental to reducing inequities. This study explored the perspectives of healthcare providers in providing diabetes care for Māori with T2D in the Ngāruawāhia region.

METHODS

Semi-structured qualitative interviews were conducted between Aug–Oct 2024 with nine clinicians (six Māori, three NZ European): a general practitioner, podiatrist, exercise physiologist, three kaiāwhina, a dietitian, pharmacist and pharmacist prescriber. Participant recruitment involved purposive sampling to ensure representation across different disciplines, reflecting the systemic nature and complexities of T2D care. Interviews were analysed using Kaupapa Māori inductive thematic analysis.

RESULTS/OUTCOMES

Key themes emerged including using patient-centred communication empowering language, the role of whānau and community, interprofessional collaboration and the use of culturally relevant narratives and language. Clinicians described effective use of metaphors and storytelling, drawing on everyday experiences and Māori cultural concepts. Additionally, normalising discussions around diabetes played a vital role in reducing stigma and fostering a non-judgemental and supportive environment.

CONCLUSIONS

This study provides valuable insights into successful communication strategies for healthcare professionals working with Māori with T2D. Widespread adoption of these strategies will likely lead to greater holistic and more culturally responsive care, which is important to address current disparities for Māori with T2D.

DIABETES EDUCATION RESOURCES FOR TAMARIKI AND RANGATAHI LIVING WITH TYPE 2 DIABETES

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INTRODUCTION

There is a growing prevalence of type 2 diabetes among young people in Aotearoa New Zealand, particularly within Māori and Pacific communities. Culturally relevant and age-appropriate diabetes education resources are essential for effective management. This study aimed to identify available diabetes education resources for young people (<25 years) with type 2 diabetes and assess healthcare providers' perspectives on resource gaps, particularly for Māori and Pacific youth and their whānau.

METHODS

A nationwide electronic survey was developed to investigate culturally and developmentally tailored educational resources. The survey was distributed to health professionals and researchers across Aotearoa. Descriptive statistics of responses were calculated, and a content analysis of comments was conducted.

RESULTS

Responses (n=49) were received across all districts. Most responders worked for Health New Zealand – Te Whatu Ora (59%) and were dietitians (31%) or diabetes nurse specialists (26%). While educational materials such as glucose monitoring, weight management, diet and physical activity exist, 70–80% of respondents noted they are adult-focussed and outdated. Respondents highlighted the need for culturally relevant resources, including Māori and Pacific food models, language translations and whānau-inclusive materials. Youth-friendly formats, such as digital tools, social media and interactive activities, were also identified as priorities to better engage tamariki and rangatahi living with type 2 diabetes.

CONCLUSION

Findings suggest a critical gap in diabetes educational resources tailored for young Māori and Pacific people living with type 2 diabetes. There is a pressing need for culturally relevant and age-appropriate materials to support effective diabetes management in these communities.

CO-DESIGNING EQUITABLE DIABETES CARE—INSIGHTS FROM MĀORI AND

PACIFIC PATIENTS IN TOKOROA, NZ

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INTRODUCTION/OBJECTIVES

Māori and Pacific people are disproportionately impacted by type 2 diabetes (T2D). Yet, few services are designed specifically to meet their needs. To address this, we undertook a co-design process in Tokoroa to enhance T2D treatment and outcomes for high-risk Māori and Pacific people. The primary objective was to understand the reasons for suboptimal glycaemic control from the patient's perspective.

METHODS

Engagement was led by Raukawa Charitable Trust and South Waikato Pacific Islands Community Services, in collaboration with two local general practices and Te Whatu Ora Waikato. Three facilitated focus group sessions were held to identify the challenges of living with diabetes, validate the identified themes and prioritise solutions for a patient-centred approach to diabetes care.

RESULTS

The experiences of 27 individuals revealed several important themes, including fear and lack of control over diabetes, challenges with food and dietary changes, social isolation and lack of community support, confusion about medications and inadequate access to glucose monitoring devices. Many also reported difficulties in accessing primary care services, leading some to rely on Tokoroa Hospital for diabetes-related issues.

CONCLUSIONS

The findings highlighted the urgent need for the development and implementation of culturally appropriate resources, community-based diabetes support groups, ethnic-specific dietary guidance and accessible educational materials in plain language. Support from skilled community workers rather than additional clinical staff was a recurrent issue. All of these are likely to improve diabetes care and reduce complications for Māori and Pacific people in Tokoroa.

USING A CITIZEN'S JURY TO INFORM DIABETES PREVENTION IN AN ETHNICALLY DIVERSE LOW-DECILE URBAN COMMUNITY IN AOTEAROA

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INTRODUCTION

Type 2 diabetes (T2D) rates continue to increase in Aotearoa, disproportionately affecting Māori, Pacific, South Asians and those living in material hardship. Although lifestyle changes can prevent or delay the onset of T2D, these communities may be unaware of this. We used a modified Citizen's Jury (CJ) approach to determine whether residents in Porirua East, an ethnically diverse low-decile urban area, considered T2D could be prevented in their community. Unlike focus groups, a CJ allows participants to learn about a particular subject, facilitating an informed discussion.

METHODS

Adult Porirua East residents were recruited to participate in a 1-day meeting. Lay and professional experts presented evidence-based information on "living with diabetes", "landmark diabetes prevention trials", "challenges of making lifestyle changes" and "environmental influences on lifestyle". Participants adjourned to a separate room and, with the assistance of a facilitator, discussed whether T2D could be prevented in their community. They presented their answer to the question, followed by their reasoning. This feedback session was audio-recorded, transcribed and thematically analysed.

RESULTS

Sixteen (eight men, eight women) residents participated, of whom four self-identified as Māori, nine Pacific and two European/Other. Participants agreed that diabetes was preventable in their community; however, significant challenges were identified. Identified themes were 1) a strong sense of community and belonging, 2) a multi-dimensional problem, not just diabetes, 3) pre-existing diabetes prevention knowledge; however, education needs persist, and 4) expectations and challenges.

CONCLUSIONS

This modified CJ provided valuable community insights to inform diabetes prevention in communities with high rates of diabetes.

EFFECTS OF SGLT2i AND GLP-1RA ON MORTALITY IN PATIENTS WITH CARDIOVASCULAR/RENAL DISEASE

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INTRODUCTION/OBJECTIVES

SGLT2i and GLP-1RA are associated with improved outcomes in type 2 diabetes (T2D), but little is known about their effect on mortality in Aotearoa New Zealand (NZ). This study compares 3-year mortality rates for people with T2D dispensed empagliflozin (SGLT2i) vs dulaglutide or liraglutide (GLP-1RA).

METHODS

Data were collected from primary care records for those aged 18–75y with T2D (n=65,251; 2021–2023) and were linked to national medication dispensing and mortality records. Using propensity matching, survival analysis with Cox regression was used to evaluate the effects of SGLT2i or GLP-1RA use (≥2 dispensing events) on all-cause mortality in those with/without cardiovascular/renal disease/elevated risk (CVRD).

RESULTS/OUTCOMES

Overall, 30,011 patients had CVRD; 12,180 were dispensed SGLT2i and 1,644 were dispensed GLP-1RA. Crude mortality rates were lower among those on SGLT2i (2.6%) or GLP-1RA (2.4%) compared with those not using these medications (7.6%). When adjusted for age and HbA_{1c}, the hazard rate ratios (HRR) for those with versus without SGLT2i were 0.47, 0.53, 0.65 and 0.78 for Māori, Pacific, Asian and European, respectively (all P <0.05). Adjusted HRR for those with versus without GLP-1RA were 0.40 for Māori (0.23, 0.71; P=0.002) and 0.80 for European (0.46, 1.41; P=0.44). (Other groups not reported for due to small sample size).

CONCLUSION

SGLT2i and GLP-1RA use is associated with lower mortality among people with T2D and CVRD, particularly for Māori compared to other ethnic groups. Work is required to further evaluate the impact of GLP-1RAs on mortality.

"I *CAN* LIVE WITH DIABETES": EXPERIENCES OF MĀORI PARTICIPANTS IN THE 2GO-CGM STUDY

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INTRODUCTION

Despite the growing inequities in diabetes incidence and outcomes for Māori in Aotearoa, there is a paucity of data capturing the lived experiences of Māori with diabetes, particularly those using diabetes technology. The 2GO-CGM study is a multi-site, longitudinal study in Aotearoa investigating glycaemic and cardiovascular risk outcomes in people with insulin-requiring type 2 diabetes utilising continuous glucose monitoring within a specialist nursing model of care. This qualitative sub-study presents insights into the past and present diabetes experiences of Māori participants in the 2GO-CGM study.

METHODS

Māori participants were invited to join this sub-study from the wider cohort of study participants. The study utilised a narrative methodology with decolonising intent. Semi-structured interviews were conducted, audio-recorded, transcribed and analysed using The Listening Guide data analysis method.

RESULTS

Nine participants were interviewed (five female, four male, age range 33–67 years). Five experiences were identified that shaped participants' sense of self as Māori living with diabetes: 1) experiences with whānau, 2) interactions with healthcare professionals, 3) social experiences with others, 4) personal health experiences with diabetes, and 5) experiences with technology. Within the 2GO-CGM study, positive experiences—particularly those supported by diabetes technology and collaborative care—enabled a shift from negative self-perceptions shaped by broader societal influences to more positive self-identities. Participants demonstrated

resistance to dominant societal narratives, challenging external influences on their diabetes experience.

CONCLUSIONS

The outcomes of this study indicate that technology-integrated models of care can transform the experience of diabetes for Māori by fostering positive self-perceptions and collaborative healthcare interactions.

USE OF REAL-TIME CONTINUOUS GLUCOSE MONITORING IN ADULTS WITH INSULIN-REQUIRING TYPE 2 DIABETES: GLYCAEMIC OUTCOMES FROM THE FIRST 18 MONTHS OF THE 2GO-CGM TRIAL

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INTRODUCTION

The impact of longitudinal use of real-time continuous glucose monitoring (rtCGM) on glycaemia for Māori and non-Māori with type 2 diabetes in Aotearoa is unestablished. The 2GO-CGM study evaluates rtCGM efficacy and safety within a specialist-supported care model in adults with insulin-requiring type 2 diabetes.

METHODS

Following a 26-week randomised one-way crossover "waitlist-controlled" trial comparing rtCGM (Dexcom G6) with self-monitoring of blood glucose (SMBG), participants entered a 12-month extension phase where they continued to use rtCGM (Dexcom G6/G7). We report here on glycaemic outcomes from baseline to extension study end (total of 18 months).

RESULTS

Of the 71 enrolled participants, 62 commenced the first extension phase and 58 completed 12 months follow-up (53% Māori, 58% female, median age 53 [17–70]). Mean time in target glucose range (3.9–10.0mmol/L) increased from 42% (SD=23) at baseline to 56% (SD=23) across 24 weeks and then reduced to 48% (SD=25) across a further 12 months. Mean HbA1c decreased from 83 (SD=16) mmol/mol at baseline to 59 (SD=11) mmol/mol at 24 weeks and rose to 64mmol/mol (SD=16) after a further 12 months. Two participants withdrew from the study due to unmanageable skin reactions to the study device, one participant died of pancreatic cancer. There were no severe hypoglycaemia or ketoacidosis events across the study period.

CONCLUSION

Extended use rtCGM within a specialist supported model of care demonstrates safe and sustained glycaemic improvement for people with insulin-requiring type 2 diabetes.

OBESITY MANAGEMENT MEDICATIONS IN INDIVIDUALS WHO DO NOT RESPOND TO A MEAL REPLACEMENT INTERVENTION

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INTRODUCTION/OBJECTIVES

There is an urgent need for effective and scalable non-surgical interventions to address the current obesity pandemic. It is unclear how those with insufficient weight loss response to meal replacement low energy diets (MR-LED) respond to subsequent treatment with obesity management medications (OMM).

METHODS

This is a retrospective review of people with BMI >35 under the care of Te Mana Ki Tua (TMKT) multidisciplinary weight management service, receiving 12-week MR-LED with group-based support. Saxenda or Contrave are funded as adjuncts, most commonly if 10% weight loss is not achieved with MR-LED.

RESULTS/OUTCOMES

One hundred and ninety-one people started MR-LED between July 2023 and November 2024. Weight after 12 weeks MR-LED was available for 145 people, with a mean change of -11.9kg (-7.9%). 100 people did not meet the 10% target. 48/75 of these individuals offered OMM accepted.

Including those started at other time points, a total of 60 people treated with OMM had 3 months follow up. OMM cessation due to side effects from Saxenda was 7/65 (11%) and from Contrave was 6/15 (40%). Seven people were lost to follow up and five requested discharge.

Mean weight change after 3 months OMM was -2.5%. Only 12% achieved ≥5% weight loss (7/21 men, 0/39 women, Māori 5/16, Pacific 2/32, other 0/12; baseline weight >150kg vs <150kg: 6/24 vs 1/36).

DISCUSSION

Non-responders to MR-LED intervention generally have low response to Saxenda or Contrave. The differential response seen by the baseline demographic group requires further study.

DIABETES NURSE SPECIALIST ASSISTED MONOGENIC DIABETES REVIEW AND CASCADE SCREENING

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OBJECTIVES

To evaluate the impact of diabetes nurse specialist (DNS) assisted virtual review of Auckland patients with Monogenic Diabetes (MD) in improving cascade testing.

METHODS

Auckland patients with MD variants curated as likely pathogenic/pathogenic (LP/P) variants or variants of uncertain significance (VUS) were obtained from diagnostic genetics LabPLUS between 2014–2024. Clinical letters, HbA_{1c}, dispensed glucose lowering therapy and genetic health service (GHS) referrals were noted. Joint DNS/endocrinologist clinic reviews and referrals to GHS were made where appropriate, in collaboration with the primary endocrinologist.

RESULTS

Twenty-eight individuals with LP/P variants (12 GCK, 5 HNF1A, 4 HNF4A, 2 WFS, 1 NEUROD1, 1 m.3243A>G, 1 INS, 1 KCNJ11, 1 ABCC8) and 14 with VUS in MD genes were virtually reviewed. Overall, 10/28 with LP/P and 6/14 VUS in MD genes had been referred to GHS, of whom 12 had been seen and two missed their appointments. Cascade screening was discussed during GH appointments but only four family members had received cascade genetic testing. Twenty-three new DNS/endocrinologist clinical reviews, 14 emails to other endocrinologists urging GHS referrals and four new referrals to GHS were completed. 3/14 probands with VUS were reclassified (1/4 HNF1A as pathogenic, 1/4 HNF1A and 1/3 HNF4A as benign).

CONCLUSION

Few cascade tests are completed for MD from low numbers referred and seen by GHS. DNS assisted clinical review can improve MD cascade testing and VUS reclassification through facilitating GHS referrals. Joint DNS/genetic health counselling reviews with DNS follow up of family members may further enhance cascade testing and care.

THE RELATIONSHIP BETWEEN DIABETIC NEPHROPATHY AND DIABETIC MACULAR OEDEMA IN PATIENTS WITH TYPE 2 DIABETES MELLITUS (T2DM)

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INTRODUCTION

Diabetic retinopathy (DR) is the leading cause of blindness in working-age adults, with diabetic macular oedema (DMO) being the primary cause of vision loss. While diabetes duration and HbA1c levels are well-established risk factors for DR and DMO, they account for only 11% of the risk. Therefore, it is important to investigate other contributing risk factors. In this regard, renal function has gained attention; however, its relationship with DMO development remains unclear. This study aims to clarify these inconsistencies by investigating the association between renal function and DMO in patients with type 2 diabetes (T2DM).

METHODS

This was a retrospective, cross-sectional study. Data were collected from the charts of T2DM patients from the Medical Retinal Clinic at the

Greenlane Clinical Centre in 2022. DMO status was recorded and compared to urinary albumin, albumin-to-creatinine ratio (uACR) and estimated glomerular filtration rate (eGFR).

RESULTS

1,201 patient records were reviewed with 253 patients included in the study. Among these, 157 (62.05%) had DMO, while 96 (37.94%) did not. The study found no significant differences in urinary albumin, uACR and eGFR between DMO and non-DMO groups when analysed as continuous (p=0.63, 0.73, 0.11, respectively) or categorical (p=0.27, 0.52, 0.08, respectively) variables.

CONCLUSIONS

Our results suggest that diabetic nephropathy is not a risk factor for DMO development. However, this finding should be interpreted with caution given the low sample size and lack of longitudinal analysis. Further studies are therefore required to validate these findings.

CHARACTERISATION AND MANAGEMENT OF TYPE 2 DIABETES IN THOSE UNDER 25 YEARS OF AGE IN AOTEAROA NEW ZEALAND

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INTRODUCTION/OBJECTIVES

Type 2 diabetes (T2D) is increasingly being diagnosed in young people in Aotearoa New Zealand (NZ) but is largely uncharacterised. This study reports on the demographics and clinical management of T2D in those aged <25 years in a large primary care cohort.

METHODS

Primary care records (February 2021–Dec 2023) were sourced from four primary health-care organisations across Waikato and Auckland, with medication data obtained from the National Pharmaceutical dataset. The T2D population was confirmed via cross-referencing with secondary care clinical datasets. Socio-demographic, clinical and prescribing data were evaluated.

RESULTS/OUTCOMES

From a dataset of 57,743 patients aged 0–70 years with diagnosed diabetes (T1D and T2D), 1,198 patients were aged <25 years (2.1%) and 335 of these (28%) were diagnosed with T2D. T2D disproportionately affected females (58.4% vs males 41.6%; P <0.01), was associated with BMI (84.5% obese) and Māori and Pacific ethnicity (69.2%) and those aged 15–24 years (92.8%; all P <0.001). Median HbA_{1c} was 63.0mmol/mol and 23.9% of patients were at target (<48mmol/mol). Nearly half of patients exhibited albuminuria (46.2%). Medication use (overall and clinically indicated) included metformin (68.7%/84.9%), insulin (24.8%/76.1%), SGLT2i/GLP-1RA (32.8%/59.5%) and ACE inhibitors (24.5%/36.5%).

CONCLUSION

T2D is now a significant proportion of diabetes in youth/young adults in Aotearoa, and often a more severe disease than in older adults. With a disproportionate burden for Māori and Pacific youth, culturally relevant, targeted lifestyle interventions are urgently required alongside optimised clinical management.

ASSOCIATION BETWEEN BARIATRIC SURGERY AND ALBUMINURIA IN ADOLESCENTS WITH AND AT-RISK OF DIABETES

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INTRODUCTION

Obesity is a significant health problem worldwide, where the prevalence of morbidly obese adolescents is disproportionately higher in the Counties Manukau region as compared to other regions in New Zealand. Bariatric surgery is established as an effective alternative for severely obese adults, but evidence is spare on its use in adolescents, with their unique metabolic, developmental and physiological needs. This study aims to investigate the effect of intensive lifestyle intervention, among adolescents, with/without bariatric surgery on Urine-Albumin-Creatinine-Ratio (UACR) as a measure of renal function.

METHODS

Consented adolescents with morbid obesity (BMI ≥35) will receive a 12-week weight-loss regimen comprising Very Low-Calorie Diet (VLCD) based

on the Optifast weight-loss programme. After 12-weeks, eligible participants will be offered a bariatric surgery procedure. Analyses incorporated mixed models to examine the effects of surgery, gender, weight change and time point on a participant's UACR, where the final model included fixed effects for time point and surgery, with repeated measures for adolescents across 14 time points.

RESULTS

Of 21 participants enrolled (12 females, nine males), six (four females, two males) received bariatric surgery. Adolescents who received surgery had significantly reduced UACR in comparison to adolescents who did not receive the surgery.

CONCLUSIONS

Significant differences exist in UACR among adolescents who received bariatric surgery versus those who did not. These findings highlight that adolescents who received a lifestyle intervention and bariatric surgery had a better outlook on renal function in comparison to those who did not receive the surgery

IMPACTS OF AGING OUT OF THE CHILD DISABILITY ALLOWANCE FOR RANGATAHI WITH TYPE ONE DIABETES

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INTRODUCTION/OBJECTIVES

In New Zealand, the Child Disability Allowance (CDA) is available to families with a child with type 1 diabetes (T1D) <18 years. We previously reported that the CDA was often used to subsidise continuous glucose monitors (CGM). This study examines the experiences of rangatahi (youth) aged 18–23 with T1D of "ageing out" of the CDA.

METHODS

A 31-question survey was developed. Recruitment was undertaken through regional young adult clinics at Waitematā and Waikato diabetes services. Additional recruitment occurred through diabetes groups on Facebook. Data were analysed descriptively.

RESULTS

Thirty-six participants completed surveys. Of the survey participants, 20 were female, mean age was 20.3 years.7±3.8 years. Loss of the CDA coincided with other significant life transitions. 16/20 reported losing the CDA had a moderate or significant impact on their ability to afford CGM. 9/20 reported a moderate or significant impact on their ability to buy quality groceries. 14/20 reported that their mental wellbeing was negatively affected by losing access to the CDA. Qualitative data highlighted that loss of the CDA was more likely to leave those with lower income unable to access CGM, while those with higher income were more likely to report feeling embarrassment at needing financial support from family to pay for CGM.

CONCLUSION

Pharmac funding has alleviated the biggest impact identified in this survey, difficulties in accessing CGM after losing the CDA. However, due to the strict means-testing for the adult disability allowance, many rangatahi with T1D may struggle to manage the additional costs of managing their diabetes.

USER-FACING INFORMATION AND GUIDES FOR FUNDED DEVICES FOR TYPE 1 DIABETES IN NEW ZEALAND ARE NOT CONSISTENTLY FIT FOR PURPOSE

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BACKGROUND

Advancements in diabetes technology, such as continuous glucose monitors (CGMs) and insulin pumps, glycaemic control and quality of life for people with type 1 diabetes (T1D). Recently Pharmac funded devices, necessitating clear, user-friendly resources for patients and their whānau.[1] However, complex medical language in existing materials may hinder comprehension, especially for individuals with limited health literacy.[2] This study assessed the readability of publicly available, user-facing resources on funded T1D devices in New Zealand.

METHODS

Relevant New Zealand-based, consumer-facing resources were selected from reputable websites, including Healthify NZ, Pharmac, Diabetes New Zealand and device manufacturers. The core informational text was extracted, cleaned and analysed using Microsoft Word's Flesch Reading Ease tool. Scores above 60 were considered easily understandable, while scores below 50 indicated poor readability.

RESULTS

Readability scores ranged from 32 to 63. Healthify

NZ (CGM–63) and Pharmac (CGM–62) achieved the highest scores, while Burwood Health (32) and Starship NZ (32) had the lowest. Government and national health resources generally scored higher, reflecting a focus on user-friendly language, whereas clinical and manufacturer websites had more technical content, resulting in lower scores. Significant variability was observed across resources covering similar device types.

DISCUSSION AND CONCLUSION

While some resources meet recommended readability levels, many fall below thresholds, potentially limiting patient understanding and informed decision-making. Clinicians should prioritise providing sources with higher readability scores to support people living with T1D to learn about the funded treatment options now available.

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GLYCAEMIC OUTCOMES OF A RANDOMISED CONTROLLED FULLY CLOSED LOOP TRIAL (CLOSE IT)

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OBJECTIVES

The real-world utility of automated insulin delivery systems may be undermined by user-associated burdens, including a recommendation to carbohydrate count and deliver manual insulin boluses prior to meals. The CLOSE IT (Closed Loop Open SourcE In Type 1 diabetes) trial assessed the safety and efficacy of a "fully closed loop" (FCL) system.

METHODS

Randomised, open-label, parallel, non-inferiority trial using a locked version of the oref algorithm (as used in AndroidAPS). Participants with type 1 diabetes aged 18–70 completed a 12-week run-in to initiate automated insulin delivery, followed by randomisation (1:1) to one of two treatment arms for a further 12 weeks: FCL—participants did not bolus for meals; and HCL (hybrid closed-loop)—participants delivered manual mealtime boluses. The primary outcome was time in range (3.9–10.0mmol/L), as assessed at days 71–84 and 155–168 (the final 2 weeks of the run-in and of the trial) with a pre-specified 7% non-inferiority margin.

RESULTS

Seventy-three participants across two sites (University of Otago, Christchurch and Baker Heart and Diabetes Institute, Melbourne) underwent randomisation (36 to FCL and 37 to HCL). Mean time in range (± standard deviation) pre-randomisation and at trial end was 69±11% and 66±8% in the FCL, and 70±9% and 69±13% in the HCL group, resulting in an adjusted mean difference -2.2% (95% confidence interval -6.2 to 1.7%). Adjusted mean difference in HbA_{1c} was 0.09mmol/mol (-1.9 to 2.2).

CONCLUSIONS

An AID system used as FCL was non-inferior to the same system used as HCL, during extended outpatient use.

PSYCHOSOCIAL IMPACTS OF CESSATION OF MEAL ANNOUNCEMENT IN A RANDOMISED CONTROLLED TRIAL OF A FULLY CLOSED-LOOP SYSTEM

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OBJECTIVES

Users of automated insulin delivery systems may still experience a significant diabetes burden, in part due to a recommendation to carbohydrate count and deliver manual insulin boluses prior to meals. The CLOSE IT (Closed Loop Open SourcE In Type 1 diabetes) trial demonstrated glycaemic efficacy of the oref algorithm (as used in AndroidAPS) when used as "fully closed loop" (FCL) (without meal announcement). This sub-study aimed to explore psychosocial impacts of cessation of meal announcement.

METHODS

All 73 participants in the CLOSE IT trial completed standardised questionnaires at pre-specified time-points: INsulin dosing Systems: Perceptions, Ideas, Reflections, and Expectations (INSPIRE); 5-level EQ-5D (EQ-5D-5L); and system usability score (SUS). Responses were scored and compared between the FCL and HCL (hybrid closed loop) arms. Ten participants in the FCL arm completed a qualitative interview at study completion. Verbatim transcripts were prepared and descriptive qualitative thematic analysis used.

RESULTS

Mean (± standard deviation) SUS score was 85±12 in the FCL and 75±15 in the HCL groups (difference 9.1, 95% confidence interval 2.8 to 15). No significant differences were identified in responses to the INSPIRE and EQ-5D-5L questionnaires. In qualitative interviews, FCL users identified a reduced cognitive burden of diabetes and greater flexibility around meals; however, they also commented on perceived weight gain and higher postprandial glucose levels.

CONCLUSIONS

Use of an FCL system when compared to an HCL system was associated with multiple user-identified psychosocial benefits, including reduced cognitive burden, greater mealtime flexibility and increased ease of use.

COMPARISON OF FASTER-ACTING INSULIN ASPART (FIASP) TO INSULIN ASPART IN USERS OF A FULLY CLOSED LOOP SYSTEM

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OBJECTIVES

Delayed absorption of current "rapid-acting" insulin analogues from the subcutaneous space may prevent automated insulin delivery systems from attaining glycaemic targets when used as "fully closed-loop" (FCL), without meal announcement. Faster-acting insulin aspart (FIAsp), containing a combination of insulin aspart and nicotinamide, has shown more rapid onset of glucose-lowering action when compared to insulin aspart in pharmacokinetic studies. This study aimed to determine if FIAsp improved glycaemic outcomes in users of an FCL system.

METHODS

Twenty adults with type 1 diabetes who were randomised to the FCL arm of the CLOSE IT (Closed Loop Open SourcE In Type 1 diabetes) trial were invited to a 28-day extension. During the extension, pump insulin was changed from aspart to FIAsp. The primary outcome was percentage time in target range (3.9–10.0mmol/L) during the final 14 days of each phase.

RESULTS

Mean (± standard deviation) time in range was 65±10% with aspart and 68±10% with FIAsp (difference 3.0%, 95% confidence interval -0.04% to 6.0%, p=0.053). Time in tight range (3.9–7.8mmol/L) was 43±9% with aspart and 47±11% with FIAsp (difference 3.6%, -0.3% to 7.4%). Time below range (<3.9mmol/L) was 1.5±1.2% with aspart and 1.6±1.2% with FIAsp (difference 0.07%, -0.5% to 0.7%).

CONCLUSIONS

Use of FIAsp in a small exploratory study of FCL users may have resulted in a small improvement in time in range; however, this result did not reach statistical significance. Larger studies are justified, investigating FIAsp in users of automated insulin delivery systems who do not attain glycaemic targets.

RURAL–URBAN DISPARITIES IN TYPE 2 DIABETES: A DEMOGRAPHIC AND CLINICAL ASSESSMENT IN NEW ZEALAND

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INTRODUCTION

Rural living in New Zealand presents challenges in healthcare access and management of chronic conditions such as type 2 diabetes (T2D). This study explores differences in demographic and clinical outcomes in patients with T2D across rural and urban areas.

METHODS

Clinical and socio-demographic data from four

large Primary Healthcare Organisations in Auckland and Waikato were analysed for individuals aged 18–75 years diagnosed with T2D (Feb 2021–Aug 2022). The study explored trends and associations between patient demographics and key health indicators.

RESULTS

The study included 56,937 patients with T2D, with 85.3% enrolled with urban practices and 14.7% with rural practices. Differences in clinical measures (HbA1c, UACR, eGFR, LDL-C and BP) were minimal between patients enrolled at rural vs urban clinics but may be skewed by a higher proportion of rural patients not being screened during the study period (e.g., 11% vs 9.4% with no HbA1c; 38.4% vs 25.5% with no UACR; P <0.001). Importantly, prescribing of diabetes related medication was up to 10% lower for both Māori and non-Māori enrolled with rural vs urban clinics (all P <0.001).

CONCLUSION

Prescribing rates and laboratory screening for disease progression continue to be lower for rural communities, and particularly for Māori compared to urban Māori. Further work is required to optimise healthcare access and monitoring of chronic disease to ensure optimal health outcomes.

THE ACCEPTABILITY AND FEASIBILITY OF INCORPORATING PERSONAL VALUES INTO SELF-MANAGEMENT ACTION PLANNING AMONG YOUNG ADULTS WITH TYPE 1 DIABETES AND HIGHER THAN RECOMMENDED HBA_{1c}

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INTRODUCTION/OBJECTIVES

Using personally chosen values (i.e., what is important, qualities of a person's behaviours) as guiding principles may increase motivation to adhere to diabetes self-management tasks. The objectives of this study were to explore the feasibility and acceptability of a values-guided self-management intervention.

METHODS

In a single-arm uncontrolled study, five participants diagnosed with type 1 diabetes ≥6 months, aged 18 to 25 years, inclusive, and an HbA_{1c} ≥58mmol/mol at a routine clinic visit in Dunedin, New Zealand, completed a guided <1-hr self-management action planning session either online or in-person. Participants identified their values, set a goal and incorporated at least one value into an action plan to achieve their goal. A handout of strategies to cope with psychological barriers was provided. Participants completed an intervention evaluation by reporting what they liked and did not like about the intervention and rating the helpfulness of the intervention from 1—extremely unhelpful to 5—extremely helpful.

RESULTS

Four participants rated the intervention as "very helpful", and one participant rated it "extremely helpful". The most liked intervention features were having a "safe" place to discuss self-management challenges, talking through action planning and focussing on small, meaningful changes and coping strategies. Participants reported difficulty understanding some open-ended questions, feeling "put on the spot" and talking about deeply meaningful topics with a stranger in one visit.

CONCLUSION

An intervention incorporating values into young adults' self-management tasks was feasible and acceptable. Future research will explore the preliminary effectiveness of the intervention on short-term glycaemic outcomes.

CASE STUDIES OF TWO YOUNG PEOPLE AFTER INTENSIVE LIFESTYLE INTERVENTION AND BARIATRIC SURGERY

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INTRODUCTION

This collaboration with Middlemore Bariatric service (2020–2025) had as an objective "to investigate the effect of intensive lifestyle intervention with or without bariatric surgery on the incidence of pre-diabetes and diabetes in a cohort of high risk morbidly obese adolescent participants".

METHODS

Twenty youth meeting study criteria had VLCD with intensive lifestyle support, and some were offered bariatric surgery. Duration of participation/follow-up was 3 years.

RESULTS

Results for the larger group will be analysed when the final participant finishes in October 2025. Currently there are seven in the no-surgery group, seven in the surgery group, two awaiting surgery and four non-complete/withdrew. Exceptional results for two of the most challenging participants are presented here.

DISCUSSION

Case study 1: Samoan male age 17 on commencement. Morbidly obese 174.4kg (BMI 46), prediabetes, hypertension. Optifast 12 weeks and lifestyle intervention intensive phone/online/meeting support. Underwent bariatric surgery. At age 19, weight 115kg, normal blood sugar and BP. At university studying, plays sports.

Case study 2: Tongan male age 18 on commencement. Morbidly obese 139.6kg. Hypertension, type 2 diabetes (HbA_{1c} 109mmol/mol), CKD 3, asthma. Optifast/lifestyle intervention phone/online/meeting support, HbA_{1c} still 100mmol/mol. Had bariatric surgery and at age 20, weight now 97.9kg, Hba_{1c} 33, off all medication. Working in early learning setting.

CONCLUSION

Bariatric surgery was life-changing for these young people. The benefits have outweighed the large amount of support they required.

Thank you to all who supported this project, particularly the young participants and their whānau.

THE AID IMPACT STUDY: AUTOMATED INSULIN DELIVERY TO IMPROVE OUTCOMES FOR MĀORI AND PACIFIC ADULTS WITH TYPE 1 DIABETES AND ABOVE-TARGET GLYCAEMIA

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INTRODUCTION

Those of non-European ethnicity have typically been under-represented in automated insulin delivery (AID) system use, across research trials and clinical care access. The AID IMPACT study investigates the use of AID systems in Māori and Pacific adults (aged 16–65) with type 1 diabetes and above-target glycaemia (glycated haemoglobin [HbA_{1c}] ≥64mmol/mol).

METHODS

Prospective, single-arm, multi-centre study. This summer studentship analyses the first 6 weeks of data for the first 12 participants (at time of writing). Following 2-week baseline continuous glucose monitoring data collection, participants were trained on the AID system (MiniMed 780G insulin pump) using a 72-hour rapid onboarding protocol. Outcomes measured include HbA_{1c}, time in glycaemic ranges, adverse events and AID system performance.

RESULTS

At baseline, participants had a mean age of 32.9 (9.1) years, mean HbA_{1c} of 89.3 (20.2) mmol/mol, and 91.7% were using multiple daily injection therapy. After 6 weeks of AID, mean time-in-range 3.9–10.0mmol/L and time-in-tight-range 3.9–7.8mmol/L improved from 27.1% (14.7%) to 68.4% (8.9%), and from 15.7% (9.3%) to 46.0% (9.5%), respectively. Time spent in hypoglycaemia <3.9mmol/L decreased from 2.3% (3.2%) to 1.4% (1.5%). There were no episodes of severe hypoglycaemia or diabetic ketoacidosis.

CONCLUSIONS

Māori and Pacific adults with above-target glycaemia using AID experience substantial glycaemic improvements without increasing time spent in hypoglycaemia. A 9-month extension phase will allow for long-term outcomes to be analysed.

TAILORING THE LIFT MENTAL HEALTH APP FOR YOUTH AND YOUNG ADULTS WITH TYPE 2 DIABETES: A QUALITATIVE STUDY

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INTRODUCTION

Type 2 diabetes (T2D) in youth and young adults presents unique challenges beyond glycaemic outcomes, including high rates of diabetes distress, anxiety and stigma. Despite these psychological burdens, mental health support is often not integrated into routine diabetes care. Digital interventions offer a promising solution, yet few are designed specifically for this population, highlighting a critical gap in accessible, tailored mental health support.

METHODS

This qualitative study explored the acceptability of the LIFT: Thriving with Diabetes app, a digital mental health intervention initially developed for youth and young adults (16–25) with T1D. Semi-structured interviews and focus groups were conducted with young individuals with T2D (n=4, 50% Māori), their caregivers (n=3, 66.7% Māori) and healthcare professionals (n=10, 10% Māori) to evaluate user needs, content relevance, engagement strategies and barriers to sustained use. Data were analysed using qualitative content analysis.

RESULTS

Participants highlighted the importance of culturally responsive, engaging and youth-centred digital mental health interventions. Participants also valued the app's focus on self-compassion and psychological wellbeing but emphasised the need for personalisation, peer support and long-term engagement strategies. Diabetes-related stigma was a key concern, impacting self-care behaviours, emotional wellbeing and overall quality of life.

CONCLUSION

This study underscores the necessity for tailored digital interventions that integrate mental health into diabetes management. By addressing psychosocial needs alongside medical care, tailored digital tools like LIFT may enhance wellbeing, promote self-management and improve mental health outcomes for youth with T2D. Further research is needed to refine and expand such interventions to maximise long-term impact.

POSTNATAL HBA$_{1c}$ SCREENING UPTAKE AND EXPERIENCES FOLLOWING A PREGNANCY WITH GESTATIONAL DIABETES AT WELLINGTON REGIONAL HOSPITAL

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INTRODUCTION/OBJECTIVES

Early identification of glucose intolerance after a pregnancy with Gestational Diabetes (GDM) is essential for prevention of type 2 diabetes (T2DM). Postnatal HbA_{1c} screening following national guidelines is inadequate and the optimal model of care to enable equitable access to screening is debated.

We evaluated HbA_{1c} screening after a pregnancy with GDM in Wellington between 2018–2022. We explored people's experiences to identify factors promoting equitable uptake of postnatal HbA_{1c} screening.

METHODS

People with GDM in Wellington who delivered between 2018–2022 were included, with data compared to all births in Wellington. Every post-pregnancy HbA_{1c} test was recorded. A questionnaire was sent to those delivering between 2022–2024.

RESULTS/OUTCOMES

GDM was diagnosed in 6.8% of births: Māori 3%, European 6%, Pacific 16%, Indian 20%, other ethnicities 7–13%; and increased with age: 3.5% <20y, 8.6% <40y. 91% who delivered between 2018–2022 have completed at least one postnatal HbA_{1c} test. HbA_{1c} at 12–16 weeks increased from 52%, 2018 to 82%, 2022 with midwife-led reminders.

Successful screening increased with age, lower

deprivation, and varied by ethnicity: Māori 40%, Pacific 39%, European 65%, Asian 72%.

70% of people felt inadequately informed about postnatal testing. Challenges included post-pregnancy overwhelm, worry of T2DM diagnosis, primary care costs, logistical barriers and inadequate reminders.

CONCLUSION

Postnatal HbA_{1c} screening was optimal led by a dedicated midwife. Annual primary care screening remains inconsistent with significant challenges and persisting inequities: lower among Māori, Pacific and younger people. A national funded equitable screening approach is imperative to reduce T2DM after GDM.

DIPPS STUDY. DIABETES IN PREGNANCY: ROUTINE SCREENING FOR PLACENTAL INSUFFICIENCY USING THE SFLT-1/PLGF

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INTRODUCTION/OBJECTIVES

Placental insufficiency, which may manifest as pre-eclampsia and/or fetal growth restriction, is one of the most common causes of iatrogenic preterm birth, and neonatal and maternal morbidity and mortality. In New Zealand, 2–7% of pregnancies are complicated by pre-eclampsia; however, the risk is increased 2–4-fold in people with type 1 diabetes (T1DM) or type 2 diabetes (T2DM). We examine, in pregnancies complicated by T1DM or T2DM, the value of routine screening for impending placental insufficiency using a blood test, sFlt-1/PlGF.

METHODS

A prospective observational cohort study of pregnant people with T1DM or T2DM. Participants were sequentially recruited from antenatal clinic and written consent was provided. Blood for sFlt-1/PlGF was drawn at 20, 24, 28, 32 and 36-weeks gestation. Clinicians were masked to sFlt-1/PlGF results unless the sFlt-1/PlGF was requested by the attending clinician outside of protocol. Outcome measures were clinical placental insufficiency and prevalence of abnormal sFlt-1/PlGF at each time point. This study was funded by a NZSSD i-SENS Pharmaco Research Grant 2022.

RESULTS

Of the 99 participants, 18.2% were Māori, 7.1% Pacific People, 18.2% South Asian, 12.1% South East Asian, 41.4% European and 3.1% other ethnicity; 58 had T2DM and 41 T1DM. Pre-eclampsia was diagnosed in 17 (29%) with T2DM and 14 (35%) with T1DM. Preterm birth occurred in 11 (19%) with T2DM and 12 (30%) with T1DM. sFlt-1/PlGF results are pending.

CONCLUSION

There was a high rate of clinical placental insufficiency in this cohort; further results will be available at the conference.