

NEW ZEALAND

TE ARA TIKA O TE HAUORA HAPORI

MEDICAL JOURNAL

PUBLISHED BY:

 **PMA** PASIFIKA MEDICAL ASSOCIATION Group

Vol. 138 | No. 1609 | 14 February 2025

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Publication information

published by the Pasifika Medical Association Group

The *New Zealand Medical Journal (NZMJ)* is the principal scientific journal for the medical profession in New Zealand. The *Journal* has become a fundamental resource for providing research and written pieces from the health and medical industry.

The *NZMJ*'s first edition was published in 1887.

It was a key asset of the New Zealand Medical Association (NZMA)
up until July 2022.

It is owned by the Pasifika Medical Association Group (PMAG).

The PMAG was formed in 1996 by a group of Pasifika health professionals who identified a need for an association with the purpose of “providing opportunities to enable Pasifika peoples to reach their aspirations”.

ISSN (digital): 1175-8716

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Further information

ISSN (digital): 1175-8716
Publication frequency: bimonthly
Publication medium: digital only

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nzmj.org.nz/contribute

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Subscription rates for 2025

Individual		Institute	
New Zealand	Free	New Zealand	\$680
International	Free	International	\$700

New Zealand rate includes GST. No GST is included in the international rate.

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Summaries

The adverse impact of disability funding cuts on individuals with intellectual disability

Richard J Porter, Henrietta Trip, Chris Daffue, Julie Fitzjohn, Peri Renison

Cuts to services for people with disabilities, which have been introduced in 2024, include a “freeze” on residential placements and cuts to some services that people who are cared for at home can access. People with intellectual disabilities have difficulties with understanding and communicating, as well as physical and mental health problems. Many people with intellectual disabilities are being severely negatively affected by the cuts in services. For example, they cannot access residential care and the level of support they receive in residential care is being reduced. This is resulting in significant distress and mental health problems for the individuals with intellectual disabilities and their whānau and carers.

Rheumatic fever trends in the context of skin infection and Group A Streptococcal sore throat programmes in the Bay of Plenty: an observational study, 2000–2022

John Malcolm, Lydia Snell, Kate Grimwade, Sandra Innes-Smith, Melissa Bennett, Lindsay Lowe, James Scarfe, Aroha Ruha-Hiraka, Liam Walsh

A recently published paper in the *New Zealand Medical Journal* found that acute rheumatic fever and skin infection rates in the Bay of Plenty have decreased since 2011 when intensified programmes began for both. The decrease in acute rheumatic fever was greatest for NZ Europeans and by a third for school-age Māori served by school-based Hauora-delivered sore throat and some skin health programmes and primary care, a decline not found for young adults aged 15–29 years. Skin infection admissions' largest decrease was by 40% from their peak for both NZ Europeans and Māori preschoolers across the Bay of Plenty. Disparities continue, with Māori having disproportionately higher skin infection admission rates than NZ Europeans, six-fold at preschool age and two-to-three-fold thereafter. The decreases for Māori at school age and for young adults were greater in the Western, more affluent, part of the Bay of Plenty. The authors recommend strengthening the frequency and coverage of school-based Hauora-delivered sore throat and skin infection programmes, especially in the Eastern Bay of Plenty, and initiatives for both young adult and Pacific peoples.

Acute rheumatic fever in Canterbury, Aotearoa New Zealand, 2012–2022

Taliah Su'a, Allamanda Faa'toese, Andrew Anglemyer, Kiki Maoate, Tony Walls

This study describes the epidemiology of patients who were diagnosed with acute rheumatic fever (ARF) in Canterbury from 2012 to 2022. ARF is less common in Canterbury when compared with other regions. In Canterbury, Pacific peoples are most likely to be diagnosed, followed by Māori. The majority of people getting long-term treatment for ARF in Canterbury have been diagnosed elsewhere and moved into the region. To ensure these patients get the healthcare they need, it is important to have effective communication between regions and a strong national monitoring system.

Epidemiology of skin infections in Auckland, New Zealand

Krishtika Mala, Michael G Baker, James Stanley, Julie Bennett

Skin infections caused by *S. pyogenes* pose an important public health issue in New Zealand, particularly among children under 10 years old of Māori and Pacific descent, where the likelihood of these infections rises with deprivation levels. *S. aureus* infections impact everyone, but they can also increase the chance of co-infection with *S. pyogenes*. There is an urgent need for improved health initiatives to address skin

infections, as these efforts could help reduce the future risk of acute rheumatic fever in Māori and Pacific communities.

Emotional after-effects of the New Zealand Whakaari eruption on burns and theatre healthcare workers

Lillian Ng, Kiralee Schache, Marie Young, Joanna Sinclair

Healthcare organisations can anticipate deep psychological effects on healthcare workers after a mass casualty event. This study examined the emotional experiences of burns and theatre healthcare workers caring for injured patients following New Zealand's Whakaari/White Island volcanic eruption in 2019 at Te Whatu Ora Counties Manukau, based in Auckland, New Zealand. Staff reckoned and wrestled with the aftermath of the disaster with collective emotional after-effects, and there was cumulative harm amidst healthcare system constraints. Opportunities for emotional processing may counter stoic medical culture, especially for staff who are recurrently exposed to trauma.

Outdoor gym equipment in parks in Aotearoa New Zealand: preliminary surveys of availability and usage

Nick Wilson, George Thomson

There is the growing international evidence that outdoor gym equipment in parks can provide health and fitness benefits to the population. In this New Zealand study we found 122 parks with outdoor gym equipment in the 10 largest territorial authorities (TAs). The prevalence ranged from zero (in three TAs) up to 5.6 parks per 100,000 population in Christchurch City (i.e., one such park per 18,000 people). Observations from one large urban park indicated that the eight pieces of equipment averaged 16 uses per hour overall (extrapolated to estimate around 18,000 episodes of use over the 3 summer months for this park). In conclusion, there is a need for further research, but this study provides preliminary data that such equipment can be extensively used by the public in some settings.

Bronchiectasis cough during the COVID-19 pandemic: a qualitative study

Julie Blamires, Mandie Foster, Wendy McRae, Sarah Mooney

This study explored how adults living with bronchiectasis experienced life during the COVID-19 pandemic, focussing on the challenges of living with a chronic cough. Many felt vulnerable and faced stigma due to their cough, which was often misunderstood. Participants adapted by prioritising self-care, building supportive networks and relying on virtual healthcare to stay connected. The findings highlight the importance of health professionals raising awareness about bronchiectasis to reduce stigma and improve public understanding of chronic respiratory conditions.

Establishing a New Zealand brain tumour registry: understanding clinical registry formation in New Zealand

Holly Wilson, Caroline Woon, Chris Tse, Jayne Sheridan, Lee-Ann Creagh, Sandar Tin Tin, George Laking, Makarena Dudley, Melissa James, Fouzia Ziad, Catherine Han, Thomas I-H Park

In New Zealand, around 2,400 people are diagnosed with a brain tumour every year, and despite their often debilitating and lethal consequences, not much is known about the brain tumour landscape in New Zealand, due to the lack of a national disease registry. This review is part of our society's effort to establish a national brain tumour registry—a database that describes in detail each brain tumour diagnosed in New Zealand. This will help us to improve our treatment and research of brain tumours. This review describes the research we have done on disease registries that already exist in New Zealand, and the discussions we have had with the clinicians and patients in the brain tumour community. Through this

work, we describe the essential pillars in building a brain tumour registry for New Zealand, and how we can implement these factors to ensure the registry is successful.

Closing the gap: the call for government-funded annual health checks for intellectually disabled New Zealanders

Shara Turner, Conal Smith

Intellectually disabled New Zealanders have a much shorter life expectancy than the general population, in part due to preventable health issues. Evidence from Australia and the United Kingdom proves that annual health checks can save lives by catching health problems early, reducing avoidable hospital stays and improving overall health. In Aotearoa New Zealand, annual health checks could prevent over 100 deaths a year while also saving money by easing demand on hospitals. A targeted, staged rollout starting in regions with high numbers of intellectually disabled people would be an effective and practical first step.

Cinacalcet-associated torsades de pointes in a haemodialysis patient: a case report

Shakir Aiman bin Sema Onsha, Fahimatul Imtiaz binti Mohd Rahiman, Marilyn Aday, Curtis Walker, Ankur Gupta

Our case report highlights a rare but serious side effect of cinacalcet, a medication often used to treat high calcium levels in people with chronic kidney disease on dialysis. We describe a patient who experienced a dangerous heart rhythm problem called torsades de pointes, which can cause the heart to stop beating normally. This condition was linked to changes in the heart's electrical activity (shown on an electrocardiogram) after taking cinacalcet. By recognising this connection, we hope to raise awareness of the potential risks of this medication and help doctors identify and prevent similar cases in the future.

The adverse impact of disability funding cuts on individuals with intellectual disability

Richard J Porter, Henrietta Trip, Chris Daffue, Julie Fitzjohn, Peri Renison

ABSTRACT

During 2024, significant changes were made to funding available for the support of individuals with intellectual disability. These included a “freeze” on funding for residential care and a restriction of what flexible funding can be used for. This article examines the serious adverse effects of these changes, which we have observed in our clinical practice with this vulnerable group of people.

As clinicians working with individuals with disabilities, we are increasingly concerned regarding the adverse impact of cuts in funding to support individuals with disabilities and their carers.

The highest proportion of funding for disability support provides services for individuals with intellectual disability (ID). Since de-institutionalisation and the National Advisory Committee’s 2003 report for the Ministry of Health, *To have an ‘ordinary’ life – Kia whai orange ‘noa’*,¹ care for these individuals has improved significantly. However, the recent cuts threaten this for many. Here we highlight the clinical risk associated with the funding cuts for these individuals and describe what we have observed regarding the consequences of these changes. In focussing on people with ID we do not want to diminish the effects of the funding cuts for individuals with other disabilities. However, we believe that individuals with ID are among the most vulnerable in our community and are also a group of individuals for whom self-advocacy can be particularly difficult.

ID and associated physical and mental health difficulties

ID is characterised by significant intellectual impairment—an IQ of less than 70 on standardised neuropsychological testing, significant difficulties in adaptive functioning and evidence of onset prior to 18 years of age. These difficulties are lifelong. In Aotearoa New Zealand, rates of ID are higher among Māori (1.3%), with rates in Pacific peoples at 0.9% and Europeans at 0.8%.²

Individuals with ID suffer from mental illness at rates of at least two to three times that of the general population, with verbal and cognitive limitations making diagnosis particularly challenging. For example, the incidence of schizophrenia is approximately four times greater, with a similarly increased rate of bipolar disorder. Individuals with ID are significantly more likely to suffer from physical illnesses—for example, epilepsy,³ diabetes, chronic obstructive pulmonary disease and coronary heart disease²—and they develop dementia at a significantly earlier age.⁴ They are more likely to be sexually (a rate of 30%)⁵ and physically abused and to suffer other adverse life events. Neurodiversity issues are also greater among individuals with ID, with the rates of attention deficit hyperactivity disorder and autism spectrum disorder (ASD) being several times greater than in the general population.^{6,7} Difficulties in accessing healthcare are significant, related to difficulties in communication and to systemic and discrimination issues in the healthcare system. Life expectancy is significantly reduced by approximately 20 years.²

Care for individuals with ID in Aotearoa New Zealand

Until the early 2000s, many individuals with ID were housed in large institutions (e.g., Braemar, Cherry Farm, Templeton, Kimberley, Māngare, Tokanui). Care in these settings was often regimented and lacked attention to individual rights and access to the community. Polypharmacy was common in attempts to control behavioural disturbance. These institutions were progres-

sively closed from 1996 onwards and many of the residents were re-housed in community-based homes. Currently, these homes usually have two to six residents, supported by staff up to 24 hours per day. The level of staffing varies according to the needs of the residents. Day services and vocational activities are provided to facilitate activities, education and supported employment outside their home. These services are often provided by not-for-profit, non-government organisations. The majority of individuals with ID are cared for by family at home. This situation can be stressful for families, and at times the situation can break down rapidly. Flexible “individualised” funding was intended to allow families to utilise a range of strategies to maximise the potential of the individual and to allow them to remain in their family home.

Given high rates of mental health difficulties, individuals with ID frequently require specialist mental health input. In contrast to most other developed countries, in Aotearoa New Zealand there is minimal access to services that specialise in treating the comorbidity of ID and mental health difficulties. The only comprehensive specialist service is in Canterbury. Generally, if individuals with ID require hospital in-patient care, they are admitted to general adult psychiatric wards, where there is usually no specific expertise in their care, the environment is often inappropriate and individuals are vulnerable.

In many cases problematic behaviour can and should be managed by the judicious application of positive behaviour support, involving consistent positive reinforcement for desired behaviour and management of the environment to minimise distress. Specialist advice and assessment is provided by behaviour support services nationwide. The waiting time for this service is generally between 1 year and 18 months.

Costs of disability support

Currently 50,000 clients access funding from Disability Support Services (DSS) (a 43% growth in 5 years from 2019).⁸ In that 5-year span, the numbers of individuals with ID accessing DSS support increased by 2,500 (to a total of approximately 19,000) and those with ASD by 9,600 (total 18,000). The greatest increase in costs has been in residential care (increased by NZ\$406 million) and in flexible funding arrangements (increased by NZ\$376 million).

The *Independent Review Disability Support*

Services notes that “Almost \$1bn is now spent on residential care facilities each year, a significant increase from \$700m in 2015/16.”⁹ This represents a 43% increase on the background of an increase in consumer price index of approximately 30%¹⁰ between 2015 and 2024, a rate of rent increase above the rate of inflation, pay equity settlements (still ongoing), increased pay rates for “sleepover staff” and a 43% increase in clients (between 2019 and 2024).

Overall, we believe that several important improvements have been made in the care of individuals with ID in residential and other settings. Increasingly, dedicated services have recognised the very complex needs of individuals with ID, and have adapted services to respond to individual needs. This has often led to smaller houses with fewer residents, sensory adaptations, a focus on staff continuity and targeted improvement of staff ratios.

The DSS funding cuts

DSS (Ministry of Social Development ([MSD]) is responsible for contracting and funding for individuals with a long-term intellectual, physical or sensory disability, including autism, that arises before the age of 65. In 2021, a decision was made to set up Whaikaha – Ministry of Disabled People, which was launched on 1 July 2022, with responsibility for administering DSS funding. This function was transferred from the Ministry of Health. In March 2024, the Government announced a “temporary pause” that narrowed the scope of what carers could purchase to support individuals with disabilities.¹¹ Examples of services that can no longer be “purchased” with individualised funding are therapies such as “*speech language therapy, psychologist involvement in behaviour support; and occupational therapy.*” These are considered “*examples where other agencies may have funding responsibilities.*”¹¹ However, these services are not available within a realistic time frame with funding from any other agency.

In May 2024, a review of DSS was commissioned and the *Phase One Report* was published on 28 June 24.⁹ On 15 August 2024, the Government announced that Whaikaha would be restructured as a policy and advisory department, that DSS functions would be taken over by MSD and that there would be no financial uplift for the care and support of individuals with disabilities. Recommendation 2 was to “*Freeze current levels of funding for residential facility-based care for 2024/25 pending*

commissioning and completion of a detailed and urgent review of the contract and pricing models”⁹—the latter is currently underway.

The *Phase One Report* was produced within 6 weeks of the appointment of a Chair, and noted that because of the time frame “*Engagement with the disability community was not possible during this phase of the review.*”⁹ No clinical staff were interviewed. In the section regarding “clinical risks”, of 10 paragraphs only one addresses clinical risks; paragraph 148 notes “*There is a risk that the quality of care being provided to disabled individuals may erode during a period of funding constraint. We consider that the monitoring proposed in Recommendation 4 will be an important part of the mitigation of this risk; but we acknowledge that it may take time to establish a responsive monitoring function. In the meantime, internal processes for complaints, concerns and ongoing stakeholder management must recognise this risk and provide transparency to executives on how risks are being managed.*”⁹ Recommendation 4 was to “*establish an effective function within the Ministry to monitor the assessment and allocation performance of NASCs (Needs Assessment and Service Co-ordination and EGL (Enabling Good Lives) demonstration sites.*”⁹

Clinical risks and consequences of the funding cuts

Effectively, what has been implemented is a cut in funding, involving a freeze in new residential placements and cuts to aspects of flexible funding for those individuals living at home. These funding cuts have significant implications, which are already impacting on the care of individuals with ID, as we have observed in our clinical practice:

1. Effectively, no new residential places are being funded and some that were planned but not yet commenced have been withdrawn. The decision to place a loved one into residential care is one of the most difficult faced by families with adult offspring or siblings with ID. In our experience, the decision is often made only when severe difficulties are being experienced, and family carers develop burnout and mental health challenges.¹² We have now seen several such individuals and families/whānau who, having made the decision to place their loved one in residential care, have had this option taken
2. Some individuals with severe difficulties who have been admitted to hospital have not been able to be transitioned back into the community due to the funding freeze. These individuals are now left in hospital, often in a general psychiatric ward—an inappropriate environment where the person is vulnerable. This also then “blocks” scarce mental health hospital beds. Residential services will not consider taking these individuals into care because of the likelihood that they may require higher levels of care, for which funding is not available.
3. Higher levels of care within residential services are now not available when individuals with ID experience worsening mental health difficulties. Previously, services requested extra, often temporary, funding to respond to a situation in which a person might suffer from an episode of significant depression, mania or psychosis. Supporting people in their usual setting with staff who they know well is usually the best option. While a “review panel” might agree to “individualised rates for residential care”, practically we have not seen this happen.
4. Individuals with ID experience dementia at an earlier age. Again, care in their own home is the best option and, in our experience, services have in the past provided this until the person dies. This was done with increased funding to provide more intensive care as the person’s cognitive function declined. Some services have specialised in caring for older individuals and have expertise in caring for these individuals when they develop dementia. These services are vulnerable, and some will be forced to close. With funding unavailable to meet changing needs, it is likely that some individuals will now be admitted to general psychiatric wards since they are not suitable for dementia-level care.
5. As funding is reviewed, some individuals have had existing packages of care reduced and providers have begun to “rationalise” by amalgamating houses and closing houses

with fewer residents. Often homes with fewer residents were set up for individuals with ASD, who require a quieter, more structured and predictable environment. We have already observed adverse effects on the mental health of individuals forced to move home because of these changes. Not only are larger group homes less suitable, but such enforced moves away from familiar long-term housemates and staff represent major adverse life events, stress and altered mental wellbeing for the individuals involved.

6. Funding for activities outside the home has become constrained, leaving residents at home without meaningful activity or distraction from sources of distress.
7. The factors noted above are leading to pressure to increase prescribing of sedative and antipsychotic medication in an attempt to “medicate” behaviour disturbance. Where there are specialist mental health services for individuals with ID, these services have spent many years reversing the polypharmacy that occurred in both institutions and contemporary healthcare. Services are now under pressure to introduce or re-introduce antipsychotic medication to mitigate the effects of inappropriate placements and low staffing levels resulting from the funding cuts.
8. A combination of factors related to the funding cuts is leading to an increase in high-risk suicidal and violent behaviour,

resulting in higher rates of presentation of individuals with ID to mental health services, emergency departments and police.

Conclusions

We have observed significant adverse consequences of the current disability funding cuts and believe that these impacts will worsen over time. We suggest that there is no justification to “freeze” residential funding while reviewing the funding system and that doing so is causing unnecessary, severe harm to those with ID and their families and carers. The harm caused will not be short term. Already, the reconfiguration of services is taking place, returning individuals with ID to a situation of non-personalised care, accompanied by reduced community involvement and chemical restraint.

The loss of individualised services and skilled staff will take many years to reverse and will be costly. The trauma of these changes and the accompanying worsening of physical and mental health for individuals with ID and their families and carers will not be reversible. Hospital beds will be blocked, resulting in increased costs and potential harm for all individuals with mental health difficulties requiring in-patient admission.

These funding cuts are largely based on a report that was produced in 6 weeks, without clinical or community engagement, and which essentially had minimal consideration of the effects, other than supposed financial benefits. We urge the Government to reconsider.

COMPETING INTERESTS

Richard J Porter uses software for research into cognitive remediation, provided at no cost by SBT-pro.

Henrietta Trip is Co-Chair of the Canterbury Disability Providers Network and Chair of the National Disability Nurses Branch, Te Ao Māramatanga – New Zealand Colleges of Mental Health Nurses.

Peri Renison is a Psychiatrist Member of the Mental Health Review Tribunal.

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<https://nzmj.org.nz/journal/vol-138-no-1609/the-adverse-impact-of-disability-funding-cuts-on-individuals-with-intellectual-disability>

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Rheumatic fever trends in the context of skin infection and Group A Streptococcal sore throat programmes in the Bay of Plenty: an observational study, 2000–2022

John Malcolm, Lydia Snell, Kate Grimwade, Sandra Innes-Smith, Melissa Bennett, Lindsay Lowe, James Scarfe, Aroha Ruha-Hiraka, Liam Walsh

ABSTRACT

AIMS: This study reports acute rheumatic fever (ARF) rates and admission rates for skin infections across the Bay of Plenty from 2000 to 2022 since health initiatives for both commenced in 2011.

METHODS: Skin infection hospital admission rates and ARF rates for those under 30 years of age focussed on 2011–2019 after interventions began, compared with 2000–2010. Outcomes/trends were estimated by age bands, ethnicity, gender and socio-economic deprivation.

RESULTS: Mean skin infection rates changed very little. However, rates increased between 2000 and 2010 then declined following skin infection programmes' implementation. Comparing 2017–2019 with 2007–2010, skin infection admission rates for Māori declined 40% for preschoolers, 14% for school-age children and 24% for young adults. Inequities persisted.

Māori experienced 90% of the ARF (Pacific peoples 6%, NZ Europeans 4%), 80% at school-age. ARF under-30-years-of-age rates 2011–2019 compared with 2000–2010 declined by 29%, with risk ratios of Māori:NZ European 24.33; Māori, High Deprivation:Moderate 3.97 and Male:Female 2.23. School-age ARF rates for Māori declined by 36%. Young adults' ARF rates were unchanged.

CONCLUSIONS: While rising skin infection admission rates during the first study period returned to baseline following interventions, ARF declined significantly and contemporaneously for under-30-year-olds and specifically for school-age Māori. Ethnic and socio-economic disparities persist, needing more concurrent focussed interventions.

Although acute rheumatic fever (ARF) triggered by Group A *Streptococcal* (GAS) infections affected New Zealanders of all ethnicities in 1920–1950, Indigenous Māori had the highest rates.¹ A century later, NZ Europeans/Pākehā rarely get rheumatic fever, which now affects mainly Māori and Pacific peoples. Rheumatic fever rates increased from the 1980s to 2009^{2,3} and increased for young adults until 2018.⁴ Nationally, Aotearoa New Zealand's Rheumatic Fever Prevention Programme (RFPP) 2012–2017 significantly lowered ARF admission rates, more so at school-age than for young adults, particularly in Counties Manukau^{5,6} and within the Bay of Plenty (BOP).⁷ The programme reviewers hypothesised five possible mechanisms for this reduction: treatment of GAS pharyngitis within school-based programmes and primary care; skin infection treatment; declining GAS prevalence/transmission;^{6,7} and these mechanisms in combination.⁵

While sore throat management should remain a key ARF prevention strategy, the national RFPP review recommended a “new focus” to address skin infections.⁵ The organisms most commonly cultured from skin infections are GAS and/or *Staphylococcus aureus*. Aotearoa New Zealand case-control, cohort and community ARF studies identified both GAS pharyngitis and skin infections,⁸ including scabies^{8–10} via secondary GAS infection, as specific modifiable risk factors. Self-reported scabies preceded 6% of ARF cases.⁸ Auckland population-level evidence supported the hypothesis that GAS skin infection triggers ARF. A review of 267 ARF cases found GAS-positive skin swabs preceded ARF in 9% of cases, pharyngeal GAS in 88% of cases and both in 3% of cases.¹¹

Other risk factors for GAS skin infections include doctor-diagnosed eczema.¹² In Auckland school-age children, 52% with a GAS-positive skin infection had eczema, as did 32% with GAS pharyngitis.¹² Recent immunology evidence found

that multiple more GAS infections precede ARF, on average 11 episodes, priming the immune system (compared to healthy children) probably from as early as 2 years of age, challenging current intervention strategies.^{13,14}

GAS pharyngitis, skin infection and ARF case-control studies also recommend adequate housing, minimising crowding and reducing barriers to primary care access.^{8,12} Nationally, primary care became free for most children under 6 years of age from 2007 but was not extended to those under 15 years of age until 2015.

The BOP District Health Board has funded twice-weekly school-based sore throat swabbing ARF prevention programmes delivered by Māori health providers, Hauora, since 2011; there are four programmes in the rural East and one in the West in Tauranga, with general practice support,⁷ following Heart Foundation NZ guidelines (Appendix 1). The East, which has high socio-economic deprivation, includes Whakatāne, Kawerau and Ōpōtiki districts, and the West, with heterogenous and more moderate deprivation, includes Tauranga and Western Bay of Plenty districts.⁷ From 2018, once-weekly symptomatic swabbing began in five of 18 Whakatāne schools, where ARF had doubled without RFPP. Of note, half of the East's school-age Māori attend Whakatāne schools.⁷

Community pharmacies in Eastern BOP and Te Puke, Western Bay of Plenty, have dispensed antibiotics for GAS pharyngitis since 2015 on standing orders for those aged 3–19 years at risk of ARF, and for their skin infections since 2020.¹⁵

Concurrently, decades of increasing childhood skin infection hospitalisations prompted sentinel Aotearoa New Zealand publications in 2010.^{16–18} Regional skin infection programmes followed. Health promotion, findings and protocols were shared nationally.¹⁹

Five BOP skin infection initiatives commenced in 2010–2012 and continue. Three involved public health, primary and secondary healthcare. Firstly, Toi Te Ora Public Health (TTO) undertook a health needs assessment of hospitalised skin infections for children aged 0–14 years in 2010.²⁰ Its strategies addressed health promotion, advocacy for affordable primary health access, training—including paediatric nurse seminars for practice and preschool nurses—and research.²⁰ Secondly, public health nurses, Hauora and paediatricians developed local skin infection resources from 2011 and intensified their skin infection service delivery. High schools appointed nurses trained to use standing orders to treat students' skin

infections and sore throats. In 2011, the Infectious Diseases service led a third initiative, a primary–secondary care collaboration that developed a new guideline website, “Bay Navigator”.²¹ Its pathways guiding the treatment of childhood and adult skin infections were analogous to its successor, the Midland Region Community Health Pathways.²¹

Two other initiatives were targeted: Whakatāne Hospital's paediatric home visiting team of a nurse and social worker²² who, from 2012, supported whānau to manage eczema and prevent recurrent skin infections and started paediatric skin clinics. In Kawerau, one school-based sore throat team initiated the Kiri Ora (Healthy Skin) programme in 2013. Pharyngeal GAS point prevalence, which declined 23–11% with their sore throat programme in 2010–2013, declined further to 8% in 2014.⁷

TTO's strategic goals included reducing ARF and respiratory and skin infections, and they reported declining childhood skin infection admission rates in 2000–2016.²³ Nationally, the socio-economic disparities of those admissions were closing.²⁴ However, while BOP's childhood skin infection rates in 2013–2017 declined below the national average,²⁵ Auckland's three districts' rates (where ARF rates were increasing) remained above the national average.²⁶

This study in BOP aimed to observe if both skin infection admissions rates and ARF rates (admissions and Ministry of Health [MOH] notifications) declined contemporaneously for preschool, school-age and young adults since 2011, when health initiatives and programmes addressing GAS sore throats and skin infections commenced; this is illustrated and detailed in Appendix 1. The study sought to monitor equity, evaluate possible programme effectiveness and identify evidence of areas for quality improvement, where available.

Methods

Skin infections

Admissions of children and young adults aged under 30 years with serious skin infections, fulfilling O'Sullivan and Baker's case definition 2010,¹⁷ and used in both previous TTO reports^{20,23} (Appendix Figure 2 with 53 ICD-10 discharge codes), were identified by NHI from BOP's two hospitals, Whakatāne, with its Eastern referral catchment, and Tauranga for the West. De-identified aggregated patient demographic data for these NHI and admissions were extracted, which informed rate sub-analyses by age, gender, hospital, year and MOH single prioritised

self-identified ethnicities aggregated into Māori, Pacific peoples, NZ Europeans and Others (MELAAA: peoples of Middle East, Latin American, African and Asian ethnicities).²⁷ A total of 17,615 admissions were identified, and 19 records (0.1%) were discarded with “ethnicity not stated”. Their family names, on digital note scrutiny, suggested similar ethnic distribution to BOP’s population. Although of another 31 people, 0.2% for whom ethnicity response was “unidentifiable”, four had Māori and one had Tongan names, hospital medical information recoded them as Other European. Another coding error was re-audited where Eskimo-USA was assigned to 1.1%, which affected 198 admissions from 2000–2007, of whom 103 were identified and recoded as Māori, 90 as NZ European, 3 as Asian and 2 as Pacific peoples. Previously filed self-identified ethnicity data completed by whānau is now destroyed after clerical coding on admission. The direction of error to underestimate Māori morbidity is consistent with prior studies.²⁸

Case numbers informed rates over the 23 years of this study, 11 years from 2000 to 2010 prior to RFPP and skin infection programmes and 12 years 2011 to 2022, inclusive, since their inception. However, the years 2011 to 2019 informed our BOP post-intervention findings prior to the COVID-19 pandemic from 2020 to 2022 when, nationally, admissions for many infectious diseases, including ARF, declined.^{29,30} Rate ratios estimated time trends when rates, with 95% confidence intervals (CI), were compared between time periods. Risk ratios within time periods informed equity of rates between ethnicities, genders and deprivation and, when compared between time periods, informed equity trends. Further annual rates/10,000 person-years were estimated for five 3-year and two 4-year periods: 2000–2002, 2003–2006, 2007–2010 pre-intervention and 2011–2013, 2014–2016, 2017–2019, 2020–2022, following. To evaluate some programme outcomes, prior annual rates from 2007 to 2010 vs post-intervention comparisons from 2017 to 2019 were made. Sub-group age bands were studied, because preschoolers 0–4 years and school-age children aged 5–14 years both receive childhood-specific services, including public health nursing plus primary care, while young adults aged 15–29 years receive mainly primary care alone; hence, age band comparisons, to some extent, compare service model outcomes.⁵ Preschool rates may be relevant to address GAS immune priming.

Acute rheumatic fever

First presentation ARF case numbers utilised discharges ICD codes I00.0–I02.9 and MOH notifications with cases confirmed after case note scrutiny, as previously reported.^{7,31} They informed estimated ARF rates/100,000/person-years for 2000–2010, 2011–2022 and 2011–2019 inclusive and trends. The two sources were utilised together for all time periods (and alone, estimating ascertainment bias risk), utilising the same age bands as skin infections. For ease of comparison with previous publications, this study’s ARF findings are reported in several formats: all ethnicities at all ages (MOH, Te Whatu Ora – Health New Zealand); under-30-years-age, wherein 93% of cases in Aotearoa New Zealand occurred between 2000 and 2018;⁴ and Māori specific in two age bands, school-age and young adults, to permit comparison of interventions and outcomes.^{5,7,32} This comparison is because many at school age, mainly Māori, are served by BOP school-based prevention programmes with primary care support,⁷ while most young adults are served by primary care alone, as also noted within the national review of RFPP.⁵ Equity analyses were as for skin infection admissions. A possible spike in ARF cases in early-COVID January–June 2020 was evaluated, as were contextual factors, comparing the odds ratio of ARF with the surrounding 6 years, and ARF rates 2011–2019 vs 2020–2022 inclusive.

Statistics New Zealand and BOP population data informed denominators, using whole district, which included Whakatāne, Kawerau and Ōpōtiki territorial land authorities (TLAs) for Eastern BOP (East) and Tauranga and Western TLA for Western BOP (West) age, ethnic-specific and gender numbers. Census data from 2006 informed 2000–2010, 2013 informed 2011–2016 and 2018 informed 2017–2022.³³ While NZ Census 2018 limitations meant there was only a 70% completion rate by Māori, it informed population growth/shifts since 2013. Population-weighted socio-economic deprivation decile scores were calculated deriving a New Zealand Index of Deprivation (NZDep) 2006 average for the East of 9 and West 6,³⁴ which changed minimally when re-estimated using 2013 data. Rate and risk ratios with 95% CI were estimated using StataCorp Texas Statistical Software: Release 14.2, 2015. Results were considered statistically significant where CIs of rates did not overlap, rate and risk ratios did not include 1, which were tabled without reliance on P-values, which in those circumstances were <0.05 but not always tabled.

The attributable proportion of ARF cases from 2015 to 2022 (since both pharyngeal and skin GAS triggers have been actively considered) with a recent preceding GAS pharyngeal or skin infection was estimated by comparing those with a positive culture taken from either or both sites. The study also assessed whether admitted skin infections, while fewer than community infections, reflected total infections and if both changed in parallel (rather than shifting one management setting to another). As an example with accessible data, scabies rates were compared over time in three settings, in the under-30-years-age group, for admissions (ICD Code B86 primary or secondary diagnoses), emergency department (ED) presentations (Read code AD30 or scabies mentioned) and community permethrin 5% total prescriptions (unique in that it is used exclusively for scabies) in 2014–2019 available on MOH's Datapharm website. Community scabies prescriptions for the under-30-years-age group were estimated by applying their proportion (74% of all ED scabies presentations 2000–2019) to total prescriptions.

Data availability

Where derived rates appear alone in the article, case numbers and exposed populations' person-years are published for replicability as full tables in the Appendices.

Ethics

This study adheres to World Health Organization Ethics Guidelines, NZ Health and Disability Ethics Committees' *National Ethical Standards for Health and Disability Research and Quality Improvement 2019* and *Standard Operating Procedure 2019* and its exemptions, as an observational study with minimal risk. Locality approvals were given by the BOP District Health Board for the initial ARF study of 2000–2018 and its successor Hauora a Toi for the extension of the ARF study to 2019–2022, inclusive, and skin infection data from 2000–2022, alongside Māori Research Panel review. The locality applications detailed the retrospective nature of the study of the impact of prevalent healthcare interventions, from their initiation within the district using routine de-identified data for skin infections and ARF, and NHI-linked data where use was limited to ARF case-certainty and prior skin and pharyngeal GAS infections and as having low privacy impact.

Māori Health consultation/support was sought alongside both locality agreements. This study adheres to the Health Research Council of New

Zealand *Guidelines for Researchers on Health Research Involving Māori 2010* and is guided by Tangata Whenua Determinants of Health 2011, Health Equity Tool 2008 and *Te Toi Ahorangi 2019*. Kawerau GAS prevalence studies obtained parental swabbing-consent and ethics approval NZ/1/77C3019.32. Reporting follows STROBE guidelines.

Results

Skin infections

Of all the skin infection admissions in 2000–2022, 29% occurred in preschoolers (on average 1,037/year of age), 27% over 10 school-age years, (475/school-age year) and 44% in young adults over 15 years (512/young adult year).

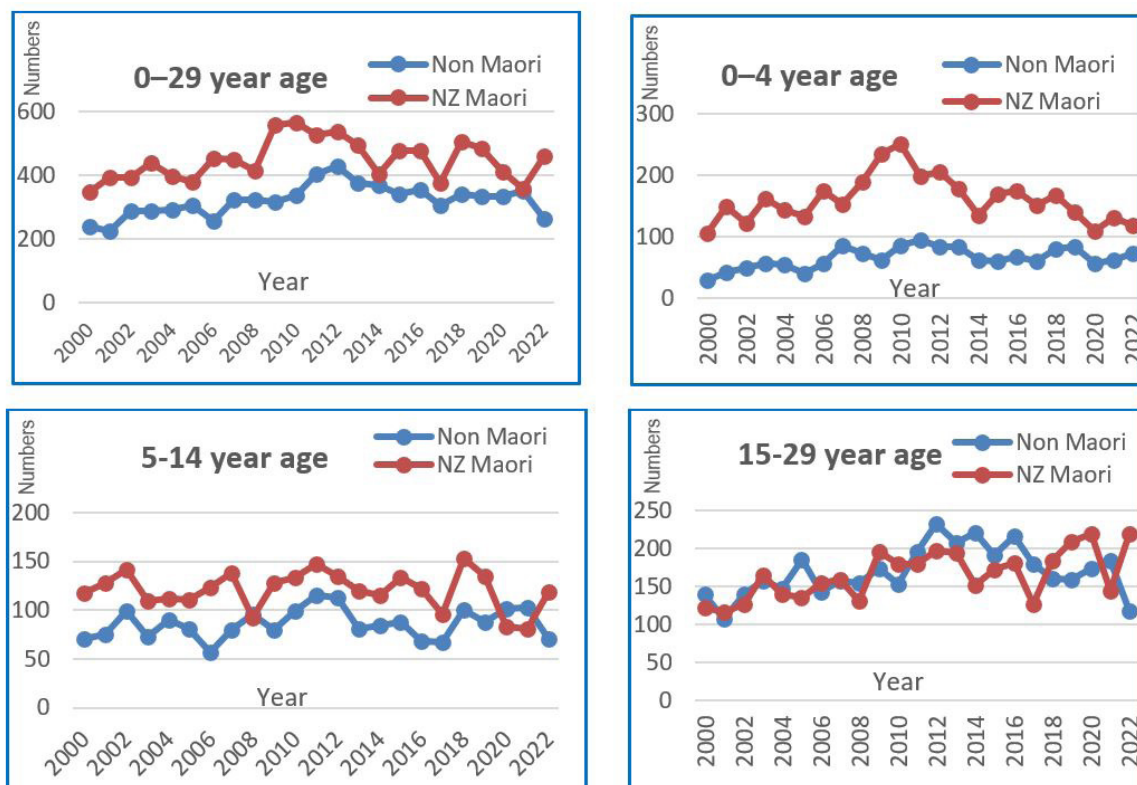
The proportion of admissions for Māori was 58%, NZ Europeans/Pākehā 34%, Pacific peoples 4% and Others 3% (of which 52% were Indian). Māori make up 30% of BOP residents under 30 years of age, NZ Europeans/Pākehā 60%, Pacific peoples 3.7% and Others (MELAAA peoples) 6.3%.

Skin infection admission rates for under-30-year-olds increased by 8% comparing the mean rate pre-intervention 2000–2010 with 2011–2019 (Table 1), which excludes the potentially confounding 2020–2022 COVID-19 pandemic period. (The skin infection rates in 2011–2022 were lower than 2011–2019; available from authors). For sub-groups, the changes were significant: NZ European rates were the lowest and declined significantly at all ages except young adults; Māori preschoolers' rates were the highest, six times that of NZ European preschoolers', and both declined, Māori by 6% and NZ Europeans by 14%. However, the inequity gaps and Māori vs NZ European risk ratios were unchanged. School-age Māori rates appeared unchanged, while NZ European rates decreased by 10%. Young adult rates were lower than preschoolers, but higher than those at school-age. Young adult Māori experienced 7% increased rates.

Pacific peoples' skin infections were 4% of the total. Pacific peoples' admission rates increased 34%. Their highest rates, for preschoolers, approached Māori rates and increased substantially for young adults, with significantly increased inequity risk ratios compared to NZ Europeans (Table 1).

Skin infection admissions rates for "Others" ethnicities increased significantly by 27% to rates similar to NZ Europeans. (The case numbers and denominator person-years exposed are in Appendix Table 3).

Figure 1: The rise and fall of skin infection admissions for Māori and non-Māori people in the Bay of Plenty under-30-years-of-age in 2000–2022.



Annual skin infection admissions rose from 2000, peaked in 2010–2011, then declined to baseline numbers in 2022, a pattern most apparent for preschoolers (Figure 1).

Therefore, analysis was undertaken of annual rates in seven time periods. Pre-intervention rates in 2007–2010 were then compared with 2017–2019 post-intervention, the most recent pre-COVID 3-year period (Table 2), rather than 2020–2022, as the decline in admissions observed for Aotearoa New Zealand during the COVID-19 pandemic also occurred in BOP and confounded observations of programme outcomes since implementation. Skin infection admission rates declined significantly from 2007 to 2010 to 2017 to 2019 by 39% for NZ European preschoolers, 31% at school-age and 32% for young adults. Rates declined 40% for Māori preschoolers, 14% at school-age and 24% for young adults. (Appendix Table 4 presents cases/exposed population person-years, and peak rate/2017–2019 comparisons).

Comparing early COVID-19 pandemic rates in 2020–2022 with 2017–2019 for BOP Māori, skin infection admissions did decline significantly at preschool and school-age but increased slightly

for young adults. Rates for NZ Europeans were similar in both time periods in all age bands (Table 2).

Māori:NZ European skin infection admission risk ratios compared pre-intervention in 2007–2010 and 2017–2019 remained almost six-fold higher for Māori preschoolers, which increased to three-fold at school-age and remained two-fold for young adults.

Māori young adults' 2007–2010 skin infection admission rates were significantly higher than school-age, risk ratio 1.48 (95% CI 1.32–1.66) and 2017–2019, risk ratio 1.30 (95% CI 1.14–1.49). School-age Māori rates in 2017–2019 declined significantly from baseline 2000–2002 rate ratio 0.82 (95% CI 0.71–0.95), whereas young adult Māori rates in 2017–2019 were not dissimilar to baseline rates rate ratio 1.04 (0.91–1.19).

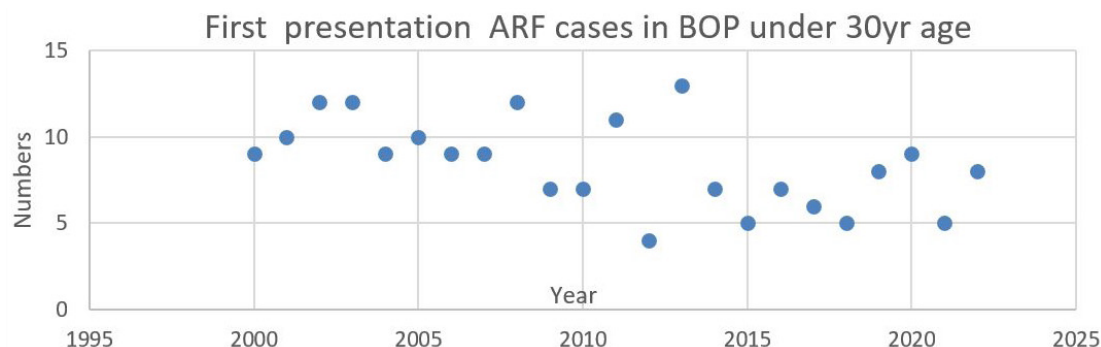
For BOP Māori under-30-years-of-age, skin infection rates were unchanged in the East and declined 43% in the West from similar peak rates. An East:West high deprivation:moderate deprivation inequity ratio of 1.4 emerged for all age bands. Comparing Māori skin infection admission rates in 2007–2010 to pre-COVID 2017–2019 rates,

Table 1: Skin infection admissions for Māori, NZ European, Pacific peoples and Other peoples in the Bay of Plenty. Time trends are informed by rate ratios, 2000–2010 vs 2011–2019. Equity trends Māori, Pacific peoples, Other:European risk ratios 2000–2010 vs 2011–2019.

Skin infections Age (years)	Ethnicity	Cases, n	2000–2010 Rate/10,000/year.	2011–2019 Rate/10,000/year	Time trend rate ratio (95% CI)	Risk ratio 2000–2010 Māori:NZ European	Risk ratio 2011–2019 Māori:NZ European
Census			2006	2013 & 2018			
<30	All	15,448	95.43	103.02	1.08 (1.05–1.11)		
<30	Māori	9,045	163.78	165.04	1.01 (0.97–1.05)	3.04 (2.90–3.19)	3.23 (3.08–3.39)
<30	NZ European	5,325	53.90	51.07	0.95 (0.90–0.99)		
0–4	Māori	3,336	318.63	298.26	0.94 (0.88–1.00)	6.10 (5.52–6.75)	6.62 (5.94–7.38)
0–4	NZ European	884	52.23	45.06	0.86 (0.76–0.98)		
5–14	Māori	2,490	109.00	110.51	1.01 (0.94–1.10)	2.87 (2.63–3.14)	3.25 (2.96–3.58)
5–14	NZ European	1,440	37.93	33.99	0.90 (0.81–0.99)		
15–29	Māori	3,219	145.08	154.63	1.07 (1.00–1.14)	2.09 (1.95–2.24)	2.23 (2.08–2.40)
15–29	NZ European	3,001	69.50	69.24	1.00 (0.93–1.07)		
						Pacific peoples:NZ European	Pacific peoples:NZ European
<30	Pacific peoples	650	90.69	121.22	1.34 (1.14–1.56)	1.69 (1.49–1.92)	2.37 (2.13–2.64)
0–4	Pacific peoples	289	168.52	233.92	1.39 (1.10–1.76)	3.22 (2.62–3.97)	5.19 (4.36–6.17)
5–14	Pacific peoples	159	64.87	60.75	0.94 (0.69–1.28)	1.71 (1.35–2.16)	1.79 (1.42–2.24)
15–29	Pacific peoples	202	70.01	117.46	1.68 (1.25–2.25)	1.01 (0.79–1.29)	1.69 (1.42–2.02)
						Others:NZ European	Others:NZ European
<30	Others MELAAA	428	39.85	50.61	1.27 (1.03–1.36)	0.74 (0.62–0.88)	0.99 (0.88–1.11)

Table 2: Māori and NZ European skin infection admissions, rates/10⁴/year, 2000–2022; 2017–2019 vs 2007–2010, and M:E equity.

Ethnicity & age band	Skin infection admission rates/10,000 person-years, with 95% confidence intervals, in seven time periods over the study 2000–2022							Rate ratio 2017–2019 vs 2007–2010	Risk ratio M:E 2007–2010	Risk ratio M:E 2017–2019
	2000–2002	2003–2006	2007–2010	2011–2013	2014–2016	2017–2019	2020–2022			
n 17,615										
Census	2006	2006	2006	2013	2013	2018	2018			
Māori 0–30 years n 10,269	142.11 (133.94–150.65)	157.11 (149.65–164.85)	187.14 (178.99–195.56)	197.49 (187.79–207.56)	172.07 (163.03–181.49)	134.38 (127.33–141.71)	120.76 (114.10–127.70)	0.71 (0.67–0.77)	3.17 (2.95–3.41)	3.39 (3.10–3.71)
NZ European 0–30 years n 6,045	47.83 (44.29–51.58)	53.38 (50.13–56.79)	58.97 (55.55–62.55)	62.27 (58.85–66.81)	53.36 (49.78–57.13)	39.60 (36.81–42.55)	38.27 (35.50–41.20)	0.67 (0.61–0.74)		
Māori 0–4 years n 3,695	242.27 (218.43–268.01)	295.93 (272.98–320.29)	398.59 (371.89–426.71)	367.42 (338.18–398.53)	301.77 (275.32–330.07)	238.36 (217.01–261.22)	186.83 (168.00–207.20)	0.60 (0.53–0.67)	5.99 (5.17–6.95)	5.83 (4.81–7.06)
NZ European 0–4 years n 1,015	40.72 (33.17–49.48)	46.57 (39.50–54.53)	66.52 (58.01–75.92)	56.82 (48.46–66.21)	38.11 (31.32–45.93)	40.85 (34.25–48.35)	39.64 (33.10–47.00)	0.61 (0.50–0.76)		
Māori 5–14 years n 2,773	116.03 (104.75–128.18)	102.31 (93.13–112.16)	110.41 (100.86–120.62)	124.84 (112.93–137.66)	115.21 (103.78–127.55)	95.30 (86.01–105.33)	70.24 (62.30–78.90)	0.86 (0.76–0.99)	2.69 (2.33–3.10)	3.37 (2.84–3.99)
NZ European 5–14 years n 1,651	38.52 (33.55–44.01)	34.37 (30.30–38.84)	41.06 (36.59–45.92)	44.01 (38.89–49.62)	30.83 (26.56–35.57)	28.29 (24.56–32.43)	28.98 (25.20–33.20)	0.69 (0.58–0.82)		
Māori 15–29 years n 3,801	119.56 (107.61–132.48)	146.18 (134.67–158.41)	163.13 (150.96–176.02)	186.00 (171.04–201.92)	164.79 (150.73–179.81)	124.23 (113.78–135.38)	139.04 (128.00–150.80)	0.76 (0.68–0.85)	2.25 (2.01–2.51)	2.53 (2.22–2.88)
NZ European 15–29 years n 3,379	59.46 (53.45–65.96)	73.95 (68.11–80.16)	72.58 (66.80–78.73)	82.81 (75.97–90.11)	81.12 (74.35–88.34)	49.10 (44.43–54.13)	45.94 (41.40–50.80)	0.68 (0.60–0.78)		

Figure 2: Number of ARF cases in the Bay of Plenty each year, under-30-years-age, in 2000–2022.

significantly larger declines were observed in the West at all ages, with a smaller 31% decrease for Eastern preschoolers. The only statistically significant male:female skin infection rate disparity for Māori was the emergence of a risk-ratio of 1.4 in the Eastern BOP for young adults (Appendix Table 5).

Annual scabies admission rates/10,000 increased significantly for under-30-year-olds from the baseline years 2000–2010 (rate 1.80 [CI 1.51–2.09]) to the peak year 2011 with the years 2011–2015 (rate 3.57 [CI 2.97–4.17]), then declined in 2016–2019 to 1.37 (CI 0.99–1.75). Similarly, scabies ED presentations/10,000 for 2000–2010 was 3.21 (CI 2.82–3.59), rose in 2011–2015 to 8.80 (CI 7.87–9.74), then declined in 2016–2019 to 2.60 (CI 2.07–3.13). The estimated community permethrin 5% prescription rate in 2011–2015 of 220.06 (CI 215.89–225.29) also declined in 2016–2019 to 127.19 (123.49–130.89). Māori and Pacific 0–29-year-olds experienced 93% of under-30-years-age scabies admissions and made up 81% of ED under-30-years-age scabies presentations.

Diagnosed scabies preceded ARF within the 3 months before ARF diagnosis¹¹ for 0.7% (1/142) Māori and Pacific 5–14-year-olds presenting with ARF in 2000–2019, whereas 2.8% (4/142) had a documented scabies admission, ED presentation or community anti-scabies prescription in the 10 years prior to ARF diagnosis.

Acute rheumatic fever

Of 49 ARF cases in BOP in 2015–2022, 35 had recent preceding positive community or hospital GAS swabs. Of positive swabs, pharyngeal GAS preceded 69% of cases, skin GAS 17% and both pharyngeal and skin GAS 14%. That is, pharyngeal GAS may have preceded ARF in 69–83% of cases and skin GAS may have preceded ARF in 17–31% of cases.

Although the plot of 194 first presentation ARF cases in BOP by year in 2000–2022 under-30-years-age shows similar numbers per year in 2020–2022 to the immediately preceding 6 years (Figure 2), ARF rates were estimated in 2011–2019 vs 2000–2010 for consistency with skin infection admission analysis, lest the COVID-19 2020–2022 findings confound estimated programme outcomes.

From 2000 to 2019 ARF cases in BOP at all ages, 13 (7%) were recurrences,⁷ leaving 181 ARF cases at all ages, of whom 162 (90%) identified as Māori, 11 (6%) Pacific peoples and 8 (4%) NZ European. Nine cases (5%) were aged 30–45 years. First ARF presentations at all ages for all ethnicities (the Te Whatu Ora – Health New Zealand, MOH website reporting measure) declined significantly by 26% using discharges plus notifications, then case note scrutiny, and appeared unchanged utilising notifications alone (Appendix Table 6).

For those under-30-years-age, the focus of this article and a recent study of New Zealand's ARF-RHD trends until 2018,⁴ BOP ARF rates declined significantly for all ethnicities by 29% and declined for Māori by 31% when comparing 2011–2019 with 2000–2010 (Table 3). The ARF rate for Māori under-30-years-age, compared with NZ Europeans, for 2000–2010, informed a risk ratio of 24.39 (11.29–54.40), which increased as low NZ European rates declined by 85%, faster than Māori rates declined. Most NZ European ARF cases occurred in 2000–2003, except the last one in 2011.

Pacific peoples reside mainly in the West. Pacific ARF case numbers rose and NZ European cases declined markedly for the same period. With small numbers and wide CIs, neither change reached statistical significance. Pacific peoples' rates were between NZ European and Māori rates, with significant Pacific peoples:NZ European risk

Table 3: ARF rates, Bay of Plenty/100,000 person-years in 2000–2019, trends by ethnicities affected, age and equity risk ratios.

Age years	Ethnicity	Cases n	Rate 2000–2010 cases/100,000 person-years	Rate 2011–2019 cases/100,000 person-years	Trend rate ratio (95% CI)	P =	Risk ratio 2000–2010 Māori vs NZ European (95% CI)	Risk ratio 2011–2019 Māori vs NZ European (95% CI)
Census			2006	2013 and 2018				
All	All	181	5.04	3.73	0.74 (0.55–0.99)	0.047		
All	Māori	162	19.29	13.85	0.72 (0.52–0.98)	0.038	39.20 (18.20–84.41)	203.10 (28.18–1463.65)
All	NZ European	8	0.49	0.07	0.14 (0.02–1.13)	0.031		
<30	All	172	12.74	9.06	0.71 (0.52–0.97)	0.029		
<30	Māori	155	32.96	22.78	0.69 (0.50–0.96)	0.025	24.33 (11.29–52.50)	113.28 (15.70–817.62)
<30	NZ European	8	1.35	0.20	0.15 (0.18–1.21)	0.387		
0–4	Māori	1	0	1/50,895				
5–14	Māori	136	71.96	45.95	0.64 (0.45–0.91)	0.012	24.66 (10.79–56.38)	107.79 (14.93–778.19)
5–14	NZ European	7	2.92	0.51	0.18 (0.02–1.47)	0.070		
15–29	Māori	19	7.15	9.69	1.36 (0.54–3.44)	0.519	15.73 (1.97–125.79)	
15–29	NZ European	1	0.45	0				
							Pacific peoples: NZ European	Pacific peoples: NZ European
All	Pacific peoples	11	9.79	13.97	1.42 (0.42–4.87)	0.569	19.90 (5.82–67.96)	204.82 (25.20–1664.77)
<30	Pacific peoples	9	10.80	18.27	1.69 (0.42–6.77)	0.452	7.97 (2.06–30.82)	90.89 (10.94–754.94)
5–14	Pacific peoples	6	17.07	29.28	1.71 (0.32–9.36)	0.528	5.85 (1.18–29.98)	56.84 (6.53–508.53)
15–29	Pacific peoples	4	10.45	17.40	1.67 (0.15–18.36)	0.674	23.00 (1.44–367.74)	

ratios (Appendix Table 7; ARF case numbers, exposed person-years).

One preschool Māori tamariki experienced ARF. Significant declines in ARF rates occurred for Māori school-age children (36%) but were unchanged for young adults. Male:female two-fold higher risk ratios continue (Appendix Table 8). The Māori school-age ARF rate compared with Māori young adults for 2000–2010 was risk ratio 10.07 (4.88–20.76) and in 2011–2019 was risk ratio 4.74 (2.40–9.37).

More than two-thirds (69% [111/162]) of all-age Māori who experienced ARF in BOP in 2000–2019 resided in the more socio-economically challenged East, which has a mean NZDep decile of 9 and is where 44% of Māori live. Conversely, one-third of Māori acquiring ARF reside in the more heterogenous West, which has a mean NZDep decile of 6. Of those Māori who experience ARF while living in the West, a third live in Census areas with NZDep deciles of 2–6, belying the stereotype that ARF is always a disease of poverty.³⁵ Higher school-age ARF rates in the East declined by 23%, but not significantly. Larger significant 49% declines from lower rates occurred in the West at school-age, but not for young adults. East:West inequities with two three-fold higher rates continued (Appendix Table 9).

During COVID-19's first wave, eight cases of ARF affected BOP school-age Māori and Pacific peoples in the first 6 months of 2020, with an odds ratio of 3.8 (CI 1.53–7.48), compared with the remainder of July 2015 to July 2021. (Presented by lead author to The Paediatric Society of NZ, Virtual ASM, November 2021). From all under-30-years-age in BOP, 66 ARF cases presented in 728,721 person-years in 2011–2019 and 22/268,043 person-years in 2020–2022, deriving estimated rates/100,000/year of 9.06 and 8.21 respectively, with rate ratio 0.91 (CI 0.56–1.47) comparing the intervention period of 2011–2019 and the COVID-19 period. As ARF numbers reduced then stabilised from 2014 (Figure 2), the rate for the period 2014–2019, inclusive 38/498,393, was also compared with the 2020–2022 COVID-19 period, deriving an annual rate of 7.62 vs 8.21/100,000 with a rate ratio of 1.08 (0.64–1.81).

Discussion

There is mounting evidence that skin infections contribute to ARF in Aotearoa New Zealand,^{8,11} supported by our finding where cultures were taken of pharyngeal GAS associated with possibly

two-thirds of ARF presentations, skin GAS with one-sixth and both one-third. Immune studies are now able to confirm or refute whether such cultured GAS triggered ARF,^{13,14} while concluding that interventions to reduce cumulative childhood GAS exposures could prevent ARF.¹³

This study found that skin infection admission rates rose, then both skin and ARF rates declined contemporaneously and significantly within BOP from 2011 after specific programmes for both commenced. The decline in skin infection rates was seen for both Māori and NZ Europeans at preschool, school-age and as young adults, while the decline in ARF rates for Māori was seen at school-age but not for young adults. NZ Europeans' ARF rates declined at school-age, with the last NZ European ARF first presentation in 2011.

We found, for one sentinel skin infection of scabies, that admission and community rates declined in parallel. However, scabies seldom (0.7%) preceded ARF in BOP within the critical preceding 3 months wherein GAS triggers ARF.¹¹ Skin infection programmes began²⁰ at the time of their peak rates in 2010–2011, and RFPP GAS pharyngitis school-based programmes with primary care support began simultaneously.⁷ As well as general and targeted direct programmes effects, both skin infection and GAS pharyngitis programmes lower GAS prevalence and thereby transmission, as well as immune priming, which may lower ARF rates.^{5–7,36,37} The wider context included free children's primary healthcare and healthy homes initiatives.

Māori make up 30% of the under-30-years-age population in BOP but experience 58% of the skin infection admissions and 90% of the ARF. Eight of every 10 people presenting with ARF in the BOP are Māori at school-age. By 2017–2019, school-age Māori skin infection admission rates declined 14% from pre-intervention in 2007–2010, down 24% from their peak and 18% from baseline years, and ARF declined by 36%. Young adult Māori are 1 in 10 of those who experience ARF, a group without targeted programmes, served by primary care alone. Their skin infection admission rates were higher than school-age Māori rates, declined 26% from 2007–2010, 33% from peak rates and increased 4% from baseline, and their ARF rates were unchanged. (Their COVID-19 2020–2022 skin infection admission rate rose 12% from 2017–2019).

NZ Europeans, who make up 60% of the under-30-years-age population in BOP, experience 34% of the skin infection admissions and 4% of

the ARF. School-age NZ Europeans experienced the largest pre- post-skin infection rate (32%) and ARF rate declines (85%), such that inequities increased. While both Māori and NZ European preschoolers had equal, almost 40% skin infection admissions rate reductions, Māori:NZ Europeans risk ratio, a measure of inequity, was unchanged, with almost six-fold higher rates.

Pacific peoples' highest skin infection rate was for preschoolers, rising to a rate similar to that experienced by Māori. Their skin infection rates increased at all ages except school-age. Pacific peoples experience 6% of the ARF in BOP, with unchanged ARF rates at all ages.

Others (MELAAA peoples) had increased skin infection rates, to rates similar to NZ Europeans', and experienced no diagnosed ARF.

This study's strengths include bringing skin infection and ARF rates alongside in identical age bands by ethnicity, gender and two districts with medium and high deprivation over 23 years from one region, with sufficient power to permit temporal observations for age-groups with and without targeted interventions.^{7,38,39} The risk of confounding has been reduced by excluding 2020–2022 from all prior and post-intervention rate comparisons in tables when considering programme outcomes. However, the COVID-19 period has been retained for ARF time trend analysis only in Appendix 10 in light of the finding that ARF did not decline in BOP during that period, although overall ARF declined in Aotearoa New Zealand. Future studies may test our hypothesis, which we evaluated only for scabies, that trends in admitted skin infections may reflect community infections too, by accessing primary care and secondary care diagnostic data. Future ARF studies may estimate more refined proportionate attributable risks from skin and throat GAS infections and guide programme weighting.

This study's multi-sourced scrutinised ARF data methodology is robust and validated,^{6,7,31,35,40} in contrast to single-sourced notifications (utilised in Aotearoa New Zealand's RFPP effectiveness evaluation),⁵ which in BOP, with ascertainment bias, suggested unchanged ARF rates.

Skin infection admission rates declined 40% for both Māori and NZ European preschoolers exposed to public health nursing, primary care and some targeted paediatric interventions, possibly lowering recurrent GAS infections' induction of immune priming and risk for ARF.^{13,14} That skin infection admission rate reductions for

Māori were more marked in the West than East, and that significant Māori:NZ European inequities continue, has strategic implications. All Hauora-delivering school-based ARF programmes might also be contracted for focussed Kiri Ora (Healthy Skin) programmes, informed by current evidence, and workplaces might be considered too. Hauora complement and collaborate with targeted pharmacies' services, predominantly in the East, but also in Te Puke in the West, for at-risk children and young adults.¹⁵ Hauora programmes with primary care support have reported positive outcomes, including for skin infections,^{41,42} and have addressed GAS pharyngitis and ARF equity gaps for Māori by encouraging presentations.⁷

The prior BOP retrospective cohort study reported substantial (60%) school-age ARF rate reductions within the rural East,⁷ where twice-weekly sore throat swabbing occurs and where the inequity gap of two-fold higher rates for Māori males closed a little, but not significantly, compared with females.⁷ The current finding that the BOP-wide ARF rate reductions were greater in the lower deprivation West than East suggests that the East's contracted service delivery model should be reviewed. A change from once to twice weekly targeted GAS sore throat swabbing in at least five Whakatāne schools is indicated, a district with moderate-high deprivation, where half the East's school-age Māori live, while twice-weekly swabbing continues in the adjacent highest deprivation areas. In the West, the substantial 49% ARF decline for school-age Māori from lower baseline rates suggests that there the mixed model of mainly primary care and school-based programmes in 3/58 schools remains responsive to Māori health needs.

Behind the higher ARF rates for Māori, especially in the Eastern Bay, lie their documented housing, education and employment inequities and challenges.⁴² The findings provide further evidence for focussed needs-based health and housing interventions to build on community strengths and cultural capital and enable Hauora and providers engaged with their communities, especially those with greatest socio-economic deprivation.

BOP's COVID-19 spike in 2020 highlighted the challenges for public health to enable other health delivery to continue during epidemics, including both GAS and COVID-19 swabbing in vulnerable communities. Initially, drive-by stations swabbed solely for COVID-19. Meanwhile, school-based GAS programmes closed, primary care became virtual,

paediatric hospital presentations declined by 30% and functional household crowding increased. In mid-2020, swabbing for both COVID-19 and GAS at BOP COVID-19 stations was enabled. Pandemic aftermaths include post-COVID absenteeism and caution.

Future co-designed skin infection and ARF strategies are indicated with Pacific peoples, and

for all young adults, as is timely re-evaluation of all altered BOP programmes.

ARF and skin infection rates declined contemporaneously across the BOP with programmes for both, especially at school-age. Ethnic, gender, age and socio-economic inequities persist, and appear amenable to targeted interventions, increasing the coverage and frequency of focussed programmes.

COMPETING INTERESTS

There are no actual or potential conflicts of interest. Bay of Plenty District Health Board, Te Whatu Ora provided decision support analyst data extraction of cases with specified diagnoses ICD-10 codes and preparation of Excel files, and graphic preparation for manuscript figure.

ACKNOWLEDGEMENTS

Duneesha Gamage (previously Mary White and Marianne Toms), data support analysts, Hauora a Toi BOP, skin infection admission data extraction. Christine Clark, graphic of interventions. Kip Mouldley, Initial 5% Permethrin DataPharm BOP search. Leanne Hall, BOPCPG (Bay of Plenty Community Pharmacy Group), pharmacy data and manuscript review. BayNavigator collaborations GPs Dr Carl Jacobsen, Dr Mark Haywood, Dr Rachel Thomson, primary healthcare teams, Haidee Barrow and Dr Daniel Jackson BayNavigator Analytics. Kiri Ora Kawerau team 2013 Liisa Waana, Kahurangi Wineti, R/N Kate Dooley. Hauora managers and kaimahi Louisa Erikson, Danny Paruru Te Pou Oranga o Whakatohea, Chris Majoribanks Tuwharetoa ki Kawerau, Pania Hetet Tuhoe Hauora, Yvonne Rurehe, Te Ika Whenua, Te Manu Toroa and Public Health School-teams Tauranga. Dr Richard Forster, Whakatane Skin clinic and Marie Hayward, Family Health team. Brian Pointon, Sarah Stevenson, Portfolio Managers Funding and Planning BOPDHB, funding prioritisation. Karen Smith, Women Child and Family Business Manager, supported paediatric contributions. Dr Melanie Cheung, Ngāti Rangitīhi, biologist previously researcher Te Puna Ora O Mataatua, critical review re study design of equity measures.

(Deceased) Hana Harawira Kaiwhakahaere Te Kaokao o Takapau Hauora, RFPP Ngai Tuhoe, Ngati Manawa liaison, Dr Barry Smith, Māori Health Lakes DHB Ethics, Lyn Hartley Ngati Rangitīhi Mayor Kawerau RFPP GAS prevalence study, echocardiograph study support. Dr Diana Lennon guidance re ARF cases, national guidelines and collegial collaborations with BOP RFPP programmes.

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URL

<https://nzmj.org.nz/journal/vol-138-no-1609/rheumatic-fever-trends-in-the-context-of-skin-infection-and-group-a-streptococcal-sore-throat-programmes-in-the-bay-of-plenty-an>

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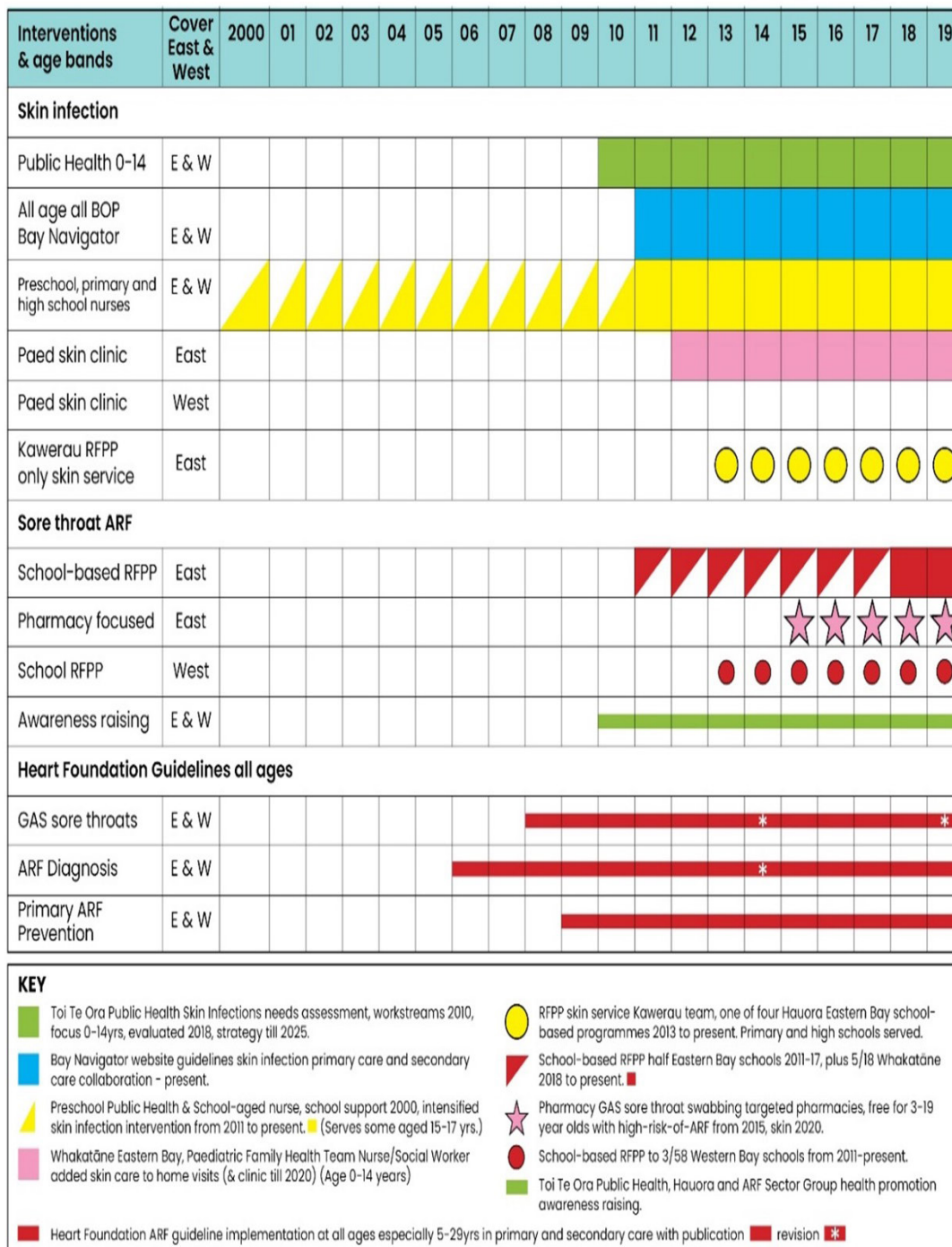
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Appendices

Appendix 1: Bay of Plenty (BOP) Group A *Streptococcal* (GAS) sore throat and skin infection intervention, figure and programme detail

Appendix Figure 1: Skin infection and GAS sore throat initiatives in BOP by year for under-30-year-olds.



GAS sore throat initiatives impacting on BOP practice

1. Heart Foundation NZ sore throat guidelines 2008, 2014, 2019 used in primary/secondary care across BOP.
2. Toi Te Ora Public Health Hauora ARF sector group health promotion ARF sore throats awareness raising using national and local pamphlets, messaging, local newspapers, radio, websites, television, intense promotion from 2010 to 2018 and ongoing to present.
3. BOP District Health Board, now Hauora a Toi, funded five Māori health providers, Hauora, who deliver twice-weekly **school-based sore throat swabbing programmes**. The funding criteria included high-risk schools with ARF incidence for children aged 5–14 years above 50/100,000/annum.¹⁵
 - **Eastern BOP:** Hauora delivered to all 26 schools in the rural Eastern areas with primary care support; programmes that cover the tribal areas of Whakatōhea and Ngāi Tai commenced in 2009, Tūwharetoa ki Kawerau in 2010, Ngāi Tūhoe in 2011, Ngāti Manawa and Ngāti Whare in 2012 (midpoint January 2011). Case for this midpoint made in Walsh et al., PIDJ 2020.⁷
 - **Western BOP:** a mixed model of mainly primary care, with initially three, and now five, of Tauranga's 58 schools served from 2010 by Tauranga's Te Manu Toroa Hauora and in recent years by community health workers of Community Health 4 Kids, Hauora a Toi.
4. **Community pharmacies** in Eastern BOP and Te Puke dispense antibiotics on standing orders to children and youth aged 3–19 years at risk of ARF for GAS pharyngitis, starting in 2015, and for skin infections from 2020. They frequently take referrals from school-based ARF teams, primary care and emergency departments.²³

BOP skin infection initiatives: most commenced in 2010–2012, and all continue. The first three involved public health, primary

and secondary healthcare, and the second three focussed or targeted on highest need.

1. Toi Te Ora Public Health (TTO) undertook a health needs assessment of hospitalised skin infections for children aged 0–14 years in 2010. Its strategies addressed health promotion, advocacy, training and research evaluating the outcomes in 2018.²⁰ TTO arranged paediatric nurse seminars for practice and preschool nurses, and providers reaching Māori and Pacific children, supported BOP-wide initiatives and advocated for affordable primary health access.²⁰ Whakatāne had no after-hours GP services and Ōpōtiki lost theirs.
2. From 2011, each of public health nurses (who service preschools, kohanga reo, primary schools and communities), Hauora and paediatricians developed local skin infection resources, adapted others and intensified their skin infection service delivery. High schools appointed nurses, who were trained to use standing orders to treat students' skin infections and sore throats.
3. In 2011, the Infectious Diseases Service led a major Bay Navigator primary–secondary care collaboration. The regional guidelines they developed on a new website “BayNav” averaged 228 hits/month. These guidelines' pathways detailed how to treat childhood and adult skin infections of increasing severity, persistent and recurrent skin infections, cellulitis and eczema, and encouraged phone consultation when needed.
4. Whakatāne Hospital's paediatric Family Health Team of a nurse and social worker practice a home visiting team model,²² and from 2012 supported many Eastern BOP whānau to manage eczema and prevent recurrent skin infections, and started hospital paediatric skin clinics with a consultant paediatrician. The skin clinic paused from 2020 to 2022 and recommenced in 2023.
5. One school-based sore throat team, Kawerau's, initiated a skincare Kiri Ora programme in 2013. Staff gave advice, antiseptics and dressings, and referred for antibiotics where indicated.

Appendix Figure 2: ICD-10 codes (53) for serious skin infections.¹⁷

Category A ICD-10 codes (serious skin infection of typical sites)	
L01.0, L01.1	impetigo
L02.0–L02.9	cutaneous abscess, furuncle and carbuncle
L03.01–L03.9	cellulitis
L0.40–L04.9	acute lymphadenitis
L05.0	pilonidal cyst with abscess
L08.0	pyoderma
L08.1, L08.8, L08.9	other infections of skin and subcutaneous tissue
Category B ICD-10 codes (serious skin infections of atypical anatomical sites)	
A46	erysipelas
H00.0	hordeolum/cellulitis/abscess eyelid
H60.0–H60.3, H62.0, H62.4	abscess/cellulitis external ear and infective otitis externa
J34.0	abscess/cellulitis nose
K61.0	anal abscess/cellulitis (excludes rectal, ischiorectal or intersphincteric regions)
H05.0	acute inflammation/cellulitis/abscess of orbit
N48.2, N49.2, N49.9	other inflammatory disorders of penis, scrotum and unspecified male genital organ (excludes deeper tissues)
N76.4	abscess/cellulitis of vulva
Category C ICD-10 codes (serious skin infections secondary to primary skin disease)	
B01.8	varicella with other complications
B86	scabies
L30.8, L30.9, L30.3 0	dermatitis unspecified and other specified (eczema) and infective eczema
Category D ICD-10 codes (serious skin infections secondary to external trauma)	
S10.13, S10.83, S10.93, S20.13, S20.33, S20.43, S20.83, S30.83, S30.93, S40.83, S50.83, S60.83, S70.83, S80.83, S90.83, T00.9, T09.03, T11.08, T13.03, T14.03, T14.03, T63.3, T63.4	insect/spider bites
T79.3	post-traumatic wound infection not elsewhere classified
T89.01, T89.02	open wound infection with foreign body ± infection and open wound with infection

Appendix Table 3: Skin infection admissions for Māori, NZ European, Pacific peoples and Other peoples in BOP. Annual rates cases/10,000 person-years, time trends informed by rate ratio 2000–2010 vs 2011–2019 in age bands for preschool children, school-age and young adults. Equity trends Māori, Pacific peoples and Other:NZ European risk ratios.

Skin infections at Age (years)	Ethnicity	Cases n	Cases/person-years Rate/10 ⁴ 2000–2010	Cases/person-years Rate/10 ⁴ 2011–2019	Trend Rate ratio (95% CI)	Risk ratio 2000–2010 Māori:NZ European	Risk ratio 2011–2019 Māori:NZ European
Census			2006	2013 and 2018			
<30	All	15,448	7,941/832,128 95.43	7,507/728,721 103.02	1.08 (1.05–1.11)		
<30	Māori	9,045	4,775/291,258 163.78	4,270/258,732 165.04	1.01 (0.97–1.05)	3.04 (2.90–3.19)	3.23 (3.08–3.39)
<30	NZ European	5,325	2,785/516,681 53.90	2,540/497,358 51.07	0.95 (0.90–0.99)		
0–4	Māori	3,336	1,818/ 57,057 318.63	1,518/50,895 298.26	0.94 (0.88–1.00)	6.10 (5.52–6.75)	6.62 (5.94–7.38)
0–4	NZ European	884	475/90,948 52.23	409/90,774 45.06	0.86 (0.76–0.98)		
5–14	Māori	2,490	1,333/122,298 109.00	1,157/104,697 110.51	1.01 (0.94–1.10)	2.87 (2.63–3.14)	3.25 (2.96–3.58)
5–14	NZ European	1,440	780/205,623 37.93	660/194,148 33.99	0.90 (0.81 –0.99)		
15–29	Māori	3,219	1,624/111,936 145.08	1,595/103,149 154.63	1.07 (1.00–1.14)	2.09 (1.95–2.24)	2.23 (2.08–2.40)
15–29	NZ European	3,001	1,530/220,143 69.50	1,471/212,454 69.24	1.00 (0.93–1.07)		
						Pacific peoples:NZ European	Pacific peoples:NZ European
<30	Pacific peoples	650	252/27,786 90.69	398/32,832 121.22	1.34 (1.14–1.56)	1.69 (1.49–1.92)	2.37 (2.13–2.64)
0–4	Pacific peoples	289	109/6,468 168.52	180/7,695 233.92	1.39 (1.10 –1.76)	3.22 (2.62–3.97)	5.19 (4.36–6.17)
5–14	Pacific peoples	159	76/11,715 64.87	83/13,662 60.75	0.94 (0.69–1.28)	1.71 (1.35–2.16)	1.79 (1.42–2.24)
15–29	Pacific peoples	202	67/9,570 70.01	135/11,493 117.46	1.68 (1.25–2.25)	1.01 (0.79–1.29)	1.69 (1.42–2.02)
						Others:NZ European	Others:NZ European
<30	Others MELAAA	428	129/32,373 39.85	299/59,085 50.61	1.27 (1.03–1.36)	0.74 (0.62–0.88)	0.99 (0.88–1.11)

Appendix Table 4: Māori and NZ European skin infections from 2000 to 2022 in seven time periods, numerator cases, denominator population exposure-years, rate ratio peak rate vs 2017–2019; equity risk-ratio at peak and 2017–2019.

Ethnicity, Ages, n 17,615	Epoch/period included years: cases/exposed population persons' years, population uses Census 2006, 2013, 2018; incidence rate/10 ⁴ person-years, 95% confidence intervals (CIs)							Rate ratio 95% CI 2017–2019 vs peak	Risk ratio; M:E at peak	Risk ratio; M:E 2017– 2019
	2000–2002	2003–2006	2007–2010	2011–2013	2014–2016	2017–2019	2020–2022			
Census	2006	2006	2006	2013	2013	2018	2018			
Māori 0–30 year, n 10,269	1,129/ 79,443	1,664/ 105,912	1,982/ 105,912	1,554/ 78,687	1,354/ 78,687	1,362/ 101,358	1,224/ 101,358	2011–2013		
Rate (95% CI)	142.11 (133.94– 150.65)	157.11 (149.65– 164.85)	187.14 (178.99– 195.56)	197.49 (187.79– 207.56)	172.07 (163.03– 181.49)	134.38 (127.33– 141.71)	120.76 (114.10– 127.70)	0.68 (0.63–0.73)	3.15 (2.91–3.41)	3.39 (3.10–3.71)
NZ European 0–30 year, n 6,045	674/140,913	1,003/ 187,884	1,108/ 187,884	970/154,611	825/154,611	745/188,136	720/188,136			
Rate (95% CI)	47.83 (44.29– 51.58)	53.38 (50.13– 56.79)	58.97 (55.55– 62.55)	62.27 (58.85– 66.81)	53.36 (49.78– 57.13)	39.60 (36.81– 42.55)	38.27 (35.50– 41.20)	0.63 (0.57–0.69)		
Māori 0–4 year, n 3,695	377/15,561	614/20,748	827/20,748	582/15,840	478/15,840	458/19,215	359/19,215	2007–2010		
Rate (95% CI)	242.27 (218.43– 268.01)	295.93 (272.98– 320.29)	398.59 (371.89– 426.71)	367.42 (338.18– 398.53)	301.77 (275.32– 330.07)	238.36 (217.01– 261.22)	186.83 (168.00– 207.20)	0.60 (0.53–0.67)	5.99 (5.17–6.95)	5.83 (4.81–7.06)
NZ European 0–4 year, n 1,015	101/24,804	154/33,072	220/33,072	164/28,863	110/28,863	135/33,048	131/33,048			
Rate (95% CI)	40.72 (33.17– 49.48)	46.57 (39.50– 54.53)	66.52 (58.01– 75.92)	56.82 (48.46– 66.21)	38.11 (31.32– 45.93)	40.85 (34.25– 48.35)	39.64 (33.10– 47.00)	0.61 (0.50–0.76)		

Appendix Table 4 (continued): Māori and NZ European skin infections from 2000–2022 in seven time periods, numerator cases, denominator population exposure-years, rate ratio peak rate vs 2017–2019; equity risk-ratio at peak and 2017–2019.

Ethnicity, Ages, n 17,615	Epoch/period included years: cases/exposed population persons' years, population uses Census 2006, 2013, 2018; incidence rate/10 ⁴ person-years, 95% confidence intervals (CIs)							Rate ratio 95% CI 2017–2019 vs peak	Risk ratio; M:E at peak	Risk ratio; M:E 2017– 2019
	2000–2002	2003–2006	2007–2010	2011–2013	2014–2016	2017–2019	2020–2022			
Census	2006	2006	2006	2013	2013	2018	2018			
Māori 5–14 year, n 2,773	387/33,354	455/44,472	491/44,472	402/32,202	371/32,202	384/40,293	283/40,293	2011–2013		
Rate (95% CI)	116.03 (104.75– 128.18)	102.31 (93.13– 112.16)	110.41 (100.86– 120.62)	124.84 (112.93– 137.66)	115.21 (103.78– 127.55)	95.30 (86.01– 105.33)	70.24 (62.30– 78.90)	0.76 (0.66–0.88)	2.84 (2.43–3.31)	3.37 (2.84–3.99)
NZ European 5–14 year, n 1,651	216/56,079	257/74,772	307/74,772	267/60,669	187/60,669	206/72,810	211/72,810			
Rate (95% CI)	38.52 (33.55– 44.01)	34.37 (30.30– 38.84)	41.06 (36.59– 45.92)	44.01 (38.89– 49.62)	30.83 (26.56– 35.57)	28.29 24.56– 32.43)	28.98 (25.20– 33.20)	0.64 (0.54–0.77)		
Māori 15–29 year, n 3,801	365/30,528	595/40,704	664/40,704	570/30,645	505/30,645	520/41,859	582/41,859	2011–2013		
Rate (95% CI)	119.56 (107.61– 132.48)	146.18 (134.67– 158.41)	163.13 (150.96– 176.02)	186.00 (171.04– 201.92)	164.79 (150.73– 179.81)	124.23 (113.78– 135.38)	139.04 (128.00– 150.80)	0.67 (0.59–0.75)	2.25 (2.00–2.52)	2.53 (2.22–2.88)
NZ European 15–29 year, n 3,379	357/60,039	592/80,052	581/80,052	539/65,088	528/65,088	404/82,278	378/82,278			
Rate (95% CI)	59.46 (53.45– 65.96)	73.95 (68.11– 80.16)	72.58 (66.80– 78.73)	82.81 (75.97– 90.11)	81.12 (74.35– 88.34)	49.10 (44.43– 54.13)	45.94 (41.40– 50.80)	0.59 (0.52–0.67)		

Appendix Table 5: Skin infection admissions for Māori by age, East–West deprivation and gender.

Skin infection admissions for Māori by age, East–West deprivation and gender	Pre-exposure cases/exposed years Rate 2007–2010	Recent cases/ exposed years Rate 2017–2019	Rate ratio 2017–2019 vs 2007–2010 (95% CI)	Equity; Risk ratio 2007–2010 (95% CI)	Equity; Risk ratio 2017–2019 (95% CI)
	Census 2006	Census 2018		East:West	East:West
Age 0–29 years					
East Mean NZDep 9	862/49,956 172.25	690/42,867 160.96	0.93 (0.84–1.03)	0.86 (0.79–0.94)	1.40 (1.26–1.55)
West Mean NZDep 6	1,118/55,932 199.89	672/58,473 114.93	0.57 (0.52–0.63)		
Age 0–4 years				East:West	East:West
East Mean NZDep 9	395/9,552 413.53	235/8,208 286.31	0.69 (0.59–0.81)	1.07 (0.94–1.22)	1.41 (1.18–1.69)
West Mean NZDep 6	432/11,196 385.85	223/11,007 202.60	0.52 (0.45–0.62)		
				Male:Female	Male:Female
Male East	213/5,064 420.62	127/4,086 310.82	0.74 (0.60–0.92)	1.04 (0.85–1.26)	1.19 (0.92–1.53)
Female East	182/4,488 405.53	108/4,122 262.01	0.65 (0.51–0.82)		
Male West	190/5,580 340.50	116/5,706 203.30	0.60 (0.48–0.75)	0.79 (0.66–0.95)	1.01 (0.78–1.31)
Female West	242/5,616 430.91	107/5,301 201.85	0.47 (0.37–0.59)		
Age 5–14 years				East:West	East:West
East Mean NZDep 9	213/22,164 96.10	192/16,956 113.23	1.18 (0.97–1.43)	0.77 (0.64–0.92)	1.38 (1.13–1.68)
West Mean NZDep 6	278/22,272 124.82	192/23,337 82.27	0.66 (0.55–0.79)		
				Male:Female	Male:Female
Male East	120/11,304 106.18	100/8,775 113.96	1.07 (0.82–1.39)	1.24 (0.95–1.62)	1.01 (0.76–1.34)
Female East	93/10,848 85.73	92/8,181 112.46	1.31 (0.98–1.75)		
Male West	145/11,580 125.21	95/11,943 79.54	0.64 (0.49–0.82)	1.01 (0.80–1.27)	0.93 (0.70–1.23)

Appendix Table 5 (continued): Skin infection admissions for Māori by age, East–West deprivation and gender.

Skin infection admissions for Māori by age, East–West deprivation and gender	Pre-exposure cases/exposed years Rate 2007–2010	Recent cases/ exposed years Rate 2017–2019	Rate ratio 2017–2019 vs 2007–2010 (95% CI)	Equity; Risk ratio 2007–2010 (95% CI)	Equity; Risk ratio 2017–2019 (95% CI)
Female West	133/10,716 124.11	97/11,394 85.13	0.69 (0.53–0.89)		
Age 15–29 years				East:West	East:West
East Mean NZDep 9	254/18,240 139.25	263/17,703 148.56	1.07 (0.90–1.26)	0.77 (0.65–0.89)	1.40 (1.18–1.66)
West Mean NZDep 6	409/22,464 182.07	257/24,147 106.43	0.58 (0.50–0.68)		
				Male:Female	Male:Female
Male East	157/11,580 135.58	150/8,685 172.71	1.27 (1.02–1.59)	1.32 (1.03–1.70)	1.38 (1.08–1.76)
Female East	97/9,444 102.71	113/9,027 125.18	1.22 (0.93–1.60)		
Male West	232/10,956 211.76	138/12,186 113.24	0.53 (0.43–0.66)	1.38 (1.13–1.67)	1.14 (0.89–1.45)
Female West	177/11,508 153.81	119/11,961 99.49	0.65 (0.51–0.81)		

Appendix Table 6: Confirmed BOP ARF rates and trends by ascertainment method, reporting all ages, all ethnicities, as per Ministry of Health, Te Whatu Ora – Health New Zealand, conventions 2000–2010 vs 2011–2019.

Ascertainment method	Cases n	2000–2010 Cases/person-years, Rate/10 ⁵ person-years	2011–2019 Cases/person-years, Rate/10 ⁵ person-years	Trend rate ratio (95% CI)	P =
All sources	181	108/2,144,241 5.04	73/1,956,519 3.73	0.74 (0.55–0.99)	0.0468
Discharges	175	104/2,144,241 4.85	71/1,956,519 3.62	0.75(0.55–1.01)	0.0586
Notifications	130	67/2,144,241 3.12	63/1,956,519 3.22	1.03 (0.73–1.45)	0.8640

Appendix Table 7: ARF rates 2000–2019, trends by ethnicities affected, age and equity risk ratios.

Age years	Ethnicity	Cases n	Rate 2000–2010 cases/10 ⁵ person-years	Rate 2011–2019 cases/10 ⁵ person-years	Trend Rate ratio (95% CI)	P =	Risk ratio 2000–2010 (95% CI)	Risk ratio 2011–2019 (95% CI)
Census			2006	2013 and 2018				
All	All	181	108/2,144,241 5.04	73/1,956,519 3.73	0.74 (0.55–0.99)	0.047		
All	Māori	162	97/502,905 19.29	65/469,197 13.85	0.72 (0.52–0.98)	0.038	39.20 (18.20–84.41)	203.10 (28.18–1,463.65)
All	NZ European	8	7/1,422,564 0.49	1/1,466,073 0.07	0.14 (0.02–1.13)	0.031		
<30	All	172	106/832,128 12.74	66/728,721 9.06	0.71 (0.52–0.97)	0.029		
<30	Māori	155	96/291,258 32.96	59/259,032 22.78	0.69 (0.50–0.96)	0.025	24.33 (11.29–52.50)	113.28 (15.70–817.62)
<30	NZ European	8	7/516,681 1.35	1/497,358 0.20	0.15 (0.18–1.21)	0.387		
0–4	Māori	1	0/57,057	1/50,895				
5–14	Māori	136	88/122,298 71.96	48/104,457 45.95	0.64 (0.45–0.91)	0.012	24.66 (10.79–56.38)	107.79 (14.93–778.19)
5–14	NZ European	7	6/205,623 2.92	1/194,148 0.51	0.18 (0.02–1.47)	0.070		
15–29	Māori	19	8/111,936 7.15	10/103,149 9.69	1.36 (0.54–3.44)	0.519	15.73 (1.97–125.79)	
15–29	NZ European	1	1/220,143 0.45	0/212,454				

Appendix Table 7 (continued): ARF rates 2000–2019, trends by ethnicities affected, age and equity risk ratios.

Age years	Ethnicity	Cases n	Rate 2000–2010 cases/10 ⁵ person-years	Rate 2011–2019 cases/10 ⁵ person-years	Trend Rate ratio (95% CI)	P =	Risk ratio 2000–2010 (95% CI)	Risk ratio 2011–2019 (95% CI)
Census			2006	2013 and 2018				
							Pacific peoples:NZ European	Pacific peoples:NZ European
All	Pacific peoples	11	4/40,854 9.79	7/50,103 13.97	1.42 (0.42–4.87)	0.569	19.90 (5.82–67.96)	204.82 (25.20–1664.77)
<30	Pacific peoples	9	3/27,786 10.80	6/32,832 18.27	1.69 (0.42–6.77)	0.452	7.97 (2.06–30.82)	90.89 (10.94–754.94)
5–14	Pacific peoples	6	2/11,715 17.07	4/13,662 29.28	1.71 (0.32–9.36)	0.528	5.85 (1.18–29.98)	56.84 (6.53–508.53)
15–29	Pacific peoples	4	1/9,570 10.45	2/11,493 17.40	1.67 (0.15–18.36)	0.674	23.00 (1.44–367.74)	

Appendix Table 8: ARF for Māori by age and gender in 2000–2010 vs 2011–2019 and equity between genders.

BOP ARF; Māori by age and gender	n	Cases/ person-years, 2000–2010 Rate/10⁵ persons/year	Cases/ person-years, 2011–2019 Rate/10⁵ persons/year	Trend rate ratio 2011–2019 vs 2000–2010 (95% CI)	P =	Risk ratio male:female 2000–2010 (95% CI)	Risk ratio male:female 2011–2019 (95% CI)
Census		2006	2013 and 2018				
Māori all age	162						
Male	113	68/243,903 27.88	45/227,871 19.75	0.71 (0.49–1.03)	0.071	2.48 (1.61–3.83)	2.38 (1.41–4.04)
Female	49	29/258,159 11.23	20/241,353 8.29	0.74 (0.42–1.30)	0.293		
Māori under 30 years	155						
Males	108	67/146,520 45.73	41/130,617 31.39	0.69 (0.47–1.01)	0.056	2.28 (1.48–3.53)	2.23 (1.28–3.88)
Females	47	29/144,705 20.04	18/128,115 14.05	0.70 (0.39–1.26)	0.234		
Māori 0–5 years male	1	0	1/26,316 3.80				
Māori 5–14 years	136						
Males	93	60/62,964 95.29	33/53,892 61.23	0.64 (0.42–0.98)	0.040	2.02 (1.29–3.16)	2.07 (1.12–3.82)
Females	43	28/59,268 47.24	15/50,805 29.52	0.62 (0.33–1.16)	0.138		

Appendix Table 8 (continued): ARF for Māori by age and gender in 2000–2010 vs 2011–2019 and equity between genders.

BOP ARF; Māori by age and gender	n	Cases/ person-years, 2000–2010 Rate/10⁵ persons/year	Cases/ person-years, 2011–2019 Rate/10⁵ persons/year	Trend rate ratio 2011–2019 vs 2000–2010 (95% CI)	P =	Risk ratio male:female 2000–2010 (95% CI)	Risk ratio male:female 2011–2019 (95% CI)
Census		2006	2013 and 2018				
Māori 15–29 years	18						
Males	14	7/54,285 12.89	7/50,436 (13.88)	1.07 (0.38–3.07)	0.891	7.43 (0.91–60.42)	2.44 (0.63–9.43)
Females	4	1/57,651 1.73	3/52,713 5.69	3.28 (0.34–31.54)	0.275		

Appendix Table 9: ARF for Māori East vs West, high deprivation vs moderate, 2000–2010 vs 2011–2019 and equity.

First ARF for, Māori East/West by Age	Mean NZDep2006 Decile	n	Cases/person-years 2000–2010 Rate/10⁵/year	Cases/person-years 2011–2019 Rate/10⁵/year	Trend rate ratio 2011–2019 vs 2000–2010 (95% CI)	P =	Equity risk ratio East:West 2000–2010 (95% CI)	Equity risk ratio East:West 2011–2019 (95% CI)
Census			2006	2013 and 2018				
All age		162	97	65				
East	9	111	66/243,474 27.11	45/207,279 21.71	0.80 (0.55–1.17)	0.250	2.26 (1.47–3.46)	2.85 (1.68–4.83)
West	6	51	31/258,423 12.00	20/261,792 7.61	0.63 (0.36–1.11)	0.110		
Under 30 years								
East	9	109	65/137,379 47.31	44/109,971 40.01	0.85 (0.58–1.24)	0.390	2.35 (1.53–3.60)	3.97 (2.21–7.13)

Appendix Table 9 (continued): ARF for Māori East vs West, high deprivation vs moderate, 2000–2010 vs 2011–2019 and equity.

First ARF for, Māori East/West by Age	Mean NZDep2006 Decile	n	Cases/person-years 2000–2010 Rate/10 ⁵ /year	Cases/person-years 2011–2019 Rate/10 ⁵ /year	Trend rate ratio 2011–2019 vs 2000–2010 (95% CI)	P =	Equity risk ratio East:West 2000–2010 (95% CI)	Equity risk ratio East:West 2011–2019 (95% CI)
Census			2006	2013 and 2018				
West	6	46	31/153,813 20.15	15/148,743 10.08	0.50 (0.27–0.93)	0.025		
School-age 5–14 years								
East	9	94	60/60,951 98.44	34/44,892 75.74	0.77 (0.51–1.17)	0.220	2.14 (1.37–3.35)	3.23 (1.74–6.02)
West	6	42	28/61,248 45.72	14/59,760 23.43	0.51 (0.27–0.97)	0.037		
Young adults 15–29 years								
East	9	13	5/50,160 9.97	8/43,965 18.2	1.83 (0.60–5.58)	0.284	2.05 (0.49–8.58)	10.77 (1.35–86.11)
West	6	4	3/61,743 4.86	1/59,193 1.69	0.35 (0.04–3.34)	0.338		

Appendix Table 10: Time trends in first episode ARF rates in BOP/100,000 person-years 2000–2010 and 2011–2022 periods, for all ethnicities, Māori, NZ European and Pacific peoples at all ages, under-30-years-age, preschool, school-age and young adults, with trends comparing recent rates in 2011–2022 vs 2000–2010 as rate ratios and equity risk ratios comparing Māori vs NZ European rates and Pacific peoples vs NZ European rates. (Note: includes COVID-19 2020–2022 years).

Age years	Ethnicity	Cases n	Rate 2000–2010 cases/person-years	Rate 2011–2022 cases/person-years	Trend rate ratio (95% CI)	P =	Risk ratio 2000–2010	Risk ratio 2011–2022
Census			2006	2013 and 2018			95% CI	95% CI
All	All	203	108/2,144,241 5.04	95/2,677,068 3.55	0.70 (0.53–0.93)	0.012		
All	Māori	183	97/502,905 19.32	86/654,732 13.14	0.68 (0.51–0.91)	0.009	39.20 (18.20–84.41)	265.29 (36.95–1,904.84)
All	NZ European	8	7/1,422,564 0.49	1/2,019,708 0.05	0.10 (0.01–0.82)	0.008		
<30	All	194	106/832,128 12.74	88/990,786 8.88	0.70 (0.53–0.92)	0.012		
<30	Māori	176	96/291,258 32.96	80/360,690 22.18	0.67 (0.50–0.91)	0.008	24.33 (11.29–52.50)	152.04 (21.16–1,092.6)
<30	NZ European	8	7/516,681 1.35	1/685,494 0.14	0.11 (0.01–0.88)	0.011		
0–4	Māori	1	0/57,024	1/70,572 1.41				
5–14	Māori	156	88/122,298 71.96	68/144,510 47.06	0.65 (0.48–0.90)	0.008	24.66 (10.79–56.38)	125.62 (17.44–904.66)
5–14	NZ European	7	6/205,623 2.92	1/266,958 0.38	0.13 (0.15–1.07)	0.024		
15–29	Māori	19	8/111,936 7.15	11/145,008 7.59	1.06 (0.43–2.64)	0.898	15.73 (1.97–125.79)	

Appendix Table 10 (continued): Time trends in first episode ARF rates in BOP/100,000 person-years 2000–2010 and 2011–2022 periods, for all ethnicities, Māori, NZ European and Pacific peoples at all ages, under-30-years-age, preschool, school-age and young adults, with trends comparing recent rates in 2011–2022 vs 2000–2010 as rate ratios and equity risk ratios comparing Māori vs NZ European rates and Pacific peoples vs NZ European rates. (Note: includes COVID-19 2020–2022 years).

Age years	Ethnicity	Cases n	Rate 2000–2010 cases/person-years	Rate 2011–2022 cases/person-years	Trend rate ratio (95% CI)	P =	Risk ratio 2000–2010	Risk ratio 2011–2022
Census			2006	2013 and 2018			95% CI	95% CI
15–29	NZ European	1	1/220,143 0.45	0/294,732				
							Risk ratio Pacific peoples:NZ European 2000–2010 95% CI	Risk ratio Pacific peoples:NZ European 2011–2022 95% CI
All	Pacific peoples	12	4/40,854 9.79	8/71,406 11.2	1.14 (0.34–3.80)	0.826	19.90 (5.82–67.96)	226.28 (28.30–1,809.15)
<30	Pacific peoples	10	3/27,786 10.8	7/46,584 15.03	1.39 (0.36–5.38)	0.630	7.97 (2.06–30.82)	103.01 (12.67–837.20)
5–14	Pacific peoples	6	2/11,715 17.07	4/19,476 20.54	1.20 (0.22–6.57)	0.831	5.85 (1.18–29.98)	54.83 (6.13–490.52)
15–29	Pacific peoples	4	1/9,570 10.45	3/16,542 18.14	1.73 (0.18– 16.68)	0.629	23.00 (1.44–367.74)	

Acute rheumatic fever in Canterbury, Aotearoa New Zealand, 2012–2022

Taliah Su'a, Allamanda Faa'toese, Andrew Anglemyer, Kiki Maoate, Tony Walls

ABSTRACT

AIM: To describe the epidemiology and clinical characteristics of acute rheumatic fever (ARF) cases in Canterbury, Aotearoa New Zealand, 2012–2022.

METHODS: Cases were identified through cross-matching public health notification data, hospitalisation discharge data and local Canterbury registry data. Cases were included if they were diagnosed with ARF or rheumatic heart disease (RHD) from January 2012 to December 2022 in the Canterbury Region and were under 30 years of age.

RESULTS: A total of 34 cases were included. Twenty-nine were diagnosed with their first episode of ARF and five were diagnosed with RHD without a previously identified episode of ARF. Overall rates of ARF were significantly lower in Canterbury than in the rest of New Zealand. Over half of the patients identified through the three datasets were excluded due to being diagnosed outside of the region.

CONCLUSION: Case numbers of ARF and RHD diagnosed in Canterbury are low when compared with other regions in New Zealand. The majority of patients receiving ongoing prophylactic treatment for ARF in the region have migrated to Canterbury from the North Island or the Pacific Region. To ensure this group of patients receive the healthcare they need, it is important that we have a highly robust national surveillance system.

Acute rheumatic fever (ARF) is a preventable immune mediated disease that arises as a complication of group A streptococcal (GAS) infections in children. During the acute illness, there is multisystem inflammation that can affect the heart, joints, brain and skin. Once the acute inflammatory phase passes, most symptoms associated with the episode resolve.¹ Inflammation that occurs in the heart can lead to permanent scarring of the heart valves, resulting in rheumatic heart disease (RHD). This progression to RHD is a significant cause of morbidity, mortality and premature death in communities affected by ARF.² Although most high-income countries have largely eliminated the disease through improvements in living standards and the use of antimicrobial drugs used to treat streptococcal infections, high rates persist in Indigenous and Pacific communities in Aotearoa New Zealand and Australia.^{1,3,4} In New Zealand, ARF almost exclusively affects Pacific and Māori children. For Pacific people <30 years, the average initial ARF hospitalisation rate from 2000 to 2018 was 38.1 cases/100,000 population, followed by Māori at 16.8 cases/100,000 and NZ European/Other with 0.86 cases/100,000 population. Pacific and Māori children aged from 5 to 14 years had 80 and 35 times the hospitalisation rate for ARF respectively compared with NZ European/Other children.⁴ In addition to being more likely to be diagnosed with ARF, disease progression is more

likely to occur faster in Pacific and Māori children.⁵

In 2011, the Rheumatic Fever Prevention Programme (RFPP) was established. The aim of the programme was to reduce national ARF incidence from 4.0 cases/100,000 to 1.7 cases/100,000.⁶ A significant focus of the programme was primary prevention through sore throat detection among high-risk school children. Other risk factors were also targeted, such as housing quality and public awareness of the disease.⁷ The programme ended in 2017 and achieved a 28% decrease to 2.9 cases/100,000.⁶ However, this reduction in ARF incidence has not been sustained with numbers appearing to gradually increase, indicating the need for ARF prevention, screening and management.⁸

Within New Zealand, the burden of ARF occurs in regions with large Māori and Pacific populations, particularly Auckland and Far North districts (Counties Manukau, Tairāwhiti, Bay of Plenty and Northland).⁹ In Canterbury, Māori make up 9.4%, Pacific peoples 3.2% and NZ Europeans 82.4% of the population. Nationally, Māori and Pacific peoples represent 16.5% and 8.1% of the population, while NZ Europeans make up 70.2%.¹⁰ Māori and Pacific communities in Canterbury are small but growing. To date, there have been no studies on ARF specifically in Canterbury. To address this paucity in the literature, this study aims to describe the epidemiological and

clinical characteristics of first episodes of ARF in the Canterbury Region.

Methods

Study setting

The Canterbury Region is defined by the boundaries of Te Whatu Ora – Waitaha Canterbury. This covers the portion of the east coast of the South Island from Kaikōura in the north to Ashburton in the south, as well as Rēkohu/Chatham Islands.

Datasets

There are three surveillance systems in New Zealand used to monitor ARF: public health notification data, hospitalisation data and regional patient registers. Eligible cases were identified through these three datasets. Cases notified to the medical officer of health from 1 January 2012 to 31 December 2022 in the Canterbury Region were extracted from electronic system EpiSurv. Canterbury hospitalisations with International Classification of Diseases (ICD) codes corresponding to ARF (ICD-9: 390–392, ICD-10: 100–102) were accessed from the National Minimum Dataset. Local Canterbury registry data were obtained from the Community and Public Health Unit.

Eligibility criteria

Cases that met all the inclusion criteria were included in the study (Figure 1).

- Patients aged below 30 years at the time of diagnosis.
- Patients diagnosed with first episode of ARF or RHD within the dates of 1 January 2012–31 December 2022.
- Patients diagnosed with first episode of ARF or RHD in the Canterbury Region.

According to the New Zealand guidelines for diagnosis of ARF, diagnoses may be categorised as either definite, probable or possible ARF.¹¹ Definite ARF is defined as two major or one major and two minor manifestations, plus evidence of a preceding GAS infection. Probable ARF is defined as one major and two minor manifestations with the inclusion of evidence of preceding GAS infection as a minor manifestation. Possible ARF is defined as when there is strong clinical suspicion but insufficient signs and symptoms to fulfil the criteria for definite or probable ARF. There are two additional exceptions where a diagnosis of definite ARF can be made where chorea or indolent

carditis are the only manifestations of ARF.

Retrospective review of electronic clinical notes, laboratory results and echocardiography reports were conducted by two of the authors (including a senior expert clinician). The New Zealand guidelines for the diagnosis of ARF were applied to each case individually by the authors. Cases that met the criteria for definite, probable or possible ARF using the New Zealand guidelines were included in the study. Due to there being variable echocardiographic follow-up of patients with RHD, data related to rheumatic valvular characteristics in those diagnosed with RHD were collected from the patients' initial echocardiograms. Paper notes were requested where the necessary information was not available electronically. Demographic information and clinical data relevant to their ARF diagnoses were collated using the Microsoft Excel software.

This paper focussed on first episode ARF presentations. However, patients who at first presentation had established RHD without active inflammation due to ARF, or a prior history of ARF, were included in the initial descriptive analysis. As this sub-group represents patients who have had unidentified episodes of ARF in the community, it is important to mention these cases. This group was excluded from any rate calculations.

Statistical analysis

ARF case notifications from all remaining district health board (DHB) regions in New Zealand from 2012 to 2022 were collected from the notifiable disease dashboard provided by the Institute of Environmental Science and Research (ESR).¹² Denominators for rate calculation used population estimates of those aged under 30 years by ethnicity and DHB region and were extracted from the populations web tool (13 February 2024) from Health New Zealand – Te Whatu Ora, based on customised population estimates and projections provided by Stats NZ according to assumptions agreed to by the Ministry of Health.¹³ Incidence rates and 95% confidence intervals (CI) for first episode ARF cases were calculated after excluding patients diagnosed with only RHD. Prioritised ethnicity was used in all cases.

Ethics

Research has been conducted in accordance with the Declaration of Helsinki. The authors sought and received ethical approval from the University of Otago Ethics Committee (Ref: H23/031).

Results

Datasets

There were no extra ARF cases identified through the cross-matching of regional and hospital discharge data. Four patients diagnosed with ARF were absent from hospital discharge data and six from regional public health data. RHD patients were identified through regional and notification data.

Patient characteristics

A total of 34 patients were included in the analysis. Twenty-nine presented with their first episode of ARF and five were diagnosed with RHD without previously diagnosed ARF in Canterbury over 2012–2022 (Figure 1). The median age at presentation with ARF was 13 years (range 5–27 years), 59% were males and 69% identified as Pacific peoples (Samoan, Tongan, Cook Island Māori, Tokelauan) while 21% were Māori (see Table 1). Patients were more commonly diagnosed between the ages of 10 and 14 in both ARF and RHD groups. All cases in the RHD group (n=5) were either Pacific or Māori.

Diagnosing ARF

Twenty-six patients fulfilled the New Zealand diagnostic criteria for definite ARF. One patient was diagnosed with chorea as their only manifestation of ARF. Two patients fulfilled the criteria for probable ARF and one for possible ARF. Fourteen (48.3%) had GAS isolated from a skin (3/14) or throat swab (11/14). No patients had concurrent GAS-positive skin and throat swab results. All patients had positive GAS serology. The following analysis includes all 29 patients diagnosed with definite, probable and possible ARF.

Signs and symptoms of ARF

The most common major manifestation was arthritis (75.9%), followed by carditis (51.7%), chorea (20.7%) then erythema marginatum (3.4%). Eighteen out of the 22 cases who presented with arthritis had polyarthritis (81.2%). Polyarthralgia was seen in five out of the seven patients who did not present with arthritis, leaving two patients who presented without joint manifestations. Two of the five patients with polyarthralgia had used non-steroidal anti-inflammatory drugs during their acute illness prior to presentation, potentially masking objective signs of inflammation. Objective findings of fever during admission

were documented for 34.5% of patients. Among cases without objective documentation of fever during admission, 41.4% reported a history of subjective fevers in the time leading up to admission. Most had raised inflammatory markers (82.8%). Over half had a prolonged PR interval (55.2%). A family history of ARF was reported by 20.7% of cases. One patient was later hospitalised with a recurrent episode of ARF.

The median length of hospital stay for ARF cases was 5 days (range 0–69 days). One case was retrospectively diagnosed with ARF as an outpatient under rheumatology and was not admitted to hospital. Among the five RHD-only cases, two were diagnosed as outpatients and three presented to hospital through the emergency department and stayed for 1–7 days.

Rates of ARF and RHD in Canterbury

The annual number of first episode ARF cases ranged from 0 to 5 from 2012 to 2022 in Canterbury (see Figure 2).

Due to a small number of cases diagnosed in Canterbury annually, incidence rates for 3-year blocks were calculated: block one (2012–2015), block two (2016–2019) and block three (2020–2022). Overall rates in both Canterbury and in the rest of New Zealand have decreased since 2012. The overall rate in Canterbury for the study period was significantly lower than the rest of New Zealand, at 1.24 cases/100,000 compared with 8.01 cases/100,000 (rate ratio [RR] 0.12, 95% CI 0.09–0.18). In a sensitivity analysis, we calculated the incidence using only definite ARF cases in Canterbury. The overall rate of ARF in Canterbury decreased to 1.11 cases/100,000. The difference between Canterbury and the rest of New Zealand was not significantly different from the primary analysis (p-value=0.99). Rates of individual year blocks are displayed in Figure 3.

Within Canterbury, Pacific peoples experienced the highest rates, followed by Māori (Figure 4). Rates per year block ranged from 19.51 cases to 22.4 cases/100,000 for Pacific peoples. Māori rates ranged from 0.98 cases to 1.59 cases/100,000 per year block and non-Pacific, non-Māori had rates ranging from 0.0 to 0.3 cases/100,000.

Overall, across all years Pacific peoples in Canterbury were approximately 20 times more likely to be diagnosed with ARF compared with non-Pacific, non-Māori (RR 19.95, 95% CI 5.93–67.14); Māori in Canterbury were approximately five times as likely to be diagnosed compared with non-Pacific, non-Māori (RR 5.69, 95% CI 1.42–22.8).

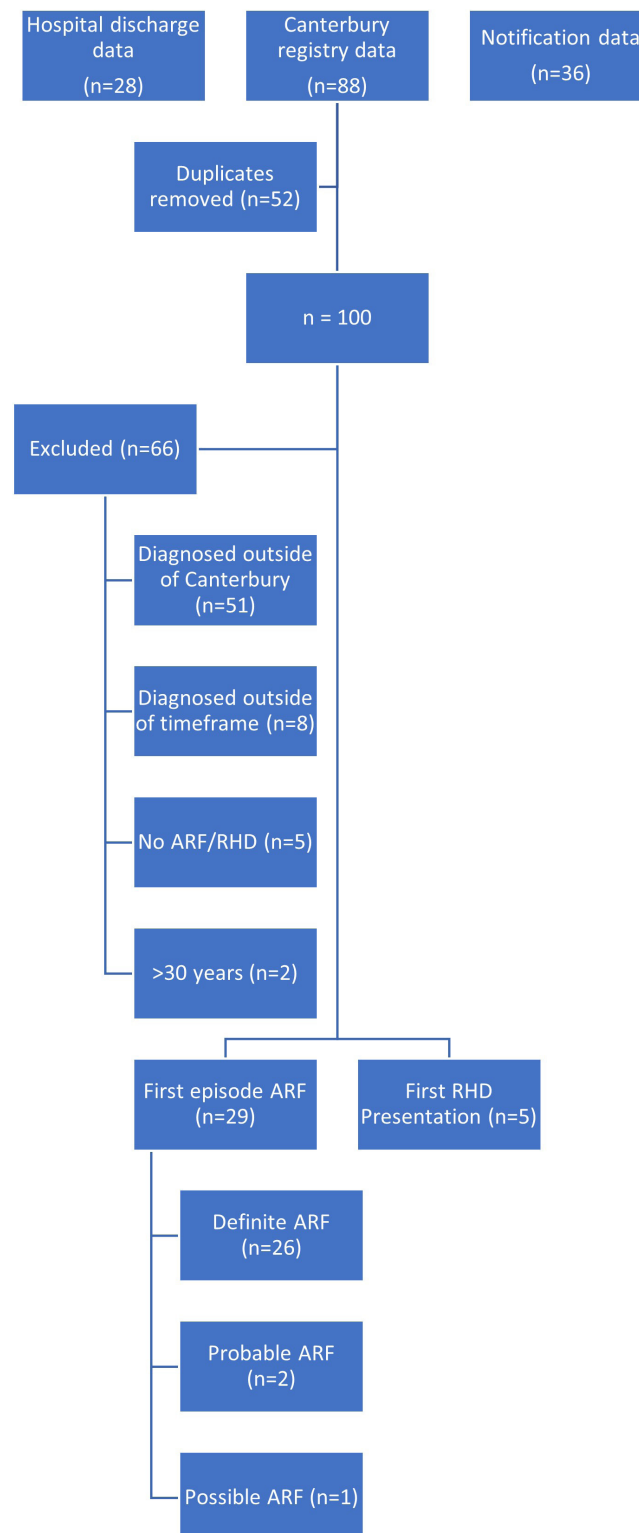
Figure 1: Study inclusion and exclusion criteria.

Table 1: Descriptive characteristics of those diagnosed with first episode ARF and RHD <30 years of age in Canterbury from 2012 to 2022 (n=34).

Characteristic	ARF n (%)	RHD n (%)
Sex		
Female	12 (41.4)	2 (40.0)
Male	17 (58.6)	3 (60.0)
Age (years)		
Median (range)	13 (5–27)	13 (8–26)
<5	0 (0.0)	0 (0.0)
5–9	7 (24.1)	1 (20.0)
10–14	11 (37.9)	2 (40.0)
15–19	7 (24.1)	0 (0.0)
20–24	3 (10.3)	1 (20.0)
25–30	1 (3.4)	1 (20.0)
Ethnicity		
NZ Māori	6 (20.7)	1 (20.0)
Pacific peoples	20 (69.0)	4 (80.0)
Asian	1 (3.4)	0 (0.0)
European/Other	2 (6.9)	0 (0.0)
Total	29	5

ARF = acute rheumatic fever; RHD = rheumatic heart disease.

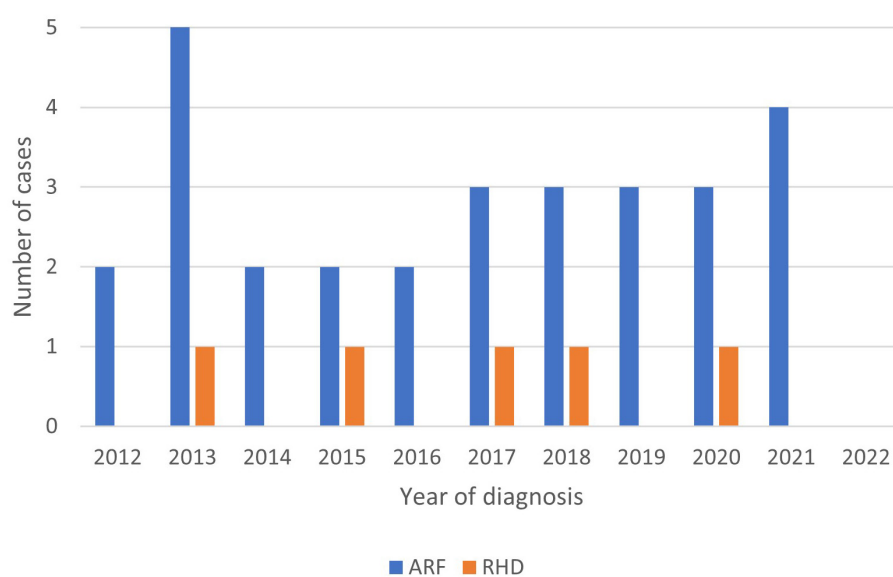
Figure 2: Number of first episode acute rheumatic fever presentations and rheumatic heart disease diagnoses, <30 years of age, diagnosed in Canterbury, New Zealand from 2012 to 2022.

Figure 3: Incidence rates per 100,000 of first episode acute rheumatic fever presentations, all ethnicity, <30 years of age, diagnosed in Canterbury vs New Zealand in year blocks from 2012 to 2022.

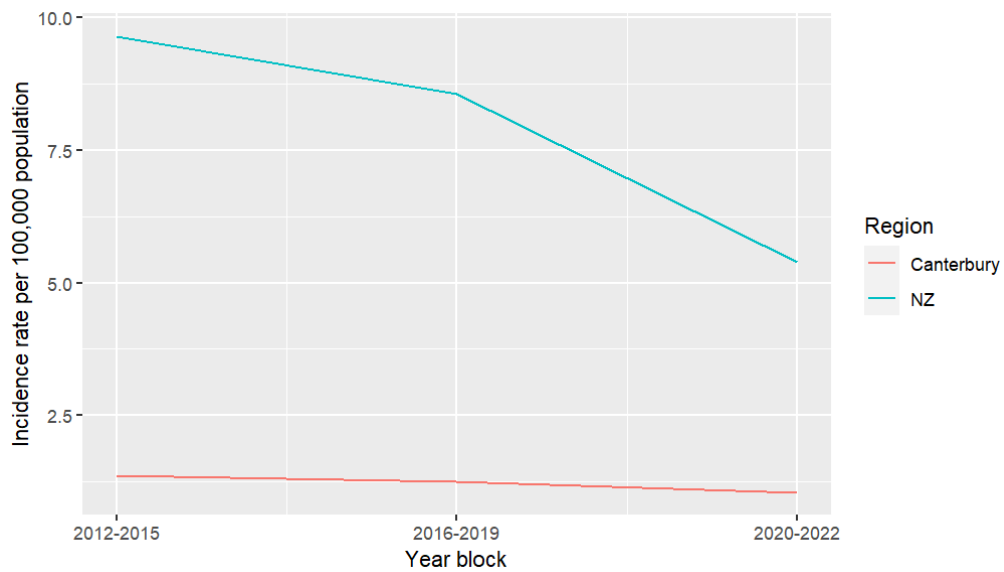


Figure 4: Incidence rates per 100,000 of first episode acute rheumatic fever presentations, <30 years of age, diagnosed in Canterbury, New Zealand, by ethnic group in year blocks from 2012 to 2022.

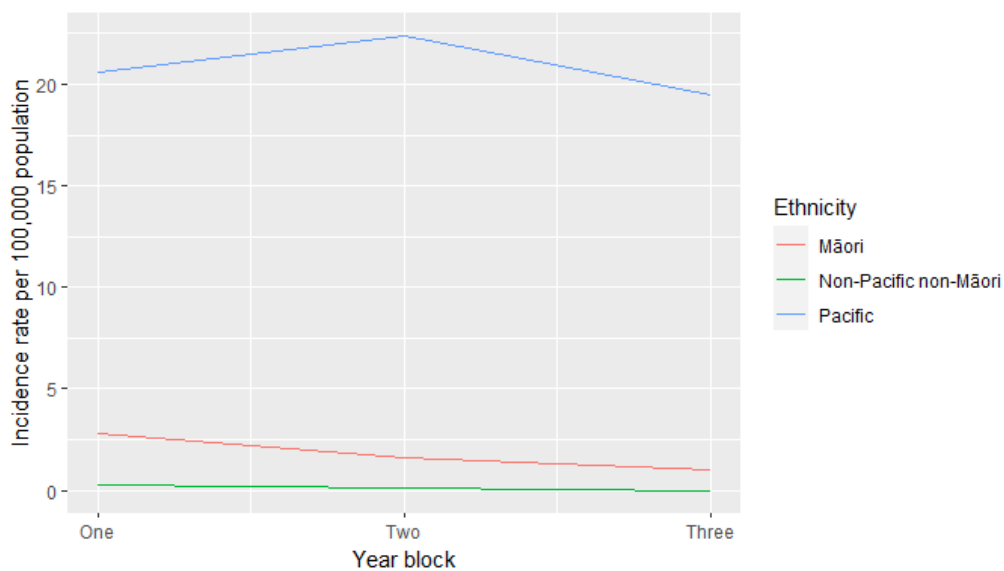


Table 2: Initial rheumatic valvular features of patients diagnosed with ARF and RHD in Canterbury from 2012 to 2022 (n=34).

n (%)		ARF patients (n=15)	RHD patients (n=5)	Total (n=20)
		n (%)	n (%)	
Mitral regurgitation	Mild [*]	3 (20)	2 (40.0)	5 (25.0)
	Mild–moderate	0 (0.0)	1 (20.0)	1 (5.0)
	Moderate	4 (26.6)	0 (0.0)	4 (20.0)
	Moderate–severe	0 (0.0)	1 (20.0)	1 (5.0)
	Severe	4 (26.6)	1 (20.0)	5 (25.0)
Mitral stenosis	Mild	1 (6.7)	1 (20.0)	2 (10.0)
	Mild–moderate	1 (6.7)	0 (0.0)	1 (5.0)
Aortic regurgitation	Mild [*]	2 (13.3)	1 (20.0)	3 (15.0)
	Mild–moderate	1 (6.7)	0 (0.0)	1 (5.0)
	Severe	3 (20.0)	0 (0.0)	3 (15.0)
Mitral^{†‡}	Valve thickening	9 (60.0)	3 (60.0)	12 (60.0)
	Restricted leaflet	1 (6.7)	1 (20.0)	2 (10.0)
Aortic^{†§}	Leaflet thickening	5 (33.3)	1 (20.0)	6 (30.0)
	Coaptation defect	2 (13.3)	0 (0.0)	2 (10.0)

ARF = acute rheumatic fever; RHD = rheumatic heart disease.

^{*}Regurgitation that was physiological or trivial was excluded.

[†]The World Heart Federation criteria for morphological features of RHD outline four morphological features for both the mitral and aortic valves that are recommended for use in the diagnosis of RHD in the New Zealand guidelines for rheumatic fever.

[‡]There are four morphological RHD features of the mitral valve. Chordal thickening and excessive leaflet tip motion are not listed in the table as no patients in this study had these features.

[§]There are four morphological RHD features of the aortic valve. Restricted leaflet motion and prolapse or excessive leaflet motion are not listed as no patients in this study had these features.

Pacific peoples living in Canterbury have a lower risk of being diagnosed with ARF when compared with Pacific peoples living in the rest of New Zealand (RR 0.05, 95% CI 0.03–0.08). Māori living in Canterbury also have a lower risk compared with the rest of New Zealand (RR 0.07, 95% CI 0.03–0.16).

Cardiac involvement

A total of 15 patients had evidence of cardiac involvement on their initial echocardiogram out of the 29 who presented with initial ARF (see Table 2). Three patients required cardiac surgery. One patient with normal echocardiographic indices on initial presentation developed severe aortic changes that required aortic valve

replacement after 6 years. This patient did not present to hospital with recurrent ARF. One patient presented with severe mitral and aortic changes requiring valvular replacement during their initial hospitalisation. The other patient developed valvular changes requiring mitral repair and aortic valve replacement 6 months after initial presentation. Table 2 shows the rheumatic features found on initial echocardiography for the 15 patients diagnosed with ARF who had cardiac involvement and patients diagnosed with RHD only.

Discussion

The overall number of ARF cases diagnosed

in Canterbury from 2012 to 2022 is relatively small, with rates significantly lower than the rest of New Zealand at 1.24 cases/100,000 compared with the national rate of ARF notifications of 8.01 cases/100,000 (RR 0.12, 95% CI 0.09–0.18). Most patients receiving antibiotic prophylaxis for ARF in Canterbury were not diagnosed in the region, usually having moved from the North Island or a Pacific nation. Of those diagnosed in Canterbury, clinical presentation is very similar to what is seen elsewhere.

Pacific peoples experience the highest incidence of ARF in New Zealand, which was similarly seen in Canterbury. While overall those living in Canterbury are less likely to be diagnosed with ARF, Pacific peoples in the region continue to face a disproportionately high risk for developing the disease. Most Pacific peoples diagnosed with ARF are diagnosed in the Auckland regions, particularly Counties Manukau. From 2010 to 2013, 47% (n=337) of all diagnosed ARF cases were from the Auckland DHB regions, of which 72.7% were diagnosed in Counties Manukau.⁹ Pacific children in Auckland have a tremendously increased risk of ARF (RR 240.4, CI 33.5–1,722.6) compared with European/Other children.¹⁴ Additionally, South Auckland has a high burden of RHD, with about 2% of young Pacific adults having definite RHD.¹⁵

During the COVID-19 years, ARF case notifications decreased in the Auckland DHB regions. One explanation for this could be the national public health interventions implemented as part of the New Zealand government's COVID-19 response (2020–2022). The Auckland Region during the national COVID-19 response was under greater lockdown restrictions than the rest of the country for a longer duration.

Other regions such as Northland, Waikato and Tairāwhiti also have high recorded rates of ARF.^{16–18} Annual ARF incidence in Tairāwhiti from 1997 to 2009 was 7.9 cases/100,000.¹⁶ Most cases were Māori, reflecting both the high population of Māori (47.1%) and an even higher proportion of children being Māori (75%).¹⁶ In Northland, two audits were carried out from 2002 to 2011 (pre-RFPP interventions) and again from 2012 to 2017 (post-PFPP interventions). The initial study found an annual incidence of 7.6 cases/100,000, with most cases being Māori (95%). Incidence rates show significant disparity between Māori (24.8 cases/100,000) and non-Māori (0.6 cases/100,000). The follow-up audit found very little improvement. From 2012 to 2017, Wauchop et al. observed an overall incidence of 7.0 cases/100,000. Rates

improved for Northland Māori by one-fifth, while rates among 4–14-year-olds showed persisting disparities between Māori (64.5 cases/100,000), Pacific peoples (54.6 cases/100,000) and non-Pacific, non-Māori (1.5 cases/100,000).¹⁷ In Waikato from 2002 to 2011 there were 106 ARF cases and an annual rate of 3.1 cases/100,000. Similar to Northland and Tairāwhiti, Māori made up the majority of cases (85%) with Māori children aged 5–14 years experiencing the highest rates at 46.1 cases/100,000.¹⁸

Clinical presentation of ARF in Canterbury is consistent with what is seen elsewhere in New Zealand.^{17,18} The most common presenting manifestation were arthritis, followed by carditis and chorea. Skin manifestations were rarely observed. Almost all patients with ARF (28/29) were aged between 5 and 25. Pacific peoples were most likely to be diagnosed with ARF followed by Māori. Despite the low number of cases diagnosed in Canterbury, it is essential that clinicians consider ARF as a differential diagnosis when caring for Pacific peoples and Māori children presenting with joint pains. In terms of local notification data, it is reassuring that no additional Canterbury-diagnosed ARF cases were identified through regional or hospital discharge data. This suggests that ARF cases are being reliably notified in Canterbury.

Although our study did not endeavour to describe the profile of RHD in Canterbury, we did incidentally identify six cases of RHD without a prior history of ARF, which indicates that some ARF occurs unnoticed within the Canterbury community. A previous study by Tilton et al. found that among first RHD presentations 41% were diagnosed without having a recognised prior episode of ARF.¹⁹ This same study found that 32% of RHD patients had changed their region of residence within New Zealand from initial RHD presentation. Over half (51%) of the patients identified through datasets were excluded due to being diagnosed outside of Canterbury, indicating a large proportion of patients move between regions. Monitoring prophylaxis delivery and sharing health information between health professionals is especially important for this group. A robust national surveillance system is urgently needed to ensure the health needs of these patients are met. Previous literature has supported the development of such a system.^{5,20} Internationally, surveillance systems in places such as Cuba²¹ and the Caribbean islands²² have been part of strategies that helped greatly reduce

ARF incidence. In June 2023, the Ministry of Health released the *Rheumatic Fever Roadmap*, outlining the government's plan for reducing ARF incidence in New Zealand.²³ The National Rheumatic Fever Care Coordination System is a national surveillance system that is being developed.²⁴ This system incorporates a national online register and is being piloted in two regions. Hopefully, the national register will address gaps in the current systems used to monitor ARF in New Zealand and help better serve those transferring to new regions, such as Canterbury.

Study limitations

There are several limitations to this study. Firstly, the Canterbury regional registry has not been active for the full duration of the study. It is unlikely to have identified additional ARF cases, although it may under-estimate the number of cases receiving care for having had ARF in Canterbury. National notification data used for comparison included cases of all ages. This is unlikely to have a significant effect due to a small proportion of cases being diagnosed over the age of 30.⁴ Additionally, some notified cases may be ARF recurrences, thus over-estimating the incidence of

initial presentations for the rest of New Zealand. Longitudinal follow-up data for some patients were unavailable; therefore, comments on outcomes such as resultant cardiac surgery were not possible for all patients. Lastly, the study incidentally identified patients diagnosed with initial RHD without prior recognised ARF. However, ICD codes corresponding to RHD were not collected; therefore, the results presented likely under-estimate initial RHD presentations occurring in Canterbury. To accurately describe RHD presentations in Canterbury, ICD codes corresponding to RHD should be collected.

Conclusion

We found a low number of ARF cases diagnosed in Canterbury compared with the rest of New Zealand. Most patients receiving treatment for having had ARF in Canterbury have moved into the region from elsewhere. Of those diagnosed in Canterbury, the majority are Pacific peoples, aged between 5 and 20 years and present with joint pains. There have not previously been any studies looking at ARF in the context of the South Island. This study provides a baseline for the future comparison of ARF within Canterbury.

COMPETING INTERESTS

Nil.

Taliah Su'a funding from: Research for Children Aotearoa for a departmental PhD award; Otago Medical School for a BMedSc(Hons) scholarship; Pūtahi Manawa, Healthy Hearts for Aotearoa New Zealand for a doctoral scholarship.

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<https://nzmj.org.nz/journal/vol-138-no-1609/acute-rheumatic-fever-in-canterbury-aotearoa-new-zealand-2012-2022>

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Epidemiology of skin infections in Auckland, New Zealand

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ABSTRACT

AIM: To describe the epidemiology of *Staphylococcus aureus* (*S. aureus*) and *Streptococcal pyogenes* (*S. pyogenes*) skin infections in Auckland, New Zealand.

METHOD: A population-based retrospective analysis of skin swab culture results (2010–2020), collected in primary care, was conducted to determine incidence rates and rate ratios (RR) with 95% confidence intervals (CI), using 2013 New Zealand Census data as the denominator.

RESULTS: Over one-quarter of Auckland's population were tested for suspected skin infections over the 11-year observation period, at 31.4 persons per 1,000 person-years. *S. aureus* affected all demographics. *S. pyogenes* infection rates were higher for children under 10 years of age (RR 3.1, 95% CI 3.1–3.2; compared with ≥10-year-olds), Māori and Pacific peoples (RR 4.7, 95% CI 4.6–4.8; compared with European/Other) and individuals in the most socio-economically deprived areas (RR 2.1, 95% CI 1.9–2.3; compared with least deprived areas). Individuals who were *S. aureus*-positive were twice (2.1, 95% CI 1.9–2.3) as likely to test *S. pyogenes*-positive, relative to those testing negative for *S. aureus* or positive for another skin pathogen.

CONCLUSION: Children, Māori, Pacific peoples and people in lower socio-economic areas are more likely to have a skin infection test positive for *S. pyogenes*. *S. aureus* infection is a risk factor for co-infection with *S. pyogenes*.

Aotearoa New Zealand has one of the highest rates of bacterial skin infections among high-income regions, with over 15,500 cases per 100,000 population documented by the Global Burden of Diseases in 2019.¹ Predominantly, these cases manifest symptomatically as pyoderma (82%), with cellulitis comprising the remainder.¹ These skin infections represent a significant health concern for New Zealand, particularly affecting children under the age of 14 years, a group with a 2019 hospitalisation rate of 3.2 per 1,000.² The risk of being hospitalised with a skin infection is notably higher among children, Māori, Pacific populations and individuals in socio-economically deprived areas.^{2–4}

Staphylococcus aureus (*S. aureus*) is the primary cause of skin infections in New Zealand,⁵ aligning with patterns observed in other countries reporting high rates of skin infections, such as India and the United States.^{6,7} *Streptococcal pyogenes* (*S. pyogenes*), commonly known as Group A *Streptococcus* or GAS, is also an important cause of bacterial skin infections in New Zealand and worldwide.^{5,8,9} In Auckland, New Zealand between 2010 and 2016, positivity rates for *S. pyogenes* and *S. aureus* in primary healthcare skin and wound swabs were reported to be 4.8 and 14.1 per 1,000 person-years, respectively.⁵ Cellulitis caused by *S. pyogenes* is a substantial contributor to total

economic and health burdens in New Zealand, with an estimated annual economic burden of NZ\$11.3 million in 2015.¹⁰

Beyond acute infection, *S. pyogenes* infection can instigate autoimmune disorders, including acute post-streptococcal glomerulonephritis (PSGN), a rare kidney disease,¹⁰ and potentially acute rheumatic fever (ARF).¹¹ ARF is a serious condition that can result in permanent heart damage, known as rheumatic heart disease (RHD).¹² Historically, ARF was thought to follow GAS pharyngitis,¹² but recent evidence indicates that New Zealand Māori and Pacific peoples face a fivefold increased risk of ARF within 8–90 days after a skin swab positive for *S. pyogenes* compared with those with negative swabs.¹¹ ARF/RHD are preventable and rare in high-income settings but prevalent among New Zealand Māori and Pacific peoples, who also face a disproportionate burden of *S. pyogenes* skin infections.^{5,12,13}

The study is an extension on a previous study looking at *S. aureus* and *S. pyogenes* in skin swabs from 2010 to 2016.⁵ This study includes data up to 2020 and aims to investigate how these bacteria impact different demographic groups both in isolation and as co-infections, as well as to investigate the potential influence of *S. aureus* on the risk of *S. pyogenes* infection. Previous research has indicated a high prevalence of *S. pyogenes*

in skin swabs from children under 10 years old, along with evidence suggesting that such early exposure contributes to the onset of ARF.⁵ Therefore, we posited that a particular demographic, specifically children under 10 years, may face an increased risk of skin infections attributed to *S. pyogenes*.

Method

Study data were obtained from Awanui Labs (formally Labtests), which has been Auckland's only accredited community pathology laboratory service provider since mid-2009.¹⁴ The Auckland Region was defined as Waitemata, Auckland and Counties Manukau catchment areas (at the time of the data collection, district health boards [DHBs]). Data included all Auckland residents who visited primary care for a wound or suspected skin infection that resulted in a wound/skin swab being sent to Awanui Labs for microbiological culture between 1 January 2010 and 31 December 2020. Samples for these swabs were collected during primary care consultations from patients presenting with symptoms characteristic of wound or skin infections that required microbiological culture for further assessment. The dataset was restricted to symptomatic cases, thereby omitting any asymptomatic individuals. Serving approximately 1.5 million people, or one-third of New Zealand's population,¹⁵ Awanui Labs primarily receives specimens from primary care, with over 95% of these coming from such facilities. Cultures were grown on tryptic soy agar with 5% sheep blood and incubated for 48 hours at 37 degrees Celsius in 5% CO₂. Until 2012, identification relied on streptococcal grouping latex and coagulase tests, respectively; thereafter, identification utilised MALDI-TOF MS Biotyper (Bruker, Germany).

Awanui Labs' microbiological testing data were provided with encrypted National Health Index (NHI) numbers supplied by the New Zealand Ministry of Health, enabling the pairing with de-identified demographic data. Auckland's demographics and population size were estimated using the 2013 New Zealand Census. The 2013 Census data provided the ethnic composition of Auckland: 11% Māori, 13% Pacific peoples, 22% Asian and 53% NZ European/Other.¹⁵ Ethnicity data used a prioritised approach, with prioritisation given to Māori, followed by Pacific peoples, then Asian and finally NZ European/Other.¹⁶ Those with multiple ethnic identifications were prioritised to

the first ethnic grouping in that schema, e.g., individuals identifying with both Māori and Pacific ethnicities were classified as Māori. The socio-economic status of residential areas was indicated by the New Zealand Index of Deprivation (NZDep) 2013.¹⁷ NZDep is a granular, area-specific metric of socio-economic deprivation that categorises New Zealand's geographical areas into 10 deciles or five quintiles, ranging from regions of least socio-economic deprivation (deciles 1–2 or quintile 1) to regions marked by highest deprivation (deciles 9–10 or quintile 5).

Data analysis

Data analysis was conducted with Stata/SE 17.0. Data missing essential information like encrypted NHI numbers were excluded. Analysis included stratified analysis by age, ethnicity, socio-economic status (using NZDep2013), gender, region and season. Age and season were determined by birth and test result dates, respectively. The methodology for defining cases of skin infections from skin swab data involved grouping swabs taken for the same person within a 3-month period as a single event, with any skin swabs taken after this period considered a new infection event. The 3-month cut-off period was determined based on the distribution of swabs collected over the 11-year period to differentiate between distinct episodes of skin infections (Appendix Figure 1). Cases were defined as infections caused by either *S. aureus*, *S. pyogenes*, co-infections of both or negative results for both pathogens.

The frequency of disease measurements was based on the fraction of Auckland's population (N=1,431,189) who sought primary care and underwent swab tests (N=360,861) for skin infections over an 11-year period. We calculated presentation and infection rates per 1,000 person-years, including rate ratios (RR) with 95% confidence intervals (95% CI) to compare risks across demographic groups. Poisson regression was applied, adjusting for age, ethnicity, socio-economic status, gender and geographic location (the three constituent DHBs within the greater Auckland Region).

To estimate the risk of *S. pyogenes* following exposure to *S. aureus*, infection events initially swabbed and re-swabbed within a 3-month period were stratified into two groups: one group tested positive for *S. aureus* only during the initial swab collection, and the other group tested negative for *S. aureus* (either positive for another skin pathogen or no significant pathogen detected) at the time of the initial swab. The *S. pyogenes*

positivity rate was then examined for both groups during the subsequent re-swabbing within the 3-month follow-up period.

Results

Overview

Between 2010 and 2020, 360,861 people with unique NHI numbers underwent clinical evaluations for suspected skin infections at primary care facilities, resulting in skin swabs being sent for bacterial culture. Annually, an average of 44,903 individuals had a swab taken, a rate of 31.4 individuals swabbed per 1,000 person-years. Approximately 22.6% of the swabs were collected within 3 months of an initial swab. The swabbing rate decreased steadily after the initial 3 months. Hence, all swabs collected within 3 months of the initial swab were categorised together to identify a single infection incident (Appendix Figure 1).

A total of 514,280 skin infection cases were identified, with 87.9% requiring a single visit and 12.1% necessitating multiple visits within 3 months, which resulted in additional wound swab/s being collected for microbiological assessment. Among these patients, 26.0% (n=93,957) experienced re-infection (excluding positive swabs in the 3 months after their previous swab) a median of 508 days later (interquartile range [IQR] 231–1,097), resulting in 153,419 recorded re-infections. Laboratory analyses revealed that 37.8% of cases were culture negative and 5.1% were positive for other pathogens, while 43.5% were positive for *S. aureus*, 4.9% were positive for *S. pyogenes* and 8.8% were positive for both (Table 1).

Figure 1 shows an increase over the 11-year period in the rate of presentations/visits at primary care for suspected skin infections, with a decline noted in 2020, corresponding to the COVID-19 pandemic and response.

Age

The population who presented for evaluation of skin infections had a median age of 36.2 years (IQR 13.6–61.7). At a population level across the study period, 38.6 primary care visits necessitated microbiology culture testing for skin infections per 1,000 person-years. The incidence rate was higher among children under the age of 10 years (45.5 per 1,000 years), in contrast to 29.1 per 1,000 years for those aged 10 years and above. Over the 11-year period, 37.8% of individuals under the age of 10 years sought primary care for microbiology

testing for skin infections, in contrast to 23.1% of individuals outside this age bracket. Individuals under the age of 10 years comprised the majority of cases (42.4%) of all infections related to *S. pyogenes*, and 18.4% of all infections solely attributed to *S. aureus*. Infections caused by *S. aureus* alone were predominantly (55.9%) found in adults aged 30 years and above (Table 1).

The overall rate of skin infection declined with increasing age. Although the rate of *S. aureus* infections remained relatively consistent across age groups, infections involving *S. pyogenes*, either as solitary infections or co-infections with *S. aureus*, peaked in individuals under the age of 10 years and demonstrated a steady decrease thereafter (Figure 2). Children under the age of 10 years exhibited a 1.3-fold higher rate of *S. aureus* infections (95% CI 1.3–1.3) compared with those aged 10 years and older, and a 3.1-fold (95% CI 3.1–3.2) higher rate of *S. pyogenes*-related infections. Analysis further established that, on average, individuals infected with *S. pyogenes* were 23.3 years younger (95% CI 23.0–23.7), with a median age of 12.9 years (IQR 5.7–31.0), as opposed to those solely infected with *S. aureus*, who had a median age of 36.2 years (IQR 14.4–63.2).

Ethnicity

Individuals who identified as Asian exhibited the lowest incidence of microbiological testing in primary care. Pacific peoples reported the highest annual rate of primary care visits for skin infection microbiology testing, at 65.1 visits per 1,000 person-years, followed by Māori (46.8 visits per 1,000 person-years) and NZ European/Other (43.1 visits per 1,000 person-years) (Appendix Table 1).

The NZ European/Other group accounted for over half (56.0%) of all identified *S. aureus*-exclusive infections. In contrast, the Māori and Pacific groups accounted for 72.8% of all *S. pyogenes*-related infections (Table 1). While infections exclusively caused by *S. aureus* showed similar incidence rates across all three ethnic groups, *S. pyogenes* infections differed substantially by ethnicity. For *S. pyogenes* alone, higher rates compared with NZ European/Other were seen for both Māori (RR 2.2, 95% CI 2.1–2.3) and for Pacific peoples (RR 2.7, 95% CI 2.6–2.8). Higher rates were also seen for *S. pyogenes* and *S. aureus* co-infections, again compared with NZ European/Other, for both Māori (RR 3.9, 95% CI 3.8–4.0) and Pacific peoples (RR 5.6, 95% CI 5.4–5.7) (Table 2).

Table 1: Description of skin infection microbiology for the Auckland Region, New Zealand 2010–2020.

Characteristic	<i>S. aureus</i>		<i>S. pyogenes</i>		<i>S. aureus</i> & <i>S. pyogenes</i>		Negative		Total	
	n	Col %	n	Col %	n	Col %	n	Col %	N	Col %
Median age (IQR)	36.2 (14.4–63.2)		13.2 (5.83–34.44)		12.8 (5.6–29.0)		44.6 (22.0–66.3)		36.2 (13.6–61.7)	
Age group										
00–04	23,603	10.6	5,155	20.5	10,034	22.1	23,924	10.9	62,716	12.2
05–09	17,594	7.9	5,483	21.8	9,183	20.3	9,809	4.5	42,069	8.2
10–14	16,689	7.5	2,704	10.8	5,702	12.6	8,148	3.7	33,243	6.5
15–19	16,253	7.3	1,820	7.3	4,113	9.1	9,281	4.2	31,467	6.1
20–24	13,091	5.9	1,453	5.8	3,058	6.7	10,808	4.9	28,410	5.5
25–29	11,281	5.0	1,207	4.8	2,310	5.1	11,823	5.4	26,621	5.2
30+	125,027	55.9	7,287	29.0	10,912	24.1	146,528	66.5	289,754	56.3
Total	223,538	100.0	25,109	100.0	45,312	100.0	220,321	100.0	514,280	100.0
Prioritised ethnicity										
Māori	27,413	12.3	6,139	24.5	12,173	26.9	19,600	8.9	65,325	12.7
Pacific	49,050	22.0	9,595	38.3	23,273	51.4	26,279	12.0	108,197	21.1
Asian	21,652	9.7	1,624	6.5	1,817	4.0	30,827	14.0	55,920	10.9
European/Other	124,761	56.0	7,708	30.8	7,983	17.6	142,963	65.1	283,415	55.3
Socio-economic deprivation										
1 (least deprived)	43,089	19.3	2,776	11.1	3,008	6.6	52,954	24.0	101,827	19.8
2	44,315	19.8	3,243	12.9	4,175	9.2	49,809	22.6	101,542	19.8
3	39,156	17.5	3,265	13.0	4,695	10.4	41,314	18.8	88,430	17.2
4	30,287	13.6	3,769	15.0	7,101	15.7	28,391	12.9	69,548	13.5
5 (most deprived)	66,669	29.8	12,055	48.0	26,332	58.1	47,826	21.7	152,882	29.7
Gender										
Male	114,404	51.2	13,273	52.9	24,662	54.4	95,291	43.3	247,630	48.2
Female	109,134	48.8	11,836	47.1	20,650	45.6	125,029	56.8	266,649	51.9
Area										
Waitematā	79,039	35.4	6,896	27.5	10,691	23.6	86,319	39.2	182,945	35.6
Auckland	64,005	28.6	6,537	26.0	11,083	24.5	66,328	30.1	147,953	28.8

Table 1 (continued): Description of skin infection microbiology for the Auckland Region, New Zealand 2010–2020.

Counties Manukau	80,494	36.0	11,676	46.5	23,538	52.0	67,674	30.7	183,382	35.7
Season										
Summer	58,454	26.2	6,644	26.5	12,490	27.6	53,753	24.4	131,341	25.5
Autumn	59,048	26.4	8,395	33.4	14,981	33.1	56,544	25.7	138,968	27.0
Winter	53,069	23.7	5,572	22.2	9,957	22.0	54,295	24.6	122,893	23.9
Spring	52,967	23.7	4,498	17.9	7,884	17.4	55,729	25.3	121,078	23.5

S. aureus = *Staphylococcus aureus*; *S. pyogenes* = *Streptococcal pyogenes*; Col % = column percentage; IQR = interquartile range.

Figure 1: Rate of primary care visits per 1,000 person-years for microbiology testing for suspected skin infections in Auckland, New Zealand, 2010–2020.

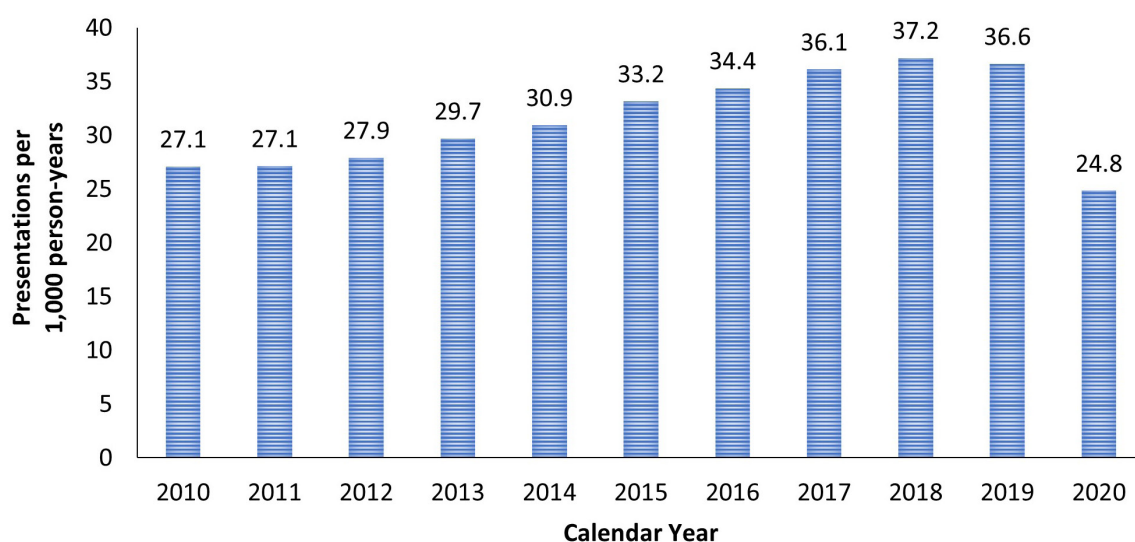


Figure 2: Adjusted incidence rate per 1,000 person-years by age group in Auckland, New Zealand, 2010–2020.

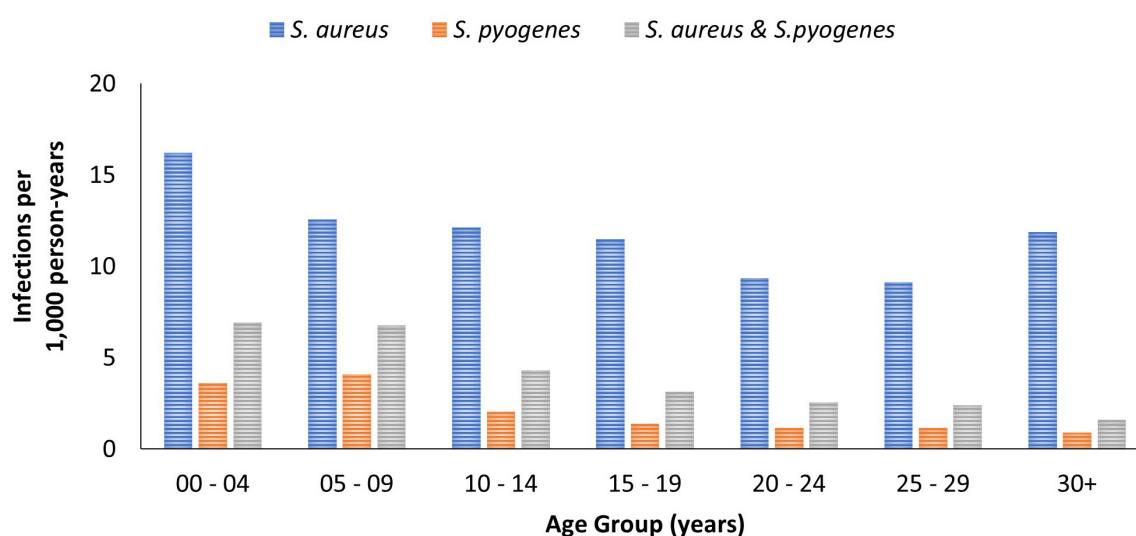


Table 2: Adjusted incidence rates and rate ratios (95% CI) for skin infections in Auckland, New Zealand, 2010–2020.

Characteristic	<i>S. aureus</i>		<i>S. pyogenes</i>		<i>S. aureus</i> & <i>S. pyogenes</i>	
	Rate	RR (95% CI)	Rate	RR (95% CI)	Rate	RR (95% CI)
Age group						
00–04	16.2	1.4 (1.3–1.4)	3.6	3.9 (3.8–4.1)	6.9	4.3 (4.2–4.4)
05–09	12.6	1.1 (1.0–1.1)	4.1	4.4 (4.3–4.6)	6.8	4.2 (4.1–4.3)
10–14	12.1	1.0 (1.0–1.0)	2.1	2.2 (2.1–2.4)	4.3	2.7 (2.6–2.7)
15–19	11.5	1.0 (1.0–1.0)	1.4	1.5 (1.4–1.6)	3.1	1.9 (1.9–2.0)
20–24	9.3	0.8 (0.8–0.8)	1.2	1.3 (1.2–1.3)	2.6	1.6 (1.5–1.6)
25–29	9.1	0.8 (0.8–0.8)	1.2	1.3 (1.2–1.3)	2.4	1.5 (1.4–1.5)
30+	11.9	<i>Ref</i>	0.9	<i>Ref</i>	1.6	<i>Ref</i>
Prioritised ethnicity						
Māori	14.9	0.9 (0.9–0.9)	3.6	2.2 (2.1–2.3)	7.1	3.9 (3.8–4.0)
Pacific	20.9	1.3 (1.3–1.3)	4.3	2.7 (2.6–2.8)	10.1	5.6 (5.4–5.7)
Asian	6.5	0.4 (0.4–0.4)	0.7	0.4 (0.4–0.4)	0.8	0.4 (0.4–0.5)
European/Other	16.1	<i>Ref</i>	1.6	<i>Ref</i>	1.8	<i>Ref</i>
Socio-economic deprivation						
1 (least deprived)	10.1	<i>Ref</i>	1.4	<i>Ref</i>	2.3	<i>Ref</i>
2	11.3	1.1 (1.1–1.1)	1.7	1.2 (1.1–1.3)	3.1	1.3 (1.3–1.4)
3	12.1	1.2 (1.2–1.2)	1.9	1.3 (1.3–1.4)	3.5	1.5 (1.4–1.6)
4	10.6	1.0 (1.0–1.1)	2.0	1.4 (1.4–1.5)	4.2	1.8 (1.7–1.9)
5 (most deprived)	16.7	1.6 (1.6–1.7)	3.3	2.4 (2.2–2.5)	6.9	3.0 (2.8–3.1)
Gender						
Male	12.4	<i>Ref</i>	2.2	<i>Ref</i>	4.4	<i>Ref</i>
Female	11.2	0.9 (0.9–0.9)	1.9	0.9 (0.9–0.9)	3.6	0.8 (0.8–0.8)
Area						
Waitematā	11.9	<i>Ref</i>	2.0	<i>Ref</i>	3.8	<i>Ref</i>
Auckland	11.9	1.0 (1.0–1.0)	2.1	1.1 (1.0–1.1)	4.0	1.0 (1.0–1.1)
Counties Manukau	11.7	1.0 (1.0–1.0)	2.1	1.1 (1.0–1.1)	4.0	1.0 (1.0–1.1)
Season						
Summer	3.7	1.1 (1.1–1.1)	0.8	1.4 (1.4–1.5)	1.5	1.6 (1.5–1.6)

Table 2 (continued): Adjusted incidence rates and rate ratios (95% CI) for skin infections in Auckland, New Zealand, 2010–2020.

Autumn	3.8	1.1 (1.1–1.1)	1.0	1.8 (1.7–1.9)	1.8	1.9 (1.8–1.9)
Winter	3.4	1.0 (1.0–1.0)	0.7	1.2 (1.2–1.3)	1.2	1.3 (1.2–1.3)
Spring	3.4	Ref	0.5	Ref	1.0	Ref

RR = rate ratio; CI = confidence interval; *S. aureus* = *Staphylococcus aureus*; *S. pyogenes* = *Streptococcal pyogenes*; Ref = reference group.
 Incidence rates and rate ratios mutually adjusted for age, ethnicity, socio-economic deprivation (NZDep), gender and area.

Figure 3: Adjusted incidence rate per 1,000 person-years by prioritised ethnicity in Auckland, New Zealand, 2010–2020.

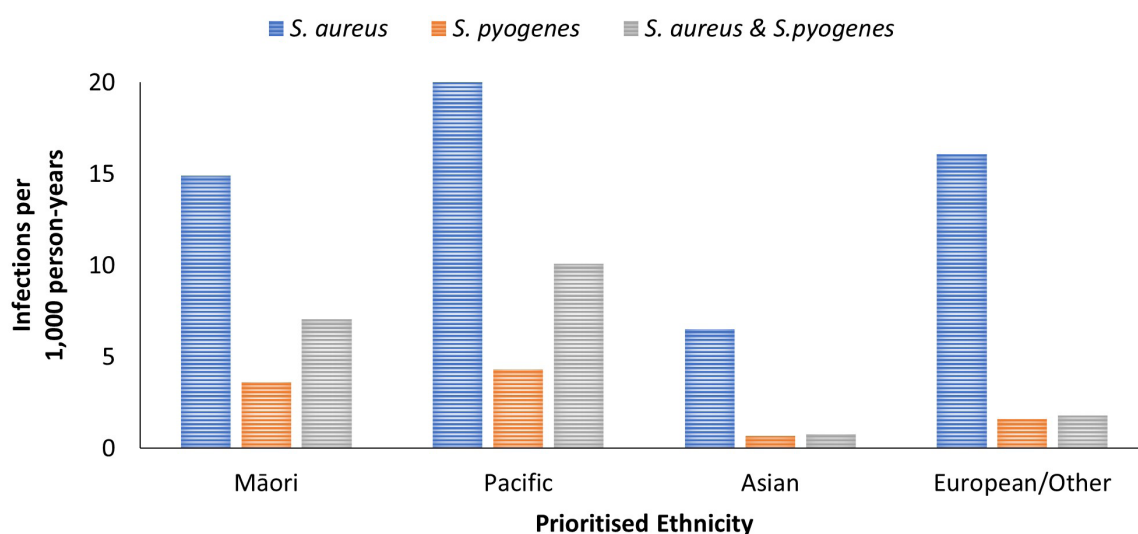
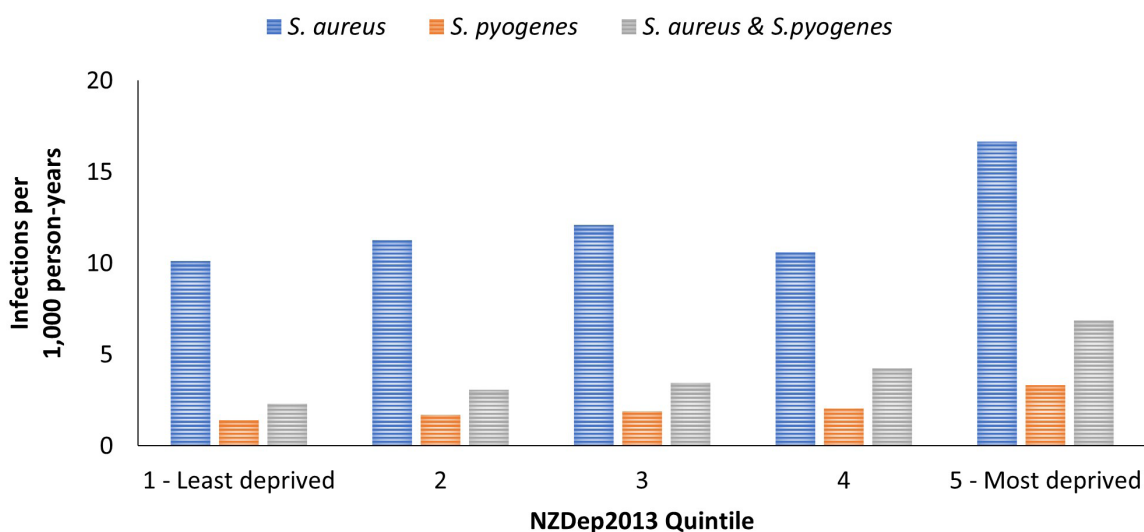


Figure 4: Adjusted incidence rate per 1,000 person-years by socio-economic levels in Auckland, New Zealand, 2010–2020.



Socio-economic deprivation

Skin infections increased with socio-economic deprivation (Figure 4). People in the most deprived areas (Quintile 5) had 54.8 primary care microbiological examinations per 1,000 person-years (Appendix Table 1). *S. aureus* had a similar incidence across all socio-economic deprivation levels (Table 2, Figure 4). However, 54.5% of infections involving *S. pyogenes* occurred among individuals living in the most deprived areas (Table 1). For *S. pyogenes* alone, higher rates were seen for individuals in the most deprived areas (RR 2.4, 95% CI 2.2–2.5, compared with the least socio-economically deprived areas). Higher rates were also seen for *S. pyogenes* and *S. aureus* co-infections for the most socio-economically deprived areas (RR 3.0, 95% CI 2.8–3.1) (Table 2, Figure 4).

Gender, geographical area and season

No significant gender differences were seen in primary care testing for skin infections (Appendix Table 1). Infection rates across these regions were comparable (Table 2). Seasonal variation was observed, with a rise in skin infections during summer and autumn, resulting in 26,338 more cases than in winter and spring (Table 1). There was a slightly higher rate of *S. aureus*-exclusive infections in these warmer and dry months, with a 1.1-fold (95% CI 1.1–1.1) increase, and a 1.5-fold (95% CI 1.5–1.5) increase in the rate of *S. pyogenes*-related infections, compared with the cooler and wet seasons (Table 2).

Role of *S. aureus* on risk for *S. pyogenes*

Over half (51.4%) of co-infections with *S. aureus* and *S. pyogenes* were seen within Pacific populations (Table 1).

A follow-up analysis examined the risk for subsequently testing positive (within 3 months) for *S. pyogenes* based on initial test results. Individuals initially testing positive for *S. aureus* were more than twice (2.1, 95% CI 1.9–2.3) as likely to subsequently test positive for *S. pyogenes* during a skin infection, compared with cases where the individual initially tested negative for *S. aureus* or was positive for a different skin pathogen (Appendix Table 2).

Discussion

Utilising data from 2010 to 2020 for Auckland, our study shows an average annual rate of 38.6 visits per 1,000 population using primary healthcare

services for skin swab culture tests for suspected skin infections. This exceeds international figures; for example, Finland reported an average of 10.8 primary care visits for skin infections per 1,000 population between 2015 and 2019.¹⁸ The true burden is probably greater than what our study shows, since not everyone seeks primary care or receives skin swabbing during their visits. For example, our estimate of 46.2 visits per 1,000 children under 15 years is significantly lower than the rate found in a 2008 small-area study in Tairāwhiti, which reported 106.7 cases per 1,000 children.¹⁹ This indicates that in some areas the burden of skin infections could be much higher.

Infections caused by *S. aureus* were reported at a rate of 14.2 per 1,000 person-years and *S. pyogenes* at 4.5 per 1,000 person-years, the latter aligning closely with previous annual estimate of 4.0 cases per 1,000 population for *S. pyogenes* in New Zealand.¹⁰ The estimates remained consistent even when individuals with distinct NHI numbers were accounted for only once each year. Consistent with similar studies in the Auckland population, skin infections solely due to *S. aureus* are prevalent across all ages and ethnicities, regardless of socio-economic deprivation levels.⁵ Our study identifies *S. aureus* as a risk factor for *S. pyogenes*, with individuals testing culture-positive for *S. aureus* having a 2.1-fold increased risk of subsequently testing positive for *S. pyogenes* upon being re-swabbed at some point during a 3-month follow-up period.

S. pyogenes involvement in skin infections, either in isolation or as a co-infection with *S. aureus*, predominantly affects young children, Māori and Pacific communities and individuals in the most socio-economically deprived areas. Approximately 42.4% of all *S. pyogenes*-related infections were identified in children under 10 years of age, at a rate of 10.7 infections per 1,000 child-years—three times higher than the rate in individuals aged 10 years and older. Studies in Australian Aboriginal and Torres Strait Islander descent children also report a higher risk of skin infections from birth, gradually declining with age.^{20–22} Māori and Pacific peoples in New Zealand are disproportionately affected by *S. pyogenes*, with a 4.7-fold increased risk compared with the NZ European/Other population. Additionally, Pacific peoples represent over half (51.4%) of all *S. aureus* and *S. pyogenes* co-infections, mirroring observations among Indigenous Australian children in remote areas of the Northern Territory.⁹

The prevalence of *S. pyogenes* in these demographics is particularly concerning in Australasian countries due to the associated risks for ARF.^{11,23} Persistent exposure to *S. pyogenes* through common infections or colonisation in early childhood can potentially increase the risk of immune system dysregulation and potential development of ARF/RHD later in life.^{24–26} Additional skin conditions, such as scabies and eczema, may also serve as risk factors for skin infections within at-risk communities by facilitating bacterial colonisation and onset of secondary infections. Research demonstrates that *S. pyogenes* skin infections are twice as prevalent in Aboriginal and Pacific children afflicted with scabies compared with their counterparts without scabies,^{9,27,28} and New Zealand children affected by *S. pyogenes* skin infections are four times more likely to receive an eczema diagnosis compared to children who did not have *S. pyogenes* infection.²⁹

While the study benefits from its well-defined population base, standardised microbiological protocols and analysis by socio-demographic factors, there are limitations, such as the reliance on skin swab data reflecting primarily purulent, weeping or leaking infections, the absence of clinical data and the inability to include individuals who did not seek medical attention. The true disease burden likely surpasses the reported figures, particularly among the most vulnerable populations who are less likely to access healthcare. Additionally, the study is limited to testing, and did not ascertain whether infections were treated and, if so, the nature and impact of such treatments.

This paper highlights the steady rising trend in primary care visits for skin infections, which may be due to an increased underlying risk of infection or more people seeking healthcare services for these conditions due to awareness or changes in

access (including funding for children's visits to general practitioners). A decline in skin swab cases was noted in 2020, coinciding with the onset of the COVID-19 pandemic. We hypothesise that the pandemic may have played a role in this reduction as individuals were in isolation, potentially impacting the frequency of in-person visits to healthcare facilities. This paper ultimately stresses the persistent issue of skin infections in New Zealand, with important implications for both clinical practice and public health policies.

The findings accentuate that health disparities are prevalent among Māori and Pacific peoples, with the root causes of these disparities remaining insufficiently understood. The disproportionate prevalence of *S. pyogenes* skin infections in Māori and Pacific people suggests that primary care practitioners should prioritise thorough assessment and treatment of skin infections within these populations. Additionally, there is an urgent necessity for more comprehensive, effective and culturally informed public health initiatives designed to address these inequities and improve health outcomes for these communities. These initiatives should address social determinants of health, such as improving access to healthcare and healthy homes, which are strongly patterned by ethnicity.²⁹ Additionally, the establishment of clinical guidelines is essential for the effective management of these infections. Establishing a primary care surveillance network to monitor skin infections and transmission of *S. pyogenes* in high-risk communities could yield valuable insights into disease mechanisms and understanding risk disparities. Such a network would be instrumental in generating critical data to better understand susceptibility to *S. pyogenes* and related conditions, such as ARF, ultimately informing strategies to effectively lessen the observed disparities.

COMPETING INTERESTS

Nil.

The research was funded by the University of Otago Doctoral Scholarship. This research did not receive any specific grant from funding agencies in the public, commercial or not-for-profit sectors.

Krishtika Mala is a participant in the University of Otago Ethics Committee.

ACKNOWLEDGEMENTS

We are grateful to Awanui Labs, Auckland (formally known as Labtests). In particular, we thank Susan Smith for her help in providing skin swab microbiology data and guidance. We also thank Dr Lucy Telfar Barnard for her valuable guidance on data analysis.

DATA SHARING STATEMENT

Deidentified participant data are available upon reasonable request.

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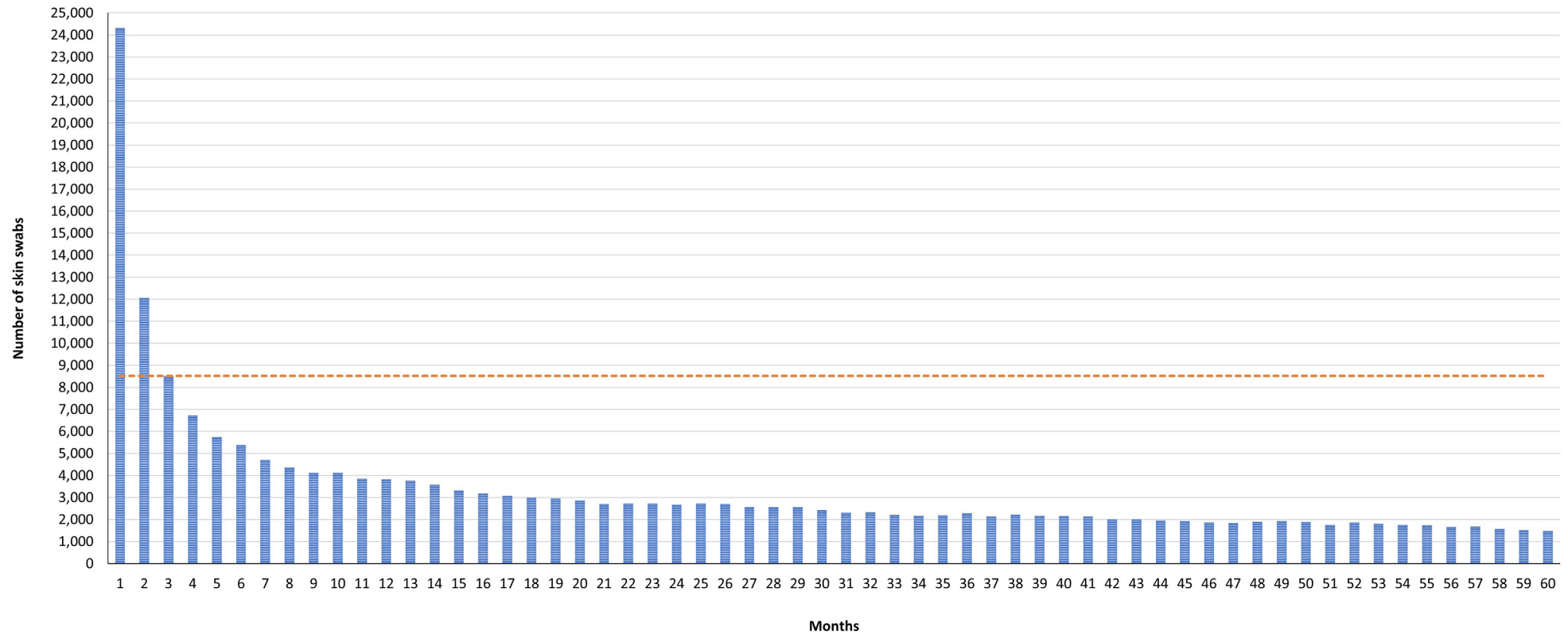
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Appendix

Appendix Figure 1: The distribution of follow-up swabs taken over the 5 years following the collection of the initial swab from 360,861 Auckland residents in New Zealand between 2010 and 2020. The orange line represents approximately 22.6% of the swabs that were collected within 3 months of the initial swab.



Appendix Table 1: 2013 Census population size, and the average annual frequency of primary care visits for testing per 1,000 person-years, Auckland, New Zealand, 2010–2020.

Characteristic	2013 Census population	Frequency of visits to primary care for microbiology testing		
	N	Frequency	Col %	Rate
Age group				
00–04	103,578	69,705	11.5%	61.2
05–09	98,859	46,242	7.6%	42.5
10–14	97,668	36,650	6.0%	34.1
15–19	103,929	35,058	5.8%	30.7
20–24	108,933	31,631	5.2%	26.4
25–29	100,641	29,626	4.9%	26.8
30+	817,581	359,004	59.1%	39.9
Total	1,431,189	607,916	100.0%	38.6
Prioritised ethnicity				
Māori	145,749	75,073	12.4%	46.8
Pacific	171,528	122,860	20.3%	65.1
Asian	298,563	62,086	10.2%	18.9
European/Other	730,281	346,117	57.1%	43.1
Socio-economic deprivation				
1 (least deprived)	320,358	121,015	19.9%	34.3
2	313,101	121,558	20.0%	35.3
3	264,936	106,321	17.5%	36.5
4	233,940	82,440	13.6%	32.0
5 (most deprived)	292,623	176,534	29.0%	54.8
Gender				
Male	695,385	292,036	48.0%	38.2
Female	735,804	315,879	52.0%	39.0
Area				
Waitematā	525,603	221,241	36.4%	38.3
Auckland	436,365	173,423	28.5%	36.1
Counties Manukau	469,221	213,252	35.1%	41.3

Appendix Table 1 (continued): 2013 Census population size, and the average annual frequency of primary care visits for testing per 1,000 person-years, Auckland, New Zealand, 2010–2020.

Season				
Summer	1,431,189	153,303	25.2%	9.9
Autumn	1,431,189	164,601	27.1%	10.6
Winter	1,431,189	146,368	24.1%	9.5
Spring	1,431,189	143,644	23.6%	9.3

Col % = column percentage.

Appendix Table 2: Risk for *S. pyogenes* following *S. aureus* infection in Auckland, New Zealand, 2010–2020.

Initial swabs	Subsequent swabs		
	<i>S. pyogenes</i> positive	<i>S. pyogenes</i> negative	Total
<i>S. aureus</i> positive	1,534	33,191	34,725
<i>S. aureus</i> negative	464	21,176	21,640

S. aureus = *Staphylococcus aureus*; *S. pyogenes* = *Streptococcal pyogenes*.

Appendix Table 2 shows that out of 34,725 individuals who initially tested positive for *S. aureus*, 1,534 tested positive for *S. pyogenes* upon re-swabbing within 3 months for a single skin infection event, while the remaining 33,191 tested negative for *S. pyogenes*. Among the 21,640 individuals who initially tested negative for

S. aureus (either positive for other non-*S. aureus* or non-*S. pyogenes* skin pathogens or no significant pathogen detected), 464 later tested positive for *S. pyogenes* upon re-swabbing within 3 months of the initial swab during a single skin infection event, and 21,176 tested negative for *S. pyogenes*.

Emotional after-effects of the New Zealand Whakaari eruption on burns and theatre healthcare workers

Lillian Ng, Kiralee Schache, Marie Young, Joanna Sinclair

ABSTRACT

AIM: The objective of this study was to examine the emotional experiences of healthcare workers after caring for injured patients following New Zealand's Whakaari/White Island volcanic eruption in 2019.

METHOD: This qualitative research used interpretive description methodology and was conducted at a public health service, Te Whatu Ora Counties Manukau, based in Auckland, New Zealand. Data were collected from two audio-recorded focus group interviews, which were transcribed and analysed using reflexive thematic analysis.

RESULTS: There were six participants from clinical, allied and technical disciplines from anaesthesia, plastic surgery and specialist burns services. Three salient themes were identified: 1) reckoning with aftermath, 2) collective emotional after-effects, and 3) cumulative harm amidst system constraints.

CONCLUSION: Healthcare organisations can anticipate deep psychological effects on healthcare workers after a mass casualty event. Opportunities for emotional processing may counter the stoicism of medical culture, particularly for those who sustain cumulative harm by recurrent exposure to trauma. More research is required to ascertain how to better meet the challenges of addressing healthcare workers' wellbeing after large-scale disasters.

On 9 December 2019 at 2:11 pm, New Zealand experienced an unheralded eruption from the Whakaari (also known as White Island) volcano situated near the North Island's Eastern Bay of Plenty coast. At the time, there were 47 people on the island, including tourists from a cruise ship. Within minutes, the eruption was recognised as a mass casualty incident. Thirty-nine people were evacuated to local healthcare facilities, with 31 injured.¹ Two hours after the eruption, the first evacuees arrived at the closest community hospital in Whakatāne.² Stabilised patients were then transferred to regional hospitals and specialist centres in New Zealand and Australia. In the first 60 hours following the incident, patients with evolving, severe and complex injuries were treated at a specialty burns unit at Middlemore Hospital, based in Auckland, New Zealand. The high volume of burns requiring surgical treatment consumed significant human resources and operating time, with most surgery occurring within the first month.³

International evidence shows varied effects on healthcare workers' emotional wellbeing after caring for survivors of mass casualty incidents.⁴⁻¹⁰ After large-scale disasters, healthcare workers have reported emotional distress, post-traumatic

stress or psychiatric symptoms.⁴⁻⁵ The persisting recollections of these incidents produce emotionally evocative detail.⁶ Vivid images anchor memories and generate strong responses, even years later.⁷⁻¹⁰ Extreme events, such as 9/11, have a unique context where deep experiences are understood by frontline staff who were present.⁸⁻¹³ The immersion in high-intensity work associated with disaster may contribute to the constellation of exhaustion, cynicism and ineffectiveness known as burnout.¹⁴ However, some healthcare workers experience personal and professional growth and strengthened emotional coping.^{11,12,15} Challenging emotional experiences associated with a disaster can open new opportunities, strengthen personal qualities, relationships and appreciation for life, and create spiritual change.¹¹

Revealing emotions can be valuable when there is a common professional context coupled with the unique shared experience of the same extreme event.⁸ Healthcare teams are an important source of psychological support after a disaster.¹⁶ Team members have innate knowledge about each other and anticipate team needs through a common understanding of the environment and expectations of performance.¹⁷ In the context of a disaster, healthcare professionals may express

a need to process difficult material. However, some do not attend formal opportunities to process events and may not discuss experiences of secondary trauma.⁹

Healthcare workers are vulnerable to cumulative long-term psychological problems⁹ when stress arising from a disaster is compounded by everyday life stressors.¹⁵ After the 2019–2020 Australian “Black Summer” bushfires, the SARS-CoV-2 pandemic exacerbated psychological distress.¹⁸ Healthcare workers face potentially morally injurious experiences when they are exposed to human suffering and engage in emotionally demanding care for others. They may reflect on the stress of such a high-stakes incident and attempt to reconcile the gap between what happened and what should have happened. Moral injury can occur when healthcare workers perceive their ability to deliver care is compromised by pressures in the healthcare system.¹⁹ This may lead to further emotional harm and subtle erosions in team cohesion. An uneven pattern of organisational and professional support can result in unmet needs and neglect of healthcare workers’ mental health.¹⁰ Effective workplace interventions to support healthcare workers’ resilience and recovery after crises focus on building staff connections for mutual support.^{18,20,21}

There has been an acknowledgement of the psychological difficulties experienced by healthcare workers who cared for patients involved in the Whakaari eruption,^{1–3} yet health professionals’ experiences of this event have not been researched. Therefore, in this study, we aimed to explore the emotional experiences of a sample of healthcare staff several years on from caring for severely injured patients involved in a disaster of national and international significance. We sought to gain insight into their perspectives on processing emotions, communication within their team and impact over time.

Methods

Ethics approval was gained for the study from The University of Auckland Human Participants Ethics Committee (UAHPEC3503). The researchers are clinicians in psychiatry, psychology and anaesthesia based at a public hospital service. All are involved with initiatives to improve the well-being of healthcare staff. Therefore, we applied a dual lens as clinician–researchers in this study, by using interpretive description methodology.²² This is an approach to qualitative research that has

pragmatic utility in applying findings to a clinical context, specifically in areas of psychology.²³ Interpretive description references deep clinical knowledge. In this study, we engaged with data in a way that acknowledges our clinical disciplines and context in gathering evidence on emotional phenomena with the goal of improving frontline healthcare workers’ wellbeing.

Since 2019, our organisation has run regular interdisciplinary Schwartz Rounds, a forum for health professionals to reflect on psychosocial and emotional aspects of care^{20,21} within a psychologically safe environment.²⁴ The focus groups comprised two purposive samples: healthcare professionals who opted to take part in and pre-prepare reflections for Schwartz Rounds in 2023, and were involved in treating patients in hospital after the Whakaari eruption. The participants had varying healthcare experience, across disciplines and specialties, and levels of the medical hierarchy. Focus groups were conducted to enquire into participants’ emotional experiences, using a semi-structured questionnaire (Table 1). Interviews were conducted with participants in two focus groups to encourage interaction and discussion. Participants were emailed a study information sheet and written consent was obtained prior to data collection.

Interviews were audio-recorded and professionally transcribed. Transcripts were returned to participants to verify their accuracy. De-identified transcripts were entered into a computer-assisted database storage system (NVivo version 14) and comprehensively read for familiarisation. Reflexive thematic analysis was performed as follows:²⁵ de-identified transcripts were co-coded separately by three members of the research team; initial themes were proposed; and final themes were robustly discussed, refined and agreed on. Two steps were employed to enhance rigour and transparency: a psychologist–researcher with expertise in qualitative methodology co-coded transcripts independently to verify and provide an external lens to the analytic process. An audit trail was documented in NVivo, using the memoranda function, containing critical reflections arising from discussions.

Results

Six participants took part in two focus groups from specialties of anaesthesia, surgery, nursing, physiotherapy, plastics and burns services. There were three males and three females, whose work

Table 1: Interview schedule.

<p>We were discussing a traumatic event for yourselves in theatre, the hospital and the country and reflecting on human and emotional aspects of care. Whakaari was unique. What did this bring up for you?</p> <p>How have you processed what happened at Whakaari?</p> <p>What emotions were brought up for you? Are you able to say what these were?</p> <p>What has helped you feel safe to talk about things related to this event and your own emotional care? How have you processed this event or what happened? What has helped you?</p> <p>What has helped you to share part of yourself? For example, role modelling by others?</p> <p>How have you processed the memories and the feelings of that time?</p> <p>What debriefing or counselling have you had to support you?</p> <p>How do you think people/your team are faring now emotionally?</p> <p>What organisational support did you receive and how could you have been better supported? What would you have wanted from the healthcare organisation?</p> <p>What forum might be potentially important or have a role to better help staff? What potential for them to open up?</p> <p>What resources and support would you have required to heal?</p> <p>How do you manage your own psychological self-care?</p> <p>How do you sustain hope working in the system, compassion? What does it mean to be compassionate in healthcare?</p>

experience ranged between 5 and 25 years. Three themes were identified: 1) reckoning with aftermath, 2) collective emotional after-effects, and 3) cumulative harm amidst system constraints. Illustrative data to support these themes are presented in Table 2.

1. Reckoning with immediate aftermath

“No one could comprehend how much work there was, a week’s work in one day, a month’s work in one week.” – Participant 5

This theme involved the recall of vivid memories, their response to the disaster, initial processing (or not) of emotions and sources of support. Participants spoke of unique challenges in the initial weeks following the disaster, despite being used to working under pressure. They clearly recalled the maelstrom of chaos that ensued as multiple patients arrived with severe trauma, the protective clothing worn to protect themselves from toxic ash, the discomfort of theatre conditions, working in 35 to 40 degrees Celsius heat, and the focus and attention required for the work. At the

time of the incident, some participants experienced flashbacks of treating terrible burns; others were affected by hearing or reading personal details about the victims. During the focus group interviews, they recalled helplessness at the futility of their efforts to save some patients due to the evolving and unusual nature of the burns they had sustained.

Participants perceived they worked harder and were more resourceful in doing the job they had been trained to do. They observed the surge in equipment and personnel as expert colleagues from around New Zealand and Australia volunteered their services and temporary contractors were sourced. All participants acknowledged exhaustion and degrees of emotional distress in working at such a high intensity. They dealt with processing emotions in various ways: not actively seeking out support at the time, visiting their family doctor, informal discussions with members of their team and attending debriefing sessions. Most did not attend formal debriefing and supervision opportunities provided by the organisation at the time. Some perceived that others in their team had coped far better than they had.

2. Collective emotional after-effects

“You feel detached and get distracted doing other things. I haven’t processed it properly.” – Participant 6

Collective after-effects reverberated through teams and the wider organisation in the months after, of raw unprocessed emotions, avoidance of displaying or discussing emotions, expression of strong emotions under stress, emergent psychological difficulties and their impact on team communication. All participants acknowledged the national significance of the Whakaari incident and the lingering emotional effects on teams. Participants described various feelings of guilt, pride, unease and anger. There was an awareness that Whakaari evoked ongoing raw emotions for some team members at unexpected times and contexts sparked by media attention and anniversaries, and of the different styles of team members’ coping. Participants noticed the vulnerability of colleagues and those who struggled to articulate their emotions, particularly senior colleagues who did not speak of the incident at all. Participants acknowledged they were most likely to share difficulties with other team members whom they felt most connected to. Those with more seniority felt a sense of responsibility to support their struggling and more junior colleagues, coupled with an imperative to attend to their own emotional needs.

The optimal time to seek help varied between participants. Some reflected on a significant person or conversation that provided impetus to seek counselling. Participants had mixed perspectives on how optimally to jointly process emotions arising from the events of Whakaari. Notably, each of the study participants had elected to speak at Schwartz Rounds that were held 3 years after the Whakaari eruption and purposefully shared their pre-prepared reflections with colleagues who were present. The main insight from the participants who had been less inclined initially to attend due to difficult emotions brought up by the Whakaari incident was the later realisation that they had not processed events, had avoided or compartmentalised emotions or had experienced unexpected distress when later working under stressful clinical situations. This was particularly evident for junior members of staff, who were more ambivalent in revealing difficult emotions as they feared this would be perceived as a weakness.

3. Cumulative harm amidst system constraints

“COVID-19 came straight afterwards ... it feels like [Whakaari] has been forgotten, passed on, and no one’s had a chance to reflect.” – Participant 2

Participants reported emotional difficulty and fatigue, compounded by high workloads without extra resources and unresolved concerns, even several years later. The cumulative harm sustained by healthcare workers over a longer timeframe was exemplified by participants’ descriptions of chronic exhaustion and feelings of desensitisation to death and injury. On 23 March 2020, the last Whakaari burns patient was discharged from the hospital. Ordinarily the teams would celebrate this achievement, but there was no respite due to the advent of another unprecedented event, the SARS-CoV-2 pandemic. Some participants expressed that working in healthcare was harmful to their own mental health and that they were placed in harm’s way by helping others. Unresolved concerns were poor remuneration and lack of financial compensation for staff working in burns services exposed to additional physical and psychological hazards.

Participants stated that much more was needed from the organisation to prioritise the emotional care of staff. They were particularly critical of token gestures to support wellbeing and concerned that insights and learning from the healthcare response to Whakaari had been lost. They attributed this to staff attrition, burnout and a 24/7 healthcare system under immense stress. The participants wanted organisational acknowledgement of detrimental and cumulative emotional effects associated with trauma. They also requested specific time during working hours to attend individual counselling and team supervision. It was salient that all participants sought to derive meaning from experiences like Whakaari. The notion of hope was important in sustaining self-compassion and system morale.

Discussion

The context of this research is unique in exploring emotional dimensions of a significant disaster in a sample of New Zealand burns and theatre healthcare workers. The findings highlight powerful emotions expressed by healthcare professionals in response to a mass casualty incident

Table 2: Data supporting themes.

Theme 1* Reckoning with aftermath	Theme 2 Collective emotional after-effects	Theme 3 Cumulative harm amidst system constraints
<p>“A maelstrom of chaos ... a blur ... patients everywhere.” – 1</p> <p>“The most toxic composition of ash, we’d seen hydrochloric acid burns, just not in this context, we’d seen ballistic injury but not in this context, we’d seen bad full thickness burns but not progressing in the same way.” – 2</p> <p>“The memories are still so fresh, still there ... the boy in theatre 7 ... knowing there are children involved, the parents lost one child, maybe they have the other. They said, the parents are dead, so there’s one boy by himself and he’ll be with burns the rest of his life, then he passed away too.” – 3</p> <p>“Pure helplessness ... you’re killing yourself [working to save them], how can they still die?” – 4</p> <p>“No one could comprehend how much work there was, a week’s work in one day, a month’s work in one week.” – 5</p> <p>“Listening to you guys talk brings up lots of emotions.” – 6</p>	<p>“It brings up feelings from the time, I reflect on things I wish I’d done differently. It’s always hard ... when it’s something that traumatic you don’t necessarily think about what other people are going through, I didn’t think about all my colleagues then, it was just really heavy for me.” – 1</p> <p>“I’m not all that good at that [emotional, psychological care] any more than any other [professional] Kiwi male.” – 2</p> <p>“There’s not a lot of time or opportunity to [talk about] mixed emotions and I’m not sure how best that’s done.” – 3</p> <p>“I was ready to explode ... at the time I was under the impression I was weak and no one around me is reacting like this ... you’re very critical of yourself.” – 4</p> <p>“We are as busy now as we were then and what extra support, if I said we had none, what have we learnt?” – 5</p> <p>“You feel detached and get distracted doing other things. I haven’t processed it properly. I was one of those transient people. You compartmentalise it, you leave it, then focus on your new job.” – 6</p>	<p>“They’ll start crying in front of me because they haven’t dealt with it, I snapped at one of the [staff], I was too busy to say ‘let’s go have a talk, can you just do this, it’s your job.’ That wasn’t helpful and then that person left. I always feel guilty about it.” – 1</p> <p>“COVID-19 came straight afterwards ... it feels like [Whakaari] has been forgotten, passed on and no one’s had a chance to reflect. I feel very upset because [the surgical team] have not had a chance to sit down with everyone involved ... pick it apart and have their say. The people involved have burnt out and left ... their good insights are gone.” – 2</p> <p>“You are going above and beyond, you see, hear and smell things that are uncommon for most operating theatres. [Emotions come up], a different context, different trigger, a lot of us go through it that way.” – 3</p> <p>“Very little hope there at the moment. You’re putting yourself in harm’s way to help people or patients out. Addressing the issue rather than covering it up ... if I kept on trying to bury it then God knows when I would have come up.” – 4</p> <p>“Some stay, some come and go, that’s the hardest part ... when the team changes, we just drop them ... we don’t do a good job of looking after them and making sure they’re okay.” – 5</p> <p>“Emotional trauma ... we get desensitised to things we see every day in hospital and we’re not good at supporting people when they need it.” – 6</p>

*Participant number after dash.

in treating patients with severe injuries that progressed in unexpected ways and challenging work conditions. Focus group members were familiar with each other as they had formed part of the team at the time. Their established relationships, combined with a potential power differential within the small group, may have influenced group dynamics and the findings. The range of effects and needs articulated by the participants demonstrate the complexity of providing emotional care, from an organisational perspective, after a disaster.

The responses to the events of the Whakaari eruption reported by participants are similar to health professionals' reactions to other major catastrophes.⁵⁻⁹ Participants endorsed an organisation-led coping environment that supports processing of the initial horror and helplessness as well as longer-term work to strengthen team emotional capabilities.¹⁶ Individual participants found ways to process difficult content, but there was perceived cumulative and collective harm in continuing to work under pressure in an under-resourced healthcare system. Bearing witness to healthcare workers' suffering, acknowledging their contributions and resolving to provide sustained care for wellbeing is central to building resilient organisations.^{19,20} The advent of the SARS-CoV-2 pandemic compounded participants' psychological distress and exhaustion, potentially contributing to burnout and moral injury.²⁶ Internationally, healthcare workers' resilience has been tested by the pandemic. This underlines the importance of compassionate leadership to support specific workplace interventions that acknowledge deep, collective experience after a crisis.¹⁸

This study has implications for healthcare organisations, as long-term impacts following major incidents can be anticipated. Power imbalances in the medical hierarchy and stigma may hinder help-seeking.¹⁶ Therefore, creating a culture that reduces stigma, shame and fear requires connection and role modelling in how to articulate emotional difficulty and vulnerability.^{18,27} We suggest that the commitment of healthcare organisations to assess the needs of healthcare professionals and support their recovery must extend to provide protected work time for them to attend to the emotional processing of large-scale events. This may help to mitigate the organisational challenges of reluctance to seek support or suboptimal staff attendance when

support sessions are provided. Skilled healthcare workers need to believe and trust that their leaders care and support their efforts.^{19,20} Expert guidance may be required to re-establish trust, connection and facilitate relationship repair when there have been ruptures between teams or management. There is also a role for compensation for healthcare workers who are vulnerable to harm by helping others, work under extreme conditions and sacrifice personal energy to support the organisation. These recommendations are not easily enacted at a time of international workforce shortages, resource constraints and burnout. Yet such strategic organisational investment, at individual, team and institutional levels, is vital and necessary to protect the long-term wellbeing of healthcare workers.

The rapport in focus groups, which provided rich, detailed data collection from focus group members with shared experiences, is a strength of this study. The universal nature of the themes may resonate in other contexts. However, there are methodological limitations to report. The small number of participants and the unique features of the incident may limit transferability of findings. There were no Māori or Pacific participants, which is a further limitation. The participants may not represent healthcare workers more generally in being able to express more vulnerable aspects of their emotions by contributing to the Schwartz Rounds and the research process. Inclusion of collaborative focus groups from other regional units would enhance the robustness of findings from a national perspective.

Conclusion

Healthcare workers endure immediate and collective emotional after-effects associated with mass casualty events, and cumulative harm amidst system constraints even years later. This research poses deeper questions about potential ways to address healthcare professionals' wellbeing after a major disaster. There are elements of stoicism and reserve that could be explored further.²⁸ Future studies may identify optimal settings to support healthcare professionals to articulate emotional difficulty and the impact of stigma and shame on help-seeking at an individual and organisational level. We recommend further research to ascertain the effect of large-scale disasters to healthcare workers' mental health, burnout and ameliorating factors.

COMPETING INTERESTS

There are no conflicts of interest to declare.
The researchers received funding from a Counties Manukau Health Tupu Award (Number 1326).

ACKNOWLEDGEMENTS

The authors gratefully acknowledge the participants involved in the research. Thank you Lyn Lavery for assistance with data analysis, and to the anonymous peer reviewers for their incisive comments that contributed to refining this manuscript.

The authors report direct access to the study data. Access to transcripts of interviews with participants is ongoing and stored in accordance with The University of Auckland Human Participants Ethics Committee guidelines. Data (deidentified transcripts and protocol) are available upon reasonable request. They are available from the first author (ORCID number 0000-0002-7189-1272).

Ethics approval was gained for the study from The University of Auckland Human Participants Ethics Committee (Reference number UAHPEC3503).

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Outdoor gym equipment in parks in Aotearoa New Zealand: preliminary surveys of availability and usage

Nick Wilson, George Thomson

ABSTRACT

AIM: There is growing international evidence that outdoor gym equipment in parks can provide health and fitness benefits to the population. As little is known concerning the availability and usage of such equipment in the Aotearoa New Zealand setting, we aimed to study this topic further.

METHODS: An internet survey identified outdoor gym equipment in parks in the 10 most populated territorial authorities (TAs). A field survey of 22 selected parks examined the actual equipment. Observational data were obtained on equipment usage in one large urban park over 3 summer months.

RESULTS: The internet survey identified 122 parks with outdoor gym equipment in the 10 TAs. The prevalence ranged from zero (in three TAs) up to 5.6 parks per 100,000 population in Christchurch City (i.e., one such park per 18,000 people). The field survey of 22 parks indicated that all the equipment worked as intended and none was vandalised. Observations from one large urban park indicated that the eight pieces of equipment averaged 16 uses per hour overall. This was extrapolated to estimate around 18,000 episodes of use over the 3 summer months for this park. Usage of the different items of gym equipment varied sixfold ($p < 0.0001$).

CONCLUSIONS: There is a need for further research on the relationship between outdoor gym equipment provision and population health and fitness in the New Zealand context. Nevertheless, this study provides preliminary data that such equipment can be extensively used by the public in some settings.

Low levels of physical activity are an important risk factor for health loss in Aotearoa New Zealand; for example, it is one of the top 10 risk factors for cardiovascular disease.¹ In particular, resistance training, where muscles contract against an external resistance, contributes to health of adults, according to an analysis of 11 systematic reviews.² Resistance training may be facilitated by access to outdoor gym equipment in parks in towns and cities. Such equipment is free to use, and the outdoor environment can be more convenient and pleasant than an indoor gym. Also, in contrast to an indoor gym, there is a likely lower risk of respiratory infectious disease transmission such as with COVID-19.

The international literature includes a 2018 systematic review of nine studies, which focussed on the outdoor gym user experience.³ It concluded “*that health was a central theme of users’ experiences*”, but also that outdoor gyms “*are also spaces where community-dwellers can find social connectedness while participating in structured physical activity at no cost.*” A subsequent 2019 systematic review of 18 studies found “*some support that outdoor*

gyms may improve physical activity, fitness and other health-related outcomes.”⁴ More specifically, “*installations of outdoor gyms were associated with an overall increased level of moderate-to-vigorous physical activity*” in four intervention studies, but not in two other studies. The two randomised controlled trials (RCTs) included in this review had some mixed results, but both also showed some benefits. One of the RCTs reported significant improvement on single-leg stance, knee strength, 2-minute walk and timed sit-to-stand.⁵ The authors of this RCT concluded that “*the exercise park program improved physical function and had high adherence and participation rate.*” The other RCT reported significant improvements “*in 3/7 fitness tests (i.e., 2-min step, push-up and 6-min walk test),*” and “*in 3/5 diabetes related outcomes (i.e., insulin, HOMA-IR, chemerin).*”⁶

A subsequent 2020 systematic review and meta-analysis considered just older adults and outdoor gyms and included nine studies. The meta-analysis results were not statistically significant, but it reported that “*older adults value the benefits of health and social interaction from the use of exercise parks.*”⁷

Since these three systematic reviews described above, a cluster RCT in Australia has reported on body muscular fitness improvements for people given a smartphone application with standardised workouts tailored to 12 outdoor gym locations.⁸ In particular, it found statistically significant improvements in upper and lower body muscular fitness at 9 months. Also, *“increases in self-reported resistance training, resistance training self-efficacy, and implementation intention for resistance training were statistically significant at 3 and 9 months.”*

Another recent RCT reported that the supervised training group using outdoor gym equipment over 8 weeks showed a range of benefits relative to the control group.⁹ These included statistically significant increases in lean mass index, maximal isometric voluntary contraction in both legs and arms, physical functioning and the role physical dimension of the 36-Item Short Form Health Survey questionnaire. In addition, this training group showed significantly greater decreases in fat mass, fat mass index and the Timed Up and Go Test.

In terms of cost effectiveness, the international literature is more limited. Nevertheless, a United States of America study found that park use increased more in parks with outdoor fitness equipment (“fitness zones” [FZ]) installed than in 10 control parks that did not get equipment (although the difference was not statistically significant).¹⁰ Also, *“self-reports of being a new park user increased more in FZ parks, and estimated energy expenditure in FZ parks was higher at both follow-ups than at baseline”*. The authors concluded that *“installing Fitness Zones appears to be cost-effective ([US\$] 10.5 cents/MET increase) and most successful in parks in densely populated areas with limited facilities.”*

In New Zealand, outdoor gym equipment in parks appears to be becoming more common in some cities, as suggested by the list of Auckland parks with such equipment.¹¹ However, the availability of such equipment around the country has not been estimated in any studies. The use of the equipment is also unknown. We therefore aimed to explore these issues further to specifically determine: i) the extent to which the most populated New Zealand territorial authorities (TAs) had parks with outdoor gym equipment; ii) key characteristics of this equipment; and iii) the usage of this equipment in one large urban park.

Methods

Internet survey of outdoor gym equipment by TA

Internet searches were conducted to identify outdoor gym equipment in the parks of the country’s 10 largest TAs by population size (as listed in Table 1). These TAs collectively contained 61.9% of the total population of the country (of 5,223,100¹²). Because this was a preliminary and unfunded study, to enable an analysis with the most population relevance the focus was on the largest 10 TAs. We included in the survey any fixed outdoor gym equipment items. Excluded were children’s play equipment (e.g., with climbing bars), basketball courts and parkour facilities (due to the latter being highly specialised).

Searches were conducted in February 2024 (with a repeat check in July 2024) using the following sites:

- The website of each TA was searched using each of the following search terms: “outdoor gym”; “fitness”; “calisthenics” (e.g., we searched the Auckland City website that specifically detailed parks with “outdoor fitness equipment”).¹¹
- “Outdoor fitness”: <https://freeoutdoorfitness.net/>
- “Calisthenics parks”: <https://calisthenics-parks.com/countries/nz-en-new-zealand>
- “Street workout”: <https://streetworkoutlist.com/countries/New-Zealand>

Field survey of parks with outdoor gym equipment

To collect additional data on the characteristics of the equipment and parks, a field survey used a convenience sample of 22 parks in four different TAs (Auckland, Hamilton City, Hastings District and Wellington City). These were visited in February/March 2024, mainly by the first author (but sometimes by both authors). Data collection covered the number of different items of gym equipment (including if these were part of a single structure with exercise components that multiple people could use simultaneously), if it was working as intended when used by a researcher, if it was vandalised or not and if it had any evidence of graffiti or not (including both the equipment and the path/signage in the park on the route taken to the equipment).

For the field survey of parks, we also examined their presence on Google Maps for any

wording descriptions of the outdoor gym equipment being shown in this digital form (e.g., the words “calisthenics park”). Also on Google Maps, the Google Street View function was used to determine if the gym equipment was visible from the street.

Observational study of equipment usage

The usage of the outdoor gym equipment in a single large urban park with eight gym equipment items was systematically observed. The selection was a convenience sample as it was near the first author’s residence: Karori Park in Wellington. This is a large destination park with car parking and sports fields and is situated in one of the largest suburbs of the capital city.

Observations were performed to cover all 7 days of the week for 1-week periods in December 2023, January 2024 and February 2024 (i.e., months comprising the summer season). Observation was from the centre of the large park and so was completely non-obtrusive. The observation period started at randomly selected hourly start times between 8 am and 8 pm (on the hour), for three times per day, 30 minutes per time. The aim was for 63 observation periods (of 30 minutes each) over the 3 summer months, totalling 32 hours.

An episode of equipment use was simply defined as the use of a specific piece of gym equipment by any one person for a single session, potentially including rests (e.g., resting beside the equipment between doing chin-ups but not moving away). If a person used one piece of equipment and then another, then that was counted as two episodes of use. Similarly, if they went away (e.g., walked a circuit around the park’s walking track) and re-used the same equipment as previously, then that repeat use was counted as a separate episode of use. Where two people used the same piece of equipment simultaneously (e.g., two people on the same chin-up bar), then that was counted as two episodes of use. However, we did not count adults who assisted children in the use of the equipment e.g., lifting children up to the chin-up bars.

Statistical analysis of the data included the calculation of basic statistics (e.g., means) and calculation of statistical differences in usage levels between the equipment items using the two by two table function in the software package OpenEpi, version 3.01.

Results

Internet survey of outdoor gym equipment by TA

The survey of these 10 TAs identified 122 parks with outdoor gym equipment (Table 1). This was equivalent to a prevalence of 3.8 such parks per 100,000 population for all 10 TAs (or, alternatively, 26,500 people per park). But the variation in prevalence was large and ranged from 0.0 (three TAs) up to 5.6 parks per 100,000 population (Christchurch City). This is equivalent to one such park per 18,000 people in Christchurch. Only two of the TAs had details of parks with outdoor gym equipment on their official websites (Table 1).

Field survey of parks with outdoor gym equipment

Site visits to 22 parks (18.0% of the total) indicated a mean of 4.0 separate gym equipment structures per park (Table 2). Equipment structures that had multiple gym items allowing for use by multiple people were also common, with a mean of 1.4 such structures per park. None of the equipment showed any evidence of vandalism and all the equipment with movable parts was working as designed. The site visits did not identify any equipment that was not detailed on at least one of the internet sources.

Besides the website listings, the presence of gym equipment could also be sometimes seen through particular digital tools. That is, 27% of the parks had the equipment described on Google Maps (e.g., “calisthenics park”) and for 55% of parks the equipment was visible on Google Street View.

Observational study of equipment usage

There were 506 episodes of gym equipment use in the 31.6 hours of observation (Table 3). The average use of any of the eight pieces was 16.0 episodes per hour. There was a highly statistically significant sixfold variation in usage of equipment items, ranging from the “step-ups” at 0.6 mean episodes of use per hour, up to the “vertical bench press” at 3.6 (Table 3).

The observational data (which were collected at three random 30-minute periods in the day during each day of the week, for a week of each of the 3 summer months) were then directly extrapolated to every day of the whole of the summer period (hours from 8 am to 8:30 pm, December to January). This extrapolation suggested a total of 17,965

Table 1: Availability of outdoor gym equipment in parks in the 10 most populated territorial authorities (TAs) in New Zealand (ordered by prevalence of such parks per 100,000 population).

TAs surveyed	Population (2023 estimate)*	Parks with any outdoor gym equipment (N)	Prevalence of parks with any outdoor gym equipment per 100,000 population	Source for equipment data** and comments (with some parks identified via multiple sources)
Christchurch City	396,200	22	5.6	Sources: TA website ¹³ (n=16); OF (n=18); CP (n=4); SW (n=1)
Auckland (supercity)	1,739,300	84	4.8	Sources: TA website ¹¹ (n=82 parks); OF (n=2); site visits (n=13) (supercity area between the Northland Region and Waikato Region)
Hastings District	91,900	3	3.3	Sources: site visits (n=3); OF (n=3)
Dunedin City	134,600	4	3.0	Sources: OF (n=3); CP (n=3); SW (n=1)
Tauranga City	161,800	3	1.9	Sources: OF (n=1); CP (n=1); SW (n=1)
Hamilton City	185,300	3	1.6	Sources: site visits (n=3); OF (n=1); CP (n=2); SW (n=2)
Wellington City	216,200	3	1.4	Sources: site visits (n=3); OF (n=2); CP (n=1); SW (n=1)
Palmerston North City	91,800	0	0.0	Parkour site excluded
Whangarei District	101,900	0	0.0	
Lower Hutt City	114,000	0	0.0	
Total	3,233,000	122	3.8	The 3.8 value is based on the totals.

*Data source:¹²

**Data sources: OF = “outdoor fitness” website; CP = “calisthenics parks” website; SW = “street workout” website (see Methods for details).

episodes of use of outdoor gym equipment in this park in the 3 summer months.

Discussion

Main findings and interpretation

This preliminary study found a highly variable presence of parks with outdoor gym equipment in the 10 most populated TAs in the country: from zero to 5.6 such parks per 100,000 population. Put another way, there were no such parks for all the

114,000 people in Lower Hutt compared to one such park per 18,000 people in Christchurch.

Where parks did have gym equipment, there was typically a range of different items. The field survey showed that for those sites visited, the equipment all worked as intended and was not vandalised. The observational study in one large park also suggested that there is a potential for the equipment to be frequently used, and that some types of equipment were much more popular with users than others.

Table 2: Studied characteristics of the outdoor gym equipment for the parks with site visits (convenience sample of 22 parks in four territorial authorities).

Selected characteristic	Key numbers (%)	Additional data
Separate gym equipment items and combined structures per park: mean number of separate items of outdoor gym equipment (including counting as just one item any connected structures that had multiple distinct pieces of gym equipment as per the next row).	Mean: 4.0, SD: 2.4	Range: 1–9, median: 3.5
Equipment structures with multiple exercise components per park: mean number of separate structures with at least two components that more than one person could use at the same time (e.g., “horse rider” in the same structure as a “twister”).	Mean: 1.4, SD: 1.8	Range: 0–7, median: 1
Equipment not working: number of individual gym equipment structures that had movable components that were not working according to their design (when used by a researcher).	0 (0%)	
Equipment vandalised: number of individual gym equipment structures that had any evidence of damage from vandalism.	0 (0%)	
Graffiti: evidence of any graffiti on the gym equipment or on the path/ signage in the park on the route taken to the equipment.	3 (13.6%)	
Signalling on digital tools: some signalling that the park has outdoor gym equipment on Google Maps, e.g., “calisthenics park”.	6 (27.3%)	
Gym equipment is visible on Google Street View.	12 (54.6%)	

SD = standard deviation.

Table 3: Use of eight items of outdoor gym equipment in a large urban park (systematic observations over 3 summer months at random times of the day between 8 am and 8:30 pm).

Equipment name and description of use	Number of episodes of use	Total minutes of observation*	Episodes of use per 1 hour of observation
Vertical bench press: the user sits on a seat and pushes on the handles, raising and lowering the seat (Station 5).	119	1,973	3.6**
Chin-ups: the user pulls themselves up on the bars (standard chin-ups or underhand chin-ups) (Station 2).	85	1,963	2.6
Twister: the user rotates their torso while standing on a rotating disc (Station 5).	76	1,883	2.4
Skier: the user swings feet from side to side on the movable foot plates (Station 3).	64	1,883	2.0
Cycle strider: the user pulls and pushes with the arms while striding with the legs to turn a crank (Station 4).	58	1,800	1.9

Table 3 (continued): Use of eight items of outdoor gym equipment in a large urban park (systematic observations over 3 summer months at random times of the day between 8 am and 8:30 pm).

Equipment name and description of use	Number of episodes of use	Total minutes of observation*	Episodes of use per 1 hour of observation
Horse rider: the user sits on a seat and pushes with the feet while pulling with the arms to raise and lower the seat (Station 3).	51	1,800	1.7
Stretching station: the user uses the bars and frame as a hold or support to stretch the desired muscle group (Station 4).	32	1,890	1.0
Step-ups: the user steps up onto wooden poles of varying heights while holding on to a central pole (Station 1).	21	1,963	0.6
Total/mean	506	1,894 (mean: 31.6 hours)	16.0 (mean for all equipment)

*The denominator varied slightly for the different items of gym equipment, since before standardising on observations from the centre of the park, in the first 3 days three different vantage points were used instead (from which not all 8 items of equipment could be seen). Times include periods (n=4) when rain prevented or disrupted the observations and for these times observations were discontinued and equipment use was assumed to be zero.

**This highest usage level was six times that of the lowest for (step-ups), a highly statistically significant difference ($p < 0.0001$; mid-p exact).

Study strengths and limitations

A strength of this work is that it is the first study (to our knowledge) of such outdoor gym equipment in New Zealand. It benefitted from at least some TAs having detailed information on their websites, and three other websites also detailed some of the information. Nevertheless, a key limitation of this preliminary work was that it only sampled 10 TAs (albeit the largest ones, covering 62% of the New Zealand population—see Methods). Furthermore, the prevalence data at the TA level are likely to be reasonably variable over time. For example, for the Auckland data we detected, over a 6-month period one park was removed from the TA's website (possibly part of a renovation) and two new ones were added.

Another limitation was that the field survey was a convenience sample and only covered 22 parks in four TAs. Also, the observational data of equipment usage were just from one large urban park over the summer months (albeit this was done systematically using randomly generated observation times).

Possible research and policy implications

The main area for further research is on the

relationship between outdoor gym equipment provision and population health and fitness in the New Zealand context. This would include the use by and effectiveness for population sub-groups. Further research on equipment usage levels and costs (installation and maintenance) could assist with designing national New Zealand guidelines on the optimal level of provision of outdoor gym equipment in parks and the optimal mix of equipment. Fitting some of the equipment with counting devices could allow for more accurate measurements of usage levels (but such devices would need to be weatherproof, tamperproof and potentially arranged with equipment manufacturers and designers). Actual surveys or interviews with equipment users could collect demographic data and attitudinal data on enabling factors and barriers to use. Such demographic data could help determine the role of this equipment in helping address health inequities, as favourably reported internationally for low-income people (using self-reported physical activity levels).¹⁴

Some remote research methods are also feasible for the 55% of parks where gym equipment was visible on Google Street View (Table 2). Finally,

collecting data on equipment installation costs from TAs could inform whether or not bulk purchasing of equipment by a national agency could be the most cost-effective approach.

Failing the development of New Zealand-specific research and national guidelines in the near term, it is probably not unreasonable for TAs to act on the international evidence favouring

outdoor gym equipment (see the introduction). If so, then they could consider moving park budget priorities over time to invest in such equipment. But since TAs in this country often have severe resource constraints, it may be necessary for funding support for this from the central government, which may in turn depend on evidence-based national guidelines being set.

COMPETING INTERESTS

Nil.

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<https://nzmj.org.nz/journal/vol-138-no-1609/outdoor-gym-equipment-in-parks-in-aotearoa-new-zealand-preliminary-surveys-of-availability-and-usage>

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Bronchiectasis cough during the COVID-19 pandemic: a qualitative study

Julie Blamires, Mandie Foster, Wendy McRae, Sarah Mooney

ABSTRACT

AIM: Cough and airway secretions are part of daily life for people living with bronchiectasis. During the COVID-19 pandemic, infections associated with airway inflammation and cough amplified the health-related stigma and social unacceptability of coughing. This study explored the experiences and perceptions of adults with bronchiectasis during the pandemic to better understand the holistic impact of cough on their lives.

METHOD: A qualitative, interpretive descriptive study was undertaken using semi-structured interviews with 15 adults living with bronchiectasis resident in Counties Manukau, Aotearoa New Zealand.

RESULTS: Insights into the lives of adults living with bronchiectasis during the pandemic highlighted how they were impacted on multiple levels. Four key themes were developed that described participants' struggle: "feeling vulnerable but keeping safe"; "being treated differently"; adjusting to "becoming a virtual patient"; and participants articulating an increased focus on "self-care and supportive communities" as key strategies. Communication with health teams became crucial, offering essential support for respiratory health, medication access, reassurance and social connectivity.

CONCLUSIONS: Health professionals play a key role in increasing public awareness around bronchiectasis and cough, helping to reduce stigma. While it is unknown when another disease outbreak mirroring that of COVID-19 will occur, the stigma of cough continues and warrants improved understanding.

Nearly 5 years have passed since the emergence of COVID-19, a disease caused by the severe acute respiratory syndrome coronavirus. The subsequent pandemic resulted in overwhelmed healthcare systems and unprecedented global disruption.¹ Symptoms associated with COVID-19 include high fever, severe cough and shortness of breath,² which are synonymous with infective exacerbations of respiratory disease, including bronchiectasis. People living with long-term respiratory conditions were a particularly vulnerable group, with many experiencing anxiety and stress related to fear of exposure to the virus.³⁻⁶

Bronchiectasis is a chronic lung condition characterised by permanent dilation of bronchial airways and an impaired mucociliary escalator, resulting in a productive cough.^{7,8} This impairment, often caused by repeated infections, leads to bacterial invasion and mucus pooling in the bronchi, increasing susceptibility to further infections and reduced quality of life.² Treatment aims to manage cough and sputum production, preserve lung function, reduce exacerbations and hospital admissions, and improve mortality and quality

of life.⁹ Effective airway clearance, alongside pharmacological management and regular health professional reviews, are crucial for long-term management and optimising quality of life.^{10,11}

An estimated 8,053, or 162 per 100,000, people live with severe bronchiectasis in Aotearoa New Zealand.¹² In addition, rates of hospitalisation (29.5 per 100,000) and death from bronchiectasis are increasing (tripling from 42 per year in 2000/2001 to 154 in 2017).¹² While it is less common than other respiratory conditions such as chronic obstructive lung disease, population patterns of bronchiectasis are associated with significant social gradient for Māori, Pacific peoples and people living in lower socio-economic communities in Aotearoa New Zealand.¹² Compared with other regions, Counties Manukau has the highest social deprivation, population of Māori and prevalence of severe bronchiectasis, making the understanding of the holistic experiences of people with bronchiectasis essential.¹²

People with bronchiectasis are accustomed to respiratory symptoms and infection risks, with cough being the most common daily symptom.¹³ However, coughing poses challenges and impacts

daily life, causing discomfort and embarrassment.^{14,15} Cough, especially a productive cough of airway secretions, is also associated with social stigma¹⁶ and a high prevalence of anxiety and depression.¹⁷ Research into cystic fibrosis (CF), a hereditary condition also typically associated with a productive cough, found stigma was evident and resulted in discriminatory attitudes and behaviours by members of the public, similar to people living with human immunodeficiency virus (HIV).¹⁸ During the early pandemic phase, Williams et al.¹⁶ highlighted how coughing took on new significance, especially in public spaces, leading to verbal exchanges, significant anxiety and fear of judgement, causing some healthy individuals to either stay home or suppress their cough in public.

Of the limited research relating to the psychological and social impact of pandemics such as COVID-19, no literature has examined living with cough in a population of adults with bronchiectasis whereby cough is both synonymous with their condition and an essential focus of treatment. This study therefore aimed to explore the experiences of adults living with bronchiectasis in Counties Manukau, Aotearoa New Zealand, during the COVID-19 pandemic.

Methods

This qualitative interpretive descriptive study¹⁹ recruited 15 participants from the outpatient Respiratory Department of Health New Zealand – Te Whatu Ora Counties Manukau. Potential participants were provided with an information flyer about the study by clinicians from the respiratory service, and if they indicated an interest in participating, permission was sought for the clinicians to provide the research team with contact details. Potential participants were required to be English-speaking adults >18 years, with confirmed diagnosis of bronchiectasis on high resolution computed tomography and resident in the Counties Manukau Region. Participation involved an individual face-to-face or online semi-structured interview conducted by a registered nurse and academic experienced in conducting qualitative interviews. Written informed consent was obtained from all participants. Anonymity was preserved by eliminating names and identifiers from transcripts and records, with each participant identified by a pseudonym.

Recruitment and interviews occurred over a period of 15 months in Auckland, from May 2021 to August 2022. A semi-structured interview guide

explored participant experiences of day-to-day life with bronchiectasis during the pandemic (Appendix). Participants were invited to have their whānau/family/support people present at the interview and were also given the option to review their transcripts for accuracy before analysis. Interviews were audio-recorded, transcribed by an independent transcriber, de-identified and entered into a Word document in a secure password-protected Teams folder. Data analysis followed Braun and Clarke's²⁰ reflexive thematic analysis. This involved repeatedly listening to the recorded interviews to grasp the subtle nuances and meticulously reading the verbatim transcripts for accuracy. Following this, a recursive inductive coding process was undertaken to capture the essential meanings. Through this method, a set of experiential themes was constructed. Ethical approval was obtained from the Health and Disability Ethics Committee (21/NTB/30) and Health New Zealand – Te Whatu Ora Counties Manukau research office (Study #1395).

Results

Individual semi-structured interviews were undertaken face-to-face (n=4), via Zoom (n=9) or telephone (n=2) with 15 adults living with bronchiectasis. This included nine females and six males, with ages ranging from 18–83 years (Table 1). Ethnicity included Māori (n=6), Tongan (n=1), Samoan (n=2), Cook Island (n=1) and New Zealand European (n=5).

Findings

Four key themes entitled “becoming a virtual patient”, “being treated differently”, “feeling vulnerable but keeping safe” and “self-care and supportive communities” were generated from the participants' responses as represented in Table 2.

Becoming a virtual patient

Living with bronchiectasis early in the COVID-19 pandemic involved alterations to the way in which participants interacted with healthcare services, often becoming a virtual patient. The response to virtual appointments was varied, with some participants loving it and others finding the social and non face-to-face disconnection challenging. Several participants talked about how the COVID-19 restrictions imposed were counterintuitive to human nature. There was still a strong need and value placed on human touch and face-to-face interactions.

Table 1: Bronchiectasis participants' demographic characteristics (n=15).

Pseudonym	Ethnicity	Age (years)	Gender
Beatrice	NZ European	70	F
Hana	Māori	43	F
Joe	Māori	34	M
Lois	NZ European	83	F
May	Cook Island	33	F
Sara	NZ European	67	F
Rachel	NZ European	63	F
Maia	Māori	73	F
Lani	Samoaan	44	F
Ben	NZ European	21	M
Ngaire	Māori	24	F
Sam	Māori	59	M
Dan	Māori	20	M
Arnold	Samoaan	18	M
John	Tongan	52	M

Table 2: Representative quotes.

Becoming a virtual patient	<p><i>"It's just that human touch is in us—that is, there is value in the face-to-face contact and being in the same, um, space, but we're all learning, we're adapting, and we still get business done. Just the quality of that is, you know, questionable." – Lois</i></p> <p><i>"I had a virtual doctor's appointment, which is perfect cause I work and live a long way from the clinic. So yeah, it was never convenient going to the doctors. I always said to them prior to COVID, 'can we just do a consult over the phone or over a video conference,' and that just wasn't an option. I said, 'I'll pay, I'll pay, just trying to get to you is impossible.' So, one of the pros of COVID for me is now I can beam in and see my doctor at anytime from anywhere and get the medicine that I need, if needed." – Hana</i></p>
Being treated differently	<p><i>"When I went in [to clinic] they would say 'have you got a cough? ... go sit over there' ... and away I would go to the naughty corner... didn't get to explain ... well yes, I have a cough, but I always have a cough ... I don't have COVID." – Lani</i></p> <p><i>"Um, you know, I think it's people, the staff that greet you, etc, don't understand, well cause there's really no difference. You know, if somebody's coughing, then somebody's coughing, whether they've got bronchiectasis or whether it's COVID ... it's all the same to them." – Sara</i></p>

Table 2 (continued): Representative quotes.

Feeling vulnerable but keeping safe	<p>“I was just so afraid of contracting it, I think I was just so anxious, really anxious! So afraid to even leave the house initially when it first came. I mean, even now, um, if I travel on the train, you know there’s been the odd person without a mask who have coughed and I’m very, very anxious about being away from them.” – Lani</p> <p>“Um, you know, I ended up sort of being very, very careful with cleanliness ... and keeping a distance were very important, and I was anxious of someone around if he was coughing or, you know, in the supermarket when everyone’s mask on and stuff like that. If I did have to go out, say to the supermarket (which I avoided as much as possible) I washed my hands many times [laughter] and, like, cleaned the steering wheel and everything, including the doorknobs and light switches ... anything just to keep yourself safe.” – Sara</p>
Self-care and supportive communities	<p>“They worry about me. But I worry about them. I know how to handle myself, look after myself and not get sick, but they are the ones that I worry will catch it, and they are old so it wouldn’t be good. I do all the things to keep them safe.” – Ngaire</p> <p>“I mean, I had much lower exposure to viruses and stuff, and, like, the kids weren’t at school, so they weren’t bringing home bugs, so in a lot of ways it was quite good like that.” – Sam</p>

The notion that interactions with health professionals via phone or Zoom were somehow less empathetic and/or less therapeutic was a sentiment shared by many participants. Older participants missed attending face-to-face appointments, whereas younger participants appreciated the convenience of having check-ups from home. Some missed the routine and elements of a typical appointment such as having lung function tests, sputum testing or X-rays.

Despite having to make these adjustments, participants felt strongly positive that advice from their specialist team members, general practice services and pharmacists were readily available and overall felt connected and supported to self-manage their bronchiectasis.

“Phone virtual appointments and conversations with the team made me feel safe and cared for. The physio was great, always there to give advice, even if I didn’t always follow it [laugh].” – Joe

For some participants, having the option of virtual appointments was seen as an improvement to a system that was sometimes described as inflexible: “... So, one of the pros of COVID for me is now I can beam in and see my doctor at any-time from anywhere.” – Hana. Many participants drew attention to their experience of accessing

medications and the ease of which they attained prescriptions and advice about medications during the pandemic. There was a strong message from the participants that although there were some downsides to not being seen in person, becoming a virtual patient was “*not all bad*,” with most participants describing easy access to advice and education, and that this connection helped their confidence and contributed to them “*feeling like they weren’t alone*.”

Being treated differently

As the pandemic evolved and lockdown restrictions lessened, some participants returned to face-to-face clinics or required hospitalisation. They described feeling that they were treated differently in healthcare spaces. Upon entering a clinic or hospital, they were always asked, “*Do you have a cough?*” Most participants answered “*yes*” and were immediately judged as “*COVID-19 suspects*,” which was a source of frustration and disappointment. This usually occurred with public-facing administrative staff, but sometimes also with healthcare professionals.

Some participants felt staff “*should know better*,” but they equally recognised how COVID-19 had resulted in widespread fear and when someone coughed “*all reason goes out the window*.” Attending any public spaces, especially clinics or a doctor’s office, was anxiety provoking, as participants

recognised everyone had a heightened sensitivity to hearing a person cough. Although participants mostly understood the rationale and accepted these inconveniences, such experiences contributed to them feeling “different.”

“Well yeah, I was treated differently because, you know, now that everybody, no matter who it is that has any kind of respiratory problem, they put them in the corner ... like, you know there’s the area separate from everyone else ... and, um, I mean, I don’t mind because, you know, everyone is trying to do their best to be safe from the virus, but it did feel a bit like I was contagious.” – May

The COVID-19 pandemic amplified feelings of “difference”, and several mentioned how it would have been nice to have had “a sign or a card” they could have held up that said, “I have a cough, it’s from bronchiectasis, not COVID-19.” They noted that as the pandemic progressed there was a shift in the way questions about cough were asked by front-facing staff, where instead of saying, “do you have a cough?”, they asked, “do you have a new cough?” This change in questioning was well received by participants, who felt this was a more inclusive, understanding approach to their situation, given coughing was a normal part of their daily life.

Numerous statements such as “coughing is socially embarrassing,” “I felt embarrassed to go out,” “I hate the cough” and “people look at you sideways” highlights how impactful the cough was to each of the participants. Participants used a range of strategies to avoid being embarrassed or “caught out” (Beatrice) by their cough, including “always having a drink handy when out in public” (Sara, Lani, Ben), “being prepared with an inhaler” (Arnold), “doing deep breathing and coughing in the car before getting out” (Lois, Joe, John), “not breathing” (Dan) and/or “holding in their cough” (Beatrice, Joe, May, Maia, Lani, Ngaire) until they could get somewhere where they felt comfortable to cough. However, the pandemic also posed challenges to where they could go to undertake their airway clearance, to cough and clear their sputum. Staying at home was a common strategy; “reduced the embarrassment of coughing and the hassle of having to deal with sputum when out in public” (Ngaire), demonstrating the social impact of living with cough during the pandemic.

Feeling vulnerable but staying safe

All participants described being afraid of catching COVID-19, feeling apprehensive to go out and nervous about being close to people (even family) when they did not know if they had been exposed to COVID-19, making the pandemic experience daunting for them.

“I was just so afraid of contracting it, I think I was just so anxious, really anxious! So afraid to even leave the house initially when it first came.” – Lani

Maia and Lani described how their own experiences of respiratory illness, cough and fatigue gave them a different perspective, an inside knowledge of what it was like to struggle with respiratory issues. They feared COVID-19 would make things worse.

“If I didn’t have a lung condition, I’d probably be totally different. I knew that if I were to get COVID it would be much worse situation for me, you know, more than for someone else.” – John

Others also echoed feelings of vulnerability, noting that “for them” the risks were more pronounced “than for others without a lung condition like bronchiectasis.” These worries and general feelings of anxiety resulted in heightened awareness of risk and a subsequent cautious approach to daily life. Participants avoided public places, kept their distance from people when they did go out and took advantage of delivery services for groceries and medications. In addition, several participants described how they developed a new hypervigilance around hygiene and cleaning. When asked to describe their experiences during different levels of lockdown, many recalled staying in their “bubbles” at home. For some, this meant spending a lot of time on their own, whereas for others they were living with multiple family members; however, they were very vigilant in following the COVID-19 mandated rules. Social distancing and isolation were viewed as a protective mechanism and survival strategy during the unknown time of the pandemic.

“We were just really mindful no one went out or no one left our premises, uh, we were not open to anyone coming over. To the point where I was nearly tempted to lock my front gate, not

so much as my back gate because no one really uses it, but, yeah, very tempted to lock it, that's how serious our household took that. – Hana

Self-care and supportive communities

A strong theme among participants was the immeasurable support from neighbours, health workers and community members, including their church. Older participants who lived alone mentioned neighbours left notes, offered to get groceries or checked in on them from a distance to ensure they were okay. Health workers also helped by shopping and picking up medications. For others, they drew strength, connection and a sense of wellbeing from their church community, even during online services.

“Being part of the community—making connections influences mood and wellbeing. Being surrounded by good people, positive energy is empowering. The church community has been a huge support throughout COVID, even when we had online services.” – Lani

Family was described as one of the most important support systems. Some saw lockdowns as *“a great time to be with family,”* while for others there were differences of opinions about isolation rules, and some participants worried about their older family members catching COVID-19.

Participants emphasised the importance of self-care during lockdowns and doing their physiotherapy i.e., airway clearance more regularly, feeling they had more time and space to walk, take breaks, get small projects completed and connect with friends/family through gaming, FaceTime and Zoom.

“I don't know, I feel like I just had more time to do my physio, and I went for walks and stuff. Normally I always make an excuse for not doing it [physio] (even though I know I should), but during the lockdowns there was just more time.” – Ben

In another positive way, the mandated isolation meant participants were *“less exposed to viruses and sick people”*; therefore, described fewer exacerbations. Only two participants out of the 15 reported they required hospitalisation for treatment of their bronchiectasis during lockdowns three and four.

Discussion

The four key themes developed from the findings of this study contribute knowledge about the experiences of people living with bronchiectasis in Counties Manukau during the COVID-19 pandemic. Participants articulated how they learned to navigate and adjust to becoming a virtual patient, how they were challenged by being treated differently in health settings and how the pandemic heightened their sense of vulnerability. Despite these challenges, participants developed a number of strategies to cope with this complex and stressful period.

Becoming a virtual patient

Individuals with bronchiectasis navigated a shift to virtual healthcare, which offered greater accessibility and convenience but sometimes lacked the empathetic touch of in-person interactions. Globally, the pandemic resulted in a shift of thinking about how education, health promotion, ongoing management and treatment of patients could occur.^{21,22} The move to telephone and video consultations in order to minimise face-to-face interactions between healthcare professionals and patients was an obvious solution during the crisis of the pandemic, and healthcare professionals must anticipate patients will continue to expect this option to remain available.²³ Adaptable healthcare systems, with business models that support virtual care with specialist services while maintaining continuity of care with primary care providers, has been touted as a potential solution.^{23,24} Evaluation of telehealth during the pandemic, however, also highlighted issues including equity, access to technology and literacy.^{23,25} Ensuring that patients affected by the digital divide can access care in safe and inclusive ways is an essential component of quality care.

While many participants missed routine diagnostics and direct contact with providers, they valued the support and ease of access to medical advice, which strengthened their confidence in self-managing their condition. This notion of improved confidence with self-management is an important and relevant clinical finding echoed by other studies of chronic disease management during the pandemic.^{26,27} Encouraging self-management through education, empowerment and providing equipment and required medications at the onset of a pandemic has potential to improve confidence and health consequences for patients, as well as decrease the demand on healthcare services.²⁶

Being treated differently

As COVID-19 restrictions eased, people with bronchiectasis returned to in-person clinics and/or required hospitalisation, where they felt judged as a potential COVID-19 case due to their chronic cough. Stigmatisation, perceived and actual discrimination, and misinformation magnified the burden on participants living with bronchiectasis. This knowledge of participant experience of stigma is important for health professionals, given its potential impact on health outcomes, healthcare-seeking behaviour and care delivery, as seen in other health-related stigma.²⁸ The uncertainty associated with COVID-19 in the beginning of the pandemic provides the background for stigmatisation among healthcare professionals; however, the findings from this study illustrate the need for further research exploring the impact of stigma and cough among bronchiectasis patients. Strategies promoting self-reflection of potential stigma-related judgements and actions by health professionals, correcting wrongful practices including discriminatory language or actions, teaching correct practices and skills and championing structural change could promote an anti-stigma environment, behaviour and health environment.²⁹ In this study, for example, health professionals addressed the screening questions asked of people with bronchiectasis when they attended clinic, so that people with “normal” cough were not ostracised. De-stigmatising cough in the community through educational forums may potentially improve engagement of people with cough and health services and promote people with cough seeking a medical review and investigation. The inclusion of quality of life questionnaires relating to cough, for example the Leicester Cough Questionnaire, within routine health assessments could be a simple strategy to raise health professional awareness and appreciation of how cough impacts on individuals.³⁰

Feeling vulnerable but being safe

Participants described high levels of stress, feelings of vulnerability and anxiety related to the COVID-19 pandemic. In addition, participants expressed fear about developing COVID-19. This amplified their sense of social embarrassment, leading them to adopt strategies to manage or suppress their cough in public. Many avoided public spaces to reduce stigma and the logistical challenges of managing sputum clearance outside the home. This has been reported in other studies involving people with other existing medical

conditions, where they feared being forgotten, experienced isolation and anxiety and felt stigmatised.^{3,31,32} Other studies have reported the compulsion to self-isolate for fear of catching/dying from COVID-19 among those with chronic obstructive pulmonary disease,³³ CF³¹ or other chronic lung diseases, including bronchiectasis.⁵ This illustrates the significant anxiety and stress created by the pandemic and points to the important proactive and supportive role of health professionals in maintaining contact with vulnerable patients who may be feeling anxious or stressed.

Vulnerability relating to cough, fear of contracting COVID-19 and having a respiratory condition associated with poor COVID-19 outcomes elicited protective strategies. Participants reported keeping well and safe and looking after themselves as being an important aspect of their COVID-19 experiences. This seemed to result in an improved sense of control, improved health and fewer infections, although this is anecdotal and not scientifically measured. Perceptions, however, are in keeping with a study by Crichton et al.³⁴ where social distancing measures during the first 12 months of the COVID-19 pandemic were associated with a marked reduction in bronchiectasis exacerbations, but no change in individual chronic respiratory symptoms or quality of life measures. Indeed, influenza virus circulation in Aotearoa New Zealand was noted to be non-existent during the 2021 winter season compared with data from the pre-COVID era,³⁵ leading to a marked reduction in triggers that would otherwise result in bronchiectasis exacerbations.

Self-care and supportive communities

Fear and social isolation exposed people, including participants, to emotional distress.³⁶ While they adopted strategies to reduce their vulnerability and optimised their self and bronchiectasis management, communication with health professionals created a lifeline. Irrespective of the form of communication, i.e., phone call, mobile phone messaging or tele-conferencing, participants felt connected and provided with opportunities for health monitoring, reassurance and correcting myths and misinformation. Conversations between participants and health professionals provided both medical and psychological care, with participants also expressing care for staff. This mutual care and reciprocal concern spoke of the unique context and broad impact of the pandemic, as well as the trust established between health professionals and adults living with

bronchiectasis in Counties Manukau. Understanding the perspectives of bronchiectasis patients may encourage other health professionals/healthcare services to adopt a proactive approach, incorporating telephone calls or virtual consultations, specifically addressing mental health needs when faced with future pandemics.

Participation in church activities and maintaining spiritual support and religious connections were also essential to the wellbeing of participants. Delivery of groceries and medications provided practical support, together with neighbourly watchfulness, all of which supported and reinforced the safety of participants, especially older participants. Previous research on past pandemics, such as the Ebola and SARS outbreaks³⁷ and on the COVID-19 pandemic,³⁸ found that social support plays a key role and is a protective factor, improving mental health and overall wellbeing.

Strengths and limitations

This study provided a unique and valuable insight into the experiences of people with bronchiectasis resident in Counties Manukau during the COVID-19 pandemic. Participants were all recruited from the respiratory outpatient clinics (virtual or face-to-face clinics) and, as such, may not be representative of the wider population of people who did not attend the clinics. Details of potential participants were not recorded, which limits analysis of patient demographics relative to clinic attendance. It is therefore unknown why, for example, Asian adults were not represented. Additionally, cultural differences were not explored in the analyses. Future research inclusive of, for example, Māori and Pacific researchers would ensure that cultural nuances

and worldviews are visible and participant voices are accurately presented.

Further research is warranted regarding barriers and facilitators of people with cough and health access and, in addition, attitudes and behaviours of health professionals relating to cough. The study's findings also suggest further research, within the Aotearoa New Zealand context, should focus on interventions enhancing social support resources for patients, given the protective role they play in reducing adverse mental health outcomes. In addition, careful evaluation of the benefits and risks to wellbeing of virtual healthcare and support is warranted.

Conclusion

The impact of COVID-19 was far-reaching and affected every participant irrespective of age, culture and gender. While chronic cough is synonymous with bronchiectasis, this symptom became feared and associated with COVID-19. Participants both feared and experienced stigmatisation, adopting strategies to protect their vulnerability and stay safe. Paradoxically, they valued the physical and social isolation that created a safe space, yet valued connecting virtually with health professionals, community members and their church. It is critical that health professionals appreciate the impact of symptoms such as cough to better understand how lives of people with, for example, bronchiectasis are affected. Health professionals play a crucial role in capturing these narratives, preventing and reducing cough stigma. Their role extends to raising public as well as peer awareness in relation to reducing cough stigma and also promoting people to seek medical assessment regarding chronic cough.

COMPETING INTERESTS

Nil.

This project was funded by a Counties Manukau Tupu research grant.

ACKNOWLEDGEMENTS

We would like to thank the study participants who shared their stories and also Counties Manukau for the Tupu research grant that funded this study.

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<https://nzmj.org.nz/journal/vol-138-no-1609/bronchiectasis-cough-during-the-covid-19-pandemic-a-qualitative-study>

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Appendix 1

Topic interview guide for semi-structured interviews

This research study employs an interpretative descriptive methodology and hence relies on the stories and experiences that participants bring to the interview.

It is not the intention of the researcher to enter the interview with prearranged questions.

I am very keen to allow the participants to shape the interview, however the participants may need a beginning point to start from, then I could employ any of the following prompts:

Warm up questions.

Tell me a little about yourself and when you were diagnosed with bronchiectasis?

Other warmups...

What do you understand the study to be about? In your own words...

Then move to study-related prompts:

What has it been like having a cough/bronchiectasis during the COVID-19 pandemic? [*Probes: people with cough/bronchiectasis have described feeling embarrassed or stigmatised about their cough ... is that something you have experienced?*]

What kind of reactions have you experienced from other people, including family, healthcare providers, public?

Tell me about a situation where you felt embarrassed by your cough/bronchiectasis?

What kind of changes or alterations to your own behaviour and management of your bx have you had to undertake during the pandemic?

What support and resources have been helpful to you?

What has been the best thing about having bronchiectasis/cough during COVID-19?

What has been the worst/hardest thing about having bronchiectasis/cough during COVID-19?

Anything else you would like to tell me?

Additional prompts which may be used throughout the interview:

When you described ... what did you mean

I'm really interested in what you just described...

Can you tell me a bit more about...

What did you understand by that ... Why do you think that was like that...

Establishing a New Zealand brain tumour registry: understanding clinical registry formation in New Zealand

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ABSTRACT

AIMS: To explore the development of clinical registries in New Zealand, examine the New Zealand neuro-oncology system and assess factors relevant to establishing a national brain tumour registry in New Zealand.

METHODS: A literature review was conducted on the establishment of clinical registries in New Zealand. Key registries were consulted to gain insights into their construction and function. Consultation with neuro-oncology clinicians was conducted to ascertain the structure of New Zealand's neuro-oncology system and to identify relevant considerations for registry development.

RESULTS: Analysis of five clinical registries highlighted preferences for: 1) simple, single-tiered registry structures, 2) utilisation of existing registry infrastructure, and 3) inclusion of essential data fields only. Consultation with neuro-oncology clinicians revealed that New Zealand's neuro-oncology system comprises five neurosurgical centres through which brain tumour patients receive care via a consistent pathway. From a clinical perspective, important considerations include the wider New Zealand healthcare system, the Treaty of Waitangi (Te Tiriti o Waitangi), Māori data sovereignty and establishing a registry governance framework.

CONCLUSIONS: Establishing a national brain tumour registry in New Zealand will require attention to registry structure, existing registry infrastructure, key data fields, integration with the healthcare system, Māori data sovereignty and governance, with adherence to Te Tiriti o Waitangi.

Brain tumours are a complex group of diseases often associated with significant morbidity and mortality. This group of diseases comprises many rare tumour types that are grossly understudied. For any group of diseases, the collection of reliable data is crucial for the understanding of natural disease course, prognosis and treatment outcomes.¹ In rarer conditions, this becomes even more vital; given the infrequency of these disorders, data are often incomplete and lack detail, hindering advancements in research and thus preventing improvements in patient outcomes.^{1,2} Importantly, data on rare disorders are often not routinely collected by governments due to limited awareness, inequitable resource allocation and underfunding of research. One potential solution to this issue is the establishment of a clinical registry. Clinical registries are databases that systemically collect, store and provide health-related information for specific diseases or conditions.¹ These databases have proven invaluable in advancing the understanding of

a wide range of diseases, particularly complex ones such as brain tumours.¹⁻³ Clinical registries, therefore, allow the landscape of diseases to be better understood, permitting more targeted research, healthcare service improvement and stronger advocacy efforts. This paper describes the first phase of research conducted into the feasibility of establishing a national brain tumour registry—assessing existing clinical registries in New Zealand, ascertaining the structure of New Zealand's neuro-oncology system and evaluating how these insights could inform the formation of a brain tumour registry.

Methods

This review was conducted in two phases. Firstly, a literature review was conducted to identify and evaluate several existing clinical registries in New Zealand, focussing on construction and function. This was achieved through the identification of published studies involving

New Zealand clinical registries using PubMed and Google Scholar. The initial search was run using “registry OR register” AND “New Zealand”. This search was further refined independently through addition of the following terms using AND: “cancer”, “clinical”, “database”, “outcomes”, “patient”, “adult” and “paediatric”. Several case studies were identified and further investigated through both the references identified and broader internet searches. Additional information was collected through consultations with key contacts from these registries, including founding members, co-ordinators and data managers.

In the second phase, neuro-oncology clinicians across New Zealand were consulted to ascertain the structures and pathways of the neuro-oncology system. This involved informal discussions with clinical nurse specialists, neurosurgeons, medical oncologists, radiation oncologists and pathologists across the country, as well as researchers and patient advocacy groups. The findings from both phases were combined to highlight key considerations for developing a national brain tumour registry in New Zealand.

The need for a national brain tumour registry

There are many international examples of brain tumour registries that have allowed for a better understanding of the brain tumour landscape in those countries. For example, the Central Brain Tumor Registry of the United States (CBTRUS) gathers and reports on data from around 90,000 brain tumour patients each year, facilitating research and raising awareness for this group of diseases.³ However, in New Zealand there is no national brain tumour registry, limiting our capacity to both accurately assess the quality of neuro-oncology services and to conduct research that is aligned with the needs of the population. As a consequence, international datasets are often used to inform research and clinical practice in New Zealand, which notably lack data from Māori and Pacific populations. Under the *Cancer Registry Act 1993*, the New Zealand Cancer Registry (NZCR) curates and reports statistics on cancer cases across the country, including brain cancer.⁴ Importantly, these data do not include non-malignant brain tumours and are limited in detail to basic incidence and mortality statistics.⁴ For this service to be relied on, advocacy to include both primary malignant and non-malignant brain tumours, as well as more comprehensive information, would need to be achieved. This

is likely to take a significant amount of time; in the United States of America (USA) and Canada, for example, such changes were advocated for and took over 10 years before legislation was put into place.^{3,5} It is therefore imperative to determine how a registry with such capabilities can be established sooner, without the need for legislative changes. As such, the New Zealand Aotearoa Neuro-Oncology Society (NANOS, <https://nanos.co.nz/>), a consortium of neuro-oncology clinicians, researchers and patient advocacy groups, has identified the establishment of a New Zealand brain tumour registry as a key priority. This registry must be comprehensive in its detail and include all paediatric and adult primary brain tumours. Further, we plan to build relationships with existing cancer registries to determine the feasibility of including secondary brain metastasis data. This registry must also prioritise comprehensive population coverage, with a particular emphasis on ensuring complete national brain tumour data collection for Māori and Pacific populations. Overall, this registry aims to provide complete and accurate brain tumour data to clinicians, researchers and the wider community. By assessing disease burden, the quality and efficacy of brain tumour treatments and patient outcomes, this resource will facilitate improving brain tumour services in New Zealand.

Existing clinical registries in New Zealand: key findings

Despite being a small country, New Zealand has several clinical registries for a variety of medical disorders. These registries provide valuable data that are not only of interest to New Zealand, but also internationally, given our unique patterns of population diversity. The analysis of several existing registries in New Zealand was conducted to identify key considerations for the construction of the forthcoming national brain tumour registry.

Registry structure

One of New Zealand's largest non-governmental organisation (NGO) clinical registries, Te Rēhita Mate Ūtaetae—the New Zealand Breast Cancer Foundation National Register (NZBCFNR) has collected comprehensive data on over 45,000 New Zealand breast cancer patients, promoting improvements in patient survival and the narrowing of ethnic survival disparities between Māori, Pacific and European patients.⁶ This registry initially existed as four regional registries: the Auckland regional register (established in 2000),

Waikato (2005), Christchurch (2009) and Wellington (2010).⁶ While this regional approach allowed data to be collected sooner, it only achieved 63% coverage of the New Zealand breast cancer patient population.⁶ In 2018, these registries were amalgamated, forming a single central registry with nationwide data submission starting in 2020.⁶ The NZBCFNR now achieves near 100% coverage of diagnosed breast cancer patients in New Zealand, with <1% of eligible patients opting out of the register.⁶ It is important to note that the earlier regional registers did not include all of New Zealand's hospitals, and, at the time, operated under an opt-in consent model, requiring individual approval for patient inclusion, which likely limited population coverage.⁶ Further, findings from the Auckland regional register revealed an upward bias in survival data under the opt-in consent model; patients who opted out were more likely to have greater disease extent, less treatment and subsequently a lower survival.⁷ However, the Prostate Cancer Outcomes Registry Australia and New Zealand (PCOR-ANZ) has also seen difficulties in achieving complete population coverage despite an opt-out model of consent, likely due to its complex structure (see Table 1). While such multi-tiered, regional registry structures can facilitate the timely execution of clinical registries, this model may not be suitable in the long term if full population coverage is desired.

Data fields

The New Zealand Trauma Registry (NZTR) is a relatively small registry compared with the NZBCFNR, yet demonstrates how simple, single-tiered registry structures can succeed from inception (Table 1). The NZTR has collected retrospective data on all trauma patients admitted to hospitals meeting eligibility criteria since 2015.⁸ The NZTR *Major Trauma National Minimum Dataset*⁸ outlines the fields collected for the registry. The dataset consists of fewer than 80 data fields, which is small compared to other registries.⁸ Despite this, the NZTR has gathered data on around 13,000 trauma cases from 2015–2023,⁹ demonstrating that the size of the registry—both in terms of structure and number of data fields collected—does not necessarily influence its capacity to record cases and, therefore, how valuable of a resource it is. Today, NZTR data have been instrumental in developing and implementing several quality improvement initiatives, including in the management of severe traumatic brain injury and

critical haemorrhage nationwide.⁹

Existing registry infrastructure

Finally, the New Zealand Children's Cancer Registry (NZCCR) demonstrates how a registry can effectively leverage existing registry infrastructure to complement data collection (Table 1). The NZCCR collaborates with the NZCR, the Late Effects Assessment Programme (LEAP) national database and the Mortality Collection (MORT) to gather accurate and comprehensive data on paediatric cancer cases in New Zealand.¹⁰ The NZCR and MORT are primarily used to validate the NZCCR dataset, ensuring its accuracy.¹⁰ The LEAP national database is used to track paediatric cancer cases to better understand long-term outcomes and to collect more complete treatment data.¹⁰ This integrated approach not only improves the quality and comprehensiveness of the NZCCR, but also reduces the data collection burden. Of particular importance to the forthcoming national brain tumour registry, the NZCCR collects data on both malignant and non-malignant paediatric brain tumours, demonstrating that such comprehensive inclusion is feasible.

Neuro-oncology service provision in New Zealand

Consultations with neuro-oncology clinicians, researchers and patient advocacy groups across the country were conducted to gain an understanding of the neuro-oncology system in New Zealand. It is important to note that, in this context, the term “neuro-oncology” encompasses all primary brain tumours, including non-malignant tumours, as these patients also receive treatment from oncology services. Service provision for secondary brain tumours is more complex and often dictated by the primary tumour site. Therefore, this paper focusses primarily on neuro-oncology service provision related to primary brain tumours.

Neuro-oncology services are typically divided into five key components: neuroradiology, neuropathology, neurosurgery, radiation oncology and medical oncology. Neurosurgery serves as the central hub in the neuro-oncology system through which all brain tumour patients will pass. Te Whatu Ora – Health New Zealand provides public health services to New Zealand. There are five Te Whatu Ora neurosurgical centres in New Zealand, as well as seven smaller private sites, which provide neurosurgery services for brain tumour treatment (Figure 1). Patients requiring

Table 1: Summary of selected clinical registries in New Zealand, outlining key characteristics and lessons that may be useful in the establishment of a national brain tumour registry.

Registry	Key characteristics	Key lessons
New Zealand Cancer Registry (NZCR)	<p>A government registry of all primary cancers diagnosed in New Zealand, functioning under the <i>Cancer Registry Act 1993</i>, which mandates the reporting of cancer cases.⁴</p> <p>Gathers incidence and mortality data on all patients diagnosed with cancer (excluding non-melanoma skin cancer).</p>	<p>Data on secondary brain metastases and benign tumours are not collected; lobbying to include this information would be required if the NZCR data were to be relied on.</p> <p>Data on treatment and non-fatal outcomes are not collected; additional information would be required if the NZCR data were to be relied on.</p>
New Zealand Breast Cancer Foundation National Register (NZBCFNR)	<p>Established in 2018 when four regional registries, each with their own governance groups, were amalgamated.⁶</p> <p>Funding from Breast Cancer Foundation New Zealand.</p> <p>Near 100% coverage of eligible breast cancer patients in New Zealand, increased from 63% prior to amalgamation.⁶</p> <p>Aims to use data to reduce inequities, improve patient outcomes and monitor progress through the provision of breast cancer data to clinicians, health workers and researchers.⁶</p> <p>Opt-out model of consent.</p>	<p>Such a comprehensive registry requires a team of data managers throughout the country to manually manage data collection.⁶</p> <p>100% coverage can be achieved with an opt-out consent model (opt-out rate <1%).⁶</p> <p>A regional registry structure is unlikely to cover the entire patient population of interest.</p> <p>The NZCR can be used to validate datasets.</p> <p>Charities and advocacy groups can be an effective and important resource for expertise and funding opportunities.</p>
Prostate Cancer Outcomes Registry Australia and New Zealand (PCOR-ANZ)	<p>An Australia and New Zealand registry focussed on patient outcomes.</p> <p>The Movember Foundation invited groups to express their interest in establishing state prostate cancer registries in 2013.¹¹ New Zealand was recruited in 2015.¹¹ Each regional register has their own governance structures.¹¹</p> <p>Substantial funding from the Movember charity allowed the project to get underway.¹²</p> <p>State-based registries submit data to the national registry. Population coverage is 59% across Australia and 78% across New Zealand.¹²</p> <p>Opt-out model of consent.</p>	<p>Collaboration with neighbouring countries can facilitate registry implementation through greater access to resources.</p> <p>Multi-tiered, complex registry structures are slower to implement and slower to reach full coverage.</p> <p>Charities and advocacy groups can be an effective and important resource for expertise and funding opportunities.</p>

Table 1 (continued): Summary of selected clinical registries in New Zealand, outlining key characteristics and lessons that may be useful in the establishment of a national brain tumour registry.

<p>New Zealand Trauma Registry (NZTR)</p>	<p>A database of every major trauma patient admitted to acute hospitals across New Zealand.^{8,9}</p> <p>Data collection dating back to 2015.⁸</p> <p>Sponsored by the Ministry of Health and the Accident Compensation Corporation (ACC).⁸</p> <p>A single, web-based website for data entry by clinicians and data managers.⁸</p> <p>Opt-out model of consent.</p>	<p>A close relationship with government bodies can help fast-track initiatives.</p> <p>A close relationship with all participating centres is vital for buy-in.</p> <p>A simple registry structure and relatively small minimum dataset can still yield strong, valuable data.^{8,9}</p>
<p>New Zealand Children's Cancer Registry (NZCCR)</p>	<p>A paediatric cancer registry established in 2000 that collects demographic, diagnostic and treatment information.¹⁰</p> <p>Under the governance of the National Child Cancer Network (NCCN).</p> <p>Data collected from the two specialist paediatric oncology centres in New Zealand.¹⁰</p> <p>Collaborate with the Late Effects Assessment Programme (LEAP) national database for comprehensive chemotherapy, radiotherapy and long-term follow-up details.¹⁰</p> <p>Both malignant and non-malignant paediatric brain tumours are included.</p> <p>Opt-out model of consent.</p>	<p>Targeting the specialist clinical centres allows for accurate data collection without involving every hospital across New Zealand.</p> <p>Collection of data on non-malignant brain tumours can be achieved.</p> <p>Can use the NZCR and Mortality Collection to validate cancer cases.</p> <p>The use of existing registries, government structures and databases can prevent unnecessary data duplication and provide supplementary information.</p>

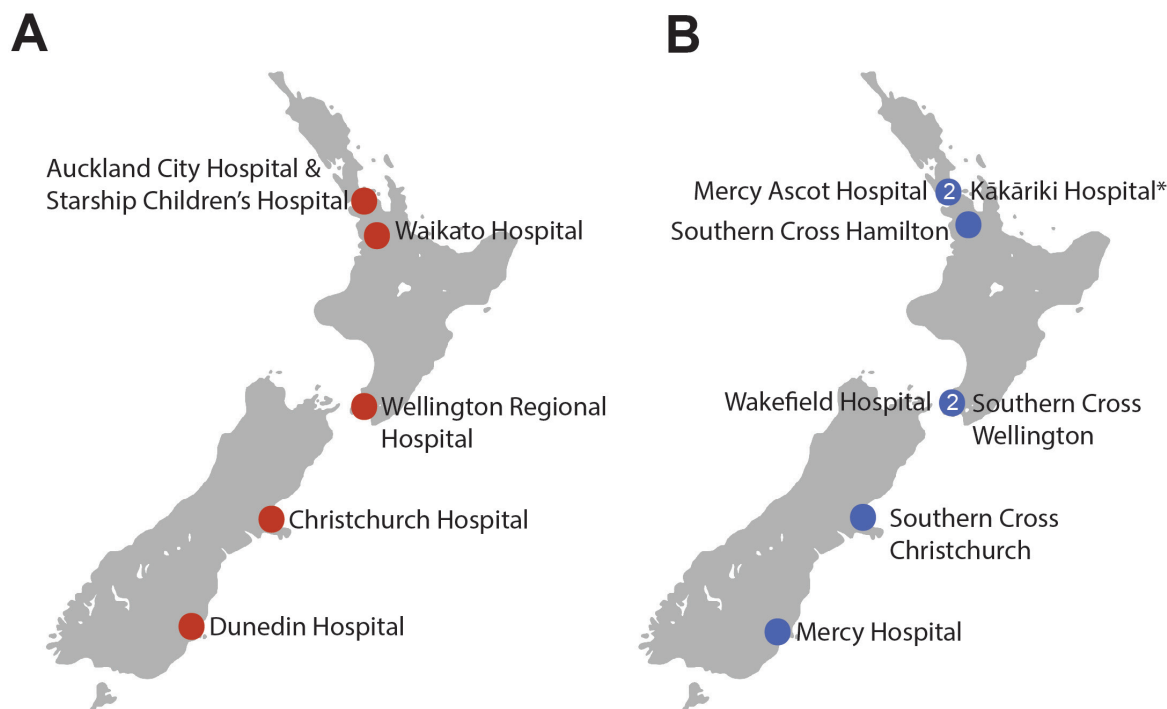
chemotherapy and/or radiotherapy may access these services at the five Te Whatu Ora centres, or through other Te Whatu Ora and private facilities. Based on international findings, around 85% of brain cancer patients undergo surgery, as evidenced by the proportion of patients with histopathologically confirmed disease.³ However, just 40% of those with non-malignant brain tumours receive histopathological confirmation.³ It is important to note that these patients will still likely undergo neurosurgical review at major neurosurgical centres. Most brain tumour patients will be discussed at regional neuro-oncology multi-disciplinary meetings (MDM) held at one of these major neurosurgical centres, regardless of whether treatment occurs at Te Whatu Ora or

private facilities. Therefore, these five neurosurgical centres are expected to be the primary sources of data for the brain tumour registry. However, it is important to include data from all private neurosurgery sites and other relevant chemotherapy and radiotherapy treatment centres to ensure complete coverage of the brain tumour population.

The brain tumour patient pathway

Consultations have also revealed the typical pathway brain tumour patients follow throughout the neuro-oncology system. Understanding this pathway will allow for the appropriate identification of data sources and data fields. The brain tumour patient pathway (BTPP; Figure 2) is divided into

Figure 1: Locations of the A) five Te Whatu Ora – Health New Zealand and B) seven private neurosurgical centres in New Zealand.



*Kākāriki Hospital is a new private hospital, opened in 2024.

three key stages: the pre-investigation phase, the investigation phase and the treatment and management phase.

1. Pre-investigation

A patient in the pre-investigation phase of the BTPP may experience symptoms that require investigations, but the patient is yet to access the healthcare system. The symptoms may include headaches, dizziness, impairments in co-ordination, blurred vision, nausea, vomiting, seizures or loss of consciousness.^{13,14} Not all patients present with symptoms, as some brain tumours are discovered incidentally.

2. Investigation

Patients with symptoms will access the healthcare system for investigations. Data from the United Kingdom suggest over 50% of brain tumour patients are diagnosed by emergency department (ED) services, with the remainder presenting to their general practitioner (GP), other outpatient services or as an inpatient.^{15,16} When a brain tumour is suspected, a series of investigations will be conducted, including neuroimaging. Neuroradiology, therefore, typically serves as the

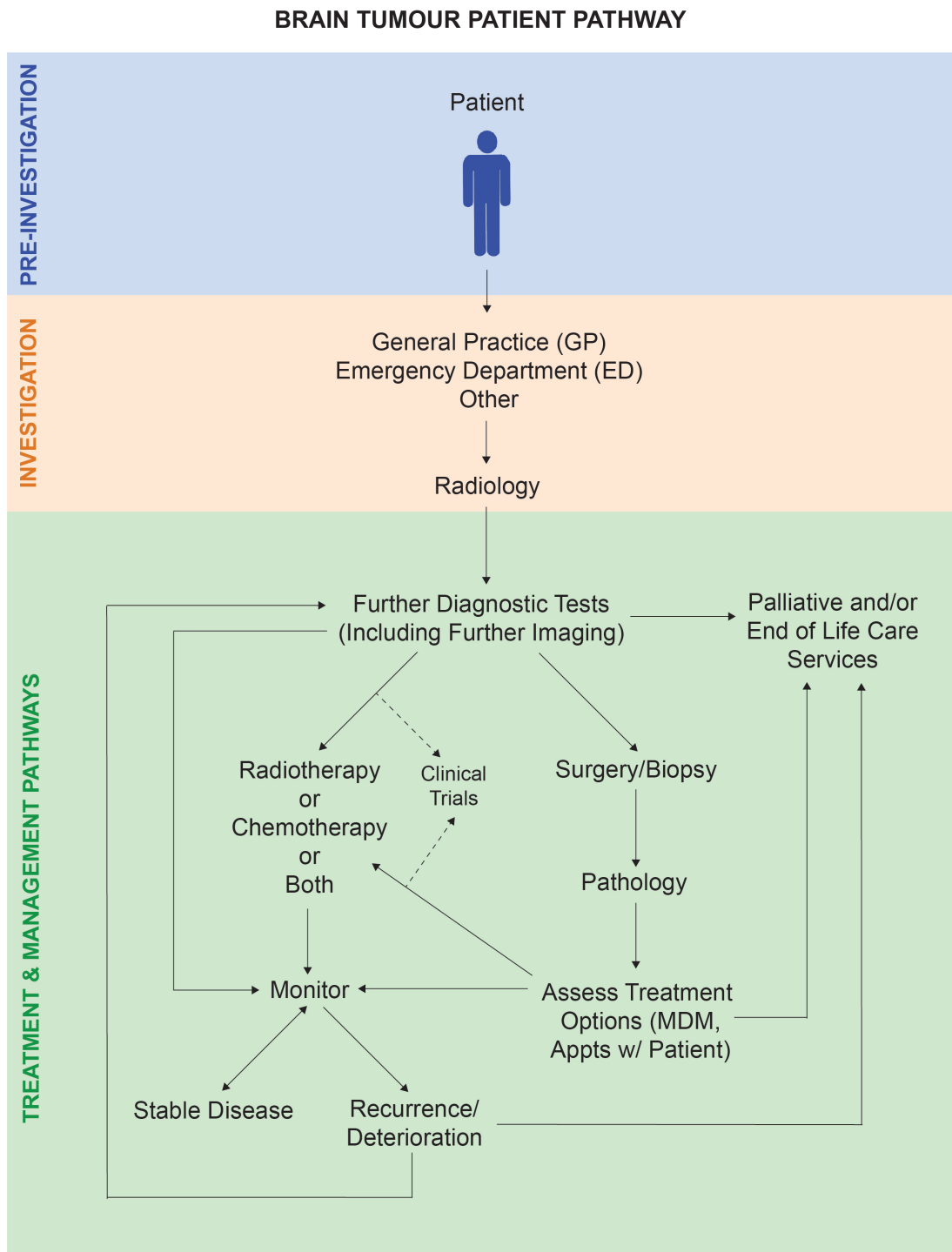
initial point of identification for brain tumours.

3. Treatment and management

Once a brain tumour is diagnosed, the patient will be referred to a neurosurgical service for further diagnostic testing and management. From this point, the patient may follow one of four potential paths:

1. Best supportive care: If the patient is particularly unwell, elderly, has significant co-morbidities and considering their wishes, they may receive best supporting care without invasive interventions.
2. Active surveillance: If the patient is not yet suitable for neurosurgery, radiotherapy or chemotherapy they may be placed under active surveillance, where they are monitored until treatment can be commenced at a later date.
3. Neurosurgery: The patient may undergo neurosurgery for maximal tumour resection or biopsy. Tumour samples will be subjected to neuropathological analysis for a formal diagnosis. Treatment options will be discussed at an MDM and the patient

Figure 2: The brain tumour patient pathway, which describes the progression of a brain tumour patient throughout New Zealand’s neuro-oncology system.



may then be referred for supportive care, chemotherapy, radiotherapy or active surveillance.

4. Radiotherapy/chemotherapy: The patient may be referred for radiotherapy and/or chemotherapy. Ongoing monitoring will assess for any evidence of tumour recurrence or progression. Patients experiencing recurrence or progression may be referred to palliative care services or undergo further investigations. The patient, therefore, re-enters the treatment cycle, potentially including clinical trials.

This pathway is not exhaustive; it does not include every MDM that may occur, every possible entry point into the neuro-oncology service or referrals to supportive services such as speech-language therapy, physiotherapy or counselling. This pathway also does not include the small subset of patients who seek care overseas.

A New Zealand brain tumour registry: key considerations

New Zealand's healthcare system

Before the major healthcare reforms in 2022, the New Zealand healthcare system was organised into 20 district health boards (DHBs), each responsible for providing health services to specific localities.^{17,18} Some DHBs served much larger populations compared to others, leading to a top-heavy system where specialist healthcare services were concentrated in major cities.¹⁷ This is evident in the neuro-oncology system, with publicly funded neurosurgery services located only in major urban areas. While this phenomenon is common globally, New Zealand's large geographic area relative to its small population exacerbates geographic disparities in healthcare access, resulting in significant inequities in healthcare services depending on location.¹⁵ In 2022, the 20 DHBs were formally disestablished and replaced by Te Whatu Ora – Health New Zealand.¹⁹ Despite this change, the healthcare system remains fragmented, with healthcare service provision still organised according to the previous DHB boundaries, perpetuating the postcode lottery. Recently, the New Zealand Government announced that Te Whatu Ora will be organised into four health regions—Northern, Te Manawa Taki, Central and Te Waipounamu,²⁰ it remains to be seen whether this new arrangement will improve these geographic inequities.

Te Tiriti o Waitangi

Achieving total population coverage is crucial to ensure all New Zealanders are represented in a national clinical registry. New Zealand's healthcare system, designed in the mid-twentieth century, was oriented around the needs of the then majority population—New Zealand Europeans.²¹ This historical system has contributed to ongoing inequitable healthcare outcomes for Māori.²¹ In 1975, the *Treaty of Waitangi Act* was passed, which allowed for the establishment of the Waitangi Tribunal.²¹ This judicial body investigates breaches of the Treaty of Waitangi/Te Tiriti o Waitangi—New Zealand's core founding document.²¹ Te Tiriti o Waitangi outlines three articles, with several references to health and wellbeing.²¹ The New Zealand government has been found in breach of its obligations under Te Tiriti o Waitangi regarding Māori health, resulting in persisting disparities in health outcomes.²² These systemic issues are well demonstrated by the postcode lottery system described above—a higher proportion of Māori reside in rural areas, where access to specialist services is limited. Consequently, the specialist service landscape in New Zealand may reinforce these inequities. In this context, studies indicate that Māori are more likely to be diagnosed with aggressive meningiomas,^{23,24} and Māori children experience a significantly higher incidence of medulloblastoma.^{25,26} Whether inequitable provision of neuro-oncology services alongside these inequities in brain tumour incidence are disproportionately affecting outcomes for Māori is unclear. Learnings from existing clinical registries can guide the development of a population-level registry and begin a thorough assessment of these inequities.

Māori data sovereignty

Another important consideration for the forthcoming national brain tumour registry is Māori data sovereignty (MDS). On a broader scale, concepts of Indigenous data sovereignty describe the right of Indigenous peoples to manage and control their own data, including collection, management, use and storage.²⁷ This emphasis on autonomy allows the determination of what information is gathered and used to achieve their own objectives.²⁷ It is a multifaceted concept, involving legal and ethical considerations related to data storage, ownership, access and utilisation of data.²⁷ In New Zealand, MDS is particularly important in relation to tino rangatiratanga (self-determination), a core principle guaranteed

by Te Tiriti o Waitangi.²⁷ Te Tiriti o Waitangi guaranteed self-determination for Māori and their taonga (treasures), including Māori data.²⁷ In line with broader Indigenous data sovereignty principles, the collection, storage, ownership and use of Māori data should be subject to Māori governance and should benefit Māori.²⁷ Te Mana Raraunga's *Principles of Māori Data Sovereignty*²⁸ and Statistics New Zealand's *Ngā Tikanga Paihere*²⁹ are two culturally centred frameworks that organisations can utilise when considering how to approach MDS. These frameworks will be invaluable in establishing a data governance structure for the national brain tumour registry, ensuring Māori data are managed according to their principles and priorities.

Governance framework

The forthcoming national brain tumour registry will require a governance framework to ensure the registry's objectives are met, resources are secured and distributed appropriately, data quality is maintained and all ethical and legal requirements are met.³⁰ The governance structure will provide guidance and oversee decisions related to the design, construction, functioning and ongoing maintenance of the registry. There are a range of possible models for a clinical registry governance framework. Typically, such frameworks will involve a project management team, a clinical/scientific committee comprising several advisory groups of interest and a quality assurance committee.³⁰ Additionally, teams focussed

on data security and collection may also be established. In New Zealand, it is particularly important to include dedicated committees representing Māori and Pacific peoples to ensure that the registry aligns with their specific needs and values. The registry will be able to leverage the expertise of over 100 members of the NANOS, who bring a diverse range of clinical, scientific and patient advisory perspectives that can contribute to this governance framework.

Conclusions

With treatment options and survival for brain tumour patients remaining largely unchanged over the last 30 years, there is an urgent need for a brain tumour registry in New Zealand. The forthcoming national brain tumour registry will enable the collection of comprehensive and accurate data on brain tumours nationwide, enhancing clinical decision-making, improving patient care and facilitating targeted research and advocacy efforts. This initial research and planning phase has identified several important considerations for the registry's development, including its structure, integrating with existing registry infrastructure, data fields of interest, alignment with the national healthcare system, Te Tiriti o Waitangi, Māori data sovereignty and the establishment of a governance framework. Further, this work has provided a clearer understanding of New Zealand's neuro-oncology system and the typical pathway a brain tumour patient follows throughout this system.

COMPETING INTERESTS

CH is co-chair of the New Zealand Aotearoa Neuro-Oncology Society and a Medical Advisory Board member for Brain Tumour Support NZ.

CT is chair for Brain Tumour Support NZ.

CW is a committee member of New Zealand Aotearoa Neuro-Oncology Society, director of New Zealand Neuro Nurses, director of Australasian Neuroscience Nurses' Association and advisor for Brain Tumour Support NZ.

LC is a New Zealand Aotearoa Neuro-Oncology Society member.

MD is chair of the Māori Advisory Board Centre for Brain Research.

MJ is a Trans-Tasman Radiation Oncology Group board member.

TP is co-chair for the New Zealand Aotearoa Neuro-Oncology Society.

FZ is a New Zealand Aotearoa Neuro-Oncology Society committee member.

Funding from the Transdisciplinary Ideation Fund – The University of Auckland; The Neurological Foundation of NZ Large Project Grant; The Centre for Brain Research Funding, The University of Auckland; Te Aka Centre for Cancer Research, The University of Auckland.

ACKNOWLEDGEMENTS

We wish to thank our many colleagues in the healthcare system and universities across the country who have contributed to this body of work. We would also like to thank the patients, whānau and other members of the community who have provided their invaluable input.

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<https://nzmj.org.nz/journal/vol-138-no-1609/establishing-a-new-zealand-brain-tumour-registry-understanding-clinical-registry-formation-in-new-zealand>

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Closing the gap: the call for government-funded annual health checks for intellectually disabled New Zealanders

Shara Turner, Conal Smith

Intellectually disabled New Zealanders die much earlier than other New Zealanders, for preventable reasons

In 2023, Aotearoa New Zealand's oldest advocacy organisation for intellectually disabled people, IHC, released a large research report containing quantitative data about the health and wellbeing of intellectually disabled New Zealanders. This report, titled *From Data to Dignity: Health and Wellbeing Indicators for New Zealanders with Intellectual Disability*, used Stats NZ's large, linked database, the Integrated Data Infrastructure (IDI), to find the intellectually disabled population and compare their outcomes across a number of domains to that of the general population.¹ Identification of the intellectually disabled population in the report relied on multiple data sources from the IDI, including hospital records, mental health services, disability support and education data, focussing primarily on individuals with moderate or severe intellectual disability who access support services.

This report shows that intellectually disabled people have the highest mortality risk of any group, with a life expectancy of up to 22 years shorter than the general population.¹ They are 2.7 times more likely to be admitted to the emergency department, 3.6 times more likely to be admitted to hospital for a condition that could have been avoided and have higher rates of lung disease, heart disease, diabetes, cancer and mental health conditions.¹

IHC's report also included details about the particular health inequalities of the intellectually disabled Māori population due to the higher rates of intellectual disability within the total Māori population. Māori with intellectual disabilities face significant health inequalities, including a life expectancy 12–14 years shorter than the

general Māori population. They are 1.63 times more likely to have coronary heart disease, 1.26 times more likely to have chronic obstructive pulmonary disease, nearly 3 times more likely to have mood disorders, almost 2 times more likely to visit the emergency room or hospital for injury care and over 2.5 times more likely to be hospitalised for preventable conditions than other Māori.¹

The increased mortality of the intellectually disabled population is not just due to worse health—research shows people with intellectual disabilities have much higher mortality, even adjusting for other conditions.² One effective intervention that could address this is government-funded comprehensive annual health checks for the intellectually disabled population.

Annual health checks may lower the risk of early mortality for intellectually disabled people by up to 35%

A meta-analysis of 28 controlled trials about the usefulness of targeted annual health checks for the geriatric population showed that those checks had the effect of reducing the early mortality risk by between 14% and 35%.³

The intellectually disabled population have things in common with the geriatric population such as highly prevalent unrecognised health conditions, impaired communication and cognition/recall difficulties.^{4,5} Intellectually disabled people also have a risk of early mortality up to three times greater than people in the general population and high levels of avoidable mortality.^{6,7}

This evidence suggests that a similar health check programme for intellectually disabled individuals could reduce their risk of preventable and premature mortality by approximately 35%. To illustrate potential outcomes, Table 1 shows how varying levels of effectiveness in reducing

Table 1: Different levels of assumed effectiveness of annual health checks.

Assumed effectiveness	Deaths avoided	
1%	3	
5%	15	
10%	30	
14%	42	Plausible range
20%	60	
25%	75	
30%	90	
35%	104	
40%	120	
45%	134	
50%	149	

mortality risk for intellectually disabled people could translate into the number of deaths avoided. These estimates use data about the deaths of intellectually disabled New Zealanders extracted from the IDI, ensuring they reflect real-world demographics and health outcomes.

Implementing health checks could save up to 104 lives per year

Based on this evidence and the mortality data from the IDI, we estimate that implementing health checks in Aotearoa New Zealand will save 104 lives a year.

To get this figure, we used data from the IDI about the deaths of intellectually disabled people in 2018. We compared the number of deaths in the intellectually disabled population to the total population of intellectually disabled people to come up with the rate of deaths. We did the same with the general population.

We then calculated the difference in the rate of death for intellectually disabled people and the general population (Figure 1). The rate is for deaths per thousand people. This then provided us with a figure showing the excess deaths per thousand that the intellectually disabled population experience.

To model the impact of health checks on the death rate for the intellectually disabled population we reduced this excess death rate by 35%. Then we used this new rate to calculate how many

intellectually disabled people would die per year compared to how many actually died in 2018.

This showed us that in 2018, 104 intellectually disabled people would not have died if we were able to lower the risk of mortality by 35%.

There is robust international evidence about the benefits of the annual health check for this population

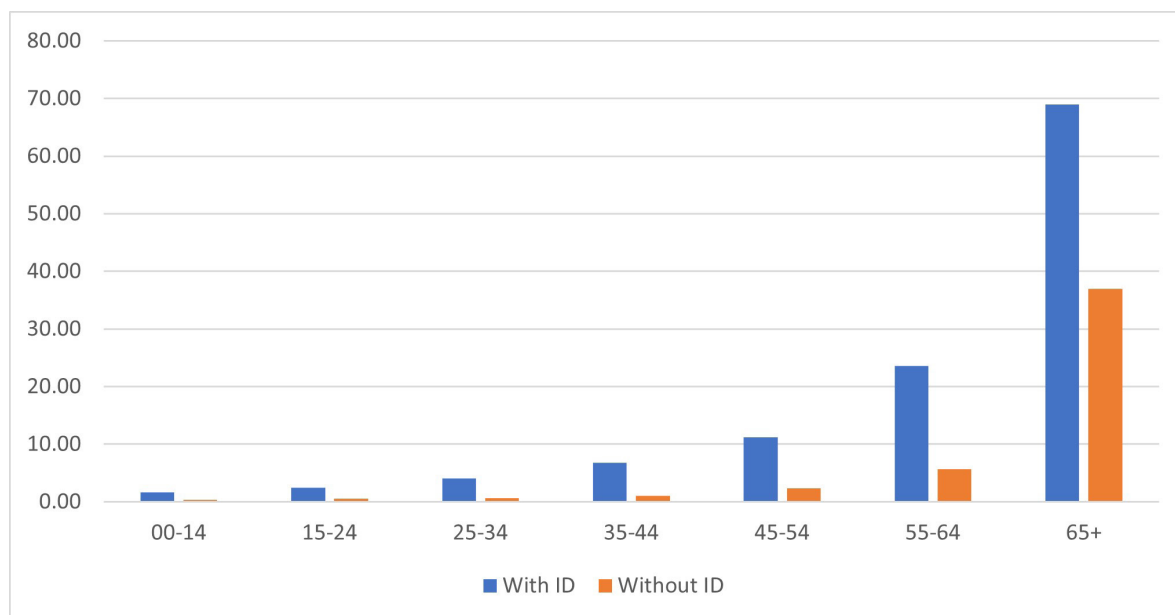
Gold-standard randomised controlled trials in Australia have created an evidence base that shows health checks for the intellectually disabled population improve health.^{4,5}

Some well-evidenced outcomes are:

- A 60% increase in new diagnoses, with 2.54 additional health problems identified⁴
- A 27% reduction in potentially avoidable hospitalisations²
- A 20% reduction in emergency department admissions for intellectually disabled people with severe health needs²

Annual health checks will ease pressure on hospitals, saving money and reducing wait times

A consistent finding of evaluations is that health checks shift intellectually disabled people

Figure 1: Rate of death for the general population and the intellectually disabled population.**Table 2:** Costs and benefits of annual health checks.

Health check cost	
One visit with practice nurse to run through, check and order tests	\$60
60-minute patient co-payment for GP (per person) after test results returned	\$147
Estimated increase in health costs due to use of health check (per person)	\$70 ⁸
Total health check cost (per person)	\$277
Current intellectually disabled pop	47,000 ¹
Total cost of health check for cohort (annual)	\$13m
Benefit of annual health check—reduce PAH	
Number of PWID who had a PAH in 2018	8,460 ¹
Annual cost of PAH for this cohort	\$63m
Cost saved if PAH reduced by 26%*	\$16.5m

GP = general practitioner; pop = population; PAH = potentially avoidable hospitalisations; PWID = person with intellectual disability.

*The 26% reduction figure is based on the 26% fall in emergency department admissions for ambulatory care sensitive conditions for practices in the United Kingdom that had high health check participation.²

Table 3: Sensitivity analysis.

Assumption	Total cost	Cost-benefit ratio
Total cost of health check without existing subsidies	\$21.5m	\$0.77
Total cost of health check if no nurse visit/two GP visits	\$16.6m	\$0.99
Total cost of health check if no increase in other medical costs	\$10.2m	\$1.65

GP = general practitioner.

Table 4: Cities with the highest numbers of intellectually disabled people.¹

Region	Approximate pop	% of ID pop nationwide
Auckland	10,300	26.7%
Hamilton	1,824	4.7%
Dunedin	1,398	3.6%
Tauranga	1,218	3.1%

pop = population; ID = intellectually disabled.

away from hospitals and towards primary care.² Since intellectually disabled people are heavy users of emergency departments,^{1,3} this will lower demand and wait times for emergency departments. Identifying treatable conditions earlier will allow more efficient prioritisation of specialist assessment and treatment.

Table 2 gives the central scenario for a benefit analysis of free health checks for the intellectually disabled population based on the best available data,² including Aotearoa New Zealand's Treasury's CBAX tool for the healthcare costs. This supports our view that annual health checks are likely to be fiscally positive.

Using the figures above we came up with a cost-benefit ratio of NZ\$1.31 for every dollar spent. Table 3 provides a sensitivity analysis for the results in Table 2. In particular, it relaxes assumptions about the health check cost. In all scenarios, except where existing subsidies provided to the intellectually disabled population are counted as new expenditure, the cost-benefit ratio is positive or almost even.

Under some assumptions listed in Table 3 the cost-benefit analysis is almost cost neutral or negative, but the benefit figure is a very conservative figure that does not include the benefits of:

- Reducing risk of mortality
- Reducing emergency department admissions

for intellectually disabled people with severe health conditions

- Reducing hospital admissions for ambulatory care-sensitive conditions
- Any other quality of life benefits that have been connected to the health checks, including improved control of seizures and weight, reduction in self-reported pain and falls and the resolution of psychiatric issues due to the discovery of underlying physical health problems^{2,9}

We know how to implement (and evaluate) this

Universal health checks for intellectually disabled people have been implemented in Australia and the United Kingdom since 2007, providing a proven and pragmatic model that could be adapted for Aotearoa New Zealand. While some service providers in Aotearoa New Zealand currently offer health checks, limited funding makes widespread implementation challenging.

The experiences of other countries and local providers offer valuable insights into the investment required, suggesting that such a programme could be introduced efficiently. Health checks are effective in identifying health conditions early, reducing hospital admissions and lowering rates

of premature mortality.

Using the IDI, it would be possible to monitor and evaluate the impacts of implementing health checks, such as improvements in health outcomes and reduced healthcare costs. An initial rollout could focus on regions with higher populations of intellectually disabled people, as research has identified where these communities are concentrated.¹

IDEA Services, Aotearoa New Zealand's largest service provider for intellectually disabled people, has been funding annual health checks for many years and healthcare staff within the organisation have streamlined the process for delivering these checks.

The health check could initially be piloted through a staggered rollout in a selection of the cities listed in Table 4. Using the code to identify the intellectually disabled population developed for the *From Data to Dignity* report within the IDI, baseline health data for intellectually disabled individuals in these areas could be extracted, providing insights into their current use of health services. These baseline metrics would enable robust monitoring and evaluation of the pilot's impact over time. Additionally, one or more comparable regions could be selected as control groups to strengthen the evaluation by providing a basis for comparison.

Conclusion

Annual health checks for intellectually disabled people are a proven intervention. With evidence showing they could prevent over 100 deaths a year and significantly reduce hospital admissions within Aotearoa New Zealand, these checks would not only improve health outcomes but also relieve pressure on emergency departments and cut healthcare costs. The successful models in Australia and the United Kingdom demonstrate that these checks are both feasible and fiscally positive. Now is the time to act—investing in annual health checks can help close the health gap and ensure better, longer lives for one of Aotearoa New Zealand's most vulnerable populations.

Limitations

Patients with milder intellectual disabilities who are not known to health services were not identified by the IDI research and therefore not included in this cost-benefit analysis. Similarly, the intellectually disabled Pacific population is small due to the health requirements of Aotearoa New Zealand's immigration laws, and this has led to potentially atypical results for the Pacific intellectually disabled population, and so data about this population are not included.

COMPETING INTERESTS

Shara Turner is a full-time employee of IHC New Zealand, advocating for intellectually disabled people, and is a member of the New Zealand division committee of the Australasian Society of Intellectual Disability.

Conal Smith is a director and shareholder of Kōtātā Insight Limited, and is a member of the OECD expert advisory board on the measurement of subjective wellbeing.

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Dr Conal Smith: Economist and Principal, Kōtātā Insight, New Zealand.

IHC is an organisation that supports people with intellectual disabilities by advocating for their rights, providing a variety of housing and work options and supporting families.

Kōtātā Insight is a multidisciplinary research organisation with expertise in economics, social psychology and statistics, utilising both quantitative and qualitative methodologies.

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<https://nzmj.org.nz/journal/vol-138-no-1609/closing-the-gap-the-call-for-government-funded-annual-health-checks-for-intellectually-disabled-new-zealanders>

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Cinacalcet-associated torsades de pointes in a haemodialysis patient: a case report

Shakir Aiman bin Sema Onsha, Fahimatul Imtiaz binti Mohd Rahiman, Marilyn Aday, Curtis Walker, Ankur Gupta

Cinacalcet is a calcimimetic agent used primarily to manage secondary and tertiary hyperparathyroidism in patients with chronic kidney disease (CKD) undergoing dialysis.^{1,2} We herein report the case of a 64-year-old male undergoing haemodialysis (HD) who developed life-threatening torsades de pointes (TdP) likely induced by cinacalcet.

Case report

A 64-year-old male with stage 5 CKD on intermittent HD, atrial fibrillation, hypertension and type 2 diabetes mellitus experienced sudden central chest pain during dialysis, followed by unresponsiveness. He had no history of ischaemic heart disease and his baseline electrocardiogram (ECG) few months prior was normal (Figure 1). There was no recent alteration in dialysate concentration (3.0mmol/l of potassium and 1.25mmol/l of calcium). Haemodynamics are shown in Table 1. Telemetry at the time of event showed ventricular tachycardia (VT), which prompted cardiopulmonary resuscitation (CPR), calcium gluconate administration and three defibrillation shocks, successfully achieving return of spontaneous circulation (ROSC). Shortly after, he developed TdP (Figure 2a), requiring another round of CPR and defibrillation, which achieved ROSC. Laboratory investigations showed normal levels of calcium, magnesium, sodium, potassium, bicarbonate and phosphate (Table 2). ECG showed prolonged corrected “ventricular depolarisation and repolarisation interval” (QT; corrected QT interval [QTc]) Bazett interval ranging from 545 to 587 milliseconds (Figure 2b). Echocardiography demonstrated normal systolic function with mild calcification of the aortic valve. His medications included oral cinacalcet 30mg daily (initiated 10 days prior), bumetanide, felodipine, doxazosin, clonidine, erythropoietin and calcitriol. He denied intake of any herbal or alternative medications.

Given the suspected drug-induced QT prolongation, cinacalcet was discontinued. Serial follow-up ECG within 9 months showed QTc reduction to 420–461 milliseconds (Figure 3).

Discussion

Our case underscores the potential for cinacalcet, even in the absence of dyselectrolytaemia, to precipitate life-threatening arrhythmias such as TdP. On the Naranjo algorithm, cinacalcet is the “probable” aetiology for this reaction.³ The QT interval represents the duration of ventricular depolarisation and repolarisation, and its prolongation is a well-recognised risk factor for TdP, particularly in patients with pre-existing metabolic imbalances and CKD. Furthermore, the QT interval and QT dispersion in HD patients are higher than in the general population.⁴ Cinacalcet has been shown to potentially prolong QT intervals in the HD population.^{5,6}

Historically, the first case of cinacalcet-induced TdP was reported in 2015, where hypocalcaemia was a contributing factor.⁷ However, our case is significant as it represents the first documented instance of cinacalcet-induced TdP in Australasia without hypocalcaemia. Cinacalcet lowers parathyroid hormone secretion and subsequently reduces serum calcium levels. Evidence has implicated that early after-depolarisation (EAD) and QT-interval-prolonging drugs are those associated with re-entrant arrhythmias like TdP.⁸ While hypocalcaemia is known to prolong action potential duration and increase the risk of EAD, our patient did not present with hypocalcaemia, suggesting that cinacalcet may contribute to QT prolongation through calcium-independent mechanisms.

Interferences with potassium channels, such as the rapid delayed rectifier potassium (IKr) channel responsible for the repolarisation phase, is probable, thus prolonging the QT interval

regardless of calcium levels.⁸ A pattern of short-cycle QT interval followed by a long one, followed by a short one, which also occurs in our patient, is typical for drug-associated TdP. Short-long-short sequences create a pause-dependent setup for TdP by facilitating the generation of EADs during the extended beat, followed by an unstable repolarisation phase, which can heighten TdP susceptibility.⁸ Alterations in IKr function may contribute to the development of TdP, especially when long-short or short-long-short sequences are present. This highlights how QT prolongation—through IKr suppression—interacts with specific ECG patterns to create a high-risk arrhythmogenic environment.

In addition, a study showed that cinacalcet, particularly in higher doses, may cause dose-related calcium-independent direct effects on cardiac electrophysiology.⁵ However, our patient in this case was prescribed the lowest recommended dose of cinacalcet.

Emerging alternatives to cinacalcet, such as evocalcet, may have a more favorable safety profile concerning QT prolongation when compared with cinacalcet. Cinacalcet is a potent CYP2D6 inhibitor, which could cause serious drug

interactions.⁹ Evocalcet has reduced non-calcium receptor off-target effects and fewer issues of CYP-related interactions.¹⁰ This could represent a vital development for patients with secondary hyperparathyroidism undergoing HD, as a safer calcimimetic could mitigate the risk of life-threatening cardiac events while effectively managing hyperparathyroidism.

Conclusion

This case emphasises the importance of recognising both calcium-dependent and independent mechanisms of QT prolongation in patients treated with cinacalcet. The normalisation of the QT interval following drug discontinuation highlights the direct role of cinacalcet in inducing arrhythmias, even in the absence of hypocalcemia. Clinicians should be aware of QT prolongation in HD patients treated with cinacalcet, particularly those with underlying cardiac disease or electrolyte imbalances. Regular monitoring of serum electrolytes including mineral balance and ECG (both prior to cinacalcet initiation and follow-up) in a dialysis clinic is advisable to prevent potentially fatal outcomes.

Figure 1: Electrocardiogram prior to cinacalcet initiation showing QTc of 402–447msec and heart rate 75/minute.



Figure 2a: Torsades de pointes (TdP) on day of hospitalisation in telemetry strip, demonstrating short-long-short cycle followed by TdP.

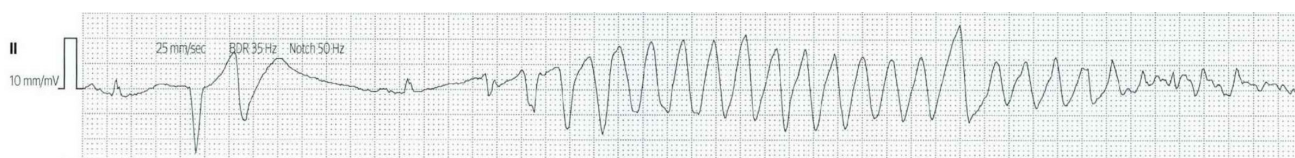


Figure 2b: Electrocardiogram on the same day after resuscitation showing QTc of 545–587ms.

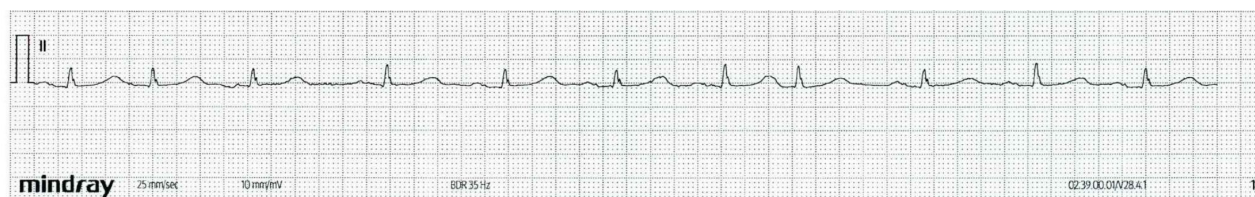
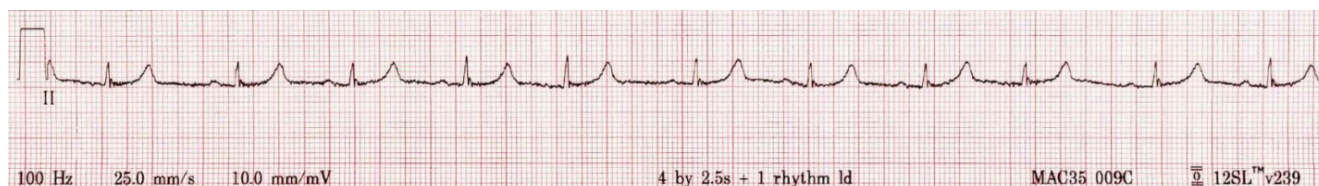


Figure 3: QTc (420–461ms) in a follow-up electrocardiogram 9 months after the event.**Table 1:** Haemodynamic parameters.

	Baseline	Pre-event	Post-event
Blood pressure (mmHg)	191/67	<u>171/94</u>	187/72
Heart rate (beats per minute)	<u>70</u>	89	<u>60</u>

Table 2: Biochemical and haematological laboratory investigations.

	Prior to cinacalcet	Pre-event	Post-event
White cell count ($\times 10^9/L$) (4.0–10)	5.3	6.1	13.4
Haemoglobin (g/L) (125–170)	71	91	98
Platelet ($\times 10^9/L$) (150–400)	117	113	128
Sodium (mmol/L) (135–145)	134	141	138
Potassium (mmol/L) (3.5–5.2)	3.7	4.4	3.4
Bicarbonate (mmol/L) (21–27)	27	23	21
Ionised calcium (mmol/L) (1.15–1.30)	1.12	1.15	1.17
Corrected calcium (mmol/L) (2.10–2.55)	2.46	2.41	2.41
Magnesium (mmol/L) (0.7–1.10)	0.68	0.69	0.64
Phosphate (mmol/L) (0.75–1.5)	1.99	0.76	0.76
Troponin T (ng/L) (0–13)	N/A	185	178
PTH (pmol/L) (1.8–7.9)	116	N/A	N/A

COMPETING INTERESTS

Nil.

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Onkar Nath Mehrotra

25 July 1931–10 August 2024
Plastic and Reconstructive Surgeon, 1956 MBBS, FRACS 1968



Onkar died peacefully in Auckland, on 10 August 2024, from pancreatic cancer.

Onkar was born in 1931 in Laharpur, a small village in Uttar Pradesh, North India. His parents, Ram Prasad Mehrotra and Nandini, were jewellers. The second eldest of a large family, with six brothers and two sisters, he attended Sitapur School. He was determined to educate himself and not follow the family business. Onkar had always desired to be a surgeon, although later confided he would become a hairdresser with his own salon if surgery had not been possible.

Onkar graduated from King George Medical School in Lucknow with MBBS in 1956 and MSurg (Hons) in 1960. He married Kusum Kacker from Jodhpur, a political science student, in 1959.

After 2 years training in general surgery in Allahabad, in 1963 he secured a post in a small district hospital in Pratapgarh, leaving Kusum

in Laharpur. Alone and feeling unchallenged in this small hospital, and determined to expand his surgical skills, he decided to emigrate. He also wanted his young children to have access to better education. He responded to an advertisement in *The Lancet* for plastic surgery registrars at Middlemore Hospital, Auckland; the initial appointment was for 10 months.

Selling his scooter to pay for his flight to New Zealand, and with £20 in his pocket, Onkar arrived alone in Auckland in 1965. His family followed later in 1967.

William Manchester, head of the Middlemore plastic surgical unit, was impressed with Onkar's superior anatomical knowledge. This was from 2 years of lecturing anatomy in Allahabad while preparing to sit the English FRCS exam. He thus offered Onkar a training post in plastics. Onkar sat and passed the FRACS in 1968 and was appointed

full-time plastic surgeon.

Onkar was a slick and accomplished surgeon. He would complete a large local anaesthetic surgical list in one of the casualty theatres in record time, with enough downtime between patients to read the *NZ Herald* from front to back page. Working with Don Liggins, using the new operating microscope donated by Sir William Stevenson, Onkar was a pioneer of early microsurgery techniques in the 1970s. In 1973, the two of them performed the first free groin flap at Middlemore. Onkar and Earle Brown, forming the famous Red Team, commenced a combined hand surgery service.

Onkar was loved and respected by generations of registrars for his enthusiasm, loyalty and “you can do it!” attitude. Numerous trainee surgeons inspired by his dexterity and precision later specialised in hand surgery. During the many years of his Middlemore practice, Onkar published a number of papers on hand, facial and lower limb trauma, head and neck cancer and flap innovations. He commenced in part-time private practice in South Auckland in 1977, sharing facilities with Brian Otto, an orthopaedic surgeon. He later established a practice in Remuera in 1978, with many of his

procedures completed using local anaesthesia. An honorary professorship was conferred on Onkar by the King George Medical School when he participated as an invited lecturer at the First National Plastic Surgical Workshop in Lucknow in 1987.

After over 30 years of service at Middlemore Hospital, Onkar retired in 1996. He enjoyed a long retirement, and golf became his new passion—having been introduced to this sport by a colleague, Patrick Beehan, a keen golfer who, in 1967, taught Onkar to play on the neighbouring Middlemore Golf Course. He was a well-liked and respected member of Akarana Golf Club and achieved a “hole-in-one” on three occasions. He also enjoyed reading the classics, travelling in style to Europe, Japan and Alaska, and making occasional visits back to India. He was a hugely generous and enthusiastic family man and was immensely proud of his children and grandchildren.

Onkar celebrated his 93rd birthday while hospitalised, and is survived by his wife Kusum, children Rina and Pancho, their partners and three grandchildren.

AUTHOR INFORMATION

This obituary was written by Rina Mehrotra, MBChB, FRCA, consultant anaesthetist, Guy's and St Thomas', London; Michael Klassen, FRACS, Sydney; and Peter Charlesworth, FRACS, Auckland.

Primary Sarcoma of Liver

NZMJ, 1925

By KENNETH SALMOND, M.B., CH.B.

From a diligent search of literature the above condition appears to be sufficiently rare to warrant publication.

Betty, S., a girl 2½ years of age, was brought to me 10th November. The mother, an educated woman, gave the following history:—Child quite healthy up to six weeks ago—since then had been fretful on occasions—asking to lie down because of either tiredness or “stomach ache.” On 17th November, her mother first noticed an enlargement of upper abdomen. On 10th November I found the liver enlarged down to the level of the umbilicus in the right nipple line—1½ inches above umbilicus in mid-line. Liver was smooth and not tender. There were distended veins over the liver area. Spleen not enlarged. Heart and lungs were normal. Temperature, pulse and respirations normal.

The child, who was well nourished and looked well, was admitted to a private hospital for observation. The urine was examined and found normal. The blood picture was negative. The diagnosis at this stage would seem to rest between:—(1) Cirrhosis, (2) hydatid cyst, (3) congenital syphilis, (4) primary sarcoma. The X-ray picture showed uniform enlargement of liver, no opacity suggesting hydatid infection. By the third day in hospital the liver had descended ½-inch in the middle line. The abdomen was more prominent. The child was still well, taking her food and running about. Blood was taken for the Wassermann and complement fixation tests: both of which were negative.

As regard the diagnosis I dismissed:—(1) Cirrhosis—because of the rapidity of the growth; (2) hydatid infection—because of the child’s age, negative X-ray picture and negative complement

fixation test; (3) congenital syphilis—because of absence of usual stigmata of the disease, negative Wassermann reaction. By the above process of elimination I diagnosed the case as primary sarcoma of liver. By 17th November the lower border of liver had reached the umbilicus in the mid-line—it was now slightly rough to the touch and to the left of the umbilicus there was a tender mass (the size of a golf ball) no continuous with the liver; presumably an enlarged mesenteric gland. By this time the child was looking definitely ill and wasted, but was not confined to bed.

The parents at this stage wished to take the child home, so I did not see the case again until 5th December. The abdomen was now enormously distended, the lower border of liver reaching 2 to 2½ inches below the umbilicus in the middle line. Child looked desperately ill, but neither jaundice nor ascites was present. Respiration, 60; pulse, 130; temperature, normal. She could stand up, but could not walk, and although the body was markedly wasted, the child was undoubtedly decidedly heavier owing to the great enlargement of the liver. The child died on 10th December, *i.e.*, ten weeks from the time of the first symptoms.

I regret now that the child’s weight and the circumference of the upper abdomen were not recorded in the first instance. Between 12th and 17th November, the case was seen by Mr. Wylie, of Palmerston North, and Drs. Duncan Stout and Hardwick Smith, of Wellington, all of whom agreed with the diagnosis.

The interesting points in this case in my opinion are:—(a) The rapidity of the growth; (b) the apparent good health of the child in the early stages; (c) the absence of ascites and jaundice; (d) the obvious increase in the weight of the child.