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Leadership and governance—what is needed to deliver Aotearoa New Zealand health reforms

Improving the provision of cataract surgery in New Zealand demands disruptive change

The priorities for future clinical trials and large cohort studies addressing health and healthcare for mothers and babies in Aotearoa New Zealand

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NZMJ Editor
Professor Frank Frizelle

NZMA Chair
Dr Alistair Humphrey

NZMJ Production Editor
Brooke Soulsby

NZMA Communications Manager
Esther Munro

Other enquiries to:
NZMA
PO Box 156
The Terrace
Wellington 6140
Phone: (04) 472 4741

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Summaries

Rate of recurrence of toxoplasmosis retinochoroiditis at a tertiary eye centre in Auckland

Himanshu Wadhwa, Joanne L Sims, Rachael L Niederer

Toxoplasmosis infection of the retina and choroid can self-resolve but tend to cause additive damage to the retina with each acute flare. Our retrospective study looked at 126 eyes from 115 patients, and found that over a 6.1 year median followup period, 73 recurrences occurred in 36 patients. Recurrence occurred in 15% in the first year, and the risk of recurrence was increased 2x for every previously documented recurrence.

Patient-reported quality of life and eligibility for cataract surgery: assessing the relationship between ethnicity and 'Impact on Life' questionnaire scores in New Zealand

Nancy Wang, Lyn Hunt, James McKelvie

The 'Impact on Life' (IoL) questionnaire is a patient reported quality-of-life assessment tool currently used to prioritise for public-funded cataract surgery in New Zealand. Our study aimed to assess the association between ethnicity and IoL questionnaire responses using Ministry of Health data for patients being prioritised for cataract surgery between November 2014 and March 2019 in New Zealand. The results show that Māori and Pacific people presented at a younger age with more advanced cataracts and worse visual acuity than other ethnic groups at the time of prioritisation. However, the IoL score did not reflect this ethnic disparity in any meaningful way, after controlling for other potential factors. While this could be due to a real lack of disparity in quality of life amongst different ethnic groups, it could also be due to the IoL questionnaire being an unsuitable tool for assessing these differences.

Caregiver survey of preschool children with obesity referred to Whānau Pakari—a multidisciplinary healthy lifestyle intervention programme

Tami L Cave, José G B Derraik, Esther J Willing, Paul L Hofman, Yvonne C Anderson

This paper aims to examine the perceptions of caregivers of preschool children related to the acceptability of weight screening at New Zealand's B4 School Check (B4SC), and the accessibility and acceptability of the Whānau Pakari healthy lifestyle programme for preschool children identified with weight issues.

The prevalence of glaucoma among 45-year-old New Zealanders

Aqeeda Singh, Jesse Gale, Kirsten Cheyne, Antony Ambler, Richie Poulton, Graham Wilson

This study aimed to estimate the prevalence of glaucoma in New Zealand using various data including spectral domain optical coherence tomography (OCT) in a population-based birth cohort of 45-year-olds. The prevalence was found to be between 0.2% and 1.4%, consistent with other population-based studies in the same age group. This is one of the first population-based studies to include OCT in the diagnosis of glaucoma, and it highlights the sensitivity of OCT and the potential for misinterpretation and over-investigation especially if used for screening in the community.

The priorities for future clinical trials and large cohort studies addressing health and healthcare for mothers and babies in Aotearoa New Zealand

Katie M Groom, Clara Mossinger, Jody Lawrence, Jane E Harding, Karaponi Okesene-Gafa, Matire Harwood, Frances Benge, Jessica Steele, Caroline A Crowther

Clinical trials and cohort studies are ways to test (research) health interventions including treatments, tests and health systems, in people and populations in real life situations to see if they work and work safely. Research prioritisation is the process of deciding which is the most important research to do. We have designed and used an equity driven framework to prioritise which clinical trials and cohort studies in mothers and babies' health should be done and supported in Aotearoa New Zealand in the future. A large number of people including pregnant women and their whanau, healthcare providers and researchers contributed to this project. The framework can be used across all areas of health research.

CPAP for paediatric patients in Aotearoa New Zealand: audit of a developing service at Capital and Coast DHB 2005–2020

Dawn Elder, Sophie Gandhi, Angela Campbell

Snoring in children and young people can indicate the presence of significant Obstructive Sleep Apnoea (OSA). This is being increasingly recognised with more patients being referred for assessment and treatment. Many of these children have obesity as their main risk factor for OSA. Untreated OSA can have longterm effects on both heart function and learning in affected children and adolescents. There is currently limited availability of assessment and treatment services for OSA in the paediatric and adolescent age range.

Telephone triage does not improve attendance rates in a paediatric audiology outpatient service

Michelle A Pokorny, Renee A Hislop, Elizabeth A L Holt

Hearing healthcare services are important for children who have a significant hearing loss or ear disease but nonattendance at appointments is a significant issue in many outpatient services for children. This study took place during the COVID-19 lockdown to see if a telephone consultation with an audiologist would improve attendance rates after services started again. Attendance was found to be associated with ethnicity and wait times. Telephone consultation did not improve attendance rates overall nor for any specific ethnicity subgroups.

Persisting variance in middle ear ventilation tube insertion in Auckland children: why ethnic disparity continues

Julia Y Seo, Randall P Morton, Catherine Gerard, Lesley Salkeld, Suzanne C Purdy

Ventilation tubes (VTs) or grommets are a common surgical treatment for recurrent middle ear disease in pre-school children (0–4-year-olds), however the rates of procedures do not appear to align with disease burden. Māori and Pacific children generally experience a greater burden of ear disease, but have lower rates of VT insertions compared to European children of the same age group. The differences in ethnicity are more pronounced in Counties Manukau DHB, compared to Auckland DHB and the national average. These persisting ethnic and regional inequities in treatment rates highlight ongoing socioeconomic and cultural barriers in accessing surgical services for Māori and Pacific populations, as well as the gaps in our current screening services for middle ear disease in children.

Leadership and governance—what is needed to deliver the Aotearoa New Zealand health reforms

Iwona Stolarek, Karina McHardy, Lloyd McCann, Andrew Simpson, Grant Howard, John Robson

Aotearoa New Zealand is implementing a significant health reform agenda heralded as a "once in a generation" opportunity, derived from the Health and Disability System Review.[1] The reforms move us from delivering more healthcare activity and accepting unwarranted variation in care, to focusing on wellbeing and health outcomes and delivering services to meet people's needs. Central to the reform agenda is the imperative to achieve equitable outcomes, particularly related to Māori, Pacific peoples, and disabled populations.

Arguably, previous major health reforms in the 1990s and 2000 have not effectively addressed inequalities, nor created an integrated, coordinated system.[2] In addition, these reforms have not meaningfully changed practice for most frontline clinicians. So, what needs to be different this time?

Today a range of complex global and local variables affect all aspects of our lives, including health. While change is a constant, COVID-19 has highlighted that we cannot predict the future precisely, and that we have complex challenges with few single causes or solutions.[3] Yet, large-scale change can happen rapidly. Globally, healthcare delivery systems are under increasing pressures from other factors including health workforce ageing and supply, consumer expectations, and climate change.

Healthcare is a complex adaptive social system (CAS). It has numerous agents including health service users, ministers, central agencies, national and community organisations and providers, healthcare professionals, educators, regulators… the list goes on. There are innumerable interactions amongst these agents (both people and organisations) who, through these interactions, learn and adapt, thereby constantly reshaping the system.[4,5]

Leadership and governance are building blocks of a well-functioning health system.[6] The multitude of largely Western definitions, and models related to these terms, highlight that there is no consensus or agreed taxonomy around their meaning. Given this, thinking in old models and roles of "management, leadership, and governance" can prove circular and ultimately unhelpful. The focus of this editorial is to reframe this thinking and consider the knowledge, mindset, and behaviours needed for leadership and governance of a CAS.

The correlation between effective leadership and overall performance is well established.[7] Here, it is worth considering the differences between complex and complicated systems, and the leadership skills needed for the respective systems. Much work has been done on this, and the Cynefin model and leadership framework is commonly used.[8] This model supports thinking about leadership and governance, and the approaches to take in the simple, complicated, complex, or chaotic domains.

In healthcare, an example that reflects the simple domain is taking a laboratory test and treating an infection. The simple domain—where cause and effect are clear—requires us to use best practice approaches. Leadership is supervisory—ensuring proper processes are in place. The danger is we apply this approach to complicated and complex problems, or continue with the same thinking when context changes.

The complicated domain—for example, management of surgery in an older adult with multiple co-morbidities—requires analysis or expertise, as there may be multiple appropriate responses available. However, it is still fact-based. Leadership is about bringing together expertise, listening to at times conflicting advice; to sense, analyse, and respond with good practice solutions. The danger here is "analysis paralysis" and experts overconfident in their solutions.

A complex system is not higher-order complicatedness; it is a fundamentally different kind of system requiring a different approach to leadership and governance. In complexity there is flux and unpredictability, no right answers, and many competing ideas. Examples in health include responding to rising national obesity rates. Here, there is a need for pattern-based leadership: ensuring

diversity of input and interaction, and encouraging safe environments to test creative and innovative ideas, thereby allowing patterns to emerge. A danger is that leadership looks for facts rather than patterns using "complicated" approaches. As many of the challenges in this domain involve social determinants of health, both diversity of input and collaboration must be significant.

In chaos—for example, the early days of a pandemic—there is need for leadership to take control, to shift the system from chaotic turbulence where patterns cannot be discerned into complexity. Leadership needs to provide strong, direct communication, and enable the system to take advantage of opportunities and innovations that arise.

Although no role sits exclusively in a single quadrant, most clinical specialty-level work functions predominantly in the complicated domain, whereas organisational and national system-level challenges, such as achieving equity, sit in complexity. Clinicians are often assumed, on the basis of proven, tested clinical expertise and sometimes leadership in the simple or complicated domains, to have appropriate knowledge and skills when stepping into new organisational or national leadership or governance responsibilities. In transitioning to more system-level roles, we may default to applying our known, "complicated" knowledge and tools—an approach that could be inadequate, inappropriate, and have negative consequences.

We need to deliberately shift our approach by acquiring knowledge of complexity and systems science, and then applying this to the design and evaluation of interventions. We need an open, outward mindset that sees the world as interconnected and interdependent with dynamic, non-linear interactions, in which relationships are fundamental. We must accept and account for inherent uncertainty and unpredictability, understanding that interventions can have positive and negative impacts on the whole, and may not deliver the anticipated change.

A CAS leader accepts that there are no simple solutions, nor can they be solved by a single person. They are humble, admitting they do not know all the answers. They use networks and an inclusive, authentic sharing of power and knowledge—especially with those impacted—to identify patterns, ensure diversity of inputs and enable creativity to try local solutions for local contexts—always working to advance collective results. They know that solutions are not static, but may adapt further over time. A focus on individual or group interests and advancement will not bring about the required system change. Ultimately, rather than leadership being done *to* the system, the complex domain demands leadership *through* the system.[7]

A CAS has a few simple operating rules that become the system's drivers and guidelines for all decision-making. In this complex domain, our shared health reform purpose to achieve the best equitable, culturally safe experiences and outcomes, at both whānau and population levels, becomes the system's operating rule to determine our decisions. Governance in complexity must accept there are no best practice solutions that can be applied everywhere and be permissive within enabling constraints. It must be tight on accountability and responsibility for outcomes, but loose on the approaches to achieve them in different contexts. We need a greater risk appetite and tolerance for failure and for lessons to be learned. Equity needs to be the frame through which everything else is viewed, approached and evaluated. To do this, we must move beyond just cost-benefit and cost-effectiveness analyses, to instead prioritise "equity-effectiveness".

As clinicians transition from direct patient-facing to system-level roles, we must be deliberate in requiring the appropriate expertise and behaviours, and providing access to training opportunities and pathways. We must ensure system leaders have the appropriate skill sets for the level of the system they work in, and that we support them to grow in these roles.

COMPETING INTERESTS
Nil.

AUTHOR INFORMATION
Iwona Stolarek: Independent Consultant, Wellington.
Karina McHardy: Independent Consultant, Auckland.
Lloyd McCann: CEO & Head of Digital Health, Mercy Radiology and Clinics & Healthcare Holdings Ltd, Auckland.
Andrew Simpson: Independent Consultant, Wellington.
Grant Howard: Intensivist, Department of Critical Care, Waikato District Health Board, Hamilton.
John Robson: General Practitioner and Medical Administrator, Wellington.

CORRESPONDING AUTHOR
Iwona Stolarek: Independent Consultant, Wellington. authorISNZ@gmail.com.

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Rate of recurrence of toxoplasmosis retinochoroiditis at a tertiary eye centre in Auckland

Himanshu Wadhwa, Joanne L Sims, Rachael L Niederer

ABSTRACT

AIM: Our aim was to examine rate of recurrence of toxoplasmosis retinochoroiditis and risk factors for recurrence. No New Zealand epidemiological data on recurrence rates of toxoplasmosis retinochoroiditis have been previously published.
METHODS: Retrospective chart review of all patients with toxoplasmosis retinochoroiditis presented to Auckland District Health Board Department of Ophthalmology between 2006–2019.
RESULTS: One hundred and twenty-six eyes of 115 patients were included with a median age at initial diagnosis of 36.7 years (IQR 23.7–53.8). Fifty-nine patients were female (51.3%), and 16 patients (13.9%) were immunosuppressed. Twenty-six of the 86 patients tested (30.2%) were IgM positive at presentation. Mean follow-up was 6.1 years and 73 recurrences occurred during the follow-up period in 36 patients (31.3%). Treatment was initiated in 87.4% of cases, with oral cotrimoxazole or clindamycin the most common options. Recurrence occurred in 14.8% in the first year (95% CI 10.3%–21.0%), and the risk of recurrence was increased 2x for every previously documented recurrence (HR 2.00; p<0.001). There was no statistically significant increased risk of recurrence with age, IgM positivity, immunosuppression or macular involvement.
CONCLUSIONS: Toxoplasmosis retinochoroiditis had a 14.8% risk of recurrence in the first year, with each previous recurrence increasing the risk by two-times.

Toxoplasmosis gondii is a ubiquitous parasitic protozoan that causes blindness worldwide. Although cats are its primary hosts, toxoplasmosis commonly infects humans and can infect any nucleated mammalian cell.[1] An estimate in 2004 suggested one third of the human population was infected with toxoplasmosis.[2] Positive toxoplasmosis serology varies between 20–85% in the world,[1] with differences largely due to cultural differences in cooking patterns and cleanliness of water supply. The most common pathological clinical presentation of toxoplasmosis is acute retinochoroiditis[1]—inflammation of the retina and choroid in the eye. This results in scarring of these structures and can lead to permanent vision loss left untreated.

Ocular toxoplasmosis typically has a recurring course[2] that can be explained by the lifecycle of the parasite. The slow-growing bradyzoite forms of toxoplasmosis can remain dormant for prolonged periods throughout a person's lifetime. Bradyzoites covert into fast-growing tachyzoites, which utilise cells of nucleated hosts to replicate. These manifest clinically with unilateral necrosis of the retina with secondary inflammation of surrounding choroid, vitreous and retinal vessels. The necrosis often occurs adjacent to a pigmented retinochoroidal scar. No cure for ocular toxoplasmosis is known, and current treatments aim to reduce inflammation, scar size, and rates of recurrence.

Knowledge of recurrence rates and risk factors for recurrence can guide treatment. Recurrence rates of ocular toxoplasmosis range from 40–79%,[3] with the highest rate of recurrence of toxoplasmosis being in the first year. Higher rates of recurrence have been reported to occur in the elderly or very young, people with existing retinal scars,[4] people affected with Brazilian strains of *T. gondii* compared to European or American strains,[5] IgM positive patients treated with intravitreal therapy compared to classic oral therapy,[3] lack of long-term antibiotic prophylaxis,[6] and immunosuppressed people. Treatment with prophylactic antibiotics for secondary prevention has been shown to reduce recurrence rates.[5] However, the only absolute indications for this are congenital toxoplasmosis, infection during pregnancy and immunocompromised status.[3] In immunocompetent individuals, an active episode of ocular toxoplasmosis can resolve without treatment. Thus, the decision to treat with antibiotics for secondary prophylaxis is controversial despite its tendency to relapse.[7]

Given the high variability between geographic locations of seroprevalence and prevalence of different strains of toxoplasmosis, local epidemiological data is important. Currently, no known studies have looked at rates of recurrence in the New Zealand population. The aim of this study was to explore rates and risk factors for recurrence of toxoplasmosis retinochoroiditis in a New Zealand population.

Methods

Patients with toxoplasmosis retinochoroiditis were identified from a database of patients with uveitis seen in Uveitis Clinic (acute clinic and specialist clinic) at Auckland District Health Board, a publicly-funded specialty eye clinic for the Auckland Region, between 2006 and 2019. To be seen in this clinic: patients with possible uveitis are referred from general practitioners, optometrists, and other ophthalmologists in public or private, or triaged from the acute eye clinic. The catchment group is therefore Auckland residents who have acute toxoplasmosis retinochoroiditis, or those who have dormant toxoplasmosis retinochoroiditis and choose to have publicly-funded follow-up appointments in Auckland. Patients with follow-up in private clinics and patients from outside Auckland were excluded. Ethics Committee approval was obtained before data collection (AH 1339).

Data was collected on a standardised pro forma including demographic characteristics, immunosuppression, presentation, toxoplasmosis serology, treatment, complications and recurrence of disease. The best-corrected visual acuity results were converted to logMAR units for analysis. For visual acuities of counting fingers or worse, the following conversion was used: counting fingers 2.0 logMAR; hand movements 2.3 logMAR; light perception 2.6 logMAR; no light perception 2.9 logMAR.

Statistical analysis

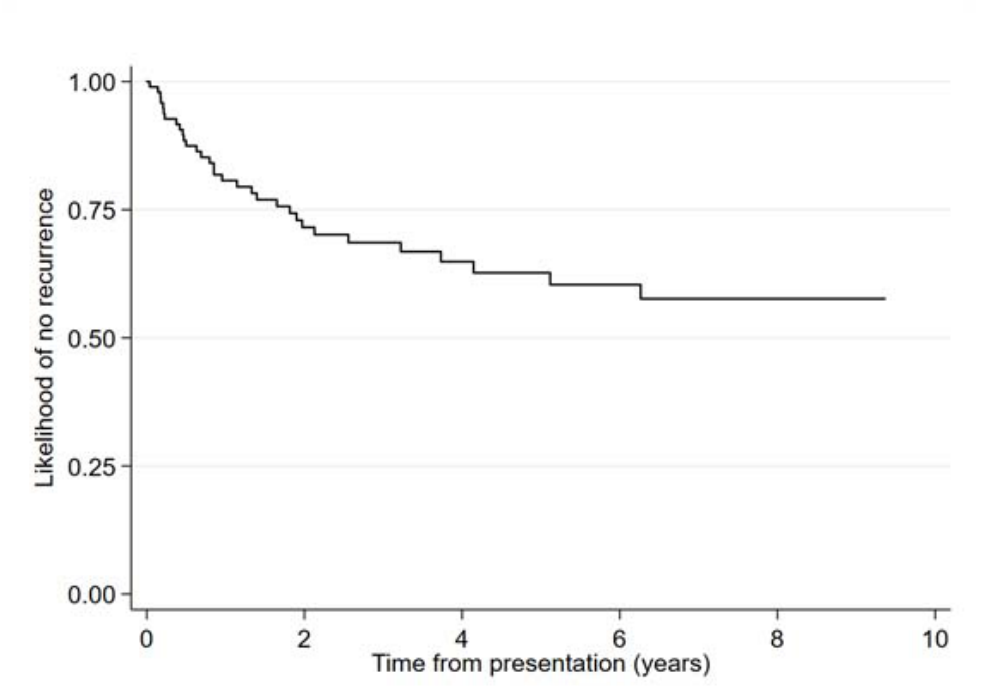
Data was entered into a spreadsheet before analysis. Risk factors for recurrence of toxoplasmosis retinochoroiditis were calculated using a marginal Cox Regression model with a robust sandwich estimate to allow for correlations between eyes. A p value <0.05 was considered significant. Data was analysed using STATA version 15 (StataCorp 2017, College Station, TX).

Results

Rate of recurrence

Toxoplasmosis was identified in 126 eyes of 115 patients, representing 4.3% of the 2659 patients in the uveitis database at the time of the study. During the study period, 199 episodes of retinochoroiditis were observed. Mean follow-up was 6.1 years, with

Figure 1: Cumulative hazard of recurrence of toxoplasmosis retinochoroiditis.



a total of 696.9 eye-years follow-up. During the follow-up period, 73 recurrences were observed amongst the 43 eyes of 37 patients. In the 126 eyes: 43 had at least one recurrence; 20 had at least two recurrences; 7 had at least three recurrences; 5 had at least four recurrences; 3 had at least five recurrences; 1 had at least six recurrences; and none had seven or more recurrences. No patients with unilateral active disease at initial presentation, and a previously unaffected contralateral eye, developed recurrence in the unaffected eye.

Cumulative incidence of recurrence is reported in Figure 1. Specifically, this shows the cumulative incidence for any recurrence from a population perspective based on the number of individuals who had one or more recurrences out of the total population after specified time intervals. The cumulative hazard of recurrence declined over time and was greatest at 1 year. The likelihood of no recurrences at 1, 2 and 3 years was 14.8% (95% CI 10.3–21.0%), 25.5% (95% CI 19.5–32.9%) and 33.4% (95% CI 26.4–41.6%), respectively.

Patient demographics

Demographic characteristics are reported in Table 1. Age at first presentation ranged between 1.8 to 85.2 years, with a median age of 36.7 years (IQR 23.7–53.8). Fifty-nine patients (51.3%) were female. Sixteen patients were immunosuppressed (13.9%), which included three patients who were HIV positive, four patients receiving chemotherapy, two patients with chronic lymphocytic leukaemia, two patients receiving immunosuppression for rheumatological disorders, and one patient with splenectomy.

Presentation

Visual acuity, intraocular pressure, presence of cells in the anterior or vitreous chambers, proportions of active lesions being macular and peripapillary, and presence of retinochoroidal scars at initial presentation are listed in Table 2. In presentations with recurrence of toxoplasmosis within our study period, active lesions were macular in 70.0% of the recurrent presentations during our study period, peripapillary in 4.7% and more peripheral in the remainder.

Table 1: Demographic characteristics.

	All patients N = 115 (%)	**Patients with ≥1 recurrences N = 37 (%)**	**Patients with 0 recurrences N = 78 (%)**
Median age at first presentation (years)	36.7; IQR 23.7–53.8	36.3; IQR 26.0–57.1	37.2; IQR 21.6–53.8
Female	59 (51)	18 (49)	41 (53)
Ethnicity			
European	67 (58)	23 (62)	44 (56)
Asian	17 (15)	8 (22)	9 (12)
Pacific Islander	17 (15)	3 (8)	14 (18)
Māori	6 (5)	1 (3)	5 (6)
Other	7 (6)	2 (5)	5 (6)
Unknown	1 (1)	0 (0)	1 (1)
Immunosuppressed	16 (14)	7 (19)	9 (12)
HIV	3 (3)	3 (8)	0 (0)
Serology done	85 (74)	25 (68)	60 (77)
IgM positive *	27 (32)	8 (32)	19 (32)
IgG levels > 100 *	53 (62)	15 (60)	38 (63)

* expressed as a percentage of patients with serology tested

Table 2: Ophthalmic clinical features at presentation of ocular toxoplasmosis.

	Initial presentations in eyes with ≥1 recurrence **N = 43 (%)**	**Initial presentations in eyes with 0 recurrences** **N = 83 (%)**	**Recurrent presentations** **N = 73 (%)**
Median best-corrected visual acuity	6/9; IQR 6/7.5–6/27	6/15; IQR 6/7.5–6/120	6/9; IQR 6/7.5–6/18
Intraocular pressure ≥24 mmHg	2 (5)	16 (19)	11 (15)
Presence of cells in the:			
Anterior chamber	24 (56)	47 (57)	45 (62)
Vitreous chamber	34 (79)	62 (75)	69 (95)
Location of active lesion(s):			
Macular	12 (28)	27 (33)	30 (41)
Peripapillary	3 (7)	14 (17)	2 (3)
Retinochoroidal scars present at initial presentation in this study	20 (47)	39 (47)	–

Table 3: Treatments initiated in active ocular toxoplasmosis.

	Initial presentations in patients with ≥1 recurrence **N (%)**	**Initial presentations in patients with 0 recurrences** **N (%)**	**Recurrent presentations** **N (%)**
Treatment initiated	31 (72)	72 (87)	71 (97)
Unknown if treatment initiated	1 (2)	3 (4)	0 (0)
Antibiotics given:			
Oral	28 (65)	64 (77)	59 (81)
Cotrimoxazole *	11 (39)	35 (55)	25 (42)
Clindamycin *	8 (29)	9 (14)	29 (49)
Triple therapy *	4 (14)	6 (9)	0 (0)
Mixed *	5 (18)	12 (19)	5 (8)
Intravitreal clindamycin	3 (7)	4 (5)	4 (5)
1 injection	0 (0)	0 (0)	4 (5)
≥1 injection			
Steroids given	30 (70)	68 (82)	67 (92)
Oral #	24 (80)	58 (85)	53 (79)
Intravitreal #	0 (0)	1 (1)	5 (7)
Topical #	20 (67)	54 (79)	41 (61)
Prophylactic antibiotics	6 (14)	21 (25)	22 (30)

* expressed as a percentage of patients given oral antibiotics in respective groups; # expressed as a percentage of patients given steroids in respective groups (individual percentages do not total 100, as some patients were given steroids via multiple routes).

Treatment

Treatment was initiated at presentation in 174 cases (87.4%). Of the 151 cases treated with oral antibiotics, antibiotic choice was documented in 149 (98.7%). Cotrimoxazole was the most common choice, followed by clindamycin and classic triple therapy (Table 3). In the remainder, different variations of combination therapy were utilised. There was no statistical difference in recurrence between clindamycin versus cotrimoxazole (p=0.70) and classic triple therapy versus cotrimoxazole (p=0.20). Intravitreal therapy with clindamycin was utilised in 15 cases. Eleven eyes received one intravitreal injection, one eye received two injections, two eyes received three injections, and one eye received four injections. No oral antibiotics were given to 75% of those who received more than one intravitreal antibiotic injection.

Oral steroid was given in 135 cases (67.8%) and intravitreal dexamethasone in 6 cases (3.0%). Topical steroid was given in 115 cases (57.8%). Long-term prophylaxis was commenced in 49 cases (24.6%). Cases involving immunosuppressed patients were significantly more likely to receive prophylactic treatment (68.0% vs 19.3%, p<0.001). There was no statistically significant difference in risk of recurrence between those given and those not given prophylactic antibiotics (p=0.38).

Treatment was commonly initiated if patients had congenital toxoplasmosis, multiple central lesions or vision-threatening features, such as significant vitritis or vasculitis, were symptomatic of floaters or blurry vision, the location of the active retinochoroidal lesion was macular, peripapillary or on the arcades, or if risks of vascular occlusion or retinal detachment were significant for the individual, although reasons were not always documented.

Risk factors of recurrence

The only statistically significant risk factor associated with increased risk of recurrence was previous recurrence (HR 2.00, p<0.001) (Table 4). Demographic characteristics like age, gender and immunosuppression, and serological parameters like IgM positivity and IgG levels >100 AU/mL had no statistically significant association with risk of recurrence. Presenting features like best-corrected visual acuity or ocular hypertension (intraocular pressure ≥24 mmHg) at initial presentation, and initiation of treatment had no statistically significant association with risk of recurrence of ocular toxoplasmosis.

Table 4: Risk factors for recurrence.

	Hazard ratio	95% CI	p value
Age	1.01	0.99–1.04	0.17
Female	0.78	0.35–1.76	0.43
Immunosuppression	1.81	0.65–4.72	0.15
IgM positive	1.11	0.40–3.13	0.82
IgG >100 AU/mL at presentation	0.91	0.35–2.07	0.83
Best corrected visual acuity of affected eye	0.70	0.39–1.18	0.082
Intraocular pressure ≥24 mmHg	0.89	0.43–2.54	0.74
Presence of cells in anterior chamber	1.52	0.96–1.86	0.29
Presence of cells in vitreous chamber	1.15	0.85–7.54	0.54
Previous recurrence	2.00	1.29–2.98	<0.001
Treated	0.94	0.35–2.78	0.89

Discussion

Toxoplasmosis retinochoroiditis is a common cause of posterior uveitis in New Zealand.[8] In our study, toxoplasmosis retinochoroiditis recurred in 32% (37/115) of patients; the highest rate of recurrence was within the first year of initial presentation. Previous recurrence was the only statistically significant risk factor for recurrence.

The three main strengths of this study were having a large catchment size, a relatively captive population to study, and relatively long follow-up periods. A moderately large number of patients with toxoplasmosis retinochoroiditis in a single area were identified. Because there is only a single emergency eye clinic for Auckland City, most acute episodes of toxoplasmosis retinochoroiditis for the region would have been captured in this study. Although episodes managed in private optometry and ophthalmology centres were excluded, practitioners in these centres would likely have been referred to the centralised emergency eye clinic for further assessment and acute management. Thirdly, patients could be followed up for longer periods (mean follow-up time was 6.1 years in our study). The 199 episodes of toxoplasmosis retinochoroiditis captured in our study are likely the majority of acute episodes that occurred for our study patients during the study period. Unlike studies where episodes are self-reported, these episodes were all clinically diagnosed episodes of recurrence.

This study also had limitations. Episodes where patients self-treated themselves, or that occurred while patients were residing outside of the Auckland Region, would not have been clinically-diagnosed, and thus no episode of active toxoplasmosis retinochoroiditis would have been recorded. Although this is likely a low number of active episodes, this may underestimate the true incidence of active episodes of toxoplasmosis retinochoroiditis. Secondly, heterogeneity of treatment criteria between clinicians may have reduced statistical differences between groups of patients with recurrences and without recurrences, and thus potentially reduces identification of other significant risk factors for recurrence.

Ocular toxoplasmosis is known to have a clustering pattern of recurrence. In our study, the rate of recurrence per person over the mean follow-up period was 0.11 recurrences/person-year (based on 73 recurrences for 115 patients over a mean follow-up of 6.1 years). Recurrence was observed in 15% in the first year and a cumulative rate of 25% in the first two years. Some patients who had no recurrences may have experienced asymptomatic or mild first episodes previously, for which no medical attention was sought. This may help explain why 63% of patients with no recurrences in our study had IgG levels more than 100 AU/mL, and 47% of patients with no recurrences in our study had retinochoroidal scars at initial presentation. Our reported recurrence rates would therefore be conservative rates of recurrence.

The rate of recurrence found in this study sits on par with some retrospective studies[9–11] but is much lower than the rate of recurrence amongst other studies, which quote recurrence rates between 0.24 and 0.35 recurrences/person-year.[12–14] Apart from the possible underestimation of true first episodes of toxoplasmosis retinochoroiditis, there may be other reasons for the differences between studies. Given the more aggressive strain of toxoplasmosis in Brazil,[5] it would make sense that the prospective study conducted in the Rio de Janeiro population found higher rates of recurrence within its study group[12] although in another area of Brazil, recurrence rates from a separate randomised controlled trial conducted in Campinas found lower rates of recurrence than our reported rate—even in its placebo arm.[6] Thus, we can only generalise that the differences in recurrence rates between studies are likely explained by a combination of differences in toxoplasmosis pathogenicity, study methodologies, population demographics and presenting features, and treatment regimens.

All isolates of toxoplasmosis globally can be divided into different haplotype groups, and haplotype prevalence can vary geographically.[16] This study did not look at specific strains, and no known studies detail the prevalence of strain types found in New Zealanders or New Zealand-origin wildlife, domesticated or farm animals. However, strains found in South America are more likely to cause more severe disease and recur more frequently than European or North American strains.[5] The recurrence rate of toxoplasmosis retinochoroiditis may be indicative of the haplotype mix in the Auckland population.

Methodological differences can under- or over-estimate the incidence of recurrence, which may also help explain some of the differences in recurrence rates between studies. Some studies counted only one eye in bilateral cases, while others excluded immunosuppressed individuals or individuals with no serological data. These factors can underestimate true rates of recurrence. Several previous studies have only included those with long follow-up periods,

which results in selection of patients that have either had more severe disease or several recurrences.[10,13,15] Heterogeneity between studies makes comparing recurrence rates between studies difficult.

There is consistency of some risk factors for recurrence with other studies. This study found an increased risk of recurrence with previous recurrence, consistent with other studies.[4] This study did not find an increased risk with age or immunosuppression, contrary to the findings of many other studies, which found higher rates of recurrence in the elderly[17,18] and people with immunodeficiency. While most studies show an increased risk of recurrence with advanced age, one study[19] found that patients younger than 20.9 were at higher risk of recurrence than patients above 20.9 years. Notably, this study is at risk of non-response bias (55% of patients identified with ocular toxoplasmosis did not respond) and also found that the interval between successive episodes was stable between the first three recurrences. The latter reported outcome seems to be an isolated finding in the current literature, which is more suggestive of increased time between disease-free intervals. On the contrary, like other studies,[11,13,19] gender, IgM and IgG status were not associated with increased risk of recurrence in this study. Notably, pregnancy has been reported as a risk factor for recurrence in other studies, [20] but there were no pregnant patients in this study.

Differences in the numbers of individuals treated with appropriate treatments may also contribute to differences in recurrence rates. For example, IgM-positive patients treated with classic oral therapy rather than intravitreal therapy had lower rates of recurrence in one randomised trial.[21] Some studies have shown that treatment with prophylactic antibiotics, such as trimethoprim/sulfamethoxazole every 2–3 days for 12 months or more, can reduce the rate of recurrence of ocular toxoplasmosis by up to 74–95%.[5,6,15] In this study, there was no statistically significant association between either initiation of treatment, or use of prophylactic antibiotics, with risk of recurrence of toxoplasmosis retinochoroiditis. This may be because there were insufficient numbers of patients given long-term prophylaxis (long-term prophylaxis was commenced in less than 25% of cases). Further studies that are adequately powered may be able to elucidate this.

In summary, this study demonstrated recurrence rates of 15% in the first year, and showed that having a previous recurrence was associated with an increased risk of recurrence in a New Zealand population. This study will help guide discussions with patients regarding long-term rates of recurrence.

COMPETING INTERESTS
Nil.

AUTHOR INFORMATION
Himanshu Wadhwa: MBChB – Junior Clinical and Research Fellow; Department of Ophthalmology, Auckland District Health Board, Auckland, New Zealand.
Joanne L Sims: MBChB FRANZCO – Consultant Ophthalmologist; Department of Ophthalmology, Auckland District Health Board, Auckland, New Zealand.
Rachael L Niederer: PhD MBChB FRANZCO – Consultant Ophthalmologist; Department of Ophthalmology, Auckland District Health Board, Auckland, New Zealand.

CORRESPONDING AUTHOR
Rachael Niederer: Department of Ophthalmology, Auckland District Health Board, Private Bag 92 189, Auckland Mail Centre, Auckland 1142, New Zealand. (+649) 367 0000. rachaeln@adhb.govt.nz.

URL
www.nzma.org.nz/journal-articles/rate-of-recurrence-of-toxoplasmosis-retinochoroiditis-at-a-tertiary-eye-centre-in-auckland

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Patient-reported quality of life and eligibility for cataract surgery: assessing the relationship between ethnicity and 'Impact on Life' questionnaire scores in New Zealand

Nancy Wang, Lyn Hunt, James McKelvie

ABSTRACT

AIMS: The 'Impact on Life' (IoL) questionnaire is a patient reported quality-of-life assessment tool used to prioritise cataract surgery in New Zealand (NZ). This study evaluated the association between ethnicity and IoL questionnaire responses.

METHODS: This is a retrospective cohort study of patients prioritised for public-funded cataract surgery between November 2014 and March 2019 in New Zealand. Data were extracted from the New Zealand Ministry of Health National Prioritisation Web Service database. Ethnic, demographic and IoL data for all patients who were prioritised for surgery were analysed after controlling for age, gender, visual acuity and cataract type.

RESULTS: Of the 58,648 prioritisation events, over the four-and-a-half-year period, 46,352 prioritisation events had documented scores for the IoL questionnaire. The study population had a mean age of 74.4 years and had a female preponderance (74%). The average IoL score was 22.5/36 (SD 7.8). After controlling for age, gender, visual acuity (VA) and cataract type, there was only a marginal difference between Māori and non-Māori IoL scores (22.8/36 vs 22.4/36) despite statistical significance for the difference (p=0.001). Māori and Pacific people presented at a younger age (68.5 years and 66.7 years, respectively) with worse visual acuity than other ethnic groups (mean range 70.1–76.7 years). Mean IoL scores were 23.0/36 for Māori and Pacific people and 22.4/36 for other ethnic groups.

CONCLUSIONS: Māori and Pacific people present younger with worse VA and more advanced cataracts at time of surgical prioritisation when compared with other ethnic groups. Despite these differences, after controlling for confounding factors, the mean IoL score did not differ to a level that was clinically significant between different ethnic groups in New Zealand at time of prioritisation for cataract surgery. These results suggest that there are no meaningful ethnic specific differences in patient reported quality of life for patients with cataract in New Zealand after controlling for other factors. Alternatively, the IoL tool may lack the sensitivity to detect meaningful ethnic disparities that may exist for quality of life in this cohort of patients.

Cataract surgery is one of the most commonly performed surgeries worldwide, with approximately 10–20 million operations completed annually.[1] In New Zealand, approximately 16,500 cataract surgeries are completed in the public sector each year, making it one of the most frequently completed surgical procedures. In the New Zealand public healthcare system, prioritisation tools are used for ensuring fair and equitable distribution of finite healthcare resources. A standardised set of criteria have been developed with the aim of enabling access for those who stand to benefit the most from elective surgical procedures, both clinically and socially.[2] This framework focuses on maintaining both transparency and consistency when deciding which patients are prioritised for elective surgery.[2] The National Priority Criteria Project was focused on developing a set of standardised criteria to ensure the fair and equitable distribution of surgical resourcing.[2] For this purpose, the New Zealand Clinical Priority Assessment Criteria (CPAC) was developed, as a prioritisation tool for determining access to cataract surgery and other elective procedures.[3] The CPAC score summates various clinical, social and patient-specific factors into a single numerical score used to rank and priori-

tise patients for surgery. Along with measures of visual acuity and cataract morphology, the CPAC score includes patient responses to the Impact on Life (IoL) questionnaire. Regional CPAC thresholds determine eligibility for elective surgery for individual patients.

The IoL questionnaire comprises self-reported quantitative measurements of quality of life in six key domains: safety, social interactions, ability to meet responsibilities to others, personal relationships, personal care and leisure activities. The IoL was originally designed as a prioritisation tool for orthopaedic surgery. The IoL is now routinely used to assess vision-related quality of life (VRQoL) for prioritisation of cataract surgery. Despite its widespread use in New Zealand, validation of the IoL as an assessment tool for VRQoL has only recently been completed and results highlighted the IoL is poorly suited for assessment of this metric.[4] The IoL questionnaire was compared to the Catquest-9SF, a widely used and well validated assessment tool for measuring VRQoL.[5,6]

Several studies have confirmed ethnic disparity in access to cataract surgery. In the United States, African-American and Latino-American patients have a higher unmet need for cataract surgery when compared with their "White" counterparts.[7,8] In New Zealand, Māori are typically under-represented in the overall number of cataract surgery patients, while commonly presenting with more advanced cataracts and worse preoperative visual acuity.[9,10] It is important to understand how systemic factors, including surgical prioritisation, may create barriers to accessing cataract surgery for Indigenous populations in New Zealand. [11]

The aim of this study is to examine the relationship between patient reported IoL scores and ethnicity for patients presenting with cataracts in New Zealand. Māori have lower life expectancy and significantly higher rates of almost all chronic and infectious diseases when compared with non-Māori.[12] The IoL is not specific to vision, and is also used in other surgical specialities in New Zealand as a tool to assess morbidity-associated quality of life. Poor health status has a significant impact on quality of life. The working hypothesis was that Māori who are prioritised for cataract surgery would report worse quality of life scores as measured on the IoL compared with non-Māori after controlling for age, gender, visual acuity and cataract type.

Methods

The current study is a retrospective cohort study of all patients prioritised for public-funded cataract surgery between November 2014 and March 2019 in New Zealand. This study adheres to the tenants of the Declaration of Helsinki and the standards set by the National Ethics Advisory Committee.[13] Furthermore, this study met the exemption criteria after formal review as outlined by the New Zealand Health and Disability Ethics Committee.[14]

The New Zealand Ministry of Health National Prioritisation Web Service (NPWS) database was used to obtain national prioritisation data for cataract surgery spanning the duration of the study. Data included best-corrected visual acuity in the operative eye, best-corrected binocular vision, cataract morphology grading, predicted postoperative visual outcome and IoL questionnaire responses. The IoL prioritisation tool consists of six questions asking the patient to score quality of life in six domains including social interactions, personal relationships, ability to fulfil responsibilities to others, personal care, personal safety and leisure activities. All six questions are scored on a scale of 1 (no difficulty) to 6 (extreme difficulty). A total IoL composite score is then calculated by summing the scores from all six questions. Patient demographic and ethnicity data was obtained from the National Health Index (NHI) database and joined to the NPWS data using the NHI as a primary key. Each patient was associated with a single ethnicity from the data provided by the NZ Ministry of Health. Joined data included date of birth, gender, ethnicity, and district health board of domicile. Patients who had had two or more prioritisation events on the same day, with differing clinical answers (a same-day re-prioritisation event), were excluded from the main analysis. The number of re-prioritisation events and ethnicity were investigated in a separate sub analysis. All data was de-identified prior to analysis.

Statistical analysis

Visual acuity was converted to logMAR units for statistical analysis. All statistical analysis was completed using R statistical software (R Foundation for Statistical Computing, Vienna, Austria). To evaluate the significance of ethnicity for patient scores recorded on the IoL, discriminant analysis and logistic regression were used to see if attributes (IoL score, age, logMAR acuity in one or both eyes) could be used to predict ethnicity. Various attributes were

used in the models to determine whether discrimination could be improved. Models were also fitted where patients who did not identify as Māori were grouped into a single non-Māori category to comprehensively evaluate any significant differences in IoL score that may exist between Māori and non-Māori. Various hierarchical and non-hierarchical cluster analysis techniques were used on the data to see if the patients could be grouped such that patients within the same group were similar to each other. The identified cluster groups were then compared to the ethnic groups, using the measured patient attributes. The expectation-maximisation (EM) algorithm[15] was used to fit a finite mixture model to the data and determine the groups to be fitted in the model.

Results

There were 58,648 prioritisation events for cataract surgery spanning four and a half years between November 2014 and March 2019 in the New Zealand public healthcare system. Of these prioritisation events, all had documented CPAC scores but 12,296 did not have the IoL questionnaire component of the score specified and were excluded from analysis. The remaining 46,352 prioritisation events with IoL scores available were included for analysis.

The study population had a mean age of 74.4 years, and had a slight female preponderance (57%). The absolute number and relative proportion of each ethnic group is summarised in Table 1. The average BCVA of the operative eye was 0.73 logMAR (6/32 Snellen equivalent) while the average binocular BCVA was 0.31 logMAR (6/12 Snellen equivalent). The overall mean IoL score was 22.5 (SD 7.8) and the average CPAC score was 59.4 (SD 13.6). The average age, mean IoL score and CPAC scores are summarised by reported ethnicity in Table 1. Māori and Pacific people presented for cataract prioritisation at a younger age (68.5 years and 66.7 years, respectively) compared with all other ethnic groups. There was only a marginal difference when comparing the mean IoL scores of Māori 22.8 (95% CI 22.6, 23.1) and non-Māori 22.4 (95% CI 22.4, 22.5). There was a mean IoL score of 22.9 (SD 7.8) for patients' first operative eye and 22.3 (SD 7.7) for second operative eye, again with no statistically significant difference between the two groups.

Discriminant analysis and logistic regression demonstrated that for each of the classifiers fitted, 66% to 69% of the observations were correctly classified. Table 3 shows that the majority of individuals with Māori ethnicity were classified with another ethnic group. Models were also fitted where the patients had been reclassified as either Māori or non-Māori. For each of the classifiers, 87 to 90% of the observations were correctly classified. However, it can be seen from Table 4 that the majority of the patients with Māori ethnicity were classified with the non-Māori ethnic group.

Analysis of the groupings identified using cluster analysis demonstrated no relationship between the cluster analysis groups and different ethnicities. The data was also investigated to determine whether subsets of various attributes were more predictive of the ethnicity groups. Mixture model analysis identified six groups when fitting models to each of IoL score and best corrected logMAR binocular vision separately (Table 5), and three groups when using all of the attributes (Table 6). These groups did not correspond to ethnicity. Discriminant analysis was also unable to separate the individuals into the ethnic groups. Models were then fitted with five groups specified. It can be seen in Table 7 and Table 8 that the identified groups also did not correspond to ethnicities. The ethnicities were combined such that the groupings were Māori versus the others. Cluster analysis found three groups in the data for Māori versus the Others. These groups did not correspond to ethnicity. In summary, no statistically significant differences in IoL scores between the ethnic groups including Māori and non-Māori were identified.

Visual acuity

Pacific people and Māori were noted to have significantly ($p<0.001$) worse best corrected visual acuity (95% CI 0.915–0.940 vs 0.688–0.698 for other ethnicities) in the operative eye at prioritisation, when compared with other ethnic groups as outlined in Table 2. Best corrected binocular vision was not significantly different ($p=0.834$) between ethnic groups (95% CI 0.306–0.319 for Māori and Pacific people vs 0.310–0.316 for other ethnicities).

Discussion

The IoL score comprises 13% of the total CPAC score used to prioritise public-funded cataract surgery in New Zealand. The ability of the IoL to discriminate between eligible patients, and prioritise those who have the greatest need and are most likely to benefit from cataract surgery, is critical to ensure fair and equitable distribution of limited healthcare resources.

There are well established disparities in health status, access to treatment and health outcomes

for Māori and Pacific people in New Zealand. The Health and Disability System Review released in June 2020 highlighted the significantly worse health outcomes for Māori, and proposed various strategies to address these disparities.[16]

Results of the current study noted that VRQoL, as assessed using the IoL, were very similar for Māori and non-Māori patients presenting with cataract. These results are surprising, as it is well established that Māori have significantly higher rates of non-communicable disease and a higher burden of all-cause morbidity when compared with non-Māori.[17] As poor health is closely associated with quality of life, it would be reasonable to expect that Māori responses to the IoL, which is not specific to vision, should reflect the greater morbidity associated with this group. The analysis of the IoL questionnaire responses in the current study suggest that Māori have similar quality of life to non-Māori as reported by the IoL, despite high rates of morbidity in the cataract age group and a sufficiently large population included in the study. This finding is at odds with a large number of studies that have identified significant inequalities for Māori.[17] It seems unlikely that Māori and Pacific people enjoy similar quality of life to patients of other ethnicities despite well-established disparities in health status. Visual impairment is closely linked to decreased quality of life, and patients who undergo cataract surgery typically report significant improvements in quality of life following surgery.[18] The more likely explanation for the results of the current study is that the IoL is poorly suited to accurately measure quality of life in Māori and/or non-Māori.

A recent study looking at validation of the IoL questionnaire identified major issues with its ability to assess VRQoL in cataract patients.[4] The Catquest-9SF, an alternative tool for measuring VRQoL, has been extensively validated for use in assessing VRQoL in New Zealand and elsewhere, and does not have the same accuracy and reliability issues that have been identified with the IoL assessment tool.[4] The current study contributes to this growing body of evidence that the IoL questionnaire may be an inappropriate tool for prioritisation of patients for cataract surgery in New Zealand, and in particular, may disproportionally disadvantage Māori and Pacific people who require cataract surgery.

The current study highlights the need for rigorous validation of clinical assessment tools used as a basis for allocation of public-funded healthcare resources. There is a very real risk that poorly validated tools may contribute to widening health inequalities and present barriers to accessing treatment for ethnic minorities.

Table 1: Self-reported ethnic background of cataract prioritisation events in New Zealand public healthcare system between Nov 2014 and Mar 2019 and average IoL scores.

Ethnicity	Mean age	N	N*	% total population	Mean IoL score (SD)	Mean CPAC score (SD)
NZ European	76.7	33,626	7,336	69.8	22.4 (7.7)	58.6 (13.6)
Māori	68.5	4,209	1,430	9.6	22.8 (8.4)	60.1 (13.1)
Pacific people	66.7	2,755	1,740	7.7	23.3 (8.1)	62.9 (12.6)
Asian	70.1	4,373	1,478	10.0	22.4 (7.6)	60.6 (14.0)
Other	73.0	1,389	312	2.9	21.9 (7.8)	58.8 (13.6)

N* = number of patients missing IoL score

Table 2: LogMAR vision by self-reported ethnicity.

Recorded Ethnicity	Mean logMAR VA operative eye	SD	Mean logMAR VA OU	SD
NZ European	0.68	0.49	0.31	0.26
Māori	0.96	0.67	0.30	0.32
Pacific people	0.88	0.64	0.32	0.35
Asian	0.75	0.55	0.33	0.29
Other	0.73	0.55	0.32	0.29

Table 3: Percentage of Māori correctly classified for the Linear (LDA) and Quadratic (QDA) discriminant and logistic models fitted to the five ethnicities.

	Classifier model		
Attributes used in model	LDA	QDA	Logistic
IoL score	0.00	0.00	0.00
IoL score, logMAR	0.00	0.50	0.00
Age, IoL score, logMAR	3.9	5.20	2.5
Age, IoL score, logMAR, logMAR OU	3.7	17.52	2.3
Age, IoL score, logMAR, total score	3.7	18.37	2.3
Age, IoL score, logMAR, total score, logMAR OU	3.8	18.37	2.3

Table 4: Percentage of Māori correctly classified for the discriminant and logistic models fitted to the data using ethnic groups Māori and non-Māori

	Classifier model		
Attributes used	LDA	QDA	Logistic
IoL score	0.00	0.00	0.00
IoL score, logMAR	0.00	0.87	0.00
Age, IoL score, logMAR	1.72	7.04	0.76
Age, IoL score, logMAR, logMAR OU	1.73	11.45	0.73
Age, IoL score, logMAR, total score	1.75	11.88	0.71
Age, IoL score, logMAR, total score, logMAR OU	1.72	14.63	0.73

Table 5: Classes to clusters evaluation when fitting a mixture model to determine the number of groups in the model with the attributes IoL score.

Ethnicity	**1**	**2**	**3**	**4**	**5**	**6**
European	7336	5186	7033	7569	2510	11328
Māori	1430	598	109	879	381	1252
Asian	1478	628	914	1005	336	1490
Pacific lsland	1740	362	768	548	214	863
Other	312	231	267	295	131	465

Table 6: Classes to clusters evaluation when fitting a mixture model to determine the number of groups in the model with the attributes age, IoL score, total score, logMAR and logMAR (bilateral).

	Cluster assigned to		
Ethnicity	1	2	3
European	25811	7336	7815
Māori	2394	1430	1815
Asian	3043	1478	1330
Pacific lsland	1681	1740	1074
Other	1013	312	376 |

Table 7: Classes to clusters evaluation for fitting a mixture model with five groups to IoL score and logMAR (bilateral).

	Cluster assigned to				
Ethnicity	1	2	3	4	5
European	11561	4516	16480	1069	7336
Māori	1284	644	2065	216	1430
Asian	1460	588	2100	225	1478
Pacific lsland	796	363	1427	169	1740
Other	477	213	642	57	312

Table 8: Classes to clusters evaluation for fitting a mixture model with five groups to the attributes age, IoL score, total score, logMAR (unilateral) and logMAR (bilateral).

	Cluster assigned to				
Ethnicity	1	2	3	4	5
European	13613	2894	7336	1608	15511
Māori	1403	951	1430	359	1496
Asian	1630	466	1478	345	1932
Pacific lsland	1004	500	1740	242	1009
Other	500	157	312	82	650

COMPETING INTERESTS
Nil.

AUTHOR INFORMATION
Nancy Wang: Department of Ophthalmology, University of Auckland, New Zealand.
Lyn Hunt: Department of Statistics, University of Waikato, New Zealand.
James McKelvie: Department of Ophthalmology, University of Auckland, New Zealand; Department of Ophthalmology, Waikato District Health Board, New Zealand.

CORRESPONDING AUTHOR
James McKelvie: Department of Ophthalmology, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand. +649 3737 999, fax +649 367 7173. james@mckelvie.co.nz.

URL
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Caregiver survey of preschool children with obesity referred to Whānau Pakari—a multidisciplinary healthy lifestyle intervention programme

Tami L Cave, José G B Derraik, Esther J Willing, Paul L Hofman, Yvonne C Anderson

ABSTRACT

aim: To examine caregiver perceptions relating to the acceptability of weight screening at New Zealand's B4 School Check (B4SC), and the accessibility and acceptability of a healthy lifestyle programme (Whānau Pakari) for preschool children (Whānau Pakari preschool programme) identified with weight issues.

method: An online survey was designed to assess agreement with statements relating to the B4SC healthy weight check and Whānau Pakari programme. Eligible participants (n=125) were caregivers of preschool children identified with obesity (BMI ≥98th centile), or overweight (BMI >91st centile) with weight-related co-morbidities, at the B4SC and referred to Whānau Pakari over the period July 2016 to March 2019.

results: Twenty-nine caregivers responded to the survey (23%). The majority (76%, n=22) were open to discussing their child's weight. However, whilst most caregivers were comfortable receiving a weight referral to a healthy lifestyle programme for their child, some were ambivalent (24%, n=7) or disagreed (21%, n=6) to feeling comfortable about this. Furthermore, only 38% (n=11) of caregivers were concerned about their child's weight.

conclusions: Findings reveal a reasonable level of acceptability by caregivers to aspects of the B4SC healthy weight check. However, caregiver perceptions may not always be in alignment with the support offered by B4SC health professionals. Regular healthy lifestyle messaging by health professionals, and positive referral experiences, are key to subsequent engagement with healthy lifestyle programmes.

The global prevalence of overweight and obesity in young children has increased steadily over the last few decades, with recent estimates suggesting approximately 40 million children aged 0–5 years are affected worldwide.[1] In Aotearoa New Zealand (henceforth referred to as New Zealand), excess weight continues to be a problem for many young children, with approximately one third of 4-year-old children experiencing overweight or obesity by the time they commence school.[2]

Given childhood obesity has a propensity to lead onto adult obesity, and to its associated co-morbidities,[3] increasing emphasis has been placed on the prevention and management of overweight and obesity in the early stages of a child's life, particularly during the preschool years. The inclusion of growth monitoring in child health programmes for this population group enables early identification of children and families that may require support from services for unhealthy weight.[4]

In 2008, the B4 School Check (B4SC) programme was established, supporting health and wellbeing amongst New Zealand preschool children.[5] As part of this programme, all children undergo a routine screening health check at 4 years of age, which aims to identify health and developmental issues that could hinder participation and learning in the school setting.[5] Height and weight measurements undertaken at the B4SC provide an opportunity for population growth surveillance and screening of a child's weight status.

In July 2016, as part of the New Zealand Government's Childhood Obesity Plan, a national health target measure known as the Raising Healthy Kids target was embedded within the B4SC programme. The target aimed for 95% of children identified with a body mass index (BMI) in the obese range to be offered a referral for clinical assessment and intervention by December 2017.[6] In Taranaki, Whānau Pakari (a multidisciplinary assessment and intervention healthy lifestyle programme)[7] became the accepted referral pathway for preschoolers identified with obesity at the B4SC. Over the study period, the no-cost programme supported

children aged 4–16 years, offering home-based weight-related assessments (including physical, dietary, and psychological review) every six months for one year, as well as additional regular group sessions delivered by physical activity and health professionals. These included family-based physical activity sessions; dietary sessions (cooking sessions, virtual supermarket tours, and healthy portion sizes); and psychology sessions (discussing topics such as self-esteem, and creating and maintaining healthy lifestyle changes as a family).[8]

There is limited research on childhood obesity in New Zealand preschool children, and it remains unclear as to whether a referral for weight from an established child health programme is acceptable to caregivers of this age group. Therefore, as an initial survey alongside wider qualitative work,[9] this study aimed to explore caregiver perceptions regarding the acceptability of the healthy weight check and weight referral as part of the B4SC. Second, views around the acceptability and accessibility of the Whānau Pakari healthy lifestyle preschool programme from caregivers who both engaged and declined to engage with the programme were assessed after receiving a referral for weight for their preschool child.

Methods

Approval for the study was granted by The University of Auckland Human Participants Ethics Committee (#022672). Electronic, verbal, or written informed consents were obtained from all participants.

Participants

Participants were recruited from a total of 143 caregivers of children aged 4–5 years referred to Whānau Pakari from the B4SC programme in Taranaki over the period July 2016 to March 2019. Children were referred to the Whānau Pakari healthy lifestyle programme if identified with obesity (BMI ≥98th centile) or overweight (BMI >91st centile) with weight-related co-morbidities[10] at the B4SC. Of those referred, the families of 75 children engaged with the programme, the families of 67 children declined any involvement, and the family of one child was identified as not meeting the above criteria upon entry to the programme. Study exclusion criteria included any caregivers involved in similar Whānau Pakari related research and caregivers with no current contact phone number on record.

Data collection

Qualtrics software (Qualtrics Labs Inc., Provo, UT, USA 2018) was utilised to develop the online survey. Survey questions were derived from a previous survey conducted with other caregivers and children/adolescents engaged with the wider Whānau Pakari service over the period January 2012 to January 2017. However, these were further refined with input from stakeholders and other researchers to ensure relevance to the target group. Beta-testing of questions was undertaken to ensure comprehension and face validity. The survey consisted of Likert scale questions appraising the agreement of participants with certain statements, demographic questions and yes/no questions. Ethnicity was collected as per the New Zealand Ministry of Health Ethnicity Data Protocols and prioritised for the purposes of analysis.[11] Participants' ages and socio-economic status were not collected.

Recruitment of survey participants was via text to mobile phones with a multimodal response strategy adopted, whereby participants could choose to either undertake the survey online by clicking on a hyperlink embedded in the text, post, or over the phone. Two reminder texts were sent during the active phase of the survey, with all texts providing the opportunity for a participant to "opt out" of receiving any further texts. Paper-based surveys were sent to participants requesting the survey by post, and telephone surveys were conducted at convenient times for those participants requesting this response mode. Families with more than one child involved with the programme received the invitation to participate in the survey only once. The opportunity to win fuel vouchers was offered as an incentive for participation in the survey.

Data analysis

Quantitative data were analysed in SPSS version 25 (IBM Corp, Armonk, USA), and frequency distribution measures (%, n) reported. Due to the survey's low response rate, additional statistical analyses were not undertaken.

Results

A total of 125 eligible caregivers were invited to participate, of which 29 (23%) completed the survey. Eighty-six percent (n=25) of respondents completed the survey online, 7% by post (n=2) and 7% by telephone (n=2). Fifty-two percent (n=15) of respondents identified as Māori, and 90% were female (n=26). Eighty-three percent (n=24) engaged with Whānau Pakari after referral to the programme,

and 17% (n=5) declined any further involvement with the programme post-referral (Table 1).

Table 2 shows the level of agreement of caregivers with four statements focused on the B4SC healthy weight check, and the subsequent referral of their preschool child to the Whānau Pakari programme. The majority of respondents agreed to feeling comfortable talking about their child's weight at the B4SC (76%, n=22), and felt weight was an appropriate topic of discussion (62%, n=18). Sixty-two percent (n=18) of caregivers were either ambivalent or not concerned about the weight of their child at the time of the health check, with 31% (n=9) expressing a strong disagreement to being concerned about the weight of their child. Thirty-eight percent (n=11) of caregivers agreed to having some concern about their child's weight. Over half of respondents (55%, n=16) agreed to feeling comfortable about receiving a referral for their child's weight, with the remainder expressing their ambivalence (24%, n=7) or disagreement (21%, n=6) with this statement.

Of respondents who engaged with Whānau Pakari (n=24, 83%), the majority perceived the location and timing of assessments to be convenient (Table 3). Among the four respondents who attended the programme's group sessions (17%), three felt that the sessions were convenient in terms of location and had transport to attend. However, two were ambivalent towards statements relating to session timing, and whether they had time to attend. Seventy-nine percent (n=19) of respondents that engaged with Whānau Pakari agreed that their families would benefit from the programme, and over half (58%, n=14) believed the programme was appropriate for their family. Three out of five respondents who declined to engage disagreed with the statement that the programme seemed appropriate for their family (Table 3).

Discussion

In this survey of New Zealand caregivers of preschool children with obesity referred to a multidisciplinary healthy lifestyle programme from a preschool health check, key findings were that over three quarters of caregivers were comfortable with discussing their child's weight as part of the B4SC, and over half of respondents were amenable to receiving a weight referral for their child. Caregivers who were referred to and engaged with Whānau Pakari perceived the home-based weight-related assessments to be convenient in terms of location and time, and the majority viewed Whānau Pakari as a programme that their family would benefit from attending.

This survey shows a reasonable level of acceptability by caregivers to aspects of the B4SC healthy weight check, such as discussing the issue of weight within the context of their child's overall health. This is supported by New Zealand research exploring nurses' experiences of undertaking the B4SC since the introduction of the Raising Healthy Kids target, which found that adopting a similar holistic approach to weight-related conversations with caregivers of preschool children ensured communication was health-enhancing and acceptable from nurses' perspectives, particularly when referral was indicated in response to target requirements.[12] Ensuring these interactions are a positive experience for caregivers has been deemed as an important factor in the acceptance of weight-related feedback following weight screening in young children.[13]

Although the majority of respondents were comfortable with receiving a weight referral to a healthy lifestyle programme as part of the B4SC,

Table 1: Demographic characteristics of (n=29).

Participants		**n (%)**
Female		26 (90%)
Ethnicity [§]	Māori	15 (52%)
	New Zealand European	12 (41%)
	Pacific	1 (3%)
	Asian	1 (3%)
Accepted referral		24 (83%)

[§] Prioritised ethnicity as per HISO protocols.[11]

it is worth noting that 45% (n=13) of caregivers were ambivalent or felt uncomfortable about this. Additionally, a reasonable proportion of caregivers were ambivalent towards, or not concerned about, the weight of their child—a perception commonly held by caregivers of children experiencing overweight and obesity.[14] This is consistent with New Zealand-based research which showed lower levels of concern related to a child's weight in caregivers who chose not to participate in a "weight management" programme, compared to those who did.[15] This highlights that caregiver perceptions may not always be in alignment with the efforts of health professionals undertaking weight screening in young children, and could potentially influence acceptance of a weight referral on to appropriate support services. Therefore, it is important for health professionals to be cognisant of the importance of caregiver perceptions related to their child's weight, and the impact these may have on the willingness of families to participate in early interventions to address unhealthy weight.

Overall, there was reasonable agreement to statements related to the accessibility and acceptabilty of Whānau Pakari, reflecting positively on the programme. However, feedback indicated room for improvement in terms of group session timing. Although a small group (n=5), most caregivers who declined further contact with the programme after referral indicated that the programme lacked appropriateness for their family. Of note, three of these five caregivers also disagreed with or were ambivalent towards the statement related to showing concern about the weight of their child—linking to the importance of caregiver perceptions identified above.

This study was limited by a low response rate, particularly affecting the representation of those caregivers who declined to engage with the programme after receiving a weight referral for their preschooler. Nevertheless, this study provides some insight into caregiver perspectives on weight screening in preschoolers, and their views on the accessibility and acceptability of a healthy lifestyle programme for younger children affected by weight issues in New Zealand. Given the limited sample size, further qualitative research has been undertaken to understand caregivers' experiences and perceptions of the B4SC healthy weight check and the Whānau Pakari preschool programme. Perceptions and experiences of caregivers, and determinants of engagement with the Whānau Pakari

Table 2: Level of caregiver agreement with statements relating to the Before School Check (B4SC) weight screen (n=29).

Statement	Strongly agree	Somewhat agree	Neither agree/ disagree	Somewhat disagree	Strongly disagree
I felt comfortable talking about the weight of my child at the B4SC	8 (28%)	14 (48%)	2 (7%)	3 (10%)	2 (7%)
I felt weight was an appropriate topic to discuss at the B4SC, as part of my child's health	9 (31%)	9 (31%)	6 (21%)	4 (14%)	1 (3%)
I was concerned about the weight of my child at the B4SC	4 (14%)	7 (24%)	7 (24%)	2 (7%)	9 (31%)
I felt comfortable about receiving a referral for my child to Whānau Pakari	6 (21%)	10 (34%)	7 (24%)	5 (17%)	1 (3%)

Data are n (%).

Table 3: Level of caregiver agreement with statements relating to Whānau Pakari programme elements by those that engaged and declined to engage.

	Engaged (n=24)					Declined to engage (n=5)				
Statement	**Strongly agree**	**Some-what agree**	**Neither agree/ disagree**	**Some-what disagree**	**Strongly disagree**	**Strongly agree**	**Some-what agree**	**Neither agree/ disagree**	**Some-what disagree**	**Strongly disagree**
Assessments in a convenient location*	14 (58%)	7 (29%)	3 (13%)	-	-					
Assessments at a convenient time*	9 (38%)	13 (54%)	2 (8%)	-	-					
Time to attend assessments*	10 (42%)	8 (33%)	4 (17%)	2 (8%)	-					
Sessions in a convenient location†*	3 (75%)	1 (25%)	-	-	-					
Sessions at a convenient time†*	1 (25%)	1 (25%)	2 (50%)	-	-					
Time to attend sessions†*	1 (25%)	1 (25%)	2 (50%)	-	-					
Transport to get to sessions†*	3 (75%)	1 (25%)	-	-	-					
Programme seemed appropriate for my family	7 (29%)	7 (29%)	9 (38%)	1 (4%)	-	1 (20%)	-	1 (20%)	3 (60%)	-
Programme could work for my family	9 (38%)	8 (33%)	5 (21%)	2 (8%)	-	1 (20%)	-	2 (40%)	2 (40%)	-
Family would benefit from the programme	13 (54%)	6 (25%)	3 (13%)	2 (8%)	-	1 (20%)	-	2 (40%)	1 (20%)	1 (20%)
Other things were more important for my family at the time	1 (4%)	11 (46%)	5 (21%)	5 (21%)	2 (8%)	1 (20%)	2 (40%)	1 (20%)	-	1 (20%)
Previous negative experiences with healthcare services made me/my family reluctant to attend	-	2 (8%)	4 (17%)	3 (13%)	15 (63%)	1 (20%)	1 (20%)	1 (20%)	-	2 (40%)
Previous positive experiences with healthcare services made me/my family keen to attend	5 (21%)	8 (33%)	11 (46%)	-	-	1 (20%)	1 (20%)	3 (60%)	-	-
Other people might judge my preschooler and I for attending	1 (4%)	4 (17%)	9 (38%)	2 (8%)	8 (33%)	2 (40%)	1 (20%)	1 (20%)	-	1 (20%)
Programme was culturally appropriate*	7 (29%)	5 (21%)	11 (46%)	1 (4%)	-					

Data are n (%). † Due to the survey's branching design, these statements were only applicable to the four caregivers in our survey who participated in Whānau Pakari's assessments-and-sessions intervention model.
* Statements not applicable to those who declined to engage.

programme have been reported elsewhere.[9] Referral experience, competing life demands, and caregiver resistance to, and motivation for, accepting external support all affected engagement with the Whānau Pakari preschool programme. Almost one third strongly disagreed that they were concerned about their child's weight, and this survey was not able to understand the reasons behind this. However, focus groups identified that caregiver perceptions were related to beliefs around genetics, the mitigating effects of healthy lifestyle factors and age.[9]

Previous research from our group has identified that past negative experiences with the healthcare system affected engagement with the Whānau Pakari programme in general.[16] However, past negative experiences were not seen in this survey as a strong determinant of engagement with the programme. Referral experience from the B4SC did affect likelihood of engagement however, as identified in the focus groups.[9] Of those referred to the Whānau Pakari preschool programme from July 2016 to March 2019, just over half (52%) engaged with the service, suggesting concern regarding child weight and referral experience are important considerations when aiming to enhance uptake of referrals to such a programme.[17]

In conclusion, caregivers of children referred for unhealthy weight from the B4SC to the Whānau Pakari preschool programme were predominantly comfortable discussing their child's weight in the B4SC, yet almost half were reticent to receiving a referral. Regular conversations by health professionals with families incorporating healthy lifestyle messages and positive referral experiences may enhance subsequent uptake of healthy lifestyle programmes in families of children when a referral is indicated.

COMPETING INTERESTS
Nil.

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AUTHOR INFORMATION
Tami L Cave: Liggins Institute, University of Auckland, 85 Park Road, Grafton, Auckland 1023, New Zealand.
José G B Derraik: Liggins Institute, University of Auckland, 85 Park Road, Grafton, Auckland 1023, New Zealand; Department of Paediatrics: Child and Youth Health, Level 1, Building 507, Grafton Campus, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand; Tamariki Pakari Child Health and Wellbeing Trust, New Plymouth, New Zealand.
Esther J Willing: Kōhatu–Centre for Hauora Māori, Division of Health Sciences, University of Otago, Dunedin, New Zealand.
Paul L Hofman: Liggins Institute, University of Auckland, 85 Park Road, Grafton, Auckland 1023, New Zealand.
Yvonne C Anderson: Department of Paediatrics: Child and Youth Health, Level 1, Building 507, Grafton Campus, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand; Tamariki Pakari Child Health and Wellbeing Trust, New Plymouth, New Zealand; Department of Paediatrics, Taranaki Base Hospital, Taranaki District Health Board, David Street, New Plymouth 4310, New Zealand.

CORRESPONDING AUTHOR
Yvonne Anderson: Department of Paediatrics: Child and Youth Health, Level 1, Building 507, Grafton Campus, University of Auckland, Private Bag 92019, Auckland 1142, New Zealand. +006467536139. y.anderson@auckland.ac.nz

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The prevalence of glaucoma among 45-year-old New Zealanders

Aqeeda Singh, Jesse Gale, Kirsten Cheyne, Antony Ambler, Richie Poulton, Graham Wilson

ABSTRACT

AIM: We aimed to estimate the prevalence of glaucoma in New Zealand using a population-based birth cohort of 45-year-olds.

METHODS: Study members of the Dunedin Multidisciplinary Health & Development Study participated (n=938 out of 1037 births (91%)). The data collected included visual acuity, visual field (VF), refraction, central corneal thickness, intraocular pressure (IOP), axial length, spectral domain optical coherence tomography (OCT), and non-mydriatic fundus photographs. Two ophthalmologists reviewed data independently to generate a consensus glaucoma status: "Normal" if no suspicion of glaucoma; "Ocular hypertension" if IOP >21 mmHg; "Glaucoma suspect" if optic disc photograph was suspicious for glaucoma with no more than borderline or non-corresponding VF or OCT abnormalities; and "Glaucoma" if optic disc photograph was suspicious for glaucoma and there were corresponding abnormalities of the OCT or VF.

RESULTS: Of 891 participants with sufficient data to assign a glaucoma status, 804 were "Normal" (90.2% [CI 88.3–92.2]), 15 were "Ocular hypertension" (1.68% [95% confidence interval (CI) 0.84–2.5]), 65 were "Glaucoma suspect" (7.30% [95% CI 5.6–9.0]), and 7 were classified as "Glaucoma" (0.79% [95% CI 0.21–1.4]). An additional 73 participants (8.2%, [95% CI 6.3%–10%]) had abnormalities on the OCT scan but were not deemed to be glaucoma suspects.

CONCLUSION: The prevalence of glaucoma in New Zealand is between 0.2% and 1.4%, consistent with other population-based studies in the same age group. The study highlights the sensitivity of OCT and the potential for misinterpretation and over-investigation.

The epidemiology of glaucoma has been defined by several large population-based studies, measuring the prevalence in different contexts (Table 1).[1–10] As the incidence of glaucoma increases with age, an increase in the number of affected people is predicted from an ageing global population.[11] Another source of increasing glaucoma prevalence is the wide dissemination of imaging technology, most notably optical coherence tomography (OCT), which is both specific and sensitive in detecting early glaucoma and is widely available as an opportunistic screening method in developed countries.[12]

In New Zealand, no glaucoma prevalence data has been collected, and it has been assumed that the New Zealand prevalence is comparable to surveys from Australia.[7,8] Establishing the prevalence in New Zealand is important to help estimate the burden of this disease.

In the present study, we measured the prevalence of glaucoma in the well-characterised population-based birth cohort of 45-year-old participants of the Dunedin Multidisciplinary Health & Development Study (Dunedin Study).[13] Using OCT allowed us to consider how this new, more sensitive technology affected the prevalence estimate, in comparison to older studies which only used optic disc photography and visual field tests.

Methods

Study design and approvals

This was an observational cross-sectional study. Participants gave written informed consent, and all study protocols were approved by the NZ Health and Disability Ethics Committee.

Study population

Participants are members of the Dunedin Study, a longitudinal investigation of health and behaviour in a population-representative birth cohort of 1,037 individuals (91% of eligible births; 52% male) born between 1 April 1972 and 31 March 1973 in Dunedin, New Zealand. The longitudinal study was established at age 3-years based on residence in the province.[13] Assessments were conducted at birth and at ages 3, 5, 7, 9, 11, 13, 15, 18, 21, 26, 32, 38, and most recently at age 45,

when 94% of the 997 participants still alive took part. Each study member was brought to the research unit for a day of interviews and examinations. Ninety-three percent of eligible age 45 participants also completed MRI scanning. The cohort represents the full range of socio-economic status in New Zealand's South Island, and as adults match the NZ National Health and Nutrition Survey on adult health indicators, eg BMI, smoking, GP visits.[14] Study participants are primarily of New Zealand European ethnicity (approximately 93%). Written informed consent was obtained from participants, and the study was approved by the New Zealand Health and Disability Ethics Committee.

Table 1: Summary of population-based studies measuring the prevalence of glaucoma in middle-aged predominantly Caucasian populations.[1-10]

Study Location, year	Age group	Prevalence	Total no. participants (response rate %)
Sweden, 1981	55–69	0.93%	1511 (77%)
Baltimore Eye Survey, MD, USA, 1991	40–49	0.92% (definite glaucoma, nil probable)	5308 (79.2%)
Beaver Dam Eye Study, WI, USA, 1992	43–54	0.9% (definite glaucoma)	4926 (83.1%)
County Roscommon, Ireland, 1993	50–59	0.72%	2186 (99.5%)
Rotterdam Study, Netherlands, 1994	55–59	0.2%	3062 (80.0%)
Casteldaccia Eye Study, Italy, 1994	40–49	0.4%	1062 (67.3%)
Blue Mountains Eye Study, NSW, Australia, 1996	<60	0.3% (definite glaucoma)	3241 (87.9%)
		0.4% (definite and probable glaucoma)	
Visual Impairment Project, VIC, Australia, 1998	40–49	0.1% (definite glaucoma)	3271 (83.0%)
		0.5% (definite and possible glaucoma)	
National Eye Health Survey, Australia, 2018	50–59	0.2% (definite glaucoma)	4792 (99.1%)
		1.8% (definite or probable)	
Northern Finland Birth Cohort Eye Study, Finland, 2019	45–49	1.1% (definite glaucoma)	3039 (58.9%)
		2.7% (definite and possible glaucoma)	

Data collection

At age 45-years, the following was assessed: first degree relative with glaucoma; best corrected visual acuity; visual field (VF) on Matrix perimeter (Carl Zeiss Meditec, Dublin, CA, USA); non-cycloplegic autorefraction; central corneal thickness (CCT) and intraocular pressure (IOP) using the Tonoref III (Nidek, Japan); axial length using IOL Master (Carl Zeiss Meditec, Dublin, CA, USA); spectral domain OCT (Cirrus HD-OCT, model 5000; Carl Zeiss Meditec, Dublin, California, USA) retinal nerve fibre layer (RNFL) by optic disc cube 200x200, macular ganglion cell layer by macular cube 512x128, vertical cup-disc-ratio (CDR), and disc area; un-dilated digital fundus photographs of each eye were taken after five minutes of dark adaptation, using an NMR-45 fundus camera (Canon, Japan).

Assessment of glaucoma

The diagnosis of glaucoma can be challenging, particularly in the early stages, and disagreement between methods of diagnosis is common.[15] Two masked independent ophthalmologists (GW, JG) viewed the fundus photographs, and subjective comments and diagnostic impressions were recorded, as well as disc damage likelihood scale (DDLS), and vertical CDR (inter-rater agreement was measured).[16–19] The DDLS was calculated for medium sized optic discs, as size could not be measured from the photographs. Discs with DDLS >5, CDR >0.5 or comments suspecting glaucoma or asymmetry of CDR ≥0.2 were noted to require further review. These suspect discs were reviewed with IOP, CCT, OCT and VF data to generate a consensus glaucoma status:

"Normal" if no suspicion of glaucoma (other non-glaucoma pathology may be present).

"Ocular hypertension" if IOP >21 mmHg and no optic disc abnormality.

"Glaucoma suspect" if optic disc photograph was suspicious for glaucoma with no more than borderline VF or OCT abnormalities (that is, no corresponding abnormalities, or abnormalities not explained by other disease or pathology).

"Glaucoma" if optic disc photograph was suspicious for glaucoma and there were corresponding abnormalities of the OCT or VF.

Each participant was assigned the glaucoma status of their worse eye.

Data analysis

All data was collated and analysed using Excel (Microsoft, Albuquerque, NM, US). To assess the intra-rater agreement for CDR and DDLS, Bland–Altmann plots were constructed, and the mean bias and limits of agreement (mean difference ± 1.96 standard deviation of differences) were calculated.[20, 21] Standard errors of the prevalence estimates were calculated for a binomial distribution to generate 95% confidence intervals (CI).

Results

Of the 938 participants, 891 (95%) were assigned a glaucoma status. The 47 who were not assigned had technical difficulties with eye data collection.

Glaucoma status

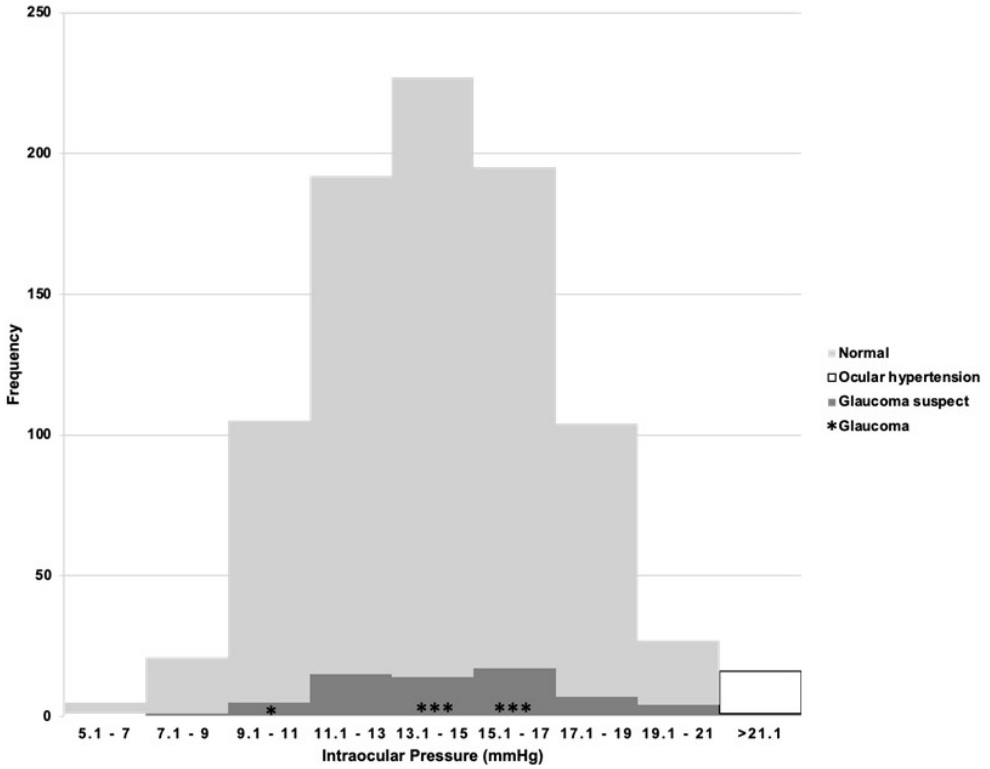
The prevalence of each glaucoma status and the 95% confidence intervals are shown in Table 2.

Among the more suspicious eyes of the 65 participants with glaucoma suspect status: 29 had suspicious discs, of which 22 had borderline abnormalities in OCT; four had borderline abnormalities in VF; one had non-corresponding abnormalities in both OCT and VF; and two had suspicious discs and other risk factors only. The remaining 36 glaucoma suspects had abnormalities in OCT alone, but low suspicion optic disc photographs in both eyes.

Table 2: A summary of the prevalence of each glaucoma status.

Glaucoma status	Number of participants	Prevalence (95% confidence interval)
Normal	804	90.2% (88.3–92.2)
Ocular hypertension	15	1.68% (0.84–2.5)
Glaucoma suspect	65	7.30% (5.6–9.0)
Glaucoma	7	0.79% (0.21–1.4)

Figure 1: Histogram of intraocular pressures (the higher of the two eyes), with glaucoma status labelled. The higher intraocular pressure in participants with glaucoma are indicated as asterisks.



Among those with glaucoma status, six had abnormalities in OCT corresponding to the glaucomatous optic disc appearance, and one had abnormalities in both OCT and VF (mild) in their more affected eyes.

There were an additional 73 participants (8.2%, CI 6.3%–10%) with abnormalities on the OCT scan who were not deemed to be glaucoma suspects in either eye (non-pathological abnormalities or artefacts) and hence classified as normal.

Inter-rater agreement of optic disc photographs

Inter-rater reliability was a little greater for CDR (mean difference 0.01, limits of agreement -0.13 to +0.15), as compared with DDLS (mean difference -0.55, limits of agreement -1.9 to +0.8, see Supplemental Figure 1). This indicated that GW rated DDLS scores lower than JG on average.

Clinical parameters

Both eyes were pooled to calculate average disc metrics (mean ± standard deviation and CI). The mean DDLS was 2.5 ± 0.88 (2.4-2.6) and mean CDR was 0.32 ± 0.14 (0.31–0.33). The IOP, CCT, and RNFL had a normal symmetrical distribution in keeping with previous cohorts. Figure 1 depicts the distribution of glaucoma statuses across the complete range of IOPs.

Discussion

In this observational, cross-sectional study of predominantly white (Pākehā) 45-year-old New Zealanders, we found the prevalence of glaucoma to be 0.79% (CI 0.2–1.4), based on fundus photographs, OCT, and VF results. The prevalence of ocular hypertension was 1.68% (CI 0.8–2.5), and glaucoma suspect status was 7.30% (CI 5.6–9.0). The prevalence aligns with other population-based studies with Caucasian/white participants of the 40–50-year age group (Table 1).

An additional 73 participants (8.2%, CI 6.3%–10%) had at least one abnormal eye on OCT imaging that was deemed to be non-pathological or artefactual. From a total of 139 participants with abnormal OCT, seven were assigned glaucoma status, and 59 were glaucoma suspects including just 23 who would be suspected of glaucoma by disc photography, IOP and visual fields. Clearly,

OCT technology is highly sensitive, but this comes with a risk of detecting false positives (artefacts).

In this younger 45-year-old cohort with a low prevalence, all of the participants with glaucoma had normal IOP in both eyes, as did all but one eye of one of the 65 glaucoma suspect (21.3 mmHg). This is a greater proportion with normal IOP than would be expected in a Caucasian cohort, and does not fit easily with the idea that ocular hypertension is presumed to be the pathogenic precursor to glaucoma in many cases.[7–10] Possible explanations include that naïve optic disc imaging with OCT detects a broader group of glaucoma cases than previous studies, or that this younger cohort may have a greater prevalence of myopia and thus more similarity to East Asian cohorts (with a very high proportion of normal tension glaucoma). Additionally, no disc haemorrhages were seen in any of the disc photos.

Limitations of this study include the lack of specialist assessment in clinic, gonioscopy or slit lamp examination in the diagnosis, or adhering to protocols for glaucoma diagnosis from other population-based studies. There was potential for non-contact tonometry and non-stereo disc imaging to reduce the diagnostic accuracy, but data collection was standardised and robust, and diagnostic classifications were made by consensus with the best available information. Due to low numbers, the findings should not be generalised to Māori, Pasifika and Asian ethnic groups, who have different prevalence of glaucoma types.[22]

The prevalence of glaucoma in 45-year-old New Zealanders appears to lie between 0.2% and 1.4%, consistent with other population-based surveys. Future examinations in the same cohort will detect incident cases over time. This is one of the first population-based studies to include OCT in the diagnosis of glaucoma, highlighting the sensitivity of these devices but also the potential for misinterpretation and over-investigation.[23]

COMPETING INTERESTS
Nil

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AUTHOR INFORMATION
Dr Aqeeda Singh, MB ChB: Dunedin School of Medicine, University of Otago, Dunedin, New Zealand.
Dr Jesse Gale, MB ChB FRANZCO: Department of Surgery & Anaesthesia, University of Otago, Wellington, New Zealand.
Dr Kirsten Cheyne, PhD: Dunedin Multidisciplinary Health and Development Research Unit, Department of Psychology, University of Otago, Dunedin, New Zealand.
Antony Ambler, MSc: Social, Genetic, and Developmental Psychiatry Centre, Institute of Psychiatry, Psychology, and Neuroscience, King's College London, London, United Kingdom.
Prof Richie Poulton, PhD: Dunedin Multidisciplinary Health and Development Research Unit, Department of Psychology, University of Otago, Dunedin, New Zealand
Dr Graham Wilson, MB ChB FRANZCO: Dunedin Multidisciplinary Health and Development Research Unit, Department of Psychology, University of Otago, Dunedin, New Zealand.

CORRESPONDING AUTHOR
Dr Jesse Gale: Department of Surgery & Anaesthesia, University of Otago, Wellington. Private Bag 7343 Wellington South 6242, New Zealand. Phone: +644385554, fax: +6443895725. jesse.gale@otago.ac.nz

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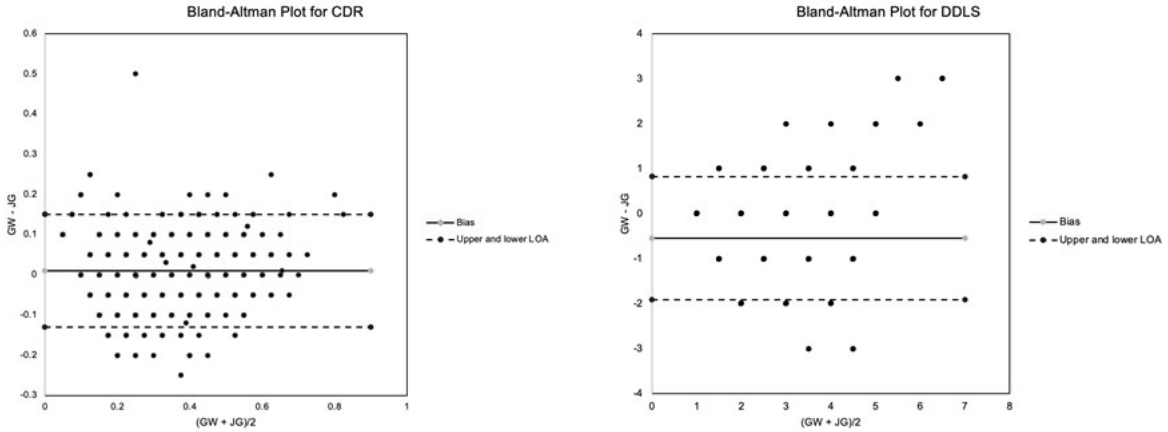
Supplemental Figure 1: Bland–Altman plots for cup-to-disc ratio (CDR), and disc damage likelihood scale (DDLS). LOA: limit of agreement.



The priorities for future clinical trials and large cohort studies addressing health and healthcare for mothers and babies in Aotearoa New Zealand

Katie M Groom, Clara Mossinger, Jody Lawrence, Jane E Harding, Karaponi Okesene-Gafa, Matire Harwood, Frances Benge, Jessica Steele, Caroline A Crowther

ABSTRACT

AIMS: To identify priorities for clinical trials and large cohort studies addressing maternal and perinatal health and healthcare in Aotearoa New Zealand.

METHODS: An Aotearoa New Zealand specific Research Prioritisation Framework was developed. Knowledge gaps were collected from an Audience Group via online questionnaires, video call interviews, and by systematic review. These were formulated into research questions. An Advisory Group reviewed questions suited to a clinical trial or large cohort study. A Ranking Group weighted the ranking criteria and ranked the research questions.

RESULTS: A total of 305 online questionnaires, 62 interviews and 62 published prioritisation projects generated 3,347 knowledge gaps. After content analysis, 358 unanswered research questions were ranked. Rating criteria weightings were: effect on equity 26.1%; potential to reduce disease burden 20.5%; effectiveness 20.0%; deliverability 17.9%; and answerability 16.0%. All of the top 20 prioritised research questions directly related to Māori and/or Pacific health and predominantly involved research into healthcare systems and workforce rather than disease conditions.

CONCLUSIONS: This project has identified the most important questions for future clinical trials and large cohort studies addressing maternal and perinatal health and healthcare in Aotearoa New Zealand. The Framework and methodology can be adapted for use across all areas of health.

Multicentre clinical trials and large cohort studies provide the most effective platforms to answer clinically important research questions that lead to improved health. The efficiency and cost-effectiveness of these types of research are significantly enhanced by well organised and co-ordinated clinical trials networks.[1] The ON TRACK Network: Better Health for Mothers and Babies, Te Awhi Rito was established in 2016 (http://ontrack.perinatalsociety.org.nz/) to be an Aotearoa New Zealand specific multidisciplinary maternal and perinatal clinical trials network. It aims to engage researchers, clinicians, consumers and other stakeholders in a systematic and constructive way across the whole pipeline of clinical research, with an ultimate goal to achieve greater equity, better health outcomes and improved quality of life for women and babies nationwide.

To enable future high quality multicentre clinical trials and large cohort studies, while ensuring the most efficient use of resources and maximum benefit, one of the first steps is to prioritise research questions.[2] Over recent decades, systematic approaches to research prioritisation have been developed.[3–9] However, no single gold standard research prioritisation method exists, as each method has advantages and disadvantages depending on the goals of the prioritisation project and the setting in which it takes place.

The aims of this project were to establish a Research Prioritisation Framework that was robust, transparent, systematic, equity-focussed, and able to consider the unique social and geographic context of maternal and perinatal health and healthcare in Aotearoa New Zealand. The aim was then then to use this framework to establish the future priorities for clinical trials and large cohort studies in addressing maternal and perinatal health and healthcare in Aotearoa New Zealand.

Methods

Development of a Research Prioritisation Framework

Established health research priority-setting methods were identified and reviewed, including: the Council of Health Research for Development;[3] Delphi studies;[4] Essential National Health Research;[5] 3D Combined Approach Matrix;[6] the Child Health Nutrition Research Initiative;[7] the James Lind Alliance;[8] and, within New Zealand, the Health Research Council's 'The New Zealand Health Research Prioritisation Framework'.[9] Each was assessed for quality using a recognised good practice tool,[10] the resources required per method, ability to engage with multiple disciplines and groups, applicability to Aotearoa New Zealand, and overall strengths and weaknesses. Considerations for the Aotearoa New Zealand context included the ability to be responsive to the needs of the Indigenous peoples, the ability to address equity, the opportunity for consumer participation, and the suitability for the New Zealand maternity care system in which the majority of pregnancy care is provided by independent practitioners. Using this information, we developed an Aotearoa New Zealand specific Framework that included 11 steps in four phases, involving four groups of participants: the Core Group, Audience Group, Advisory Group and Ranking Group (Figure 1).

Figure 1: The ON TRACK Network Research Prioritisation Framework.

Phase	Step	Step	Group responsible
Information gathering	1	Scope and context	Core Group
	2	Situational analysis	Core Group
	3	Collection of knowledge gaps	Audience Group
Content analysis	4	Synthesis	Advisory Group
	5	Screening evidence	Advisory Group
	6	Sorting and subdivision	Advisory Group
Ranking	7	Multi criteria decision analysis	Ranking Group
	8	Setting research priorities	Core Group
	9	Final consultation	Ranking Group
Dissemination	10	Implementation and publication	Core Group
	11	Evaluation and updates	Core Group

The **Core Group** was responsible for the oversight and steering of the project and included the principal study investigators and invited senior advisors to represent Māori health, Pacific health, consumers and funders. A senior midwifery representative joined the Core Group during the project to ensure the views of midwives as lead care providers for the majority of maternity care. Activities led by the Core Group were supported by a project management team (principal study investigators, project manager, student and research staff).

The **Audience Group** was a large and diverse range of stakeholders with an interest in maternal and perinatal health, invited to participate by contribution of ideas of knowledge gaps via an online questionnaire or via a video or telephone call interview.

The **Advisory Group*** were technical experts representing a broad range of disciplines including neonatology, obstetrics, midwifery, nursing, epidemiology, reproductive medicine, Māori health, Pacific health and science.

The **Ranking Group*** included all members of the Advisory Group and additional consumer representatives, policy-makers, funders, clinicians and research active stakeholders from a broad range of disciplines.

*Invitations to join the Advisory and Ranking groups commenced in February 2020 this included successful requests for representatives from Australasian College of Neonatal Nurses, New Zealand College of Midwives, Royal New Zealand College of General Practitioners, Royal Australasian College of Physicians, Royal Australian and New Zealand College of Obstetricians and Gynaecologists, Ministry of Health, National Maternity Monitoring Group, and Perinatal & Maternal Mortality Review Committee.

Information gathering

Maternal and perinatal health and healthcare was considered by the Core Group to include: before pregnancy (where there is impact on maternal and perinatal health outcomes); during pregnancy and antenatal care; at the time of birth; maternal postnatal care; and newborn health. Infertility was not included because a recent international consensus development study identifying top priorities for future infertility research, led by New Zealand investigators, has reported on issues relevant to Aotearoa New Zealand.[11] Knowledge gaps were collected from the Audience Group, and research priorities already identified were collected by a systematic review of published research prioritisation projects.

To enable a large and diverse group of individuals to participate in the Audience Group, we planned to use online semi-structured questionnaires and face-to-face (kanohi ki te kanohi) hui and focus groups. However, due to COVID-19-related restrictions, in-person group meetings were not feasible. We therefore used video and telephone semi-structured interviews for those who wished to interact in person. Some one-on-one in-person interviews were possible towards the end of the information gathering phase.

Invitations to contribute to the Audience Group were distributed via email and newsletters to: all ON TRACK Site Network leaders at each district health board participating in the Network; professional bodies of maternity and perinatal healthcare providers; consumer groups; Māori and Pacific maternity health groups; funders of research; academic institutions undertaking research; relevant Ministry appointed committees; and, directly to identified Māori and Pacific health researchers. Each group was asked to distribute the invitation to participate via membership circulation lists. Invitations, poster displays and social media posts included introductory information, contact details and links and QR codes to the online questionnaire.

Participants eligible to contribute to the Audience Group were 16 years or older, living in Aotearoa New Zealand, and belonging to at least one of three groups:

- Healthcare professionals involved in the provision of care for pregnant women and their offspring in Aotearoa New Zealand, ie midwives, obstetricians, neonatologists, paediatricians, neonatal nurses, obstetric physicians and other allied health professionals.
- Consumers involved or recently involved with pregnancy, defined as: woman with current or recent experience (within the last five years) of maternity healthcare (including preconception, pregnancy, pregnancy loss, birth, postnatal and lactation care); partner, whānau and support persons of a woman with current or recent experience in maternity healthcare; caregiver of a newborn/infant/child born within the last five years; or, consumer representative of a group related to maternal and perinatal health.
- Other stakeholders involved in maternal and perinatal health and healthcare research such as scientists, researchers, funders, policy-makers and members of Ministry appointed committees.

Qualtrics® software was used to host the online questionnaire. Demographic data was requested from each participant, together with open-ended questions to invite free text responses relating to knowledge gaps before pregnancy, during pregnancy and antenatal care, at time of birth, postnatal care and newborn health. Responses were not linked to individuals. Two members of the project management team undertook all interviews using the same approach, and these were then recorded and transcribed.

The *Collection of Knowledge Gap Study* nested within the Research Prioritisation Project was approved by The University of Auckland Human Participants Ethics Committee (024469), April 2020. Participants gave written, informed consent for interviews. Submission of the questionnaire provided a record of consent for the online questionnaire.

Knowledge gaps were also identified by a systematic review of all prioritisation studies that included women and/or their offspring published since 2009. Only those specific to an Aotearoa New Zealand setting were included.

Content analysis

Knowledge gaps generated by all three methods (survey, interview and systematic review) were reviewed by the project management team. The depth and breadth of research ideas were considered as research avenues, options and questions.[12] Using clinical and research knowledge, specific research questions were assigned as already answered or unanswered. Unanswered questions that still require new knowledge were formulated into practical research questions, assigned to one of four domains (delivery, development, discovery, description)[12] and assessed for their suitability to be answered in a randomised clinical trial or a large cohort study.

Research questions suitable for assessment by these two methods were further analysed to consider: to whom the "intervention" would be applied (mother, offspring, mother and offspring, family/whānau, healthcare professional and healthcare system); the timing at which the "intervention" would be applied (preconception, in pregnancy/foetal, during birth, neonatal—preterm baby, neonatal—unspecified or term baby, postpartum—maternal or, unspecified/crossover); the intended health beneficiary (mother, offspring, mother and offspring); and, the most suitable Advisory Group member disciplines for review (up to four disciplines per research question including anaesthetics, epidemiology/public health, Māori health, maternal mental health, midwifery, primary care/general practice, neonatology, neonatal nursing, obstetric medicine, obstetrics, Pacific health, science, reproductive health, other allied health). Each question was specifically considered with regards to relevance to Māori and Pacific health (if the research question only included Māori and Pacific people, or if the health condition included was one where Māori and Pacific people are over-represented).

Once the analysis of all research questions was complete, the results were reviewed by two principal study investigators, any discrepancies in judgement were resolved by discussion. Closely related research questions were combined where feasible without impacting on the original meaning of the knowledge gap. Research questions generated from the Audience Group by survey and interview were then grouped by discipline, and circulated to the appropriate Advisory Group members via email.

Advisory Group members were asked to review their allocated research questions and consider whether this remained a genuine knowledge gap, to provide a reference to the evidence if this was no longer a knowledge gap, and to review the wording to ensure clinical relevance and understanding. Responses were collated and reviewed by two principal study investigators. Where discrepancies were identified, additional literature searches were undertaken, and research questions were retained unless there was clear evidence that the knowledge gap no longer existed.

Ranking

Members of the Ranking Group received written information including project background and ranking methodology before an online meeting, in which an overview of maternity and perinatal healthcare in Aotearoa New Zealand, and some of the challenges faced, were presented alongside an overview of the prioritisation framework. Time was allowed for discussion, including smaller discipline-based breakout groups.

The ranking of research questions was completed in two steps by Multi-Criteria Decision Analysis (MCDA) using an established online decision-making tool, developed by 1000minds Ltd. through the University of Otago (https://www.1000minds.com). To first determine the weighting of the different criteria, five rating criteria were selected from

Figure 2: Rating criteria used in Multi-Criteria Decision Analysis.

Answerability—what is the likelihood the research question is answerable within the New Zealand maternity and newborn services environment?

Deliverability—what is the likeihood that the health intervention identified/developed will be implementable, affordable and sustainable within the New Zealand maternity and newborn services environment?

Effectiveness—what is the likelihood that the health intervention identified/developed will be effective within a New Zealand context?

Potential to reduce disease burden—what is the likelihood that the health intervention identified/devloped will sustainably reduce maternal and perinatal mortality, mobidity and long-term disease and disability in New Zealand?

the Child Health and Nutrition Research Initiative (CHNRI) Guidelines for Implementation of CHNRI Method for Setting Priorities in Global Child Health Research Investments,[7] and adapted to suit maternal and perinatal health research in Aotearoa New Zealand (Figure 2). The Ranking Group completed the weighting survey which used the PAPRIKA (Potentially All Pairwise RanKings of all possible Alternatives) method to determine the relative importance of each criterion.[13]

Ranking Group members were then asked to review each research question against the five rating criteria as high, medium-high, medium, low-medium or low, in importance. They were supplied with detailed descriptors of each criterion to support their assessments (Appendix 1). To limit bias and the effect of reviewer fatigue, the order in which questions were presented to each reviewer was allocated in a random manner. Rating of research questions was undertaken independently by each reviewer following the online meeting. The content of individual research questions was not discussed by the Ranking Group.

The 1000minds software used reviewer responses, and applied the relative weighting for each criterion assigned by the weighting survey to score and generate a ranked list of research questions. The ranked list was reviewed by the Core Group and the top 49 were grouped by themes (models of care/service provision, workforce, and specific interventions/conditions).

Results

The Research Prioritisation Framework (Figure 1) developed includes: key features of a transparent, structured approach; Māori participation at all levels and all steps;[14] an equity lens applied at each step;[15] wide engagement with diverse stakeholders; women and whānau (consumer) participation at all levels and all steps;[16] methods to accommodate cultural needs and location; and, use of a validated metric-based decision-making tool. The Framework includes 11 steps, in 4 phases, including 4 groups of participants.

Invitations to join the Audience Group were distributed to: 17 professional colleges and societies; 7 funding agencies; 5 Māori and Pacific specific health groups and agencies; 19 consumer groups, 6 academic units/departments; 16 individual Māori health contacts; and, via 3 national newsletters. The online questionnaire was accessible from 1 May to 1 August 2020; 305 questionnaires were submitted. The majority of responders were New Zealand European/European (235, 77%), 29 (9.5%) were Māori and 4 (1.3%) were Pacific. Responses were received from all geographical regions and included a variety of stakeholder groups including 147 (48.1%) healthcare professionals, 122 (40.0%) consumers and 36 (11.8%) other stakeholders (Table 1). Interviews were offered from 1 May to 14 August 2020; 62 interviews were completed. The majority of interviewees were New Zealand European/European (39, 62.9%) but a higher proportion were Māori (12, 19.4%) and Pacific (8, 12.9%), in comparison to the online questionnaire. Interviewees covered a variety of stakeholder groups including 34 (54.8%) healthcare professionals, 21 (33.9%) consumers and 7 (11.3%) other stakeholders (Table 1). More than half were from the Auckland Region (34, 54.8%).

A total of 3347 knowledge gaps were identified: 1610 from online questionnaires, 892 from interviews, and 845 from the systematic review of 62 eligible research prioritisation projects. After content analysis, 358 unanswered research questions were considered potentially able to be answered in a randomised clinical trial or large cohort study and entered the Ranking phase (Table 2). Of these 358 research questions 175 were identified by on-line questionnaires, 115 by interviews and 68 by the systematic review.

Twenty-nine individuals contributed to the Advisory Group and a further 23 agreed to join the Ranking Group (52 in total), of whom 47 (90.0%) completed the weighting survey and 46 (88.5%) completed the rating survey. Six Ranking Group members (11.5%) identified as Māori, but only two (4.3%) completed both surveys. All three Pacific Ranking Group members completed the weighting (5.8%) and rating surveys (6.5%) (Table 3). Representation by regions was focussed to areas including academic units and involved all the major professional health disciplines that provide maternal and perinatal care (Table 3).

The mean weights generated for the five rating criteria were: effect on equity 26.1%; potential to reduce disease burden 20.5%; effectiveness 20.0%; deliverability 17.9%; and answerability 16.0%. Ranking Group members reviewed a mean of 239 (range 2–358) of the 358 questions against the five rating criteria. The total score generated, and the ranking of each research question, are shown in Appendix 2. The top 49 ranked research questions grouped by themes within each ranked score group are shown in Table 4. Of the 20 research questions ranked highest, 13 related to models of care and service provision, five related to the

health workforce and only two to specific interventions (smoking cessation programmes and maternal mental health support); 14 were directly specific to Māori, two to Pacific peoples and four to both Māori and Pacific peoples, covering interventions for healthcare systems (16), the mother (3) or, healthcare professionals (1); and all having both the mother and offspring as intended beneficiaries of the intervention.

Table 1: Demographic descriptors of online questionnaire and video/telephone interview responders.

	Questionnaire responders n (%) **Total 305**	**Interview responders n (%)** **Total 62**
Ethnicity		
Māori	29 (9.5)	12 (19.4)
Pacific people	4 (1.3)	8 (12.9)
New Zealand European	180 (59.0)	32 (51.6)
Other European	55 (18.0)	7 (11.3)
Chinese	7 (2.3)	0
South East Asian and other Asian	12 (3.9)	1 (1.6)
Latin American	2 (0.7)	1 (1.6)
Middle Eastern	1 (0.3)	0
Other/not reported	15 (4.9)	1 (1.6)
Region		
Auckland	112 (36.7)	34 (54.8)
Bay of Plenty	25 (8.1)	3 (4.8)
Canterbury	36 (11.8)	3 (4.8)
Hawkes Bay	10 (3.3)	2 (3.2)
Marlborough	1 (0.3)	0
Nelson/Tasman	3 (1.0)	0
Northland	11 (3.6)	1 (1.6)
Otago	15 (4.9)	2 (3.2)
Southland	4 (1.3)	1 (1.6)
Tairāwhiti	3 (1.0)	1 (1.6)
Taranaki	2 (0.7)	0
Waikato	22 (7.2)	5 (8.1)
Wellington	34 (11.1)	8 (12.9)
West Coast	3 (1.0)	0
Whanganui	18 (5.9)	2 (3.2)

Table 1 (continued): Demographic descriptors of online questionnaire and video/telephone interview responders.

	Questionnaire responders n (%) **Total 305**	**Interview responders n (%)** **Total 62**
Not reported	6 (2.0)	0
Place of residence		
Rural	39 (12.8)	6 (9.7)
Semi-rural	58 (1.9)	11 (17.7)
Urban	205 (67.2)	45 (72.6)
Not reported	3 (1.0)	0
Role		
Allied health	3 (1.0)	1 (1.6)
Anaesthesia	4 (1.3)	0
Childbirth education/health promotion	1 (0.3)	1 (1.6)
Clinical researcher (non-clinician)	16 (5.2)	1 (1.6)
Consumer	122 (40.0)	21 (33.9)
Core midwifery	33 (10.8)	10 (16.1)
Dietician	1 (0.3)	1 (1.6)
General practice/primary care	15 (4.6)	3 (4.8)
Funder	2 (0.7)	0
Lactation consultant	3 (1.0)	1 (1.6)
LMC midwifery	27 (8.9)	5 (8.1)
Medical practitioner in training	4 (1.3)	0
Mental health	1 (0.3)	0
Midwifery education/management	3 (1.0)	1 (1.6)
Neonatal nursing	7 (2.3)	0
Neonatology/paediatrics	16 (5.2)	3 (4.8)
Nursing	3 (1.0)	6 (9.7)
Obstetrics	21 (6.9)	3 (4.8)
Pharmacy	2 (0.7)	0
Policy	2 (0.7)	1 (1.6)
Scientist/non-clinical researcher	11 (3.6)	0
Other	5 (1.6)	4 (6.5)
Not reported	3 (1.0)	0

Table 2: Content analysis of knowledge gaps.

Method of collection	Total knowledge gaps reported	Research questions identified*	Research questions requiring new knowledge	Research questions suitable for RCT or LCS	Research questions distributed to Advisory Group	Research questions included in ranking phase
Questionnaire	1610	663	515	181	181	176
Interview	892	459	322	122	122	115
Systematic review	845	256	148	68	–	68
Total	3347	1378	985	371	303	359

*exclusion of research avenues, research options, comments only and out-of-scope questions
RCT—randomised clinical trial
LPS—large cohort study

Table 3: Demographic descriptors of Ranking Group members.

	Ranking Group members n (%) Total 52	Ranking Group members completing weighting and rating surveys n (%) Total 46
Ethnicity		
Māori	6 (11.5)	2 (4.3)
Pacific people	3 (5.8)	3 (6.5)
New Zealand European	31 (59.6)	29 (63.0)
Other European	10 (19.2)	10 (21.7)
Chinese	1 (1.9)	1 (2.2)
South East Asian and other Asian	1 (1.9)	1 (2.2)
Region		
Auckland	28 (53.8)	25 (54.3)
Canterbury	8 (15.3)	8 (17.4)
Hawkes Bay	1 (1.9)	0
Lakes	1 (1.9)	0
Otago	2 (3.8)	2 (4.3)
Tairāwhiti	1 (1.9)	1 (2.2)
Waikato	2 (3.8)	2 (4.3)
Wellington	7 (13.5)	6 (13.0)
West Coast	1 (1.9)	1 (2.2)
Whanganui	1 (1.9)	1 (2.2)

Table 3 (continued): Demographic descriptors of Ranking Group members.

	Ranking Group members **n (%) Total 52**	**Ranking Group members completing weighting and rating surveys** **n (%) Total 46**
Area of expertise/representation*		
Allied health	2 (3.8)	2 (4.3)
Anaesthesia	2 (3.8)	2 (4.3)
Consumer representatives	5 (9.6)	5 (10.9)
Epidemiology	2 (3.8)	2 (4.3)
Funding agency	3 (5.8)	3 (6.4)
General practice/primary care	2 (3.8)	2 (4.3)
Maternal mental health	3 (5.8)	3 (6.4)
Māori health	5 (9.6)	2 (4.3)
Midwifery	7 (13.5)	7 (15.2)
Neonatology	5 (9.6)	4 (8.7)
Neonatal nursing	3 (5.8)	3 (6.4)
Obstetrics	11 (21.1)	11 (23.9)
Obstetric medicine	1 (1.9)	1 (2.2)
Pacific health	4 (7.7)	4 (8.7)
Policy maker	2 (3.8)	1 (2.2)
Reproductive health	3 (5.8)	3 (6.4)
Science	3 (5.8)	3 (6.4)

*Some individuals identified as working in more than one role.

Table 4: The ON TRACK Network Research Prioritisation Project top 49 research questions.

Rank/ score group	Research question theme	Research question	Specific relevance to Māori*	Specific relevance to Pacific people*	'Intervention' applied to	Timing of 'intervention'	Intended beneficiary
1st=- Score 90.1	Models of care/ service provision	Evaluate the effect of a Māori model antenatal care on long-term maternal and perinatal outcomes	Direct		healthcare system	in pregnancy	mother and offspring
		Design, implement and evaluate an effective model of antenatal care for Māori and assess the impact on preterm birth and other health outcomes	Direct		healthcare system	in pregnancy	mother and offspring
		Identify strategies that support Māori concepts of wellness and spirituality within maternity care and assess their effectiveness on maternal and perinatal health outcomes	Direct		healthcare system	unspecified/ crossover	mother and offspring
		What is the impact of Kaupapa Māori healthcare services on maternal and perinatal health outcomes for Māori women and whānau	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Compare the effectiveness of antenatal education located in Māori led entities/on Marae grounds with other locations (i.e. families home, District Health Board, Lead Maternity Carer clinic) on health outcomes	Direct		healthcare system	in pregnancy	mother and offspring
		Determine and evaluate the best methods to meet the needs of Māori and Pacific women to engage early with a Lead Maternity Carer	Direct	Direct	Mother	unspecified/ crossover	mother and offspring
		Identify the barriers and enablers to Pasifika women in accessing and engaging with maternity health care services in New Zealand and evaluate the effectiveness of strategies to increase access.		Direct	healthcare system	unspecified/ crossover	mother and offspring
	Workforce	Evaluate strategies to increase Māori Lead Maternity Carer service provision	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Evaluate strategies to increase Pacific Lead Maternity Carer service provision		Direct	healthcare system	unspecified/ crossover	mother and offspring
		Assess the feasibility and effectiveness of collaborations of General Practitioners and Lead Maternity Carer care with Marae and other Kaupapa Māori services/roopu to improve access to healthcare for Māori mothers and babies	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Evaluate ways to develop the Māori workforce in maternity and newborn health services	Direct		healthcare system	unspecified/ crossover	mother and offspring
	Specific interventions/ conditions	What smoking cessation strategies support Māori women and whānau to become smoke free	Direct		mother	unspecified/ crossover	mother and offspring

Table 4 (continued): The ON TRACK Network Research Prioritisation Project top 49 research questions.

Rank/ score group	Research question theme	Research question	Specific relevance to Māori*	Specific relevance to Pacific people*	'Intervention' applied to	Timing of 'intervention'	Intended beneficiary
13th = Score 86.9	Models of care/ service provision	Develop and evaluate culturally responsive programmes to best support bonding, attachment and parenting practices in Māori and Pacific families	Direct	Direct	healthcare system	unspecified/ crossover	mother and offspring
		Determine and assess the effect of wrap-around whānau-based maternity and newborn healthcare that is located in community focus points on maternal and perinatal health outcomes	Direct	Direct	healthcare system	unspecified/ crossover	mother and offspring
		Assess the feasibility and effectiveness of co-locating maternal and newborn healthcare services on Marae grounds	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Assess the feasibility and effectiveness of mobile clinics to improve access to healthcare for Māori mothers and babies	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Evaluate different approaches to maternity health service provision for Māori in rural and urban areas in New Zealand and the impact on maternal and perinatal health outcomes	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Evaluate the effectiveness of strategies to reduce morbidity and mortality rates for Māori and Pacific women and babies in New Zealand	Direct	Direct	healthcare system	unspecified/ crossover	mother and offspring
	Workforce	Determine and evaluate ways to increase practitioner engagement with culturally responsive healthcare practice for Māori and measure the effect of this engagement on Māori health outcomes	Direct		health care professionals	unspecified/ crossover	mother and offspring
	Specific interventions/ conditions	Identify strategies to provide maternal mental health support for Māori pregnant women and implement and evaluate their effectiveness	Direct		mother	unspecified/ crossover	mother and offspring

Table 4 (continued): The ON TRACK Network Research Prioritisation Project top 49 research questions.

Rank/ score group	Research question theme	Research question	Specific relevance to Māori*	Specific relevance to Pacific people*	'Intervention' applied to	Timing of 'intervention'	Intended beneficiary
21st = Score 85.9	Models of care/ service provision	Evaluate strategies to enhance the use of tikanga Māori into maternity care	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Compare the effectiveness of community led and culturally and spiritually appropriate antenatal education to other forms of antenatal education for Pacific women on health outcomes		Direct	healthcare system	in pregnancy	mother and offspring
		Evaluate ways to increase effective antenatal education within Pacific Island communities		Direct	mother	In pregnancy	mother and offspring
		Identify Pasifika women's experience, as to why and how to access antenatal care in New Zealand, and develop a proposal to evaluate culturally safe strategies to improve access to antenatal care		Direct	healthcare system	unspecified/ crossover	mother and offspring
		Assess the feasibility and effectiveness of follow-up phone call and home-visit after non-attendance at maternity and newborn healthcare appointments for the Pasifika community		Direct	healthcare system	unspecified/ crossover	mother and offspring
		Determine the optimal model of care to engage Māori women in effective (and early) antenatal care and assess effects on health outcomes	Direct		healthcare system	unspecified/ crossover	mother and offspring
	Workforce	Determine the effect of providing education about racism and discrimination to healthcare providers on the antenatal, birthing and postnatal experience of women and their whānau and on the health outcomes of women and babies (including child safety, care and protection)	Direct	Direct	health care professionals	unspecified/ crossover	mother and offspring
	Specific interventions/ conditions	Evaluate the effectiveness of different wound care practices for obese women on maternal health	Indirect	Indirect	mother	postpartum	mother
		Evaluate the effectiveness of strategies to increase maternal vaccination rates in Pacific women		Direct	healthcare system	unspecified/ crossover	mother and offspring
		Determine the most effective ways to increase rates of influenza immunisation in pregnant women	Indirect	Indirect	healthcare system	unspecified/ crossover	mother and offspring
		Evaluate the impact of early diagnosis and treatment of gestational diabetes on maternal and infant outcomes	Indirect	Indirect	mother	in pregnancy	mother and offspring
		Evaluate the effectiveness of dietary and lifestyle interventions compared with pharmacotherapy for women whose HbA1c at booking in early pregnancy is in the range of 41–49 mmol/mol on maternal and infant outcomes	Indirect	Indirect	mother	in pregnancy	mother and offspring
		Develop effective and New Zealand culturally appropriate tools to screen for maternal mental health problems	Indirect	Indirect	mother	unspecified/ crossover	mother and offspring
		Assess the universal use of a validated screening tool to identify women with maternal mental health issues in New Zealand	Indirect	Indirect	mother	unspecified/ crossover	mother and offspring
		Determine and assess the impact of fully funded long term contraception on health outcomes in socially disadvantaged families in New Zealand	Indirect	Indirect	healthcare system	unspecified/ crossover	mother and offspring

Table 4 (continued): The ON TRACK Network Research Prioritisation Project top 49 research questions.

Rank/ score group	Research question theme	Research question	Specific relevance to Māori*	Specific relevance to Pacific people*	'Intervention' applied to	Timing of 'intervention'	Intended beneficiary
36th Score 83.7	Specific interventions/ conditions	Determine the most effective strategy to provide culturally responsive wrap-around care (He Korowai Manaki) for women with substance abuse in pregnancy and the impact on maternal and perinatal health	Indirect	Indirect	mother	unspecified/ crossover	mother and offspring
37th = Score 82.9	Models of care/ service provision	Evaluate ways to increase access to kaupapa Māori birthing options	Direct		healthcare system	unspecified/ crossover	mother and offspring
		Determine the impact of appropriate whānau space in neonatal units to enable culturally responsive care for Māori babies	Direct		healthcare system	neonatal - preterm baby, neonatal - unspecified or term baby	offspring
		Evaluate ways to increase the provision of traditional Māori birthing practices within secondary/tertiary birthing facilities	Direct		healthcare system	unspecified/ crossover	mother and offspring

Table 4 (continued): The ON TRACK Network Research Prioritisation Project top 49 research questions.

Rank/ score group	Research question theme	Research question	Specific relevance to Māori*	Specific relevance to Pacific people*	'Intervention' applied to	Timing of 'intervention'	Intended beneficiary
40th = Score 82.7	Models of care/ service provision	Evaluate approaches to provide equitable access to wrap-around pregnancy care that includes health and social services support during pregnancy	Indirect	Indirect	healthcare system	unspecified/ crossover	mother and offspring
		Evaluate approaches to enable a national maternity and newborn health record to be accessible to all health care professionals involved in maternity care			healthcare system	unspecified/ crossover	mother and offspring
		Determine the effectiveness of multidisciplinary team based maternity care for high risk women in New Zealand (Lead Maternity Carer, General Practitioner and secondary care)			healthcare system	unspecified/ crossover	mother and offspring
		Evaluate the effect of different packages of care to support parents and whānau/carers when an infant born preterm is discharged from hospital	Indirect	Indirect	healthcare system	neonatal - preterm baby, neonatal - unspecified or term baby	mother and offspring
		Determine and assess the impact of poverty reduction interventions (provision of clothing, shelter and food) on maternal and perinatal health outcomes within vulnerable populations	Indirect	Indirect	healthcare system	unspecified/ crossover	mother and offspring
		Evaluate ways to more effectively implement existing maternal and perinatal health research findings within high-needs communities	Indirect	Indirect	healthcare system	unspecified/ crossover	mother and offspring
		Determine the effectiveness of a walk-in centre for Pasifika women and their newborns for access and attendance for maternity care		Direct	healthcare system	unspecified/ crossover	mother and offspring
	Workforce	Evaluate strategies to increase numbers of Lead Maternity Carer providers			healthcare system	unspecified/ crossover	mother and offspring
		Develop and evaluate interventions to increase the proportion of health care professionals practicing in rural and other under-served areas	Indirect	Indirect	healthcare system	unspecified/ crossover	mother and offspring
	Specific interventions/ conditions	Evaluate the effectiveness of strategies to increase knowledge of, and access to, appropriate contraception including in areas and groups of need	Indirect	Indirect	mothers	unspecified/ crossover	mother and offspring

*Specific relevance to Māori and/or Pacific people was determined as 'direct' if research questions only included these groups or as 'indirect' if the health condition included is one where Māori and Pacific people are over-represented.

Discussion

We developed a new Aotearoa New Zealand specific Research Prioritisation Framework and used this to identify and answer the most important research questions through randomised clinical trials or large cohort studies in maternal and perinatal health and healthcare. This is the first systematic health-area-wide research prioritisation project undertaken for Aotearoa New Zealand. The developed Framework includes all the steps and recommended questions in a checklist for good practice[10] and enabling an equity-oriented approach,[15] as well as all the critical steps, which have since been identified in the recently published Australian Clinical Trials Alliance (ACTA) guideline for clinical trial networks interested in setting priorities for the conduct of clinical trials.[2]

We were successful in addressing the majority of key features planned in our framework. Key stakeholder groups contributed to the Core, Advisory and Ranking groups and a diverse group of stakeholders were included in the Audience Group. Consumer participation was included in all steps of the process with the exception of the Advisory Group consultation, as this was deemed to be an area where clinical practice and evidenced-based knowledge was required.

The use of two different methods for the collection of knowledge gaps was intended to accommodate cultural needs and different locations of potential participants. On-line questionnaires provided an efficient and cost-effective method of data collection. This allowed participation by a large number and variety of stakeholders, including those who may prefer to participate anonymously or are geographically distant, using their own choice of timing and location. The inclusion of face-to-face data collection has been demonstrated to be effective in enabling participation by healthcare consumers in research[17,18] and kanohi ki te kanohi hui were also expected to support and encourage participation by Māori.[14] Although this could not be undertaken due to COVID-19 restrictions, the higher rates of Māori and Pacific peoples' participation in the collection of knowledge gaps via interview suggests that the use of video and telephone calls still provided some level of personal connection, thereby supporting their willingness to participate. However, it is also possible that a more targeted approach to include Māori and Pacific people was possible by using interview rather than survey methodology.

In designing the Research Prioritisation Framework, equity was considered a key feature, and essential to supporting the vision of the ON TRACK Network "to achieve greater equity, health outcomes, and quality of life for women and babies nationwide". Consideration of an equity lens, as developed to ensure an equity-oriented approach to agenda and priority setting of Cochrane Reviews,[15] was utilised at each step of the project. The importance of equity was further supported by the inclusion of the rating criteria "effect on equity" as part of the ranking process, which was found to be the criterion most heavily weighted by the Ranking Group (26.1%), and hence made the most significant contribution to overall research question scores. This approach appears to have been effective in prioritising equity focussed research questions, since all of the top 20 prioritised research questions related specifically to Māori and/or Pacific peoples' health and healthcare, and predominantly focussed on models of care and service provision. Within the top 49 prioritised research questions, a further 12 were specific to Māori and/or Pacific people. The remainder were mainly focussed on specific health conditions where Māori and/or Pacific people are disproportionately over-represented (mental health, obesity and diabetes in pregnancy) or inequities existing due to social disadvantage, poverty, access to care, rural location or high needs communities.

Through the ranking process it was highlighted that equity issues, and meeting the obligations of Te Tiriti o Waitangi, must be considered separately. We were able to achieve Māori participation at all levels and all steps of the process but we were not able to achieve equal partnership with Māori (50% of all participants), or indeed, reach levels that are representative of Māori within the Aotearoa New Zealand population (16.7%, NZ Stats 2020)[19] with only 11.2% of the Audience Group and 11.5% of the Ranking Group identifying as Māori, and only two of the six Māori participants in the Ranking Group completing both the weighting and rating surveys. This partly related to the lack of capacity for overstretched Māori healthcare workers and health researchers, but also to reservations relating to the framework, which by the nature of its design does not follow Kaupapa Māori research theory and practice. It was suggested that a Māori-led and -focused future research project should be considered. However, this may not provide opportunities to directly compare, measure and

prioritise research for Māori against research for non-Māori or the general population, and would currently be significantly limited by capacity of those Māori working in this area. The prioritisation project itself identified the need for further research on how to develop and support our Māori healthcare and health research workforce, with two research questions within the top 12 relating to the Māori maternity and newborn health workforce.

The list of prioritised research questions will be promoted by the ON TRACK Network through peer-reviewed publication, presentation at scientific and public meetings, through the media and social media including the ON TRACK "Forum for Women and Whānau" Facebook page for consumers, and through the ON TRACK Network's monthly national newsletter which is distributed across district health board members of the Network. The ON TRACK Network will support development of the top prioritised research questions in future activities including their annual trial development workshop. We expect that the list of prioritised research questions will be used by clinicians and researchers to develop clinical trials and large cohort studies in the future. It is also anticipated the list will attract more clinicians and researchers to this area and be of value to hospitals, consumer and advocacy groups, colleges and societies, funders and policy-makers when considering what research to support and where resources should be applied.

Further exploration of data will identify any differences in research priorities by subgroups, such as healthcare provider groups and consumers, and will provide opportunity to explore the methodology used including the impact of each criteria and their relative weightings. Furthermore, where knowledge gaps were suggested but evidence exists, there is scope for a number of research translation and implementation projects as well as national practice guidelines, with work focussed both for clinicians and consumers. A number of broader research avenues and options were also commonly identified, for example, preterm birth and gestational diabetes, and these findings support larger programmes of research, many of which may need randomised trials nested within them. Research questions identified under the domains of discovery (fundamental and inventive research) and description (epidemiological analysis) should be of interest to scientists and epidemiologists as well to clinicians and clinical researchers, funders, hospital managers and policy-makers. The use of a robust, systematic and transparent approach to prioritisation will allow later evaluation and updates.

This first systematic health-area-wide research prioritisation project, undertaken specifically for Aotearoa New Zealand, has identified the most important questions for future clinical trials and large cohort studies in maternal and perinatal health and healthcare. This Framework and methodology could be adapted for use in other areas of health and healthcare in Aotearoa New Zealand.

COMPETING INTERESTS
Nil.

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AUTHOR INFORMATION
Katie M Groom: Associate Professor of Maternal and Perinatal Health and Maternal Fetal Medicine Subspecialist; Liggins Institute, University of Auckland and National Women's Health, Auckland City Hospital, Auckland District Health Board, Auckland.
Clara Mossinger: PhD student, Liggins Institute, the University of Auckland, Auckland.
Jody Lawrence: Project Manager,Liggins Institute, the University of Auckland Auckland.
Dame Jane E Harding: Distinguished Professor of Neonatology, Liggins Institute, University of Auckland, Auckland.
Karaponi Okesene-Gafa: Senior Lecturer and Obstetrician and Gynecologist, Department of Obstetrics and Gynecology, University of Auckland and Counties Manukau District Health Board, Auckland.
Matire Harwood: Associate Professor of General Practice and Primary Healthcare,School of Population Health, University of Auckland, Auckland.
Frances Benge: Chief Executive Officer, Cure Kids, Auckland.
Jessica Steele: Consumer representative ON TRACK Network Auckland.
Caroline A Crowther: Professor of Maternal and Perinatal Health, Liggins Institute, University of Auckland, Auckland.

CORRESPONDING AUTHOR
Associate Professor Katie Groom: Liggins Institute, the University of Auckland. Private Bag 92019, Auckland 1142, New Zealand. +64 9 373 7599 ext 89823. k.groom@auckland.ac.nz.

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Appendix 1: Descriptors for rating criteria used in Multi-Criteria Decision Analysis

- **Answerability**—Is the research question likely to be answerable within the New Zealand maternity and newborn services environment?
    - Can a single study or a small number of studies be designed to answer the research question?
    - Would a study designed to answer the proposed question be likely to obtain ethical approval in New Zealand without major concerns?
    - Would a study designed to answer the proposed question be likely to be acceptable to women, whānau and maternity and newborn healthcare providers in New Zealand?

- **Deliverability**—Would any health intervention identified/developed in response to the proposed research question be likely to be deliverable within the New Zealand maternity and newborn services environment?
    - Would the intervention be likely to be implementable based on current infrastructure, resource, attitudes and beliefs?
    - Would the intervention be likely to be affordable based on health funding?
    - Would the intervention be likely to be sustainable based on current services and environment?

- **Effectiveness**—What is the likelihood that any health intervention identified/developed in response to the proposed research question will be effective within a New Zealand context?
    - Based on the best existing evidence and knowledge, is the intervention likely to be efficacious ie produces a beneficial result under ideal conditions?
    - Based on the best existing evidence and knowledge, is the intervention likely to be effective ie produces a beneficial result in an average clinical environment?
    - If the intervention is thought to be efficacious and effective is this based on high quality evidence?

- **Potential to reduce disease burden**—Would any health intervention identified/developed in response to the proposed research question be likely to substantially reduce disease burden that impacts on maternal and perinatal mortality, morbidity and long-term disease and disability in New Zealand?

    - Would the results of this research fill an important knowledge gap in a common and/or major issue that negatively impacts on maternal and perinatal health?
    - Would the results from this research be likely to implemented and influence future health-care provision?
    - Does the proposed research have the potential to improve maternal and perinatal health over the next 10 years?

- **Effect on equity**—Would any health intervention identified/developed in response to the proposed research question be likely to lead to improved equity in maternal and perinatal health outcomes in New Zealand?
    - Is the proposed research question likely to support Te Tiriti o Waitangi principles of partnership participation and protection of Māori and lead to better pregnancy and newborn health outcomes for Māori?
    - Does the current distribution of the target disease burden/health issue disproportionately affect different groups based on factors such as ethnicity, culture, religion, disability, geography, sexual orientation, social class and wealth?
    - Would the most disadvantaged be the most likely to benefit from the results of the proposed research and so improve equity in health outcomes?
    - Does the proposed research have the potential to improve equity in maternal and perinatal disease burden over the next 10 years?

Appendix 2:
https://uploads-ssl.webflow.com/5e332a62c703f6340a2faf44/6253a0eb2800cf781f945a00_5288-appendix%202-final.pdf

CPAP for paediatric patients in Aotearoa New Zealand: audit of a developing service at Capital and Coast DHB 2005–2020

Dawn Elder, Sophie Gandhi, Angela Campbell

ABSTRACT

AIMS: To document the establishment of a Paediatric Continuous Positive Airway Pressure (CPAP) service within the Wellington Region, and review outcomes over the last 15 years.

METHODS: A retrospective audit of the Paediatric Sleep Service records including clinic letters and polysomnography (PSG) studies for all paediatric patients commenced on CPAP treatment, or for whom CPAP treatment was offered, from November 2005 to December 2020. Data were collected on demographics, medical diagnoses, indications for respiratory support, ENT involvement and surgery. Factors related to CPAP use were also recorded.

RESULTS: Seventy-four children were offered CPAP in the time frame, 52 (70%) male. The age range at onset of CPAP treatment was <1 year of age to 23 years with 12 cases ≥16 years of age. There were 3 (4%) cases presenting before 2006, 11 (15%) cases from 2006–2010, 16 (22%) cases from 2011–2015 and 44 (59%) cases between 2016–2020. Ethnicities included were, 32 (43%) NZ European, 18 (24%) Māori, 19 (26%) Pacific and 5 (7%) Indian/Asian. The most common primary diagnoses were Obesity 21 (28%), Down Syndrome 10 (14%) and Craniofacial abnormalities 8 (11%). One family declined a CPAP trial and there were eight failed CPAP trials. For the remaining 65 patients, compliance with treatment was good/usually good for 25, variable for 19, and poor for 21. Māori patients were less likely to have good/usually good compliance than NZ European and Pacific patients (25% versus 44% and 47% respectively).

CONCLUSION: Referrals for CPAP treatment in the paediatric age range are increasing and obesity is the commonest co-morbidity. Services need to be culturally appropriate to ensure the best outcomes.

Obstructive sleep apnoea (OSA) is characterised by repetitive episodes of upper airway obstruction during sleep leading to hypoxia and sleep fragmentation. Prevalence rates in the paediatric population vary between 1.2% to 5.7%.[1] When symptoms of apnoea are recorded separately from snoring, snoring is more common (1%–2% versus 3.6%–7.7% for always snoring and 9.6% to 21.2% for habitual snoring).[2] Both complete obstruction (apnoea) and partial obstruction (hypopnoea) are associated with oxygen desaturation and arousal in children. The commonest cause is adenotonsillar hypertrophy, but obesity is increasingly being associated with OSA in later childhood and adolescence. Other risk factors include craniofacial anomalies, neuromuscular disorders, congenital/chromosomal syndromes (most commonly trisomy 21) and central nervous system disorders.[3,4]

The prevalence of OSA in the child and youth population of Aotearoa New Zealand is not known. In a community sample of 839 3-year-old children, of whom around half were followed up at 7 years of age, prevalence of habitual snoring was similar at the two time points (11.3% versus 9.2%) but there were individual changes in status over time, highlighting the need for regular screening for symptoms including after adenotonsillectomy.[5] Untreated OSA has been associated with impairments in memory and attention, learning deficits and difficult behaviour and so attention to treatment is important.[6] Obstructive sleep apnoea can lead to daytime sleepiness and hyperactive behaviour. At night, sleep is restless and waking common with consequent secondary effects on caregivers including sleep disturbance, fatigue and mood changes.

The first line of treatment in children, adenotonsillectomy, improves quality of life but may not resolve all symptoms in all children.[7–9] Those with predisposing factors such as obesity, craniofacial anomalies and neuromuscular or other congenital syndromes may require alternative treatments such as continuous positive airway pressure (CPAP).

Paediatric sleep services are well established in the main centres in Australia. Currently in Aotearoa New Zealand, only Wellington and Auckland have established services for paediatric sleep studies reported by a paediatric sleep physician, although a developing specialist service is now available in Christchurch with the recent arrival of a paediatric specialist trained in sleep medicine. In 2005, colleagues at Starship hospital Auckland reported on non-invasive ventilation use in the paediatric population in New Zealand including 47 patients on CPAP.[4] A trend was noted then of increasing numbers of children receiving respiratory support at home. In 2013, the Australasian Paediatric Respiratory Group reported data on paediatric home ventilatory support across Australasia, providing estimates of numbers using CPAP and expressing concern about data quality and equity of access to services.[10]

The collaboration between Capital and Coast DHB (CCDHB) and the University of Otago WellSleep adult sleep laboratory started in 1997. Initially, with regard to the paediatric age range, there was more emphasis on neonatal polysomnography (PSG) and research in infant breathing. Paediatric sleep clinics commenced at CCDHB in 2005 and were led by a qualified paediatric sleep physician from 2008. Since then, a growing number of children have been seen, assessed and offered CPAP therapy. This review aimed to determine the effectiveness of the establishment of CPAP treatment in children within the Wellington Region, and to see if there had been improvements over the last 15 years. We also examined the reasons for CPAP treatment and associated demographic factors.

Method

This was a retrospective review of paediatric sleep service records at CCDHB including clinic letters and PSG studies to identify all children offered CPAP treatment from November 2005 to December 2020. CCDHB contracts paediatric sleep assessment services also for Hutt Valley and Wairarapa DHBs from the WellSleep sleep laboratory at the University of Otago, Wellington. Data were collected on demographics, medical diagnoses, indications for respiratory support, Ear Nose and Throat (ENT) specialist involvement and surgery. The NZ Deprivation Index was calculated from NZDep2013 or NZDep2018 data depending on when the patient was first seen.[11,12] A BMI at or above the 95th percentile for age and gender was considered overweight. Factors related to CPAP use were also recorded including the year first seen by the service, number of PSG studies undertaken and initial apnoea hypopnea index (AHI).

Compliance was assessed from clinical information rather than machine downloads, as the availability of these changed over the review period. Compliance was documented as either "usually good" (patient using CPAP for >4 hours each night for >70% of the week), "good" (patient using CPAP 50% of the week), "variable" (intermittent use of CPAP) or "poor" (patient never established on CPAP). A "failed trial" was recorded if the patient had not completed the initial one-month CPAP trial. A "declined trial" was recorded if the family did not take up the offer of CPAP treatment. Patient characteristics and compliance were compared between two time periods, 2005–2014 and 2015–2020. Data were collated into a Microsoft Excel database, and summary statistics generated using Excel functions. The audit was approved by the Child Health Service governance group at CCDHB.

Results

Seventy-four patients were offered CPAP therapy over the time period, of whom 52 (70%) were male. Age at commencement varied between less than one year of age to 23 years of age, the latter being a Down syndrome patient. Patients were offered CPAP across the child and youth age range with 12 cases being ≥16 years of age. (Figure 1). Patient demographics are shown in Table 1. NZ European cases were under-represented and Pacific and Other ethnicities over-represented.

The Deprivation Index quintile for cases is illustrated in Table 1. Although all quintiles were represented, the highest number of cases were from Quintile 5. This is not representative of data for the <15-year age group from Capital and Coast, Hutt Valley and Wairarapa district health boards (DHBs), where Quintile 4 is the predominant quintile for Hutt Valley and Wairarapa and Quintile 1 for Capital and Coast DHB.[13] Forty-five (61%) patients were from Capital and Coast DHB, 24 (33%) from Hutt Valley DHB, three (4%) from Wairarapa DHB and one (1%) each from Whanganui and Nelson Marlborough DHBs.

Patients were initiated on CPAP therapy every year from 2005 to 2020. Early on in the time period, two Wellington patients were started on CPAP at Auckland Starship hospital. Three other patients commenced CPAP elsewhere and then transferred to Wellington because of a change in personal circumstances. There was a marked increase in numbers of patients offered CPAP treatment over the audit period (Figure 2).

Table 1: Patient demographics compared between two time periods 2005–2014 and 2015–2020.

	2005–2014	2015–2020	Total
Patients offered CPAP	25	49	74
Sex % male	17 (68%)	35 (71%)	53 (70%)
Age <5 years	3 (12%)	11 (22%)	14 (19%)
Ethnicity			
NZ European	9 (36%)	23 (47%)	32 (43%)
Māori	7 (28%)	11 (22%)	18 (24%)
Pacific	9 (36%)	10 (21%)	19 (26%)
Other	0 (0%)	5 (10%)	5 (7%)
Deprivation Index			
Quintile 1	4 (16%)	4 (8%)	8(10%)
Quintile 2	1 (4%)	9 (18%)	10(14%)
Quintile 3	5 (20%)	14 (29%)	19 (26%)
Quintile 4	5 (20%)	6 (12%)	11(15%)
Quintile 5	10 (40%)	16 (33%)	26 (35%)
BMI (Mean and SD)			30.6 ± 11.0 kg/m^2
NZ European	30.2 ± 12.7 kg/m^2	29.14 ± 11.2 kg/m^2	25.7 ± 7.7 kg/m^2
Māori			36.2 ± 10.2 kg/m^2
Pacific			38.5 ± 10.2 kg/m^2

Figure 1: Age at which CPAP was first offered or commenced.

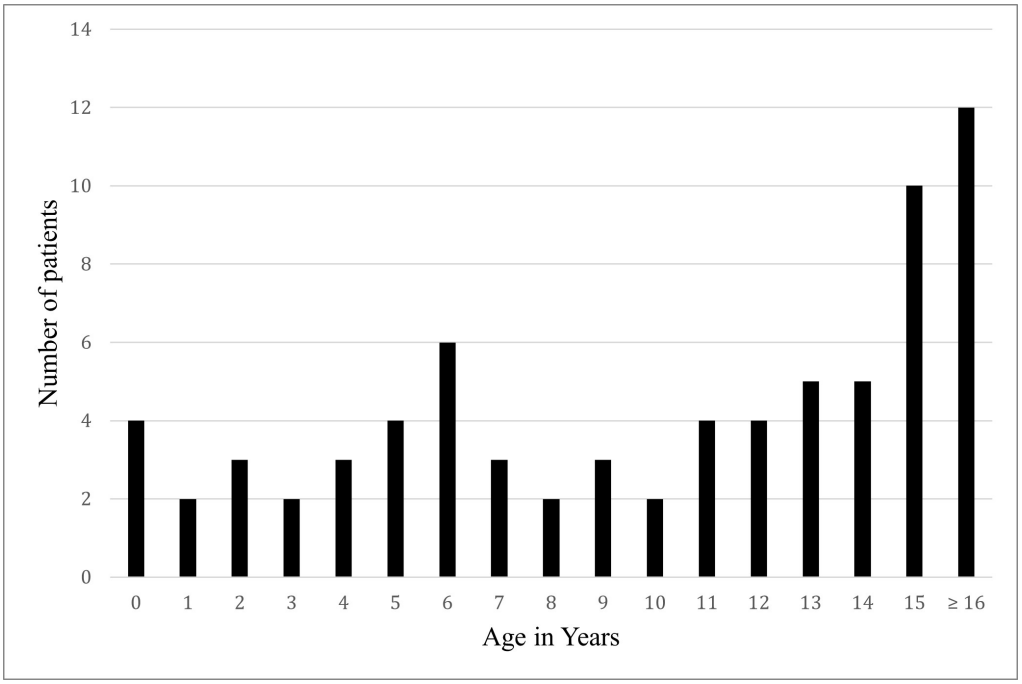

Figure 2: Year CPAP offered or commenced.

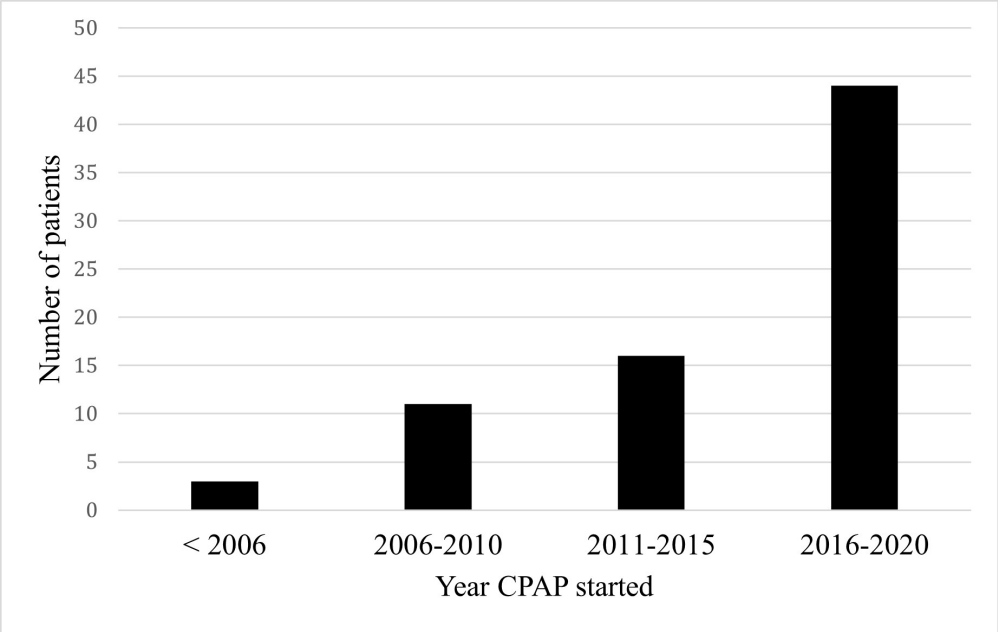

Table 2: Main co-morbidity diagnosis associated with need for CPAP treatment.

Co-morbidity	Number (%)
Obesity	21 (29%)
Down syndrome	10 (14%)
Craniofacial abnormality (includes micrognathia)	8 (11%)
Severe cerebral palsy	4 (6%)
Chromosomal abnormality	4 (6%)
Nasal obstruction	4 (6%)
Muscular dystrophy	4 (6%)
Prader–Willi syndrome	4 (6%)
CNS lesion	3 (4%)
Respiratory—asthma, recurrent infection, chronic lung disease	3 (4%)
Airway—subglottic stenosis, tracheomalacia etc	3 (4%)
Other	6 (8%)

Table 3: Patient compliance compared between two time periods 2005–2014 and 2015–2020 and by ethnicity and age.

Time period	**2005–2014**	**2015–2020**	**Total**
Offered CPAP	*n=25*	*n=49*	*n=74*
Treatment >1 month	24	41	65
Failed trial	1	7	8
Declined CPAP		1	1
Compliance >1 month	*n=24*	*n=41*	*n=65*
Good/usually good	6 (25%)	19 (46%)	25 (34%)
Variable	8 (33%)	11 (27%)	19 (26%)
Poor	1 (42%)	11 (27%)	21 (28%)
Compliance >1 month	**Good/usually good**	**Variable**	**Poor**
Ethnicity			
NZ European (n=25)	11 (44%)	6 (24%)	8 (32%)
Māori (n=16)	4 (25%)	7 (44%)	5 (31%)
Pacific (n=19)	6 (47%)	5 (26%)	8 (42%)
Age			
0–4 years (n=14)	7 (50%)	4 (29%)	3 (21%)
5–9 years (n=18)	7 (39%)	6 (33%)	5 (28%)
≥10 years (n=33)	11 (33%)	9 (27%)	13 (39%)

Table 4: Reasons for stopping CPAP and/or discharge from the paediatric sleep service for patients offered or commenced on CPAP.

Reason for discharge	**Number of cases n=74**
Current patient	20
Discharged poor tolerance or compliance	13
Transferred to adult services	12
Improved after ENT surgery	9
Improved/not required	6
Discharged failed trial	5
Moved out of 3DHB area	4
Offered and declined	1
Improved after ENT and plastic surgery	1
Discharged—improved after weight loss	1
Moved to bilevel ventilation	1
Improved due to medical treatment of immune deficiency	1

The mean Body Mass Index (BMI) when offered CPAP therapy was 30.6 kg/m ^{2} (SD 11.9), ranging from 13.1kg/m2 to 68.6kg/m2. BMI was unavailable for three patients. There were 40 (54%) patients with a BMI >95th centile for age. The mean BMI was higher for Māori and Pacific patients than for NZ European patients (Table 1). Obesity was the most commonly documented co-morbidity contributing to the need for CPAP treatment followed by Down syndrome and craniofacial anomalies (Table 2).

The most common sleep diagnosis resulting in offering CPAP was OSA (69 (82%) patients). Three patients had a mixed picture of central and obstructive apnoea on PSG, and one patient had evidence of OSA with a degree of hypoventilation. A further patient had catathrenia without significant OSA on overnight PSG. Diagnostic PSG was unavailable for five (18%) patients. For the remainder, six had an apnoea hypopnoea index (AHI) between 1–5 events per hour, 13 had an AHI between 5–9 events per hour, and 11 had an AHI between 0–14 events per hour. The remaining 39 patients had an AHI ≥15 events per hour with four having an AHI >90 events per hour. Some patients had a full night diagnostic study, and some had a split study with a shorter diagnostic period and CPAP applied during the night of the initial study, which would explain some variation in the initial AHI

Twenty-nine (39%) patients had at least one type of ENT procedure prior to CPAP treatment. The most common procedure was adenotonsillectomy (n=20) followed by other nasal surgery (n=7), adenotonsillectomy plus revision adenoidectomy (n=4), tonsillectomy alone (n=3) and adenoidectomy alone (n=1). Seven patients had two procedures and three patients had three procedures. There were also a number of patients who had ENT procedures after being offered CPAP. These procedures included adenotonsillectomy (n=9), other nasal surgery (n=6), tonsillectomy (n=5), revision adenoidectomy (n=3) and lingual tonsillectomy (n=1).

With regard to acceptance of treatment, one family declined the offer of CPAP treatment, and eight patients did not complete the initial trial period. The eight patients not completing the CPAP trial were all ≥10 years of age as was the patient for whom a CPAP trial was declined. Compliance data are shown in Table 3.

When age was considered for patients using CPAP beyond a month, the best compliance was seen in the 0–4 year age group. When ethnicity was considered, Māori patients appeared less likely to have good or usually good compliance. For those patients who completed the one-month trial, good/usually good compliance was more commonly documented in the second time period.

During CPAP treatment, overnight PSG recordings were undertaken for monitoring pressure requirements over time. The average number of studies per patient, including the initial diagnostic study, was 2.5 studies (median 2, range 1–11). Younger children continuing CPAP over a longer period of time had studies undertaken every one to two years to review pressure requirements.

By the end of 2020, 54 patients were discharged from the service or stopped using CPAP and 20 patients remained current patients. Reasons for discharge are shown in Table 4. The most common reasons for discharge were poor tolerance and compliance (n=13) and transfer to adult sleep services (n=12). Nine patients demonstrated an improvement in OSA symptoms after ENT surgery and six improved for other reasons. Some of these were infants who demonstrated improvement in micrognathia during the first year of life.

Discussion

This review of patients managed through the paediatric sleep service at CCDHB indicates the wide range of ages and underlying diagnoses of children presenting with OSA and requiring treatment with CPAP. Also, just as there has been an explosion of CPAP use for adult patients in recent years, so also in the infant, child and youth age range an increasing number of patients are being treated with CPAP. These cases are likely just the tip of the iceberg in regard to the numbers who would benefit from this treatment. The increased referrals suggest greater recognition by a range of clinicians that CPAP may be a useful treatment for these patients.

The most common indication for CPAP commencement was, as expected, OSA and the most common primary clinical associations were obesity (without other co-morbid factors), Down syndrome and craniofacial abnormalities. Children with neurological disorders compromising upper airway function during sleep are also increasingly being referred for consideration of CPAP. These findings are similar in some respects to the Starship hospital study reporting on 108 children started on CPAP between 1999 to 2004.[4] The most common indication for respiratory support in the Auckland cohort was respiratory airway disease followed by neuromuscular disease and central nervous system disorder. Obesity was “not a

common indication". Machalaani et al. reported in 2016 on the effectiveness of CPAP in 55 children 0–18 years of age from the Children's Hospital at Westmead in Sydney.[14] Just under 90% of CPAP users were in diagnostic categories grouped as chromosomal, neuromuscular, lung disorder, central nervous system disorder or "other" disorder. Only five CPAP users were documented as being obese.

In contrast, just over half the patients in the current study had a BMI >95th centile. For 29% of the group, obesity was the main reason for the OSA whereas for others the obesity was a co-morbidity in association with diagnoses such as Prader–Willi syndrome, Down syndrome and Duchenne muscular dystrophy. The current data therefore suggest that although CPAP is being used for patients with a wide variety of diagnoses as previously documented, its use is increasing in children and youth with obesity without other clinical co-morbidities. It is not clear why the current data are different from Auckland and Sydney cohorts, but this may reflect an increase in recognition of OSA in obese children and therefore referrals to the sleep service from general paediatricians and primary care.

Of the patients in the Wellington cohort, over a third had undergone at least one type of ENT intervention prior to referral for CPAP. Although adenotonsillectomy can be helpful for obese children and youth with OSA, some patients continue to have ongoing symptoms requiring further treatment.[15] In our group, because of the severity of their OSA, 18 obese patients were referred for CPAP without prior ENT surgery. Of these, seven went on to have ENT surgery at a later date. The other patients referred for CPAP without prior ENT surgery had craniofacial anomalies or other co-morbidities like muscle disorders. We documented ENT surgery events but do not know the number of patients who were assessed by ENT, and where surgery was not recommended.

The use of CPAP to reverse OSA was first reported by Sullivan et al, who documented use in five patients including one 13-year-old.[16] This adolescent had been thought to have an intellectual disability however a large part of his learning disability was related to his inability to stay awake at school. This group in Sydney, Australia further expanded the use of CPAP in children reporting in 1995 on the use of nasal CPAP for OSA in 80 children (average age 5.7 years).[17] In a report from the USA published the same year documenting use of CPAP in 94 patients, 29% were 1–5 years of age, 36% 6–12 years of age and 32% 13–19 years of age. In the current study, corresponding values were 16%, 32% and 43%, respectively, although the older group did include a few patients >19 years of age. Just over half the patients commenced on CPAP in the current cohort were adolescents (aged ≥10).

This shift to a relatively older age at CPAP initiation may be related to the increase in use of CPAP in obese adolescents. The large age range of patients started on CPAP, particularly those treated past the age of 16, also highlights the need for continuation of care for youth with developmental delay such as patients with Down syndrome. For young people referred approaching the age of cut off for transfer to adult services, it is in the best interests of the patient to commence CPAP in the paediatric sleep service as waiting lists are long in adult sleep services, and services are less flexible in regard to managing adolescents with complex co-morbidities that include intellectual disability. The younger patients treated in the first year of life were infants with OSA related to micrognathia or early tonsillar hypertrophy. For those with isolated micrognathia, symptoms resolved as the jaw grew forward, and so for this group of patients CPAP treatment was not long-term.

With regard to ethnicity, Pacific patients were over-represented in the Wellington group. The average BMI was also higher for Māori and Pacific patients. Māori patients appeared less likely to be compliant with treatment than NZ European and Pacific patients, although this was not tested statistically because of the small numbers in the study, and possible cofounding by other factors such as patient age and reason for treatment. Both Māori and Pacific patients were more likely to live in a more deprived neighbourhood, so these were not differentiating factors. A previous local study assessed CPAP adherence in adult Māori and non-Māori, and found that the poorer adherence demonstrated by Māori was explained, in part, by lower education levels and socio-economic status.[18] However, the differences in adherence in that study, while statistically significant, were not very clinically significant. We suspect that in our group, a factor is our failure to consistently provide culturally appropriate services.

Factors such as access to equipment, damage to equipment, social issues, co-morbidities and tolerance to CPAP equipment can impact compliance.[19,20] When patients have an intellectual disability or are very young it can be hard for them to describe side effects, especially issues with

mask fit. Only around a third of the patients in the current study demonstrated good or usually good compliance. Nixon et al reported on patterns of CPAP adherence during the first three months of treatment in 30 children prescribed CPAP at the Melbourne Children's Sleep Centre between 2004 and 2008.[21] Similar to our report, just 33% met the standard definition of four or more hours use on 70% of nights. Usage in the first week of treatment predicted longer term use over 2–3 months. Hours of use were not affected by age, sex, baseline obstructive apnoea hypopnoea index, or socio-economic status.

Simon et al assessed barriers to CPAP use in a group of American CPAP users aged between 8 and 17 years.[22] The average use was 3.35 hours per night and 5 hours per night when only nights of CPAP use were included in the calculation. In this study, 43.1% of youth reported that they just wanted to forget about OSA, and 29.4% reported they were embarrassed to use CPAP. In our local clinical group, we have noted difficulties with machines not being taken when patients go to stay with other family members, or if taken; left behind when the child returns to home base. This suggests that they have not fully accepted the importance of the CPAP treatment. Caregivers may also be embarrassed to report issues with masks, tubing and machines especially if they think they may be responsible for paying for replacement parts.

The addition of a respiratory therapist to CPAP follow-up clinics has been shown to improve compliance for those patients where compliance is <50%.[23] Roles can include evaluating the CPAP machine including: masks and tubing; verifying correct CPAP settings; reviewing mask fit; educating parents and patients about the machine including care of the machine; and viewing downloads of treatment. In the Aoteraroa New Zealand setting, these tasks are more likely to be undertaken by a specialist respiratory nurse or a sleep physiologist. At CCDHB, a specialist respiratory nurse has assisted with management of CPAP patients since mid-2017 and we feel this is likely to have contributed to the improvement in compliance in the 2015–2020 period (25% versus 46% for those using CPAP for longer than one month). However, we also had more failed trials in the later period. We have also found it very helpful to have input from whānau care services in the DHB working with Māori whānau in the home setting. Starting a child on CPAP can be a big step for a family, and acclimatisation can require time and patience from both clinicians and whānau. Most of our discharges due to poor compliance or tolerance were in adolescents who had not found that CPAP treatment was sufficiently efficacious for them to persist with daily compliance with treatment.

In summary, this review of children and youth offered or commenced on CPAP through the CCDHB paediatric sleep service over the last 15 years highlights the need for increased availability of services for these high-risk patients. While we have greatly increased our ability to provide an assessment and treatment service for infants and children with persistent symptoms of OSA, we still have quite a way to go to ensure we support our patients to achieve optimal treatment adherence, especially with regard to our young Māori patients. To make improvements in this area we need to ensure we work with culturally appropriate support services, both in the hospital and the community. A qualitative research approach would be valuable to try to understand differences in compliance rates by both age and ethnicity. Services also need to be free for all. We have noted that the need to start paying for consumable equipment can be a barrier to transition to adult services. As we observe the tsunami of referrals for adults requiring treatment of OSA by CPAP, we also need to ensure there is optimal service provision for children and youth with significant OSA. Given the risks to children and youth of suboptimal developmental progress when OSA is untreated, and lifetime increased risks of hypertension and associated cardiovascular morbidity, this area of clinical need must be given greater priority.

COMPETING INTERESTS
WellSleep has a contract to provide sleep assessment and treatments services for all age groups for CCDHB, HVDHB and WrDHB.
Professor Dawn Elder receives remuneration to supervise and report sleep studies undertaken in children and youth at WellSleep.

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AUTHOR INFORMATION
Professor Dawn Elder: Professor and HOD, Department of Paediatrics and Child Health, University of Otago, Wellington, Child Health Services, Capital and Coast DHB.
Dr Sophie Gandhi: Medical Student (at time study undertaken), Otago Medical School.
Associate Professor Angela Campbell: Manager, WellSleep, Department of Medicine, University of Otago Wellington.

CORRESPONDING AUTHOR
Prof. Dawn Elder: HOD, Department of Paediatrics and Child Health, University of Otago, Wellington. 0212796140. dawn.elder@otago.ac.nz

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Telephone triage does not improve attendance rates in a paediatric audiology outpatient service

Michelle A Pokorny, Renee A Hislop, Elizabeth A L Holt

ABSTRACT

AIMS: To investigate the impact of clinician-led telephone consultation during the New Zealand COVID-19 lockdown on subsequent appointment attendance in a paediatric audiology service, particularly for Māori and Pacific families.

METHODS: A retrospective clinical audit at Counties Manukau Health of all children (>3 years old) on the audiology waiting list. Binary logistic regression analysis tested for association of appointment attendance following attempted audiologist-led telephone consultation, with ethnicity, waiting times, socio-economic deprivation levels and telephone consultation contact.

RESULTS: Of 349 eligible children, 208 families participated in telephone consultations (59%). Ten percent of those contacted were able to be discharged as no longer requiring care. There were no differences in attendance rates between those who had participated in telephone consultation and those who had not (77.5% versus 77.8%). Pacific and Māori children were 68% and 64% less likely to attend appointments after adjusting for socio-economic deprivation level, waiting time and telephone consultation compared to NZ European children. Longer waiting times were significantly associated with decreased attendance rates.

CONCLUSIONS: Attendance was found to be associated with ethnicity and waiting times. Telephone consultation did not improve attendance rates overall nor for ethnicity subgroups. It is therefore concluded that telephone consultation was found to be of only limited benefit in paediatric audiology services.

Paediatric audiology diagnostic services play an important role in ensuring that children who have a significant hearing loss are diagnosed in a timely manner and referred for habilitation (eg hearing aids) or surgical treatment (for middle ear disease). Despite the importance of paediatric services, attendance rates across many paediatric outpatient services (including audiology) are traditionally poor.[1–3] Non-attendance rates of up to 21–38% have been reported in audiology and otolaryngology (ORL) outpatient services.[4,5] Suggested reasons for non-attendance have included socio-demographic and economic factors,[2,6] long waiting times[3,6] and parental forgetfulness.[3,7] Strategies to improve attendance rates have included SMS reminders,[6,8] telephone reminders[9] and pre-delivered information packs.[10]

Māori and Pacific children have lower first appointment attendance rates in otolaryngology (ORL) outpatient departments compared to NZ European and Asian or Indian children.[5] Māori and Pacific children are also known to have higher prevalence of middle ear disease compared to the overall population,[11] and Māori children are overrepresented in the diagnoses of permanent hearing loss, comprising 32% of notifications compared to the population proportion of 26%.[12] Difficulties accessing healthcare for Māori in particular have been found to include organisational, cost, health provider and cultural fit barriers, and are greatest for Māori with disabilities.[13]

The current study came about due to the COVID-19 lockdown in March–April 2020. At this time, there was a waiting list of over 400 children (3–19 years old) waiting for diagnostic audiology assessments at Counties Manukau Health. The waiting time for this group extended up to seven months at the time of the lockdown period. The Audiology Department implemented non-face-to-face telephone consultations using the departmental audiologists for all children on this waiting list. The initial purpose of this telephone consultation process was to allow improved triaging of referrals. The aim of this study was to investigate whether the lockdown telephone consultation with an audiologist improved the likelihood of children attending the outpatient appointment, particularly for Māori and Pacific families.

Methods

Design

A retrospective clinical audit was conducted within the Audiology Department at Manukau SuperClinic (Counties Manukau Health).

Participants

Participants were families with children (aged 3–19 years old) who were referred to the audiology outpatient waiting list for diagnostic audiology assessment and were eligible for services through Counties Manukau (CM) Health. A total of 349 participants were included in this study. Socio-economic deprivation levels were obtained using the registered home addresses of participants and generating a deprivation index score using the NZDep2013 Index of Deprivation.

Process

Eligible participants received at least two telephone call attempts (separated in time >24 hours) by a CM Health audiologist in April 2020. The telephone call attempts were made during the COVID-19 lockdown, which, at the time, required the population of New Zealand to remain at home, leaving their place of residence only to obtain essential services and brief exercise. If families were able to be contacted, the audiologist introduced themselves, explained that their child had been referred to the audiology department for hearing assessment, and gained consent to ask them a few questions regarding their child's current hearing and history. All participants who were contacted by telephone gave consent and provided information regarding their child's hearing, speech and language development, ear infections and risk factors for hearing loss (Appendix 1). Children whose parents/caregivers reported no further concerns, and who had prior normal hearing results on screening tests, were discharged at this point. Children whose parents reported symptoms suggestive of significant hearing loss were upgraded to higher priority on the waiting list. Children who were unable to be contacted by telephone remained on the waiting list in approximate date order. A small number of eligible participants had insufficient information in their medical charts to conduct a telephone consultation.

Business as usual clinics recommenced on 13 May 2020, and appointments were made according to the standard care. The process to book appointments is through the administrative officer contacting patients by telephone to make an appointment offer. If families are unable to be contacted by telephone, a letter is sent inviting families to make contact to book an appointment. If no response is received from the letter invitation, contact details are checked with the general practitioner (GP). Families that are unable to be contacted or are no longer eligible for services through CM Health are removed from the waiting list at this point. In addition, SMS text reminders are sent to all patients on the day before the outpatient appointment.

All demographic and appointment details were recorded in the DHB electronic patient management system (iPM). Clinical results were recorded in paper medical charts with an electronic record of clinic letters and referrals generated stored in the electronic Clinical Portal.

Data analysis

All data were obtained from the available information stored in the electronic patient management systems (iPM and Clinical Portal). Nominal variables were described using descriptive statistics, and analysed for significance between groups using Chi-squared tests. Continuous variables were assessed for normality and analysed for significance between groups using non-parametric tests (Mann–Whitney U test). Binary logistic regression analysis was conducted to assess the association between telephone contact, attendance and multivariate variables, including ethnicity, waiting times from referral and socio-economic deprivation level. All statistical analysis were performed using Statistical Package for Social Sciences, version 27.0 (SPSS Inc, an IBM Company, Chicago, Illinois).

Ethical approval

HDEC ethical approval was not required for this clinical audit. AHREC approval (AH3097) and CM Health Locality approval (CM Health Research Registration Number 1366) were obtained.

Results

Overall cohort descriptive statistics

The overall process flow chart is shown in Figure 1.

The ages and ethnicities of all participants referred to Counties Manukau Health for hearing testing are shown in Table 1. Pacific children make up the largest proportion referred to CM Health for hearing testing, and were significantly older at point of referral compared to NZ European children (Mann–Whitney U test; p=.003).

In all, 248/349 (71.1%) of children referred were from household addresses within the highest

levels of socio-economic deprivation (Deprivation Index score 7–10), with 44.7% (156/349) from the highest level of deprivation (10).

The majority of referrals were made by GPs (159/349; 45.6%), followed by referrals from public health nurses (53/349; 15.2%) and paediatricians (51/349; 14.6%). The remaining referrers accounted for 5% or less for each group.

Telephone contact groups

Two hundred and eight participants underwent telephone consultations with an audiologist forming the contact group and 141 participants did not have contact with an audiologist by telephone, forming the non-contact group (Figure 1).

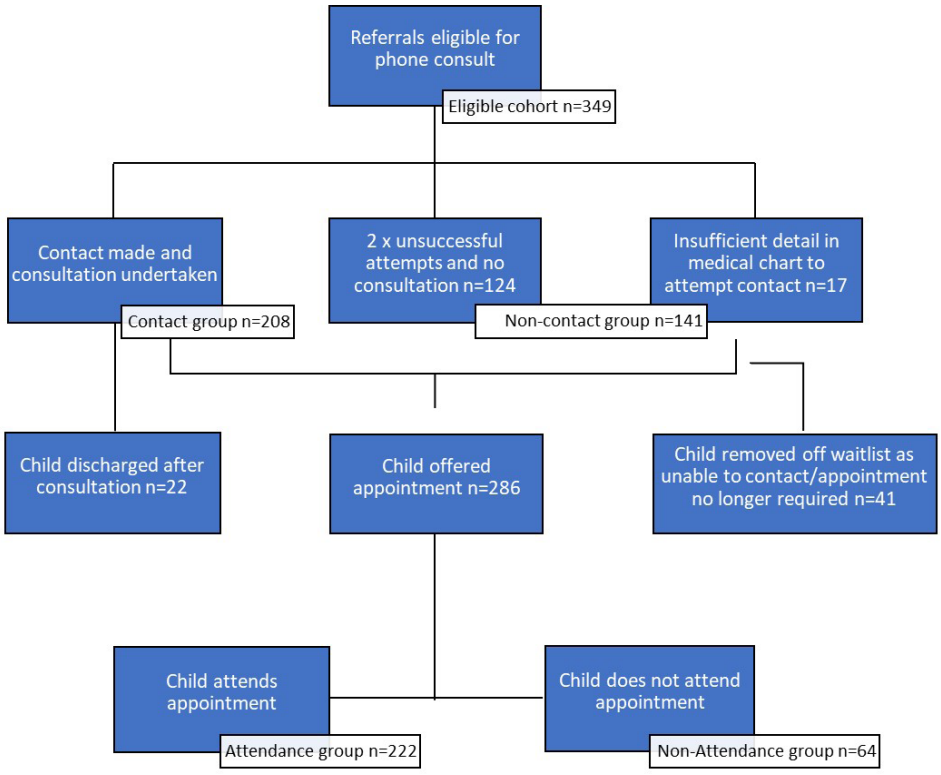
Table 2 shows the unadjusted models for binary logistic regression showing significant associations between ethnicity and socio-economic deprivation level and ability to establish telephone contact. After adjusting for socio-economic deprivation levels, Māori had 73% lower odds of being contacted compared to NZ European/Other, and Pacific had 59% lower odds of being contacted. There was no significant association between socio-economic deprivation level and ability to make phone contact after adjusting for ethnicity.

The outcomes recommended by the audiologist from these consultations are shown in increasing urgency in Table 3.

Table 1: Participant ages and ethnicities.

Ethnicity	Number (%)	Mean (SD)	Median (IQR)
NZ European/Other (95)	95 (27.2)	6.3 (2.7)	5.7 (4.1–8.2)
Māori (78)	78 (22.3)	7.2 (3.3)	6.5 (4.4–9.5)
Pacific (139)	139 (39.8)	7.8 (3.6)	7 (4.8–10.5)
Asian (37)	37 (10.6)	6.5 (3.1)	5.8 (4.5–6.9)
Total	349	7.1 (3.3)	6.3 (4.4–9.3)

Figure 1: Flow chart of process.



First appointment offer

A total of 286 children were offered appointments within the Audiology department from the original 349 eligible participants (81.9%) in date order of referral and according to priority (Figure 1).

The median waiting times from the date of telephone consultation to the offered appointment date generally increased with decreasing priority (Table 4).

Attendance rates

Of the 286 participants offered audiology appointments, 222 participants attended (77.6%). Attendance rates by ethnicity and telephone contact group are shown in Table 5. There were significant disparities between ethnicity groups in attendance rates (Chi-squared test p=.032). Overall, attendance rates did not significantly differ between the telephone contact and non-contact groups (138/178; 77.5% vs 84/108; 77.8%, respectively; Chi-square test p>.05) (Table 5); nor by deprivation level (low deprivation attendance rate 67/82; 81.7% versus high deprivation attendance rate 155/204; 76%; p>.05).

Pacific children were 56% less likely to attend appointments compared to NZ European children (p= .032, unadjusted model, Table 6). This finding increases to 68% less likely to attend after adjusting for socio-economic deprivation level, telephone contact, and wait time from referral (adjusted model Table 6, p=.019). Māori children were 64% less likely to attend (odds ratio 0.36) compared to NZ European children after adjusting for all variables in the model (p=.038).

There was a small but significant difference (18.5 days) between the waiting time from referral for participants attending (median of 235.5 days) versus not attending (median of 254 days) (Mann–Whitney U test; p=.012). Binary logistic regression analysis (Table 6) shows that waiting times were significantly associated with decreased likelihood of attendance both in the univariate model and after adjusting for ethnicity, deprivation level and whether they received telephone contact.

Clinical outcomes for attendance group

Of the 222 participants attending appointments in the Audiology Department, results were obtained on 214 participants (96.4%). The majority with available results had normal hearing (65.4%) and/or were able to be discharged back to GP care (65%) (Tables 7 and 8). However, a substantial proportion of cases had moderate degrees of hearing impairment, active disease, or permanent hearing loss (20.6%). Twenty (56.8%) and eight (18.2%) of these children were of Pacific and Māori ethnicities, respectively. Thirteen of the children re-prioritised as urgent following the telephone consultation were found to have significant permanent hearing loss or ear disease.

Discussion

The overall aims of this study were to investigate whether introducing a telephone-based consultation during the waiting time period would translate to improved attendance rates in the study's Audiology outpatient Department. Although the concept of telephone consultation was theoretically to encourage the engagement from parents of children with the Audiology Department, these results did not demonstrate any significant improvements in attendance rates for the populations most at risk, namely Māori and Pacific children. Overall, attendance rates were significantly associated with ethnicity and waiting times since referral. Some limited benefits were realised from the telephone consultations, including the ability to discharge children who no longer required appointments, and triage children with higher urgency based on reported symptoms. These findings will be discussed in turn.

Referral characteristics

As both Pacific and Māori children are known to experience higher levels of ear disease and hearing loss compared to NZ European and Asian children,[14] it would be expected that referral rates would be proportionately higher. This appears to have occurred for Pacific children (referral proportion of close to 40% compared to a population proportion of 28%) but has not occurred for Māori children (referral proportion of 22% compared to a population proportion of 23%). These findings support the anecdotal evidence suggesting that Māori children are not being referred to hospital services at rates commensurate with the level of need in this population.[15]

The population sample in this study was defined as those children who were likely to developmentally be able to complete play audiometry testing (normally ≥three years old). Approximately half of the referrals were generated from GPs highlighting concerns raised during a primary healthcare visit, as opposed to referrals resulting from failed hearing screening tests (eg B4SC screening of 4-year-olds). This study found that Pacific children were significantly older than NZ European children at the point of referral, potentially reflecting delayed presentation to primary healthcare services with concerns or

Table 2: Binary logistic regression models of phone contact (unadjusted and adjusted).

	Unadjusted model (univariate)		Adjusted model	
	OR (95% CI)	**p**	**OR (95% CI)**	**p**
High level deprivation (248/349)	0.32 (0.19–0.55)	<.001	0.54 (0.28–1.00)	.053
Ethnicity		<.001		<.001
Māori (78/349)	0.21 (0.11–0.40)	<.001	0.27 (0.13–0.56)	<.001
Pacific (139/349)	0.29 (0.16–0.52)	<.001	0.41 (0.21–0.82)	.011
Asian (37/349)	1.47 (0.54–3.98)	.453	1.77 (0.64–4.94)	.273
NZ European/Other (95/349)	Reference		Reference	

Table 3: Audiologist recommended triage following phone consultation.

Clinical Outcome	N/208 (%)
Discharge to GP	22 (10.6)
Screening audiology assessment	64 (30.8)
Audiology assessment (routine priority)	5 (2.4)
Audiology assessment (semi-urgent priority)	63 (30.3)
Audiology assessment (urgent priority)	54 (26)

Table 4: Waiting times from telephone consultation to offered audiology appointment.

Clinical urgency	Median waiting time (days)	Range (days)
Audiology assessment urgent	76	39–255
Audiology assessment semi urgent	108	57–192
Audiology assessment routine	122	120–155
Screening audiology assessment	107.50	75–294

Table 5: Attendance rates by ethnicity and contact group.

		Attendance rates n/n (%)	
	Overall	**Contact group**	**Non-contact group**
NZ European/ Other	62/73 (84.9)	50/58 (86.2)	12/15 (80)
Māori	46/62 (74.2)	23/31 (74.2)	23/31 (74.2)
Pacific	84/118 (71.2)	41/62 (66.1)	43/56 (76.8)
Asian	30/33 (90.9)	24/27 (88.9)	6/6 (100)
Total	**222/286 (77.6)**	**138/178 (77.5)**	**84/108 (77.8)**

Table 6: Logistic regression models for attendance at appointment by ethnicity, deprivation level, telephone contact and waiting times.

	Unadjusted model (univariate)		Adjusted model	
	OR (95%CI)	**p**	**OR (95%CI)**	**p**
High deprivation (low deprivation=reference)	0.71 (0.37–1.35)	.30	1.154 (0.512.60)	.73
Ethnicity		.041		.036
Māori	0.51(0.22–1.20)	.124	0.36* (0.13–0.94)	.038
Pacific	0.44* (0.21–0.93)	.032	0.32* (0.12–0.83)	.019
Asian	1.774 (0.46–6.84)	.405	1.32 (0.33–5.30)	.698
NZ European/Other	Reference			
Telephone contact (non-contact=reference)	0.99 (0.55–1.75)	.96	0.72 (0.39–1.33)	.299
Waiting time from referral (days)	0.99* (0.99–1.0)	.006	0.99* (0.99–1.0)	.004

Table 7: Clinical outcomes at first attended appointment in audiology (n=214).

Clinical outcome	**N/214 (%)**
Normal hearing	140 (65.4)
Mild conductive hearing loss	30 (14)
Moderate conductive hearing loss	27 (12.6)
Significant active disease/perforation	4 (1.9)
Permanent hearing loss	13 (6.1)

Table 8: Management pathways from first attended appointment in Audiology (n=214).

Management option	**N/214 (%)**
Discharge to GP care	139 (65)
Review in Audiology	30 (14)
Refer to ORL	36 (16.8)
Refer to ear nurse for wax suction	5 (2.3)
Refer to paediatrician	1 (.5)
Hearing aid fitting	3 (1.4)

ORL= Otolaryngology

delayed referral from GP practices. Similar findings in ORL services have found that Pacific children receive grommets at significantly older ages compared to NZ European children.[16] The reasons for this delayed access are not explored in the current study, but there are significant implications of delayed diagnosis of permanent or chronic hearing loss secondary to middle ear disease for the long term educational and social outcomes for these children.

Attendance rates

The study's hypothesis that telephone consultation would increase the likelihood of subsequent clinic attendance was based on informal feedback from Māori and Pacific families included in the study: that the consultations were well received and appreciated during a difficult time in New Zealand. However, the results demonstrated that there was no difference in attendance rates between those families that participated in the telephone consultation (77.5%) and those that did not (77.8%). There were, however, some significant associations with Pacific families overall being 68% less likely and Māori families 64% less likely to attend appointments after adjusting for socio-economic deprivation level, waiting times and telephone contact, compared to NZ European children. With Māori and Pacific children making up substantially greater proportions of the sample not attending appointments it is essential that research is focussed on understanding why this may be, and to develop culturally responsive solutions. Linguistic and transport barriers, along with lack of community-based services, have been identified as influencing access to hearing care services in older Pacific peoples in New Zealand.[17]

Waiting times from referral were also significantly correlated with the likelihood of attendance, as has been found with previous studies in outpatient services.[3,6,18] Although families who engaged in telephone consultation generally had a shorter residual waiting time to the first appointment compared to those families that did not participate in telephone consultation, this variable had no significant association with attendance. Waiting times are often used as key indicators of how well a service is meeting demand within the available resources. It is evident that children waiting the longest time are less likely to attend audiology appointments, and there is no reason to assume that this is because they no longer require services.

Socio-economic deprivation level factors

Paediatric audiology referrals (as shown in this study and previously) are disproportionately from households with high levels of deprivation.[14] Although socio-economic status may be linked to poorer health outcomes,[19] there were no significant associations found between deprivation level and attendance rates. This is an interesting finding, as traditional thinking has linked non-attendance rates to difficulties accessing transport, paying for parking and other financially related factors. The lack of association with deprivation levels suggests that there may be broader reasons impacting on attendance rates not necessarily associated with deprivation. Potential factors for Pacific peoples have been discussed in detail in the recent publication *Bula Sautu.*[20]

Impact of telephone consultation on clinical outcomes

Audiology is an allied health specialty that is heavily reliant on technology to conduct assessments, and as yet, effective tele-audiology service models are not yet readily available. Approximately 10% of those contacted by telephone were able to be discharged following the telephone consultation, however, this equated to only 6.2% of the whole cohort. Yet, over 65% of children seen in face-to-face consultation were considered asymptomatic and discharged back to primary care. It may, therefore, be worthwhile to reconsider community-based, targeted approaches in addition to the two screening programs currently available. Given that hearing loss is difficult to assess without formal testing, and doesn't correlate well with the level of parental concern,[14] it is unlikely that telephone triage will provide an effective means of screening for asymptomatic cases.

However, for a small subset of the referral population, the telephone consultation process showed the ability to improve triaging based on the information provided by the caregiver/parent. There were over 20% of children who were diagnosed with hearing loss or ear disease requiring treatment or management. Pacific children were disproportionately affected, making up 56.8% of this group. The telephone consultation triage process effectively allowed 13 of these children with serious disease/hearing loss to be re-categorised as urgent referrals, thus allowing expedited access to treatment.

Limitations and future directions

This study has been limited by its retrospective design, and therefore potential confounding vari-

ables may not have been captured. The telephone consultation process was developed within the Audiology Department at very short notice due to the suddenness of the lockdown. These results represent the outcomes from an intervention that was initially designed as a means to better triage children waiting on a long audiology waiting list. Furthermore, although associations have been found, no conclusions can be drawn as to causative factors. Multiple statistical tests have been performed and positive results may reflect Type 1 errors. In addition, there may be lack of statistical power to detect associations due to the sample size limitations.

There is a possibility that part of the failure of the telephone consultation to improve attendance rates is partly due to cultural discordance. Despite the high levels of Māori and Pacific children in the catchment population, there is very low representation of Māori and Pacific peoples within the audiology workforce. Although long-term commitment is required by the hearing and ear healthcare professions to increase representation within the workforce at all levels of service, in the interim, solutions utilising alternate workforces could be implemented, as well as strategies to improve cultural safety of existing non-Māori and non-Pacific clinicians.

A second observation regarding the telephone contact process was that mobile phones were used with caller ID disabled. Māori families were significantly less likely (73% lower odds) to answer the telephone call compared to NZ European families. Alternate means of contacting patients should be employed for Māori and Pacific families, allowing a mechanism to provide the opportunity to introduce the clinician when making cold calls or unexpected calls.

Conclusion

This study did not demonstrate any effective reduction in inequities experienced by Māori and Pacific children in accessing audiology services by using a telephone consultation model. Significant associations with attendance were found for ethnicity and long waiting times, but the level of socio-economic deprivation was not found to be a significant factor. More research is required to further develop an understanding of how to improve engagement and responsiveness for at-risk populations.

COMPETING INTERESTS
Nil.

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AUTHOR INFORMATION
Michelle A Pokorny: Paediatric Audiologist, Audiology Department, Counties Manukau DHB, 901 Great South Road, Manukau City Centre, Auckland, New Zealand.
Renee A Hislop: Clinical Team Leader, Audiology Department, Counties Manukau DHB, 901 Great South Road, Manukau City Centre, Auckland, New Zealand.
Elizabeth A L Holt: Pacific Research Coordinator, Eisdell Moore Centre for Hearing and Balance Research, University of Auckland, Auckland, New Zealand.

CORRESPONDING AUTHOR
Michelle A Pokorny: Audiology Department, Counties Manukau DHB, 901 Great South Road, Manukau City Centre, Auckland, New Zealand. +64 22 588 9298. michellepokornynz@gmail.com

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Appendix 1: Structured history questions asked during telephone consultations.

- Level of parental concern
- Academic progress at school/teacher concerns/ level of extra support required/teacher concerns
- Number of recent ear infections (last 12 months)/treatment required/symptoms associated with them/last known ear infection
- Snoring/frequency/loudness/sleep apnoea/daytime sleepiness or difficulty waking in morning
- Speech development/prior Speech Language Therapy input/clarity/comprehension
- Family history of congenital or early onset Sensorineural Hearing Loss
- Pregnancy/birth complications
- Overall development
- Overall health/medical conditions/major illnesses

Persisting variance in middle ear ventilation tube insertion in Auckland children: why ethnic disparity continues

Julia Y Seo, Randall P Morton, Catherine Gerard, Lesley Salkeld, Suzanne C Purdy

ABSTRACT

AIM: Insertion of ventilation tubes (VTs) is a common surgical treatment for recurrent and persistent otitis media, but surgical practice varies internationally. The current study explored variations in practice within New Zealand by examining VT insertion rates. The aim of the study was to determine time trends and current variations in VT insertion rates by ethnicity and district health board (DHB), with a focus on comparison of two DHBs in Auckland (Counties Manukau and Auckland DHB) to national average data.

METHOD: Data for surgical procedures were analysed in the Atlas of Healthcare Variation domain, available via the Health Quality & Safety Commission website. Publicly funded events for New Zealand residents over a 10-year period (2009–2018) were examined for 0–4-year-olds. Individuals were assigned to their DHB of residence. VT rates for each DHB are presented per 1,000 population, with upper and lower confidence intervals calculated to the 95% level.

RESULTS: There was a general decline in the rates of VT insertions for the 0–4-year-olds over the 2009–2018 decade. Analysis of the 2018 year showed variation by ethnicity and DHB. In CMDHB, ADHB and nationally, Asian and Pacific ethnic groups had the lowest rates of VT insertions compared to other ethnic groups. In CMDHB, the VT rates for Māori, Pacific and Asian children were less than half that of their respective groups in ADHB. The NZ European/Other ethnic group had the highest rates of VT insertions in CMDHB and nationally, but in ADHB, the rate for the NZ European/Other group was similar to that for Māori.

CONCLUSION: These results are incongruent with evidence that Māori and Pacific children in New Zealand experience a greater burden of middle ear disease than NZ European children. The finding of persisting inequities in VT treatment for middle ear disease in 0–4-year-olds, with greatest impact on Pacific children, suggests that there may be a need for targeted middle ear screening for preschool children to detect pre-schoolers with ear disease, earlier than the 4-year-old B4 School Check.

Acute otitis media (AOM) is a leading childhood illness accounting for many physician visits and antibiotic prescriptions in developed countries.[1] It is experienced by more than 80% of children globally by the age of three years, with 10–30% experiencing repeated episodes.[2] Persistent otitis media with effusion (OME), commonly known as "glue ear", occurs in up to 25% of children following AOM,[3] though it can also occur as a primary disorder.[4] OME is associated with fluid collection in the middle ear, which may result in a conductive hearing loss of variable severity.[5] Though most cases of OME resolve spontaneously, complications may include chronic otitis media with structural changes to the middle ear.[4] Hearing loss resulting from chronic OME in early childhood is also associated with delayed acquisition of speech and language, as well as attention, learning and behavioural problems, and typically occurs during the most intensive period for a child's language development.[6]

Insertion of ventilation tubes (VTs), also known as tympanostomy tubes, or "grommets", is a common surgical treatment for recurrent AOM and persistent OME. At the time of insertion of VTs, the surgeon is able to aspirate middle ear fluid, allowing for an abrupt change in the natural history of the disease. Systematic reviews[4,7] have found that VTs are able to reduce the duration of OME episodes, as well as improve hearing at both six months and one year after surgery, compared to watchful waiting.

Rates for insertion of VTs vary geographically according to local practice, clinical guidelines and

availability of surgical resource.[8,9] In New Zealand, general practitioners (GPs) most often refer children to specialist services for consideration of VT insertions. Children may be referred to GPs if a hearing problem is identified by providers of the Well Child Tamariki Ora (WCTO) programme—a series of eight free health visits available to all New Zealand families.[3] The final preschool visit, referred to as the B4 School Check, occurs when the child turns four years of age. The hearing component of the screen involves a pure tone audiometry test, followed by tympanometry if the child does not pass pure tone screening.[10]

New Zealand has an increasingly diverse population.[11] Ethnic and regional disparities in the disease burden and treatment rates of AOM and OME exist in NZ. For example, McCallum and colleagues[3] found that between 2002-2008, among 0-4-year-olds, Māori and Pacific children had higher rates of acute hospitalisations for AOM, yet lower rates of elective admissions for VTs, compared to European children. These differences were also more pronounced for children from the most deprived areas, suggesting that children with higher levels of need may be receiving lower levels of treatment.[3] Māori and Pacific children are also less likely to have a completed B4 School Check, which perpetuates existing ethnic disparities in hearing problems and middle ear disease.[10]

In the Auckland Region of New Zealand, the Counties Manukau and Auckland district health boards (DHBs) are neighbouring and largely metropolitan DHBs with relatively different population profiles.[12,13] CMDHB serves a much higher proportion of Pacific and Māori people (22% and 16.3% of the DHB population, respectively) compared to ADHB (11% and 8.2%). These DHBs also differ in their levels of deprivation. CMDHB has proportionally more people in the most deprived quintile (majority Māori and Pacific people) and fewer people in the less deprived quintiles. In contrast, ADHB has more people in the less deprived quintiles, and fewer people in the more deprived quintiles.[12,13]

The Health Quality & Safety Commission of NZ (the Commission) provides an Atlas of Healthcare Variation, which presents nationwide rates for specific health services on tables, graphs and geographical maps,[14] and allows monitoring of VT insertion rates and other surgical procedures. Using the Atlas domain (last updated in September 2020), in the current study we aimed to determine the time trends and explore current variations in VT insertion rates by ethnicity and district health boards (DHBs), with a focus on comparison of two DHBs in Auckland to the national average. Data from the latest available year (2018) were analysed to discern more recent variations.

Method

Data for surgical procedures were analysed in the Atlas of Healthcare Variation domain, available via the Commission website.[15] The data encompass publicly funded events for New Zealand residents (including publicly funded procedures outsourced to private hospitals) over a 10-year period (2009–2018). Data relating to VT procedures were taken from the National Minimum Dataset (NMDS), which is a collection of nationwide hospital discharge information, including coded clinical data for day-stay and inpatients.[16] The specific procedure codes corresponding to VT insertion were under "myringotomy with insertion of tube, unilateral" and "myringotomy with insertion of tube, bilateral". In the Atlas of Healthcare Variation domain, individuals were assigned to their district health board (DHB) based on their residential address.

VT rates for each DHB are presented per 1,000 population (of the specific ages and ethnic groups in question) with upper and lower confidence intervals calculated to the 95% level. Individuals identifying with more than one ethnic group were assigned to a single mutually exclusive group, based on the following hierarchy: Māori, Pacific peoples, Asian, NZ European/Other. In order to maintain confidentiality, data are not presented if the resulting number of people was less than 10.[17] Population data relating to ethnicity and DHBs were taken from Statistics NZ and the Ministry of Health.[17] The data were then filtered to include only the age group of interest (0–4-year-olds), and a time graph for rates of VT insertions between the years of 2009–2018 was generated. The national average rates for this age group during the latest available year (2018) were also further analysed, alongside the rates for Auckland and Counties Manukau DHBs. These results were then stratified by ethnicity for these respective regions (national, ADHB, CMDHB).

Results

Variation over time

National average rates of VT insertions for the 0–4-years age group showed a general downwards trend over the 10-year period, with 12.0

procedures per 1,000 population in 2009, and 9.3 procedures per 1,000 population in 2018 (Figure 1). The rates for CMDHB also showed a general downwards trend over the same time period, with 9.6 and 6.1 procedures per 1,000 population in 2009 and 2018, respectively. CMDHB consistently showed lower rates of VT insertions from 2009–2018 compared with the national average rates. In comparison, ADHB procedure rates were 11.8 and 10.2 per 1000 population in 2009 and 2018, respectively, and were similar to that of the national average (taking confidence intervals into consideration). Figure 1 shows a transient drop in VT insertions in 2010 at ADHB; we believe this reflects a re-organisation of the services at that time rather than a change in disease presentation or incidence of disease.

Variation by ethnic group and DHB (2018)

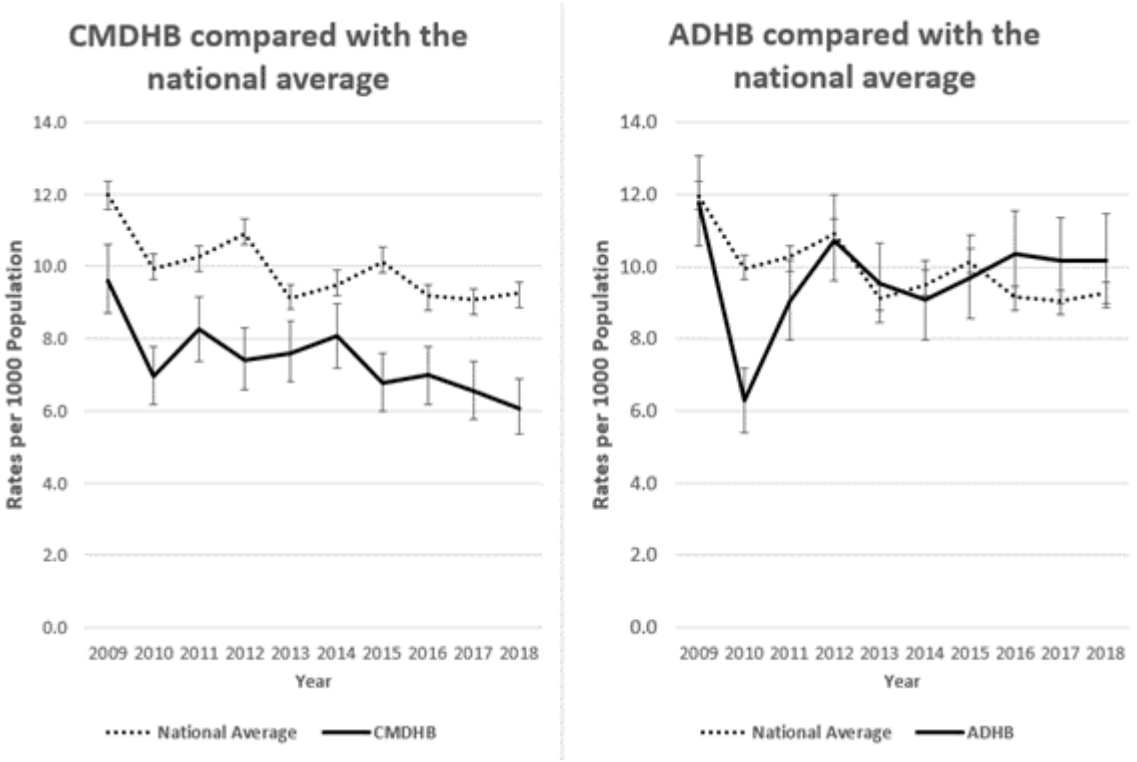
Table 1 and Figure 2 present results separated by primary ethnicity. Focusing on the results for the 2018 year, ADHB's 0–4-year-olds had the highest rates of VT insertions for all ethnic groups, compared to the corresponding ethnic groups in CMDHB and the national average. CMDHB's 0–4-year-olds had the lowest VT insertion rates for all ethnic groups compared to ADHB and the national average, except for the NZ European/Other group. The NZ European/Other group in CMDHB had rates of VT insertions that were higher than that of the national average.

Overall, the Asian ethnic group had the lowest rates, and the Pacific group had the second lowest rates of VT insertions compared to all other ethnic groups, nationally and for ADHB and CMDHB. Figure 2 shows that the pattern of VT insertions across ethnicity groups for ADHB is comparable to the national average. VT rates for CMDHB show a greater imbalance across groups, when the NZ European/Other group is compared to other ethnicity groups. The NZ European/Other group had the highest rates of VT insertions compared to all other ethnicity groups in CMDHB and the national average.

Discussion

On the whole, there was a general decline in the rates of VT insertions for the 0–4-years age group over the 2009–2018 decade. This aligns with the general decline in the incidence of AOM and OME internationally since the mid-1990s with stricter diagnostic criteria,[18] as well as the move towards more conservative management guidelines.[19] Another potential explanation may be the introduction of the pneumococcal vaccine into

Figure 1: Rates of VT insertions for the 0–4-years age group over 2009–2018.



Note: error bars represent 95% confidence intervals.

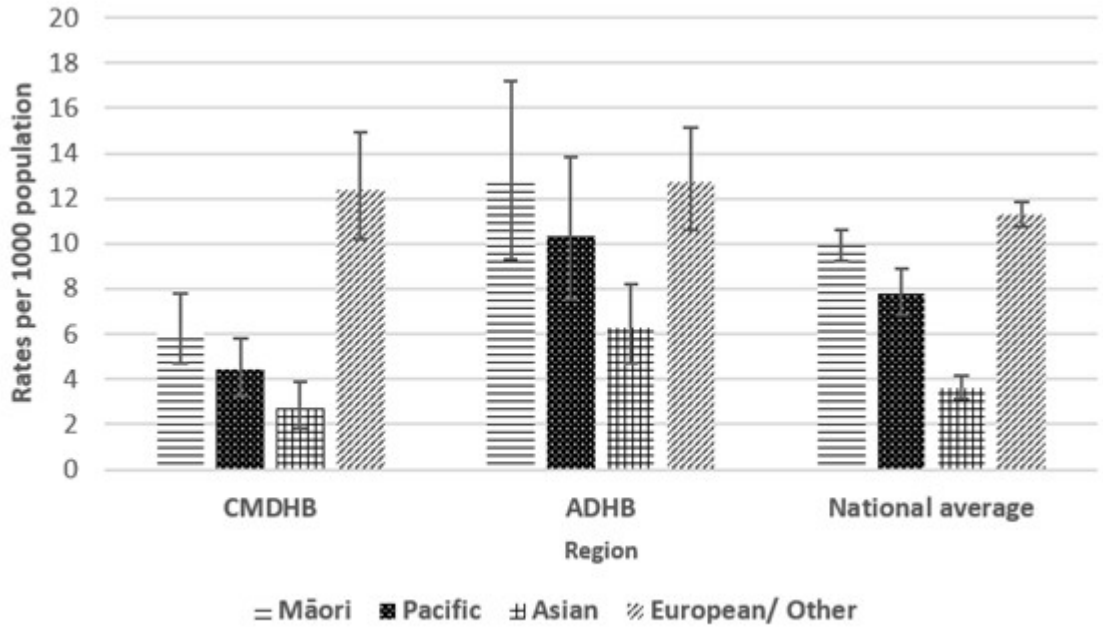
New Zealand's national immunisation schedule in 2008. In 2016, however, Best et al.[20] reported the impact of the change in immunisation regime on otitis media microbiology, and found no change in the microbiology of middle ear fluid in two cohorts of children having VT insertion.

Analysis of the 2018 year showed variation by ethnicity and DHB. Two neighbouring, largely metropolitan DHBs within the Auckland Region were compared because their proximity removes some of the potential explanations for variation. Given that there is an overlap in the specialists working in the two DHBs, it is less likely that any differences can be explained simply by different medical practice or clinical decision-making once children enter the service. This does not preclude different decisions on the basis of availability of services. For example, GPs may refer differently depending on how likely they think it is that a referral will be accepted. In CMDHB, ADHB and nationally, the Asian and Pacific ethnic groups had the lowest and second lowest rates of VT insertions, respectively, compared to other ethnic groups. The NZ European/Other ethnic group had the highest rates of VT insertions in CMDHB and nationally, but in ADHB, the rate for the NZ European/Other group was similar to that for Māori. In CMDHB, the VT rates for Māori, Pacific and Asian children, in particular, were less than half that of their respective groups in ADHB. This is striking, and raises the question as to why there was such a large difference for these ethnic groups across DHBs.

Table 1: Rates of VT insertions for the 0–4-years age group per 1,000 population, 2018.

	Ethnicity			
Region	**Māori**	**Pacific**	**Asian**	**NZ European/ Other**
CMDHB	6.1	4.4	2.7	12.4
ADHB	12.8	10.3	6.3	12.7
National average	9.9	7.8	3.6	11.3

Figure 2. Rates of VT insertions for the 0-4-years age group per 1000 population, 2018.



Note: error bars represent 95% confidence intervals.

The results related to ethnicity are incongruent with the evidence that Māori and Pacific children experience a greater burden of middle ear disease than NZ European children.[3,6,21] Recent data show rates of hospitalisations due to AOM for 0–4-year-olds between 2014–2018 were higher for Māori (1.7 per 1000) and Pacific (2.5 per 1000) children compared to NZ European (1.6 per 1000).[22] Pacific children are also greatly affected by conditions that may improve with VT insertion,[23] and the Pacific Islands families study estimated that prevalence of OME or AOM among Pacific two-year-olds was 26.9%.[6] The lack of an apparent relationship between burden of ear disease and VT insertion rates leads us to consider other explanations for these ethnic and geographic disparities in surgical interventions.

Socio-economic status is one likely contributing factor, as suggested by both national and international findings. Health inequities associated with poverty persist in New Zealand, despite children being able to access free primary healthcare and publicly-funded interventions.[24,25] In the current analysis, ethnic disparities in VT insertions for the 0–4-years age group in 2018 were more pronounced in CMDHB than in ADHB, which is relatively consistent with other study findings where ethnic disparities in surgical admissions were greater in areas of higher deprivation.[3] Socio-economic factors may be contributing to this, given the difference in deprivation profiles of the CMDHB and ADHB populations.[12,13] Overseas data also point to socio-economic influences on VT insertion rates. For example, Falster et al.'s study[26] of VT insertions in New South Wales (NSW) found that Australian Aboriginal children (disproportionately affected by socio-economic disadvantage) were less likely to undergo VT insertions than non-Aboriginal children, despite the group experiencing a higher prevalence of otitis media. The situation is consistent with the inverse care law, where the availability of quality medical care is inversely proportional to the level of need experienced by groups in a population.[27] While socio-economic status and financial access barriers are drivers of the inverse care law in themselves,[28] they are interrelated with other social factors. For example, socio-economically advantaged children generally have better means of accessing health services beyond simply having private health insurance, as parents with higher levels of education or health literacy may be more equipped to navigate complex health systems, granting their children easier access to specialist health services.[26,28] McCallum et al.[3] allude to other possible barriers related to socio-economic disadvantage, including inability of parents to seek time off work to take children to appointments and/or costs related to attendance for their health check.

In association with socio-economic status, however, barriers to health service access related to ethnicity cannot be overlooked. Adverse impacts of colonisation on Māori wellbeing stem from key losses including land, cultural identities, political/economic independence and whānau Māori as a protective collective.[29] The resulting effect is that Māori (and Pacific) groups continue to face access barriers at multiple stages throughout the clinical continuum (for example, at screening, follow-up and treatment). A recent review of the WCTO programme commissioned by the Ministry of Health emphasises how the effect of colonisation is evident within these screening services.[29] While WCTO has its merits as a universal programme, it is fundamentally built on a Western model of care without involvement from Māori leaders or families, using tools which have not been validated for other cultures.[23,29] A recent report on Pacific health from the Commission highlights similar issues around WCTO for Pacific families, with the majority of current screening providers not able to provide holistic care, or respond to the specific needs of families as well as the smaller Pacific providers can.[23] These cultural barriers to access may contribute to why only 59% of infants from Pacific families received all WCTO core contacts in their first year of life in 2019, compared to 81% of infants from non-Māori, non-Pacific families.[23] It is also evident that when Pacific children do access screening services such as the B4 School Check, children with serious problems like speech/language or behavioural challenges are not being detected by the programme.[23] In 2007–2008, Pacific 0–4-year-olds were found to have lower first Ear Nose and Throat (ENT) clinic appointment rates than NZ European children of the same age.[3] Both Māori and Pacific 0–4-year-olds also had higher non-attendance rates for their first ENT clinic appointments compared to their NZ European counterparts, suggesting that barriers to health services are faced not only at the point of primary care, but also once referral is made to specialist services.[3]

Reviewers of the WTCO express a need for the redesign of the programme to be framed on Kaupapa Māori concepts of health and wellbeing.[30] This takes the form of Māori leaders, whānau

Māori and community in key decision-making roles that oversee the design, implementation and governance of the programme, ensuring a whānau-centred and strength-based approach. There is emphasis on offering flexibility, consistency and reliability, as well as the need to work seamlessly with other services in addressing the social determinants of health.[30] With the upcoming reform of the New Zealand public health system to include a new Māori Health Authority,[31] and recent public discourse focusing on ethnic variance in the provision and acceptance of medical treatments in light of the COVID-19 pandemic, there may be an opportunity to ensure these requirements are fulfilled.

A strength of this study is the analysis of a national dataset that captures all New Zealand children receiving services through the DHBs. There are limitations, however. Firstly, only public data are accounted for, though inclusion of privately funded events would likely accentuate the demonstrated disparities among different ethnicity groups and the two DHBs. Secondly, the data are observational and do not reveal any impact of treatment. There is also uncertainty around some of the factors potentially influencing risk, disease prevalence and treatment pathways, such as socio-economic status and differences in how referral guidelines are used. Due to the differences in the CMDHB and ADHB demographics, VT insertion rates are also not directly comparable, and the discussion points around "expected" rates of intervention are based on what is understood about the burden of AOM or OME in existing literature. Furthermore, it is difficult to determine a standard rate of VT insertions against which DHBs should be compared. With this in mind, clinical reasons for referral (and potential barriers) for consideration of VT insertions should be explored, to determine whether there is over- or under-use in New Zealand.

Further research could also investigate Māori and Pacific families' experiences in accessing screening programmes and specialist services such as otolaryngology. Families' experiences within ADHB and CMDHB could inform how such services could be made more culturally responsive and appropriate for the needs of their communities. Hearing issues in Māori and Pacific children continue to be missed under the current New Zealand hearing screening regime, and hence this also warrants further research.[23] Though this regime includes universal newborn hearing screening and a pure tone hearing test at age four years as part of the B4 School Check, it overlooks the high prevalence and impact of ear disease in 2–3-year-olds. It also does not universally check children in later school years, despite evidence for the impact of ongoing conductive hearing loss on learning and development.[32] This is problematic given the apparent greater burden of ear disease particularly amongst Pacific children and the persistence of this into later school years.[33]

Conclusion

This study highlights the value of comparing surgical intervention rates across DHBs, over time and across ethnicity groups. The data show a general trend of declining VT insertion rates across the country, which may be linked to a change in prevalence of ear disease in New Zealand. Although recent changes in the immunisation regime may be contributing to lower rates of AOM, and consequently (perhaps) lower rates of OME, to our knowledge there is as yet no published evidence supporting this. The finding of inequities in VT treatment for middle ear disease, with greatest impact on Pacific children, suggests significant socio-economic and cultural barriers to access. It also suggests that there may be a need for targeted middle ear screening for preschool children to detect 2–3-year-olds with ear disease, as well as the 4-year-olds who may not be completing the B4 School Check.

COMPETING INTERESTS
Nil.

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AUTHOR INFORMATION
Julia Y Seo: Medical Student, Faculty of Medical & Health Sciences, The University of Auckland, New Zealand. juliaseo.yj@gmail.com.
Professor Randall P Morton: Otolaryngology–Head & Neck Surgery, Counties Manukau District Health Board, Auckland, New Zealand; Department of Surgery, Faculty of Medical & Health Sciences, The University of Auckland, New Zealand. Randall.Morton@middlemore.co.nz.
Catherine Gerard: Assistant Director, Health Quality Intelligence, Health Quality & Safety Commission, New Zealand. cgerard@orcon.net.nz.
Dr Lesley Salkeld: Paediatric Otolaryngologist, Otolaryngology–Head & Neck Surgery, Counties Manukau District Health Board, Auckland, New Zealand. Salkeld@middlemore.co.nz.
Professor Suzanne C. Purdy: School of Psychology, Faculty of Science; Eisdell Moore Centre for Hearing and Balance Research, The University of Auckland, New Zealand. sc.purdy@auckland.ac.nz.

CORRESPONDING AUTHOR
Julia Y Seo: Auckland, Waitemata and Counties Manukau District Health Boards, Private Bag 92189, Victoria Street West, Auckland 1142. juliaseo.yj@gmail.com.

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Improving the provision of cataract surgery in New Zealand demands disruptive change

Samuel Burridge, Jonathan Wood, Jesse Gale, Albie Covello, James McKelvie, Graham Wilson

ABSTRACT

Cataract surgery is a highly cost-effective treatment, but the surgical intervention rate in New Zealand ranks poorly compared with other high-income countries. The combination of a growing and ageing population, lost operating time due to the COVID-19 pandemic, and geographical disparities, is driving up an unmet demand for cataract surgery. We present several evidence-based strategies with overlapping benefits in access, equity, efficiency and sustainability. Key strategies include that Health New Zealand mandate a national prioritisation threshold for surgical access, and that PHARMAC leverage cheaper access to surgical supplies using nationally agreed equipment standards, establishing high-throughput cataract units, offering same day bilateral cataract surgery when appropriate, and rationalising post-operative care.

Cataracts are the leading cause of blindness globally, and the most common correctable eye disease causing blindness and sight loss in New Zealand.[1,2] Across high-income countries, cataract surgery is one of the most commonly performed surgical procedures.[3] Cataract surgery improves vision, with numerous secondary benefits including improved quality of life, slower rates of cognitive decline, and reduced risk of falls, hip fractures, and road traffic injuries.[4–7] Conversely, under-treatment of cataracts results in negative economic consequences, as there is lower employment participation from patients and their families that care for them.[8] It is for these reasons that public spending on cataract surgery yields a significant return on investment, with the cost per quality-adjusted life year (QALY) gained ranking as one of the most favourable of any healthcare intervention.[9] New Zealand specific evidence also shows the high cost-effectiveness of cataract surgery at NZ$4380 per QALY gained (95% uncertainty interval: 2410 to 7210), including for expedited cataract surgery where waiting time is shortened by 12 months.[10]

However, New Zealand's surgical intervention rate (SIR) for cataract surgery ranks lower than many other high-income countries in the Organisation for Economic Co-operation and Development (OECD).[3] In 2018, New Zealand's SIR was recorded at 373/100,000 population. In the same year, the United Kingdom (UK) had a SIR of 782/100,000 population, whilst Australia and Canada both had SIRs of over 1,000/100,000 population.[3] Comparisons using OECD data must be done cautiously, as data from New Zealand and the UK only includes publicly funded surgery, whereas Australia and Canada include all cataract surgeries. Nonetheless, New Zealand ranked 28th out of 32 OECD countries with available SIR estimates.[3] New Zealand's overall SIR, including private surgeries, is estimated at 800/100,000 population. This still ranks poorly by international comparison.[11]

The combination of a growing and ageing population, lost operating time due to the COVID-19 pandemic, and geographical disparities, is driving up an unmet demand for cataract surgery in New Zealand.[12] Ethnic inequalities also require attention; research suggests Māori patients present with more visually mature cataracts and may have higher rates of intra-operative complications.[12,13] Furthermore, the significant carbon footprint associated with cataract surgery requires leadership and action from ophthalmologists.[14]

These factors necessitate disruptive change in the delivery of publicly funded cataract surgery. Here, we explore strategic ways in which the "status quo" could be disrupted to facilitate greater efficiency, equity, and sustainability of cataract surgery in New Zealand.

Table 1: Cataract surgical intervention rate in selected OECD countries (2018).

OECD country	Total annual cataract operations per 100,000 population
Canada	1,128
Australia	1,111
United Kingdom	782*
New Zealand	373*

* Only includes publicly funded surgery
Source: OECD Statistics. Health Care Utilisation: Surgical Procedures.[3]

Prioritisation

In any public health system with finite resources, prioritisation is necessary to ensure fair and timely access to surgery. For cataract surgery in New Zealand, this is assessed through the Clinical Priority Assessment Criteria (CPAC) score—a value of 0 to 100 is generated based on visual acuity, cataract morphology, and an "Impact on Life" questionnaire.

However, current use of the CPAC score leads to grossly unequal access to cataract surgery based on geographical location. From 2014–2019, the SIR varied significantly between regions, ranging from 95 to 737/100,000 population/year.[12] Over the same timeframe, rates of declined referrals for surgery ranged from 7% to 48% between regions.[12] CPAC thresholds differ between district health boards (DHBs), and fluctuate over time in response to demand and capacity, though the specific criteria for changes in threshold are not published.[12,15] RANZCO regularly collects CPAC thresholds across New Zealand—in October 2021 they ranged from 45 to 61.

Furthermore, the "Impact on Life" questionnaire currently used in generating a CPAC score is not well suited in assessing vision-related quality of life (VRQoL), with poor correlation between score and change in post-operative visual acuity, as well as unsatisfactory statistical validation.[16] Other scoring systems, such as the Catquest-9SF questionnaire, have demonstrated more credibility at assessing VRQoL.[16]

Introducing a national threshold that incorporates a validated VRQoL questionnaire would represent a more equitable and patient-centred approach to prioritisation, as well as ending the "postcode lottery" that currently exists for cataract surgery in New Zealand. The introduction of the new organisation that will replace DHBs (Health New Zealand) is well suited to create this national threshold and reduce geographic inequity.

Theatre efficiency and high-throughput units

Most cataract surgeries are performed under local anaesthesia and follow a standardised procedure—these unique factors are well suited to high-volume surgery. The number of cataract operations performed on a four-hour public list varies within New Zealand hospitals. Personal communications suggest that most units complete between 3–7 cataracts per list using phacoemulsification. Substantial variation is also observed in the UK, where an average of seven cataracts per list with a range of 5–14 was recorded across five UK hospitals.[17] In contrast, surgeons at the Aravind Eye Care System (AECS) in India can perform 10–16 cases per hour using manual small incision cataract surgery (MSICS).[18] Their visual outcome and safety data are equivalent to high-income countries.[18–21] Though there are important differences in surgical technique and health settings, there is clearly scope for improved efficiency in New Zealand theatres.

In the UK, Sunderland Eye Infirmary (SEI) is well recognised for running a best practice high-throughput unit.[22,23] They achieve up to 14 cataracts per list and 170–180 surgeries per week with two dedicated theatres. Amongst numerous structural, procedural, and cultural factors attributed to SEI's efficiency, three key factors were identified by one observer.[22] Firstly, they employ higher numbers of nursing staff who facilitate the flow of patients, and nurses have increased responsibilities, including skin preparation and surgical consent. Secondly, patients

are risk-assessed and stratified into three types of lists: consultant-only high-volume lists (with up to 14 cataracts per list), complex-sedation lists (with 8–10 cataracts per list) and training lists (with 6–8 cataracts per list depending on trainee experience). Finally, the physical design of the unit facilitates efficient patient flow and minimises downtime between operations.[22] Furthermore, patients are waitlisted and undergo pre-operative assessment with biometry on the same, initial visit.

Establishing similar high-throughput cataract surgery units in New Zealand, as well as adopting key learnings from AECS and SEI in existing units, could improve New Zealand's SIR and preserve a balance of high-quality teaching with high-volume surgery.

An additional consideration is whether all ophthalmologists should perform cataract surgery. A Canadian cohort study of over one million cataract surgeries demonstrated that highly diversified surgeons (more than 50% non-cataract procedures) had almost three times as many adverse events as cataract-exclusive and moderately diversified surgeons (1–50% non-cataract procedures).[24] A retrospective Swedish study also demonstrated an association between the rate of capsule complications and surgeon operating volume.[25] Whilst New Zealand will require a growing number of cataract surgeons to elevate our SIR, treating cataract surgery as a sub-speciality may improve efficiency, safety, and visual outcomes.

Immediately sequential bilateral cataract surgery (ISBCS)

ISBCS is safe and effective compared to traditional delayed sequential surgery, with equivalent visual outcomes and complication rates.[26] Major advantages of ISBCS include faster visual rehabilitation, fewer clinic visits, decreased waiting times for surgery, higher productivity, and an estimated cost-saving of over 30% for the healthcare system.[26,27] ISBCS is already widely accepted and performed in countries such as Sweden and Finland.[28] The COVID-19 pandemic has also acted as a catalyst for increasing rates of ISBCS by minimising the number of patient encounters.[29] In the public hospitals of New Zealand, where CPAC determines access to cataract surgery, ISBCS is usually only considered for patients with two severe cataracts or requiring general anaesthesia; however, it is increasingly performed in the private sector.

Careful patient selection is crucial in ISBCS. Important factors are reproducible optical biometry, low risk of intra- and post-operative complications, and adequate home support.[27] Routinely offering ISBCS to appropriate patients would be a safe and cost-effective strategy to meet the rising demand for cataract surgery. Redesign of the public access criteria would be necessary to facilitate this.

Post-operative follow-up

Current practice regarding post-operative follow-up varies amongst DHBs. A typical regimen may involve a face-to-face review on post-operative day 1 (POD1), then again two to four weeks later, followed by a final visit to a community optometrist for refraction.

The current literature does not support the practice of POD1 follow-up after uneventful phacoemulsification cataract surgery by an experienced surgeon in patients without ocular co-morbidities.[30] Furthermore, rationalisation of post-operative follow-up is supported by widespread clinical practice abroad; the standard of care in the UK does not include a POD1 review unless there is co-existent pathology.[31]

Rationalisation of post-operative follow-up at a national level has the capacity for significant savings and increased efficiency without compromising safety. Alternatives to the face-to-face POD1 visit are telephone consults, or elimination of the clinical encounter entirely for appropriate patients with a low threshold for review in case of complaints.[30] There is also scope to utilise other healthcare professionals in post-operative care. In the UK, only 11% of all post-operative patients are seen by an ophthalmologist at any point; 57% are seen by hospital nurse practitioners or optometrists, and 27% are discharged immediately following surgery and followed up by community optometrists.[31]

However, post-operative review provides the opportunity for a feedback-loop with trainee surgeons as to the outcome of their surgery, and to become familiar with the usual post-operative course. It is therefore an important educational encounter in training hospitals, but could be rationalised to teaching lists only.

Strategies for cost-saving

The overall cost of cataract surgery in New Zealand is similar to Australia and the United States (US).[32] Surgeons at the AECS deliver cataract surgery at a fraction of the estimated cost in high-income countries.[33] Though there are important differences in health settings, factors contributing to the highly

cost-effective care delivered by AECS that could be applied in New Zealand include: the use of standardised processes and instrumentation; bulk sourcing; appropriate re-use of equipment; and specialised nursing and support staff facilitating high-volume service delivery with optimal efficiency.

At present, there is substantial variability in practice across DHBs with differing operating equipment, intra-ocular lens (IOL) types and peri-operative treatment regimens. Developing standardised evidence-based protocols at a national level could significantly reduce costs, both by supporting PHARMAC to negotiate lower equipment prices, and by rationalising peri-operative treatment regimens.

For instance, there is widespread use of topical antibiotics post-operatively, despite low-level evidence for their efficacy in preventing endophthalmitis.[34,35] Stopping topical antibiotics could save money, reduce confusion for patients, decrease unnecessary consumption and greenhouse gas emissions, and may reduce the risk of antimicrobial resistance.

In patients with significant pre-existing astigmatism, a toric IOL may be considered. Toric IOLs correct for astigmatism and reduce lifetime economic costs by decreasing the need for glasses and contact lenses.[36] Thresholds for their use presently remains at the discretion of individual DHBs, with resultant geographic inequities and missed opportunities for cost reduction. This could be remedied by establishing a national standard and threshold for the use of toric IOLs. Similarly, extended depth of focus (EDOF) lenses improve functional vision and decrease the need for glasses. One type of EDOF lens is only $100 more expensive than a standard monofocal lens and could be considered for use within the public system.

Equity for Māori and Pasifika

Cataract-related vision loss is 1.5 to 2 times more prevalent in Māori in comparison to non-Māori up to age 84.[37] Similarly, Māori and Pasifika are listed for surgery on average 6–7 years younger than the national mean, with more advanced cataracts and worse pre-operative visual acuity.[12,13] In turn, this may result in higher rates of intra-operative complications in Māori patients.[13] Higher rates of diabetes, cardiopulmonary disease and smoking may contribute to earlier cataract development and must also be addressed.[38]

Given that Māori and Pasifika are waitlisted for surgery at equivalent rates to other ethnic groups, access to timely referral appears to be a key area for improvement.[12] Barriers to accessing timely referral include socio-economic deprivation and geographic accessibility.[13] For example, in patients from the Waikato Region defined as having remote access, Māori were 27% geographically further from an optometrist than New Zealand Europeans, and had worse visual acuity at the time of referral for surgery.[39] Funding optometry visits and improving accessibility to community optometry in more rural areas are two strategies worth exploring. Given higher rates of diabetes and associated cataract formation, upskilling community diabetes services may result in more prompt diagnoses and referrals. However, we recognise a need for further research to understand ethnic inequalities in cataract surgery, and the adoption of Te Tiriti o Waitangi principles in addressing disparities.[40,41]

Sustainability

Cataract surgery in New Zealand has a measurable carbon footprint (152 kgCO2e per procedure), equivalent to an economy seat on a one-hour flight.[14] Extrapolated over approximately 30,000 operations each year, this amounts to 4,500 tonnes of carbon, which would require 134 ha of growing forest to absorb. When the carbon footprint of cataract surgery was measured in Wellington hospitals, the most striking finding was that 84% of emissions were related to the consumption of single-use items such as gowns, drapes, surgical instruments, tubing and cassettes, gauze, dressings, eye shields and medications.[14] When a similar footprinting exercise was conducted in AECS, India, it was shown that reuse of many items, as well as limited local recycling or reprocessing, was able to reduce the overall footprint of cataract surgery to 6 kgCO2e per procedure, with similar large reductions in cost.[42] As outlined earlier, while we might presume trade-offs between safety or quality and cost-saving activities, recent reports of large cohorts at AECS show that post-operative endophthalmitis rates of 0.01% rival the rate of 0.04% reported in the United States registry.[20,21] This casts an interesting light on how operating theatre regulations and practice patterns may not be optimising safety, efficiency, cost-saving and environmental impact.[43]

In the near future, New Zealand health sector agencies will become accountable for their carbon footprint.[44] Initially, this will require measuring emissions and budgeting to offset emissions. Decarbonisation of the health sector will then be

incentivised by the financial effects on our health systems. Ophthalmologists within this much larger system have several means to support decarbonisation. The travel emissions related to cataract surgery can be reduced with: "one-stop shop" pre-assessment with same-day surgery; longer operating lists (less staff travel per case); ISBCS; and phone and community-based follow up for suitable cases. The footprint related to pharmaceutical consumption can be reduced by: using topical anaesthesia wherever possible; avoiding single-use sterile drops when unnecessary; reusing bottles of liquid medications such as povidone-iodine and irrigating solutions for multiple cases; and, avoiding the prescription of any unnecessary post-operative drops such as antibiotics. Likewise, the consumption of surgical supplies can be reduced, and surgeons can have a powerful voice as leaders and advocates to their hospital management and industry suppliers.

Audit

A continuous audit cycle at both local and national levels is essential in improving efficiency, safety, and visual outcomes. To provide culturally appropriate and patient-centred care, patient reported outcome measures must also be central to this audit process. We should aspire to the Swedish National Cataract Register model, which has collected data on over one million surgeries since 1992.[45] A number of DHBs and private providers in New Zealand now use CatTrax, a web-based health intelligence platform, to manage their entire cataract pathway. CatTrax includes automated reporting on all relevant clinical and refractive outcome measures, including patient reported outcomes using the CatQuest-9SF and other assessment tools. CatTrax has enabled improvements in quality, access to cataract surgery and equity. To date, over 15,000 cataracts have been tracked using CatTrax in New Zealand.

Conclusion

Cataract surgery is a highly cost-effective treatment, but the surgical intervention rate in New Zealand ranks poorly compared with other high-income countries. We have presented several evidence-based strategies with overlapping benefits in access, equity, efficiency and sustainability. Key strategies include that Health New Zealand mandate a national CPAC threshold for surgical access, and that PHARMAC leverage cheaper access to surgical supplies using nationally agreed equipment standards, establishing high-throughput cataract units, offering ISBCS when appropriate, and rationalising post-operative care. As we transition to a new healthcare system, we should seize the opportunity to reimagine our public cataract service.

COMPETING INTERESTS
Nil.

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AUTHOR INFORMATION
Samuel Burridge: Ophthalmology Registrar, Taranaki Eye Centre, New Plymouth.
Jonathan Wood: Ophthalmology Registrar, Department of Ophthalmology, Tairāwhiti District Health Board, Gisborne.
Jesse Gale: Ophthalmologist, Department of Surgery & Anaesthesia, University of Otago, Wellington.
Albie Covello: Ophthalmologist, Taranaki Eye Centre, New Plymouth.
James McKelvie: Ophthalmologist, Department of Ophthalmology, Waikato District Health Board, Hamilton.
Graham Wilson: Ophthalmologist, Department of Ophthalmology, Tairāwhiti District Health Board, Gisborne.

CORRESPONDING AUTHOR
Samuel Burridge: Taranaki Eye Centre, 17 Weymouth Street, New Plymouth, 4310. (06) 758 3553. samlburridge@gmail.com.

URL
www.nzma.org.nz/journal-articles/improving-the-provision-of-cataract-surgery-in-new-zealand-demands-disruptive-change-open-access

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An audit of dog-related injury notification practices in a New Zealand public hospital

Natasha Duncan-Sutherland, Calum Cunningham, Suzannah Cooper, Sylvia Boys

ABSTRACT

BACKGROUND: Dog bites and other dog-related injuries (DRIs) are an ongoing and increasing cause of unintentional injury in New Zealand. Secondary prevention strategies implemented primarily by animal management services following an incident with a dog rely on notification of incidents. Mandatory notification of DRIs is not currently required in New Zealand, however, is a strategy used internationally for either the purposes of rabies control or dog bite prevention.
AIM: This study aimed to investigate the rate of notification by health professionals to an appropriate authority, for all DRIs that presented during the 2018/19 year to a New Zealand public hospital, and to describe the incidence and characteristics of these presentations.
METHOD: Data were obtained from all discharges from a New Zealand public hospital, with the primary external cause of injury code W54.0 (Bitten by Dog) + W54.1 (Struck by Dog) or W54.8 (Other Contact with Dog) as per the Australian Modification of the 10th revision of the International Classification of Diseases, during the period from 1 July 2018 to 30 June 2019. Clinical notes were screened for documentation of notification of the incident to an appropriate authority, including local animal management, social work, Oranga Tamariki (NZ's child protection services), or police.
RESULTS: There were 329 presentations to the emergency department with a DRI, 97% of which (n=320) were dog bites. There was a non-significant higher one-year cumulative incidence in children aged 0–9 years compared to adults aged 15 years and over. Children aged 0–9 years were also more likely to be injured on the head, face or neck, compared to adults or children 10–14 years, who were more likely to be injured on their limbs or torso. Notification of incidents were notified to an authority in 1.5% of incidents, including animal management services or a social worker.
CONCLUSION: This study found a low rate (1.5%) of documented notification by health professionals of dog bites and other DRIs. Further research is required to investigate the evidence for introducing strategies to increase reporting on the incidence of injuries, and any potential impact on presentations for medical attention.

Dog bites and other dog-related injuries (DRIs) are an increasing cause of unintentional injury in New Zealand, with an annual average of 21,665 Accident Compensation Company (ACC) claims for all DRIs during the 2014/15 to 2018/19 years, 10,951 of which were dog bite injuries.[1] There were 2,869 DRIs occurring in children aged 0–14 years, of which 2,160 were dog bite injuries. Inequity also exists with higher rates of injury in more socio-economically deprived areas and in those of Māori ethnicity[1] on a background of a socio-political environment that has resulted in the current inequity.[2,3] Both ACC claims and hospitalisations increased over this time period, with a three-fold risk of being hospitalised from a dog bite injury compared to 30 years ago.[1,4]

With an increasing prevalence of injury, prevention strategies become all the more important. Prevention strategies are primarily provided by animal management services within each local government area. Primary prevention focuses on education, dog-training, dog access and leash legislation, breed-specific restrictions, or stray dog management including registrations and microchipping.[5,6]

Secondary prevention strategies implemented following an incident of dog aggression may include: further education to dog-owners or rehabilitation training; re-homing; enforced safety requirements such as fencing, muzzling, leashes or signage; sterilisation; infringements; or prosecution with restrictions on dog ownership or in more extreme cases, dog euthanasia.[5,6] The need for secondary prevention is supported by studies showing that dogs who bite frequently have a history of dog aggression to either humans or animals.[7–11] However this requires appropriate authorities becoming aware of incidents of dog aggression for enactment.

Members of the public are also able to report incidents of dog aggression. As with other significant public or child safety issues, health professionals

and veterinarians can also report concerns with or without patient consent, and may also make reports of concern to other organisations such as police, social work or Oranga Tamariki (NZ's child protection service).

Clinical practice guidelines at Middlemore Hospital Emergency Department (ED) encourages health practitioners to consider notification of dog bite injuries to Auckland animal management services with patient consent. However, it is unknown to what degree this is implemented. The importance of including all injuries caused by a dog has also been highlighted in a previous study of paediatric injuries,[12] and in a more recent study of injuries caused by dogs in New Zealand.[1]

A related study *The Epidemiology of Dog-Related Injuries*, used DRI ACC claims and hospitalisations by territorial authority as two consistent measures of injury that can be monitored over time.[1] The current audit is primarily aimed to measure notification practices by health professionals within a single DHB. This will be repeated following implementation of a revised notification guideline within the region.

METHOD

This study was guided by a Kaupapa Māori approach to research,[13] with Māori involvement at all stages. The study developed following a suggestion by a member of the Independent Māori Statutory Board during consultation with the Auckland Council in the 2019 review of dog-access legislation, that health professionals take responsibility for notification of dog related injuries to animal management services.

Data were obtained from all discharges for ED presentations and hospitalisations to any department with the primary external cause of injury code W54.0 (Bitten by Dog) + W54.1 (Struck by Dog) or W54.8 (Other Contact with Dog) as per the Australian Modification of the 10th revision of the International Classification of Diseases (ICD–10), during the period from 1 July 2018 to 30 June 2019.

Hospital discharge summaries and other relevant electronically accessible notes were reviewed. Secondary presentations for the same incident were removed. Notes were screened for documentation of incidents having been reported to an authority, including local animal management services, Oranga Tamariki, or police. Information from the animal management service, on whether incidents were reported, was not available. Further information regarding potential risk factors were collected for each unique event including: primary cause of injury code; prioritised ethnicity (Māori, Asian, Pacific Island, or Other); age; domicile; location of injury on the body; length of stay in hospital; number of operations required during the hospital stay. Notes were also searched for the geographical location of injury, including if this occurred in public or private.

Data were collected on Microsoft Excel, with the open-access website Open-Epi version 3.01[14] used for statistical analysis. To calculate one-year cumulative incidence rates, population data from the 2018 census for the Counties Manukau District Health Board (DHB) were used.[15] Given the categorical data, the two-tail mid-p exact test was used to compare differences between age and ethnic groups, with 95% confidence intervals reported. A p-value of <0.05 was considered a statistically significant result. The cumulative incidence of dog bites per year was also analysed by ethnicity. Age-specific rates were calculated for each five-year age category. Further comparison was made by age groups 0–9 years, 10–14 years and 15 years and over (adults), for consistency with a previous study.[1]

RESULTS

There were 329 presentations of DRIs to Middlemore Hospital during the 2018/19 fiscal year, with an incidence of 58.4 per 100,000 people per year (95% CI 52.3, 64.9). Three hundred and twenty of these were coded as dog bite injuries. Only nine were non-bite injuries (fractures, head injuries or scratches). Seven were police dog bite injuries. Twenty had no documentation; however, they were included in the analysis due to being coded as a DRI. There were no injuries with the ICD code W54.1 (Struck by dog).

Age

Of 329 patients presenting with a DRI, 19.5% (n=64) were children aged 0–9 years, 6.7% (n=22) were children aged 10–14 years, and 73.9% (n=243) were adults aged 15 years and over (Table 1). Within the 0–4 age group, five victims were 1–2 years old, and seven victims were 2–3 years of age.

While the one-year cumulative incidence was higher in children aged 0–9 years (76.6 per 100,000; 95% CI 59.5, 97.2) compared to adults (58.6 per 100,000; 95% CI 51.6, 66.3), this was not statistically significant (p=0.062) (Figure 1). There was also no significant difference between the 10–14-year age group (55.4 per 100,000; 95% CI 35.6, 83.9) and adults (p= 0.825) (Figure 1). There was no identifiable trend across the age group categories (Figure 2).

Table 1: DRIs in 2018/19 year by age group.

	0–9 years	10–14 years	15 years and over
Incidence per 100,000 people (95% CIs)	76.6 (59.5, 97.2)	55.4 (35.6, 83.9)	58.6 (51.6, 66.3)
n (%)	64 (19.5%)	22 (6.7%)	243 (73.9%)
p-value	0.062	0.825	–

Figure 1: Cumulative Incidence of DRI's per 100,000 people in 2018/19 year by age group.

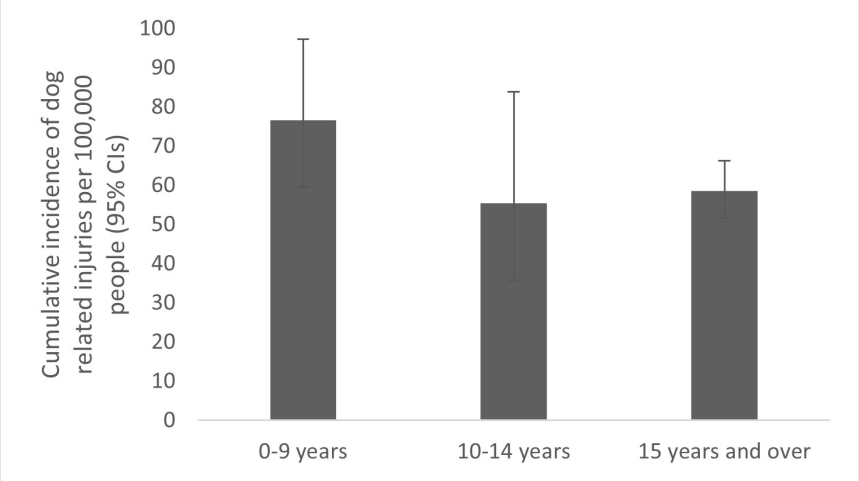
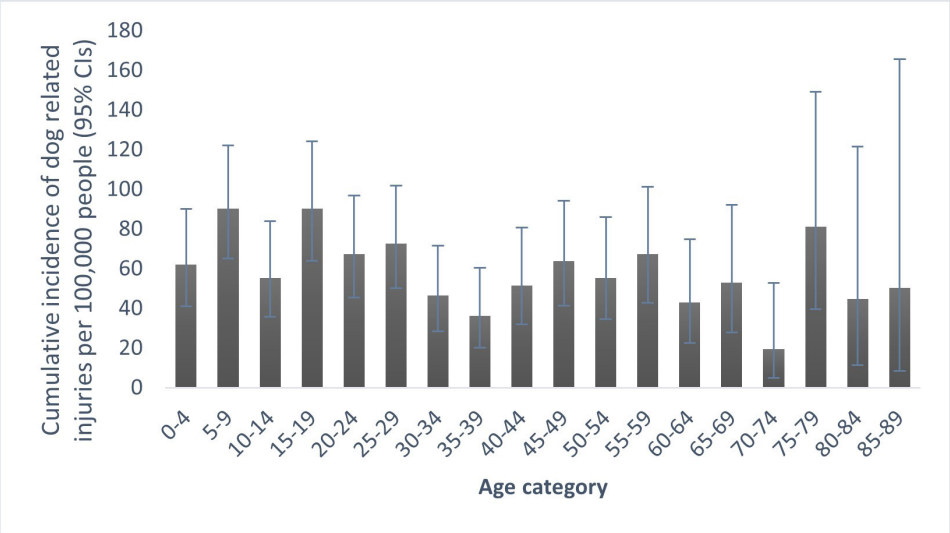


Figure 2: Cumulative Incidence of DRI's per 100,000 people in 2018/19 year by five-year age groups.



Ethnicity

The cumulative incidence was significantly higher in Māori (111.0 per 100,000; 95% CI 90.5, 134.8) compared to all non-Māori (43.9 per 100,000; 95% CI 38.5, 49.9, p<0.001) (Table 2). Rates were lowest in those of Asian ethnicity (20.2 per 100,000; 95% CI 14.0,28.3), with higher rates also present in the Pacific Island ethnic group (70.8 per 100,000; 95% CI 57.7, 86.1).

Severity of injuries

Injuries to children aged 0–9 years were more likely to occur on the head, face or neck region (64%, n=41/64), compared to adults and children aged 10–14 years, who were more likely to be injured on the torso or limbs (50%, n=11/22, and 83%, n=202/243, respectively). Multiple injuries occurred in 8% of children aged 0–9 years (n=5/64), 23% of 10–14 years (n=5/22), and in 8% of adults (20/243).

Half of patients presenting were hospitalised (50%, n=166/329), with 66% of these (n=110/166) requiring operative management with a general anaesthetic, and 7% (n=12/166) needing more than one. The average length of stay was 4.4 hours, in 87% of cases where this was recorded. Six per cent of patients (n=19/329) re-presented with cellulitis, following their initial presentation.

Circumstances

Eighteen percent (n=58/329) of clinical notes had the geographical location of injury described. Of these, 62% (n=36/58) were in public places, including six attacks described as being by stray dogs; 21% (n=12/58) occurred in the home; 14% (n=8/58) at the property of a friend, neighbour or family member; and 10% (n=6/58) were following a worker entering a private property. Very few notes (10%, n=34/329) described the relationship of the dog to the victim. Most injuries occurred in people residing in Counties Manukau DHB (68%, n=224/329). Fifteen percent (n=50/329) resided in Auckland DHB, 9% (n=30/329) in Waitematā DHB, and 2% (n=6/329) were overseas residents.

Notification rates

Five injuries were documented as being reported to an authority (1.5%). Four were reported to local animal management services, and one to a social worker. Victims of incidents that were reported were aged 8 years, 14 years, 7 years, and 50 years. Two other health professionals documented having a safety discussion (with victims aged 12 years and 6 years). One other patient (60 years old) had made a report to an animal management service prior to ED attendance. All victims with documented notification or safety discussions identified as being of Pacific Island or Māori ethnicity.

DISCUSSION

Patterns of injury were comparable to previous studies showing higher rates of DRIs in children compared to adults, with children more likely to be hospitalised or receive bites to the head/neck region.[4,16–18] This is in contrast to a more recent study using a broader measure of injuries presenting for any medical attention, including within the community, showing similar rates of injury in children and adults.[1] While the circumstances around DRIs have not been well studied in children, most likely the head/neck injuries are due to their height relative to a dog.

The finding of a higher rate of injury in Māori is also consistent with previous studies.[1,16] The reasons for this are uncertain, but may be explained

Table 2: DRIs in 2018/19 year by ethnicity.

	Māori	All non-Māori (Asian, PI, Other)	Asian	Pacific Island	Other
Incidence per 100,000 people (95% CIs)	111.0 (90.5, 134.8)	43.9 (38.5, 49.9)	20.2 (14.0, 28.3)	70.8 (57.7, 86.1)	43.9 (36.1, 53.0)
Number of injuries	97	232	31	96	105
Population identifying as ethnic group	87,375	528,162	153,594	135,519	239,049
p-value		p<0.001	p<0.001	p=0.002	p<0.001

by differences in rates of dog ownership, socio-economic deprivation on a background of the ongoing effects of colonisation,[3] or inequity of investment into culturally appropriate prevention strategies. A key component of secondary prevention strategies in reducing inequity will require empowerment of Māori with involvement of Māori-led services.

The incidence of injury 58.4 per 100,000 people per year (95% CI 52.3, 64.9) was low compared to ACC claims within the South Eastern Auckland Region (220 per 100,000 people), demonstrating that many people with DRIs present to community health centres rather than to hospital, consistent with a recent New Zealand study.[1] Likewise, the plastic surgery department for the Auckland Region is also located at Middlemore Hospital, with patient referrals received from outside the Counties Manukau DHB area.

While 64% of injuries occurred in public places, the accuracy of this result was limited by the number of discharges where this was documented (18%). This is in contrast to a previous study showing a higher rate of injuries in private places,[16] and is likely a reflection of the inaccuracy of medical notes as a method for investigating the circumstances surrounding an injury. The residential address of a victim may also not reflect the location of injury, particularly given injuries frequently occur when either visiting a property or in public.[8]

The low rate of notification of injuries was surprising given the severity of injuries that presented. Eighty-six injuries occurred in children aged 0–14 years; 93 occurred on the head/neck, 30 victims had injuries in multiple locations, 166 were hospitalised; and 110 required a general anaesthetic with operative management—yet only five had documented notification.

The low notification rate found in this study is, however, consistent with international studies of presentations to emergency departments showing a paucity of dog bite reporting by health professionals.[19,20] A UK study found only 4% of clinicians in one hospital made a follow-up referral to a social or health worker relating to dog safety in 160 paediatric patients presenting to an emergency department with a dog bite. Although, this increased to 38% when a paediatric liaison team retrospectively reviewed all notes for the purpose of identifying child protection issues.[19] A Canadian study showed that of 302 people with dog bite injuries presenting to an emergency department, only 19.5% were reported to either public health (for rabies prevention) or to police, and only 1% had a safety or preventive discussion.[20]

Other studies showing a lack of reporting of DRIs in New Zealand include a survey of 535 adults presenting for medical attention for a dog bite in 2002, showing that only 30% of dog bite injuries were reported to an authority.[8] Likewise, a survey of 228 New Zealand veterinary students, revealing a high lifetime incidence of dog bites (38%), found that only 5% were reported to authorities.[8] Similar results are reflected internationally. An online survey conducted in the UK with self-identified dog bite victims showed no further action was taken in over half of dog bite incidents (53%).[7] Likewise, a study in Ireland found that dog bites frequently went unreported in both non-legislated (72.7%) and legislated breeds (45%).[21]

New Zealand's lack of implementation of safety standards around dogs with a history of aggression poses a risk of further serious harm to people living within the home, or those in surrounding houses and local community. This is of particular concern for children, who may have aggressive dogs living with or near them, including schools or playgrounds, without adequate safety precautions. Improved reporting would also enable implementation of secondary prevention strategies for injuries occurring within private spaces, which, in turn, are less likely to be reported.[8,9]

Notification to animal management services also

Table 3: Number of reported dog attacks on people, compared to ACC claims for DRIs within the Auckland Region.

	2014/15	2015/16	2016/17	2017/18	2018/19
Dog attacks on people reported to Auckland animal management service [22–25]	N/A	740	792	745	716
ACC claims for dog bite injuries only within the Auckland Region [1]	3,065	3,259	3,502	3,562	3,626
ACC claims for all DRI's within the Auckland Region [1]	4,125	4,434	4,618	4,831	4,885

allows for more accurate knowledge of geographical areas in which to focus strategies, improved monitoring of incidents over time, and presents an opportunity to increase dog-registrations, resulting in further financial investment into prevention strategies. As can be seen in table three, services may report a decrease in dog bite rates, when this apparent decline is due to under-reporting, and rates are in fact increasing. Of note, some reports to animal management may be from people who have not presented for medical attention.

Reasons for under-reporting by the public may be because the blame for dog bites can be directed toward the victim with a reluctance to accept the aggressive behaviour of dogs,[26–29] because people underestimate the risk[27] particularly if it is their own dog,[7] or if there is a less severe injury or non-legislated breed.[21] Under-reporting may also occur because people are reluctant to report their own dog or a dog that is known to them, out of concerns for the consequences to the dog including the potential for euthanasia, or because of fear of retribution by the dog owner.

Most countries, including New Zealand, do not have national mandatory notification policies for dog bite and other DRIs for the purposes of dog bite prevention. Some hospitals in the UK and US have local notification practices for dog bite injuries—usually to police—with geographical disparities in reporting rates due to the lack of national policy.[30] Other countries have notification policies for the purposes of rabies prevention.[20,31]

Switzerland is the only country with national mandatory notification in place for the purposes of reducing dog bites, with 40% of physicians reporting at least half of dog bites presenting for medical attention after the strategy was introduced in 2006, which were thought to be the most relevant cases.[32] There was a subsequent reduction in insurance claims for DRIs from 3,600 in 2005, to 2,500 in 2007.[33]

The most common reason that physicians and veterinarians in Switzerland gave for not wanting to report a DRI, was that they did not want to break confidentiality when the patient was the owner of the dog, or if the patient did not want it reported because it was a minor injury, or because they were unaware of the requirement.[32] There may also be concerns around deterring patients from presenting for medical attention.

However, with higher rates observed in Māori children this is clearly an equity issue, and mandatory notification to an appropriate authority may improve safety for our children. Likewise, patients and professionals may prefer mandatory notification, as removing a barrier to reporting may allow them to have the incident notified while maintaining relationships. The challenges of reporting dog-related issues within small communities were recognised in a qualitative study of a small Indigenous community in Northern Australia.[34] A further study in a small Indigenous community in Canada with a high level of community involvement also promoted reporting as part of the strategy.[35] This is an area for future research in the New Zealand context.

The main limitation of this study is the investigation of documented notification only. Some incidents may have been reported by either the patient or health professional, but not documented. There may be variable accuracy of documentation by health practitioners, coding administration staff or the data analyst. The number of non-bite DRIs was low, and may be due to inaccuracy in coding for injury caused by a dog.

CONCLUSION

This study found a low rate (1.5%) of documented notification by health professionals of dog bites and other DRIs. Further research is required to investigate the evidence for introducing strategies to increase reporting on the incidence of injuries and any potential impact on presentations for medical attention.

COMPETING INTERESTS
Nil

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AUTHOR INFORMATION
Dr Natasha Duncan-Sutherland: Emergency Department, Middlemore Hospital, Otahuhu, Auckland.
Dr Calum Cunningham: Emergency Department, Middlemore Hospital, Otahuhu, Auckland.
Dr Susannah Cooper: Emergency Department, Middlemore Hospital, Otahuhu, Auckland.
Dr Sylvia Boys: Emergency Department, Middlemore Hospital, Otahuhu, Auckland.

CORRESPONDING AUTHOR
Dr Natasha Duncan-Sutherland: Emergency Department, Middlemore Hospital, Otahuhu, Auckland 1640. Private Bag 93311. +64 9 276 0000. Natasha.DUNCAN-SUTHERLAND@middlemore.co.nz.

URL
www.nzma.org.nz/journal-articles/an-audit-of-dog-related-injury-notification-practices-in-a-new-zealand-public-hospital

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Solar maculopathy and dissociative symptoms: a case report on a patient on buprenorphine opioid replacement therapy

James Redmayne, Lewis Lam

ABSTRACT

Solar maculopathy refers to thermal and photochemical macular damage caused by excessive exposure to light.[1] Risk factors include behaviour (eg welding, sunbathing), refraction, pupillary size and clarity of ocular media.[2] Drugs, both prescribed and recreational, can contribute to solar maculopathy through analgesic, photosensitization and psychiatric effects.[2] We report a case of solar retinopathy associated with a brief dissociative episode. Written informed consent was obtained from the participant.

A 38-year-old male was referred for ophthalmology assessment with reduced visual acuity and bilateral central scotoma. One week prior, he reported gazing toward the sun while listening to music. He reported "zoning out", and looked toward the sun for around five minutes before regaining awareness. He then noticed immediate distortion of his central vision. Previous ocular history was unremarkable. Past medical history involved bipolar affective disorder (BPAD), currently well managed with aripiprazole, and previous opioid use disorder treated with buprenorphine. The participant reported a history of heroin use, but denied use of heroin, marijuana or other drugs for >6 months. A urinary drug screen was not performed. The participant denied intrusive daydreaming as being a prior issue, and was observed to maintain attention for an extended time during ophthalmological examination.

On examination, visual acuity was 6/18 (right) and 6/12 (left). Intraocular pressure was normal at 12mmHg (right) and 14mmHg (left). Pupil size/reactivity and extra-ocular muscle function was normal. Fundoscopy revealed an orange/red foveal spot surrounded by a ring of pigment, consistent with solar maculopathy (Figure 1A). Optical Coherence Tomography imaging revealed focal hyperreflective changes at the fovea and subfoveal retinal pigment epithelium (Figure 1B).

Treatment involved education regarding eye protection and counselling regarding the natural course of solar retinopathy. Spontaneous improvement is expected but residual visual deficit likely.

Discussion

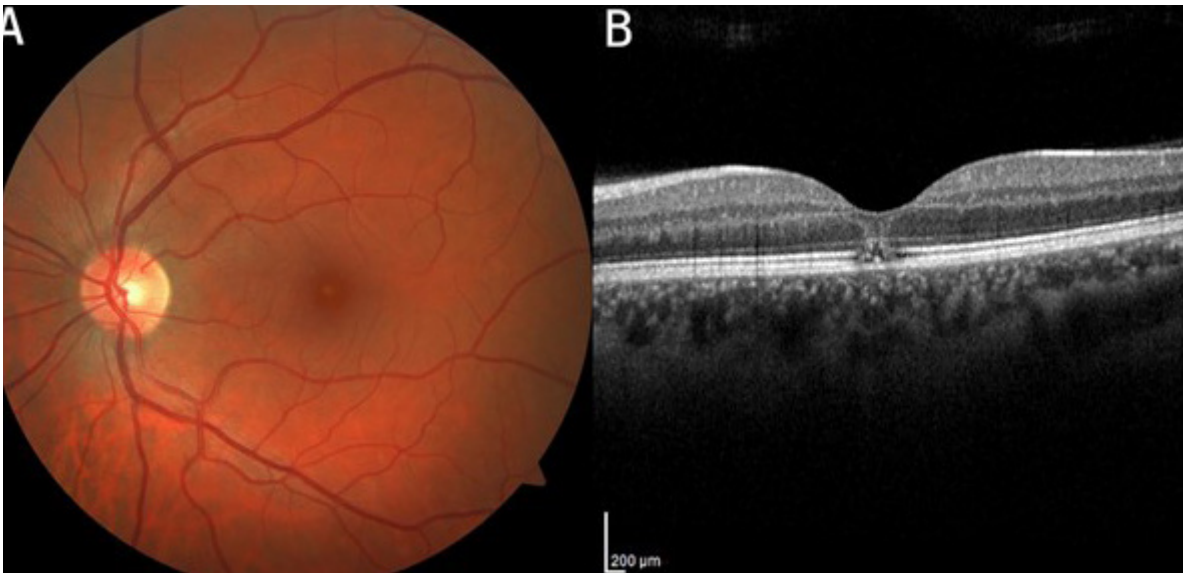
Solar maculopathy is a well-established pathological process. This case is significant due to the dissociative episode contributing to the injury. Dissociative symptoms are defined in the DSM-V as the "disruption of and/or discontinuity in the normal integration of consciousness, memory, identity, emotion, perception, body representation, motor control, and behaviour".[3] These experiences exist on a continuum of severity; pathological dissociation can involve symptoms such as feelings of depersonalisation or out-of-body experiences, while non-pathological dissociation includes experiences such as daydreaming or becoming absorbed in a task.[4] Dissociative symptoms have been associated with trauma, schizophrenia, substance use disorder and BPAD.[4] Dissociation can also be induced chemically; dissociative anaesthetics such as ketamine induce dissociation via action on the NMDA receptor, while opioids can mimic psychogenic dissociation.[5,6]

This case involves buprenorphine, a long-acting partial opioid agonist that can be used for analgesia and in opioid replacement. In opioid replacement therapy, buprenorphine acts on mu receptors to reduce cravings and prevent withdrawal symptoms.[7] A recent study demonstrated increased frequency of dissociative symptoms in patients with substance use disorder treated with buprenorphine, compared with those treated with either methadone or naltrexone.[4] Buprenorphine may also increase risk of solar maculopathy

through analgesic effects, by masking discomfort usually induced by looking toward the sun.[2]

Substance use and psychiatric disorders have previously been associated with solar maculopathy, independent of dissociative symptoms. In the case of psychiatric disorders, this association has traditionally been related to deliberate self-harm or disease driven sungazing.[8] Solar maculopathy has been associated with hallucinogens, such as Lysergic acid diethylamide (LSD) and methylenedioxymethamphetamine (MDMA). [9,10] In contrast to these previous reports, our case lacks an intentional component, consistent more with a dissociative episode than a delusion or self-harm driven act. To our knowledge, an association between dissociative episodes and solar maculopathy has not been previously explored in the literature. It is possible that patients with risk factors for dissociative symptoms are at increased risk of solar maculopathy, and should be counselled regarding adequate eye protection.

Figure 1: Fundus photograph and Optical Coherence Tomography (OCT) scan demonstrating solar maculopathy.



A: Left fundus photograph demonstrating orange/red spot at fovea with surrounding pigmentation.
B: Coherence Left macula OCT scan demonstrating hyperreflective changes at the fovea and subfoveal retinal pigmented epithelium.

COMPETING INTERESTS
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AUTHOR INFORMATION
James Redmayne: Lecturer, School of Medicine, Griffith University; Registrar, Eye Specialist Institute, Gold Coast, Australia.
Lewis Lam: Ophthalmologist, Eye Specialist Institute, Gold Coast, Australia.

CORRESPONDING AUTHOR
Dr James Redmayne: Level 2, Bermuda Point, 1 Lake Orr Drive, Varsity Lakes, QLD, 4227, Australia. +64211098974. j.redmayne@griffith.edu.au

URL
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Access to acute secondary healthcare services is for all

Brian Cox

The recent editorial by Saxon Connor proposes a discussion about rationing acute secondary care. The underlying premise of the editorial appears that, due to inadequate resourcing, some people with health need should be denied acute secondary care. Such a discussion automatically requires a decision about who should be left to die by chance. Surely, unless care is ineffectual, that would be unethical. A key measure of a society's worth is how well it provides healthcare for its members, particularly the young and the elderly. The increasing fashion of finding reasons not to provide effective care undermines the worth of society and can ferment a loss of societal cohesion with widespread consequences.

The wide variation in individual health status in any broad population group ensures that invoking some average life-expectancy, age or ethnicity, in such a decision for any patient with symptoms is unethical. Dr Connor suggests that such decisions can be made in a just and fair way. These terms involve value judgements about someone's life, so who's values are most relevant? I would propose that it is the judgement of the patient and family that should come first, and that the medical practitioner tries to fit this to the oath to provide benefit for any patient presenting for care. Individual medical decisions about denying access to acute secondary healthcare services could be justifiably criticised as part of a "god-complex". Sometimes the individual patient's need is either left to administrators who, sometimes without the knowledge needed, judge what care may be beneficial for general groups of patients, or is treated on a first-come first-served basis.

There have been major increases in the cost of healthcare which have strained the health services of many countries driven by increased life-expectancy, partly from a reduction in smoking among men. This has increased the length of life for which care may benefit, concurrent with major advances in effective therapy for the illnesses that now commonly occur. Whether society is prepared to try and meet the health needs of the population, or ration access to pursue other ventures, should be watched closely by all.

COMPETING INTERESTS
Nil.

CORRESPONDING AUTHOR INFORMATION
Dr Brian Cox: Hugh Adam Cancer Epidemiology Unit Dept. Prev. and Soc. Medicine, DSM, New Zealand. brian.cox@otago.ac.nz.

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Maternal Mortality: The problem of the Private Maternity Hospital [extract]

NZMJ, April 1922

url: www.nzma.org.nz/journal-articles/maternal-mortality-the-problem-of-the-private-maternity-hospital-extract

In many districts of New Zealand the private maternity hospital problem is a difficult one. The majority if hospitals are too small to be really efficient, and in this connection it seems a pity that there should be rally in existence in any one district a number of 2, 3, 4, 5 and 6 bedded institutions each relatively poorly and inadequately equipped and unable to carry out effective sterilisation or to isolate suspicious or septic cases properly, when by proper co-operation it should be possible to have one 20 bedded hospital with complete equipment.

The ideal procedure would be of course, to erect a maternity block in connection with the local public hospital of sufficient size to be efficient, to which all classes of the community could be admitted on a sliding scale of payment according to the accommodation chosen by them, and with the right of being looked after the medical practitioner of their choice. This is an adaptation to obstetric work of what is known as the "Toronto System," which as you know has met with the approval of the Hospitals Commission which sat last year, and is favoured by the Health Department, and I know is looked upon favourably by many Hospital Boards. The stumbling-block in the way of its general adoption is entirely that of finance. As you are aware the majority of Hospital Boards in this country have a considerable amount of leeway to make up in their building programmes owing to the fact that these building programmes were either partially of completely suspended during the years of the war. This leeway must be made up before other ventures can be embarked upon, as far as I can judge it will be some time yet before we see obstetric blocks attached to our district hospitals. It should surely, however, be possible in the ordinary town with its number of small and inadequate maternity hospitals for the medical men to combine financially and otherwise and run their own maternity hospital with a first-class matron in charge. This would be far better from all points of view than to allow the present unsatisfactory state of affairs to continue. At the Hospital Board, of in a St. Helens Hospital, is certainly under infinitely better conditions than her sister who seeks accommodation in a private maternity hospital and has to pay for that accommodation 3, 4 or 5 times the price charged at a Hospital Board's institution.

To illustrate my remarks let me submit to you an analysis of the private hospital facilities of one medium sized town in New Zealand, which has recently been inspected. It is fairly illustrative of the average position. In the town there are four separate hospitals with a total bed capacity for 18 cases; amongst these four hospitals there is not a single labour room, no satisfactory sterilising, not a single sink-room and no effective means for isolating suspicious or infected cases. As things are at present it is practically impossible to improve matters on account of the small size of each individual hospital, and because of the impossibility of such small institutions incurring the expense of installing satisfactory equipment. Yet were the 18 beds apparently necessary in this town accommodated under one rood the whole problem could be satisfactorily solved, and an efficient service provided.

For a long time it has been felt by those responsible for the inspection of the private hospitals that in certain directions the legislation relating to them required amending and certain proposals were put forward in the Hospitals Amending Bill recently before Parliament. Although the proposals affected all classes of private hospitals, it was the average maternity hospital which it was desired to improve, and I propose therefore to briefly traverse the various proposals to which legislative enactment was asked in order that members present may be given an opportunity during the ensuing discussion of stating their

views. I will make my remarks as brief as possible, and will preface them by giving you an account of a few of the conditions found during visits to private hospitals which emphasise the necessity for inspection and the carrying out of necessary improvements:—

1. The existence of general unhygienic conditions, e.g., dirty, torn wallpapers, unclean floors, accumulations of rubbish in rooms, dirty, badly kept cupboards, unclean milk-safes, meat-safes, etc., defective drainage.
2. Overcrowding.
3. Understaffing, particularly with refence to the provision of properly trained night staffs.
4. General mismanagement evidenced by untidy badly kept rooms; poor, unappealing meals, etc.
5. Unlicensed rooms frequently used for patients' use.
6. Unauthorised, unregistered persons are sometimes found in charge of private hospitals.
7. Alterations and additions are on occasion made to private hospitals without first consulting the Department as should be the case.
8. The transfer of a private hospital is sometimes made without reference to the Department.
9. The actual transference of a hospital to new premises is sometimes made without the knowledge of the Department.
10. Notifiable cases are not always reported.
11. Certain cases (such as Caesarian section) are not always entered on the hospital register.
12. Maternity cases are often admitted to private hospitals licensed for medical and surgical cases only, and vise versa, when hospitals of both types exist in the same district.
13. Places are conducted as private hospitals without licenses.
14. Hospital registers are often not kept up-to-date.

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