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EDITORIAL

Alcohol-related harm and Aotearoa New Zealand emergency departments

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Alcohol-related harm is preventable. It contributes to ED overcrowding, with a significant impact on all patients requiring care, puts considerable stress on hospital staff and resources, and places a high financial burden on the entire health system. A centralised inter-agency dataset is required to fully understand the level of harm that alcohol is causing within our communities and allow us to evaluate the impact of changes in policy over time. The implementation of evidence-based alcohol policies, both local and national, is urgently required to improve the health of our communities.

The impact of intensive blood pressure management in the post-thrombolysis setting: a real-world observational study

Bethan Harper, Syrah M Ranta, Harry K McNaughton, Anna Ranta

Very high blood pressure after giving a stroke clot busting medication can trigger dangerous brain bleeds. We assessed if aggressive blood pressure lowering might reduce this risk and improve patient outcomes. Our study found that more aggressive blood pressure lowering reduces the risk of high blood pressure but is not clearly associated with better patient outcomes. Because some very low blood pressures resulted and infusions require more nursing resource, we propose that a moderately aggressive approach to blood pressure lowering might be most appropriate.

Long-term health conditions among household families in Aotearoa New Zealand: cross-sectional analysis of integrated Census and administrative data

Lisa Underwood, Andrea Teng, Nicholas Bowden, Ofa Dewes, Lukas Marek, Barry Milne

Our project aims to understand the challenges facing families in Aotearoa New Zealand who are affected by long-term physical and mental health conditions. We want to find out what helps some families thrive in these situations. We used Census and Ministry of Health data to obtain information on over 3 million people who were living in a family in New Zealand in 2013. Among the 1 million families in our study, three in five (60%) included at least one person with a long-term health condition (cancer, chronic obstructive pulmonary disease, heart disease, diabetes, dementia, gout, stroke, traumatic brain injury or mental health/behaviour conditions). Around half a million children were living with a family member who had a long-term health condition and three in four multi-generation families (74%) included at least one person with a long-term health condition. Our finding suggests a need for culturally appropriate healthcare strategies that include the whole family to help prevent long-term health conditions and the impact they have on family members.

Exploring melanoma shifts: a two-decade analysis in New Zealand

Daniel Wen, Jack S Pullman, Avinash Sharma, Bert van der Werf, Richard C W Martin

This study examines the incidence of melanoma in New Zealand from 2000 to 2022. By analysing data from the New Zealand Cancer Registry, researchers found that while the incidence of invasive melanoma grew from 2000 to 2008, it appears to have levelled off between 2008 to 2022. Meanwhile, melanoma *in situ* (an early form of melanoma in which the abnormal cells are contained within the very top layer of the skin) rates rose steadily throughout the same period. Although this stabilisation in invasive melanoma rates is promising, more research is needed to confirm if this remains true going forward and if there is a decline in incidence.

Preliminary assessment of using mobile point-of-care human papillomavirus (HPV) testing with the option of immediate colposcopy in a rural area in a high-income country: a case study

Helen Paterson, Emma Macfarlane, Tania Slater, Jo-Ann L Stanton, Evelyn Jane MacDonald, Melanie Gibson, Bev Lawton

Recent advances in technology allow screening tests for cervical cancer, caused by the human papillomavirus (HPV), to be carried out by identifying viral genetic material in samples taken from a vaginal swab, which can be self-administered. Structural barriers, such as the timing of appointments, travel difficulties and enrolment in primary care impede access to HPV screening (and timely and equitable diagnostic colposcopy where indicated) for many women in rural Aotearoa New Zealand, and particularly wāhine Māori. This case study demonstrates that effective cervical cancer screening can be offered in a rural community event setting—a fast and convenient option for rural women, providing on-the-spot HPV testing and analysis, and immediate further diagnostic examination if required. The success of this initiative, held at the Shear 4 A Cause event in February 2023, was made possible through community, clinical and research partnership.

Impacts of raising a child with a feeding difficulty in Aotearoa New Zealand

Stacey-Louise Corney, Givona Rush, Sarah A Taylor, Bianca N Jackson

Paediatric feeding disorders can include restricted or selective eating, or the requirement of tube feeding. We explored the impact of paediatric feeding disorders on families/whānau in Aotearoa, via a nationwide survey. Many whānau experience financial strain owing to their child's feeding difficulty. Some may not be able to seek or sustain employment, or find appropriate childcare. It is difficult for parents to find support for their own wellbeing as they care for their child with a feeding difficulty.

Specialist vape store audit reveals poor compliance with new e-cigarette regulations

Jude Ball, Lesieli Katoa, Janet Hoek

This study used a 20-year-old "mystery shopper" to test the compliance of specialist vape stores in the Wellington region to regulations intended to address youth vaping. Only one store (1.4%) requested age identification (ID) on entry to the R18 premises. In 50% of stores, ID was requested when a purchase was made; however, a third of those retailers proceeded with the sale despite the buyer not providing ID. Disposable vapes remained available for NZ$10 or less in most stores, and reusable starter kits were also widely available for NZ$10–20. Discounted high-nicotine disposables were sold for as little as NZ$2.50 each, with the cheapest vapes sold in the most socio-economically deprived suburbs, where vape stores were clustered. Most low-price disposables did not comply with the new nicotine limits and safety regulations that came into force in December 2023.

An upstream approach to addressing the childhood obesity epidemic in New Zealand—a call to action

Velia Men

Childhood obesity in New Zealand has reached an alarming level; one in three children is currently overweight or obese, raising serious concerns about the health of our future generations. The issue lies in our "obesogenic environment", characterised by the widespread availability of energy-dense, nutrient-poor foods that are heavily marketed. Experts and WHO have consistently advocated for policies such as sugary beverage taxation, restrictions on unhealthy food marketing and healthy food policies in schools to address this issue. However, despite strong evidence, economic rationale and community support, the Government's implementation of these policies has been slow, falling behind international benchmarks. This viewpoint article argues that collective action is needed to break through policy inertia and make the health of our future generations a priority.

Bilateral macular oedema secondary to docetaxel treatment

Francesc March de Ribot, Patchara Jirapanyayut, Anna March de Ribot

Chemotherapeutic drugs like docetaxel, commonly used for treating various cancers, including prostate cancer, can sometimes have unintended effects on the eyes, specifically the retina. In our case, a 67-year-old man undergoing palliative treatment for advanced prostate cancer experienced vision loss after three cycles of docetaxel. After discontinuing the chemotherapy due to an inadequate response after three cycles, the patient's vision improved. This case emphasises the importance of monitoring patients undergoing docetaxel chemotherapy for potential ocular side effects. We recommend regular ophthalmological examinations for individuals reporting visual issues during or after receiving docetaxel. The key takeaway is that every patient's therapy should be personalised to achieve the best possible outcomes, considering potential side effects and adjusting treatment accordingly.

A minimally invasive endoscopic approach to oesophageal lipoma

Haylie M Griffen, Chun-Yen Wu

Lipomas are fatty growths of tissue and their growth in the oesophagus or food pipe is rare. Despite the fact that they are non-cancerous growths, they can be life-threatening and require treatment before they cause issues. Previously, this used to involve a major surgical procedure. However, there are now much simpler and less invasive ways in which they can be removed using a camera down the gullet.

Long COVID impacts people's ability to work: cross-sectional study in Aotearoa New Zealand

Mona Jeffreys, Fiona McKenzie, Maite Irurzun Lopez, Lynne Russell, Lis Ellison-Loschmann

We analysed survey data from 990 people who had COVID-19 prior to December 2021. At the very least, 2.5% had long COVID, i.e., symptoms that lasted longer than 3 months. People with long COVID were less able to work, and less able to work the same number of hours or as productively as prior to having COVID-19. Long COVID is likely to continue to be a burden to individuals, families/whānau and employers. Supportive return to work policies are likely to help people with long COVID to work within their abilities.

Alcohol-related harm and Aotearoa New Zealand emergency departments

Laura R Joyce, Andrew McCombie, Rose Crossin

Alcohol and the burden on the Aotearoa New Zealand health system

Alcohol is the most widely consumed drug in Aotearoa New Zealand, with one in five New Zealanders regularly consuming alcohol at a level that increases their risk of alcohol-related injury or illness.[1] The burden on society of alcohol-related harm is significant, with an estimated cost of NZ$7.85 billion per year in lost productivity, unemployment, crime, healthcare, ACC and welfare costs.[2] The consequences of harmful drinking are seen regularly in emergency departments (EDs), with people presenting with acute alcohol intoxication or injuries related to alcohol use. ED presentations also occur due to acute exacerbations of chronic diseases related to alcohol, including numerous cancers, neuropsychiatric conditions and cardiovascular and gastrointestinal diseases. The burden of alcohol-related presentations on already-overcrowded EDs is preventable. Major reform on how alcohol is promoted, legislated and consumed in Aotearoa New Zealand is required to reduce the harm that alcohol is causing—both on individuals and on the wider healthcare system.

Alcohol and ED overcrowding

Emergency departments around the world are increasingly overcrowded, which has been shown to cause harm to all patients. The contributor to ED crowding that is most strongly associated with adverse outcomes for patients is hospital access block for admitted patients. For every patient who arrives in an Aotearoa New Zealand ED at a time when more than 10% of admitted patients had an ED length of stay greater than 8 hours, there is a 10% increased risk of death within 7 days.[3] Recent data from the United Kingdom has shown that there is one excess death for every 82 patients who spend longer than 6–8 hours in ED.[4] Alcohol use contributes to ED overcrowding, with 5–7% of ED presentations thought to be alcohol-related,[5] and results in longer lengths of stays than non-alcohol-related presentations.[6] Alcohol is a factor in 16–21% of injury-related ED attendances,[7] with a fivefold risk of death in the year after admission for those presenting to ED with an injury associated with alcohol use.[8]

Violence and aggression in ED

Alcohol is a significant contributor to violence and aggression within acute healthcare settings.[9] For staff working in an ED that is already under considerable pressure due to overcrowding, occupational violence and aggression associated with alcohol use can contribute to and exacerbate emotional exhaustion, moral distress, anxiety, depression, burnout and post-traumatic stress disorder.[10] The consequences for a health system in crisis with inadequate staffing levels is significant, with decreased job satisfaction, diminished productivity, absenteeism and difficulties with recruitment and retention of staff. In a recent survey by the Australasian College for Emergency Medicine, 71% of staff reported that they frequently experience alcohol-related abuse, threats, intimidation or harassment from patients, and that this has negatively impacted on their wellbeing, job satisfaction, safety and workload.[11]

Alcohol in relation to suicide and mental health

Emergency departments across Australasia are seeing increases in presentations related to mental health and suicidal thoughts and behaviours.[12] Alcohol has a complex but intertwined relationship with these issues, and thus, may contribute to these presentations. At a distal level, Aotearoa New Zealand cohort studies have shown that heavy alcohol use is causally associated with major depression and associated with an increased risk of suicidal ideation.[13] At a proximal level, using meta-analysis, acute alcohol use is associated with seven times the risk of suicide attempt.[14] A recent Australian study found that the two most common principal diagnoses that involved prior alcohol use were mental and behavioural disorders, and suicidal ideation.[15] Patients' presentations

related to mental health and suicidal ideation are complex, and as such, ED staff may require a significant amount of time to deliver appropriate healthcare. While acknowledging that brief interventions relating to alcohol are possible within an ED environment, given that alcohol-related harm is modifiable, we argue that a greater focus on alcohol harm reduction at a population-level is likely to have more overall impact.

Current Aotearoa New Zealand alcohol purchase and consumption behaviours

Although media attention often focusses on young people drinking in pubs and bars on a Saturday night, a recent study showed that this may not be the case.[16] Over one-third of older New Zealanders are drinking at levels which may result in harm.[17] Older people are more likely to have additional co-morbidities and the potential for medication interactions, therefore increased risk of serious consequences. Off-license alcohol venues, such as bottle stores, supermarkets and online sales, remain the primary source of alcohol purchase. This highlights the need for stronger local alcohol policies for off-license venues, particularly as they are a key supplier of large quantities of cheap alcohol and contribute to Aotearoa New Zealand's drinking culture as a whole. With the recent passing of the *Sale and Supply of Alcohol (Community Participation) Amendment Bill*, councils can now implement strong controls on alcohol availability without the risk of alcohol industry appeals, particularly from alcohol retailers.

Data and monitoring and public health

Public health relies on surveillance data to identify population-level trends and assess the impacts of policy changes. EDs are an important monitoring site, as they see a diverse range of alcohol-related harms, both chronic and acute, and with varying degrees of severity. Current systems for routine data collection on alcohol within EDs are inconsistent in Aotearoa New Zealand, which is hindering evidence-based decision making. It is vital that location-specific data be collected, particularly as local councils across Aotearoa New Zealand are developing and reviewing local alcohol policies. Therefore, there is a need for standardised data collection to be implemented across Aotearoa New Zealand EDs. Harms from alcohol can be diverse, and broader than just medical, thus requiring triangulation across data sources to build an accurate picture of harm.[18] ED data could be supplemented with police data, which has the benefit of also being location-specific but measures other harms such as crime and violence. Aotearoa New Zealand should also consider the implementation of detailed ambulance data collection for alcohol-related harm, such as what is done in Australia.[19]

Conclusions

Alcohol-related harm is preventable. It contributes to ED overcrowding with a significant impact on all patients requiring care, puts considerable stress on hospital staff and resources and places a high financial burden on the entire health system. A centralised inter-agency dataset is required to fully understand the level of harm that alcohol is causing within our communities and allow us to evaluate the impact of changes in policy over time. The implementation of evidence-based alcohol policies, both local and national, is urgently required to improve the health of our communities.

COMPETING INTERESTS
None to declare.

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The impact of intensive blood pressure management in the post-thrombolysis setting: a real-world observational study

Bethan Harper, Syrah M Ranta, Harry K McNaughton, Anna Ranta

ABSTRACT

AIM: Systolic blood pressure (SBP) >180mmHg following stroke thrombolysis has been associated with increased bleeding and poorer outcome. Aiming for the guideline SBP of <180mmHg often leads to SBP overshoot, as treatment is only triggered if this threshold is passed. We tested whether a lower target would result in fewer high SBP protocol violations.

METHOD: This is a single-centre, sequential comparison of two blood pressure protocols. Between 2013 and 2017, the guideline-based post-thrombolysis SBP target of <180mmHg was compared with a new protocol aiming for 140–160mmHg. The primary outcome was rate of patients with SBPs >180mmHg. Secondary outcomes included rates of SBP <120mmHg, antihypertensive infusion use, symptomatic intracerebral haemorrhage (sICH) and 3-month functional independence (modified Rankin Score [mRS] 0–2). Results were adjusted for age, baseline function and stroke severity using regression analysis.

RESULTS: During the 23 months preceding and 18 months following the transition to the new protocol, 68 and 100 patients were thrombolysed respectively. Baseline characteristics were similar between groups. The odds of one or more SBPs >180mmHg trended lower in the intensive group (adjusted odds ratio [aOR] 0.61; 95% confidence interval [CI] 0.32–1.17; p=0.14). There was a higher rate of SBPs <120mmHg (aOR 3.09; 95% CI 1.49–6.40; p=0.002) in the intensive BP protocol group. sICH rate and 3-month mRS 0–2 were similar between groups.

CONCLUSIONS: The more intensive post-thrombolysis BP protocol was associated with a significant increase in sub-optimally low BP events, with a non-significant trend toward fewer high BP protocol violations and unaffected patient outcomes.

Stroke remains one of the major causes of mortality and morbidity worldwide.[1] Treatment with thrombolysis for acute ischaemic stroke (AIS) has improved outcomes but carries an increased risk of symptomatic intracerebral haemorrhage (sICH).[2] Up to 60% of patients presenting with AIS have hypertension.[3] This may be attributable to a compensatory mechanism to increase cerebral perfusion pressure, pre-existing hypertension, pain, stress and inflammatory state.[4] Systolic blood pressure (SBP) at presentation is an important prognostic factor, with both lower and higher values associated with worse outcome (U-shaped curve).[5,6]

The optimal target for blood pressure (BP) within the first 24 hours remains uncertain and is likely impacted by stroke type, cause of hypertension, type of reperfusion therapy received—if any—degree of recanalisation, type and timing of the drug, BP variability and speed of BP lowering.[2] Some guidance is available specifically for the post-thrombolysis setting. The current American Heart Association/American Stroke Association and European Stroke Organisation guidelines recommend maintaining BP below 180/105mmHg during the first 24 hours post-thrombolysis.[7,8] The ENCHANTED trial tested an intensive post-thrombolysis SBP target of 130–140mmHg compared with the guideline target. There was no improvement in independence at 90 days but there was a significant reduction in any intracranial haemorrhage.[9] In the Safe Implementation of Treatment in Stroke-International Stroke Thrombolysis Registry (SITS-ISTR) patients with SBP between 141–150mmHg had a four times lower risk of sICH than patients with SBP over 170mmHg.[7] Several observational studies have found that higher post-thrombolysis SBP and BP protocol violations have been associated with an increased risk of sICH and a lower rate of favourable outcomes.[10–12] Taken together, these data suggest that post-thrombolysis SBPs >180mmHg are sub-optimal for risk of sICH and possibly functional outcomes.

A review of our thrombolysis service found that post-thrombolysis SBPs of >180mmHg were not infrequent and that use of intravenous (IV) labetalol boluses as first-line management was associated with delays in achieving SBP control. If SBP of 180mmHg is the trigger for treatment, then avoiding protocol violations of SBP >180mmHg is impossible as the protocol has to be violated in order for treatment to be initiated. We hypothesised that setting a slightly lower treatment trigger and treatment range would more consistently achieve SBP maintenance within guideline parameters without risking high rates of hypotension, and that use of protocolised continuous anti-hypertensive infusion may offer faster SBP target attainment and lower SBP variability.

The primary aim of this study was to assess whether a more intensive SBP management strategy in the first 24 hours post-thrombolysis using an "ideal range" of 140–160mmHg, and a low threshold for initiation of IV antihypertensive infusion, would reduce the frequency of SBP >180mmHg recordings.

Methods

This is a single-centre, open-label, unblinded observational cohort study using a sequential comparison design to compare the rate of SBP >180mmHg protocol violations with guideline-based post-thrombolysis BP management to a more intensive strategy with an "ideal range" of SBP 140–160mmHg and a low threshold for IV antihypertensive infusion.

At Wellington Regional Hospital, the stroke service changed the protocol for management of hypertension after thrombolysis in mid-2014. The earlier protocol aimed for target SBP of <185mmHg pre- and <180mmHg post-thrombolysis for the first 24 hours after treatment. The new protocol aimed for a target SBP of <185mmHg pre-thrombolysis and 140–160mmHg post-thrombolysis for the first 24 hours. Bolus IV labetalol 10mg was to be used for SBPs above >185mmHg pre-thrombolysis. IV anti-hypertensive infusions were to be initiated if BP remained >160mmHg despite three or more IV labetalol boluses in both the pre- and post-thrombolysis period. The type of IV infusion was at the discretion of the treating physician, with IV glyceryl trinitrate (GTN), labetalol and hydralazine available. The protocol recommended GTN as the first-line drug and specified increments and decrements in the infusion rate depending on the SBP, with frequent measurement and readjustment until the SBP was within range.

We identified patients from our prospectively collected thrombolysis database with supplementary retrospective chart review to collect additional baseline characteristics, BP recordings and patient outcome data. Our patient group included all adult patients treated with IV thrombolysis for ischaemic stroke from January 2013 to January 2017. All patients had a clinical diagnosis of AIS and all received thrombolysis with IV alteplase within 4.5 hours of symptom onset. Computed tomography (CT) perfusion imaging was not in common usage during this period and a consistent thrombectomy service had not yet been implemented. There were no other service or protocol changes relevant to the post-thrombolysis management of patients at Wellington Regional Hospital during the study period.

The primary outcome was number of patients experiencing one or more SBP of >180mmHg during the first 24 hours following thrombolysis. Secondary outcomes included the proportion of patients experiencing SBPs <160mmHg, <140mmHg, <120mmHg or >200mmHg during first 24 hours, number of SBPs >180mmHg per patient, median SBP over 24 hours, >50% SBP drop between highest and lowest SBP recorded (to indicate variability), proportion receiving IV antihypertensives, sICH rate and 3-month favourable modified Rankin Score (mRS) defined as 0–2 and also as mRS 0–1. sICH was defined as a National Institutes of Health Stroke Scale (NIHSS) deterioration of >4 points or death attributable to an ICH on post-thrombolysis 24-hour CT imaging. All 24-hour CT images reporting any degree of bleeding were adjudicated by a blinded assessor (AR).

Sample size was estimated using a 60% rate of SBP >180mmHg for the standard protocol based on internal audit data and an estimated reduction of such events to 40% with the intensive protocol. With a 95% confidence level (CI) and 80% study power, this required a minimum sample size of 95 patients per group.

Statistical analysis was performed using StataIC 17.0. Dichotomous and continuous variables were compared using Chi-squared test and either *t*-test for normal and Wilcoxon Rank-Sum Test for non-normally distributed continuous variables. Logistic regression incorporated common confounders and any differences in baseline characteristics of >0.1 using a backward elimination technique to optimise model fit. Variables retained in the

final model included age, baseline NIHSS and pre-morbid mRS.

This study received Wellington Regional Hospital institutional ethics approval under the category of "service audit". The need for informed consent was waived by the Wellington Hospital Ethics Committee. This study received no external funding.

Results

During the 23 months preceding and 18 months following the transition to the new protocol, 68 and 100 patients, respectively, with AIS received IV thrombolysis. Baseline characteristics were similar between groups (shown in Table 1).

Overall, the mean (95% CI) SBP over the first 24 hours was 140.8 (137.8–143.9) in the intensive group and 147.1 (142.4–151.7) in the guideline group (mean difference [95% CI] 6.3 [0.97–11.6, p=0.02]). Fewer patients in the intensive group had one or more SBPs >180mmHg (intensive 46 [46%] vs guideline 40 [59%]), but this was not statistically significant (adjusted odds ratio [aOR] 0.61; 95% CI 0.32–1.17; p=0.14). There was a statistically significant increase in the rate of hypotension (SBP <120mmHg) recorded for the intensive management group (aOR 3.09; 95% CI 1.49–6.40; p=0.002). There was no difference in the number of patients with one or more SBP of

Table 1: Patient baseline characteristics by study group.

Patient characteristic	Guideline N=68	Intensive N=100	P-value
Age, mean (SD)	72.8 (12.3)	71.7 (15.6)	0.65
Ethnicity, n (%)			0.43
European	50 (73.5)	83 (83)	
Māori	5 (7.4)	5 (5)	
Indian	5 (7.4)	0	
Chinese	1 (1.5)	1 (1)	
Pacific	4 (5.8)	7 (7)	
Other	1 (1.5)	0	
Unknown	2 (2.9)	0	
Female sex, n (%)	25 (37)	36 (36)	0.92
Hypertension, n (%)	40 (58.8)	49 (49)	0.21
Diabetes, n (%)	14 (20.6)	13 (13)	0.19
Atrial fibrillation, n (%)	18 (26.5)	24 (24)	0.72
Anticoagulation, n (%)	5 (7.4)	7 (7)	0.93
SBP pre-thrombolysis, median (range)	159 (109–212)	156 (102–241)	0.79
mRS prior to admission, median (range)	0 (0–4)	0 (0–5)	0.22
NIHSS at presentation, median (range)	9 (2–30)	9 (0–30)	0.96

Standard deviation = SD; systolic blood pressure = SBP; modified Rankin Score = mRS; National Institutes of Health Stroke Scale = NIHSS.

Table 2: Blood pressures and patient outcomes by study group.

	Intensive N=100	Guideline N=68	Odds ratio (95% confidence interval)	Adjusted odds ratio[§] (95% confidence interval)	P-value
SBP >200, n (%)	23 (23)	16 (24)	0.97 (0.47–2.01)	0.97 (0.46–2.01)	0.96
SBP >180[†], n (%)	**46 (46)**	**40 (59)**	**0.60 (0.32–1.11)**	**0.61 (0.32–1.17)**	**0.14**
SPB >160, n (%)	73 (73)	51 (75)	0.90 (0.45–1.82)	0.94 (0.44–2.01)	0.87
SBP <140, n (%)	98 (98)	64 (94)	3.01 (0.55–17.2)	2.7 (0.47–15.8)	0.27
SBP <120, n (%)	81 (81)	40 (59)	2.99 (1.49–5.98)	3.09 (1.49–6.40)	0.002
SBP <100, n (%)	22 (22)	10 (15)	1.64 (0.72–3.72)	1.69 (0.73–3.90)	0.22
>50% drop in SBP, n (%)	89 (89)	65 (96)	3.06 (0.55–17.2)	2.97 (0.78–11.3)	0.11
Patients given infusion, n (%)	46 (46)	21 (31)	1.91 (0.10–3.64)	2.04 (1.05–3.99)	0.04
sICH at 24 hours, n (%)	4 (4.0)	3 (4.4)	0.9 (0.20–4.17)	1.26 (0.26–6.27)	0.76
mRS 0–2 at 3-months, n (%)	55 (55)	38 (56)	1.00 (0.54–1.87)	1.27 (0.58–2.80)	0.56
mRS 0–1 at 3-months, n (%)	37 (37)	28 (41)	0.84 (0.45–1.58)	0.69 (0.32–1.52)	0.36

Systolic blood pressure = SBP; symptomatic intracerebral haemorrhage = sICH; modified Rankin Score = mRS.
†Primary study outcome.
§Model adjusted for age, premorbid mRS and National Institutes of Health Stroke Scale at presentation.
Wilcoxon Rank-Sum test p=0.93—see Figure 1 for mRS distribution.

Figure 1: Three-month modified Rankin Score Grotta chart (median [interquartile range] intensive: 2 (1–4), guideline: 2 (0–4); Wilcoxon Rank-Sum: p=0.93).

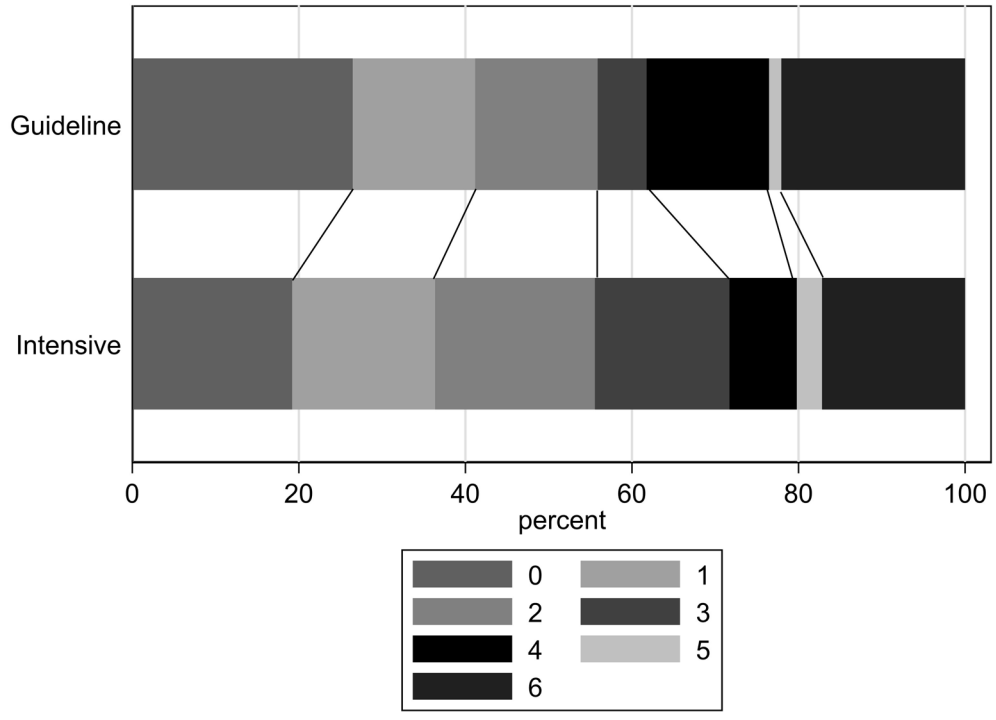

Table 3: Additional exploratory analyses.

	sICH		mRs 0–2 at 3 months	
Across entire cohort*	aOR (95% CI)	P-value	aOR (95% CI)	P-value
Number of >180mmHg events	1.25 (1.01–1.5)	0.01	0.85 (0.73–0.99)	0.04
Number of >185mmHg events	1.30 (1.01–1.59)	0.009	0.72 (0.56–0.93)	0.01
>50% drop in SBP (variability)	5.46 (0.82–36.4)	0.08	0.69 (0.18–2.7)	0.59
SBP at presentation	0.98 (0.95–1.02)	0.37	1.02 (0.99–1.04)	0.07
Added to study group model (aOR for intensive vs guideline group)**				
Number of >180mmHg events	3.4 (0.43–26.7)	0.25	0.83 (0.34–2.01)	0.68
Number of >185mmHg events	3.6 (0.43–29.8)	0.24	0.80 (0.33–1.97)	0.63
>50% drop in SBP (variability)	1.07 (0.21–5.5)	0.94	1.07 (0.45–2.56)	0.88
SBP at presentation	0.91 (0.16–5.01)	0.92	0.89 (0.37–2.15)	0.79

Symptomatic intracerebral haemorrhage = sICH; modified Rankin Score = mRS; adjusted odds ratio = aOR; confidence interval = CI; systolic blood pressure = SBP.
All models include age, pre-morbid mRS and National Institutes of Health Stroke Scale at presentation; *here, model also includes the variable listed for which the aOR is reported while study group was removed; **here, study group is included as well as the variable listed in far left column, and the aOR is reported for the intensive group compared with the guideline group.

>200, >160, <140 or <100 mmHg recorded, or with a ≥50% difference between highest and lowest recorded SBP between groups (shown in Table 2).

Favourable outcomes (mRS 0–2) at 3 months and sICH were similar between groups with and without adjustment for potential confounders (Figure 1). More patients received an IV infusion of either GTN or labetalol in the intensive BP protocol group (intensive group 46 [46%] vs guideline 21 [31%]; aOR 2.04 [1.05–3.99]; p=0.04). See Table 2 for additional detail.

We conducted additional exploratory analyses of number of SBPs >180mmHg per patient, BP variability and SBP at presentation. The mean number (standard deviation [SD]) of SBPs >180mmHg per patient was significantly lower in the intensive group (1.5 [0.22] compared with 2.8 [0.49] in the guideline group; p=0.009). A similar pattern was observed for BPs >185mmHg: there were 0.84 (1.6) events per patient in the intensive and 1.8 (3.2) in the guideline group, p=0.002. For the study group as a whole, the number of high BP events was significantly correlated with poorer functional outcome (aOR=0.85 [0.73–0.99]; p=0.038) and a higher rate of sICH (aOR 1.25 [1.06–1.48]; p=0.01) adjusting for age, pre-morbid mRS and NIHSS at presentation. SBP at presentation and BP variability were not associated with outcome or sICH (Table 3).

Discussion

Patients in the intensive group had a higher rate of IV antihypertensive use, lower mean SBP over the first 24 hours, non-significantly fewer SBP >180mmHg events and significantly more SBP <120mmHg events. There was no difference in sICH rate or 3-month clinical outcome.

The lack of improved clinical outcomes is in keeping with the ENCHANTED trial,[9] a phase 3 randomised control trial of intensive BP lowering in the post-thrombolysis setting, which pursued a more aggressive target (130–140mmHg) than our protocol (140–160 mmHg), although resultant SBP levels were similar: the ENCHANTED mean SBP in the intervention group was 138.8mmHg vs control 144.1mmHg at 1 hour and 144.3mmHg vs 149.8mmHg respectively at 24 hours, compared with our mean 140.8mmHg in the intensive group vs 147.1mmHg in the guideline group over the 24

hour period. Similar to our results, ENCHANTED failed to demonstrate an improvement in either 3-month mRS or sICH rate, although they did find a reduction in any ICH.

Our study was intended to be powered to detect a difference of 20% in high BP events between the groups. Our control sample fell short of the recruitment target and as a result we would have required a reduction of 23.5% to achieve statistical significance. In the event, we observed a reduction of 15%, arguably still clinically relevant but requiring a larger study to demonstrate statistical significance. The higher frequency of very low SBPs cannot be ignored. One reason for this may have been too much attention to SBP at the higher end of the scale so that nurses were less attentive when the SBP was in the "ideal range" but falling, and delayed reduction and/or stopping of the antihypertensive infusion. The protocol for changing the infusion rate may have erred on the side of too aggressive, lowering down to a too-low floor level (i.e., SBP=140mmHg). If so, these issues could be remedied by training and a slightly higher floor to the "ideal range"—e.g., SBP=150mmHg. We acknowledge, along with others, that BP management post-thrombolysis needs to be individualised, taking into account stroke type, presence of large vessel occlusion, success of recanalisation and other factors.[2] For example, it is likely that sICH risk is highest in recanalised larger strokes (implying tighter SBP control is required), while infarct growth due to hypoperfusion is of greatest concern in large vessel occlusion patients who did not recanalise where somewhat higher SBP targets are likely to be appropriate.

The choice of antihypertensives and rapidity of BP lowering may be relevant to successful outcomes. We note that the INTERACT4 trial is testing very early ambulance-based BP lowering in AIS or ICH and is using the antihypertensive agent urapidil—an α_1-adrenoceptor antagonist and a 5-HT1A receptor agonist—which may have advantages over labetalol and GTN.[13]

This study had several limitations. The relatively small sample size may have introduced type 2 error, and was under-powered for the difference in SBP detected between the groups. The observational sequential design carries the usual risks of potential confounding. The single-centre nature may limit generalisability. Finally, patients with less well-controlled BP and on IV infusions had more BPs recorded than those with primarily normal-range BPs, which may have led to potential reporting bias, especially as regards BP extremes. Strengths of the study were the prospective acquisition of data, "real-world" comprehensive coverage and completeness of follow-up.

A more aggressive approach to early BP lowering requires higher use of IV antihypertensive medication—in ENCHANTED, 63% of intensive patients vs 35% of control patients received IV medication, while in our study 46% of intensive vs 31% of guideline patients received IV medication. This has implications for nursing resource, cost of medications and equipment and the potential for IV site-related complications.

At this stage, the absence of clear benefit in our study (and ENCHANTED) and evidence of potential for harm argue against a more aggressive approach. We are trialling a new protocol with an "ideal range" of SBP 150–170mmHg, combined with training to prevent low SBP events and a more tailored approach to patients post-thrombectomy based on the presence or absence of successful recanalisation.

COMPETING INTERESTS

BH, HM and AR disclose employment at Wellington Regional Hospital during the period this study was conducted. AR also discloses employment at the University of Otago Wellington and contract work for the New Zealand Ministry of Health – Manatū Hauora, and HM discloses employment at the Medical Research Institute of New Zealand. AR is an executive committee member of the Australian and New Zealand Stroke Organisation, a board member of the New Zealand World Stroke and Asia Pacific Stroke organisations and the medical director of the New Zealand Stroke Foundation. SM has no disclosures.

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Long-term health conditions among household families in Aotearoa New Zealand: cross-sectional analysis of integrated Census and administrative data

Lisa Underwood, Andrea Teng, Nicholas Bowden, Ofa Dewes, Lukas Marek, Barry Milne

ABSTRACT

AIM: Little is known about the extent to which families in Aotearoa New Zealand are affected by long-term health conditions (HCs). This study aimed to explore the rates of nine selected HCs among New Zealand family members within the same household.

METHOD: Linked population and administrative health data were obtained for families living in the same household according to the 2013 New Zealand Census (N=1,043,172). Health data (2008–2013) were used to ascertain whether people in these families (N=3,137,517) received treatment or services for nine selected HCs: cancer, chronic obstructive pulmonary disease, heart disease, diabetes, dementia, gout, stroke, traumatic brain injury (TBI), or mental health/behaviour conditions (MHBCs).

RESULTS: Over 60% of families included at least one person with a HC, and this rate was higher among multi-generation families (73.9%). The most common HCs were MHBCs (39.4% of families), diabetes (16.0%) and TBI (13.9%). At the highest level of socio-economic deprivation, 57.6% of children aged under 18 years lived with a family member who had a HC.

CONCLUSION: Three in five New Zealand household families included someone with at least one of nine selected HCs, with differences in the proportion affected according to family composition, socio-economic status and an individual's ethnicity. This suggests that there are a substantial number of people at risk of the poor outcomes associated with the experience of HCs within their family.

Non-communicable, long-term physical and mental health conditions (HCs) are increasing in prevalence globally, and are associated with high levels of impairment and multimorbidity.[1] In Aotearoa New Zealand, there are well-established inequities in the burden of HCs such as diabetes and mental health conditions, particularly with regards to health services access for Māori, Pacific peoples and those in difficult socio-economic circumstances.[2,3] Recent national studies have reported wide-spread impacts of HCs on individuals and costs to society.[4–10] The disabling impacts of HCs can be compounded by inequitable health systems and societal processes/responses; thus, it is important to understand the social environments in which HCs are experienced and how these might disadvantage or benefit outcomes.[11]

Living with a family member who has a HC is likely to affect individuals across the life-course.[12] In addition to indirect costs, such as loss of productivity due to caregiving,[13] there can be "intangible" costs to family quality of life, health and wellbeing.[14–16] A recent appraisal of 86 studies found considerable impacts of a relative's chronic HC on family members' emotional and psychological wellbeing, physical health, social, leisure and daily activities, family relationships and work.[17] The one New Zealand study identified for that review found that family members supporting relatives with traumatic brain injury (TBI) experienced high levels of burden and health needs.[18] Estimates from international surveys indicate that around 26% of families include a child with a health problem and a considerable proportion of children have a parent with a serious physical illness (3–4%), mental health problem (19.5%) or either of these (25–29%).[19–23] A recent study in the United States, using the National Health Interview Survey, reported the proportion of adults who lived with a partner (7.6%), minor child (4.7%) or parent (4.8%) with major health needs.[16]

Aside from the studies described above, population-wide research on the overall amount or proportion of families, and family members, affected by HCs is lacking.[24] This has led to calls

for research with more culturally and socio-economically representative study samples on broader family types with a wider range of covariates, including family characteristics.[22,25] Understanding the number and characteristics of families and family members affected by HCs is vital to inform policy development and research. This descriptive study was designed to explore the socio-demographic characteristics of New Zealand families affected by at least one of nine HCs: cancer, chronic obstructive pulmonary disease (COPD), coronary heart disease (CHD), diabetes, dementia, gout, stroke, TBI or mental health/behaviour conditions (MHBCs). The aim is to provide a starting point to help us understand ways that we might improve the lives and livelihoods of families affected by HCs.

Methods

Design and data sources

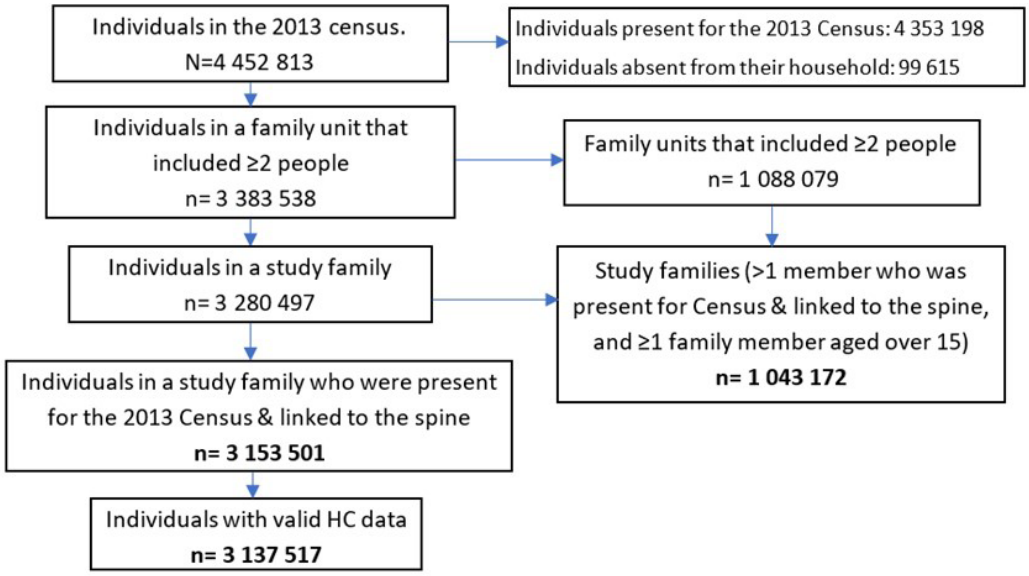
This study involved cross-sectional, descriptive analyses of linked administrative health and population data sourced from the New Zealand Integrated Data Infrastructure (IDI). The IDI is a national database that holds de-identified microdata about people and households from multiple government agencies and the Census.[26] Individuals in different datasets can be linked via the spine using unique probability-matched identifiers (IDs). The spine aims to record everyone who has ever been a resident in New Zealand. People not linked to the spine are those with no tax, visa or birth data, which are used to construct the spine. IDI data were accessed at Statistics New Zealand (Stats NZ) and The University of Auckland Data Labs by the lead author using the September 2021 IDI Refresh.

Population

The initial sample (N=4,452,813) included all individuals recorded by the New Zealand Census on 5 March 2013 (see Figure 1). Census 2013 family and extended family IDs (derived by Stats NZ from household information) for these individuals were used to construct family units, obtain family-level information and link to family members' individual data. People with the same family ID, who were not also a member of an extended family, were grouped into a family unit. People with the same extended family ID were grouped together into one family unit. Thus, a *study family* could include one or multiple family nuclei, with or without other related people.

Within the initial sample, 3,383,538 people had a family or extended family ID, resulting in the construction of 1,043,172 study families for inclusion in the study. All families were made up of two or more people, with least one family member aged 15 or over (in accordance with Stats NZ definitions).[27] Individuals within these families were included if they could be linked to the spine and were present in their household for the 2013 Census, since absentees' data are recorded but they are not assigned an individual ID that allows them to be linked to other datasets.

Figure 1: Study flowchart.



Measures

Socio-demographic characteristics

Individual and family socio-economic status was measured using area-level 2013 New Zealand Index of Deprivation (NZDep) data from Census, population and address datasets.[28] NZDep deciles were grouped into quintiles, with quintile 1 indicating people/families in the least deprived areas. Gender (as self-identified in Census 2013) was male or female, and age on 5 March 2013 was calculated in years. A child was defined as a person who was under 18 years of age. Categorisation of ethnicity (grouped total responses) was: European, Māori, Pacific peoples, Asian, Middle Eastern/Latin American/African (MELAA) and Other.[29] Multi-generation families were identified using the Census 2013 extended family type variable, which indicates whether extended families are one-generation, two-generation or three-or-more generation.

Health conditions

The HCs selected for this study were those that are included in the Manatū Hauora – Ministry of Health chronic condition/significant health events dataset (an IDI summary table): cancer, COPD, CHD (including myocardial infarction), diabetes, gout, stroke and TBI. With the addition of dementia and MHBCs, which were selected based on the availability of evidence-based case identification algorithms and criteria (see Appendix 1). MHBCs included attention-deficit hyperactivity disorder, anxiety disorders, autism spectrum disorder, bipolar disorder, conduct and disruptive disorders, depression, eating disorders, emotional problems, personality disorders, psychotic disorders and sleep disorders.

The following IDI datasets were searched for people who had received treatment or services for the HCs listed above: Accident Compensation Corporation (ACC) injury claims; disability needs assessment and service coordination (SOCRATES); the Cancer Registry; laboratory claims, outpatient and emergency visits (National Non-Admitted Patient Collection); pharmaceutical dispensing; public and private hospital discharges; mental health service contacts (Programme for the Integration of Mental Health Data); and the chronic condition/significant health events table. Searches were limited to records dating from 5 March 2008 up to and including 5 March 2013 (i.e., 5 years prior to identification of individuals within families). People who only had records of COPD or gout when they were under the age of 20, or dementia under the age of 40, were excluded from these analyses (n=15,984), since there appeared to be some error in either linkage or data entry for at least one of their health records and thus it could not be determined that they did or did not have a HC (see Figure 1).

Analysis

Analyses were carried out in IDI Data Labs using SAS Enterprise Guide (version 8.3). Confidentiality rules required suppression of small numbers (<6) and random rounding of all counts to base 3, therefore some totals may not precisely add up. It was assumed that individuals with no records detected in health datasets did not have a HC, since they did not have treatment or service interactions for any of the HCs in any of the datasets searched.

Descriptive analyses were carried out at individual and family levels. Individual-level analyses included stratification by gender, age, ethnicity and NZDep quintile. Individuals were included in multiple ethnicity categories, where relevant. Individuals were divided into four groups: 1) no HC themselves or in a family member, 2) people who had a HC themselves but no other family members with a HC (HC person only), 3) no HC themselves but at least one family member with a HC (HC family only), or 4) people who had a HC and at least one family member with a HC (HC person and family). Families were stratified by composition and NZDep but not by individual-level characteristics (e.g., gender and ethnicity).

Results

Socio-demographic characteristics of the 3,137,517 individuals in families are reported in Table 1. Family composition and NZDep for the 1,043,172 study families are reported in Table 2.

Individuals living within a household family

In total, 899,949 people (28.7%) were identified as having at least one of the nine specified HCs (see Table 2; G2+G4) and an additional 1,020,987 people (32.5%) lived in a household family where other member(s) experienced a HC (G3). Thus overall, 61.2% of people (n=1,920,933) were experiencing at least one HC, either themselves or through a household family member (G2+G3+G4).

Table 2 shows a similar distribution across the four HC groups for males and females. Pacific peoples and those over 65 years old were most likely to be in a family affected by HCs, compared with other ethnicities and age groups. The proportion of people living in a family affected by any HC increased as area-level deprivation increased.

The proportion of individuals who were the only family member with a HC (G3) increased with age, was higher for Europeans and lower for Pacific peoples and those in the highest NZDep quintile. Adults and Europeans were more likely to have a HC themselves *and* have another family member with a HC (G4) compared with children and other ethnicities, respectively.

Overall, children had a low rate of HCs themselves (11.0%, n=100,455), but more than half (53.3%; n=495,597) had a family member with a

Table 1: Percentage of individuals affected by HCs according to socio-demographic characteristics.

(% of individuals)	No HC (G1)	HC person only (G2)	HC family only (G3)	HC person and family (G4)
Total (N=3,137,517)	1,216,584 (38.8%)	397,929 (12.7%)	1,020,987 (32.5%)	502,017 (16.0%)
Female (48.6)	39.1	12.9	32.2	15.7
Male (51.4)	38.4	12.4	32.9	16.3
0 to 5 years (10.0)	47.3	3.2	45.2	4.3
6 to 17 years (19.2)	40.3	4.6	46.9	8.2
18 to 34 years (19.5)	45.4	11.7	31.1	11.9
35 to 64 years (40.2)	38.5	16.8	26.4	18.4
65 years and over (11.1)	18.0	22.2	21.1	38.7
Children (29.5)	42.7	4.1	46.3	6.9
Adults (70.5)	37.2	16.2	26.9	19.8
European (72.9)	37.7	13.7	31.5	17.1
Māori (15.4)	37.5	10.7	38.0	13.7
Pacific peoples (8.2)	32.3	8.2	45.2	14.4
Asian (12.4)	50.3	8.9	30.8	10.0
MELAA (1.2)	47.3	9.6	32.1	11.1
Other ethnicity (1.7)	38.9	13.7	30.8	16.5
NZDep Quintile 1* (22.6)	40.8	12.8	31.3	15.0
NZDep Quintile 2 (20.8)	40.6	13.0	31.1	15.4
NZDep Quintile 3 (19.7)	39.7	13.1	31.3	15.9
NZDep Quintile 4 (18.6)	37.5	12.9	32.6	17.0
NZDep Quintile 5 (18.4)	34.6	11.5	36.9	17.0

Health condition = HC; Middle Eastern/Latin American/African = MELAA; 2013 New Zealand Index of Deprivation = NZDep.
*NZDep Quintile 1 = least deprived.

HC, compared with 46.6% of adults (n=1,036,767). At the highest level of deprivation, 57.6% of children (n=119,196) had a family member with a HC (see Figure 2).

The proportion of people exposed to a HC either themselves or through a family member varied according to ethnicity and NZDep (see Figure 3). It was highest among Pacific peoples (67.7%, n=174 393) and those in the highest NZDep quintile (65.4%, n=376 707). Figure 3 shows the interaction between ethnicity and deprivation. Relative disparities between the lowest and highest NZDep quintiles were greatest for Europeans (6.9% difference), and smallest for Māori (2.4%) and Asian peoples (3.3%).

Figure 2: Percentage of adults and children within each NZDep quintile who were living in a family in which at least one person had a HC.

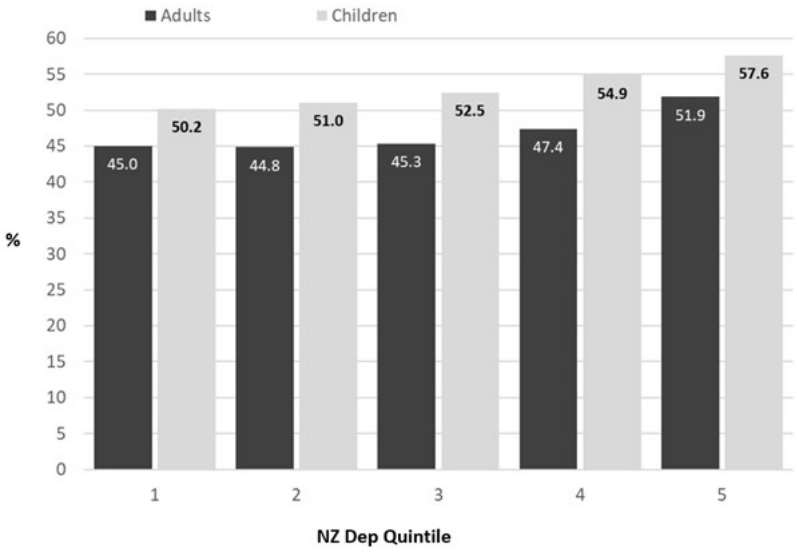
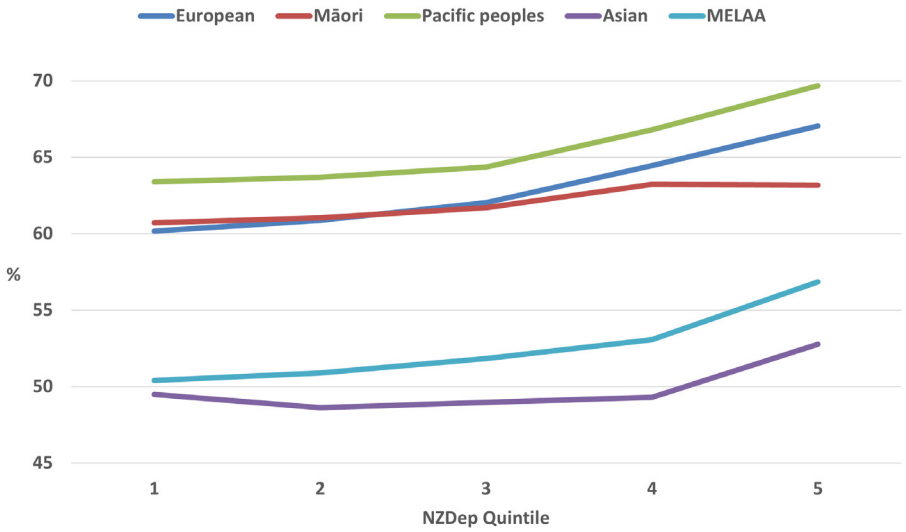


Figure 3: Percentage of people who were living in a family in which at least one person had a HC.



Health condition = HC; Middle Eastern/Latin American/African = MELAA; 2013 New Zealand Index of Deprivation = NZDep.

Table 2: Percentage of families with a HC according to family composition and area-level deprivation (NZDep).

n (% of families)	≥1 person with a HC	≥2 people with a HC	Cancer	COPD	CHD	Dementia	Diabetes	Gout	MHBCs	Stroke	TBI
Total 1,043,172 (100)	60.4	22.3	6.0	7.0	6.1	0.4	16.0	7.6	39.4	1.1	13.9
Families with ≥1 child 512,163 (49.1)	55.8	19.3	2.5	4.0	2.0	0.1	11.8	4.8	36.2	0.5	18.9
Multi-generation families 93,864 (9.0)	73.9	38.4	6.2	10.9	9.0	0.8	32.3	13.8	44.6	2.0	21.3
NZDep Quintile 1* 236,913 (22.7)	59.2	20.9	6.5	5.6	5.2	0.4	12.4	6.3	40.2	0.9	13.3
NZDep Quintile 2 221,469 (21.2)	59.2	21.1	6.2	6.2	5.7	0.4	13.9	6.5	39.6	1.0	13.2
NZDep Quintile 3 210,648 (20.2)	59.9	21.7	6.2	7.0	6.2	0.5	15.2	7.1	39.8	1.1	13.2
NZDep Quintile 4 195,366 (18.7)	61.7	23.3	5.9	8.1	6.8	0.5	17.5	8.1	40.4	1.2	14.1
NZDep Quintile 5 172,236 (16.5)	63.8	25.4	5.2	9.0	6.9	0.4	23.3	11.1	37.6	1.5	16.5

Health condition = HC; chronic obstructive pulmonary disease = COPD; coronary heart disease = CHD; traumatic brain injury = TBI; mental health/behaviour conditions = MHBCs; 2013 New Zealand Index of Deprivation = NZDep. *NZDep Quintile 1 = least deprived.

Household families experiencing health conditions

Table 2 shows the percentage of families that included at least one person with a HC (60.4%, n=629,700), two or more people with a HC (22.3%, n=232,627) and at least one person with a specific HC (0.4–39.4%). There were 397,932 families (38.1%) that included one person with a HC, 19.1% (n=199,185) had two people with a HC and 2.6% (n=27,585) had three or more people. Twenty-one families had more than seven members with a HC. Families with children had a lower rate of HCs (55.8%), while 73.9% of multi-generation families included at least one person with a HC. The proportion of families in which at least one person had a HC was highest for NZDep quintile 5 (63.8%). These patterns were similar for families that had two or more people with a HC (see Table 1).

The most common HCs within families were MHBCs (39.4%), followed by diabetes (16.0%), TBI (13.9%) and gout (7.6%). Families with children had lower rates of specific HCs compared to total population, except for TBI (18.9%). Multi-generation families had higher rates of each specific HC. The proportion of families affected by specific HCs generally increased with higher levels of deprivation, with the exception of cancer, where there was a decrease in the proportion of families affected as deprivation increased, and dementia, which was relatively uniform across groups.

Discussion

The burden and societal impact of HCs may be underestimated if research focusses on individuals rather than the whānau as a whole and does not account for outcomes of family members, especially children. Conversely, without understanding the social environments in which HCs are experienced, positive effects may be overlooked. An understanding of the extent to which HCs are experienced by New Zealand families provides an evidence base that can be built on to identify areas in which families need support, and factors that promote their success.

This nationwide study reported the rates of nine selected HCs among over 1 million New Zealand household families, and the more than 3 million individuals living in those families. In 2013, three in five household families (60.4%) had at least one person with at least one selected HC, and one in five (22.3%) had more than one person with a HC. Two in five families (39.4%) included at least one person with a MHBC; diabetes (16.0%) and TBI (13.9%) were also common in families. Disparities in the proportion of families that experienced HCs were found across family composition and socio-economic status. Families with children had a lower rate of HCs (55.8%), while 73.9% of multi-generation families included at least one person with a HC. The latter is likely because multi-generation families were more likely to include people aged over 65 years.

Similar patterns were found for the individuals living in these families—48.6% of whom were living with a family member with a HC and 61.2% of whom either experienced a HC themselves or through a family member. There were variations across ethnic groups at each level of deprivation. Around half a million New Zealand children were living with a family member who had a HC; almost 25% of these children were living in the highest NZDep quintile (18–19% were living in each of the lower quintiles).

This was the first study to estimate the extent of a selected group of HCs among New Zealand household families and demonstrate the socio-demographic patterns associated with the presence of these HCs. These patterns align with previous New Zealand and global findings of inequity in health outcomes for these conditions, particularly for minority ethnic groups and those living in deprived areas.[2,14] These characteristics are also likely to affect the extent to which having a family member with a HC affects health and wellbeing outcomes for individuals and the family as a whole.[16] Evidence shows that caring for a family member with a HC has significant detrimental effects on wellbeing, particularly with regards to employment, financial stress and mental health.[13,30] People living with a relative who has a HC appear to have a different socio-demographic profile compared with individuals that identify as family carers, who are more likely to be female, older European and Māori.[13]

Strengths

The main strength of the study was the use of population-wide linked data that provided a large, representative sample and high-quality individual- and family-level information.[26] A broad definition of family was used; people in multiple family nuclei that were living together, and other extended family members, were included in a single family unit. As such, there was a lower number of study families (n=1,043,172) compared with the Stats NZ 2013 Census count of 1,136,397 nuclear families,[31] but an increased number of people were linked together within a family unit.

This method better represents the diversity of New Zealand family structures, particularly for Māori and Pacific peoples.[32]

2013 Census data on socio-demographic characteristics, including family composition and individual-level ethnicity, has been rated as high quality.[33] Linking self-reported Census ethnicity data to health datasets improves representation for Māori and Pacific peoples, who are under-counted in health and disability data on ethnicity.[34] Using total response categorisation of ethnicity, rather than external prioritisation, reduces under-counts and age-related bias among non-Māori ethnic groups, particularly for those who identify with more than one ethnicity.[35]

The HC case identification methods used in the study were more extensive than previous New Zealand research.[4,10] For example, including ACC data and a broad range of diagnostic terms led to a high level of identification of TBI cases.[8] That said, many people who experience a TBI do not present to secondary healthcare services or submit an ACC claim.[36] The high number of people with MHBCs was largely attributable to the inclusion of pharmaceutical data. This method has been shown to increase estimated rates of MHBCs, particularly for those with less severe conditions.[4]

Limitations

Family membership was not identifiable for 2.6% of households in the 2013 Census.[33] Therefore, some family members may have been missed from families in this study and some New Zealand families may not have been included. Our inclusion criteria did not include unrelated individuals who live together or sole-person households. In addition, our methods do not account for family members who live in more than one household (e.g., children in co-parenting families), related individuals who live in different households, or related people who live together but are not in a couple or parent–child relationship with another household member (e.g., adult siblings). As such, our findings cannot address potential impacts on individuals who have family members with HCs living in other households. Younger adults, Māori and Pacific peoples were under-counted in the 2013 Census, therefore our results for these groups may be less generalisable.[33]

The majority of the IDI health searches used diagnostic codes to identify HCs (see Appendix 1). However, pharmaceutical, laboratory and outpatient service datasets were searched using medicine, test and health specialty codes, respectively. IDI health searches do not identify people who only present to primary care, unless they are dispensed medication by a community pharmacy or undergo laboratory testing. As such, people with milder conditions may not have been identified by this study. Differing rates of HCs among specific groups may reflect disparities in recognition, access to health services, timeliness of diagnosis and reporting. The scope of the study was limited to nine selected HCs, and the inclusion of other conditions known to impact New Zealand families in future research may result in different findings. These conditions include, but are not limited to, asthma, arthritis, substance use, chronic kidney disease and rheumatic fever.

We used evidence-based case identification methods that have acknowledged strengths and limitations, particularly with regards to the risk of false positive case identification by inferring diagnosis from pharmaceutical data.[5,10] The limitations of relying on administrative data for the case identification of HCs are widely recognised.[5] Linkage across datasets within the IDI (e.g., between Census and health data) is based on probabilistic matching of individuals carried out by Stats NZ; this can result in false negative and false positive links between specific datasets and the IDI spine. False positive rates for Census 2013 and Manatū Hauora – Ministry of Health data for the September 2021 refresh were 0.9% and 0.8%, respectively.[37] Data management for the study mitigated for false positive matches by cross-checking dates of birth and removing individuals who appeared too young to receive a diagnosis for COPD, dementia or gout.

Conclusion

Three in five New Zealand household families included someone with at least one of the nine selected HCs included in this study, with differences in the proportion affected according to family composition, socio-economic status and an individual's ethnicity. As global populations age and multi-generational family living increases, more individuals are likely to experience HCs within their household.[38] Our results indicate that in New Zealand, high levels of family-based support may be needed among Pacific peoples, multi-generation families and those living in areas with a high level of deprivation. Our finding that almost one in four New Zealand families include more than one person with a HC suggests potential gains from culturally appropriate,

family-based preventative interventions that address modifiable risk factors for HCs, family-wide health screening/assessment and interventions for HCs that include the whole family.[39]

These findings have implications for the Mahi Aroha – Carers' Strategy Action Plan that is due to be updated in 2024. The previous plan (2019–2023) acknowledged the need for research on the needs of carers, recognising that this should include family members who do not necessarily identify with the term "carer".[40] Further research is needed on factors associated with the long-term impact of HCs on family members across the life-course, regardless of whether individuals are providing care for relatives with a HC. An understanding of the geographic distribution of New Zealand families affected by HCs, particularly multi-generation families, could further determine levels of need at the regional level.

COMPETING INTERESTS
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Appendix 1: Case identification of selected health conditions (HCs)

HC case identification algorithms were sourced from the data dictionary for the Manatū Hauora – Ministry of Health chronic condition/significant health events dataset (CC),[1] the Virtual Diabetes Register (VDR) Technical Guide,[2] the Social Investment Agency mental health and addiction conditions data definition (SIA),[3] Bowden et al. (MHBC),[4] ACC (TBI)[5] and Walesby et al. (dementia).[6] The IDI health datasets searched were: Accident Compensation Corporation (ACC) injury claims; disability needs assessment and service coordination (SOCRATES); the Cancer Registry; laboratory claims, National Non-Admitted Patient Collection (NNPAC); pharmaceutical dispensing; public and private hospital discharges (NMDS); Programme for the Integration of Mental Health Data (PRIMHD); and chronic condition/significant health events (CC).

Appendix Table 1 shows the search criteria and datasets used for each HC, and Appendix Table 2 shows a summary of the definitions for each HC.

Appendix Table 1: Search algorithm sources and IDI datasets used for HC case identification.

HC	Cancer	COPD	CHD	Dementia	Diabetes	Gout	Stroke	TBI	MHBCs
Algorithm source	CC	CC	CC	Walesby	VDR	CC	CC	ACC	SIA & Bowden
ACC claims (diagnosis codes*)	X	X	X	X	X	X	X	X	X
Cancer register (all entries)	X	-	-	-	-	-	-	-	-
Chronic conditions table (all)	X	X	X	-	X	X	X	X	-
interRAI (diagnosis codes)	X	X	X	X	X	-	X	-	X
NNPAC (health specialty and purchase unit codes)	-	-	-	-	X	-	-	-	X
NMDS (private and public) (diagnosis* and procedure codes)	X	X	X	X	X	X	X	X	X
PRIMHD (diagnosis codes*)	X	X	X	X	X	X	X	X	X
SOCRATES (diagnosis codes)	X	X	X	X	X	X	X	X	X
Pharmaceutical dispensing (medication codes)	-	X	X	X	X	X	-	-	X
Laboratory tests (test codes)	-	-	-	-	X	-	-	-	-

**International Classification of Diseases 10th Revision (ICD-10) codes were used for these datasets.*
Chronic obstructive pulmonary disease = COPD; coronary heart disease = CHD; mental health and behavioural conditions = MHBCs; traumatic brain injury = TBI.

Appendix Table 2: Summary of definitions for each HC.

HC	ICD codes	Other codes
Cancer	C00–C96, D45–47	SOCRATES: 2901 (Cancer). interRAI: Cancer.
COPD	J40–J44	SOCRATES: 2501 (COPD). interRAI: Pulmonary disease. Medication: Ipratropium Bromide, Salbutamol with Ipratropium Bromide, Tiotropium Bromide, or, only if no previous diagnosis of asthma: Aminophylline, Theophylline.
CHD (and AMI)	I20–25	SOCRATES: 2404 (AMI); 2405 (CHD). interRAI: Heart disease. NMDS procedures codes: 3530400, 3530500, 3531000–2, 3849700–7, 3850000–4, 3850300–4, 3863700, 9020100–3. Medication: Two or more dispensings within 12 months: Glyceryl trinitrate, Isosorbide dinitrate, Isosorbide mononitrate, Nicorandil, or Perhexiline maleate.
Dementia	F00–F04, F051, F107, F137, F187, F197, G3	SOCRATES: 1401 (Alzheimer's); 1405 (Vascular dementia); 1499 (Other dementia). interRAI: Alzheimer's or dementia. Medication: Donepezil or Rivastigmine
Diabetes	E10–11, E13–14 0240–0243	SOCRATES: 2801 (Diabetes). interRAI: Diabetes mellitus. NNPAC purchase unit codes: M96, M98, M20006, M2007. Medication: Insulin or oral hypoglycaemic agent (2 or more dispensings in 24m); Laboratory tests: 4 or more Glycated haemoglobin tests in 24 months (BG=2) AND 2 or more ACR, microalbumin or early morning urine tests (BP=8).
Gout	M10	SOCRATES: 2004 (Gout). Medication: Colchicine or Allopurinol (without malignant neoplasm C81–C96)
Stroke	I60–I64	SOCRATES: 2401 (Stroke). interRAI: Stroke/CVA
TBI	See Horspool et al. (2017)[5]	SOCRATES: 1802 (Brain injury)
MHBCs	See Bowden et al. (2020)[4]	SOCRATES: 1201 (ADHD); 1206, 1207, 1211 (ASD); 9006 (Social Communication Disorder); 130 (Psychiatric disorders [excluding 1301 Alcohol/drug related disorders]) interRAI: anxiety, bipolar disorder, depression, schizophrenia. NNPAC (service provision codes): Y00–Y18, Y30–Y39, Y50–Y58, Y71–Y77. Two or more dispensings within 12 months of any mental health medication, see Bowden et al. (2020) for codes.[4]

Attention-deficit hyperactivity disorder = ADHD; autism spectrum disorder = ASD; chronic obstructive pulmonary disease = COPD; coronary heart disease = CHD; acute myocardial infarction = AMI; mental health and behavioural conditions = MHBCs; traumatic brain injury = TBI.

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Exploring melanoma shifts: a two-decade analysis in New Zealand

Daniel Wen, Jack S Pullman, Avinash Sharma, Bert van der Werf, Richard C W Martin

ABSTRACT

AIMS: New Zealand melanoma incidence rates are amongst the highest in the world. The study aims to provide information on the incidence of cutaneous melanoma in New Zealand from 2000 to 2022.

METHODS: De-identified data were extracted from the New Zealand Cancer Registry using the ICD-10 code for malignant melanoma (C34) and melanoma *in situ* (MIS) (D03) from 2000 to 2022. Statistical analysis was performed to calculate melanoma incidence rates.

RESULTS: Invasive melanoma (IM) incidence rates demonstrated an increasing trend from 2000 to 2008 (+1.10 per 100,000 person-years per year), followed by an inflection point at 2008 and then a decreasing trend from 2008 to 2022 (-0.28 per 100,000 person-years per year), which was not statistically different from zero/no change. MIS incidence increased from 30.3 to 72.1 per 100,000 person-years between 2000 and 2022.

CONCLUSIONS: The incidence of IM in New Zealand has plateaued in the last decade and was associated with an increase in MIS incidence over the same period. While this trend is encouraging, further research is required to investigate whether there is an actual decline in IM incidence.

World-wide cutaneous melanoma incidence has been increasing over time, with 324,635 new cases diagnosed in 2020.[1] New Zealand melanoma incidence rates are among the highest in the world and, in New Zealand, melanoma is the third most common cancer among both females and males. It ranks only behind breast and colorectal cancers in females, and prostate and colorectal cancers in males.[2]

The historical increase in invasive melanoma (IM) incidence rates has recently been slowing, and was expected to peak—and even reduce—by 2016.[3] This effect has been attributed to the maturity of mass prevention campaigns and the corresponding change in behaviour towards skin protection.[4]

Increase in melanoma thickness at presentation is associated with poorer prognosis.[5] Previous New Zealand data have shown an increase over time in the thickness of melanoma at presentation.[6,7] This differs from studies in the United States that show a decrease in Breslow thickness over time, possibly reflecting earlier detection.[8]

While the management of melanoma is an ever-evolving field, understanding of the latest trends in incidence are important to guide national and regional decision making. We examined melanoma incidence in previous studies covering the 1995–1999 and 2000–2004 periods.[6,7]

The study aims to provide the most recent information on the incidence of cutaneous melanoma in New Zealand by analysing data from the New Zealand Cancer Registry (NZCR) from 2000 to 2022.

Methods

Data collection

De-identified data were obtained from the NZCR by way of a systematic computerised search of the ICD-10 code for malignant melanoma (C34) from 2000 to 2022. Statutory notification of cancer in New Zealand has been present since 1994. The information obtained included: gender, age at diagnosis, year of diagnosis, district health board (DHB) of domicile and Breslow thickness. Ethnicity and mortality data were not recorded for this study and the authors intend to perform a separate analysis based on these parameters in a future analysis. Melanoma T-Stage was calculated using the American Joint Committee on Cancer (AJCC) 8th Edition staging system.[9] A second computerised search of the ICD-10 code for melanoma *in situ* (MIS) (D03) was performed to give overall incidence comparison data.

Inclusion criteria were all melanoma registrations from 2000 to 2022 according to ICD-10 code. Only one registration per person was included to avoid cases of metastatic melanoma. The New Zealand Census is performed every 5 years and has accounted for 97.4–98.0% of the population across

the three most recent censuses. New Zealand census data was retrieved from Stats NZ and population data from the 2006, 2013 and 2018 censuses was used in the statistical analysis.[10–12]

Statistical methods

All calculations were done using the statistical package R, version 4.1.1.[13] Age-standardised incidence rates for IM and MIS were calculated with standardisation to the US2000 standard population and confidence intervals [CI] were calculated with the Tiwari method using the R package dsrTest.[14] The overall trends for IM and MIS incidence were analysed using Joinpoint trend analysis software version 5.01.[15] The population data used for these calculations include the 2006, 2013 and 2018 census data with use of linear interpolation for the years between censuses.

A mixed-effect logistic regression model was used to: estimate the absolute IM and T-stage incidence rate for every 5-year age band; investigate the association between IM and MIS incidence; and examine the interactions of other variables such as domicile DHB. The best-fitted model between alternative models was identified using the minimum Akaike information criterion (AIC) value and the significance of variables was analysed using the Type II Wald Chi-squared test.[16] For all analyses, the assumptions of homogeneity of variances and normality of residuals were checked using the R package DHARMa.[17]

The median Breslow thickness per year was estimated by back transformation of data fitted on the logarithmic scale with a linear mixed-effect model. The logarithmically transformed values of the Breslow thickness were used to meet the analysis's assumptions: homogeneity of variances and normality of residuals. The same analysis was performed for Breslow thickness for each 5-year age band.

Results

There were 52,933 registered cases of IM between 2000 and 2022. All cases were included for analysis; however, 3,909 cases did not include a Breslow depth and therefore were excluded from Breslow thickness analyses but otherwise were included in all other analyses. Of these IM patients, 28,351 (53.6%) were male. The median age at diagnosis for females was 63.0 years (range 1–104 years), and 67.0 years (range 10–103 years) for males. Over the same period, 58,948 cases of MIS were registered.

Age-standardised incidence rate for IM and MIS

IM incidence rates demonstrated an increasing trend from 2000 to 2008 (+1.10 per 100,000 person-years per year), followed by an inflection point at 2008 and then a decreasing trend from 2008 to 2022 (-0.28 per 100,000 person-years per year), which was not statistically different from zero/no change. Over the study period there was a statistically significant increase in MIS incidence rates. MIS incidence increased from 30.3 per 100,000 person-years (95% CI 28.6–32.2 per 100,00 person-years) in 2000 to 72.1 per 100,000 person-years (95% CI 70.0–74.3 per 100,00 person-years) in 2022. Further details are available in Figure 1 and 2.

Gender

There was a significant difference in incidence rates between males and females (Figure 3). Trends show a similar incidence below the age of 60, with females having a slightly higher incidence between ages 25–50. After the age of 60, males had a significantly higher incidence than females ($p<0.01$).

Breslow thickness

The statistical model suggested that median Breslow thickness was reducing over the last 8–10 years of the study period (Figure 4). Across the entire study period, the median Breslow thickness was greater for males (0.80mm) than females (0.70mm).

T-stage

With increasing age, there was a greater incidence across all T-stage melanomas; however, beyond the age of 80 there appears to be a plateau in T1 and T2 incidence and an increasing proportion of higher T-stage melanomas (T3 and T4) with a greater increase in incidence for the higher stages (Figure 5). Age was a significant variable ($p<0.001$) for all T-stages except for T1 melanoma, and gender was a significant variable ($p<0.001$) for all T-stages.

DHB of domicile

There was a significant difference in age-standardised incidence of IM at different DHBs ($p<0.001$). When comparing DHB incidences averaged across the entire study period, Taranaki DHB had the greatest IM incidence rate at 77.5 per 100,000 person-years, whereas Counties Manukau DHB had the lowest melanoma incidence rate at

Figure 1: Joinpoint model displaying US2000 age-standardised incidence rate per 100,000 person-years between 2000 and 2022.

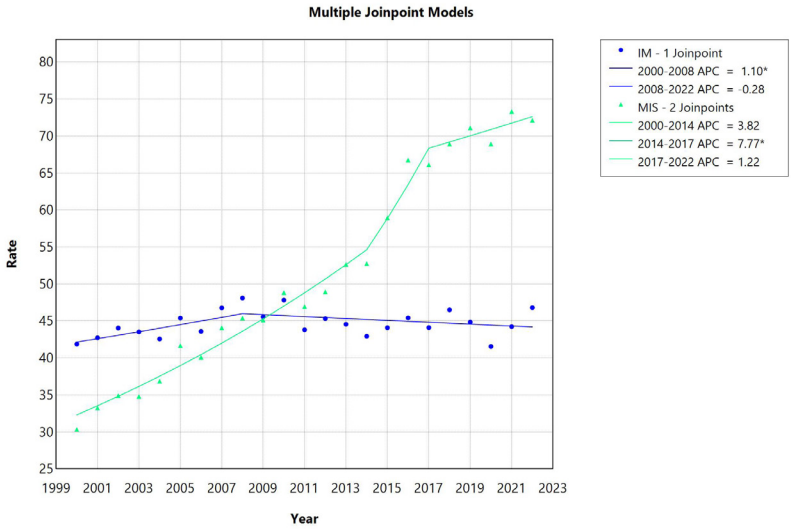


Figure 2: US2000 age-standardised incidence rate per 100,000 person-years between 2000 and 2022, separated by T-stage.

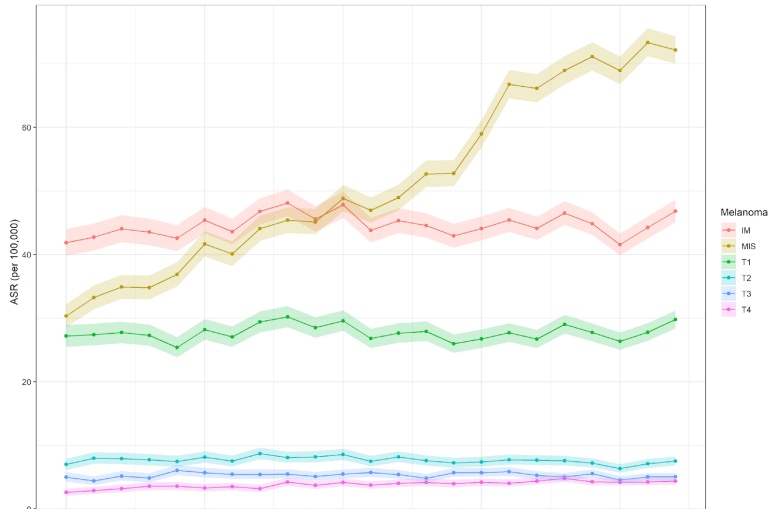


Figure 3: Combined IM and MIS incidence rate per 100,000 person-years for each age group among males and females between 2000 and 2022, with 95% CI.

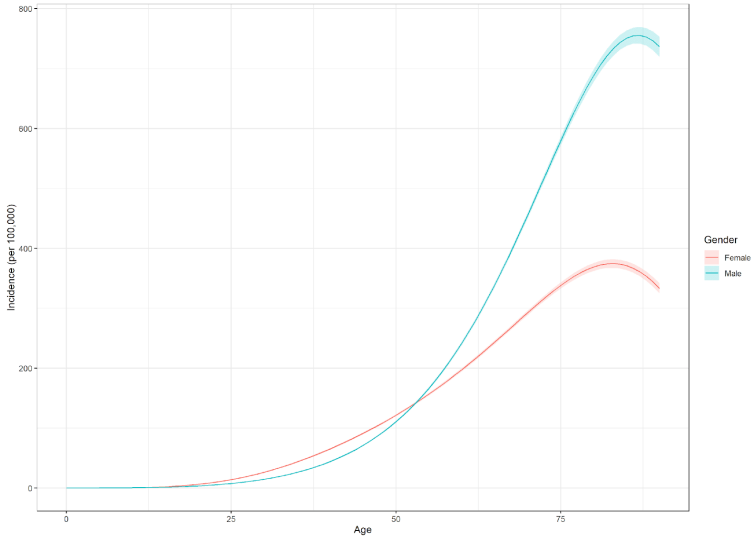


Figure 4: Median Breslow thickness between 2000 and 2022, with 95% CI.

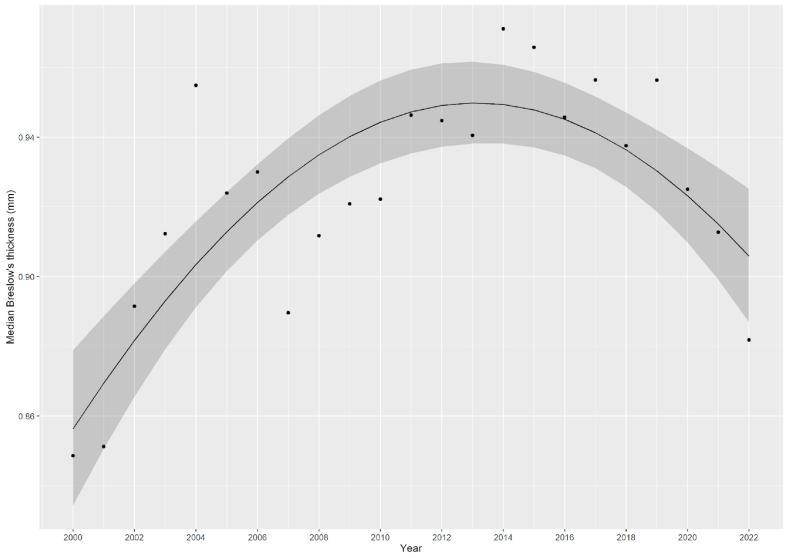


Figure 5: T-stage specific incidence rate per 100,000 person-years for each age group between 2000 and 2022, with 95% CI.

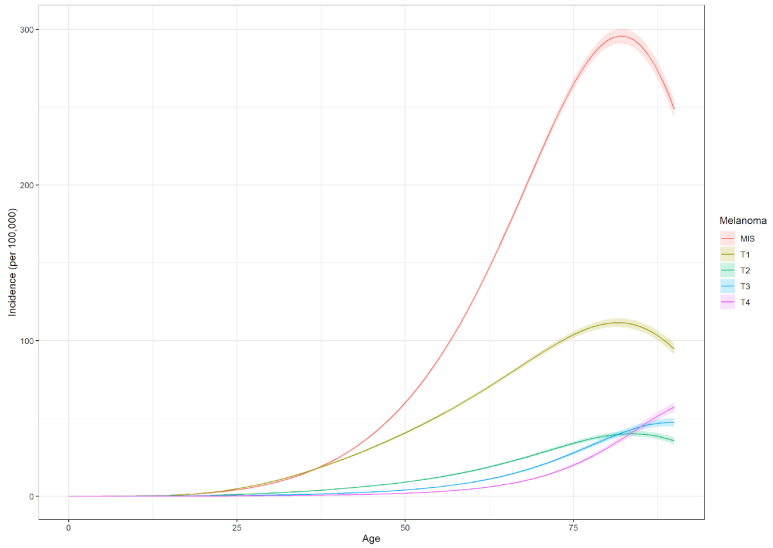
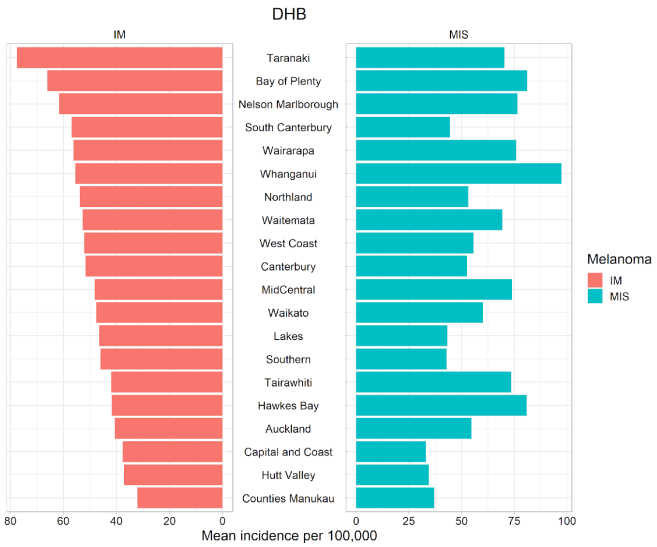


Figure 6: Mean incidence rate per 100,000 person-years by DHB region.



32.1 per 100,000 person-years (Figure 6). Across all DHBs, there was no association identified between MIS and IM incidence.

Discussion

This study looked at overall incidence rates of IM and MIS for the entire New Zealand population, with data taken from a national database. Mandatory reporting of cancer diagnosis to this database has been in place since 1994, and the authors believe it to be the most accurate way of obtaining data from the whole country.

The results of this study suggested a plateau or non-statistically significant decrease in the incidence of IM from 2008 onwards according to the Joinpoint analysis. This is a shift compared to data from the twentieth century, which showed exponential increases in melanoma incidence, and previous studies from the early 2000s, which had shown a plateau.[7,18]

The study also showed the incidence rates of MIS are increasing with time, which has been seen as a trend in previous literature.[19] However, care must be taken when interpreting MIS data due to the possibility of over-diagnosis of dysplastic naevi, with high rates of inter-observer variability between pathologists due to overlapping morphological features noted.[20]

Both the plateau in IM incidence and corresponding increase in MIS incidence may be due to the improved public awareness and early detection of pigmented lesions. Furthermore, there may be a contribution from the maturity of prevention campaigns and the corresponding change in behaviour towards skin protection. There has also been a push by local organisations advocating the increased use of dermatoscopy as part of routine skin assessment in primary care, although the nation-wide prevalence of this practice has not been measured. Interestingly, the plateau in IM incidence was predicted by algorithms performed by Whiteman et al.[3] They hypothesised a plateau phase in the early 2000s, where we were both seeing the positive effects of education campaigns in the younger population, but also an increasingly larger older population with a higher incidence of melanoma, therefore no overall change in incidence rates. Once the younger population ages, people who have been exposed to education campaigns from birth will make up a larger proportion of the overall population, and a decrease in the overall melanoma incidence would be observed. Other countries that have high incidences of melanoma (Australia, Denmark, Norway and the Netherlands) have yet to see a decrease in incidence.[21–23] The evolution in ethnic composition of New Zealand over time may be a confounding factor to the plateau in IM incidence. From the 2013 to 2018 census, the proportion of the New Zealand population that identified as European has decreased from 66.7% to 62.3% with a corresponding increase in mostly the Asian ethnic groups, in whom there is a notably lower melanoma incidence rate.[11,12] Further investigation on the specific incidence for each ethnicity is required.

The International Agency for Research on Cancer Global Cancer Observatory database (GLOBOCAN) reported a combined Australian and New Zealand age-standardised melanoma incidence of 35.8 per 100,000 person-years in 2020, which is different to our reported rate of 41.5 per 100,000 person-years for the 2020 year.[1] This discrepancy arises from a difference in data sources. GLOBOCAN calculated the 2020 incidence rates based on pre-2012 historical data projected and applied to the 2020 population,[24] whereas our calculations are derived from up-to-date 2023 New Zealand Ministry of Health data. Similarly, a recent publication describing the global burden of cutaneous melanoma in 2020, and further projecting melanoma incidence rates to the year 2040, has been based on this GLOBOCAN data,[25] and its accuracy may be limited. Caution must be taken when interpreting these large, worldwide database reports as accurate information for every country may not be available at the time of publication.

Males had a higher incidence of IM than females for the overall study period. When broken down by age band, there was a trend towards females having a higher incidence in the 25–50-year age groups, but a large divergence favouring males at a later age. This has been demonstrated previously,[6,7,26] and possible reasons for this are higher rates of intermittent sun exposure in younger females due to sun-tanning practices but a higher chronic life-time exposure to sun in males due to an increase in occupational sun exposure.[26] The reasons for differences seen between sexes is likely multifactorial, with immunological, endocrine, genetic and behavioural factors all playing a part.[27]

Median Breslow thickness at presentation appeared to be showing signs of decrease in the final 8–10 years of the study period. This is a trend that has been observed in other developed

countries and differs from previous data that showed increases in Breslow thickness over time in New Zealand.[7,28] As Breslow thickness is closely related to prognosis[5] it is encouraging to see this trend. T-stage based on AJCC 8th Edition provides a more detailed clinically significant indication of stage at presentation compared with Breslow thickness alone. While overall IM incidence appears to have a downward trend from 2008 onwards, there was not a statistically significant downward trend for any particular T-stage throughout the study period. Increasing age at presentation saw higher incidences of IM across all T-stages, with one exception. After the age of 80, there was a plateau and decrease in the incidence of T1 melanomas and a plateau in T2 melanomas. For the same age group, we saw increases in T3 and T4 melanomas with increasing age, reflecting a later presentation with more advanced melanomas for this group.

Historically, some regions of New Zealand have been reported to have incidence figures as high as 77.7 per 100,000 person years; the results of this study again confirm wide variation in IM incidence between regions.[29] Similar to 2000–2004, Taranaki DHB recorded the highest incidence (77.5 per 100,000 person-years), with Bay of Plenty (66.1 per 100,000 person-years) and Nelson Marlborough (61.6 per 100,000 person-years) second and third respectively. The differences in incidence between DHBs cannot be completely explained by sunshine hours, as some high sunshine areas such as Hawke's Bay had a low incidence of IM (41.7 per 100,000 person-years), and other DHBs that traditionally have fewer sunshine hours, such as Southern DHB, had a higher incidence (46.1 per 100,000 person-years). The underlying reason is likely to be multifactorial with contributions from confounding factors such as population ethnic composition, health literacy and ease of access to healthcare. The lowest incidence of IM was recorded in Counties Manukau DHB (32.1 per 100,000 person-years), likely due to the ethnic composition of the DHB catchment area.

We saw a low incidence of MIS in South Canterbury DHB (44.6 per 100,000 person-years), despite this region not having a similarly low figure for IM (56.8 per 100,000 person-years). Given that the results are derived from NZCR data, we consider this outlier recording to be likely due to incomplete reporting of MIS to the NZCR in this region. Alternatively, later diagnosis or lack of access to medical assessment may account for this.

Limitations

The ethnic composition of New Zealand has changed over time, with a relative increase in the proportion of the Asian population.[11,12] This may influence the incidence calculations by introduction of a larger proportion of the population that has a documented lower incidence rate and subsequent dilution of the at-risk group within the overall population. Further investigation on the specific incidence for each ethnicity is required. Furthermore, the COVID-19 pandemic spanned across the final 3 years of the study (2000–2022), which may have resulted in delayed presentations due to the hesitancy of patients to access healthcare during this period; to note, there was not an observed significant reduction in number of cases between 2000 and 2022. The authors' decision to limit registration to one per person avoids the risk of over-estimation due to cases of metastatic melanoma and recording residual melanoma at the primary site as a new melanoma; however, it also under-appreciates the burden of disease of patients in whom multiple primary melanoma develop during the study period. Unfortunately, the NZCR is limited in its ability to allow for specific data extraction to include the latter cases and this should be taken into account during the interpretation of the results of this study. The US2000 standard population was selected for statistical analysis purposes due to its similarity to New Zealand in being a developed nation and with the specific age population weightings; however, the authors acknowledge the differences in ethnic composition between these two populations, notably the lack of representation of the Indigenous Māori and Pacific populations.

Conclusion

The incidence of IM in New Zealand appears to have plateaued in the last decade and was associated with an increase in MIS incidence over the same period. We believe this is due to the maturity of prevention campaigns, increasing public awareness and increased GP and specialist use of dermatoscopy. While this trend is encouraging, further research is required to investigate whether there is a decline in IM incidence going forwards. The impact of changing incidence on melanoma-specific mortality and the influence of ethnicity are areas for future investigation.

COMPETING INTERESTS
We declare that all authors involved in the preparation and submission of this journal article have no commercial financial incentives related to the publication. We affirm that there are no competing interests that could compromise the integrity, objectivity or impartiality of the research and its reporting. We disclose no conflicts of interest that could potentially bias the findings or conclusions.
This study was registered and approved by the Waitematā District Health Board research ethics committee.

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Preliminary assessment of using mobile point-of-care human papillomavirus (HPV) testing with the option of immediate colposcopy in a rural area in a high-income country: a case study

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ABSTRACT

AIM: Cervical cancer is now preventable with human papillomavirus (HPV) vaccination and HPV screening. However, structural health system barriers in rural areas can inhibit screening access. Inequitable access for rural Māori is exacerbated by social determinants and racism. Pro-equity tools, such as self-taken swabs point-of-care (POC) testing, now exist. This study aimed to investigate whether POC HPV testing and immediate offer of colposcopy by a mobile colposcopy service is possible at a rural community event.

METHODS: This case study was a collaboration between a research centre, a women's health bus, a molecular diagnostics company, a Māori health provider and a community charity, and took place prior to the new cervical screening programme introduction at a 2-day community event—a shearathon. Eligible participants were offered a self-taken swab for HPV, which was analysed by POC testing. If high-risk HPV was detected, they were offered an immediate colposcopy. The Māori-centred qualitative component explored women's experiences of the process.

RESULTS: Fourteen women undertook a self-test for HPV. High-risk HPV was detected in six women and all were offered immediate colposcopy. Six women were interviewed. All were supportive of the service. Culturally safe staff taking time to put women at ease contributed to acceptability and positive experiences.

CONCLUSION: This case study shows that provision of POC HPV testing and colposcopy at a rural community event setting is possible through cross-sector collaboration. This service was acceptable to rural transient workers who face barriers to healthcare in a high-income country.

Cervical cancer is preventable with human papillomavirus (HPV) vaccination and screening.[1] Screening can detect treatable pre-cancer of the cervix, halting the development of a potentially fatal outcome.[2] The World Health Organization (WHO) has called for the elimination of cervical cancer.[3]

The causative agent of cervical cancer is HPV. Infection with certain oncogenic types of HPV (known as high-risk or HrHPV) causes changes in the cells of the cervix that can lead to cancer.[4] In this paper we will use HPV to indicate HrHPV. Compared with cytology, HPV-based screening is a more sensitive test; it provides 60–70% greater protection against developing invasive cervical cancers.[5,6] It is also internationally recognised that a self-taken swab (HPV self-test) analysed using molecular amplification tests such as polymerase chain reaction (PCR) is as effective at detecting HPV as a clinician-taken sample.[7] HPV self-testing is an equity tool for cervical screening. It has been shown to be acceptable to under-screened wāhine Māori, and a randomised controlled trial showed that offering HPV self-testing achieved nearly three times the screening rates of offering cervical cytology.[8] Aotearoa New Zealand introduced a new National Cervical Screening Programme (NCSP) in September 2023 using HPV testing as the primary screening test to prevent cervical cancer.[9]

Most cervical cancers occur in women (wāhine) and people with a cervix who have either not received screening or screened less frequently.[10] Structural health system barriers such as limited availability of healthcare in rural areas can

inhibit access to screening. Inequitable access for rural Māori is further exacerbated by social determinants, systemic failures in healthcare and racism.[11,12] The lower part of Te Waipounamu (South Island of Aotearoa New Zealand) is predominantly rural, with a low population density and with the main centres situated on the periphery of the area. The 2023 screening coverage data for this region shows that the overall screening coverage was 72%. However, this was only 61.9% for Māori, 60.7% for Pacific peoples and 54.7% for Asian women. As of January 2023, over 25,000 of the eligible population in this region had not been screened.[13] The same structural barriers contribute to a failure to provide timely and equitable diagnostic colposcopy after abnormal cervical cytology for women in rural Aotearoa New Zealand, and particularly wāhine Māori.[10,14] Once screened, there is a failure to achieve timely diagnosis and treatment of abnormalities for Māori.[10] Fewer wāhine Māori have a colposcopy within an appropriate timeframe following a high-grade abnormality when compared to non-Māori women. Furthermore, the proportion of women who had no record of any subsequent follow-up at 90 days is 4.4% for NZ European but 8.6% for wāhine Māori.[15] Recent evidence from Aotearoa New Zealand also shows that the current cervical screening programme does not serve the transgender and non-binary population well.[16]

Point-of-care technology (POC) enables on-site HPV testing of self-collected vaginal swabs. The Cepheid Xpert HPV test (CA, USA) is clinically validated to detect infections with 14 HPV types (16, 18, 31, 33, 35, 39, 45, 51, 52, 56, 58, 59, 66, 68) associated with over 90% of cervical cancers.[7,17,18] The Xpert HPV test differentiates types HPV16 and HPV18/45, which cause ~70% of cervical cancers. The non-16/18/45 types are grouped together and referred to as HPV "other". The sensitivity and specificity of the Xpert HPV test are comparable to the other well-established HPV central laboratory-based assays, and it fulfils the WHO criteria for use.[19] POC testing can be administered and run by non-laboratory staff, such as nurses or kaiāwhina (non-clinical health workers), when suitable accredited training and audit processes are in place. POC testing has the potential to increase equitable access[7,20–22] to cervical screening, because it can be implemented in a range of settings. Equitable access to cervical screening and follow-up could be further facilitated by co-locating HPV self-testing, POC and immediate diagnostic colposcopy. Implementing this co-located pathway in rural community event settings in a high-income country has not been fully explored previously.

The aims of this case study were to:

1. Investigate whether POC HPV testing and immediate offer of colposcopy by a mobile colposcopy service is possible at a rural community event.
2. Explore participant experiences of accessing cervical screening and healthcare, including acceptability of POC HPV testing and immediate offer of colposcopy by a mobile colposcopy service at a rural community event.

Methods

This case study was a cross-sector collaboration between Te Waka Wahine Hauora – The Woman's Health Bus (a clinical mobile health service), Te Tātai Hauora o Hine (National Centre for Women's Health Research Aotearoa), Cepheid (the molecular diagnostics company who provided the GeneXpert® IV instrument), Uruuruwhenua Health (a Māori community health non-governmental organisation) and Shear 4 A Cause 24-hour Shearathon. The staff who ran this case study included a gynaecologist (also the bus driver), a nurse colposcopist, a molecular scientist to run the POC testing, two community health workers to support the women and two researchers to consent the women and conduct interviews.

Shear 4 A Cause is a 24-hour sheep shearing event that has been run in the lower part of Te Waipounamu (rural Otago) for 3 years, raising funds for charities. In February 2023, one of the benefiting charities was Talk Peach, a gynaecological oncology awareness charity, which led to an invitation for Te Waka Wahine Hauora to attend the event. The environment was a rural farm next to a shearing shed located 150km (2 hours' drive) from the nearest referral centre for colposcopy and 35km away from the nearest town. There was no Wi-Fi available and very little cell phone coverage at this site. Negotiation with an on-site commercial media company live-streaming the event provided temporary access to their microwave feed.

Te Waka Wahine Hauora (the bus) is a mobile health service with AAA-NZ accreditation. It is a free-standing 8.5m purpose-built campervan that includes heat/air-conditioning, a toilet, a clinical consultation area and an examination space with

a gynaecological bed (www.womanshealth.nz). It has a total tonnage under 5t to enable driving with a normal New Zealand Class 1 license. The clinical space is powered by an in-built petrol generator. Colposcopy is performed using an Eva mobile colposcope to enable image capture and sharing with a patient screen and a Zeiss mobile colposcope.

POC set up and process

An outdoor laboratory space for POC HPV analysis was set up in a 3m-by-3m marquee-style tent with three sides closed to block sun and wind. The front of the tent remained open for ventilation and for participants to see the testing process if they wished. The floor of the tent was covered in cardboard, and two 1.8m by 0.76m trestle tables provided laboratory surfaces to hold the GeneXpert® IV, the laptop for instrument control and the sample preparation area. Electricity was supplied by the mobile clinic generator.

A self-collected vaginal FLOQSwab® (Copan, Italy) was transferred to a 20mL vial of ThinPrep® (Hologic, USA), the swab handle shortened using scissors and the vial capped. The sample in ThinPrep® was vigorously vortexed for 30 to 60 seconds and 1mL immediately transferred to the GeneXpert® IV HPV cartridge (Cepheid, CA, USA). Patient details were entered into the run log (either the NHI number or patient name, depending on what was available) and the sample set to run as per manufacturer's instructions. Each run took 1 hour. Laboratory surface areas and equipment were wiped with a 10% bleach solution regularly and between patients to cope with accumulated dust from the shearing shed environment. No testing was undertaken until the laboratory set-up and performance of the full system passed quality control using samples of known provenance.

Inclusion criteria

Eligible participants were women or people with a cervix between the age of 25–69.9 years whose cervical screening was due or overdue. Eligibility was confirmed using the NCSP register. When there was no access to the NCSP register due to lack of Wi-Fi, eligibility was determined by asking the woman about her screening history.

Recruitment and HPV testing

Participants were recruited opportunistically from shearing gangs and those attending the event as observers and supporters. Participants provided informed consent and were offered an HPV self-test. If requested, sampling for other sexually transmitted infections was offered but processed off-site. Women could do the self-test in the toilets provided for the event, or on the bus. Alternatively, they could request that a clinician take the vaginal swab.

The vaginal swab was processed immediately using the GeneXpert® IV operated by the molecular biologist on the research team (Te Tātai Hauora o Hine, National Centre for Women's Health Research Aotearoa), who is an expert in POC testing. Results were available in 1 hour, and healthcare staff advised participants of the result by text or in person. If the result was negative, i.e., no HPV detected, the woman was advised that she would not need HPV screening for 5 years. If the test detected HPV (16/18/45 or "other"), the woman was given the result with information and support. She was then offered an immediate colposcopy on the bus, or a referral to a colposcopy service (including colposcopy clinics provided by the bus at a later date). If the participant was registered with a primary healthcare provider, and with her permission, a letter was later sent to the provider with this information.

Qualitative methodology

The qualitative component was Māori-centred and undertaken by a senior Māori researcher. It explored women's current and previous experiences of accessing healthcare and cervical screening. Women were eligible for inclusion if they accessed the Woman's Health Bus. They were asked during the consent process to consider being interviewed, and those who signalled an interest undertook a further informed consent process. One-off semi-structured interviews were completed at the Shearathon in tents and cars on site. Kōrero (conversations) were audio recorded and transcribed verbatim. Data were uploaded to NVivo, a qualitative data analysis software program (QSR International Pty Ltd, 2018). Transcripts were coded inductively and analysed using reflexive thematic analysis.[23,24]

Ethics

The protocol was reviewed by the national Health and Disability Ethics Committee. Ethical approval was covered by two existing HPV studies: Rural Empowerment (HDEC 20/NTB/311) and Te Ara Waiora - Implementing HPV primary testing to prevent cervical cancer in NZ: Te Tai Tokerau (HDEC 21/STH/188).

Funding

The study was funded by the Health Research Council of New Zealand (HRC 20/550). Cepheid loaned the GeneXpert® IV.

Results

Achievability

Twenty-one participants used the "no cost to person" sexual and reproductive healthcare services on offer through the mobile clinic. There were 14 POC HPV tests performed. High-risk HPV was detected in six of the 14 patient samples using the GeneXpert® IV POC test. Mixed viral types (HPV18/45 and HPV "other") were detected in two samples, and HPV "other" was detected in four samples. Of the participants who had a positive HPV result, two chose to have a colposcopy on the day, with four deferring for a variety of reasons. Women who elected to defer were booked in with either a hospital or with Te Waka Wahine Hauora at its usual mobile clinic sites.

There were challenges to this venture (see Table 1). The main challenge was lack of internet. This impeded access to the NCSP register to check if people were due a cervical screen. It also inhibited the writing of medical notes with reporting to the NCSP using Solutions Plus, which is an internet-dependent patient management system. Another challenge was visibility and identification of the bus. Despite advertising on Facebook© about the availability of the bus at the Shearathon, often people at the event were not aware of the purpose of the bus, mistaking it for a mobile home. The weather at the event had an impact, including significant wind, rain, dust and temperatures reaching 35°C. It was difficult to provide a confidential, safe space to explain the health services and research in these conditions.

Factors that contributed to the success of the project included the cross-sector partnership, multidisciplinary expertise, building on existing relationships, an invitation from the community and the willingness of all partners to quickly resource the venture (Figure 1). Our collaboration with Uruuruwhenua Health, a Māori community health organisation, was critical in engaging and sustaining community awareness and support of our service. Talk Peach is one of the charities supported by the Shearathon, and both Talk Peach and Shear 4 a Cause provided the opportunity by inviting Te Waka Wahine Hauora to attend the event. All partners had recognised the importance of this novel opportunity and were willing to act in response to the invitation. Talk Peach supported the no-cost provision of sexual and reproductive healthcare including colposcopy, provided by the clinicians on Te Waka Wahine Hauora. Te Tātai Hauora o Hine provided the expertise in HPV and POC. The existing trusted relationships between Te Waka Wahine Hauora, Te Tātai Hauora o Hine, Cepheid and Southern Community Laboratories meant that the bus, equipment, research time and expertise could be mobilised quickly and provided at no cost for this event.

Qualitative findings—accessibility and acceptability

Six women, aged between 24 and 45 years, participated in an interview. Two participants were wāhine Māori and four were NZ European. When asked about access to healthcare and cervical screening, three main themes emerged: 1) the value women placed on health and wellbeing for their whānau (family) and themselves, 2) practicalities of accessing primary care for a transient population who work long hours, and 3) accessibility and acceptability of the bus. First, access to healthcare was discussed in terms of women looking after themselves but also their partners, children and wider whānau.

> *"My partner is full-time shearing … I feel like I've helped him with some good food choices and helped him get some training underway." – Participant 1*

> *"I kept up with all their [whānau] injections. They all got COVID-19 shots. That's just how we are. We do it to protect ourselves." – Participant 4*

Structural barriers to accessing healthcare included difficulties enrolling in general practice and limited ability to book appointments. Shearing work requires transience, and finding a practice who could take on new patients was time consuming for women who work in shearing gangs.

> *"…You've just finished hard days at work, and you think, 'Oh no, I've still got to ring the doctors.'" – Participant 7*

Almost all participants described difficulties in securing an appointment with a healthcare provider. The main barrier was finding time. Those who worked in shearing gangs did not know their availability ahead of time, and generally found

out at 5 in the morning if they would be working.

> *"Because we are 7 days a week, you never really know that we're going to have next Monday off, and you can't get an appointment at the doctors." – Participant 5*

Participants were unanimous in their support of the bus. A health service that came to them and did not require an appointment was highly accessible. Culturally safe staff who took time to put the women at ease, introduced themselves and made connections also contributed to acceptability and positive experiences.

> *"We sort of had a different chat about work and then all of a sudden it was done ... Just a very bubbly ... I just got a good lady. You've got a bunch of good ladies, that's what it is." – Participant 6*

Discussion

This case study shows that provision of POC HPV testing and colposcopy by a mobile health service in a rural community event setting is possible through community, clinical and research partnership.

This study identified how co-located HPV self-testing, POC and immediate diagnostic colposcopy can be implemented at rural community events. Factors that influenced provision of this novel pathway included both practical and technical aspects of care and the manner of care provision, i.e., care that prioritised the wellbeing of women and whānau.

The findings have implications for any mobile service considering provision of POC testing, implications for delivering healthcare at community events and for services considering novel modes of healthcare delivery for people whose needs are not met by mainstream healthcare models. It is difficult to compare with other studies using HPV self-testing and POC in the community, as in developing countries ablative treatment is offered rather than colposcopic diagnosis. However, two studies in Kenya and Uganda that piloted POC HPV testing in the community found that, similar to our case study, self-testing for HPV was more acceptable to many women who did not access healthcare easily, but there were many logistical challenges. A Ugandan study also used community fair events to reach women to good effect.[21,22]

Our qualitative data emphasised the importance of whānau wellbeing. Shearing events are for the whole whānau. Manaakitanga (showing respect, generosity and care) to support people who choose to have their colposcopy on the day could include childcare, a relaxing space for recovery and refreshments. Not all people want immediate colposcopy, and it is critical to be linked into local services to enable access to an acceptable service in a time and place that is suitable for the patient.

Communities require trust to engage with healthcare and research. Our collaboration with Uruuruwhenua Health, a Māori community health organisation, was critical in engaging and sustaining community awareness and support of our service. Our collaborators in this case study have the connections and trust to ensure whānau experience awhi (a cloak of support) and feel safe to engage with the mobile health service.

Lessons learned include the need for a separate, private space for completing registration details, as people may not have engaged with health services and do not have their medical details readily available. Having a safe space and allowing time for informed consent around the procedure was also critical for patient understanding that a positive test leads to a recommendation for colposcopy. This case study is limited by a lack of available data about the study population, i.e., the number of eligible people attending the event, their ethnicity and screening history. People came from all over the country for this event, meaning that regional screening coverage data may not apply. Because the event took place before the release of the NCSP guidelines, we did not offer cervical cytology for HrHPV type "other" and cannot comment on participants' experience of this. Also, although the women who tested negative will not require a screen for 5 years, the NCSP may call them earlier and the women were informed of this possibility.

A young film maker with crowdfunding also made a short documentary about the case study that has had national media attention (https://thespinoff.co.nz/society/12-04-2023/the-struggle-for-access-to-cervical-screening-in-rural-aotearoa).

Recommendations for future buses would include POC testing built into the design infrastructure of the mobile service, such that it is contained within an environmentally managed space. Vaccination could also be offered for the whānau who also attend. Future research work could include a cost–benefit evaluation for the mobile

Table 1: Challenges to implementation of offers of HPV self-tests, POC testing and colposcopy on a mobile bus at a rural event in Aotearoa New Zealand.

Challenges to implementation	Reason	Possible solutions
Lack of internet	• Writing medical notes in an internet-dependent patient management system • Checking the national screening register for screening history (eligibility).	• Satellite broadband • "Hot-spotting" from cell phone data when possible. Even cell phone network coverage was unavailable in this location, so screening history sometimes relied on self-report.
Visibility and identification of the bus by the shearers and public	• Public unaware what bus was, why it was there and the service it offered.	• Widespread advertising on social media pre-event • Media involvement before event • Signs/posters at the event.
Weather—heat, rain, wind	• Difficulty with tent for POC testing.	• A space (such as a tent) protected from the outside environment to complete registration details and the informed consent process.
Dust being blown from the shearing shed	• Potential contamination of lab equipment .	• Laboratory surface areas and equipment were wiped with a 10% bleach solution regularly and between patients.
Privacy	• Bus was fully utilised for clinical care, meaning that another space was needed for explaining the services offered, the research and taking medical history.	• A separate and private space for consultations before the HPV test and to fully explain in advance the next steps if high-risk HPV is detected.
Enabling immediate colposcopy	• Lack of knowledge and awareness of what colposcopy was and why it was needed • Looking after children.	• Supporting people choosing to have colposcopy on the day means supporting their whanau too: • Provision of childcare during the colposcopy appointment • A relaxing, whānau-friendly area for recovery • Offering refreshments after the colposcopy.
Separate space needed for POC testing	• POC testing was not built into the bus design.	• Incorporating and building in POC testing space on bus.

woman's health bus and, if cost-effective, expanding the mobile service to other rural community events throughout Aotearoa New Zealand.

Conclusion

Despite multiple challenges, successful collaboration between community charitable event planners, a local rural NGO, a research team and clinicians running a mobile gynaecology bus enabled provision of POC HPV testing and colposcopy for 2 days of a community event. This service was found to be acceptable to rural transient workers in a high-income country. Women want to look after their health. The bus removed barriers to cervical screening such as appointments, travel and being enrolled in primary care. However, it is critical to be flexible to each community's needs. One model will not fit all and if we want to achieve the WHO goal of eliminating cervical cancer we need to adapt to the needs of each community.

Figure 1: The mobile bus and POC testing tent.

COMPETING INTERESTS
Cepheid loaned the GeneXpert® machine but had no part in the conceptualisation, study design, protocol development, project administration or findings of the study. The study was funded by the Health Research Council of New Zealand (HRC 20/550).

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Impacts of raising a child with a feeding difficulty in Aotearoa New Zealand

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ABSTRACT

Economic barriers to accessing support for children with paediatric feeding difficulties can have serious repercussions, including parental stress and emotional fatigue, the child developing a negative relationship with food and health risks such as undernourishment, aspiration pneumonia or choking. We explored the financial and psychological impact experienced by parents and caregivers raising a child with a feeding difficulty in Aotearoa.

Respondents were 88 parents or caregivers of a child with a feeding difficulty, living in Aotearoa. Respondents completed an online survey with 34 questions, the majority of which were multi-choice. Open-ended responses provided exemplars and detail.

The results indicate that many families (64.3%) experience a significant but small impact associated with raising a child with feeding difficulties in Aotearoa. However, 36.4% of respondents reported a moderate to significant financial impact. Barriers to working caused by feeding challenges and childcare, as well as non-medical expenses, contributed to financial strain and psychological impacts experienced by respondents. Parents struggled to find support for their own wellbeing.

Paediatric feeding difficulties (PFD) are disruptive, hindering family life and routines as well as being the cause of many health issues for children. Further, PFD cause financial and psychological stress to whānau (family, extended family connections). Feeding may be a challenge from birth, may become more difficult over time or may coincide with a period of illness.[1] Children may have chronic complex medical situations or be otherwise healthy. There is currently little research that reports on the financial and psychological impacts of having a child with a feeding difficulty from an Aotearoa perspective. There is no exact data on the prevalence of feeding problems in children in Aotearoa. Existing research focussed on the economic challenges associated with childhood disability, for whom feeding difficulties are prevalent, is commonly from Census data. Feeding difficulties are not reported on in the New Zealand Disability Survey; however, if we apply the widely accepted prevalence data of 20% of typically developing children (20% of 837,479 = 167,495.8) and 80% of children with disabilities (80% of 103,521 = 82,816.8) having a feeding difficulty (PFD), this would mean that more than 250,000 children in Aotearoa will experience PFD at some point in their childhood, with approximately 43,303 (17.3%) predicted to be Māori.

Māori are the Indigenous people of Aotearoa, and the role of kai (food) is highly important in whānau relationships. Māori and Pacific grandparents and extended whānau often care for children from birth (or soon thereafter) to the age of 3 years.[2] Being with whānau is an important component of Māori hauora (Māori philosophy of health).[2,3] PFD may particularly impact on the nurturing aspect of feeding for Māori,[3,4] and there are known barriers to accessing public health system care and support.[2,5,6]

Extant literature does little to address the cost of PFD in Aotearoa. Canadian studies identified most families of children with disabilities were unable to engage in paid work to the same extent as families of typically developing children.[7,8] In Australia, parents of children with intellectual disabilities faced between AUD$15,000 and AUD$25,000 in additional costs, depending on the severity of their child's disability.[9] This was on top of costs associated with reduced labour, estimated to add up to around AUD$48,000 per year. In a study focussed on PFD, Australian parents reported considerable financial impacts, including the cost of the appointment itself, the time taken to attend (at least half a day) and the associated disruption to work and other daily activities.[10] These impacts are likely to be magnified for Māori.

The diverse ways that healthcare is funded internationally affects cost comparisons with Aotearoa. The 2022 Household Economic Survey[11] found that one in five children with disabilities in Aotearoa lived in material hardship—more than twice the rate for typically developing children. Economic barriers to accessing support and intervention for children with PFD can have serious repercussions, including parental stress and emotional fatigue, the child developing a negative relationship with food and health risks such as undernourishment, aspiration pneumonia or choking.[12] These often life-endangering risks can be avoided with appropriate multidisciplinary input.[13]

This study explored the economic costs and psychological impact associated with raising a child with PFD in Aotearoa. Furthermore, a clearer description of the financial and psychosocial consequences associated with feeding difficulties specifically would guide health professionals and service providers to more tailored support for families.

Method

This cross-sectional study had approval from The University of Auckland Human Participants Ethics Committee #22188. Data were collected via an online survey on the Qualtrics platform.

Table 1: Respondent demographics (N=88).

Variables		n (%)
Relationship to child with PFD (*n*=88)	Caregiver or father	10 (11%)
	Mother	78 (89%)
Region (*n*=81)	Upper North Island	34 (42%)
	Lower North Island	28 (35%)
	South Island	19 (23%)
Employment status (*n*=78)	Employed full-time (>30 hours/week)	17 (22%)
	Employed part-time	25 (32%)
	Home maker	23 (29%)
	Self-employed	6 (8%)
	Unemployed (seeking/not seeking work)	7 (9%)
Marital status (*n*=81)	Married/domestic partnership	70 (86%)
	Separated/divorced/single	11 (14%)
Number of adults in the home (*n*=86)	One	8 (9%)
	Two	67 (78%)
	Three or four	11 (13%)
Number of children in the home (*n*=86)	One	27 (31%)
	Two	29 (34%)
	Three or four	30 (35%)

Note: *Cell counts of less than 5 have been merged.

Thirty-four quantitative and qualitative questions covered demographic data, financial impacts and psychological impacts of raising a child with PFD (Appendix 1). The survey design was adapted, with permission, from the Economic Impact Study created by Feeding Matters.[14]

Demographic questions were based on Aotearoa Census classifications.[15] Options for additional expenses incurred reflect the financial support offered to parents raising a child with a disability in Aotearoa ($200 per month).[16] Changes to financial providers reflect local options.

Recruitment occurred online and in-person through advertisements in special interest groups on Facebook, and professional networks. All parents or carers of children with PFD in Aotearoa were eligible to participate. Relevant Facebook groups were identified by searching "Children with feeding difficulties Aotearoa", "Parenting children with disabilities Aotearoa" and "Parenting support group Aotearoa" in the Facebook group search function. Respondents could enter a prize draw to win one of 10 $50 vouchers. Data collection occurred exclusively online. Respondents accessed the survey via a link in the Participant Information Sheet on their own internet-capable devices. The survey ran from August 2021 to October 2022.

Descriptive statistics were calculated for select data using Microsoft Excel and Statistical Package for Social Sciences (SPSS). Qualitative comments are included to illustrate the numerical findings.

Results

A total of 101 respondents began the survey, with a completion rate of 87% (n=88). Twenty-one respondents had children with PFD 12 months old or less, 66 children were older (range, 2 months–17 years). Of the 59 (67%) children who were tube-fed, 38 (43%) had a gastrostomy and 21 (23%) a nasogastric tube. Five respondents identified as Māori, two as Pacific peoples and 70 as Pākehā. Respondents were able to identify with more than one ethnicity. Demographic information is shown in Table 1.

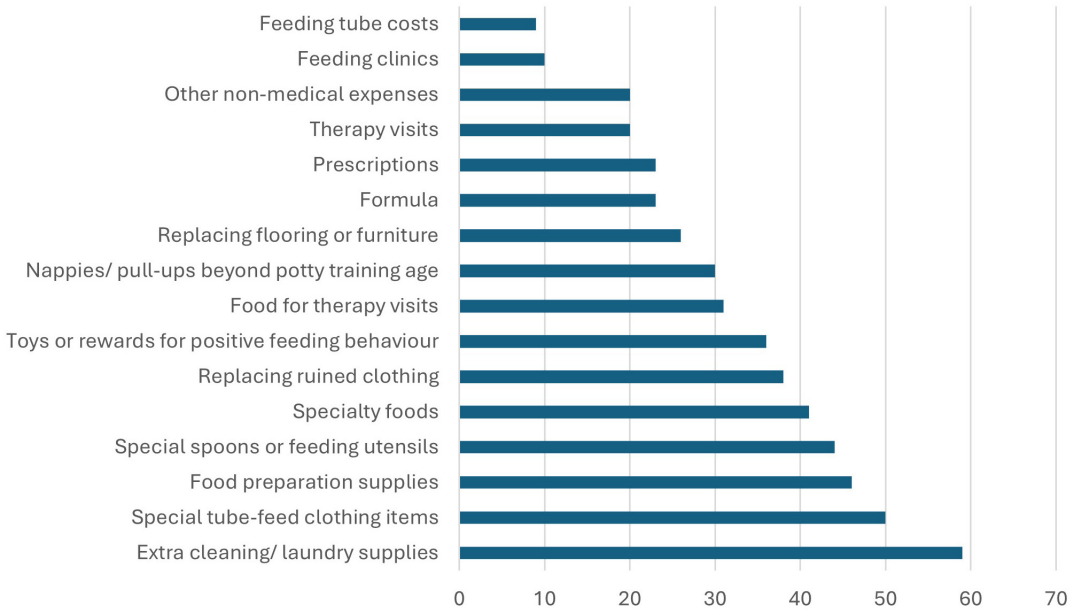
Levels of reported financial strain

A majority of respondents (n=73, 82%) reported their income was at least enough to meet their needs and a majority (n=68, 80%) experienced at least minor financial strain, with 15 (18%) respondents reporting significant strain. Chi-squared between perceived income sufficiency and financial strain was not statistically significant ($\chi 2[9]=13.565$, p=.139).

Expenses incurred by parents/caregivers of a child with PFD

Almost half of respondents (*n*=39, 45%) have

Figure 1: Medical and non-medical expenses related to child's PFD paid for out-of-pocket by whānau (n=88).



not had to pay for any medical expenses out-of-pocket. However, all respondents in the survey reported paying for at least one non-medical expense out-of-pocket, with the most common expense being extra cleaning/laundry supplies due to reflux and/or vomiting (Figure 1).

Thirty-two percent of respondents indicated they were not experiencing extra travel costs because of their child's PFD: 70% reported they did not travel extensively to appointments, 48% indicated they spent $1–200 per month and 20% spent over $200 on travel costs. Over 50% of respondents spent additional money each month on childcare related to their child's feeding difficulties (up to $200 n=24 [27%], more than $201 n=23 [26%]).

Several parents reported a significant loss of earnings due to extra time spent looking after children at home or in hospital: *"... There is a financial burden as I didn't qualify for maternity leave and planned to be back at work after 4 months. At 10 months I am still not able to return to work"* – P12; *"I've been unable to work due to my youngest's issues, yet there is no other funding or help available"* – P23; *"We live in a small community, and I haven't been able to go back to work, our small daycare has only just agreed to take her. Financially we have run out of savings"* – P56.

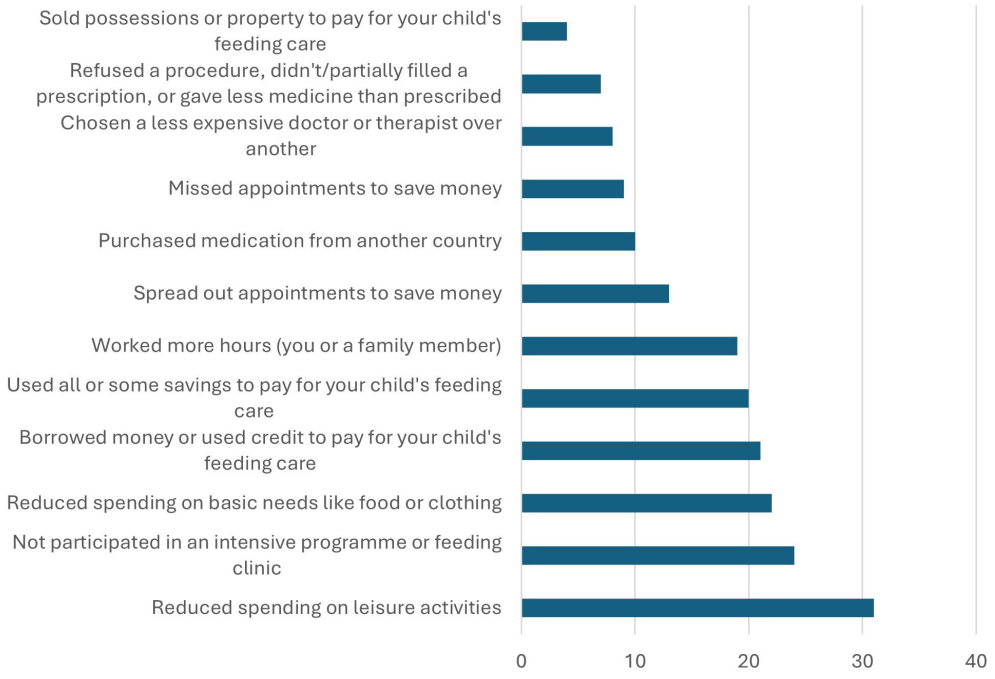
Money saving strategies

Respondents were using a wide range of strategies to save money on costs related to their child's feeding difficulty (Figure 2). The most common strategies included reducing spending on leisure activities (n=27, 42%), reducing spending on basic needs (n=18, 28%), working more hours (n=18, 28%) and not participating in a treatment programme due to cost (n=18, 28%).

Psychological impacts

Most whānau said their relationship with food or mealtimes had changed because of their child's feeding difficulty. Most respondents (94.4%) reported feeling stressed about their child's feeding. Typically, mealtimes were more complex: *"Very stressful environment around mealtimes. We are unable to all eat the same meal and eat as a family"* – P22. Parents reported differing significance of feeding difficulties, which frequently co-occurred with other needs: *"Although my child has general special needs, it is the tube feeding and feeding difficulty which causes the most strain on our day to day lives by far!"* – P60, whereas P57 commented *"They do correspondence school. This is in part due to feeding issues but also in part due to anxiety etc. Also, marriage issues and stress cannot be entirely blamed on feeding issues, but it's played a part."*

Figure 2: Strategies employed by whānau to save money on costs related to their child's feeding difficulty (n=63).



Parents reported PFD resulted in them experiencing depression (n=46, 52%), anxiety (n=62, 70%) and relationship struggles with their spouse/domestic partner (n=36, 41%), as well as disconnection from their community (n=39, 44%). Some (n=13, 15%) noted challenging relationships between other siblings, particularly resentment over "special treatment": *"I feel like my other kids resent him for always having special things"* – P23; *"My older son … resents his brother terribly and it's causing all sorts of problems"* – P14.

Supportive people, groups or organisations for parents

Most respondents were able to identify at least one person or organisation that was helpful or supportive (Table 2)—some named specific people. Forty percent had accessed free support. A minority felt whānau were supportive. Unfortunately, several felt unsupported: *"None, I have tried so hard, but I can't seem to get anywhere"* – P7, *"No one—I'm in this alone"* – P14. Parents reported feeling judged negatively: *"To be honest, no one has helped, just say I'm a bad parent [and] that he is just fussy"* – P40. Others had mixed experiences with the support that was available: *"Our DHB physio team have been the most helpful. Our SLT is a lovely lady—but useless. We don't know where else to access help and can't afford private"* – P70.

There was difficulty in accessing sufficient or timely mental health support through the public health system: *"I was offered six sessions of counselling via my GP but needed much more to deal with the PTSD I have from being in hospital so much with my child"* – P87; *"Little mental health support—took over 6 months to get any counselling"* – P30.

Discussion

The aim of this study was to gain perspectives from caregivers in Aotearoa regarding the financial and psychological impact of caring for a child with PFD. Overall, results highlighted that there was a substantial experience of financial strain and little opportunity for psychological support for parents.

The majority of parents/caregivers of a child with PFD experienced some degree of financial strain. More than 60% reported feeling at least minor financial strain, with nearly 40% of respondents rating their level of financial strain as moderate or significant. This result is consistent with results of the Feeding Matters Economic Impact Study,[14] as well as literature on the financial impact of raising a child with a disability.[9,17]

There was a positive relationship between number of non-medical items purchased out-of-pocket and levels of reported financial strain.

Table 2: People or groups who have been particularly supportive or helpful (n=71).

Helpful and supportive people, groups or organisations	n (%)
Facebook groups related to tube feeding or child's condition	17 (24)
Whānau (grandparents, extended whānau, children)	9 (13)
In-person community groups, church, friends	6 (8)
Family Centres related to child's condition or disability	10 (14)
General Practitioner, Paediatrician, Specialist Tertiary Team, Dietitian, Physiotherapist	16 (23)
Mental Health Service, Psychotherapist, Psychologist, Counsellor	7 (10)
Nurse—community, homecare and outreach services	6 (8)
Speech-Language Therapist—community and inpatient	14 (20)
No one/none*	5 (7)

Note: Multiple responses were possible. Cell counts of less than 5 have been merged. *These respondents did not choose multiple options.

This could be due to Health New Zealand – Te Whatu Ora funding, whereby financial support is not provided for items costing less than $50, nor for toileting products if the child is younger than 4.5 years.[18] This correlation suggests that the lack of funding for smaller items specifically related to feeding and swallowing, like special feeding utensils, food preparation supplies, bibs and nappies, are having a significant impact on the cost of raising a child with PFD.

Medical expenses, as opposed to non-medical expenses, do not appear to be a major source of financial strain for the respondents. This contrasts with the findings from the original Economic Impact Study.[14] Some Aotearoa respondents reported having to pay for prescriptions, therapy visits, formula and feeding tube costs; however, a third of respondents reported that they were not paying for any medical expenses related to their child's PFD. Further investigation is required to determine why some whānau are paying for medical expenses that should be covered by Health New Zealand – Te Whatu Ora, such as formula feeds for children over 1 year old. Respondents were paying for a maximum of two medical expenses, and up to 10 non-medical expenses. Unfunded costs such as additional kitchen utensils, formula feed and extra laundry can make healthcare unaffordable.[6] Children's healthcare visits and prescriptions are currently free in Aotearoa, and some feeding difficulties have funded medical expenses (e.g., tube feeding costs, formula prescriptions). It is positive that medical expenses are not a major source of financial strain. The lack of travel expenses for around half the families is consistent with the health professionals being community-based, and increasingly using telehealth methods of service delivery.

Respondents reported a wide range of money-saving strategies they used. These strategies can be broadly classified into three groups: saving money on household expenses, seeking extra money and saving money on healthcare expenses related to their child's feeding difficulty. Respondents reduced spending on both basic needs like food and clothing, as well as on leisure and community activities. Findings suggest the financial strain is leading to a reduced quality of life for the entire whānau.[17] Lastly, while the known impacts of credit card debt are variable, medical debt may lead to a cycle of poverty, including poorer physical and mental health and disruption to whānau life.[19–21]

The burden of hospital stays and reduced opportunity for working was a reported cause of stress for many families. Rather than additional expenses, a lack of income due to not being able to work was a substantial cause for parents' concern. For many, partner and spousal relationships were impacted, along with relationships between parents and children who were typical feeders. Whānau were a source of support for only a few families, which may reflect the mainly Pākehā demographic. Māori and Pacific whānau were under-represented in this study and are likely to experience greater whānau support. Previous studies show high levels of stress and increased risks of anxiety and depression in parents of children with feeding difficulties, with impacts on relationships with spouses, wider social relationships and employment.[12] Parents commented that it was difficult to access mental health support when they needed it, with a small number indicating they were under care of local Maternal Mental Health services. Approximately one third of families/whānau spent money to address psychological issues arising from the stress of their child's PFD.

Our sample mainly captured the perspectives of Pākehā whānau in Aotearoa. Overall, 38% of respondents indicated they were not employed outside of the home and 14% were not in a relationship. Further, one third of our sample paid out-of-pocket to access psychological support (broadly construed).[22] The sample population was strongly tauiwi. An online survey may not adequately capture voices of Māori or Pacific whānau, due to accessibility, or the lack of kanohi ki te kanohi (face-to-face) recruitment or delivery. Further qualitative research with a Kaupapa Māori approach is needed; a notable example is a recent paper focussing on Māori experiences of treatment and recovery from eating disorders.[23]

For Māori, we also acknowledge the impact of colonisation on health outcomes, and the current systemic and institutional biases in the healthcare system that act as barriers to accessing care.[24] Especially for PFD, there are few and inconsistently funded services, and none that are designed by Māori or involve a Kaupapa Māori approach.

There are many informal networks accessed by whānau and families to mitigate stress and fulfil a need for advice and support when caring for a child with a feeding difficulty. This, however, does not replace the medical advice and assistance needed for whānau and families to safely care for children with feeding difficulties alongside very complex health needs and medical challenges. Overall, the results indicate that for most families

there is a substantial financial burden posed from raising a child with PFD. Parents/caregivers reported experiencing financial strain, but psychological impacts were more emotive, and further consideration should be given to a whānau-centred approach, addressing the mental wellbeing of the whole whānau where there is a child with a feeding difficulty.

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Appendices

Appendix 1: Whānau of children with feeding difficulties in Aotearoa survey

2. Are you the parent or caregiver of a child or children with a feeding difficulty?

- Yes
- No

3. Please state which best describes you:

- Mother of a child with feeding difficulty
- Father of a child with feeding difficulty
- Caregiver of a child with feeding difficulty

4. How many adults (18 years or older) live in your household, including yourself?
5. How many children (under 18 years old) live in your household?
6. How old is your child (in years and months) with the feeding difficulty? If more than one of your children has a feeding difficulty, please just focus on the oldest child with a feeding difficulty.
7. Which of the following diagnoses/challenges does your child face?

- Autism spectrum disorder
- Fear of choking
- Cleft palate or velopharyngeal insufficiency
- Colic
- Dysphagia
- Food allergies
- Gastrostomy-tube fed
- Gastrointestinal condition (e.g., reflux, short gut syndrome, esophagitis, gastritis, etc.)
- Head or neck abnormalities
- Heart condition
- Medications that cause decreased appetite
- Nasogastric tube fed
- Nervous system disorder (e.g., cerebral palsy, encephalopathy, etc.)
- Oral motor dysfunction
- Premature/low birth weight
- Reflux
- Respiratory difficulties
- Vomiting
- Other diagnosis or challenge not listed here (please enter details)

8. Are any of your child's feeding expenses covered by any financial provider?

- Yes—private health insurance
- Yes—carer support (Ministry of Health)
- Yes—ACC
- No
- Unsure/rather not say
- Yes—other (please name)

9. Which of the following medical expenses have you or anyone in your whānau had to pay for because of your child's feeding difficulty? Check all that apply:

- Feeding clinics

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

- Feeding tube costs
- Formula
- Prescriptions
- Therapy visits
- Other medical costs not listed here (please specify):
- We have not had to pay for any medical expenses

10. Which of the following non-medical supplies have you/your whānau purchased to care for your child with a feeding difficulty and not been reimbursed for? Check all that apply:

- Special food preparation supplies
- Special clothing items for tube-fed child e.g., clothing, bibs, etc.
- Special spoons or feeding utensils
- New toys or rewards for positive feeding behaviour
- Organic/speciality food
- Food to take to therapy visits
- Extra cleaning/laundry supplies due to vomiting or reflux
- Replacing flooring/furniture due to vomiting or reflux
- Replacing ruined clothing due to vomiting or reflux
- Nappies/pull-ups beyond appropriate potty-training age
- Other supplies not listed here (please specify):

11. Do you or anyone in your whānau pay additional rates or fees for childcare and/or babysitting due to the special needs surrounding your child's feeding difficulty?

- Yes—we pay extra
- No—we don't pay extra
- There are no suitable services for my child, so we don't use paid childcare or babysitting
- Other—please tell us how you and your family organise childcare

12. Have you or anyone in your whānau ever used any of the following strategies to help cope with the costs of your child's feeding difficulty? Check all that apply:

- Missed appointments to save money
- Spread out appointments to save money
- Not participated in an intensive programme or feeding clinic due to cost
- Reduced spending on basic needs, like food or clothing, in order to pay for your child's feeding care
- Reduced spending on leisure activities, like vacations, eating out, or going to the movies, in order to pay for your child's feeding care
- Chosen a less expensive doctor or therapist over another
- Refused a procedure or test for your child because of cost
- Gave your child less than the prescribed amount of medicine to make it last longer
- Didn't fill or partially filled a prescription for your child's feeding care because it cost too much
- Purchased medication from another country
- Worked more hours (you or a family member) to help pay for your child's care
- Sold possessions or property to pay for your child's feeding care
- Took out a second mortgage on your house to pay for your child's feeding care
- Used all or a portion of your savings to pay for your child's feeding care
- Borrowed money or used credit to pay for your child's feeding care
- Other (please specify):

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

13. Overall, to what degree have the costs of your child's feeding difficulty been a financial strain for you or your whānau?

- Not a financial strain at all
- Minor financial strain
- Moderate financial strain
- Significant financial strain
- I'm not sure

14. When thinking about your household income, which of the following statements best describes your situation?

- My household income is more than enough to meet mine and my whānau's needs
- My household income is enough to meet mine and my whānau's needs
- My household income is just enough to meet mine and my whānau's needs
- My household income is not enough to meet mine and my whānau's needs
- Prefer not to answer

15. Do you or anyone in your whānau travel extensively for doctor or therapy appointments for your child with feeding difficulty?

- Yes
- No

16. How much extra, beyond typical childcare costs or sitter costs, do you or anyone in your whānau spend due to the special needs of your child with a feeding difficulty? Please estimate your extra costs in a typical month.

- $1–200
- $201–401
- $401 or more
- No extra cost

17. Please estimate your/your whānau's mileage (in kilometres) for these appointments in a typical month.
18. Please estimate your/your whānau's additional expenditure on costs related to travelling for appointments (e.g., hotel, airfare, gas, food costs while travelling, parking, etc.) in a typical month.

- $1–200
- $201–400
- $401 or more
- No extra cost

19. Do you pay extra for private school or education services necessary to accommodate your child's feeding needs?

- Yes
- No

20. Please estimate your additional education expenditures in a typical month.

- $1–200
- $201–400
- $401 or more

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

- No extra cost

21. Do you or anyone in your whānau feel that your relationship with food or mealtimes has changed because of your child's feeding difficulty?

- Yes
- No

22. Do you/your whānau feel stress over your child's feeding difficulty?

- Yes
- No

23. Has the stress resulted in any health problems for you or anyone in your whānau?

- Yes
- No

24. Have you, or anyone in your whānau, experienced an increase or development of the following because of your child's feeding difficulty? Check all that apply:

- Depression
- Substance use
- Substance abuse
- Anxiety
- Relationship struggles with spouse/partner
- Separation from spouse/partner
- Divorce
- Relationship struggles with PFD children
- Relationship struggles with children who are typical feeders
- Relationship struggles with wider family
- Disconnection from community
- Loss of personal identity
- Other (please specify):

25. Do you or your whānau spend money to address these psychological costs (e.g., on therapy, self-care, etc.)?

- Yes
- No

26. Please estimate how much you/your whānau spend on care for these psychological costs in a typical month.

- $1–200
- $201–400
- $401 or more
- We do not spend money on psychological costs

27. Have you accessed any free support systems for psychological support (e.g., Healthline, Lifeline, depression.org.nz, CALM app)?

- Yes
- No

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

- Prefer not to say

28. Please tell us about any people or groups who have been particularly supportive or helpful in helping you or your whānau care for your child.
29. Have you or anyone in your whānau gained any beneficial knowledge and/or experiences through raising your child with a feeding difficulty?

- Yes (please comment):
- No
- Unsure

30. What do you and your whānau enjoy doing together with your child with a feeding difficulty?
31. What does your child particularly enjoy doing?
32. Thank you for your responses. Is there anything else you want to tell us?
33. What ethnicity do you most identify with?

- Māori
- Pacific
- Asian
- Middle Eastern/Latin American/African
- NZ European or European
- Other

34. What is your marital status?

- Married/domestic partnership
- Single
- Divorced
- Widowed
- Separated
- Prefer not to answer

35. Which region of New Zealand do you live in?

- Northland/Te Tai Tokerau
- Auckland/Tāmaki Makaurau
- Waikato
- Bay of Plenty/Te Moana-a-Toi
- Gisborne/Tūranganui-a-Kiwa
- Hawke's Bay/Te Matau-a-Māui
- Taranaki
- Manawatū-Whanganui
- Wellington/Te Whanganui-a-Tara
- Tasman/Te Tai-o-Aorere
- Nelson/Whakatū
- Marlborough/Tauihu
- West Coast/Tai Poutini
- Canterbury/Waitaha
- Otago/Ōtākou
- Southland/Murihiku
- Prefer not to answer

Appendix 1 (continued): Whānau of children with feeding difficulties in Aotearoa survey

36. What is your employment status?

- Employed full-time, 30 hours a week or more
- Employed part-time, less than 30 hours a week
- Unemployed and seeking work
- Unemployed and not seeking work
- Student
- Self-employed
- Homemaker
- Retired
- Prefer not to answer

37. Would you like to be entered into the prize draw or receive a summary of the results at the end of the project?

- Yes (you will be redirected to a new survey where you can enter your details NOTE: these details will not be linked to the answers you provided in the main survey) Please click on this link to prize draw entry and/or register to receive to a summary of the results.
- No (you will end the survey at this point and your answers will be submitted)

Appendix 2: Changes made to the original Feeding Matters Economic Impact survey (2019)

Original Feeding Matters Economic Impact survey*	Modifications to the questions
• What gender is/are your child(ren) with the PFD? • Please estimate the dollar amount you spend on medical expenses related to your child(ren)'s PFD in a typical month. • Please estimate the dollar amount you spend on these supplies related to your child(ren)'s PFD in a typical month. • Have you or your spouse or partner had to quit working, not take a job or promotion, or cut back on work hours in order to care for your child(ren) with PFD? • If you can, please estimate your total lost income due to caring for your child(ren) with PFD. • How much extra, beyond typical childcare costs or sitter costs, do you spend due to the special needs of your child(ren) with a PFD? If you can, please estimate your extra costs in a typical month. • Does your family spend more money on convenience food that you normally wouldn't have purchased as a result of accommodating your child(ren)'s PFD? • Which of the following things require your extra time due to your child(ren)'s PFD? • If you can, please estimate how much your health problems related to this stress cost you in a typical month. • What is the highest level of education that you have completed?	These questions were not included in our survey as they were either irrelevant to the research aim or would require too much effort from participants.
Which of the following diagnoses/challenges do/does your child(ren) face? • Check all that apply: • Autism or autism spectrum • Choking phobia • Food allergies • Cleft palate or palate defect • Vomiting • Dysphagia	The wording of certain diagnoses was modified to reflect the terms commonly used in Aotearoa, and the "non-diagnosed" option was removed.

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

• Oral motor dysfunction • Nervous system disorder (like cerebral palsy or encephalopathy) • Gastrointestinal condition (like reflux, short gut syndrome, esophagitis, or gastritis) • Premature/low birth weight • Heart disease • Head or neck abnormalities • Respiratory difficulties • Reflux • Medications that cause decreased appetite • Colic • NG tube fed • G-tube fed • Non-diagnosed • Other diagnosis or challenge not listed here	
What type of health insurance do(es) your child(ren) with PFD have? • Health insurance from my employer or my spouse/partner's employer • Health insurance I purchase personally out of pocket • Medicaid/public insurance • No health insurance • Other	Modified or removed these questions to be more reflective of the variety of publicly funded financial support options for children with disabilities available in Aotearoa. Also added a free-text option for participants to enter the name of their private health insurance provider (if applicable).
Do(es) your child(ren) with PFD have insurance from any of the following companies? • BCBS • Kaiser Permanente • UnitedHealthcare • Cigna • Anthem • Humana • Magellan • Aetna • None, n/a	Removed mentions of insurance in this question as health insurance is not as common in Aotearoa as it is in North America.

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

Which of the following medical expenses have you incurred as a result of your child(ren)'s PFD? • Feeding tube costs • Various medical payments to meet insurance deductible • Insurance co-pays • Formula not covered by insurance • Prescriptions not covered by insurance • Therapy visits • Feeding clinics • Other medical costs not listed here	
Do you travel in town for doctor or therapy appointments for your child(ren)'s PFD care? And Do you travel out of town for doctor or therapy appointments for your child(ren)'s PFD care?	Combined these two questions for brevity.
If yes: If you can, please estimate your additional expenditures in a typical year. Please consider hotel, airfare, gas, food costs while travelling, etc.	This question was made multi-choice to make it easier for participants to answer accurately.
Have you or anyone in your family experienced an increase or development of any of the following as a result of your child(ren)'s PFD? • Depression • Substance use • Substance abuse • Anxiety • Relationship struggles with spouse/partner • Separation from spouse/partner • Divorce • Relationship struggles with PFD children • Relationship struggles with children who are typical feeders	Added in more options to reflect the importance of whānau, community and personal identity.
Do you spend money to address these psychological costs, for example, on therapy, self-care, etc?	Added a question regarding participants' use of the free mental health support options available in New Zealand.

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

Have you ever used any of the following strategies to help cope with the costs of your child's PFD? • Missed appointments or therapies to save money • Spread out appointments or therapies to save money • Not participated in an intensive programme or feeding clinic due to cost • Reduced spending on basic needs like food or clothing in order to pay for your child(ren)'s PFD care • Chosen a less expensive doctor or therapist over another because of cost • Refused a procedure or test for your child(ren) because of cost • Asked the doctor for a less expensive medicine or prescription • Gave your child(ren) less than the prescribed amount of medicine to make it last longer/save money • Didn't fill or partially filled a prescription for your child(ren)'s PFD care because it cost too much • Enrolled in a programme to help pay for prescription medicines • Purchased medication from another country • Worked more hours (you or a family member) to help pay for your child(ren)'s PFD care • Sold possessions or property to pay for your child(ren)'s PFD care • Took out a second mortgage on your house to pay for your child(ren)'s PFD care • Used all or a portion of your savings to pay for your child(ren)'s PFD care • Borrowed money or used credit to pay for your child(ren)'s PFD care • Other	Added an option "worked more hours (you or a family member) to help pay for your child's care".

Appendix 2 (continued): Changes made to the original Feeding Matters Economic Impact survey (2019)

Overall, to what degree have the costs of your child(ren)'s PFD been a financial burden for you or your family? • Not a financial burden at all • Minor financial burden • Moderate financial burden • Significant financial burden • Catastrophic financial burden • I'm not sure	Changed the wording of the options to have a less negative connotation (changed burden to strain and removed the option for "catastrophic").
What race do you most identify with? • American Indian or Alaska Native • Asian/Pacific peoples • Black or African American • White • Two or more races • None of the above/Other • Prefer not to answer	Changed to ethnicity and used the groups used in the New Zealand Census.
What is your employment status? • Employed full-time • Employed part-time • Unemployed and seeking work • Unemployed and not seeking work • Student • Self-employed • Homemaker • Retired • Prefer not to answer	Defined full-time as 30+ hours, and part-time as 30 or less.
What is your household's annual income? • Less than $20,000 • $20,000 to $34,999 • $35,000 to $49,999 • $50,000 to $74,999 • $75,000 to $99,999 • $100,000 to $124,999 • $125,000 or more • Prefer not to answer	Rather than ask participants to share their income, we asked participants to rate the adequacy of their household income to meet their needs.

* In an email from H. Van der Molen, FirstEval Ltd (mkovacs@firsteval.com) in 2021.

Specialist vape store audit reveals poor compliance with new e-cigarette regulations

Jude Ball, Lesieli Katoa, Janet Hoek

ABSTRACT

AIM: Regulations announced in mid-2023 aimed to reduce youth vaping by curtailing the availability of cheap high-nicotine e-cigarettes (vapes). This study tested compliance with the new regulations for single-use vapes, which came into force on 21 December 2023.

METHODS: A 20-year-old "mystery shopper" visited 96% of specialist vape retailers (SVRs) in Wellington, Porirua, Lower Hutt and Upper Hutt (N=74) in January 2024, and observed i) R18 signage, ii) age verification practices, and ii) prices and brands of the cheapest available vaping products. Low-price vapes were purchased and inspected for compliance with new nicotine limits and safety regulations.

RESULTS: All but three stores (96%) displayed an R18 sign; however, signage in 29 stores (39%) was suboptimal. Only one store (1.4%) requested age identification (ID) on entry to the R18 premises. In 50% of stores, ID was requested when a purchase was made; however, a third of those retailers proceeded with the sale despite the buyer not providing ID. Single-use vapes remained available for NZ$10 or less in most stores, and reusable starter kits were also widely available for NZ$10–20. Discounted high-nicotine products were sold for as little as NZ$2.50 each. Most low-price products did not comply with the updated regulations.

CONCLUSION: Cheap, high-nicotine vaping products remained widely available following the introduction of stricter regulations in December 2023; products for sale included discounted and non-compliant vapes. The majority of SVRs had poor age verification practices. There is an urgent need to clarify rules, increase enforcement efforts and disallow discounting and giveaways of vapes.

E-cigarettes (commonly known as "vapes") ostensibly provide a less harmful alternative to tobacco smoking. Research suggests that vaping can help people stop smoking,[1] and the Ministry of Health – Manatū Hauora believes that vaping products have a role to play in achieving Aotearoa New Zealand's Smokefree 2025 goal.[2] Although vaping poses fewer physical health risks than smoking, vaping may harm respiratory, cardiovascular and oral health.[3–7] Additionally, most vaping products contain nicotine, which is highly addictive and may undermine psychological and social wellbeing, especially among children and adolescents.[8–11]

Vaping prevalence has increased rapidly in Aotearoa New Zealand in recent years, particularly among young people, most of whom have never smoked. For example, in 2022/2023 people aged 18–24 had the highest prevalence of daily vaping at 25%, compared with 10% in the adult population overall.[12] Daily vaping among 15–17-year-olds was 15%, a dramatic increase from 2% in 2019/2020.[12] Youth smoking has continued to decline in recent years; however, the easy availability of high-nicotine vapes has seen an increasing proportion of young people transition from experimental to daily vaping, and become addicted.[8,13,14]

Rapid vaping uptake among young people reflects the aggressive marketing undertaken to position vapes as lifestyle accessories.[15] Although the Government introduced legislation to regulate vape product marketing and sales in 2020 (The *Smokefree Environments and Regulated Products (Vaping) Amendment Act 2020*),[16] the measures failed to adequately protect young people[17,18] and further regulations, including limits on the nicotine content of disposable vapes, came into effect in 2023.[19]

Among other measures, the 2020 *Act* and accompanying regulations prohibited the supply of vaping products to people under 18 and required retailers to display R18 sales restriction notices. Under the *Act*, specialist vape retailers (SVRs) must be registered, and must take "*all practicable steps to prevent a person under the age of 18 years from entering the retailer's approved vaping premises*."[16,20] Changes introduced in 2023 affected single-use (disposable) vaping products; from 21 December 2023, these products had to meet new product safety requirements, including a nicotine limit of 20mg/mL, removable batteries and a child safety mechanism. From 21 March 2024, regulations will limit flavour descriptions and packaging

(e.g., disallowing cartoon imagery), limit reusable pods and e-liquids to nicotine strength of 28.5mg/ml and extend battery and child safety requirements to reusable vapes.

While the new 2023 regulations have also introduced some proximity limits (new SVRs may not trade within 300m of schools or marae), they do not address the proliferation of vape outlets that has occurred, particularly in lower-income communities—a pattern that has also been observed internationally.[21] Many of these outlets have evolved as "stores-within-a-store" that exist inside an existing dairy's retail footprint.[22] This phenomenon does not respect the law's intent, which aimed to prevent normalisation of vaping and reduce children's exposure to vaping products. Furthermore, it has contributed to the easy availability of vaping products in lower-income neighbourhoods.

Although few studies have examined retailers' compliance with vaping regulations, the existing research suggests inconsistent compliance. Within Aotearoa New Zealand, qualitative research exploring how underage youth access vaping products found many knew of retailers who did not require age identification (ID).[23] Overseas studies examining compliance with restrictions (e.g., nicotine content or flavour restrictions) also report widespread non-compliance and enforcement challenges.[24–30]

Given the serious community and public health concerns about underage sales and youth vaping, we examined compliance with vape regulations in Aotearoa New Zealand in January 2024. We focussed on regulations intended to prevent sales of vapes to minors and curtail the availability of cheap, high-nicotine disposable vapes favoured by underage users. Specifically, we audited SVRs' compliance with R18 laws and new regulations that came into force on 21 December 2023, which lowered the maximum nicotine strength from 50mg/ml to 20mg/ml in single-use vapes and required all single-use devices to have removeable batteries and a child safety mechanism.

Methods

The audit used an observational study design and employed a "mystery shopper" approach to evaluate compliance with the *Smokefree Environments and Regulated Products Act 1990* (the primary legislation that the 2020 *[Vaping] Amendment Act amended*) and related regulations. The mystery shopper was a 20-year-old medical student (LK).

Ethical approval

The study was approved by the University of Otago Human Ethics Committee, reference 23/147.

Identification of SVRs

The study area was defined by the City Council boundaries of Wellington, Porirua, Lower Hutt and Upper Hutt cities. We identified retailers currently operating within the study area using a list of registered SVRs supplied by Regional Public Health (dated November 2023) and supplemented this list with the "vape store near me" search function on Google Maps to identify any new or additional stores.

Audit questions

We drew on relevant Aotearoa New Zealand legislation and regulations and overseas vaping-related compliance projects, and consulted with an advisor from Regional Public Health (Health New Zealand – Te Whatu Ora) when developing the audit questions.

The audit focussed on low-price products because these are the most affordable devices and are favoured by young people, the priority group for vaping prevention. We also examined measures to prevent underage sales as set out in the 2020 legislation.

The key audit questions were:

1. Is there an R18 sign displayed outside the store?
2. Is the outlet a store-within-a-store (i.e., within the footprint of another store)?
3. Is ID checked at retail entrance when entering the store?
4. What is the price and brand of the cheapest single-use (disposable) vape in the store?
5. What is the price and brand of the cheapest starter pack for reusable vapes?
6. Is ID requested upon purchase of vape products?
   - If so, is sale refused due to failure to provide ID?
7. For purchased single-use products, does the vape meet product safety requirements for
   - nicotine content;
   - removable batteries;
   - child safety mechanism?
8. Other observations related to the store or sale of vaping products.

Procedure

Store visits by LK took place between 3 and 23 January 2024. LK followed the fieldwork protocol, which defined key terms (e.g., "highly visible" vs "less visible" R18 signage), the process for engaging with retailers and recording audit findings, and safety procedures as required by our ethics approval (see Appendix).

Responses to the audit questions were recorded using a Qualtrics survey on a mobile phone device, with the initial questions (e.g., location, signage) being completed before LK entered the store.

Upon entering each store, LK enquired about the cheapest single-use product and the cheapest starter kit, noting the price and brand of each. She asked to purchase one of these products. If she was asked to show ID, she said she had accidentally left it at home/in the car and asked to make the purchase without ID.

If the vape price was NZ$20 or less, and LK had not already purchased that model/brand, she made the purchase (if not refused due to failure to show ID). If an example of the cheapest brand/model had previously been purchased, or the device cost more than NZ$20, LK began the purchase to test whether she would be asked for ID, but then said she had forgotten her wallet.

Remaining responses were entered into Qualtrics immediately after leaving the store, and a detailed inspection of the purchased products was carried out by JB following fieldwork completion.

On two occasions LK was refused a sale after failing to show ID, and JB (who had accompanied LK on 2 out of 6 fieldwork days to provide transport) then entered the store to purchase the product.

Results

Location of SVRs

We identified 77 SVRs currently operating in the study area: 34 in Wellington, 16 in Porirua, six in Upper Hutt and 21 in Lower Hutt (Table 1). All were on the list of registered SVRs supplied to the researchers. Three stores were temporarily closed when we visited (one each in central Wellington, Kenepuru and Wainuiomata), leaving 74 stores (96%) included in the audit.

We observed clustering of SVRs in city centres, particularly in the entertainment district of Wellington (Cuba St, Manners Street, Courtenay Place), areas where young people congregate. Suburban stores were often located in communities with high socio-economic deprivation e.g., Newtown, Porirua East, Tītahi Bay, Naenae, Taitā (Table 1). We found no SVRs in affluent suburbs such as Thorndon, Kelburn, Seatoun, Khandallah or Plimmerton.

Store-within-a-store vs standalone SVRs

Of the SVRs visited, 43% (n=32) were stores-within-a-store (i.e., an SVR within the footprint of another store). Almost all of these were within superettes or dairies, mostly in suburban areas.

One suburban dairy was registered as an SVR and was selling both groceries (e.g., bread, pies, soft drinks) and a wide range of vaping products at a single counter, apparently contravening the requirement that at least 70% of the total sales from an SVR must be from the sale of vaping products. A child was in the store when LK entered and could easily view the array of vaping products for sale.

R18 signage and age verification practices

Of stores audited, 42 (57%) displayed a highly visible R18 sign outside the store (i.e., eye level, large, bold type). A further 29 stores (39%) displayed a less visible R18 sign (e.g., faint font, small, positioned away from the entrance, perpendicular to the entrance, or below eye level), and three stores (4%) did not display an R18 sign at all.

Only one store (1.4%) asked for ID when LK entered the store.

Half of the SVRs (n=37) requested ID when LK attempted to make a purchase, and of these 36% (n=13) proceeded with the sale, even though she did not provide ID. (Typically, the retailer would say, "*Make sure you bring it next time*" or similar). Half did not ask for ID at all.

Availability of low-price vaping products

Several stores sold non-compliant disposable vapes at heavily discounted prices. For example, we purchased two AirsPops vapes (50mg/ml nicotine strength) for NZ$5 (NZ$2.50 each) in a Porirua store. We observed non-compliant "old stock" available at discounted prices throughout the study area, with AirsPops the most widely available brand. Some retailers spontaneously explained that the products were discounted because they were no longer legal.

The cheapest non-discounted single-use vapes ranged from NZ$10 to NZ$35; most stores (63%) sold solo (n=26, 35%) or alt. Nu brands (n=21, 28%) as their cheapest disposable (both NZ$9.99). AirsPops was the cheapest brand in 14 stores

Table 1: Location of specialist vape retailers operating in Wellington, Porirua, Upper Hutt and Lower Hutt, January 2024.

Location	Number of stores	NZ Deprivation Index decile
Wellington		
Wellington Central City	22	3–6
Newtown/Mt Cook	4	6–9
Kilbirnie	2	7
Tawa Central/North	2	5
Strathmore	1	8
Brooklyn	1	2–3
Newlands	1	3–4
Johnsonville	1	3
Porirua		
Porirua Central City/Kenepuru	5	10
Tītahi Bay	5	8–9
Waitangirua	2	10
Porirua East/Ranui	2	10
Takapūwāhia	1	9
Whitby	1	1
Upper Hutt		
Upper Hutt Central City	3	4
Te Mārua	1	3
Silverstream	1	2
Trentham	1	7
Lower Hutt		
Wainuiomata	5	7–8
Lower Hutt City Centre	3	2–4
Naenae	3	10
Petone	3	5
Taitā	2	10
Stokes Valley	2	7
Boulcott	2	4
Moera	1	10
Total	**77**	

(19%), with non-discounted prices at NZ$10 (single use, 3ml) or NZ$15 (eco single use). Only one store did not sell disposable vapes.

The cheapest starter kit (comprising a device plus e-liquid or pods), ranged from NZ$10 (solo brand) to NZ$50. The cheapest starter kit in most SVRs sold for NZ$15–20.

Compliance of low-price single-use products

We purchased 11 different low-price vape products. Table 2 summarises the characteristics of purchased products. Figure 1 provides examples of single-use products purchased.

Based on our interpretation of the law, none of the single-use products purchased were compliant with the new regulations that came into force on 21 December 2023. Some were clearly non-compliant (Figure 1a), while others were ambiguous and compliance depended on the interpretation of "removeable batteries" (Figure 1b) and "single use" (Figure 1c).

Nicotine limit

Only two single-use products purchased complied with the new nicotine limit of 20mg/ml for single-use vapes: solo and alt. Nu 2% disposables (Figure 1b). Other products that we classed as single use based on our reading of the legislation (Figure 1a, 1c) exceeded the nicotine limit.

Removeable batteries

Three single-use products purchased were moulded disposable vapes that did not have removeable batteries; these clearly did not comply with the new regulations (Figure 1a).

Three vapes (solo and alt. Nu disposables, AirsPops Eco) had tiny screws in the base; theoretically these could be unscrewed to disassemble the body of the vape and remove the battery. However, the screw holes were less than 1mm wide and removing the batteries would require specialist tools (Figure 1b, 1c iii). User instructions for alt. Nu and solo state: "*We do not recommend removing the battery from this device*." These three products did not meet our interpretation of "removable batteries."

Two products, Vorteke puk. and ALLO Nexus 6000 (Figure 1c), had a rechargeable battery that could be removed from the disposable vaping device and re-used with replacement devices. In our view, these products complied with the new removable battery regulations.

Child safety mechanism

None of the vapes pictured in Figure 1a had a child safety mechanism and were clearly non-compliant. All new single-use products (Figure 1b–c) had a locking mechanism of some kind.

Users could lock and unlock the AirPops Eco vape (Figure 1c) by performing three quick puffs on the mouthpiece; this device locked automatically if unused for 1 hour. We consider that this device does not comply with the child safety requirements, since a child could easily pick up the unlocked device within an hour, activate a locked device by mimicking an adult seen taking three puffs or inadvertently turn the device on by simply trying to puff on it.

The puk. device (Figure 1c) requires the user to connect and disconnect the pod to the battery three times to activate the device. The instructions do not state how to power off the device; nor do they describe an automatic locking mechanism. Based on inadequate child safety instructions, we consider this product non-compliant.

solo, alt. Nu, and ALLO Nexus 6000 devices (Figure 1b, 1c) unlocked by rapidly clicking a button on the base five times and locked automatically 10 minutes after the last puff. We consider these child safety mechanisms adequate to meet the new regulations.

Compliance of low-price reusable products

Characteristics of reusable products purchased are summarised in Table 2. Of the three low-price starter kits we purchased, one was clearly non-compliant because it did not meet labelling requirements (Figure 2a), and two were compliant at the time of purchase, but do not meet nicotine limits or child safety requirements that came into effect on 21 March 2024 (Figure 2b).

Discussion

We found that cheap, high-nicotine vapes remained widely available following the implementation of new regulations intended to curtail these products' availability. Products offered for sale included both non-compliant "old stock", often sold at heavily discounted prices, and ambiguous new products intended to meet (or circumvent) current regulations, most of which we deemed non-compliant based on our interpretation of the law. Over half of the SVRs visited had poor age verification practices and either did

Table 2: Characteristics of low-priced vapes purchased in January 2024.

Brand, model	Flavour(s) purchased	Price (NZ$)	Volume	Nicotine strength (nicotine salt)	Nicotine limit compliance	Child lock compliance	Removable battery compliance	Notes
Single-use products								
AirsPops one use	Ice Cola, Bubble Bum, Pink Crystal, Aromango	$2.50–9	3ml	50mg/ml	No	No	No	Generally discounted, e.g., two for $5
AirsPops Eco	Freezy Grape, Energy Power	$14.90	3ml	50mg/ml	No	No*	No*	Marketed as recyclable, $5 credit when used vape is returned
ALLO Nexus 6000	Raspberry Peach	$22	14ml	50mg/ml	No	Yes	Yes	Rechargeable battery, single-use vaping device
alt. Nu	Lemon	$10	3ml	20mg/ml	Yes	Yes	No*	Batteries cannot be removed without specialist equipment
Smok Stick Bar	Taro Ice Cream	$5	3ml	50mg/ml	No	No	No	Discounted. Flavour may be designed to appeal to Pacific people
solo	Strawberry Mint, Sour Apple, Mint	$10	3.5ml	20mg/ml	Yes	Yes	No*	Batteries cannot be removed without specialist equipment

Table 2 (continued): Characteristics of low-priced vapes purchased in January 2024.

Brand, model	Flavour(s) purchased	Price (NZ$)	Volume	Nicotine strength (nicotine salt)	Nicotine limit compliance	Child lock compliance	Removable battery compliance	Notes
Vorteke puk.	Mint	$14.95	10ml	35mg/ml	No	No*	Yes	Rechargeable battery, single-use vaping device
Vozol Bar	Refreshing Mint	$10	4ml	46mg/ml	No	No	No	Discounted
Reusable starter packs								
R and M Dazzle	Peach Ice Cream	$15	10ml	Not stated	Unclear	NA	NA	Non-compliant labelling
solo kit	Mint	$9.99	2.5ml	50mg/ml	Yes	NA	NA	
Vozol Switch	Grape Ice	$20	4.5ml	50mg/ml	Yes	NA	NA	

*Based on authors' interpretation of the law.
Note that compliance of reusable starter packs was based on the law at time of purchase (January 2024).

Figure 1: Examples of low-price single-use vapes purchased in January 2024.

a)

b)

c)

a) Clearly non-compliant single-use vapes, old stock

i) Vozol Bar, 46mg/ml strength (nicotine salt), 4ml volume, NZ$10.

ii) Smok Stick Bar, 50mg/ml strength (nicotine salt), Taro Ice Cream flavour, 3ml volume, NZ$5.

iii) AirsPops, 50mg/ml strength (nicotine salt), 3ml volume, NZ$2.50–9.

b) New single-use products, do not appear to comply with removeable battery requirement

i) alt. Nu 2%, 20g/ml strength (nicotine salt), 3ml volume, NZ$10. Batteries cannot be removed without specialist equipment.

ii) solo 2%, 20mg/ml strength (nicotine salt), 3.5ml volume, NZ$10. Batteries cannot be removed without specialist equipment.

c) Ambiguous new products, exceeded nicotine limit for single-use vapes

i) ALLO Nexus 6000, 50mg/ml strength (nicotine salt), 14ml volume, NZ$22. Removeable, rechargeable battery but vaping device itself is single use. Marketed as “device + pod”.

ii) Vorteke puk., 35mg/ml strength (nicotine salt), 10ml volume, NZ$14.95. Removeable, rechargeable battery but vaping device itself is single use. Marketed as “device + pod”.

iii) AirsPops Eco one use, 50mg/ml strength (nicotine salt), 3ml volume, NZ$14.90. Marketed as recyclable, with a $5 discount on next purchase when used vape is returned to the store.

Figure 2: Examples of low-price reusable vape starter packs purchased in January 2024.

a) **b)**

a) Non-compliant reusable vape starter pack

R & M Dazzle device + 10ml e-liquid, nicotine strength not stated, NZ$15. Does not comply with labelling requirements, e.g., lacks health warning, nicotine strength, ingredients. At time of writing, cartoon imagery was still permitted but has become illegal from 21 March 2024.

b) Reusable vape starter packs—compliant when study was undertaken

i) solo kit: vaping device + charging cable + 2.5ml pod, 50mg/ml (nicotine salt), NZ$9.99. At the time of purchase, pod systems were not subject to reduced nicotine limits or safety requirements. This kit is longer compliant from 21 March 2024.

ii) Volzol Switch device + prefilled pod 50mg/ml strength (nicotine salt), 4.5ml capacity, NZ$20. At the time of purchase, pod systems were not subject to reduced nicotine limits or safety requirements. This kit is longer compliant from 21 March 2024.

not request ID or made sales even in the absence of ID.

Discounted prices on old stock meant high-nicotine vapes (50mg/ml) remained available for as little as NZ$2.50 each in the month following the regulation change. The cheapest products we purchased were available in the poorest neighbourhoods (New Zealand Deprivation Index decile 10). Inspection of online vape retailer websites in November and December 2023 showed that discounted disposable vapes were also promoted immediately prior to the regulatory change. Although the regulations aimed to reduce vaping products' addictiveness and affordability, in the short term, discounting and bundling promotions have had the opposite effect and high-nicotine products have become cheaper.

SVRs are currently exempt from measures in the *Smokefree Environments and Regulated Products Act* that prohibit free or discounted distribution or supply of regulated products. We strongly recommend removing this exemption and aligning vaping products with other regulated products to prevent heavily discounted vapes from flooding the market whenever regulations change. The National–New Zealand First coalition agreement includes plans to ban disposable vapes, which is likely to lead to heavy discounting of these products if implemented. A law against price discounting would also disallow loyalty schemes, giveaways and "buy one, get one half price"-type deals, which are currently used extensively by retailers to promote low-price vapes, making them very affordable for children and adolescents.

Until very recently, only disposable vapes were available for NZ$10 or less; however, pod system "starter packs" are now available at that price, making them easily affordable to young people. For example, the solo website (examined in January 2024), sold NZ$10 starter kits online and at 1,864 physical outlets around Aotearoa New Zealand, including SVRs and general vape retailers (the latter may only sell tobacco, mint and menthol flavours). Continuous innovation allows vape companies to evade regulations while undercutting competitors' pricing and the appearance of cheap pod systems means NZ$10 vapes are likely to remain available, even if single-use vapes are disallowed.

"Hybrid disposables", a new product category,

appear to meet the removable battery requirement but many contain high-nicotine (50mg/ml) e-liquid (illegal for single-use products from December 21 2023), which suggests suppliers do not view these products as "single use." However, the vaporising mechanism (i.e., the vaping device) appears to be located in the disposable "pod" and the reusable component contains only the battery. We consider that the "puk." and "Nexus 6000" are therefore single-use products and should be subject to the 20mg/ml nicotine limit, as should the AirPops Eco one use. Regulators must clarify this ambiguity, either via prosecution of test cases or by revising the regulations.

Greater clarity regarding compliance with removable battery regulation is also required. Products such as solo, alt. Nu and AirsPops Eco require specialist tools to remove the batteries and thus do not appear to align with the Vaping Regulatory Authority's advice: "[T]*he intention of the regulation is to allow easy inspection of the battery and removal if necessary. A product requiring a specialist screwdriver that an average consumer wouldn't have easy access to may not be meeting the intention*" (personal communication in: email from Senior Advisor – Regulated Products, Public Health Policy and Regulation, Ministry of Health – Manatū Hauora, 30 January 2024). A clear response outlining what is and is not acceptable would provide product manufacturers and consumers with clarity and avoid the "grey areas" that are rapidly developing.

Although SVRs did not break the law by selling to our 20-year-old mystery shopper, we find the lack of robust age verification practices unacceptable. Guidelines for selling alcohol state that "*All customers who look under the age of 25 should be asked for valid ID*";[31] vape retailers should have to apply similar guidelines.

While existing regulations have restricted vape product advertising, they have not effectively controlled sales promotions. Tobacco advertising restrictions in the 1980s and 1990s saw a large growth in retail promotions (e.g., loyalty schemes, discounts, point of sale promotions) as tobacco companies re-aligned their marketing strategies;[32] vaping product marketers appear to be responding in a similar way, and our findings show that SVRs are pushing (if not breaking) the boundaries set by regulations. As a result, low-cost, addictive products remain highly visible and affordable to young people and will continue to undermine their wellbeing if decisive action is not taken.[4,6,9,10]

Since our audit, the Government has repealed laws aimed at reducing tobacco's availability and addictiveness. The repealed measures would have significantly reduced the risk of youth transitioning from vaping to tobacco addiction, since denicotinised tobacco would hold little appeal and would be difficult to access. Given the repeal, it is vital that policymakers designing new policies governing tobacco, vapes and other nicotine products consider youth wellbeing and the difficulty of changing behaviour once addiction is established. Poorly designed regulations could inadvertently drive young people towards tobacco for their nicotine "hit", given its easy availability. There is an urgent need for guidance and support services to help children and adolescents overcome nicotine addiction.

This study is the first to audit compliance with Aotearoa New Zealand's vaping-related legislation. As with any research, it has limitations. We only audited SVRs and did not include general retailers that sell vapes (e.g., convenience stores/dairies, service stations), which greatly outnumber SVRs and operate under different rules (e.g., the flavour restrictions noted earlier). Future research should audit these stores' compliance with current policy. Our audit only covered four City Council areas in the Greater Wellington Region, and thus may not be representative of other regions. Nonetheless, because compliance problems were not limited to a particular area or sub-group of stores, we think it likely that the problems identified are systemic and nation-wide. We could not check compliance of all products for sale at the SVRs audited and focussed on a selection of low-price products. Future studies should take a more comprehensive and systematic approach to product compliance testing, including testing whether nicotine strength is true to label.

In conclusion, our findings indicate that recent regulations have been largely ineffective; post-implementation, high-nicotine vapes remained widely available at prices school children could easily afford. While we have called for stronger policy, we also believe existing regulations require more comprehensive enforcement. Addressing the regulatory gaps and breaches we have identified must become an urgent priority if the Government is serious about reducing vaping among young people.

COMPETING INTERESTS
None to declare.

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Appendix

Protocol SVR Compliance Audit Fieldwork

January 2024

Safety:

- Fieldwork must only be conducted during daylight hours.
- If conducting fieldwork alone, check in with Jude by text/phone at the beginning of each shift stating WHERE you will be working and, after, that you've finished safely.
- If at any time you feel unsafe, please withdraw and return to a safe place.
- If your cover is exposed, please hand over a letter to the retailer explaining the project and withdraw immediately, saying they should contact Dr Ball with any questions.

Identifying SVRs:

- Use the "master list" from RPH, and cross them off as you go.
- If a store has closed down, note this on the master list.
- If you can't find a store, try Google Maps and/or phone Jude for support.
- In each suburb/area, use Google Maps ("vape store near me") to check in case there are new or unregistered stores.
- Please include new/unregistered stores in the audit and note the name and address on the master list.

Before entering store:

- Enter name and address of SVR in Qualtrics and complete all the initial questions, using definitions below.
- Is the store located next to/opposite bus/transport?
  - **Definition**: within 20m? Easy line of sight from bus stop to store, thereby making vapes highly visible to people waiting at bus stop.
- Is there an R18 sign on display outside the store?
  - **Definition:**
    - **Highly visible** = eye height, straight on, next to or on door, large and/or bold type. Can't miss it.
    - **Not very visible** = small, faded/faint type, at an angle to person entering, not located well. Could easily miss it.
- Is there a window display with vaping products visible from outside the store?
  - **If yes, take a photo** (if possible/comfortable to do so).
- Is this a store-within-a-store?
  - **Definition: (if "yes" to ANY of the following)**
    - Has the SVR been subdivided from a larger store (i.e., it is within the footprint of another retailer)?
    - Do customers have to walk through another store to get to the SVR (i.e., the SVR doesn't have a separate entrance from the street)?
    - Does the SVR have a door connecting to a different retailer?
    - Does a staff member have to come from the "main" store to the SVR to serve customers?

In the store:

1. Look around, notice posters, promotional materials.
2. Ask price of cheapest disposable vape—remember it!
3. Ask price of cheapest starter-pack for reusable vapes—remember it!

Definition: "Disposable" = single-use, all-in-one product with no replaceable components—you can't insert new pods or refill it. **"Reusable"** = a vaping device that you can refill or insert new pods into.

- Ask to buy the lowest priced product (if there are options, go for the most youth-appealing one, or a brand you haven't purchased yet). "OK, I'll take the…"
- If cost is $20 or less, go through with the sale. **GET A RECIEPT please!**
- If more than $20, pretend to go through with the sale and see if they ask for ID before realising you left your wallet at home.
- If asked for ID, try to get away without it. (e.g., "It must be in the car.")

Other observations could include:

- Detail about the store-within-a-store set up
- Proximity to other SVRs
- Age-checking policy displayed

- Don't sell disposables at all
- Children/underage youth in store (including children of customers)
- Young people loitering outside the store
- IQOS is being promoted
- Detail about promotional displays in store
- Other discounts, promotions
- Vape vending machine, self-service touchscreen
- Sale of other youth-oriented products
- Vape emissions passing into adjoining store

After leaving the store:

- Complete remaining Qualtrics questions.
- Use envelopes/rubber bands to keep the product and the receipt together.

Back at the office:

- Analysis of compliance, marketing attributes of purchased products.
- Investigate SVR locations—NZ Deprivation Index.

An upstream approach to addressing the childhood obesity epidemic in New Zealand—a call to action

Velia Men

ABSTRACT

Childhood obesity is a critical issue in New Zealand that we can no longer afford to ignore. Currently, one in three children is overweight or obese, putting the health of an entire generation at risk if we continue to delay taking action. This issue highlights a significant matter of equity. Māori and Pacific children and those from socio-economically deprived backgrounds are disproportionately affected, reminding us of the systemic barriers rooted in historical factors that exist within our society. Efforts focussed on changing individual behaviour have achieved limited success in reducing childhood obesity rates. Therefore, it is necessary to shift our focus upstream and address the root causes of this issue. This viewpoint piece underscores the role of the obesogenic environment as the primary driver of childhood obesity, advocating for an upstream approach to enact broader changes in the food environment.

Within this framework, this piece puts forward three policy measures that could be essential in addressing the childhood obesity epidemic: implementing a tax on sugary beverages, restricting unhealthy food marketing and ensuring access to healthy food in schools. These policies are backed by substantial evidence of their efficacy, cost-effectiveness and potential to improve health equity, including contextual evidence from successful international models. However, despite ample evidence and support, New Zealand has fallen behind international standards in adopting these measures, partly due to resistance from the food industry and the need for stronger political leadership. Thus, a "call to action" is needed to overcome these challenges, mobilise against the current policy inertia and make addressing childhood obesity a priority.

We are currently in the midst of a serious epidemic. In the past four decades, obesity rates have tripled globally, leading to a surge in chronic diseases like heart disease, stroke and diabetes.[1] Meanwhile, children in New Zealand are constantly exposed to energy-dense, nutrient-poor foods that are widely available and heavily promoted.[2] Consequently, one in three children is now overweight or obese, making our country the second-worst in the OECD for childhood obesity rates.[1] Urgent action is needed to implement stronger policy interventions targeting the root causes of this issue. While ample research exists, the challenge lies in political will rather than a lack of evidence-based policy interventions. This viewpoint article is a call to action urging decisive policy action and collective efforts across sectors of society to prioritise addressing the childhood obesity epidemic in New Zealand.

The burden of childhood obesity in New Zealand

Childhood obesity is a significant public health concern due to its long-term impact on adult weight status and morbidity. Studies show that around 80% of obese children carry obesity into adulthood, increasing the risk of developing numerous non-communicable diseases.[3] Early intervention is crucial as treating adult obesity is challenging, and weight patterns established early in life tend to be persistent.[4] For instance, being overweight or obese in early adulthood has been shown to have the highest impact on the cumulative lifecourse risk of developing type 2 diabetes compared to in later life.[5]

In New Zealand, excess weight contributes directly to around NZ$2 billion in annual healthcare expenses, constituting 8% of the total healthcare budget.[6] In a 2018 systematic review, the lifecourse economic impact of childhood obesity, including direct healthcare costs and productivity loss, was estimated to be around €149,000 per child compared to those of normal weight.[7] Paradoxically, funding for population nutrition initiatives has decreased in New Zealand over the past decade and is relatively insufficient compared to the preventable healthcare costs associated with childhood obesity.[8]

Figure 1 illustrates the trend in childhood

Figure 1: Prevalence of obesity or overweight status in children aged 2–14 in New Zealand (statistics from the Ministry of Health Obesity Statistics 2022/2023).[9]

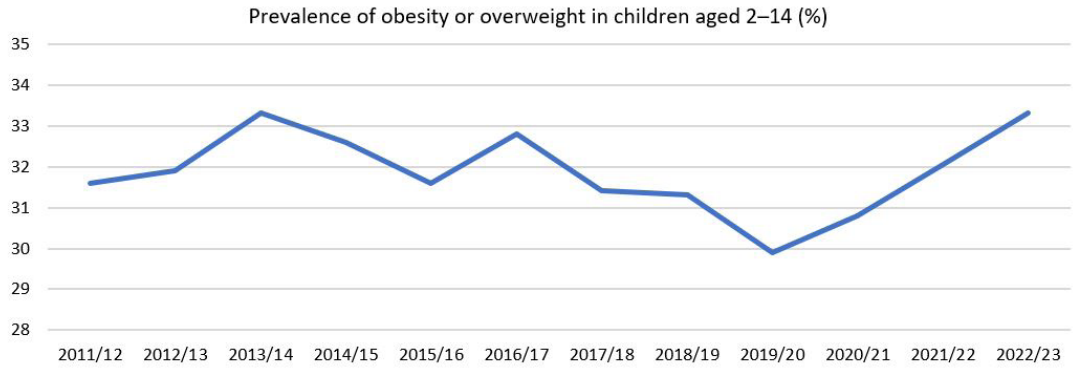
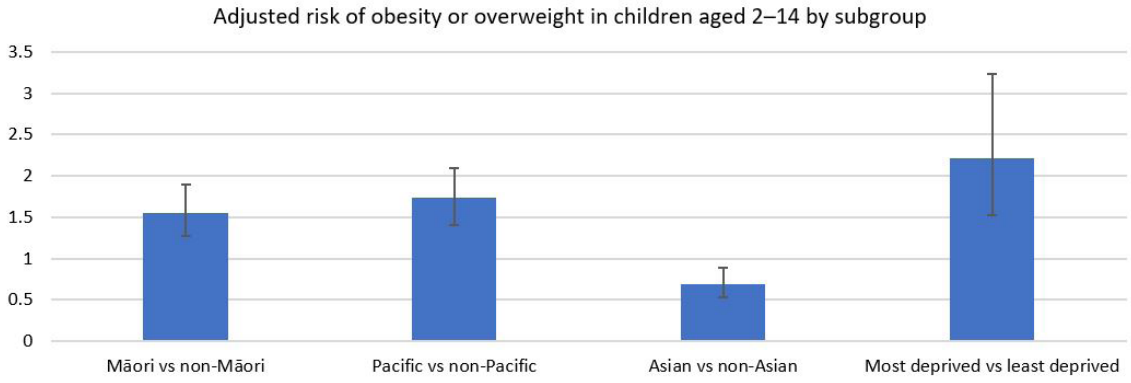


Figure 2: Adjusted risk ratio of obesity or overweight status in children aged 2–14 in New Zealand (statistics from the Ministry of Health Obesity Statistics 2022/2023).[9]

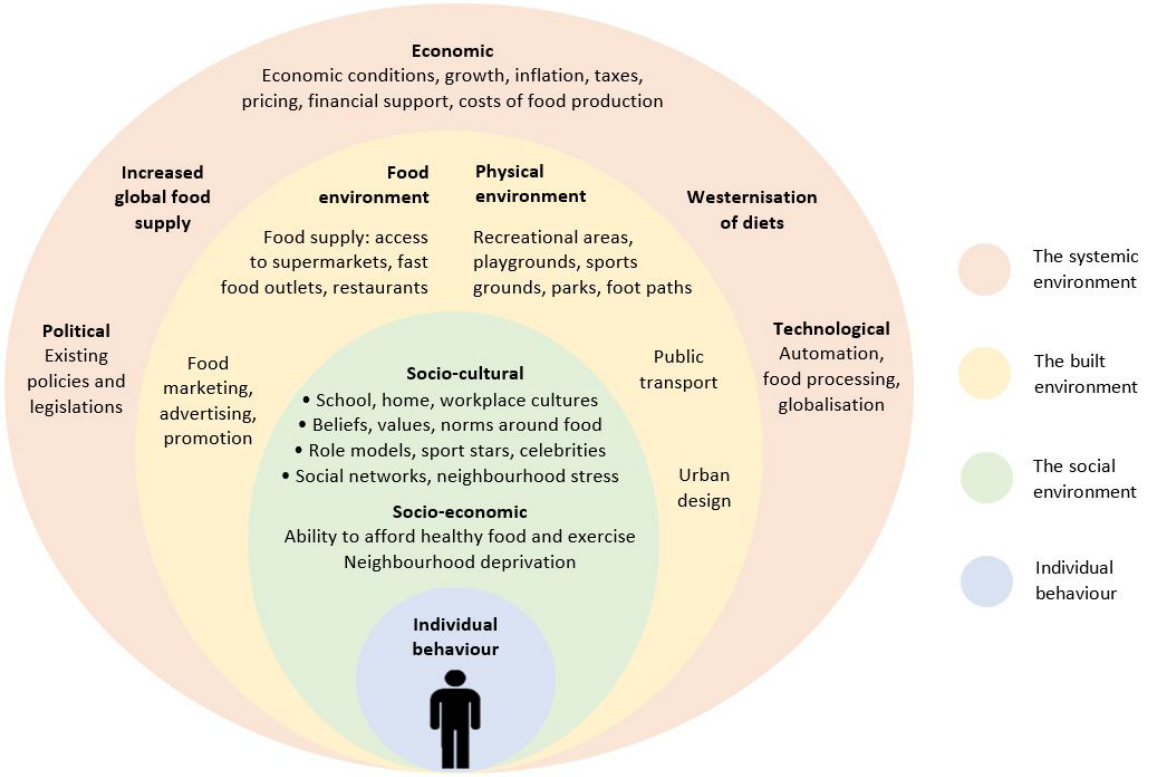


overweight or obesity rates over time, highlighting a notable increase in the prevalence since 2019/2020 after a decade of stabilisation. Disparities are evident in overweight and obesity rates based on ethnicity and socio-economic status (SES), with higher rates observed in Māori and Pacific children and those living in more socio-economically deprived areas (Figure 2).[9] Moreover, disparities in the prevalence of obesity exist across different geographical communities.[10] While ethnicity, urbanicity and socio-economic deprivation account for nearly half of this variability, the remaining 50% is likely influenced by factors relating to the local environment, such as the availability of energy-dense foods, recreational spaces and transportation options.

The upstream causes of childhood obesity

Obesity is a highly stigmatised condition, often blamed on individual genetics and lifestyle choices. However, growing evidence suggests the "obesogenic environment" is a major driving force behind the global rise of obesity rates.[11] Furthermore, there is evidence that upstream interventions aimed at addressing the obesogenic environment are a promising approach for addressing the global obesity epidemic.[12] Figure 3 illustrates a simplified model of the obesogenic environment, highlighting how individual behaviours are shaped within this broader context. Arguably, the primary driver of this trend is the global change in food energy supply and the Westernisation of diets.[13] These systemic changes have led to the current state of New Zealand's food environment, characterised by the widespread availability of packaged foods and beverages, fast food outlets and processed foods.[8] Simultaneously, changes in the physical environment, such as urban planning, transportation and community infrastructure, have reduced

Figure 3: The obesogenic environment and the upstream causes of obesity. The obesogenic environment, a term coined by Swinburn et al., refers to the collective physical, economic, political and socio-cultural factors that promote obesity in individuals and populations.[11] Broader systemic conditions have resulted in changes in the built (food and physical) environment that promote high energy intake and sedentary behaviour. This is further modulated by the social (cultural and economic) environment, which exacerbates or mitigates the effects of the upstream obesogenic drivers on individual behaviour.

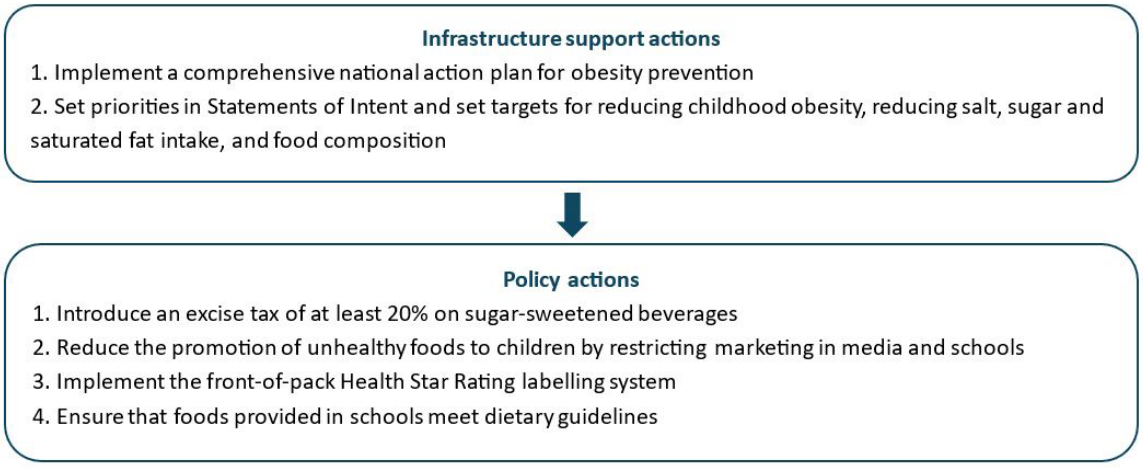


opportunities for physical activity, further exacerbating the imbalance between energy intake and expenditure.[14]

While systemic and built environments have been the primary drivers of childhood obesity, the social environment also plays a significant role in moderating these effects. In today's digital age, media and technology have a profound impact on children's socio-cultural environments. Online platforms, television ads and celebrity endorsements contribute to the extensive marketing efforts shaping children's food preferences and consumption patterns.[15] Social, cultural and spiritual norms also influence individual behaviours; for example, Māori and Pacific youth express greater acceptance of larger body sizes.[16] However, the social environment can also include protective factors. Social connections, positive role models and safe neighbourhoods are also factors that form part of the socio-cultural environment, and have been associated with decreased rates of childhood obesity.[17]

In New Zealand, disparities exist within the obesogenic environment, which are closely tied to SES and ethnicity. Within the built environment itself, disparities arise, as more socio-economically deprived areas have a higher concentration of fast food outlets, while access to healthy food options, such as supermarkets, is more limited.[18] Children living in these areas tend to be exposed to more unhealthy food advertising and have lower access to quality green spaces and recreational resources.[19,20] These disparities in the built environment are further exacerbated by inequities in the social environment. In New Zealand, approximately one in five children live with food insecurity.[21] Socio-economic deprivation increases vulnerability to unhealthy food environments as it becomes more difficult to afford a nutritious diet, making inexpensive, energy-dense options more appealing. Ultimately, these issues stem from systemic inequities that make affording healthy food and

Figure 4: Priority actions recommended by the 2023 Healthy Food Environment Policy Index (Food-EPI) expert panel for implementation by the New Zealand government.[8]



accessing physical exercise opportunities unattainable for many disadvantaged families.[22]

Shifting the spotlight to systemic solutions

Addressing the upstream environmental factors driving unhealthy behaviours has become a key focus of obesity research and interventions.[23] This has led to the establishment of international benchmarks for policy actions aimed at creating healthier food environments, outlined in action plans by the World Health Organization (WHO) and other international health bodies.[24,25,26] While many countries have adopted these policies, New Zealand has been slow to embrace such measures. Over the past decade, the government's implementation of healthy food policies has seen little progress, with over half of the infrastructure and policy indicators showing "low" or "very little" implementation compared to international standards.[8]

In 2023, a panel of over 50 public health experts put forward seven priority measures to improve the healthiness of New Zealand's food system, including four specific policy actions aimed directly at modifying the food environment (Figure 4).[8] These policies are backed by substantial research and have been prioritised based on factors such as the current implementation gap, the importance of each action considering its relative need, impact and effects on equity and its achievability within the New Zealand context. Emphasis is placed on the necessity of mandatory regulation, as existing voluntary and self-regulatory codes have not brought about significant change.[8]

The first priority action is sugary beverage taxation (SBT), a policy already adopted by over 50 countries and endorsed by WHO.[27] Research indicates that SBT effectively reduces sugar consumption, as well as raising public awareness and prompting the food industry's reformulation of sugary products.[28,29] Theoretical models suggest that SBT could lead to a 1–8% reduction in obesity prevalence and significant reductions in cardiovascular disease, diabetes and diet-related cancers.[30] Moreover, SBT has proven highly cost effective through direct healthcare savings and generating revenues to fund other public health initiatives.[31] In the United States, the US$13 billion annual revenue from SBT has been used for health-promoting projects, such as making healthy foods more affordable, physical activity programmes and improving health education.[32] From an equity standpoint, SBT has been argued to be progressive, meaning that those with the highest burden of obesity benefit the most.[33] For example, low-income families are particularly impacted by the financial disincentive due to their higher price sensitivity, resulting in a more significant reduction in sugary beverage consumption.

Restricting unhealthy food marketing (UFM) is another key step towards creating a healthier food environment. In 2023, WHO issued a consensus guideline emphasising the need for mandatory policies to control the promotion of unhealthy products to children.[34] This recommendation is based on recent systematic reviews that have

demonstrated the adverse effects of UFM on children's health, eating habits, and development of norms around food consumption.[35] Currently, UFM in New Zealand is self-regulated through voluntary codes, which contain inherent loopholes that allow companies to continue advertising unhealthy products to children. To align with WHO's guidance, New Zealand needs comprehensive mandatory regulations on UFM to ensure compliance, following successful models in countries such as the UK, South Korea and Spain.[34,36] A challenge to ensuring the effectiveness of such policies is minimising ambiguity so that they cover a comprehensive range of age groups, media platforms and products, and actually reduce children's exposure to UFM.[35]

The third policy action is ensuring healthy food options are provided or sold to children in schools. A successful initiative is the Ka Ora, Ka Ako Healthy School Lunches Programme, which reduces food insecurity by supplying nutritious lunches to children attending schools in socio-economically deprived areas. Initial evaluations of the programme have shown promising results, including delivering nutritious food, improving children's wellbeing and alleviating financial stress for families.[37] Beyond these outcomes, international evidence has shown that universal school food provision can improve the healthiness and sustainability of food environments and drive broader food system change.[38] A priority action for the future is expanding the programme's reach and increasing its funding, particularly as the initiative operates in a critical setting for children's development.

Policy stagnation in New Zealand has been influenced by several factors. One of the main issues is the lack of strong governmental leadership, exacerbated by significant lobbying by the food industry.[39,40,41] A critical gap is the absence of a comprehensive national action plan to address childhood obesity, highlighting insufficient intersectoral coordination and a need for greater prioritisation of the issue. Industry lobbyists have significantly influenced policy decisions and public opinion by contesting evidence and advocating for personal responsibility in addressing obesity.[42] The strong impact of industry lobbying in New Zealand may be due to the economy's relatively heavy reliance on agriculture and food production for export income, giving these industries more political and economic influence.[43] Furthermore, the smaller scale of New Zealand's political system makes it easier for lobbying groups to directly engage with policymakers, compounded by the absence of lobbying regulations.[44]

A key challenge moving forward is advocating for these policies to various stakeholders. Policymakers have compelling reasons to implement the necessary policy actions, including the evidence-based nature of these policies, the responsibility to promote population health and equity and the success of similar measures in other countries. Industry stakeholders may be willing to offer cooperation and partner with these health-promoting initiatives if they recognise the business case for innovation and market differentiation. By demonstrating social responsibility and a commitment to promoting health and sustainability, the industry can position itself positively and improve its brand reputation, aligning with consumer expectations and evolving global trends. In terms of community engagement, research has shown strong public support for policies aimed at improving the food environment. Despite industry claims that such policies impede consumer freedom, statistics reveal that 51% of New Zealanders endorse a tax on sugary drinks, and 92% of parents support a ban on unhealthy television advertisements.[45,46]

Conclusion

Childhood obesity in New Zealand is a critical issue, but the real issue lies in our obesogenic environment. This environment disproportionally burdens low-SES, Māori and Pacific children, perpetuated by systemic inequities ingrained in our society. Children are not to blame for their obesity; it is society that needs to protect them. Mandatory policies combining taxation, marketing regulation and school-based policies are needed to foster a healthier food environment conducive to healthy behaviours. These policies are backed by evidence-based arguments, economic rationale and community support. Nonetheless, achieving them requires collective action to build momentum, overcome industry opposition and drive the necessary policy agenda forward.

COMPETING INTERESTS
There are no competing interests to declare.

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Bilateral macular oedema secondary to docetaxel treatment

Francesc March de Ribot, Patchara Jirapanyayut, Anna March de Ribot

Chemotherapeutic agents can have side effects on the retina, causing cystoid macular oedema (CME). Docetaxel is a taxane class of drugs widely used to treat a range of malignancies including prostate cancer. We present a 67-year-old male patient who was referred with vision loss after receiving three cycles of docetaxel as palliative treatment for advanced prostate cancer. On presentation, visual acuity was 6/12 (0.3 LogMAR) bilaterally with significant CME on fundoscopy and optical coherence tomography (OCT) in both eyes. Chemotherapy was discontinued following three cycles of docetaxel with insufficient response. Visual acuity improved to 6/7 (0.1 LogMAR) bilaterally, along with a resolution of the CME. We recommend an ophthalmological examination in patients with visual complaints receiving docetaxel chemotherapy. Every patient therapy must be individualised to optimise the best outcomes.

Background

CME is characterised by the increase of retinal thickening and the formation of cyst-like spaces in the macula. CME is due to the disruption of the normal blood-retinal barrier that leads to fluid leakage from the perifoveal retinal capillaries into the intra-cellular space of the retina, primarily affecting the outer plexiform layer of the retina.[1] Several chemotherapeutic agents, such as tamoxifen, interferon, trametinib, imatinib, cytarabine and taxanes have been reported to be associated with CME, but uveitis, optic neuritis, optic oedema and retinal vein and artery occlusions can also be associated.[2–4] BRAF inhibitor drugs, such as vemurafenib, have been associated with CME secondary to uveitis.[5,6] Additionally, all mitogen-activated protein kinase (MEK) inhibitor drugs, such as refametinib, selumetinib and cobimetinib, are associated with varying degrees of retinopathy effects. MEK inhibitors cause the accumulation of subretinal fluid, altering the retinal pigment epithelial (RPE) permeability.[7]

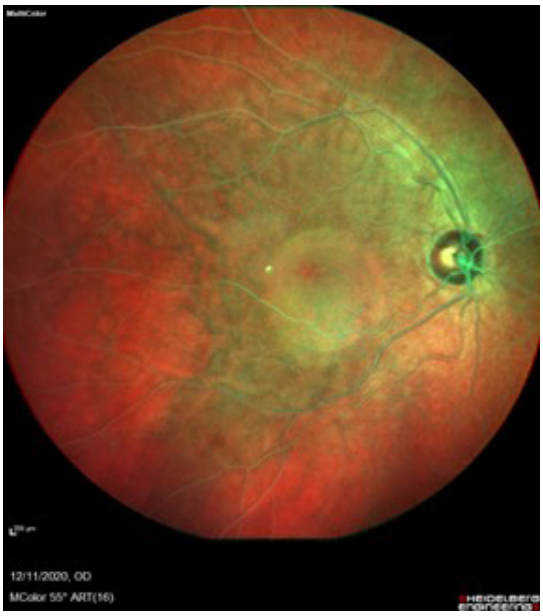
Symptoms of CME can manifest as visual disturbances, decreases in visual acuity, metamorphopsia, photosensitivity and altered colour perception.[8] These symptoms typically resolve spontaneously after stopping the chemotherapy treatment.[9,10] The prevalence of CME related to docetaxel is unknown, and only a few cases have been published. It looks reasonable that patients experiencing visual changes during chemotherapy undergo an evaluation by an ophthalmologist. Here, we present a case of bilateral CME secondary to docetaxel treatment.

Case description

A 67-year-old male was referred to the ophthalmology department following a bilateral visual loss. The patient had metastatic prostate cancer with lymph nodes metastasising (adenocarcinoma of the prostate stage T4 N0 M1). Over 3 years, he underwent multiple treatments, including androgen deprivation therapy (ADT), zoladex 3-monthly for 6 months, a radical dose of radiotherapy of 75 Gy delivered over 37 fractions, and a combination of abiraterone and prednisone. Finally, the patient received docetaxel as a palliative treatment. He experienced decreased vision following the first cycle and was then in the third cycle. The initial visual acuity was 6/12 (0.3 LogMAR) in both eyes, with an intra-ocular pressure of 16mmHg. The ophthalmological examination presented a clear cornea with mild cataracts. The posterior segments revealed a normal optic nerve along a significant bilateral CME (Figure 1). OCT confirmed the presence of CME with fovea involvement (Figure 2). The fluorescein angiography revealed CME with no leakage or increasing hyperfluorescence in the late phase (Figure 3). After excluding all the other probable causes of CME, it was considered secondary to docetaxel. The patient finished the third cycle of docetaxel, but due to an insufficient response and considering the eye side effects, the treatment was discontinued. Upon a follow-up examination at 6 weeks, symptomatology improved with a vision of 6/7 (0.1 LogMAR) bilaterally and a resolution of the CME. Unfortunately, the tumour progressed, leading the patient to opt for palliative care until his passing a few months later.

Figure 1: Colour fundus photography of the right (a) and left eye (b) showing CME.

a.



b.

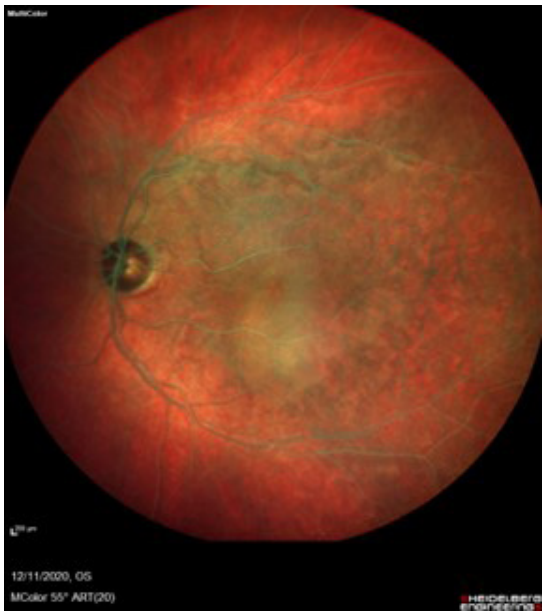
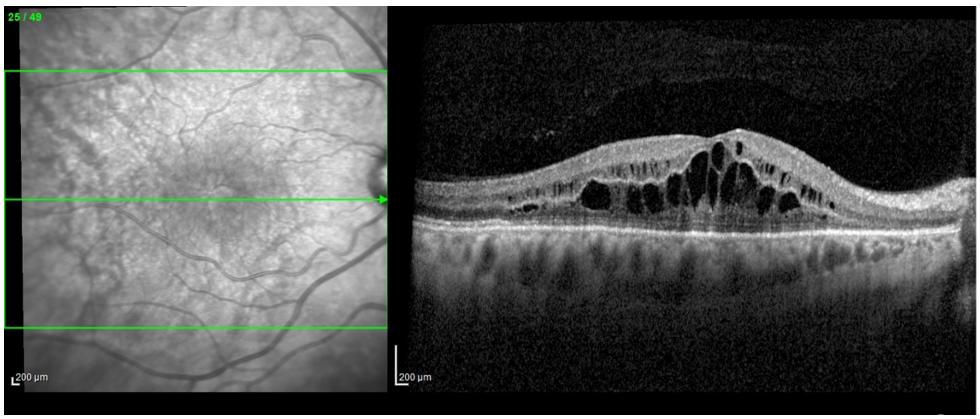


Figure 2: Spectral-domain optical coherence tomography of the right (a) and left eye (b) showing CME with intra-retinal fluid in the outer plexiform layer and cystoid changes in the inner retinal layer.

a.



b.

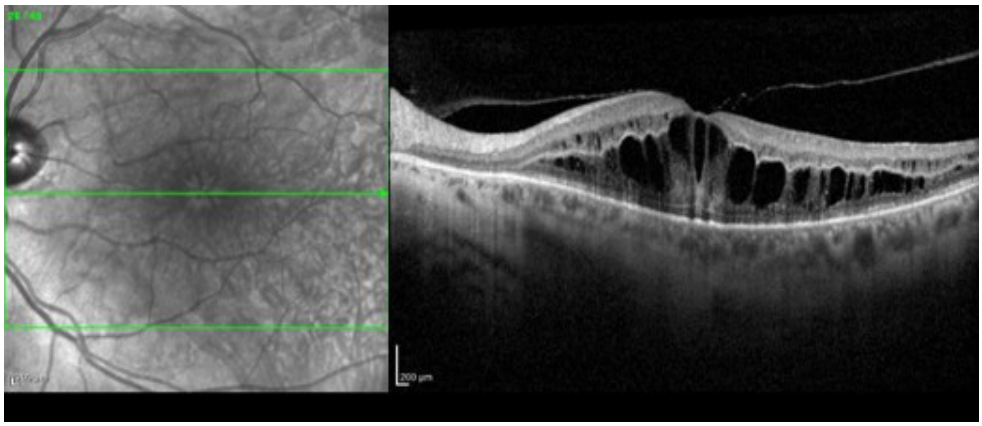
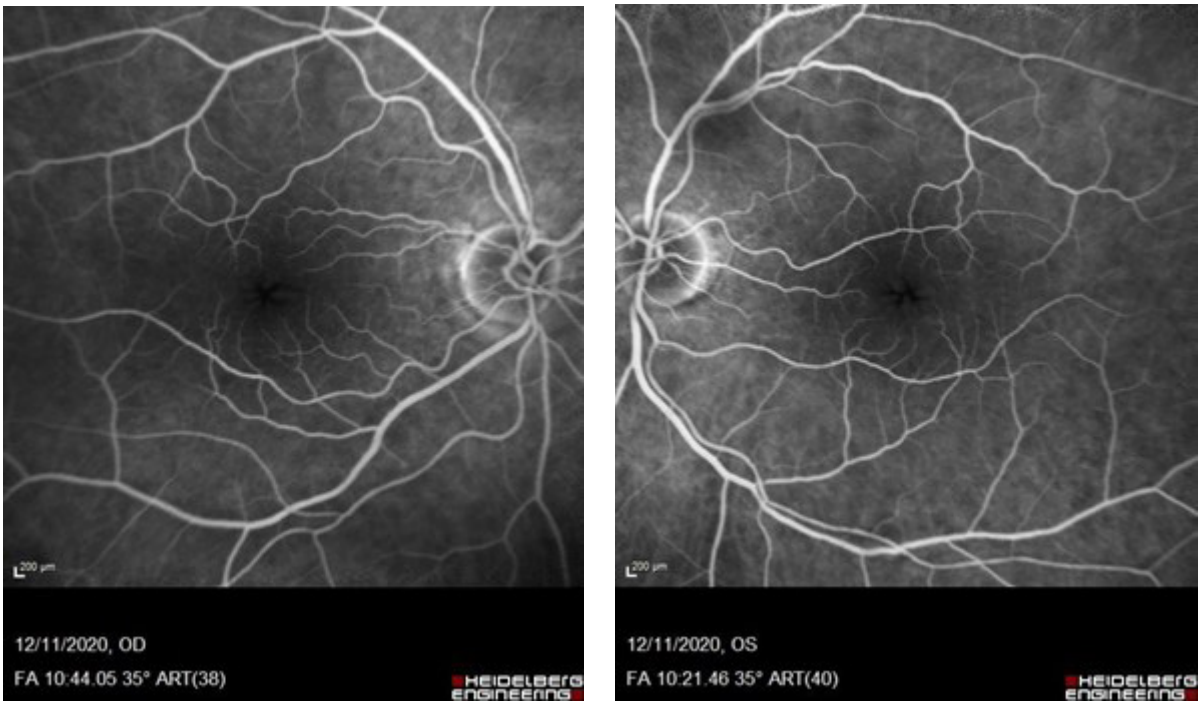


Figure 3: Fluorescein angiography showed bilateral CME with no leakage or increasing hyperfluorescence in the late phase.



Discussion

Docetaxel is a second-generation chemotherapeutic agent in the taxane drug family. Docetaxel prevents mitosis by interfering with microtubule growth and inhibiting microtubule network reorganisations. It is widely used as a chemotherapeutic agent in many types of cancers like breast cancer, certain stomach cancers, head and neck cancer, lung cancer and prostate cancer.[11,12]

Treatment with docetaxel has been exceptionally linked to CME, often appearing bilaterally with normal vascularity.[13] Published case reports commonly depict a pattern of bilateral vision loss secondary to the usage of docetaxel followed by improvement of CME after discontinuation of the treatment. The timeline for CME resolution post-treatment cessation varies from 2 weeks to 24 weeks depending on the severity of the CME itself.[14] Additionally, some cases report an association with fluid retention syndrome and retinitis pigmentosa.[3,15–18]

The pathophysiology underlying docetaxel-induced CME, as well as that of other taxane agents, remains unclear. Several theories have been proposed, including the dysfunction of RPE with intact choroid pigment epithelium border, Müller's cell toxicity and toxicity on microtubules leading to a decrease in fluid absorption across the RPE.[15,19]

Managing docetaxel-induced CME can pose challenges. Ceasing docetaxel may improve visual symptoms but could limit treatment options. However, oral carbonic anhydrase inhibitors (CAIs) have been described as helpful in paclitaxel- and docetaxel-induced CME.[20,21] CAIs function by altering the polarity of the ionic transport systems in the RPE, redirecting fluid away from the intra-cellular spaces. Topical CAIs have also been described to be effective, with fewer systemic side effects compared to their oral counterpart.[22,23]

Clinicians should remain vigilant about potential vision changes in patients undergoing docetaxel or other taxane therapies because the incidence is unknown. Management has to be individualised after discussing the benefits and risks of cessation of the treatment or other treatments with a multi-disciplinary approach.

COMPETING INTERESTS
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A minimally invasive endoscopic approach to oesophageal lipoma

Haylie M Griffen, Chun-Yen Wu

Lipomas of the oesophagus are rare and often asymptomatic.[1,2] Symptomatic oesophageal lipomas have historically been treated with invasive procedures using an open cervical or thoracic approach.[3,4] This case demonstrates that lipomas with certain favourable characteristics are amenable to endoscopic resection, which is a safe, less invasive and effective approach.

Case presentation

We present the case of a 74-year-old man who was found to have a 2.5 x 1cm benign-appearing, pedunculated lesion of the upper oesophagus during endoscopic investigation of iron deficiency anaemia (Figure 1). Retrospectively, the patient described a history of atypical dysphagia for 10 years with intermittent coughing and choking.

Due to the patient's symptomatology, he was recalled for repeat endoscopic evaluation under general anaesthesia. Biopsy of the lesion was attempted, at which point it was clear that the lesion was entirely in keeping with an oesophageal lipoma. The lesion was removed using hot snare to the stalk base, and three endoclips were used to close the mucosal defect (Figure 2).

The patient underwent barium-swallow 24 hours post-procedure, which demonstrated brisk flow of contrast without leak and no residual filling defect (Figure 3).

Histology confirmed a benign oesophageal lipoma. The patient reported complete resolution of symptoms.

Discussion

Lipomas of the oesophagus are extremely rare, accounting for only 0.4% of all benign tumours of the gastrointestinal tract.[2] Their eitiology is not completely understood, with some authors reporting an association with prior trauma[3] and others reporting development from redundant mucosal folds.[1] The uniting feature among authors is that they most often originate from two distinct areas of lower resistance in the upper oesophagus—Killian's dehiscence and Laimer's triangle.[1,4,5]

The majority of oesophageal lipomas are asymptomatic.[1,2,4] However, they are prone to elongation as a result of propulsive forces within the oesophagus and tend to become symptomatic as they increase in size.[1,4] Some authors suggest that any lipoma over 2cm in diameter is capable of producing symptoms, although there are a number of case reports in the literature where the symptomatic lipomas are smaller than this.[6,7]

The most commonly described symptoms are

Figure 1: Endoscopic visualisation of oesophageal lipoma.

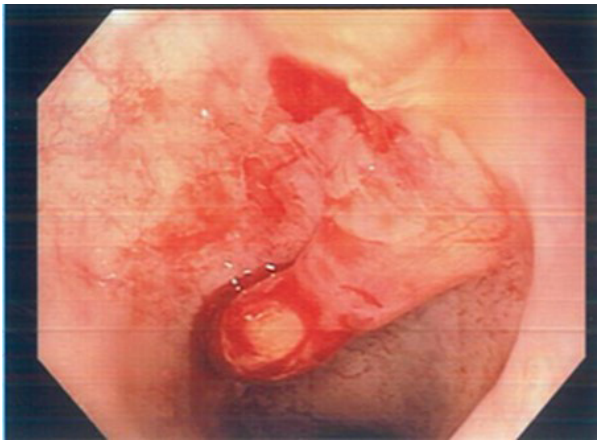


Figure 2: Mucosal defect post-resection closed with endoclips.

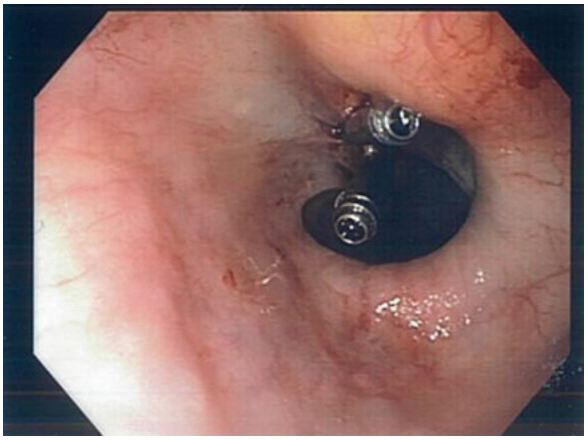
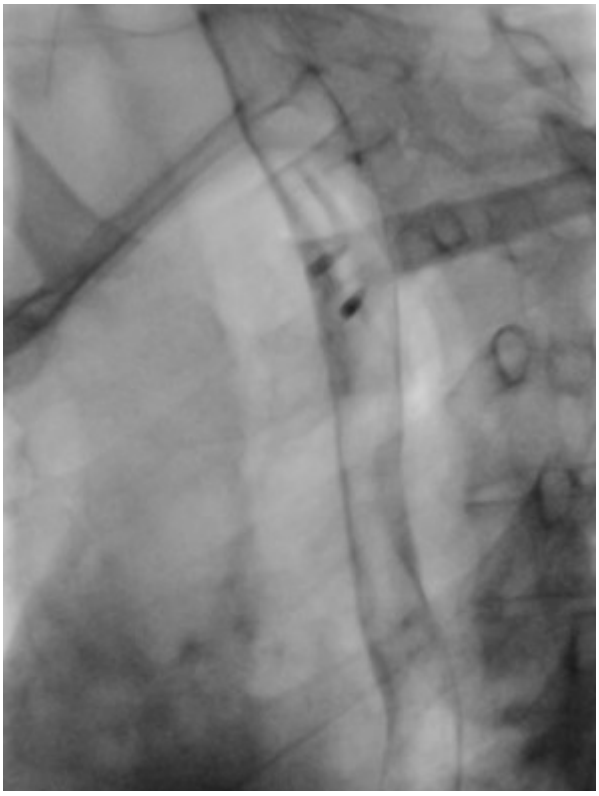


Figure 3: Post-procedure barium swallow; endoclips are seen with no evidence of leak identified.



dysphagia and globus sensation.

Iron deficiency anaemia is uncommon and usually only occurs in lipomas of the lower oesophagus that are exposed to gastric acidity causing ulceration and occult bleeding.[4]

Laryngeal prolapse is a rare symptom, with some patients providing the remarkable history of regurgitating and then swallowing a fleshy mass. Even more rare is that of airway occlusion leading to asphyxiation and sudden death.[1,3,4]

Evaluation and resection of the offending lipoma is required to avoid these potentially life-threatening events. The imaging modalities of choice include barium swallow and computed tomography. An intraluminal filling defect and/or hypoattenuating submucosal mass with fat characteristics are the key radiological features, respectively.[2,8] Direct visualisation with endoscopy reveals a pliable mass with uniformly yellow colour, smoothly covered in squamous epithelium.[2] The use of endoscopic ultrasonography has also been described, which may be useful in identifying the presence of a large feeding vessel in the stalk of pedunculated lesions.[4]

The treatment of symptomatic oesophageal lipomas has historically been invasive, with surgical techniques that include cervical or thoracic oesophagotomy and even oesophogectomy.[4,8]

Advancement in endoscopic technology has seen a shift in the paradigm whereby selected cases are now amenable to endoscopic resection.[4,9,10] Size and location are key considerations, with smaller and pedunculated lesions naturally easier to snare than their larger counterparts.[4,10] The most important risk to consider is that of uncontrollable bleeding from a large feeding vessel,[6] although studies suggest that with the correct application of the snare, this risk remains low.[4]

In conclusion, this case supports the existing research that endoscopic resection of small, symptomatic oesophageal lipomas is safe and effective, may prevent the risk of potentially life-threatening events and reduces the morbidity and mortality associated with more invasive procedures.[3,4,7]

COMPETING INTERESTS
None declared.

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Long COVID impacts people's ability to work: cross-sectional study in Aotearoa New Zealand

Mona Jeffreys, Fiona McKenzie, Maite Irurzun Lopez, Lynne Russell, Lis Ellison-Loschmann

Long COVID is defined as COVID-19 symptoms or sequelae that persist for longer than 3 months without an alternative explanatory cause.[1] It is increasingly being recognised as a serious global health concern that has a significant impact on people's ability to fulfil their desired social roles and is associated with a low quality of life.[2] This ongoing, debilitating condition varies in severity, with symptoms affecting people's ability to work.[3] These impacts are likely to disproportionately affect Indigenous and economically disadvantaged populations.[4]

The impacts of not being able to work extend beyond the individual to affect whole families/whānau, through caregiving, lost income, change in identity and lower self-esteem, which are all likely to directly affect physical and/or mental health. Inability to work also affects employers, occupational health services and the wider economy.[5] International data suggests that among people with long COVID, about half work fewer hours and a quarter do not work as a direct result of being ill.[6]

Methods

Full details of the recruitment strategy and data collection of the *Ngā Kawekawe o Mate Korona | Impacts of COVID-19 in Aotearoa* study have been described previously.[7] Briefly, all people aged 16 or over in Aotearoa New Zealand who had definite or probable COVID-19 before 1 December 2021, and were not living in a dementia unit, were eligible for inclusion. Quantitative data were collected through an online survey between February and June 2022. Survey questions included health-related quality of life (HRQoL),[8] income sufficiency, job loss and productivity questions. HRQoL were compared to normative population values.[9] Ethical approval was given by the Health and Disability Ethics Committee on 15 January 2022 (ref 2021 EXP 11900), and an amendment approved on 26 April 2022 (ref 2022 AM 11900).

Results

Of 8,735 eligible people, 990 answered at least one of the four available survey modules. The median follow-up period, i.e., time from having COVID-19 to completing the survey, was 16 months (inter-quartile range 6 to 23 months). Of the 405 people who answered the long COVID module, 217 people (33 Māori, 184 non-Māori) reported at least one symptom lasting 3 months or more and were classified as having long COVID; results reported below relate to these 217 people. The most conservative estimate of the prevalence of long COVID is thus 2.5% (217/8,735).

Persisting symptoms had significant effects on people's day-to-day lives, with moderate, severe or extreme impacts on mobility (16% vs 10.2% in the general population), self-care (5% vs 2.1%), usual activity (28% vs 9.9%), pain (30% vs 18.9%) and anxiety/depression (30% vs 17.5%). The mean EQ-5D-5L utility score among people with long COVID was 0.750 for Māori and 0.730 for non-Māori, compared to 0.847 in the general population.[9]

Three-quarters (74%) of respondents had time off work or study during the follow-up period; the median time off was 22 days, and 11% had more than 3 months off work, because of having had COVID-19. In the first month of being ill, only 5% of people could work or study as normal; 42% could not work at all, 30% had to cut down their hours and 17% reported working the same amount of time, but that it felt harder and/or they got less done. After the first month, 3% could not work at all, 24% had cut down their hours and 36% reported working the same amount of time, but that it felt harder and/or they got less done. In real terms, this translates to about 40,000 people in Aotearoa New Zealand who are likely to be less able to work or less productive at work due to the ongoing effects of COVID-19.

In the first month of being ill, one-third (34%) of

people who subsequently developed long COVID reported a decrease in income due to COVID-19, 37% reported financial worries and 20% agreed or agreed strongly that their households struggled to pay basic living costs. Each of these latter metrics was more common in Māori than non-Māori, see Table 1.

Discussion

People with long COVID face difficulties in being able to work and/or retaining pre-illness levels of productivity, resulting in economic hardship. Given the low response rate, the results must be interpreted with some caution, due to the potential of selection bias. Qualitative work (unpublished data) carried out alongside the survey reported here found evidence of people returning to work too early in their post-COVID recovery, which subsequently necessitated more time off work, while other people felt compelled to return to work due to financial circumstances.

The financial impacts that we reported are greater for Indigenous Māori than non-Māori. Although we did not have data on financial impacts beyond the first month, this will be the focus of future work. However, the data indicate that any return-to-work interventions could benefit Māori and be a pathway through which to address long-standing socio-economic inequities.

The Ministry of Business, Innovation and Employment advises employers to treat people with long COVID as they treat anyone with a chronic illness. This differs from the legal obligation on employers to make reasonable adjustments to workplace conditions for employees with a disability. In the absence of legislation, we need evidence-based guidance to inform policy and practice. A UK agency has identified some good practice points but acknowledges that evidence is needed on how to best support people with long COVID to stay in or return to work.[10] The New Zealand Ministry of Health has acknowledged the impact that long COVID has on work,[11] but has not made recommendations about how to mitigate this. In the absence of national guidance, a patient group has developed a best-practice framework for managing employees with long COVID in Aotearoa New Zealand.[12]

Prevention of long COVID is only possible by avoiding SARS-CoV-2 infection. As infections continue to occur, so will the incidence and burden of long COVID. Supportive return-to-work policies will have benefits for employees and their dependents, as well as employers and the economy.

Table 1: Effect of COVID-19 on income in the first month of being unwell among people with long COVID.

	Māori	Non-Māori	P value
Income decreased	50%	31%	0.015
Had money worries	63%	33%	0.068
Struggled to pay for basic living costs	56%	15%	<0.001

COMPETING INTERESTS
Nil. The work was funded by the New Zealand Ministry of Health (2021), who had no role in the design, analysis or reporting of this work.

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False or Careless Medical Certificates.

NZMJ, 1924

A meeting of the medical board of New Zealand was held in the rooms of the Auckland Hospital Board, Kitchener Street, Auckland, at 2pm., on Monday, 3rd March, 1924.

PRESENT.—Sir Henry Lindo Ferguson (*Chairman*), Drs. W. H. Parkes, J. P. D. Leahy, W. Newlands, W. Irving, J. P. Frengley, and J. S. Elliott.

While the Board was dealing with applications for registration. Etc., Sir Donald McGavin, Director-General of Medical Services, waited upon the Board by appointment, to seek its assistance in dealing with several cases where registered medical practitioners had given untrue and misleading medical certificates to pensioners whose cases had to be dealt with by his Department. Sir Donald explained that there was power in the War Pensions Act to prosecute medical practitioners in such cases, but that before recommending such action, he would be glad if the Board could see its way to take the matter up with a view to stopping what was going on. Sir Donald then cited a number of typical cases which were, he said, only a few out of many.

Case No. 1.—This man returned to New Zealand on 26th May, 1919, and was discharged from the New Zealand Expeditionary Force, on 22nd June, 1919. On medical examination immediately prior to his discharge he was found medically fit. In November, 1923, *i.e.*, about 4½ years after his discharge, application was made for the granting of war pension and treatment of this man on account of pulmonary tuberculosis. Two medical certificates were forwarded, one dated 19th November, 1923, setting out the man's then condition, and a second which reads as follows:—"This is to certify that in February, 1919, I examined ———— and found him suffering from tuberculosis of the lungs. His sputum was also examined and tubercle bacilli were found present." It will be noted that the medical officer who gave the latter certificate stated that he had found him suffering from pulmonary tuberculosis in February, 1919, although the man had not arrived in New Zealand until the end of May, 1919. I may state that the medical man was not out of New Zealand at this time, so that no excuse could exist on these grounds. It is clear that had this certificate been accepted, as it certainly would have been but for this inconsistency in dates, a pension and treatment would have been granted without hesitation.

I interviewed the medical man who gave this certificate and he informed me that he had been written to by the applicant for a certificate, and that he had given the certificate on the applicant's statements, although he had no recollection of ever having seen the man. He was profuse in his apologies for the misrepresentation by the applicant for pension, but appeared quite unable to appreciate the difference between certifying to a fact within his own knowledge and to a statement made by an individual.

Case No. 2.—This man had been in receipt of war pension on account of neurasthenia. From several irrefutable sources of evidence, the Department learned that this man indulged excessively in alcohol, and his pension was therefore cancelled.

A medical man wrote to the Commissioner of Pensions as follows:—"I have never seen ———— the worse for drink, nor have I ever any reason to suppose he indulges in it. He tells me that he has never tasted liquor while in ———— hospital, and I have found this man always truthful . . . . I feel that this man is being unjustly treated."

In January, 1922, he had forwarded the following statement to this office:—"The man ———— has been an inmate of the ———— Hospital since 20th November, 1921, when he was admitted in a state of acute alcoholism. He is certainly now quite unfit for work. During his period in hospital he had several attacks of severe muscular pain that appeared to be rheumatism, and on one occasion he appeared to have a malarial attack. He had undoubtedly been drinking too freely before his admission.

It is unnecessary to comment further on this case.

Case No. 3.—Medical Examiners are asked to complete their reports on forms sent out from this office, on the head of which is written the disability for which the individual is granted his pension. A form was sent to a medical man for this pensioner, on the top of which it appeared that he was granted a pension for "malaria." The

report rendered was as follows:—Q.—1. Describe his general state of health and physical condition: A.—Fair. Q. 2 What is the nature of his present disability? A.—Not able to do hard work. Has attacks of malaria still.

Incidentally it may be pointed out that such a report is no value to this Department as it contains no information beyond a reiteration of the pensioner's statements. The point, however, to which I wish to draw attention is that by a clerical error "malaria" had been written on the top of the form instead of "myalgia." The pensioner had never claimed pension on account of malaria, or alleged himself to be suffering from that disability, nor had he apparently ever been in a country in which malaria might have been contracted.

The Board decided to ask the Editor of the NEW ZEALAND MEDICAL JOURNAL to publish a reasonably full statement of the minutes of this meeting together with the details supplied by Sir Donald McGavin, and also to be good enough to publish a warning that in future if any such case is brought under the notice of the Board, the Board will immediately take action with a view to having the name of the medical practitioner concerned struck off the Register.