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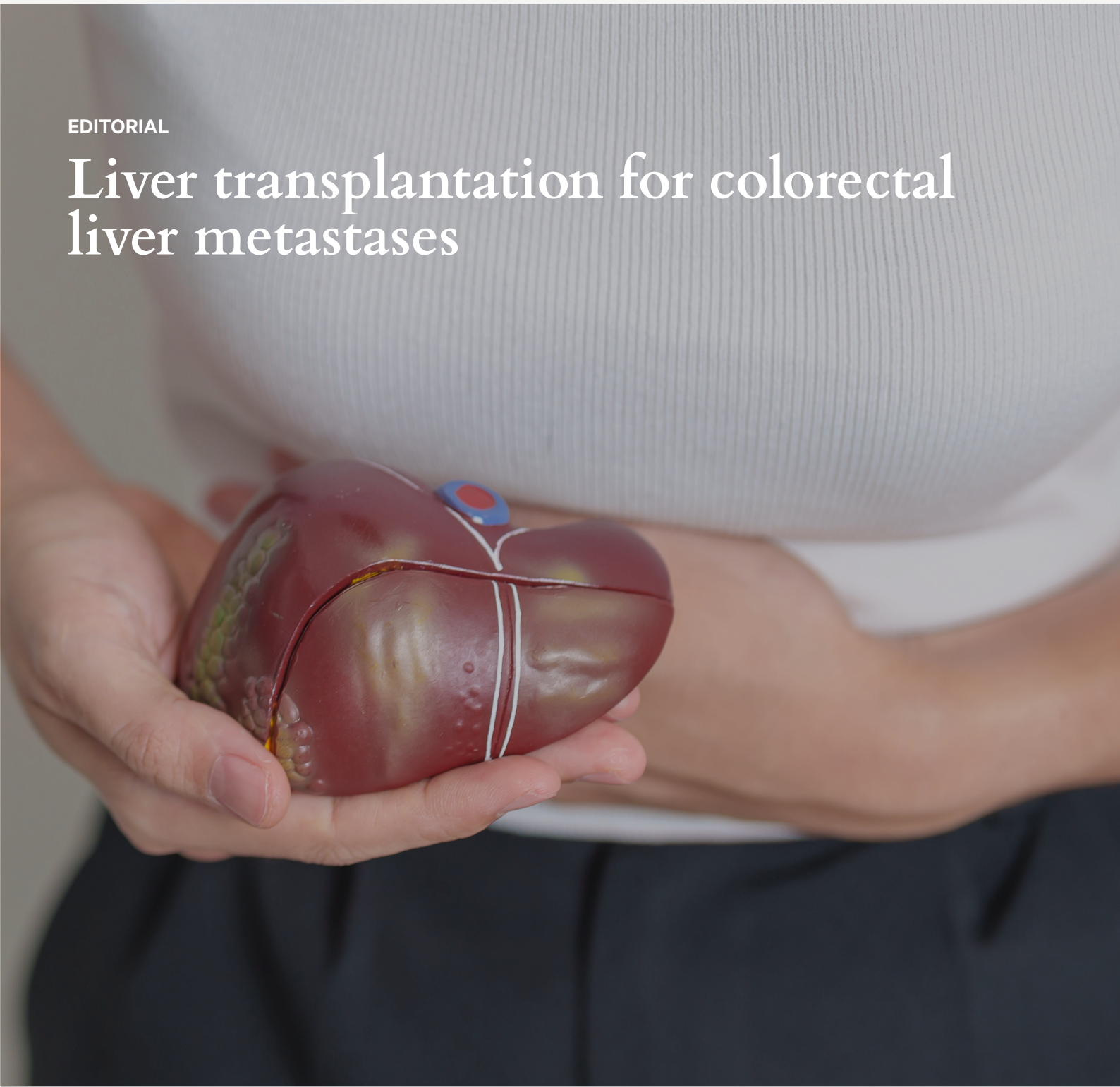
Liver transplantation for colorectal liver metastases



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100 years ago in the *NZMJ*

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Liver transplantation for colorectal liver metastases

John McCall

Bowel cancer is one of the most common causes of cancer death in New Zealand, and occurs mainly due to spread to the liver and other parts of the body. Some patients with spread to the liver can be cured by surgical removal, but usually this is not possible due to the extent of liver involvement. Recent trials overseas have shown that removal of the entire liver and liver transplantation can give good results in very carefully selected patients. The New Zealand Liver Transplant Unit will now offer this treatment to patients who meet the strict selection criteria.

The incidence of atrial fibrillation and its impact on the length of stay following valvular heart surgery

Yeu-Shiuan Fu, Lesley Doughty, Rachael Parke

There has been minimal evidence about the predictors, preventative measures and treatments of new onset of post-operative atrial fibrillation—an arrhythmia of the heart—in patients undergoing valvular heart surgery. This paper presents findings that the incidence of atrial fibrillation was relatively high and was associated with a longer intensive care unit and hospital length of stay.

Access to gluten-free foods for people with coeliac disease in New Zealand

Sophie Hall, Kristin Kenrick, Andrew S Day, Angharad Vernon-Roberts

Adherence to a strict gluten-free (GF) diet is the mainstay of treatment for those diagnosed with coeliac disease (CD). GF foods are available on prescription for those diagnosed with CD, but the range is limited. In addition, GF foods purchased in shops tend to be more expensive than their gluten-containing equivalents. This survey, circulated via the Coeliac New Zealand membership in June 2023, sought to understand how New Zealanders with CD are obtaining their GF products, associated costs and how this is meeting their needs. A total of 550 people from across New Zealand competed the survey, with 97% not accessing GF foods on prescription, indicating a very low uptake in the service. The survey suggests that awareness of the availability of GF food on prescription and how to access this may be contributing to low uptake. As well as the costs associated with accessing GF foods on prescription, the limited range of products available and convenience are limiting factors. The majority of respondents would prefer financial support in the form of discount cards to purchase GF products from their local supermarket or store.

Equity of access to pathological diagnosis and bronchoscopy for lung cancer in Aotearoa New Zealand

Jason Gurney, Anna Davies, James Stanley, Jesse Whitehead, Laird Cameron, Shaun Costello, Paul Dawkins, Jonathan Koea

Māori are less likely to survive their lung cancer once diagnosed. This could be driven by poorer access to lung cancer diagnosis. We used national data and looked at all lung cancer registrations in New Zealand between 2007–2019 and compared ethnic groups in terms of whether they received a pathological diagnosis, whether they received a bronchoscopy, and travel distance and time to access their bronchoscopy. We found no differences in access to a pathological diagnosis and found that Māori within the cohort were marginally more likely to access bronchoscopy than the majority European

group. However, we found that Māori had to travel further than Europeans to access their bronchoscopy.

Urban–rural geographic distribution of Otorhinolaryngologist, Head and Neck surgeons in Aotearoa New Zealand

Thomas Napier, David Waterhouse

This paper reports the results of a workforce survey of the membership of the New Zealand Society of Otolaryngology and Head and Neck Surgery. It identifies the current working patterns across Aotearoa New Zealand for Otolaryngologist, Head and Neck surgeons (Ear, Nose and Throat surgeons). The survey found that most surgeons work in a main centre and that surgeons in smaller regional centres work longer hours, are on call more often and as a group intend to retire earlier. Training Otolaryngologist, Head and Neck surgeons were also surveyed, and reported barriers to regional practice included social and professional isolation, remoteness and perceived on call burden. Strategies to maintain a regional workforce are discussed, including positive selection for rural candidates.

Per-oral endoscopic myotomy: a multi-centre New Zealand experience

Christopher Graddon, Rees Cameron, Frank Weilert, Ravinder Ogra, Gary Lim, Imran Khan, Ratna Pandey, Aung Htoo, Georgia Buddle, Alexander Wynne, Cameron Schauer

Per-oral endoscopic myotomy (POEM) is a minimally invasive procedure completed using only a gastroscope with no cuts on the skin or body. It was pioneered in Japan to treat patients with a rare swallowing condition called achalasia. This is a condition characterised by tight muscles within the oesophagus, leading to problems with swallowing, regurgitation and weight loss. The POEM procedure cuts these muscles, thereby alleviating the swallowing symptoms. This is the first documented New Zealand experience with this procedure in achalasia, which shows excellent safety and success, comparable to high-volume, big international hospitals.

Holding a mirror to society? The socio-demographic characteristics of students commencing health professional programmes, and all courses, at Ōtākou Whakaihu Waka (the University of Otago), 1994–2023

Andrew Sise, Sam Feeney, Griffin Manawaroa Leonard, Gabrielle McDonald, Greg Murray, Peter Crampton

This paper reports a longitudinal analysis of the socio-demographic characteristics of students entering all courses at Ōtākou Whakaihu Waka (the University of Otago), all health professional programmes combined and 11 individual health professional programmes between 1994 and 2023. During this 30-year period there was a notable increase in the proportion of domestic health professional programme students who were Māori or Pacific, and an increase in students from rural backgrounds. The socio-economic profile of incoming students remained unchanged with students being highly skewed towards those from more socio-economically privileged backgrounds. While efforts to enhance health professional student diversity have had a positive impact, the university's vision of a health workforce that represents Māori and the diverse contexts of Aotearoa New Zealand's society will require long-term ongoing commitment.

Paediatric palliative care in Aotearoa New Zealand—current state and future direction

Gemma E Aburn, Merryn Gott, Tess Moeke-Maxwell, Ross Drake

This paper explores the current state of paediatric palliative care in Aotearoa New Zealand. The low priority afforded to paediatric palliative care for more than two decades has had a significant impact on service provision, education and research within the specialty. Provision of specialist paediatric palliative

care for children with serious illness and their whānau is inequitable and vastly inadequate. This means that children and whānau are missing out on their basic right to this essential care. The consequences of this avoidable poor care for children are far reaching and must be considered unacceptable.

Vision loss secondary to cerebral venous sinus thrombosis as the first presenting symptom of a JAK2 positive myeloproliferative neoplasm

Nicholas J Theis, Louis Han, Antony Bedggood

Under rare circumstances, blood clots within the venous system of the brain may present primarily with visual blurring, and result in swelling of the nerves at the back of the eye. The underlying cause is easily missed if the wrong type of brain imaging is utilised, and our case report draws attention to this. Underlying blood clotting problems may also contribute to this problem, and this occurred in our case.

Liver transplantation for colorectal liver metastases

John McCall

New Zealand has one of the highest rates of colorectal cancer (CRC) in the world and the incidence appears to be increasing in younger people.[1] CRC remains a leading cause of cancer death, mostly due to metastatic disease, with the liver being the commonest site of metastatic spread.

It was once thought that liver metastases from CRC signified incurability, but we now know there is a subset of patients who develop liver-only metastases and can be cured by surgical removal (liver resection) or *in situ* destruction (ablation) of the disease.[2] The role of systemic chemotherapy in preventing relapse after such treatment is still debated, but there is no doubt that a favourable response to chemotherapy portends a better outcome after resection or ablation of liver metastases. So much so that surgical treatment of liver metastases from CRC is less defined by the size, number and distribution of lesions than by the technical feasibility of complete removal, within acceptable safety limits.[3] Furthermore, a number of technical surgical innovations, often combined with downstaging by chemotherapy, have greatly extended the limits of resectability. But, despite such advances, more often than not liver metastases from CRC are unresectable and therefore not amenable to potentially curative treatment.

Meanwhile, liver transplantation has become a highly successful and routinely performed procedure for end-stage liver disease from a variety of causes. It is only logical that total hepatectomy and liver replacement was an idea that would be tried to treat otherwise unresectable liver metastases from CRC. Indeed, it was first tried early in the history of liver transplantation, with somewhat discouraging results—only 18% 5-year survival.[4] In part, this reflected the poorer results of liver transplantation, per se, in those early days, but the poor results were also attributable to high rates of cancer recurrence post-transplant. It was assumed that the immunosuppression required to maintain the liver graft led to early and aggressive post-transplant cancer recurrence in these patients. However, there are other plausible explanations including the limited understanding of tumour biology and relatively crude staging tools available at the time, which led to poor patient selection. Whatever the explanation, liver transplantation for colorectal metastases fell out of favour—and besides, the shortage of donor organs to meet the demand for other indications associated with better outcomes discouraged further exploration of the idea. That is, everywhere except for in Norway, where two critically important factors facilitated further evaluation of the role of liver transplantation to treat unresectable liver metastases. The first was a uniquely fortunate situation in Norway where the supply and demand for donor organs was well balanced and waiting times for liver transplantation were short. The second was a commitment to high-quality prospective clinical studies with carefully documented outcomes that enabled selection criteria to be refined. Thus, a group from the University of Oslo showed it was possible to achieve 5-year overall survival above 70% in carefully selected patients transplanted for unresectable liver-only CRC metastases:[5] survival rates that are comparable to other accepted indications for liver transplantation. The main caveat is that many of these patients experienced cancer recurrence post-transplant; however, the recurrences were mostly in the lungs and were sometimes amenable to further radical treatment, or behaved in a biologically indolent way with limited impact on survival.[6]

The Norway experience prompted a worldwide resurgence of interest in liver transplantation for metastatic CRC, and international consensus guidelines were published in 2021.[7] In 2024, a French multi-centre randomised clinical trial (TransMet) was reported, which compared systemic chemotherapy alone with systemic chemotherapy plus liver transplantation.[8] Of the 94 patients randomised (47 in each group), intention-to-treat analysis found 57% 5-year survival in the transplant group vs 13% in after chemotherapy alone (p=0.0003), and per protocol analysis found 73% 5-year survival in transplanted patients vs 9% in after

chemotherapy alone (p<0.0001). The per protocol analysis is the relevant metric with respect to liver graft utility since candidates who drop out prior to transplant, usually due to disease progression, avoid futile transplantation and a graft is not wasted. The French study confirmed the prior Norway experience that liver transplantation for highly selected patients with CRC liver metastases appears to yield comparable results to other accepted aetiologies, at least out to 5 years of follow-up. Numerous other clinical trials, including randomised clinical trials, are currently underway.

Given the strength of the evidence to date, and the significance of CRC in New Zealand, the New Zealand Liver Transplant Unit has developed a detailed protocol for liver transplantation for unresectable liver metastases from CRC and will offer liver transplantation to patients who meet strict selection criteria. Similar protocols have been developed in Australia, the United Kingdom, North America and Europe. Importantly, the protocol also includes emerging surgical techniques designed to expand the existing donor pool to help meet any resulting increase in demand for donor organs.[9]

In addition to meeting the general eligibility criteria for liver transplantation, patients need to meet strict oncological criteria, including unresectability of liver-only metastatic disease, sustained response to chemotherapy, absence of unfavourable disease subtypes (right-sided primary and BRAF mutated tumours), no extrahepatic disease and no progression through multiple lines of chemotherapy. Norway has a similar population and rate of CRC as New Zealand and, based on their experience applying strict selection criteria, only a handful of patients per annum are expected to meet these criteria and proceed through to transplantation.

Patients, support groups and doctors need access to accurate information regarding all therapeutic options, and liver transplantation is now one of those options, albeit for a select few. Early enquiry regarding potential candidates is encouraged. A multidisciplinary assessment group has been set up to provide rapid response to enquiries and, where appropriate, map out pathways for potentially eligible candidates.

COMPETING INTERESTS
Nil.

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The incidence of atrial fibrillation and its impact on the length of stay following valvular heart surgery

Yeu-Shiuan Fu, Lesley Doughty, Rachael Parke

ABSTRACT

AIM: There is minimal evidence regarding predictors, preventative measures and treatments of new onset of post-operative atrial fibrillation (POAF) in patients undergoing valvular heart surgery. This study aimed to determine the incidence of new onset atrial fibrillation (AF) and its impact on outcomes and length of stay (LOS) for patients following valvular heart surgery.

METHODS: A single-centre, retrospective study was conducted.

RESULTS: New onset AF was observed in 51/120 (42.5%) patients. Baseline and surgical characteristics were similar between patients who did and did not develop AF, although suggestive older age may increase the risk of developing POAF (p=0.06). New onset AF was significantly associated with longer intensive care unit (ICU) LOS—median increase of 2 days (p=0.002)—and overall hospital LOS—median increase of 1.5 days (p=0.006). Patients who received double valve surgery spent 2.5 times longer in the ICU compared to patients who had an aortic valve replacement (AVR) (p=0.033).

CONCLUSION: The incidence of new onset AF following valvular heart surgery was high, with associated prolonged ICU and hospital LOS. Patients undergoing double valve surgery were more likely to have a longer ICU LOS compared with those who received an AVR.

Atrial fibrillation (AF) is one of the most commonly reported post-operative complications following cardiac surgery.[1] Despite advances in surgical techniques and post-operative care, the incidence of post-operative atrial fibrillation (POAF) remains around 31.5% following cardiac surgery.[2]

POAF has been associated with prolonged length of intensive care unit (ICU) and hospital stay and adverse outcomes including stroke, myocardial infarction and death.[3] While advances have been made in the prediction, prevention and treatment of POAF to minimise the associated complications and adverse outcomes,[1,4] the incidence of POAF following cardiac surgery remains relatively unchanged in past decades.[1] The majority of research has focussed on patients undergoing coronary artery bypass grafting (CABG) surgery, with limited relevance to other cardiac surgery patient groups, such as those undergoing valvular heart surgery. There are no national guidelines in Aotearoa New Zealand to guide prevention and treatment of POAF following cardiac surgery. Further understanding of the incidence and effects of POAF could identify areas for future research to adapt preventative and curative interventions for patients following valvular heart surgery. The primary aim of this study was to determine the incidence of new onset POAF following valvular heart surgery and its impact on length of stay (LOS) in hospital.

Methods

This single-centre, observational, retrospective study enrolled patients admitted to the Cardiothoracic and Vascular Intensive Care Unit (CVICU) following valvular heart surgery using cardiopulmonary bypass (CPB) at Auckland City Hospital, Auckland, Aotearoa New Zealand between 1 January 2021 and 30 June 2021. Auckland City Hospital is a large tertiary metropolitan teaching hospital. The study was approved by the Auckland Health Research Ethics Committee (AH23353), with the need for informed consent waived due to the retrospective, non-interventional design of the study.

Study eligibility

Patients who were 16 years or older undergoing valvular heart surgery with or without concomitant CABG surgery were eligible for inclusion.

The collective term of valvular heart surgery referred to either repair or replacement using both mechanical and tissue valves of the aortic, mitral, tricuspid and pulmonary valves, or a combination of these procedures.

Patients were excluded based on the following criteria: history of congenital heart conditions, undergoing isolated CABG or valve-sparing aortic root replacement surgery, and any previously documented history of AF, atrial flutter or paroxysmal AF.

Study end points

The primary end points of the study were the incidence of new onset POAF and the LOS in both the ICU and overall hospital admission.

Data collection

Patients fulfilling eligibility criteria were identified through the CVICU database and patient-coded data of Auckland City Hospital and were included in the study. The occurrence of POAF was determined by the researcher through manual inspection of patient medical records for any documented arrhythmia reported by the medical team or recorded on the observation chart, or an electrocardiogram (ECG) recording a heart rhythm with undiscernible P waves and irregular RR intervals longer than or equal to 30 seconds.

Demographic data were collected, including age, gender, ethnicity and the European System for Cardiac Operative Risk Evaluation II (EuroSCORE II), which is a risk model predicting the risk of mortality after major cardiac surgery. Surgical characteristics of patients and clinical outcomes including mortality and ICU readmission were also collected. Post-operative interventions, including cardiac pacing use, and physiologic variables, including potassium and magnesium levels measured closest to the development of the arrhythmia, were extracted if routinely recorded.

The ICU LOS was determined as the time from admission into CVICU to the time that the patient was documented by the medical team as appropriate for discharge from CVICU. Where this was unavailable, the discharge time recorded on the transfer letter from ICU or co-located high dependency unit to the surgical ward was used. The overall hospital LOS was calculated from the time of admission into CVICU until the patient was discharged from the surgical ward to their home, identified from the discharge letter.

Statistical analysis

Data were collated into an Excel spreadsheet with missing data omitted. A statistician from The University of Auckland was consulted to assist with data analysis using the software R (version 4.2.0). Data were tested for normality using Shapiro–Wilk test. Mann–Whitney–Wilcoxon test was applied to all continuous variables when comparing between medians. Comparison between categorical data was performed using Pearson's Chi-squared test or Fisher's exact test. Bivariate analysis using simple logistic regression was conducted to examine the significance of the type of valvular heart surgery on the ICU and hospital LOS. A two-sided p-value <0.05 was determined to be of statistical significance. Descriptive data are presented as mean ± standard deviation, median (interquartile range [IQR]) or number (percentage), where appropriate.

Results

Between 1 January 2021 and 30 June 2021, a total of 428 patients were identified as having received valvular heart surgery. Of these, 311 patients were assessed for eligibility for the study (see Figure 1). A total of 120 patients were included in the data analysis.

Overall, the median patient age was 67 years (IQR 58–74) (Table 1). Patients who were of Māori (60% vs 40%) or Asian (75% vs 25%) ethnicity were more likely to develop AF than not, but this was not statistically significant. Other baseline characteristics were similar between groups (Table 1).

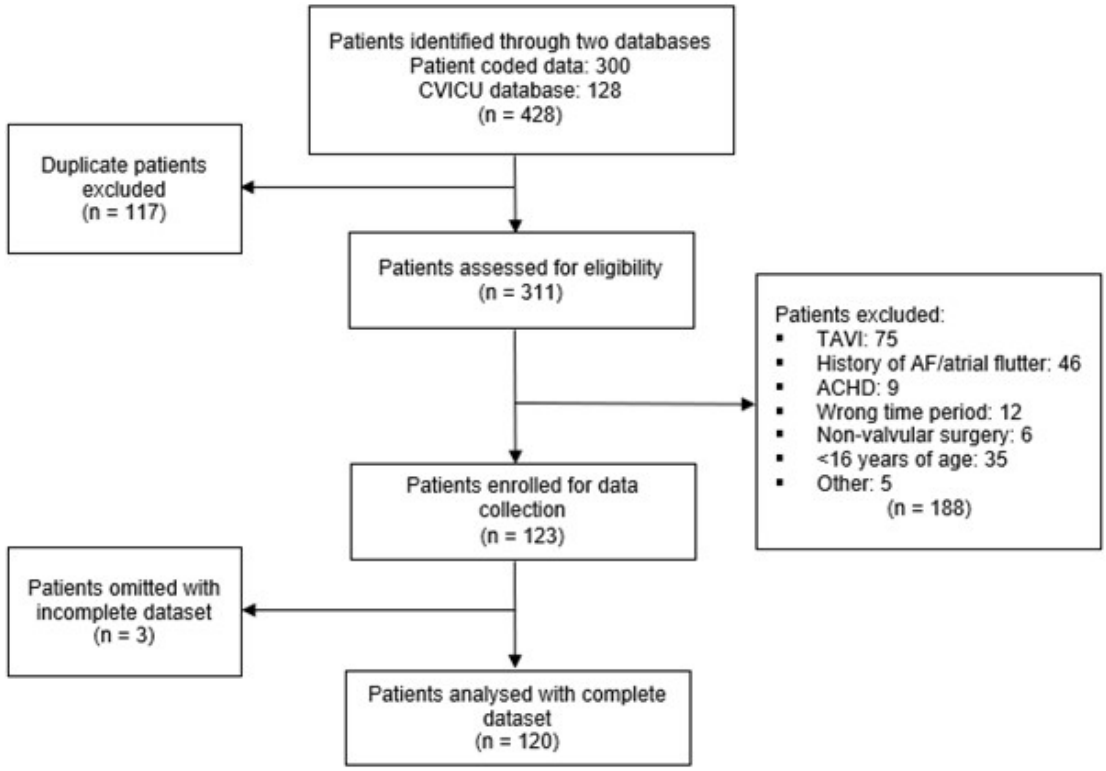
Surgical characteristics were similar between those who developed AF and those who did not (Table 2). The most common type of surgery was valvular surgery in combination with CABG (n=40, 33.3%) followed by aortic valve replacement (AVR) (n=33, 27.5%) and mitral valve replacement or repair (n=24, 20%). There were no significant differences in the incidence of new onset AF following the different types of valve surgery (p=0.6), and whether the patient received amiodarone intraoperatively or not (p=1). Of those who were administered amiodarone intraoperatively, 42% (n=21) developed new onset AF post-operatively.

Primary end points

The overall incidence of new onset AF following valvular heart surgery was 42.5% (n=51), developing mostly on the second post-operative day (Figure 2).

LOS in the ICU was significantly longer in those who developed new onset AF compared with those who did not (2.8 days vs 1.2 days; p=0.002) (Table 3), as was overall hospital LOS (9 days vs 7.6

Figure 1: Flowchart of patients' eligibility and enrolment.



Abbreviations: CVICU = Cardiothoracic and Vascular Intensive Care Unit; n = number; TAVI = transcatheter aortic valve implantation; AF = atrial fibrillation; ACHD = adult congenital heart disease.

days, p=0.006). No differences were observed in mortality or readmission rate to the ICU between the two groups. The ICU LOS was 2.5 times longer in patients who had a double valvular heart surgery compared to patients who had a single AVR (p=0.033), and 3.1 times longer in patients who had a mitral valve repair surgery (p=0.026). However, there was no significant difference in the overall hospital LOS observed between all other types of valvular heart surgery (p=0.56).

Of the 51 patients that developed new onset AF post-operatively, the majority were not receiving epicardial pacing at the time, with only 3.9% (n=2) receiving atrial pacing and 7.8% (n=4) receiving dual chamber pacing. The potassium level recorded closest to the development of the patients' first AF episode following their valvular heart surgery was median (IQR) 4.3mmol/L (0.4), and the magnesium level was median (IQR) 0.93mmol/L (0.17).

Discussion

This study found that the incidence of new onset POAF was 42.5% and was significantly associated with prolonged ICU and hospital LOS.

The overall incidence of new onset POAF identified in this study is consistent with other studies.[5–8] This is not surprising, as valvular heart surgery has been shown to substantially increase the risk of developing POAF.[9] Furthermore, a recent study found a significantly higher incidence of POAF following valvular heart surgery in combination with CABG than a singular valvular heart surgery (p<0.001), suggesting that patients are at higher risk of developing POAF when undergoing combined procedures.[8] This may be due to prolonged CPB and cross-clamp durations, as patients who experience longer CPB and cross-clamp times

Table 1: Baseline characteristics of patients.

	Overall (n=120)	Patients without AF (n=69)	Patients with AF (n=51)
Age (years)	67 (58–74)	66 (57–71)	69 (61.5–74.5)
Sex, n (%)			
Male	78 (65%)	46 (59%)	32 (41%)
Female	42 (35%)	23 (55%)	19 (45%)
Ethnicity, n (%)			
NZ European	63 (52.5%)	37 (58.7%)	26 (41.3%)
Māori	15 (12.5%)	6 (40%)	9 (60%)
Pacific peoples	19 (15.8)	11 (57.9%)	8 (42.1%)
Asian	4 (3.3%)	1 (25%)	3 (75%)
Other	19 (15.8)	14 (73.7%)	5 (26.3%)
BMI	28.5 (25.6–32.6)	28.6 (25.6–32.4)	28.4 (25.1–31.5)
EuroSCORE II	1.7 (1.1–2.8)	1.7 (1.1–2.4)	1.9 (1.2–3.0)
Ejection fraction, n (%)			
Good (>50%)	98 (81.7%)	57 (58.2%)	41 (41.8%)
Moderate (31–50%)	17 (14.2%)	11 (64.7%)	6 (35.3%)
Poor (21–30%)	3 (2.5%)	1 (33.3%)	2 (66.7%)
Very poor (20% or less)	2 (1.7%)	0 (0%)	2 (100%)
Previous MI, n (%)			
0	101 (84.2%)	56 (55.4%)	45 (44.6%)
1	17 (14.2%)	11 (64.7%)	6 (35.3%)
2	2 (1.7%)	2 (100%)	0 (0%)

Note: Data are shown as median (interquartile range) unless otherwise indicated. Percentages may not add up to 100% due to rounding error.
Abbreviations: AF = atrial fibrillation; n = number; NZ = New Zealand; BMI = body mass index; EuroSCORE II = European System for Cardiac Operative Risk Evaluation II; MI = myocardial infarction.

Table 2: Intraoperative characteristics of patients.

	Overall (n=120)	Patients without AF (n=69)	Patients with AF (n=51)
Type of valvular heart surgery, n (%)			
Aortic valve replacement	33 (27.5%)	17 (51.5%)	16 (48.5%)
Mitral valve replacement	11 (9.2%)	5 (45.5%)	6 (54.6%)
Mitral valve repair	13 (10.8%)	10 (76.9%)	3 (23.1%)
Double valve surgery	12 (10%)	6 (50%)	6 (50%)
Valve + CABG	40 (33.3%)	24 (60%)	16 (40%)
Other	11 (9.2%)	7 (63.6%)	4 (36.4%)
Redo valvular surgery, n (%)			
0	107 (89.2%)	60 (56.1%)	47 (43.9%)
1	12 (10%)	8 (66.7%)	4 (33.3%)
2	1 (0.8%)	1 (100%)	0 (0%)
Bypass duration (mins)	121 (93–148.2)	126 (93–163)	114 (93–135.5)
Cross-clamp duration (mins)	87 (65.75–109.25)	89 (69–114)	79 (55.5–102.5)
Intraoperative use of amiodarone, n (%)			
No	70 (58.3%)	40 (57.1%)	30 (42.9%)
Yes	50 (41.7%)	29 (58%)	21 (42%)

Note: Data are shown as median (interquartile range) unless otherwise indicated. Percentages may not add up to 100% due to rounding error.
Abbreviations: AF = atrial fibrillation; n = number; CABG = coronary artery bypass grafting; mins = minutes.

Figure 2: Post-operative day of first atrial fibrillation (AF) episode.

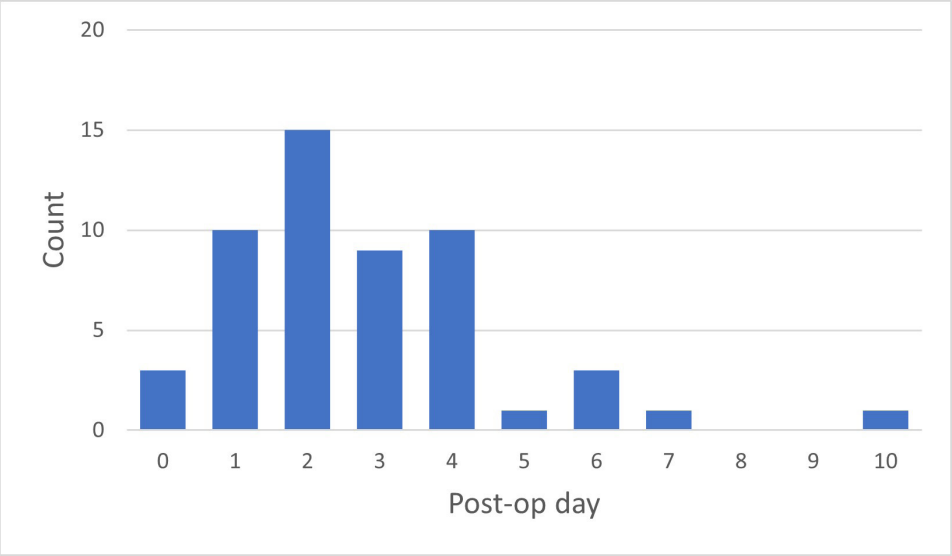


Table 3: Clinical outcomes of patients.

	Overall (n=120)	Patients without AF (n=69)	Patients with AF (n=51)	p-value
LOS				
ICU LOS (day)	1.8 (0.8–3.7)	1.2 (0.7–2.8)	2.8 (0.9–4.85)	0.002
Hospital LOS (day)	8 (6.7–12.9)	7.6 (5.9–11.8)	9 (7–13.85)	0.006
ICU readmission, n (%)				0.65
0	109 (90.8%)	62 (56.9%)	47 (43.2%)	
1	9 (7.5%)	5 (55.6%)	4 (44.4%)	
2	2 (1.7%)	2 (100%)	0 (0%)	
Hospital mortality, n (%)				1
Alive	116 (96.7%)	67 (57.8%)	49 (42.2%)	
Dead	4 (3.3%)	2 (50%)	2 (50%)	

Note: Data are shown as median (interquartile range) unless otherwise indicated. Percentages may not add up to 100% due to rounding error.
Abbreviations: LOS = length of stay; ICU = intensive care unit.

were also reported to be more likely to develop POAF.[8] This may be explained by the systemic inflammation CPB induces, which is a contributing factor for POAF, increasing the likelihood of AF following a combined surgery compared to isolated valvular heart surgery.[10] In this study, we saw no association between the type of valve operated on, CPB and cross-clamp durations and the development of new onset POAF. The inconsistent findings may be due to previous studies being conducted in different countries with different patient baseline characteristics. Turkkolu et al. conducted a study in Turkey with baseline characteristics such as reduced ejection fraction, diabetes and renal impairment, found to be independent predictors of POAF,[8] whereas these were not observed in this study. The number of patients who underwent a combined surgery observed in the previous study (12.6%) compared to the current study (33.3%), as well as its larger sample size of 1,191 participants, may contribute to the varying results observed between studies.[8]

None of the other variables analysed in this study, such as age, lower ejection fraction, male gender and post-operative serum electrolyte levels, were associated with the development of new onset POAF to be suggestive of being possible risk factors. Post-operative hypokalaemia and hypomagnesaemia are often monitored following cardiac surgery.[4,11] A recent study determined an increased risk of developing POAF associated with a post-operative potassium level below 4.5mmol/L, whereas a magnesium level below 1mmol/L post-operatively was not associated with the increased risk of AF.[12] In our study, a median potassium level of 4.3mmol/L and median magnesium level of 0.93mmol/L measured closest to the development of AF was found, suggesting that targeting a higher level of electrolytes may play a role in reducing risks of POAF.

Previous studies have identified risk factors significantly associated with the development of new onset POAF, with advanced age a consistently identified variable, although different median ages were identified.[8,11,13,14] Conversely, the current study did not find an association between older age and development of POAF, which agrees with an earlier study that found no difference between age and the likelihood of developing new onset POAF.[7] The differing findings may be due to studies being conducted in different countries with patients undergoing other cardiac procedures such as isolated CABG or isolated AVR surgery, whereas this study included all types of valvular heart surgery.

In this study, patients who underwent valvular heart surgery and developed new onset POAF had an ICU LOS of approximately 2 days more than those who did not, which was evident in another study.[14] Furthermore, this study also demonstrated that patients who developed POAF stayed longer in hospital compared to those who remained in sinus rhythm. A significantly longer hospital LOS of approximately 3.5 days for patients who developed AF post-operatively was also indicated in a previous study.[5] The longer LOS observed may be due to the management required to restore haemodynamic stability and to optimise the patient's condition to revert back to sinus rhythm.[14] However, the longer ICU LOS may have been confounded by bed availability on the post-operative ward, causing delays in patients being discharged from the ICU. Prolonged hospitalisation is associated with increased total cost and resource utilisation, as well as compromising patient quality of recovery with increased risks of hospital-acquired infections.[15] Delayed discharges place increased demands on hospitals, causing cancellations in elective surgery, delayed treatment and repercussions for following services.[16]

Interestingly, despite there being no difference seen in the incidence of POAF and the type of valvular heart surgery, there was a significantly longer ICU LOS observed in patients who underwent double valve surgery in comparison to patients who had a single valve surgery. The longer ICU LOS may be due to patients having poorer outcomes with developing AF in conjunction with post-operative complications associated with valvular heart surgery—as identified by the Society of Thoracic Surgeons Adult Cardiac Surgery Database—which can include prolonged ventilation, renal failure, mediastinitis, reoperation and stroke.[17] Other studies reporting the outcomes of patients undergoing double valve surgery have also shown greater hospital and long-term mortality risks when compared to single valvular heart surgery, with no mention of the impact on the LOS in hospital.[18,19]

The contrasting results may be attributed to studies investigating cardiac surgeries that have included a larger proportion of patients undergoing isolated CABG procedures, varying amiodarone dosages and inconsistent timing of amiodarone administration peri-operatively.[8,13,14]

With no guidelines in place at the study centre, intraoperative amiodarone was administered in this study based on the preference of the surgeon or anaesthetist, in conjunction with the condition and heart rhythm the patient was in during surgery.

As POAF remains an identified issue with an associated prolonged LOS following cardiac surgery, consideration of future studies that are more inclusive and specify the type of heart valve being operated on may advance knowledge regarding the applicability and efficacy of the potential prevention and management strategies against POAF. The incidence and burden of new onset AF following cardiac surgery may be reduced through establishing standardised guidelines that could be adopted locally and internationally. Addressing the issue of not having a national guideline in Aotearoa New Zealand to prevent and manage AF following cardiac surgery that is inclusive of all types of common cardiac procedures, especially for valvular heart surgery, may lead to a reduction in the incidence of new onset POAF, shorter LOS in hospital and improved patient outcomes.

Limitations

The retrospective nature of this study design may have introduced bias and with the observational design causal relationships cannot be established. The small sample size, as a result of the time constraints of this project, may have led to selection bias.[20] Due to the variables chosen for this study, other risk factors may be present that were not measured in the dataset. This exposes the study to confounding bias and may produce inconsistent findings compared to other studies that may choose different risk factors to measure. The internal validity of this study, therefore, may be compromised, as unaccounted confounding variables may potentially mislead the association the study is attempting to identify.[20] Furthermore, findings may not be generalisable to other settings that care for post-operative cardiac patients in Aotearoa New Zealand or other countries.

Conclusion

This single-centre study found that valvular heart surgery was associated with a high incidence of new onset POAF, and prolonged ICU and hospital LOS, particularly following double valve surgery. An introduction of a national guideline for the management of POAF could lead to a reduction in POAF and associated adverse outcomes following valvular heart surgery in Aotearoa New Zealand.

COMPETING INTERESTS
None.

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Access to gluten-free foods for people with coeliac disease in New Zealand

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ABSTRACT

AIM: A strict gluten-free (GF) diet is the current mainstay of treatment for coeliac disease (CD). A limited range of GF foods are available on prescription for those with CD. GF foods purchased in shops are typically more expensive than gluten-containing equivalents. This study sought to understand how New Zealanders with CD obtain GF products and the changes associated with this.

METHOD: Coeliac New Zealand members were asked to complete an anonymous electronic survey in June 2023.

RESULTS: Although 24% of the 522 respondents had accessed GF foods on prescription in the past, only 2% currently used the service. One-third of the respondents were unaware of the service. Cost and limited product range were the key reasons for not accessing prescriptions. Most non-prescription GF foods were purchased from a supermarket, with 54% spending over $50 per week on GF foods. Most respondents (90%) would prefer a discount card to purchase GF products. Preferences regarding the prescription service would be to collect products from a local shop (84%) or a pharmacy (42%).

CONCLUSION: This study indicates a very low uptake of GF products on prescription, with awareness, cost, product range and convenience limiting use of the service. Most respondents would prefer financial support for discounted GF products.

Coeliac disease (CD) is an autoimmune enteropathy occurring in response to dietary exposure to gluten in those who are genetically susceptible.[1] It occurs in around 1% of the population internationally, with higher rates in certain groups, and prevalence is thought to be increasing.[2–4] In New Zealand, the prevalence has been shown to be as high as 1.2%, but recent epidemiological data are lacking.[5] For those diagnosed with CD, adherence to a strict, life-long, gluten-free (GF) diet is currently the only treatment available. Strict adherence to the GF diet achieves resolution of any symptoms, and induction and maintenance of remission in most individuals, with less than 0.4% experiencing persistent symptoms when on a strict GF diet.[6–8] Maintaining adherence to the GF diet can also reduce the risk of complications of uncontrolled CD, such as osteoporosis, infertility and lymphoma, and can support normal growth in children.[9–11]

However, maintenance of a strict GF diet has its challenges. The ubiquitous nature of gluten in the Western diet, and specifically in the New Zealand diet, requires people with CD to be constantly vigilant about what they consume, and to have a good understanding of hidden sources of gluten in food and potential sources of gluten contamination. Many foods that would ordinarily be naturally GF can be altered to contain gluten during processing. Additionally, non-food sources, such as cosmetics and Playdough, can lead to inadvertent exposure.[12,13] This can have lifestyle implications such as anxiety and concern about eating outside the family home, sharing food and food-related activities at school.[14]

In many countries, including New Zealand, a range of specialist GF products have been developed to supplement the use of other naturally GF staples and to replace gluten-containing alternatives. However, although widely available for purchase, they tend to be more expensive than their gluten-containing equivalents.[15] Hence, maintaining a GF diet can add a significant financial burden to individuals and families. A number of countries have implemented policies to support those diagnosed with CD in accessing reliable, clearly labelled GF products. This includes establishing labelling legislation and setting up cutoffs for foods deemed GF, ranging from <3 to 20 parts per million (the milligrams of gluten per kilogram of product).[16,17] In addition, a number of countries have also established various systems and policies to support access to GF products for those diagnosed with CD, such as tax deductions, a partial or total subsidy via prescription or direct provision of GF products.[18]

Historically in New Zealand, specialist GF products have been available on prescription for those who have been diagnosed with CD by a health professional, implemented as a partial prescription subsidy for a range of staple GF

products. This was managed by Pharmac—a scientific advisory board appointed by the New Zealand minister of health to determine which medicines and medical products will be publicly funded within the national budget—under the guidance of the special foods advisory committee.[19] However, these products ceased to be actively managed by Pharmac on 1 April 2011 and the range of products available on prescription has gradually diminished since, along with ease of access.[20] As of 2023, the range of prescription GF products available in New Zealand includes only GF bread mix, GF flour and GF baking mix.[21] The home delivery service, unique to parts of the South Island of New Zealand, was also discontinued in 2023, with all prescription products now requiring pharmacy collection.

The aim of this study was to ascertain how New Zealanders with CD are accessing their GF products, both prescribed and commercially purchased, the cost associated with these and how these products/services are currently meeting their needs.

Methods

Participants

Participants were eligible to take part in the study if they were aged 18 years and had been diagnosed with CD, or had a partner or dependent with CD, and they resided in New Zealand.

Ethics

The study was granted ethics approval by the University of Otago Human Ethics Committee (Health) on 17 May 2023 (HD23/035).

Study design

The study took the form of a prospective observational survey.

Survey

The survey was designed with input from experts in CD and stakeholders/patient advocates from the patient support group Coeliac New Zealand.[22] The survey was developed using Qualtrics (Qualtrics, Provo, UT).

All participants provided consent prior to being able to access the survey. On completion of consent, participants were asked basic demographic questions, then questions around the use of prescription GF products, the purchase of non-prescription GF products and the cost associated with these. Questions were also asked on consumer preference with regards to the range of prescription GF products in New Zealand, access to prescription products and preference for future financial support. The survey was designed to include both multiple choice and free-text questions to allow for a range of data to be gathered (see Appendix).

Survey distribution

The survey invitation was distributed by Coeliac New Zealand. An invitation to participate in the survey was included in the Coeliac New Zealand newsletter in June 2023 (n=2,195) with further promotion with a link and invitation posted on the Coeliac New Zealand Facebook page during the month of June 2023.

Statistical analysis

Data were extracted from Qualtrics into Microsoft Excel™ for analysis. All responses were collated and reviewed, with statistical analyses of the data being descriptive in nature. Data were presented as a percentage of the total responses.

Results

Demographics

Five hundred and twenty-two people from across New Zealand completed the survey either for themselves (70%) or for their spouse (3%) or dependents (27%), indicating an estimated response rate of 24%, with all regions and age ranges represented in the survey (Table 1).

Usage of prescription GF foods

Of those surveyed, only nine participants (2% of the whole cohort) currently accessed GF foods on prescription. Of the 513 participants (98%) that did not access GF foods on prescription, 127 (24%) had received GF foods on prescription in the past, 189 (37%) were not aware of the service and 197 (38%) chose not to access GF food prescriptions.

Respondents who were current users of prescription GF foods

Of the nine respondents (2% overall) who still obtained GF products on prescription, seven people accessed these through their general practitioner (GP) and two accessed these from their dietitian. The most common product received on prescription was Healtheries Baking Mix (n=7), followed by three using Horleys Flour and one using Horleys Bread Mix.

For two-thirds (n=6) of those who currently use

Table 1: Demographics of all survey respondents (n=522), as reported for people with coeliac disease.

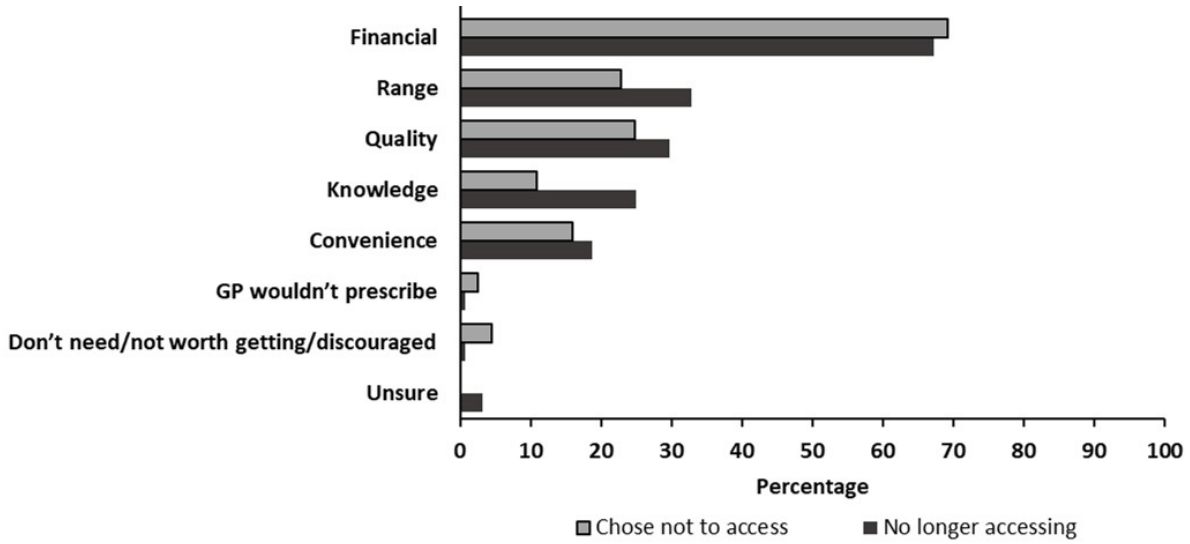
		Number (n=522)	Percentage (%)
Respondents	Person with CD	363	70
	Partner with CD	18	3
	Parent of child with CD	140	27
Age of respondent	On behalf of child <18yr	121	23
	18–24yr	26	5
	25–34yr	51	10
	35–44yr	86	16
	45–54yr	88	17
	55–64yr	69	13
	over 65yr	81	16
Gender identifies with	Male	82	16
	Female	437	84
	Non-binary	2	0.4
	Prefer not to say	1	0.2
Ethnicity	New Zealand European	480	86
	Māori	20	4
	Pacific	3	0.5
	Asian	2	0.4
	Middle Eastern, Latin American or African	8	1
	Other	40	7
	Prefer not to say	2	0.4
Region	Northland	9	2
	Auckland	130	25
	Waikato	43	8
	Bay of Plenty	37	7
	Gisborne	4	1
	Hawke's Bay	8	2
	Taranaki	11	2
	Manawatū-Wanganui	24	5

Table 1 (continued): Demographics of all survey respondents (n=522), as reported for person with coeliac disease.

	Wellington	79	15
	Tasman/Nelson	12	2
	Marlborough	5	1
	West Coast	2	0.4
	Canterbury	94	18
	Otago	49	9
	Southland	15	3
Number of household members with CD	1	404	77
	2	98	19
	3	13	2
	4+	7	1

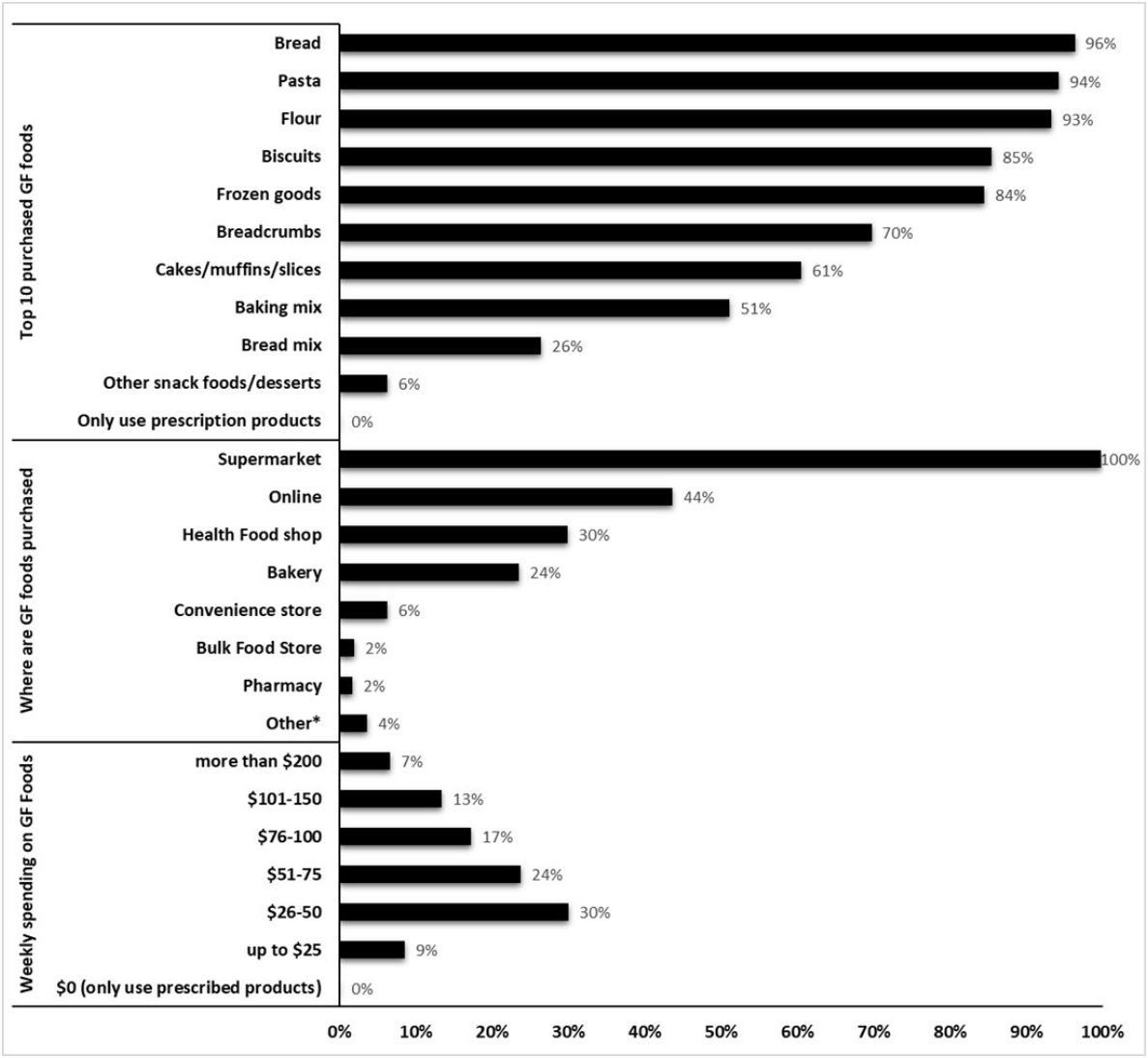
CD = coeliac disease; yr = years.

Figure 1: Reasons given by survey respondents for not accessing gluten-free foods on prescription.



Not accessing n=197, no longer accessing n=127.
GP = general practitioner.

Figure 2: Survey responses regarding which non-prescription gluten-free foods are purchased, where respondents buy them and the associated costs (n=522).



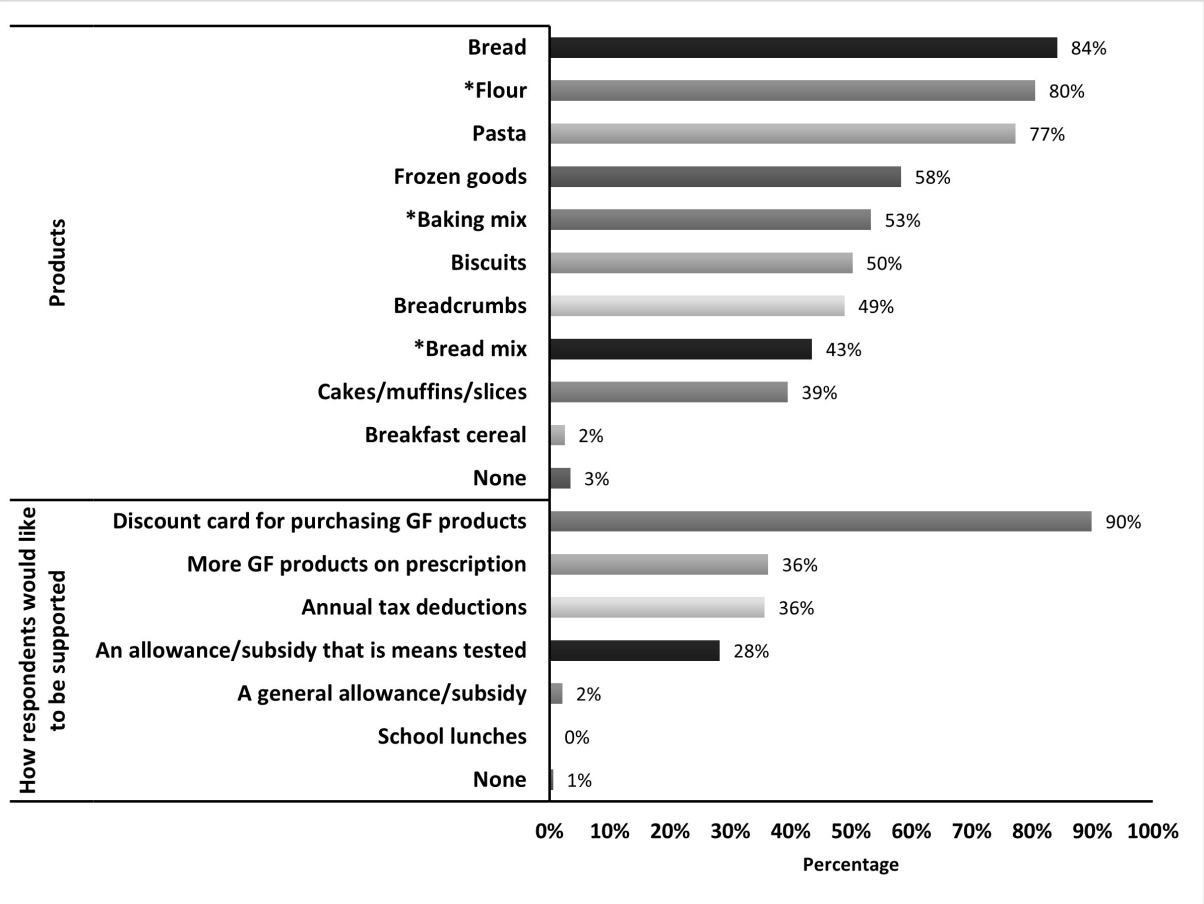
*Other includes: Asian food store (n=4), specialty GF store (n=3), fruit and vegetable shop (n=3), market (n=3), food importer (n=3), delicatessen (n=2) and butcher (n=1).

prescribed products, these products accounted for less than half of all GF food consumed. The reported cost of prescriptions was no more than NZ$25 per month for seven out of the nine respondents.

Respondents who were previous users of prescription GF foods

One hundred and twenty-seven respondents (24%) had previously received GF foods on prescription. Of these, 58 (46% of this sub-group) had stopped over 10 years prior and the remainder in the intervening years. These GF prescription products were accessed via their GP by 103 respondents (73%), via their dietitian by 13 respondents (9%) and via a specialist (paediatrician, paediatric gastroenterologist or gastroenterologist) by 27 respondents (18%) at the time. The main reasons reported for stopping were related to the associated costs of prescription products (n=86, 67%), not being happy with the range (n=42, 33%) or quality (n=38, 30%) of the

Figure 3: Response rates to show preferences for future financial support for purchasing gluten-free foods, and which foods are preferred (n=522).



*Currently available on prescription.

GF foods available on prescription, knowledge of ongoing access to products on prescription (n=32, 25%) and the convenience of access (n=24, 19%).

Respondents who chose not to access prescription GF foods

One hundred and ninety-seven respondents (38% of the overall cohort) had chosen not to access GF foods on prescription. Cost was the most common reason given for not using the service (n=139, 70% of this sub-group), followed by the quality of the products offered (n=50, 25%) and the range offered (n=46, 23%) (Figure 1). Two respondents who had never accessed GF products on prescription reported that this was not ever an option for them due the products not being suitable with their other concomitant allergies.

Respondents not aware of GF products on prescription

Of the 189 respondents who weren't aware of GF foods on prescription, 178 (95% of this sub-group) would consider accessing them. Seventy-five respondents (40%) said that they would have accessed them had they been aware, 90 respondents (48%) would consider accessing them on prescription depending on the associated costs and 13 respondents (7%) would access them on prescription depending on convenience, range available and quality of the products offered.

Use of non-prescribed GF foods

All participants who completed the survey reported purchasing some GF products. When asked where respondents purchased these, 520

(99.6%) reported purchasing non-prescription GF foods from the supermarket, with 228 (44%) purchasing products online. Other sources were health food shops, bakeries and convenience stores. The most common purchases were bread (95%), pasta (93%) and flour (92%), followed by biscuits (85%) and frozen foods (84%) (Figure 2). Respondents tended to spend $26–75 per week on additional GF items (54%) with 61% of respondents (n=319) spending over $50 per week on GF foods alone. Eighty-five percent of respondents did not receive any benefits to support their GF diet.

Preferred support for GF food purchases

When asked how best they would like to be supported to purchase GF foods, 469 respondents (90%) preferred some form of GF food discount card to purchase GF products at a supermarket or other store. One hundred and eighty-six respondents (36%) would like to see an annual tax deduction for people with CD irrelevant of income, and 147 respondents (28%) would like to see allowances for GF foods based on income (Figure 3). The GF foods that respondents wished to have available on prescription tied in with the most commonly purchased GF foods (Figure 2), with most wanting pasta, bread and flour. Over half would also like to see frozen goods (n=305) and baking mixes (n=278) available on prescription (Figure 3). When asked how they would like to access these prescription products, 439 respondents (84%) said they would like to collect them from their supermarket or local store, 357 (69%) would like free home delivery and 216 (42%) would like to collect it from their pharmacy (as is current practice).

Discussion

This survey was undertaken to ascertain how New Zealanders with CD are accessing their GF products, the cost implications of this and how these products/services are currently meeting their needs. The results of this survey show a very low uptake of prescription GF products, with poor awareness of the service being a contributing factor. Compared with previous research this highlights reduced engagement with the prescription GF product service throughout New Zealand, with barriers reported as associated costs, the limited range of products available and convenience. The majority of respondents would prefer future financial support for GF food purchases to be in the form of discount cards to purchase GF products from their local supermarket or store.

The maintenance of a strict GF diet is essential for management of CD. As many dietary staples contain gluten, the advent of specialty GF alternatives allowed for increased dietary variety for people with CD. In recent years, the GF diet has become more popular for those who have not been diagnosed with CD,[23] which may have encouraged the growth in range and availability of GF products seen in many countries. This trend, however, may not be universal, with availability to GF food still more limited in some countries, including Canada, Chile, Saudi Arabia, Turkey and the United Kingdom (UK).[24–28] Burden et al.[28] reported that although there was good availability of GF foods in UK supermarkets and online, availability in regional budget supermarkets in the UK remained poor. Similarly, Jegede et al.[24] found the number of GF foods sold in chain stores to be significantly higher than in local stores in Manitoba, Canada. In fact, Qashqari et al.[26] found that local/budget supermarkets in Jeddah City, Saudi Arabia did not supply any GF products. Overall, this highlights the potential for significant inequities in access to suitable GF products for people diagnosed with CD, which has significant dietary adherence and health implications for these individuals.

Furthermore, despite improvements in availability and cost, GF products continue to be significantly more expensive than their gluten-containing equivalents.[29,30] Although there are expected weekly food costs for all related to the purchase of suitable foods, regardless of coeliac status, a review by Coeliac New Zealand in 2021 showed GF products to be on average 2.5 times more expensive than their gluten-containing equivalents, with bread being 5 times more expensive.[31] This difference has also been seen in a number of other countries, including Austria, Chile, Greece, Saudi Arabia and Turkey.[25–27,32,33] In order to overcome these cost disparities, a number of countries have implemented various forms of support for those requiring a GF diet. These include tax offsets, financial support and the provision or subsidising of GF foods.[18,34] The financial implications to the health system of offering support to those requiring a GF diet were highlighted by a recent UK study, where some regions now no longer offer GF foods on prescription.[35] In England, national guidelines for prescribing GF products were in place until 2015, at which time local clinical commissioning groups took over, prompting significant variations in GF prescribing across England.[36] Participants living in regions that no

longer offered GF prescriptions tended to spend significantly more each month on GF products than those in areas that did offer prescription products, highlighting the potential financial implications for those in the lowest income brackets.[35]

A partial subsidy for prescription GF products offered by Pharmac, the organisation appointed by the New Zealand Ministry of Health to determine funding of medicines and medical products, is available to support people diagnosed with CD who live in New Zealand. However, uptake of this service was found to be very low, with only 2% of the respondents in the current study accessing GF products on prescription. The apparent low uptake of prescription GF products seen in this survey is consistent with data provided by Pharmac, indicating a 38–71% decline in the number of people obtaining the three remaining available prescribable products over the last 7 years.[37] Nationally, only 21 unique users ordered Horleys Bread Mix in 2023.[37] This may be due to a number of factors, such as poor awareness of the availability of GF food on prescription and how to access this service. With such a high reported unfamiliarity with prescription products and how these could be accessed, further investigation is warranted. Literature exploring access to support schemes provided to those with CD appears sparse both in New Zealand and internationally. Pharmac stopped actively managing prescribed GF products in New Zealand in 2011.[20] This means that no new products have been added to the range offered, and subsidies for the products available have not changed since. Subsequently, the range of products available has gradually decreased over this time, while the cost of these products has increased due to increasing product costs, without increasing subsidy. Considering the perceived cost barriers to accessing prescription GF foods, such as charges for the GP appointment, prescription, pharmacy, and the cost of the products after the subsidy, it is often not financially viable to obtain products on prescription. This is circumvented in a number of countries with the use of subsidies or cash transfers; however, this requires people with CD to source their own GF products and then be reimbursed.[18]

The associated healthcare utilisation costs of non-adherence to a GF diet for people with CD should also be considered if access to GF foods becomes prohibitive. Long-term untreated (or under-treated) CD could lead to reduced work productivity (due to sick days), impaired quality of life or reduced achievement in education.[38,39] Furthermore, this could lead to higher rates of complications such as osteoporosis (leading to costly treatment or management of related fractures), or costs for fertility support.[40] Therefore, providing ongoing support for people to adhere to a GF diet as the only current treatment modality for CD is imperative, particularly for more vulnerable populations. A recent study indicated that restriction or withdrawal of prescription GF products was shown to disproportionately affect access in those with an illness or disability, those with mobility issues and those on lower incomes.[41] This raises equity concerns with the gradually declining range and increasing cost of GF products available on prescription in New Zealand. Although there appears to be a good availability of GF products online and in larger supermarkets, as shown by studies in the UK and Canada these require access to transport or sufficient literacy with online platforms to access suitable GF products and do not take in to account the increased costs of GF products seen both in New Zealand and internationally.[24,28,31] Some potential limitations to the results should be mentioned. Firstly, there was a strong female response bias. Although we do know that slightly more females than males are affected by CD, it does not account for the significant female bias in the response rate of 84%.[42] Further to this, due to our recruitment and distribution methods using a Coeliac society membership—a paid membership society—respondents are likely to be more informed and have differing needs and opinions to that of the general CD population, which must be considered when interpreting findings.

Conclusions

With the very low uptake of prescription GF products throughout New Zealand seen in the current survey, more research is required to assess how this population can be supported to access a GF diet, the current mainstay of treatment for CD. Poor awareness of the availability of prescription GF products seen in a large proportion of the cohort indicates that increased promotion of the service may be required if the service is to continue being offered. However, clear limiting factors such as the increasing associated costs and diminishing range available on prescription may still limit uptake. This study highlights that the majority of respondents would prefer future financial support in the form

of discount cards to independently purchase GF foods, as opposed to offering prescription products. This would allow more flexibility of access, convenience and range of products, and may in turn drive the innovation and development of more palatable, less expensive GF products in the future. Further investigation is warranted into how those with CD want to be supported and how best to maximise equity of care across New Zealand.

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Appendix

Gluten Free Products in NZ

Section 1: Demographics

D1. How would you describe yourself?

- Adult with coeliac disease (1)
- Adult with a partner who has coeliac disease (filling in the survey on their behalf) (2)
- Adult with a child who has coeliac disease (filling in the survey on their behalf) (3)

Firstly, we would be grateful if you would provide a few details about yourself, or person you are completing this survey for.

Please note that if you are completing the survey for someone else (partner/child) then all questions are phrased as "you/yours" but we are looking for their answer, not yours. For example—when we ask "What is your age" we need you to respond with their information. If completing the survey for your child you would select "I am answering for my child who is less than 18". Or if completing the survey for your partner who is 50 you would select their age bracket, not yours.

D2. What is your age?

- I am answering for my child who is less than 18 (1)
- 18–24 years (2)
- 25–34 (3)
- 35–44 (4)
- 45–54 (5)
- 55–64 (6)
- Over 65 (7)

D3. What gender do you identify with?

- Male (1)
- Female (2)
- Non-binary/third gender (3)
- Prefer not to say (4)

D4. Which ethnic group(s) do you belong to? Select all that apply.

- New Zealand European (1)
- Māori (2)
- Pacific Island (3)
- Asian (4)
- Middle Eastern, Latin American or African (5)
- Other (6)
- Prefer not to say (7)

D5. What is the highest level of education that you have completed?

- Child—preschool/school age (6)
- High school (1)
- Polytechnic or vocational training (2)
- University (3)
- Postgraduate (4)
- Prefer not to say (5)

D6. What is your estimated household income each year? This includes income from all sources.

- Less than $50,000 (1)
- $50,001–$75,000 (2)
- $75,001–$100,000 (3)
- $100,001–$125,000 (4)
- $125,001–$150,000 (5)
- $150,001–$200,000 (6)
- $200,001 or more (7)
- prefer not to say (8)

D7. Where in New Zealand do you live?

- Northland (1)
- Auckland (2)
- Waikato (3)
- Bay of Plenty (4)
- Gisborne (5)
- Hawke's Bay (6)
- Taranaki (7)
- Manawatū-Wanganui (8)
- Wellington (9)
- Tasman/Nelson (10)
- Marlborough (11)
- West Coast (12)
- Canterbury (13)
- Otago (14)
- Southland (15)

D9. How many people in your household have been diagnosed with coeliac disease

- 1 (1)
- 2 (2)
- 3 (3)
- 4 or more (4)

D10. At what age were you diagnosed with coeliac disease?

_____

D11. Do you receive additional benefits due to your diagnosis of coeliac disease? Please select all that apply.

- Child Disability Allowance (6)
- Disability Allowance (2)
- Other (4)
- Prefer not to say (5)
- None (8)

D12. What "other" additional benefits do you receive due to your diagnosis of coeliac disease? Please specify:

_____

Section 2: Prescription Gluten Free Products

For the following questions, think about gluten free products that you get **on prescription**.

P1. Do you *currently* get gluten free products on prescription?

- Yes (1)
- No, but I have in the past (please select this even if you only stopped recently) (2)
- No, I choose not to (5)
- No, I didn't know about them (3)

P5. If yes, which gluten free products do you CURRENTLY get on prescription? Please select all that apply.

- Healtheries Baking Mix (1)
- Horleys Bread Mix (2)
- Horleys Flour (3)

P7. If no, but I have in the past, how long ago did you stop getting gluten free products on prescription?

- Less than 1 year ago (4)
- 1–5 years ago (5)
- 6–10 years ago (6)
- Over 10 years ago (7)

P8. If yes, you currently get prescriptions, who provides your prescription for gluten free products? Please select all that apply.

- Your GP (1)
- Dietitian (2)
- Gastroenterologist (3)
- Other (4)

P9. Who is the "other" service that provides your prescriptions?

_____

P10. If yes, you used to get prescriptions, who used to provide your prescription for gluten free products? Please select all that apply.

- Your GP (1)
- Dietitian (2)
- Gastroenterologist (3)
- Other (4)

P11. Who is "other" service that provided your prescriptions?

_____

P13. If you received products on prescription in the past, why do you no longer get gluten free products on prescription? Please select all that apply.

- I didn't know it was still possible (1)

- I don’t know who prescribes them (2)
- My GP won’t prescribe them (3)
- The range is not available in my pharmacy/area (4)
- I don’t like the gluten free foods available on prescription (5)
- I would have to pay for the prescription (6)
- It is cheaper to get them from the supermarket (7)
- Other (8)
- They stopped providing the product I wanted (9)

P14. If you *currently* get gluten free products on prescription, how much of all the gluten-free food you eat is what you get on prescription?
Example: half the GF food you eat is from prescriptions and half is bought in the supermarket.

This relates to products that would normally contain gluten such as pasta and baked goods rather than naturally gluten free foods such as rice or fresh vegetables.

- ALL of the gluten free food I eat is prescribed (1)
- Most of it (2)
- Half of it (3)
- Less than half (4)
- Occasionally use it (5)

P15. If you currently get gluten free products on prescription, how much do you spend per month on prescribed gluten free products?

- Nothing (1)
- Up to $25 (2)
- $26–50 (3)
- $51–75 (4)
- $76–100 (5)
- More than $100 (6)

P16. If you got GF products on prescription *in the past*, how much did you spend per month on *prescription* gluten free products? e.g., cost of the prescription/delivery fees/GP prescription charges, etc.

- Nothing (1)
- Up to $25 (2)
- $26–50 (3)
- $51–75 (4)
- $76–100 (5)
- More than $100 (6)
- I can't remember (7)

P17. Why else do you no longer get gluten free products on prescription?

_____

P18. If you choose not to get GF products on prescription, why do you choose not to get gluten free foods on prescription? Please select all that apply.

- I don’t know who prescribes them (2)
- My GP won’t prescribe them (3)
- The is range not available in my pharmacy/area (4)

- I don't like the gluten free foods available on prescription (5)
- I thought I would have to pay for the prescription (6)
- It is cheaper to get then from the supermarket (7)
- Other (8)

P19. For what "other" reasons do you choose not to get gluten free products on prescription?

_____

P23. If no, I didn't know about them, if you had been informed of gluten free products being available on prescription do you think you would have used them?

- Yes (1)
- No (2)
- It would depend on the cost (3)
- Other (4)

P24. What "other" reasons would affect your decision to use gluten free products on prescription?

_____

P26. What gluten free products (if any) would you like to be available on prescription? Please select all that apply.

- Pasta (1)
- Bread (2)
- Flour (3)
- Bread mix (4)
- Baking mix (5)
- Biscuits (6)
- Breadcrumbs (7)
- Cakes/muffins/slices (8)
- Frozen goods (e.g., pizza, fish fingers, sausage rolls) (10)
- Other: _____ (9)

P27. Which "other" products would you like to be available on prescription?

_____

P28. How would you like to access gluten free products available on prescription? Please select all that apply.

- From my pharmacy (1)
- From my GP (2)
- From my gastroenterologist (3)
- From my dietitian (4)
- Delivered to my home (if it was free) (5)
- Delivered to my home (if it incurred an additional delivery charge) (6)
- Collection from my supermarket or local store (7)
- Other (8)

P29. Which "other" ways would you like to access products available on prescription?

_____

P30. We are aware that there is an increased cost associated with the purchase of gluten free products. If there was a form of subsidy available, how would you prefer to be supported? Tick all that apply.

- More gluten free products on prescription (1)
- Discount card for gluten free products purchased at the supermarket or other store (2)
- Annual tax deductions for people with coeliac disease (3)
- Allowances for gluten free foods based on your income (4)
- Other (please specify next) (5)

P31. What "other" ways would you like to be supported with the cost of your gluten free products?

_____

Section 3: Purchased Gluten Free Product Use

The following questions are looking at what gluten free products you are currently **purchasing (not on prescription)**.

For the purposes of this survey, when we refer to **gluten free products**, this describes products that would normally contain gluten such as pasta and baked goods rather than naturally gluten free foods such as rice or fresh vegetables.

Q1. Where do you buy gluten free products that are not prescribed? Tick all that apply.

- Supermarket (1)
- Health food shop (2)
- Bakery (3)
- Convenience store (7)
- Pharmacy (4)
- Online (5)
- Other (6)

Q5. Which "other" places do you buy gluten free products?

_____

Q2. What gluten free products do you buy (do not include any products you get on prescription)? Tick all that apply.

- Pasta (1)
- Bread (2)
- Flour (3)
- Bread mix (4)
- Baking mix (5)
- Biscuits (6)
- Breadcrumbs (7)
- Cakes/muffins/slices (8)
- Frozen goods (e.g., pizza, fish fingers, sausage rolls) (11)
- Other: _____ (9)
- We only use prescription gluten free products (10)

Q3. What "other" gluten free products do you buy?

_____

Q4. How much do you spend each week on gluten free products (not including prescribed gluten free products)?

- $0–I only spend money prescribed gluten free food (1)
- Up to $25 (2)
- $26–50 (3)
- $51–75 (4)
- $76–100 (5)
- $101–150 (6)
- More than $200 (7)

Q6. Do you have any further questions or comments to add?

_____

Section 4: Conclusion

Thank you for completing our survey. We appreciate your time and thoughts!

If you know of anyone else with coeliac disease who would like to complete the survey please copy/paste and send them the survey link below:

[survey link]

If you have any further questions please don't hesitate to get in touch via the email:

[email]

Equity of access to pathological diagnosis and bronchoscopy for lung cancer in Aotearoa New Zealand

Jason Gurney, Anna Davies, James Stanley, Jesse Whitehead, Laird Cameron, Shaun Costello, Paul Dawkins, Jonathan Koea

ABSTRACT

BACKGROUND: Māori are less likely to survive their lung cancer once diagnosed, but it remains unclear whether this is partially driven by poorer access to best-practice diagnostic services.

METHODS: We examined all lung cancer registrations in Aotearoa New Zealand between 2007–2019 (n=27,869) linked to national administrative health datasets and further stratified by ethnicity, tumour type and stage of disease. Using descriptive and regression analyses, we compared ethnic groups in terms of the basis of diagnosis (e.g., histology, cytology), receipt of bronchoscopy and travel distance and time to access bronchoscopy.

RESULTS: We found no differences in access to a pathological diagnosis between ethnic groups regardless of cancer type or stage. We found that Māori within the cohort were marginally more likely to access bronchoscopy than the majority European group; however, we also found that Māori had lower odds of living close to the location of their bronchoscopy, and correspondingly higher odds of living 100–200km (adjusted odds ratio [adj. OR] 1.46, 95% confidence interval [CI] 1.26–1.69) or more than 200km away (1.36, 95% CI 1.15–1.61) than Europeans.

CONCLUSION: Interventions that aim to further support Māori to overcome the systematic and cumulative disadvantages in access to cancer care should be broadly supported and resourced.

Māori are more likely to die of their lung cancer regardless of deprivation level or comorbidity burden.[1] Part of this survival disparity is likely to be driven by differential access to an early diagnosis, with Māori less likely to be diagnosed with localised disease than non-Māori (but similarly likely to be diagnosed with metastatic disease).[2] While evidence on differential receipt of lung cancer diagnostic testing between Māori and non-Māori is scant, during the COVID-19 pandemic access to bronchoscopy services was differentially disrupted for Māori compared to non-Māori[3]—suggesting that disparities in access to this testing may indeed exist. If this is the case, then Māori patients may be less likely to receive a pathological diagnosis, which could reflect inequitable differences in access to best-practice diagnostic workup between Māori and non-Māori. There is evidence from other cancers that supports this notion: a national colon cancer study found that, among those who had a primary resection of their tumour, Māori were less likely to have a diagnosis based on a pathology report (crude proportion: 45% compared to 55% of non-Māori/non-Pacific), and also had fewer lymph nodes examined as part of cancer staging.[4]

A potential driver of disparities in access to diagnosis could include a mismatch in where diagnostic services are located, relative to where Māori live. In a recent study on liver cancer, we found that Māori needed to travel more than 120km (or over 2 hours) to access their first surgery compared to 60km (or less than 1 hour) for Europeans—with this disparity likely driven by the centralisation of liver cancer surgical services.[5] However, in the same study, we observed no such differences in travel requirement to access first surgical treatment for stomach cancer, possibly because stomach cancer treatment is more diffusely distributed around the country.[5] It remains unclear whether the diagnosis of lung cancer follows a similar pattern to liver or to stomach cancer with respect to differences in travel burden between Māori and non-Māori ethnic groups.

This manuscript uses national-level data to examine ethnic disparities among those diagnosed with lung cancer in terms of a) receipt of a pathological diagnosis, and b) receipt of a

diagnostic bronchoscopy, including travel required to access bronchoscopy. These factors are examined in relation to lung cancer tumour type and stage, to account for potential differences between ethnic groups in these factors. While data are shown for all ethnic groups in Aotearoa New Zealand, the primary focus of the manuscript is on Māori and the majority European population due to the disparities in lung cancer outcomes described above. This study is led by a Māori researcher (JG), supported by Māori and non-Māori researchers and clinicians.

Methods

Participants and data sources

We included all lung cancer registrations (ICD-10-AM code: C33–C34) between 2007–2019 on the New Zealand Cancer Registry (NZCR; N=27,869, 5,601 Māori, 1,267 Pacific peoples, 1,180 Asian, 123 Middle Eastern/Latin American/African/Other [hereafter "MELAA/Other"], 19,698 European). NZCR data were linked to other National Collections health datasets, including all public and reporting private hospital inpatient records (National Minimum Dataset [NMDS]) and emergency department and outpatient records (National Non-Admitted Patients Collection [NNPAC]).

Demographic variables

Age at diagnosis was taken from the NZCR (by subtracting the date of cancer diagnosis from the patient's date of birth) and categorised as <50, 50–64, 65–74 and 75+. **Prioritised ethnicity** was derived from National Collections datasets and categorised into Māori, Pacific peoples, Asian, European or MELAA/Other. **Area-level socioeconomic deprivation** was defined using the New Zealand Index of Deprivation (NZDep) at the time of cancer diagnosis (NZDep 1–2 [least deprived], 3–4, 5–6, 7–8, 9–10 [most deprived]).[6] **Rurality** was defined using the Geographical Classification for Health (GCH) at the time of cancer diagnosis, (Urban 1 ["most" urban], Urban 2, Rural 1, Rural 2, Rural 3 ["most" rural]), based on population density and travel time to the edge of an urban area.[7] **Comorbidity** at time of cancer diagnosis was defined using the C3 cancer comorbidity index, which uses public and private inpatient hospitalisation data (NMDS) to define the presence of 42 individual conditions and derive a weighted score.[8] Condition weights were then summed to give the final C3 score, categorised as "0" (score <=0), "1" (<=1), "2" (<=2) and "3" (>2).[8] The C3 index was used as both a categorical variable (for descriptive analysis) and as a splined variable for regression modelling using restricted cubic splines with three knots placed at the 50th, 90th and 95th percentiles.[9]

Tumour variables

Tumour type was determined using morphology data from the NZCR at the time of cancer diagnosis (**Appendix 1**) and categorised into small cell lung cancer (SCLC), non-small cell lung cancer (NSCLC) or "other/unspecified" (the last primarily being tumours where the morphology code is unspecified).[10] **Stage of disease** was derived from the NZCR and based on the SEER Summary Stage method (A to F).[11] Stage was categorised into Local (B), Regional (C and D), Advanced (E) and Unstaged (F).[12]

Outcome variable

Basis of diagnosis and receipt of a pathological diagnosis was derived from the NZCR and categorised into cytology, histology, clinical (including endoscopy/imaging), death certificate only, other (including exploratory surgery/autopsy without histology, or biochemical/immunological tests) and missing data. To define receipt of a pathological diagnosis, we set a binary indicator of whether the diagnosis was based on pathological results (cytology or histology), or not.

Access to diagnostic bronchoscopy was examined by extracting data on bronchoscopies in the 1 year prior to diagnosis (and 90 days post-diagnosis) within both inpatient (NMDS) and outpatient (NNPAC) settings. We scanned NNPAC (outpatient) data for evidence of outpatient bronchoscopy within the time period (purchase unit code MS02003), and scanned NMDS (inpatient) data using relevant ICD-10-AM ACHI codes (418890x, 418920x, 418950x, 418980x, 419010x and 491040x). We set a binary indicator (yes/no) to indicate whether a given patient underwent a bronchoscopy during the time period.

Statistical analysis

Descriptive analysis

For each of the variables, we used descriptive analyses to describe a given outcome for the total lung cancer cohort and stratified by ethnicity. We calculated both crude proportions and age-standardised proportions, the latter via direct age standardisation in SAS v9.4 (SAS Institute Inc., USA), using the total Māori lung cancer population from the analysis cohort as the standard population.[13]

Travel to access bronchoscopy

To compare the distance and time taken to access bronchoscopy between ethnic groups, we used Geographic Information Systems (GIS) analysis to determine the distance between where a given patient lived at the time of their bronchoscopy, and the facility where their procedure took place. To do this, we derived the domicile code of residence[14] at the time of their bronchoscopy (i.e., domicile code recorded in NMDS/NNPAC for the bronchoscopy event), and the geocoded coordinates of the hospital or facility where they underwent their bronchoscopy.[15] Distance and travel times were estimated using the OD-Matrix function within the GIS software ArcGIS (Environmental Systems Research Institute, USA). One-way distance by road from domicile of residence to location of treatment was expressed in kilometres (km), and categorised as follows: <25km, 25–99km, 100–199km and >200km. One-way travel time was expressed in minutes (mins), and categorised as follows: <60 mins, 60–149 mins and >150 mins. These travel distances and times were chosen to approximately represent close, across-town or surrounding district travel.[5]

Travel to access bronchoscopy was only calculated for Māori and Europeans within the cohort for the following three reasons: a) there are established disparities in travel to access cancer care between Māori and Europeans,[5] b) the vast majority of the other ethnic groups (Pacific peoples, Asian and MELAA/Other) reside in urban areas (**Appendix 2**), close to treatment centres, reducing the value of examining this outcome in these populations, and c) once categorised into travel distance and time categories, sparse data prevent the calculation of precise estimates for most non-Māori or non-European strata.

Regression analysis

We used logistic regression models to compare the odds of a given outcome between ethnic groups, both overall and stratified by tumour type and stage of disease (odds ratios [ORs] and 95% confidence intervals [CIs], European = reference). After calculating crude (unadjusted) models, we then iteratively adjusted for age, sex, deprivation, rurality, comorbidity, tumour type and stage of disease, with final models including all covariates. When examining differences in travel times and distances, the deprivation and rurality indicators were not included as adjustment factors for two reasons: a) because living in a rural area will be strongly related to the distance needed to travel to undergo bronchoscopy, and b) because of the relationship between rurality and deprivation in Aotearoa New Zealand, particularly for the Māori population.[16]

Ethical approval was sought and received from the University of Otago Human Ethics Committee (reference code 18/056).

Results

The **demographic and tumour characteristics** of the cohort are shown in **Appendix 2**, and a descriptive analysis of the **basis of diagnosis and receipt of a pathological diagnosis** is shown in **Table 1**. The most common basis for diagnosis across the total cohort was histology (crude proportion: 51%), followed by cytology (27%), clinical diagnosis (including those based on endoscopy and/or imaging; 16%) and death certificate only diagnoses (6%). Combined, around 78% of the total diagnoses were based on pathology (histology or cytology). When examined by tumour type, nearly all small cell tumours (97%) and non-small cell tumours (98%) were diagnosed based on pathology, while only a minority of other/unspecified tumours were diagnosed based on pathology (17%). The proportion of cancers diagnosed based on pathology decreased with increasing stage of disease, from local (100%), to regional (93%), to advanced (80%). Around 67% of unstaged cancers received a pathological diagnosis.

Māori and Europeans appeared similarly likely to receive a pathological diagnosis (age-standardised proportions: Māori 81%, European 84%), with this marginal difference likely explained by the lower proportion of other/unspecified tumours that had a pathological diagnosis for Māori (21%) compared to Europeans (31%) once the younger age distribution of the Māori cohort was taken into account (**Table 1**). Other ethnic groups appeared to have similar or marginally higher proportions of pathological diagnoses relative to Europeans (e.g., Pacific peoples 87%).

Receipt of diagnostic bronchoscopy is shown for all ethnic groups in **Table 2**, including descriptive analysis and crude and adjusted ORs. Around 42% of those diagnosed with cancer received a diagnostic bronchoscopy. Bronchoscopy rates were highest among those diagnosed with small cell tumours (57%), followed by non-small cell tumours (48%), and lowest for those with other/unspecified tumours (17%). In terms of stage of disease, bronchoscopy rates were highest for those with regional disease (59%) and lowest for those with advanced disease (34%).

Table 1: Descriptive analysis of the basis of diagnosis and access to a pathological diagnosis, by ethnicity.

	Total	**Māori**			**Pacific peoples**			**Asian**			**MELAA/Other**			**European**		
	n	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*
Basis of diagnosis[1]																
Cytology	7,515	1,535	27%	27%	417	33%	34%	368	31%	31%	28	23%	21%	5,167	26%	27%
Histology	14,350	3,015	54%	54%	660	52%	54%	673	57%	59%	82	67%	69%	9,920	50%	57%
Clinical[2]	4,413	788	14%	14%	150	12%	10%	112	9%	8%	9	7%	7%	3,354	17%	12%
Death certificate only	1,581	262	5%	5%	40	3%	2%	27	2%	2%	4	3%	2%	1,248	6%	4%
Other	7	1	0%	0%	0	0%	0%	0	0%	0%	0	0%	0%	6	0%	0%
No data	3	0	0%	0%	0	0%	0%	0	0%	0%	0	0%	0%	3	0%	0%
Pathological diagnosis[3]																
Total	21,865	4,550	81%	81%	1,077	85%	87%	1,041	88%	90%	110	89%	91%	15,087	77%	84%
By tumour type																
Small cell	2,947	884	98%	98%	114	98%	98%	63	95%	96%	6	100%	-	1,880	97%	98%
Non-small cell	17,747	3,465	98%	98%	910	99%	99%	942	98%	98%	95	99%	99%	12,335	98%	98%
Other/unspecified	1,171	201	18%	21%	53	23%	34%	36	23%	33%	9	43%	56%	872	17%	31%
By stage																

Table 1 (continued): Descriptive analysis of the basis of diagnosis and access to a pathological diagnosis, by ethnicity.

	Total	**Māori**			**Pacific peoples**			**Asian**			**MELAA/Other**			**European**		
	n	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*
Local	1,773	243	100%	100%	68	100%	100%	130	99%	99%	8	100%	-	1,324	100%	100%
Regional	3,422	772	94%	93%	152	94%	94%	197	97%	97%	22	96%	95%	2,279	92%	94%
Advanced	10,065	2,084	83%	82%	616	88%	89%	488	88%	89%	51	94%	93%	6,826	78%	83%
Unstaged	6,605	1,451	72%	74%	241	72%	79%	226	78%	86%	29	76%	86%	4,658	65%	78%

[1]n represents the number of people within a stratum (Total, or by ethnicity) who received a particular diagnosis. Crude and age-standardised percentages are calculated within columns.
[2]Clinical diagnoses include those made following endoscopy and/or imaging diagnostics.
[3]Pathological diagnoses include those made via cytology or histology.
- indicates that percentages were not calculated due to insufficient data.

Table 2: Receipt of diagnostic bronchoscopy in the year prior to diagnosis (and 90 days post-diagnosis) from National Collections data for New Zealanders diagnosed with lung cancer from 2007–2019, by ethnicity, including a) descriptive analysis and b) crude and adjusted odds ratios (ORs; reference = European group).

a) Descriptive analysis:[1]

	Total	**Māori**			**Pacific peoples**			**Asian**			**MELAA/Other**			**European**		
	n	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*
Total	11,600	2,649	47%	47%	560	44%	45%	483	41%	41%	64	52%	51%	7,844	40%	44%
By tumour type																
Small cell	1,711	531	59%	58%	75	65%	65%	34	52%	51%	3	50%	0%	1,068	55%	57%
Non-small cell	8,736	1,881	53%	53%	443	48%	48%	417	43%	43%	58	60%	59%	5,937	47%	48%
Other/unspecified	1,153	237	21%	23%	42	18%	19%	32	21%	26%	3	14%	12%	839	16%	26%

Table 2 (continued): Receipt of diagnostic bronchoscopy in the year prior to diagnosis (and 90 days post-diagnosis) from National Collections data for New Zealanders diagnosed with lung cancer from 2007–2019, by ethnicity, including a) descriptive analysis and b) crude and adjusted odds ratios (ORs; reference = European group).

a) Descriptive analysis:[1]

	Total	**Māori**			**Pacific peoples**			**Asian**			**MELAA/Other**			**European**		
	n	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*
By stage																
Local	678	96	39%	39%	26	38%	38%	38	29%	29%	1	13%	0%	517	39%	39%
Regional	2,169	529	64%	64%	110	68%	69%	109	53%	53%	16	70%	68%	1,405	57%	59%
Advanced	4,306	969	39%	38%	254	36%	36%	189	34%	35%	29	54%	50%	2,865	33%	36%
Unstaged	4,447	1,055	52%	54%	170	51%	55%	147	51%	54%	18	47%	45%	3,057	43%	54%

b) Crude and adjusted odds ratios (ORs):[2]

	Māori		**Pacific peoples**		**Asian**		**MELAA/Other**	
	Crude OR	*Adj. OR*[1]	*Crude OR*	*Adj. OR*[1]	*Crude OR*	*Adj. OR*[1]	*Crude OR*	*Adj. OR*[1]
Total	1.36 (1.28–1.44)	1.09 (1.02–1.17)	1.20 (1.07–1.34)	0.96 (0.84–1.09)	1.05 (0.93–1.18)	0.80 (0.71–0.91)	1.64 (1.15–2.34)	1.34 (0.92–1.96)
By tumour type								
Small cell	1.14 (0.98–1.34)	0.99 (0.82–1.20)	1.48 (1.00–2.19)	1.39 (0.91–2.12)	0.86 (0.53–1.40)	0.81 (0.48–1.37)	0.81 (0.16–4.01)	0.91 (0.18–4.66)
Non-small cell	1.26 (1.17–1.36)	1.12 (1.03–1.22)	1.04 (0.91–1.19)	0.93 (0.80–1.07)	0.86 (0.75–0.98)	0.81 (0.71–0.93)	1.71 (1.13–2.58)	1.52 (1.00–2.32)
Other/ unspecified	1.35 (1.15–1.59)	1.07 (0.89–1.29)	1.16 (0.82–1.63)	1.03 (0.71–1.48)	1.36 (0.91–2.02)	1.04 (0.67–1.59)	0.86 (0.25–2.94)	0.71 (0.20–2.55)

Table 2 (continued): Receipt of diagnostic bronchoscopy in the year prior to diagnosis (and 90 days post-diagnosis) from National Collections data for New Zealanders diagnosed with lung cancer from 2007–2019, by ethnicity, including a) descriptive analysis and b) crude and adjusted odds ratios (ORs; reference = European group).

b) Crude and adjusted odds ratios (ORs):[2]

	Māori		**Pacific peoples**		**Asian**		**MELAA/Other**	
	Crude OR	*Adj. OR*[1]	*Crude OR*	*Adj. OR*[1]	*Crude OR*	*Adj. OR*[1]	*Crude OR*	*Adj. OR*[1]
By stage								
Local	1.02 (0.77–1.35)	0.93 (0.69–1.26)	0.97 (0.59–1.60)	0.91 (0.54–1.55)	0.64 (0.43–0.95)	0.68 (0.45–1.03)	0.22 (0.03–1.83)	0.22 (0.03–1.85)
Regional	1.38 (1.17–1.62)	1.15 (0.96–1.39)	1.64 (1.16–2.30)	1.23 (0.86–1.78)	0.87 (0.65–1.16)	0.77 (0.57–1.04)	1.74 (0.71–4.23)	1.37 (0.56–3.39)
Advanced	1.30 (1.18–1.42)	1.08 (0.98–1.20)	1.17 (1.00–1.37)	0.93 (0.78–1.11)	1.06 (0.89–1.27)	0.84 (0.69–1.01)	2.40 (1.40–4.10)	2.16 (1.23–3.81)
Unstaged	1.45 (1.31–1.60)	1.12 (0.99–1.26)	1.37 (1.10–1.70)	0.97 (0.75–1.25)	1.38 (1.09–1.75)	0.92 (0.71–1.20)	1.19 (0.63–2.26)	0.97 (0.48–1.96)

[1]n represents the number of people within a stratum (Total, or by ethnicity). Crude and age-standardised percentages are calculated within columns.
[2]Fully adjusted ORs are adjusted for age, sex, deprivation, rurality, comorbidity, tumour type and stage. Tumour type was not adjusted for within the tumour type-stratified analysis, and stage was not adjusted for within the stage-stratified analysis.

Table 3: Travel to access bronchoscopy for Māori and Europeans diagnosed in Aotearoa New Zealand with lung cancer from 2007–2019, including descriptive analysis and crude and adjusted odds ratios (ORs; reference = European group).

		Total	**Māori**					**European**			
		n	*n*	*Crude %*	*Age std. %*	*Crude OR*	*Adj. OR*	*n*	*Crude %*	*Age std. %*	*OR*
Distance to bronchoscopy (kilometres [km]):	<25km	6,904	1,377	52%	52%	0.78 (0.71–0.85)	0.79 (0.72–0.87)	4,568	58%	57%	Ref
	25–100km	2,888	699	26%	26%	0.99 (0.89–1.09)	1.00 (0.90–1.11)	2,087	27%	27%	Ref
	100–200km	1,029	329	12%	12%	1.50 (1.30–1.72)	1.46 (1.26–1.69)	678	9%	9%	Ref
	200+km	762	242	9%	9%	1.47 (1.26–1.73)	1.36 (1.15–1.61)	501	6%	7%	Ref
	Median in km (IQR)	16.3km (51.9)				22.4km (80.1)		17km (51.4)			
Travel time to bronchoscopy (minutes [mins])	<60 mins	8,889	1,815	69%	69%	0.65 (0.59–0.72)	0.68 (0.61–0.75)	6,036	77%	76%	Ref
	60–150 mins	1,774	556	21%	21%	1.51 (1.35–1.69)	1.49 (1.33–1.68)	1,175	15%	15%	Ref
	150+ mins	920	276	10%	10%	1.35 (1.16–1.56)	1.24 (1.06–1.45)	623	8%	9%	Ref
	Median in minutes (IQR)	22.1 mins (43.9)	27.8 mins (64.6)					22.8 mins (44)			

[1]Fully adjusted ORs are adjusted for age, sex, comorbidity, tumour type and stage.

Māori appeared to have marginally higher odds of diagnostic bronchoscopy than Europeans (age-standardised proportions: Māori 47%, European 44%; adj. OR 1.09, 95% CI 1.02–1.17; **Table 2**). However, when examined by tumour type, there was only evidence that Māori had higher odds of bronchoscopy for non-small cell lung cancers (Māori 53%, European 48%; adj. OR 1.12, 95% CI 1.03–1.22). There was no clear evidence of differences between Māori and Europeans when stratified by stage. Across all tumour types and stages, the Pacific peoples group had similar odds of bronchoscopy as the European group (45% vs 44%; adj. OR 0.96, 95% CI 0.84–1.09), while the Asian group appeared to have marginally lower odds (41% vs 44%; adj. OR 0.80, 95% CI 0.71–0.91). The MELAA/Other group appeared to have greater odds of bronchoscopy, although this was based on sparse data (51% vs 44%; adj. OR 1.34, 95% CI 0.92–1.96).

Adjusting for the younger Māori age distribution had the greatest attenuating impact when iteratively adjusting for covariates (crude OR 1.36; age-adjusted OR 1.15), with other covariates having little to no impact on the OR (**Appendix 3**).

Travel to access bronchoscopy is shown in **Table 3**, including descriptive analysis and crude and adjusted ORs for Māori and Europeans within the cohort. We have also presented box plots of the travel distance and time in **Appendix 4**. Māori needed to travel marginally further to access their bronchoscopy than their European counterparts (median travel distance: Māori 22.4km, inter-quartile range [IQR] 80.1km; European 17km, IQR 51.4km). After adjusting for differences between Māori and Europeans with lung cancer in age, sex, tumour type, stage and comorbidity, Māori had lower odds of living within 25km of the location of their bronchoscopy (adj. OR 0.79, 95% CI 0.72–0.87), and higher odds of living more than 200km away (adj. OR 1.36, 95% CI 1.15–1.61). In terms of travel time, this distance equated to Māori being required to travel for longer (median time in minutes: Māori 27.8 mins, European 22.8 mins). After adjusting for the above covariates, Māori had lower odds of living less than an hour away from the location of their bronchoscopy (adj. OR 0.68, 95% CI 0.61–0.75), and higher odds of living more than 2½ hours away (adj. OR 1.24, 95% CI 1.06–1.45).

Discussion

In this study we used national-level data among a lung cancer cohort to examine ethnic disparities in a) receipt of a pathological diagnosis, and b) receipt of a diagnostic bronchoscopy, including travel required to access bronchoscopy. We found no meaningful difference in terms of the basis of diagnosis or receipt of a pathological diagnosis, with most diagnoses accompanied by either a cytological or histological investigation regardless of ethnicity. The relationship between receipt of a pathological diagnosis and both tumour type and stage of disease was also consistent between ethnic groups. We note that while substantial differences were not found between Māori and other ethnic groups in terms of receipt of a pathological diagnosis, it is unclear whether the absence of such a diagnosis for a substantial minority of the cohort (19% Māori lung cancer patients, 16% European) is clinically appropriate or not. Given the importance of pathological diagnosis in informing treatment options, a high proportion of pathological diagnoses is desirable; on the other hand, because of inherent risks associated with the procedures needed to produce a pathological diagnosis, some patients may not benefit from these procedures.[10] A more granular investigation (perhaps using clinical notes data) of those patients who do not receive a pathological diagnosis is required in order to assess this further.

We found that Māori appeared somewhat more likely to undergo bronchoscopy than the majority European population, although this difference was marginal (adj. OR 1.09, 95% CI 1.02–1.17). There are several possible explanations for this marginal difference. Firstly, European patients may be more likely to access computed tomography (CT)–guided biopsy rather than bronchoscopy as part of their diagnostic testing, perhaps due to increased propensity towards peripheral tumours, for which CT-guided biopsy is clinically indicated over bronchoscopy;[17] however, the available data are unable to indicate whether such a difference exists. The second possible explanation for Māori being marginally more likely to access bronchoscopy may be differential misclassification of bronchoscopy receipt by ethnicity—wherein we may be more likely to be missing bronchoscopy data for Europeans because a) this population are more likely to seek privately funded care than Māori for some cancers,[18] and b) a minority of private healthcare providers do not provide (or sporadically provide) data on privately funded care to the National Collections health datasets.[10]

We found that, on average, Māori appeared to need to travel further than Europeans to receive

their bronchoscopy. The difference in the median travel distance (and travel time) was modest, with Māori needing to travel around 5km (or 5 minutes) extra compared to Europeans. However, Māori appeared less likely to live within 25km of their bronchoscopy location, and more likely to live more than 100 or 200km away from the location —with corresponding impact on travel time. The key explanation for this difference is that bronchoscopy services are primarily located in main city centres, and while the majority of Māori diagnosed with lung cancer live in urban areas (69%), Māori are less likely to live in urban areas than Europeans (75%; **Appendix 2**).

The paradox with this observation is that despite having a higher relative need for lung cancer diagnostic services due to extreme disparities in lung cancer incidence experienced by Māori,[19] the places where diagnostics procedures such as bronchoscopy are performed are less likely to be located close to where Māori live. This treatment location paradox is compounded by additional barriers that Māori are more likely to face when seeking cancer care than Europeans,[5] including substantial disparities in level of socio-economic deprivation,[20] which impacts the affordability of transport to access care, and the accessibility of the healthcare system, wherein the system is often experienced by Māori as alienating and hostile.[21]

Our observations regarding a propensity towards increased travel for Māori to access their bronchoscopy is a further indication that this population faces cumulative disadvantage when it comes to accessing cancer services. For example, a previous study in the context of Stage III colon cancer[22] found that compared to non-Māori, Māori were slightly less likely to be referred to an oncologist (Māori: age-standardised proportion 79%, non-Māori 83%), and slightly less likely to be reviewed by an oncologist (75% vs 80%). A downstream ramification of this incremental disparity in care access is that only 50% of Māori colon cancer patients actually received adjuvant chemotherapy in this cohort, compared to 64% of non-Māori.[22]

The intersecting relationship between access to cancer services and the ethnicity of an individual seeking that care is intertwined with socio-economic disadvantage.[23] Māori in our study cohort were substantially more likely to live in deprivation and more likely to live outside urban areas (**Appendix 2**), which should have theoretically corresponded to a lower likelihood of accessing a histological diagnosis and/or a bronchoscopy. To this end, a recent examination of 32,000 lung cancers in the United Kingdom found that those individuals living in areas that were both heavily deprived and geographically distant to a diagnostic service had the lowest likelihood of receiving a histological diagnosis.[24] However, in our study we observed that despite an increased propensity to needing to travel further to access their diagnostic work-up, and despite being more likely to need to overcome the other barriers mentioned above, Māori did not appear less likely to access a histological diagnosis, nor a bronchoscopy upon which such a diagnosis could be made. This inverse relationship between barriers to care and likelihood of accessing that care is strongly indicative of Māori resilience—wherein Māori overcome more barriers in order to receive the same level of care as Europeans with the same cancer. This is supported by our own previous examinations of receipt of surgical care for liver and stomach cancer, which found equivalence in access despite heightened barriers, including deprivation.[25,26] This is further supported by qualitative evidence regarding the resilience and agency of Māori and their whānau to successfully navigate the lung cancer care pathway despite these increased barriers, with the support and care of whānau thought to be a key driver of this resilience.[27] Similarly, the availability of a support structure has also been suggested as important in helping Indigenous Australians overcome barriers to accessing cancer services.[28] As such, initiatives that focus on supporting Māori patients across their cancer journey could be one way in which disparities in the need to travel for care are overcome, and as such should be prioritised and resourced.

Although we did not observe differences in receipt of a bronchoscopy, in line with our previous findings[2] we did observe that a lower proportion of Māori were diagnosed when their cancers were at an early (i.e., Local) stage of disease (4%) compared to Europeans (8%; **Appendix 2**). As such, despite equal access to bronchoscopy, proportionally fewer of our Māori cohort will have had access to curative treatment options relative to Europeans, with subsequent impact on survival outcomes. This observation reinforces that while providing equal access through diagnostic pathways is important, we still do not have equal access from a timeliness perspective. Interventions such as lung cancer screening and improvements in symptom detection through community and primary healthcare need to be further evaluated

and resourced in order to close the gap in access to early detection between Māori and Europeans.

Strengths and limitations

This is a national study of all lung cancer registrations occurring over more than a decade. The availability of home domicile for each individual in our cohort, and the exact location where they received their bronchoscopy, enabled us to estimate the distance travelled to access care with some confidence.

Some smaller private healthcare providers in Aotearoa New Zealand do not provide complete data on privately funded healthcare delivered in their hospitals.[29] For reasons given earlier in this section, the most likely impact on the current study is that we may be under-estimating the number of bronchoscopies received by Europeans; however, we would need to be missing a substantial number of bronchoscopies (and primarily just for Europeans) in order to meaningfully alter our results, which is unlikely.

In terms of diagnostic testing, because of data limitations we only examined bronchoscopy. However, there are other forms of diagnostic testing for lung cancer, including image-guided diagnosis (including positron emission tomography [PET], CT or combination of the two).[30] We attempted to examine access to bronchoscopy conducted under endobronchial ultrasound (EBUS bronchoscopy), but found that this was not straightforward within the available datasets, and thus further work is required to enable national analysis of access to this form of bronchoscopy. While it would be ideal to have data on all lung cancer diagnostics, we note that our key findings regarding travel distance and time would likely remain unchanged whether we had these data or not, given that these additional diagnostic tests are also likely to be performed in main urban centres.

Conclusions

In this national study of the equity of diagnostic testing for lung cancer between ethnic groups in Aotearoa New Zealand, we found no differences in access to a pathological diagnosis between ethnic groups regardless of cancer type or stage. We found that Māori within the cohort were marginally more likely to access bronchoscopy than the majority European group; however, we found that Māori were less likely to live close to the location of their bronchoscopy, and correspondingly more likely to live 100–200km (adj. OR 1.46, 95% CI 1.26–1.69) or 200+km away (1.36, 95% CI 1.15–1.61) than Europeans. Interventions that aim to further support Māori to further overcome the systematic and cumulative disadvantages in access to cancer care should be broadly supported and resourced.

COMPETING INTERESTS
The authors have no relevant financial or non-financial interests to disclose.
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Data cannot be shared publicly because of data restrictions put in place by the New Zealand Government. The data underlying the results presented in this study are available from the National Collections team at Te Whatu Ora – Health New Zealand, following a project review and approval process. For further information regarding access to these data, email data-enquiries@health.govt.nz.

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Appendices

Appendix Table 1: New Zealand Cancer Registry (NZCR) Morphology codes used to define lung cancer tumour type.

	NZCR Morphology codes
Non-small cell lung cancer (NSCLC) Adenocarcinoma, squamous cell carcinoma, other NSCLC	8004, 8012, 8013, 8014, 8022, 8031, 8032, 8033, 8046, 8052, 8070, 8071, 8072, 8073, 8074, 8082, 8083, 8123, 8140, 8144, 8200, 8201, 8230, 8246, 8250, 8251, 8252, 8253, 8254, 8255, 8260, 8265, 8310, 8323, 8430, 8480, 8481, 8490, 8500, 8550, 8551, 8560, 8562, 8574, 8576, 8802, 8810, 8825, 8830, 8901, 8972, 8973, 8980, 9043, 9071, 9120, 9220, 9364
Small cell lung cancer (SCLC) Small cell carcinoma	8041, 8042, 8043, 8044, 8045
Other lung cancer Carcinoid tumours, unknown tumours	8000, 8010, 8020, 8240, 8244, 8249, 8333, 8720, 8772, 8772, 8800, 8801, 8803, 8805, 8815, 8890, 9040, 9041, 9133

Appendix Table 2: Characteristics of the cohort, by ethnicity.

	Total	**Māori**			**Pacific peoples**			**Asian**			**MELAA/Other**			**European**		
	n	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*
Total	27,869	5,601	20%	24%	1,267	5%	5%	1,180	4%	5%	123	0%	0%	19,698	71%	66%
Sex																
Female	13,432	3,160	56%	56%	478	38%	37%	546	46%	46%	45	37%	35%	9,203	47%	49%
Male	4,437	2,441	44%	44%	789	62%	63%	634	54%	54%	78	63%	65%	10,495	53%	51%
Age (years)																
<50	1,089	337	6%		102	8%		122	10%		12	10%		516	3%	
50–64	7,115	2,310	41%		416	33%		350	30%		40	33%		3,999	20%	
65–74	9,206	1,913	34%		406	32%		371	31%		30	24%		6,486	33%	
75+	10,459	1,041	19%		343	27%		337	29%		41	33%		8,697	44%	
Deprivation (NZDep decile)																
1–2 (least deprived)	3,357	196	3%	3%	43	3%	3%	235	20%	20%	23	19%	16%	2,860	15%	15%
3–4	3,942	410	7%	7%	102	8%	8%	253	21%	22%	23	19%	18%	3,154	16%	16%
5–6	5,353	673	12%	12%	115	9%	9%	269	23%	23%	24	20%	20%	4,272	22%	21%
7–8	6,925	1,283	23%	23%	241	19%	19%	222	19%	18%	34	28%	28%	5,145	26%	26%
9–10 (most deprived)	8,212	3,037	54%	54%	743	59%	59%	194	16%	16%	17	14%	17%	4,221	21%	22%
Missing	80	2	0%	0%	23	2%	0%	7	1%	0%	2	2%	0%	46	0%	0%

Appendix Table 2 (continued): Characteristics of the cohort, by ethnicity.

	Total	**Māori**			**Pacific peoples**			**Asian**			**MELAA/Other**			**European**		
	n	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*
Rurality (GCH category)																
Urban 1	14,902	2,387	43%	43%	1,104	87%	87%	1,081	92%	91%	100	81%	84%	10,230	52%	52%
Urban 2	6,129	1,478	26%	26%	66	5%	5%	45	4%	4%	10	8%	5%	4,530	23%	23%
Rural 1	4,175	868	15%	15%	46	4%	3%	37	3%	3%	7	6%	6%	3,217	16%	16%
Rural 2	2,065	653	12%	12%	17	1%	2%	5	0%	0%	3	2%	3%	1,387	7%	7%
Rural 3	403	198	4%	4%	3	0%	0%	2	0%	0%	-	0%	0%	200	1%	1%
Missing	195	17	0%	0%	31	2%	0%	10	1%	0%	3	2%	0%	134	1%	0%
Comorbidity (C3 Index score)																
<=0	13,382	2,593	46%	46%	665	52%	54%	783	66%	68%	73	59%	59%	9,268	47%	54%
0–1	3,672	644	11%	11%	116	9%	9%	130	11%	11%	16	13%	13%	2,766	14%	14%
1–2	4,116	908	16%	16%	169	13%	13%	111	9%	9%	12	10%	10%	2,916	15%	14%
>2	6,699	1,456	26%	26%	317	25%	24%	156	13%	11%	22	18%	18%	4,748	24%	18%
Tumour type																
Small cell	3,025	906	16%	16%	116	9%	10%	66	6%	6%	6	5%	5%	1,931	10%	11%
Non-small cell	18,107	3,549	63%	63%	921	73%	75%	960	81%	83%	96	78%	78%	12,581	64%	69%
Other/unspecified	6,737	1,146	20%	20%	230	18%	16%	154	13%	11%	21	17%	17%	5,186	26%	20%

Appendix Table 2 (continued): Characteristics of the cohort, by ethnicity.

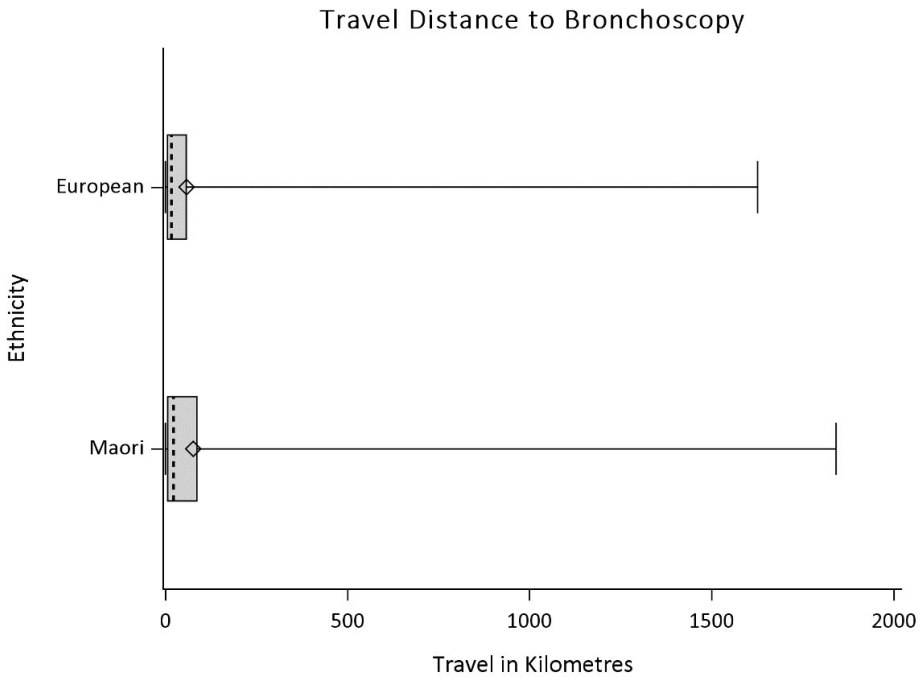
	Total	**Māori**			**Pacific peoples**			**Asian**			**MELAA/Other**			**European**		
	n	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*	*n*	*Crude %*	*Age std. %*
Stage																
Local	1,779	244	4%	4%	68	5%	6%	131	11%	12%	8	7%	6%	1,328	7%	8%
Regional	3,681	821	15%	15%	161	13%	13%	204	17%	18%	23	19%	22%	2,472	13%	14%
Advanced	12,614	2,515	45%	45%	703	55%	56%	557	47%	48%	54	44%	44%	8,785	45%	47%
Unstaged	9,795	2,021	36%	36%	335	26%	25%	288	24%	22%	38	31%	29%	7,113	36%	30%

Appendix Table 3: Odds ratios for receipt of diagnostic bronchoscopy, with iterative adjustment for covariates (Māori vs European only for brevity).

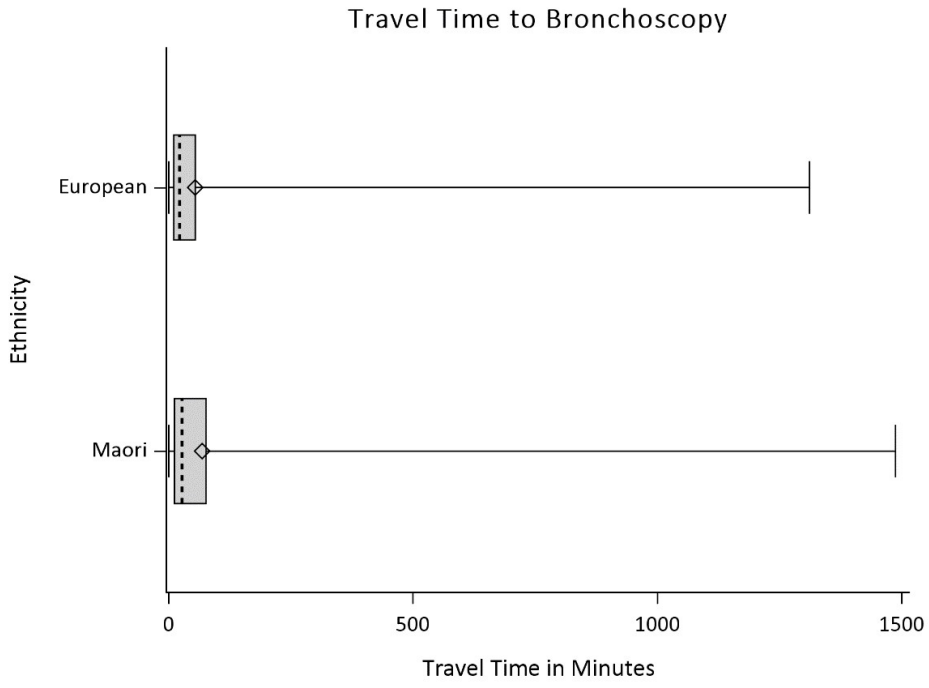
		Māori						
		Crude	*+ Age & sex*	*+ Deprivation*	*+ Rurality*	*+ Comorbidity*	*+ Tumour type*	*+ Stage*
	European	*OR (95% CI)*	*OR (95% CI)*	*OR (95% CI)*	*OR (95% CI)*	*OR (95% CI)*	*OR (95% CI)*	*OR (95% CI)*
Total	Ref	1.36 (1.28–1.44)	1.15 (1.08–1.23)	1.11 (1.04–1.19)	1.12 (1.05–1.20)	1.15 (1.07–1.22)	1.12 (1.05–1.20)	1.09 (1.02–1.17)
By tumour type								
Small cell	Ref	1.14 (0.98–1.34)	1.03 (0.87–1.22)	1.03 (0.87–1.23)	1.04 (0.87–1.24)	1.04 (0.87–1.25)		0.99 (0.82–1.20)
Non-small cell	Ref	1.26 (1.17–1.36)	1.22 (1.13–1.32)	1.15 (1.06–1.25)	1.15 (1.06–1.25)	1.16 (1.07–1.26)		1.12 (1.03–1.22)
Other/unspecified	Ref	1.35 (1.15–1.59)	0.97 (0.82–1.16)	0.98 (0.82–1.17)	0.99 (0.83–1.19)	1.00 (0.84–1.20)		1.07 (0.89–1.29)
By stage								
Local	Ref	1.02 (0.77–1.35)	1.01 (0.76–1.35)	0.89 (0.66–1.20)	0.89 (0.66–1.20)	0.91 (0.67–1.23)	0.93 (0.69–1.26)	
Regional	Ref	1.38 (1.17–1.62)	1.27 (1.07–1.50)	1.19 (0.99–1.42)	1.20 (1.00–1.44)	1.21 (1.01–1.45)	1.15 (0.96–1.39)	
Advanced	Ref	1.30 (1.18–1.42)	1.09 (0.99–1.20)	1.08 (0.98–1.20)	1.08 (0.98–1.20)	1.10 (0.99–1.21)	1.08 (0.98–1.20)	
Unstaged	Ref	1.45 (1.31–1.60)	1.09 (0.98–1.21)	1.07 (0.96–1.19)	1.08 (0.96–1.20)	1.13 (1.01–1.26)	1.12 (0.99–1.26)	

Appendix 4: Box plots showing the a) travel distance and b) travel time to access bronchoscopy, by ethnicity. The total width of the lines represents the width of the data; the width of the boxes represents the interquartile range; the dashed line represents the median; the diamond represents the mean.

a)



b)



Urban–rural geographic distribution of Otorhinolaryngologist, Head and Neck surgeons in Aotearoa New Zealand

Thomas Napier, David Waterhouse

ABSTRACT

AIM: We identified geographic distribution of Otorhinolaryngologist, Head and Neck surgeons in Aotearoa New Zealand. To identify the future workforce pipeline, we explored trainee intentions for specialist practice.

METHOD: A survey was distributed to all New Zealand Society of Otolaryngology, Head and Neck Surgery (NZSOHNS) members and all current New Zealand Otolaryngology, Head and Neck surgery trainees. Data were gathered on work location and patterns of work, including on-call commitments and full-time equivalent hours worked. Trainees were asked about future career plans.

RESULTS: An 88% response rate was achieved encompassing senior medical officers (SMOs) and trainees. A total of 64.8% (68) of respondents reported primarily working in a metropolitan hospital and 26.7% (28) reported working in a regional centre. Rates of internationally trained surgeons were significantly higher in regional centres compared to metropolitan hospitals (64.3% vs 32.4%, $p<0.05$). Regional respondents had higher after hours on-call burden, a higher full-time equivalent (FTE) worked and higher average hours worked per week. Retirement intentions within the next 10 years were high in both groups (64% regional and 52.9% metropolitan, $p<0.05$).

CONCLUSIONS: The regional workforce in ORLHNS work longer hours, are older and are reliant on internationally trained surgeons. Current training of ORLHNS surgeons is unlikely to keep pace with expected retirements.

In Aotearoa New Zealand, approximately 25% of the population resides in non-urban areas, yet the specifics of Otorhinolaryngology, Head and Neck Surgery (ORLHNS) care provision in these regions remain unclear. The challenge begins with the absence of a universally accepted definition for urban and rural areas. Health workforce New Zealand, Statistics New Zealand (Stats NZ) and the Royal Australasian College of Surgeons (RACS) each offer different criteria, complicating efforts to assess and address the disparities in healthcare delivery effectively.[1,2] RACS has acknowledged significant disparities in healthcare delivery for rural patients, underscoring a pressing need for focussed research in this area.[3–5]

ORLHNS training in Aotearoa New Zealand has historically been urban-centric, with only two (Whangārei and Palmerston North) true regional training units. Historically, the application requirements for surgical education and training (SET) have favoured aspiring surgeons employed in large units that offer support for research and a broad range of sub-specialty surgical experiences. This environment facilitates the accumulation of points with fewer barriers compared to those working in smaller regional centres. This trend, coupled with a reliance on specialist international medical graduates (SIMGs) in non-urban hospitals, risks exacerbating service provision gaps in regional areas. Recognising these challenges, RACS has initiated the rural action plan, aiming to retain regional trainees through strong social or cultural connections. Our own Aotearoa New Zealand selection board has introduced increased weighting to rural hospital placements and rural-focussed research, with an aim to positively discriminate for trainees likely to return to regional centres. However, without clear data on service coverage, optimising these efforts remains a challenge.[3,6]

We address a critical gap in our understanding of ORLHNS workforce distribution across Aotearoa New Zealand. By examining the current landscape and exploring the future career intentions of ORLHNS Surgical Education and Training (SET) trainees, we aim to shed light on the dynamics of healthcare provision and its implications for rural or regional communities.

Methodology

This study employed an online survey to gather comprehensive insights from members of the New Zealand Society of Otolaryngology, Head and Neck Surgery (NZSOHNS) and NZ ORLHNS SET trainees. The decision to use an online survey was driven by the need to efficiently reach a wide and geographically dispersed audience, ensuring a high level of participation and diversity in responses.

The survey was designed to include questions on demographics, sub-specialty practice, work volume, on-call frequency, service to non-urban areas and attitudes towards rural service provision. Prior to distribution, the survey underwent a pilot testing phase among a select group of ORLHNS professionals to refine questions for clarity and relevance.

All members of NZSOHNS and ORLHNS SET trainees were invited to participate, aiming for a comprehensive capture of perspectives across Aotearoa New Zealand. The survey was distributed via email by the NZSOHNS administrative team, with follow-up reminders sent 3 weeks and 1 month later to maximise response rates.

Respondents were categorised into specialist medical officers (SMOs) and trainees, allowing for nuanced analysis of workforce distribution and attitudes by career stage.

Metropolitan hospitals were defined as those located in Auckland, Hamilton, Wellington, Christchurch or Dunedin, with all other hospitals considered regional. This distinction enabled a focussed analysis on urban versus regional service provision.

Southland receives ORLHNS services from Otago for both acute and elective patients. For analytical purposes, and due to the historical consolidation of the Otago and Southland health boards into the Southern Health Board, the populations of Otago and Southland have been considered together as a single entity under Dunedin's catchment.

Table 1: Specialist medical officer demographics.

		Overall (n=105)	Metropolitan (n=68)	Regional (n=28)	
Age	20–29				
	30–39	6.70%	7.4%	3.6%	P=0.275
	40–49	31.40%	33.8%	21.4%	P=0.12
	50–59	25.70%	20.6%	35.7%	P=0.068
	60–69	29.50%	32.4%	28.6%	P=0.366
	70+	6.70%	5.9%	10.7%	P=0.219
Gender	M	81.00%	77.9%	89.3%	P=0.104
	F	18.00%	20.6%	10.7%	P=0.133
	Prefer not to say	1%	1.5%	0.0%	P=0.354
Ethnicity	European/Pākehā	66.40%	75.0%	57.1%	p<0.05
	Māori and Pacific peoples	2%	0.0%	3.6%	P=0.1458
	Asian	17.30%	13.2%	21.4%	P=0.168
	Middle Eastern/Latin American/African	2.90%	0.0%	3.6%	P=0.1458
	Other	14.40%	11.8%	17.9%	P=0.222

Table 1 (continued): Specialist medical officer demographics.

Country of primary medical training	New Zealand	59%	67.6%	35.7%	p<0.05
	International	41%	32.4%	64.3%	p<0.05
Fellow of the Royal Australasian College of Surgeons (FRACS)	Yes	75.50%	83.8%	57.1%	p<0.05
	No	24.50%	16.2%	42.9%	p<0.05

Table 2: Specialist medical officer respondents by region.

Region	Number of surgeons	Full-time equivalent (public only)	Mean hours of work (public and private)
Northland	5	0.78	45.23
Auckland	31	0.6	39.62
Waikato	6	0.65	46.33
Bay of Plenty	10	0.94	45.23
Gisborne	1	0.6	24
Taranaki	0	0	0
Manawatū-Whanganui	5	0.65	41.25
Hawke's Bay	2	0.63	48.5
Wellington	10	0.86	39.5
Nelson	4	0.73	40
Canterbury	13	0.93	50.5
Otago	9	0.68	46.5

Table 3: On-call commitment.

	Overall	Metropolitan	Regional	
1 in 3	12.4%	4.4%	35.7%	p<0.05
1 in 4	5.7%	0.0%	21.4%	p<0.05
1 in 5	5.7%	2.9%	14.3%	p<0.05
1 in 6	4.8%	4.4%	7.1%	0.301
1 in 7	12.4%	19.1%	0.0%	p<0.05
1 in 8 or more	47.6%	63.2%	14.3%	p<0.05
NR	11.4%	5.9%	7.1%	

Table 4: Trainee demographics.

Age	30–39	100%
Gender	M	68.2%
	F	31.8%
Ethnicity (multiple can apply)	European/Pākehā	72.7%
	Māori	31.8%
	Pacific peoples	0.0%
	Asian	13.6%
	MELAA	0.0%
	Other	9.1%
Country of primary medical training	New Zealand	90.9%
	International	9.1%
Completed Rural Medical Immersion Programme (RMIP)	Yes	13.6%
	No	86.4%

Table 5: Support for rural fellowship.

Strongly agree	28.6%
Agree	41.0%
Neutral	15.2%
Disagree	6.7%
Strongly disagree	2.9%
NR	5.7%

Data from the survey were analysed using OpenEPI employing descriptive statistics to examine differences between groups and identify trends. P-values were calculated using mid-P exact. The analysis was structured to ensure a clear understanding of the workforce distribution and the challenges faced in non-urban healthcare delivery. For purposes of maintaining anonymity in the SMO group, Māori and Pacific peoples ethnicity groups were collated together due to small numbers. Ethnicity was reported in line with Stats NZ's methodology. Data for regional populations were taken from Stats NZ reporting on population at June 2023.[7] Partially completed surveys were included for analysis of the questions that were answered. Nine individuals did not provide details of primary work location but provided responses to other questions and were included in the overall analysis. Full-time equivalent (FTE) was specified as public work only. Hours of work were assessed as per individual respondent.

Results

Our survey yielded a response rate of 88%, with 127 out of a possible 145 participants responding, of which 105 were SMOs and 22 were SET trainees.

Geographical distribution and workforce analysis

Among the SMO respondents, 96 provided details about their primary work location, revealing

a significant distribution across Aotearoa New Zealand. Approximately 64.8% (68 SMOs) reported working predominantly in metropolitan hospitals, with 31 (29%) based in the greater Auckland region. Population analysis revealed metropolitan hospitals have a ratio of 1.84 surgeons per 100,000 patients, compared to 2.1 surgeons per 100,000 patients in regional hospitals. This suggests a slightly denser surgical coverage in non-metropolitan areas but did not reach statistical significance (Table 1 and Table 2).

Hours worked and on-call commitments

The analysis of work hours and FTE ratios revealed that surgeons in regional centres generally reported higher work hours (average of 43.4 vs 42.7 hours per surgeon) and a greater FTE per surgeon (0.77 vs 0.69) compared to those in metropolitan centres. The difference did not reach statistical significance (p=0.301). On-call commitments were notably more demanding in regional centres, with 71.4% of surgeons undertaking on-call at a ratio of 1:5 or less. Comparatively, a significantly lower frequency of on-call duty was reported in metropolitan centres (1:7 or greater, p<0.05). This highlights a disproportionately higher on-call burden on surgeons outside major urban centres.

Training background and sub-specialty practice

A notable disparity in training backgrounds was observed between surgeons in metropolitan and regional areas. Specifically, 83.8% of metropolitan surgeons hold a fellowship from the Royal Australasian College of Surgeons (FRACS), compared with just 53.7% of their regional counterparts (p<0.05). This difference highlights concerns about the training and accreditation of future surgeons, particularly in regional centres, given that the RACS mandates a FRACS qualification for accreditation in ORLHNS training. Furthermore, regional surgeons are more likely to have obtained their primary medical degree from overseas (64.3% vs 32.4% for metropolitan surgeons, p<0.05), suggesting a greater dependence on internationally trained professionals in these areas.

Sub-specialty practice trends also varied by location, with regional surgeons more likely to identify as generalists (75% vs 41.2% for metropolitan surgeons, p<0.05), despite all respondents reporting at least one area of sub-specialty practice. This suggests a broader scope of practice required in regional areas, potentially due to the varied demands of these communities.

Trainee results

Twenty-two SET trainees responded to the survey out of 24 on the training scheme at the time of the survey.

As expected, trainees were younger than SMO counterparts, with all trainees aged between 30–39. The proportion of female surgical trainees and Māori were higher than in the SMO respondents (31.8% vs 18% and 31.8% vs 2% respectively). The proportion of trainees who undertook their primary medical training in Aotearoa New Zealand is higher than the SMO respondents too (91% vs 59%); this is likely reflective of the positive selection for cultural competency that is taught heavily in Aotearoa New Zealand's medical schools. ORLHNS trainees recognise the importance of regional training exposure, with 18 of 22 trainees supporting a regional placement either during or prior to training. Social isolation (68%), professional factors such as case mix and on-call burden (55%), remoteness (45%) and professional isolation (50%) were the most commonly cited barriers to regional practice for ORLHNS trainees.

Service provision, training exposure and workforce sustainability

The survey revealed a strong commitment to regional service provision, with 63% of respondents indicating their departments offered outreach services to rural areas. Regional training exposure was reported by 40.4% of all respondents, highlighting the significance of rural experiences in surgical training pathways. Future workforce considerations appear positive, with 31.8% of trainees expressing an intention to practice in regional hospitals, supporting the potential for sustainable service provision in these areas.

SMO respondents were surveyed on a rural fellowship as a pathway to regional practice, with 69.6% strongly agreeing or agreeing with the concept. If implemented, this could act as a pathway to provide new surgeons with broad generalist exposure and experience of supported regional practice.

Retirement intentions

The ageing workforce is more pronounced in regional areas, with 75% of surgeons over the age of 50 compared to 58.8% in metropolitan areas (p<0.05). The intention to retire within the next 10 years was high across both groups but more so in regional areas (64% vs 52.9%, p<0.05). This underscores the urgent need for strategic planning

to address the impending retirement wave and ensure continuity of care.

Discussion

By providing detailed insights into the demographics, practices and attitudes of the ORLHNS workforce, this survey contributes valuable data towards addressing the disparities in rural healthcare provision in Aotearoa New Zealand.

The findings from our study highlight the vulnerabilities in the provision of ORLHNS services across Aotearoa New Zealand. The impending retirements of a significant portion of the workforce, both in urban and regional areas, signal a looming crisis that could exacerbate the existing disparities in ORLHNS healthcare access. A total of 52.9% of metropolitan ORLHNS surgeons and 64.3% of regional ORLHNS surgeons are intending to retire within the next 10 years. This equates to 55 surgeons. Over the same period, 48 new surgeons would pass through the NZSOHNS training scheme. The reliance on overseas-trained surgeons to fill these gaps, while necessary, underscores the urgent need for a more sustainable solution to workforce development and retention in regional settings.

Urban vs rural definitions and implications

A key challenge identified in our analysis is the lack of a standardised definition for "urban" and "rural", complicating efforts to accurately assess service needs and allocate resources. Adopting an operational definition that reflects the unique geographic and demographic realities of Aotearoa New Zealand would facilitate more targeted and effective research. Specialist healthcare delivery does not map well to the currently used definitions. We feel our use of metropolitan and regional hospitals works well in the context of our Aotearoa New Zealand ORLHNS workforce and could be used for longitudinal research into workforce trends.

There was no statistical difference in the number of hours worked by regional or metropolitan surgeons; however, surgeons working in regional centres have a significantly more frequent on-call commitment.

International comparisons and learning opportunities

Our data reveal that Aotearoa New Zealand's ratio of surgeons to patients in regional centres, while higher than in urban areas, still falls short of international benchmarks. The United States of America (USA) describes ratios of between 2.5 and 3.6 per 100,000 patients, while international estimates put global averages at 2.19 per 100,000 patients.[8–10] The ratio of regional surgeons in our study may be influenced by the concentration of surgeons in some regional centres. Whangārei (2.45/100,000), Tauranga (2.82/100,000) and Nelson (2.39/100,000) have higher ratios of surgeons per 100,000 patients, which may represent influential data points skewing the overall figures. Conversely, some regions rely on single surgeon coverage or have no resident service, in the case of Taranaki.

Trainee selection

Our study highlights the importance of the existing positive rural selection practices for the Aotearoa New Zealand ORLHNS trainees to directly address the impending shortage of ORLHNS professionals in regional areas. Trainees selected through this process are likely to bring a diverse set of skills and a strong commitment to rural healthcare, contributing to the resilience and sustainability of ORLHNS services outside urban centers.[11,12]

Trainee pipeline

The rural workforce appears to have an established pipeline, with 31.8% of trainees intending to have rural practice as an SMO and 13.8% of trainees having completed the Rural Medical Immersion Programme (RMIP). Work from Shelker and colleagues shows a high rate of progression to rural practice for doctors who completed the RMIP in medical school.[13] Regional training centres are vulnerable to the loss of FRACS surgeons, which could have significant implications on the national pipeline of new ORLHNS surgeons. Introduction of a rural fellowship is generally supported by respondents and could bolster the regional pipeline.

Limitations

Non-responder bias

Our study did not capture data from 12% of NZSOHNS members and did not include responses from some practicing surgeons who are not affiliated with NZSOHNS. This could introduce bias in our findings, as the perspectives and characteristics of non-responders may differ from those who participated.

Variability in definitions

The lack of a standardised definition for

"urban" versus "rural" poses a limitation. Our classification into metropolitan and regional hospitals, while practical, may not fully reflect the nuances of geographic and demographic variations across Aotearoa New Zealand, potentially impacting the accuracy of our findings regarding healthcare provision.

Self-reported data

The survey relied on self-reported data from respondents, which may be subject to inaccuracies or biases. Respondents might have under-reported or over-reported certain aspects of their work, such as hours worked or on-call commitments.

Generalisability of findings

The study's findings are specific to the ORLHNS workforce in Aotearoa New Zealand and may not be generalisable to other countries or healthcare systems. Differences in healthcare delivery models and workforce structures could influence the applicability of our results in other contexts.

Incomplete data

Some respondents did not provide complete information regarding their primary work location or other key variables. Although partially completed surveys were included in the analysis where relevant, missing data could affect the robustness of our conclusions.

Survey response rate

Although we achieved a high response rate of 88%, the survey's responses may not fully capture the diversity of experiences and perspectives within the ORLHNS community.

Policy and practice recommendations

1. Enhancing the visibility and attractiveness of rural practice through targeted incentives, support systems and career development opportunities could mitigate the reliance on overseas-trained surgeons
2. Expanding and promoting programmes like the RMIP, which have shown success in encouraging rural practice, could strengthen the rural ORLHNS workforce pipeline.
3. Addressing the upcoming wave of retirements requires not only boosting the number of trainees but also ensuring that training programmes are responsive to the evolving needs of rural communities.
4. Encouraging the role of generalism in regional ORLHNS in keeping with the RACS Rural Health Equity plan, which identifies the adaptable nature of a rural surgeon and the need for a broad skill base.[3,14,15]
5. Exploring the introduction of a rural fellowship to further generalist training in a supported environment.

Summary

Our findings highlight the complex dynamics of Aotearoa New Zealand's ORLHNS workforce, with clear distinctions in geographical distribution, work hours, training backgrounds and service provision patterns. We confirmed that regional areas relying on internationally trained surgeons have a greater on-call burden and a higher proportion of generalists. These factors contribute to the unique challenges in maintaining a diverse and skilled workforce outside urban centres. The data reveal a concerning trend of impending retirements within the metropolitan and regional ORLHNS surgeon populations, signalling a potential workforce crisis in the near future. However, the interest shown by trainees in regional practice—coupled with the positive influence of programmes like the RMIP and positive rural/regional trainee selection represent a beacon of hope for the revitalisation of regional ORLHNS services. By enhancing training pathways and ensuring a concerted focus on the unique demands of non-metropolitan healthcare delivery, we can anticipate a future where disparities in regional ORLHNS services are substantially reduced, if not eliminated. Our findings underscore the urgent need for strategic planning and resource allocation to ensure equitable healthcare access for all New Zealanders, regardless of their geographic location.

COMPETING INTERESTS
Nil.

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Per-oral endoscopic myotomy: a multi-centre New Zealand experience

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ABSTRACT

BACKGROUND AND AIMS: Per-oral endoscopic myotomy (POEM) is an established treatment for achalasia. We aim to review outcomes of all POEM cases performed in New Zealand for achalasia.

METHODS: A retrospective review of all POEM procedures performed in the five hospitals offering POEM between November 2015 and December 2022 was undertaken. The primary outcome was clinical success, defined as Eckardt score ≤3. Secondary outcomes included procedural complications.

RESULTS: One hundred and sixty-six index and four redo POEM procedures were performed by seven clinicians. Ninety-six (58%) were male and mean age was 49.6 years (standard deviation [SD] 19.2 years). Eighty-three (50%) had a previous achalasia intervention. Median length of hospital stay was 1 day (interquartile range [IQR] 1–2 days). Median pre-POEM Eckardt score was 8 (IQR 6–9) and improved to 0 (IQR 0–2) at 6 months ($p<0.001$). Technical success was achieved in 164 (99%). Clinical success was achieved in 124 (93%) at 6 months and sustained to 12 months in 37/42 (88%) of these patients with follow-up data. Clinical success was achieved in 92% who underwent any prior intervention. There were five reported complications: tunnel leak (three), significant pain (one) and pneumothorax (one). One tunnel leak required thoracotomy for empyema debridement, all other complications were managed conservatively. Forty-seven (31%) reported symptomatic reflux after POEM.

CONCLUSIONS: This first review of all POEM procedures performed in New Zealand for achalasia demonstrates high 6-month clinical success and safety for the management of achalasia.

Achalasia is an idiopathic motility disorder of the oesophagus, characterised by failure of the lower oesophageal sphincter to relax and by disordered oesophageal peristalsis.[1] It is rare, with an incidence and prevalence of 1–5 and 7–32 per 100,000 respectively.[1]

Until the development of the per-oral endoscopic myotomy (POEM) procedure by Inoue in 2008,[2] management of achalasia had been with pneumatic dilatation (PD) or laparoscopic Heller myotomy (LHM).[3] Despite comparable efficacy to 2 years,[4] multiple PDs are required to maintain efficacy, and both are associated with considerable complications including perforation.[5,6]

POEM involves the creation of a submucosal tunnel and myotomy of the lower oesophageal sphincter.[2,7] This combines the precision myotomy of LHM in a minimally invasive endoscopic technique.[8] International evidence reports high technical success[3] and low complication rates with the POEM procedure,[9] and randomised control trial data have confirmed superiority of POEM over PD and non-inferiority compared with LHM.[10,11]

To date, most POEM research emanates from China, Japan, Europe and the United States of America (USA).[12] Recent reports from Australia and Norway reported good clinical success and safety.[13,14] New Zealand is an island nation of 5 million people, and there are few studies of POEM from lower-population countries and low-volume centres. There are no studies describing an entire country's experience. Here we report real-world data on the first New Zealand experience with POEM for the management of achalasia with regard to clinical success and complications.

Methods

We conducted a retrospective study of all consecutive POEM cases completed at five tertiary hospitals where POEM is offered in New Zealand—North Shore (Auckland), Middlemore (Auckland), Waikato, Wellington and Christchurch—between November 2015 and December 2022. Seven interventional endoscopists (RC, FW, RO, GL, IK, RP, CS) completed the procedures. All are gastroenterologists who also perform endoscopic submucosal dissection (ESD). Patients were excluded if the POEM procedure was completed for an indication other than achalasia.

POEM cases were identified from

procedural databases at each centre. Clinical notes were reviewed to obtain baseline demographic information, disease characteristics including achalasia subtype according to the Chicago classification,[1] manometry recordings, previous intervention and complete procedural data including myotomy location and length, adverse events and length of hospital stay. Eckardt scores and symptoms of gastro-oesophageal reflux disease (GORD) were obtained from follow-up clinic reviews at 6 and 12 months where available. Routine gastroscopy or pH after POEM were not performed.

POEM procedures and post-POEM management were at the discretion of the proceduralist at each individual hospital. However, consistency between all sites was in the manner described by Inuoe[2] with the use of general anaesthesia, gastroscope and distal attachment with CO2 insufflation and submucosal injection of a lifting agent with dissection and myotomy.

The primary outcome was clinical success, defined as an Eckardt score of ≤3 at 6-month clinic review. The secondary outcome was adverse events. Reflux was defined as any retrosternal burning discomfort.

Statistical analysis was performed using IBM SPSS Statistics, version 23 (IBM Corp., New York, USA). Kolmogorov–Smirnov test was used to test normality of data. Continuous variables with normal distribution were presented as mean with standard deviation (SD) and non-normal variables were reported as median with interquartile range (IQR). Chi-squared and Fisher's exact tests were used for categorical variables and Wilcoxon Signed-Rank Test, Mann–Whitney U test or Kruskal–Wallis were used for non-parametric continuous variables. Binomial logistic regression was used for binomial categorical dependent variables.

The study received ethics exemption from the New Zealand Health And Disability Ethics Committee (ID12630).

Results

One hundred and eighty-eight consecutive POEM cases were identified during the study period. Eighteen cases were excluded for non-achalasia indications. There were 170 POEM cases, including 166 patients undergoing their index POEM procedure and four second-attempt POEM cases, which were not included in the main analysis (three patients from the original 166 cases and one from another centre).

Baseline characteristics are described in Table 1: 96 (58%) were male with a mean age of 49.6 years (SD 19.2), and 61 (37%) were ≥60 years. Seventy percent had type 2 achalasia and 83 (50%) had had a prior intervention of any type. The median pre-POEM Eckardt score was 8 (IQR 6–9). There was no difference between pre-POEM Eckardt scores across achalasia subtypes (p=0.294) or between those who had and had no prior intervention (p=0.990).

The median time from first diagnosis to POEM was 299 days (IQR 94–1,412 days). The median time to POEM was significantly longer in patients with prior intervention compared to without: 1,242 days (IQR 210–2,912 days) and 146 days (IQR 54–356 days) respectively (p<0.01).

All patients had a general anaesthetic with positive pressure ventilation. A posterior incision was used in 119 (72%) (Table 2). The median myotomy length was 11cm (IQR 9–12cm). The median length of hospital stay was 1 day (IQR 1–2 days). Technical procedural success was achieved in 164 (99%).

Follow-up Eckardt data were complete in 134/166 (81%) of patients undergoing their index POEM at 6 months and 45/166 (27%) at 12 months (Table 3). Clinical success was achieved in 124/134 (93%) and maintained to 12 months in 37/42 (88%) of those who achieved 6-month clinical success with 12-month data available (Table 4). There was overall improvement in median Eckardt score from 8 (IQR 6–9) pre-procedure to 0 (IQR 0–2) at 6 months (p<0.001). There was no difference in success between achalasia types (p=0.30). Ninety-two percent of patients with any prior intervention had clinical success at 6 months with a reduction of Eckhardt score from 8 (IQR 6–9) to 1 (IQR 0–2). Clinical success was high in patients who had undergone both isolated PD and isolated LHM, but was considerably lower in the group who underwent both LHM and PD (Table 4).

There were five (3%) reported complications (Table 5). Four of these complications occurred within the first 20 cases at each of those centres, along with the two failed procedures. One tunnel leak that occurred in a patient with mega-oesophagus required a thoracotomy due to increasing collection despite a chest drain, with empyema debridement and lung decortication. They made a full recovery after a 2-week hospitalisation. All other complications were managed conservatively. All patients with a complication had a complete recovery. One of the failed procedures went on to have a successful redo POEM.

Median length of stay after a complication was 3 days (IQR 2–13). Forty-seven (31%) patients reported symptomatic GORD after POEM.

Of the four redo POEM cases, three achieved clinical success. Median Eckardt score improved from 9 (IQR 6–9) pre-procedure to 1 (IQR 0.5–2) post-procedure. The unsuccessful redo POEM was found to have no visible remaining muscle tissue for further myotomy.

Discussion

We report on the first complete POEM series from New Zealand for achalasia, and the first real-life nation-wide dataset, demonstrating this procedure as safe and effective. Over the last 15 years, POEM has evolved from a novel third-space endoscopic technique to first-line endoscopic management of patients with achalasia, as reflected here with uptake at five tertiary hospitals in New Zealand.

We demonstrate 6-month clinical success in 93% of patients, comparable to recent Australian data[13] and consistent with international data reporting initial success of up to 95.5%.[3,15] There are mixed data on the long-term efficacy of POEM, with 12-month success ranging from 82–91%,[2,3,13,15,16] but higher long-term success reported in series with significant loss of follow-up. While our data suggest that 12-month clinical success can be maintained, data were not available for the majority and a prospective study could be done to confirm this.

Our study confirms POEM suitability for all achalasia types, with excellent clinical success seen in each group. Notably, we report success in all type 3 achalasia cases, with significant Eckardt score improvement to 1 (IQR 0–2) at 6 months. This confirms the considerable evidence for POEM in type 3 achalasia, where the extended myotomy that a POEM can provide produces superior symptom control compared to an LHM.[17]

The utility of POEM extends past first-line management of achalasia, with a meta-analysis showing 85% success after any prior endoscopic or surgical intervention.[18] Our POEM success rate of 92% across any prior intervention, including success in all prior LHM cases, confirms the efficacy of POEM as salvage therapy. The lower clinical success in the group of patients who had undergone both prior PD and LHM (57%) could reflect increased scarring or oesophageal dysmotility.

Our overall complication rate of 3% is in keeping with international reports.[9] The five complications occurred at four of the participating centres, and four complications occurred within the first 20 cases at those centres, which may reflect an aspect of the learning curve: operator experience of <20 cases is noted to be a risk factor for complications.[9] Thus, it is likely that over time the complication rate will reduce. Our serious complication rate (1.8%), although higher than in international cohorts (0.5%),[9] may reflect each centre having their own learning curve, inflating our overall rates. In comparison, LHM may carry a higher complication rate of up to 7%.[10]

The only other New Zealand data on the management of achalasia reviewed 99 patients treated with balloon dilation (BD) and LHM between 1997 and 2010. Thirty-eight percent of the 76 patients undergoing BD required multiple procedures, with satisfactory outcomes achieved in 79%—which, when compared with our data, suggests POEM should be considered as first-line endoscopic management. In this study there was one complication (perforation) in the BD group and five in the LHM group (including perforation, splenic tear and thoracic duct injury). Six (17%) LHM patients required further treatment due to dysphagia or reflux.[6] However, LHM was only introduced 4 years prior to this study, and so may not accurately reflect a more modern cohort of LHM patients.[6]

GORD remains a concern and topic of discussion in the post-POEM cohort. A recent systematic review and meta-analysis found higher rates of symptomatic GORD (18.1% vs 8.1%), endoscopic oesophagitis (30.7% vs 8.3%) and abnormal acid exposure on pH studies (39.3% vs 14.9%) in POEM patients compared to LHM with fundoplication.[19] However, the majority of endoscopic oesophagitis was mild and most responsive to proton pump inhibitor therapy,[19] and so to date there has been limited requirement for definitive anti-reflux surgery after POEM.[20] There is, however, a recent description of endoscopic fundoplication during the same POEM procedure showing good efficacy to 12 months.[21] Our study, while having higher reported GORD symptoms, lacks follow-up data and objective investigations like endoscopy and pH studies. There may be other contributors to GORD symptoms in achalasia, including oesophageal fermentation,[22] and so future prospective research in New Zealand should incorporate data on post-POEM GORD using the Lyon Consensus[23] to help characterise and

standardise the diagnosis.

With the changing shape of the New Zealand healthcare system, the idea of centralisation of the POEM procedure could be considered—given the rarity of the condition, in particular. However, POEM is an extension of other interventional third-space endoscopy, such as ESD, which all of these clinicians also perform. We feel this shows that POEM can still be safely performed in a number of different centres to avoid inconvenience for patients, if the expertise is available.

To the best of our knowledge, we present the first complete POEM dataset for a nation. Countries with a similar population to New Zealand, like Norway, have limited patient numbers from single centres, and countries with a population of up to twice the population size of New Zealand, like Greece and Portugal, even when multi centre, are limited by patient numbers.[14,15,24–27]

The strengths of this study include its real-world dataset with complete case capture. There is inherent heterogeneity between centres in terms of POEM technique and follow-up, and differences in case volume, interventional experience and training between proceduralists. A considerable limitation is lack of 12-month follow-up, confounded by a number of patients not attending further appointments, potentially reflecting the inherent geographical isolation that many patients in New Zealand face in having to travel for this procedure. While one could infer that patients who didn't reattend appointments were likely improved, we cannot definitively comment on complete clinical efficacy at 12 months. Finally, our GORD rates were only subjectively assessed and may not be a reflection of the true GORD rates. Overall, these data must be encouraging and generalisable to similar smaller-population countries and small-volume centres that POEM success and safety is possible, and we feel support the international trend that POEM be considered as first-line endoscopic management for achalasia.

In conclusion, this nation-wide review of all New Zealand data on the POEM procedure shows high clinical success at 6 months and low complication rates, comparable with international data.

Table 1: Baseline characteristics of the 166 index POEM cases.

Characteristic	Value
Age	
Mean (SD)	49.6 (19.2)
Gender	
Male, n (%)	96 (58)
Ethnicity, n (%)	
NZ European	126 (76)
Māori	17 (10)
Indian	6 (3.6)
Pacific	5 (3.0)
Chinese	4 (2.4)
Other	8 (4.8)
Indication	
Achalasia, n (%)	166 (100)
Type 1	12 (7)
Type 2	116 (70)
Type 3	13 (8)
Type not specified	25 (15)
Prior intervention, n (%)	
Any	83 (50)
Isolated botox	11 (7)
Isolated PD	45 (27)
Isolated LHM	17 (10)
PD and LHM	10 (6)
Manometry pre-POEM, mmHg	
Resting pressure, mean (SD)	42.7 (19.7)
Relaxation pressure, mean (SD)	34.1 (13.8)

POEM = per-oral endoscopic myotomy; SD = standard deviation; NZ = New Zealand; PD = pneumatic dilatation; LHM = laparoscopic Heller myotomy.

Table 2: POEM procedural technical information.

	Value
Anaesthesia type, n (%)	
GA	166 (100)
Myotomy orientation, n (%)	
Anterior	47 (28)
Posterior	119 (72)
Median myotomy length, cm (IQR)	
Overall	11 (9–12)
Achalasia type 1	9.5 (8–11)
Achalasia type 2	11 (9–11)
Achalasia type 3	13 (11–15)
Achalasia NOS	11 (10–11)
Inpatient stay, days	
Median, IQR	1 (1–2)

POEM = per-oral endoscopic myotomy; GA = general anaesthesia; IQR = interquartile range; NOS = not otherwise specified.

Table 3: Eckardt scores pre-POEM, at 6 months and at 12 months post-POEM.

	Value
Pre-POEM Eckardt score, median (IQR)	
Overall	8 (6–9)
Achalasia type 1	8 (6.8–9)
Achalasia type 2	8 (7–9)
Achalasia type 3	8 (7–9)
Achalasia NOS	6 (4.5–8)
Prior intervention	8 (6–9)
No prior intervention	8 (7–9)
6-month Eckardt score, median (IQR)	
Overall	0 (0–2)
Achalasia type 1	0.5 (0–2)
Achalasia type 2	0 (0–2)
Achalasia type 3	1 (0–2)
Achalasia NOS	1 (0–1)
Prior intervention	1 (0–2)
No prior intervention	0 (0–1)
12-month Eckardt score, median (IQR)	
Overall	1 (0–2)
Achalasia type 1	0.5 (0–1)
Achalasia type 2	1 (0–3)
Achalasia type 3	1 (0–2)
Achalasia NOS	0 (0)
Prior intervention	1 (0–3)
No prior intervention	0 (0–1)

POEM = per-oral endoscopic myotomy; IQR = interquartile range; NOS = not otherwise specified.

Table 4: Clinical success.

	Value
6-month clinical success, n (%)	
Overall	124 (93%)
Achalasia type 1	10 (91%)
Achalasia type 2	87 (88%)
Achalasia type 3	12 (100%)
Achalasia NOS	15 (100%)
Any prior intervention	60 (92%)
12-month sustained clinical success, n (%)	
Overall	37 (88%)
Achalasia type 1	5 (83%)
Achalasia type 2	25 (89%)
Achalasia type 3	5 (83%)
Achalasia NOS	2 (100%)
Any prior intervention	23 (82%)
6-month clinical success by prior intervention, n (%)	
Isolated PD	27 (96%)
Isolated LHM	11 (100%)
LHM and PD	4 (57%)

NOS = not otherwise specified; PD = pneumatic dilatation; LHM = laparoscopic Heller myotomy.

Table 5: Complications.

	Value
Complications, n	
Tunnel leak	3
Pneumothorax	1
Pain	1
GORD, n (%)	
Yes	47 (31%)
No	103 (69%)

GORD = gastro-oesophageal reflux disease.

COMPETING INTERESTS
There are no conflicts of interest to declare.

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Holding a mirror to society? The socio-demographic characteristics of students commencing health professional programmes, and all courses, at Ōtākou Whakaihu Waka (the University of Otago), 1994–2023

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ABSTRACT

AIM: To present selected key findings from a longitudinal analysis of the socio-demographic characteristics of students entering all courses at Ōtākou Whakaihu Waka (the University of Otago), all health professional programmes combined, and 11 individual health professional programmes between 1994 and 2023.

METHOD: Data sources: 1) university electronic collections of student data (programme details, demographics, schooling, home address), and 2) publicly available datasets (some socio-demographic variables). Analyses included counts and proportions of commencing students, disaggregated by time period and socio-demographic variables, and commencement rates per 100,000 population aged 18–29 years.

RESULTS: During this 30-year period, there was a notable increase in the overall proportion of domestic health professional programme students who were Māori or Pacific, and an increase in enrolments of students from rural backgrounds. The socio-economic profile of incoming students remained unchanged, with students being highly skewed towards those from more socio-economically privileged backgrounds. The proportion of domestic health professional programme students who were female increased across all years, reaching nearly two-thirds by the study end.

CONCLUSION: While efforts to enhance health professional student diversity have had a positive impact, the university's vision of a health workforce that represents Māori and the diverse contexts of Aotearoa New Zealand's society will require long-term ongoing commitment.

Academic institutions play a pivotal role in shaping the health workforce via the effects of their policies and practices on recruitment and retention of students.[1,2] Ōtākou Whakaihu Waka (the University of Otago) recognises its responsibility to develop a health workforce that is equipped to meet the needs of society, and strives to ensure that health professional programme student cohorts reflect the varied ethnic, socio-economic and geographic contexts of Aotearoa New Zealand (Aotearoa) communities.[3]

"Affirmative action" refers to strategies that aim to increase representation of groups that have historically been under-represented or excluded, and is undertaken in health professional education with a number of Te Tiriti o Waitangi–based and equity-based justifications.[4] These include honouring the Crown's obligations under Te Tiriti o Waitangi (in Aotearoa specifically); correcting current and historical injustices; the benefits that concordant backgrounds have for patient–practitioner relationships; and the observation that practitioners from under-represented communities are more likely to return to serve those communities.[4–9] Although initially limited and with major shortcomings, affirmative action admission policies have existed at Ōtākou Whakaihu Waka since at least as early as 1951.[10,11] The university's current policy, *Te Kauae Parāoa*,[3] applies to eight health professional programmes and aims to facilitate the entry of students who are Māori, Indigenous Pacific, from rural backgrounds, from refugee backgrounds or who

studied at schools that serve communities with higher socio-economic disadvantage.

With these measures in place, it is important to evaluate what changes have occurred in the composition of student cohorts. Cross-sectional analyses of the socio-demographic profile of students entering health professional programmes at Ōtākou Whakaihu Waka were previously undertaken for the years 2010 and 2016.[12,13] Recently we undertook more extensive analyses, using automated processes to produce a longitudinal socio-demographic "atlas" of students entering all courses at Ōtākou Whakaihu Waka, all health professional programmes combined and 11 individual health professional programmes between 1994 and 2023 (see supplementary material: https://nzmj.org.nz/media/pages/journal/vol-137-no-1605/holding-a-mirror-to-society-the-socio-demographic-characteristics-of-students-commencing-health-professional-programmes-and-all-/ee09bc98a7-1729551472/6685-supplementary-full-copy.pdf). This research was initiated by academics in the university as a further contribution to monitoring student participation, and was carried out in collaboration with the University of Otago's Strategy, Analytics and Reporting Office. This paper presents an overview and discussion of selected key findings.

Methods

This section summarises key aspects of methods that are relevant to findings described in this article. Full methods are outlined in the accompanying report (see supplementary material, p. 5).

University data

Ōtākou Whakaihu Waka maintains electronic collections of student data extending back to 1993, covering programme details as well as demographics, information on schooling and home addresses. Ethnicity is self-identified within university records, with students currently being able to select up to three different groups. For most of the study period, collection of gender information has been limited to a binary male/female classification; students have only been able to self-select that they identify with another gender in recent years. Home addresses used for this study were the addresses that students provided at their first-ever enrolment with the university. Commencement data for 1993 include all students who were enrolled at any level in the university during that year; therefore, commencement dates for students enrolled in 1993 are not reliable.

Derivation of study cohorts

Enrolment data were extracted from university records from 6 to 11 October 2023 and were used to derive two cohorts. The first cohort comprised all students who commenced **health professional programmes** offered by Ōtākou Whakaihu Waka between 1994 and 2023 that would normally lead to registration under the *Health Practitioners Competence Assurance Act 2003*[14] (Table 1). Students were included once for each health professional programme they fully enrolled in, such that students who commenced more than one health professional programme over time were included for each instance.

The second cohort comprised all students who commenced **any programme** at Ōtākou Whakaihu Waka between 1994 and 2023. Inclusion in this cohort aimed to approximate students coming to the university for the first time or returning to start a new episode of study after a substantial period away. Therefore, students were included for any discrete instance where they 1) commenced a new programme of study not previously enrolled in; **and** 2) had no other enrolment recorded at Ōtākou Whakaihu Waka during the previous two academic years **and**; 3) were not already included due to enrolment in another programme in the same year.

Identification of students commencing health professional programmes was undertaken independently of identification of students commencing all programmes university-wide.

Key variables

Socio-demographic variables

Socio-demographic variables were derived and classified using information present in enrolment data and linkage to other publicly available datasets.[15–18]

Residency status was classified based on students' recorded residencies at the time of programme commencement. Students who were not **New Zealand citizens or permanent residents** were excluded from most analyses.

Ethnic group was classified from the most recent available university records using the Statistics New Zealand (Stats NZ) level one categories.[19] For most analyses, prioritised output was used (whereby individuals identifying with multiple ethnic groups are assigned a single ethnic

Table 1: Included health professional programmes and years of the study period (1994–2023) for which they were available for new enrolments.

Programme	Division of university	Years of study period available*
Bachelor of Dental Surgery	Health Sciences	1994–2023
Bachelor of Dental Technology	Health Sciences	2001–2023
Bachelor of Medicine and Bachelor of Surgery	Health Sciences	1994–2023
Bachelor of Medical Laboratory Science	Health Sciences	1994–2023
Bachelor of Oral Health	Health Sciences	2007–2023
Bachelor of Pharmacy	Health Sciences	1994–2023
Bachelor of Physiotherapy	Health Sciences	1994–2023
Radiation Therapy†	Health Sciences	2001–2023
Bachelor of Health Sciences with Dental Hygiene endorsement	Health Sciences	2002–2006
Bachelor of Health Sciences with Dental Therapy endorsement	Health Sciences	2002–2010
Diploma in Dental Hygiene	Health Sciences	2001–2006
Diploma in Dental Therapy	Health Sciences	1999–2006
Diploma in Dental Technology	Health Sciences	2002–2002
Master of Nursing Science	Health Sciences	2016–2023
Postgraduate Diploma in Clinical Psychology	Sciences	1994–2023
Dietetics‡	Sciences	1994–2020

*Based on university records, and years for which enrolling students were identified within the study cohort. At the time of writing, all programmes listed as being available for new enrolments in 2023 remain active.
†For the purpose of analyses, the Bachelor of Radiation Therapy and (earlier) Bachelor of Health Sciences with Medical Radiation Therapy endorsement were considered together as a single radiation therapy programme.
‡For the purpose of analyses, the Master of Dietetics and (earlier) Postgraduate Diploma in Dietetics were considered together as a single dietetics programme.

group using an order of priority). The groups used (in descending order of priority) were: Māori; Pacific peoples; Asian; Middle Eastern/Latin American/African (MELAA); and European or Other. For calculation of rates, the same groups were used but ethnicity was classified using total response output (where individuals identifying with multiple ethnic groups are included in totals for each), to match available population denominators.

Age group was classified based on students' ages on 1 March in the year of commencement. **Gender** was classified based on the Stats NZ standard output for gender[20] (male, female or another gender) using the most recent available university records.

Socio-economic deprivation was classified as the New Zealand small-area index of relative socio-economic deprivation (New Zealand Index of Deprivation [NZDep])[21] quintile of students' home addresses. NZDep is an index of relative socio-economic deprivation produced for small areas using aggregated information from census data. NZDep versions have been produced for each census year since 1991.[16] The "tidygeocoder" package[22] in R was used to pass addresses to the ArcGIS geocoding service, which identified the latitude and longitude of students' home addresses that in turn enabled matching of those addresses to the relevant meshblocks.

School socio-economic quintiles were derived from the decile of students' last-attended schools.[18] School deciles were used by the Ministry of Education between 1995 and 2022 (after which they were replaced by the new Equity Index system), and were derived in each census year from the socio-economic makeup of attending students' neighbourhoods.[23] Decile 1 schools were the 10% of schools with the highest proportion of students from low socio-economic communities, and decile 10 schools were the 10% of schools with the lowest proportion of these students. A school decile did not measure the standard of education delivered at a school. In most instances, NZDep and school deciles were applied such that the version that most closely approximated students' year of programme commencement was used (see supplementary material, p. 12, for more detail).

Urban/rural status was defined using the 2018 Geographic Classification for Health (GCH)[17,24] of students' home addresses. The GCH uses a combination of census-derived urban area population counts and travel time to the edge of urban areas to classify small areas into five levels of urbanicity/rurality.[24] For most analyses, the GCH was determined at Statistical Area 1 level; however, for calculation of rates, Statistical Area 2 classifications were used to match available population denominators.

Admission details

Admission categories and **subcategories** were available for most health professional programmes from 2017 onwards. **Admission categories** are based on the amount and nature of study previously completed by applicants (e.g., secondary school, health sciences first year, bachelor-level qualification, alternative [health-related professional experience in a relevant field]). **Admission subcategories** are open to students at all levels of study, and include affirmative action pathways as well as the international subcategories. General category applicants are those who do not apply via a subcategory pathway.

Analyses

Most analyses in this article present simple counts and proportions of commencing students, disaggregated by time period (where applicable) and socio-demographic variables. For longitudinal analyses of students commencing by 5-year time period (Figure 1–3), the mean number commencing per year in each period was plotted. Small numbers (<5 students) were not reported in order to protect privacy.

Analyses of commencement rates per 100,000 population (undertaken for ethnic group, GCH and region) were restricted to students aged 18–29 years and used populations aged 18–29 years as the denominator to account for differences in underlying population age structures. For ethnicity rate calculations, total response output was used to match available population denominators. Population denominators were derived from publicly available[25] and bespoke estimates of Aotearoa sub-populations over the study period (Stats NZ, customised report and licensed by Stats NZ for re-use under the Creative Commons Attribution 4.0 International licence). See supplementary material, p. 15, for full details on rate calculations.

Software and automation

These analyses were undertaken primarily using R version 4.3.2.[26] To produce the breadth of included analyses (see supplementary report, p. 17), an automated approach was taken whereby functions were developed to undertake all calculations across all variables and programmes and produce formatted tables and figures. A template was developed using the document writing package RMarkdown[27] that applied these functions to write "chapters" for each programme category (e.g., "All Health Professional Programmes", "Bachelor of Physiotherapy"), containing all desired statistical output. The template was run in sequence across each of the 13 included programme categories to produce the results section of the full report (supplementary material, p. 17).

Ethics statement

This project received ethical approval from the Ōtākou Whakaihu Waka Human Ethics Committee (reference number D23/277).

Results

This section presents an overview of key findings, with a focus on students commencing all courses at Ōtākou Whakaihu Waka, all health professional programmes combined and the Bachelor of Medicine and Bachelor of Surgery. The Bachelor of Medicine and Bachelor of Surgery is highlighted as it is the largest programme, and the programme for which affirmative action policies have had the most influence. Comprehensive statistical summaries for each programme category including analyses of age, regional origins and programme completion (for health professional programmes) are in the full report (supplementary material).

Total numbers and residency status

This study identified 182,932 records for students commencing new episodes of study in all programmes at Ōtākou Whakaihu Waka between 1994 and 2023, of whom 148,653 (81.3%) were Aotearoa citizens or permanent residents. Over that same period, 20,978 records were identified for students who newly commenced health professional programmes, including 18,632 (88.8%) who were Aotearoa citizens or permanent residents. The number of students commencing health professional programmes increased over time, while the number and proportion who were international students peaked between 2004 and 2013 (Table 2).

Ethnic group

Analyses of commencing students by ethnic group, and all subsequent analyses presented in this article, are restricted to students who were Aotearoa citizens or permanent residents.

Ethnic diversity increased within health professional programmes (Table 3, Figure 1) and across the wider university (Figure 1) over time. While the proportion of commencing students who were Māori or Pacific increased overall, parity with other ethnic groups was not approached in most instances. The exception to this was in the Bachelor of Medicine and Bachelor of Surgery (Figure 1) where, by the 2019–2023 period, Māori students comprised 20.1% of all incoming students and had commenced at a rate (per 100,000 estimated resident population aged 18–29) comparable with that of Asian and European students (see supplementary material, p. 118, 128). Overall, students within the Asian ethnic grouping comprised a greater proportion of students

Table 2: Residency status of students (n=20,978) commencing health professional programmes at Ōtākou Whakaihu Waka, 1994–2023.

Residency status	Time period (n [%])		
	1994–2003	2004–2013	2014–2023
Total			
All students	5,525 (100.0)	7,317 (100.0)	8,136 (100.0)
Residency status			
International student	399 (7.2)	899 (12.3)	763 (9.4)
Australian citizen or permanent resident	89 (1.6)	107 (1.5)	86 (1.1)
Tokelau, Niue or Cook Islands citizen*	0 (0.0)	<5 (-)	<5 (-)
Aotearoa citizen or permanent resident	5,037 (91.2)	6,310 (86.2)	7,285 (89.5)

*To safeguard privacy, data (other than "missing" values) have been suppressed where one to four enrolments in any given category have been recorded.

Table 3: Socio-demographic characteristics of Aotearoa citizens or permanent residents (n=18,632) commencing health professional programmes at Ōtākou Whakaihu Waka, 1994–2023.

Characteristics	Time period (n [%])		
	1994–2003	2004–2013	2014–2023
Total			
All Aotearoa citizens or permanent residents	5,037 (100.0)	6,310 (100.0)	7,285 (100.0)
Ethnic group (prioritised)			
Māori	267 (5.3)	417 (6.6)	924 (12.7)
Pacific peoples	79 (1.6)	156 (2.5)	347 (4.8)
Asian	1,362 (27.0)	1,956 (31.0)	2,130 (29.2)
MELAA*	19 (0.4)	176 (2.8)	251 (3.4)
European or Other	3,310 (65.7)	3,605 (57.1)	3,633 (49.9)
Gender			
Female	3,138 (62.3)	4,058 (64.3)	4,735 (65.0)
Male	1,899 (37.7)	2,252 (35.7)	2,543 (34.9)
Another gender	0 (0.0)	0 (0.0)	7 (<0.1)
NZDep quintile†			
1 (least deprived)	1,702 (33.8)	2,062 (32.7)	2,510 (34.5)
2	1,136 (22.6)	1,507 (23.9)	1,698 (23.3)
3	850 (16.9)	1,067 (16.9)	1,238 (17.0)
4	569 (11.3)	794 (12.6)	921 (12.6)
5 (most deprived)	378 (7.5)	509 (8.1)	619 (8.5)
Missing	402 (8.0)	371 (5.9)	299 (4.1)
School quintile			
5 (high socio-economic)	1,817 (36.1)	2,654 (42.1)	2,776 (38.1)
4	1,096 (21.8)	1,559 (24.7)	2,108 (28.9)
3	870 (17.3)	1,030 (16.3)	1,130 (15.5)
2	477 (9.5)	446 (7.1)	567 (7.8)
1 (low socio-economic)	110 (2.2)	114 (1.8)	133 (1.8)
Missing	667 (13.2)	507 (8.0)	571 (7.8)
GCH‡			
U1 (most urban)	3,167 (62.9)	4,096 (64.9)	4,739 (65.1)

Table 3 (continued): Socio-demographic characteristics of Aotearoa citizens or permanent residents (n=18,632) commencing health professional programmes at Ōtākou Whakaihu Waka, 1994–2023.

U2	837 (16.6)	1,032 (16.4)	1,221 (16.8)
R1	433 (8.6)	545 (8.6)	679 (9.3)
R2	159 (3.2)	215 (3.4)	301 (4.1)
R3 (most rural)	37 (0.7)	51 (0.8)	46 (0.6)
Missing	404 (8.0)	371 (5.9)	299 (4.1)

*Middle Eastern/Latin American/African.
†New Zealand small-area index of relative socio-economic deprivation.
‡Geographic Classification for Health.

commencing health professional programmes than other courses within the wider university (Figure 1), although the ethnic composition of individual professional programmes varied widely (supplementary material).

Gender

Students who identified as female predominated within health professional programmes across all years, increasing from 62.3% of commencing students during the 1994–2003 period to 65.0% during 2014–2023 (Table 3). Female students also predominated within the wider university (supplementary material, p. 32). Although a small number of programmes (Bachelor of Dental Technology, Bachelor of Dental Surgery, and Bachelor of Medicine and Bachelor of Surgery) had a roughly equal gender balance or male majority towards the beginning of the study period, female students were a majority across all health professional programmes by the mid-2010s (supplementary material, p. 50). Very few students who identified as another gender were recorded (Table 3), reflecting limitations to data collection processes.

Socio-economic measures

Incoming cohorts were highly skewed towards students from more socio-economically privileged backgrounds. Students from schools in the lowest socio-economic quintile (least socio-economically advantaged) were nearly absent from health professional programme admissions, comprising approximately 2% of students entering those programmes across time (Table 3). A strong predominance of students from higher quintile schools was also observed consistently within the wider university and individual health professional programmes (Figure 2). A similar pattern, although somewhat less pronounced, was observed by NZDep quintile (Table 3).

Urban/rural classification

There was a strong predominance of urban backgrounds among incoming students (Table 3, Figure 3), reflecting the geographic distribution of the underlying populations. The commencement rate (per 100,000 estimated resident population aged 18–29 years) for health professional programmes combined was broadly similar for students with home addresses within the U1 (most urban), U2 and R1 GCH categories throughout the study period (supplementary material, p. 59). While lower initially, the commencement rate for the R2 category increased to meet that of the aforementioned categories over time. The commencement rate for health professional programme students with home addresses within the R3 category remained consistently lower throughout the study period.

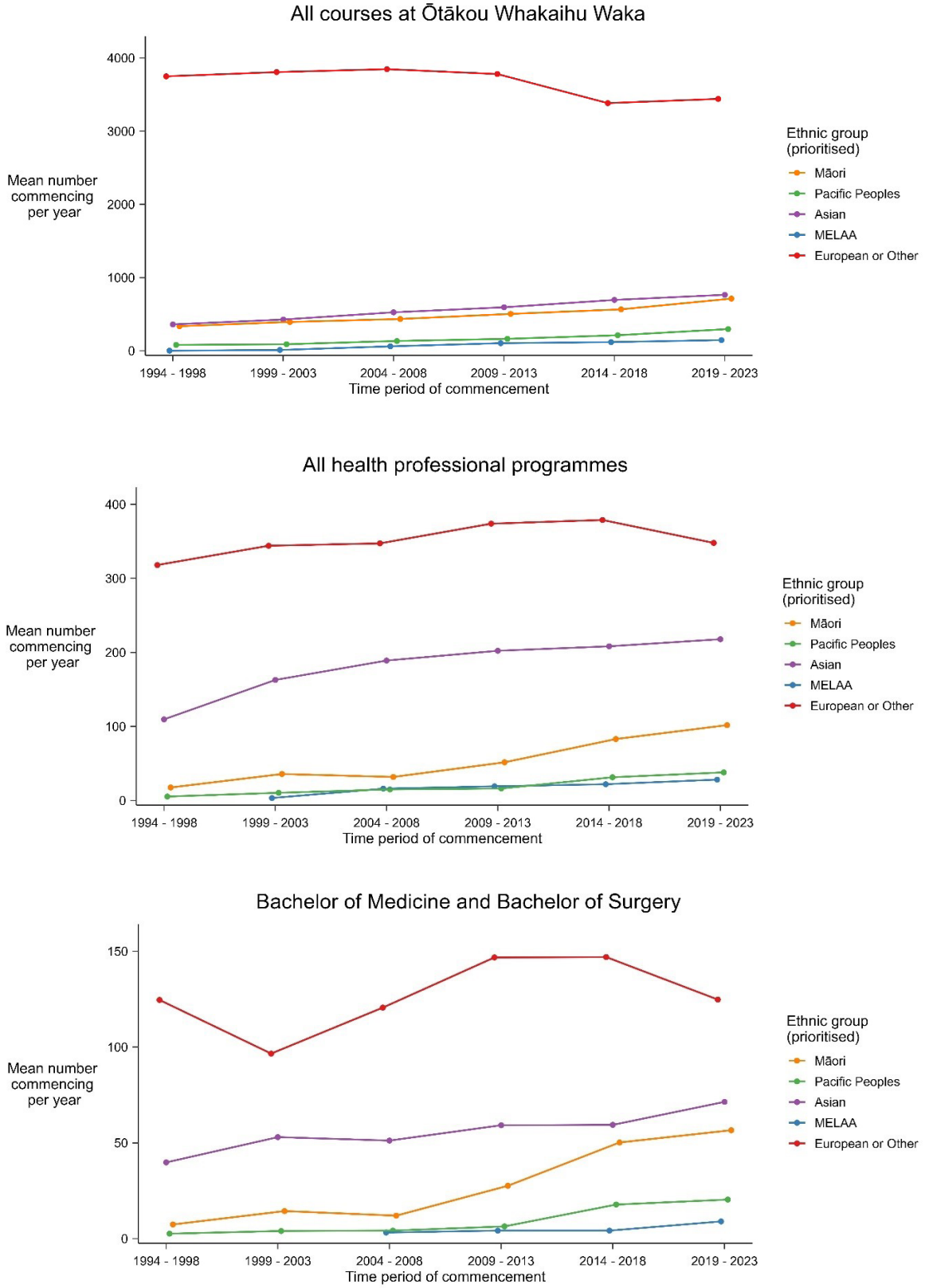
Admission category

Approximately two-thirds of admissions since 2017 across all undergraduate health professional programmes within the Division of Health Sciences were for students who had applied via the health sciences first year admission category (Table 4), with the remainder being a mixture of graduate students and students admitted via other pathways, which vary between programmes.

Affirmative action admission subcategories

Admissions under the general category made up the majority of admissions within undergraduate health professional programmes (68.2%) and the Bachelor of Medicine and Bachelor of

Figure 1: Mean annual number of commencements of students who were Aotearoa citizens or permanent residents in all courses at Ōtākou Whakaihu Waka (n=148,652), all health professional programmes (n=18,632) and the Bachelor of Medicine and Bachelor of Surgery (n=6,697), by time period and ethnic group.



"MELAA" refers to Middle Eastern/Latin American/African. To safeguard privacy, data were suppressed where fewer than five enrolments in a category were recorded in a given time period. Students with missing ethnicity data (n <5) were excluded from the analysis of all courses at Ōtākou Whakaihu Waka.

Figure 2: Mean annual number of commencements of students who were Aotearoa citizens or permanent residents in all courses at Ōtākou Whakaihu Waka (n=148,653), all health professional programmes (n=18,632) and the Bachelor of Medicine and Bachelor of Surgery (n=6,697), by time period and socio-economic quintile of last attended secondary school.

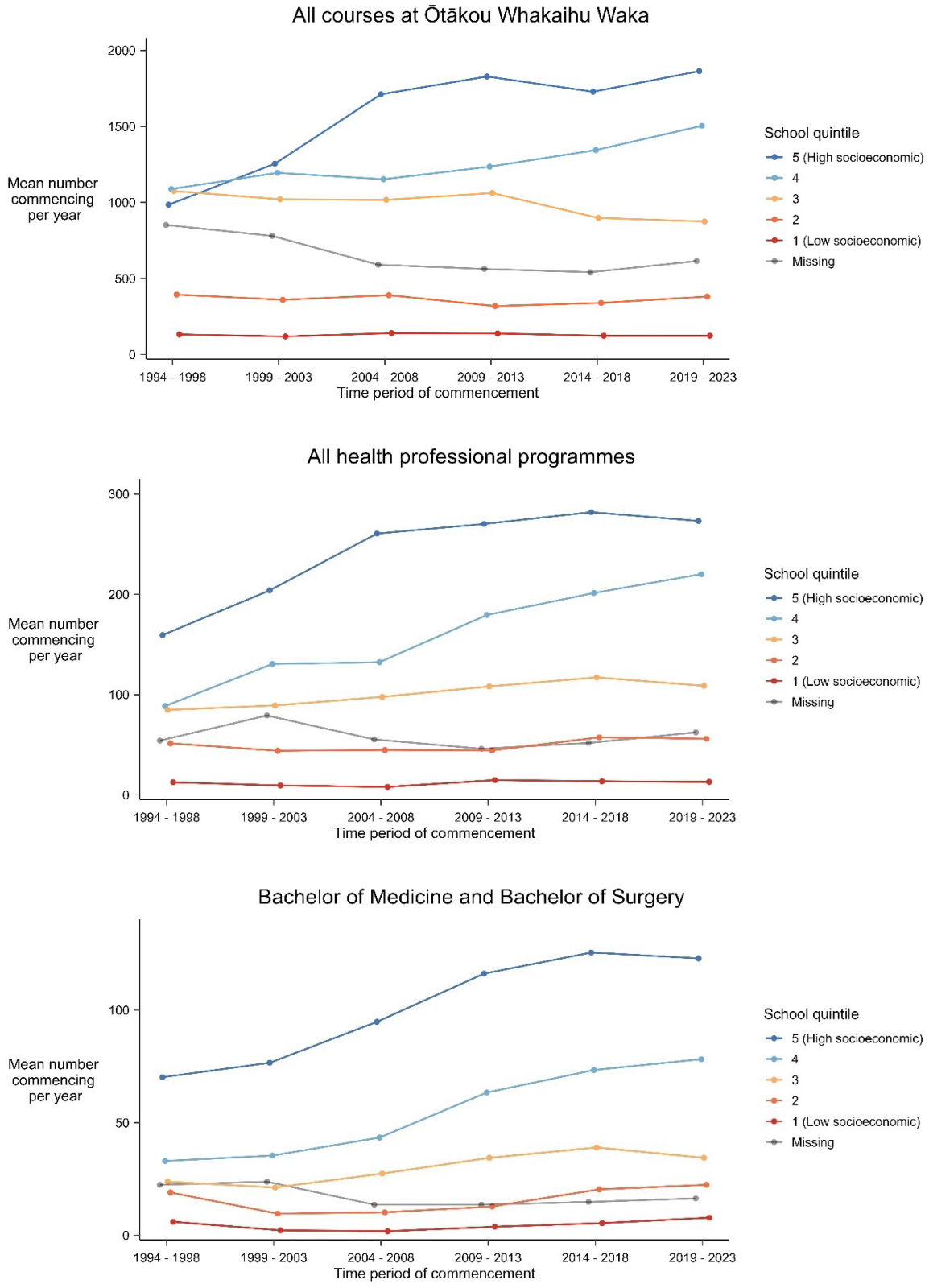


Figure 3: Mean annual number of commencements of students who were Aotearoa citizens or permanent residents in all courses at Ōtākou Whakaihu Waka (n=148,653), all health professional programmes (n=18,632) and the Bachelor of Medicine and Bachelor of Surgery (n=6,697), by time period and Geographic Classification for Health of home address. To safeguard privacy, data were suppressed where fewer than five enrolments in a category were recorded in a given time period.

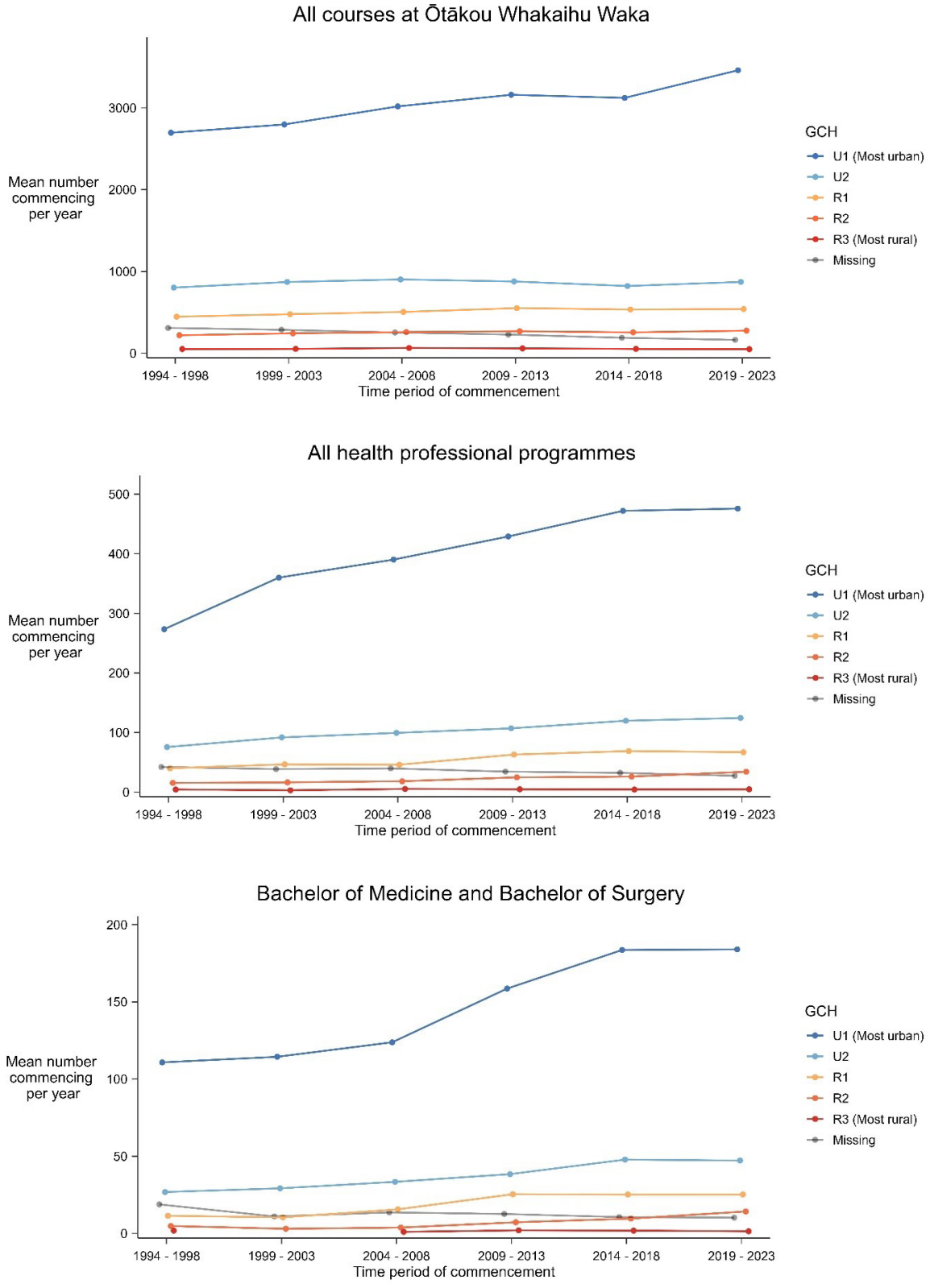


Table 4: Category and subcategory of admission for Aotearoa citizens or permanent residents commencing undergraduate health professional programmes within the Division of Health Sciences* and the Bachelor of Medicine and Bachelor of Surgery, 2017–2023.†

Category/subcategory	Programme (n [%])	
	All programmes	MB ChB
Total		
All Aotearoa citizens or permanent residents	4,820 (100.0)	1,970 (100.0)
Admission category‡		
Health sciences first year	3,206 (66.5)	1,368 (69.4)
Graduate	777 (16.1)	452 (22.9)
Alternative	266 (5.5)	118 (6.0)
Two or more years of university study	232 (4.8)	0 (0.0)
One year of university study	120 (2.5)	0 (0.0)
Secondary school	169 (3.5)	0 (0.0)
Missing	50 (1.0)	32 (1.6)
Admission subcategory§		
Māori	615 (12.8)	384 (19.5)
Indigenous Pacific	216 (4.5)	136 (6.9)
Socio-economic equity	70 (1.5)	40 (2.0)
Refugee background	66 (1.4)	42 (2.1)
Rural	506 (10.5)	332 (16.9)
International¶#	9 (0.2)	<5 (-)
General	3,288 (68.2)	1,002 (50.9)
Missing	50 (1.0)	32 (1.6)

*Students commencing the Master of Nursing Science, Master of Dietetics and Postgraduate Diploma in Clinical Psychology are excluded from this analysis, as admission categories and subcategories do not apply to those programmes.
†Admission category and subcategory data are only available from 2017.
‡Available admission categories vary between programmes.
§The socio-economic equity and refugee background subcategories have only been in use since 2020. Prior to 2020, the rural subcategory only applied to the Bachelor of Medicine/Bachelor of Surgery and Bachelor of Dental Surgery.
¶A small number of students who were classified as Aotearoa citizens or permanent residents were recorded as having gained entry to a health professional programme via the international subcategory. These students have been included for all analyses.
#To safeguard privacy, data (other than "missing" values) have been suppressed where one to four enrolments in any given category have been recorded.

Surgery (50.9%) since 2017 (Table 4). The largest proportion of admissions via affirmative action pathways was for the Māori subcategory, closely followed by the rural subcategory. A smaller number of admissions occurred via the Indigenous Pacific, socio-economic equity and refugee background subcategories (the latter two subcategories having only commenced in 2020).

Discussion

In this paper and the accompanying supplementary report, we present extensive analyses of the socio-demographic characteristics of students entering all courses, all health professional programmes and 11 individual health professional programmes at Ōtākou Whakaihu Waka between 1994 and 2023. These analyses provide unique insights into who has had the opportunity to study at a leading Aotearoa academic institution over a timeframe spanning a generation.

During this 30-year period, there was a notable increase in the proportion of domestic health professional programme students who were Māori or Pacific, and an increase in enrolments of students from rural backgrounds. At the same time, the socio-economic profile of incoming students remained unchanged, with the students entering essentially all programme categories, across all years, being highly skewed towards those from more socio-economically privileged backgrounds. A steady increase in the proportion of students who were female continued across all years, with nearly two-thirds of all domestic health professional programme students identifying as female by the study end. These findings confirm and extend patterns and trends identified by earlier cross-sectional analyses of health professional students at Ōtākou Whakaihu Waka.[12,13] They also broadly reflect patterns identified by more recent nation-wide, cross-sectional analyses of health professional students undertaken across multiple institutions.[28]

The findings of this study have important implications. The increase in students who are Māori or Pacific within the Bachelor of Medicine and Bachelor of Surgery is a success, particularly given the earlier barriers that existed for such students.[11] For example, by the 2019–2023 period, Māori students comprised 20.1% of all incoming students in the Bachelor of Medicine and Bachelor of Surgery and had commenced at a rate comparable to that of Asian and European students. This increase was a result of stronger recruitment, admissions and student support policies, reinforced by medical school accreditation requirements. Increases were not seen to the same extent across all programmes, however, and in some there was little change. In such instances there is a need for stronger policies to be introduced and evaluated; for example, for outreach and recruitment, bridging/foundation programmes for Māori and Pacific students, equity-focussed admissions policies and student support programmes. Furthermore, while findings for the medical programme are encouraging, Māori and Pacific peoples remain severely under-represented among the current workforce of practicing doctors.[29] Given the time scale of medical training pipelines and careers, even if Māori and Pacific students entered Aotearoa medical schools at a much higher rate, inequities in workforce representation would take many years to reduce.

Analyses of socio-economic measures paint a consistently bleak picture of stratified educational opportunity that persisted and, if anything, worsened over time. The near exclusion of students from schools in the lowest socio-economic quintile across essentially all of our analyses is a notable finding that should prompt reflection as to how our education system and society marginalise such students, and fail to enable them to pursue tertiary education at anywhere near the level of their more socio-economically advantaged peers. With the importance of education as a determinant of income,[30] such inequities are highly likely to be self-perpetuating. Recently, Ōtākou Whakaihu Waka implemented affirmative action policies and programmes to facilitate entry to health professional programmes for students who attended schools that serve less socio-economically privileged communities.[3,31] However, as only a small number of years have passed since the inception of those programmes it was not possible for our study to provide a meaningful evaluation of their effect.

This study has some important strengths. The large temporal span, and the use of automated processes to replicate detailed analysis across multiple programme categories, has enabled comprehensive statistics across a broad scope of programmes to be produced (supplementary material). This approach will also support the undertaking of updated analyses in future years. There are also limitations. Most notably, while extensive data exploration and checking of statistical

output were undertaken, scrutiny of individual numbers and figures for all outputs could not occur to the same level as if bespoke analyses had been developed and undertaken for each individual programme.

Other limitations related to specific variables are outlined in more detail in the accompanying report (supplementary material, p. 2–22). Briefly: Ōtākou Whakaihu Waka currently only stores data on up to three ethnicity classifications for each student (at least six are recommended);[19] the broad level one "Asian" ethnic category has acknowledged shortcomings;[32] historic data collection processes meant that gender data were essentially limited to a binary male/female classification across most included years; errors in recording and geocoding home addresses may have translated into small errors in findings for spatially derived measures (NZDep, GCH); use of students' commencement year to assign NZDep quintiles and school deciles will not have resulted in the most appropriate version being assigned in all cases; use of 2018 GCH classifications across all years means that changes in the rural/urban status of some areas over time will have resulted in some misclassification; and, finally, admission category and subcategory data were only available since 2017.

Nevertheless, our findings provide valuable insights that will support the continuing conduct and development of Ōtākou Whakaihu Waka affirmative action programmes. While efforts to enhance health professional student diversity have had a positive impact, it is clear that the university's vision of a health workforce that represents Māori and the diverse contexts of our society in Aotearoa[3] remains far from being realised. Achieving this vision will require long-term ongoing effort and commitment. The methods that we have developed for evaluating health professional programme student demographics will provide a valuable source of intelligence to support these efforts on an ongoing basis.

COMPETING INTERESTS
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Paediatric palliative care in Aotearoa New Zealand—current state and future direction

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ABSTRACT

This paper seeks to explore the current state of paediatric palliative care in Aotearoa New Zealand. The low priority afforded to paediatric palliative care for more than two decades has had a significant impact on service provision, education and research within this specialty. As a result, provision of specialist paediatric palliative care to children with serious illness and their whānau (family, including extended family) is inequitable and vastly inadequate. This paper considers the consequences of having limited access to specialist palliative care for children and whānau, and outlines what is required for both service development and current priorities for research.

The palliative care needs of pēpi (babies), tamariki (children) and rangatahi (young people) and their whānau (family, including extended family) have been acknowledged in Aotearoa New Zealand for the last 25 years.[1] Unfortunately, despite consistent advocacy over this time, there has been a low priority afforded to paediatric palliative care policy, service delivery and funding in Aotearoa. This has resulted in inequitable access to quality generalist and specialist paediatric palliative care, which is largely dependent on the geographical location of the child and the skills, knowledge and capacity of the clinicians around individual children and their whānau.

There is currently **only** one permanent, publicly funded specialist children's palliative care service, based at Starship Children's Hospital in Auckland. There has been limited, accessible and regular professional development for clinicians providing generalist paediatric palliative care within Aotearoa. Furthermore, while there is a body of international research to support the growing need for paediatric palliative care services and support, there is a lack of specific research in Aotearoa to identify and assist the needs of tamariki and whānau. For example, little is known about the nature and scale of inequities faced by tamariki Māori and whānau, and Pacific children and their families at end-of-life, or the extent to which current services are meeting their needs.

This paper will discuss the current state of provision of children's palliative care throughout Aotearoa and highlight the urgent attention required to address the needs of all babies and children and, more specifically, Māori pēpi, tamariki and rangatahi living with serious illness and their whānau. The paper will also present research priorities within children's palliative care in Aotearoa.

Background

Paediatric palliative care has been well defined by the World Health Organization (2018).[2] In short, paediatric palliative care is an approach to care that improves the quality of life of children with serious illness and their families, through the identification and assessment of suffering and treatment of distressing symptoms—physical, psycholgical and spiritual.[2] In Aotearoa, paediatric palliative care is informed by a widely accepted Māori model of healthcare, Te Whare Tapa Whā.[3] This model uses a whāre (house) to symbolise oranga (wellbeing) as a collective of Taha Wairua (spiritual wellbeing), Taha Tinana (physical wellbeing), Taha Whānau (family and psychosocial wellbeing) and Taha Hinengaro (mental and emotional wellbeing), with a child and whānau connected to and situated within the land and environment. To achieve oranga using the Te Whare Tapa Whā model, a collaborative, multidisciplinary approach is required, integrating generalist (primary paediatric teams and primary care) and specialist paediatric palliative care.

International standards published recently by Benini et al.[4] highlight the importance of ensuring access to palliative care for children with

life-threatening, life-limiting or serious illness. Access to paediatric palliative care is a fundamental right for children with serious illness and their whānau. It is a right to care that enhances quality of life, and addresses the needs, choices and wishes of the child and their whānau.[4] Quality of life responds to the physical, mental, emotional, social, spiritual and cultural dimensions that are important to each whānau. Sadly, these standards are not met internationally[5] or within Aotearoa.[6] Table 1 highlights where Aotearoa falls short in meeting the published international standards.[4]

In 2022, significant health reforms were introduced in Aotearoa. These reforms have seen 20 district health boards merged to form a single entity, Te Whatu Ora – Health New Zealand. A separate Māori Health Authority, Te Aka Whai Ora, was also established to advocate for the

Table 1: International standards for paediatric palliative care.[4] This table refers to the most pressing needs that are not met in Aotearoa currently; it is not an exhaustive list of all standards.

Child's needs: • Address physical, psychosocial, spiritual and developmental needs of a child. • Distress caused by disease minimised to improve quality of life. • Symptom control adapted to the child's age, setting and culture. • Evaluation, treatment and monitoring of symptoms should be performed by qualified health providers within an interdisciplinary team.	**Not met:** • Dependent on child's location and availability of specialist paediatric palliative care (PPC) provider. • Children are often cared for by adult palliative care providers, many of which have limited or no experience in meeting the developmental needs of children. In some regions, this is done in partnership with a general paediatric service, who can support developmental needs. • PPC specialist providers are very limited and only available in two regions; not all have a full interdisciplinary team.
Psychological and social needs: • Support for children with serious illness to cope with a range of feelings, thoughts and behaviours. • Psychological concerns and needs should be evaluated by trained specialists with the multidisciplinary team (MDT). • Child's social abilities should be promoted and adpated to their developmental age and physical condition.	**Not met:** • Limited specialist psychology/psychotherapy support available for children with serious illness, which is even more difficult to access in smaller centres. • Limited resources to support social abilities when children are medically fragile.
Family needs: • Parents and family members involved at all care steps. • Psychological support available from trained members (ideally specialist mental health professionals) of the interdisciplinary team for family members. • Psychological support should be available to all family members following the death of a child, for as long as needed.	**Partially met:** • General paediatric teams operate in a philosophy of whānau-centred care, and consistently involve whānau in a child's care. • Limited mental health or psychological support available in main centres, and this can be absent in smaller centres. • Bereavement support reliant on charity and non-governmental organisations. Dependent on a child's underlying diagnosis. Limited support.

Table 1 (continued): International standards for paediatric palliative care.[4] This table refers to the most pressing needs that are not met in Aotearoa currently; it is not an exhaustive list of all standards.

Need for home care and organisational support: • Parents and family should be trained and supported 24/7 in caring for their child at home. • They should be assisted in maintaining their social roles, e.g., work, future perspectives. • Economic issues should be investigated and addressed.	**Not met:** • Access to caregiver support is extremely difficult for whānau. • Funding models do not allow for parents to be in employment. • Many whānau struggle in poverty, as caring for a seriously ill child requires having to give up work, and there is insufficient resource from a benefit for whānau to survive.
Care models and settings of care: • PPC offered by trained health providers should be ensured for all eligible children and their families, regardless of financial or health insurance status. • Each child and family must have a defined person of contact for PPC, who should co-ordinate the care plan. • The support of a specialised PPC team should be available continuously, all days of the year, 24/7. • The gold standard for the place of care is where the child and family want to be and feel the most supported. • Perinatal palliative care should be considered in routine obstetric and neonatal care. • Hospitals providing neonatal and maternal care need to develop perinatal palliative care pathways.	**Not met:** • PPC dependent on geographical location of the child and whānau. • Not all children and whānau have access to a care co-ordinator for their child's PPC. • Specialist PPC support is currently only available during working hours, with no funding for after hours support. • Lack of after hours funding means whānau are not always able to be cared for in their location of choice. • Perinatal palliative care is available but not routine in obstetric or neonatal care. • No perinatal palliative care pathway currently.
Education and training for healthcare providers: • PPC education must be a core part of all paediatric healthcare professionals. • Interdiscipliary education should be promoted. • Curricula should be adapted to the three levels of PPC provision—palliative approach by all, generalised PPC education and specialist PPC education. • Every country must develop specific education curricula for all professionals in PPC.	**Not met:** • PPC education is not universally embedded in undergraduate education. • Interdisciplinary education programme and curriculum are established for the first two levels, but there is no funding to ensure the sustainability of the programme.

health needs of tangata whenua or Māori, the Indigenous population of Aotearoa, ensuring health services are accessible and meet the needs of all New Zealanders.[7] Te Aka Whai Ora has since been disestablished following a change in government, with an intention for the work of Te Aka Whai Ora to be integrated into Te Whatu Ora – Health New Zealand. One of the driving forces of these reforms was to reduce the "postcode lottery" for New Zealanders, where access to treatment and healthcare is dependent on the patient's location or address. This has seen people living in rural and regional areas have a limitation in timely access to specialist services, which reflects the current provision of palliative care services for children in Aotearoa.[8]

The *Pae Ora (Healthy Futures) Act 2022* was legislated[9] with the introduction of the health reforms, the purpose of which was to provide for the public funding and provision of services to: protect, promote and improve the health of all New Zealanders; achieve equity in health outcomes among New Zealanders; and build towards Pae Ora for all New Zealanders. Furthermore, this *Act* stipulates that all New Zealanders should have access to services to meet their needs and receive equitable levels of service.[9] This has yet to translate to children across the mōtu receiving adequate palliative care services, with anecdotal evidence of substantial geographical and cultural inequity, especially for Māori and Pacific whānau.

Paediatric palliative care service delivery

Paediatric palliative care has been recognised as a subspecialty of paediatric medicine in Aotearoa since the late 1990s, which coincided with the establishment of the only specialist centre in Auckland—the Starship Palliative Care service (1999). Despite consistent advocacy from leaders in the field, there has been limited progress in further development of paediatric palliative care services throughout Aotearoa.[6,8]

The advocacy did result in the commissioning and publication of a report *Guidance for integrated Paediatric Palliative Care services in New Zealand* by the Ministry of Health in 2012. The goal of this report was to provide an implementation-focussed guide to improve the integration of palliative care service delivery to children and young people across Aotearoa.[8] This report highlighted the need for service development and growth, and provided a 3-year implementation plan to develop a co-ordinated approach to care delivery. The co-ordinated approach envisaged the Starship service remaining as the specialist paediatric palliative care centre in Aotearoa, with a funded clinician identified in each district and training and expertise to support the delivery of children's palliative care. Regardless of the clearly identified need and the outlining of a robust implementation plan, no further investment in paediatric palliative care was forthcoming.

The Starship Palliative Care service remains the only Te Whatu Ora – Health New Zealand funded specialist multidisciplinary paediatric palliative care service in Aotearoa. The service remains small and vulnerable to workforce pressures. This vulnerability has recently been highlighted by a long-standing pioneer in paediatric palliative care leaving the service to work overseas. Furthermore, given the lack of funding of training positions and education opportunities in paediatric palliative care, there remains only a very small number of trained and skilled specialists across medical, nursing and allied health. The current trained workforce in this subspecialty of paediatrics is inadequate to meet the needs of the current population of children with palliative care needs and their whānau, let alone the needs of the expected increase in the population of children with serious illness over the next 10 years.

Current data

There is a paucity of available data of the nature and extent of palliative care need among children in Aotearoa and, even more concerningly, the population of children currently accessing services. However, clinical experience, as well as informal and formally published reflections from whānau across the country, suggest current service provision is staggeringly inadequate to meet the needs of the approximately 350 children who die of serious illness in Aotearoa each year, and the much larger group of children who could benefit from specialist palliative care input.[8,10,11] While general paediatric services across Aotearoa currently provide palliative care to children and their whānau in regional centres, many have commented they feel ill-equipped to manage the palliative care need of children with serious illness.

Additionally, international research has identified the number of children and young people living with serious illness is increasing rapidly due to advances in medical technology and treatments of many conditions. In the United Kingdom, it is estimated the prevalence of serious illness in children 0–19 years could be as high as 84.22 per 10,000 children as soon as 2030.[12,13] For

the current Aotearoa population of 1.2 million children, this translates to a threefold increase in children requiring palliative care support within the next 10 years, or 10,000 children and their whānau with 10% of this group, or 1,000 children, requiring end-of-life care in any given year. This makes it critical we address inequities and expand paediatric palliative care service provision to ensure *Pae Ora (Healthy Futures) Act 2022* can be achieved for all Aotearoa whānau, as legislation stipulates.[9]

Inequity

It is widely acknowledged by clinicians and whānau around Aotearoa that access to specialist services is inequitable for tamariki. Paediatric palliative care is a prime example, as it looks very different across the motu, with wide regional variability in care provision, contact with specialist palliative care and access to integral supports such as psychosocial care. While inequity exists geographically in Aotearoa, it is also well documented that tamariki Māori and their whānau also experience inequity of access to healthcare.[14] This has been highlighted in tamariki Māori access to primary care. Currently, there is no information on whether tamariki Māori have equitable access to children's palliative care services.

However, the adult palliative care literature has emphasised the challenges whānau Māori face in accessing palliative care services.[15,16] Palliative care services throughout Aotearoa have long been under-resourced and supported by charitable donations. This has meant government funding has tended to prioritise physical symptom management and, by default, neglected the importance of spiritual, cultural and psychosocial wellbeing as core to the patient and whānau's experience of health.[15,17] This is in direct contrast to the te ao Māori approach, which acknowledges a much broader understanding of health,[16] represented in Sir Mason Durie's Te Whare Tapa Whā model of healthcare.[3,18]

Urgent work is needed to evaluate current accessibility and acceptability of service provision in paediatric palliative care for whānau Māori. It is essential that Māori approaches to healthcare are considered and integrated into service delivery, education and professional development of clinicians and research being carried out in this field. We must also consider how we can develop a sustainable paediatric palliative care workforce in Aotearoa that reflects the population of children and whānau cared for. This must include increasing the number of Māori clinicians working in the speciality.

Impact of investment in paediatric palliative care

The literature suggests children with serious illness who have access to palliative care services have an improved quality of life and improved symptom management.[19,20] This can result in children living longer, with an improved quality of life, and whānau being enabled to care for their child in their preferred place of care at the end-of-life.[21] While the benefits are apparent for child and whānau, it is also important to acknowledge the impact adequate palliative care provision can have on the healthcare system.

Quality paediatric palliative care delivery often means children require fewer bed nights in hospital by remaining in the community with their whānau.[21,22] Furthermore, paediatric palliative care input may mean unnecessary and futile interventions are avoided at end of life. This has a direct impact on the healthcare dollar spend, as well as the quality of life and wellbeing of child, whānau and health professionals.[22,23] The whānau of children who die without adequate access to paediatric palliative care can carry the burden of care and memories of distress and suffering through the remainder of their lives.[24] This can contribute to complex grief responses in bereavement and lead to whānau requiring further access to health services for support through the remainder of their lives.[22,25,26]

What are the priorities moving forward?

Service delivery

It is clear that further investment in paediatric palliative care is needed to ensure every child with a serious illness has access to quality palliative care. In order to achieve this, there needs to be:

- Growth and development of current specialist services, including recognition of the need for training positions to ensure sustainability of service delivery.
- Recognition of, and embedding the role of, general paediatric palliative care providers, including paediatric teams, primary care and adult palliative care providers within a national co-ordinated approach.
- Access to ongoing professional development and education in paediatric palliative care for generalist providers across Aotearoa.
- Integration of tikanga Māori into service

delivery and partnership with Māori health providers and iwi to ensure services meet the needs of tamariki Māori and their whānau. This requires consideration of the experience of whānau Māori and ability to access services, which requires consideration through research.

At a minimum, every child with a serious illness and their whānau, across the motu, should be receiving quality, evidence-based and compassionate generalist paediatric palliative care from their primary healthcare team. Furthermore, every paediatric healthcare team in Aotearoa should have 24/7 access to a specialist paediatric palliative care service for support and advice in managing and supporting children and whānau. This will only be possible with further education of generalist providers, and increasing the workforce of specialist providers. Given Aotearoa is a small country, the provision of integrated, high-quality care will be reliant on a national co-ordinated approach to delivery of paediatric palliative care.

Research

There is also an urgent need to develop research that is specific to the Aotearoa context.

Priority areas for future research include:

- Identifying the prevalence, and nature, of palliative care need among children in Aotearoa.
- Describing the population of children currently accessing specialist children's palliative care in Aotearoa and identifying inequities in access.
- Exploring the child and whānau experience of palliative care and end-of-life care in Aotearoa, with a particular focus on communities known to be under-served by healthcare, including Māori and Pacific whānau, children living with a non-cancer condition or disability and whānau living in regional and rural Aotearoa.
- Capturing rangatahi and whānau experiences of transition from paediatric to adult palliative care services.
- Examining the education and support needs of clinicians working in generalist paediatric palliative care and identifying effective education and training interventions.

Conclusion

This paper highlights the urgent requirement for action to ensure equitable and sustainable specialist palliative care services for children with serious illness throughout Aotearoa. While Aotearoa recognised the value of paediatric palliative care in the late 1990s, there has been a woeful and shameful lack of policy and service development since, while research has been essentially forgotten. This means that many children and whānau are missing out on their basic right to this essential care.[4] The consequences of this avoidable poor care for children are far reaching and must be considered unacceptable. They include the financial burden on the health system of increased hospital stays and unnecessary interventions, and the physical and emotional burden to children and their whānau of poor symptom management, impaired quality of life and complex grief responses following a child's death for bereaved whānau.[22,24,25] It is essential that Aotearoa invests in children's palliative care to give every child with a serious illness the opportunity to reach their full potential with appropriate specialist support.[4,14]

COMPETING INTERESTS
Nil.

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Vision loss secondary to cerebral venous sinus thrombosis as the first presenting symptom of a JAK2 positive myeloproliferative neoplasm

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Myeloproliferative neoplasms (MPNs) are a group of acquired haematopoetic stem cell disorders that include essential thrombocytosis (ET), polycythaemia vera (PCV) and primary myelofibrosis (PMF). The majority of patients with MPNs share a mutation in *JAK2* that affects haematopoetic signal-transduction pathways (95–98% of patients with PCV and 50–60% of those with ET/PMF), resulting in haematologic disruption that increases thrombotic risk across all organ systems, including the central nervous system and the eye.[3]

Vision loss due to MPN is uncommon but may occur in the setting of cerebral venous sinus thrombosis (CVST) secondary to severe papilloedema. Less than 1% of patients with known MPN develop CVST, and fewer still present with vision-threatening papilloedema as a consequence.[4–6] We report a case of progressive bilateral vision loss secondary to CVST as the initial presentation of an underlying *JAK2*-associated MPN.

Case report

A 56-year-old man presented to the acute ophthalmology clinic with a 3-month history of progressive generalised visual blurring in both eyes and an associated generalised dull headache for 2 months. He denied any diplopia, transient loss of vision, nausea or focal neurological symptoms. His past ocular and medical history were unremarkable other than previous appendicectomy 6 years prior. There was no known personal or family history of thrombophilia.

Visual acuity at presentation was 6/60 on the right and 6/120 on the left, improving with pinhole to 6/24 and 6/30 respectively. Intraocular pressures were normal and there was a full range of eye movements with no relative afferent pupillary defect noted. The patient was unable to read any numbers on Ishihara testing in either eye. Slit lamp examination demonstrated bilaterally swollen optic nerves consistent with papilloedema (Figure 1). Formal visual field testing showed gross visual field defects in both eyes. The patient was also noted to be hypertensive at 145/89mmHg.

An urgent computed tomography (CT) head and CT venogram (CTV) were arranged but did not reveal any obvious pathology to account for the patient's symptoms. Following consultation with neurology a lumbar puncture (LP) was performed, showing a cerebrospinal fluid (CSF) opening pressure of 46cm of water (reference range: 6–25cm H_2O) and resulting in a provisional diagnosis of idiopathic intracranial hypertension (IIH). The patient was started on oral acetazolamide 500mg three times daily.

Review of the medical records subsequently revealed that the patient had a documented raised haemoglobin between 175–185g/L (reference range: 130–175g/L) for 2 years prior to presentation. This was associated with thrombocytosis ranging from 455–525 x 109/L (reference range: 150–400 x 109/L) over the same 2-year period, and a raised haematocrit (>0.54) for the last 12 months. Given the patient's high haemoglobin, thrombocytosis and newly diagnosed CVST, haematology input was sought. A subsequent diagnosis of MPN with a phenotype of polycythaemia was made, with confirmatory genetic testing revealing a mutation in *JAK2* (pVal617Phe genetic variant).

Due to the fundus appearance and aforementioned laboratory findings, a magnetic resonance venogram (MRV) was obtained, revealing thrombosis of the left transverse and sigmoid sinuses (Figure 2). The patient was anticoagulated using subcutaneous 1mg/kg low molecular weight heparin (Enoxaparin sodium) twice daily and continued on acetazolamide 500mg three times daily for intracranial hypertension. Serial LPs were performed on days 3, 10 and 12 of admission and revealed persistently raised opening pressures

Figure 1: Pseudo-colour images of the left and right optic discs (right and left respectively). A/B—appearance of discs at presentation. C/D—appearance of discs after ventriculo-peritoneal (VP) shunt placement.

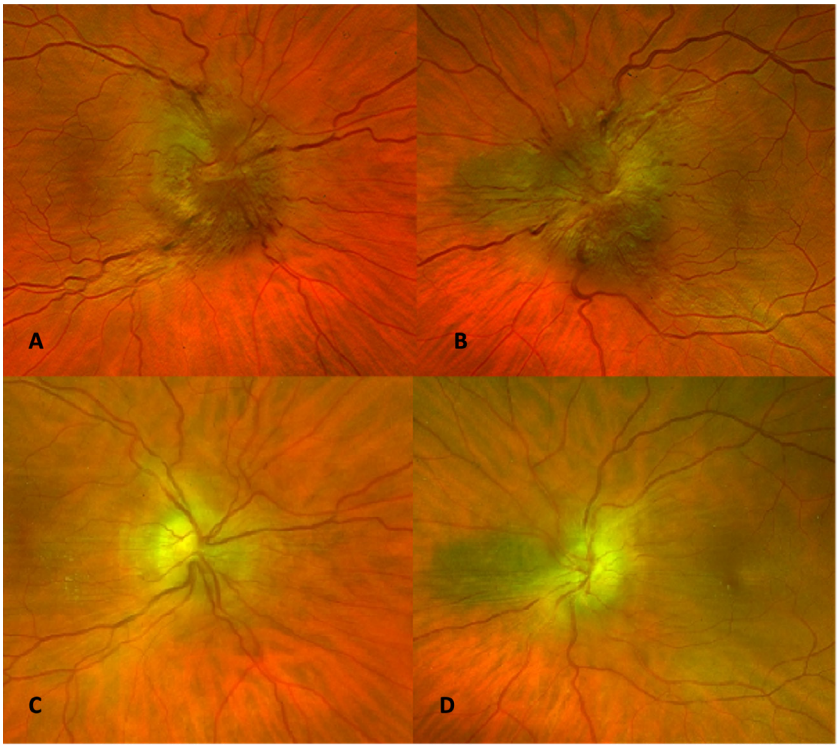
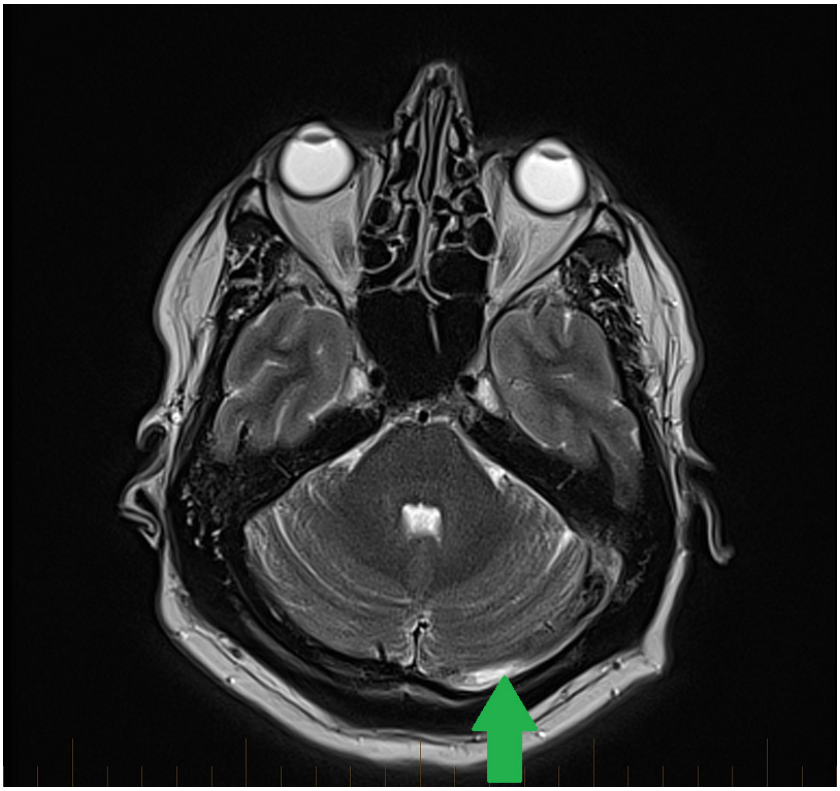


Figure 2: T2-weighted magnetic resonance venogram (MRV) of the brain with Gadolinium contrast demonstrating thrombus in the left transverse sinus, denoted by the green arrow.



above 25cm of water (26cm, 33cm and 29cm respectively). Due to concern regarding persistently raised intracranial pressure (ICP) despite serial therapeutic LPs, the patient was referred for neurosurgical intervention and a ventriculo-peritoneal shunt (VP shunt) was placed. This resulted in gradual resolution of the patient's papilloedema over the course of 3 months, with development of optic disc pallor noted post-operatively (Figure 1).

Gradual clinical improvement was noted following VP shunting, with vision improving to 6/9.5 and 6/7.5 on the right and left respectively, and visual fields improving to above the minimum driving standard by 12 months post-operatively. Colour vision did not recover, indicating chronic optic neuropathy. Initial venesection combined with Hydroxycarbamide was effective in reducing the patient's haematocrit, however he subsequently developed pyrexia (>39.0°) secondary to this medication and it was consequently ceased. He then developed thrombocytosis despite good control of his haematocrit, and therefore he commenced intermittent pulsed oral Busulphan at an initial dose of 4mg per day tapered over 8 weeks (maintaining a platelet count <400 x 109/L) after counselling for leukaemia risk associated with the medication. He remains anticoagulated on Dabigatran 150mg twice daily and has monthly venesection alongside regular haematology follow-up to ensure his thrombotic risk remains well managed, and he does not presently require ongoing cytoreductive treatment.

Discussion

MPNs are a group of haematopoetic stem cell disorders including polycythaemia vera, essential thrombocythaemia and primary myelofibrosis. Approximately 60% of cases are associated with a mutation in the *JAK2* gene.[7] These haematopoetic disorders confer increased thrombotic risk and may result in vision-threatening CVST. Prior research has shown that MPN is present in approximately 3.8% of patients with CVST, and a mutation in *JAK2* is present in 6.6% of cases of CVST without a known MPN at presentation.[1]

CVST may present with non-specific neurological and ocular symptoms, including headache (present in 88% of cases), visual disturbances (present in 78%), nausea, vomiting and seizure activity.[1,8,9] Papilloedema is a frequent finding at presentation (present in 30–50% of patients) and may result in permanent visual loss.[10,11] In a series of 131 patients presenting with papilloedema and clinical suspicion for IIH, 10% had previously undiagnosed CVST on subsequent MRI—this diagnostic overlap highlights the importance of excluding CVST in patients presenting with symptoms of raised ICP.[12]

For cases of CVST in the context of MPN, raised ICP usually occurs as a result of occlusion of the superior sagittal sinus and typically results in bilateral symmetric papilloedema.[2] Up to 20% of patients experience progressive papilloedema despite treatment, and 40% of patients have resultant permanent visual field loss. Longstanding optic neuropathy due to papilloedema may occur and can permanently affect colour vision (as was the case with our patient). VP shunting in the setting of CVST occurs in less than 10% of patients.[10]

As demonstrated by our case, non-contrast CT scanning alone may not be sufficiently sensitive to make a definitive diagnosis of CVST. Non-contrast CT is a rapid and easily accessible initial imaging choice; however, it has been shown to be normal in up to two-thirds of patients with CVST at presentation. This is thought to be due to heterogenous radiographic appearances of thrombus depending on time of presentation, which may result in subacute or chronic cases being missed, particularly in subacute cases where density of the thrombus is similar to that of the surrounding brain parenchyma and vasculature.[13] In the current case, isodensity of the thrombus on both CT and CTV due to this phenomenon was the likely cause for the diagnosis initially being missed. Current literature suggests that MRV has a high sensitivity and negative predictive value irrespective of acuity of presentation (93% and 91% respectively); however, T2-weighted MRI sequences may be more specific, with a superior positive predictive value (95% and 93% respectively).[14–16] Furthermore, MRI is more useful than CT in discriminating features of IIH (e.g., posterior globe flattening, optic nerve tortuosity and emptiness of the sella turcica), making combined MRV/MRI the imaging modality of choice in suspected CVST.[17]

Multi-specialty input was vital for this patient, with involvement of ophthalmology, neurology, neurosurgery and haematology at different stages along the patient journey—a reflection of the multisystem impact of *JAK2*-associated myeloproliferative neoplasm. CVST is a rare cerebrovascular disease that makes up only 1–2% of all cases of stroke and frequently suffers from diagnostic delay (a mean 7 days from time of presentation

to diagnosis).[9,11] Exclusion of CVST is essential in cases of suspected IIH due to their similar presenting features, and therefore a blood count should be performed in the setting of vision loss due to papilloedema, irrespective of the presence of a headache. If polycythaemia or thrombocytosis is present, genetic testing for a mutation in *JAK2* should be strongly considered.[10,18]

COMPETING INTERESTS
Nil.

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The alarming trend of off-label quetiapine use in New Zealand: an ongoing public health crisis

Pablo Richly

In 2010, United States (US) Attorney General Eric Holder warned of the dangers posed by pharmaceutical companies' illegal acts, stating that such actions "*can put public health at risk, corrupt medical decisions by health care providers, and take billions of dollars directly out of taxpayers' pockets*." This statement coincided with AstraZeneca facing charges for off-label promotion of quetiapine (Seroquel) for unapproved conditions, including insomnia and anxiety.[1]

AstraZeneca's marketing practices resulted in a US$520 million fine, a mere fraction of quetiapine's annual US sales of $6.8 billion in 2010.[2] The case exposed a troubling trend: between 2000 and 2007, publications suggesting off-label uses for quetiapine significantly outnumbered confirmatory trials, with AstraZeneca engaging doctors to conduct studies on unapproved uses.[3]

Despite legal repercussions and lack of solid evidence, off-label quetiapine prescriptions, particularly for insomnia, have surged globally.[4] Studies in New Zealand revealed that nearly half of patients prescribed an antipsychotic received quetiapine,[5] with up to 72% receiving it for off-label indications.[6] This trend persists despite substantial risks associated with quetiapine use, even at low doses, including:

- Weight gain and metabolic disorders, including increased triglycerides[7]
- Higher risk of major adverse cardiovascular events, non-fatal ischemic stroke and cardiovascular death compared to Z-drugs[8]
- Potential for intentional abuse, with quetiapine being the most commonly misused antipsychotic in the US, accounting for 60.6% of all antipsychotic abuse cases.[9]

Despite warnings issued for over a decade, this growing health problem remains unmitigated. As of 2023, up to 1 in 41 adults in New Zealand were dispensed 25mg quetiapine, accounting for 63% of people dispensed an oral antipsychotic (excluding clozapine).[10]

In conclusion, the current pattern of quetiapine prescribing, particularly its widespread off-label use for insomnia, lacks evidence-based support and poses significant risks to patient health and healthcare sustainability. It underscores the ongoing challenges in ensuring that pharmaceutical use is driven by scientific evidence rather than marketing or convenience. The current off-label use of quetiapine in New Zealand is an ingrained practice of the prescribers based only on the ongoing exploitation of the deceptive marketing of its sedative side effect, which results from its H1 receptor binding profile (similar to that of promethazine or amitriptyline). In contrast, medications specifically developed, tested and approved for short-term insomnia management, such as zopiclone, are classified as controlled substances, while quetiapine prescribing remains relatively unrestricted.

Patients deserve treatments that have been thoroughly tested for both efficacy and safety in their specific conditions. Until robust evidence supports its use for insomnia, healthcare providers should exercise caution when considering low-dose quetiapine prescriptions for this purpose. The potential harm to individual patients and the broader public health implications of this prescribing trend demand immediate attention and action.

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Virulent Staphylococcal Infections.

NZMJ, 1924

A CLINICAL AND PATHOLOGICAL STUDY OF TWENTY CASES.

By P. P. Lynch, M.D., Ch.B., B.Sc. (*from the Departments of Bacteriology and Pathology, Otago University*), *being an abstract from a thesis submitted for the degree of M.D.*

Preliminary Discussion.—At intervals during the past two or three years my attention has been drawn to the frequency with which the staphylococcus has been encountered in the cases which have come under my notice, for the most part at the Dunedin Hospital. Some of these were studied first from the bacteriological side, but many were seen for the first time at *post mortem*. One has been accustomed to look upon this organism as being commonly enough met with in mild superficial infections, but only rarely in grave visceral lesions and in fatal cases. A study of the clinical and pathological records of previous years has served to confirm this view.

In searching for the causes underlying this comparatively sudden appearance of severe staphylococcal infections, the first fact to be noticed (and it has been remarked on more than once), was that in the influenza epidemic of 1918–19 a variety of organisms was encountered as secondary invaders in the lung lesions, and very frequently the nature of the invader determined the type of lesion found, and likewise in a large measure influenced the prognosis. It was remarked at the time by several independent observers that in quite a number of cases an unusual feature was the occurrence of a staphylococcus aureus as the chief or sole secondary invading organisms. On studying the literature of that epidemic one finds that this observation was made by observers in many different countries.

The type of lesion associated with this organism is sufficiently definite and characteristic to be easily recognised, and on going through the case records and *post mortem* reports of the epidemic in Dunedin, we find several cases in which the staphylococcus was found as the principal organism. A study of the pathology of these cases, both macroscopically and microscopically, is contained in the case reports which follow in the second part of this paper. Although they may appear to have little direct bearing on the subject, nevertheless these cases are mentioned because I consider they help us to a fuller understanding of the pathogenicity of the staphylococcus as studied in the later cases. Within a short time after the subsidence of the epidemic we find cases occurring in which the staphylococcus is the infecting agent, and which are of such grave severity and rapidly fatal course as at once to attract our attention. It is interesting to note that a similiar observation was made by *Chickering* and *Park* in New York in the early months of 1919 (11). They record a series of cases in which rapidly fatal pulmonary conditions were found *post mortem*, associated with acute hæmorrhagic areas with multiple abscess formation. From these abscesses a pure culture of staphylococcus aureus could in all cases be obtained. The lesions present in these cases were most unusual, but nevertheless correspond in site and nature with those found in Case III. quoted below. Furthermore, when *Minowski* (21) published his study of the empyemata arising from the pneumonias of 1918–19, it was noticed that in a considerable percentage of the cases the staphylococcus aureus was found as the responsible organism. In those cases which came to *post mortem* the pathology of the lung condition was quite different from that encountered in the frank pneumonias commonly met with in ordinary practice. There was almost always present a sub-pleural abscess. This is all the more remarkable because in the cases to follow the presence of sub-pleural abscesses was noted frequently enough in all stages of formation, and some had recently ruptured into the pleural cavity. These would in time have ultimately given rise to staphylococcal empyemata, had the cases survived. I record this observation because I think it has a considerable bearing on the pathology of empyema in epidemic pneumonias. We observed the phenomenon in 1918 and again in 1923 (15).

In February, 1922, an opportunity arose of studying, both clinically and pathologically, a case of staphylococcus aureus endocarditis in a young man of 23. The rapid onset and tragically sudden *exitus* were very startling. The occurrence of a second case of the same nature and with almost exactly similar lesions, which I had an opportunity of examining *post mortem*, served to confirm this impression and I had yet to see a third case of the same kind, during the short period over which this study extends.