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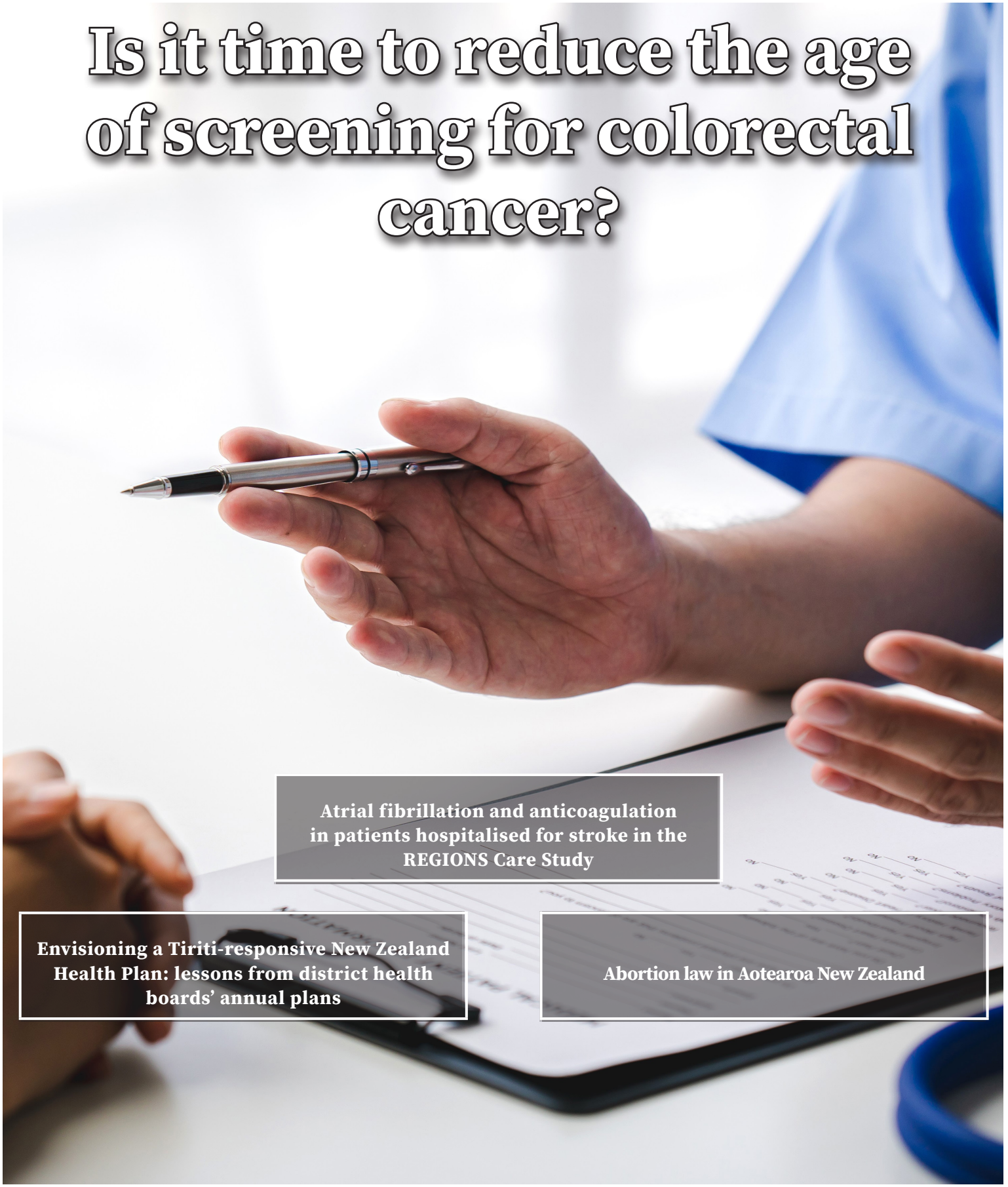
Is it time to reduce the age of screening for colorectal cancer?



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PMA PASIFIKA MEDICAL ASSOCIATION Group

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Atrial fibrillation and anticoagulation in patients hospitalised for stroke in the REGIONS Care study

Syrah M Ranta, Ralph Stewart, Stephanie Thompson, Alan Davis, P Alan Barber, Matire Harwood, Anna Ranta

Atrial fibrillation is an irregular heartbeat that can lead to blood clot formation in the heart, leading to stroke. About a third of people with stroke have atrial fibrillation as an underlying condition and strokes in this setting can be prevented by taking blood thinners. Both prescribers and patients can be reluctant to take blood thinners because they may be concerned about bleeding side effects. Our study showed that one third of people with atrial fibrillation were not taking blood thinners when they presented with a stroke, that most of these would have been eligible to take blood thinners, but both patients and prescribers showed reluctance. Our study also found that people taking blood thinners were no more likely to present with a bleeding type of stroke than those not taking blood thinners. Māori are at particularly high risk for stroke due to atrial fibrillation, and it was reassuring to see that blood thinner use among Māori was no less than among non-Māori. However, both groups could benefit from higher rates of prescribing/use of these life-saving medications and tools to support, especially primary care providers, in the shared decision-making process.

Implementing and assessing the acceptability of a portable, readily accessible, and actionable end of life planning tool for patients with advanced serious illness or frailty in southern New Zealand

Laura Mulligan, Amanda Charity Sommerfeldt

The Clinical Order Articulating Scope of Treatment (COAST) form was designed as a single-page medical order communicating plans for medical treatment for adult patients believed to be in their final year of life, following discussion with a health professional. Prior to introducing COAST, each health provider or agency in the Southland region of New Zealand had its own forms and processes; the COAST pilot attempted to consolidate and streamline these varied processes into one form that is valid throughout the region. This three-phase initiative involved piloting use of the COAST form in Southland between May 2019 and January 2020. Surveys were given to patients at the time of COAST form completion and distributed electronically to health professionals at the end of each phase to assess attitudes towards COAST form use and obtain feedback. The response rates for patient and health professional COAST experience surveys were relatively low but the feedback was positive, with the majority of respondents expressing that the COAST form improved patient care. Implementation of the COAST form has been widely accepted by patients, families, and health professionals alike.

Envisioning a Tiriti-responsive New Zealand Health Plan: lessons from district health boards' annual plans

Nina Bevin, Kyle Eggleton, Sarah Herbert

While District Health Boards' annual plans expressed commitment to Te Tiriti o Waitangi, their content did not give effect to these commitments. Significant shifts are necessary if future New Zealand Health Plans are to meaningfully deliver Tiriti-responsive health services.

Identifying potential patients with diabetes-related dementia: a descriptive approach using routinely collected data

Cristian Gonzalez Prieto, Ruby Hosking, Jasmine Appleton, Susan Yates, Yu-Min Lin, Bede Oulaghan, Claudia Rivera-Rodriguez, Daniel Wilson, Gillian Dobbie, Sarah Cullum

A new subtype of dementia associated with diabetes has been studied in Japan since 2013, called diabetes-related dementia. Given the high occurrence of diabetes and dementia in New Zealand, the suggestion of a diabetes-related dementia is of interest. Our findings may indicate a new subtype of dementia which could influence future personalised treatment and prevention approaches.

Multiple symptom illness in New Zealand contemporary veterans

David Iain McBride, Amy Richardson, Dianne Gardner, Emma Wyeth, Daniel Shepherd, Sarah Derrett, Claire Cameron

Persistent physical symptoms, such as joint pain, stiffness and loss of sensation, along with psychological symptoms such as avoiding doing things, sleeping difficulties and tiredness, was first described in veterans as "Gulf War Illness" and was medically unexplained—not fitting within a medical diagnosis. We looked for this in New Zealand veterans and, based on severity, grouped 26 symptoms in three groups: firstly, arthro-neuromuscular (muscle and joint pains, tingling, loss of balance), secondly, psychological (feeling distant, avoiding doing things, sleeping difficulties and dreams), and thirdly, "ill-defined physical symptoms" (swollen glands, fever, sore throat). Our results suggest that, while there may be no unique symptom pattern, multiple symptoms, especially if severe and persistent, may be related to post-traumatic stress disorder (PTSD). It may be worthwhile to do a more formal evaluation for PTSD in these cases.

Voices for health: going, going, going…

Boyd A Swinburn

The new health reforms aim, as their core purpose, to improve the health of New Zealand's population, especially for those groups currently experiencing worse health outcomes. The most effective way to do this is through prevention measures, which lie outside the hospital walls or GP surgeries. We need many voices calling for these prevention strategies, but the centralisation of the new health systems has resulted in a loss of public voices for health from within, and the demise of the NZ Medical Association after 136 years of service is a lost voice for prevention from without. Health Coalition Aotearoa is building a collective voice from health organisations for stronger preventive regulations on tobacco, alcohol, and unhealthy food.

Abortion law in Aotearoa New Zealand

Felicity Goodyear-Smith

This article outlines the history of abortion law in Aotearoa New Zealand from colonial times to the present. The abortion struggle serves as an illustration of our changing political and social landscape. This was a remarkable period in our history, and there are many tales of extraordinary events and courageous acts, with moral crusaders, activists, legislators, abortion-providers and many others on both sides of the debate putting their reputations and sometimes their lives on the line to do what they thought was right. With the 2020 law change abortion is no longer a crime, but events in the United States have shown how quickly change can occur, with their Supreme Court overturning *Roe v Wade* and states now banning abortions, so we should not be complacent.

Is it time to reduce the age of screening for colorectal cancer?

Oliver Waddell, Tamara Glyn, Frank Frizelle

The incidence of bowel cancer in people aged under 50 in Aotearoa New Zealand is increasing. This is part of a worldwide trend that is occurring despite the overall incidence of bowel cancer decreasing in many countries.[1,2] From 1995 to 2012, colon cancer in New Zealand men aged under 50 increased by 14%, and the incidence of rectal cancer increased by 18% in men and 13% in women aged under 50.[3] This finding is consistent with other studies from Australia, the United States, Canada, the United Kingdom, France and Asia, which all show a rapid increase in early-onset bowel cancer.[1,4–8] In the United States, the incidence of early-onset bowel cancer has doubled since the 1990s and by 2030 it has been estimated that more than one in 10 colon cancers and nearly one in four rectal cancers will occur in people aged under 50.[4,5,9]

Early-onset bowel cancer is different in many ways to late-onset bowel cancer. There is a different distribution within the colon, with early-onset cancer often occurring in the distal bowel involving the rectum, rectosigmoid and sigmoid colon. Patients with early-onset bowel cancer also tend to present with more advanced disease, have a more aggressive histopathology with more poorly differentiated cancer and are more likely to have lymphatic and peri-neural involvement.[2,5,10] Despite this, stage for stage they tend to have a better prognosis.

The aetiology of this epidemiological change is unknown;[11] however, it is likely to be an environmental influence, and likely associated in some way with the gut microbiota and their interaction with the gut mucosa.[11–16] With regard to early-onset colorectal cancer (EOCRC), individuals born after 1960 have an increased risk compared to previous generations,[17] suggesting that shared risk factors—common across a generation—are likely to be contributing. A wide variety of loosely associated factors have been suggested to explain this trend, such as changing trends in obesity, sedentary lifestyles, smoking, Westernisation of diets and/or the use antibiotics in early life;[2] the contraceptive pill in the late 1950s[18] is another potential risk factor, as is the increasing level of microplastics in the environment.[19] However, as yet, no proven causal relationship to any specific factor has been established.[20]

Countries that have screening starting at age 40 seem to have avoided the impact of this shift. While direct data to show that screening populations under 50 will reduce EOCRC are lacking, there are some observational data that support this claim. A review of international trend in EOCRC incidence rates across five continents found only three countries where the incidence rates were decreasing.[21] Two out of these three countries (Italy and Austria) have been screening patients from the age of 40 or 44 since the 1980s.[22] In recent years (2003–2016), while Austria has seen rising rates of colorectal cancer (CRC) diagnosed under the age of 35, they have ongoing decreases in incidence of all age groups aged 45 and over, which may be evidence that the lower age of bowel screening is preventing the same rise across EOCRC incidence seen elsewhere.[23] Likewise, when looking at a large review of international trends in bowel cancer screening, the only other two countries who have also been screening people down to the age of 40 are China and Japan,[22] neither of whom have seen a statistically significant increase in EOCRC incidence in recent years.[21] A large systematic review including data on over 50,000 average risk screening colonoscopies found that the rates of finding CRC in patients aged 45–49 was very similar to in those aged 50–59 years, and concluded that expanding screening to this population could result in a similar impact on CRC outcomes.[24]

Currently, the National Bowel Screening Programme is only open to people aged 60–74, whereas most countries with programmes begin screening for bowel cancer at age 50. The American Cancer Society recommends that screening should begin at age 45.[25] A modelling study from the United States preventative task force concluded that screening from age 45 is cost effective and results in an additional 22–27 life years gained per 1,000 people screened.[26]

If the age of eligibility for screening in New Zealand were lowered to 40 or 45 it would be likely to result in a proportional decrease in the diagnosis

of EOCRC, as seen in countries with a lower age of screening. This is particularly important for Māori, as 30% of bowel cancer in Māori females and 25% in Māori males occurs before age 50.[27] Unpublished data describing the trends of all EOCRC incidence here in New Zealand over the past 25 years from 1995–2020 found that 45% of all EOCRC diagnosed were in the oldest 5-year age bracket of 45–49, meaning almost half of EOCRC may either be prevented or diagnosed earlier if screening was lower to 45, and more so if reduced to 40. Until the cause of this avalanche can be identified and addressed, we must act to mitigate the consequences. Lowering the screening age is the most effective tool we have to combat this epidemic. This simple action would improve equity and outcomes for all New Zealanders.

COMPETING INTERESTS
Frank Frizelle is the Editor in Chief of the *New Zealand Medical Journal* and a Medical Advisor to Bowel Cancer New Zealand.

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Atrial fibrillation and anticoagulation in patients hospitalised for stroke in the REGIONS Care study

Syrah M Ranta, Ralph Stewart, Stephanie Thompson, Alan Davis, P Alan Barber, Matire Harwood, Anna Ranta

ABSTRACT

AIM: To describe atrial fibrillation (AF) patient characteristics and anticoagulation patterns in stroke patients in Aotearoa.

METHODS: Reducing Ethnic and Geographic Inequities to Optimise New Zealand Stroke (REGIONS) Care study is a prospective, nationwide observational study of consecutive adult stroke patients admitted to hospital between 1 May and 31 October 2018. AF and anticoagulation prescribing, intracerebral haemorrhage (ICH) and differences by Māori ethnicity and hospital location are described.

RESULTS: Of 2,379 patients, 807 (34.3%) had a diagnosis of AF. AF patients were older than non-AF patients (mean 79.9 [SD 11] versus 72.5 [14.2], p<0.0001). AF was diagnosed before stroke in 666 patients (82.5%), of whom 442 (66.4%) were taking an anticoagulant. The most common documented reasons for non-anticoagulation were prior bleeding (20.5%), patient preference (18.1%), frailty, comorbidities/side effects (13.2%) and falls (6.8%). The ICH rate was similar for AF patients on versus not on an anticoagulant (adjusted odds ratio [aOR] 0.99, 95% confidence interval [CI] 0.55–1.80). Rates and reasons for oral anticoagulant non-prescribing were similar for Māori, non-Māori, urban and non-urban populations.

CONCLUSIONS: Although anticoagulation prescribing in AF has improved, one third of stroke patients with known AF were not taking an anticoagulant prior to admission and the majority did not appear to have an absolute contraindication offering a multidisciplinary opportunity for improvement. There were no significant differences for Māori and non-urban populations in anticoagulant prescribing.

Stroke occurs in around 9,000 people each year in Aotearoa New Zealand (Aotearoa) and is one of the most common causes of death and disability globally.[1] Atrial fibrillation (AF) increases the risk of ischemic stroke fivefold through the formation of left atrial thrombi that embolise to the brain.[2,3] Prior research has identified that Māori have greater odds of developing AF than non-Māori, with an adjusted odds ratio (aOR) of 1.91 (95% confidence interval [CI] 1.80–2.03) taking into account age, sex, socioeconomic deprivation and clinical risk factors.[4] Little is known about other differences in characteristics based on AF status in people presenting with acute stroke in Aotearoa.

Oral anticoagulants are highly effective in decreasing AF-related ischaemic stroke risk.[5] However, anticoagulants are associated with a risk of intracerebral haemorrhage (ICH) as a potentially life-threatening side effect. While this risk has reduced since the introduction of the newer direct oral anticoagulants, prescriber and patient concerns persist. This has resulted in under-prescription of anticoagulants. A United States study reported that only 20% of people known to be in AF were taking anticoagulants at the time of stroke presentation.[6] The fourth Auckland Regional Community Stroke Study (ARCOS IV) reported an anticoagulant rate of 26.5% among AF patients with stroke.[7] Another Aotearoa-based study found that among high-risk AF patients in the general population, 39.5% of people had no record of anticoagulant dispensing.[4] The primary analysis of the Reducing Ethnic and Geographic Inequities to Optimise New Zealand Stroke Care study (REGIONS Care) found a potential relationship between lower anticoagulation prescription and Māori ethnicity[8] and suboptimal access to best practice stroke care in non-urban areas in New Zealand,[9] suggesting that rural Māori may be at particularly high risk of under-treatment with anticoagulants.

In the REGIONS Care study population, we explored characteristics of patients with and without AF hospitalised for stroke, those with a pre-stroke diagnosis of AF compared to those with an AF diagnosis made at the time of stroke, AF-related anticoagulant prescribing patterns, reasons for non-prescribing and haemorrhage risk. We also

considered the potential impact of ethnicity and geography on pre-stroke prescribing and ICH risk.

Methods

REGIONS Care was a multi-part observational study designed to assess the impact of geography and ethnicity on stroke care access and outcomes. It involved nation-wide, prospectively collected patient data with a subset of patients recruited to undergo extended follow-up, linkage with health administrative data, focus groups and surveys. The full study methods have been described elsewhere,[12] and are outlined briefly below. Here, we report the results of a *post hoc* analysis focussing on AF.

Study sample

This study involved all 28 New Zealand hospitals caring for patients with acute stroke and associated rehabilitation and community services. All adult patients admitted to hospital with a discharge diagnosis of stroke (ICD codes I61, I63, I64) between 1 May and 31 July 2018 were captured. After this date, consecutive patient recruitment continued until hospitals achieved a minimum sample size of 150 (in stroke clot retrieval centres), 100 (in other stroke centres) or until 31 October 2018, whichever occurred first. We grouped patients by self-identified ethnicity, based on Statistics New Zealand coding: New Zealand European, Māori, Pacific peoples, Asian and Other.[13]

Patients aged <18 years, and those with transient ischaemic attack (TIA) or subarachnoid haemorrhage, were excluded. For each patient, only the first admission during the study period was counted as an index event with subsequent admissions considered outcome events.

Data collection

Front-line clinical teams collected data at the time of hospital admission and during 3-month follow-up encounters and entered this into a central database. A central study team collected follow-up data at 6- and 12-months via telephone interviews, supplemented by mailed questionnaires. Baseline data included patient demographics, vascular risk factors and pre-morbid level of function, among others. For those patients identified as having a pre-stroke diagnosis of AF, anticoagulant use was recorded and where none was in use the reason for this was documented where possible. Patients prescribed but not actively taking anticoagulants at the time of presentation for reasons where this was not under the direction of a health professional were classed "not on anticoagulant" due to "patient preference".

Post-admission data included in-hospital interventions and services, investigations to determine stroke aetiology and therapies up to 3 months post-admission, follow-up appointments up to 12 months and outcome variables. Outcome variables for this *post hoc* analysis included anticoagulant prescription rate and ICH.

Data analysis

All data were analysed in Stata/IC 17.0. Patient baseline characteristics were summarised using proportions for dichotomous, means and standard deviations (SD) for continuous, and medians and interquartile ranges for non-normally distributed continuous variables. The main focus of this study was a descriptive analysis of AF patients compared with non-AF patients, anticoagulation prescribing and reasons for non-prescribing across the cohort. Sub-group analyses compared Māori with non-Māori and urban to non-urban patients. Pearson's Chi-squared and logistic regression was used for dichotomous variables and t-test for continuous variables.

Study funding and ethics

The Health Research Council of New Zealand (HRC 17/037) funded the REGIONS Care study. The study received ethics approval from the Central Region Health and Disability Ethics Committee (17CEN164).

Results

2,379 patients presented with stroke and met inclusion criteria during the study period. AF, diagnosed either pre- or post-stroke, was documented in 807/2,379 (34.3%) of patients; in 627/1,937 (32.4%) patients with ischaemic stroke and 67/285 (23.5%) with ICH. The mean (SD) age of patients with AF was higher than those without AF (79.9 [11] vs 72.5 [14.2] respectively, p<0.0001).

Compared with non-AF patients, those with AF were more likely to be of New Zealand European or Māori ethnicity, to present with anterior circulation ischaemic stroke of cardioembolic source, to experience anticoagulation-related intracerebral haemorrhage (ICH) or haemorrhagic transformation of an ischaemic stroke, to have prior stroke or ischaemic heart disease, to arrive sooner in the hospital and

to present with more severe stroke symptoms. See Table 1 for additional patient characteristics.

AF had been diagnosed prior to the stroke in 666/807 (82.5%) patients, of whom 66.4% (442/666) were not taking anticoagulants at the time of stroke. Patients with known AF but not anticoagulated pre-stroke were older, were less likely to have a diagnosis of diabetes or hypertension and were less likely to be independent than those treated with an anticoagulant. Patients diagnosed with AF at the time of stroke were younger, were less likely to have a prior stroke, TIA or ischaemic heart disease and were less likely to be living in residential care than those with known AF (Table 2).

Among those with a pre-stroke diagnosis of AF, the most commonly documented reason for not taking anticoagulants was "unknown" (66/205 [32.2%]). The most commonly known reasons for not taking an anticoagulant were prior bleeding ("ICH, GI bleed or other bleed") at 20.5% (42/205), followed by "patient preference" at 18.1% (37/205), "frailty, comorbidities, or side effects" at 13.2% (27/205), and "falls" at 6.8% (14/205). Procedure-related treatment interruption and AF duration deemed too insignificant accounted for about 3% each (Table 3).

A similar proportion of patients with known AF who were not anti-coagulated experienced ICH compared to those with known AF who were anticoagulated: 8.5% (19/224) and 8.1% (36/442), respectively. Adjusting for age and pre-stroke independence the odds of an ICH remained similar for those with AF on versus not on anticoagulation (aOR 0.99 [0.55–1.80]; p=0.99). The rate of ICH in patients diagnosed with AF only after the stroke also had a similar ICH rate (8.5% [12/141]) to those diagnosed and anticoagulated before the stroke, suggesting that the similar rates are not explained by prescriber patient selection (Table 3). Of the 292 people with ICH in the overall study cohort, only 3.1% (9/292) were documented as AF patients in whom anticoagulation was deemed the primary cause for the bleed (Table 1).

Differences between Māori and non-Māori people with AF

There was a trend towards a higher rate of AF in Māori presenting with stroke compared to non-Māori people (39.2% [107/273] vs 33.7% [700/2,079], respectively, p=0.07). The mean (SD) age of Māori was 68.7 (13.2) compared with 81.1 (10.1) for non-Māori; p <0.0001. More Māori were taking anticoagulants prior to stroke, but this fell short of statistical significance (75.0% [66/88] vs 65.0% [376/578)], p=0.06; aOR [age, pre-stroke independence 0.57 [0.17–1.9]; 0.35]). There were no significant differences in reasons for anti-coagulation non-prescribing between Māori and non-Māori (Table 3). ICH rates in Māori patients with AF (either anticoagulated or not) were generally lower (4.6–5.3%) than in non-Māori (8.7–9.0%) and this trend persisted when adjusting for age and pre-stroke independence (aOR for Māori on anticoagulant 0.62 [0.17–2.3]; p=0.49 and aOR for all Māori with AF 0.49 [0.19–1.31]]; p=0.16) compared with non-Māori).

Regional variations

There were no significant differences noted in prescribing patterns between urban and non-urban patient cohorts (Table 4). There were numerical differences between individual districts, but case volumes for some regions were very small and need to be interpreted with caution. The urban/non-urban data are mainly included to aid with local service improvement efforts rather than to support an inter-district comparison (Appendix Table).

Discussion

In this Aotearoa-wide cohort, we found several important differences between patients admitted with stroke who do and do not carry a diagnosis of AF. The described characteristics may aid clinicians in their search for AF in patients admitted with stroke of unclear aetiology. In those who are older, of Māori or European decent, with anterior circulation ischaemic strokes, prior stroke, non-smokers, history of ischaemic heart diseases, and more severe strokes in whom the underlying cause is not immediately clear, pursuit of prolonged cardiac monitoring and/or cardiac imaging may be especially warranted. AF was more likely to be diagnosed after stroke in younger, independent patients without the typical risk factors of prior stroke, TIA or ischaemic heart disease, and wider electrocardiography screening may need to be explored.

In this study, 66.4% of patients admitted with stroke and a previously known diagnosis of AF had been treated with anticoagulants. Compared to international data, New Zealanders fare well and there is evidence of significant improvement in anticoagulant prescription rates compared to the 2015 ARCOS IV study, which reported a rate of 26.5%.[7] While this is reassuring, there remains

Table 1: Patient baseline characteristics by atrial fibrillation status.

	All	AF*	Non-AF*	p†
Number, n(%)	2379	807 (34.8)	1,509 (65.2)	-
Age, mean (SD)	75 (13.7)	79.9 (11)	72.5 (14.2)	<0.0001
Sex, female, n (%)	1,160 (48.8)	392 (48.6)	733 (48.6)	1.0
Ethnicity, n (%)				
European	1823 (76.6)	638 (79.2)	1,144 (75.8)	
Māori	273 (11.5)	107 (13.3)	149 (9.9)	<0.0001
Pacific	114 (4.8)	7 (5.0)	86 (5.7)	
Asian	115 (4.8)	6 (4.3)	90 (6.0)	
Other	54 (2.3)	12 (1.5)	40 (2.7)	
Primary diagnosis, n (%)				
Ischaemic stroke	1,937 (81.5)	696 (86.3)	1,191 (78.9)	
Haemorrhagic stroke	292 (12.3)	67 (8.3)	218 (14.5)	<0.0001
Stroke not specified	116 (4.9)	35 (4.3)	77 (5.1)	
Other/unknown	32 (1.4)	6 (1.1)	23 (1.5)	
Ischaemic stroke location, n (%)				
Anterior circulation	1,276 (68.8)	521(74.9)	763 (65.7)	<0.0001
Posterior circulation	459 (24.7)	144 (20.1)	311 (26.8)	
Other/unknown	120 (9.5)	31 (4.5)	88 (7.6)	
Ischaemic stroke cause, n (%)				
Cardioembolic—AF	627 (32.4)	575 (80.8)	68 (5.6)	
Cardioembolic—non-AF	277 (14.3)	2 (0.3)	27 (2.2)	
Carotid stenosis	96 (5)	11 (1.5)	68 (5.6)	
Vertebrobasilar stenosis	25 (1.3)	4 (0.6)	21 (1.7)	<0.0001
Small vessel	33 (1.7)	21 (3.0)	254 (20.8)	
Intracranial stenosis	30 (1.6)	6 (0.8)	26 (2.1)	
Dissection	9 (0.5)	1 (0.1)	8 (0.7)	
Other/unknown	838 (43.3)	92 (12.9)	732 (60.1)	
Haemorrhagic stroke location, n (%)				
Lobar	136 (49.1)	33 (54.1)	100 (47.4)	0.8
Deep	114 (14.2)	23 (37.7)	89 (42.2)	
Other/unknown	27 (9.7)	5 (8.2)	22 (10.4)	

Table 1 (continued): Patient baseline characteristics by atrial fibrillation status.

	All	AF	Non-AF	p
Haemorrhagic stroke cause, n (%)				
Hypertensive	147 (53.3)	23 (36.5)	119 (57.5)	
Anticoagulation	13 (4.7)	9 (14.3)	4 (1.9)	
Haemorrhagic transformation	36 (13)	17 (27.0)	19 (9.2)	<0.001
Amyloid Angiopathy	15 (5.4)	3 (4.8)	8 (3.7)	
Underlying SOL/AVM/aneurysm	6 (2.2)	0 (0)	6 (2.9)	
Other	10 (3.7)	10 (15.9)	40 (19.3)	
Unknown	49 (17.8)	3 (4.8)	6 (2.9)	
Risk factors, n (%)				
Prior stroke	515 (21.9)	211 (26.1)	287 (19.0)	0.0001
Prior TIA	303 (12.9)	104 (12.9)	192 (12.7)	0.89
Carotid stenosis	180 (7.8)	56 (6.9)	119 (7.9)	0.39
Hypertension	1,695 (71.7)	596 (73.9)	1,057 (70)	0.048
Diabetes	571 (24.2)	175 (21.7)	379 (25.1)	0.07
Dyslipidaemia	998 (42.6)	310 (38.4)	661 (43.8)	0.01
Atrial fibrillation	807 (34.3)	807 (100)	0 (0)	-
Smoker	287 (12.2)	52 (6.4)	227 (15)	<0.0001
Ischaemic heart disease	575 (24.5)	270 (33.5)	295 (19.5)	<0.0001
Rheumatic heart disease	40 (1.7)	23 (2.9)	17 (1.1)	0.056
Family history of stroke	161 (6.9)	41 (5.1)	116 (7.7)	0.018
Pre-stroke situation, n (%)				
Pre-stroke independent (mRS<3)	2,040 (86.7)	678 (83.8)	1,322 (87.6)	
Employed	465 (19.7)	82 (10.2)	374 (25)	0.01
Living situation	681 (28.7)	274 (34)	392 (26)	<0.0001
Home alone	1,491 (62.8)	448 (55.5)	1,003 (66.5)	<0.0001
Home with others	178 (7.5)	78 (9.7)	96 (6.4)	
Residential care	26 (1.1)	7 (0.9)	18 (1.2)	
Other				
ED arrival <4 hours n (%)	1,020 (43.8)	376 (47.5)	615 (41.6)	0.007
ED arrival <24 hours n (%)	1,784 (76.8)	626 (79.4)	1,111 (75.5)	0.03
Level of disability on arrival n (%)				
GCS verbal <5	858 (36.1)	368 (45.7)	465 (30.8)	<0.0001
Requires assistance to walk	1,332 (56.2)	508 (63.2)	787 (52.2)	<0.0001
Upper limbs MRC <3/5	871 (36.7)	342 (42.5)	506 (33.6)	<0.0001

*64 missing values for AF status.
†Compares patients with versus without AF diagnosed at any time—either pre- or post-stroke SOL = space-occupying lesion; AVM = arteriovenous malformation; for other abbreviations see Table 2.

Table 2: Patient baseline characteristics by timing of atrial fibrillation diagnosis and anticoagulant treatment.

	Known AF before stroke			**New AF diagnosis at time of stroke**	
Number, n/N (%)	**666/807 (82.5)**			**141/807 (17.5)**	
	Known AF on anticoagulant	**Known AF not on anticoagulant**	**p***		**p†**
	442/666 (66.3)	**224/666 (33.6)**			
Age, mean (SD)	79.4 (11.1)	82.6 (10.4)	<0.0001	77 (10.8)	<0.0001
Sex, male, n (%)	206 (46.6)	116 (51.8)	0.20	70 (49.7)	0.27
Urban, n (%)	191 (43.2)	87 (38.8)	0.28	51 (36.2)	0.22
Ethnicity, n (%)					
European	350 (79.2)	182 (81.3)	0.09	106 (75.2)	0.49
Māori	66 (14.9)	22 (9.8)		19 (13.5)	
Pacific	14 (3.2)	7 (3.1)		7 (5.0)	
Asian	9 (2.0)	7 (3.1)		6 (4.3)	
Other	3 (0.7)	6 (2.7)		3 (2.8)	
Primary diagnosis, n (%)					
Ischaemic stroke	373 (84.4)	199 (88.8)	0.12	124 (87.9)	0.51
Haemorrhagic stroke	36 (8.1)	19 (8.5)		12 (8.5)	
Other/unknown	33 (7.5)	6 (2.7)		5 (3.6)	
Risk factors, n (%)					
Prior stroke or TIA	179 (45.0)	88 (39.3)	0.17	28 (19.9)	<0.001
Hypertension	337 (76.2)	154 (68.8)	0.041	105 (74.5)	0.84
Diabetes	112 (25.3)	34 (15.2)	0.003	29 (20.6)	0.73
Dyslipidaemia	177 (40.0)	74 (33.0)	0.08	59 (41.8)	0.36
Current smoker	28 (6.3)	9 (4.0)	0.22	15 (10.6)	0.03
Ischaemic heart disease	170 (38.5)	70 (31.3)	0.07	30 (21.3)	<0.001
Rheumatic heart disease	18 (4.1)	3 (1.3)	0.05	2 (1.4)	0.27

Table 2 (continued): Patient baseline characteristics by timing of atrial fibrillation diagnosis and anticoagulant treatment.

Pre-stroke situation, n (%)					
Independent (mRS<3)	381 (86.2)	162 (72.3)	<0.0001	125 (88.6)	0.04
Employed	50 (11.3)	15 (6.7)	0.06	17 (12.2)	0.39
Living situation	142 (32.1)	80 (35.7)	0.09	52 (34)	0.02
Home alone	257 (58.1)	109 (48.7)		82 (58.2)	
Home with others	41 (9.2)	33 (14.7)		4 (2.8)	
Residential care	2 (0.5)	2 (0.9)		3 (2.1)	
Other					
Level of disability on arrival n (%)					
GCS verbal <5	187 (42.4)	110 (49.3)	0.34	368 (47.7)	0.55
Requires assistance to walk	274 (62.3)	142 (63.7)	0.72	92 (63.2)	0.88
Upper limbs MRC <3/5	186 (42.2)	92 (41.3)	0.82	64 (45.4)	0.42

*Compares patients diagnosed with AF pre-stroke on anticoagulant versus not on anticoagulant.
†Compares all patients diagnosed with AF pre-stroke to those newly diagnosed at time of stroke.
TIA = transient ischaemic attack; mRS = modified Rankin score (0–6); GCS = Glasgow coma scale (0–15); MRC = Medical Research Council motor strength scale (0–5).

Table 3: Oral anticoagulation in stroke patients with atrial fibrillation for all patients and for Māori and by non-urban hospitals.

	All	Māori	Non-Māori	P-value	Urban	Non-Urban	P-value
Overall AF prevalence*	807/2,352 (34.9)	107/273 (39.2)	700/2,079 (33.7)	0.07	478/1,420 (33.7)	329/932 (35.3)	0.42
Known AF on anticoagulant	442/666 (66.3)	66/88 (75.0)	376/578 (65.0)	0.06	251/388 (64.7)	191/278 (68.7)	0.28
New AF diagnosis at time of stroke (not on anticoagulant at time of stroke)	141/807 (17.5)	19/107 (17.8)	122/700 (17.4)	0.92	90/478 (18.8)	51/329 (15.5)	0.23
Known AF but not on anticoagulant	224/666 (33.6)	22/88 (25.0)	202/578 (34.9)	0.07	137/388 (35.3)	87/278 (31.3)	0.28
Reason for no anticoagulation							
Falls	14/205 (6.8)	2/20 (10)	12/185 (6.5)	0.56	9/123 (7.3)	5/82 (6.1)	0.74
ICH, GI bleed, other bleed	42/205 (20.5)	3/20 (15)	39/185 (21.1)	0.52	26/123 (21.1)	16/82 (19.5)	0.78
Frailty, comorbidities, side effects	27/205 (13.2)	1/20 (5)	26/185 (14.1)	0.25	12/123 (9.8)	15/82 (18.3)	0.79
Pre-/peri-procedure	7/205 (3.4)	1/20 (5)	6/185 (3.2)	0.67	6/123 (4.9)	1/82 (1.2)	0.15
Patient preference/non-compliant	37/205 (18.1)	5/20 (25)	32/185 (17.3)	0.40	22/123 (17.0)	15/82 (18.3)	0.81
Stopped for procedure and never restarted	7/205 (3.4)	1/20 (5)	6/185 (3.2)	0.67	3/123 (2.4)	4/82 (4.9)	0.33
AF duration felt not significant	5/205 (2.4)	0/20 (0)	5/185 (2.7)	0.46	4/123 (3.3)	1/82 (1.2)	0.34
Unknown	66/205 (32.2)	7/20 (35)	59/185 (31.9)	0.78	41/123 (33.3)	25/82 (20.5)	0.05

Data are number of patients (% of group)
*Missing values/unknown: n=63
#Missing values=19

room for improvement as several of the stated reasons for non-prescription are potentially inappropriate. While prior bleeding—the most commonly documented reason for non-prescription—may be an appropriate rationale for withholding medication, it often is appropriate to restart an anticoagulant post bleeding, and specialist determination of the risks and benefits of anticoagulation should be sought. Frailty and falls are debated contraindications for anticoagulation. Concerns around frailty are not unique, with a study from Singapore identifying "fall risk" as the most common reason (38.3%) for the non-prescription of anticoagulants.[10] However, it has been reported that a patient has to fall 295 times a year before the risks of anticoagulants outweigh their benefits.[11] Failure to reinitiate anticoagulation after a procedure is inappropriate and should be addressed. The large number of undocumented reasons for withholding anticoagulation also suggests the need for further patient education and/or practitioner prioritisation. Where there is clinician uncertainty around prescribing anticoagulants, specialist input should be available. One option is to take advantage of online tools such as the recently launched BPAC AF decision support tool.[12]

Our ethnic comparison identified that Māori compared to non-Māori AF patients with stroke are younger, a finding previously reported.[8] The reasons for this are unclear but may relate to different risk factors including diabetes, rheumatic and other heart disease, and sleep apnoea.[8,13] The lower mean age of AF diagnosis in Indigenous peoples is also a trend seen in other countries. Australian Aboriginal and Torres Strait Islander patients with diagnosed AF were younger than non-Indigenous Australians aged 54.8 vs 69.3 years.[14] There is a similar pattern among Indigenous peoples of Canada, who have a mean age of stroke of under 65 years.[15] The finding that Māori presenting with stroke had a similar rate of undiagnosed AF and a trend towards a higher rate of anticoagulation stands in contrast to prior work,[8] and suggests recent improvements in care and health equity. Of further reassurance is that we did not find a significant difference in anticoagulant prescribing rates between urban and non-urban treatment settings. However, some variation by hospital was observed and further follow-up by individual stroke services is encouraged.

One finding that is noteworthy is the 20% "patient preference" in favour of non-anticoagulation, and this reason was numerically more common among Māori patients. This is not unique to New Zealand. In a cohort from the United States, "patient/family declined" (22%)[16] anticoagulation, with similar findings in other studies.[17,18] The decision for a patient to decline anticoagulation suggests ongoing concern about side effects, including bleeding complications. Health practitioners play a very important role and if they are apprehensive or do not feel confident about risks and benefits, specialist involvement in this conversation may be beneficial.

Our finding of similar ICH rates in anticoagulated and non-anticoagulated patients, diagnosed either pre- or post-stroke, should offer reassurance to both patients and prescribers around anticoagulation safety, especially with novel direct anticoagulants that carry a substantively similar bleeding risk to antiplatelets.[19] There may be additional barriers to accepting anticoagulation treatment in disadvantaged populations who may be distrustful or apprehensive based on prior or even recent experiences with health providers. Health providers may also be ill equipped to conduct effective conversations with patients of different cultural backgrounds and unconscious bias may play a role. Extra work may be required to address this potential treatment gap.

This study has several strengths and limitations. Strengths include the overall large sample size, the nation-wide dataset with complete hospitalised case ascertainment and high data quality. Additionally, our study reports multiple factors including general anticoagulation rates, prescribing patterns and differences by ethnicity and geography. Limitations include the *post hoc* design, observational nature and smaller sample size of those with AF in ethnic sub-groups, precluding any analysis beyond Māori and NZ Europeans. Even for Māori, the sample size may be too small to conclusively exclude potentially important differences. Therefore, the ethnicity data should be interpreted with caution. In addition, we did not have data on congestive heart failure and thus could not calculate relevant AF stroke risk scores, nor did we have information on type of direct oral anticoagulant or time in the therapeutic range.

In summary, patient characteristics of those presenting with stroke with or without underlying AF differ and can help guide post-stroke work-up. Anticoagulation rates in the setting of AF, while improved, still fall short of what should

be achievable, and we report several reasons that may not justify withholding this highly effective therapy. The low risk of ICH in the setting of modern anticoagulants is further emphasised by our finding of numerically lower rates of ICH in AF patients on anticoagulation compared to those without. Future work should focus on individual service audits to identify local treatment gaps, patient and practitioner focus groups to identify concerns and barriers and further studies exploring how justified non-prescribing is in each case. Finally, where prescribers experience uncertainty they should consult specialists, available guidelines or electronic decision support.

COMPETING INTERESTS
Authors have nothing to disclose.

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Appendix

Appendix Table 1: Atrial fibrillation (AF) and oral anticoagulant use (OAC) by district.

DHB of domicile	No AF	Known AF on OAC	Known AF not on OAC	AF Dx post-stroke	Unknown	Total	% AF	% known AF not on OAC/all stroke	% known AF not on OAC/known AF
Northland	58	12	15	12	0	97	40%	15%	56%
Waitematā	157	27	22	14	0	220	29%	10%	45%
Auckland	77	21	5	2	0	105	27%	5%	19%
Counties Manukau	117	53	8	10	1	189	38%	4%	13%
Waikato	117	42	13	8	9	189	38%	7%	24%
Lakes	62	16	11	9	5	103	40%	11%	41%
Bay of Plenty	108	37	20	13	0	178	39%	11%	35%
Tairāwhiti	18	12	0	3	2	35	49%	0%	0%
Taranaki	57	17	18	4	1	97	41%	19%	51%
Hawke's Bay	57	33	3	2	0	95	40%	3%	8%
MidCentral	67	16	7	5	8	103	35%	7%	50%
Whanganui	50	7	7	4	2	70	29%	10%	30%
Capital and Coast	93	17	13	18	1	142	35%	9%	43%
Hutt	71	7	11	3	0	92	23%	12%	52%
Wairarapa	27	14	1	0	1	43	37%	2%	7%
Nelson Marlborough	35	10	7	0	0	52	33%	13%	41%
West Coast	15	5	4	1	2	27	44%	15%	44%

Appendix Table 1 (continued): Atrial fibrillation (AF) and oral anticoagulant use (OAC) by district.

Canterbury	162	52	39	22	3	278	42%	14%	43%
South Canterbury	25	11	3	2	0	41	39%	7%	21%
Southern	124	33	16	8	1	182	32%	9%	33%
Overseas	12	0	1	1	0	14	14%	7%	50%
Total	1,509	442	224	141	36	2,352	36%	10%	27%

Implementing and assessing the acceptability of a portable, readily accessible, and actionable end of life planning tool for patients with advanced serious illness or frailty in southern New Zealand

Laura Mulligan, Amanda Charity Sommerfeldt

ABSTRACT

The Clinical Order Articulating Scope of Treatment (COAST) form was designed as a single-page medical order documenting and communicating the resuscitation status and scope of appropriate medical treatment for adult patients believed to be in their final year of life. Prior to introducing COAST, each health provider or agency in the Southland Region of New Zealand had its own forms and processes; the COAST pilot attempted to consolidate and streamline these varied processes into one actionable medical order that is valid throughout the region. This three-phase initiative involved piloting use of the COAST form in Southland between May 2019 and January 2020. Surveys were given to patients at the time of COAST form completion and distributed electronically to health professionals at the end of each phase to assess attitudes towards COAST form use and obtain feedback. The hypothesis was that COAST would be acceptable to patients, families, and health providers. The response rates for patient and health professional COAST experience surveys were low (24% and 27% respectively) but the feedback was positive, with the majority of respondents expressing that the COAST form improved patient care. Implementation of the COAST form has been widely accepted by patients, families, and health professionals alike.

Advance care planning is an individualised process of discussion and shared decision making for future healthcare.[1] An Australian study from 2010[2] found that elderly hospital inpatients with an advance care plan (ACP) were more likely to have their end of life wishes known by their doctor and had higher levels of patient and family satisfaction than those without an ACP. Potential barriers to ACP completion that were identified included availability of staff, confidence to discuss advance care planning with patients, and ensuring that doctors understood and supported advance care planning. Generating and implementing ACPs with patients and their whānau is a competency of both general practice training and physician specialty training in New Zealand.

Generally accepted best practice is to discuss and document end of life treatment preferences well in advance of the need for treatment, primarily due to concerns that patients may be unable to participate in such planning or communicate their wishes when the time comes. Toolkits such as the Aotearoa Serious Illness Conversation Guide[3] can be used to guide these discussions. As advance care planning is typically done prior to the diagnosis of a serious, life-limiting illness or significant infirmity, there may be a gap of weeks, months, or years between when an ACP discussion occurs and when the plan is actually implemented. Unfortunately, the scenarios anticipated when an ACP is prepared may look very different from the clinical picture that eventuates. Conversely, waiting too long to engage in advance care planning can result in late hospice referral and unhelpful or unwanted transitions between healthcare settings in the final weeks or months of life. In 2013, Teno and colleagues[4] reported that transitions during the last 90 days of life for patients with cancer, chronic obstructive pulmonary disease, and dementia in the United States increased from an average of 2.1 per decedent in the year 2000, to 3.1 in 2009, despite increased use of hospice support and considerable promotion of advance

care planning. As patients with advanced dementia lack the capacity to complete and sign an ACP document, this vulnerable population is at even greater risk of experiencing unwanted, unhelpful and/or potentially burdensome treatments and transitions at end of life.

In March 2011, the Goals of Care (GOC) clinical framework was introduced at Royal Hobart Hospital in Tasmania as part of a Healthy Dying Initiative. The GOC form stratifies patient care into one of three possible phases: curative/restorative, palliative, or terminal. The GOC plan is formulated with the patient or surrogate decision-maker. The form itself is signed only by the clinician, as the developers intended it to be a clinical directive as a culmination of ongoing medical assessment and communication, rather than a patient directive along the lines of ACP. A retrospective audit of admissions to the hospital's assessment and planning unit found that Not for Resuscitation forms were completed for only 34% of admitted patients in August 2009 (prior to the initiative), whereas GOC forms were completed for 75% of admitted patients in August 2011.[5] The initiative was associated with improved hospital recognition of the dying process and was found to be safe, effective, and widely acceptable, with no associated reportable incidents or complaints.

In New Zealand, there are a variety of ACP documents and forms being used, and there is no consistent, portable document that is recognised and honoured across all care settings. For example, a patient and their general practitioner may complete an ACP and "Do Not Resuscitate" order at an aged residential care facility, but that signed order would not be recognised if the patient is subsequently transferred to an acute care hospital. Each aged residential care facility, hospital, and hospice provider has its own advance care planning and ceiling of treatment order process. Patients/families are often asked to clarify and document treatment preferences with each transition; this has the potential to negatively impact perceptions of healthcare quality and coordination.

In 2018, Nelson Marlborough Health piloted use of a 2-page document titled Options for Treatment and Resuscitation, or OtTER.[6] Use of this tiered resuscitation form resulted in improved documentation and visibility of goals of treatment decisions compared to the existing Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form. Canterbury District Health Board have also developed a 2-page DNACPR order that incorporates free-text fields to document any additional diagnostic and treatment preferences, the rationale for the DNACPR decision, and details of the pertinent discussions that have occurred. Both initiatives are used in the acute hospital setting but have not been widely incorporated into the outpatient or aged residential care setting. To our knowledge, no similar initiatives exist in the North Island.

This pilot initiative involved the development and implementation of a one-page medical order used to provide appropriate and goal-directed care for adult Southern District Health Board (SDHB) patients with serious medical illnesses or frailty and an expected prognosis of 1 year or less. The document is titled Huarahi Rangimārie, a Māori term which translates to "peaceful path" and is a Clinical Order Articulating Scope of Treatment (which became known as a "COAST form"). The intervention was not designed to influence discussions around ACP, but rather to consolidate multiple forms and processes into a one-page universally accepted medical order.

The aim of the study was to assess the acceptability of the document to healthcare professionals involved in its use, as well as patients and/or proxy decision makers. Ethical approval for this project was obtained from the New Zealand Health and Disability Ethics Committee (Reference 19/STH/44).

Methodology

COAST form development

The pilot COAST form (Appendix 1) was developed over a 4-month period by the investigators, and the layout was revised following an initial stakeholder's meeting at Hospice Southland, which introduced the proposed COAST form and process to local health providers and solicited feedback. A logo was then created and added to the form alongside the Southern DHB and Hospice Southland logos. Pre-COAST data questionnaires were distributed to gauge the current practice around ACP (Appendix 2).

Education

Education regarding the rationale for the study and the introduction of the COAST form was then delivered to local healthcare providers by presenting at Hospital Grand Rounds, holding evening education sessions at Hospice Southland, conducting on-site health provider education sessions, delivering written information, and also producing an educational video which was

available on the COAST website (www.COAST-form.net).

Eligibility

All adults >18 years were eligible to be included if they were deemed to be in the final year of life due to advanced, progressive illness and/or frailty as identified by a doctor or nurse practitioner for whom the clinician answers "**no**" to the surprise question: "*would you be surprised if this patient died in the next 12 months?*" Patients were excluded if they were under the age of 18 years, or they did not consent to involvement in the study.

Health professionals who completed at least one COAST form were invited to complete an online survey at the end of each phase.

Recruitment

Patients were recruited in three phases, each lasting three months, to allow staggered education sessions for health professionals in each area, and to allow the study coordinator to manage the data in a timely manner. Figure 1 demonstrates the geographical roll out of the pilot project.

Written information regarding the COAST form and process was provided to patients identified as eligible to participate, and written consent was obtained from patients who agreed to participate. Patients who were unable to provide written consent were included if it was deemed by their health provider to be in their best interest, and with permission from the proxy decision maker.

Implementation

Phase one invited all eligible Southland Hospital inpatients, patients referred to the Southland Hospital Palliative Care Advisory Service, and patients admitted to the Hospice Southland programme to engage in the COAST process. Forms were completed by both hospice and hospital medical staff.

Phase two invited all eligible residents in aged residential care in the Invercargill area to participate, with general practitioners being invited to complete forms, and phase three incorporated all eligible residents within the Southland Region in hospice, hospital, general practice, and community settings.

The project was overseen by a volunteer COAST Steering Committee consisting of a nurse practitioner working in aged residential care, a rest home clinical manager, two local GPs, the Māori chaplain working at Southland Hospital, and two hospice patients. This steering group was formed to guide COAST study implementation, provide stakeholder perspectives, and champion the project. Members were active in troubleshooting and offering suggestions throughout the study period. Meetings were convened by the study investigators and nurse study coordinator, and the committee met on 17 April 2019 (prior to the study commencing) and then at the end of each of the three study phases.

Data collection

Patients and/or proxies were given a survey to complete following completion of the COAST process (Appendix 3), along with a postage-prepaid return envelope. An electronic survey was distributed at the end of each implementation phase to address the aim of elucidating health provider satisfaction with the COAST form and process, and any enablers or barriers to COAST form completion (Appendix 4). Surveys generated primarily descriptive data.

Completed feedback forms were received by the study coordinator at Hospice Southland; data were uploaded to a spreadsheet and held securely.

Results

One hundred and eighty-three patients consented to be involved in the study, with 207 COAST forms completed. COAST forms were updated to reflect new treatment goals in 21 patients.

Pre-COAST survey

Twenty-two responses were received for the pre-COAST survey, which was distributed after the stakeholders' meeting. Responses were received from 10 GPs (45%), two other doctors (9%), two nurses (9%), two identified as "other" (9%), and six respondents left this section blank.

Nineteen out of 22 had experience with advance care planning (86%):

> *"I attended the 2-day ACP course but have had difficulty implementing."*

> *"Very time consuming, means often not done."*

Twenty-one out of 22 respondents (95%) viewed a Not for Resuscitation form as being different from an ACP.

All respondents thought the introduction of the COAST form would be beneficial to them:

"One page form which is easier to use. More effective and clear for planning of care."

"Great, single page, simple."

Three respondents suggested incorporating an area for optional patient signature on the COAST form.

The main barriers identified to COAST form implementation were time needed to discuss the options and complete the form, and IT issues such as differing systems between establishments.

Patient survey

Questionnaires were completed and returned by 37 patients or family members—a response rate of 20%. The majority of respondents were patients (27, 73%), with 27% (6) of surveys completed by the activated Enduring Power of Attorney (EPOA), 8% by a family member, and one did not specify a relationship (3%).

Ninety-two percent were familiar with the idea of Advance Care Planning, and 25 out of 37 respondents had completed an ACP. Thirty-five (95%) respondents had spoken with someone they trust (e.g., friend, family member, EPOA), and 27 (73%) had spoken to their doctor about what treatments they would or wouldn't want if they were seriously ill or dying. Thirty-two (86%) of respondents were familiar with the COAST form.

Figure 1 demonstrates the responses to the free-text comments about the purpose of the COAST form represented as a word cloud.

Seventy percent of respondents (26) had completed a COAST form for themselves and seven (19%) had been involved in COAST completion for someone else. Seventy-eight percent thought the COAST form was explained well. Thirty-five percent of respondents felt having a COAST form had made no difference to their/the person's healthcare, 22% felt it had made the care somewhat better and 27% felt that it made the care a lot better.

Sixteen respondents stated that they had no concerns about the form or process. Free-text comments included:

"I want everybody to listen to me and know what I want. I'm afraid that some nurses may not follow the COAST form information."

"More people throughout New Zealand need to know about COAST. It should be mandatory for all adults."

Seven respondents stated in the free-text comments that they were supportive of the project, with one respondent writing "*I believe it is a valuable document that everyone should have*" and another stating:

"I'm in agreement with COAST because it is my choice and I want to make my opinion clear. I understand my healthcare will not be compromised. It is a good idea which gives peace of mind to me and those I love."

Practitioner survey

There were 14 survey respondents by the conclusion of the pilot. Fifty-four practitioners completed COAST forms; two of these were study investigators, so were excluded from the survey. The response rate was 27%. The majority of respondents (seven) worked in General Practice; six respondents worked at Southland Hospital and one at Hospice Southland.

The word cloud in Figure 2 depicts what health professionals knew about the COAST form and process.

Fifty percent of respondents had completed between one and three COAST forms, with 21% completing between four and nine forms, and 29% completing more than ten forms. All 14 respondents felt they had adequate education and training about the COAST form and process.

What practitioners thought worked well about the COAST form and process:

"One form, good summary, easy to use."

"It is a good trigger to have these discussions."

"Concise, clear and easy to access."

"Clear form and shared across GP/Hospital and Hospice."

"It sets clearer expectations when patients arrive to the ED with acute

illnesses. It also gives patients/whānau a framework for dealing with end of life discussions and ceilings of care. The patients I've had who have had a COAST completed had an understanding of supportive care, dying with dignity and aggressive medical intervention."

Thirteen out of 14 respondents either "somewhat agreed" or "completely agreed" that the COAST form improved the care provided to their patients, as shown in Figure 3.

Respondents identified the following barriers to COAST form completion:

"Taking time to have the conversation."

"GP consults too short to do it justice."

"Lack of awareness among health professionals and patients."

"Uncertainty of patient prognosis."

All respondents were "somewhat comfortable" or "very comfortable" completing the COAST form. All respondents were "somewhat comfortable" or "very comfortable" following COAST form orders if they did not complete the form themselves.

Feedback on how the COAST form could be improved:

"Make it online."

"Clarity on how it gets disseminated to GP/ambulance/ED/hospital records."

"Clarify what selective treatments a person agrees to; clarify if oxygen etc. is part of comfort care."

Other free-text comments were positive about the introduction of COAST forms:

"Been very positive experience using COAST forms—generally process is liked by patients and families."

"I think it's a great initiative and has certainly benefited the patients I've interacted with."

"It is an organised way of having a hard conversation."

"I agree with keeping to one page; make it electronic immediately available on HealthOne and accessible to St Johns."

Discussion

This study was designed to assess the impact of introducing a new, transferable, actionable anticipatory care plan across all healthcare settings in the Southland Region of New Zealand. To our knowledge, no other studies have assessed the impact of such a document in New Zealand. Results indicated that the COAST form is acceptable to health professionals, patients, and families, compared with usual standard practice. The project rapidly became well integrated in clinical practice, in part due to it being a ground-up initiative developed by clinicians who work regularly with seriously ill and dying patients in multiple settings, and with input from others who work with this population. Education of junior doctors and other staff about the importance of having discussions to explore patient wishes and treatment goals, and providing care that is medically appropriate and goal-directed, has been crucial in embedding the COAST process. Quantitative data collection showed that the implementation of COAST forms correlated with reduced hospital admissions and emergency department presentations; those findings are outside the scope of this paper but have been published elsewhere.[7]

The initial stakeholders' meeting demonstrated widespread support within the local area, and following the pilot, every rest home and hospital in Southland continue to support and honour COAST forms within their setting. The success of the initiative is further demonstrated by the fact that at the end of the pilot, ambulance crews and staff within the emergency department continued to support the initiative and proactively asked patients if they had a COAST form.

A limitation of the study is that the response rates for patient and health professional surveys were low, at 20% and 27% respectively. This is a challenge that is well described in the literature, and our response rates are comparative with response rates of other palliative care studies.[8,9] The low patient survey response rate could be explained by the significant number of deaths in the participant group during the study period. The survey comments that were received were generally positive and supportive of the initiative.

The COAST form was updated in response

Figure 1: Keywords in patient free-text responses to COAST survey.

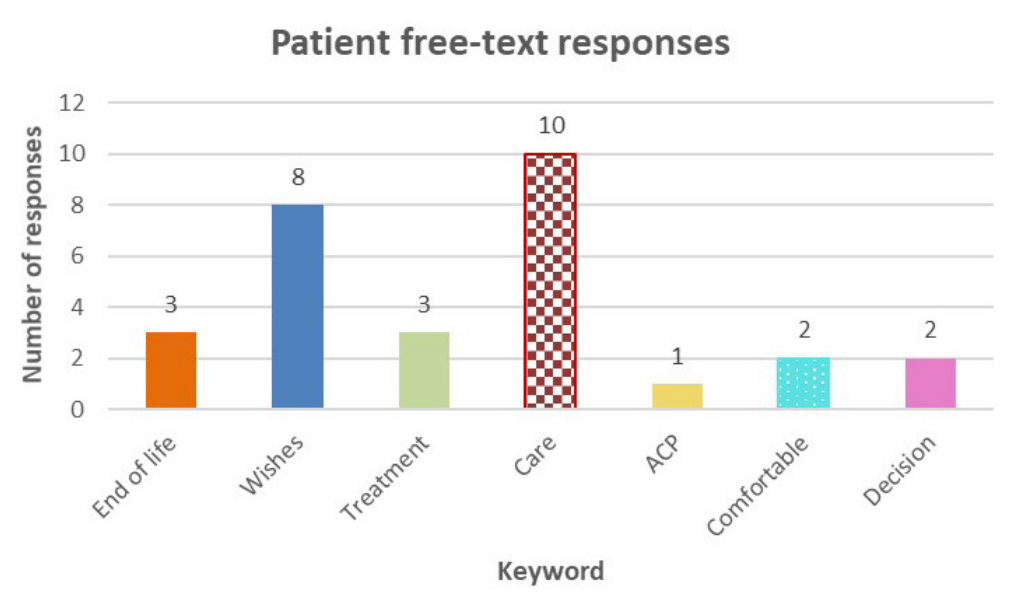


Figure 2: Practitioner free-text comments to COAST survey.

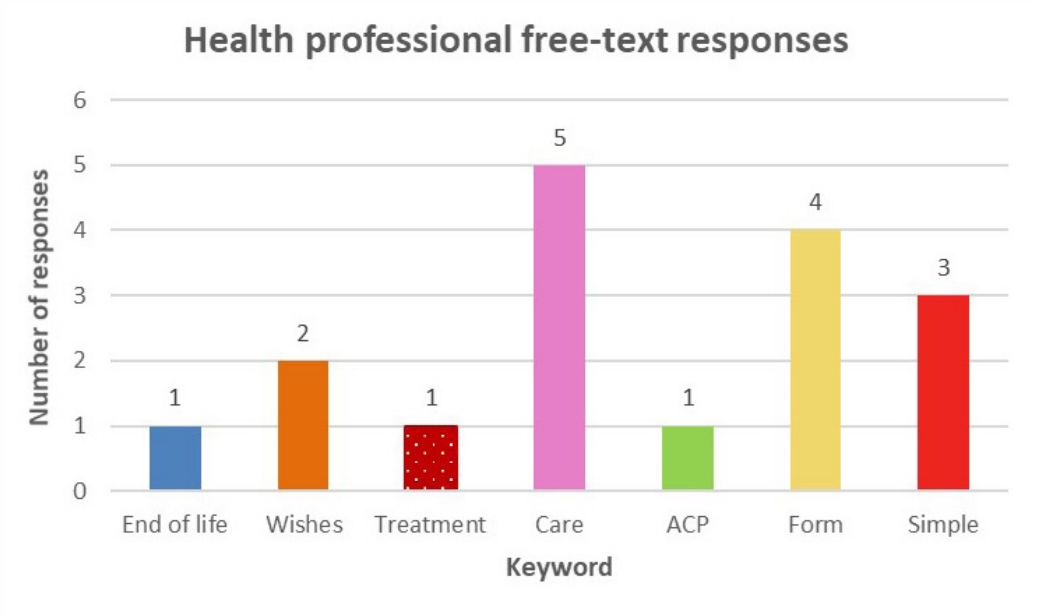
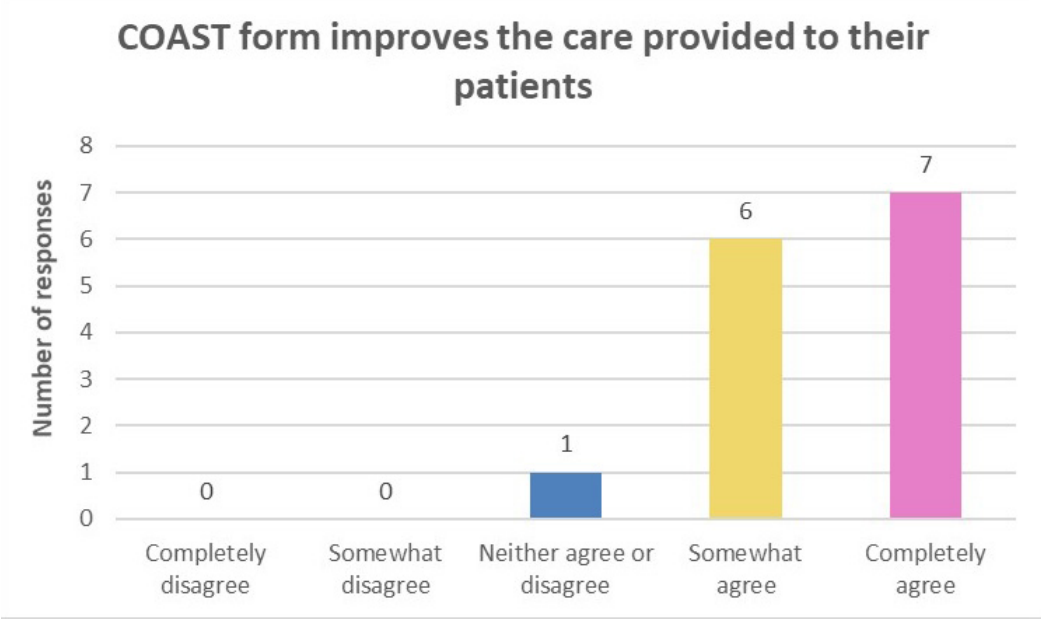


Figure 3: Perceived improvement in patient care.



to valuable feedback obtained at the initial stakeholders' meeting, feedback from the COAST Steering Committee, and survey comments. As the COAST form and process has been so well-received in the region, our hope is that an electronic COAST form—or a straightforward, universally-accepted document similar to COAST—can be developed at the regional or national level. IT and graphic design expertise would be beneficial, as such support could enhance the visual appeal of the form and allow it to be electronically completed, saved, reviewed, updated, printed, and disseminated to involved parties including rest homes, primary care, partner health agencies, ambulance personnel, and patients.

There was a further survey comment suggesting that the patient should sign the COAST form. This idea was discussed and debated extensively in the study design period, with the conclusion that as the COAST form is a medical order, a patient signature is not appropriate. The clinician who completes the COAST form is required to record the date of the relevant discussion with the patient or surrogate decision maker, and the original form stays with the patient. COAST education for patients and providers was clear that COAST forms were only to be completed with the approval of the patient or surrogate and only after the appropriate discussion took place. Patients or surrogate decision makers have the right to revoke a COAST form at any time. For the purposes of this study, patients did have to sign a consent form to be recruited.

Advance care planning has been associated with higher levels of patient and family satisfaction,[2] so it may be useful to assess whether having a COAST form has any psychological impact for patients; there may be benefits to patients having healthcare teams aware of their wishes and ceiling of treatment without the need for repeated discussions and multiple forms. This could be assessed using a validated quality of life tool, such as the EORTC QLQ-C30.[10]

Conclusion

Implementation of the COAST form has been widely accepted by patients, families, and health professionals alike. Health professionals within the Southland DHB continue to strongly support the project, with over 1,000 COAST forms completed to date. Our hope is that the project could be rolled out on a national basis.

COMPETING INTERESTS
Nil.

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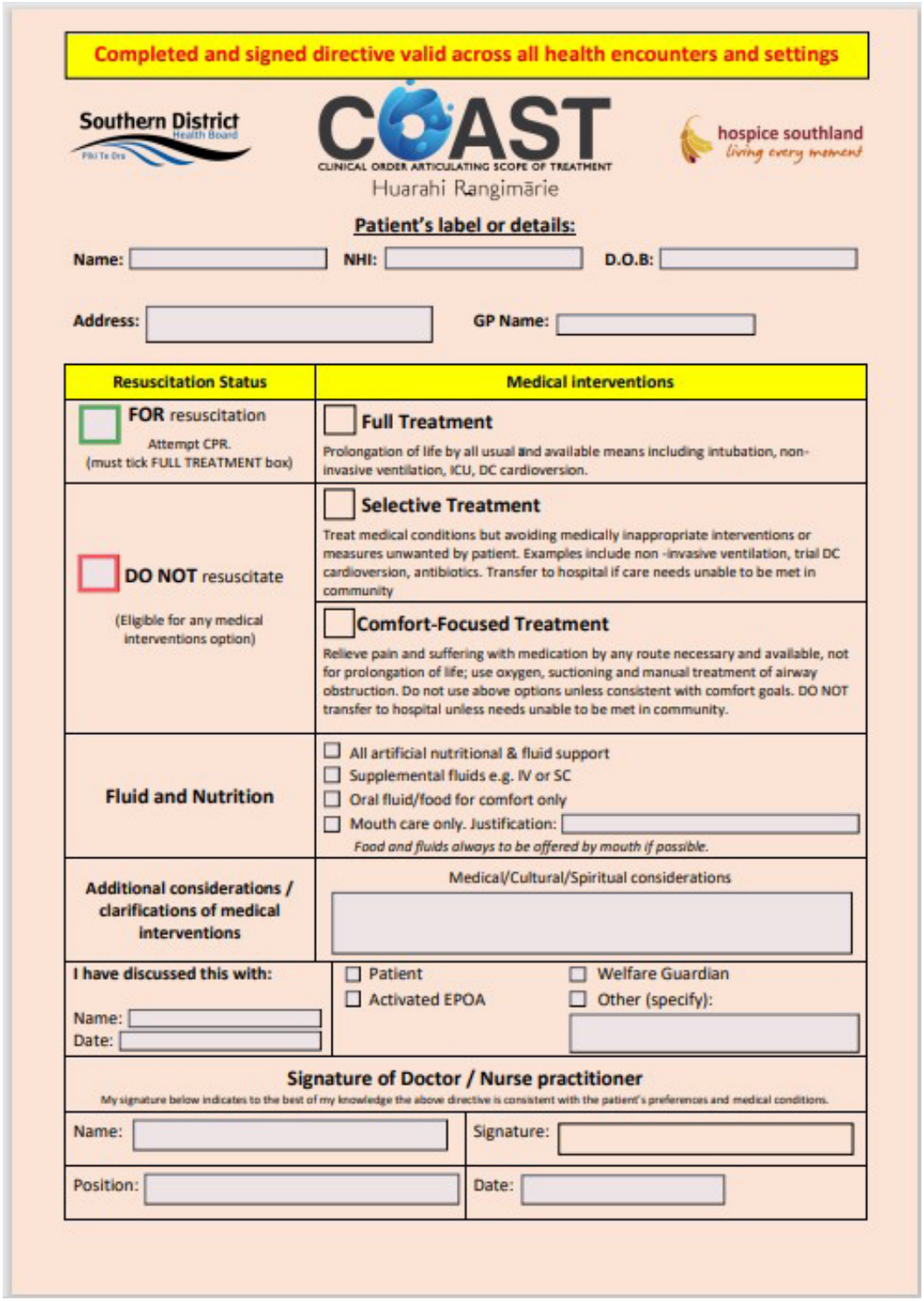
Appendix 1: COAST form.



Completed and signed directive valid across all health encounters and settings

Southern District Health Board Pihi Te Ora

COAST
CLINICAL ORDER ARTICULATING SCOPE OF TREATMENT
Huarahi Rangimārie

hospice southland
living every moment

Patient's label or details:

Name: NHI: D.O.B:

Address: GP Name:

Resuscitation Status	Medical interventions
☐ **FOR** resuscitation Attempt CPR. (must tick FULL TREATMENT box)	☐ **Full Treatment** Prolongation of life by all usual and available means including intubation, non-invasive ventilation, ICU, DC cardioversion.
☐ **DO NOT** resuscitate (Eligible for any medical interventions option)	☐ **Selective Treatment** Treat medical conditions but avoiding medically inappropriate interventions or measures unwanted by patient. Examples include non -invasive ventilation, trial DC cardioversion, antibiotics. Transfer to hospital if care needs unable to be met in community ☐ **Comfort-Focused Treatment** Relieve pain and suffering with medication by any route necessary and available, not for prolongation of life; use oxygen, suctioning and manual treatment of airway obstruction. Do not use above options unless consistent with comfort goals. DO NOT transfer to hospital unless needs unable to be met in community.
Fluid and Nutrition	☐ All artificial nutritional & fluid support ☐ Supplemental fluids e.g. IV or SC ☐ Oral fluid/food for comfort only ☐ Mouth care only. Justification: *Food and fluids always to be offered by mouth if possible.*
Additional considerations / clarifications of medical interventions	Medical/Cultural/Spiritual considerations
I have discussed this with: Name: Date:	☐ Patient ☐ Welfare Guardian ☐ Activated EPOA ☐ Other (specify):

Signature of Doctor / Nurse practitioner

My signature below indicates to the best of my knowledge the above directive is consistent with the patient's preferences and medical conditions.

Name:	Signature:
Position:	Date:

Appendix 2: Pre-implementation questionnaire for healthcare professionals.

COAST STAKEHOLDERS MEETING FEEDBACK

1. Please identify the capacity in which you attended this meeting (please circle):

Patient/Professional (please indicate job title):_____

2. Do you have experience with Advanced Care Planning?	**Yes**	**No**
Comments:		

3. Do you view a Not for Resuscitation (NFR) form as being different from an Advanced Care Plan?	**Yes**	**No**

4. Do you think the introduction of COAST form would be beneficial to you?	**Yes**	**No**
Comments:		

5. Do you have any ideas on how the COAST form could be improved?	**Yes**	**No**
Comments:		

6. What barriers do you perceive to COAST form implementation?

7. What education or training about the COAST form/process would you require if the COAST form were to be introduced?

8. What other thoughts do you have about the COAST form or about advance care planning in general?

Appendix 3: Post-implementation questionnaire for patients/proxy decision makers.

Southern District Health Board
Piki Te Ora

Please complete this survey and return in the pre-paid addressed envelope to Hospice Southland

hospice southland

POST-COAST SURVEY QUESTIONS FOR PATIENTS/PROXY DECISION MAKERS

Relationship of person completing survey (please tick):
Patient ☐ Activated EPOA ☐ Welfare Guardian ☐ Other ☐ (specify)_____

Are you familiar with the idea of advance care planning (ACP)?	Yes	No

Have you completed a written advance care plan (ACP) document?	Yes	No	Unsure

Have you talked with someone you trust - like a family member or friend - or with your Enduring Power of Attorney (EPOA) about what treatments you would or wouldn't want if you are seriously ill or dying?	Yes	No
Comment:		

Have you and your doctor talked about what treatments you would or wouldn't want if you are seriously ill or dying?	Yes	No
Comment:		

Are you familiar with the COAST form?	Yes	No	Unsure

As far as you know, what is the purpose of the COAST form?

Do you have a completed COAST form for yourself or someone you care about?		
Yes, for myself	Yes, for someone else (please specify)	No

Appendix 3 (continued): Post-implementation questionnaire for patients/proxy decision makers.

Southern District Health Board
Piki Te Ora

Please complete this survey and return in the pre-paid addressed envelope to Hospice Southland

hospice southland

If you or someone you care about has a COAST form, how well was COAST explained to you?				
No discussion with me at all	**Not explained well**	**Explained well**	**I do not recall**	**Does not apply (No COAST form)**

Were you in agreement with having a COAST form in place for yourself or the person you care about?	Yes	No
Why or why not? Comment:		

If you or someone you care about has a COAST form, how has this affected your/that person's health care?					
Made care a lot worse	**Made care somewhat worse**	**No difference to care**	**Made care somewhat better**	**Made care a lot better**	**Does not apply (No COAST form)**

What concerns do you have about the COAST form or process?

How could the COAST form and process be improved?

What else would you like us to know?

Appendix 4: Post-implementation questionnaire for healthcare professionals.

POST-COAST SURVEY QUESTIONS FOR PROVIDERS

What do you know about the COAST form and process?

How many of your patients/clients have had a completed COAST form?	None	A few (1-3)	Several (4-9)	More than 10

Did you receive adequate education and training about the COAST form and process?	Yes	No
Comment:		

What works well about the COAST form and process?

How much do you agree with the following statement: The COAST form improves the care provided to my patients/clients?				
Completely disagree	Somewhat disagree	Neither agree or disagree	Somewhat agree	Completely agree

What barriers are there to COAST form completion?

Appendix 4 (continued): Post-implementation questionnaire for healthcare professionals.

Southern District Health Board Piki Te Ora

hospice southland

What barriers are there to COAST form implementation?

How comfortable are you completing the COAST form?		
Not at all comfortable	Somewhat comfortable	Very comfortable

How comfortable are you following the COAST form orders if you yourself did not complete and sign the form?		
Not at all comfortable	Somewhat comfortable	Very comfortable

How could the COAST form be improved?

What other thoughts do you have about the COAST form or about advance care planning in general?

Envisioning a Tiriti-responsive New Zealand Health Plan: lessons from district health boards' annual plans

Nina Bevin, Kyle Eggleton, Sarah Herbert

ABSTRACT

AIMS: Over recent decades, a body of research has established the presence of pervasive health inequities experienced by Māori. Work to identify the root causes of inequities has focussed on the unequal distribution of the determinants of good health, access to healthcare, and racism. This study contributes to a small but growing field of work which engages with Te Tiriti o Waitangi to critique key health documents, focusing on district health boards' (DHBs) annual plans.

METHODS: A qualitative, directed content analytical approach was used to investigate whether DHBs' 2019/2020 annual plans were consistent with the principles of Te Tiriti o Waitangi, as identified by the Wai 2575 Waitangi Tribunal inquiry.

RESULTS: While annual plans contained actions that aligned with the principles of active protection and equity, comparatively few related to the principles of options, partnership, and tino rangatiratanga. Overall, DHB actions operated to constrain options available to Māori and efforts to exercise the Tiriti-guaranteed right of tino rangatiratanga in the provision of health services.

CONCLUSION: While DHBs' annual plans expressed commitment to Te Tiriti o Waitangi, their content did not give effect to these commitments. Significant shifts are necessary if future New Zealand Health Plans are Tiriti-responsive documents that deliver Tiriti-responsive health services.

Over decades, a large body of research has documented pervasive health inequities experienced by Māori. Inequities are differences in outcomes that are avoidable, unnecessary, unfair, and unjust.[1] This includes higher incidence of infectious and non-communicable diseases among Māori,[2] worse outcomes than non-Māori for the same diseases,[3] poorer access to healthcare,[4,5] and receiving poorer quality care.[6] On average, Māori live 7 years fewer than other New Zealanders.[7] These inequities reflect a health system that systematically disadvantages Māori.

Health inequities illustrate a failure by the Crown to uphold Māori rights to health as guaranteed in Te Tiriti O Waitangi, an agreement signed between Māori and the British Crown in 1840. Broadly, Te Tiriti o Waitangi granted the Crown the right to govern non-Māori residents, while guaranteeing Māori te tino rangatiratanga (absolute sovereignty) over their lands and taonga (that which is treasured), and promised Māori the same rights and privileges of all British subjects.[8,9] Using Te Tiriti o Waitangi as a framework to undertake critical analyses of the Crown's delivery of health services is appropriate as it affirms Māori rights to health and to monitor Crown performance.[10] Critical Tiriti Policy Analysis is another approach which places Tiriti rights at the centre of policy analyses; however, this deliberately centres the Articles of the Māori text.[11]

The subject of this research was district heath boards' (DHBs) 2019/2020 annual plans. Although Māori health plans were developed by DHBs, these were not statutorily required at the time of the study. Under previous health system arrangements, annual plans were statutorily required documents in which DHBs communicated how they would deliver health services to meet their legislative and Treaty [sic] obligations and make measurable progress towards health equity for Māori.[12] They represented the most detailed publicly available documents relating to health service delivery at a population level. Plans play an important role within organisations, communicating how strategic goals will be achieved, and highlighting key priorities. DHB annual plans are worthy targets for critical scrutiny as potential enablers or barriers to achieving equity. Despite improving Māori health outcomes being a primary objective of DHBs, this had not occurred over their 20 years of existence.[13]

In April 2021, Aotearoa New Zealand's Minister of Health announced the government's intention to undertake major health system reforms. A key influence on this decision was cited as the pervasive health inequities experienced by Māori.[14] Our research involved a critical review of DHBs' annual plans to examine the extent to which they meaningfully operationalised the principles of Te Tiriti o Waitangi, offering insights for the New Zealand Health Plan. Te Pae Tata, the interim New Zealand Health Plan, was released in 2022 as a replacement for DHB annual plans.

Methods

The study methodology aligned with principles of Kaupapa Māori Research, including seeking to centre Māori health priorities while reviewing each annual plan, adopting an overarching aim of eliminating health inequities for Māori, upholding Māori rights to health and wellbeing, and striving for social justice.[15] The study design and ownership of the research sits with Māori and the analysis was informed by a Māori world view. In this study, the first and third authors are Māori, and the second author is NZ European.

A qualitative directed content analysis design was used, which involves selecting a pre-existing theory or framework to focus the research question, guide the definition of categories and codes, and test alignment of the study data.[16,17] A coding framework was developed using Te Tiriti o Waitangi principles identified as particularly relevant by the Waitangi Tribunal in the first stage of the Wai 2575 Hauora Kaupapa inquiry, namely active protection, equity, options, partnership, and tino rangatiratanga.[18] The Tribunal's report provided examples of how these principles might be operationalised in the context of the health system, and these were used to form codes. Māori scholars have critiqued the reduction of the text of Te Tiriti o Waitangi to principles.[9] While this study does not presume to dispute the views of these experts, Crown entities such as DHBs and Manatū Hauora – Ministry of Health have predominantly operationalised Te Tiriti o Waitangi obligations using the principles identified as relevant for health and health services by the Waitangi tribunal and which are subsequently reflected in, for example, Whakamaua: Māori Health Action Plan.[19] Given the widespread use of principles in the health sector, this study took a pragmatic approach to measure DHBs' performance against such principles.

Copies of the 2019/2020 annual plans for each DHB were obtained in March 2020, and uploaded into NVivo (Version 12 for Windows, QSR International) for analysis. Each plan was read, and codes were applied to the text, with some having multiple codes applied. Coding was tested on a single annual plan by the lead author to assess feasibility of the proposed coding scheme. It was then independently coded by the other authors to check reliability and refine interpretations of coded data. The remaining data were coded by the lead author. Analysis was restricted to the annual plan proper, and did not include performance measures, statements of intent, or statements of performance expectation. Portions of text determined to be contravening the codes were allocated to a separate category, labelled inductive, for further analysis. Annotations were made during the coding process to flag pertinent details or latent meaning.

For coding purposes, taha Māori services were defined as those delivering Māori health services within the DHB system. These services often employ Māori staff and aim to align Westernised health service delivery mechanisms with Māori values and tikanga. In contrast, Kaupapa Māori services are developed, led, and governed by iwi (tribal groups) or Māori organisations for whānau Māori.[20]

Coded data were examined in detail in the context of the corresponding Te Tiriti o Waitangi principle, including reading the text fragments to identify commonalities and divergent responses, and quantifying coded units for each principle. The incidence of each category was calculated to provide a snapshot of the total DHB response to each principle.[16] Overall, the analysis sought to determine the extent to which annual plans upheld these principles.

This study was exempt from requiring ethical approval as the source material consisted solely of publicly available documents.

Results

As shown in Table 1, 84% of data were coded under active protection and equity, with only 16% under options, partnership, and tino rangatiratanga.

Table 1: Quantification of codes for each principle of Te Tiriti o Waitangi.

Principle	n (%)	Code	n (%)
Active protection	1273 (48)	Culturally appropriate health services	563 (21)
		Data disaggregated by ethnicity, and for Māori, access, unmet need, and outcomes are measured	528 (20)
		Māori health workforce development	182 (7)
Equity	943 (36)	Prioritisation of Māori to achieve health equity	359 (14)
		Intervention to address barriers to accessing healthcare for Māori	515 (19)
		Targets for Māori access and outcomes that are at least equal to that of the population as a whole	69 (3)
Options	164 (6)	Development of new kaupapa Māori services	15 (0)
		Support of existing kaupapa Māori services	107 (4)
		Funding for kaupapa Māori and Māori-led services	42 (2)
Partnership	262 (10)	Designing health services with Māori	124 (5)
		Genuine co-governance	138 (5)
Tino rangatiratanga	7 (0)	Māori autonomy	7 (0)

Active protection

Active protection was detailed in annual plans primarily as improving cultural appropriateness of DHB-provided services, and by providing data disaggregated by ethnicity. There were no mechanisms to measure unmet need for Māori. Examples of improving cultural appropriateness of DHB-provided services included incorporating tikanga Māori into health services, publishing education resources in te reo Māori, and modifying the site of healthcare delivery, for example, to marae. Some DHBs aimed to implement culturally appropriate initiatives for specific services, such as "Manaaki Mana: Excellence in Emergency Care for Māori," aimed at achieving equity for Māori using the emergency department.[21]

DHBs planned to improve cultural responsiveness among staff, mainly by improving cultural competence. While training in Te Tiriti o Waitangi and equity was offered by many DHBs, only three suggested more critical approaches such as understanding colonisation, institutional racism, and bias.[22–24]

All DHBs used disaggregated ethnicity data, allowing for Māori/non-Māori comparisons. Dashboards to help staff identify areas of inequity were an example of how this data was used.[25–27] Many DHBs identified problems with data quality, for example, incomplete workforce ethnicity data, and had plans for improvement.[21,28,29]

While every DHB stated their intention to increase the number of Māori employees, the particular focus was on Māori midwives, nursing, and allied health. Five DHBs aimed to achieve proportionality of Māori employees with the Māori population in their regions, though nearly half of DHBs failed to state a measurable target.[21,23,25,28,29] Increasing Māori senior management and clinical leadership roles were only mentioned by three DHBs.[21,30,31]

Equity

Barriers to access were addressed by DHBs by moving services closer to the communities who need them, providing outreach and telehealth services, providing services outside of normal work hours, reducing financial barriers, and improving integration of related services. To address problems with navigating complex health services, support was offered to Māori by many DHBs in the form of Equity Clinical Nurse Specialists or navigators.

Prioritisation of Māori to achieve equal utilisation or health outcomes was an expected finding, as DHBs were explicitly instructed to do so by the Manatū Hauora – Ministry of Health annual plan guidance across pre-selected action areas.[12] While overt prioritisation of Māori to achieve equitable outcomes was observed, this occurred infrequently. A positive example was Hawke's Bay and Lakes DHBs noting in their annual plans that in order for the National Bowel Screening Programme to deliver equal health gains for Māori compared with non-Māori, they would need to ensure 73% of eligible Māori participated compared with 62% of non-Māori.[24,32]

Targets were used as an outcome measure in all DHB annual plans, and while many were equity-consistent, examples of lower targets for Māori were also evident, for example with respect to immunisation: "*coverage for total population at eight months is 91% by 31 March 2020 … coverage for Māori at eight months is 86%*".[26]

Options

Two large urban DHBs planned to offer taha Māori mental health and addiction services.[27,30] Discrete packages of healthcare, such as smoking cessation interventions and screening, represented the majority of services contracted to Kaupapa Māori providers. While many DHBs expressed their intent to partner with Kaupapa Māori providers in various ways, only Waikato, Capital and Coast and Tairāwhiti committed to financial support, with the latter committing a defined percentage of its community funding to Māori health providers.[25] Options informed by mātauranga Māori were limited to five examples in Northland, Bay of Plenty and Tairāwhiti DHBs, including Te Kuwatawata, a service for whānau experiencing mental health distress.[25]

Partnership

With respect to co-governance, nearly all DHBs discussed their engagement with an iwi relationship board; however, considerable variation was evident in the nature and functionality of these relationships. Descriptors of the iwi board's role included influencing planning, strategy, and analysing performance.[25,33,34] At an operational level, DHBs planned to involve Māori in governance across a range of health services, but often implied this would be undertaken by a single Māori representative within a larger leadership group.

Tino rangatiratanga

Across annual plans, articulation of Māori autonomy was scarce. A positive example was the commitment of Bay of Plenty DHB to implement an independent iwi-developed health strategy.[26] In contrast, a second example of the exercise of tino rangatiratanga involved a dispute between Tairāwhiti DHB and an iwi health provider, leading to the iwi invoking their Te Tiriti o Waitangi right to deal directly with the Crown regarding the inequitable health status of their people.[25]

Discussion

This study used a qualitative, directed content analysis approach to investigate whether DHBs' annual plans were consistent with the principles of Te Tiriti o Waitangi.

With respect to active protection, evidence demonstrated that DHBs focussed on making their own services more culturally appropriate, when an alternative and more successful approach could have been to increase contracts for service provision to Kaupapa Māori providers. This bias towards DHB provided services is reflected in a Manatū Hauora – Ministry of Health report on DHB spending, which showed that funding to Māori health providers as a percentage of DHBs' Crown funding remained small and static at around 1.5% over a five year period.[35] There was a lack of focus on measuring and responding to unmet need for Māori, and references in annual plans largely related to secondary care, despite evidence demonstrating that Māori experience high levels of unmet need in accessing primary care services.[2] While efforts to increase Māori representation among DHB employees was positive, it tended to focus on patient-facing clinical roles rather than enabling Māori leadership within the system. This is problematic, given recent evidence to suggest that Māori were gravely under-represented in DHB senior leadership roles,[36] and acts to perpetuate the

marginalisation of Māori voice across the health system.

DHBs' interpretations of equity within annual plans was concerning. While DHBs prioritised Māori across a range of health issues, some predetermined by Manatū Hauora – Ministry of Health guidance,[12] it was unclear how priority areas were chosen and how Māori voice was reflected in this process. For example, very few actions related to coronary disease and lung cancer, which could be reasonably expected to be prioritised, given they are the primary contributors to the life expectancy disparity between Māori and non-Māori.[37,38] Additionally, aligning with Wai 2575 findings, DHB statements about reducing inequities rather than the Te Tiriti o Waitangi-consistent goal of eliminating them altogether illustrated a superficial understanding of the meaning of equity. A further example was the use of proportional utilisation of health services by Māori as a target, regardless of greater Māori health need for that service.

Annual plans failed to demonstrate genuine options for Māori, particularly those grounded in mātauranga Māori (Māori knowledge). They often conflated Kaupapa Māori services with culturally adapted generic services, suggesting a lack of understanding around the distinction between the two, and Te Tiriti o Waitangi obligations to provide options. Similar to previous findings, annual plans contained some evidence that DHBs subjected Kaupapa Māori providers to more onerous accountability than DHB-delivered services.[39] As noted by the Waitangi Tribunal, Kaupapa Māori health providers are an expression of tino rangatiratanga,[2] therefore by limiting service provision by Kaupapa Māori providers, DHBs not only failed to uphold the principle of options, but also the guarantee of tino rangatiratanga.

Actions within annual plans relating to the principle of partnership were scarce. Engaging with Māori to co-design health services was planned by many DHBs; however, it was difficult to ascertain how Māori voice was incorporated in resulting outputs, or the degree of agency afforded to Māori. Actions to compensate for participants' time and costs were few. Similar to Came, McCreanor et al. who investigated Māori DHB board member experiences,[40] the present study found that governance arrangements constrained tino rangatiratanga, with annual plan descriptions of the relationship between Māori boards and their DHB counterparts reflecting a passive or advisory role without the ability to exercise authority or vote on board decisions. Furthermore, there were instances where Māori were framed as one of many stakeholders in DHB services, rather than as equal Tiriti partners.

Conclusion

In summary, while DHBs' annual plans universally contained expressions of commitment to Te Tiriti o Waitangi, their content did not sufficiently realise these commitments, amounting to a response grounded in rhetoric and non-performativity. The *Pae Ora (Healthy Futures) Act 2022* sets out the requirement for a New Zealand Health Plan. These plans will be jointly developed by Te Whatu Ora – Health New Zealand and Te Aka Whai Ora – Māori Health Authority and consist of a population health needs assessment and a 3-year costed plan for the delivery of publicly funded health services. The plans are acknowledged in the *Act* as a mechanism by which the Crown will "*give effect to the principles of Te Tiriti o Waitangi*".[41] Applying the findings of this study, some critical enablers are evident if future plans are to achieve this aim.

With regards to active protection, the availability of high-quality data, disaggregated by ethnicity will be essential to conduct health needs assessments, and to measure performance and outcomes as required by the *Act*. To "*empower Māori to improve their health*,"[41] Māori must be present in leadership roles, not only in Te Aka Whai Ora – Māori Health Authority, but across all health system entities. To uphold the principle of equity, plans must explicitly prioritise Māori to achieve health equity, maximise Māori health gain, and allocate resources proportional to Māori health need. A fresh approach to commissioning of services from Kaupapa Māori providers will be essential to provide legitimate options for Māori, removing undue bias towards Te Whatu Ora – Health New Zealand provided services.

Whether New Zealand health plans will allow for genuine partnership between iwi Māori and the Crown is complex. As both Te Aka Whai Ora – Māori Health Authority and Te Whatu Ora – Health New Zealand are Crown entities, Iwi–Māori partnership boards are Tiriti partners within the new structure. They will have indirect influence over the New Zealand Health Plan through their relationships with its co-authors, Te Aka Whai Ora – Māori Health Authority and Te Whatu Ora – Health New Zealand, and their approval

of locality plans. The extent to which the boards are treated as equal partners, enabled to exercise tino rangatiratanga and empowered to make key decisions remains to be seen.

Limitations of the study include the restriction of our sample to the 2019/2020 annual plans, meaning findings may not be generalisable to other years, or to assess adherence to Te Tiriti o Waitangi over time. Critics of directed content analysis state that its use of pre-existing frameworks can lead to bias when interpreting data.[16] However, placing Te Tiriti o Waitangi at the centre of our analysis is consistent with Māori rights to monitor the Crown,[10] and enables a critical Kaupapa Māori lens to be cast on the health system, thereby exposing the role of colonisation, and resulting privileging and normalising of Pākehā views and values.

COMPETING INTERESTS
Nil.

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Identifying potential patients with diabetes-related dementia: a descriptive approach using routinely collected data

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ABSTRACT

AIMS: Diabetes-related dementia (DRD) is a new dementia subtype associated with type 2 diabetes mellitus, first described in 2013. This study investigated data from a local New Zealand memory service to identify patients that met the criteria for DRD.

METHODS: Using routinely collected data from 2013–2021, we selected a sample of people with dementia, diabetes, and no CT evidence of Alzheimer's disease (AD), vascular dementia, or frontotemporal dementia. We compared their socio-demographic, clinical, and cognitive characteristics with a sample of patients with diabetes and Alzheimer's disease.

RESULTS: Forty (16%) of 249 patients with diabetes and dementia had "normal" CT scans (DRD subgroup), and 38 (15%) had AD (AD subgroup). Compared to NZ Europeans, disproportionally more Māori and Pacific Islanders (70.2%) were in the DRD subgroup. In the Pacific subgroup (n=31), the DRD subgroup had higher memory subscores than the AD subgroup (p=0.047), and the Kaplan–Meier plot suggested poorer survival (p=0.13). Māori patients with diabetes and dementia were more likely to meet all four criteria for DRD.

CONCLUSION: We have replicated the findings of the 2013 DRD research and have demonstrated a higher risk for the DRD subtype of dementia among the Māori and Pacific Islander patients in our sample.

Type 2 diabetes mellitus has been shown to increase the risk of cognitive decline and dementias such as Alzheimer's disease dementia (AD) and vascular dementia.[1] A number of mechanisms may be involved in the pathophysiology, including vascular disease, glucose toxicity, and changes in amyloid metabolism.[1] A research group in Japan have suggested that type 2 diabetes is also associated with another new dementia subgroup, which they have called diabetes-related dementia (DRD).[2–7] Diabetes-related dementia was first described by Fukasawa et al. in 2013.[2] Patients at a memory clinic with dementia and type 2 diabetes were categorised into four subgroups by findings on single photon emission computed tomography (SPECT) and magnetic resonance imaging (MRI): 1) those showing an AD pattern but not showing cerebrovascular disease (CVD), 2) those showing CVD only, 3) those showing AD with CVD (mixed), and 4) those without AD or CVD (which they called the DRD subgroup). The research group then examined the four groups for differences in clinical characteristics. Compared to the AD group, the DRD subgroup was characterised by higher haemoglobin A1c (HbA1c), longer duration of diabetes, higher frequency of insulin therapy, lower frequency of apolipoprotein E4 carriers (ApoE4), less severe medial temporal lobe atrophy, and cognitive assessment showed more impaired attention and executive functions but less impaired memory.

In follow-up studies on the same sample, the patients in the DRD group had a different clinical course to those in the AD group.[3,7] There were differences in SPECT on follow-up, suggesting that the underlying pathophysiology in the DRD group differs from the AD group. Patients in the AD subgroup showed a significant widespread reduction in regional cerebral blood flow (rCBF) in the parietotemporal and limbic lobes, whereas rCBF reduction in the DRD subgroup was more scattered. Patients with DRD had slower progression in cognitive decline compared to the AD group. Despite a slower decline, significantly more patients in the DRD group were admitted to hospital.[7] It is likely that more severe diabetes and a higher risk of frailty[5] contributed to higher rates of medical conditions and hospitalisation.

Based on these findings, the authors defined diabetes-related dementia (DRD) as a new subtype of dementia, with characteristics as follows:[4]

i. Type 2 diabetes mellitus: long duration and less well-controlled hyperglycemia.
ii. Impaired attention but less-impaired word recall, slow progression of cognitive impairment.
iii. No evidence of vascular lesions or medial temporal lobe atrophy on CT/MRI scan.
iv. No decreased hypoperfusion/hypometabolism in the posterior cerebral lobe on SPECT, negative or equivocal amyloid accumulation.
v. Cerebrospinal fluid: normal p-tau and normal Ab1–42 levels.
vi. ApoE4 carrier: low frequency.
vii. Exclusion of other causes of dementia (hypothyroidism, vitamin B1, B12 deficiency, head trauma, chronic alcoholism, cerebrovascular disease, other neurodegenerative diseases).

The proposed DRD subgroup has only been demonstrated by one research group so far, but has potentially important implications for New Zealand, where the prevalence of diabetes is high[8] and is projected to increase by 70–90% within the next 20 years.[9] The burden of diabetes disproportionately affects Māori and Pacific Islander populations living in New Zealand, with a prevalence two to three times higher than NZ Europeans,[9] which may be one of the reasons that the prevalence of dementia is higher among Māori and Pacific Islanders.[10] The Lancet Commission for Dementia[11,12] identified 12 modifiable risk factors which contribute to potentially reversible causes of dementia. These risk factors were less education, hypertension, obesity, alcohol, traumatic brain injury (TBI), hearing loss, smoking, depression, physical inactivity, social isolation, air pollution, and diabetes. Together they were estimated to contribute to 40% of potentially preventable dementias worldwide. Population attributable fraction (PAF) estimates vary between countries as prevalence of these risk factors differ,[13] and in New Zealand the PAF estimate exceeds worldwide estimates at 47.7%.[14] The PAF estimates for dementia are higher among Māori (51.4%) and Pacific Islanders (50.8%) compared to European (47.6%) and Asian (40.8%) peoples.[14] The findings are supported by evidence from routinely collected New Zealand national administrative health data that suggest significantly higher prevalence of *diagnosed* dementia in Māori (5.4%) and Pacific Islander (6.3%) populations compared to Asian (3.4%) and Europeans (3.7%) in the age 60+ population (with the true rate, including unidentified dementia, likely to be double these estimates).[15] The prevalence of dementia is projected to more than double by 2050, especially for Māori and Pacific Islander populations, which have more rapid demographic ageing and higher prevalence of risk factors.[10]

Given the high prevalence of diabetes and dementia in New Zealand, especially in Māori and Pacific Islanders, the suggestion of the existence of a diabetes-specific subgroup of dementia (DRD) is of interest, as it may have a different prognosis and require different prevention/treatment approaches. The aim of this study is to investigate data from a local New Zealand memory service cohort to identify a group of patients that meet the criteria for DRD, and to compare their clinical and cognitive characteristics with the sample described in Japan.[2–7]

Methods

Adapted criteria for diabetes-related dementia (DRD)

We attempted to identify people with DRD guided by the seven criteria listed above.[4] We were unable to address criteria 4, 5, and 6 in our sample, as SPECT, cerebrospinal fluid, and ApoE4 carrier status are not routinely collected in the memory service. We judged that the remaining criteria would be sufficient to investigate the possibility of a subgroup with DRD using routinely collected data. We therefore used the following criteria to define DRD:

i. Type 2 diabetes mellitus, defined as HbA1c≥50 at the time of initial assessment.
ii. Impaired attention but less-impaired word recall on cognitive testing at the time of initial assessment.
iii. No evidence of vascular lesions or frontotemporal/medial temporal lobe atrophy on CT/MRI scan (defined as "normal" findings on CT scan report at the time of initial assessment).
iv. Exclusion of other causes of dementia (hypothyroidism, vitamin B1, B12 deficiency, head trauma, chronic alcoholism, cerebrovascular disease, or other neurodegenerative diseases).

Setting and sample

The sample was ascertained from consecutive referrals to Te Whatu Ora Counties Manukau Memory Service at Middlemore Hospital between 2013–2021. It extends by two years a cohort previously used to investigate the predictors of aged residential care placement in dementia.[16] The memory service accepts referrals mostly from primary care and from some secondary care services but does not assess people in residential care. The referred patients must have a primary concern of subjective and/or objective cognitive decline to meet the referral criteria for the memory service. We selected only those patients that received a new diagnosis of dementia for inclusion in this study, to attempt to capture patients at a similar clinical stage of dementia.

Study design

In our study we selected a sample of people with a new diagnosis of dementia (AD, vascular dementia [VD], mixed AD/VD, and other) and diabetes (defined as HbA1c≥50 at the time of initial assessment). We then ascertained a DRD subgroup in the sample that had "normal" CT/MRI scan reports, that is with no evidence of cerebrovascular pathology (e.g., strokes or ischaemia), and/or focal lobar atrophy in frontal, temporal and/or parietal lobes (but mild diffuse global atrophy in keeping with age was allowed), or any other abnormality such as evidence of brain tumour or subarachnoid haemorrhage. We compared the DRD subgroup with a second subgroup from the same sample who did *not* have a "normal" CT scan and had previously been given a clinical diagnosis of AD. Our aim was to investigate whether there were socio-demographic and clinical differences between these two groups (e.g., age, sex, ethnicity, HbA1c levels, cognitive profile, and mortality).

The cognitive tests we examined were the total scores, memory, and attention subscores for the Addenbrooke's Cognitive Assessment-III (ACE-III),[17] and the total scores and memory subscores for the Rowland Universal Dementia Assessment Scale (RUDAS),[18] as the RUDAS does not have an attention subtest. A higher score on either test signifies better cognitive function.

Data collection

Socio-demographic and clinical details were ascertained from routinely collected health data, including age, gender, ethnicity, HbA1c levels, CT scan reports, dementia subtypes and severity, and cognitive function. In English speakers, cognitive function was assessed using the ACE-III.[17] The RUDAS[18] was used for non-English speakers (via interpreters) or where English was the second language. Dementia diagnoses, subtypes, and dementia severity were made by clinical consensus at weekly memory service multidisciplinary team meetings, using clinical and neuroradiological information. Dementia diagnosis was made using DSM-IV criteria[19] and dementia severity utilising Clinical Dementia Rating (CDR) criteria.[20] Dementia subtyping was guided by NINCDS-ADRDA criteria for Alzheimer's disease dementia,[21,22] NINDS-AIREN criteria for vascular dementia,[23] Lewy body dementia[24,25] and frontotemporal dementia.[26] The HbA1c data, CT scan reports, and mortality data were extracted by Middlemore Hospital Health Informatics Department. This research was approved by the Northern B Health and Disability Ethics Committee (HDEC) reference number: 17/NTB/191.

Statistical analysis

All data were de-identified prior to analyses. Patient ethnicities were categorised as NZ European, Māori, Pacific Islander, and other. Dementia severity ratings were dichotomised to mild dementia or "moderate to severe" dementia. Cognitive scores on ACE-III and RUDAS were recorded as raw scores (with incomplete answers scored as zero). The total ACE-III and RUDAS scores (100 and 30, respectively) and memory subscores (26 and 8, respectively) were standardised by calculating the proportion of the score achieved by each patient concerning the total score that could be achieved in each test. We also compared the median ACE-III attention subscores across the two groups. We carried out *k*-means cluster analysis on the standardised memory scores to identify patients with high values that met criterion (ii) for DRD.

We reviewed CT/MRI reports closest to time of acceptance by the memory service and classified findings into "normal" or "abnormal" based on criteria (iii) above. The CT scan reports were checked independently by two of the authors (CGP, SC) to classify referrals, and discrepancies were discussed to reach a consensus opinion.

Wilcoxon Rank-Sum Test, t-Tests and Fisher's exact tests were used with a significance level of 5%. $P<0.05$ was considered statistically significant. All statistical analyses were made using statistical software R 4.2.1 version.[27]

Results

Between 2013–2021, there were 3,950 referrals to the memory service for dementia assessment. Of these, 2,250 had a clinical assessment by the memory service. Around half were diagnosed with dementia, of whom 1,077 had a *new* diagnosis of dementia. Patients with a new diagnosis of dementia were classified by HbA1c level (where available, n=1071). Table 1 compares patients with a new diagnosis of dementia and HbA1c ≥50 mmol/mol (n=249) and patients with a new diagnosis of dementia and HbA1c<50 mmol/mol (n=822). There were a higher proportion (60.3%) of Māori and Pacific Islanders in the high HbA1c group and proportionally more European people (56.4%) in the low HbA1c group. Alzheimer's disease was more common in the low HbA1c group (40.1%), and vascular dementia was more common in the high HbA1c group (53.4%). Dementia subtypes in Table 1 were the clinical diagnoses given *prior* to this study; the study was designed to identify those that would meet criteria for the new dementia subtype of DRD.

The 249 patients with high HbA1c levels were then classified by their CT scan report findings. Forty of the 249 patients' CT scan reports were classified as "normal", and we called this group the DRD subgroup, of whom 36/40 had cognitive data (RUDAS or ACE-III). The comparison group was 38 patients with high HbA1c, an "abnormal" CT scan report, and a clinical diagnosis of Alzheimer's disease (AD subgroup), of whom 35/38 had cognitive data. In the DRD subgroup, we used the *k*-means algorithm on standardised memory scores to identify 17 patients who met the HbA1c, neuroradiological, *and* cognitive (less impaired memory subscore) criteria for DRD. Figure 1 shows the process of ascertaining the AD and DRD subgroups. Table 2 describes the characteristics of the subsamples at each stage to establish the DRD subgroup. Māori and Pacific Islanders made up the highest proportion of patients with high HbA1c and "normal" CT scans (70%), and Pacific Islanders had the highest mean HbA1c levels. Of patients with a new diagnosis of dementia, Māori were four to eight times more likely to meet all four criteria for DRD compared to other ethnic groups. The sample size was too small to test the statistical significance.

Socio-demographic and clinical characteristics of DRD and AD

Table 3 shows the socio-demographic variables and cognitive scores comparing DRD and AD subgroups for all ethnic groups (n=78) and for the Pacific Islander subgroup (n=31).

All ethnicities

Patients in the DRD subgroup were significantly younger than patients in the AD subgroup (p<0.001), but this may be due to confounding, as the majority in the DRD subgroup were Māori or Pacific Islanders (70.2%) and patients from these ethnic groups have a younger overall mean age compared to Europeans. The mean HbA1c level was slightly higher in the DRD subgroup, but did not reach statistical significance (p=0.290). Standardised and raw total scores on cognitive tests and memory subtests (ACE-III and RUDAS) were higher in the DRD subgroup than in the AD subgroup, but these also did not reach statistical significance. The median ACE-III memory subscore was 12/26 in the DRD subgroup and 10/26 in the AD subgroup (p=0.112), but we found no difference in the ACE-III attention subscores between the two groups (p=0.730). The median total RUDAS score was 19/30 in the DRD group and 15/30 in the AD subgroup (p=0.068), and the median RUDAS memory subscore was 2/8 in the DRD subgroup and 0/8 in the AD subgroup (p=0.304). Regarding missing data, it is important to note the following instances: for dementia severity, six patients in the DRD subgroup and one patient in the AD subgroup had missing data; concerning cognitive scores, there were no cognitive data available for four out of 40 patients in the DRD subgroup and three out of 38 patients in the AD subgroup. Additionally, one patient in the AD subgroup lacked total ACE-III scores, while four patients in the DRD subgroup and two patients in the AD subgroup did not have RUDAS memory subscores. These instances of missing data are denoted in Table 3 with asterisks (* and **).

Pacific subgroup

As ethnic differences may cause heterogeneity and spurious findings, we stratified by ethnicity and examined the findings for the largest subgroup (Pacific, n=31). There were 19 Pacific Islanders in the DRD group and 12 in the AD subgroup, of whom 29/31 had cognitive test data. Pacific Islanders in the DRD group were slightly younger than in the AD subgroup, but this was not significant (p=0.215). The total standardised cognitive score (ACE-III and RUDAS) was higher in the DRD group (p=0.013). Most Pacific Islander patients were tested with the RUDAS (21/31) rather than ACE-III (8/31). Compared to the AD subgroup, the total RUDAS

Table 1: Socio-demographic variables by HbA1c status.

		High HbA1c	Low HbA1c	p-value
Variable		Mean (SD)		
Age (years)		80.2 (7.4)	82.8 (8.1)	<0.001
	Category	n/249 (%)	n/822 (%)	
Gender	Female	142 (57.0)	457 (55.6)	0.716
	Male	107 (43.0)	365 (44.4)	
Ethnicity	European	61 (24.5)	463 (56.4)	<0.001
	Māori	35 (14.1)	76 (9.2)	
	Pacific Islander	115 (46.2)	207 (25.2)	
	Other	38 (15.2)	76 (9.2)	
Dementia subtype	Alzheimer's disease (AD)	62 (24.9)	330 (40.1)	<0.001
	Vascular dementia (VD)	133 (53.4)	299 (36.4)	
	Mixed dementia (AD/VD)	13 (5.2)	35 (4.3)	
	Other dementias	41 (16.5)	158 (19.2)	

Table 2: Dementia group status by ethnic group.

	Patient category							
Ethnicity	**All (n=1077)**		**Dementia and HbA1c≥50 (n=249)**		**Dementia, HbA1c≥50, and normal CT scan (n=40)**		**Meeting all four DRD criteria* (n=17)**	
	n (%)	**HbA1c mmol/mol Mean (SD)**	**n (%)**	**HbA1c mmol/mol Mean (SD)**	**n (%)**	**HbA1c mmol/mol Mean (SD)**	**n (%)**	**HbA1c mmol/mol Mean (SD)**
European	527 (48.9)	42.1 (10.5)	61 (24.5)	65.9 (14.1)	7 (17.5)	66 (22.3)	5 (29.4)	59.4 (9.4)
Māori	111 (10.3)	47.8 (14.0)	35 (14.1)	63.5 (15.0)	9 (22.5)	59 (9.14)	7 (41.2)	59.6 (10.1)
Pacific	325 (30.2)	53.0 (21.4)	115 (46.2)	75.4 (21.7)	19 (47.5)	76.1 (22.4)	4 (23.5)	80.2 (27.6)
Other	114 (10.6)	48.1 (13.7)	38 (15.3)	63.6 (13.1)	5 (12.5)	58.2 (6.91)	1 (5.9)	61.0 (-)

*DRD criteria defined as dementia, diabetes, “normal” CT scans, and less impaired memory subscore.

Table 3: Socio-demographic variables by DRD and AD for all ethnicities and for Pacific subgroup.

		All ethnicities (n=78)			Pacific subgroup (n=31)		
		DRD (n=40)	AD (n=38)	p-value	DRD (n=19)	AD (n=12)	p-value
		Mean (SD)			Mean (SD)		
Age (years)		77.7 (7.9)	83.6 (6.9)	0.001	77.4 (9.0)	80.2 (8.4)	0.215
HbA1c level (mmol/mol)		68.2 (19.8)	64.2 (12.9)	0.290	76.1 (22.4)	66.2 (17.8)	0.128
		n/40 (%)	n/38 (%)		n/19 (%)	n/12 (%)	
Gender	Female	26 (65.0)	24 (63.2)	1.000	12 (63.2)	8 (66.7)	1.000
	Male	14 (35.0)	14 (36.8)		7 (36.8)	4 (33.3)	
Ethnicity	European	7 (17.5)	15 (39.5)	0.174			
	Māori	9 (22.5)	6 (15.8)				
	Pacific	19 (47.7)	12 (31.6)				
	Other	5 (12.5)	5 (13.1)				
Dementia severity*	Mild	26 (84.6)	22 (60.61)	0.139	9 (64.3)	6 (54.5)	0.697
	Mod–Severe	8 (15.4)	15 (39.39)		5 (35.7)	5 (45.5)	
Cognitive scores (Mean and median scores)**		**ACE-III (n=19) RUDAS (n=17)**	**ACE-III (n=20) RUDAS (n=15)**	**p-value**	**ACE-III (n=5) RUDAS (n=12)**	**ACE-III (n=3) RUDAS (n=9)**	**p-value**
Total cognitive score, ACE-III or RUDAS (standardised)	Mean (SD)	0.64 (0.12)	0.59 (0.14)	0.159	0.63 (0.09)	0.51 (0.14)	0.013
Total ACE-III score (max 100)	Median (IQR)	67 (59.5, 72.5)	65.5 (55.8, 69.5)	0.693	58 (55, 60)	55 (49.5, 65)	0.881

Table 3 (continued): Socio-demographic variables by DRD and AD for all ethnicities and for Pacific subgroup.

		All ethnicities (n=78)			Pacific subgroup (n=31)		
		DRD (n=40)	AD (n=38)	p-value	DRD (n=19)	AD (n=12)	p-value
		Mean (SD)			Mean (SD)		
Cognitive scores (Mean and median scores)**		**ACE-III (n=19) RUDAS (n=17)**	**ACE-III (n=20) RUDAS (n=15)**	**p-value**	**ACE-III (n=5) RUDAS (n=12)**	**ACE-III (n=3) RUDAS (n=9)**	**p-value**
Total ACE-III score	Mean (SD)	63.6 (11.4)	63.3 (11.8)	0.932	52.9 (9.3)	58 (15.7)	0.638
Total RUDAS score (max 30)	Median (IQR)	19 (16, 21)	15 (13, 17)	0.068	20 (18.8, 21)	15 (12, 16)	0.014
Total RUDAS score	Mean (SD)	18.4 (4.1)	15.7 (4.3)	0.083	19.4 (3.0)	14.7 (3.9)	0.008
Total memory score: ACE-III or RUDAS (standardised)	Mean (SD)	0.37 (0.24)	0.31 (0.26)	0.285	0.32 (0.20)	0.19 (0.27)	0.232
ACE-III memory sub-score (max 26)	Median (IQR)	12 (9.5, 14)	10 (6, 13)	0.112	9 (9, 10)	12 (11, 12)	0.089
ACE-III memory sub-score	Mean (SD)	11.9 (4.5)	9.9 (4.1)	0.13	9 (3.3)	12 (1.2)	0.054
RUDAS memory sub-score (max 8)	Median (IQR)	2 (0, 2)	0 (0, 0)	0.304	2 (1.5, 2.5)	0 (0, 0)	0.047
RUDAS memory sub-score	Mean (SD)	1.7 (2.0)	1.4 (2.8)	0.75	2.3 (2.0)	0.8 (2.1)	0.054
ACE-III attention sub-score (max 18)	Median (IQR)	13 (11, 14)	13 (11, 16)	0.730	13 (11, 13)	12 (11.5, 14)	0.815
ACE-III attention sub-score	Mean (SD)	12.5 (2.0)	12.9 (3.4)	0.67	11.9 (2.0)	13 (2.7)	0.55

Figure 1: Flowchart showing the finding of the DRD and AD subgroups.

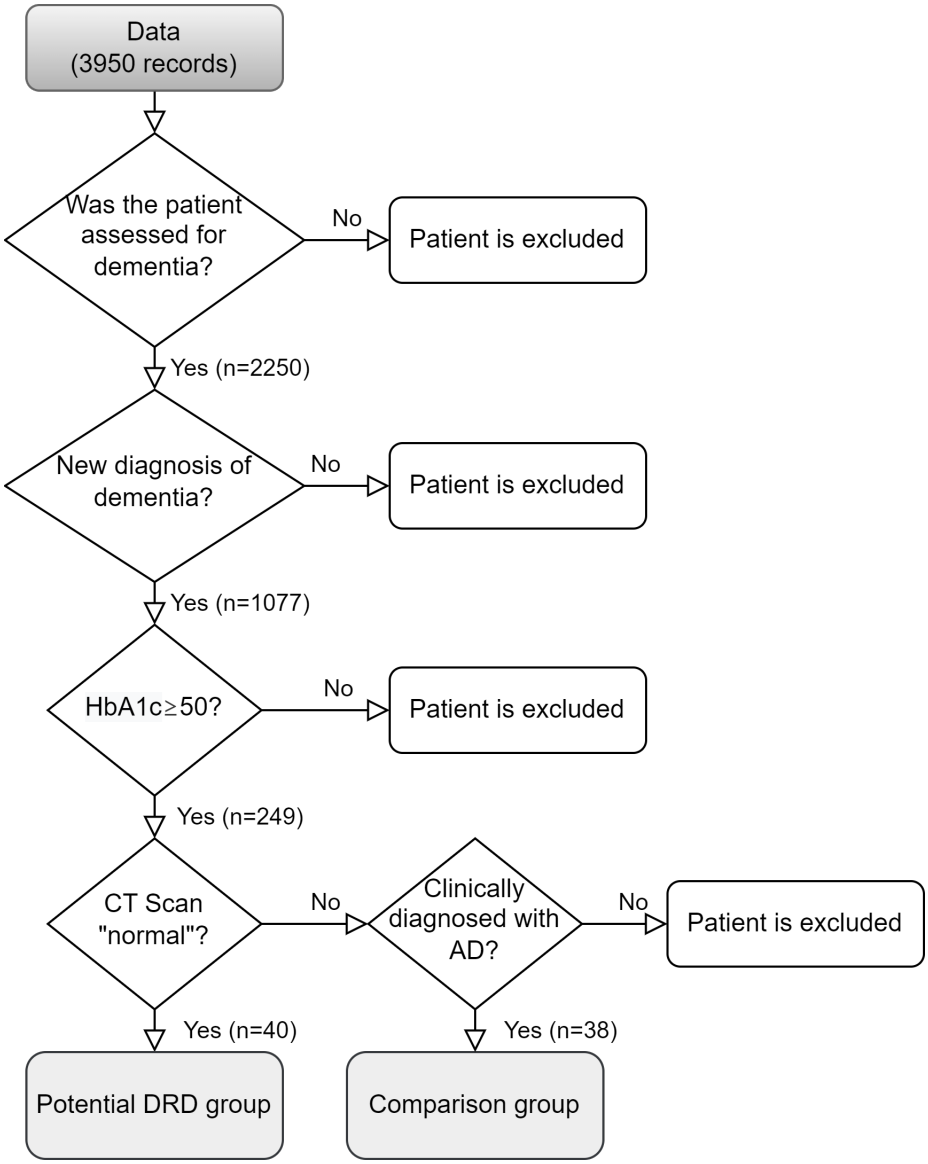
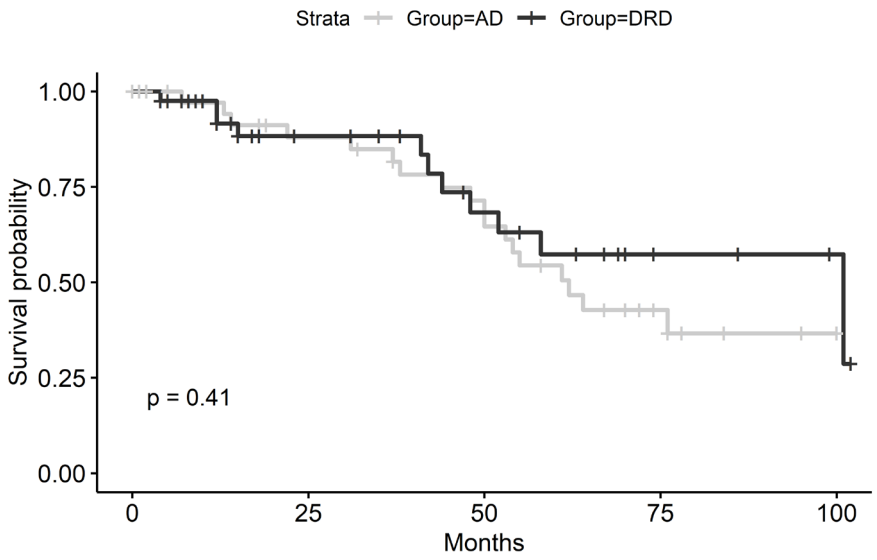
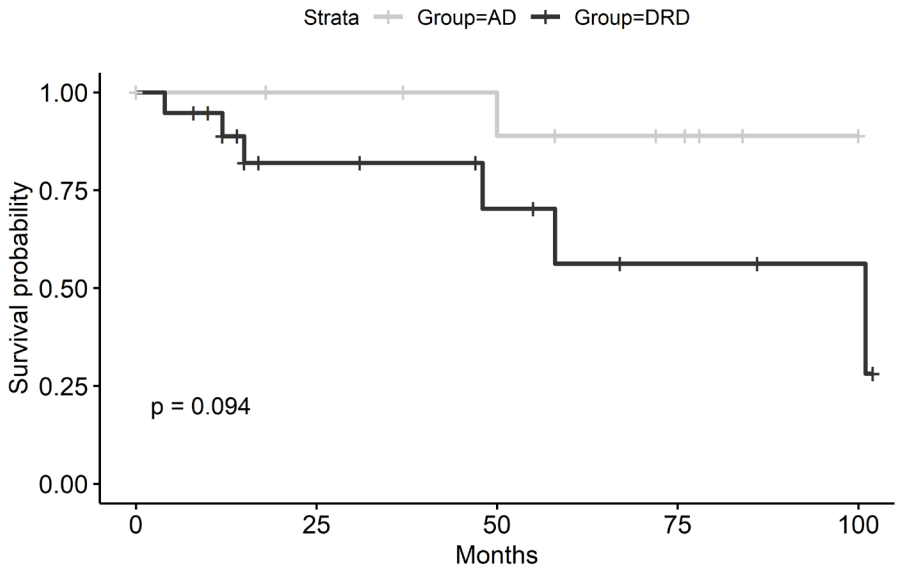


Figure 2: Kaplan–Meier plots for survival by DRD group and AD subgroup.

Whole group, all ethnicities (n=78).



Pacific subgroup (n=31).



score was higher in the DRD group (p=0.014), and mean RUDAS memory subscores were also higher (p=0.047). There were no significant differences in ACE-III scores, probably due to the small sample size. Regarding missing data, it is noteworthy that five patients in the DRD subgroup and one patient in the AD subgroup had missing data for dementia severity. Furthermore, for cognitive data, there were no available records for 2 out of 31 patients. Additionally, missing data were observed for RUDAS memory subscores, with four patients in the DRD subgroup and one patient in the AD subgroup affected. These instances of missing data are indicated in Table 3 using asterisks (* and **).

Survival

Figure 2 shows the Kaplan–Meier plots comparing survival curves for the whole group and for the Pacific subgroup classified into DRD or AD subgroups. In total (for all ethnicities), 18 patients died in the DRD group (47.4%), and 11 died in the AD subgroup (27.5%). The median survival time for the DRD group was 101 months, as opposed to 62 months for the AD subgroup, which means that although there were more deaths in the DRD group, their survival time was longer. However, this was not statistically significant (p=0.56), even after adjustment for the difference in mean age and severity between the two groups at baseline (p=0.42).

In the Pacific DRD subgroup 6/19 patients died (31.6%), and 1/12 died in the AD subgroup (8.3%). The Kaplan–Meier plot for the Pacific subgroup suggests a difference in survival but is not statistically significant (p=0.09), possibly due to small sample size and inadequate statistical power.

Discussion

Our study used routinely collected data to examine the potential existence of a group of patients meeting the criteria for diabetes-related dementia (DRD). Of 249 patients with dementia and diabetes, we found a mixed ethnicity group (40/249) who met the CT scan criteria for DRD. This group had higher memory scores and higher mortality compared to the AD subgroup, but these findings were not statistically significant. This may have been due to the heterogeneity, as the differences *were* statistically significant in the smaller Pacific subgroup. The Pacific subgroup who met criteria for DRD had higher total cognitive score and memory subscore compared to the subgroup with diabetes and AD, and their risk of dying was higher. These findings replicate those of the research group in Japan,[2–7] in that the DRD group had higher mean HbA1c, less impaired memory, and a higher risk of death than the AD subgroup. There were 17/249 patients that met HbA1c, CT scan *and* cognitive (memory) criteria for DRD; compared to the source population of people with dementia, disproportionally more of these (up to eight-fold higher) were Māori.

The main weakness of our study is that the final sample was relatively small and was unlikely to have statistical power to test for significant differences. However, the findings that the Pacific subgroup displayed the cognitive criteria for DRD and that there were proportionally more Māori in the group that met all four criteria for DRD are of interest, as, compared to NZ Europeans, Māori and Pacific Islanders living in New Zealand have a higher prevalence of diabetes and dementia. These findings may suggest a potential avenue for dementia prevention in populations that already suffer health inequalities. The findings are hypothesis-generating and may warrant further investigation in a larger, more representative, community-based sample.

Due to the limitations of using routinely collected data (rather than research data), we were only able to approximate the research diagnostic criteria described by Hanyu et al. in 2015.[4] However, the use of routinely collected administrative data is a cost-effective way of examining research questions of importance to the New Zealand population, and our findings suggest that there may indeed be a group of patients with dementia who have DRD. Another limitation is the relatively blunt nature of cognitive screening tests, which may not capture the more subtle or complex aspects of cognition. The study also relied on CT reports rather than a thorough review of CT scan images themselves, which could have led to some inaccuracies in the ascertainment of dementia subtype.

The broader question is whether DRD is a real phenomenon, or, given the potential harmful impact of hyperglycaemia on cognition, is this a potentially reversible stage of cognitive decline? Several studies have demonstrated that diabetes causes cognitive deficits in older adults without dementia,[28] and this process is likely to be on a continuum through cognitive decline to mild cognitive impairment, and then to various dementias including Alzheimer's disease and vascular dementia.[29] A 2018 meta-analysis[30] suggested that

treatment with metformin lowered the risk of dementia in type 2 diabetes, and a recent study in China[31] found that cognitive function of actively treated older diabetic patients was better than that of patients without diabetes. The main clinical priority then is to ensure adequate treatment of people with type 2 diabetes in order to prevent the onset of cognitive decline and dementia. The current cost of dementia in New Zealand is $2.5 billion NZD, and due to the rapid rise in prevalence, this will increase to $6 billion NZD by 2050.[10] In Māori, Pacific, and Asian populations, much of the cost is borne by families who provide most of the dementia care, increasing the financial burden on those who already have high socioeconomic deprivation. Thus, we should prioritise those population groups most at risk, both in terms of individual and population-level approaches to prevent diabetes and dementia, and by developing culturally appropriate dementia prevention strategies as part of diabetes health education.

Conclusion

We have replicated the 2013 findings of a research group in Japan who described a new diabetes-related dementia subtype that did not have features of Alzheimer's disease or vascular dementia, and we have demonstrated a higher risk for this subtype of dementia among the Māori and Pacific Islander patients in our sample. This may represent a potentially reversible form of dementia. Further research is required to examine the effect of anti-diabetic treatments and prevention strategies on cognitive function as an important outcome in these populations.

COMPETING INTERESTS
Nil.

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Multiple symptom illness in New Zealand contemporary veterans

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ABSTRACT

AIMS: To describe patterns of multiple symptom illness (MSI) in New Zealand military veterans, defined as clusters of "medically unexplained" symptoms not fitting within a specific medical diagnosis, and to investigate the relationship with exposure to traumatic events.

METHODS: We designed an online cross-sectional survey. The participants of interest were the 3,874 currently serving veterans who had been deployed to a conflict zone, but all veterans were eligible to participate. A modified Centers for Disease Control (CDC) 54-item symptom checklist identified MSI, the post-traumatic checklist—military version (PCL-M) identified symptoms of post-traumatic stress disorder (PTSD) and the brief trauma scale assessed "war zone" service. Factor analysis was used to identify unobserved "latent factors" in the data, factor severity scores and the number of symptoms being calculated for each respondent.

RESULTS: The CDC questionnaire was completed by 1,819 veterans, with 1,672 completing the PCL-M. The factor analysis revealed three factors, explaining 86% of the variation in the data. Factor 1 symptoms were of an arthro-neuromuscular nature, Factor 2 cognitive and Factor 3 psycho-physiological. Discriminant function analysis showed that the factors could discriminate between those with and without PTSD but could not discriminate between those who did and did not serve in a war zone.

CONCLUSIONS: In veterans, multiple symptoms including pain, sleep disorders, cognitive problems and avoidance, especially when severe, may be worthy of further investigation by health professionals because of the possible association with PTSD.

In New Zealand, military veterans can only access assistance from New Zealand Veterans' Affairs (NZVA) if they have undertaken "qualifying operational service" as defined by the *Veteran Support Act 2014*,[1] thus being veterans in a legal sense. NZVA support some 12,000 veterans, with an average age of 80 years, 5,000 being actively case managed.[2] The majority will have seen operational service in Korea, Borneo, Malaya and Vietnam. Post-Vietnam, smaller numbers were deployed with the United Nations and on other missions, but the tempo of operations rose with the deployment to Bosnia in 1992, and some 9,000–10,000 "legal" veterans were deployed between then and the withdrawal of New Zealand troops from Afghanistan in 2021. The ministerial Veterans' Health Advisory Panel—established under the *Veteran Support Act*—are specifically charged with funding research on this "contemporary veteran" group, NZVA acknowledging that they "*have had different experiences, and have different needs, compared to the older veterans. They are likely to have served in a number of deployments during their career, and come to us with more complex health issues.*"[2] Multiple symptom illness (MSI) in veterans is a cluster of "medically unexplained" chronic symptoms that do not fit within a specific medical diagnosis, first described in veterans of the 1991 Persian Gulf war, occurring in both military personnel and civilians as "Gulf War Syndrome". This conflict was one of the first in which there were multiple chemical, physical and biological stressors, the association between putative exposures and symptoms being generally weak;[3,4] however, psychological stressors were not considered at the time.[5]

Although the symptoms originate from multiple body systems, data on self-reported health conditions have been structured using factor analysis to extract one or more "unobserved" or "latent" variables from the symptom data. Forbes et al.[6] identified 1,871 Gulf War veterans, largely Navy, and a matched stratified random sample of 2,924 participants from operational units. Of these, 2,781 subjects (1,322 Gulf War, 1,459 comparison group) completed a 63-item questionnaire derived from previous studies, analysing 62 items. Three factors labelled psychophysiological distress, cognitive distress and arthro-neuromuscular distress were found to explain most of the variability in symptoms in the veterans, but a similar factor structure existed in the comparison group.

The changes were then observed longitudinally

at a 10-year follow-up,[7] with no change in the pattern of symptoms being reported over time and the underlying symptom pattern remaining similar to that in the comparison group. The levels of somatic distress and arthro-neuromuscular distress increased comparably for the veteran and comparison group, but the levels of psycho-physiological distress increased only for the veteran group, possibly explained by the delayed onset of post-traumatic stress disorder (PTSD).

Gwini et al.[8] used a latent class model to identify groups, the best fit based on symptom counts in three groups, low (average 5 symptoms), medium (16 symptoms) and high (34 symptoms). Concerningly, a small proportion of veterans with high symptom counts had developed chronic conditions including sleep apnoea, psychological disorders and cardiovascular conditions. In keeping with this pattern, they also had risk factors: high prevalence of obesity, diabetes, asthma, high waist circumference and harmful alcohol use.

As military cohorts age, the initial "healthy soldier effect", engendered by the selection process, wears off. Chronic conditions become more common, with increases in health service utilisation and disability claims, a possible explanation for the complex health problems seen by NZVA. The Australian researchers also investigated this wear-and-tear effect, defining three groups: military personnel with MSI (but no chronic diseases), those with chronic diseases, and those without MSI or chronic diseases. Health service use by those with MSI was higher than the non-MSI group and similar to those with chronic diseases. Furthermore, the general health of the MSI group was poorer.[9]

In summary, MSI, rather than being an inexplicable pattern of health effects, remains stable across time and is linked to both chronic illness and poorer quality of life. Because of the pattern of symptom reporting and the veteran group reporting it, there is a plausible association between MSI and PTSD. The aim of this study was to describe the pattern of reporting of MSI among New Zealand veterans and to investigate the relationship with PTSD as a risk factor. The intention was to highlight the symptom profile and any relationship with PTSD. Ethics approval was received from the Northern B Health and Disability Ethics Committee, ref. 17/NTB/118.

Methods

There is no comprehensive New Zealand veteran registry; however, the New Zealand Defence Force (NZDF) identified serving veterans holding the New Zealand Operational Service Medal at the time of the survey, numbering 3,874 personnel. Our steering group advised us to include retired "legal" veterans in the community, also veterans who had served but not been deployed to a conflict. Data were collected via an online survey, a postal version being available on request. In July 2018, a link to the online questionnaire was sent by email to the 3,874 currently serving (NZDF) members. An introductory message and link to the questionnaire were also presented on the NZDF "intranet landing page", a secure internal webpage from which all regular force personnel can access relevant work-related content, tools and resources. Retired military personnel were invited to participate through posters distributed to reserve units and the 43 local social clubs identified by the RSA national office to be "veteran active". Paper questionnaires with return postage envelopes were made available at these sites. Announcements were also made on military social media pages, and both retired and currently serving personnel were invited to participate through announcements on social media and veteran support websites. The questionnaire was available for completion from June to December 2018.

We used a 54-item questionnaire derived from the Centers for Disease Control (CDC) consensus case definition[5] as "*the presence of one or more chronic symptoms (for at least six months) from at least two of three categories namely fatigue, mood-cognition (symptoms of feeling depressed, difficulty remembering or concentrating, feeling moody, feeling anxious, trouble finding the right words or difficulty sleeping) and musculoskeletal (symptoms of joint pain, joint stiffness or muscle pain)*". Participants indicated whether they had experienced one or more of the listed symptoms in the preceding month, each symptom classified in terms of severity (mild, moderate, severe) and duration, lasting shorter or longer than 6 months.

The post-traumatic checklist—military version (PCL-M)[10] is a 17-item instrument asking about DSM-IV symptoms of PTS related to stressful military experiences, with response options ranging from 1 = not at all to 5 = extremely. A total symptom severity score is calculated by summing responses to each option (range = 17–85); scores of 30–45 indicate the presence of significant PTS symptoms, or probable cases of PTSD, and scores of greater than 45 indicate a presumptive PTSD diagnosis.

Trauma exposure was assessed with the brief trauma scale (BTS),[11] which captures past exposure to situations that were life threatening or capable of

producing serious injury. This included the question "*Have you ever served in a war zone, or have you ever served in a non-combat job that exposed you to war-related casualties (for example, as a medic or on graves registration duty)?*"

Factor analysis (using an orthogonal varimax rotation) was used to group the 54 symptoms based on their severity score. As the data were on an ordinal scale, the analysis was based on a polychoric correlation matrix rather than using the raw scores. Variables were removed if the communality, or proportion of variation explained, was less than 0.4, which resulted in 20 symptoms (variables) being excluded. A further 8 did not load clearly onto a particular factor. Therefore, the three final factors were based on 26 symptoms. Those three factors were also selected (rather than 4) as they had eigenvalues greater than 1.

A discriminant function analysis[12] was used to see if the factor scores could be used to discriminate firstly between the groups who had served in a war zone or had not, and secondly people who had PTSD (according to our scale) or did not have PTSD. All analyses were undertaken using Stata version 15.[13]

Results

Of the 2,024 people who clicked on the online survey link, 1,056 (24%) were currently serving. Of these, 79 did not provide any data or only personal data, 1,945 partially completed the survey, 1,819 completed the CDC questionnaire (967 currently serving, 831 ex-serving and 21 with missing data on service) and 1,672 completed the PCL-M. Factor analysis of the 1,819 completed CDC questionnaires revealed three factors having eigenvalues of 1 or more, which explained 86% of the variation in the data (Table 1). Ten variables loaded onto Factors 1 and 2; six loaded onto Factor 3.

On inspection, Factor 1 has a largely arthro-neuromuscular profile including joint pains, joint stiffness and muscle aches and pains; Factor 2 has psychological characteristics, with cognitive symptoms, sleep problems (unrefreshing sleep, sleeping difficulties, distressing dreams) and avoidance, and Factor 3 has psycho-physiological characteristics with gastro-intestinal/inflammatory symptoms.

No particular factor was indicated for loss of interest in sex; shaking; dizziness or blackouts; increased sensitivity to light; itchy or painful eyes; double vision; dry mouth; and chest pain.

Twenty symptoms were dropped from the factor analysis (as their communality was less than 0.4): irritability/outbursts of anger; difficulty finding the right word; increased sensitivity to noise; alcohol intolerance; night sweats; increased sensitivity to smell; loss of or decrease in appetite; headaches; ringing ears; flatulence or burping; constipation; persistent cough; unintended weight gain >4 kilograms; rapid or pounding heartbeat; rash or skin irritation; low back pain; skin infections;

Table 1: Factor grouping of symptoms.

Factor 1	Factor 2	Factor 3
Problems with sexual functioning	Loss of concentration	Diarrhoea
Passing urine more often	Feeling distant from others	Stomach cramps
Loss of balance or coordination	Unrefreshing sleep	Nausea
Loss of sensation hands/feet	Forgetfulness	Feverish
Tingling or burning hands/feet	Sleeping difficulties	Sore throat
Joint pain	Avoid doing things or situations	Tender/painful swelling of lymph glands
Joint stiffness	Fatigue	
Muscle aches/pains	Distressing dreams	
Wheezing	Feeling jumpy/easily startled	
Shortness of breath	Difficulty speaking	

mouth ulcers; toothache; and indigestion—all 54 symptoms being accounted for.

The groups for the discriminant function were the 1,672 respondents who completed the MSI and PCL-M, 59% having served in a war zone, and 29% having PTSD.

Using the "war zone" discriminant function (with factor scores as predictors) did not have much utility (Table 2).

Thus, 64% of people who were not in a war zone were predicted to be in that group, and only 45% of the people who were in a war zone were predicted to be in that group.

Using the PTSD function in a similar manner gives results as in Table 3.

That is to say, 82% of people who do not have PTSD were predicted to be in that group, while 72% of the people who do have PTSD were predicted to be in that group.

Discussion

The factor analysis reveals Factor 1 to have an arthro-neuromuscular profile, Factor 2 cognitive and Factor 3 psycho-physiological; the factor scores discriminating only those who had PTSD, and not those who had been to a war zone. This tends to confirm that PTSD is associated with MSI, as did the finding that those with PTSD had more severe symptoms.

The strengths of the study are the relatively large sample size and the inclusion of all veterans, both those who had deployed and those who had not.

A weakness is the response rate—24% from serving veterans—and we know neither the total number of veterans in New Zealand, nor whether those with PTSD were more or less likely to respond, so any direction of bias is difficult to assess, but a higher or lower prevalence may affect the symptom profile. We asked only about present symptoms, so recall bias will not be present, but this limits our conclusions to this particular sample. The cross-sectional design does not allow the direction of any effect to be investigated, so we cannot conclude that PTSD contributes to, or causes, multiple symptoms.

In previous cross-sectional analyses of this sample,[14,15] we found, in comparison with the general population, a higher self-reported prevalence of problems with pain or discomfort, mobility, self-care and carrying out usual activities. Age, length of service, deployment, psychological flexibility and better sleep quality were associated with better self-reported health and distress with poorer health. With post-traumatic stress disorder as the outcome, factors associated with higher PCL-M scores were trauma exposure, older age, male sex and Māori ethnicity; asso-

Table 2: Discriminant analysis for having served in a war zone.

		Classified war zone		
		No N(%)	**Yes N(%)**	**Total**
In a war zone	No	441 (64)	243 (35)	684
	Yes	539 (55)	449 (45)	988
	Total	980 (58)	692 (41)	1,672

Table 3: Discriminant analysis for having PTSD.

		Classified PTSD		
		No N(%)	**Yes N(%)**	**Total**
True PTSD	No	995 (82)	224 (18)	1,219
	Yes	143 (28)	365 (72)	508
	Total	1,138 (66)	589 (34)	1,727

ciated with lower PCL-M scores were greater length of service, psychological flexibility and better-quality sleep.

The Australian Defence Force provides the closest comparisons. The Forbes et al.[6] factor analysis in Royal Australian Navy Gulf War veterans also found three factors, labelled psycho-physiological distress, cognitive distress and arthro-neuromuscular distress. There is almost certainly no "unique" MSI signature: it is the number of symptoms and their severity that is important, as these have associations with chronic ill health and high health service use.[8,9]

Although Gulf War veterans "*were exposed to an impressive array of biologic and chemical agents*,"[5] the association with psychological factors were not pursued. The cognitive distress factor is, however, the most reproducible across studies, and the discriminant analysis for PTSD showed that symptom scores are predictive of PTSD, tending to confirm that PTSD is a signature disorder in this population.

Health practitioners might find that a patient presenting with multiple symptoms including muscle and joint aches and pains, cognitive problems, disorders of sleep and avoidance is worthy of further investigation, including whether or not they have military service, and enquiry about PTSD symptoms. More precise definition around, and refinement of, a parsimonious set of questions should give guidance as to when intervention is necessary, the likely direction of future research efforts.

Further follow-up should be possible, as we asked permission to contact participants again. In this case we would be able to assess any changes in the number and severity of symptoms. We are hopeful that a behavioural intervention will have become available in the interim, in which case we can assess the effects.

COMPETING INTERESTS

Nil.

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Voices for health: going, going, going…

Boyd A Swinburn

This time last year, I was feeling quite optimistic about the potential for real action on improved public health from this Government. We were entering a new phase for health as the Simpson report[1] was about to be implemented on steroids, with its explicit priorities on population health and joined-up health structures for improved health equity. Voices for health were heard from within and outside the healthcare system and the Labour Government seemed open to listening to ways to tackle the big health questions of our time—not only the acute infectious disease pandemics, like COVID-19, but also the chronic pandemics of obesity and non-communicable diseases. Consideration was also being given to the capacity and resilience of our wider societal and infrastructural systems to cope with health threats from the multiple climate, economic and social disruptions we will be facing in the future as a nation.

Health Coalition Aotearoa, which I co-chair, argued strongly for the two new health entities, Health New Zealand (Te Whatu Ora) and the Māori Health Authority (Te Aka Whai Ora) to have a legislative responsibility in the new Pae Ora health structures to address the underlying social determinants of health.[2] It was therefore pleasing that the *Pae Ora (Healthy Futures) Bill* was amended to explicitly include these responsibilities. The Simpson report noted that about 80% of our population's health and health equity status is determined by factors outside the healthcare system,[1,3] so it is appropriate that the healthcare system should be a strong advocate for prevention policies beyond the hospital walls—the ambulances at the bottom of the cliff should have a strong voice in the need for fences at the top of the cliff. It is also pleasing to see that Associate Minister of Health, Barbara Edmonds, has the specific responsibility for "health in all policies". This is in keeping with the purpose of the Pae Ora health reforms, whereby the health sector needs to influence health-relevant policies under other ministers' jurisdictions.

However, the last 12 months has also seen a progressive, and concerning, loss of voices for public health with the firing of Rob Campbell, chair of Te Whatu Ora's Board, as a recent, visible, example.

In May 2022, the New Zealand Medical Association (NZMA) went into receivership after 136 years of service as a highly respected advocacy voice for improved healthcare services and prevention policies. While not related to the changes in health structures, the timing of this significant loss of independent voice for health was very unfortunate. NZMA was a true champion for health, but we have now lost that valuable platform for doctors working at the clinical and public health coalface to bring their experiences and calls for action to the national policy table.

Independent, evidence-based health advocacy is essential for improving clinical care and public health. The health experts who conduct research in New Zealand, understand the international evidence and deliver health on the clinical and public health frontlines need to be able to bring this knowledge and these insights into the public arena for debate. This is especially true for commercially available products backed by strong counter-lobby voices, like alcohol and ultra-processed food, that are creating such health harm.

Shortly after the change to the new Pae Ora health structures in July 2022, the then Health Minister, Andrew Little, shut down the ability of these new structures to continue to provide a range of public submissions on government consultations, including Select Committee processes. This came as a shock to the sector because it was not signalled as part of the new regime. This has closed off a critically important avenue for various parts of the healthcare sector to publicly comment on consultations that involve the underlying determinants of health that lie outside the jurisdiction of the healthcare sector (e.g., justice, housing, education, tax, social welfare). Mechanisms are apparently underway within Te Whatu Ora to collate the plurality of expert comments across the government-funded health sector into a single, corporate submission. However, this runs the risk of burying the diversity of evidence, stories and perspectives within a single, centralised submission. For example, the impacts of alcohol policies are experienced very differently in emergency departments, mental health services, licensing processes and paediatric

services, and their voices are likely to be more impactful if they can be heard separately.

As a further illustration, the Ministry of Education ran a consultation in mid-2022, just prior to changing to the Pae Ora health structures, on whether schools should be required to ensure that any foods and drinks they sell or provide to students would be healthy.[4] Such a policy was obviously seen as very important by the health sector that is dealing with the downstream consequences of childhood obesity, dental caries and poor mental health. Among the 52 submissions from health organisations, there were 12 from government health agencies (e.g., public health units, district health boards and the Ministry of Health), 10 from government-funded organisations and programmes (e.g., Healthy Families NZ, regional sports trusts) and six from NGOs, which receive some government funding.

If this consultation had been held a few months later, all the health agencies and probably the government-funded programmes would have been barred from publicly submitting to this important health consultation conducted by the Ministry of Education. Now there is the added bureaucracy and time delays involved in organising the inputs from the myriad parts of Te Whatu Ora into a single corporate submission under central control and the loss of the diversity of frontline perspectives, both of which risk a weakening of the health voice.

While it is true that Chris Hipkins, as the then education minister, did not heed the concerns of the health sector and allowed schools to continue to feed or sell unhealthy food to their students, the fact that we previously heard the variety and number of expert voices from within the health system on behalf of children's health, and now we won't, signals a significant loss of health democracy.

In late-2022, two senior health people were admonished by the health minister for supporting an important piece of preventive legislation—Chlöe Swarbrick's Private Member's Bill to strengthen Local Alcohol Plans and buy-out alcohol sponsorship of sports and events. Minister Little argued that Dr Gary Jackson, Director of Population Health at Counties Manukau Health, and Rob Campbell, chair of Te Whatu Ora's Board, had overstepped the mark in voicing support for a non-Government Bill.[5]

Minister Little may have been technically correct in his judgment, but the public nature of Dr Jackson's telling off and Mr Campbell's subsequent firing (triggered by his later comments on managing water systems) have sent negative ripples through staff and boards of the new health entities—the message seems to be "*no matter how important the population health issue is, do not speak up in favour of preventive action the government should be taking*".

Clinical doctors have a duty of care to speak up on behalf of patients. If there are evidence-based, effective practices in hospitals that would really benefit patients, we expect them to advocate for those practices to be implemented. We still hear from some courageous senior doctors in the media about ways the hospital system should act to improve patient outcomes, despite a perception that speaking out may affect their career. Similarly, the public has come to expect advocacy from public health physicians who have a duty of care to the populations they serve. If there are evidence-based, effective policies to prevent death and disease, we expect public health physicians to speak up on behalf of their communities.

Unfortunately, public health physicians who are classified as public servants may feel constrained in their ability to advocate by the rather outdated 2010 *Standards of Integrity and Conduct* managed by the Public Services Commission.[6] Statements such as "*We must avoid any activities that may harm the reputation of our organisation*", "*We must always be careful that our actions do not compromise our organisation or our Minister*", "*The importance of keeping politics out of our job and our job out of politics is undiminished*" are problematic when these aspects of the code clash with doctors' ethical duty to speak up on behalf of the health of patients and communities. There is no distinction between "party politics", which public servants should clearly not be commenting on in their professional roles, and "politics" in general—most systemic clinical and public health decisions are intrinsically political because they involve resource allocation and policy-making. Much greater clarity is needed on these matters from the Public Service Commission.

In addition, Medical Officers of Health used to provide free, frank and relatively independent public health advice to their communities through the media, but we now rarely hear from them. The centralised public health messaging, which was so valuable during the COVID-19 pandemic, appears to be now entrenched, including through a new section of the *Health Act* (s7A[9]), which was inserted in July 2022 giving explicit powers to the Director-General to revoke the designation

of a Medical Officer of Health for reasons unspecified.[7] The centralisation and control of communications and the clamp downs on senior doctors speaking out for health has created a chill effect on health democracy and it is a serious impediment to improving the health of New Zealanders.

These negative ripples have also impacted the way that public health services operate. For example, some public health units work in collaborative alliances with NGOs and community organisations to improve population health locally. This is what they should be doing, but there is a palpable nervousness within those services about whether they are allowed to participate in wider community efforts to advocate for healthier environments. In addition, Health Coalition Aotearoa has heard concerns from some of its members about Te Whatu Ora's heavy-handedness if an NGO is undertaking advocacy activities, even if advocacy is part of their government contracts. The fear of losing government contracts has further dampened the voices of the NGO sector for addressing the determinants of health.

In such a short space of time, we have lost many important voices for health and the nervousness about speaking up for health has become pervasive. This is the opposite of what my hopes were for population health under the new health structures a year ago. I believe this has been a backward step for public health in New Zealand. We desperately need policies to prevent the huge harm from products like alcohol and ultra-processed foods. For decades, the lobbying from these harm industries has dominated the political power dynamics resulting in no meaningful government policies for many years despite overwhelming evidence of their harm.

The obesity epidemic and appalling dental health in this country have remained untouched by government policies to tax sugary drinks, subsidise healthy food, ban junk food marketing to children, require healthy food provision in schools or even have a useful front-of-pack food labelling system. The voices for public health action have historically been swamped by industry opposition and now this imbalance is even worse.

Health Coalition Aotearoa was established in 2019 to bring the voices of the health sector together for improved health and health equity through reductions in harm from tobacco, alcohol and ultra-processed foods, as well as through strengthening public health infrastructure to better address the commercial causes of ill health. These three harmful products cause almost one third of our population's premature death, disease and disability, as measured by disability-adjusted life-years lost,[8] and there are many evidence-based policies recommended by the World Health Organization,[9] New Zealand's own experts[10] and government reports,[11] which are simply not being enacted.

The approach being taken by the current Minister of Health, Ayesha Verrall, gives some hope for action. As Associate Minister of Health, she implemented some excellent policies around folate in flour to prevent neural tube defects, fluoridation of water supplies to prevent dental caries, and, of course, the new world-leading legislation for tobacco control. All of these public health policies have been preceded by years of advocacy from health professionals. Minister Verrall will definitely need the strong, diverse voices of the health sector to back her on reducing the harm from alcohol and ultra-processed foods, given the formidable lobby power behind those harmful products.

The Health Coalition does not take government funding so that it can have an independent voice backed by its membership of individual health professionals and health organisations. The rapid demise of advocacy voices for health that I have outlined means that the collective voice of the Coalition is needed now more than ever. Having doctors and other health professionals—who spend much of their working lives managing the consequences of preventable diseases—as Health Coalition members is essential for the sustainability of the organisation. Previous NZMA members know the value of this input.

The loss of advocacy voices or activities from within the new health structures runs counter to the promises of joined-up action for improved population health and health equity under the new Pae Ora health system. The commercial lobbyists for health-harm products not only get direct, non-transparent access to ministers due New Zealand's lack of lobby regulations and monitoring, but they now face a diminished public health voice calling for the regulation of these products. It is the responsibility of the Minister of Health, leaders of the Pae Ora health organisations and the Public Services Commission to create a stronger, safer environment for the experts on the clinical, public health and research frontlines to advocate for better health and health equity outcomes for Aotearoa New Zealand.

COMPETING INTERESTS
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Abortion law in Aotearoa New Zealand

Felicity Goodyear-Smith

ABSTRACT

This article outlines the history of abortion law in Aotearoa New Zealand from colonial times to the present. The struggle for law reform has been long and difficult, with marches and rallies, protests and placard-waving, and firebombing of abortion clinics. Aotearoa New Zealand elections have been fought on this issue. Abortion was regulated here under the Crimes Act until 2020. Finally, after 150 years, procuring an abortion in Aotearoa New Zealand is no longer a crime, it is a women's healthcare issue along with others relating to women's reproductive health, including obstetric, contraceptive, sexually transmitted disease and other gynaecological care. The new law promotes autonomy, reproductive health, patient safety and health equity. The abortion struggle serves as an illustration of our changing political and social landscape, with a public move from conservative towards more liberal values. However, the issue continues to divide people, and events in the United States have shown how quickly change can occur, with their Supreme Court overturning *Roe v Wade* and states now banning abortions. We should not be complacent.

Throughout history, many women have found themselves unhappily pregnant through a variety of circumstances. Until recent times, the choices to address this were limited, and consequences were often dire. Procuring an abortion in Aotearoa New Zealand is no longer a crime, it is a woman's healthcare issue along with others relating to women's reproductive health, including obstetric, contraceptive, sexually transmitted disease and other gynaecological care. It promotes autonomy, patient safety and health equity. The abortion struggle serves as an illustration of our changing political and social landscape, with a public move from conservative towards more liberal values. This article is a bare-bones account of the evolution of our abortion law in Aotearoa New Zealand.

In Great Britain, prior to the nineteenth century abortion was only prohibited after quickening (when a woman first feels movement inside her womb, at about 18 to 20 weeks gestation).[1] In 1803, the *Offences Against the Person Act* made all abortion illegal. "*To procure the miscarriage of any women then being quick with child*" incurred the death penalty, regardless of whether the child was born alive or dead.[2] Inducing an abortion before quickening was less serious, with punishments including fines, flogging or transportation not exceeding 14 years. However, determining whether quickening had actually occurred relied on a woman reporting that she had felt movement, and it may not have been in her best interest to say so.

In 1837 the *Act* was amended, abolishing the death sentence, but increasing the maximum penalty for procuring an abortion to transportation for life, whether or not quickening had occurred, and regardless of whether the woman was actually pregnant.[3] A further amendment in 1861 made the woman herself liable for prosecution if she attempted to procure her own abortion, with a maximum penalty of life imprisonment. Abortionists and women who self-induced abortions were criminals under the law, and women who sought abortions were accomplices to the crime.[4]

Aotearoa New Zealand inherited its legal system from Great Britain. European settlement of Aotearoa New Zealand started in the 1830s, and the colony adopted British law in 1840. In 1867 the British statute was replicated as the New Zealand *Offences Against the Person Act*.[5] Punishment of abortion procured by any means, including self-induced, was up to life imprisonment or "transportation beyond the seas", although of course Aotearoa New Zealand was already "beyond the seas"! In reality, unless there were fatal consequences, most abortions did not come to the attention of the courts.

In 1893, all indictable offences in Aotearoa New Zealand were codified as the *Criminal Code Act*.[6] The maximum term of imprisonment for a woman who tried to procure an abortion on herself, even if she was not actually pregnant, was reduced from life to 7 years. Men who supplied the means to procure an abortion by buying an abortifacient or paying an abortionist faced whipping or flogging.[7]

However, because Victorian morality condemned women having children out of wedlock, and impoverished married women found themselves unable to feed yet another child, many women had little

choice than attempt self-abortion, or visit an illegal abortionist. Use of traditional methods such as hot baths, physical exertion, drinking gin or deep massages of the lower abdomen were unlikely to be effective. Chemists and herbalists did a brisk trade in potions and pills touted to bring on a missed period, made from compounds such as oil of juniper and parsley oil, which were relatively safe, but with little evidence that they worked. More toxic compounds including pennyroyal, ergot, quinine and lead may have been more effective, but were easily overdosed and potentially lethal. When these methods failed, illegal abortionists were sought out.[8] If abortion was not an option, another choice was to pay someone to take the child, with "baby farmers", usually women, looking after a number of children, who were sometimes neglected or even deliberately murdered.[9]

The *Crimes Act 1908* succeeded the *Criminal Code Act 1893*, with little change to the abortion law, except that if someone caused the death of a child before or during its birth to preserve the life of the mother, then no crime was committed.[10] While abortion was now permitted when the mother's life was deemed to be in serious danger, in reality few doctors would perform the operation, hence back-street or self-induced abortions were still the norm.

After the first World War, criminal abortions causing sepsis requiring hospital admission were a growing problem.[11] In 1937, a government Committee of Inquiry into septic abortion estimated that about 4,000 illegal abortions occurred in Aotearoa New Zealand each year. It concluded that although abortion was mainly due to economic hardship and unmarried pregnancies, relaxing the law was not recommended—the focus should be on increasing the birth rate.[12]

A 1938 test case in Britain led to a ruling that if a doctor believed that continuing a pregnancy would render a woman "*a physical or mental wreck*", then abortion was justified to save her life.[13] However, the abortion debate came to a standstill during World War II, and when the soldiers returned, Aotearoa New Zealand experienced a baby boom. Finally, in 1961 a clause was added to the New Zealand *Crimes Act* stating that procuring an abortion before 20 weeks gestation was lawful if "*the person doing the act believed that the continuance of the pregnancy would result in serious danger… to the life, or to the physical or mental health, of the woman or girl*".[14] Theoretically, getting a legal abortion was a little easier. National Women's and other hospitals set up "termination committees" comprising senior gynaecologists plus co-opted others such as psychiatrists.[15] However, few abortions were approved.

The debate intensified in the 1970s, and there was a rise in action groups both for and against abortion. The New Zealand Society for the Protection of the Unborn Child (SPUC) was established in 1970, and its membership grew rapidly, mostly but not exclusively Roman Catholic.[16] Their strategy was to enlist MPs as members and encourage their general membership to engage in mass letter-writing to their MPs. Later that year the Abortion Law Reform Association of New Zealand (ALRANZ) was also formed, lobbying that contraception should be freely available to all who needed it, and that abortion should be a decision between a woman and her doctor. They focussed on disseminating evidence to counter misleading rhetoric.

In 1974 the first Aotearoa New Zealand abortion clinic, the Auckland Medical Aid Centre (AMAC), was opened, with trained counsellors and an experienced Australian abortionist operating and training other medical practitioners. SPUC reacted swiftly. The prime minister and the police were supplied with affidavits from senior SPUC members, alleging that the clinic provided a poor-quality and illegal service. Armed with these affidavits, the police raided the clinic and removed and read all 500 clinical records. Despite outrage from the medical profession, police subsequently arrived unannounced at some of the women's homes or workplaces to interview them, in the presence of family or colleagues who were unaware that they had had an abortion. Subsequently, in February 1975 the lead abortionist at AMAC, Dr Jim Woolnough, was charged with 12 counts of illegally procuring an abortion.

Concurrently, Dr Gerard Wall, a Labour MP and SPUC member, introduced a private member's Bill into Parliament to amend the *Hospitals Act*, restricting abortions to public hospitals. This was clearly designed to close down AMAC. An amendment changed the requirement to a hospital run by a hospital board, or any licensed hospital approved by the director-general of health. The "Wall" Bill was rushed through Parliament without proper scrutiny by Select Committee, and enacted in May 1975. However, in anticipation of the law change, the Auckland Medical Aid Trust had purchased Aotea Private Hospital, and AMAC was able to continue to provide their services there. Subsequently on appeal, it was ruled that the new law

amended the wrong section of the *Crimes Act*. The judge ruled that it was an "*ill-drafted piece of legislation*", and that the *Act* was invalid.

Woolnough's case proceeded through depositions to a trial in August 1975 with a hung jury, a second trial in November 1975 where he was acquitted, and an appeal by the prosecution that was dismissed by the Court of Appeal in July 1976. AMAC continued to provide a service throughout, including weathering a fire-bomb attack of Aotea Hospital in April 1976.

Prior to the November 1975 general election, SPUC conducted active campaigns against MPs who had voted against the *Hospital Amendment Bill*.[6] The Catholic Church became actively involved, advising their congregations to vote on the basis of the candidate's attitude towards abortion.[17] The outcome of the general election was the defeat of the Labour Party. National Party's Robert Muldoon, who vocally opposed abortion, was elected prime minister. It is unknown to what extent the abortion issue influenced these results. A nation-wide survey conducted immediately post-election found a substantial majority of New Zealanders favoured easier access to abortion, and wanted a referendum on the topic.[18] There were 78 pro-life MPs in the new Government (23 National and 35 Labour) compared with 39 pro-abortion (9 National and 20 Labour), unrepresentative of the Aotearoa New Zealand public.[19]

During this time, a Royal Commission on Contraception, Sterilisation and Abortion, set up by the prime minister in June 1975, was investigating whether current law on abortion met the needs of society, and whether any law changes should be made in regard to abortion.

In August 1976 Air Commodore Frank Gill, the Minister of Health, proposed the *Health Amendment Bill* to revisit Wall's failed *Hospital Amendment Act*. "Gill's Bill" required women seeking legal abortions to appear before a committee of an obstetrician and gynaecologist and at least one other doctor. This Bill faced widespread opposition from the medical profession, and was viewed by the pro-abortion lobby as an attempt to pre-empt the report from the Royal Commission. At its second reading in September 1976, National MP George Gair managed to pass an amendment which deferred it for 12 months until after the Royal Commission had reported, on the condition that no further clinics would be opened before that time. The *Bill* lapsed.

The Royal Commission conducted public hearings with oral submissions.[20] The Commission was clearly anti-abortion. SPUC employed two Queen's Counsel who aggressively attacked those making pro-abortion submissions. The Commission sat for nearly 2 years at a cost of a quarter of a million dollars, and released their report in April 1977.[21] They agreed with SPUC proponents that human life begins at conception. They recommended changes to the *Crimes Act*, including the setting up of a statutory committee to oversee the working of abortion law, and the establishment of panels to decide whether an abortion being sought was justified under the law. Each panel was to comprise two doctors and a non-voting social worker, and operate under the oversight of the statutory committee. The aim was a reduction in the number of abortions taking place.

Dismayed by the recommendations, which would make abortion law even more restrictive than the status quo, pro-abortion groups demonstrated in force and ALRANZ lobbied Parliament. SPUC launched a huge public campaign with full-page advertisements in newspapers,[22] had brochures delivered to all households nation-wide, and called for pro-life supporters to write to the prime minister and other ministers of Parliament.[19]

The *Contraception, Sterilisation and Abortion Bill* was introduced into Parliament in August 1977, based on recommendations from the Royal Commission. The Bill was rushed through with no discussion regarding abortion at Select Committee, and was passed under urgency in December. Getting an abortion was now much more difficult. Women seeking consideration for abortion must be referred by their GP to two certifying consultants, one of whom must be an O&G specialist, and neither to be the operating doctor. An Abortion Supervisory Committee was established to appoint and regulate the certifying consultants and decide which institutions would be licenced to provide abortions. Neither socio-economic hardship, rape, incest, the health of the mother nor carrying a grossly abnormal baby that would be born with serious handicaps were grounds for an abortion. On a positive note, the *Bill* specified that hospital boards were to fund abortions.

The passing of the 1977 *Contraception, Sterilisation and Abortion Act (CSA)* led to the abrupt closure of AMAC. Across the country, feminist groups raced to set up the Sisters Overseas Service to help women travel to Australia to have their abortions. There was public outcry, and calls for the *Act* to be repealed, but this was unsuccessful. However, there were some amendments made to the *Crimes Act* in December 1977 and to the

Crimes and *CSA Acts* in July 1978. The clause "*and the danger cannot be averted by any other means*" was removed, and foetal abnormality was a legal ground for abortion but only up to 20 weeks gestation. Abortion of a pregnancy resulting from incest was also lawful. The pregnancy being due to rape or occurring at either extremity of child-bearing age remained not being legal grounds for abortion in themselves, although these factors could be taken into consideration.

The Abortion Supervisory Committee gave licences to a number of public hospitals to perform abortions, but they declined AMAC's application, which meant that the clinic had to remain closed. The Committee struggled to appoint the necessary number of certifying consultants, and it became clear that the *Act* was not working. Eventually, in 1979, an appeal by AMAC to be granted a licence was successful, and the clinic opened again.

SPUC protested the clinic reopening with rallies and calls to further amend the law. AMAC was regularly picketed. Staff faced threatening phone calls and protestors outside their homes, waving placards and planting wooden crosses in their gardens. However, slowly public clinics were set up by Auckland, Wellington and Christchurch hospitals, and by the mid-1980s, Aotearoa New Zealand women were served by one private and three public abortion services. Over the next two decades, the four main clinics (Auckland Medical Aid Centre, Epsom Day Unit, Parkview and Lyndhurst) provided the vast majority of abortions in Aotearoa New Zealand.

During this period, Aotearoa New Zealand saw unprecedented protests for and against abortion, with petitions, rallies and marches on Parliament. There was a further arson attack at AMAC in 1984, and Epsom Day Hospital suffered fire-bombing in 1985 and 1987. At Parkview in Wellington, patients and staff had to make their way past protesters waving banners to get to the front door. Lyndhurst in Christchurch was firebombed in May 1985 before it even opened its doors,[23] and suffered a further arson attack in October 1989. In 1999, a man tunnelled under the perimeter fence, broke through under the floorboards, and was in the process of planting a bomb when he was apprehended by the police.

Over time things quietened down, and by the 1990s abortion took less of a front-seat role in politics. Abortion providers found ways to make the law work, and most women who needed an abortion could get one.

Although Aotearoa New Zealand had led the way with the women's right to vote, it was more conservative regarding abortion than many other countries. Laws had been passed in England in 1967 and Australia in 1969 justifying abortion if a woman's mental health would suffer from a continued pregnancy. Importantly, in 1973 the United States Supreme Court hearing *Roe v Wade* recognised abortion as a constitutional right.

Over the years SPUC attempted to introduce more restrictive laws, such a Bill proposing that all foetuses be officially registered in the national Registrar of Births, Deaths, and Marriages (requiring death certificates for all miscarriages), and one requiring that girls under the age of 16 must notify their parents before having an abortion, but these did not progress.

Aotearoa New Zealand society became much more broadminded, with the passing of the *Homosexual Law Reform Act* in 1986, decriminalising consensual sexual conduct between men,[24] contraceptives able to be freely provided to those aged under 16 under amendment to the *CSA Act* in 1990[25] and decriminalisation of prostitution in 2003. However, the abortion legislation persisted. Providers had found ways to work around a bad law. A law change might make the situation worse, and for many years those who were pro-abortion had little desire to rock the boat.

During the 2010s, a wave of international abortion reform law changes in countries such as Canada, India and Brazil led to a renewed campaign by Aotearoa New Zealand abortion rights advocates to decriminalise abortion. ALRANZ and other abortion rights groups argued that abortion was a health and reproductive rights issue.

By 2017 a poll found that a majority of New Zealanders supported legalisation of abortion. The Law Commission drafted some proposals to help realign abortion law towards a health approach. The turning point was the second leader's general election debate in September 2017. Labour leader Jacinda Arden clearly articulated her stand on abortion when she told Prime Minister Bill English that in her opinion, abortion should not be in the *Crimes Act*. She became prime minister in October 2017.

The *Abortion Legislation Act 2020* was enacted on 24 March 2020, the day before Aotearoa New Zealand went into Alert Level 4 lockdown due to the COVID-19 pandemic. It removed abortion from the *Crimes Act*. The Abortion Supervisory Committee was abolished, and its responsibilities given to the Minister of Health and to the

Director-General of Health. Any qualified health practitioner may now provide abortion services up to 20 weeks gestation. When a woman is more than 20 weeks pregnant, an abortion can only be provided where clinically appropriate, and after consultation with another qualified provider. Certifying consultants are no longer required, premises do not need licencing and women may self-refer. The health practitioner must advise the woman that counselling is available, but she can decline to make use of this service.

The increased number of providers, especially for early medical abortion, and no requirement for licenced premises has increased access across the country, and development of training programmes and clinical guidelines have reduced national variation and facilitated more standardised, equitable care.

Moving from crime to care has been a long journey, but is it over? In 2022 the United States (US) has experienced the undoing of their liberal abortion laws. The Supreme Court overturned the *Roe v Wade* ruling,[26] which had previously decriminalised abortion nation-wide.[27] Individual states have now passed laws to ban abortions. Further, on 7 April 2023, Texas-based federal judge Matthew Kacsmaryk ruled to suspend the Food and Drug Administration (FDA)'s approval of mifepristone, which had been approved by regulators 23 years ago and is used in about half of abortions in the US. He argued that FDA had been wrong to approve mifepristone. This would remove the option of an early medical abortion in states where abortion is still legal. Legal authorities were concerned that this could undermine the FDA's drug-approval authority.

This decision would further reduce access to abortion for US women. About 35 million women of reproductive age (55% of the US total) live in a county that has an abortion provider. Without medication abortion using mifepristone, this number could drop by as much as 2.4 million women, or 51% of the US total.[28] The Department of Justice appealed this decision. On 21 April the Supreme Court preserved the status quo of the FDA approvals, so use of mifepristone for early medical abortions remains.[29] Further attempts to prevent abortion services in states where it is still legal can be anticipated.

Could this happen here? This is unlikely, as in Aotearoa New Zealand legal abortion is enshrined in our law, whereas *Roe v Wade* was merely a judicial ruling. Further, Aotearoa New Zealand is a much more secular nation, and much less politically polarised than the US. However, we cannot be complacent.

The abortion struggle serves as an illustration of our changing political and social landscape. This was a remarkable period in our history, and there are many tales of extraordinary events and courageous acts. Moral crusaders, activists, legislators, abortion providers and many others on both sides of the debate put their reputations and sometimes their lives on the line to do what they thought was right. These human stories can be found in my book *From Crime to Care: the History of Abortion in Aotearoa New Zealand*, 2023, https://www.nationwidebooks.co.nz/product/from-crime-to-care-the-history-of-abortion-in-aotearoa-new-zealand-9780473663063.

COMPETING INTERESTS
Nil.

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Candida auris: lessons learnt from the first detected case in Aotearoa New Zealand

Shivani Fox-Lewis, Leanne Buckwell, Wendy McKinney, Ruishan Tang, Graham Upton, Bindu Francis, Sally Roberts

Candida auris (*C. auris*), a multidrug resistant yeast, is a global threat. It can cause outbreaks within healthcare facilities, and presents treatment, laboratory diagnostic and infection prevention and control (IPC) challenges.[1,2] Due to its rapid global spread, there is a risk of importation to Aotearoa New Zealand, especially following the relaxation of COVID-related border restrictions.[3] We describe the first detection of *C. auris* in Aotearoa New Zealand and lessons learnt for laboratory diagnosis and IPC.

Case report

A 69-year-old man was admitted from an overseas hospital for the ongoing management of cancer. Screening for multidrug-resistant organisms (MRO) occurred on the third day of admission. Passive surveillance for *C. auris* was occurring, whereby yeast-like colonies growing on routine MRO screening plates were identified. A white colony on the CARBA-SMART (bioMerieux) plate from a groin swab was identified by MALDI-TOF (bioMerieux Vitek MS) as *C. auris*.

Phenotypic test results (API ID32C strip; growth at 27°C, 37°C, 40°C, and 42°C, with no growth at 45°C) and growth on chromogenic agar (Figure 1) were consistent with *C. auris*. 18S rRNA gene PCR and sequencing found 100% sequence identity to *C. auris*. Antifungal susceptibility testing revealed minimum inhibitory concentrations consistent with non-susceptibility to fluconazole and amphotericin B (as described in previous studies).[4]

Following the detection of *C. auris* colonisation, Contact Precautions were implemented. The patient had been admitted to a single room. Environmental cleaning with sporicidal disinfectants reduced the risk of fomite-mediated transmission. Two rounds of screening were performed on all patients on the ward at the same time as the case, before correct IPC precautions were implemented. Patients discharged prior to screening had an alert linked to their electronic patient record and were screened at their next presentation. Groin and axilla swabs were placed into salt Sabouraud dulcitol broth and blind subbed on to CHROMagar Candida Plus at day 5, or earlier if the broth became cloudy. Of 39 patients screened, 12 samples resulted in cloudy broths which were subbed on to non-selective blood agar; all colonies were bacterial (identified by MALDI-TOF). No other patients were colonised with *C. auris*.

Discussion

This case highlights learning points for laboratory diagnostics and IPC. The actions discussed are consistent with the Australasian *C. auris* IPC guidelines, and the Aotearoa New Zealand Public Health Expert Briefing.[5,6]

Although active *C. auris* screening was not practiced at the time, passive surveillance was underway, allowing for detection of this case. The case was colonised, not infected, so treatment for *C. auris* was not required. Colonisation can be detected from various body sites, though groin and axilla swabs are the most sensitive samples.[7]

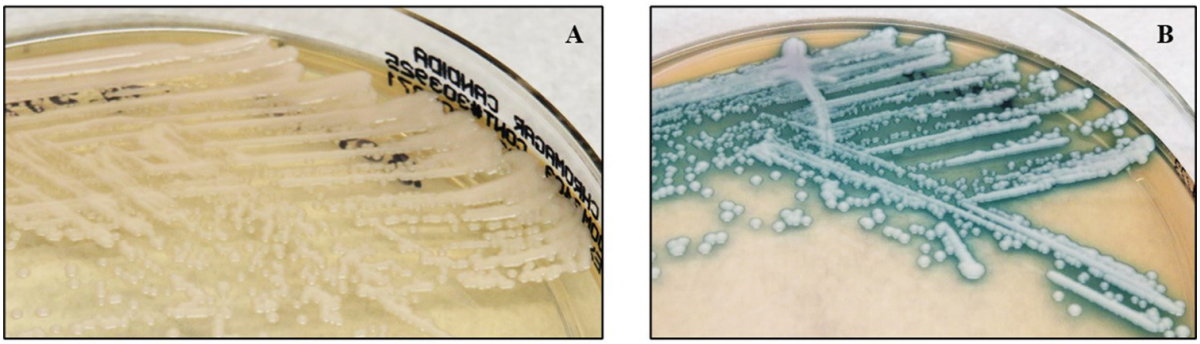
MRO screening for all overseas hospital transfers at admission is expected practice. This did not occur until the third day of admission, a missed opportunity. The most effective IPC actions in the hierarchy of controls aim to eliminate hazards.[8] The cornerstone of eliminating MRO transmission is the triage of patients for risk factors with subsequent screening, which must occur at the point of admission. Fortunately, this patient was admitted to a single room; however, medical equipment was shared with patients in nearby rooms. Shared patient equipment was decontaminated with sporicidal peracetic acid wipes, then exposed to vapourised hydrogen

peroxide. Screening of ward inpatients confirmed that there was no cross-transmission of *C. auris*.

C. auris can be difficult to distinguish from other *Candida* species. Identification requires molecular technology and specific materials and expertise for susceptibility testing. The multidrug resistance detected is typical of *C. auris*; indeed, pan-resistant isolates have been reported.[4] During the ward screening 12 broths became cloudy, raising the concern of cross-transmission, because they were from patients with a plausible link to the case. Fortunately, this was found to be due to bacterial growth only. Consequently, the addition of vancomycin to the broth formula to eliminate bacterial growth is being evaluated.

This case is a reminder to healthcare practitioners to be vigilant to the risk of *C. auris* importation, to triage all patients for risk factors for acquisition and to conduct screening at admission. Healthcare facilities must prepare for the diagnostic and IPC requirements for the management of *C. auris* colonisation and infection.

Figure 1: The colonial appearance of *C. auris* on CHROMagar Candida and CHROMagar Candida PLUS.



(A) shows growth of *C. auris* on CHROMagar Candida; the appearance is of white colonies that cannot be distinguished between *Candida* species.
(B) shows growth of *C. auris* on CHROMagar Candida PLUS; the appearance is of characteristic light blue colonies with a blue halo. This specialised agar specifically allows distinction of *C. auris* from other *Candida* species.

COMPETING INTERESTS
Nil.

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A Scheme for the Establishment of an Association of New Zealand Surgeons

NZMJ, 1923
By L.E. BARNETT, C.M.G., F.R.C.S., *Professor of Surgery, University of Otago*.

Every year during the last four years I have had something to say about the formation of a Fellowship, or Brotherhood, or Association of New Zealand surgeons. The deficiencies in surgical service, both in public hospitals and private practice, have been borne in upon me as the result of a long and arduous experience of over 30 years, and I feel somehow that it is my duty, before my retirement from active surgical work, to draw pointed attention to these deficiencies, and to indicate a method by which I think such deficiencies can be made good.

I noticed recently, in the *British Medical Journal*, a report of the proceedings of the Royal Society of Medicine, dealing with Exophthalmic Goitre, its medical and surgical treatment, and reference was made to the fact that a similar discussion had taken place ten years previously, and that little to no progress in the direction of standardising methods of treatment had been made in that long interval. Physicians, radiologists and surgeons are still all in need of guidance in handling this grave malady, and only by the publication and study of careful records of cases with their end-results can we learn what to do, and what not to do, in the best interests of the patients. I read, also, a surgical discussion at the Glasgow meeting of the British Medical Association which centred itself on the question of removal *versus* drainage of the gall-bladder for cholecystitis, and which left this much-vexed problem still unsolved. Records, careful records, with end-results, can alone establish a standard operation for gallstones.

At the same meeting various distinguished surgeons enunciated their views on the treatment of visceroptosis, and intestinal stasis. For similar grades or results of these common, and often serious, troubles, one surgeon recommended an ileo-sigmoid anastomosis, or a total colectomy, whilst another would stop short at a semi-colon, and still another would fix the ascending colon against the posterior abdominal wall, and so on. Such discussions teach us what methods are available in the treatment of these maladies, but they leave us confused as to what the standard method should be. We must have careful and intimate records of end-results to guide us.

What is the best standard operation for the average case of hæmorrhoids? I am quite sure that at least half-a-dozen methods are in vogue in this Dominion—varying in degree from a Whitehead to a carbolic injection, but the surgeons who operate are too often content with the rapid recovery made by the patient from the operation, and remain in ignorance of the trials and tribulations endured later on. So it is with varicose veins, variocele and hernia operations. Recurrence of trouble is common in all these cases after operative treatment, as any surgeon of large experiences, or any general practitioner, can testify.

I have quoted only a few out of very many examples that could be brought forward to show that the procedure of the surgeons at the present time in New Zealand is not calculated to diffuse the knowledge born of experience. What chiefly is lacking, is the publication by trained surgeons of their hospital records, with end-results. In New Zealand we have, I consider, a country singularly favoured for the compilation of such records. It would not be difficult to keep in touch with all but a very few of our patients, and I feel confident that very valuable contributions to surgical progress and research could be made from this country. We New Zealand surgeons should take a more prominent place in the surgical world, and we should do better work for the country than we are doing at present. We ought to raise our standard of efficiency—our main hospitals should be re-organised and standardised. These should be at every one, a full stuff, not only of hon. surgeons, but of assistant-surgeons, all working on a definite plan calculated to increase individual efficiency, and to stimulate research and community effort. Greater opportunities should be afforded to those members of our profession who are anxious to fit themselves for surgical practice, and the Health Department should see to it that arrangements are made in all the larger hospitals to provide facilities for modern surgical work by a full stuff of earnest workers. When a

member of such a surgical staff has proved his competency, and has given to the community a due measure of public service, his efforts should be rewarded by admission to an Association of New Zealand Surgeons. Needless to say every encouragement should be given to the holding of regular meetings by such a hospital staff as I have indicated, for the discussion, particularly of anæsthetic and other fatalities, errors and failures, delays and disappointments, and for the concerting of measures for the improvement of surgical service.

I venture to believe that the hall-mark of a New Zealand surgical brotherhood would be a much coveted distinction. The service required for its attainment would be willingly given, and I am sure no one would grudge the payment of an adequate fee, say £20, for the privilege such a distinction would confer. In this way a fund could be established for the expenses of management, and also, perhaps, for the institution of research scholarships.

In America the progress of surgery during the last few years has been very remarkable. American surgeons, American hospitals, American journals, have all reached a very high standard of excellence, undoubtedly surpassing the surgical standard in most, if not all, other countries. In my opinion the greatest surgical advance ever made in any country was the establishment of the Fellowship of the American College of Surgeons, 10 years ago. You must all be more or less aware of the activities of this body, and how much it has done for the promotion of surgical efficiency in the United States and Canada and other parts of America. I wish to see an association of similar character established in New Zealand, and constituted in a way that would suit our particular conditions. We need not, for instance, use the term Fellowship in this connection, as done in America. There the fellowship is a purely clinical distinction, whereas with us a Fellowship of the Royal College of Surgeons of England, Edinburgh or Ireland indicates academical status. I shall, therefore, in the meantime at any rate, speak of membership and not fellowship of the Association of New Zealand surgeons, and I shall proceed now to repeat and elaborate the ideas I have formed in my own mind regarding the establishment of such an Association. The Association of Surgeons be a part and dependency of the New Zealand Branch of the British Medical Association. There is to be no disruption of the parent body, and the new offspring is designed to be a source of strength and not of weakness.

To begin with, a foundation body of members should be selected by The Divisions, and these foundation members should be only those about whose surgical efficiency and high professional and ethical standing there is no manner of doubt. They should be surgeons of wide experience in both hospital and private practice, and might include gynæcologists, ophthalmologists, and other specialists. Such a foundation body might number 25 or 30 members, or more. The foundation body would then meet and draw up a constitution, and formulate regulations for the admission of other members, subject to confirmation by the Branch. Surgeons recognised by the profession generally as of wide experience and established reputation could be elected without further investigation or examination on the unanimous vote, or even a three-fifths majority vote, of the foundation body. I would recommend a very generous admission under this category. Provided a man had received a good surgical training and had a wide surgical experience, especially in hospital practice, and possessed the esteem and confidence of his colleagues, I would advocate his admission to the Association of New Zealand Surgeons.

Other candidates who had not reached this high surgical status, but who were desirous of obtaining the hall-mark of surgical efficiency connoted by membership of the Association of New Zealand Surgeons, would be admitted on a majority vote, preferably a three-fifths majority, provided that the credentials submitted were reported as satisfactory by a specially-selected examination committee. Candidates coming under this category should be practitioners of at least eight years' standing, and should produce evidence of having been on the staff of an approved hospital (note the term *approved*) as house surgeon, assistant surgeon, or full surgeon, for at least five years in all. They should be required to hand in careful and detailed records of fifty major operations performed personally, and of fifty others in which they took a prominent part. These records should include history, clinical features on which the diagnosis was made before operation, laboratory investigations, description of operation, post-operative history, and end-results.

An approved hospital must be staffed and equipped to the satisfaction of the Association of Surgeons. There should be on the staff both surgeons and assistant-surgeons, and a surgical registrar to look after the records, paying particular attention to end-results. Needless to say, there should be proper operation-room facilities, X-ray

department, and pathological laboratory. Regular meetings of the staff should be held for discussion of such things as sepsis, failures, mistakes in diagnosis, death, and so on. The Inspector-General of Hospitals would, I am sure, co-operate in classifying our hospitals, and in trying to raise the standard of those not conforming to the regulations and requirements of the Association of Surgeons. The knowledge that ordinary candidates for membership must serve for a number of years in a recognised hospital would soon bring about a radical alteration for the better in our hospitals. At present, with very few exceptions, the honorary staffs in such New Zealand hospitals as have them, attend in perfunctory fashion, and the great bulk of the work is done by the medical superintendent and his paid staff. That means a very fine experience for these officers, but it is an experience that should be shared by all those aspiring to a surgical practice. If there were a large number of honorary appointments, junior as well as senior, open to those surgically inclined, and if it were understood that, after a faithful and successful term of service in a properly-run hospital, the holders of such appointments would have their service and surgical fitness recognised by the hall-mark of membership of the Association of New Zealand Surgeons, then, I claim, that an immense and enduring stimulus would be given to surgical progress in this country. A criterion of surgical efficiency and worthiness would be established. Those practitioners who, by special study, painstaking effort, and long hospital service, have qualified themselves as efficient surgeons should possess a hall-mark of some kind to raise them in status above practitioners who practise major surgery, but who have not gone through a full course of instruction and hospital service to equip themselves adequately for a position of such importance and responsibility.

If a practitioner holds one of the higher qualifications, such as Master of Surgery, or Fellowship of one of the Royal Colleges, so much the better; that is an indication of special intensive and successful study on his part, and entitles him to a higher status than those who have not such a qualification, but it is not essential for membership of the Association of New Zealand Surgeons.

The Association of Surgeons should meet at least once a year, probably about the time of the annual Branch meeting. Surgical matters in general and the affairs of the new Association would be discussed, clinical demonstrations provided, research encouraged, and efforts made to improve by all possible means the standard of surgery in this Dominion. New Zealand surgeons should not be content with mediocrity, they should set a high standard and try to keep at any rate near the van of progress.

The foregoing paper was read at a largely-attended meeting of the New Zealand Branch on 22nd February, 1923, and at its conclusion a free discussion took place on the merits and demerits of the proposed scheme. It was speedily seen that the paper published by myself in the NEW ZEALAND MEDICAL JOURNAL of April, 1922, and which had been submitted to the Divisions prior to this annual meeting, had been misunderstood in several respects, and some delegates to the Council had been instructed to vote against the scheme, largely owing to these misunderstandings. Two or three of the delegates, after hearing the address as published above, expressed their conversion from hostility to the support of the scheme, and although the first voting in the Council resulted unfavourably to my proposal, the final decision of the New Zealand Branch was that the question should again be submitted to the Divisions for further consideration, in the light of the additional explanations I was in a position to give.

I beg, therefore, to ask the members of the Divisions, before voting again on this important matter, to read carefully the address published above, and in answer to the various questions and criticisms made by speakers at the annual meeting just concluded, I wish to emphasise the following points:—

1. In my opinion the time *is* ripe for the establishment of an Association of New Zealand Surgeons on the lines laid down in my paper. I cannot see why the obvious advantages should be indefinitely delayed, and, on the other hand, the disadvantages alleged by those hostile to the proposal will not be lessened by the waiting.
2. There is no suggestion in the scheme that members of the proposed Association of Surgeons should practise surgery only. General practitioners who have by study and experience, and especially by hospital service proved their surgical efficiency, would be welcomed in the ranks of the Association, and would be, of course, permitted to do such general practice as they desired.
3. Some of the larger hospitals—for example, Invercargill, Timaru and several others—are at present carried on without the

services of an honorary staff, and therefore no opportunity is afforded to the private practitioners of the district to obtain hospital surgical experience. These practitioners feel that they would be penalised in their desire to obtain membership in the Surgical Association. In answer to this I would say that one of the planks of the proposed Association is the standardisation of hospitals, so as to ensure that they shall be staffed and equipped in the best interests, not only of surgeons, but of the community generally. Public opinion would be enlightened on the recognised deficiencies of hospitals that do not come up to the standard, and public opinion once aroused as to the backwardness and inefficiency of such hospitals, would force upon the authorities the necessity of a change to the recognised establishment of an honorary visiting staff.

4. It is necessary to start the scheme by the election of a body of foundation members, who will meet together to draft a constitution, and submit rules and regulations for the approval or otherwise of the New Zealand Branch of the British Medical Association. In my opinion this Association of Surgeons should be a dependency of our Medical Association and, therefore, the selection of the foundation of members should be made by the Medical Association, and all rules and regulations, and subsequent additions in membership, should be submitted for approval or otherwise to the parent body. My idea is, that each Division should be asked to send in the names of such surgeons as it selects for the foundation body, and this first selection should include only the names of those men, including specialists, of course, who have proved themselves by experience and hospital service, and high ideals to be good surgeons in the best sense of the term. I would make it an essential condition for foundation membership that each man selected should have had at least ten years of hospital service. It is difficult for me to be more explicit in this matter of selecting foundation members, but a better understanding of my own particular views on this point might be gleaned if I stated that, personally, I would like to see appointed as foundation members from the Otago District the following:—Dr. H. Lindo Ferguson, Dr. L. E. Barnett, Dr. F. R. Riley, Dr. F. S. Batchelor, Dr. E. O'Neill, Dr. A. J. Hall and Dr. W. Newlands.
5. Subsequent to the election of foundation members, a large addition to the Association would be made by invitation or application. I, personally, would welcome to membership any practitioner, desirous of joining, who was held in high surgical and ethical repute amongst his colleagues, and who had served at least eight years on the surgical staff of an approved hospital, part of which time might have been spent as a house surgeon or resident medical officer. Candidates under this category should require a three-fifths majority for their election by the foundation body, and their names should go before the Council or the whole Association for approval.
6. Those who have not yet won their surgeon's spurs, but who by training and hospital experience wish to equip themselves adequately for surgical practice, will be required to submit evidence of fitness and worthiness for investigation by an examination committee as explained in my address. One of the important and obvious advantages of the scheme is that it would encourage the younger members of the profession to take the right path for acquiring surgical proficiency, and would provide for the granting of a hall mark of the surgical status earned by hard work and devotion to duty.
7. It need hardly be said that no interference whatever is contemplated with the right of those members of the profession who do not become members of the Surgical Association, to practise surgery. Those amongst them who have already obtained the confidence of their patients will still maintain their surgical practice. But I admit that, of two younger practitioners seeking to establish a surgical reputation, the man who possesses the hall-mark of the Association of Surgeons would have, and should have, a very decided advantage over his colleague who has not taken the time and trouble to educate himself adequately for the important responsibilities involved in operative surgery.

In conclusion I plead for the thoughtful consideration of the scheme by the Divisions. Sooner or later some such surgical reform as I have described is bound to come. I can see no valid reason for delay, and I should dearly like to see the scheme launched at our next annual meeting, when Dr. W. J. Mayo, one of the founders of the American College of Surgeons, is to honour us with his presence. The establishment of an Association of Surgeons would be of no particular benefit to me, as I shall very soon be retiring from active surgical practice, nor would it, from a business point of view, be of any particular benefit to the surgeons who have already won a high reputation in this country, but it would confer a very real and deserved advantage on the younger generation of efficiently-trained men who are desirous of practising surgery; it would raise the standard of surgery throughout the Dominion, both in hospital and private practice, and the whole community would thereby reap the benefit of a vastly improved surgical service.

Proceedings of the New Zealand Society for the Study of Diabetes Annual Scientific Meeting 4–6 May 2023, Wellington

Clinical characteristics of patients undergoing dental clearance: focus on diabetes

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INTRODUCTION

There is a bi-directional relationship between oral health and glycaemic control. People with diabetes are at greater risk of developing end stage dental disease, which may require full dental clearance. This retrospective clinical audit aimed to describe the clinical characteristics of adult patients with and without diabetes undergoing full dental clearance at a specialist hospital service, focusing on low-income populations.

METHODS

Data were obtained from the local dental departmental database and relevant e-health records, spanning January 2021 to July 2022. Social deprivation index (NZDep2018) data is expressed as quintiles, with 5 being most deprived.

RESULTS

Thirty-seven out of two hundred and twenty (17%) of patients undergoing dental clearance had diabetes, which contrasts with a local diabetes prevalence of about 5%. People with diabetes had a mean HbA1c of 55mmol/mol; 16/37 were on hypoglycaemic medications. Only one referral to the dental clearance pathway was received from the secondary care diabetes team.

The dental department was successful in focusing on low-income populations, as shown in the distribution of social deprivation scores. This audit found 64% of people with diabetes in the most-deprived two quintiles (quintiles 4 and 5), compared with 30% of the local general population ($p<0.001$).

CONCLUSIONS

People with diabetes and end stage oral disease may benefit nutritionally, cosmetically, and socially from dental clearance. While people with diabetes are over-represented in this treatment pathway, specialist diabetes input has been minimal. This may be due to lack of awareness among diabetes clinicians, regarding both the severity of this condition and the availability of treatment pathways.

Initiation of SGLT2i/GLP1RA Aotearoa New Zealand—what we know about the first 18 months

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AIMS AND OBJECTIVES

Empagliflozin and dulaglutide were funded for use in New Zealand in 2021 under special authority criteria (including a Māori/Pacific ethnicity clause). Here we report on the first 18 months of medication availability.

METHODS

Primary care data was sourced from Auckland and Waikato Primary Healthcare Organisations (302 general practices) for type 2 diabetes (T2D) patients aged 18–75 years during the period of Feb 2021 to July 2022 (n=53,142). We reviewed initiation of empagliflozin and dulaglutide by ethnicity and

presence of cardiovascular and/or renal disease (CVRD), and the incidence of diabetic ketoacidosis (DKA) in those prescribed empagliflozin (via linkage to the Ministry of Health datasets).

RESULTS

The cumulative initiation of these medications in eligible patients was 35–55% of at 18 months, and higher in Māori and Pacific patients compared to other groups (P<0.05). Prescribing of empagliflozin and dulaglutide was ~12% higher (41% and 43% vs 30%; P<0.05) and ~20% higher (56% and 51% vs 29.5%; P<0.01) in Māori and Pacific with and without CVRD, respectively, compared to non-Māori, non-Pacific patients. The incidence of DKA with empagliflozin use was 0.23% (167 cases in 40,523 patients) and more common in European patients (0.35% vs 0.10–0.17% for other ethnicities).

CONCLUSIONS

The addition of ethnicity as a criterion for funded access to SGLT2i/GLP1RA appears to have been successful at addressing the inequity in prescribing seen with other therapies. The rate of DKA with empagliflozin use is low and similar to that reported internationally.

Newly diagnosed type 2 diabetes—does primary care appropriately prepare patients to succeed?

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AIMS AND OBJECTIVES

Diabetes management is multifaceted, involving appropriate management by both healthcare professionals (HCPs) and patients. The aim of this study was to explore how well primary care is preparing newly diagnosed patients to optimally manage their type 2 diabetes (T2D).

METHODS

T2D patients diagnosed after January 2020 were recruited via text and social media and invited to complete a 20-question online survey. Questions included demographic information (n=4), their diagnosis pathway (who, where, when and type of diabetes; n=5), the provision of information and resources (n=6) and their current diabetes management (n=5).

RESULTS

Responses were collected from 165 participants: 43.1% identified as Māori and the majority (87%) were diagnosed in primary care. Information provided by HCPs was identified as being "the most useful" diabetes management resource by 50% of patients, followed by whānau/family (40%) and self-led research (32%). Overall, 73% indicated that primary care provided them with enough information to manage their diabetes, 71% said they understood their medications, and 64% understood their HbA1c measurements. Less than a third of participants received referrals to specialist services (dieticians, pharmacists etc), and Asians were less satisfied with their HCP experiences than Māori and Pakeha respondents. Free-text comments included the need for empathy/understanding, as well as more culturally relevant diet-related information and language.

CONCLUSIONS

Primary care appears to be doing relatively well in supporting newly diagnosed patients to manage their T2D. Key areas for improvement include increasing access to support services, empathy from HCPs, and the provision of culturally appropriate resources.

A comparison of FreeStyle Libre 2 to self-monitoring of blood glucose in children with type 1 diabetes and sub-optimal glycaemic control: a 12-week randomised controlled trial

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BACKGROUND AND AIMS

Compare FreeStyle Libre 2, second-generation intermittently scanned glucose monitoring (isCGM) system (Abbott Diabetes Care, Witney, UK) to self-monitoring of blood glucose (SMBG) in children (4–13 years inclusive) with type 1 diabetes and HbA1c 58–110 mmol/mol.

MATERIALS AND METHODS

Open label randomised controlled trial from 5 centres. Following 2 weeks of blinded sensor, children were randomised 1:1 to control (SMBG) or intervention (FreeStyle Libre 2). The primary outcome was the difference in HbA1c at 12 weeks. Trial registration February 2020 (ACTRN12620000190909p).

RESULTS

There were 100 participants, 25% Māori, 22% Pasifika, 53% NZ European, mean age (SD) 10.9 (2.3) years, 41% males, duration of diabetes 4.2 (2.9) years, mean Hba1c 75.1 (13.6) mmol/mol with 83% on injections, 16% insulin pump. Fifty-one randomised to control and 49 to intervention. Ninety-one participants completed the trial—there was no difference in Hba1c between groups at 12 weeks: 74.7 (12.8 vs 76.1 [14.8] mmol/l; p=0.3), delta difference 0.23 (0.21, 0.67 CI; p=0.3). There was both an increase in SMBG frequency with isCGM (delta +4.89 [2.97, 6.81]; p<0.001) and a reduction in % time below target (<4mmol/l) difference -6.4 (-10.6, -4.2; p<0.001).

DISCUSSION

This is the first trial of second-generation isCGM in children and showed no overall improvement in Hba1c, but a reduction in time in hypoglycaemia in children with sub-optimal control aged 4–13 years was seen. Wider access to isCGM alone may not improve diabetes control.

FUNDING

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Creation of a dietitian-led gestational diabetes diet-controlled telehealth pathway at Christchurch Women's Hospital

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INTRODUCTION

Data collected between 2019–2020 showed a 17% increased prevalence of women diagnosed with gestational diabetes (GDM) at Christchurch Women's Hospital (CWH). With no increase in resources, a new dietitian-led telehealth model of care was initiated for diet-controlled GDM women.

AIM

To evaluate the reduced physician and obstetric workload and financial cost savings of the service delivery with the move to a dietitian-led telehealth model of care.

METHOD

To review and develop a dietitian-led telehealth model of care for our women with GDM and to secure funding for permanent resourcing for a diabetes dietitian.

RESULTS

Our telehealth model of care was rolled out successfully in June 2021 with 429 referrals in the first 12 months. Each patient was initially part of our telehealth model and continued so if they remained diet controlled. Twenty eight percent of our cohort (n=119) remained diet-controlled and under the care of a dietitian throughout pregnancy. We successfully reduced the workload and clinic space of 464–696 physician/obstetrician appointments with a cost avoidance of upwards of $235,000 per annum. We also successfully introduced Diabetes Midwifery metformin prescribing, further reducing the workload and clinic space of physicians, and secured permanent 0.6 FTE dietetic funding to continue our model of care.

CONCLUSION

We have successfully introduced a dietitian-led telehealth model of care for diet-controlled women with GDM at CWH, with large savings in terms of reduced physician and obstetric input and cost avoidance. It is hoped this model of care can be extended nationwide.

Analysis of patients with diabetes admitted with foot ulcerations at Middlemore Hospital from January 2010 to December 2018, Te Whatu Ora – Health New Zealand

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INTRODUCTION

Analysis of the patients who have been admitted to Middlemore Hospital with diabetes with foot ulcerations over an 8-year period.

AIMS AND OBJECTIVES

Identify the cause of the ulceration, demographics of the patient population, ethnicity, age, type of diabetes and level of diabetes control, their comorbidities, length of stay, and to see if they had been seen by the MDT foot clinic prior and after their admission.

METHODS

Using Casemix data to identify patients with diabetes and foot ulcerations over the timeframe. Using clinical portal to identify cause of ulcer, their comorbidities, level of diabetes control, and type of diabetes.

RESULTS

There were 2,504 admissions in 1,200 patients. A third of this group overlapped with the patients having amputations. Total bed-stay in the whole group was 12,503 days, with an average of 10.6 days, range 0–111. The group predominantly have type 2 diabetes, 59% are male, ethnicity: Māori 19%, European 29%, Pacific 42%, and other 10%. Age range: 20–94, mean age 62.

DISCUSSION AND RECOMMENDATIONS

This group of patients are admitted on multiple occasions, and not always for a foot ulcer and re-ulcerations. They have comorbidities that are exacerbating and worsening outcomes. Pacific people are overrepresented in this group. This group are costly due to time spent in hospital, and they have a poorer quality of life. Their feet are examined every time they are admitted, and they need lifelong follow up when discharged.

Online diabetes education in primary care is effective but needs to be individualised to maximise uptake

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INTRODUCTION

Lack of specialist knowledge is acknowledged as a major barrier to diabetes management in the community. The aim of this study was to determine the most preferred/effective form of diabetes education for healthcare professionals (HCPs) in primary care.

METHODS

Eighty-one PHCPs (22 GPs, 45 nurses, 9 pharmacists, and 5 others) participated in the research component of the free online 2022 Waikato Primary Care Diabetes Education Programme. The programme consisted of 16 weekly 30-minute endocrinologist-led sessions, with eight webinars followed by eight case discussion sessions on various aspects of diabetes management. Participants completed a standardised 14 x 7-point Likert scale questionnaire (maximum score 98) on self-efficacy of various aspects of diabetes management before and after the programme and completed an education preference questionnaire.

RESULTS

Self-efficacy scores improved for all PHCPs with similar increases in all disciplines (GPs 60+11 to 80+11; nurses 58+19 to 81+12; pharmacists 52+12 to 75+10; others 45+14 to 66+16; all $P<0.05$). All forms of education were identified as important, with the most preferred form of education being live webinars for GPs (36%), nurses, and others (both 60%), while case discussions were the most preferred form for pharmacists (44%). Recorded webinars were the least preferred option for all groups (59–71%). Ninety-eight percent would strongly recommend this programme to their peers.

CONCLUSIONS

Online education on diabetes management can be effective for all PHCPs. To maximise effectiveness, education needs to be individualised and ideally delivered live at times suitable for PHCPs.

Ma te rongo ka mohio: initial engagement determines the extent of supportive self-management for T2DM aged between 20 and 40 years

Timothy Ryan, Richard Rautjoki

Health Research Council of New Zealand

INTRODUCTION

Those patients diagnosed with type 2 diabetes aged between 20 and 40 have worse health and wellbeing outcomes than those diagnosed over 40.[1]

OBJECTIVE

To provide space for a "voice" from someone with lived experiences.[2,3]

METHOD

We conducted a review of supportive self-management programmes, including Māori health initiatives. The review was supplemented with patient interviews of their health system journeys, specifically exploring barriers and facilitators to supportive management.

RESULTS

A variety of themes emerged which focused on primary engagement and relationships:

Mana—respect: participants wanted to be understood and to have the clinician see their life circumstances from their perspective, including whānau at every opportunity.

Whakarongo—listening: the information a patient "hears" at first diagnosis seems to stay with them throughout their health journey, and this can mitigate further consultations. Written material is less important, so oral and visual information at this key initial stage is critical.

Haepapa—responsibility: a strong theme in self-supportive management was the effort to organise life while living with diabetes.

Hangarau—technological advances: giving better options for self-supportive management.

Ataata rongo—visual prompts: the use of alternative prompts became a powerful motivator in managing diabetes.

CONCLUSION/DISCUSSION

The initial service engagement and subsequent patient–clinician relationship can determine the degree of self-supportive management. A supportive self-management of T2DM model should include crucial steps in the initial consultation process.

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Continuous glucose monitoring ameliorates diabetes outcomes inequity based on ethnicity and social deprivation evident 12 months after diagnoses of type 1 diabetes

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INTRODUCTION

Socio-economic status and ethnicity predict type one diabetes (T1D) outcomes. We aimed to investigate if inequities (HbA1c, access to continuous glucose monitoring [CGM]) are evident 12 months after diagnosis in children with T1D in New Zealand, and if CGM access impacts observed disparities.

METHODS

Deidentified clinical data were collected 12 months after diagnosis on all under 15-year-olds in New Zealand diagnosed with T1D in a secondary care centre between 1 October 2020–1 October 2021. Socio-economic status (SES) was estimated using the

New Zealand Deprivation Index.

RESULTS

Two hundred and six children were analysed (30 Māori, 149 European). At 12 months, Māori mean HbA1c was 9.4 (4.0 to 14.8, p<0.001) mmol/mol higher than Europeans (69.6 vs 60.2 mmol/mol respectively). After fully adjusting, HbA1c remained 10.83 (2.3 to 19.4, p=0.013) mmol/mol higher in Māori than Europeans.

SES predicted higher HbA1c, with those in the most vs least deprived regions having an adjusted HbA1c 10.78 (4.7 to 16.9, p<0.001) mmol/mol higher.

Fifty-six point seven percent of Māori children with T1D were using CGM compared to 77.2% European, with differences somewhat but not entirely predicted by SES.

Differences between Māori and European adjusted HbA1c were much smaller for children on CGM (2.2 [-4.5 to 8.9, p=0.52]) vs children not on CGM (10.8 [2.3 to 19.4, p=0.013]).

CONCLUSION

Social deprivation and Māori ethnicity are strong independent predictors of higher HbA1c 12 months post diagnosis of T1D; however, Māori had higher HbA1c even after accounting for deprivation. CGM use ameliorates this ethnic difference, regardless of SES.

Impact of Advanced Hybrid Closed-Loop on youth with high-risk type 1 diabetes using multiple daily injections

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INTRODUCTION/OBJECTIVES

Automated insulin delivery (AID) is the gold standard therapy for type 1 diabetes. However, there is little data on advanced AID outcomes in those who are struggling with glucose control on traditional injection therapy. The objective of this prospective 3-month single-arm, dual-center study was to evaluate glycemic outcomes in youth (aged 13–25 years) with type 1 diabetes and high-risk glycemic control ([HbA1c >8.5% [69 mmol/mol]) on multiple daily injections (MDI) after transitioning to advanced hybrid closed-loop (AHCL) therapy.

METHODS

This prospective, single-arm, dual-center study investigated AHCL in youth with high-risk glycemia using MDI. Participants were recruited through clinics based out of Dunedin and Christchurch on a first-come, first-served basis. Participants were eligible if they had type 1 diabetes as per American Diabetes Association classification for >1 year, aged 13–25 years (inclusive), current HbA1c of >8.5% (69 mmol/mol), and on MDI.

RESULTS

Twenty participants were enrolled, and all completed the study. HbA1c decreased from 10.5+2.1% (91.2+22.8 mmol/mol) at baseline to 7.6+1.1% (59.7+11.9 mmol/mol) and time spent in target range 70–180 mg/dL (3.9–10.0 mmol/L) increased from 27.6+13.2% at baseline, to 66.5+9.8% after 3 months of AHCL. Two episodes of diabetic ketoacidosis attributed to infusion set failure occurred.

DISCUSSION/CONCLUSION

AHCL has the potential to considerably improve suboptimal glycemia in youth with type 1 diabetes previously on MDI.

Epidemiology of diabetic retinopathy among paediatric patients from a regional centre (Auckland, New Zealand) over 15 years (2006–2020)

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INTRODUCTION/OBJECTIVES

Diabetic retinopathy (DR) is the most common microvascular complication of type 1 diabetes (T1D). Glycaemic control is a key modifiable risk factor. DR prevalence estimates in youth show marked variability. This study aims to estimate DR incidence and examine demographic and clinical factors associated with DR and its severity in children with T1D in Auckland, New Zealand.

METHODS

Data were extracted from the Starbase database, which documents >95% of children with diabetes in Auckland. Children were included if they were diagnosed with T1D before 2015, had attended >1 clinic in 2006–2020 when aged <16 years, and had undergone >1 retinopathy screening.

RESULTS

Included children (n=646) were diagnosed at 7.4 years (SD=3.6); 47% were female, and 69% were NZ Europeans. First DR assessment was 5.2 years after T1D diagnosis (SD=2.2). At first screening, incidence was 24%. Fifty-six percent had DR at least once, with worst results mostly minimal (58%) and mild (41%). Predictors of DR at first screen were older age at T1D diagnosis (p=0.033), diabetes duration (p=0.005), and higher HbA1c levels (p=0.056). Mean HbA1c was 71.8 (SD=15.0) and 69.0 (SD=16.1) in those with and without DR, respectively. Pasifika ethnicity was also associated with a diagnosis of DR during the study period (p=0.005).

DISCUSSION/CONCLUSIONS

DR incidence at first screening was relatively high, and over half of patients had DR at least once. Glycaemic control needs significant improvement to prevent microvascular complications. Some evidence was noted supporting current duration- and age-based screening thresholds. Inequitable patterns of DR negatively impact Pasifika patients.