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EDITORIAL

The future of Hospital HealthPathways: are we killing the goose?

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The future of Hospital HealthPathways: are we killing the goose?

Michael Ardagh, John Garrett

Hospital HealthPathways is an online clinical guidance platform for hospital clinicians at Canterbury hospitals. Over 10 years it has become inextricably woven into the fabric of the Canterbury health system. Unfortunately, and without consultation, Health New Zealand – Te Whatu Ora has made the decision to discontinue the site and replace it with an "in-house" platform. The authors criticise both this decision and the way it was made, likening it to killing the goose that lays golden eggs—a fable that describes a desire for short-term gain destroying something that has long-term value.

National and regional projections of gynaecological cancers in Aotearoa New Zealand: a projection model to 2045 highlighting an opportunity for collective action

Michael Walsh, Karen Bartholomew, Georgina McPherson, Bryony Simcock, Sathana Ponnampalam

Gynaecological cancers in Aotearoa New Zealand are projected to increase substantially over the next 20 years, with the number of cases expected to rise by more than 80% by 2045. Most of this growth is driven by uterine cancer, which is projected to more than double. The largest increases are expected among Māori and Pacific women and in the Northern Region, meaning the impact will not be evenly distributed. Although cervical cancer rates are expected to decline due to vaccination and screening, overall demand for diagnosis and treatment services is likely to grow. These findings highlight the need for earlier detection, prevention efforts and forward planning to ensure services can meet future demand.

Diagnoses of blood-borne viruses and other sexually transmitted infections in a sample of 356 sex workers attending a sexual health outreach clinic in Auckland over a two-year period

Sunita Azariah

This is the largest known study of diagnoses of sexually transmitted infections and blood-borne viruses (STBBI) in New Zealand sex workers. Chlamydia and gonorrhoea rates in female sex workers were lower than in females presenting to general sexual health clinics during the same time period. There were no diagnoses of HIV but a large proportion of those tested for hepatitis C had evidence of past or current infection (15.7%). Therefore, it is recommended that STBBI testing in sex workers should include testing for hepatitis C as effective treatment is available. Results from this study should not be considered representative of the entire sex worker community in New Zealand as participants were attending an outreach clinic and were likely more vulnerable.

Pacific nurses' experiences of informal interpreting and language assistance in healthcare settings in Aotearoa New Zealand: results of an alumni survey

Debbie Ryan, Abel Smith, Safaatoa Fereti, Alisi Vudiniabola, Tamasin Taylor, Harriette Kimiora, David Nicholson, Gerard JB Sonde

This study examined the experiences of Pacific nurses in Aotearoa New Zealand who provide language assistance to patients during healthcare. Many Pacific patients have limited English proficiency, so nurses are often asked to interpret in their own language. While this improves patient trust, understanding and engagement, nurses face challenges such as complex medical terminology, competing work priorities and ethical concerns. They typically perform this role without formal training or additional

compensation, despite its positive impact on care. The findings highlight the need for health services to invest in professional interpreters, to offer training for bilingual staff and to formally recognise the cultural and linguistic contributions of Pacific nurses.

Evolving roles and workforce trends among nurse practitioners in Aotearoa New Zealand (2014–2022)

Deborah L Harris, Diane Williams, Lisa Woods, Julia Liu, Nadine Gray

Nurse practitioners are experienced nurses with advanced education and skills. They improve access to care and plan, provide and evaluate healthcare for patients and whānau. This study analysed data from five national surveys collected between 2014 and 2022, with over 1,000 responses from nurse practitioners across New Zealand. The findings show that nurse practitioners deliver a large amount of front-line care across hospitals, general practice and community services. Overall, the results show a skilled, flexible and established workforce that makes a positive contribution to patients, whānau and communities.

Correlation between patient-determined inflammatory bowel disease severity and the inflammatory bowel disease severity index

Andrew Mark McCombie, Corey A Siegel, Stephen B Hanauer, Timothy McAuliffe, Jessica Salwen-Deremer, Hannah Hughes, Richard Gearry

Existing measures of patient inflammatory bowel disease (IBD) experiences are focussed on a snapshot in time (i.e., how the patient feels today and what their symptoms and blood and stool tests are saying today). It is also important to incorporate historic factors into a measure of severity, such as phenotype (where the disease is located, how deep the ulcers are and what age of diagnosis was), previous surgery (such as bowel resections) and previous medication (including steroids and strong immunosuppression). It is also important to know which aspects drive patients to self-report more severity. Our study showed an objective measure of disease correlated well with patient self-reported severity. Patients with less severe disease tended to overestimate their disease more than those with more severe disease.

Traditional knowledge, planetary health and healthcare: a systematic review

Jihae Abou El Ela, Mercedes Mudgway, Niki Harré, Jane Thomas, James Hamill

We could have a healthier Aotearoa New Zealand if we thought about health more along the lines of many traditional knowledge systems (or worldviews). These knowledge systems often involve a wider definition of health, which includes a healthy environment and a healthy society. A practical way to achieve this is for Indigenous communities, especially Māori and Pacific communities in Aotearoa New Zealand, to have genuine involvement in healthcare planning and delivery.

Breast density reporting in Aotearoa New Zealand: policy imperatives and research priorities

Avisak Bhattacharjee, Fay Sowerby

Breast density is the white and bright area of breast on a mammogram that can act as a risk factor for cancer and hide the tumour on a mammogram. New Zealand women are not currently notified about their breast density within the breast screening programme. There is no clear roadmap regarding future implementation steps of breast density reporting to women. This article highlights the urgent requirements of local research and a co-ordinated national approach so all women can receive clear and culturally appropriate information to support informed decision making.

Addressing significant inequity

John W Pickering, Anna P Pilbrow, Allamanda Fa'atoese, Laura Joyce

In health research we almost never look at everybody in a population—rather, we have a sample that we hope is representative of the population of interest. When we analyse data, we use statistics to help us understand the likelihood of the effect of treatment or association between things we measure truly reflecting what would happen if we studied the entire population. Sometimes within that sample we have a small sub-group of people—perhaps based on ethnicity or age—in which we want to understand if the effect or association we observed still applies. In this paper we talk about some pitfalls in interpreting the statistics that may lead to false conclusions and how to avoid some of those pitfalls.

A decade of an online clinical guidance platform for hospital clinicians: they use it, they like it and it makes a difference

Michael Ardagh

Hospital HealthPathways is an online clinical guidance platform for hospital clinicians, with evidence-informed practice localised for the Canterbury environment—"how we do things around here". It is integrated with Community HealthPathways—"the combination is worth more than the sum of its parts". It has been part of the Canterbury health system for 10 years and is used extensively, is greatly liked and it makes a difference.

Scurvy in a non–weight-bearing paediatric patient

Weisi Xia, Michaela Mullen, Ryan Johnstone

Scurvy is a rare condition caused by severe vitamin C deficiency, traditionally thought historical and seen in sailors with fresh fruit and vegetable restrictions. We present a case of scurvy in a child in New Zealand who presented with weight-bearing restrictions. An effective interdisciplinary approach to its diagnosis and management is detailed. This case highlights that, although rare, scurvy should still be considered in New Zealand in at-risk populations.

Laparoscopic retrieval of a large gastric trichobezoar

Yuen Liu, Binura Buwaneka Wijesinghe Lekamalage, Lucinda Jane Duncan-Were, David McGouran, Barnaby Blair Smith

A young female developed a giant hairball in her stomach (gastric trichobezoar) due to compulsive hair pulling and hair eating. This condition is usually managed with surgery involving a large incision (laparotomy) rather than minimally invasive key-hole surgery because of the risk of contaminating the abdomen. We used a hybrid approach with key-hole surgery and smaller incision (mini-laparotomy) to remove the hairball, which was effective. This hybrid approach has the benefits of minimally invasive surgery while also reducing the risk of contamination.

Ethnic differences in population-level intracerebral haemorrhage incidence in Aotearoa New Zealand: findings from three Auckland Regional Community Stroke cohorts

Karim M Mahawish, Valery Feigin, Harvey White, Rita Krishnamurthi

In this population-based study of Auckland residents, Pacific peoples had consistently higher rates of brain haemorrhage compared with other ethnic groups over a 20-year period. Although survival after brain haemorrhage has improved, substantial ethnic inequities remain. These findings highlight the importance of targeted prevention strategies.

The future of Hospital HealthPathways: are we killing the goose?

Michael Ardagh, John Garrett

The fable of the goose that laid golden eggs describes a desire for short-term gain destroying something that has long-term value.[1] Is this what is happening to Hospital HealthPathways?

In this issue of the *New Zealand Medical Journal* (*NZMJ*), Ardagh (who also co-authored this editorial) celebrates the success of 10 years of Hospital HealthPathways (HHP) in the Waitaha Canterbury health system.[2] HHP started as a companion to Community HealthPathways (CHP), as a tool in the toolkit used to build an efficient and integrated health system. It described carefully constructed, evidence-informed, practical, locally agreed, accessible, "how we do things around here" guidance for hospital clinicians. Over those 10 years, as detailed in Ardagh's paper, it has become inextricably woven into the fabric of the Canterbury health system. It is well used and greatly liked by hospital clinicians. No matter how you measure value (opinion, process improvements, cost or clinical outcomes) there is evidence for its value. A second site was developed in the MidCentral region, and there was hope that it would spread throughout the motu, with localised iterations in each region.

However, in the time between acceptance of Ardagh's paper by the *NZMJ* and its publication, Health New Zealand – Te Whatu Ora suddenly and surprisingly announced that the contract for HHP with Streamliners (the technical writers and platform providers for HealthPathways iterations in over 60 sites around the world, and the provider for HHP and CHP in Canterbury from the beginning) would be discontinued, and instead Health New Zealand – Te Whatu Ora would provide its own "in-house" technical writing and platform.

Regrettably, this decision was made without consulting either the users or creators of HealthPathways. Despite the national care pathways programme having clinical advisors, no clinical advice was sought. Instead, the relevant deliberations and the ultimate decision were not communicated widely until after the event. Indeed, no advice was sought from anyone with knowledge of how HHP works nor experience in its operations. Subsequent advice from such people that this decision is short sighted, ill informed and is a risk to patient safety has been dismissed.

What is at-risk is described in Ardagh's paper. It was hard won, clinically led, opportunistic at times, sometimes serendipitous, but ultimately highly successful by any measure. Its role in the Canterbury health system is a manifestation of the strong and trusting relationships with the clinical community. Pathways are written prioritising end user experience, with easy-to-follow content but with comprehensive information tucked away in "drop-boxes" (often going four or five levels deep). Formatting is done by those with expertise in maximising end user clarity and navigability, following a detailed style guide. There are links to information within HHP, its sibling CHP site, or elsewhere. The content can be aligned with any of the wider New Zealand and international HealthPathways sites, but is defined, localised and approved by local clinicians. Users are able to provide feedback directly from a pathway page, and this feedback, in conjunction with planned reviews, keeps the information in a pathway correct and current.

The Health New Zealand – Te Whatu Ora plan is to take all the Hospital HealthPathways content, in the form of approximately 900 two-dimensional PDFs, and disconnect them from the complex systems that create, maintain and display them. CHP in New Zealand will remain with Streamliners, so the new HHP will be expected to continue technically separated from its sibling CHP and from the international network of HealthPathways teams with which material and work is currently shared. It is unclear how the integration objectives of HHP and CHP working together and sharing content will be maintained, if at all. Nor is it certain that much of the content

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that HHP users currently access via links to CHP will still be available. Maintaining currency of HHP depends on close relationships with the health system, frequent updates and a regular 3-year review cycle. No detail has been provided about how the new site will be maintained.

The authors, among many others, think it is unlikely that this transition will successfully recreate a site achieving the success of the one it is replacing. To the casual observer, there might still appear to be a goose in the farmyard, but, to users, it will be clear that it is not the same goose.

While the authors' view might be challenged by those who made this decision, why are we taking the risk when the current site is so successful? Of course, the reason is cost. A budget sheet has seduced fiscally pressured decision makers with the promise of short-term cost savings. However, the promised cost savings are likely specious, with efforts to match the value of the incumbent site ultimately requiring more and more investment. In the fable, the hoped for cache of gold was not found inside the slaughtered goose, but only then, after realising the folly of the decision, did they see there was no going back.

Apparently ignored in the deliberations about the future of HHP is the potential to negotiate a reduction in the cost of the current provider, thereby achieving the cost-saving objective while keeping the goose alive.

Aesop allegedly told the fable about the goose that laid golden eggs more than two and a half millennia ago. If he was admitted to hospital in Canterbury now, he might be pleased his fables remain popular but disappointed we have not learnt from them. If he was asked to contribute to this discussion he would, no doubt, join the chorus urging us not to kill the goose.

COMPETING INTERESTS
Michael Ardagh is professor of Emergency Medicine at the University of Otago, Christchurch and an emergency physician with Health New Zealand – Te Whatu Ora Waitaha. He is national clinical lead for Hospital HealthPathways, Health New Zealand – Te Whatu Ora, clinical lead for Hospital HealthPathways Canterbury and a part-time, contracted advisor to Streamliners regarding Hospital HealthPathways implementations internationally. He has no other pecuniary interest in Streamliners.
John Garrett is a paediatrician who works in Health New Zealand – Te Whatu Ora Waitaha and Te Tai o Poutini. His experience of safety systems includes being a medical advisor to the Health Quality & Safety Commission for the Paediatric Early Warning System, and he has provided expert advice to the Health and Disability Commissioner. He was a clinical editor for Hospital HealthPathways for 8 years but finished in this role at the start of February 2026. He has no pecuniary interest in Streamliners..

AUTHOR INFORMATION
Michael Ardagh: University of Otago, Christchurch, New Zealand.
John Garrett: Health New Zealand – Te Whatu Ora Waitaha Canterbury, New Zealand.

CORRESPONDING AUTHOR
Michael Ardagh: University of Otago, Christchurch, New Zealand. E: michael.ardagh@cdhb.health.nz

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National and regional projections of gynaecological cancers in Aotearoa New Zealand: a projection model to 2045 highlighting an opportunity for collective action

Michael Walsh, Karen Bartholomew, Georgina McPherson, Bryony Simcock, Sathana Ponnampalam

ABSTRACT

INTRODUCTION: Gynaecological cancers are an increasing concern in Aotearoa New Zealand, with rapid growth in uterine cancer incidence in recent years. Understanding future incidence patterns is essential for planning and service delivery at a sub-national level.

METHODS: Cancer registry data (2001–2022) were combined with population projections to estimate incidence of gynaecological cancers to 2045. Projections were generated using age-period-cohort Poisson regression models, with non-parametric bootstrapping to quantify uncertainty.

RESULTS: Annual gynaecological cancer cases are projected to increase 82% by 2045, reaching 2,497 (95% uncertainty interval [UI] 2,263–2,774) compared with 1,375 in 2020–2022. The overall age-standardised rate is projected to rise 21% from 36.6 (95% confidence interval [CI] 35.5–37.8) to 44.2 per 100,000 (95% UI 38.9–50.3). Uterine cancer contributes the largest increase, more than doubling from 717 to 1,506 cases annually (110%). Among Māori, cases rise 132% from 214 to 497 per year (95% UI 449–553); for Pacific women, they rise 137% from 165 to 391 (95% UI 340–449). Uterine cancer age-standardised rates are projected to increase from 27.3 to 39.6 per 100,000 for Māori, and from 74.3 to 97.5 for Pacific women. Regional variation is expected: the Northern Region is projected to have the largest absolute increase (+506 cases, 527 to 1,033) and the largest percentage increase (96%).

CONCLUSION: Gynaecological cancer incidence in Aotearoa New Zealand is projected to rise substantially over the next 20 years, driven by demographic change and increasing incidence of uterine cancer likely associated with risk factors such as excess body weight and diabetes. Findings highlight the need to prioritise prevention, proactive service planning and equity-focussed early detection.

Gynaecological cancers are increasing globally, with incidence rates rising across multiple cancer types. In 2022, an estimated 1.47 million new cases and 680,000 deaths from gynaecological cancers were recorded worldwide, and both figures are projected to grow substantially over the coming decades.[1,2] The incidence of uterine cancer has risen sharply in high-income countries, driven in part by population ageing, changes in reproductive patterns and increasing prevalence of various risk factors including diabetes and excess body weight.[3] Ovarian cancer incidence has also grown globally, with the number of new cases nearly doubling between 1990 and 2021.[2]

In Aotearoa New Zealand, similar trends are emerging. Recent data show a marked increase in uterine cancer incidence, which has risen by nearly 60% over the past decade, and this rate of increase is among the highest reported for any country.[4–7] Higher cancer incidence and lower survival for Pacific peoples is increasingly being recognised as an area that needs focussed attention.[8] These patterns signal a need for more data to support targeted planning and service delivery at both national and regional levels, particularly as the patterns of gynaecological cancer become more unevenly distributed across age and ethnic groups.

As the only gynaecological cancer with a national screening programme, the incidence rates of cervical cancer are projected to decline further with the continuing impact of human papillomavirus (HPV) vaccination and HPV-based screening.[9] The World Health Organization (WHO) has also set elimination targets for cervical cancer.[10] However, for other cancers such as uterine cancer, incidence is rising, there are few

population-level strategies in place for early detection or prevention and there is no clear screening intervention at present.[5] The patterns of incidence are likely to affect some regions in Aotearoa New Zealand more than others given the variations in demographic makeup and may widen existing inequities if not planned for, particularly given the capacity constraints on both general gynaecology and gynaecological oncology services nationally (including the additional colposcopy demands related to HPV primary screening).

Existing cancer projections in Aotearoa New Zealand are generally presented only at the national level and do not include cancer-specific breakdowns by ethnicity.[11] While nationally aggregated figures are useful for high-level policy decisions, they are often too general to guide service delivery and planning at the regional or district level. This limits the ability to understand how future demographic shifts, such as the projected increase among Pacific peoples, will shape cancer incidence, and it constrains hospital services, cancer planners and regional health planners in anticipating and responding to emerging pressures.

This paper partly addresses this gap by presenting both national and regional projections of gynaecological cancer incidence to 2045. Using historical cancer registry data and population projections, we estimate projected case counts for uterine, cervical, ovarian and other gynaecological cancers. Projections are provided at the national level and disaggregated by region and ethnicity to support targeted planning and identify where a more tailored or equity-focussed response may be needed.

Methods

Data sources

National cancer registration data for Aotearoa New Zealand from 2001 to 2022 were used to project gynaecological cancer incidence. The analysis covered cervical (International Classification of Diseases 10 [ICD-10] C53), uterine (C54 and C55), ovarian and fallopian tube (C56 and C57.0) and other gynaecological cancers including vulva (C51), vagina (C52), placenta (C58) and unspecified female genital organs (C57 excluding C57.0). Data were aggregated by calendar year, 5-year age groups, prioritised ethnicity (Māori, Pacific, Asian, Other) in line with Health Information Standards Organisation 10001:2017 protocols[12] and the four Health New Zealand – Te Whatu Ora regions. Population estimates for 2001 to 2022 and official population projections for 2023 to 2045 with the same stratification were sourced from Statistics New Zealand. These projections were used as denominators in the projection period so that expected future population growth, ageing and ethnic composition are reflected in the projected case numbers.

Modelling approach

An age-period-cohort (APC) model was developed to estimate incidence trends. Separate Poisson generalised linear models with a log link were fitted for each cancer site, with case counts as the outcome and log population as an offset. Predictors included age group, calendar year, birth cohort, prioritised ethnicity (see limitations section for discussion on ethnicity) and region.

The APC structure was broadly based on the Norwegian Prediction Model (Nordpred),[13] which captures period and cohort effects alongside age. Despite the similarities, a new model was built to better reflect Aotearoa New Zealand data and policy needs, allowing stratification by ethnicity, region and age group, while retaining sparse or zero case counts. No interaction terms were included to reduce overfitting and maintain interpretability. Bootstrapping (described below) helped address instability in small strata.

To emphasise recent data, cancer registrations were weighted by year, with weights raised to the power of 1.5. Incidence rates were forecast to 2045 by extending the period and cohort components beyond 2022, and projected case numbers were obtained by applying these forecast rates to the corresponding Statistics New Zealand projected populations within each stratum. Analyses were conducted in R (version 4.4.3; R Core Team, 2024).

Bootstrap procedure

Uncertainty was modelled using non-parametric bootstrapping. For each cancer site, 1,000 bootstrap samples were generated by resampling historical incidence data and adding random variation to the population denominator (mean=1, standard deviation [SD]=0.01). A new Poisson model was fitted for each sample and applied to future population projections (2023–2045). For each stratum, median projected counts and 95% uncertainty intervals (UI) (2.5th–97.5th percentiles) were calculated across iterations.

This approach produced distributions of

plausible future trends, reflecting variability in historical data and providing a more realistic measure of uncertainty than a single fitted model. To account for increasing uncertainty in population projections, additional perturbation was applied stepwise (SD=0.005 for 2023–2025, 0.01 for 2026–2030, 0.015 for 2031–2035, 0.02 for 2036–2040 and 0.025 for 2041–2045). Projected case counts were obtained by exponentiating the linear predictor from each fitted model.

Age-standardised rates (ASRs)

ASRs were calculated for both observed and projected data from 2001 to 2045. Rates were produced separately for each cancer site and for total gynaecological cancer, stratified by year, Health New Zealand region and prioritised ethnicity. The WHO 2001 population standard was used as the standard population.

Classification changes

Since around 2014, increasing adoption of the fallopian tube origin hypothesis for high-grade serous carcinomas has influenced coding practices.[14–16] Many cancers previously coded as ovarian (C56) are now classified as fallopian tube (C57.0), creating an apparent decline in ovarian incidence and a rise in C57.0 that largely reflects coding shifts rather than real changes. To account for this in our model, ovarian cancer was defined here as C56 plus C57.0, consistent with current understanding of disease origin and to maintain comparability over time. Nonetheless, some misclassification may persist, and projections assume coding consistency, so caution is warranted when interpreting site-specific trends, particularly ovarian cancer.

An increase was also observed from 2014 in unspecified or overlapping gynaecological sites (C57.7–C57.9). Unlike C57.0, which was combined with ovarian cancers, these were grouped as "other gynaecological cancers" and retained as coded. Their rise may reflect changes in diagnostic or coding practices when the primary site was uncertain or involved multiple locations and a primary cancer site could not be established.

Study approval

This study was considered low risk and was out of scope for Health and Disability Ethics Committee review. Locality authorisation was granted by Health New Zealand – Waitematā District, Research & Knowledge Centre (Approval Code: WAI20367).

Results

National projections

During 2020–2022, an average of 1,375 gynaecological cancers were diagnosed annually (Table 1): uterine cancers comprised just over half (717), followed by ovarian/fallopian tube (327), cervical (169) and other gynaecological cancers (162). The combined ASR was 36.6 per 100,000 (95% confidence interval [CI] 35.5–37.8), with uterine cancer having the highest site-specific rate (18.6; 95% CI 17.8–19.4).

By 2035, annual cases are projected to rise 44% to 1,982 (95% UI 1,854–2,120). Growth is driven by uterine (+59%) and other gynaecological cancers (+90%), while cervical (+6.5%) and ovarian/fallopian cancers (+5.5%) increase only slightly. The overall ASR rises to 40.0 (95% UI 36.2–44.1), with increases for uterine (23.0) and other cancers (5.1), but declines for cervical (5.1) and ovarian/fallopian cancers (6.7).

By 2045, nearly 2,500 cases are projected to occur annually (95% UI 2,263–2,774), an 82% increase from baseline. Uterine cancers more than double to 1,506 (95% UI 1,310–1,739), and other gynaecological cancers rise 184% to 460 (95% UI 358–612). Cervical and ovarian/fallopian cancers show only modest increases in numbers (~5%) but declining ASRs. The overall ASR reaches 44.2 (95% UI 38.9–50.3), with uterine cancer increasing 46% to 27.1 and other cancers 78% to 6.4, while cervical and ovarian/fallopian ASRs fall by 19% and 33%, respectively.

Ethnic-specific projections

For Māori women, annual gynaecological cancer cases (Table 2) are projected to more than double from 214 in 2020–2022 to 497 by 2045 (95% UI 449–553), mainly from uterine cancers (118 to 308; ASR 27.3 to 39.6) and other gynaecological cancers (21 to 82; ASR 5.0 to 9.4). ASRs for cervical and ovarian/fallopian cancers show slight declines.

Among Pacific women, total gynaecological cancer cases are projected to rise from 165 to 391 (95% UI 340–449), with the overall ASR increasing from 97.3 to 122.3, the highest of any group. Uterine cancers more than double (126 to 312; ASR 74.3 to 97.5). Cervical and ovarian/fallopian ASRs decline modestly, despite small increases in case numbers.

For Asian women, case numbers are projected to more than triple (131 to 423; 95% UI 375–479),

Table 1: National projections for gynaecological cancers by cancer site.

	Cervical	Ovarian	Uterine	Other	Total
2020–2022					
Observed[a]	169	327	717	162	1,375
ASR[b]	5.8 (5.3–6.3)	8.6 (8.1–9.2)	18.6 (17.8–19.4)	3.6 (3.3–4.0)	36.6 (35.5–37.8)
2035					
Projected[c]	180 (152–214)	345 (304–393)	1,143 (1,036–1,254)	308 (258–374)	1,982 (1,854–2,120)
ASR[d]	5.1 (4.1–6.4)	6.7 (5.5–8.0)	23.0 (20.1–26.3)	5.1 (3.9–6.6)	40.0 (36.2–44.1)
% Change in cases[e]	6.5%	5.5%	59.4%	90.1%	44.1%
2045					
Projected[c]	178 (140–227)	342 (283–411)	1,506 (1,310–1,739)	460 (358–612)	2,497 (2,263–2,774)
ASR[d]	4.7 (3.5–6.2)	5.8 (4.6–7.2)	27.1 (22.9–32.2)	6.4 (4.6–9.0)	44.2 (38.9–50.3)
% Change in cases[e]	5.3%	4.6%	110.0%	183.9%	81.6%
% Annual change cases[f]	0.2%	0.2%	3.3%	4.6%	2.6%
% Change ASR[g]	−19.0%	−32.6%	45.7%	77.8%	20.8%

[a] Average observed cases per year over the period.
[b] Age-standardised rate (ASR) over the 3-year period with 95% confidence intervals.
[c] Projected cases with 95% uncertainty intervals.
[d] ASR of projected cases with 95% uncertainty intervals.
[e] Total percentage change in cases from observed 2020–2022 average.
[f] Annual percentage change represents the compound annual growth rate (CAGR) between the 2020–2022 average and 2045.
[g] Total percentage change in the ASR from observed 2020–2022.

but the ASR remains relatively stable (28.4 to 30.0), indicating growth largely due to population growth. Cervical and ovarian/fallopian ASRs decline, while uterine cancers increase slightly (ASR 14.1 to 18.4).

Among European and Other women, cases rise from 866 to 1,185 (95% UI 1,069–1,312), a 37% increase. Uterine cancers grow from 409 to 626 (ASR 13.5 to 19.6), and other cancers increase from 131 to 293 (ASR 3.8 to 6.9). Both cervical and ovarian/fallopian cancers show declining case numbers and ASRs.

Regional projections

In the Northern Region, cases are projected to rise from 527 in 2020–2022 to 1,033 by 2045 (95% UI 922–1,151), driven largely by uterine (296 to 662; ASR 22.4 to 31.4) and other gynaecological cancers (50 to 168; ASR 3.3 to 6.3). Cervical case numbers remain stable, and ovarian cases increase slightly, though ASRs for both decline.

In Te Manawa Taki, total cases are projected to increase from 267 to 496 (95% UI 447–550). Uterine cancers rise from 134 to 291 (ASR 16.0 to 25.4) and other cancers from 35 to 97 (ASR 3.8 to 6.6). Cervical cancers increase modestly (27 to 36), but ASRs remain largely unchanged.

In the Central Region, cases increase from 256 to 427 (95% UI 385–473), driven by uterine cancers (132 to 253; ASR 17.3 to 25.6) and other cancers

Table 2: National projections for gynaecological cancers by prioritised ethnicity and cancer site.

	Cervical	Ovarian	Uterine	Other	Total
Māori					
2020–2022					
Observed[a]	31	43	118	21	214
ASR[b]	7.9 (6.4–9.7)	10.4 (8.7–12.4)	27.3 (24.5–30.4)	5.0 (3.9–6.5)	50.7 (46.8–54.8)
2035					
Projected[c]	45 (38–53)	51 (44–58)	216 (195–238)	48 (38–60)	360 (335–387)
ASR[d]	8.1 (6.5–10.2)	8.1 (6.7–9.8)	34.5 (30.2–39.4)	7.3 (5.4–9.7)	58.1 (52.5–64.4)
% Change in cases[e]	45.2%	18.6%	83.1%	128.6%	68.2%
2045					
Projected[c]	49 (39–63)	56 (46–67)	308 (267–353)	82 (62–113)	497 (449–553)
ASR[d]	7.3 (5.5–9.7)	7.0 (5.5–8.8)	39.6 (33.5–46.9)	9.4 (6.6–13.5)	63.6 (55.8–72.6)
% Change in cases[e]	58.1%	30.2%	161.0%	290.5%	132.2%
% Annual change cases[f]	2.0%	1.2%	4.3%	6.1%	3.7%
% Change ASR[g]	−7.6%	−32.7%	45.1%	88.0%	25.4%
Pacific peoples					
2020–2022					
Observed[a]	12	23	126	4	165
ASR[b]	7.0 (4.9–9.7)	13.5 (10.5–17.1)	74.3 (67.0–82.2)	2.5 (1.3–4.4)	97.3 (88.9–106.3)
2035					
Projected[c]	17 (13–20)	28 (24–34)	218 (193–247)	18 (13–24)	281 (254–311)
ASR[d]	7.0 (5.3–9.0)	10.9 (8.8–13.6)	84.8 (72.7–98.7)	6.6 (4.6–9.3)	109.5 (96.5–124.2)
% Change in cases[e]	41.7%	21.7%	73.0%	350.0%	70.3%
2045					
Projected[c]	17 (13–23)	31 (25–39)	312 (263–370)	31 (22–45)	391 (340–449)
ASR[d]	6.3 (4.5–8.6)	9.5 (7.3–12.2)	97.5 (80.6–118.1)	8.6 (5.8–12.9)	122.3 (104.0–143.7)

Table 2 (continued): National projections for gynaecological cancers by prioritised ethnicity and cancer site.

	Cervical	Ovarian	Uterine	Other	Total
% Change in cases[e]	41.7%	34.8%	147.6%	675.0%	137.0%
% Annual change cases[f]	1.5%	1.3%	4.0%	9.3%	3.8%
% Change ASR[g]	−10.0%	−29.6%	31.2%	244.0%	25.7%
Asian					
2020–2022					
Observed[a]	25	35	64	7	131
ASR[b]	5.2 (4.1–6.5)	7.7 (6.2–9.3)	14.1 (12.2–16.3)	1.4 (0.9–2.2)	28.4 (25.6–31.4)
2035					
Projected[c]	35 (28–44)	54 (45–66)	157 (138–180)	27 (20–35)	274 (250–301)
ASR[d]	3.9 (3.0–5.0)	5.4 (4.3–6.8)	16.0 (13.6–18.8)	2.5 (1.7–3.5)	27.9 (24.7–31.5)
% Change in cases[e]	40.0%	54.3%	145.3%	285.7%	109.2%
2045					
Projected[c]	39 (29–51)	67 (54–87)	262 (220–308)	53 (37–74)	423 (375–479)
ASR[d]	3.5 (2.6–4.8)	4.7 (3.6–6.2)	18.4 (15.1–22.3)	3.3 (2.1–4.9)	30.0 (25.9–34.8)
% Change in cases[e]	56.0%	91.4%	309.4%	657.1%	222.9%
% Annual change cases[f]	2.0%	2.9%	6.3%	9.2%	5.2%
% Change ASR[g]	−32.7%	−39.0%	30.5%	135.7%	5.6%
European and Other					
2020–2022					
Observed[a]	101	225	409	131	866
ASR[b]	5.8 (5.1–6.5)	8.0 (7.3–8.7)	13.5 (12.7–14.3)	3.8 (3.4–4.2)	31.0 (29.6–32.3)
2035					
Projected[c]	84 (71–100)	212 (187–239)	551 (498–607)	215 (179–262)	1,066 (995–1,137)
ASR[d]	4.4 (3.5–5.6)	6.3 (5.3–7.6)	17.1 (15.0–19.5)	5.3 (4.1–7.0)	33.3 (30.1–36.7)
% Change in cases[e]	−16.8%	−5.8%	34.7%	64.1%	23.1%

Table 2 (continued): National projections for gynaecological cancers by prioritised ethnicity and cancer site.

	Cervical	Ovarian	Uterine	Other	Total
2045					
Projected[c]	73 (57–94)	188 (156–223)	626 (542–721)	293 (226–390)	1,185 (1,069–1,312)
ASR[d]	4.0 (2.9–5.3)	5.5 (4.4–6.9)	19.6 (16.5–23.2)	6.9 (4.9–9.7)	36.1 (31.8–41.1)
% Change in cases[e]	−27.7%	−16.4%	53.1%	123.7%	36.8%
% Annual change cases[f]	−1.4%	−0.8%	1.9%	3.6%	1.4%
% Change ASR[g]	−31.0%	−31.3%	45.2%	81.6%	16.5%

[a] Average observed cases per year over the period.
[b] Age-standardised rate (ASR) over the 3-year period with 95% confidence intervals.
[c] Projected cases with 95% uncertainty intervals.
[d] ASR of projected cases with 95% uncertainty intervals.
[e] Total percentage change in cases from observed 2020–2022 average.
[f] Annual percentage change represents the compound annual growth rate (CAGR) between the 2020–2022 average and 2045.
[g] Total percentage change in the ASR from observed 2020–2022.

Table 3: Regional projections for gynaecological cancers by cancer site.

	Cervical	Ovarian	Uterine	Other	Total
Northern					
2020–2022					
Observed[a]	70	112	296	50	527
ASR[b]	6.2 (5.4–7.1)	8.8 (7.8–9.8)	22.4 (20.9–23.9)	3.3 (2.8–3.9)	40.6 (38.6–42.7)
2035					
Projected[c]	71 (59–86)	122 (107–142)	487 (436–540)	111 (83–135)	794 (734–856)
ASR[d]	5.1 (4.0–6.4)	6.5 (5.4–7.9)	26.8 (23.1–30.8)	5.0 (3.8–6.6)	43.5 (39.1–48.3)
% Change in cases[e]	1.4%	8.9%	64.5%	122.0%	50.7%
2045					
Projected[c]	72 (56–92)	125 (103–153)	662 (568–767)	168 (130–224)	1,033 (922–1,151)
ASR[d]	4.6 (3.4–6.2)	5.6 (4.4–7.1)	31.4 (26.1–37.7)	6.3 (4.5–8.9)	48.1 (41.9–55.1)
% Change in cases[e]	2.9%	11.6%	123.6%	236.0%	96.0%
% Annual change cases[f]	0.1%	0.5%	3.6%	5.4%	3.0%
% Change ASR[g]	−25.8%	−36.4%	40.2%	90.9%	18.5%

Table 3 (continued): Regional projections for gynaecological cancers by cancer site.

	Cervical	Ovarian	Uterine	Other	Total
Te Manawa Taki					
2020–2022					
Observed[a]	27	70	134	35	267
ASR[b]	4.7 (3.7–5.9)	8.9 (7.6–10.2)	16.0 (14.4–17.7)	3.8 (3.0–4.7)	33.4 (30.9–35.9)
2035					
Projected[c]	36 (30–43)	71 (62–81)	222 (201–244)	65 (53–79)	394 (366–422)
ASR[d]	5.3 (4.2–6.6)	6.6 (5.4–8.0)	21.6 (18.8–24.8)	5.1 (3.8–6.7)	38.8 (35.0–42.8)
% Change in cases[e]	33.3%	1.4%	65.7%	85.7%	47.6%
2045					
Projected[c]	36 (28–45)	70 (57–85)	291 (253–333)	97 (74–129)	496 (447–550)
ASR[d]	4.9 (3.7–6.5)	5.7 (4.5–7.3)	25.4 (21.4–30.2)	6.6 (4.7–9.4)	42.8 (37.5–48.8)
% Change in cases[e]	33.3%	0.0%	117.2%	177.1%	85.8%
% Annual change cases[f]	1.3%	0.0%	3.4%	4.5%	2.7%
% Change ASR[g]	4.3%	−36.0%	58.8%	73.7%	28.1%
Central					
2020–2022					
Observed[a]	34	63	132	27	256
ASR[b]	6.1 (4.9–7.4)	8.0 (6.9–9.3)	17.3 (15.5–19.1)	2.9 (2.3–3.7)	34.3 (31.8–36.9)
2035					
Projected[c]	33 (27–39)	65 (57–75)	200 (180–220)	53 (43–64)	351 (328–377)
ASR[d]	5.2 (4.0–6.5)	6.8 (5.6–8.2)	21.8 (19.0–24.9)	4.7 (3.5–6.1)	38.5 (34.8–42.6)
% Change in cases[e]	−2.9%	3.2%	51.5%	96.3%	37.1%
2045					
Projected[c]	32 (24–41)	63 (52–76)	253 (219–291)	77 (59–101)	427 (385–473)
ASR[d]	4.7 (3.5–6.4)	5.9 (4.6–7.5)	25.6 (21.6–30.5)	6.0 (4.3–8.5)	42.5 (37.4–48.5)
% Change in cases[e]	−5.9%	0.0%	91.7%	185.2%	66.8%

Table 3 (continued): Regional projections for gynaecological cancers by cancer site.

	Cervical	Ovarian	Uterine	Other	Total
% Annual change cases[f]	−0.3%	0.0%	2.9%	4.7%	2.2%
% Change ASR[g]	−23.0%	−26.3%	48.0%	106.9%	23.9%
Te Waipounamu					
2020–2022					
Observed[a]	39	81	155	51	325
ASR[b]	5.8 (4.8–7.1)	8.5 (7.4–9.8)	15.9 (14.4–17.5)	4.6 (3.8–5.4)	34.8 (32.5–37.2)
2035					
Projected[c]	40 (33–48)	86 (76–99)	234 (210–259)	80 (66–101)	443 (411–477)
ASR[d]	5.0 (3.9–6.3)	6.9 (5.7–8.3)	19.3 (16.8–22.2)	5.4 (4.0–7.2)	36.6 (33.3–40.7)
% Change in cases[e]	2.6%	6.2%	51.0%	56.9%	36.3%
2045					
Projected[c]	39 (30–50)	84 (70–102)	302 (260–350)	118 (89–160)	544 (490–610)
ASR[d]	4.5 (3.4–6.1)	5.9 (4.7–7.5)	22.8 (19.1–27.1)	6.9 (4.8–9.9)	40.3 (35.4–46.2)
% Change in cases[e]	0.0%	3.7%	94.8%	131.4%	67.4%
% Annual change cases[f]	0.0%	0.2%	2.9%	3.7%	2.3%
% Change ASR[g]	−22.4%	−30.6%	43.4%	50.0%	15.8%

[a] Average observed cases per year over the period.
[b] Age-standardised rate (ASR) over the 3-year period with 95% confidence intervals.
[c] Projected cases with 95% uncertainty intervals.
[d] ASR of projected cases with 95% uncertainty intervals.
[e] Total percentage change in cases from observed 2020–2022 average.
[f] Annual percentage change represents the compound annual growth rate (CAGR) between the 2020–2022 average and 2045.
[g] Total percentage change in the ASR from observed 2020-2022.

(27 to 77; ASR 2.9 to 6.0). Cervical and ovarian rates decline, with case counts staying relatively stable.

In Te Waipounamu, total cases grow from 325 to 544 (95% UI 490–610). Uterine cancers increase from 155 to 302 (ASR 15.9 to 22.8), and other cancers from 51 to 118 (ASR 4.6 to 6.9). Cervical and ovarian ASRs decline, while case numbers remain steady.

Discussion

This analysis projects a substantial rise in gynaecological cancer cases in Aotearoa New Zealand by 2045, with uterine cancers showing the largest absolute growth. These trends are consistent across regions and ethnic groups and align with national and international studies documenting an expected 3% annual increase in endometrial cancer, particularly among younger women and Māori and Pacific populations.[4,17] Excess body weight and diabetes are likely major drivers of changing risk patterns. Excess body weight, strongly linked to endometrial cancer

through hormonal and inflammatory pathways, remains highly prevalent, especially among Māori and Pacific women, and is estimated to account for ~40% of cases in Māori and over half in Pacific women.[18–20] Diabetes prevalence is also increasing (~7% annually) and is three times higher in Māori and Pacific peoples, conferring a two- to three-fold increased risk independent of body weight.[21–23]

Cervical cancer rates are projected to decline, reflecting the impact of screening and HPV vaccination,[9] though inequities persist for Māori and Pacific women.[24] However, the shift to HPV testing may produce a temporary short-term incidence spike as existing precancers and early-stage cancers are detected.[25,26]

While rising incidence partly reflects shifting risk factor profiles, demographic growth is also a major contributor. For example, Asian women are projected to see cases more than triple by 2045, yet ASRs increase only slightly (28.4 to 30.0 per 100,000), suggesting much of the growth in this group is as a result of this demographic change. By contrast, ASRs rise more than 20% in other groups, suggesting stronger risk factor contributions.

Interpretation of ovarian cancer projections requires some caution, given the shift in reclassification of high-grade serous carcinomas to fallopian tube origin,[14] which may have led to lower ovarian rates. Increases in "other" gynaecological cancers (C57.7–C57.9) may also reflect coding and diagnostic uncertainty rather than true increases.[27]

Regional projections show the largest absolute growth in the Northern Region, reflecting both population growth and higher baseline incidence in Pacific women concentrated in Auckland, while other regions show smaller absolute but still substantial relative increases.

Our findings are broadly consistent with those of Teng et al.,[11] who also projected rising uterine cancer and stable ovarian cancer incidence to 2044. Differences include slightly higher growth in uterine cancers and lower cervical cancer incidence in our model, but overall alignment supports the validity of these projections and reinforces the urgent need to address the growing burden of uterine cancer and associated inequities.

A pathway to action—endometrial cancer

The rise of endometrial cancer is increasingly being identified as a global concern.[1] In Aotearoa New Zealand, the trajectory is particularly steep among younger Pacific women.[6] While these trends are not inevitable, reversing them will require coordinated action across the full prevention and care continuum. Figure 1 illustrates this spectrum, from community awareness to prevention activities targeting key risk factors such as excess body weight and diabetes, to ensuring timely and culturally safe investigation and management of abnormal uterine bleeding and improving access to surgical and non-surgical interventions for endometrial hyperplasia and cancer. Supportive survivorship care is also essential, including fertility preservation.[28]

Emerging research, both internationally and in Aotearoa New Zealand, is contributing to these efforts by exploring the role of endometrial microbiota in cancer development and investigating biomarkers that may support less invasive diagnostic approaches.[29–32] When addressing the risk associated with excess body weight, it is important to do so in a way that is holistic and pro-equity, as well as anti-stigmatising, and that acknowledges the broader and complex drivers of excess body weight.[18,28]

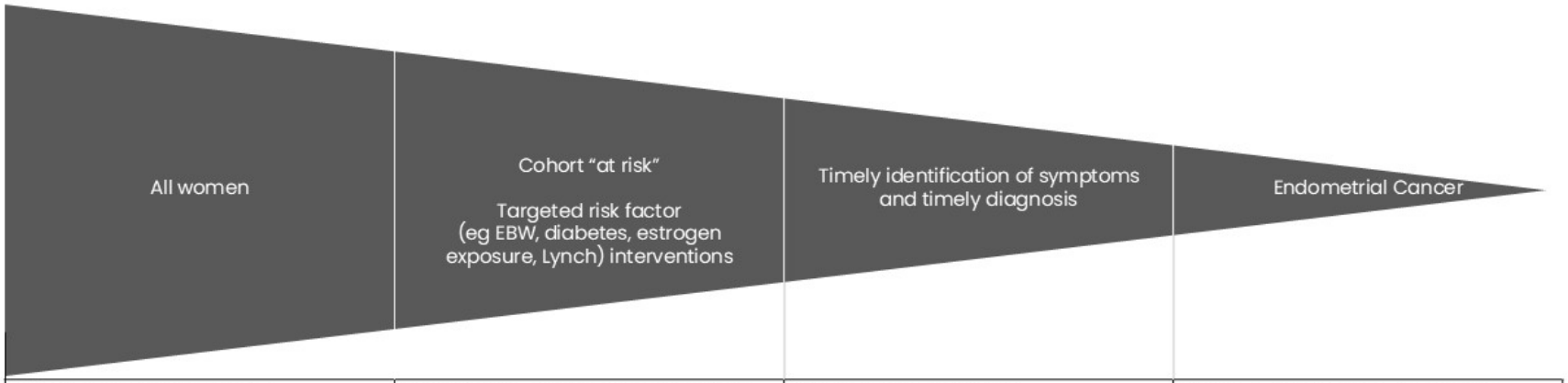
The inequities identified in this study highlight the need for targeted, research-informed strategies, particularly for Pacific populations and in areas with high Pacific populations. Prognosis generally remains good, with 5-year relative survival for localised disease at 90–96%.[33] However, patterns are changing, with earlier age associated with later stage disease and a rise in more aggressive cancers, both of which are associated with poorer survival. Treatment almost always entails a loss of fertility, underscoring the need for early detection and supportive survivorship care.

Cervical cancer elimination

The WHO defines elimination of cervical cancer as an annual rate below four cases per 100,000 women, with 2030 targets of 90% HPV vaccination by age 15, 70% of women screened at ages 35 and 45 and 90% of women with cervical disease receiving treatment.[10] While countries such as Australia have adopted national elimination goals and are projected to reach the threshold within the next decade,[34] Aotearoa New Zealand has no explicit goal in place.

Despite not having an elimination goal, our projections indicate that Aotearoa New Zealand is unlikely to meet the elimination threshold even by 2045 based on current trajectories. The projected national ASR in 2045 is 4.7 per 100,000, above the WHO benchmark.

Figure 1: Proposed framework for coordinated action across the prevention spectrum.



General awareness raising	Potential to identify at risk cohorts in primary or secondary care including risk prediction tools	National AUB guidelines implementation – reducing variation in access to endometrial sampling and ultrasound in the community	Improve timeliness to treatment
Tailored community specific awareness eg young Pacific women	Risk factor management	Quality improvement to support National AUB guidelines implementation	Conservative management options
	Targeted awareness raising by risk factor	Proactive identification of symptoms in primary care	Fertility sparing
	Health professional education including cultural safety	Accessible rapid response clinics	Mutation guided treatment
			Survivorship

Note: At a total population level this includes actions to address the broader environmental factors related to excess body weight. AUB = abnormal uterine bleeding.

By ethnicity, projected 2045 ASRs are 7.3 for Māori women, 6.3 for Pacific women, 4.0 for European/Other women and 3.5 for Asian women. Thus, only Asian women, and possibly European/Other, are on track to reach the elimination threshold, while rates for Māori, Pacific and the overall population remain above the WHO threshold.

Implications for service planning

From a service-planning perspective, the rising number of gynaecological cancers will increase demand across specialist assessment, diagnosis, treatment and follow-up care. The regions should plan capacity increases over the medium term, with clear referral pathways from primary care and timely access to specialist services. Workforce planning will be needed across clinical and diagnostic services, with actions to recruit, retain and upskill staff and to enable care closer to home. Equity must be built in from the outset, including culturally anchored navigation and outreach for Māori and Pacific peoples and active monitoring of access and waiting times. Regional capacity modelling can align with these projections, supported by consistent, high-quality data to forecast demand and capacity across the pathway, monitor access and waiting times, identify bottlenecks and track equity of care, with attention to Māori and Pacific peoples given the uneven distribution of gynaecological cancer incidence.

Strengths

This study provides the first sub-national projections of gynaecological cancer incidence in Aotearoa New Zealand, disaggregated by cancer site, ethnicity and region, through to 2045. Reporting both case counts and ASRs with UIs allows assessment of absolute and relative changes while reflecting statistical variability and a range of future scenarios. Presenting results across Māori, Pacific, and regional populations highlights where the greatest increases are projected to occur, supporting equity-focussed planning and targeted health system responses. Importantly, the model distinguishes between cancer types rather than treating gynaecological cancers as a single category, enabling clearer insights into site-specific trends with different risk factors, screening approaches and treatment pathways. The projections therefore provide timely, policy-relevant evidence to inform prevention, early detection and service delivery strategies in anticipation of rising cancer burden and widening inequities.

Limitations

The accuracy of these projections depends on the validity of the APC assumptions and the stability of historical trends, yet changes in risk factors, screening uptake, diagnostic practices or coding may alter future incidence in ways not captured. For example, the introduction of primary HPV testing and HPV self-test access is likely to cause a short-term spike in cervical cancer incidence not fully reflected here. The projections should be treated as descriptive tools for planning rather than formal predictive models.

The analysis also relies on registry data coded with ICD-10, which may not fully reflect evolving tumour classification. Diagnostic shifts, such as reclassifying high-grade serous carcinomas from ovarian to fallopian tube origin or increases in overlapping/unspecified sites (C57.7–C57.9), may produce artefactual trends.

Undercounting of some groups is a further limitation, particularly where people identify with multiple ethnicities.[35,36] Use of prioritised ethnicity supports national reporting but may understate the burden for some populations, especially Pacific peoples.[37] The broad Level 1 groupings used in this analysis may mask important heterogeneity within the Asian and Pacific populations. More detailed disaggregation—for example, by Chinese, Indian and Other Asian, or by specific Pacific sub-groups such as Samoan, Tongan and Cook Islands Māori—would provide a clearer understanding of differences in cancer risk and projected burden. However, the data required for such analyses, including consistent historical and projected population estimates at this level of detail, are not yet available.

Projections based on APC models are inherently uncertain and should be interpreted as indicative rather than predictive. The models capture long-term incidence patterns and indirectly reflect changes in underlying risk, but they assume that the APC relationships continue in a broadly similar way. The uncertainty intervals presented alongside our projections incorporate both statistical variation in model estimates and uncertainty in future population projections, yet they cannot fully account for all sources of potential error. For context, the projected total number of gynaecological cancers ranges from approximately 1,850 to 2,120 cases in 2035 and from 2,260 to 2,770 in 2045, corresponding to increases of about 35–55% and 65–100% relative to 2020–2022. These ranges illustrate that while the direction of change is

robust, there remains some uncertainty around the true magnitude of the projected increase. The projections should therefore be regarded as plausible scenarios that describe the likely direction and relative magnitude of change, providing a useful guide for planning under a range of possible futures.

Conclusion

This study presents the first sub-national projections of gynaecological cancer incidence in Aotearoa New Zealand to 2045 by cancer site, ethnicity and region. Cases are projected to rise substantially, led by rising incidence of uterine cancer, with the largest increases among Māori and Pacific women. These findings highlight the need for equity-focussed prevention, timely diagnosis and culturally responsive care, alongside investment in service capacity to meet future demand.

COMPETING INTERESTS
GM receives honoraria from ASCCP for committee duties, teaching on update course twice a year. GM is a committee member for the NCSP partnership & equity group and chair of the NCSP clinical guidelines group.

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AUTHOR INFORMATION
Michael Walsh: Epidemiologist, Planning, Funding and Outcomes, Health New Zealand – Te Whatu Ora, Auckland, New Zealand.
Karen Bartholomew: Director of Health Gain Development, Planning, Funding and Outcomes, Health New Zealand – Te Whatu Ora, Auckland, New Zealand.
Georgina McPherson: Nurse Practitioner, Gynaecology Department, Health New Zealand – Te Whatu Ora Waitematā, New Zealand.
Bryony Simcock: Gynaecologist, Health New Zealand – Te Whatu Ora, Christchurch Hospital, New Zealand.
Sathana Ponnampalam: Gynaecologist, Gynaecology Department, Health New Zealand – Te Whatu Ora, Auckland, New Zealand.

CORRESPONDING AUTHOR
Michael Walsh: Epidemiologist, Planning, Funding and Outcomes, Health New Zealand – Te Whatu Ora, Level 2, Q4 Building, Smales Farm, 74 Taharoto Road, Takapuna, Auckland 0622 | Private Bag 93-503, Takapuna 0740.
E: michael.walsh@tewhatuora.govt.nz

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Diagnoses of blood-borne viruses and other sexually transmitted infections in a sample of 356 sex workers attending a sexual health outreach clinic in Auckland over a two-year period

Sunita Azariah

ABSTRACT

AIM: We aimed to describe demographics and rates of diagnoses of blood-borne viruses and other sexually transmitted infections (STBBI) in sex workers attending an outreach clinic in Auckland.

METHODS: Sex workers attending an outreach clinic in Auckland from 31 December 2018 to 31 December 2020 were eligible for inclusion. Gonorrhoea and chlamydia rates in sex workers were compared to rates in two comparator groups: attendees to general sexual health clinics and a population-based sample.

RESULTS: Three hundred and fifty-six sex workers were eligible for inclusion. The majority were cisgender-gender females (93.5%, n=333). Test positive rates for chlamydia (5.1%) and gonorrhoea (3.9%) in cisgender-female sex workers were lower than for females attending general sexual health clinics. Chlamydia and gonorrhoea rates were higher in transgender-female sex workers than in cisgender-female sex workers, but the numbers were small (n=14). Of the 159 sex worker participants tested for hepatitis C antibody, 25 were antibody positive (15.7%).

CONCLUSIONS: Cisgender-female sex workers had lower rates of diagnosis of chlamydia and gonorrhoea than females attending general sexual health clinics. STBBI testing in sex workers should routinely include assessment and testing for hepatitis C. The data indicate that sex workers should continue to be a priority population in the STBBI strategy.

Sex workers are a designated priority population in the Aotearoa New Zealand Sexually Transmitted and Blood Borne Infection (STBBI) Strategy[1] as they have been identified as a group experiencing inequities in this area. The illicit nature of sex work in many countries renders sex workers vulnerable to exploitation and can be a barrier to effective health promotion and risk-reduction activities. A United Kingdom review of STBBIs in sex workers identified a number of structural factors that could contribute to increased STBBI risk, including illicit drug use, gender identity, stigma, criminalisation and enforcement-based approaches.[2] In 2003 New Zealand passed the *Prostitution Reform Act* (*PRA*), which was intended to enable sex workers to have the same protections afforded to people employed in other types of work and to create an environment to protect the human rights, public health and the occupational safety and health of sex workers. A study in 2007 concluded that there had been many positive outcomes from the implementation of the *PRA* and there was little or no evidence of negative consequences for the health and safety of sex workers following decriminalisation.[3]

The NZPC: Aotearoa New Zealand Sex Workers' Collective (NZPC) was founded in 1987 by sex workers as an organisation seeking equal rights for people engaging in sex work, and it provides a range of services with a particular focus on HIV and AIDS prevention. A pilot study of 20 sex workers commissioned by the NZPC in 1991 found that sex workers had high levels of knowledge and awareness of HIV/AIDS, and this was accompanied by extensive use of condoms with clients.[4] However there are very little available data on STBBI diagnoses in New Zealand sex workers to help guide future policy and risk-reduction activities.

There were two aims for this study. The first was to describe demographics and frequency of diagnoses of STBBIs in a sample of Auckland sex workers. The second was to compare rates of

diagnoses of chlamydia and gonorrhoea in sex workers to two comparator groups, which were attendees to Auckland Sexual Health Service (ASHS) general sexual health clinics and a population-based sample.

Methods

ASHS provides secondary-level sexual health services to the greater Auckland Region, including a weekly nurse-led outreach clinic located at the NZPC offices in central Auckland. Serology for HIV and syphilis and testing for chlamydia and gonorrhoea is offered to all people requesting or requiring a sexually transmitted infection (STI) screen. Screening for viral hepatitis is offered selectively based on disclosure of specific risk factors. Multiple anatomical sites may be tested for gonorrhoea and chlamydia depending on sexual practices and behaviour, including the oropharynx, vagina and ano-rectum. All pharyngeal and rectal swabs are dual tested for chlamydia and gonorrhoea, and vaginal swabs are also tested for trichomoniasis. (Trichomoniasis testing data have not been included).

Diagnostic tests performed at ASHS clinics are all processed at the Auckland City Hospital laboratory (LabPLUS). This study is reporting on laboratory data that were collected during the period from 31 December 2018 to 31 December 2020.

Gonorrhoea test positive rates and chlamydia test positive rates were compared across three different comparator groups:

1. Sex workers attending the ASHS NZPC clinic during the study period
2. Attendees to ASHS general clinics for STI testing during the study period
3. A population-based sample derived from laboratory testing data for chlamydia and gonorrhoea in the Auckland Region

Inclusion criteria—sex worker sample

Sex workers who had attended the NZPC clinic during the study period were eligible for inclusion. Attendees who were not sex workers or who were not at risk of STI through their work (e.g., sensual massage only) were excluded. Demographic data were collected from the electronic patient management system including age, sex and ethnicity. As the patient's registered sex is not always concordant with gender identity, the notes for each participant were checked to correctly assign gender. Ethnicity was categorised as: New Zealand or other European, Māori, Pacific, Asian, Other (African, Latin American/Hispanic, Middle Eastern) and not stated or specified. Laboratory test results for the following STBBIs were collated for each participant over the study period: chlamydia, gonorrhoea, syphilis, HIV, hepatitis B (HBV) and hepatitis C (HCV). Clinic records of people with reactive syphilis serology were reviewed to determine if the reactive test represented a new infection, as syphilis serology usually remains reactive for life following treatment. If HBV testing had not been requested during the relevant time period, results of previous serological testing were reviewed to check for previous immunity or infection as per standard clinical practice to reduce unnecessary testing or vaccination. Notes were also reviewed for documentation regarding methamphetamine or injecting drug use (IDU).

STBBI test positive rates were calculated by dividing the total number of positive tests taken during the study period by the total number of requested tests in the same time period. Individuals could have multiple tests for gonorrhoea and chlamydia collected from different anatomical sites on a single visit, so the denominator for the gonorrhoea and chlamydia testing data was the total number of tests requested, not individuals tested. Data were entered into a password-protected Microsoft Excel spreadsheet and stored in a password-protected computer.

Inclusion criteria—ASHS general clinic attendees

Gonorrhoea and chlamydia laboratory quarterly testing data are routinely provided by the hospital laboratory in the form of password-protected Excel spreadsheets. These include the following variables: date of test, unique national health identifier (NHI), date of birth (DOB), patient sex, anatomical site of test and test result for each site tested. Testing data from people who had attended ASHS general clinics during the study period were included in the analysis. Sex and age data for ASHS general clinic attendees were derived from the testing data. Due to the large numbers involved it would have been too logistically challenging to manually review each individual health record for ethnicity and gender; therefore, ASHS general clinic volumes data from 2019 and 2020 for priority populations were used to give some limited comparative data for gender, ethnicity and sexual behaviour.

Gonorrhoea and chlamydia testing data for quarter two of 2020 were not able to be accessed for unknown technical reasons, so testing data from 2020 only included results from available

quarters one, three and four. LabPLUS was not routinely supplying serological testing data for HIV, syphilis and viral hepatitis during that time period, so blood-borne infection (BBI) testing data for general ASHS clinic attendees were not included in the analysis.

Inclusion criteria—population-based sample

These data were derived from population-based anonymised chlamydia and gonorrhoea laboratory testing data for the Auckland Region during the 2019 and 2020 time periods. These data are collated by the New Zealand Institute for Public Health and Forensic Science (PHF Science) and mainly reflect testing in primary care. The data were provided by personal communication from Putu Duff, PHF Science.

Safety and data monitoring

Due to sensitivity of the data, the study was conducted under the guidance of a small, informal committee that included ASHS clinical staff and representatives of NZPC.

Ethics review

The study was approved by the Health and Disability Ethics Committee (reference 2023 EXP 13385).

Results

Demographics

NZPC cohort

There were 356 eligible participants who attended the NZPC clinic during the study period. The age range of participants was 20 to 61, with a median age of 31. The majority were cisgender-females (93.5%; n=333), with 14 transgender-females, seven cisgender-males and two transgender-males. The majority identified as New Zealand or other European (n=152; 42.7%), 62 identified as Māori (17.4%), 87 as Asian (24.4%), 15 as Pacific (4.2%) and 38 as Other (10.7%). Ethnicity was not stated for two participants (Table 1).

Table 1: Demographics.

NZPC: Aotearoa New Zealand Sex Workers' Collective (NZPC) cohort **N=356**	**Auckland Sexual Health Service (ASHS) 2019 testing data** **No. of tests=24,434**	**ASHS 2020 testing data** **No. of tests=16,325***
Age range 20–67 **Median** 31	15–87 37	14–84 31
Gender Female 333 (93.5%) Male 7 (1.9%) Transgender-male 2 (0.005%) Transgender-female 14 (3.9%)	**Sex** Female 4,398 (18.0%) Male 20,008 (82.0%)	**Sex** Female 2,909 (18.0%) Male 13,391 (82.0%)
Ethnicity	**ASHS volumes data for priority populations** **Total visits=31,755**	**ASHS volumes data for priority populations** **Total visits=25,658**
Māori 62 (17.4%) European 152(42.7%) Asian 87 (24.4%) Pacific 15 (4.2%) Other 38 (10.6%) Not stated 2 (0.6%)	Māori 4,434 (15.3%) Pacific 3,362 (10.6%) Gay or bisexual men (GBMSM) 11,630 (36.6%) Transgender 1,385 (4.4%)	Māori 3,461 (13.5%) Pacific 2,865 (11.1%) GBMSM 9,079 (35.3%) Transgender 1,063 (4.1%)

*Quarter two data missing.

ASHS general clinic attendees

The age range of those tested for gonorrhoea and chlamydia in 2019 was 15–87 in 2019 (median age 37) and 14–84 in 2020 (median age 31) (Table 1). Clinic volumes of people attending ASHS general clinics were 20% lower in 2020 (n=25,658) than in 2019 (n=31,755) due to the COVID-related lockdowns that occurred during 2020 in Auckland. In 2019, 4,434 of clinic visits to ASHS general clinics were for people of Māori ethnicity (15.3%) and 3,362 were for people of Pacific ethnicity (10.6%). The data for 2020 were similar, with Māori accounting for 13.5% of clinic visits and Pacific people for 11.1% of clinic visits. The NZPC sample had a higher proportion of Māori participants (17.4%) and a lower proportion of Pacific participants (4.2%) when compared with encounter volumes data for those attending ASHS general clinics (Table 1). Gay and bisexual men (GBMSM) accounted for over a third (n=11,630; 36.6%) of clinic visits in both 2019 and in 2020 (n=9,079; 35.3%). Transgender people accounted for a similar proportion (n=1,385; 4.4%) of clinic visits in 2019 and in 2020 (n=1,063; 4.1%). However, transgender people mainly access ASHS for gender-affirming healthcare so not all visits would have been due to STI-related concerns.

Chlamydia testing results

NZPC cohort

There were 1,429 chlamydia and gonorrhoea tests requested from the 365 NZPC participants during the study period (Table 2). All participants were tested at least once during the study period; some were tested multiple times. Over 90% of tests at NZPC were requested in cisgender-females. The overall test positive rate was 4.9%. Transgender-female sex workers had a higher chlamydia test positive rate (7.4%) than cisgender-female sex workers (5.1%).

ASHS general clinic attendees

In 2019, there were 24,434 chlamydia and gonorrhoea tests requested in individuals attending ASHS general clinics, and there were 16,325 tests requested in 2020 in quarters one, three and four.

Table 2: Chlamydia test results.

NZPC: Aotearoa New Zealand Sex Workers' Collective (NZPC) clinic	Auckland Sexual Health Service (ASHS) general clinics 2019/2020*	Public Health and Forensic Science (PHF Science) sexually transmitted infection surveillance data 2019/2020
No. tests by gender	**No. tests by sex**	**No. tests by sex**
N (%)	**N (%)**	**N (%)**
Female 1,342 (91.4%)	Female 7,307 (18.0%)	Female 230,849 (67.7%)
Male 46 (3.2%)	Male 33,399 (80.0%)	Male 110,264 (32.3%)
Transgender-female 67 (4.7%)		
Transgender-male 9 (0.63%)		
Total 1,429 (100%)	Total 40,706 (100%)	Total 341,113 (100%)
Positive tests by gender	**Positive tests by sex**	**Positive tests by sex**
N (%)	**N (%)**	**N (%)**
Female 66 (5.1%)	Female 660 (9.0 %)	Female 14,544 (6.3%)
Male 1 (2.1%)	Male 1,857 (5.6%)	Male 8,578 (7.8 %)
Transgender-female 5 (7.4%)		
Transgender-male 0 (0%)		
Total 72 (4.9%)	Total 1,509 (6.2%)	Total 23,122 (6.8%)

*Quarter two ASHS lab data not available.

(As stated previously, 2020 data were incomplete as no data were available from quarter two). In contrast to the NZPC clinic, over 80% of tests requested at ASHS general clinics were requested in males (Table 2). The chlamydia test positive rates for females (9.0%) attending ASHS general clinics were higher than that of males (5.6%). They were also higher than rates in cisgender-females presenting to NZPC (5.0%) (Table 2).

PHF Science data

In the Auckland STI surveillance data for 2019 and 2020, chlamydia test positive rates for females were lower than females attending ASHS general clinics (6.3%) but were higher than cisgender-female sex workers (5.1%). In contrast to the ASHS testing data, most tests in the PHF Science data were requested in females (Table 2).

Gonorrhoea test results

NZPC cohort

The overall gonorrhoea test positive rate was 4.4%. Transgender-female sex workers had higher gonorrhoea test positive rates (12.7%) than cisgender-female sex workers (3.9%) (Table 3). Cisgender-female sex workers had lower test positive rates than females attending ASHS general clinics (5.0%). There were 32 participants who were diagnosed with gonorrhoea on at least one occasion during the study period: 25 were cisgender-female (78.1%), two were cisgender-male and five were transgender-female (15.6%). The ethnic breakdown was as follows: 12 were Māori (37.5%), 13 were European (40.6%), three were Pacific (9.4%), three were Asian (9.4%) and one identified as Other (3.1%). In cisgender-females, the site of infection was predominantly urogenital (22) followed by pharyngeal infection (13). Ten had dual site infections. All the transgender-females had either pharyngeal or anorectal infections. Of the two cisgender-males, one had urogenital infection and the other had both ano-rectal and pharyngeal infection.

ASHS general clinic attendees

The overall test positive rate for gonorrhoea was higher for ASHS general clinic attendees (6.0%) than for the NZPC cohort. Males had higher test positive rates (6.4%) than females attending ASHS general clinics (5.0%) (Table 2).

Table 3: Gonorrhoea test results.

NZPC: Aotearoa New Zealand Sex Workers' Collective (NZPC) clinic	Auckland Sexual Health Service (ASHS) general clinics 2019/2020*	Public Health and Forensic Science (PHF Science) sexually transmitted infection surveillance data 2019/2020
No. tests by gender	**No. tests by sex**	**No. tests by sex**
N (%)	**N (%)**	**N (%)**
Cisgender-female 1,342 (93.9%)	Female 7,307 (18.0%)	Female 251,637 (67.0%)
Cisgender-male 23 (1.6%)	Male 33,399 (80.0%)	Male 117,100 (33%)
Transgender-female 55 (1.7%)		
Transgender-male 9 (0.62%)		
Total 1,429 (100%)	Total 40,706 (100%)	Total 368,737 (100%)
Test positive	**Test positive**	**Test positive**
N (%)	**N (%)**	**N (%)**
Cisgender-female 53 (3.9%)	Female 364 (5.0 %)	Female 3,654 (1.5%)
Cisgender-male 3 (13.0%)	Male 2,125 (6.4 %)	Male 6,783 (5.8%)
Transgender-female 7 (12.7%)		
Transgender-male 0 (0.0%)		
Total 63 (4.4%)	Total 2,449 (6.0%)	Total 10,437 (2.8%)

*Quarter two ASHS lab data not available.

PHF Science data

Female gonorrhoea test positive rates (1.5%) in PHF Science data were lower than cisgender-female sex workers (3.9%) and also lower than females attending ASHS general clinics (5.0%). Male gonorrhoea test positive rates (5.8%) were similar to the test positive rates for male ASHS general clinic attendees (6.4%) (Table 3).

Serology results for NZPC cohort

HIV

During the study period there were 615 HIV tests requested for the NZPC clinic sample. All those who had serology for HIV also had syphilis serology requested on the same sample. All participants were tested at least once during the study period, apart from one person with previously diagnosed HIV who was on anti-retroviral treatment with an undetectable viral load. There were no new diagnoses of HIV during the study period in any of the participants.

Syphilis

Sixteen people (2.6%) had reactive syphilis serology test results, but after excluding those with previously treated syphilis only four participants had a new diagnosis (0.65% of tests). Of the four NZPC participants with new diagnoses of syphilis, three were cisgender-females and one was a cisgender-male.

HBV

HBV serological status was known for 253 (71%) of the 356 NZPC participants, either due to testing that was undertaken during the study period or from previous testing results. The majority of those who had been tested for HBV were either immune (48.2%) or had negative serology (36.0%). Three participants had serology results indicating chronic HBV infection; all were of Asian ethnicity.

HCV and documentation of drug use

There was no documentation in the notes regarding methamphetamine or injecting drug use in 189 participants (53.0%). One hundred and twenty-two responded no to use of methamphetamine or IDU (34.2%). Forty said yes to methamphetamine use (11.2%). Four were currently injecting drugs and one person had previously injected drugs.

One hundred and fifty-nine (44.4%) of the NZPC clinic participants were tested for HCV antibody (HCV Ab). The majority of those tested for HCV Ab were cisgender-females, (n=141; 88.6%), five were cisgender-males (3.1%), 12 were transgender-females (7.5%) and one was a transgender-male. One hundred and thirty-four of those tested were negative for HCV Ab (84.2%) (Table 4). Twenty-five participants had HCV Ab detected (15.7%): 17 cisgender-females, seven transgender-females and one transgender-male (Table 4). Seven of the 25 people with reactive HCV Ab tests had HCV RNA detected, indicating current infection: five were cisgender-females and two were transgender-females (4.4% of those tested). Only four of the 25 people with reactive HCV Ab had a history of past treatment for HCV (16%). Only about two-thirds of those tested for HCV Ab (n=100; 63%) had documentation regarding whether they were taking illicit drugs or the indication for testing. Five of the people with reactive HCV Ab tests were documented as having a current or past history of injecting drugs (20%) and three of them had active infection with detectable HCV RNA. Of the 25 people with reactive HCV Ab, six had no documentation in the notes regarding illicit drug use, 13 were past or current users of methamphetamine, three had a current or previous history of injecting drugs and three denied any illicit drug use (Table 4).

Discussion

This study addresses an important gap in the literature, as there has previously been very little published data available on STBBI diagnoses in sex workers in New Zealand apart from some limited enhanced surveillance data for gonorrhoea and syphilis.[5]

It was interesting to note that test positive rates of chlamydia were lower in cisgender-female NZPC participants (5.1%) than in females in the PHF Science data (6.3%) and lower than females attending ASHS general clinics (9.0%). Gonorrhoea rates in cisgender-females in the NZPC cohort, however, were higher (3.9%) than female test positive rates in the PHF Science data (1.5%) but were lower than female rates in ASHS general clinic attendees (5.0%). The finding of higher test positive rates for chlamydia and gonorrhoea in females attending ASHS general clinics in comparison to the PHF Science data was not unexpected, as following a review of the service in 2015 primary access to ASHS clinics was restricted to priority (key) populations with known inequities in STBBIs. These populations were identified from STI surveillance data and include people under the age of 30, people of

Table 4: Hepatitis C results and documentation of drug use.

Tested for HCV antibody (HCV Ab) **N=159 (44.4%)**	**Documentation of drug use in those tested for HCV Ab**
Gender	**HCV Ab negative** N=134 (84.3%)
Female 141 (88.6%) Male 5 (3.1%) Transgender-female 12 (7.5%) Transgender-male 1 (6.2%)	Not documented 55 (41.0%) Meth use yes 21 (15.7%) Meth use no 57 (42.5%) Current or past injecting drug use (IDU) 2 (1.5%)
HCV Ab positive N=25 (15.7%)	**HCV Ab positive** N=25 (15.7%)
Female 17 (68.0%) Male 0 (0%) Transgender-female 7 (28.0%) Transgender-male 1 (4.0%)	Not documented 6 (24%) Meth use yes 13 (52%) Meth use no 3 (12.0%) Current or past IDU 3 (12.0%)
HCV RNA detected N=7 (4.4 %)	**HCV RNA detected** N=7 (4.4%)
Female 5 Male 0 Transgender-female 2 Transgender-male 0	Not documented 1 Meth use yes 4 Meth use no 1 Current or past IDU 1

Māori and Pacific ethnicity, GBMSM, people living with HIV, transgender people, sex workers and people who inject drugs.[6]

It is not known why gonorrhoea rates were higher in NZPC participants than rates in PHF Science data when chlamydia rates were lower, but this may be due to differing risk factors within the cohort for acquisition of gonorrhoea. There were 32 NZPC participants who were diagnosed with gonorrhoea on at least one occasion during the study period. Their median age (30) was similar to the whole NZPC sample but there were ethnic and gender differences. The majority of those diagnosed with gonorrhoea were of non-white ethnicity (n=19; 59.3%), and there was a much higher proportion of Māori diagnosed (n=12; 37.5%). Similar to chlamydia, the gonorrhoea rate was higher in transgender-females (n=5; 22.7%). Three of the transgender-females were of Māori ethnicity, one was Pacific and the other was European. It has been a consistent finding in STI surveillance data that Māori have disproportionately higher rates of gonorrhoea compared with other ethnicities. In the 2020 PHF Science annual report, 85 out 3,738 notified gonorrhoea cases were diagnosed in sex workers (2.3%).[5] The majority were female sex workers (n=64; 75.2%) and 29 were of Māori ethnicity (34%).[5] The proportion of cases reported to be of Māori ethnicity had increased across all sexual behaviours compared with 2019. Further, a recent study of bacterial STI in New Zealand found higher rates of gonorrhoea infection and re-infection in people of Māori and Pacific ethnicity.[7]

Apart from ethnicity, other factors to consider are that street-based or migrant sex workers may be more vulnerable to acquisition of gonorrhoea. A previous study of STI diagnoses at the NZPC clinic in 2012 (personal written communication from Sygrove C, Auckland Regional Sexual Health

Service on 2024 Mar 20), found low prevalence rates of chlamydia and gonorrhoea in sex workers attending the NZPC clinic (4.8% and 1% respectively) but higher rates in self-taken samples from street-based sex workers that did not attend the NZPC clinic (10% and 2% respectively). A study conducted in female sex workers (FSW) in Sydney from 2005 to 2019 found increasing prevalence rates of chlamydia and gonorrhoea over time and an increase in rates of pharyngeal gonorrhoea.[8] Pharyngeal infection rates were higher for FSW born in China, and the authors considered this may be due to reduced condom use for oral sex. A high proportion of the cisgender-females in the NZPC sample who were diagnosed with gonorrhoea had pharyngeal infection, and this may be due to similar factors to the Australian study.

There were no new HIV diagnoses in the largely cisgender-female NZPC sample during the study period, and this is consistent with the epidemiology of HIV in New Zealand in that locally acquired infections are most often diagnosed in GBMSM.[9] Case detection of syphilis was low in sex workers. Similar to HIV, syphilis is more commonly diagnosed in GBMSM, who made up 62.9% of cases reported to PHF Science in 2019 and 56.4% of cases in 2020, although the proportion of cases diagnosed in women who have sex with men did increase from 2019 to 2020 (12.6% and 17.6% respectively).[5]

A large proportion of the NZPC sample were tested for HCV during the study period (44.4%), but only just over half of participants had documentation in their notes regarding illicit drug use or other indications for testing. At the time of the study there was a pilot intervention in place to try to increase HCV diagnosis and access to treatment in the clinic, so more opportunistic testing was being carried out, regardless of whether risk factors were disclosed or not. There is a known intersection with sex working and illicit drug use, so it is likely drug use was underdocumented. In a Christchurch study, street-based sex workers more frequently reported using money from sex work for drugs and using drugs at work when compared with indoor workers. They also reported higher levels of violence than indoor workers.[10] There was also a significant difference between the proportion of street workers (76%) and indoor workers (33%) who said they used drugs at work.

These studies highlight the importance of risk assessment and opportunistic testing for HCV in sex workers, particularly in more vulnerable street workers. It is estimated that up to 40% of people living with HCV in New Zealand are unaware, and almost all new infections are diagnosed in people who inject drugs. [11] The funding of direct anti-viral treatment for HCV has provided an opportunity to potentially eliminate this infection in New Zealand if enough testing is done in key populations; however, linkage to care remains challenging. A large overseas study of over 11,000 people tested in an STI clinic setting found significantly lower test positive rates for HCV Ab than this study (1.6%) but only 16.5% of the 121 (1.1%) of HCV Ab positive people with detectable HCV RNA completed treatment.[12]

Finally, stigma associated with sex work is still real despite decriminalisation. In their literature review, Jordon commented: "*Historically sex workers have often been reviled for being disease carriers and held responsible for the transmissions of venereal diseases. Such thinking gave rise to the Contagious Diseases Act in both New Zealand and the United Kingdom. More recently it has been linked to perceptions of sex workers as a high at-risk group for the transmission of HIV/AIDS.*"[4] It is hoped that these data may help to dispel some of those myths.

Limitations of this study include the time period when it was conducted, which overlapped with the first year of the COVID-19 pandemic, and the 5-year period that has elapsed since the data were collected. Other limitations are that the laboratory datasets did not include gender or ethnicity demographics and would have included some data from sex workers attending general clinics for testing; however, this is unlikely to impact significantly on interpretation of the results due to the large numbers of tests. It is not known how representative this sample is of sex workers in Auckland or the rest of New Zealand as there are no reliable data. A strength of the study is that this was a relatively large sample of sex workers, and that testing data were able to be compared with that of general sexual health clinic attendees and PHF Science population-based data. While these data may not reflect current epidemiology, they do represent a snapshot in time that could be used to compare with any future research.

Conclusions

Cisgender-female sex workers had lower rates of diagnoses of chlamydia and gonorrhoea than females attending general sexual health clinics. STBBI testing in sex workers should routinely include assessment and testing for HCV to enable

linkage to care and assistance with harm reduction. Further research in this area should be encouraged; in particular more data are needed in male sex workers. Sex workers should continue to be considered a priority population for STBBI-related policies and guidelines.

COMPETING INTERESTS
Nil.

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CORRESPONDING AUTHOR INFORMATION
Dr Sunita Azariah: Sexual Health Physician, Auckland Sexual Health Regional Service, Health New Zealand – Te Whatu Ora Te Toka Tumai Auckland, New Zealand. E: sunitaa@adhb.govt.nz

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Pacific nurses' experiences of informal interpreting and language assistance in healthcare settings in Aotearoa New Zealand: results of an alumni survey

Debbie Ryan, Abel Smith, Safaatoa Fereti, Alisi Vudiniabola, Tamasin Taylor, Harriette Kimiora, David Nicholson, Gerard JB Sonder

ABSTRACT

AIM: We aimed to examine the experiences of Pacific nurses in Aotearoa New Zealand who provide informal language assistance to Pacific patients with limited English proficiency (LEP).

METHODS: A cross-sectional online survey was distributed to 229 alumni of the Aniva Leadership Programme. The survey included quantitative and qualitative questions about interpreting experiences. Descriptive statistics and logistic regression were used for quantitative analysis; framework analysis was applied to free-text responses.

RESULTS: The response rate was 69% (n=159). Of respondents, 80% spoke a Pacific language and 85% of these had been asked to interpret in clinical settings, most commonly by patients, families and colleagues. While 75% felt confident interpreting, many reported difficulties with technical terminology. Nurses observed improved patient trust, understanding and engagement when using Pacific languages. However, interpreting often conflicted with core duties, raised ethical concerns and was not formally recognised or supported.

CONCLUSION: Pacific nurses routinely provide informal interpreting, significantly enhancing patient care. Yet this work is uncompensated, untrained and exposes nurses to professional risks. Health systems must reduce reliance on informal interpreting by investing in professional services, offering interpreter training for bilingual staff and formally recognising the cultural and linguistic labour of Pacific nurses to support equitable care.

Effective communication between patients and clinicians in a shared language is critical for safety and positive health outcomes.[1] Research from English-speaking countries demonstrates that patients with limited English proficiency (LEP) face barriers to accessing services, incomplete information transfer, reduced understanding of medical care, less effective self-management and longer or additional follow-up consultations.[1]

In Aotearoa New Zealand, for example, research with Pacific mothers has highlighted that those who speak Pacific languages at home are significantly less likely to receive or act on safe sleep information, pointing to system-level communication failures within mainstream services and underscoring the need for linguistically aligned communication within the health system.[2]

The New Zealand Code of Health and Disability Services Consumers' Rights[3] guarantees the right to a competent healthcare interpreter,[4] while the *Health Practitioners Competence Assurance Act 2003* mandates cultural safety standards, including effective communication.[5] Consistent with global literature, professionally trained and, where applicable, certified in-person interpreters are considered the gold standard for addressing patient–clinician language discordance.[6] However, untrained interpreters are often being utilised instead.[7–9] The reasons for the reliance on untrained interpreters include budget constraints; workforce shortages, particularly for Pacific languages with low diffusion; and the dynamic nature of healthcare, where pre-planning for interpreters is not always feasible. International literature has documented how clinicians and health workers navigate language barriers,[10,11] often relying on family members or untrained bilingual staff and facing structural constraints in accessing professional interpreters.[12] Aotearoa New Zealand research similarly shows that even when clinicians

recognise the risks of poor communication associated with LEP patients, trained interpreters are under-utilised.[13] Although there is substantial qualitative research in this area,[14] little work has examined how often nurses themselves are called upon to interpret, and almost none has explored this in Pacific or Aotearoa New Zealand contexts.

Aotearoa New Zealand has a limited tradition of integrating Pacific language interpreting services into public healthcare,[4] compounded by insufficient data on the number of LEP individuals or those requiring interpreters.[8] Pacific peoples, the fourth largest ethnic group in Aotearoa New Zealand, make up approximately 9% of the national population[15] and encompass over 17 distinct ethnic, cultural and linguistic communities. Two-thirds of Pacific peoples are Aotearoa New Zealand–born, with 25% identifying with multiple ethnicities. Among overseas-born Pacific peoples, 46% have resided in Aotearoa New Zealand for over 30 years.[16]

An immigration survey (2005–2009) found that Pacific migrants had significantly lower English proficiency than non-Pacific migrants, with only 38% reporting English as the language they spoke best, compared with 62% of non-Pacific migrants.[17] English proficiency varied widely: 58% of Fijian migrants reported English as their best language, compared to 16% of Samoans and 20% of Tongans. The 2018 Census indicated 92% of Pacific people spoke English, leaving 8% (33,684 individuals) who did not.[18] The ability to speak Pacific languages varied among groups, ranging from 9% who spoke Cook Island Māori to 50% who spoke Samoan.[19] However, the accuracy of these findings is limited by a 65% census response rate, which is skewed toward Aotearoa New Zealand–born, English-speaking individuals, likely leading to an underestimation of language proficiencies.[20]

In 2023, Pacific nurses represented 4% (2,722) of Aotearoa New Zealand's nursing workforce.[21] Ethnic composition included Fijian (32%), Samoan (31%), Tongan (18%), Niuean (5%) and Tokelauan (4%). Most Pacific nurses trained in Aotearoa New Zealand, while 17% trained overseas, primarily in Pacific countries.[22] This study reports on nurses' experiences providing informal language assistance to Pacific patients and families with LEP in healthcare settings.

Methods

Study design and setting

This cross-sectional study was conducted using an online survey. Data were collected between 9 October and 27 November 2023. This research is part of a broader evaluation of the first 11 years of the Aniva Pacific Workforce and Leadership Development Programme (Aniva) for Pacific nurses in Aotearoa New Zealand.[23] Funded by Health New Zealand – Te Whatu Ora (HNZ) and delivered through Whitireia Polytechnic by Pacific Perspectives Ltd (an independent Pacific health provider), the primary strategic goal of the programme is to significantly increase the number of Pacific nurses and midwives holding postgraduate qualifications in Pacific health leadership, thereby preparing them for leadership roles within the health sector. The Aniva programme offers New Zealand Qualification Authority (NZQA)–approved qualifications including a Postgraduate Certificate and Diploma (Pacific Health), and a Master of Professional Practice (Leadership).

Ethics

This study received approval from the Te Pukenga—Whitireia and Weltec Ethics and Research Committee (RP 483—2025).

Recruitment and data collection

The survey was open to all 229 individuals who had previously enrolled in the Aniva programme. While this group included a small number of midwives, the vast majority were registered nurses. Therefore, for clarity and consistency, we refer to participants collectively as "nurses" throughout this article. Recruitment was conducted via email invitations using contact details in the Aniva administrative database. Reminder emails and follow-up phone calls were used to boost response rates. As an incentive, all nurses who completed the survey were entered into a draw to win one of 10 grocery vouchers. The survey was administered using Jotform, a Cloud-based online survey platform (Jotform Inc., San Francisco, California, United States of America), selected for its user-friendly interface. Responses were exported into Microsoft Excel (version 16) for data management and descriptive analysis.

Questionnaire

The questionnaire comprised 104 questions (Appendix Table 1), predominantly closed-ended with some open-ended prompts, covering demographics, experiences with the Aniva programme, qualifications and alumni work roles. Demographic questions were aligned with the Te Kaunihera Tapuhi o Aotearoa | Nursing Council of New Zealand tracking survey. This article focusses on responses to questions 20–24 regarding Pacific languages

and interpreting in the workplace, with additional insight from an open-ended question (question 25). The questionnaire was developed by the research team (DR, DN, SF, AV, AS, HK, GS) drawing on their practical and academic experiences in education, nursing workforce development and Pacific health, and piloted among the first 20 alumni.

Analysis of quantitative data

Descriptive statistics and Chi-squared tests were used to summarise participants' characteristics and asses participation-related associations. To evaluate potential response bias, we compared the demographic and professional characteristics available in the Aniva administrative dataset between respondents and non-respondents. Logistic regression identified factors linked to confidence and training in interpreting or translation tasks. Analyses were conducted using R version 4.2.2 (R Foundation for Statistical Computing, Vienna, Austria) and IBM SPSS Statistics version 29.0.2.0 (IBM Corp., Armonk, New York, United States of America).

Analysis of the free-text responses

The open-ended (question 25) responses provided insights into participants' experiences. Framework analysis, a systematic qualitative method, was chosen to enhance rigour and transparency when working with this multidisciplinary team and large dataset.[24] This method involved two main stages and five steps: stage one was creating an analytical framework and stage two was applying this framework to the dataset. The five steps were: 1) familiarisation with responses, 2) development of a coding framework (informed by both the survey topics and an initial scan of the free-text answers), 3) indexing data to codes (applying the coding framework), 4) charting coded responses into a matrix (summarised text entered into cells) and 5) mapping and interpretation (finding patterns, clarifying concepts, developing themes). This approach facilitated the identification of patterns, comparisons and variation across the free-text dataset, leading to themes beyond the predefined closed question responses. Coding was performed independently by two researchers (DR and TT). Discrepancies were resolved through discussion with other team members (GS, HK, AA, SF, AS) at regular team meetings, enhancing the rigour and consistency of the analysis.

Results

The response rate for the survey was 69% (159/229). Respondents were more likely than non-responders to be younger (χ^2=14.22, df=3, p=0.0026), born in Aotearoa New Zealand (χ^2=8.35, df=1, p=0.0039) and of Samoan descent (χ^2=7.19, df=1, p=0.0073). They were also more likely to be enrolled more recently in Aniva (χ^2=41.76, df=2, p<0.0001) and to have been more recently registered as nurses (χ^2=4.58, df=1, p=0.0324). In contrast, city/region of residence, gender, Pacific ethnicity other than Samoan descent, country of birth within Pacific sub-groups, country of citizenship and country of residence showed no significant association with survey response (all p>0.05).

Quantitative findings

The characteristics of the 159 respondents are shown in Table 1. The majority were female (91%), aged between 36 and 65 years (83%), and over half (52%) were born in a Pacific country. Most overseas-born respondents had migrated to Aotearoa New Zealand in the past 25 years, or since the 2000s (39%), followed by the 1990s (20%) and 1980s (13%).

Eighty percent (127) of respondents spoke a Pacific language, and 46% reported that it was their first language. The most spoken languages were Samoan (45%), Tongan (20%) and Fijian (17%). Among these, 113 (91%) spoke one Pacific language, 12 (9%) spoke two, and two spoke three Pacific languages (data not shown).

Of the 127 respondents who spoke a Pacific language, 120 answered questions about language use at work (questions 21–25). Of these, 118 (98%) reported using their Pacific language in the workplace, and 102 (85%) indicated that they had received requests to translate or interpret for patients and families in other areas of the workplace. Requests for assistance with interpreting or translating were made by colleagues (89%), patients and families (75%), and supervisors or managers (64%); 51% had been asked by all three groups. The majority of respondents (75%) reported feeling confident and possessing the skills to provide this assistance (Table 2). Confidence with interpreting or translating appeared higher among older participants, Fijian speakers and those with a Pacific first-language; however, none of these associations reached statistical significance (all odds ratios [ORs] 1.6–3.5, all p>0.05). By contrast, being born in a Pacific country was a statistically significant predictor (OR 3.2, 95% CI 1.3–8.1, p=0.015).

Qualitative findings

The open-ended prompt (question 25) yielded

Table 1: Characteristics of Aniva participants who participated in the Aniva Alumni Survey 2023, including Pacific languages spoken.

Characteristics	Total n (%)	Speaks Pacific language/s
Highest Aniva qualification	**159 (100%)**	**127 (80%)**
Master's	35 (22%)	26 (74%)
Diploma	53 (33%)	41 (77%)
Certificate	65 (41%)	54 (83%)
Not completed	6 (4%)	6 (100%)
Gender	**159 (100%)**	**127 (80%)**
Female	145 (91%)	116 (80%)
Male	14 (9%)	11 (79%)
Age category	**159 (100%)**	**127 (80%)**
≤25 years	0	0
26–35 years	16 (10%)	13 (81%)
36–45 years	35 (22%)	33 (94%)
46–55 years	65 (41%)	48 (74%)
56–65 years	32 (20%)	26 (81%)
>65 years	11 (7%)	7 (64%)
Ethnicity[a]	**230 (100%)**	**166 (72%)[b]**
Samoan	78 (34%)	62 (79%)
Tongan	32 (14%)	29 (91%)
Fijian	27 (12%)	24 (89%)
Cook Island Māori	18 (8%)	6 (33%)
NZ European	15 (7%)	<5 (n/a)
Tokelauan	13 (6%)	8 (62%)
Niuean	11 (5%)	8 (73%)
Tuvaluan	5 (2%)	<5 (n/a)
Other Pacific	12 (5%)	10 (83%)
Other non-Pacific	19 (8%)	14 (74%)
First language	**159 (100%)**	**127 (80%)**
English[c]	84 (53%)	52 (62%)
Pacific	73 (46%)	73 (100%)
Other	2 (1%)	2 (100%)
Country of birth	**159 (100%)**	**127 (80%)**
Pacific country	82 (52%)	79 (96%)
Aotearoa New Zealand	75 (47%)	46 (61%)
Other	2 (1%)	2 (100%)

Table 1 (continued): Characteristics of Aniva participants who participated in the Aniva Alumni Survey 2023, including Pacific languages spoken.

Speak a Pacific language	**159 (100%)**	
Yes	127 (80%)	-
No	32 (20%)	-
Pacific languages spoken[d]	**143 (100%)**	
Samoan	65 (45%)	
Tongan	28 (20%)	
Fijian	24 (17%)	
Niuean	8 (6%)	
Tokelauan	7 (5%)	
Cook Island Māori	5 (3%)	
Other Pacific	6 (4%)	
First arrival in Aotearoa New Zealand (decade)[e]	**84 (100%)**	**81 (96%)**
1960s	2 (2%)	2 (100%)
1970s	8 (10%)	6 (75%)
1980s	13 (15%)	12 (92%)
1990s	17 (20%)	17 (100%)
2000s	39 (46%)	39 (100%)
2010s	5 (6%)	5 (100%)
2020s	0	0

Notes: [a)] Total numbers add up to more than the total number of participants because some people identify with more than one ethnic group. [b)] The total number of participants, by ethnic group they identify with, who speak a Pacific language. [c)] Participants who identify with more than one ethnicity may be counted more than once as Pacific language speakers. [d)] One participant reported both English and Pacific as their first language. We have categorised them as "Pacific". [e)] Total numbers add up to more than the total number of participants because some people speak more than one language. Only includes the participants who were born in a Pacific country.

101 free-text responses. Of these, 115 useable quotes were identified, systematically coded and charted using the predefined thematic framework. The analysis resulted in three main themes and nine sub-themes, which are summarised in Table 3 and elaborated below with representative participant quotes.

Theme one: nurses' linguistic and professional capabilities

Respondents frequently reported high levels of confidence in their interpreting abilities, often attributing this to fluency in Pacific language(s), prior training and personal backgrounds including upbringing in traditional church settings.

> *"I am fluent in Samoan and confident to interpret for clients/families."*

> *"I am a confident Fijian speaker, and I speak two different types of Fijian language."*

> *"…growing up in a Niuean traditional church, taught me to vagahau Niue* [the Niuean language], *I was happy to* [interpret]."

Table 2: Characteristics of 102 alumni who participated in the Aniva Alumni Survey 2023 who had been asked to translate or interpret in other areas of the workplace, and determinants influencing their confidence and skill.

Characteristics	Total n (%)	Confident/skilled n (%)	OR (95% CI)	p-value
Total	**102 (100%)**	**76 (75%)**		
Gender				
Female	94	69 (73%)	1	0.395
Male	8	7 (88%)	2.5 (0.3–21.7)	
Age Category				
≤25 years	0	-	-	
26–35 years	12	6 (50%)	1	0.485
36–45 years	26	19 (73%)	2.7 (0.7–11.3)	
46–55 years	39	30 (77%)	3.3 (0.7–13)	
56–65 years	18	14 (78%)	3.5 (0.7–17.1)	
>65 years	7	7 (100%)		
Country of birth				
Aotearoa New Zealand	39	24 (62%)	1	0.015*
Pacific country	61	51 84%)	3.2 (1.3–8.1)	
Other	2			
First language				
Pacific	60 (59%)	47 (78%)	1.6 (0.7–4.0)	
English	42 (41%)	29 (69%)	1	0.292
Country first registered				
Aotearoa New Zealand	78	56 (72%)	1	0.081
Pacific country	22	20 (91%)	3.9 (0.8–18.2)	
Other	2	-		
Time since registration in Aotearoa New Zealand				
0–10 years	23	17 (74%)	1	0.784
11–20 years	28	19 (68%)	0.7 (0.2–2.5)	
21–30 years	27	21 (79%)	1.2 (0.3–4.5)	
>31 years	24	19 (79%)	1.3 (0.3–5.2)	

Table 2 (continued): Characteristics of 102 alumni who participated in the Aniva Alumni Survey 2023 who had been asked to translate or interpret in other areas of the workplace, and determinants influencing their confidence and skill.

Who asked participant to translate or interpret[a]				
Asked by colleague				
Yes	91 (89%)	67 (74%)	1	0.559
No	11 (11%)	9 (82%)	1.6 (0.3–8.0)	
Asked by supervisor/ manager				
Yes	65 (64%)	48 (74%)	1	0.839
No	37 (36%)	28 (76%)	1.1 (0.4–2.8)	
Asked by patient/ patients' family				
Yes	77 (75%)	59 (77%)	1.5 (0.6–4.2)	
No	25 (25%)	17 (68%)	1	0.392
Languages spoken[b]				
Speaks Samoan				
Yes	53	39 (74%)	1	0.824
No	49	37 (76%)	1.1 (0.5–2.7)	
Speaks Fijian				
Yes	16	14 (88%)	2.7 (0.6–12.8)	
No	49	62 (72%)	1	0.209
Speaks Tongan				
Yes	24	18 (75%)	1.0 (0.4–3.0)	
No	78	58 (74%)	1	0.950

Notes: [a)] Participants were allocated to one or more categories based on their responses. [b)] Participants are counted more than once if they speak more than one of these languages. OR = odds ratio; CI = confidence interval.

Nurses reported being comfortable using their Pacific language for general conversations, but for many, there were challenges with formal language and technical medical terminology lacking direct Pacific translations, such as anatomical terms.

> *"When it comes to organs in the body and the science … it's very hard to explain or even know what those organs are called."*

Despite these challenges, interpreting was consistently described as "*rewarding*" and "*gratifying*", driven by cultural values like *tautua* (service) and a desire to "*give back to my community*". Many viewed language support as central to their professional and cultural identity. Nurses drew on their clinical expertise and cultural insights to translate complex clinical details, employing diagrams and culturally relevant metaphors, for example, using Lali (Fijian) drumbeats to explain

Table 3: Thematic framework for analysing Pacific nurses' experiences with language interpretation developed as part of the Aniva Alumni Survey 2023.

Themes and definitions	Sub-themes and definitions
1. Nurses' linguistic and professional capabilities: Nurses' Pacific language abilities, experiences with interpreting/translation in the workplace and the professional context for taking on interpreting roles.	**Language proficiency and confidence:** Nurses' self-reported fluency, perceived skill level in Pacific languages, confidence in providing interpreting, challenges when using Pacific languages in more formal contexts and challenges with interpreting complex medical terms and information.
	Motivations and professional values: The personal, professional and cultural factors—e.g., *tautua* (concept of service/duty)—that motivate nurses to provide language support, expressing it as part of their professional and Pacific identity.
	Use of prior experience, clinical knowledge and networks: Nurses drawing on clinical expertise, prior interpreter training, work experience and family and community networks to facilitate interpretation and communication in healthcare settings.
2. Impact on patient experiences and clinical outcomes: Positive contributions to healthcare delivery and other impacts.	**Enhanced patient comfort, trust and engagement:** How language support and cultural connections foster a sense of comfort, strengthen trust and increase patient and family participation in healthcare.
	Improved health literacy and quality of care: Examples of where nurses interpreting leads to better patient understanding, informed consent, improved health literacy and more timely and appropriate care.
	Cultural work and building rapport: The role of nurses in mediating cultural nuance, understanding cultural protocols and building rapport to overcome communication and cultural barriers beyond transfer of information.
3. Health system gaps and concerns: Structural issues and health system gaps and their impact on Pacific nurses.	**Structural issues with the formal interpreter services:** The problem with the lack of availability of professional interpreters and systems that do not attend to cultural safety, leading to reliance on Pacific nurses for last-minute requests and nurses feeling obligated to fill gaps and assume advocacy roles.
	Absence of training and support: The lack of training for nurses in medical interpretation and translation and the desire for skill development.
	Unrecognised and unpaid work, "cultural loading". Potential risks and ethical challenges: The professional and personal costs to Pacific nurses associated with informal interpreting, including unpaid time, increased workload, interference with core role, privacy concerns, anxiety about getting translations wrong and the lack of recognition in job descriptions and remuneration. The unacknowledged assumptions and expectations that Pacific nurses will step into the role of interpreter, cultural broker and patient advocate.

atrial fibrillation. They also utilised prior training and personal networks to enhance their support.

Theme two: impact on patient experiences and clinical outcomes

Communicating in a patient's Pacific language significantly enhanced their "*sense of comfort, trust and engagement*" leading to "*immediate positive change in demeanour*", including relaxation and expressions of "*relief*", "*happiness*" and "*appreciation*". The support also improved patients' understanding of their medical conditions, health literacy and experiences of medical processes. "*When patients understand their care plan, they feel more confident and are more likely to follow through with treatment.*"

Nurses described interpreting to assist in emergency medical situations and pre-operative preparations and how this support contributed to improved clinical outcomes. Nurse interpreting roles were a "*clinical necessity*" for "*appropriate care in a timely manner*".

A shared cultural background was essential for rapport, navigating cultural protocols and respectfully addressing sensitive or "*tapu*" (prohibited or sacred) topics.

Theme three: health system gaps and concerns

Despite positive impacts of their interpreting roles, nurses consistently raised concerns about system gaps in professional interpreter resourcing and availability. They often felt "*obligated … to step in at the last minute*" due to limited availability of translators, "*last minute cancellations* [by] *interpreting services*" or acute patient conditions, despite a lack of formal training or recognition of this role. Nurses advocated for equitable patient care to address language barriers. "*I believe that language barriers can adversely impact the person … advocating for them is paramount in my focus to ensure they get a fair deal.*"

On the other hand, informal interpreting was time-consuming, interfering with core duties, and raised anxiety about translation accuracy. The absence of institutional support led to a desire for formal medical interpreter training. Significant ethical dilemmas, particularly concerning patient privacy, when interpreting on sensitive topics for individuals they knew personally, were common. "*I had to interpret for someone I knew, and it was a sensitive topic.*"

Despite these concerns, nurses often felt obligated to assist, particularly if the patient's condition was acute or in the absence of viable alternative options. This additional work and responsibility to act as interpreters, cultural brokers and patient advocates suggested a significant cultural loading that was uncompensated and absent from job descriptions. "*It's like we're wearing multiple hats, but no one sees the extra work we're doing.*"

Discussion

This study highlights the essential yet largely informal and unacknowledged role that Pacific nurses play in interpreting for Pacific patients with LEP in Aotearoa New Zealand. Their linguistic capability and deep cultural knowledge enable effective communication, improve patient engagement and enhance clinical outcomes. These contributions are vital to health equity, yet remain structurally unsupported.[19,25] These findings align with prior research during the COVID-19 response, where Pacific nurses were called upon to provide language and cultural support across the health sector, often voluntarily and without recognition.[26]

A key finding is the scale at which Pacific nurses are called upon to interpret. Among those who spoke a Pacific language, 85% reported being asked to interpret or translate in areas beyond their usual nursing role. These requests came not only from patients and families, but also from colleagues and supervisors, with more than half receiving requests from all three groups. This clearly demonstrates that Pacific nurses are not merely stepping in informally; they are actively and routinely approached to provide language support, revealing both their value and the systemic gaps in professional interpreter provision. Interpreting is not an occasional task for many; it is woven into the fabric of their everyday clinical responsibilities. This reflects broader patterns seen in the health workforce, where Pacific nurses are regularly relied upon to bridge cultural and linguistic gaps without formal support.[26,27]

Our findings build on and extend the current literature, which largely focusses on the risks and benefits of using trained versus untrained interpreters.[6,8] While international and national guidelines often frame the use of trained interpreters as best practice,[1,4,28] they rarely consider the culturally nuanced, context-sensitive communication provided by bilingual healthcare staff.[6,16] Pacific nurses in this study described interpreting complex medical concepts using diagrams, metaphors and cultural references that made infor-

mation more understandable and relatable for patients.[16,22] Their shared cultural background not only improved comprehension but also helped to build rapport, ease patient anxiety and ensure communication aligned with cultural protocols and sensitivities.[6,16] These interactions were more than translation, they were a form of cultural mediation that directly supported patient dignity, safety and engagement.[4,16] The COVID-19 pandemic demonstrated the critical role of culturally grounded communication, with studies showing that the use of Pacific languages improved community understanding and trust, while a lack of such communication contributed to delays in contact tracing and exacerbated health disparities among Pacific populations.[26,29,30]

Despite their contributions, Pacific nurses in this study faced ethical and professional challenges in taking on interpreting roles. Many described feeling obligated to say yes, even for highly technical or sensitive procedures, because of last-minute cancellations, a lack of available professional interpreters or an overarching sense of cultural responsibility. These experiences disrupted their primary nursing duties and introduced stress around accuracy, privacy and professional liability, echoing patterns also observed among Māori nurses navigating dual cultural and clinical responsibilities.[31] For some, the pressure to interpret for individuals they knew personally further complicated ethical boundaries and emotional wellbeing. It has previously been observed that Pacific nurses often internalise stress and avoid labelling their experiences as burnout, instead continuing to meet community needs out of cultural commitment.[26]

This unrecognised labour is compounded by cultural drivers embedded in Pacific worldviews, such as *tautua* (service), *alofa* (love) and *tausi* (provide care or stewardship).[16,32,33] Unlike Western notions of volunteering, these acts of service are often understood as inherent cultural obligations, not optional extras. Pacific nurses may feel an intrinsic responsibility to help their communities, which the health system can inadvertently exploit.[16,26,32] As other authors have argued, public services may "*cynically and knowingly exploit these values and behaviours*" and thereby abdicate formal responsibility for resourcing culturally safe care.[29,32] Our study confirms that while Pacific nurses are motivated by cultural values, their contributions are not formally recognised, resourced or protected, creating a moral and operational imbalance. This dynamic has also been noted in workforce responses during public health emergencies, where Pacific nurses were mobilised to serve in high-pressure contexts but later saw their needs and professional contributions deprioritised once the crisis subsided.[26]

Implications and recommendations

To address the challenges identified in this study, a coordinated set of reforms in policy and practice is urgently needed. First, there is a clear need for the development of targeted training programmes for bilingual nurses. These should focus on Pacific medical terminology, the ethics of interpreting in clinical settings, and guidance on when to refer to professional interpreters, ensuring nurses are equipped to navigate these responsibilities safely and effectively.

In addition, greater investment in professional interpreter services is essential to improve accessibility and reduce the over-reliance on informal interpreting, particularly in under-resourced or high-pressure healthcare environments. It is also important to establish formal recognition and compensation for nurses who regularly provide language and cultural support. This includes defining the scope of these roles, ensuring appropriate workload protections and implementing systems of support and supervision.

Furthermore, policy language and data collection tools should be reviewed and adapted in consultation with Pacific communities.[16,22] Standard terms such as "unpaid work" often fail to capture the cultural significance of contributions embedded in Pacific values like *tautua* and *tausi*. Recognising these forms of cultural service within official frameworks would enable more accurate reflection of Pacific nurses' work and support more culturally responsive policy development.[32,33]

Finally, a system-wide commitment is needed to embed culturally informed approaches to workforce planning, resource allocation and care delivery. This will not only lead to improved service outcomes for Pacific patients but also support the wellbeing and professional sustainability of the Pacific health workforce.

Strengths and limitations

This study's key strength lies in its mixed-methods approach, combining quantitative data on prevalence and demographic patterns with rich qualitative insights into nurses' lived experiences. The high response rate (69%) strengthens the representativeness of the findings, though some

response bias may exist, as participants were more likely to be younger, Aotearoa New Zealand–born, and Samoan.

Limitations include the self-reported nature of the data and the constraints of written responses to open-ended questions, which may not have fully captured the complexity of nurses' experiences. Time constraints, survey format (e.g., mobile devices), or discomfort with written expression may have limited participation. Future studies should consider in-depth interviews or focus groups to build on these findings and explore the emotional, cultural and ethical dimensions of informal interpreting in more detail.

Conclusion

This study reveals a significant gap in Aotearoa New Zealand's healthcare system: the informal, unpaid and under-recognised interpreting work carried out by Pacific nurses. While their contributions are vital to clinically competent and culturally safe care and patient and family wellbeing, the burden of responsibility has been shifted onto individuals, often without adequate support or acknowledgement. If left unaddressed, this practice risks undermining both patient safety and nurse wellbeing.

Structural solutions, not individual goodwill, must underpin safe and equitable care. This requires a coordinated response: one that recognises and supports Pacific nurses' dual roles as clinical professionals and cultural intermediaries,[31] backed by meaningful investment, policy reform and a deeper understanding of the cultural frameworks they bring to healthcare practice. These issues were also observed during the COVID-19 Delta outbreak, when Pacific nurses were central to the health system's frontline response, yet their professional wellbeing and workforce needs were deprioritised once the immediate crisis passed.[26] Addressing this recurring undervaluing of Pacific nurses will require sustained attention beyond times of emergency response.

Finally, the anticipated use of AI-supported interpreting tools in healthcare raises new research questions. These include the need to validate tools for Pacific languages, assess cultural appropriateness and clinical safety and understand how such technologies might alter the ethical responsibilities of nurses asked to use them. These issues should be part of wider implementation research on language access strategies in clinical settings.

COMPETING INTERESTS
Nil.

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AUTHOR INFORMATION
Debbie Ryan: Principal, Pacific Perspectives Ltd, Auckland, Aotearoa New Zealand.
Abel Smith: Lecturer, Aniva Programme Nursing Adviser, Aniva Future Leaders Programme, Pacific Perspectives Ltd, Auckland, Aotearoa New Zealand; Pacific Health, Health New Zealand – Te Whatu Ora, Auckland, Aotearoa New Zealand.
Safaatoa Fereti: Aniva Programme, Nursing Adviser, Aniva Future Leaders Programme, Pacific Perspectives Ltd, Auckland; Independent Nurse Consultant, Auckland, Aotearoa New Zealand.
Alisi Vudiniabola: Curriculum Lead & Lead Lecturer, Aniva Programme, Pacific Perspectives Ltd, Auckland Aotearoa New Zealand; Fiji National University, Suva, Fiji.
Tamasin Taylor: Pacific Health Researcher, Pacific Perspectives Ltd, Auckland, Aotearoa New Zealand; Faculty of Medical and Health Sciences, The University of Auckland, Auckland, Aotearoa New Zealand.
Harriette Kimiora: Programme Manager, Aniva Future Leaders, Research Assistant, Pacific Perspectives Ltd, Auckland, Aotearoa New Zealand.
David Nicholson: Operations Manager, Pacific Perspectives Ltd, Wellington, Aotearoa New Zealand.
Gerard JB Sonder: Public Health Physician and Epidemiologist, Pacific Perspectives Ltd, Wellington, Aotearoa New Zealand; Faculty of Medical and Health Sciences, The University of Auckland, Auckland, Aotearoa New Zealand.

CORRESPONDING AUTHOR
Debbie Ryan: Principal, Pacific Perspectives Ltd, Auckland, PO Box 59, Whangamatā 3643.
E: debbie@pacificperspectives.co.nz

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Appendix

Appendix Table 1: Aniva nurses survey questions 2023.

Ref	Survey question
1	What Aniva qualification/qualifications have you completed? Aniva Postgraduate Certificate in Specialty Care Pacific Health Aniva Postgraduate Diploma in Specialty Care Pacific Health Aniva Master of Professional Practice (Leadership) Did not complete an Aniva qualification
2	Which Aniva qualification did you not complete? Aniva Postgraduate Certificate in Specialty Care Pacific Health Aniva Postgraduate Diploma in Specialty Care Pacific Health Aniva Master of Professional Practice (Leadership)
3	What were the factors that contributed to you withdrawing/not completing?
4	Which Pacific country/countries are you descended from? (Select all that apply) American Samoa Cook Islands Federated States of Micronesia Fiji French Polynesia (Tahiti) Hawaii Kiribati Marshall Islands Nauru New Caledonia Niue Palau Papua New Guinea Rapanui (Easter Island) Rotuma Samoa Solomon Islands Tokelau Tonga Tuvalu Vanuatu Wallis and Futuna

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
5	What ethnic group/groups do you belong to? (Select all that apply) New Zealand European Māori Samoan Cook Island Māori Tongan Niuean Chinese Indian Other (please specify)
6	What is your gender? Male Female Non-binary
7	What is your date of birth?
8	What is your country of birth? New Zealand Australia Pacific Island Other

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
9	Which Pacific country were you born in? American Samoa Cook Islands Federated States of Micronesia Fiji French Polynesia (Tahiti) Hawaii Kiribati Marshall Islands Nauru New Caledonia Niue Palau Papua New Guinea Rapanui (Easter Island) Rotuma Samoa Solomon Islands Tokelau Tonga Tuvalu Vanuatu Wallis and Futuna
10	What year did you first arrive in New Zealand?
11	What is your country/countries of citizenship? (Select all that apply) New Zealand Australia Pacific Island Other (please specify)

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
12	Which Pacific country/countries do you hold citizenship in? American Samoa Cook Islands Federated States of Micronesia Fiji French Polynesia (Tahiti) Hawaii Kiribati Marshall Islands Nauru New Caledonia Niue Palau Papua New Guinea Rapanui (Easter Island) Rotuma Samoa Solomon Islands Tokelau Tonga Tuvalu Vanuatu Wallis and Futuna
13	Street address
14	Street address line 2
15	City
16	Postal/zip code
17	What is your usual address?
18	Is English your first language? (Yes/No—please specify)
19	Do you speak any Pacific languages? (Yes/No)

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
20	Which Pacific language/languages do you speak? (Select all that apply) Cook Island Māori Fijian Hawaiian I-Kiribati Marshallese Nauruan Palau Rotuman Samoan Tahitian Tongan Tuvaluan
21	Are there times at work when you need to use your Pacific language to communicate with colleagues, patients and families? (Yes/No)
22	Have you been asked to assist other areas of the workplace to translate or interpret for patients and families? (Yes/No)
23	Who has asked you to translate or interpret? (Select all that apply) Colleagues Supervisor Manager Patients Patients' families
24	Did you feel you had the confidence, skills and/or training to undertake this interpretation/translation? (Yes/No)
25	Please provide any insights from your experience in this area.
26	Do you speak any other languages? (Yes/No)
27	Which other language/languages do you speak?
28	In which country did you first register as a registered nurse? New Zealand Pacific country Other

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
29	Which Pacific country did you first register as a registered nurse? American Samoa Cook Islands Federated States of Micronesia Fiji French Polynesia (Tahiti) Hawaii Kiribati Marshall Islands Nauru New Caledonia Niue Palau Papua New Guinea Rapanui (Easter Island) Rotuma Samoa Solomon Islands Tokelau Tonga Tuvalu Vanuatu Wallis and Futuna
30	In what year did you first register as a registered nurse?
31	Have you practiced as a registered nurse before you came to New Zealand? (Yes/No)
32	How many years did you practice as a registered nurse before you came to New Zealand?
33	Did you have any issues with any of the following when you moved to New Zealand? (Select all that apply) Immigration Work permits Citizenship Recognition of skills Nursing registration Other
34	Please describe the issue/issues.

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
35	In what year did you first register as a registered nurse in New Zealand?
36	Tell us about your current employment (Add rows for additional/secondary employment): Job title (in full) Employer Employment setting (please select): Health New Zealand – Te Whatu Ora hospital (acute), Health New Zealand – Te Whatu Ora (community), Health New Zealand – Te Whatu Ora hospital (other), educational institution, government agency, Māori health service provider, nursing agency, Pacific health service provider, primary healthcare/community, private hospital, rest home/residential care, rural, self-employed, other Location (please select): Auckland, Bay of Plenty, Canterbury, Hawke's Bay, Manawatū/Whanganui, Nelson/Marlborough, Northland, Otago, Southland, Tairāwhiti, Taranaki, Waikato, Wellington, West Coast, Other Area of nursing (please select): addiction services, assessment & rehabilitation, child health, continuing care (older person), district nursing, emergency & trauma, intellectually disabled, intensive care/cardiac care, medical, mental health (community), mental health (inpatients), nursing administration & management, nursing education, nursing professional advice/policy, nursing research, obstetrics/maternity, occupational health, oncology, palliative care, perioperative care, primary healthcare, public health, school health, surgical, youth health, non-nursing role, other Hours per week (please select): 1 to 4 hours, 4 to 8 hours, 8 to 12 hours, 12 to 16 hours, 16 to 20 hours, 20 to 24 hours, 24 to 28 hours, 28 to 32 hours, 32 to 36 hours, 36 to 40 hours, 40 hours, 40 to 44 hours, 44 to 48 hours, 48 to 52 hours, more than 52 hours
37	Please list all your tertiary education qualifications including the institution and year of completion. Qualification (including specialisation) Tertiary institution City Country Year completed
38	Overall, how would you rate your Aniva experience? (1=Did not meet expectations, 5=Exceeded expectations)
39	Comment.
40	Why did you choose the Aniva pathway for gaining postgraduate qualifications?
41	Rate: Teaching (1=Did not meet expectations, 5=Exceeded expectations)
42	Comment.
43	Rate: Mentoring/pastoral care (1=Did not meet expectations, 5=Exceeded expectations)
44	Comment.
45	Rate: Supervision/guidance (1=Did not meet expectations, 5=Exceeded expectations)
46	Comment.
47	Rate: Networking/exposure to Pacific and health sector leaders through Aniva (1=Did not meet expectations, 5=Exceeded expectations)
48	Comment.

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
49	During your Aniva studies, did you receive any additional support other than through the Aniva programme? (Yes/No)
50	What was the nature of the additional support?
51	Did you have any family commitments or caregiver responsibilities that put additional demands on you during your Aniva studies? (Yes/No)
52	Please describe.
53	Did you get any assistance? (Yes/No)
54	What was the nature of the assistance?
55	Were there any financial factors that affected your Aniva studies? (Yes/No)
56	Were these (select all that apply): Cost of living for family Remittances to family in the Islands
57	How well were you supported by your employer to complete your Aniva studies? (1=Did not meet expectations, 5=Exceeded expectations)
58	In what ways did your employer support you?
59	The requirement for COVID-19 positive people to isolate began in 2020 and was lifted in August 2023. Did COVID-19 affect your Aniva studies? (Yes/No)
60	In what ways did COVID-19 affect your Aniva studies?
61	Did you work in the COVID-19 response for Pacific health? (e.g., testing, outreach, vaccination, healthline, contact tracing, care in the home, etc.) (Yes/No)
62	Please specify the area/areas in which you worked. (Select all that apply) Testing Outreach Vaccination Healthline Contact tracing Care in the home Management Policy Other

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
63	What setting/settings did you work in? (Select all that apply) Pacific provider organisation Primary and community care Public health Hospital Aged care Community organisation Managed isolation facility Quarantine facility
64	What was the nature of this work? Part of my regular job A temporary deployment A change of job Voluntary community work Other
65	Please describe.
66	Were you well supported by the organisation/organisations you worked for to carry out this work? (1=Not supported at all, 5=Supported very well)
67	Please describe.
68	For this work, how important were the following: Knowledge of the local communities (Not important/Very important/Not applicable)
69	Knowledge of the local churches (Not important/Very important/Not applicable)
70	Community networks (Not important/Very important/Not applicable)
71	Ability to speak a Pacific language (Not important/Very important/Not applicable)
72	Nursing skills (Not important/Very important/Not applicable)
73	What other factors were important?
74	Did you return to your previous role? (Yes/No)
75	What was the reason?
76	Since your Aniva studies began, have you worked in an emergency response role? (Yes/No)

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
77	Please provide details, such as: Role Organisation (please select): MFAT, DHB, PMA, philanthropic, other Pacific provider, other Deployment location Duration Nature of emergency (e.g., flood, tsunami, cyclone) Type of deployment (please select): paid, voluntary Year
78	Were you well supported by the organisation/organisations you worked for to carry out this work? (1=Not supported at all, 5=Supported very well)
79	Please describe.
80	What was your role when you started your first Aniva qualification? Job title Employer Place of work Nature of work City Country
81	How many jobs/roles have you held between commencing your first Aniva qualification and your current job/role? (Including contract, temporary, secondment, full-time, part-time, etc.)
82	Please list the different roles you have held, including any overseas work experience and periods off work, between commencing your first Aniva qualification and your current job/role. Job title Employer Place of work Nature of work City Country
83	How has your role/employment changed since you commenced your first Aniva qualification? (e.g., promotion to charge nurse, new area of practice, new employer, new geographic location, role outside health sector)

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
84	Do you plan to change your current employment such as seeking: (Select all that apply) Promotion New area of practice New employer New geographic location Role outside the health sector No changes
85	Please explain.
86	Have you been employed as a nurse in a Pacific country since completing your Aniva qualification? (Yes/No)
87	In which Pacific country/countries? (Select all that apply) American Samoa Cook Islands Federated States of Micronesia Fiji French Polynesia (Tahiti) Hawaii Kiribati Marshall Islands Nauru New Caledonia Niue Palau Papua New Guinea Rapanui (Easter Island) Rotuma Samoa Solomon Islands Tokelau Tonga Tuvalu Vanuatu Wallis and Futuna
88	For how long?

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
89	As part of what organisation were you working? (Select all that apply) New Zealand government Pacific country health organisation Pacific country volunteer organisation Other local employer Other
90	Please list: Organisation name Your role
91	What leadership roles have you held since the completion of your Aniva qualification? (Work-related team leader, manager with direct reports, committees, boards, community/church/other)
92	Did your Aniva experience contribute to attaining these leadership roles? (Yes/No)
93	In what ways did your Aniva experience contribute to attaining these leadership roles?
94	Please list the advisory groups and professional organisations you are involved in and/or support: Organisation/group name Your role
95	Have you enrolled in and/or completed any course/courses other than Aniva since completing your Aniva qualification? (Yes/No)
96	Please provide the course details: Course name Provider Year
97	Did you experience any of these benefits from participating in the Aniva programme? (Select all that apply) Knowledge about Pacific culture, worldviews and academic frameworks Strengthening cultural identity Identification of gaps in current settings for policy, service and resources with respect to meeting the needs of Pacific people Awareness of Pacific nursing leadership Exposure to Pacific leaders and health leaders Knowledge of evidence and research resources for Pacific health Pacific clinical networks Increased personal advocacy for Pacific health and Pacific communities Increased understanding of Pacific health outcomes and equity Other (please specify)

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
98	What is your master's thesis topic area? (Select all that apply): Addiction services Assessment & rehabilitation Child health Continuing care (older person) District nursing Emergency & trauma Intellectually disabled Intensive care/cardiac care Medical Mental health (community) Mental health (inpatients) Nursing administration & management Nursing education Nursing professional advice/policy Nursing research Obstetrics/maternity Occupational health Oncology Palliative care Perioperative care Primary healthcare Public health School health Surgical Youth health
99	How have you used the learnings/recommendations from your master's thesis? (Select all that apply) Conference presentation Seminar presentation Publication (peer-reviewed journal) Publication (other) Workplace application Other

Appendix Table 1 (continued): Aniva nurses survey questions 2023.

Ref	Survey question
100	Please describe.
101	Are you planning to enrol in further Aniva qualifications? (Yes/No)
102	Reasons.
103	Please add any further comments you would like to add about the areas covered in this questionnaire.
104	Can we contact you if we have further questions? (Yes/No)

Evolving roles and workforce trends among nurse practitioners in Aotearoa New Zealand (2014–2022)

Deborah L Harris, Diane Williams, Lisa Woods, Julia Liu, Nadine Gray

ABSTRACT

AIM: We aimed to describe nurse practitioner (NP) workforce characteristics, clinical practice and enablers and barriers in Aotearoa New Zealand.

METHODS: Five cross-sectional, self-reported online surveys were distributed biannually in collaboration with Nurse Practitioners New Zealand. Eligible participants were registered Aotearoa New Zealand NPs. Quantitative items covered demographics, practice activities and work environment; qualitative items captured priorities for change. Data were cleaned and reclassified to ensure comparability across survey rounds, and descriptive statistics were used to report findings. Ethics approval: Te Herenga Waka—Victoria University of Wellington, Human Ethics Committee, 2024/HE000107.

RESULTS: Of the 1,004 valid responses (52–74% of the workforce per survey), most respondents were practicing clinically (>94%). By 2022, prescribing was near-universal (98%), with most ordering laboratory (92%) and radiology (70%) investigations. Employment was concentrated in district health boards/Health New Zealand – Te Whatu Ora, with increasing representation in primary health organisations, private practice, non-governmental organisations and self-employment. Respondents reported barriers to practicing at full-scope of practice, limited succession planning and challenges to workforce sustainability.

CONCLUSION: NPs are an established part of Aotearoa New Zealand's health workforce. However, persistent structural barriers, limited succession planning and variable support for full-scope practice continue to constrain their contribution. Strengthening integration and sustainable policy support are essential to realise the full potential of the NP role.

Nurse practitioners (NPs; mātanga tapuhi) are registered nurses who have completed an accredited clinical Master's programme, have demonstrated expert nursing and have clinical and scientific knowledge coupled with complex decision-making skills within an area of practice.[1] The role is grounded in nursing values, knowledge and experience, and is distinguished in part by its capacity for autonomous clinical care. NPs are authorised to assess, diagnose, prescribe and manage patient and family (whānau) care independently and collaboratively with other members of the healthcare team.[2,3] In addition to their clinical responsibilities, NPs are positioned as change agents, advancing clinical practice and knowledge through research, health policy, education and workforce development.[4]

The NP role was established in Aotearoa New Zealand in the early 2000s as part of a strategic response to persistent health system challenges.[5] The purpose was to improve access to high-quality healthcare, with a particular focus on rural Māori and other underserved populations. The role is now seen as a partial solution to workforce shortages in primary care and as a means of strengthening continuity of care across the sector. NPs are expected to deliver culturally responsive, whānau-centred care while responding to the increasing complexity of population health needs.

Initial growth of the NP workforce was slow. Structural and regulatory barriers limited awareness, and the absence of formal training pathways constrained early implementation. However, legislative and policy changes have progressively expanded the NP scope of practice. The introduction of the Nurse Practitioner Training Programme has played a pivotal role in increasing the number of NPs by providing structured clinical and academic pathways to registration.[6,7]

NPs practice across a wide range of settings, including primary care, aged residential care, rural health services and high-acuity environments such as emergency departments and neonatal intensive care units. They work collaboratively with interdisciplinary teams, whānau and communities to provide timely, person-centred and culturally responsive care. Their practice reflects a strong commitment to social

justice and health equity, with a focus on reducing access barriers and supporting integrated models of care.[4]

Despite more than two decades of NP practice, there is little longitudinal evidence on workforce characteristics, the evolution of practice or the barriers and enablers shaping sustainability. Existing administrative datasets, such as those collected by the Nursing Council of New Zealand, provide demographic information but offer little insight into how NPs practice, the conditions that support or hinder their work and the wider impact on patients and whānau. Evaluation of outcomes also remains scarce.

To offer greater insight into NP practice, a series of national surveys was conducted between 2014 and 2022. This paper reports findings on NP workforce characteristics, clinical practice and systemic enablers and barriers across five survey rounds, providing the first longitudinal overview of the role in Aotearoa New Zealand.

Methods

Eligible respondents were registered NPs who were practicing in Aotearoa New Zealand. Recruitment for the survey was conducted via social media, email distribution and word of mouth. Key organisations, including Nurse Practitioners New Zealand (NPNZ), the College of Nurses Aotearoa (CoN), the New Zealand Nurses Organisation (NZNO) and directors of nurses, supported the dissemination of the survey, seeking to maximise the reach and participation.

Data were collected electronically via SurveyMonkey and surveys were conducted biennially between 2014 to 2022. The timing for each survey varied but all were open for at least 8 weeks, during which fortnightly reminders were placed on social media platforms and emailed to key organisations, including NPNZ. Due to the snowball method of data collection, the number of eligible participants who the survey reached was unable to be determined.

The development of the survey content was led by the primary investigator (DW) in collaboration with the executive committee of NPNZ. Each survey collected quantitative and qualitative data through multiple-choice questions, Likert scale items and open-ended text responses. The content of the questions included basic demographics, area of practice, barriers to practice, and professional development. Prior to each survey being circulated, feedback was sought from executive members of NPNZ to ensure the questions were comprehensive and reflective of the profession's priorities. NPs completed the survey with the awareness that completion of the survey gave consent.

The five standalone survey datasets were cleaned, with questions and response options compared for consistency across survey rounds. Duplicate responses were removed and all five surveys were amalgamated for clear comparison and analysis. Following this, retrospective ethical approval to use the cleaned data was been approved by Te Herenga Waka—Victoria University of Wellington, Human Ethics Committee, reference 2024/HE000107.

The single master dataset is supported by a comprehensive data dictionary describing variable definitions and coding. The dataset is securely stored at the CoN under research team oversight. De-identified data may be requested from the corresponding author, with access considered in accordance with the approved ethics protocols.

For the purposes of this study, respondents' workplaces were categorised using standard definitions of healthcare settings in Aotearoa New Zealand. Primary healthcare was defined as the first point of contact with the health system and included health promotion, prevention, early diagnosis and treatment of common conditions and chronic disease management. Secondary healthcare was defined as specialist services usually provided following referral from primary care, typically delivered in hospitals or specialist clinics. Tertiary healthcare was defined as highly specialised services delivered in major centres, involving advanced technology and multidisciplinary teams.[8,9]

A descriptive summary of quantitative responses, using counts and percentages, is provided for each survey round, and split into three sections. The first section reports the demographics of respondents, including the number of years since NP registration and geographic area of practice. The second section provides details of clinical practice, including the frequency of prescribing, laboratory testing and radiology investigations. The third section gives a description of the work environment, details whether respondents report working at the full extent of their education and training (top of scope), what activities are participated in to promote the NP role and the prevalence of succession planning. In 2020 and 2022, respondents were asked to report the

one thing they would change about being a NP; themes were identified within the qualitative data and presented as counts and percentages of total responses.

The wording of some questions changed slightly between the survey rounds. However, the intent was the same. Some response categories from the original surveys were collapsed to aid clarity and consistency in reporting. For example, responses of *yes*, *partially* and *not really* were amalgamated and reported as *partially.* This approach was applied consistently across all survey rounds.

Results

Response rate

A total of 1,036 responses were collected between 2014 and 2022. After removal of 32 duplicates, 1,004 responses remained for analysis. Response rates ranged from 52% to 74% of registered NPs (Table 1). Most respondents were practicing clinically (>94% each year). Of the 40 who were not in clinical NP roles, the most common reasons were working as a clinical nurse specialist or in leadership/management roles, followed by a change in practice area, leave, retirement or research.

Demographics

Across surveys, the proportion of respondents reporting <2 years since NP registration was similar in 2014 and 2022 (24% vs 22%), while those reporting ≥10 years rose from 0% to 15%, indicating a maturing NP workforce (Table 2). Respondents were located in all regions of Aotearoa New Zealand, with the Northern Region consistently having the largest proportion. Over time, the numbers of NPs increased in all regions.

Across surveys, most respondents reported employment with district health boards (47/85 [56%] in 2014 to 132/307 [45%] in 2022). Private practice ranged from 14/85 (16%) to 79/307 (26%), primary health organisations (PHOs) from 9/85 (11%) to 59/307 (19%), non-governmental organisations from 10/85 (12%) to 30/307 (10%) and self-employed from 8/85 (9%) to 34/307 (11%). Categories labelled "independent practice" were inconsistently defined and excluded from analysis. The proportion of respondents employed in universities ranged from 3/85 (4%) in 2014 to a peak of 22/257 (9%) in 2020, before decreasing to 16/307 (5%) in 2022.

Clinical practice

Between 2014 and 2022, daily or weekly prescribing became almost universal among respondents (98% in 2022). The proportion of daily or weekly laboratory investigations increased marginally, along with ordering of radiology investigations. Fewer respondents reported rarely or never prescribing or ordering investigations over time (Table 3).

Signing standing orders was reported by 110/257 (43%) in 2020 and 140/307 (46%) in 2022. Responsibility for signing official documentation also expanded: for example, signing death and

Table 1: Responses per survey round.

Year	2014	2016	2018	2020	2022
Total respondents	88 (100)	122 (100)	206 (100)	269 (100)	319 (100)
Clinical	85 (97)	115 (94)	200 (97)	257 (96)	307 (96)
Non-clinical	3 (3)	6 (5)	4 (2)	8 (3)	8 (3)
Missing	0 (0)	1 (1)	2 (1)	4 (1)	4 (1)
Registered NPs at year's end*	129	164	300	459	612
Response rate %	68	74	69	57	52

Data are number (%)* data provided by the Nursing Council of New Zealand.

Table 2: Demographics of respondents.

		2014	2016	2018	2020	2022
Years since NP registration	<2 years	21 (24)	37 (30)	89 (43)	90 (33)	71 (22)
	2–5 years	33 (38)	31 (25)	53 (26)	98 (36)	118 (37)
	5–10 years	33 (38)	45 (37)	40 (19)	38 (14)	83 (26)
	10 years or more	0 (0)	9 (7)	23 (11)	40 (15)	47 (15)
	Missing	1 (1)	0 (0)	1 (0)	3 (1)	0 (0)
Geographical area of practice	Northern	31 (35)	36 (30)	66 (32)	80 (30)	88 (28)
	Te Manawa Taki	18 (20)	25 (20)	37 (18)	49 (18)	67 (21)
	Central	20 (23)	31 (25)	47 (23)	63 (23)	80 (25)
	Te Waipounamu	14 (16)	30 (25)	53 (26)	75 (28)	84 (26)
	Missing	5 (6)	0 (0)	3 (1)	2 (1)	0 (0)
	Total	88 (100)	122 (100)	206 (100)	269 (100)	319 (100)

Data are number (percent).

Table 3: Reported frequency of prescribing, laboratory testing and radiology investigations of nurse practitioners practicing clinically (2014–2022).

	Frequency	Year				
		2014	2016	2018	2020	2022
Prescribing	Daily/weekly	76 (89)	109 (95)	193 (96)	252 (98)	300 (98)
	Rarely	3 (4)	5 (4)	6 (3)	5 (2)	6 (2)
	Not prescribing	6 (7)	1 (1)	0 (0)	0 (0)	0 (0)
	Missing	0 (0)	0 (0)	1 (0)	0 (0)	1 (0)
Laboratory investigations	Daily/weekly	73 (86)	98 (85)	170 (85)	233 (91)	281 (92)
	Fortnightly	4 (5)	8 (7)	13 (6)	8 (3)	8 (3)
	Monthly	6 (7)	4 (3)	6 (3)	11 (4)	14 (5)
	Not ordering	2 (2)	5 (4)	10 (5)	5 (2)	4 (1)
	Missing	0 (0)	0 (0)	1 (0)	0 (0)	0 (0)

Table 3 (continued): Reported frequency of prescribing, laboratory testing and radiology investigations of nurse practitioners practicing clinically (2014–2022).

Radiology investigations	Daily/weekly	50 (59)	70 (61)	124 (62)	172 (67)	215 (70)
	Fortnightly	8 (9)	14 (12)	12 (6)	7 (3)	16 (5)
	Monthly	15 (18)	16 (14)	30 (15)	57 (22)	49 (16)
	Not ordering	8 (9)	13 (11)	25 (12)	21 (8)	23 (7)
	Missing	4 (5)	2 (2)	9 (4)	0 (0)	4 (1)
Total		85 (100)	115 (100)	200 (100)	257 (100)	307 (100)

Data are number (percent).

Table 4: Reported changes or extensions to area of nurse practitioner practice, 2016–2022 surveys.

Response	**Year**			
	2016	**2018**	**2020**	**2022**
No, not planning to change	61 (53)	109 (55)	153 (60)	175 (57)
Planning to change/ extend specialty	25 (22)	56 (28)	41 (16)	38 (12)
Yes	24 (21)	33 (16)	60 (23)	94 (31)
Missing	5 (4)	2 (1)	3 (1)	0 (0)
Total	115 (100)	200 (100)	257 (100)	307 (100)

cremation certificates rose from 45/200 (22%) in 2018 to 124/307 (40%) in 2022; Accident Compensation Corporation documentation went from 114/200 (57%) in 2018 to 210/307 (68%) in 2022; work and income documentation increased from 93/200 (46%) in 2018 to 172/307 (56%) in 2022; and enduring power of attorney applications rose from 40/257 (16%) in 2020 to 62/307 (20%) in 2022.

Change or extension in area of NP practice

As shown in Table 4, most respondents reported not changing or extending their area of practice. However, by 2022, nearly half (43%) reported either having changed/extended (31%) or planned to do so (12%).

There were changes over time in how respondents reported practicing at the top of scope of practice. While most respondents reported working at or near their full scope, the data suggest underutilisation remains an issue. Although the proportion answering *absolutely* increased from 20/85 (24%) in 2014 to 157/307 (51%) in 2022, nearly half of respondents still reported less than full alignment with their scope.

Employer support for funding to maintain Nursing Council of New Zealand competencies varied by setting. Among primary care respondents, *partial support* was the most frequent arrangement but fell over time (20/34 59%) in 2014 to 79/186 (42%) in 2022, while *full support* increased (7/34 [21%] to 67/186 [36%]). In secondary care, *full support* rose substantially (14/47 [30%] to 110/141 [78%]), with a corresponding reduction in *partial support* (30/47 [64%] to 28/141 [20%]). While the absence of any support was uncommon in secondary care, it remained an issue for a small group in primary care.

Succession planning has been reported as being consistently limited since its inclusion in

Figure 1: Trends in self-reported practice at top of scope practice among nurse practitioners, 2014–2022.

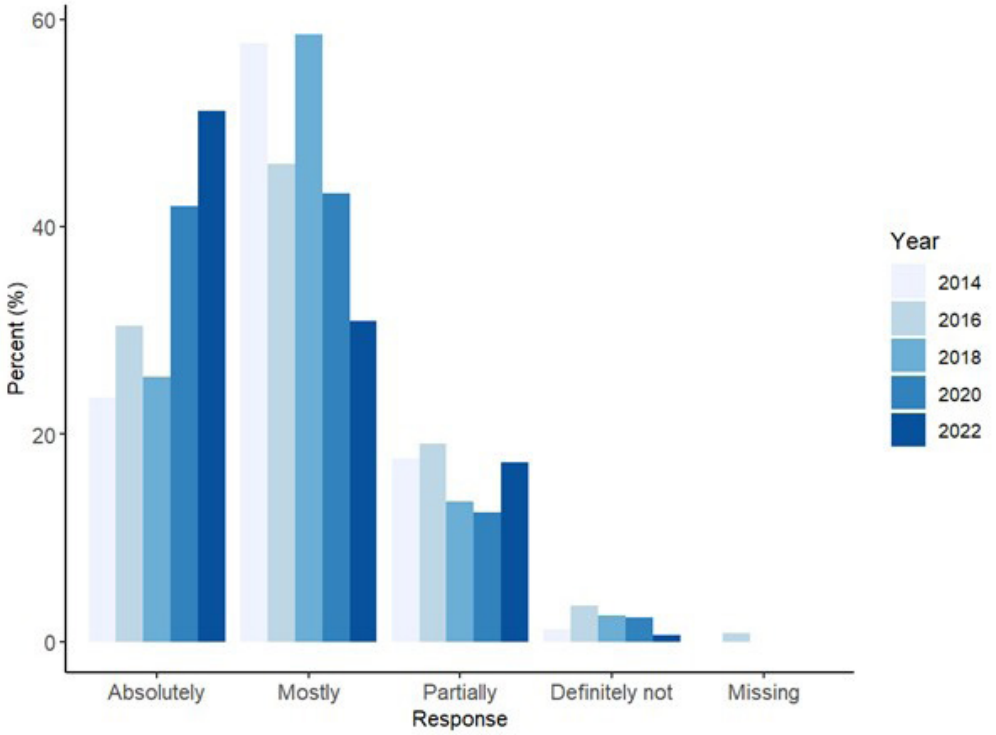


Table 5: Succession planning in the workplace and intention to retire in the next 2–5 years as reported by respondents, 2020 and 2022 surveys.

Succession planning	Planning retirement in the next 2–5 years?	Year	
		2020	2022
No	Yes	23 (16)	32 (17)
	Not likely	97 (69)	124 (66)
	Non-applicable	20 (14)	32 (17)
	Total	140 (100)	188 (100)
Yes	Yes	16 (14)	20 (17)
	Not likely	79 (70)	79 (68)
	Non-applicable	18 (16)	18 (15)
	Total	113 (100)	117 (100)
Missing	Yes	0 (0)	0 (0)
	Not likely	3 (75)	0 (0)
	Non-applicable	1 (25)	1 (50)
	Missing	0 (0)	1 (50)
	Total	4 (100)	2 (100)
Total		257 (100)	307 (100)

the 2016 survey. In 2016, 38/115 (33%) respondents reported that succession planning was in place, increasing to 113/257 (44%) in 2020 before declining to 117/307 (38%) in 2022. Overall, from 2016, 55% of respondents indicated that no succession planning was in place.

Of the 188 respondents indicating there was no succession planning for their role in 2022, 32 respondents (17%) indicated they were planning retirement in the next 2–5 years.

When asked in 2020 and 2022 what one thing they would change about being an NP, respondents most frequently identified issues related to recognition and systemic barriers. Across both survey years, 21% (119/564) cited recognition and 18% (99/564) reported systemic barriers as the main issues they would address. A common barrier to practice was reported to be Section 29 of the *Medicines Act* constraining NP prescribing for unapproved medicines, with 15% (39/257) of NPs in 2020 and 20% (60/307) in 2022 identifying Section 29 as a barrier leading to duplicated consultations and delays.

Professional development (76/564 [13%]) and pay (57/564 [10%]) were also commonly mentioned. Other less-frequent themes included workload and autonomy, the education pathway, isolation and scope of practice. Twenty-eight percent (157/564) of respondents provided no response to this question.

Discussion

Over the five surveys (2014 to 2022), NPs reported strong engagement in clinical practice, with more than 90% providing direct patient care. Prescribing medications was almost universal, and most ordered laboratory and radiology investigations. Many also contributed to the workforce with clinical teaching, mentoring and service development. At the same time, issues of sustainability were reported. The proportion of NPs working fully to scope increased over time. However, almost half reported not practicing at their full scope, suggesting the role being valued but not yet realising its full potential. Our findings highlight both the strength of the NP workforce and the systemic barriers that continue to limit the role's contribution to health and social care in Aotearoa New Zealand.

Although the surveys were conducted between 2014 and 2022, the themes remain highly relevant given current workforce shortages. Underutilisation of NPs represents a significant loss of capacity when health and social care demand is rising. NPs are educated to deliver expert, whānau-centred care and manage complex health needs, yet legislative barriers continue to constrain their practice.[10] Section 29 of the *Medicines Act* illustrates this inefficiency.[11] Originally intended as a mechanism for occasional use of unapproved medicines, in practice it encompasses many treatments that form part of routine care. While doctors can prescribe under Section 29, NPs cannot. Successive ministers of health have acknowledged the need for reform, and decades of effort from lobbying NPs has resulted in the first reading in Parliament for a change to the *Medicines Act*.[12] However, until the legislation is changed there remains avoidable patient care delays, bottlenecks and duplication of appointments, which reduce system capacity and compromise patient safety. Supporting NPs to practice at their full scope would provide an immediate, evidence-based means of improving access, strengthening service delivery and alleviating pressure on an already stretched workforce.

Employment diversification was evident across the survey period, with increasing numbers of NPs working in PHOs, private practice and self-employed roles. This expansion suggests improved access to care, mirroring international patterns of NP deployment into underserved areas. However, without succession planning and deliberate workforce strategies, these gains are fragile. Integration across macro, meso and micro levels is required to sustain access for many communities vulnerable to poor access and healthcare equity.

These findings sit against the backdrop of almost 25 years of NP practice in Aotearoa New Zealand.[5] Despite this milestone, there is little longitudinal evidence on patient outcomes, cost effectiveness or equity impact. This evidence gap is striking—given the shift in healthcare delivery, where nurses and other professionals increasingly provide services once led by doctors—yet not surprising, as the care provided by NPs is often invisible in hospital and primary care datasets. This means that the NP contribution is difficult to quantify and measure. International evidence consistently shows that well-integrated NPs achieve equivalent or better outcomes at stable or reduced cost.[13] Building an Aotearoa New Zealand evidence base that captures outcomes, equity and patient safety is essential.

Furthermore, the absence of a dedicated workforce dataset explains in part why evidence on NP contribution remains limited. While the

Nursing Council collects limited workforce data,[14] the Nurse Practitioner Workforce Survey (NPWORKS) has been established to continue to generate longitudinal, self-reported data, governed jointly by Māori and non-Māori leadership.[15] The first round of data collection is complete, and findings are expected in 2026. This will provide the first opportunity to monitor equity and outcomes systematically. However, funding is currently restricted to a Health Research Council Activation Grant and support by the CoN. Without secure, long-term investment, this critical infrastructure risks being lost.[15]

Taken together, the surveys highlight that underutilisation is not a professional shortcoming but a policy limitation. Health New Zealand – Te Whatu Ora has acknowledged NPs in its workforce strategy and continues to invest in NP education.[9] However, the absence of a nursing workforce strategy contributes to the lack of accountability for integration of the role, and for many the NP role remains unclear. International experience demonstrates that systematic NP integration improves access, safety and cost effectiveness.[13,16,17] Aotearoa New Zealand can achieve the same gains, but only if NPs are embedded as essential contributors to the health workforce rather than positioned as supplementary.

When the NP role was established in 2001, registration was tied to a defined area of practice (e.g., neonatology), with annual practicing certificates listing the specialty. Following a review (2014–2016), the Nursing Council implemented a regulatory change in April 2017, creating a single, flexible NP scope of practice.[18] NPs are now registered simply as *nurse practitioner*, with their practice defined by education, competence, experience and employment context.[2] This shift aimed to reduce barriers, improve adaptability to service needs and simplify regulation while maintaining accountability through competence assessment, professional development and employer credentialling. Since the 2017 regulatory change, NPs have greater flexibility to move across areas of practice, but there is little formal reporting on how these shifts occur in practice. In this context, our survey data provide valuable insight into workforce mobility that is not otherwise captured.

These surveys relied on self-reported data, which may have introduced bias in how activities were described. More critically, there was no capture of ethnicity- or equity-related information. In Aotearoa New Zealand, where equity is a central policy goal, this omission is a substantial limitation. This is particularly important given that equity is central to improving health and social outcomes;[19,20] NPs are expected to practice in ways that actively advance equity, regardless of political winds. Recent evidence has reported Māori NPs as being fundamental in improving patient safety for Māori patients, whānau and communities, demonstrating the critical importance of increasing Māori NPs in the workforce.[21] There is an unfortunate scarcity of Pacific NP workforce data. The findings from NPWORKS, funded through a Health Research Council Activation Grant, will collect ethnicity data, which will increase the visibility of Māori and Pacific representation and support equity-focussed workforce planning.[22]

The NP role is delivering tangible benefits.[23–27] Respondents reported managing complex patients, leading service improvements, improving access and strengthening interprofessional teams. Yet outcomes-focussed research in Aotearoa New Zealand is scarce. Data on patient outcomes, cost effectiveness and equity impact remain limited. Embedding research capacity within NP roles, and supporting NP-led studies, is necessary to influence policy and optimise workforce use. Research must be core business, not an optional extra.

Conclusion

NPs are now a firmly established part of Aotearoa New Zealand's health workforce, delivering advanced care, service innovation and workforce leadership. Yet systemic barriers continue to prevent the role from reaching its full potential. Legislative reform, sustainable workforce planning, equity-focussed deployment and investment in data and research are required to secure the NP role as a core part of a modern, high-performing health system. International evidence shows that when NPs are systematically integrated, health systems benefit through improved access, safety and sustainability. The opportunity now is for the Ministry of Health to recognise NPs as essential to workforce strategy and ensure that their contribution is embedded, equitable and enduring.

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AUTHOR INFORMATION
Professor Deborah L Harris: Neonatal Nurse Practitioner, Hunter New England Local Health District, Newcastle, Australia; Professor of Nursing and Midwifery Research, The University of Newcastle, Newcastle, Australia.
Diane Williams: Nurse Practitioner, Marlborough Primary Health, Marlborough, Aotearoa New Zealand.
Dr Lisa Woods: Statistician, School of Mathematics and Statistics, Te Herenga Waka—Victoria University of Wellington, Wellington, Aotearoa New Zealand.
Julia Liu: Research Assistant, Graduate School of Nursing, Midwifery and Health Practice, Te Herenga Waka—Victoria University of Wellington, Wellington, Aotearoa New Zealand.
Nadine Gray (Te Whakatōhea): National Chief Nursing Officer, Health New Zealand – Te Whatu Ora, Wellington, Aotearoa New Zealand.

CORRESPONDING AUTHOR
Professor Deborah L Harris: Neonatal Nurse Practitioner, Hunter New England Local Health District, Newcastle, Australia; Professor of Nursing and Midwifery Research, The University of Newcastle, Newcastle, Australia. Ph: +61 416591713
E: Deborah.Harris@newcastle.edu.au

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Correlation between patient-determined inflammatory bowel disease severity and the inflammatory bowel disease severity index

Andrew Mark McCombie, Corey A Siegel, Stephen B Hanauer, Timothy McAuliffe, Jessica Salwen-Deremer, Hannah Hughes, Richard Gearry

ABSTRACT

AIM: The inflammatory bowel disease severity index (IBD-DSI) aims to describe inflammatory bowel disease (IBD) severity over the duration of disease. We aimed to correlate the IBD-DSI with a patient-completed disease severity score (PCDSS). We also aimed to investigate whether individual factors such as psychological measures or clinical characteristics moderate this correlation.

METHODS: This multicentre trial involved gastroenterologists completing the IBD-DSI and Harvey-Bradshaw Index or Simple Clinical Colitis Activity Index for each participant while patients completed a self-reported IBD severity score and psychological questionnaires. The excess severity score (ESS) was calculated by subtracting the IBD-DSI from the PCDSS.

RESULTS: One hundred and sixty-four patients with IBD participated (98.2% response rate; average age 41.2 years; 105 [62.9%] female; 100 [59.9%] Crohn's disease) and 164 IBD-DSI were completed. The IBD-DSI and PCDSS were positively correlated ($r=0.44$, $r^2=0.19$, $p<0.001$) although the mean ESS was 29.0 (23.2). The relationship between the scales is reflected in the equation: PCDSS=39.53+0.59*IBD-DSI. There were larger discrepancies at the lower end of IBD-DSI. After controlling for IBD-DSI, previous colectomy (p=0.03), any IBD or bowel-related surgery (p=0.01) and ulcerative colitis extent of disease (p=0.049) were associated with ESS while 5-aminosalicylic acid use (p=0.01) was negatively associated with ESS.

CONCLUSIONS: IBD-DSI and PCDSS are significantly positively associated with each other and with larger discrepancies at the lower end of the IBD-DSI. Possible contributing factors to the discrepancy are floor effects, regression to the mean and patients putting different implicit weights on particular factors than the IBD-DSI does.

Inflammatory bowel diseases (IBD) are relapsing inflammatory diseases of the intestine, which lead to debilitating symptoms and progressive intestinal damage over time.[1] Effectively assessing the impact of IBD on patients over time is important to determine the disease burden for an individual and across an IBD population. There are many domains by which to measure the impact of IBD on patients including disability (e.g., IBD Disability Index[2]), symptoms (e.g., Harvey-Bradshaw Index [HBI][3]) and Simple Clinical Colitis Activity Index [SCCAI][4]), quality of life (IBD questionnaire[5]), and composite scores of clinical symptoms as well as biomarkers (e.g., Crohn's Disease Activity Index[6]). Although these and other measures provide useful cross-sectional data to describe how sick patients with IBD are at a given point in time, they do not reflect the cumulative burden and severity of disease.

The IBD Disease Severity Index (IBD-DSI) was developed in order to describe the severity of disease over the duration of time that a patient has been diagnosed with IBD.[7] The methods for developing this score were meticulous and included a systematic review to find all possible components of disease activity and severity, panel discussion among IBD specialists and adaptive choice-based conjoint analysis. This type of conjoint analysis enables a list of variables to be presented within clinical scenarios to determine the importance of each for a clinician aiming to determine disease severity. Clinical scenarios are repeatedly presented until the variables can be consistently ordered by the group of clinicians undertaking the exercise. These variables were then weighted in the final index based on the level of significance determined through the process.

Since its publication, the IBD-DSI has been further studied to determine its validity by a number of groups. Swaminathan et al.[8] prospectively followed 172 patients with IBD for 1 year and demonstrated that an elevated DSI was associated

with an increased risk of depression, anxiety, perceived stress, reduced quality of life and a complicated IBD course. As part of a wider validation exercise, a multicentre study was undertaken to confirm inter-relator reliability and internal consistency.[9] Construct validity was demonstrated with endoscopic indices, patient-reported outcomes measures and level of disability. The IBD-DSI accurately predicted a complicated disease course out to 24 months.[9]

Although the IBD-DSI was meticulously developed, it was done so by academic gastroenterologists with an interest in IBD and has not been evaluated or compared with patient perspectives of disease severity. Given the inherent subjectivity of the term "disease severity", it is likely that there will be differences between patients and physicians regarding perspectives of IBD disease severity.

We aimed to correlate the physician-generated IBD-DSI with patient-perceived IBD severity. We also aimed to investigate whether individual factors modulate this correlation.

Methods

Setting

Three study centres (Christchurch Hospital, New Zealand, Dartmouth Hitchcock University Medical Center, United States of America [USA] and Northwestern University Medical Center, USA) took part in this cross-sectional study (ethics reference H19/027). Recruitment was undertaken between May 2019 and July 2021 and was delayed and curtailed by the COVID-19 pandemic.

Participants were eligible if they were aged 18 years and older, had IBD for 1 year or longer and were able to understand English fluently. Participants were recruited from outpatient clinics at the three centres.

Demographic and clinical data were extracted from the medical record including age, disease type, Montreal classification, gender, years since diagnosis, present medications and previous surgery.

The patient's gastroenterologist completed the IBD-DSI score based on the medical record and patient interview. This index considers the following domains: a) the impact of the disease (i.e., symptoms and impact on daily activities), b) inflammatory burden (i.e., biomarkers and mucosal lesions) and c) disease course (i.e., how complicated the disease is, whether they respond to medication and what the disease extent is). Separate scoring systems for ulcerative colitis (UC; Table 1) and Crohn's disease (CD; Table 2) are used. The IBD-DSI is scored 0–100, with 0 indicating the lowest severity possible and 100 the highest severity possible.

Variables

Patient-completed disease severity score (PCDSS)

For the PCDSS, participants were asked to rate the severity of their disease on a scale of 0–100 (Figure 1). Patients were asked to rate their disease severity based a composite measure of symptoms (e.g., abdominal pain, number of bowel motions per day), how IBD impacts their daily activities (e.g., impact on work and leisure), inflammatory burden (e.g., how bad results from blood tests and colonoscopies are) and their disease course (e.g., how many operations they have had and whether they have needed steroids before). These domains mirrored those in the IBD-DSI. Participants were given a linear scale from 0 to 100 and asked to mark on the scale how severe their disease was, with 0 reflecting no severity and 100 reflecting maximal severity. This scale was piloted on three patients with IBD for face validity before its use in this study.

Other variables of interest

To measure gastrointestinal symptoms at recruitment, the HBI[3] was completed by the treating physician for participants with CD and the SCCAI[4] for participants with UC. Neuroticism was measured using the relevant questions from the self-reported Eysenck Personality Questionnaire Brief Version (EPQ-BV) using a five-point Likert scale.[10] EPQ–BV has good internal consistency, test–retest reliability and concurrent validity.[10]

Coping strategies of participants were measured using the self-reported IBD-Cope, which is a concise IBD-specific coping strategy questionnaire that is reliable and valid.[11] It contains six questions, of which three interrogate "good" coping strategies and three interrogate "bad" coping strategies.

The four-item Pain Catastrophizing Scale (PCS) was used to measure pain catastrophising.[12] The PCS measures the negative emotional response to anticipated or actual pain[13] and the questions are answered using a five-point Likert scale (ranging from not at all to all of the time). The four-item version correlates very highly with the original 13-item version (r=0.96).[12] Age, disease type, Montreal classification, gender, years since diagnosis,

Table 1: UC overall disease severity index (Siegel et al.[7]).

Attribute	Level	Score
Mucosal lesions	No active erosions or ulcers	0
	Active erosions confirmed by endoscopy	14
	Active ulcers confirmed by endoscopy	18
Daily activity impact	Disease does not significantly impact daily activities	0
	Disease significantly impacts daily activities	14
CRP level	Normal CRP levels (1–3mg/L)	0
	Slightly elevated CRP levels (3–5mg/L)	4
	Elevated CRP levels (above 5mg/L)	11
Biologics use	Has never used biologics/ immunomodulators	0
	Has experienced some symptom improvement with the use of biologics/immunomodulators	4
	Has not experienced symptom improvement with the use of biologics/immunomodulators	10
Recent hospitalisation	No disease-related hospitalisation within last 12 months	0
	Has disease-related hospitalisation within last 12 months	8
Steroid use	No steroid use within the past year	0
	Has steroid use within the past year	8
Anaemia	Not anaemic (according to WHO criteria)	0
	Anaemic (according to WHO criteria)	5
Frequency of loose stools	No change in frequency of loose stools compared with baseline	0
	Increase in frequency of loose stools by one per day compared with baseline	4
	Increase in frequency of loose stools of at least two per day compared with baseline	5

Table 1 (continued): UC overall disease severity index (Siegel et al.[7]).

Albumin level	Normal albumin level (>3.5–5.0g/dL)	0
	Low albumin level (<3.5g/dL)	5
Disease extent	Distal colitis (inflammation potentially treatable using enemas)	0
	Extensive colitis (inflammation extending beyond the reach of enemas)	5
Nocturnal bowel movements	Does not have nocturnal bowel movements	0
	Has nocturnal bowel movements	4
Anorectal symptoms	None of the following: anorectal pain, bowel urgency, incontinence, discharge, tenesmus	0
	At least one of the following: anorectal pain, bowel urgency, incontinence, discharge, tenesmus	4
Rectal bleeding	No rectal bleeding	0
	Has rectal bleeding	3

UC = ulcerative colitis; CRP = C-reactive protein; WHO = World Health Organization.

Table 2: CD overall disease severity index (Siegel et al.[7]).

Attribute	Level	Score
Mucosal lesions	No mucosal lesions	0
	Small mucosal lesions as confirmed by MRI or endoscopy	6
	Large or deep mucosal lesions as confirmed by MRI or endoscopy	16
Fistula	No fistula at the time of clinic visit	0
	Has fistula at the time of clinic visit	11
Perianal abscess	No perianal abscess at the time of clinic visit	0
	Has perianal abscess at the time of clinic visit	10

Table 2 (continued): CD overall disease severity index (Siegel et al.[7]).

Intestinal resections	No intestinal resections	0
	At least one intestinal resection <40cm	2
	At least one intestinal resection ≥40cm	7
Stoma	No stoma at the time of clinic visit	0
	Has stoma at the time of clinic visit	7
Disease extent	Limited disease (<40cm ileal involvement, or absence of pancolitis)	0
	Extensive disease (ileal involvement of at least 40cm or presence of pancolitis)	6
Frequency loose stools	<10 loose stools per week	0
	At least 10 loose stools per week	6
Stricture	No stricture at the time of visit	0
	Has stricture at the time of visit	5
CRP level	Normal CRP levels (1–3mg/L)	0
	Slightly elevated CRP levels (3–5mg/L)	2
	Elevated CRP levels (above 5mg/L)	5
Biologics use	Has never used biologics/ immunomodulators	0
	Has experienced some symptom improvement with the use of biologics/immunomodulators	2
	Has not experienced symptom improvement with the use of biologics/immunomodulators	5
Daily activity impact	Disease does not significantly impact daily activities	0
	Disease significantly impacts daily activities	5
Albumin level	Normal albumin level (>3.5g/dL)	0
	Low albumin level (<3.5g/dL)	4

Table 2 (continued): CD overall disease severity index (Siegel et al.[7]).

Anorectal symptoms	None of the following: anorectal pain, bowel urgency, incontinence, discharge, tenesmus	0
	At least one of the following: anorectal pain, bowel urgency, incontinence, discharge, tenesmus	4
Anaemia	Not anaemic (according to WHO criteria)	0
	Anaemic (according to WHO criteria)	4
Abdominal pain	Infrequent abdominal pain (less than daily)	0
	Daily abdominal pain	3
Steroid use	No steroid use within the past year	0
	Has steroid use within the past year	2

CD = Crohn's disease; MRI = magnetic resonance imaging; CRP = C-reactive protein; WHO = World Health Organization.

present medications and previous surgery were collected via the clinical records. The treating physician completed the IBD-DSI, HBI and SCCAI. The participant-completed PCDSS, neuroticism, coping and pain catastrophising were all self-reported by the participant via pen and paper.

Participants completed the PCDSS before the physician completed the IBD-DSI to ensure that participants came up with their score independently.

To help determine for which patients there was the greatest discrepancy between IBD-DSI and PCDSS, an "excess severity score" (ESS) was calculated by subtracting the physician-determined IBD-DSI from the PCDSS.

Study size

The initial power calculation determined that 300 participants would be needed across six sites to provide >80% power (two-tailed α=0.05) when correlation coefficients are >0.18. However, the COVID-19 pandemic halved the number of study centres. A recalculation determined a sample size of 150 participants across the three centres would enable correlations >0.23, to be detected as statistically significant (two-tailed α=0.05) with >80% power.

Ethical considerations

Ethical approval was obtained according to the institutional guidelines at each site.

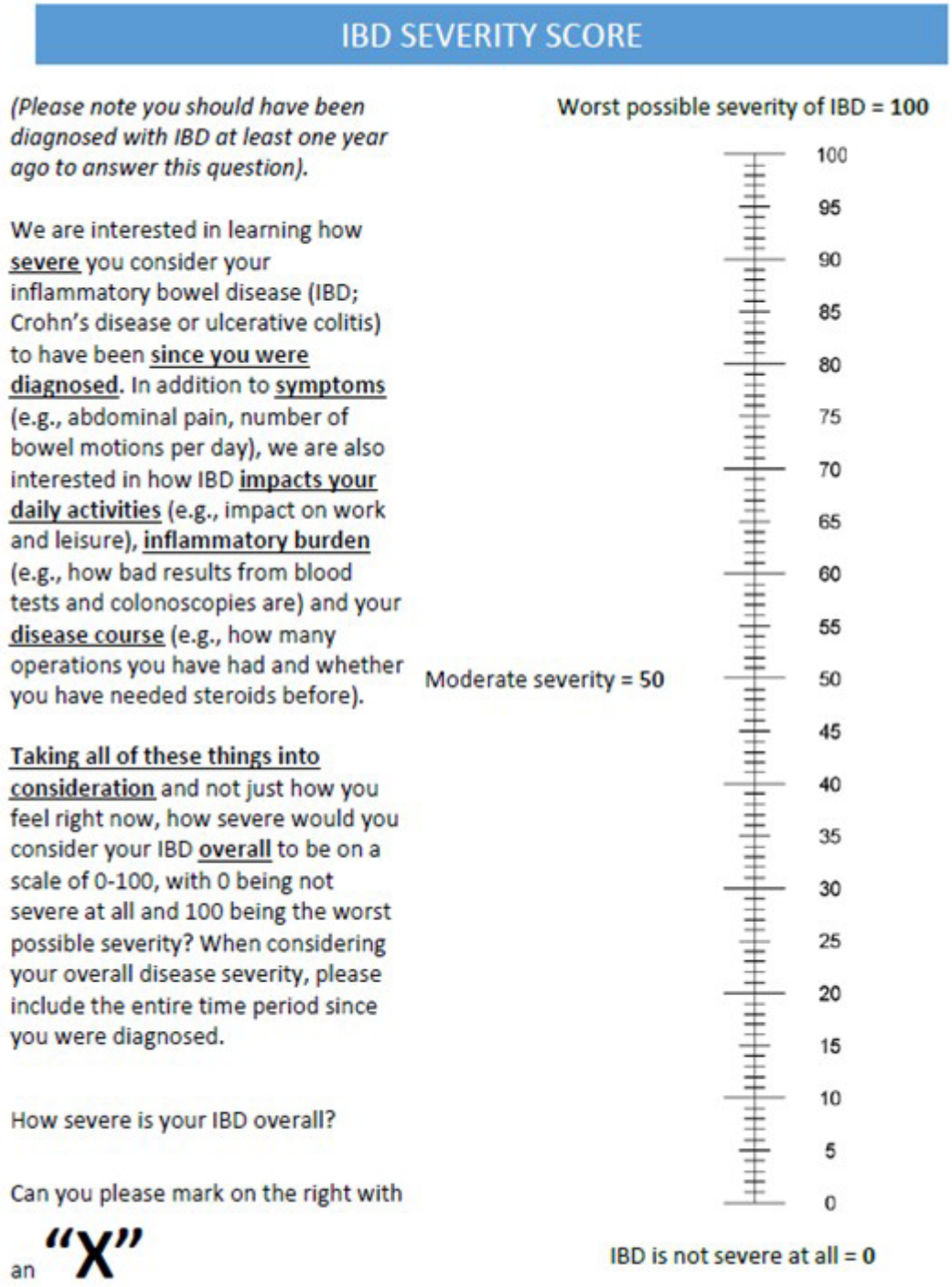
Statistical methods

Statistical Packages for Social Sciences (SPSS) version 28 was used for analyses. For each discrete variable a frequency and percentage were calculated and for continuous variables a mean and standard deviation was calculated. An ESS was calculated by subtracting the physician-determined IBD-DSI from the PCDSS. For each variable, a general linear model was built with ESS as the dependent variable, IBD-DSI as a covariate and the variable of interest as a covariate for continuous or fixed for discrete. The file was split into UC and CD for analysing Montreal classifications and the clinical indices SCCAI and HBI. Interactions between predictors and diagnosis were also examined to see whether any predictors differed for UC vs CD. The alpha level was 0.05.

The histograms of the distributions of the IBD-DSI, PCDSS and ESS were examined and were found to be acceptably normal. Therefore, Pearson correlations were produced containing the IBD-DSI, PCDSS and ESS. A scatterplot was produced comparing IBD-DSI and PCDSS, with different coloured dots for centres, an x=y line and a regression line.

Finally, a stepwise regression was performed for predicting ESS based on IBD-DSI unconditionally and all other variables conditionally,

Figure 1: Patient-completed disease severity score (PCDSS).



with criteria being probability of F entry=0.05 and removal=0.10. The other variables included ones measured across CD and UC and not variables exclusive to CD or UC (i.e., HBI and Montreal classification for CD and SCCAI and disease extent for UC).

Data availability statement

The data underlying this article will be shared on reasonable request to the corresponding author.

Results

Participants

There were 170 participants approached from the three centres, with three having incomplete IBD-DSI data, leaving 167. Of these 167, three people declined participation (98.2% response rate). There were 71, 46 and 47 participants recruited from Christchurch, Dartmouth Hitchcock and Northwestern, respectively. The average age was 41.6 years, 103 (62.8%) were female, and there were 98 participants (59.8%) with CD (Table 3).

Comparison of patient- and physician-estimated IBD severity

The ESS was determined by subtracting the IBD-DSI from the PCDSS. There were 164 complete IBD-DSI and therefore 164 calculatable ESSs. The mean ESS was 29.0 (Table 4), with a moderate positive correlation between the PCDSS and IBD-DSI ($r=0.44$, $r^2=0.19$, $p<0.001$). Furthermore, there was a strong association between ESS and PCDSS ($r=0.71$, $p<0.001$) and a significant negative association between IBD-DSI and ESS ($r=-0.32$, $p<0.001$). The association between IBD-DSI and PCDSS is shown in Figure 2. As physician-determined severity gets higher, the ESS reduces. The regression equation reflecting this relationship is PCDSS=39.53+0.59*IBD-DSI.

Excess severity correlates

Variables that were positively associated with ESS at an alpha level of 0.10 or lower after IBD-DSI was accounted for were previous colectomy (p=0.03), any IBD- or bowel-related surgery (p=0.01) and UC extent of disease (p=0.049). Variables that trended insignificantly towards a positive association with ESS were resection (p=0.08), fistula/seton/abscess (p=0.07) and CD (p=0.06). 5-aminosalicylic acid (5-ASA) (p=0.01) was significantly negatively associated with ESS after controlling for IBD-DSI (Table 5). There was no difference in ESS between study centres (p=0.99).

Excess severity in UC vs CD

Significant interactions, signifying differing relationships between predictors and the ESS for UC and CD after controlling for IBD-DSI, were demonstrated for oral steroids (3.75 CD vs −28.52 UC, p=0.03) and bad coping (0.16 CD vs −0.21 UC, p=0.007). Colectomy (4.13 CD vs 32.38 UC, p=0.12), any IBD- or bowel-related surgery (3.89 CD vs 28.63 UC, p=0.099) and pain catastrophising (0.21 CD vs 0.004 UC, p=0.10) trended towards significance (Table 6).

5-ASA

Participants who took 5-ASA scored higher on the IBD-DSI (31.1 vs 24.7, p=0.17) but lower on the PCDSS (49.4 vs 56.5, p=0.16), meaning that the ESS was lower in those who were on a 5-ASA (p=0.003).

Multivariable analysis

A stepwise regression with the IBD-DSI being entered unconditionally revealed the significant variables were IBD-DSI (beta=−0.39, 95% confidence interval [CI]=−0.58–−0.21, p<0.001), any IBD- or bowel-related surgery (beta=8.03, 95% CI=0.80–15.27, p=0.03), and 5-ASA (beta=−9.67, 95% CI=−18.69–−0.65, p=0.04).

Discussion

Understanding the disease severity over a lifespan is essential to determine the impact on patients and communities. The IBD-DSI has been designed to achieve this through assessing a wide range of variables that may contribute to the IBD severity. A number of studies have shown that the IBD-DSI is a valid instrument that can also predict adverse disease outcomes out to 2 years.[9] However, the IBD-DSI was not co-designed with patients and it is important to understand how well the IBD-DSI correlates with patients' opinions of their own IBD severity. Furthermore, if the IBD-DSI does not correlate well, it is useful to understand the main drivers of such discrepancies.

In this study we have further extended the validation of the IBD-DSI by demonstrating a significant positive correlation between it and the PCDSS. Discrepancies regarding this correlation were greatest at lower disease severity with a mean 29.4-point ESS (patient-determined severity minus physician-defined severity). The equation: PCDSS=39.53+0.59*IBD-DSI accurately defines this

Table 3: Baseline characteristics of 164 participants.

	Variable	N (%) or mean (SD)
Centre	Christchurch	71 (43.3%)
	Dartmouth Hitchcock	46 (28.0%)
	Northwestern	47 (28.7%)
Demographics	Age (years)	41.6 (15.6)
	Female sex	103 (62.8%)
	Non-Caucasian[a]	7 (6.1%)
Disease phenotype	Disease duration (years)	13.4 (9.4)
Crohn's disease	N	98 (59.8%)
	Harvey-Bradshaw Index	3.4 (3.7)
Montreal classification		
Age of diagnosis	A1	25 (25.5%)
	A2	60 (61.2%)
	A3	11 (11.2%)
Location of disease	L1	19 (19.4%)
	L2	23 (23.5%)
	L3	49 (50.0%)
	L4	6 (6.1%)
Disease behaviour	B1	45 (45.9%)
	B2	21 (21.4%)
	B3	32 (32.7%)
	Perianal disease	19 (19.4%)
Ulcerative colitis		
	N	66 (40.2%)
	Simple Clinical Colitis Activity Index	3.0 (3.0)
Montreal classification		
Disease extent	E1	7 (10.6%)
	E2	24 (36.4%)
	E3	34 (51.5%)
Surgery	Colectomy	16 (9.8%)
	Resection	24 (14.6%)

Table 3 (continued): Baseline characteristics of 164 participants.

	Fistula/seton/abscess	8 (4.9%)
	Ileocecectomy	11 (6.7%)
	Any IBD- or bowel-related surgery	53 (32.3%)
Medication	Oral steroids	9 (4.9%)
	Biological	90 (54.9%)
	5-aminosalicylic acid	28 (17.1%)
	Immunomodulator	45 (27.4%)
	No medication	27 (16.5%)
Psychological variables	Neuroticism	28.5 (9.8)
	Good coping	3.7 (2.5)
	Bad coping	2.8 (2.0)
	Pain catastrophising	6.4 (4.0)

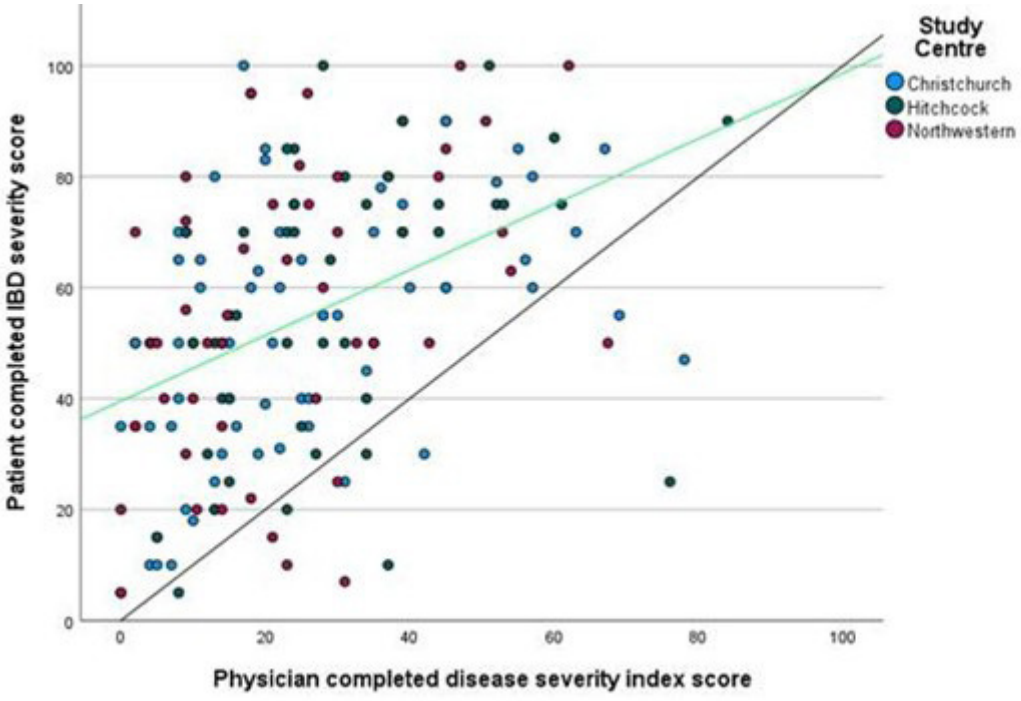
[a]Fifty missing ethnicities.
SD = standard deviation; IBD = inflammatory bowel disease.

Table 4: Mean (SD) severity scores of patients.

	Mean (SD)			
Severity score	**Total**	**CD only**	**UC only**	**UC and no bowel surgery**
IBD-DSI (physician-determined) (n=164)	25.8 (18.1)	21.7 (15.1)	32.0 (20.5)	31.8 (20.7)
PCDSS (patient-determined) (n=167)	55.2 (24.4)	55.5 (24.6)	54.9 (24.4)	53.6 (24.0)
Excess severity score (PCDSS–IBD-DSI) (n=164)	29.0 (23.2)	33.3 (21.1)	22.6 (24.8)	21.4 (24.4)

SD = standard deviation; CD = Crohn's disease; UC = ulcerative colitis; IBD-DSI = IBD Disease Severity Index; PCDSS = patient-completed disease severity score.

Figure 2: Scatterplot of inflammatory bowel disease severity index (IBD-DSI) vs patient-completed disease severity score (PCDSS).



Green line depicts regression line and black line indicates x=y.

Table 5: Predictors of excess severity after controlling for IBD-DSI.

Variable	Test statistic	Coefficient	p-value[a]
Centre		NA	0.99
Christchurch	EMMD	ref	
Dartmouth Hitchcock	EMMD	−.70	
Northwestern	EMMD	−.15	
Demographics			
Age	SB	−.32	0.87
Female sex	EMMD	4.6	0.20
Non-Caucasian[b]	EMMD	1.1	0.89
Years since diagnosis	SB	0.049	0.51
Surgery			
Colectomy	EMMD	12.8	0.03
Resection	EMMD	8.6	0.08
Fistula/seton/abscess	EMMD	14.4	0.07

Table 5 (continued): Predictors of excess severity after controlling for IBD-DSI.

Ileocecectomy	EMMD	35.5	0.61
Any IBD- or bowel-related surgery	EMMD	9.7	0.01
Medication			
Oral steroids	EMMD	−6.8	0.40
Biologic	EMMD	4.7	0.18
5-aminosalicylic acid	EMMD	−11.7*	0.011
Immunomodulator	EMMD	5.2	0.18
No medication	EMMD	−6.5	0.16
Psychological variables			
Neuroticism	SB	.067	0.37
Good coping	SB	.11	0.15
Bad coping	SB	.006	0.94
Pain catastrophising	SB	.12	0.13
CD			
CD diagnosis	EMMD	7.0	0.06
Harvey-Bradshaw Index	SB	.23	0.047
Age of diagnosis			0.73
A1	EMMD	ref	
A2	EMMD	−4.1	
A3	EMMD	−3.4	
Disease location			0.69
L1	EMMD	ref	
L2	EMMD	−6.5	
L3	EMMD	−3.5	
L4	EMMD	2.7	
Disease behaviour			0.68
B1	EMMD	ref	
B2	EMMD	5.1	
B3	EMMD	2.0	
Perianal disease	EMMD	5.8	0.28

Table 5 (continued): Predictors of excess severity after controlling for IBD-DSI.

UC			
UC diagnosis	EMMD	−7.0	0.06
Simple Clinical Colitis Activity Index	SB	−.1	0.53
Disease extent			0.049
E1	EMMD	ref	
E2	EMMD	3.3	
E3	EMMD	16.1	

[a]For association with excess severity after controlling for IBD-DSI.
[b]n=114 due to 50 missing ethnicities within the 164.
IBD-DSI = IBD Disease Severity Index; EMMD = estimated marginal mean difference; SB = standardised beta; IBD = inflammatory bowel disease; CD = Crohn's disease; UC = ulcerative colitis.

Table 6: Predictors of excess severity after controlling for IBD-DSI, split by UC vs CD.

Variable	Test statistic	CD (n=98)		UC (n=66)		p-value[a]
		n	Coefficient	n	Coefficient	
Centre						0.88
Christchurch	EMMD	47 (48.0%)	ref	24 (36.4%)	ref	
Dartmouth Hitchcock	EMMD	25 (25.5%)	−3.31	21 (31.8%)	1.85	
Northwestern	EMMD	26 (26.5%)	−0.51	21 (31.8%)	0.99	
Demographics						
Age	SB	98 (100%)	−0.04	66 (100%)	−.001	0.82
Female sex	EMMD	62 (63.3%)	1.27	41 (62.1%)	9.78	0.31
Non-Caucasian[b]	EMMD	4 (5.6%)	−1.27	3 (7.0%)	4.40	0.76
Years since diagnosis	SB	98 (100%)	−.009	66 (100%)	−0.006	0.92
Surgery						
Colectomy	EMMD	14 (14.3%)	4.13	2 (3.0%)	32.38	0.12
Resection[c]	EMMD	23 (23.5%)	4.88	1 (1.5%)	20.03	0.65
Fistula/seton/ abscess	EMMD	8 (8.2%)	10.71	0 (0%)	NA	NA
Ileocecectomy	EMMD	11 (11.2%)	−6.43	0 (0%)	NA	NA

Table 6 (continued): Predictors of excess severity after controlling for IBD-DSI, split by UC vs CD.

Any IBD- or bowel-related surgery	EMMD	50 (51.0%)	3.89	3 (4.5%)	28.63	0.099
Medication						
Oral steroids	EMMD	5 (5.1%)	3.75	3 (4.5%)	−28.52	0.03
Biologic	EMMD	64 (65.3%)	3.47	26 (39.4%)	3.15	0.72
5-aminosalicylic acid	EMMD	10 (10.2%)	−14.85	18 (27.3%)	−5.38	0.35
Immunomodulator	EMMD	30 (30.6%)	6.28	15 (22.7%)	1.92	0.55
No medication	EMMD	13 (13.3%)	−7.65	14 (21.2%)	−1.76	0.44
Psychological variables						
Neuroticism	SB	97 (99.0%)	0.14	66 (100%)	−0.01	0.35
Good coping	SB	97 (99.0%)	0.17	66 (100%)	−0.001	0.27
Bad coping	SB	97 (99.0%)	0.16	66 (100%)	−0.21	0.007
Pain catastrophising	SB	98 (100%)	0.21	66 (100%)	0.004	0.10

[a]For association of interaction between variable and diagnosis of UC or CD with excess severity after controlling for IBD-DSI.
[b]Missing ethnicity for 27 CD and 23 UC.
[c]One UC patient had a colonic resection for comorbid diverticular disease.
IBD-DSI = IBD Disease Severity Index; UC = ulcerative colitis; CD = Crohn's disease; EMMD = estimated marginal mean difference; SB = standardised beta; IBD = inflammatory bowel disease.

relationship. This positive association evidences a level of concurrent validity for the PCDSS and IBD-DSI and is worthy of future study. While correlation does not imply causation, it is reasonable to infer that how severe a patient perceives their illness to be has some relationship to how severe an objective measure finds it to be, but future longitudinal studies with repeated measures would strengthen the argument that they are causally related.

In addition, variables that were positively associated with ESS included previous colectomy, any IBD- or bowel-related surgery and UC extent of disease. The only variable associated negatively with ESS was 5-ASA use. However, the present study has shown that the IBD-DSI and patients with IBD measure disease severity in a similar way. The stepwise multivariable model determined IBD-DSI, any IBD- or bowel-related surgery and 5-ASA use to be most strongly associated with ESS.

Overall, no psychological variables were associated with ESS. There were non-significant trends for good coping (p=0.15) and pain catastrophising (p=0.13) to be positively associated with ESS while neuroticism (p=0.37) and bad coping (p=0.94) had no significant association.

The reduction in ESS with increasing disease severity may be due to floor effects of determining disease severity for patients with less disease severity. These patients may concentrate on the few symptoms they have, driving up the severity score. Furthermore, regression to the mean may occur when participants in a study tend to score closer to the middle if they are not sure of their answer. Given that the mean IBD-DSI score for the study cohort was 25.8, regression to the mean could explain the larger ESS in those with less disease severity. It is important for clinicians to recognise that patients' subjective experiences of severity may still be high even if they seem

to have less severe IBD on objective measures; perhaps patients experience more severity than their treating team appreciates.

Another factor that could contribute to a wider ESS, which is specific to these questionnaires, may relate to patients scoring greater or lesser severity for a specific variable. For example, patients with a stoma may have different experiences leading them to over- or under-estimate the contribution of such a variable to the overall score. Furthermore, the IBD-DSI was not specifically designed for patients with UC who have had a colectomy. For example, resection or colectomy are not offered as variables in the IBD-DSI but would clearly reflect increased disease severity.

The only significant medication that was negatively correlated with ESS was 5-ASA. 5-ASA use was positively associated with an IBD-DSI and negatively with PCDSS. On the PCDSS side, it is possible that people on 5-ASA medications are aware that there are more potent medications for IBD and factor this into their score. On the IBD-DSI side it is possible some aspect of 5-ASA use is built into the scores. In addition, there was a non-significant trend towards steroids being negatively associated with ESS and it is likely that those on steroids are in steroid-induced remission and so are actually feeling well. There was also an interesting interaction effect in that oral steroids were a negative predictor of ESS in UC, more so than CD, although there were small numbers in each diagnosis group.

It is possible participants were subject to the Hawthorne effect, wherein they answered differently because they knew their answers would be observed.[14] Participants were recruited from specialist gastroenterology outpatient clinics and it is possible this affects their beliefs about their disease severity, especially when one considers that many patients with IBD are not under the care of a specialist.[15–17]

This study under-recruited due to the COVID-19 pandemic and so there were limitations in the power of the study, especially with regards to the psychological variables. Nevertheless, some significant associations were found. Moreover, some potentially important variables were not collected, such as dose and duration of medications as well as comorbidities. Future studies should ideally collect these datapoints.

The PCDSS was used for the first time in this study but was shown to correlate with the IBD-DSI and so seems to have measured what it purports to measure. It is intended as a subjective scale, not unlike the 0–100 visual analogue scale used in the EQ-5D-5L questionnaire.[18–22] Because it is intended as a patient-defined and subjective measure of disease, it should not be expected to correlate perfectly with the IBD-DSI, which was indeed a finding of this study. It does mention symptoms (e.g., abdominal pain, number of daily bowel motions), impact on daily activities (e.g., work and leisure), inflammatory burden (blood test and colonoscopy results), and disease course (e.g., previous operations or steroids) and so is comprehensive while being partly subjective.

The calculation of ESS may seem unusual given the apparent heterogeneity of IBD-DSI and PCDSS in terms of what they purport to measure. However, this was necessary to identify variables with the greatest discrepancy between IBD-DSI and PCDSS, and where patients assigned different weights than in the gastroenterologist-developed IBD-DSI.

This study recruited from New Zealand and the USA, and excess severity was the same across the centres despite the different subcultures, economies and health systems. This suggests both instruments are generalisable across continents.

A similar study from Germany[23] that compared 89 pairs of the physician-completed IBD-DSI to a patient global self-assessment and visual analogue scale also reported moderate agreement between physicians and patients. Furthermore, patients tended to rank their disease severity higher than physicians in the German study as well. Given that there are now two studies in different languages and using different scales reporting similar associations, it is likely that the IBD-DSI is valid. The moderate correlations reported in both studies reflect the comparisons between different constructs, namely objective severity and subjective patient experience.

Conclusions

There is a moderate positive association between PCDSS and IBD-DSI but with greater discrepancies at the lower levels of IBD-DSI. The CD and UC IBD-DSI are differently calculated and so there were some differences between CD and UC in terms of ESS as well as what predicted ESS. Surgical procedures especially predicted ESS, at least in part driven by surgical procedures not being included in the IBD-DSI for UC, demonstrating the IBD-DSI is not valid for UC patients who have had a colectomy.

COMPETING INTEREST

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AUTHOR INFORMATION

Andrew Mark McCombie: Department of General Surgery, Health New Zealand – Te Whatu Ora, Christchurch Hospital, Christchurch, New Zealand.

Corey A Siegel: Center for Digestive Health, Dartmouth Hitchcock Medical Center, Lebanon, New Hampshire, United States of America.

Stephen B Hanauer: Northwestern Medicine, Chicago, Illinois, United States of America.

Timothy McAuliffe: Geisel School of Medicine at Dartmouth, Hanover, New Hampshire, United States of America.

Jessica Salwen-Deremer: Department of Psychiatry & Center for Digestive Health, Dartmouth Hitchcock Medical Center, Lebanon, New Hampshire, United States of America.

Hannah Hughes: University of Canterbury, Christchurch, New Zealand.

Richard Gearry: Health New Zealand – Te Whatu Ora Waitaha, Christchurch, New Zealand.

CORRESPONDING AUTHOR

Andrew Mark McCombie: Research Officer and Data Analyst, General Surgery, Christchurch Hospital, Private Bag 4710, Christchurch 8140, New Zealand. E: Andrew.mccombie@cdhb.health.nz

URL

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Traditional knowledge, planetary health and healthcare: a systematic review

Jihae Abou El Ela, Mercedes Mudgway, Niki Harré, Jane Thomas, James Hamill

ABSTRACT

BACKGROUND: Traditional knowledge takes a more holistic view of the interconnectedness between nature and human health compared to modern healthcare systems. This review synthesises literature on the nexus between traditional knowledge, the environment and health, with the goal of an environmentally sustainable healthcare system.

METHODS: We searched Web of Science, Scopus, Medline and Embase for peer-reviewed publications using keywords related to the natural environment or planetary health, Indigenous/traditional knowledge, and healthcare. Themes were developed by thematic synthesis in an eight-step process.

RESULTS: We identified 22 reports across 21 studies; 15 were published in the last 10 years. Six initial themes were identified and subsequently collapsed into two overarching themes: "holistic wellbeing" and "epistemological pluralism". The first theme highlights the need for healthcare to adopt a holistic concept of health centred on nature. The second theme emphasises the importance of embracing diverse epistemologies to achieve optimal health outcomes. Together, these themes suggest that healthcare systems should be guided by a more inclusive, environmentally focussed understanding of health rather than by a predominantly technical paradigm.

CONCLUSIONS: Literature on the relationship between traditional knowledge, planetary health and healthcare is both limited and recent. The review suggests that healthcare systems should incorporate respect for nature, diverse cultures and local contexts.

Healthcare plays a crucial role in managing disease and injury, yet tensions exist within its broad scope, from public health to highly technical medical interventions. Resource allocation between public health initiatives and hospital care is one example of a tension, while a larger-scale tension exists between planetary health and healthcare's environmental impact. Healthcare, which accounts for 4.4% of global greenhouse gas emissions,[1] contributes significantly to climate change. Healthcare generates large volumes of waste, often disposed of through environmentally harmful methods like incineration.[2] Some healthcare supply chains involve unethical labour practices,[3] making them a double-edged sword, benefitting some people at the expense of others, usually in different localities.

The recognition that human health and the health of Earth are inextricably linked[4,5] has led clinicians to create a movement for planetary health.[6] Although the literature on planetary health has been substantial in recent time, much of it appears to come from a "modern" paradigm[7] in which the issue of climate change is viewed as a problem to be solved external to ourselves. By contrast, traditional viewpoints often regard the world and all living beings as interconnected,[8] as expressed by Al-Delaimy et al.: "*Earlier civilisations … consider the earth, nature, and its bounties a privilege to be cherished and respected because of the interdependence with the environment for their survival … They have ensured that they are part of the eco-system and are a positive force to live and let animals, plants and all other creations live.*"[9]

Interconnectedness is also explained in a statement made at the 23rd World Conference on Health Promotion in 2019: "*Core features of Indigenous worldviews are the interactive relationship between spiritual and material realms, intergenerational and collective orientations, that Mother Earth is a living being – a 'person' with whom we have special relationships that are a foundation for identity, and the interconnectedness and interdependence between all that exists, which locates humanity as part of Mother Earth's ecosystems alongside our relations in the natural world.*"[10]

The burden of climate change does not fall equally on all. Indigenous populations are one of the vulnerable groups that are disproportionately burdened by biodiversity loss, climate change and rising sea levels.[11] The reasons are multifactorial. Indigenous peoples often have a close relationship

with and dependence on the land, sea and other natural resources. Additionally, Indigenous populations often carry the burden of social and economic inequity.[12] Added to this is the growing body of evidence that Indigenous management and land tenure provide valuable lessons in how to safeguard natural resources.[13]

Therefore, the purpose of this review is to scope the international literature on scientific research at the nexus of the natural environment, traditional knowledge and healthcare and to identify opportunities for future research and policy.

Methods

The protocol for this review was registered at the Open Science Framework (OSF), reference osf.io/r4yh2. Study data are openly available on OSF (see: https://osf.io/r4yh2/). This report conforms to the Preferred Reporting Items for Systematic reviews and Meta-Analyses – Scoping Reviews[14] and the Enhancing Transparency in Reporting the Synthesis of Qualitative Research,[15] as shown in Tables S1 and S2 at OSF (see: https://osf.io/r4yh2/).

The eligibility criteria included research papers that addressed environmental sustainability, Indigenous or traditional knowledge or ways of knowing and human healthcare. Excluded were reviews, editorials and opinion pieces. No date or language limits were applied. Information sources for database searches were the Web of Science, Scopus, Medline and Embase. Two researchers (JA and JH) developed the search strategy with advice from librarians at The University of Auckland's Philson Library. Searches reflected the three main concepts: the natural environment, traditional knowledge and healthcare. Combinations of key words and Medline subject headings were trialled in an iterative process to arrive at the final search strategy. The search strategy for Web of Science was as follows: TS = (Indigenous or "first nation people*" or "native people*" or tribe* or "Indigenous population*" or "Indigenous health services" or "Indigenous Canadians" or "Pacific Islander*" or "Native Hawaiian" or "American Indian" or "Australian Aboriginal" or "Torres Strait Islanders" or "oceanic ancestry group" or Māori) AND TS = (healthcare or health-care or "health care" or "health service*" or "health system*" or "community-based care" or "primary care") AND TS = ("planetary health" or "environmental* sustainab*" or "environmental health*" or "environmental restoration*" or "environmental remediation" or "natural resources conservation" or "conservation of natural resources" or deforestation or "environmental protection*" or "environmental policy"). The search strategy for Medline is available in Table S3 at OSF (see: https://osf.io/r4yh2/files/osfstorage). Searches were performed from June to August 2023 and updated in April 2024.

Two reviewers (JA and JH) performed the searches, imported the results into the online platform Rayyan,[16] removed duplicates, screened titles and abstracts and screened full text articles for eligibility. Screening was performed independently and blinded. Blinding was then removed and the two reviewers resolved any discrepancies around eligibility by discussion and consensus. In addition to database searches, the two reviewers citation tracked and searched the internet for relevant papers.

Two reviewers extracted data from each paper onto a spreadsheet. This recorded the article's characteristics (author, country of origin and year of publication), the aims/purpose of the study (which was obtained either from the abstract or the introduction of the paper), the study population and sample size if available, the methodology if relevant, the study outcomes and details, and key findings related to the scoping question. The quality of included papers was assessed using a checklist based on the Standards for Reporting Qualitative Research[14] that scored each paper's compliance with each of the 20 items.

For thematic synthesis, we adapted Braun and Clarke's method of reflective thematic analysis[17,18] and Noblit and Hare's method of meta-ethnography[19] into the following steps:

1. Identify the area of study and the theoretical paradigm.
2. Literature search and paper selection.
3. Quality assessment of each included paper.
4. Familiarisation with the dataset/papers.
5. Code key metaphors, ideas, phrases and concepts.
6. Generate initial themes.
7. Refine, define and, as necessary, rename themes to minimise overlap and ensure overall coherence.
8. Express the results in a written report and other forms of communication.

A detailed description of thematic synthesis is available in the study protocol at OSF (see: https://osf.io/r4yh2/).

Results

After removing duplicates, we identified a

total of 374 references, which, after screening, were narrowed down to 22 reports[20–41] from 21 studies, as shown in Figure 1. Publication dates ranged from 2006 to 2024 with 15 studies within the last 10 years, as shown in Table 1. Geographically, research originated from Africa, Australia, India, Indonesia, and Central and North America as shown in Table S4 at OSF (see: https://osf.io/r4yh2/files/osfstorage). Quality scores are shown in Table S5 at OSF (see: https://osf.io/r4yh2/files/osfstorage). Quality assessment yielded a mean score of 12/20 (range 6–18, SD 3.5).

From the coded studies, six initial themes emerged: holistic wellbeing, multiple ways of knowing, Earth, community, justice and healthcare system diversity, as shown in Table S6 and Figure S1 at OSF (see: https://osf.io/r4yh2/). These were further refined into two overarching themes: "holistic wellbeing" and "epistemological pluralism" as shown in Figure S2 at OSF (see: https://osf.io/r4yh2/files/osfstorage). The holistic wellbeing theme encompasses the relationship between nature and health, emphasising the need for healthcare to adopt a nature-centred, culturally informed understanding of health. The epistemological pluralism theme highlights the value of integrating diverse knowledge systems in healthcare to enhance health outcomes.

Theme 1: holistic wellbeing

The core idea of the holistic wellbeing theme is that healthcare needs a more holistic concept of wellbeing as a basis of healthcare planning than it currently has. Nineteen papers had codes pertaining to holistic wellbeing, as shown in Table S6 at OSF (see: https://osf.io/r4yh2/files/osfstorage). Beaudin[24] explored the health concepts of the Oneida Nation in Canada as they relate to a World Health Organization (WHO) framework called the International Classification of Functioning, Disability and Health (ICF). Although the ICF framework promotes a holistic approach, it lacks a cultural dimension, which is essential for mutual understanding. Beaudin proposed a three-step process for cultural system improvement: 1) learning through engagement, 2) interpretation and reform, and 3) application and engagement.[24]

The Mandala of Health, a model proposed by Hancock,[42] was adapted by Langmaid et al.[32] to incorporate traditional knowledge systems in Australia. The authors found that "*The cultural context of communities and … understanding of Indigenous cultures are crucial elements of health promotion.*"[32] Building upon this framework, Langmaid et al. [32] developed a modified Mandala of Health that emphasised the interconnected aspects of ecosystems with the human mind, body and spirit.

Redvers et al.[37] used a consensus approach led by Indigenous people from around the world to develop a model of planetary health that interconnected the following components: Mother Earth–level determinants (respect of the feminine and ancestral legal personhood designation); interconnecting determinants (human interconnectedness within nature, self and community relationships, the modern scientific paradigm, and governance and law); and Indigenous peoples–level determinants (Indigenous land tenure rights, Indigenous languages, Indigenous peoples' health, and Indigenous elders and children).[34]

Models that support planetary health consider nature to be an integral foundational aspect rather than a single "leg" so to speak. DiPrete Brown et al. reflected this in their "three-legged stool" model.[30] In their initial model they equated three aspects of sustainability—environmental protection, economic development and social development—with a three-legged stool. However, the environment is not merely a component but the foundation of life on Earth; therefore, the authors modified the model to make the environment the "floor" on which the stool stands and the three legs of the stool became 1) human rights and related legal frameworks, 2) gender analysis and gender mainstreaming practices, and 3) local and Indigenous history, knowledge and ways of knowing.

The importance of place-based local environments, variously referred to as Earth, land or country, was prominent in the literature.[20,25–27,38] Brand et al. explained that "*The Aboriginal flag, like the roots keeps me grounded, turn to my boodja* [land or country], *to keep connected you know, that my spirit my Wirrin* [spirit] *is keeping me strong.*"[38] A participant in the study by Kingsley et al. explained that "*If the land's healthy, the animals are healthy, it makes the people healthy … but if the animals don't have habitat than that means the land and people are sick.*"[26] Other determinants of health referred to in the studies included: land and country; sense of Mother Earth; intergenerational health; reciprocity—caring, respect and gratitude; social, cultural and economic determinants of health; and justice, self-determination, community empowerment.

Theme 2: epistemological pluralism

The second major theme is epistemological pluralism, which advocates for the integration of

multiple knowledge systems in healthcare. Redvers et al.[34] discussed epistemological pluralism using the metaphor of a "two-eyed seeing lens" as originally described by Bartlett et al.: "*Two-eyed seeing is the gift of multiple perspectives treasured by many aboriginal peoples and explains that it refers to learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing, and to using both these eyes together, for the benefit of all.*"[43]

2.1: systems thinking

Traditional knowledge connects nature with society in a way comparable to complex systems thinking. In an ethnographic study on First Nations peoples' perspective on health and wellness, Beaudin[24] found that connectedness was experienced within the community between the community and the environment, and at the level of planet Earth. Participants spoke of being stewards of the land and how land contamination from landfill sites, and other environmental challenges, influenced individual's and the community's health: "*That's our connection to Mother Earth, it's our medicines. So our health has a lot to do with it, of who we are and what we believe in … when something happens to the land, it will affect us too.*"[24]

In an Indigenous-led project, Smith et al. found that the Indigenous people of Central America and the Caribbean conceptualised health as a relationship with nature: "*What the Maya present is an understanding of health and wellbeing that is attained via strong, reciprocal relationships with land, forests, plants and people – factors which are frequently absent within Western accounts of health.*"[36]

Systems thinking is characteristic of traditional knowledge as expressed by one of the participants in the study by Carrington et al.: "*What's happening is that the science is catching up to the mātauranga* [traditional knowledge] *Māori way of thinking… in that through whakapapa* [genealogy]*, everything is connected, or maybe in the natural environment anyway. Things are connected.*"[39]

2.2: coming together

Traditional knowledge could have a role not only in environmental sustainability but in the way the research is conducted. Grande et al. argued for a participatory approach with Indigenous stakeholders, especially young people: "*The results showed that capacity building and partnership between Indigenous and non-Indigenous communities at the systems and individual levels are critical in underpinning sustainable system-level change.*"[40]

Poland et al. related Indigenous methods ("talking circles") to planetary health and to the ecological determinants of human health: "*Recognising that problems cannot always be solved from the same level of thinking that created them, contemporary sustainability and social challenges are prodding us to look beyond conventional approaches to 'greening' business as usual … and to release the fiction that sustainability is a technical risk management problem, or even one of political will. In so doing, we create space to acknowledge the existence and relevance of alternative and hitherto marginalised worldviews, ways of knowing, and perspectives.*"[33]

Beaudin described the coming together of traditional and Western knowledge in an "ethical space" where there is common ground and mutual respect: "*An 'ethical space' is a place where two worldviews come together.*"[24] The "personal factors" component within the ICF "conceptual factors" component is ideally suited to assist in identifying potential areas where two worldviews intersect (i.e., an ethical space), and it would certainly be most beneficial to identify ethical spaces and potential solutions during the programme planning and service development stages related to healthcare. Traditional knowledge and voices should not only be incorporated into decision making but also into health-professional education, as explained by Brand et al.: "*This change will ensure that health professionals, and others, are prepared to be environmental and human stewards of a healthy planet for all.*"[38]

Discussion

This systematic review shows that there is a small but growing interest in the nexus of traditional knowledge, healthcare and the environment. The two themes developed from our thematic synthesis are inter-related and claim that we in the health sector could widen our view of what constitutes wellbeing and broaden the ways in which we gain understanding. The two themes could be thought of as forming parts of a whole, in that a holistic concept of wellbeing gives direction to healthcare's efforts while epistemological pluralism drives better understanding. Healthcare must learn through the diverse knowledge systems present in society; however, it is also important to avoid simply subsuming traditional knowledge, as explained by Redvers

et al: "*Traditional knowledges are not meant to be an assortment of information that can be simply merged with western scientific knowledge systems … traditional knowledges are collective, holistic, community-based, land-informed ways of knowing that are inherently interconnected with people and the environment … As such, they can be a source of knowledge for environmental strategic management in distinct ecosystems.*"[44] Therefore, healthcare approaches should be grounded in Earth in general and in place-based local environments in particular.

The planetary health movement, which grew out of the environmental movements of the 1970s and 1980s,[45] recognises that "*Human health and human civilisation depend on flourishing natural systems*".[6] In 2018, the Canmore conference defined the principles of planetary health as: 1) the sustainable vitality of all systems, 2) values and purpose, 3) integration and unity, 4) narrative health, 5) planetary consciousness, 6) nature relatedness, 7) biopsychosocial interdependence, 8) advocacy, 9) countering elitism, social dominance and marginalisation, and 10) personal commitment to shaping new normative behaviours.[46] These principles could also be used to formulate a definition of human health.

The WHO defined health as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*".[47] Schramme argued that the word "complete" in the WHO definition of health should be interpreted as holistic, or "*exhaustive of all constitutive features of well-being*"[48]—that is, physical, mental and social wellbeing. Schramme argued that interpreting the word "complete" to mean "perfect" health is problematic[48]—can elderly people or those living with disabilities or chronic illnesses not also experience wellbeing? Redvers et al. modified the WHO definition to emphasise humans' interconnectedness to nature: "*Health is a state of dynamic balance within and between our physical, mental, social and spiritual well-being that is completely dependent on planetary health.*"[49]

Building on their definition of health, the WHO developed the ICF framework. Although relatively holistic in its approach, the present review found that the ICF misses a cultural dimension. This cultural dimension includes language, connectedness, traditional values, traditional medicines, cultural appropriateness of healthcare services, and environmental issues such as climate change; all of which are important determinants of health.[24] Other studies in our review emphasised the connection with nature, Mother Earth, land and country as central to the wellbeing of Indigenous peoples;[20,26,28,34,38,44] therefore, although some health and economic organisations have come a long way,[46] they still need "*a new set of values, which heed and privilege the wisdom of Indigenous worldviews, as well as a renewed sense of spirituality that can re-establish a reverence for nature*".[8]

A clue as to the way forward for healthcare lies in the second theme of the present study: epistemological pluralism. Epistemologically, Indigenous peoples use oral traditions, which represent collective knowledge acquired over thousands of years.[50] The concept of "two-eyed seeing" is a metaphor for many ways of knowing, a concept not only in the Indigenous literature but also debated in science studies literature. Orthia observed that: "*Actions that steer the world towards a sustainable path must be rooted in science that is multidisciplinary, equitable and inclusive, openly shared and widely trusted, and socially robust.*"[51] Two examples of epistemological pluralism in Aotearoa New Zealand are Te Whare Tapa Whā[52] and Rongoā Māori.[53] Te Whare Tapa Whā uses the metaphor of a meeting house to represent health: the four walls represent spiritual, mental, physical and family health respectively, and connection with the land (whenua) forms the foundation.[52] Jenkins and Egger discussed Te Whare Tapa Whā in relation to how ecological restoration projects and Indigenous-led governance can promote public mental health.[54] The Rongoā Māori model encompasses spirituality, love (aroha), connections with the land, and herbal remedies.[53] The Aotearoa New Zealand health system introduced the Rongoā Māori Action Plan in 2024 to promote better health outcomes for Māori and non-Māori.[55] Recently, Rongoā Māori has been investigated in the public hospital surgical setting[56] and early results indicate a positive effect on patient care.[57]

Our review indicates the need for more epistemological diversity in healthcare planning. DeShazo addressed the question of health disparities from the perspective of epistemological recalcitrance in health systems, concluding that alternative epistemologies could be a saving grace for healthcare: "*By including a more diverse set of professionals, a diversity of tools can be added to the toolbox from which all healthcare professionals could draw.*"[58] In this way, DeShazo operationalised the abstract concept of epistemology for healthcare: include diverse people of diverse knowledge systems in healthcare policy, planning and delivery. For example, in a collaborative

project involving Māori health providers, regional district health boards and local iwi authorities, a cost-effectiveness analysis can be used to articulate both quantitative outcomes (such as reduced hospital admissions) and qualitative benefits (such as strengthened cultural identity). A recent report prepared for the Ministry of Health – Manatū Hauora recommended engaging "*Māori leaders, healthcare providers, and communities in the planning and evaluation process (consistent with a Treaty partnership approach)*".[59] Internationally, Redvers et al. engaged with Indigenous elders in Canada's circumpolar north to map out how to discuss health systems change.[60] Future research could follow a similar collaborative process.

Future research could also explore what constitutes health and wellbeing, perhaps in relation to specific groups such as children, the elderly, specific ethnic groups and certain socio-economic groups. Special attention should be applied to methods that adhere to the "ethical spaces" concept discussed in this review—that is, coming together on mutually respectful and equal footings. Research on national issues, such as how best to spend a limited health budget, is fundamentally societal and would benefit from diverse epistemological views. Other Indigenous health models that did not show up in the present review could be investigated—for example, the Fonofale model of health and wholeness of Pacific peoples, which could be explored in relation to connection to nature and to healthcare delivery.[61]

Limitations

The databases we searched cover the majority of health journals, but we may have missed relevant studies in the grey literature. The number of papers were small, most were qualitative, and quality scores were quite low for several papers, limiting generalisability. The choice of themes was a judgement call based on our purpose to inform health systems and the reflexivity of the research team, in keeping with our use of reflexive thematic analysis[17] as a methodological basis. As noted by Redvers et al.: "*Indigenous-specific land pedagogies are embedded directly within the respective lands stewarded by Indigenous peoples.*"[44] Therefore, we need to be cautious about broad generalisations that remove the knowledge from its context. We hope the main points—holistic health conceptualisation and epistemological pluralism—are generalisable enough to overcome this limitation, particularly in relation to the consideration of diverse knowledge systems.

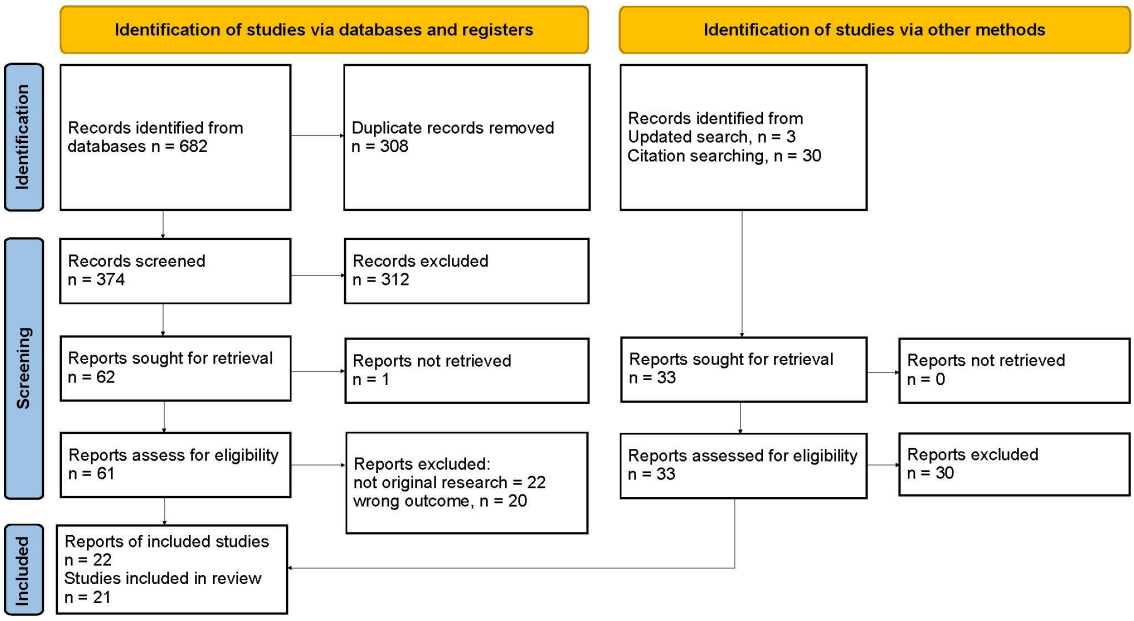
Conclusions

Literature on traditional knowledge as related to planetary health and healthcare remains underexplored, but it is gaining relevance. Healthcare systems in Western culture may benefit by adopting a broader, more inclusive definition of health that incorporates environmental stewardship and diverse cultural perspectives. The concept of health could extend the definition of the WHO charter by emphasising nature and the diversity of different cultures and localities. More research is needed on geographically specific, local Indigenous perspectives on healthcare and wellbeing. Locality-specific engagement with Indigenous communities and incorporating their knowledge into health-professional education is an important step towards creating a more sustainable and holistic healthcare system.

Table 1: Summary of studies included in the scoping review (in ascending order of date published).

Author	Year	Country	Population
Furgal[20]	2006	Canada	2 Inuit regions
Ali[21,22]	2006, 2007	Borneo	Rural populations in Kalimantan
Nettleton[23]	2007	Cambodia, Laos, Guatemala, Namibia, Burma	20 communities in 6 countries, 35 people
Beaudin[24]	2010	Canada	Oneida Nation of the Thames First Nation
Torri[25]	2010	India	22 households of farmers and sales representatives in the Tamil Nadu district
Kingsley[26]	2013	Australia	Victorian Aboriginal peoples
Kanene[27]	2016	Zambia	39 elders and herbalists
Schultz[28]	2018	Australia	85 service providers and users
Kay[29]	2019	Australia	21 staff members, 9 community members investigating 32 projects
DiPrete-Brown[30]	2020	Guatemala, Malawi, Peru, Aotearoa New Zealand, Côte d'Ivoire, Sri Lanka	Multiple experts
Jones[31]	2020	Borneo	28,400 patients, 23 districts in Gunung Palung National Park
Langmaid[32]	2020	Australia	10 experts
Poland[33]	2020	Canada	18 public and student participants
Redvers[34]	2020	Multiple	The authors
Bradby[35]	2021	Australia, Aotearoa New Zealand	Multiple
Smith[36]	2021	Central America, Caribbean	39 Maya communities
Redvers[37]	2022	Multiple	Indigenous scholars, elders, practitioners, land and water defenders
Brand[38]	2023	Australia	Medical students
Carrington[39]	2023	Aotearoa New Zealand	Māori experts in human, animal or environmental health
Grande[40]	2023	Brazil	Indigenous university students
Redvers[41]	2024	Canadian Northwest Territories	Doctors

Figure 1: Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow diagram of study identification and screening.



COMPETING INTERESTS
Nil.

AUTHOR INFORMATION
Dr Jihae Abou El Ela: Rotorua Hospital, Paediatric Surgery, Rotorua, Bay of Plenty, New Zealand.
Mercedes Mudgway: Starship Children's Hospital, Paediatric Surgery, New Zealand.
Professor Niki Harré: The University of Auckland, The School of Psychology, New Zealand.
Dr Jane Thomas: Starship Children's Health, Anaesthesia, Auckland, New Zealand.
Dr James Hamill: The University of Auckland, Paediatrics, Auckland, New Zealand.

CORRESPONDING AUTHOR
Dr James Hamill: The University of Auckland, Paediatrics, Auckland, New Zealand.
E: jham011@aucklanduni.ac.nz

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Breast density reporting in Aotearoa New Zealand: policy imperatives and research priorities

Avisak Bhattacharjee, Fay Sowerby

ABSTRACT

Breast density influences both breast cancer risk and the sensitivity of mammographic screening. Several countries routinely notify women of their breast density in community-based screening programmes and provide guidance directly or through general practitioners. In contrast, BreastScreen Aotearoa (BSA) does not currently notify breast density to women, resulting in limited awareness and raising concerns relating to equitable care, patient autonomy in decision making, trust in health professionals and uncertainty regarding clinical pathways. Although the recent Health New Zealand – Te Whatu Ora technical review provides a comprehensive evidence summary and identifies areas for further investigation, policy progression has not occurred as anticipated. An implementation timeline, governance responsibility, communication planning and culturally responsive approach have not yet been specified. Although emerging evidence suggests that artificial intelligence may offer more consistent and reproducible breast density assessment than radiologists, planning for its integration has not been outlined. Research from the comparable settings suggests that misunderstanding, rather than notification itself, drives anxiety. This highlights the importance of communication design, health literacy considerations and primary care readiness. Ethical considerations around transparency and informed decision making remain relevant for screening equity. Addressing the implementation barriers is now crucial, and a coordinated and equity-driven approach is required to inform future policy on breast density notification.

Breast density reporting within community-based breast screening has drawn significant attention in the scholarly literature. The practice of reporting to women about their breast density has been recognised as encompassing both potential benefits and harms. Despite these recognised complexities, many breast screening authorities—for instance, those in the United States of America (USA),[1] Canada[2] and Australia[3]—have adopted policies to notify women of their breast density status within community-based screening settings. Additionally, the European Society of Breast Imaging has issued recommendations encouraging member countries to inform women about breast density during breast screening.[4] A recent technical review of breast density in cancer screening by Health New Zealand – Te Whatu Ora has outlined the country's current position on breast density reporting within cancer screening, highlighting the practical challenges faced domestically.[5] This comprehensive report manifested that the evidence needs at a system level relate to workforce capacity, supplemental imaging access and infrastructure readiness. This view highlights persisting implementation gaps that emphasise the absence of timeliness, governance accountability, communication strategies and policy progression.

Breast density refers to the proportion of fibroglandular and connective tissue that appears as white and bright area of breasts on a mammogram, in contrast to the darker appearance of fatty tissue.[6] It matters principally for two reasons. Firstly, it is a strong independent risk factor for breast cancer and, subsequently, high breast density can mask a tumour on a mammogram, thereby reducing the modality's diagnostic sensitivity. Breast density is routinely classified in four categories, as outlined in the fifth edition of Breast Imaging Reporting and Data System (BI-RADS) for mammography proposed by the American College of Radiologists.[7] Among them, BI-RADS a/b (entirely fatty/scattered areas of fibroglandular tissue) are grossly classified as low density and BI-RADS c/d (heterogenously dense/extremely dense) are labelled as high density. Despite mammography's widespread use as a primary breast cancer screening tool globally, it is concerning that its sensitivity is inversely proportionate with increasing breast density. For example, the sensitivity of mammography declines from approximately 84% in

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heterogeneously dense breasts (BI-RADS c) to about 64% in extremely dense breasts (BI-RADS d).[1]

Breast density reporting policy in Aotearoa New Zealand

Current policy of BreastScreen Aotearoa (BSA) is to not notify women about their breast density within the community-based screening programme.[8] Established in 1998, BSA initially targeted women aged 50–64 years for biennial screening, subsequently expanding the eligible age range from 45–69 years in 2004.[9] The screening age is being progressively extended from 69 to 74 years across New Zealand since October 2025.[10] Additionally, BSA depends on double-reading by two independent radiologists, rather than employing artificial intelligence (AI) based mammography tools for reporting.[5] While this approach provides the benefit of expert human judgement, it may also introduce subjectivity into assessments both within and between observers,[11,12] including the evaluation of breast density. These may limit standardisation achievable with automated systems. Recent evidence from a large-scale longitudinal cohort demonstrates that AI systems generate markedly more consistent BI-RADS breast density assessments than radiologists, with high accuracy and inter-observer variation.[13,14] Additionally, it is evident that AI combined with radiologists is capable of reducing workload by 38% and ensuring a productivity gain.[15] A recent Harvard University study has confirmed AI tools' superiority in determining interval breast cancer, claiming that AI tools successfully identified approximately one-third of interval breast cancers that were initially missed during routine screening by human judgement.[16] Interval breast cancers are diagnosed between screening rounds after a negative screening, which shows biological aggressiveness at the time of detection.[17] These cancers are classified based on mammography and ultrasonography findings into several categories: 1) true interval cancers, which show no signs on prior screening mammograms, 2) occult carcinomas, with no suspicious findings on both screening and diagnostic mammograms (often detected by supplementary imaging like ultrasound), 3) minimal signs, which present subtle changes retrospectively, visible but not initially recognised, 4) false-negatives due to reporting errors, where cancers were overlooked during screening, and 5) false-negatives due to technical errors, involving inadequate imaging quality or positioning during screening.[18] BSA is progressing a study involving AI as a second reader together with AI research to better understand how AI tools may be integrated into mammographic reporting.

To minimise the incidence of interval breast cancers by developing awareness among women, breast density reporting has been introduced into community-based screening in several countries. Consequently, supplemental imaging is advised to the women with highly dense breasts in a plethora of community-based screening settings. Evidence indicates that supplemental screening for women with dense breast tissue—for instance, contrast-enhanced mammography, ultrasonography and magnetic resonance imaging—have already shown increased cancer detection rates, earlier detection of cancer and decreased rate of interval cancer.[5] The current position of the Royal Australia and New Zealand College of Radiologists is to support the notification of breast density in all mammographic assessments.[19] However, introducing breast density notification and subsequent arrangement of supplemental imaging for women with high breast density in New Zealand would likely impose significant additional demands on the screening infrastructure, with potential implications for resource allocation, workforce capacity and overall system sustainability.[8,9] Considering different challenges relating to consumers and resource management, BSA is still not routinely incorporating breast density reporting into community-based screening, although they recommend the referral of women with high breast density and co-existing strong family history of breast cancer or pathogenic variants for additional medical support outside their programme.[20] Indeed, a transition timeline or framework for breast density reporting has not been specified by BSA. However, witholding breast density information from women limits their autonomy and right to shared decision making about their breast health. Moreover, this policy also undermines trust and equitable care.[6] In contrast, women paying for their private mammogram might receive this information.[21] Therefore, the dichotomy between BSA's omission and the private sector's selective action may contribute to inequity unless a national, co-ordinated approach to breast density reporting and follow-up is implemented.

Breast density reporting challenges and implementation gaps

BSA continues to face critical questions regarding

the appropriate approaches to breast density notification and management.[5] New Zealand's existing guidance and decision making concerning breast density notification is substantially depending upon the research literature based in Australia, the United Kingdom and the USA. However, the population demographics for New Zealand differ significantly from those countries as a sizeable proportion of the women in the target age group represent Māori and Pacific women who have differing traits to Europeans and Asians. This distinct ethnic composition underscores a clear need for local research that captures the real-world perspectives, understanding and informational needs of New Zealand women regarding breast density measurement and reporting. Generating robust evidence tailored to the New Zealand context will be essential for informing equitable, culturally responsive breast screening policy and practice in the future. To mitigate these gaps and challenges, comprehensive studies in relation to current understanding of women from different cultural backgrounds are recommended as it is not clear what New Zealand women know about this risk factor.

To understand breast density, women exhibit diverse preferences for sourcing information.[22] A recent study indicated that healthcare providers (71%), online resources (14%), friends and family including colleagues (14%), print media (8%), patient advocacy groups (6%), electronic media (3%) and social media (2%) are the principal sources of breast density information for women.[23] However, understandability and readability of available online resources are of critical concern. Moreover, misconceptions might arise due to improper comprehension of breast density. This diversity of understanding is already observed among different racial/ethnic backgrounds and literacy levels.[24] Therefore, information available to women may at times lack clarity or consistency, potentially affecting comprehension. Indeed, there is a paucity of research about comprehensive assessment of the accuracy, understandability and readability of the currently available New Zealand online resources specific to breast density. A recent Australian study confirmed that average grade reading level across 42 websites displaying breast density information was 12.4.[25] Regrettably, the readability of BSA and Breast Cancer Foundation New Zealand websites were grade levels 14.9 and 13.1 respectively, which are way above the recommended grade level 8. Additionally, existing online resources in New Zealand are barely successful in explicit display of common misconceptions and key facts statistics. Considering these circumstances, there is a pressing requirement to evaluate existing breast density information resources in New Zealand.

There is a concern that reporting breast density to women during screening might escalate their anxiety. In this context, the latest Australian study revealed that there are no significant differences of heightened anxiety between the groups of women with high and low density. This research utilised the highly reliable and validated psychological tool titled the State-Trait Anxiety Inventory.[26] Moreover, it was also evident in this study that women exhibited escalated anxiety even after knowing that they belong to a low breast density group. This was the first study that showed that low density status could also escalate the anxiety if there is lack of perfect understanding about breast density. Therefore, further research is required to understand New Zealand women's responses to receiving density information. Although the technical review recognised this need, an implementation timeframe has not been established and operational responsibility has not been defined. Moreover, it remains necessary to assess women's current opinions regarding the absence of breast density notification, as well as the psychological, informational and behavioural impact of disclosing such information. This approach will provide critical data to guide policymakers in aligning notification strategies with the needs and preferences of New Zealand's diverse and distinct population.

Additionally, communication of complex information like breast density is always challenging. It is important to know what could be the best way to report breast density. BreastScreen Western Australia generates a letter to women with high density (category c and d) incorporating the information about the masking effect, sends educational material and advises them to consult their general practitioners (GPs) for the next steps.[6] On the contrary, all participants in BreastScreen South Australia irrespective of density status (category a to d) receive density information with mammogram findings, and a fact sheet explaining its impact.[27] Similar courses of action are also taken by BreastScreen Victoria and New South Wales.[26] However, only BreastScreen Western Australia and BreastScreen South Australia directly notify the GPs of their clients about breast density. To notify both the clients

and their GPs is good practice and ensures a duty of care. A USA study confirmed that breast density notification letters are usually written at reading levels higer than recommended for the greater population.[28] Moreover, the actual understandability of the content is not standard, with scores ranging from 11% to 33% based on formal assessment reflecting poor clarity and comprehension.[28] This indicates that a substantial proportion of participants are not fully informed about the implications of their breast density status, highlighting gaps in communication and information delivery. Therefore, an important recommendation is to structure the letters with the best readability and understandability using simplified language and keeping the content at grade 7 and 8 readability. In this way, equitable communication can be ensured by designing the materials to make them understandable for women with wide spectrum of literacy status. Additionally, the content of the letter may be designed considering the women's cultural and ethnic backgrounds—for instance, Māori and Pacific cultural content can be incorporated to make it more familiar and interesting for them. Therefore, a pilot study can be planned following the footsteps of BreastScreen South Australia, where they reported breast density to their consumers in three centers. Thereafter, they announced the breast density reporting policy for all women, which is based on their study outcome.[29]

The clinical management and consultation of women with high breast density by GPs remains an area of ongoing development and uncertainty. However, recent research from the University of Adelaide provides important insights into how breast surgeons address these issues in practice.[30] To begin in New Zealand there is a need to assess GPs' current understanding of breast density and how best to manage this cohort.

Conclusion

Breast density notification is increasingly embedded within international breast screening policy due to dual relevance for breast cancer risk and reduced mammographic sensitivity. While Health New Zealand – Te Whatu Ora's technical review outlines evidence requirements and identifies areas for further evaluation, a persistant implementation gap remains. There is no defined timeline, assigned governance leadership for implementation or policy pathway to progress density notification. Addressing implementation barriers is crucial to ensure that New Zealand women are not left without transparency regarding their breast density status. A co-ordinated, ethically grounded and equity-focussed approach is important to advance policy deliberation and align New Zealand with contemporary global breast screening practice.

COMPETING INTERESTS
AB is a lecturer/professional practice fellow of the School of Biomedical Science, University of Otago (February 2025–present), a visiting academic fellow, Breast Biology and Cancer Unit, Discipline of Surgery, The Queen Elizabeth Hospital and Basil Hetzel Institute, University of Adelaide, Australia (September 2025–present), a member of the Australasian Epidemiological Association (October 2022–present), an ex-EC member of Early and Mid Career Research Committee, Robinson Research Institute, Adelaide, Australia (February 2022–April 2024), an ex-EC member, Basil Hetzel Research Institute, Adelaide, Australia (July 2023–June 2024) and an ex-president of the Health Science Postgraduate Student Association, University of Adelaide (2022–2023 committee).
FS is a member of the national BreastScreen Aotearoa Action and Equity Group (2022–present), a chair of Breast Cancer Cure (2009–present; funder of breast cancer research), a co-lead of Against Genomic Discrimination in Aotearoa (2022–present) and a secretary and member of the Breast Cancer Aotearoa Coalition (2014–present).

AUTHOR INFORMATION
Avisak Bhattacharjee: Otago Medical School, University of Otago, Dunedin, Aotearoa New Zealand.
Fay Sowerby: Breast Cancer Cure, Breast Cancer Aotearoa Coalition, Auckland, Aotearoa New Zealand.

CORRESPONDING AUTHOR
Avisak Bhattacharjee: Otago Medical School, University of Otago, Dunedin, New Zealand.
E: avisak.bhattacharjee@otago.ac.nz

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Addressing significant inequity

John W Pickering, Anna P Pilbrow, Allamanda Fa'atoese, Laura Joyce

ABSTRACT

Achieving equity in health research requires sub-groups to have meaningful, if not equal, explanatory power, ideally through similiar sample sizes. Obtaining equal sample size, though, is often not possible. Small sub-group sizes increase the risk of false conclusions being drawn, which may reinforce inequities if results are misinterpreted (e.g., saying there is a difference between study arms when there is not and, conversely, saying there is no difference when there is). Here we provide examples of common pitfalls and potential considerations to guide researchers, reviewers and editors when analysing and interpreting sub-group data. We propose that researchers focus on presenting effect sizes and confidence intervals rather than statistical significance.

Health research in Aotearoa New Zealand shows persistent inequities. Within the context of national health surveys, there has been recognition that for Māori this is at least in part due to sample size disparities of cohorts that did not give "equal explanatory power". Equal explanatory power was defined as "Māori statistical needs as having equal status with those of the total New Zealand population".[1] Equal explanatory power is achieved by equal sample sizes for Māori and non-Māori and has been framed as a right for tangata whenua and a Te Tiriti o Waitangi/the Treaty of Waitangi obligation. The authors also identified equal explanatory power's corollary "equal analytical power": the power of definition, explanation and meaning.

We believe the right for equal explanatory power and equal analytical power applies to all health research within New Zealand and for all cohorts based on sex, gender, ethnicity and age. Some journals have called for action to address demographic inequity by reducing enrolment imbalances or conducting sub-group analysis.[2] The recognition of sex- and ethnicity-based differences in pathophysiology, biochemistry and clinical outcomes highlights the importance of the inequity issue.[3,4]

Researchers often face small or undercounted minority sub-groups,[5] and equal explanatory power will not always be possible. Here we show that some common sub-group or small sample statistical analysis practices risk increasing inequities and provide practical steps to reduce them.

How small sample sizes lead to inequity

Most healthcare studies use sampling methods that may result in p-values that fail to reflect the true difference between groups in a population. This includes the use of exclusion criteria that systematically exclude older people, pregnant women or other minority groups. Even if the cohorts were true random samples, they may misrepresent the overall population due to chance, so any difference observed may be erroneous. This is more likely for small cohorts and sub-groups. Small cohorts are therefore less likely to represent the underlying population than large cohorts (i.e., less likely to be externally valid). The findings for small cohorts may erroneously support conclusions that lead to either over- or under-investigation or treatment of the sub-group involved.

The smaller the sample size, the less likely to observe a rare event (e.g., an adverse reaction). For example, for a sub-group comprising 20% of the overall sample, the likelihood of a rare event would be five times smaller than for the overall sample. The rare event rate in the small sub-group may truly be much higher than in all patients (e.g., two to three times), but it will still be more likely to be missed. In some cases, the size of a sub-group is determined by the chosen analytical methods, particularly where continuous variables are clustered into groups. Analysis by age group or by discretising a measurement like systolic blood pressure or a biomarker is common, seemingly to aid interpretation of results. Such discretisation is effectively extreme rounding. This causes loss of information, resulting in less power to detect real relationships and increased probability of false positives.[6] Where appropriate, discretisation should be avoided and continuous variables should be treated as continuous.

Even where the estimated effect size is the same in all patients as in a sub-group, the p-values and confidence intervals will be larger in

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the sub-group. The commonly applied notion of statistical significance, usually defined as p<0.05, along with the misinterpretation of the meaning of p-values, can lead to inequity. A common example is when a "statistically significant" association between two variables in the overall study population is re-analysed in a sub-group (e.g., Indigenous sub-population) giving a p-value >0.05, which results in a conclusion of "no association". Using a p-value threshold of 0.05 as a prompt for interpretation of a sub-group analysis is based on two common mistakes. The first is to forget that the null hypothesis is being tested. The assumption of the null hypothesis is that there is "no association". Therefore, one can never conclude "no association" but merely recognise the p-value *along with the associated effect size* as quantifying the evidence against the null hypothesis. A correct interpretation is that the p-value is the probability of observing the effect size or greater *if the null hypothesis is true* and given all the assumptions of the statistical methods used. The second mistake is assuming that the arbitrary threshold of 0.05 represents a clinically significant difference, which results in the erroneous conclusion that there is "no difference". This dichotomisation, simply, does not make sense. Indeed, the difference in probability between 0.055 and 0.045, say, could well be down to one or two patients when the sample size is small. The same mistakes are made by interpreting 95% confidence intervals by whether they cross the value representing the null (e.g., a hazard ratio of 1, or a difference in proportions of 0). A concomitant error is interpreting p-values slightly above 0.05 as demonstrating a "trend"; they do nothing of the sort.[7]

Good practices for handling small sample sizes

There are no magic statistical bullets by which to handle small sample sizes, but there are better practices in study design and analysis that could at least reduce the possibility of drawing erroneous conclusions and introducing or perpetuating inequities and perhaps provide meaningful explanatory power where equal explanatory power is not possible. We have outlined some examples in Table 1.

Collecting more data to achieve the ideal of samples with equal explanatory power may not always be possible, although co-design methods[8] to improve sample sizes for specific sub-groups may help overall numbers and/or ensure the

Table 1: Practical tips to improve equitable interpretation of data in small cohorts or sub-groups.

Do	Do not
1. Determine *a priori* the necessary sample size for a meaningful clinical difference in the sub-group.	1. Artificially create small groups (e.g., age groups).
2. If possible, collect more data.	2. Use "statistical significance" or interpret based on a confidence interval "crossing" the null value.
3. If collecting more data is not feasible, ensure that important sub-groups are purposively over-sampled.	3. State "no difference" based on p-values (no difference is the null hypothesis assumption).
4. Work with sub-group populations to improve representation.	4. Interpret p-values slightly above 0.05 as demonstrating a "trend".
5. Use single sided tests if the hypothesis is single sided (it commonly is!).	5. Adjust for covariates when n is small (overfitting).
6. Only look for differences between sub-groups if there are biologically/sociologically plausible reasons for differences.	6. Speculate when evidence is weak.
7. Report results with a measure of uncertainty (e.g., confidence interval).	
8. Be realistic regarding at what point your sample size becomes too small to be informative. Consider qualitative over quantitative studies for small n.	
9. Highlight the limitations of small n.	

sub-group is truly represented. This may include "over-sampling", which means the targeted sub-group will be represented beyond the proportion in the underlying population. Another method to improve explanatory power may be to use one-tailed instead of two-tailed tests.[9] Often, we are interested in only one side of the null hypothesis —"did the intervention help?"—rather than "did it help or hinder?". The effect of using a one-tailed test instead of a two-tailed test for a given sample size is the equivalent of having a 20% larger sample size (at the same alpha and power for the sample size calculation). However, this is not a universal panacea, and there will be situations where two-sided testing remains appropriate.

Consideration should be made at a study design stage of whether there is any biological or sociological plausibility for a difference between sub-groups. If so, this becomes a priority and should drive recruitment. On the other hand, if there is no *a priori* plausibility and the size of sub-groups is small, then one is only justified in doing a sub-group analysis if a very large difference in effect size would have major implications, as only a very large effect size difference could be detected. This does not preclude reporting on raw data from sub-groups that may aid future meta-analyses from multiple studies.

Perhaps the most important consideration for researchers, reviewers and editors is not to use the concept of statistical significance at all. While an α of 0.05 (usually offered with no justification!) along with a power (1-β) and clinically meaningful effect size is often used in power calculations, this does not mean one must define p<0.05 as "statistically significant". Indeed, as many have noted, this has led to false interpretations of results,[10] along with "p-hacking" and the failure to publish when p>0.05.[11] Statistics is a young science and, as such, it changes. Because of the prevalence of using the arbitrary p=0.05 threshold, in 2016 the American Statistical Association released a statement on p-values that included: "*The widespread use of 'statistical significance' (generally interpreted as 'p≤0.05') as a license for making a claim of a scientific finding (or implied truth) leads to considerable distortion of the scientific process.*"[12] New Zealand health statisticians have since argued that "*We should be challenging ourselves to write and interpret results from studies without using the words 'statistically' or 'significant.'*"[13] Leading members who formulated the American Statistical Association's statement have taken the additional step of recommending abandonment of the term "statistical significance".[14] We believe that if New Zealand researchers and journals were to take that step, it would inhibit the perpetuation of some inequities and potentially prevent the emergence of new ones. This will require researchers to invest some time into better understanding and presenting the meaning of p-values and confidence intervals, particularly to avoid misinterpretations.[15]

It is common to use analysis techniques that adjust for covariates. Such multivariable analysis is good practice. However, if sample sizes are small with few events, then there is danger of overfitting. The rules of thumb commonly used for binary outcome events are that 10 or 15 events in the sample per variable are needed. That is, if the sub-group has only 19 events, then one should not have any covariates in the model and stick to the simple univariate analysis. There are, though, more sophisticated methods being developed for determining the minimum number of events per variable for a variety of statistical models.[16]

Two practices to aid interpretation and presentation of results may reduce the risk of unintended conclusions being drawn from them: first, always present p-values in relation to the effect size; and second, preferably present the effect size with a confidence interval and provide an interpretation of the confidence interval. Thus, instead of stating (erroneously) "there was no difference between A and B, p=0.06", state "the difference between A and B was 7% (95% CI [confidence interval]: −1% to 15%), indicating a plausible reduction in <the outcome> of 1% but equally plausible an increase in <the outcome> of 15%". It is then helpful to the reader to indicate if either of these plausible values is clinically meaningful. Second, if p-values are to be used, and in particular if they are to be compared, then the concept of s-values (binary surprisals) may aid researchers' interpretation of results.[17] An s-value is just the $-\log_2$(p-value), so for p=0.6 s=4.1. Its beauty is that it can be interpreted as "how surprised would I be if a coin was fair to get s-value heads in a row?", and that unlike the p-values, the difference between two s-values is consistently indicative of the difference in evidence against the null hypothesis (Box 1).

In summary, significant inequity in health research exists, but this inequity could be reduced by adopting better interpretation of statistics, study design and analysis, which includes intentional decision making as to whether sub-group analyses should be performed or not.

Box 1: A worked example of how to use s-values to better understand the evidence given by p-values.

Box 1.

Binary surprisals (s-values), calculated as $-\log_2$(p-value), can be used to compare the difference between p-values. For example, if p1=0.10 and p2=0.025 the difference $\Delta p=0.075$, wheras $s1=-\log_2(0.1)=3.3$ and $s2=-\log_2(0.025)= 5.3$ with $\Delta s=2$, or as much evidence as two heads in a row is against the coin being fair.

But, if p3=0.15 and p4=0.075 then $\Delta p=0.075$ again, but s3=2.7 and s4=3.7 which is a $\Delta s=1$, or as much evidence as is contained in one correct called coin toss.

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AUTHOR INFORMATION
Professor John W Pickering, PhD: Christchurch Heart Institute, Department of Medicine, University of Otago Christchurch; Department of Emergency Medicine, Christchurch Hospital, Christchurch, New Zealand.
Associate Professor Anna P Pilbrow, PhD: Christchurch Heart Institute, Department of Medicine, University of Otago Christchurch, Christchurch, New Zealand.
Dr Allamanda Fa'atoese, PhD: Christchurch Heart Institute, Department of Medicine, University of Otago Christchurch, Christchurch, New Zealand.
Dr Laura Joyce, MBChB: Department of Surgery and Critical Care, University of Otago Christchurch, Christchurch, New Zealand; Department of Emergency Medicine, Christchurch Hospital, Christchurch, New Zealand.

CORRESPONDING AUTHOR
John W Pickering, PhD: Christchurch Heart Institute, Department of Medicine, University of Otago Christchurch; Department of Emergency Medicine, Christchurch Hospital, Christchurch, New Zealand.
E: john.pickering@otago.ac.nz

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A decade of an online clinical guidance platform for hospital clinicians: they use it, they like it and it makes a difference

Michael Ardagh

Hospital HealthPathways (HHP) is an online clinical guidance platform for hospital clinicians in Waitaha Canterbury, and it turned 10 years old in November 2025. In those 10 years it has become inextricably woven into the fabric of the Waitaha Canterbury health system.

What is it?

It followed the successful precedent of Community HealthPathways (or simply HealthPathways, as it was known then; CHP), which went live in 2008 as a clinical guidance platform for general practice (primary care) teams. CHP was an outcome of a project largely based around facilitated meetings among general practice representatives and particular groups of specialists to gain a common understanding of each other's perspectives regarding access to specialist hospital services for particular patient types—what was going well and what wasn't. Ultimately, the meetings arrived at an agreed list of "what we can do tomorrow" actions to improve what wasn't going so well. A clear and recurrent stated need was to make the agreements visible to relevant clinicians. HealthPathways was created and soon grew well beyond defining the interface between community and hospital care to include a local, authoritative collation of guidance for the management of many hundreds of conditions. It became the foundation for evidence-informed, locally agreed "how we do it around here" advice. Evidence mounted for its value, including its use for implementing and embedding new models of care for numerous conditions from colorectal cancer to mental health.[1–15]

Based on these results, and results from other health systems that adopted HealthPathways, and taking into account the cost associated with the provision of the platform, technical writing and the time of local clinicians as pathway writers (clinical editors), modelling of a CHP programme for a population of 5 million people over a 5-year time frame estimated NZ$9.76 (New Zealand dollars) of potential cost savings for every $1 invested.[16]

Other health systems signed up to develop their own sites, using the Waitaha Canterbury content initially, and localising it for their own context. Now there are HealthPathways sites in over 50 health regions, covering all of Aotearoa New Zealand, most of Australia, increasing numbers in the United Kingdom and, more recently, Canada. Each of these regions explicitly shares content to promote both standardisation of care (particularly among regional groups, such as New Zealand, Wales and the states of Australia) and to share the workload. This collaborative "network" is called the HealthPathways Community, and is enabled by the structural and technical hub provided by Streamliners, a social enterprise that is owned 20% by the New Zealand government and 80% by the Joined Up Systems Trust (https://justnz.org)—a charitable trust with their stated purpose "*to encourage and support the integration of health and social care services*".[17]

Meanwhile, in the Waitaha Canterbury hospitals, particularly Christchurch City Hospital—which provides secondary care for the city and tertiary/quaternary services for much larger catchments—clinicians were using a locally produced clinical guidance book known colloquially as the Blue Book. This book had evolved over generations and was a well-loved and much-used local resource. However, the Blue Book was getting big, with more content being added over time. It relied on mostly voluntary input from specialists, usually in their own time. The content was becoming more difficult to maintain and, ultimately, some who had shouldered the significant burden of this work retired from the role. Willing replacements were not easily found.

The year was 2014 and work began to replace the Blue Book with a hospital version of HealthPathways, using Streamliners and the same layout, style and methodology for pathway production. This site became "Hospital HealthPathways" (HHP), necessitating the re-branding of the sites for general practitioners as "Community HealthPathways" (CHP). It went live for the end user audience in November 2015.

HHP is written for hospital clinicians—particularly (but not only) junior doctors and other doctors working outside their specialist area of expertise, and with information, and links to information, for nursing and allied health staff.

Canterbury HHP has about 900 live pages, more than 400 of which are clinical pathways. The site also has many resource pages and placeholder pages, linking the end user to pathways in CHP or other useful documents on the intranet or internet. Request pages, advising how to make referrals, get advice and how to access other services for the patient, are a crucial component, both for end users and for the health system to define access criteria and relevant processes.

A foundation objective is that it provides "single-source, common format" guidance—the "single-source" site for clinical information for hospital clinicians, with a common format that makes it familiar and easy to follow.

It contains evidence-informed clinical guidance and local process guidance: how to get things done and how we do it around here. The concept of "evidence-informed" is that it is the translation of evidence (which is often not definitive or might give options) into locally agreed guidance for what the clinician should do in their context. The process guidance is particularly important. It tells the end user how to get things done—who they need to talk to and how they contact them, the steps needed to get a computed tomography scan, for example, or add a patient to the theatre list and so on. The local consensus on clinical management and the process guidance for the local context is achieved by local "clinical editors" working with local specialists (subject matter experts), and is a popular feature not provided by many clinical guidance platforms. In addition, because it is "localised" with the input of local clinical leaders, it has authority when there might be debate about management options.

HHP uses the same methodology as CHP and works closely with CHP when developing material. The close collaboration both reduces workload (and cost) and enhances health system integration; the patient journey is "joined up" by this collaboration, and all clinicians share a common view of that journey. A foundation belief in this relationship is that the combination of HHP and CHP is worth more than the sum of its parts. In addition, partner guidance sites for allied health clinicians (Allied HealthPathways) and for patients (HealthInfo) have enhanced the opportunities for collaboration and integration.

The combination promotes integration of care—community to hospital referral, hospital to community discharge planning, and within the hospital it promotes standardisation of care—agreed ways of doing things among relevant in-hospital specialties.

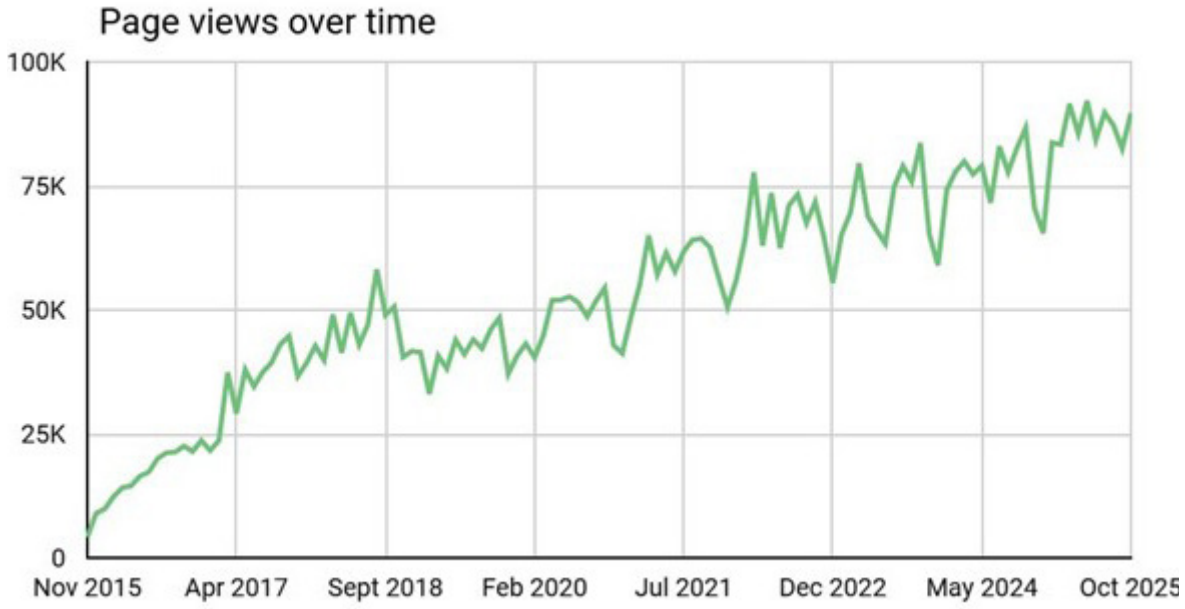
Hospital crowding and delays in care are increasingly under the spotlight of time-based performance targets, such as the "Shorter Stays in the Emergency Department" target in New Zealand and the "National Emergency Access Target" in Australia. In Waitaha Canterbury, HHP is seen to promote efficient patient flow by establishing agreed process decisions, such as criteria for direct admission to acute assessment wards, agreed scopes of investigation for different departments (e.g., emergency department [ED] vs general surgery), agreed patient disposition decisions (e.g., gynaecology vs general surgery, or orthopaedics vs general medicine) and clearer guidance about the transfer of care back to the community. It is explicitly seen as a tool in the toolkit for addressing overcrowding and patient flow.

They use it

In 2019, a survey of doctors and medical students at Christchurch hospitals showed that almost all recipients (98%) use HHP at least once a week, with 72% saying they used it every or most working days, and particularly on acute days and after-hours (in: survey commissioned by the author, 26 July 2019). In August 2025, another survey of junior doctors had 95% strongly agree and 4% agree (99% total agreement) with the statement that they use HHP frequently to treat and manage patients (in personal communication: resident medical officers, 8 August 2025).

Figure 1 shows the total page views on the HHP site per month since the site went live in November 2015, demonstrating the inexorable rise with a current rate of more than 75,000 page views per month.

Figure 1: Hospital HealthPathways page views per month.



They like it

The 2019 survey mentioned above had 101 respondents from a denominator of approximately 550 junior doctors. (in: survey commissioned by the author, 26 July 2019). It was commissioned by the Waitaha Canterbury health pathways team and was distributed by the Canterbury District Health Board via its mailing list. In addition to using HHP regularly, 96% of respondents agreed or strongly agreed that it made their job easier, 92% agreed or strongly agreed that it improved the care they provided to their patients, 96% agreed or strongly agreed that it is easy to use in clinical practice, 97% agreed or strongly agreed that it is clear and easy to understand and 97% agreed or strongly agreed that it contains high-quality information.

Free-text responses were numerous and very positive: for example, "*It's an incredibly useful resource that's been invaluable in day-to-day practice, especially as a junior doctor, and especially out of regular working hours when seeking the advice of senior colleagues is potentially less easily accessible.*"

The August 2025 survey had different origins. Cost-saving objectives saw a Health New Zealand – Te Whatu Ora "reset", which was perceived to threaten the ongoing viability of HHP. With this threat apparent a survey was constructed and distributed by members of the local junior doctor population, with no involvement, nor even awareness, from the HealthPathways leadership team. Within 24 hours the survey received 112 responses and was submitted. As detailed above, the responses indicated that HHP was used extensively (in personal communication: resident medical officers, 8 August 2025). In addition, 96% strongly agreed and 4% agreed (total 100% agreement) that the content and quality of HHP is of high value, 92% strongly agreed and 7% agreed (total 99% agreement) that HHP information increased efficiency as a doctor and 59% strongly disagreed and 38% disagreed (total 97% disagreement) that there are suitable alternatives to HHP for Christchurch Hospital. Again, the free-text responses were numerous and positive but also demonstrated a depth of feeling associated with the threat of loss of HHP. For example: "*It is practically impossible to overstate the value of this resource to my daily work. It takes an exceptional set of circumstances to move me to fill in an online survey, but this is a hill I'm willing to die on.*"

It makes a difference

HHP has not been subjected to a large amount

of research and when it has been it is difficult, in a complex and continually evolving system, to attribute outcomes to specific interventions such as HHP. The junior doctors' strong perceptions of the value of HHP, demonstrated in the two surveys discussed above, are very important. In addition, the evidence attesting to the value of CHP presented earlier can be extrapolated to indicate a likely similar value for HHP. The following discussion will include some other research that has been done, both where there is good evidence for attribution and where HHP was a component of a bigger health system change process.

A postgraduate masters student studied HHP and, in particular, compliance with the Community Acquired Pneumonia (CAP) pathway,[18] and found that approximately two-thirds of patients presenting with CAP had an associated hit on the HHP CAP pathway within 4 hours of their presentation to hospital (implying clinicians were using the HHP pathway to manage patients with CAP) and presentation of the same clinical guidance for the management of CAP on HHP, compared to a previous clinical guidance format (the Blue Book), improved compliance with the guidelines and reduced variation in practice. Specifically, inappropriate use of amoxicillin and clavulanic acid, when amoxicillin was all that was required, showed a 9% absolute reduction of inappropriate use (from 75% to 66%).

A follow-up masters project[19] included concurrent interviews of clinicians managing patients with CAP to examine their reasons for compliance or non-compliance with the pathway. Unsurprisingly, about half of those who did not comply exactly with the pathway deviated for good reasons—the presentation was more consistent with another pathway (e.g., sepsis in adults or acute chronic obstructive pulmonary disease [COPD]) or there were pre-existing microbiology results to guide antibiotic choice. This "appropriate non-compliance" emphasised the role of HHP guidance in partnership with the clinician who applies the guidance according to their clinical wisdom.

A small but significant study showed clear attribution of HHP to the reduction of unnecessary tests. Addition of explicit advice (called a "practice point") regarding amylase blood tests on the pancreatitis pathway advised the end user that repeat amylase testing is usually not required as the utility of the test is for diagnosis and not for monitoring. This intervention improved compliance with amylase testing by an absolute increase of 13%, from 65 % to 78%.[20] (Note: amylase is no longer the recommended test for diagnosis of pancreatitis as lipase is preferred).

Although HHP was only a part of a new model of care for transient ischaemic attack (TIA; a new way of managing TIA with facilitated outpatient investigation and management), a revised TIA pathway on HHP was one of the vehicles for implementing and imbedding the change. The outcome was a 34% absolute reduction in hospital admissions with TIA (from 69% to 35%), with no increase in representations with ischaemic stroke (in personal communication: summary of research findings communicated by Dr Laura Joyce, 18 November 2025).

Similarly, a new model of care for atrial fibrillation (AF) was introduced with HHP assisting as an implementation and imbedding vehicle. The new "Rate-and-Wait" process introduced rate control, anticoagulation and discharge from the ED for review in an AF clinic the next day for delayed cardioversion if still in AF. Cardioversions in the ED dropped from 32 out of 182 AF presentations before the new process to six out of 178 after the new process. Total cardioversions (ED, cardiology or the AF clinic) dropped from 65 out of 182 presentations to 32 from 178 presentations after the new process. Total admissions as a hospital inpatient dropped from 79 out of 182 to 54 out of 178 with no increase in adverse events (ischaemic or bleeding events, re-presentations to hospital or death).[21]

Chest pain is a common presentation to EDs and the requirement to "rule out" acute coronary syndrome (ACS) traditionally requires a prolonged ED stay or admission to hospital to do two or more blood tests at least 6 hours apart. Consequently, a series of projects have been undertaken to iteratively introduce accelerated diagnostic pathways (ADP), which include clinical risk stratification and (ultimately) a single blood test, allowing prompt discharge of many patients with ACS adequately excluded. Again HHP, while not being the actual change in practice, assisted with both the implementation of change and imbedding the improved processes over many years. For more than 10 years of this research theme, while presentations to EDs have increased, ED length of stay and inpatient admission rates for these patients have decreased markedly, and the unnecessary admission numbers of patients to inpatient cardiology services, who ultimately prove not to have ACS, have reduced from nearly 1,400 per annum to about 400.[22]

Summary

HHP in Waitaha Canterbury is 10 years old. In its short life it has become "part of the furniture" with clinicians, particularly junior doctors, using it routinely. The evidence for benefit presented, although not definitive, is very positive. They use it, they like it and it makes a difference.

Beyond that, the passion evidenced in the recent survey of junior doctors who were faced with losing HHP is testament to the value we know it adds. Indeed, it is intuitive that a well-constructed, well-presented, easily accessible, authoritative, localised guidance suite, partnered with its community siblings, improves quality, efficiency, standardisation, integration and the wellbeing of both clinicians and patients.

If our future is governed with good sense and vision, the next 10 years should continue to realise the value of HHP in Waitaha Canterbury and ultimately throughout the motu.

COMPETING INTERESTS
MA is contracted as a clinical advisor for Hospital HealthPathways implementations worldwide with Streamliners, and is clinical lead for Hospital HealthPathways for the national HealthPathways programme.

CORRESPONDING AUTHOR INFORMATION
Michael Ardagh: Professor of Emergency Medicine, University of Otago Christchurch, Aotearoa New Zealand; Emergency Physician and Clinical Lead Hospital HealthPathways, Health New Zealand – Te Whatu Ora Waitaha, Aotearoa New Zealand; National Clinical Lead Hospital HealthPathways, Health New Zealand – Te Whatu Ora, Aotearoa New Zealand.
E: Michael.Ardagh@cdhb.health.nz

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Scurvy in a non–weight-bearing paediatric patient

Weisi Xia, Michaela Mullen, Ryan Johnstone

Scurvy, or hypovitaminosis C, was seen in sailors in the sixteenth to eighteenth centuries on long-distance voyages with restrictions on fresh fruit and vegetables.[1] Often thought of as a historic disease in high-income nations, it is seldom considered high in the differential diagnosis. Sporadic case reports in New Zealand have been published in the literature, but none in a paediatric population.[2,3] We present a case report of scurvy in New Zealand of a child presenting with undifferentiated limp with pathognomonic X-ray findings.

Case report

A 5-year-old boy with non-verbal autism spectrum disorder associated with restricted eating was seen in the orthopaedic clinic with the parents having noted significant discomfort and reduced motion of his left lower extremity and progressive non–weight-bearing status. Physical examination demonstrated non-specific tenderness and his left femur and knee with reduced range of motion. He was admitted for inpatient orthopaedic workup. The patient remained apyrexial with stable normal vital signs during this time.

Plain film imaging demonstrated abnormalities around his distal femur and proximal tibia physeal regions. Initial blood work demonstrated neutropenia with white blood cells (2.3x10^9/L), neutrophils (1.3x10^9/L). C-reactive protein was normal (<4mg/L). He proceeded to undergo magnetic resonance imaging (MRI) which demonstrated periosteal elevation of the distal femur and proximal tibia. Diffuse bone marrow signal was noted with hyperintense signal on inversion recovery sequences in the femoral and tibial metaphysis mirrored with hypointense signal on T1-weighted sequences. A differential of multifocal infection and chronic recurrent multifocal osteomyelitis was initially made.

Paediatric rheumatology and infectious diseases teams were consulted, and the patient was started on empiric intravenous cephazolin. Further clinical assessment elicited the patient had swollen, bleeding gums. A faint rash was also noted in his lower extremities (Figure 1). Further blood work was subsequently sent off for nutritional deficiencies, with low vitamin C (<1umol/L) eventually returning.

A detailed history revealed a diagnosis of autism with avoidant/restrictive food intake with a restricted diet consisting solely of chicken and biscuits, devoid of any vegetables or fruit. A presumed diagnosis of scurvy was made secondary to this restricted diet. The antibiotics were ceased and a nasogastric tube was inserted for regular feeding and vitamin supplementation. The patient made a rapid clinical improvement and was able to ambulate after 3 days of inpatient therapy. He was subsequently discharged with community nursing and dietician follow-up. Subsequent clinic reviews showed resolution of his rash and improvement with mobility.

Plain imaging was subsequently reviewed with a musculoskeletal radiologist, and several pathognomonic features of hypovitaminosis C were identified. Generalised osteopenia and cortical thinning were noted over the distal femoral and proximal tibial epiphyses. Subtle soft tissue shadowing in the distal femur (subperiosteal elevation) was also noted. Plain films demonstrate flaring of the metaphyses with Pelken's spurs at the tibial metaphysis (Figure 2). White line of Frankel present at the tibial and femoral epiphyses with Trummerfield zone present.[4] MRI shows marrow oedema around the knee metaphysis with irregularity of the growth plate, with surrounding periosteal and soft tissue oedema (Figure 3). MRI findings are not pathognomonic but when combined clinically aid in establishing the diagnosis.[5]

Discussion

Scurvy is a rare condition caused by severe vitamin C deficiency characterised by gingival bleeding, skin lesions, poor wound healing and bone abnormalities. This case demonstrates the importance of a dietary history as part of the clinical assessment, especially in at-risk populations with restricted eating such as in patients with autism and in the hospitalised elderly.[6] Early identification and treatment should be instituted

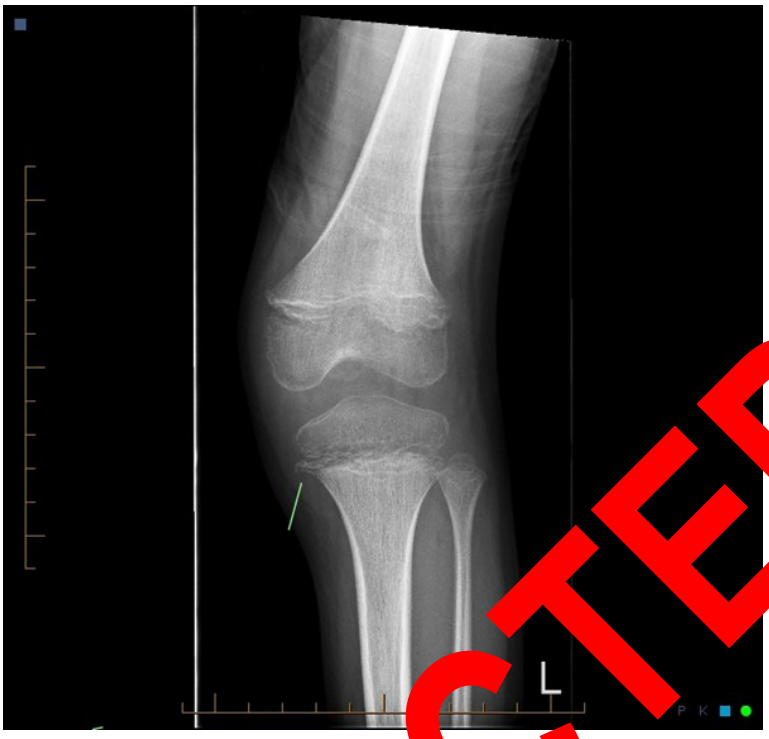
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as the treatment is relatively simple. However, these vulnerable groups with food selectivity may require ongoing long-term nutritional supplementation to prevent recurrence. The involvement of dietitians is especially useful in evaluation and education. Treatment is typically started empirically when suspected, and patients are expected to make a full recovery.[7] Although rare in high-income countries, case studies have suggested it is not a historical disease.[8] The clinician should consider hypovitaminosis C as a rare differential diagnosis in at-risk children. This case highlights the effectiveness of an interdisciplinary approach to a challenging diagnosis with an astute clinical assessment and a high index of suspicion when evaluating children with non-specific lower limb limp.

Figure 1: Faint petechiae rash in bilateral lower extremities.



Figure 2: X-ray of a left knee anteroposterior view. Green marking is indicative of a Pelkin's spur.



Note the alternating lucent and sclerotic lines within the femoral ar ial metap es. White line of Frankel present at both the distal femoral and proximal tibial epiphyses with Trum feld zones p t.

Figure 3: Magnetic resonance imaging with short tau ersi ry (STIR) sequences of the left lower extremity coronal view. Marrow oedema seen in b ral dis moral and proximal tibial metaphyses. Mild surrounding periosteal and soft tissue oedema, pr minan along lateral aspects of the distal femur. Mild irregularity and widening of growth plates of the dist mur



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AUTHOR INFORMATION
Weisi Xia, MBChB, PhD: Orthopaedic Registrar, Department of Orthopaedic Surgery, Hutt Valley Hospital, Wellington, New Zealand.
Michaela Mullen, MBChB: Orthopaedic Registrar, Department of Orthopaedic Surgery, Hutt Valley Hospital, Wellington, New Zealand.
Ryan Johnstone, MBChB, FRACS: Orthopaedic Surgeon, Department of Orthopaedic Surgery, Hutt Valley Hospital, Wellington, New Zealand.

CORRESPONDING AUTHOR
Weisi Xia, MBChB, PhD: Orthopaedic Registrar, Department of Orthopaedic Surgery, Hutt Valley Hospital, Wellington, New Zealand.
E: weisi.xia@middlemore.co.nz

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Laparoscopic retrieval of a large gastric trichobezoar

Yuen Liu, Binura Buwaneka Wijesinghe Lekamalage, Lucinda Jane Duncan-Were, David McGouran, Barnaby Blair Smith

A 16-year-old female with a background of trichotillomania presented with epigastric pain and nausea. An abdominal X-ray revealed a distended stomach with a speckled gas pattern, concerning for a bezoar, without obstruction (Figure 1). Gastroscopy demonstrated a large trichobezoar with a superficial gastric ulcer (Forrest class III). Given its size and density, chemical dissolution and endoscopic extraction were unsuitable.

The patient proceeded to theatre for laparoscopic-assisted removal. An anterior gastrostomy was made laparoscopically. Given the size of the specimen, a small midline laparotomy incision with Alexis O wound protector (Figure 2) was used to extract the large trichobezoar (Figure 3). The gastrotomy was closed with interrupted sutures using 2-0 Maxon. The postoperative course was uneventful. Follow-up gastroscopy at 8 weeks confirmed healing of the gastric ulcer.

Trichobezoars are rare gastric foreign bodies composed of ingested hair, occurring predominantly in young females with trichotillomania and trichotillophagia.[1,2] In some cases, there is post-pyloric extension (Rapunzel syndrome), with reported complications including obstruction, perforation and, less commonly, pancreatitis.[2,3] Because endoscopic removal is rarely successful unless the trichobezoar is small, surgical intervention remains the definitive treatment.[1]

Computed tomography (CT) is useful for evaluating large trichobezoars and suspected Rapunzel syndrome. In addition to confirming the diagnosis, CT defines extension and identifies associated complications, such as perforation, obstruction and intussusception, thereby guiding management and operative planning.[2,4] Gastric mucosal ulceration due to pressure-induced ischaemia is a recognised complication of trichobezoars,[1,2] and was present in this patient.

Complete removal of the trichobezoar should be ensured by running the bowel to the ileocaecal valve, as retained fragments or satellite bezoars have been reported to migrate and precipitate distal obstruction requiring reoperation.[1,5] For large trichobezoars, conventional laparotomy remains the most reported and reliable method for *en bloc* removal[1] and permits systematic inspection for satellites.[6]

Pure laparoscopy offers the advantage of smaller incisions, shorter hospital admissions and reduced complications.[7] However, for large trichobezoars, it often necessitates intragastric fragmentation with piecemeal extraction, which increases the risk of spillage and distal fragment migration with obstruction.[1]

In selected patients, a laparoscopic-assisted approach may represent a pragmatic compromise by isolating the gastrotomy to the mini-laparotomy incision and utilising a wound protector to facilitate extraction of the trichobezoar and closure of the gastrotomy.[8] This minimises intraperitoneal contamination while limiting incision length, with small series reporting uneventful recovery and favourable cosmetic results.[6,9] However, when post-pyloric extension is present (Rapunzel syndrome), most series strongly favour conventional laparotomy for complete removal.[1,10]

This case demonstrates that safe *en bloc* removal of large trichobezoars can be achieved via a laparoscopic-assisted mini-laparotomy with wound protection, offering a practical operative strategy for surgeons faced with this rare presentation.

Figure 1: Abdominal X-ray showing an intragastric mass with a mottled gas pattern consistent with a trichobezoar.

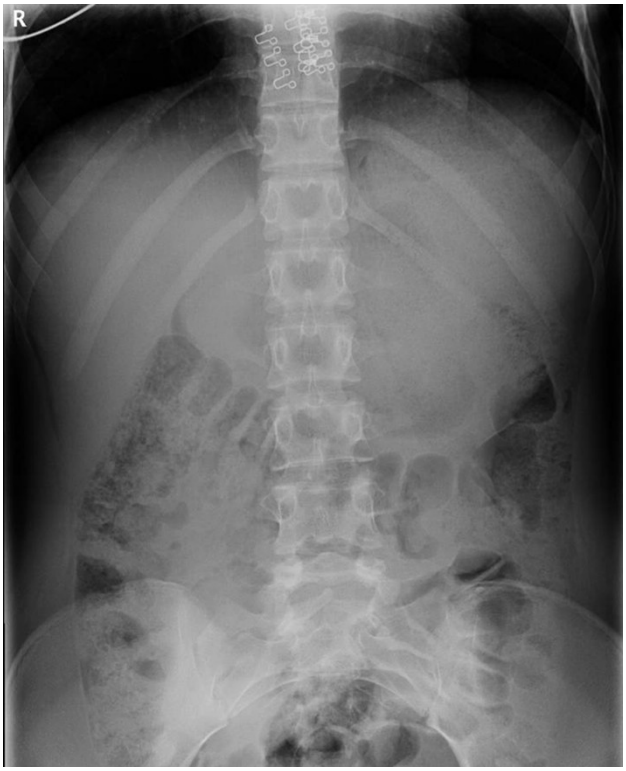


Figure 2: Wound-protected upper-midline mini-laparotomy and superficial gastric ulcer.

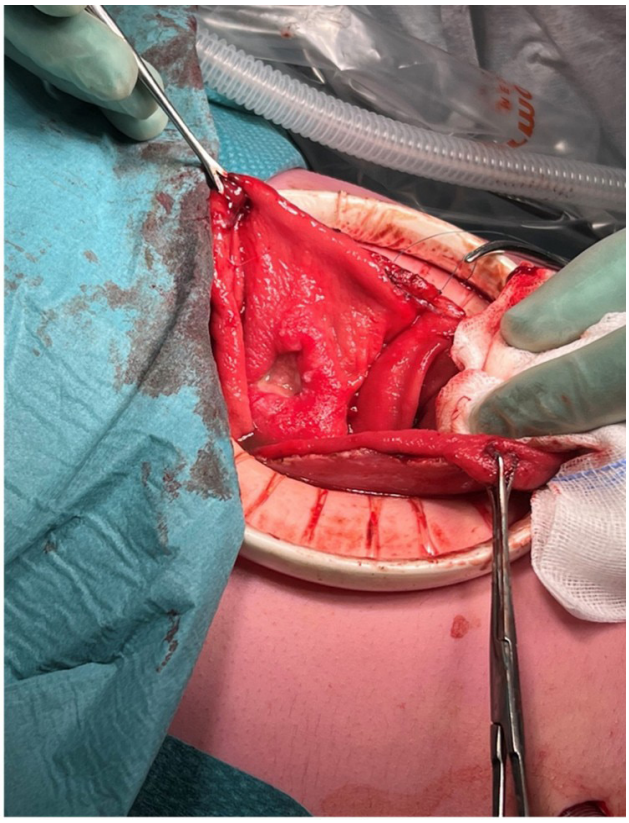


Figure 3: Trichobezoar, weighing 500g.



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AUTHOR INFORMATION
Yuen Liu: Medical Student, Tauranga Hospital, Bay of Plenty.
Binura Buwaneka Wijesinghe Lekamalage, MBChB: General Surgical Trainee Registrar, Tauranga Hospital, Bay of Plenty.
Lucinda Jane Duncan-Were, MBChB: General Surgical Trainee Registrar, Tauranga Hospital, Bay of Plenty.
David McGouran, MBChB: Consultant Gastroenterologist, Tauranga Hospital, Bay of Plenty.
Barnaby Blair Smith, MBChB: Consultant General Surgeon, Tauranga Hospital, Bay of Plenty.

CORRESPONDING AUTHOR
Binura Buwaneka Wijesinghe Lekamalage: General Surgery, Tauranga Hospital, Bay of Plenty, New Zealand. E: binura.lekamalage@gmail.com

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Performance first: why the economic success of our nation is dependent on the health of our people and why privatisation by stealth won't fix New Zealand's health system

David Galler, Louisa Wall

As New Zealand enters another election year, the *New Zealand Medical Journal*'s editor rightly states that it will be the economy that will dominate the political debate, with health becoming a major secondary issue.[1] We agree but wish to point out that these two areas, health and the economy, are intimately related to each other and that the economic imperative for investing in health and healthcare as an investment in the nation's future is well founded.[2–5]

From an economic, social and equity point of view, New Zealand simply cannot afford to have so many of its citizens unable to access healthcare and not be in good health. That is an essential element in allowing us to be socially and economically productive and be the collective asset the nation needs.

Hence, a big question for this election should be the cost to the public finances and our economy of the current approach of cost containment and poor health planning that denies so many access to much needed health and healthcare services.

In the report Managed Decline,[6] its author details those second-, third- and fourth-order fiscal consequences to the nation of so many being in poor health. The figures are staggering, such that should the status quo remain unchecked, by 2035 only 6.6% of adults in New Zealand will meet the World Health Organization definition of being in good health. That's a future we just cannot afford and an approach the author calls out as being fiscally reckless.

Instead of managing short-term costs, more attention needs to be placed on the economic value good health delivers by way of public policies to prevent harm from the social and commercial drivers of ill health, expanding and supporting our healthcare workforce and in the provision of publicly funded, publicly provided services.[7,8]

We agree with the editor that, once again, health is framed as a contest of one-off promises for shorter waiting lists, better cancer care and more access to medicines; all necessary interventions, but as it stands this is simply the minister playing whack-a-mole to manage politically sensitive issues instead of planning for a sustainable health and healthcare system for the future.

As Professor Frizelle has argued, the real test of health policy is not aspiration but performance—whether people can access timely, affordable care in practice, and whether inequities are genuinely reduced.

International evidence should give us pause. Compared with countries such as New Zealand, the United States of America spends a far higher share of gross domestic product (GDP) on health than any other developed country yet performs poorly on life expectancy and in achieving good health outcomes.[9] We have much to learn from the failures of their approach, notably the massive expense, inefficiencies and shocking inequities that are created by their fragmented approach to funding, planning and provision.

We recognise that not everything can be fixed by additional funding, but not much can be fixed without it and right now it is abundantly clear that a major boost of funding is urgently required in the next Budget and in each of those that follow until we have taken the necessary steps to put funding of our services on a stable and predictable footing for the future.

The alternative to expand public capacity and capabilities is critical as the Government actively promotes expanded private provision, justified as a pragmatic response to pressure in the public system. Private provision may offer short-term relief for individuals and those who can pay to bypass public waiting lists, but international

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experience shows that, without strong public stewardship, privatisation by stealth will undermine system performance and population health, be more costly and increase inequity.[10–15]

There are three predictable consequences. First, private expansion draws scarce workforce and infrastructure away from the public system, where need is greatest. In a country already facing critical shortages of doctors, nurses and allied health professionals, shifting capacity does not solve the problem. It redistributes it,[16] usually away from rural communities and lower-income populations. Second, incremental privatisation normalises a two-tier system, where access to timely diagnosis and treatment increasingly depends on income rather than clinical need. Once this becomes embedded, public waiting lists lengthen,[17] preventable harm increases and trust in the system erodes. Third, highly privatised systems cost more overall without delivering better population outcomes. The United States of America is not only an outlier because it spends too much. It is also because fragmentation drives inefficiency, duplication and inequity.[9] New Zealand should not mistake higher private activity for improved system performance.

These are not ideological objections. They are practical everyday concerns. A fragmented health system struggles to coordinate care, reduce waiting times or address entrenched inequities, particularly when workforce constraints are already binding.

From a Te Tiriti o Waitangi perspective, the risks are even more pronounced. Māori already experience delayed diagnosis, reduced access to specialist care and poorer outcomes across multiple conditions, including cancer, cardiovascular disease and mental health.[18–22] Incremental privatisation threatens to exacerbate these inequities, not resolve them. Te Tiriti obligations require the Crown to actively protect Māori health, ensure equitable outcomes and partner with Māori in governance and service design.[23] A two-tier system, where those with means bypass public pathways while others wait longer for care, is fundamentally incompatible with these obligations. Fragmentation weakens accountability for equity and shifts risk onto individuals and whānau least able to absorb it.

New Zealand's relatively strong health outcomes have not been achieved by solely chasing high spending as a percentage of GDP. They have been built on a predominantly public, universal system that pools risk, supports prevention and enables access based on need. As fiscal pressures tighten and workforce shortages deepen, protecting the capacity of public provision becomes even more important.

This does not mean the system should stand still. As the *Journal*'s editor notes, performance will be judged on whether Health New Zealand – Te Whatu Ora can restore access to primary care, reduce waiting times and improve equity. That requires sustained investment in general practice, integrated models of care, workforce development and genuine Māori partnership, not the quiet expansion of private alternatives that leave structural constraints untouched.

If election year health debates are to be credible, they must confront trade-offs honestly. Earlier cancer screening, better access to medicines, strengthened mental health services and improved primary care all require capacity and workforce. That means addressing pay equity across health professions, particularly in nursing, midwifery and allied health, where chronic undervaluation of predominantly female and Māori workforces undermines recruitment, retention and professional sustainability. In a globally competitive labour market, failure to resolve pay equity is not a fiscal saving but a direct contributor to workforce loss. Promising delivery without addressing these structural workforce constraints fuels public scepticism and undermines trust.

The test for voters is therefore straightforward. Does the Government's direction of travel strengthen the public system at scale, or does it shift pressure onto individuals and households while leaving the underlying causes of delay and inequity unresolved and our economic future in jeopardy?

Outcomes and equity, not ideology or spending headlines, must be the benchmarks of success. Sustained privatisation risks eroding both at precisely the moment when New Zealand needs coherence, confidence and courage in health policy.

The challenge for political leaders is clear. Stop treating private provision as an easy release valve for public system failure. Be honest about limits, deliberate about choices and explicit about delivery. If this election is to mark a genuine reset, health must be judged not by promises made or pathways outsourced, but by fair, timely care delivered for all New Zealanders.

COMPETING INTERESTS
DG is a board member for NorthAble, Fisher & Paykel Healthcare Foundation and Health Coalition Aotearoa. DG reports stock/stock options (managed funds) for Milford Asset Management and Forsyth Barr.
LW is chair, Tūwharetoa Iwi Māori Partnership Board.

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AUTHOR INFORMATION
David Galler: Spokesperson, Kaitiaki Hauora.
Louisa Wall: Executive Member and Spokesperson, Kaitiaki Hauora.

CORRESPONDING AUTHOR
David Galler: Spokesperson, Kaitiaki Hauora.
E: davidgaller00@gmail.com

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Ethnic differences in population-level intracerebral haemorrhage incidence in Aotearoa New Zealand: findings from three Auckland Regional Community Stroke cohorts

Karim M Mahawish, Valery Feigin, Harvey White, Rita Krishnamurthi

Primary intracerebral haemorrhage (ICH) accounts for one-sixth of all strokes and is associated with higher mortality and long-term disability than ischaemic stroke.[1] Marked ethnic inequities in stroke incidence and outcomes persist in Aotearoa New Zealand, with Māori and Pacific peoples experiencing a higher burden than Europeans.[2] However, contemporary population-level data describing ethnic-specific trends in ICH incidence over time remain limited.

Understanding temporal trends in ICH is particularly important in the context of evolving cardiovascular risk profiles, increasing use of anticoagulation for atrial fibrillation (AF) and ongoing inequities in hypertension prevalence and control.[3] Whether these changes have translated into differential ICH trends across ethnic groups is unknown.

The Auckland Regional Community Stroke (ARCOS) study collects data on all stroke and transient ischemic attack (TIA) events over a 12-month period once every decade. It contains data on patient demographics, comorbidities and outcomes.[2]

Using aggregate data from three successive ARCOS studies, we examined ethnic-specific population incidence trends of ICH.

Methods

We analysed population-based ICH incidence data derived from three successive ARCOS studies (ARCOS III, IV and V), each corresponding to a 1-year observation period between 2002 and 2021. All cases of first-ever ICH were ascertained using standard ARCOS methodology.

Cases were classified using standard prioritised self-identified ethnicity methods into four groups: Māori, Pacific peoples, European and Asian/Others. The Asian/Other category included individuals identifying with Asian ethnic groups (e.g., East Asian, South Asian, Southeast Asian) and smaller residual groups (including Middle Eastern, Latin American, African and other ethnicities). Annual population denominators for each ethnicity were obtained from Auckland population estimates as previously reported.[2]

Descriptive statistics were used to assess baseline socio-demographic and comorbidities of patients with stroke by ethnic group across the 20-year study period. Statistical significance of changes in the distribution of categorical variables was tested using the Cochran–Armitage test and for continuous variables using the Kruskal–Wallis test.

Ethnicity-specific ICH incidence rates were expressed as events per 100,000 population with exact 95% Poisson confidence intervals (CI). Ethnic differences in population-level ICH incidence were then estimated using Poisson regression models fitted to aggregated ARCOS III–V data, with adjustment for ARCOS study period and Europeans as the reference group. Time-by-ethnicity interaction was assessed using interaction terms to examine whether ethnic incidence rate ratios varied across ARCOS periods. Since only summary data were available, adjustment for individual-level comorbidities or treatment exposures was not possible. A two-sided p-value of <0.05 was considered statistically significant.

This study has been approved by the Health and Disability Ethics Committee (ref: 2023 AM 9094). All statistical analyses were performed using Stata BE version 17 (StataCorp, College Station, Texas, United States of America).

Results

We identified 717 first ICH events across

the three cohorts. The mean age of ICH cases remained stable (~69 years), while diabetes prevalence increased significantly (10.2% to 22.8%, p=0.0003). The proportion of females declined modestly across cohorts. There were no significant differences in history of hypertension, hyperlipidaemia, myocardial infarction or AF prevalence across cohorts. Twenty-eight-day and 1-year mortality declined significantly over time (Table 1).

Across the three ARCOS study periods, Pacific peoples consistently exhibited higher population-level ICH incidence than other ethnic groups (Table 2).

In period-adjusted Poisson regression models pooling ARCOS III–V data, Pacific peoples had approximately 60% higher ICH incidence than Europeans (incidence rate ratio [IRR] 1.60 [95% CI 1.31–1.94], p<0.001), Table 3. Māori and Asian/Other populations had significantly lower ICH incidence compared with Europeans. There was no statistically significant evidence of time-by-ethnicity interaction (p=0.069), suggesting that relative ethnic differences in ICH incidence did not vary significantly across study periods.

Conclusion

In this population-based analysis spanning three ARCOS cohorts over a 20-year period,

Table 1: Clinical characteristics of first-ever intracerebral haemorrhage (ICH) cases across Auckland Regional Community Stroke (ARCOS) III–V.

	ARCOS III N=177 mean (SD)/N (%)	**ARCOS IV N=211 mean (SD)/N (%)**	**ARCOS V N=329 mean (SD)/N (%)**	**p-value**
Age (years)	69.2 (14.2)	69.9 (14.7)	68.3 (17)	0.488
Female	97 (55)	113 (54)	150 (46)	0.032
ICH cases/Auckland population:	177/897,882	211/1,119,192	329/1,346,900	0.0002
• Europeans	111/596,181	130/568,257	153/625,500	
• Māori	5/80,832	8/94,737	20/134,700	
• Pacific peoples	34/95,202	31/117,366	69/161,800	
• Asians/Others	26/125,667	41/338,829	87/425,000	
Hypertension	94 (53)	137 (65)	188 (57)	0.630
Hyperlipidaemia	28 (16)	64 (30)	75 (23)	0.208
Myocardial infarction	14 (8)	29 (14)	41 (13)	0.189
Diabetes	18 (10)	33 (16)	75 (23)	0.0003
Atrial fibrillation	25 (14)	40 (19)	48 (15)	0.904
Current/ex-smoker	85 (48)	80 (40)	123 (39)	0.066
Mortality at 28 days	64 (36)	89 (42)	93 (28)	0.025
Mortality at 1 year	79 (45)	102 (48)	115 (35)	0.013

Table 2: Crude intracerebral haemorrhage (ICH) incidence per 100,000 population calculated by Poisson method with exact 95% confidence intervals, stratified by ethnicity across Auckland Regional Community Stroke (ARCOS) III–V.

Ethnicity	ARCOS III	ARCOS IV	ARCOS V
Europeans	18.6 (15.3–22.4)	22.9 (19.1–27.2)	24.5 (20.7–28.7)
Māori	6.2 (2.0–14.4)	8.4 (3.7–16.6)	14.9 (9.1–22.9)
Pacific peoples	35.7 (24.7–49.9)	26.4 (18.0–37.5)	42.7 (33.2–54.0)
Asians/Others	21.5 (14.2–31.3)	12.4 (8.9–16.8)	20.5 (16.4–25.3)

Table 3: Pooled Poisson incidence rate ratios (IRR) stratified by ethnicity.

Ethnicity	IRR (95% CI)	p-value
Europeans	Reference	Reference
Māori	0.47 (0.33–0.67)	<0.001
Pacific peoples	1.60 (1.31–1.94)	<0.001
Asians/Others	0.77 (0.64–0.93)	0.007

we observed marked ethnic differences in ICH incidence; Pacific peoples experienced substantially higher population-level rates than other ethnic groups. This finding is in keeping with an Australian-based study that found a significantly increased risk of ICH in Polynesians compared with Europeans.[4] This excess burden persisted across study periods and remained evident after adjustment for cohort year, supporting the presence of a stable and substantial inequity in ICH risk among Pacific communities in Auckland.

In contrast, we observed lower ICH incidence among Māori compared with Europeans. This finding differs from earlier population-based ARCOS analyses that reported a substantially higher age-adjusted risk of ICH among Māori and Pacific peoples combined.[5] A hospital-based series from the Waikato Region (1998–2008) similarly reported lower crude ICH incidence per 100,000 in Māori (9.6), Pacific (9.2) and Asian (9.4) populations than in NZ Europeans (16.4).[6] The authors attributed this to differential healthcare access and case ascertainment rather than biological protection. The lower crude ICH incidence reported in Pacific and Asian populations in Waikato compared with population-based data from Auckland is consistent with this interpretation. In ARCOS, Māori also had lower recorded incidence of ischaemic stroke and did not have a higher proportion of undetermined stroke compared with NZ Europeans, arguing against stroke subtype misclassification as the sole explanation for the lower ICH incidence. Given the small numbers, changes in stroke classification over time and the absence of age standardisation in our data, the Māori-specific findings in the present study should be interpreted cautiously.

Interpretation of temporal changes in ICH incidence across ARCOS waves is limited by major reductions in undetermined stroke classification (11.6% in ARCOS III vs <2% in ARCOS IV and V), indicating that improved diagnosis is likely to have contributed to the higher observed ICH incidence in later cohorts. Further, case ascertainment improved across ARCOS waves, with the proportion of missing cases declining over time.[2] These methodological changes limit causal interpretation of apparent secular trends. In addition, age-standardised incidence rates were not available for this analysis, and therefore the contribution of demographic ageing to observed temporal differences cannot be determined.

The clinical profile of ICH cases evolved across cohorts, with a significant rise in diabetes prevalence but stable mean age and no significant

change in recorded history of hypertension or AF. Despite this, both 28-day and 1-year mortality declined over time, consistent with improvements in acute stroke systems of care in Aotearoa New Zealand, including greater access to stroke unit care and advances in the supportive management of ICH.[7–9] However, as only aggregate summary data were available, we were unable to examine ethnicity-specific risk factor profiles or treatment exposures, precluding causal inference.

Recent randomised trials have demonstrated the safety of earlier anticoagulation initiation after AF-associated ischaemic stroke, but these studies included relatively low proportions of non-European participants.[10,11] In prior work using ARCOS IV and V data, we reported an increase in AF-associated ICH coinciding with a period of substantially increased anticoagulant prescribing.[12] While the present findings do not permit any inference regarding anticoagulation-related bleeding risk, this highlights that background haemorrhage risk is not ethnically uniform at the population level, a factor that may be relevant when translating predominantly European-derived trial evidence into Aotearoa New Zealand clinical practice.

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AUTHOR INFORMATION
Dr Karim M Mahawish: Stroke Physician, Adult Rehabilitation & Health of Older People, Health New Zealand – Te Whatu Ora Counties Manukau, Auckland; Doctoral Student, National Institute for Stroke and Applied Neurosciences, School of Community & Public Health, Auckland University of Technology, Auckland.
Prof Valery Feigin: Director of the National Institute for Stroke and Applied Neurosciences, School of Community & Public Health, Auckland University of Technology, Auckland.
Prof Harvey White: Director of the Cardiovascular Research Unit, Health New Zealand – Te Whatu Ora Te Toka Tumai, Green Lane Cardiovascular Service, Auckland City Hospital, Auckland; John Neutze Scholar.
Prof Rita Krishnamurthi: Deputy Director of the National Institute for Stroke and Applied Neurosciences, School of Community & Public Health, Auckland University of Technology, Auckland.

CORRESPONDING AUTHOR
Dr Karim M Mahawish: Stroke Physician, Adult Rehabilitation & Health of Older People, Health New Zealand – Te Whatu Ora Counties Manukau, Auckland; Doctoral Student, National Institute for Stroke and Applied Neurosciences, School of Community & Public Health, Auckland University of Technology, Auckland. E: kmahawish@doctors.org.uk

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Splenectomy in Banti's Disease

NZMJ, 1926

By Chas. D. Read, M.B., Ch. B., *Dunedin Hospital*.

The following is a brief resumé of a case of more than usual interest which was in Dunedin Hospital during 1925. I must acknowledge thanks to Drs. Williams and Newlands, Hon. Physician and surgeon respectively to the children's wards of Dunedin Hospital, under whose joint care the child was placed.

The patient, a girl of 10 years, residing in the country, was quite well up to the date of admission on 30th March, 1925, when she had a profuse haematemisis—said to be about one pint. No other symptoms whatever. On admission patient was not very anaemic—temperature 99, pulse 110, respiration 28—and seemed comparatively comfortable.

On examination the liver was found to be one and a-half inches below the costal margin, and the spleen about two inches down, while there was shifting dullness in flanks and fluid thrill obtainable. Blood examination :—Reds, 1,700,000; whites, 18,600; haemoglobin, 60 per cent. Differential :—Polymorphs, 44.5 per cent ; large lymphocytes, 7 per cent. ; small lymphocytes, 40 per cent. Wasserman reaction and hydatic complement fixation, negative.

The child was placed on medical treatment, and by 5th June, 1925, was apparently well, although she had occassional attacks of epistaxis and recurrent melena. Blood count on 5th June :—Reds, 5,200,000; whites, 8,600; haemoglobin, 85 per cent. Differential count shows normal proportions of the different white cells. At this stage patient was discharged relieved ; liver and spleen still enlarged.

She remained well until 1st August, when she began to feel "off colour" and "tired," and, on the 4th, again vomitted about one pint of blood stained material—said to be almost pure blood. She was readmitted to hospital on the 4th with pulse 120, respiration 30, temperature 97.4. Very pale and listless, and just after admission about eight ounces of blood was again vomitted. This time patient had extreme ascites—enlarged abdominal veins. Liver one inch below costal margin and spleen two and a-half inches down, and there was a haemic murmur at the apex. Count—Reds, 1,900,000, whites, 8,600.

On 23rd August paracentesis abdominis was performed and one and a-half pints fluid removed. On 3rd September this was repeated and half pint removed. On 16th, and 30th Spetember and 10th October half pint citrated bood was transfused. The patient was much improved after these, and by 12th October, was sufficiently well to warrant the performance of splenectomy.

Operation.—The operation was performed by Dr. Newlands and anaesthetic administered by Dr. H. S. Kenrick (ether). Left paramedial incision was employed, and just above the umbilicus this was continued obliquely outwards across the left rectus muscle, which was divided after the sheath had been stitched.

On opening the abdomen there was very little free fluid. The liver was slightly enlarged and nodular showing early cirrhotic change. The spleen was isolated and found to have many omental adhesions which were divided between stout ligatures. The hilus was isolated and clamped off and tied, and tail of pancreas in the lieno-renal ligament was carefully avoided and spleen removed without much difficulty. All vein areas were oversewn and the abdomen closed with tension sutures for the lower part of the wound. At the end of the operation another half-pint of citrated blood was transfused.

Pathology.—The removed spleen was reported on by Dr. Drennan to have lymphoid hyperplasia, with thickening of the capsule.

Subsequent Progress.—The patient had an uneventful convalescence, and by 16th November she was up and walking about—apparently perfectly well. Blood count :—Reds, 4,800,000 ; white, 8,400. Differential count :—Polymorphs, 55 per cent. ; lymphocytes, 25 per cent. ; haemoglobin, 85 per cent.

Child was reported on 15th January, 1926, to be still perfectly well with no symptoms whatever.

In view of the above encouraging result, and one subsequent similar result apparently, it seems that the question of splenectomy should be raised in most cases of splenic anaemia.