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Tūtakarerewa—Indigenous advocacy and structural racism in bowel cancer screening in Aotearoa New Zealand

EDITORIAL

# Are we there yet? Aotearoa's Smokefree 2025 goal and what comes next



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## **Are we there yet? Aotearoa's Smokefree 2025 goal and what comes next**

*Jude Ball, Janet Hoek, Richard Edwards, Lani Teddy, Andrew Waa*

Aotearoa's Smokefree 2025 goal has not been met: daily smoking remains well above the 5% benchmark for Māori and Pacific peoples, tobacco is still sold in thousands of outlets and national progress has stalled. The reversal of world-leading policies in 2023 derailed momentum, prioritising individual responsibility over proven, equity-focussed measures that would have reduced tobacco's availability, addictiveness and appeal. To get tobacco control back on track, rebuild trust and meet its binding obligations under the World Health Organization Framework Convention on Tobacco Control, the Government must restore evidence-based policy, introduce measures to prevent tobacco industry interference and protect young people from tobacco industry predation and nicotine addiction. Despite recent setbacks, the Smokefree goal remains both urgent and achievable; it is a unifying vision that must continue to inspire action to support the many people who want to quit smoking and to protect future generations.

## **“You receive the diagnosis, but your whānau have the cancer”: patients’ perspectives on breast cancer treatment in Wellington, Aotearoa New Zealand**

*Tātila Helu, Emma O’Loughlin, Witana Petley, Aleksandra Popadich*

This study explored the experiences of seven women who had completed breast cancer treatment in the Wellington Region, including Māori, Pacific, and non-Māori participants. Many said the information they received was either too overwhelming or not well timed, especially after surgery. Māori and Pacific participants wanted information presented in ways that felt culturally right—including visual tools and support for their whole whānau. Some participants struggled to attend appointments, contact services or balance treatment with work. The study shows that better support, clearer communication and whānau-based care could make a big difference.

## **Computed tomography colonography performs poorly in detection of sessile serrated lesions**

*Shiristi Kumar, Andrew McCombie, Simon Richards, Tamara Glyn, Emma Bone, Tim Eglinton*

Bowel cancer often starts from small growths called polyps in the bowel. Sessile serrated lesions (SSLs) are a particular type of flat, saw-toothed polyps that can be hard to detect and have a higher risk of becoming cancer if not removed. In New Zealand, computed tomography (CT) colonography—a type of non-invasive bowel CT scan—is frequently used as an alternative to colonoscopy. However, our study found that CT colonography missed most of these high-risk polyps, detecting only about one in seven (14.5%) that were later found during colonoscopy. Although larger lesions are generally easier to detect on CT imaging, even sizable right-sided sessile serrated lesions (where these polyps most often occur) were frequently missed on CT colonography. These findings indicate that CT colonography is not reliable for detecting SSLs, and colonoscopy remains the gold standard method for finding and removing these precancerous growths to prevent bowel cancer.

## **The health of New Zealand cardiology: senior medical officer workforce survey**

*Selwyn P Wong, Martin K Stiles*

Health New Zealand – Te Whatu Ora has a cardiology/senior medical workforce that is experienced but ageing. The current vacancy rate is 14%. On a per population basis, Aotearoa has fewer cardiologists than comparable countries. Furthermore, there is disparity, with fewer cardiologists in non-major urban regions and those with higher Maori/Pacific peoples.

## Half a century of declining acute coronary syndrome incidence is ending and ethnic inequity is rising: ANZACS-QI 88

Andrew J Kerr, Matire Harwood, Corina Grey, Suneela Mehta, Tegan Stone, Mildred Lee, Sue Wells, Rod Jackson, Katrina Poppe

Acute coronary syndromes (ACS) include heart attacks and acute angina. An emergency hospital admission with an ACS is often the first time people know they have heart disease. Rates of ACS hospitalisations have been declining for half a century, but in this study we found that the decline in Aotearoa New Zealand has stalled in the last decade. These rates have plateaued at a higher level for Māori and Pacific people compared with Europeans. Furthermore, over the last 15 years the relative gap between European and Māori/Pacific peoples has widened, resulting in increasing inequity for both younger and older Māori and Pacific people. Comprehensive actions across health and non-healthcare sectors are required.

## Reform, repeal, replace: a case study of policy whiplash in New Zealand's health sector

Dylan A Mordaunt

This paper looks at why New Zealand first created, and then quickly repealed, a new law (the *Therapeutic Products Act 2023*) that would have updated how medicines, medical devices and natural health products are regulated. The Act would have checked device safety before products reached the market ("pre-market approval") and covered health software ("software as a medical device", meaning apps or programs used for diagnosis or care), but those features did not carry over after repeal. It also formally acknowledged Rongoā Māori (traditional Māori healing), whereas the repeal-era papers did not address Rongoā or Te Tiriti considerations. The analysis compares official documents and submissions to show how the policy narrative switched from safety and modernisation to cutting "red tape" and what protections were lost as a result.

## Tūtakarerewa—Indigenous advocacy and structural racism in bowel cancer screening in Aotearoa New Zealand

Nina Scott, Jacquie Kidd, Hayley Arnet, Cynthia Dargaville, Moahuia Goza, Sue Crengle, Rhys Jones, Clarence Kerrison, Rawiri McKree Jansen

Aotearoa New Zealand has one of the highest bowel cancer rates globally, with Māori and Pacific peoples disproportionately affected. More Māori are diagnosed before age 60, facing higher mortality rates than non-Māori. A national bowel screening programme was launched in 2016 for ages 60–74, despite equity modelling showing non-Māori would benefit more. Māori cancer leaders advocated lowering the screening age to 50 for Māori and Pacific peoples, utilising evidence, whānau experiences, media and engagement with government. In 2020, the Government refused to lower the bowel screening age for Māori and Pacific peoples. However, advocates persisted, supported by new data confirming rising Māori bowel cancer incidence. The 2022 Government supported lowering the screening age, but implementation was limited. A year later, the new Government embarked on a politically motivated agenda, rejecting ethnically targeted policies. This paper highlights the sustained advocacy for an equitable screening programme, and the government resistance and structural racism delaying such screening, costing Māori lives.

## Abdominal aortic aneurysm in women in Aotearoa New Zealand

Oliver Lyons, Sue Crengle

Women with an abdominal aortic aneurysm (AAA) in Aotearoa New Zealand experience inequity at every stage of diagnosis and management. We currently treat women too late in their clinical course,

where increased age, comorbidities, larger AAA diameter, preventable ruptures, loss of eligibility for simple endovascular repair (EVAR) and clinical “turn down for surgery” rates all add to higher AAA mortality. There is scope for great improvements in cardiovascular risk reduction for people living with a small AAA, and for considering the inclusion of women in proposals for an AAA screening programme.

### **An approach to make general practitioner referrals suitable for artificial intelligence deployment**

*Evelyn Lesiawan, Bruce Sutherland, Christoph Schumacher, Andrew Cave, Guy Armstrong*

The current system for triaging general practitioner referrals can be modified to make it suitable for artificial intelligence (AI) automation. Safety of individual patients is paramount and can be achieved by introducing the AI incrementally and by using simple decision trees as guardrails.

### **Reactive arthritis following intravesical *Bacillus Calmette–Guérin* therapy in a patient with kidney failure—a case report**

*Aksa Sara Thomas, Ankur Gupta*

A 60-year-old woman with kidney failure developed a rare condition called reactive arthritis after receiving *Bacillus Calmette–Guérin* (BCG) therapy for bladder cancer. After her fourth BCG treatment, she experienced eye inflammation and severe joint pain in her knees and wrists, which made it hard for her to move. Doctors initially suspected an infection, but tests showed no bacteria, confirming the arthritis was caused by the BCG treatment. She was treated with anti-inflammatory drugs, which quickly improved her symptoms, and she fully recovered within months. This case shows the importance of recognising this rare side effect to ensure proper treatment and recovery.

### **Haemorrhagic cholecystitis: a rare but life-threatening variant of acute cholecystitis**

*Amy Van der Sluis, Divyansh Panesar*

Haemorrhagic cholecystitis is an uncommon yet potentially fatal variant of acute cholecystitis characterised by intraluminal or mural haemorrhage of the gallbladder. It presents diagnostic and therapeutic challenges due to its non-specific symptoms, rapid progression and association with significant morbidity and mortality. This case report details the presentation of an 83-year-old man presenting with haemorrhagic cholecystitis in the setting of new anticoagulation for deep vein thrombosis following orthopaedic surgery, and summarises the pathophysiology, clinical presentation, diagnostic modalities and management strategies.

### **Diffuse astrocytoma presenting with parkinsonism and gliomatosis-like infiltration**

*Gabriel F Vieira, Laura G Silva, Letícia A Queiroz, Victor S Takahashi, Gustavo Andreis, Márcio L Duarte*

This report describes a 51-year-old woman who initially presented with symptoms resembling Parkinson’s disease but later was found to have a rare brain tumour called diffuse astrocytoma with gliomatosis-like infiltration. Her first magnetic resonance imaging scan was normal, delaying the correct diagnosis for 6 years. Despite the tumour usually carrying a poor prognosis, she survived 15 years from the onset of symptoms, likely due to the tumour’s low grade and her individualised supportive care. This case highlights the need to reconsider Parkinson’s diagnoses when symptoms evolve atypically or do not respond well to treatment.

# Are we there yet? Aotearoa's Smokefree 2025 goal and what comes next

Jude Ball, Janet Hoek, Richard Edwards, Lani Teddy, Andrew Waa

In 2011, the National-led Government set the bold ambition of "reducing smoking prevalence and tobacco availability to minimal levels, thereby making New Zealand essentially a smoke-free nation by 2025."<sup>1</sup> As 2025 comes to an end, we reflect on the Smokefree 2025 goal, assess whether it has been achieved and propose next steps.

## Smokefree Aotearoa 2025

In the mid-2000s, Māori leaders pioneered the Tupeka Kore (Tobacco Free) vision, which would see Aotearoa return to a nation without tobacco.<sup>2,3</sup> The Māori Affairs Select Committee (MASC) inquiry into the impact of tobacco on Māori developed this vision and recommended the Government adopt a goal of becoming a smoke-free nation by 2025.<sup>4</sup> Importantly, the inquiry emphasised that tobacco control must target the tobacco industry and addictive products that sustain the tobacco epidemic.<sup>4</sup>

The inquiry highlighted the devastating, inequitable and preventable burden tobacco use imposes on Māori whānau and communities, and on society, undermining all pillars of wellbeing. At the time, nearly half of Māori adults (45%) smoked, along with one in five non-Māori (21%).<sup>4</sup>

To address these gross inequities, the health sector and successive governments interpreted the prevalence component of the Smokefree goal as requiring daily smoking to fall below 5% for all population groups.<sup>5,6</sup> The goal's second component—reducing tobacco availability to minimal levels—has received less attention but is crucial to creating a context in which non-smoking is the default.

## Progress towards the Smokefree 2025 goal

So, has Aotearoa achieved the Smokefree 2025 goal? The answer is clearly "no".

There has been no progress in reducing tobacco availability to minimal levels. Deadly and addictive tobacco products are still sold in almost every dairy, service station and supermarket—around 6,000 outlets—with clustering in low socio-economic areas.<sup>7</sup>

Although the prevalence of daily smoking has decreased markedly since the Smokefree goal was set in 2011, it remains at 15% among Māori and 10% among Pacific peoples—three and two times higher than the 5% threshold, respectively (Figure 1). Only Asian peoples are below the threshold at 4.5%, although, concerningly, smoking appears to be rising in this group.

Among adults overall, daily smoking declined to 6.8% in 2022/2023, but progress has since stalled (Figure 2). A plateau across three annual surveys is unprecedented in the history of the New Zealand Health Survey.

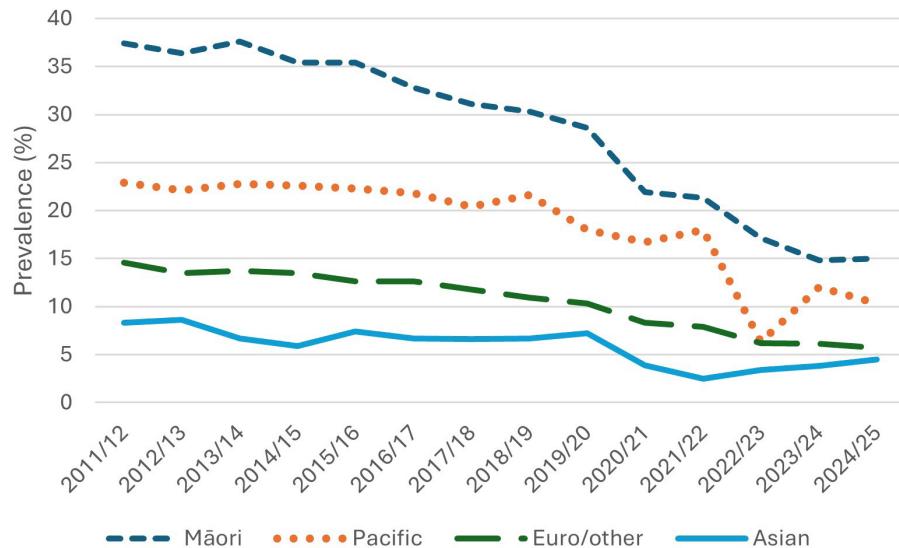
## Disappointing, but not surprising

While immensely disappointing, the failure to achieve the Smokefree 2025 goal and singular lack of progress since 2023 is not surprising.

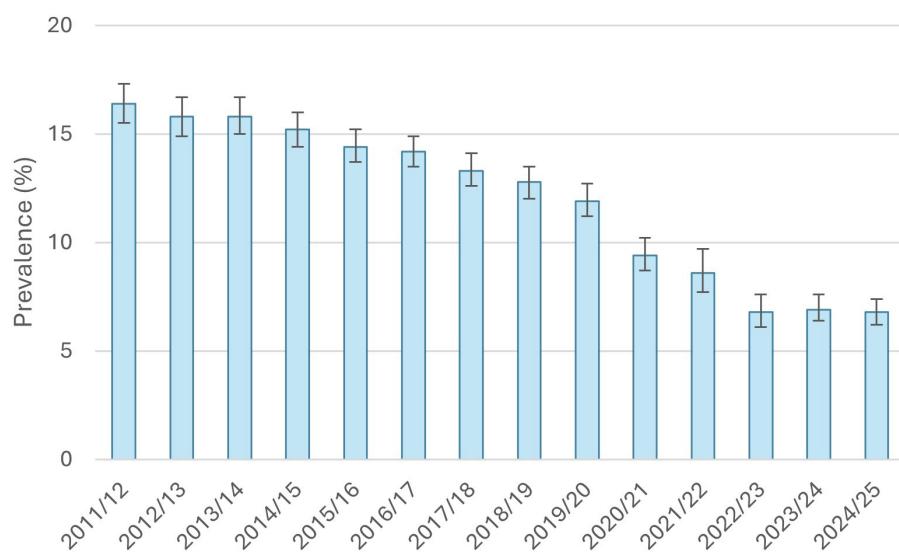
The coalition Government elected in 2023 dashed hopes of achieving the Smokefree 2025 goal and shocked the nation by repealing world-leading tobacco control policies.<sup>8</sup> The repealed measures would have greatly reduced the availability, addictiveness and appeal of smoked tobacco products, making it much easier for people who smoke—most of whom want to quit<sup>9</sup>—to do so. The measures were evidence based,<sup>10,11</sup> equity focussed,<sup>12</sup> had strong public support<sup>13,14</sup> and were predicted to bring rapid, profound and equitable reductions in smoking prevalence.<sup>12</sup>

The coalition Government pledged ongoing support for the Smokefree goal and promised that "decisions will be based on data and evidence."<sup>15</sup> Yet several measures it introduced lacked robust evidence, aligned with tobacco industry interests and went against official advice. Analyses concluded

**Figure 1:** Prevalence of daily smoking by ethnic group, 2011–2025, New Zealand Health Survey.



**Figure 2:** Prevalence of daily smoking, 2011–2025, New Zealand Health Survey.



that halving the excise tax on heated tobacco products and distributing free vaping kits would deliver minimal public health benefit.<sup>16,17</sup> Unsurprisingly, they have failed to sustain the decline in smoking.

The Government's approach places the onus squarely on individuals to stop smoking, while ignoring the most important known barriers to quitting: tobacco's extraordinary addictiveness and widespread availability. Behavioural science

shows individual-focussed interventions produce "disappointingly modest" results<sup>18</sup> and deflect attention away from systemic interventions (e.g., regulation, taxation), which have strong evidence of effectiveness.<sup>18</sup>

## Getting tobacco control back on track

The results of the current approach are now

clear: smoking rates have flatlined since the new Government took office 2 years ago. The coalition Government must acknowledge that its strategy is not working.

The World Health Organization (WHO) Framework Convention on Tobacco Control (FCTC), an international treaty Aotearoa ratified in 2005, sets out legally binding obligations designed to protect population health. Importantly, the FCTC preamble recognises the disproportionate harm experienced by Indigenous peoples, and Article 4 calls on parties to promote Indigenous communities' participation in developing, implementing and evaluating tobacco control measures that are culturally relevant and appropriate.<sup>19</sup>

Grounded in Aotearoa's obligations under the FCTC, we outline three key areas for action.

### 1. Restore evidence-based, pro-equity policymaking

FCTC Article 5.2(b) requires parties to “*Adopt and implement effective legislative, executive, administrative and/or other measures ... for preventing and reducing tobacco consumption, nicotine addiction and exposure to tobacco smoke.*”<sup>19</sup> This legally binding obligation aligns with the Government's stated commitment to evidence-based policy and rigorous evaluation.<sup>15</sup>

The Government has many evidence-based, pro-equity and cost-effective measures available to it, with several repeatedly recommended by expert groups, the MASC review and international evidence reviews.<sup>4,10,11,20-22</sup> These include well-established approaches Aotearoa has yet to implement, such as retailer licensing, increasing the minimum legal age for tobacco sales and routinely refreshing pictorial health warnings and mass media campaigns. They also include innovative measures to manage the industry and create an environment that cues and supports cessation, such as retailer reduction, mandating non-addictive nicotine content levels, disallowing or phasing out commercial tobacco sales and placing a moratorium on the market entry of new commercial tobacco or nicotine products. International interest is also growing in “producer pays” policies that hold the tobacco industry financially responsible for the harms it causes.<sup>11</sup>

Re-centring policy on this strong evidence base would prevent further backsliding and support equitable progress towards Aotearoa's Smokefree goal.

### 2. Protect public policy from tobacco industry interference

FCTC Article 5.3 requires parties to protect policy development from tobacco industry influence. Aotearoa's Global Tobacco Industry Interference Index ranking plummeted from second to 53rd in 2025,<sup>23</sup> and the Cancer Society's 2025 country report provides convincing evidence of industry interference in policymaking.<sup>24</sup>

WHO issued Article 5.3 implementation guidelines in 2013,<sup>25</sup> and both the MASC report<sup>4</sup> and past Cancer Society country reports<sup>26</sup> urged stronger protections against tobacco industry interference. These recommendations were ignored, and the consequences are now evident. The latest Global Index<sup>23</sup> and a recent *The Lancet* paper<sup>27</sup> highlight escalating industry interference worldwide, noting that strong safeguards are more important than ever.

To restore trust and prevent future tobacco industry influence, the Government must embed Article 5.3 obligations across the whole of government, following WHO guidance and the Cancer Society's recommendations.

### 3. Protect the next generation from nicotine addiction

Under FCTC Article 5.2(b), quoted above, Aotearoa is obligated to reduce *nicotine addiction*, as well as tobacco consumption, an obligation consistent with the Tupeka Kore vision. Current policy settings have failed young people in this regard.

The New Zealand Health Survey shows daily nicotine use (cigarettes or vapes) among 18–24-year-olds has risen from 17% in 2019/2020 to 26% in 2024/2025, and from under 15% to 17% in adults overall. Aotearoa has among the highest youth vaping rates globally.<sup>28</sup>

While “lower harm” products may help some people stop smoking, regulators must recognise that tobacco and nicotine companies aim to maximise profit rather than population health.<sup>29</sup> After the aggressive marketing of vaping to young people rather than people who smoke, it is essential to protect young people from the tobacco industry's latest attempt to hook them: oral nicotine products.<sup>30-32</sup>

Smoked tobacco should remain the central focus of tobacco control, but measures to end industry exploitation and addiction of the next generation are also vital.

## Conclusion

Aotearoa has come a long way, but progress has stalled under current policy settings. Nearly 300,000 people still smoke daily; this figure has not fallen in recent years. Two-thirds of these people will die prematurely unless they stop, and many will be from Māori, Pacific and low-income communities, which continue to face gross inequities. Tobacco caused an estimated 3,660 deaths in 2023<sup>33</sup>—more than 10 times the road toll—and imposes huge costs on whānau, the

health system and society.<sup>34</sup> Yet allowing tobacco companies to profit while the public pays is not inevitable. Restoring evidence-based policy can yet see Aotearoa achieve its smokefree vision.

*Kua tawhiti kē tō haerenga mai, kia kore e  
haere tonu. He nui rawa ō mahi kia kore e  
mahi tonu.*

*We have come too far to not go further.  
We have done too much to not do more.*

—Sir James Hēnare

**COMPETING INTERESTS**

J Ball has received consulting fees from: the Ministry of Social Development (paid to institution); The University of Auckland; and the Government of South Australia. JB has been/is the secretary of the Public Health Association, Wellington branch, and a member of the Smokefree Expert Advisory Group, Health Coalition Aotearoa.

J Hoek has received: ITC programme advisory fees; funding from the Japan Tobacco Society to present to the 2022 conference; and small gifts for speaking at conferences. JH has received: travel and accommodation paid to attend the IASLC meeting in Singapore 2023; funding from the Thoracic Society of Australia and New Zealand to present to a conference in 2023 (Singapore) and 2025 (Adelaide); funding from La Fondation Contre le Cancer to present in Brussels in 2025; and funding from UniSante to present in Lausanne in 2025. JH is: the co-director of ASPIRE Aotearoa; part of the Health Coalition Aotearoa Smokefree Expert Advisory Group; part of various Australian health advisory groups; a senior editor, *Tobacco Control* journal; a co-opted member of the Public Health Advisory Committee, Health Research Council; and a member of the Ministry of Health Smokefree Advisory Committee. R Edwards has received: consultancy payments for contributing to an International Tobacco control project (from NIH grant), annually 2022–2024; payment for membership of the CENIC study advisory board (from NIH grant), 2003; occasional fees for external PhD marking; occasional honoraria for invited presentations at international scientific meetings; payment for deputy editor services to the Society of Research on Nicotine and Tobacco (*Nicotine & Tobacco Research* journal); honorarium for a paper published in *Tobacco Control* anniversary edition 2022; honorarium for an editorial published in *The Lancet* in 2022; travel costs covered by Hāpī te Hauora for attendance at the national SUDI conference in Rotorua, New Zealand in May 2022; and travel costs covered by an NHMRC grant at University of Queensland for attendance at SRNT-O meeting/NHMRC Research Centre meeting in Brisbane, May 2024. RE has been/is: a member of Expert Advisory Group, Asthma and Respiratory Foundation (2013–2022); a member of the Smokefree Expert Advisory Group, Health Coalition Aotearoa (2019–2024); a member of the National Tobacco Control Advocacy Service Advisory Group, Hāpī te Hauora Māori Public Health (2016–2024); a member of the New Zealand Cancer Society's National Scientific Advisory Committee (2020–2023); chair, Public Health Communication Centre Expert Advisory Board (2021–2024); president, Society for Research on Nicotine and Tobacco (SRNT) Oceania branch (2025–2026), and board member (president elect) (2024–2025).

L Teddy received registration costs covered by conferences hosts (cancer councils NSW, WA and Queensland) for the Oceania 2024 conference, and travel and accommodation costs covered by Hāpī te Hauora for the national tobacco and SUDI conference in 2024.

LT is a board member of the Society for Research on Nicotine and Tobacco (SRNT) Oceania branch.

A Waa has had travel and accommodation costs covered by Hāpī te Hauora for the national tobacco and SUDI conference 2024, and travel, accommodation and registration costs covered by conference organisers for the World Tobacco Control Conference, Dublin, 2025.

AW is a board member for the Society for Research on Nicotine and Tobacco (SRNT) Oceania branch and a deputy editor for *Nicotine & Tobacco Research*.

**AUTHOR INFORMATION**

Jude Ball: Department of Public Health, University of Otago, Wellington, Aotearoa New Zealand.

Janet Hoek: Department of Public Health, University of Otago, Wellington, Aotearoa New Zealand.

Richard Edwards: College of Medicine & Public Health, Flinders University, Adelaide, Australia.

Lani Teddy: Department of Public Health, University of Otago, Wellington, Aotearoa New Zealand.

Andrew Waa: Department of Public Health, University of Otago, Wellington, Aotearoa New Zealand.

**CORRESPONDING AUTHOR**

Jude Ball: Department of Public Health, University of Otago, Wellington 6242, PO Box 7343, Aotearoa New Zealand. E: jude.ball@otago.ac.nz

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# “You receive the diagnosis, but your whānau have the cancer”: patients’ perspectives on breast cancer treatment in Wellington, Aotearoa New Zealand

Tātila Helu, Emma O’Loughlin, Witana Petley, Aleksandra Popadich

## ABSTRACT

**AIM:** This study aims to investigate the perceptions of Māori, Pacific, and non-Māori/Pacific breast cancer patients’ treatment experience in Wellington, Aotearoa New Zealand. It will also explore the support they received throughout their treatment journey and the information provided to them over the course of their care.

**METHOD:** Qualitative semi-structured focus groups were carried out including breast cancer patients who had completed treatment within the past 2 years. Participants were recruited through breast cancer clinics. Data were analysed using reflexive thematic analysis.

**RESULTS:** Participants reported a need for more tailored information from health professionals. Many participants reported barriers accessing services and follow-up appointments. Additionally, many participants, especially Māori and Pacific participants, emphasised the importance of ongoing support from healthcare professionals and their personal networks.

**CONCLUSION:** The findings highlight the need for improving patient-centred communication, recognising the important role of patient support systems and providing more tailored information and resources throughout breast cancer treatment. Addressing these factors could improve different patient groups’ experiences and outcomes by fostering a more informed and supported treatment journey.

Breast cancer is the most common cancer affecting women worldwide, with significant ongoing physical, emotional and social impacts.<sup>1</sup> Advances in surgical and non-surgical treatments have improved survival rates in Aotearoa New Zealand over the past decades, and patients now often undergo many different surgical and non-surgical treatment options, and post-treatment rehabilitation.<sup>2</sup> Patients are provided with a significant load of information and resources from different specialists and health professionals during their breast cancer treatment. In Aotearoa New Zealand, there is currently no known literature examining the experiences of breast cancer patients in relation to their treatment journey and the information they received during their treatment. Notably, Aotearoa New Zealand has a diverse patient population, including Māori, Pacific, and non-Māori groups; however, recent research has identified that the current surgical evidence base is not responsive to Māori.<sup>3,4</sup> Therefore, there is a need for research that explores and elevates Māori experiences. Understanding patient experiences is essential for improving patient-centred care,

addressing gaps in service delivery and ensuring equitable access to supportive healthcare interventions. This exploratory qualitative study seeks to generate insights into the treatment experiences of groups often under-represented in surgical and cancer care literature. Small, focussed samples are widely accepted in health equity research to centre voices that may otherwise be excluded from population-level data.<sup>5,6</sup> In this context, qualitative findings can inform improvements in patient-centred communication, culturally responsive care and service delivery design—especially for Māori and Pacific patients navigating breast cancer treatment in Aotearoa New Zealand. Therefore, this qualitative study aimed to investigate i) breast cancer patients’ perceptions of their treatment, ii) the support they received during their treatment, and iii) the information they received over their treatment.

## Method

### Study design

This was a qualitative focus group study. The University of Otago Ethics Committee approved

this study (ethics reference code: H23/023). The Interim Research Advisory Group – Māori (IRAG-M #999) also approved this study. Additionally, locality approvals for the different hospitals were obtained for this study. This study took a Kaupapa Māori (Māori-centred) approach, guided by the Te Ara Tika framework for Māori ethical research.<sup>7</sup> While not a Kaupapa Māori study, Māori values and practices were embedded throughout. The research was developed with Māori and Pacific researchers, included tikanga (Māori customs) (e.g., karakia [prayer], whakawhanaungatanga [relationship building]) and prioritised culturally safe engagement. The study followed principles of whakapapa (genealogy), tika (doing what is right), manaakitanga (care) and mana (authority/dignity). Māori researchers were involved in coding and interpreting data from the Māori focus group.

## Participants

Patients were purposively recruited from April 2023 to June 2023 from various breast care centres located in Wellington and Boulcott Hospitals. Patients aged 18 years and older were eligible for this study if they had completed breast cancer treatment, including surgery, in the wider Wellington Region within the past 5 years, either in a private or public setting. The exclusion criteria consisted of people who have undergone breast reconstruction and patients with metastatic disease, as these were considered separate population groups that warrant dedicated investigation. The primary researcher screened the breast clinic list for eligible patients and informed the registered nurse in charge of the clinic for the day. Eligible patients were approached in-person by a registered nurse and informed about the study. If interested, they were provided with the participant information sheet and were also given the opportunity to discuss the study with the primary researcher in a private room or were noted down for the primary researcher to contact later. Completed consent forms were collected before the focus group or interview session.

## Data collection

Two focus groups and one interview took place. Participants were grouped by ethnicity to promote cultural safety and depth of kōrero (discussion), although data were analysed together due to the small sample size. Focus Group 1 was face-to-face at the University of Otago (Wellington). Focus Group 2 was a combination of face-to-face at the University of Otago and

over Zoom (Zoom Video Communications, Inc., San Jose, United States of America). The research team was made up of one Tongan (TH), one Irish (EOL), one Māori (WP) and one NZ European researcher (AP). The primary researcher and lead of the project is a Tongan medical doctor (TH). EOL is a female Irish academic physiotherapist, experienced in qualitative research, WP is a male Māori academic physiotherapist, also an experienced qualitative researcher, and AP is a female NZ European breast surgeon. We received extra help from an experienced talanoa researcher (LLT) also to have further talanoa knowledge for the interview. The primary researcher, TH, a Tongan 5th-year female medical student, conducted all discussions, during which field notes were taken. WP was present at the Māori focus group to support the research team with tikanga Māori. The Pacific interview was conducted using the Pacific methodology of talanoa, a traditional approach to revisit knowledge and discussions about a chosen subject within Pacific cultures.<sup>8</sup> The talanoa was held face-to-face at the participant's home. Three members of the research team were present, including an experienced Pacific researcher (LLT) to support the team and ensure a culturally safe interaction. Audio software Otter.AI (Otter.AI, Mountain View, United States of America) was used to record each discussion. Each session lasted approximately 2 hours. All discussions were conducted using the same protocol and questioning as outlined in Table 1 and Table 2.

The focus group and interview included three questions highlighted in Table 4. These questions were not pilot tested but were discussed and underwent iteration among the research team. The Māori focus group kōrero included revision of the questions with an experienced Māori researcher to ensure that questions were phrased in a culturally safe manner that will be understood by Māori participants. Similarly, for the Pacific talanoa, questions were also revised by an experienced Pacific researcher. Repeating and summarising were used as a form of informal checks during sessions. Transcripts were not returned to the participant, but a one-page result sheet was sent to the participants with an invitation to comment if information discussed was interpreted correctly. No repeat interviews were carried out.

## Data analysis

Data analysis was supported by NVivo software (v.14.23.2; NVivo 14. QSR International Pty,

**Table 1:** Focus group and talanoa protocol.

<b>1</b>	The primary researcher will welcome the participants and whānau by briefly introducing herself and the research team.
<b>2</b>	The primary researcher will lead with a karakia to open the session and bless the kai.
<b>3</b>	The primary researcher will initiate whakawhanaungatanga and follow by allowing participants and whānau to collect kai or hot drinks and return to their seats.
<b>4</b>	Once participants and whānau are settled and comfortable, the primary researcher will explain the method and outline the flow of the discussion.
<b>5</b>	The primary researcher will outline the purpose of the group and the goals of the meeting.
<b>6</b>	The primary researcher will re-emphasise that the findings will be anonymised. She will also explain that discussion will be audio recorded and transcribed later to writing. This is to ensure that we will not miss anything important from the discussion.
<b>7</b>	The primary researcher will ensure to address any questions and/or concerns that the participants and whānau have before continuing.
<b>8</b>	The primary researcher will discuss the ground rules, and open participation will be encouraged.
<b>9</b>	The first question of the focus group protocol will follow.
<b>10</b>	The primary researcher will give the participants enough time to discuss each question thoroughly until there are no more opinions.
<b>11</b>	The primary researcher will relay the main findings of each question and ask if anyone has anything further to add.
<b>12</b>	Once there are no other questions to ask, and the participants express all opinions, the primary researcher will thank the participants and close the session with a karakia.

**Table 2:** Focus group and talanoa guiding tailored questions.

	<b>Māori focus group questions</b>	<b>Non-Māori/non-Pacific focus group questions</b>	<b>Pacific talanoa questions</b>
<b>1</b>	What information do you know now that you wished you were informed of earlier during your breast cancer treatment?	What information do you wish you were informed of earlier during your breast cancer treatment?	What are services and initiatives that would have encouraged you during your breast cancer treatment that you felt were not addressed?
<b>2</b>	What kind of support did you have and found helpful during your treatment, i.e., support person or whānau involvement?	What kind of support did you have and found helpful during your treatment, i.e., support person or whānau involvement?	What kind of support did you have and found helpful during your treatment, i.e., support person or whānau involvement?

**Table 2 (continued):** Focus group and talanoa guiding tailored questions.

<b>3</b>	<p>What were the resources that you utilised and found most helpful during your breast cancer treatment (i.e., patient information sessions, breast cancer foundation website, support group discussions)? What was particularly helpful about those services for you?</p>	<p>What resources did you utilise and find most helpful during your breast cancer treatment (i.e., patient information sessions, breast cancer foundation website, support group discussions)? What was particularly helpful about those services for you?</p>	<p>Were resources and information provided regarding your breast cancer treatment (i.e., patient information sessions, breast cancer foundation website, support group discussions)? What was particularly helpful about those services for you?</p>
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United States of America). Focus groups and interviews were voice recorded and transcribed by the primary researcher. The study utilised Braun and Clarke's six-phase reflexive thematic analysis framework.<sup>9</sup> An inductive, latent and critically realist approach to the reflexive thematic analysis was used to capture a better understanding of the experience of breast cancer survivors. Using this critical realist approach, the research team focussed on reporting an assumed reality that was evident in the data, i.e., the participants' perceptions of the information they received. However, the analysis also acknowledged the participants' meanings and experiences, and the ways the broader social context interprets those meanings.<sup>10,11</sup>

The research team reviewed and familiarised themselves with the data, reading and re-reading the transcripts. Subsequently, the primary researcher (TH) carried out reflexive, inductive analysis that informed the codes. This process was repetitive, and codes were revised multiple times. A second researcher (EOL) also coded the data. Furthermore, a third researcher (WP) coded the Māori focus group transcripts. Themes were then established from these codes. All authors discussed the codes, initial interpretation of codes, themes and theme names. This theme construction phase was consultative, with the primary researcher seeking advice from the other researchers in regular weekly meetings to ensure that themes captured the story of the data. The final iterations of thematic construction were carried out by the three non-Māori (one Pacific) team members. We acknowledge this as a limitation.

## Results

There were 35 patients who were considered eligible and agreed to be contacted by the primary researcher. There were 28 patients who were not able to participate in the study due to personal

commitments. Many participants cited personal or family commitments, and Pacific women in particular expressed discomfort with group settings. The research team took this into consideration and adjusted accordingly. Overall, seven female patients participated in the study: three participants were included in the Māori focus group discussion, three participants were included in the non-Māori/non-Pacific focus group discussion and there was one Pacific interview (talanoa). The participants were grouped into three separate cohorts (Table 3) by the research team based on their ethnic background. Table 3 describes the participants' demographic details.

Reflexive inductive thematic analysis, using transcripts of discussions from the focus groups and interview, along with comprehensive notes, resulted in three key themes.

For the first theme, "a lack of tailored breast cancer treatment information and guidance for patients", participants described a need for more tailored information and clearer direction of treatment for each individual patient, especially post-surgical treatment. For the second theme, "many barriers to accessing and benefitting from health services", participants conveyed various barriers they encountered to accessing and effectively engaging with health services. They also reflected on their whānau and friends' experiences that influence their interaction with healthcare. For the third theme, "patients and their whānau (family) need a holistic management approach", participants conveyed the importance of understanding the entirety of whānau commitments and responsibilities as part of their breast cancer journey.

### A lack of tailored breast cancer treatment information and guidance for patients

The first theme, "a lack of tailored breast cancer treatment information and guidance for patients", reflects participants' reported need for

**Table 3:** Demographic characteristics of participants.

Grouping	Participants	Ethnicity	Age (years)	Location	Health provider
<b>Focus Group 1</b>	Participant 1	Māori	51	Face-to-face	Private
<b>Focus Group 1</b>	Participant 2	Māori	59	Face-to-face	Private
<b>Focus Group 1</b>	Participant 3	Māori	51	Face-to-face	Public
<b>Focus Group 2</b>	Participant 4	Indian	63	Hybrid: online/face-to-face	Public
<b>Focus Group 2</b>	Participant 5	NZ European	79	Hybrid: online/face-to-face	Public
<b>Focus Group 2</b>	Participant 6	NZ European	47	Hybrid: online/face-to-face	Private
<b>Interview</b>	Participant 7	Samoan	53	Face-to-face	Public

tailored information and reassurance from health professionals at different points of a patient's breast cancer treatment journey to ensure optimum health outcome. In the first sub-theme, "lack of direction and reassurance", participants from the three different sessions highlighted that based on their personal experiences in both the private and public health sectors there was a lack of information addressing the treatment process after diagnosis with breast cancer.

Participants highlighted a dearth of information also preceding the initiation of treatment, specifically concerning the commitment required, work responsibilities and the invasiveness of investigations, i.e., biopsies. Participants conveyed a lack of understanding of the direction and expectations following surgery. They expressed the perception that the information provided was disjointed and inconsistent, contributing to feelings of uncertainty about the trajectory of their treatment. In contrast, in the second sub-theme, "overwhelming information at diagnosis", Māori and Pacific participants conveyed that the information presented during their pre-surgical appointments was overwhelmingly dense, making it challenging to process. In the third sub-theme, "need for tailored information", participants from across the three discussions and, in particular, Māori and Pacific emphasised the need for more tailored information that is staggered and easily digestible for the patient and whānau.

### Many barriers to accessing and benefitting from breast cancer services

The second theme, "many barriers to accessing and benefitting from breast cancer services," reflected personal experiences of the participants and their whānau. In the first sub-theme, "barriers to attending appointments", participants emphasised that where post-operative appointments and other services, i.e., cancer support sessions and physiotherapy, were located posed a significant obstacle to utilising them. Therefore, it was difficult to receive the treatment they needed. In the second sub-theme, "barriers to interacting with health services", some participants also reported bad experiences with ringing services when they needed help. These experiences reflect poorly on the health services promised to be available, leading to further mistrust in the health system among minority populations such as Māori and Pacific. One participant also reported being made feel guilty for seeking help as her cancer was not deemed critical. Furthermore, in the third sub-theme, "limitations by pandemic", participants outlined further issues during the COVID-19 pandemic, with family not being allowed to stay as support for ill patients.

### Patients and their whānau need a holistic management approach

The third theme was inspired by a very powerful quote from one of the patients: "*You receive the diagnosis, but your whānau have cancer.*"

**Table 4:** Quotes supporting “a lack of tailored breast cancer treatment information and guidance for patients”.

“Yeah. Well, I didn’t really know what to tell my boss. And I didn’t know what I needed. And I didn’t know what to say. And I didn’t know who to tell or whom not to tell. And it was just a bit like, I don’t really know what to do. Yeah. Yeah.” – Participant 6 (47, F, non-Māori/non-Pacific)
“I kind of found a lot of, uhm I guess, yeah inconsistencies. There were times that I felt like, who do I call [post-surgery]? What do I do?” – Participant 3 (51, F, Māori)
“I’m a verbaliser. I like to be told so I do not need to trawl through a lot of information like I am visual you know. That is how I learn. I am a visual learner.” – Participant 2 (59, F, Māori)
“I made them also print out what they were showing me on the screen, because a lot of the time, we’re looking at the screen.” – Participant 7 (53, F, Pacific)
“Just give me what I need to know now. So, like for this next 2 weeks, you just need to know this booklet here. Don’t worry about the rest of it, because you keep going back to it like what am I meant to do with all of this.” – Participant 1 (51, F, Māori)

**Table 5:** Quotes supporting “many barriers to accessing and benefitting from breast cancer services”.

“I mean I would have to come all the way to town … It will take a whole day.” – Participant 3 (51, F, Māori)
“Mine is at Boulcott Hospital and I have to drive from work to Boulcott Hospital and then back to work … For 3 weeks it was back and forth.” [1 hour total commute] – Participant 6 (47, F, non-Māori/non-Pacific)
“Because I got crook a few times on chemotherapy and have to come into hospital, but even trying to ring, uhm, the ward … Uhm, it was one night I was it took me 2 hours to get through … So I am on the phone, coming through into town, trying to ring someone and no one is picking up the phone.” – Participant 3 (51, F, Māori)
“But you[’re] constantly being made to feel guilty because you’ve only got a little cancer that’s, you’re one of the lucky ones. But it’s, it’s not look, I’ve still gonna … do this crap!! [laughter from group].” – Participant 6 (47, F, non-Māori/non-Pacific)

**Table 6:** Quotes supporting “patients and their whānau need a holistic management approach”.

“I had real troubles with work and like trying to navigate, how to get time off work? How to heal properly and keep your job? … But it was pretty, that was worse than any of the treatments or anything was not knowing what’s available … I think I just needed an advocate to help me get time off.” – Participant 6 (47, F, non-Māori/non-Pacific)
“Even knowing that having support for, for families, how to the you know, how, how do they, you know, live with cancers.” Participant 7 (53, F, Pacific)
“And my niece… There’s three. And I just lost my cousin 3 weeks ago.” – Participant 2 (59, F, Māori)
“I was having to take somebody to every appointment because I just go on like. What is going on here and I just sit down. My partner would always say to me, no that’s not what the breast surgeon said. Like you know. Like your head goes somewhere else.” – Participant 2 (59, F, Māori)
“Yeah, well, mum was supportive of me. And, you know … she keeps away from me when she’s unwell as well … Uhm I’m not able I’m not well enough to support her fully, but my sister’s there so she’s her main caregiver. And my daughter’s helped out sometimes but, yeah with me, I’m well supported my fam.” – Participant 7 (53, F, Pacific)

Participants reported that when one individual in the whānau is experiencing pain or illness, the whole whānau feel the pain and experience the suffering together with that individual. They often referred to the whānau as the “body”, meaning that if one part of the body, i.e., an arm, is injured, the whole body would feel it. This theme reflects the need for a holistic approach to patients’ management, including their whānau. In the first sub-theme “advocates for optimum quality of life with breast cancer”, participants highlighted that it was crucial to have a support person during appointments. This was especially illustrated by Māori and Pacific participants. Participants emphasised the significance of having an advocate who can provide occupational support alongside managing treatment commitments, as it was unclear when and how they could or should take time off work. The second sub-theme, “whānau support”, outlines how, for many patients, whānau play a major role in providing support throughout the treatment process and offer another perspective on decision making as the diagnosis influences everyone. In the third sub-theme, “support for whānau”, participants underscored the importance of offering support for these carers or extended whānau to help support them living with a person with breast cancer. Additionally, participants described how prevalent breast cancer is in whānau and therefore emphasised the importance of a whānau-based approach to breast cancer treatment.

## Discussion

### A lack of tailored breast cancer treatment information and guidance for patients

The first theme, “a lack of tailored breast cancer treatment information and guidance for patients”, was consistent between the three sessions. Participants highlighted a dearth of information preceding treatment, specifically concerning the commitment required by patients, how to handle work responsibilities and the invasiveness of upcoming investigations, i.e., biopsies. Consequently, this lack of clarity left participants feeling lost and lacking direction regarding what to expect in the post-surgical phase of intervention. This was reported by participants who received their breast cancer surgery in the private health sector as well as the public health sector. They expressed the perception that the information provided was disjointed and inconsistent, contributing to feelings of uncertainty

about the trajectory of their treatment. Previous research has identified that breast cancer patients in Aotearoa New Zealand reported shock and distress on receiving their cancer diagnosis, which is the time that patients are generally also provided with important diagnostic and treatment information.<sup>12</sup> They reported how this shock impacted their ability to retain the diagnostic information presented to them. This inability to retain this information may explain the perceived dearth of information participants in this study reported. However, other international studies have previously documented that patients perceived their perioperative information as insufficient and poorly timed.<sup>13</sup> The recurrence of these themes in past literature underscores the necessity for innovative methods to enhance healthcare accessibility.

In contrast, some participants conveyed that the information presented during appointments was overwhelmingly dense, making it challenging to process. Māori and Pacific participants emphasised the significance of incorporating visual tools alongside verbal information to facilitate their comprehension of treatment-related information. This has been noted in previous research that investigated wāhine (women) Māori with breast cancer, who expressed a lack of clear, culturally relevant guidance at key points in their treatment journey and recommended a multi-modal presentation of medical information, with inclusion of te reo Māori.<sup>11</sup> Ultimately, these findings reinforce the value of redesigning breast cancer information in Aotearoa New Zealand using co-design approaches that reflect the needs and realities of our diverse population.

### Many barriers to accessing and benefitting from health services

Participants reflected on personal experiences and those of their whānau to identify barriers that they encountered in accessing and benefitting from breast cancer services. Participants emphasised that the location where services and appointment locations were offered posed a significant obstacle to utilising them. Barriers to healthcare access for Māori and Pacific patients in Aotearoa New Zealand are well documented and include institutional racism, geographic and financial challenges and distrust in services due to historical and ongoing inequities.<sup>14,15</sup> Our study findings reflect many of these broader systemic issues, with participants describing logistical difficulties, emotional burdens and fragmented support

systems. However, this study uniquely captures participants' emotional tolls and sense of abandonment that results from insufficient follow-up and lack of guidance post-surgery. These experiences of being unsure who to contact, or feeling guilty for seeking help, reflect the relational harms that can occur when healthcare systems fail to deliver culturally safe, responsive care. It would also seem to lead to further mistrust in the health system among minority populations such as Māori and Pacific.<sup>16</sup> For example, some participants found it quite frustrating and frightening to reach out to services instructed to be contacted in case of concerns, such as calling the emergency department if they developed a fever while on chemotherapy. One participant expressed feeling guilty for seeking help as her cancer was not deemed urgent by health professionals. These insights expand current understandings of how cultural safety and health equity must be embedded not just in access and during the surgical cancer journey, but in every stage of care delivery. This also underscores a need for ongoing investment and training in relationship-centred models of care.

### **Patients and their whānau need a holistic management approach**

The third theme outlines when one individual in the whānau is experiencing pain or illness, the whole whānau feel the pain and experience the suffering together with that individual. Previous research noted that excessive focus on viewing the patient solely as a "site of disease" with an overemphasis on risk management can undermine holistic, patient-centred perspectives and can diminish the effectiveness of crucial non-medical aspects associated with patient care.<sup>17</sup> The need for holistic, whānau-inclusive cancer care in Aotearoa New Zealand has been articulated in many studies.<sup>18,19</sup> However, our study results outline how it remains inconsistently embedded in practice. Our findings are a reminder that for many families, including Māori and Pacific families, illness is a shared experience, and that treatment and care planning must reflect this reality.

Similarly, participants expressed a need for advocates to aid patients with their personal responsibilities, which were in addition to commitments associated with treatment. One participant emphasised the importance of having an advocate who could provide support with respect to employment-related issues alongside the management of treatment-related commitments. This

included factors such as sick leave entitlements, the physical demands of their job and flexibility of employment to work from home. Previous research has described significant employment rate reductions, income support increases and income losses in the 4 years after first breast cancer diagnosis in Aotearoa New Zealand.<sup>20</sup> This is also an issue of equity for Māori, Pacific and lower socio-economic status patients who are more likely to work in the construction and service industries.<sup>21,22</sup> These women may also have responsibilities for their children, whānau and community. Therefore, it is vital to investigate thoroughly in a respectful and non-judgemental manner the circumstances of each patient. Here, this study adds nuance by illustrating that economic dimensions of post-treatment recovery are an important part of the treatment process for patients in the healthcare system—especially for women balancing caregiving and employment. This study supports that healthcare or associated services must consider return-to-work planning and financial navigation as core components of care, especially when caring for patients facing structural disadvantage.

Additionally, some participants underscored the importance of the offer of support due to high prevalence of disease within the whānau. This is a critical observation, given that for numerous patients, their whānau plays a major role in the provision of support throughout the treatment process. Whānau also provide another perspective regarding treatment and disease-related decision making. Previous research has shown that whānau involvement is central to culturally responsive cancer care in Aotearoa New Zealand. For example, previous research highlighted the critical role Māori health providers play in supporting whānau across the cancer continuum—offering not only clinical navigation but also transport, advocacy and emotional support through family-based care rather than individual-based care.<sup>19</sup> While their work focusses on the delivery of services from the provider perspective, our study adds the lived experiences of wāhine Māori, Pacific, and non-Māori/Pacific breast cancer survivors themselves. More broadly, in stroke patients, rehabilitation sessions including family members significantly enhanced outcomes when compared to those without family involvement.<sup>23</sup> The authors also suggested that caregiver strain reduced with family participation in patient care, and additional family support led to increased social activities and improved quality of life for

all parties involved. These findings suggest that similar approaches in cancer care—where whānau are included and supported throughout the treatment journey—may improve both patient and family outcomes.

## Implications for equity and health system improvement

These findings reflect wider systemic barriers that contribute to health inequities for Māori and Pacific women undergoing breast cancer treatment. In line with *Te Tiriti o Waitangi* and the *Pae Ora (Healthy Futures) Act*, this study underscores the need for culturally responsive care that recognises the collective experience of whānau, the importance of clear and tailored communication and the logistical barriers that affect access to services.<sup>24,25</sup> These issues mirror known inequities outlined in the Waitangi Tribunal's Health Service and Outcomes Inquiry (Wai 2575) and highlight opportunities to improve cancer care pathways in Aotearoa New Zealand.<sup>26</sup>

The findings also align with the goals of the Women's Health Strategy 2023, which calls for health services that are more equitable, whānau-centred and responsive to the needs of wāhine Māori and Pacific women.<sup>27</sup> In particular, the strategy highlights the importance of providing health information that is culturally appropriate, accessible and co-designed with communities. Our participants' experiences reinforce these priorities and point to practical improvements, including the redesign of post-operative information materials, development of whānau-inclusive models of patient education and more culturally responsive service planning. While based on a small sample, the study contributes meaningful, patient-led insights to support breast cancer care in Aotearoa New Zealand.

## Strength and limitations

This study included patients from various ethnic backgrounds and categorised them into different groups based on ethnicity. This approach offered a platform for Māori, Pacific, and non-Māori to precisely express their individual healthcare needs and explore effective ways to address these needs in the future. Although the sample is small, the study prioritised depth over breadth to understand culturally specific experiences that are often under-represented in surgical literature. We considered sample

adequacy through the lens of information power, where smaller samples may be sufficient if the data are rich and focussed, and the aim is narrow.<sup>28</sup> Given the specific focus of our study, participant specificity and high-quality dialogue, our sample was deemed appropriate to address the research aims.

However, the study was conducted solely in the Wellington Region, with a modest number of participants; therefore, the data are limited in their interpretation and may not be extrapolated to fully represent healthcare needs throughout Aotearoa New Zealand, such as women in rural settings. Also, there was only one Pacific participant (Samoan). This participant's viewpoints are not representative of the whole Pacific population, who make up 6.9% of the overall population of Aotearoa New Zealand.<sup>21</sup> This includes a combination of ethnic groups, including but not limited to Samoan, Tongan and Cook Islander. Furthermore, participants were not explicitly asked to describe aspects of their breast cancer care that worked well, which may have limited insights into strengths or successful components of current services. Finally, this study was not conducted under a Kaupapa Māori research framework. We acknowledge that Kaupapa Māori research centres Māori ways of knowing, tino rangatiratanga (self-determination) and Māori leadership at every stage.<sup>29</sup> Conducting research with Māori outside such a framework poses risks—such as reinforcing power imbalances, limiting cultural safety, marginalising Indigenous knowledge and misinterpreting data.<sup>30</sup> To mitigate these risks, this study was developed by a team that included one Māori researcher, incorporated tikanga Māori processes such as karakia and whakawhanaungatanga and involved Māori input in data interpretation. However, we recognise these efforts do not fully address the limitations of working outside a Kaupapa Māori approach.

## Conclusion

This qualitative study aimed to explore breast cancer patients' perceptions of their treatment, the information received during their treatment and the support received during their treatment. It investigated preferred resources and perceptions of healthcare providers and emphasised the importance of involving family—“*You receive the diagnosis, but your whānau have the cancer.*” This study identified a need for tailored information

relevant to the specific population groups and a need to be holistic when considering patient management approaches. The study also identified barriers to accessing health services

in local communities. These findings hope to influence health strategies to support various breast cancer patient groups.

**COMPETING INTERESTS**

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**AUTHOR INFORMATION**

Dr Tātila Helu: Junior House Officer, Department of Surgery and Anaesthesia, University of Otago, Wellington, Aotearoa New Zealand.

Dr Emma O'Loughlin: Senior Lecturer, Department of Surgery and Anaesthesia, University of Otago, Wellington, Aotearoa New Zealand.

Witana Petley: Centre for Health, Activity, and Rehabilitation Research, School of Physiotherapy, University of Otago, Dunedin, Aotearoa New Zealand.

Dr Aleksandra Popadich: Breast, Endocrine and General Surgeon, Professional Practice Fellow, Department of Surgery and Anaesthesia, University of Otago, Wellington, Aotearoa New Zealand.

**CORRESPONDING AUTHOR**

Dr Emma O'Loughlin: Senior Lecturer, Department of Surgery and Anaesthesia, University of Otago, 23 Mein Street, Newtown, Wellington 6021, Aotearoa New Zealand. E: emma.oloughlin@otago.ac.nz

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# Computed tomography colonography performs poorly in detection of sessile serrated lesions

Shiristi Kumar, Andrew McCombie, Simon Richards, Tamara Glyn, Emma Bone, Tim Eglinton

## ABSTRACT

**BACKGROUND:** Computed tomography colonography (CTC) is an alternative to colonoscopy for the detection of polyps and colorectal cancer (CRC). One-third of CRCs arise via the sessile serrated pathway. Evidence supports using CTC to detect adenomas and CRC; however, its accuracy for sessile serrated lesions (SSLs) remains uncertain. This study aimed to determine the accuracy of CTC in detecting SSLs compared with colonoscopy.

**METHOD:** Electronic records identified all colonoscopy procedures where a histologically validated SSL was excised over a 11-month period. In those patients who had a CTC within 1 year prior to colonoscopy, the presence, size and location of SSLs were compared to determine the accuracy of CTC in SSL identification.

**RESULTS:** A total of 4,346 procedures were performed (2,548 people, 2,082 [47.9%] male, mean age 59.6). A total of 2,204 SSLs were removed, representing 24% of all polypectomies. SSLs were predominantly located in the right colon (65.1%) and were typically (85%) <10mm in size. A total of 110 SSLs were obtained from 39 procedures with a prior CTC. Of these procedures, 12 (30.8%) had lesions identified on CTC; however, CTC only accurately identified 14.5% of the total SSLs. Five of 16 (32%) SSLs ≥10mm were correctly identified compared with 11 of 94 (11%) SSLs 1–9mm, (odds ratio 3.42,  $p=0.0495$ ).

**CONCLUSION:** This study demonstrated that CTC has poor efficacy in detecting SSLs, irrespective of polyp size and location. Based on these findings, CTC as a substitute for colonoscopy is not advisable in patients at risk of SSLs.

Globally, colorectal cancer (CRC) is the third most common cancer and is the second leading cause of cancer-related mortality. The incidence of CRC is higher in developed countries and is increasing in middle- and low-income countries.<sup>1</sup> Aotearoa New Zealand is no exception: CRC is the second most commonly diagnosed cancer and the second most common cause of cancer-related death, with over 1,200 deaths annually.<sup>2</sup> Its prevalence increases with age, with most cases occurring in individuals ≥50 years.<sup>1,3</sup> It is widely recognised that the CRC-associated health burden can be significantly reduced by early detection and timely management.

CRC develops within pre-cursor lesions, justifying screening and polyp resection in at-risk individuals.<sup>4</sup> The majority of current screening and detection guidelines focus on detection of conventional adenomas, which progress via the chromosomal instability pathway (CIN).<sup>5</sup> Contemporary CRC research suggests that at least one-third of CRCs arise from the progression of serrated lesions via the serrated pathways.<sup>6–8</sup>

Sessile serrated lesions (SSLs), previously referred to as sessile serrated adenomas,<sup>9</sup> gained pathological recognition in 1990 after identification of polyps that shared features of both hyperplastic and adenomatous polyps.<sup>10</sup> Despite this, global recognition and reporting of SSLs did not begin until the early 2000s, at which time SSLs were described as their own entity<sup>11</sup> and, importantly, differentiated from their low malignant potential counterpart, the hyperplastic polyp.

Computed tomography colonography (CTC) utilises low-dose radiation and pneumatic colonic insufflation to obtain views of the colon. Its advantages lie in it being non-sedative, non-invasive and minimising the risk of bleeding and colonic perforation.<sup>12</sup> CTC has demonstrated high sensitivity for large polyps in both asymptomatic<sup>13</sup> and symptomatic populations.<sup>14</sup> As such, meta-analysis data illustrate the sensitivity of CTC for polyps 6mm or larger and 10mm or larger as 85.3% and 90.8% respectively.<sup>15</sup>

Previous work from this institution<sup>16</sup> questioned whether CTC is a viable screening tool for SSL, in particular for smaller polyps, given

over 85% of SSLs in this study were <10mm. Flat colonic lesions are a known source of false-negative CTCs;<sup>17</sup> this in turn raises questions regarding its utility for the detection of SSLs, given their flat morphology. To date, there have been mixed results with respect to the adequacy of CTC in identifying SSLs,<sup>12,18-22</sup> with many studies predating the recent histological classification of SSLs and technical improvements in both colonoscopy and CTC. Few studies have specifically looked at the efficacy of CTCs in detecting flat SSLs in direct comparison with colonoscopy. A recent study<sup>18</sup> of 79 patients, evaluating the efficacy of CTC in detecting polyps, identified a high false-negative rate with almost one-third of large SSLs (>1cm) being missed by CTC, and, overall, CTC identified less than half of all SSLs seen on subsequent colonoscopy.

This study aimed to determine the accuracy of detection of SSLs in patients undergoing CTC within a year prior to colonoscopy, in an Aotearoa New Zealand tertiary centre. Additionally, acknowledging the previously reported right-sided abundance of SSLs and greater sensitivity of CTCs for large polyps, it secondarily aimed to determine whether the location and/or size of SSLs affects their detection rate on CTC.

## Method

### Population

The methodology used to collect this dataset has been previously described.<sup>16</sup> All adult patients undergoing either a colonoscopy or flexible sigmoidoscopy within the Canterbury District Health Board (DHB) between 1 January 2022 and 1 December 2022 were identified retrospectively through the local prospectively maintained endoscopic database, Provation® (Provation Software Inc, Minneapolis, United States of America). Procedures were excluded if there was inadequate clinical, demographic or pathological information. This study was approved by the New Zealand Health and Disability Ethics Committee as an out-of-scope review. Locality approval was obtained from Te Whatu Ora – Health New Zealand Waitaha Canterbury (RO#22215). This study included patients from our previously published paper known to have had both (at least) one SSL and undergone a CTC. All CTCs were subject to standard bowel preparation and were exempt from polyp detection aids like oral barium contrast and/or faecal tagging. The centre at which this study was conducted has a 97% caecal intubation rate and 94.6%  $\geq$ 6-minute withdrawal time.

The inclusion criteria for this study comprised adult patients who underwent colonoscopy within the Canterbury DHB between 1 January 2022 and 1 December 2022. Eligible participants were patients who had at least one SSL diagnosed using the latest World Health Organization (WHO) classification system during the study period and undergone a CTC within 1 year prior to the SSL resection. A 1-year cutoff period was chosen, given that a short follow-up period would identify lesions that were “missed” rather than SSLs that were interval growths. Additionally, only records with complete demographic and clinicopathological data, including age, gender, ethnicity, indication for examination, polyp location and polyp size, were considered for inclusion.

Exclusion criteria for this study included procedures with incomplete or inadequate clinical, demographic or pathological information, as well as any CTCs performed more than 1 year prior to the assessment. Suboptimal CTCs (e.g., through inadequate insufflation) were excluded.

### Data extraction

Demographic and clinicopathological data were extracted from patient medical records and anonymised. Collected variables included age, gender, ethnicity and examination indication. Procedure and pathology reports provided data on polyp location (categorised as right colon, left colon, and rectum) and size (small [<10mm] or large [ $\geq$ 10mm]). The latest WHO classification system for SSLs was employed. This determines that the presence of one unequivocally distorted crypt is diagnostic of an SSL, and crypt distortion was defined by the presence of any of: horizontal crypts, dilated basal third of the crypt and/or serrations extending into the crypt base.<sup>23</sup>

When patients with an SSL were identified their record was searched, and all those who had a CTC within 1 year prior to the colonoscopy were included in this analysis. The CTC reports were reviewed and the presence, size and location of any lesions recorded. The endoscopic data were compared with the CTC findings on both a per-polyp and per-procedure basis to determine the accuracy of CTC in identifying SSLs.

### Statistical analysis

RStudio<sup>24</sup> was used for statistical analysis. For the per-procedure analysis, percentages of each gender and ethnicity were calculated and it was cross-tabulated whether there was at least one large polyp ( $\geq$ 10mm) versus whether at least one

small polyp (<10mm) was detected on CTC. For the per-polyp analysis, whether or not the polyp was seen on CTC was cross-tabulated against the size ( $\geq 10$ mm versus <10mm) and location (left colon or rectum versus right colon). All cross-tabulations were calculated using binary logistic models and odds ratios (ORs) and p-values reported.

## Results

A total of 4,346 colonoscopy procedures (2,548 people, 2,082 [47.9%] male, mean age 59.6) were performed between 1 January 2022 and 1 December 2022 (inclusive), of which 2,786 (64.1%) underwent polypectomy. As reported previously,<sup>16</sup> data on 10,026 individual polyps were collected. After excluding "normal tissue", "adenocarcinoma" and "other" non-polypoid histology, of the 9,166 polyps there were 2,204 SSLs (24%), of which 3.6% were dysplastic. SSLs were typically (85%) less than <10mm and predominantly (65%) located within the right colon (versus 33% in the left colon and 2% in the rectum). Table 1 describes the patient and SSL characteristics.

A CTC was performed within a year prior to 39 endoscopic procedures where a total of 110 SSLs were removed with polypectomy and were histologically confirmed (Table 1). All of the CTCs were of excellent quality. The maximum time to polypectomy was 5 months, with most (>97%) of SSLs resected within 3 months of the CTC. Of the 39 procedures, 20 (51.3%) were males versus 19 (48.7%) in females, and 36 (92.3%) were in patients of European descent. Median age was 62 years (interquartile range 62–79 years). In only 12 of the CTCs performed prior to these 39 procedures (30.8%), at least one SSL was detected and CTC only correctly identified 16 (14.5%) of all 110 SSLs.

### SSL detection rate based on size and location

#### Size of polyps

CTC had a poor detection rate for both small and large SSL. Five of 16 (32.25%) large polyps ( $\geq 10$ mm) versus 11 of 94 (11.7%) small polyps (<10mm) were detected (OR 3.42, p=0.0495). Four of eight (50%) procedures that contained at least one large polyp ( $\geq 10$ mm) had at least one detected on CTC versus eight of 31 (25.8%) that did not have at least one large polyp ( $\geq 10$ mm) (OR 2.88, p=0.20).

#### Locations of polyps

Despite the well-known right-sided distribution

predominance of SSLs, also evident in our study, CTC failed to detect the majority of right-sided SSLs. Fourteen of 75 (18.7%) polyps were detected in the right colon compared with two of 35 polyps (5.7%) in the left colon/rectum (OR 3.79, p=0.09). Breaking down the left-sided lesions, detection rates within the left colon itself were two of 32 (6.3%) and zero of three in the rectum (0%).

## Discussion

This study found that CTC has poor efficacy in detecting SSLs, irrespective of size and/or location and, overall, correctly identified only 14.5% of all SSLs, resulting in a high miss rate. This finding aligns with emerging literature showing poor efficacy of CTC in detecting SSLs.<sup>18,19,22</sup>

Deiss-Yehiely et al.<sup>22</sup> compared multitarget stool DNA with CTC in the detection of SSLs; the authors identified a CTC detection rate of 14.4% at 6mm and 25.9% at 10mm thresholds. Of note, however, they used low-density oral barium to aid polyp detection.<sup>22</sup> Singla et al.<sup>18</sup> directly compared the efficacy of CTC and colonoscopy in detecting SSLs and concluded that 51.3% of SSLs were missed by CTC. In keeping with the current study, they had a poor detection rate regardless of size, with nearly one-third of large (>10mm) SSLs being missed on CTC.

This finding of a high miss rate is of particular concern given the recent recognition that SSLs are premalignant lesions<sup>25</sup> that may progress to CRC at higher and more rapid rates than previously reported.<sup>26–28</sup> As a result, timely detection and treatment of SSLs is of significant clinical importance. Having previously been predominantly used in those patients with contraindication to colonoscopy or in resource-constrained environments, more recently CTC has been increasingly used as a screening tool due to its non-invasive nature, faster procedure time, better safety profile and ability to avoid sedation.<sup>19,29,30</sup> Recent publications from Australasia<sup>19</sup> and Asia<sup>29</sup> promote the use of CTC in both the screening and non-resource-constrained environment.<sup>29</sup> These recommendations are likely a result of previous studies identifying high accuracy for polyp detection, even those polyps <10mm<sup>12,31,32</sup> and not differentiating polyp subtype. It is likely that many studies also predate the modern histological classification of SSLs.<sup>23</sup> As a result, we recommend caution in the use of CTC for CRC screening due to this high miss rate and thereby recommend high-quality colonoscopy as our preferred screen-

ing modality due to its ability to detect and remove all types of colonic polyps.

SSLs are infrequently detected by faecal immunochemical tests (FIT), with meta-analysed pooled detection rates of only 4.1%.<sup>33</sup> However, SSLs frequently coexist with conventional adenomas,<sup>34</sup> making it more likely that patients undergo follow-up colonoscopy after a positive FIT triggered by an advanced adenoma rather than the SSL itself. While diagnostic colonoscopy is usually performed following a positive FIT result, in our study the main indication for colonoscopy leading to SSL resection was abnormal polyp detection on CTC imaging.

A recent Australian report<sup>19</sup> suggested that with the growing demand for endoscopies, increased utilisation of CTC could reduce waiting times for colonoscopy, thereby broadening access to timely and effective CRC screening. However, the need to subject patients to a follow-up colonoscopy after a positive CTC can negatively affect the cost-benefit ratio of this approach.

Due to concerns regarding waiting times and resource limitations, stool-based tests, such as quantitative FIT or faecal DNA testing, can serve as non-invasive alternatives for initial screening, prompting follow-up colonoscopy if abnormalities are detected. Additionally, given the challenge of detecting SSLs with CTCs, a risk-stratified approach to screening, prioritising colonoscopy for individuals at higher risk of SSLs—such as those with a family history of CRC or prior polyps—can help optimise resource allocation and improve overall screening to ensure accurate diagnosis and prevention of CRC.

In those patients where colonoscopy is contraindicated and/or timely access to colonoscopy may be limited, the use of adherent contrast material may aid in SSL detection.<sup>35-37</sup> In a retrospective study of flat polyps, Kim et al. demonstrated that oral contrast in conjunction with CTC improved sessile serrated polyps and traditional serrated polyp detection rates with an OR of 40.4 (95% confidence interval 10.1–161.4).<sup>36</sup> Our centre does not routinely employ oral barium or contrast agents to facilitate polyp detection; however, this remains an area of interest for future research.

The strengths of this study include a large sample size from a tertiary healthcare institution with expert endoscopists and reporting radiologists, with synoptic reporting allowing for complete data capture and more robust results. While many radiology centres across Aotearoa New Zealand do not routinely report on polyps <5mm visible on CTCs, our centre did, hence small polyps were included in the present study. Given SSLs drive an accelerated pathway to CRC, with rapid development of microsatellite instability, BRAF mutations and CpG island methylator phenotype, resulting in faster progression compared with conventional adenoma,<sup>38</sup> and our initial work illustrated the majority of SSLs were <10mm, focussing on smaller SSLs was thought to be clinically significant. The main limitation is the retrospective design allows for only a snapshot of SSL incidence within a local population. Furthermore, the high incidence and miss rate of SSLs with CTC observed in an Aotearoa New Zealand population may not be directly generalisable to other populations. This study did not specifically investigate post-imaging CRC as key performance indicator (KPI). Future research could look at the post-CTC and colonoscopy CRC rate as a KPI as this information was not available for the present study. Nonetheless, this notable increase in miss rates highlights the need for consideration of contemporary SSL data in other regions and necessitates a re-evaluation of CTC efficacy in CRC surveillance on a global scale.

## Conclusion

This study demonstrated a high prevalence of SSLs at colonoscopy and that CTC has poor efficacy for detecting SSLs, irrespective of size and location. In light of these findings, CTC cannot be considered as equivalent to colonoscopy for detecting SSLs and is not recommended by the authors. With CRC rates continuing to rise across Western populations, the detection and removal of precursor lesions remains the cornerstone of combatting CRC pathogenesis. Advanced techniques including contrast tagging offer potential improvement in detection rates, and further research is required to examine these.

**Table 1:** Patient and sessile serrated lesion (SSL) characteristics.

<b>Patient characteristics</b>	
Patients (n)	39
Procedures (CTC)	39
Males	20 (51.3%)
Females	19 (48.7%)
Median age	62 (interquartile range 62–79)
<b>SSL characteristics</b>	
Total SSL	110
Dysplastic SSLs	0
SSL <10mm	94
SSL >10mm	16
At least one SSL detection per CTC	30.8% (12 procedures)
% SSLs correctly identified by CTC	14.5% (16/100)

SSL = sessile serrated lesion; CTC = computed tomography colonography.

**COMPETING INTERESTS**

None declared.

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**DATA AVAILABILITY STATEMENT**

Can be made available on request.

**AUTHOR INFORMATION**

Shiristi Kumar: Department of Surgery and Critical Care, University of Otago Christchurch, Aotearoa New Zealand; Junior Registrar, Department of General Surgery, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Aotearoa New Zealand.

Andrew McCombie: Honorary Senior Research Fellow, Department of Surgery and Critical Care, University of Otago Christchurch, Aotearoa New Zealand; Research Officer and Data Analyst, Department of General Surgery, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Aotearoa New Zealand.

Simon Richards: Senior Lecturer, Department of Surgery and Critical Care, University of Otago Christchurch, Aotearoa New Zealand; General Surgeon, Department of General Surgery, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Aotearoa New Zealand.

Tamara Glyn: Senior Lecturer, Department of Surgery and Critical Care, University of Otago Christchurch, Aotearoa New Zealand; General Surgeon, Department of General Surgery, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Aotearoa New Zealand.

Emma Bone: Trainee Intern, Department of Surgery and Critical Care, University of Otago Christchurch, Aotearoa New Zealand.

Tim Eglinton: Professor, Department of Surgery and Critical Care, University of Otago Christchurch, Aotearoa New Zealand; General Surgeon, Department of General Surgery, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Aotearoa New Zealand.

**CORRESPONDING AUTHOR**

Andrew McCombie: Honorary Senior Research Fellow, Department of Surgery and Critical Care, University of Otago Christchurch, Aotearoa New Zealand; Research Officer and Data Analyst, Department of General Surgery, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Aotearoa New Zealand.

E: Andrew.mccombie@cdhb.health.nz

**URL**

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# The health of New Zealand cardiology: senior medical officer workforce survey

Selwyn P Wong, Martin K Stiles

## ABSTRACT

**AIM:** To quantify the current state of the cardiology specialist workforce in Health New Zealand – Te Whatu Ora.

**METHODS:** The Cardiac Society of Australia and New Zealand sent a survey to all Health New Zealand – Te Whatu Ora cardiology departments in 2024, requesting information on specialist cardiac staff. Population information was obtained from Health New Zealand – Te Whatu Ora. International comparisons were obtained by website search.

**RESULTS:** Of 154 Health New Zealand – Te Whatu Ora-employed cardiologists, 119 (77%) were male, and 113 (73%) received cardiology training in New Zealand. Over half were aged >50, 35% >55, including 18% >60 years. Time in current position was 12±9 years and the vacancy rate was 14%. The current ratio of persons per cardiologist is 35,000. In the five districts with the highest proportion of Māori and Pacific peoples, this ratio exceeds the national average: Tairāwhiti 54,000; Counties Manukau 38,000; Lakes 61,000; Northland 52,000; Hawke's Bay 47,000. For cities with cardiac surgery the ratio is 32,000 and without is 46,000. International ratios include: United States of America (USA) 15,000; Canada 25,000; United Kingdom (UK) 40,000 and Australia 25,000 persons per cardiologist.

**CONCLUSIONS:** Health New Zealand – Te Whatu Ora has an experienced but ageing cardiologist workforce, with many vacancies. Districts with higher Māori/Pacific populations have fewer cardiologists per capita than the national average of 1:35,000, which is similar to the UK, but less than the USA, Australia and Canada.

**C**ardiovascular disease demand on Health New Zealand – Te Whatu Ora services is increasing. Nationally, the number of first specialist assessment referrals and the wait times for those appointments are rising. This also pertains to cardiology investigations of both outpatients and inpatients (especially cardiac ultrasound and cardiac catheterisation). There is an increasing strain on the workforce that is apparent from collegial discussion. Furthermore, the public hospital health workforce has been of growing concern to clinicians working in the sector for years. Inadequacies were exacerbated by demands and employment patterns during and after the COVID-19 pandemic. Cardiology services face an increasing demand with human resource a major constraint to appropriate service delivery. Hence, the New Zealand Region of the Cardiac Society of Australia and New Zealand (CSANZ) sought to quantify the current state of the workforce in New Zealand.

## Methods

In 2024, a survey was sent to each public hospital clinical head (cardiology or department of

medicine) with a request for information regarding their senior medical officer workforce (those vocationally qualified as adult medicine cardiologists). Data requested included demographics and length of service. Department heads were also asked about any vacant cardiologist positions. Similar requests were sent to cardiology nursing leads and cardiac technologists and will be the subject of a separate report. The data from the senior medical workforce are presented in this paper.

Where necessary, additional information was obtained from the CSANZ database, Health New Zealand – Te Whatu Ora data, the Te Kaunihera Rata o Aotearoa | Medical Council of New Zealand (MCNZ) register and information from the Royal Australasian College of Physicians (RACP). Age was quantified in 5-year bands. Ethnicity was self-identified.

Population data were obtained from Health New Zealand – Te Whatu Ora populations web tool.<sup>1</sup> The population was divided according to Health New Zealand – Te Whatu Ora districts. Within each district, the population of Maori and Pacific peoples was also obtained. Further division was performed according to “metro” districts;

defined as those with cardiac surgical services in the same city, i.e., Waitematā, Auckland, Counties Manukau, Waikato, Wellington, Christchurch and Dunedin. The correct statistical analysis comparing districts by ethnicity and metro/non-metro was uncertain. Limited statistical analysis did not lend weight, and hence, we have let the data stand on their own.

Comparison data from other jurisdictions were obtained from online sources. This included the Association of American Medical Colleges 2021,<sup>2</sup> the Canadian Medical Association 2019,<sup>3</sup> the British Cardiovascular Society estimate 2015,<sup>4</sup> the United Kingdom (UK) cardiovascular workforce report 2022,<sup>5</sup> the Australian Institute of Health and Welfare data 2016,<sup>6</sup> the Western Australian Department of Health data 2021<sup>7</sup> and the New South Wales Government 2019.<sup>8</sup> The metric used in this

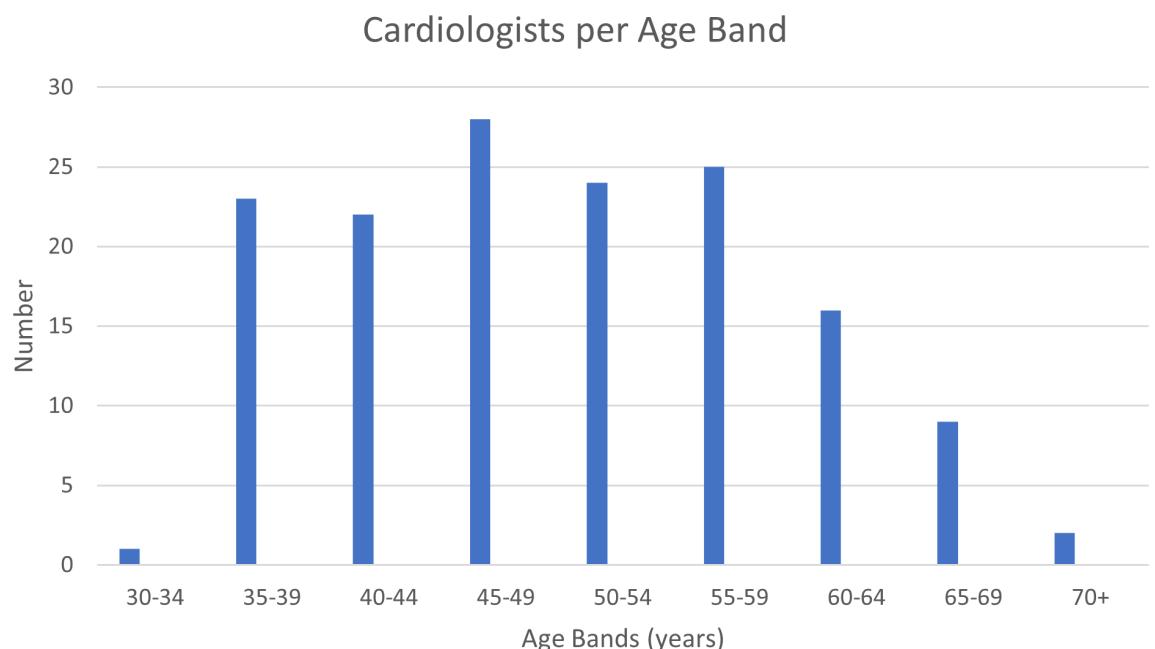
paper is the calculated or reported population per cardiologist. Paediatric cardiologists were not included in our numbers.

## Results

As of July 2024, complete data were obtained on all Health New Zealand – Te Whatu Ora cardiologists. At the time of writing, there are 154 cardiologists employed by Health New Zealand – Te Whatu Ora. Of these, 119 (77%) are male. Those that received their specialist cardiology training (FRACP) in New Zealand numbered 113 (73%). Age data were available from 150 of the cardiologists whose information was included in the survey.

This is an experienced workforce with 50% being over 50 years of age (Figure 1). Time spent in their current position was on average 11.9±9

**Figure 1:** Number of cardiologists in age bands\*.



\*No age data for four, n=150.

**Table 1:** Cardiologists by ethnicity.

Ethnicity	NZ European	Other European	Indian	Chinese	Other Asian	Māori	Pacific peoples	Other
N (%)	72 (51)	24 (17)	22 (16)	15 (11)	5 (2)	2 (1)	1 (1)	13 (9)

\*No ethnicity data for 13 cardiologists, n=141.

**Table 2:** Population per cardiologists by region—listed according to Māori/Pacific proportion.

	<b>Total population (000)</b>	<b>Māori n(%)</b>	<b>Pacific peoples n(%)</b>	<b>Māori/Pacific (%)</b>	<b>Cardiologist (number)</b>	<b>Population per cardiologist (000)</b>
<b>All district health board regions</b>	<b>5,325.9</b>	<b>918.5 (17%)</b>	<b>373.2 (7%)</b>	<b>24</b>	<b>154</b>	<b>35</b>
Tairāwhiti	54	29.8 (55)	1.3 (2)	57	1	54
Counties Manukau*	642	103.0 (16)	143.7 (27)	43	17	38
Lakes	122	46.6 (38)	3.2 (3)	41	2	61
Northland	207	75.2 (36)	4.8 (2)	38	4	52
Hawke's Bay	187	53.5 (29)	8.8 (5)	34	4	47
Whanganui	71	20.8 (29)	2.3 (3)	32	0	
Bay of Plenty	285	74.2 (26)	5.7 (2)	28	9	32
Waikato*	473	115.2 (24)	15.1(3)	27	17	28
Hutt Valley*	164	31.2 (19)	13.0 (8)	27	5	33
MidCentral	196	43.3 (22)	6.8 (3)	25	5	39
Taranaki	130	28.3 (22)	2.0 (2)	24	2	75
Wairarapa	52	9.9 (19)	1.2 (2)	21	1	52
Waitematā*	663	70.1 (11)	49.9 (8)	19	18	37
Auckland*	533	40.8 (8)	56.9 (11)	19	27	20
Capital and Coast*	331	41.2 (12)	23.7 (7)	19	11	30
Nelson Marlborough	169	19.6 (12)	4.1 (2)	14	6	32
Southern*	368	41.2 (11)	9.3 (3)	14	9	41
West Coast	33	4.3 (13)	0.4 (0)	13	0	
Canterbury*	615	63.3 (10)	19.8 (3)	13	15	41
South Canterbury	64	6.4 (10)	1.3 (1)	11	1	64
Metro*	4,157			128		32
Non-metro	1,202			26		46

\*Metro—city with cardiac surgical services within or abutting region.

Population data is from Health New Zealand – Te Whatu Ora populations web tool.<sup>8</sup>

years. However, there is a concerning number who may be nearing retirement with 52 (35%) over 55 years of age, including those over 60 years numbering 27 (18%).

The number of unfilled cardiology positions was 21, giving a vacancy rate (vacant positions/filled positions) at the time of collection of 14%.

## By region

Table 2 ranks the districts according to the percentage of Māori/Pacific peoples (e.g., Tairāwhiti has a 57% Māori/Pacific peoples population). Māori/Pacific peoples have a higher prevalence of cardiovascular disease than other ethnicities. Metro regions are defined by regions that have cardiac surgery services in a city within their region—hence limited to the three Auckland regions, Waikato, Wellington/Hutt Valley, Canterbury and Southern/Dunedin.

The New Zealand national rate of **persons per cardiologist is 35,000**. There is disparity between metro and non-metro districts with respect to number of persons per cardiologist. In the non-metro regions, there are 43% more persons per cardiologist: 46,000 vs 32,000 ( $p=0.11$ ). All the metro districts, except Southern, are staffed with better than average ratios. There are disproportionately fewer cardiologists per head of population in districts with higher rates of Māori/Pacific peoples. The top five districts with the highest Maori/Pacific proportion all have disproportionately fewer cardiologists than average: Tairāwhiti 54,000; Counties Manukau 38,000; Lakes 61,000; Northland 52,000; Hawke's Bay 47,000. There is a disparity of cardiologists per head of population between metro/cardiac surgical services and non-metro districts/districts without cardiac surgical services; 32,000 versus 46,000.

## Comparison to international data

Published data are available for other healthcare systems. These are from professional medical bodies in the United States of America (USA), Canada and the UK, or from Australian State and Federal Government sources.

### USA

- From the Association of American Medical Colleges 2021—people per physician:<sup>2</sup>
  - Cardiovascular disease **14,600**
  - Clinical cardiac electrophysiology 124,000
  - Interventional cardiology 70,000
  - Thoracic surgery 73,000

### Canada

- From the Canadian Medical Association 2019:<sup>3</sup>
  - Nationwide **25,000** per physician (cardiologist)
  - Quebec **17,000**—this is the only province with lower than average population per physician
  - Ontario **26,000** and British Columbia **34,000** (the two most populous provinces)

### UK

- From the British Cardiovascular Society 2015 estimate:<sup>4</sup>
  - 45,000** per cardiologist
- From the UK cardiovascular workforce report 2022:<sup>5</sup>
  - 1,700 cardiologists, which equates to **40,000** per cardiologist

### Australia

- Australian Institute of Health and Welfare data 2016:<sup>6</sup>
  - 1,199 cardiologists (public and private), 1,141 clinicians
  - 21,000** persons per cardiologist
  - South Australia 19,000**. QLD/NSW/VIC lower than average, WA/TAS/NT higher than average
- Western Australian Department of Health data 2021:<sup>7</sup>
  - 85 cardiologists—**WA 31,000** persons per cardiologist
- NSW Government 2019:<sup>8</sup>
  - NSW clinical workforce 409—20,000** persons per cardiologist
  - Sydney 311—16,000** persons per cardiologist

## Discussion

This survey documents that the Health New Zealand – Te Whatu Ora cardiologist senior medical officer positions have a vacancy rate of 14% and a majority are held by people over 50 years old. Hence, there is concerning vulnerability of our cardiologist workforce in New Zealand. On average, New Zealand has 35,000 people per cardiologist. There is regional disparity according to population, ethnicity and cardiac surgical services. Furthermore, we have fewer cardiologists per population than comparable healthcare systems.

There have been recent resignations due to advancing age and burnout. The usual number

of qualifying specialists in New Zealand via the RACP is 10 per year. There have recently been RACP-qualified specialists who have chosen positions in Australia or the USA. There has been an uptake of overseas cardiologists via the MCNZ Council/RACP Overseas Trained Physicians pathway (from Mexico, Canada, Brazil, the Netherlands, Sweden, USA). Addressing the current vacancies and turnover due to the ageing workforce, as well as increasing the workforce to address demand, will require a multifaceted approach, including increased funding for positions that are appealing professionally and financially, particularly in comparison to Australian positions. Increase in local training numbers should be considered—there is a high demand from trainees for these positions. Flexibility in recruitment from Health New Zealand – Te Whatu Ora to appoint New Zealand-trained cardiologists prior to departing for overseas fellowships (i.e., a guaranteed job on return to New Zealand) would improve recruitment. Flexibility in reduced hours/call work would improve retention of older cardiologists and those with parenting responsibilities.

With respect to the number of people per cardiologists, there is disparity in non-metro regions and in regions with higher Māori/Pacific populations (i.e., likely a higher cardiovascular disease burden). Districts with higher populations and with cardiac surgical services have significantly fewer people per cardiologist. This will reflect larger hospitals in metro centres with tertiary cardiology services and relatively well-staffed, larger cardiology units. Districts with higher Māori/Pacific representation have significantly more people per cardiologist. The inference is that the highest-need regions are underserved. Under-resourcing is exacerbated by the greater high-risk ethnic groups in those regions. It would be beneficial for flexibility in Health New Zealand – Te Whatu Ora contracts to attract health workers to areas of higher need.

The number of cardiology clinicians in comparable healthcare systems is useful information. Our workforce data suggest that there are markedly fewer cardiologists per head of population than in the comparable healthcare systems of Australia and (urban) Canada. In the UK, it is likely that optimising cardiovascular care would require an increase in cardiologists (thereby reducing the population per cardiologist from current relatively high levels). The USA likely is

not a comparable system, but the data suggest that there is double the number of cardiologists per head of population than here. While the UK numbers are inferior to New Zealand, New Zealand is likely closer to an optimal number than the UK. The Canadian cardiology workforce per head of population is superior to New Zealand, and Australia is even better—our view is that those two countries should serve as aspirational benchmarks for all of New Zealand.

### Limitations

The survey canvassed only those qualified as adult cardiologists and did not account for the general physicians providing cardiology care. The smaller New Zealand hospitals are reliant on cardiology care from these practitioners. Paediatric cardiologists were excluded but population does include all ages. There are a small number of cardiologists (authors' estimate is nine) working solely in the private sector who are not included. Most (seven) of these individuals have served long careers in public hospitals and now work part-time. The subspecialty of the cardiologists is not well captured. Most hospitals have their cardiologists doing general cardiology work or covering more than one subspecialty. Specific subspecialty identification would be useful in national workforce planning.

### Summary

Health New Zealand – Te Whatu Ora has an experienced cardiologist workforce, but a concerning proportion may be nearing retirement by way of age. There is a high (14%) vacancy rate. Non-metro regions have fewer cardiologists per head of population (by 40%). Additionally, the top 25% of districts with higher Māori/Pacific population proportions also have fewer cardiologists per head of population than the national average of one per 35,000. In comparison, recent data show much better rates of cardiologists per head of population in Canada (one per 25,000) and Australia (one per 21,000). Increased efforts from Health New Zealand – Te Whatu Ora in the recruitment and retention of cardiologists is vital to the preservation of current workforce numbers. There also needs to be an expansion to address growing demand and unmet need, particularly in non-metro regions and those with higher Māori/Pacific populations.

**COMPETING INTERESTS**

Nil.

**AUTHOR INFORMATION**

Selwyn P Wong: Cardiologist, Department of Cardiology, Middlemore Hospital, Auckland.

Martin K Stiles: Cardiologist, Department of Cardiology, Waikato Hospital; Professor of Medicine, Faculty of Medical and Health Sciences, The University of Auckland, Hamilton.

**CORRESPONDING AUTHOR**

Selwyn P Wong: Cardiologist, Department of Cardiology, Middlemore Hospital, Auckland.

E: spwong@middlemore.co.nz

**URL**

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# Half a century of declining acute coronary syndrome incidence is ending and ethnic inequity is rising: ANZACS-QI 88

Andrew J Kerr, Matire Harwood, Corina Grey, Suneela Mehta, Tegan Stone, Mildred Lee, Sue Wells, Rod Jackson, Katrina Poppe

## ABSTRACT

**AIMS:** Despite dramatic declines in coronary heart disease (CHD) incidence in Aotearoa New Zealand over more than 50 years, the burden of CHD is still inequitable, particularly for Māori and Pacific peoples. We studied recent trends in first hospitalisations for acute coronary syndromes (ACS) by ethnicity.

**METHODS:** All first ACS hospitalisations (2005–2019) were identified from national administrative datasets. Population denominators were constructed using multiple linked national data sources. Trends in rates of incident ACS and incidence rate ratios (IRRs) were analysed for younger (20–59 years) and older (60–84 years) patients.

**RESULTS:** The ACS cohort (n=69,161) comprised 74.7% European, 14.2% Māori, 6.1% Pacific peoples, 2.8% Indian and 2.2% non-Indian Asian peoples. For younger patients, annual ACS incidence initially decreased in all ethnic groups but plateaued between 2013 and 2015 for Māori, non-Indian Asians and Europeans; the decline was minimal for Pacific peoples across the time period. In older patients ACS incidence initially fell for all groups, but plateaued for Māori from 2015, and slowed after 2014 for Europeans.

IRRs, compared with Europeans, increased between 2005 and 2019 for younger Māori (IRR 1.5 to 2.25, p=0.017) and Pacific peoples (IRR 1.25 to 1.5, p<0.001), and for older Māori (IRR 1.35 to 1.6, p=0.006) and Pacific peoples (IRR 1.0 to 1.6, p<0.001).

**CONCLUSION:** Rates of decline in ACS incidence have stalled or slowed for most younger ethnic groups, and for older Māori and Europeans. The differential rate of change between ethnic groups has resulted in increasing inequity for Māori and Pacific peoples across the age range.

The dramatic reduction in the burden of coronary heart disease (CHD) over the past 60 years is a public health success story.<sup>1,2</sup> The decline is attributable to improvements across the spectrum of primary and secondary prevention.<sup>3–5</sup> However, in Aotearoa New Zealand, reports demonstrate a persisting inequitable burden of CHD experienced by Māori and Pacific peoples compared with European people.<sup>6,7</sup> To achieve equity, the rates of CHD for Māori and Pacific peoples will need to continue to fall and converge with the European rates.<sup>8</sup> Hospitalisation for an acute coronary syndrome (ACS) is the most clinically important, common and discrete first presentation of CHD,<sup>9</sup> making it a sensitive early indicator of change in CHD trends. A prior study in Aotearoa New Zealand showed ACS incidence continuing to fall until 2015, but data for separate ethnic groups were unavailable.<sup>10</sup> The aim of this study is therefore to study trends in first hospitalisations for ACS

between 2005 and 2019 for each major ethnic group.

## Methods

In Aotearoa New Zealand, everyone in contact with the public health system (>98% of the population) has a unique identifier (the National Health Index [NHI]). The NHI can be used to link individuals across multiple national health datasets, enabling the tracking of a person's journey through the health system until death. This made it possible to examine trends in first hospitalised ACS events for all New Zealanders, excluding people with any record for previous hospitalised CHD.

## Ethnicity

The NHI records up to three ethnicities for each person. For the purposes of this study, people with more than one recorded ethnicity were allocated to a single ethnic group using a modified

version of the prioritisation process outlined in the Health Information Standards Organisation Ethnicity Data Protocols.<sup>11</sup> Those coded as both Fijian and Indian were categorised as Indian based on prior work showing the CVD risk profiles for Fijian Indian people were more closely related to Indian than to Pacific peoples.<sup>12</sup> The ethnic groups in order of prioritisation were: Māori, Pacific, Indian, Chinese, Other Asian, and European, with the Chinese and Other Asian groupings combined into “non-Indian Asian” peoples for these analyses due to small numbers of ACS events. Of note, the CHD and ACS burden is likely to be similar among Indian and other South Asian communities in Aotearoa New Zealand based on international evidence. However, Indian people (who comprise around 90% of South Asians nationally) are currently the only South Asian subpopulation that can be identified in routinely collected health data based on national ethnicity data protocols in use during the study period, so South Asian peoples other than Indians were included in the non-Indian Asian grouping. There were 1,059 (1.5% of total) people of other ethnicities (including Middle Eastern, Latin American and African peoples) who are not reported in this study because numbers were insufficient to perform meaningful trend analyses.

### **Establishment of the study annual denominator populations**

Individual-level population denominators (in age bands) for each ethnic group were derived from annual health contact populations between 2005 and 2019 constructed using multiple NHI-linked national health data sources. To be included in the denominator for a calendar year, an individual had to be aged 20 to <85 years, have had contact with the health system in that calendar year as shown by an entry in one of the national health datasets listed below and have had no prior recorded primary- or secondary-coded CHD hospitalisation or coronary intervention since 1990. The national health datasets used to determine the denominators were: primary health organisation enrolment, primary care reimbursement (to capture primary care visits by non-enrolled patients), community laboratory requests, community pharmaceutical dispensing, hospitalisations, outpatient visits and mortality.<sup>13</sup> The vast majority of people in the health contact populations were identified from the primary health organisation enrolment data-

set. New Zealand residents are expected to actively re-enrol with a primary health organisation every 3 years and were defined as being in contact with the health system in a specified calendar year if they had re-enrolled in that year or in the previous 2 years. Linked hospital records were available from 1990, enabling a look-back period of at least 15 years (before the 2005 study start date) to exclude people with prior CHD hospitalisations.

### **Identification of incident cases (numerators)**

Numerators for calculating annual hospitalisation rates from 2005 to 2019 included people within a specified year’s denominator who had a first ever (since 1990) ACS hospitalisation in a public hospital during that year. A person could only be recorded in the numerator once during the entire 15-year study period, as after their first event they were no longer eligible to be in either the numerator or denominator for the remainder of the study period. ACS hospitalisations were defined as those where the primary or secondary discharge diagnosis included the relevant ICD-10AM (International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification) codes. The ACS outcome combined ST-elevation myocardial infarction (MI) (I21.0–I21.3, I22.0–I22.9), non-ST-elevation MI (I21.4), unstable angina (UA) (I20.0) and unspecified MI (I21.9). It was not necessary to include private hospital data in the numerator as virtually all ACS admissions in Aotearoa New Zealand are to public hospitals.

### **Statistical analysis**

First ACS hospitalisation rates were calculated for each calendar year and were stratified by ethnicity. In prior analyses we found that the recent plateauing of CHD incidence was most pronounced in younger people.<sup>14</sup> Based on these prior analyses, two age categories were chosen for this study: 20–59 years and 60–84 years. Individuals younger than 20 years and aged 85 years or older were excluded. The upper age limit was applied due to uncertainty regarding the accuracy of capture of ACS diagnoses in the very elderly due to the increasing complexity of comorbidity and concern that ACS events may have been missed in hospital or not recognised in the community and referred to hospital.

To obtain annual hospitalisation rates, the numerator for each calendar year was divided by the respective denominator and additionally

split into quarters for time series modelling. Plots showing the temporal trend of ACS hospitalisation rates by ethnicity and age were then examined and analysed using piecewise linear regression (joinpoint regression) to investigate statistically significant changes in the trend over time.<sup>15</sup> The time series demonstrated heteroscedasticity (non-constant variance), including seasonal variation, so log transformation was used to reduce the variation. Transformation also meant changes in incidence rates could be reported as relative changes, rather than absolute changes. Model assumptions, including the absence of significant autocorrelation, were assessed to validate the results.

The Davies' test was used to assess any potential change points in the regression by comparing the slope after a time break to the slope preceding that time break. If the Davies' test was statistically significant ( $p < 0.05$ ), the change in slope was significant and the change point was retained in the model. For  $p$ -values between 0.05 and 0.10, the time break was similarly included if the change of slope made sense visually, i.e., by looking at the plot. What appeared to be time breaks within five quarters of the start or end of the series were not included as insufficient data were present to assess the validity of the change. Time breaks that were not whole numbers were rounded to the nearest quarter. The slopes of trends are represented by the coefficients of the model, and a plateau in the trend was defined when the slope after (or potentially before) a significant change point had a slope that was not statistically significantly different from zero. Where a time break was identified, slope 1 describes the annual percent change (APC) in rates prior to the change, and slope 2 describes the APC after the change. When no time break was identified, the slope over the entire period was obtained using linear regression on the log-transformed data.

When displaying trends graphically the quarters were combined to display annual rates. To compare ethnic-specific trends, relative differences expressed as the ratio of incident ACS hospitalisation rates (incidence rate ratio [IRR]) were calculated for each age–ethnicity sub-group per quarter using Europeans as the reference group. Temporal trends in quarterly IRRs were analysed using Mann–Kendall trend analysis. For graphical display the quarterly IRRs were combined into annual IRRs. RStudio version 1.2.5033 and the “segmented” package were used for analyses.

## Ethics

This is an Aotearoa New Zealand All Cardiology Services Quality Improvement (ANZACS QI) sub-study. ANZACS-QI is part of the wider Vascular Risk Equity in Aotearoa New Zealand (VAREANZ) study. This study was originally approved by the Northern Region Ethics Committee Y in 2003 (AKY/03/12/314), with subsequent approval by the National Multi-region Ethics Committee in 2007 (MEC07/19/EXP) as well as annual re-approval since as part of a vascular research programme (2022 EXP 13442). Individual patient consent is not required as all data were de-identified at source.

## Results

Between 2005 and 2019 there were 69,161 people admitted with a first ACS hospitalisation, 29.3% of whom were under 60 years of age (Table 1). The ACS cohort comprised 51,638 (74.7%) European, 9,853 (14.2%) Māori, 4,205 (6.1%) Pacific, 1,932 (2.8%) Indian and 1,533 (2.2%) non-Indian Asian people. The proportion of ACS events that occurred in those under 60 years was higher for Māori (50.7%), Pacific (45.2%) and Indian people (45.4%) than for European (23.3%) or non-Indian Asian (32.9%) people. Over the time period Māori and Pacific people comprised 14.5% and 6.8% of the population aged 20–59 years but experienced 24.6% and 9.4% of the incident ACS events, respectively. For those aged 60–84 years, Māori and Pacific people comprised 6.6% and 3.5% of the population but had 9.9% and 4.7% of events. In contrast, European people aged 20–59 years comprised 66.2% of the population and had 59.2% of the ACS events: those aged 60–84 years comprised 82.9% and had 81.1% of the events.

Temporal trends in incident ACS hospitalisations by ethnic group are shown in Figure 1, Table 2, and Appendix Table 1a and 1b. Figure 2 shows the IRRs for each ethnic group relative to the rate for European people.

### Younger age group (20–59 years)

The annual rate of first ACS hospitalisations decreased in all ethnic groups over the first part of the period, but the rates plateaued between 2013 and 2015 for Māori, Other Asians and Europeans. For Indian and Pacific people the incidence rate continued to decline across the time period but more steeply for Indian (APC -8.2%) than for Pacific people (APC -2.1%). Prior to plateauing, the APC was -6.2% for Māori, -9.3% for non-Indian Asian and -5.0% for European people.

**Table 1:** Number (row %; col %) of first acute coronary syndrome hospitalisations in Aotearoa New Zealand between 2005 and 2019, stratified by ethnicity and age group.

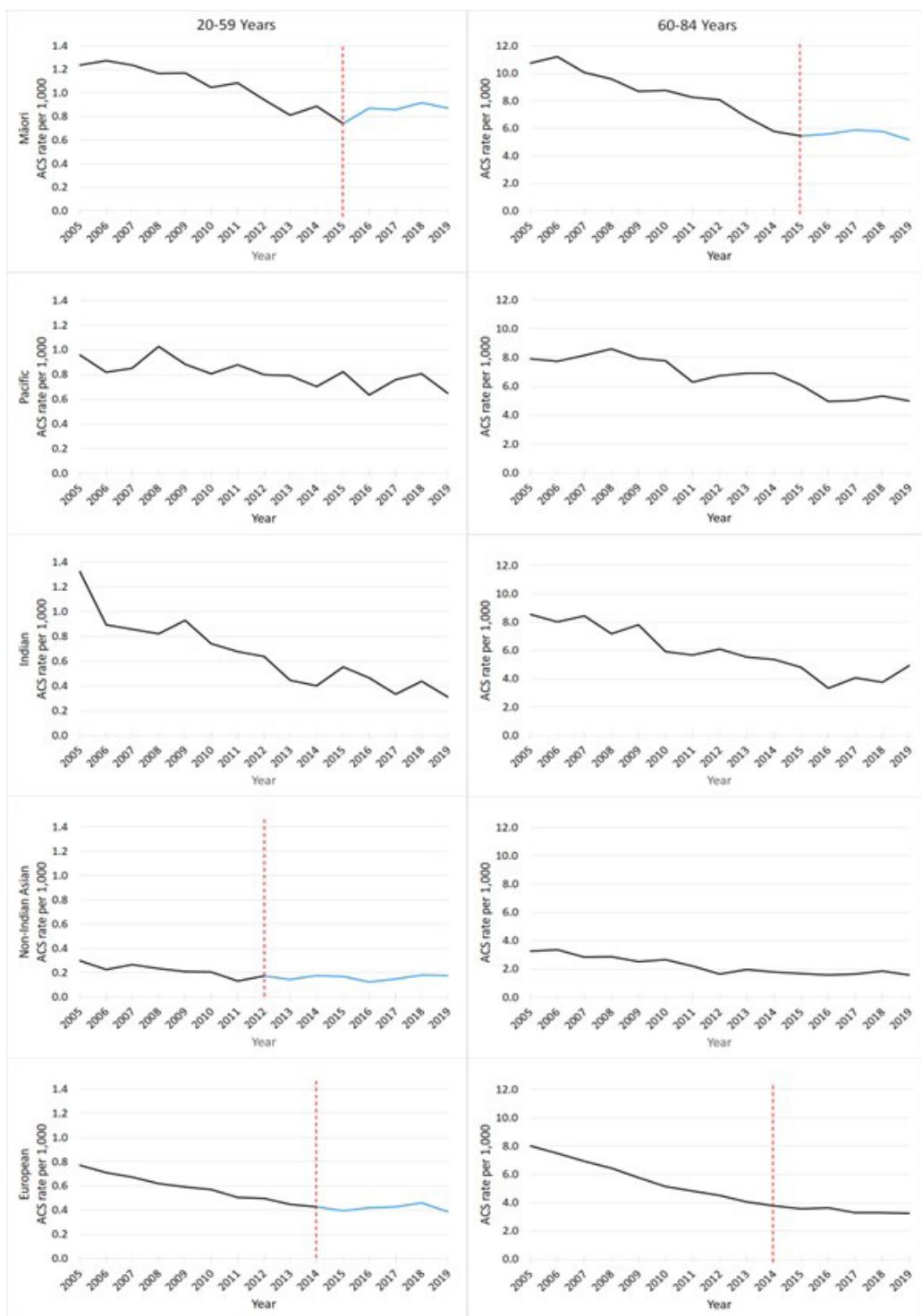
Ethnicity	Age group, years		Total (col %)
	20–59	60–84	
Māori	4,998 (50.7%; 24.6%)	4,855 (49.3%; 9.9%)	9,853 (14.2%)
Pacific peoples	1,899 (45.2%; 9.4%)	2,306 (54.8%; 4.7%)	4,205 (6.1%)
Indian	878 (45.4%; 4.3%)	1,054 (54.6%; 2.2%)	1,932 (2.8%)
Non-Indian Asian peoples	505 (32.9%; 2.5%)	1,028 (67.1%; 2.1%)	1,533 (2.2%)
European	12,009 (23.3%; 59.2%)	39,629 (76.7%; 81.1%)	51,638 (74.7%)
<b>Total (row %)</b>	<b>20,289 (29.3%)</b>	<b>48,872 (70.7%)</b>	<b>69,161</b>

**Table 2:** Acute coronary syndrome trends 2005–2019 by age and ethnicity.

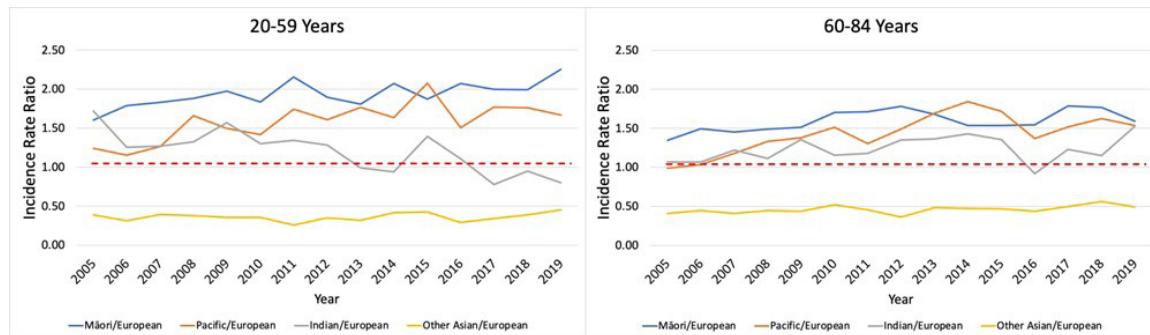
Ethnicity	Time break	Davies' test p-value	Slope(s) Annual % change	95% confidence interval
<b>20–59 years</b>				
Māori	Q2 2015	0.0009	-4.97% +2.74%	(-6.11%–−3.82%) (-1.12%–+6.74%)
Pacific peoples	N/A	–	-2.08%	(-3.10%–−1.06%)
Indian	N/A	–	-8.23%	(-9.84%–−6.59%)
Non-Indian Asian peoples	Q1 2012	0.0279	-9.27% +1.71%	(-13.82%–−4.47%) (-3.39%–+7.08%)
European	Q4 2014	<.001	-6.24% +0.14%	(-7.07%–−5.41%) (-2.35%–+2.70%)
<b>60–84 years</b>				
Māori	Q3 2015	0.0703	-6.63% -1.77%	(-7.65%–−5.60%) (-5.54%–+2.15%)
Pacific peoples	N/A	–	-3.86%	(-4.82%–−2.89%)
Indian	N/A	–	-5.73%	(-7.00%–−4.44%)
Non-Indian Asian peoples	N/A	–	-5.28%	(-6.98%–−3.54%)
European	Q4 2014	<.001	-8.20% -2.72%	(-8.68%–−7.71%) (-4.17%–−1.25%)

The Davies' test p-value tests the statistical significance of a change of slope at the time break; only time breaks with  $p<0.1$  are shown. When a time break is identified, the first slope is the annual percent change (APC) prior to the time break, and the second slope the APC after the time break.

**Figure 1:** Temporal trends in acute coronary syndrome incidence by ethnicity. Trends before or after each time break (red dotted line) are decreasing (black line) or flat (not statistically significant from zero—blue line).



**Figure 2:** Temporal trends in annual rate ratios of acute coronary syndrome incidence for each ethnic group relative to European incidence rates.



Incidence rates had plateaued by 2015 for Māori at 0.9/1,000, by 2014 for Europeans at 0.4/1,000 and by 2012 for Other Asians at 0.2/1,000. Despite an ongoing minimal decline, the incidence rates for Pacific people remained relatively high in 2018–2019 (0.6–0.8/1,000). For Indian people, rates had declined to 0.3–0.4/1,000 in 2018–2019.

IRRs compared with European people increased between 2005 and 2019 for Māori (IRR 1.5 to 2.25,  $p=0.017$  for trend) and Pacific peoples (IRR 1.25 to 1.5,  $p<0.001$  for trend), and decreased for Indian people (IRR 1.6 to 0.75,  $p<0.001$  for trend). There was no significant change for non-Indian Asian people (IRR 0.4 to 0.5,  $p=0.59$ ).

### Older age group (60–84 years)

ACS incidence rates in the older cohort fell for all ethnic groups in the first part of the time period. The decline plateaued for Māori in 2015 after initially declining at 6.6% per year. For Europeans the initial steep decline slowed after 2014 (APC -8.2% pre-2014, -2.7% post-2014). Rates continued to decline in Pacific (APC -3.9%), Indian (APC -5.7%) and non-Indian Asian people (-5.3%). By 2019 rates had plateaued among Māori at 5.2/1,000. For the other ethnic groups, in whom ACS incidence continued to decline, the rates in 2019 were as follows: Pacific people 5.0/1,000, Indian people 4.9/1,000, non-Indian Asian people 1.6/1,000 and Europeans 3.2/1,000.

IRRs compared with Europeans increased between 2005 and 2019 for older Māori (IRR 1.4 to 1.6,  $p=0.006$  for trend) and Pacific peoples (IRR 1.0 to 1.6,  $p<0.001$  for trend) but the changes in trends were not statistically significant for Indian (IRR 1.1 to 1.5,  $p=0.09$ ) or non-Indian Asian people (IRR 0.4 to 0.5,  $p=0.11$ ).

## Discussion

In Aotearoa New Zealand the long-term declining incidence of ACS has stalled for younger Māori, European and non-Indian Asian people in the last decade. In younger Pacific people the rate of decline is minimal. The rate of decline has also plateaued for older Māori and markedly slowed for older Europeans. Over the 15-year period of this study, ethnic inequities widened across the age range. Although rates have slowed or stalled for Europeans, the incidence of ACS relative to Europeans has progressively increased for Māori and Pacific peoples. By 2019 Māori and Pacific peoples had incidence rates 1.5 times to more than twice European rates. Rates for younger Indian people appear to have converged towards those of European people after previously being much higher, but rates in older Indian people remain higher than for Europeans.

Multiple prior publications have documented a decline in CHD morbidity and mortality in high-income countries up until the last decade.<sup>2,16</sup> In Aotearoa New Zealand we have previously documented a progressive fall in incident CHD hospitalisation and mortality rates and in CHD hospitalisations by ethnic group until the mid-2010s, with no evidence of plateauing.<sup>7,12</sup> Similarly, ACS rates were continuing to fall in men and women and all age groups up until 2016.<sup>10</sup> Internationally, however, there is evidence that the decline in cardiovascular disease (CVD) and CHD mortality rates in high-income countries has been slowing or plateauing in younger people since the 1990s.<sup>17–19</sup>

The decline in incident CHD has been attributed to improvements in both prevention and treatment.<sup>3–5</sup>

In Aotearoa New Zealand this has included progressive improvements in population health through improved nutrition and smoking cessation, together with increased availability and adoption of effective blood pressure and lipid-lowering therapy for primary prevention of CVD. The plateauing of incident ACS is likely associated with a plateauing of the implementation of some prevention and treatment efforts and offset by the rise of new risk factors. Overall rates of smoking fell markedly from 2000 to relatively low levels by the mid-2010s.<sup>20</sup> Mean systolic blood pressure fell until the 1990s but may have increased in the first decade of the twenty-first century,<sup>21</sup> and most current blood pressure-lowering agents have been available since the early 2000s. There was a rapid uptake of statin medications for primary prevention of CVD in Aotearoa New Zealand and internationally in the early 2000s, but by 2014 the rate of increase had plateaued in Aotearoa New Zealand.<sup>22</sup> In contrast, there has been an increase in cardiometabolic risk factors. In particular, obesity rates continue to climb<sup>23</sup> and overall rates of diabetes mellitus continue to increase by about 7% per year.<sup>24</sup>

### Reasons for persisting inequity among Māori and Pacific peoples

The persisting and widening gap in ACS rates for Māori and Pacific peoples relative to European people is related to systemic deficits across the continuum of prevention and treatment. Structural causes, including colonisation and institutional racism, have established advantages for Europeans and disadvantages for Māori and Pacific peoples within the wider (social, economic, political and environmental) determinants of health. These advantages and disadvantages have resulted in differential access to healthcare and differences in the quality of healthcare.<sup>25</sup> They also impact multiple dimensions of preventative health, including access to healthy diets, spaces to engage in physical activity, health-promoting environments and appropriate assessment and treatment in primary healthcare. Despite the documented improvement in many cardiac risk factors discussed above, Māori and Pacific people continue to have a relative excess of traditional risk factors, including elevated blood pressure, hyperlipidaemia and smoking.<sup>26,27</sup> Similarly, though rates of diabetes are increasing in the total population, they are highest among Māori and particularly Pacific and Indian peoples.<sup>24,26</sup> Identification of risk factors and of people at

elevated CVD risk to facilitate targeted interventions is enabled in Aotearoa New Zealand by nationwide CVD risk assessment in primary care. However, due to inequities in access to healthcare, there are significant gaps for Māori and Pacific people in the receipt of CVD risk assessment and management.<sup>28</sup> Although the data on ethnic inequities in use of primary prevention medications are mixed and limited,<sup>28</sup> several studies report that Māori and Pacific patients are less likely to be maintained on secondary prevention medications.<sup>29-31</sup>

### Findings among Indian and non-Indian Asian peoples

Interpretation of trends in ACS incidence for Indian people is complicated by the large numbers of working-age Indian migrants who have arrived in Aotearoa New Zealand over the last 10 years. This is likely to have influenced the decrease in IRR relative to Europeans due to the healthy migrant effect, whereby immigrants to a high-income country can have better health outcomes than the native-born population, despite often facing socio-economic disadvantages.<sup>32</sup> There will be a far smaller proportion of new migrants among older Indians, for whom the IRRs relative to Europeans remain elevated. The high burden of diabetes in particular, as well as raised total cholesterol to high-density lipoprotein ratios, are likely to be relevant for the elevated ACS burden among older Indians.<sup>26,33</sup> The IRRs were much lower across non-Indian Asian people, consistent with the lower burden of CVD risk factors averaged across the grouping as a whole;<sup>26</sup> nevertheless, there is heterogeneity in the burden of ACS across the diverse Asian subpopulations in this grouping, including non-Indian South Asian peoples who are likely to have a similar burden to Indian people.

For this analysis male and females were combined. Further analyses are needed to determine if trends differ by sex within the ethnic groups, including for Indian people (and non-Indian South Asian peoples) where the burden of CHD is known to be higher among males than females.

### What can be done to reduce inequities in incident ACS?

The factors contributing to inequities are broad and complex and require careful consideration when developing health interventions to improve preventive CVD care, particularly for Māori and Pacific peoples.<sup>28</sup> If we are to reverse the observed worsening inequities and stop ACS

incidence increasing across all ethnic groups, a whole-of-system approach is needed.<sup>34</sup> Political leaders must address the socio-economic determinants of health, including equitable access to safe, healthy housing, adequate income and high-quality education. Improved regulation of the food industry and food retail sector is needed to address the underlying determinants of obesity, the key factor driving the increasing burden of diabetes. These actions should be particularly focussed on younger people. We need ongoing population tobacco control initiatives to address the higher rates of smoking among Māori. An important finding of a recent review of CVD risk assessment and management in Aotearoa New Zealand by Wheeler et al. is that Māori and Pacific peoples are not provided equitable levels of CVD health literacy, which affects primary prevention, secondary prevention and cultural safety in CVD care, including language support where required.<sup>28</sup> Improved provision of health literacy through the education and health systems is needed. In primary care, CVD risk screening can identify those at risk for more intensive input and preventive treatment.<sup>35</sup> Important factors that improve access to CVD care include a multi-disciplinary approach, a focus on communities, culturally safe care centred on manaakitanga and support for Māori and Pacific providers.<sup>28</sup> However, there remain multiple barriers to primary healthcare, CVD risk assessment and subsequent management, which need to be overcome.

### Limitations

Valid interpretation of trends depends on stability of definitions over time. In this study we chose ACS (MI or UA) as the incident condition because the definition has not changed over the time period. This is in contrast to the definition of MI, which has been progressively redefined by the increasing sensitivity of the troponin assays used to identify MI. This redefinition has resulted in some patients previously diagnosed as UA now being classified as having an MI and consequently fewer being diagnosed with UA.<sup>36</sup> In Aotearoa New Zealand, ethnicity is defined as the “*ethnic group or groups that people identify with or feel they belong*

*to.*”<sup>23</sup> The 2004 Ministry of Health Information Standards Organisation Ethnicity Data Protocol and subsequent 2017 update aimed to improve the recording of ethnicity data by progressive standardisation of the methods of data collection, the minimum data field requirements and the frequency of updates.<sup>11</sup> Nevertheless, Māori continue to be undercounted in NHI datasets.<sup>37,38</sup> The extent of undercount of Māori in NHI data was 21% in 2013 and 16% in 2018 using comparable methodology,<sup>38</sup> and this undercount will have impacted on the current study. A more recent Stats New Zealand publication reports considerable improvements in the quality of ethnicity recording in the NHI dataset, but there are persisting deficiencies in the recording of Māori and Pacific ethnicity.<sup>39</sup> Further work is required to address ethnicity data quality. In this study we used a health contact population denominator to allow us to exclude patients with known CHD from the denominator and to minimise numerator/denominator bias related to the undercount of Māori in the NHI dataset. We acknowledge that there are people who have no contact with the health system who will not be captured in the denominator. Our group has recently assessed the difference between the health contact denominator of adult New Zealand residents and the equivalent Stats New Zealand Integrated Data Infrastructure (IDI) denominator. Our health contact denominator includes 92% of the complete IDI population (in personal communication from Professor Rod Jackson, 2025). We chose to report trends until 2019 because of concern that the COVID-19 pandemic would affect hospitalisation rates in 2020 to 2022.

### Conclusion

Rates of decline in ACS incidence have stalled or slowed for both young and old in ethnic groups that comprise the majority of the Aotearoa New Zealand population. The differential rate of change between ethnic groups has resulted in increasing inequity for both younger and older Māori and Pacific peoples. Comprehensive actions across health and non-healthcare sectors are required.

**COMPETING INTERESTS**

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**AUTHOR INFORMATION**

Andrew J Kerr: Department of Cardiology, Middlemore Hospital, Auckland, Aotearoa New Zealand; Department of Epidemiology and Biostatistics, School of Population Health, The University of Auckland, Auckland, Aotearoa New Zealand; Department of Medicine, The University of Auckland, Aotearoa New Zealand.

Matire Harwood: Department of General Practice and Primary Care, School of Population Health, The University of Auckland, Aotearoa New Zealand.

Corina Grey: Department of Epidemiology and Biostatistics, School of Population Health, The University of Auckland, Auckland, Aotearoa New Zealand.

Suneela Mehta: Department of Epidemiology and Biostatistics, School of Population Health, The University of Auckland, Auckland, Aotearoa New Zealand.

Tegan Stone: Department of Epidemiology and Biostatistics, School of Population Health, The University of Auckland, Auckland, Aotearoa New Zealand; Department of Statistics, The University of Auckland, Aotearoa New Zealand.

Mildred Lee: Department of Cardiology, Middlemore Hospital, Auckland, Aotearoa New Zealand.

Sue Wells: Department of General Practice and Primary Care, School of Population Health, The University of Auckland, Aotearoa New Zealand.

Rod Jackson: Department of Epidemiology and Biostatistics, School of Population Health, The University of Auckland, Auckland, Aotearoa New Zealand.

Katrina Poppe: Department of Epidemiology and Biostatistics, School of Population Health, The University of Auckland, Auckland, Aotearoa New Zealand; Department of Medicine, The University of Auckland, Aotearoa New Zealand.

**CORRESPONDING AUTHOR**

Professor Andrew J Kerr: Section of Epidemiology and Biostatistics, The University of Auckland, Private Bag 92019, Auckland, Aotearoa New Zealand.

E: a.kerr@auckland.ac.nz

**URL**

<https://nzmj.org.nz/journal/vol-138-no-1627/half-a-century-of-declining-acute-coronary-syndrome-incidence-is-ending-and-ethnic-inequity-is-rising-anzacs-qi-88>

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## Appendix

**Appendix Table 1a:** Total first acute coronary syndrome hospitalisations, population values and crude rates from 2005 to 2019 (for those aged 20–59 years).

	Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Māori	Numerator	360	380	378	365	374	342	362	317	276	305	258	308	308	335	330
	Denominator	291,143	298,553	305,579	312,872	320,333	327,147	332,905	336,842	340,372	343,500	347,828	353,421	359,542	365,414	378,670
	Crude rate/1,000	1.2	1.3	1.2	1.2	1.2	1.0	1.1	0.9	0.8	0.9	0.7	0.9	0.9	0.9	0.9
Pacific	Numerator	123	109	118	148	132	124	138	128	128	115	137	107	131	143	118
	Denominator	128,279	133,152	138,368	143,990	149,471	153,509	156,984	160,309	161,733	163,930	166,475	168,896	172,297	176,764	182,520
	Crude rate/1,000	1.0	0.8	0.9	1.0	0.9	0.8	0.9	0.8	0.8	0.7	0.8	0.6	0.8	0.8	0.6
Indian	Numerator	75	56	59	61	75	64	62	62	45	43	63	57	44	63	49
	Denominator	56,470	62,709	68,750	74,300	80,730	86,433	91,401	97,351	101,184	107,006	114,075	122,373	132,184	144,469	158,380
	Crude rate/1,000	1.3	0.9	0.9	0.8	0.9	0.7	0.7	0.6	0.4	0.4	0.6	0.5	0.3	0.4	0.3
Non-Indian Asian	Numerator	34	28	36	34	33	34	23	32	27	35	35	27	34	45	48
	Denominator	113,323	124,753	135,589	145,165	157,370	167,704	175,341	184,908	189,525	197,543	207,631	219,969	233,581	252,175	274,666
	Crude rate/1,000	0.3	0.2	0.3	0.2	0.2	0.2	0.1	0.2	0.1	0.2	0.2	0.1	0.1	0.2	0.2
European	Numerator	1,136	1,062	1,017	941	906	878	778	765	687	653	603	640	653	701	589
	Denominator	1,472,117	1,493,789	1,506,929	1,517,590	1,533,193	1,542,291	1,542,764	1,540,560	1,530,859	1,524,563	1,521,599	1,520,652	1,522,393	1,52,4815	1,522,011
	Crude rate/1,000	0.8	0.7	0.7	0.6	0.6	0.6	0.5	0.5	0.4	0.4	0.4	0.4	0.4	0.5	0.4

Appendix Table 1b: Total first acute coronary syndrome hospitalisations, population values and crude rates from 2005 to 2019 (for those aged 60–84 years).

	Year	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
Māori	Numerator	312	342	324	327	315	336	336	347	310	278	279	304	340	355	350
	Denominator	28,983	30,520	32,179	34,096	36,139	38,370	40,569	42,990	45,334	48,112	51,112	54,298	57,708	61,310	67,763
	<b>Crude rate/1,000</b>	<b>10.8</b>	<b>11.2</b>	<b>10.1</b>	<b>9.6</b>	<b>8.7</b>	<b>8.8</b>	<b>8.3</b>	<b>8.1</b>	<b>6.8</b>	<b>5.8</b>	<b>5.5</b>	<b>5.6</b>	<b>5.9</b>	<b>5.8</b>	<b>5.2</b>
Pacific	Numerator	133	138	152	169	162	165	139	155	165	173	159	135	143	160	158
	Denominator	16,830	17,801	18,625	19,678	20,432	21,224	22,035	22,964	23,920	24,978	26,043	27,228	28,548	30,040	31,739
	<b>Crude rate/1,000</b>	<b>7.9</b>	<b>7.8</b>	<b>8.2</b>	<b>8.6</b>	<b>7.9</b>	<b>7.8</b>	<b>6.3</b>	<b>6.7</b>	<b>6.9</b>	<b>6.9</b>	<b>6.1</b>	<b>5.0</b>	<b>5.0</b>	<b>5.3</b>	<b>5.0</b>
Indian	Numerator	52	56	67	64	76	63	65	76	74	77	75	56	74	74	105
	Denominator	6,083	6,979	7,928	8,922	9,725	10,621	11,425	12,437	13,332	14,330	15,566	16,809	18,242	19,644	21,239
	<b>Crude rate/1,000</b>	<b>8.5</b>	<b>8.0</b>	<b>8.5</b>	<b>7.2</b>	<b>7.8</b>	<b>5.9</b>	<b>5.7</b>	<b>6.1</b>	<b>5.6</b>	<b>5.4</b>	<b>4.8</b>	<b>3.3</b>	<b>4.1</b>	<b>3.8</b>	<b>4.9</b>
Non-Indian Asian	Numerator	51	58	55	62	60	70	63	51	67	67	70	73	84	102	95
	Denominator	15,594	17,301	19,401	21,476	23,832	26,220	28,562	31,240	33,892	37,457	41,753	46,293	50,996	55,311	59,722
	<b>Crude rate/1,000</b>	<b>3.3</b>	<b>3.4</b>	<b>2.8</b>	<b>2.9</b>	<b>2.5</b>	<b>2.7</b>	<b>2.2</b>	<b>1.6</b>	<b>2.0</b>	<b>1.8</b>	<b>1.7</b>	<b>1.6</b>	<b>1.6</b>	<b>1.8</b>	<b>1.6</b>
European	Numerator	3,546	3,434	3,299	3,171	2,926	2,693	2,608	2,511	2,322	2,207	2,147	2,256	2,119	2,170	2,220
	Denominator	442,844	457,814	475,648	492,276	508,082	523,970	539,390	554,649	569,942	586,902	604,110	622,600	642,189	662,247	685,067
	<b>Crude rate/1,000</b>	<b>8.0</b>	<b>7.5</b>	<b>6.9</b>	<b>6.4</b>	<b>5.8</b>	<b>5.1</b>	<b>4.8</b>	<b>4.5</b>	<b>4.1</b>	<b>3.8</b>	<b>3.6</b>	<b>3.6</b>	<b>3.3</b>	<b>3.3</b>	<b>3.2</b>

# Reform, repeal, replace: a case study of policy whiplash in New Zealand's health sector

Dylan A Mordaunt

## ABSTRACT

**AIMS:** For over a decade, New Zealand pursued a comprehensive reform of its outdated medicines legislation, culminating in the passage of the *Therapeutic Products Act 2023 (TPA)* in 2023. In a policy reversal, the *Act* was repealed by a new government in 2024. This study provides an analysis of this policy cycle to understand the drivers of the reform, its subsequent repeal and the implications for future health policy. We take a political economy perspective, foregrounding health policy instability and its consequences for patients, clinicians and Māori health interests.

**METHODS:** We conducted a qualitative documentary policy analysis of 25 key government and stakeholder documents, including legislation, regulations, cabinet papers and select committee reports with their submissions. We employed a framework method for a systematic thematic analysis of the corpus to map and interpret the policy narratives.

**RESULTS:** The impetus for the *TPA* was a consensus that the *Medicines Act 1981* and its associated regulations from 1984 and 1985 were “no longer fit for purpose”. The repeal was driven by an ideological shift, reframing the *TPA* as an unacceptable “regulatory burden”. This has tangible consequences, including the loss of a pre-market approval framework for medical devices and the erasure of legislative provisions designed to protect and recognise Rongoā Māori (traditional Māori healing).

**CONCLUSION:** The *TPA* policy cycle is a case study in the fragility of evidence-based health reform. It demonstrates that without a durable, cross-party political consensus, long-term policy projects are highly vulnerable to being dismantled by short-term shifts in political ideology, with downstream harms from regulatory instability. It also illustrates how a targeted “micro-reform” can generate outsized system-level consequences.

The regulation of therapeutic products is a core function of the modern state, representing a critical balance between fostering innovation, ensuring timely public access to beneficial products and protecting citizens from harm.<sup>1</sup> Globally, regulatory systems are in a constant state of evolution, adapting to new technologies such as biologics, software as a medical device, and cell-based therapies.<sup>2</sup> In this context, New Zealand's legislative framework had, for many years, been an outlier.<sup>3</sup> The *Medicines Act 1981* and its key supporting regulations—the *Medicines Regulations 1984*<sup>4</sup> and the *Dietary Supplements Regulations 1985*<sup>5</sup>—were widely acknowledged by policymakers and health professionals as being out of date.<sup>6</sup>

Recognising this deficit, successive New Zealand governments from 2011 onwards embarked on a long and detailed policy process to create a new comprehensive regulatory scheme.<sup>7</sup> This decade-long effort, involving extensive consultation with the industry, clinical bodies and the public, culminated in the passage of the *Therapeutic Products*

*Act (TPA)* in July 2023.<sup>8</sup> The *TPA* was a key piece of legislation, designed to create a single, modern and flexible scheme for all therapeutic products, finally bringing New Zealand into line with its international counterparts like Australia's Therapeutic Goods Administration (TGA).

However, the *TPA* was repealed in its entirety by a newly elected government in early 2024, before it had been fully implemented.<sup>9</sup> The repeal was followed by the introduction of the *Medicines Amendment Bill (MAB)*, a more limited piece of legislation that sought to amend the original 1981 *Act* rather than replace it.<sup>10</sup> This rapid cycle of reform, passage, repeal and replacement offers a case study in the dynamics of health policy and the challenges of achieving durable legislative change.<sup>11</sup>

**Brief political context:** The 2023 general election produced a coalition government whose coalition agreement and early ministerial statements emphasised reducing “regulatory burden” and “red tape” for therapeutic products, particularly natural health products and medical devices.<sup>12</sup>

We note these political signals as context for the repeal, but a comprehensive analysis of party manifestos and the coalition text is outside scope and is acknowledged as a limitation.

This study is a documentary policy analysis of this policy cycle through the lens of political economy. It seeks to move beyond the political headlines to systematically analyse the documentary record. In doing so, we can gain insight into the competing narratives and forces that shape policy decisions. Our analysis is guided by theories of the policy process, particularly John Kingdon's Multiple Streams Framework, which helps to explain how policy windows open and close,<sup>13</sup> and the Advocacy Coalition Framework, which illuminates how groups with shared beliefs compete to translate those beliefs into policy.<sup>14</sup>

This paper addresses the following research questions:

1. What key policy problems led to the creation of the *TPA*?
2. What were the primary drivers and justifications behind its subsequent repeal?
3. What specific consumer and patient protections were included in the *TPA* and subsequently lost with its repeal?
4. How was *Te Tiriti o Waitangi*, particularly in relation to *Rongoā Māori*, addressed in the *TPA* and its repeal?
5. What does this policy cycle reveal about the challenges of comprehensive health legislative reform in New Zealand?

New Zealand's reversal from a comprehensive, risk-proportionate regime to an incremental amendment provides an unusual natural experiment in how policy frames can rapidly displace one another within a single reform cycle. Yet systematic, document-based analyses of this pivot are scarce. We address this gap by assembling a defined corpus across legislative, cabinet and stakeholder sources and applying a transparent framework analysis to compare problem definitions, frames and concrete protections gained and lost across regimes. Figure 2 summarises our theory of change from inputs to outcomes, and Figure 3 shows the end-to-end workflow we followed.

## Methods

This study employed a qualitative documentary policy analysis, guided by the reporting standards

of the Standards for Reporting Qualitative Research (SRQR) checklist.<sup>15</sup> This approach was chosen to allow for a deep, contextualised understanding of the policy process as it unfolded through the official documentary record.<sup>16</sup>

### Data

The data corpus consisted of 25 publicly available documents, including the core legislation and regulations (*Medicines Act 1981*, *Medicines Regulations 1984*, *Dietary Supplements Regulations 1985*, *TPA*, *MAB*), associated cabinet papers and minutes, regulatory impact statements (RIS) and select committee reports. Because there were 16,756 submissions to the *TPA* repeal process,<sup>17</sup> a focussed approach was taken. We used purposeful sampling of organisational submissions (e.g., peak industry bodies, clinical/professional colleges) to represent key stakeholder groups rather than attempt an exhaustive review. Selection aimed to maximise coverage across sectors while avoiding duplication of substantively identical positions; sampling decisions were prespecified in the protocol and are documented in the Appendix. These documents were sourced from the official New Zealand Parliament and Ministry of Health – Manatū Hauora websites. Table 1 lists the corpus and document IDs used across the analysis.

### Analysis

We analysed the data using a framework method: a systematic and flexible approach to qualitative data analysis that is well suited to policy research.<sup>15</sup> The process involved five distinct stages:

1. **Familiarisation:** We read and re-read the documents to gain a comprehensive overview of the policy timeline, key actors and core arguments.
2. **Identifying a thematic framework:** We developed a coding framework of seven core themes. The initial framework was deductive, based on our five research questions. However, during the familiarisation stage, we allowed for inductive themes to emerge from the data. For example, the theme of "framing contest" was not pre-specified but became apparent as we analysed the documents.
3. **Indexing:** We systematically applied the thematic framework to the entire data corpus.
4. **Charting:** We summarised the data from the

documents into a framework matrix, with columns for each theme and rows for each document. This allowed for a systematic comparison of themes across the different documents and stakeholder groups.

5. **Mapping and interpretation:** We used the charted data to identify patterns, contradictions and dominant narratives across the documents.

We used the framework method with an *a priori* theme set derived from the research questions, refined during familiarisation and extended inductively to capture emergent concepts. One coder developed the initial codebook, then re-reviewed it after a 2-week wash-out to enhance consistency (intra-coder reliability step). The final framework comprised seven themes spanning problem definition, repeal drivers, lost protections, Rongoā Māori, reform dynamics, framing contest and stakeholder positions. This process was guided by our protocol; the protocol, reporting checklist, coding framework and the populated framework matrix are provided in the Appendix. For audit and reproducibility, we also supply a corpus registry with canonical links, a full framework matrix (25 documents×7 themes) and an excerpts compendium (doc-ID-linked quotes) in the Appendix.

**Reliability check:** To assess consistency of coding in this single-author study, we conducted an intra-rater reliability exercise on a stratified sample of six of 25 documents after a 14-day wash-out. Using binary presence/absence per theme, mean Cohen's  $\kappa$  was 0.95 (range 0.67–1.00). Full details and per-theme results are provided in the Appendix.

## Results

Our analysis of the documentary record reveals a narrative of a reform being disrupted by an ideological shift, with consequences for health regulation and Indigenous health rights.

Three patterns were salient across the corpus. First, provisions recognising Rongoā Māori present in the TPA—such as establishment of a Rongoā advisory committee and safeguards to avoid inadvertent capture—are absent from repeal and amendment materials (Table 2). Second, the dominant frame shifts from “modernisation for public safety and international alignment” to “regulatory burden and cost”, with justification audiences moving from clinicians/patients to

businesses/consumers (Table 3). Third, several concrete protections embedded in the TPA—most notably pre-market medical device oversight and enhanced information-gathering powers—do not persist under the *Medicines Act* framework post-repeal (Table 4).

### The uncontested case for reform

The documents leading to the passage of the TPA reveal a consensus on the core problem: the *Medicines Act 1981* and its supporting regulations were obsolete. A 2022 regulatory impact statement from the Ministry of Health – Manatū Hauora was unequivocal, stating that the old *Act* “is not fit for purpose for a modern, globalised healthcare environment” and that its limitations “create risks for patient safety and prevent timely access to needed products.”<sup>18</sup> This was not a contested view; it was the foundational assumption of the entire reform project. The documents detail specific, critical gaps the TPA was designed to close, including the lack of a pre-market approval system for medical devices under the *Medicines Regulations 1984*,<sup>4</sup> the inability to regulate software as a medical device and the minimal oversight for natural health products under the *Dietary Supplements Regulations 1985*.<sup>5</sup>

### The repeal: a new narrative of “regulatory burden”

The documents justifying the repeal of the TPA do not challenge the original problem diagnosis. Instead, they introduce a new, competing narrative that reframes the issue. The language shifts dramatically from a focus on safety and modernisation to a focus on economic efficiency and compliance costs, providing clear evidence of a framing contest (see Table 3). A key 2024 cabinet minute justifying the repeal states the government’s primary objective is to “remove the unnecessary compliance costs the TPA would have imposed on the natural health products and medical device sectors.”<sup>12</sup> This narrative of “regulatory burden” and “red tape” is the central justification for the repeal; a position supported by a wide range of industry stakeholders, from large dairy exporters to small health food companies, in the context of 16,756 submissions to the Health Select Committee on the *Therapeutic Products Act Repeal Bill*.<sup>17,19</sup>

### Select consequences of the policy reversal

#### 1. The loss of key regulatory protections

A consequence of the repeal was the loss of a modern, comprehensive regulatory framework for medical devices and other products. The *TPA* would have closed major gaps in the 1981 *Act* and its 1984 regulations. As detailed in Table 4, these lost protections include the power for pre-market approval of all medical devices, a clear framework for regulating software as a medical device and consistent oversight for clinical trials. The impact of this was a key point of contention for clinical stakeholders. One clinical submission on the repeal *Bill* expressed concern that removing pre-market approval would return New Zealand to a regulatory deficit and expose patients to unacceptable device risks.<sup>20</sup> The *MAB*, which replaced the *TPA*, did not reinstate these provisions, instead making more limited amendments to the 1981 *Act*.<sup>21</sup>

## 2. The erasure of *Rongoā Māori* protections

A second consequence of the repeal is the erasure of specific legislative protections for *Rongoā Māori*. The *TPA* was a landmark in this regard. Part 7, Clause 151 of the *Act* mandated the creation of a “*Rongoā Advisory Committee*” to ensure Māori perspectives were integrated into the regulatory process.<sup>8</sup> An accompanying RIS document justified this by stating a key objective was “*to provide a framework that acknowledges the unique and special status of Rongoā Māori and is consistent with the Crown’s obligations under Te Tiriti o Waitangi*.”<sup>22</sup>

In contrast, the documents justifying the repeal are silent on this matter. The cabinet papers and the *MAB* itself contain no mention of *Rongoā*, *Te Tiriti* or the impact of the repeal on Māori health interests.<sup>12</sup> This absence effectively nullifies the legislative recognition and protection that had been achieved, representing a policy reversal on Indigenous health rights; albeit, the *Bill* also has the effect of being less restrictive of natural therapeutic products, including those used in *Rongoā* (see Table 2).<sup>23</sup> While some submitters to the select committee on the repeal *Bill* raised this issue, the final report recommended the *Bill* be passed without amendment.

## Discussion

The rise and fall of the *TPA* is a case study in the fragility of health policy reform. Our analysis, viewed through the lens of policy theory, suggests that while the policy may have been well founded on technical and safety grounds,

its fate was ultimately determined by political forces, illustrating key concepts from policy theory.<sup>24</sup> The decade-long development of the *TPA* can be seen as a “policy window”<sup>13</sup> opening, where a recognised problem (outdated act) and a developed solution (the *TPA*) aligned. However, the change in government created a new political stream that abruptly closed this window.<sup>13</sup>

**Contribution and novelty:** This analysis formalises, in a transparent and auditable way, what many practitioners perceived informally—namely that targeted, seemingly “small” legislative changes can create outsized system-level effects. By situating the *MAB* as a micro-reform with macro consequences, we add to international literature and to the under-developed political economy of health in New Zealand and Australia. As in clinical epidemiology, codifying “the obvious” via systematic documentation provides a citable evidence base that can influence practice and policy.

Taken together, our findings indicate that the repeal reflected a successful reframing campaign rather than new evidence overturning the case for modernisation. In small markets, where regulatory capacity and political attention are thin, durable reform likely requires *ex ante* consensus devices (e.g., cross-party commitments on core safety provisions), phased commencement to de-risk early implementation and statutory review points tied to public reporting. Absent these design features, comprehensive frameworks may be vulnerable to rapid policy reversal when electoral incentives favour short-horizon deregulatory narratives.

The repeal was facilitated by the success of a new “advocacy coalition”,<sup>14</sup> composed of the new governing parties and industry groups (particularly from the natural health products [NHP] sector), which prioritised economic deregulation. This coalition successfully reframed the *TPA* from a necessary safety modernisation to an instance of excessive “regulatory burden”. This framing contest is central to understanding the outcome. The “patient safety” narrative, while technically sound, was complex and long term. The “regulatory burden” narrative resonated with a broader political agenda of reducing the size of the state. This narrative is not new to therapeutic regulation and indeed Sam Peltzman’s work on drug regulation specifically describes the trade-off between access to therapeutic products and restrictive regulation—

consumer safety is impacted in both polarities of this trade-off.<sup>25</sup> This offers a lesson for public health advocates: the technical merits of a policy may be insufficient for its political survival without a supporting narrative that is equally simple and powerful.<sup>26,27</sup>

The consequences of this policy reversal are significant. The loss of a modern regulatory framework for medical devices leaves New Zealand as an outlier among developed nations and arguably compromises consumer safety.<sup>28</sup> The erasure of the Rongoā Māori provisions is arguably a significant setback for Māori health equity (in terms of recognition and representation) and the Crown's commitment to its Te Tiriti o Waitangi obligations.<sup>29,30</sup> It highlights the risk that when complex, comprehensive reforms are dismantled, specific, hard-won protections for minority or less powerful groups can be the first to be discarded as politically expendable.

This "policy whiplash" is not a new phenomenon in New Zealand. The country has a history of ideologically driven health reforms across the political spectrum, followed by periods of reversal or course correction.<sup>3,31</sup> The market-oriented reforms of the 1990s, for example, were substantially unwound in the 2000s. The TPA policy cycle, however, is an example of this trend, given the decade-long development process and the broad consensus that underpinned the original reform. The *Pae Ora (Health Futures) Act 2022* reforms themselves have arguably flipped from a devolved model into a full centralised model, with signs of progressive devolution from regional to district level, in less than 3 years.<sup>32</sup> This suggests that the New Zealand health policy landscape may be becoming more polarised and that the potential for long-term, evidence-based policy is being undermined by short-term political cycles (again, across the political spectrum).

The repeal of the TPA can be seen as a case of "punctuated equilibrium" in policymaking, where long periods of incremental change are interrupted by rapid, transformative shifts. In this case, the "punctuation" was the 2023 election, which brought to power a government with a different set of policy priorities. The new government was able to challenge the dominant policy narrative and to replace it with a new one that was more in line with its own ideological commitments. This highlights the importance of understanding the political context in which policy is made. The TPA was not repealed because the evidence base for it was weak, but because the political environment

had changed.

This has important implications for the future of evidence-based policymaking in New Zealand. If long-term evidence-based policies can be so easily overturned by short-term political shifts, then there is a risk that policymakers will become more reluctant to invest in them. This could lead to a more reactive and less strategic approach to policymaking, with a greater focus on short-term political gains than on long-term public good. To avoid this, it is essential that there is a broad-based political and public consensus on the importance of evidence-based policymaking. This will require a commitment from all political parties to engage in a more constructive and evidence-based debate about the future of the country.

This study has limitations. We prioritised timeliness to document an active policy reversal; accordingly, we traded some completeness for speed, focussing on a defined, auditable corpus. Coding was undertaken by a single analyst and is restricted to publicly available documents; unpublished advice and private lobbying may not be fully captured. New Zealand's *Official Information Act 1982* regime and common redactions limit access to internal documents, and some materials may never be released. We did not triangulate with key-informant interviews. Strengths include a pre-specified framework, a defined corpus spanning legislation, cabinet and stakeholder submissions (Table 1), and full transparency of the codebook and framework matrix in the Appendix. As a documentary analysis, it cannot capture private deliberations, lobbying efforts or informal negotiations that undoubtedly influenced the outcome. While we sought to analyse a wide range of submissions, the official documentary record does not fully capture the views of all stakeholders, particularly individual patients or smaller community groups; the author's positionality as a medical professional and health economist may have influenced interpretation. We also did not undertake a comprehensive analysis of party manifestos, coalition agreements or Hansard beyond targeted references; this broader political analysis is acknowledged as outside scope. To avoid tokenism, Te Ao Māori aspects are treated briefly here and are the focus of a dedicated follow-up analysis on Rongoā Māori and Article 2 of Te Tiriti.<sup>33</sup> Future research employing interviews with key policymakers and stakeholders would add explanatory depth. To support trustworthiness in this single-author study, we also performed an intra-rater reliability check on a stratified sample

of six of 25 documents after a 14-day wash-out; mean Cohen's  $\kappa$  was 0.95 (range 0.67–1.00), with full details provided in the Appendix.

## Conclusion

The repeal of the *Therapeutic Products Act 2023* was a key moment in New Zealand's health policy history. It was not a simple administrative change but an ideologically driven policy reversal with significant consequences. It resulted in the specific loss of a modern regulatory framework for medical devices and the removal of legislative recognition for Rongoā Māori. More broadly, this case study provides an illustration of the challenges of achieving long-term, evidence-based policy change. It demonstrates that for major health reforms to be durable, they must not only be technically sound and supported by evidence, but they must also command a resilient political and public consensus capable of withstanding the inevitable shifts in government and ideology.

## Ethics

This study is based entirely on the analysis of publicly available documents and does not

involve human participants. Therefore, formal ethics committee review is not required.

## Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

## Data availability

All source materials are publicly available; the complete corpus list, protocol, codebook and the populated framework matrix are provided in the Appendix.

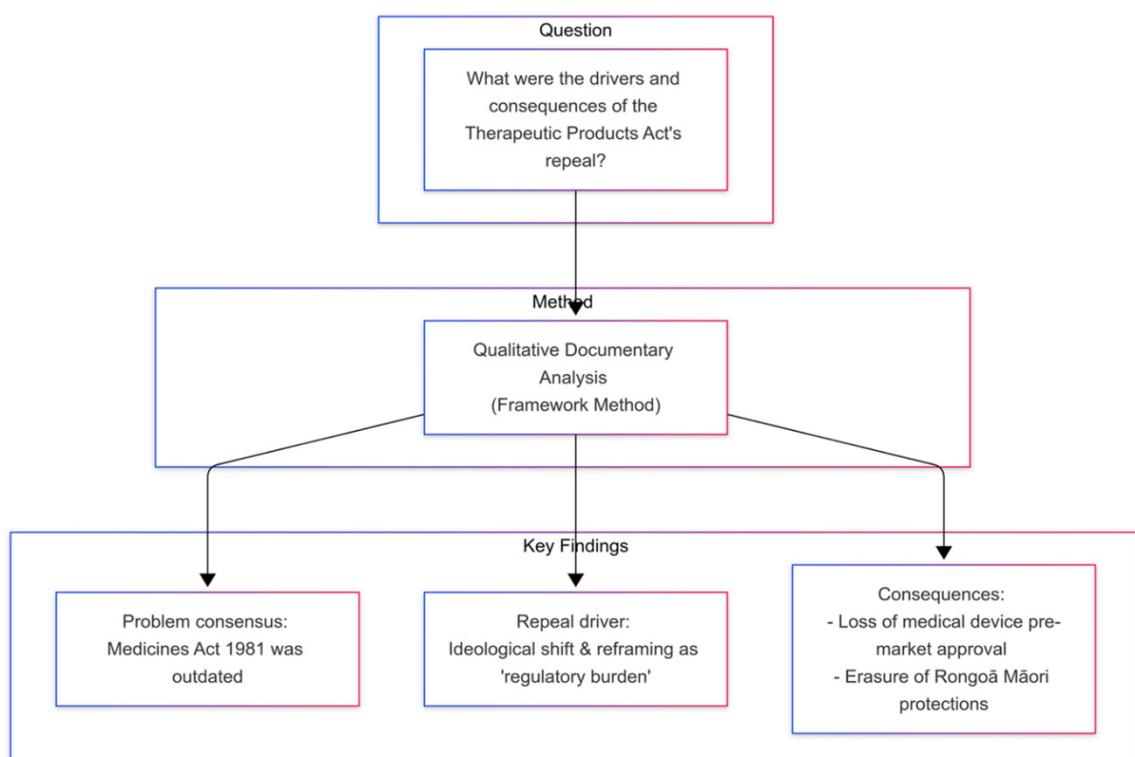
## Figures

Figure 1 provides a compact visual summary of the study's core question, method and key findings.

Figure 2 illustrates the conceptual flow of the study, linking the inputs (source materials and theoretical frameworks) to the research activities, outputs and ultimate outcomes.

Figure 3 shows the end-to-end workflow for the study, from the initial collection of data sources through to the final submission of the manuscript.

**Figure 1:** Graphical abstract.



## Tables

Table 1 details the 25 primary source documents that constitute the corpus for the qualitative documentary policy analysis. The documents were collected from publicly available New Zealand government, parliamentary and stakeholder sources. They cover the legislative and policy cycle of the *Therapeutic Products Act 2023*, from its development to its subsequent repeal and replacement by the *Medicines Amendment Bill*. Each document is assigned a unique ID used for reference within the analysis.

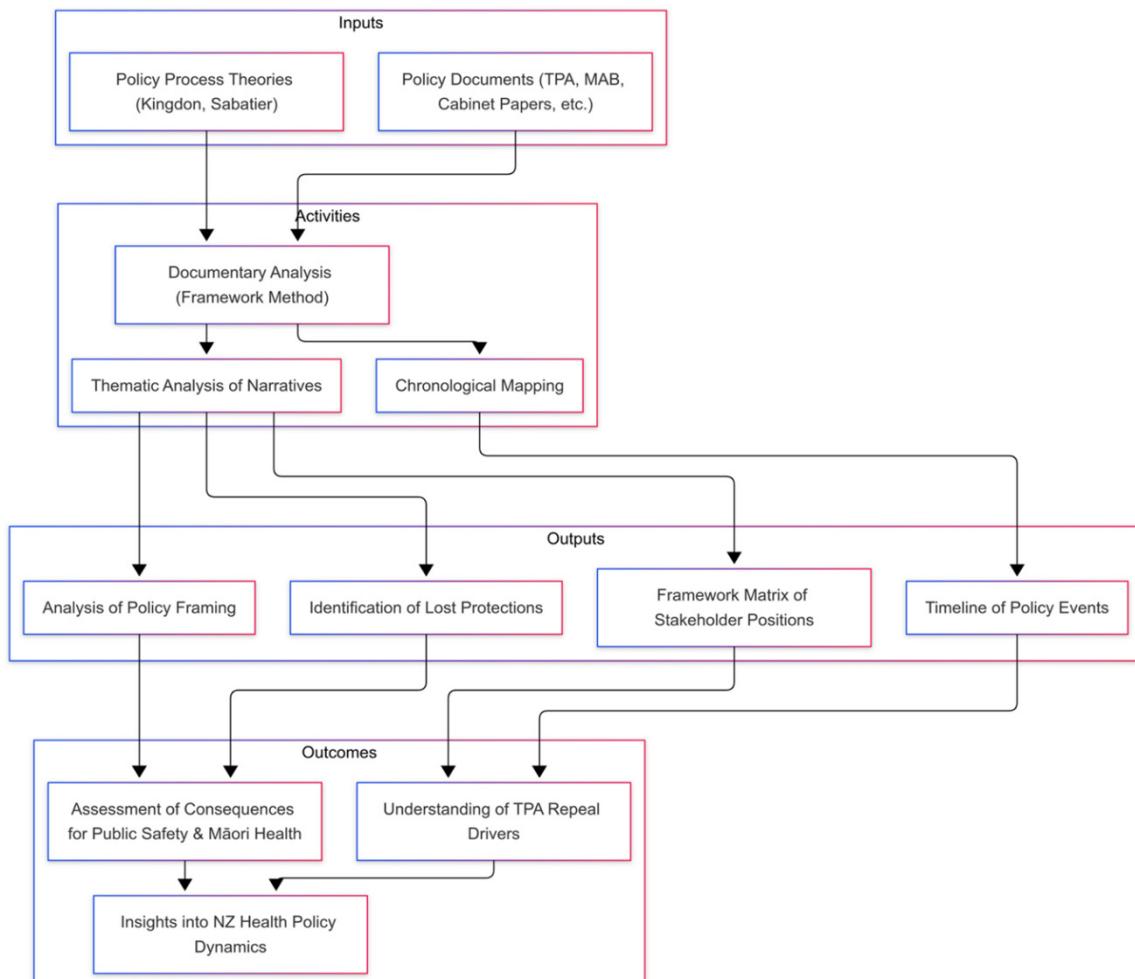
Table 2 compares the treatment of Rongoā

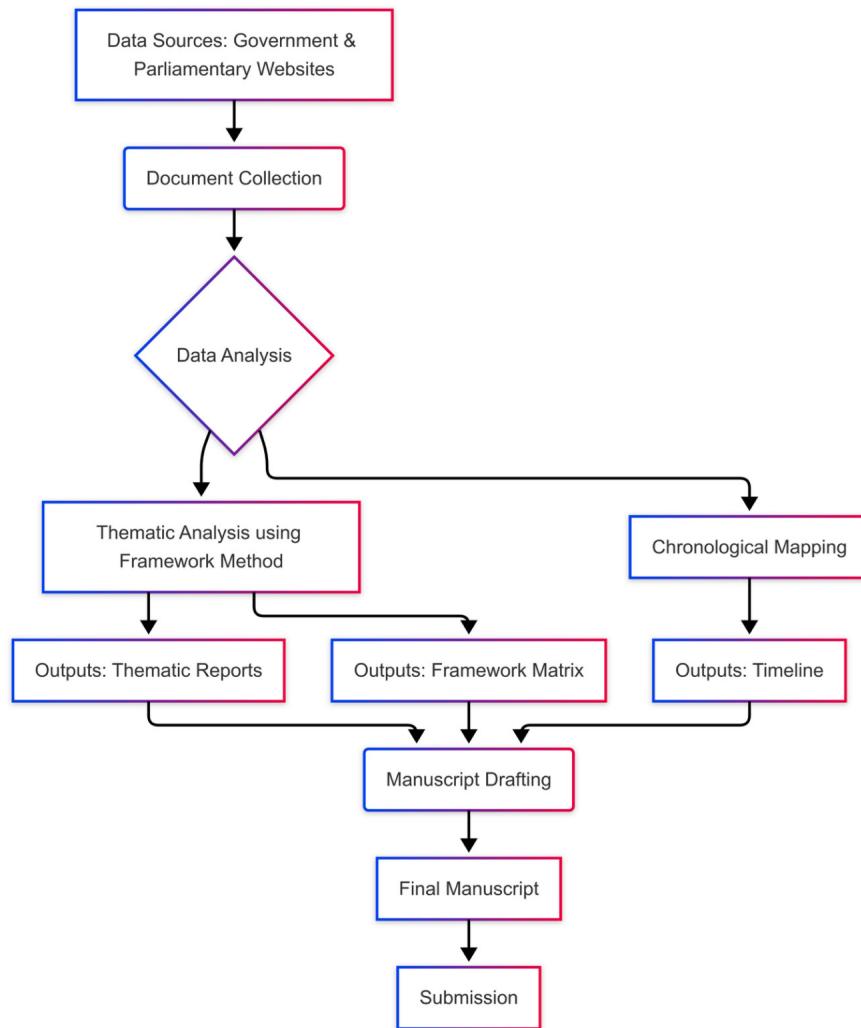
Māori (traditional Māori healing) in documents related to the *Therapeutic Products Act (TPA)* versus those related to the *Medicines Amendment Bill (MAB)* and the *TPA's* repeal.

Table 3 provides evidence for the shift in policy framing by comparing the language used in documents from the *TPA* era (focussed on safety and modernisation) with the *Repeal* era (focussed on regulatory burden and cost).

Table 4 details specific regulatory powers and consumer protections that were included in the *Therapeutic Products Act 2023* but are absent from the *Medicines Act 1981* framework that remains in place following the repeal.

**Figure 2:** Conceptual model.



**Figure 3:** Methods workflow.**Table 1:** Corpus of documents analysed.

Document ID	Title	Source	Year	Citation
doc01	Therapeutic Products Act 2023	New Zealand Parliament	2023	8
doc02	Medicines Amendment Bill	New Zealand Parliament	2024	10
doc03	Medicines Act 1981	New Zealand Parliament	1981	34
doc04	Cabinet Paper: Repealing the Therapeutic Products Act	Ministry of Health – Manatū Hauora	2024	12
doc05	Regulatory Impact Statement: Therapeutic Products Bill	Ministry of Health – Manatū Hauora	2022	18
doc06	Select Committee Report: Therapeutic Products Bill	New Zealand Parliament	2023	35

**Table 1 (continued):** Corpus of documents analysed.

Document ID	Title	Source	Year	Citation
doc07	Select Committee Report: TPA Repeal Bill	New Zealand Parliament	2024	17
doc08	Submission: ANZCA on TPA Repeal	Stakeholder	2024	36
doc09	Submission: CNA on TPA Repeal	Stakeholder	2024	37
doc10	Submission: CMC on TPA Repeal	Stakeholder	2024	38
doc11	Briefing and Cabinet material	Ministry of Health – Manatū Hauora	2022	39
doc12	cab-22-min-0536	Ministry of Health – Manatū Hauora	2022	40
doc13	crown-liability-un-der-the-therapeutic-products-bill...	Ministry of Health – Manatū Hauora	2022	41
doc14	Final report (Therapeutic Products Act Repeal Bill)	New Zealand Parliament	2024	42
doc15	Modernising the Regulation of Medicines...	Ministry of Health – Manatū Hauora	2024	43
doc16	regulating-natural-health-products-cab-paper-redacted	Ministry of Health – Manatū Hauora	2022	44
doc17	Repealing the Therapeutic Products Act...	Ministry of Health – Manatū Hauora	2024	45
doc18	RIS Pharmacy Ownership and Licensing	Ministry of Health – Manatū Hauora	2022	46
doc19	RIS TPB Rongoā and Small-Scale Producers	Ministry of Health – Manatū Hauora	2022	22
doc20	Medicines Regulations 1984	New Zealand Parliament	1984	4
doc21	Dietary Supplements Regulations 1985	New Zealand Parliament	1985	5
doc22	Submission: NZ Dental Association on TPA Repeal	Stakeholder	2024	20
doc23	Submission: NZ Health Food Company on TPA Repeal	Stakeholder	2024	47
doc24	Submission: Fonterra on TPA Repeal	Stakeholder	2024	48
doc25	Coalition Agreement 2023	New Zealand Government	2023	49

**Table 2:** Comparison of Rongoā Māori provisions.

Document set	Provisions and mentions of Rongoā Māori
<b><i>Therapeutic Products Act (TPA) &amp; associated documents</i></b>	<ul style="list-style-type: none"> <li>- The <i>TPA</i> itself contained a specific clause (Part 7) creating a Rongoā Advisory Committee to provide advice to the regulator.</li> <li>- The <i>Act</i> included provisions to ensure Rongoā products were not inadvertently captured by the definition of a “therapeutic product”.</li> <li>- The regulatory impact statement explicitly analyses the impact of the legislation on Rongoā practitioners and discusses the Crown’s obligations under <i>Te Tiriti o Waitangi</i>.</li> <li>- Cabinet papers leading to the <i>TPA</i> discuss the need for a culturally appropriate framework that respects and protects the practice of Rongoā.</li> </ul>
<b><i>TPA Repeal Bill &amp; Medicines Amendment Bill (MAB) documents</i></b>	<ul style="list-style-type: none"> <li>- The <i>TPA Repeal Bill</i> contains no mention of Rongoā Māori or the disposition of the <i>TPA</i>’s Rongoā provisions.</li> <li>- The <i>Medicines Amendment Bill</i> is silent on the issue of Rongoā Māori.</li> <li>- The cabinet papers and minutes justifying the repeal of the <i>TPA</i> and the introduction of the <i>MAB</i> make no mention of Rongoā, <i>Te Tiriti</i> or the impact of the repeal on Māori health interests. The focus is exclusively on economic impacts and reducing regulatory burden.</li> </ul>

**Table 3:** Comparative analysis of policy framing.

Policy theme	TPA-era documents (2022–2023)	Repeal-era documents (2024)
<b>Primary problem definition</b>	<p><i>“The current Medicines Act 1981 is no longer fit for purpose and does not adequately protect the public from the risks associated with modern therapeutics.”</i> (Ministry of Health – Manatū Hauora RIS, 2022)</p>	<p><i>“The Therapeutic Products Act 2023, in its current form, would impose an unacceptable level of regulatory burden on industry...”</i> (Cabinet Minute, 2024)</p>
<b>Goal of legislation</b>	<p><i>“To provide for the comprehensive and risk-proportionate regulation of therapeutic products in a way that protects public health and safety, while supporting access to necessary and innovative products.”</i> (TPA, Part 1, Clause 3)</p>	<p><i>“This repeal will remove unnecessary red tape and ensure that New Zealanders have access to a wide range of affordable natural health products without the excessive costs imposed by the TPA’s proposed scheme.”</i> (Cabinet Minute, 2024)</p>
<b>View of regulation</b>	<p>Regulation is presented as a necessary tool for public protection and a facilitator of international alignment and innovation.</p>	<p>Regulation is presented as a primary barrier to business, innovation, and consumer choice, particularly for the NHP sector.</p>

**Table 3 (continued):** Comparative analysis of policy framing.

Policy theme	TPA-era documents (2022–2023)	Repeal-era documents (2024)
<b>Key language</b>	“Modernisation”, “Patient Safety”, “Fit for Purpose”, “International Best Practice”, “Comprehensive Framework”	“Regulatory Burden”, “Compliance Costs”, “Red Tape”, “Unnecessary”, “Costly”
<b>Target audience of justification</b>	The justification is aimed at the public and health professionals, emphasising safety and improved health outcomes.	The justification is aimed at business owners and consumers, emphasising lower costs and freedom of choice.

**Table 4:** Analysis of lost regulatory protections (TPA vs *Medicines Act 1981*).

Feature/regulatory power	Provision in <i>Therapeutic Products Act 2023 (TPA)</i>	Status under <i>Medicines Act 1981 (post-Repeal)</i>	Implication of loss
<b>Medical device regulation</b>	Required pre-market approval for all medical devices based on their risk classification. (Part 5, Clause 82)	No general pre-market approval authority for medical devices. Regulation is largely post-market, relying on notifications and adverse event reporting.	Higher risk of unsafe or ineffective medical devices reaching the public. New Zealand remains an outlier among developed countries.
<b>Software as a medical device (SaMD)</b>	Explicitly included SaMD within the definition of a “therapeutic product”, allowing for modern, risk-based regulation.	The 1981 Act has no clear or adequate mechanism for regulating software, creating significant ambiguity and regulatory gaps.	Lack of oversight for health apps and clinical software, which may pose risks to patients if they are inaccurate or faulty.
<b>Regulation of natural health products (NHPs)</b>	Created a risk-based pathway for NHPs, requiring evidence for health claims and manufacturing quality standards.	NHPs are primarily regulated as “dietary supplements”, with minimal requirements for proving efficacy or quality.	Consumers may be misled by unsubstantiated health claims, and there is less assurance of product quality and consistency.
<b>Clinical trial regulation</b>	Established a single, consistent framework for approving and overseeing all clinical trials for therapeutic products.	Clinical trials are regulated under a less comprehensive and more fragmented set of guidelines.	Potential for inconsistencies in ethical oversight and safety standards for clinical trials across different types of products.
<b>Regulator’s information-gathering powers</b>	Granted the regulator broad powers to require information from any person in the supply chain to assess the safety and quality of a product.	The regulator’s powers are more limited and less clearly defined, potentially slowing down safety investigations.	Slower response to emerging safety signals and greater difficulty in ensuring compliance across the supply chain.

**COMPETING INTERESTS**

The author has previously been an advisor to Pharmac, is a member of multiple medical professional organisations such as the Royal Australasian College of Physicians (RACP) and Royal Australasian College of Medical Administrators (RACMA). The author submitted to Parliament on the *Medicines Amendment Bill*, in relation to section 19 and use of unapproved medicines by paramedics.

**CORRESPONDING AUTHOR INFORMATION**

Dylan A Mordaunt: Faculty of Health, Te Herenga Waka—Victoria University of Wellington, New Zealand; College of Medicine and Public Health, Flinders University, South Australia; Faculty of Health, University of Adelaide, South Australia; Centre for Health Policy, University of Melbourne, Victoria.  
E: dylan.mordaunt@vuw.ac.nz.

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## Appendix

### Study protocol: the rise and fall of the Therapeutic Products Act 2023

#### Introduction

##### Background and rationale

In 2023, New Zealand passed the *Therapeutic Products Act (TPA)*, a comprehensive piece of legislation designed to modernise the regulation of medicines, medical devices and natural health products (NHPs). It was the culmination of a decade of policy development intended to replace the outdated *Medicines Act 1981*. However, in a significant policy reversal, the *TPA* was repealed in 2024 by a new government before it fully came into force. It was replaced by the *Medicines Amendment Bill (MAB)*, which amended the original 1981 *Act* rather than replacing it.

This rapid cycle of comprehensive reform followed by abrupt repeal and incremental amendment presents a critical case study in health policy dynamics. Understanding this process is essential for comprehending the current state of medicines regulation in New Zealand and the challenges facing future legislative reform efforts.

##### Research questions

1. What key policy problems led to the creation of the *TPA*?
2. What were the primary drivers (political, industry, consumer) behind its subsequent repeal?
3. What specific consumer and patient protections were included in the *TPA* and subsequently lost with its repeal?
4. How was *Te Tiriti o Waitangi*, particularly in relation to Rongoā Māori and Māori health equity, addressed in the *TPA* and its repeal?
5. What does this policy cycle reveal about the challenges of comprehensive health legislative reform in New Zealand?

#### Methods and analysis

##### Study design

This study uses a qualitative documentary policy analysis design (Framework Method), with an explicit political economy lens on policy instability and downstream harms. This approach is appropriate for tracing the evolution of policy, comparing competing frames and interpreting concrete protections gained and lost.

#### Data sources and inclusion criteria

The corpus comprises 25 publicly available documents related to the *TPA* and its repeal (including the 2023 coalition agreement), selected to represent key stakeholder groups and core legislative/government sources. These include:

- The *Therapeutic Products Act 2023*.
- The *Medicines Amendment Bill*.
- The *Medicines Act 1981*.
- Cabinet papers and minutes.
- Regulatory impact statements.
- Select committee reports.
- Submissions from key stakeholders to select committees.
- Coalition agreement and targeted ministerial/cabinet materials.
- Explanatory notes and official guidance documents.

Documents were sourced from the New Zealand Parliament website, the Ministry of Health – Manatū Hauora website and other government repositories. We purposively sampled organisational submissions to maximise coverage across sectors while avoiding duplication of substantively identical positions (representative, not exhaustive). The Health Select Committee received 16,756 submissions on the repeal; our subset represents peak bodies and professional organisations.

##### Analysis plan

The analysis was conducted in two main stages:

- **Chronological mapping:** All sourced documents will be organised chronologically to construct a detailed timeline of events.
- **Thematic analysis (framework method):** We applied the framework method. A coding framework was developed from the research questions, refined during familiarisation and extended inductively to capture emergent concepts. We compared “official” narratives in government documents with stakeholder submissions. Final themes comprised seven domains:

1. Problem definition (policy drivers): justifications for the *TPA*.
2. Repeal drivers: arguments for the repeal.
3. Lost protections: concrete protections/ powers in *TPA* not present post-repeal (e.g., devices pre-market oversight, SaMD, trials,

regulator powers).

4. Rongoā Māori/Te Tiriti: legislative recognition and its removal.
5. Reform dynamics: the policy cycle dynamics and durability considerations.
6. Framing contest: competing frames (modernisation/safety vs regulatory burden/cost).
7. Stakeholder positions: categorised by groups such as:
  - Medical and clinical bodies
  - Pharmaceutical and medical device industry
  - Natural health products industry
  - Consumer and patient advocacy groups
  - Māori health and Rongoā organisations
  - Pharmacy and pharmacist bodies
  - Academics and research institutions

Data were charted into a framework matrix to enable systematic comparison across documents and stakeholder groups.

## Ethics and dissemination

### Researcher positionality

The researcher is a health policy analyst with a background in public health. The analysis will be conducted through this lens, with a focus on understanding the systemic and population-level implications of policy decisions. The researcher acknowledges their position as a non-Māori and will approach the analysis of documents related to Te Tiriti and Rongoā Māori with care and respect, ensuring the voices and perspectives from the original documents are represented authentically.

### Ethical considerations

This study is based entirely on the analysis of publicly available documents and does not involve human participants. Therefore, formal ethics committee review is not required. All sources will be appropriately cited to ensure academic integrity.

### Dissemination plan

The findings of this study will be written up as a research article for publication in a peer-reviewed health policy or public health journal. The findings will also be used to populate a pre-print. To enhance policy impact, a one-page policy brief summarising key findings will be created.

### Patient and public involvement

No patients or members of the public were involved in the design or conduct of this specific

study. However, the analysis will pay special attention to how patient, public and, particularly, Māori community voices were incorporated or excluded within the policy process documented in the source materials.

## Thematic codebook v1.1—R1 (decision rules)

This version extends the codebook with decision rules, inclusion/exclusion criteria and borderline examples for each theme.

General coding rule: Code at the document level per theme (presence/absence) and add 1–3 line summaries in the framework matrix; attach at least one excerpt per positive code in the excerpts compendium.

### 1. Problem definition (policy drivers)

- Include: Statements that the 1981 *Act*/regulations are outdated, safety/fit-for-purpose gaps, international alignment needs.
- Exclude: Generic statements about “health system reform” without direct linkage to therapeutic regulation.
- Borderline: If a statement references efficiency or innovation without safety context, code only if tied to regulatory modernisation.

### 2. Repeal drivers

- Include: Claims about regulatory burden, cost, complexity; deregulatory intent.
- Exclude: Critiques of unrelated agencies or funding not tied to *TPA/MAB* repeal.
- Borderline: If a source mixes safety concerns with cost rhetoric, code both themes if each is explicit; otherwise prioritise the dominant frame.

### 3. Lost protections

- Include: Device pre-market approval, SaMD capture, clinical trial framework, regulator information-gathering powers.
- Exclude: Operational issues not tied to statutory powers.
- Borderline: Ambiguous references to “device safety” without mechanism—seek statutory clauses before coding.

### 4. Rongoā Māori/Te Tiriti

- Include: Rongoā provisions, advisory committee, Te Tiriti obligations; explicit silence in repeal materials can be noted.
- Exclude: Generic cultural statements without regulatory linkage.
- Borderline: References to natural health products—code here only if tied to Rongoā or Te Tiriti.

5. Reform dynamics

- Include: Durability mechanisms (cross-party consensus, phased commencement, statutory review), policy window language.
- Exclude: Purely descriptive timelines without interpretation.
- Borderline: Political commentary—code only if tied to reform design/durability.

6. Framing contest

- Include: Modernisation/safety vs regulatory burden/cost contrasts; change in target justification audience.
- Exclude: Single, isolated remarks without an identifiable frame.
- Borderline: Use excerpts to justify coding if the frame is implicit but sustained.

7. Stakeholder positions

- Include: Positions of defined groups; always pair with group label in matrix.
- Exclude: Anonymous media commentary.
- Borderline: Multi-stakeholder letters—split positions if distinct; otherwise code to the dominant group.

This document provides a detailed, illustrative example of the framework matrix used for analysis. It reflects the revised seven-theme framework and the final corpus (25 documents), including the 2023 coalition agreement. The full table is embedded in the next section.

**Appendix Table 1:** Framework analysis matrix (illustrative).

Document	Theme	Summary of content	Illustrative quote
<b>Cabinet Minute: Repealing the TPA (2024)</b>	<b>2.0 Repeal drivers</b>	The primary justification is economic, focussing on removing compliance costs and regulatory burden, especially for the natural health products and medical device sectors. The paper frames the TPA as an impediment to innovation and business.	<i>“The Therapeutic Products Act 2023, in its current form, would impose an unacceptable level of regulatory burden on industry... The Government has therefore agreed to repeal the Act to reduce compliance costs and support innovation.”</i>

Appendix Table 1 (continued): Framework analysis matrix (illustrative).

Document	Theme	Summary of content	Illustrative quote
RIS: Rongoā & Small- Scale Producers (TPA era)	<b>4.3 Regulatory burden</b>	The concept of “red tape” is central. The TPA is consistently framed as excessive, costly, and unnecessary for certain sectors, which is a direct reversal of the previous government’s position.	<i>“This repeal will remove unnecessary red tape and ensure that New Zealanders have access to a wide range of affordable natural health products without the excessive costs imposed by the TPA’s proposed scheme.”</i>
	<b>6.0 Te Tiriti o Waitangi</b>	The document is completely silent on Rongoā Māori and Te Tiriti. The specific provisions from the TPA are not mentioned, and the impact of the repeal on these provisions is not considered.	(No quote available—the finding is based on the absence of content)
Submission: Clinical body (CMC on MAB)	<b>1.0 Policy drivers</b>	The paper argues for a culturally appropriate framework that protects the practice of Rongoā while ensuring safety. It acknowledges the unique status of Rongoā and the need for a bespoke solution.	<i>“A key objective of the new regime is to provide a framework that acknowledges the unique and special status of Rongoā Māori and is consistent with the Crown’s obligations under Te Tiriti o Waitangi.”</i>
	<b>6.0 Te Tiriti o Waitangi</b>	The document explicitly links the proposed Rongoā provisions to the principles of Te Tiriti, particularly partnership and protection. It details the plan for a Rongoā Advisory Committee.	<i>“The establishment of a Rongoā Advisory Committee, with a majority of members being Rongoā experts, is a critical mechanism for ensuring partnership and active protection under Te Tiriti.”</i>
Therapeutic Products Act 2023 (The Act itself)	<b>5.0 Lost protections</b>	The submission expresses significant concern over the loss of a comprehensive regulatory framework for medical devices, which the TPA would have introduced. It frames this as a major patient safety issue.	<i>“Our primary concern with the repeal of the TPA is the loss of pre-market approval for medical devices. This returns New Zealand to a state of significant regulatory deficit and exposes patients to unacceptable risks from unevaluated devices.”</i>
	<b>2.0 Repeal drivers</b>	The submission critiques the rationale for the repeal, arguing that the focus on “regulatory burden” has dangerously overshadowed the core need for patient safety and a modern, fit-for-purpose system.	<i>“While we acknowledge the need for efficient regulation, the argument that the TPA was an unnecessary burden is, in our view, a false economy that prioritizes commercial interests over public health and safety.”</i>
Coalition agreement (2023)	<b>5.0 Lost protections</b>	The text of the Act contains the specific powers for the regulator to evaluate and approve medical devices before they can be supplied in New Zealand; a power that does not exist in the 1981 Act.	<i>“Part 5, Clause 82: A person must not import, supply, or export a medical device unless the device is approved under this Act and conforms to the approval.”</i>
	<b>6.0 Te Tiriti o Waitangi</b>	The text of the Act contains the specific clause establishing the Rongoā Advisory Committee and its functions.	<i>“Part 7, Clause 151: The Regulator must establish a committee called the Rongoā Advisory Committee... to provide advice... on the regulation of rongoā.”</i>
<b>2.0 Repeal drivers/4.0 Framing contest</b>	Emphasises reducing regulatory burden and red tape; frames repeal as pro-business and pro-choice.	<i>“The Government will remove unnecessary red tape for natural health products and streamline device regulation.”</i>	

Appendix Table 2: Framework matrix (full table).

doc_id	Problem definition	Repeal drivers	Lost protections	Rongoā_Tiriti	Reform dynamics	Framing contest	Stakeholder positions	Key quotes
doc01	Outdated 1981 framework; need modern, risk-proportionate regulation and international alignment.	N/A ( <i>TPA</i> era).	Provides pre-market device approval, SaMD capture, clinical trial framework, regulator info-gathering powers.	Part 7 created Rongoā Advisory Committee and safeguards.	Long development; comprehensive replacement of obsolete regime.	Frame: modernisation/patient safety/ fit for purpose.	Clinicians supportive; alignment with international best practice.	<i>TPA</i> Part 5, cl 82; Part 7, cl 151.
doc02	N/A (amendment instrument).	Repeal justified on reducing regulatory burden/cost; limited amendments to 1981 <i>Act</i> .	Does not reinstate pre-market device approvals; limited changes under 1981 framework.	No explicit mention of Rongoā or Te Tiriti.	Incremental amendment post-repeal.	Frame: red tape/ compliance costs; consumer choice/ affordability.	Industry support from NHP and some device sectors.	Select committee and Cabinet materials emphasise burden/cost.
doc03	Legacy act; gaps for devices, SaMD, and contemporary products.	N/A.	No general pre-market authority for devices; fragmented oversight.	No recognition of Rongoā.	Baseline regime revived post-repeal.	Minimalist, post-market oversight.	-	<i>Act</i> text shows absence of device pre-market approval.
doc04	Acknowledges reform background but pivots to cost concerns.	Primary objective: remove unnecessary compliance costs and regulatory burden (NHP, devices).	Accepts loss of <i>TPA</i> powers as trade-off for deregulation.	Silent on Rongoā/Te Tiriti.	Rapid repeal pre-implementation.	Strong “red tape” framing.	Business/industry audience.	Quote: “remove unnecessary red tape...” (Cabinet Minute).
doc05	1981 <i>Act</i> not fit for purpose; risks to safety and access; need comprehensive framework.	N/A.	Justifies <i>TPA</i> ’s stronger authorities incl. device approvals and SaMD.	Addresses Rongoā Māori and Te Tiriti obligations (see RIS Rongoā).	Supports comprehensive reform.	Modernisation/ patient safety.	Clinical and public interest audience.	RIS language on fit-for-purpose and safety risks.
doc06	Supports <i>TPA</i> aims and structure.	N/A.	Endorses device oversight and modern powers.	Considers cultural provisions as appropriate.	Parliamentary scrutiny affirmed need.	Modernisation/ safety framing.	Varied submitters; overall supportive of reform.	Report text.

Appendix Table 2 (continued): Framework matrix (full table).

doc_id	Problem definition	Repeal drivers	Lost protections	Rongoā_Tirīti	Reform dynamics	Framing contest	Stakeholder positions	Key quotes
doc07	Notes repeal context.	Repeal framed as burden reduction and cost relief.	Recognises that TPA powers will not persist.	No references to Rongoā/Te Tiriti.	Rapid legislative process.	Regulatory burden/cost framing.	Industry and consumer-choice arguments salient.	Final report text.
doc08	-	Varies; likely focussed on clinical safety.	Supports patient safety via device oversight (inference from clinical stance).	-	-	Safety framing.	Clinical college position.	See evidence_excerpts_R1_v20250925.md
doc09	-	-	-	-	-	-	-	See evidence_excerpts_R1_v20250925.md
doc10	-	-	-	-	-	-	-	See evidence_excerpts_R1_v20250925.md
doc11	Reform background.	-	-	-	-	-	-	See evidence_excerpts_R1_v20250925.md
doc12	-	-	-	-	-	-	-	See evidence_excerpts_R1_v20250925.md
doc13	-	-	-	-	-	-	-	See evidence_excerpts_R1_v20250925.md
doc14	-	Summarises repeal justifications (burden/cost).	Notes absence of TPA powers post-repeal.	No substantive Rongoā content.	-	Burden/cost.	-	Report text.

Appendix Table 2 (continued): Framework matrix (full table).

doc_id	Problem definition	Repeal drivers	Lost protections	Rongoā_Tirīti	Reform dynamics	Framing contest	Stakeholder positions	Key quotes
doc15	Overview of modernising medicines regulation; context for TPA/MAB.	-	-	-	-	-	-	See evidence_excerpts_R1_v20250925.md
doc16	NHP regulation options; risk-based approaches.	Concerns about over-regulation raised.	-	-	-	Regulatory burden theme present.	NHP sector.	See evidence_excerpts_R1_v20250925.md
doc17	-	Cabinet material on repeal; reiterates burden reduction aims.	Accepts rollback of TPA authorities.	Silent on Rongoā.	-	“Red tape” frame.	Business focus.	See evidence_excerpts_R1_v20250925.md
doc18	Pharmacy ownership/licensing RIS provides context for system gaps.	-	-	-	-	-	-	See evidence_excerpts_R1_v20250925.md
doc19	Explicitly acknowledges need for culturally appropriate framework re Rongoā.	-	Supports Rongoā safeguards within TPA.	Links to Te Tiriti obligations; proposes Advisory Committee.	-	-	-	Quote: “provide a framework that acknowledges ... Rongoā Māori ... consistent with the Crown’s obligations under Te Tiriti ...”
doc20	-	-	-	-	-	-	-	Act shows notification/adverse event model, not pre-market approvals.

Appendix Table 2 (continued): Framework matrix (full table).

doc_id	Problem definition	Repeal drivers	Lost protections	Rongoā_Tirīti	Reform dynamics	Framing contest	Stakeholder positions	Key quotes
doc21	-	-	-	-	-	-	-	Dietary supplements regime - minimal efficacy/quality requirements.
doc22	-	-	Warns of risks without device pre-market approval; patient safety concerns.	-	-	Safety framing.	Clinical stakeholder.	Paraphrase: removal of pre-market approval exposes patients to device risks.
doc23	-	Supports repeal to reduce burden; consumer choice.	-	-	-	Burden/choice.	NHP industry.	See evidence_excerpts_R1_v20250925.md
doc24	-	Supports repeal due to compliance costs; export considerations.	-	-	-	Burden/cost.	Dairy exporter.	See evidence_excerpts_R1_v20250925.md
doc25	-	Coalition agreements emphasise removing red tape for NHP and streamlining device regulation.	-	Silent on Rongoā in agreements.	Signals deregulatory priorities.	“Red tape” framing.	Political parties.	Beehive coalition agreements page.

**Appendix Table 3:** Sample results table (to fill).

Theme	% Agreement	$\kappa$	Notes
Problem definition			
Repeal drivers			
Lost protections			
Rongoā /Te Tiriti			
Reform dynamics			
Framing contest			
Stakeholder positions			

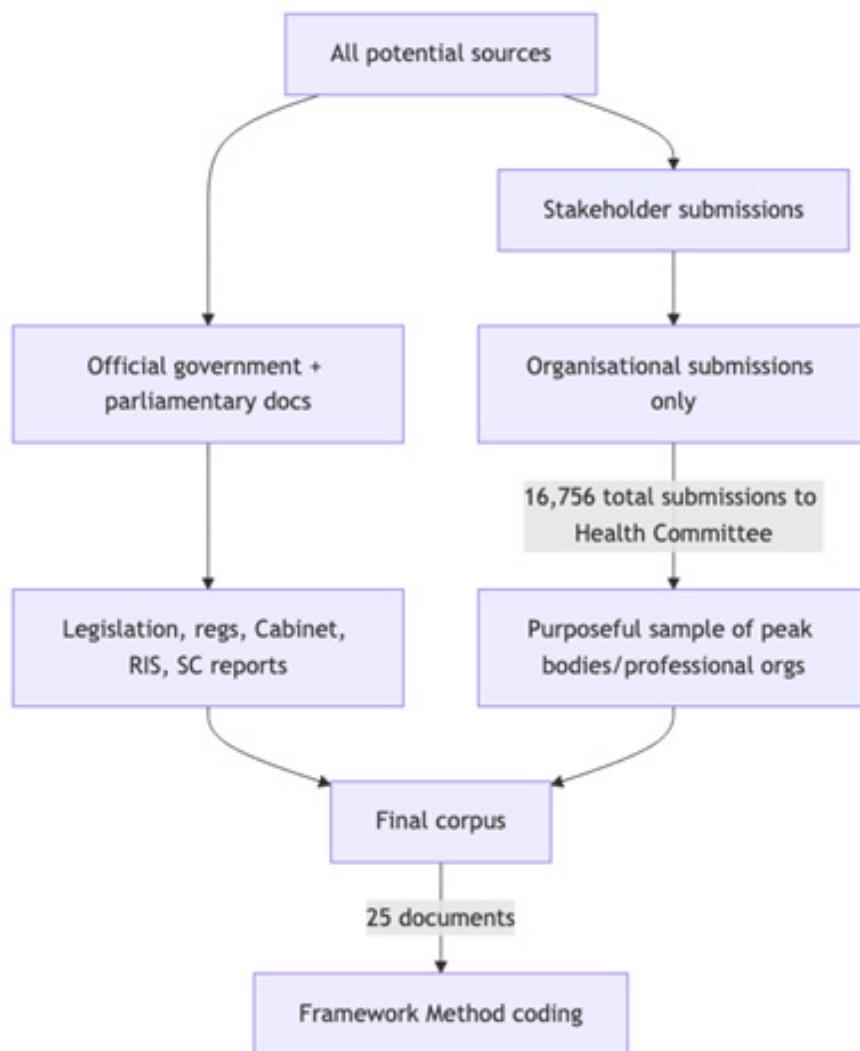
**Appendix Table 4:** Intra rater reliability results.

Theme	% Agreement	$\kappa$	Notes
Problem definition	0.83	0.67	One discrepancy (doc07 coded as context in recode)
Repeal drivers	1.00	1.00	Full agreement
Lost protections	1.00	1.00	Full agreement
Rongoā /Te Tiriti	1.00	1.00	Full agreement
Reform dynamics	1.00	1.00	Full agreement
Framing contest	1.00	1.00	Full agreement
Stakeholder positions	1.00	1.00	Full agreement

Mean  $\kappa$  across themes: 0.95 (range 0.67–1.00).

**Appendix Table 5:** Reliability results.

Theme	Percent agreement	Cohens kappa
Framing contest	1.00	1.00
Lost protections	1.00	1.00
Problem definition	0.83	0.67
Reform dynamics	1.00	1.00
Repeal drivers	1.00	1.00
Rongoā/Te Tiriti	1.00	1.00
Stakeholder positions	1.00	1.00

**Appendix Figure 1:** Selection flow.

# Tūtakarerewa—Indigenous advocacy and structural racism in bowel cancer screening in Aotearoa New Zealand

Nina Scott, Jacquie Kidd, Hayley Arnet, Cynthia Dargaville, Moahuia Goza, Sue Crengle, Rhys Jones, Clarence Kerrison, Rawiri McKree Jansen

## ABSTRACT

Aotearoa New Zealand has one of the highest bowel cancer rates in the world. Bowel cancer incidence is increasing for Māori (the Indigenous people of Aotearoa), while trending downwards for non-Māori. Over half of Māori who get bowel cancer are diagnosed before the age of 60 years and are more likely than non-Māori to die within 2 years. Pacific people also experience bowel cancer inequities.

In 2016, a national bowel screening programme for Aotearoa was announced, with an age range of 60–74 years. However, equity modelling showed that the proposed programme would disproportionately benefit non-Māori and that lowering the screening age for Māori and Pacific peoples to 50 years could achieve equal health gains. Over subsequent years, Māori cancer leaders advocated for policy change to lower the bowel screening age by 10 years for Māori. They used academic publications, presentations, letters, position statements, media stories and meetings with government leaders. Despite this advocacy, in 2020, the Government announced it was not going to lower the bowel screening age for Māori and Pacific peoples.

The advocates persevered. They were supported in their efforts by new data that further confirmed the increasing bowel cancer incidence for Māori. In 2022, the Government committed to lowering the bowel cancer screening age to 50 for Māori and Pacific peoples. However, what followed was a tardy, phased rollout in only three regions. A year on, a new government embarked on a politically motivated agenda to reject ethnically targeted policies, with further significant equity changes to the programme announced.

This paper summarises the lobbying efforts of cancer leaders and the government response, revealing structural and institutional racism, represented by inaction and active rejection of evidence-based advice. We describe the perseverance required to advocate for equity in the face of structural racism and the cost to Māori lives while inaction and racism persist.

Māori, the Indigenous people of Aotearoa New Zealand (Aotearoa), have a younger age profile and die almost 8 years earlier than non-Māori.<sup>1,2</sup> Māori are disproportionately affected by cancer at younger ages, are more likely to be diagnosed at a more advanced stage of disease and are more likely to die from cancer compared with non-Māori people.<sup>3–5</sup>

Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa is a charitable network of Māori cancer specialists and whānau in clinical, research, management and advisory positions right across the health service and health research spectrum. Our members have backgrounds in oncology, general medicine, epidemiology and public health, onco-surgery, wairua (spiritual) healing, health promotion, biomedical cancer science, mātauranga Māori (Māori knowledge), cancer research, cancer screening, equity, haematology, pharmacology, advocacy, nursing, Māori health and cancer care service provision.

We provide system leadership to inform and influence national cancer control policy and advocate on issues affecting whānau Māori (Māori families and communities). We focus on cancer research, system-level cancer issues and collaboration with Māori leaders across the health sector.

Aotearoa has one of the highest rates of bowel cancer in the world.<sup>6</sup> Although both Māori and non-Māori have a similar chance of being diagnosed with bowel cancer, this tends to happen at older ages for non-Māori. In addition, bowel cancer incidence is increasing for Māori, while the incidence has been trending down in non-Māori.<sup>7,8</sup> Further, Māori have much lower cancer survival rates than non-Māori and are more likely to die within 2 years of a bowel cancer diagnosis compared with non-Māori.<sup>9</sup>

Although Pacific peoples are less likely to be diagnosed with bowel cancer compared to the NZ European population, bowel cancer is the third-most common cause of cancer death among

Pacific peoples. This represents a significant mortality burden.<sup>10</sup>

In this policy review we trace the timeline, delays and advocacy in the 15 years since 2010, as cancer leaders from Aotearoa fought for an equitable bowel screening programme (BSP) in the face of sustained structural racism.

## Background

Screening programmes provide opportunities to improve health by identifying people within a population who are at higher risk of a health problem or a condition. The rationale is that, for those with the condition, early intervention or treatment can be provided, resulting in reduced incidence and/or risk of illness or death.<sup>7</sup> Bowel screening is an effective approach for preventing bowel cancer and improving survival by identifying and diagnosing bowel cancer earlier and removing polyps that have potential to develop into bowel cancer.<sup>11,12</sup>

Screening programmes for breast and cervical cancer have existed for decades in Aotearoa. Cancer screening programmes invest heavily in quality, including monitoring screening pathways by ethnicity.<sup>7</sup> Regardless of this, screening programmes consistently fail to deliver on equity for the Indigenous population in Aotearoa.<sup>13</sup>

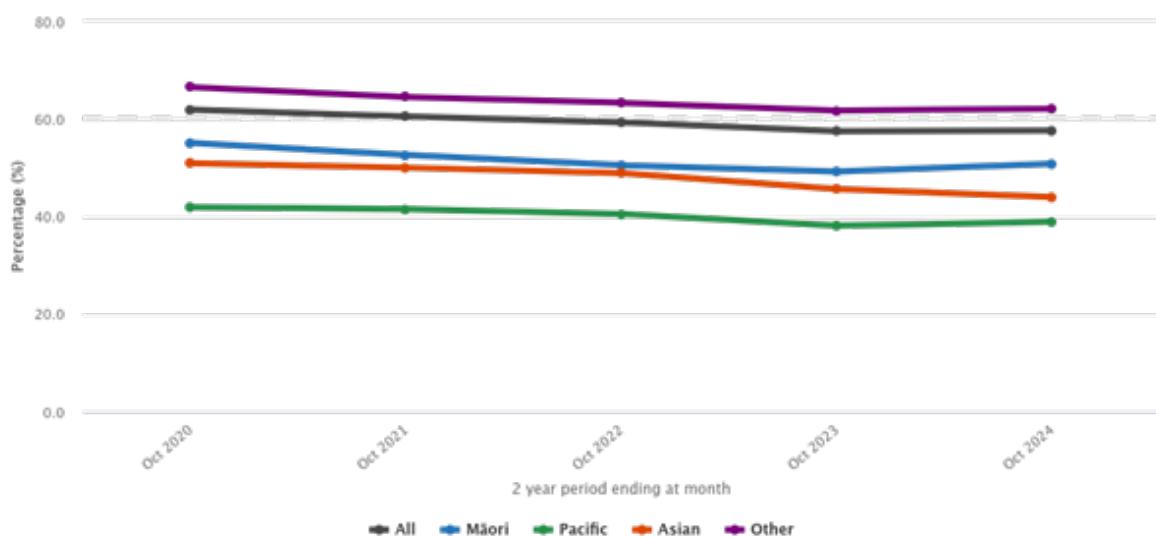
The national breast and cervical screening programmes continue to underserve Māori with

regard to reaching the 70% (breast) and 80% (cervical) minimum access target rates. This is illustrated by equity gaps of 10% for breast screening between Māori (63.4%) and Other (73.4%) and 14.8% for cervical screening between Māori (66.8%) and Other (81.6%).<sup>14,15</sup> The National Bowel Screening Programme (NBSP) follows the same pattern of underserving Māori with regards to access. This is depicted in Figure 1, which reveals an 11.3% equity gap between Māori (50.8%) and Other (62.1%) in access to the programme.<sup>16</sup>

Done well, national screening programmes could lead the way to achieving equity, accelerating Māori health gains and upholding Māori rights to health. In the case of breast screening, evidence shows that when women are screened and diagnosed with breast cancer through the national breast screening programme (BreastScreen Aotearoa [BSA]) there are no survival inequities between Māori and non-Māori due to coordinated cancer control measures over many years.<sup>17</sup>

For cancer screening programmes to be equitable, multiple factors such as prevalence, mortality rates, invitation, diagnosis and treatment pathways need to be considered from design through to delivery and monitoring. An obvious and evidence-based way to ensure that screening programmes deliver on equity for Indigenous populations is to have Indigenous cancer experts involved in leading the design, implementation and monitoring of cancer screening programmes

**Figure 1:** National bowel screening rates across all ethnicity groups. Data sourced from National Bowel Screening Programme, Health New Zealand – Te Whatu Ora 2024.



for their own populations. The NBSP team has had considerable input from Indigenous cancer experts about how to ensure that the NBSP is equitable. However, this advice has not been consistently incorporated into the planning and delivery of the NBSP.

## Methods

A search was carried out of documentation relating to the NBSP, including minutes of meetings, correspondence between Hei Āhuru Mōwai members and government departments, government policy and strategy documents, media releases and publications, and position statements. A summary of the content was included in the review of bowel screening, and the bowel screening age extension was mentioned. From this information, a draft timeline of events was created. Key informants identified in the search were interviewed to help source further documentation and to review the timeline and content.

The draft analysis was circulated to subject experts who collaboratively reviewed it for key decision and delay points. Findings from these steps are presented below, with critique and discussion at each key point.

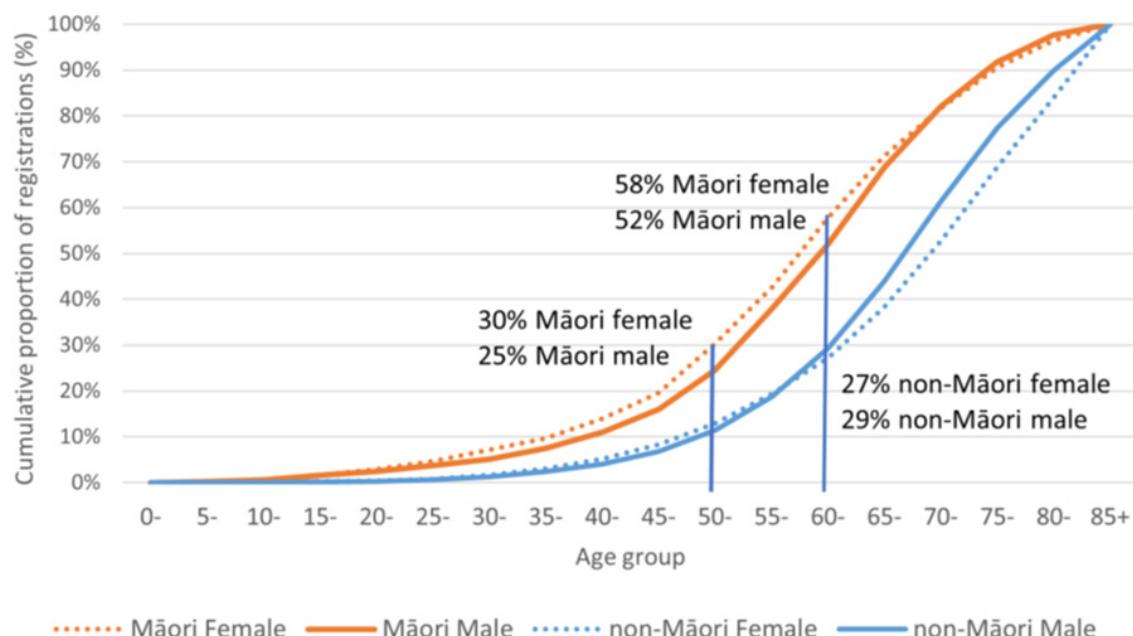
## NBSP

A national screening programme for bowel cancer was officially announced by the New Zealand Government in 2016 for those aged between 60 and 74 years.<sup>18</sup> However, the 4-year pilot leading up to the announcement had utilised an eligible age range of 50 to 74 years.<sup>19</sup> Māori cancer leaders, particularly those from Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa, recognised the implications of this 10-year age difference for increasing inequities. They reviewed the evidence, recommended changes and started an advocacy campaign to have the age lowered for Māori and Pacific peoples.

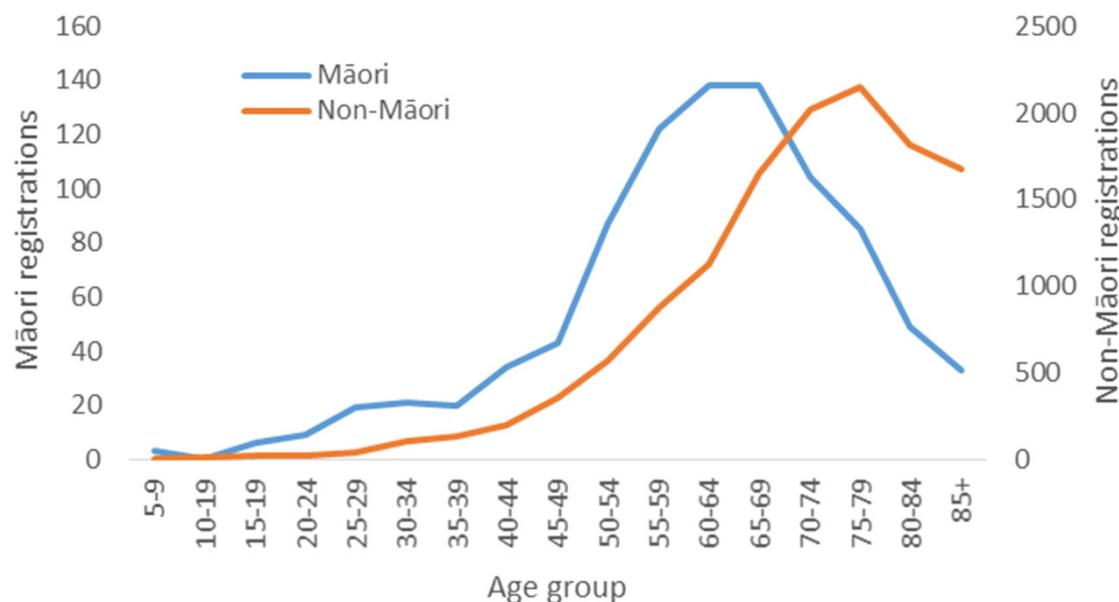
## New inequities created

In 2016, in pursuit of solid evidence of the impact of the BSP on equity, Hei Āhuru Mōwai sought data modelling expertise. Markov model analysis found that health gain, measured in Quality-Adjusted Life Years (QALYs), for those who had access to the BSP, would be over twice as high for non-Māori than for Māori.<sup>13</sup> Thus, the proposed programme would create new inequities between Māori and non-Māori by providing more health gain for non-Māori.<sup>20</sup>

**Figure 2:** Bowel cancer cumulative registrations (%) by age group, sex and ethnic grouping, 2011–2020. Data sourced from the National Screening Unit, Ministry of Health – Manatū Hauora 2020.



**Figure 3:** Number of bowel cancer registrations by age and ethnic grouping, 2013–2017 (excluding Waitematā District Health Board). Data sourced from the National Screening Unit, Ministry of Health – Manatū Hauora 2020. Categories are presented as provided in the data.



Markov modelling was also employed to identify adjustments to the bowel screening pathway that would create equal health gains for Māori and non-Māori.<sup>20</sup> This showed that lowering the starting age of screening to 50 years for Māori, and keeping it at 60 years for non-Māori, would result in equal proportions of diagnosed cancers occurring within the eligible age ranges for both groups. This solution was also shown to result in equal health gain from bowel screening for both groups.<sup>20</sup>

Over the next several years, reiteration of these key messages continued via an informal coalition of entities, including chief executives and Māori general managers of the (then) district health boards, Te Ohu Rata o Aotearoa (the Māori Medical Practitioners Association) and a national representative body for general practitioners. Methods and forums included peer-reviewed publications and unpublished papers, presentations, letters and meetings held with ministers in Parliament (particularly the minister of health), position statements on bowel screening and media stories. Formal structures and spaces also brought together those with an advocacy agenda, specifically, the National Māori Bowel Screening Network and the National Pacific Bowel Screening Network.

## Evaluation reports and an independent review

The *Final Evaluation Report of the Bowel Screening Pilot 2016*<sup>19</sup> had numerous recommendations for equity. It acknowledged that the interim BSP evaluation had reported that the programme was exacerbating inequities for Māori and those living in deprived areas, due to low participation in the context of high disease burden.

The report recognised that while Māori and Pacific expert advisory groups were set up during the early implementation of the pilots, support for these groups to participate in and influence the pilot diminished over the course of the programme. In their initial work, these groups identified that a systematic and structural focus on equity for Māori and Pacific peoples was not being consistently applied and resourced. They also highlighted that methods to increase participation were stymied by the pilot's invitation pathway, which did not initially support active follow-up for people who did not return their screening tests.<sup>19</sup>

The final evaluation report of the BSP pilot concluded that the NBSP must lead with an equity focus to avoid increasing inequities in bowel

cancer outcomes. It made 11 comprehensive equity recommendations, which included having a clear equity statement: Māori and Pacific leadership at the governance level, dedicated resource to address structural and systemic approaches to equity, a focus on structural and systems improvement, multifaceted and multidisciplinary approaches, monitoring of data and key performance indicators (KPIs) by an independent Māori and Pacific monitoring group, connecting with Māori and Pacific primary health and other community providers, and that an equity focus be developed and implemented for the symptomatic bowel cancer pathway.<sup>19</sup> Of the 11 recommendations made in the final evaluation report of the BSP pilot, the authors of this study conclude that three have been partially implemented.

In 2018, an independent review of the NBSP was released by the Health Quality & Safety Commission.<sup>21</sup> The review was conducted by a panel with no Māori involvement, and its terms of reference did not include a specific focus on understanding the programme's impact on equity. Disturbingly, the report framed inequities in access to bowel screening between Māori and Pacific and non-Māori/Pacific populations as a health literacy issue, suggesting that a lack of understanding among Māori and Pacific populations resulted in low participation in the programme.<sup>21</sup>

Nevertheless, the report restated concerns from the final report of the 4-year BSP pilot—that “*The current NBSP has not adequately addressed inequities for Māori.*”<sup>21</sup> Furthermore, two of the 19 high-level recommendations from the review included equity. One critical recommendation was the need to strengthen resourced Māori involvement in design of the programme and one essential recommendation was that the Ministry of Health – Manatū Hauora note the health and disability sector's concern about the current age-range restrictions, in particular in relation to the equity impact for Māori “*as additional data becomes available*”<sup>21</sup>. However, they did not reference the published 2017 equity-focussed modelling research<sup>13</sup> in the report, and, in a move that would continue to exacerbate equity issues, further recommended that the National Screening Unit should plan for an extended age range for all population groups.

## Bowel screening expert forum

In early 2019, following persistent pressure

from Hei Āhuru Mōwai and others, a bowel screening expert meeting was hosted by the National Screening Unit. The meeting drew representatives from key national organisations and experts from across the cancer care sector. The focus was on achieving equity for Māori in bowel screening, with the latest evidence presented as the basis for robust discussion. The evidence included an updated evaluation of bowel cancer trends, showing that the age-standardised rates of bowel cancer for Māori were increasing while the rates for non-Māori were decreasing.<sup>7</sup> The conclusion from this evidence was that “*In the next few years we will face a new inequity in health for Māori: a higher incidence of bowel cancer.*”<sup>20</sup> Based on the evidence at that time, a series of equity recommendations for government were established.<sup>22</sup>

The principal recommendation from this forum was that the bowel screening age should be lowered to 50 years of age for Māori. While those in attendance had been advised from the outset that changes would not be considered until after the national rollout was complete, there was consensus among attendees that it would be unethical to wait any longer to correct this inequity-by-design. A note of urgency was placed on this recommendation.<sup>22</sup>

Another recommendation from that meeting was that “value added” initiatives be explored to increase health gains from the NBSP.<sup>22</sup> Such initiatives can not only improve Māori health through directly reducing death and disease rates from the condition being screened for, but they can also include other health-enhancing initiatives, such as provision of on-the-spot care such as blood pressure checks or referring to other screening programmes or further targeted care.

## Evidence ignored

In September 2020 the Government, via the Ministry of Health – Manatū Hauora, announced the decision not to proceed with considering a NBSP age extension for Māori and Pacific peoples until the existing programme was fully rolled out—at that time estimated to be late 2021. Documentation sought under the *Official Information Act 1982* shows the advice provided to the country's leaders at the time.<sup>23</sup> Despite numerous redactions in the documents provided, it is clear that the argument against lowering the screening age for Māori and Pacific peoples focussed on unfavourably comparing its gain against other,

less resource-intensive interventions. The incapacity of the health sector to provide colonoscopies was a significant consideration in the final decision not to extend the programme.<sup>23</sup>

A flurry of media articles ensued, representing the many health leaders, researchers and providers, both Māori and non-Māori, who were frustrated with this decision given that it was discriminatory and delayed required actions.<sup>24-27</sup> This was a major setback for a long and complicated journey. In fact, the rollout of the national programme would not be complete until mid-2022, almost 2 full years after the announcement and approximately 5 years after the NSBP commenced.

## Māori cancer leaders persevered

Continuing their campaign, Hei Āhuru Mōwai persevered for another 2 years after the announcement. Their messages remained unchanged. They were delivered at all appropriate opportunities and forums, particularly those where government employees and officials were present. The media became an important partner in collaborative efforts to generate the necessary change.<sup>28</sup>

Finally, in Budget 2022, the Government committed to extending the bowel screening age for Māori and Pacific people to 50 years of age in 2023.<sup>29</sup> While this announcement was celebrated, it was long overdue and would initially only apply to three regions, covering approximately 13% of the country's total population and 20,000 Māori and Pacific people.<sup>23</sup>

## A bittersweet victory

The decision to lower the screening age for Māori would help to fix long-standing issues with the programme. It would not, however, detect bowel cancer earlier for those that were missed during the years that this issue was being considered and debated. While it is difficult to quantify the impact of structural racism, sharing details of the journey can add to the evidence base. It can also draw attention to those that have suffered the consequences of a long, arduous and anticlimactic journey.<sup>30,31</sup> Of these there are many, including one of our own. Our māreikura (esteemed friend) was diagnosed with late-stage bowel cancer in 2022, at age 58; 2 years too young for the eligibility criteria at the time, but 8 years past the eligibility age recommended for Māori. Her story illustrates some of the issues highlighted by the data.

*During the early months of 2022, I began to experience the typical "bowel changes" of pain and rectal bleeding that indicated I should make a visit to my GP. I was 58 years old. My GP was reluctant to refer me for a colonoscopy because he considered that I was underage and that his request would be declined by the hospital service unless I was 60 or had more significant symptoms. His tone changed when I said I had health insurance that would cover the procedure.*

*I was ultimately diagnosed with metastatic colorectal adenocarcinoma.*

*My long history as a researcher into cancer inequities for Māori had somewhat prepared me for a diagnosis like this. After all, why should I be any different to my research participants? However, in my sadness, fear and acceptance, I am also angry. I would not be facing illness, pain and early death if I had had access to bowel cancer screening at an equitable age. I [along with] my research [was] a part of the consistent calls for the screening age to be lowered to 50 for Māori. The surgeon who resected my bowel was unequivocal in his statement that, had I been screened, my cancer would have been either prevented or caught early enough that it would not have metastasised. I received an invitation to join the national bowel screening programme on the week I turned 60, but it was too late.*

*My story is no more or less important than any of the hundreds of stories I have heard from bereaved whānau. I share it here as yet another piece of evidence that the decisions made to maintain an inequitable bowel screening age are costing Māori lives. This time, the life it has taken is mine.<sup>32</sup>*

## Ongoing inaction

It is undeniable that there was inaction in the face of need during this time, evidenced by expert data modelling and supported by experts in the sector.<sup>24</sup> A number of justifications for the

repeated decisions to not extend the age range had been provided throughout the years. There was always a reason. According to personal communication from one of our most resolute advocates, *“The hold-up was fear of white backlash, [it] was the number one factor holding this progress back. This is a stark expression of whiteness; such decisions provide clear evidence that Pākehā [NZ European] feelings are valued more than Māori lives.”* While the 2022 announcement was somewhat anticlimactic with its slow, phased rollout, it seemed that the years of perseverance had achieved the necessary result to eventually achieve an equitable NBSP.

In 2023, however, a new government was voted in partially on a campaign of rolling back Māori equity and sovereignty gains. They immediately commenced a programme of defunding, disestablishing and reversing initiatives that sought to address Māori inequities and agency across the health, education, justice and social sectors.<sup>33</sup> By mid-2024, concerns were being raised about the future of the NBSP age reduction rollout for Māori and Pacific peoples. During media investigations, it emerged that the previous Government had not completed the ministerial approval required to progress the rollout and that the application of the policy was again under consideration.<sup>34</sup> The inaction on the part of the previous Government had increased the already substantial risk to the programme posed by the racist agenda of the current Government.

## Discussion

Structural racism “normalises historical, cultural and institutional practices that benefit white people and disadvantage people of colour”<sup>35</sup> thereby making whiteness both central to society and invisible to advantaged observers. It establishes and reinforces the unequal distribution of resources, as well as the attendant socio-culturally embedded justifications for such inequalities. Structural racism functions in tandem with institutional racism, whereby institutions or organisations act (or fail to act) in accordance with the norms established by structural racism.

In this paper, structural racism describes the focus of successive governments on the bowel cancer trajectory of non-Māori, non-Pacific peoples. It normalises the expectation that a successful programme should focus on addressing the health needs of the older population aged 60–74; primarily white people. It asserts that consequent inequi-

ties represent a failure of the Māori and Pacific population to protect their own wellbeing, even though the majority of Māori diagnosed with bowel cancer in a given year are not eligible for bowel screening. More than that, it doubles down on blaming the victims of such inequities by portraying their cancer diagnoses as evidence of low health literacy.<sup>21</sup>

The enactment of a structurally racist BSP is undertaken at the institutional level, where organisations such as the Ministry of Health – Manatū Hauora, the National Screening Unit and Te Aho o Te Kahu – Cancer Control Agency make decisions based on societal assumptions about what is normal.<sup>23</sup> The strength of the normalisation created by structural racism is such that even epidemiological modelling was disregarded in the development of the NBSP. This pattern of ignoring, reframing, delays and inaction is consistent with the findings from a national Māori review of the health sector, which concluded that institutional racism is a significant feature of the Aotearoa health system.<sup>36</sup>

In a call to action, United States cancer researchers issued a challenge to “explicitly name structural racism and describe its operation in scientific research.”<sup>37</sup> In this paper we name its impact on Māori lives affected by bowel cancer. Our own call to action to the current New Zealand Government, its advisors and political allies is to recognise and address the healthcare system as a colonial institution, and that “just doing their job” is a profoundly racist act. Radical transformation is required to achieve the opposite of what the current system is designed to do. We recommend that these three key questions be applied to the ongoing consideration of implementing an equitable screening programme, whether for bowel cancer or for other conditions:

- What is the status quo in terms of Māori and Pacific equity in this and associated areas?
- Who have you included in the design, implementation and monitoring of the programme?
- How is this decision/proposal going to address the identified inequities in the short and long term?

## Conclusion

Structural racism delayed the decision to lower the age range of bowel screening for Māori, to the detriment of Māori lives. This advocacy journey

provides evidence of structural and institutional racism in Aotearoa New Zealand—specifically, deliberate inaction in the face of need. It showcases the perseverance displayed by and required of Māori leaders in cancer control to respond to the ongoing push-back from government and its employees, despite substantial evidence to support the advocacy efforts. While the advocacy efforts

resulted in some belated pro-equity action, a change in government has placed equitably designed population health programmes in jeopardy.

*Tawhitawhi noho, teretere ngaro*

*Teretere tū, taea te pare*

**COMPETING INTERESTS**

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**AUTHOR INFORMATION**

Dr Nina Scott: Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa.  
 Prof Jacquie Kidd: Auckland University of Technology.  
 Dr Hayley Arnet: Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa.  
 Cynthia Dargaville: Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa.  
 Moahuia Goza: Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa.  
 Prof Sue Crengle: University of Otago, Dunedin, Aotearoa.  
 Assoc Prof Rhys Jones: The University of Auckland, Auckland, Aotearoa.  
 Dr Clarence Kerrison: Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa.  
 Dr Rawiri McKree Jansen: Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa.

**CORRESPONDING AUTHOR**

Dr Nina Scott: Hei Āhuru Mōwai Māori Cancer Leadership Aotearoa. E: [Nscott.waikato@gmail.com](mailto:Nscott.waikato@gmail.com)

**URL**

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# Abdominal aortic aneurysm in women in Aotearoa New Zealand

Oliver Lyons, Sue Crengle

## ABSTRACT

Women with an abdominal aortic aneurysm (AAA) in Aotearoa New Zealand experience inequity at every stage of diagnosis and management. We currently treat women too late in their disease course, where increased age, comorbidities, larger AAA diameter, preventable ruptures, loss of eligibility for simple endovascular repair (EVAR) and clinical “turn down for surgery” rates all add to higher AAA mortality. There is scope for great improvements in cardiovascular risk reduction for people living with a small AAA and for considering the inclusion of women in proposals for an AAA screening programme.

**A**n abdominal aortic aneurysm (AAA) is a weakening and expansion of the main abdominal blood vessel.<sup>1</sup> Women with AAA experience inequitable outcomes at every stage of management. This has long been known and should be addressed.<sup>2</sup> This inequity stems from a lack of sex-adjusted diagnostic thresholds, quadruple the risk (compared to men) of rupture prior to meeting current repair thresholds, higher clinical turn-down rates, older age at the time of repair, more frequent presentation with symptoms requiring high-risk emergency repair and higher palliation rates when their aneurysm ruptures. Inequity for women is present in Aotearoa New Zealand but has been identified worldwide and has been underpinned by a failure to adequately consider women in research, clinical practice and national planning.<sup>3</sup>

## Diagnosis and prevalence

The global prevalence of abdominal aortic aneurysms has been falling due to decreasing rates of smoking, but significant disease remains.<sup>4</sup> The prevalence has been thought to be much lower in women than in men, but this partly stems from a failure to use an appropriate diagnostic threshold in women. AAA should be diagnosed at 30mm in men and at 26mm in women.<sup>5,6</sup> In an AAA screening trial, the crude prevalence of undiagnosed AAA in Māori men aged 60–74 years was 3.6% while in women aged 60–74 years it was 2.3%.<sup>7</sup> There appears to be a particular excess risk for women who smoke.<sup>3,7</sup> AAA prevalence in Māori aged 65–74 years is highest among current smokers (women 6.9%, men 7.5%). Some

ethnic groups, for example Asians, have lower AAA prevalence.<sup>7,8</sup>

## Surveillance and treatment thresholds

Small AAA growth rates are the same for men and women and are increased by smoking.<sup>9</sup> A small “sub-threshold” AAA has a very low risk of rupture (at least in men) and patients are monitored in ultrasound surveillance programmes until reaching a predetermined size threshold for considering intervention. In non-Māori men this threshold is 55mm, based on the outcome of four randomised controlled trials, and is safe.<sup>10</sup> In Aotearoa New Zealand a 50mm threshold is often used for Māori men, due to observation of earlier disease onset and more frequent presentation with rupture.<sup>11</sup> In the four international trials that established the size threshold for AAA repair only 9% of the participants were women and there was an inadequate sample size to recommend sex-specific treatment thresholds.<sup>3,12</sup> Internationally and in Aotearoa New Zealand a 50mm threshold is often used for women, simply by subtracting 5mm off the threshold used for men. The National Institute for Health and Care Excellence (NICE) in the United Kingdom (UK) is a notable outlier in recommending a 55mm threshold for women.<sup>13</sup> A meta-analysis of 15,475 people undergoing surveillance of a sub-threshold AAA found that women have a fourfold higher risk of rupture of a sub-threshold AAA, and women’s AAAs rupture at smaller diameters.<sup>9,14,15</sup> The observational evidence suggests that a treatment threshold of 42mm in women would provide a comparable

rupture risk to the 55mm threshold currently used internationally in men.<sup>9</sup> Importantly, in practice, the mean size at the time of intact repair in Aotearoa New Zealand women is far higher, at 59mm (versus 63mm in men).<sup>16</sup>

## Medical therapy in those with AAA

Patients with AAA have a very high cardiovascular risk, rendering primary prevention risk scoring systems redundant. In a large AAA cohort, women's estimated 10-year risk of cardiovascular events was 43%.<sup>17</sup> Full implementation of guideline-directed risk management was estimated to result in an 18.3% (8.8–25.6%) absolute 10-year risk reduction for cardiovascular events. Patients with small AAA are often monitored for many years, providing ample opportunity for interventions to improve health, but these are more poorly implemented in women.<sup>18</sup> The major modifiable risk factor is smoking, which is associated with disease prevalence, faster aneurysm growth and increased rupture risk.<sup>9</sup> Hypertension is also associated with aneurysm rupture.<sup>9</sup> There is currently no effective pharmacotherapy to prevent AAA growth or rupture, but randomised controlled trials are ongoing to test the effect of metformin.<sup>1</sup>

In Aotearoa New Zealand the population risk of AAA rupture increases with socio-economic deprivation and with smoking.<sup>19,20</sup> Māori have a higher likelihood of needing high-risk emergency repairs, meaning that the opportunity for low-risk elective repair has been missed.<sup>11</sup> The higher rates of emergency repair are hypothesised to be due to greater exposure to risk factors, poorer access to primary care services and care in hospital and a lack of AAA screening in Aotearoa New Zealand.<sup>8,11,21</sup> While no country has a national screening programme that includes women, it is notable that AAA prevalence in Māori women is higher than that used to justify screening in men in Europe.<sup>7</sup>

## AAA repair

The surgical intervention is similar for intact or ruptured AAA and is either an endovascular repair (EVAR) or open repair (OAR). EVAR does not routinely require an intensive care stay, while treatment by open surgery or treatment of ruptured AAA currently places a much more substantial burden on health services in Aotearoa New Zealand.<sup>22</sup> Randomised controlled trials demonstrate similar long-term survival after

elective EVAR and OAR, but concerns have been raised as to the long-term durability of EVAR, which has become the predominant method of elective AAA repair.<sup>15,19</sup> Operative mortality from elective AAA repair in women (internationally OAR 6%, EVAR 2.3%) is higher than in men, and women have higher post-operative complication rates even after adjusting for age.<sup>23,24</sup> At the current diameter treatment threshold, women in Aotearoa New Zealand (and internationally) are less likely to be selected for EVAR than men (Table 1).<sup>15</sup> Internationally, women are more likely to be selected for conservative (palliative) management (34% versus 19%).<sup>25</sup> This is partly because eligibility for low-risk EVAR by anatomical criteria declines at significantly lower AAA diameter for women compared with men.<sup>26</sup> Overall, women are 25% less likely to receive elective AAA repair, but women are increasingly likely to present with AAA rupture, which carries ~10-fold increased mortality.<sup>19</sup> In Aotearoa New Zealand, approximately 215 people per year are recorded as dying of ruptured AAA. Despite women's lower disease prevalence, one in three people with a ruptured AAA is a woman.<sup>19</sup> Eighty percent of those women with a ruptured AAA do not receive any emergency repair (i.e., receive palliative care or die out of hospital), compared with 62% for men.<sup>19,27</sup>

The Australasian Vascular Audit (AVA) is not compulsory but is widely used throughout Aotearoa New Zealand. Annual reports are produced but the outcomes have not previously been stratified by sex, and ethnicity data are not collected. Most patients are asymptomatic until rupture, but patients may present with acute pain prior to rupture, termed a "symptomatic aneurysm". In-hospital mortality outcomes are provided in Table 1 and reveal that women are more likely than men to require very urgent (typically "next-day") repair of a symptomatic AAA and that the in-hospital mortality rate from open surgery for a symptomatic AAA in women is 14%, compared with 5.3% in men. This is consistent with international data, but it is unclear why mortality is so high in women.<sup>28</sup> The discrepancy in in-hospital mortality is much smaller for an elective endovascular repair (1% compared with 0.5%).

## Screening for AAA in Aotearoa New Zealand

Screening has the potential to reduce the impact of ruptured and "symptomatic" AAA on patients

**Table 1:** In-hospital deaths after repair of non-ruptured (intact) abdominal aortic aneurysm (AAA) in Aotearoa New Zealand 2011–2023.

		<b>Women</b>		<b>Men</b>	
<b>Open repair (OAR)</b>	Elective	18/315	5.7%	28/1,130	2.5%
	Symptomatic	12/85	14.1%	13/243	5.3%
	<b>All open:</b>	<b>30/400</b>	<b>7.5%</b>	<b>41/1,373</b>	<b>3.0%</b>
<b>Endovascular repair (EVAR)</b>	Elective	4/418	1.0%	11/2,020	0.5%
	Symptomatic	0/61	0%	1/171	0.6%
	<b>All EVAR:</b>	<b>4/479</b>	<b>0.8%</b>	<b>12/2,191</b>	<b>0.5%</b>

The table shows the number of procedures done for asymptomatic and symptomatic intact (non-ruptured) AAA repair in Aotearoa New Zealand in 2011–2023, along with the in-hospital mortality rate. The proportion of intact AAA repairs done urgently for symptoms was 17% in women versus 12% in men. These data were obtained from the prospective Australasian Vascular Audit (AVA), which is based in Australia and does not currently collect information on ethnicity. The AVA has an 80.2% AAA case-capture rate in Aotearoa New Zealand.<sup>34</sup> Using the National Minimum Dataset, the crude estimated incidence of AAA per 100,000 person-years is 30.34 (95% CI 29.84–30.85) for men and 12.44 (95% CI 12.13–12.76) for women, using a 30mm diagnostic threshold.<sup>19</sup>

and the healthcare system.<sup>22</sup> Because Health New Zealand – Te Whatu Ora does not yet have an AAA screening programme, planned AAA management is dependent upon incidental detection of asymptomatic AAA. This likely disadvantages Māori, who have a higher disease prevalence and are more likely to require high-risk emergency repair.<sup>11</sup> In 2016 the National Screening Advisory Committee approved support in principle for screening in Aotearoa New Zealand.<sup>7,19,22,29</sup> Including women would lead to more low-risk elective EVAR and fewer presentations with high-risk and expensive symptomatic or ruptured AAA.

## Information for general practitioners:

- Be aware that the medical management of small AAA is the same for men and women. Recognise that the presence of an AAA indicates very high risk of future cardiovascular events including stroke, myocardial infarction and peripheral vascular disease.<sup>30</sup>
- Educate patients that an AAA is a manifestation of “sick arteries” (i.e., not just an anatomical problem) and is associated with very high cardiovascular risk.<sup>30</sup>
- Encourage smoking cessation. Rupture rates double in current smokers.<sup>9</sup>
- Encourage regular exercise. Sex is safe.<sup>31</sup>
- Prescribe an antiplatelet, unless contraindicated or anticoagulation is

indicated.<sup>3,32</sup>

- Prescribe a high-intensity statin (e.g., 40–80mg atorvastatin or 20–40mg rosuvastatin).<sup>3,32</sup> There is no reason to use lower statin doses in women. Even after AAA repair, use of appropriate medications is associated with improved long-term survival.
- Monitor blood pressure and treat to target (systolic <130mmHg). Hypertension increases rupture risk.<sup>9</sup>

## Information for the emergency department and radiology services:

- Be aware that in Aotearoa New Zealand one in three patients with a ruptured AAA is a woman.
- Detection of AAA by clinical examination is very poor; consider early imaging.
- Use sex-specific AAA diagnosis thresholds (women 26mm, men 30mm) and ensure that incidentally detected asymptomatic AAA are referred for consideration of surveillance.

## National interventions:

- Aotearoa New Zealand does not have an AAA screening programme. The National Screening Advisory Committee should reconsider options for screening in women.<sup>29</sup>
- Current guidelines recommend a treatment

threshold of 50mm in women, but further evidence is needed.<sup>3</sup> Consideration should be given to further lowering the treatment threshold for women's AAA in the context of a randomised controlled trial. This is supported by Aotearoa New Zealand vascular surgeons, and a large international trial is underway.<sup>13,33</sup>

- National tobacco control methods would further reduce the incidence of AAA and associated cardiovascular diseases.

### **The international women's small aneurysm trial**

The international women's small aneurysm trial (known internationally as the WARRIORS trial, NCT06394271) is due to begin recruiting in Aotearoa New Zealand in 2026 and aims to reduce inequity in care and improve the survival and quality of life of women with AAA. The trial will test the hypothesis that lowering the size threshold

for AAA repair for women, while addressing their cardiovascular risk, will prevent AAA rupture and save lives. The trial intervention is early elective EVAR versus current care in women with small asymptomatic AAA who are eligible for EVAR, and the primary outcome is AAA-related mortality and AAA rupture at 5 years. All participants will be followed for clinical outcomes, quality of life and AAA-related anxiety.<sup>13,33</sup>

### **Conclusions**

We currently treat women's AAA too late in their clinical course, where increased age, comorbidities, larger AAA diameter, preventable ruptures, loss of eligibility for simple EVAR and clinical "turn down for surgery" rates all add up to higher AAA mortality. There is scope for inclusion of women in AAA screening and great improvements in cardiovascular risk reduction for people living with an AAA.

**COMPETING INTERESTS**

OL and SC are recipients of Health Research Council funding for the Aotearoa New Zealand arm of the international women's small aneurysm trial (WARRIORs: <https://www.imperial.ac.uk/department-surgery-cancer/research/surgery/clinical-trials/international-warriors-trial/>).

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**AUTHOR INFORMATION**

Oliver Lyons: Consultant Vascular, Endovascular and Transplant Surgeon, Christchurch Public Hospital; Senior Lecturer, University of Otago.

Sue Crengle: Professor, Hauora Māori; General Practitioner; Public Health Medicine Specialist; Ngāi Tahu Māori Health Research Unit, University of Otago; Ngāti Porou Oranga.

**CORRESPONDING AUTHOR**

Dr Oliver Lyons, Surgery and Critical Care, University of Otago, Christchurch. Ph: 03 364 0640  
E: [oliver.lyons@otago.ac.nz](mailto:oliver.lyons@otago.ac.nz).

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# An approach to make general practitioner referrals suitable for artificial intelligence deployment

Evelyn Lesiawan, Bruce Sutherland, Christoph Schumacher, Andrew Cave, Guy Armstrong

## ABSTRACT

Outpatient referrals for hospital specialist assessment are an increasing workload that carry significant risk if not attended to in a timely manner.

This viewpoint discusses how decision support (including artificial intelligence and machine learning) may address this problem. Of the many possible approaches, we choose a combination of two that illustrate the breadth of available tools and how they combine to complement each other.

To understand the issues and inform this discussion, a survey of general practitioners' views was conducted (Appendix 2), an audit of declined referrals was undertaken (Appendix 3) and draft decision trees were constructed (Appendix 4).

To have data suitable for automated decision support, the current referral needs to change from free text to a structured format that ensures every patient has a complete minimum dataset. Regarding triaging decisions, at present there is human variability, but the decision support tools will need to be trained on a set of referrals that have an agreed gold-standard decision. In order to maintain patient safety throughout, the process needs to be incremental. We suggest that one way to assure patient safety is to combine simple decision trees with sophisticated contemporary machine learning.

**S**upport for applying artificial intelligence (AI) to healthcare has recently been expressed at ministerial levels.<sup>1,2</sup> In a healthcare sector beset by staff shortages and limited funding, AI is said to have "*the potential for very high return on investment*".<sup>3</sup> This viewpoint examines the potential for decision support, such as AI, to assist with triaging general practitioner (GP) referrals to cardiology outpatients at Health New Zealand – Te Whatu Ora Waitematā. The general principles and approach discussed have the potential to scale and extend more widely to other districts and specialities.

Keeping pace with the number of outpatient referrals is challenging for hospital specialities. The challenges include the sheer volume of referrals, with their year-on-year increase (Figure 1), as well as the need for timeliness in investigating and treating.<sup>4</sup> Some cardiology conditions carry a mortality risk, making prompt assessment important for more than quality of life reasons alone. AI and conventional decision support techniques have the potential to assist, and we examine how current processes could be adapted for such deployment.

Many decision support tools could be applied to

this problem. We have chosen two techniques that are particularly illustrative for clinicians seeking to understand the available options. There are many other tools available that could be applied to this problem.

The two techniques used for illustration are human-designed decision trees and contemporary machine learning (ML). They are at opposite ends of the complexity spectrum of available methods. We suggest that, by employing two complementary approaches, the power of contemporary, sophisticated ML is harnessed while ensuring clinical safety through a simpler, more transparent technique, particularly during the initial deployment.

This viewpoint first defines relevant terms, then describes the current process for handling outpatient referrals, followed by a discussion of barriers to implementing decision support. We then describe a possible approach to addressing these issues by combining decision support techniques in a stepwise process. The aim is to maintain patient safety at every stage of the development process, yet culminate in maximising the benefit from contemporary sophisticated decision support tools. Our findings and proposals

are informed by a survey of GP views (Appendix 2) and an analysis of declined referrals (Appendix 3).

This is an account “from the trenches” designed for the non-expert; a comprehensive position paper is available.<sup>3</sup>

## Definition of terms

### Decision support: decision tree versus ML

A **decision tree** (flow chart) can help GPs provide all relevant information by using structured questions. A decision tree breaks the decision into a series of simple “yes/no” questions, as per the examples in Appendix 4. The transparency of the decision process makes the tree educational for users. By forcing a stepwise assessment, the chart ensures that referrals are graded on a consistent set of criteria, thus reducing the variation that occurs between human triagers.

A **ML** model would learn from a large dataset of past referrals that have an agreed triaging decision. The model can detect patterns too subtle or complex for a simple decision tree—for instance, combinations of symptoms that, while individually mild, tend to lead to referral acceptance when seen together. Unlike the static decision tree, the ML model continues to learn as more referral and outcome data are fed in, making it adaptive and more accurate than rigid criteria. ML could either replace or augment the decision tree.

### AI: ML compared with large language model (LLM)

ML refers broadly to algorithms that learn patterns from data to make predictions or classifications. In contrast, **LLMs** are statistical systems trained on vast amounts of text and other unstructured data to generate language that resembles human communication. In medicine, ML might be applied to imaging or laboratory data to predict disease or identify abnormalities. In contrast, LLM can summarise patient records, draft clinical correspondence, provide natural language responses to medical queries or interpret text entries.

ML models offer a significant advantage over traditional approaches because they do not require researchers to fully specify the structure of relationships in advance. Instead, they sift through data and detect subtle or unexpected patterns that humans might never have anticipated, making them powerful tools for uncovering new insights. The trade-off, however, is that these

models often operate as a “black box”, producing results without making clear why certain connections were drawn. This can lead to spurious or misleading associations being treated as meaningful, including the embedding of existing biases. For this reason, while ML expands the frontier of what can be uncovered, oversight remains essential to interpret results responsibly and to ensure that identified patterns are both accurate and relevant. An ML tool with excellent average performance will still produce a small percentage of incorrect decisions, and these may be consequential for individual patients.<sup>5</sup>

## The problem

### Overview of outpatient service and staffing

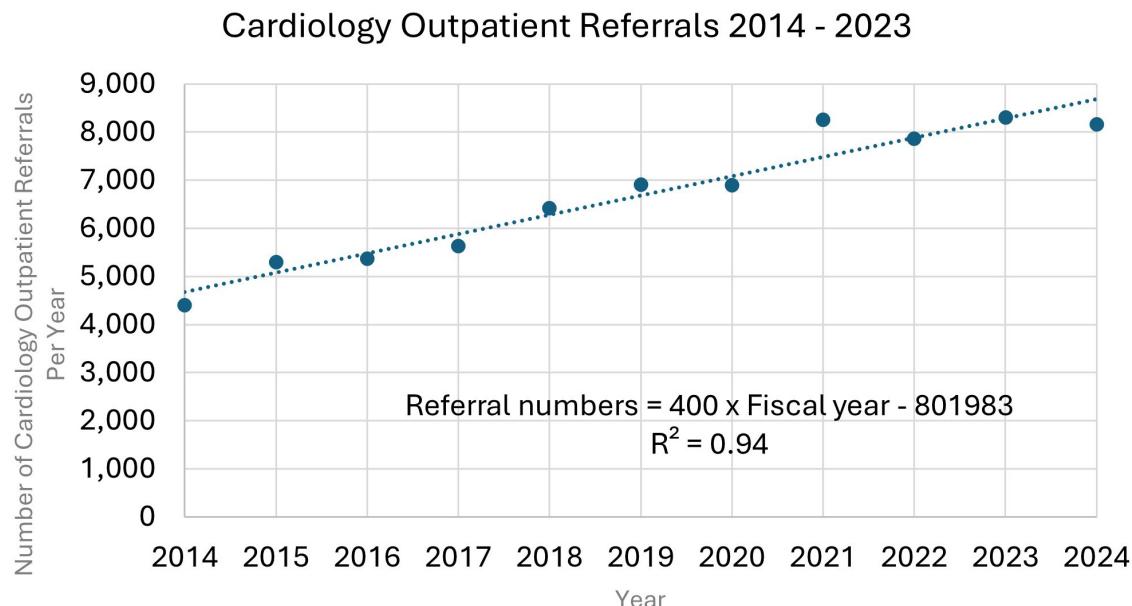
The current referral process entails a GP making an electronic, largely free-text referral. Once registered by the booking and scheduling clerk, the triaging cardiologist either accepts (and prioritises) the referral or declines it. The clerks then act on these decisions. There are no automated decision aids.

### Problems with the current triage service

Processing cardiology outpatient referrals consumes a considerable amount of resources. At Waitematā, nine doctors and one nurse do not keep pace with the triaging of referrals, which increase by 1,374 each year (see Figure 1). The number of clerical staff required for this manual process is not quantifiable, as they are shared across departments. Clinical risk to patients increases with delays at every step, initially with referrals waiting to be triaged, then accepted referrals waiting to be seen and finally seen patients awaiting subsequent investigations (Table 1). Automation with appropriate decision aids could expedite the triage of referrals and thereby reduce wait times and associated clinical risk.

However, the current free-text format delivers varying amounts of information. Triaging cardiologists want referrals to consistently contain specific information relevant to the reason for referral. If automated decision aids are to be useful and trustworthy, this minimum dataset for every patient becomes mandatory.

Another issue with the current human-led service is the (understandable) variation in decisions between individual cardiologists (e.g., see variation in referral decline rates in Appendix 3). This is despite regional recommendations on triaging (Appendix 1). Automation has the potential

**Figure 1:** Number of cardiology outpatient referrals to Health New Zealand – Te Whatu Ora Waitematā, 2014–2023.**Table 1:** Outpatient referral pathway.

<b>Node</b>	<b>Aim</b>	<b>How to achieve aim</b>
<b>A) GP referral</b>	Capture information that is structured and adequate	Information fields filled by clicks and drop-downs, or by voice recognition
	Facilitate GP efficiency	GP dashboard
<b>B) Referral triage</b>	Increase appropriate declines and acceptances	Iterative development of algorithms/decision trees
	Facilitate triager efficiency	Triager dashboard
<b>C) Accepted referral</b>	Increase proportion of FSA done at triage (combined triage and non-contact FSA)	Incentivise triagers
<b>D) Clinic FSA</b>	Reduce need for follow-ups	Incentivise contingent planning in initial FSA letter
	More remote evaluations	Test novel approaches such as telehealth and biomarkers

Possible intervention points to improve the outpatient referral process and prepare the ground for AI: A) Instead of free text, decision trees capture an adequate amount of information in a structured way. Informational aspects are built in to assist GPs in determining what conditions and severity warrant referral. A dashboard containing representations of (and links to) all pertinent information on one screen enhances efficiency and reduces clicks per task. B) Decision trees are iteratively refined until they can reject or accept a proportion of referrals without human intervention. A dashboard allows triaging cardiologists to access relevant cardiac information for the patient more readily. C) Not covered in this study, but once referrals are accepted, a greater proportion of FSA are carried out as a virtual non-contact FSA by the triager providing written advice to the GP. Concluding the FSA at this stage avoids the bulge of referrals moving on to increase wait times for clinic FSA and procedures such as echocardiography and Holter monitoring. D) Not addressed in this study. See text for details.

GP = general practitioner; FSA = first specialist assessment; AI = artificial intelligence.

to reduce variability with its more consistent decisions better reflecting clinical risk. However, training a decision aid is best done with a library of referrals, each with an agreed reference decision.

## A solution

### Summary

We are concerned that applying black box ML to this dataset may be clinically risky without an intermediate step; for this reason, we suggest using human-designed decision trees. These two decision aids may prove complementary by feeding back to each other. We acknowledge that any decision aid can make mistakes, and the process needs to be structured to minimise the impact on individual patients. Table 2 explains some of the important concepts. Other suitable options, such as “explainable” AI, are not considered here.

### Information from GPs that is sufficient and structured

Our illustrative strategy involves a first step of generating, for each patient, a sufficient minimum set of data relevant to the presenting symptom. The draft decision trees in Appendix 4 contain examples of relevant information for some common conditions; they will need to be further developed and improved. Taking chest pain as an example, it is essential to know whether it is exertional and whether it is accompanied by shortness of breath. Such a minimum dataset will help both the current human triagers and any subsequent automation.

This specific information required by cardiologists for each condition could be obtained from GPs using a structured form using tick boxes (still with room for free-text additions). The information would then be digitally incorporated into the hospital information system, relieving clerical staff of the chore of (error-prone) manual entry.

Without the use of structured forms, those patients lacking the minimum dataset of information are at risk of variable and erroneous decisions, whether made by humans or automation. It is not realistic to expect GPs to know what information specialists require. Our GP questionnaire found that only 29% of GPs are confident about the information required for a cardiology referral, and only 50% are confident about which conditions are typically seen by cardiology (Appendix 2).

Only limited information (variables) can

be requested from the GP to avoid the process becoming too time-consuming. However, GPs are increasingly using “AI medical scribes”, which may facilitate gathering more information without them being overwhelmed. Nevertheless, there will always be substantial amounts of pertinent information missing from a referral. Some information is currently unavailable because it has not yet been obtained (e.g., through a future Holter monitor or echocardiogram), while other details are missing because it would be unreasonable to expect GPs to provide too much information. Furthermore, individual patients will have uncommon factors that are idiosyncratically predictive for them but are not captured by any manageable process. Only a small fraction of the many relevant variables (dimensions) can be captured. These limitations mean that the training of any automation carries a risk to individual patients that needs to be managed carefully.

### Agreed end points for training decision support

To train automated decision aids, a gold-standard decision is needed for reference. Currently, this doesn’t exist, as human triagers (being human) exhibit variability in their decisions (Appendix 3). Such variation needs to be eliminated to supply a gold standard or reference decision for automation training. This could be achieved by a small number of cardiologists reaching consensus on cases to develop and validate decision trees. Human oversight would need to be an ongoing, iterative process, as new cases challenge the algorithm, clinical practice changes and thresholds alter due to changes in resourcing.<sup>3</sup> Below, we suggest that this onerous human oversight of ML may possibly be devolved to decision trees.

### Going straight to ML may be problematic

ML learning in these sparse representations of high-dimensional data carries a risk of unpredictable outcomes, which is an unpalatable risk in clinical medicine.<sup>6</sup> We suggest that success with ML will be more likely if the ground is prepared before deployment. This could be achieved iteratively by first transitioning from free-text electronic referrals to a structured referral form that can support the implementation of decision trees, before considering full-blown black box ML (Appendix 4). The idea of having a transitional state of decision trees inserted between human triage and ML made even more sense when we

became aware that there had been a previous failed attempt at deploying AI to triage cardiology referrals at Waitematā.<sup>7</sup> We have been unable to obtain further information and so do not know the reason for failure.<sup>7</sup>

### Human-designed decision trees

Decision trees mimic how a cardiologist makes decisions. By making these thought processes explicit, transparent and fully explainable, decision trees will serve as a helpful bridge between human triaging and subsequent ML.

Decision trees function predictably with small numbers of variables, although at the expense of being biased.<sup>8</sup> However, bias is easy to detect in decision trees, and their transparent nature allows identification and inclusion of the additional variables needed to mitigate the bias.

The act of cardiologists developing decision trees will facilitate the development of consensus reference decisions for subsequent training of ML.

Over time, decision trees may be able to replace humans in the task of ongoing oversight of ML decisions.

In a feedback loop, ML may identify new predictive variables that can then be incorporated into the structured questionnaire, enabling this variable to be obtained for all patients and thereby improving the predictive power of the ML.

### Decision support makes mistakes

Like humans, any automated decision support will make mistakes. It may be that, as with self-driving cars, society will be less tolerant of automation error than of human error.<sup>9</sup> Decision trees exemplify the concept of “satisficing”, which is finding a good-enough solution when it is not practical to find the optimal solution.<sup>10,11</sup> They may work better than ML when there are many unknown variables (as here).<sup>12</sup> In this setting, their output is more predictable than ML and more readily modified.<sup>3,12</sup> Simple decision trees mimic the decision making of legal judges surprisingly faithfully and may perform similarly for cardiologists, regardless of how sophisticated we view our own decisions as.<sup>12</sup>

Decision trees or ML can only ever be “probably approximately correct”<sup>5</sup> when evaluated on large numbers of patients. That means that decisions on individual patients have the potential to deviate sufficiently to be a clinical safety issue. At the outset, the error bounds for both the approximation and the probability are unknown, hence the need for oversight. We

believe the human-designed decision trees provide the necessary safety, at least for the initial stages. Their deployment is carried out in a stepwise fashion, allowing for iterative refinement with minimal clinical risk and helping to maintain clinician trust.<sup>3</sup> Regardless, some misclassification will occur at the conceptual level due to the challenge of crystallising the diversity of human symptoms into binary variables. However, if data collection is digital, misclassification due to data entry errors and data handling will be minimised.<sup>13</sup>

At the opposite end of the spectrum are the black box forms of ML, where it is not possible to explicate or understand the rationale behind the algorithm’s recommendation, or even which variables were used to predict the recommended outcome.

### Sequence of deployment

ML is more powerful than decision trees, but, initially at least, it will be more prone to erratic and deviant results, given that the available information is sparse. ML needs a library of reference decisions before it can be trained.

Structured forms will provide more complete information, which is a necessary condition for any automation. Initial deployment of decision trees would be alongside, but invisible to, the human triagers. The discrepancies between human and algorithmic outcomes will be reviewed, and the algorithm will be refined accordingly. Next, the tree results are made visible to the human triagers for further refinement. Finally, a decision is made on whether some classes of referrals can be accepted or declined solely by the algorithm. There will be an indeterminate group where acceptance or rejection will need human input. Further iterations are performed to minimise the size of this indeterminate group. However, indeterminate presentations should never fall to zero, as there will always be complex and poorly differentiated cases. Forcing these into the algorithm risks misclassification.

Declined referrals should be accompanied by standardised information to the GP on why the referral was rejected, together with suggestions for management. This will assist the 42% of GPs who perceive that a referral has been declined inappropriately, and it functions as a just-in-time education tool for the GP referrer (Appendix 2).<sup>14</sup>

The next step is to train the ML model on the entire content of the referral, including both structured information and free text. This latter may be

**Table 2:** Elements of automated decision support for GP referrals.

Term	Description
Structured information	Required for whatever decision support method is chosen. Provides a minimum dataset, which makes ML predictions less variable and facilitates more rapid training of AI.
Human-designed decision trees (transparent predictions)	<p>Designing these will facilitate cardiologists' consensus in the development of reference decisions for training ML.</p> <p>Can be improved iteratively as cases are encountered that don't fit the current tree decision.</p> <p>Contain domain knowledge of cardiologists that can frontload the training of ML.</p> <p>Can replace human oversight of ML decisions.</p> <p>Interacts in a continuous feedback loop whereby new predictors from ML are added to the decision tree, which then provides a more complete dataset on every patient. This makes ML predictions more consistent and reliable.</p>
Machine learning (opaque predictions)	<p>Extends the predictive power of decision trees by incorporating free-text information contained in referrals.</p> <p>Identifies new predictors that are then incorporated in the structured questionnaire, thus improving the minimum dataset obtained on each patient.</p>

GP = general practitioner; ML = machine learning; AI = artificial intelligence.

extracted by an LLM and fed into the ML algorithm. The LLM output is a probabilistic tool (i.e., it may give a different result each time it is fed the same information) and so adds an additional element of unpredictable variation that needs oversight to ensure the safety of individual patients.

It may be most useful for the decision trees and ML to proceed in parallel. If the ML identifies novel variables, these could be fed back and incorporated into the decision trees. As clinical safety is assured, increasing weight can be given to ML, which should eventually overtake the decision tree in its predictive ability.

### Limitations

The current Auckland Region eReferral system is not suited to our proposals. We understand there is a project to review and upgrade the software, which will be more suited to deliver the dashboard views (Appendices 2 and 3).

This report is on the current system for referral triaging. However, this is embedded within the larger New Zealand health IT infra-

structure, and the need for compatibility will influence which solutions are most appropriate.

The decision tree concept was developed with support and input from the Waitematā cardiology liaison GP, but has not yet been discussed more widely within the GP community. However, the orthopaedic service has successfully implemented decision trees with tick boxes and drop-down selections. Informal discussions with GPs indicate that they have accommodated the increased time required to complete the forms by scheduling a separate appointment specifically for the orthopaedic referral. They see an advantage in the form, as it provides an immediate answer as to whether the patient qualifies for joint replacement surgery and at what priority. This enables real-time discussion between the GP and the patient about the reasons for acceptance or rejection. GP practice software will need to incorporate the decision trees and AI software, which will take time to implement. It may also be helpful to incorporate the existing GP guidelines ("health pathways") into this software, providing more

ready access to advice.<sup>14</sup>

Insufficient information is available for a quantitative cost-benefit analysis. There are alternative approaches to this problem, utilising different automation tools. We view the approach outlined here as particularly illustrative for those unfamiliar with decision support tools.

## Conclusion

There are many opportunities for AI to assist healthcare. This viewpoint examines the potential for automated decision support, including AI, to assist in triaging GP referrals. It has the potential to improve efficiency, reduce personnel requirements and provide more consistent decisions when compared with human triagers. We review

an approach that is illustrative for those unfamiliar with decision support, while acknowledging that other options will be suitable.

The volume of GP referrals is substantial and poses significant challenges. However, two steps are required to prepare the ground for automation. Firstly, adequate information is crucial, especially for black box ML. A minimum dataset is necessary for every patient, which requires switching to a structured referral form instead of free text. Secondly, a library of historical referrals with reference (gold standard) decisions is needed for the training of automation.

We suggest that human-designed decision trees can complement contemporary black box ML by mitigating the risk of erroneous decisions that may affect the safety of individual patients.

**COMPETING INTERESTS**

Nil.

**AUTHOR INFORMATION**

Evelyn Lesiawan: Advanced Physician Trainee, Health New Zealand – Te Whatu Ora, New Zealand.  
 Bruce Sutherland: General Practitioner, Kawau Bay Health, Warkworth, Auckland, New Zealand.  
 Christoph Schumacher: Professor of Economics, School of Economics and Finance, Massey Business School, Albany, Auckland, New Zealand.  
 Andrew Cave: Digital Hospital Implementation Lead, Data & Digital, Integration & Delivery, Health New Zealand – Te Whatu Ora Northern, New Zealand.  
 Guy Armstrong: Cardiologist, Health New Zealand – Te Whatu Ora Waitematā, Auckland, New Zealand.

**CORRESPONDING AUTHOR**

Guy Armstrong: Lakeview Cardiology, North Shore Hospital, Private Bag 93 503, Takapuna, Auckland, New Zealand.  
 E: guy.armstrong@waitematadhb.govt.nz

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## Appendices

### Appendix 1



### Northern Regional Cardiology Follow-up Guidelines

Version: May 2023 Review Due: May 2024

- These are follow-up guidelines only. Individual patient requirements may differ
- Always consider virtual follow-up
- Registrars should discuss follow up arrangements with their supervising SMO
- Letters to GP must clearly state follow up arrangements
- In general patients with hypertension or dyslipidaemia should be followed long term in primary care once condition stable/treated adequately
- Valves – clinical and echo follow up. If frail and comorbid (where valve intervention inappropriate) consider returning care to GP
- Rheumatic valve disease patients - refer to rheumatic fever nurse specialists if available, or ensure appropriate secondary prevention and follow-up as per valve lesions

#### Valves - follow-up frequency

Pre-Op	Mild	Moderate		Severe without current surgical indication
<b>Aortic stenosis (including bicuspid valve)</b>	5 years	2 years		6-12 months
<b>Aortic regurgitation</b>	Discharge	Normal LV 2 years	Dilated LV 1 year	6 months
<b>Mitral stenosis</b>	5 years	2 years		12 months
<b>Mitral regurgitation</b> *consider TOE for? repair	Discharge – Unless abnormal valve then 5 years	Normal LV size & function - 2 years	Dilated LV* - 1 year	6 -12months*

#### Post valve replacement/surgical mitral valve repair

- All should have baseline post-op echo
- TAVI: 3 years until evidence of valve degeneration then annually
- Mechanical: 3 years
- Bioprosthetic: 3 years until evidence of valve degeneration then annually
- Surgical mitral valve repair: 1 year then every 3 years

#### Post elective PCI and post ACS

If EF>50%, no further revascularization or device therapy planned, no other medical issues than nurse led cardiac rehabilitation clinic only. Otherwise, medical FU, timing to be determined at discharge.

#### Post CABG

Routine cardiac rehab follow-up 2-4 weeks, with medical FU up 6-12 weeks post op, then discharge unless EF<50% in which case repeat echo after 3 months of max. tolerated medical treatment to inform need for device therapy.





## Heart failure

- Initiation/titration of heart failure disease-modifying drugs:
  - refer to (Nurse-led) Heart Function/Heart Failure Clinic, depending on local pathway/criteria
- Resistant/fragile clinical heart failure requiring case-management (especially diuretic regimes):
  - refer to (Nurse-led) Heart Function/Heart Failure Clinic
  - consider if suitable, referral for heart transplant assessment if not improving on medical/device therapy
- Patients < 75yrs with HFrEF (EF < 40%), once Rx optimised:
  - consider yearly FU
- Stable/max. medical treatment, no device therapy planned:
  - discharge to GP and/or referring clinician
- CRT/ICD + HF patients should be followed long term - 1-2 yearly
- If uncertainty re FU plans, please discuss with lead cardiologist

## Atrial fibrillation

1. Anticoagulation decision finalised/good rate control and no other cardiac reason for follow-up: Discharge
2. Post DCCV: 4-6 weeks with an ECG, clear plan for future management including eligibility for repeat DCCV, rhythm or rate control communicated to GP
3. On flecainide/sotalol/amiodarone – 1-2 year FU
4. Post ablation FU – d/w EP team

## Aortopathy

### Genetic Aortopathy

- If suspected or confirmed: comprehensive history and refer to CIDG
- Refer to guidelines for timing and type of serial imaging and treatment for specific conditions

### Degenerative aortopathy

Aortic dimension	3.5-3.9cm	4.0-4.4cm	4.5-4.9cm	5.0-5.4cm
Follow-up	Not required (consider follow-up at 5 years)	Repeat at 1 year If no progression, 5 yearly review	Repeat at 1 year If no progression 2 yearly review	Annual imaging
Other imaging modalities	Repeat assessments should use the same imaging modality. Consider CT or MRI if reliable images cannot be obtained by echo. CT or MRI should be performed if being considered for surgical intervention.			

## Other

- CRT/ICD patients should be followed long term - 1-2 yearly
- HCM aged <70 every 1-2 years, >70 consider discharge



## Appendix 2: outpatient cardiology referrals—a survey of views held by general practitioners (GPs)

### Methods

A convenience sample of GPs within Waitematā completed an anonymous Google survey of their views on the current cardiology referral process. Auckland Health Research Ethics Committee approved the project (AH28636). When the authors were fielding phone calls from GPs during their clinical work, they invited each caller to participate in the survey. It was anonymous by design so as to encourage participation; therefore, no information is available on the profile of practices who participated.

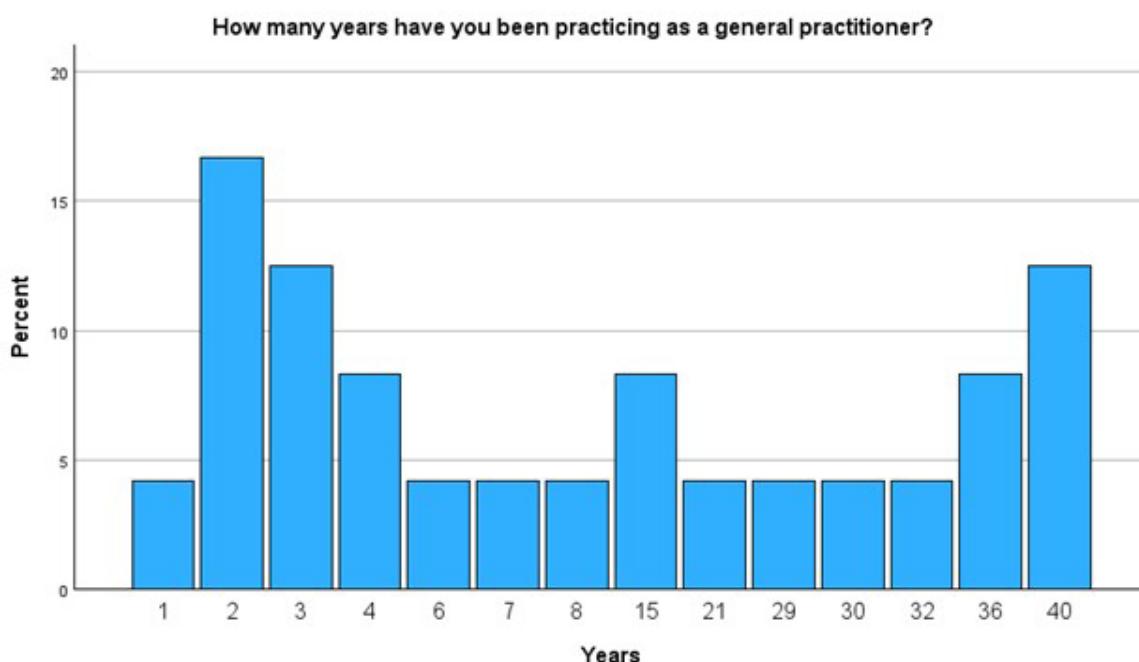
### Data analysis

This is a descriptive study. Responses are reported as percentages. There was no comparator group, and numbers were too small for statistical analysis.

### Results: questions and response rates

1. How many years have you been practicing as a general practitioner?

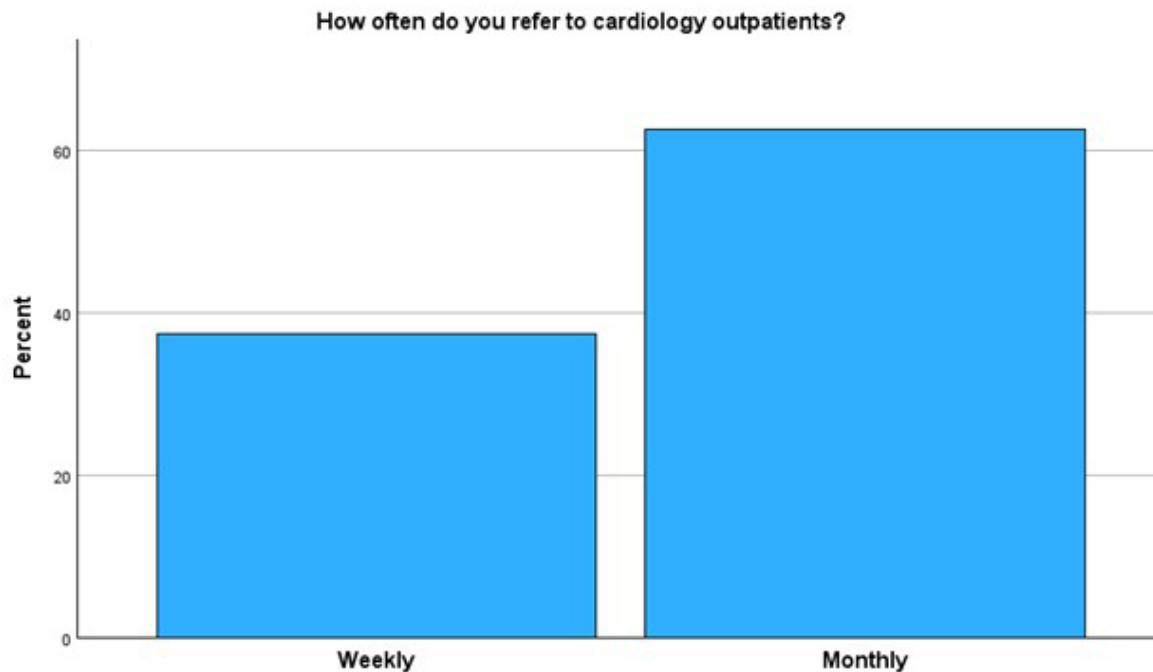
Twenty-four GPs answered the questionnaire. Years in practice ranged from 1 to 40 years, with most



2–4 years and 36–40 years. Most (61%) referred to cardiology monthly, and 39% referred weekly.

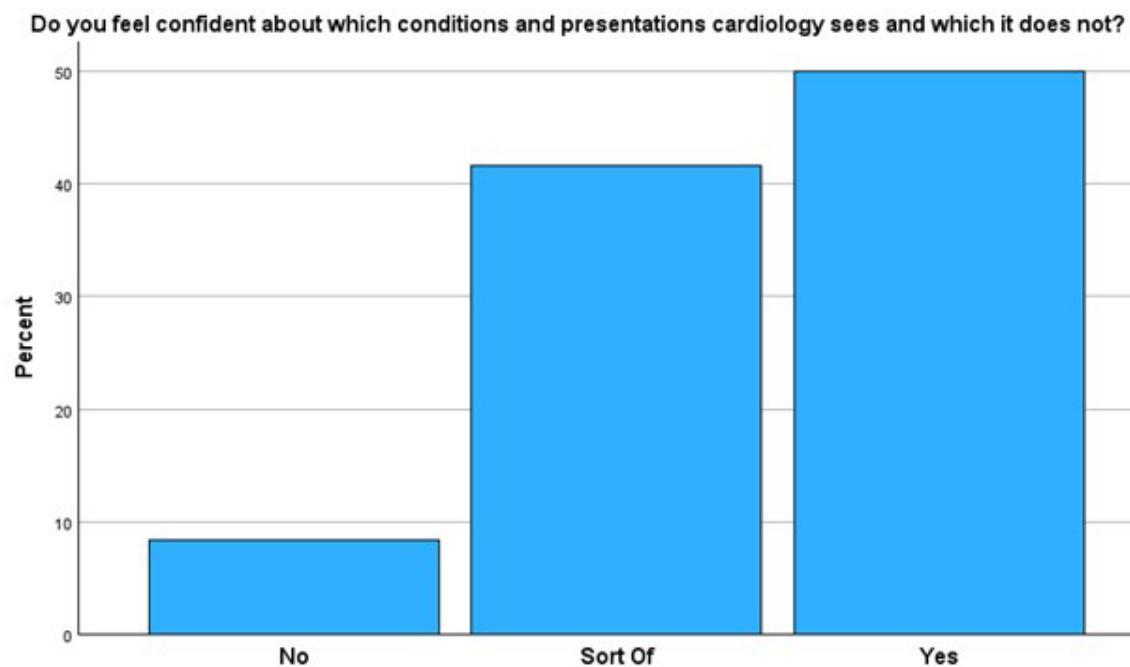
2. How often do you refer to cardiology outpatients?

- Daily
- Weekly
- Monthly



3. Do you feel confident about which conditions and presentations cardiology sees and which it does not?

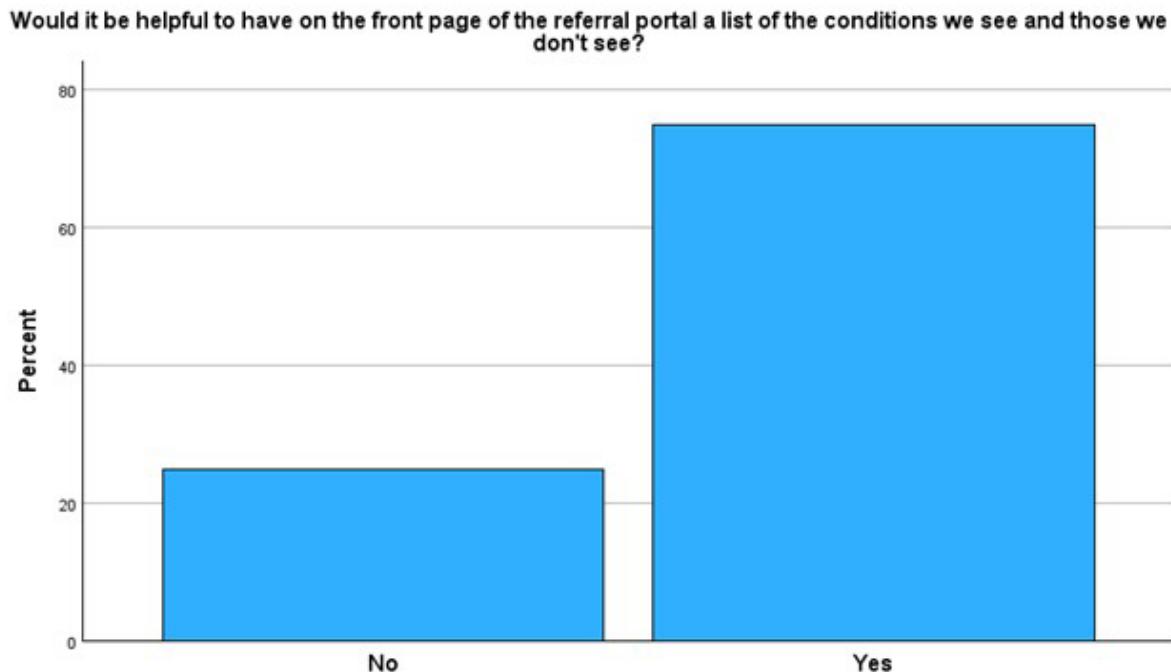
- Yes
- No
- Sort of



Only half are confident about which conditions and presentations were seen by cardiology.

4. Would it be helpful to have on the front page of the referral portal a list of the conditions we see and those we don't see?

- Yes
- No

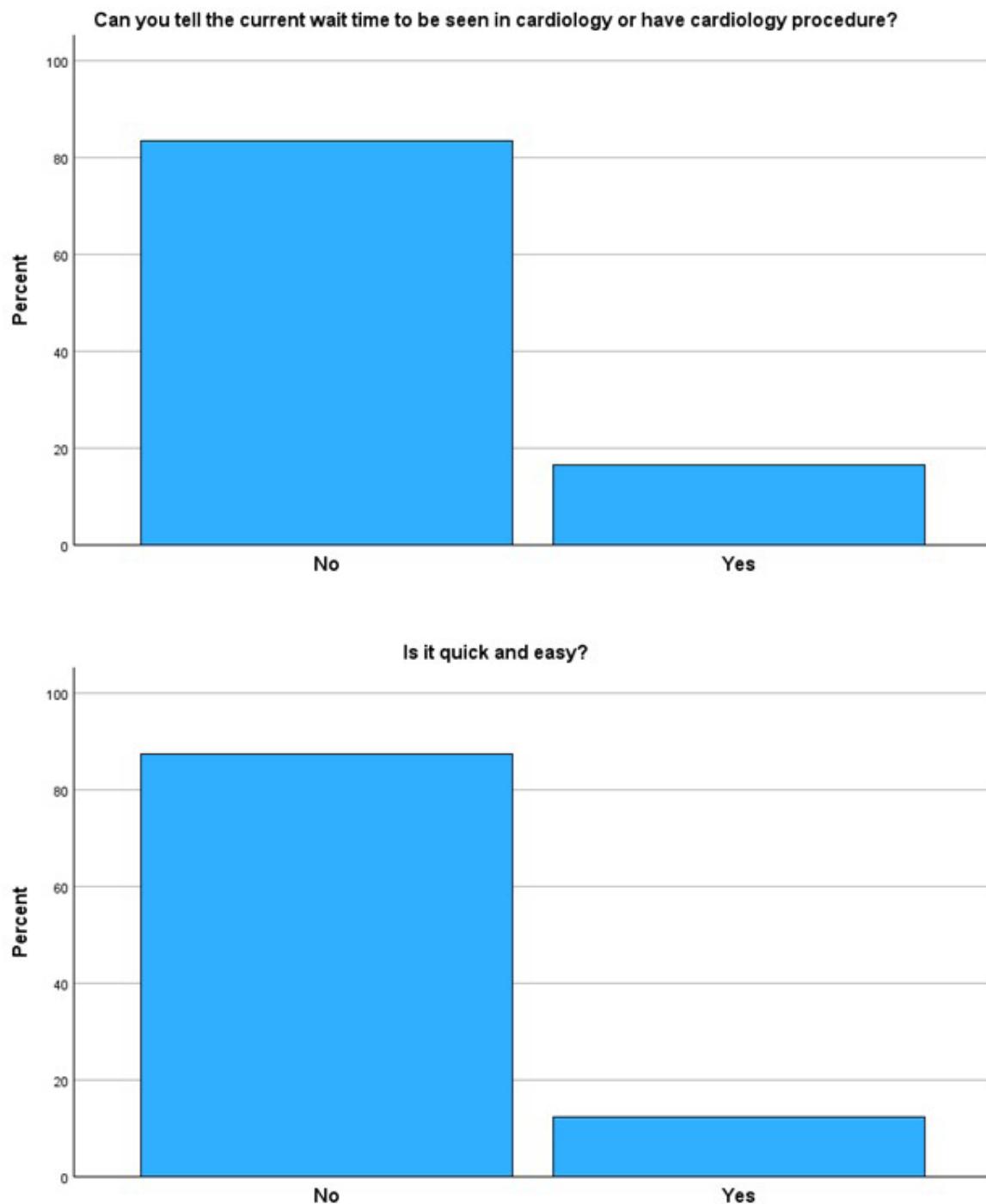


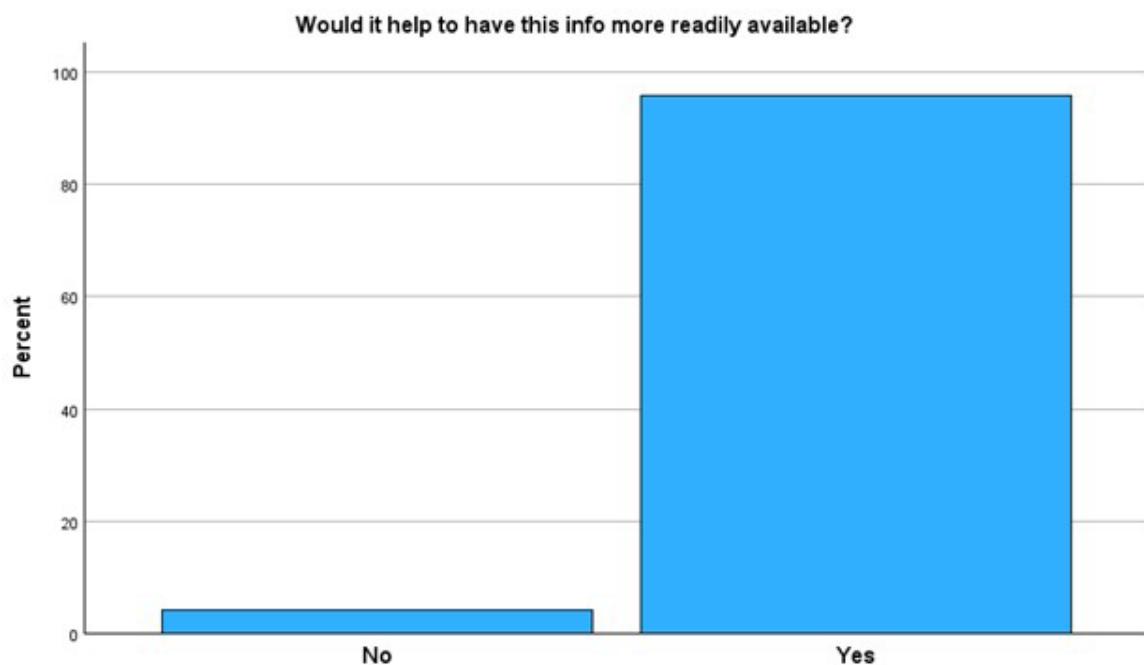
The majority (75%) would like a list on the referral portal of which conditions cardiology accepts and suggestions/links where to refer other conditions.

5. Can you tell the current wait time to be seen in cardiology or have a cardiology procedure? Yes/no

Is it quick and easy? Yes/no

Would it help to have this info more readily available? Yes/no



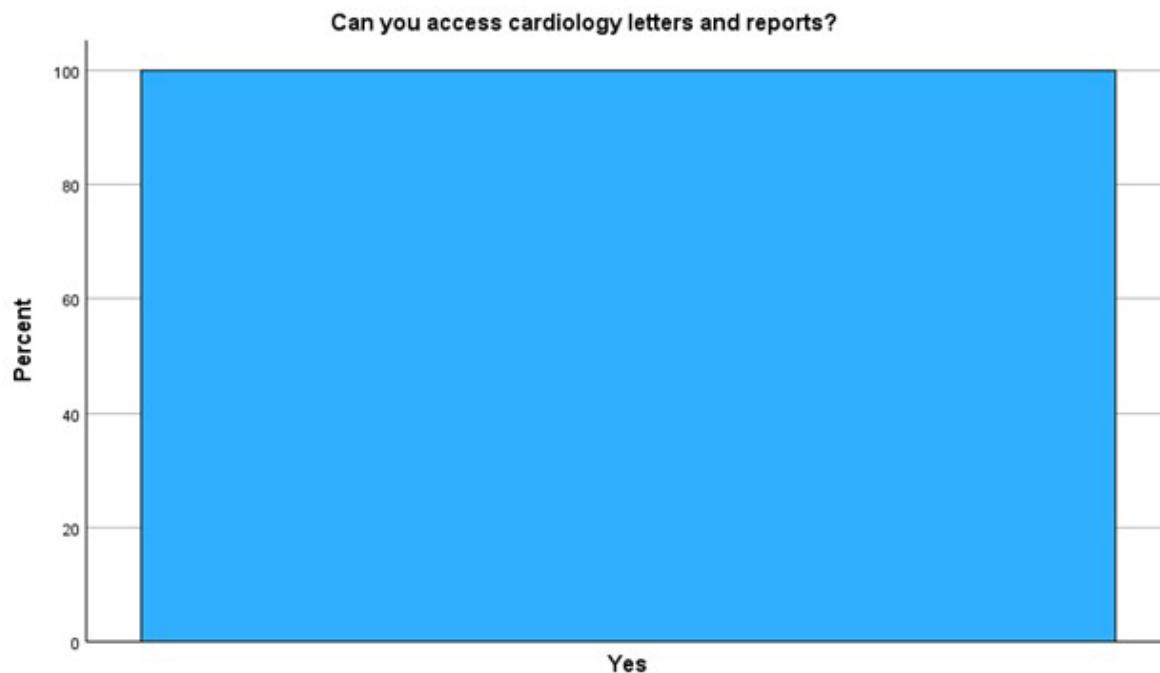


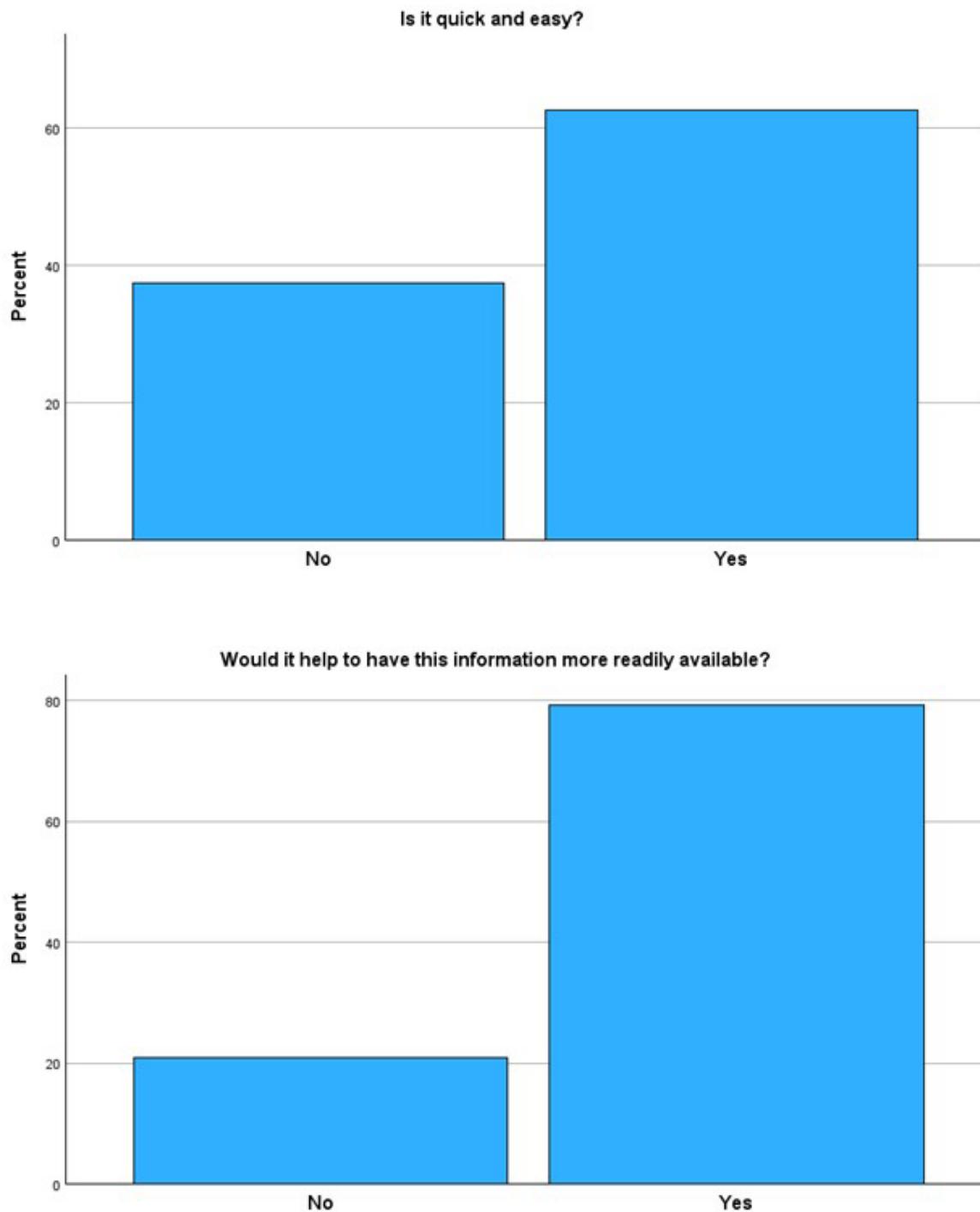
Most (83%) GPs cannot access the current wait times for clinic, with 96% wanting this information to be more readily available.

6. Can you access cardiology letters and reports? Yes/no

Is it quick and easy? Yes/no

Would it help to have this info more readily available? Yes/no

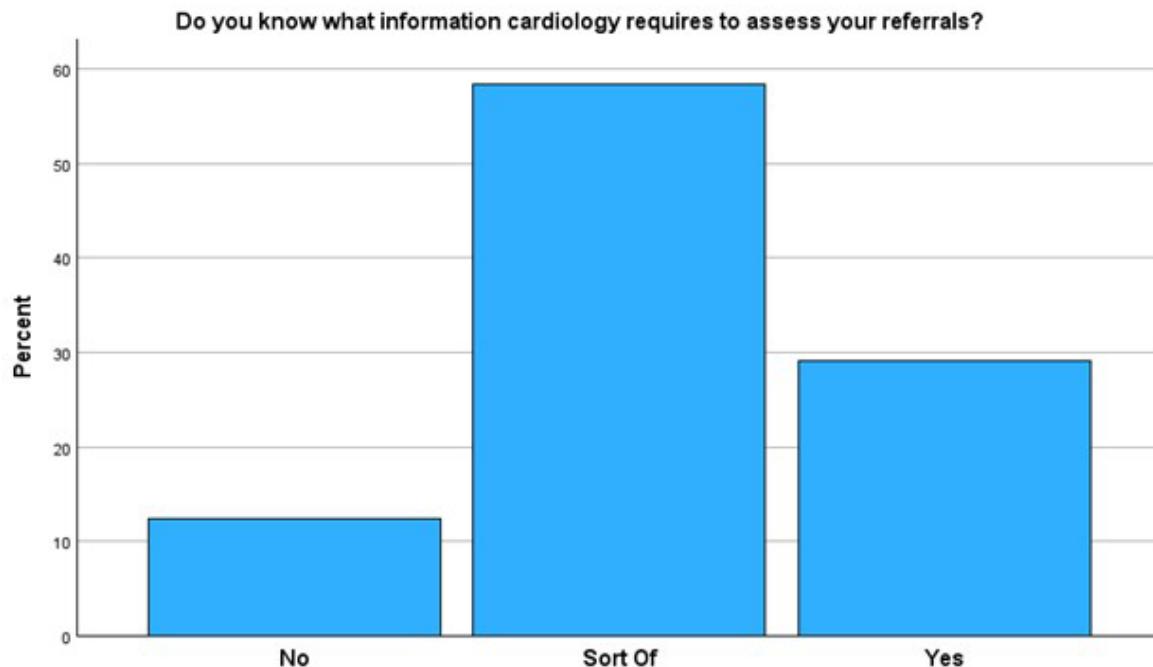




All respondents could access cardiology reports and letters, and it was quick and easy for 61%. Yet 79% felt it could be more accessible.

7. Do you know what information cardiology requires to assess your referrals?

- Yes
- No
- Sort of



Only 29% felt confident about the information required for cardiology to triage a referral.

8. What resources do you use to assist with management of cardiology patients?

Please tick the resources that you have heard of:

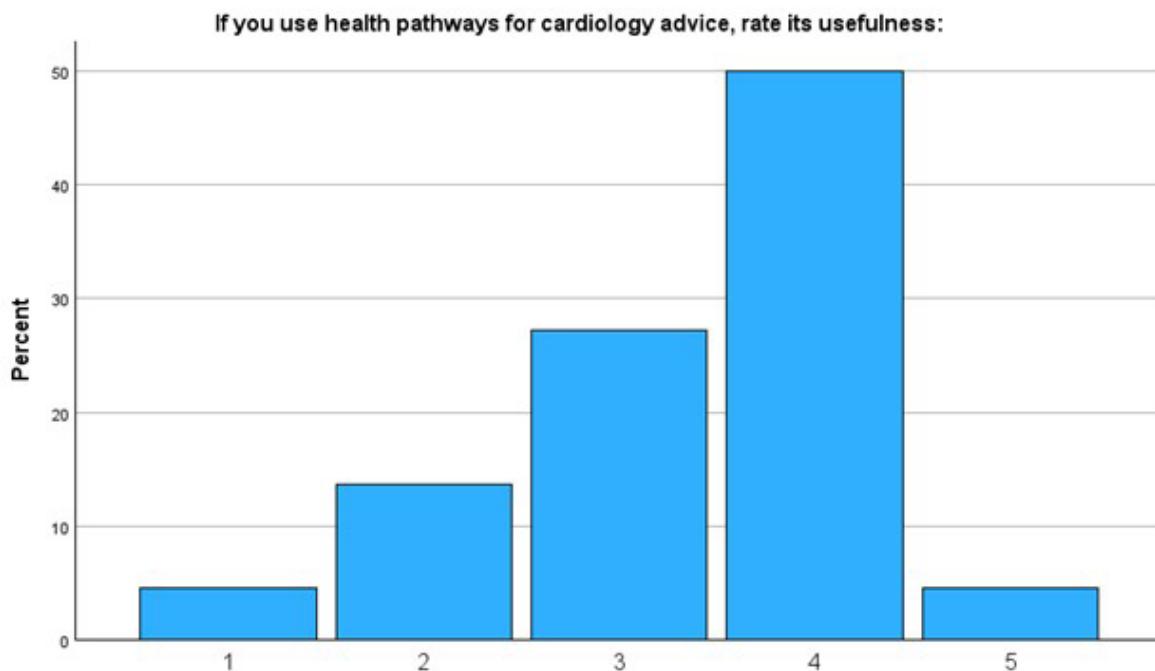
- Regional cardiology guidelines
- NZTA guidelines
- Health pathways
- Other:

9. Please tick the resources that you use:

- Regional cardiology guidelines
- NZTA guidelines
- Health pathways
- Other:

10. If you use health pathways for cardiology advice—rate its usefulness:

[Not at all useful] 1, 2, 3, 4, 5 [Extremely useful]



**11. How can health pathways be improved?**

Prominent on GP respondents' wish lists were shorter wait times and better availability of investigations (45%), quicker specialist advice (21%) and more comprehensive referral guidelines (health pathways) (29%).

**12. Do you prefer obtaining the information you need via online resources or sending referrals to cardiology?**

When it comes to preferred resources for cardiology issues, GPs were divided. Some relied on referrals to cardiology (33%), others used online resources (25%), and a significant portion used both (38%). Health pathways emerged as the most popular online resource, with 92% of respondents using it. However, not all found it helpful, as indicated by the responses to questions 10 and 11 above.

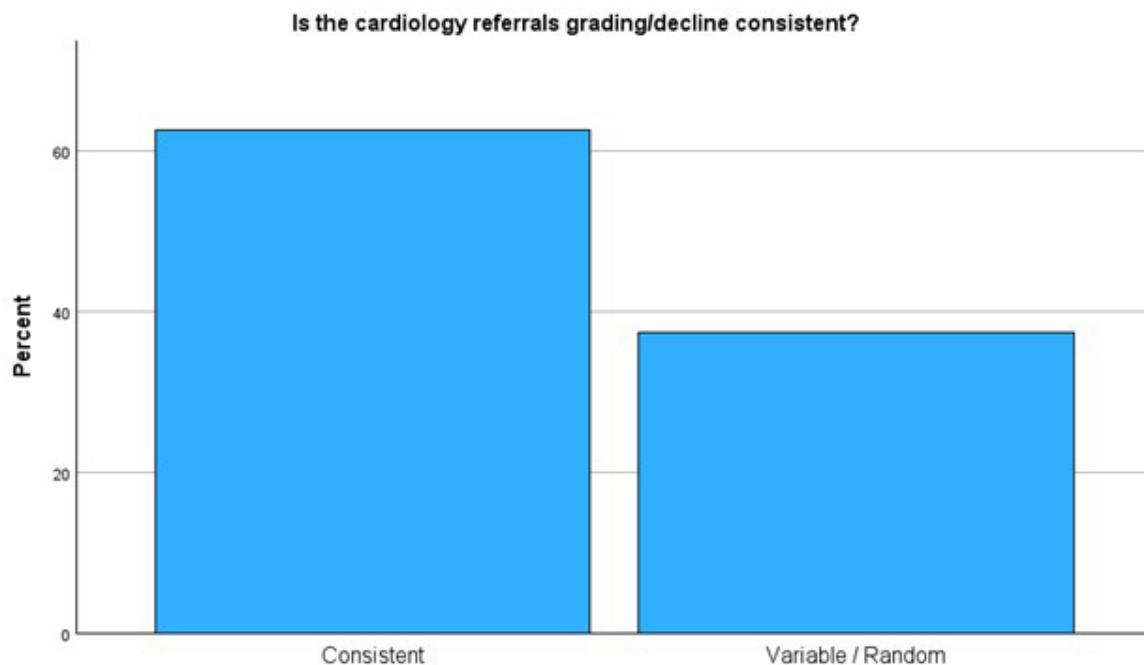
**13. How could the cardiology referrals process be made easier?**

**14. What else would make it easier for GPs to access the information they need to manage cardiovascular conditions?**

GPs' suggestions for improvement included flow charts, more explicit referral guidelines, surveillance information and information on cardiac medication. Notably, many GPs preferred succinct information, highlighting the need for simplicity and clarity in the referral process.

**15. Is the cardiology referrals grading/decline consistent, or does it seem variable/random? (Circle)**

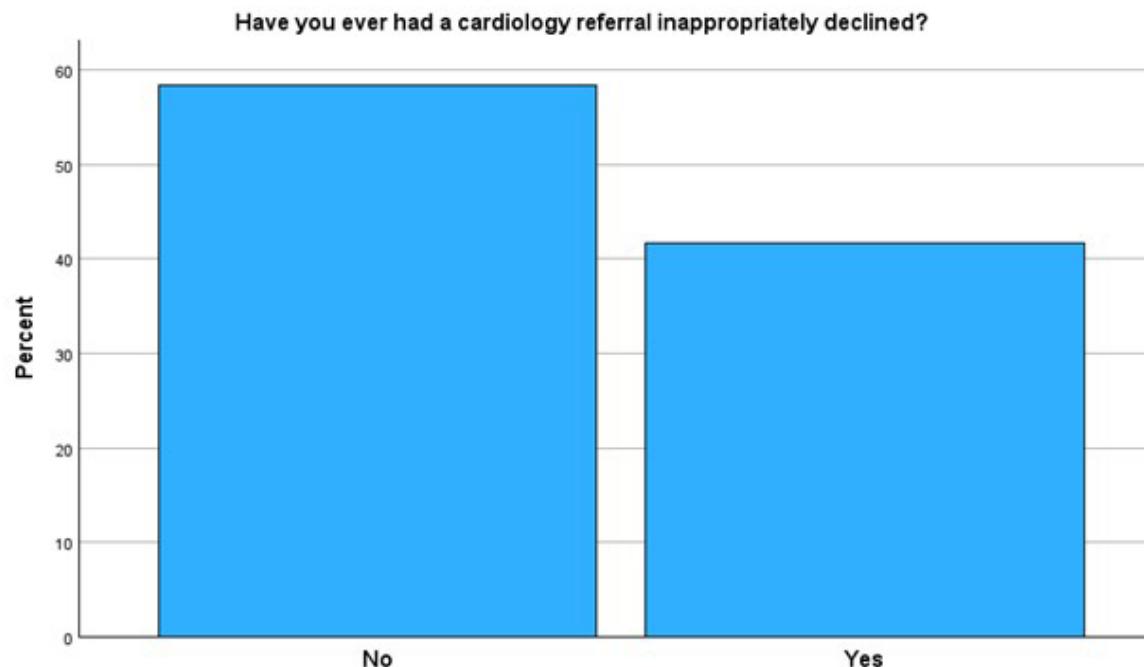
- Consistent
- Variable/random

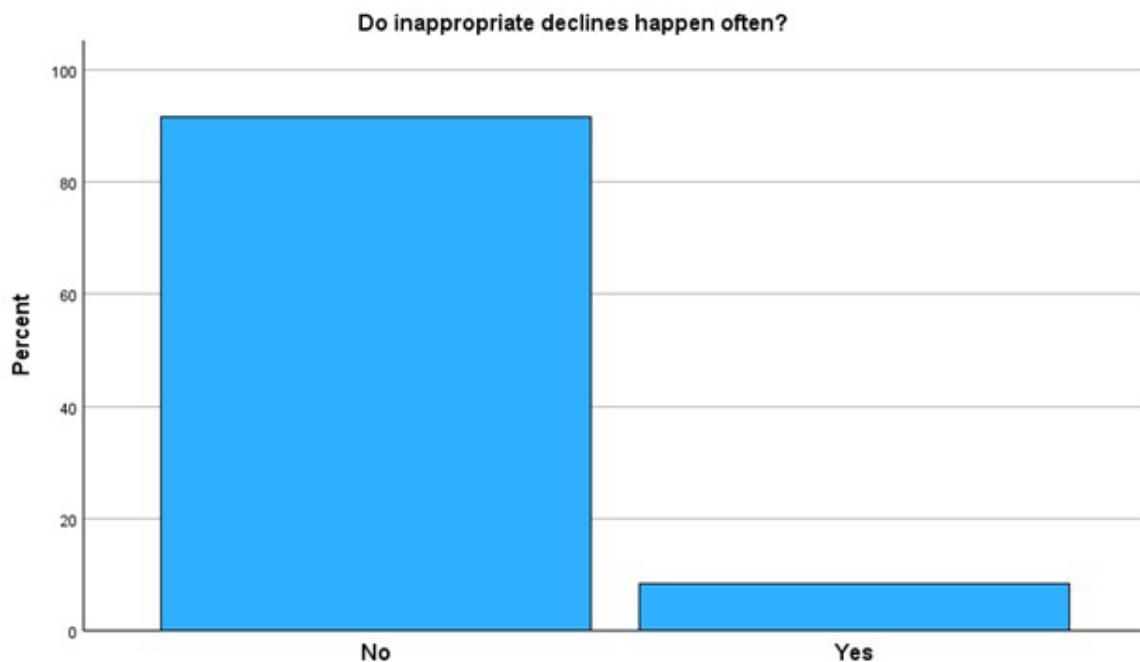


Inconsistent referral grading had been experienced by 38% of respondents.

16. Have you ever had a cardiology referral inappropriately declined? And does this happen often?

Inappropriately declined? Yes/no  
Does this happen often? Yes/no





Less than half (42%) had a referral declined inappropriately, but this was infrequent (8%).

#### ***Discussion***

It is a struggle for triaging cardiologists to keep up with the volume of referrals. The cardiologist shouldn't deal with those that can be handled clerically, and it would help to provide the GP with direct access to relevant information. A GP comment highlighted a perverse incentive in the current system. Sending a referral requesting a cardiologist to provide the result of a Holter monitor test (four mouse clicks) is easier than finding the report online (eight mouse clicks, including a log-in page). Streamlining the system to make it easier for GPs to find information themselves will benefit all parties. We understand that more information is being made accessible to GPs but note that GPs cannot always find available information. One reason is the so-called "friction" in the navigation process. Other reasons need to be explored.

An option to improve accessibility to GPs is to compile relevant links on a single dashboard page, like the Snapshot used for Health New Zealand – Te Whatu Ora Waitematā inpatients (Appendix 2 Figure 1).

**Appendix 2 Figure 1:** Example of the current Snapshot page for Waitematā inpatients.

The screenshot shows a complex web-based medical record interface. At the top, patient details are listed: Name (Testsp, Prodmoketst), Age (20/11/2000 (24 Years)), Gender (Female), and Ward/Room (Recent, Change, Close). Below this, a 'Presenting Complaint' section is shown, along with a 'Current Clinical Pathway(s)' section. A 'Documents / Procedures' section lists various medical records with dates and descriptions. The interface includes a 'Links' section with icons for Book Bed, Eclat, EDS, and others. A 'Selected Biochemistry & Haematology Results' and 'Selected Microbiology Results' section are also present, showing lists of tests and their results. A 'Referrals' section shows a list of referrals with dates and types. The bottom of the page includes a footer with copyright information.

The aim is to reduce the number of declined referrals by providing GP referrers with more information and easier access to that information.

It is suggested that the dashboard have single-click links to the following:

- List of conditions seen by cardiology.
- List of conditions frequently referred to cardiology incorrectly, with links to the correct recipient.
- Current list of approximate wait times for clinic and investigations.
- Regional guidelines on follow-up intervals for surveillance of valvular lesions and dilated aortas (have now been posted).
- Patient-specific information:
  - Pending referrals and appointments.
  - Recent encounters (inpatient/outpatient).
  - Results of recent cardiac investigations.

### Limitation

Only 24 GPs were surveyed. Greater numbers would give more confidence in the findings.

### Conclusion

The GPs canvassed had positive views on aspects of the referral process but wanted more guidance on who and when to refer. They desired information on waiting times and better access to patient information held by the hospital. Options for improvement are discussed.

## Appendix 3: audit of declined outpatient cardiology referrals

### Introduction

Some declined referrals may be wasteful when they invoke fruitless time and effort by the referring general practitioner (GP) and triaging cardiologist. This can be a type of inefficiency (or “churn”). We catalogue reasons for referral rejection. Auckland Health Research Ethics Committee approved the project (AH28636).

### Methods

Administrative coding proved inaccurate (which suggests caution about deploying artificial intelligence [AI] on such a data source). Between 3 January 2022 and 28 November 2023 (22 months), there were 3,505 referrals with a clerical categorisation of “declined”. Reviewing individual patients’ records, the total fell to 3,145, and these were manually categorised according to the reasons for referral and rejection.

### Results

#### Clinical reason for referral

Palpitations comprised the largest volume of declined referrals (25%), followed by chest pain (10%) and valvular (10%) (Table 1).

**Appendix 3 Table 1:** Declined GP referrals; reason for referral.

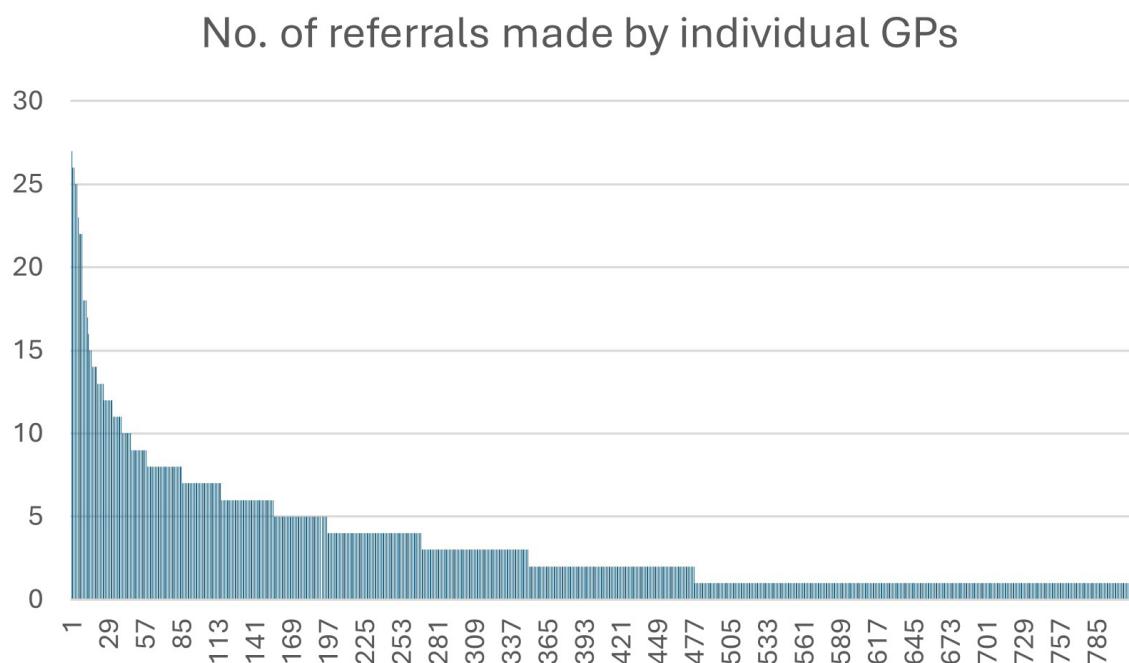
Disease category	Frequency	Percent
Palpitations;brady/ECG	786	25
Other	646	21
Chest pain	321	10
Murmur/valvular	315	10
AF/flutter/SVT	244	8
Heart failure	241	8
Risk factor management	153	5
Hypertension	152	5
Breathlessness	139	4
Syncope/presyncope	96	3
Dilated aorta	28	0.9
Cardiomegaly	17	0.5
Not a GP referral	7	0.2

GP = general practitioner; ECG = electrocardiogram; AF = atrial fibrillation; SVT = supraventricular tachycardia.

During the time period, there was a total of 28,496 GP referrals. Only 49% were categorised, and we did not manually confirm the category of those that were. Roughly, the clerical reasons for referral were: chest pain 58%, palpitations 19%, breathlessness 8%, murmur 7% and heart failure 5%.

*GP referral rates*

**Figure 1.**



The number of rejected referrals made by individual GPs varied from 27 to one (Figure 1). The median was two, and the mode was one. Little can be inferred from these data without knowing how many patients each GP sees.

*Reason for referral rejection*

**Appendix 3 Table 2:** Declined GP referrals; reason for being declined.

Reason for decline	Frequency	Percent	Avoidable
Bespoke advice or interpretation	765	24	
Admin transfer to another service	555	18	Possibly
Relevant booking pending, no change to priority	394	13	Possibly
Generic advice given	297	9	Possibly
More information requested	248	8	Possibly

**Appendix 3 Table 2 (continued):** Declined GP referrals; reason for being declined.

Seen/admitted since referred	179	6	Possibly
Relevant results communicated	170	5	Possibly
Other	126	4	
Communication for filing	115	4	
Referral declined but procedure ordered	105	3	
Duplicate referral	60	2	Possibly
Referral not declined	33	1	
Advised to refer elsewhere, bespoke	32	1	
Follow-up advice as per regional valve, aorta guideline	33	1	Possibly
Relevant booking pending, priority increase requested	23	0.7	
Patient uncontactable	10	0.3	

The reasons for the referral being declined are in Table 2. The “more info requested” category is usually a request for an ECG. The commonest “bespoke advice” is for the duration of dual antiplatelet therapy, followed by lipid management, other medication, surveillance of aortic dilation, and anticoagulation.

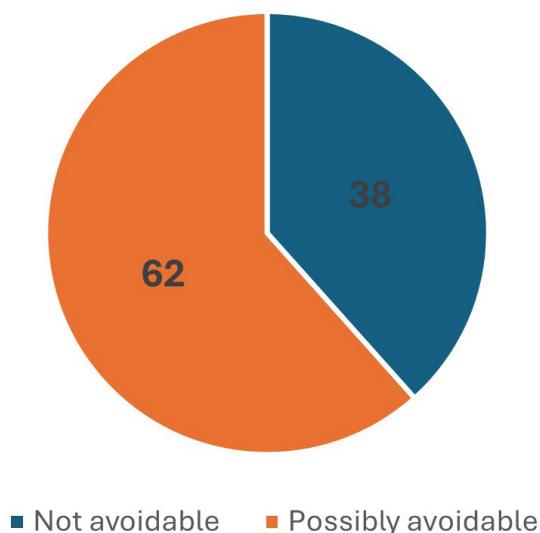
“Admin transfer to another service” is the biggest category of possibly avoidable referrals. Many of these are palpitations transferred to general medicine, and hypertension transferred to the renal service. Such transfers don’t relieve the overall demand for hospital services.

#### *Avoidable referrals*

We defined “possibly avoidable” referrals as those that would not need to be dealt with by a cardiologist if simple measures were instituted, such as: providing GPs with access to more information such as where to refer certain conditions, thresholds for referral of specific conditions, easily accessible results of investigations and the current appointment status of patient. We deemed 1,936 (62%) of declined referrals potentially avoidable (Figure 2). These included: “sent to wrong service” (24%), “already has appointment” (13%), “does not require review” (10%), “inadequate information” (8%), “seen since referred” (6%), “relevant results sent” (5%) and “duplicate referral” (2%). These are a drag on the efficiency of the triage process, increasing workload for clerical and clinical staff, with an ultimate adverse impact on patient care.

Figure 2.

## Percentage of declined referrals that could possibly have been avoided



### *Patient outcomes after a declined referral*

Twenty-four patients (0.8%) died within 90 days of a declined referral. Four patients died at -7, 1, 1 and 2 days after referral, suggesting that rejection of the outpatient referral could not have influenced the outcome. Review of the referrals for patients who subsequently died was not informative. The numbers are small and the information contained in the referrals was variable and often succinct, although not different from the referrals for patients who did not die. It is anticipated that changing from free-text referrals to the collection of structured information appropriate to the particular clinical indication will allow informative audit of adverse events. The learnings can then be used to iteratively refine the choice of variables collected and the decision thresholds for rejection.

Hospital admissions as adverse event were not assessed but should be part of the ongoing audit that iteratively improves future collection of structured data.

We did not manually assess re-referrals. The following data from the administrative coding provide ballpark estimates:

- 60% (1,245) of declined referrals do not get re-referred
- 2/3 (826) subsequent re-referrals are accepted

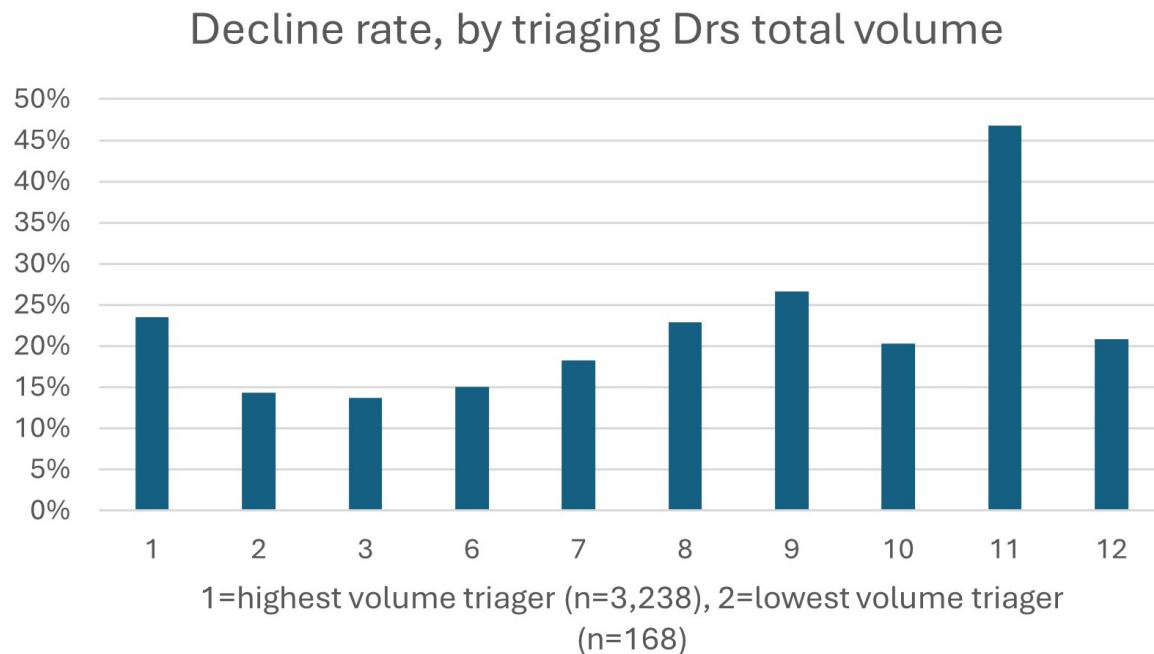
As an observation, if the accepted referrals had adequate information to be accepted the first time, that would be 413 fewer referrals to process on this basis alone. Even declining a referral requires opening several windows in the electronic medical record. Each has a lag time, which is worse during working hours. Therefore, getting the correct information upfront saves a worthwhile amount of time.

### *Cardiologist variability in rejection rate*

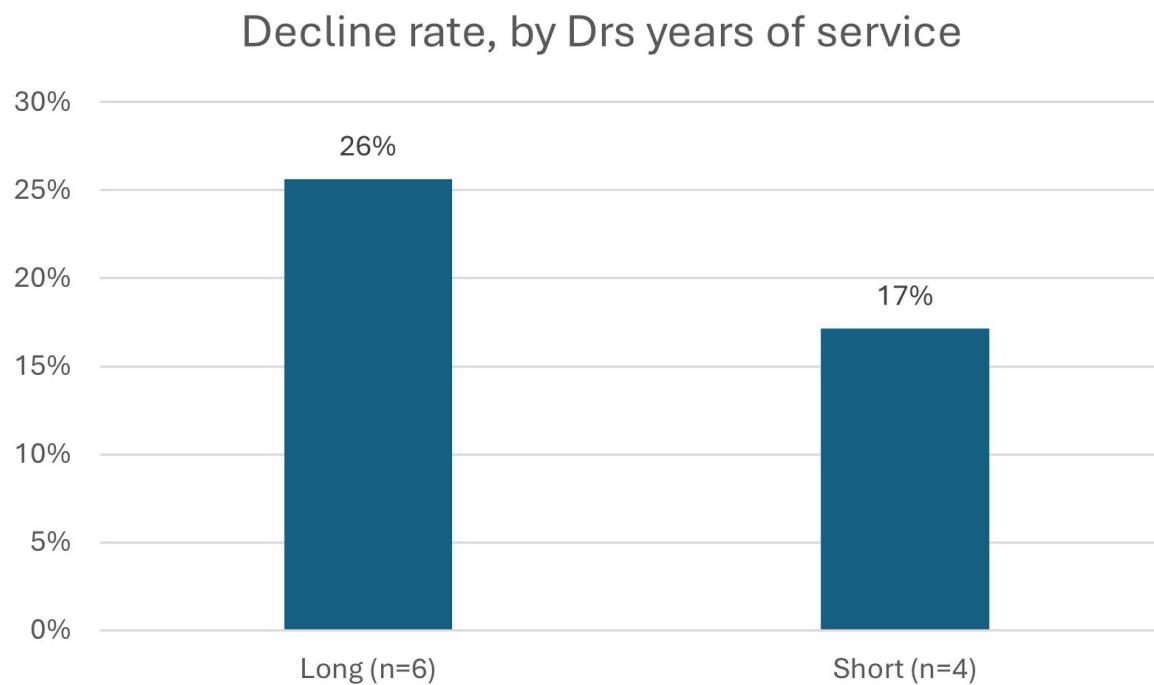
Cardiologist decline rates varied widely from 14% to 47%. Variability is an adverse indicator of health-care quality. Its reduction is the specific goal of recent national initiatives.<sup>1-5</sup>

Six doctors with more than 10 years of clinical cardiologist experience had a decline rate of 26%, and four cardiologists with less than 10 years of experience had a rate of 17% (Figure 4). These numbers are too small for statistical analysis.

The decline rate was unrelated to the cardiologists' triaging volume (Figure 3).

**Figure 3.**

The decline rate is not related to the triaging cardiologists' overall volume.

**Figure 4.**

### *Under-resourcing causes more work via positive feedback*

Anecdotal experience has always been that when patient delays increase, there is a concomitant increase in referrals solely due to the delays. The category “relevant booking already pending” comprises a fifth of potentially avoidable referrals and is due to delays in patient investigations. In addition, the category “other” contains a proportion of procedures that have yet to be reported. Similarly, the frequency of “request increased priority” is likely related to waiting times. These are examples of how busyness begets busyness, potentially leading to a spiral of increasing delays and inefficiencies.

### **Limitations**

Some people with functional or non-cardiac symptoms (palpitations, chest pain) may benefit from a normal cardiology work-up and subsequent cardiologist reassurance. We acknowledge this, but the current body of work is driven by an inability to service demand with available resources. Accordingly, the consensus was to design systems that sift out organic heart disease. Being swamped with other patients will delay us seeing patients for whom we may reduce the risk of serious events.

### **Discussion**

This study focussed on declined referrals for two reasons. From a behavioural aspect, removing unnecessary referrals gives the triaging cardiologist more time to devote to necessary referrals. More importantly, the analysis of declined referrals provides a window into the shortfalls and inefficiencies in the overall referral process.

The job of the triaging cardiologist could be facilitated by a “cardiologist triager’s dashboard”, similar to the Snapshot used for Health New Zealand – Te Whatu Ora Waitematā inpatients. It is a single page containing relevant single-click links to facilitate and speed up the cardiologist’s task of triaging referrals.

Such a page should contain single-click links to:

- Pending referrals and appointments.
- Recent encounters (inpatient/outpatient) with emphasis on those that have occurred since the date of referral—it is not uncommon for the patient to have been admitted since the referral was made. At present, this information is not quickly available to the triager, resulting in time wasted.
- Results of recent investigations, including laboratory, radiology and cardiology.

### **Conclusion**

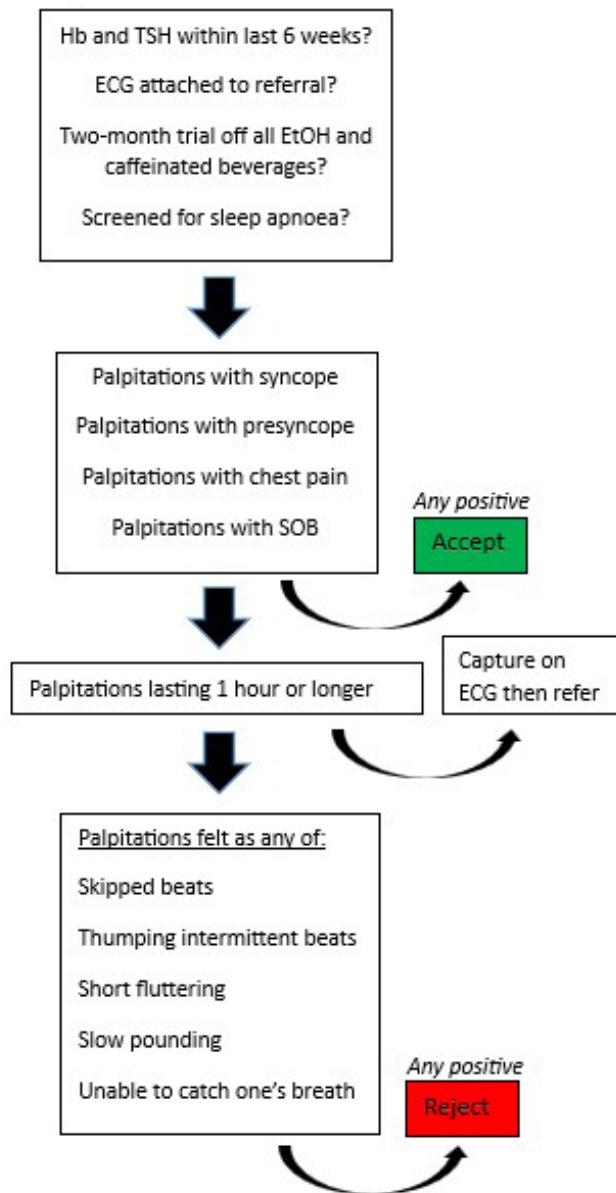
Most declined referrals were possibly avoidable altogether, mainly by providing GPs with ready access to information. There is no signal of harm from a declined referral, and most declined referrals are not re-referred. The decline rates vary between triaging cardiologists, suggesting practice standardisation is needed. Suggestions are made to improve the process.

### **REFERENCES**

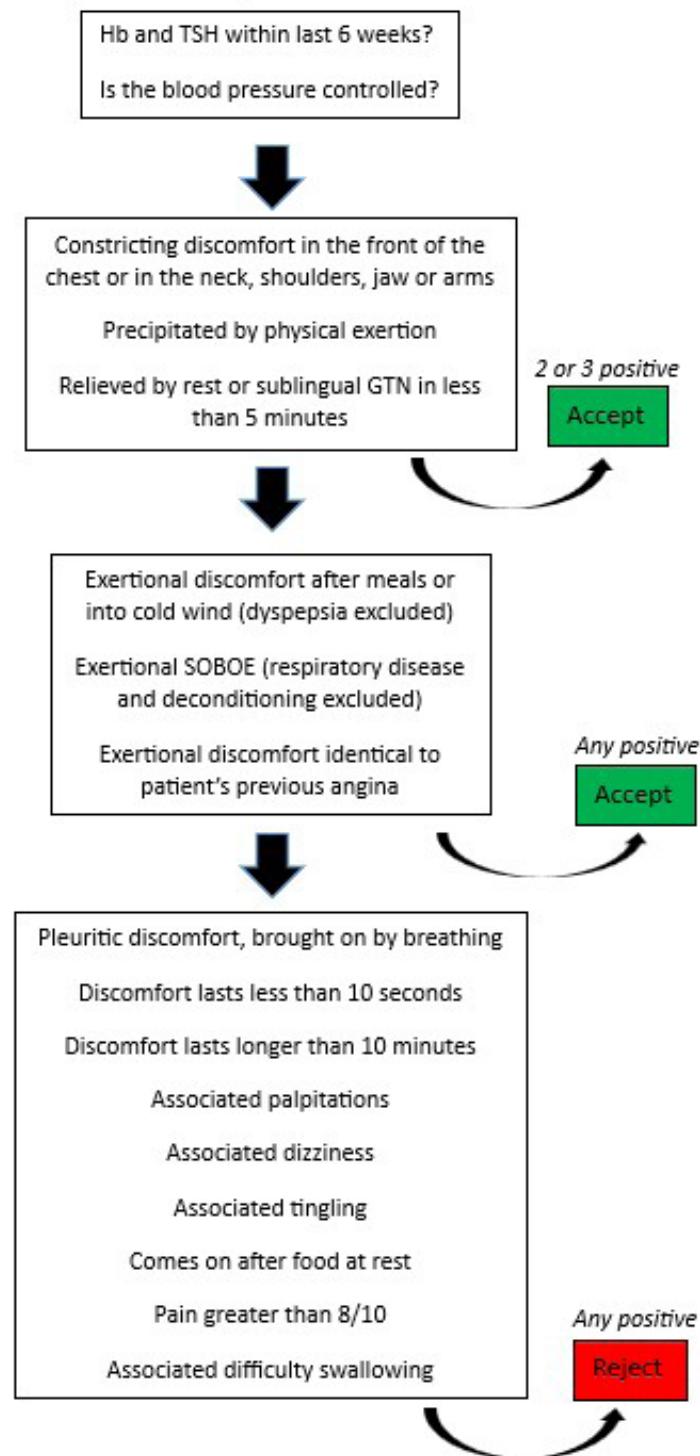
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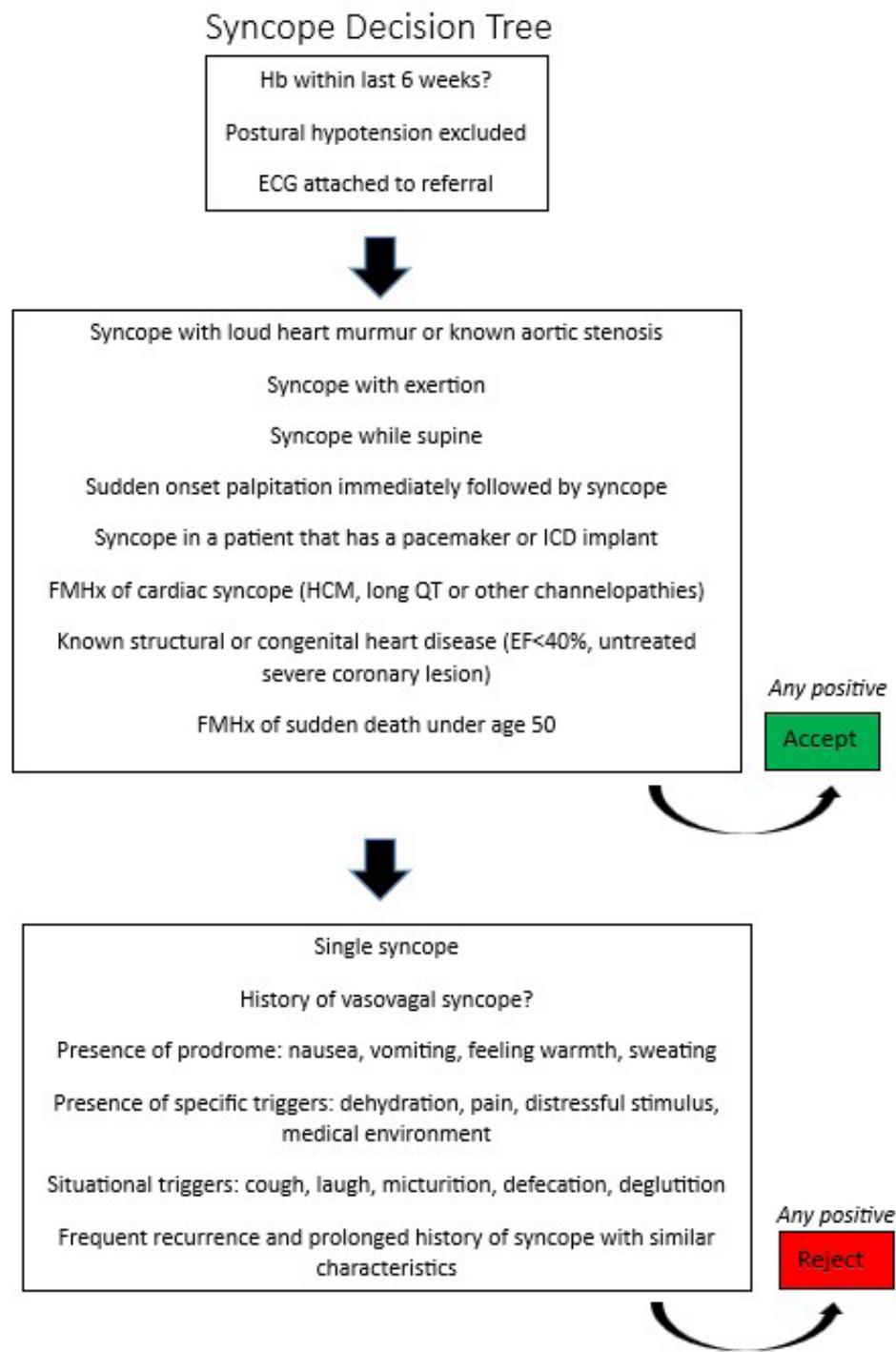
#### Appendix 4: draft decision trees for illustrative purposes

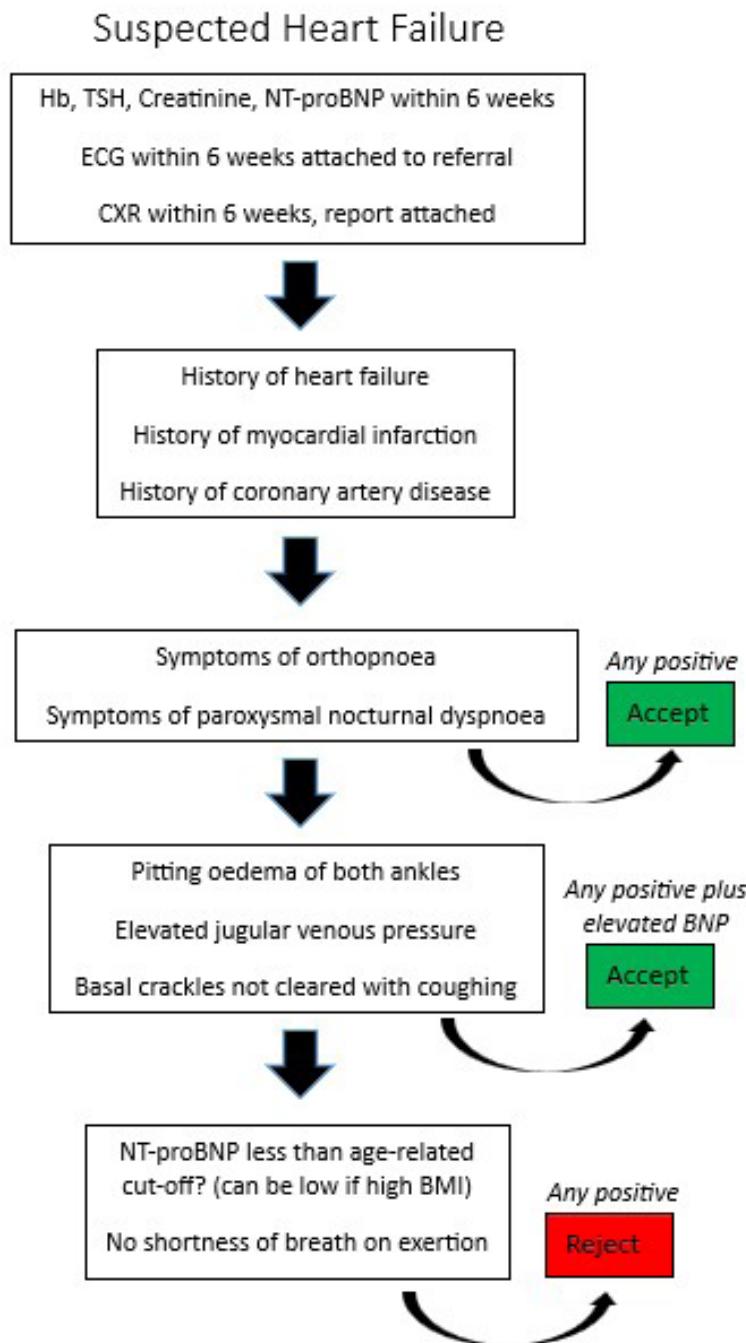
##### Palpitations Decision Tree



## Suspected Angina Decision Tree







# Reactive arthritis following intravesical *Bacillus Calmette–Guérin* therapy in a patient with kidney failure—a case report

Aksa Sara Thomas, Ankur Gupta

Intravesical *Bacillus Calmette–Guérin* (BCG) is the standard adjuvant therapy for high-risk non-muscle-invasive bladder cancer (NMIBC), leveraging local immune activation for anti-tumor efficacy.<sup>1–3</sup> Although BCG-related side effects are often mild and self-limited, rare systemic complications such as reactive arthritis (ReA) can occur. ReA is a sterile inflammatory arthritis associated with preceding mucosal or genitourinary infections and has been reported following BCG therapy, particularly in genetically predisposed individuals such as human leukocyte antigen B27 (HLA-B27) positive cases—but it also occurs in HLA-B27-negative patients.<sup>1,4,5</sup> We report a case of severe BCG-induced ReA in a haemodialysis-dependent individual requiring hospitalisation and surgical intervention.

## Case

A 60-year-old woman with hypertension, secondary hyperparathyroidism, and kidney failure on maintenance dialysis was diagnosed with high-grade pT1 NMIBC following transurethral resection of bladder tumour (TURBT). Induction intravesical BCG therapy was initiated 3 weeks later, planned as weekly instillations for 6 weeks.

Following the fourth BCG dose, she experienced transient dysuria and lower abdominal discomfort—that resolved spontaneously. One week later, she developed bilateral conjunctivitis (more pronounced in the left eye), followed by polyarthritis involving the knees and wrists, leading to immobility and a fall, prompting a visit to the emergency department.

On presentation, she was febrile and hypotensive, with bilateral knee effusions (Table 1, Figure 1). Arthrocentesis yielded haemarthrosis without crystals or identifiable organisms. Initial inflammatory markers were significantly elevated (C-

reactive protein [CRP] 180mg/L; white blood cell  $15 \times 10^9/L$ ), peaking at CRP 550mg/L during admission. Despite empiric intravenous antibiotics and surgical washout of the knees and right wrist (which revealed purulent material), all microbiological cultures remained negative—except for a single isolate of *Staphylococcus hominis*, considered a contaminant.

A transoesophageal echocardiogram excluded infective endocarditis. Serological investigations were unremarkable, with negative antinuclear antibody (ANA), rheumatoid factor (RF), anti-cyclic citrullinated peptide (anti-CCP) and HLA-B27. Viral screening for hepatitis B, hepatitis C, HIV and parvovirus B19 was also negative. Radiographs of affected joints demonstrated soft tissue swelling without erosions or joint space narrowing, consistent with non-destructive inflammatory arthritis. In the context of recent BCG exposure, sterile purulent arthritis, systemic inflammation and negative infectious and autoimmune workup, a diagnosis of BCG-induced ReA was made in consultation with immunology and rheumatology teams. Non-steroidal anti-inflammatory drugs (NSAIDs) (naproxen 250mg twice daily) were commenced, resulting in rapid clinical improvement and reduction of CRP to 217mg/L within 2 weeks. Antibiotics were discontinued, and disease-modifying anti-rheumatic drugs (DMARDs) were not required. With multidisciplinary team support, she regained mobility and remained symptom-free at 6-month rheumatology follow-up. BCG therapy was discontinued. A follow-up cystoscopy 3 months later showed an unhealed TURBT site, and she is currently awaiting bladder biopsies.

## Discussion

BCG immunotherapy is the mainstay treatment for high-risk NMIBC, particularly for pT1 tumours.

Although generally well tolerated, BCG therapy can, rarely, cause systemic complications such as ReA, occurring in less than 1% of cases.<sup>1,2</sup> Typically, it presents as seronegative oligoarthritis, primarily affecting the lower limbs, with associated conjunctivitis and urethritis, resembling Reiter's syndrome.<sup>6</sup>

Our individual exhibited bilateral conjunctivitis followed by the rapid onset of asymmetric arthritis in the knees and wrists shortly after her fourth BCG dose, which is characteristic of BCG-induced ReA.<sup>6,7</sup> Systemic inflammatory response features including fever, purulent joint effusions and hypotension initially raised suspicion for septic arthritis. However, repeated cultures were sterile, and joint aspirates lacked crystals or organisms. A single *Staphylococcus hominis* isolate was deemed a contaminant. Negative autoimmune serology and failure to respond to antibiotics further supported a diagnosis of BCG-induced ReA.<sup>4</sup> Rapid improvement with NSAIDs confirmed the clinical suspicion. Echocardiographic evaluation ruled out endocarditis, excluding another potential source of infection.

The pathogenesis is thought to involve local immune activation in the bladder post-BCG, triggering T-helper 17 (Th17) responses and cytokine release (e.g., IL-6, IL-17, TNF- $\alpha$ ), which may result in systemic immune cell migration and synovial inflammation.<sup>4,7</sup> Molecular mimicry—especially involving heat shock proteins (HSP65 and HSP60)—may also lead to autoimmunity.<sup>8</sup> While HLA-B27 increases susceptibility and disease severity,<sup>7</sup> our patient was HLA-B27-negative. Importantly, patients with kidney failure have impaired immune regulation and reduced antigen clearance, likely increasing the risk and severity of systemic immune responses to BCG.<sup>5</sup>

Diagnosing ReA requires exclusion of other causes of inflammatory arthritis, especially infection. Joint aspiration, cultures and autoimmune testing are essential. The presence of conjunctivitis, sterile effusions and the close temporal link to BCG instillation supported the diagnosis in our case.

Management involves halting BCG therapy and initiating anti-inflammatory treatment. NSAIDs are first-line and were effective in our patient, though they must be used cautiously in dialysis-dependent individuals due to risks like gastrointestinal bleeding and fluid retention. We chose NSAIDs in view of negligible residual kidney function in our case. Corticosteroids or DMARDs may be needed in refractory cases.<sup>9</sup> A multidisciplinary approach, including rheumatology, oncology, nephrology and rehabilitation, is key to optimal recovery. Most patients with BCG-induced ReA recover within 1–3 months. Chronic or relapsing arthritis is uncommon, though more likely in HLA-B27-positive individuals.<sup>10</sup> In our patient, symptoms resolved fully with NSAIDs, though BCG therapy was discontinued, and cystoscopy later revealed an unhealed TURBT site—underscoring the importance of ongoing oncologic monitoring.

This case highlights the diagnostic challenge of distinguishing ReA from septic arthritis, particularly in immunocompromised patients. Awareness of this rare complication is crucial to prevent misdiagnosis, guide appropriate treatment and ensure coordinated multidisciplinary care.

## Conclusion

BCG-induced ReA is a rare but significant complication of intravesical BCG therapy for high-risk NMIBC. While typically presenting as seronegative oligoarthritis with features resembling Reiter's syndrome, its clinical course can be challenging, often mimicking septic arthritis and posing diagnostic dilemmas. A thorough diagnostic workup—including exclusion of infection and autoimmune disease—is essential for accurate diagnosis. Prompt discontinuation of BCG and initiation of anti-inflammatory therapy can lead to full recovery. Regular follow-up and rehabilitation are crucial to support functional recovery, particularly when BCG therapy is interrupted. Clinicians must remain vigilant for this rare yet reversible complication to ensure timely management and optimal outcomes.

**Table 1:** Time of the blood investigations.

	<b>Before initiation of BCG therapy</b>	<b>During ReA</b>	<b>After initiation of NSAIDS</b>	<b>Current</b>
<b>White cell count</b>	$8.0 \times 10^9/L$	$14.9 \times 10^9/L$	$12 \times 10^9/L$	$9.1 \times 10^9/L$
<b>Neutrophil</b>	$4.1 \times 10^9/L$	$12.1 \times 10^9/L$	$7.9 \times 10^9/L$	$7.0 \times 10^9/L$
<b>C-reactive protein</b>	<0.6mg/L	539mg/L	217mg/L	6.1mg/L
<b>Calcium</b>	2.5mmol/L	2.03mmol/L	2.48mmol/L	2.47mmol/L
<b>Phosphate</b>	1.32mmol/L	1.94mmol/L	1.37mmol/L	2.04mmol/L
<b>Parathyroid hormone</b>	74.7pmol/L	-	-	50.7pmol/L

BCG = *Bacillus Calmette–Guérin*; ReA = reactive arthritis; NSAIDs = non-steroidal anti-inflammatory drugs.

**Figure 1:** a) X-ray of the knee and b) wrist at presentation.

**COMPETING INTERESTS**

Nil.

**AUTHOR INFORMATION**

Dr Aksa Sara Thomas: House Officer, Palmerston North Hospital.

Dr Ankur Gupta: Nephrologist, Palmerston North Hospital.

**CORRESPONDING AUTHOR**

Dr Aksa Sara Thomas: House Officer, Palmerston North Hospital. E: draksawilson@gmal.com

**URL**

<https://nzmj.org.nz/journal/vol-138-no-1627/reactive-arthriti...>

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# Haemorrhagic cholecystitis: a rare but life-threatening variant of acute cholecystitis

Amy Van der Sluis, Divyansh Panesar

**H**aemorrhagic cholecystitis (HC) is a rare complication of cholecystitis. Since its first description in the 1970s, HC remains under-recognised and may result in catastrophic intraperitoneal bleeding or gallbladder rupture if not promptly identified and treated. The condition may mimic more common biliary pathologies but is distinguished by haemorrhage into the gallbladder lumen or wall, frequently leading to necrosis and perforation. Awareness of this diagnosis is critical in the emergency, surgical and radiologic settings.

HC represents a small percentage of acute cholecystitis cases—incidence estimates range from 0.5% to 1.5% in retrospective surgical analyses, with likely overestimation in older literature of up to 5%. Primarily, it affects elderly patients and is more frequently associated with comorbidities such as coagulopathy, anticoagulant therapy, trauma, malignancy and systemic vasculitis. However, it can also occur in otherwise healthy individuals in the context of severe inflammation.

## Case presentation

Mr X, an 83-year-old man, was admitted with a 3-day history of epigastric pain and nausea. He had recently been transferred to the rehabilitation hospital following an admission for open reduction and internal fixation of a periprosthetic femur fracture under the orthopaedic team 20 days prior. During this admission he developed an ultrasound-proven occlusive thrombus of his peroneal and soleal veins. Rivaroxaban was commenced to prevent upstream migration of the deep vein thrombosis. He had a background of congenital deafness, prostate cancer (grade 1, Gleason 3+3 adenocarcinoma), autoimmune hepatitis, primary biliary cirrhosis, previous total hip joint replacement and hypertension. Notable regular medications included prednisone and aspirin. Prior to admission he was fully independent, lived with his wife and was a non-smoker.

The general surgical team were contacted 72 hours post-diagnosis of deep vein thrombosis, following an onset of tachycardia and hypoxia with computed tomography (CT) pulmonary angiogram findings suggestive of HC, without evidence of pulmonary embolus. On examination, he had right upper quadrant tenderness, and a positive Murphy's sign. Biochemical analysis revealed liver function derangement with a bilirubin of 31umol/L, alkaline phosphatase of 300IU/L and gamma-glutamyl transferase of 164IU/L. His white cell count was  $11.1 \times 10^9/L$  and C-reactive protein was 116mg/L. His haemoglobin was stable at 99g/L. He had a moderate acute kidney injury with serum creatinine of 176umol/L and estimated glomerular filtration rate of 30mL/min/1.73m<sup>2</sup>. A dedicated CT abdomen–pelvis with intravenous contrast across portal venous and arterial phases was performed. It confirmed the diagnosis of HC with hyperdense material in the gallbladder and biliary tree. No active bleed was noted. Subsequent biliary ultrasonography exonerated gallstone pathology. He was commenced on cefuroxime and metronidazole and resuscitated with intravenous crystalloid fluid. He was afebrile throughout.

Given the underlying case complexity and anti-coagulation requirement, hepatobiliary input was sought. The recommendation was for non-operative management given his advanced age, comorbidity burden and absence of gallstone disease. A multidisciplinary guided discussion with the patient resulted in cessation of his rivaroxaban therapy. Following initial haemodynamic and clinical improvement, the liver function deteriorated transiently. After medication reconciliation and antibiotics adjusted for renal impairment, he improved and was discharged with oral antibiotics.

## Discussion

HC comprises approximately 0.5–1.5% of

acute cholecystitis cases in surgical series and is relatively under-represented in surgical literature.<sup>1</sup> It primarily affects elderly patients and is more frequently associated with comorbidities such as coagulopathy, anticoagulant therapy, trauma, malignancy and systemic vasculitis.<sup>2</sup> Zhang et al.<sup>3</sup> suggest that the inhibition of platelet and prostaglandin function of non-steroidal anti-inflammatories and aspirin therapy may be overlooked at time of admission. Other pharmaceutical agents with haemorrhagic risk should be considered, including methotrexate (risk of thrombocytopenia and hepatotoxicity), and systemic glucocorticoids (impaired clotting ability and mucosal injury).<sup>4</sup> Nonetheless, HC can also occur in otherwise healthy individuals in the context of severe inflammation. The proposed pathophysiological mechanism is of mucosal ischaemia and necrosis secondary to gallbladder distension and inflammation, which leads to erosion of small blood vessels or the cystic artery itself.<sup>4,5</sup> This is exacerbated by infection-related inflammatory mediators and can be worsened by mucosal erosion by gallstones, reperfusion injury, coagulopathy, malignancy or vascular disease.<sup>4,5</sup> The resultant intraluminal haemorrhage may increase gallbladder pressure, perpetuating ischaemic injury and potentially leading to wall necrosis, haemobilia and perforation. Perforation occurs in 2–15% of cases and is predominantly at the fundus.<sup>2,6</sup> Symptoms and signs are often indistinguishable from uncomplicated acute cholecystitis and, in some cases, hypotension or shock may be the presenting feature, especially in patients with massive haemorrhage or rupture and can at times present with pain like aortic dissection.<sup>7</sup>

Imaging plays a crucial role in diagnosis. Ultrasonography may reveal echogenic intraluminal material (clots) without acoustic shadowing, suggestive of intraluminal haemorrhage with thrombosis. CT is superior in detecting high-attenuation intraluminal contents suggestive of blood, gallbladder wall thickening and active extravasation.<sup>4,5,8</sup> Magnetic resonance imaging and magnetic resonance cholangiopancreatography (MRCP) can further delineate haemobilia or differentiate blood from bile or exudate and also intraluminal and intramural haemorrhage.<sup>9</sup> Endoscopic evaluation (e.g., endoscope retrograde cholangiopancreatography [ERCP]) may demonstrate blood draining from the ampulla of Vater in cases of haemobilia.<sup>2</sup> Laboratory findings often include leucocytosis, elevated liver enzymes,

anaemia and coagulopathy, particularly in anti-coagulated patients.<sup>5</sup>

Management of HC depends on multiple factors, including the patient's overall stability, comorbidities, anticoagulation status, risk of further bleeding and underlying aetiology. Initial treatment includes fluid resuscitation, reversal of coagulopathy and broad-spectrum antibiotics. Laparoscopic cholecystectomy remains the mainstay in patients with acceptable operative risk.<sup>10</sup> In high-risk patients or those unfit for surgery, percutaneous cholecystostomy may be a temporising measure.<sup>4</sup> In cases of active bleeding, interventional radiology-guided embolisation of the cystic artery can be life-saving.<sup>10</sup> In those that are medically comorbid, a trial of antibiotics with avoidance of interventional measures is a reasonable alternative. Overall, timely intervention is essential, as delayed treatment is associated with increased risk of gallbladder rupture, peritonitis and death. Mortality rates for HC are reported between 10% and 20%, particularly in elderly or anticoagulated patients.<sup>7</sup>

In this case, our patient was elderly, with a significant comorbidity burden including biliary cirrhosis and autoimmune hepatitis, which may have further complicated surgical decision making. His recent orthopaedic surgery and concurrent venous thrombosis necessitated anticoagulation therapy. The multidisciplinary decision to pursue non-operative management was guided by the absence of gallstones, the lack of evidence of ongoing haemorrhage or perforation on CT angiogram and the patient's relative haemodynamic stability. Conservative management involved intravenous antibiotics, close monitoring and temporary cessation of anticoagulation, with plans to reassess the need for cholecystectomy should his clinical condition have deteriorated. Were anticoagulation deemed necessary, surgical management may have been more strongly considered to prevent recurrent haemorrhage and complications from a potential re-bleed. However, in patients where anticoagulation can be safely withheld or reversed, conservative management may allow the inflammation and haemorrhage to resolve, especially in the absence of gallstones.

This nuanced approach reflects the need to balance surgical risks with the potential benefits of definitive management in complex patients. Ultimately, each case of HC must be managed on an individual basis, considering the unique interplay of patient factors, disease severity and

resource availability. Multidisciplinary collaboration between surgeons, medical specialists and radiologists is essential to determine the most appropriate course of action. Continued vigi-

lance and early surgical consultation remain key in optimising patient outcomes in this rare but life-threatening condition.

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**AUTHOR INFORMATION**

Amy Van der Sluis: General Surgery Department, Christchurch Hospital, New Zealand.

Divyansh Panesar: General Surgery Department, Christchurch Hospital, New Zealand.

**CORRESPONDING AUTHOR**

Amy Van der Sluis: General Surgery Department, Christchurch Hospital, New Zealand.  
E: amy.vandersluis@cdhb.health.nz

**URL**

<https://nzmj.org.nz/journal/vol-138-no-1627/haemorrhagic-cholecystitis-a-rare-but-life-threatening-variant-of-acute-cholecystitis>

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# Diffuse astrocytoma presenting with parkinsonism and gliomatosis-like infiltration

Gabriel F Vieira, Laura G Silva, Letícia A Queiroz, Victor S Takahashi, Gustavo Andreis, Márcio L Duarte

In 2007, a 51-year-old woman presented with progressive left-sided bradykinesia, rigidity, micrographia and gait disturbance without a resting tremor. An initial brain magnetic resonance imaging (MRI) performed within weeks of symptom onset was unremarkable. The initial diagnosis of Parkinson's disease was made by a clinical neurologist, and dopaminergic therapy provided partial benefit. Although a causal link between the tumour and the parkinsonian syndrome is possible, the coexistence of two unrelated pathologies—such as an atypical parkinsonian disorder preceding tumour development—cannot be excluded. Over the ensuing 6 years, the patient's parkinsonian symptoms persisted until a generalised tonic-clonic seizure in 2013 prompted repeat imaging and diagnosis of a diffuse infiltrative glioma (Figure 1).

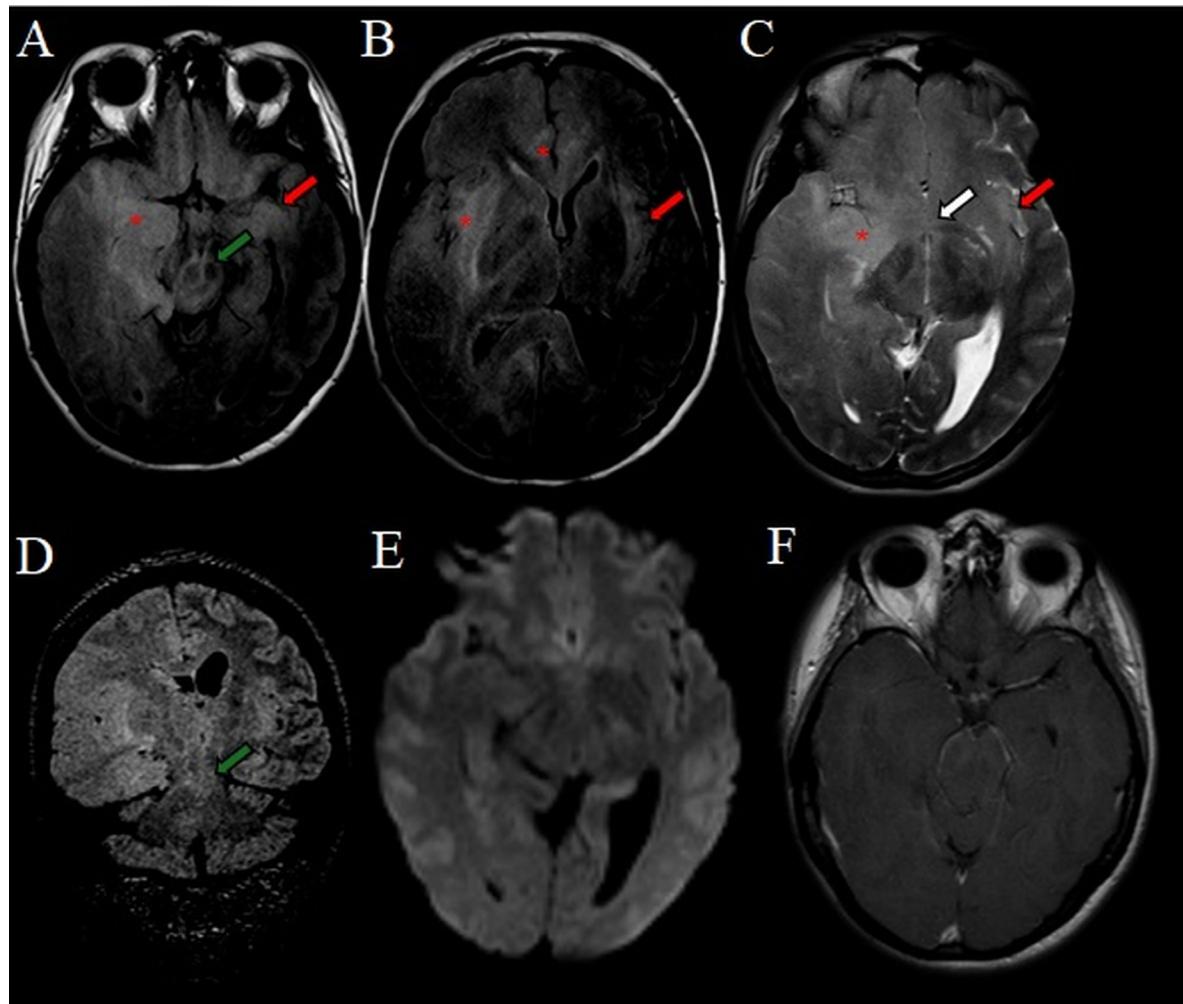
Gliomatosis cerebri—no longer a distinct entity in the World Health Organization (WHO) classification—describes diffuse infiltration of three or more cerebral lobes, typically with preserved architecture but extensive white matter spread.<sup>1</sup> Early imaging may be normal, delaying diagnosis,

as in this case.<sup>2</sup> Advanced imaging and MR spectroscopy can aid recognition when parkinsonian symptoms are atypical or refractory to dopaminergic therapy.<sup>3</sup>

Treatment is often palliative, as complete resection is rarely feasible. While median survival for gliomatosis-like diffuse astrocytoma is typically reported as 12–30 months,<sup>4</sup> our patient survived 9 years after tumour diagnosis and 15 years from symptom onset. This prolonged course likely reflects the tumour's lower histological grade (WHO grade 2) and the influence of individualised supportive care.

This case highlights the importance of periodic reappraisal of parkinsonism diagnoses, particularly when clinical evolution is atypical, regardless of whether gliomatosis-like infiltration is suspected. While the temporal association in our case raises the possibility of a causal link, we cannot exclude two unrelated pathologies. The unusually long survival of 15 years from symptom onset likely reflects the tumour's lower histological grade (WHO grade 2) and the benefit of individualised care.

**Figure 1:** Magnetic resonance imaging (MRI) sequences in axial FLAIR (A and B), axial T2-weighted (C), coronal FLAIR (D), axial diffusion-weighted (E) and axial post-contrast T1-weighted (F) images. The cortico-subcortical infiltrative lesion shows mass effect and T2/FLAIR hyperintensity, without diffusion restriction or enhancement after intravenous contrast administration. The lesion involves the right temporal lobe, mesial temporal region, amygdala, insula and cingulate gyrus (\*). Extension through the anterior commissure (white arrow) is observed, with additional involvement of the anterior aspect of the mesial temporal region and insula on the left (red arrow). The midbrain and pons are also affected (green arrow).



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**AUTHOR INFORMATION**

Gabriel F Vieira: Department of Internal Medicine, Faculdade de Medicina do Centro Universitário Atenas, Paracatu (MG), Brazil.

Laura G Silva: Department of Internal Medicine, Faculdade de Medicina do Centro Universitário Atenas, Paracatu (MG), Brazil.

Letícia A Queiroz: Department of Internal Medicine, Faculdade de Medicina do Centro Universitário Atenas, Paracatu (MG), Brazil.

Victor S Takahashi: Department of Internal Medicine, Universidade de Ribeirão Preto, Campus Guarujá, Guarujá (SP), Brazil.

Gustavo Andreis: Department of Radiology, Diagnósticos da América SA, DASA, São Paulo (SP), Brazil.

Márcio L Duarte: Department of Radiology, Diagnósticos da América SA, DASA, São Paulo (SP), Brazil; Department of Radiology, Universidade de Ribeiro Preto, Campus Guarujá, Guarujá (SP), Brazil.

**CORRESPONDING AUTHOR**

Dr Márcio L Duarte: Radiologist, Universidade de Ribeirão Preto (UNAERP), Campus Guarujá, Av. D. Pedro I, 3.300, Enseada, Guarujá-SP, Brazil, 11440-

003. E: marcioluisduarte@gmail.com

**URL**

<https://nzmj.org.nz/journal/vol-138-no-1627/diffuse-astrocytoma-presenting-with-parkinsonism-and-gliomatosis-like-infiltration>

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# Predictors of early-onset cancer risk: insights from machine learning analyses of the Christchurch Health and Development Study data

Simranjeet S Dahia, Laalithya Konduru, Joseph M Boden, Savio G Barreto

The global incidence of early-onset cancers in adults is rising, posing a significant public health challenge.<sup>1</sup> Unlike cancers in older populations, the risk factors for early-onset cancers remain poorly understood. Perinatal and early life stressors have been postulated to modulate the risk of early-onset adult cancers.<sup>2</sup> A prospective lifecourse cohort study provides the ideal framework to study perinatal and early-life stressors. Existing prospective lifecourse cohorts were established to study childhood diseases and chronic health conditions to test the developmental origins of health and disease (DOHaD) hypothesis.<sup>3</sup> These cohorts, thus, lack cancer-specific variables and have low (cancer) event rates, reducing statistical power.

Traditional epidemiological methods, such as univariate screening with false discovery rate (FDR) correction (a statistical method used to control the rate of false positives when performing multiple hypothesis tests), frequently yield null results in high-dimensional datasets with rare outcomes due to low power and inability to capture complex interactions.<sup>4</sup> Some studies using such datasets and methods failed to identify significant associations between perinatal factors and early-onset cancers due to these limitations.<sup>5</sup> To overcome these challenges, we applied a hybrid machine learning (ML) and logistic regression pipeline to data from the Christchurch Health and Development Study (CHDS) to identify perinatal predictors of early-onset cancers in adults, with an aim to gain insight into the underlying aetiological pathways for these cancers.

## Methods

We analysed data of the cohort members of the CHDS—a longitudinal birth cohort study of children born in the Christchurch, New Zealand urban region over a 4-month period during 1977.<sup>6</sup>

We applied a hybrid pipeline<sup>7</sup> that integrated ML feature selection (LASSO and tree-based models) with multivariable logistic regression to estimate odds ratios (ORs) to overcome the challenges with univariate testing (with FDR correction) inherent to a wide dataset. Analyses were conducted in Python (Python algorithm version 3.12.5, Python Software Foundation, Wilmington, DE, USA), leveraging a high-performance computing cluster for computational power.

## Results

Among the 1,265 children included in the CHDS, there are 41 recorded cancer cases by the age of 40 years within the cohort (target variable), along with 158 perinatal, demographic and lifestyle factors (predictors), resulting in a wide dataset.

The hybrid pipeline identified four significant factors associated with early-onset cancer risk. Antenatal care provided by a hospital or clinic (OR 3.16, 95% CI 1.30–7.68), antenatal vitamin use (OR 3.96, 95% CI 1.40–11.20) and antenatal cough medicine use (OR 2.96, 95% CI 1.07–8.20) were associated with increased odds of cancer by age 40 years. Conversely, antenatal care by a family doctor (OR 0.28, 95% CI 0.10–0.79) was associated with reduced odds. The ML model achieved an area under the receiver operating characteristic curve of 0.78 (95% CI 0.72–0.84) and a Brier score of 0.12, indicating robust predictive performance.

## Discussion

Our study adds to the literature by identifying novel predictors using a hybrid ML approach, overcoming the low power and high-dimensionality challenges. By detecting associations missed by traditional methods, our findings support the hypothesis that perinatal stressors are predictive of early-onset cancer risk.<sup>2</sup>

The identified factors may modulate early-onset cancer risk through epigenetic processes and metabolic pathways. Patients selected to undergo hospital-based antenatal care are more likely to represent high-risk pregnancies, with attendant maternal stressors (e.g., chronic illness, infections, eclampsia, etc.) that can induce foetal epigenetic changes such as DNA methylation.<sup>8</sup> Conversely, pregnant females deemed suitable to undergo antenatal care with their family doctors would be more likely to have low-risk pregnancies, with consequent lower maternal and foetal stressors. Maternal vitamin supplementation (including folic acid in larger doses) and the risk of cancer in the offspring is a controversial finding that has been previously reported.<sup>9</sup> The increased risk of colon and breast cancers is postulated to occur via disruption of foetal metabolic pathways and modulation of DNA methylation.<sup>9</sup> Maternal cough medicine as a predictor of early-onset cancer in the offspring more likely concurs with previous evidence implicating underlying respiratory infections as a risk factor,<sup>10</sup> rather than the actual cough medicine used.

The limitations of the study include the reliance on a single cohort, limiting generalisability. Also, the observational design of the cohort precludes

derivation of causal inference. There was also no adjustment for confounding. The CHDS did not collect information on cancer type; this limits the ability to analyse associations by cancer subtype. The dataset included 158 parameters spanning the spectrum of perinatal, demographic and lifestyle factors, with the main aim of studying the same cohort of children at repeated intervals throughout their lifecourse. While over the course of the study, this resulted in over 40 million characters of data, the data lacked granularity for specific matters, such as type of vitamin used or if the cough medicine was used for a viral illness where the patient also received paracetamol or another over the counter medication. However, future mediation analyses of the CHDS data will assess whether combined perinatal and early-life stressors increase the risk of early-onset cancer compared to either alone. We will also explore whether ML-identified, non-significant predictors become significant in combination with other variables.

The findings of this study demonstrate novel information on the perinatal predictors of early-onset cancer development relevant to the CHDS cohort, presenting avenues for future research exploring mechanistic pathways.

**COMPETING INTERESTS**

The authors declare no conflict of interest.

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**AUTHOR INFORMATION**

Simranjeet S Dahaia: College of Medicine and Public Health, Flinders University, South Australia, Australia. Laalithya Konduru, MD: College of Medicine and Public Health, Flinders University, South Australia, Australia. Joseph M Boden, PhD: Department of Psychological Medicine, University of Otago, Christchurch, New Zealand. Savio G Barreto, FRACS, PhD: College of Medicine and Public Health, Flinders University, South Australia, Australia; Division of Surgery and Perioperative Medicine, Flinders Medical Center, Bedford Park, Adelaide, South Australia, Australia.

**CORRESPONDING AUTHOR**

Savio G Barreto, FRACS, PhD: Department of Surgery, Flinders Medical Centre, Bedford Park, South Australia, Australia 5042. E: [georgebarreto@yahoo.com](mailto:georgebarreto@yahoo.com); [savio.barreto@sa.gov.au](mailto:savio.barreto@sa.gov.au).

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# Intravenous vitamin C as a primary cause of renal failure is not supported by the evidence base

Anitra C Carr

A couple of recent *Otago Daily Times* articles have made reference to a patient having died (more than a decade ago) from kidney stones and eventual renal failure due to high-dose intravenous (IV) vitamin C administration.<sup>1,2</sup> This statement is not supported by the evidence-based literature. Despite cases of acute renal failure ascribed to IV vitamin C being reported in the literature,<sup>3</sup> as with any case report there is no control comparator and there are invariably confounders such as disease- or medication-related complications.

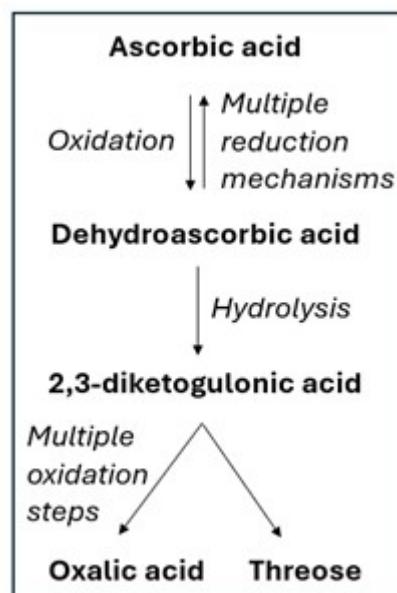
In a United States (US) survey of nearly 10,000 patients who received IV vitamin C, adverse events were reported in only 1%, and were mostly minor.<sup>3</sup> One patient only had renal failure as a "not confirmed (possible)" complication as the "patient had partial renal failure and cancer metastases to the kidneys"; thus, likely a complication of the disease rather than the vitamin C therapy.<sup>3</sup> Further interrogation of the US Food and Drug

Administration (FDA) Adverse Event Reporting System database for patients treated with IV vitamin C was inconclusive due to the inability to eliminate confounders.<sup>3</sup>

Although vitamin C (ascorbic acid) can be converted to oxalate, and has been implicated in oxalosis and calcium oxalate nephrolithiasis, this reaction requires multiple oxidation steps (Figure 1). Oxalate formation also often occurs as an *ex vivo* artefact in urine samples rather than *in vivo* due to the numerous endogenous reduction mechanisms that convert the oxidised vitamin (dehydroascorbic acid) back to ascorbic acid.<sup>4</sup> In support of this, a prospective case series study of 157 adults with 1-year follow-up carried out in a New Zealand setting indicated no reported renal stones with high-dose IV vitamin C administration, despite 8% of the patients having a history of renal stones.<sup>5</sup>

Calcium oxalate crystals are quickly passed in healthy individuals; however, intratubular

**Figure 1:** Pathway for vitamin C (ascorbic acid) conversion to oxalic acid.



**Table 1:** Alternate risk factors for renal failure and secondary oxalosis reported in the literature.

Renal failure risk factors	Secondary oxalosis risk factors
Medications causing crystal deposition (e.g., ceftriaxone and amikacin, and other antibiotics, darunavir, triamterene, etc.)	Medications (e.g., methoxyflurane, orlistat, xylitol, topiramate, indinavir and other antivirals, etc.)
Renal transplantation failure (e.g., antibody-mediated rejection, reoccurrence of disease)	Excessive intake (e.g., ethylene glycol, specific foods)
Direct infection of kidneys (e.g. SARS-CoV-2/ACE2 interaction)	Increased absorption (e.g., gastrointestinal diseases, gastrointestinal surgery)
Septic shock/severe burns (e.g., renal hypoperfusion, cytokine storm, vasopressor administration, drug toxicity, mechanical ventilation)	Decreased excretion (e.g., dehydration/diarrhoea, acute and chronic renal failure, chronic haemodialysis)
Chronic diseases (e.g., diabetes, hypertension, autoimmune diseases)	Vitamin deficiencies (e.g., thiamine, pyridoxine)

retention is believed to occur in areas of damaged and regenerating tubular epithelium, where molecules with potential crystal-binding capacity are expressed.<sup>6</sup> High-dose IV vitamin C administration produces high (millimolar) peak concentrations in the circulation,<sup>7</sup> which are normally cleared by functioning kidneys with a half-life of approximately 2 hours.<sup>8</sup> Pre-existing renal failure, however, results in sustained high circulating concentrations of the vitamin, which may have untoward side effects.

There are numerous risk factors for renal failure (e.g., drug toxicity, renal transplantation failure, infection and septic shock, severe burns, chronic diseases—see Table 1) as well as many alternate risk factors for secondary oxalate nephrolithiasis, such as certain medications, excessive intake of specific foods, increased absorption due to gastrointestinal diseases/surgery, decreased elimination due to dehydration or renal failure and specific vitamin deficiencies (Table 1).<sup>9</sup> As such, vitamin C administration should not be automatically ascribed to renal failure due to oxalate nephrolithiasis in patients who happen to be receiving IV vitamin C therapy,

particularly if there are other pre-existing risk factors.

This premise also applies to studies that have reported associations between vitamin C intake or oral supplementation and kidney stones;<sup>10</sup> not all of the possible confounders are able to be taken into account. Furthermore, vitamin C plasma concentrations are limited in these cases by the regulated intestinal uptake of oral vitamin C via specialised vitamin C transporters, meaning that only a specific proportion of the ingested vitamin is absorbed,<sup>11</sup> thereby minimising its potential toxicity.

Overall, IV vitamin C-dependent oxalate nephrolithiasis appears to be a result of pre-existing renal dysfunction, and the inability of the kidneys to adequately clear high plasma concentrations of the vitamin, rather than the vitamin being the primary cause of the renal failure. Thus, it is vital for renal function to be assessed prior to administration of IV vitamin C, and high doses of the vitamin not administered if pre-existing renal dysfunction is apparent, or be discontinued if renal function should decline due to disease- or medication-related complications.

**COMPETING INTERESTS**

A C Carr has received honoraria from Pascoe for conference presentations (2025), and support for conference attendance, paid to institution, from Pascoe (2025), National Institute of Integrative Medicine (2024) and Linus Pauling Institute (2023).

**CORRESPONDING AUTHOR INFORMATION**

Anitra C Carr, PhD: Research Professor & Director, Nutrition in Medicine Research Group, Department of Pathology & Molecular Medicine, University of Otago, Christchurch, New Zealand; Research Fellow, Department of General Practice, University of Otago, Christchurch, New Zealand.  
E: anitra.carr@otago.ac.nz

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# Specialism in Medicine

NZMJ, 1925

**I**t is a common saying that to-day is the day of the specialist, and in the present state of public opinion there is no doubt that anyone who puts himself forward as a "specialist," whether it be in the realm of medical practice or in the more humble pursuit of applying cosmetics or "shingling" the hair, is sure of a certain prestige, which he may or may not maintain, depending upon the discernment of the public, which is an uncertain and varying quantity. It was Bacon who said that the practice of medicine is more open to chicanery than any other calling, and a patient may be between Scylla and Charybdis on the one hand, a specialist who may have too restricted a view of the case, and on the other, a general practitioner who may be willing to undertake what is beyond his powers. The patient's safety depends upon a proper perspective on the part of both the specialist and of the general practitioner, and loyal co-operation between the representatives of the two classes of practitioner, for the good of the patient and for the good of the patient alone.

It falls to the lot of every specialist to act as a consultant at times, and in such cases the responsibility would appear to rest equally on the shoulders of the family doctor who invokes the aid of the consultant, and on the shoulders of the consultant. The race of consultants, even in England, who only see patients when asked so to do by the family doctor, is becoming rapidly extinct.

We have said that in a consultation the responsibility would appear to be evenly divided, but a writer in the Educational Number of the *British Medical Journal* states that the general practitioner should be "capable, not only of selecting the specialist suitable for a particular case, but also of criticizing, in the light of his knowledge of the patient and his surroundings, the opinion of the specialist, and of advising the patient whether he shall adopt the specialist's advice or not." As an instance of the advice that may come from

specialists, the case may be cited of a gentleman, the subject of occasional attacks of asthma, who went from New Zealand to London to consult specialists, believing that he would obtain the best advice without an introduction and outline of his case supplied by his regular medical adviser. He paid a fee of three guinea four times in one day, and the first specialist advised liquid paraffin, the second dental extraction, the third an operation on the nose, and the fourth vaccine treatment. In each instance the patient was assured by his adviser that no other treatment than the particular one specified would cure the disease. The result of these consultations was that the victim concluded that medical practice differed little from ordinary humbug. It was unfortunate that this patient, a very intelligent man, was not informed that his case was not ripe for dogmatic assertion. The writer we have already quoted says that special practice is rightly regarded as a higher grade than general practice, and its practitioners should be doctors of high intellectual capacity. It might also be added that they should have wide experience. Edmund Burke said that the only safe rule of conduct is experience, and generally it is advisable that a doctor should have some years of experience in general practice before he restricts his practice to a branch for which he feels he has special aptitude. There are always senior practitioners who cannot be more than almost specialists who drop gradually work for which they have no special liking or aptitude and concentrate on special branches, and this is wholly for the good of the public. Specialism raises enormously the standard of medical service given to the public by the medical profession, and it is desirable that specialism should increase as the sum total of medical knowledge increases, because the conscientious general practitioner has a herculean task in trying to keep his knowledge as near as possible abreast of the time.

# Erratum

**URL:** <https://nzmj.org.nz/journal/vol-135-no-1560/paediatric-forearm-fractures-manipulated-in-the-emergency-department-incidence-and-risk-factors-for-re-manipulation-under-genera>

**Paediatric forearm fractures manipulated in the emergency department: incidence and risk factors for re-manipulation under general anaesthesia**

*Shaye Seefried, Kim Chin-Goh, Vahe Sahakian, Nicholas Lightfoot, Matthew Boyle*

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On 12 December 2025, two corrections were applied to this manuscript:

- The author's name Kim Chin-Goh has been corrected to Kimberley Chin-Goh.
- Kimberley Chin-Goh's qualifications were incorrectly listed as MBChB, and these have been corrected to MBBS BSc(Hons).