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## EDITORIAL

# The new Mental Health Act? A potentially wasted opportunity



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# Summaries

## **The new Mental Health Act? A potentially wasted opportunity**

*Paul Glue, Giles Newton-Howes, Jessie Lenagh-Glue, Armon Tamatea, Johnnie Potiki*

New Zealand has the opportunity to update its mental health legislation and implement a person-centric, human rights approach that fosters supported decision making and allows people who experience psychosocial distress the ability to have their voices heard and will and preferences followed by a rigorous inclusion of advance directives in the new legislation. The current *Bill* fails to do this; it is essentially the old *Act* with some new lipstick. We urge anyone who has been—or has yet to be—impacted by psychosocial distress to make a submission to Parliament on the draft *Bill* to encourage it to be made human rights compliant for the coming generation.

## **Process of development of decentralised clinical trial methodology for cancer clinical trials in Aotearoa New Zealand**

*Nicola J Lawrence, Bobbi B Laing, Joseph Tyro, Scott Babington, Marina Dzhelali, Adele Gautier, Dixon Grant, Prashanth Hari Dass, Michael Jameson, Carolyn Lauren, Jessica Maxwell, Ngapei Ngatai, Rix du Plessis, Charlie Stratton, Alvin Tan, Madison Williams, Michelle Wilson*

Decentralised clinical trials (DCTs) are a new model to enable access to a cancer clinical trial independent of where someone lives. The model allows patients to remain in their local area with whānau and support networks, and their local treating team, increasing clinical trial accessibility and quality of care. This aims to make clinical trials more inclusive, accessible and whānau centred. This manuscript describes the processes undertaken to develop the methodology applicable to Aotearoa New Zealand with a strong focus on embedding equity and appropriateness to whānau Māori and those in rural areas.

## **Assessing the impact of physical, mental and cognitive impairments on health-related quality of life in sepsis survivors following intensive care admission in New Zealand**

*Patrice Rosengrave, Jonathan Williman, Geoff Shaw, Anitra C Carr*

Survivors of septic shock experience elevated physical, mental and cognitive issues at hospital discharge. Most mental health issues had resolved by 6 months, but some physical and cognitive issues had not returned to population norms. Short-term vitamin C administration did not improve long-term health-related quality of life, however, and ongoing vitamin C supplementation may be required.

## **A laboratory-developed extraction free real-time PCR for Group A Streptococcus in throat swabs: greater detection and faster results**

*Rebecca Lucas, Emma Tapp, Rumbi Chimwayange, Luiza Hermoso, Matthew R Blakiston*

Throat swabs for Group A *Streptococcus*, a cause of sore throat and post-infectious complications such as rheumatic fever, have traditionally been tested by culture, which takes up to 48 hours to get a confirmed result. Laboratory-developed PCR offers an alternative testing method that provides much faster results and detects more Group A *Streptococcus*, while having a similar reagent cost. Throat swabbing for Group A *Streptococcus* does, however, need to be better targeted at those populations at high risk of post-infectious complications.

## **Favourable outcome of acute myocarditis diagnosed by cardiac magnetic resonance imaging**

*Sophie Rees, Ammar Alsamarrai, Jessica Fulton, Jithendra B Somaratne*

Acute myocarditis is inflammation of the heart muscle, called the myocardium. This study looked at how people with acute myocarditis presented and how they were affected. The myocarditis was detected by cardiac magnetic resonance imaging (cMRI) between mid-2012 and mid-2022. We found that patients with acute myocarditis diagnosed by cMRI had favourable short- and medium-term outcomes. Major adverse cardiac events occurred in only 15% of patients and admission to the intensive care unit (ICU) was rare.

## **Representation of Asian ethnic sub-groups in Aotearoa's regulated health workforce pre-registration students**

*Navneet N Lal, Gabrielle McDonald, Andrew Sise, Warwick Bagg, Zoe Bristowe, Paul Brunton, Chris Hendry, Bridget Kool, Damian Scarf, Susan Shaw, Collin Tukuitonga, Jonathan Williman, Denise Wilson, Peter Crampton*

This research is the first to provide detailed information on Asian sub-group representation in health professional programmes in Aotearoa New Zealand. Despite being well-represented overall, Asian students were under-represented in specific programmes: midwifery, occupational therapy and paramedicine, all of which relate to areas of healthcare need for specific Asian sub-groups. Taken in the context of known health needs of different Asian sub-groups, these data may facilitate health workforce planning and targeted policies within health professional programmes, in order to better match the health workforce to Aotearoa's health needs. We recommend that the health and tertiary education systems should, together, ensure that there is improved measurement of ethnicity (including more complete and more accurate collection of Asian sub-group data for the health workforce in-training) with a view of monitoring and meeting the healthcare needs of diverse Asian communities.

## **The first trimester abortion journey Aotearoa: health practitioners' perspectives**

*Emma Macfarlane, Pauline Dawson, Michael Stitely, Helen Paterson*

This research involved interviews with a range of health practitioners in Aotearoa to determine their perspectives on what it is like for people accessing abortion care. Results show that multiple barriers to abortion care remain, despite law reform. However, several potential solutions to improve how abortion care is accessed and experienced were identified. Health practitioners were supportive of facilitating primary care provision of first trimester abortion care.

## **Ethnic variations in traumatic injury hospitalisations in a health region of Aotearoa New Zealand—10-year review**

*Ishani Soysa, Sheena Moosa, Grant Christey*

Research indicates that certain ethnic groups experience a disproportionate burden of trauma compared to others, making it a significant public health concern both globally and in Aotearoa New Zealand. Māori, as the Indigenous population of Aotearoa New Zealand, have been identified as particularly vulnerable to trauma due to historical and ongoing socio-economic disparities, along with cultural factors that contribute to higher rates of these injuries. In Aotearoa New Zealand socio-economic and ethnic differences have been noted with respect to trauma incidence, patterns, specific injuries, severity and among different age groups. Understanding these nuances is essential for designing culturally appropriate prevention and intervention strategies. The research aims to describe the ethnic variations in trauma hospitalisations in the Te Manawa Taki health region of Aotearoa New Zealand. The study also

analyses the demographic characteristics of patients hospitalised due to trauma across different ethnic groups and explores disparities in injury severity, outcomes and healthcare utilisation.

### **Cultural safety and the medical profession in Aotearoa New Zealand: a training framework and the pursuit of Māori health equity**

*David Tipene-Leach, Shirley Simmonds, Marnie Carter, Helena Haggie, Virginia Mills, Mataroria Lyndon*

Cultural safety is a process whereby professionals (in this case doctors) carefully reflect upon their practice of medicine, or indeed a single case, to see whether their own biases or an uneven power relationship in the consultation has affected health outcomes for the patient. The doctor is then required to change their behaviour based upon that reflection. The best outcome is improved outcomes for the patient and improved satisfaction for the practitioner. The Training Programme has been developed to make it much easier for medical colleges to develop their own programme teaching cultural safety as a normal part of the training of specialists. Given that things like power, privilege, racism and bias can be difficult topics to broach, this is likely to be challenging for some.

### **Case study of a potential West Polynesian variant of von Hippel-Lindau disease**

*Eugene Michael, Peter Hadden, Stephen Robertson*

von Hippel Lindau (vHL) syndrome is a genetic disease that can affect multiple organ systems. A common manifestation of the disease includes the growth of benign blood vessel tumours in the retina, at the back of the eye. In this article, we discover vHL in a family of West Polynesian individuals where genetic testing for the *VHL* gene was negative. This raises the possibility of a novel variant of *VHL* (i.e., the gene that causes this syndrome) in this unique population.



# The new Mental Health Act? A potentially wasted opportunity

Paul Glue, Giles Newton-Howes, Jessie Lenagh-Glue, Armon Tamatea, Johnnie Potiki

The New Zealand Government Inquiry into Mental Health and Addiction published the *He Ara Oranga* report in 2018.<sup>1</sup> It identified the *Mental Health Act 1992* as outdated and proposed replacing it with new legislation that reflected a human rights-based approach, promoting supported decision making aligned with a recovery and wellbeing model of mental health that sought to minimise compulsory or coercive treatment. Consequently, several initiatives were launched between 2021 and 2023 and included public consultation on a new mental health act and the creation of an expert advisory group to refine policy proposals. The new *Mental Health Bill* was introduced to Parliament on 1 October 2024 for its first reading.<sup>2</sup> It offers a once-in-a-generation opportunity for New Zealand to again provide international leadership in the space of social inclusion and equality.

As a group of clinicians, academics and service users with a deep knowledge of mental health legislation both at home and abroad, we recognise this *Bill* is an important juncture in our legislative arc both in terms of medical law and human rights. However, the *Bill* raises significant concerns with regard to stale notions of care, inefficiently using resources, promoting the status quo of substitute decision making, increasing stigma and risk in the community and lack of consistency with international conventions. Each of these issues will be briefly described in turn.

Firstly, despite much reworking, the *Bill* reads much the same as the current *Mental Health Act*. This “new” *Bill* appears to not reflect a new direction of travel with regard to intended outcomes or mechanisms for wellbeing. The *Bill* adds a crucial capacity assessment and makes it clear that it cannot be used if capacity is present. The *Bill* also requires a support person and supportive hui and suggests that advanced directives<sup>3</sup> take the weight of a decision—referred to here as “compulsory care directives”, which we believe is an oxymoron, because care should be *provided* rather than compelled. Advance choice directives should be a tool to enable to people experiencing psychosocial distress to direct their care and

treatment, and should address issues broader than just medical treatment.

Secondly, there is some concern from a clinical perspective that this *Bill* will lead to a “revolving door” into and out of services, where people are detained and treated, then subsequently have their treatment discontinued—only to again become unwell, requiring further treatment. If this further treatment involves the *Act* being invoked again then it will be highly distressing for individuals and will unnecessarily consume limited mental health resources as the legislation is invoked again and again for the same people. The continuation of this approach promotes the *status quo* of substitute decision making. A much better developed process of supported decision making would help to reduce any likelihood of repeated applications of the new legislation to the same person.

Thirdly, we acknowledge that this *Bill* purports to promote supported decision making (a person-centred, patient-led approach) rather than substituting it. However, this appears to be a semantic issue rather than supporting clinical practice. For instance, if a person is found to lack capacity, then another person by definition is making a decision *for* them—which means the *Bill* promotes *substitute* decision making. Including a capacity assessment simply overrides any option for this to be supported decision making. Despite emphasising advanced directives—the need to consider a person’s will and preferences—the *Bill* remains conflicted. This balance of power ultimately comes down to the assessor, who, if they find that capacity lacking, will use substitute decision making. Examining rates of use of the current *Act* is revealing. Use incrementally increases year on year and use in Māori continues to outstrip use in other ethnic groups.<sup>4</sup>

Fourthly, the ongoing civil and criminal provisions remaining in the same piece of legislation mean that psychosocial distress and the stigma of being a danger to self and/or others are compounded. While we acknowledge a societal urge to detain people to protect themselves and the public, we also recognise that by

continuing to include civil and criminal components of responses to people experiencing psychosocial distress in the same *Bill* these groups are interwoven and treated as the same in terms of both disorder and risk—increasing stigma and accompanying mental health compromises.

Lastly, we note the new *Bill* does not meet the requirements of the Convention on the Rights of Persons with Disabilities (CRPD).<sup>5</sup> The CRPD is a United Nations (UN) convention signed by New Zealand almost two decades ago, and both visits by the UN to New Zealand have produced damning reports about our mental health legislation.<sup>6</sup> Changes in Australia (and elsewhere) that reflect some of the changes in the new *Bill*, such as the inclusion of a capacity assessment in the definition of mental disorder, have been criticised by the committee for the CRPD and there is no reason to believe this will not be the case here. By signing the CRPD, New Zealand has committed to making local law compliant with international good practices. Many jurisdictions have struggled to become CRPD compliant, and we have an opportunity to show it can be done.

Taken together, we consider ourselves at a crossroads in the way people should be supported when experiencing psychosocial distress. If the system

is considered unhelpful for the many thousands of people who access it, then why does it exist? The new *Mental Health Bill* could provide a unique opportunity to support those in need, protect all New Zealanders' human rights and again move New Zealand to the forefront of socially liberal legislation. In today's global environment, such a statement of intent would not only be powerful, but also make clear the value New Zealand places on liberal democracy and human rights. In our view, the *Bill* reflects these efforts, but ultimately is not transformative: however, it could be. We encourage everyone who has been—or has yet to be—impacted by psychosocial distress to make a submission and have their views heard.

As final thoughts, we 1) advocate placing supported decision making at the heart of the *Bill*, 2) urge the wholesale adoption of advance directives as a comprehensive voice for people who experience psychosocial distress, 3) argue that much more robust processes of supported decision making will help reduce the likelihood of continued and sustained substitute decision making, and 4) encourage the *Bill* to be truly CRPD compliant. We truly have the chance to make a once-in-a-generation change to our mental health law.

**COMPETING INTERESTS**

Paul Glue has a research contract with Douglas Pharmaceuticals to develop an extended-release ketamine tablet formulation. He has received funding from James Hume Fund and Oakley Foundation for work on advance directives and is on two DSMCs for HRC-funded psychedelic studies.

Jessie Lenagh-Glue is a HDEC Central lay member and the vice president of New Zealand Brain Tumour Trust.

Giles Newton-Howes is a member of the SAC Mental Health for Pharmac and the immediate past president of the ISSPD board.

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**AUTHOR INFORMATION**

Paul Glue: Professor of Psychological Medicine, University of Otago, Dunedin, New Zealand.

Giles Newton-Howes: Associate Professor of Psychological Medicine, University of Otago, Wellington, New Zealand.

Jessie Lenagh-Glue: Senior Research Fellow, Psychological Medicine, University of Otago, Dunedin, New Zealand.

Armon Tamatea: Associate Professor, Department of Psychology, University of Waikato, New Zealand.

Johnnie Potiki: Consumer Advisor, Te Whatu Ora Southern, Dunedin, New Zealand.

**CORRESPONDING AUTHOR**

Paul Glue: Professor of Psychological Medicine, University of Otago, Dunedin, New Zealand.

E: paul.glue@otago.ac.nz

**URL**

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**REFERENCES**

1. Government Inquiry into Mental Health and Addiction. He Ara Oranga: Report of the Government Inquiry into Mental Health and Addiction [Internet]. 2018 [cited 2024 Nov 15]. Available from: <https://mentalhealth.inquiry.govt.nz/assets/Summary-reports/He-Ara-Oranga.pdf>
2. Beehive.govt.nz. Mental Health Bill passes first reading [Internet]. 2024 Oct 23 [cited 2024 Nov 15]. Available from: <https://www.beehive.govt.nz/release/mental-health-bill-passes-first-reading>
3. Lenagh-Glue J, Potiki J, O'Brien A, et al. Help and Hindrances to Completion of Psychiatric Advance Directives. *Psychiatr Serv*. 2021;72(2):216-218. doi: 10.1176/appi.ps.202000080.
4. Lees M, Newton-Howes G, Frampton C, Beaglehole B. Variation in the use of compulsory community treatment orders between district health boards in New Zealand. *Australas Psychiatry*. 2023;31(3):349-352. doi: 10.1177/10398562231157246.
5. United Nations, United Nations Human Rights – Office of the High Commissioner. Convention on the Rights of Persons with Disabilities [Internet]. 2006 [cited 2024 Nov 15]. Available from: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>
6. Ministry of Health – Manatū Hauora. Mental health and human rights – an assessment [Internet]. 2017 [cited 2024 Nov 15]. Available from: <https://www.health.govt.nz/regulation-legislation/mental-health-and-addiction/mental-health-act/mental-health-and-human-rights>

# Process of development of decentralised clinical trial methodology for cancer clinical trials in Aotearoa New Zealand

Nicola J Lawrence, Bobbi B Laing, Joseph Tyro, Scott Babington, Marina Dzhelali, Adele Gautier, Dixon Grant, Prashanth Hari Dass, Michael Jameson, Carolyn Lauren, Jessica Maxwell, Ngapei Ngatai, Rix du Plessis, Charlie Stratton, Alvin Tan, Madison Williams, Michelle Wilson

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## ABSTRACT

**AIM:** To develop processes for the development of decentralised clinical trial methodology for Aotearoa New Zealand, focussing on equity of access to cancer clinical trials for Māori, Pacific people, vulnerable communities and those in rural settings.

**METHODS:** A national steering committee supported by Te Aho o Te Kahu – Cancer Control Agency was formed to: guide the adaptation and implementation of overseas decentralised clinical trial models to suit the needs of Aotearoa New Zealand with an equity focus; provide high-level oversight and expertise for direction and development of policies, procedures and infrastructure compliant with ICH GCP R2; and implement a national strategy.

**RESULTS:** Twelve standard operating procedures were developed, as well as a supervision plan and a glossary. These were made freely available on the New Zealand Association of Clinical Research website.

**CONCLUSION:** Decentralised clinical trials offer a novel method of trial conduct that is patient- and whānau-centred. The model allows patients to remain in their local area with whānau and support networks, and their local treating team, increasing clinical trial accessibility and quality of care. This methodology has the potential to support improvement in research capabilities nationally and be utilised beyond oncology. It would benefit from significant investment in national clinical trial infrastructure.

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Māori and Pacific people suffer untenable inequities in health outcomes, especially in cancer.<sup>1-5</sup> Those who live in socio-economically deprived areas also have worse outcomes.<sup>6</sup> *Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029 (The New Zealand Cancer Action Plan)* has four main goals: i) New Zealanders have a system that delivers consistent and modern cancer care, ii) New Zealanders experience equitable cancer outcomes, iii) New Zealanders have fewer cancers, and iv) New Zealanders have better cancer survival.<sup>2</sup>

Embedding clinical trials within our health system is a priority initiative to improve quality of care and patient outcomes.<sup>7-11</sup> International guidelines recommend clinical trial participation as it significantly benefits many cancer patients.<sup>12</sup> Historically, clinical trial participants have not been diverse, nor have they represented the general population, with under-representation from Indigenous populations, women and marginalised groups.<sup>13</sup> These exclusions have

significant consequences and continue to reduce confidence in institutions and people who are conducting research, as well as limiting the generalisability of results.<sup>14</sup> Recent publications have articulated the goals of increasing diversity in clinical trial participation, which include earning and building trust, promoting fairness and generating biomedical knowledge.<sup>15</sup> Opportunities for participation in clinical trials across Aotearoa New Zealand are inequitable, particularly for whānau (extended family) living outside of major centers and for Māori and Pacific people.<sup>9,10,16,17</sup> However, the majority of New Zealanders (86%) want the choice to take part in a clinical trial.<sup>18</sup>

Traditionally, clinical trials involve whānau attending hospitals for face-to-face interaction with trial staff. Barriers to participation include: the lack of clinical trial availability and resources; infrastructure; staffing expertise close to home; lack of awareness and transparency related to information sharing of available clinical trials; financial and time costs of participation; stringent

trial-related screening criteria; and, in some cases, the impossibility of travel to major centres where the trials are being conducted.<sup>19,20</sup> Decentralised clinical trials (DCTs), also known as teletrials, are a novel model to enable access to a trial independent of where you live.<sup>21</sup> This makes clinical trials more inclusive, accessible and whānau-centred, as DCT infrastructure allows a clinical trial to become available in smaller centres and patients can continue care with their local oncology treatment team.<sup>22</sup> The Clinical Oncology Society of Australia (COSA) has been instrumental in the development and implementation of this model across Australia.<sup>19</sup> This model has also been successfully implemented across Canada and the United Kingdom, and has facilitated increased access to clinical trials at rural and remote sites.<sup>23,24</sup> Internationally, the implementation of DCTs has increased the recruitment of rural patients.<sup>25–27</sup> Currently, there are no reports of the impact of DCTs on the recruitment of Indigenous populations.

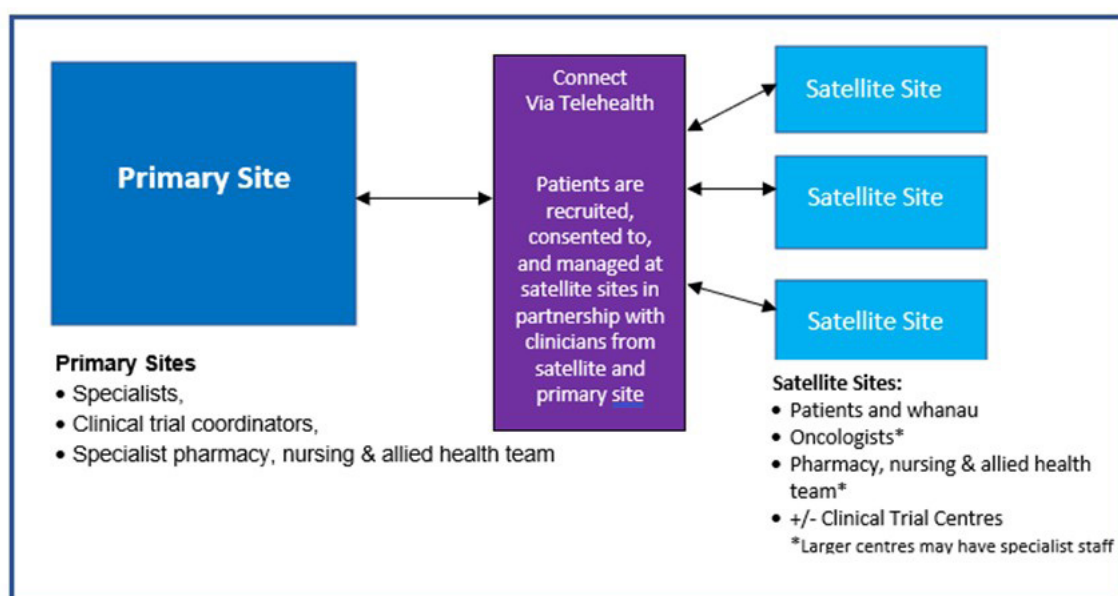
Access to clinical trials through DCTs has been given impetus by the COVID-19 pandemic, which acted as a catalyst for the uptake of new technologies such as telehealth.<sup>28</sup> A cross-sectional survey in 2022 of institutions in the European Union conducting DCTs before the COVID-19 pandemic indicated that DCT methodology was used more often during the pandemic to mitigate its effects.<sup>29</sup> It highlighted concerns including DCT methodology not being accepted by

some regulators, the variety of DCT policies and methodologies both internationally and institutionally and the challenges of keeping up to date with the shifts in the regulatory landscape. Concerns for regulators included participant safety, privacy, source data verification, data integrity and access to internet systems.<sup>29</sup> However, a recent study showed that data integrity can be maintained through this methodology.<sup>30</sup> Other barriers to conducting DCTs include limited engagement with trial sponsors and potential industry partners.<sup>28,29,31,32</sup> Regulatory agencies, including the United States Food and Drug Administration (FDA), have recently published guidelines on the implementation of DCTs to address many of these issues.<sup>24,33</sup>

## What is the DCT model?

In a standard multi-centre clinical trial, the trial lead investigator and trial steering committee take overall responsibility for the conduct of the trial, but delegate responsibility for activities related to the enrolled patients to principal investigators (PIs) at each individual participating trial site (e.g., an individual hospital). In the DCT model, one trial site (called the primary site) works collaboratively with sites in smaller centres and rural areas (called satellite sites) to enrol, consent and treat patients in the trial (Figure 1).<sup>17</sup> Each combination of a primary site with its individual satellite sites is called a cluster.

**Figure 1:** Schema for decentralised clinical trial cluster (adapted from COSA teletrial design<sup>1</sup>).



There can be more than one cluster per clinical trial, and clinical trials can operate as both multi-centre clinical trials and DCTs.

Health professionals at primary sites and satellite sites work collectively, with their roles and responsibilities formally agreed upon and documented (for example, in supervision plans). The primary trial site(s) takes overall responsibility for the supervision and coordination of trial-related matters for both the primary and satellite sites, in collaboration with the satellite site staff (Figure 1). The PI at the primary site can delegate responsibility to sub-investigators at satellite sites. This methodology enables patients from more remote areas to participate without the need to travel to the primary site.<sup>21</sup> DCTs essentially aim to increase access to clinical trials by decentralising the processes of a clinical trial (consent, randomisation, delivery of investigational products, trial activity and, potentially, trial monitoring).<sup>23</sup> Each supervision plan is unique to the trial being conducted and the sites involved.

### Development of the Aotearoa New Zealand Oncology Decentralised Clinical Trial Steering Committee

In February 2019, a National Oncology and Haematology Research Day was attended by delegates across Aotearoa New Zealand and supported by Te Aho o Te Kahu – Cancer Control Agency. Attendees identified the need to provide a DCT infrastructure fit for the Aotearoa New Zealand cancer clinical trial landscape that was relevant for Māori and their whānau. The aim was to improve equity of access to cancer clinical trials for Māori and those in rural settings and to increase the diversity of people participating in trials, and therefore be more reflective of the Aotearoa New Zealand population.<sup>34</sup> Initial discussions and collaboration began with international leaders instrumental in the development and delivery of DCTs, particularly with colleagues in Australia. To ensure that the developed DCT processes were appropriate for Aotearoa New Zealand, there was extensive consultation nationally in the cancer clinical research space. This included consultation with clinicians and research managers based in both urban and rural hospitals with cancer services. Engagement with Te Aho o Te Kahu followed. From this, a national oncology DCT steering committee was formed. This committee's role was to:

- guide the adaptation and implementation of the Australian model to suit the needs of Aotearoa New Zealand;
- provide oversight and expertise to the development of infrastructure, resources and clinical trial research activity for the implementation of DCTs at a national level across radiation oncology, haematology and medical oncology;
- provide high-level oversight and direction with respect to DCT activities including development of policies and procedures, implementation of a national strategy, research compliant with ICH Good Clinical Practice (GCP) R2, and with an equity focus.

Terms of reference were developed based on the following principles:

- commitment to partnership with Māori to ensure DCTs will be relevant and appropriate for whānau Māori;
- commitment to Pacific people and those in rural areas that DCTs will improve health opportunities for patients;
- actively explore opportunities to enable the delivery of DCTs at a national level;
- commitment to the implementation of DCTs to grow research activity;
- create and encourage an environment that addresses barriers to the delivery of clinical trials via the DCT model;
- ensure equity underpins the policies and pathway for DCT implementation in Aotearoa New Zealand.

Members of the committee included three co-leads (including a Māori health researcher), representation from medical oncology, haematology and radiation oncology, research management, rural sites and consumers. In addition, the committee successfully sought funding from Te Aho o Te Kahu (0.6 FTE for 12 months) for a project manager (*ex officio*) to assist with the development of the infrastructure required for Aotearoa New Zealand-specific DCTs.

### Development of guidelines to enable the conduct of a DCT

The Aotearoa New Zealand Oncology Decentralised Clinical Trial Steering Committee had oversight of the development of the infrastructure

required for DCTs: standard operating procedures (SOPs), a supervision plan, a glossary and a document explaining the terms commonly used in DCTs. The aim of the SOPs (Appendix Table 1) was to outline the variations to normal clinical trial procedures that need to be followed when undertaking DCTs in Aotearoa New Zealand. These were adapted from guidelines already in place in Australia.<sup>35–37</sup> The infrastructure developed was deliberately planned to be suitable for use for both academic- and pharmaceutical-sponsored clinical trials. The SOPs were designed to support DCT methodology and should be used in conjunction with local institutional SOPs, rather than as a replacement. The SOPs encompass ICH GCP E6 R2 and align with the guidelines from the New Zealand Association of Clinical Research (NZACRes),<sup>38</sup> the Ministry of Health *Guidelines on the Regulation of Therapeutic Products in New Zealand – Part 11*<sup>39</sup> and the New Zealand Medsafe guidelines.<sup>40</sup> Each SOP focusses on a particular purpose (Appendix Table 1). Collectively, they encompass all aspects of clinical trial conduct including documentation, ethics, governance, delegation of duties, investigational products (IP) and consent.

Under the Aotearoa New Zealand DCT model, the co-ordinating investigator (CI) is the health professional who is the investigator at one of the primary sites, who is assigned the responsibility for the overall conduct of the study, and the coordination of investigators at different sites participating in a multi-centre trial under the international committee on ICH GCP guidelines. (MEDSAFE uses the term “principal investigator” for the CI role.) The PI is the investigator responsible for the conduct, management, monitoring and reporting of a trial at their own site and the associated satellite sites. Other personnel include sub-investigators (sub-i) based at satellite sites and the study staff at primary and satellite sites. The roles and responsibilities of these staff are outlined in the SOPs (Appendix Table 1).

The DCT supervision plan is a key document that details the roles and responsibilities of those at the primary and satellite sites for each cluster for a specific clinical trial. It includes how sites communicate with each other, and gives details of who is responsible at each of the sites for staff training, fund management, research governance (which includes initial application and any amendments), start-up procedures, IP used in the trial, consent and randomisation, data and electronic case report form management of

participants, clinical trial decisions, staff cover, safety reporting and safety management and satellite closing-out responsibilities. The financial implications for each site are considered as part of this.

The supervision plan ensures that the primary and satellite sites set out an agreed pathway for reviewing the appropriate support and oversight of the satellite site. This will ensure that any challenges with protocol adherence or quality are identified early, and the supervision plan can be adapted to reflect this.

This supervision plan is complementary to:

- the feasibility assessment
- the site selection process
- site initiation
- the protocol
- the delegation log
- standard processes according to ICH GCP
- the SOPs at the primary site and satellite sites
- clinical trial research agreements

To ensure the SOPs and the supervision plan template were appropriate to the Aotearoa New Zealand clinical environment they were developed and peer reviewed by research managers and clinicians from different clinical trial research units throughout Aotearoa New Zealand, the members of the steering committee and finally by NZACRes. The SOPs are now freely available on the NZACRes website ([https://www.nzacres.org.nz/contract\\_templates/](https://www.nzacres.org.nz/contract_templates/)).

## Current context

Following the development of the infrastructure and processes for DCTs, elements of this methodology have now been utilised for a small number of cancer clinical trials in Aotearoa New Zealand. This choice of whether to use DCT methodology should be considered at the time of assessment of trial feasibility, not later. Early discussion with the trial sponsor is vital, as are discussions with potential satellite sites. While it may not be possible for all aspects of a trial to be decentralised, the DCT model allows components of the trial to be delivered remotely to reduce the burden of travel for patients and their whānau. This DCT methodology is an important part of a larger solution to increase more equitable participation in clinical trials.

## Future considerations

It is important to ensure that equity and the articles of Te Tiriti o Waitangi underpin the DCT infrastructure, and that this enables DCTs to be conducted in a way that is relevant and appropriate for whānau Māori. The Aotearoa New Zealand Oncology Decentralised Clinical Trial Steering Committee has received further funding support from Te Aho o Te Kahu to develop an evaluation framework to assess the implementation of the DCT methodology. This work is currently underway, with key focusses on programme evaluation, Māori and Pacific people accessibility, participation and quality of care. Interviews will be conducted with a wide range of stakeholders including patients, whānau, clinicians and research staff to identify the barriers and enablers to the set-up, establishment and participation in DCTs, particularly for Māori and rural participants, while also considering the processes involved including governance, data quality and patient safety.

Another important consideration for the development of DCT infrastructure within Aotearoa New Zealand is to consider a capability framework to guide and support the growth of clinical trial units and support DCTs' long-term sustainability with appropriate funding. The state of Victoria in Australia has developed a capability framework to assess what is needed to conduct trials safely (i.e., resources, processes and practices) and how to target investment appropriately for these.<sup>41</sup> Similarly in Canada, the Canadian Remote Access Framework for Clinical Trials (CRAFT) has been developed.<sup>26</sup> In Aotearoa New Zealand, there has been recent work undertaken to provide an evidence base to inform the development of an infrastructure roadmap and operating model to support a sustainable and nationally coordinated clinical trial enterprise and contribute to improved and more equitable health outcomes for New Zealanders.<sup>42</sup> This could be built on further by developing a capability framework that details clinical trial workforce capacity and capability in a systematic way and with infrastructure funding to support clinical trials at rural and remote sites that currently do not have research capability.

The DCT model would be further enabled by the streamlining of governance structures. For example, the current system of individual locality approvals for sites participating in a DCT throughout Aotearoa New Zealand would be more efficient if this could be done through one approval process. It is anticipated that the recent

changes in the Aotearoa New Zealand health system with the introduction of Health New Zealand – Te Whatu Ora may enable this. There also needs to be an efficient way for funding to be transferred from a primary site to the satellite sites that are participating in a DCT. Having appropriate frameworks and governance structures in place means that potential satellite sites can be opened within a short timeframe. In Australia, due to the streamlined regulatory and ethical review processes, studies can be commenced within 5–6 weeks of submission to ethics.<sup>43</sup> Governance structures need to be enabled in Aotearoa New Zealand (a much smaller country than Australia) to make this possible here too. This will make us more attractive to industry sponsors and support the DCT aim of people in Aotearoa New Zealand having equitable access to clinical trials.

Digital enablement is important for DCTs to operate safely, especially with respect to patient confidentiality and privacy. With the internet being a prominent communication vehicle between primary and satellite sites in DCTs it is essential that internet systems of health providers and participants are accessible, robust and protected from cyber-attacks, and that patient data are stored and transmitted safely with no breaches of privacy. Source data verification and data integrity are also important to reduce human and instrument errors.<sup>29</sup> International guidelines have been published by the FDA and the European Medicines Agency to guide robust DCT processes.<sup>23,44</sup> The establishment of a national clinical trial management system may help mitigate some of this risk.

Digital enablement also needs to be considered at a patient level. Access to Wi-Fi and technology may still remain a barrier for some. The Ministry of Business, Innovation and Employment predicted that by the end of December 2023, 87% of New Zealanders would have access to fibre at their home and 99.8% would have improved broadband access. However, rural-based New Zealanders have reduced quality connectivity and some remote and rural New Zealanders have little or no connectivity at their principal residence.<sup>45</sup> In order to overcome digital barriers for those of lower socio-economic status, DCT methodology can be used with patients attending local hospitals in person, with support from local staff and infrastructure (including digital infrastructure).

To ensure the long-term success of DCT infrastructure in Aotearoa New Zealand there



needs to be adequate long-term funding within the health system. The current reform of the Aotearoa New Zealand health system provides an ideal opportunity to streamline processes, and investment in clinical trial infrastructure has the potential to significantly improve both patient care and access to clinical trial opportunities. It is important to acknowledge that while there is a cost to implementing and supporting DCTs, clinical trials have significantly wider economic benefits. In 2017, an economic evaluation of investigator-initiated clinical trials in Australia showed the overall consolidated benefit-to-cost ratio for the networks is 5.8:1, or a return of AU\$5.80 for every \$1 invested.<sup>25,46</sup> There are also considerable benefits in terms of access to unfunded interventions (usually expensive pharmaceuticals) and cost saved through clinical trial participation.<sup>47</sup> A single haematology clinical research unit demonstrated AU\$3,971,357 in financial benefit from early access to subsequently approved investigational new drugs from 36 clinical trials involving 245 participants, \$12,209,538 in financial benefit from accessing approved medications not Pharmaceutical Benefits Scheme-listed and \$6,728,576 in government cost avoidance.<sup>47</sup>

There are also considerable and important indirect benefits in terms of improved patient care and outcomes in hospitals that participate in clinical trials, attributed to them more broadly implementing the higher standard of care demanded in clinical trials.<sup>7</sup>

It is important to recognise that the DCT methodology is one part of a larger solution to increase access to clinical trials across Aotearoa New Zealand. There will still be some studies

better suited to the multi-site model and some studies that lend themselves to a combination. It is important that, as we look to increase trial opportunities, we continue to explore multiple models for our patients and their whānau.

## Conclusion

DCTs offer a novel method of trial conduct that is patient- and whānau-centred. The model allows patients to remain in their local area with their whānau and support network, as well as their local treating team. It reduces the burden on patients to travel and have time off work while participating in clinical research. Internationally, the DCT model has increased recruitment of patients from rural areas to clinical trials, but the impact on Indigenous populations is unknown.

The model developed in Aotearoa New Zealand will be evaluated to ensure that it is relevant and appropriate to whānau Māori and Pacific people and is fit for the purpose to improve equity of access to clinical trials. The DCT model will not be appropriate for every trial but is a key component of a larger solution to increase more equitable participation in clinical trials, particularly for those in smaller regional centres. DCTs have the potential to support improvement in research capabilities nationally but require significant investment in national clinical trial infrastructure to be successful. Long term, this will grow and support research staff and clinicians across centres leading to a more resilient system that enables more trials to be conducted.

**COMPETING INTERESTS**

Nicola J Lawrence received support from Te Aho o Te Kahu for a project manager for this work and is co-lead of the New Zealand DCT committee.

Marina Dzhelali is a New Zealand Association of Clinical Research board member.

Ngapei Ngatai received support from CTNZ for this manuscript.

Alvin Tan is director at SalutisCare.

Michelle Wilson received support from Te Aho o te Kahu for a project manager for this work and is co-lead of the New Zealand DCT committee.

**AUTHOR INFORMATION**

Nicola J Lawrence: Deputy Director, Cancer Trials New Zealand, Discipline of Oncology, The University of Auckland, Auckland, Aotearoa New Zealand; Medical Oncologist, Te Whatu Ora – Health New Zealand Te Toka Tumai Auckland, Auckland, Aotearoa New Zealand.

Bobbi B Laing: Project Manager, Cancer Trials New Zealand, Discipline of Oncology, The University of Auckland, Christchurch, Aotearoa New Zealand.

Joseph Tyro: Principal Advisor, Te Aka Whai Ora – Māori Health Authority, Christchurch, Aotearoa New Zealand.

Scott Babington: Radiation Oncologist, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Christchurch, Aotearoa New Zealand.

Marina Dzhelali: Research Manager, Medical Research Institute of New Zealand, Wellington, Aotearoa New Zealand.

Adele Gautier: Research & Strategic Programmes Manager, Breast Cancer Foundation New Zealand, Auckland, Aotearoa New Zealand.

Dixon Grant: Haematologist, Te Whatu Ora – Health New Zealand Te Pae Hauora o Ruahine Tararua MidCentral, Palmerston North, Aotearoa New Zealand.

Prashanth Hari Dass: Medical Oncologist, Te Whatu Ora – Health New Zealand Lakes, Rotorua, Aotearoa New Zealand.

Michael Jameson: Co-director, Cancer Trials New Zealand, Department of Oncology, The University of Auckland, Auckland, Aotearoa New Zealand; Dean, Waikato Clinical Campus, The University of Auckland, Hamilton, Aotearoa New Zealand; Medical Oncologist, Te Whatu Ora – Health New Zealand, Hamilton, Aotearoa New Zealand.

Carolyn Lauren: Haematology Clinical Trials Team Lead, Te Whatu Ora – Health New Zealand Waitaha Canterbury, Christchurch, Aotearoa New Zealand.

Jessica Maxwell: Medical Oncologist, Te Whatu Ora – Health New Zealand South Canterbury, Timaru, Aotearoa New Zealand.

Ngapei Ngatai: Kaimanāki Oranga/Consumer Representative, Te Whatu Ora – Health New Zealand Taranaki, Aotearoa New Zealand.

Rix du Plessis: Radiation Oncologist, North West Cancer Centre, Burnie, Tasmania, Australia.

Charlie Stratton: Health Research Manager, Te Whatu Ora – Health New Zealand Hauora a Toi Bay of Plenty, Tauranga, Aotearoa New Zealand.

Alvin Tan: Medical Oncologist, Department of Medical Oncology, Te Whatu Ora Health New Zealand Waikato, Hamilton, Aotearoa New Zealand.

Madison Williams: Senior Clinical Research Co-ordinator, Cancer and Blood Research, Te Whatu Ora – Health New Zealand Te Toka Tumai Auckland, Auckland, Aotearoa New Zealand.

Michelle Wilson: Medical Oncologist, Clinical Director for Cancer and Blood Research, Te Whatu Ora – Health New Zealand Te Toka Tumai Auckland, Auckland, Aotearoa New Zealand.

**CORRESPONDING AUTHOR**

Nicola J Lawrence: Deputy Director, Cancer Trials New Zealand, Discipline of Oncology, The University of Auckland, Auckland, Aotearoa New Zealand; Medical Oncologist, Te Whatu Ora – Health New Zealand Te Toka Tumai Auckland, Auckland, Aotearoa New Zealand. E: [nicky.lawrence@auckland.ac.nz](mailto:nicky.lawrence@auckland.ac.nz)

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**REFERENCES**

1. Jackson C, Robinson B, Findlay M. Cancer services to 2025 in New Zealand--investing in research-driven quality care. *N Z Med J.* 2014;127(1395):5-9.
2. Ministry of Health – Manatū Hauora. New Zealand Cancer Action plan 2019–2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029 [Internet]. Wellington, New Zealand: Ministry of Health; 2019 [cited 2023 Sep 20]. Available from: [https://consult.health.govt.nz/cancer-services/cancer-action-plan/supporting\\_documents/newzealandcanceractionplan20192029.pdf](https://consult.health.govt.nz/cancer-services/cancer-action-plan/supporting_documents/newzealandcanceractionplan20192029.pdf)
3. Gurney J, Campbell S, Jackson C, Sarfati D. Equity by 2030: Achieving equity in survival for Māori cancer patients. *N Z Med J.* 2019;132(1506):66-76.
4. Gurney J, Stanley J, Jackson C, Sarfati D. Stage at diagnosis for Māori cancer patients: disparities, similarities and data limitations. *N Z Med J.* 2020;133(1508):43-64.
5. Reid P, Paine SJ, Te Ao B, et al. Estimating the

- economic costs of Indigenous health inequities in New Zealand: a retrospective cohort analysis. *BMJ Open*. 2022;12(10):e065430. doi: 10.1136/bmjopen-2022-065430.
6. Ministry of Health – Manatū Hauora. New cancer registrations 2018 [Internet]. 2020 [cited 2021 Mar 23]. Available from: <https://www.health.govt.nz/publications/new-cancer-registrations-2018>
  7. Downing A, Morris EJ, Corrigan N, et al. High hospital research participation and improved colorectal cancer survival outcomes: a population-based study. *Gut*. 2017;66(1):89-96. doi: 10.1136/gutjnl-2015-311308.
  8. Harding K, Lynch L, Porter J, Taylor NF. Organisational benefits of a strong research culture in a health service: a systematic review. *Aust Health Rev*. 2017;41(1):45-53. doi: 10.1071/AH15180.
  9. HRC NZ. Study to get more Kiwis participating in clinical trials [Internet]. 2020 [cited 2021 Mar 23]. Available from: <https://www.hrc.govt.nz/news-and-events/study-get-more-kiwis-participating-clinical-trials>
  10. Selby P, Liu L, Downing A, et al. How can clinical research improve European health outcomes in cancer? *J Cancer Policy*. 2019;20(6):100182. doi: 10.1016/j.jcpo.2019.100182.
  11. Unger JM, Barlow WE, Martin DP, et al. Comparison of survival outcomes among cancer patients treated in and out of clinical trials. *J Natl Cancer Inst*. 2014;106(3):dju002. doi: 10.1093/jnci/dju002.
  12. National Comprehensive Cancer Network. Clinical Trials [Internet]. [cited 2022 Oct 13]. Available from: <https://www.nccn.org/patientresources/patient-resources/resources-for-patients-caregivers/clinical-trials>
  13. Mutale F. Inclusion of Racial and Ethnic Minorities in Cancer Clinical Trials: 30 Years After the NIH Revitalization Act, Where Are We? *J Adv Pract Oncol*. 2022 Nov;13(8):755-757. doi: 10.6004/jadpro.2022.13.8.2.
  14. Editors; Rubin E. Striving for Diversity in Research Studies. *N Engl J Med*. 2021;385(15):1429-1430. doi: 10.1056/NEJMe2114651.
  15. Schwartz AL, Alsan M, Morris AA, Halpern SD. Why Diverse Clinical Trial Participation Matters. *N Engl J Med*. 2023;388(14):1252-1254. doi: 10.1056/NEJMp2215609.
  16. Goldberg RM, Wei L, Fernandez S. The Evolution of Clinical Trials in Oncology: Defining Who Benefits from New Drugs Using Innovative Study Designs. *Oncologist*. 2017;22(9):1015-1019 doi: 10.1634/theoncologist.2017-0153.
  17. Wong EWM, Bengé S, Brenman E, et al. Clinical trial participation in New Zealand patients with cancer: A survey of oncology and haematology centre. INSIGHTFUL. Poster presented at: NZSO 2021.
  18. So YJ, Jameson M, Newton V, et al. Investigating strategies to improve clinical trial opportunities for patients with cancer in New Zealand-INSIGHT. *N Z Med J*. 2019;132(1498):10-31.
  19. Sabesan S, Burgher B, Buettner P, et al. Attitudes, knowledge and barriers to participation in cancer clinical trials among rural and remote patients. *Asia Pac J Clin Oncol*. 2011;7(1):27-33. doi: 10.1111/j.1743-7563.2010.01342.x.
  20. Unger JM, Vaidya R, Hershman DL, et al. Systematic Review and Meta-Analysis of the Magnitude of Structural, Clinical, and Physician and Patient Barriers to Cancer Clinical Trial Participation. *J Natl Cancer Inst*. 2019;111(3):245-55. doi: 10.1093/jnci/djy221.
  21. Goodson N, Wicks P, Morgan J, et al. Opportunities and counterintuitive challenges for decentralized clinical trials to broaden participant inclusion. *NPJ Digit Med*. 2022;5:58. <https://doi.org/10.1038/s41746-022-00603-y>.
  22. Steinhubl SR, Wolff-Hughes DL, Nilsen W, et al. Digital clinical trials: creating a vision for the future. *NPJ Digit Med*. 2019;2:126. doi: 10.1038/s41746-019-0203-0.
  23. Price J, Goodson N, Warren EJ, et al. Resilient design: decentralized trials recovered faster from the impact of COVID-19 than traditional site-based designs. *Expert Rev Med Devices*. 2021;18(sup1):1-4. doi: 10.1080/17434440.2021.2014818.
  24. Vayena E, Blasimme A, Sugarman J. Decentralised clinical trials: ethical opportunities and challenges. *Lancet Digit Health*. 2023;5(6):e390-e394. doi: 10.1016/S2589-7500(23)00052-3.
  25. Sabesan S, Zalcborg J, Underhill C, et al. Implementation of the Australasian Teletrial Model: lessons from practice. *Asia Pac J Clin Oncol*. 2019;15:3-14. <https://doi.org/10.1111/ajco.13249>.
  26. Sundquist S, Batist G, Brodeur-Robb K, et al. CRAFT-a Proposed Framework for Decentralized Clinical Trials Participation in Canada. *Curr Oncol*. 2021;28(5):3857-65. doi: 10.3390/curroncol28050329.
  27. Van Norman GA. Decentralized Clinical Trials: The Future of Medical Product Development? *JACC Basic Transl Sci*. 2021;6(4):384-7. doi: 10.1016/j.jacbs.2021.01.011.
  28. Roberts NA, Cubitt A, Lindsay D, et al. Teletrials, the new norm? Expert recommendations for teletrials into the future: Findings from the Clinical Oncology Society of Australia Clinical Trial Research Professionals Group Workshop. *Asia Pac J Clin Oncol*. 2022;18(6):650-9. doi: 10.1111/ajco.13737.

29. Suman A, van Es J, Gardarsdottir H, et al. A cross-sectional survey on the early impact of COVID-19 on the uptake of decentralised trial methods in the conduct of clinical trials. *Trials*. 2022;23(1):856. doi: 10.1186/s13063-022-06706-x.
30. Andriani L, Oh J, McMinn E, et al. Telehealth utilization in gynecologic oncology clinical trials. *Gynecol Oncol*. 2023;177:103-8. doi: 10.1016/j.ygyno.2023.08.011.
31. Wong AR, Sun V, George K, et al. Barriers to Participation in Therapeutic Clinical Trials as Perceived by Community Oncologists. *JCO Oncol Pract*. 2020;16(9):e849-58. doi: 10.1200/JOP.19.00662.
32. Djuriscic S, Rath A, Gaber S, et al. Barriers to the conduct of randomised clinical trials within all disease areas. *Trials*. 2017;18:360. <https://doi.org/10.1186/s13063-017-2099-9>.
33. United States Food & Drug Administration Conducting Clinical Trials With Decentralized Elements [Internet]. [cited 2023 May 27]. Available from: <https://www.fda.gov/regulatory-information/search-fda-guidance-documents/decentralized-clinical-trials-drugs-biological-products-and-devices>
34. Aiyegbusi OL, Davies EH, Myles P, et al. Digitally enabled decentralised research: opportunities to improve the efficiency of clinical trials and observational studies. *BMJ Evid Based Med*. 2023;28(5):328-331. doi: 10.1136/bmjebm-2023-112253.
35. Clinical Oncology Society of Australia. Australasian Tele-Trial Model – access to clinical trials closer to home using tele-health: A national guide for implementation. 2016 [cited 2023 Jul 20]. Available from: <https://www.cosa.org.au/media/332325/cosa-teletrial-model-final-19sep16.pdf>
36. Sabesan S, Malica M, Gebbie C, et al. Implementation of the Australasian teletrial model: Translating idea into action using implementation science frameworks. *J Telemed Telecare*. 2023;29(8):641-647. doi: 10.1177/1357633X211017805.
37. Collins IM, Burbury K, Underhill CR. Teletrials: implementation of a new paradigm for clinical trials. *Med J Aust*. 2020;213(6):263,265.e1. doi: 10.5694/mja2.50741.
38. New Zealand Association of Clinical Research. Home [Internet]. 2023 [cited 2023 Jul 20]. Available from: <https://www.nzacres.org.nz/>
39. Ministry of Health – Manatū Hauora. Guideline on the Regulation of Therapeutic Products in New Zealand. Part 11: Clinical trials – regulatory approval and good clinical practice requirements [Internet]. [cited 2023 Apr 18]. Available from: <https://www.medsafe.govt.nz/regulatory/guideline/GRTPNZ/Part11.pdf>
40. MEDSAFE. Current Guidelines on the Regulation of Therapeutic Products in New Zealand [Internet]. [cited 2023 Apr 18]. Available from: <https://www.medsafe.govt.nz/regulatory/current-guidelines.asp>
41. Woollett A, Duncan J, Voskoboynik M, et al. A capability framework to inform the fundamental requirements for clinical trial unit development, growth and long term success in outer metropolitan and rural areas *Contemp Clin Trials Commun*. 2023;32:101072. doi: 10.1016/j.conctc.2023.101072.
42. Stamp LK, Harwood M, Dalziel S, et al. Towards a national equitable and sustainable clinical research infrastructure for Aotearoa New Zealand. *N Z Med J*. 2023;136(1578):100-12. doi: 10.26635/6965.6134.
43. Edwards B. Australia, home to a world-class early phase clinical trial ecosystem [Internet]. *Endpoint News*; 2020 [cited 2022 Jul 15]. <https://endpts.com/sp/australia-home-to-a-world-class-early-phase-clinical-trial-ecosystem>
44. Khin NA, Francis G, Mulinde J, et al. Data Integrity in Global Clinical Trials: Discussions From Joint US Food and Drug Administration and UK Medicines and Healthcare Products Regulatory Agency Good Clinical Practice Workshop. *Clin Pharmacol Ther*. 2020;108(5):949-63. doi: 10.1002/cpt.1794.
45. Ministry of Business, Innovation & Employment. Communications and Broadband [Internet]. [cited 2023 Dec 5]. Available from: <https://www.mbie.govt.nz/science-and-technology/it-communications-and-broadband>
46. Australian Commission on Safety and Quality in Healthcare. Economic evaluation of investigator-initiated clinical trials conducted by networks: final report [Internet]. 2017 [cited 2023 Dec 5]. Available from: <https://www.safetyandquality.gov.au/publications-and-resources/resource-library/economic-evaluation-investigator-initiated-clinical-trials-conducted-networks-final-report>
47. Truong K, Kwan YL, Nigro L, et al. Retrospective pharmaceutical financial benefits and cost avoidance analysis of clinical trial participation in the Australian haematology setting. *Intern Med J*. 2019;49(9):1092-1098. doi: 10.1111/imj.14302. Erratum in: *Intern Med J*. 2019 Nov;49(11):1464. doi: 10.1111/imj.14665.

## Appendix

**Appendix Table 1:** Standard operating procedures (SOP) and purposes.

<b>SOP number and name</b>	<b>Purpose of SOP</b>
SOP-01 <b>Decentralised cancer trial processes</b>	To describe the variations to normal clinical trial procedures when undertaking a decentralised clinical trial in New Zealand.
SOP-02 <b>Informed consent</b>	To describe the procedure for obtaining informed consent of participants for enrolment in a clinical trial.
SOP-03 <b>Clinical trial training</b>	To describe the procedure for documenting training that has been undertaken by members of the study teams.
SOP-04 <b>Delegation of duties</b>	To describe the procedure for delegating clinical trial-related duties undertaken by members of the study teams.
SOP-05 <b>Handling investigational products</b>	To describe the procedure for the management of all aspects of the investigational product (IP), either medicinal product or device.
SOP-06 <b>Management of safety information</b>	To describe the procedure related to the management of safety information.
SOP-07 <b>Handling and shipping of biological samples</b>	To describe the procedure for handling and shipping biological samples.
SOP-08 <b>Hosting a regulatory inspection sponsor or other audit</b>	To describe the procedure and activities for facilitating a regulatory inspection, either by the sponsor or an initiated audit by the Health and Disability Ethics Committee (HDEC).
SOP-09 <b>Archiving</b>	To describe the procedure for archiving essential documents for clinical trials for primary site (PS) and satellite site (SS).
SOP-10 <b>Document management version</b>	To describe the procedure for the creation and implementation of standard operating procedures (SOP) documents used for Decentralised Clinical Trials NZ, including version control and tracking amendments.
SOP-11 <b>Essential document management</b>	To describe the procedures relevant to the collection and maintenance of essential documents for clinical trials at the primary site (PS) and satellite site (SS).
SOP-12 <b>Ethics and governance</b>	To describe the procedure for obtaining ethical and governance approval for new and existing decentralised clinical trials.

# Assessing the impact of physical, mental and cognitive impairments on health-related quality of life in sepsis survivors following intensive care admission in New Zealand

Patrice Rosengrave, Jonathan Williman, Geoff Shaw, Anitra C Carr

## ABSTRACT

**AIM:** To assess the impact of physical, mental and cognitive impairments on health-related quality of life (QoL) of individuals who have survived sepsis after admission to an intensive care unit (ICU) in New Zealand.

**METHODS:** Survivors from a trial investigating vitamin C as an adjunctive therapy in patients with sepsis in Christchurch Hospital ICU were invited to enrol in a longitudinal QoL follow-up study. Patients were interviewed at hospital discharge, 30, 90 and 180 days, using validated physical and mental health assessment questionnaires (Short-Form-36, EuroQol-5-Dimension). Cognitive function was monitored and results compared with New Zealand population norms.

**RESULTS:** Eighteen of the 26 survivors participated in the 6-month QoL follow-up. At hospital discharge, there were significant physical and mental health issues in the participants interviewed, and although a majority of the subscales improved over the 6-month follow-up, physical function, role—physical and general health were still below population norms. Following discharge, objective parameters (mobility, self-care, usual activities) normalised within 3–6 months, while subjective measures (pain/discomfort and anxiety/depression) improved earlier and were better than population norms at 3–6 months. Cognitive dysfunction persisted over the follow-up period. Short-term (4-day) vitamin C intervention in the ICU did not affect health parameters post-hospital discharge.

**CONCLUSIONS:** Survivors of septic shock experience elevated physical, mental and cognitive issues at discharge. Most mental health issues had resolved by 6 months, but some physical and cognitive issues had not returned to population norms. Short-term vitamin C administration did not improve long-term health-related QoL; however, ongoing vitamin C supplementation may be required.

Sepsis is a life-threatening response to severe infection characterised by profound circulatory, cellular and metabolic abnormalities.<sup>1</sup> Sepsis has mortality rates greater than 40%, with comorbidities and older age being major contributors.<sup>1</sup> The incidence of sepsis is continuing to grow globally, driven by an ageing population.<sup>2,3</sup> Sepsis is managed through empiric antimicrobial therapy, source control of infection, fluid resuscitation, vasopressor administration and organ support via mechanical ventilation and renal replacement therapy.<sup>4</sup> As a result of both the disease process and invasive interventions in the intensive care unit (ICU), patients who survive sepsis can experience long-term physical disabilities, cognitive dysfunction and psychological issues such as anxiety and depression, which significantly affect their health-related quality of life (QoL) and ability to live independently.<sup>5</sup> There are currently limited

longitudinal data within the first 6 months of hospital discharge, with QoL questionnaires primarily being administered from 6 months onwards.<sup>6–11</sup> Furthermore, there are limited data from a New Zealand context, with many trials comprising mixed cohorts.<sup>6,8,9</sup> To address these gaps in the literature, comprehensive post-discharge QoL data comprising physical, mental and cognitive function measures were collected from a small New Zealand ICU cohort during the first 6 months following hospital discharge and compared with New Zealand population norms.

The QoL follow-up cohort comprised a sub-group from a randomised controlled trial (RCT) investigating the effects of vitamin C as an adjunctive therapy in patients with septic shock.<sup>12</sup> Vitamin C is an essential nutrient with numerous supportive functions in the immune, respiratory, cardiovascular and central nervous systems.<sup>13–15</sup> Critically ill patients with sepsis have severely

depleted circulating concentrations of the vitamin, lower than non-septic patients and only one-third the concentration of the general population,<sup>16</sup> despite recommended enteral and parenteral intakes, suggesting a higher turnover and requirement for the vitamin in these patients.<sup>17</sup> In fact, requirements appear to be at least 10-fold higher than non-hospitalised individuals, with parenteral administration of up to 2–3 grams required to saturate the blood.<sup>18,19</sup> Furthermore, due to vitamin C's water-soluble nature, it is not retained by the body and is lost through urine;<sup>20</sup> therefore, there is an ongoing need for supplementation after hospital discharge.<sup>14</sup>

To our knowledge, no comprehensive studies have assessed the effects of vitamin C intervention on the post-discharge QoL outcomes of survivors of septic shock. Vitamin C administration to critically ill patients with sepsis may improve organ function, as evidenced in various trials by reduced requirements for fluid resuscitation, vasopressor administration, mechanical ventilation and renal replacement therapy,<sup>14,21</sup> which could be anticipated to improve long-term patient QoL. Vitamin C also has numerous important functions in the central nervous system, with neurological tissue containing some of the highest concentrations of vitamin C in the body.<sup>15</sup> Furthermore, observational and interventional studies have shown inverse associations between vitamin C and cognitive dysfunction, as well as mental health disorders such as depression and anxiety.<sup>22,23</sup> Thus, we hypothesised that administering vitamin C to patients with septic shock may improve measures of post-discharge health-related QoL.

## Methods

### Participant enrolment and intervention

The current study comprised a 6-month QoL follow-up of septic shock participants enrolled in an intravenous (IV) vitamin C RCT in Christchurch Hospital, described previously.<sup>12</sup> Ethical approval for the main trial and the follow-up study was obtained from the New Zealand Northern A Health and Disability Ethics Committee (16NTA238). The study was registered with the Australian New Zealand Clinical Trials Registry (ACTRN12617001184369). Participants meeting the study inclusion criteria for septic shock were randomised (1:1) to receive either placebo infusions or up to 96 hours of IV vitamin C (total dose of 100mg/kg/day, administered 6 hourly), as described previously.<sup>12</sup> The clinical study

coordinator, treating physicians and participants were blinded regarding treatment arm.

### Collection of clinical and QoL data

Baseline data were collected between May 2018 and Dec 2019, and QoL follow-up data were collected between June 2018 and August 2020. Clinical data were collected and managed using Research Electronic Data Capture (REDCap), a secure, web-based data collection and storage tool hosted at the University of Otago, New Zealand. Data were de-identified using a patient study code. The following demographic and clinical data were recorded at baseline for the QoL study: age, gender, weight, ethnicity, primary diagnosis contributing to sepsis, comorbidities, ICU mortality and organ function performance scores (simplified acute physiology score [SAPS], acute physiology and chronic health evaluation [APACHE III] and sequential organ failure assessment [SOFA]), and ICU and hospital length of stay (LOS). QoL follow-up data were collected face-to-face at hospital discharge and then via phone call at days 30, 90 and 180 after discharge. Data for half of the patients were captured at hospital discharge, of which only two were in the vitamin C intervention arm.

### Physical and mental health assessment (SF-36)

The Short Form-36 (SF-36, version 2) comprises 36 items to measure eight multi-item QoL domains: physical functioning (PF), role limitation due to physical problems (RP), bodily pain (BP), general health (GH), vitality (VT), social functioning (SF), role limitation due to emotional problems (RE) and mental health (MH).<sup>24</sup> It has demonstrated acceptability, reliability and validity in the ICU<sup>25,26</sup> and has New Zealand norms available.<sup>27</sup> The SF-36 also has two population-normalised summary scores, the Physical Component Summary (PCS) that comprises PF, RP, BP and GH, and the Mental Component Summary (MCS) that comprises VT, SF, RE and MH.<sup>28</sup> These values can be transformed to T-scores and thereby related to a population mean of 50 with each 10-point increment equivalent to a SD from the mean.<sup>28</sup>

### Quality of life assessment (EQ-5D-5L)

The EuroQol 5 Dimension 5 Level (EQ-5D-5L) comprises a visual analogue scale (VAS) and five descriptive multi-item dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression issues.<sup>29</sup> The VAS records the

respondent's self-rated health on an analogue scale with the end points labelled "the best health you can imagine" and "the worst health you can imagine". Each descriptive dimension has five levels: no problems, slight problems, moderate problems, severe problems and extreme problems. These were converted into a single index value using an online calculator<sup>30</sup> and were based on New Zealand population valuation surveys

that used VAS methods.<sup>31</sup>

### Cognitive function assessment (COBRA)

Cognitive dysfunction was assessed using a 16-item self-reported Cognitive Complaints in Bipolar Disorder Rating Assessment (COBRA) questionnaire that measures subjective cognitive dysfunctions of executive function, processing speed, working memory, verbal learning and

**Table 1:** Participant baseline characteristics.

Parameter	Enrolled cohort (n=40)	Survivors (n=26)	QoL sub-group (n=18)
Age (y)	68 (61, 75)	65 (57, 71)	65 (60, 71)
Sex (male)	27 (67)	17 (65)	11 (61)
<b>Ethnicity:</b>			
NZ European	34 (85)	21 (81)	16 (89)
Māori	4 (10)	3 (12)	2 (11)
Pacific peoples	1 (3)	1 (4)	0 (0)
Other	2 (5)	1 (4)	0 (0)
Weight (kg)	80 (69, 98)	85 (72, 101)	94 (76, 107)
<b>Sepsis source:</b>			
Abdominal	14 (35)	11 (42)	9 (50)
Pulmonary	9 (23)	3 (12)	2 (9)
Skin/soft tissue	7 (18)	6 (23)	4 (22)
Blood	7 (18)	3 (12)	3 (16)
Other/unknown	6 (16)	4 (15)	1 (6)
SAPS2	50 (41, 58)	46 (39, 56)	49 (38, 58)
APACHE-III	84 (73, 97)	77 (68, 93)	85 (73, 95)
SOFA score	9.0 (7.0, 10)	9.0 (6.8, 10)	9.0 (6.8, 10)
ICU LOS	5.2 (2.7, 9.4)	4.5 (2.5, 9.8)	3.9 (2.4, 8.4)
Hospital LOS	13 (8, 31)	16 (9, 35)	14 (9, 29)
Number with comorbidities	9 (23)	7 (27)	5 (28)

Data represent n (%) or median (Q1, Q3).

APACHE = acute physiology and chronic health evaluation; ICU = intensive care unit; LOS = length of stay; QoL = quality of life; SOFA = sequential organ failure assessment; SAPS = simplified acute physiology score.



memory, attention/concentration and mental tracking.<sup>32</sup> All of the questions are rated using a 4-point scale: 0 = never, 1 = sometimes, 2 = often and 3 = always. The total score is obtained when the scores of each question are combined. Higher scores indicate the patient was experiencing more subjective complaints, the maximum score being 48 points.

### Statistical analyses

Participant characteristics were summarised using descriptive statistics with continuous variables presented as mean or median and 95% confidence intervals (95% CI) or mean and standard deviation (SD), as indicated, and categorical variables as number and percentage. Correlations were carried out using Spearman's coefficient, with  $p < 0.05$  indicating statistical significance. Time course data were analysed using repeated measures mixed effects models (with Geisser–Greenhouse correction) and Tukey *post hoc* analyses to correct for multiple comparisons. Statistical analyses and graphical outputs were generated using GraphPad Prism 9 (GraphPad, San Diego, CA, USA).

## Results

### Participant characteristics

Of the cohort of 40 participants enrolled in the main vitamin C RCT, hospital mortality was 35% ( $n=14$ ).<sup>12</sup> Of the 26 survivors, 18 (69%) enrolled in the 6-month QoL follow-up phase, with data for half of these participants captured at discharge. The baseline characteristics of the full cohort, survivors and the QoL sub-group are shown in Table 1. The median (IQR) age of the QoL participants was 65 (60, 71) and 61% were male. The predominant sources of sepsis were abdominal (50%), skin/soft tissue (22%) and blood (16%). The median (IQR) SAPS2 score was 49 (38, 58), APACHE-III score was 85 (73, 95) and SOFA score was 9.0 (6.8, 10).

### Physical and mental health

The SF-36 questionnaire was used to assess the physical and mental health of the participants over the 6 months following discharge from hospital. All subscales were lower than New Zealand norms at discharge but improved over time, although bodily pain, role—emotional and mental health did not change significantly (Table 2). However,

**Table 2:** SF-36 findings for the total QoL cohort.

	Hospital discharge	30 days	90 days	180 days	P-value	New Zealand norms
	( $n=9$ )	( $n=18$ )	( $n=17$ )	( $n=18$ )		( $n=12,378$ )
Physical function (PF)	31 (13, 49)	52 (41, 64)	60 (46, 75)	70 (57, 84)	0.001	86 (22)
Role—physical (RP)	3 (-4, 9)	19 (3, 36)	43 (23, 62)	61 (42, 80)	<0.001	86 (23)
Bodily pain (BP)	47 (14, 79)	69 (54, 84)	65 (48, 81)	76 (61, 92)	0.1	75 (24)
General health (GH)	38 (21, 55)	47 (34, 60)	59 (46, 71)	62 (51, 73)	0.002	75 (20)
Vitality (VT)	39 (20, 59)	51 (42, 61)	58 (46, 70)	67 (56, 78)	0.01	64 (18)
Social functioning (SF)	40 (15, 66)	55 (42, 68)	78 (67, 94)	87 (74, 100)	<0.001	88 (21)
Role—emotional (RE)	59 (21, 97)	67 (46, 87)	78 (61, 96)	91 (81, 100)	0.1	94 (15)
Mental health (MH)	67 (50, 84)	78 (68, 88)	83 (73, 92)	84 (75, 92)	0.1	82 (13)

Data represent mean and 95% CI. P-value is for trend over time (mixed effects model). New Zealand norms were from Frieling et al.<sup>27</sup> and represent mean (SD).  
QoL = quality of life; SF-36 = Short Form-36.

even after 6 months, physical function, role—physical and general health appeared lower than New Zealand norms, whereas the emotional wellbeing parameters (vitality, social functioning, role—emotional and mental health) appeared comparable to New Zealand norms after 6 months. The physical component summary (PCS) was less than two-thirds of the New Zealand norm at discharge, while the mental component summary (MCS) was three-quarters of the New Zealand norm. Both the PCS and MCS improved significantly over time ( $p < 0.006$ ; Table 3).

### Quality of life

At hospital discharge, 75–100% of the survivors had problems with mobility, self-care, usual activities, pain/discomfort and anxiety/depression, as determined by the EQ-5D (Table 4). Mobility, self-care and usual activities continued to improve

over the 6-month follow-up period and became comparable to New Zealand norms (Figures 1A–C), while the subjective measures of pain/discomfort and anxiety/depression improved earlier and were better than population norms at 6 months (Figures 1D and E). The EQ-5D index score, a composite of the individual parameters, was observed to increase over time ( $p = 0.04$ ; Table 5). Similarly, the participant visual analogue scale (VAS) scores improved over time ( $p = 0.003$ ). There was a significant positive correlation between the EQ-5D index and VAS values ( $r = 0.77$  [0.64, 0.86],  $p < 0.0001$ ).

### Cognitive function

Cognitive dysfunction remained unchanged from hospital discharge for 6 months (mean [95% CI] scores of 13 [6, 20] points at discharge, 11 [8, 14] at 30 and 90 days, and 10 [6, 15] by 6 months;

**Table 3:** Summary T-scores of self-reported physical and mental health measures for the SF-36v2.

	Hospital discharge	30 days	90 days	180 days	P-value	Population norm
	(n=9)	(n=18)	(n=17)	(n=18)		
Physical component summary (PCS)	31 (8)	37 (10)	41 (11)	45 (11)	<0.001	50 (10)
Mental component summary (MCS)	38 (12)	43 (10)	47 (11)	52 (10)	0.006	50 (10)

Data represent mean and SD. P value is for trend over time (mixed effects model).  
SF-36v2 = Short Form-36, version 2.

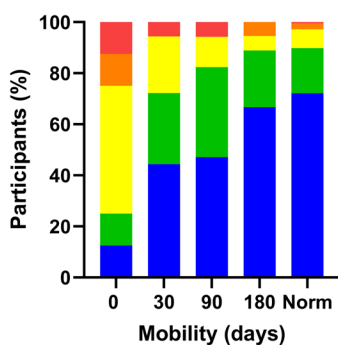
**Table 4:** Participant summary of self-rated physical and mental health measures as assessed by the EQ-5D.

	Hospital discharge	30 days	90 days	180 days	P-value	New Zealand norms
	(n=8)	(n=18)	(n=17)	(n=18)		(n=2,468)
Mobility	88	56	53	33	0.03	28
Self-care	75	28	6	11	0.01	9
Usual activities	100	67	35	28	0.004	30
Pain/discomfort	75	59	41	39	0.1	62
Anxiety/depression	75	33	33	28	0.08	46

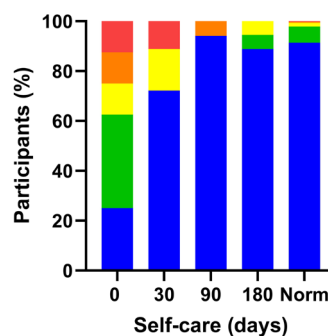
Data represent percentage (%) with physical and mental health issues. P-value is for trend over time (mixed effects model). New Zealand norms were from Sullivan et al.<sup>33</sup>  
EQ-5D = EuroQol 5 Dimension.

**Figure 1:** The proportion of participants with health problems for A) mobility, B) self-care, C) usual activities, D) pain/discomfort and E) anxiety/depression over 6-month period post-discharge. Problems were graded as none (blue), slight (green), moderate (yellow), severe (orange) or extreme (red). “Norm” is New Zealand norm values from Sullivan et al.<sup>33</sup>

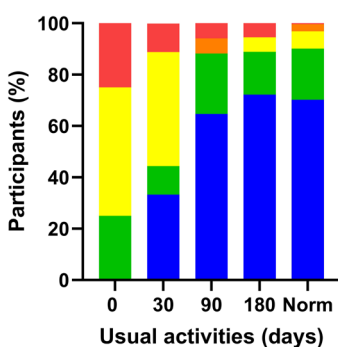
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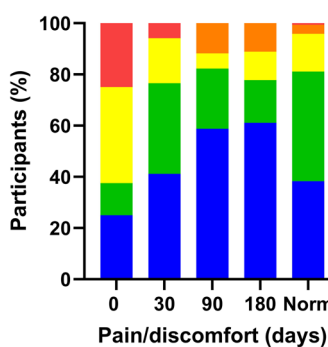
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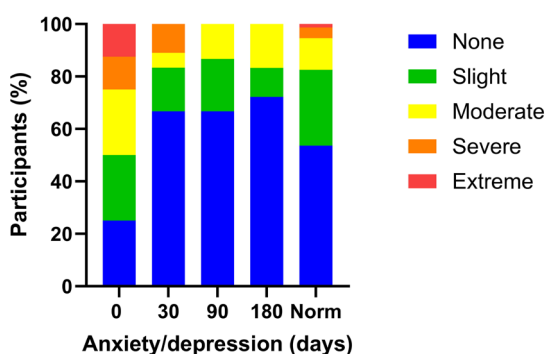
C



D



E



**Table 5:** The EQ-5D index and VAS scores.

	Hospital discharge	30 days	90 days	180 days	P-value	New Zealand norms
	(n=8)	(n=18)	(n=17)	(n=18)		(n=2,468)
EQ-5D index (%)	37 (11, 63)	61 (47, 75)	70 (53, 87)	76 (60, 91)	0.04	85 (24)
VAS (%)	51 (32, 69)	60 (47, 72)	71 (59, 82)	80 (72, 88)	0.003	75 (18)

Data represent mean and 95% CI. P value is for trend over time (mixed effects model). New Zealand norms were from Sullivan et al.<sup>33</sup> and represent mean (SD).

EQ-5D = EuroQol 5 Dimension; VAS = visual analogue scale.

p=0.6). The proportion of participants with a score >14 points was 30% at baseline and 33% at 6 months.

### Effect of vitamin C intervention

Although short-term (4-day) intravenous vitamin C administration appeared to improve median SF-36 PCS scores post-discharge, these were not significantly different to placebo (Figure 2A). No significant difference between vitamin C and placebo was observed for MCS scores post-discharge (Figure 2B). Vitamin C intervention also did not have any effect on the EQ-5D index or VAS scores post-discharge (Figures 2C and D), or the individual physical and mental parameters (p>0.05). There was no significant effect of short-term vitamin C intervention on COBRA scores post-discharge relative to placebo (Figure 2E).

## Discussion

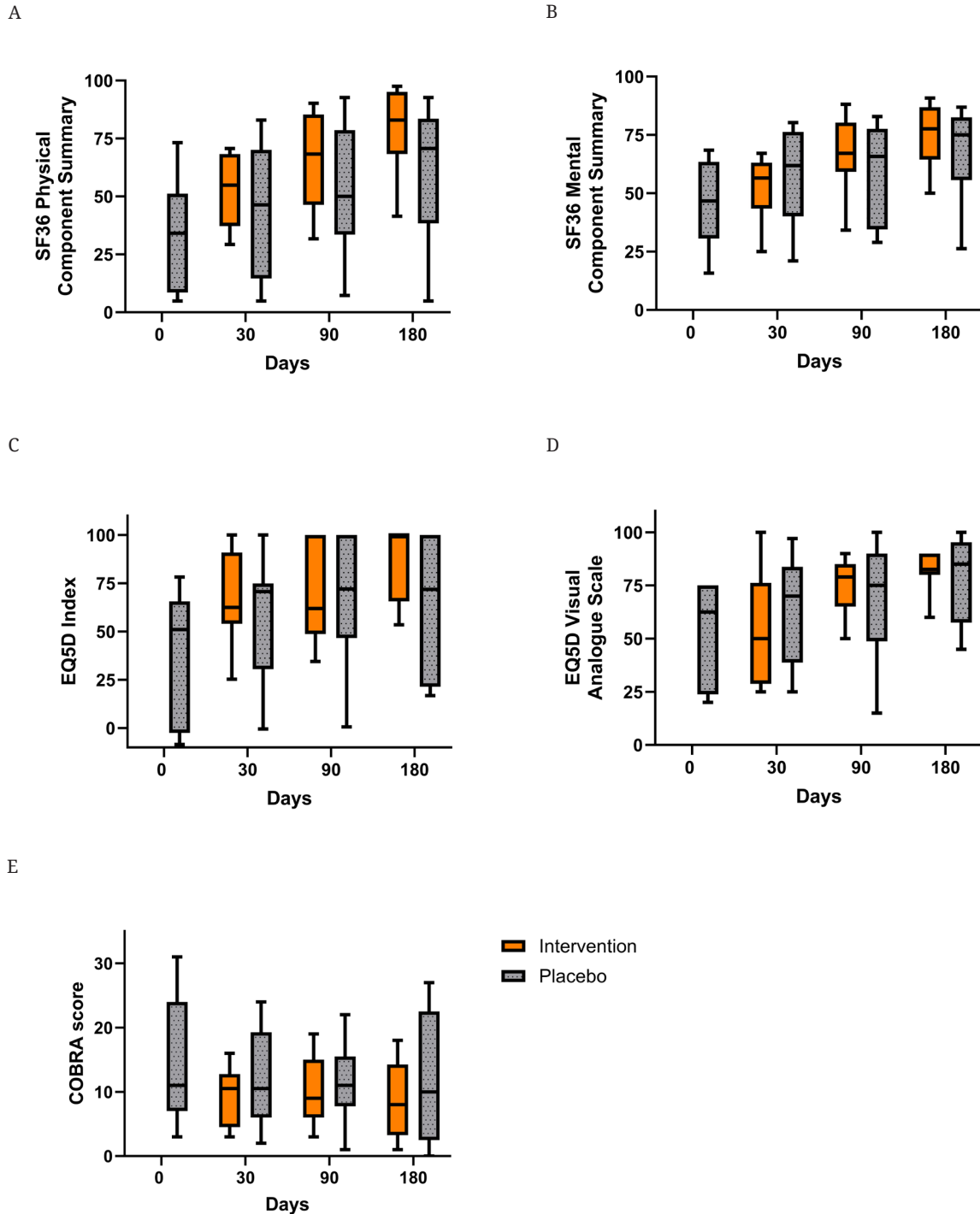
This study is the first comprehensive and systematic assessment of health-related QoL and its various domains following ICU admission for survivors of sepsis in New Zealand. The study monitored the post-hospital discharge impact of physical, mental and cognitive issues on the health-related QoL trajectory of survivors of septic shock over a 6-month period. In agreement with Heyland et al.,<sup>26</sup> who assessed the QoL of 30 sepsis survivors after hospital discharge in Ontario using the SF-36 health domains, we observed dramatically lower physical and mental health subscale scores at discharge compared with New Zealand norms, with physical health generally scoring lower than mental health. Most of these scores improved over the 6-month follow-up period, although the physical function, role—physical and general health scores still appeared

lower than population norms after 6 months. In contrast, the mental health scores had recovered to population norms within this time.

The SF-36 data was supported by EQ-5D data, which also showed a high proportion of physical and mental health issues at discharge, with improvements in mobility, self-care and usual activities to New Zealand norms within 6 months. Interestingly, the more subjective issues of pain/discomfort and anxiety/depression appeared to improve beyond New Zealand norms. This could reflect the small sample size and/or selection bias. Alternatively, subjective measures relate to perceived health and, following a severe illness, participants may feel they are in much better health relative to how they felt at discharge, resulting in higher scores than New Zealand norm populations, who have not experienced a life-threatening illness to compare their current subjective state against.<sup>34</sup> Other researchers have shown comparable EQ-5D results between survivors of sepsis and non-sepsis survivors,<sup>11,35</sup> although older patients in the sepsis group had a higher prevalence of problems.<sup>35</sup>

Survivors of severe sepsis can have substantial and long-term cognitive impairment,<sup>36</sup> and research suggests that the combination of cognitive complaints and depressive symptoms can negatively impact on health-related QoL.<sup>37</sup> We used the COBRA to assess cognitive dysfunction; this has not previously been used in an ICU cohort, although data exist for ~500 non-hospitalised adults.<sup>37,38</sup> Our septic cohort had a mean (SD) post-discharge COBRA score of 13 (10) relative to a non-hospitalised mean (SD) COBRA score of 8.5 (6.5).<sup>38</sup> Furthermore, 30% of the septic cohort had a COBRA score greater than 14, relative to 18% in non-hospitalised adults.<sup>38</sup> Cognitive impairment in the survivors of sepsis was still present at 6

**Figure 2:** Effect of vitamin C intervention on physical and mental quality of life and cognitive function post-hospital discharge. A) The physical component summary (PCS) comprised physical function (PF), role—physical (RP), bodily pain (BP) and aspects of general health (GH). B) The mental component summary (MCS) comprised general health (GH), vitality (VT), social functioning (SF), role—emotional (RE) and mental health (MH). C) EQ-5D index comprising mobility, self-care, usual activities, pain/discomfort and anxiety depression (converted to percentages). D) EQ-5D visual analogue scale (VAS). E) Cognitive function (COBRA) scores. Grey bars = placebo (n=7–10), orange bars = intervention (n=8). Day 0 data are not shown for the vitamin C arm as n=2. Bars represent median and 25<sup>th</sup> and 75<sup>th</sup> percentiles, and error bars the range.



months, and has been reported to persist for up to 8 years.<sup>36</sup> Thus, abnormal cognitive function appears to persist for significantly longer than subjective mood issues. Furthermore, the slow neuro-recovery, in combination with lower physical health, may impact on the survivor's ability to live independently.<sup>36</sup>

Pre-clinical studies suggest that vitamin C may act as a neuroprotective agent through improving biomarkers of neuroprotection, functional outcomes and mortality.<sup>39</sup> Although these results have not been translated to all human studies, the clinical trials used approximately one-tenth of the vitamin C doses relative to the animal studies. Thus, high-dose IV vitamin C may be anticipated to be more effective at preserving neurological function. However, the participants in the current trial who were randomised to 4 days of 100mg/kg/day intravenous vitamin C administration did not appear to have any improvement in post-discharge cognitive function relative to placebo participants, as was also reported recently with combination therapy.<sup>40</sup> Furthermore, there were no apparent effects of short-term vitamin C administration on post-discharge physical and mental health parameters as determined by the SF-36 and EQ-5D, as was also previously reported for intravenous hydrocortisone administration relative to placebo.<sup>8</sup> However, prior research in critically ill patients has indicated a rapid drop in vitamin C to baseline concentrations following withdrawal of intervention.<sup>19,41</sup> Thus, ongoing oral vitamin C supplementation following cessation of intravenous administration may be required to maintain adequate circulating concentrations to support normal vitamin C-dependent bodily functions.<sup>42</sup>

This research had several limitations, including the relatively small numbers of participants recruited to the QoL follow-up, although clear trends in QoL were still observed over time despite this. However, due to the small numbers, we were unable to correlate clinical parameters

with QoL outcomes. Although this is the first study describing sepsis recovery in a New Zealand cohort, it is an ICU cohort, which is a treated rather than a true population of people with sepsis. Thus, the outcomes of the larger non-ICU population with sepsis may not be the same as reported in the current study. Another limitation was the use of COBRA to assess cognitive function of the participants as, to our knowledge, this has not previously been tested in ICU cohorts, being primarily used for participants with bipolar disorder. Nevertheless, it has previously been used for non-hospitalised adults.<sup>37,38</sup> A further limitation of the research was the inability to continue supplementing the participants with oral vitamin C or placebo following hospital discharge due to the main RCT protocol parameters.<sup>12</sup>

Overall, our QoL study provides novel descriptive findings relating to the trajectory of sepsis recovery in a New Zealand cohort, and highlights the long-lasting consequences of sepsis, emphasising the need for ongoing support post-hospital discharge to address the physical, mental and cognitive challenges faced by survivors. The participants had severe physical and mental health issues at hospital discharge, and although many subscales improved over the 6-month study period, particularly the mental health subscales, some physical health subscales remained below New Zealand norms. Cognitive dysfunction was worse than non-hospitalised adults, with a much higher proportion of post-septic participants having COBRA scores of greater than 14. Cognitive dysfunction persisted over the 6-month study period. Short-term intravenous vitamin C administration had no effect on the post-hospital discharge physical, mental or cognitive parameters, but future research should also focus on assessing the QoL measures of sepsis survivors who receive sufficient ongoing vitamin C administration to maintain adequate circulating plasma concentrations post-hospital discharge.

**COMPETING INTERESTS**

Nil.

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**AUTHOR INFORMATION**

Patrice Rosengrave: Research Fellow, Department of Pathology and Biomedical Science, University of Otago, Christchurch; Lecturer, Department of Nursing, University of Otago, Christchurch.

Jonathan Williman: Biostatistician, Department of Population Health, University of Otago, Christchurch.

Geoff Shaw: Intensivist, Department of Intensive Care, Te Whatu Ora – Health New Zealand Waitaha Canterbury.

Anitra C Carr: Research Professor and Director of Nutrition in Medicine Research Group, Department of Pathology and Biomedical Science, University of Otago, Christchurch.

Author contributions: Conceptualisation, AC, PR and GS; data collection, PR; data analyses, AC and JW; funding acquisition, AC and PR; writing paper, AC; editing paper, PR, JW and GS.

**CORRESPONDING AUTHOR**

Anitra C Carr: Department of Pathology and Biomedical Science, University of Otago, Christchurch, PO Box 4345, Christchurch 8140, New Zealand. Ph: +64 3 364 0649. E: anitra.carr@otago.ac.nz

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**REFERENCES**

- Singer M, Deutschman CS, Seymour CW, et al. The third international consensus definitions for sepsis and septic shock (Sepsis-3). *JAMA*. 2016;315(8):801-10. doi: 10.1001/jama.2016.0287.
- Kadri SS, Rhee C, Strich JR, et al. Estimating Ten-Year Trends in Septic Shock Incidence and Mortality in United States Academic Medical Centers Using Clinical Data. *Chest*. 2017;151(2):278-85. doi: 10.1016/j.chest.2016.07.010.
- Lakbar I, Munoz M, Pauly V, et al. Septic shock: incidence, mortality and hospital readmission rates in French intensive care units from 2014 to 2018. *Anaesth Crit Care Pain Med*. 2022;41(3):101082. doi: 10.1016/j.accpm.2022.101082.
- Rhodes A, Evans LE, Alhazzani W, et al. Surviving sepsis campaign: international guidelines for management of sepsis and septic shock: 2016. *Intensive Care Med*. 2017;43(3):304-377. doi: 10.1007/s00134-017-4683-6.
- Prescott HC, Angus DC. Enhancing Recovery From Sepsis: A Review. *JAMA*. 2018;319(1):62-75. doi: 10.1001/jama.2017.17687.
- Higgins AM, Peake SL, Bellomo R, et al. Quality of Life and 1-Year Survival in Patients With Early Septic Shock: Long-Term Follow-Up of the Australasian Resuscitation in Sepsis Evaluation Trial. *Crit Care Med*. 2019;47(6):765-73. doi: 10.1097/CCM.0000000000003762.
- Cuthbertson BH, Elders A, Hall S, et al. Mortality and quality of life in the five years after severe sepsis. *Crit Care*. 2013;17(2):R70. doi: 10.1186/cc12616.
- Hammond NE, Finfer SR, Li Q, et al. Health-related quality of life in survivors of septic shock: 6-month follow-up from the ADRENAL trial. *Intensive Care Med*. 2020;46(9):1696-706. doi: 10.1007/s00134-020-06169-1.
- Yende S, Austin S, Rhodes A, et al. Long-term quality of life among survivors of severe sepsis: Analyses of two international trials. *Crit Care Med*. 2016;44(8):1461-7. doi: 10.1097/CCM.0000000000001658.
- Karlsson S, Ruokonen E, Varpula T, et al. Long-term outcome and quality-adjusted life years after severe sepsis. *Crit Care Med*. 2009;37(4):1268-74. doi: 10.1097/CCM.0b013e31819c13ac.
- Granja C, Dias C, Costa-Pereira A, et al. Quality of life of survivors from severe sepsis and septic shock may be similar to that of others who survive critical illness. *Crit Care*. 2004;8(2):R91-8. doi: 10.1186/cc2818.
- Rosengrave P, Spencer E, Williman J, et al. Intravenous vitamin C administration to patients with septic shock: a pilot randomised controlled trial. *Crit Care*. 2022;26(1):26. doi: 10.1186/s13054-022-03900-w.
- Carr AC, Maggini S. Vitamin C and immune function. *Nutrients*. 2017;9(11):E1211. doi: 10.3390/nu9111211.
- Carr AC. Vitamin C in pneumonia and sepsis. In: Chen Q, Vissers M, editors. *Vitamin C: New Biochemical and Functional Insights*. Oxidative Stress and Disease. Boca Raton, FL CRC Press/Taylor & Francis; 2020. p. 115-35.
- May JM. Vitamin C transport and its role in the central nervous system. *Subcell Biochem*.

- 2012;56:85-103. doi: 10.1007/978-94-007-2199-9\_6.
16. Pearson JF, Pullar JM, Wilson R, et al. Vitamin C status correlates with markers of metabolic and cognitive health in 50-year-olds: Findings of the CHALICE cohort study. *Nutrients*. 2017;9(8):831. doi: 10.3390/nu9080831.
17. Carr AC, Rosengrave PC, Bayer S, et al. Hypovitaminosis C and vitamin C deficiency in critically ill patients despite recommended enteral and parenteral intakes. *Crit Care*. 2017;21(1):300. doi: 10.1186/s13054-017-1891-y.
18. Long CL, Maull KI, Krishnan RS, et al. Ascorbic acid dynamics in the seriously ill and injured. *J Surg Res*. 2003;109(2):144-8. doi: 10.1016/s0022-4804(02)00083-5.
19. de Grooth HJ, Manubulu-Choo WP, Zandvliet AS, et al. Vitamin C pharmacokinetics in critically ill patients: a randomized trial of four intravenous regimens. *Chest*. 2018;153(6):1368-77. doi: 10.1016/j.chest.2018.02.025.
20. Lykkesfeldt J, Tveden-Nyborg P. The pharmacokinetics of vitamin C. *Nutrients*. 2019;11(10):2412. doi: 10.3390/nu11102412.
21. Carr AC. Vitamin C administration in the critically ill: a summary of recent meta-analyses. *Crit Care*. 2019;23(1):265. doi: 10.1186/s13054-019-2538-y.
22. Travica N, Ried K, Sali A, et al. Vitamin C status and cognitive function: A systematic review. *Nutrients*. 2017;9(9):960. doi: 10.3390/nu9090960.
23. Kocot J, Luchowska-Kocot D, Kielczykowska M, et al. Does vitamin C influence neurodegenerative diseases and psychiatric disorders? *Nutrients*. 2017;9(7):659. doi: 10.3390/nu9070659.
24. RAND. 36-Item Short Form Survey (SF-36) Scoring Instructions [Internet]. Santa Monica, CA (US): RAND; 2024 [cited 2021 Feb 16]. Available from: [https://www.rand.org/health-care/surveys\\_tools/mos/36-item-short-form/scoring.html](https://www.rand.org/health-care/surveys_tools/mos/36-item-short-form/scoring.html)
25. Chrispin PS, Scotton H, Rogers J, et al. Short Form 36 in the intensive care unit: assessment of acceptability, reliability and validity of the questionnaire. *Anaesthesia*. 1997;52(1):15-23. doi: 10.1111/j.1365-2044.1997.015-az014.x.
26. Heyland DK, Hopman W, Coe H, et al. Long-term health-related quality of life in survivors of sepsis. Short Form 36: a valid and reliable measure of health-related quality of life. *Crit Care Med*. 2000;28(11):3599-605. doi: 10.1097/00003246-200011000-00006.
27. Frieling MA, Davis WR, Chiang G. The SF-36v2 and SF-12v2 health surveys in New Zealand: norms, scoring coefficients and cross-country comparisons. *Aust N Z J Public Health*. 2013;37(1):24-31. doi: 10.1111/1753-6405.12006.
28. Andersen JR, Breivik K, Engelund IE, et al. Correlated physical and mental health composite scores for the RAND-36 and RAND-12 health surveys: can we keep them simple? *Health Qual Life Outcomes*. 2022;20(1):89. doi: 10.1186/s12955-022-01992-0.
29. van Reenen M, Janssen B. EQ-5D-5L User Guide: Basic information on how to use the EQ-5D-5L instrument. Rotterdam (NL): EuroQol Research Foundation; 2015.
30. The Economics Network. EQ-5D index calculator [Internet]. UK: The Economics Network; 2024 [cited 2024 Apr 2]. Available from: [https://www.economicsnetwork.ac.uk/health/EQ\\_5D\\_index\\_calculator.xls](https://www.economicsnetwork.ac.uk/health/EQ_5D_index_calculator.xls)
31. EQ-5D Value Sets: Inventory, Comparative Review and User Guide. NL: Springer Dordrecht; 2007.
32. Rosa AR, Mercadé C, Sánchez-Moreno J, et al. Validity and reliability of a rating scale on subjective cognitive deficits in bipolar disorder (COBRA). *J Affect Disord*. 2013;150(1):29-36. doi: 10.1016/j.jad.2013.02.022.
33. Sullivan T, Turner RM, Derrett S, et al. New Zealand Population Norms for the EQ-5D-5L Constructed From the Personal Value Sets of Participants in a National Survey. *Value Health*. 2021;24(9):1308-18. doi: 10.1016/j.jval.2021.04.1280.
34. Weech-Maldonado R, Miller MJ, Lord JC. The Relationships Among Socio-Demographics, Perceived Health, and Happiness. *Appl Res Qual Life*. 2017;12(2):289-302. doi: 10.1007/s11482-017-9517-8.
35. Contrin LM, Paschoal VD, Beccaria LM, et al. Quality of life of severe sepsis survivors after hospital discharge. *Rev Lat Am Enfermagem*. 2013;21(3):795-802. doi: 10.1590/S0104-11692013000300020.
36. Iwashyna TJ, Ely EW, Smith DM, et al. Long-term cognitive impairment and functional disability among survivors of severe sepsis. *JAMA*. 2010;304(16):1787-94. doi: 10.1001/jama.2010.1553.
37. Toyoshima K, Inoue T, Baba T, et al. Associations of Cognitive Complaints and Depressive Symptoms with Health-Related Quality of Life and Perceived Overall Health in Japanese Adult Volunteers. *Int J Environ Res Public Health*. 2021;18(18):9647. doi: 10.3390/ijerph18189647.
38. Toyoshima K, Inoue T, Shimura A, et al. Associations between the depressive symptoms, subjective cognitive function, and presenteeism of Japanese adult workers: a cross-sectional survey study. *Biopsychosoc Med*. 2020;14:10.
39. Kangisser L, Tan E, Bellomo R, et al. Neuroprotective properties of vitamin C: A Scoping Review of pre-clinical and clinical studies. *J Neurotrauma*.



- 2021;38(16):2194-2205. doi: 10.1089/neu.2020.7443.
40. Williams Roberson S, Nwosu S, Collar EM, et al. Association of Vitamin C, Thiamine, and Hydrocortisone Infusion With Long-term Cognitive, Psychological, and Functional Outcomes in Sepsis Survivors: A Secondary Analysis of the Vitamin C, Thiamine, and Steroids in Sepsis Randomized Clinical Trial. *JAMA Netw Open*. 2023;6(2):e230380. doi: 10.1001/jamanetworkopen.2023.0380. Erratum in: *JAMA Netw Open*. 2023 Apr 3;6(4):e2312173. doi: 10.1001/jamanetworkopen.2023.12173.
41. Fowler AA 3rd, Truwit JD, Hite RD, et al. Effect of vitamin C infusion on organ failure and biomarkers of inflammation and vascular injury in patients with sepsis and severe acute respiratory failure: The CITRIS-ALI randomized clinical trial. *JAMA*. 2019;322(13):1261-70. doi: 10.1001/jama.2019.11825. Erratum in: *JAMA*. 2020 Jan 28;323(4):379. doi: 10.1001/jama.2019.21469.
42. Carr AC, Vlasjuk E, Zawari M, et al. Low Vitamin C Concentrations in Patients with Community-Acquired Pneumonia Resolved with Pragmatic Administration of Intravenous and Oral Vitamin C. *Antioxidants (Basel)*. 2023;12(8):1610. doi: 10.3390/antiox12081610.

# A laboratory-developed extraction free real-time PCR for Group A *Streptococcus* in throat swabs: greater detection and faster results

Rebecca Lucas, Emma Tapp, Rumbi Chimwayange, Luiza Hermoso, Matthew R Blakiston

## ABSTRACT

**AIM:** This work describes the validation of an in-house extraction free real-time polymerase chain reaction (PCR) for the detection of Group A *Streptococcus* (GAS) in throat swabs collected in general practices.

**METHOD:** Throat swabs received by the laboratory were prospectively tested by routine bacterial culture and an in-house PCR assay targeting the GAS *SpeB* gene with a multiplexed RNaseP internal control. Samples with discrepant culture/PCR results had additional testing using the commercial Xpert Group A Strep PCR assay (Cepheid). Post-introduction of the in-house GAS PCR the comparative laboratory turn-around time between PCR and historic culture results was determined.

**RESULTS:** Of the 1,093 throat swabs included in the final analysis, GAS was detected by culture and GAS PCR in 262 (24.0%) and 319 (29.2%) respectively. The overall, positive and negative agreement of the GAS PCR with culture was 94.2%, 98.9% and 92.8% respectively. Of the 63 discordant samples, one (33.3%) of three culture positive/in-house PCR negative samples and 56 (93.3%) of 60 culture negative/in-house PCR positive samples were GAS positive on the Xpert Group A Strep assay. Median turn-around time from laboratory receipt to result decreased from 44 to 16 hours with the introduction of the GAS PCR into routine practice. Forty-five percent of samples came from European patients and 25% from persons aged over 30 years, suggesting over-testing in persons at low risk of GAS pharyngitis complications.

**CONCLUSION:** The in-house GAS PCR provided greater and faster detection of GAS from throat swabs compared to culture. However, throat swabbing for GAS needs to be better targeted to those populations at high risk of post-GAS pharyngitis complications.

Group A *Streptococcus* (GAS) is a common cause of acute pharyngitis, responsible for up to 30% and 10% of cases in children and adults respectively.<sup>1</sup> Group A *Streptococcus* pharyngitis is mostly self-limiting, with suppurative complications including peritonsillar abscess, mastoiditis and otitis media occurring in a small minority.<sup>2</sup> However, most important in the Aotearoa New Zealand setting are the post-infectious autoimmune sequelae of rheumatic fever (RF) and post-streptococcal glomerulonephritis (PSGN).<sup>2</sup> Aotearoa New Zealand has a high and inequitably distributed rate of RF, with a pre-COVID (and the associated non-pharmaceutical interventions) incidence of 28.6/100,000 and 83.2/100,000 for Māori and Pacific children (5–14 years) respectively, compared to <1/100,000 in children of European and other ethnicities.<sup>3</sup>

The Aotearoa New Zealand sore throat guidelines recommend a throat swab for bacterial culture and the prescription of empiric antimicrobials for patients at high risk of RF.<sup>4</sup> Laboratory testing

is utilised to make a diagnosis, as clinical presentation does not reliably distinguish GAS from other non-RF associated bacterial or viral causes of pharyngitis.<sup>5</sup> The extended turn-around time of current culture-based testing favours empiric as opposed to diagnostics directed therapy. The use of nucleic acid amplification tests (NAATs) for GAS has, however, been expanding in recent years, including in Aotearoa New Zealand, and these methods have the advantages of a decreased turn-around time, improved sensitivity and potential labour savings.<sup>1,6–8</sup> The use of a molecular GAS assay, with an associated decrease in turn-around time, could also facilitate less unnecessary antimicrobial use (through either less empiric therapy or the ability to stop antimicrobials if GAS PCR is negative) while allowing prompt treatment when required.<sup>1,2</sup> The cost of commercial NAATs for GAS are currently prohibitive for implementation of large-scale testing in the community setting. However, the use of a laboratory-developed extraction free PCR assay that can be performed

on routinely utilised gel amies throat swabs can help overcome this cost barrier.

Medlab Central is a diagnostic laboratory located in Palmerston North, Aotearoa New Zealand, and tests hospital and community samples from the MidCentral, Tairāwhiti and Whanganui health districts. The annual number of throat swabs processed by the laboratory is approximately 23,000. This study describes the validation of an in-house GAS PCR as compared to routine bacterial culture.

## Methods

This was a prospective study comparing the performance of an in-house real-time GAS PCR versus bacterial culture using throat swabs collected as part of routine clinical care. The study used a predefined sample size of 1,094 consecutive throat swabs received by the laboratory from 4 September 2023. The sample size was calculated on a 95% confidence level, 2% margin of error and the local 2022 prevalence of GAS in throat swabs of 13.1%. Demographic data (age, sex, ethnicity and health district) for each sample/patient were extracted from clinical records. Throat swabs (Copan 108C rayon swabs, gel amies without charcoal) were collected and underwent routine culture on sheep blood agar with 3% NaCl. Plates were incubated for 48 hours with reading at 24 and 48 hours. After a standard 1-week clinical sample retention period, the swabs were tested on the GAS PCR. The template for PCR was created by swirling the throat swab in 500µL of phosphate-buffered saline (PBS) for 5–10 seconds.

The in-house GAS real-time PCR assay was a multiplex assay with a GAS target and an RNaseP internal control. The GAS primers targeted the *SpeB* gene with primer and probe sequences and cycling conditions as described by Dunne et al.<sup>9</sup> The probe fluorophore was changed from Cy3 to FAM. The internal control utilised RNaseP primer and probe sequences as per the Centers for Disease Control and Prevention (CDC) SARS-CoV-2 multiplex assay with Cal Fluor orange 610 as the fluorophore.<sup>10</sup> The PCR was run in 10µL reactions with each reaction made to contain: 100nM forward and reverse *SpeB* primers, 150nM *SpeB* probe, 200nM forward and reverse RNaseP primers, 300nM RNaseP probe and 1X PerfeCTa ToughMix (Quantabio). Each reaction used 2µL of the PBS template described above. PCR was performed on MIC induction cyclers (BMS) using the following conditions: 95°C for 3 minutes, then 40 cycles

of 95°C for 20 seconds followed by 60°C for 20 seconds. To determine the assay limit of detection, DNA extracted from pure GAS culture containing 100,000 copies of GAS was used (with DNA concentration determined by nanodrop). Four tenfold serial dilutions were made, and PCR was performed in duplicate at 100,000, 10,000, 1,000 copies, four times at 100 copies, and eight times at 10 copies. The specificity of the assay was tested using extracted DNA from culture isolates of the following organisms; Group C/G *Streptococcus* (n=25), Group B *Streptococcus* (n=10), viridans *Streptococci* (n=10), *Escherichia coli* (n=10), *Staphylococcus aureus* (n=10), *Enterococcus* species (n=11), *Pseudomonas aeruginosa* (n=10), *Candida albicans* (n=10), *Neisseria gonorrhoeae* (n=1) and *Haemophilus influenzae* (n=10).

Samples were considered PCR-positive for GAS if there was amplification of the *SpeB* GAS target regardless of the RNaseP internal control result. Samples were considered negative for GAS if there was no amplification of the *SpeB* GAS target and a Ct value of <37.00 for the internal control. Samples negative for GAS with an internal control Ct of ≥37.00 were subject to repeat PCR. If repeat PCR gave the same result, they were subject to additional PCR using a spike control containing human DNA to assess for inhibition. 20µL of the spike control was added to the PBS solution for each sample and the PCR repeated in parallel with a PBS blank containing 20µL spike in 500µL PBS. Samples with RNaseP (internal control) Ct >2 cycles above the PBS blank were considered inhibitory and the GAS result invalid. Samples with discordant results between culture and the in-house GAS PCR were tested using the Xpert Group A strep PCR assay (Cepheid).

The percent agreement between culture and the in-house GAS PCR was described. Post-introduction into practice, the turn-around time from receipt in laboratory to reporting of the result was also compared between the culture-based period of testing in January 2023 to PCR-based period of testing in January 2024. Study approval was obtained from the New Zealand Health and Disability Commission Ethics Committee (HDEC approval: 2023 FULL 18386).

## Results

The assay could reliably detect 100 copies of GAS and showed good linearity over the range of 10<sup>2</sup> to 10<sup>5</sup> copies. No non-specific amplification was observed with any of the non-GAS organisms

tested. Of the 1,094 samples tested, 1,083 produced a valid initial PCR result. Eleven *SpeB* and RNaseP negative samples required additional testing with the spike control, with one sample subsequently excluded due to PCR inhibition. This resulted in 1,093 samples included in the final analysis. The basic demographic information for the study population is shown in Table 1.

Group A *Streptococcus* was detected by culture and GAS PCR in 262 (24.0%) and 319 (29.2%) of 1,093 throat swabs respectively (Table 2). GAS Ct values had a median of 25.4 (IQR: 23.5–28.2). The

RNaseP internal control had a median Ct of 32.7 (IQR: 31.3–34.2). The overall, positive and negative agreement of the in-house GAS PCR with culture was 94.2%, 98.9% and 92.8% respectively. There were 63 discordant results with three culture-positive/PCR-negative samples and 60 culture-negative/PCR-positive samples (Table 2). One (33.3%) of three culture-positive/PCR-negative samples and 56 (93.3%) of 60 of the culture-negative/PCR-positive samples were GAS-positive on the GeneXpert Group A strep assay.

The median laboratory turn-around time

**Table 1:** Demographic information of study population.

Variable		Number (%)
Sex	Male	447 (40.9)
	Female	646 (59.1)
Age	0–4 years	144 (13.2)
	5–9 years	248 (22.7)
	10–14 years	215 (19.7)
	15–29 years	205 (18.8)
	≥30 years	281 (25.7)
Ethnicity	NZ European	491 (44.9)
	NZ Māori	365 (33.4)
	Pacific peoples	37 (3.4)
	Other	118 (10.8)
	Unknown	82 (7.5)
Health district	MidCentral	685 (62.7)
	Whanganui	124 (11.3)
	Tairāwhiti	284 (26.0)

**Table 2:** Agreement between culture and PCR for GAS detection.

		GAS PCR result	
		Detected	Not detected
Culture result	Positive	259	3
	Negative	60	771

between culture-based testing in January 2023 (1,151 swabs) and PCR-based testing in January 2024 (1,191 swabs) reduced from 44 to 16 hours. In January 2023 95% of throat swab results were reported within 65 hours, while in January 2024 95% of results were reported within 24 hours.

## Discussion

The in-house GAS PCR under evaluation had an absolute and relative increase in GAS detection of 5.2% and 21.8% respectively compared to culture. This is consistent with prior descriptions of GAS NAATs.<sup>6,8</sup> As the PCR was performed post-swab inoculation onto culture media and with a 7-day delay in testing, the described increase in detection likely represents a lower bound estimate. There were three culture-positive/PCR-negative samples that are presumed to represent false negative PCR results and 60 culture-negative/PCR-positive specimens, 56 of which were also GAS-positive on the GeneXpert Group A strep assay. These culture-negative/PCR-positive results are presumed to represent true positives detected due to the increased analytical sensitivity of PCR. The increased sensitivity can in part be attributed to PCR being relatively unaffected by delays between sample collection and processing, while the sensitivity of culture is likely to be more negatively affected by such delays. The four specimens with a positive in-house PCR/negative Xpert PCR result may represent stochastic detection in specimens with low levels of GAS DNA or false positivity.

In the 11 specimens with no RNaseP detection, the use of an external spike control excluded inhibition in all but one sample. This suggests that the lack of RNaseP detection largely reflects sampling quality or potentially the age of samples at testing. Sampling can be impacted by factors such as patient age, recent eating and drinking and excessive pus, and self-sampling may also contribute.<sup>11</sup> Since the methods introduction into routine diagnostic testing, RNaseP has been not detected in only 0.2% of samples, suggesting sample age was a significant contributor in the initial evaluation.

The in-house PCR method presented here has a reagent cost of NZ\$1.20 per sample, making it comparable to culture (NZ\$1.00 per sample) from a reagent cost perspective. Locally there was no change in staffing (and associated cost), as testing of throat swabs moved from the Microbiology to Molecular departments, where the work was absorbed within existing staffing and hours with minimal additional training required. The method has potential labour savings, with an estimated hands-on time of less than 5 minutes per sample (including preparation of PBS tubes, sample swirling, bulk preparation of PCR master-mix and sample transfer to PCR tubes) compared to culture, which requires multiple plate reads and additional identification steps for positives. These labour savings could be increased with the use of swabs in liquid transport media, and through the use of automation.

A significant advantage of the PCR method is the impact on turn-around time. The MIC cyclers are capable of running 46 samples and two controls per batch with a running time of 1 hour. Testing is performed daily (except Sunday), with there generally being a morning, midday and afternoon run. The in-house PCR reduced median laboratory turn-around time by 63.6% from 44 to 16 hours, which may decrease time to antimicrobial treatment initiation or discontinuation in certain populations. This TAT does not, however, consider the time between sample collection and arrival in the laboratory. For samples from MidCentral, the delay between collection and receipt can be a few hours, while for the most distant samples from Tairāwhiti this delay can be up to 36 hours.

Although full case information (e.g., socio-economic status or occupation) was not available, it is notable that 45% of samples came from European patients and 25% from persons aged over 30 years, which suggests over-testing (and likely over-treatment) in individuals at low risk for complications of GAS pharyngitis. Testing and treatment should largely be targeted to those populations at high risk of post-infectious complications, such as RF, as per the Aotearoa New Zealand sore throat guidelines.<sup>4</sup>

**COMPETING INTERESTS**

Nil.

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**AUTHOR INFORMATION**

Rebecca Lucas: HOD Molecular Department, Medlab Central, Palmerston North.

Emma Tapp: Medical Laboratory Scientist, Molecular Department, Medlab Central, Palmerston North.

Rumbi Chimwayange: Medical Laboratory Scientist, Molecular Department, Medlab Central, Palmerston North.

Luiza Hermoso: Medical Laboratory Scientist, Molecular Department, Medlab Central, Palmerston North.

Matthew R Blakiston: Clinical Microbiologist, Microbiology/Molecular Departments, Medlab Central, Palmerston North.

**CORRESPONDING AUTHOR**

Rebecca Lucas: Molecular Department, Medlab Central, Palmerston North Hospital, Ruahine Street, Palmerston North 4414. Ph: 06 952 3173.  
E: rebeccal@medlabcentral.co.nz

**URL**

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**REFERENCES**

1. Uhl JR, Adamson SC, Vetter EA, et al. Comparison of LightCycler PCR, rapid antigen immunoassay, and culture for detection of group A streptococci from throat swabs. *J Clin Microbiol.* 2003;41(1):242-9. doi: 10.1128/JCM.41.1.242-249.2003.
2. Pritt BS, Patel R, Kirn TJ, Thomson RB Jr. Point-Counterpoint: A Nucleic Acid Amplification Test for *Streptococcus pyogenes* Should Replace Antigen Detection and Culture for Detection of Bacterial Pharyngitis. *J Clin Microbiol.* 2016;54(10):2413-9. doi: 10.1128/JCM.01472-16.
3. Institute of Environmental Science and Research Limited. Rheumatic fever bi-annual report: January 2018 to December 2018 [Internet]. Auckland (NZ): Institute of Environmental Science and Research Limited; 2019 [cited 15 Feb 2024]. Available from: <https://www.esr.cri.nz/digital-library/rheumatic-fever-annual-report-2018/>
4. Heart Foundation New Zealand. New Zealand Guidelines for Rheumatic Fever, Group A Streptococcal sore throat management guideline: 2019 update [Internet]. Auckland (NZ): Heart Foundation New Zealand; 2019 [cited 15 Feb 2024]. Available from: <https://assets.heartfoundation.org.nz/documents/shop/heart-healthcare/non-stock-resources/gas-sore-throat-rheumatic-fever-guideline.pdf>
5. Shaikh N, Leonard E, Martin JM. Prevalence of streptococcal pharyngitis and streptococcal carriage in children: a meta-analysis. *Pediatrics.* 2010;126(3):e557-64. doi: 10.1542/peds.2009-2648.
6. Amrud K, Slinger R, Sant N, et al. A comparison of the Quidel Solana GAS assay, the Luminex Aries Group A Strep assay and the Focus Diagnostics Simplexa Group A Strep Direct assay for detection of Group A *Streptococcus* in throat swab specimens. *Diagn Microbiol Infect Dis.* 2019;95(3):114866. doi: 10.1016/j.diagmicrobio.2019.07.004.
7. Ralph AP, Holt DC, Islam S, et al. Potential for Molecular Testing for Group A *Streptococcus* to Improve Diagnosis and Management in a High-Risk Population: A Prospective Study. *Open Forum Infect Dis.* 2019;26(6(4)):ofz097. doi: 10.1093/ofid/ofz097.
8. Taylor A, Morpeth S, Webb R, Taylor S. The Utility of Rapid Group A *Streptococcus* Molecular Testing Compared with Throat Culture for the Diagnosis of Group A *Streptococcal* Pharyngitis in a High-Incidence Rheumatic Fever Population. *J Clin Microbiol.* 2021;18;59(12):e0097821. doi: 10.1128/JCM.00978-21.
9. Dunne EM, Marshall JL, Baker CA, et al. Detection of group a streptococcal pharyngitis by quantitative PCR. *BMC Infect Dis.* 2013;13:312. doi: 10.1186/1471-2334-13-312.
10. Brukner I, Eintracht S, Papadakis AI, et al. Maximizing confidence in a negative result: Quantitative sample adequacy control. *J Infect Public Health.* 2020;13(7):991-993. doi: 10.1016/j.jiph.2020.01.307.
11. Schrader C, Schielke A, Ellerbroek L, John R. PCR inhibitors - occurrence, properties and removal. *J Appl Microbiol.* 2012;113(5):1014-26. doi: 10.1111/j.1365-2672.2012.05384.x.

# Favourable outcome of acute myocarditis diagnosed by cardiac magnetic resonance imaging

Sophie Rees, Ammar Alsamarrai, Jessica Fulton, Jithendra B Somaratne

## ABSTRACT

**AIM:** Acute myocarditis (AM) is increasingly diagnosed in the era of more sensitive imaging techniques. The natural history of AM diagnosed on cardiac magnetic resonance imaging (cMRI) may be different to historic cohorts due to the detection of milder disease. This study aims to measure the outcome of patients with AM detected by cMRI.

**METHODS:** We retrospectively reviewed all cMRI studies performed over a 10-year period between 2012 and 2022. Patients with a diagnosis of AM based on cMRI criteria and clinical assessment were selected for inclusion.

**RESULTS:** One hundred and ninety-six patients were included. The mean age was 42 years and 79% were male. Chest pain, fever or viral prodrome and dyspnoea were the most common presenting symptoms, and one patient presented with cardiac arrest. On cMRI, nine patients had left ventricular ejection fraction <40% and 174 patients had evidence of late gadolinium enhancement, most commonly affecting the basal inferolateral and inferior segments in a subepicardial and mid-wall distribution. Five patients required admission to the intensive care unit (ICU). Important outcomes included the occurrence of ventricular arrhythmias in 17, recurrent or chronic myocarditis in 15 and implantable cardioverter defibrillator insertion in five patients, respectively. After a median follow-up of 4.6 years, there were no cardiac-related deaths, and three patients died from malignancy-related causes.

**CONCLUSION:** Patients with AM diagnosed by cMRI have a favourable medium-term outcome. Severe left ventricular dysfunction and ICU admission are rare. cMRI should be considered early in patients with suspected AM.

Acute myocarditis (AM) is a clinically challenging entity characterised by a wide spectrum of presentation—ranging from no symptoms to fulminant heart failure—and it can also present in a similar fashion to acute coronary syndrome. Historically, endomyocardial biopsy (EMB) was the only diagnostic test available, and it remains the diagnostic gold standard, but utilisation of this test is limited by its invasive nature, complication rates and low sensitivity. The availability of cardiac magnetic resonance imaging (cMRI) provides an alternative, non-invasive method of myocardial tissue characterisation and has been applied with high diagnostic accuracy in AM.<sup>1</sup> In addition to diagnostic utility, cMRI also provides unique prognostic information in AM, where the pattern of late gadolinium enhancement has been shown to predict subsequent major adverse cardiovascular events.<sup>2,3</sup>

Previous studies on clinical presentation and survival following AM have focussed on EMB-proven cases, but these are limited by selection bias where only severe cases would warrant biopsy.<sup>4,5</sup> Furthermore, cMRI is now increasingly utilised for patients presenting with myocardial

infarction with non-obstructive coronary arteries (MINOCA), and up to 37% of these patients are found to have AM when cMRI is used.<sup>6</sup> Patriki et al. systematically screened all patients presenting with MINOCA with cMRI and concluded that the incidence of AM is 0.63 per 1,000 of all hospital admissions. This is one of the few existing estimates of the true incidence of AM in the general population.<sup>7</sup>

As the availability and uptake of cMRI increases, it follows that more cases of AM may be diagnosed, and this may represent a lower risk group compared to previously described populations. The aim of this study is to review the clinical features and natural history of cMRI-diagnosed AM, and to assess the inpatient and medium-term outcome of this patient group.

## Materials and methods

### Patient selection

All patients undergoing cMRI at Te Whatu Ora – Health New Zealand Te Toka Tumai Auckland (formerly Auckland District Health Board) for any indication between 1 July 2012

and 30 June 2022 were retrospectively identified. Consecutive patients with a final diagnosis of AM based on cMRI imaging criteria and on clinical grounds were included. This study received institutional approval for falling within recommended research methodologies defined by the New Zealand Health and Disability Ethics Committees' standard operating procedures.

### Data collection and definitions

All data were retrieved from electronic medical records. Baseline demographics, clinical features, in-hospital complications, long-term outcome measures and vital status were recorded. Follow-up was until 1 January 2023 or until the last documented healthcare encounter for patients who left the region. We recorded important clinical outcomes including the occurrence of ventricular arrhythmia during the index admission, cardiac ablation procedure, insertion of implantable cardioverter defibrillator (ICD), subsequent hospitalisation for heart failure, recurrent or chronic myocarditis, cardiac transplantation and death. Ventricular arrhythmia included ventricular fibrillation (VF) or ventricular tachycardia (VT) (more than 4 beats). Continuous variables were reported as mean with standard deviation or median with interquartile range. Categorical variables were reported in absolute values with percentages.

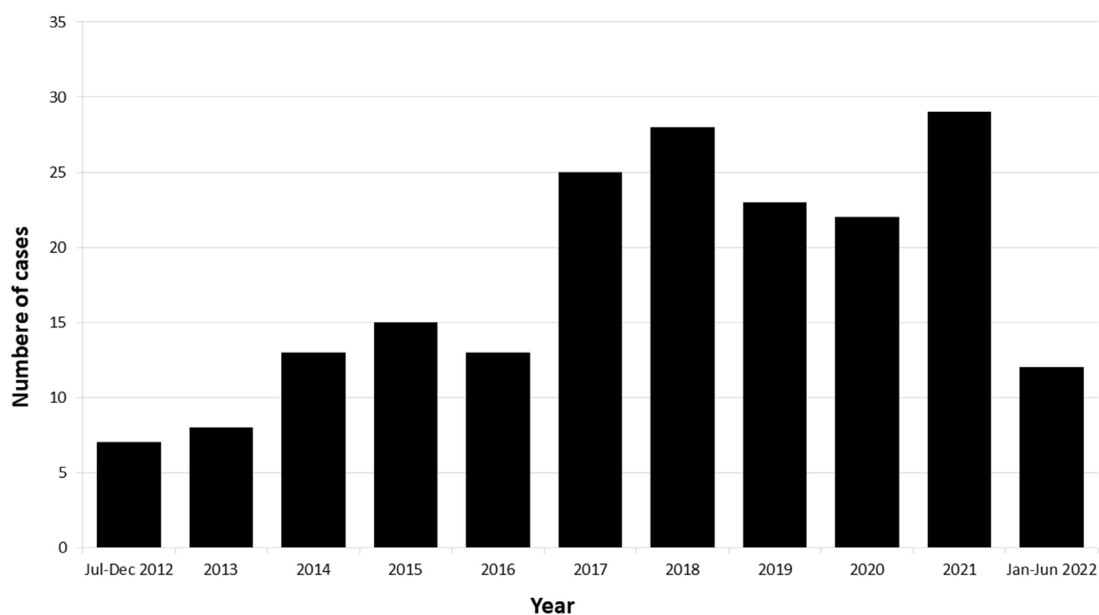
### cMRI protocol and imaging criteria

All scans were performed on 1.5T (Avanto, Siemens, Germany) or 3T (Skyra, Siemens, Germany) magnets. Standard imaging sequences to assess left ventricle (LV) volumes, mass and function (SSFP) as well myocardial oedema (T2 weighted imaging) and late gadolinium enhancement as per Society for Cardiovascular Magnetic Resonance guidelines were performed.<sup>8</sup> Gadolinium contrast was administered at a dose of 0.1mmol/kg. Diagnosis of myocarditis on cMRI was based on the Lake Louise criteria.<sup>9</sup>

### Results

A total of 196 cases of AM were identified, and there was a gradual increase in the number of cases diagnosed over time (Figure 1). The mean age at index presentation was 42 years, and 155 (79%) were male (Table 1). The most common presenting symptom was chest pain, which was present in 157 patients (80%), followed by fever or a viral prodrome in 95 patients (48%) and dyspnoea in 52 patients (27%) respectively. One patient presented with resuscitated cardiac arrest. ST-segment elevation was present in 64 patients (33%), coronary angiography was undertaken in 117 patients (60%), and none had obstructive coronary artery disease. EMB was undertaken in 10 patients, of which six revealed normal findings.

**Figure 1:** Number of cases of acute myocarditis diagnosed per year.





**Table 1:** Baseline demographics, clinical features and relevant investigations.

Parameter	Frequency (n=196)
<b>Demographics</b>	
Age	41.8 (17.6)
Male	155 (79%)
<b>Ethnicity</b>	
New Zealand European	99 (51%)
Māori	21 (11%)
Pacific	11 (6%)
Asian and Indian	21 (11%)
Other	44 (22%)
<b>Medical background</b>	
Body mass index 25–29.9kg/m <sup>2</sup>	76 (39%)
Body mass index ≥30kg/m <sup>2</sup>	50 (26%)
Hypertension	36 (18%)
Dyslipidaemia	29 (15%)
Current smoker	24 (12%)
Known coronary artery disease	9 (5%)
Heart failure	5 (3%)
Diabetes	6 (3%)
Connective tissue disease	6 (3%)
Previous pericarditis or myocarditis	5 (3%)
<b>Clinical presentation</b>	
Chest pain	157 (80%)
Fever or viral prodrome	95 (48%)
Dyspnoea	52 (27%)
NYHA Class I	179 (91%)
NYHA Class II	12 (6%)
NYHA Class III	3 (2%)
NYHA Class IV	2 (1%)
Presyncope	19 (10%)

**Table 1 (continued):** Baseline demographics, clinical features and relevant investigations.

Syncope	11 (6%)
Palpitations	17 (9%)
Cardiac arrest	1 (1%)
<b>Laboratory investigations</b>	
Raised leucocyte count ( $\geq 11 \times 10^9/L$ )	48 (24%)
C-reactive protein (mg/L)	21 (5–80)
Creatinine ( $\mu\text{mol/L}$ )	79 (69–88)
Creatine kinase (IU/L)	249 (149–687)
Troponin T (ng/L) <sup>a</sup>	391 (144–913)
NT-ProBNP (pmol/L) <sup>a</sup>	113 (23–368)
<b>Electrocardiography</b>	
Sinus rhythm	185 (94%)
ST-segment elevation	64 (33%)
Bundle branch block	18 (9%)
<b>Coronary angiography</b>	
Non-obstructive coronary artery disease	41 (21%)
Normal	76 (39%)
Not performed	79 (40%)
<b>Endomyocardial biopsy</b>	
Normal	6 (3%)
Lymphocytic infiltrates	2 (1%)
Eosinophilic infiltrates	1 (1%)
Giant cells	1 (1%)

NYHA = New York Heart Association; NT-ProBNP = N-terminal pro-brain natriuretic peptide.

<sup>a</sup>Institutional upper limit of normal for Troponin T assay 15ng/L and for NT-ProBNP assay 100pmol/L.

**Table 2:** Data from cardiac magnetic resonance imaging.

<b>Parameter</b>	<b>Frequency (n=196)</b>
Indexed left ventricular end diastolic volume (mL/m <sup>2</sup> )	86 (74–96)
Indexed left ventricular end systolic volume (mL/m <sup>2</sup> )	38 (28–44)
Pericardial effusion	50 (26%)
<b>Left ventricular ejection fraction (%)</b>	56 (+/- 8.8)
≥40%	186 (95%)
<40%	9 (5%)
Wall motion abnormality	78 (40%)
Presence of late gadolinium enhancement	174 (89%)
Number of affected segments	3.4 (1.5)
<b>Distribution</b>	
Subepicardial	125 (64%)
Mid-wall	131 (67%)
Subendocardial	31 (16%)
<b>Most commonly affected segments</b>	
Basal inferolateral	104 (53%)
Basal inferior	79 (40%)
Mid-inferolateral	75 (38%)
Mid-anterolateral	59 (30%)
Mid-inferior	53 (27%)

**Table 3:** Important cardiac events.

<b>Parameter</b>	<b>Frequency (n=196)</b>
Ventricular arrhythmia during index admission	17 (9%)
Recurrent or chronic myocarditis	15 (8%)
Implantable cardioverter defibrillator	5 (3%)
Cardiac ablation procedure	2 (1%)
Readmission for heart failure	3 (2%)
Cardiac transplantation	1 (1%)
Cardiac-related death	0

On cMRI, mean left ventricular ejection fraction (LVEF) was 56%, and in nine patients it was <40% (Table 2). Other common findings included wall motion abnormality in 78 patients (40%) and pericardial effusion in 50 patients (26%). Late gadolinium enhancement was observed in the majority (89%), and this was most commonly seen in the basal inferior and inferolateral segments, with a predominant mid-wall and subepicardial distribution.

Most patients had a benign in-hospital course, and the median length of stay was 4 days. Arrhythmias were the most common event, occurring in 24 patients (12%), which was primarily due to VT. Acute kidney injury occurred in 19 patients (10%) during the index admission. Five patients required admission to intensive care, and one had cardiogenic shock requiring venoarterial extracorporeal membrane oxygenation, acute dialysis and a prolonged recovery period.

We observed two cases of presumed COVID-related AM and nine cases of presumed COVID-19 vaccine (Pfizer) related AM. This latter group consisted of seven males and two females, mean age 27 ( $\pm 13$ ) years. One case occurred after the first vaccination, seven after the second and one after the third vaccination. The median time from vaccination to presentation to hospital was 3 days. All of these patients had normal LVEF. One patient had inpatient ventricular arrhythmia, but there were no other important cardiac events either during the index hospitalisation or at follow-up (median 1.2 years) (Table 3).

Immunosuppression was used in 22 patients (11%), consisting of prednisone alone in 13 patients (7%) and other immunosuppressive agents in the remaining nine patients (5%), which included methylprednisolone, intravenous immunoglobulins, sirolimus, leflunomide, mycophenolate, tocilizumab and cyclophosphamide. The indication for immunosuppression was usually severe left ventricular impairment or a coexisting underlying autoimmune disorder.

All patients survived the index admission, and after a median follow-up of 4.6 years there were no cardiac-related deaths, but three patients died from advanced malignancy. Important cardiac events included recurrent or chronic myocarditis in 15 patients (8%), with a median time to recurrence of 2 years. ICD insertion was done in five patients (3%), one during the index admission and four following discharge, all for the indication of recurrent VT. Three patients were readmitted for heart failure after 16, 17 and 31 months, and one

patient received a cardiac transplant for giant cell myocarditis. Two patients underwent cardiac ablation procedure for recurrent VT and multifocal ventricular ectopy with VT, respectively.

## Discussion

Our results demonstrate the favourable clinical course and medium-term prognosis of patients with AM that is diagnosed by cMRI. This is in keeping with findings of previous cMRI studies, which have reported short- and medium-term mortality rates of 0–3.5%.<sup>2,10</sup> In contrast, Grün et al. examined 203 cases of EMB-proven myocarditis (45% of patients presenting with New York Heart Association [NYHA] III or IV symptoms) and reported a mortality rate of 19.2% at 4.7 years. This highlights the spectrum of disease severity seen with AM. Further, these studies support the notion that patients who are determined to be clinically suitable for cMRI tend to have milder manifestations of the disease, and this underlies the need to define biomarkers that identify a “lower risk” cohort who can be reassured without follow-up surveillance imaging.<sup>11</sup>

We observed few serious in-hospital complications of AM in this study. Importantly, all patients survived the index admission, and only five required intensive care. VT was the most frequently observed event, and it occurred in 16 patients. Chopra et al. found that the occurrence of VT was more commonly observed in patients that presented in a pseudo-infarct manner of AM (i.e., when the clinical presentation mimics acute coronary syndrome), and this subset of patients had a higher cumulative event rate at follow-up than those that did not present in a pseudo-infarct manner.<sup>2</sup> Similarly, the presence and extent of late gadolinium enhancement is recognised to be an important prognostic factor in AM, where it is estimated to be associated with a >3-fold increased risk of adverse cardiac outcomes compared to those that do not have late gadolinium enhancement.<sup>12</sup>

Although the majority of patients in our study presented with mild disease, immunosuppression was used in 22 patients, mostly in the form of corticosteroids. Further, VT occurred in five of these 22 patients and VF occurred in one, which is likely consequent to the more aggressive and active nature of their disease. We observed one case of a patient who developed autoimmune myocarditis due to a novel monoclonal antibody (nivolumab). This patient was treated with

intravenous methylprednisolone and intravenous immunoglobulins, as well as a tapering course of oral corticosteroid; however, he eventually died from advanced malignancy. Autoimmune myocarditis is an emerging category of AM and is seen in patients treated with novel immune checkpoint inhibitors. This group of patients can only be expected to grow as the indications for and uptake of these drugs increase, and clinicians should have a high index of suspicion of this adverse effect in the cardio-oncology patient group.<sup>13</sup>

Further, we observed cases of presumed COVID-19 vaccine-related AM, and this entity has received considerable research and public interest. Though it is a very uncommon occurrence, estimated at 1.08 per 100,000 in one nation-wide study, a subset of these patients manifest severe cardiac impairment and require advanced therapies including cardiac transplantation.<sup>14</sup> In our current study, all patients had uneventful outcomes; however, these cases likely represent only a small subset of patients with mild clinical manifestations.

Appropriate follow-up after hospital discharge remains an unclear aspect in the management of patients with AM. Importantly, while most patients can expect recovery, some develop chronic myocarditis or progress to dilated cardiomyopathy.<sup>15</sup> The European Society of Cardiology guidelines advise “*long-term non-invasive cardiological follow-up*” after normalisation of cardiac enzymes;<sup>16</sup> however, several studies have demonstrated a lack of correlation between cardiac enzyme release and clinical outcomes

in AM, and a novel implementation of cMRI in AM demonstrated persistent abnormal myocardial tissue processes (including late gadolinium enhancement) despite normalisation of cardiac enzymes and inflammatory parameters.<sup>17</sup> On the other hand, absence of late gadolinium enhancement in AM is a powerful predictor of cardiovascular survival,<sup>11</sup> which has resulted in the suggestion that convalescent cMRI could form part of the short-term follow-up of these patients regardless of cardiac enzyme level.

## Limitations

This study is retrospective and from a single centre, and thus is subject to the usual limitations of this design. Second, although cMRI has very high diagnostic accuracy for AM, it is possible that some included cases reflected alternative aetiologies as the gold standard test of EMB was not performed in the majority of patients. Last, we included all aetiologies of AM, which may be a heterogenous group, each with its own risk of complications and natural history.

## Conclusion

Patients with mild forms of AM diagnosed by cMRI have a favourable in-hospital clinical course and medium-term prognosis. Clinicians should have a low index of suspicion for AM in patients presenting with supporting clinical features, and cMRI should be considered early in the work-up process, particularly in those presenting with MINOCA.

**COMPETING INTERESTS**

The authors have no conflict of interests to declare.

**AUTHOR INFORMATION**

Sophie Rees, MBChB: Registrar, Health New Zealand – Te Whatu Ora, General Medicine Department, Middlemore Hospital, Hospital Road, Otahuhu, Auckland, New Zealand.

Ammar Alsamarrai, MBChB: Cardiology Registrar, Health New Zealand – Te Whatu Ora, Green Lane Cardiovascular Services, Auckland City Hospital, Auckland, New Zealand.

Jessica Fulton, MBChB: Registrar, Health New Zealand – Te Whatu Ora, General Medicine Department, Middlemore Hospital, Hospital Road, Otahuhu, Auckland, New Zealand.

Jithendra B Somaratne, FRACP PhD: Consultant Cardiologist, Health New Zealand – Te Whatu Ora, Green Lane Cardiovascular Services, Auckland City Hospital, Auckland, New Zealand.

**CORRESPONDING AUTHOR**

Sophie Rees, MBChB: Registrar, Health New Zealand – Te Whatu Ora, General Medicine Department, Middlemore Hospital, Hospital Road, Otahuhu, Auckland, New Zealand. E: [sophierees6@gmail.com](mailto:sophierees6@gmail.com)

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**REFERENCES**

- Kotanidis CP, Bazmpani MA, Haidich AB, et al. Diagnostic Accuracy of Cardiovascular Magnetic Resonance in Acute Myocarditis: A Systematic Review and Meta-Analysis. *JACC Cardiovasc Imaging*. 2018;11(11):1583-90. doi: 10.1016/j.jcmg.2017.12.008.
- Chopra H, Arangalage D, Bouleti C, et al. Prognostic value of the infarct- and non-infarct like patterns and cardiovascular magnetic resonance parameters on long-term outcome of patients after acute myocarditis. *Int J Cardiol*. 2016;212:63-9. doi: 10.1016/j.ijcard.2016.03.004.
- Gräni C, Eichhorn C, Bière L, et al. Prognostic Value of Cardiac Magnetic Resonance Tissue Characterization in risk Stratifying Patients With Suspected Myocarditis. *J Am Coll Cardiol*. 2017;70(16):1964-76. doi: 10.1016/j.jacc.2017.08.050. Erratum in: *J Am Coll Cardiol*. 2017 Nov 28;70(21):2736. doi: 10.1016/j.jacc.2017.10.042.
- McCarthy RE 3rd, Boehmer JP, Hruban RH, et al. Long-term outcome of fulminant myocarditis as compared with acute (nonfulminant) myocarditis. *N Engl J Med*. 2000;342(10):690-5. doi: 10.1056/NEJM200003093421003.
- Ammirati E, Veronese G, Brambatti M, et al. Fulminant Versus Acute Nonfulminant Myocarditis in Patients With Left Ventricular Systolic Dysfunction. *J Am Coll Cardiol*. 2019;74(3):299-311. doi: 10.1016/j.jacc.2019.04.063.
- Pathik B, Raman B, Mohd Amin NH, et al. Troponin-positive chest pain with unobstructed coronary arteries: incremental diagnostic value of cardiovascular magnetic resonance imaging. *Eur Heart J Cardiovasc Imaging*. 2016;17(10):1146-52. doi: 10.1093/ehjci/jev289.
- Heidecker B, Ruedi G, Baltensperger N, et al. Systematic use of cardiac magnetic resonance imaging in MINOCA led to a five-fold increase in the detection rate of myocarditis: a retrospective study. *Swiss Med Wkly*. 2019;149:w20098. doi: 10.4414/smw.2019.20098.
- Kramer CM, Barkhausen J, Bucciarelli-Ducci C, et al. Standardized cardiovascular magnetic resonance imaging (CMR) protocols: 2020 update. *J Cardiovasc Magn Reson*. 2020;22(1):17. doi: 10.1186/s12968-020-00607-1.
- Friedrich MG, Sechtem U, Schulz-Menger J, et al. Cardiovascular magnetic resonance in myocarditis: A JACC White Paper. *J Am Coll Cardiol*. 2009;53(17):1475-87. doi: 10.1016/j.jacc.2009.02.007.
- Sanguineti F, Garot P, Mana M, et al. Cardiovascular magnetic resonance predictors of clinical outcome in patients with suspected acute myocarditis. *J Cardiovasc Magn Reson*. 2015;17(1):78. doi: 10.1186/s12968-015-0185-2.
- Grün S, Schumm J, Greulich S, et al. Long-term follow-up of biopsy-proven viral myocarditis: predictors of mortality and incomplete recovery. *J Am Coll Cardiol*. 2012;59(18):1604-15. doi: 10.1016/j.jacc.2012.01.007.
- Georgiopoulou G, Figliozzi S, Sanguineti F, et al. Prognostic Impact of Late Gadolinium Enhancement by Cardiovascular Magnetic Resonance in Myocarditis: A Systematic Review and Meta-Analysis. *Circ Cardiovasc Imaging*. 2021;14(1):e011492. doi: 10.1161/CIRCIMAGING.120.011492.
- Mahmood SS, Fradley MG, Cohen JV, et al. Myocarditis in Patients Treated With Immune Checkpoint Inhibitors. *J Am Coll Cardiol*. 2018;71(16):1755-64. doi: 10.1016/j.jacc.2018.02.037.
- Cho JY, Kim KH, Lee N, et al. COVID-19 vaccination-

- related myocarditis: a Korean nationwide study. *Eur Heart J*. 2023;44(24):2234-43. doi: 10.1093/eurheartj/ehad339.
15. Kindermann I, Barth C, Mahfoud F, et al. Update on myocarditis. *J Am Coll Cardiol*. 2012;59(9):779-92. doi: 10.1016/j.jacc.2011.09.074.
16. Caforio AL, Pankuweit S, Arbustini E, et al. Current state of knowledge on aetiology, diagnosis, management, and therapy of myocarditis: a position statement of the European Society of Cardiology Working Group on Myocardial and Pericardial Diseases. *Eur Heart J*. 2013;34(33):2636-48, 2648a-2648d. doi: 10.1093/eurheartj/ehd210.
17. Berg J, Kottwitz J, Baltensperger N, et al. Cardiac Magnetic Resonance Imaging in Myocarditis Reveals Persistent Disease Activity Despite Normalization of Cardiac Enzymes and Inflammatory Parameters at 3-Month Follow-Up. *Circ Heart Fail*. 2017;10(11):e004262. doi: 10.1161/CIRCHEARTFAILURE.117.004262.

# Representation of Asian ethnic sub-groups in Aotearoa's regulated health workforce pre-registration students

Navneet N Lal, Gabrielle McDonald, Andrew Sise, Warwick Bagg, Zoe Bristowe, Paul Brunton, Chris Hendry, Bridget Kool, Damian Scarf, Susan Shaw, Collin Tukuitonga, Jonathan Williman, Denise Wilson, Peter Crampton

## ABSTRACT

**AIM:** To provide a socio-demographic profile of Asian students enrolled in their first year of a health professional programme in polytechnics and universities in Aotearoa New Zealand and to explore differences in enrolment rates (ERs) within Asian sub-groups and by socio-economic deprivation, citizenship status, urban/rural location and gender.

**METHODS:** Ethnic group/sub-group and socio-demographic characteristics of students enrolling within 21 health professional programmes were collected and averaged over 5 years (2016–2020). Age- and ethnicity-matched denominator data from the 2018 Census were used to calculate yearly ERs and ratios (ERR) using generalised linear modelling with the European ethnic group as the reference.

**RESULTS:** The overall ER for Asian students was higher than for Europeans (ERs [95% confidence interval: 280 [269–292] per 100,000 population aged 18–29 per year vs 149 [144–154]). However, Indian, Chinese and Southeast Asian students were under-represented in occupational therapy (ERR: 0.33–0.67,  $p < 0.017$ ), midwifery (ERR: 0.46–0.61,  $p < 0.002$ ) and paramedicine (ERR: 0.23–0.29,  $p < 0.001$ ). There were proportionately fewer female Asian students compared with European students (68% vs 82%,  $p < 0.001$ ).

**CONCLUSION:** This novel research provides detailed information on Asian sub-group representation in health professional programmes in Aotearoa. Taken in the context of known health needs of different Asian sub-groups, these data may facilitate health workforce planning and targeted policies within health professional programmes in order to better match the health workforce to population health needs.

Training and retaining health professionals who reflect the communities they serve should be a key driver of health workforce development because ethnic concordance and lived-experience-informed practice improves outcomes for under-served populations—a powerful strategy to improve health outcomes and reduce inequities.<sup>1–5</sup> The *Pae Ora (Healthy Futures) Act 2022*<sup>6</sup> states that the health sector should develop and maintain a health workforce that is representative of the communities it serves. Despite this, Aotearoa New Zealand's (Aotearoa) health workforce inadequately mirrors the society it serves, particularly for Māori (Aotearoa's Indigenous population) and Pacific populations.<sup>7,8</sup>

Te Tiriti o Waitangi, the foundational constitutional document of Aotearoa, states that Māori retain the right of self-determination and the benefits of protection and citizenship, which afford Māori rights-based entitlement to equal health outcomes.<sup>9,10</sup> Despite this, since British colonisation of Aotearoa in the first half of the

nineteenth century, the rights of Māori have been systematically breached—with Pākehā benefitting from these actions at the expense of Māori—causing marginalisation and oppression.<sup>11</sup> This has resulted in inequitable outcomes across a number of areas, including but not limited to the realms of health and education, with substantial under-representation of Māori in nearly all aspects of the health workforce.<sup>12</sup>

In responding to structural inequities and under-representation of Māori professionals in the health workforce, affirmative action selection policies for entry into health professional programmes have been developed at both universities of Auckland and Otago.<sup>13–16</sup> Because Pacific people also experience structural inequities that result in inequitable social and economic outcomes and under-representation in the health workforce, affirmative action selection policies for entry into health professional programmes also apply to Pacific students.<sup>15,16</sup> While these steps have helped to increase the number of Māori and Pacific



peoples in Aotearoa's health workforce, there is still significant under-representation that continues to drive health inequities, as highlighted by us previously.<sup>7,8,13</sup> Māori and Pacific students have significantly lower enrolment rates (ERs) in health professional programmes (99 and 100 per 100,000 of eligible population, respectively) compared with NZ European students (152 per 100,000). The under-representation of Māori students in health workforce training is at odds with the health sector's commitment to Te Tiriti o Waitangi and is of particular concern given the significant health inequities experienced by Māori.

The current study is part of a wider series of analyses aimed at exploring the demographics of health professional students in Aotearoa.<sup>7,8</sup> The overall aim for the wider study is to provide a socio-demographic profile of all students enrolled in their first year of a health professional programme offered within Aotearoa's tertiary institutions. These data can be leveraged by future national and local initiatives to inform, monitor and enable the regulated health professional workforce to better reflect Aotearoa's society as a whole. Our preliminary analysis exploring the demographics of health professional students in Aotearoa indicated that Chinese and Southeast Asian students had higher overall rates of enrolment compared with other ethnic groups.<sup>7,8</sup> However, as was the case with all ethnic groups, ERs for the pan-Asian group had a linear negative relationship with increasing small area deprivation (New Zealand Index of Deprivation [NZDep] 2018), indicating that disparities exist within and among Asian students.

Asians comprise the third largest ethnic population in Aotearoa (following Europeans and Māori)<sup>17</sup> and have well-documented healthcare needs.<sup>18-20</sup> The first Chinese immigrants arrived in Aotearoa at the time of the Otago gold rush in the 1860s.<sup>21</sup> Asian immigration to Aotearoa has accelerated over recent decades, with about 17% of the population now identifying as Asian.<sup>22</sup> Despite increasing research on Asian health, the Asian grouping is poorly reflected in Aotearoa's health policies,<sup>23</sup> perhaps leading to the false impression that there are no specific unmet healthcare needs for this community.<sup>20,24</sup>

### **“Asian” ethnic group**

Statistics New Zealand (Stats NZ) defines ethnicity as a measure of cultural affiliation<sup>25</sup> and

not a measure of race, ancestry, nationality or citizenship. While the definition of ethnicity provided by Stats NZ<sup>25</sup> focusses on identity, in contemporary Aotearoa the concept of ethnicity can equally be understood as a marker of societal power differentials, and the differences in health outcomes that are observed as a result. The term “Asian” lacks a universal and uncontested meaning, but gained currency through usage by the state; for example, by Stats NZ, Aotearoa's lead government statistical agency.<sup>26</sup> Stats NZ defines “Asians” as individuals with origins in the Asian continent, spanning countries bordered by the Pacific Ocean in the east to Afghanistan (inclusive) in the west. It includes geographies as disparate as Japan and India while excluding the Middle East and Central Asia (Table 1).<sup>27</sup> Despite the obvious deficiencies of “Asian” being used as a pan-ethnic grouping, the term has salience for health because of the context: Aotearoa is a racialised colonial society where the state categorises a significant proportion of the world's population into one ethnic grouping—Asian—in a way that reflects the imperial and colonial history of England.

There is huge diversity within Asians in Aotearoa and health outcomes vary between different Asian sub-groups. These differences in health outcomes are often missed when data are aggregated and examined for the pan-Asian group, masking important differences due to an averaging effect. For example, Indian and other South Asian ethnic populations experience high rates of low birth weight and pre-eclampsia,<sup>28-30</sup> cardiovascular and metabolic diseases,<sup>18,19</sup> nutrient deficiencies<sup>18</sup> and poor youth mental health.<sup>31</sup> The Chinese ethnic sub-group has low rates of perinatal and maternal morbidity and mortality, but high rates of gastric cancer, stroke and smoking.<sup>32</sup> The “Other Asian” category problematically groups people from countries such as Sri Lanka, Japan and Korea (Table 1) and their healthcare needs remain poorly characterised. Essentially, the Asian grouping agglomerates diverse ethnic groups with specific unmet healthcare needs that require tailored solutions.

Understanding the needs of those in the Asian ethnic group in the context of health and education is complicated by the “model minority myth”, the “healthy migrant effect” and “divide and conquer” strategies rooted in colonisation. The model minority myth is the perception of high economic and academic achievement in certain minority groups (particularly Asian) attributed to work ethic and merit, which is used to undermine

**Table 1:** The Asian pan-ethnic grouping as classified by Statistics New Zealand and broken into its four constituent levels with population counts and proportions (%) of the total population from the 2018 Census data.<sup>17</sup> Overlapping cells denote how the individual ethnic groups (on the right) are reconstituted into sub-groups, groups and pan-ethnic groups (on the left).

Level 1	Level 2	Level 3	Level 4	Population in 2018		
Asian 707,598 (15%)	Southeast Asian 126,072 (2.7%)	Other Southeast Asian 27,483 (0.58%)	Asian, NFD*	11,811 (0.25%)		
			Southeast Asian, NFD*	6,219 (0.13%)		
			Filipino	72,612 (1.5%)		
			Cambodian	9,672 (0.21%)		
			Vietnamese	10,086 (0.21%)		
			Burmese	2,475 (0.053%)		
			Indonesian	6,033 (0.13%)		
			Lao	1,608 (0.034%)		
			Malay	3,729 (0.079%)		
			Thai	10,623 (0.23%)		
			Southeast Asian, NEC <sup>†</sup>	1,638 (0.035%)		
			Chinese 248,919 (5.3%)		Chinese, NFD*	231,387 (4.9%)
					Hong Kong Chinese	3,177 (0.068%)
	Cambodian Chinese	1,413 (0.03%)				
	Malaysian Chinese	4,866 (0.10%)				
	Taiwanese	6,570 (0.14%)				
	Indian 241,050 (5.1%)		Indian, NFD*	221,916 (4.7%)		
			Fijian Indian	15,132 (0.32%)		
			South African Indian	1,632 (0.035%)		
	Other Asian 91,143 (1.9%)	Sri Lankan 16,920 (0.36%)	Sri Lankan, NFD*	4,245 (0.090%)		
			Sinhalese	9,171 (0.20%)		
			Sri Lankan Tamil	3,501 (0.074%)		
		Other Asian 20,418 (0.43%)	Afghani	5,250 (0.11%)		
			Bangladeshi	2,337 (0.050%)		
			Nepalese	3,630 (0.077%)		
			Pakistani	6,135 (0.13%)		
			Eurasian	1,389 (0.030%)		
Japanese			18,141 (0.39%)			
Korean			35,664 (0.76%)			

NFD\* = not further defined; NEC<sup>†</sup> = not elsewhere classified.

Only ethnic groups with 1,000 (0.02% of the population) or more responses have been shown here.

the existence of structural racism.<sup>33–35</sup> The healthy migrant effect posits that migrants enter the country with a high quality of health that deteriorates over time given the difficulties in sustaining adequate standards of nutrition, housing, income and healthcare. Consequently, the health of many Asian migrants in Aotearoa deteriorates faster than expected following migration.<sup>36</sup> The British Empire deliberately employed divide and conquer strategies to dissipate solidarity between minority groups through the establishment of a racial hierarchy (white supremacy)<sup>37</sup> and propagandised assimilation while exploiting minority groups for labour.<sup>38</sup>

Acknowledging the diversity among Asians in Aotearoa, this sub-study aims to provide a socio-demographic profile of Asian students enrolled in their first year of a health professional programme and explore if differences are found in ERs within Asian sub-groups and by socio-economic deprivation, citizenship status, urban/rural location and gender. It is not our intention in this paper to recommend policy solutions or specific selection policies: any such responses to observed misalignments between unmet health need and health workforce composition will need to be considered within the context of specific health professional programmes.

## Methods

This section describes the materials and methods relevant to the current study focussed on students of Asian origin. A more detailed overview of the methods and data sources used in the wider series of analyses that this study is a part of is provided in Crampton et al.<sup>8</sup>

### Programme and student eligibility

During the 5-year data collection period (2016–2020) students were eligible if they were within their “first professional year” (e.g., second year of medicine) of a health professional programme that would lead to registration under the *Health Practitioners Competence Assurance Act 2003*.<sup>39</sup>

Students were included if they were citizens or permanent residents and self-identified with an Asian ethnicity. European students were included for reference purposes, which included students classified as NZ European and Other European as both groups form the majority population and overall share the most privilege within the context of Aotearoa as a racialised colonial society.

Students without recorded ethnicity, gender,

citizenship status, school decile or NZDep2018 classification (see Variables) data were excluded.

### Data sources

Data were sourced from the central records of participating institutions.<sup>8</sup> Of the eligible institutions, 10 of 23 provided data. Non-participating institutions cited privacy concerns as their reason for not participating and were mostly composed of nursing, psychology/psychotherapy and paramedicine (complete breakdown found in Crampton et al.).<sup>8</sup>

Denominator populations were matched to the central records from the 2018 Census “usually resident population” according to gender, ethnicity, NZDep2018 and age band of each programme (see Appendix Table 1).

### Variables

Variables included: ethnicity, area-level socio-economic deprivation (NZDep2018), secondary school socio-economic decile, citizenship status, urban/rural location (based on the Geographic Classification for Health 2018 or GCH2018) and gender.

In Aotearoa, self-identification of ethnicity occurs at the point of ethnicity data collection, although we note that the educational data we draw from do not align with Ministry of Health ethnicity data protocols<sup>40</sup> as only three (as opposed to six) responses are recorded. Ethnicity was self-identified by students and collected by institutions upon enrolment. Ethnicity was analysed according to the Stats NZ ethnicity data protocols using prioritised or total response reporting methods.<sup>27</sup> Level 1 groupings (Asian and European) were created by “prioritised response” (single ethnicity assigned with priority given to Asian before European) and level 2, 3 and 4 sub-groups were created using “total response” (a single student could be counted in multiple ethnic groups) in order to capture the different Asian sub-groups that students identified with.<sup>27,40,41</sup> Level 2 sub-groups were used to ensure there were sufficient counts to adequately power statistical analyses.

Socio-economic deprivation was measured using NZDep2018.<sup>42</sup> NZDep2018 scores were assigned to each student’s home address at the time of their first enrolment at their tertiary institution. Scores range from 1 (least) to 10 (most socio-economically deprived). During the study period, the Ministry of Education used a separate scoring system (school decile) to indicate the extent to which each school draws students from low socio-economic communities, ranging

**Table 2:** Data completeness (prioritised ethnicity) (number [%]).

Variable	Asian, N=5,460	European, N=12,411	Total, N=20,606*
Ethnicity	5,460 (100%)	12,411 (100%)	20,514 (100%)*
Gender	5,460 (100%)	12,410 (100%)	20,605 (100%)*
Age	5,168 (95%)	12,060 (97%)	19,454 (94%)*
Secondary school name/ location	5,195 (95%)	12,149 (98%)	19,935 (97%)*
Secondary school in New Zealand	4,433 (81%)	11,928 (96%)	18,671 (91%)*
Secondary school decile	4,100 (75%)	11,218 (90%)	17,382 (84%)*
New Zealand residential address	4,654 (85%)	11,691 (94%)	18,438 (89%)*
New Zealand Index of Deprivation coded	4,655 (85%)	11,676 (94%)	18,416 (89%)*

\*The totals provided above account for the entire cohort in the original study,<sup>8</sup> including non-Asian and non-European students.

from 10 (least) to 1 (most socio-economically deprived).

Citizenship status was collected and verified by institutions upon enrolment and classified as citizen or resident. Urban/rural location was classified according to the GCH2018 classification tool using students' home addresses.<sup>43</sup> GCH2018 classifies locations as urban (U1: major urban area; U2: large urban area) or rural (R: medium and small urban area to rural settlement or other) based on drive time to access major urban centres.

Gender was self-identified; however, many institutions restricted options to male/female. This limitation meant we could not meaningfully include gender-diverse students within our analyses.

### Data completeness

Missing data for the whole cohort, including non-Asian and non-European students, were very low for gender (missing=1), ethnicity (missing=92), age (missing=0 for all except for one institution, which did not provide age: n=1,152), low for secondary school (missing=671) and relatively low for school decile (1,935 overseas, 1,289 unknown/not codable). NZDep and urban/rural location were available for about 90% of students (again excluding one institution's students, and otherwise would have been 95%+) (Table 2).

### Statistical analyses

Analyses were conducted in Microsoft Excel and R studio. Unadjusted ERs and 95% Wilson binomial confidence intervals (CI) were calculated as the number of students enrolling per 100,000 population per year (ethnicity and age matched according to programme-specific age bands) (Appendix Table 1). Population estimates for each ethnic grouping/sub-group were taken from the 2018 Census. Representation was quantified with enrolment rate ratios (ERR), calculated using Poisson regression with European as the model intercept (reference group). ERRs and their derivatives (i.e.,  $\text{Log}_2[\text{ERR}]$ ) were qualitatively interpreted by the terms "well represented" (enrolment rate of an ethnic grouping was higher than the reference population—European—and statistically significant), "equally represented" (ER of an ethnic grouping was equal to European) and "under-represented" (ER of an ethnic grouping was lower than European and statistically significant). Heat maps were constructed using `ggplot2`<sup>44</sup> and `ggtree`,<sup>45</sup> where row (programmes) and column data (ethnicity) were ordered by hierarchical clustering (Euclidean distance) of  $\text{Log}_2$ -transformed ERRs (which makes colour scales symmetric).

Intersectional characteristics (gender, NZDep2018, GCH2018 urban/rural classification)

were only available for level 1 ethnic groupings (see Table 1). The relationship between intersectional characteristics and ERs was modelled via Poisson regression, allowing for model interactions between gender and area (urban/rural location), and gender and NZDep2018. Relationships between individual programme ERs and NZDep2018 were modelled with linear regressions. The resulting correlation coefficients were output to cluster analysis alongside gender (fraction of females) and rurality (fraction of students from rural areas) to allow visualisation of converging and diverging associations. Fractions of female or rural students were calculated from ERs rather than counts.

To account for multiple comparisons, all p-values were corrected for false discovery rate (FDR) using the Benjamini–Hochberg method.

## Results

This study included 14,193 students, of whom 9,609 (47%) were European and 4,584 (22%) were Asian (Table 3). There were several baseline differences between groupings. The Asian grouping, compared with the European grouping, were younger (19 years [interquartile range (IQR) 19–22] vs 20 years [IQR 19–25],  $p < 0.001$ ), had fewer females (68% vs 82%,  $p < 0.001$ ), were from more socio-economically deprived neighbourhoods (NZDep2018 quintile 1–2: 17% vs 30%,  $p < 0.001$ ) and fewer were from rural locations (2.1% vs 14%,  $p < 0.001$ ) (Table 3). Both ethnic groups predominately came from schools with high deciles; however, more Asian students attended low-decile schools (1–3) (12% vs 6.8%,  $p < 0.001$ ). Compared with Europeans, more Asian students were permanent residents (30% vs 14%,  $p < 0.001$ ), indicating a higher proportion of first-generation immigrants.

### Overall ER by level 1 Asian ethnic groupings

Across all programmes, the overall ER was higher for Asian students (ER [95% CI]: 280 [269–292] per 100,000 population aged 18–29 per year) (Figure 1A) than Europeans (149 [144–154] per 100,000 population aged 18–29 per year) (Figure 1A). However, level 2 ethnic sub-group ERs showed considerable heterogeneity, i.e., Indian ERs (160 [147–174] per 100,000 aged 18–29 per year) were similar to European, while “Other Asian” ERs were much higher (659 [610–712] per 100,000 aged 18–29 per year) (Figure 1A).

### ERRS by programme and level 2 Asian ethnic groupings

All four Asian sub-groups exhibited converging associations (unidirectional effect) towards well represented ( $\text{Log}_2[\text{ERR}] > 0$  or  $\text{ERR} > 1$ ) within optometry and optical dispensing, dental technology, oral health, medical laboratory science, podiatry, pharmacy and dentistry (Figure 1B, Appendix Table 1). Converging associations towards under-representation ( $\text{Log}_2[\text{ERR}] < 0$  or  $\text{ERR} < 1$ ) were evident among Indian, Chinese and Southeast Asian sub-groups in occupational therapy (ERRs: 0.33–0.67,  $p < 0.017$ ), midwifery (ERRs: 0.46–0.61,  $p < 0.002$ ) and paramedicine (ERRs: 0.23–0.39,  $p < 0.001$ ) (Figure 1B, Appendix Table 1). Divergent associations were also evident, with Indian and Chinese sub-groups under-represented in nursing (ERRs: 0.42 and 0.59, both  $p < 0.001$ ) while Other Asian and Southeast Asian sub-groups were adequately represented (ERRs: 1.43 and 1.67, both  $p < 0.001$ ) (Appendix Table 1). Similar trends were evident with physiotherapy, medical imaging and osteopathy (Figure 1B, Appendix Table 1).

Unadjusted student ERs (average number of students per 100,000 ethnicity-matched population aged 18–29 years per year) across all health professional programmes are shown in Graph A in Figure 1. The average enrolment rate of the European grouping is shown as a pink vertical line and the Asian grouping as a teal vertical line. The individual data points represent the enrolment rate and 95% CIs of level 2 ethnic subgroups. In Figure 1 Graph B, the ERs of Asian ethnic subgroups have been quantified as unadjusted ERRs (sub-group enrolment rate divided by European ER and  $\text{Log}_2$  transformed to make the scale symmetric and centred at 0) and grouped according to health professional programmes. The ERRs and their derivatives (i.e.,  $\text{Log}_2[\text{ERR}]$ ) were qualitatively interpreted by the terms: well represented (ER of an ethnic grouping was higher than the reference population—European—and statistically significant), equally represented (ER of an ethnic grouping was equal to European) and under-represented (ER of an ethnic grouping was lower than European and statistically significant). Red shades denote “under-represented” while blue denotes “well represented”. The size of each dot denotes p-values corrected for multiple comparisons (see Appendix Table 1 for values), with the black circles indicating the statistical significance ( $p = 0.05$ ) threshold. Data points have been ordered by hierarchical clustering using Euclidean distance to show converging associations between programme  $\text{Log}_2(\text{ERR})$  and ethnic sub-groups.

**Table 3:** Socio-demographic characteristics of students within Asian and European ethnic groupings.

Characteristic	Asian, N=4,584*	European, N=9,609*	p-value†
Age (mid-year)	19 (19–22)	20 (19–25)	<0.001‡
<b>Gender</b>			<0.001§
Male	1,443 (31%)	1,674 (17%)	
Female	3,141 (68%)	7,935 (82%)	
Diverse¶	3 (0.060%) <sup>5</sup>	11 (0.11%) <sup>5</sup>	
<b>NZDep2018 quintiles</b>			<0.001#
1–2 (least deprived)	716 (17%)	2,767 (30%)	
3–4	960 (23%)	2,204 (24%)	
5–6	981 (23%)	1,866 (21%)	
7–8	920 (22%)	1,401 (15%)	
9–10 (most deprived)	605 (14%)	842 (9.3%)	
<b>School deciles (grouped by tertile)</b>			<0.001#
8–10 (least deprived)	1,976 (52%)	4,385 (50%)	
4–7	1,379 (36%)	3,752 (43%)	
1–3 (most deprived)	471 (12%)	592 (6.8%)	
<b>Rurality by three aggregated groups (GCH)</b>			<0.001#
U1: major urban area	3,791 (91%)	6,303 (69%)	
U2: large urban area	302 (7.2%)	1,535 (17%)	
R: smaller urban and rural areas	89 (2.1%)	1,243 (14%)	
<b>Citizenship</b>			<0.001#
New Zealand citizen	3,219 (70%)	9,015 (94%)	
New Zealand permanent resident	1,365 (30%)	594 (6.2%)	

\*Median (interquartile range); n (%).

†p-values have been false discovery rate-corrected for multiple comparisons.

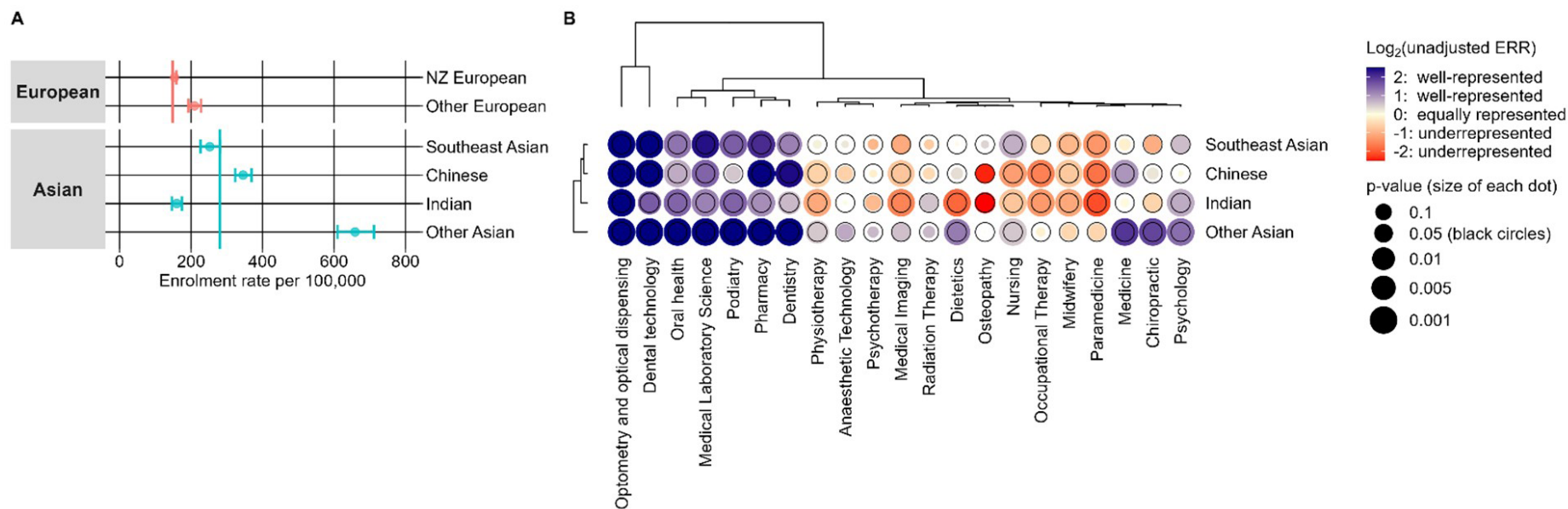
‡Wilcoxon Rank-Sum test.

§Fisher's exact test.

¶Gender-diverse individuals are shown here (gender totals will be >N in header) but not included elsewhere.

#Pearson's Chi-squared test.

**Figure 1:** Student enrolment rates by health professional programme and level 2 Asian ethnic groupings (total response ethnicity).



## Intersectionality

### NZDep2018

Across all socio-economic deprivation indices, ERs were higher (compared with Europeans) for students within the Asian ethnic grouping except for females within NZDep2018 decile one (ERR [95% CI]: 1.08 [0.99–1.19],  $p=0.099$ ) (Appendix Table 2). With increasing NZDep2018 scores, ERRs increased for both males (NZDep1 to NZDep10: 2.21 [1.98–2.47] to 2.87 [2.56–3.22],  $p<0.001$ ; respectively) and females (NZDep1 to NZDep10: 1.08 [0.99–1.19] to 1.40 [1.27–1.55],  $p<0.001$ ; respectively), indicating that students from the Asian ethnic grouping were more likely to have lived in areas with higher socio-economic deprivation than Europeans (Appendix Table 2).

When analysed by individual programmes, negative correlations were observed between ER and NZDep2018 (higher ERs with lower deprivation) for optometry and optical dispensing, radiation therapy, medical imaging, dentistry, chiropractic, physiotherapy, pharmacy and medicine (Figure 2A, Appendix Table 3) for both the European and the Asian ethnic groupings. More programmes (17 vs nine) had significant negative correlations between NZDep2018 and ERs among the European grouping compared with the Asian ethnic grouping (Appendix Table 3). Dental technology was the only programme that exhibited a significant negative correlation between ER and NZDep2018 for the Asian ethnic grouping but not the European.

### Gender

Only four of the 10 included institutions provided data on gender-diverse students. The proportion of gender-diverse students was low in the Asian ethnic grouping (0.06% compared with 0.11% European). The Asian grouping contained fewer females compared with the European (68% vs 82%, Table 3). Males from the Asian ethnic grouping were also more likely to come from areas with lower socio-economic deprivation scores (ERR at NZDep1 for females: 1.08 [0.99–1.19] vs 2.21 [1.98–2.47] for males,  $p<0.001$ ; Appendix Table 2).

### Rurality

Rural students from the Asian ethnic grouping were under-represented across the health professional programmes (2.1% vs 14%,  $p<0.001$ ; Asian grouping vs European respectively). This disparity did not meet statistical significance when comparing ER with ERRs (Appendix Table 2). However, osteopathy, psychotherapy and

dietetics contained no rural students from the Asian ethnic grouping. Similarly, dental technology contained no rural European students. By contrast, paramedicine drew the highest proportion of rural students from the Asian grouping (Figure 2B).

### Associations between intersectional variables

Hierarchical cluster analysis of all three intersectional variables (NZDep2018, gender, rurality) revealed two prominent clusters of programmes: those with converging associations between the Asian grouping and the European (left block, Figure 2B) and those with diverging associations (right block, Figure 2B). Programmes with converging associations (dental technology, radiation therapy, medical imaging, optometry and optical dispensing, medicine, pharmacy, physiotherapy, podiatry, chiropractic, dentistry) showed that the compositions of their students were similar regardless of ethnic grouping, i.e., similarly strong negative correlations between ER and deprivation index, similar proportions of females and similar proportions of rural students. Programmes with diverging associations (midwifery, dietetics, psychotherapy, medical laboratory science, occupational therapy, nursing, oral health, anaesthetic technology, osteopathy, paramedicine and psychology) had weaker correlation coefficients between NZDep2018 and ERs among the Asian grouping but not the European, and higher proportions of females for both ethnic groupings.

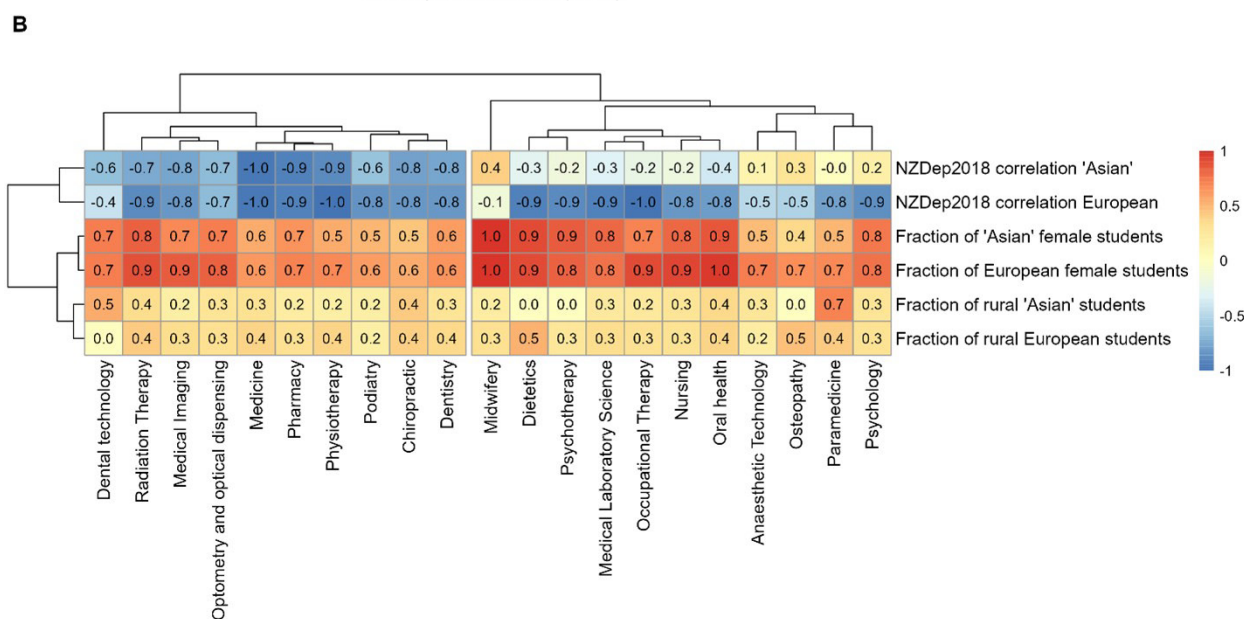
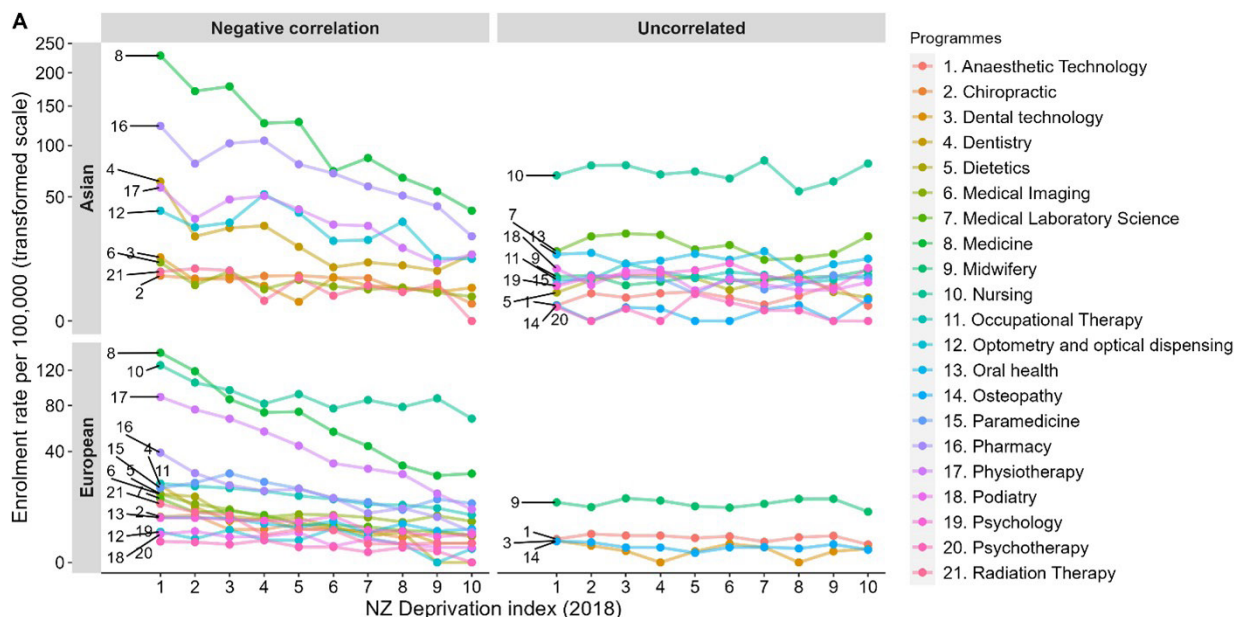
The relationship between ERs (number of students per 100,000 ethnicity-matched population aged 18–29 per year) and NZDep2018 index is shown using line charts in Figure 2 Graph A (treating NZDep2018 as a continuous variable) for each health professional programme with the Asian ethnic grouping and European (Europeans) faceted vertically (Appendix Table 3). Significant negative correlation coefficients (higher ERs observed with lower deprivation scores) have been faceted horizontally. The y-axes have been square root-transformed to allow easier visualisation of the individual lines. Intersectional variables (Pearson's correlation coefficients between ER and NZDep2018, fraction of females and rural students) were hierarchically clustered and displayed as a heat map in Figure 2 Graph B.

## Discussion

This is the first nationally co-ordinated study of the socio-demographic composition and



**Figure 2:** Comparison of the relationship between enrolment rates and socio-demographic profile between health professional students from Asian and European ethnic groupings (prioritised ethnicity).



representation of first year Asian students enrolled across individual health professional programmes in Aotearoa. The findings add to the evidence base on representation of populations within health workforce training programmes nationally,<sup>7,8</sup> and highlight the importance of disaggregating data for the pan-Asian group to gain a better understanding of difference within and among Asian sub-groups.

Compared with European students, the Asian

grouping overall had less privileged socio-economic backgrounds, more frequently attended high schools with lower socio-economic decile scores and had lower citizenship rates. Despite these disparities, the overall ER for the Asian grouping was higher than that for the European. While the Asian grouping was well represented overall within the health workforce in training, they were under-represented in specific programmes: midwifery, occupational

therapy and paramedicine—these correspond to areas of unmet healthcare need for this population.<sup>18,19,28–30,32</sup>

At the sub-group level, overall ERs varied widely, highlighting the need to examine Asian sub-groups separately. Several programmes showed divergent representation patterns among sub-groups: Indian and Chinese students were under-represented in physiotherapy, medical imaging, osteopathy and nursing, while the Southeast and Other Asian sub-groups were equally or well represented. Indian students were under-represented in dietetics, while students from the Other Asian sub-group were well represented. Students from the Chinese and Other Asian sub-groups were well represented in medicine, whereas the Indian and Southeast Asian sub-groups were equally represented. The Indian and Other Asian sub-groups were well represented in psychology, but Indian students trended toward under-representation in psychotherapy.

Intersectional variable analysis divided programmes into two groups; the first group (dental technology, radiation therapy, medical imaging, optometry and optical dispensing, medicine, pharmacy, physiotherapy, podiatry, chiropractic and dentistry) tended to draw students from more privileged socio-economic backgrounds and had reduced gender imbalance across both the European and the Asian groupings. By contrast, the second group (midwifery, dietetics, psychotherapy, medical laboratory science, occupational therapy, nursing, oral health, anaesthetic technology, osteopathy, paramedicine and psychology) tended to draw in more females, and ERs were not associated with NZDep2018 for the Asian grouping but were for the European.

The overall proportion of females in the Asian grouping was lower than that for Europeans and while this may be interpreted as reduced gender imbalance, it was associated with reduced representation in programmes that were disproportionately composed of females. This is particularly concerning considering Indian and other South Asian populations suffer high rates of perinatal and maternal morbidity and mortality<sup>28</sup> and students from these communities are under-represented in midwifery. Poor perinatal and maternal outcomes for this population have been attributed to systemic barriers to accessing culturally appropriate health services.<sup>28</sup> These issues are particularly amenable to lived experience-informed practice. The latest midwifery workforce survey (2022) represents students in this study

(2016–2020) entering the workforce and shows that among 3,085 registrations only 30 midwives (<1%) were Indian,<sup>46</sup> which was fivefold lower than the proportion of Indians in Aotearoa's total population at that time.<sup>17</sup> Since the Indian population is projected to increase<sup>36</sup> (and has done so according to the latest census data),<sup>22</sup> Indian representation in midwifery relative to the Indian population can be expected to worsen and recruitment strategies must account for this.

In Aotearoa, several health conditions occur at higher rates among Indians and South Asians, which likely contribute to poor perinatal and maternal outcomes including cardiovascular disease, and metabolic and blood disorders.<sup>18,19,28–30,32</sup> Health professional programmes that aim to manage these conditions (midwifery, dietetics, paramedicine, physiotherapy, occupational therapy) had relatively poor Indian student representation in the current study, and the underlying reasons for this need further exploration. This study identified differences between Asian and European students by socio-economic background and gender. Programmes lacking representation from the Asian grouping had higher proportions of females overall, perhaps indicating a barrier to entry for females in the Asian grouping. Other factors, like pressure to uphold the model minority myth,<sup>33–35,47</sup> may divert students from the Asian grouping to professions with higher salaries and higher social standing within their communities. We are not aware of any studies to compare our results with.

There were several limitations in this study. The participation rate among tertiary institutions was 10 out of 23 eligible institutions. It was not possible to measure any bias in the calculation of ERs of Asian students that may have resulted from the non-participation of 13 institutions. As discussed above, the Asian grouping does not properly represent the immense diversity of its constituent communities and potentially masks differences in their healthcare needs and representation within the health workforce in training because of averaging various characteristics.<sup>26,48</sup> That intersectional characteristics were only available for level 1 ethnic groupings is a limitation, and this issue persists even to level 2 sub-groups—for example, Other Asian includes individuals from South and East Asia, making findings non-specific and difficult to interpret. This study is based on enrolment data only; data on course completion rates, employment rates within Aotearoa post-qualification and how many graduates leave Aotearoa once qualified were not

collected. In addition, Aotearoa grants a 3-year job search visa after graduating, but this study was not able to measure whether international students of Asian ethnicity contributed to the health workforce after graduation. Institutional collection of gender-diverse data was inconsistent and insufficient for analysis. Lastly, data were collected over 5 years and cannot provide trends over time. Longitudinal analyses should be the subject of future investigations.

This novel research provides detailed information on Asian sub-group representation in health professional programmes in polytechnics and universities in Aotearoa. Taken

in the context of known health needs of different Asian sub-groups, these data may facilitate health workforce planning and targeted policies within health professional programmes in order to better match the health workforce to population health needs. We recommend that the health and tertiary education systems should, together, ensure that there is improved measurement of ethnicity, including more complete and more accurate collection of Asian sub-group data for the health workforce in training with a view of monitoring and meeting healthcare needs of diverse Asian communities.

**COMPETING INTERESTS**

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**AUTHOR INFORMATION**

Navneet N Lal: Te Whatu Ora Southern, Dunedin Public Hospital, Dunedin, Aotearoa New Zealand; Kōhatu Centre for Hauora Māori, University of Otago, Dunedin, Aotearoa New Zealand.

Gabrielle McDonald: Kōhatu Centre for Hauora Māori, University of Otago, Dunedin, Aotearoa New Zealand.

Andrew Sise: Kōhatu Centre for Hauora Māori, University of Otago, Dunedin, Aotearoa New Zealand.

Warwick Bagg: Faculty of Medical and Health Sciences, The University of Auckland, Auckland, Aotearoa New Zealand.

Zoe Bristowe: Te Whatu Ora Southern, Dunedin Public Hospital, Dunedin, Aotearoa New Zealand.

Paul Brunton: Faculty of Dentistry, University of Otago, Dunedin, Aotearoa New Zealand.

Chris Hendry: Centre for Postgraduate Nursing, University of Otago Christchurch, Christchurch, Aotearoa New Zealand.

Bridget Kool: Section of Epidemiology & Biostatistics, School of Population Health, Faculty of Medical and Health Sciences, The University of Auckland, Auckland, Aotearoa New Zealand.

Damian Scarf: Department of Psychology, University of Otago, Dunedin, Aotearoa New Zealand.

Susan Shaw: Faculty of Health and Environmental Sciences, Auckland University of Technology, Auckland, Aotearoa New Zealand.

Collin Tukuitonga: Faculty of Medical and Health Sciences, The University of Auckland, Auckland, Aotearoa New Zealand.

Jonathan Williman: Department of Public Health and General Practice, University of Otago Christchurch, Christchurch, Aotearoa New Zealand.

Denise Wilson: Faculty of Health and Environmental Sciences, Auckland University of Technology, Auckland, Aotearoa New Zealand.

Peter Crampton: Kōhatu Centre for Hauora Māori, University of Otago, Dunedin, Aotearoa New Zealand.

**CORRESPONDING AUTHOR**

Peter Crampton: Kōhatu Centre for Hauora Māori, University of Otago, Dunedin, Aotearoa New Zealand.  
E: peter.crampton@otago.ac.nz

**URL**

<https://nzmj.org.nz/journal/vol-137-no-1607/representation-of-asian-ethnic-sub-groups-in-aotearoa-s-regulated-health-workforce-pre-registration-students>

**REFERENCES**

1. Abid Y, Connell CJW, Sijnja B, et al. National study of the impact of rural immersion programs on intended location of medical practice in New Zealand. *Rural Remote Health*. 2020;20(4):5785. doi: 10.22605/RRH5785.
2. De Vries E, Reid S. Do South African medical students of rural origin return to rural practice? *S Afr Med J*. 2003;93(10):789-93.
3. Komaromy M, Grumbach K, Drake M, et al. The role of black and Hispanic physicians in providing health care for underserved populations. *N Engl J Med*. 1996;334(20):1305-10. doi: 10.1056/NEJM199605163342006.
4. Matthews C, Bagg W, Yelder J, et al. Does Pūkawakawa (the regional-rural programme at the University of Auckland) influence workforce choice? *N Z Med J*. 2015;128(1409):35-43.
5. Traylor AH, Schmittiel JA, Uratsu CS, et al. Adherence to cardiovascular disease medications: does patient-provider race/ethnicity and language concordance matter? *J Gen Intern Med*. 2010;25(11):1172-7. doi: 10.1007/s11606-010-1424-8.
6. *Pae Ora (Healthy Futures) Act 2022* (NZ).
7. Bagg W, Curtis E, Eggleton KT, et al. Socio-demographic profile of medical students in Aotearoa, New Zealand (2016–2020): a nationwide cross-sectional study. *BMJ Open*. 2023;13(12):e073996. doi: 10.1136/bmjopen-2023-073996.
8. Crampton P, Bagg W, Bristowe Z, et al. National cross-sectional study of the sociodemographic characteristics of Aotearoa New Zealand's regulated health workforce pre-registration students: a mirror on society? *BMJ Open*. 2023;13(3):e065380. doi: 10.1136/bmjopen-2022-065380.
9. Fletcher N. *The English Text of the Treaty of*

- Waitangi. Wellington, New Zealand: Bridget Williams Books; 2022.
10. Orange C. *The Treaty of Waitangi*. 2nd ed. Wellington, New Zealand: Bridget Williams Books; 2011.
  11. Reid P, Cormack D, Paine SJ. Colonial histories, racism and health—The experience of Māori and Indigenous peoples. *Public Health*. 2019;172:119-24. doi: 10.1016/j.puhe.2019.03.027.
  12. Health New Zealand – Te Whatu Ora. Health Workforce Plan 2023/24 [Internet]. Wellington, New Zealand: Health New Zealand – Te Whatu Ora; 2023 [cited 2024 Apr 22]. Available from: <https://www.tewhatauora.govt.nz/publications/health-workforce-plan-202324>
  13. Crampton P, Weaver N, Howard A. Holding a mirror to society? Progression towards achieving better sociodemographic representation among the University of Otago's health professional students. *N Z Med J*. 2018;131(1476):59-69.
  14. Curtis E, Wikaire E, Jiang Y, et al. Examining the predictors of academic outcomes for indigenous Māori, Pacific and rural students admitted into medicine via two equity pathways: a retrospective observational study at the University of Auckland, Aotearoa New Zealand. *BMJ Open*. 2017;7(8):e017276. doi: 10.1136/bmjopen-2017-017276.
  15. University of Auckland. About MAPAS [Internet]. Auckland, New Zealand: The University of Auckland; 2022 [cited 2024 Aug 31]. Available from: <https://www.auckland.ac.nz/en/fmhs/study-with-us/maori-and-pacific-at-the-faculty/maori-and-pacific-admission-schemes.html>
  16. University of Otago. Te Kauae Parāoa: Division of Health Sciences Policy on Admissions [Internet]. Dunedin, New Zealand: University of Otago; 2021 [cited 2024 Aug 31]. Available from: <https://www.otago.ac.nz/healthsciences/staff/otago838748.html>
  17. Statistics New Zealand. Ethnic group summaries reveal New Zealand's multicultural make-up [Internet]. Statistics New Zealand; 2020 [cited 2023 Oct 13]. Available from: <https://www.stats.govt.nz/news/ethnic-group-summaries-reveal-new-zealands-multicultural-make-up/>
  18. Chiang A, Simon-Kumar R, Peiris-John R. A decade of Asian and ethnic minority health research in New Zealand: findings from a scoping review. *N Z Med J*. 2021;134(1542):67-83.
  19. Ministry of Health – Manatū Hauora. Asian Health Chart Book 2006 [Internet]. Wellington, New Zealand: Ministry of Health – Manatū Hauora; 2006 [cited 2023 Aug 7]. Available from: <https://www.health.govt.nz/publications/asian-health-chart-book-2006>
  20. Rasanathan K, Ameratunga S, Tse S. Asian health in New Zealand—progress and challenges. *N Z Med J*. 2006;119(1244):U2277.
  21. Carpenter L, Fraser L, editors. *Rushing for Gold: Life and commerce on the goldfields of New Zealand and Australia*. Dunedin, New Zealand: Otago University Press; 2016.
  22. Statistics New Zealand. 2023 Census population counts (by ethnic group, age, and Māori descent) and dwelling counts [Internet]. Statistics New Zealand; 2024 [cited 2024 Aug 21]. Available from: <https://www.stats.govt.nz/information-releases/2023-census-population-counts-by-ethnic-group-age-and-maori-descent-and-dwelling-counts/>
  23. Ministry of Business Innovation and Employment – Hīkina Whakatutuki, Ministry of Health – Manatū Hauora. *New Zealand Health Research Strategy 2017-2027* [Internet]. Wellington, New Zealand: Ministry of Business Innovation and Employment – Hīkina Whakatutuki, Ministry of Health – Manatū Hauora; 2017 [cited 2023 Oct 2]. Available from: <https://www.health.govt.nz/system/files/2017-06/nz-health-research-strategy-jun17.pdf>
  24. Wong A. Challenges for Asian health and Asian health promotion in New Zealand. *Asian J Med Health Res*. 2015;11(1):71-90.
  25. Statistics New Zealand. Ethnicity [Internet]. Statistics New Zealand. [cited 2023 Dec 15]. Available from: <https://www.stats.govt.nz/topics/ethnicity>
  26. Rasanathan K, Craig D, Perkins R. The novel use of 'Asian' as an ethnic category in the New Zealand health sector. *Ethn Health*. 2006;11(3):211-27. doi: 10.1080/13557850600565525.
  27. Statistics New Zealand. Ethnicity (information about this variable and its quality) [Internet]. Statistics New Zealand; 2021 [cited 2023 Oct 12]. Available from: [https://datainfolplus.stats.govt.nz/Item/nz.govt.stats/7079024d-6231-4fc4-824f-dd8515d33141?\\_ga=2.82882902.1339593584.1697077291-338103323.1689808057](https://datainfolplus.stats.govt.nz/Item/nz.govt.stats/7079024d-6231-4fc4-824f-dd8515d33141?_ga=2.82882902.1339593584.1697077291-338103323.1689808057)
  28. Dawson P, Auvray B, Jaye C, et al. Social determinants and inequitable maternal and perinatal outcomes in Aotearoa New Zealand. *Womens Health (Lond)*. 2022;18: 17455065221075913. doi: 10.1177/17455065221075913.
  29. de Graaff E, Sadler L, Lakhdir H, et al. An in-depth analysis of perinatal related mortality among women of South Asian ethnicity in Aotearoa New Zealand. *BMC Pregnancy Childbirth*. 2023;23(1):535.

- doi: 10.1186/s12884-023-05840-x.
30. Te Tāhū Hauora – Health Quality and Safety Commission. Fifteenth Annual Report of the Perinatal and Maternal Mortality Review Committee: Reporting Mortality and Morbidity 2020 [Internet]. Perinatal and Maternal Mortality Review Committee; 2024 Mar 28 [cited 2024 Mar 24]. Available from: <https://www.hqsc.govt.nz/resources/resource-library/fifteenth-annual-report-of-the-perinatal-and-maternal-mortality-review-committee-reporting-mortality-and-morbidity-2020/>
  31. Peiris-John R, Kang K, Bavin L, et al. East Asian, South Asian, Chinese and Indian Students in Aotearoa: A Youth19 Report [Internet]. Auckland, New Zealand: The University of Auckland; 2021 [cited 2024 Feb 24]. Available from: <https://www.youth19.ac.nz/publications/asian-students-report>
  32. Mehta S. Health needs assessment of Asian people in the Auckland region [Internet]. Auckland, New Zealand: Northern DHB Support Agency; 2012 [cited 2023 Oct 14]. Available from: <https://www.waitematahnb.govt.nz/assets/Documents/health-needs-assessments/AsianHealth2012.pdf>
  33. Kawai Y. Stereotyping Asian Americans: The Dialectic of the Model Minority and the Yellow Peril. *The Howard Journal of Communications*. 2005;16(2):109-30.
  34. Wong F, Halgin R. The “Model Minority”: Bane or Blessing for Asian Americans? *Journal of Multicultural Counseling and Development*. 2006;34(1):38-49. <https://doi.org/10.1002/j.2161-1912.2006.tb00025.x>
  35. Yi SS, Kwon SC, Suss R, et al. The Mutually Reinforcing Cycle Of Poor Data Quality And Racialized Stereotypes That Shapes Asian American Health. *Health Aff (Millwood)*. 2022;41(2):296-303. doi: 10.1377/hlthaff.2021.01417.
  36. Parackal S, Coppel K, Yang CL, Sullivan T, Subramaniam RM. Hidden figures and misnomers: a case for disaggregated Asian health statistics in Aotearoa New Zealand to improve health outcomes. *N Z Med J*. 2021;134(1546):109-16.
  37. Mishra SK. The Colonial Origins of Territorial Disputes in South Asia. *Journal of Territorial and Maritime Studies*. 2016;3(1):5-23.
  38. Hassankhan MS, Lal BV, Munro D, editors. *Resistance and Indian Indenture Experience: Comparative Experiences*. New Delhi, India: Manohar Publishers and Distributors; 2014.
  39. *Health Practitioners Competence Assurance Act 2003* (NZ).
  40. Ministry of Health – Manatū Hauora. Ethnicity Data Protocols: HISO 10001:2017 [Internet]. Wellington, New Zealand: Ministry of Health–Manatū Hauora; 2017 [cited 2023 Oct 14]. Available from: [https://www.tewhatauora.govt.nz/assets/Our-health-system/Digital-health/Health-information-standards/hiso\\_10001-2017\\_ethnicity\\_data\\_protocols\\_21\\_apr.pdf](https://www.tewhatauora.govt.nz/assets/Our-health-system/Digital-health/Health-information-standards/hiso_10001-2017_ethnicity_data_protocols_21_apr.pdf)
  41. Cormack D, Robson C. Classification and output of multiple ethnicities: issues for monitoring Māori health. Wellington, New Zealand: Te Rōpū Rangahau Hauora a Eru Pōmare; 2010 [cited 2023 Oct 14]. Available from: <https://www.fmhs.auckland.ac.nz/assets/fmhs/Te%20Kupenga%20Hauora%20M%C4%81ori/docs/classification.pdf>
  42. Atkinson J, Salmond C, Crampton P. NZDep2018 Index of Deprivation User’s Manual [Internet]. University of Otago Department of Public Health; 2019 [cited 2023 Oct 14]. Available from: [https://www.otago.ac.nz/\\_\\_data/assets/pdf\\_file/0030/314976/nzdep2018-index-of-deprivation-users-manual-730391.pdf](https://www.otago.ac.nz/__data/assets/pdf_file/0030/314976/nzdep2018-index-of-deprivation-users-manual-730391.pdf)
  43. Whitehead J, Davie G, de Graaf B, et al. Defining rural in Aotearoa New Zealand: a novel geographic classification for health purposes. *N Z Med J*. 2022;135(1559):24-40. doi: 10.26635/6965.5495.
  44. Wickham H. *ggplot2: Elegant Graphics for Data Analysis*. New York, USA: Springer; 2016.
  45. Yu G, Smith DK, Zhu H, et al. ggtree: an R package for visualization and annotation of phylogenetic trees with their covariates and other associated data. *Methods in Ecology and Evolution*. 2016;8(1):28-36. doi:10.1111/2041-210X.12628.
  46. Te Tatau o te Whare Kahu – Midwifery Council. 2022 Midwifery Workforce Survey and Non-Practising Survey [Internet]. Wellington, New Zealand: Te Tatau o te Whare Kahu – Midwifery Council; 2022 [cited 2023 Oct 13]. Available from: <https://midwiferycouncil.health.nz/common/Uploaded%20files/Workforce%20surveys/Midwifery%20Workforce%20Survey%202022.pdf>
  47. Peiris-John R, Bavin L, Kang K, et al. Factors predicting forgone healthcare among Asian adolescents in New Zealand: unmasking variation in aggregate data. *N Z Med J*. 2022;135(1549):63-80.
  48. De Graaff E, Sadler L, Lakhdhir H, et al. Grouping women of South Asian ethnicity for pregnancy research in New Zealand. *Aust N Z J Obstet Gynaecol*. 2023;63(4):499-508. doi: 10.1111/ajo.13626.

## Appendix

**Appendix Table 1:** Enrolment rate ratios for Asian ethnic sub-groups using European as the reference group (total response ethnicity).

Programme	Age band	Chinese ERR* (95% CI <sup>+</sup> ) & p-value <sup>‡</sup>	Indian ERR* (95% CI <sup>+</sup> ) & p-value <sup>‡</sup>	Other Asian ERR* (95% CI <sup>+</sup> ) & p-value <sup>‡</sup>	Southeast Asian ERR* (95% CI <sup>+</sup> ) & p-value <sup>‡</sup>
Anaesthetic technology	18–49	0.66 (0.39–1.05) p=0.100	0.98 (0.65–1.43) p=0.908	1.74 (0.89–3.07) p=0.077	1.15 (0.54–2.13) p=0.679
Chiropractic	18–39	1.17 (0.88–1.53) p=0.270	0.68 (0.49–0.93) p=0.019	3.51 (2.50–4.8) p<0.001	0.48 (0.21–0.94) p=0.057
Dental technology	18–29	10.09 (5.56–19.17) p<0.001	2.99 (1.37–6.37) p=0.005	16.36 (7.50–34.89) p<0.001	10.24 (4.12–23.56) p<0.001
Dentistry	18–29	5.30 (4.20–6.69) p<0.001	1.56 (1.13–2.12) p=0.005	8.09 (5.84–11.04) p<0.001	2.29 (1.31–3.73) p=0.002
Dietetics	18–29	1.23 (0.84–1.76) p=0.261	0.27 (0.13–0.49) p<0.001	2.37 (1.36–3.85) p=0.001	0.97 (0.41–1.93) p=0.945
Medical imaging	18–39	0.60 (0.44–0.8) p<0.001	0.34 (0.23–0.48) p<0.001	1.50 (0.99–2.17) p=0.043	0.47 (0.23–0.83) p=0.018
Medical laboratory science	18–29	2.80 (2.13–3.66) p<0.001	2.26 (1.72–2.95) p<0.001	5.62 (3.89–7.92) p<0.001	5.14 (3.54–7.26) p<0.001
Medicine	18–29	1.99 (1.82–2.17) p<0.001	0.97 (0.87–1.08) p=0.539	3.93 (3.47–4.43) p<0.001	0.88 (0.69–1.10) p=0.269
Midwifery	18–49	0.61 (0.49–0.75) p<0.001	0.46 (0.36–0.57) p<0.001	0.70 (0.45–1.03) p=0.085	0.52 (0.33–0.77) p=0.002
Nursing	18–39	0.42 (0.38–0.46) p<0.001	0.59 (0.54–0.64) p<0.001	1.43 (1.27–1.61) p<0.001	1.67 (1.50–1.85) p<0.001
Occupational therapy	18–49	0.33 (0.25–0.42) p<0.001	0.40 (0.32–0.5) p<0.001	0.89 (0.64–1.21) p=0.478	0.67 (0.47–0.91) p=0.017

**Appendix Table 1: (continued)** Enrolment rate ratios for Asian ethnic sub-groups using European as the reference group (total response ethnicity).

Optometry and optical dispensing	18–29	18.52 (13.57–25.8) p<0.001	6.51 (4.57–9.39) p<0.001	32.19 (22.42–46.68) p<0.001	12.25 (7.67–19.26) p<0.001
Oral health	18–39	1.71 (1.32–2.2) p<0.001	2.79 (2.27–3.43) p<0.001	5.68 (4.23–7.51) p<0.001	2.51 (1.7–3.59) p<0.001
Osteopathy	18–49	0.19 (0.03–0.61) p=0.021	0.17 (0.03–0.54) p=0.013	1.00 (0.16–3.19) p=0.995	1.31 (0.40–3.21) p=0.597
Paramedicine	18–39	0.30 (0.22–0.39) p<0.001	0.23 (0.17–0.31) p<0.001	0.69 (0.45–1) p=0.066	0.39 (0.23–0.62) p<0.001
Pharmacy	18–29	5.60 (4.89–6.42) p<0.001	2.09 (1.77–2.47) p<0.001	11.56 (9.77–13.64) p<0.001	4.22 (3.31–5.31) p<0.001
Physiotherapy	18–29	0.66 (0.55–0.78) p<0.001	0.46 (0.38–0.55) p<0.001	1.41 (1.10– to 1.77) p=0.005	1.09 (0.83–1.40) p=0.528
Podiatry	18–39	1.44 (0.91–2.22) p=0.106	2.82 (2.01–3.95) p<0.001	8.67 (5.75–12.82) p<0.001	2.93 (1.59–5.00) p<0.001
Psychology	18–49	1.03 (0.79–1.33) p=0.817	1.72 (1.39–2.11) p<0.001	2.62 (1.85–3.61) p<0.001	1.52 (1.01–2.20) p=0.032
Psychotherapy	18–59	0.86 (0.45–1.52) p=0.636	0.54 (0.24–1.04) p=0.093	1.57 (0.55–3.49) p=0.329	0.52 (0.09–1.64) p=0.358
Radiation therapy	18–29	0.72 (0.39–1.22) p=0.252	1.46 (0.98–2.13) p=0.054	1.56 (0.65–3.12) p=0.260	0.63 (0.15–1.66) p=0.424

ERR\* = enrolment rate ratio calculated using European enrolment rate as a reference group; CI<sup>†</sup> = confidence interval.  
p-values<sup>‡</sup> are false discovery rate–corrected for multiple comparisons.



**Appendix Table 2:** Poisson regression model output with contrasts between ethnic groupings—enrolment rate ratios are calculated as an average across all programmes (prioritised ethnicity).

Contrast	NZDep2018/ GCH2018§	Gender	ERR* (95% CI <sup>†</sup> )	p-value <sup>‡</sup>
Asian/European	NZDep1	Female	1.08 (0.99–1.19)	0.099
Asian/European	NZDep2	Female	1.11 (1.02–1.22)	0.015
Asian/European	NZDep3	Female	1.15 (1.06–1.25)	0.001
Asian/European	NZDep4	Female	1.18 (1.09–1.28)	<0.001
Asian/European	NZDep5	Female	1.22 (1.12–1.31)	<0.001
Asian/European	NZDep6	Female	1.25 (1.16–1.35)	<0.001
Asian/European	NZDep7	Female	1.29 (1.19–1.40)	<0.001
Asian/European	NZDep8	Female	1.32 (1.21–1.45)	<0.001
Asian/European	NZDep9	Female	1.36 (1.24–1.50)	<0.001
Asian/European	NZDep10	Female	1.40 (1.27–1.55)	<0.001
Asian/European	NZDep1	Male	2.21 (1.98–2.47)	<0.001
Asian/European	NZDep2	Male	2.28 (2.05–2.53)	<0.001
Asian/European	NZDep3	Male	2.35 (2.12–2.59)	<0.001
Asian/European	NZDep4	Male	2.41 (2.19–2.66)	<0.001
Asian/European	NZDep5	Male	2.48 (2.26–2.73)	<0.001
Asian/European	NZDep6	Male	2.56 (2.32–2.81)	<0.001
Asian/European	NZDep7	Male	2.63 (2.39–2.90)	<0.001
Asian/European	NZDep8	Male	2.71 (2.45–3.00)	<0.001
Asian/European	NZDep9	Male	2.79 (2.50–3.11)	<0.001
Asian/European	NZDep10	Male	2.87 (2.56–3.22)	<0.001
Asian/European	Major urban area	Female	1.05 (0.97–1.14)	0.191
Asian/European	Large urban area	Female	1.15 (0.99–1.33)	0.068
Asian/European	Medium urban area	Female	1.03 (0.83–1.28)	0.787
Asian/European	Small urban area	Female	0.88 (0.69–1.12)	0.303
Asian/European	Rural settlement	Female	0.65 (0.35–1.19)	0.16
Asian/European	Rural other	Female	0.93 (0.75–1.16)	0.536
Asian/European	Major urban area	Male	2.15 (1.95–2.37)	<0.001
Asian/European	Large urban area	Male	2.33 (2.00–2.73)	<0.001

**Appendix Table 2 (continued):** Poisson regression model output with contrasts between ethnic groupings—enrolment rate ratios are calculated as an average across all programmes (prioritised ethnicity).

Asian/European	Medium urban area	Male	2.10 (1.67–2.63)	<0.001
Asian/European	Small urban area	Male	1.79 (1.39–2.30)	<0.001
Asian/European	Rural settlement	Male	1.32 (0.72–2.42)	0.375
Asian/European	Rural other	Male	1.90 (1.51–2.38)	<0.001

NZDep = New Zealand Index of Deprivation; GCH2018§ = Geographic Classification for Health 2018—defines urban/rural locations based on drive time to major urban centres; ERR\* = enrolment rate ratio; CI† = confidence intervals. p-values‡ are false discovery rate-corrected for multiple comparisons.

**Appendix Table 3:** Pearson's correlation coefficients between New Zealand Index of Deprivation 2018 (as a continuous variable) and enrolment rate for level 1 ethnic groupings (prioritised ethnicity).

Programmes	Asian*	European*
Medicine	-1.0, p<0.001	-1.0, p<0.001
Physiotherapy	-0.9, p<0.001	-1.0, p<0.001
Pharmacy	-0.9, p<0.001	-0.9, p<0.001
Radiation therapy	-0.7, p=0.015	-0.9, p<0.001
Chiropractic	-0.8, p=0.007	-0.8, p=0.003
Dentistry	-0.8, p=0.009	-0.8, p=0.003
Medical imaging	-0.8, p=0.010	-0.8, p=0.003
Podiatry	-0.6, p=0.054	-0.8, p=0.002
Optometry and optical dispensing	-0.7, p=0.032	-0.7, p=0.038
Medical laboratory science	-0.3, p=0.360	-0.9, p<0.001
Occupational therapy	-0.2, p=0.538	-1.0, p<0.001
Dietetics	-0.3, p=0.436	-0.9, p<0.001
Oral health	-0.4, p=0.269	-0.8, p=0.005
Dental technology	-0.6, p=0.046	-0.4, p=0.226
Psychotherapy	-0.2, p=0.651	-0.9, p<0.001
Nursing	-0.2, p=0.619	-0.8, p=0.003
Paramedicine	0.0, p=0.990	-0.8, p=0.006
Psychology	0.2, p=0.665	-0.9, p=0.001
Anaesthetic technology	0.1, p=0.723	-0.5, p=0.159
Osteopathy	0.3, p=0.444	-0.5, p=0.118
Midwifery	0.4, p=0.246	-0.1, p=0.685

\*Pearson's correlation coefficient treating NZDep2018 as a continuous variable.

# The first trimester abortion journey Aotearoa: health practitioners' perspectives

Emma Macfarlane, Pauline Dawson, Michael Stitely, Helen Paterson

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## ABSTRACT

**AIM:** To gain insight into health practitioners' understanding of how people experience the first trimester abortion journey.

**METHODS:** Qualitative interviews informed by phenomenology with health practitioners from a range of practice settings across Aotearoa New Zealand. Participants were recruited via a separate but related study. Inductive thematic analysis was used to develop themes.

**RESULTS:** Interviews were undertaken with 18 health practitioners. Analysis revealed three main themes: 1) abortion is a stepwise process, 2) barriers to accessing abortion care, and 3) solutions to improve access to abortion care. There were a number of sub-themes.

**CONCLUSION:** While there remain multiple personal, institutional and societal barriers to abortion in Aotearoa, this study identifies potential solutions and that a desire for positive change among health practitioners exists. To achieve this, a strategy is required to ensure that the health consumer is placed at the centre of abortion services to provide accessible, equitable and culturally appropriate care. The primary care sector stands to play a significant role in future abortion provision but requires appropriate funding and support to do so.

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The Aotearoa New Zealand *Abortion Legislation Act 2020* allows the right to choose abortion (up to 20 weeks' gestation), self-referral, and for abortion provision in a range of settings, by a range of practitioners.<sup>1</sup> While law reform resolved many legal barriers, abortion funding remains with pre-existing abortion services, despite recent research demonstrating many health practitioners in Aotearoa have transferrable skills and are willing to provide first trimester abortion.<sup>2</sup>

Other high-income countries also face barriers to abortion relating to travel, insufficient training and stigma.<sup>3</sup> In Northern Ireland, despite repeal of the Irish Constitution's Eighth Amendment, barriers to abortion remain, including a mandatory reflection period, requirement for clinician referral and funding.<sup>4</sup> Those most affected are people with complex needs.<sup>5</sup> The *New Zealand Aotearoa Abortion Clinical Guideline* recognises inequity in Aotearoa for Māori and for those that are young, homeless, unemployed and LGBTQIA+.<sup>6</sup> Achieving equitable health outcomes in abortion care is a priority.

The aim of this study is to gain insight into health practitioners' understanding of how people experience the first trimester abortion journey. The objective is to determine what is required to enable provision of equitable and

optimal first trimester abortion care in Aotearoa.

## Methods

This study is informed by phenomenology, with the purpose of undertaking research that "discovers, explores and describes" a phenomenon. This design was selected to ensure rich and descriptive data to capture the experience of the abortion journey in all its facets.<sup>7</sup>

Health practitioners (doctors, registered nurses [RNs], midwives, counsellors and social workers) from across Aotearoa who participated in a previous study,<sup>2</sup> and who declared no conscientious objection to abortion and consented to be contacted by email for future research, were emailed an invitation to participate in an interview regarding their perspectives of how first trimester abortion care is experienced by the consumer. The email included a REDCap survey link so that participants could be purposively selected for a range of characteristics and demographics. Questions included profession, scope of practice, experience, geographical location, age and gender. These data were used for recruitment only and were not included in the findings. The survey tool was tested by a selection of health practitioners for clarity and useability. If no response was received

after 7 days, a follow-up email was sent. After a further 3 days of no response, participants were presumed to have declined. All interviews were conducted over February–March 2022 by secure video conferencing.

To open, the interviewer asked participants to describe how people access abortion in their area. Other pre-determined questions included “How is contraception provided postabortion?” Prompts were used to further encourage participants, for example “Can you tell me more about that?” Effort was made to avoid leading the participant. Refer to Table 1 for further examples of interview questions.

Audio was transcribed by a human-based transcription service and anonymised. NVivo<sup>8</sup> was used to assist in a process of inductive thematic analysis.<sup>9</sup> While an inductive approach was used to capture the experience of the participants, it is impossible for the researcher to place themselves outside of the analysis. The interviewer is a health practitioner and is pro-choice. A deductive process of viewing data through the lens of the researcher and the research question is inevitable.<sup>9</sup>

Analysis began with close reading, then assigning codes to meaningful phrases that were collated into themes with shared meaning. Themes were merged, split or deleted to make sense of the data. Themes were named to reflect their meaning and to represent participant narratives. Co-coding was undertaken by a research assistant with experience in qualitative methods. Discrepancies were discussed until agreement was reached.

This study was approved by the University of Otago Ethics Committee (H21/047). Consultation with Māori was undertaken with The Ngāi Tahu Research Consultation Committee and within the Department of Women’s and Children’s Health, Dunedin School of Medicine.

## Results

Of the 24 people who responded to the invitation, 18 (doctors=12, RNs/counsellors/social workers=6) were contactable and consented to interviews. The non-doctors were grouped due to numbers fewer than 10 to maintain anonymity. Participants represented a range of specialities, including abortion, primary care and specialist services, and had various roles in abortion care.

Analysis of qualitative data revealed three themes with sub-themes: 1) abortion is a stepwise process, 2) barriers to accessing abortion care,

and 3) strategies to increase access to abortion.

### Theme one: abortion is a stepwise process

The abortion journey is a linear process of pre-abortion requirements, the abortion itself and then the post-abortion experience. Pre-abortion events involve initial decision making and, if abortion is chosen, what method. Decisions may be pragmatic or complex.

*“I think for some people it’s just simply a case that they’re pregnant, they don’t want to be pregnant and there’s a solution that’s relatively easy and it’s very safe.” – Participant 3*

People can self-refer into abortion services or be referred by practitioners. Bloods, swabs and ultrasound may be required. Counselling is optional.

For the abortion itself, people can have an early medical abortion (EMA) or surgical abortion. Some participants reported anecdotally an increase in people choosing EMA.

*“There’s a huge proportion now having EMA; overwhelmingly women are very positive about that, about it being very straightforward, clearly explained to them, not too painful, not traumatic.” – Participant 15*

Post-abortion care may include contraception at the time of abortion, depending on the abortion and contraceptive methods. People having EMA may have a blood test or low sensitivity urine pregnancy test to confirm a complete abortion.

### Theme two: barriers for people accessing abortion care

#### Personal barriers

While self-referral was generally seen as positive, navigating this pathway may be problematic.

*“You’ve gotta go online, and for our local abortion provider, you’ve got to click through a lot of screens to find the information that you need. It’s difficult, they have to find that information out for themselves.” – Participant 15*

Travel was identified as a barrier, particularly for rural people.

*“It’s all very well for us to say, ‘This is where you can go to have your abortion,’ but it’s about getting there for a lot of them.” – Participant 3*

There are costs for travel, time off work, childcare and, depending on location, ultrasound.

*“Some private providers charge NZ\$40 and some don’t charge at all. They’ve got the biggest capacity, so you can get in quicker, but the ones that are cheaper are a little bit harder to get into.” – Participant 17*

Non-residents eligible for funded maternity care may be ineligible for funded abortion.

*“I still think it’s insane that you can be eligible for maternity care if you are a female who might have a 2-year work visa, but the father or partner is Kiwi or has a visa, but you’re not eligible for termination.” – Participant 2*

### **Within service barriers**

Reproductive healthcare, particularly abortion services, were seen as under-resourced, with restraints on service capacity.

*“The big one is really time and manpower. They’re just always running out of slots and time, and they just never have enough resources, which is frustrating.” – Participant 19*

Some clinics require people to have EMA on specific days due to lack of clinical support at weekends. Clinics may require multiple visits.

*“This whole day one/day two thing, so they have to come twice. You should just be able to come and see a doctor, have your pills, or see a nurse and have your pills. There’s quite a lot of paternalistic traits still, because that’s how it’s always been and that’s what makes us comfortable.” – Participant 11*

Some pre-abortion tests were seen as not clinically indicated.

*“It’s still a little bit thorough here, a little bit over the top, so I have to arrange*

*the path lab to take their bloods and their double swabs. They still need to get a scan for an early medical abortion here.” – Participant 19*

Access to long-acting reversible contraception (LARC) post-EMA varied according to location but was identified as problematic with telemedicine EMA.

*“Next on my agenda is more LARC access or contraception access because I’m really keen and happy that there’s gonna be a telemedicine service nationwide, but we really need to be following up with how our patients are gonna access contraception.” – Participant 15*

### **Societal barriers**

Many participants identified systemic issues in sexual reproductive healthcare in Aotearoa.

*“I think there’s a lot of work to do in women’s health generally. I think it’s just another example of how women’s health isn’t always treated with the best knowledge and the best care that it could be.” – Participant 3*

Consequences of conscientious objection were identified as delays in accessing abortion and stigmatisation.

*“We have two GPs; one doesn’t do contraception—definitely doesn’t do termination care. And another GP who won’t refer for terminations, but the women don’t know that. They turn up; ‘I have an appointment. I would like a termination.’ The receptionists know, and if they can veer people in the right direction, they do, but it still happens at times that they come across these two GPs who just block them.” – Participant 9*

### **Lack of culturally appropriate care**

Some participants spoke unprompted about a lack of culturally appropriate abortion services.

*“I think any engagement with the healthcare system for Māori is going to inherently be a barrier because it’s a system built with a Pākehā worldview and try as you might to translate every*

*possible word and whatever into te reo Māori, it's a bit of whoop de doo when the system itself doesn't have a Kaupapa Māori approach." – Participant 7*

### **Theme three: strategies to increase access to abortion**

#### **Self-referral**

Seamless self-referral pathways were seen as removing barriers to care. However, this has shifted the workload associated with the referral to abortion services.

*"Now, they're able to self-refer and go straight to the abortion clinic, although talking to the booking clerk at the TOP clinic, she prefers the referrals to be done because it saves work for her." – Participant 19*

#### **Point-of-care ultrasound**

Some abortion services provide point-of-care ultrasound (POCUS), streamlining the process and removing ultrasound fees. Providing POCUS places demand on abortion providers.

*"Yeah, I only do a transabdominal one. I don't do a transvaginal and I know I should, but it's too hard right now to get the probe and have to clean it to bring it back to use for the next patient." – Participant 4*

#### **Abortion normalisation and education**

People may not consider abortion as an option due to lack of awareness or family/cultural barriers. Strategies to overcome this include abortion education in schools.

*"I think it's something that needs to be normalised. Now, that may mean that the providers that provide sexual health and contraception in schools also have the opportunity to discuss abortion as an option for an unintended pregnancy." – Participant 3*

#### **Telemedicine EMA**

Telemedicine EMA facilitates self-managed care and should be an option for all.

*"I think people who opt for medical terminations are wanting to have a bit of control over it anyway. They're*

*generally wanting to do it at home. They want to be able to look after their kids and it's a lot about fitting in with their lives. I think if they can do that from home or work, if they have to, I think that would be amazing." – Participant 6*

Many participants expressed concern about telemedicine EMA, including inability to provide LARC. Telemedicine may pose barriers to the therapeutic relationship, particularly for people with communication challenges. Failure to identify people requiring additional support was recognised, for example intimate partner violence.

*"Yeah, and if she's had a non-consensual episode that led to a pregnancy and she just wants the abortion, she doesn't want to discuss anything else, there's a lot more involved there. She can turn up for her EMA and get her pills and go home, but if I was sitting, talking to her, I'd probably gauge something more than that." – Participant 18*

Participants expressed concern for how complications are managed in the telemedicine EMA setting.

*"I guess the only thing would be is if there's some complications, if a woman is not near a service provider, then that potentially could have issues, particularly if they're in a remote place and there's only one GP and they didn't want them to know." – Participant 8*

#### **Primary care provision of abortion**

Participants were supportive of first trimester primary care provision, especially EMA. Apart from one participant, there was support for nurse abortion provision.

*"Well, like contraception, I think you need this attitude of every door is the right door. I think if women are looking for help or a service, the important thing is that the service is agnostic and they shouldn't feel that they're only able to go to one type of practitioner." – Participant 15*

Participants identified requirements for abortion in primary care, including appropriate training, support from secondary services and

access to counselling. Adding another service to an already burdened primary care sector was recognised. Appropriate funding is essential for primary care to provide abortion services.

*“Well, some kind of funding model that’s gonna fund it and make it free for the patient but give you adequate time to spend with them to do all the required tasks.” – Participant 5*

## Discussion

This study shows that the first trimester abortion experience in Aotearoa is influenced by a range of factors, including the individual’s circumstances, health services and society. Three main themes were identified: abortion is a stepwise process, multiple barriers to abortion care exist and solutions to overcome abortion barriers.

Self-referral was seen as facilitating abortion access but requires further development to make navigation simpler. Telemedicine EMA also increases access by reducing the burden of travel, increasing convenience and autonomy. However, telemedicine may not provide sufficient psychological support, particularly for those in complex social situations. Access to LARC is also challenging for telemedicine EMA. In 2021, 12.6% of people having EMA in Aotearoa were provided with a LARC, compared to 53.6% of people having a surgical procedure.<sup>10</sup>

Participants expressed concern for a lack of support for sexual reproductive health services in Aotearoa. Abortion services have absorbed work associated with self-referrals, and many provide POCUS. While this facilitates access for consumers, abortion clinics also require sufficient funding and support to provide a range of care that may include telemedicine EMA as a routine option, expanded clinic hours and access to LARC post-EMA.

A strategy to increase abortion access is to increase the number of providers.<sup>11</sup> This study identifies support for abortion provision in primary care, including by nurses. Nurse-led EMA and LARC provision in primary care is safe and effective and increases access, particularly for rural people.<sup>12–14</sup> Theory training for EMA and surgical abortion and POCUS can be accessed via the Best Practice Advocacy Centre New Zealand.<sup>15</sup> Task shifting of EMA into primary care may increase the burden on the sector and requires careful consideration.<sup>16</sup> In Aotearoa, there is

limited funding for abortion in primary care via the New Zealand Maternity Benefits Schedule first trimester single service fee of NZ\$75.<sup>17</sup>

This study identifies that people accessing abortion in Aotearoa potentially face unnecessary clinical tests. The finding that bloods, ultrasound and screening for sexually transmitted infections (STIs) may be routinely requested/required is contrary to the *New Zealand Aotearoa Abortion Clinical Guideline*.<sup>6</sup> Ultrasound should be reserved for when gestational age is unclear or there is risk for ectopic pregnancy. Routine ultrasound increases the number of visits and anxiety for the person and places a burden on ultrasound as a health resource.<sup>6</sup> The *New Zealand Aotearoa Abortion Clinical Guideline* recommends selective haemoglobin testing for those with symptoms or a history of anaemia, or those at risk of bleeding. STI screening should be opportunistic, and screening/treatment should not prevent or delay the abortion. Further research is required to confirm whether unnecessary testing prior to an abortion exists and if this creates barriers to timely abortion care.

Study findings indicate that abortion stigma and conscientious objection remain barriers to abortion in Aotearoa. Abortion stigma is closely linked with conscientious objection.<sup>18</sup> Conscientious objection may be invoked in the absence of moral objection but as a protection, for example when the practitioner feels vulnerable for their clinical decisions, or they lack the training and support to provide abortion care.<sup>19</sup> Improved education and support, including development of GP abortion champions, has been suggested.<sup>20</sup> Values clarification workshops are considered integral to abortion training, where attitudes can be shifted towards supporting people who choose abortion.<sup>11</sup> Provision of abortion services that are not only safe, but non-judgemental, is outlined in the United Nations’ Sustainable Development Goals.<sup>21</sup> In developing first trimester abortion services in Aotearoa, a thorough implementation process is required in recognition of complex societal perspectives regarding abortion.

Abortion services that meet the needs of Māori is a priority. The findings of this study suggest a lack of culturally competent abortion care. In a literature review by Rebekah Laurence in 2019, several barriers and facilitators for wāhine accessing abortion in Aotearoa were identified, including a lack of culturally competent care.<sup>22</sup> A 2021 review of regulated health practitioner cultural competency documents found them to be “not yet fit for purpose as frameworks for

upholding te Tiriti.”<sup>23</sup> It is important that health practitioners have the clinical knowledge and cultural skills to practice in a culturally safe way with whānau, and is a requirement under Te Tiriti o Waitangi.<sup>6,23</sup>

Limitations of this study include that it was conducted in early 2022 and abortion services may have evolved since then. It is also the perspectives of health practitioners and not people seeking abortion. The participants expressed no moral objection to abortion, and thus represent a specific viewpoint on abortion care. A strength is that participants encompass a range of health practitioners and provide a comprehensive picture of

the abortion journey from a health practitioner perspective.

This study identifies barriers to accessing first trimester abortion care and a desire among participants to be part of positive change. To provide optimal first trimester abortion care in Aotearoa, a strategy is required to strengthen and develop abortion services, placing the health consumer at the centre of services that are accessible, equitable and culturally appropriate. The primary care sector has potential to play a significant role in this, but requires funding, training and collaboration with stakeholders, including consumers and the primary and secondary health sectors.

**Table 1:** Question examples.

How do people access abortion in your area?
<ul style="list-style-type: none"> <li>• Have you noticed any changes in how people access abortion care since law reform?</li> <li>• How would people know they can self-refer?</li> </ul>
Can you tell me how your role relates to abortion care?
What do you see as potential barriers for people accessing abortion in your area?
<ul style="list-style-type: none"> <li>• What is like for people accessing ultrasound?</li> <li>• How far do people have to travel to a clinic?</li> <li>• Does your local service offer telehealth?</li> </ul>
Do you have any thoughts about how access to abortion care could be improved?
<ul style="list-style-type: none"> <li>• Primary care provision</li> <li>• Non-doctor providers (e.g., nurses, nurse practitioners, midwives)</li> </ul>
If not an abortion provider
<ul style="list-style-type: none"> <li>• Do you know how to become an abortion provider?</li> </ul>
If an abortion provider
<ul style="list-style-type: none"> <li>• Can you tell me about some of the changes you may have noticed in your service post law reform?</li> <li>• What is the process like for people having an abortion in your service?</li> </ul>
What are your thoughts about abortion being provided by non-doctors? (e.g., nurses, nurse practitioners, midwives)



**COMPETING INTERESTS**

Emma Macfarlane is a member of the Abortion Providers Group Aotearoa New Zealand (APGANZ), an associate member of and LARC trainer for the New Zealand College of Sexual and Reproductive Health (NZCSRH) and an associate member of the New Zealand College of Sexual and Reproductive Health (NZCSRH).

Michael Stitely and Pauline Dawson have no competing interests to report relating to the article content.

Helen Paterson is the co-director of the Women's Health Bus, deputy chair NZCSRH and an abortion provider for Te Whatu Ora – Health New Zealand.

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**AUTHOR INFORMATION**

Emma Macfarlane: Lecturer/PhD Student, Department of Women's and Children's Health, Otago Medical School – Dunedin Campus.

Dr Pauline Dawson: Senior Lecturer, Department of Women's and Children's Health, Otago Medical School – Dunedin Campus.

Michael Stitely: Associate Professor, Otago Medical School – Invercargill.

Dr Helen Paterson: Senior Lecturer, Department of Women's and Children's Health, Otago Medical School – Dunedin Campus.

**CORRESPONDING AUTHOR**

Emma Macfarlane: Lecturer/PhD student, Department of Women's and Children's Health, Otago Medical School – Dunedin Campus, PO Box 56, Dunedin 9054.  
E: Emma.macfarlane@otago.ac.nz

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**REFERENCES**

1. *Abortion Legislation Act 2020* No 6 (NZ).
2. Macfarlane E, Stitely M, Paterson H. What skills do New Zealand clinicians have to provide first trimester abortion in primary care and are they willing? *Sex Reprod Healthc.* 2023;35:100810. doi: 10.1016/j.srhc.2022.100810.
3. Doran F, Nancarrow S. Barriers and facilitators of access to first-trimester abortion services for women in the developed world: a systematic review. *J Fam Plann Reprod Health Care.* 2015;41(3):170-80. doi: 10.1136/jfprhc-2013-100862.
4. Broussard K. The changing landscape of abortion care: Embodied experiences of structural stigma in the Republic of Ireland and Northern Ireland. *Soc Sci Med.* 2020;245:112686. doi: 10.1016/j.socscimed.2019.112686.
5. Carnegie A, Roth R. From the grassroots to the Oireachtas: abortion law reform in the Republic of Ireland. *Health Hum Rights.* 2019;21(2):109-120.
6. Ministry of Health – Manatū Hauora. New Zealand Aotearoa Abortion Clinical Guideline [Internet]. Wellington (NZ): Ministry of Health – Manatū Hauora; 2021 [cited 2023 Dec 7]. Available from: <https://www.health.govt.nz/publications/new-zealand-aotearoa-abortion-clinical-guideline>
7. Taylor B, Francis K. *Qualitative research in the health sciences: Methodologies, methods and processes.* UK: Routledge; 2013.
8. International Q. NVIVO [Internet]. US: Lumivero; 2022 [cited 2022 Jul 31]. Available from: <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>
9. Braun V, Clarke V. Thematic analysis. In: Cooper H, Camic PM, Long DL, et al, editors. *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological.* Washington, DC (US): American Psychological Association; 2012. p. 57-71.
10. Ministry of Health – Manatū Hauora. *Abortion Services Aotearoa New Zealand: Annual Report 2022* [Internet]. Wellington (NZ): Ministry of Health – Manatū Hauora; 2022 [cited 2024 13 Feb]. Available from: <https://www.health.govt.nz/publications/abortion-services-aotearoa-new-zealand-annual-report-2022>
11. Harries J, Constant D. Providing safe abortion services: experiences and perspectives of providers in South Africa. *Best Pract Res Clin Obstet Gynaecol.* 2020;62:79-89. doi: 10.1016/j.bpobgyn.2019.05.005.
12. Moulton JE, Mazza D, Tomnay J, et al. Co-design of a nurse-led model of care to increase access to medical abortion and contraception in rural and regional general practice: A protocol. *Aust J Rural Health.* 2022;30(6):876-883. doi: 10.1111/ajr.12937.
13. Abbott P, Dadich A, Hosseinzadeh H, et al. Practice nurses and sexual health care: enhancing team care within general practice. *Aust Fam Physician.* 2013;42(10):729-33.
14. Jejeebhoy SJ, Kalyanwala S, Mundle S, et al. Feasibility of expanding the medication abortion provider base in India to include ayurvedic physicians and nurses. *Int Perspect Sex Reprod*

- Health. 2012;38(3):133-42. doi: 10.1363/3813312.
15. The New Zealand College of Sexual and Reproductive Health. Abortion training [Internet]. Dunedin (NZ): Best Practice Advocacy Centre New Zealand; 2023 [cited 2023 Dec 6]. Available from: <https://bpac.org.nz/ema/>
  16. Zhou J, Blaylock R, Harris M. Systematic review of early abortion services in low- and middle-income country primary care: potential for reverse innovation and application in the UK context. *Global Health*. 2020;16(1):91. doi: 10.1186/s12992-020-00613-z.
  17. Ministry of Health – Manatū Hauora. Primary Maternity Services Notice 2021 [Internet]. Wellington (NZ): Ministry of Health – Manatū Hauora; 2021 [cited 2022 Jul 13]. Available from: <https://www.health.govt.nz/publications/primary-maternity-services-notice-2021>
  18. Hanschmidt F, Linde K, Hilbert A, et al. Abortion stigma: a systematic review. *Perspect Sex Reprod Health*. 2016;48(4):169-77. doi: 10.1363/48e8516.
  19. Harris LF, Halpern J, Prata N, et al. Conscientious objection to abortion provision: Why context matters. *Glob Public Health*. 2018;13(5):556-66. doi: 10.1080/17441692.2016.1229353.
  20. Dawson AJ, Nicolls R, Bateson D, et al. Medical termination of pregnancy in general practice in Australia: a descriptive-interpretive qualitative study. *Reprod Health*. 2017;14(1):39. doi: 10.1186/s12978-017-0303-8.
  21. United Nations. Sustainable development goals: Goal 3: Ensure healthy lives and promote well-being for all at all ages [Internet]. United Nations; 2024 [cited 2024 Sep 10]. Available from: <https://www.un.org/sustainabledevelopment/health/>
  22. Laurence R. Māori women and abortion: A Kaupapa Māori literature review. NZ: Te Whāriki Takapou; 2019.
  23. Came H, Kidd J, Heke D, McCreanor T. Te Tiriti o Waitangi compliance in regulated health practitioner competency documents in Aotearoa. *N Z Med J*. 2021;134(1535):35-43.

# Ethnic variations in traumatic injury hospitalisations in a health region of Aotearoa New Zealand—10-year review

Ishani Soysa, Sheena Moosa, Grant Christey

## ABSTRACT

**AIM:** To examine the ethnic variations in trauma hospitalisations in a health region of Aotearoa New Zealand over a 10-year period.

**METHODS:** A retrospective, observational study utilised data from the Te Manawa Taki (TMT) regional trauma registry to identify individuals of all ages and injury severities who were hospitalised due to injuries between 2013 and 2022. This investigation focusses on the epidemiology of trauma, examining factors such as ethnicity, gender, Injury Severity Score (ISS) and injury characteristics.

**RESULTS:** In the TMT region, out of the 60,753 trauma patients admitted to hospitals, the distribution across ethnic groups was as follows: 39,291 (64.7%) were European and other ethnic group, 18,015 (29.7%) were Māori, 1,998 (3.3%) were Asian and 1,411 (2.3%) were Pacific peoples. Notably, there were significant differences in incidence rates among these groups, with Māori exhibiting the highest rate. Moreover, males were more predisposed to hospitalisation due to trauma compared to females. This gender discrepancy was consistent across all ethnicities.

Regardless of ethnicity, falls and road traffic crashes emerged as leading causes of trauma across all severity levels. Additionally, the primary location of injury varied depending on the severity of trauma. For high-severity cases, street and highways were the predominant sites, whereas homes were more commonly associated with low-severity admissions.

**CONCLUSIONS:** The study examines the incidence, demographic characteristics, severity and outcomes of trauma patients across various ethnic backgrounds admitted to hospitals within the TMT region of Aotearoa New Zealand over a decade. The disparities in injury rates among different ethnic groups underscore the substantial strain on the healthcare system. Pinpointing high-risk demographics and recognising these disparities will be instrumental in devising targeted prevention measures, enhancing access to culturally sensitive trauma services and advancing health equity.

Trauma presents a significant public health concern world-wide,<sup>1,2</sup> as well as in Aotearoa New Zealand,<sup>3</sup> impacting individuals, families and healthcare systems. Research indicates that certain ethnic groups experience a disproportionate burden of trauma compared to others.<sup>4</sup> Māori, as the Indigenous population of Aotearoa New Zealand, have been identified as particularly vulnerable to trauma.<sup>5,6,7</sup> Historical and ongoing socio-economic disparities, coupled with cultural factors, contribute to higher rates of injury among Māori communities.<sup>6,7</sup> Similarly, Pacific peoples—another significant ethnic group in Aotearoa New Zealand—also experience a higher prevalence of trauma, often linked to socio-economic challenges, cultural norms and lifestyle factors. Ethnic inequalities of trauma incidence in general<sup>8</sup> and specific traumatic injury have been observed in several settings.<sup>9</sup> In Aotearoa New Zealand, socio-economic and ethnic differences have been noted with respect to trauma incidence<sup>10</sup> and specific injuries,<sup>6,11</sup> and among different age

groups.<sup>12</sup> Furthermore, studies have shown variations in trauma patterns and severity across different ethnic groups. For instance, while motor vehicle crashes are a leading cause of injury for Europeans and Asians, interpersonal violence and self-harm are more prevalent among Māori and Pacific peoples.<sup>7,13–15</sup> Understanding these nuances is essential for designing culturally appropriate prevention and intervention strategies.

The primary objective of this study is to examine the ethnic variations in trauma hospitalisations in the Te Manawa Taki (TMT) health region of Aotearoa New Zealand. Specifically, we aim to analyse the demographic characteristics of patients hospitalised due to trauma across different ethnic groups and explore disparities in injury severity, outcomes and healthcare utilisation using 10-year data from the TMT Trauma Registry (TMTTR). The TMT health region of Aotearoa New Zealand supports a population of 1,007,405 people, 28% of whom identify as Māori.<sup>16,17</sup> The TMT health

region has broad demographic characteristics for age groups, ethnicity and rurality that are representative of Aotearoa New Zealand as a whole.<sup>5,18,19</sup> This study reports the descriptive epidemiology of trauma patients from different ethnic groups admitted to hospitals across all ages and severities within a health region in Aotearoa New Zealand over a 10-year period.

## Methods

A retrospective analysis of data from the TMTTR of all ages admitted to TMT hospitals with an injury during the 10-year period from 1 January 2013 to 31 December 2022 was conducted. Ethical approval was provided under the locality authorisation process by the Te Whatu Ora – Health New Zealand Waikato Research Office (RD023079).

TMTTR has been in operation since 2012, covering trauma patient admissions across six hospitals in the region. The registry is designed to capture injury characteristics, interventions and inpatient costs of all trauma admissions.<sup>5</sup> The registry follows international standards, and excludes patients who sustained injuries such as insufficiency or peri-prosthetic fractures, exertional injuries, hanging/drowning/asphyxiation without evidence of external force, poisoning, ingested foreign body, injury as a direct result of pre-existing medical conditions or late effects of injury, or if the injury occurred more than 7 days prior to admission.<sup>20</sup> The registry collects demographic and injury event information from prehospital records, hospital systems and directly from patients. The cause, place and types of injury are classified using the International Classification of Disease (ICD-10-AM).<sup>21</sup>

Ethnicity is a self-perceived parameter of cultural affiliation, and people can identify with more than one ethnic group.<sup>22,23</sup> As such, the collection and recording of ethnicity in the health and disability sector in Aotearoa New Zealand are guided by the ethnicity protocol of the Ministry of Health (MoH).<sup>24</sup> The trauma registry collects and records ethnicity information consistent with this protocol. The MoH also provides population projections for each district health board (DHB) that further classifies into four groups: Asian, Māori, Pacific peoples, and European and other.<sup>15</sup> In this study, ethnicity of trauma patients was classified into the four groups consistent with TMT region's annual population projections, which were provided by the MoH to Te Whatu

Ora – Health New Zealand Waikato (DHB population projections 2018 update). Additionally, injury event information, type, intent, cause and place of injuries, hospital length of stay (LOS) and outcomes were also taken into account. The intent of injury was categorised as unintentional, by other or self-inflicted as per the ICD-10-AM. Hospital LOS was calculated at an event level considering the duration of stay at each hospital admission from arrival date–time to discharge date–time at each facility, summed at a patient level. The case fatality rate was calculated by taking into account the proportion of trauma patients who died while in the hospital. It only includes deaths resulting directly from their injuries and excludes “medical deaths” related to non-traumatic disease. The Abbreviated Injury Score (AIS)<sup>25</sup> was used to quantify injury patterns, and the Injury Severity Score (ISS) was assigned based on AIS version 2015. The ISS scores from all years using the 2008 version have been mapped to the 2015 version using an R script for TMTTR data extracts reported to the National Major Trauma Registry (NMTR). To analyse injury severity, the trauma ISS was classified into high (ISS >12),<sup>26</sup> moderate (ISS 9–12) and low (ISS 1–8) severity to show the variation in patients' characteristics in the transition from the larger “non-Major” trauma group to “Major” as defined in the NMTR.<sup>27</sup> The data were extracted from the TMTTR using DI Writer/Collector™, and all statistical analyses were performed using RStudio v 4.3.1. Analysis is presented as counts, percentage and rates.

## Results

From 1 January 2013 to 31 December 2022, 60,753 trauma patients were admitted to hospitals within the TMT region. Of these, 39,291 (64.7%) were European and other ethnic group, 18,015 (29.7%) were Māori, 1,998 (3.3%) were Asian and 1,411 (2.3%) were Pacific peoples. The demographic characteristics of these patients are shown in Table 1. Regardless of ethnicity, males had higher hospitalisation rates for any trauma than females. Rates were higher for Māori and Pacific men.

Overall, there is a significant difference in incidence rates ( $p < .001$ ) between the Asian and the European and other groups, as well as between the Māori and the European and other groups, with Māori having the highest rate (Table 2). The population-adjusted incidence rates for Asians are significantly lower than European and other

**Table 1:** Demographic characteristics of trauma patients admitted to TMT hospitals 2013–2022 by ISS band and ethnicity.

Characteristics		ISS band			Total
		>12 (High)	9–12 (Moderate)	1–8 (Low)	
Total events, n (%)		4,635 (7.6)	6,614 (10.8)	49,504 (81.4)	60,753 (100)
<b>Ethnicity</b>					
Asian	Male, n (% in group)	110 (58.5)	136 (61.5)	1,017 (64)	1,263 (63.2)
	Female, n (% in group)	78 (41.4)	85 (38.4)	572 (35.9)	735 (36.8)
	Total, n (% total)	188 (4)	221 (3.3)	1,589 (3.2)	1,998 (3.3)
	Age, mean years (SD)	38.4 (20.1)	35.7 (21.6)	29.9 (20.5)	31.4 (20.8)
Māori	Male, n (% in group)	1,045 (8.6)	1,224 (10.1)	9,751 (81.1)	12,020 (66.7)
	Female, n (% in group)	368 (6.1)	527 (8.7)	5,100 (85)	5,995 (33.3)
	Total, n (% total)	1,413 (30.4)	1,751 (26.4)	14,851 (29.9)	18,015 (29.7)
	Age, mean years (SD)	36.6 (19.5)	31.7 (21.5)	26 (18.9)	27.4 (19.6)
Pacific peoples	Male, n (% in group)	63 (84)	91 (74.5)	894 (71.4)	1,024 (72.6)
	Female, n (% in group)	12 (16)	31 (25.4)	358 (28.5)	387 (27.4)
	Total, n (% total)	75 (1.6)	122 (1.8)	1,252 (2.5)	1,411 (2.3)
	Age, mean years (SD)	37.9 (20.1)	30.3 (19.9)	25.5 (17.5)	26.6 (18.1)
European and other	Male, n (% in group)	2,102 (71)	2,769 (61.2)	18,844 (59.2)	23,715 (60.4)
	Female, n (% in group)	857 (28.9)	1,751 (38.7)	12,968 (40.7)	15,576 (39.69)
	Total, n (% total)	2,959 (7.5)	4,520 (11.5)	31,812 (64.2)	39,291 (64.7)
	Age, mean years (SD)	50.9 (22.8)	50.4 (26.2)	42.6 (25.8)	44.1 (25.9)

TMT = Te Manawa Taki; ISS = Injury Severity Score; SD = standard deviation.

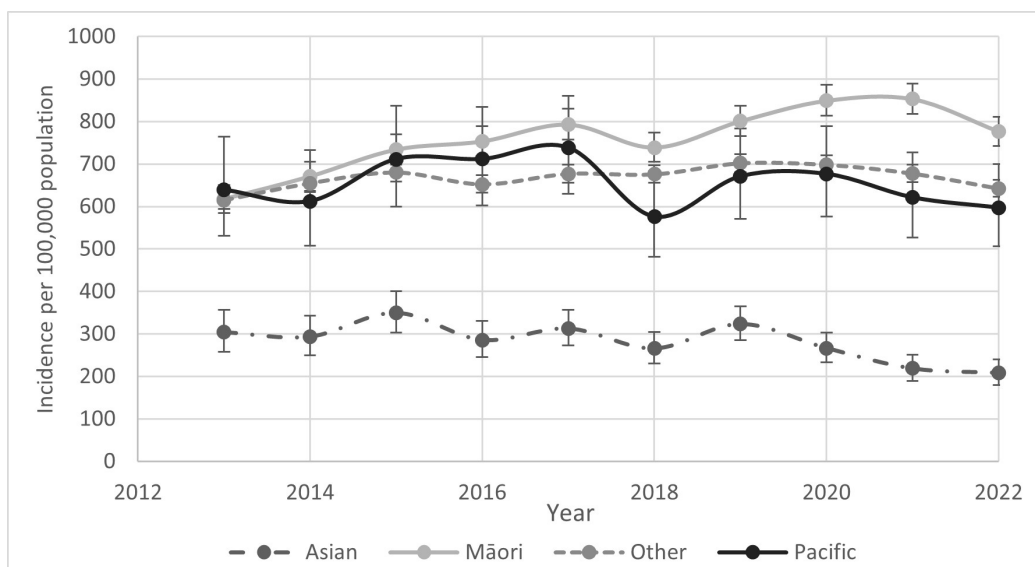
**Table 2:** aIRR by ethnicity and ISS band, 2013–2022.

	Average annualised events	Population*	aIRR	95% CI	P-value
<b>All ISS</b>					
Asian	1,998	76,005	0.40	0.38–0.42	<.001
Māori	18,015	239,100	1.14	1.08–1.2	<.001
Pacific peoples	1,449	22,740	0.96	0.82–1.13	ns
European and other	39,291	594,200	Reference		
<b>&gt;12 (High)</b>					
Asian	19	76,005	0.50	0.40–0.62	<.001
Māori	141	239,100	1.18	1.00–1.44	<.001
Pacific peoples	8	22,740	0.70	0.43–1.14	ns
European and other	296	594,200	Reference		
<b>ISS 9–12 (Moderate)</b>					
Asian	22	76,005	0.04	0.04–0.05	<.001
Māori	175	239,100	0.96	0.83–1.12	ns
Pacific peoples	12	22,740	0.69	0.46–1.02	ns
European and other	452	594,200	Reference		
<b>ISS 1–8 (Low)</b>					
Asian	159	76,005	0.05	0.05–0.05	<.001
Māori	1,485	239,100	1.16	1.09–1.23	<.001
Pacific peoples	125	22,740	1.02	0.85–1.23	ns
European and other	3,181	594,200	Reference		

aIRR = adjusted incidence rate ratio; ISS = Injury Severity Score; CI = confidence interval; ns = not significant.

\*Midland (Te Manawa Taki) region population at midpoint 2018.

**Figure 1:** Annual incidence of trauma per 100,000 population 2013–2022, bars—95% confidence intervals (\*Te Manawa Taki region population-standardised).



for all severity injury scores across the ISS 1–8, ISS 9–12 and ISS >12 bands. Incidence rates of all severities are not significantly different between the European and other group and Pacific peoples.

The annual incidence of all ethnicities has been variable over the study period, with a drop in 2018 (Figure 1), particularly among Pacific peoples. In 2022, the incidence per 100,000 population was found to be 208 for Asian, 776 for Māori, 642 for European and other and 597 for Pacific peoples. A decline in incidence can be seen since 2020 for all ethnic groups except Māori. From 2020 to 2022, the incidence per 100,000 declined by 58 for Asian, 56 for European and other and 79 for Pacific peoples. Among Māori, the incidence fluctuated over these 2 years, with a small increase of 4 in 2021, followed by a decline of 76 in 2022. The non-overlaps of confidence interval for Asians' trauma incidence suggest a significant difference between incidences of Asians with the other ethnic groups.

Regardless of ethnicity, falls and road traffic crashes were among the top three causes of all severities (Table 3). The top three causes cover 60% of all events for Asian, 55% for Māori, 54% for Pacific peoples and 58% for European and other. The leading cause of severe trauma for all ethnic groups, except for European and other, was road traffic crashes. However, for the European and other group, falls were the primary cause. Falls were the most common cause of injury among patients with moderate- and low-severity trauma, regardless of ethnicities. Among Māori and Pacific peoples, assault was one of the top three causes

of injury.

The leading place of injury resulting in hospitalisations of all severities combined was home for all ethnic groups (Table 4). Regardless of ethnicity, street and highways were the leading place of injury for high-severity trauma, while homes were the primary location of low-severity admissions. The primary location of moderate trauma varied among different ethnic groups. For Asian and Māori, it was street and highway, while for Pacific peoples and European and other it was home.

For all ethnic groups except the European and other group, there were slightly more penetrating injuries among severe trauma compared to other severity groups (Table 5). The blunt injuries were slightly high in moderate trauma, while the burn injuries were slightly high in low-severity trauma across all ethnic groups. Proportionately more injuries were caused by the injury intent category labelled "others" in the high-severity group than in the low- and moderate-severity groups for all ethnicities. Self-inflicted injuries were more common in low-severity hospitalisations among all ethnic groups except Asian.

Table 6 shows that Asian patients had a higher average LOS of 11 days for high-severity trauma across 2013–2022 compared to other ethnic groups. In contrast, the LOS for moderate- and low-severity trauma was relatively similar across all ethnic groups except for European and other. High-severity trauma events had the highest case fatality rate (CFR) of 7% for European and other compared with a CFR of 5% for Māori

**Table 3:** Top three causes of injury of trauma patients admitted to TMT hospitals by ethnicity and ISS band, 2013–2022.

ISS band							
>12 (High)		9–12 (Moderate)		1–8 (Low)		All ISS	
<b>Asian, n (%)</b>							
Road traffic crash	105 (55.8)	Fall	85 (38.4)	Fall	576 (36.2)	Fall	689 (34.5)
Fall	28 (14.8)	Road traffic crash	74 (33.4)	Road traffic crash	213 (13.4)	Road traffic crash	392 (19.6)
Pedestrian	16 (8.5)	Motorcycle	9 (4)	Sharp glass/knife/ hand tool	120 (7.5)	Sharp glass/knife/ hand tool	121 (6.1)
<b>Māori, n (%)</b>							
Road traffic crash	530 (37.5)	Fall	524 (29.9)	Fall	4,878 (32.8)	Fall	5,581 (31.0)
Assault	210 (14.8)	Road traffic crash	337 (19.2)	Assault	1,706 (11.4)	Assault	2,177 (12.1)
Fall	181 (12.8)	Assault	261 (14.9)	Sharp glass/knife/ hand tool	1,336 (8.9)	Road traffic crash	2,111 (11.7)
<b>Pacific peoples, n (%)</b>							
Road traffic crash	30 (40)	Fall	40 (32.7)	Fall	442 (35.3)	Fall	494 (34.1)
Fall	12 (16)	Road traffic crash	28 (22.9)	Road traffic crash	114 (9.1)	Road traffic crash	172 (11.9)
Assault	9 (12)	Assault	10 (8.1)	Stuck by/ against person	112 (8.9)	Stuck by/ against person	119 (8.2)
<b>European and other, n (%)</b>							
Fall	791 (26.7)	Fall	2,121 (46.9)	Fall	14,011 (44)	Fall	16,923 (43.1)
Road traffic crash	749 (25.3)	Road traffic crash	536 (11.8)	Pedal cycle	2,015 (6.3)	Road traffic crash	3,122 (7.9)
Motorcycle	467 (15.7)	Motorcycle	447 (9.8)	Machinery	1,984 (6.2)	Motorcycle	2,824 (7.2)

TMT = Te Manawa Taki; ISS = Injury Severity Score.



**Table 4:** Top three places of injury of trauma patients admitted to TMT hospitals by ethnicity and ISS band, 2013–2022.

ISS band							
>12 (High)		9–12 (Moderate)		1–8 (Low)		All ISS	
<b>Asian, n (%)</b>							
Street and highway	131 (69.6)	Street and highway	91 (41.1)	Home	541 (33.8)	Home	630 (31.5)
Home	34 (18)	Home	56 (25.3)	Street and highway	342 (21.4)	Street and highway	555 (27.8)
Other specified place	7 (3.7)	Other specified place	19 (8.5)	Sports and athletic area	136 (8.5)	Other specified place	157 (7.9)
<b>Māori, n (%)</b>							
Street and highway	875 (61.9)	Street and highway	637 (36.3)	Home	6,565 (44.2)	Home	7,421 (41.2)
Home	272 (19.2)	Home	584 (33.3)	Street and highway	2,764 (18.6)	Street and highway	4,276 (23.7)
Other specified place	81 (5.7)	Other specified place	123 (7)	Sports and athletic area	1,239 (8.3)	Sports and athletic area	1,360 (7.5)
<b>Pacific peoples, n (%)</b>							
Street and highway	40 (53.3)	Home	41 (33.6)	Home	443 (35.3)	Home	498 (34.4)
Home	14 (18.6)	Street and highway	40 (32.7)	Sports and athletic area	227 (18.1)	Street and highway	289 (19.9)
Unspecified place	5 (6.6)	Farm	11 (9)	Street and highway	209 (16.6)	Sports and athletic area	237 (16.4)
<b>European and other, n (%)</b>							
Street and highway	1,354 (45.7)	Home	1,506 (33.3)	Home	12,917 (40.6)	Home	15,023 (38.2)
Home	600 (20.2)	Street and highway	1,192 (26.3)	Street and highway	4,896 (15.3)	Street and highway	7,442 (18.9)
Other specified place	267 (9)	Other specified place	456 (10)	Other specified place	3,257 (10.2)	Other specified place	3,980 (10.1)

TMT = Te Manawa Taki; ISS = Injury Severity Score.

**Table 5:** Injury characteristics of trauma patients admitted to TMT hospitals by ISS band and ethnicity, 2013–2022.

Characteristics		ISS band			Total n (%)
		>12 (High)	9–12 (Moderate)	1–8 (Low)	
Total events injury type determined, n (%)		4,781 (7.9)	6,198 (10.2)	49,766 (81.9)	60,745 (100)
<b>Ethnicity, n (% in group)</b>					
Asian	Blunt	177 (94.1)	213 (96.4)	1,470 (92.5)	1,860 (3.2)
	Burn	4 (2.1)	3 (1.4)	91 (5.7)	98 (5.9)
	Penetrating	7 (3.7)	5 (2.3)	28 (1.8)	40 (2.3)
	Total	188 (100)	221 (100)	1,589 (100)	1,998 (3.3)
Māori	Blunt	1,307 (92.5)	1,630 (93.2)	13,564 (91.4)	16,501 (28.8)
	Burn	26 (1.8)	28 (1.6)	687 (4.6)	741 (44.8)
	Penetrating	80 (5.7)	91 (5.2)	596 (4.0)	767 (45.0)
	Total	1,413 (100)	1,749 (100)	14,847 (100)	18,009 (29.6)
Pacific peoples	Blunt	69 (92.0)	117 (95.9)	1,160 (92.7)	1,346 (2.3)
	Burn	2 (2.7)	2 (1.6)	47 (3.8)	51 (3.1)
	Penetrating	4 (5.3)	3 (2.5)	45 (3.6)	52 (3.1)
	Total	75 (100)	122 (100)	1,252 (100)	1,449 (2.4)
European and other	Blunt	2,869 (97.0)	4,432 (98.1)	30,377 (95.5)	37,678 (65.7)
	Burn	31 (1.0)	32 (0.7)	702 (2.2)	765 (46.2)
	Penetrating	59 (2.0)	56 (1.2)	731 (2.3)	846 (49.6)
	Total	2,959 (100)	4,520 (100)	31,810 (100)	39,289 (64.7)
Total events injury intent determined, n (%)		4,611 (7.6)	6,584 (10.9)	49,402 (81.5)	60,597 (100)
<b>Ethnicity, n (% in group)</b>					
Asian	Self-inflicted	2 (1.1)	1 (0.5)	12 (0.8)	1,913 (3.4)
	Unintentional	175 (93.6)	210 (95.4)	1,528 (96.3)	15 (2.8)
	By other	10 (5.3)	9 (4.1)	47 (3)	66 (1.9)
	Total	187 (100)	220 (100)	1,587 (100)	1,994 (3.3)
Māori	Self-inflicted	32 (2.3)	26 (1.5)	172 (1.2)	230 (42.8)
	Unintentional	1,157 (82.6)	1,439 (83)	12,865 (87)	15,461 (27.3)
	By other	212 (15.1)	268 (15.5)	1,742 (11.8)	2,222 (63.7)
	Total	1,401 (100)	1,733 (100)	14,779 (100)	17,913 (29.5)

**Table 5 (continued):** Injury characteristics of trauma patients admitted to TMT hospitals by ISS band and ethnicity, 2013–2022.

Pacific peoples	Self-inflicted	61 (82.4)	98 (90.7)	1,163 (92.1)	13 (2.4)
	Unintentional	3 (4.1)	2 (1.9)	8 (0.6)	1,322 (2.3)
	By other	10 (13.5)	8 (7.4)	92 (7.3)	110 (3.2)
	Total	74 (100)	108 (100)	1,263 (100)	1,445 (2.4)
European and other	Self-inflicted	48 (1.6)	28 (0.6)	204 (0.6)	280 (52.0)
	Unintentional	2,785 (94.4)	4,324 (95.9)	30,768 (96.8)	37,877 (67.0)
	By other	116 (4)	157 (3.5)	815 (2.6)	1,088 (31.2)
	Total	2,949 (100)	4,509 (100)	31,787 (100)	39,245 (64.8)

TMT = Te Manawa Taki; ISS = Injury Severity Score.

Excludes eight patients with injury type unknown/undetermined and 156 patients with injury intent unknown/undetermined.

**Table 6:** Hospital length of stay and case fatality rate of trauma patients admitted to TMT hospitals by ethnicity and ISS band, 2013–2022.

Characteristics	ISS band			Total
	>12 (High)	9–12 (Moderate)	1–8 (Low)	
<b>Average hospital length of stay (SD)</b>				
Asian	11.2 (12.5)	5.3 (4.9)	2.8 (3.5)	3.9 (5.8)
Māori	9.1 (13.6)	5 (6.7)	2.5 (3.6)	3.3 (5.7)
Pacific peoples	9.9 (13.0)	6.1 (7.3)	3.5 (4.9)	3.1 (5.5)
European and other	7.8 (10.5)	5.1 (12.9)	2.7 (3.3)	4.3 (6.4)
<b>Case fatality rate (%)</b>				
Asian	5.0	1.5	0.1	0.8
Māori	5.3	0.7	0.1	0.6
Pacific peoples	4.0	0.0	0.2	0.4
European and other	6.9	0.9	0.1	0.7

TMT = Te Manawa Taki; ISS = Injury Severity Score; SD = standard deviation.

Excludes medical deaths.

and Asian and a CFR of 4% for Pacific peoples. Pacific peoples had the lowest or no (for moderate) CFR across all ISS bands compared to other ethnicities.

## Discussion

Ethnic disparities in trauma hospitalisations in Aotearoa New Zealand highlight significant public health concerns tied to broader social and economic inequities. This study is the first to detail the epidemiology of trauma patients across ethnic groups admitted to hospitals of all ages and severities in a specific health region over 10 years.

Notable differences in incidence rates were found, with Māori experiencing the highest rates and Asians the lowest. Literature indicates that socio-economic status may be a key factor driving these disparities.<sup>7,9,28,29</sup> Māori populations in Aotearoa New Zealand often face socio-economic disadvantages, including lower income, poorer housing and limited access to education and healthcare.<sup>12,28</sup> These factors can elevate trauma risk through unsafe working conditions, inadequate housing and limited access to preventive healthcare.<sup>28,30</sup>

Study results show a decline in incidence since 2020 for all ethnic groups except Māori, likely due to reductions in injury-related hospitalisations during the COVID-19 pandemic,<sup>31,32</sup> which may have affected marginalised communities differently.<sup>8</sup> The fewer penetrating injuries among severe trauma for the European and other group possibly reflect generally higher socio-economic status, granting access to safer neighbourhoods with less violence.<sup>7,29</sup> Falls and traffic crashes were among the top three causes of all severities, with falls being the primary cause for moderate- and low-severity trauma. Assault was one of the top three causes of injury among Māori and Pacific peoples, consistent with existing literature.<sup>5,11–14,18</sup>

The higher average LOS for high-severity trauma among Asians could be related to socio-cultural factors. The European and other group had a high average LOS for moderate- and low-severity trauma. The findings suggest that the increased admission volumes for moderate- and low-severity trauma were the main reason for the higher average LOS of the European and other group when compared to the other ethnic groups.

Study revealed that Pacific peoples had the lowest or no (for moderate) CFR across all ISS bands compared to other ethnic groups. In contrast, Asians had a higher CFR for moderate-severity trauma that could be due to the same

socio-cultural factors leading to a higher LOS. The factors contributing to mortality and survival outcomes in moderate- and low-severity trauma need further study in exploring trauma injury care practices of different ethnic groups.

As the study presents the findings of cumulative 10-year data, it limits identifying changes of injury characteristics over time. Furthermore, the classification of European and other as one group tends to overlook some other ethnic groups, such as Middle Eastern, Latin American and African ethnicities. Future studies may explore the minority ethnic groups to identify injury parameters. Another inherent limitation is the accuracy of the ethnicity data in healthcare systems, including trauma registries. Previous studies have reported significant variation between self-identified ethnicity and recorded ethnicity in the hospital systems,<sup>33,34</sup> which is further complicated by people shifting their ethnicity identity over time.<sup>23</sup> However, as this study uses a large dataset of over 60,000 records and uses four groups of ethnicity, it allows for drawing reasonable conclusions at aggregate levels.

Addressing ethnic disparities in trauma hospitalisations in Aotearoa New Zealand requires a multifaceted approach that encompasses upstream interventions to address socio-economic inequalities, culturally sensitive healthcare delivery, targeted injury prevention strategies and efforts to address systemic biases within the healthcare system. Collaboration between healthcare providers, policymakers, community organisations and ethnic communities is essential for developing effective interventions to reduce these disparities.

## Conclusions

Over the 10-year study, annual trauma incidence varied slightly among different ethnic groups, with a notable decline in 2018. Noteworthy disparities were observed, with Māori exhibiting the highest rates and Asians the lowest. Falls and road traffic crashes consistently ranked among the top three causes of injuries across all severity levels. This study has illuminated the ethnic inequities in traumatic injury hospitalisations, paving the way for targeted interventions to reduce the injury burden on vulnerable populations. Ultimately, addressing these disparities aligns with broader efforts to promote health equity and ensure optimal health outcomes for all residents of Aotearoa New Zealand.

**COMPETING INTERESTS**

The authors declare no competing interests.

**AUTHOR INFORMATION**

Ishani Soysa: Research Manager, Te Manawa Taki Trauma Research Centre, Te Whatu Ora – Health New Zealand Waikato, Hamilton, Aotearoa New Zealand.

Sheena Moosa: Research Fellow, Te Manawa Taki Trauma Research Centre, Te Whatu Ora – Health New Zealand Waikato, Hamilton, Aotearoa New Zealand.

Grant Christey: Clinical Director, Te Manawa Taki Trauma System, Te Whatu Ora – Health New Zealand Waikato, Hamilton, Aotearoa New Zealand; Honorary Associate Professor, Faculty of Medical and Health Sciences, Surgery, University of Auckland, Aotearoa New Zealand.

**CORRESPONDING AUTHOR**

A/Prof Grant Christey: Clinical Director, Te Manawa Taki Trauma System, Meade Clinical Centre, Waikato Hospital, Hamilton; Honorary Associate Professor, Faculty of Medical and Health Sciences, Surgery, University of Auckland, Aotearoa New Zealand.  
E: grant.christey@waikatodhb.health.nz

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**REFERENCES**

1. GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet*. 2020;396(10258):1204-1222. doi: 10.1016/S0140-6736(20)30925-9. Erratum in: *Lancet*. 2020;396(10262):1562. doi: 10.1016/S0140-6736(20)32226-1.
2. Rossiter ND. “Trauma-the forgotten pandemic?” *Int Orthop*. 2022;46(1):3-11. doi: 10.1007/s00264-021-05213-z.
3. Civil I, Isles S, Campbell A, Moore J. The New Zealand National Trauma Registry: an essential tool for trauma quality improvement. *Eur J Trauma Emerg Surg*. 2023 Aug;49(4):1613-1617. doi: 10.1007/s00068-023-02310-z.
4. Kendi S, Macy ML. The Injury Equity Framework - Establishing a Unified Approach for Addressing Inequities. *N Engl J Med*. 2023 Mar 2;388(9):774-776. doi: 10.1056/NEJMp2212378.
5. Christey G, Soysa I, Smith A. Characteristics of low, moderate, and high severity trauma hospitalisations in a health region of Aotearoa New Zealand-10-year review. *N Z Med J*. 2024 Jul;137(1599):37-48. doi: 10.26635/6965.6428.
6. Pryymachenko Y, Wilson R, Abbott JH. Epidemiology of cruciate ligament injuries in New Zealand: exploring differences by ethnicity and socioeconomic status. *Inj Prev*. 2023 Jun;29(3):213-218. doi: 10.1136/ip-2022-044761.
7. Flett RA, Kazantzis N, Long NR, et al. Gender and ethnicity differences in the prevalence of traumatic events: evidence from a New Zealand community sample. *Stress Health*. 2004 Aug;20(3):149-157. <https://doi.org/10.1002/smi.1014>.
8. Tomas CW, Flynn-O’Brien KT, Harris J, et al. Increase in traumatic injury burden amidst COVID-19 was disproportionately shouldered by racial and ethnic minority patients: An urban case study. *Trauma*. 2023;26(3):241-249. doi:10.1177/14604086231165127.
9. Maldonado J, Huang JH, Childs EW, Tharakan B. Racial/Ethnic Differences in Traumatic Brain Injury: Pathophysiology, Outcomes, and Future Directions. *J Neurotrauma*. 2023 Mar;40(5-6):502-513. doi: 10.1089/neu.2021.0455.
10. New Zealand Trauma Registry, National Trauma Network. Annual Report 2021/22 [Internet]. Wellington, New Zealand; 2022 [cited 2023 Sep 7]. Available from: <https://www.majortrauma.nz/assets/Annual-reports/NZMT/NZMT2021-2022.pdf>
11. Bolam SM, Konar S, Gamble G, et al. Ethnicity, sex, and socioeconomic disparities in the treatment of traumatic rotator cuff injuries in Aotearoa/New Zealand. *J Shoulder Elbow Surg*. 2023 Jan;32(1):121-132. doi: 10.1016/j.jse.2022.06.010.
12. Dwight E, Cavadino A, Kool B, et al. Association of ethnicity with unintentional injury-related hospitalisation and mortality among older people residing in two regions of Aotearoa New Zealand. *Australas J Ageing*. 2024 Jun;43(2):359-378. doi: [10.1111/ajag.13279](https://doi.org/10.1111/ajag.13279).
13. Fergusson D. Ethnicity and Interpersonal Violence in a New Zealand Birth Cohort. In: Hawkins DF, editor. *Violent Crime: Assessing Race and Ethnic Differences*. New York: Cambridge University Press; 2003. p. 138-153.
14. Rankine J, Percival T, Finau E, et al. Pacific Peoples, Violence, and the Power and Control Wheel. *J Interpers Violence*. 2017 Sep;32(18):2777-2803. doi: 10.1177/0886260515596148.
15. Creamer G, Civil I, Ng A, et al. Ethnicity of severe trauma patients: results of a population-based study, Auckland, New Zealand 2004. *N Z Med J*. 2010 Jun;123(1316):26-32.
16. O’Leary K, Kool B, Christey G. Characteristics of older adults hospitalised following trauma in

- the Midland region of New Zealand. *N Z Med J.* 2017;130(1463):45-53.
17. Te Manawa Taki Trauma System. Annual Report 2022 [Internet]. Hamilton, New Zealand: Waikato District Health Board; 2022 [cited 2023 Sep 7]. Available from: <https://www.midlandtrauma.nz/publications-resources/annual-reports/>
  18. Simpkins C, Soysa IB, Christey G. Falls at home: hospital admissions in a health region of Aotearoa New Zealand. *N Z Med J.* 2024;137(1588):47-56. doi: 10.26635/6965.6264.
  19. Jones AR, Smith A, Christey G. Equine-related injuries requiring hospitalisation in the Midland Region of New Zealand: a continuous five-year review. *N Z Med J.* 2018;131(1483):50-58.
  20. Nwomeh BC, Lowell W, Kable R, et al. History and development of trauma registry: lessons from developed to developing countries. *World J Emerg Surg.* 2006 Oct;1:32. doi: 10.1186/1749-7922-1-32.
  21. National Centre for Classification in Health. International Classification of Disease (ICD-10-AM). 6th ed. Sydney, Australia: Australian Institute of Health and Welfare; 2006.
  22. Ministry of Social Development. Improving how we report ethnicity [Internet]. [cited 2024 Feb 29]. Available from: <https://www.msd.govt.nz/about-msd-and-our-work/tools/how-we-report-ethnicity.html>
  23. Statistics New Zealand. Ethnicity [Internet]. [cited 2027 Jul 17]. Available from: <https://www.stats.govt.nz/topics/ethnicity/>
  24. Health New Zealand – Te Whatu Ora. Ethnicity Data Protocols HISO 10001:2017 version 1.1 [Internet]. Wellington, New Zealand: Ministry of Health – Manatū Hauora. [cited 2024 Jul 17]. Available from: <https://www.tewhatauora.govt.nz/health-services-and-programmes/digital-health/data-and-digital-standards/approved-standards/identity-standards>
  25. Association for the Advancement of Automotive Medicine. Abbreviated Injury Scale (AIS) [Internet]. [cited 2023 Aug 30]. Available from: <https://www.aaam.org/abbreviated-injury-scale-ais/>
  26. Palmer CS, Gabbe BJ, Cameron PA. Defining major trauma using the 2008 Abbreviated Injury Scale. *Injury.* 2016 Jan 1;47(1):109-15. doi: 10.1016/j.injury.2015.07.003.
  27. National Trauma Network. National Minimum Data Set for trauma [Internet]. [cited 2023 Sep 18]. Available from: <https://www.majortrauma.nz/nz-mtr/national-minimum-data-set-for-trauma/>
  28. Ministry of Health – Manatū Hauora. Wai 2575 Māori Health Trends Report [Internet]. Wellington, New Zealand: Ministry of Health – Manatū Hauora; 2019 [cited 2023 Sep 18]. Available from: <https://www.health.govt.nz/publications/wai-2575-maori-health-trends-report>
  29. Blakely T, Tobias M, Atkinson J, et al. Tracking Disparity: Trends in ethnic and socioeconomic inequalities in mortality, 1981-2004 [Internet]. Wellington, New Zealand: Ministry of Health – Manatū Hauora. 2007 Aug [cited 2023 Sep 18]. Available from: <https://www.health.govt.nz/system/files/2011-11/tracking-disparity-inequalities-in-mortality-1981-2004.pdf>
  30. Bierre S, Keall M, Howden-Chapman P. Framing home injury: opportunities and barriers to regulating for safer rental housing in Aotearoa/New Zealand. *Hous Stud.* 2023;39(11):2787-2805. <https://doi.org/10.1080/02673037.2023.2224242>.
  31. Christey G, Amey J, Campbell A, Smith A. Variation in volumes and characteristics of trauma patients admitted to a level one trauma centre during national level 4 lockdown for COVID-19 in New Zealand. *N Z Med J.* 2020;133(1513):81-88.
  32. Law RK, Wolkin AF, Patel N, et al. Injury-Related Emergency Department Visits During the COVID-19 Pandemic. *Am J Prev Med.* 2022;63(1):43-50. doi: 10.1016/j.amepre.2022.01.018.
  33. Norris P, Horsburgh S, Padukkage P, et al. Coverage and accuracy of ethnicity data on three Asian ethnic groups in New Zealand. *Aust N Z J Public Health.* 2010 Jun;34(3):258-261.
  34. Scott N, Clark H, Kool Bet al. Audit of ethnicity data in the Waikato Hospital Patient Management System and Trauma Registry: pilot of the Hospital Ethnicity Data Audit Toolkit. *N Z Med J.* 2018 Oct;131(1483):21-29.

# Cultural safety and the medical profession in Aotearoa New Zealand: a training framework and the pursuit of Māori health equity

David Tipene-Leach, Shirley Simmonds, Marnie Carter, Helena Haggie, Virginia Mills, Mataroria Lyndon

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## ABSTRACT

The concept of cultural safety, developed in the training of nurses over 30 years ago, was adopted by the Medical Council of New Zealand in 2019. We report on the journey of the Medical Council of New Zealand, Te ORA (the Māori Medical Practitioners Association) and the Council of Medical Colleges, and our increasing understanding of cultural competence and cultural safety in promoting best outcomes for Māori patients over the years. We describe in detail the key components of a cultural safety training framework as a tool for medical colleges' training of registrars and the Continuing Professional Development (CPD) of specialist medical practitioners. Finally, we discuss pathways forwards for cultural competence and cultural safety training that apply to a society with diverse cultural needs, noting that such training has been proposed as significant in shifting "difficult to change" Māori health inequities.

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This paper traces the origin of cultural competence and cultural safety in teaching programmes in New Zealand medical schools, and their journey into the standards of the Medical Council of New Zealand (MCNZ) and then into the training programmes of the Council of Medical Colleges (CMC). Beginning with cultural safety within the nursing profession in the early 1990s, we describe the contemporaneous pathways that medical cultural competence teaching programmes took in their own effort to improve health service delivery for Māori.

Longstanding inequitable Māori health outcomes saw the MCNZ introduce a cultural competency statement for medical practitioners in 2006. In 2016 the MCNZ and Te ORA (Te Ohu Rata o Aotearoa, the Māori Medical Practitioners Association) sought to review that work and held two national workshops and a programme of research. These activities spearheaded the 2019 development of a statement on cultural safety. Later collaboration with the CMC investigated cultural safety training in vocational training colleges and, finding it lacking, a cultural safety training framework for specialist vocational training and the re-accreditation of specialist medical practitioners was developed.

The cultural safety training programme is herein described in detail. We highlight the context of a robust cultural safety training

programme alongside other learnings, with its focus on self-reflective practice, power relationships and its potential to contribute to a shift in the many "difficult to change" Māori health inequities. We conclude that Māori health requires a body of teaching that stands apart as an Indigenous body of knowledge including knowledge, skills and reflective aspects of practice designed to promote a culturally safe medical practice and culturally safe places to train and work.

## Background

Cultural safety has its origins in the late 1980s, when Dr Irihapeti Ramsden, a prominent nurse educator, introduced a programme called He Kawa Whakaruruhau.<sup>1</sup> The intention was to improve health outcomes for Māori and other marginalised groups by encouraging nurses to develop a reflective "critical consciousness" practice around patient engagement—looking critically at their own attitudes, assumptions, stereotypes and prejudices (including racism) at work. It sought to transform power relationships in the clinical encounter and champion patient rights to determine what culturally safe care is. Cultural safety was to be applied across ethnicity, gender, age, ability, sexuality and religious groups. It has subsequently become an integral part of

nursing training. At the time, however, Ramsden noted “*outraged responses on the part of some students and some teachers and the notion that students were being ‘socially engineered’ by Indigenous interest groups.*”<sup>2</sup>

The medical profession’s adoption of training in culturally safe practice involved a more conservative pathway. The introduction of teaching around Māori health began in the 1970s; for example, in the Auckland medical training programme, there were experiential “*marae trips*” as part of the Behavioural Science course. Later, more formal Māori health teaching began when the medical schools appointed lecturers in Māori Health—Auckland in 1987 and Otago in 1989. The teaching involved imparting information (a knowledge base) about Māori history and culture to contextualise the presentation of a Māori patient. It was, at the time, called “*cultural sensitivity*”. It came to include the development of culturally appropriate behaviours (a skills base); for instance, the correct pronunciation of Māori names and appropriate traversing of Māori rituals of exchange and other customary practices. In both medical schools, this became an increasingly more significant teaching component, and more latterly, a comprehensive public health approach to the health of Māori populations was adopted. The “*self-reflective*” critical consciousness-based cultural safety teaching developed in medical schools in the 2010s. The knowledge, the skills and the self-reflective practices are mostly now all taught in medical schools under the label of *Hauora Māori*.

The notion that cultural knowledge and cultural skills constituted a distinct health-related competency for all medical practitioners (around diverse groups of patients) was introduced into the wider medical environment in the *Health Practitioners Competence Assurance Act 2003*. Section 4; Part 6(b) (iv) referred to “*... setting standards of clinical competence, cultural competence and ethical conduct.*” In 2006, the MCNZ issued the *Statement on cultural competence*.<sup>3</sup> Another document published at the same time, *Best health outcomes for Māori: practice implications*, outlined what cultural competence meant in relation to Māori.<sup>4</sup> Subsequently, larger medical colleges began to develop teaching programmes within their training and Continuing Professional Development (CPD) programmes.

In 2015, the MCNZ sought to review their 2006 cultural competence statement and to explore its effect on Māori health equity and participation

by Māori in health services. This process started a collaboration with Te ORA in developing the 2016 *Cultural competence, participation and health equity* symposium. The outcome was a joint advisory and governance group on cultural competence and equity, with a programme of research on cultural competence in New Zealand medical practice.

A second *Cultural competence, participation and health equity* symposium in June 2019 had an extensive programme that highlighted the health effects of racism and colonisation, two medical colleges’ initiatives around equity-focussed cultural competency and two engagement models for cultural competence. Finally, a comprehensive literature review of cultural competence and cultural safety was presented, which noted mixed and unclear definitions of cultural competence and cultural safety and the potential for cultural competency alone to actually do harm.<sup>5</sup> A new definition of cultural safety was proposed, and the authors concluded that medical practice based on cultural safety, with its emphasis on reflective practice around power, privilege and bias, was better suited to address health inequities than the skills-based cultural competency model. Embedding cultural safety training across all medical colleges was recommended. In particular, the authors asserted that we should systematically apply cultural safety within a healthcare organisational context as well as the individual health provider–patient interface. This workpiece was the basis of the MCNZ issuing the *Statement on cultural safety*<sup>6</sup> in October 2019 to replace the 2006 *Statement on cultural competence*. In a fashion similar to the 2006 statement, a document called *He Ara Hauora Māori: A pathway to Māori health equity* was also published.<sup>7</sup>

The MCNZ commissioned *Baseline Data Capture: Cultural Safety, Partnership and Health Equity Initiatives*, which published, in October 2020,<sup>8</sup> the baseline data required to measure the progress of change. This document detailed the need to acknowledge the disempowering role that structural barriers and systemic racism within health systems play, alongside the privilege that advantages Pākehā patients, in inequitable health outcomes. It also recognised the additional cultural loading on doctors who identify as Māori. Workforce recruitment strategies of Māori staff were also mooted, Māori representation in health governance was recommended, and the collection and use of robust ethnicity data for equity monitoring was highlighted—all to foster thinking



and focus on self-reflection and culturally safe practice.

Around the same time, the CMC enlisted Te ORA to evaluate the equity implications of the Choosing Wisely campaign, an international programme seeking to reduce unnecessary medical care by the facilitation of shared decision-making between practitioner and patient. Feedback from Māori health consumers and Māori health providers highlighted that enabling shared decision-making for Māori in a healthcare context would require promotion of cultural safety, patient-centred care, quality improvement and equity-based training.<sup>9</sup>

A collaboration between the CMC, Te ORA and the research group Allen + Clarke asked what cultural safety and health equity training was being undertaken by the colleges, and how Māori fellows and trainees experienced their medical specialty training. The *Cultural safety within vocational medical training*<sup>10</sup> research project involved the repeat of an online survey of medical colleges (which had been conducted by Te ORA in 2017), and the pursuit of supplementary qualitative data from Māori fellows and trainees was sought by the focus group. The findings illustrated that while cultural competence training in the larger colleges was often adequate, cultural safety training was not well developed, and this was further complicated by varying definitions of cultural safety. It showed that there were few Māori in the training programmes, few Te Tiriti o Waitangi statements in college documents and little, if any, Māori participation in governance. It also noted that the cultural safety of the training environment for Māori trainees was supervisor-dependent rather than college-dependent—in other words, they had no cultural safety standards for their trainer/supervisors. Māori trainees said they felt culturally unsafe and that their main support was their Māori peers. Subsequently, it was decided by the CMC and Te ORA that the development of a formal cultural safety training framework should be embarked on to support the formal development of cultural safety training in colleges.

The *Literature and Environmental Scan of Cultural Safety in Medical Training*<sup>11</sup> research aimed to identify and assess cultural safety training programmes in Aotearoa New Zealand medical training and elsewhere, and to determine to what extent Aotearoa New Zealand initiatives focussed on “cultural safety” versus “cultural competence”. It reviewed 44 journal articles or reports and added interviews with representatives from a sample of six small and large Aotearoa

New Zealand and Australasian medical colleges. The findings identified: that teaching consisted, for the most part, of health knowledge and cultural competency relevant only to Māori; that training programmes utilised a variety of teaching methods and had no consistent assessment procedures; that the content of the training was relatively brief and was not well embedded in the overall training programme; and that there was no evidence in the literature that current cultural competence or cultural safety programmes impacted on health outcomes, particularly equitable outcomes. It concluded that significant organisational commitment in the form of position statements, action plans, resourcing and staff are needed if cultural safety training is to be embedded in training programmes.

## The cultural safety training plan

The development of the *Cultural Safety Training Plan for Vocational Medicine in Aotearoa*<sup>12</sup> (the *Plan*) was intended to help colleges successfully add an effective cultural safety component of training to their existing (noting nomenclature variations) Hauora Māori or cultural competence training programmes. The *Plan* starts by briefly describing the journey of Hauora Māori, cultural competence and cultural safety training in Aotearoa New Zealand. It reiterates the importance of cultural safety in the pursuit of health equity for Māori. Cultural safety is then presented within a broad conceptual framework, defining the proficiencies of the culturally safe practitioner and providing a teaching and assessment framework to support practitioners’ development of cultural safety skills. Finally, it includes a simple assessment mechanism to self-monitor progress.

A proposed conceptual framework on which to build the *Plan* poses the attainment of “optimal health for Māori” as the focal point of the model (Figure 1). Such “optimal health” is embedded in the three “domains” of Hauora Māori, cultural competence and cultural safety. These are posited as essential items that contribute to optimal health.

These three domains are then defined, and the performance outcomes for the medical practitioner, if they should acquire these, are stated (Figure 2). We note here, recognising that these three components are inextricably related, that in our framework Hauora Māori refers to a Māori health knowledge base, but that in medical school training the Hauora Māori teaching programme has all three components in a single programme.

Figure 1: The conceptual framework.



Figure 2: The domains in which “optimal health for Māori” is nested.

CULTURAL SAFETY	CULTURAL COMPETENCE	HAUORA MĀORI
<p>Culturally safe medical practitioners engage in ongoing development of critical consciousness, involving self-reflection on their own biases, attitudes, assumptions, stereotypes, prejudices, structures and characteristics that may affect their practice.</p> <p>They examine and redress power relationships in consultations, with colleagues, and within the healthcare ecosystem, and they commit to transformative action internally, horizontally and vertically.</p> <p>They ensure that cultural safety is defined by the patients, whānau, and communities that they serve.</p>	<p>Culturally competent medical practitioners are committed to ongoing development of the knowledge and skills to work effectively within cross-cultural contexts. They recognise that the definition of culture is wider than ethnic understandings, and includes other social groups defined by their behaviours, beliefs and values.</p> <p>They accommodate for the cultural preferences of patients, whānau and communities, and have knowledge of cultural protocols, beliefs, and language, and use this to facilitate engagement with patients during clinical encounters.</p> <p>They have the communication skills and confidence to ask about cultural expectations and traditional practices, including the correct pronunciation of names.</p>	<p>Medical practitioners have knowledge of the historical and contemporary Māori health situation, use Māori health models within clinical practice, engage appropriately with Māori patients, whānau and communities, and are familiar with te reo Māori and tikanga Māori, and the diversity of Māori beliefs, values and experiences.</p> <p>Health is considered a property of the collective rather than the individual, and is holistically viewed, incorporating physical, mental, emotional, spiritual, and whānau dimensions, and the relationship with whenua and environment.</p>

**Figure 3:** Cultural safety has four broad key proficiencies.

Culturally safe medical practitioners:
<ol style="list-style-type: none"> <li>1. Engage an ongoing development of critical consciousness</li> <li>2. Examine and reduce power relationships</li> <li>3. Commit to transformative action</li> <li>4. Ensure that cultural safety is determined by patients and community served</li> </ol>

**Figure 4:** Each proficiency is described in depth with references.

Key proficiency 1: Culturally safe medical practitioners engage in ongoing development of critical consciousness
<p>Being a culturally safe practitioner requires doctors to first turn the lens on themselves. Doctors need to have knowledge of their own ethno-cultural heritage, and the values and assumptions they bring to clinical interactions (Dargaville, 2020; Downing et al., 2011; Medical Council of New Zealand, 2019a; Ramsden 2002; Sjøberg &amp; McDermott, 2016; Waitoki, 2012; Zaidi et al., 2017).</p> <p>Culturally safe doctors are aware that they bring conscious and unconscious assumptions and bias to their interactions with patients and colleagues (Downing et al., 2011; Jennings et al., 2018; Kirmayer, 2012; Watt et al., 2016). They work hard to identify these biases, critically consider how this affects their interaction with patients, communities, and colleagues, and commit to transformative action to ensure that their biases do not negatively affect the quality of care they provide to patients.</p> <p>Critical consciousness is an empowering, strengths-based approach that promotes introspective practices and active engagement in solutions to challenge inequity and oppression. The development of critical consciousness is central to being a culturally safe practitioner. Culturally safe doctors engage in ongoing self-reflection and self-awareness (Curtis et al., 2019). Their practice is also characterised by the knowledge that patients and whānau are the ones who determine and define whether the care they provide is culturally safe. This commitment to reflexive practice is foundational to developing proficiency in the other domains of culturally safe practice.</p>

**Table 1:** The cultural safety proficiencies have five “enabling” proficiencies.

Critical consciousness	Power relationships	Transformative action	Patients and communities
<p>1.1</p> <p>Demonstrate understanding of their own cultural heritage, values and history</p>	<p>2.1</p> <p>Recognise and advocate for the rights of patients, whānau, communities and tangata whenua</p>	<p>3.1</p> <p>Analyse and critique the healthcare ecosystem and its structures and processes that reinforce health advantage and disadvantage</p>	<p>4.1</p> <p>Make provision for regular feedback and input from patients, whānau and communities on the cultural safety of the healthcare environment, interactions and care provided</p>

**Table 1 (continued):** The cultural safety proficiencies have five “enabling” proficiencies.

1.2 Identify and address their own biases, attitudes, assumptions, stereotypes, prejudices, privileges and characteristics that may affect the quality of healthcare they provide	2.2 Examine and redress power imbalances between themselves and patients, whānau, the community and tangata whenua	3.2 Identify structural barriers to equitable culturally safe care within the institution or entity they are employed by	4.2 Advocate for their workplace to ensure regular feedback and input from tangata whenua/mana whenua on the cultural safety of the healthcare environment and interactions
1.3 Engage in ongoing self-reflection and self-awareness of own conduct and interactions to identify and remedy oppressive practices in interactions with patients, whānau and communities	2.3 Relinquish and leverage their own power to develop reciprocal relationships with patients and their whānau to foster shared decision-making and informed consent throughout treatment	3.3 Analyse and critique the culture and relationships among colleagues in their workplace and identify oppressive elements in workplace culture, and support their colleagues on the journey of cultural safety	4.3 Implement recommendations from patients, whānau and communities, and tangata whenua, in personal practice
1.4 Engage in ongoing self-reflection and self-awareness of own conduct and interactions with colleagues in the workforce to uphold culturally safe spaces	2.4 Examine and redress power imbalances within the healthcare profession and workforce	3.4 Examine health outcomes for Māori patients in clinical audit and case reviews, and identify interventions to alleviate inequities and progress towards optimal health	4.4 Identify and critique research and information that draws on a diverse range of patient perspectives and experiences to shape policy, practice and healthcare interactions
1.5 Commit to transformative change, and identify and implement alternative personal practices that contribute to equity and ongoing progression towards optimal health for Māori	2.5 Examine and influence power imbalances in the institution or organisation they work for, and the wider healthcare ecosystem	3.5 Identify solutions to structural and institutional barriers and contribute to, implement and embed transformative change	4.5 Identify Kaupapa Māori research that represents tangata whenua perspectives and experiences, to shape policy, practice and healthcare interactions

**Table 2:** Suggested teaching and assessment methods.

Cultural safety proficiencies	Suggested teaching methods and activities	Assessment tasks/CPD activities
<b>Proficiency 1: Culturally safe medical practitioners engage in ongoing development of critical consciousness</b>		
1.1 Demonstrate understanding of their own cultural heritage, values and history	<p><b>Self-directed learning:</b></p> <ul style="list-style-type: none"> <li>Research practitioner’s own cultural background</li> <li>Undertake critical analysis of a case study within own medical specialty to recognise stereotyping and discrimination that create barriers for Māori to high-quality healthcare</li> </ul> <p><b>Didactic learning:</b></p> <p>Workshops, seminars or presentations on implicit bias, stereotypes, privilege, racism and strategies to counter own biases</p> <p><b>Peer group learning:</b></p> <p>Discussions to reflect on interactions with patients and colleagues, identify biases within these interactions, discuss case critical analysis, reflect on workshops and develop strategies to implement equity enhancing practices</p>	<p><b>Assessment/CPD task 1:</b></p> <p><b>Self-reflection journal</b></p> <p>This assessment should focus on the practitioner’s critical and honest reflections on a clinical encounter (or encounters). The journal should include evidence of self-reflection against the proficiencies, including the biases they brought to the clinical encounters and interactions with colleagues, and the identification of transformative change strategies they will implement within their scope of practice and their workplace</p>
1.2 Identify and address their own biases, attitudes, assumptions, stereotypes, prejudices, privileges and characteristics that may affect the quality of healthcare they provide		
1.3 Engage in ongoing self-reflection and self-awareness of their own conduct and interactions to identify and remedy oppressive practices and interactions with patients, whānau and communities		
1.4 Engage in ongoing self-reflection and self-awareness of own conduct and interactions with colleagues in the workforce to uphold culturally safe spaces		
1.5 Commit to transformative change and identify and implement alternative personal practices that contribute to equity and ongoing progression towards optimal health for Māori		

There are also wider trainings pertinent to more diverse ethnic, religious, gender and ability groups in which other equitable outcomes are sought.

In turn, these three domains sit nested within a milieu of varied health system “concepts underpinning optimal health for Māori” (Figure 1). These items include “adherence to continuous

quality improvement (CQI)” and a citizen’s “right to health”, through to more Māori-directed factors like “Indigenous rights” and “Te Tiriti o Waitangi”. All eight of these “concepts underpinning optimal health for Māori” are discussed in detail in the *Plan*.

The conceptual framework retains what Ramsden has framed as “*health practitioner as*

*a navigator and border worker to the health care ecosystem.*” This recognises the ongoing importance of the mediation that medical practitioners do across the differing social, cultural and indeed emotional borders between patients and the interconnected stakeholders, organisations and structures in the healthcare ecosystem that contribute to the health of individuals and communities.

Four broad cultural safety “proficiencies”, consistent with Ramsden’s original thesis, exemplifying a culturally safe medical practitioner were identified and described (Figure 3).

These are the abilities to a) engage in ongoing development of critical consciousness, b) examine and redress power relationships, c) commit to transformative action, and d) ensure that cultural safety is determined by patients and communities served. Each of these proficiencies is then described in depth with reference to relevant literature (Figure 4).

Within each cultural safety proficiency there are five “enabling proficiencies” (Table 1) that the practitioner should be equipped with following cultural safety education and training.

For each proficiency, there are suggested teaching methods and activities and assessment tasks or CPD activities (Table 2).

The training plan goes on to provide guidance to colleges for the plan’s implementation. This begins with stressing the need for colleges themselves to create a strong culturally safe organisational environment as a firm foundation. It then describes the need to implement the training into curricula, taking into consideration particular needs and resources of the specialist colleges, and stresses the importance of employing appropriate educators, trainers and supervisors without putting undue cultural load on Māori practitioners.

## Discussion

The journey of cultural safety training for medical practitioners in Aotearoa New Zealand, particularly in relation to Māori health, is marked by significant milestones and collaborative efforts among key stakeholders, including the MCNZ, Te ORA and the CMC. The integration of cultural competence and then cultural safety into the standards of the MCNZ and its introduction into medical vocational training programmes by the CMC reflects a broad commitment to embed cultural safety as a core practitioner competency, the promotion of culturally safe practices in

healthcare environments and the addressing of Māori health inequities.

Regarding cultural safety, the importance of self-reflective practice, power relationships and patient determination of culturally safe care has always been to the fore. The shift by the medical profession from cultural competence standards to the inclusion of cultural safety signifies the recognition of the limitations of skills-based approaches and the need for deeper reflection on power, privilege, racism and bias within healthcare settings.<sup>13</sup> It is worth noting that, reflecting its origins in Ramsden’s work, the term “cultural safety” is primarily used in Aotearoa New Zealand. Other jurisdictions focus on cultural sensitivity, cultural competence, cultural appropriateness and cultural awareness and, where they do use the words “cultural safety”, they often have yet to broach the issues of self-reflective and transformative practice.

The *Cultural Safety Training Plan for Vocational Medicine in Aotearoa* provides a structured framework for developing cultural safety skills among medical practitioners. It will require strong leadership from colleges to implement and then to have their graduate fellows effectively navigating the complexities of healthcare ecosystems and the pursuit of health equity outcomes for Māori and other culturally diverse populations. And this will require robust evaluation—not least because the medical workforce and its associated infrastructure are being sorely tested by under-resourcing at the present time.

There are significant challenges ahead for the integration of this programme into medical colleges producing systematic change. Although cultural safety is taught in medical schools, a large proportion of the medical workforce is internationally trained, and medical colleges can only effect change through CPD rather than years-long vocational training. Secondly, there is a limited evidence base for cultural safety standards and training programmes improving health outcomes for population groups, like Māori, who have pervasive health inequities.<sup>14</sup> More research is needed to evaluate the training plan and build the evidence base for cultural safety interventions. Finally, cultural safety programmes have a far wider application than Māori health. Indeed, a recent Te ORA cultural safety symposium in March 2024 involving six different Indigenous jurisdictions and various Aotearoa New Zealand health institutions and

medical colleges noted that health inequities are endured by other cultural groups, including those with diverse gender identities and sexualities, and the disabled and immigrant communities. While there is a need for a stand-alone Hauora Māori teaching programme that incorporates cultural competence, cultural safety and the creation of culturally safe environments for Māori doctors, there is also a need for teaching framed specifically around other groups with diverse cultural needs.

Perhaps we simply need to train more doctors from these populations of need. This too would serve Ramsden's original thesis on cultural safety, which, while rooted in her concern for Māori health, was an attempt to address the safety of all marginalised groups. It is also interesting to note that the development of cultural safety in the medical field has been incremental and slow-moving, reflecting perhaps a very conservative stance on change. It started with the acquisition of a knowledge base, moved then to the development of skill-based competencies and, only recently, to the acquisition of a reflective cultural safety practice. Ramsden, on the other hand, was able to move directly, despite some significant resistance, to cultural safety. Māori health professionals have maintained her imperative in medical schools, teaching all three in one integrated Māori health-focussed programme.

In addition, in our previous enquiries with

Māori doctors themselves,<sup>8,9,10</sup> doctors consistently mentioned “cultural load”—those additional workplace tasks outside of the standard job description that are placed on the shoulders of Māori doctors because they are Māori. This research provides considerable evidence that this is a very real workload with its attendant stresses and pressures and that the working environment for Māori doctors is often unsafe. This warrants further research.

To implement the cultural safety training plan effectively, it is also crucial that clinical educators themselves practice cultural safety. The proficiencies of the training plan should be applied beyond patient care and integrated into teaching, clinical supervision, assessment and creating culturally safe learning environments.<sup>15,16</sup> This will include developing strategies for continuous learning and reflection on cultural safety in a clinical educator's teaching practice.

In conclusion, the emphasis on cultural safety training in medical education represents a positive step towards promoting health equity for Māori and addressing systemic barriers in healthcare delivery. By embracing the principles of cultural safety, medical practitioners will aspire to create inclusive and culturally safe environments that prioritise the wellbeing and autonomy of all patients, irrespective of their cultural backgrounds.

**COMPETING INTERESTS**

ML was contracted by Allen + Clarke as an independent researcher to undertake advice and peer review towards the development of the Cultural Safety Training Plan. MC is an employee of Allen + Clarke and completed the research as part of her paid employment.

SS was contracted by Allen + Clarke as an independent researcher to undertake research work towards the development of the Cultural Safety Training Plan; by the Council of Medical Colleges as an independent researcher to support the implementation of the Cultural Safety Training plan March 2023–Dec 2024; by the Australian & New Zealand College of Anaesthetists for advisory support for the development of the Cultural Safety and Health Equity Framework Oct 2023–Nov 2024.

VL was contracted by the Council of Medical Colleges in the role of Executive Director during this project. The Council of Medical Colleges funded her time on the project and provided funding for external researchers (Allen + Clarke). Choosing Wisely New Zealand also sponsored the project, contributing funding for the external research component, following on from the Choosing Wisely means Choosing Equity report. Te Ohu Rata o Aotearoa provided time and expertise of a lead researcher on the project. VL has been employed at the Association of Salaried Medical Specialists (ASMS) since April 2023 and has been contracted by Allen + Clarke to provide planning and peer review of a project on cultural loading from May 2023 (16 hours work).

HH was a co-opted Māori member to the executive board of the Council of Medical Colleges 2019–2022; Te Whatu Ora Waikato contracted Project Manager and General Practitioner in which she led the Cardiology Access Equity project and provided Clinical oversight of the clinical team, April 2022–July 2023; and has a current position as General Practitioner at Tu Tonu Hauora.

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**AUTHOR INFORMATION**

David Tipene-Leach: Research Professor, Te Kura i Awarua Rangahau Māori Research Centre, Eastern Institute of Technology | Te Pūkenga, Hawke's Bay.  
Shirley Simmonds: Independent Kaupapa Māori Researcher, Council of Medical Colleges, Wellington.  
Marnie Carter: Senior Researcher, Allen + Clarke Policy

and Regulatory Specialists, Wellington.

Helena Haggie: Specialist General Practitioner, Tū Tōnu Hauora Medical Centre, Hamilton.

Virginia Mills: Policy and Research Advisor, Association of Salaried Medical Specialists, Wellington.

Mataroria Lyndon: Senior Lecturer, Centre for Medical and Health Sciences Education, The University of Auckland, Auckland.

**CORRESPONDING AUTHOR**

David Tipene-Leach: Te Kura i Awarua Rangahau Māori Research Centre, Eastern Institute of Technology | Te Pūkenga, 462 Gloucester St, Hawke's Bay. Ph: 4112 027 477 3483. E: dtipene-leach@eit.ac.nz

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**REFERENCES**

1. Ramsden I. Cultural safety in nursing education in Aotearoa (New Zealand). *Nurs Prax N Z*. 1993;8(3):4-10.
2. Ramsden IM. Cultural Safety and Nursing Education in Aotearoa and Te Waipounamu [dissertation]. Wellington (NZ): Victoria University of Wellington; 2002.
3. Medical Council of New Zealand. Statement on Cultural Competence (abstract) [Internet]. Wellington (NZ): Medical Council of New Zealand; 2006 [cited 2024 Nov 20]. Available from: <https://uat.mcnz.org.nz/our-standards/current-standards/cultural-competence/>
4. Medical Council of New Zealand. Statement on best practices when providing care to Māori patients and their whānau (abstract) [Internet]. Wellington (NZ): Medical Council of New Zealand; 2006 [cited 2024 Nov 20]. Available from: <https://uat.mcnz.org.nz/our-standards/current-standards/cultural-competence/>
5. Curtis E, Jones R, Tipene-Leach D, et al. Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition. *Int J Equity Health*. 2019;18(1):174. doi: 10.1186/s12939-019-1082-3.
6. Medical Council of New Zealand. Statement on cultural safety [Internet]. Wellington (NZ): Medical Council of New Zealand; 2019 [cited 2024 Nov 20]. Available from: <https://www.mcnz.org.nz/assets/standards/b71d139dca/Statement-on-cultural-safety.pdf>



7. Medical Council of New Zealand. Te Ara Hauora Māori: A pathway to better Māori health equity [Internet]. Wellington (NZ): Medical Council of New Zealand; 2019 [cited 2024 Nov 20]. Available from: <https://www.mcnz.org.nz/assets/standards/6c2ece58e8/He-Ara-Hauora-Maori-A-Pathway-to-Maori-Health-Equity.pdf>
8. Allen + Clarke. Baseline data capture: Cultural safety, partnership and health equity initiatives [Internet]. Wellington (NZ): Medical Council of New Zealand and Te Ohu Rata o Aotearoa; 2020 [cited 2024 Nov 20]. Available from: <https://www.mcnz.org.nz/assets/Publications/Reports/f5c692d6b0/Cultural-Safety-Baseline-Data-Report-FINAL-September-2020.pdf>
9. Tipene-Leach D, Adcock A, Abel S, Sherwood D. The Choosing Wisely campaign and shared decision-making with Māori. *N Z Med J.* 2021;134(1547):26-33.
10. Carter M, Pōtiki M, Haggie H, Tipene-Leach D. Cultural safety within vocational medical training [Internet]. NZ: Te ORA and the Council of Medical Colleges; 2021 [cited 2024 Nov 20]. Available from: <https://www.cmc.org.nz/media/w0be4zv5/final-te-ora-cmc-cultural-safety-report-20210512.pdf>
11. Carter M, Simmonds S, Haggie H, et al. Literature and environmental scan of cultural safety in medical training [Internet]. NZ: Te ORA and the Council of Medical Colleges; 2022 [cited 2024 Nov 20]. Available from: <https://www.cmc.org.nz/media/f03dvuw/literature-and-environmental-scan-of-cultural-safety-in-medical-training.pdf>
12. Simmonds S, Carter M, Haggie H, et al. A Cultural Safety Training Plan for Vocational Medicine in Aotearoa [Internet]. NZ: Te ORA and the Council of Medical Colleges; 2023 [cited 2024 Nov 20]. Available from: <https://www.cmc.org.nz/media/4xmpx1dz/cultural-safety-training-plan-for-vocational-medicine-in-aotearoa.pdf>
13. Zaitoun RA, Said NB, de Tantillo L. Clinical nurse competence and its effect on patient safety culture: a systematic review. *BMC Nurs.* 2023;22(1):173. doi: 10.1186/s12912-023-01305-w.
14. Browne AJ, Varcoe C, Smye V, et al. Cultural safety and the challenges of translating critically oriented knowledge in practice. *Nurs Philos.* 2009;10(3):167-79. doi: 10.1111/j.1466-769x.2009.00406.x.
15. Pimentel J, López P, Cockcroft A, Andersson N. The most significant change for Colombian medical trainees going transformative learning on cultural safety: qualitative results from a randomised controlled trial. *BMC Med Educ.* 2022;22(1). doi: 10.1186/s12909-022-03711-1.
16. Mattingly JA. Fostering cultural safety in nursing education: experiential learning on an American Indian reservation. *Contemp Nurse.* 2021;57(5):370-378. doi: 10.1080/10376178.2021.2013124.

# Case study of a potential West Polynesian variant of von Hippel-Lindau disease

Eugene Michael, Peter Hadden, Stephen Robertson

This clinical correspondence is a case study of patients of West Polynesian heritage presenting to a single centre in Auckland, New Zealand with retinal capillary haemangioblastoma (RCH). Case 1 was a 54-year-old Tongan woman with right juxtapapillary RCH (Figure 1a) first diagnosed in 2010. She had a past medical history of bilateral renal cell carcinoma and pancreatic neuroendocrine tumours, diagnosed at ages 41 and 42 respectively, and had been investigated with magnetic resonance imaging of the brain, spine and abdomen (MRI B/S/A). Family history revealed that her mother died of an undiagnosed brain tumour in Tonga in the third to fourth decade of life and her older brother also passed away in similar circumstances. Her late father was not known to be affected. Her 7-year-old son (Case 2) had MRI B/S/A showing brain haemangioblastoma and multiple renal cysts; audiology testing was normal. Her youngest son, aged 3, had a normal ophthalmic examination. Her sister, Case 3, was a 52-year-old with bilateral juxtapapillary RCH (Figure 1b). She had a history of spinal haemangioblastoma, bilateral renal cell carcinoma and multiple pancreatic neuroendocrine tumours—recent MRI B/S/A showed stable tumour size with no new lesions. Her RCH and non-ocular tumours were diagnosed at age 44.

The family pedigree (Figure 2) is consistent with autosomal dominant inheritance and plausibly a von Hippel-Lindau (vHL)-like syndrome.

All cases had genetic testing for vHL performed at Auckland District Health Board, which was non-confirmatory. The entire coding region of *VHL*, including intron-exon splice junctions, was sequenced. A copy number analysis of this locus was also performed using an Agilent custom comparative genomic hybridisation array. No pathogenic variants were identified.

## Discussion

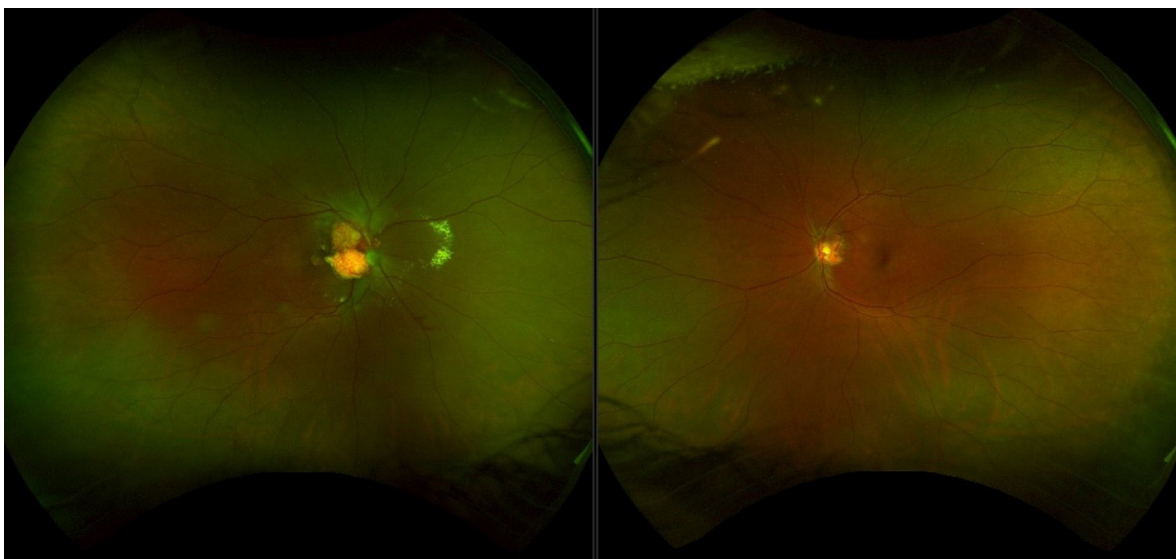
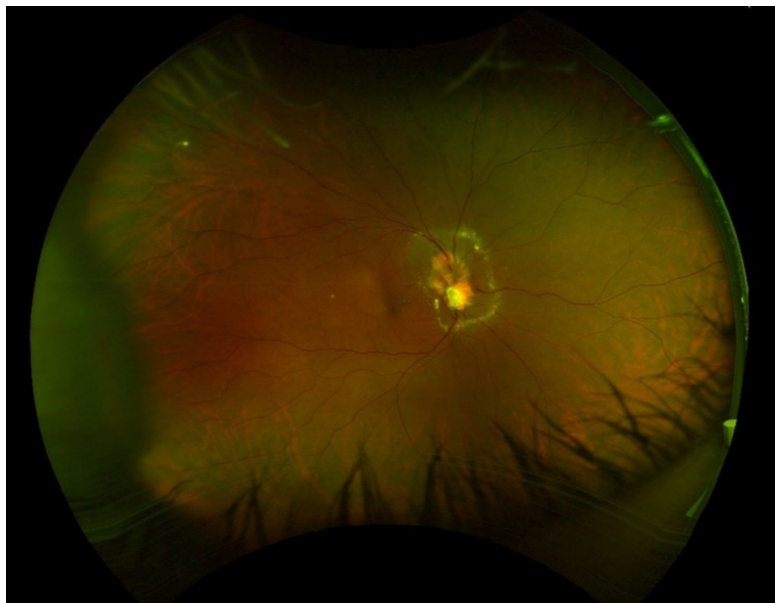
RCH is often a key early sign in vHL disease,

with a mean age of diagnosis of 18 years.<sup>1</sup> This may have significant implications due to multi-system involvement including central nervous system haemangioblastoma, pheochromocytoma, pancreatic islet carcinoma, increased risk of renal cell carcinoma and cyst formation in the liver, lung, pancreas and kidney.<sup>2</sup> RCH may also be observed as an isolated phenomenon and it is estimated that up to half of patients with solitary RCH have vHL disease.<sup>1</sup> Approximately 85% of RCH are located in the peripheral retina and 15% are juxtapapillary.<sup>3</sup>

vHL is an autosomal dominant condition with high penetrance, occurring in one in 36,000 individuals whereby 20% are *de novo* pathogenic variants.<sup>4</sup> As with all phakomatoses, there is no ethnic predisposition.<sup>4</sup> In non-familial cases, a retinal or cerebral tumour plus a visceral tumour (or two or more retinal or cerebral tumours) are required for diagnosis.<sup>5</sup> However, in those that test negative for gene sequencing and have not met the diagnostic criteria for disease, almost 100% will not develop vHL.<sup>6</sup> For those that meet clinical diagnostic criteria, 5% will have no demonstrable pathogenic variant using this diagnostic approach in Case 1.<sup>7</sup> Causative *VHL* variants that would escape detection using the approach utilised here could lie within introns or be epigenetic in nature.

This raises the possibility of a West Polynesian variant of vHL in individuals of Tongan ancestry with manifest angiomas and visceral pathology. During the chart review, two patients of Niuean background were identified: a 38-year-old female with left juxtapapillary RCH and a 35-year-old male with right juxtapapillary RCH, neither of whom had any family history of vHL. Interestingly, there are strong historical and ancestral ties between Tonga and Niue, which have small populations in close geographical proximity. Despite this, there was no familial link between these two patients and systemic screening to-date (MRI B/A) revealed no other associated pathology to fulfil the diagnostic criteria for vHL.<sup>7</sup> They therefore represent solitary,

**Figure 1:** Composite image of RCH: a) Case 1, photo of right eye juxtapapillary RCH, with circumpapillary exudation, serous detachment and radial folds in the retina, and b) Case 3, photo of right eye juxtapapillary RCH, with nasal peripapillary exudation; photo of left eye with small juxtapapillary RCH.

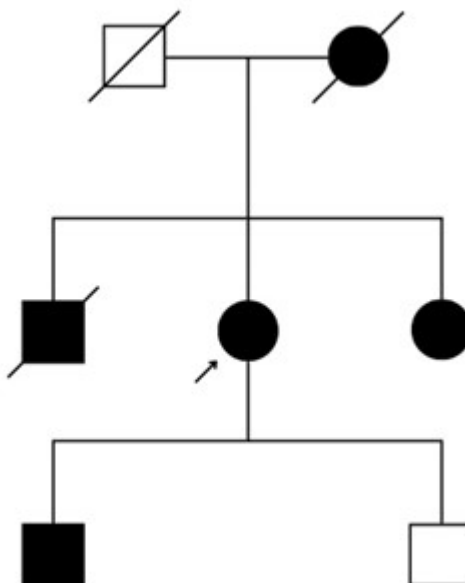


non-syndromic RCH, but further follow-up for detection of new retinal lesions and completion of systemic screening is pending.

The location of these tumours next to the optic nerve increases the risk of vision loss due to exudation and oedema, tractional maculopathy, vitreous haemorrhage and neovascular glaucoma.<sup>3</sup> This is of particular relevance, as those of Polynesian ancestry have a greater burden of disease (both ocular and

systemic) in the New Zealand healthcare setting.<sup>8</sup> The familial disorder described here is strongly suggestive of vHL, but access to exhaustive screening, post-mortem analyses and genetic evaluations are restricted in resource-constrained Pacific countries, limiting diagnostic ability. Adoption of a more comprehensive genetic evaluation (exons, introns and methylation) of the *VHL* locus using “long-read DNA sequencing” (LRDS) is a possible next step to

**Figure 2:** Diagram of family pedigree, indicating the proband (Case 1).



detect an as yet pathogenic variant in these families. The potential of LRDS is that it may offer an affordable, portable and adaptable solution, thereby obviating the need for expensive radiographic screening to make the diagnosis. Another approach could include the characterisation of the transcripts produced from the *VHL* locus in an affected individual. Both techniques have potential to ameliorate the current 95% detection rate and preclude the need for surveillance in those with monosymptomatic presentations, such as RCH.<sup>9</sup> However, optimal analysis would require normative epigenetic data from appropriate tissues as well as an understanding of population-specific genetic variation to make categorical diagnostic conclusions, both of which are yet to be attained at an appropriate scale. Currently, such isolated findings should prompt the screening of other organs for vascular “vHL-like” tumours even when genetic analysis is inconclusive.

## Conclusion

Polynesian patients who present with juxta-papillary RCH should be screened for systemic tumours. They should be monitored and treated to prevent vision loss and genetically evaluated using methodologies that can detect the full spectrum of possible causative *VHL* alleles.

Polynesian peoples have been isolated from other populations for a long period of time and are likely to have genetic diseases that are as yet unrecognised. Paradoxically, in Pacific nations where genetic services are limited, the employment of more comprehensive genetic methodologies used earlier rather than later during diagnostic evaluation would bring economies and efficiencies to clinical practice as well as improve the lives of patients. Such lessons are likely to be replicated across a broad number of genetic disorders and their presentation in Pacific peoples.

**COMPETING INTERESTS**

None declared.

**STATEMENT OF ETHICS**

This was conducted in accordance with the tenets of the Declaration of Helsinki and the National Ethics Advisory Committee guidelines and met the criteria for exemption from formal review by the New Zealand Health and Disability Ethics Committee in accordance with national guidelines.

**AUTHOR INFORMATION**

Eugene Michael, FRANZCO, MBChB: Ophthalmologist, Department of Ophthalmology, Greenlane Clinical Centre, Auckland, New Zealand.

Peter Hadden, FRANZCO, MBChB: Ophthalmologist, Department of Ophthalmology, Greenlane Clinical Centre, Auckland, New Zealand.

Stephen Robertson: Department of Women's and Children's Health, Dunedin School of Medicine, University of Otago, New Zealand.

**CORRESPONDING AUTHOR**

Dr Peter Hadden: Department of Ophthalmology, Greenlane Clinical Centre, Auckland, New Zealand. Ph: +64 21 528252. E: peter.h211@gmail.com

**URL**

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**REFERENCES**

1. Singh A, Shields J, Shields C. Solitary retinal capillary haemangioma: hereditary (von Hippel-Lindau disease) or nonhereditary? *Arch Ophthalmol*. 2001 Feb;119(2):232-234. Erratum in: *Arch Ophthalmol* 2001 Aug;119(8):1226.
2. Chou A, Toon C, Pickett J, Gill AJ. von Hippel-Lindau syndrome. *Front Horm Res*. 2013;41:30-49. doi: 10.1159/000345668.
3. Wong WT, Agrón E, Coleman HR, et al. Clinical characterization of retinal capillary haemangioblastomas in a large population of patients with von Hippel-Lindau disease. *Ophthalmology*. 2008;115(1):181-188. doi: 10.1016/j.ophtha.2007.03.009.
4. Lonser RR, Glenn GM, Walther M, et al. von Hippel-Lindau disease. *Lancet*. 2003 Jun;361(9374):2059-2067. doi: 10.1016/S0140-6736(03)13643-4.
5. Maher ER, Kaelin WG Jr. von Hippel Lindau disease. *Medicine (Baltimore)*. 1997 Nov;76(6):381-391. doi: 10.1097/00005792-199711000-00001.
6. Decker J, Neuhaus C, MacDonald F, et al. Clinical utility gene card for: von Hippel-Lindau (VHL). *Eur J Hum Genet*. 2014 Apr;22(4). doi: 10.1038/ejhg.2013.180.
7. van Leeuwaarde RS, Ahmad S, van Nesselrooij B, et al. Von Hippel-Lindau Syndrome. 17 May 2000 [updated 21 Sep 2023]. In: Adam MP, Feldman J, Mirzaa GM, et al., editors. *GeneReviews*® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2024. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK1463/>
8. Sheridan NF, Kenealy TW, Connolly MJ, et al. Health equity in the New Zealand health care system: a national survey. *Int J Equity Health*. 2011;10:45. <https://doi.org/10.1186/1475-9276-10-45>.
9. Oehler JB, Wright H, Stark Z, et al. The application of long-read sequencing in clinical settings. *Hum Genomics*. 2023 Aug;17(1):73. doi: 10.1186/s40246-023-00522-3.

# Medical Ethics Up-to-Date

NZMJ, 1924

(With acknowledgements to DR. E. H. DEARBORN, in "Pacific Coast Medical Journal.")

If called by night to attend a stranger at a great distance, dress quickly and go, never stopping to ask who wants you, or if the bill will ever be paid, lest you be counted inhuman.

Never ask how many physicians are in attendance in a case, or how many kinds of patent medicines the patient is taking. Such curiosity on the part of the physician is vulgar.

Never insult a stranger by asking for credentials, nor a patient by asking for money—dollars and cents is the vernacular of lawyers, bankers, tradesmen and "workers."

Never send in a "statement," patients will think you are hard up.

In writing a prescription, invoke Jove and cultivate mystery; a splash of ink and wiggle of the pen is sufficient. The druggist will put in "something just as good."

Be sure to taste of the medicine left by the other physician, and "wonder if it will kill you." The remark is strictly original with you and impresses the patient and nurse with the brilliancy of your humour.

Be sure to mention the fact of your being overworked. Operative work, abdominal surgery, appendectomy, blood pressure, toxæmia, cholecystitis, are words that impress the laity. Use them often. Your wife must tell her friends how

busy you are.

When going by a patient's house, step in socially and tell her of some interesting case or of some operation you have just performed, and incidentally mention how busy you are.

Never be friendly with any other physician. It's unethical.

If you think another physician makes five dollars more a month than you do, cut him dead.

If another physician's name is mentioned in your presence, bite your tongue and compress your lips, and the patient will understand that your hypertrophied good principles keep you from "telling the truth, the whole truth," and a few other things about him.

If called in after another physician has been treating a case of pneumonia, make your diagnosis "inflammation of the lungs," and be sure to say if you had been called in twenty-four earlier you could have saved the patient.

Never (or rarely) tell the truth; patients won't stand it. They will have you charge them up with one dollar and pay a liar 75 dollars in advance. The laity love a cheerful liar.

If the other fellow doesn't think as you do, it proves his inferior intellect.

Don't have your principles so high you can't reach them.

Be generous before you are just—otherwise you will never be generous at all.

# Proceedings of the Waikato Clinical Campus Research Seminar, Thursday 31 October 2024

## Examining climate change impacts on health service access in Aotearoa New Zealand: an experimental proof-of-concept

Mitchell Pincham,<sup>1</sup> Sam Quinsey,<sup>2</sup> Marcus Blake,<sup>2</sup> Jesse Whitehead<sup>1\*</sup>

<sup>1</sup>*Te Ngira: Institute for Population Research, University of Waikato, New Zealand*

<sup>2</sup>*Centre of Australian Research into Accessibility, Deakin Rural Health, Deakin University, Australia*

\*Corresponding author: [jesse.whitehead@waikato.ac.nz](mailto:jesse.whitehead@waikato.ac.nz)

### AIMS

To develop a proof-of-concept methodology to rapidly estimate accessibility to health services in Aotearoa in the context of extreme weather events.

### METHODS

An exploratory quantitative analysis used publicly available geospatial data to estimate distance to nearest GP and hospital for every address (2.3 million) in Aotearoa under “normal” conditions. The road network dataset was then modified to reflect closures following Cyclone Gabrielle and access to health services estimated under new conditions. Estimates of access to services post-Cyclone Gabrielle and under normal conditions were compared.

### RESULTS

The exploratory results revealed the extent of service access disruption due to Cyclone Gabrielle related road closures. Approximately 80,000 addresses were isolated from a GP, with approximately 100,000 addresses isolated from hospital services. Increased travel distances of more than 1km affected approximately 38,000 and 101,000 addresses, requiring increased travel to a GP and hospital respectively.

### CONCLUSIONS

This research demonstrates a viable approach to creating dwelling-level accessibility datasets and evaluating the impacts of extreme weather on health service access. Future work will focus on refining the methodology and assessing its feasibility for health service providers to enhance care coordination in times of crisis.

## Cancer WHIRI; a holistic, culturally safe healthcare model that enhances delivery of cancer care, and social and family wellbeing

Deanne King,<sup>1</sup> Nina Scott,<sup>1</sup> Myra Ruka,<sup>1</sup> Amy Jones,<sup>1</sup> Jacquie Kidd,<sup>2</sup> Lotta Bryant,<sup>3</sup> Frances Robbins,<sup>1</sup> Nadine Riwai<sup>1</sup>

<sup>1</sup>*Te Whatu Ora Waikato, Hamilton, New Zealand*

<sup>2</sup>*Auckland University of Technology, Auckland, New Zealand*

<sup>3</sup>*University of Waikato, Hamilton, New Zealand*

### BACKGROUND

Māori are twice as likely to die after a diagnosis of cancer compared to non-Māori in Aotearoa New Zealand. Māori receive delayed poorer quality treatment, and those with comorbidities are under-treated. Coordination of care is crucial for Māori patients and whānau (family), but poorly developed along this early part of the cancer pathway. Our vision is that a potential diagnosis of cancer results in positive racism-free health engagement, timely access to high-quality care and wellbeing gain for individuals and their whānau.

### AIMS

This study sought to co-design, implement and evaluate a holistic cancer service that is patient- and whānau/family-centred using WHIRI, an established Māori model of care. This comprehensive, racism-free, wellbeing-enhancing and responsive approach was redesigned for the early part of the secondary care cancer pathway.

### DESIGN AND METHOD

The WHIRI model includes navigation and an electronic holistic assessment tool with follow-up protocols. WHIRI includes nurse-led case management, including a general practice doctor and daily clinical case reviews with proactive team management for making systems changes. Over 1 year, the team developed a WHIRI model of cancer care using Kaupapa Māori methodology incorporating the Meihana Model and access to traditional Māori medicine, rongoā. Key to this was working in partnership with patients, whānau, cancer clinicians, Māori navigators and key stakeholders in the cancer space. We used “He Pikinga Waiora” (Māori

implementation framework) to guide the research process. The cancer WHIRI programme was piloted with 34 Māori patients referred for suspicion of cancer to Waikato Hospital.

#### RESULTS

Cancer WHIRI included the following components: patient- and whānau-centred care; relationships; maximised hauora/wellbeing and equity gain; systems; and tino rangatiratanga/Māori autonomy. Following these components within the pilot allowed healthcare professionals to create culturally safe environments to enhance the delivery of care, while incorporating modern and traditional medical practices such as rongoā Māori. The team will present results of the pilot and discuss the model, which has potential to expand nationally with reach from primary care through to palliative care.

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### Comparative study of severe traumatic brain injury outcomes using crash and impact prognostic calculators to predict FIM scores on discharge from rehabilitation services

Harini Ravi,<sup>1</sup> Sheena Moosa,<sup>2</sup> Thirayan Muthu,<sup>1</sup> Sami Raunio,<sup>1</sup> Peter Gan,<sup>1</sup> Alastair Smith,<sup>2</sup> Tony Young,<sup>3</sup> Grant Christey<sup>2,4</sup>

<sup>1</sup>Department of Neurosurgery, Te Whatu Ora Waikato, Hamilton, New Zealand

<sup>2</sup>Te Manawa Taki Trauma System, Te Whatu Ora Waikato, Hamilton, New Zealand

<sup>3</sup>ABI Rehabilitation New Zealand

<sup>4</sup>Waikato Clinical School, The University of Auckland, Aotearoa New Zealand

#### INTRODUCTION

Traumatic brain injury (TBI) is a common and devastating condition affecting predominantly the younger population, with variable prognosis depending on severity. Predicting and communicating prognosis is often a difficult discussion with whānau in the ICU setting.

#### AIM

To assess functional outcomes of severe TBI (sTBI) in the Te Manawa Taki (TMT) cohort, and to compare the prognosis parameters with both CRASH and IMPACT cohorts.

#### METHODS

This is an observational retrospective cohort study spanning from June 2012 until December 2022. We recruited 79 sTBI patients using the TMT Trauma Registry, who were subsequently transferred to and discharged from the Acquired Brain Injury (ABI) Rehabilitation Service. ED admission CRASH

and IMPACT prognostic model parameters and ABI discharge Functional Independence Measure (FIM) scores were analysed.

#### RESULTS

71% of the TMT cohort were male and 40% were of Māori ethnicity. The FIM scores on discharge from ABI showed 10% severe, 33% moderate and 57% mild disability respectively. CRASH and IMPACT 6-month unfavourable outcome estimates are 39% and 49% lower than previous studies. Our cohort had higher rates of major extra-cranial injury, one reactive pupil and non-evacuated haematoma compared to CRASH and greater GCS motor score of 1, hypoxia and hypotension compared to IMPACT. The results are statistically significant.

#### CONCLUSION

We successfully externally validated discrimination and calibration of CRASH and IMPACT using the TMT cohort. Our study showed feasibility to apply prognostic calculators to the TMT cohort; however, the rate of unfavourable outcomes was overestimated partly because of our small sample size.

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### WHIRI: a culturally safe approach to supporting Māori with chronic conditions

Lynley Uerata,<sup>1</sup> Ross Lawrenson,<sup>2</sup> Nina Scott,<sup>1</sup> Amy Jones,<sup>1</sup> Jade Tamatea,<sup>1,3</sup> Polly Atatoa-Carr,<sup>1,2</sup> Nikki Barrett,<sup>2</sup> Lynne Chepulis,<sup>2</sup> Ryan Paul<sup>1,2</sup>

<sup>1</sup>Te Whatu Ora Waikato, Hamilton, New Zealand

<sup>2</sup>University of Waikato, Hamilton, New Zealand

<sup>3</sup>Te Kupenga Hauora Māori, The University of Auckland, Aotearoa New Zealand

#### BACKGROUND

Socio-economic determinants shape the wellbeing of populations and are causative drivers of ethnic inequities in health outcomes. Māori experience differential access/exposure to socio-economic determinants, manifesting in higher rates of both chronic and acute disease compared to non-Māori. Māori also experience marked health determinant inequity, such as those measured in education, un/employment, housing, economic and justice sectors. In turn, Māori experience stark and enduring inequities in health, including higher rates of cancer, diabetes, asthma, kidney disease and other chronic conditions. Therefore, health determinants need to be considered in the design and delivery of health-care models. This project aimed to develop and pilot a holistic hauora (wellbeing) needs assessment and clinical support for Māori living with chronic



conditions, which acknowledges the importance of health determinants and provides culturally safe support to address needs.

#### **METHOD**

Weaving together elements of the Kaupapa Māori and mixed methods approaches and the He Pikinga Waiora framework, the research team co-designed with patients and practitioners a WHIRI model of care for chronic conditions. WHIRI includes an integrated team structured around navigators, a wellbeing assessment that acknowledges the health determinants with follow-up pathways, and links to a multidisciplinary, nurse-led clinical team. Overseen by an Indigenous clinical governance team, the model was piloted with 30 Māori patients, referred via Waikato Hospital, living with chronic conditions.

#### **RESULTS**

Different kinds of expertise identified ways to make healthcare more culturally safe and accessible for healthcare providers to deliver to patients and whānau. Drawing on Māori engagement practices (such as whakawhanaungatanga [making connections], karakia [prayer] and koha [offering]) and the Meihana model, navigators worked with patients and whānau to deliver WHIRI. We will present findings that show that Indigenous governance and co-design of the WHIRI approach enabled the safe identification and support for a range of unmet social determinants and clinical needs, resulting in important hauora/health gains for Māori and their whānau.

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