

FEATURES: MĀORI HEALTH REVIEW SERIES

Health equity, tobacco smoking and biobanking

Emma Espiner

Introduction

The editorial team of the New Zealand Medical Student Journal (NZMSJ) welcomes a new regular series on Māori health, launched to coincide with our special issue on health equity. This series will feature case studies of kaupapa Māori health initiatives, interviews with experts, and analysis of research and emerging issues in health equity for Māori.

Our first instalment features a discussion about the Health Quality and Safety Commission report into Māori health equity, a case study of a successful kaupapa Māori smoking cessation programme in South Auckland, and an update from the Royal Australasian College of Surgeons Annual Scientific Congress on indigenous attitudes to biobanking and genomics research and the implications for Māori health research.

Health equity for Māori: a life course perspective from the Health Quality and Safety Commission

In July 2019, the Health Quality and Safety Commission (HQSC) released “A window on the quality of Aotearoa New Zealand’s health care 2019 – a view on Māori health equity” (Window 2019).¹ The report quantifies the effects of institutional racism and the ongoing impacts of colonisation on Māori health, and lays a challenge to the sector about the imperative for change. The HQSC Window series is an annual report authored by the Commission, but this is the first time that equity has been the primary focus and the first time that the report has been approached as a collaborative piece of work in line with Te Tiriti o Waitangi principles.

The report’s findings support those from other recent analyses of the health system’s responsiveness to Māori. These include the report on stage one of the health services and outcomes kaupapa inquiry by the Waitangi Tribunal,² the mental health and addictions review,³ and countless studies from Māori health experts over the last 150 years. The findings from each of these reports coalesce around a single point: the health system does not, and has never, provided equity for Māori.

Window 2019 interrogates the health status of Māori by comparing data for Māori and non-Māori across five stages of the life course — maternity and birth, childhood, youth, adulthood, and old age. A life course epidemiological approach is used to reflect the compounding impact of experiences across the life course and inter-generationally. Life course frameworks allow policy-makers and researchers to identify interventions that will have the greatest impact to individuals and populations by addressing the causes, rather than the consequences, of ill-health. This approach also allows researchers to attempt to account for the ongoing impact of colonisation. The report’s authors note, “with each generation, this has resulted in accumulating

disadvantage for Māori”.¹ They assert the value of this approach for turning around these accumulated disadvantages by demonstrating that interventions early in the life course can positively alter negative trajectories for whānau. The data are interpreted through three questions: what are the health inequities between Māori and non-Māori?; why are there health inequities between Māori and non-Māori?; and how do we resolve health inequities between Māori and non-Māori, and advance Māori health?

The report emphasises a system view of health equity issues, encouraging readers to think about the way systems create and influence health equity and inequity. HQSC Chair Professor Alan Merry says in the introduction to the report, “we need to change the conversation from one where the system is ‘broken’ to understanding that each system delivers precisely the outcome that it was intended to deliver — the systems themselves need to be changed before they can deliver different outcomes.”¹

Window 2019 shows that there is inequity in access and inequity in service quality, and even when Māori access services, the quality of that service delivery is poorer than the same service accessed by non-Māori. Evidence that quantifies the barriers to access for Māori includes lower access to maternity services, oral health services, and specialist appointments when compared with non-Māori. Older Māori are less likely to receive specialist equipment for disability needs and there is a mismatch between sexual health services testing rates for chlamydia among Māori relative to non-Māori, despite a higher prevalence of chlamydia infection among Māori. Health inequity for Māori is sometimes attributed to socioeconomic status alone and the authors of this report demonstrate that, even when poverty is accounted for, Māori still experience barriers to access compared with non-Māori. This shows that Māori experience barriers beyond those that can be explained by poverty alone.

The measures of service quality found to be inequitable by the report’s authors include sub-optimal asthma control, inappropriate medication prescribing among older Māori, longer surgery wait times following hip fractures, and discrepancies in gout and diabetes management leading to worse outcomes. Māori also consistently report fewer positive experiences communicating with health practitioners compared to non-Māori.

The report shows that interventions to improve the health system have historically offered uneven gains for Māori compared with non-Māori, and have on some occasions worsened inequity, even when equity is identified as a key outcome from the outset. Examples given by the authors include the reduction in equity in childhood immunisation rates since 2014, with Māori rates being nearly ten percentage points lower than non-Māori. They also interrogate apparent improvements in equity, which are not supported by evidence. For example, the improvement in human papillomavirus vaccination rates among Māori compared to non-Māori appears to have been driven

by worsening of vaccination rates for non-Māori, instead of an improvement for Māori. Institutional racism is named specifically by the report's authors and the need to identify and remove racism from organisations is concluded to be fundamental to the resolution of inequitable health outcomes for Māori. Institutional racism is given a specific definition in the report — it is said to include “inappropriate action and/or inaction in response to need. It also includes monocultural perspectives and worldviews embedded in health, education, legal and other systems.”¹

One of the external reviewers of the report, Associate Professor (Faculty of Medical and Health Sciences, the University of Auckland) Elana Taipapaki Curtis (Ngāti Rongomai, Ngāti Pikiao, Te Arawa), BHB, MBChB, MPH, NZCPHM, told the author that the timing is important, even if the message is not a surprise to Māori health experts (phone interview, 2019 Aug 2). “The report's findings reiterate the evidence we already have, showing the depth and breadth of inequities and putting a name to institutional racism as a causal factor for inequity in Māori health.”

The solutions put forward by the report's authors include the need for a sustained and multi-level approach, underpinned by Te Tiriti o Waitangi. Tā Mason Durie (Rangitāne, Ngāti Kauwhata, Ngāti Raukawa) writing in the report's conclusion states, “Te Tiriti o Waitangi should be recognised as a 21st century prescription for Māori health”.¹ The author spoke to Māori health consultant Gabrielle Baker, (LLB, BA, DPH, (phone interview, 2019 Aug 1), who says that the solutions need to be explicitly anti-racist in addition to elevating Māori perspectives and recognising the role of Te Tiriti o Waitangi. She said, “there's no point putting Māori at every level of the health system and expecting that to change everything when we've clearly identified that institutional racism is entrenched in every part of the system. We have to call it racism and act on it where we find it for any meaningful change to occur”.

For medical students and future health professionals, this report offers an important insight into the legacy of colonisation on the health of Māori. We will all encounter whānau Māori among our patients, irrespective of our field of practice. This report shows us that an awareness of the issues is not enough and that our approach to Māori health must account for and eradicate institutional racism in order to provide equitable care for Māori. This includes adopting life course approaches, which address causes, rather than consequences, of ill health, and finding ways to support equity and leaders in equity within our field.

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Te ara tika hau ora wāhine: addressing the needs of young Māori women who smoke

Smoking rates have been steadily decreasing since a landmark report in 2010 to the Māori Affairs Committee into the role of the tobacco industry in New Zealand.¹ The Committee recommended that the government commit to a smoke-free nation by 2025. The comprehensive response in 2011 to the report's findings includes excise tax

increases and regulations around the sale and supply of tobacco products.² Nationwide smoking cessation services were also established in support of the goal to reduce smoking rates across all population groups in New Zealand to less than 5% by 2025. In 2008, 21% of adults were current smokers and by 2018 this had reduced to 14.7%.³

Despite the 2010 report firmly establishing the disproportionate burden of tobacco-related morbidity and mortality on whānau Māori, the decrease in overall smoking rates and consequent improvement in health outcomes has not been equitably distributed, with young Māori women continuing to suffer the most from the consequences of tobacco use. The prevalence of smoking among Māori adults has decreased from 42% in 2006/2007 to 33% in 2017/2018. However, the prevalence of smoking among Māori women in 2017/2018 was the highest out of any population group at 37%. This was a decline from 42%, but still demonstrates a significant inequity with Māori women being 3.4 times more likely to be current smokers than non-Māori.³

Ministry of Health data demonstrated that the strategies to reduce tobacco use were not reaching everyone equally. The differential benefit received by non-Māori in response to these interventions compared with Māori had the effect of entrenching tobacco-related harm among Māori women. Advice was then sought by the Ministry from four kaupapa Māori services with a track record of work in Māori communities. One of those services was Turuki Health Care. Turuki is a charitable trust that was initially established by a group of Māori midwives in the mid-90s to provide health services to wāhine and tamariki Māori in South Auckland. It has since expanded and has GP contracts, oral and mental health services, pharmacists, public health contractors, and whānau ora services.

Hikuwai Winiata-Kelly (Ngāti Ranginui), the project lead for the Te Ara Tika pilot smoking cessation programme at Turuki,⁴ was interviewed by the author. She had previously recruited women for smoking cessation programmes used in the local District Health Board catchment area, and she said she was not surprised that young Māori women were not presenting to these programmes. Winiata-Kelly told the author (2019 Jul 31) that “often it wasn't properly explained to the women what they were getting themselves into. Someone just told them that they were getting a referral for smoking cessation because they told someone at some point in the health system that they smoked”.

Winiata-Kelly said that the narrowness of the contract requirements meant she was not able to support the women in the way she felt they needed, saying “I had so many frustrations, I found that house after house I went to they were struggling with so many other things and I had to just talk to them about quitting smoking. They expect us to go in and ask these questions and there's no food on the table and no power on in the house and there's nothing we can do about that”.

Te Ara Tika brought together a group of nine Māori women over a 12-week period. The women were incentivised to attend the first meeting with a voucher, with no expectation that they would have to commit to the programme and reassurance that their relationship with Turuki and its staff would not be impacted if they decided not to continue.

Winiata-Kelly said the 12-week timeframe, compared to a standard six-week group behavioural therapy programme, was critical to the success of Te Ara Tika. “Normally in the Pākehā world they go for six weeks which doesn't allow for relationship building or anything so I purposely built that in to our programme — time to get to know each other and get on top of the issues they were experiencing in their lives. We didn't even talk about smoking for the first four weeks.” This is an instructive example of how a key concept in te ao Māori — whakawhanaungatanga, or relationship-building — is incorporated into the smoking cessation programme and how it improves the efficacy of the intervention for Māori.

Each woman was dealing with complex issues. Common experiences included domestic violence, drug and alcohol use, sole parenting, joblessness, interactions with the justice system, and poverty. The

programme evaluators found that the women needed space and support to come to terms with those issues before a conversation about smoking cessation could be initiated.

The initial programme structure allowed for the women to meet once a week, but the group asked to meet twice a week — two full days every week for three months. There was no funding for the programme, so the women met and did free or low cost activities — walking, free fitness classes, and meeting for picnics. The space was always child-friendly and supportive of the women's parenting commitments. Each of the women had quit smoking by the end of the 12 weeks.

Winiata-Kelly says that the main intervention that the women used to quit was vaping. This was not a smoking cessation intervention that was introduced by the programme facilitators. It was an incidental occurrence arising from the use of vape products by one of the facilitators who went outside to use it and attracted the attention of the women who were all still smoking cigarettes at that point. By the end of the programme each of the women had quit smoking using vaping and some remain smoke-free a year later.

The author interviewed the CEO of Turuki, Te Puea Winiata (Ngāti Ranginui. 2019 Jul 31). She told us that “Te Ara Tika tells the story of the complexity of Māori women's lives and the effort and empathy that is required to get through the door to be able to support these women to achieve hauora”. Winiata took exception to the commonly used “hard to reach” label given to Māori. Her response was, “we know that their isolation is not of their own making — it is the isolation of poverty, of a punitive criminal justice system and isolation from whakapapa and from te ao Māori”.

She concluded her interview by saying “these women are not hiding from us, they are doing what they need to survive. We must understand that before we can start to think about entering their lives to help them to quit smoking or whatever our externally defined goals are. Programmes for Māori women need to acknowledge all of who they are first and foremost and the challenges they face, in a mana-enhancing way. Looking at wellbeing and quitting smoking comes next.”

Future health professionals have much to learn from this programme's success. It showcases a co-design approach, which is increasingly utilised by policy-makers. This is an approach that doesn't pre-determine the goals of a programme like Te Ara Tika, but which allows the participants to take part in shaping their own intervention. In this instance, it was rigorously evaluated and the findings provide valuable insights into successes and failures that can inform similar programmes in future. Philosophically, it also demonstrates to aspiring researchers and clinicians the practical application of tikanga and how this has the potential to support better outcomes for Māori.

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Indigenous attitudes towards biobanking and genomics research: reflections from the Royal Australasian College of Surgeons Annual Scientific Congress 2019

Equity was a key focus of the Royal Australasian College of Surgeons (RACS) 88th Annual Scientific Congress, with an indigenous health programme convened by Associate Professor Jonathan Koea (Ngāti Mutunga, Ngāti Tama) and keynote speeches by Professor Papaarangi Reid (Te Rarawa), from Te Kupenga Hauora Māori at the University of Auckland, who was also awarded an honorary fellowship of the College.

During the Indigenous trainee research session, Dr Jaclyn Aramoana-Arlidge (Waikato-Tainui) presented on barriers to Indigenous peoples' participation in biobanking and genomic research, sharing insights from a systematic review published in the *Journal of Global Oncology*.¹ The review contributes the first formal analysis of the global research into Indigenous peoples' views on the barriers they face to participation in biobanking and genomic research, an increasingly important area for research into the causes of disease and the identification of opportunities for disease prevention.

The history of Indigenous and non-European peoples' experiences with medical research is often bleak, with instructive stories found in the experiences of Henrietta Lacks,² the Tuskegee syphilis study participants,³ the Havasupai Indians,^{4,5} and — closer to home — the “Māori warrior gene” scandal.^{6,7} This paper is important because it centralises Indigenous peoples' experiences and highlights the gaps in the literature where Indigenous voices have been neglected and excluded. It is also timely as it provides context for the consideration of issues in emerging medical science such as targeted gene therapies.

The review grouped Indigenous peoples' attitudes towards biobanking and genomic research into four themes. These are: 1) concepts of interconnectedness between land, ancestors, culture and bodily substances; 2) that tissue and blood can provide important information about a person — both in biomedical and cultural terms; 3) notions of ownership and guardianship are key in Indigenous peoples' consideration of participation in research; and 4) that of the beneficence of the researchers and the research team.

The authors assert that barriers to Indigenous peoples' participation in biobanking and genomic research risk entrenching inequities.⁸ Globally, non-indigenous population groups are more likely to participate in this research than Indigenous peoples. This means that advances in disease prevention and treatment are more likely to benefit non-indigenous communities.⁹

The author interviewed Associate Professor (Surgery, the University of Auckland) Jonathan Koea (BHB, MBChB, MHBiol, MD, FRACS, FACS. Phone interview, 2019 Aug 1), a co-author on the paper. He said that the systematic review shows that the burden of proof of the value of biobanking and genomic research for Indigenous peoples lies with researchers themselves. “The challenge for researchers is to develop relationships and culturally safe approaches which will enable them to demonstrate that improvements in collective wellbeing can be achieved through participation in biobanking and genomic research. If they don't, they will contribute to worsening health equity for Indigenous communities.”

There are frameworks and guidelines available for researchers seeking to work in a culturally safe way with Māori. Te Mana Raraunga, the Māori Data Sovereignty Network, has developed a set of principles to guide researchers, policy writers, and governance bodies in protecting the rights of Māori.¹⁰ The six principles encompass authority, relationships, obligations, collective benefit, reciprocity, and guardianship. Te Mata Ira: guidelines for genomic research with Māori offers more specific advice for researchers in the field of genomics,¹¹ and a researcher from Ngāti Porou Hauora — one of the five iwi who contributed to the development of these guidelines — says that culturally safe practice is the expected norm for her team.

Dr Jennie Harré Hindmarsh (BA(Hons), MSc, PhD), is the Research Coordinator for the Ngāti Porou Hauora Te Rangawairua o

Paratene Ngata Research Centre. She told the author that they are continually having to stay at the cutting edge of the emerging trends in order to uphold and protect the interests and integrity of their people (phone interview, 2019 Aug 3). She said, "since Ngāti Porou Hauora's inception, many researchers want to work with us because of the important data they see available in our majority-Māori population. However, we are committed first and foremost to doing what's right and best for whānau, hapū and iwi so we have been vigilant about developing clear and, what some perceive as quite strict, terms of engagement with research teams as a basis for developing trustworthy relationships which are integral to best research practice."

Dr Harré Hindmarsh says this includes: additional agreements and clauses about re-approval and re-consent when researchers want to use gifted data that has been collected for one purpose to use for a different purpose than previously understood; about data use, storage and access protocols, ownership and guardianship; and about co-dissemination strategies, which first and foremost involve discussing with, and returning back to, participants and the community the iterative and final research findings.

This systematic review and the supporting literature should be instructive for future medical professionals and researchers. Not only do they provide essential historical context for Indigenous peoples' interactions with the scientific community, they also offer guidance for culturally safe approaches to research with Indigenous communities. Specialist colleges, funding bodies, and policy-makers are increasing their requirements for applicants to demonstrate cultural safety as a bare minimum. The pace of this transformation suggests it will be impossible for the medical practitioners of the future to succeed without engaging with Indigenous communities in a different way to what was acceptable in the past.

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About the author

➤ Emma Espiner (Ngāti Tukorehe, Ngāti Porou) is a fifth year medical student at the School of Medicine, University of Auckland. She works part-time as the National Communications Lead for Hāpai Te Hauora, a Māori Public Health NGO and is the host of the upcoming RNZ podcast series on Māori health equity 'Getting Better.'

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Correspondence

Emma Espiner: ewehipeihana@gmail.com