

Inequities in people with gout: a focus on Māori (Indigenous People) of Aotearoa New Zealand

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Abstract: Health equity can be defined as the absence of systematic disparities in health between more and less advantaged social groups. Gout is one of the most common forms of arthritis and disproportionately affects Indigenous peoples, including Māori in Aotearoa New Zealand. Inequities in gout management are well documented and clearly evidenced in Indigenous populations. For example, while gout occurs at a younger age and is more severe in Māori, there is less regular dispensing of urate-lowering therapies. Indigenous peoples are also under-represented in clinical trials. Herein, we will review inequities in gout using Aotearoa New Zealand as an example. We will explore reasons for health inequities and challenges that need to be faced to achieve health equity.

Keywords: health disparity, health equity, gout

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Introduction

Health equity can be defined as the absence of systematic disparities in health between more and less advantaged social groups.¹ Health inequities put disadvantaged groups at further disadvantage with respect to health and reduce the opportunities to attain full health potential. Inequities in health and health care, therefore, not only affect the groups facing disparities, but also limit overall gains in quality of care and health for the broader population and result in unnecessary costs. Thus, it is essential for both individuals and society as a whole that health care inequity is eliminated.

To be able to address them, it is important to understand how inequities arise. Wilkinson and Marmot present the life-expectancy of populations as a gradient,² based on social determinants of health, including the impacts of long-term stress. For Indigenous people, these ‘social determinants’ are compounded by pervading political determinants of health, described as the ‘cause of causes’ shaping Indigenous health inequities.³ The combined components of colonialism (political, cultural, economic marginalisation, and

racism) shape contemporary Indigenous health outcomes.⁴

Gout is one of the most common forms of arthritis and disproportionately affects Indigenous people. While it is eminently treatable, it is in general poorly managed, resulting in poor outcomes. Herein, we examine health inequities and disparities as they relate to gout with a focus on Indigenous peoples, using Aotearoa New Zealand as an example. The lead author is Tangata Whenua (Indigenous New Zealander, LTK, Muaūpoko, Ngāti Rangī) and the other authors are Tangata Tiriti (settler New Zealanders, ND and LKS). All authors are working in Aotearoa New Zealand to improve gout management.

Disparities in gout

Disease burden disparities

In Aotearoa New Zealand, Māori, Indigenous New Zealanders, have a high prevalence of gout, with evidence of incidence dating back to around 1300 AD.⁵ People from the 20 or so different ethnic groups of the Pacific (Pasifika peoples) who

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Table 1. Estimated gout prevalence expressed as a percentage in Aotearoa New Zealand in 2019 (based on New Zealand Census data: 2013 <https://www.stats.govt.nz/census/previous-censuses/2013-census/>).

Ethnicity	Age and gender							
	20–44 years		45–64 years		65+ years		All age groups	
	Female	Male	Female	Male	Female	Male	Female	Male
Māori	1.0	5.6	5.1	18.9	18.0	35.4	4.3	13.1
Pasifika peoples	1.9	12.5	9.7	34.4	26.1	49.6	7	22.8
Non-Māori, non- Pasifika ^a	0.3	1.8	1.4	7.8	6.1	17.5	2.1	7.4
All ethnic groups	0.5	3.2	2.3	10.5	7.5	19.6	2.7	9.0

Source: Atlas of Healthcare Variation, gout domain, Health Quality & Safety Commission New Zealand, www.hqsc.govt.nz/atlas.

^aIt is estimated that 83% of this group are European, 13% Asian, 2% Middle Eastern/Latin American/African, and 2% other ethnicities.

have made Aotearoa New Zealand home have also demonstrated a high prevalence of gout. Whilst not indigenous to Aotearoa New Zealand, Pasifika peoples have increased gout prevalence in their countries of origin, where they are Indigenous.⁶ Biological and anthropological studies present gout as an ancient disease in Pasifika peoples as far back as 3000 years ago.⁵ In 2019, national-level data estimated gout prevalence in Aotearoa New Zealand for Māori as 8.5%, for Pasifika peoples as 14.8%, and other New Zealanders (predominantly New Zealand European) as 4.7% (Table 1). Despite these high percentages, it is thought they underestimate the burden of gout by approximately 20% due to the limitations of methodology used.⁷

Gout is more common in Māori and in Pasifika peoples in all age groups, and in both men and women. Notably, over one-third of older Māori men and almost half of older Pasifika men in Aotearoa New Zealand were estimated to have gout in 2019. In addition to higher prevalence, gout develops at a younger age in Māori and Pasifika; for Māori aged 39 years, for Pasifika peoples, 34 years, compared with New Zealand European 46 years (Table 2).⁸

Internationally, there is clear evidence that genetic variants play an important role in regulation of serum urate and development of gout, with the strongest effects observed with genetic variation in kidney and gut urate transporters.⁹ These variants also contribute to gout risk in Māori and Pasifika peoples in Aotearoa New Zealand,¹⁰ and population-specific variations in urate transporters influence the development of gout and

complications of treatment in Māori and Pasifika peoples.^{11,12} It is likely that non-genetic factors also play an important role in the development of incident gout and complications of established disease, especially inappropriate management of gout and engagement with Māori and Pasifika peoples in Aotearoa New Zealand.

In Aotearoa New Zealand, Māori and Pasifika peoples experience disproportionately severe disease, with more frequent gout flares, higher rates of hospitalisation for gout, and more tophaceous disease^{8,13,14} (Table 2). Gout is associated with cardiovascular and kidney disease, which also disproportionately affects Māori and Pasifika peoples, and this may be particularly so for those living in rural areas.¹⁵

Health-related quality of life in people with gout tends to be worse in Indigenous populations. Māori and Pasifika people with gout have greater activity limitation assessed by health assessment questionnaire II (HAQ-II) and lower physical role function on the short-form 36 (SF-36) compared with non-Māori non- Pasifika peoples.¹⁴ Qualitative studies involving Māori men have demonstrated immense suffering, isolation and negative effects on employment and relationships.¹⁶ These effects impact not only the individual but also their whānau (family) and community.

Treatment disparities

That there are inequities in the quality of gout management globally is well documented.¹⁷ Like other Indigenous populations the world over,

Table 2. Gout clinical presentation and co-morbidities from participants in the 'Genetics of Gout in Aotearoa study'. Modified from Phipps-Green *et al.*⁸

	Māori (n = 185)	Pasifika peoples (n = 173)	New Zealand European (n = 214)
Sex, % male (patients)	73.6	95.7	86.2
Mean age of onset, years	39.0	33.5	46.2
Mean (range) no. of gout attacks in past year	13.1 (0 to >1/week)	18.6 (0 to >1/week)	8.5 (0 to >1/week)
Percent with first-degree relative with gout	71.8	62.8	51.2
Mean body mass index, kg/m ²	34.8	37.	31.0
Co-morbidities, %			
Type 2 diabetes	28.6	21.4	15.7
Hypertension	65.5	53.6	51.6
Cardiovascular disease	47.9	24.2	42.1
Kidney disease	35.0	29.7	30.0

Māori have poorer health outcomes than the country's settler population.^{13,18}

Long-term urate-lowering therapy is a key aspect of successful gout management; when taken regularly to achieve target urate, dissolution of monosodium urate crystals and prevention of gout flares, gouty tophi, and joint damage occur.¹⁹⁻²¹ Māori and Pasifika peoples with gout have comparable rates of any dispensing of urate-lowering therapy to other New Zealanders with gout (Table 3); while this may appear at first reassuring, equitable care would see substantially higher rates of urate-lowering therapy prescribed to those groups with higher burden of disease. Furthermore, regular dispensing of urate-lowering therapy is significantly lower in Māori and Pasifika peoples than in other New Zealanders (Table 3); the odds ratio (OR) [95% confidence interval (CI)] for regular dispensing of urate-lowering therapy for Māori compared with non-Māori/non-Pasifika New Zealanders is 0.84 (95% CI 0.82, 0.86), and for Pasifika New Zealanders compared with non-Māori/non-Pasifika New Zealanders is 0.72 (0.70, 0.74).

A key determinant of the inequity of regular urate-lowering therapy relates to rates of regular dispensing in different age groups. In Aotearoa New Zealand, regular dispensing of

urate-lowering therapy is very low in younger people and increases with increasing age.²² Given the earlier age of gout onset, the consequence is lower overall rates of regular urate-lowering therapy in Māori and Pasifika peoples. This, in turn, leads to longer time with elevated urate levels and the amplified impact of poorly managed gout, such as frequent gout flares, joint damage and disability. Equitable approaches to management would include building systems that reduce barriers to receiving regular urate-lowering therapy for younger people with gout such as no associated costs of dispensing urate lowering therapy, comprehensive adherence support programmes potentially delivered by community pharmacists, nurses and community health workers, workplace partnerships with general practice to support people with gout and out of hours phone access to holistic care for gout sufferers.

There is no current evidence that the available treatments for gout are less effective in Māori, Pasifika or other Indigenous peoples. However, under-representation of Indigenous and 'minority' populations in clinical trials, particularly industry-sponsored trials,¹⁷ required for regulatory approval needs addressing.

Efforts have been made by funders such as the National Institutes of Health (NIH). The

Table 3. Number and percentage of patients with gout dispensed urate-lowering therapy in Aotearoa New Zealand in 2019.

Dispensing type	Māori (n=41,002)	Pasifika (n=29,990)	Non-Māori, non-Pasifika (n=137,721)
Any dispensing	24,630 (60%)	17,820 (59%)	77,113 (56%)
Regular dispensing	16,168 (39%)	10,768 (36%)	60,220 (44%)

Source: Atlas of Healthcare Variation, gout domain, Health Quality and Safety Commission New Zealand, www.hqsc.govt.nz/atlas.

Revitalisation Act of 1993 requires the Director of the NIH to ensure that members of ‘minority’ groups are included in clinical trials and that the trial is designed and carried out in a manner sufficient to provide for a valid analysis of whether the variables being studied in the trial affect members of ‘minority’ groups differently compared with other trial participants.²³ In Aotearoa New Zealand, the Health Research Council assessment process for all grant applications includes the research proposal’s potential to advance Māori health.²⁴

Research needs to be undertaken in authentic partnership with Indigenous and other disproportionately affected populations. While there are no specific studies in gout, studies of the barriers and facilitators to clinical trial involvement in other disease has been undertaken. In a systematic review of participation in randomised controlled trials by Indigenous people in Aotearoa New Zealand, Australia, Canada and the United States (US), research-level barriers identified included lack of recognition or incorporation of Indigenous knowledge systems in trial design and protocols as well as failure to adequately address likely participant barriers such as travel costs and availability to methods of communication such as phone and internet.²⁵ Bias, conscious or unconscious, among health care professionals, researchers and the health care system likely also impacts on recruitment of Indigenous people into clinical trials. In a study of research and clinical professionals in five oncology centres in the US, some respondents viewed racial and ethnic minorities as less promising trial participants and withheld trial opportunities based on this perception.²⁶ There is no reason to think that such perceptions are limited to cancer trials. Given the high burden of gout in Indigenous peoples, we should see more Indigenous people enrolled in gout clinical trials rather than less. This is particularly important when considering therapeutic drug trials

where genetic variations in urate and/or drug handling may differ in Indigenous populations and will be missed if studies are underpowered to allow analysis by ethnicity.

In Aotearoa New Zealand the Kaupapa Māori Research paradigm guides research to be undertaken by Māori, for Māori, with Māori. In Kaupapa Māori based research, self-determination is fundamental with Māori tikanga (customary beliefs and practices) and processes followed and incorporated throughout the research, from inception and study design to the dissemination of results and the ongoing relationship between the researcher(s), the research participant(s) and their communities. Culturally safe practices at all stages are required, including recognition of data and tissue sample sovereignty and reporting. The recent CONSolidated critERia (CONSIDER) statement for strengthening the reporting of health research involving Indigenous Peoples is an essential step in providing guidance.²⁷

Indigenous rights

Article 24 of The United Nations Declaration on the Rights of Indigenous Peoples signed by all 144 member Nations states:

Indigenous peoples have (i) the right to their traditional medicines and to maintain their health practices, including the conservation of their vital medicinal plants, animals and minerals; (ii) the right to access, without any discrimination, all social and health services and (iii) equal right to the enjoyment of the highest attainable standard of physical and mental health.

It also documents that ‘States shall take the necessary steps with a view to achieving the full realisation of this right progressively.’ In addition, for Māori, Article 3 of Te Tiriti o Waitangi, the founding Treaty document of Aotearoa New Zealand, guarantees Māori the same rights and

privileges as non-Māori. More recently, the Waitangi Tribunal, a permanent commission of inquiry, has determined the principle of equity, which 'requires the Crown to commit to achieving equitable health outcomes for Māori.'²⁸ With this in mind, Aotearoa New Zealand and all signatories to The United Nations Declaration on the Rights of Indigenous Peoples are obliged to implement strategies to eliminate health care disparities for people with gout.

Claiming superiority in worldview by settler populations is universal to colonised countries, and is by definition, racism. That health systems are built upon this superiority stance with dismissal of Indigenous health beliefs is the basis for a structurally racist and misaligned Western health system. People do not always feel safe approaching the dominant system; access is a barrier for multiple reasons, including fiscal and accommodative factors; and the system is hard to negotiate, full of jargon and lacking in cultural literacy with health practitioners' practice variable. For Māori, whether it was the intent or not, the outcome of a significant piece of legislation, the Tohunga Suppression Act 1907,²⁹ is that traditional healing methods were quashed or driven underground along with the leadership surrounding such practice.³⁰ This legislation further helped to privilege the Western world view over the Indigenous. In failing to acknowledge the value and sustainability of traditional Indigenous practices, settler populations are also denied the richness of an integrated and holistic pathway to health delivery. Māori politicians at the time of the Tohunga Suppression Act pled that there was a 'large and unexplored field in the flora of New Zealand if only the medical men would devote their attention to it,' and a deep underpinning of a holistic health approach that was in danger of being lost if rejected.³¹

In theory, given there are readily available and inexpensive medicines to prevent the pain and associated burden of gout, it should be a relatively straightforward health condition to manage.³² In practice, however, this is not the case.^{33,34} The numerous pieces required to achieve medicines optimisation have been described both in a general sense and from an Indigenous perspective where disadvantage pervades and complexities are compounded.³⁵

The management of gout occurs predominantly in the primary care setting. At every step on the

journey to optimal gout management, there is evidence of the health system's failure for Māori.³⁶ This can be despite the goodwill and good intent of health care providers within the system.³⁷ Structural barriers such as costs, location and opening times of services and a focus on health targets in the dominant system can thwart even Indigenous providers working in it. It is alarming that, given the prevalence of gout and the unnecessary and preventable sequelae of unmanaged gout, the association with co-morbidity and overall worse health outcomes for Māori, such inequity exists.

Expecting equity by solely relying on health service delivery to be more culturally responsive is met with criticism.³⁸ The argument of retrofitting or 'cultural tailoring' into a Western-dominant health system can never be wholly successful. This is not to diminish the importance of culturally safe health interactions. Facilitating reciprocity and safety within a health interaction is critical to a Western system and indeed has been the premise of life works by prominent Indigenous clinician-researchers.^{39,40} However, adding culturally safe practitioners to a structure developed by a belief of superiority limits outcomes and framing Indigenous health as a problem of poor health indicators to be solved through targeted service delivery tactics is reductionist.⁴¹ Thus, there is a danger that adapting service delivery to address Indigenous health outcomes without enabling active decision making at every step will only cause further inequity.

Examples of this exist in Aotearoa New Zealand where programmes have been designed to address gout management and gout inequity, and instead have led to anti-equity outcomes. For instance, the 'Gout Stop' programme is a collaboration between general practitioners, community pharmacists and one kaiawhina (Indigenous support person). The 'Owning My Gout' programme is another collaborative care model where community pharmacists and nurses work under standing orders from general practitioners to supply urate-lowering therapy. Despite both programmes' good intentions, the engagement with Non-Māori, Non-Pasifika peoples has been greater than that with Māori and Pasifika peoples.⁴² As a result, inequity has increased, with Non-Māori, Non-Pasifika peoples more likely to achieve clinical success.

Toward solutions

Oetzel *et al.* provide an implementation framework for preventing and treating non-communicable diseases in Indigenous peoples to guide against such situations where the outcomes have been the opposite of the intention.⁴³ Their *He Pikinga Waiora Implementation Framework* consists of four pillars: cultural-centeredness, community engagement, systems thinking and integrated knowledge translation. Importantly at the core of these pillars and key to the process is Indigenous self-determination.

Cultural centeredness ensures the community defines the issues and identifies the solutions. Allocating problem definition to the community can be easily overlooked. In the lead author's experience, when Indigenous communities are empowered to define issues, they do so from a holistic perspective as opposed to a biomedical approach. For instance, in one community where Western health providers were looking to design a gout management programme, the problem was defined as 'failure to achieve and maintain a target serum urate of less than 0.36 mmol/l.' This contrasted with Indigenous members of the same community defining the issue as a 'lack of a Hauora (holistic, wellness) approach to gout.' If the 'problem' to be solved is defined from different ends of the perspective continuum, one cannot expect the solution to be effective in every respect. Cultural centeredness looks to address structural transformation so that the system fits the community's needs and not the reverse.

Community Engagement is about a strong partnership where decision making and communication is shared throughout the process of development and implementation. A situation where a community is initially engaged and the intervention designs change to the system in response but without continued participation and ownership from the community would be a poor exemplar of community engagement.

System Thinking acknowledges different world-views and the values that they bring. It prioritises an understanding of relationships and demonstrates a strong understanding of the complex relationships between different aspects of the system.

Integrated Knowledge Translation refers to equity in the partnership and ensures a process of mutual

or bi-directional learning is tailored to users' needs.

To critique and monitor interventions, we posit another framework rooted in critical policy analysis and Indigenous responsiveness.⁴⁴ Came *et al.* developed an evaluative method of analysing 'policy and programmes' designed to advance equity goals and improved health outcomes in Aotearoa New Zealand.⁴⁴ It uses Te Tiriti o Waitangi and looks to build on earlier work with similar aims for health promotion.⁴⁵ Although the framework is predicated on a Treaty between the Indigenous people of New Zealand and the Queen of England, the authors advocate applicability to other circumstances where 'Indigenous and settler values must come into a just relationship.' This 'Critical Treaty Analysis' enables a process for both those designing or implementing policy or programmes to reflect substantively on responsibility, authority and ownership. Additionally, it provides a basis for allowing Indigenous holistic values, spiritual practices, awareness and well-being.⁴⁴

It is essential to understand that inequities occur when there is inequity in power-sharing. Power-sharing and self-determination are central to addressing inequities, and the key themes arising from the scholarship of health delivery transformation to address those in need. Axelsson *et al.* state that 'by focusing policy interventions solely on Individual-level behaviour change rather than underlying power inequalities, contemporary forms of inequality are decoupled from the unequal institutional arrangements that structure the relationship between Indigenous peoples and the State, itself a product of colonialism'.³

In 2014/2015, the lead author delivered and led a gout optimisation community-based engagement model through a 'pilot' of co-creation—the aim to build capacity and capability to self-manage gout. At the time of the pilot, the frameworks above were unpublished; however, there is synergy in these frameworks with the pilot. Three Māori communities determined when, where, how long and how the lead author would deliver empowerment sessions. The communities defined issues and presented solutions in 12 wānanga (learning sessions). Community members reported the importance of a Kaupapa Māori approach following the lore of Indigenous customs, beliefs, wishes, knowledge and rights. Outcomes included the development of a health literacy resource and

passing an assessment previously developed to educate clinicians. The assessment included community members being able to recommend starting doses of allopurinol and flare prophylaxis. Important, however, was a stated ‘restoration of pride’ to the community members who had felt overwhelmed by the burden of gout. Despite this different model facilitating ownership and setting the priority of health outcome and despite the demonstration of decreased symptomatic treatment (non-steroidal anti-inflammatory drugs) and increased urate-lowering therapy, ultimate success was systematically limited. Others have warned this lack of transformational change points to systemic issues.⁴⁶ The solution still requires the significant issue of entering back into the Western system and the misalignment with resource allocation coherent with the community’s desires.

In acknowledging health inequity as its own ecosystem for Indigenous people, the environment in which gout services are delivered, when they are delivered, whom they are delivered by, accessibility and responsiveness of the system are key.³⁶

We promote using Indigenous frameworks to facilitate and evaluate community-based participatory research alongside a holistic approach enabling self-determination to eliminate gout inequities. At the very least, our previous research indicates that the western health system requires consideration of extended hours of access, and includes service delivery from traditional places of gathering and homes, culturally safe health practitioners, culturally congruent non-clinical support, culturally appropriate and acceptable health literacy messaging and resources, transport to health interactions, free appointments, reduced wait times and a public messaging campaign.^{36,37} We strongly assert and endorse that a system rethink is evidentially needed to change the paradigm from a linear view of adjusting isolated and consecutive components to a macro view of the complexities and emergent outcomes.⁴¹

Conclusion

That there are disparities in gout care in Indigenous people is without a doubt. The challenge for healthcare providers in every country, including Aotearoa New Zealand, is to authentically partner with Indigenous people to develop culturally appropriate, acceptable and effective systems to overcome disparities and enable a

pathway to health equity and beyond for people with gout. To fail to do so is acceptance of the status quo, and is, by definition, structural racism.

Conflict of interest statement

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