

Optimal medication therapy in Indigenous populations

A case study of gout in Māori

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Karakia

| | |
|---|--|
| Pūnganangana ki tawhito-o-te-rangi e tū nei | Forbidding the sky above, full of dread, |
| He ngana riri ; he ngana tauā ; | Angrily raging; striving |
| Ue-ue 'Nuku ; Ue-ue Rangi | The earth quakes; the heavens quiver |
| Tē tūngia te kawaru rā | Nought stands before the shattering gale |
| Ko te hau tonga ka maranga mai rā | The southerly winds blowing forth |
| Toki nui te toki | Grasping the renowned adze |
| Toki roa te toki | The famed long-handled adze |
| Toki tā wahie | The adze rending asunder the great trees |
| Ka whanatu au | I stride forth boldly |
| Ka hahau i te takapū | Striking the base of the tree, |
| O Rangi e tū nei | Tho' sky-piercing |
| Ka hinga | It falls |
| Ka mate | It expires. |
| Whakataka te hau ki te muri | Cease now O wind from the west |
| Whakataka te hau ki te tonga | Cease now O wind from the south |
| Kia mākinakina ki uta | Murmuring breezes sigh o'er the land |
| Kia mātaratara ki tai | The stormy and boisterous seas subside |
| Kia hīia ake te ātākura | And the red evening sky shines resplendent |
| He tio, | With a sharpened air |
| He huka. | A touch of frost |
| He hau-hūnga! | A promise of a glorious day |

Abstract

The overarching topic of this thesis is optimal medication therapy in Indigenous populations with a focus on Māori. Medicines are a foundational element of western health systems. They have the potential to cure, control, prevent, or cause illness. The goal, therefore, is to ensure optimal use. Throughout the world, Indigenous peoples experience inequities in health outcomes compared with non-Indigenous people, in part due to inequitable access to medicines optimisation. To obtain an insight into opportunities to transform this situation, a targeted approach was identified by focusing on gout – a health condition prevalent in Māori and treatable with medicines. Underpinned by Kaupapa Māori research theory, this thesis aimed to investigate how gout medication therapy for Māori can be optimised.

The study was undertaken in seven phases: contextualising the medicines system in Aotearoa New Zealand; identifying initiatives involving two or more components to address medicines optimisation through a scoping review; developing and implementing a decision-support tool for gout management at the point of prescribing medicines; developing and implementing a multi-level care initiative to improve gout management in a predominantly Māori primary care setting; identifying the barriers to and enablers of implementing these initiatives; developing advice on promoting equitable gout management; and identifying the barriers to medicines optimisation from a medicines environment perspective, and therefore opportunities for transformation in the approach to medicines use in Aotearoa New Zealand.

Findings: The systems around medicines are complex, and Māori are still impacted by legislation, especially the Tohunga Suppression Act. The scoping review identified a gap in focused research demonstrating outcomes for Indigenous people; the decision-support tool and multi-level care initiatives met multiple barriers, including at patient, provider, and system levels; there was misalignment in the definition of ‘optimal’ between the community and providers. The complexity of problems and solutions were drawn together in Ngā Rau o Kawakawa – a diagrammatic representation of the gaps in the medicines environment in Aotearoa New Zealand. There are times when Indigenous researchers need to get on with advocating for transformation. A coherent, strategised, holistic, mātauranga inclusive approach to the medicines environment does not exist in Aotearoa New Zealand.

In conclusion, there is an urgent need:

- for a national gout strategy led by those with gout and their families
- to establish an entity (a Centre of Medicines Optimisation) with delegated responsibility for oversight of the medicines environment, equally inclusive of Indigenous perspectives and values.

Dedicated to my precious Dad

Peter Te Karu

1934-2021

Whaia i te pare-i-te-taitonga. Tērā taku Ika e muramura ana te ahi kā o Paerangi

Pursue that which wards off the southern winds (Paretetaitonga).

There you will find my land where the fires of occupation of Paerangi kindle.

Acknowledgements

With mixed emotions, I submit this thesis and acknowledge the many people who have contributed to it. It is with a heavy heart I reflect that some of these contributors have since passed, and I wonder if non-Indigenous researchers are impacted to the same degree in their research journeys.

This thesis leans heavily on a project conducted at Papakura Marae Clinic in 2017–2018. It would not have been possible without the support, encouragement, and efforts of the community, marae staff and board, and the primary health organisation staff. Many of the community contributors have passed away. These people gave interviews, workshopped, attended hui, and provided many laughs and authenticity to the project.

Equally, we were dealt some heavy blows with the untimely passings of Dr Martin (Marty) Davis and registered nurse Jennell Bonner – both staunchly committed to hauora Māori outcomes. It is with their family’s permission that I mention them specifically.

Marty was one of the most clever, kind and wonderful humans – freely giving of his seemingly unlimited knowledge. This made him an extraordinary doctor, still deeply missed by colleagues and ‘patients.’ In typical Marty style, he became the ‘GP lead’ on the project in the clinic, and I am grateful for his wisdom and contribution.

Jennell was a beautiful young woman, determined to address injustices and improve Māori health outcomes. Her work ethic, empathy for whānau, organisational skills, and sense of humour made her perfect for this project and for bringing a smile to us all when required. I treasured our time together.

I hold steadfast to the collective memories of these special people to ensure transformation and the protection of their efforts.

E āku kākākura, e āku mōtoi amorangi, haere atu rā koutou ki tua o Paerau. Kia rere ki te puku o tō iwi, tō whānau, ki reira whakapiri ai. May they rest in eternal peace.

I would also like to express my special thanks to ‘my team.’

At the outset, my primary supervisor Professor Bruce Arroll’s commitment to social justice and continuing education, personally and throughout the health sector via an integrated lens, drew me to the faculty. It has been an honour to come to know you more and receive your erudite direction and support.

It is impossible not to acknowledge Associate Professor Matire Harwood during the period of my research and that of the COVID-19 pandemic. She has been at the forefront in communities and nationally to expose the compounding inequity for Māori and Pasifika communities. I am very grateful for your approaches to consider, and contribution to safety in Kaupapa Māori, especially when your time was so limited.

Associate Professor Tim Kenealy stepped into this research at a critical time and assisted me in bringing forward a provisional review that the university accepted. Tim's ability to lead me through aspects of the academic requirements for this thesis cannot be understated. We came from different paradigms at times, but Tim, your patience and timely responses to covering core basics through to the complexity of methodology have been so very much appreciated.

Dr Linda Bryant has uniquely been in a position of providing supervision to me without academic association or acknowledgement. Essentially, she has given her time freely for my research journey. This is an unrepayable debt. I am blessed to know you, Linda, as the most knowledgeable pharmacotherapist globally and a wise and truly dear friend.

My heartfelt thanks to you all for your supervision, for your contributions, and for sticking with me over this journey.

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To my whānau, who are my heart and soul – my parents who have been my greatest supporters forever, including my Mum, who still drops everything to help me with anything. To my partner Darryn who has been a rock and sounding board throughout this period, you have had to endure my 'distraction' more than anyone else. My children, who have been the greatest gifts in my life and their wonderful partners who also share my heart. And now my mokopuna, who carry the mauri of that love.

Nei rā te mihi hōhonu. Aroha mo ake tonu atu.

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List of Abbreviations

| Abbreviation | Definition |
|--------------|--|
| ACEI | Angiotensin-converting enzyme inhibitor |
| ARB | Angiotensin-receptor blocker |
| BP | Blood pressure |
| CAD | Coronary artery disease |
| CHART | Congestive Heart Failure Adherence Redesign Trial |
| CHF | Congestive heart failure |
| CI | Confidence interval |
| Commission | Refers to the Health Quality and Safety Commission |
| COPD | Chronic obstructive pulmonary disease |
| COURAGE | Clinical Outcomes Utilizing Revascularization and Aggressive DruG Evaluation |
| CVD | Cardiovascular disease |
| DHB | District health boards |
| DST | Decision-support tool |
| ESCISIT | EULAR Standing Committee For International Clinical Studies Including Therapeutics |
| EULAR | European Alliance of Associations for Rheumatology |
| GP | General practitioner |
| GST | Goods and services tax |
| HART | Heart Failure Adherence Retention Trial |
| HDCEC | Health and Disability Ethics Committee |
| HFrEF | Heart failure with reduced ejection fraction |
| HRPHOW | He Rongoā Pai, He Oranga Whānau |
| IQ | Improving quality |
| IT | Information technology |
| LDL | Low-density lipoprotein |
| MHA | Māori Health Authority |
| MOH | Ministry of Health |
| MOU | Memorandum of understanding |
| MP | Member of Parliament |
| MPA | Māori Pharmacists' Association |
| MUSIQ | Model for Understanding Success in Quality |
| NICE | National Institute for Health and Care Excellence |
| NSAID | Non-steroidal anti-inflammatory drug |
| NZ | Aotearoa New Zealand |
| OR | Odds ratio |
| PCI | Percutaneous coronary intervention |
| PDGPD | Prescribing Data in General Practice Demonstration |

| | |
|------------|---|
| PDSA | Plan, do, study, act |
| Pharmac | Pharmaceutical Management Agency |
| PHO | Primary Health Organisation |
| PMC | Papakura Marae Clinic |
| PMS | Practice management system |
| PRIDOC | Pacific Region Indigenous Doctors Congress |
| PTAC | Pharmacology and Therapeutics Advisory Committee |
| QI | Quality improvement |
| SARS-CoV-2 | Severe acute respiratory syndrome coronavirus 2 (coronavirus disease 2019 [COVID-19]) |
| SPHERE | Secondary prevention of heart disease in general practice trial |
| START | Screening tool to alert doctors to the right treatment |
| SUA | Serum uric acid |
| Te Tiriti | Te Tiriti o Waitangi |
| TSA | Tohunga Suppression Act |
| USA | United States of America |
| VA | Veterans Affairs |
| VLCA | Very low-cost access |
| WHO | World Health Organization |

Glossary

| Non-English | Translation* |
|--|---|
| Aotearoa | 'Land of the Long White Cloud', New Zealand |
| Aroha | Love, compassion, empathy |
| Awa | River |
| Hapū | Sub-tribe, collective of whānau |
| Hauora | Holistic health and well-being |
| He Rongoā Pai, He Oranga Whānau | Whānau staying well with medicines |
| Hinengaro | Mind, thought, intellect, consciousness, awareness |
| Hui | Meeting, gathering |
| Io | The Supreme Being |
| Iwi | Tribal grouping |
| Ka mua, ka muri | Looking back to go forwards |
| Kahungunu | Tribal group of the southern North Island east of the ranges from the area of Nūhaka and Wairoa to southern Wairarapa |
| Kai | Food |
| Kaimahi | Worker |
| Kaimanaaki | Care worker |
| Kaimoana | Seafood/shellfish |
| Kāinga | Home, village, settlement |
| Kaitiaki | Guardian |
| Kaiwhakahaere | Māori director |
| Kapa haka | Māori cultural performing group |
| Karakia | Incantation, prayer, blessing, service |
| Kaumātua | Elder, man or woman, a person of status within the whānau |
| Kaupapa | Central purpose, initiative, issue |
| Kaupapa Māori | By Māori, with Māori, for Māori; a term used to describe traditional Māori ways of doing, being and thinking, encapsulated in a Māori worldview |
| Kawakawa | (Piper excelsum) Small, densely-branched tree used for medicinal purposes |
| Kete | Basket, kit |
| Kia Pokapū te Panekiretanga hei Pou mō te Whānau | To be a centre of excellence for whānau |
| Kina | Sea urchin |
| Kīngi | King |
| Kīwaha | Colloquialism, colloquial saying, |
| Koha | Gift |
| Kōrero | Conversation, talking, discussion |
| Koroua | Elderly man, elder, grandfather |
| Korowai | Cloak |
| Mahi | To work, perform |
| Mahia kia ea, kia toa | A 'can do' attitude |

| | |
|-----------------------|--|
| Mana | Prestige, status, authority, influence, integrity; honour, respect |
| Mana Motuhake | Autonomy, self-determination, sovereignty, self-government |
| Manaakitanga | Hospitality, generosity |
| Māori | Indigenous people of Aotearoa New Zealand |
| Marae | Complex of buildings around a sacred open meeting area |
| Māramatanga | Enlightenment, insight, understanding, light, meaning. A Māori movement centred among the people of the Ruapehu district of Aotearoa |
| Mātauranga | Knowledge originating from Māori ancestors, including Māori worldview and perspectives, Māori creativity and cultural practices, tradition, epistemology |
| Mauri | Life force/vital essence |
| Mihi whakatau | Speech of greeting, official welcome speech |
| Moko kauae | Traditional tattoo on female chin or jawbone |
| Moko/mokopuna | Grandchild, grandchildren |
| Mua | The front, in front of |
| Ngā wā o mua | Translated as ‘in the past/ past times’ but recognises one doesn’t know what is ahead and walks backwards into the future |
| Oranga Rongoā | Health and sustenance with medicines |
| Pā | Fortified village, fort, stockade, |
| Pae ora | Healthy futures – a Parliamentary Act reforming NZ’s publicly funded health system. |
| Pākehā | New Zealander of European descent |
| Papa kāinga | Home base, village |
| Parihaka | Peaceful community in western Taranaki invaded by English troops, with atrocities committed |
| Pasifika | Peoples from the different Indigenous groups of the Pacific who have made Aotearoa home |
| Pōtatau Te Wherowhero | First Māori King, Tainui chief |
| Pou | Central pillar |
| Pōwhiri | Welcome ceremony |
| Rangatira | Leaders, chiefs |
| Rangatiratanga | Chieftainship, authority, right to exercise authority, chiefly autonomy, chiefly authority |
| Rohe | Tribal territory |
| Rongoā | Indigenous medicine, traditional healing and treatment |
| Rongoā rākau | Rongoā made from plant material |
| Rōpū | Group, party of people |

| | |
|--------------------------|--|
| Rua Kēnana | Ngai Tūhoe prophet/leader who established a thriving community at Maungapōhatu |
| Runga | Above, over, up, upwards, up above |
| Takahia | To trample, disregard |
| Tāngata | People, men, persons, human beings |
| Taonga | Prized possession, property, treasure |
| Tapu | Be sacred, prohibited, restricted |
| Tauparapara | Incantation to begin a speech |
| Te Ao Māori | Māori world view |
| Te reo | Māori language |
| Te Tiriti o Waitangi | The Treaty between rangatira and the British monarchy |
| Tikanga | Correct procedure/protocol, a system of values and practices, lore |
| Tinana | Body, physical |
| Tino rangatiratanga | The fullest expression of rangatiratanga, autonomy, self-determination, sovereignty, self-government |
| Tipuna | Ancestors, grandparents |
| Tira Hoe Waka | Annual Whanganui iwi spiritual and educational river journey |
| Tohunga | Skilled person, chosen expert, priest, healer, leader, specialist in Māori ritual |
| Tuku | To release, leave, resign, offer, grant |
| Tupuna (tūpuna – plural) | Ancestor (ancestors) |
| Tūroa | Chief of Ngāti Patutokotoko hapū of Te Āti Haunui-a-Pāpārangi |
| Urewera | Mountainous homeland of Ngāi Tūhoe |
| Waewae tapu | First-time visitors |
| Waiata | Song, chant, psalm |
| Wairua | Spirit, soul |
| Wānanga | Educational seminar, forum provided under a mātauranga Māori frame, classes of Māori knowledge |
| Whā | Four |
| Whaia | To be followed, searched for |
| Whaikōrero | Oratory, oration, speech |
| Whakaaro | Thoughts/opinion |
| Whakairo | Carvings |
| Whakakotahi | To unify, integrate, to be one |
| Whakamā | Shy |
| Whakamāori | To make clear or transparent |
| Whakanuia | To celebrate, honour |
| Whakanuia te whānau | Celebrate Indigeneity |
| Whakapapa | Genealogy, ancestry, familial relationships |
| Whakatau | Welcome, greeting |
| Whakataurangi | To pledge, assure, promise |
| Whakautuutu | Reciprocal, reciprocity |

| | |
|----------------------|--|
| Whakawhanaungatanga | Connection of persons through genealogical ties and/or topic/purpose/theme |
| Whānau | Family, extended family |
| Whānau auaha | Everyone an innovator |
| Whānau whai hua | Outcomes matter |
| Whānau whakaaro tika | Think like whānau |
| Whānau whakataurangi | Keep our word |
| Wharenuī | Meeting house |
| Wheke | Octopus |
| Whenua | Land/homeland |

*The translations are specific to what has been used in this thesis. They may have slightly different meanings in different contexts and to different hapū and iwi. Some, e.g., Pasifika, have been sourced from personal communication. The translation provided is not intended to be exhaustive and may warrant further investigation to appreciate their meaning and usage fully.

Foreword (Pepeha – Tribal Saying)

Whaia e au te awa Manganui-o-te-Ao, kia tau au ki runga i a Ruapehu ki a Ngā Turi ō Murimotu ko te ahi-kā o Paerangi-i-te-Whare-Toka i puta mai ai Rangituhia, Rangiteauria me Uēnuku-Manawa-Wiri.

E rere kau ana mai i te Awa nui mai te kāhui maunga ki Tangaroa – ko au te Awa, ko te Awa ko au.

I te taha o tōku Pāpā he uri ahau o te kāhui maunga ki Tangaroa, rere atu ki te moana o Punahau, - he uri anō o Muaūpoko.

Ko Ngāti Rangi, Te Ati Haunui-a-Pāpārangi, Ngāti Hine ōku iwi

I follow the Manganui-o-te-Ao river; I settle on Ruapehu and the sacred altar of Nga Turi o Murimotu, the eternal flame of Paerangi, from which we originate. Paerangi begat Rangituhia, Rangiteauria, and their sister Ueunuku-Manawa-Wiri.

The river flows from the sacred mountain clan to the sea – I am the river, and the river is me.

From my father's veins flows the lineage to the sacred mountain clan and to the ancestor Tara.

Ngāti Rangi, Te Ati Haunui-a-Pāpārangi, Ngāti Hine ki Muaūpoko are my people.

Introduction to Thesis

This chapter introduces the reader to the thesis. It begins with personal context and rationale for undertaking this research, explaining how I arrived at this journey. It concludes with a section on environmental context, prefacing the environmental changes that occurred during this thesis, namely the restructuring of the Aotearoa New Zealand (hereafter ‘NZ’) health system and the global severe acute respiratory syndrome coronavirus 2 (coronavirus disease 2019 [COVID-19]) pandemic.

Personal Context

Many years ago, while sitting at a marae in Northland, I heard the Ngāti Hine writer and television personality Te Waihoroi Shortland state that his upbringing and life experiences have informed everything he has done. This is, of course, true for us all and underpins the rationale for the direction and topic of this thesis.

Therefore, in this following section, I will introduce myself as a prelude to introducing the thesis itself. This will be in two parts. In the first part, I discuss my identity, upbringing, and heritage to contextualise my view on biculturalism. The second focus is my clinical and health sciences experiences.

The insights are a preamble to the underpinning of the thesis and topic of *Optimal medication therapy in Indigenous Populations – A Case Study of Gout in Māori*. Given these perspectives are embedded in the content of this thesis, I detail the foundational principles and beliefs as the researcher and author.

By way of introduction, I am the product of a bicultural marriage. Biculturalism was and remains what I have been privileged in my life to know. It is primarily framed by my father, my Māori side (the term Māori was imposed to describe the Indigenous peoples of NZ). My Ngāti Rangi/Whanganui/Muaūpoko ancestry (presented in the foreword through my pepeha) and my mother – my Pākehā (non-Māori) side. My upbringing was based in rural communities of predominantly Māori ethnicity, where te reo and tikanga were present in almost every facet of life. My mother’s side of the whānau was integral in my early life and embraced ‘Māori culture’ and all its richness. My grandmother came from rural Christchurch to a small, exclusively Māori, Central Plateau village. She developed a deep bond with her

neighbour, who had a moko kauae and little English language, in a manner that could only be described as true reciprocity.

In contrast, I witnessed many incidents over the years where people were less embracing of such richness. For instance, I knew never to question my mother in front of a salesperson when she gave our surname as her maiden name when putting items on lay-buy. She had experienced being declined under her married Māori surname too many times to believe it was a coincidence. With their dark skins, I knew the rationale of my dad and my sister having to wait outside a motel on the rare family motel stays while my mum and I, with our fairer skins, confirmed a room. It was intriguing how such rooms suddenly became unavailable, despite the 'vacancy' sign outside, if my dad asked. I heard multiple stories of my dad's sporting prowess alongside those of him being prevented from playing tennis in Wellington because "Māori were not admitted to the tennis club."

Growing up in a town where the majority were Māori, I recall many hours at school spent in kapa haka and where te reo Māori was the norm. It was such a surprise years later when the debate about and resistance to compulsory Māori language in schools began. I had no idea it was not already, as it had been the case for me at my high school, where Māori accounted for some 80% of the student roll. I have always been fiercely proud of both my Māori and non-Māori heritage. Proud of my direct lineage to the rangatira, Tūroa, who was offered the role of Kīngi before Pōtatau Te Wherowhero. Proud of the pioneering settler ancestors who arrived in NZ without understanding the impact their arrival would have on those already here.

I am of a generation where the history of NZ was not taught in depth at primary and secondary school. I was cognisant, however, that one side of my heritage was afforded a comparative privilege, albeit that early settler life was not without challenges. I have paddled with my Māori whānau on our annual pilgrimage along our ancestor Te Awa o Whanganui (Whanganui River), who is now legally recognised as a person. I learned things that will never be printed in history journals, but certainly, the consequences of land confiscation and of the River Boards Act 1884 are. This legislation gave control of all rivers, streams, and watercourses in a district to a local river board, which for the Whanganui River meant it would be navigable by a steamship. The scenery also had to be of a certain view for those sightseeing on the ships. For my wider whānau, the pā tuna (eel weir) and netting were forcibly removed from the river, so it no longer provided the level of sustenance required for the many marae settlements along the river. Therefore, even if land confiscation did not

occur, there was little possibility of a sustainable future. Displaced, some whānau moved to reside at the Taranaki pā settlement of Parihaka, which does appear in history journals. My paternal grandfather, Rangitupito Te Karu Tukupua, was one of many that lived there for a time. Therefore, the reality of these events was known to me. Naively, I thought people resident in NZ would have a similar awareness.

Growing up, I had not ventured much further than the central plateau of the North Island. For instance, before leaving high school, I had never visited our capital city of Wellington. It is interesting, therefore, that when my sporting interests ultimately led to a scholarship in the United States of America (USA) after high school, this presented less of a ‘culture shock’ than undergraduate pharmacy training. Perhaps expectation formed an element of this: I expected a cultural shift travelling overseas. However, the divide at pharmacy school felt more apparent in the main because my rural, bicultural, comparatively lower socioeconomic upbringing was significantly underrepresented. At pharmacy school, I realised that being raised in a community where Māori were a majority and te reo was the norm was a vast departure from the cohort I was now studying alongside. The same could be said for the system in which I was studying, as reflected in the curriculum content, the environment, the language, the case studies, and the staff demographics. My undergraduate training did not touch any part of hauora Māori or the wider euphemistic view of social accountability. I was privileged to have had te ao Māori in my upbringing, which in no way compromised my Pākehā identity, rather demonstrated the natural synergy and strength of having two perspectives by which to view the world, within health and beyond. It was not until post-qualification that biculturalism as a foundation became increasingly important and apparent. Biculturalism, for me, crossed into understanding disparity and equity as it relates to Te Tiriti o Waitangi (Te Tiriti; the Treaty between Indigenous Māori and the Crown).

In essence, after completing my undergraduate study, my career further solidified my clarity of inequity premised within ‘the system’ that frames the clinicians’ conditions and approach.

This chapter's second focus is to outline my professional and clinical experience in health sciences and the reality of health outcomes in NZ. Medicines have fascinated me from a young age, particularly how to balance the effect being sought and the undesirable effects. The pathway to becoming a pharmacist began while studying in the USA, where I undertook a pharmacology course.

Before starting my journey in health formally, I was aware of the potential value of medicines to decrease morbidity and manage health conditions via my family circumstances and my own health. My maternal and paternal grandfathers suffered from emphysema and heart failure, respectively, and were but a small example. As a teenager, I was aware of the importance of both prescribing effectively and health literacy when my maternal grandmother took to taking glyceryl trinitrate tablets as though they were breath mints kept in a container that was not brown glass in her handbag.¹ She always had a plentiful supply of these Anginine tablets, seemingly prescribed and dispensed without question, as she certainly had no understanding of any safety concerns. It is believed she passed from an aortic aneurysm. Therefore, the genesis of my decision to undertake a PhD rather than solely focusing on being a clinician is driven by the passion for sharing the weaving of these threads: the recognised disparity and inequity in health outcomes for Māori and my eternal quest for knowledge to enable medicines to achieve the best possible outcomes.

In considering these points, and my lens for responding to the needs of Māori, I have been fortunate to have roles and responsibilities in an array of mahi (work). These experiences are summarised into the following three themes.

Clinical Roles Within the Health Profession

My career as a qualified pharmacist began at NZ's largest base hospital, where I was privy to a new approach called 'clinical pharmacy.' The manager at the time was a proponent of pharmacists working outside of the dispensary, interacting with 'patients' and the wider healthcare team in a manner that utilised their pharmacological expertise. This was an informative period of noting the wider medical team's response, from consultants to house officers and nurses, engaging positively with a field that was not their core training.

I maintained links with hospital 'clinical pharmacy' by working part-time when I took on locum community pharmacy work in rural communities. My strongest memory of this time was the number of people who would negotiate our gravel farm driveway seeking help to unravel the health system and their health conditions. This involved a creek crossing and would comprise all forms of transport, including horseback, foot, and various forms of motorised vehicle – a reflection of desperation and a desire to understand and manage.

¹ Glyceryl trinitrate (trade name Anginine) tablets should be stored in amber glass bottles to prevent degradation. If a person is taking them without a resolution in symptoms, they should seek urgent medical assistance as they may be having a major heart event.

My clinical practice has included working part-time as a pharmacist prescriber in two general practice settings. Both settings represent a predominantly Māori and lower socioeconomic demographic – Papakura Marae Clinic (PMC) in South Auckland and Pihanga Health in the central plateau of the North Island. PMC is also the site of the practice intervention used in this research. In 2014, I delivered a 12-month project at PMC and developed a relationship with clinic staff. The project was a Ministry of Health (MOH)-funded initiative that looked to work with the community and with primary care around the health conditions of cardiovascular disease, respiratory disease, and gout to increase medicines optimisation. It was acknowledged a sustainable approach to medicines optimisation would be meritorious rather than a one-off project. This is discussed further in Section 4.32 – Cultural Literacy Project.

My role as a pharmacist prescriber is to individualise medicines for people, most often for people with multi-morbidity. This can involve initiating, ceasing, or tapering medicines according to patient priorities, preferences, and experiences.

Ancillary roles have included providing clinical oversight to the Best Practice Advocacy Centre (an independent provider of medical education) and the Medicines Adverse Reactions Committee (set up under the jurisdiction of Medsafe). These roles have further provided depth concerning pharmacotherapy.

Voluntary Roles

In 2003, I led the establishment of what was to become formally incorporated as Ngā Kaitiaki o te Puna Rongoā, the Māori Pharmacists Association, in 2006. The association represents the right for Māori pharmacists to be represented in the profession and to harness the value of members' cultural knowledge and identity in directly having representation in policy and strategy of 'pharmacy' while providing a forum for inter- and intra-collaboration and professional development.

The formation of this organisation was met with many challenges. Not all members of the pharmacy profession were welcoming, to the point that I received multiple pieces of 'hate mail.' Alongside this was a lack of resourcing. Nevertheless, I remained in the roles of co-president and president for 10 years, with significant activities, including contributing to the development of measurable cultural competency standards for registered pharmacists and the development of accreditation standards for pharmacy education providers. The group of six

in 2003 has grown to a group of more than 130 in 2022. Despite this growth, the total cohort represents less than 2% of the registered pharmacist workforce in NZ.

Professional Service to a Wider Audience

A substantive part of my work that gave realisation to the extent of inequity in health has been through the delivery of a programme called He Rongoā Pai, He Oranga Whānau (HRPHOW). This dynamic and foundational innovation targeted the empowerment of Māori in understanding their rights within the health system as it relates to medicines. There have been several iterations of HRPHOW since its inception in 2006 as a Pharmaceutical Management Agency-funded initiative. It was first framed by bringing a Māori pharmacist, a Māori general practitioner (GP), and a rongoā practitioner (traditional healer) together in marae across the length and breadth of NZ for an intense two-day wānanga. More latterly, it existed as a single-day programme delivering to more than 1,000 attendees. Participants are primarily unregistered healthcare workers and whānau, with a smaller percentage of Māori nurses and registered health professionals. The feedback from HRPHOW is overwhelmingly that access, understanding, trust, and medication adherence are far from optimal.

The primary discourse of participants in this programme has been that health services for Māori are primarily monocultural. Even Māori health providers state that the accountability they have imposed on them is a very Western model that infers a Western way of delivering services. Therefore, bicultural practice is often invisible across the country, irrespective of the diversity of the country's demographics. Despite the points previously raised, Māori enter the health system with a desire to have their concerns resolved/addressed. However, attaining that outcome is premised on the system's failure and its architects and practitioners as part of that system more often than it is on the patient.

This is further evidenced if read in conjunction with my work and experiences at the Health Quality & Safety Commission (the Commission). My input has been external to the organisation in that I have advised on multiple versions of the *Atlas of Health Variation*. The Atlases highlight variations by geographic area in providing and using specific health services and health outcomes. These data can be further analysed to highlight variations in care according to ethnicity, specifically for Māori. An additional role at the Commission was through an external advisory committee advising on matters Māori. This provided an insight into a Crown entity's governance and management approach to matters of equity as they apply to Indigenous people.

I was an appointee to the pharmacy profession's regulatory authority – The Pharmacy Council of New Zealand – for 7 years. This role incorporated leading a Māori perspective to bring bicultural competence and confidence into being. The leverage for such influence is embedded in the Health Practitioners Competence Assurance Act 2003, which requires health professionals to be clinically, ethically, and culturally competent. Previous contributions to the Māori health strategy for the pharmacy profession correlated to the development of standards, policies, and regulations to respond to the needs of Māori. This was an opportunity to move the responsiveness of pharmacists to meet cultural competency standards and, in turn, the aspiration to improve Māori health outcomes.

Lastly, a 2-year MOH project for which I was the sole deliverer became a further demonstration of the value of empowerment of whānau and the quality of health outcomes in their lives. This innovation was framed on providing wānanga in marae with two underlying activity streams. The first was to empower whānau with an understanding of how certain health conditions affect the body and the treatment and management process. The second was to empower health professionals to work with whānau to manage these health conditions effectively.

While this project was summarised as a 'health literacy' project by the MOH, I believe using the term cultural literacy was more accurate. I was able to frame it on a convergence of the success of He Rongoā Pai, He Oranga Whānau, with the Atlas work of health variation for Māori, alongside my clinical experience over the last 30 years. This project is outlined further in [Chapter 4](#).

My various roles cumulatively represent the merge of my identity and culture with my clinical education and development into applied health practice. These life and clinical experiences underpin the drive for this thesis. It is intended to be my contribution towards medicines optimisation for Māori, founded on my lived experience and knowledge of:

- observing the benefit of accepting equality in the belief systems of Indigenous and non-Indigenous people and
- the role medicines can play in both preventing and causing morbidity and mortality.

Environmental Context

It is necessary to preface this thesis with two significant events during its time for the reader to bear in mind.

1. Health System Changes

In April 2021, the NZ Health Minister, Hon. Andrew Little announced forthcoming sweeping changes to NZ's health and disability system (New Zealand Government, 2021). This was on the back of a major review that commenced in 2018, with implementation for July 2022. The announcements detailed:

- a refocused MOH dedicated to setting strategic policy and monitoring performance
- the creation of a new Crown entity to replace the 20 district health boards (DHBs) and commission health services
- the creation of a Māori Health Authority (MHA) tasked with delivering equity of health outcomes for Māori and commissioning services accordingly
- the creation of a new Public Health Unit.

In October 2021, the Minister further announced that a Ministry for Disabled People would be established.

Essentially, these changes heralded a paring back of the MOH from its stewardship of the health and disability system, including its responsibility to work directly with communities, shifting its role as purchaser and regulator of national health and disability services to the newly created entities. Also, the role of DHBs, as Crown agents, historically responsible for delivering services within their regions according to a fixed budget, shifted to the new entities and 'localities.' Localities are locality networks of healthcare providers in the community. In part, localities are projected to replace primary health organisations (PHOs), which commissioned general practice services under contract from DHBs. In May 2022, there were 20 DHBs and 30 PHOs, with all their complexities and staffing. By dissolving DHBs and forming different entities, the reforms intend to make health delivery and healthcare equitable, accessible, simpler, and more responsive to communities.

While the health reform changes are system-level changes, any changes to the medicines' journey were not fully defined when submitting this thesis. For example, changes to how medicines are regulated, advertised, prescribed, dispensed, sold, classified, manufactured, and stored have been signalled for over two decades with the crafting of the Therapeutic Products and Medicines Bill (King, 2006). However, in 2022, prescribers of prescription medicines are medical practitioners, dentists, nurse practitioners, optometrists, midwives, pharmacist prescribers, and registered nurses (with particular scopes of practice as nurse-designated prescribers).

In parallel, in 2019 and 2021, the Waitangi Tribunal (a commission of inquiry investigating alleged breaches of the Treaty of Waitangi principles) reported multiple Treaty breaches in the primary healthcare system. The Tribunal recommended giving effect to partnership and ownership by Māori in the health reform process alongside appropriate resourcing and monitoring of services. They saw that the Crown's commitment to partnership should be explicit in all policies and documents of the primary health system. On that basis, they further recommended that the following be adopted as the Treaty principles for the primary healthcare system (Waitangi Tribunal, 2019):

- the guarantee of tino rangatiratanga, which provides for Māori self-determination and mana motuhake in the design, delivery, and monitoring of primary healthcare
- the principle of equity, which requires the Crown to commit to achieving equitable health outcomes for Māori
- the principle of active protection, which requires the Crown to act, to the fullest extent practicable, to achieve equitable health outcomes for Māori. This includes ensuring that it, its agents, and its Treaty partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity
- the principle of options, which requires the Crown to provide for and properly resource Kaupapa Māori primary health services. Furthermore, the Crown is obliged to ensure that all primary healthcare services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care
- the principle of partnership, which requires the Crown and Māori to work in partnership in the governance, design, delivery, and monitoring of primary health services. Māori must be co-designers with the Crown of the primary health system for Māori.

These threads, in parallel, create a different environment for medicines optimisation yet to be wholly defined. Any recommendations for transformative change will need to consider the implications of these changes.

2. The COVID-19 Global Pandemic

Friday 28 February 2020 saw the first case of COVID-19 confirmed in NZ. The coronavirus, identified in a Wuhan, China, seafood and poultry market in December 2019, has altered life as we knew it before that date. In its ongoing wake are many deaths, overstretched health systems, and suffering global economies. On balance, residents of NZ have enjoyed more

freedoms than those in many other countries. However, ripples spread far and wide, and the implication for this research has meant some tweaking of objectives. When plotting this thesis, the objectives included interviewing prescribers working in Indigenous communities. This was planned to happen at the 2020 Pacific Region Indigenous Doctors Congress (PRIDOC) that I first attended in 2006. The membership of this group includes the Association of Native Hawaiian Physicians, Australian Indigenous Doctors Association, Indigenous Physicians Association of Canada, the Medical Association for Indigenous People of Taiwan, the Association of American Indian Physicians, and the Māori Medical Practitioners Association. The 2020 congress was initially delayed until 2021. In 2021, it was further rescheduled to 2022. Therefore, it became necessary to consider an alternative, with this objective changing to advocating for equitable gout management during COVID-19 restrictions and mapping out the gaps in medicines optimisation in NZ. This is further discussed in Section 4.3.

Research Approach

This thesis uses a mixed-methods approach to weave the parallel threads of medicines expertise and hauora Māori experience. The general topic of this thesis is aimed at understanding ‘optimal medication therapy’ and, more specifically, how access to medicines, prescription of evidence-based drug therapy, and administration of medicines can be optimised. Further, it looks to do this with an equity approach aimed at those with the poorest health outcomes. Generally, this is all Indigenous peoples, but notably, it is Māori people in NZ. However, considering optimal medication therapy in its entirety for Indigenous populations with a focus on Māori is beyond the scope of a doctoral thesis. Given the depth and breadth required to research this broad aspiration, a targeted approach is identified by focusing on a specific health condition that predominantly affects Māori and that medicines can help prevent and manage – namely, gout.

Specifically, the research question will investigate how gout medication therapy for Māori can be optimised.

| |
|--|
| <p>Research question: How can gout medication therapy for Māori be optimised?</p> |
|--|

This thesis is primarily presented on a publication basis in accordance with the University of Auckland guidelines for including publications in a thesis, “the core of the thesis comprises a series of published [and] unpublished research papers” and contextual discussions in other

chapters. Where chapters are published in a journal, specific details are provided at the beginning of each chapter. The publications and other outputs associated with this thesis are listed in Appendix 1. The publications are mainly unchanged unless noted at the beginning of the chapter. For this reason, the pronoun ‘we’ appears in the publications due to co-authorship.

Chapter 1 includes the first published paper and sets out the medicines system as a foundation for understanding the impact of medicines optimisation as an integral part of ensuring equitable health outcomes. It discusses the requirement for multiple cogs to be working in synchronicity to achieve optimal medicines management and raises the point that addressing health inequity requires a multi-dimensional approach. It considers this from an Indigenous perspective and specifically for Māori. It argues why this is even more important, given the status of Māori health in general. Further, this chapter introduces gout as a health condition of significance and the rationale of using gout to study medicines optimisation for Māori. It also introduces the ‘predominantly Māori primary care setting’ from which a multi-level care initiative for gout was delivered. It discusses why this site was ideal for studying the ecosystem of medicine optimisation for gout.

Chapter 2 looks to understand the unique place of Māori within NZ. This is important for developing a view and consideration of equity outlined in Chapter 1. The historical context for Māori is imperative in discussing traditional approaches to health. This narrative also presents colonial arrival and what impacted those approaches, particularly the Tohunga Suppression Act 1907 (TSA). Importantly this chapter also outlines an embedded te ao Māori methodology, which underpins this entire thesis.

Chapter 3 presents a literature review undertaken to help inform the design of the multi-level care gout initiative.

Chapter 4 builds on this literature review and the MOH community cultural literacy project (described above) as contributions to the response to the thesis question and the approach taken with the multi-level care initiative. This chapter concludes by describing the journey to the multi-level care initiative implementation and evaluation, which was the case study for this thesis.

Chapters 5, 6, and 7 are published papers detailing aspects of the multi-level care initiative from a community and provider perspective. These chapters shine a light on the barriers and enablers of optimal management of gout in Māori to consider the thesis question.

Chapter 8 outlines why an objective change to this thesis was required in the face of the COVID-19 pandemic. It presents the alternative path, mindful of the transformative aim of this thesis. Chapter 8 subsequently summarises and conflates the learnings from the identified barriers and enablers to the initiative and proposes an approach to optimisation during the global pandemic when access to healthcare became more challenging. It contains a publication intended to be directly informative to prescribing clinicians advocating equitable gout management when it was conceivably even more required.

Chapter 9 takes the learnings from the previous chapters to set out a more substantive description of where the gaps in medicines optimisation lie so that they may be addressed. It presents a model of those gaps from a te ao Māori perspective.

Chapter 10 is a summary of the thesis. It includes a published editorial arguing for a coherent, responsive, holistic medicines system and concludes this thesis with recommendations and final reflections. This consolidates the independent discussions into a whole-of-system proposal to consider the general topic of addressing optimal medication therapy with an equity approach aimed at those who have been most disadvantaged.

Chapter 1 Medicines Optimisation – Health Outcomes

This chapter includes the first publication of this thesis:

Te Karu, L., Bryant, L., Harwood, M., & Arroll, B. (2018). Achieving health equity in Aotearoa New Zealand: The contribution of medicines optimisation. *Journal of Primary Health Care*, 10(1), 11–15. <https://www.publish.csiro.au/hc/pdf/HC17067>.

It is not included as the whole chapter but forms the basis of Sections 1.2 and 1.4 through to and including Section 1.7.

It is included in the thesis with permission from the *Journal of Primary Health Care*.

1.1 Introduction

This chapter builds a foundation of background information relevant to the thesis. It begins with definitions of ‘Indigenous’ and ‘inequity.’ Briefly, why health outcomes for Indigenous peoples should be prioritised. It outlines the importance of medicines to health outcomes. It also provides context to medicines access and sets the scene for understanding the impact of medicines optimisation. The chapter then introduces gout as a health condition of significance to Māori and describes why gout provides an ideal framework for studying medicines optimisation for Māori. Further, it presents why Papakura Marae Clinic (PMC) provides an ideal site to study the layers of medicine optimisation for gout. Finally, a summary draws those threads together to conclude the chapter.

1.2 Indigenous Health

Throughout the world, Indigenous health outcomes are poorer than for non-Indigenous people, with increased rates of mortality, morbidity, and disability (Anderson et al., 2016; United Nations Inter-Agency Support Group on Indigenous Peoples’ Issues, 2014).

The word ‘Indigenous’ is derived from Latin and is often used synonymously with words like ‘native, aboriginal, or first.’ In 1972, the United Nations accepted a definition of Indigenous to encompass the concept of colonisation (Martinez Cobo, 1981, p. 10). International law has since defined Indigenous people as “living descendants of pre-invasion inhabitants of lands now dominated by others. They are culturally distinct groups that find themselves engulfed by other settler societies born of forces of empire and conquest” (Anaya, 2004). This is an important distinction in terms of health outcomes, which are influenced by the loss of culture and traditional societal construct.

In NZ, a large body of evidence describes Māori (the Indigenous people) as having the poorest health outcomes and shortest life expectancy compared with other ethnicities resident in the country (Robson & Harris, 2007). The major health conditions causing death for Māori are long-term conditions, namely ischaemic heart disease, lung disease, stroke, and diabetes (Ministry of Health, 2015a).

1.3 Equity

The word ‘equity’ is derived from the Latin word *aequitas*, meaning ‘justice or fairness,’ whereas the term disparity derives from the Latin *dispar*, meaning ‘unequal.’ It is important

to understand that equity is not equality unless it refers to outcome. An equal outcome (and attainment of equity) requires unequal input unless populations are homogenous.

Health equity can be defined as the absence of systematic disparities in health between more and less advantaged social groups. Health inequities put disadvantaged groups at further disadvantage with respect to health and reduce the opportunities to attain full health potential. Within a global health context, the World Health Organization (WHO) defines equity as “the absence of avoidable, unfair, or remediable differences among groups of people, whether those groups are defined socially, economically, demographically or geographically or by other means of stratification” (World Health Organization, nd). The WHO recognises the importance of the outcome and aspiration that everyone should attain their full health potential. It also reflects that no one should be disadvantaged from achieving such potential. The Ministry of Health (MOH) defines equity in a health context in NZ. They state, “people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.” (Ministry of Health, 2019).

Disparity typically refers to a difference that is unequal or unfair. Health disparity can be defined as a health difference that is closely linked with economic, social, or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, age, mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.

Disparities in health and healthcare, therefore, affect the groups facing disparities, 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 healthcare inequity is eliminated.

It is important to understand how inequities arise to be able to address them. Wilkinson and Marmot (2003) present the life expectancy of populations as a gradient 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 (Axelsson et al., 2016). The combined components of colonialism (political, cultural, economic

marginalisation, and racism) shape contemporary Indigenous health outcomes (Czyzewski, 2011). For Indigenous people, health inequity is an expression of inequity of power (Hernández et al., 2017).²

1.4 Medicines Optimisation

Medicines are the most common tools used in healthcare. Medicines can decrease morbidity and mortality by both preventing and treating illness. All medicines can cause adverse effects. The aim, therefore, is to ensure optimal use of medicines whereby decreased morbidity or mortality from illness is achieved and drug-related morbidity or mortality is mitigated under an umbrella of person-owned care. According to the UK National Institute for Health and Care Excellence (NICE) (2015) and the NZ MOH (2015b), “Medicine optimisation is a person-centred approach to safe and effective medicine use, to ensure people obtain the best possible outcomes from their medicines”. Picton and Wright (2013, p. 3) describe the optimal use of medicines as “ensuring that the right patients get the right choice of medicine, at the right time. By focusing on patients and their experiences, the goal is to help patients to: improve their outcomes; take their medicines correctly; avoid taking unnecessary medicines; reduce wastage of medicines; and improve medicines safety. Ultimately medicines optimisation can help encourage patients to take ownership of their treatment.”

The phrase ‘responsible use of medicines’ precedes ‘medicines optimisation’, but there is a lack of clarity regarding the differences and whether there was a collective agreement to adopt optimisation. The WHO (nd.) defines responsible use as “first and foremost, the commitment and competency of doctors, nurses, pharmacists and patients but also of politicians, policymakers, patient groups and professional associations, which need to ensure availability of the needed resources, provide evidence for the best therapy choices, study the most effective prescribing regimens and get commitment from health professionals and patients to ensure the proper use of the medicines.”. A systems approach is still implicit, but perhaps the transition lies in the name’s connotation. The etymology of *responsible* lies in being accountable or responding to a situation, whereas *optimal* lies in meaning best or most favourable. To ensure responsible use with a strong focus on a systems-wide and societal approach by all participants involved with/affected by medicines acquisition and use requires

² The final paragraph of Section 1.3 is reproduced from Te Karu, Dalbeth, and Stamp (2021).

an optimal approach. Responsible use could therefore be considered a component of medicines optimisation.

Similarly, ‘medicines management’ is often judged against adherence to evidence-based therapy for a medical condition as recommended in a population-based guideline or the more contemporary health pathways (Gill et al., 2018). This may be ideal for a ‘standard’ population without comorbidities, but it may not necessarily be optimal for an individual when accounting for individual biological responses, other comorbidities, and the person’s perspective, priorities, values, experiences, and health beliefs. Evidence-based ideal therapy from a population basis, therefore, may not necessarily constitute optimal therapy.

1.5 The Journey to the Best Possible Outcomes From Medicines

In the first instance, for a person to engage in a health system, they must recognise a need, particularly more so in asymptomatic conditions. They must then feel ‘safe’ to approach it, including feeling that the service will satisfactorily respond to their individual beliefs, experiences, and values. They must also be able to access, interact with, and navigate their way through the system. The service/intervention must therefore be available with adequate supply. Utilisation can depend on financial, organisational, and social or cultural barriers as well as the physical accessibility and acceptability of services.

For the interaction to be respectful and effective, the practitioner should be culturally safe and competent. A practitioner must ensure the person in front of them feels understood and able to share personal information. In turn, the practitioner must impart understandable information. This principle applies to all health practitioners, including doctors, pharmacists, and nurses, and should be at the core of any interaction. Legislation within NZ demands that regulatory authorities of respective health professions set standards for clinical and cultural competence alongside ethical conduct (New Zealand Government, 2003). A mechanism to robustly monitor and assess the cultural competence of health practitioners and the wider health team (e.g., receptionists, healthcare assistants, etc.) does not currently exist.

Whether prescribers choose to prescribe a medicine is influenced by multiple person and whānau attributes, in addition to prescribers’ own personal attributes. For example, studies have demonstrated a difference in the treatment of patients according to the gender of clinicians and patients (Baumhake et al., 2009; Tsugawa et al., 2017). If medicines are prescribed, clinicians must draw on up-to-date clinical knowledge and apply this, alongside

experience, to individual situations. Whether prescribing is according to ‘best practice’ is not always definitive but, regardless, should ideally be approached as a ‘partnership’ (de Vries et al., 2004). This should incorporate the individual’s perspective, including values and the concept of shared decision-making, ensuring people are provided with understandable information on the risks and benefits of medicines administration to make a fully informed decision and enable self-management (Yudkin et al., 2016).

Expert opinion on the process of prescribing describes it as “a complex task that requires diagnostic skills, knowledge of medicines, communication skills, an understanding of the principles of clinical pharmacology, appreciation of risk and uncertainty and, ideally, experience” (Maxwell, 2010, p. 540). While recognising the complexity of prescribing, this definition appears to overlook patient contribution. Alternatively, the aim could be considered as a meeting of clinical expertise and the best available clinical evidence alongside patient preferences, priorities, values, experiences, culture, and beliefs.

Of course, as medicines knowledge increases and more medicines and the delivery thereof become available, this is an ever-changing ‘art.’ There are numerous examples of how prescribing practice has changed with new evidence, e.g., calcium supplements that are no longer prescribed widely to prevent osteoporosis and are associated with potential harm (Bolland et al., 2015).

Prescribers in any setting must be confident they have a fully reconciled list of medicines and that the person feels able to disclose the use of any other pharmacological agents—legal or otherwise—therapeutic products and any traditional Indigenous medicines. It is not uncommon for users of ‘alternative’ medicines, including traditional practices premised on intergenerational knowledge transfer, to feel reticent about sharing this information (Nicholson, 2006).

It must also be remembered that prescribing is but one component of overall medicines optimisation.

In NZ, the provision of medicines in a primary care setting most commonly occurs through a community pharmacy. The government’s national Pharmaceutical Management Agency (Pharmac) has a duty to “secure for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment and from within the amount of funding provided” (Pharmac, 2020). Medicines subsidised by Pharmac currently incur prescription charges of generally \$5 per item for people aged >13 years if they are

receiving a prescription from a public service. The intent is that the charge is capped to 20 items in a calendar year for an individual or a family unit, after which there should not be a co-payment charge. However, evidence exists that there is inconsistency and that people are asked to pay co-payments beyond 20 items (Norris et al., 2014). Although these charges may be comparatively lower than in other Western countries, New Zealanders are not exempt from affordability issues and, therefore, access to medicines. Specifically, Māori report the struggle to prioritise medicines acquisition over daily living expenses (Horsburgh & Norris, 2013; Norris et al., 2016). Medication co-payments, therefore, add to the complexity of medicines optimisation as they influence access and adherence.

In public hospitals, receiving medicines as an inpatient is generally without direct involvement from patients and can happen through various mechanisms. A prescription can happen at discharge from the hospital, and tertiary clinic appointments can also result in prescriptions. A health professional may also provide medicines directly, but this is relatively infrequent.

When prescriptions are provided, people then have a choice as to whether to present the prescription. Further, the interaction itself at the pharmacy can influence whether the medicine is administered as prescribed. Of course, once a person returns home with the dispensed medicine, how it is stored, used, and/or continued is without direct oversight. Continued administration or administration as intended by the prescriber is influenced again by health-provider interactions in addition to patient factors such as perceived need.

Monitoring of medicines use and continual reassessment of appropriateness is further integral to this whole optimisation process. It is a complex system, and failure can occur at any or many of those steps. Achieving the collective parts required to ensure the 'optimal use of medicines' clearly requires a collaborative approach, with the end-user of the medicine(s) being at the centre of decision-making at all levels. Where ethnic congruence does not exist between the provider(s) and end-user, an extra layer of complexity may be added at every turn.

When considering the many steps along the pathway to achieving this optimal state, the potential for it to go awry is perhaps unsurprising. In a cross-cultural setting, that potential is further compromised.

1.6 The Requirement to Address Medicines Optimisation for Māori

Inequity in access to medicines exists for Māori (Jatrana et al. 2016). Potential solutions must be considered when describing the many facets of medicines optimisation and inequity. For Māori, engagement with a medicines optimisation process is more than the provision of ‘understandable’ information founded on clinical competence. Instead, Māori require genuine relationships that are connected to culture and underpinned by trust and collaboration (Cram et al. 2003). In the study by Cram et al., Māori discussed the necessity of clinicians to understand that wairua and whānau are fundamental to health in a Māori worldview.

A person or whānau may therefore have negotiated the health process to the point of having an evidence-based medicine prescribed and dispensed for them. However, they may still be without the final necessary tools to administer it correctly, or they may feel a lack of trust and collaboration in the process such that they choose not to take the medicine.

Anecdotes within the health profession are plentiful of people not using or administering medicines correctly. Often the blame is laid on patients rather than the failure of the system to ensure the transfer of knowledge and to tailor the process for individuals. Personal experience, premised on decades of working alongside whānau, reveals a long history of mistrust towards Western medicines and one of simply wanting to understand things like:

- medication mechanism of action
- origin of medicine (does it pertain to the ‘natural world?’)
- aim of use
- likely side effects
- alternatives to treatment, including no treatment
- and length of treatment.

Māori are less likely than non-Māori to receive this information in an understandable manner (Bassett-Clarke et al., 2012), despite evidence that increased adherence and resultant improvements in clinical outcomes occur for Māori if this is the case (Gu et al., 2014).

Further, there is a perceived misalignment of Western-based health services (Kidd et al., 2010). Cultural differences in perceptions of health and preferences in communication styles may also contribute to inequities in medicine optimisation between Māori and non-Māori (Capstick et al., 2009). In addition, there is a request for different communication preferences for Māori compared with non-Māori (Raval et al., 2015). Counterintuitively, evidence from

the National Primary Care survey (2001/2002) demonstrated that general practitioners were quicker to show Māori the door during a consultation (i.e., shorter consultations) than they were for non-Māori (Crengle et al., 2012). This is despite knowing that Māori were more likely to be ‘sicker,’ with greater need for more doctor time. Although that study has not been repeated in the last decade, there is no evidence to suggest the situation is different today. Some evidence demonstrates the status quo remains (Jansen et al., 2011). Consequently, Māori have expressed the need for culturally competent and congruent medication information to be provided in healthcare interactions (Crengle et al., 2014).

In addition, there has been a call for the focus to be on health outcomes as opposed to outputs as a lens for Indigenous health delivery (Harwood, 2010). For example, funding for cardiovascular risk assessment targets means more assessments occur, but it does not necessarily mean that optimal medicines management is undertaken as part of that. Examples of collaborative multi-disciplinary, culturally appropriate models do exist (Hotu et al., 2010; Ratima et al., 1999), and dedicated policy to address this has been proposed (Jones et al., 2010). However, equity is not currently the lens that is used consistently in policy or outcome measures (Scott, 2014; Sheridan et al., 2011). This is unreasonable, given the body of evidence demonstrating that an equity approach benefits all people (Chin et al., 2012).

In terms of prescribing medicines, inequity exists in the provision of pharmacological treatment for Māori at both primary (Gillies et al., 2013; Horsburgh & Norris, 2013) and secondary care levels (Seneviratne et al., 2014). Furthermore, Metcalfe et al. (2013) collated evidence of medicines dispensed to Māori across all medicine groups and found the inequity so substantive that it became known as the “missing million prescriptions paper.” While providing detailed evidence that Māori were much less likely to receive medicines according to burden of illness, this paper also demonstrated that there are instances where Māori are more likely than non-Māori to receive some medicines. These medicines used more often by Māori include non-steroidal anti-inflammatory drugs (NSAIDs), which can cause substantial side effects. They generally do not ‘treat’ the cause of illness or prevent illness; instead, they may only provide symptomatic resolution.

Therefore Māori were less likely to receive medicines for cardiovascular disease, which is the most common cause of death, yet are more likely to receive medicines that can cause cardiovascular events, gastric ulceration, renal damage or even death (Ingrasciotta et al., 2015; Pirlamarla & Bond, 2016).

1.7 Medicines Optimisation with an Equity Approach as a Priority

Equitable access to medicines optimisation is critical for ensuring equitable health outcomes are achieved, and perhaps especially so in those requiring long-term treatment for chronic conditions. Dr Martin Luther King (1966) has been quoted as saying, “of all forms of inequality, injustice in health is the most shocking and the most inhumane.” Indeed, it is counterintuitive and surely unethical that the inverse law of healthcare exists, with those requiring the greatest care often receiving the least care (Hart, 1971). This situation can compound the inequity and lead to worse health outcomes (Ministry of Health, 2002). In 2017, Pharmac announced a strategic and bold goal of aiming to achieve medicines access equity by 2025 and released a statement that not all New Zealanders are achieving ‘best health outcomes’ from funded medicines. They reported that Māori uptake of funded medicines showed that Māori continue to receive medicines in the community at a lower rate than non-Māori, despite higher health needs – contributing to greater inequities in health. “This gap in access to medicines is seen in long-term conditions like diabetes, heart disease, and respiratory conditions like asthma” (Pharmac, 2019, p. 3) and chronic obstructive pulmonary disease (COPD).

Equity often represents the driver for addressing response when an imbalance exists.

It is important to understand that equity is one of two drivers that uniquely prioritises Māori in NZ. As partners of Te Tiriti, there is a governmental obligation to ensure Māori have at least the same level of health as non-Māori (New Zealand Government, 2014). Te Tiriti entrenches the rights of access to and uptake of health and, in this instance, medicines access and optimisation. In addition, NZ is a signatory to Article 24 of the United Nations Declaration on the Rights of Indigenous Peoples, which asserts Māori, as the Indigenous people of NZ, “have an equal right to the enjoyment of the highest attainable standard of physical and mental health” (United Nations Inter-Agency Support Group on Indigenous Peoples’ Issues, 2014, p. 18). This is discussed further in Chapter 2.

Equity in medicines optimisation for Indigenous peoples will occur only when the right approach is taken. In developing *Equity of Health Care for Māori: A Framework* (Ministry of Health, 2014), the MOH has been explicit in its expectation of health practitioners, organisations, and systems to achieve health equity for Māori. The framework’s application as it relates to medicines optimisation requires urgent action. Despite the overwhelming evidence of health disparity, co-creation and co-understanding are largely unseen between

health professionals and end-users of medicines. Reframing medicines optimisation to focus on the desired outcome and the necessary input to achieve these, needs to be considered.

There is a clear and urgent need to understand how medicines management can be improved for Indigenous peoples to eliminate health inequity. Further, applying an equity lens enables planning to consider how such an approach could be prioritised to eliminate disparities. In summary, overall medicines optimisation involves multiple cogs in synchrony. Research should be supported to qualify, quantify and support ‘medicines optimisation’, both in a general sense and also for the Indigenous people of NZ, because if we get it right for people who are currently missing out, the whole nation will benefit.

1.8 Gout

1.8.1 Gout Epidemiology

Gout is the most common form of inflammatory arthritis in adults (Kuo et al., 2015; Zhu et al., 2011). It is a chronic disease of monosodium urate crystal deposition, typically presenting as recurrent attacks of severe joint inflammation (Robinson & Horsburgh, 2014). Gout causes severe joint pain, work disability, and reduced social participation (Te Karu et al., 2013). Untreated, tophi (hardened lumps of urate crystals) can develop, leading to joint damage (Dalbeth et al., 2007). Gout is independently associated with cardiovascular disease, diabetes, kidney disease, and overall mortality (Krishnan et al., 2008; Kuo et al., 2010; Perez-Ruiz et al., 2014). There is evidence that the gap in premature mortality between those with and without gout has not decreased over time despite other inflammatory arthritic conditions demonstrating a narrowing in this gap (Fisher et al., 2017). The two risk factors for gout are chronic hyperuricaemia and local tissue characteristics that facilitate crystal formation and growth. Globally, the incidence and prevalence of gout are increasing in developed countries (Kuo et al., 2015).

1.8.2 Gout Management

A large body of evidence describes the poor management of gout (Dalbeth, 2013; Doherty et al., 2012; Edwards, 2011). This is difficult to reconcile when methods are available to diagnose gout with certainty and medicines are available to ‘cure’ gout by lowering serum uric acid (SUA) concentrations to <0.36 mmol/L or 0.30 mmol/L over the long term, depending on disease severity (Richette et al., 2017). Allopurinol is recommended as the

first-line medicine for urate-lowering therapy. This is a widely available, inexpensive medicine that has a good safety profile if prescribed according to renal function (Stamp & Barclay, 2018).

In considering this suboptimal management, multiple factors could be influencing the achievement of guideline-based management:

- misconceptions of both providers and users of health systems about the long-term nature of gout
- misconceptions of both providers and users of health systems around the causation of gout
- the ability of people to present at a health service when they are struggling to be mobile in an acute situation
- the ability of people to present at a health service because of life commitments when they feel well, e.g., accessibility during work hours
- the ability of people to present at a laboratory service for urate testing
- the health literacy skills of the provider(s) to ensure misconceptions are addressed
- the clinical knowledge of the provider to implement urate-lowering therapy according to evidenced-based data (Mikuls et al., 2005)
- adherence to urate-lowering therapy.

People often do not continue taking or remain adherent to urate-lowering therapy, if indeed they are prescribed it in the first instance, possibly due to these factors (Briesacher et al., 2008; Harrold et al., 2009; Mantarro et al., 2015; Sarawate et al., 2006). This can mean the cycle of all those influencing factors arise again if gout flares re-present.

As an alternate means of ‘management’, providers and health users look to control only the acute manifestations of gout (Rai et al., 2018; Riedel et al., 2004; Spencer et al., 2012; Zandman-Goddard et al., 2013).

1.8.3 Gout in Aotearoa

The prevalence of gout in NZ is higher than in other developed countries. Gout is particularly prevalent in Māori and Pacific peoples, with estimates of gout prevalence of greater than 38% and greater than 30% in Māori and Pasifika men aged ≥ 65 years, respectively (Jackson et al., 2012). This makes NZ a hot spot in the world, where rates of prevalence in general practice

have been shown to exceed those for diabetes and cardiovascular disease (Stokes et al., 2018).

This increased prevalence is at least partly due to genetic variance in urate excretion and not necessarily to lifestyle factors that have historically been promoted and which the public feels they will be judged on (Hollis-Moffatt et al., 2009; Merriman & Dalbeth, 2011). Ethnicity and family history of gout are independent risk factors for gout (Major et al., 2018; Sun et al., 2018); while serum urate concentration is a significant risk factor for gout, not all people with hyperuricaemia over extended periods develop gout (Dalbeth et al., 2018a).

In terms of gout management, significant evidence demonstrates that gout is not managed well for all people resident in NZ and is even less well managed for Māori and Pacific peoples (Jackson et al., 2014). This is an example of the inverse care law, with Māori and Pacific peoples more likely to experience the effects of gout at an earlier age with greater negative consequences (Dalbeth et al., 2012) yet less likely to receive urate-lowering medicines than other ethnicities (Dalbeth et al., 2016, 2018b).

NZ is not dissimilar to other countries in that adherence to urate-lowering therapies is suboptimal (Scheepers et al., 2018) and that regular dispensing for Māori is more suboptimal (Horsburgh et al., 2014). Further evidence from NZ shows that clinicians in primary practice perceive gout management to be mainly acute and that diet is emphasised over urate-lowering therapy, which patients found stigmatising (Humphrey et al., 2016).

1.8.4 Papakura Marae Clinic (PMC)

PMC is a unique primary care setting in NZ in that the health premises sit inside an urban, interactive marae. Papakura Marae itself was registered as an incorporated society with charitable status in 1979 to provide cultural, health, and social services for the people of Papakura and its surrounding suburbs. The clinic serves a population of >3,000 people living in the Papakura community of South Auckland. The practice has an enrolled population of ~92% Māori and Pacific Island ethnicity and predominantly lower socioeconomic status. The practice sits under NZ's largest Māori-led PHO. The staff at PMC are predominantly Māori. The articulated vision of PMC is “Kia Pokapū te Panekiretanga hei Pou mō te Whānau – To be a centre of excellence for whānau,” with the following values: mahia kia ea, kia toa (a ‘can do’ attitude); whānau whakaaro tika (think like whānau); whakanuia te whānau (celebrate Indigeneity); whānau auaha (everyone an innovator); whānau whai hua (outcomes matter); and whānau whakataurangi (keep our word).

PMC is an ideal place to trial implementing an initiative that aims to improve health outcomes for Māori.

1.9 Summary

The interplay between medicines access, optimal prescribing, medication adherence, and monitoring to achieve optimal medication management is complex. There is a clear need to understand this further, specifically in an Indigenous realm, to decrease health inequities.

Achieving the collective aims required to ensure this optimal state requires a multi-level collaborative approach, with the person administering the medicine(s) at the centre of decision-making at all levels.

These minimum requirements appear to address primarily patient and provider factors at a superficial level but, at a deeper level, will likely require microsystem, organisational, and community input. For instance, ensuring the prescriber uses up-to-date best-prescribing practices may involve organisational changes with information technology. Likewise, the response to cultural safety may involve integrating community health workers. Equally, access to a prescriber may require an organisational approach to help people with transport. Investigating policy influences is not the focus of this thesis but should any findings lend towards advocating for policy changes, this will not be overlooked.

My overarching aspiration is to investigate barriers/enablers to contribute to finding a pathway for optimal medication therapy in Indigenous people. However, a more focused approach is identified, given the depth and breadth required to research this broad aspiration.

Given that:

- Māori have the shortest life expectancy of all ethnicities in NZ;
- gout is highly prevalent in Māori;
- gout is associated with cardiovascular disease, renal disease, and premature mortality;
- gout can be prevented with medicines;
- gout is managed inequitably for Māori;

there is a solid argument for the optimal treatment of gout in Māori to be given priority.

This thesis is therefore based mainly on work at PMC, as Papakura provides a cohort of patients who are predominantly Māori, the majority of whom are living with the challenges of social deprivation. PMC also represents a practice underpinned by seeking excellence of

care in a Māori paradigm. The following chapter seeks to provide a deeper understanding of a Māori worldview.

Chapter 2 Te Ao Māori – I Belong, Therefore I Am

2.1 Introduction

The previous chapter presented the health significance of optimal medicines management and the inequity in optimisation between Māori and non-Māori.

This chapter focuses on Māori, presenting some key concepts around shared values and worldviews. However, it is essential to bear in mind that Māori are not homogenous, with no unitary Māori approach. Māori was not a name we collectively applied to ourselves as representing a single demographic. It was initially used as an adjective but also became a noun meaning any or all of the following: *ordinary, normal, native, or Indigenous* (Wilson, 1963). Royal adds *mystical* and *clarity* to the adjectives (as in whakamāori – to make something clear or transparent) and evidences that Māori was a term used long before European arrival (Royal, 2012). Understanding the historical diversity of ‘Māori’ beyond contemporary society's ethnic and cultural label is pertinent.

Tribal affiliation and geographic location are important considerations for Māori with tikanga, kawa and access to and concepts of rongoā (traditional Māori healing) varying. There are nevertheless common and uniting values and knowledge.

This chapter outlines the methodological approach for this thesis. Potentially, it is not traditional to outline methodology in a section dedicated to the Indigenous perspective. However, my position is to underpin te ao Māori at the core of this thesis, infiltrating knowledge gain and systematic inquiry.

A brief overview of the historical health context is outlined with particular relevance to the changes in health status observed since the arrival of non-Māori in NZ. While it is not the intent to describe in detail the health practices of Māori before the implantation of the ‘Western model of health’ or ‘the system’ that we know today, it is nevertheless important to have a basic understanding of where there is misalignment between world perspectives on health. To conclude, this chapter briefly touches on Te Tiriti, with a more considered inquiry into the Tohunga Suppression Act (TSA). This chapter posits the TSA as a significant piece of legislation with an enduring impact on health outcomes as a relevant example of injustice for this thesis and a contributor to inequity in medicines optimisation.

2.2 Methodology

This section addresses the argument for the methodological approaches undertaken. In doing so, it is pertinent to reconsider the research question and the associated objectives provided in Box 1 for ease of access.

Box 1 Research Question and Objectives

Research question: How can gout medication therapy for Māori be optimised?

Objectives

1. Implement a decision-support tool to improve prescribing of medicines for gout according to guideline recommendations in a predominantly Māori primary care setting (Section 4.3.1).
2. Implement a multi-level care approach to improving medicines and disease knowledge in patients with gout in a predominantly Māori primary care setting (Section 4.3.2).
3. Identify the barriers to and enablers of the implementation of these initiatives (Section 4.3.3).
4. Develop advice on promoting equitable gout management during the COVID-19 restrictions. (Please note, this objective was an amendment and is further discussed in Section 4.3.4).
5. Describe the barriers to medicines optimisation in NZ (Section 4.3.5).

2.2.1 Kaupapa Māori Indigenous Theory

The options for addressing this question are multiple, with one's ontological beliefs influencing the epistemology. In undertaking this research, I am acutely aware of the beliefs, experiences, and worldview that I bring. For this reason, I have explicitly detailed these in the personal context section. Perhaps academic reasoning would assert there is no right or wrong way to best address the approach. I felt that there was a wrong way. A wrong way would have involved non-Indigenous etic epistemology or a 'goldfish bowl' outsider view where there is a power imbalance, and people are merely the passive objects of research. For Indigenous researchers to undertake research within a Western institution that, by default, is built on a system of Western philosophy can present challenges. Eminent professor Linda

Tuhiwai-Smith's book dedicated to Indigenous research discusses the requirement to decolonise research methods involving Indigenous peoples (Smith, 1999, 2012). Western epistemologies may be suited to Western academic thought, but they are foreign to Indigenous ways of knowing, making it essential to escape the confines of Western approaches. For Indigenous researchers, this is "about centring our concepts and worldviews and then coming to know and understand theory and research from our own perspectives and for our own purposes" (Smith 1999, p. 39). Although there is no single Māori approach, some commonalities underpin fundamental differences in ontological reality. For instance, time is collapsible to Māori in that those who have passed are with us all the time, and the past is in front of us.

For all Polynesian languages, the words for the past are 'the times in front of us' or, in Māori, *ngā wā o mua*. We are not engaged in a linear past and walk backwards into the future. It is customary to ask who one's ancestors are and what mountain they belong to before learning their name. It is impolite to ask names first because there is no separate existence from the deep and powerful circle into which you were born. Whanaungatanga – or the centrality of kinship and careful attention to relationships – is the core tenet of Māoridom. That kinship extends to the environment – the mountains and rivers who are our ancestors, and the tracing of our genealogical connection to our environment. If we take liberties with Descartes' famous dictum 'I think therefore I am' – and consider this a proposition centred in the individualism that underlies a Western worldview – then we might contrast a Māori and Indigenous proposition asserting 'I belong therefore I am.'

To me, the 'tika' or right way to approach this research holds the principles of Smith's (1999, p. 39) articulation of Indigenous research purpose – to allow "our own perspectives" and use Indigenous epistemology to provide visibility and value to what is needed. Being required to defend this approach and explain it in a Western paradigm is both challenging and insulting. Eketone (2008) discusses this as being asked to fit *mātauranga Māori* into the academy as opposed to where the academy fits into *mātauranga Māori* (if it can); otherwise, it is yet again, defining Māori knowledge and experience in terms of Western concepts. C. W. Smith (2000) describes this further as Māori researchers being required to leave their culture at the door to participate in the academy. Not dissimilar to Eketone, this thesis journey began with a view of *Kaupapa Māori* as simply operating under a Māori philosophy where the axiology of Indigenous research follows the lore of Indigenous customs, beliefs, aspirations, and knowledge. Despite her many books, lectures, presentations, and writings, L. T. Smith (1999,

2012) states that a Kaupapa Māori framework should be simple. Consistent with the ongoing struggles of colonisation, the requirement to decolonise is, however, never simple.

Māori academics have countered Western academics for decades on appropriate methodologies. G. H. Smith (1997) is one of the earlier advocates for transformational and philosophically aligned Māori research. Since that time, the development of Kaupapa Māori Research Theory as a Māori theoretical framework has been discussed, layered, and built upon (Barnes, 2000; Cram et al., 2004; Henry & Pene, 2001; Pihama, 2001). The initial impetus acknowledged decolonisation alignment to critical theory as a basis for academic conceptualisation. This is important to Māori and other Indigenous peoples from an emancipatory and politicisation perspective. Others have since argued against this basis and challenged that Indigenous frameworks, including Kaupapa Māori research, should not be required to sit within a discourse that needs to align with a Western perspective (Eketone, 2008). Such constraint will only ever be reductionist to the intersectionality of Indigenous ontology where, for example, there is a transcendence of spirituality to the environment. Eketone (2008) has posited an alternate view centring on constructivism and ‘native theory’ alongside critical theory to frame Māori research. This asserts that Kaupapa Māori has use of critical theory but must not be defined or limited by Marxist/socialist grand theory seeking to challenge and transform oppressive structures. Russell (2001) presents Native Theory in her thesis challenging Western discourse as the culture of power where Māori have variously been placed within other peoples' paradigms and theoretical parameters for over a century and a half, rather than placing ourselves within our own context. The right of Indigenous people to make sense of our time and place in the world does not need ‘mainstream’ to acknowledge, research, record, and affirm our knowledge for it to be valid and useful in research, in practice and in life (Eketone, 2008; Russell, 2001). Constructivism allows for the difference in social construct to hold varying ontological perspectives (Fosnot, 2005). Whilst decolonisation and self-determination underpin most Indigenous methodologies (Drawson et al., 2017), the diversity of Māori has not produced a unified theoretical approach (Ratima, 2008). Cram (1993) argues the Western view of knowledge is cumulative, where parts can be drawn together to discover universal laws, whereas the purpose of Māori knowledge is to uphold the mana of the community.

From an academic perspective, the research methodology employed in this thesis most closely aligns with Eketone’s model in that it is aligned but not defined by critical theory. Critical theory is a methodology familiar to me from my Masters' dissertation, premised on

the aim to reveal or expose layers of how things come to be to liberate marginalised groups and challenge power imbalances. Horkheimer, credited with first defining critical theory, states it seeks “to liberate human beings from the circumstances that enslave them” (Horkheimer, 1982, p. 244). Critical theory acknowledges historical circumstances and that situations and people do not arrive at a point in time without this history. This thesis looks to enhance and uphold the mana of the community through an Indigenous and holistic social constructivist framework.

In terms of health environments, critical theorists do not see society as a “well-functioning organism” (Alderson, 1998, p. 1010). Critical theorists, for example, may investigate how political change might prevent and reduce a painful disease, such as by reducing inequities instead of focusing solely on the disease and its treatment. Strong advocates of critical theory purport social construction of health systems must be investigated and that interdisciplinary studies are needed to prevent the reinforcement of structures that already produce inequities (Unger et al., 2011). Others posit the importance of critical theory to highlight how power relations function ideologically to sustain hierarchies of oppression, enabling some groups to become privileged over others (Straus & Brown, 2019).

However, this thesis aligns with the view of Pihama et al. (2015) that Kaupapa Māori Research Theory is an evolving theoretical framework engaged in a struggle for recognition, validation and affirmation of our cultural worldviews as Māori with the academy. It acknowledges Kaupapa Māori is organic by nature, necessarily diverse, and positioned within and against Western epistemology, but with consistency in the principles of intent to decolonise, to self-determine and to hold steadfast to our varying ontological perspectives.

From an application and community perspective, this thesis asserts that Kaupapa Māori theory is a theory underpinned by Māori philosophies of the world that have Māori foundations and Māori understandings (Hutchings et al., 2011). It further aims to align with Curtis’s (2016) framework in her guide to embracing Kaupapa Māori positioning in research, by being:

- transformative;
- beneficial to Māori;
- informed by mātauranga Māori;
- aligned with a ‘structural determinants’ approach to critique issues of power, privilege, and racism and promote social justice;

- non-victim-blaming and rejecting of cultural-deficit theories
- emancipatory and supportive of decolonisation;
- accepting of diverse Māori realities and rejecting of cultural essentialism
- an exemplar of excellence
- free to dream.

These are crucial points to the overarching concept of this whole thesis.

Kaupapa Māori, as it has evolved therefore provides the korowai (cloak) that envelops and underpins this research and findings. Beneath the korowai is a mixed-methods approach that is discussed below.

2.2.2 Mixed Methods

A mixed-methods approach has become increasingly used in health research (O'Cathain et al., 2007). The rationale that a mixed approach allows for the investigation of multi-faceted complexities and the nature of health (Tariq & Woodman, 2013). This is also true for Indigenous research (Drawson et al., 2017). A qualitative and quantitative approach for this thesis lies in the belief that a more complete result is possible instead of using either approach alone – that is, the attainment of the objectives would be less without using both methods.

In considering the epistemological basis of both qualitative and quantitative approaches, quantitative research has historically dominated health research. It enables an objective measurement defining health problems and presenting the magnitude of the situation or an observed change. Quantitative research is still very much the basis of drug trials where the benefits and risks require quantification, for example. Quantitative research enables objectivity and is termed positivism in nature, a term reportedly first used by Auguste Comte in the nineteenth century when describing research informed by scientific evidence or to that which owes “their first origin to the occupations of practical life” (Comte, 1865, p. 20).

On the other hand, qualitative research allows an understanding of complex social phenomena related to human behaviour and social reality (Kaur, 2016). Qualitative research generates subjective theories and is, therefore, non-positivist (Kaur, 2016). In considering this point, positivist and non-positivist could be deemed to juxtapose. My alternative view is that they complement one another. A mixed-methods approach enables my investigation of a complex situation with a holistic perspective, deconstructing and factoring in where there is divergence in worldviews.

Furthermore, a mixed-methods approach is, by default, considered a straightforward but effective means of triangulation (Jick, 1979). Jick states that convergent validation or triangulation is complementary and originates in maritime and military strategy where more than one method was used for location purposes. Considering this thesis's objectives and the overarching aspirational goal of finding a pathway for optimal medication therapy for Indigenous populations, it would be incomplete to employ only quantitative or qualitative methods.

With respect to the qualitative component of this thesis and critical inquiry and social transformation, much evidence demonstrates that inequity in medicines access and inequity in gout management exists. Exploring why these inequities pervade and, importantly, discovering solutions to optimise care, specifically for gout in this instance, is 'what remains'. It was imperative that the voices of those affected, both indirectly and directly, were sought to identify the barriers and enablers to optimising gout therapy in Māori. This was the foundation underpinning both the design of the multi-level care approach and the rationale for patient and staff interviews. Equally, it was imperative the interviews were valued appropriately. The applicability of a Kaupapa Māori approach for the qualitative interviews requires consideration of the taonga participants offered in their kōrero. Recognising the importance of whakawhanaungatanga, which represents a kōrero of connection of persons through genealogy and/or kaupapa, was central to the engagement. Tikanga and kawa dictate that the rangatiratanga (authority) and mana motuhake (autonomy) of participants were upheld alongside the concept of whakautuutu, or reciprocity.

Te Awekotuku, in her identification of the principles for research engagement with Māori communities, proposes seven kaupapa that should support and empower engagement with Māori (Te Awekotuku, 1991):

1. Aroha ki te tangata (A respect for people)
2. Kanohi kitea (the seen face – being physically present)
3. Titiro, whakarongo ... kōrero (look, listen ... speak)
4. Manaaki ki te tangata (share and host people, be generous)
5. Ki a tupato (be cautious)
6. Kaua e takahia te mana o te tangata (do not trample over the mana of people)
7. Kaua e mahaki (do not flaunt your knowledge)

These seven principles and those of tikanga and whakawhanaungatanga are a demonstration of how Kaupapa Māori theory underpinned the participant interviews at a micro-level.

2.2.3 Reflexivity/Autoethnography

Reflexivity involves being aware in the moment, examining and consciously acknowledging the assumptions and preconceptions that are brought to the research and that shape the outcome. In emancipatory research, where there is a social responsibility to change an inequitable situation, reflexivity is essential to ensure validity (Baker et al., 2004). It is asserted that reflexivity is a technology of self, and researchers must critique and appraise themselves at every step, being open to questions and information-gathering from their participants to ensure emancipation (McCabe & Holmes, 2009). The acknowledgement of the need for reflexivity in this thesis journey began a process to include autoethnography as a methodological component of this thesis. Although there are numerous methodological ways to approach this journey, my experiences, beliefs, and assumptions informed how the research was approached. Again, this is why I have overtly and transparently attempted to outline my ontological perspective as it relates to this research.

Narrative inquiry and nested within it, the autoethnographic approach, is a methodology used by Indigenous and non-Indigenous researchers when working with Indigenous communities (Dowsley & Oliveira, 2018; McIvor, 2010). McIvor (2010, p.141) promotes the synergy between an Indigenous research paradigm and autoethnography. She discusses “the centrality of self in the work, without a sharp separation between the researcher and the subject and the shared modality and intentional use of storytelling as method,” as fundamental to autoethnography and a powerful and traditional part of oral societies. (Māori are an oral and visual society played out through multiple modalities including but not limited to oral recitals, songs, carvings, incantations, weaving, traditional tattooing, and artwork.)

White (2010) proffers that auto-ethnography using the researcher’s own experience to understand a phenomenon is particularly pertinent for marginalised groups, such as Indigenous peoples. Wilson (2008) adds that promoting relational accountability and narration of the researcher’s journey is integral to truth-telling and a platform for transformation.

While continual self-analysis and analysis through discussion with supervisors created transparency in the research process, it was important to share the journey of self-learning along the way.

Therefore an auto-ethnographical component is included, especially so when detailing the implementation of the multi-level care approach to improving medicines.

2.3 Hauora – Key Concepts

The previous section on methodology discussed foundational differences in ontological and epistemological perspectives between Māori and non-Māori. This section goes on to consider some differences in key concepts of well-being.

For Māori, the holistic nature of health cannot be defined within the same context as Western health. It is fair to say that, for Māori, health and spirituality are intertwined. Death or illness was/is believed to be a transgression of tapu (sacredness). Karakia existed for all activities. Māori guarded their well-being by observing tikanga, that is, by observing tapu, and by karakia and rituals, which were strictly adhered to with the possibility of punishment by the deity to whom had been appealed (Hīroa, 1949). As will be discussed below, the tohunga (expert healer/leader) was the sole medium of communication with the ancestral gods. My own wider whānau, with deep spiritual beliefs, known as the ‘People of the Māramatanga’ are the entire subject of a book on spirituality driving thoughts, beliefs and practices (Sinclair, 2002, p. 14). This book presents the belief that “wairua are known to come back, to give advice or assistance when things were not going well” that Tohunga are “Messengers of Io, the Supreme Being maintaining a link to uniquely Māori beliefs.” Translated more loosely – health is not in isolation of the physical being, and there are ‘experts’ who can span the spiritual and physical worlds.

These underlying beliefs have been the premise of describing Māori models of health. Sir Mason Durie³ was the first to publish a Māori model of health (Durie, 1985) called ‘Te Whare Tapa Whā.’ The Māori Women’s Welfare League presented the concept in 1982 after they commissioned a report called Rapuora (Murchie, 1984). It asserts the four components of health: taha tinana (physical health), taha wairua (spiritual health), taha hinengaro (thoughts and feelings/mental health), and taha whānau (family health) are analogous to the walls of a house, in that all are imperative to total function. This is arguably the most widely known Māori health model and remains well-used today 35 years after publication. In saying that, however, there appears to have been a dilution of its original content. That is, the genesis of this was an academic exercise to give visibility to the holistic nature of health from a

³ Sir Mason Durie is a retired Māori Psychiatrist and Eminent Scholar in contemporary Maori health literature. He remains an active leader in contributing to Maori Health.

Māori perspective. However, it has been interpreted and reframed by Crown entities and agencies, the wider health sector, and professionals into frameworks that do not always have the depth or breadth and understanding of te ao Māori to claim them as the same. For instance, te taha wairua is very much about a spiritual communion with the environment – land, lakes, mountains, and reefs – which all have spiritual significance and are regularly commemorated in song and formal oratory. Land is a symbol of continuity with those who have passed on to the spiritual world, and respect for land augments one’s spiritual strength (Durie, 1985). Access to traditional or tribal land and protecting those lands are deemed central to well-being. Durie (1985) also talks about te taha wairua encompassing the vital ingredient of ‘mana,’ not as contemporary society defines it as personal strengths or individual pursuits. Instead, he proposes that possessing mana is to know health as a conferred state of spiritual authority and power, denoting a high level of health without an egocentric core. This juxtaposes with the application of te taha wairua as it is often seen today, with an emphasis on religious belief and associated activity. Notably, Durie also presents an overarching chasm in worldview when health professionals and kaumātua were asked to name the most prominent health problems affecting Māori people. For health professionals, it was diabetes, gout, hypertension, carcinoma of the lung, respiratory infections of childhood, and mental ill health. In contrast, kaumātua highlighted pollution of food sources, environmental health and children's health (Durie, 1985). One could reasonably argue that these differences in worldview remain central to the argument of health today.

The concept of trying to provide disruption to the Western model of health, i.e., to say there is a different model which includes the metaphorical, is not isolated to Te Whare Tapa Whā. Other models have endeavoured to disrupt the dominant perspective of health, including Rangimarie Rose Pere’s *Te Wheke*, which uses the analogy of an octopus to describe a Māori philosophy of health (Pere, 1997). There has been an argument that models are sometimes too simplistic and that applying any model will require adaptation to a heterogenous society of Māori in a modern world (McNeill, 2009). The point, however, is that Māori do have a different perspective on well-being, and on the whole, Māori have not fared equitably in a system constructed of Western beliefs.

Rongoā, in its wider sense, incorporates all the cultural dimensions and values of hauora and includes the likes of karakia, waiata, kōrero, and mirimiri (types of traditional massage). However, personal experience details that clinicians and Western health providers have an unbalanced preoccupation with rongoā rākau (plant-based medicines). This is evidenced by

requests for information on Western scientific parameters of plants, e.g., how they might interact with mainstream medication. This preoccupation ignores the tikanga and kawa associated with plant gathering, preparation, and administration and reduces this taonga simply to herbal medicine – an affront to rongoā practitioners and Māori in general.

2.4 Historical Context Māori Health

Much has been written on the physical appearance of Māori in initial contact with the sailors of the Endeavour. Captain James Cook wrote that Māori are “strong rawboned well-made active people ... They seem to enjoy a good state of health and many of them live to a good old age” (Cook, 1770, p. 18932009). This view was endorsed by botanist Joseph Banks, who was also on board: “the men are of the size of the larger Europeans, stout, clean-limbed and active, fleshy but never fat. Among them, I have seen many very healthy old men and in general the whole of them are as vigorous a race as can be imagined” (Banks, 2011, p. 239).

This health status and longevity of life were clearly not maintained with the arrival of more settlers to NZ. Indeed, James Busby had stated his concerns in the House of Lords since at least 1837 (Hansard, 1838). He told of rape and murder of Māori and

“... it must not be lost sight of, that the mortality has not been confined to those who have been the victims of violence or who have been exposed to the effects of vices or diseases of foreign origin. Disease and death prevail even amongst those natives who by their adherence to the missionaries have received only benefits from English connections; and even the very children who are reared under the care of the missionaries are swept off in a ratio which promises at no very distant period to leave the country destitute of a single aboriginal inhabitant.”

Sadly, there is a hint that this report was met with genuine concern not of life on a humanitarian basis but of the lack of a labour workforce awaiting intended settlers. Cook estimated the Māori population to be around 100,000 people in 1769, although Pool and Kukutai (2011) suggest this was an underestimate. By 1858, a more robust attempt at a population count estimated numbers of Māori to be around 60,000; by the mid-1870s, Māori had gone from being the dominant population to numbering less than 10% of the total population. Te Rangi Hīroa⁴ states that the population of Māori fell to as low as 37,502 in 1871 (Hīroa, 1910). At least one politician felt this was no cause for alarm, saying, “taking all things into consideration, the disappearance of the race is scarcely subject for much regret.

⁴ Te Rangi Hīroa (Ngāti Mutunga Iwi) – also known as Sir Peter Buck – was a doctor, military leader, health administrator, politician, and prominent leader in the earlier part of the twentieth century.

They are dying out in a quick, easy way and are being supplanted by a superior race” (Newman, 1881). Equally, Featherstone, an early NZ physician/politician, stated, “the Maoris (sic) are dying out, and nothing can save them – our plain duty as good, compassionate colonists is to smooth down their dying pillow” (Dow, 1999, p. 48).

There is some inconsistency in ascertaining robust written evidence from reliable sources on the specific health conditions affecting Māori to the end of the eighteenth century when contact with Europeans was increasing. Hanham (2003) investigated the impact of introduced infectious diseases on pre-Treaty Māori and argued that many writings were not necessarily an accurate picture. This may not have been with intent but rather a product of casual observers “who came to New Zealand with a specific purpose such as commerce, colonisation, to pursue an interest in science, or by long-term residents such as the missionaries who came to convert Māori to Christianity” (Hanham, 2003, p. 3). However, it is undeniable that infectious disease in this immunologically naive population, alongside warfare, dispossession, and social change, had a devastating effect on health outcomes (Anderson et al., 2006). And whilst Western recordings of health perspectives during that time were sparse and inconsistent, the Indigenous perspective is plentiful. The history for Māori lies in waiata, tauparapara, karakia, and whaikōrero. On the Tira Hoe Waka alluded to in the personal context section, this history of our tribal ancestors is shared through all those mechanisms. The associated learnings included advanced thinking about health; for example, whānau who once lived along the Whanganui river recognised the importance of isolation from all these unencountered diseases and of sanitisation well before the ‘germ theory’ had been espoused.

In summary, the colonisers' belief that Māori were unimportant and should be supplanted by a superior race had catastrophic consequences for Māori. Health outcomes and life expectancy have suffered immensely since the nineteenth century and continue to lag behind that of non-Māori in NZ today.

2.5 Te Tiriti

The previous section presents a comparatively healthy Māori population before mass non-Māori migration with deleterious effects through the introduction of disease and far-reaching injustices, including the systematic dispossession of land. This was despite the promises and hopes of partnership as per Te Tiriti, the country’s foundational document. The rights inherent in Te Tiriti for rangatira, hapū, and iwi are important considerations for health, both

as an entitlement right and a moral right. The genesis of equity in health for Māori is demanded in the three articles of Te Tiriti, itself, a statement of equality where the authority of the Crown and mana of Māori come together. Article 1 allows the government to govern and to trade off for article 2, which is the continued access of ‘te tino rangatiratanga’ – the unqualified exercise of chieftainship, lands and treasure. In other words, Chiefs allow the Crown to establish a government, while Queen Victoria allows Chiefs to continue to protect their rangatiratanga. Article 3 recognises the outcome of protection and equity for all. Through colonisation, the rights of article 2 were not upheld, with Māori denied land, power, and all taonga, including language and cultural practices. The discourse of Western dominance, including health system practices and determinations, has isolated Māori health as simply an article 3 issue. That is, the Western view is one of focussing on equity. This in itself contradicts the rights Māori have in article 2 and those obligated through article 3. Te Tiriti aimed to provide terms for a relationship, but each side found different interpretations. One would argue that at a minimum, *contra proferentem* (a legal doctrine in contract law which states that any clause considered to be ambiguous should be interpreted against the interests of the party that created the clause (s) should be applied) (Sarbazian & Rostamzade, 2017). Some have argued that the *contra proferentem* rule places too much weight on the English text and that only the Māori version – written or oral – should be used (Suter, 2014). Regardless, the application of Te Tiriti went with a non-Māori interpretation until the late twentieth century, with Māori severely disadvantaged through the juggernaut of colonisation. This disadvantage includes a health perspective through a key piece of legislation, namely the TSA, which is discussed below.

2.6 The Tohunga Suppression Act

In order to describe the perceptions whānau have in accessing health today, the assimilation processes with colonisation is a significant remaining issue. This part of the chapter focuses on the TSA, as I purport it helps underpin this contemporary view. I do recognise it is not isolated to this one piece of legislation, but in considering decisions of modern-day health access, its place is primary. Without exception, when I am in marae discussing health, the TSA is raised. I stress that the discussion has never been solicited on my behalf, but it has never not been discussed. It is raised with significant resentment on behalf of Māori, who express a sense of loss at being blocked from using traditional health methods overtly. I have spent many hours working alongside the modern-day ‘rongoā practitioner’, and I have spent

days sitting in marae listening to whānau lament and grieve over a fundamental right they were denied.

British colonisation saw the introduction of systems of government and services framed on a belief of superior knowledge and practice. The services ranged across social domains and needs for development, including education, health, and justice. Robert Ludbrook, lawyer and dedicated campaigner of children's rights and social justice, discussed the impact of legislation in NZ, stating, "we are all captives of the past – the law, instead of being the protector and friend of the Māori, soon came to be a means of exploitation and expropriation" (Ludbrook, 1975, p. 422). Given the domain of health for this thesis, I will discuss the deconstruction and delegitimisation of Tohunga as a critical piece of legislation contributing to a homogenous health system and denying an Indigenous perspective.

The TSA was an Act of Parliament enacted in 1907 (New Zealand Legal Information Institute, 1907). The Act specifically states,

Every person who gathers Maoris around him by practising on their superstition or credulity, or who misleads or attempts to mislead any Maori by professing or pretending to possess supernatural powers in the treatment or cure of any disease; or in the foretelling of future events, or otherwise, is liable on summary conviction before a Magistrate to a fine not exceeding twenty-five pounds or to imprisonment for a period not exceeding six months in the case of a first offence, or to imprisonment for a period not exceeding twelve months in the case of a second or any subsequent offence against this Act.

No prosecution for an offence against this Act shall be commenced without the consent of the Native Minister first had and obtained.

The TSA was introduced by Sir James Carroll, Minister of Native Affairs and of Māori and Irish descent. For all intents and purposes, the Act made it an offence for Māori to seek the services of a tohunga and essentially drove traditional healing practices to extinction or underground.

There is no doubt the Act achieved as its name indicates – the suppression of traditional Māori healing practices. This, as mentioned, has led to such resentment today, with some commenting it was as devastating as the Terrorism Suppression Act, which enabled the raids in the Urewera Rohe in 2008 (Stephens, 2007).

Before commencing this PhD, I believed that the true intent of the TSA was primarily to incarcerate or at least limit the activities of Rua Kēnana. This was informed by kōrero at many different marae around the country, including Tūhoe marae, and my own superficial research in books. Rua was a leader who established a self-sustaining community at

Maungapōhatu in Te Urewera, the mountainous homeland of Ngāi Tūhoe. He claimed to have had multiple religious experiences, which led the Government of the time to feel increasingly threatened by his following. Of Rua's many prophecies, Voyce (1989, p. 108) argues that the catalyst was his prediction of a Māori "millennium" that would see the return of Māori land at a time European farmers were demanding more land. The Government of the time could ill afford settler unrest and Māori congregating in numbers after the NZ land wars. Another rationale for believing this piece of legislation was aimed at Rua was because there was the ability to prosecute tohunga well before the passing of the TSA. That is, if tohunga were the true aim of the legislation, there already existed a mechanism to do so. Section 240 of the Criminal Code Act 1893 provided a means for imprisoning tohunga. In fact, tohunga were jailed with harsher penalties with this legislation than those subsequently charged under the TSA itself (Stephens, 2007). The Criminal Code Act 1893 (p. 368) provided for the imprisonment for up to 1 year of anyone who "pretends to exercise or use any kind of witchcraft, sorcery, enchantment, or conjuration," fraudulently claiming any knowledge or skill. In addition, the Indictable Offences Summary Jurisdiction Act 1894 and the Māori Councils Act 1900 also made provisions for addressing behaviour deemed harmful by tohunga.

If there was already the ability to charge tohunga, why then was there a need for more legislation? The TSA differed from the Criminal Code Act by covering three areas of deemed wrongdoing. As mentioned above, it details it an offence to:

- gather Māori
- mislead or attempt to mislead Māori
- to foretell or prophesize to Māori.

This explicit language appeared to validate the earlier thinking that Rua was behind the push for this Act. There does not appear to be any literature that outrightly refutes this hypothesis. Multiple books and articles have covered the Act in depth (Anderson, 2000; Dow, 1999, 2001; Lange, 1999; Voyce, 1989). In addition, the transcript of the Bill presentation provides context and insight into the thinking of the times (New Zealand Government, 1907). Some of that insight includes understanding the fear of non-Māori that Māori were leaving employment to follow 'prophets.' This was discussed as being unhelpful to this new colony. The preamble set about reflecting this concern by stating:

WHEREAS designing persons, commonly known as tohungas, practise on the superstition and credulity of the Maori people by pretending to possess supernatural powers in the treatment and cure of disease, the foretelling of future events, and otherwise, and thereby induce the Maoris to neglect their proper occupations and gather into meetings where their substance is consumed and their minds are unsettled, to the injury of themselves and to the evil example of the Maori people generally.

That Rua was never charged under the TSA appears to indicate more complexity to the situation than initially appreciated. The biggest penalty made under this Act was imposed on a Pākehā nurse Mary-Ann Hill, in 1914, who called herself the ‘White Tohunga’ (Dow, 1999). All the previously mentioned writings do not reach a consistent conclusion, reflecting the layers and complexities.

It is hard to pinpoint the exact moment for the genesis of the TSA.

Raeburn Lange’s book (1999) is an investigation of newspapers, meeting reports, minutes from Crown agency proceedings, other books, theses, church reports, diaries of prominent people, and other sources from the late nineteenth century and the early twentieth century. In it, he presents a humanitarian view with concern over Māori mortality – a population significantly threatened, as discussed. A lot of writing at the time compared tohunga to snake-oil merchants or charlatans. Before the arrival of non-Māori, tohunga were the keepers of ‘tapu’ and communicated with the unseen world. With the arrival of non-Māori and their guns, diseases, and tapu ignorance, tohunga who continued to practice as they always had, often met with disastrous outcomes. This was especially so where infectious disease was the issue. It is apparent that Māori doctors, Maui Pomare and Te Rangi Hīroa, were frustrated by tohunga, who were not only ineffective with infectious diseases but were also considered dangerous to public health.

Also caught up in the layer of the humanitarian view were those frustrated by tohunga who held steadfast to the belief that a transgression of the unseen world was the cause of the illness. For example, the practice of holding people briefly under cold water was unhelpful in bronchial illness, which was prevalent. In addition, another cohort of self-proclaimed ‘tohunga’ were unscrupulous in using extortion to prey on their fellow kinsmen, who were desperately struggling to survive all the perils of the time. One example comes from evidence in the prosecution of a self-proclaimed tohunga, Hoani Poti, who was charged under the Criminal Code Act 1893 (Voyce, 1989). The complainant described how Poti had requested money before placing the complainant’s mother in Blue Gum water. When she died, he

demanded more money and decreed that the whānau should dive into the water 28 times (Lange, 1999).

Māori were particularly vulnerable in these times. The world in which they lived had changed inconceivably. I once sat with elders at a marae in Northland who shared the story of their tupuna (ancestors) being so overwhelmed with not knowing how to deal with such dreadful disease that they took to tearing pages from Bibles and grinding them into a paste for eating. They had seen the missionaries live through conditions such as measles and typhoid and could not comprehend how they fared so much worse.

Sir Āpirana Ngata⁵ described men who preyed on the vulnerable as “bastard tohunga” (New Zealand Government, 1907). The parliamentary debate transcription of the TSA demonstrates the broader view of the Māori politicians at the time, in that they wanted to see this ‘second-class quack’ stopped but not the wider application of traditional knowledge.

Ngata (p. 519) eloquently stated,

the word Tohunga in old Māori meant a man set apart - an expert. The Tohunga was tapu; he was sacred; his person was sacred. Everything he touched was sacred. He was the most important man.Only the very clever boys were chosen to become Tohunga. Before the arrival of Captain Cook he was the genuine article, the Tohunga of pre-European days was not only the chief of the clan but he supplied its laws and its government. ...The law that governed the tribe emanated from him. The law which meant life and death, which dealt with everything pertaining to the cultivations, everything pertaining to the industries, everything pertaining to their moral life and everything pertaining to the religious life emanated from the Tohunga. His word was law. This Bill does not purport to deal with that class of Tohunga. ... This Bill deals with a bastard tohungaism.

Ngata explained that leaving Māori to discern who was legitimate and who was not, was fraught, and therefore the Bill must protect them.

Alongside this humanitarian view, and in considering the second part of the TSA, which required the consent of the Native minister to prosecute, Māori members potentially saw this as a point of leverage. That is, given prosecution could not be undertaken without support from Māori evidence and the eye of the Native minister, they felt secure that:

- the Act would be used appropriately to stop unethical activities

⁵ Sir Āpirana Ngata of Ngāti Porou iwi was the first Māori to graduate from university, in 1893. He was a renowned leader, lawyer, land reformer, politician, and cultural proponent, dedicating his life to improving the social and economic conditions of Māori.

- that traditional healing practices would never be lost as such since they were intergenerational and entrenched.

Perhaps their support in the House for something non-Māori felt insecure about could be traded for what they saw as the real need: significantly enhanced resourcing of health access and public health initiatives for Māori.

Evidence of this exists where Ngata used a greater part of his speech to lobby for resourcing comprehensive health services for Māori as an alternative to tohunga. Alongside this advocacy, Ngata (New Zealand Government, 1907, p. 520) also acknowledged what no doubt was intrinsic to him by stating, “legislate as you will, you will never suppress tohungaism. You cannot do it. All the laws that could be passed in this House could not do it. You are getting down to bed-rock when you get to tohungaism.”

Countering the humanitarian view is that the TSA was part of the intended colonisation machine. Some believe the evidence in the newspapers of the time provided an important clue to the propaganda of Māori being portrayed as gullible and inferior, cementing the superiority of non-Māori (Voyce, 1989). That Maui Pomare had been such a strong campaigner for the TSA does not lend itself wholly to this theory unless he was a mere pawn or that the truth lay in a combination of many factors.

The TSA and many other Acts were repealed with the implementation of the Māori Community Development Act in 1962.

Recognising the legislation's complexity and the scholarly analysis of its reasons for drafting three threads or themes that have important relevance to this thesis are outlined in the next section.

2.7 Ka Mua, Ka Muri

The previous sections demonstrate how important it is to look back in order to move forward. However, we can only move forward and optimise access to medicine for Māori by looking at the historical issues that continue to play out today. The contemporary reality is that Māori are still impaired by mistrust and an ability to access ‘the system’ due to three long-standing barriers:

- racism
- equity

- cultural safety/ethnic congruence.

They are presented as themes, and despite possible correlation, their independence is important for this thesis. The importance is how each theme is seen in the health ecosystem, whether by policy, strategy, or innovation/development. To consider any findings from this thesis, they are discussed independently.

2.7.1. Racism

The Oxford Dictionary (2005, p. 925) defines racism as discrimination, or antagonism directed against someone of a different race based on the belief that one's own race is superior.

A 1988 NZ Government-commissioned panel, chaired by Ngāi Tūhoe leader John Te Rangi-Aniwaniwa Rangihau, produced a report called *Pūao-te-ata-tū* (The heralding of a new dawn) (Te Rangihau, 1988). Considered ‘ground-breaking’ (Human Rights Commission, 2012 p. 3) and immeasurably authentic as a voice for the people (Brooking, 2018), it described three levels of racism – individual, cultural, and institutional.

Individual or personalised racism is most easily identified where an individual's discriminatory attitudes or actions are directed at others. As mentioned above, NZ's colonial history is well littered with examples of individualised racism. Another demonstration is seen in the words of NZ's first Attorney General, who stated, “it shall be given to the founders of this colony to be also the instruments of preserving a barbarous native race, and of raising them in the scale of civilisation to a level with ourselves” (Ludbrook, 1999, p. 421). While such sentiments are a personalised view of racism, it is crucial to understand that governors and architects of NZ's laws and systems espoused this superior view, and this became a legacy for the future.

Cultural racism manifests as negative attitudes towards a culture where essential dimensions of the minority's values and lifestyle are discarded to its detriment (Te Rangihau, 1988).

The overarching attitude and dismissal of *tohunga* demonstrates cultural racism. Te Rangi Hīroa, who requested balance in the debate, reflected on both worldviews, given his *whakapapa* to English and Māori. He had widely discussed his concern over experiences with ‘*tohungaism*,’ but added,

We subject customs and faiths to the light of comparative criticism and we ridicule the ideas of more primitive races as absurd. But in times of stress, despondency and

lowered vitality, there is a tendency to revert to the mother's fears which slumber within, beneath the veneer of civilisation. How much more so in the case of the full Maori who has not had the advantage of even primary education: Clodd says, "In structure and inherited tendencies each of us is hundreds of thousands of years old, but the civilised part of us is recent" (Hīroa, 1910, p. ii).

Te Rangi Hīroa, it seems, was promoting this 'essential dimension of Māori' as a cultural imperative. In times of stress and poor health, how often do Māori and other Indigenous cultures revert to their default – to what is deep in their whakapapa and look to more than the Western scientific medicine model? When there is an intergenerational disconnect with a Western worldview, is it the inherent value system that prevails?

The hypocrisy of 'acceptable' spiritual belief seemed to be lost with the early colonialists of NZ when making statements like "I found him (a tohunga) and put the fear of God in him" (Voyce, 1989). Similarly, Alfred, Lord Tennyson, who lived at a time similar to those debating the TSA said, "More things are wrought by prayer than this world dreams of" (Phillips, 2002, p. 246), yet the barbarous native healer with his incantations was purported as evil. Such statements are examples of this duality in acceptability based on the voice of superiority and contrasts in the associated power.

Pūao-te-ata-tū (Te Rangihau, 1988, p. 19) defines institutional racism as:

The most insidious and destructive form of racism, though, is institutional racism. It is the outcome of monocultural institutions which simply ignore and freeze out the cultures of those who do not belong to the majority. National structures are evolved which are rooted in the values, systems and viewpoints of one culture only. Participation by minorities is conditional on their subjugating their own values and systems to those of 'the system' of the power culture.

The implementation of the TSA neatly demonstrates these three levels of racism where personalised racism became structural or codified such that a cultural dimension was suppressed, further leading to institutional racism where differential access became legalised. National structures evolved that were premised on only one worldview – that of non-Māori. Had there been a Te Tiriti responsive approach to health and worldviews equally valued, holistic healthcare would have been the starting point and not a modern-day aspiration. Failure to implement a partnership approach through Te Tiriti with equal governance, equal resourcing, and self-determination has been an intergenerational blight for NZ, denying all residents of this country an Indigenous holistic health approach and underpinning a plethora of inequities in health outcomes.

In many countries traditional medicine is a mainstay of healthcare delivery or at least integrated with it (World Health Organization, 2013). Furthermore, Indigenous medicines, usually plant-based, have been the source of many Western medicines, with more still being discovered (World Health Organization, 2013).

The WHO (World Health Organization, 2013, p. 15) defines traditional medicine as having a long history:

It is the sum total of the knowledge, skill, and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness.

It is this richness of history and intergenerational knowledge systems that all of NZ has been denied, but the sad reality for whānau in our health system is that their perspectives of health are invalidated by our Western health system, which, rather than coexisting and cross-pollinating, competes with traditional Māori perspectives and healing practices. This includes whether they are explicable in a Western paradigm or not.

Ironically, the epistemological view of tohunga that beliefs and expectations have a physiological effect is the subject of a large body of evidence today. Experts such as Fabrizio Benedetti (2009), doctor/professor of neuroscience and published author of several hundred peer-reviewed research papers, won a British Medical Association award for his book *Placebo Effects: Understanding the Mechanisms in Health and Disease*. This book essentially presents the importance of the 'ritual' as integral to health outcomes and not necessarily the health intervention itself. Other medical practitioners/researchers endorse this view in books of similar content (Jonas, 2018). The value of ancient cultures and the concept of ritualism is emphasised. These authors agree that such an approach to health does not work for all conditions and, importantly, not for infectious diseases. It is perhaps this understanding that tohunga of old lacked.

In summary, racism through the TSA played out at individual, cultural, institutional, and, therefore, societal levels, creating differential access and, ultimately, mistrust in Western medicines and the practice of Western medicine. This continues to impact medicines access and optimisation.

2.7.2 Equality/Equity

Chapter 1 introduced the definition of equity and the concept of unequal input to achieve an equal outcome. The corollary is also true in that inequity is caused by unequal input and unequal power sharing. As discussed, where Indigenous peoples exist, health structures are framed from a colonial application of power. This unequal power sees a harmful imbalance creating inequity. Māori may have envisaged equity when signing Te Tiriti with promises of continued rangatiratanga in exchange for governorship. The Crown did not accept the worldview of Māori as equal; therefore, an authentic partnership has never been realised.

That there should be fairness or equal footing when drafting the TSA was dismissed at the time. For example, Hone Heke Ngapuha, also a Member of Parliament (MP) in 1907, argued that if the legislation was to protect Māori from quackery, the same suppression needed to apply to European quacks who he claimed were plentiful. He told of cases where Europeans professed supernatural powers to Māori audiences and supplied Māori with sedatives and alcohol. He and others continued to advocate on this point. The Quackery Prevention Act was subsequently implemented in 1909 and “claimed to offer a direct parallel with the Tohunga Suppression Act” (Voyce, 1989). There is no obvious ‘parallel’, however, in that the Quackery Act made it an offence to publish false statements about the efficacy of any ‘medicine.’ There was no reference in the Quackery Act to the conduct of a person outside of this publishing. This is despite modern medical journals inaccurately reporting statements such as “the activity of quack doctors was also suppressed with the Quackery Prevention Act 1908” (Best Practice Advocacy Centre, 2008). This Act had no reach to the conduct of anyone outside of medicines and the publishing thereof. Products not covered by the definition of ‘medicine’ but claiming therapeutic use were also outside this Act's coverage. For instance, in the latter part of the nineteenth century, a lucrative business was had from selling “galvanic belts delivering magnetic fields to the genital sac to aid with spermatorrhea” (Watson, 2013). Men without medical qualifications sold these belts all over NZ. One may well ponder what was worse – to be immersed in cold water or to have ‘soothing electricity’ delivered to genitalia. This type of medical treatment eventually ceased due to the legislation in the country of manufacture of the product, not from the Quackery Prevention Act. It also proved difficult to prosecute under the Quackery Prevention Act because defendants could usually produce testimony that such remedies worked. One example was Chamberlain’s cough syrup containing alcohol and chloroform. This syrup was sold extensively, including

for use in children but came with testimony meaning it was not banned, and no one was prosecuted for publishing its therapeutic claims (Otago Witness, 1908).

In a contemporary sense, one wonders how different the situation is today with the likes of homoeopathic products and ‘alternate’ remedies circumnavigating current legislation by stopping short of claiming cure of disease. Rather such products use phrases like ‘support for a healthy heart’, ‘maintains joint health’, and ‘supports your body’s natural response to winter ills and chills’. People could access the likes of chloroform and alcohol, yet Māori could not openly access plant-based rongoā.

There was further unequal treatment with respect to the regulation of practitioners. The Māori Councils Act of 1900 provided for the regulation of tohunga via the Native Health Officer, where a tohunga had to register for the sum of 1 pound. This early attempt at regulating tohunga was not applied to ‘herbalists’. Registration of herbalists was non-existent and remains so today. In addition, there had been a patchy approach to medical registration (Porritt, 1967), with a continuum of practice. This included the doctor practising in Northland who appeared drunk more often than sober and who local Māori believed was attempting to poison them (Lange, 1999). Regulation of doctors was a haphazard and provincial affair. Conduct or practice unbecoming of a medical practitioner was not legislated until 1914 but required application to the Supreme Court for the removal of the name of the practitioner concerned (McLintock, 1966). It is likely that the cost and effort required to progress this to the Supreme Court was a deterrent for addressing poor behaviour until a decade later when the Medical Council was formed.

During the TSA debate, Ngata (New Zealand Government, 1907, p. 520) stated that

all Tohunga are not bad. There are Tohunga who supply a real want. They are no worse than the herbalists you have. There is a large and unexplored field in the flora of New Zealand if only the medical men would devote their attention to it. Real remedies for certain complaints natural to the human being are to be found in our own flora. And the Tohunga of old were acquainted with the medical virtues and curative properties of a good many of the plants which are not in the recollection of the present generation. There are herbalists who fulfill a want amongst the Māoris. Some of the Tohunga also supply a real want especially in such a district as the Ureweras.”

To summarise, before 1907, tohunga had to be registered and pay a fee, yet doctors and herbalists did not. Post the TSA, tohunga were prohibited from openly existing and therefore could not use rongoā rākau (plant-based medicines), yet ‘medicines’ of dubious efficacy and

potential harm (e.g., chloroform) were freely available, demonstrating further unequal treatment leading to an inequitable situation.

Without using the word 'equity,' Ngata also discussed the inequitable spending on health for Māori. He pointed to the fact that a sum of £3,000 had been allocated amongst 46,000 people and asked, "what is £3,000?" Te Rangi Hīroa (1910, p. 114), in his thesis, was more explicit in terms of equity, stating, "the present system of health work should be encouraged until such time as the Māori people shall have advanced to such a degree that they can be put under the control of the European District Health Officers." In other words, additional work and input were required for Māori to attain an equal health status to Europeans.

For Māori MPs supporting the Bill, was it a case of 'fighting the war and not the battle' in terms of being seen to support the TSA as a platform for demanding housing and healthcare services? If they genuinely believed the legislation would never extinguish the very essence of traditional healing practices, did they plan to use this trusted position to advocate for significantly enhanced resourcing? Did they feel secure that Māori Council support was required for prosecution? Stephens (2007, p. 470) also considers this a possibility, stating that support was perhaps well-judged in that rogue individuals could be addressed while "questions of Māori loyalty to the House were allayed," but concluded that attempts to use the legislation to gain more health resources for Māori failed, however, and the Act must be seen as a failure.

Furthermore, it remained that the Act's name was not the 'rogue Tohunga Suppression Act' or the 'bad Tohunga Suppression Act,' which was the language of the MPs at the time. They spoke at length about the 'good' tohunga and the 'bad' tohunga as being unequal yet stopped short of explicitly naming the target of this legislation.

Indeed, the skill of the 'reputable' tohunga was legendary, with even the medical fraternity complimenting greater skill at surgery, for example removing bullets during the Land Wars and setting bones (Porritt, 1967).

One early 1880s account of 'Māori medicine' triumphing over 'Western medicine' occurred when a decorated NZ soldier fell in a boiling geothermal pool, scalding both legs to upper thigh level (Mair, 1923). In a show of compromise, the soldier agreed that each 'side' be given a leg to treat. The leg tended to by Māori was not painful and had fully healed in 5 weeks. In contrast, the leg tended to by a London Royal College of Surgeons graduate and Rotorua's first Medical Officer was painful and slower to heal. In the eyewitness account, Dr

Hope Lewis, Medical Officer, was “bitterly disappointed at being outpointed by ignorant savages, (but) too much of a sport to show it” (Mair, 1923, p. 30).

That one part of the population in NZ was significantly disadvantaged was not always acknowledged by those that were advantaged. In terms of health outcomes, Māori had fought hard to keep land as a determinant of their survival. At the time of the TSA implementation, Hīroa (1910, p. 114) had advocated for Māori to return to owning land because the effect upon the people's health would be incalculable, and “they would be assisted in the war against disease and would regain the magnificent physique which is their racial heritage.”

However, Dow (1999) claims that land loss having a disastrous effect on health from a non-Māori perspective was not offered until 1955 and was ‘soon’ adopted in the early 1990s. That the connection between land loss and health outcomes was not documented until more than 100 years after the signing of Te Tiriti and that the 40-year gap for adoption was defined as ‘soon’ is surprising. Given that colonisation was a well-rehearsed process, it is hard to believe its architects would not have foreseen the impact on Indigenous health as a significant correlation to:

- land loss
- language loss and
- deconstruction of traditional societal structures.

Pomare and Hīroa, already in anguish of the potential harm of ‘tohungaism,’ were equally alarmed by the social circumstance of Māori living in cold shacks without such things as sewerage and wastewater infrastructure. These ‘settlements’ were possibly not dissimilar in principle to the refugee camps of today, where multitudes of people are given no option but to make do on pieces of land that had not been their historic home. It was not explicit that Māori were forced onto land with sanitary infrastructure so different from what they had historically known and promulgated (Dann, 2010). Prior to this displacement, Captain Cook had been impressed with the environmental consideration given to sewerage and rubbish disposal. Upon observing village life through his early interactions, he was led to remark that the sanitation of Māori villages was in a far higher state of efficiency than many of the cities of Europe (Hīroa, 1910).

Pomare and Hīroa were well-versed in public health promotion and, given this was the pre-antibiotic, pre-public immunisation era, their focus was on substandard housing. Between 1905 and 1909, they were instrumental in ensuring that 1,256 houses were demolished and

2,103 new ones built, along with 1,003 ‘privies’ (Ferguson, 1995). Although a step forward, only half of the new houses were serviced with water, drainage, or toilets, and these new dwellings were not built to the same standards insisted upon for the new suburban European dwellers. Further, all the improvements were paid for by Māori without resourcing to assist all those in need.

Laying out the inequitable circumstances of the TSA demonstrates the unequal treatment of Māori worldview, with that disadvantage continuing to this day. An essential dimension of Māori culture was suppressed along with the associated leadership and the access to Māori ‘medicines’ or rongoā rākau becoming invalidated in the process. At the multiple wānanga, I have facilitated over the years, the question is always asked as to why rongoā rākau is not integrated into mainstream medicine. Ironically indigenous therapies, particularly plant-based therapies, have contributed immensely to the pool of Western medicines and continue to be a source of discovery (Yuan, 2016). It is also common for people to discuss mainstream medications as ‘chemicals’ or ‘poisons’ and ask about their manufacture. It is hard to believe there would be this mistrust had there been equal weighting, and therefore equity had the TSA never been passed. The United Nations Assembly has published a position statement on Indigenous Peoples and traditional healing in more recent times (United Nations, 2008). NZ was slow to sign but has done so along with members from 147 nations. The statement includes the following (p. 18):

“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...States shall take the necessary steps with a view to achieving the full realisation of this right progressively.”

The Crown overlooked the inequity in this situation, and they did not act to describe and address it.

2.7.3 Cultural Safety, Cultural Congruence

As presented in Section 1.5, cultural safety is foremost at a health interaction's commencement. Cultural safety demands a practitioner to critically self-reflect in delivering safe and appropriate care as defined by the person and/or community (Curtis et al., 2019). If there is no cultural safety, there is only a clinical lens, which may be appropriate in a Western paradigm but not so where there are differences in health perspective. If cultural safety is not

central to a health engagement, an inequitable situation is perpetuated. Māori nurse and pioneering advocate for cultural safety in health provision, Dr Irihapeti Ramsden, described cultural safety as being about power-sharing and acknowledging the barriers to clinical efficacy that arise from a power imbalance between clinicians and the public (Ramsden, 2001). Cultural safety balances out the reliance on the clinical side and can be the rate-limiting step to achieving the best possible health outcome. Cultural safety must also include the organisation and system itself. This barrier or thread of cultural congruence and safety is perhaps a subsidiary of both the racism and equity threads, as there is a cross-over between all threads.

Te Rangi Hīroa (1910, p. 114) discussed the concepts of cultural competence and safety, albeit those terms were not in use then. He wrote that European practitioners should receive specific training so that they “may yet understand their (Māori) patients and treat them as individual cases not as automatons.”

Te Rangi Hīroa also promoted the value of ethnic congruence by describing the shared ethnicity of medical officers and communities. He stated, “in knowing the language, customs and ideas of the Maoris they [Māori medical officers] were in a better position to teach the people and institute reform than Europeans would have been” (Hīroa, 1910, pp. 112–113).

Other prominent people at the time of the TSA also looked to ethnic congruence to enable a deeper understanding of worldviews. As mentioned above, Ngata used his parliamentary speech on the TSA to lobby for health service resourcing. He asserted simply that Māori trusted Māori, so more Māori doctors and Māori nurses were required. Maui Pomare, who campaigned vigorously in favour of the TSA, was equally strong in his resolve that there was a significant need “of our own doctors to heal the sick” (Dow, 1999). He believed that ethnic congruence was integral.

In attempting to shed more light on the advocacy to realise cultural safety either through cultural competence programmes or through an investment in cultural congruence, it is pertinent to consider the journey of Māori nursing.

From the late 1880s, many agreed that the concept of Māori ‘nursing’ could be an essential contribution to Māori health outcomes. This approach crosses clearly into the domain of racism, well articulated in a publication by Ngāti Kahungunu nurse Margaret Holdaway (Holdaway, 1993). She presents a background steeped in a superiority view, whereby the Crown envisaged Māori nurses only helpful as ‘efficient preachers of the gospel of health’

and not as nurses. Young Māori women were deemed unlikely to have the intelligence necessary to be a nurse and, therefore, would be limited to assisting Pākehā nurses so long as they did not get in the way.

A scheme offering annual scholarships to two young Māori women was unsuccessful because the entry criteria, training, and opportunities post-qualification did not recognise different worldviews. Te Rangi Hīroa was engaged in 1905 to help design a course specific to Māori nurses, given issues like language and perspective were chasms apart. Despite this, the view that Māori nurses were inferior in knowledge to their non-Māori counterparts persisted, and funding for their services never met parity with the situation continuing today (Waitangi Tribunal, 2019). Their claim includes the absence of pay parity and cultural safety issues with their non-Māori counterparts.

Despite lobbying for the provision of cultural congruence and cultural safety at the time of the implementation of the TSA, this went unheeded, and the effects continue to play out today, impacting medicines optimisation. Modern-day regulatory authorities are charged with ensuring the cultural safety of practitioners, but as mentioned in Section 1.5, they do not have robust mechanisms to monitor every practitioner. In terms of cultural congruence, no health profession in NZ has population parity with non-Māori. Pharmacists are among the least represented, with 1.5% of pharmacists identifying as Māori, compared with a total Māori population of 17% (Pharmacy Council of New Zealand, 2021).

2.8 Summary

This chapter outlines Indigenous theory, which frames and informs this entire thesis. This methodology is the rubric by which I approach my practice as well as this thesis.

This chapter also provides evidence of Māori well-being prior to the colonisation of NZ. The concept of partnership was hoped for by Māori, premised on Indigenous rights and in the constitution-like principles underpinning Te Tiriti.

Central to the attempted deconstruction of traditional healing was the TSA, which contests the choices Māori make and how we think about and access the Western health system. To consider health as a separate aspect for Māori well-being is a reframing of the aforementioned collective and holistic perspective necessary to respond and recreate balance for that person in their collective context.

On the one hand, it is disingenuous to report the TSA as having “outlawed Māori traditional healers and religion” as some historians have quoted (Consedine, 2012, p. 70). The Law itself did not technically do that. That prominent Māori supported the legislation is unequivocal. Other prominent Māori leaders have also written it is an inaccurate picture to say Māori traditional healing became illegal (Ramsden, 2001). Regardless of the technicality, Māori felt this was the case.

If the intent of the TSA was humanitarian in nature, it is challenging to understand why the Act was bestowed a title explicit in its aim of suppressing traditional healing and traditional practice. It is hard to accept that those prominent Māori who supported this legislation envisaged the outcome as it has been.

The decisions that whānau make in accessing health services in NZ today are not dislocated from the complexity of the TSA. In my engagement with whānau across many settings, a significant distrust of the current health system is expressed through the impact of the TSA. The modern reality for whānau choosing to enter the health system is that their health perspective can still be impaired by the Western system competing with traditional healing and formulating legislation which led to its demise.

What is apparent is that a true partnership in terms of viewing the other as equal has never been realised. Not only is this an injustice, but it is also sad to consider that society has been denied the opportunity to benefit from an alternative perspective. The research question of this thesis is based on the contemporary context of a Western-dominated health system. This context has a clear priority for ‘closing the gap’ and eliminating inequities. These priorities endeavour to disrupt health and bring change that represents quality health outcomes for all. However, the reality for Māori health has continued to be represented with inequitable outcomes. The overwhelming emphasis on system change has been about the system leading the change, not about a genuine partnership with communities and patients. Te Rangi Hīroa stated, “the greatest factor which retards the progress of the Māori in health matters is the influence of the past.” (Hīroa, 1910, p. 102). For Māori, rangatiratanga cannot be compartmentalised as it is today into either health, education, social services, or justice structures – it crosses all of these.

Chapter 3 Initiatives Involving More Than One Component to Address Medicines Optimisation: A Scoping Review

3.1 Introduction

The introduction to this PhD presented the question this thesis aims to answer, specifically, how can gout medication therapy for Māori be optimised. Chapter 1 asserts that medicines are an important health intervention with the aim of administration to improve health outcomes for people. It argues that attaining medicines optimisation requires a multi-level approach and must include patient access, preference, priorities, values, experiences, culture, and beliefs. This is particularly true where health inequity exists and where people have been less likely to engage in a health system that has not been shaped to their needs.

Chapter 2 presents a view of Māori experiences, culture, values, and beliefs alongside the methodology underpinning this thesis.

This chapter presents a scoping review that helped inform the development of the multi-level care intervention at PMC. This review was conducted early in this PhD journey; despite its limitations, it fed into the interventions and the methods for addressing the research question (Box 2). It is, therefore, accurate to report this as conducted.

This review was undertaken with the assistance of the university librarian.

Box 2 Review Context

This search is written as it occurred at the time, with an update of results. Provided is an accurate picture of the information used as background for developing the multilevel care initiative. The limitations of the review became more apparent as time progressed; however, this learning was in part used to develop the initiative presented in the following chapter.

The chapter concludes with an update to the scoping review.

3.2 Scoping Review

Initiatives involving more than one component to address medicines optimisation: a scoping review.

3.2.1 Background

Chapter 1 discussed the definition of medicines optimisation, with ‘optimal’ being the keyword to describe the best possible. I have further presented the aim of optimal use of medicines, whereby decreased morbidity or mortality from illness is achieved and drug-related morbidity or mortality is mitigated under an umbrella of person-owned/whānau-owned care (Te Karu et al., 2018).

At a simplistic level, to attain a state where medicines are used for the greatest possible benefit for an individual, I assert minimum requirements that:

- safe and effective medicines must be available to prescribe
- people feel/are able to access a prescriber
- the prescriber uses up-to-date, evidence-based clinical knowledge alongside cultural competence/cultural safety
- people are involved in the decision-making process as to whether a medicine is prescribed, recognising the multitude of factors involved in the interaction
- the medicine is accessed, provided, and administered as prescribed, recognising that people need to be enabled/empowered to do so
- the medicine is monitored and reviewed according to continued appropriateness.

As outlined in Chapter 1, the current and historical situation in NZ is that there are multiple steps to accessing prescription medicines. Medicines are almost always provided or ‘dispensed’ from pharmacies, which means that more than one professional discipline is involved in the medicines transaction. Therefore, it stands to reason that the fundamental tenet and concept of medicines optimisation is a whole-of-system approach, requiring proactivity at multiple levels. It may, however, be inaccurate to term medicines optimisation as a ‘system’ because systematic means “interacting units that function as a unified whole” (Hennessy, 2000, p. 543). Rather ‘medicines use environment’ is apt because medicines use has not been strategised as systematic in totality across any country (Hennessy, 2000).

The recognition of needing a joined-up strategy or mechanisms to deliver optimal medicines use is not new. In 1986, the WHO endorsed the ‘Revised Drug Strategy’ which called on governments to implement a national medicinal drug policy (World Health Organization, 1986). Primarily, this was aimed at countries where medicines access and quality is exceptionally poor. The premise of needing a more cost-effective and robust method of medicines approach has led to a progression of activity in this arena, with various countries

adopting their own policies with extensions to include appropriate and quality use of medicines (World Health Organization, 2001). By 1999, 107 countries had introduced or were introducing a national medicines policy to enable the best possible outcomes from medicines. The need for optimal use of medicines was even more apparent with the availability of more medicines and prescribing according to multiple guidelines. The UK's NICE published a guideline entitled *Medicines optimisation – the safe and effective use of medicines strategies* (National Institute for Health and Care Excellence, 2015). The drive for this document was the growing concern about polypharmacy in multimorbid populations. The UK national health service reported that 58% of people over 60 years diagnosed with at least one chronic condition in England were prescribed an average of 13 prescription items per year in 2003, increasing to an average of 19 items in 2013 (National Institute for Health and Care Excellence, 2015). The guideline aims to promote principles required to optimise medicines, including ensuring a patient-centred model, evidenced-based prescribing, and consideration of polypharmacy alongside a continual review process.

Following this guideline, the UK has been notably active in publishing on medicines optimisation and progressing associated initiatives. While the framework promotes integrated and multidisciplinary care, the initiatives have been weighted toward pharmacist involvement in medicines reconciliation, adherence, prescribing advice, and safety reporting (National Institute for Health and Care Excellence, 2015; Avery et al., 2012). Single-component initiatives have been plentiful and have had varying results (Alldred et al., 2016; Huiskes et al., 2017). A systematic review also concluded interventions for adherence should be implemented concurrently at the patient, provider, and institutional levels with continued quality improvement analysis to achieve optimal results (Petrilla et al., 2005).

However, it was unknown how much evidence existed for multicomponent initiatives, and it was important to investigate them in planning for the initiative at PMC. This thesis argues that, without system-wide consideration, there is no surety of achieving medicines optimisation and that, by default, this must address more than one step in the transaction. Therefore, a scoping review was undertaken with the assistance of a university librarian to ascertain a baseline of optimal medicines management interventions previously trialled. Arksey and O'Malley (2005) identify reasons for a scoping review, including:

- to examine the extent, range, and nature of available research on a specific topic or question

- to summarise and disseminate research findings across a body of research evidence that may be heterogeneous and/or complex
- to identify research gaps in the literature.

Scoping reviews are increasingly used, particularly by health workers and researchers to explore the breadth and extent of evidence and summarise evidence irrespective of study design (Tricco et al., 2016).

The specific aim of this review was to identify initiatives that used more than one intervention component concurrently to address medicines optimisation (Box 3).

Box 3 Study Question

What initiatives have been trialled that involve more than one component to address medicines optimisation?

3.2.2 Methods

The report follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses for scoping reviews (Tricco et al., 2018). The protocol was not registered.

Eligible studies: All study designs were eligible, including qualitative, quantitative, protocol, and methods papers. Opinion pieces were not eligible. Search dates were from the year 2000 until January 1, 2017. Before 2000, computers were not routinely used in dispensing or prescribing medicines. This was considered a large enough timeframe; an earlier start date risked capturing a disproportionate number of studies on the implementation of computer systems. Eligible studies were also limited to those published in English and involving humans.

Information sources: The search engine recommended by the university librarian was the Scopus database because it is the largest database of peer-reviewed literature and covers MEDLINE, Embase, and Compendex and includes scientific journals, books, and conference proceedings in the fields of science, technology, medicine, social sciences, arts, and humanities (Burnham, 2006).

Search: Given that the major health conditions causing death for Māori and other Indigenous populations are long-term conditions, and this thesis intends to focus on the overwhelming burden of non-communicable diseases, the search was limited to studies of one or more of cardiovascular disease, respiratory disease, gout, or diabetes.

Inclusion criteria were as follows:

- studies involving more than one health profession aimed at optimal medicines management OR
- studies involving more than one initiative aimed at optimal medicines management AND
- studies aimed at optimal medicines management of cardiovascular disease, respiratory disease, gout, and/or diabetes.

Exclusion criteria were any of the following:

- studies involving complementary and alternative medicines
- interventions delivered in secondary care only.

The Scopus database works on keywords rather than medical subject headings. Google was searched for synonyms of or more commonly known terms for keywords. The following combinations were then entered into the Scopus database:

(medicine OR medication OR drug)

AND (management OR use OR adherence)

AND ('evidence based') OR (optimal) OR (best practice)

AND (prescribing OR prescription)

AND (doctor) OR (pharmacist) OR (nurse)

AND (cardiovascular) OR (heart) OR (respiratory) OR (asthma) OR (gout) OR (chronic obstructive pulmonary) OR (COPD) OR (diabetes).

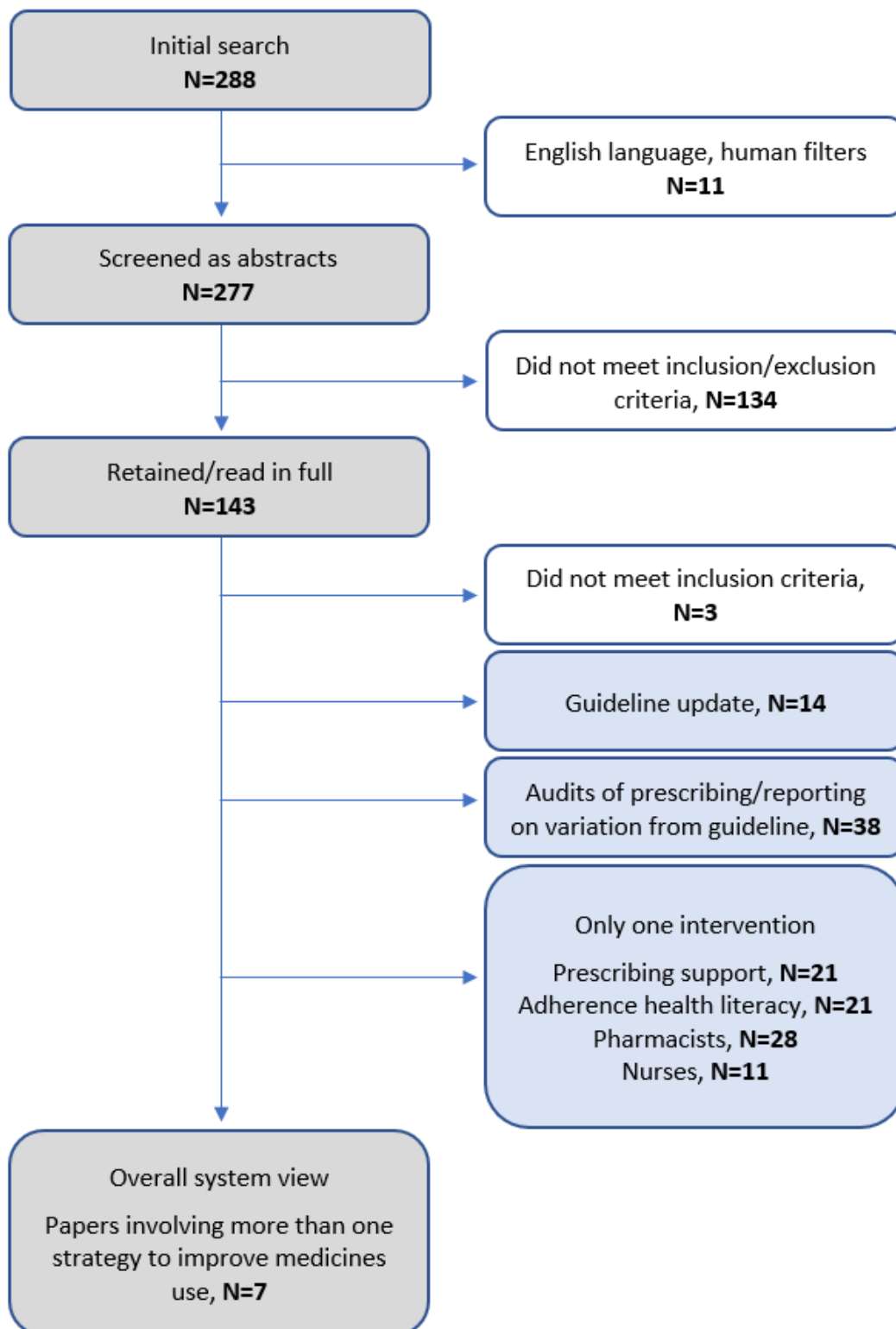
In addition, the title and abstracts of studies flagged by Scopus as 'cited by', 'similar to,' and 'related documents' of the studies found on the formal search were themselves screened. The full article was read and included if it fit the inclusion and exclusion criteria.

Attempts were made to contact by email the authors of all studies included in the final selection.

3.2.3 Results

The initial search identified 277 published papers after filtering, seven of which were included in the final selection (see Figure 1). Many of the initially excluded papers did not focus on non-communicable diseases and mentioned antimicrobial stewardship.

Figure 1 Flow Diagram for Search Review Process



Seven papers were retrieved that involved investigation into more than one mechanism to achieve optimal medicines management (Table 1)

Table 1 Resultant Papers Included in the Scoping Review

| Author | Intervention | Participants | Professions involved | Criteria met |
|-------------------------|---|--|--|--|
| Mangla et al., 2018 | Individualised prescribing support, audit feedback to prescribers Tailored education, support to patients and empowerment to self-manage | Previously hospitalised patients with HF _r EF with an annual income <\$US30,000 living in Chicago, USA | Family physicians, cardiologists, nurses, community health workers, community members, 'behavioural scientists' | Protocol for prospective cluster trial. Cohort demographics described; trial results yet to be published. |
| Hayek et al., 2016 | DST to calculate CVD risk prompting GPs to tailor advice Communication tool to discuss options with patients Polypill with reduced co-payment fee. Pharmacists to monitor adherence and provide support Electronic communication between pharmacist/GP practice | Aboriginal and Torres Strait Islander people aged ≥35 years and all others aged ≥45 years (no upper age limit) who had attended GP practice three or more times in the previous 24-month period and at least once in the previous 6-month period | GPs and pharmacists | Protocol for open-label, pragmatic, cluster RCT. Results of pilot published in 2021 concluded no benefit (Webster et al., 2021) |
| Williamson et al., 2012 | Data extraction and reporting tool Group education sessions with GPs Individual trained facilitator support | Adult patients with a diagnosis of hypertension and suboptimal control of BP. Adult patients with CHF using an ACEI below the recommended | Physicians, GPs, pharmacists, consumers, and policy makers. Professional background of facilitators unclear. Practice staff, | Protocol for open-label, pragmatic, cluster RCT. No results yet. 12-month trial commenced in 2009. |

| | | | | |
|---------------------|--|---|--|---|
| | | dose or a drug that may exacerbate CHF | including nurses, and practice manager | |
| Murphy et al., 2005 | <p>Medication training for GPs and practice nurses</p> <p>Behaviour change training for GPs and practice nurses</p> <p>Support for practices from a trial nurse and through newsletters</p> <p>Tailored patient care plans, including patient booklets</p> <p>Four monthly consults over 2 years</p> | <p>Patients with existing CVD, excluding those with significant mental or physical illness likely to impair capacity to change lifestyle behaviour or to assimilate new information</p> | Nurses and GPs | <p>Protocol for cluster RCT, with practice-level randomisation to intervention and control groups. Results at 18 months showed decreased hospitalisation in intervention group but no benefit at 6-year follow-up (Murphy, 2015; Murphy, 2009).</p> |
| Maron et al., 2010 | <p>Each patient assigned a nurse case manager to manage lifestyle and medication matters</p> <p>Intensive medication therapy</p> <p>Free medication</p> | <p>Symptomatic CAD indication for PCI. Canadian Cardiovascular Society class I to III angina and significant ST-T changes.</p> <p>Exclusion of unstable heart disease and heart failure</p> | Nurses and GPs | <p>Randomised open-label interventional single-group study. Intervention therapy was noninferior to surgical revascularization</p> |
| Shegog et al., 2004 | <p>DST for clinicians. Tailored prompts for prescribers</p> <p>Tailored communication package for patients enhanced</p> | <p>Undefined patients with asthma</p> | Doctors and nurses | <p>Feasibility study</p> <p>Clinician-reported clinical reasoning and communication with patients improved.</p> |

| | | | | |
|----------------------|---|---|---|---|
| | adherence by patients | | | Consultation time increased. No clinical efficacy results available |
| Schulke et al., 2007 | A variety of quality improvement projects addressing medication use | People enrolled with 'quality improvement organisations' – private organisations with public and private customers, including Medicare patients | Variance within projects, including doctors, nurses and pharmacists | Descriptive report with no results available |

ACEI, angiotensin-converting enzyme inhibitor; BP, blood pressure; CAD, coronary artery disease; CHF, congestive heart failure; CVD, cardiovascular disease; DST, decision-support tool; GP, general practitioner; HFREF, heart failure with reduced ejection fraction; PCI, percutaneous coronary intervention; RCT, randomised controlled trial.

The Congestive Heart Failure Adherence Redesign Trial (CHART) is an equity-based trial targeting disadvantaged people with heart failure with reduced ejection fraction (Mangla et al., 2018). It is a multilevel trial from Chicago enrolling predominantly African-American people. It builds upon the outcomes of the HART (Calvin et al., 2012) and CHART P (Mangla et al., 2014) studies. (HART was an audit study investigating adherence and retention to guidelines, and CHART P was the theoretical feasibility thinking to inform CHART.) These studies proposed that optimal medicines use in heart failure requires multilevel input from clinicians and patients. The authors stated that input must extend beyond the four walls of a medical centre, with the CHART intervention involving community health workers visiting people in their homes and phoning them regularly over 30 months. In addition, a multidisciplinary team consisting of a 'behavioural scientist,' a cardiologist, a health educator, and a community representative led the development of resources. Clinicians also received specific training on the American College of Cardiology Foundation/American Heart Association Guidelines for Heart Failure and patient-specific support from cardiologists. The corresponding author advised (Dr Rami Doukky, personal communication, January 2018) that data were being "analysed with the intent to present the data at the American Heart Association 2018 Conference." It was intimated that all results were embargoed until formal dissemination. A search of the conference proceedings for this

author and co-authors at the time found no mention of the study. Follow-ups in January 2020 and November 2021 went unanswered.

Similarly, a study protocol published in 2016 by Australian researchers described their experience of limited gain from addressing one component of medicines management to outline an intent to investigate the collaboration of multiple mechanisms (Hayek et al., 2016). Hayek et al. proposed to use a previously studied multifaceted tool called *HealthTracker* (Peiris et al., 2015). This trial (INTEGRATE) prompted prescribers to consider evidence-based treatment for cardiovascular disease during a health interaction with data extraction from electronic records to determine cardiovascular risk. A ‘risk communication tool’ then guided the prescriber to engage with the person around variables of risk and the benefits of management, including non-pharmacological treatment and lifestyle advice. The *HealthTracker* tool advised a treatment regimen corresponding to one of eight possible combinations of a polypill. The polypill was an encapsulated product containing a possibility of four medicines, but the co-payment charged to the patient was for one medication. The final step in this collaboration was a structured interaction program with a community pharmacist to enhance adherence. *HealthTracker* enabled a secure communication mechanism between the community pharmacist and the GP and provided regular audit information to the GP.

Outcome measures were the proportion of patients at high cardiovascular disease (CVD) risk who were not treated (‘under-treated’) but who achieved recommended target blood pressure (BP) and low-density lipoprotein cholesterol (LDL-C) levels at the study end. This research concluded in early 2019, and results were to be disseminated thereafter. It is important to note that we did not have this outcome information when developing the PMC initiative.

In addition to email contact, I met one study author (IK) in person in 2017, who confirmed that, at that stage, there were no results to disseminate. An update was published in 2021 wherein the authors concluded no real benefit, “despite evidence for the efficacy of its individual components, the INTEGRATE intervention was not broadly implemented and did not improve CVD risk management in participating Australian general practice.” (Webster et al., 2021, p. 425) The decision-support tool (DST) was used for only 10.7% of patients (of which none were Aboriginal or Torres Strait Islanders), so the opportunity for improving CVD management was minimal. Polypills were prescribed for less than 2% of eligible patients, and pharmacist adherence support was used even less often. Discussion with the lead author (Dr Ruth Webster, personal communication, December 2021) revealed anecdotal

evidence that one practice was a clear standout. That practice predominantly served Pasifika patients and was run by a Pasifika GP. There had been no individual investigation of this practice, but the author felt the intervention would have demonstrated value in this practice if data had been evaluated separately. This raises the possibility of different drivers for practices to take up interventions.

The Prescribing Data in General Practice Demonstration (PDGPD) project is a further research protocol from Australia (Williamson et al., 2012). The study began in 2009 in 166 general practices across Australia that were randomly allocated to receive ‘prescribing indicator reports’ on managing hypertension and heart failure with feedback at the individual provider level and in small group discussions. The clinical indicators were developed by medical experts, GPs, pharmacists, consumers, and policymakers. The initial engagements at the practice involved the nurses and practice manager over 12 months. Unfortunately, the results are unpublished. Contact with the corresponding author in 2017 indicated that the research team were hoping to publish in the ‘near future.’ Follow up in 2020 and early 2021 went unanswered. In November 2021, one of the researchers (JE) confirmed that no results had been published and that the original research team was no longer working together. However, he provided some information, including that 303 GPs had taken part in the study, 185 of whom had been surveyed. The survey indicated that 94% of GPs surveyed reported they were likely to participate in similar quality improvement activities. They felt more confident managing these health conditions, and as a result, the clinical discussions with patients were believed to be better approached. Time was deemed to be a barrier for the GPs to spend on the project. A further survey with the initiative’s facilitators failed to adequately cover barriers encountered in the reality of general practice.

An Irish study – the secondary prevention of heart disease in general practice (SPHERE trial) also involved a multifaceted approach (Murphy et al., 2005). This trial began in 2004/2005 and enrolled 903 people with established coronary heart disease. The intervention consisted of tailored practice plans, regular newsletters, two training sessions for practitioners in medication prescribing and behavioural change, tailored patient care plans with resources, and patient recall for consultations with the GP or practice nurse every 4 months. At the completion of the study, practice and mortality data were unavailable for 207 and 17 people, respectively. The 18-month follow-up indicated that the number of patients admitted to hospital significantly decreased in the intervention group compared with the control group 25.8% vs 34.0%; odds ratio [OR] 1.56 (95% confidence interval [CI] 1.53–2.60; P=0.03)

(Murphy et al., 2009). The authors recognised the positive effect on hospitalisation but stated that “no other clinical benefits were shown, possibly because of a ceiling effect related to improved management of the disease.” Data on the remaining 696 participants was further investigated 6 years later (Murphy et al., 2015). This time, there were no significant findings for mortality, hospitalisation, and achieving target values of clinical variables. The authors recognised the possibility of cross-pollination once the trial had concluded, i.e., it is possible the intervention and control practitioners and the practice treated all people the same after the study had finished. Also, participants and practitioners did not necessarily remain affiliated with the original practice, making it hard to draw any robust conclusions.

The Clinical Outcomes Utilizing Revascularization and Aggressive Drug Evaluation (COURAGE) trial was based in the USA and was designed to investigate lifestyle and intensive pharmacological management with or without percutaneous coronary intervention (PCI) (Maron et al., 2010). The study was a multicentre study in US Veterans Affairs (VA), non-VA, and Canadian centres. It involved 2,287 participants and is included in the results because it spanned both primary and secondary care. Participants received multiple interventions facilitated by a specifically trained nurse case manager. This included comprehensive behavioural counselling focusing on lifestyle and medication adherence. GPs were responsible for prescribing medicines to reach individualised targets (Boden et al., 2006). Medicines were provided without charge, a significant deviation from usual practice in the USA, as was the large contribution of time by nurses and doctors under their current payment model. This led to criticism that the intervention was not achievable/sustainable in ‘real life’ (Diamond & Kaul, 2007). The authors nevertheless reported that intensive lifestyle management alongside targeted pharmacologic therapy was non-inferior to surgical revascularisation in stable coronary artery disease.

A real-time DST using asthma guidelines to prompt physicians through an engagement process was also included (Shegog et al., 2006). *The Stop Asthma Clinical System* involved a complex, multilayered knowledge base using prescription and patient details to determine asthma severity and subsequently considered the patient’s specific requirements to tailor advice and interventions to enhance adherence and prescribing according to guidelines. Essentially, the study aimed to help physicians identify and implement behavioural change strategies for the patient to self-manage. The tool included context-specific behavioural prompts for the clinician, e.g., when to sit back and actively listen and when to praise, encourage, or inform. The researchers stated that optimal treatment required multilevel

interventions and multiple interactions. Eight clinicians, one with nursing and seven with medical backgrounds, showed self-reported improved clinical reasoning and improved communication with patients, but consultation time increased. Liaison with the corresponding author (Dr Ross Shegog, personal communication, May 2017) revealed that *The Stop Asthma Clinical System* was not maintained mainly because of the departure of the two principal investigators from the clinic in the pilot. There was no continued study to determine the clinical efficacy and no information on the participants' demographics.

The Medicare Quality Improvement Organisations in the USA reported various activities intended to improve prescribing and use of medicines (Schulke et al., 2007). A list of interventions in each state detailed the intended aim, but no outcomes were reported. The interventions varied considerably between states, with many focused on inappropriate prescribing or deviation from guideline prescribing. Many employed methods already mentioned, e.g., DSTs or educational outreach. However, they looked to use more than one intervention in each project, e.g., a DST in conjunction with nurse or pharmacist follow-up and education. Contact was attempted with all 34 of the corresponding authors of individual projects both via email addresses provided in the papers and, where possible, via LinkedIn profiles. No responses were received. Contact was also made with the author responsible for the overall coordination of presenting information on the detail and scope of projects. In August 2017, an explanation for nonresponse was given: "people had moved on in the wake of substantial Quality Improvement Organisation program revision by the U.S. Medicare Agency – The Centers for Medicare & Medicaid Services" (David Schulke, personal communication, August 2017).

3.2.4 Discussion

This literature review revealed only seven papers that included more than one factor designed to address medicines optimisation. Of these, four were protocols, one a feasibility study, and one a descriptive report. There were no robust associated health outcome data.

From the excluded papers, our findings were that most papers focused on only one aspect of the overarching process of medicines optimisation instead of an integrated approach.

Although it is helpful to investigate single components of the multilayered process, there is no guarantee of overall improvement if a systems approach is not considered. For example, if a prescriber is prompted to consider best practice at the point of prescribing, but the person receiving the medicine cannot access it or is not provided with the tools to understand how to

administer the medication, optimisation cannot occur. Regardless, the INTEGRATE study demonstrated that it is not guaranteed that multiple components will be successful without sufficient understanding and support (Hayek et al., 2016). These researchers did not follow up on why the aspired success was not achieved. Reasons may well be multifactorial, e.g., should there have been associated payment to the GPs to use *HealthTracker*. Why did some practices see value in it and others did not? Perhaps they believed they were managing CVD risk well already, that they were simply too busy, or that others were more invested in their communities to strive for better.

3.2.5 Excluded Papers

Of the 143 retrieved papers, most were excluded as they addressed only one component of medicines management. These papers are described in groups according to the intervention they aimed to investigate.

Variance from Best Practice

The biggest number of excluded papers focused on what was deemed suboptimal management of morbidity and deviance from best practice. Specifically, 38 papers focused on what was considered ‘variance’ from evidence-based medicine, and some included audit information (Borges et al., 2012; Borgstedt et al., 2009; Buono et al., 2013; Selak et al., 2009). Some used surveys to propose a simulated patient and investigated the proposed treatment variance amongst practitioners (Braido et al., 2010; Peterson et al., 2002; Swennen et al., 2013). Some studies detailed gaps in perceptions of management between patients and physicians and identified barriers to optimal management and why variation can occur in some instances (Bagnall et al., 2010; Desalu et al., 2013).

Audit data demonstrated a technical or transactional view only. This is conceivably easier to investigate but does not allow for patient input. The end-user or whānau perspective of the medicines and what is valuable or ‘best practice’ to them is not incorporated. Data are analysed according to adherence to guideline criteria only, without the ‘value’ part of the interaction, including patient preferences and belief systems.

Pharmacist Intervention

Pharmacists proved prominent in models of care, which included the various scopes of practice of pharmacists. For example, community pharmacists showed value in increasing adherence and improving inhaler technique for patients with asthma or COPD (Ottenbros et

al., 2014), whereas ‘clinical’ pharmacists with added qualifications aided improved ‘prescribing practice’ of GPs and overall management in the community (Hill et al., 2014; Lowrie et al., 2014). A further extended role of pharmacists with prescribing rights demonstrated increased attainment of guideline-adherent ‘optimal doses’ of angiotensin-converting enzyme inhibitors/angiotensin-receptor blockers and β -blockers compared with cardiologists in outpatient nurse-run clinics (Martinez et al., 2013). However, these papers did not investigate clinical outcomes.

Adherence/Health Literacy

Given the estimate that 90% of Americans do not receive health information in a way they can use or understand (Kutner et al., 2006; Nielsen-Bohlman et al., 2004; Rudd et al., 2007), it is perhaps unsurprising that mechanisms to address adherence health literacy featured. Some papers looked specifically at communication from the health provider with messages tailored to suit the audience (Lewis et al., 2012; Noureldin et al., 2012). Others looked at mechanical ways to address adherence, e.g., fixed-dose combination medicines or ‘polypills’ to decrease complexity and increase adherence (Patel et al., 2015). A critical review of single modality ways to improve optimal medicines use reported on 79 different interventions (Petrilla et al., 2005). The authors reported merit in decreasing pill burden, unit-dose packaging, educational counselling by telephone, case management by pharmacists, treatment in pharmacist- or nurse-operated disease management clinics, mailed refill reminders, and self-monitoring. However, they projected that personalised, patient-focused programs involving frequent contact with health professionals or a combination of interventions would be most effective at improving adherence to medicines.

Also included in this list was a paper investigating mobile health technology (Logan, 2013). It focused on hypertensive management and relied on participants to monitor their blood pressure and self-manage with guidance. Favourable outcomes were demonstrated, with improved blood pressure control.

Patient nonadherence to a medicines regimen was often discussed, yet the nonadherence of clinicians to consider evidence-based medicine and present it in a manner that empowers the patient to make informed decisions on how to self-manage was not discussed.

Prescribing

Investigating methods to enhance prescribing according to best practice guidelines or suggestions on how to improve prescribing included involving a greater number of doctors in

the guideline development (Thilly et al., 2003), a medication assessment tool providing a pathway for people with coronary artery disease (Garcia et al., 2011), a ‘screening tool to alert to right treatment’ (START) (Barry et al., 2007), computer decision support (Eccles et al., 2002), and targeted education to prescribers (Zillich et al., 2008).

Not all studies reported positive results regarding enhanced prescribing adherence to guidelines. Lu et al. (2008) undertook a systematic review of cost-effective interventions to improve the quality of medication prescription in managed care facilities in the USA. They evaluated 51 studies and found initiatives such as internet-based feedback and the dissemination of educational materials alone were ineffective, but that one-to-one educational outreach or ‘academic detailing’ and computerised clinical decision support led to positive changes in prescribing patterns. In contrast, group education using didactic or problem-based approaches and audit feedback had mixed results, with overall less efficacy than one-on-one education. Tiered formularies with different levels of patient co-payment did lead to changes in prescribing. In the NZ context, there is an overarching parallel: if Pharmac does not subsidise medicines, they are less likely to be prescribed. Also, the special authority system under Pharmac usually means drugs are prescribed in a tiered manner.

A similar earlier review on optimising medicines prescribing in managed care in the USA (Czubak et al., 2004) discussed almost identical findings. It recommended more research on initiatives involving more than one intervention. The rationale was that it is reasonable to suggest that implementing more than one intervention will have enhanced efficacy. Others advocated the importance of communication and forming partnerships as a key modality to enable better prescribing (Aronson, 2006; Partridge, 2003).

Guideline Development

Other studies investigated changes for best practice by adherence to guidelines, including three studies recommending changes to current guidelines (Cazzola et al., 2012; Kirby, 2004; Lu et al., 2014).

However, the premise of using guidelines as a barometer to determine ‘the gold standard’ of medicinal treatment is potentially flawed. Problems with using this method of assessment could be that:

- the sheer numbers of guidelines available and their variations make for inconsistent treatment

- the authors of guidelines are sometimes not sufficiently inclusive of those charged with implementing them
- the authors of guidelines are often not inclusive of patient involvement
- the level of evidence can vary widely.

Without overstating this, recognising it is incumbent on the user to assess guideline value and applicability to their own context, these points are worthy of further definition and investigation but are outside the scope of this paper.

Nurse Intervention

Eleven papers looked specifically at nurses' assistance to ensure increased adherence to guideline-based management (Andersen et al., 2005; Berra et al., 2011; Carey & Courtenay, 2008; Courtenay & Carey, 2008; Delaronde et al., 2005; Güder et al., 2015; Halterman et al., 2011; Health Quality Ontario, 2013; Levie & Findlay, 2002; Ogedegbe et al., 2014; Radhakrishnan et al., 2014). Three of these evaluated heart failure clinics, with nurse input demonstrating improved guideline adherence (Andersen et al., 2005; Güder et al., 2015; Radhakrishnan et al., 2014). One paper focused on 'task shifting' among medical professionals to aid health outcomes in non-wealthy countries (Ogedegbe et al., 2014). They found that nurses tasked to prescribe with oversight and offer health advice was an effective mechanism.

3.2.6 Limitations

The biggest limitation of this study was the search terms employed, including limiting to one or more of cardiovascular disease, respiratory disease, gout, or diabetes. However, during the exclusion process and reading abstracts, no further studies identified an approach to medicines optimisation that included more than one component. In addition, the inclusion of clinician terms into the search strategy may have further limited the identification of studies. However, the rationale was based on needing clinician input in at least one of the layers. Searching for multicomponent initiatives was also limiting, demonstrated by the number of excluded papers. However, we were clear that focusing on improving one component of a medicines system, albeit contributory, cannot achieve optimal therapy without all cogs working synchronously. Lastly, the approach of using just one database may well have been limiting. A limited set of data may also mean medicines optimisation is so vast it is beyond the focus of a study.

3.2.7 Conclusion

International medicines policies acknowledge that optimal medicines management needs to be multidimensional, and from an equity perspective, researchers believe the approach must be multilevel.

Evidence for investigating one component of the overall picture is plentiful, e.g., DSTs at the point of prescribing or tools to explain efficacy versus harms of treatment (patient tools).

However, published evidence around developing an overarching system approach to optimal medicines management is lacking, as is published evidence describing outcomes for collaborated activities.

Optimal medicines management is defined and described in the published literature in various ways. Articles primarily focus on one part of the overarching picture or are written by a single scope of health professionals focused on their own contribution. Models of collaborative approaches as applied to overall medicines optimisation and subsequently analysed and reported are even more scarce.

The analysis of audit data according to guideline criteria adherence does not incorporate the value part of the interaction. The ‘values’ input that allows the end-user or whānau to make decisions on what is valuable to them is absent. It is also clear from the variation section that guidelines do not consider patient preferences or belief systems.

More work is required to understand the most efficient and appropriate methods for optimal medicines management.

3.3 Addendum

A rerun of this literature review up until 2022, using the same method, identified an additional 86 studies (a total of 363 compared with the 277 in the original review). Of these, a further six are included for review (Table 2).

Four were identified directly through the search (Diesveld et al., 2021; Fontil et al., 2018; Gulayin et al., 2019; Ramirez et al., 2020), and a further two were identified by looking at ‘cited by’ references (Fields et al., 2017; Schwalm et al., 2019).

Table 2 Additional Papers for Scoping Review Update

| Author | Intervention | Participants | Professions involved | Study |
|-----------------------|--|--|--|---|
| Diesveld et al., 2021 | <p>Development of drug–disease interaction recommendations by a multidisciplinary panel</p> <p>Implementation of clinical decision-making tools based on recommendations at the point of care</p> <p>Implementation of practice recommendations for drug–disease interactions at the point of care</p> | Any person for whom a potential drug–disease interaction occurs | Community, hospital, and clinical pharmacists; physicians, GPs, and internists | Descriptive study detailing the development and implementation of a drug–disease alert initiative |
| Ramirez et al., 2020 | <p>DST prompting GPs to prescribe renin-angiotensin agents</p> <p>Pharmacist input for medication reconciliation, therapy management, education to patients, and addressing cost-related issues</p> | Adults with hypertension, diabetes | GPs and clinical pharmacists | Quasi-experimental study. Primary outcome: likelihood of ACEI or ARB prescription |
| Gulayin et al., 2019 | <p>Intensive 2-day training delivered to medical staff</p> <p>Educational outreach visits</p> <p>Mobile health application installed on the physician’s smartphones to facilitate evidence-based and guideline-driven decision aids to improve patient management</p> | People aged 40–74 years with a history of CVD in whom statin medication was deemed appropriate | Cardiologists, internal medicine specialists, nurses, local clinicians, pharmacy staff | Cluster RCT Primary outcome was 12-month net change in LDL-C levels. Secondary outcomes were proportion of patients receiving statins, mean annual number of follow-up visits to a clinic, and patients’ |

| | | | | |
|----------------------|--|--|--|--|
| | <p>Web-based platform designed to send weekly SMS messages to promote healthy lifestyles and regular visits to the clinic and to improve medication adherence for study patients</p> <p>Pharmacy package including onsite training to pharmacist assistants on patient counselling on medication adherence; educational flyers</p> | | | stated level of treatment adherence |
| Fontil et al., 2018 | <p>Development of a patient registry to provide performance feedback and outreach to schedule patients for visits</p> <p>Medicine treatment intensification protocol</p> <p>BP measurement protocol</p> <p>BP visits led by nurses and pharmacist staff</p> | Low-income, racially diverse adults with suboptimal control of BP | Physicians, GPs, nurses, pharmacists | Pragmatic, observational study |
| Schwalm et al., 2019 | <p>Door-to-door household and community outreach screening at local events in public spaces</p> <p>Treatment of CVD risk factors by community health workers using algorithms and counselling programs</p> | Adults aged >50 years with hypertension in 30 urban and rural communities in Colombia and Malaysia | Community health workers, doctors, and support people for patients | <p>An open, community-based, cluster RCT</p> <p>Primary outcome: change in Framingham Risk Score 10-year CVD risk estimate at 12 months between intervention and</p> |

| | | | | |
|---------------------|--|---|---|---|
| | Free antihypertensive and statin medications recommended by community health workers and supervised by physicians Support from a family member or friend (treatment supporter) to improve adherence to medications and healthy behaviours | | | control participants |
| Fields et al., 2017 | Nurse educational intervention via a structured gout curriculum Pharmacist phone structured monthly follow-up Rheumatologist oversight | Adult patients with gout enrolled in the rheumatology service | Rheumatologists, nurses, pharmacists, social worker | Single-arm, pilot study Primary outcome measures: retention rate and programme evaluation. Secondary outcome measures: patient gout self-management knowledge, compliance, flare frequency, severity measures, and uric acid level |

ACEI, angiotensin-converting enzyme inhibitor; ARB, angiotensin-receptor blocker; BP, blood pressure; CVD, cardiovascular disease; DST, decision-support tool; GP, general practitioner; LDL-C, low-density lipoprotein cholesterol.

Diesveld et al. (2021) describe a national multidisciplinary approach to preventing drug-disease interactions in the Netherlands. An expert panel of 12 healthcare professionals (pharmacists of different scopes: community, hospital pharmacists, and pharmacists experienced in evidence-based medicine and clinical decision support, and physicians of different scopes, GPs, and internists) developed recommendations to manage drug-disease interactions for 57 diseases and conditions. The monthly updated recommendations are implemented in clinical decision-support systems, supporting both prescribers and dispensers

at the point of care and improving medication safety. In the Netherlands, pharmacies are generally a repository for all the medicines a person is dispensed, as people almost always use the same pharmacy. One example presented was a physician consulted for the replacement of metoclopramide in a patient with Parkinson's disease in whom there was a higher risk for QT prolongation. In consultation with the patient, the prescription was altered to domperidone. No information was provided on the clinical impact of the initiative, but the authors stated this could be adopted in other countries to contribute to safer medication use (Diesveld et al., 2021).

In another initiative, researchers at the University of California at Los Angeles Health developed a 'hard stop' DST to prevent clinicians from closing a patient's chart without responding to the alert (Ramirez et al., 2020). The alert was designed to prompt prescribers to prescribe renin-angiotensin agents for patients with comorbid hypertension and diabetes. Previous work from these researchers found that responses to the alerts increased more than tenfold (from 5.7% to 68.2%) with the addition of the chart closure hard stop (Ramirez et al., 2018). Although on the surface, this study appears to use only a DST, it is included in this review as the findings indicated that only implementation sites with clinical pharmacists experienced significant improvements in prescribing these antihypertensive agents. The pharmacists collaborated with primary care physicians to manage medication therapy, educate patients, help patients address cost-related issues, conduct medication reconciliation, and correct potential medication problems.

In another attempt to optimise medicines for CVD, an Argentinian randomised controlled trial used a mixture of internet-based support and education to prompt prescribing of cholesterol-lowering statin medication for people with moderate to high CVD risk (Gulayin et al., 2019). Cardiologists and internal medicine specialists delivered to local clinicians: a 2-day workshop, education outreach visits, individual feedback, clinic assistance, and identified barriers that prevented appropriate prescription. Also included in this intervention was patient counselling on medication adherence delivered by pharmacist assistants and educational flyers in pharmacies. For 697 people followed up over 12 months from 2015 to 2016, no significant difference was observed between the intervention group and control group for the primary outcome of LDL decrease. The proportion of patients prescribed an appropriate statin dose was significantly higher in the intervention group. The authors posited that the lack of benefit displayed could be due to a lack of adherence, which remained low in both groups. Medicines were free of charge to all participants in both arms.

Fontil et al. (2018) reported on adapting and evaluating an intervention from Kaiser Permanente to improve hypertension management in a network of safety-net clinics in San Francisco, USA. San Francisco Health Network consists of 12 adult primary care clinics providing care for more than 65,000 patients. The network has a shared electronic care platform, which enabled the development of a patient register for monthly performance monitoring and outreach to schedule appointments for BP checks. Nurses and pharmacists led the checks, facilitating access, leading to more frequent visits and treatment intensification developed by medical personnel. The intensification protocol incorporated fixed-dose combination drugs (usually an ARB alongside a thiazide) or amlodipine if laboratory follow-up was projected to be problematic. (It is standard practice to monitor kidney function after implementing medicines affecting the renin-angiotensin system). The fixed-dose medications were aimed at efficient management from a fiscal and pill burden perspective. Aldosterone antagonists (e.g., spironolactone) were advised in the schedule for patients with resistant hypertension. Of these patients, 37% and 21%, respectively, were classified as having diabetes or chronic kidney disease; 45% of the patients identified as Black or Hispanic. The results demonstrated an absolute increase of 6% in the proportion of patients with controlled BP within 9 months, which was maintained at 15 months. The authors stated this rate compared favourably with the national control rate trends, which have increased by 1% per year. The improvements in BP control rates were similarly statistically significant ($P < 0.01$) across all racial and ethnic groups (Black 60–66%; white 69–75%; Latino 67–72%; Asian 78–82%), but there was no closing in the disparities between groups. As such, the authors advocated a pro-equity approach. They also noted that Black patients experienced greater improvement rates, likely because more patients started with lower BP control.

The Heart Outcomes Prevention and Evaluation 4 (HOPE 4) was an open, community-based, cluster-randomised controlled trial involving 1,371 individuals with new or poorly controlled hypertension from 30 communities (defined as townships) in Colombia and Malaysia (Schwalm et al., 2019). Of these, 16 were randomly assigned to the control arm (usual care, $n=727$) and 14 ($n=644$) to the intervention arm. After community screening, the intervention included treatment of CVD risk factors: by using tablet computer-based simplified management algorithms and counselling programs; free antihypertensive and statin medications recommended by community healthcare workers and supervised by physicians; and support from a family member or friend (treatment supporter) to improve adherence to medications and healthy behaviours. The primary outcome was the change in Framingham

Risk Score 10-year CVD risk estimate at 12 months between intervention and control arms. The trial demonstrated a reduction in Framingham Risk Score for 10-year CVD risk of –4.78% (95% CI –7.11 to –2.44, $p < 0.0001$) with associated significant reductions in systolic BP and LDL in the intervention arm.

Of added specificity to this thesis was a single-arm pilot, multidisciplinary pilot study of a team approach to comprehensive gout management (Fields et al., 2017). The model was designed for sustained learning, beginning with a Gout Self-Management Knowledge Exam followed by nurse-led educational sessions, repeated at 6-month intervals. This was coupled with monthly pharmacist phone calls focused on encouraging regimen adherence and addressing patient questions, with social work intervention to address potential barriers to care. The educational curriculum was based on the American College of Rheumatology gout management guidelines with rheumatology, nurse, and social worker input. Of the 45 enrolled participants, 40 completed the 12-month study. The nurse-educator experience was viewed as favourable, with approximately 80% of patients affirming it impacted their management. In contrast, there was ambivalence with the pharmacist component, with slightly less than half (46.1%) of participants stating this intervention was helpful at 12 months. Participant commentary suggested that tailoring the communication to patient preference may improve satisfaction. Although the focus of this study was gout management knowledge, secondary outcomes were urate levels, flare frequency, and severity. The median serum urate level was 7.6 mg/dL (~0.45 mmol/L) at baseline, reducing to 5.1 mg/dL (~0.30 mmol/L) at 12 months, with a corresponding decrease in flares from a median of two at baseline to one at both 6 and 12 months.

3.4 Discussion

These studies confirm and add to the body of knowledge gained in the first iteration of this review. Some studies reinforced the learning that collaboration and design of multiple components can lead to greater gain (Ramirez et al., 2020). However, sometimes, even with multiple components, the intended benefits may be lost, e.g., if a person does not administer the medicine for some reason (Gulayin et al., 2019).

A key learning of the HOPE 4 trial was that non-medically trained workers with easy-to-use algorithms, alongside whānau support, are effective tools in preventive medicine. The positive benefit of medicines adherence was attributed, at least in part, to the support person's involvement. The trend towards benefit was less so for tertiary-trained participants. The

authors acknowledged that more work would be required to ascertain whether the benefits would be similar in low- and high-income countries. They subsequently undertook a feasibility pilot study in Canada using the same concept of non-physician care and support from family/friends (Schwalm et al., 2021). This study involved 56 people from two communities and also significantly reduced the Framingham Risk Score 10-year risk estimate and improved BP control, but there were no changes in LDL or health behaviours. There was no control group, and the authors acknowledge the study was underpowered but that this strategy could potentially mitigate barriers to medical clinic visits.

Chapter 4 Research Objectives and Initiative

4.1 Introduction

This chapter builds on the previous one to describe the underpinning of the response to the thesis question. The response was informed by the convergence of prior experience and published evidence, including that from the scoping review. Although independent aspects of medicines optimisation have been researched, published research focusing on multicomponent initiatives is lacking. The independent aspects demonstrating evidence to help achieve best practice or published guidelines included audit feedback, DSTs, nurse-led clinics, community engagement, health literate messages, and adherence aids.

The first section of this chapter outlines a marae-based health initiative delivered in 2014/2015. It does not involve any data collection, only broad learning. It is included as it helps feed into the kete (basket) of ‘prior experience’, informing the development of the multilevel initiative that was part of the thesis project. It also provides background on how I came to work at Papakura Marae Clinic (PMC).

The second section outlines the objectives, methods, and interventions chosen to address the research question.

The third section provides detail on the development and delivery of the Papakura Marae Clinic (PMC) initiative, which forms the basis of the thesis project. Oranga Rongoā was the name given to this initiative - developed with the community - to mean health and sustenance with medicines. Included in this final section is quantitative data as to its effect.

4.2 Cultural Literacy Project

The background to this project is that the Ministry of Health (MOH) had approached me to deliver a 12-month project to build whānau health literacy in a marae-based setting focusing on gout, particularly preventing gout and the importance of ongoing self-management. I proffered to deliver the project under the umbrella of Ngā Kaitiaki o Te Puna Rongoā o Aotearoa – The Māori Pharmacists’ Association Inc. (MPA) to involve the wider membership. We were contracted to deliver 12 marae-based gout information hui across three recruited marae (four quarterly hui) for individuals with gout and their whānau. The three marae sites were in Ōpotiki, a small provincial community in the Whakatohea rohe of the Bay of Plenty; in Waikato Tainui rohe with Ngāti Koroki Kahukura; and at Papakura Marae.

Papakura Marae differed from the other sites in that I was asked to run clinics in the general practice within the marae boundary, alongside the hui. This enabled group discussions and priming in the gatherings, followed by treatment of individuals in the clinic. At the other sites, I did not deliver clinics in general practices. I delivered the project with administration support from the MPA. Additionally, one of the members helped host at her own marae in Ōpotiki and facilitated her whānau to attend. We also involved Māori pharmacy students in using the evaluation as research projects for summer studentships.

The project's goal was to build health literacy in a setting where people felt safe sharing experiences, discussing with, and learning from one another. The initial focus was on gout and expanded to include other health conditions.

The aims were to:

1. give people the skills to effectively manage gout, including using medications and understanding their role,
2. deliver the message that gout is a serious long-term condition that can be managed, and
3. give whānau the knowledge base and health literacy skills to support family members with gout to self-manage their condition and enable better understanding and communication with health professionals.

The project recognised that the public is a largely untapped resource and looked to empower communities to manage their health outcomes – or for Māori, to enable rangatiratanga.

Participants chose when, where, and how we would meet; who would attend; and how the discussions would proceed.

This first part of the project saw 12 hui and 542 contacts, with overwhelmingly positive feedback from 312 follow-up contacts. Several key findings were provided in the confidential MOH reporting *Gout Health Literacy – Final Project Report 2015* (Te Karu, 2015). The key outcomes and learnings included the following:

- Enabling whānau to determine their health outcomes and the health outcomes of the wider whānau, hapū, and iwi in an understandable and informed manner is possible and preferred compared with that delivered by mainstream health delivery.
- Creating community champions who embrace their roles, speaking of their experiences of optimising gout treatment and management, is important to iwi, hapū, and whānau. The community was respectful and supportive of this approach. It led to

broader discussions on how empowered people felt and how they used this empowerment to manage other health conditions.

- The development of a gout literature resource. Whānau co-created and led many aspects of its development and expressed their feelings of ownership and positivity at its completion.

In 2016/2017, I led and delivered another series of hui following the same format – this time in the South Island in Ōtautahi (Christchurch) and in Tauranga Moana at a large central marae. Again, the significant evaluation and accountability process back to the MOH was only positive, with people describing the project as ‘life-changing.’

I was approached by other iwi and marae to deliver the same wānanga, but there was no commitment from central government or DHBs to provide further resourcing.

As outlined, the PMC part of this project differed from other sites with general practice involvement. As such, the genesis for the subsequent PMC initiative had begun, with staff feedback highlighting variations in prescribing practice that changed with my presence. Staff estimated that they were more likely to prescribe preventive medicine and less likely to prescribe symptomatic treatment under my guidance. It was reported that the shift towards more preventive management was lost when staff turnover occurred. Some clinicians admitted a knowledge deficit for gout management, and others discussed feeling like they needed a prompt to remember. Added to this was my experience with the cultural literacy project, where inappropriate management of gout often led to overall failure of response. For example, there were many instances where whānau had been empowered to calculate the dose of urate-lowering therapy required for themselves, alongside the knowledge that they should also be prescribed urate crystal prophylaxis (cover). Yet, many times this did not occur because prescribers did not enable it. There were occasions when whānau discussed pushing back at clinicians and stated their understanding of what should happen but did not. The assimilation of experience and investigation led me to propose one component of a new initiative could involve computerised clinical decision support to prescribe for and manage gout.

4.3 Objectives and Interventions

The synthesis of the experience from the cultural literacy project and the scoping review led to the development of the objectives and interventions used to answer the research question (Table 3).

Table 3 Objectives and Interventions Employed to Answer the Research Question

| Research question: How can gout medication therapy for Māori be optimised? | |
|---|---|
| Objective | Intervention |
| Implement a DST to improve prescribing medicines for gout according to guideline recommendations in a predominantly Māori primary care setting | Develop and implement a DST for providers to prompt and improve prescribing of preventive medicines for gout for Māori See Section 4.3.1 |
| Implement a multilevel care approach to improving medicines and disease knowledge in patients with gout in a predominantly Māori primary care setting | Develop a multilevel care approach that aims to empower people to self-manage gout See Section 4.3.2 |
| Identify the barriers and enablers to the implementation of these initiatives | Conduct interviews and observations at the organisation, provider level and at the patient/whānau level identifying the barriers and enablers to the implementation of these initiatives See Section 4.3.3 |
| Develop and publish advice on promoting equitable gout management during the Covid19 restrictions | Publish an article to help guide primary care clinicians to consider equitable gout management during COVID-19 restrictions See Section 4.3.4 |
| Identify the barriers to medicines optimisation from a medicines environment perspective | Describe the barriers to medicines optimisation from a medicines environment perspective and develop a visual contextualisation of medicines optimisation as a reflection of the broader healthcare system See Section 4.3.5 |

DST, decision-support tool.

4.3.1 Intervention 1: Develop and Implement a Provider Decision-Support Tool to Improve Prescribing of Gout Medicines for Māori

Developing a DST was seen as a way to fill the knowledge gaps and prompt clinicians, addressing provider, microsystem, and organisation influences (Chin et al., 2012).

National guidelines/regional pathways underpinned the clinical component of the DST. (Accepted best practice in NZ for gout management is achieving a serum urate level of <0.36 mmol/L on an annual serum level test [Dalbeth, 2013]). The PHO enabled the programme development component.

The DST provided an alert to clinicians, appearing as part of a traffic light system.

The road to the DST development and personal involvement is discussed more fully in Section 4.4.

Study Design

The study design was a before and after observational design, a widely used technique for assessing changes in health services (Eccles et al., 2003). Other disciplines have also termed this ‘multiple baselines’ (Cook & Campbell, 1979).

Data collection: Clinical variables and prescribing data were accessed from the practice management system (PMS). The Health and Disability Ethics Committee (HDCEC) stated that the intervention fitted within the definition of an audit and, therefore, did not require formal ethics assessment and approval (Appendix 2).

Setting

PMC, which serves more than 3,000 Māori living in the Papakura district.

Population

All people enrolled at PMC identified with gout as of May 1, 2017.

Definition of gout

The definition of gout is based on that used to determine national prevalence (Winnard et al., 2012) and employed by the Commission to present the Gout Atlases (Health Quality & Safety Commission, 2018). Specifically, people were defined as having gout if they had a classification of gout within the MedTech practice management system (PMS) OR prescription of allopurinol or colchicine as captured within the PMS. Read codes for gout classification are listed in Appendix 3. Individuals classified with leukaemia or lymphoma were excluded.

Outcome measures:

1. People prescribed allopurinol within the last 12 months.
2. People who have had a serum urate test within the last 12 months.

3. People who have a serum urate <0.36 mmol/L.

4.3.2 Intervention 2: Develop a Multilevel Care Approach that Empowers People to Self-Manage Gout

This intervention component aimed to address patient and community influences by empowering people to self-manage gout and the complexities of adherence (Chin et al., 2012). It factored in learning from the scoping review alongside co-design with stakeholders.

A multi-layered, multidisciplinary care package was developed in collaboration with community health workers, whānau, and community champions, GPs and nurses.

Development was through a series of hui with staff and community members (champions).

The champions were people with gout and their whānau.

This road to developing both the DST and the multi-care initiative are more fully described in Section 4.4.

4.3.3 Intervention 3: Conduct Interviews and Observations with Staff and Patients/Whānau

Chapter 1 discussed suboptimal gout management with contributions from both health providers and misconceptions from patients with gout and their families.

Participants

The participants' (gout cohort) view of the initiative; self-reported change in understanding of medicines and gout as a condition, and self-reported adherence; enablers and barriers to medicines optimisation; and the acceptability of the initiative to patients and their whānau were studied.

Semi-structured interviews with open-ended questions were undertaken with people in the gout cohort to investigate whether these initiatives improved gout self-management. A general inductive method was employed, a common approach in the analysis of qualitative research in medicine, enabling overlapping approaches and facilitating the emergence of themes (Thomas, 2006). Thomas (2003) expresses this as an efficient and straightforward method of thematic analysis to address research objectives, perhaps considered grounded theory without the jargon.

Concerning the recruitment of participants for the qualitative interviews, purposive sampling occurred until there was a saturation of themes. Acknowledging saturation is complex (Fusch

& Ness, 2015), but increasing interview numbers does not necessarily translate to more data (Guest et al., 2006). Also, the sample size should ideally depend upon a consideration of factors, such as how broad the aim is and the specificity of experiences, knowledge, or properties among the participants included in the sample. This cannot be predetermined (Malterud et al., 2015). Therefore, there was neither a fixed sample nor an ideal sample size (Mason, 2010).

Purposive sampling or judgement sampling was the framework used for sampling from:

- those who have taken part in community hui, both male and female, under the age of 40 years and those aged ≥ 40 years
- those who have had interaction in the clinic only, both sexes and a range of ages
- those who have had no interaction at all, both sexes and a range of ages
- those who have achieved ‘target’ serum urate levels
- those who have not achieved ‘target’ serum urate levels.

Participants may have aligned to more than one part of the framework.

In the first instance, participants were approached by kaimahi (Indigenous community workers) in the marae, who have a trusted relationship with whānau. (Kaimahi engage with whānau outside the clinic for multiple reasons, sometimes just to collect them and take them to various appointments; to help with budgetary and social circumstances; running programmes for engagement outside the marae setting, e.g., one of the kaimahi runs a ‘boys club’ who meet for walks in the bush and sometimes fishing expeditions. The kaimahi are often called upon for help with all manner of things simply because they are so trusted.)

As emphasised, a Kaupapa Māori approach is the overarching framework for this entire research and will be applied to interviewing participants.

Ethics approval was granted by the Northern B Health and Disability Ethics Committee (ref. 18/NTB/213) (Appendix 4).

This part of the research is presented in Chapter 5.

Health Providers

Previous research has indicated that clinicians are slow to implement preventive therapy, relying on symptomatic treatment and its associated risks (Te Karu et al., 2013). Added to this are provider beliefs about gout as a disease of ‘lifestyle’ excess, beliefs that seep into the community and become pervasive (Dalbeth et al., 2019a).

Therefore, the objective of staff interviews was to identify enablers and barriers to medicines optimisation through the initiative, acceptability of the initiative, and their experience of the multidisciplinary collaborative team approach regarding what worked and what could be improved.

Semi-structured interviews with open-ended questions were undertaken with staff about their experience using the DST and whether it helped overcome potential clinical inertia and any observation of the empowerment component. This qualitative component enhanced the understanding of whether these initiatives helped change prescribing/managing gout behaviour. The aim was to interview all staff as opposed to continuing until saturation. Interviews were recorded, transcribed, and analysed for themes with triangulation with supervisors. The HDCEC advised that interviewing staff did not need a full review.

This component of the research is presented in Chapter 6.

Further investigations were undertaken to assess the pharmacoepidemiology of the gout cohort and domains of access to gout management. The practice management system and staff knowledge informed this part of the study, which is presented in Chapter 7.

4.3.4 Intervention 4: Develop and publish advice to primary care clinicians on gout management with an equity approach during Covid19 restrictions

This objective initially set out to investigate the barriers and enablers to medicines optimisation in an Indigenous context by interviewing Indigenous prescribers attending PRIDOC 2020. When this became impossible and an alternative was required, the thinking was reprioritised as a call for action advocating equitable gout management during COVID-19 restrictions. This is detailed in Chapter 8.

4.3.5 Intervention 5: Develop a diagrammatic contextualisation of medicines optimisation to reflect the broader healthcare system

The objective tied to this intervention was to identify the barriers to optimal gout management from a medicines environment perspective. Whilst the objective did not change, this intervention was tweaked with the thesis journey. The complexity of the gaps as a reflection of the broader healthcare system and, therefore, opportunities in the medicines environment required articulation of that complexity more simply than a written description. This subsequently led to the concept of a visual contextualisation of medicines optimisation

through diagrammatic representation and is presented in Chapter 9 (Swiss Cheese and Ngā Rau o Kawakawa models).

4.4 The Journey to Oranga Rongoā

This section presents the PMC initiative journey, which directly delivers the first two objectives of this thesis and premises a knowledge base for the remaining three.

Underpinning the clinical engagement for Māori in a health interaction are the specific rights in the second article of Te Tiriti o Waitangi of rangatiratanga, or self-determination. Equally, in the third article, Māori also have the right to partner with health systems to achieve hauora, or well-being. Given biomedical guidelines have been developed in the absence of Māori, they may not always be aligned with the aspiration of rangatiratanga for individual and whānau well-being. Therefore, this section profiles and encapsulates these factors with a narrative account of Oranga Rongoā –developing and implementing gout medication optimisation at PMC.

Firstly a chronological order of key aspects of the initiative is given, providing a framework for the qualitative and self-reflective narrative. This is followed by the development processes and implementation components that framed the initiative. Lastly, this section explores the definition of best practice and whether this meets optimal medicines management with reflections on the contrasting measures of success or outcome expectations.

This PMC initiative also reflected wider partnering with the Health Quality & Safety Commission (the Commission), a NZ Crown Agency. I provide reflections on the partnership's complexity and contestation and how this shaped the initiative. Exploring these challenges will contribute to the whakaaro of Don Berwick.⁶

“All improvement is change but not all change is improvement” (Berwick, 1996).

4.4.1 Timeline Overview

The following is a timeline overview of key aspects of the PMC initiative. The qualitative and self-reflective narrative correlated with these events and the period of the initiative.

- 2014–2015: Cultural literacy project – first engagement with PMC

⁶ Sir Don Berwick is a physician, academic, author, and health improvement systems expert.

- November/December 2015: Approach made to PMC regarding a gout project as a case study associated with my PhD. DST mooted.
- July 2016: The Commission's 'quality initiative' announced
- September 2016: The Commission shortlisted the PMC initiative as a potential project for supporting
- October 2016: Shortlisting meeting with the Commission; clinical staff and community engagement in PMC initiative design
- November 2016: Commission interview with PHO clinical lead and myself
- December 2016: Commission confirmation of PMC initiative to be supported
- January to March 2017: DST drafting
- May 2017: DST developed
- May 2017: First Commission workshop
- May 2017: 271 Patients with gout were identified as the cohort classified in preparation for the PMC
- June 1, 2017: DST goes live for PMC staff in daily practice. The cohort identified in May (now 268 people) ringfenced and prospectively followed
- July 2017: Collaborative partnering with rheumatology
- September 2017: Commission evaluation process
- October 2017: Commission workshop two
- October 2017: Review with PMC staff and community champions
- November 2017: Commission wānanga that identifies Māori thinking in principles and values
- March 2018: Final Commission workshop PMC initiative.

4.4.2 Phase 1 Decision-Support Tool

The journey to medicines optimisation with PMC began at the end of 2015 following my preliminary thesis proposal submission to Auckland University, and noting the underpinnings above that one component of the initiative could involve a gout DST with all the staff contributing where appropriate.

The PHO had already developed its own practice management tools, including a prompting system. The system is designed to integrate in 'real time' with the PMS. It prompts practice staff to complete health interventions aligned to national health targets or local DHB and

PHO performance measures. This prompt system was unique at the time in NZ, as it was not delayed by sitting outside the PMS. It is fully integrated, ensuring up-to-date and faster responses than traditional patient dashboard systems.

All people defined as having gout who have a health interaction at PMC would be exposed to the DST. Whether the advice of the tool is adhered to depends on the prescriber.

The software supports monthly audits of serum urate levels and prescription of allopurinol.

If effective, consideration could be given to developing DSTs for other health conditions.

The tool aimed to:

- focus on the long-term management/prevention of gout with allopurinol
- be included in the patient prompts as an alert
- be used as a source of discussion with the patient
- be used as a resource for improvement in clinical management (if, for instance, someone had not reached their target serum urate and they were classified as having gout, the prompt should alert the clinician to this and encourage conversations that may lead to a change in the therapeutic management)
- self-populate with renal function to provide initial doses of allopurinol for prescribers according to renal function
- guide how to prescribe cover for allopurinol implementation and links to things like health pathways and gout guidelines
- be easy to apply and understand for busy clinicians in general practice.

Successive meetings were held with the PHO, the umbrella organisation under which the general practice operates. While I had forged relationships with the clinic staff, I had dealt with only one PHO staff member through the health literacy project. That I offered my services without compensation to co-design, co-develop, and co-deliver a project was helpful. Still, human and fiscal resourcing would also be required from the PHO and must be factored in.

The marae board and the senior management at PMC endorsed researching gout optimisation as part of my doctoral thesis. This was important for ensuring clarity of the proposition across the organisation while also providing the PHO with a process around me to ensure that my intentions aligned with the mana whānau, whānau ora vision underpinning all of the PHO's work.

Similarly, I saw this as an avenue to explore contributing to PMC without being a resource cost. On reflection, I recognised one of the stumbling blocks for the PHO was that a big chunk of estimating their resourcing costs was wrapped up in the belief that a GP would need to lead the process and would require a budget.

4.4.3 Health Quality & Safety Commission and Fishbones

The foundation of the PMC initiative was engagement with and across the PMC healthcare staff and community. In July 2016, when developing a process for this engagement, I became aware of an opportunity with the Commission. The Commission announced the intention to launch a programme to partner with the primary healthcare sector to enable small-scale quality improvement projects. It is essential to highlight the word ‘partner’ as it will become apparent throughout this journey that each party had a different idea of what partnership looked like and meant around the definition of associated equity outcomes.

Applicants were invited to apply for a small funding pool. The Commission stated that priority would be given to initiatives that addressed equity, consumer engagement, and integration between primary and secondary care.

I quickly commenced framing up an application to the Commission initiative and worked with the PHO nurse to consider broader applicability. In discussion with staff from the PHO, it was seen that the funding attached to this initiative, albeit small, could contribute to administration costs and capability building in quality improvement within the practice and the PHO. As such, the PHO assigned clinical nurse provider support as the project manager and considered how a pilot in one medical practice (or phase 1) could be extended to other member practices of the PHO. The Commission offered to reimburse staff time up to NZ\$6,000, excluding GST, and to cover backfill costs to release up to four staff to attend three meetings hosted by the Commission, alongside disbursements to participate in these meetings. If successful, the thinking was it would be an opportunity to initiate phase 1.

By September 2016, the Commission advised that we had been shortlisted as one of the successful applicants for this initiative. A half-day site visit was required to assess our organisational capabilities for the shortlisting process.

This shortlisting hui took place in October, advancing the initiative and, in particular, further framing a clinical DST. After negotiation and discussion on our need to maintain clinical obligations, two Commission staff visited the marae, meeting with myself and the PHO nurse

lead for 3 hours and members of the practice team for up to an hour, when they were able to be released from practice duties. This included the nurse and GP clinical leads at the practice. Given this was the first time these visitors had been to our marae, they were acknowledged as ‘waewae tapu’ (first-time visitors). As such, we followed tikanga and welcomed them as visitors with a mihi whakatai and the sharing of kai. We engaged in whakawhanaungatanga and found our two visitors were less comfortable in these processes. While we did not dwell on it as a team, it became clear, as already been alluded to, that each party had a very different view of a partnership engagement; this became more apparent as the relationship continued.

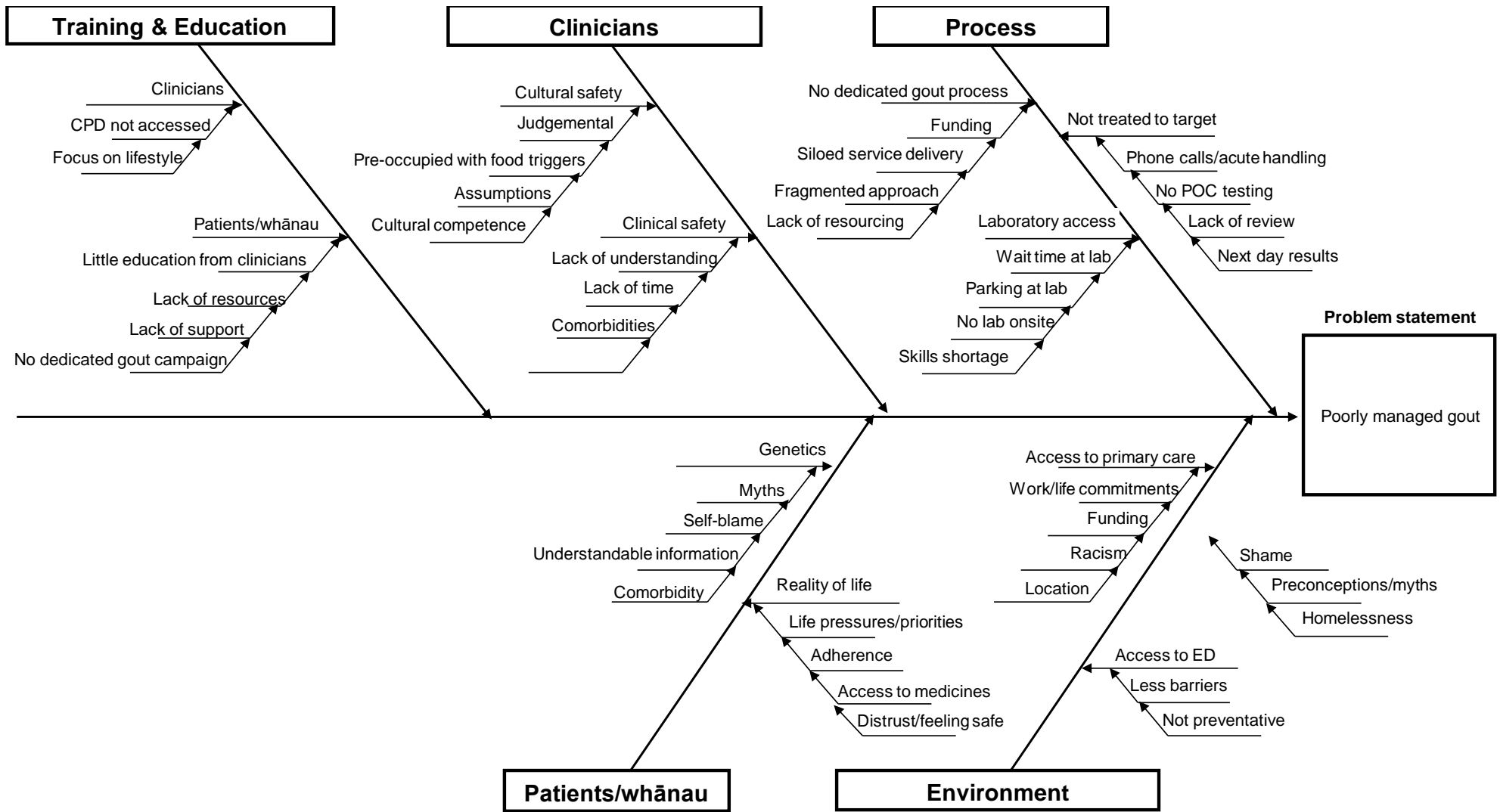
Two male community members attended and became our ‘champions,’ having experienced gout for decades, along with members of their whānau.

During this October hui, those present undertook a process of developing a fishbone or Ishikawa diagram. I had no prior experience with a fishbone diagram. I learned the diagrams are a tool for understanding the many potential causes of a quality-of-care problem (Harel et al., 2016).

The process involves attributing a problem to the head of the fish with bones determining the problem’s causes. In that sense, the fishbone can be regarded as a root-cause analytical tool.

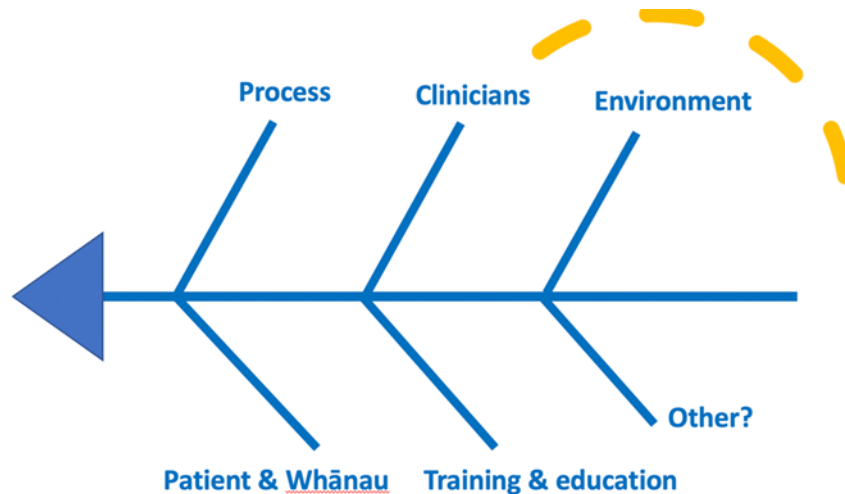
Brainstorming enables the identification of issues contributing to a problem. On this occasion, the problem was named for us as ‘poor management of gout’ (Figure 2). In retrospect, problem attribution was not ideal and a missed opportunity.

Figure 2 Fishbone from the Health Quality & Safety Commission Visit, October 2016



My reflection on this missed opportunity was subsequently demonstrated using the fishbone tool in some work in Whanganui. The session encouraged whānau attending to brainstorm their definition of the ‘problem.’ The diagram in Figure 3 was provided to participants to fill in themselves.

Figure 3 Template Provided to Whanganui Participants



When replicating the previously noted exercise in a different community, the problem was not predefined. Whānau defined the problem as a “lack of a whānau ora approach to gout,” with the bones representing a holistic view instead of a biomedical one. This, to me, represents a fundamental divergence of worldview – i.e., the biomedical approach versus a conceptual framework requiring an all-encompassing holistic view of health and wellness.

On reflecting upon the pre-empting of the problem, I also realised the application submission to the Commission had been framed without whānau input. Working in haste to meet timelines, I had been equally quick to define a biomedical outcome and not one defined by whānau. The project aimed for 70% (initially 80%, then scaled back) of the enrolled population with gout to achieve a serum urate target of <0.36 mmol/L, i.e., to achieve what is purported in guidelines as ‘best practice.’ This is discussed in Section 4.4.6. Still, it became apparent that the definition of best practice from a guideline perspective differs from what whānau deem best practice. Best practice is a term used frequently in the medical world, but this is often in the absence of the end-user or the people the practice applies to. I was reminded of that in 2006 when, attending the PRIDOC for the first time, I was chatting to a Native American lady from the Moose Clan. At some point in the conversation, I mentioned

best practice. She turned to me and gently said “whose best practice, dear? I bet not my best practice and I especially bet not the Moose Clan best practice.” That has remained with me.

The fishbone exercise laid a platform for collective discussions on identifying other strategies to apply to assist our desired outcome. This included:

- community design and community ‘champions’
- community hui
- DST
- practice staff education
- point-of-care urate testing
- nurse standing orders
- gout health literacy resource
- direct communication with a rheumatologist
- evening clinic.

During the process of working with the Commission as a partner to develop the internal capability of quality improvement in the PMC initiative, I continued parallel work of meeting and promoting the development of a DST to the GP lead primary care network and with the information technology (IT) leads at the PHO.

4.4.4 Phase 2 – Journey

In recognising the challenges with the Commission and the ‘problem’ definition using the fishbone process, momentum in the PMC initiative continued, albeit slowly. By January 2017, the PHO IT team had no progress with the DST. I travelled to Auckland to meet with PHO senior management to better understand the resourcing barriers and prompt progress. The primary care network lead had left the organisation, and all prior work had halted, with no documentation left behind. There had also been some changes in the IT team, with technicians moving on. Looking back, I realise the reliance on key personnel for an initiative of this type is fraught in a PHO where resources are limited. My notes became the sole source of previous thinking and discussion. This meeting emphasised the obstacle of estimated resourcing in the belief that a GP would need to lead the process and was the only appropriate subject matter expert. A budget of 60 hours of GP time had been dedicated to providing expertise in building the DST alongside the IT team. This was not only a cost in hours, but also a diversion from other projects also focused on improving health outcomes. In a follow-

up meeting with the PHO clinical leads, we established that I was suitable to provide subject matter expertise. At the time, this seemed to negate concerns over GP time being diverted, but I still had to be mindful of the IT workload.

By January 10, 2017, the IT team confirmed the development of a report that would lead to an online form.

The intent was still to consider applicability to the whole PHO network, which required going clinic by clinic for authorisation/permission to extract data. There was discussion that agreements with practices were being updated so that consent for this type of work would be standard in the future. However, this was PHO business and not for me to ascertain, so my focus continued with PMC. I met with a new IT developer in early February and worked up the DST outline and requirements. The timeframe for completion was indicated as 2 weeks. A month later, no tangible progress had been made as the IT team were working hard to release a new version of the real-time data-gathering system on which the DST was dependent.

At the beginning of March, IT management further advised me that the clinical decision support form around prescribing had not been started, as GP input into this was again deemed necessary. Attempts were being made to find a suitable GP who could work on this. This was disappointing, given I had provided what I thought was sufficient to build a robust tool from a prescriber perspective. Although I was very happy to have GP support, I did not want it to be at the expense of the timeframe and potentially the project. On March 13, we had another scheduled onsite visit with Commission staff, and I was concerned the meeting was premature with the incomplete DST.

The PHO contracted a GP who had previously held a GP lead primary care network position for up to 60 hours of advice.

In our continuing focus on data, approval was provided in the middle of March 2017 to extract data on:

- classification of gout
- prescription of allopurinol with or without classification of gout
- prescription of colchicine with or without classification of gout
- last serum uric acid (SUA) concentration and date
- last estimated glomerular filtration rate (eGFR) and date
- last creatinine and date

- gender, age, ethnicity.

In parallel with this work, the Commission sought a project meeting, which was delayed until April 2017, as the DST was incomplete. The rationale for an onsite session with the Commission was to discuss the initiative's aim, establish measures, and arrange monthly teleconference meetings and commitments. In February, the Commission had provided an orientation manual outlining the initiative's requirements regarding obligation and input. It was clear that we would struggle to fulfil this obligation as a practice, demonstrating the misalignment from the Commission's intent to have an equity focus. While such a focus was commendable, it was a personal reflective point that these projects required significant human resourcing to meet the demands of the Commission's programme. This was not conducive to collaboration with under-resourced practices typical of those serving disadvantaged populations and counterproductive to the stated aims of the Commission.

As a practice, we were already facing challenges with the time expectation and differences in what we saw as a partnership approach. I took the opportunity to meet with the PHO clinical lead to discuss this, recognising that he had seen some merit in extracting ourselves from the project partnership altogether after the first engagement at the marae when there was little capability to respond in the mihi whakatau. We were both mindful of the danger of the approach being a Western construct potentially supplanting our Kaupapa Māori approach. We wanted to balance this fear against maximising the potential for the best outcome and decided to 'plough on' after deliberation with others. The project management staff from the Commission were always very approachable and mindful of our unique challenges. Perhaps they also felt challenged by being tasked to deliver on the programme, yet they could see difficulties.

More meetings were held with the PHO IT developer, starting with mock-ups of the alerts on the patient dashboard, as it appeared when the clinician opened the patient details on their PMS. A traffic light system was proposed with green and red lights. A green light would follow NZ guidelines and mean the person had achieved target serum urate within the previous 12 months.

Work continued on the part of the tool that assisted in the dose titration of allopurinol (Appendix 3). Paper-based nurse standing orders for allopurinol titration were also developed alongside the DST. The standing orders were written by me and approved by the medical director of the PHO.

The GP contracted by the PHO to provide expertise was back on board at the end of March 2017. We met in early April 2017 with the IT team and PHO nurse-lead to recap and plan.

The absolute requirement to have a contracted GP to be part of the development of the DST slowed the process, and there was minimal input on reflection. The email trail shows that the IT developer frequently directly messaged me when trialling the tool and form without the involvement of the GP. The main requirement would be to obtain clinical pathways advice from a suitable clinician. The contracted GP was out of the country when we went live with the DST, and I had no evidence of any input from him.

In late April, I also attended the clinical meeting at PMC with staff to update them on the project. This was helpful as one of our full-time GPs agreed to be part of the project team and a champion to the other GPs. Toward the end of phase 2, we held the delayed hui with the Commission with further engagement from the community champion representatives. The hui was held in our beautiful wharehau named Te Ngira with two community champions (koroua –elderly men) and the wife of one. She provided valuable insight into her husband's difficulties obtaining appointments and pain relief over the previous four decades. Most of that time, they had lived in a different community. The hui lasted around 3 hours with myself and the PHO nurse-lead present. As before, some staff attended when they could manage in between managing their busy clinic work. This became a theme and caused tension with those involved in the project and management of our clinic.

From the audit presented by the IT team, we identified a cohort of people on May 1 as per the gout definition and committed to following this group prospectively. From a total of 271 people meeting our definition, 160 had a gout classification; however, only 76 of these had recent prescriptions of allopurinol. 'Recent' prescription was defined as a three-month supply within the last 4 months. An extra month was permitted, recognising that most studies work on an 80% compliance rate. Of the 160, 114 had an SUA measured within the previous 12 months, with only 44 at target. A further 111 patients had no gout classification but had allopurinol or colchicine prescribed at some time in the past. Of the 111, 52 had hyperuricemia coded. Three people had no record of ever having an SUA level.

June 1st was the day the DST was planned to go live, giving us time to analyse the data before doing so. The IT team had worked hard to slot this in between other projects.

The criteria used to trigger the alert (the red traffic light) were:

- a Read code classification of gout or a prescription for allopurinol or colchicine at any prior date;
- no Read classification for a myeloproliferative disorder
- no serum urate level measured at <0.36 mmol/L in the previous 12-month period.

The tool alerted the clinician to the ‘status’ of the patient through the dashboard traffic light system. The dashboard would display green if a classified patient had been prescribed allopurinol and had attained the target within the previous 12 months. Any other patient would display red. If the clinician decides urate-lowering therapy with allopurinol is appropriate, the prescribing tool self-populates based on clinical variables as to the correct dose to prescribe and prompts to prescribe ‘cover’ for urate-lowering therapy, essentially helping write the prescription. Links to the area's regional clinical pathway for gout treatment were also incorporated.

If a person presents for the first time without a diagnosis of gout and never having had allopurinol or colchicine prescribed, that person will not show up in the dashboard. There is no prompt to ensure clinicians add classifications when they make a diagnosis. They would only do so after classification has been made or pharmacological agents had been prescribed.

People enrolling in the practice after June 1 and those diagnosed with gout after this date would still be exposed to the DST and the multilayered initiative as they wished. They were not included in our data for improvement analysis.

These two phases had realised a DST and identified cohort, despite the complex engagement and process of design and consultation, including the ‘problem’ definition conflict.

Implementation was the next phase of the PMC initiative.

4.4.5 Phase 3 – Implementation

As the PMC initiative commenced the implementation phase, partnering with the Commission persisted and continued to raise elements of disconnectedness in both the aims and drivers of the initiative. One of the mechanisms that framed the relationship and represented this disconnect was a proposed memorandum of understanding (MOU) between PMC and the Commission. We were advised that an MOU between organisations required signing to access travel and employee backfill funding. The Commission had provided a template containing a schedule of regular meetings and a commitment to group learning sessions. The PHO policy was that MOU documents require board review and approval. The

Commission requested an additional meeting to discuss the MOU. This was an added pressure and not one possible from a PHO perspective at short notice, demonstrating a further disconnect in understanding. The PHO offered to construct a senior executive document of agreement instead of an MOU as a solution and an alternate pathway that enabled continued progress and attendance at the learning session.

The disjunction was seen clearly at the first group learning session on May 23, 2017. This hui was where PMC, along with other project and host organisations, were brought together by the Commission. There were presentations from experts in equity application and primary care improvement theory. It was also an opportunity to meet the other teams. In attendance from our team were the GP champion, nurse lead, PHO nurse, and myself. One team was also based in the North Island and was a collaboration between a PHO and general practices. In this case, the PHO was driving the campaign as opposed to us, where the practice was largely responsible for the project. The third team was from the South Island and was a DHB-driven initiative. This team had sufficient resourcing to bring their 'consumer' representation, which was an intriguing choice in my mind. Their project was on medicines used in post-surgical intervention for a cardiovascular condition. Data for this DHB had demonstrated an inequity, with Māori much less likely to receive the medication than non-Māori. The consumer advising this project did not have the health condition, had not had the surgical intervention, and was not Māori.

The obvious difference between our team and the others was the amount of available human resourcing. The others had teams of dozens, with people such as data analysts supporting the project managers and care providers. In essence, we had a team of five, with only myself involved outside of working in the clinic. As mentioned, the time I dedicated to this was for this part-time PhD. However, it did mean that I was not sitting in a busy clinic like my four other colleagues during the time I committed. They were either full-time in the practice or, in the case of the PHO nurse, covering improvement projects at all the network practices.

Despite the aforementioned differences, the day allowed us to consider our project alongside the learnings. We discussed urate stratification with the equity presenter – Professor Dr Sue Crengle (a well-known and highly respected researcher and equity advocate in NZ). Serum urate levels have long been shown to be higher in Māori than in non-Māori (Prior et al., 1964). Saturation of serum urate is deemed to occur above concentrations of 0.42 mmol/L (Martillo et al., 2014), but the crystallisation of urate is a complex multifactorial process with wide variation as to when it happens (Chhana et al., 2015). For instance, only 24% of

asymptomatic individuals with serum urate concentrations above 0.54 mmol/L demonstrate crystallisation on dual-energy computed tomography (Dalbeth et al., 2015).

We settled on three tiers of serum urate stratification:

- ≤ 0.35 mmol/L
- 0.36 to 0.55 mmol/L
- > 0.55 mmol/L.

We also discussed aiming to contact people (if any) with an SUA > 0.55 mmol/L, no history of gout, and no history of allopurinol/colchicine to see if they had ever had gout symptoms. In preparing for the initiative's implementation, I recognised my struggle with the demand for us to apply a Western improvement science methodology to measure success. It was apparent to me that people can be disadvantaged in a Western health system, and using Western tools to measure improvement will never get to the heart of improvement from an Indigenous perspective. I discussed this on the day and with the Commission staff.

After the group learning session, Commission staff requested another meeting to cover some of the learning around outcome measures and plan, do, study, act (PDSA) cycles. The expectation for us to be available for meetings was an ongoing challenge. In a summary communication to me, I received a request from the Commission to elaborate on my points about Kaupapa Māori improvement models and different measures of success. I discussed my concern that the current model was underpinned by a failure to co-create the project's aim with whānau, which was compounded by being asked to apply Western evaluation tools. At this phase of the project, there was no resolution on these points.

By May 31, we had the DST operational for trial purposes. Two GPs, (including the GP champion) and I conducted live testing with patients before announcing its availability to the practice the following day. As expected, we did come across glitches. My first patient of the day appeared as a red light on the dashboard, with the alert stating there was no classification and no recent measurement of SUA. In fact, the SUA was completed on November 28, 2016, and was 0.28 mmol/L, fitting the definition of 'gold standard best practice.' Rectifying the classification status was straightforward, but ensuring all the serum urate levels were being recognised by the software was for the IT team to investigate. Thankfully this was also solved as it resulted from nomenclature recognition between uric acid and urate.

Additionally, the IT team set up a 'Give Feedback' link on the dashboard, which – through a process of taking a screenshot – enabled prompt action and understanding of this issue and others as they arose.

Another problem surfaced in a separate cohort (not our study cohort) of people who had never had a gout attack (confirmed through phone calls or direct contact) but had been prescribed allopurinol for hyperuricaemia. Some people had been prescribed allopurinol regularly for ≥ 8 years, whereas some were more recent at 3 years. The hyperuricaemia varied from 0.50 mmol/L upwards to 0.85mmol/L at the time of allopurinol initiation.

These people appeared to be adherent to the allopurinol, with the majority having SUA levels < 0.36 mmol/L, the lowest being 0.28 mmol/L. However, some people had SUA levels between 0.40–0.49 mmol/L despite having been on urate-lowering therapy for years. This, I believed, was a compromised position. On the one hand, there was no evidence-based indication to commence allopurinol. However, since it had been implemented, it did not seem right to stop it; likewise, it felt inappropriate to increase the dose to a target below saturation of monosodium urate crystals to a target of < 0.36 mmol/L. I sought advice from a rheumatologist recognised nationally and internationally for his gout expertise. His advice acknowledged the absence of trials addressing allopurinol for asymptomatic hyperuricemia versus the proverbial 'an absence of evidence is not evidence of absence.' His suggestion was to leave people on their current dose with the rationale that reducing the urate load may well have benefits, and the lower the urate concentration, the less likely it is that gout will occur. This recommendation was followed.

The sustained request for meetings by the Commission and the tension surrounding this continued. We were asked to arrange another meeting on June 15 for 4 hours on top of the weekly teleconferences. We were unable to accommodate this request as a physical meeting. The staff could not be released from the clinic and were, therefore, not in attendance. The PHO nurse and I organised a virtual kōrero (conversation by telephone). In this meeting, Commission staff discussed the following:

- the establishment of baseline data
- the learning delivery from the Commission evolving differently at PMC compared with the other teams
- Kaupapa Māori improvement models

In response to the first point, we had our baseline data ringfenced, as discussed. In response to the second and third points, I was unaware of a Kaupapa Māori model or framework specifically for quality improvement initiatives. The Health Equity Assessment Tool⁷ and He taura tieke: measuring effective health services for Māori⁸ would have some applicability, but not from the perspective that the Commission were looking for in terms of a quality improvement initiative. Instead, the Commission had provided a link to the Model for Understanding Success in Quality (MUSIQ) calculation with instructions to fill it in monthly. MUSIQ is a USA-based model that aims to enable users to conceptualise context-sensitive quality improvement implementation features. It comes with a scoresheet that ranks components of the healthcare system, including micro and macrosystem factors (Kaplan et al., 2012). Although I filled the scoresheet in, its applicability challenged me.

Given that the quality improvement project followed a Western framework, I further wrestled with how we could apply a tool with similar intent from a Kaupapa Māori conceptualisation. Kaupapa Māori, as discussed in the methodology section, conceptualises the world from a Māori perspective, unconstrained by a Western systems approach. It should always look to deconstruct and critically appraise or conscientise. On this occasion, my constructive feedback centred around the definition of partnership and rangatiratanga from a Māori perspective. I felt the Commission's aim to provide coaching/support/guidance for a practice improvement initiative had merit but should not dictate or decide the 'how' part.

The start date of our project was 6 months behind the other Commission projects, given June 1st 2017, was when we went live with the DST for all staff using the PMS. We were unperturbed about the start date, acknowledging that we did not have the same resources available to others and needed to work sustainably.

Nurses and kaimahi could see the dashboard and gout status, allowing everyone to use it. The week after we went live, I delivered a staff presentation to detail the project, recognising that communication across the PMC (including the whānau engagement) was essential. On this occasion, the call to staff was for input into tweaking any parts of the programme, particularly the DST. I also continued to analyse our ringfenced cohort and the data.

⁷ The Health Equity Assessment tool is a series of questions that challenge people to assess health initiatives for their current or future impact on health equity.

<https://www.health.govt.nz/system/files/documents/publications/health-equity-assessment-tool-guide.pdf>

⁸ He taura tieke is a framework measuring the effectiveness of health services for Māori based on the expectations of Māori consumers presented as a checklist.

The PMC nurse lead and I began a discussion with the PHO IT team for assistance with the idea of a webinar for clinical education purposes. This was not something they had done before, and it never came to fruition. In hindsight, given that we all became so skilled with Zoom in 2020 with COVID-19 lockdown situations, this would have been a simple solution. I also scheduled a meeting with the community pharmacist within the practice and made the gout resource available to the pharmacy. The pharmacy most used by enrolled patients is situated within PMC, with the pharmacist-owner having a trusted relationship with the community. The intent for him was to follow up with patients with gout, reiterate the need for long-term prevention, and provide the gout booklet (described in Section 4.2) if that had not already occurred.

In July, I updated the practice and scheduled to meet with the rheumatologist, who had been the long-time advocate for improved gout management. He asked to be involved as a source of advice if required. I welcomed his contribution. He subsequently sent an email to our practice team stating that he would like to be a team member for any patient with gout, and if a message was sent direct to him, he could offer advice that might increase the percentage of patients reaching the target level of <0.36 mmol/L.

Also, in July, the Commission considered where to hold the October workshop. I suggested it be held at the marae, giving the other teams a view of our paradigm. Both our team and the marae committee were very supportive of this as an extension of our manaakitanga. The invitation was not accepted. We were advised it would take too much time to get people to and from the airport to the marae, along with the formalities of a pōwhiri process. They projected that people might have been required to spend a night in Auckland.

In August, I drove to Auckland specifically to meet with the PHO nurse lead as she struggled with the capacity required for the project, which included requirements such as weekly teleconferences with the Commission, weekly updates, and monthly reports. She was also dealing with personal health issues. I picked up the monthly reports and any other tasks she required.

I continued to interrogate the data concerning classification or misclassification. In May, of the ringfenced cohort, 59% were classified with either gout or hyperuricaemia. This meant that 41% of people had no classification but had a history of being prescribed allopurinol or colchicine. By August, 97% of the cohort was classified as having gout or hyperuricaemia. Nine people had no evidence of having gout confirmed with direct contact. I worked with IT

to include a classification of ‘not gout’ and then filter for it so these people would not keep coming up on the dashboard to prompt prescribers to implement urate-lowering therapy. This could be potentially frustrating and add to alert fatigue.

Additionally, I finished the standing orders, which the medical director signed off for the nurses to implement.

In September, the Commission evaluated the programme via a contracted company. The evaluation team requested onsite visits with each of the three projects. We were advised that the feedback would ‘support the ongoing development of the programme.’ Again, the practice demands did not allow a site visit with the team. However, the PHO nurse lead and I spent individual time with the researchers in an interview. I emphasised and reiterated my concerns about the lack of equity and partnership approaches. In part, this appeared to be captured when the evaluation report indicated that “it was important to understand contextual factors that impacted on ‘partners’ and their abilities to engage in different ways, including cultural differences; levels of capacity; patient population and practice environment. There is a balance between spending enough time to understand the local context so the Commission can engage in ways that best suit each project team and respecting the time invested by the team members. The Commission should invest this time early, and it may involve engaging cultural or other advisors to understand how people are already engaging and support appropriate engagement strategies across the different project teams.”⁹

Other teams talked about how they had logged participation hours for their teams. One team had spent 220 hours in 4 months outside of help they were receiving from the PHO or the DHB. Another team discussed dedicating two people full-time in the practice, alongside the PHO and DHB assistance. This again highlighted inequity issues, with our practice being unresourced to meet this demand or to match this input. With the PHO nurse lead now unable to contribute due to health reasons, I was the only person explicitly dedicating time. Practice staff could only contribute if they could incorporate it within their day. It was clear that if Crown entities are genuine about an equity approach, they need to resource accordingly, or it becomes an anti-equity approach.

In September, I also hosted the rheumatologist and his senior nurse, who wished to observe how the DST worked and to share our other activities. The rheumatologist, as mentioned, has a long history of promoting best-practice gout treatment in South Auckland. He was also

⁹ Synergia report on Whakakotahi programme 2017.

interested in community education and agreed to provide an education session to the men's group. I linked our kaimanaaki, who coordinates the men's rōpū as well as multiple wellness and whānau ora activities at the marae, with the rheumatologist to enable this. They decided on a date in early December. I also worked with the kaimanaaki to ensure gout was part of the education package he delivered in his other programmes. He was provided with the gout booklet to disseminate as an education platform.

In early October 2017, my discussions with the administrative team at PMC led to them making a suggestion. They recognised that the traffic light dashboard system was not always enough to prompt action from clinicians. They suggested manually adding an alert in the notes section of the PMS to pop up as an additional prompt.

October also saw the second learning workshop held in Auckland. As mentioned, the invitation to host at the marae was declined based on timing. The organisers mooted any travel the night before would be met with resistance. It was instead held at a function room within proximity to the airport. This thwarted our hopes of getting some of our whānau along to the day. In conversation, they had discussed that they would feel uncomfortable attending a hotel seminar with health professionals instead of being in their marae or papa kāinga.

Although the Commission provided backfill resourcing for some staff, it was challenging to organise cover, particularly a GP who was available and able to provide culturally safe services to our whānau. GP cover proved possible with the medical director stepping in on a day he was not rostered to be. However, the Auckland venue proved helpful, with our kaimanaaki and the PHO nurse both able to attend without having to factor in air travel. We appreciated that the PHO nurse, in particular, could join us as she had significant health challenges. A presentation on integrated care largely took up the morning session. Our team found it insulting that we should be lectured on the point that “people should be at the centre of healthcare and that relationships are key.” I found it disappointing that this appeared to be a revelation to the speaker. Our clinical nurse lead threatened to walk out, such was her umbrage on this and his labouring of what we deemed a given – that health delivered in a collaborative, multidisciplinary approach is more effective – as well as his definition of Māori as ‘high needs.’ Our PMC team were all glad our ‘consumer’ whānau had not attended. I later discussed these points and the use of the term ‘kaupapa care’ with the speaker. He spoke from a non-Māori perspective and used the term when writing care plans for patients instead of empowering them to write the care plan themselves. The Commission

had requested the presentation and that the presenter was merely doing what was asked of him.

This second workshop with the Commission reinforced the inequity in partnering and participating organisations. Despite the other teams having dedicated personnel and data analysts, we felt our knowledge and approach were more authentically kaupapa-driven. This was reinforced at this October workshop when the South Island team sought our assistance in engaging with their local Māori health provider. Although 10 months into their project, they had no Māori input into any part of it. I had previously done work in their area with the Māori health provider (of which there was only one) and offered some contacts. The afternoon lectures covered Western models of change theory and presentations from each of the three teams. We were asked to present a framework of problem and analysis, including our fishbone and driver diagrams.

A couple of days after this event, I had a full and frank discussion with one of the Commission project managers on health inequities as a product of Western system imposition and power imbalance. To assess health improvement initiatives through a Western framework would fundamentally miss the point. She recognised this difference from us as Indigenous health providers and that she did not have the answers. She offered to fly up to Auckland from Wellington and meet with us as she knew our team at times felt challenged to continue the project. However, I had recent reassurance from the whole team of their desire and commitment to continue.

4.4.6 Optimal Medicine Management – Definitions

The processes described in the PMC initiative revealed a disconnect in the definition of optimal medicines management. This was demonstrated in the engagement exercises alongside the community champion definition through ‘problem’ identification. My reflections on the processes provided a unique insight into the research question of how gout medication therapy for Māori can be optimised. This section discusses the variance in outcomes or measures for optimal medication therapy.

Given that the fishbone diagram troubled me because we had developed an outcome without whānau input, I organised another educational session with staff and another hui with our gout champions/community. We had set our aim for the project without co-creation of that aim. It was the biomedical model against which we would continue to be measured. We had hung on to the Western approach (according to literature) and what the best practice/gold

standard looks like, as opposed to what whānau want – which should have been the fundamental core question. The community hui was attended by 17 people. Their united definition of ‘optimal’ was:

- absence of gout flares
- unencumbered access to regular allopurinol.

Attendees did not care whether their SUA level was 0.30 mmol/L or 0.38 mol/L as long as they did not have gout attacks and could enjoy ‘trigger food’ within reason, such as eating mussels without immense pain.

Consequently, they also did not care about annual blood tests – their barometer of SUA concentration being flares, with or without triggers. One of our champions discussed his trigger of banging his foot, which had historically ended in a gout attack. Since commencing allopurinol, he could knock his foot without feeling the impending doom. Annual blood tests were considered irrelevant if flares did not occur in the presence of a trigger. If an SUA level had been measured 3 years ago and was 0.32, and they were taking the same dose of allopurinol, they were unsure about the need for annual tests. However, we did discuss what ‘too low’ might look like and whether it may not be helpful to be too low. I presented the concept of a U- or J-shaped curve for health outcomes and SUA concentration. People suggested that it would be prudent to update at least every 3 years but more regularly if people were experiencing attacks or commencing urate-lowering therapy. This was a strong personal lesson for me in that I had not sought this outcome from the start. That is, I quickly framed up an application with a project aim that I had only considered from a biomedical perspective, not a whānau perspective.

Furthermore, feedback from the community indicated that auditing NSAID prescriptions was fraught with too much inaccuracy as people were far more likely to buy or borrow NSAIDs. It was significantly easier and cheaper to purchase Nurofen at the supermarket or ask a friend, for instance, than to access them via a prescription from the practice. Auditing for keywords in the notes to indicate how often flares were occurring was similarly deemed inaccurate.

I shared these lessons with the other Commission teams and suggested they may like to do something similar – e.g., I have never met a person with diabetes who aimed to decrease their glycated haemoglobin (HbA1c) by 10%. When I have had discussions around the treatment aims, they might proffer something like ‘I want to get back driving my truck again’, but not a biochemical parameter, as a priority. The teams discussed measuring such parameters as

being challenging. While understanding the complexity of measuring these, I proposed the need to appropriately define outcomes if they were committed to equity and a holistic health model. The other two teams did not seek to explore this further.

We left biomedical measurement parameters in our project for reporting purposes. Still, we were mindful of the outcomes whānau were looking for and wondered whether the DST could be tweaked to prompt a question to every patient with gout about the presence or absence of flares. Any staff member could do this and log in the records. Unfortunately, the IT expert who had been part of building the DST had left in September, and I was advised this was not possible. I saw such a prompt as helpful in many other health conditions, e.g., in people with asthma using short-acting beta-agonists. This was a missed opportunity and a big lesson on the determinants of best practice.

On December 6, I met with the PMC team. The men's only group had the evening session with the rheumatologist the following night. The kaimanaaki later reported that the men received this well, with free discussion evidenced by the questions posed. I also met up with the PHO nurse lead and updated her on our recent happenings to keep her in the loop and help her feel she was still part of the whānau. She had not been able to contribute or be present with us since the second workshop in October.

We had received quite a lot of feedback from the community on how hard it was to get in for appointments. Opening hours in the clinic conflicted with their work commitments. We resolved to trial an evening clinic session the week before Christmas, offering a free health interaction and prescribing for gout in our smaller wharenuī – Rangimārie. The administration team made an effort to prioritise contact with people we had not seen for 12 months. There were 41 names on the list; disappointingly, only six people attended. In hindsight, the period before Christmas was too busy to slot in this part of the initiative. However, it was an opportunity to have a group education session and use point-of-care urate testing for some. I resourced the purchase of the meter and the strips.

The kaimanaaki had often undertaken point-of-care testing when out and about in the community. He reported (later presented in the qualitative feedback from staff) that people always accepted a test, even when they denied having gout. This provided a challenge to ensure our data were correct. Once a person had a point-of-care urate test, I added the result into the PMS under 'measurements.' The system that populated the PHO dashboard did not initially pick up this. This caused some frustration for the clinicians with the traffic light

system, as people who had undertaken a test would appear red, but the warning may not necessarily be accurate. We had to wait until February for some IT assistance to rectify the problem.

Nevertheless, the data showed increased urate testing of those well overdue for testing, but unfortunately, it also demonstrated that we did not always act upon that information. The nurses had not used the standing orders to titrate therapy. I offered added assistance in terms of education. Although the nurses recognised education as necessary, time spent with people was most critical, and it was time that the nurses were short of.

In January, I received an email from the Commission team stating how pleased they were with our ‘amazing’ consistent improvement. Continued help would still be available if we needed it (given the other teams had now completed their projects). The Commission also questioned how they could be more responsive to the needs of Māori and, in particular, what changes were required for further iterations of the Commission initiative to be congruent with an Indigenous approach.

This message was prompted when I escalated my concerns about lack of equity outcomes in the programme, having discussed it with the Chief Executive and Te Rōpū Māori of the Commission. In response, a hui was held at Massey University with Sir Mason Durie and some staff from his department. I was not invited but was supplied with meeting notes which presented a distinction between the concepts of ‘improving quality’ (IQ) and ‘quality improvement’ (QI). QI included compliance activities such as auditing and ensuring best efforts. In contrast, IQ is a mechanism of empowering the health workforce to think about the continuous scientific method to improve health delivery. It requires understanding evidence, systems, human factors, improvement science, data and measurement, change processes, PDSA cycles, collaboration, trust and learning, fidelity and trust/just culture (Gabbay et al., 2018).

In contrast, it was noted that Māori think in values and principles, with Sir Mason identifying the following principles that operate within te ao Māori:

- engagement
- lifting the spirit
- integrated approaches – cultural and clinical, dual competencies
- whānau-centredness
- outcomes – measuring outcomes against clinical and cultural gains

- equity
- accessibility
- knowledge transfer
- healing vs treatment
- health.

The quality improvement team's soft skills are as necessary as the technical skills and learning skills. Soft skills encompass political skills, people-reading skills, and local knowledge. Technical skills include run charts and fishbone diagrams, whereas learning skills include group learning and critical reflection. The notes did not discuss the next actions and how such values and principles could be incorporated into a QI assessment tool. My suggestion was that the hui held with Sir Mason required building upon from a Māori practitioner and potentially Māori consumer perspective, perhaps through wānanga. To my knowledge, no further action was taken.

As noted throughout this section, the conflicting definition of medicines optimisation correlates directly to what hauora may mean when considering rangatiratanga of Māori versus Western medicine best practice associated with serum urate measurements of <0.36 mmol/L. This reflection was critical, and considering this point, the PMC project biomedical data showed that a major barrier to achieving our target appeared to be the annual blood test requirement. I was mindful of the outcome whānau were looking for (flare-free on challenge with triggers) and pondered how we might engage with people to check whether they were achieving this outcome. The opportunistic approach of waiting until people came into the clinic was not bringing any significant gains. A team dedicated to contacting and following up with people (whose contact details can change regularly) would have been ideal. However, our practice's real-world nature did not enable this. By the end of December (6 months since the implementation of the initiative), of 191 registered people with gout, 141 (74%) had been prescribed allopurinol recently (i.e., a 3-month supply within the last 4 months). However, only 55 (29%) achieved the gold standard definition of an SUA <0.36 mmol/L within the previous 12 months. Of the 154 people who had an SUA within 12 months, 61 had an SUA at target (40%), and 44 had no record of an annual SUA. Our denominator had increased from 160 to 191, classified with gout. This occurred by confirming classification and reclassifying some people from hyperuricaemia to gout. Investigation of urate levels >0.36 mmol/L demonstrated that 58 people (38%) had SUA between 0.36 and 0.45 mmol/L. In total, 113 (60%) people had an SUA <0.45 mmol/L in the

year previously. If we were to consider blood tests older than 12 months, 130 people (68%) had an SUA <0.45 mmol/L. Seventy people (37%) achieved the target if annual monitoring was not a requirement.

The final learning session was held in Nelson in the middle of March and was attended by our GP and nurse leads, our kaimanaaki and myself. As it eventuated, the session was not held in a marae, rather in a hotel conference centre. Nevertheless, Nelson required an overnight stay for us from the Papakura practice but not those from Wellington. In light of the prior concern over people potentially needing to stay the night in Auckland, when we offered to host at our marae, this seemed unfair. This was voiced to the Commission kaiwhakahaere, who attended.

Each of the teams presented their projects. Given that the other two groups had finished by December, they presented their final achievements. The South Island team had not engaged with any Māori consumers or health providers. They stated that they had tried via the PHO without a response. Their project had evolved to include the provision of reading material about the medicines. The information was presented in a bound folder alongside some website links to find more information. Our team discussed our concern about this approach and the issues of cultural literacy and access to data capability.

In the afternoon, we workshopped on ‘unconferencing’ – participant-oriented meetings where the attendees decide on the agenda and discussion topics. During this time, we could circulate and chat amongst ourselves. The Wellington consumer group were present again. They talked to our PMC team about how they thought the process or ‘partnership’ had been unsafe for them. They discussed being present at their project meetings but feeling they were never listened to and were only there to provide a tick. Sometimes, it was just one or two of them at a meeting, and they felt unable to share their feelings. I asked whether they had discussed this individually with any of their team leads, as surely this was not an outcome they sought. The answer was no. Our GP lead wrote on workshop pads about racist processes having no place and only contributing to further inequity. His understanding was that these thoughts would be collected and information acted upon.

I relayed this conversation to the Commission kaiwhakahaere and followed up with an email. I expressed concern that a Commission programme with a stated intent to address inequity had evolved into an anti-equity initiative. The people involved, especially the two lead Commission project managers, were well-meaning, but it was unacceptable for a Crown

entity to facilitate inequity. I was aware that a second round of the same programme was underway, and expedient action was required to prevent replication. Our GP lead also provided similar feedback.

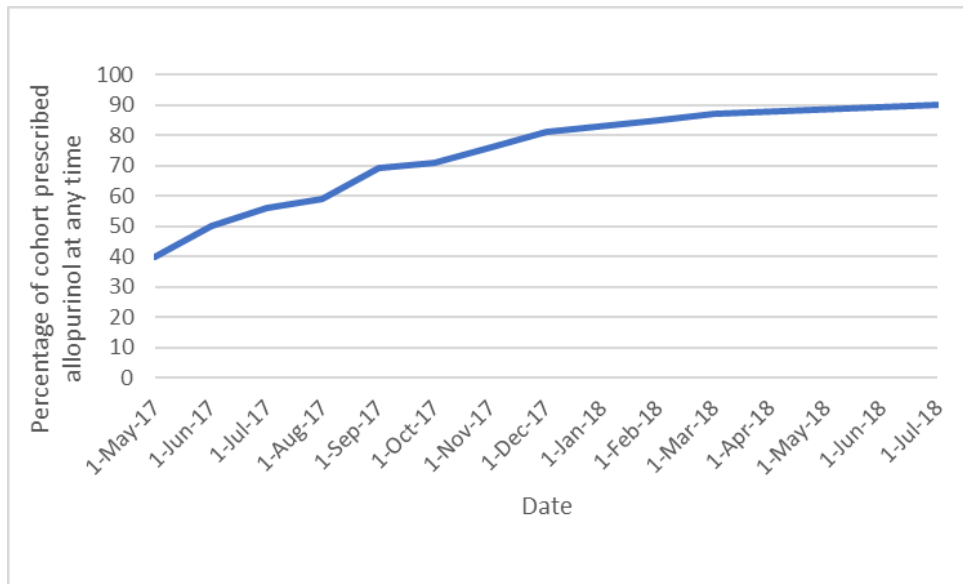
Added to this, the evaluation company disseminated their collation of interviews. They listed recommendations for future programmes. They emphasised that project capacity was imperative and that there should be two co-leaders. A dedicated project manager should be located within the practice, whose role includes time allocated to managing quality improvement and involvement with the team's activities. Again, the reality for us at PMC was that we did not have the luxury of such resourcing. There was no presentation of my earlier feedback and concerns about anti-equity. I saw this as a perpetuation of how inequity pervades. The company enlisted to provide evaluation had no Māori staff or equity expertise yet was tasked with assessing an initiative purported to address inequity. I requested that the Commission board be made aware urgently. I was advised they had been and that whatever steps were necessary to ensure that a repeat would not occur would be undertaken. I understand significant changes have been made to this programme and the Commission's governance and management since.

4.5 Results

The March workshop, in theory, marked the end of the programme with the Commission. However, since we started later than the other teams, we wanted to complete our 12 months and build on our learning. The Commission project managers, and one in particular, offered her assistance from a QI perspective, which was well received. However, we needed human resourcing within the practice and funds to undertake activities. Of course, there was the more sweeping and vital issue of solving inequity in social determinants for the whānau enrolled in our practice and the driver for demand.

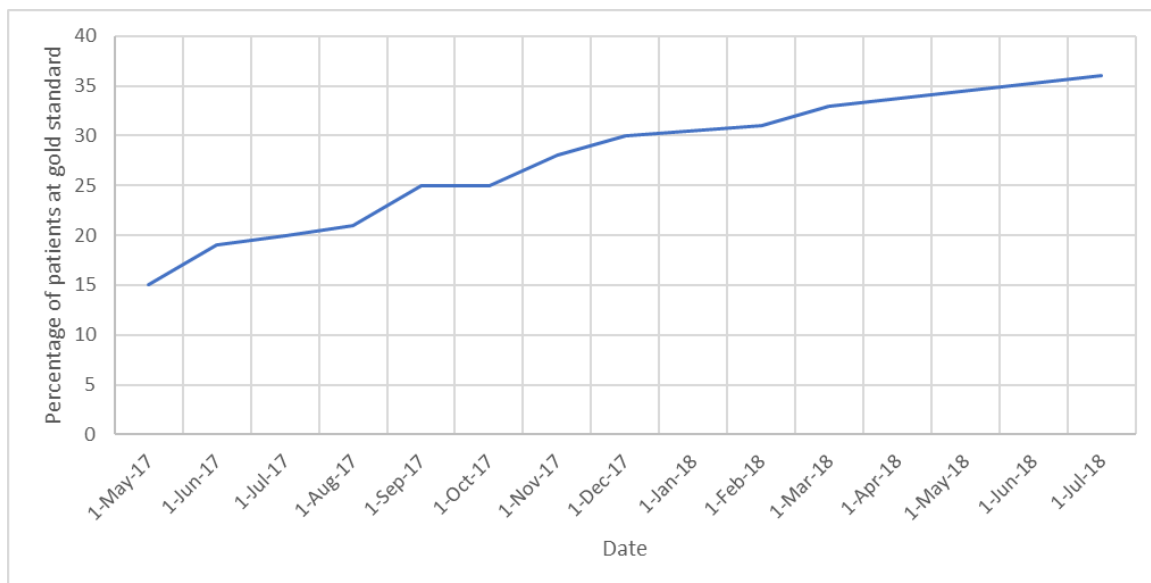
Regardless, we continued with our initiative monitoring data. On June 30, we had a cohort of 241 (30 people were no longer included for reasons such as death, incarceration, and transfer to other practices). Of those registered with gout (185), 62% had been on allopurinol 'recently,' with 90% prescribed allopurinol at one time (Figure 4). The average age of those not at target was 57 years; 13 people (11%) had no record of allopurinol ever being prescribed, and three people had no history of having an SUA result.

Figure 4 Percentage of Patients Receiving Allopurinol by Date, May 2017–July 2018



Short of contacting every person individually to ascertain flare occurrence and frequency, we were not able to define how many people achieved the definition of community best practice (i.e., flare-free despite challenge with known triggers). Throughout those 12 months, in our ringfenced cohort, 36% of people (up from 16%) achieved the biomedical model definition – i.e., a serum urate <0.36 mmol/L within the previous 12 months (Figure 5). A further 31% of people were in the next tier of SUA 0.36–0.45 mmol/L.

Figure 5 Percentage of Patients with Serum Urate <0.36 mmol/L (‘Gold Standard’) Within the Previous 12 months, May 2017–July 2018



Testing serum urate was one area we did have particular success with. In June 2017, the cohort had a baseline testing rate of 43% with an SUA test within the previous 12 months. In June 2018, that rate had risen to 93%.

4.6 Summary

The genesis of this initiative began in 2015 with an identified need. There was synergy with the intent to undertake this PhD, and the management of gout was deemed to provide an appropriate and helpful view into the layers of health inequity for Māori. Findings from the literature review and previous experience informed initial thinking into the types of interventions that might provide benefit. Work on a DST began with the PHO in addition to gaining momentum and cementing relationships. In 2017, an opportunity arose to ‘partner’ with a Crown entity to assist in the process. This was seen as a mechanism to advance our response in managing gout appropriately. From June 2017, we began the project with the Commission. As outlined above, we:

- conducted an audit that allowed us to ringfence a cohort of patients with ‘gout’, reclassifying or classifying people where necessary
- engaged ‘consumers’ (whānau) to ‘co-design’ a gout management initiative
- developed a DST to prompt prescribing according to ‘best practice’ for gout
- installed a traffic light system on the dashboard of the PMS to alert any user to whether people needed follow-up
- developed standing orders for nurses to implement urate-lowering therapy
- provided extra professional development for practice staff on the importance of consistent advice for gout
- provided access to gout health literacy resource previously co-created with whānau
- involved a community pharmacist and enabled access to the gout resource
- provided an evening clinic
- organised a men’s session with a rheumatologist
- organised a direct contact system to a rheumatologist for specialist support.

The major learnings from this part of the study are as follows.

Although key differences in partnership approaches are not new and have stained NZ’s history, the importance of the definition and the application of partnership should not be overlooked in contemporary times. Despite good intentions, we found differences in

expectations in our relationship with the Commission. Workload and ability to respond to requests became mismatched, which itself ebbs into inequity. Larger, well-resourced organisations and providers were better placed to respond to such initiatives. However, they were less likely to be immersed in disadvantaged communities. Furthermore, involvement in this project demonstrated that equity competence/capability should be embedded across all organisations and entities if the aim is a pro-equity outcome.

Reframing the application process to ensure lead-in time and a direction to seek the community view on the project's aim would have been appropriate. Not engaging the community before submitting our application was a fundamental flaw in the process. I should have articulated this to the Commission team, and if I had the opportunity again would undoubtedly do so. Equally, the Commission was responsible for ensuring appropriate consultation before submitting such applications. I understand this is now the process for this programme since my feedback. It is integral to provide a framework for applicants to demonstrate how they will authentically partner with their communities and allow sufficient time for that to occur.

This oversight impacted many facets of the initiative, e.g., the dashboard light system was built on the biomedical model. It prompted action if someone was 1 month outside the annual blood test requirement. Alternatively, they may have had a serum urate reading of 0.38 mmol/L and not experienced attacks in the presence of triggers, yet the red light would remain. This further added to the possibility of alert fatigue or dashboard dismissal. Importantly, it ran contrary to the community's priorities, which wanted the outcome of no flares in the presence of known triggers and were unconcerned about annual tests if flares were not occurring.

It is not new that clinical indicators, including biomarkers, often have no tangible connection for people, for example, blood pressure and serum cholesterol. However, biomarkers can provide meaningful guidance for clinicians managing risk. Achieving a balance between risk mitigation and patient priority can sometimes require a mix of approaches (Williams et al., 2016).

In principle, I have no objection to the definition of medicines optimisation provided by the UK National Institute of Health and Care Excellence: "medicines optimisation is a person-centred approach to safe and effective medicines use, to ensure people get the best possible outcomes from their medicines" (National Institute for Health and Care Excellence, 2015). I

came to appreciate the subtleties that are not necessarily implicit. For instance, who gets to define ‘best health outcomes’; are people empowered through cultural and clinically appropriate mechanisms to make their right decisions; does the definition include the availability and accessibility of pharmacotherapy to ensure the best possible outcomes? This definition also speaks to a utilitarian view that does not address inequities.

There is no current consensus that a serum urate of 0.39 mmol/L carries an increased mortality or morbidity risk over that of a serum urate of 0.35 mmol/L. This is on the proviso that flares are not occurring at that higher level. Similarly, there is no evidence that a person is at risk of worse outcomes if their blood tests are taken at 11 months or 22 months.

We did not achieve the improvement we had originally aspired to: we reached 36% of people achieving gold standard therapy after 12 months versus the 70% we aimed for. We did not see 70% as an unrealistic target when we set it, but on reflection, it was naïve. The pervasion of community disadvantage seeps through to how the health system sets up the practice delivery. This is presented in Chapter 6. Further, gold standard is a biomedical guideline measurement arrived at without whānau input. One area we did have immense success with was in testing serum urate. I believe this was because we involved all staff in the project. The difference was in the kaimanaaki visiting people at home, at the pools, and at church for point-of-care testing and capturing them in the clinic with the administration prompts. This demonstrates that non-regulated workers are as important in delivering healthcare as regulated workers. They are, at times, more valuable. This is shown in Chapter 5.

The perspectives of the PMC staff and the Papakura community on this initiative are covered in the three subsequent published papers. These papers shine a light on the compounding inequity that is alluded to here.

The PMC initiative highlights the challenges of contrasting ‘measures,’ yet within this conflict, self-determination can be a commensurate response to Western ‘best practice.’

Chapter 5 The Community View

This chapter explores the community's view on the PMC initiative and on a partnered health delivery model to manage gout.

It was originally published in the *MAI Journal*:

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This publication is inserted as published, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis. It is included in the thesis with permission from the *MAI Journal*.

The Long Shadow of Inequity for Māori with Gout: *I Just Kind of Wanted to Close Myself Off and Die*

5.1 Abstract

Gout is a health condition that can be managed to prevent morbidity and premature mortality. Māori have a higher prevalence of gout yet are less likely to receive appropriate care than non-Māori. There is scant literature presenting the patient/whānau voice relating to the health system response to gout.

The study reported in this article aimed to highlight barriers and enablers in achieving best practice management of gout as defined by patients to inform the development of appropriate pathways and services. Using a Kaupapa Māori approach, interviews were undertaken with 23 participants as part of a multi-layered intervention to improve the management of gout for Māori. Two domains emerged from the analysis of the interview data, the first relating to biomedical practice and the second relating to Kaupapa Māori. Both domains were overarched by the theme of te ara pai—creating interwoven solutions to shift power. Reframing the health system to enable rangatiratanga for Māori would address inequity for Māori with gout and is likely to benefit other health conditions.

5.2 Background

With increasing discussion on reframing the health system to produce equitable health outcomes for residents of NZ, this article highlights some of the gaps where attention is needed for this to be realised. It brings to the fore issues that are pertinent to processes such as the Health and Disability System Review (2019) and the Waitangi Tribunal Health Claims (Waitangi Tribunal, 2019). These processes are looking to address inequity and improve models of care, especially for Māori who are most disadvantaged within the current system.

Māori have the highest mortality rate across genders and all ethnicities in NZ (Ministry of Health, 2015a). There is overwhelming evidence of inequity in multiple health outcomes for Māori (Robson & Harris, 2007), including cardiovascular disease, diabetes, and gout (Stokes et al., 2018). Gout is associated with significant morbidity and premature mortality (Clarson et al., 2015; Fisher et al., 2017; Dalbeth et al., 2012); it is present in an estimated 38% of Māori men aged 65 years and over (Jackson et al., 2014). Recent developments in the understanding of gout indicate that it is best considered a disease of urate transport, with the

occurrence of gout principally due to genetic variation. The earlier understanding of gout was that it is a disease of purine metabolism with occurrence primarily due to intake of alcohol and specific foods (Dalbeth et al., 2019b). The former lends itself to an informed discussion about preventing gout; the latter lends itself to blaming patients for ‘poor lifestyle’ choices. In NZ, there is an inverse relationship between those regularly receiving gout-prevention medicines and those experiencing gout (Dalbeth et al., 2016). For Māori, this inequitable management of gout is described as not only unjust and unfair but contravenes both versions of NZ’s founding Treaty document and the United Nations Declaration of Indigenous Rights (United Nations, 2008; Dalbeth et al., 2018).

Gout is readily diagnosed and treated with inexpensive and relatively safe medicines to prevent acute attacks (Doherty et al., 2012). Allopurinol, taken regularly and long term, is the preferred medicine to manage the cause of gout. Prevention becomes increasingly important with disease progression and in the presence of reduced kidney function (Richette et al., 2017). Best practice clinical management of gout consists of lowering serum rate to a target depending on whether tophi – hardened lumps of monosodium urate crystals under the skin – are present (Dalbeth et al., 2019b). Gout is predominantly managed in primary care.

Studies have investigated gout perception, beliefs, and understanding from both patient and clinician perspectives nationally (Humphrey et al., 2016; Martini et al., 2012) and internationally (Harrold et al., 2012; Harrold et al., 2013). We are unaware, however, of gout studies that explore systems issues, nor have we found any such studies undertaken in an Indigenous research framework, in this case, a Kaupapa Māori approach (Curtis, 2016). Such a research approach intends to be ‘conscientising’ and transformative with Māori at the centre. It also seeks to be guided by principles that enable self-determination by Māori and to undertake a critical analysis that unpacks and exposes the current system (Smith, 1997).

The work reported here is part of a larger project that seeks to understand and importantly to address the barriers and enable optimal gout management for Māori, in the context of historical and current inequity in health services and outcomes for Māori. This study sought stakeholder experiences of a ‘gout programme’ at a marae clinic with a focus on the key factors in the ecosystem for Māori. It aimed to describe these factors and their relationships within the ecosystem, in addition to the impact of the programme on the system.

5.3 Methods

The study was sited in a single general practice (a marae clinic) in Auckland, NZ. The practice serves an enrolled population of more than 3000 people and sits under the umbrella of a Māori primary health organisation (PHO). The enrolled population is predominantly of Māori ethnicity (~80%), with the remainder Pacific (~12%), NZ European (~6%), Asian (2%), and other (2%) ethnicities. Most people (98%) enrolled at this clinic (98%) live in neighbourhoods categorised in the lowest deprivation quintile as measured by NZDep13 (Crampton et al., 2020).

From June 2017, a multilayered ‘gout programme’ evolved in response to the evident and urgent problem of uncontrolled gout in the practice patients (Table 4). The approach looked to improve both clinician response, based on current best clinical practice, and community engagement, to empower whānau to support self-management. Evaluation of the programme commenced in 2019 and included interviews with stakeholders and an audit.

Table 4 Outline of Problem and Response

| The problem | Stakeholder engagement | Multilayered initiatives |
|--|------------------------|---------------------------------|
| Before programme implementation, only 14% of those enrolled at the practice achieved clinical best practice management of gout | Community members | Community design and hui |
| | Practice clinicians | Decision-support tool |
| | Kaimahi | All-of-practice staff education |
| | Rheumatologist | Nurse standing orders |
| | | Point-of-care urate testing |
| | | Health literacy resource |
| | | Evening clinic |

5.4 Participants

Māori enrolled at the practice were eligible to participate in an interview if they had experienced any component of the multilayered intervention. People were purposively selected for invitation to be interviewed, seeking to include people from one or more of the following categories:

- those who had taken part in community hui, both males and females with a range of ages
- those who had interaction in the clinic only, both males and females with a range of ages

- those who have achieved ‘target’ serum urate levels
- those who have not achieved ‘target’ serum urate levels.

Participants were initially approached at the marae where the practice is situated by kaimahi, who have a trusted relationship with whānau. This was followed by one or more meetings with the lead investigator to explain the study, answer questions, and obtain written consent. Interview meetings were scheduled individually and took place at a venue of the patient’s choice (in people’s homes or at the marae). Interviews were conducted by the lead investigator, generally lasted about 60 minutes, and were audio-recorded and transcribed verbatim, also by the lead investigator. Participants were offered a \$20 grocery voucher as koha at the end of the interview but were unaware of this during recruitment. Whānau were encouraged to attend alongside participants.

Given the lead investigator/interviewer had a part-time role in the practice, the possibility of a perceived conflict of interest was managed by being explicit with participants that their feedback was anonymous. Further, it was essential to receive all types of feedback, both negative and positive.

The interviews were semi-structured, with open-ended questions used flexibly, to allow the conversation to flow. As part of the process, whakawhanaungatanga was essential in building the relationship with the participants. Engagement with the participants was guided by the seven Kaupapa Māori practices intended to guide Māori researchers – Box 4 (Te Awekotuku, 1991).

Box 4 Kaupapa Māori Practices

Aroha ki te tāngata (a respect for people)
 Kanohi kitea (the seen face; that is, present yourself to people face to face)
 Titiro, whakarongo, kōrero (look, listen, speak)
 Manaaki ki te tāngata (share and host people, be generous)
 Kia tūpato (be cautious)
 Kauga e takahia te mana o te tāngata (do not trample over the mana of the people)
 Kauga e māhaki (do not flaunt your knowledge).

5.5 Analysis

From listening to the interviews during the transcription process and through the iterative reading of the transcripts, phrases and sentences recognised as recurrent themes were

categorised using qualitative research software (NVivo, QSR International). Braun and Clarke's (2006) six-step phased approach was used as a general inductive method of analysis with consistent and pertinent kōrero allowing themes to emerge (Thomas, 2006). Reviewing, defining, and naming themes was conducted several times. Reflexivity was a core component of the process in that this research is emancipatory, being underpinned by the social responsibility to change an inequitable situation (Baker et al., 2004).

Triangulation and consensus were undertaken with all authors, using this general inductive method of analysis and agreement on themes. Participants were invited to a hui at the marae, at which initial themes were presented. Their collective feedback was discussed and confirmed the validity of the provisional themes presented.

Ethics approval was granted by the Northern B Health and Disability Ethics Committee – reference: 18/NTB/213 (Appendix 4).

5.6 Results

From a list of 192 potentially eligible people, 23 were invited to be interviewed, and all accepted. Some were more recent enrollees, and some were long-time patients at the practice. Whakawhanaungatanga revealed all participants had a strong connection to their Māori heritage. Sixteen were male (average age 55 years, range 24–82 years) and seven were female (average age 62 years, range 47–85 years). Twelve people had achieved the target serum urate level of <0.36 mmol/L. Eleven people had attended educational sessions.

Participants often responded in a mix of English and te reo Māori, reflective of the participants and kaupapa of the research. This process provided participants with an opportunity to respond using their own terms. Communicating bilingually was an important practice for participants and reflected their worldviews.

Five core themes emerged, which were unanimously endorsed by participants. The themes have been situated into two domains, representing two contrasting perspectives: Western biomedical practice and Kaupapa Māori understandings of health and wellbeing (Table 5).

5.6.1 Themes

Table 5 Core Themes Endorsed by Participants

| Themes | |
|--|--|
| Domain A – Biomedical practice | Domain B – Kaupapa Māori |
| Western health system - access and health professionals | Hauora – holistic health and well-being (Whānau – collective embodiment) |
| Medicines – prevention versus treating symptoms | Mātauranga – Embedded knowledge and knowing |
| Te Ara Pai – creating interwoven solutions of shifting power | |

There is an inherent crossover between themes. They are separated to support analysis for systematic change. The first domain is Western in the sense that it represents the health system and medicines. While medicines sit within the system, they were a specific element discussed beyond the system itself. The second domain is Indigenous, specifically Māori, and highlights participants' perspectives on their lives and experiences.

5.6.2 Domain A - Western Health System

The NZ health system provided the most significant overarching theme raised by every participant. In presenting this theme, the points of discussion will include access and health professionals.

Access

The single most common theme expressed by interviewees was access to the health system. Access was represented in two streams of commentary. The first was physical access. Participants referenced the ability or lack thereof to get into the clinic. For those in employment, this was especially problematic. Some had to take the whole day off work to be able to attend a consultation. This was due to the logistics of the hours and place of employment. If, for example, one participant worked on a roading crew, and the collective transport left at 6:30 a.m. and returned after 5.00 p.m., there was no way they could ‘pop in’ for a consult. Hours of employment were often outside the clinic hours, and places of work were sometimes a long commute from the clinic and participants’ residences.

For some, a lack of transport was integral. One man discussed not having access to a vehicle, and with public transport unavailable, he simply could not get to the clinic. For acute

conditions like a gout flare, exacerbation of heart failure or pulmonary disease, walking was not an option.

Despite the acknowledgement of clinic staff working to capacity, another point of discussion was the inability to acquire an appointment promptly. For acute conditions, the delay was considered too long. Waiting times, once appointments were made, could be stressful. Employment absence was especially challenging to manage and, at times, led to participants leaving before being seen:

[I] find it hard to say to my boss, “Hang on, boss, I might be another hour because I can’t get into my appointment yet.” I mean I still got to get the medicines and maybe even get to the lab if the nurses are too busy to take my bloods. (male, 46–60 years)

The second aspect of access is framed as financial or economic. Cost was a significant barrier that prevented participants from accessing services, including making initial contact by phone. This was a barrier if participants did not have credit on their phones. Further to transport issues already mentioned, there was an added concern over the cost of transport. The direct costs of ‘the system’ were, however, proffered more often as a significant barrier. The cost to see a general practitioner (GP), including losing income when taking time off work alongside medicines co-payments, was most often talked about. For participants who owed money, this situation was compounded:

I think it’s like 15 or 17 bucks a visit, and because they might have already had three other visits that haven’t been paid, it’ll stop them from coming in. And yeah, most of them are just too whakamā to come in and sort it. (male, 24–45 years; referring to whānau members)

Participants lived on such a fine line in terms of finances that several discussed going without GP consults or medicines if an unplanned expenditure occurred. One man talked of inadvertently losing his medications when moving house and simply not having the money to get another prescription to replace them. Another man discussed starting a job working in the freezer department at a food factory. This required him to buy warm clothes, which became the priority over medical access. As disease progression occurred, participants in more physical work roles were unable to continue their jobs:

I was quite a physical man back then. I used to work on the rubbish trucks and then a lot of real physical work. Then I went into roading—because it was less [physical] so that sort of caught up with me as well, so I had to chuck them all in. (male, 46–60 years)

I was working as a fork hoist driver and was in the warehouse doing a lot of lifting [and had to leave]. (male, 24–45 years)

Ironically, when participants lost employment due to gout, this improved their access in terms of being able to attend appointments during the day—but money became tighter, creating a different barrier: “And it’s so disabling—I went onto the sickness benefit for [gout] because it kept coming that continuously” (male, 24–45 years).

This man had been employed as an underwater engineer and eventually lost the ability to hold a welding torch due to joint damage of tophi. He went from earning a “good wage” to being on a benefit and struggling to pay for clinic appointments.

Health Professionals

Health professionals were often the first point of diagnosis and, as such, the first point of providing information about gout. Doctors at both primary and secondary levels were explicitly mentioned, as were primary care nurses and community pharmacists. People discussed the continuum of care and the ability of health professionals to influence and assist with health outcomes. The feedback centred on the variance of engagement and the provision of information that people found later to be incomplete or inaccurate. This was particularly so for people who had a long history of inadequately managed gout. One man discussed his first experience of gout some 20 years ago, diagnosed by his family GP. Management, he recalled, was the advice to cease consumption of seafood and tomatoes alongside daily colchicine administration, which he estimated was for 14 years. He understood now that this was not best practice management or gout prevention.

The most common message people heard from all the different health professionals mentioned above was that gout is caused by food and alcohol. The advice was therefore aimed at directing people to avoid certain foods and alcohol. Even if people expressed their non-consumption of such items, the focus remained.

But he asked me, I don’t know how many times, did I drink. And I said no. He couldn’t understand why my uric acid level was so high. And I just couldn’t understand either. I said no, I don’t drink a drop (female 40–59 years)

Without exception, the belief that food and drink were the sole cause of gout was either a long-held belief or the current belief. This belief had either been initiated or perpetuated by health professionals. Participants also identified a lack of information provided by health professionals that enabled them to understand that urate-lowering therapy can prevent gout flares. Therefore it was common for people to believe the management of gout consisted of only pain relief rather than prevention with urate-lowering therapy. Many people used the terminology ‘gout pills’ when discussing medicines for symptomatic relief, especially

diclofenac. This is raised under the umbrella of health professionals as it reflects the competency of the health professional to follow evidenced guidelines engaging further with people and imparting understandable information. This issue is also discussed under 'Medicines' below.

One participant discussed the feeling of being let down by a series of different health professionals (doctors, community pharmacists, nurses) and feeling the need to find an alternate path themselves.

I thought, you're not making me better, you're just prolonging my (illness), you're just keeping it at bay so it won't hurt no more and telling me to come back next week and get some more gout pills and that's the way I was thinking, crikey I'm sure there's a better way of getting rid of this (male 61–82 years)

It was common for participants to report feeling that practitioners' communication was ineffective. Some agreed that perhaps they might have been told about the management of gout, but because they could not understand the conversation, they could not recall it. Further, they found that health professionals, in general, and doctors, in particular, were quick to give instructions without engaging: "And that's what is aye – Drs talk on top of you. They keep saying – you gotta do this, you gotta do that, you shouldn't do this, you should do that" (male 24–45 years).

This type of commentary ranged from clinical competencies to discussing the realm of cultural safety. Participants spoke at length about the relationship between the provider being the key to access and understanding: "The barrier for me is having people that connect with me. Health professionals need to think aye – they need to think like normal people. They need to come back down to earth" (male 24–45 years).

Participants discussed feeling judged by health professionals, and this prevented them from sharing or receiving information: "They feel like they'll be judged – that happens that's what it is. ... Ask me that, I've been there done that. I've been to lots of doctors" (male 24–45 years).

One man felt his "mana had been trampled", while another talked about the propensity of health professionals to approach the interaction from a deficit model.

Oh yeah and they mostly say all the negative stuff – that's how I think of it – because you are dragging the person down. Why don't they get on and give them what they really need – a bit of love – bring their spirits back up again – aye that can go a long way. (male 24–45 years)

One participant had become convinced that it worked in health professionals' favour to provide only symptomatic treatment as this would ensure revenue.

Yeah, all they wanted was their fee, prescription, and then see you later, come back, and here's a month's supply. And that was it, and that's how I believe they made their money. (male 61–82 years)

Another thread presenting itself under the umbrella of cultural safety of health professionals surfaced when participants discussed being advised not to consume kaimoana. It was clear that some participants saw kaimoana as more than just a food group. Participants discussed kaimoana as a cultural rite and a right, as a connection to their upbringing and their whenua. The elimination of this food is, therefore, often incomprehensible as it is part of participants' identity. As one expressed, "I mean to say it is our kai" (male 61–82 years).

Another commented, "Kaimoana. It's our cultural thing isn't it" (male 24–45 years).

Medicines

The class of medicines most often discussed were non-steroidal anti-inflammatory drugs (NSAIDs). Whilst this class of medicines can be helpful in acute circumstances, they have the potential to cause significant side effects, including kidney damage, and should not be used frequently (Richette et al., 2017). In particular, the most talked about and valued was Voltaren, which was generally referred to as 'gout pills', as noted above. Only one person proffered the generic name of diclofenac. This medicine was prized as being effective for most:

I was buying them for 12, 13 years maybe 14 years or even longer. When I first got the gout my mate said, 'you got the gout' and he gave me the pill and that same afternoon from the morning the pain was gone. (male 61–82 years)

This commentary was from a man who stated he bought Voltaren from the same pharmacy for all those years without being questioned or redirected. He admitted there had been a cost to purchasing the tablets. Still, this cost he had calculated was significantly less than having to take time off work to see a doctor and pay the associated costs.

It was common that participants would acquire Voltaren through multiple mechanisms. Buying was one method. The most common method, however, was 'borrowing' or 'sharing.' One man talked about his workmates having a 'pool' of supply that they could all access to prevent absenteeism. Another participant also discussed using food to barter for Voltaren, paying people in eggs or bread for some of their supply. Every participant knew of Voltaren.

Some people knew it as the 'pink triangle gout pill,' but most knew the trade name. Many were confused about its role: "We only know them as gout pills" (male 24–45years).

As participants often took NSAIDs before enjoying food triggers, they misattributed Voltaren and NSAIDs as preventative medication: "Prevent it from coming on, isn't that what Voltarens do?" (male 24–45 years).

Participants had no concern over the dose of the medicine they were administering, rather the priority of pain resolution. One man discussed his regular approach of administering 450 mg diclofenac in a 6- to 8-hour time frame. This being three times the maximum dose in a 24-hour period. Two participants reflected on buying ibuprofen when diclofenac was unavailable. Nurofen (ibuprofen) was viewed as being more readily accessible through supermarkets at a much-reduced cost. Two participants spoke about purchasing packs of Nurofen Zavance (sodium ibuprofen) tablets during an attack and using the entire pack to get relief. Participants sometimes volunteered that they were aware medicines could have unwanted effects, but this knowledge was incomplete and inconsistent.

In contrast, participants who had been administering allopurinol were clear that its purpose is gout prevention and said it had changed their lives. Many adjectives were used to praise allopurinol, including "wonderful" and "amazing." People stated they did not mind taking medication every day if it meant the pain of gout would be prevented: "All I know is that it's (allopurinol) got magic in it. It is magic. If you don't take it you're gonna be in pain" (male 24–45 years).

One man discussed a 50-year history of gout flares and how he did not realise life could be flare-free until he was prescribed allopurinol.

I think the priority of not having the gout is good for me and it is good for my family. You know I can spend a longer time with my mokos (sic) and you know I look back on the past and how I used to struggle with gout and it's not that good and it's awesome how I take the pills now. (male 61–82 years)

When asked hypothetically whether they would have administered allopurinol regularly if they had been prescribed it after the first couple of attacks, participants were adamant that they would have, with one answering, "Yeah, oh yes, wholeheartedly I would have signed on the dotted line too myself" (male 46–60 years).

Six participants stated they also believed it was helpful to get the allopurinol in blister packs. They found blister packs very helpful, especially in trying to recollect whether the medicines had been taken for the day or not

5.6.3 Domain B – Kaupapa Māori

This domain's themes relate to Māori concepts and participants' perspectives on them in relation to their experiences with gout. It should be stated, however, that there is difficulty in isolating single themes in the commentary due to the concepts behind the words being complex in their interconnectedness.

Hauora

The Waitangi Tribunal (2019, p. xxi) defines hauora as “holistic health and well-being.” For Māori, this means to be well and in balance with the physical, spiritual, and environmental community in which people live. It is reflected in whānau and is interconnected to the environment and mauri of a person. In considering the ‘vital essence’ or wellness of a person, the key point made by participants was the scale of pain to their bodies. Without exception, they spoke of how significant, disabling, and demoralising it was, such that they “wouldn’t wish it on their worst enemy.”

It was common for participants to be unable to weight-bear on affected joints, and therefore they struggled to walk. This made it challenging for people to function at the most basic level. Participants talked of the different sites that the pain could occur, often describing initial attacks occurring in the feet with extension upwards: “Yeah, and it was just my foot, then knee, elbow, shoulders, fingers, toes, just moves everywhere on the body. Man and it’s so sore and disabling” (male 24–45 years).

People talked about feeling like the pain of gout was happening without any breaks: “I was getting gout after gout after gout” (male 61–82 years).

For some participants, this could also mean an extension to urate kidney stones, and they talked of admission to hospital with the sequelae of this.

The barriers in access to timely, appropriate, safe healthcare led to disease progression and many years of painful suffering for participants. For some participants, the repeated cycle of gout flares had led to permanent damage to joints. This had broader implications apart from employment as discussed above. Participants talked about losing the functional ability to carry out activities that had been part of their lives, including being able to play sport, undertake cultural activities like kapa haka, or even just being active.

Hauora reflection and engagement for participants ultimately revealed what became an erosion of their spirit or wairua. It often began insidiously, with employment changes as gout

progressed: “I went to Security after the farm, but prior to that, I was always an outside doors person. I like being outside. I don't like being stuck inside” (male 24–45years).

For others, the loss of functional ability to carry out a treasured activity also meant a disconnect from a wider whānau subset, for example, kapa haka and sporting whānau.

That's the most hurtingest [sic] thing, like I see my mates now and heaps of them are in good teams like Auckland Blues [a rugby team] and some of them fly over to Australia for their games, and they're always telling me bro, you're better than all of us. And I always think oh man, I can't even play rugby anymore. (male 24–45 years)

Participants for whom the pain of gout was a regular occurrence and for whom the downward trajectory of losing employment, losing functional ability, and losing confidence led to them feeling worthless and questioning life.

Yeah, like being that disabled when you can't do anything, it does drop your self-esteem, your motivation, everything goes out the window. Like when I had it real bad eh, I didn't want to do anything. I didn't want to talk to anyone, I just kind of wanted to close myself off and die. (male 24–45years)

Whānau

This subtheme is included under the theme of hauora because health is not an individual endeavour to Māori: whānau are intertwined with well-being and flourishing. The concept of whānau is a collective representation of generations who share genealogical descent. It also includes nonbiological relationships that are important to the individual. Whānau are often connected to a physical place and, in a more metaphoric concept, descend from a narrative of Māori creation stories. The literal translation of family from a Western perspective differs from the extensive interconnectedness of physical, spiritual, and geographical identity that inform whānau.

Whānau featured prominently as a component of participants' well-being and a reality in thinking about health outcomes. Participants had lots of experience of watching other whānau members with gout: “Dad had the gout for as long as I can remember” (male 46–60 years).

People recognised the possibility of genetic predisposition with gout. Participants reported “gout runs in the whānau.” One participant identified gout was not only prevalent in his whānau but Māori generally.

We were eating the same kind of kai, me and my pākehā mates, we go to school at the same time. You know, we're partying the same time aye, you know. Next minute I'm walking around with a big fat toe and they aren't. (male 61–82 years)

There was an association between the experience of their loved ones and the pathway that the participants followed themselves. Those whānau members who had ‘managed’ only symptomatic treatment of pain over many years often provided medicines for symptomatic treatment to the participants. This became the model of treatment the participants discussed.

Conversely, if a whānau member was well controlled on allopurinol, the outcome was different.

Yes, I thought it was an older person’s sickness, and never thought that I could get it as young as I did. But, Dad became a good friend to talk with as well, – got advice from him and he kept drilling into me, take your pills every day (male 24–45 years)

Not only were whānau sometimes the diagnosticians, a repository of knowledge and suppliers of medicines for pain, but they were also the greatest sources of support.

I’ve been stuck like this and couldn’t stand up, and my partner’s had to shower me and stuff like that. It’s been that bad, and I’m surprised she’s stuck by my side this long, but she’s helped me a lot and I’m getting my health back on track. (male 24–45 years)

As a corollary, the ripples of gout strongly affected whānau. Participants were unable to partake in whānau activities, they required extra support, there were fiscal implications at several layers, and whānau became emotionally upset at watching their loved ones suffer repeatedly.

You’re crying too, and it’s so sore and you look up and see everybody who cares about you trying to help you. But you know they can’t really do anything, and you go to the ambulance and the hospital. And it’s happened a few times too, so I’m used to it now, I’m in and out of hospital too many times. (male 24–45 years)

Participants also spoke about how they viewed their roles as a resource for the next generation of whānau. Those who were no longer suffering painful attacks wanted to ensure the transmission of correct knowledge to avert unnecessary suffering. They were already taking the opportunity to share their knowledge and experiences where appropriate.

Mātauranga

For the purposes of this research, mātauranga is the realm in which knowledge is transferred from generation to generation. Its genesis is the creation story of the world today and is inclusive of new knowledge and new development. It provides a framework for societal lore and engagement physically, environmentally and spiritually. To possess knowledge is to enable empowerment. Concerning knowledge of gout, participants discussed the gaps they had come to recognise: “You know, there was nobody out there that educated me on how you get gout” (male 61–82 years).

Many discussed inaccurate information or knowledge, conjuring negative connotations. The common threads for this tied back to believing gout was caused entirely by ‘poor lifestyle,’ especially food and alcohol, and that it was associated with old age. This lack of knowledge had consequences of its own. Participants talked about the denial that they saw or experienced.

...Maybe it’s bravado, I don’t want to be seen as the person stuck with a label, he’s got gout or he’s sick. Possibly because of some of the reasons that the associated causes like alcohol. I used to think, ‘cos I didn’t drink, I used to hate saying that I’ve got gout ‘cos people just associate gout with alcohol. And some that did know me through Church, and I didn’t want that stigma. (male 24–45 years)

One person went so far as to say that people were “afraid” of the word gout because of this misinformation, while others discussed being whakamā or shy about admitting they had gout.

These emotions were predicated on perceptions that were not wholly accurate. The most common ‘myth’ that had become so entrenched was that of food again. People discussed spending an extraordinary amount of time thinking about what they could do to solve this issue. The concept that food was the sole cause of gout was reinforced by participants’ experience of linking pain with eating ‘trigger food.’ Some people, however, realised there must be more to the aetiology by observing food avoidance did not necessarily lead to gout prevention.

I stopped the kaimoana for a couple of years and it was still coming back, so I thought man, it must be the way I’m eating. You know, so I tried to change the eating, but it still comes back, and I’m thinking what is it. (male 24–45 years)

Participants presented overwhelming kōrero that they should be provided with tailored, logical understanding to integrate their thinking and approach to gout. They referenced wanting education and communication to move away from the focus on food and alcohol.

Yeah not food and alcohol and all of that. It's the acid within, where it is, how it's produced, why it's produced. All those little things that we're never told about ... when people do understand it then they get, they recognise what's going in. (female 40–59 years)

Participants talked about the need to understand the condition and the medicines.

I think everybody should have education right across gout. Everybody should know what causes gout. Everybody should know how to manage it. I didn't know those things before I got on the allopurinol. Education everybody should have it. (male 61–82 years)

Education was hence identified as the key to empowerment with a proviso that knowledge needed to be provided under the umbrella of cultural safety to enable self-management.

Te Ara Pai

Te ara pai could be loosely translated to meaning ‘the right path.’ This theme, therefore, captures participants' reflections and recommendations across the other four themes. It considers what has worked well for participants and what advice they have. Te ara pai is a platform for transformational change to enable the flourishing of health outcomes.

While most of the feedback stresses failures of professionals, policy, and process in the health sector, there are also reflections on how the system can respond, highlighting the elements of success. These represent insight and opportunity for systematic change. The participants also provided specific recommendations on what is required to bring about change.

Perhaps unsurprisingly, the recommendations centred on mitigating barriers. It was recommended that access hours be available outside of what is currently an option.

You've got nothing between say 4 and 10 at night when they can access. They need that kind of treatment and there's no funding for Māori after hours. ... that would be good for all those ones working, 'cos they're not getting a lot of money. (Female 60–85 years, discussing her observations)

This participant also promoted the idea that hauora clinics – designed explicitly by and for Māori – needed increased resources. She discussed the benefits of a marae-based clinic, where cultural safety was a key component appealing to whānau. But it was at times inaccessible due to the limitations of a Western system construct. Others also advocated a marae setting for the delivery of health services with appropriately skilled staff. Participants' own experiences informed this recommendation of this model of health delivery.

Well my whakaaro is that everything would be nice if we had it at the Marae. ... I think the staff makes such a difference towards anybody doesn't matter who it is. Now what I mean by that is staff can make you feel like it is okay to come in. (male 61–82 years)

Three participants recommended the marae clinic studied receive resourcing to increase the size of the clinic. Another participant discussed the increasing of hauora funding for this to occur:

So that would be helpful if they had a hauora, you know.... Maybe they need more for the hauora, maybe funding's going the wrong way, the wrong places. (Female 60–85 years)

Another recommendation included that, in an ideal model, healthcare should be at times provided in people's homes.

There were examples of health professional behaviour being held as a model for other health professionals to follow. People talked of doctors at this marae clinic who were not dissimilar to them – just “normal people” who understood their lives and were able to tailor the consultation to them. Some people spoke of the community pharmacist who knew more than just their names and engaged with them at a level to provide understandable information.

Exclusive commentary about the approach of health professionals also extended to a rheumatologist who had been very active in the area of gout over many years. He had attended hui with participants, and they evidenced the transmission of knowledge by him in a culturally safe environment. Others provided positive commentary on the nurses: “You know (nurse X) and (nurse Y) they don't run you down. They're always there to help you. ... You can feel the aroha” (male 24–45 years).

There was much commentary about the role of kaimahi and how important it is to have people who have had life experiences that whānau have also had. The non-regulated healthcare workers at the practice were recognised as more like ‘kaitiaki’ in terms of helping to provide guardianship of participants’ health journeys. There was recognition of the programmes that kaimahi delivered at the practice. A male kaimahi was singled out as being necessary for other men to connect with and as a source of support and aroha for many. There was a recognition that all went above and beyond to assist with all manner of things.

That the practice offered transport to and from appointments was also acknowledged as valuable and integral to receiving healthcare. Without this service, some people stated they simply would not be able to come in. There was also commentary about the gratitude people felt towards the kaimahi who transported them and the level of assistance she provided.

In terms of specific education and empowerment around the condition of gout, people provided an overarching directive that the situation needed to change to create a culture where people felt able to discuss and communicate about gout. People also needed to receive the correct information tailored to meet their needs.

Participants advocated knowledge dissemination should be consistent and multilevel, from an individual perspective to community engagement and national campaigns.

Many suggested the concept of dedicated media and health campaigns. A common suggestion was the development of television commercials made in conjunction with whānau so that they resonated. Role models like rugby and rugby league players to lead media campaigns was also advocated.

I think they need to advertise more aye. Cos you see on the TV breast cancer awareness. You see suicide awareness. You see everything else, but nothing about gout. (Female 60–85 years)

The younger participants recommended social media campaigns to ensure younger people received appropriate messages. Some of the senior participants discussed their preference for paper resources and suggested pamphlet drops. Participants also recommended campaigns be developed so that Māori felt connected to receiving messages – that the imagery and faces needed to be reflective of Māori. Some people discussed a previously co-designed gout resource booklet as an excellent example of enticing Māori to learn: “Look yeah, this (booklet) is exactly what I'm talking about, gout there look. Living without pain okay, this is it, this is what you should put out” (female 40–59 years).

A final, unsolicited point concerned the research itself. Participants stated the pathway of kaimahi contact and subsequent engagement by a Māori researcher premised on whakawhanaungatanga worked well.

5.7 Discussion

This research, albeit focused on gout, evidences how health inequity is its own ecosystem for Māori. From the consideration of the physical environment in which health services are delivered, when they are delivered, and by whom they are delivered, to the ability to access whether by phone or physically, and the associated costs- all these factors are crucial. Māori suffer disproportionately from a debilitating condition, yet are forced to engage in a system that is often hard to access, does not always provide best practice clinical treatment, and does not always provide a ‘safe’ environment where understanding and understandable messages are communicated. Healthcare providers have a responsibility to manage the complexity of health literacy demands on patients but often approach it from a deficit frame where the onus is on the patient to understand (Reid, 2020).

That Māori are more likely to be employed in labouring roles and more likely to be socially disadvantaged is not new. This is the effect of history shared with most other Indigenous populations globally. A disadvantaged position is a challenging place from which to thrive. What was clear was that, for some participants, it was nigh on impossible for them to access regular gout-prevention therapy without significant impact on employment security.

The significant pain of gout, the length of suffering, the overuse of inappropriate NSAIDs, and difficult relationships with health providers have been previously described (Te Karu et

al., 2013). This research delves deeper into understanding health system issues and presents recommendations from those who have been directly affected. It also presents the breadth of health professionals' contribution to poor care and inaccurate information, which further stigmatises gout and the people suffering from it. Additionally, it highlights people's desperation, such that they feel the only option is to seek medicines for symptomatic relief from various sources, including presentation to emergency departments and purchase at supermarkets and pharmacies.

The authors are unaware of previously published research on the consideration of advice to cease eating kaimoana as a breach of cultural rights. This feedback and perspective are underpinned by the traditional connection of well-being to resources over which rangatira exercised authority. Article II of the Treaty of Waitangi specifically states fisheries as a taonga for continued access and authority. This raises the prospect of a breach of the Treaty if healthcare workers unnecessarily advise people to avoid kaimoana.

Racism within the NZ health system has been well documented (Jansen et al., 2008; Harris et al., 2012; Huria et al., 2014), with a recent meta-analysis of NZ studies consistently demonstrating racism is an important health determinant contributing to inequities (Harris et al., 2018). We have previously reported barriers in the journey to optimisation of medicines that did not include patient voices (Te Karu et al., 2018). In this study, we heard the consequences of people feeling judged and being the recipients of culturally unsafe care. To add insult to this situation, there are associated costs with this system, which does not always respond well.

5.7.1 Strengths and Limitations

Selecting Kaupapa Māori as the framework within which this research was conducted and ensuring that participants felt safe and empowered to pass over their whakaaro was a strength of this research. Participatory research conducted in this way can inform system and policy-based changes to address inequity. That the participants unanimously endorsed the themes at the follow-up hui was further validation.

A collaborative approach was adopted to explore participant experiences of gout and gout management, with some forays to extend these learnings to broader Māori contexts. This, we argue, was necessary to honour our approach to Kaupapa Māori and means that, while there may be ideas of value to diverse groups, there is no claim of generalisability. The intention

was to contribute to positive change for participants and whānau as well as provide learnings for the health sector and systems.

5.8 Conclusion

This study, conducted with a Kaupapa Māori approach, is the first to describe Māori experience of having to negotiate the complexity of gout, in the context of not having been afforded the societal privileges of non-Māori. The most significant finding articulated by the participants is the failure of the health system's response to their condition. The nature and extent of this has been years in the making, with the health system systemically failing to provide a solution to a manageable condition. Individual context compounds the disease for patients, but overwhelmingly, the practitioners and/or system have failed. To continue not to act in the face of this demonstrated need is, by definition, institutional racism.

A secondary theme within this overarching failure is the clinical practitioners' focus on food and associated triggers, not the prevention of the disease through urate-lowering therapy. Whānau also articulated the connection to food, raising the question of whether this is experiential or learned from health professionals. A national campaign for both clinicians and whānau is evidentially required.

Patients grappled with the conflict of self-determination within the context of hauora and the power within Western health models. While both the patient and the clinician pursue well-being, their engagement is dominated by Western policy and process.

Māori perspectives are often overlooked within health structures imposed by colonial underpinnings of superiority, restricting practices of hauora, whānau, and honouring mātauranga. The long shadow of inequity is the reality of this failure and a missed opportunity to engineer health systems so all benefit. The barriers creating the shadows of inequity must be removed to support transformation in health aspiration for whānau.

“Mehemea ka moemoeā tātou, ka taea e tātou – if we dream together, we achieve together”

Princess Te Puea Herangi

Chapter 6 The Health Provider View

The previous chapter presented the participants' experiences of the PMC gout initiative, focusing on the key factors in the ecosystem of gout management for Māori. This chapter presents the health provider's experience of the initiative to inform the development of appropriate pathways and services.

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This publication is inserted as published, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis. It is included in the thesis with permission from the *Journal of Primary Health Care*.

Competing interests: LTK has a small part-time role working at the clinic. She has no one reporting to her and is not involved in any management decisions. She was involved in the development of the initiative. MH also has a part-time role at the clinic as a general practitioner. She was not interviewed.

Compounding Inequity – A Qualitative Study of Gout Management in an Urban Marae Clinic in Auckland, Aotearoa New Zealand

6.1 Abstract

Introduction: Gout remains a health equity issue: Māori and Pacific peoples are disproportionately afflicted, with significant burden and loss of quality of life, yet are less likely to receive appropriate management, which mainly occurs in primary care.

Aim: This study aims to understand the perspectives of predominantly Māori and Pacific clinicians and staff at an urban marae practice about the barriers and challenges to delivering effective care to a Māori and Pacific community with high burden of gout.

Methods: Semi-structured interviews were conducted with 10 staff members delivering healthcare to a predominantly Indigenous community. Interviews sought to ascertain staff views of enablers and barriers to optimal gout management and analyse them thematically.

Results: Three themes were identified: community disadvantage; demands unique to Indigenous providers; and challenges and opportunities for optimising gout management. High prevalence and heavy impact of gout on well-being in the community was intertwined with socioeconomic disadvantage, employment precarity, and entrenched inaccurate (yet pliable) patient views on gout, to the detriment of focused, effective care. Structural and funding demands on the provider inhibited staff focus on the clear community need. A culturally safe and competent approach with community empowerment, appropriate clinical tools, and adequate resourcing was seen as necessary for improvement.

Discussion: Despite provider intent to deliver culturally appropriate and safe care and equitable health outcomes for those suffering from gout, general practice initiatives without aligned resourcing or incentives are inhibited when inequity is pervasive. Simply asking Māori providers to do more for the same amount of resource may not be effective.

Key words: general practice; uric acid; health equity; Indigenous, primary health care, Māori

WHAT GAP THIS FILLS

What we already know: Gout places a heavier burden on Māori and Pacific well-being than on other ethnicities, with treatment also worse for Māori and Pacific peoples. Barriers to optimal gout management have been examined from the perspective of patients, community

and health professionals in general practice, but the perspective of Indigenous providers faced with high need has not been examined in NZ.

What this study adds: Māori healthcare providers report structural limitations that are barriers to the provision of tailored gout prevention to people who are most in need. Initiatives are structurally inhibited and likely to be ineffective if they do not encompass whānau, workplaces, and communities, without appropriate resourcing or alongside conflicting incentives embedded in the system.

6.2 Introduction

Historically known as the ‘disease of kings’ due to its prevalence among the wealthy and privileged (Gow et al., 2011), the contemporary reality of gout in NZ is one of socioeconomic and ethnic inequity in both prevalence and management in primary care (Dalbeth et al., 2018b). Compared to non-Māori, gout is more prevalent among Māori, occurs at an earlier age and has worse outcomes (Dalbeth et al., 2013). People of Pasifika ethnicity also experience increased prevalence and poor outcomes (Dalbeth et al., 2018b).

Gout may best be understood as a genetically determined deficiency of urate transport (Dalbeth et al., 2019b). Urate-lowering pharmacotherapy, primarily with allopurinol, is an effective and inexpensive first-line treatment to reduce serum urate levels below saturation concentrations, preventing gout flares, tophi development, joint damage, and loss of quality of life (Best Practice Advocacy Centre, 2018; Khanna et al., 2011). However, health professionals, particularly in primary care, continue to prioritise lifestyle advice such as avoidance of specific foods and alcohol over current best practice guidelines, which favour preventative medication (Humphrey et al., 2016).

Models of care to improve gout management have attempted to integrate two key stakeholders – health professionals and people living with gout (Dalbeth, 2013; Jeyaruban et al., 2015). Multidisciplinary approaches that address prescribing and monitoring of urate-lowering medicines have shown benefit (Doherty et al., 2018; Mikuls et al., 2019), as have patient-focused programmes encompassing patient education and health literacy (Dalbeth et al., 2019a). However, these approaches often ignore critical players in gout and its management, including whānau (extended families), workplaces, and communities. These approaches are also blind to the unintended effects of structures and barriers created by the health system itself, including prioritisation and funding of gout care, particularly in practices

serving high numbers of Māori and Pacific patients suffering from gout. As such, gout and its treatment remain a critical issue of inequity.

The Indigenous community perspective of barriers and enablers in achieving best practice management of gout has previously been reported (Te Karu et al., 2020), as have the wider perspectives of clinicians in primary practice across South Auckland (Humphrey et al., 2016). The current research, using Kaupapa Māori methodology, aimed to explore the predominantly Māori and Pacific staff perspectives at an urban marae of the enablers and barriers to medicines optimisation for gout, the acceptability of an intervention including a DST, staff experience of the multidisciplinary collaborative team approach. We also sought their views on possible improvements that might eliminate the burden of gout for the predominantly Māori and Pacific patients of a very low-cost access (VLCA) practice. We present the qualitative analysis of these staff views, collected 12 months after implementation of the intervention.

6.3 Methods

A Kaupapa Māori approach underpinned the interview process and overall methodology, appropriate to the participants and community they serve. This approach emphasises self-determination by Māori, and Kaupapa Māori principles of respect, generosity, caution, and humility, with the aim of enabling fruitful and emancipatory kōrero, and deconstruction and transformation of a methodological approach towards advancement of Māori, in line with the principles of ownership and empowerment of Māori set out in the articles of Te Tiriti o Waitangi (Smith, 2012; Smith, 1997; Curtis, 2016). Protecting and incorporating the knowledge, skills, attitudes, and values of Māori society were further demonstrated by engaging Kaumātua to assist the development of the multi-layered initiative and by seeking marae leadership opinion and approval for representation of data.

6.3.1 Study Setting

The general practice is situated within the grounds of an urban marae complex offering clinical and multiple social services. The practice serves an enrolled population of more than 3,000 people, predominantly of Māori ethnicity (~80%), with the remainder Pacific (~12%), NZ European (~6%), Asian (2%), and other ethnicities (2%). Most people (98%) enrolled at this clinic live in neighbourhoods categorised in the lowest deprivation quintile as measured by NZDep2013 Index of Deprivation (Crampton et al., 2020). It is a VLCA practice where

most of the enrolled population are deemed ‘high needs,’ and the patient co-payment is capped.

6.3.2 Participants

All staff employed within the clinic were eligible and were invited by author LTK to an interview. Ten staff participated; nine were of Māori and Pacific ethnicity (overall, 92% of clinic staff are Māori and Pasifika, mirroring the enrolled patient population). Roles included one locum and three long-term general practitioners, all mid-career; three nurses, all senior; two community health workers; and one practice administrator/manager. One community health worker declined an interview, stating they had no direct dealings with the intervention. To help de-identify participants, given the small numbers involved, quote attribution is presented here only as clinical staff (doctors and nurses) or non-clinical staff.

Participants were interviewed individually, audio-recorded, and interviews were transcribed verbatim by author LTK. Interviews varied in length from 17 to 48 minutes. Participants were offered a chance to edit their transcripts.

Participants were informed both verbally and in writing that being interviewed was their choice, that there would be no consequences if they declined to be interviewed, and that they could withdraw their interview up to 1 month after it had taken place.

Semi-structured interviews were conducted with mostly open-ended questions using an interview guide, providing a framework for discussion (see Box 5).

Box 5 Guide for Interviews

Interviews sought feedback on the following questions:

- What was your experience with the gout initiative?
- What worked well in terms of the gout initiative? What were the enablers?
- Did you use the decision-support tool? (Clinicians – for prescribing? Non-clinicians – as a prompt? Any recommendations?)
- What could be improved in the implemented project? What barriers did you encounter?
- What would enable optimal management of gout for the enrolled population?
- Any comments?

6.3.3 The intervention

From June 2017, a multi-layered initiative was progressively implemented in the study general practice. In brief, the intervention (summarised in Box 6) aimed to improve clinician management of gout for Māori in line with current evidence. At the same time, community engagement sought to empower whānau to promote self-management and improve community understanding of gout risk factors and appropriate pharmacotherapy.

Box 6 Components of the Multi-layered Initiative to Improve Gout Care

| |
|--|
| Community design and community ‘champions’ |
| Community hui |
| Decision-support tool |
| Practice staff education |
| Point-of-care urate testing |
| Nurse standing orders |
| Gout health literacy resource |
| Direct communication to a rheumatologist |
| Evening clinic |

A key component of the intervention, a tapered DST, aimed to prompt and guide delivery of best-practice management of gout in consistent and sustainable ways. It prompted and guided clinicians to prescribe urate-lowering therapy, including its ‘cover’ and titration, to achieve a target serum urate concentration below saturation. The tool appeared as a traffic light system on the front or dashboard of the practice management system (PMS). The dashboard system was open to all users of the PMS.

6.3.4 Analysis

Thematic analysis of interviews was supported by NVivo software (QSR International) following an iterative reading of each transcript. Cyclical reviewing and refining coded excerpts of transcripts occurred using categorisation and analytic reflection until themes were identified (Saldaña 2015). The themes were agreed upon by consensus with author BA, then the other authors.

Ethics approval was given by the Northern B Health and Disability Ethics Committee (18/NTB/213). (Appendix 4)

6.4 Results

The analysis identified three themes relating to enablers and barriers to optimal management of gout for Māori at this urban marae practice in South Auckland: community disadvantage, Indigenous health provider demands, and achieving gout optimisation.

6.5 Themes

6.5.1 Community Disadvantage

The first theme identified was that gout was identified as being highly prevalent in this community, impacting heavily on people's lives, but that it was intertwined with the effects of socioeconomic disadvantage to the detriment of optimal care: "There are a lot of people with gout – so many of them – every second person" (non-clinical staff).

Disadvantage was a substantial issue that affected many facets of care, both directly and indirectly. The prioritisation of addressing socioeconomic marginalisation competed with optimising gout management. Staff were spending time addressing broader social issues, including food and housing insecurity, assistance with clothing, finance, and transport, which consumed consultation time. All participants consistently raised the reality of socio-economical marginalisation in the community: "The environment we are working in, the whānau we are working with, the desperation that is there, the comorbidities, the social issues and all those sorts of things, are wrapped up in a patient that has gout" (non-clinical staff).

Employment impacted access to care. Patients were often employed in blue-collar roles, unable to easily leave work to access healthcare, and where job security could be an issue: "The thing is the majority of people with gout are men and they are working so they have to take time off work and it's job security. It is very tricky for men. It is inequitable" (clinical staff).

Staff felt people had not always received appropriate education from previous providers, nor a dedicated campaign to empower people. The importance of empowerment was discussed, as was that inaccurate information had become entrenched in people's minds. For instance, it was common for members of the community to deny they had gout – 'feeling whakamā', or shame. This denial was tied back to misconceptions leading to behavioural blame: "They all think it is the food side – that that's why they get gout ... a lot is that they need education" (non-clinical staff).

However, participants noted that no patients refused urate-level testing when offered. It was felt that this was reflective of underlying deeper concerns despite a tendency to minimise or deny the effects of gout.

6.5.2 Indigenous Provider Demands

The second theme related to conflicts in priorities created by structural and funding demands on providers. All participants discussed the breadth and depth of community need and how this flows on to health provider demands. Addressing wider determinants of health was layered upon a constant need to protect practice income, such as achieving funded, nationally set health targets. This competition redirected activity: "... you have limited resource, and you have to spread it where you can. Resources are being put into areas where the money is coming from. So that's the competitive environment that it needs to work in" (clinical staff).

A key issue raised by all staff was health targets as a pay-for-performance mechanism and how they influence clinical practice. Staff were cognisant that these targets drove behaviours and that this was not the ideal situation, but the reality of a practice in a struggling community.

Targets are what matters. If conditions are not a target, the wider staff are not paying attention to it. I think it is not on our radar ... You know if gout was sitting in the health targets it would be done! (clinical staff)

For this reason, there was suggestion that health targets should have more flexibility for practices managing the health needs of specific populations.

It would be great if the Ministry would give us some money and allow us to do with it what we deem to be important. ... It's one of those things that when you don't want the money to drive how we perform but also too we have to have systems in place so that we can focus on certain things and do those things. (non-clinical staff)

Interwoven with health targets was the concept of a 'practice champion.' As funding is attached to health targets, 'champions' focused on ensuring revenue was maximised: "If you don't have someone who is a champion for it in the practice, then these things have not got such attention. Having champions is really important" (clinical staff).

Again, the ability for champions to function optimally was linked back to payment and health targets.

I think the funding is key – you still have to have a champion, but the funding is key. The champion is less powerful without the funding. I find that if there is funding attached to it, there is a drive to meet that health target – it will happen. (clinical staff)

Similarly, gout not being a health target to promote activity meant that, in an overworked environment, standing orders for nursing staff were not used optimally: “I didn't use the standing orders sorry ... it came down to being time-poor for us. It's a busy clinic – we have so much going on” (clinical staff).

Hours of access were an issue to the community, and participants discussed the challenges and wanting to be able to respond but lacking resource to do so: “There is definitely a demand for longer clinic hours – I get that all the time” (non-clinical staff).

Equally, access to laboratory services was recognised as conflicting with patients' work commitments and rippling through to the provider to solve. Patients generally use or exceed their time off work to be seen in the practice, and accessing a community laboratory adds to that pressure. Locations of laboratories may mean further prohibitive travel across town.

While it is possible for a nurse to collect blood in the clinic for later delivery to the laboratory, this was seen as another competing task for overloaded nurses: “Bloods are really important – some [patients] haven't had bloods for 2–3 years Our nurses will take labs here if they have time – it is so full in town at the lab” (non-clinical staff).

Further, staff noted that the practice accepts patients that other clinics have rejected, implying that the enrolled practice population may become progressively more medically and socially complex over time.

There's a lot of clinics that don't accept them (patients) – they even tell them – come to ours. We get heaps of them – we get a lot of 'rejects' – people get told they are full. Practices can pick and choose. (non-clinical staff)

Staff commented that ageing facilities did not always meet the needs of staff and patients, such as recurrent issues with internet technology and phone access. As such, infrastructure was deemed a barrier to optimising use of the DST.

I thought it (tool) was actually very good because it kept it in everyone's face but the thing was that the internal server would crash and the password protection would lock people out – the whole system locks down and locks you out. (clinical staff)

This was disappointing as some clinicians also reported the value of the tool: “The form is conveniently presenting all the information I need to get to make a decision in one spot, and I've got the dashboard running, and it takes me one click to do it – I am in” (clinical staff).

One clinician discussed being upskilled simply by using the tool.

It was helpful for me in prompting me to do a couple of things I otherwise wouldn't have. Make sure that I have colchicine cover was a big part of it and it helped me

think about how long I am doing cover for ... that was a big thing for me. (clinical staff)

Most, however, either did not use the platform on which the dashboard sits or took no notice of it because of the lack of associated funding as discussed above: “It never prompted me even if red because my focus is not gout because it is not a health target. I am just being honest” (clinical staff).

6.5.3 Achieving Gout Optimisation

The third theme related to how to optimise gout care for the clinic’s population. Despite the barriers identified, all participants emphasised the importance of the project and that the initiative was helpful and essential to providing a focus: “... project itself has been blimmin useful – if nothing else it has brought more focus to this practice to consider this significant condition” (clinical staff).

In discussing the burden of gout, all participants also stated their intent to continue to do better with achieving optimal management and that they had learned through the process. This re-messaging to improve adherence to urate-lowering therapy required understanding across the spectrum at all levels; therefore, community empowerment was necessary: “I think the approach that you take with the community is really really important” (clinical staff).

The importance of community empowerment was emphasised as needing to be under the umbrella of a culturally safe and competent approach: “We approached it from a te ao Māori aspect/perspective, which was important and helpful, we provided expertise when it was needed, and I think the messages were repeated reasonably consistently” (clinical staff).

There were instances where community education had a powerful effect on assisting clinician management. Value was placed on patients being ‘activated’ so they already understood aims of treatment and associated pathways and drove the consultation.

I did not have all the ins and outs of specifically what that programme was, but certainly, the patients reported about the programme. So there seemed to be a good awareness ... they knew there was a plan to get their urate levels to a certain target and to the normal range so yeah there were patients with established gout who knew what they were aiming for. That was good. (clinical staff)

As an incentive to do better or to drive response, some staff thought a better emphasis on monitoring would have been helpful.

I would have added more strength into monitoring to target and how that was done. Even to the point [of] a monthly report of how many of those people came in and had

a visit – how many had a spot urate done or a blood test and was medicine uptitrated. (clinical staff)

All participants discussed resourcing as a key to future success.

Thinking it through you know if we had two full-time people here driving it, it would be all done and dusted by next Christmas – well in the real world, what can be done? Can we throw money at it – like can we get five bucks every time we do something – no. Well, that's probably not going to happen either. (clinical staff)

Trouble is that nobody in the clinic has time for that follow-up and that's where we are – If we had that dedicated person and that time, it would run well I think. It would be awesome if we did have that, but the reality is different. (non-clinical staff)

Resourcing dedicated appointment times for using that tool. Book the patient just for gout because if the patient is coming and we are just taking the opportunistic time for gout, obviously we are limited ... That is the competing type of environment that we are in. (clinical staff)

In terms of the DST paradoxically, the clinicians who had not used it discussed the merits of its intent and function.

I think it would be really useful if gout was a classification on the patient's file that would be a prompt as you open it to say what is the gout management – this is where you do it. That sort of thing that would be quite helpful. You do need to hand us some tools to help us work through that. And I do believe pathways and dynamic tools are really really helpful. (clinical staff)

While fiscal and human resourcing were seen as being key, the importance of having the 'right' resource was also highlighted. Human resourcing was discussed as needing to be underpinned by a philosophical approach where whānau-centred health is the driver.

We are all in it together. One thing I have learned about since working here is we don't need to convince our team that it is about whānau. They all know that, and that is a blessing in itself. Sometimes you have to convince people that it is about family first. We don't need to do that here. It is embedded in everybody, and they know exactly why they are here, that is why they work here. They could be somewhere else, but it is the how, how we achieve it. (non-clinical staff)

6.6 Discussion

Gout remains an equity issue. Māori are disproportionately afflicted, with significant burden. Despite higher prevalence in Māori, at least in part due to genetic variability, Māori are less likely to receive recommended treatment (Dalbeth et al., 2018b). This qualitative study reporting interviews with 10 health workers at a Māori primary care clinic in a neighbourhood of high deprivation identified three themes. The participants were aware that the community they serve was disproportionately affected by gout and yet received insufficient funding to improve their outcomes. They felt that as an Indigenous provider, they

experienced further, unique demands, including having to address wider determinants of health, being overworked, and infrastructural problems. All participants discussed the benefit of the intervention but lack of support to realise its potential, including clinical champions, specific targets, and funding. Staff consistently highlighted the overarching systemic issues of funding and prioritisation that affected their ability to respond to their already disadvantaged population.

This research highlights that disadvantage can be compounded by a healthcare response when the system is not proactively addressing inequity. The Commission has identified that “historical acts of taking land, resources and culture, compounded by the monocultural nature of today’s health system and service delivery”, leads to accumulated intergenerational disadvantage for Māori (Health Quality & Safety Commission, 2019a). This research suggests that societal disadvantage can ripple through to the service deliverer if people have significant and complex needs, and the system does not fully recognise this and compensate accordingly.

Pay-for-performance healthcare has met with criticism, both nationally and internationally (Buetow and Entwistle, 2011; Wilson, 2013). Various iterations of pay-for-performance initiatives have been implemented in NZ, with the appropriate balance to achieve quality, equity, and efficiency yet to be struck (Chalmers et al., 2017). The broader distortionary effects of targets, in particular, those with financial incentives attached, on health service behaviours internationally and in NZ are now well described in the literature (Bevan and Hood, 2006; Tenbensen et al., 2020). The granular effects on decision-making, and allocation of resources and attention, and indeed the anti-equity effects of services forced to ignore the apparent needs of Indigenous people to hit targets and maintain revenues, were demonstrated in this research.

The Crown’s obligation to provide primary healthcare for the Indigenous people in this country is currently the subject of legal investigation, with alternative models being sought (Baker et al., 2019). Additionally, previous research has concluded there is institutional racism in contracting practices between government-funded accountability processes for Māori-led public health providers compared with providers whose services are designed for the overall population (Came et al., 2018).

Previous research has identified a lack of unity in physician and patient views on gout management (Harrold et al., 2010; Spencer et al., 2012). This Auckland research, however,

demonstrated alignment between what Indigenous providers of healthcare saw as barriers and what the community had previously reported (Te Karu et al., 2020). The site for this intervention was purposively chosen in that it was a practice with a stated aim of delivering a culturally safe environment for whānau guided by principles of tikanga Māori. This removal of a major identified barrier allows a focus on understanding potentially unknown or less well-identified barriers, such as pressure to deliver on health targets driving clinician behaviour to maintain funding levels for critical service delivery.

Evidence demonstrating efficacy for computerised decision support exists, though it is variable (Lu et al., 2008; Cheung et al., 2012). Eccles et al. (2002), for instance, found that full technological support for asthma and angina did not provide the complete answer for busy practitioners managing patients with complex, multiple conditions. Similarly, the impact of the DST in this study proved to be moderate when structural barriers remained, while the empowerment of community was a powerful tool to change clinician behaviour. Participants discussed wanting to respond in more accessible and responsive ways as needed by their community but felt constrained by the construct of a health system primarily funded on 15-minute appointments occurring every 3 months.

Humphrey et al. (2016) claimed to provide the first qualitative study to report clinician experience of treating gout. They identified the need for primary care to respond to and manage gout appropriately and identified the business model of healthcare as a barrier to optimum management. This research aimed to build on that study and understand how optimal management could occur to benefit Māori who are disproportionately disadvantaged.

6.6.1 Strengths and Limitations

This research advances understanding of Indigenous health providers' perspective of barriers to optimal gout management in NZ. It raises new ideas on ways to achieve optimal management with equity as the driver. That the research occurred at a site where cultural safety and equity are already drivers of health delivery enabled analysis of potential wider issues.

However, the number of participants was finite and relatively small due to the size of the practice. The lead author led the development of interventions, so there was potential bias in favouring the overall project. This was mitigated by critical reflection and triangulation with co-authors in thematic analysis and discussion.

6.7 Conclusion

Despite provider intent to deliver culturally appropriate, culturally safe care and equitable health outcomes for those suffering from gout, initiatives without aligned resourcing or incentives do not provide the answer when inequity is pervasive. This research highlights the importance of transformative and holistic thinking. For these healthcare workers working in a predominantly Māori setting in a colonised, inequitable society, the challenge of providing people with optimal gout management requires the mitigation of multiple barriers far beyond providing safe, culturally appropriate care. Enablers include addressing historic socioeconomic injustice, addressing ingrained inaccurate beliefs about gout, and better and more context-specific practice resourcing. Gout affects Māori more than others, and optimising treatment by, for, and with Māori requires more than simply asking Māori providers to do more for the same amount of resource.

Chapter 7 Access Issues

This chapter investigates some of the barriers to access promoted by both the community and staff in Chapters 5 and 6. In Chapter 5, participants most commonly reported access to optimal gout management as a significant barrier. This theme was endorsed by staff in Chapter 6.

This chapter presents a quantitative investigation of these access issues and describes domains of access to optimisation of gout care as identified through the PMC initiative. This chapter also includes quantitative evidence on pharmacoepidemiology and was originally published in *The New Zealand Medical Journal*:

Te Karu, L., Arroll, B., Bryant, L., Harwood, M., & Kenealy, T. (2021). The inequity of access to health: A case study of patients with gout in one general practice. *The New Zealand Medical Journal*, 134(1543), 51–58.

This publication is inserted as published, with the exception of minor edits and formatting changes to maintain consistency throughout the thesis. It is included in the thesis with permission from *The New Zealand Medical Journal*.

The Inequity of Access to Health: A Case Study of Patients with Gout in One General Practice

7.1 Abstract

Aim: Gout is a health equity issue for Māori and Pacific peoples because disparities in quality of care exist. This study aims to describe domains of access that may contribute to the optimisation of gout care and, therefore, address health inequity.

Methods: The practice management system (PMS) at one general practice in Auckland was used to identify enrolled patients with gout, using disease codes and medication lists. Barriers to access for the cohort were investigated using staff knowledge and the PMS. The general practice is uniquely situated within an urban marae (traditional meeting house) serving a predominantly Māori community. This enables a focus on domains of access other than cultural safety.

Results: Of 3,095 people enrolled at the practice, 268 were identified as having gout. Of these, 94% had at least one other long-term health condition. The majority of people with gout enrolled at the practice have employment roles incongruent with the clinic's opening hours.

Conclusions: Social circumstances, such as employment and availability of transport, should be actively discussed with all patients and recorded in the PMS. Reorientation of health services, including hours of access, is evidentially required to ensure optimal gout management and possibly other health conditions.

7.2 Introduction

Achieving health equity in NZ is a stated aim of the government and those responsible for managing and developing its health and disability system (Ministry of Health, 2018). This is against a background of a long history of inequitable health outcomes and life expectancy for Indigenous Māori compared to non-Māori (Robson & Harris, 2007; Ministry of Health, 2015a). A recent review of NZ's health and disability system sought to identify barriers within the system with a "goal of achieving equity of outcomes and contributing to wellness for all, particularly Māori and Pacific peoples" (New Zealand Government, 2018). Additionally, the Waitangi Tribunal (the Tribunal) is currently hearing national claims relating to health services and health outcomes for Māori (New Zealand Government, 2019).

The Tribunal is alarmed that pro-equity action is still not embedded within the system, despite the Crown stating 14 years ago that Māori health inequities were unacceptable (Waitangi Tribunal, 2019).

Gout has been described in Māori since the thirteenth century (Buckley et al., 2010), and although its prevalence has increased for over 50 years (Prior et al., 1966; Brauer & Prior, 1978; Jackson et al., 2012), it is significantly less likely to be optimally managed to prevent painful attacks and long-term sequelae than in non-Māori (Dalbeth et al., 2016). A large body of evidence confirms that uncontrolled serum urate levels, together with gout flares, lead to unnecessary joint and organ damage and premature mortality (Clarson et al., 2015; Dalbeth et al., 2015; Jaffe et al., 2019; Choi & Curhan, 2007; Fisher et al., 2017). This is despite that gout can be diagnosed with certainty, and inexpensive pharmacotherapy to lower serum rates is readily available (Zhang et al., 2006). Inequity in gout prevention also exists for Pasifika peoples (Dalbeth et al., 2016). Given non-Māori, non-Pasifika enjoy better health outcomes and longer life expectancy than Māori and Pasifika, the gap in the quality of healthcare for gout is disturbing and in line with longstanding observations such as the ‘inverse care law’ (Hart, 1971). Gold standard treatment of gout in NZ has the potential to not only eradicate the disease but also to contribute to a substantial reduction in this nation’s health inequity.

Penchansky and Thomas (1981) and Levesque et al. (2013) define “access” as a general concept that summarises a set of more specific domains encompassing approachability, acceptability (which includes cultural safety), availability and accommodation (which includes service opening hours), affordability, and appropriateness (which provides for quality of care). NZ’s Pharmaceutical Management Agency (Pharmac) has provided another layer to the taxonomy of access to health by including the availability of medicines or those subsidised so that people pay a minimum fee (NZ\$5 per medication at the time of this study) (Pharmac, 2019).

The complexity and multifaceted nature of access to health services for Indigenous peoples has been further described (Shukla et al., 2020; Davy et al., 2016). Davy et al. (2016) advocated that previous models needed to be less linear and more inclusive of the healthcare system to understand and address access for Indigenous people. They stressed the importance of access to culturally safe healthcare services to meet the needs of communities.

This chapter aims to describe domains of access to gout services at one specific general practice in NZ. This practice is Māori-led and oriented to its community (79% Māori), with

formal links to the marae (traditional meeting house) and its social services including housing, food banks, and kaumātua (elder) support. There is ethnic congruence between clinic staff and the community. These factors explicitly address cultural safety (acceptability) to the community and allow for considering other health system factors that may impact other domains of access for Māori and Pasifika patients.

7.3 Methods

The study site is a general practice, situated in a marae complex. It is a 'very low-cost access' practice, meaning that fees to patients are relatively low (maximum NZ\$18 per adult consultation at the time of this study). Some clinic staff speak te reo Māori and Samoan languages. Transport is available to help people attend appointments. Community health workers are integrated into the practice and run programmes co-designed with the community, addressing long-term health conditions, including diabetes and cardiovascular disease, with routine conversations around gout.

The practice's enrolled gout population was determined on 1 June 2017 from the electronic medical records in the PMS. Descriptive statistics are reported here. The PMS records only data collected at the practice. For health services provided outside the practice, data is dependent on the outside service returning a record to the practice in which the patient is enrolled. As per previous definitions (Winnard et al., 2012; Health Quality & Safety Commission, 2012), people were classified as having gout if the PMS recorded a classification of gout or a prescription for allopurinol or colchicine. People who had been prescribed allopurinol and had a diagnosis of myeloproliferative disease were excluded. Author LTK reviewed the PMS records of each person with gout for evidence of employment status, health status, and difficulties with access. This review was supplemented by a discussion of patients with practice staff.

Ethnicity was classified according to that recorded in the PMS, and if more than one ethnicity was recorded, priority was assigned to Māori followed by Pacific.

Ethics approval was not sought for this study as it was based on routinely collected records. All enquiries were undertaken by staff with clinical responsibilities to care for these patients, and all results are anonymised.

7.4 Results

Of the 3,095 people (all ages) registered at the site practice, 268 were identified as having gout (Table 6).

Māori made up 72% of the gout cohort and 79% of the practice population; Pacific peoples made up 20% and 12%, respectively; 69% were male across all ethnicities. Mean age was lowest for Pasifika. Non-Māori, non-Pasifika males tended to be older, although numbers were small.

Table 6 Ethnicity, Gender, and Age of Enrolled Patients with Gout, N = 268

| Characteristic | Gender, N | Age, years, mean (range) | Percentage of 268 patients with gout |
|----------------|-----------|--------------------------|--------------------------------------|
| Māori | | | 72 |
| Female | 61 | 60 (23–83) | |
| Male | 131 | 53 (23–84) | |
| Pacific Island | | | 20 |
| Female | 21 | 57 (40–89) | |
| Male | 33 | 47 (23–81) | |
| NZ European | | | 6 |
| Female | 2 | 59 (47–70) | |
| Male | 14 | 63 (45–79) | |
| Other* | | | 2 |
| Female | 0 | | |
| Male | 6 | 54 (39–71) | |
| Total | | | 100 |
| Female | 84 (31) | 58 (23–89) | |
| Male | 184 (69) | 54 (23–84) | |

*Other included Asian (n=2), Indian (n=2), South African (n=1), and American (n=1).

Nearly every person (94%) with gout had one or more long-term conditions in addition to their gout; only 15 people had gout alone. The four most common comorbidities are listed in Table 7. The average number of long-term medicines per person prescribed to this cohort was 4.5 (range 0–16). Thirteen people had been prescribed ten or more medicines concurrently, and 128 had five or more. Polypharmacy is commonly defined as five or more medications (Masnoon et al., 2017).

Table 7 The Four Most Common Comorbidities

| Comorbidity | Patients (n) |
|--------------------------|--------------|
| Cardiovascular disease* | 194 |
| Type 2 diabetes mellitus | 92 |
| Prediabetes | 19 |
| Asthma | 27 |

*Cardiovascular disease included hypertension, familial hyperlipidaemia, ischaemic heart disease, congestive heart failure, atrial fibrillation, or chronic kidney disease in the absence of diabetes.

7.4.1 Employment Status

In total, 144 (55%) people worked in labouring/manual jobs. This included 40 people working in construction (concrete, roofing, roading); 38 people driving machinery – cranes, buses, trucks (stock trucks, refrigerator trucks); and 37 people working in factories or as shift workers. A further 29 were listed as ‘labourer’ without detail.

Of the remaining 124 people, 41 were receiving invalid benefits for an array of health conditions; some had significant levels of disability, including being wheelchair users. Retired people, homemakers, or solo parents numbered 49. Nine people had educative roles (teacher aides, te reo [Māori language] teachers, youth workers). For 25, either information was insufficient or they were homeless people who did not request medical certificates for invalid benefits.

Individual lookup within the PMS also revealed specific commentary for 18 people (Box 7), detailing how employment affected their ability to access health services.

Box 7 Examples of Notes Recording Access Issues Within the Clinical Record

- Works on cranes at wharf; struggles to get in
- Works on road construction; usually gone 13 hours/day
- Works in a dry-cleaning factory; 13-hour days; struggles to get in
- Labourer; works long hours and shifts; has eight kids, and 11 moko live with him and wife; always stretched
- Plastic laminator sometimes both night shifts and day shifts
- Labourer; on road construction, now struggles to get employment; was in jail in 20s for drink driving; job security an issue
- Works days in fish processing and on the trains at nights; diabetic; HbA1c 98 mmol/mol

- Plasterer; out on construction sites
- Linesman; works out of town
- Roofer; just changed to cleaner because of multiple osteoarthritis issues; can't finish work until after 5.00 pm
- Truck driver; can be out of town for weeks
- Caretaker cleaner; struggles to get in
- Machine operator; can't get in
- Gout at 30 years; now gets every 2/52; roofer; can't be off work
- Works until 7.00 pm each day; hard to get in; mother rings in for scripts
- Labourer; gets gout flares three times per year; difficult to get in
- Labourer; works in the city; starts at 5.00 am
- Truck driver; hard to get in

7.5 Discussion

PMS records of diagnostic codes, clinician notes, and staff knowledge provided background on a cohort of people with gout enrolled in a predominantly Māori general practice in South Auckland, NZ. More than half (55%) of patients had limited or no ability to access the general practice during clinic opening hours. Still, the practice has little flexibility to respond to these barriers, constituting shortfalls in the access domain of availability and accommodation. We believe the nature and extent of this issue has received insufficient attention and is therefore not fully appreciated.

The concept of barriers to accessing the NZ health system is not new. For example, costs can be an issue for the patients, even though NZ's fees can be low. The 2016/17 NZ Health Survey reported affordability as a domain with “unmet need due to general practitioner costs” in 22% of adult Māori respondents compared with 18% for Pacific, 10% for Asian, and 14% for European/other (Ministry of Health, 2017). Equally, racism – a failure in the domain of acceptability – has been shown to impact on access to general practice and contribute to unmet need (Harris et al., 2019).

In addition to this, the people who experienced challenges accessing services had comorbidities that should elevate care and prioritise them for health services. While the co-prevalence of other health conditions alongside gout is not new, the extent is not yet fully understood. Winnard et al. (2013) found that diabetes and/or ischaemic heart disease affected

40% of people with gout. They further identified that a person with diabetes and gout had an age-standardised mortality rate ratio of 2.0 compared with a person with diabetes without gout ($p < 0.001$). Likewise, a person with CVD and gout had an age-standardised mortality rate ratio of 1.4 compared with a person with CVD who did not have gout. This reinforces the double impact, and the implications of even less access, for those who are most needing treatment. Our study found a co-prevalence of 72% with CVD and 94% with any long-term health condition.

These barriers to accessibility were further compounded for people with a disability. The assumption that standard clinical health service hours are sufficient to meet the needs of those who most require support must be challenged. We could not determine the number of people in this cohort who were unable to 'pop in' to see their doctor or healthcare professional. This study indicates that accessibility issues may be wider than envisaged.

Collecting and storing data on social determinants and barriers to access in electronic medical records is gaining momentum internationally (Tan et al., 2020; Trinacty et al., 2019), but it is not seen routinely in NZ. We, therefore, propose that employment status should be recorded within the PMS, and enablers to access must be discussed with patients. This should include disability information, the ability to pay for services, and possibly developing a practice template on which any staff member may record issues consistently. Services could include evening/weekend clinics, more mobile practitioners, virtual engagement using information technology, and targeted funding support for fees. The challenge of providing health services timed to meet patient needs has been one that many countries have grappled with (Kelly et al., 2018). Despite heterogeneity in study design and reporting, there has been consistent evidence that those accessing services outside routine hours are from lower socioeconomic populations and with chronic illnesses (Foster et al., 2020). One study from rural general practice in NZ noted that Māori people were three times more likely than non-Māori to access out-of-hours health services when provided (Scott-Jones et al., 2008). How these services can be supported and funded in NZ is also keenly debated. Resourcing general practice to respond has previously met with claims that adequate and appropriate out-of-hours services are not fiscally supported at a national level, at least for rural services (Murdoch, 2006). Implementation of the current health system review and commissioning should consider authentic engagement with communities to understand and meet their needs in a sustainable and attainable manner for those delivering primary care services – from both a human and a fiscal resourcing perspective.

The Waitangi Tribunal reported that a ‘one size fits all’ model tends to suit the needs of the majority, not those most in need, and recommended a principle of ‘options’ (Waitangi Tribunal, 2019). This point talks explicitly to advocating for the availability of health services premised on Māori models of health and engagement. Correspondingly, this would align with the proposed Indigenous access framework in considering a non-linear health system configuration. Regardless, the status quo of continuing to provide existing services in existing hours of operation is to fail to deliver excellent health outcomes for those most in need, creating further inequity. The current model of traditional hours of operation, i.e., 8.30 am to 4.30 pm or similar, is not compatible with patient lives or priorities.

Many factors contribute to poor management of gout. A qualitative investigation examined this practice’s response to preventing the burden of gout from the perspective of patients (Te Karu et al., 2020). Interviews with 23 community participants articulated the key features pertaining to barriers as shortfalls in physical, financial, and cultural access. Participants highlighted challenges with employment security and place of work as well as financial co-payments for GP visits and medicines. This study provides quantification of some of these challenges.

A nurse-led gout initiative in the United Kingdom achieved best-practice management in more than 90% of patients with gout, compared with 30% under usual GP-led care (Doherty et al., 2018). However, this was largely a cohort of older, retired, white British men. Only 16 of 512 participants were believed to be non-white and of Indian or Pakistani ethnicity (M. Doherty, personal communication, October 2018). The service was offered in traditional working hours, and therefore, even with appropriate resourcing, it may not be the model to emulate for the Indigenous people in this study with significant life pressures.

7.5.1 Strengths and weaknesses

This study represents a view of the life challenges of accessing primary healthcare for people enrolled in a low-cost general practice servicing a predominantly Indigenous cohort of people with gout in NZ. We are unaware of similar published data and believe it is unusual for primary care to include records of employment and social circumstance. This is a marker of a particular model of practice. Additionally, it provides a practice-level view of the co-prevalence of long-term conditions alongside gout in this cohort.

Given this study was undertaken in a suburban community of low socioeconomic status and predominantly in a population enduring the legacy of colonisation, it may not be

generalisable to all populations. Further, the PMS and its inherent limitations inform much of the data reported.

7.6 Conclusion

Māori people with gout are disproportionately limited in access to health services because of their employment and social circumstance. For those in paid employment, accessibility is a significant issue due to the opening hours of primary care. Those not working represent a level of social disadvantage where costs and travel to services are challenging. All components of access must be considered. In this general practice, where staff strive to deliver approachable, acceptable (culturally safe), and affordable healthcare, availability and accommodation of access was a significant limiting factor.

Further, it is very uncommon for Māori and Pasifika peoples not to have comorbidity of long-term health conditions. These people represent the demographic that every effort should be made to assure ease of access to comprehensive holistic services. The system does not have the patient at the centre in terms of access and co-creation of engagement. No matter how you consider the rhetoric for greater access for those most in need, this research highlights the reality as being the opposite for most people in this cohort. Effort must be made to ascertain and document the availability of services to people, as is the case with clinical variables. Services should be appropriately supported to reconfigure to suit all people's lives. The Crown has a duty to ensure the resourcing, the expectation and accountability that health services are responsive and accessible to those most in need.

A right delayed is a right denied.

Martin Luther King

Chapter 8 Viewpoint – Getting on with it: What counts as evidence when it comes to equity?

8.1 Introduction

Having presented research objectives (and interventions) 1 to 3 (as per Section 4.3), the following chapter details objective 4, also set out in Section 4.3.

The original plan for this thesis was to travel into the Pacific and meet with Indigenous stakeholders from other nations to explore barriers and enablers to medicines optimisation in an Indigenous context. However, COVID-19 and its lockdowns changed that.

This chapter revisits the initial intent and the impact of COVID-19 and its lockdown on this thesis. Interestingly this phenomenon provided new opportunities. One example was to promote to practitioners in Aotearoa how they could contribute to equitable gout management during a time when the COVID-19 pandemic limited primary care access. This advice was published in NZDoctor, a magazine for primary healthcare stakeholders in Aotearoa. The piece drew on the findings of Chapters 3 to 7 yet was also based on the principles and frameworks discussed in Chapters 1 and 2. The article concludes this chapter.

The second opportunity arose in writing that article, as I was also attempting to undertake a scoping review of relevant literature. I reflected on the ways in which Indigenous knowledge is valued in different spheres and by peoples; and the role of publication – how, where, what - in validating this knowledge. It became apparent that sometimes we need to get on with it and use what we count or consider as excellent evidence to achieve health equity.

Therefore, this chapter also provides the context for the NZDoctor article, outlined in the middle section.

8.2 The Intent

As indicated in Section 4.3.4, the original objective was to investigate Indigenous medicines optimisation perspectives by interviewing attendees at the Pacific Region Indigenous Doctors' Congress (PRIDOC). In the face of the pandemic of COVID-19, the conference/congress was cancelled, with global travel becoming highly limited. Health providers in these Pacific regions naturally prioritised responding to their communities' health concerns, not attending Zoom research sessions. In reassessing this objective and

method, a scoping review investigating holistic Indigenous health delivery models was considered.

This section presents how my thinking and conscientisation of this second method altered as my understanding progressed to a richer understanding of the underlying issues. As an intellectual and academic journey, this thesis has carved two streams of knowledge, Western and mātauranga Māori, into the pou (central pillar) of my research question. This, at times, contests the existing framework which underpins Western theses as mātauranga is marginalised and diminished in favour of Western regimes of knowledge validation. The following narrates this journey and presents relevant findings.

8.3 To Review or Not to Review

*I went home. I took a walk along the beach that curves around Te Matau o Maui in Kahungunu, towards what Pākehā call Cape Kidnappers. It was a lovely sea-breezed walk but I call it a literature review because where the cliffs tumble down to the foreshore – there are actually stories in the land. **Stories are knowledge, and knowledge is literature.** Then I clambered up one of the cliffs to a little hilltop called Tiromoana. Like its name suggests, it looks out across the sea from where our ancestors came and it is the site where our people built one of the first pā in that area, not long after one of our tipuna called Taraia brought some of Kahungunu down from the Mahia Peninsula. There is no pā there now but when I reached the summit I sat for a while where you can still see the indentations of the old palisades and the round circle holes in the ground where the supporting posts used to be. I found stories in the land there as well. **Stories are knowledge, and knowledge is literature***
Dr Moana Jackson (2011).

March 31 2022, was a bleak day for Aotearoa, New Zealand, with the passing of Dr Moana Jackson. In attempting to describe him, the superlatives started flowing - *esteemed Māori lawyer, author and academic, highly respected, pioneering, global authority on Indigenous people's rights, advocate for Māori mana motuhake and Indigenous rights, Constitutional law and Treaty of Waitangi expert, one of the greatest Māori minds of our time, facilitator, and human rights and social justice visionary* were some. Sir Joe Williams (the first Māori person appointed to the Supreme Court of New Zealand) stated Moana was simply “Te Tāwera, the morning star — rising bright in the east just before sunrise, never too far from the position on the horizon at which the sun would eventually appear. Like Te Tāwera,

Moana always rose in roughly the same place and his message was always the same: a new day is coming” (E-tangata, 2022).

Although I had only ever fleetingly met him, I became a major fan in 2003 when a friend (a Māori lawyer) asked whether I knew about Moana’s work. Embarrassingly, I did not at that time and quickly acquainted myself. When he passed, I revisited some of his writings and listened to him again online. While listening to a keynote address given by him in 2016, I found his words particularly pertinent and better articulated my own struggles concerning a further scoping review for this thesis. Moana (Jackson, 2016) was speaking at the Lowitja Institute International Indigenous Health and Wellbeing Conference in Melbourne, Australia, when he said,

Every major piece of academic work in a university has to have a literature review. What they mean by their literature review is stuff written as literature by white people, yet in our knowledge system, literature, as written, is only a recent innovation.... to try to get a university to accept that (alternate) ways of knowing and seeing the world constitutes a valid literature review is one of those many issues that indigenous peoples throughout the western academy continue to wage, so the links between knowledge and identity, the way in which knowledge, is used to define identity, go inevitably to the question of inherent survivability and strength of indigenous peoples.

During his address, Moana talked about colonisation working hard to convince Indigenous peoples that there is only one way of seeing the world: one system of knowledge. That, at most, Indigenous knowledge may appear exotic, but it is not ‘universal knowledge,’ and what is deemed universal has been European.

I had undertaken the literature review presented in Chapter 3 on the basis that it is part of the process required for PhD completion. However, Moana’s words on what constitutes a literature review resonated with me. I learned from the first review with those learnings presented in Chapter 3. I also thought about my intended commitment to Kaupapa/Indigenous theory and recognised that I had strayed from this commitment in order to appease the academy.

Indigenous and non-Indigenous researchers have questioned the usefulness of systematic reviews to Indigenous health research (McDonald et al., 2010). A project team within the Cochrane Collaboration and Indigenous academics from Australia, Canada, NZ, and the USA were tasked with identifying issues when synthesising evidence to inform the health system response to address inequities for Indigenous peoples. Some Indigenous participants left the group stating review methods have little to offer Indigenous health. Other members warned

the applicability of Western research is not transferable to Indigenous peoples, making reviews unsuitable. Criticism was also aimed at narrowly focused reviews when Indigenous people face disadvantages from multidimensional influences (McDonald et al., 2010).

Some Indigenous researchers have demonstrated alternative methods. For their review of chronic disease health interventions with a Kaupapa Māori philosophical basis, Rolleston et al. (2020) used a synthesis of three approaches for evidence which were weighted towards whanaungatanga (kinship) – i.e., using their own connections to Māori communities. They discussed how peer-reviewed Western literature overlooks or dismisses an equally rigorous Māori worldview and were also critical of assessing the quality of an evidence source based on a Western checklist (e.g., the Joanna Briggs Institute). This was deemed a pervasion of injustice given that these benchmarks against which quality is measured would rarely enable the capture of Kaupapa Māori programmes. Fundamentally this is a flawed process as they found the whanaungatanga search enabled the most relevant data capture. Non-Indigenous researchers have also found flaws with checklists and even how the Joanna Briggs Institute applies its own framework to research (de Vaal & Tamás, 2021).

A fellow Indigenous doctoral candidate described the challenge of maintaining her identity in the doctoral process and the challenge with how she would cite her friends, her whenua (ancestral lands), her tūpuna (ancestors), and the fire (Burgess et al., 2021). Burgess and her supervisors have committed to pushing back at the academy by saying ‘no’ to a self-fulfilling prophecy that serves the ‘colonising knowledge paradigm’. Instead, they committed to saying ‘yes’ to citation as an expression of whanaungatanga and only citing research that upholds Kaupapa Māori ideology.

In attempting to investigate Indigenous Models of primary healthcare to identify initiatives addressing medicines optimisation, I had regularly undertaken literature searches. My Scopus Library lists seven saved searches since 2016. I was particularly interested in the Pacific region from my experience at the Pacific Region Indigenous Doctors’ Congress, given the potential ability to follow up with previous contacts. Also, these countries are high-income countries and English speaking with well-described health systems

The searches comprised various takes on (medicine OR medication) AND (best AND practice) OR (evidence AND based) OR (optimal) AND (indigenous) OR (Maori) (aborigine) OR (torres) OR (Hawaiian) OR (native) OR (American AND Indian)) OR (first AND nations) OR (American AND Indian) AND (LIMIT-TO (LANGUAGE , ‘English’) The

variations largely comprised changes such as using wildcard search terms, e.g., aborigin* or alask* or Hawai* or adding in (patient AND focussed). The searches were not limited by disease states.

Over the years, my records show I scrolled through at least 4,791 papers. Of these, I read 270 papers in full, with none adding to the principles of knowledge gained in the first review. A strong theme was the advocacy for those working in the health system to do more than deliver evidence-based interventions and ensure a 'safe environment' for Indigenous people to access services (Durey et al., 2012). Others promoted the concept of race congruence (Stuart & Nielsen, 2011), which Te Rangi Hīroa had strongly pushed more than 100 years earlier (Hīroa, 1910). Variance from guideline practice for Indigenous people was common (Gu et al., 2014; Roe et al., 2016). Most interventions were aimed at one component: a very narrow focus compared with the richness of Indigenous thinking.

I struggled to be confident that a literature review defined by Western academia would comprehensively investigate Indigenous models of medicines optimisation. My experiences and connections had already lent themselves to believing the answers lay with Indigenous people's self-determination. These answers may not necessarily be reported in a peer-reviewed academic journal. Aside from the priority a literature search places on the privilege of journal publication, my thesis journey had conscientised me to a compartmentalised approach to a literature search as contrary to Indigenous thinking. Just as gout is a trojan horse for this doctoral thesis to understand medicines optimisation, and medicines optimisation reflects the health system and how it enables medicines optimisation, Indigenous epistemology would lean toward seeing this in reverse. If an understanding of medicines optimisation in an Indigenous realm is the target, then it would be necessary to consider this from a holistic perspective and look to a systems and environmental approach. A search strategy using a medicines optimisation focus would likely be insufficient for capture. An Indigenous self-determined solution would look to a holistic approach, not the separation of medicines from that overall person approach.

In addition, it has been argued that 'best practice' or 'evidenced based' are not terms that acknowledge dimensions of evidence produced within and outside of science (Buetow & Kenealy, 2000). Indigenous scholars and healthcare workers extend this argument to promote incorporating Indigenous consideration (Luke et al., 2022). The term 'wise practice' has been endorsed as an alternative that integrates Indigenous knowledge and practice, e.g., sharing knowledge through discussion circles (Firestone et al., 2020). A case in point for this thesis

was the community definition of best practice gout management did not consider annual blood tests or target serum urate levels as the outcome they would choose as the gold standard. Instead, they prioritised being symptom-free in the context of known triggers, e.g., food or injury.

In line with the approach of Rolleston et al. (2020), many of my experiences of medicines optimisation have been collected through interactions and whanaungatanga. They have not been published in a peer-reviewed journal. They have been forged through relationships and identified through Indigenous ways of knowing, through hui and wananga – connections of whakapapa and kaupapa. The HRPHOW project first presented in the introduction is an example that is not published yet directly contributed to medicines optimisation with a Kaupapa Māori approach. Throughout the decade of this project's delivery, I have seen many wonderful initiatives that I would deem as medicines optimisation. For example, a Whānau Ora project that involved whānau recreating walking and trading tracks that their tupuna had long since travelled. Some community members, including kaumatua, recognised they would not have the physical fitness to walk these tracks. It led to the community hiring out the local pool and recreation centre at night. They supported one another to get fit enough to do so. The fitness goal morphed to include weight loss. Anecdotal reports were of people reversing diabetes and no longer needing antihypertensive medication. On the day the trails were formally opened, all age groups traversed the whenua their tupuna did.

Experiences have not been limited to a national scene but have included international initiatives. They include such experiences as the Native American community's approach to opioid substitution programmes. This initiative was tribal-led and delivered. The reservation looked to intergenerational history to explain why drug addiction was so prevalent. Whilst acknowledgement of land loss was a prime driver, they also recognised that their connection to their 'tribal spirit' (horses) had been taken from them. Historically, horses were deemed intertwined and inseparable from this tribe. When the ancestors were rounded up and displaced to reservations many generations ago, they were forced to walk to their unchosen destination as their horses had been taken from them. The denial and removal of their spirit animal was seen as a prime driver of spiritual erosion and to be addressed. Their initiative involved purchasing a horse for each child of a particular age. The children and family cared for, trained, and looked after the horse. They were provided with professional help and got to keep the horse when the children graduated from high school. The results over time demonstrated the first decline in the demand for opioid substitution seen for decades. This

initiative also showed that the children with parents who had developed addictions were able to lead their parents away from addiction. I assert this is medicines optimisation, yet it does not appear in any peer-reviewed journal. Western science would potentially want it to be published: to understand, proliferate, and capitalise under an umbrella of evidenced-based development. The Indigenous perspective would be to share the experience in person, to learn in a reciprocity-based understanding with no underlying expectation to regurgitate through a perceived superior lens – a convergence of different ideals underpinned by a different perspective.

Another international example has been witnessed through a relationship with a native Hawaiian comprehensive health service for over 15 years. This health service is native Hawaiian-owned, governed and predominantly staffed. Theirs is a holistic approach with medical appointments for patients and their families simultaneously attended by traditional healers, relevant specialists, family doctors, nurses, psychologists, and social workers as desired. One initiative uncovered from this relationship is the provision of food parcels to native Hawaiian people diagnosed with diabetes and/or hypertension. Some of the food is from a garden project where the gardeners can earn horticultural qualifications. People are asked to keep a log of food intake, and whilst there is an acknowledgement for error with recall, people have had greater gains in HbA1c and blood pressure lowering, with down titration of medicines in some instances, than their previous approach of annual diabetic review alone. Again, this is not published.

These are but a small number of individual experiences or threads which have accumulated and could be woven into a rope of experience. This rope of experience has provided more background to the model of medicines optimisation from which I would claim an Indigenous perspective than which I have uncovered from attempts at non-Indigenous literature review.

There is likely a major postdoctoral opportunity or other research that could explore whanaungatanga in relation to medicines optimisation through other contacts in Aotearoa, Australia, Alaska, and Hawaii. This is a significant area to explore both in breadth and depth but is beyond the scope of this current thesis.

8.4 An Opportunity to Get On with Advocating for Equitable Management of Gout

Therefore the global context of travel restrictions and the inability to capture Indigenous models of medicines optimisation through relationships and processes of whanaungatanga meant an alternative was required. There was no confidence in completing such an exercise through a traditional literature review. While COVID-19 necessitated a change in approach, it also brought an opportunity to advocate for equitable management of gout at a time when those already disadvantaged were becoming more vulnerable (Charlesworth et al., 2020). It is challenging to describe the sense of urgency felt by many practitioners when NZ was plunged into anti-COVID public restrictions whereby people remained at home unless working in an ‘essential’ industry such as food or health provision. While the country remained relatively locked off from other countries, the global death toll from COVID-19 grew exponentially. There was significant concern over managing long-term conditions in this context of strict lockdowns and restricted contact, based on what was happening internationally and particularly the threat to the continuity of regular care amongst the consequences of the anti-COVID measures (Verhoeven et al., 2020). Initial reports of increased morbidity with gout (increased frequency and severity of flares,) were subsequently confirmed alongside a growing concern about an increased mortality rate for uncontrolled gout in those contracting COVID-19 (García-Maturano et al., 2022).

During these extraordinary times, prioritising a practical approach through differing means because of context became the focus. Given the deep concerns associated with reduced access to healthcare and the possibility of increased morbidity/mortality of COVID-19 in those with uncontrolled gout, the PhD plan pivoted to educate clinicians on appropriate and equitable management of gout. The decision to approach *New Zealand Doctor Rata Aotearoa*, NZ’s widely read and national medical magazine, was pragmatic as most prescribers and clinicians access the journal. The article adopted the form of a hypothetical case study that responded to the research question of this thesis – how can gout medication therapy for Māori be optimised. The following section provides the case study/article targeting the principles of the thesis question, presents the treatment options for gout, and discusses how COVID-19 might affect prescribing decisions. Importantly, it addresses this optimisation from an equity and Hauora Māori perspective. The article consolidates key learnings from previous chapters and provides the genesis for Chapters 9 and 10.

8.5 Avoid Perpetuating Inequities when Managing Gout in the Setting of COVID-19

This article is inserted as submitted for publication, except for minor edits and formatting changes to maintain consistency within the thesis.

It is included with permission from New Zealand Doctor Rata Aotearoa.

Te Karu, L., & Bryant, L. (2020, April 22). Avoid perpetuating inequities when managing gout in the setting of COVID-19. *New Zealand Doctor Rata Aotearoa*.

<https://www.nzdoctor.co.nz/article/print-archive/avoid-perpetuating-inequities-when-managing-gout-setting-covid-19>

8.5.1 Case Study

It's 8:30 on Tuesday morning and Jack rings telephone triage with yet another gout flare, wanting more diclofenac. He says that he probably had the 'wrong food'. You note Jack has made multiple requests for similar over the years, with requests becoming more frequent – three in the last six months.

Jack is a 39-year-old Māori man with prediabetes and a cardiovascular risk of 5%, with his blood pressure averaging 144/88 mmHg over the last year. His eGFR is 72 ml/min/1.73m², and he has microalbuminuria. Although you have previously discussed his cardiovascular risk, Jack has not been keen to take any medicines for this. Weight is 90 kg.

A recent article you read indicated inequitable gout treatment in NZ with variation in care for Māori and Pacific peoples, where gout occurs at an earlier age with worse outcomes compared to non-Māori and non-Pacific. In the setting of COVID-19, it is important that inequity gaps are not perpetuated and that a pro-equity approach is applied. Gout is a health condition that can be relatively easily managed to help prevent morbidity and premature mortality.

The ability to provide face-to-face consultation is limited with the current preferred delivery of virtual consults. Jack, without a device or data to enable this, is already at a disadvantage. The easy path would be to repeat the diclofenac and flick a script to the pharmacy. In the circumstances, you decide to ring Jack, so he does not have to pay for the call, and revisit gout management with him.

As with the starting point of any health conversation, you start by unravelling Jack's thoughts, beliefs, and experience of gout. Even before 'lockdown' Jack states his employers were becoming frustrated, and he risked losing his job as a labourer. He feels he simply needs larger supplies of diclofenac so he can start them before symptoms become debilitating.

Further, Jack doesn't fully appreciate that while some foods may trigger gout, the actual **cause** is that he has an elevated serum urate level and that there is genetic variation in urate handling. The discussion on genetic differences between Māori and non-Māori provides a better understanding for Jack as to why allopurinol is the gold standard for treating the cause and reducing complications such as bone deformity, renal disease, cardiovascular disease, tophi – and job loss and relationship problems. You impress that **gout does not go away when the pain goes away!**

Some useful resources that will help generate discussion with Jack (Box 8)

Box 8 Useful Learning Resources for People with Gout

| | |
|------------------|---|
| Health Navigator | www.healthnavigator.org.nz |
| Gout Happy Feet | https://www.goodfellowunit.org/gout-how-it-effects-you (sic) |
| Arthritis NZ | https://www.arthritis.org.nz/gout-arthritis/ |
| Pharmac | https://www.pharmac.govt.nz/medicines/your-health/gout/ |

Because the beliefs around food have become so entrenched with people, you state that focusing on food avoidance is unhelpful and is culturally inappropriate to some in the case of kaimoana (shellfish). However, you discuss fructose with Jack and how ubiquitous it is. Fructose-containing fruit juice increased the risk of gout by 81%, and sweetened soft drinks increased the risk by 85% compared with 49% from 15–30 g of alcohol (Choi & Curhan, 2008; Dalbeth et al., 2016). You add that by lowering his 'uric acid' or serum urate to below 0.36 mmol/L, he may be able to enjoy kaimoana again.

Jack remembers he has heard of allopurinol and that he has been provided with it previously but it only made his gout worse. He heard through whānau that allopurinol can be 'really bad at making gout worse', so he is not keen to try it again. A quick search shows you that Jack has been prescribed allopurinol twice before. On both occasions, he was not given 'cover,' and the starting dose was not matched with his renal function on a 'start low – go slow' approach.

You recall that you also tried getting Jack to come back between gout attacks to start allopurinol, but this has not worked. You establish that there were a few barriers for Jack – his hours of work, transport getting to the practice, cost of the consult and the prescriptions, and how easy it is to get ‘gout pills’ (which you learn are usually diclofenac) from friends and whānau in the community. He has bought diclofenac from the pharmacy before, but these are not nearly as strong as the ones you can prescribe. He has also presented to the hospital emergency department before, which mitigated some of the costs.

8.5.2 Gout Treatments and COVID-19

Jack’s cardiovascular disease risk and microalbuminuria, suggesting endothelial dysfunction, mismanaged gout, and prediabetes, doesn’t mean that he is at greater risk of becoming infected with COVID-19 but that he may experience more severe sequelae if infected.

The acute treatment choices are generally NSAIDs, prednisone or colchicine (Box 9).

You are aware that there have been internet discussions advising against the use of ibuprofen, but none of these is reputable, and beyond the standard cautions, there is nothing robust to validate this. There is a dose-related 20 to 50% increase in cardiovascular risk with NSAIDs, and they can be nephrotoxic. As Māori and Pasifika generally have a tendency for renal impairment and cardiovascular disease, your approach has been towards using short courses of prednisone as a first-line treatment for gout. Currently, you worry about prednisone’s broad ability to be immunosuppressive. You know that you should not stop it for people who use it regularly for other rheumatological conditions but wonder whether to use it during the COVID-19 pandemic.

This concern needs to be balanced with attack severity and using the most effective treatment to avoid treatment failure and seeking medicines elsewhere, including secondary care. The principle of the lowest effective dose for the shortest time for the individual person, rather than ‘standard’ dosing, becomes more crucial. For Jack, the cardiovascular and renal risks are more quantifiable at this time rather than the unclear impact of prednisone and immunosuppressive risks.

Colchicine has been used for millennia for acute treatment of gout, although in more recent times, the dosing has changed considerably, with fatalities occurring at doses high enough to induce diarrhoea. It is generally slower to provide relief and, as a result, less likely to be the first line. Recruitment is underway by the Montreal Heart Institute for a phase 3, multi-centre,

randomised controlled trial to evaluate the efficacy and safety of colchicine in adult patients diagnosed with COVID-19 infection. This is to determine whether short-term treatment with colchicine reduces the rate of death and lung complications related to COVID-19 on the basis of its blood vessel anti-inflammatory properties. This sounds feasible in rationale, but in the absence of any results, no conclusions can be made. Jack says the pain began this morning and is not so bad now but will become so if he doesn't get on to it.

8.5.3 Options for the Acute Management of Gout

Box 9 Options for the Acute Management of Gout

Nonsteroidal anti-inflammatory drugs (NSAIDs)

Naproxen initially 750 mg, followed by 500 mg after 8 hours, then reduce to 250 mg every 8 hours until attack has passed [NZ Formulary]

Diclofenac: 75 mg once or twice daily [No more than five days at maximum dose]

Adverse effects of NSAIDs are dose-related

Renal – if eGFR is less than 60 ml/min, limit the daily dose of diclofenac to 75 mg, or naproxen to 1000 mg. Be very careful and limit the dose if the patient is on an angiotensin-converting enzyme (ACE) inhibitor or angiotensin II receptor blocker as well as a diuretic, 'triple whammy' (Loboz & Shenfield, 2005).

Cardiovascular – check the patient's cardiovascular risk calculation and add 20 to 50% (dose-related increase in risk with NSAIDs).

It is strongly recommended not to give NSAIDs within 24 months of myocardial infarction or acute coronary syndrome.

Prednisone

Concerns surrounding immunosuppression and unknown risks with COVID-19 mean caution should be taken.

Dose depends on the severity of the gout attack and patient factors, such as size. By dosing at 0.5 mg/kg and rounding off this calculation, the dose for Jack would be 40 mg for 3–5 days, then 20 mg for up to 5 days if needed. Tapering the dose over 10 days can reduce the likelihood of a rebound flare, although tapering is not always necessary.

Blood glucose may rise, usually in the late afternoon, but this is transient.

Colchicine (low dose)

Give 1 mg stat, followed by 0.5 mg one hour later. A further 0.5 mg may be taken once or twice daily for 2–3 days more.

For people less than 50 kg or with a creatinine clearance of less than 50 ml/min, the maximum dosage is 1 mg (two tablets) in 24 hours; and no more than 3 mg (six tablets) over 4 days.

Once the maximum cumulative dosage is reached, colchicine should not be used again for at least 3 days.

The maximal dosage and hazards of excessive colchicine needs to be stressed to avoid the acute toxicity likely to result from a ‘more is better’ perception.

The New Zealand Formulary-approved dosing is 1 mg (two tablets) immediately, then 0.5 mg every 6 hours to a maximum of 2.5 mg (five tablets) on the first day. A maximum of 1.5 mg (three tablets) on subsequent days and no more than 6 mg (12 tablets) in 4 days.³ Do not repeat the course within 3 days – caution with CYP450-3A4 inhibitors, e.g., diltiazem and erythromycin.

Starting Jack on Prophylactic Allopurinol

Having attempted to introduce allopurinol in the past and being aware of the evidence that allopurinol can be commenced during an acute flare of gout, you contemplate this in light of the information you have gathered. You don’t want to lose Jack’s confidence and decide to treat Jack with naproxen acutely. As there is funding available for short-term blister packing (at \$5 a pack, the cost would be an extra \$15 for three months of blister packaging), you start allopurinol after 2 weeks at 100 mg daily, titrating up by 100 mg monthly, alongside prophylactic colchicine 0.5 mg daily for 3 months. The blister packing will help manage the complexity of dose changes and stopping and starting medicines during the initiation of allopurinol.

Although laboratory services are currently limited, ordering a serum urate during an acute flare can be inaccurate as it can reduce. **A ‘normal’ serum urate during an attack does not exclude gout.** With an established diagnosis of gout and a priority of obtaining a serum concentration of less than 0.36 mmol/L, you task yourself to measure Jack’s serum urate in 3 months. In NZ, the mean dose to achieve a urate concentration of less than 0.36 is

approximately 450 mg, so you are confident that monthly testing for the initial dosage adjustment is not necessary and challenging for Jack each month. The maximum allopurinol dosage is 900 mg.

The target for people with severe gout, e.g., those with tophi, chronic gouty arthritis or frequent attacks, is 0.30 mmol/L.

8.5.4 Notes on Introducing Allopurinol

Starting allopurinol

Dose and titration must be based on renal function to reduce the risk of allopurinol hypersensitivity syndrome and flare occurrence (Table 8).

Table 8 Allopurinol Dose and Titration

| eGFR (ml/min/1.73m ²) | Starting dose | Titration |
|-----------------------------------|-------------------------|---|
| >60 | 100 mg daily | Increase by 100 mg monthly |
| 30–60 | 50 mg daily | Increase by 50 mg monthly |
| <30 | 50 mg on alternate days | Increase to 50 mg daily in 4 weeks, then increase by 50 mg 4-weekly |

eGFR, estimated glomerular filtration rate.

Cover

Prophylactic colchicine 0.5 mg daily or twice daily for the first 3–6 months of urate-lowering therapy is usually recommended. For people with tophi, this may need to be extended. The risk of a flare without colchicine prophylaxis is approximately 67%. With colchicine, it is about 20%.

An NSAID may be used instead of colchicine for prophylaxis, but Māori and Pacific people have a propensity to renal impairment. Consider a proton pump inhibitor if covering with NSAID. Low-dose prednisone, e.g., 5 mg daily, may also be used. Colchicine has less renal and cardiac toxicity and may potentially be cardioprotective. Warn against diarrhoea and cease colchicine if this occurs.

Acute Flares

If the patient is starting allopurinol during an acute flare, prescribe acute therapy and ensure the patient completes the whole course rather than just stopping when the pain is resolved. The ‘Happy Feet’ website recommends a 14-day course of prednisone. Sometimes there is no

choice but to commence when there is little time between critical periods or when gout pain is not present.

Notes on continuing allopurinol - because allopurinol plus prophylactic colchicine, and sometimes the acute treatment, start at the same time, it is strongly recommended that blister packaging is used for at least the first three months, and preferably six months. This is likely to make the right thing the easy thing to do and would entail a discussion of Jack's values and preferences before commencing.

- Warn to stop allopurinol if fever and/or rash occur.
- Ensure you tell the person that treatment is long.-term. It is not stopped when the 'target uric acid' concentration is achieved.
- Once at the person's target serum urate, there is no need to reduce the dose if renal function deteriorates.
- Monitor for flares, and confirm that the flare is gout rather than joint pain due to new-onset osteoarthritis.

Aware that Jack needs some encouragement, you make a note to text Jack in a fortnight and then monthly to help him persist with the allopurinol introduction.

You are also aware that Jack has no ability to print out resources or access appropriate ones on the internet so you print off some and arrange to leave in his mailbox.

Further, you discuss with Jack that it is important to manage all heart risk appropriately, and this can be addressed the next time a face-to-face consultation is possible.

8.5.5 Take-Home Messages

It is essential during such extraordinary times that inequities are not perpetuated and increased.

There is debate and a lack of clear evidence around the use of prednisone (immunosuppression) and NSAIDs (impact on renal and cardiovascular disease) at this time of a COVID-19 pandemic.

Gout is the most common inflammatory arthritis in NZ. Medicines are available to manage and prevent it.

Give flare prophylaxis/cover with urate-lowering therapy and always begin with a 'start low – go slow' approach.

Follow-up with people and continue to reinforce messages at every interaction. **Check for understanding.**

Treat cardiovascular risk in gout patients.

Having set out the rationale and the approach taken for objective 4, the following chapter presents the approach for objective 5.

Chapter 9 Swiss Cheese and Ngā Rau o Kawakawa

9.1 Introduction

Medicines are a foundational element of a health system. They are the most common intervention in health, and integrating medicines holistically across systems and society has been the evolving thread throughout this thesis. Chapter 1 starts at the point a person engages with a health system and describes the journey to the best possible outcomes from medicines. It included the importance of cultural safety across all providers, access to prescribers, clinical knowledge of providers, and the ability of patients to collect medicines. This view of medicines optimisation was from a funded primary care perspective and included implementing and monitoring funded medicines. Policies and legislation surrounding this funded perspective were not interrogated at the time. This chapter presents a more comprehensive view of medicines optimisation as a reflection of the broader healthcare system at micro, meso and macro levels. It synthesises learning throughout the thesis journey to present opportunities for transformation.

This chapter addresses the objective of identifying the gaps in medicines optimisation as a reflection of the broader healthcare system (Section 4.3.5). It also presents the intervention of visual contextualisation, commencing with a reframing of the well-known Swiss Cheese model and concludes with a diagrammatic representation of the gaps and opportunities to depict a te ao Māori view.

Because gout can be prevented with medicines, this thesis has used this health condition to deconstruct the layers of inequitable management that disproportionately affect Māori. A view of medicines access at the meso level has thus been described. This thesis has evidenced the heavy burden on whānau and communities when people suffer unnecessarily from gout. I have promoted a holistic approach to gout management where people are not managed in isolation of other health conditions or their social circumstances and, importantly, not in isolation of their worldview and the sociohistoric context that informs that worldview. In essence, I have used gout as the micro view identifying barriers and enablers at the meso and macro levels of the 'system.' Identified barriers included a lack of a hauora Māori response, direct and indirect costs, accessibility, cultural safety expertise, clinical expertise and the environment in which services are delivered. For healthcare providers, structural barriers such as the emphasis on health targets impeded health delivery in a manner aligned with

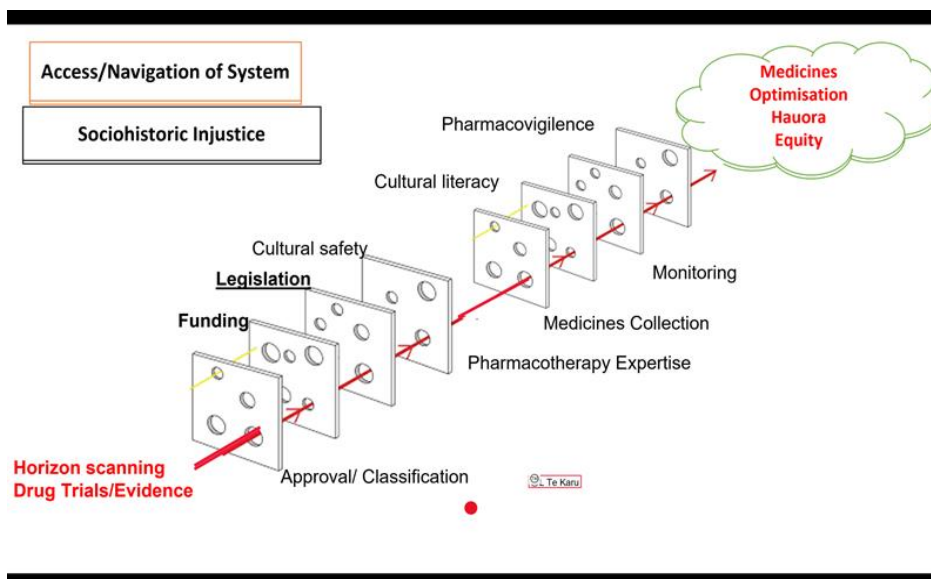
holistic transformation (Te Karu, Harwood, et al., 2021). Predictably, enablers addressed these points and included the concept of 'by Māori, for Māori, with Māori.'

Adapting Reason's metaphor of the Swiss Cheese model (Figure 6) (Reason, 2000) provides a diagrammatic representation of the many layers required to optimise medicines to present a more comprehensive, macro view. The Swiss Cheese model was initially developed to describe medical failure and was most comprehensively applied to investigate intrathecal administration of the vinca alkaloid, vincristine (Toft, 2001). Such administration of this medicine generally results in a catastrophic outcome – rare but indeed a medical failure. In this thesis, the model is flipped to describe a positive outcome, albeit one which I assert is also rare, given the layers required to align for achieving medicines optimisation both in a general sense and with a pro-equity, Indigenous approach. The cost to our health system and society of not achieving this rare outcome is immense.

9.2 Swiss Cheese of Medicines Optimisation

Elements of the Swiss Cheese model of medicines optimisation not previously covered in Chapter 1 are discussed below and are followed by a case study demonstrating the relevancy of the layers to gout and equity. The Swiss Cheese model is reconsidered to one more suitable to a hauora Māori concept – (Ngā Rau o Kawakawa – Section 9.5) alongside the explanation of this model.

Figure 6 Swiss Cheese of Medicines Optimisation



9.2.1 Horizon Scanning, Drug Trials, Evidence

The ultimate aim of achieving medicines optimisation and medicines optimisation with a hauora and pro-equity approach begins with horizon scanning. Horizon scanning considers pharmacological versus non-pharmacological treatment of health problems from a future, experimental, investigational, established, and obsolete perspective (Carlsson & Jorgensen, 1998). Other countries have dedicated horizon scanning units to effect health, health services and/or society where they are considered essential (Vogler, 2022). However, a substantive, proactive approach to pharmaceutical health technology in preventing, diagnosing, treating, and curing health conditions is lacking in NZ (Pharmac Review Panel, 2022). Horizon scanning must also incorporate diagnostic services and technology as a therapeutic package. For example, many biological advances in cancer therapy require genetic testing.

How we consider medicines as part of a holistic approach to health delivery across the health, social development, education, justice and disability systems in NZ, for example, does not happen. Furthermore, as argued in Chapter 2, how NZ's health system (and therefore medicines environment) values and includes Indigenous thinking and knowledge within this paradigm is absent.

In NZ, the 'availability' of medicines is generally not a planned, proactive process. Primarily it begins with an application to NZ's medicines' regulatory authority – Medsafe. Drug companies must deem the approval process worth investing in to make an application that subsequently flows into the funding process. Drug companies must also consider the likelihood of their medicine receiving Pharmac (the Pharmaceutical Management Agency described in Section 1.5) funding before submitting to Medsafe. In the case of new drug applications, funding is arguably the highest hurdle to NZ's medicines market. Cases do exist (e.g., benzbromarone), but it is exceptional for a medicine to be funded without prior approval. If there is no faith their drug will be publicly funded, the pharmaceutical company may not apply to Medsafe (Coughlan, 2021). If it is a new drug application, Medsafe must decide on the potential risks versus the potential benefits of medicines with data or evidence that is likely received from international studies and not generated in NZ.

Similarly, Pharmac must critically evaluate drug trials in cohorts of people that never mirror the population of NZ. This is an ongoing problem related to the size of our country but is compounded by the funding process, which limits opportunities for innovation, and clinical trials to gather and test population-specific data (Pharmac Review Panel, 2022). As a result,

very few clinical trials with medicines have been undertaken in NZ with enough statistical power to demonstrate effectiveness and safety for Māori.

9.2.2 Legislation

Medsafe must further classify medicines according to the deemed appropriate level of access, e.g., general sales (available in supermarkets, petrol stations); pharmacy only (available only from a pharmacy shop); pharmacist only (restricted and can only be sold by a pharmacist); prescription medicine (can only be prescribed by legislated prescribers) and Controlled Medicines (only prescribed by specified prescribers under defined conditions). Legislation in the Medicines Act 1981 and Medicines Regulations 1984 defines this activity and others, such as the assessment of new medicines and adverse reactions monitoring. This includes the composition of committees that make these decisions. The Committees are required by law to provide technical expertise but are not required to include an Indigenous worldview, pro-equity competence, or even public health expertise.

Pharmac have a legislative requirement to secure for eligible people in need of pharmaceuticals the best health outcomes that are reasonably achievable from medicines and from within a fixed budget (Pae Ora (Healthy Futures) Act, 2022). Pharmac have not engaged with the wider population of NZ as to the definition of 'best health outcomes' and have historically translated this objective to focus on getting the lowest price for medicines, not necessarily the best health outcome. Ministerial review of this Crown Entity strongly recommended that Pharmac not focus on fiscal spending alone and consider societal impact more robustly and effectively (Pharmac Review Panel, 2022). The Review Panel also recommended legislative changes to the Minister, urging the incorporation of equity as an objective. This was not upheld, and it is too early to ascertain whether there will be a genuine culture change in the organisation.

Consequences of a lack of legislative expertise at the point of drafting laws exist across multiple places in the medicines system. For instance, legislation requires every pharmacy to be majority owned by a pharmacist or pharmacists, who have effective control of the pharmacy at all times (Medicines Act, 1981). The Act also states the pharmacist(s) cannot have majority ownership in more than five pharmacies. However, pharmacists have managed ways to get around this rule, including under the umbrella of a chain company. Prescribers are also banned from majority-owning pharmacies unless with special consent. Hence a

doctor, for example, may not own a pharmacy, but a pharmacist could be permitted to own a medical clinic.

Māori pharmacists make up less than 2% of registered practising pharmacists (Pharmacy Council of New Zealand, 2021). This woefully low percentage has been the case since pharmacist ethnicity records began some 20 years ago. However, a professional scope of practice and fiscal resourcing is not enough to own a pharmacy outright. A pharmacy licence and then a pharmacy contract are two more requirements, further limiting ownership. This situation makes it unlikely that a Māori person would routinely engage with a Māori pharmacist and rare that a Māori pharmacist would own a pharmacy. This ownership clause prevents iwi or whānau collectives from owning pharmacies. If the pharmacy ownership law is intended to protect against unscrupulous pharmacy business activities, yet has allowed loopholes for corporate ownership, it poses the question of whether an iwi-owned pharmacy would provide any less protection or whether it would be more acceptable and protective for Māori. Again, this law assumes a superiority view and represents structural racism.

Another example of legislative impact pertains to medicine supply issues. Supply shortages have arguably magnified globally during the extraordinary circumstances of the COVID-19 pandemic, and NZ is not immune. In practice, NZ may be more vulnerable because of the tendering system for the supply of medicines, often relying on a sole supplier. When shortages do occur, there is no alternative but to source medicines from different suppliers. For NZ, this means the medicine is not assessed, and acquisition is as an ‘unapproved’ or ‘Section 29’ medicine. The legislation states that only a ‘medical practitioner’ (doctor) can prescribe Section 29 drugs, thereby dismissing nurse practitioners and pharmacist prescribers who often work in rural and underprivileged communities where the need is potentially greater for full and continued access to medicines. Shortages have also meant policies restrict the supply a person may be given. They are sometimes asked to return to a pharmacy more frequently than usual such as monthly or weekly rather than 3 monthly. This disadvantages those living rurally, those with transport issues or any other access barrier.

Legislative impact on medicines optimisation does not solely lie with the Medicines Act. The Misuse of Drugs legislation covers controlled drugs such as ‘strong opioids’ (e.g., morphine or oxycodone). These statutory obligations were drafted in the 1970s and arguably need updating. But one example is the requirement of a bound book in which a handwritten record of every controlled drug (Class A or Class B) dispensed by a community pharmacist must be logged (Misuse of Drugs Act 1975). These books have been the subject of theft from

pharmacies over the many years and constitute a repository of patient names, addresses, and type/amount of medication supplied. In turn, people's homes have been entered, and medication demanded based on the information gained in these books (S.A. Bauld,¹⁰ personal communication, 2022). Perhaps less obvious is legislation like the Resource Management Regulations (2004), which requires medicines used in chemotherapy (cytotoxics) to be destroyed by incineration. As incineration of pharmaceuticals is not permitted in NZ, they are shipped overseas along with the associated environmental footprint of international shipping of hazardous waste.

Therefore legislation and policy directly impact the approval, manufacture, marketing, registration, procurement, acquisition, advertising, distribution, prescribing, dispensing, storage, disposal, and use of every medicine in NZ. This has occurred in a systematically unpartnered way with Māori, resulting in an unbalanced system.

9.2.3 Unfunded Medicines, Medicines Costs

In discussing the medicines journey, Chapter 1 omitted the circumstance under which a medicine is not publicly funded. If medicines are unfunded, people or their whānau are left to meet their cost and associated administration fees; otherwise, they risk going without the medicine(s). Those that can afford unfunded medicines simply pay for them. A small number may have private medical insurance, and some people try through various mechanisms to raise sufficient funds to make the purchase. Others leave NZ to live in countries where the drug is funded, e.g., Spinraza (nusinersen) for children with spinal muscular atrophy (Espiner, 2021). Spinraza has a high annual 'list price'¹¹ of around NZ\$390,000 per annum (Espiner, 2021). On the surface, this makes the purchase an unwise one as few people would be deemed to benefit from a high price. Parents of these children, however, discuss the costs of medical care (including frequent hospital visits, helicopter transfers, multiple care providers and other medicines). The projected costs also do not factor in personal and environmental costs such as required housing additions, vehicle conversions, time off work for parents, or loss of productive life if the family move to another country or the child dies, as is usually the case with spinal muscular atrophy if untreated. These are the societal costs.

¹⁰ Bauld, Samuel Arthur - Ngāti Wai/Ngāpuhi/Te Rarawa/Ngāti Toa/Ngāti Raukawa. Chair Pharmacy Council of New Zealand, Addictions Pharmacist Opioid Services, Community Pharmacist.

¹¹ List price - the price a drug company displays even though it is unlikely to be close to accurate, as prices must be kept confidential

Even when medicines are funded, there are different levels of funding. Some medicines are partially funded, so they incur the government co-payment fee discussed in Section 1.5 (if the pharmacy charges these), plus the shortfall in funding and any possible markup by the pharmacy. Some medicines require the recipient to meet certain clinical criteria to be subsidised under the Pharmac Special Authority scheme. Similarly, clinicians can apply under an ‘exceptional circumstance’ scheme to obtain unfunded medicines but must meet extra criteria and enquiry. Additionally, although some medicines are fully funded, other costs can prevent access, e.g., long-acting reversible contraceptives, which require a qualified health professional to insert, who may charge a fee to do so (Te Karu, Habib, and Crengle, 2021). This extra cost means the medicine remains out of reach regardless of being considered ‘free’.

For medicines more generally, there is evidence that, even when funded, co-payment costs are prohibitive or mean that people select to receive only the medicines they feel they can afford (Norris et al., 2016). The duty of co-payment collection has fallen to community pharmacists who wrestle with this issue.

It should be noted that ‘discount pharmacies’ in NZ do not charge co-payments. These are generally large chain pharmacies, e.g., Chemist Warehouse, Bargain Chemist, and Countdown Pharmacies, operating in NZ since late 2017. They are primarily restricted to NZ’s major population centres, where the support of a model that relies on retail sales is more possible. This situation creates an urban-rural disparity for the possibility of free, subsidised prescription medicines and reduced-cost unsubsidised medicines.

9.2.4 Pharmacovigilance

Pharmacovigilance is the last component of medicines optimisation that we have not elaborated on. Pharmacovigilance is the post-market surveillance or the ongoing analysis of real-world medication use. It is integral to ascertaining the efficacy, safety, and cost-effectiveness of medicines. This analysis should be used to inform how, when, and whether medicines remain appropriate and, therefore, available for continued use. Sometimes it is used to plan for addressing findings, e.g., cardiac monitoring post-treatment with certain chemotherapeutic agents. There is evidence of drug mortality and morbidity being more common than realised. One NZ study estimated that 45,000 people suffer ‘severe harm’ from medicines annually (Robb et al., 2017). Another study using a retrospective analysis of primary care records in NZ, instead of relying on self-reporting or scanning for medication

types, calculated the incidence rate of medication-related harm in NZ general practice to be even greater (Leitch et al., 2021a). These researchers described the incidence as ‘common’ at 73.9 harms per 1,000 patient-years. The challenge, therefore, becomes one of ensuring all data is captured, so programmes are designed to prevent harm.

Throughout this thesis, barriers to medicines optimisation across the primary care system have been described. The Swiss Cheese model of medicines optimisation encompasses primary healthcare delivery and enables in-depth scrutiny into the gaps where access in its wider sense sits.

In considering the Swiss cheese model from a Hauora Māori or equity perspective, the holes in the slices of cheese become smaller and even closed in some circumstances such that obtaining optimal medicines management is not only rare but not possible.

The following section presents a case study to demonstrate this further. The case study is anonymised but is a real case.

9.3 Case Study – Kemp

Kemp is a 40-year-old Māori man who comes to the clinic after a recent admission (6 weeks prior) to hospital for gout. His whakapapa (ancestral connection) is to the iwi of Ngāpuhi in Te Tai Tokerau (the north of NZ in the Hokianga region).

Kemp works as a nightshift forklift operator six nights per week. He generally leaves home at 5.30 pm, and when his shift ends at 6.30 am, he is usually home by 7.00 am. He and his wife, Darlene, have four children. Three are school age, and one is preschool. Darlene cleans at three different employment sites, and when Kemp arrives home, Darlene leaves soon after.

In between helping with the children and chores, Kemp manages around 4 hours of sleep (in blocks) before returning to work.

He had his first gout attack in his twenties. There is a strong history of gout on both sides of his family. Kemp recalls from his early childhood, his father suffering terribly from gout. His father passed away at 55 years of age from ‘some sort of heart attack’. Kemp's mother is still alive at 62 years of age and has gout, like many of her family members.

Kemp is a wiry man (body mass index 21) who says he is very active at work. He is on and off the forklift helping load pellets. He likes the physicality of his work and has good friends at work but is concerned his boss will fire him. He has used up all his sick leave, and if he has

gout, his boss sends him home, and he does not get paid. Last week he had an attack in his hands and borrowed diclofenac 75 mg tablets from an uncle. He took four tablets at once as it is hard to drive the forklift when his hands are so sore. He cannot risk his boss knowing.

The recent hospital admission was after 2 days of spontaneous onset of pain in Kemp's left groin, which increased to the point where he was unable to work and not able to weight bear. He says the pain was excruciating, but there were no other symptoms, e.g., fever or pain elsewhere. Kemp was taken to the operating theatre, where his left hip was aspirated and washed out. He was commenced on high-dose intravenous antibiotics as septic arthritis was a possible diagnosis. After 8 days, the aspirate and tissue samples continued to show an absence of organisms, only the presence of white cells and urate crystals (indicative of a gout attack). Kemp was reviewed by the infectious diseases team, who dismissed a diagnosis of septic arthritis and agreed with a diagnosis of gout. He was discharged on the 9th day after admission. During this hospital stay, Darlene could not attend her different jobs, and the costs associated with visiting Kemp (petrol, parking, time off work) became prohibitive.

Kemp says he visits the hospital emergency department at least annually because there are no direct costs. There are other benefits in that he has at times been given injections for pain that seem to work very quickly. At other times, he has been given medicines to take home, which negates paying a prescription fee. On this last admission, he was sent home with prednisone, diclofenac and codeine tablets, which he is happy about as it was more medication than he needed for that attack. He says this will save borrowing or buying when the next attack comes. He buys Nurofen (ibuprofen) at the supermarket and sometimes diclofenac at the pharmacy. He finds diclofenac superior for some reason, but the strength he buys at the pharmacy is lower than that he gets from a prescriber and is more expensive.

On examination in clinic, he has tophi on his left hand, right elbow, and both feet. The tophi on his hand prevent him from forming a fist and holding eating utensils. He has trouble holding the steering wheel of the forklift and operating levers on the left-hand side of the machine. Kemp fears further progression may mean he has to leave work voluntarily.

His blood pressure is elevated at 150/92.

Kemp says he does recall being prescribed allopurinol once previously but did not understand its role or why he needed to take it every day. He has real trouble remembering medication with his working hours. He and Darlene find it hard to afford a healthy, well-balanced diet,

but they do their best. The rental accommodation is a duplex setup, and whilst neither he nor Darlene know a lot about gardening, there isn't room or the ability to have one. Kemp does not drink alcohol, explaining his father prohibited it in the house and strongly discouraged any consumption. Kemp states he wants to be adherent to health advice. He does not intentionally forget medication. Life, in general, feels a struggle.

9.4 Swiss Cheese Application

9.4.1 Horizon Scanning

As discussed, there is no dedicated process in NZ that scans the horizons for new medicines and considers optimising medicines at a systems and societal level to achieve equity. For Kemp, this means no proactivity scanning for new ways to treat/manage gout nor any proactivity in joining similar workstreams. For example, given gout disproportionately affects Māori and Pasifika people, there could be a focus on promoting the pharmaceutical industry to partner with independent biomedical research institutes, especially those focused on immunology and, importantly, with communities where this disproportionate burden exists to advance innovative therapies. Support for innovation in technology and diagnostic services for gout would also be helpful. For example, there is debate as to when gout begins - whether it is at the first presentation of pain or when crystals are present. The former definition neglects that some people, particularly older women, may present with advanced, debilitating tophaceous gout yet state they have never had pain (MacFarlane & Dieppe, 1985). Similarly, reliance on pain as a definition neglects the association between asymptomatic crystal deposition and severe coronary calcification (Andrés et al., 2016). Also, a recent nested case-control study has suggested that gout attacks are associated with a transient rise in heart attacks or strokes. (Cipolletta et al., 2022). Yet, current guidelines recommend waiting to commence urate-lowering therapy until people experience more than two attacks per year (Richette et al., 2017). Enabling earlier diagnostic capability and knowing when to commence treatment would reduce disease burden. The development of handheld imaging equipment could replace current expensive, non-portable imaging equipment to improve access to diagnosis and timely treatment (Sivera et al., 2022).

As a low-level first stop, horizon scanning could involve working with domestic medicine manufacturers to combine allopurinol and colchicine into one pill in various strengths to be used during the implementation stage of urate-lowering therapy. As discussed in this thesis,

the implementation of urate-lowering therapy currently requires cover with anti-inflammatory prophylaxis. A gout polypill could have advantages for prescribers and people (Selak et al., 2020) like Kemp.

Imagine a system that looked for solutions to the many issues that Kemp and Darlene face when living with poorly managed gout. A system that would factor in Kemp and Darlene's work absences along with the possibility of unemployment and the ripples that would flow onto Kemp and Darlene's children. A system that recognises the health system costs when Kemp is admitted to the hospital or frequents the emergency department or if Kemp suffers a gastrointestinal bleed from excessive NSAID administration. Equally, the centrality of people in their wider whānau environment would factor in the risk to Kemp's cardiovascular health from both untreated gout and his reliance on symptomatic medication.

A recent publication reported the association between gout and cardiovascular disease by using linked administrative data highlighting disadvantaged outcomes for Māori. For both men and women, compared with New Zealand Europeans, Māori had a much higher risk of a fatal or non-fatal cardiovascular event within 5 years (adjusted hazard ratio for women 1.79 [95% CI 1.21–1.90] and for men 1.59 [95% CI 1.51–1.68]) (Cai et al., 2022).

Consideration of these many factors, the many touch points, and the many stakeholders from a solution-focused, societal perspective needs to occur if medicines optimisation is to be realised.

9.4.2 Drug Trials/Approval/Classification

Indigenous involvement in clinical trials is well recognised as lacking. Where health conditions disproportionately affect populations, these populations need to be overrepresented, and trials should be statistically powered to enable assessment by ethnicity. With a health condition like gout, where there is genetic variance in urate handling (the greatest risk for the development of gout), this issue becomes more significant. Again this highlights the importance of proactivity and ensuring communities feel safe to participate in research projects as equal partners, not in a subservient capacity (Selak et al., 2013).

The approval process of any novel, innovative treatments should require equity expertise to factor in the disproportionate burden on life that gout carries for Māori and Pasifika. That is, approval is about the balance of harm versus benefit, and those considering any benefits must be immersed in knowing the weight for specific populations.

The classification process would need to substantively factor in safety as part of the access. For example, NSAIDs can be bought in unchecked amounts from supermarkets and pharmacies. Whilst a balance is required for appropriate access, there has never been a conversation with Māori about how safety concerns can be mitigated. In one of the very few population studies looking at medicine-related harm by ethnicity, Māori and Pasifika people were at greater risk of hospital admission (compared with New Zealand Europeans after adjustment of confounders) due to NSAID-associated heart failure and gastrointestinal bleed (Tomlin et al., 2020). Māori were also at greater risk of acute kidney injury. Of note is that this study could only investigate prescribed NSAIDs. There is no robust data to estimate the harm from ubiquitous NSAID access from pharmacies, supermarkets, and those shared amongst whānau.

9.4.3 Funding

In terms of funding, the recent review into Pharmac revealed that systemic failings across the organisation disproportionately contributed to adverse health outcomes for Māori (Pharmac Review Panel, 2022). The review panel identified significant deviations from the responsibility to be Te Tiriti responsive and to have equity expertise. The failings were many. The Board did not ensure that strategic planning around equity was being delivered and that appropriate decision-making criteria were applied to funding decisions. The statutorily appointed Pharmacology and Therapeutics Advisory Committee (PTAC) is tasked with aiding these decisions. Evidence defined as appropriate for decision-making at PTAC tended to be large, randomised controlled trials, giving useful outcome measures when looking specifically at pharmacology, but this meant that observational, epidemiological evidence, particularly for the NZ environment, was not included. Prioritisation of medicines for funding did not use NZ-specific data. One example of this was observed by analysing the funding consideration for empagliflozin, a diabetes medicine. Pharmac analysis did not account for the prevalence of diabetes in Māori, that diabetes occurs at a younger age, or that there is a much higher progression to renal failure in Māori than in non-Māori (McLeod & Harris, 2021). This translated to an underestimation of the health benefits of empagliflozin in Māori and a failure to apply equity in the modelling of empagliflozin.

Māori membership of PTAC occurred by happenstance, not by intent. Members tended to work for academic institutions where time could be more flexible. Membership disadvantaged the inclusion of those not financially supported by their workplace, those in

primary care, and Māori voices, with only one of the 14 members identifying as Māori in 2022.

The structures, the systems, and the processes that drove the decision-making for publicly funded medicines did not ensure equity and hauora Māori expertise. The review panel also found that Pharmac did not apply its own framework criteria at times and that there was no separate analysis when it knew of significant inequities affecting Māori. Māori staff at Pharmac have been scant in numbers, and the inaugural chief advisor, Māori, was not appointed to Pharmac until October 2020 (27 years after inception). The review panel stated, “Pharmac's decision-making errors and omissions could be increasing inequities” (Pharmac Review Panel, 2022, p. 55).

These failings have a significant effect on Kemp. There are novel therapies available in other countries for gout, but not in NZ. An example is the uricases. Uricase is the enzyme present in animals that degrades uric acid to allantoin, which is readily excreted from the body. Humans lost this enzyme and the ability to do the same during the mid-Miocene period, some 15 to 9 million years ago (Oda et al., 2002). Pegloticase is a recombinant uricase developed specifically for gout treatment and is approved by the US medicines regulatory authority (the US Food and Drug Administration). It is used in the USA (and European countries) to treat gout in people where target serum urate has not been achieved, or there are tophi to resolve. Pegloticase works rapidly (within 24 hours) to lower the serum urate. It may be helpful when there is a need to get severe gout controlled or dissolve tophi more rapidly than traditional urate-lowering therapy. Initial concerns over immunogenicity appear to be mitigated by the co-administration of immunosuppressive medicines (Khanna et al., 2021). Pegloticase has demonstrated significant improvement in the quality of life for patients with gout (Mandell et al., 2018). Regardless, the analysis of whether pegloticase would be helpful in the NZ setting has never been undertaken. The manufacturers would be required to believe the cost and effort of approval application (>NZ\$100,000) is worthwhile and that pegloticase would be appropriately considered and made available through public funding.

Rasburicase is another recombinant uricase. It is available in some NZ hospitals but only when recommended by a haematologist for people at risk of tumour lysis syndrome. Globally it has, however, been used successfully in people who have been refractory to previous oral urate-lowering therapies (Khanna et al., 2021). Again, regardless of whether it could be valuable in a NZ setting, it has not been given due analysis. The real expense to the health system and to people has not been factored in when considering whether these more

expensive agents have a place. The Pharmac funding model has evidenced incompetence in making this consideration. Similarly, treatment with anti-interleukin-1 β biological therapies aimed at inhibiting pro-inflammatory cytokines are not publicly available in NZ. These agents include canakinumab, rilonacept, and anakinra.

9.4.4 Cultural Literacy

In Chapter 1, we covered many components of the Swiss Cheese model in our discussion of the journey to medicines optimisation, including cultural literacy, although this may require clarification. We discussed that NZ legislation demands that regulatory authorities set standards of cultural competence. Over time, the language has changed to recognise that cultural competence should not have an endpoint and that the person receiving health practitioner services should judge whether it is a culturally safe service (Curtis et al., 2019). I have chosen to separate cultural safety and cultural literacy despite that cultural literacy requires a foundation of cultural safety. Culturally safe practice should be routine at individual and organisational levels to influence healthcare, reduce bias, and achieve equity. This is fundamental to the provision of services where there is cultural incongruence and health inequity. Cultural literacy differs from cultural safety in that it requires practitioners and organisations to ensure people receive understandable health information to make appropriate decisions. Whilst it must be from a platform of culturally safe practice, it goes beyond that to assimilate information. People are dependent on the ability of health practitioners and organisations to impart applicable health information.

Cultural literacy is a broad topic that spans race, socioeconomic status, religion, and education level and relies on communicative ability (Hirsch, 1983; Kelleher, 2002; Stein, 2004). Health literacy historically assumes a level of ‘mainstream knowledge’ to have a platform on which people communicate. Cultural literacy accounts for ‘diverse knowledge’ and ensures people are provided with all the tools to feel empowered in their care. Cultural safety can be the rate-determining step of whether a person will engage with a health system. Still, it does not follow that the service will ensure comprehension of information so people can prioritise health management. Carlson et al. (2019) contend that for Māori, social and cultural considerations are rarely addressed and configured within mainstream health literacy delivery in NZ. Delivering health services differently with appropriately trained staff requires workforce development commitment. The underrepresentation of Indigenous health professionals requires prioritisation beyond what is currently demonstrated (Curtis et al.,

2012). Participation in education is layered with structurally racist barriers for Indigenous students compared with non-Indigenous counterparts (Maaka, 2019).

That Kemp has suffered from a preventable health condition for almost two decades without being provided the necessary tools to self-manage is the outcome of this. The lack of cultural literacy or ensuring people understand health information is one reason people become non-adherent to medicines and can be a source of medicines waste (Nikora et al., 2011). In 2016, a NZ health IT company projected that an estimated NZ\$40 million worth of drugs was wasted annually (SimpliHealth, 2016). This figure considered only direct costs, not the costs associated with therapeutic cessation or associated disposal and environmental costs. A more recent study found that pharmaceutical waste collected from hospitals and pharmacies in Auckland alone increased more than fourfold from 2016 to 2020 (Hanning et al., 2022). The true costs to NZ society are unknown, but for Kemp, as discussed, the costs go much further than a supply of allopurinol not administered.

Throughout this thesis, I have discussed access issues to the primary care system. In Chapter 5, I captured the voices of Māori who discussed cost barriers; wait times at general practices, laboratories, and pharmacies; and the importance of cultural safety. Chapter 6 presented barriers to access around the opening hours of health services. For Kemp, all of these have been relevant barriers. Other researchers have had similar findings and added that, at times, Māori men have felt compelled to use their partners or daughters as a proxy for accessing services (Nikora et al., 2011).

9.4.5 Pharmacotherapy Expertise

Allopurinol is publicly funded and remains the drug of choice for gout prevention. The list price indicates it can cost less than NZ\$0.02 per tablet, yet the associated dispensing costs mean it attracts the discussed \$5 co-payment tax in most community pharmacies. As evidenced throughout this thesis, the consequences of not collecting allopurinol have overall costs far greater than the health system costs. The estimated costs of uncontrolled gout in the USA range from US\$7.7 billion for gout-specific costs to more than US\$20 billion for total costs (Kabadi et al., 2016). This is reported as a conservative estimate due to the difficulty in factoring in the risks of over-the-counter analgesic and anti-inflammatory drugs, missed wages of significant others, and the need for caregivers or transport providers. In NZ, where the highest global rate of gout exists, similar robust cost predictions of uncontrolled disease have not been undertaken. Suffice to say, Kemp is one example of the ravages of poorly

managed gout, finding it easier to borrow or buy symptomatic relief over the counter in pharmacies and supermarkets and visiting the emergency department where medical consult is without cost and, on occasion, medicines too.

I have described prescribing or applied pharmacotherapy as the intersection of diagnostic skills, knowledge of medicines, communication skills, clinical pharmacology, appreciation of risk and uncertainty and, ideally, experience. Prescribing urate-lowering therapy for gout has complexities that prescribers have struggled with over time (Dalbeth, 2013). The reasons may be all or any of the above. There is a body of evidence demonstrating that people are underprescribed allopurinol and that it can be many years before prevention is implemented (Dalbeth et al., 2018b). When it is prescribed, it should be commenced at a low dose appropriate to kidney function and should be increased slowly. It is also recommended to co-prescribe anti-inflammatory 'cover', usually colchicine, to mitigate against flares, which are common when commencing urate-lowering therapy (Yamanaka et al., 2018). People must be empowered to manage the concepts of long-term prevention whilst navigating an initial, potentially rocky period with the need for multiple medicines, dose titration, and avoiding a flare. Other medicines or alternate therapies a person is administering must also be considered as part of a holistic approach and requires applied pharmacotherapy expertise. Interaction with patients with gout over decades has revealed that people are often started at a dose that is too high for their kidney function (Te Karu et al., 2013), increasing the risk of inducing an acute attack and the rare but severe side effect of allopurinol hypersensitivity syndrome (Stamp & Barclay, 2018).

Furthermore, they are often not provided with cover, and when people experience a gout attack, they are reluctant to keep using allopurinol (Te Karu et al., 2013). If people are commenced on low-dose urate-lowering therapy, they are sometimes left on a dose that does not get the serum urate level to where they no longer suffer acute attacks. Rather, the dose should be escalated to enable prevention (Robinson & Stamp, 2016). The domain of applied pharmacotherapy has impacted Kemp. When he was prescribed allopurinol, even if he had been given the tools to understand the intent of urate-lowering therapy, he was not provided with anti-inflammatory cover and, as a result, suffered a gout attack and a loss of confidence in continued administration.

9.4.6 Monitoring

Monitoring of gout management repeats all the barriers to accessing healthcare. International guidelines recommend serum urate levels are measured initially every 4 weeks while urate-lowering treatment is being titrated and then every 6–12 months for monitoring (Hui et al., 2017). Chapter 4 presents a whānau view of what ‘best practice’ could look like, which was less demanding than guideline recommendations. Regardless, for Kemp to access repeat medication and, at times, laboratory services means the same navigation of barriers.

Monitoring is more often suboptimal than not. A systematic review of studies from the USA, the UK, and Germany found less than 40% of patients had regular serum urate-level monitoring (Jeyaruban et al., 2015). Findings from the New Zealand Gout Atlas of Health Variation showed that just over half of people (range 38–64%; average 56% for all ethnicities and 53% for Māori) identified as having gout had a recorded serum urate test in the 6 months following urate-lowering therapy dispensing (Health Quality & Safety Commission, 2018).

The barriers become more evident when considering regular dispensing of urate-lowering therapy, which is significantly lower in Māori and Pasifika peoples than in other New Zealanders. The odds-ratio 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) (Te Karu, Dalbeth, and Stamp, 2021).

Furthermore, as evidenced in the PMC project, people with gout seldom have no other health conditions, and cardiovascular disease is the most prevalent (Te Karu, Arroll, et al., 2021). From a te ao Māori perspective, it is imperative that gout monitoring should include other health conditions where people are not carved up into disease states and addressed in isolation.

Suboptimal monitoring of gout therapy is problematic as it represents another obstacle in attaining gout prevention.

9.4.7 Pharmacovigilance

The concern is that under-reporting and under-capturing adverse events mean underestimating the actual situation. For Māori, this unknown appears more pronounced, with less likelihood of reporting adverse events. This was the finding of a 2019 report from the Commission, which promoted three cultural pillars: reporting culture, learning culture, and a just culture (Health Quality & Safety Commission, 2019b). A ‘just culture’ is important for

Māori as clinicians appear less likely to take action even when the harm is known. This is also true for Pasifika peoples and women (Leitch et al., 2021). Harms include treatment failure due to communication, such as not using preventative asthma inhalers because of a lack of understanding. Non-adherence to medicines is also a significant issue with associated morbidity and mortality. (Ho et al., 2009; Ho et al., 2006) Non-adherence can be addressed with tapered education to empower, yet the Commission's adult primary care patient experience survey demonstrated that Māori were less likely to receive medicines information (Zullig et al., 2015). For Kemp, the interwoven story of treatment failure with allopurinol includes communication and reinforces the overlapping components. Similarly, the lack of precise knowledge on the full extent of harm from overuse or any use of NSAIDs has not given the necessary weight to delivering dedicated programmes addressing the disproportionate harm for Māori.

9.4.8 Swiss Cheese Reality for Kemp

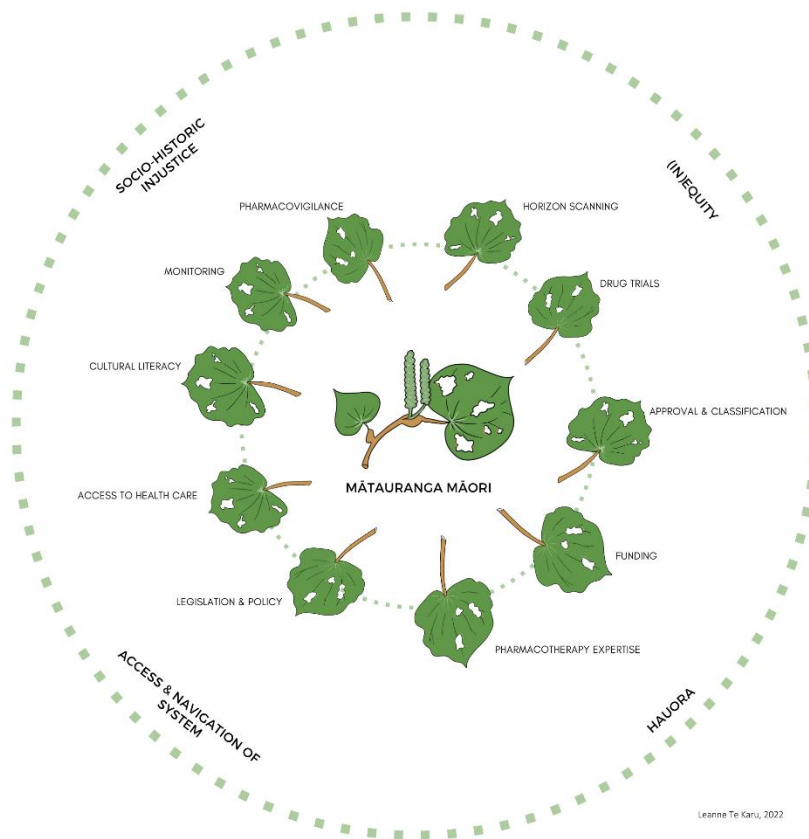
It is fundamental to understand that the holes in the Swiss cheese layers are inequitably smaller for Māori, such that reaching the aspiration of medicines optimisation is rare. A lack of oversight of each component impacts this outcome. The reality for Kemp is that he has recently spent 9 days in a public hospital without his whānau able to visit frequently. Employment insecurity is an issue for him. Should he lose employment, housing insecurity, alongside an already established food insecurity concern, may also become a reality. The absence of a medicines system underpins the catalyst for this alternate outcome.

In this section, I have not been explicit about legislation's impact on Kemp, except that all of the components presented in this section are impacted by statute. The most significant legislative impact on Kemp and accessing medicines is discussed at length in Chapter 2. For Kemp, Darlene, and their children and whānau, mātauranga Māori has not been central to their experiences in and engagement with the health system.

9.5 Ngā Rau o Kawakawa | The Leaves of the Kawakawa Plant

Acknowledging medicines optimisation is not linear in nature, with overlapping and intersecting components, and that our Swiss cheese model does not incorporate a te ao Māori perspective, it has been reconfigured to depict ngā rau o kawakawa (Figure 7).

Figure 7 Ngā Rau o Kawakawa | The Leaves of the Kawakawa Plant



A Kaupapa Māori illustrator, Gabrielle Baker¹² was engaged to provide this illustration based on my narrative and conceptualisation of how the Swiss Cheese model could be reframed with mātauranga as the foundation.

Several factors determined the rationale for deciding on a different framework. First and foremost, the Swiss cheese model is in no way Indigenous. In contrast, kawakawa leaves represent one of the most widely used traditional fauna in NZ, a rongoā, or source of Indigenous medicine. Engaging Indigenous communities in optimising medicines will require a representative affinity and correlation with the literal and metaphorical concepts of well-being.

Similarly, mātauranga Māori (Māori ways of knowing) represents the underpinning of the diagram. The framing of health post Te Tiriti was an imposed replication of the British system where Western medicine was deemed superior to an Indigenous approach. This approach has meant completely dismissing mātauranga. If one were to consider whether

¹² Gabrielle Baker (Ngāpuhi, Ngāti Kuri) is also a consultant with policy expertise in hauora and health equity.

colonisation had never occurred and Māori had been able to continue with a te ao Māori perspective, our health system would be grounded in mātauranga. The tragic loss of this worldview to inform a modern-day health system has been the discussion of the two major reviews, the Waitangi Tribunal Hauora Report (Wai 2575) and the Health and Disability System Review (HDSR). The HDSR proclaimed that a system which does not reflect mātauranga Māori or enhance rangatiratanga will not be effective at improving the health and well-being of Māori (Health and Disability System Review, 2020). Consequently, the HDSR recommends ensuring that mātauranga Māori is incorporated into all aspects of the system. The Tohunga Suppression Act introduced in Chapter 2 as a significant piece of legislation impacting contemporary NZ, was almost a final blow to the last bastions of mātauranga Māori after the land wars. Te Ahukaramū Charles Royal purports that, had the health system been built off a mātauranga Māori base, the starting point would have been a different cultural foundation (Royal, 2006). He proposes that, for Māori, the ultimate calamity is not physical death but the loss of mana at individual, cultural, and societal levels. Similar to our findings with the fishbone exercise, if one considers nurturing and restoring mana the central driver to addressing holistic health needs, then an entirely different decision-making model comes into play. The values underpinning health delivery move from focusing on morbidity and mortality through a biomedical lens of avoiding physical calamity to ensuring inherent life quality through the special and non-ordinary presence or essence that is mana. Royal explains the intersectionality of mana with tapu, mauri, and identity that imbues the fullness of rongoā.

The linear nature of the Swiss cheese model did not correlate with the holistic viewpoints of Māori and Indigenous ways of thinking. The intersections, whether Western or Indigenous, may occur at different domains during health management or on multiple occasions during the cycle.

This is more sensory in the redesign of the model, despite some content correlation. Swiss Cheese did not allow for these paradigms and how they may apply to medicines optimisation and, in turn, health outcomes or the impacts thereof.

9.6 Conclusion

In summary, the NZ health system has been founded on a dominant culture and worldview. Any opportunity to exercise rangatiratanga and enhance mana has not been afforded. It is challenging for Kemp and his whānau to see themselves and what is familiar to their

worldview in this paradigm. This is not only consequential for Kemp and whānau but has a negative and detrimental outcome for the health sector and wider society.

This is further discussed in Chapter 10.

Chapter 10 Thesis Conclusion

10.1 Introduction

In this concluding chapter, the findings of the previous chapters are summarised, integrated, and applied to consider how gout medication therapy for Māori can be optimised.

Furthermore, these findings are drawn upon to consider how medicines optimisation can be addressed.

The chapter begins with a synopsis of the preceding chapters. It includes a published editorial reinforcing the view of medicines optimisation from an Indigenous perspective which aligns with the overarching aim of this thesis – to highlight optimal medication therapy and how access to medicines, prescription of evidenced base drug therapy, and administration of medicines can be optimised for Māori.

Based on the thesis findings, recommendations to optimise gout therapy for Māori are set out in Section 10.6. The recommendations also consider a societal and systems approach to medicines.

Finally, this chapter and this thesis ends as it began – with reflection – in the form of a conclusion and final word.

10.2 Chapter Synopsis

Chapter 1 laid out the background to the thesis discussing health outcomes for Indigenous people, particularly Māori in Aotearoa. It further presented the place of medicines in preventing and treating health conditions and included the first published paper of this thesis (Te Karu et al., 2018). The paper discussed multiple steps required for medicines optimisation, focusing on funded and approved medicines. One major limitation was its lack of focus on the systematisation of medicines or how a societal view may be obtained. Central to the lack of positioning of a societal perspective was the gap in Indigenous ways of knowing or, for Māori, mātauranga.

Chapter 2 presented the context of medical optimisation for Māori in Aotearoa, with consideration of an ontological perspective, health history and the enduring legacy of legislation, in particular, the TSA. The fact that Māori were not equal partners at the outset of the relationship with the Crown has had far-reaching negative consequences. Inequities occur when there is unequal power and unequal resources. Failure to value Indigenous peoples as

an equal because of superior beliefs is racist and denies the benefits of an Indigenous values system for all. Investigating the many layers of the TSA led to considering all legislation related to medicines supply in this thesis. Chapter 2 also describes the central tenet of this thesis, Kaupapa Māori research theory. Our contemporary world gives precedence to knowledge produced from a non-neutral colonising position, and to effect change requires compensatory mechanisms of science and the health disciplines to reconfigure and reconstruct this ‘fabricated hierarchy of humankind’ (Reid et al., 2019). Chapter 2 recognises Kaupapa Māori theory is best practice for Māori research ethics (Hudson et al., 2010) and that, as with all Indigenous people, qualities of resilience, aspiration, and perseverance are required to see transformation and power redistribution.

Chapter 3 highlighted the many cogs in the wheel of medicines optimisation and that a multiprong approach was required. The scoping review presented in this chapter found a lack of published evidence describing outcomes for multi-component activities delivered in collaboration across professional groups. A study from Australia looked most promising, with initiatives aimed at targeted prescribing support, medication formulation, cost reduction, and adherence support (Hayek et al., 2016). Feedback from study authors, however, indicated the initiative was believed to be the most effective in a practice where race congruence was a factor (led by a Pacific GP in this case).

A key finding from the rerun of this review found that a trial (HOPE4) using non-medically trained workers with easy-to-use algorithms alongside whānau support was an effective tool for lowering cardiovascular risk in people with poorly controlled hypertension (Schwalm et al., 2021).

Chapters 4 to 7 present the thesis project – the PMC initiative investigating how gout medication therapy for Māori can be optimised. Chapter 4 describes the development and implementation of the project. Chapter 5 reports the qualitative investigation of 23 participants and their experience of the PMC initiative, along with key factors in the ecosystem of gout management for Māori. Chapter 6 describes the healthcare provider’s view of the project and the structural barriers to providing tailored gout prevention for those most in need. Chapter 7 presents a quantitative description of domains of health access, in particular employment and social circumstances for which health services are not tapered. The interventions and a summary of the key learnings from this thesis project are presented in Table 9.

Table 9 Summary of Key Learnings of the thesis project

| Intervention | Learnings |
|---|--|
| <p>Develop and implement a DST for providers to prompt and improve prescribing of preventative medicines for gout for Māori at PMC</p> <p>Develop a multi-level care approach that aims to empower people to self-manage gout at Papakura Marae</p> | <p>DST development requires significant resourcing and subject matter expertise</p> <p>Whānau definitions of ‘optimal’ and ‘best practice’ can be different to the biomedical definition and must be included</p> <p>There was variable uptake in the DST use by prescribers</p> <p>DST alerts were not always given attention</p> <p>The enrolled population identified with gout was almost certain (94%) to have comorbidity of health conditions</p> <p>Clinical pathways advice can come from any suitable clinician.</p> <p>In a general practice environment where socio-historic inequity pervades, there are many competing interests for staff, such that it is difficult to focus on one health condition when there is no direct funding attached</p> <p>The community should define the problem to be solved</p> <p>A quality improvement primary care initiative led by a Crown Entity at the time did not deliver upon a stated pro-equity intent</p> <p>‘Partnership’ needs to be defined and underpinned by shared values</p> <p>There are a lack of Kaupapa Māori models or Indigenous frameworks to assess quality improvement initiatives</p> <p>The non-regulated workforce was key to engaging the community and updating serum urate levels</p> <p>Nurses did not use standing orders</p> <p>There is value in priming patients before they present in clinic</p> <p>All staff saw value in the project</p> |
| <p>Identify the barriers and enablers to the implementation of these initiatives</p> | <p>Barriers:</p> <p>A lack of a hauora approach in the health system</p> <p>A lack of mātauranga in the health system</p> <p>Clinic hours</p> <p>Laboratory testing</p> <p>Costs</p> <p>Waiting times</p> <p>Appointment times</p> <p>Transport</p> |

| | |
|--|--|
| | <p>Health practitioners delivering culturally unsafe practice</p> <p>Culturally literate health messages failing to be delivered</p> <p>Inappropriate prescribing</p> <p>Inappropriate sale of NSAIDs</p> <p>A focus on funded health targets</p> <p>Insufficient resourcing in general practices where gout is prevalent</p> <p>Gaps in monitoring preventative gout therapy</p> <p>Inefficient IT infrastructure</p> <p>Enablers:</p> <p>Marae-based clinics</p> <p>Hauora (holistic) health delivery</p> <p>Culturally safe practitioners</p> <p>Kaimahi – non-regulated health worker navigators</p> <p>Clinical education sessions for staff</p> <p>Extended clinic hours</p> <p>Community-driven social marketing and education campaigns</p> <p>Empowered whānau who inform the clinicians on what best practice should look like</p> <p>Dedicated resourcing of general practice staff to lead initiatives</p> <p>Appropriate funding to address health conditions outside targets</p> <p>Race congruence between staff and community if possible</p> <p>General practices where there is an embedded commitment to community outcomes</p> <p>Nurse education and support to use standing orders</p> <p>Transport assistance</p> <p>Removal of financial barriers</p> <p>Mobile point-of-care testing</p> <p>Regular feedback to clinicians on their response</p> <p>Induction for any new staff members</p> <p>Recording within the PMS of social determinants</p> <p>Administrative alerts added to patient files</p> <p>Culturally safe research</p> |
|--|--|

DST, decision-support tool; NSAID, nonsteroidal anti-inflammatory drug; PMC, Papakura Marae Clinic.

The project component of this thesis involved significant time and resources to plan and develop. From the seed of development for a DST through to its implementation took 17 months—the development of this particular component required continued advocacy with the PHO. Although not expected to be a panacea, the DST was less effective than hypothesised. This was the reality of a busy general practice operating with disadvantage in a location where inequity pervaded. Real world data ensued. Elements of the multi-level approach were variable in delivery, but all were welcomed by whānau. For instance, that we delivered only one late-night clinic was a product of staff availability and resourcing, yet those patients that came said it was “revelationary.” Whānau were also very responsive to kaimahi undertaking point-of-care testing in the community, but this task fell to one person who could not be at all the events.

Chapter 8 explained why the original objective of investigating the Indigenous perception of medicines optimisation necessitated change brought about by the global pandemic of COVID-19. One option could have been to undertake a further scoping review investigating holistic Indigenous health delivery models. However, ongoing literature searches for models built on Indigenous paradigms, i.e., Indigenous-owned, governed and predominantly staffed showed this investigation was far more suited to the original intent of attendance at PRIDOC than searching peer-reviewed academic journals.

In parallel, the reality of working and researching in and with the ‘Maori and gout’ community during the thesis journey contested with what appeared to be research of Maori, almost voyeurism research or as an academic exercise. These approaches highlighted the disconnect and non-understanding of mātauranga in health research in NZ. Given an alternative to the original intervention was required and that this thesis was committed to delivering transformation, the decision was made to develop advice on managing gout during the COVID-19 restrictions based on findings from this thesis. Publishing in a fortnightly medical newspaper enabled sharing of these findings to front-line clinicians at an extraordinary time, aligning with Kaupapa Māori practice to support and advocate for the transformation of care for those with gout.

Chapter 9 detailed the importance of a systems and societal approach to medicines. It presented the gaps in attaining medicines optimisation. It did this by reversing the Swiss Cheese model of medical misadventure to describe the gaps and where transformation could occur in a medicines optimisation environment. Chapter 9 goes on to present the diagrammatic representation to contextualise this situation in NZ – Ngā Rau o Kawakwa.

10.3 Personal Perspective Editorial

What follows is an editorial that provides a personal perspective and narrative that summarises and reflects on the optimisation of medicines focusing on Indigenous issues. Some of the content overlaps with that previously discussed. It is included for reiteration, emphasis and as a representation of the publication.

This editorial was originally published in the *Journal of Primary Health Care*:

Te Karu, L. (2021). Restoration of the health system must not neglect medicines – but who has the power of reform? *Journal of Primary Health Care*, 13(2), 96–101.

This publication is inserted as published, except for minor edits and formatting changes to maintain consistency throughout the thesis. It is included in the thesis with permission from the *Journal of Primary Health Care*.

10.4 Restoration of the Health System Must Not Neglect Medicines – But Who Has the Power of Reform?

The broad changes to Aotearoa New Zealand’s (NZ) health system recently announced are arguably the most significant for Māori to date (Department of the Prime Minister and Cabinet & Health and Disability Review Transition Unit, 2021). The disestablishment of DHBs and creation of a new dedicated public health agency and an independent Māori Health Authority (MHA) provide hope for improved hauora (health and well-being) in this country. Hope comes with caution: this reformation must be more than the proposed structural changes outlined. It must also reframe approaches to rangatiratanga (sovereignty) and create synergy and strategic partnership.

British colonisation of Aotearoa saw the introduction of systems of government, services and institutions founded on inherent belief in the superior knowledge and practice of the colonisers. This belief of superiority is, by definition, racism. Te Tiriti o Waitangi – the Treaty between Indigenous Māori and the Crown – created a framework for Aotearoa, promising a continuation of rangatiratanga for Māori in exchange for governorship by the Queen of England. Instead, it delivered and delivers immense anguish and intense dispute (Waitangi Tribunal, 2019). In recent times, ‘Treaty principles’ developed by the Court of Appeal have been criticised as consolidating the power of the Crown, reversing sovereignty attribution and watering down Crown commitments (Te Puni Kōkiri, 2002). Even if this

watered-down or ‘blind to rangatiratanga’ view of principles is applied, it is hard to see where partnership exists horizontally, valuing the worldview of both parties equally.

Dr Moana Jackson recently promoted the word ‘restoration’ as a better alternative to ‘decolonisation’ (Jackson, 2021). The premise of restoration is that addressing the plague of inequities in health processes and outcomes for Māori will require a change of minds and hearts as much as a change of health system structure (Health Quality & Safety Commission., 2019a). Failure to achieve a partnership with equal governance, equal resourcing, and self-determination has been an intergenerational blight on Tāngata Whenua of Aotearoa, not only denying all residents of this country an Indigenous holistic health approach but also underpinning a plethora of inequities in health outcomes.

The absence of adequate partnership has led to monocultural biomedicine and missed opportunities for the richness of an holistic approach and deep appreciation of interdependence with each other and the environment that is common to Indigenous cultures. To consider physical health as the sole aspect of hauora is a reframing of the all-inclusive perspective necessary to respond and recreate balance for that person in their collective context. For Māori, whanaungatanga, or the centrality of kinship and careful attention to relationships, means something can never be viewed in isolation but only with reciprocity that is mutually enhancing.

Contemporary Western thinking is finally exploring this view of the interdependence of individual, context, and relationships as crucial to the resilience of both individuals and systems (The Spin Off, 2020). The contemporary reality for whānau in our health system is that their perspectives of health are invalidated by our western health system which, rather than co-existing and cross-pollinating, competes with (and historically has banned) traditional Māori perspectives and healing practices.

I am a prescribing pharmacist based in general practice, working to decrease morbidity and mortality from health conditions and from medicines. Medicines are foundational to health systems, so a truly partnered, well-regulated medicines system is long overdue and should be a key indicator of successful restoration that delivers for Māori.

10.4.1 The Current Health System's Approach to Medicines

There is overwhelming evidence that a coherent, responsive, holistic medicines system is not currently in play. Antibiotics, gout management, NSAIDs, and medicines costs provide illustrative examples of current inequities in medicine policy and practice.

Antibiotics

Māori are less likely to receive medicines to prevent illness yet more likely to receive potentially more toxic medicines for symptomatic disease (Metcalf et al., 2018). Diseases for which antibiotics are indicated affect Māori and Pacific peoples more than other ethnicities (Baker et al., 2012; Bibby et al., 2015; de Boer et al., 2018; Metcalf et al., 2019; O'Sullivan et al., 2012; Webb & Wilson, 2013) yet Māori do not receive antibiotics when needed (Auckland UniServices Ltd, 2018; Metcalf et al., 2018).

Gout and NSAIDs

Gout is a health condition characterised by layers of inequity that change the entire trajectory of lives without access to low-cost preventative medicines (Te Karu et al., 2020). The heaviest burden of gout weighs on Māori and Pasifika whānau and communities. There is mismanagement and, consequently, long-term inequities in outcomes (Dalbeth et al., 2018b; Dalbeth et al., 2016b; Guillén et al., 2020). I have previously advocated a holistic approach to gout management where people are not 'managed' in isolation of other health conditions or their social circumstances and ignoring their worldview and the socio-historic context that informs that worldview (Te Karu et al., 2018; Te Karu, Harwood, et al., 2021; Te Karu et al., 2013). I have used gout as an example of the barriers and enablers both of the medicines system (or lack thereof) and the 'system' in a broader sense (Te Karu et al., 2018).

Allopurinol, for example, the drug of choice for gout prevention, can cost as little as \$0.02 per tablet. Yet, there are instances of people becoming unemployed and reliant on emergency department care with the ravages of poorly managed gout (Te Karu et al., 2020). People report seeking symptomatic relief from potentially dangerous NSAIDs available over the counter in pharmacies and supermarkets (Te Karu et al., 2020). Pharmacy dispensing rates of NSAIDs to Māori and Pacific peoples with gout are higher than for other ethnic groups, with all the attendant risks (Health Quality & Safety Commission, 2018). Widespread access to NSAIDs has led to ethnic disparities in hospital admissions of Māori and Pacific peoples for serious adverse outcomes – including upper gastrointestinal bleeding, heart failure, and acute kidney failure (Tomlin et al., 2020).

Māori and Pasifika are less often the recipients of medicines optimisation and are paying the price.

Costs

For medicines more generally, there is evidence that, even when funded, costs are prohibitive or mean that people ‘select’ which medicines they feel they can afford (Norris et al., 2016). The duty of co-payment collection has fallen to community pharmacists who wrestle with this issue. Nearly one in five (18%) Māori and Pacific adults did not collect a prescription due to costs in 2019, which is nearly three times the percentage of non-Māori, non-Pacific, and non-Asian adults (Health Quality & Safety Commission, 2020). These data include only direct medicine costs — not costs associated with prescribing, transport, and time off work. The ability to collect medicines is further restricted for adults living in the most socioeconomically deprived areas. An estimated 18,000 children were denied access to medicines due to cost in 2019–2020 (Ministry of Health, 2020). A study investigating prescriptions written at discharge from Middlemore Hospital in South Auckland found 48% of people did not fill at least one medication item on their prescription. Younger age and Māori ethnicity were strong predictors of not receiving prescriptions (Martini et al., 2020). I do not advocate a universalist approach to abolishing co-payments as there is evidence that this builds inequity where resourcing is unnecessarily distributed and not targeted (Goodyear-Smith & Ashton, 2019). The situation needs addressing, however, and perhaps targeted subsidies facilitated through Māori health providers or prescribers, as deemed necessary, could be usefully introduced.

If medicines are not publicly funded, people or their whānau are left to raise their cost and associated administration fees; otherwise, they go without. Some medicines (e.g., Ventolin inhalers) are partially funded so they incur the government co-payment fee plus the shortfall in funding and any mark-up from where the medicine is dispensed. Some medicines (e.g., Sacubitril-Valsartan) require recipients to meet certain clinical criteria to be subsidised under the Pharmac Special Authority scheme. Similarly, applications can be made under an ‘exceptional circumstance’ scheme to obtain unfunded medicines, but extra criteria must be met. Additionally, although some medicines currently are fully funded, administration costs can prevent access, such as intravenous iron and long-acting reversible contraceptives (McGinn et al., 2019). This means these medicines remain out of reach, regardless of funding.

Whether it is cost, complexity or quality of medicines care, the inequities are clear.

10.4.2 The Inequitable Legislative Context and its Consequences

Medicines are the most-used common intervention in primary care and our legislation is a barrier to an integrated, fully functional medicines system that enables equitable access and medicines optimisation.

In Aotearoa, the process for ‘availability’ of medicines generally starts with approval from the medicines regulatory and safety authority, Medsafe. It is primarily a reactive process initiated by drug companies who make a financial decision to invest in the approval process, followed by an application for subsidy from the funding process.

In assessing these applications, Medsafe must critically evaluate pre-existing drug trials in cohorts of people that never mirror our population. This is an ongoing problem related to the size of the country: where possible, we need trials that are conducted here. The lack of Indigenous involvement globally is well recognised, with scant evidence of authentic partnering to address the suspicions of Indigenous involvement being any more than providing specimens to be studied and reported upon (Glover et al., 2015). Where health conditions disproportionately affect populations, these populations need to be over-represented and studies powered to enable assessment by ethnicity. Not the reverse, as is the case with a health condition like gout, where there is genetic variance in urate handling (the greatest risk for development of the disease) (Tai et al., 2019; Watson & Roddy, 2018).

Medsafe must also classify medicines according to the level of access deemed appropriate: general sales, prescription, pharmacy only, or restricted access (e.g., where the pharmacist input is required).

Legislation in the Medicines Act 1981 and Medicines Regulations 1984 defines these processes and the composition of the committees that help make these decisions. Committees are required to provide technical expertise, but if we consider the premise of Te Tiriti as a partnership, these Medicines laws should, as a minimum, also require a te ao Māori worldview or pro-equity competence, or even public health expertise. They do not. Thus, unpartnered legislation and policy directly impact approval, manufacture, marketing, registration, procurement, acquisition, advertising, distribution, prescribing, and dispensing of every medicine in the country. The results are a systematically unbalanced system.

Consequences of absent mapping and partnership are plentiful. One small example is the global medicine supply issue heightened due to the COVID-19 pandemic. Medicines are sought through different suppliers when shortages occur and may be acquired as ‘Section 29’. This means the medicines have not received regulatory assessment and approval, carrying inherent risk at one level and limiting access at another. Only a ‘medical practitioner’ (doctor) can prescribe Section 29 drugs, thereby excluding nurse practitioners and pharmacist prescribers who serve rural and underprivileged communities – where the need is potentially greater for full and continued access to medicines.

A Pro-Equity Approach

Pro-equity attention needs to be paid to the value of medicines across the lifetime of people, including and especially societal costs; to clinical trials protecting and promoting Indigenous peoples; to the intricacies of approval and funding of medicines; to patient acquisition and distribution of medicines; to prescribing of medicines; to pharmacovigilance; to monitoring that includes medicines purchased without prescription, and to public administration and education and empowerment. The vision for medicines optimisation needs to be co-created with Māori, not siloed.

I have not considered the in-depth complexities of the medicines funding system nor access to immunisations and medical devices in this article. I have also left out workforce planning requirements covering both direct and indirect care (e.g., cardiac monitoring post certain chemotherapeutic agents) due to word limitation. Similarly, I have not discussed Rongoā (traditional Māori healing beliefs and practice) and its place in the health system. Only to say self-determination and autonomy of Māori must be prioritised in the restoration of health decision-making and provision, so that the benefits of such thinking and knowledge can be drawn upon in contemporary times.

10.4.3 A Change in the System Needs a Change of Mind and Change of Heart

Just as the western view of patient healthcare delivery is compartmentalised and does not consistently or holistically see each person, their health needs, social circumstances, and health beliefs, so it goes for our medicines system. There is no current medicines strategy, and the 2015–2020 plan lacked vision (Ministry of Health, 2015b). It did not include proactivity in planning the types of medicines that may be required. There was no shared community vision of the value of medicines at a societal level and the activities that must be undertaken to achieve that vision. There is little cross-government mapping of medicines use,

e.g., antibiotics for non-human use. There is no single centre of excellence for applied pharmacotherapy expertise in Aotearoa to aid prescribers with individual decisions and monitoring of medicines. There is no single entity encompassing clinicians and non-clinicians with overall responsibility to monitor the single most used tool in the health system. There is no consistent programme addressing medicines literacy. There is no formal and structured facilitation of Māori and other peoples of Aotearoa to use Rongoā alongside western medicines if desired.

Existing legislation will require redrafting before reforms occur. That cannot and should not be done without a place at the table for people who can interpret the impacts for Māori and Pacific peoples, and I strongly recommend at a minimum the critical treaty analysis framework of Came et al. (2020) be applied. No single person, professional discipline, or skillset can ensure medicines achieve best possible health outcomes.

I question whether our health system has ever been wholly fit for purpose, given its founding on a dominant worldview that denies a partnership of mutual advantage. The genesis of equity in health is embedded in Te Tiriti o Waitangi. Te Tiriti itself is a statement of equality where the authority of the Crown and mana of Māori come together. Sadly, this aspiration has not been realised, and the country as a whole has suffered. The disadvantage spans multiple domains, including the economy and well-being. To achieve holistic healthcare that values more than one worldview, a medicines system needs to be developed with consideration across the breadth of the health system and for future generations.

A medicines system that achieves equity of access to high-quality, appropriate pharmacological agents, minimal wastage, maximum adherence, and minimal drug mortality and morbidity is a barometer of the wider health system. Further, how we position pharmacological against non-pharmacological value can be a window onto societal values, such as in pain management, opioid addiction, and mild depression, where medicines should not necessarily be the first intervention to trial. Things like 3D printing of medicines, pharmacogenomics, and immunotherapy are but a few examples of a rapidly changing landscape. These advances are fraught with ethical issues, making it more crucial that partnership, restoration, and a community approach to decisions are interwoven. If we do not strategise for such changes, reactivity will be our only available response.

Cultural alignment for achieving medicines optimisation in a general sense – let alone as a core outcome with a pro-equity, Indigenous approach – is rare. The cost to our health system

and society is immense and must be the impetus to adopting a health system and societal approach to the value of medicines.

Substantive health reform is welcomed as opposed to yet another retrofit. The announced changes present a real opportunity for recreation from within rather than adding to the existing malfunctioning system. The MHA is an unprecedented development in the history of Aotearoa health provision: in its development, partnership must be framed authentically with co-creation in structure, legislation, policy, and delivery.

A change of mind and heart alongside a change of structure is well overdue for Māori, but for all peoples of Aotearoa, surely it is also time.

10.5 Thesis Strengths and Limitations

The editorial provides a connection and expansion of the objectives and learnings as discussed in Section 10.2. It takes key discoveries from the research project and extends them to explore how they apply at a systems and societal level. The strengths and limitations of the previous chapters and the thesis are now discussed.

10.5.1 Strengths

Whilst strengths (and limitations) have been discussed throughout the thesis, the overarching strength of this research process is the weaving together of experience, expertise, leadership, and mātauranga. Examples include the author and her background and experience in applied pharmacotherapy; the opportunities to engage with leaders at multiple points in the medicines and health system; the experiences of whānau across the country where mātauranga is the worldview; and interaction with leaders nationally and internationally where alternative models of health delivery exist.

To the best of my knowledge, there is no prior published work from an Indigenous person who has produced research or shared experiences of gout management from a holistic perspective. Equally, there is no awareness of another Indigenous person globally who has produced research or a view of medicines through the lens of optimisation when considering a whole-of-systems and societal analysis. This is a key finding of this research. Mātauranga Māori and Kaupapa Māori theory as a research domain is well traversed in humanities and many elements of the sciences. Still, when it comes to medicines optimisation across its breadth, there is no currently well-defined and evaluated model to guide the sector. When

paralleling thesis findings with personal exposure to the knowledge of medicines optimisation from an Indigenous community perspective, a whole-of-systems understanding and analysis are not evidenced. In the United Kingdom, NHS clinical commissioners have recently advocated for the systematisation of medicines (Rule & Jones, 2021). Their report, however, does not include an Indigenous or alternate worldview and is arguably weighted towards pharmacist activity and financial context, although it promotes integrated care.

Also, to the best of my knowledge, there is no other detailed description of medicines optimisation from an Indigenous perspective nor a graphic describing where the gaps lie in the environment.

The Kaupapa Māori component of this thesis enabled a level of connection with providers and the community not afforded to non-Indigenous researchers. This immense privilege enabled sharing of experiences and thoughts directly impacted by systems and policies. In particular, obtaining a perspective of barriers to optimal gout management in Aotearoa from providers who are Indigenous-governed, led, and predominantly staff enabled a view not previously described. Equally, this research was the first to detail the perspective of whānau on the conflict of advice from health professionals regarding the contravention of Indigenous rights with traditional food intake.

10.5.2 Limitations

The most significant limitation of this thesis was the lack of data, identified in the literature review in Chapter 3. However, since 2011, I have had a journal watch looking for Indigenous-led or equity focussed gout initiatives and, as discussed, a general watch for medicines optimisation with an Indigenous focus since 2016. For example, the journal watch for gout identified a more recent journal publication from NZ, setting out a systematic review investigating initiatives to improve the uptake of urate-lowering therapy in patients with gout (Gill et al., 2020). Of the 20 studies in the systematic review, only one initiative aimed to address Indigenous disadvantage — the ‘Gout Stop’ programme (Lawrence et al., 2019). The ‘Gout Stop’ programme is from the Northland (a large geographical area covering the northern part of the North Island) DHB. The programme relied on clinicians seeing patients across 36 general practices, followed by the presentation and dispensing of prescriptions at one of 25 community pharmacies that were paid for new enrolments and completions. There was the ability to refer to a gout kaimahi for support. Despite the pro-equity intent, data demonstrated the initiative was anti-equity in engaging and maintaining engagement with

Māori and Pasifika. The programme completion rate was 55% for Māori and Pasifika compared to 84% in the non-Māori/non-Pasifika group. Non-Māori/Non-Pasifika were more likely to achieve target serum urate (50%) than Māori (39%) or Pasifika (30%).

The journal watches have ensured I am not disconnected from newly published research. Further, the personal connection to professional activities has equally provided the same. For instance, another initiative not identified in the above systematic review, also from NZ, was the ‘Owning My Gout’ programme — a model where community pharmacists and nurses work under standing orders from general practitioners to supply urate-lowering therapy (Phone, 2018). Again this programme had good intentions to deliver equitable management. However, it demonstrated that inequity increased with non-Māori, non-Pasifika more likely to achieve clinical success. Initially, 179 people were enrolled but 64% were not visibly active in the programme after 3 months. Of those achieving a serum urate of less than 0.36 mmol/L, 17% identified as Māori, and 29% Pasifika compared to 40% non-Māori, non-Pasifika (Andrews et al., 2020).

Other thesis limitations included the impact of COVID-19 on the ability to travel and the (un)generalisability of findings, which have been discussed in the previous chapters.

10.6 Recommendations

10.6.1 Gout Optimisation

This thesis has highlighted a number of gaps in the provision of gout management to Māori and therefore drives thinking about ways to improve gout outcomes. The findings have informed the recommendations, which are set out in Table 10.

Three major areas (people, provider, and system levels) are used to frame the recommendations.

The first recommendation promotes the development of a national gout strategy. It may be argued that an effective strategy could deliver the remainder of the recommendations, but they are included for completeness and an aversion to oversimplification. It is further acknowledged that there are overlapping themes, e.g., workforce development could include upskilling kaimahi and improving clinicians' cultural and clinical safety. These activities could also sit under education alongside social marketing campaigns for whānau and research. Similarly, for those same recommendations, it is imperative they attract policy and

funding support, which could be other themes. As a result, the recommendations are kept as separate points instead of themes.

Table 10 Recommendations on Optimising Gout Management

| Recommendations | Individuals/whānau | Providers* | System |
|---|--|---|---|
| National gout strategy | Individuals/whānau are resourced to lead/develop a national gout strategy | Providers give effect and contribute to the national goals and prioritise funding accordingly | The MOH, health entities and systems stakeholders resource the development and implementation of the strategy to deliver the recommendations. Health entities (e.g., Te Aka Whai Ora, Te Whatu Ora) monitor provider and system response |
| Holistic/whānau ora approach to gout | Individuals/whānau are not compartmentalised and treated as one health condition or in the absence of a socio-historic construct | Providers are not resourced to provide compartmentalised care and are incentivised to demonstrate collaboration and delivery of holistic care | |
| Marae-based clinics | Individuals/whānau have access to care provision from culturally acceptable/physically accessible preferred sites | Resourcing of Māori health providers and others capable of delivering hauora care in marae | |
| Access to trusted and gout knowledgeable kaimahi | Individuals/whānau have access to kaimahi who are integrated into primary care delivery | A non-regulated, culturally congruent workforce is empowered/upskilled to help provide integrated gout self-management ability to whānau. This should include the ability to undertake mobile point-of-care testing | |
| Culturally safe and culturally literate practitioners deliver gout care | Individuals/whānau feel safe to access care and are empowered to self-manage gout | Providers ensure a culturally safe environment where understandable messages are conveyed. Judgemental messages are prohibited, e.g., focusing primarily on food and physical activity | |

| | | | |
|---|---|---|--|
| Transport options are available | Individuals/whānau have access to transport if required | Providers have a social needs analysis and are resourced to provide transport assistance if required | |
| Removal of financial barriers for gout care | Individuals/whānau have access to gout management without financial barriers | Providers have a social needs analysis to assist with financial barriers, including medicines access/blister packing. Recording social determinants | |
| Gout clinical care is evidence-based and appropriate | Individuals/whānau receive up-to-date clinical advice, medication, and care | Providers ensure clinicians have resources, e.g., DSTs, clinical education sessions to support direct care and associated activities such as nurse standing orders, and regular feedback to clinicians on their performance | |
| Clinical expertise is available outside of current hours | Individuals/whānau have access to healthcare during hours that are congruent to their employment and lives | Providers are required to undertake a needs analysis for extended hours and are supported/required to deliver care that is commensurate with people's availability | |
| Appropriate funding /dedicated resourcing of providers to lead initiatives to address health conditions outside national health targets | Individuals/whānau are exposed to more comprehensive strategies for providers to engage with Māori on gout | Providers have greater flexibility with funding to address areas of inequity | |
| A public multi-media gout awareness campaign is delivered | Individuals/whānau assist in the creation of the campaign. Anyone who might interact with someone with gout or their whānau are | Providers will help support and disseminate the programme, e.g., through their own social media pages, development of health | |

| | | | |
|--|---|--|--|
| | educated on gout aetiology and management | resources or waiting room videos | |
| Culturally literate self-management programmes are available to whānau | Individuals/whānau are able to attend hui/ wānanga self-management programmes. Empowered whānau will know what best practice should look like when interacting with health services | Patients are ‘primed’ when seeking health services | |
| NSAID use comes with appropriate warnings | Individuals/whānau are aware of the potential side effects of NSAIDs | Providers consider ways to help support clinicians prescribe appropriately, including amount of supply | Includes Medsafe looking at mechanisms to help, e.g., warnings on the outside of OTC supply |
| Culturally safe research and monitoring inform ongoing gout care | Whānau determine research priorities and sovereignty over data | Providers recognise they are stakeholders in research not controllers | Research institutions and ministries resource and support culturally safe and appropriate research |

*Providers refers to Māori health providers, Pasifika health providers, general practices, and primary health organisations

DST, decision-support tool; NSAID, nonsteroidal anti-inflammatory drug; OTC, over the counter.

10.6.2 Medicines Optimisation

Recommendation 1: A Centre for Medicines Optimisation be Established

This thesis has explicitly outlined an overarching aim to understand ‘optimal medication therapy’ and, more specifically, how access to medicines, prescription of evidence-based drug therapy, wise practice, and administration of medicines can be optimised. In particular for those with the most disadvantaged health outcomes – Indigenous people. This is in the knowledge that when a response is aimed at the most disadvantaged, all of society benefits.

This thesis has found a lack of oversight and coordination of medicines activities resulting in multi-organisation suboptimisation. The strong recommendation is, therefore, to establish a Centre for Medicines Optimisation that would be responsible for this oversight.

In parallel to a lack of medicines oversight and coordination, administration underpinned by colonialism means an absence of Indigenous ways of knowing, where compartmentalising Indigenous health outcomes is the opposite of what is required and voiced by Indigenous people. The Swiss Cheese of medicines optimisation presented the pathway to Ngā Rau o Kawakawa. It is imperative that a Centre of Medicines Optimisation equally values Indigenous ways of knowing (mātauranga for Māori).

This research has not investigated the competency or capacity within existing national resources to establish such a centre. However, there appears to be synergy with Treasury. Across the Crown agencies, Treasury is closest to being horizontally focused on considering using a centre for analysis, metrics, and measures of hauora and pae ora.

For the first time since colonisation, the current health system reforms have defined policy and structure and recognised and established Māori leadership and definition.

Te Aka Whai Ora | the Māori Health Authority is a Crown Agency and, therefore, not placed to deliver rangatiratanga. However, it recognises the rights of Māori to self-determination. The MHA will enhance the mātauranga perspective but arguably may not have all the levers to ensure a whole-of-society approach to medicines.

The Centre would require a strong connection with Health as this is where medicines are founded. Still, the optimisation itself is about what determines the best outcomes for whānau and society economically, socially, culturally and physically. This is a vast departure from the existing metrics (value of the cost versus whether the cost is valuable) from within health and its associated agencies, e.g., Pharmac. The autonomy of Treasury enables qualitative and quantitative metrics to be visible to Ministers as much as they would be to the public. The difference is that the centre would not be self-validating health systems, structures, or costs with purely a health lens. This lens is what has defined a NZ health system from inception. Arguably, this function has been embedded in Treasury over time but needs definition and clarity.

A Centre for Medicines Optimisation is expected to include a dedicated horizon scanning unit, as promoted in Chapter 9.

Appendix 5 includes a paper prepared for the MHA to promote the concept of a centre with mātauranga at its core.

Recommendation 2: A Medicines Strategy be Developed, Adopted, and Monitored.

This thesis has expressed that medicines' overuse, underuse, and misuse are a NZ and global problem. The current NZ medicines strategy to address this issue was adopted in 2007 and is considered outdated (Pharmac Review Panel, 2022). A new medicines strategy needs to be developed to guide the Centre of Medicines Optimisation in its work. The strategy must observe Indigenous rights and have an unapologetic commitment to enabling Indigenous leadership into the strategy. It must also have equity as a guiding principle working in partnership with communities to develop the strategy.

10.7 Future Research

10.7.1 Indigenous Perspective

This thesis has highlighted a lack of definition and contribution from Indigenous populations as to the contemporary positioning of medicines optimisation underpinned by Indigenous ways of knowing. This is unsurprising, given coloniality is omnipresent. In NZ, 182 years have elapsed since the signing of Te Tiriti, where a monocultural view became the predominant one. An expectation that regaining the knowledge from those 182 years in the short term is unrealistic. Similarly, for Indigenous cultures globally. Even in so far as the term 'medicines optimisation' and whether this would be the preferred term for Indigenous populations cannot be sought overnight. In reality, this thesis is signalling a direction, and the name of this field of study will evolve. However, if an investigative start is made, the pathway will be much further along and less challenging to regain in the years to come. Graham Hingangaroa Smith and Linda Tuhiwai Smith posit that "there is a need for all of us to appreciate that what may seem a utopian vision is worth striving for and may be won through a series of small and incremental gains rather than singular and spectacular actions" (Smith & Smith, 2019, p. 1098-1099).

The author and this thesis posit that the time has long since passed to obtain an Indigenous perspective on medicines optimisation. There is urgency from a health needs, environmental, and fiscal perspective. This is an essential point for all countries. The international movement to understand and create 'integrated care' would have been superfluous had the equal weighting of an Indigenous view been the starting point.

Further research is required on the approach to a systems and societal approach to medicines optimisation in other jurisdictions and the contribution of Indigenous cultures. A post-doctoral study of unpublished activities through whanaungatanga (established relationships)

would add considerably to the current knowledge. I have already alluded to relationships in other countries (Australia, Alaska, Hawaii, North America) that could be extended to collaborate formally.

10.7.2 Medicines Optimisation – Non-Indigenous View

As mentioned, the United Kingdom has been the most active internationally in promoting the systematisation of medicines. Investigating the mechanisms, workflow, and associated monitoring is important for planning how NZ and other countries could undertake similar work.

10.8 Conclusion

Medicines optimisation, including that for gout management, goes beyond what seems to be available in the literature. Akin to a value direction, it should be the aspiration with a systems and societal approach.

Self-reflection on the undertaking of this thesis and its associated research has opened new ways of thinking, new ideas, and broadening of the systemic requirements as the genesis for real change in medicines optimisation. My years of engagement in the system, innovation, and leading whānau change, tell me such elements remain critical but that constructing a Centre of Excellence, where multiple strands are accommodated to make up an interacting whole, would extend all practices. Understanding will not be derived from a western scientific micro-analysis of component parts but from synthesis into a wider context that recognises the interface of both Indigenous and non-Indigenous values (Durie, 2005).

Royal (nd.) asserts that Indigenous peoples, through the process of dispossession, have been bequeathed many insights about justice, rights, liberty, and freedom that can teach us about the nature of human relationships and the kind of society we wish to build in the future. Indigeneity, as such, represents a net national opportunity for countries, not net national problems.

A Centre of Excellence for Medicines Optimisation (or alternate name for Medicines Optimisation co-created in wānanga with whānau) would consider Ngā Rau o Kawakawa from an overarching solution-focused societal perspective with mātauranga at its core.

I opened this thesis by discussing my personal context and remain of the belief that a bicultural approach that brings Western science and mātauranga Māori together in an

authentic partnership is an unrealised opportunity. Te Tiriti was more than facilitating the establishment of government and the exchange of rights. It remains an instrument that could enhance understanding of knowledge and worldviews, enabling all communities to leverage taonga tuku iho (ancient intergenerational treasures).

Change is difficult but it is a wonderful difficulty because it challenges the intellect, it challenges the courage, and it challenges the ability to dream

– Moana Jackson (2021).

Appendix 1 Outputs Associated with This Thesis

Journal articles (by order of publication date)

- Te Karu, L.,** Bryant, L., Harwood, M., & Arroll, B. (2018). Achieving health equity in Aotearoa New Zealand: The contribution of medicines optimisation. *Journal of Primary Health Care, 10*(1), 11–15.
- Dalbeth, N., Douglas, M., Mackrill, K., **Te Karu, L.,** Kleinstäuber, M., & Petrie, K., J. (2020). The impact of the illness label ‘gout’ on illness and treatment perceptions in Māori (Indigenous New Zealanders). *BMC Rheumatology, 4*(1), 1–6.
- Guillén, A. G., **Te Karu, L.,** Singh, J. A., Dalbeth, N. (2020). Gender and ethnic inequities in gout burden and management. *Rheumatic Disease Clinics, 46*(4), 693–703.
- Te Karu, L.,** Kenealy, T., Bryant, L., Arroll, B., & Harwood, M. (2020). The long shadow of inequity for Māori with gout: I just kind of wanted to close myself off and die. *MAI Journal, 9*(2), 152–165.
- Te Karu, L.,** & Bryant, L. (2020). Avoid perpetuating inequities when managing gout in the setting of COVID-19. *New Zealand Doctor / Rata Aotearoa*. <https://www.nzdoctor.co.nz/article/print-archive/avoid-perpetuating-inequities-when-managing-gout-setting-covid-19>
- Te Karu, L.,** Kenealy, T., Bryant, L., Arroll, B., & Harwood, M. (2021). Compounding inequity – a qualitative study of gout management in an urban marae clinic in Auckland, Aotearoa New Zealand. *Journal of Primary Health Care, 13*(1), 27–35.
- Te Karu, L.,** Dalbeth, N., & Stamp, L. K. (2021). Inequities in people with gout: a focus on Māori (Indigenous People) of Aotearoa New Zealand. *Therapeutic Advances in Musculoskeletal Disease, 13*, 1759720X211028007. <https://doi.org/10.1177/1759720X211028007>
- Te Karu, L.,** Harwood, M., Bryant, L., Arroll, B., & Kenealy, T. (2021). The inequity of access to health: A case study of patients with gout in one general practice. *New Zealand Medical Journal, 134*(1543), 51–58.
- Te Karu, L.** (2021). Restoration of the health system must not neglect medicines – but who has the power of reform? *Journal of Primary Health Care, 13*(2), 96–101.
- Stamp, L. K., & **Te Karu, L.** (2022). Gout in Indigenous people: Inequity and culturally appropriate management. *BMJ Medicine, 1*(1), e000279. <http://dx.doi.org/10.1136/bmjmed-2022-000279>

Waitangi Tribunal Claims

- WAI2633:** Waitangi Health Claims 2575 under The Treaty of Waitangi Act 1975 and IN THE MATTER OF Gout – a claim by Leanne Te Karu on behalf of Māori generally.
- WAI2919:** Waitangi Health Claims 2575 under The Treaty of Waitangi Act 1975 and IN THE MATTER OF Medicines Optimisation in the Health Services and Outcomes Kaupapa Inquiry a claim by Leanne Te Karu on behalf of Māori generally

Conference proceedings

- Te Karu, L. (2017, November 23–25). *A community cultural literacy programme becomes the trojan horse* [Oral presentation]. 4th World Congress on Integrated Care, Wellington, New Zealand
- Te Karu, L. (2019). *Culturally safe gout care* [Breakout presentation]. Goodfellow Symposium professional development for primary healthcare professionals (<https://www.youtube.com/watch?v=mammaq6RtI4>)

Te Karu, L. (2018, July). *A model of medicines optimisation in partnership with whānau* [Breakout session presentation]. PRIDOC. Changing Systems of Care.

Te Karu, L. (2019). *The importance of cultural safety for gout* [Oral presentation]. Australian Regulatory Colloquium. Social accountability with health outcomes.

Te Karu, L. (2022, October 28). *Inequities in gout in the Indigenous population of New Zealand: Recommendations for Improvement* [Presentation]. American College of Rheumatology Conference.

Video

Goodfellow Unit MedTalk: Gout in Aotearoa New Zealand
(<https://www.youtube.com/watch?v=hpnIHfhegus>)

Professional development programmes

Midland Community Pharmacy Group Gout Management Service. Development of online assessment programme for community pharmacists followed by submission of a case study assessed by the author.

Northland District Health Board – Community pharmacist training – same format as for Midland Community Pharmacy Group Gout Management Service, followed by submission of a case study assessed by the author.

Radio interviews

Te Karu, L. (2018, November). *Why are Māori and Pacific peoples more susceptible to gout*. Radio Waatea

Te Karu, L. (2019, April). *The layers of inequity to medicines for Māori and Pacific peoples*. Radio Waatea

Political advocacy

Te Karu, L. (2020, July). *The Swiss cheese of medicines optimisation*. [Presentation to political health leaders at Parliamentary dinner]. Parliament buildings, Wellington, New Zealand

Appointment to PHARMAC review panel post the parliamentary dinner presentation. Contribution to all chapters of the review but almost exclusive contribution to the medicines optimisation chapter. Pharmac Review Panel. (2022). *Pharmac Review: Final report*. Wellington: Ministry of Health. Available from: <https://www.health.govt.nz/system/files/documents/publications/pharmac-review-final-report.pdf>

Te Karu, L. (2022, June 11). *Pharmac*. Breakfast television.
<https://www.youtube.com/watch?v=3ViJB3ANX3o>

Health organisation advocacy

Development of board paper to Te Aka Whai Ora | Māori Health Authority. Paper supplied in Appendix 6

Appendix 2 Ethics out of Scope



Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011
0800 4 ETHICS
hdecs@moh.govt.nz

Wednesday, 24 May 2017

Ms Leanne Te Karu
Papakura Marae Clinic,
6 Dorothy Drive,
Taupō 3330

Dear Ms Te Karu,

| | |
|--------------|---------------|
| Study title: | Oranga Rongoā |
|--------------|---------------|

Thank you for emailing HDEC a completed scope of review form on 23 May 2017. The Secretariat has assessed the information provided in your form and supporting documents against the Standard Operating Procedures.

Your study will not require submission to HDEC, as on the basis of the information you have submitted, it does not appear to be within the scope of HDEC review. This scope is described in section three of the Standard Operating Procedures for Health and Disability Ethics Committees.

Your scope of review form described the development of several tools to improve care for people with gout. This includes decision support and practice management tools and education for practice staff as well as community education initiatives. This project aims to improve the responsiveness of practice and assess current practice against guidelines. This meets the HDEC definition of an audit.

As your study is an Audit or related activity it does not require HDEC review as it does not involve the use, collection, or storage of human tissue without consent (paragraph 33 of the Standard Operating Procedures for Health and Disability Ethics Committees).

If you consider that our advice on your project being out of scope is incorrect please contact us as soon as possible giving reasons for this.

This letter does not constitute ethical approval or endorsement for the activity described in your application, but may be used as evidence that HDEC review is not required for it.

Please note, your locality may have additional ethical review policies, please check with your locality. If your study involves a DHB, you must contact the DHB's research office before you begin. If your study involves a university or polytechnic, you must contact its institutional ethics committee before you begin.

Please don't hesitate to contact us for further information.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Tom Kent'.

Tom Kent
Advisor
Health and Disability Ethics Committees
hdecs@moh.govt.nz

Appendix 3 Decision-Support Tool Details

Readcodes included for Gout Classification and Allopurinol Starting Dose.

| READCODE | READDOT | TERM |
|----------|---------|------------------------------------|
| 1443.00 | .1443 | H/O: gout |
| 669.00 | ..669 | Gout monitoring - |
| 6693.00 | .6693 | Joints gout affected |
| 6695.00 | .6695 | Date gout treatment started |
| 6696.00 | .6696 | Date of last gout attack |
| 6697.00 | .6697 | Gout associated problems |
| 6698.00 | .6698 | Gout drug side effects |
| 6699.00 | .6699 | Gout treatment changed |
| 669A.00 | .669A | Date gout treatment stopped |
| C34.00 | ..C34 | Gout - |
| C340.00 | .C340 | Gouty arthropathy |
| C341.00 | .C341 | Gouty nephropathy |
| C3410.00 | C3410 | Gouty nephropathy unspecified |
| C341z.00 | C341z | Gouty nephropathy NOS |
| C342.00 | .C342 | Idiopathic gout |
| C344.00 | .C344 | Drug-induced gout |
| C345.00 | .C345 | Gout due impairment renal function |
| C34y.00 | .C34y | Other specified gouty manifest |
| C34y0.00 | C34y0 | Gouty tophi of ear |
| C34y1.00 | C34y1 | Gouty tophi of heart |
| C34y2.00 | C34y2 | Gouty tophi of other sites |
| C34y3.00 | C34y3 | Gouty iritis |
| C34y4.00 | C34y4 | Gouty neuritis - |
| C34y5.00 | C34y5 | Gouty tophi of hand |
| C34yz.00 | C34yz | Other specified gout NOS |
| C34z.00 | .C34z | Gout NOS |
| G5573.00 | G5573 | Gouty tophi of heart |

| | | |
|----------|-------|--------------------------------|
| N023.00 | .N023 | Gouty arthritis |
| N0230.00 | N0230 | Gouty arthritis-site unspecif. |
| N0231.00 | N0231 | Gouty arthritis-shoulder |
| N0232.00 | N0232 | Gouty arthritis-upper arm |
| N0233.00 | N0233 | Gouty arthritis-forearm |
| N0234.00 | N0234 | Gouty arthritis-hand |
| N0235.00 | N0235 | Gouty arthritis-pelvic/thigh |
| N0236.00 | N0236 | Gouty arthritis-lower leg |
| N0237.00 | N0237 | Gouty arthritis-ankle/foot |
| N023x.00 | N023x | Gouty arthritis-multiple sites |
| N023y.00 | N023y | Gouty arthritis-other specif |
| N023z.00 | N023z | Gouty arthritis-NOS |
| Nyu17.00 | Nyu17 | [X]Other secondary gout - |

Allopurinol starting dose

Starting dose allopurinol based on eGFR – use 1.5mg/eGFR unit with rounding.

For

eGFR mL/minute/1.73 m²

<5 use 50 mg allopurinol ONCE weekly

5 to 15 use 50 mg, twice weekly

16 to 30 use 50 mg, every 2 days

31 to 45 use 50 mg, daily

46 to 60 use 50 mg and 100 mg, alternate days

61 to 90 use 100 mg, daily

91 to 130 use 150 mg, daily

> 130 use 200 mg, daily

Increase by 50 to 100 mg increments every 4 weeks, aiming for a target serum urate <0.36 mmol/L. Testing is every 4 weeks until at target, then testing is only annually.

Appendix 4 Ethics Approval



Health and Disability Ethics Committees
Ministry of Health
133 Molesworth Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdec@mh.govt.nz

14 February 2019

Ms Leanne Te Karu
PO Box 42013
Taupo 3330

Dear Ms Te Karu,

| | |
|-----------------|---|
| Re: Ethics ref: | 18/NTB/213 |
| Study title: | Oranga Rongoā - a collaborative community approach to improve best practice management of gout. |

I am pleased to advise that this application has been approved by the Northern B Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Northern B Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at *any* locality in New Zealand, it must be registered in a clinical trials registry. This should be a WHO-approved registry (such as the Australia New Zealand Clinical Trials Registry, www.anzctr.org.au) or <https://clinicaltrials.gov/>.
3. Before the study commences at *each given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

- Please remove the YES NO options from the statements in the Consent Form, unless that statement refers to an optional component of the study i.e. a participant could answer NO but still be part of the study.

Non-standard conditions must be completed before commencing your study, however, they do not need to be submitted to or reviewed by HDEC.

If you would like an acknowledgement of completion of your non-standard conditions you may submit a post approval form amendment through Online Forms. Please clearly identify in the amendment form that the changes relate to non-standard conditions and ensure that supporting documents (if requested) are tracked/highlighted with changes.

For information on non-standard conditions please see section 128 and 129 of the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz)

After HDEC review


Please refer to the *Standard Operating Procedures for Health and Disability Ethics Committees* (available on www.ethics.health.govt.nz) for HDEC requirements relating to amendments and other post-approval processes.

Your next progress report is due by 14 February 2020.

The Northern B Health and Disability Ethics Committee is satisfied that your study is not a clinical trial that is to be conducted principally for the benefit of the manufacturer or distributor of the medicine or item being trialled. Participants injured as a result of treatment received as part of your study may therefore be eligible for publicly-funded compensation through the Accident Compensation Corporation (ACC).

Please don't hesitate to contact the HDEC secretariat for further information. We wish you all the best for your study.

Yours sincerely,



Chairperson
Northern B Health and Disability Ethics Committee

Encl: appendix A: documents submitted
appendix B: statement of compliance and list of members

Appendix A
Documents submitted

| <i>Document</i> | <i>Version</i> | <i>Date</i> |
|---|----------------|-------------------|
| CVs for other Investigators: Condensed CV of my primary supervisor Professor Bruce Arroll | 1 | 12 May 2017 |
| CV for CI | 1 | 12 May 2017 |
| PIS/CF: Participant Information Sheet | 1 | 24 September 2018 |
| PIS/CF: Consent Form | 1 | 24 September 2018 |
| Invitation Follow Up Letter | 1 | 24 September 2018 |
| Survey/questionnaire: Questionnaire | 1 | 24 September 2018 |
| Protocol: Protocol | 2 | 07 November 2018 |
| Evidence of scientific review: A.Jull Review | 1 | 09 November 2018 |
| Application | | 09 November 2018 |
| Covering Letter: Cover Letter in response to provisional approval | 1 | 02 January 2019 |
| PIS/CF: Revised PIS/CF following provisional approval | 2 | 02 January 2019 |
| PIS/CF: PIS/CF for staff | 2a | 02 January 2019 |
| Home visit health and safety considerations | 1 | 02 January 2019 |
| Response to Request for Further Information | | |

Appendix B Statement of compliance and list of members

Statement of compliance

The Northern B Health and Disability Ethics Committee:

- is constituted in accordance with its Terms of Reference
- operates in accordance with the *Standard Operating Procedures for Health and Disability Ethics Committees*, and with the principles of international good clinical practice (GCP)
- is approved by the Health Research Council of New Zealand's Ethics Committee for the purposes of section 25(1)(c) of the Health Research Council Act 1990
- is registered (number 00008715) with the US Department of Health and Human Services' Office for Human Research Protection (OHRP).

List of members

| Name | Category | Appointed | Term Expires |
|----------------------------|---|------------|--------------|
| Mrs Maliaga Erick | Lay (consumer/community perspectives) | 01/07/2015 | 01/07/2018 |
| Mr John Hancock | Lay (the law) | 14/12/2015 | 14/12/2018 |
| Dr Nora Lynch | Non-lay (health/disability service provision) | 24/07/2015 | 24/07/2018 |
| Miss Tangihaere Macfarlane | Lay (consumer/community perspectives) | 20/05/2017 | 20/05/2020 |
| Mrs Kate O'Connor | Lay (ethical/moral reasoning) | 14/12/2015 | 14/12/2018 |
| Mrs Stephanie Pollard | Non-lay (intervention studies) | 01/07/2015 | 01/07/2018 |
| Mrs Leesa Russell | Non-lay (intervention studies), Non-lay (observational studies) | 14/12/2015 | 14/12/2018 |
| Mrs Jane Wylie | Non-lay (intervention studies) | 20/05/2017 | 20/05/2020 |

Unless members resign, vacate or are removed from their office, every member of HDEC shall continue in office until their successor comes into office (HDEC Terms of Reference)

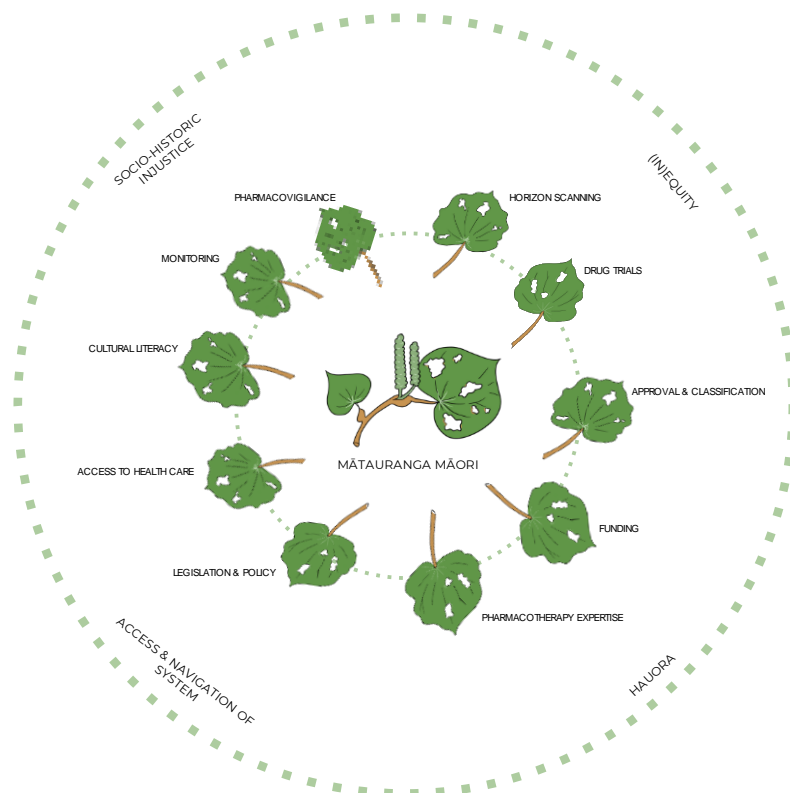
<http://www.ethics.health.govt.nz>

Appendix 5 Medicines Optimisation, Nga Rau o Kawakawa, & Te Aka Whai Ora

Medicines Optimisation, Ngā Rau o Kawakawa, & Te Aka Whai Ora

Background paper prepared for the Board of Te Aka Whai Ora

Leanne Te Karu (September 2022)



Purpose

This short paper provides background on medicines optimisation as a Māori health and equity issue and introduces Ngā Rau o Kawakawa as a conceptual model for thinking through how the health system can address the unfair and unjust impacts of its current approaches to medicines.

The aim of this paper is to support a discussion with the Board of Te Aka Whai Ora about the role it can play in ensuring equitable health outcomes for Māori through medicines.

What is medicines optimisation

Medicines are a foundational element of our health system, as the most common intervention in health. They have the potential to cure, control or prevent the development of illness. All medicines can cause adverse effects. The aim therefore is to ensure optimal use of medicines whereby the impacts of illnesses are reduced and drug-related harms mitigated.

Medicines optimisation is a way of looking at the how the various systems around medicines interact, with the aim of the best possible outcomes from medicines. It has had increasing attention, both in New Zealand and internationally, because of the growing awareness that prescribing the right medicines to the right patients at the right time and in the right way requires a systems-wide approach by all participants in a health sector,¹ including policy makers, monitors, researchers, practitioners, and patients themselves. Medicines optimisation can therefore act as a barometer of how the whole health system performs.

Why are medicines and medicines optimisation important Māori health and equity issues?

In New Zealand, a great deal of our medicines are funded through Pharmac, meaning prescriptions are often subsidised. However, not all populations benefit from medicines. There are inequities for Māori in accessing medicines and prescriptions in both primary and secondary care. (Te Karu, Bryant, Harwood, & Arroll, 2018). For example nearly 1 in 5 (18%) of Māori and Pacific adults did not collect a prescription due to costs in 2019, which is nearly three times the percentage of non-Māori, non-Pacific and non-Asian adults. (Health Quality & Safety Commission, 2020) There are also instances where Māori are more likely than non-Māori to receive some medicines inappropriately. For example, Māori are more likely to use non-steroidal anti-inflammatory agents, which can cause substantial side-effects and generally do not treat the causes of illnesses, instead only relieving symptoms. (Te Karu, 2021)

This is part of an overarching pattern of inequity, with Māori as a population having lower access to the things that help us stay healthy, greater exposure to the things that put our health and wellbeing at risk, lower access to health care services (including medicines),

¹ It can even extend beyond the health system, for example, antibiotic resistance, for example, is an issue for primary industries and animal health, too.

levels of care from non-Māori, non-Pasifika populations (including unjust or unfair differences in the kinds of referrals they receive, and are subject to differences in prescriber behaviour and quality of care).¹

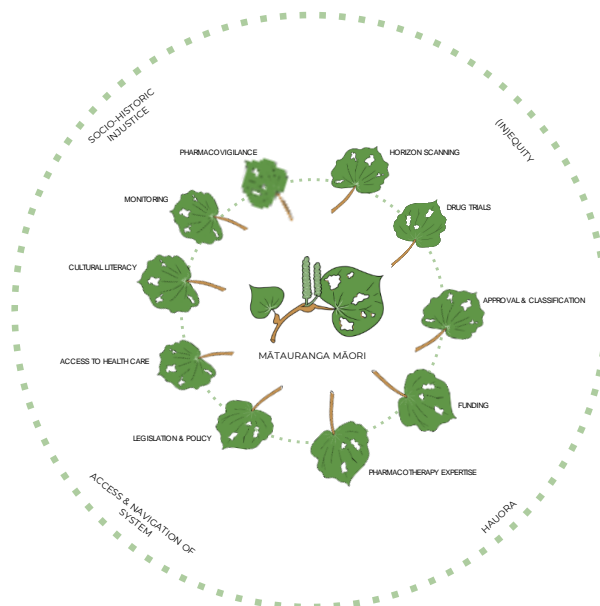
Often these inequities are compounding, with racism, ableism, and gender discrimination each impacting on many tāngata whaikaha Māori (Māori with lived experience of disability), for example.

Ngā Rau o Kawakawa model

While medicines optimisation helps us to think about the best ways to improve medicines outcomes, conceptualisations of medicines optimisation identify it as a linear process. Thinking about medicines optimisation only as a linear process with discrete steps also tends to ignore the cumulative impacts of unjust and unfair barriers at each stage of the optimisation process that lead to inequitable access to medicines. Critically in an Aotearoa New Zealand context, they do not incorporate a Te Ao Māori perspective.

In response, I have developed Ngā Rau o Kawakawa as a way to understand how medicines optimisation could work.

Figure 1: Ngā Rau o Kawakawa²



¹ This framework is based on Jones (2001) as quoted in Reid et al *Understanding Health Inequities* 2006, Hauora IV, University of Otago.

² Ngā rau o Kawakawa graphic supplied by Gabrielle Baker – Baker Consulting Ltd <https://www.bakerconsulting.co.nz/>

Ngā Rau o Kawakawa reverses this model, and adopts the more culturally appropriate and relevant imagery of kawakawa leaves to describe a positive outcome where the leaves and their holes align creating an environment that achieves medicines optimisation with an emphasis on equity and improved Indigenous outcomes.

Mātauranga Māori is the centre of Ngā Rau o Kawakawa, emphasising the critical need for the health system that works for Māori to be driven by nurturing and restoring mana, and for Māori knowledge and understandings to play a central role in decision-making on medicines throughout the health system. With mātauranga Māori at the centre, the intention is to find ways for each component of optimisation to lead to the best outcomes for Māori and have a compounding positive impact on health equity.

There are ten kawakawa leaves representing different components of a systems approach to medicines optimisation, which each present significant opportunities to improve the overall medicines system to better reflect Te Tiriti o Waitangi commitments, and achieve improved Māori health outcomes and health equity. These ten components are set out in Appendix 1, along with commentary on the opportunities available across the health and disability systems.

Next steps and discussion

As outlined in Appendix 1, there are considerable opportunities for improvement to New Zealand's approach to medicines optimisation, drawing on Ngā Rau o Kawakawa. Many of these fall within the roles and responsibilities of Te Aka Whai Ora, and this paper is meant to act as a prompt for a larger discussion by Te Aka Whai Ora and its Board in determining strategic priorities and areas of focus for the organisation and determining how a more cohesive approach to medicines, centred on mātauranga Māori, can lead to a better performing health system.

Appendix 2 provides a table produced by the Pharmac Review Panel outlining the various Crown organisations responsible for different components of medicines optimisation. Although it was prepared at the start of the year, before the Pae Ora Act 2022 came into force, it gives a sense of the fragmentation of medicines optimisation that is still largely in place today. Appendix 2 also illustrates how little explicit focus there has been on Māori being able to exercise rangatiratanga, and access Kaupapa Māori options when it comes to medicines.

A Centre of Excellence for Medicines Optimisation (or alternate name for Medicines Optimisation co-created in wānanga with whānau) would consider Ngā Rau o Kawakawa from an overarching solution-focused societal perspective with mātauranga at its core.

Appendix 1: Components and opportunities of Ngā Rau o Kawakawa

|  Component of Ngā Rau o Kawakawa |  Opportunities |
|--|--|
| <p>Horizon Scanning</p> <p>Looking ahead to understand health problems and interventions of the future. Horizon scanning also helps to identify approaches that will become obsolete in the future.</p> | <p>Done well, horizon scanning considers a broad range of treatments (not just pharmacological treatment), considers issues from a pro-equity perspective, and looks at diagnostic services as well as therapies as part of a full pathway to prevention/treatment.</p> |
| <p>Drug Trials</p> <p>Testing the efficacy and safety of new medicines.</p> | <p>It is rare for drug trails to be undertaken on populations that mirror our population in New Zealand. This has flow on impacts for other components of medicine optimisation and is an ongoing problem related to the size of our country. However, it is compounded by the funding process, which limits opportunities for innovation, and clinical trials to gather and test population-specific data. (Pharmac Review Panel, 2022)</p> |
| <p>Approval and classification</p> <p>Determining the conditions under which medicines may be available in New Zealand (if at all). This role is currently carried out by Medsafe.</p> | <p>There is significant scope to incorporate Te Ao Māori worldviews, pro-equity competence and public health expertise into the approval and classification process and to adopt partnership approaches. Such approaches would ensure Māori are part of decision-making, including in classifying medicines according to the deemed appropriate level of access, e.g., general sales (available in supermarkets, service stations etc.) or prescription, controlled prescription, pharmacy only, or restricted access such as requiring the input of a pharmacist. But one example of the structural racism to this point is that pharmacy only medicines must be purchased from a retail salesperson (likely without health practitioner qualification) but a person working in a Māori health provider cannot do so without obstacles.</p> |
| <p>Funding</p> <p>This is about how decisions are made in the health system as to what aspects of medicines are publicly funded, and by association which parts are left for consumers (patients and whānau) to fund themselves. This is primarily the role of Pharmac in New Zealand</p> | <p>The issues of funding, and how equity should and could be embedded into decisions on publicly funded medicines was canvassed in the Pharmacy Review Panel’s findings (Pharmac Review Panel, 2022). This includes using appropriate analytical tools and incorporating Māori health and health equity expertise into funding advice.</p> <p>Funding rules can also increase barriers to accessing medicines for some groups beyond the requirements for co-payments for drugs. For example, some medicines require the recipient to meet certain clinical criteria to be subsidised under the Pharmac Special Authority scheme, which requires patients to have access to culturally safe and clinically competent primary care practitioners, the ability to make and pay for an appointment, and transport to appointments and diagnostic tests. As such funding is inextricably linked to legislation and policy, access to health care, and cultural literacy.</p> |

| | |
|---|---|
| <p>Pharmacotherapy expertise</p> <p>Pharmacotherapy is the intersection of diagnostic skills, knowledge of medicines, communication skills, clinical pharmacology, appreciation of risk and uncertainty and, ideally, practical experience. It is a role that</p> | <p>Examples from our research and experience highlight that there is substantial opportunity for pharmacotherapy expertise to inform prescribing to benefit Māori. This includes looking at the body of evidence demonstrating that Māori are under prescribed many medicines and overprescribed some that carry significant side effect burden.</p> <p>Pharmac has historically discharged general guidance largely through contracts (e.g. with BPAC, the NZ Formulary, the Goodfellow unit and now Matui Ltd,)</p> <p>There has never been a single applied pharmacotherapy centre whereby clinicians can access direct information or pharmacotherapy expertise with mātauranga as a central pou.</p> |
| <p>Legislation and policy</p> <p>Legislation and policy directly impact approval, manufacture, marketing, registration, procurement, acquisition, advertising, distribution, prescribing, dispensing, storage, disposal, and use of every medicine in NZ. Including the Medicines Act 1981, the Health Practitioners Competency Assurance Act 2002, the Misuse of Drugs Act 1975 and even legislation like the Resource Management Act</p> | <p>While some aspects of the legislative framework around medicines aim to ensure safety, others – such as pharmacy ownership requirements – present barriers to Māori-health provider or Iwi-owned pharmacies (and therefore preventing full Māori participation in offering holistic health care). This is but one example.</p> <p>There are also opportunities to think about how legislative provisions can be updated to protect personal information, create more modern approaches to medicines restrictions or manage the environmental impacts of shipping hazardous waste internationally (as is the case with chemotherapy medicines, which cannot be incinerated in New Zealand).</p> |
| <p>Access to health care</p> <p>Being able to access a full range of appropriate medicines requires access to high quality primary health care and the ability to navigate the primary and secondary health care systems and a range of providers.</p> | <p>Differential barriers to accessing health care for Māori are well articulated, and addressing them requires a joined up approach to all aspects of health and disability system policy, funding, commissioning and delivery. There are also significant opportunities to ensure Māori have the option to access all forms of health care, including from Kaupapa Māori Providers and Māori health professionals (Māori pharmacists make up less than 2% of practising pharmacists in New Zealand).</p> |
| <p>Cultural literacy</p> <p>Cultural literacy requires practitioners and organisations to ensure people receive understandable health information to make appropriate decisions. Whilst it must be from a platform of culturally safe practice, it recognises how dependent people and whānau are on the ability of health practitioners and organisations to impart applicable health information.</p> | <p>Cultural literacy accounts for 'diverse knowledge' and ensures people are provided with all the tools to feel empowered in their care. Research tells us that it can determine whether a person engages with the health system at all. In addition to the impact this has on health outcomes, it can also be a source of medicines waste as lack of cultural literacy is one reason people do not follow medicine regimes. Yet for Māori, social and cultural considerations are rarely addressed within the mainstream application of "health literacy" (Carlson, Moewaka Barnes, & McCreanor, 2019) and there is considerable scope for activity focused on ensuring culturally safe services incorporate cultural literacy.</p> |

| | |
|--|---|
| <p>Monitoring</p> <p>Focused at an individual level, monitoring in this context means checking that treatment is appropriate, and aligned with best practice.</p> | <p>Monitoring at an individual level encounters many of the same barriers as outlined in all previous components of Ngā Rau o Kawakawa.</p> <p>Using research on gout management, for example, monitoring repeats all the barriers to accessing healthcare, cultural literacy pharmacotherapy expertise. To the latter point if for example a person is commenced on allopurinol but becomes non-adherent then decides to recommence, if the prescriber re-prescribes a previous higher dose rather than an initiation dose, the person is at risk of serious side-effects.</p> |
| <p>Pharmacovigilance</p> <p>This involves post-market surveillance of the ongoing analysis of real-world medication use is integral to ascertaining the efficacy, safety and cost-effectiveness of medicines.</p> | <p>Issues with data across the health and disability system are evidenced in pharmacovigilance issues, with under-reporting and under-capturing of adverse events connected to medicines, and is likely to be more pronounced for Māori (especially for Tāngat Whaikaha Māori).</p> <p>Pharmacovigilance should be used to inform public health campaigns and messaging.</p> |

Appendix 2: Agencies involved in helping ensure optimal use of medicines as at February 2022 (Source: Pharmac Review Panel, 2022)

| Role | Agency | Commentary |
|--|--|--|
| Horizon scanning – Scanning for emerging trends | Pharmac Te Aho o Te Kahu (for cancer-related matters) Ministry of Health | Scanning takes place in a piecemeal fashion, and no agency has explicit responsibility for such work. We have noted other jurisdictions with a dedicated unit have a continual and focused approach. |
| Drug trials | Ministry of Health Medsafe Health Research Council of New Zealand Health and Disability Ethics Committees | Trials in New Zealand must be approved by the Director-General of Health, on advice of the Health Research Council of New Zealand (Medicines Act 1981). Medsafe, a business unit of the Ministry, runs the application process for clinical trials. HDEC administer the ethics approval system, which applies to all clinical trials conducted in New Zealand. |
| Approval and classification of medicines | Medsafe Ministry of Health | New medicines cannot be marketed in New Zealand without the consent of the Minister of Health. Changes to use of medicines require consent of the Director-General of Health. Data that satisfactorily establishes the quality, safety and efficacy of a product must be submitted for evaluation before consent can be granted (Medicines Act 1981). |

| | | |
|----------------------------|--------------------------------------|--|
| Funding of medicines | Pharmac Ministry of Health ACC | <p>Pharmac is primarily responsible for funding and buying medicines (New Zealand Public Health and Disability Act 2000), although ACC can, in some circumstances, fund medicines not on the pharmaceutical schedule.</p> <p>Some medicines listed in the pharmaceutical schedule have conditions, determined by Pharmac, that must be met before funding will be granted.</p> <p>Pharmac manages the negotiation and purchase of subsidised medicines.</p> <p>Patients and their whānau may pay for some medicines directly. Medicines not appearing on the schedule require full payment by patients. For medicines that are partially funded by Pharmac, the patient pays the shortfall. Additionally, pharmacies can charge for extras such as out of hours dispensing or blister packing.</p> <p>Costs may also include prescription co-payments, which are currently set at \$5 for most subsidised medicines. There is also a prescription subsidy scheme available for people and families who have more than 20 prescriptions per year.</p> |
| Pharmaco-therapy expertise | Pharmac | <p>Pharmac has contracted out this function to specialist providers since the 1990s.</p> <p>Other groups outside of government provide support to health professionals too, such as:</p> <p>The Goodfellow Unit delivers continuing professional development for primary health care professionals through multiple mechanisms</p> <p>NZ Formulary, an independent resource for health professionals providing clinical validated medicines information and guidance on best practice in order to support prescribers to select safe and effective medicines for each of their patients.</p> <p>Best Practice Advocacy Centre (BPAC) which continues to provide articles and prescribing tools</p> <p>Matui Ltd, which provides He Ako Hiringa (discussed above)</p> <p>Clinical Advisory Pharmacists Association (who provide advice to the above and also write regular columns for NZDr).</p> |
| Legislation and policy | Ministry of Health | The Ministry is the primary policy agency and is responsible for health-related legislation and associated strategies. |

| | | |
|-------------------------------------|--|---|
| <p>Access to health services</p> | <p>Ministry of Health District health boards Health providers</p> | <p>The New Zealand Public Health and Disability Act 2000 sets out the personal health, public health and disability services available to New Zealanders and establishes district health boards with functions to ensure provision of services for their populations and the reduction in health disparities.</p> <p>Subsequent policies, such as the Primary Health Care Strategy and He Korowai Oranga (the Māori Health Strategy), have set policy directions for access to services generally.</p> |
| <p>Cultural safety and literacy</p> | <p>Ministry of Health District health boards Health providers Health professional responsible authorities Health professional bodies Health Promotion Agency Medsafe</p> | <p>Ministry of Health has provided frameworks and guidance to district health boards and health providers on health literacy and communication.</p> <p>Responsible authorities are required to set out competency standards under the Health Practitioner Competence Assurance Act 2003, including cultural competence, which includes cultural safety.¹</p> <p>Ministry of Health has also provided information specifically around medicines in residential services (disability, mental health and addiction services). Other targeted messaging, focused on promoting health and wellbeing, can fall within the functions of the Health Promotion Agency (New Zealand Public Health and Disability Act 2000). Pharmac has in the past also worked on building health literacy around medicines – contracting this out to third-party providers.</p> <p>Medsafe provide detailed consumer medicine information factsheets (often available from pharmacies or prescribers and online).</p> <p>The Health Navigator Charitable Trust also runs a website (www.healthnavigator.org.nz) that provides a range of health information to New Zealanders, including about prescription medications.</p> |

¹ See, for example, the Medical Council of New Zealand’s cultural safety standards: <https://www.mcnz.org.nz/our-standards/current-standards/cultural-safety>.

| | | |
|-------------------|---|--|
| Monitoring | Ministry of Health (date collection) Medsafe Medicines Control ESR Pharmac Health Quality and Safety Commission Providers/ Health professionals | <p>Monitoring happens at different levels and can range from monitoring the effectiveness of medicines, licencing of pharmacies, to monitoring access to services and prescriber behaviour.</p> <p>In some instances, the Ministry may work with ESR to monitor specific medications, such as vaccines. Pharmac reviews prescription patterns. The Health Quality and Safety Commission runs the Atlas of Healthcare Variation, which looks at variations across a range of clinical domains, including medicines for asthma, contraception, diabetes, gout and mental health. It also looks at opioid use, antibiotic use and polypharmacy.</p> |
| Pharmacovigilance | Medsafe The New Zealand Pharmacovigilance Centre | <p>Medsafe undertakes post-marketing surveillance with the New Zealand Pharmacovigilance Centre, which umbrellas the Centre for Adverse Reactions Monitoring. This includes:</p> <ul style="list-style-type: none"> monitoring adverse reactions to medicines used in New Zealand and monitoring international literature and other information sources testing marketed medicines against product quality standards handling complaints and investigations auditing and licensing medicine manufacturers. <p>The Independent Safety Monitoring board monitors the safety of Covid-19 vaccines.</p> |

References

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Appendix 6 Information for Participants

Oranga Rongoā INFORMATION SHEET FOR PARTICIPANTS

Study title: Oranga Rongoā

Locality: Papakura Marae Clinic

Ethics Committee ref: 18/NTB/213

Lead Investigator: Leanne Te Karu

Contact phone number: 0274624359

You are invited to take part in a study on improvement of gout services. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can still pull out of the study without providing a reason.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide today whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends, or healthcare providers. Feel free to do this.

If you agree to take part in this study, you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep.

This document is 5 pages long, including the Consent Form. Please make sure you have read and understood all the pages.

What is the Aim of the Project?

Papakura Marae Clinic is trying to improve the management of gout. This is because gout is associated with a poorer quality of life. It is also associated with heart and kidney health. Gout is especially common in Māori and Pacific Island people. This is because of genetic differences, and not necessarily because of food and drink. This is a common misunderstanding. The Clinic is looking for ways to help make it easier for people to manage gout themselves. Also, to help people understand the medicines better. The aim is not to have painful attacks that prevent normal daily activities. It would be very valuable to hear your thoughts on how improvements could be made to make things easier for you. The information gathered will be used to identify ways to improve services. This study will also form part of a PhD (doctoral) study for the lead investigator – Leanne Te Karu.

What Type of Participants are being sought?

1. People who have experienced gout or have had a diagnosis of gout
2. Over the age of 20 years

What is involved?

If you agree to be involved, you will participate in an interview to discuss your thoughts and experiences of gout management at Papakura Marae Clinic. This interview is estimated to take a minimum of 20 minutes and will take place at a venue chosen by yourself. For example, it could occur at your home or at Papakura Marae, Travel costs will be reimbursed.

It is also possible for the interview to take place by videoconferencing should that suit you better. Your feedback will be anonymous to Papakura Marae Clinic. There is no danger that your care will be disadvantaged because of anything you say. All feedback is very welcome. In fact, feedback on things that are not working well is particularly helpful for change to occur.

If you agree, the interviews will be audio taped to keep an accurate record. The recordings will not be made available to anyone else. The audio recording will be transcribed, and you will have the opportunity to check and approve the transcription. The transcriptions of the recording may be available to Leanne's supervisors in an anonymised manner. They will not be available to anyone else.

If you do not wish to be taped, notes will be taken. Information collected will be in an anonymous form.

All written data collected will be stored in a locked cabinet at the University of Auckland for up to ten years or until publication of the findings. After this the data will be destroyed by paper shredding. Digital voice recordings will be wiped immediately after transcription. There will be community hui once the interviews have been completed in order to share the findings. There is also the option of having study results provided to you directly if you wish.

What are the possible benefits and risks of this study?

The benefits are that your feedback will be used to inform possible changes to how gout is managed at Papakura Marae Clinic. These may or may not be directly valuable to you. The themes of feedback will be shared, e.g. in medical journals so that other health providers may learn and implement changes.

There are no perceived risks to you, but should you feel uncomfortable at any stage and not want to continue with the interview, it will be erased and there will be no negative consequence for you. If you leave the interview and feel you want to withdraw, then you need only say so without providing a reason. If it is your preference to contact the cultural advisor to withdraw, then you may do so.

What are my rights?

Please note that you have the same rights as those covered by the Code of Health and Disability Services Consumers' Rights of which a brochure will be provided.

Importantly you have the right to withdraw from this research at any stage up until after your final approval of the transcription. There will be no disadvantage if you do choose to withdraw.

As mentioned you will be provided with the transcript of your interview and have the right to amend it or again as above to withdraw.

You have the right for complete privacy and confidentiality. The themes from interviews will be presented anonymously.

Are there any costs to participate?

There will be no associated costs if you decide to participate. If you would prefer the interview to take place outside your home, any travel to the venue of choice will be reimbursed. There is also the option of transport being provided by Leanne Te Karu to travel to a venue. There will be a small koha in recognition of your time contribution.

WHO DO I CONTACT FOR MORE INFORMATION OR IF I HAVE CONCERNS?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

Professor Bruce Arroll

Telephone number: 021378180

Email: b.arroll@auckland.ac.nz

If you want to talk to someone who is not involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050

Fax: 0800 2 SUPPORT (0800 2787 7678)

Email: advocacy@hdc.org.nz

For Māori Cultural support please contact:

Mr Brian Joyce JP

Kaumatua Papakura Marae

Phone: 09 298 9507

You can also contact the health and disability ethics committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS

Email: hdecs@moh.govt.nz

Leanne M Te Karu

Principal Investigator

PhD Candidate Phone: 0274624359

Consent Form

Please tick to indicate you consent to the following (Add or delete as appropriate)

| | | |
|--|------------------------------|-----------------------------|
| I have read, and I understand the Participant Information Sheet. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I have been given sufficient time to consider whether or not to participate in this study. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I have had the opportunity to use whanau/ family support or a friend to help me ask questions and understand the study. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I agree to an interview with Leanne Te Karu. I may stop the interview at any time and no information will be kept about what I have said. I can stop the interview and withdraw my contribution without giving a reason. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I understand that this consent form will be kept for 10 years at the university and then destroyed. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I understand that the information collected on the audiotape will be transcribed into a written (paper and electronic) format. I will have a chance to read the interview and make any changes up until one month after I receive a copy of the interview. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I give permission for my contribution from the interview to be published anonymously in a medical journal or presented at a meeting for other health professionals. I understand that the information reported will not be identifiable. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I know who to contact if I have any questions about the study in general. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |
| I wish to receive a written informal summary of the results from the study. | Yes <input type="checkbox"/> | No <input type="checkbox"/> |

Appendix 7 Oranga Rongoā Questionnaire

Oranga Rongoā Questionnaire

Semi-structured interview template

This is a thematic engagement, and these are intended to be open ended questions that will derive further questions based on responses. Further questions will keep these themes in mind, however.

After mihimihi and whakawhanaungatanga process is conducted there will be a general discussion around what ‘best practice’ treatment of gout according to guidelines and health pathways looks like. (Aim of achieving a serum urate level of <0.36mmol/l.) Papakura Marae Clinic have been looking to improve how prescribers prescribe medicines for gout and looking to improve how people can be empowered to self-manage gout.

Overarching Questions

- Tell me about your experience of gout management.
- Who has mostly informed your understanding of gout? (Whānau, health professionals, internet??)
- Have you had any specific interaction on gout at Papakura Marae Clinic over the last year? If so tell me about it – what happened? What sort of information was provided? What do you know now that you didn’t know before?
- Have you attended any of the community hui on gout? If so tell me about that – was it helpful? What did you learn? What do you know now that you didn’t know before? What could have been done better?
- If you didn’t attend any community hui, were there specific barriers – timing/feeling ‘safe’ to attend? What might have helped you to attend?

Management

- What medicines have you been prescribed for gout? What is your understanding of how they work? What information have you been given on them? Understanding of long-term management?
- How often do you get gout?
- Are you aware of what your uric acid level is? How easy/hard is it for you to access the laboratory for blood testing?
- What would be helpful in your life for the Clinic to do that would help you to manage gout? What sorts of things have been a barrier to management?
- What are your thoughts on what best practice management should look like for you specifically? Any further comments on what could be implemented/changed at Papakura Marae Clinic to make things easier for you to manage gout. What could clinicians – doctors, nurses, pharmacists do better for you?

Appendix 8 Participant Consent Form

Professor Bruce Arroll
Department of General Practice & Primary Health Care,
School of Population Health,
University of Auckland,
Private Bag 92019,
Auckland

I have read the participant information sheet, understand the content and have had a chance to ask questions. I agree to take part in this research.

I am aware that this study has received ethical approval from the Northern Region Ethics Committee.

I understand that this consent form will be kept for 10 years and then destroyed.

I understand that I was invited to undertake an interview and I am in no way disadvantaged if I do not agree.

I agree to an interview with Leanne Te Karu. I may stop the interview at any time, and no information will be kept about what I have said. I can stop the interview and withdraw my contribution without giving a reason. I am permitted to withdraw from the research altogether at any stage and will in no way be disadvantaged.

I understand that the information collected on the audiotape will be transcribed into a written (paper and electronic) format. I will have a chance to read the interview and make any changes until one month after receiving a copy of the interview.

If I do not agree to being audio-taped, I understand that notes will be taken.

I give permission for my contribution from the interview to be published anonymously in a medical journal or presented at a meeting for other health professionals. I understand that the information reported will not be identifiable.

Signed.....Date.....

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