



Consulting with Māori experts to ensure mainstream health research is inclusive of Māori

Te toro whakaaro ki ngā mātanga Māori kia noho tonu ngāi Māori i roto i ngā rangahau hauora auraki

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Abstract

Understanding the lived realities of Māori patients with long-term health conditions (LTCs) is essential if the health system in Aotearoa New Zealand is to eliminate current Māori health disparities and support Māori patients appropriately. Culturally responsive researchers can gain insights by ensuring the inclusion of Māori participants in research on LTCs. To strengthen her capability to be culturally responsive, a tauīwi (non-Māori) health researcher consulted Māori experts throughout her in-depth research with 16 people with long term conditions, including six Māori participants. The trust built during consultation aided the recruitment of Māori participants through experts' networks. Advice received about culturally responsive engagement with Māori participants helped the researcher safeguard participants' mana (dignity and status) during and after the research and ensured their voices were heard accurately and represented well. The research findings consequently offered guidance for the transformation of health services to facilitate positive Māori health development.

Ngā ariā matua

He mea tino nui kia mārama te tangata ki ngā āhukatanga o te noho o ngā tūroro Māori whai ngoikoretanga hauora wā-roa (LTC) kia whakakorea atu ngā rerekētanga o ngā āhukatanga hauora Māori ki ō te nuinga i raro i te pūnaha hauora o Aotearoa, kia tika hoki te tautoko i ngā tūroro Māori. Ka āhei ngā kairangahau mārama ki te ahurea te katokato māramatanga mā te whakauru i a ngāi Māori kia whai wāhi ki ngā rangahau mō ngā LTC. Hei whakapakari i tōna māramatanga ki ngā āhukatanga ahurea, i toro atu tētahi kairangahau ehara i te wahine Māori ki ētahi mātanga Māori, nā roto i āna rangahau hōhonu ki ētahi tāngata 16 whai ngoikoretanga hauora wā-roa, ā, e 6 o rātou he Māori. Nā te whakapono i hua ake i te torotoronga i ngāwari ake ai te kimi tāngata whai wāhi Māori, nā roto i ngā kupenga tāngata o ngā mātanga. Nā ngā tohutohu mō te tūhono i runga i te whakaaro-nui ki te ahurea ki te hunga Māori whai wāhi mai i āwhina te kairangahau ki te tiaki i te mana o te hunga whai wāhi mai i roto, i muri hoki i te rangahau, i tino rangona ai ō rātou reo, kia tika, kia pai. Nā ngā kitenga o te rangahau ka puta ake ētahi aratohu mō te whakaumutanga o ngā ratonga hauora hei whakangāwari i te whanaketanga hauora Māori takatika.

Francis, H., Carryer, J., & Cram, F. (2019). Consulting with Māori experts to ensure mainstream health research is inclusive of Māori. *Nursing Praxis in New Zealand*, 35(3), 7-14. doi: 10.36951/NgPxNZ.2019.010



Keywords / Ngā kupu matua

chronic conditions / ngā ngoikoretanga pūputu; health research / rangahau hauora; self-management / whakahaere ā-kiri; long-term conditions / ngā ngoikoretanga wā roa; Māori consultation / te torotoro whakaaro Māori; Māori or Indigenous health / te hauora Māori, iwi taketake rānei

Introduction

In Aotearoa New Zealand, and globally, there are increasing numbers of people living for many years with complex, multiple, long-term health conditions (World Health Organization, 2014). Long-term conditions (LTCs) and multi-morbidity are socially patterned (Cockerham, Hamby, & Oates, 2017) and many of the people who have several LTCs are also contending with complicated lives alongside the implications of their illnesses. Health systems internationally have devised approaches intended to meet the needs of people with LTCs. These have largely been based on the theories of the Chronic Care Model and the self-management framework (Bodenheimer, Wagner, & Grumbach, 2002), underpinned by assumptions of innate agency (Bandura, 2018). There is little information about whether these assumptions are correct.

The study drawn from for this article set out to discover how people with complex, multiple long-term health conditions lived their lives and managed their health over time, and how they engaged with and experienced self-management approaches within a primary care setting (Francis, 2017). The purpose of this article is to describe the role of consultation with Māori experts to support the cultural responsiveness of such research.

Māori involvement in research

In Aotearoa, Māori are over-represented amongst people with multiple LTCs (Tobias, Blakely, Matheson, Rasanathan, & Atkinson, 2009) and yet under-represented in research (Cram, 2014). Despite this, research findings are often extrapolated to the entire population leaving Māori

further marginalised by health system ‘improvements’ that do not reflect their realities (Wilson, Heaslip, & Jackson, 2018). It is hard for Indigenous peoples to find themselves, their lives, their culture, or their world within this inquiry paradigm (Cram & Mertens, 2015).

As well as strengthening Māori research capacity, Māori have discussed how tauiwi (non-Māori) might respectfully and responsively research with them through research mentoring and partnering relationships (Cram, 1997). Guidelines are now available for involving Māori in health research (Pūtaiora Writing Group, 2010) and ethics committees hold researchers more accountable for their responsiveness to Māori participants (Amundsen, 2018). Barnes (2013) noted, when he contemplated his own responsiveness as a Pākehā (white) researcher, that Pākehā have a responsibility to “unsettle taken-for-granted Eurocentric notions of research ... and create new ways to meaningfully engage with diverse Māori on critical ... issues” (p. 2). Many tauiwi (including Pākehā) researchers are committed to journeying well with Māori and as such actively reflect upon and seek advice about what that looks like for their projects.

Consultation with Māori

A prerequisite of scholarship and ethical health research in Aotearoa is the process of Māori consultation (Health and Disability Ethics Committees, 2018), whereby Māori are partners in the research endeavour and their interests protected. Consultation is therefore more than a tick box or lip service; it is ensuring that research is



responsive to and relevant for Māori (Kirkhart, 2005). Within Te Ara Tika – the Māori research ethics guidelines – research consultation is seen as a minimum requirement that supports risk management while helping ensure that research processes and outcomes support Māori aspirations (Pūtaiora Writing Group, 2010).

Many Māori are willing to support tauwi researchers to take this journey, even if it means that tauwi researchers have to commit to building their own capacity to work in culturally responsive ways with Māori. As Putt (2013) notes, such “respect leads to an openness and comprehension that lends itself to collaboration and the building of trusting relationships and reciprocal obligations” (p. 5). One such journey is described here.

The present research

The research study described here involved a tauwi researcher (Helen Francis) undertaking in-depth interviews with 16 people with multiple LTCs, including six Māori participants. Māori research experts came together as a Research Whānau (family, extended family) to guide this study. This article is a response to Barnes’ (2013) call for tauwi researchers to write about their experiences of undertaking research with Māori so “we can learn from them about what has worked well, what needs to change, and what has been rewarding” (p. 3).

Research Whānau

The initial consultation process began with an approach to two Kaumātua (Māori elders) who were known to the Pākehā researcher and who were experienced in the health field. This occurred prior to the development of the research questions or the application for ethical approval, as beginning the consultation process as early as possible was considered essential to the validity of the study.

The initial two Kaumātua remained a constant support throughout the study and they suggested (and when

necessary, introduced the researcher to) other potential Māori advisors. As a result, six Māori with health expertise joined the Research Whānau (their name choice) (see Table 1 at end of article for membership). Throughout the study, this group held up what Snow (2018) describes as an “honest mirror” (p. 9) to facilitate the researcher’s critical reflections about her engagement with Māori. They provided advice, feedback and support, along with encouragement to shore up the researcher’s courage. They did this during regular face-to-face meetings, telephone and Skype sessions, and text and email question and answer exchanges. The next section outlines the broad outcomes and the ‘turning points’ from this consultation with the Research Whānau.

General advice from the Research Whānau

Study method

The key messages from the Research Whānau were about developing long-term relationships between the researcher and the participants, echoing Cram (2014) who asserts “establishing relationships is the foundation of working with Māori in a culturally responsive way” (p. 5). At an ontological level, the Māori world is relationships; the genealogical ties binding people to one another, to the environment and to the cosmos (Barlow, 1991). Specific aspects such as the importance of the initial engagement process (such as cultural protocols for introductions) and the value of *kanohi ki te kanohi* (face-to-face) encounters were also echoed in the texts they recommended (Bell, Tumilty, Smith, Hale, & Kira, 2016; Brewer, Harwood, McCann, Crengle, & Worrall, 2014; Cram & Pipi, 2000). This encouraged the researcher to undertake interviews with participants where and when they wanted, ensure there was flexibility in interview guides, and allow participants to be in the driver’s seat and guide the direction their interview took.

The choice of longitudinal case study as a research design, where enduring relationships inevitably grow



whilst developing an in-depth understanding of the individual case, sat well with the advice given (Abma & Stake, 2014). Case study echoes some of the principles of Māori-centred research approaches that aim to “uncover the many experiences and ‘voice’ of the participants emphasising complexities rather than commonalities” (Bishop, 1995, p. 78). As the name implies, Māori-centred research puts Māori participants at the centre and privileges their worldview. This then gives rise to a structural analysis about what facilitates and what prevents Māori wellbeing, as opposed to a research lens that emphasises personal deficits (Forster, 2003). A case study approach similarly stresses the importance of the whole person situated firmly in their whānau, social and wider ecological context, and considered in their entirety (Cram, 2013).

Advice from the Research Whānau also helped to support the analysis of the data being through a Pākehā lens and helped the researcher to do justice to the participants’ stories. Feedback received from the Research Whānau after the researcher shared the first two anonymised interview transcripts, was that the approach was right because the participants were “opening up to you”.

Ethical approval

Informed, written consent was received from each participant. Formal ethical approval for the study was received from the Health and Disability Ethics Committees (CEN/12/EXP/007). Proof of appropriate Māori consultation was a prerequisite for this approval, with this coming in the form of a letter from a member of the Research Whānau. While ethics approval came from the Ethics Committee, the permission to commence the research with Māori effectively came from the Research Whānau.

Recruitment and retention of participants

Following advice, initial engagement with potential Māori participants occurred with support from the Research

Whānau, who talked to their community networks and came back with contact details of people willing to participate. Like snowball sampling, this method of recruitment acknowledged and worked through the chain of relationships the Research Whānau had within their own extensive networks, a process one member called whakapapa (genealogical) sampling. Whakapapa connectedness gives rise to whanaungatanga (kinship relationships), and both invoke notions of shared responsibility, belongingness, and support for one another across the generations. This very early consideration of the importance of a diverse group of participants including Māori, resulted in 12 of the 16 participants being from the populations who experience much higher rates of LTCs and are typically less involved in research (Abma & Stake, 2014).

It is impossible to know definitively the effect of the Research Whānau’s involvement on the decision of all the Māori participants to continue their participation throughout the study. However, it seems likely that the advice about initial engagement and building relationships with the participants was an important contributor to this outcome. Their advice also provided protection for participants and the researcher, including a culturally responsive protocol for ending their research relationship.

Terminating research relationships

As the research period began to reach its conclusion the researcher met with the Research Whānau to consider the process of how to respectfully terminate the research relationships. Typically, less attention is paid to terminating research relationships than the recruitment process (Iversen, 2009), despite the “moral complexities of research relationships” (Hewitt, 2007, p. 1149). The advice was to have a conversation with each participant during the final interview, to make it clear that this was the end of the formal part of the study, but the participants were asked how they wanted any relationship to be in the future. The researcher ensured



all still had a contact number or email in case they wanted any further contact, which many subsequently did, mostly enquiring how the study was progressing. This met the “moral and ethical imperative to enter into the dialogue of closure” (p. 424) in qualitative research (Morrison, Gregory, & Thibodeau, 2012).

Terminology

Several of the ideas emerging from the research were better explained using Māori terms. Translations can vary and often seem to offer a shallow or superficial comparison. The researcher used the definitions the Research Whānau offered and was advised to settle on these and clearly explain how a term was to be used in order to remain with that meaning. While the researcher appreciated that her understanding may have been simplistic, she aimed to be respectful and consistent in the use of these terms. They also stressed the importance of not presuming a response was due to culture. The consultation provided some reassurance that issues related to culture were not being overlooked.

Turning points

There were at least three occasions when issues, with which the researcher was grappling relating to culture or shared, taken for granted practices (Napier et al., 2014), were clarified by a member of the Research Whānau.

Whanaungatanga

Māori participants described a conflict between what they felt was being asked of them by their health care practitioners and their own priorities. Several described aspects of suggested self-management as essentially “a selfish way of doing things” that did not sit comfortably with their own values. For example, many participants were carers for others and felt unable to put their needs first, despite volunteering that they “knew” their health was important to allow them to continue to care for whānau. A participant recalled taking her brother to his general practitioner and coming out with medication for

her own pneumonia, despite not acknowledging that she was especially unwell. Her priority remained her brother, who was the “biggest problem for the family”. Others felt belittled by clinicians when they could not attend clinic appointments due to carer responsibilities. One was told, “Well, if you don’t think your health is important ...”. This was an issue discussed extensively with the Research Whānau, who helped the researcher to gain an understanding of the impact of communal thinking. Individual health is far from being a priority and instead having compassion for people and genuinely valuing other’s welfare is central.

Manaakitanga

The second turning point arose when listening to a young participant who lived with his elderly mother: his health was very fragile, he had multiple, significant LTCs, and was morbidly obese. He had a genuine yearning to eat healthily but felt he could not overrule his mother’s choices of food, despite stating that she “force feeds” him as a way of showing love. He described this himself as an excess of manaakitanga, which can best be described as kindness or hospitality, which he said was something common in many “Māori mums”. He described feelings of being torn between the belief his mother was sabotaging his health and enjoying the manaakitanga. This was another area where culture and health overlapped for Māori and which raised discussion with the Research Whānau. They explained that the sharing of food has traditionally linked hospitality, nurturing and identity, and so affected the daily habits of Māori and their subsequent health. Enjoying communal eating and sharing of food at home or on the Marae was a big part of the participant feeling of belonging, with “wellbeing ... socioculturally generated and understood” (Napier et al., 2014, p. 1611).

Whakamā

On another occasion, the researcher struggled to understand why a participant attended, or perhaps



over-attended, his general practice but described how he also tended to ignore any advice he was given. Other participants, apparently willingly, set self-management goals with primary care clinicians but described how they did not have any intention of working towards the goals, with one describing how he “tend(s) to leave my goals in the car park [at the health centre]”. Another described being “told to complete a food diary, which I didn’t really do. I said I had a lot of vegetables. A bit of lettuce in the burger that’s all I was having!” Discussion with a member of the Research Whānau explained the idea of whakamā more deeply than the researcher had previously understood. Whakamā is a psychosocial construct in Māori, with no exact Western equivalent (Kidd, Gibbons, Kara, Blundell, & Berryman, 2013; Metge, 1986; Sachdev, 1990). It is often understood as shyness, shame, modesty or embarrassment, but it has a wider meaning. Experiencing whakamā can mean Māori avoid asking for help, say what they think is expected of them or mask their whakamā with anger or apparent indifference (Kidd et al., 2013).

Concluding comments

The article describes one example of successful consultation, describing the journey so that others may learn from our experience. Consultation with the Research Whānau enabled the tauwiwi (non-Māori) researcher to refine her research practices and hone her ways of seeking to create a culturally responsive research space for Māori participants in the study of people’s experiences of LTCs. Ongoing engagement mitigated some of the difficulties experienced by other researchers, particularly recruitment and prolonged engagement with Māori participants. It is impossible to know definitively the effect of the consultation process on the decision of all the Māori participants to continue their participation throughout the study. However, it seems likely that the advice received about initial engagement and building relationships with the participants was an important contributor to this outcome.

This consultation enabled research with Māori that maintained their mana (dignity) and ensured that their voices were heard describing the impact of LTCs on their lives. This appeared to allow the participants to feel included, understood, and represented well in the research findings. While the study was by no means fully participatory in terms of involving people with LTCs as key drivers of the study, it did follow another pathway of facilitating Māori experts to be the kaitiaki (guardians) of Māori participants in the study. It is likely that had this process not been embarked upon and the turning points missed, their omission would not have been noticed.

The Māori participants showed a high level of interest in the findings which they all said accurately reflected their own experience of living with LTCs. A male participant said: “It is always good to talk to you. I look forward to it. You are a new friend I have made this year”. When visited, many had made a note to tell the researcher about something related to their health. The relationships that developed seemed important to the participants, as well as to the researcher, and several participants expressed regret that the data collection was over. The feedback from participants gave reassurance that the research reflected their experiences; for example, a woman said, “Yes – that’s my life there. Looks like bloody hard work when I see it written down. No wonder I’m exhausted”.

On reflection, we advocate a humble and appreciative approach to inquiry. Genuine interest and intent to pursue what seemed like common sense in seeking Māori expertise made the process pain free, rewarding, and enjoyable. Advice for other tauwiwi is to simply “identify someone you know and begin a conversation”. If the potential researcher knows no-one, then our experience of the generosity of time and wisdom given in this research would lead us to encourage people to simply keep asking: make contact with health or social agencies such as the local District Health Board Māori Health Unit to seek advice, support or to facilitate



contact with a Kaumātua. If those people cannot help, then it is very likely they will know someone who can and, if genuine consultation is being sought, they will be happy to facilitate an introduction.

Finally, although there may be helpful suggestions within this article for tauwiwi completing culturally responsive research, or other non-Indigenous researchers working with Indigenous populations, it must be emphasised that there is no one-size-fits-all template for the process in any research context. However, what is transferable is that when guidance is sought for inclusion of Māori voices within population research, Māori can be immensely generous. The advice provided then gives both tauwiwi researchers and Māori participants confidence that the research space created will be nurturing and safe.

Acknowledgments: Thanks to the sixteen people with LTCs and the Research Whānau (see Table 1) who all gave their time so generously for this study.

TABLE 1: Research Whānau membership

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| <p>Research Whānau</p> <p>Nāku te rourou, nāu te rourou, ka ora ai te iwi</p> <p>Potace Bennett RN, Tainui/Ngāti Kahungunu/TeArawa. Māori and Pacific Health Coordinator, Long-term Conditions Service.</p> <p>Mathew Bennett, Te Arawa/Ngāti Kahungunu/Tainui/Ngāti Raukawa. Māori Health Strategist.</p> <p>Ann McClelland RN, MA, MN, Tainui. Experienced Nurse, Nurse Educator and Māori Researcher.</p> <p>Heather Te Au Skipworth QSM, Ngāi Tahu/Ngāti Kahungunu. IronMāori Founder.</p> <p>Tracee Te Huia, Ngāpuhi/Ngāti Kahungunu. Director Māori Health.</p> <p>Na Raihania, Ngāti Porou.</p> <p>Amber Logan-Riley BApSci, MSc, PGDipHlthPsy. Ngāti Kahungunu. Health Psychologist and Māori Researcher (Ao Marama Health Research).</p> |
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