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# Making Health Data Work for Māori attitudes and current challenges

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## Abstract

This article explores the experience of health services decision makers using Māori health data to inform decision making. It draws on selected findings from the second phase of a three-year Health Research Council-funded study and discusses how Māori health data identification, data analysis and data interpretation processes are being used by decision makers to help to identify the most promising strategies to improve Māori health. Data is critical to monitoring inequity and has the potential to drive health service change. However, improvement is needed at all steps in the decision-making process to better facilitate utilising data to leverage change in Māori health outcomes.

**Keywords** Māori health data, health services decision making

## Background

Using district health board (DHB)-level, routinely collected Māori-specific health data to improve Māori health outcomes requires decision makers to prioritise Māori data, meaningfully engage with the multiple stories the data is telling them, support Māori leaders to help define data priorities, and, using available data, generate solutions to the issues identified.

Disparities in health outcomes between Māori and non-Māori are widely recognised as a major focus for health system improvement (Gauld et al., 2011; Pega et al., 2014). While gains have been made, issues concerning collation, access and use of data are contributing to slow progress in successfully reducing disparities (Coster, 2004; Suckling et al., 2015). A key current government policy objective is the delivery of equitable health outcomes supported by insightful data interpretation (Ministry of Health, 2018a).

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Under the New Zealand Public Health and Disability Act 2000, DHBs are tasked with ‘reducing health disparities by improving health outcomes for Māori and other New Zealanders’ (s5(3)(c)). With regard to Treaty of Waitangi principles, the act also requires DHBs to ensure the participation of Māori in decision making (s23(1)(d)), and to provide information to support this participation (s23(1)(f)).

While DHBs gather a wide range of data, for a variety of policy and administrative purposes, there is an increased demand for data to inform strategic decision making for Māori health gain. Data on inequities in health outcomes, service access and service utilisation is relevant to DHB decision-making processes in two main ways. First, data is used to support the ‘funding arm’ of DHBs, in which resources are allocated across the range of publicly funded health and disability services. Contracts with non-governmental providers, including Māori health providers, fall under this ambit. Second, data can be used to inform decisions within specific service areas directly provided by DHBs (i.e. the ‘provider arm’). A key challenge for both Māori leaders and organisational decision makers is to use data in ways that lead directly to improvements in health services. Improving Māori service access, service utilisation and patient care will contribute to a reduction in disparity in health outcomes between Māori and non-Māori.

This article reports findings from the second phase of a qualitative study, D3: Data, Decision-making and Development: using data to improve health outcomes. This four-phase study is examining the processes of data identification, analysis and interpretation employed by decision makers in order to identify the most effective and promising strategies for improving health outcomes for Māori.

### The study

Kaupapa Māori theory (Walker, Eketone and Gibbs, 2006; Mahuika, 2008; Smith, 2012) and methodological principles drive all aspects of the research design, from establishment of the study through to data collection methods, analysis and translation. Participatory action research methods (Bradbury and Reason, 2001; Baum,

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MacDougall and Smith, 2006) within a case study design (Stake, 1995, 2005) are being utilised. The case study sites are three DHBs selected to reflect a degree of diversity by overall population size and by the proportion of their Māori population: site one (small, 24% Māori); site two (large, 9% Māori) and site three (medium, 17% Māori). We considered a small DHB would have a population below 65,000, a medium DHB would have a population over 65,000 but less than 180,000 and a large DHB would have a population greater than 235,000 (Te Pou o te Whakaaro Nui, 2018). We employed convenience sampling to select DHB sites. Considerations influencing research relationships with the DHBs and key staff within each DHB, together with geographical proximity to members of the research team.

In the first phase of the study we established the research, including research planning with the case study site partners, gaining ethics approval, and exploring potential cases for further investigation in each case study site. Case selection criteria included that the case identified a specific Māori health issue from routinely collected data (i.e. indicator and health service

utilisation data) and was considered a high priority by the site’s Māori decision makers. Confirmation of case study partners in each site also occurred in phase one. The role of case study partners in the research is to act as sponsors assisting with research design, interpretation, and translation of findings into action. In collaboration with each case study partner, we identified a core group of key decision makers to participate in phase two.

In phase two, potential cases were the subject of an investigation which aimed to understand the broader context of data and its link to health service improvement. Cases which warranted more detailed investigation for the planned phase three were also identified. The research is primarily concerned with how data is being used rather than with examining data accuracy. In phase four we will identify facilitators of, and barriers to, the effective use of Māori health data, as well as how findings can be translated into improvements in practice, or service provision, within the sites and across the wider health sector.

### Key informants

In phase two we interviewed 18 key informants across the three sites. Decision makers who had access to Māori data, and were involved in decision making concerning health service responses to access and outcomes inequities, were targeted. We were particularly interested in Māori decision makers’ perspectives regarding potential case options, the use of data, and its role in planning services as well as in Māori health gain.

Informants included 14 Māori and four non-Māori decision makers: ten based at DHBs and eight with Māori health service providers (MHSPs). At one site, eight interviews were conducted, with five each being conducted at the others. Quote codes used in this article include informant number, ethnicity and organisational affiliation by DHB or MHSP. Decision makers largely fell into two groups: those in management roles and those in governance roles. Māori governance members included those appointed by the Crown or publicly elected onto DHB governance groups along with mana whenua groups or Māori relationship

boards (members nominated by the respective iwi residing in the DHB region) working alongside DHB governance members as te Tiriti partners.

Informants' primary organisational affiliations are cited in the results section of the article. It should be noted that, in addition to their decision-making roles in their DHBs and/or MHSPs, all Māori informants held decision-making roles in a range of other capacities. Examples include on tribal boards and rūnanga and representing iwi on a variety of governance and advisory bodies across central and local government and the non-governmental organisation sector.

#### Data collection

An open-ended interview guide was developed based on the overarching research objectives and questions defined in the phase two plan. The questions used as the basis for the interview guide were:

- Which data that highlights Māori health inequities are the most useful for your DHB planning purposes, and why?
- What other potential data that is underutilised, or could be further developed, has the potential to influence outcomes for Māori? How could use be improved?
- How has this data been used for health service planning – development of interventions, policies, redirected resources?
- What are the challenges and highlights for this DHB in using Māori health data to leverage change in health services?
- Which potential case is most useful for addressing the aims of this research?

Ethics approval for the study was granted by the University of Auckland's Human Participants Ethics Committee (Protocol #020 455, December 2017).

Interviews were conducted by a primary interviewer, with a secondary interviewer observing and taking notes. Interviewer roles were flexible, with both posing additional questions as required. In-depth information was elicited using this collaborative approach. After each interview, the researchers debriefed and compiled field notes. All interviews were conducted face to face and averaged 40 minutes to one hour in length. Interviews

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were audio-recorded and transcribed in full, with transcripts each being allocated a unique code. Transcripts were checked by informants prior to analysis.

#### Data analysis

Data was analysed using a qualitative thematic approach to identify patterns in meaning and to make sense of seemingly unrelated material within and across transcripts (Braun and Clarke, 2006). Members of the research team independently analysed at least two transcripts from each of the three case study sites before meeting to carry out a mahi a rōpū process (Boulton et al., 2011), a form of group-level analysis used to further refine independent findings and confirm key themes emerging from the data. The analysis framework used to review the transcripts was developed from key questions in the interview schedule.

#### Results

Results are discussed below under four major themes arising from the analysis, namely: attitudes towards data; capacity to engage with data; data contributing to more robust decision making; and using data to improve equity.

#### Attitudes towards data

Attitudes towards data were diverse among informants across the case studies. Key sub-themes emerging included awareness of the potential for using data to address inequity; and scepticism about, and appreciation of, data.

When considering the potential for using data to address inequity, an informant noted that it was critical to use data that would best highlight the inequity issue and expose potential problems in achieving improved Māori health outcomes:

I think some of that is about knowing ... what data is there. What levers to pull ... how to present it. What data is the 'right' data or the most appropriate data? ... it could be data everywhere – but what's the 'right' data to use? (non-Māori, DHB, KI 11)

The transformational potential of quantitative data in the equity space was further described by another informant:

we use data to shape, to inform our decisions all the time ... we've just done a review of [service] ... and the data has been really, just in terms of attendance and proportion of Māori who are attending and, some of the child health outcomes and inequities in those child health outcomes ... that's been really useful in terms of informing what we decided to do. (Māori, DHB, KI 4)

Others too were positive about the potential for data to make a difference, with one describing an increased willingness among Māori to engage with it:

Māori have had a fear ... of research generally. Then we've moved, in terms of our journey, to if we like research, we like the qualitative stuff. And I think the next step on the journey is that we're coming to see the importance of quantitative data ... that could have a positive influence for us. (Māori, MHSP KI 15)

There was also scepticism, however, about the quality of the Māori data presented by DHBs to inform service-related decision making, with one informant commenting:

I'm not a great believer ... I know that data can be skewed and how data that is presented is the wrong data ... I'd prefer to know the story behind it. (Māori, MHSP, KI 9)

Even though some were sceptical about the use of quantitative data, they could nevertheless see its potential if adequate interpretation and a willingness to hear the real issues facing Māori were factored in, as the following excerpt illustrates:

I think data ... can be your friend. But it can be your enemy ... it isn't just the data. It's the interpretation. It's the messenger. It's the story – and then it's the willingness to hear the challenges. (Māori, DHB, KI 11)

#### *Capacity to engage with data*

Informants described significant data capacity issues evident in planning and funding services in the smaller DHB site and in some MHSPs. MHSP informants were often asked to respond to data that identified continuing inequity in outcomes for Māori. When talking about DHB-level data such as rates of immunisation uptake by ethnicity and age, MHSP participants described feeling unable to respond adequately to the data. A lack of dedicated personnel to assist with data review and analysis within some MHSPs was reported, along with the nature of some DHB reports which failed to include adequate analysis information:

there are times when I kind of feel like I'm ticking their [DHB] boxes. Because we're asked to go to hui constantly where they're presenting us with data and then kind of asking us what our perception is. And I don't have any issue in giving our perception, but I just wonder to myself, so what? What next? What does this mean? (Māori, MHSP, KI 15)

Another informant described her frustration around continually having to rely on somebody else's data and data analysis:

We're really reliant on data from other people because we don't have someone

## Informants observed that the manner in which data was presented affected their ability to engage with it at a deeper level.

in this organisation currently – and maybe that's the goal moving forward – who can gather data. Who can have an analytical lens on that data and who then can produce it in a productive manner for us ... the next step on the journey is that we're coming to see the importance of quantitative data, um, that could have a positive influence for us. (Māori, MHSP, KI 16)

MHSP informants were not alone in their frustration with the lack of data analyst capacity. A DHB informant observed:

Our decision support and data framework is quite amateurish ... we don't have a sophisticated level of data analysis and information analysis, or the infrastructure to support it. (non-Māori, DHB, KI 17)

Capacity issues were limited not only to type of service provider; some governance groups also had varying capacity to strategically respond to data. The following informant identified challenges around how, and at what level, to 'pitch' information:

[name of group] are a challenge because of the different levels of understanding ... sometimes they dive into 'three years ago with what happened to [name of relative]' ... and you can't get them up to a level of understanding and across

data and information. (Māori, DHB, KI17)

#### *Data contributing to more robust decision making*

There was an appetite among informants for multi-method approaches to data collection and to considering data from a range of perspectives, including those of whānau. Such approaches, it was suggested, would offer decision makers a more complete picture to better inform planning decisions, recognising that a more nuanced understanding of health for Māori communities requires greater appreciation of whānau perspectives and taking these into account in decision making. An informant observed that this does not tend to happen:

quite often in consultation there's a critical voice missing and that's the voice of our whānau ... We think we know what whānau need. We go ahead and do things. (Māori, MHSP, KI 15)

There were those who believed that qualitative data was of particular value and that it should be used to complement, and to contribute to more accurately interpreting, quantitative data. Improved understanding would in turn inform effective approaches to addressing Māori health need. Some wanted a more targeted, or focused, understanding of what population-level data means for communities, as the following example illustrates:

If you're asking me about use of data for decision-making, then I want the qualitative stuff to support that ... what we don't get at the moment is the analysis behind the information that is given to us ... What we're getting is target-based – hit the target and miss the point ... I think that at a population level ... the data should be highlighting specific areas to focus on. With the caution that ... the data has to be accurate ... (Māori, MHSP, KI 8)

Informants observed that the manner in which data was presented affected their ability to engage with it at a deeper level. Using dashboards or traffic light graphics,

such as is used in Trendly performance data by DHBs, was described by an informant as being well received by many decision makers, who found these formats accessible. An informant went on to note that, despite the advantages of presenting data in graphic formats, standard statistical data presentation, often described as technical or hard to understand by participants, remained the norm. Another informant further highlighted the importance of presenting data to decision makers in accessible ways:

smoking cessation or ... overnight stays in the hospital – that's the sort of data I think that takes my eye more than ... anything that looks too sort of technical. Because I think unless you've been part of preparing that data and have a real understanding of how it reads and what it should look like and all the rest of it, then you don't quite get the full picture. (Māori, DHB, KI 17)

An analyst routinely involved in presenting Māori data described some of the challenges it involved:

You need the right kind of skills. You need the right kind of questions and ... the biggest thing I found ... the data doesn't speak for itself. It never speaks for itself. You have to speak for it. You have to frame your ... question ... You have to ... put your graph up ... and you actually have to spend quite a lot of time saying what's my audience going to respond to? What's going to get them out of their seat to say 'actually, that's not okay. Actually, that's in my power to change'. (non-Māori, DHB, KI 10)

One informant argued in favour of a clearer direction from management about how those in governance roles should engage with data being presented:

We're really receiving poor reports from managers ... from a data perspective. They're very lengthy reports with a lack of clarity from the outset [around] why we are receiving the report and what management expected from governance ... we don't get the analysis behind the information. (Māori, MHSP, KI 9)

## Several identified the importance of Māori participating, at an early stage, in designing health services to achieve better outcomes for Māori.

Another informant described using ethnicity data as a lever for health service change. The informant described consciously presenting data to decision makers in ways that best position it to be used to support Māori health gain:

We strategically structure the information and how we can ... get the best gain out of the data; through reporting, through information sharing, through how we structure it. (non-Māori, MHSP, KI 2)

Several informants highlighted the need for data, including health targets, to reflect a strengths-based approach. One informant described this as focusing on what is working well and encompassing a positive view of being Māori:

I ... think I wanna be focused on growing us to be wonderful Māori people and those targets don't help that. And I think what helps that is strengthening people's inner being about their uniqueness and perfectness of being Māori. (Māori, DHB, CS 2)

Others were aware, however, that taking a strengths-based approach to data necessitates a balancing act. It requires data that continues to expose inequity in outcomes while at the same time

demanding a commitment to using data positively to support Māori aspiration.

### *Using data to improve equity*

Data was seen as a potential tool for leveraging health service change, provided there was a willingness among decision makers to apply an equity focus to interpretation. In relation to this, one informant favoured prioritising relationships between groups of decision makers:

We've had the whole discussion about 'the numbers aren't changing' ... but we wanted to have a different conversation which didn't necessarily mean looking just at the numbers. Because we know the story ... just getting more numbers wasn't going to help us shift ... which was why we moved to ... 'let's get ... the relationship working well so that we can then start to ... identify the priority areas and reconfirm those and then look at what's actually happening'. (Māori, MHSP KI 8)

Informants were asked to comment on the role of Māori as a Treaty partner in relation to data. Several identified the importance of Māori participating, at an early stage, in designing health services to achieve better outcomes for Māori. For example, one of these informants observed:

There's a core point somewhere in the journey where it might be useful if you had people sitting around the table, whether it's iwi reps or, you know ... before the decisions are made. Where you're analysing the data as opposed to decisions made and then you take it to iwi ... or whether you've got a collection of managers and people like ourselves who are able to see ... this is the data, these are the trends, but actually this is the way we think it might be best in our communities and in our context moving forward. So, it's about the interpretation of the data. (Māori, MHSP, KI 15,16)

Another informant promoted using data as a critical tool for advancing Māori health gain:

I'm not interested in the system getting defensive about, you know, 'has it performed for Māori'? Of course, it hasn't. It's pretty obvious when you look at any system measure that we've got in place at the moment that the system has failed its Māori population. So, let's not waste energy on trying to defend the fact that it's been ineffective. Let's just move straight from discovery into solutions. (Māori, DHB, KI 12)

The same informant shared his observations about the requirement for leadership from central government if data was going to effectively drive changes in equity:

[We are] working on this with the Ministry at the moment ... we've said to them that the one thing they can do to be champions for Māori health equity is just by default ... start reporting everything by ethnicity ... How hard is that? But not only that, they should be when you look at the legislation ... around reducing disparity for Māori. (Māori, DHB KI 12)

#### Discussion

The study results highlight that attitudes towards health data among participants range along a continuum from difficulty engaging with data, or scepticism about the potential of data to really effect changes in health service outcomes for Māori, to realising and appreciating the potential for data to be a catalyst for improvements to health inequity through more informed decision making. While a few Māori informants were clustered at the 'disengaged' or 'sceptical' end of the continuum, most were closer to the opposite end: they valued health data, saw the opportunities for change that data presented, yet were also mindful of the challenges it posed. Challenges include ensuring data is accessible and relevant to Māori, as well as strengthening the capacity and opportunities for Māori to authentically participate in decision making.

Qualitative and quantitative data is needed to inform decision making that draws on nuanced understandings of

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health issues. Decision makers want to be able to 'see themselves' and their whānau in data that ostensibly represents their situation. They identified a role for strengths-based perspectives on issues highlighted by data if data is to inform improved health outcomes for Māori rather than being used to blame or further stigmatise Māori (Curtis, 2016). Strengths-based perspectives place emphasis on Māori self-determination, appreciating that Māori communities are resourceful and resilient in the face of adversity as well as capable of designing responses and services that best address their needs.

If we were considering how this strengths-based approach might be implemented in the data and decision-making arena, we would suggest that Māori are supported and resourced to be involved in all phases of data gathering and analysis; that Māori-led explanations and options for achieving equity are considered when reviewing data, and specifically that issues are considered from a systems perspective whereby the health system is examined for

opportunities for change rather than placing emphasis on the 'problem' with the users of the system.

To engage community in decision making around health service design takes time, resources, a genuine relationship and being open to hearing alternative views. The results of our study indicate that the voice of whānau is predominantly filtered through MHSPs, and through Māori decision makers. Exploring options that enable whānau as consumers to engage more directly in decision making around health service design may lead to improved access and outcomes for Māori.

The study highlights a critical role for strengthened Māori data interpretation and related decision-making capacity, a need also identified by Te Mana Raraunga, the Māori Data Sovereignty Network (Kukutai, 2019), and apparent across fields ranging from iwi development (Gifford and Mikaere, 2019) through to lifecourse studies examining ways to prevent Māori ill-health (Theodore et al., 2019).

The passing of the New Zealand Health and Disability Act 2000, and the formation of DHBs, signalled enhanced Māori decision-making opportunities (Boulton et al., 2004). However, recent WAI 2575 findings (Waitangi Tribunal, 2019) indicate that the DHB model has not delivered on the Treaty partnership relationship. Māori relationship boards do not have the statutory recognition and status of the committees described in sections 34–6 of the act. The Tribunal report concludes that there is scant evidence of the Treaty principle of partnership in action.

Addressing the issues raised in our study as well as by the WAI 2575 report is urgent at a number of levels, nationally and locally. Strong leadership, both on the part of central government and locally by DHBs, is crucial if improvements in Māori health outcomes are to be achieved. At central government level, the health minister's letter of expectations (Clark, 2019)<sup>1</sup> and long-term strategic policy guidance in the form of documents such as the New Zealand Health Strategy (2016) and He Korowai Oranga (2014) provide unambiguous direction to the health sector as to the priorities for investment and focus. The minister's most recent letter of expectations (Clark, 2019) overtly

references the need for improved information to support efforts on the part of the sector to achieve equity. The focus on equity within a Treaty framework is critical, ensuring Māori are prioritised in any decision making to improve equity as of right as tangata whenua and as the Crown's Treaty partner, a commitment the Ministry of Health Output Plan (Ministry of Health, 2018b) confirms.

For DHBs to enact these high-level expectations, dedicated expertise, capacity and support to improve engagement with Māori in decision making is necessary. The level of expertise to, first, produce reliable, high-quality data, and then the ability to present data and reports in ways that better meet the needs of Māori is inconsistent across the DHB network. Smaller DHBs in particular struggle to attract and retain data analysts and those able to interpret

data for a Māori audience. Investment in data analysis capacity and the communication of that analysis would greatly enhance DHB efforts to make the most of the data that they collect. Finally, a key task confronting Māori decision makers is to embrace the power of data and take responsibility themselves for using the data, or challenging it if need be, to ensure improvements in health outcomes.

### Conclusion

Improvement is needed at all steps in the decision-making process to better facilitate utilising data to leverage change in Māori health outcomes. Data is critical to monitoring inequity, and has the potential to drive health service change, if the optimum configuration of data and decision making is in place. Data must meet the needs of Māori decision makers

as well as of other central government and health institution decision makers. Māori must be meaningfully included at all levels and stages of decision making. Effective partnerships are critical, not only to challenging the system but to developing viable solutions.

<sup>1</sup> The 2018 minister's letter of expectations stated that DHBs would be held accountable for achieving equity for Māori and for meeting Treaty of Waitangi obligations and commitments to increasing equity through, among other mechanisms, 'the use of smart data, analytics and rich insight' (Ministry of Health, 2018b, p.13).

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