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Disclaimer

Care has been taken in the quotes used in this report to accurately report what participants said. Our apologies if this is found not to be the case. Some editing of quotes has occurred to assist readability.

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### He Mihi

E ngā mana, e ngā reo,

E ngā karangatanga maha,

Tēnā koutou katoa,

He mihi maioha tēnei ki a koutou e awhi nei i tēnei kaupapa,

Nō reira, e rau rangatira mā,

Tēnā koutou, tēnā koutou katoa.

# Acknowledgements

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### Notes

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In early 2020, Aotearoa New Zealand (like many other nations) experienced the impacts of the global COVID-19 (novel coronavirus) pandemic. Respondent validation of the research findings took place during this time. Concerns were raised about the potential impact of COVID-19 on health inequities for Māori, and on the dissemination and knowledge translation of this research. Participants emphasised the importance of supporting opportunities for shared decision-making during the COVID-19 pandemic and beyond.

### **Executive Summary**

Although the health system in Aotearoa New Zealand acknowledges Te Tiriti o Waitangi principles of partnership, participation, and protection, and aspires to health equity, Māori (the Indigenous peoples) experience marked inequities in health outcomes, <sup>1-4</sup> mortality, <sup>5</sup> health care access, <sup>6</sup> <sup>7</sup> and satisfaction with health services. <sup>58</sup> Choosing Wisely is an international campaign that aims to reduce unnecessary tests/treatments and ensure high quality care in healthcare settings by promoting better shared decision-making between health professionals and consumers/patients. The idea is that sometimes doing less is better. The five principles of the campaign are that it must be: health professional led, consumer focused, multi-professional, evidence-based, and transparent. Choosing Wisely Aotearoa New Zealand was launched in 2016 by the Council of Medical Colleges, and has been implemented by many District Health Boards (DHBs) and medical colleges.

As Choosing Wisely is adopted, care must be taken to ensure that the 'do less' aim does not increase existing inequities for Māori. For example, Māori children and adults are more likely (than non-Māori) to experience unmet need for primary health care, including not being able to get an appointment at their usual medical centre within 24 hours, not being able to attend because of cost or lack of transport, or to miss out on prescription medication because of cost. Māori also tend to receive fewer tests and referrals. During consultations, Māori are less likely to get satisfactory answers when they do ask questions, less likely to have things explained to them well, and less likely to feel listened to by health professionals. Health campaigns, such as Choosing Wisely New Zealand, must be careful to not exacerbate these existing inequities.

Implementing healthcare decision-making in a culturally safe fashion has the potential to address inequities among Indigenous populations by facilitating participation in health care that better meets self-identified need. 9-13 The focus of the present research was whether or not Choosing Wisely Aotearoa New Zealand could be implemented in a way that serves the interests of Māori by promoting culturally safe shared decision-making with Māori consumers that maintains a focus on equity. The research aimed to develop an in-depth understanding of Māori health consumers and health providers/practitioners' perspectives on healthcare shared decision-making, and make recommendations for strategies to inform an equity focused Choosing Wisely campaign in Aotearoa New Zealand. It had three objectives:

- 1. To explore Māori health consumers' and Māori health providers/professionals' feelings and advice about the Choosing Wisely campaign.
- 2. To explore Māori health consumers' and Māori health providers/professionals' experiences of and recommendations for shared decision-making in healthcare settings.
- 3. To make recommendations for practical, cost-effective, and evaluable strategies (i.e., tools and/or resources and/or approaches) to improve shared decision-making with Māori in healthcare settings.

### Methods

This qualitative research drew on Kaupapa Māori (by Māori, for Māori) Research (KMR) methodologies. KMR centres the experiences and aspirations of Māori, and seeks to be transformative, by identifying structural inequities and working to address them. The research was developed and implemented with support and guidance by Māori experts - whānau (families), health providers, and academics. Key informants were also provided a summary of research findings and asked for their feedback before the report was finalised.

Fifteen key informants, eight Māori consumers of health care and seven Māori providers of health care, were interviewed between November 2019 and February 2020. Interviews were conducted in person, by telephone, or by Zoom (online video call), and were semi-structured.

The interviews involved discussion about the origin and principles of Choosing Wisely, and reviewing a consumer resource. Key informants were asked about their perspectives on the Choosing Wisely campaign, including its principles, aims, and potential value for Māori; and their experiences of and recommendations for shared decision-making in healthcare settings. Each interview took between 25-90 minutes and was audio-recorded and transcribed. The data were analysed thematically.

### **Findings**

This report presents the findings from the key informant interviews, organised into two sections: feedback on Choosing Wisely, and feedback on shared decision-making in healthcare settings. Following the findings and discussion/conclusion, recommendations for Choosing Wisely and shared decision-making in Aotearoa are given.

#### **Feedback on Choosing Wisely**

Key informant feedback about Choosing Wisely is grouped into three themes: governance and decision making, messaging, and resources/tools.

Feedback about Choosing Wisely was mixed. Concerns were raised, by health provider key informants in particular, about its governance and decision-making - that it has not engaged with Māori communities and Māori health professional groups, and that it lacks any reflection of mātauranga Māori (Māori knowledge systems) and tikanga Māori (Māori practices and customs). These are all important for not undermining the principles of Te Tiriti o Waitangi.

Key informants indicated that narrow campaign messages that focus on reducing tests/treatment and on Māori themselves questioning medical advice are problematic. Both groups did, however, see value in Choosing Wisely, especially if it promotes better communication between Māori consumers and their health provider/s. The caveat is that health providers must be delivering appropriate care and encouraging shared decision-making.

Choosing Wisely resources/tools were described by both groups as needing to be simple and realistic at a health literacy level, and both socially and culturally engaging for Māori. I.e., incorporating the target audience in their design.<sup>13</sup>

### Feedback on shared decision-making in healthcare settings

Drawing inspiration from Fiona Cram's report on improving Māori access to health care, <sup>18</sup> key informant talk about shared decision-making in healthcare settings is grouped into four health domain themes: consumer, provider, organisation, and health system – although they are all interconnected. Each domain has between one to four subthemes.

Inequities in access to health care for Māori consumers are well documented, <sup>1-8</sup> therefore, it was not surprising that key informants from both groups frequently discussed the lack of access to resources experienced by many Māori as a barrier to shared decision-making. Both groups stressed the importance of consumer trust, a sense of autonomy (knowing one's rights to question and be informed, to not feel coerced, and to expect to be treated as an equal), good relationships/rapport with health providers, and culturally appropriate tools/resources. <sup>10-13</sup> Advocates and support people, and collective decision-making strategies, such as whānau hui (gatherings), were promoted as supporting shared decision-making.

Provider clinical competence and efficacious communication – encouraging collaboration, consideration, discussion, and mutual understanding, 11 12 were described as critical for shared decision-making by key informants in both groups. Being thorough and proactive in sharing information, rather than waiting for questions, were viewed as good practice, as was health provider cultural safety - being non-judgemental, genuine, supportive, and understanding of context. This research indicates that, for Māori, culturally safe care involves health providers acknowledging the validity of te ao Māori (the Māori world), such as the importance of whanaungatanga (connecting/ relationships) and holistic models of health.

Organisational culture, in particular - the business model of primary care resulting in short appointment times, and workforce shortages disrupting continuity of care - were discussed as barriers to shared decision-making by both groups of key informants. Training programmes that teach skills to identify biases and build cultural empathy, 10-12 such as the Meihana model and hui models (e.g., the Hui Process), were suggested by health provider key informants as good for supporting the health workforce to be more culturally safe.

Both groups of key informants contributed feedback that relates to health system failures to fulfil Te Tiriti o Waitangi obligations. Health provider key informants in particular highlighted rampant health inequities for Māori and the lack of Māori input into issues that affect Māori, and promoted tino-rangatiratanga (self-determination/autonomy) of communities and whānau to determine their own health needs. Consumers were concerned with the lack of Māori in the health workforce. The findings suggest that to address systemic inequities in health requires a centring of Māori and Te Tiriti o Waitangi in the health sector. This would improve Māori access to appropriate care, and therefore, access to shared decision-making.

### Conclusion

The current research corroborates themes found in the extant literature on shared decisionmaking (and healthcare decision-making) with Indigenous peoples - that shared decision-making has the potential to address health inequities among Indigenous populations by facilitating participation in health care that better meets self-identified need. 9-12 However, there is work to be done to ensure that Māori consumers know they have the right to ask questions, and that health providers are open to and encouraging of two-way dialogue. The research highlights several key elements required for optimal healthcare shared decision-making with Māori. First, equity must be prioritised. This includes committing to eliminating inequities, as well as privileging the mātauranga (knowledge) and tikanga (practices, customs) Māori that are part of a holistic understanding of Māori health and wellbeing. Second, the importance of developing whanaungatanga - connections and relationships between Māori consumers and health services cannot be stressed enough. Trust and cultural safety were deemed vital to enabling the right kind of environment for shared decision-making to occur. Finally, given the significance of autonomy for shared decision-making, the tino-rangatiratanga of Māori consumers and communities to actively participate in health care and healthcare decision-making must be supported. Any national health campaign, such as Choosing Wisely, would benefit from centring Te Tiriti o Waitangi and committing to equity by prioritising the needs and aspirations of Māori.

### **Recommendations for Choosing Wisely and shared decision-making in Aotearoa**

Recommendations for the Choosing Wisely Aotearoa New Zealand campaign and resources, and for improved shared decision-making for health providers and consumers, which have been drawn from the data, are summarised here. They are listed in full on pages 34-35.

### **Choosing Wisely Aotearoa New Zealand campaign**

- 1. Uphold Te Tiriti o Waitangi and centre Māori in governance and decision-making.
- 2. Acknowledge and incorporate mātauranga Māori (Māori knowledge systems) and tikanga Māori (Māori practices and customs) in Choosing Wisely work. For example, Māori health models.
- 3. Along with the main message of the campaign being 'Choosing Wisely', consider including other messages that encourage health providers to consider the best options for consumers and to instigate shared decision-making, such as, 'Advise Wisely'.
- 4. Utilise local evidence to support the campaign.
- 5. Promote cultural safety, patient-centred care, quality improvement, and equity based training.
- 6. Undertake work to ensure that consumers know that they have the right to ask questions. Advocates, such as whānau members, friends, community health workers, and navigators, can play an important role in supporting shared decision-making in healthcare settings.

### **Choosing Wisely Aotearoa New Zealand resources**

- Work with Māori to design resources/tools that are engaging and relatable for Māori. Use realistic, plain, simple, relatable messaging. Consider different levels. Use visual aids/graphics.
- 2. Develop resources/tools to encourage health providers to communicate efficaciously.
- 3. Create resources/tools for advocates, to support/promote shared decision-making.
- 4. Support the development of decision-making tools for specific health issues.
- 5. Advertise and supply resources/tools and key messages among networks and within health settings so that they become routine. Consider media/online tools.
- 6. Seek user feedback (from providers and consumers) about resources/tools through networks, such as Te Ohu Rata o Aotearoa, and health services (e.g., through DHBs and primary care).

# Health providers and consumers Health providers

# 1. Avoid assumptions about consumers, instead talk through issues/concerns.

- 2. Build relationships with consumers, develop trust.
- Instigate shared decision-making by using tools to guide consumers through different options. Do not wait for consumers to ask.
- 4. Be open to questions and willing to engage.
- 5. Check understanding in an affirming way (e.g., the teach-back method).
- 6. Utilise visual aids/tools to guide discussions.
- Connect consumers to relevant information and services/support.
- 8. Encourage the role of advocates and support people in decision-making.

#### **Consumers**

- Expect respect. If you are not happy with the care you receive, talk to someone about it.
- 2. Ask questions. It is your right to have things explained to you in a way you understand.
- 3. Check if there are resources (e.g., brochures or online information) that you can see.
- 4. Talk to whānau and friends about any health concerns or worries.
- 5. Take support (e.g., whānau, friends, or health workers/navigators).

### Background

### **Health Equity**

Te Tiriti o Waitangi (Te Tiriti) sets the expectations for the relationship between Te Tiriti partners, in particular Crown or Government entities and Māori (Indigenous peoples). As acknowledged by the Ministry of Health, the three principles of Te Tiriti are: partnership, participation, and protection. Partnership refers to the responsibility to engage in meaningful collaboration with Māori Iwi (tribes), hapū (kinship groups), and whānau (families) to develop health strategies. Participation requires Māori to be involved in all levels of health and disability services. Protection refers to the obligation of Crown and Government to work towards equity in health outcomes for Māori, and to protect Māori assets, values, and practices.<sup>19</sup>

Despite these principles, Māori continue to experience marked inequities in health outcomes,<sup>1-5</sup> <sup>13</sup> access,<sup>6</sup> <sup>7</sup> and satisfaction.<sup>5</sup> <sup>8</sup> Māori children and adults are more likely (than non-Māori) to experience unmet need for primary care, including not being able to get an appointment at their usual medical centre within 24 hours, not being able to attend due to cost or transport issues, and to miss out on medication because of cost. <sup>7</sup> Māori receive fewer tests and referrals; <sup>6</sup> are less likely to get satisfactory explanations or answers to questions, or feel listened to by health professionals; <sup>8</sup> and are more likely to experience racism/discrimination. <sup>20</sup> These inequities are well documented, uncontested, and persistent. <sup>21</sup> And are also reflected in the lack of equitable Māori representation in the health and disability sector workforce. For example, in mid-2019, Māori made up 3.4 percent of doctors, and between 4.8-13.9 percent of District Health Board employees around the country. <sup>22</sup>

The recent Waitangi Tribunal Report WAI 2575 recommended the expansion of Te Tiriti principles to include the *Principle of Equity* (the right to expect equitable outcomes) and the *Principle of Options* (the right to expect good service at mainstream health outlets as well as access to Kaupapa Māori (by Māori, for Māori) services). This was based upon the Crown systematically defaulting to 'Participation' and under-mining the effectiveness of 'Partnership'.<sup>21</sup> Continued work is required to address these issues and realise the intrinsic principles of Te Tiriti.

Equity has become a top-level strategic priority of agencies such as the Ministry of Health, <sup>23</sup> <sup>24</sup> the Health Quality and Safety Commission (HQSC), <sup>5</sup> <sup>25</sup> and PHARMAC <sup>26</sup> over the last five years. While equality promotes sameness, the Ministry of Health definition of equity recognises that, "people have differences in health that are not only avoidable but unfair and unjust... [and] different people with different levels of advantage require different approaches and resources to get equitable health outcomes" (p 7). <sup>24</sup> The Ministry of Health has, acknowledging the shortcomings of our health system, previously said that it "can struggle to give all New Zealanders equitable access to health services: some population groups continue to benefit less from the health system than the population as a whole" (p 1). <sup>27</sup> The 2016 New Zealand Health Strategy, however, was criticised strongly for not addressing obligations to Te Tiriti, or the existence of institutional racism explicitly. <sup>28</sup>

In 2019 the Medical Council of New Zealand released He Ara Hauora Māori – a Pathway to Māori Health Equity.<sup>29</sup> In the same year, they released a statement on cultural safety, explaining that medical practitioners are now expected to be culturally safe, not just culturally competent.<sup>30</sup> Cultural competence is defined as when a doctor or health professional has the right attitude, skills, and knowledge to work with people of different backgrounds.<sup>30</sup> However, cultural safety, as defined by nursing scholar Irihapeti Ramsden and now taken on by the Medical Council, is more about examining biases and assumptions, respecting and recognising difference, and is centred on the experience of consumers or patients, i.e., they are to decide whether they feel safe and whether trust has been established. This puts the obligation on the health provider and requires constant reflexivity<sup>31</sup> and an exercise of critical consciousness around their practice.

### **Choosing Wisely**

Choosing Wisely is an international campaign, launched by the American Board of Internal Medicine and Consumer Reports in 2012, in the United States of America (USA). It aims to reduce unnecessary tests/treatments and ensure high quality care in healthcare settings. The idea is that sometimes doing less is better. The five core principles of Choosing Wisely are that it must be health professional led, consumer focused, multi-professional, evidence-based, and transparent.<sup>32</sup>

The mission is to promote conversations that enable shared decision-making.<sup>33</sup> It is assumed that if consumers make well-informed decisions about treatment options together with their health professional (shared decision-making), unnecessary treatments/tests can be avoided. Recommendations to reduce unnecessary treatments/tests or low value care are aimed at both health professionals and consumers.

Choosing Wisely Aotearoa New Zealand was launched in 2016 by the Council of Medical Colleges, and has been implemented by District Health Boards (DHBs) and medical colleges. For example, the streamlining of physiotherapy and vascular services in Hutt DHB, 34 35 recommendations from the New Zealand Microbiology Network around unnecessary urinalysis, 36 as well as general resources for consumers, such as, 'Four Questions For Patients To Ask':37

- 1. Do I really need this test or procedure?
- 2. What are the risks?
- 3. Are there simpler, safer options?
- 4. What happens if I don't do anything?

The 'Four Questions' above are intended to aid shared decision-making for consumers in Aotearoa. However, health campaigns, such as Choosing Wisely Aotearoa New Zealand, need to be cognisant of health contexts in Aotearoa, in order to not exacerbate existing inequities.

Although most evidence indicates that Māori are underserved by the health system, research from the USA shows that Black and Hispanic consumers, who routinely do not receive enough care also

receive overtreatment with unnecessary care.<sup>38</sup> Māori may also experience a double burden of under-treatment/overtreatment.<sup>39</sup> The Health Quality and Safety Commission (HQSC) highlights potential areas of overtreatment for Māori, although questions remain over the causes of the higher rates of treatment and whether they do indicate overtreatment or higher need.\* The notion of appropriate care is complex, requires a nuanced approach, and must prioritize equity.

### **Shared Decision-Making**

The concept of shared decision-making has been used in the field of medicine since the 1970s, with early contributors such as Veatch discussing the roles of patient-provider relationships in informing health care decisions. <sup>44</sup> As a process that aims to improve communication and reduce conflict and unnecessary treatment, shared decision-making is now seen as a key part of patient-centred care. <sup>45-50</sup> It involves health professionals/providers and patients/consumers sharing information, exploring options, and agreeing on an appropriate treatment or plan. <sup>48 51-53</sup>

Studies have indicated shared decision-making can increase patient satisfaction as they feel more informed and that their values are incorporated. The emphasis is on ensuring patients understand that there is choice and that the health provider is there to support decision-making. In this way it promotes consumer self-determination or empowerment. However, it relies on a certain amount of health literacy and good relationships - involving active participation, openness, and respect. This puts underserved groups at increased risk of not experiencing shared decision-making, when health literacy is considered low and health services lack cultural safety. As the safety of the safety

The Connecticut Choosing Wisely Collaboration explored Choosing Wisely as an equity tool for promoting health and shared decision-making with underserved consumers. They held four consumer focus groups to ask about health care experiences, trust, and provider relationships; and to evaluate a patient resource (similar to the 'Four Questions For Patients To Ask'). They then developed a pilot with resources including scripts to help train health providers to encourage shared decision-making. They found the resources helpful but suggested staff training must be ongoing, with the aim of creating a question friendly environment. They implore Choosing Wisely campaigns to work on cultural appropriateness, including language, literacy, and consumer empowerment.<sup>61</sup>

Studies evaluating shared decision-making with Indigenous peoples are limited. <sup>9 62</sup> However, recent publications from Aotearoa and comparatively high-income settler-colonial nation states, which explore shared decision-making or healthcare decision-making with Indigenous peoples, highlight several key themes.

Māori children under 15 years have higher rates of antibiotic use than New Zealand Europeans/NZE, and although this may be explained by higher infection rates, there is no data to explain whether the use is appropriate. Rates of antibiotic dispensing within 30 days of major or acute surgery in a public hospital are also significantly higher for Māori and the reason are unknown. 40 Māori with diabetes, particularly younger people, have higher rates of angiotensin-converting enzyme inhibitor (ACEI) and angiotensin II receptor blocker (ARB) medicine use than NZE and the HQSC offers that may be because of higher rates of end-stage renal disease. 41 Māori also experience higher rates of gout than NZE but are less likely to regularly receive urate-lowering therapy and more likely to receive non-steroidal anti-inflammatory drugs (NSAID) associated with kidney damage. As kidney disease is more common for Māori, the HQSC calls for more research on the use of these drugs. 42 In polypharmacy, the 'triple whammy' is a term used to describe a combination of ACEI, ARB and NSAID use — a combination that indicates an increased risk of acute kidney failure. Māori under 75 years have significantly higher rates of the triple whammy. The HQSC recommends this combination be avoided. 43

Systemic issues impact shared decision-making for Indigenous peoples. Health models that do not reflect the values and knowledge systems of Indigenous peoples or take strengths-based approaches to care undermine and negatively impact Indigenous health and wellbeing. 62-64 Health services need to avoid the deficit modelling that blames Indigenous consumers for negative health outcomes, and understand how the dominance of biomedical language/discourses marginalise Indigenous knowledge systems and holistic understandings of health and wellbeing. The biomedical model lacks understanding and acknowledgment of diverse cultures and differences, and thus inhibits effective information exchange and mutual understanding. Western ideas of individual decision-making and autonomy also conflict with Indigenous views of collective decision-making, 12 67 which arguably also involve a large degree of autonomy.

When health providers do not acknowledge Indigenous worldviews and attempt to build trust, they will likely fail. 11 68 Health providers' lack of cultural awareness, differing medical beliefs/values, lack of resources/training, and time constraints, as well as linguistic communication and cost barriers inhibit shared decision-making with Indigenous peoples. 65 69 70 For example, health providers may rely on stereotypes or biases about Indigenous peoples unless trained otherwise, preventing shared understanding and increasing the likelihood of poor outcomes. Whereas, cultural safety training and educational interventions for health providers can increase effective care for Indigenous consumers, by teaching skills to identify and address biases, and build cultural empathy. 10-12 71 72

Culturally safe strategies, tools, and practices are crucial for shared decision-making, and can mitigate the negative impacts of historical and systemic inequities, and discrimination. They are culturally adapted, and support autonomy, informed consent, and consumer empowerment by acknowledging Indigenous perspectives, values, preferences, and self-identified needs. 9-13 62-69 72-75 They should be developed in partnership with Indigenous communities, 62 72 75 support Indigenous workforces, 10 11 and promote health equity. 63 64 69 71-74 For example, community-governed health services strengthen capacity for shared decision-making. 10 69 72 Additionally, family-centred health models that recognise the importance of collective decision-making for Indigenous peoples, and that accommodate and support family involvement, facilitate shared decision-making. 12 67 69 72 76

Efficacious communication (that which achieves what is intended) is important for shared decision-making. Shared decision-making requires a supportive and inclusive environment, a relationship-centred two-way information exchange, where power is more equalised and health literacy is supported. This involves high-quality information and education, openness, collaboration, consideration, discussion, mutual agreement, and importantly, empathetic and compassionate care built on reciprocity and trust. 9-13 45 53 62-68 72-75 Decision-making tools, aids, and decision-coaching enhance engagement in the decision-making process. 13 62 72 75 However, they need to be consistent with Indigenous communication precepts, such as, accounting for avoidance of hostile confrontations and respect for authority, and value for warm interactions and family support and inclusion. 11 12 72 They should be affirming of cultural identity, incorporating language, culture, spiritual beliefs and practices, and respect for Indigenous health and healing approaches. 10-12 62 63 65-73 Relationship building, utilising visual aids with plain engaging language/design, using teach-back to check understanding, and creating an empowering environment are recommended. 13

Shared decision-making has the potential to improve quality of care, and reduce health inequities for Indigenous peoples, by facilitating engagement in health care that better meets self/community-identified need. In Aotearoa New Zealand, where Māori have expressed the need for culturally appropriate and congruent medication information, have expressed the need support tino-rangatiratanga (self-determination/autonomy) of health and wellbeing. Listening to the voices of Māori consumers, learning from their experiences, is important for identifying the variables that impact health inequities so that they can be addressed. Achieving health equity for Māori is important, as if we get it right for those currently missing out, the whole nation will benefit.

### **Choosing Wisely Means Choosing Equity**

The focus of the research was whether or not Choosing Wisely could be implemented in a way that serves the interests of Māori by promoting culturally safe shared decision-making and equity. It aimed to develop an in-depth understanding of Māori health consumers and health providers' perspectives on healthcare shared decision-making, and make recommendations for strategies to inform an equity focused Choosing Wisely campaign. It had three objectives:

- 1. To explore Māori health consumers' and Māori health providers/professionals' feelings and advice about the Choosing Wisely campaign.
- 2. To explore Māori health consumers' and Māori health providers/professionals' experiences of and recommendations for shared decision-making in healthcare settings.
- 3. To make recommendations for practical, cost-effective, and evaluable strategies (i.e., tools and/or resources and/or approaches) to improve shared decision-making with Māori in healthcare settings.

### **Methods**

### A Kaupapa Māori Research Methodology

This qualitative research drew on Kaupapa Māori (by Māori, for Māori) Research (KMR) methodologies. KMR centres the experiences and aspirations of Māori, and seeks to be transformative, by identifying structural inequities and working to address them. 14-17

An initial focus group with six Māori medical students explored perceptions of the Choosing Wisely campaign and gave the researchers a starting point for the research design. To hold the research to account, a Reference Group of Māori medical/public health professionals and Māori consumers of health guided the design, implementation, and interpretation of the research. Key informants were also provided a summary of research findings and asked for their feedback before the report was finalised.

### **Key Informant Interviews**

Fifteen key informants, eight Māori consumers of health care and seven Māori providers of health care (Figure 1), were interviewed between November 2019 and February 2020. Interviews were conducted in person, by telephone, or by Zoom (online video call), and were semi-structured.

Key informants were asked about their perspectives on the Choosing Wisely campaign, including its principles, aims, and potential value for Māori; and their experiences of and recommendations for shared decision-making in healthcare settings. Each interview took between 25-90 minutes and was audio-recorded.

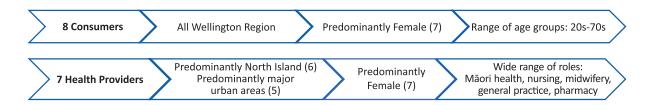


Figure 1: Overview of participants

### **Analysis**

Transcripts of the key informant interviews (the data) were analysed thematically.<sup>77</sup> This entailed reading, rereading, and coding the transcripts for an emergent conceptual framework, themes, and subthemes. The feedback from the key informants was then arranged to group together views that were shared or interrelated.

In writing the report we have decided to use the term health 'provider' rather than 'professional', as it is inclusive of non-medical health workers, i.e., Māori health provider employees like community health workers and 'navigators'. To ensure confidentiality when using quotes, key informants are identified as either 'C' (for consumer) or 'HP' (for health provider), along with an identifying number, e.g., C1.

### **Findings**

This section presents the findings from the key informant interviews, organised into two sections: feedback on Choosing Wisely, and feedback on shared decision-making in healthcare settings.

### **Feedback on Choosing Wisely**

The interviews involved discussion about the origin and principles of the Choosing Wisely campaign, and reviewing one of the Choosing Wisely Aotearoa New Zealand resource sheets - 'Communicating with your health professional'<sup>37</sup> (Figure 2).



#### Communicating with your health professional

#### Before your appointment

Make a longer appointment if the problem you want to discuss is complex, or you need to discuss several issues.

Prepare a summary of your health problems, prioritise the issues you want to discuss, and make a list of questions as you think of them.

Let your health professional know if you need an interpreter or other assistance with communicating.

#### **During your appointment**

You should expect to be listened to – and be given clear and adequate explanations of your condition, any recommended tests, treatment options and the expected results.

When you describe your problems, be as accurate, complete and honest as possible.

If your health professional recommends a test, treatment or procedure and you are not clear of its purpose or benefits, you may want to discuss this.

- Asking the following questions around potential tests or procedures
- Do I really need to have this test, treatment or procedure?
- What are the risks?
- Are there simpler safer options?
- What happens if I do nothing?

If you don't understand anything, tell your health professional - and ask them to repeat or clarify the information until you do understand.

If you don't feel confident about your appointment, take a family/whānau member or friend with you. Take notes if you think you may have trouble remembering important details (or ask your health professional or support person to take notes for you).

If you want to know more, ask your health professional for some written information, or suggestions of where you might find it.

#### After your appointment

You may want to make a follow-up appointment to ask further questions, discuss continuing issues or talk to your health professional about your decisions after you've had time to consider the options.

If you want to discuss the issues with another health professional, don't hesitate to get another opinion.

Figure 2: Communicating with your health professional (consumer resource)

Key informant feedback about Choosing Wisely is grouped into three themes: governance and decision making, messaging, and resources/tools (Figure 3). Themes are described and illustrated with selected quotes.



Figure 3: Feedback on Choosing Wisely (themes)

### **Governance and decision-making**

Health provider key informants in particular questioned the appropriateness of Choosing Wisely to Aotearoa, given that it is an international campaign originating in the United States of America. Concerns were raised about governance and decision-making - that Choosing Wisely has not involved appropriate consultation with Māori professional groups, and that it excludes Māori community-based ('non-professional') organisations that support whānau (family) health and wellbeing. For example, a health provider talked about the important role that Whānau Ora navigators play in supporting whānau to make healthcare decisions —

Who's part of those decision-making processes? Is there good Māori representation?... Terms like health professional, what does that mean? We have Whānau Ora navigators, who our whānau trust in giving them information... it's not always a health professional that will be the person the whānau want to share their journey with. (HP1)

They went on to talk about the need for community-based health strategies, emphasising that one-size-fits-all approaches often do not work. Rather, different groups and communities have different needs and aspirations. This view was shared by several other health providers.

It was suggested the Choosing Wisely campaign incorporate a Māori lens, acknowledging the importance of mātauranga Māori (Māori knowledge systems) and tikanga Māori (Māori practices and customs) to Māori health and wellbeing. These include: holistic models of hauora and oranga (health/wellbeing), rongoā (medicines), karakia (prayers/ incantations), and community input/ governance. One health provider spoke of the importance of centring Māori knowledge systems and practices, rather than trying to adapt non-Māori models -

Choosing Wisely hasn't taken into consideration our mātauranga, our own hauora practices, and oranga practices, our rongoā, our karakia... treatment that consists of te ao Māori... These campaigns go, 'Oh well that's great we'll put that in New Zealand and that'll work,' and they haven't addressed the existing issue. If those campaigns came from us in an Indigenous way we wouldn't have to tweak around the edges, to try and make it fit. (HP3)

It was highlighted that mātauranga Māori and tikanga Māori need to be viewed as legitimate (or at least accepted) by health practitioners, the medical discipline, and campaigns such as Choosing Wisely. For example, a health provider articulated this as not being 'disparaging' -

Some whānau want to use rongoā. And usually that's not considered... And sometimes I think when they come to the health system... they don't feel comfortable. Because the whole emphasis is on medical procedures... All they [health providers] need to do is not be disparaging about it, it is understanding people's contexts and being accepting. (HP7)

While most consumer participants did not query the governance or decision-making of Choosing Wisely, one did talk about how the campaign seemed to lack a Te Tiriti based 'equitable approach', which they described as being typical of health campaigns in Aotearoa.

### Messaging

Key informants were critical of the campaign messaging that focuses on reducing tests/treatments. The focus on reducing tests and treatments, and therefore costs to the health system, for Māori, who tend to be under-served, caused concern for key informants from both groups. One health provider described this as inducing 'alarm bells', while a consumer described it as raising a red flag -

When you first started talking about cutting costs and things that was an immediate red flag to me... would that compromise the kind of advice that they would get if they're not getting all those tests done in some situations? (C8)

Health provider key informants emphasised that what is needed is to have Choosing Wisely framed as being about more evidence based, equitable care, rather than cut-backs. For example, a health provider stated -

I think that the explicit focus on overtreatment and over utilization of resources can over shadow the other important aspects that make up good quality care for any person.... So how about shifting it towards being about the right thing, at the right time, and the right way, for the right person? (HP5)

Several health providers talked about current inequities in care for Māori and the fear that a focus on reducing over-treatment will see Māori miss out more. It was emphasised that health providers need to have the appropriate communication skills and respect to engage with Māori. One health provider talked about this as a need to change the focus from whānau to providers -

I don't think this is about our whānau asking those questions, I think that it's about the medical staff having the appropriate people skills.... the communication tools and respect needed to engage with Māori. (HP3)

The campaign messaging about 'Choosing Wisely' was also questioned by both key informant groups. For some Māori it can be hard enough to even access services, without then being

expected to challenge the provider. Key informants from both groups talked about the fear, dislike, and whakamā (reticence) associated with attending health services and communicating with health providers. For example, a consumer talked about some Māori lacking confidence to ask questions —

I think some Māori would be a bit reticent if that's the word, to ask these questions... Some might be shy, whakamā... maybe they just don't feel confident and don't want to appear to be ignorant or not confident. (C4)

It was suggested that while the campaign promotes consumer autonomy and decision-making, there needs to be more emphasis on the role of health providers in providing appropriate care and creating environments that are welcoming of discussions about treatment options for Māori. A health provider suggested more onus should be put on the provider –

Even the name Choose Wisely that puts so much onus back on whānau. Why should they Choose Wisely? Why shouldn't it be that they're given the best possible pathway? I think it should be Advising Wisely, and it should be communicating with your whānau, not communicating with your health professional. We need to put the onus back on the health professionals to ensure that they are providing a quality service for Māori. (HP1)

Another health provider suggested the message for health providers to 'Act Wisely'. This sentiment was shared by many of the consumers and health providers. For example, when discussing the notion of 'Choosing Wisely', a consumer suggested that health providers should be responsible for instigating discussions and providing good advice -

I hate going to the doctors. I would never ask any of those other things because I would just assume that the doctor is right... I don't think the onus should be on the patient to ask all these things, I think the doctor should definitely be telling you all these things. (C1)

As shown above, a common assumption discussed by key informants, is that Māori consumers believe their health provider is the expert and therefore will be making the best recommendation for them. Therefore, to question them seems unnecessary, or even disrespectful.

Questioning the health provider was posed as especially problematic (by both groups of key informants) for Māori who frequently experience health provider bias (some called it implicit or unconscious), and are labelled tricky, resistant, non-compliant, or aggressive if they ask questions or challenge advice. For example, one health provider talked about the assumptions made about Māori and medicine use, and how this could result in practitioners being dismissive of open dialogue -

If there's the assumption that [Māori] can't or won't engage with discussion around better use of medicines, or they're tricky... if you've got this practitioners' implicit bias that Māori are less likely to want intervention, are less likely to want to access care, then I can see the practitioner saying, 'Oh well, that's fine, if you don't want to, that's fine.' (HP6)

Another expressed similar concerns that health providers have the power to react to questions like 'Do I really need to have this test?' with a discriminatory attitude, effectively 'silencing' consumers by ending the conversation. A consumer talked about being made to feel bad for offending the 'white privilege' of health providers by correcting them on the pronunciation of their Māori name. Concerns were raised that the focus on consumers questioning more could further negatively impact health interactions for Māori unless health providers create a question friendly environment.

Despite concerns about messaging, both groups of key informants saw potential value in the campaign if it encourages open communication with health providers and promotes consumers' rights to ask questions. A consumer talked about this as promoting autonomy -

I think it is something that is required for Māori to bring them in to a partnership at the decision-making table. Rather than being told what their treatment is, what's going to happen, and just sort of not having any autonomy in that process. Allowing them, encouraging, and informing them to be part of it can only be a good thing. (C2)

Both groups of key informants generally agreed with the five principles of the campaign (being health professional led, consumer focused, multi-professional, evidence-based, and transparent), as this seems to put the onus on health professionals. However, some health providers stressed that it needs to be more about partnership, or tailored to individual consumer preferences.

### **Resources/tools**

When key informants were shown the resource (Figure 4), it elicited a lot of discussion about the barriers that exist for whānau in order to access care, and the aspects of the resource that were deemed to need more consideration. Key informants from both groups talked about some of the language being too complex, confusing, not relatable, or negative. A consumer described the resource as being too wordy -

Sometimes words just straight like this it's harder to understand... Sometimes if I just read these words I need more to understand and relate, to get a better picture... if I were to pick this up it would just be hard for me to be interested in reading it... You gotta make sure you can relate to it, be informative. (C7)

The resource also asks consumers to be honest about their health issues, which was perceived by some key informants as insinuating that the consumer would be dishonest. For example, a health provider talked about the implicit judgement in the suggestion —

I don't like it when they tell people to be honest because who are they to say that they're dishonest. It's not a good term to use, and often the only time that whānau aren't upfront is because they're in an environment where they feel that they can't be up front in, because lots of judgement... first of all for their ethnicity and second of all, like, 'You're fat...' (HP2)

Some of the other resource suggestions were deemed unrealistic. For example, asking consumers to make a longer appointment if their health issues are complex is unfeasible for many due to cost, and it assumes that consumers will know if their health issue is complex, which is not always the case. The suggestion that consumers prepare a list of issues to talk about was viewed as potentially unrealistic by some key informants, but was proposed by others as a good idea to promote.

As well as suggestions for improving the resource (Figure 5), both groups of key informants also gave positive feedback about it, in particular how the resource could be used as a tool for preparing for appointments and asking questions. One consumer said that they thought the resource is 'awesome' because they had never thought about asking such questions before –

I feel like it is your patient right to ask all these questions and until today I was never really aware of them if I think about it... I'd actually love to be asked or offered these sort of things... these are really good questions. (C5)

A health provider talked about the benefits of reinforcing expectations –

I think it's a good idea for people to come in with a list of questions... because often you forget what your question is... I think it's really good to reinforce to people that they should expect to be listened to and be given good information... I personally think they're good questions. (HP4)

It was emphasised that health providers should use the resource as a tool to instigate discussions around treatment options, and be welcoming of questions and consumer perspectives. Key informants' talk about the resource suggests that it has beneficial aspects, but could do with fine-tuning to be more consumer friendly.

## Feedback on shared decision-making in healthcare settings

Drawing inspiration from Fiona Cram's report on improving Māori access to health care, <sup>18</sup> key informant talk about shared decision-making in healthcare settings is grouped into four health domain themes: consumer, provider, organisation and health system – although they are all interconnected. Each domain includes 1-4 subthemes (Figure 4) that are described and illustrated with selected quotes.

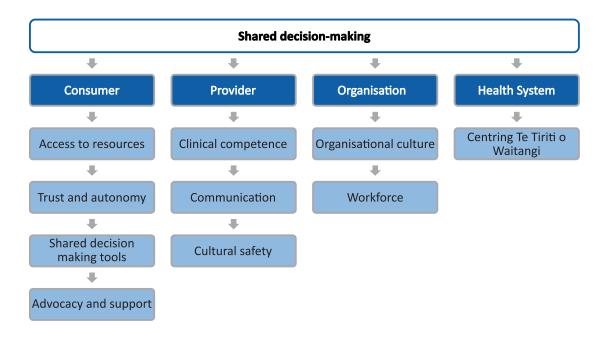


Figure 4: Feedback on shared decision-making (domain themes and subthemes)

#### Consumer

#### Access to resources

A barrier to shared decision-making that was frequently discussed is the lack of access to resources experienced by many Māori. This includes the cost of attending health services, availability of transport and childcare, and the impact of trauma and life stresses that left unaddressed may inhibit proactive health seeking behaviour. One health provider talked about this as 'emotional overload' –

Because of the emotional overload in people's lives due to housing problems, stress, domestic violence, past history of trauma, it sounds terrible but this is a reality.... prioritizing health issues, it's very difficult. (HP5)

While a consumer noted -

Some Māori just can't even afford to go to the doctor in the first place. (C1)

These issues can be compounded when health services are not organised in a way that support whānau. For example, when appointments are booked at bad times or tricky locations, and no support is offered —

There's the cost as well of having to travel... And that's happening quite a bit now with some of our whānau, they have to go all the way out there for some of their appointments. Nobody ever asks them if they can get out there, or if it's appropriate for them to get out there. (HP2)

This was talked about as frustrating for consumers and those who support them, such as Whānau Ora navigators, especially when it comes to chronic conditions or illnesses that require frequent health appointments in different locations.

Both groups of key informants discussed the benefits of free or subsidised health care and health insurance for improving access to health services, and in doing so, providing the opportunity for shared decision-making to take place. These included, free/low cost health services, such as university-based student health services, pharmacies offering free prescriptions, and marae (tribal/pan-tribal Māori community centres) or community-based care. A health provider gave an example of specialists providing care as a koha (gift) in a community setting —

They are absolutely valuable, and it's all koha, they come because they see a huge gap for Māori... They provide the clinics for us on a monthly basis... And of course, it's free. Whānau who have been sitting on waiting lists for months have come into the clinic and gone straight through to have procedures... because suddenly the pathway has opened up more. (HP2)

This service was described as being of value because it is free for whānau, because the specialists seem to really care and look after the whānau medically, and because it is provided on a marae, where whānau may feel more comfortable and supported culturally.

Some consumer key informants talked about the advantages of being able to access Iwi (tribe) health services and/or Iwi health insurance. For example, one consumer talked about their Iwi reimbursing their medical care —

You can go to any health provider... take a photo of the receipt and they'll pay for it. I've been going to the [after hours]... They're so expensive, I didn't even realise they're like one of the more expensive ones, but [it's] paid for anyway so this it's fine... Free health care for everyone I think would solve so many problems. (C1)

Other health insurance was talked about as well, although the cost barrier was acknowledged. Key informants suggested that when health care is too costly it places a burden on individuals, who may avoid care out of necessity, and on whānau, who may take on costs to look after their loved ones.

#### Trust and autonomy

Key informants talked about how, for shared decision-making between health providers and consumers to happen, there needs to be a connection there, some kind of positive communication – in short - trust. For consumers who find it difficult enough to even access health services (due to cost or other access issues), when that communication is negative or disparaging, this can start a snowball effect of disengagement, distrust, and even fear.

Autonomy was also frequently talked about as an important facilitator of shared decision-making by both groups of key informants. Talk about autonomy included the importance of knowing

one's rights to be able to question, to not feel coerced, to expect to be informed, to have clear explanations, and to expect to be treated as an equal.

Descriptions of fearing or distrusting health services included: hating going, being scared of/daunted, being whakamā (reticent), feeling the opposite of respected, feeling powerless, and being dissatisfied with services, time given, or explanations. For example, a consumer talked about how some Māori are "whakamā to ask questions or to even open up and communicate" (C5) in health settings, as they are worried about coming across as not knowledgeable.

These feelings were often described as preventing shared decision-making for two reasons. First, they create a level of anxiety that may discourage consumers from attending health services to begin with. Secondly, they are likely to inhibit the open communication that is necessary for healthcare shared decision-making to take place. It was emphasised that it is the responsibility of health providers to ensure that whānau are supported to understand and make positive health decisions, and promote health literacy in strengths-based ways. One health provider talked about this as giving whānau the right 'tools' for success —

From the patient's perspective, from the whānau perspective, they've always been taught that they're passive. And then they're encouraged to be another way which is great, to take control. But you have to give them some tools so you don't set them up to fail. (HP7)

Another health provider key informant emphasised the importance of health providers taking responsibility for the communication of health information, rather than defaulting to blaming consumers for a lack of health literacy. They talked about health literacy being closely tied up in the trust relationship and how well health providers listen and understand consumers' talk and feelings.

Autonomy was frequently, as we have noted, talked about as the right to question, to be informed, to have clear explanations, to not feel coerced, and to expect to be treated as an equal. The importance of being given options, space to think about them, and time to ask questions was emphasised. Some consumer key informants talked about age playing a role in feeling autonomous and confident in their health interactions. They talked about acutely feeling the power imbalance between health providers and themselves when they were younger. One consumer described taking 10 years to realise they have the right to question their care —

I'm assuming that everyone wants to have authority and autonomy over their health, their life... So I'm a total fan of shared decision-making... There should be ongoing correspondence and check-ins... that's the kind of communication you need when the power dynamics aren't even... It's taken me 10 years to work out how to speak to medical people... to figure out what I'm entitled to, how to ask for information. So that's 10 years of feeling like crap. (C8)

Similar to the need for autonomy, trust was discussed as a key facilitator of shared decision-making. Key informants talked about the benefits of consumers feeling comfortable and unpressured during consultations, and being able to take time to develop relationships with health

providers. This was frequently referred to as rapport, which was deemed to be crucial for building a trust relationship. For example, a consumer spoke of the benefits of seeing the same health provider for many years —

I've been with my GP's for a very long time. Built up quite a rapport... I've been at the same GP clinic since I was around seven... I know them so well. Like we're not friends outside of that but we do have a good relationship... They've just got my whole history and I know them so well, I don't want to switch. (C2)

From the key informants' talk, when rapport is established, advice that is given is much more likely to be taken on board even if it is challenging. For example, one consumer reported, "I have a positive relationship with my doctor... I feel comfortable, I can ask her anything... she's been good, she listens, lets me have my say, and then tells me if I'm wrong. Which is fine" (C4). Another consumer talked about the importance of trust, rapport, and not feeling coerced —

[It's good when] you feel comfortable, you don't feel coerced, don't feel pressured or pushed into a decision... Definitely think seeing a regular doctor would help... Rapport would make it a lot easier... It definitely comes down to how comfortable you feel with someone. (C5)

According to the key informants, trust in health providers, that they know and understand the context and lived realities of whānau, facilitates communication that is important for shared decision-making to occur.

### Shared decision-making tools

Both groups of key informants talked about the benefits of appropriate shared decision-making tools and resources. These were described as needing to be culturally appropriate/friendly, and including text and graphics/visuals that are relevant and engaging for Māori. Other important aspects given were having simple text, and messages that are gently guiding.

Shared decision-making tools were also described as needing to be health literacy appropriate - to be tailored to different levels of understanding and suited to the activity, be it self-directed or aided by a health provider, whānau member, or other support person. One health provider described a shared decision-making tool that was designed to be used with provider support, and how using such a structured tool can help manage bias -

If you have a shared decision-making tool with a lot of the information then it might be that a nurse could go through it and then the patient could make the decision... But it needs to be health literacy appropriate, culturally friendly... And the person doing it needs to be culturally safe and a really good communicator... I like things that structure what health professionals do because that's one way of dealing with implicit bias. (HP4)

Although providing tools/resources for consumers to read and use as guides was talked about positively, it was emphasised that health providers need to be trained in how to engage with

whānau and assist with using tools when needed. I.e., the tools do not replace the need for discussions with health providers, they should enhance them.

### **Advocacy and support**

Most key informants emphasised the importance of advocates in healthcare settings, as supporters and facilitators of shared decision-making. Key informant talk about advocates included talk about whānau members, representatives, nurses, and community support workers, such as Whānau Ora navigators. These advocates were deemed important for many reasons.

When decision-making capacities are compromised or if someone is not in the 'right frame of mind' to take in a lot of information, an advocate can ensure that the right questions get asked, and help to clarify any misunderstandings. For young people, who might be shy to ask questions, or for anyone uncomfortable to challenge health provider advice, it is beneficial to include someone trusted like a parent or other advocate as support. For example, a consumer talked about their mother supporting them at a consultation when they were feeling vulnerable and not up to asking questions –

Have someone to advocate for you when you aren't necessarily in that right frame of mind to ask those questions, when you're just vulnerable... when you're really uncomfortable and not thinking along the right lines. I had my mum with me and so she was asking a lot of these questions. (C3)

They recommended that other whānau do the same if they are feeling unsure and want extra support. Another consumer talked about their daughter going with them to consultations because their GP had told them that if they wanted anybody to accompany them, they were welcome to do so.

Not only were individual whānau members talked about as key advocates and support, some key informants suggested group settings, such as a whānau hui (gathering), for discussing serious health issues. Having a hui in a safe, comfortable environment, where multiple whānau members can attend, would ensure that the whānau are informed and involved, and would prevent overburdening the consumer with repeating information to different people.

Health provider key informants talked about three additional benefits of involving advocates in consultations. First, is having another person to contribute information when the consumer is asked about their history or the history of their condition, in case they have not covered everything that is pertinent. Second, is having another 'set of ears' to help interpret the information that has been shared, in case the consumer has misunderstood anything. Third, is having a support person there to ensure that rights and wishes are met. For example, a health provider talked about this as having an 'extra face in the room' to ensure that the consumer is taken more seriously -

[Advocacy] works magic for anything: navigators, community workers, nurses, because often what happens when you're dealing with the health system or even like WINZ, people tend to sort of sit up and think, 'Oh yes I better give them their

entitlement.' It makes a big difference, even just an extra face in the room makes a difference. (HP7)

It was noted that some people may not feel comfortable having whānau members in consultations, but this was given as a reason supporting the role of community support workers. For example, a health provider talked about the important role of Whānau Ora navigators —

Community health workers play a massive role, have huge input into the support and advocacy for our whānau... Often they break down what's been said so that whānau can understand. Quite a few of our whānau prefer to have navigators because they're not ready for their own whānau to come with them on that journey. (HP2)

Advocates were described as playing an important role in ensuring consumers receive appropriate care, but it was emphasised that it should be about consumer preference.

#### Provider

### Clinical competence

Key informants talked about providers needing to demonstrate clinical competence, to take their time and be thorough. Consumer key informants in particular talked about negative personal or whānau experiences, where health providers appeared lazy or were not thorough in their care, and so shared decision-making did not take place. One consumer talked about the impacts of this on their whānau —

Whānau have gone to the doctor and the GP's just pooh-poohed it... and not really delved in further to do a proper investigation... they miss the underlying issue. And for a couple of people I know that's turned out to be a fatal error... they're just lazy health professionals... ... The process of elimination, to me that's a good doctor, they'll go through every possible scenario to figure out what is wrong, they're thorough. (C2)

Another consumer described discovering that a whānau member had not been looked after properly in hospital overnight when they were not in the right head space to challenge the care they were receiving. Another talked about finding out that the medicine prescribed to their infant was above the recommended dose, and that they had obviously not been given adequate information —

I'd seen a new doctor [about my baby's skin]... and they prescribed another cortisone but a different strength. I didn't realise at the time, see this is when information should've been shared... He did tell me not to use it longer than a week so I knew it was going to be quite strong. But then I saw the specialist and she freaked out, she's like, 'Whoa! I never would've prescribed that!' (C5)

Consumer key informants discussed feeling like they were able to make good decisions when their health providers were thorough and informative. This included when health providers go through different scenarios and demonstrate their knowledge of health issues and treatment options. Health provider key informants emphasised the importance of demonstrating competent judgement and providing opportunities for shared decision-making with all consumers regardless of whether their conditions are acute or chronic. For example, a health provider suggested taking the time to talk about any other/outstanding issues with consumers who present with acute illness, in order to utilise preventative care measures.

### Communication

Both groups of key informants often talked about poor communication on the part of health providers being a barrier to shared decision-making. Descriptions of when health providers do not communicate well with whānau included: communication that is not positive, consistent, friendly, understandable, acknowledging, or empowering. Or, when it is incomprehensible, negative, abrupt, harsh, or disempowering. One consumer stated, "You should be treated like a human... And be acknowledged, because sometimes you feel like you aren't actually... because you're not a qualified professional, you don't know anything" (C7). It was emphasised that poor communication inhibits shared decision-making, as it silences consumers and deters them from engaging in healthcare services in the future (as discussed earlier).

In contrast, efficacious communication was described as being a key facilitator of shared decision-making. This was described as being when health providers open up dialogue, seek the views and aspirations of consumers, and create space for them to feel comfortable, valued, and safe to ask questions. It was also described as being when health providers proactively provide key information that is tailored to consumers and their level of understanding, rather than waiting for questions. For example, a consumer talked about the importance of good communication —

Different health professionals... the way that they offer advice and treatment can be night and day from one to the next... There's a way of communicating with people and sharing so that they become informed and empowered to be part of that decision-making process... Whereas, if it comes from an aggressive, confrontational point of view it's obviously not going to get the uptake that is actually needed. (C2)

Key informants talked about good communication sometimes involving connecting whānau up to services outside the health system, e.g., housing assistance, financial assistance, or social workers. It can also involve providing take-home information or follow-up care. For example, one consumer talked about recent positive experiences with their new dentist. The dentist emailed them a report after each appointment, including photographs of any treatment, so they can check their understanding and keep record. This was described as being an unexpected and much appreciated example of good communication after many negative experiences of health providers not communicating well. Seeing the same health provider regularly was frequently talked about as being important.

Health provider key informants talked about the importance of discussing options, checking understanding, and continuity of care. One health provider talked about the importance of health providers being able to "translate information into messages that are going to be appropriate for who's sitting in front of them" (HP7). Another talked about the importance of using the 'teach-back method' to ask consumers to repeat key information in order to check that communication has been clear. They emphasised that this needs to be done in a way that ensures that the focus is on making sure the health provider has explained things properly, rather than testing the consumer.

According to the key informants, when health providers communicate in efficacious ways, they support consumers to feel empowered, autonomous, knowledgeable, and respected. Subsequently, trust relationships are established and nurtured. For example, a consumer talked about this as demonstrating flexibility -

It's important that health professionals are flexible to adjust to the different people they're serving... giving answers or responses in a way that they understand... to use the right terminology... Different people digest information differently, and so it is one thing to ask questions, it's another to understand the answers...and have the confidence to challenge... Because shared decision-making is a two-way conversation, it is about opening the lines of communication both ways. (C3)

Key informants from both groups frequently emphasised the importance of two-way, reciprocal communication. The significance of efficacious communication was talked about more frequently than health literacy, and was sometimes directly ventured as more important for shared decision-making.

#### Cultural safety

Key informants talked about shared decision-making being compromised by health providers lacking cultural safety, including acting in discriminatory ways based on assumptions about ethnicity, age, gender, weight, and/or lifestyle. A lack of cultural safety was usually described as being when health providers communicate judgement rather than understanding or care. For example, a consumer key informant described feeling racially profiled in a hospital –

I actually didn't feel heard at all. If anything, I was put into a box... Yeah it was quite bad. It just all felt very dramatic having a small child that's struggling to breathe and no one listening to you because you've pretty much been racially profiled... it felt really horrible. (C5)

Health provider key informants expressed frustration that despite training, non-Māori health providers are often not culturally safe. One health provider key informant spoke of their disappointment with this -

I've been battling all of my career to try and make [providers] appropriate and then new ones come in and you'll start from the beginning and so in the end we get nowhere. We just end up training [non-Māori from] over the place who are

interested in our culture but we don't get anything out of it... and all they do is make fun and ostracize the way we do things. (HP3)

Cultural safety, cultural literacy, and cultural competency were frequently discussed as key to shared decision-making with Māori. In line with aspects of good communication, this was talked about as existing when a trust relationship is established and nurtured. Being non-judgemental, genuine, supportive, and understanding context were described crucial for these trust relationships. A consumer key informant talked about bringing in culture as "bringing in comfort, support, and a safe environment" (C6). A health provider key informant talked about the importance of health providers being role models for establishing relationships -

As a health professional you're taught to not show too much of yourself. But what we're talking about is cultural safety, and realizing how you can impact on people... For Māori it's really important - engaging and encouraging them to be part of the planning and decision-making... You have to establish and maintain trust for it to be effective... Health professionals sometimes don't realise how much they can be a role model by being a nice, caring person. (HP7)

Another health provider described this work as whanaungatanga (connecting/relationships) - a foundational concept in te ao Māori (the Māori world). They called this whānau-centred care, and emphasised the importance of a holistic view of health and wellbeing (often referred to as Te Whare Tapa Whā/the four dimensions of wellbeing), including the spirit, mind, and family, as well as the body/physical. They saw this as a way of improving shared decision-making for Māori -

If you know the person and their goals, their aspirations, their family, what they value, what's important to them, and where they're from, that means you're much more likely to be able to get that shared decision-making. (HP5)

A consumer key informant described requesting a specific GP in her local practice who is non-Māori because they have a good reputation for working with Māori and Pacific peoples. Even though the GP had a closed list, they accepted taking on the consumer when the consumer explained that they were Māori and wanted someone who was culturally safe. The GP was described as being awesome, patient (never interrupting), interested in the consumer's opinion, and really understanding their life context. The consumer said that this made them feel more confident, and that subsequently they always came up with a treatment plan together.

#### **Organisation**

### **Organisational culture**

Key informants from both groups talked about organisational culture, in particular the business model of primary care health services, as an organisational barrier to shared decision-making. Consumers and health providers frequently discussed feeling rushed to get through consultations due to short appointment times, with needs left unmet. A lack of opportunity for whānau to follow-up on concerns without paying extra was also discussed. For example, a consumer key informant talked about turning to Google to decipher information —

There have been times I've gone to the doctor and they've just kind of skipped over a whole bunch of detail... but I felt out of line to question, I felt a bit rushed... Quite often after I go to the doctor I end up going home and Googling everything all over again, because I felt like it was rushed or I almost need to go in with a tape recorder and a pen and paper. (C8)

A health provider key informant talked about the stress of short appointment times from their perspective -

People do come in with lists of things which can be difficult particularly if they've got 5 or 6 things, some of which are quite important and you've got a 15-minute appointment. That situation is quite stressful because you actually don't have enough time to deal with each thing properly. (HP4)

Another talked about how the business model of general practice enables gatekeepers, who further inhibit access to care for whānau -

The GP service is like a little empire... The receptionists weed people out... can put people off from coming in, because they'll look at Medtech and go, 'Oh you owe \$150.' So, they can be the barrier... And the receptionist is probably not getting much money but they have a certain amount of power in their community because they've got that ability to shut people down. (HP7)

Health provider key informants often suggested that the business model of primary care conflicts with aspirations of health equity. They also talked about the reluctance of organisations and the individuals within them to change culture and practices to be more responsive to Māori and health equity. One described their frustrations at trying to affect some change -

[They] think that if you ask them to do anything new, they just have to add that on top of what they already do. They don't think about changing what they already do in some way to actually bring about this improvement... 'We've always done it this way, we're not going to change, and now you're asking us to do this as well?' HP4

This resistance to change was talked about as inhibiting efforts to improve standards of care.

#### **Workforce**

Key informants from both groups talked about workforce issues that inhibit the relationship building process that is important for shared decision-making. In particular, workforce shortages and the subsequent reliance on casual or temporary staff were frequently discussed. Health provider key informants suggested that these shortages are caused by high provider turnovers and burnout rates. Relying on casual or temporary staff disrupts the continuity of care that is important for building trusting relationships. For example, a health provider expressed concern that this affects both access to and quality of care for whānau —

There's GP shortages all over the country so whānau are struggling to get in, and the other thing is about the consistency of the GP you're seeing. [If you're] seeing locums there's no consistency in what the messages will be. (HP2)

Consumer key informants often talked about the importance of seeing the same health provider and developing a relationship over time, and the disruption that changes cause.

Health provider key informants emphasised the need for continuous training for health providers, especially to enhance cultural safety. Māori health models, such as the Meihana model (a clinical assessment framework), hui models (such as the Hui Process - a framework to enhance the doctor—patient relationship with Māori), and Mason Durie's Te Whare Tapa Whā (a holistic model of health) were suggested as key resources for training health providers to be more responsive to Māori. For example, a health provider talked about the importance of putting resources into training the workforce —

I'd be putting more around the health professional working and using good principles of quality improvement in primary care... That's going to help drive the reduction in these tests... I think that if it happens in a peer environment and we've got access to the data it will start to encourage a reflection rather than just then lumping it on the consumer. (HP5)

A consumer key informant talked about the differences they have observed in clinician approaches over the years. They suggested that the training must be better than before, as clinicians seem more open to shared decision-making. The importance of professional development training, continuing medical education, and quality improvement programmes were discussed as tools to encourage the reflection and communication skills that are vital for shared decision-making with Māori.

#### **Health system**

#### Centring Te Tiriti o Waitangi

Throughout the interviews Te Tiriti o Waitangi and aspects that relate to the principles of protection, partnership, and participation were frequently discussed. Health provider key informants in particular described the health system as dysfunctional and designed inequitably, thus failing to protect the health of Māori. For example, one referred to it as 'sick' -

[Māori] don't know they're going to be labelled because they act a certain way too, so they're in a really powerless position. Can't win unfortunately, so our health system is quite sick at the moment... Our health system isn't working well enough, it's not set up that way at the moment. (HP7)

Another argued that the recent WAI 2575 report is a long awaited "platform for articulating how inequitable" (HP5) the health system is for Māori. This health provider key informant, as well as others, talked about the detrimental impacts of the underfunding of health services that serve Māori communities, and their wishes for these to be addressed. It was suggested that more

resources need to be put into Māori models that "give us more identity and security around who we are" (HP3), rather than into non-Māori models that do not reflect Māori values.

The failures of the health system to fulfil partnership obligations were talked about as being role-modelled from 'the top' in Government, filtering right throughout the health system. For example, a health provider key informant talked about the lack of recognition of the important role that Māori health providers play in supporting whānau in secondary care —

And often we're the silent voices behind our whānau. We're not recognised as being part of their journey, but we play such a crucial role in ensuring that they actually have a test or procedure. (HP1)

Talk about the lack of Māori in the health sector workforce is related to a failure of the health system to fulfil participation obligations. Some consumer key informants lamented not seeing any Māori doctors. For example, one thought it would help them relax —

Honestly, I don't ever think I've had a Māori or Pasifika doctor, and I think we just need more of them, because I feel like if I saw that I had a Māori or Pasifika doctor I would just completely relax and I would not be scared anymore. (C1)

The importance of whanaungatanga (connections/relationships) within healthcare settings and tino-rangatiratanga (self-determination/autonomy) of communities and whānau to determine their own health needs and aspirations were highlighted. For example, a health provider key informant talked about the critical role of community leadership —

Ask the community... 'So, what are you going to need to be able to do better for you and your whānau? How do you want to be involved with your care? What ways do you want us to communicate with you? What sorts of things would you like in the resources that we provide?' I think that's really important... those ideas around consumer involvement, and how that influences the leadership of health care. (HP5)

Key informants' talk emphasised the need to address systemic inequities in the health system and centre Māori and Te Tiriti o Waitangi in all domains. Doing so was positioned as key to improving Māori access to appropriate care, and therefore, access to shared decision-making.

#### Discussion

Māori consumer and health provider key informants were asked to provide feedback about the Choosing Wisely campaign and, more broadly, healthcare shared decision-making for Māori.

Feedback about Choosing Wisely was mixed. Concerns were raised, by health provider key informants in particular, about its governance and decision-making - that it has not engaged with Māori communities and Māori health professional groups, and that it lacks any reflection of mātauranga Māori and tikanga Māori. These are all important for not undermining the (latest) principles of Te Tiriti o Waitangi (partnership, participation, protection, equity, and options).<sup>21</sup>

Key informants indicated that with current inequities in health,<sup>1-8</sup> narrow campaign messages that focus on reducing tests/treatment and on Māori themselves questioning medical advice are problematic. Both groups did, however, see value in Choosing Wisely, especially if it promotes better communication between Māori consumers and their health provider/s. The caveat is that health providers must be delivering appropriate care and encouraging shared decision-making.

Choosing Wisely resources/tools were described as needing to be simple and realistic at a health literacy level, and both socially and culturally engaging for Māori. When utilised as such, these can enhance engagement in the decision-making process. <sup>13 62 72 75</sup> The key informant feedback supports the findings of the Connecticut Choosing Wisely Collaboration's research with underserved consumers. I.e., Choosing Wisely tools/resources are helpful, but require the ongoing training of health providers to work in ways that are culturally, linguistically, and health literacy appropriate, and supportive of consumer empowerment. <sup>61</sup>

Feedback about healthcare shared decision-making related to consumer, provider, organisation, and health system domains. Inequities in access to health care for Māori consumers are well documented,<sup>21</sup> therefore, it was not surprising that key informants from both groups frequently discussed the lack of access to resources experienced by many Māori as a barrier to shared decision-making. As found in the literature, both groups stressed the importance of consumer trust,<sup>10 11 66 68</sup> autonomy,<sup>49 58 70</sup> good relationships/rapport with health providers,<sup>10 12 45 58 66 68</sup> and culturally appropriate tools/resources.<sup>11 12 62 72</sup> The findings highlight the importance of advocates and support people for Māori in healthcare settings, in assisting both consumers and health providers in their understanding and confidence. Collective decision-making,<sup>12 67 69 72 76</sup> such as whānau hui, were encouraged.

Provider clinical competence and efficacious communication – encouraging collaboration, consideration, discussion, and mutual understanding, <sup>11</sup> <sup>12</sup> <sup>45</sup> <sup>53</sup> <sup>62</sup> <sup>63</sup> <sup>66</sup> <sup>70</sup> <sup>73</sup> were described as vital for shared decision-making by both groups. Being thorough and proactive in sharing information, rather than waiting for questions, were viewed as good practice. The importance of health provider cultural safety<sup>30</sup> <sup>31</sup> - being non-judgemental, genuine, supportive, and understanding of context, was highlighted. Much research asserts that culturally safe shared decision-making strategies acknowledge Indigenous perspectives, values, preferences, and self-identified needs. <sup>9-13</sup> <sup>62-69</sup> <sup>72-75</sup> For the participants in the present study, this involves health providers acknowledging the validity of te ao Māori, such as the importance of whanaungatanga and holistic models of health.

Organisational culture, in particular - the business model of primary care resulting in short appointment times, and workforce shortages disrupting continuity of care - were discussed as barriers to shared decision-making by both groups of key informants. Health provider key informants also emphasised the importance professional development, so that organisations and individuals can change their culture and practices, and especially address deficit biomedical discourses that marginalise Māori experience, knowledge, and understandings of health and wellbeing.<sup>10</sup> Workforce training programmes that teach skills to identify biases and build cultural empathy, 10-12 71 72 such as the Meihana model and hui models (e.g., the Hui Process), were suggested.

Local and international literature indicates that health systems and models that do not reflect the values and knowledge systems of Indigenous peoples or take strengths-based approaches to care undermine and negatively impact Indigenous health and wellbeing. 62-64 In this research, the health system was described as inequitable and as failing to fulfil Te Tiriti o Waitangi obligations of protection, partnership, and participation – evidenced in Māori health inequities, in the lack of Māori input into issues that affect Māori, and in the lack of Māori workforce. It is not good enough to simply aspire to bring more Māori into the workforce, Māori need to be included in governance and decision-making as well. Expression well informants highlighted the importance of tino-rangatiratanga of communities and whānau to determine their own health needs and health services. The findings suggest that centring Te Tiriti o Waitangi in the health sector would improve Māori access to appropriate care and, therefore, access to shared decision-making.

In conclusion, the current research corroborates themes found in the extant literature on shared decision-making (and healthcare decision-making) with Indigenous peoples - that shared decisionmaking has the potential to address health inequities among Indigenous populations by facilitating participation in health care that better meets self-identified need. 9-12 62 63 76 However, there is work to be done to ensure that Māori consumers know they have the right to ask questions, and that health providers are open to and encouraging of two-way dialogue. The research highlights several key elements required for optimal healthcare shared decision-making with Māori. First, equity must be prioritised. This includes committing to eliminating inequities, as well as privileging the mātauranga (knowledge) and tikanga (practices, customs) Māori that are part of a holistic understanding of Māori health and wellbeing. Second, the importance of developing whanaungatanga - connections and relationships between Māori consumers and health services cannot be stressed enough. Trust and cultural safety were deemed vital to enabling the right kind of environment for shared decision-making to occur. Finally, given the significance of autonomy for shared decision-making, the tino-rangatiratanga of Māori consumers and communities to actively participate in health care and healthcare decision-making must be supported. Any national health campaign, such as Choosing Wisely, would benefit from centring Te Tiriti o Waitangi and committing to equity by prioritising the needs and aspirations of Māori.

#### Limitations of the research

The focus of this qualitative research was to explore Māori consumer and health provider feelings, advice, and recommendations about Choosing Wisely and shared decision-making for Māori. While consumers from a range of age groups and health providers from a range of disciplines

participated, the majority of participants were urban-based and female. We may have missed an important data opportunity by not having more rural-based and male or non-binary informants.

## Strengths of the research

This qualitative Kaupapa Māori Research, utilising semi-structured interviews, enabled an in-depth exploration of a diverse range of Māori views. The research is the first to examine the Choosing Wisely campaign from a 'by Indigenous, for Indigenous' methodology. While diverse views were sought, common themes around equity, whanaungatanga, and tino-rangatiratanga arose. These add to the growing body of local and international literature that seeks to improve healthcare shared decision-making for Indigenous peoples.

# Recommendations for Choosing Wisely and shared decision-making

The feedback from the key informants suggests that there is much work to be done to ensure that Māori consumers know they have the right to ask questions and expect equitable care, and that health providers are open to and encouraging of two-way dialogue. Culturally safe care and positive relationships between health providers and consumers are vital to shared decision-making, and are thus essential to the Choosing Wisely mission.

Recommendations drawn from the data, for the Choosing Wisely Aotearoa New Zealand campaign and resources, and for improved shared decision-making for health providers and consumers, are listed here.

## **Choosing Wisely Aotearoa New Zealand campaign**

- Uphold the principles of Te Tiriti o Waitangi and centre Māori in governance and decision-making, and encourage Colleges and DHBs to do the same in their Choosing Wisely work.
   For example, involve community and Iwi (tribal) based health providers, and develop strategies with communities that reflect their needs and aspirations.
- 2. Acknowledge and incorporate mātauranga Māori (Māori knowledge systems) and tikanga Māori (Māori practices and customs) in Choosing Wisely work. For example, Māori health models promote relationship building (e.g., the Meihana model, the Hui process, Te Whare Tapa Whā), and in doing so can improve shared decision-making.
- 3. Along with the main message of the campaign being 'Choosing Wisely', consider including other messages that encourage health providers to consider the best options for consumers and to instigate shared decision-making, such as, 'Advise Wisely'. While the campaign's promotion of consumer autonomy was viewed positively, health providers should retain responsibility for ensuring that they are creating a question friendly environment and providing appropriate care. Focus on the provision of appropriate care rather than over-treatment.
- 4. Utilise local evidence to support the campaign. This could involve applying a logic model, or moving towards a quality improvement or assurance framework that recognises local contexts that impact shared decision-making and access to appropriate care for Māori.
- 5. Promote cultural safety, patient-centred care, and equity based professional development training, continuing medical education, and quality improvement programmes. For optimal shared decision-making to happen, the right environment is required. Trust and cultural safety are important.

6. Undertake work to ensure that consumers know that they have the right to ask questions and expect equitable care, promoting autonomy and confidence to ask questions. As emphasised by the participants in this research, advocates, such as whānau members, friends, community health workers, and navigators, can play an important role in supporting shared decision-making in healthcare settings.

#### **Choosing Wisely Aotearoa New Zealand resources**

- 1. Work with Māori to design resources/tools that are engaging and relatable for Māori.
  - a. Be realistic with suggestions, i.e., can consumers book longer appointments?
  - b. Use plain, simple, relatable messaging, i.e., consider whether consumers understand that their health issues are complex, or whether it is appropriate to tell them to be honest. Consider different resources pitched to different levels of understanding.
  - c. Ensure the layout of resources for consumers are engaging with visual aids/graphics.
- 2. Develop resources/tools to encourage health providers to communicate efficaciously with whānau and create a question friendly environment (rather than just educating whānau on how to communicate with health providers).
- 3. Create resources/tools for advocates, be they whānau members, friends, community health workers, or navigators, so that they can support/promote shared decision-making.
- 4. Support the development of decision-making tools for specific health issues, in line with College recommendations, which can be self-directed or aided by a health worker or advocate.
- 5. Advertise and supply shared decision-making resources/tools and key messages widely among networks and within health settings so that they become part of routine care. Consider the use of media and online resources/tools that are simple and accessible.
- 6. Seek user feedback (from providers and consumers) about the resources/tools through networks, such as Te Ohu Rata o Aotearoa, and health services (e.g., through DHBs and primary care). Web based feedback could be utilised.

## **Health providers and consumers**

#### **Health providers**

- Avoid assumptions about consumers, instead talk through issues/concerns.
- 2. Build relationships with consumers, develop trust.
- Instigate shared decision-making by using tools to guide consumers through different options. Do not wait for consumers to ask.
- 4. Be open to questions and willing to engage.
- 5. Check understanding in an affirming way (e.g., the teach-back method).
- 6. Utilise visual aids/tools to guide discussions.
- Connect consumers to relevant information and services/support.
- 8. Encourage the role of advocates and support people in decision-making.

#### Consumers\*

- 1. Expect respect. If you are not happy with the care you receive, talk to someone about it.
- 2. Ask questions. It is your right to have things explained to you in a way you understand.
- 3. Check if there are resources (e.g., brochures or online information) that you can see.
- 4. Talk to whānau and friends about any health concerns or worries.
- 5. Take support (e.g., whānau, friends, or health workers/navigators).

The recommendations for consumers closely align with some of the messages of the current Choosing Wisely Aotearoa New Zealand resource (Figure 2), as these were affirmed in the key informant interviews.

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