Appendix H.5 — Evidence to Decision: Whānau Education and Involvement

EtD 55. How do whānau Māori prefer to engage in discussions and receive information when making shared decisions about the care of their preterm pēpi?

POPULATION:	Preterm infants
INTERVENTION:	Whānau Māori engaged in discussions and receive information when making decisions about the nutrition care of their pēpi?
COMPARISON:	Standard care
MAIN OUTCOMES:	**Critical outcomes** Clear and culturally safe communication Upholding tikanga Māori **Less important for decision making** Faltering growth/body composition Fully breastfed or breastmilk feeding at hospital discharge Time to full sucking feeds Time to full enteral feeds Breastmilk supply/volume Duration of initial hospital stay Cost: cost of intervention, cost of neonatal care and life-long cost Mortality Neurodevelopmental impairment
SETTING:	Neonatal care
PERSPECTIVE:	Clinical guideline recommendation. Patient perspective
BACKGROUND:	Literature on the experience of the public health system by whānau Māori highlight experiences of racism and discrimination, including a lack of information provision and a lack of positive communication with healthcare providers. In the often-unfamiliar context of neonatal intensive care units (NICU), whānau Māori may feel particularly vulnerable and unsure how to provide for the specific needs of their preterm pēpi. Pēpi Māori have the highest overall rate of admission to SCBU/NICU and it is therefore paramount to ensure information is relayed to their whānau in a culturally appropriate way so that they can engage confidently in the care of their pēpi and bond with their pēpi. Studies show that, when faced with a lack of essential health information, whānau Māori find it difficult to ask questions and may fear that they are disturbing the staff. Within this power differential, it is the healthcare providers' duty of care to ensure they provide the necessary medical information in a way that is understood by the recipient. This would be described as mana enhancing behaviour from the medical staff, ensuring the parents are feeling empowered by the medical discussion not disempowered. Getting this right will contribute to increasing equity in Māori and is part of culturally safe care.
CONFLICT OF INTERESTS:	The following qualitative research (references 1 and 4) co-author is on the Guideline Development Group: Liza Edmonds

Assessment

Desirable Effects

How substantial are the desirable anticipated effects?		
JUDGEMENT	**RESEARCH EVIDENCE**	**ADDITIONAL CONSIDERATIONS**
○ Trivial ○ Small ● Moderate ○ Large ○ Varies ○ Don't know	The evidence was based on two qualitative studies [1,2] Adcock *et al* [1] followed 19 whānau of preterm pēpi Māori (19 mothers, 9 fathers and 13 non-parents whānau Māori). The study followed their journey from birth to one year, with the majority of the interviews occurring while the pēpi Māori were in NICU. Themes that emerged from the interviews, regarding communication with healthcare providers were: The importance of having supportive providers who encouraged whānau Māori to not only take part but also lead the care of their pēpi. This was supported by clear communication around the need of the pēpi, with the opportunity to ask for more information and follow-up questions. Good communication involved information delivered at an understandable level, often involving playfulness and jokes, thus making participants feel at ease. Being involved in the care of the pēpi allowed whānau Māori to gain autonomy, to become familiar with the NICU environment and to become experts in the needs of their pēpi. Supportive healthcare providers were those who provided culturally safe care, with loving and empathetic communication. Continuity of care was seen as a key component of culturally safe care and allowed for whakawhanaungatanga (process of establishing relationships). Such providers became like family and participants often used familial terms to describe them. Of note the majority of healthcare providers identified as champions were non-Māori. The need to acknowledge the importance and legitimacy of extended whānau rather than only allowing the mother and father to participate in the care of the preterm pēpi. The need for healthcare providers to build relationship with the wider whānau was seen as a cultural imperative. Whānau Māori felt respected when healthcare providers made an effort to pronounce their name and their pēpi's name	In Adcock's 2021 study [1]: Not being involved in the care of the pēpi and having to follow the hospital schedule and routine made whānau Māori feel as if their pēpi was not really theirs. Being told by healthcare providers who could hold the pēpi Māori and when the pēpi could be held fostered feelings of fear and guilt. Whānau Māori reported feeling scared to hurt the pēpi, who, as a preterm pēpi, was already seen as fragile. Those feelings were enhanced when healthcare providers did not allow non-parents whānau members to hold the pēpi. The lack of understanding of the extended whānau and wide support system felt isolating to the parents. Giving too much information during the early days in NICU was described as overwhelming. Conflicting advice was also an issue that left whānau frustrated and unfairly treated. Communication was hindered when providers made assumptions about the participants, such as their smoking status, parental skills, age or relationship status. In the Masters-Awatere study [2], the whānau Māori who did not receive the Harti tool but instead received usual care said negative experiences that occurred were due to: Feeling shamed by healthcare providers rather than helped Feeling rushed and as if they were intruding on the hospital staff's time when they wanted to ask questions. This left them feeling isolated and alone Participant's expectation of hospital care was very low, with some participants feeling happy as long as their tamariki received clinical care and were still alive at the end of their hospital stay In another study, Adcock et al interviewed 10 healthcare providers (7 nurses, 1 medical officer, 1 kaiāwhina and 1 counsellor) identified as champions of culturally safe neonatal care by whānau of preterm pēpi Māori [4]. Themes that emerged from those interviews with champions were similar to those described by whānau Māori: The importance of collaboration between whānau Māori and healthcare provider in NICU, with mutual trust and respect. This included ensuring correct use of te reo Māori by healthcare providers. The need to ensure extended whānau Māori were involved in the care of the pēpi and in the decision-making processes. Champions of culturally safe care adapted their level of communication to the health literacy of the whānau and checked understanding with strategies such as open questions

	correctly. The study by Masters-Awatere *et al* [2] yielded similar themes. In this study, 15 whānau who had experienced the Harti tool* during their child's hospital stay were interviewed about their experience. The child were aged 0-5 years old. The Harti tool allowed for positive communication based on: Culturally appropriate and respectful interactions, facilitated by the use of te reo Māori and by cultural matching between the healthcare provider and whānau Māori. Kaupapa Māori practices such as whakawhanaungatanga (process of establishing relationships): this was facilitated by health practitioners creating a calm and relaxing environment, taking the time to listen to whānau Māori concerns and to answer their queries, and offering information and practical advice that promoted confidence and self-autonomy. Connection based on genuine care and practical actions to address identified needs. * The Harti Hauora Tamariki Tool (The Harti tool) is a tamariki and whānau-based need assessment tool, developed at the Waikato Hospital and designed to reduce health inequities [3].	or teach-back method. Champions believed their role was not just taking care of the preterm pēpi but also to spend time with the extended whānau and build a relationship with them through everyday conversation and through continuity of care. Culturally safe communication is based on aroha (love), compassion and empathy and an understanding that childbirth and care of the preterm pēpi are sacred time and spaces for whānau Māori. Culturally safe care did not rest on technological performances but on genuine and respectful relationship building between healthcare providers and whānau Māori. In a qualitative study by Abel *et al* [5] on the experience of 12 wāhine Māori using a wahakura, it was noted that the making of the wahakura was an opportune time for healthcare providers to engage with whānau Māori on safe sleep recommendations. The activity was perceived as having cultural value and a way to connect or reconnect with ''being Māori''. This culturally safe environment facilitated engagement of whānau Māori with healthcare providers and their messages.

Undesirable Effects

How substantial are the undesirable anticipated effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
● Trivial ○ Small ○ Moderate ○ Large ○ Varies ○ Don't know	No undesirable effects were identified	

Certainty of evidence

What is the overall certainty of the evidence of effects?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ Very low ○ Low	The evidence provided is rich qualitative data, that amplifies whānau Māori experience of health. The methodology used	* CASP criteria: 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to

○ Moderate ● High ○ No included studies	to analyse the data includes, for example kaupapa Māori methodologies and grounded theory. Nine references were included, which is significant for this area of research. The Critical Appraisal Skills Programme (CASP) checklist* for qualitative studies was used to assess the strength of the including qualitative studies. Overall, included studies ranked high on the checklist (high to moderate quality). The majority of the included studies directly or closely answered the PICO, meaning the information was not extrapolated from indirect evidence. Results of the CASP checklist were as follow: •Adcock et al., 2021: 20/20 (high quality) [1] •Masters-Awatere et al., 2019: 20/20 (high quality) [2] •Malek et al., 2018: 18/20 (moderate quality) [6] [criteria for both recruitment strategy and relationship between research and participants partially met]	address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research? CASP critical score: a) Criterion is completely met = 2; b) criterion is partially met = 1; c) criterion not applicable, not met, or not mentioned = 0; Total score 20 = high quality; 16–19 moderate quality; ≤ 15 low quality

Values

Is there important uncertainty about or variability in how much people value the main outcomes?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ Important uncertainty or variability ○ Possibly important uncertainty or variability ● Probably no important uncertainty or variability ○ No important uncertainty or variability	A review by Wilson *et al* noted that Māori worldviews consider people's physical, psychosocial, spiritual and, importantly, relational needs [7] Relational care is defined as the deliberate nurturing of respectful and meaningful relationships with Māori and their whānau. The review therefore highlighted the key elements for a Māori-centred model of care: Whanaungatanga (connectedness) and whakawhanaungatanga (the process of building relationships) using tikanga (cultural protocols and processes). Informed by cultural values of aroha (compassion and empathy), manaakitanga (kindness and hospitality), mauri (binding energy) and wairua (importance of spiritual wellbeing). In the 2022 New Zealanders' Experiences and Perceptions of	In the Malek *et al* study, Australian and New Zealand parents of children aged <12 months, who were using infant formula were interviewed in focus groups [6]. Among the 136 participants, 30 were Māori/Pacific People (no distinction made in the study). The authors noted that healthcare providers were rarely able to answer parents' query on the best infant formula to choose and that parents were therefore left to their own devices when making a decision. The focus group highlighted parents thought process regarding the selection of an infant formula. In the three Māori/Pacific People focus groups, the main themes that emerged around communication of information were: Lack of understanding of the ingredients listed - parents would rather see layman's terms and/or visual explanations (e.g. pictures). Lack of understanding of nutrient claims - nutrition information was deemed important if the pēpi had specific nutritional needs. Parents therefore preferred claims that stated health benefits, as they found those easier to understand. Parents sometimes checked the sugar, fat and/or salt content. Parents were sometimes swayed by specific claims such as "for hungrier babies".

	the Maternity and Perinatal System Report, whānau Māori reported that not having their cultural needs met was a source of dissatisfaction. This included: Cultural needs being assumed, based on their physical appearance. No help to meet cultural needs. A general lack of awareness amongst hospital staff about what was culturally appropriate and respectful.	

Balance of effects

Does the balance between desirable and undesirable effects favour the intervention or the comparison?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ Favours the comparison ○ Probably favours the comparison ○ Does not favour either the intervention or the comparison ○ Probably favours the intervention ● Favours the intervention ○ Varies ○ Don't know	Studies are primarily qualitative data summarising experiences and not the effect of an intervention. There is clear qualitative evidence supporting the inclusion of whānau as essential team members.	

Resources required

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ Large costs ● Moderate costs ○ Negligible costs and savings ○ Moderate savings ○ Large savings ○ Varies	The evidence presented highlight that the barriers to information delivery in the context of caring for preterm pēpi Māori are not technical but relational. Cultural training of staff is therefore required for healthcare providers to better understand te ao Māori, to ensure whānau-centred care and to improve the quality of interactions and information delivery with whānau Māori. Ongoing quality	

○ Don't know	assessments and improvement programmes (e.g. Plan-Do-Study-Act cycles) involving champions of Māori-centred care may be necessary to improve outcomes and increase equity.	

Certainty of evidence of required resources

What is the certainty of the evidence of resource requirements (costs)?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ Very low ○ Low ○ Moderate ○ High ● No included studies	No included studies	

Cost effectiveness

Does the cost-effectiveness of the intervention favour the intervention or the comparison?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ Favours the comparison ○ Probably favours the comparison ○ Does not favour either the intervention or the comparison ○ Probably favours the intervention ○ Favours the intervention ○ Varies ● No included studies	No included studies	Evidence from Reid and colleagues on the economic costs of Māori health inequities demonstrates that the cost of inaction is substantial and enduring [8]. While incorporating mana-enhancing tikanga practices that support whānau Māori breastfeeding and embed Te Ao Māori values such as whanaungatanga and manaakitanga may require moderate investment in workforce capability, service redesign and time, these costs are likely outweighed by the consequences of not acting. Failure to provide culturally safe, mana-affirming breastfeeding support risks lower breastfeeding rates, poorer maternal and infant health outcomes and the perpetuation of inequities, all of which carry significant downstream health system and societal costs.

Equity

What would be the impact on health equity?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ Reduced ○ Probably reduced ○ Probably no impact ○ Probably increased ● Increased ○ Varies ○ Don't know	In 2023, 8.5% of pēpi Māori were born before 37 weeks' gestation, compared to 7% of NZ European/other pēpi and 7.8% of pēpi Māori were born weighing less than 2500 g compared to 5.5% of NZ European/other pēpi. In the 2019 review of neonatal care in New Zealand pēpi Māori had the highest overall rate of admission to SCBU/NICU, accounting for 28% although pēpi Māori had lower occupancy in level 3 units compared with pēpi from other ethnic groups [9]. The review noted that the NICU staff did not reflect the population it supports, as Māori staff represented 4% of the workforce in 2019 compared to 73% for NZ European staff. Adcock *et al* [1] also noted that many pēpi Māori were transferred to a NICU far from home. This had various consequences: Financial consequences, with many parents not knowing about or having difficulties accessing government-funded travel assistance, needing to take unpaid time off work, needing to access accommodation Loss of whānau support. When parents had other pēpi, the mother was often transferred alone to NICU - many participants reported on the subsequent feeling of isolation in a foreign environment, making whakawhanaungatanga with healthcare providers even more important Lack of access to spiritual practices such as whenua ki te whenua (returning the placenta to the earth) due to the placenta being lost/destroyed during transfer.	A systematic review by Graham *et al* on Māori experiences of the public health system reported on institutional level barriers, including racism and discrimination [10]. Experiences from whānau Māori described in the review included: Being aware of negative perceptions by healthcare providers, through the provider's body language, facial expressions and mispronunciation of their name. Inability to build a relationship with and absence of warmth from healthcare providers. When in an unfamiliar setting, information provision was poor, leaving whānau Māori unsure of what to ask. When information was provided, it was often in an inappropriate form, such as a pamphlet. Access to additional resources and ancillary support services was rare and difficult. Unwillingness to "disturb" busy healthcare providers and "waste their time", leading to whānau Māori downplaying their pain and symptoms. Having to focus on physical health only and having to ignore mental and spiritual health.

Acceptability

Is the intervention acceptable to key stakeholders?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ No	Promoting culturally safe communication and healthcare	

○ Probably no ● Probably yes ○ Yes ○ Varies ○ Don't know	delivery is acceptable, equitable, and is necessary to fulfil the Crown's obligations under the Te Tiriti o Waitangi.	

Feasibility

Is the intervention feasible to implement?

JUDGEMENT	RESEARCH EVIDENCE	ADDITIONAL CONSIDERATIONS
○ No ○ Probably no ● Probably yes ○ Yes ○ Varies ○ Don't know	Culturally appropriate initiatives such as the wellbeing needs assessment tool Harti Hauora Tamariki Tool (The Harti tool) show that whānau-centred approaches are feasible. The Harti tool is currently being assessed in a randomised controlled trial conducted at the Waikato hospital. Early qualitative results highlight an improvement in whānau Māori experiences of communication with healthcare providers [2,3].	

Summary of judgements

	JUDGEMENT						
DESIRABLE EFFECTS	Trivial	Small	**Moderate**	Large		Varies	Don't know
UNDESIRABLE EFFECTS	**Trivial**	Small	Moderate	Large		Varies	Don't know
CERTAINTY OF EVIDENCE	Very low	Low	Moderate	**High**			No included studies
VALUES	Important uncertainty or variability	Possibly important uncertainty or variability	**Probably no important uncertainty or variability**	No important uncertainty or variability			
BALANCE OF EFFECTS	Favours the comparison	Probably favours the comparison	Does not favour either the intervention or the comparison	Probably favours the intervention	**Favours the intervention**	Varies	Don't know
RESOURCES	Large costs	**Moderate costs**	Negligible costs and savings	Moderate savings	Large savings	Varies	Don't know

	JUDGEMENT						
REQUIRED							
CERTAINTY OF EVIDENCE OF REQUIRED RESOURCES	Very low	Low	Moderate	High			**No included studies**
COST EFFECTIVENESS	Favours the comparison	Probably favours the comparison	Does not favour either the intervention or the comparison	Probably favours the intervention	Favours the intervention	Varies	**No included studies**
EQUITY	Reduced	Probably reduced	Probably no impact	Probably increased	**Increased**	Varies	Don't know
ACCEPTABILITY	No	Probably no	**Probably yes**	Yes		Varies	Don't know
FEASIBILITY	No	Probably no	**Probably yes**	Yes		Varies	Don't know

Type of recommendation

Strong recommendation against the intervention	Conditional recommendation against the intervention	Conditional recommendation for either the intervention or the comparison	Conditional recommendation for the intervention	**Strong recommendation for the intervention**
o	o	o	o	●

References

1. Adcock, A.; Cram, F.; Edmonds, L.; Lawton, B. He Tamariki Kokoti Tau: Families of Indigenous Infants Talk about Their Experiences of Preterm Birth and Neonatal Intensive Care. *Int. J. Environ. Res. Public Health* **2021**, *18*, doi:10.3390/ijerph18189835.
2. Masters-Awatere, B.; Graham, R. Whānau Māori explain how the Harti Hauora Tool assists with better access to health services. *Australian Journal of Primary Health* **2019**.
3. Scott, N.; Atatoa Carr, P.E.; Jones, A.R.; Sandiford, P.; Masters-Awatere, B.; Clark, H. Harti Hauora Tamariki: randomised controlled trial protocol for an opportunistic, holistic and family centred approach to improving outcomes for hospitalised children and their families in Aotearoa, New Zealand. *Frontiers in Paediatrics* **2024**.
4. Adcock, A.; Cram, F.; Edmonds, L.; Lawton, B. Culturally Safe Neonatal Care: Talking With Health Practitioners Identified as Champions by Indigenous Families. *Qual. Health Res.* **2023**.
5. Abel, S.; Stockdale-Frost, A.; Rolls, R.; Tipene-Leach, D. The wahakura: a qualitative study of the flax bassinet as a sleep location for New Zealand Māori infants. *N. Z. Med. J.* **2015**.
6. Malek, L.; Fowler, H.; Duffy, G.; Katzer, L. Informed choice or guessing game? Understanding caregivers' perceptions and use of infant formula labelling. *Public Health Nutr.* **2019**, *22*, 273-286, doi:10.1017/S1368980018003178.
7. Wilson, D.; Moloney, E.; Parr, J.M.; Aspinall, C.; Slark, J. Creating an Indigenous Māori-centred model of relational health: A literature review of Māori models of health. *J. Clin. Nurs.* **2020**.

8. Reid, P.; Paine, S.J.; Te Ao, B.; Willing, E.J.; Wyeth, E.; Vaithianathan, R.; Loring, B. Estimating the economic costs of Indigenous health inequities in New Zealand: a retrospective cohort analysis. *BMJ Open* **2022**, *12*, e065430, doi:10.1136/bmjopen-2022-065430.
9. Malatest International. Review of neonatal care in New Zealand. Wellington: Ministry of Health; 2019/2020.
10. Graham, R.; Masters-Awatere, B. Experiences of Maori of Aotearoa New Zealand's public health system: a systematic review of two decades of published qualitative research. *Aust. N. Z. J. Public Health* **2020**, *44*, 193-200, doi:10.1111/1753-6405.12971.

Back to question list