

Kōrero Mai: A Kaupapa Māori study

exploring the experiences of
whānau Māori caring for
tamariki with Atopic
Dermatitis

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MEDICAL AND
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Inequity
Deprivation
Discrimination

Eczema is a chronic skin condition.

There are challenges that come with caring for tamariki who have eczema.

Eczema affects over 20% of New Zealand children and tamariki Māori are 1.2 times more likely than non-Māori to have eczema.



DermNetNZ.org

Atopic eczema

Infantile atopic dermatitis, face



 Reusing this image



Tamariki Māori are more unfairly impacted. This is evidenced by severe symptoms, complications, and hospitalisation.

To date, there has been no research in Aotearoa exploring the experiences of whānau Māori.

Kaupapa methodology:

- ❖ Tikanga
- ❖ Te reo
- ❖ Kawa
- ❖ Highlight meaning within kōrero





WHAT IS YOUR STORY?

GOOD
VIBES
ONLY

A close-up photograph of two hands, one from a lighter-skinned person on the left and one from a darker-skinned person on the right. Both hands are heavily stained with dark, greasy dirt and show significant signs of wear, including cracked and calloused skin. The hands are positioned palm-up, facing each other, with fingers slightly spread. The background is dark and out of focus, suggesting an industrial or workshop setting.

Aroha (Love)

"In the morning, we'd come back with blood everywhere...so you would get up in the night to go help her if she needed help. I was sleep deprived."

"If I could do anything and just put it all on me. I would."

"It took us a very long time to fix it [the eczema] up into a state where we were happy, that took months. If you don't treat it and keep on top of it, you're gonna have a hell of a time and the child will have a very bad time. I do what I have to do because they're my kids."

Whakamā (Embarrassment)

"When you're sitting there at the doctor's, you can see eyes. You can just sense that stuff."

"I get judged. When I go and see my family my dad, he's the worst critic, and he's never been in this position, of treating a child with really bad eczema. He doesn't know what it's like for me."

"I see people look at him. I go into protective mum mode. Don't look at my child. Right? Don't judge us because we do try."





Mamae (Pain)

"When you couldn't control it [the eczema] then you as a parent felt bad for getting to that point? Just feeling helpless. When you're doing everything you've been told to do and it's not healing fast enough."

"When you see them stressed out because of their skin [and] you don't know what else to do. You just mamae for them."

"I felt so bad as a father having to tie her up every night. Then every night I knew my child was basically sleeping in a straitjacket in order to make it through, which was hell for me emotionally."

Toihara (Discrimination)

"It's frustrating when the doctors think they know your child and what works, I dreaded going to the doctors... Why won't the doctors listen to me?"

"The doctor had no compassion. I felt like I'm not doing my job properly and you feel useless"

"No GP would refer us. Despite us insisently coming back to the professionals we didn't get to the right people...they're supposed to advocate for us."





Aukati (Barriers)

"We don't know what's available. Why assume that no one can afford or wants to pay for anything? There probably think they cant afford and so wont bring up private services because most of the people around you cant afford private services and why would we give you hope?"

"It's ridiculous to wait 3 years for a specialist. Ive just asked the doctor last week if we could get another referral. Because I think we've persevered enough."

"I use WINZ for extra help. But all my kids use that. They're not meant to, but because I've already tried to apply many times, they always decline it. Reapplying just gets hōhā, so I don't bother. What more do you need to get the funding? It's probably within their own system."



Mātauranga Māori

A close-up photograph of a woman with long dark hair and glasses kissing a young child on the cheek. The child is wearing a light-colored jacket. The background is bright and out of focus, suggesting an outdoor setting with sunlight. The overall mood is warm and intimate.

Wairuatanga (Spirituality)

"I didn't really separate my physical being from the way that the emotional toll reflected on my body and my wife's body? I felt sad for her. But I'd always gauge my response by hers.... because I'm not really wearing that thing. She is the one that is actually wearing a bandage. She is the one who is suffering in pain."

"Because when he's all flared up, he's miserable. And it's so sad. So, when he's happy, I'm happy."

The background of the entire image is a dense, overlapping pattern of vibrant green leaves, likely from a plant like hosta or similar, with prominent veins and wavy edges. The leaves are set against a dark, almost black background, which makes the green color stand out. The lighting is soft, highlighting the texture and color of the foliage.

Rongoā (Traditional Medicine)

"If I can't afford it then I can't afford it but there's alternative to use at home, you just have to do a little bit of research and you'll come up with a solution."

"We would rather not go on pills. Let's try this water thing."

"That needs to be an option. Instead of here give him all these hydrocortisone and steroids. When like, kawakawa was working, but nobody told me about that they didn't make that an option. We've got some in our backyard, and I didn't even know. So, I'm making my own."



Whakawhānaungatanga (Relationships)

"We don't let it [the eczema] be a burden for her because she's still learning. She's still a child. And she wants to go and have fun."

"Because contact is essential in Māori culture and lockdown, it's just one of the most difficult times of all because they can't go out there and go play sports or anything you know. They can't check in with their mates or anything and that I find that that's more stressful for them."



Whānau (Family)

"It doesn't really matter what race they [health professionals] are, as long as they're open to the families, and they're not forcing their own culture onto everybody or looking down on people. People will accept anybody you know as long as they do it on a genuine basis."

"It's a whānau, it's a wider community. It's not isolation, individual type of approach, he [the doctor] had more care, but it was more than that though he had clinical skills. But he also understood the wider part."

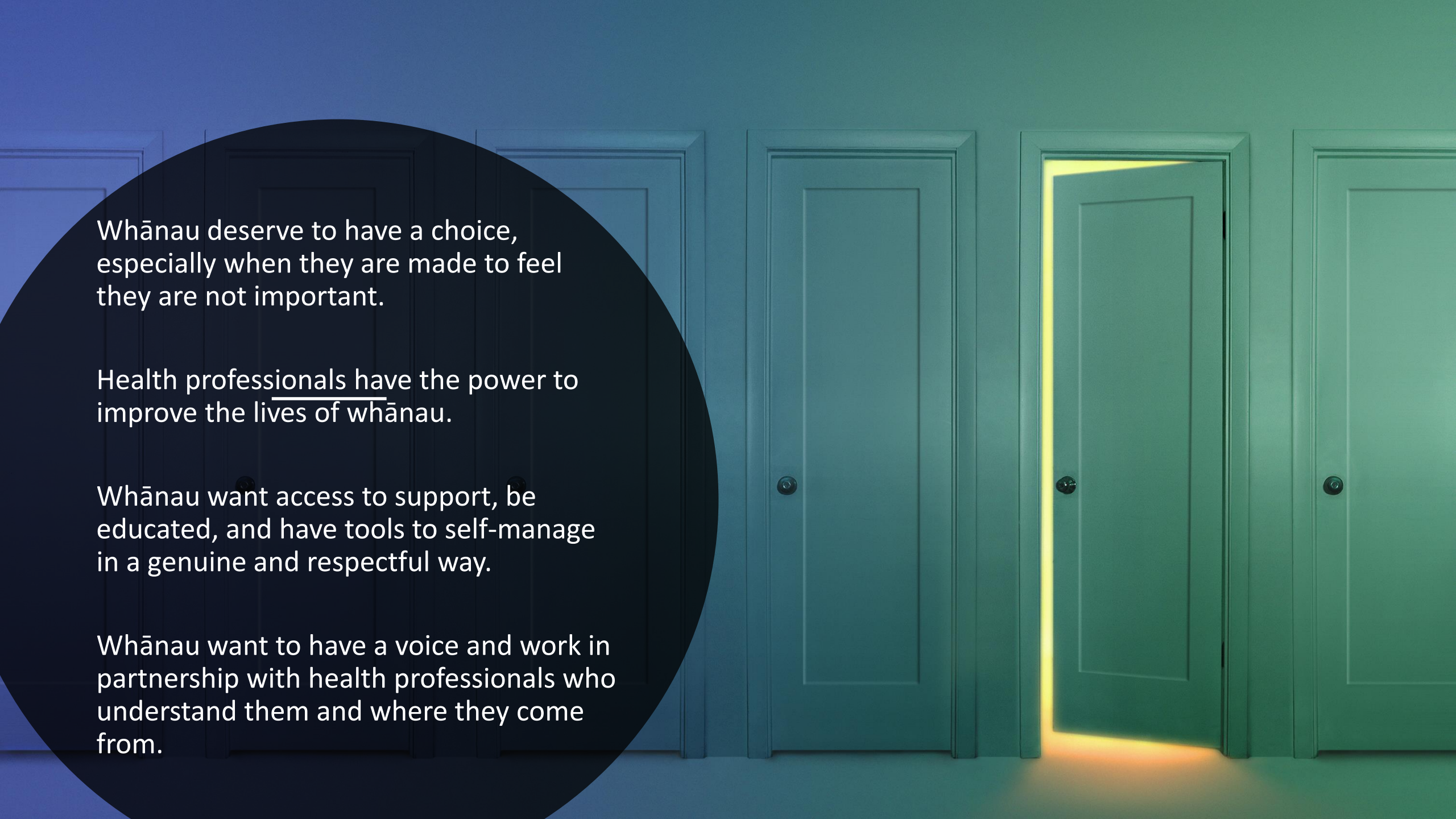


Caring for a child with eczema is hard, relentless work for whānau.

Whānau are often shamed with judgments about their ability to care.

Although whānau utilise mātauranga Māori to help them through, health systems continued to fail whānau Māori by not putting them and their tamariki first.

But they tackle the holistic challenges that come with caring for tamariki with courage, persistence, and aroha.

A row of teal doors is shown against a teal wall. The door in the center-right is slightly ajar, revealing a bright, warm yellow light that illuminates the floor and the inner edge of the door. The other doors are closed and have dark circular handles.

Whānau deserve to have a choice, especially when they are made to feel they are not important.

Health professionals have the power to improve the lives of whānau.

Whānau want access to support, be educated, and have tools to self-manage in a genuine and respectful way.

Whānau want to have a voice and work in partnership with health professionals who understand them and where they come from.



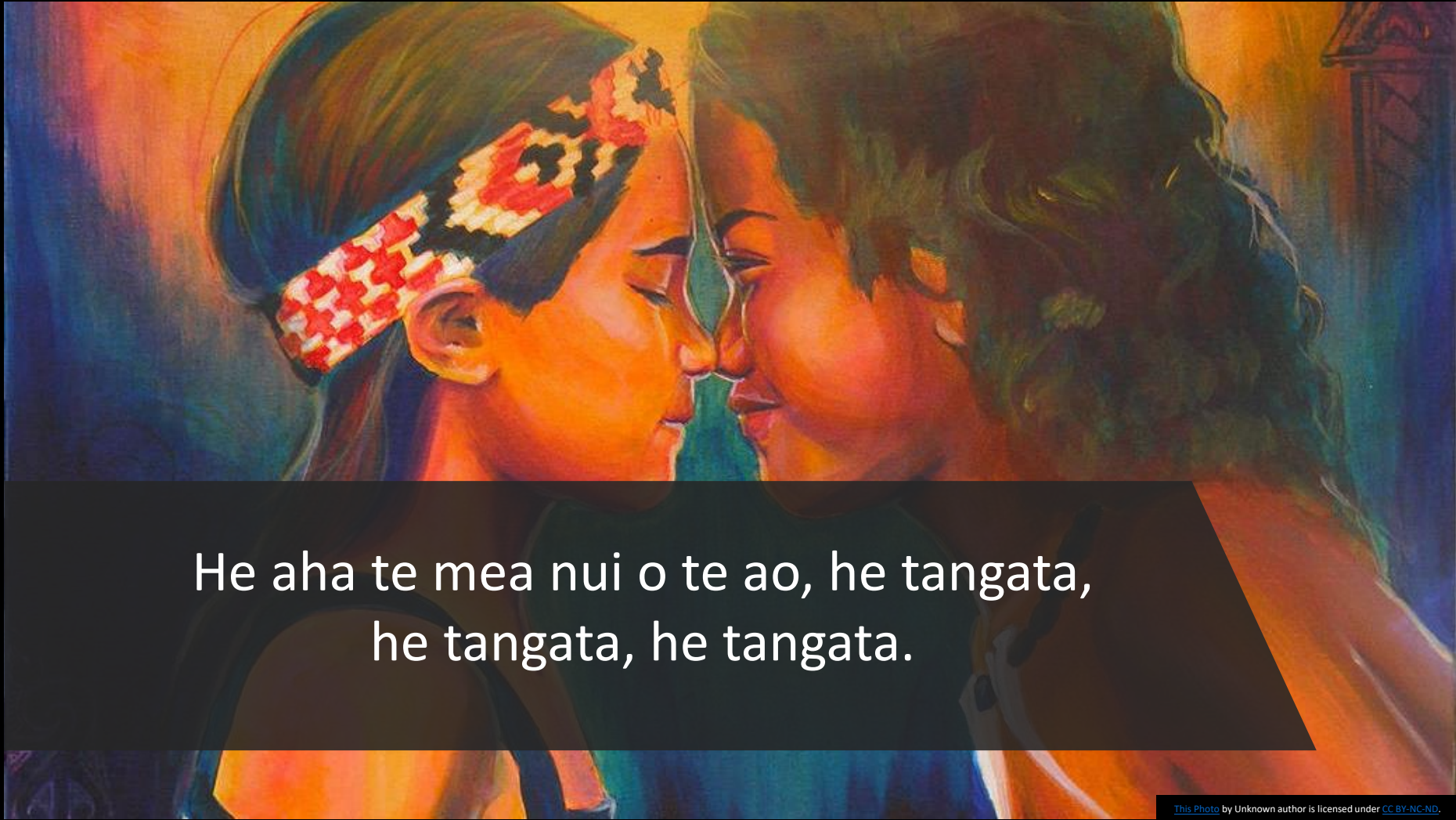
What works for everyone else is **not working** for Māori.

Services need to **redefine** the rules for engagement on Māori terms.

We need to **include** mātauranga Māori in models of care.

Open the space for whānau to be self-determining.

Change how racism and inequity intersect for whānau Māori.



He aha te mea nui o te ao, he tangata,
he tangata, he tangata.

Publications and proceedings

- **Komene, E., Adams, S., & Clark, T. (2022).** Korero mai: A Kaupapa Maori study exploring the experiences of whanau Maori caring for tamariki with atopic dermatitis. *Nursing Praxis in New Zealand Inc.*, 38(2), 12. <https://doi.org/10.36951/27034542.2022.09>
- **Komene, E., Adams, S., & Clark, T. (2022).** Korero mai: A Kaupapa Maori study exploring the experiences of whanau Maori caring for tamariki with atopic dermatitis. Referenced in Skin Infections. Cure Kids, New Zealand Child & Youth Epidemiology Service, Paediatric Society of New Zealand, Royal Australasian College of Physicians. State of child health in Aotearoa New Zealand 2022. Auckland: Cure Kids; May 2023.
- **Komene, E. (2022).** Exploring the experiences of whānau Māori caring for their tamariki with atopic dermatitis. *School Of Nursing Research Showcase 2022*. Auckland, New Zealand: The University of Auckland. 17th November 2022.
- **Komene, E. (2022).** Kōrero Mai: A Kaupapa Māori study exploring the experiences of Māori parents caring for children with atopic dermatitis. *Te Tiriti-Based Futures: Anti-Racism 2022*. Auckland, New Zealand. 28th March 2022.
- **Komene, E. (2020)** Kōrero Mai: a narrative inquiry exploring the experiences of Māori parents and careers of children with atopic dermatitis. *Māori Nursing Research Seminar 2021*. Auckland, New Zealand: Counties District Health Board. 25th November 2020.

Any patai?