Whitia Kia Ora: a culturally responsive model of Bicillin L-A® delivery for people with rheumatic fever in the Waikato region of Aotearoa New Zealand

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ABSTRACT

AIM: Acute rheumatic fever (ARF) is an autoimmune response to group A *Streptococcus* (Strep A) infection that can lead to rheumatic heart disease (RHD). To prevent Strep A infection for people with ARF or RHD, clinical guidelines recommend monthly intramuscular penicillin (Bicillin L-A®) injections for at least 10 years. However, multiple barriers to accessing healthcare affect adherence. This research aimed to improve adherence by developing a Māori and Pacific–centred model of care.

METHODS: Qualitative, Kaupapa Māori and Kakala methodology underpinned the research. Data collection from people in the Waikato region with ARF, their whānau and healthcare providers included interviews, wānanga and fono. Data were analysed using a general inductive approach.

RESULTS: Forty-seven participants were included: nine people with ARF, 10 whānau, eight health professionals and 21 whānau navigators. Three themes were identified: impacts of a colonial health system on Indigenous whānau; life defined by a disease status; and catalysts of healthcare engagement. A community informed, Whānau Ora model of care was also developed.

CONCLUSION: Indigenous methodologies are effective methods to develop community informed, culturally responsive models of care. Although designed for ARF in Waikato, there is potential to adapt this approach for other health conditions and different regions of Aotearoa New Zealand.

Acute rheumatic fever (ARF) is an autoimmune response to group A *Streptococcus* (Strep A) infection, historically in the throat. ARF is influenced by social determinants of health including institutional racism, poverty, household crowding, poor housing conditions and limited access to primary healthcare.[1–3] In Aotearoa New Zealand, ARF almost exclusively affects Māori and Pacific children aged 5–14 years old.[4] The most severe sequela is rheumatic heart disease (RHD) with mitral and/or atrial valve damage.[5] People with RHD are at risk of multiple complications including heart failure, stroke, the need for multiple cardiac medications, and many require cardiac operations; at worst, it is fatal, at best, it is preventable.[5]

At the time of this research (2020), Waikato had one of the highest rates of ARF hospitalisation nationally, with a rate of 3.4 per 100,000 population reported in 2020/2021. This was exceeded by Northland with a rate of 6.6 per 100,000 population, and Lakes District Health Board and Hawke's Bay with rates of 5.1 and 3.9 per 100,000 population respectively.[6]

Current ARF health services operate at primary and secondary levels. Primary care focusses on prompt sore-throat diagnosis and treatment, while secondary care aims to prevent disease progression. People with ARF require frequent secondary prophylaxis, typically given as intramuscular benzathine penicillin G (BPG/Bicillin L-A®) injections every 21–28 days in Aotearoa New Zealand for a minimum of 10 years.[7] This regimen is critical to prevent further ARF episodes, progression to RHD, the need for cardiac surgery and, ultimately, premature death.[7]

Although secondary prophylaxis with penicillin is supported by evidence[8] recurrences of ARF still occur, predominately for Māori and Pacific rangatahi (youth between 15 and 24 years).[9]

Recurrences related to non-adherence highlight systemic challenges in secondary prophylaxis services. As of April 2019, 22.5% of patients on the Waikato ARF/RHD register were receiving Bicillin L-A® intermittently and 11.8% were lost to follow-up (including patients who were unable to be located, had declined prophylaxis or had moved within or between regional ARF health services).[10]

Research on Māori and Pacific people's experiences of ARF secondary prophylaxis has identified the significant impact that an ARF diagnosis and treatment has on people with ARF and their whānau (families). This literature highlights mismatches between ARF services and the contexts of people with ARF and their whānau, particularly for rangatahi.[2] Whānau and health providers reported difficulties with Bicillin L-A® provision, identifying challenges in transitioning from paediatric to adult ARF/RHD services, experiences of racism and structural barriers. These service gaps contribute toward missed injections, recurrent episodes of ARF and increased incidence and severity of RHD.[2] The impact of these gaps is further supported by an audit of recurrent ARF episodes from 2010 to 2014 commissioned by the Ministry of Health – Manatū Hauora, which found that the highest recurrence rates occurred among rangatahi Māori and Pacific people over 15 years who were non-adherent to Bicillin L-A® injections.[9]

These studies highlight notable gaps in culturally responsive, age-appropriate care for rangatahi Māori and Pacific people with ARF and RHD. This research aimed to bridge these gaps by developing a rangatahi Māori and Pacific patient-centred model to improve ARF secondary prophylaxis health services and treatment.

Methods

Consultation and ethics

Ethics approval was granted in 2020 from the Health and Disability Ethics Committee (reference ID 10798). Prior consultation was undertaken with iwi, hapū, people with ARF/RHD and their whānau, and healthcare professionals working in ARF contexts.

Methodology

The Indigenous methodologies of Kaupapa Māori and Kakala framed the study that was led by Māori and Pacific researchers. Kaupapa Māori operates under a decolonising lens by simultaneously critiquing colonial power structures and employing Māori epistemologies, allowing research to operate within an empowering, critical framework avoiding cultural deficit explanations.[11]

Kakala is a participatory Pacific research approach that symbolises the Tongan garland-making process through the three stages of research: toli (data collection); tui (data analysis); luva (dissemination of findings).[12]

Research sites

The research was based across three areas in Waikato: Kirikiriroa/Hamilton, Rāhui Pōkeka/Huntly, and Ngāruawāhia. These areas were identified during community consultations and provided diversity of rural and urban locations, Māori and Pacific ethic groups and ARF/RHD health services. Waikato ARF/RHD services included community-based (home, school and work) and clinic-based delivery to approximately 175 people with ARF when the research began in 2020 (in: email from Kelly Reddington on 10 February 2020).

Participants

Two groups of participants were included in the study:

1. People on secondary prophylaxis, and their whānau, who self-identified as Māori and/or Pacific (including tamariki [children under the age of 15 years] and rangatahi).
2. Health professionals involved in Bicillin L-A® provision and ARF/RHD contexts in Waikato, and whānau navigators who provide advocacy, support and guidance to whānau to achieve better health outcomes.

Recruitment

People receiving secondary prophylaxis were identified through the Waikato ARF/RHD register as currently receiving Bicillin L-A® from a Waikato-based health professional. They were asked to take part in the study and if interested were contacted by a researcher and provided with information and consent forms.

Healthcare professionals were identified and recruited using purposeful sampling via existing community contacts in Waikato. Recruitment occurred through word of mouth or email.

Data collection

Data collection occurred across COVID-19 restriction periods (2020–2022), which meant that

most of the interviews were held online following approaches outlined by Phillipson-Puna and colleagues.[13] Whānau interviews, wānanga (Māori culturally based workshops) and fono (Pacific culturally based workshops) were used to gather perspectives from people receiving Bicillin L-A®, and their whānau, on how current ARF secondary prophylaxis services could be improved. Each of these Indigenous methods drew on cultural protocols and norms including karakia (blessings), prayers, whakawhanaungatanga (creating and maintaining relationships/relating well to others), providing koha (acknowledgements) and, if in person, sharing kai (food).

Wānanga, following the same Indigenous approaches, were held with Waikato healthcare professionals and whānau navigators to gather their perspectives on the findings and the proposed model of care, particularly the implementation feasibility of the model.

Analysis

Audio data from whānau interviews, wānanga and fono were transcribed verbatim and, when needed, translated into English. Data were independently coded by two Māori, two Pacific (Niuean and Rarotongan/Samoan) and one Pākehā (New Zealand European) researcher. Ethnic concordance in data collection and analysis allowed for more fluid communication, mutual trust, understanding and prioritisation of cultural values and contexts. The analysis aimed to provide a broad understanding of participants' experiences of ARF care to help ground and inform the model of care. To achieve this aim, a coding framework was developed collectively by the researchers. The framework was used to guide thematic analysis using a general inductive approach[14] to identify broad themes from the coded data. The coding framework was shared with the broader research team and a Māori researcher with lived experience of RHD.

Model development

The model was developed using an iterative general inductive and deductive thematic approach. Themes from the general inductive findings relating to broad experiences of healthcare (for example tino rangatiratanga—having choice in healthcare), were included in a coding framework. A deductive analysis was also applied to wānanga/fono questions relating specifically to the research aim and recommendations of what elements should be included in the model of care (e.g., whānau navigators, transport support, health information). As the model developed from one wānanga/fono to the next, it was shared with participants for feedback to assist in an iterative co-development of the model. The draft model was then shared with healthcare professionals (including whānau navigators) and independently with a Māori researcher with RHD to gain an understanding of its feasibility in practice.

Results

Forty-seven participants were included in the research. Participants included: eight people with ARF/RHD, 10 whānau members (Table 1), eight healthcare professionals and 21 whānau navigators. Participants ranged in age from tamariki to pakeke (adults). Of the people with ARF/RHD and whānau participants, six identified as Māori, seven as a Pacific ethnicity and five as both Māori and a Pacific ethnicity. The eight healthcare professionals included district nurses and clinical specialists; two identified as Māori, three as Pākehā, one as Tauiwi (non-Māori, non-Pākehā) and two did not disclose their ethnicity. All 21 whānau navigator participants identified as Māori.

Participants provided insights into their broad experiences of ARF healthcare and what an ARF/RHD model of healthcare should entail. Three themes were identified from experiences of healthcare: 1) impacts of colonial health systems on Indigenous whānau; 2) life defined by a disease status and 3) catalysts of healthcare engagement. Each of these are described below, followed by a description of the model.

1. Impacts of colonial health systems on Indigenous whānau

Whānau described a health system that was based on Western culture that emphasised individualised, adult-centric care, limited whanaungatanga, trust and, at times, respect. Some experiences of people with ARF reflected inflexible clinical structures that lacked respect, acknowledgement or consideration of rangatahi life stages, as Putiputi recounted:

> *"It's really hard when you have your period if you've got to pull down your pants* [for the injection], *it's like 'hurry up and get it over and done with'."*

Many participants felt their healthcare provision

Table 1: Description of participants.

People with acute rheumatic fever/rheumatic heart disease and whānau					
Whānau	**Name (pseudonyms)**	**Participant**	**Ethnicity**	**Age group**	**Gender**
1	Kalei	Patient	Māori	Pakeke	Female
2	Mapa	Grandmother	Māori, Tongan	Pakeke	Female
	Pua	Mother		Pakeke	Female
	Totara	Father		Pakeke	Male
3	Leilani	Patient	Rarotongan	Tamariki	Female
	Lose	Mother		Pakeke	Female
4	Siale	Patient	Samoan	Rangatahi	Female
	Malia	Mother		Pakeke	Female
5	Maanuka	Patient	Samoan	Tamariki	Male
	Fiti	Mother		Pakeke	Female
6	Sei	Patient	Māori, Samoan	Tamariki	Female
	Kauri	Guardian		Pakeke	Male
7	Milo	Patient	Kiribati	Pakeke	Female
8	Lehua	Patient	Māori	Tamariki	Female
	Tipani	Mother		Pakeke	Female
9	Putiputi	Patient	Māori	Rangatahi	Female
	Kamomaire	Mother		Pakeke	Female
	Tohetaka	Father		Pakeke	Male
Healthcare professional and whanau navigators					
Name (pseudonyms)	**Role**	**Ethnicity**			
Margaret	District nurse	Pākehā			
Mary	District nurse	Pākehā			
Susan	District nurse	Pākehā			
Mike	Clinical specialist	Tauiwi			
Kiri	Clinical specialist	Māori			

Table 1 (continued): Description of participants.

Healthcare professional and whanau navigators		
Name (pseudonyms)	**Role**	**Ethnicity**
Mana	Clinical specialist	Māori
Sophia	Clinical specialist	Not disclosed
Gordon	Clinical specialist	Not disclosed
Maia	Whānau navigator	Māori
Nikau	Whānau navigator	Māori
Manaia	Whānau navigator	Māori
Anahera	Whānau navigator	Māori
Ana	Whānau navigator	Māori
Wiremu	Whānau navigator	Māori
Ari	Whānau navigator	Māori
Rui	Whānau navigator	Māori
Kaia	Whānau navigator	Māori
Hana	Whānau navigator	Māori
Ataahua	Whānau navigator	Māori
Tia	Whānau navigator	Māori
Kora	Whānau navigator	Māori
Amaia	Whānau navigator	Māori
Ariki	Whānau navigator	Māori
Ihaka	Whānau navigator	Māori

Table 1 (continued): Description of participants.

Healthcare professional and whanau navigators		
Name (pseudonyms)	**Role**	**Ethnicity**
Tama	Whānau navigator	Māori
Tawhiri	Whānau navigator	Māori
Tai	Whānau navigator	Māori
Kai	Whānau navigator	Māori
Mikaere	Whānau navigator	Māori

was often inflexible and not able to accommodate their complex contexts, including juggling work and childcare, lack of transport to access health services and challenges with transport and parking. Some participants noted how health professionals commonly used complex medical jargon that was difficult to understand and described being "*seen but not heard*" in clinical encounters. Whānau navigators also emphasised the importance of providing clear, visual and verbal communication to whānau and using text reminders to assist whānau appointments. Tipani's experience illustrates the challenges with inflexible services and communication whānau experienced:

> *"The communication here* [rural area] *is very poor. It's quite bad here like we have to ring because it* [Bicillin L-A® injection] *has to be done at the hospital* [urban clinic] *and they don't have enough staff and so we're having to ring them to be like 'um it is meant to be today, what time?' And they're like 'oh we can't do it till such and such'. Ever since we've been here, she's had every injection late."*

2. Life defined by a disease status

People with ARF described how an ARF/RHD diagnosis and the associated label often felt disempowering. This affected their interpersonal relationships, eroded their confidence and aspirations, and created a stigma where they felt they lost or had to re-negotiate their identity by embodying the disease. As Milo stated:

> *"Because it's quite embarrassing, like people, they say 'Oh that's the girl who has that heart disease', like I'd just rather stay home than go out."*

Definitions of and discourse around ARF and RHD were attributed to the recolonisation of Indigenous bodies, where racialised associations of the diseases with Māori and Pacific people placed blame on these communities. Participants felt that this discourse impacted policy and health practices. For rangatahi, this association often ignited feelings of anger, fear and mistrust, as described by Putiputi:

> *"They were racist as. They* [health professionals] *were like, 'it's* [ARF] *only common in your people, it's only your people and the Polys* [sic]*."*

Healthcare professionals were also aware of the ARF stigma, and Margaret noted the importance of "*normalising the conversations and not make it taboo*".

3. Catalysts of healthcare engagement

Participants were able to identify key facilitators of their ARF/RHD healthcare experience that promoted engagement with health services. Having access to culturally safe spaces where whānau felt included and valued were important

for participants, especially at the diagnosis stage. Whanaungatanga was also seen as an important facilitator for healthcare professionals, as Kiri stated:

> *"Cultural safety* [training] *comes and goes, cultural safety always comes down to relationship building."*

Practices such as whanaungatanga and being able to access ethnically concordant health professionals were valued by whānau, as noted by Kamomarie:

> *"There was a positive … we had a Māori doctor come to us … we relaxed better when we were around our own people because he made us feel more at ease."*

Having flexible health services that could accommodate whānau schedules and ongoing communication and support were considered helpful for participants. For rangatahi and tamariki, the use of pain management for the injections, which were commonly described as painful, and using incentives and distractions were also considered helpful, as Maanuka explained:

> *"Sometimes when they're talking to me it takes my mind off the injection. Something to distract me from thinking about it too much and making it worse. When I started I wasn't too keen on getting them* [injections]*, but I got chocolate fish."*

Development of Whitia Kia Ora

When the draft model was presented to health professionals and whānau navigators, the feedback was positive and supportive. They endorsed all seven elements of the proposed model and many empathised with the challenges whānau experienced with transport, parking, adequate health information and pain associated with injections. Healthcare professionals noted the importance of including a whānau navigator in the model to assist stretched clinical environments with high workloads and staff shortages. They also recommended that the model would need external funding as Mary explained:

> *"We need funding because it may run on love but not all the time."*

Whānau navigators felt the model reflected good practice and embodied whānau values and contexts well. For them, the strength was in filling a recognised gap in the health system, as Nikau stated:

> *"I think the main thing is to bridge the gap between the medical side of this and the community. We just need to fill that gap."*

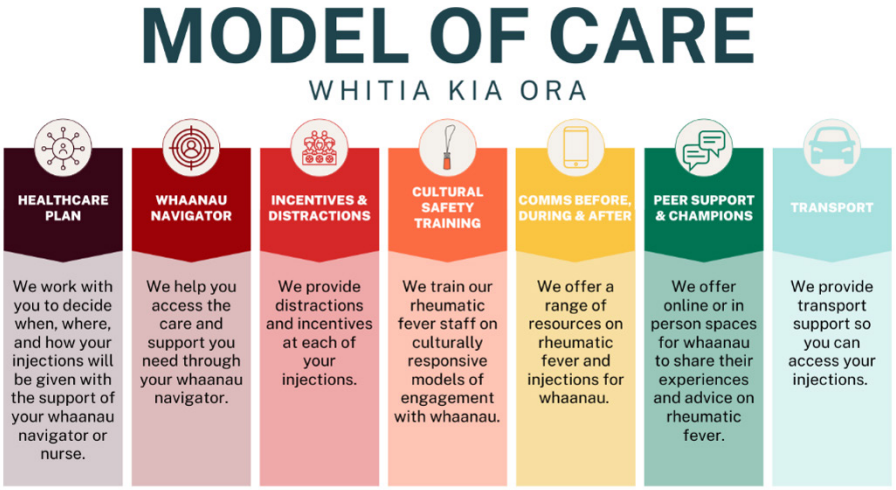
The finalised model of care, Whitia Kia Ora, comprises of seven key elements (Figure 1). It is a multifaceted, holistic model founded on a culturally responsive approach to healthcare delivery. It applies a Whānau Ora approach, centring whānau in health services via provision of support, connection and decision making.[15] The model empowers rangatahi and their whānau to decide what Bicillin L-A® and health information delivery works best for them. A critical element of this model was cultural safety implemented within the service delivery. ARF/RHD–specific training was developed for Bicillin L-A® providers to encourage a critically reflective and responsive healthcare practice that is evaluated by people with ARF/RHD and whānau. The model was implemented in Rāhui Pōkeka, Ngāruawāhia and Kirikiriroa for 12 months.

Discussion

The research into the development of a culturally responsive model of care for Bicillin L-A® delivery in Aotearoa New Zealand demonstrated gaps in ARF/RHD health services. These gaps ultimately stem from a health system based on Western colonial values[16] that places power on health providers rather than health users, privileges individual rather than whānau-based care and prioritises clinically based rather than community-placed healthcare. These colonial biomedical approaches are non-inclusive of and Māori and Pacific people's cultural values, encourage the use of jargon heavy communication by health professionals, and create inflexible health services and the deficit impacts of ARF/RHD stigma arising from racialised language used in health service and health policy discourses. These findings are not novel and are consistent with a growing body of ARF/RHD research.[2,17,18]

One of the key outcomes of this research is highlighting the urgent need to improve the cultural safety of health services in Aotearoa New

Figure 1: Whitia Kia Ora model of acute rheumatic fever/rheumatic heart disease Bicillin L-A® delivery.



Zealand to assist people with ARF and whānau to feel more included, respected, and heard in their healthcare journeys. The 2024 *Aotearoa New Zealand Guidelines for the Prevention, Diagnosis, and Management of Acute Rheumatic Fever and Rheumatic Heart Disease* recommend that cultural safety is "*prioritised in health services for sore throat, ARF and RHD management*".[7] Developing, implementing and evaluating a cultural safety training programme specifically for ARF Bicillin L-A® providers could be a useful intervention to address this challenge.

Additionally, the research identified key facilitators of engagement with ARF/RHD health services, including flexible Bicillin L-A® appointments and delivery allowing whānau to get prophylaxis delivered at times and places that worked into their busy lifestyles, and access to culturally safe healthcare spaces and practices. Strengthening these facilitators of care through Whitia Kia Ora could improve secondary prophylaxis adherence, reducing the inequitable rates of recurrent ARF and RHD in Aotearoa New Zealand. Mana Tū is a culturally responsive, co-designed model of care for people with type 2 diabetes.[19] Mana Tū, as with Whitia Kia Ora, is based on a Whānau Ora approach where whānau navigators, trained in cultural safety, work alongside patients. Evaluations of Mana Tū demonstrated its effectiveness in improving the blood sugar levels, blood pressure, lipid levels, body mass index and smoking status of patients, demonstrating the strength of culturally responsive, community-informed Indigenous models of care.[20] Following the 12-month implementation of Whitia Kia Ora, it will be evaluated to assess its responsiveness to people with ARF and their whānau, and if it improves Bicillin L-A® adherence. It is hoped this evaluation will show a positive effect on health outcomes.

One limitation of this research is its geographic application in the Waikato region, whose demography and health services may differ to other regions of Aotearoa New Zealand. Therefore, the findings may not be representative of other national regions. The data collection commenced during 2020–2022, when COVID-19 restrictions affected healthcare access at national and regional levels, and may have affected participants' perceptions of their healthcare. No healthcare professionals or whānau navigators of Pacific ethnicities were included in the study. This sampling may impact the responsiveness of the model to Pacific communities and will need more Pacific-focussed research. The study included a disproportionate number of health professionals —particularly whānau navigators—compared to people with lived experience of ARF. This may have created a bias in the Whānau Ora–focussed

approach of the model.

Despite these limitations, Whitia Kia Ora remains an example of how Indigenous methodologies can be used to develop culturally responsive models of ARF healthcare. This model has the potential to be adapted for different health contexts and to different regions of Aotearoa New Zealand, and perhaps internationally, to improve adherence and the unacceptable rates of these preventable diseases, shifting the research from exploratory to translational and impactful for people most affected from ARF and RHD.

COMPETING INTERESTS
Nil.

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