Co-design of youth appropriate services for young people with rheumatic fever/rheumatic heart disease in Counties Manukau District

Lucy Wong, Agnes Wong, Lynne Maher, Bridget Farrant, Kate Palmer-Neels, Fofoa Pio, Philippa Anderson, Belinda Paku

ABSTRACT

AIM: To co-design a rheumatic fever service model which enables young people with acute rheumatic fever/rheumatic heart disease (ARF/RHD) and their families to access the health and wellbeing services they need.

METHOD: Co-design, a collaborative and participatory approach, was used to gather experiences and ideas from 21 consumers and 30 health professionals. Thematic analysis was undertaken.

RESULTS: Māori and Pacific patients and their whānau/aiga identified the importance of whānau/aiga support and involvement throughout their ARF/RHD journey. They described that the way care was delivered was often frustrating, fragmented and lacked effective communication. Participants expressed the need for information to improve their understanding of ARF/RHD. Health professionals identified the need for better continuity of care and felt that they were currently working siloed from other professionals with little visibility of other roles or opportunity for collaboration. The ideas for improvement were grouped into themes and resulted in development and prototyping of peer support groups, patient and staff education resources, clinical dashboard and pathway development, and an enhanced model of care for delivery to patients receiving penicillin prophylaxis.

CONCLUSION: The co-design process enabled consumers and staff of ARF/RHD services to share experiences, identify ideas for improvement, co-design prototypes and test initiatives to better support the needs of those delivering and receiving ARF/RHD services.

The incidence of rheumatic fever in Aotearoa New Zealand is much higher than in comparable countries and regions such as North America and the United Kingdom. Within Aotearoa New Zealand, the incidence varies greatly by geographic region and ethnicity. Māori and Pacific peoples are disproportionately affected, for both acute rheumatic fever (ARF) and chronic rheumatic heart disease (RHD).

Counties Manukau has the highest burden of ARF/RHD of any region in Aotearoa New Zealand. In 2021, 26 out of 94 new cases of ARF nationally were from Counties Manukau District, and 14 of these were in young people aged 15–24 years at the time of diagnosis. It should be noted that this relies on ICD coded discharge data, which has been shown to over-estimate cases of rheumatic fever. People diagnosed with ARF require secondary prophylaxis (usually a monthly injection of benzathine penicillin G [Bicillin]), generally for 10 years or until they reach 21 or 30 years of age, depending on degree of cardiac involvement, alongside dental, rheumatic fever specialist clinic and cardiology (including echocardiography) follow-up. This places considerable burden on young people and whānau. Concern has been raised that the health system may not be providing developmentally and culturally appropriate care that would benefit young people and whānau/aiga.

In 2020, Manatū Hauora – Ministry of Health allocated funding to Counties Manukau Health (CMH) to prototype changes and improve services for young people aged 12–24 with ARF/RHD. The aim was to strengthen age appropriateness and cultural competency of the service and deliver a holistic service that meets the health needs of young people.

This study used a participatory co-design approach to gather patient, whānau/aiga and health professionals’ experience and to enable them to design potential solutions to improve the rheumatic fever service. It had two phases:

1. To understand the experiences of young people, their whānau/aiga and health
professionals using the ARF/RHD services in the South Auckland community and support them to identify any ideas for service improvement.

2. To co-design and test solutions based on the experiences and ideas shared.

Phase one

Phase one focused on understanding the life journey, experiences and ideas for improvement from young people, their whānau/aiga and health professionals using the ARF/RHD services in the South Auckland community. A Consumer Advisory Group (CAG) was established, who supported the project team, providing expertise in personal experiences of ARF/RHD, Te Ao Māori and Pasifika worldviews.

Phase one methods

Study design

Phase one consisted of engaging patients, whānau/aiga and health professionals, gathering experiences and ideas through interviews and hui and undertaking thematic analysis of these data.

Setting and location

The study was conducted in Counties Manukau between June and November 2021. A range of disruptions caused by the global COVID-19 pandemic particularly impacted on the recruitment and engagement of patient and whānau/aiga participants.

Ethics approval was obtained from Auckland Health Research Ethics Committee (reference: AH22496).

Data collection

Patients and whānau/aiga

To ensure recruitment of a representative sample, a purposively selected sample seeking diversity of both ethnicity and disease severity was considered. Based on patient registration information for young people receiving healthcare for ARF/RHD in Counties Manukau, approximately 40% identify as Samoan ethnicity, 25–30% are NZ Māori, 15% are Tongan and 15% are of Cook Island ethnicity. Patients with differing levels of severity are likely to have different experiences, so engagement was sought with young people from each of the following groups:

1. History of ARF with no or mild cardiac involvement prescribed Bicillin prophylaxis.
2. Moderate to severe RHD disease with no history of valve surgery prescribed Bicillin prophylaxis.
3. History of ARF with RHD and post-valve surgery (includes those with valve repair, replacement with homograft valve and replacement with mechanical valve requiring warfarin anticoagulation) and prescribed Bicillin prophylaxis.

In line with a pro-equity and pro-Te Tiriti approach, this study aimed to oversample Māori to ensure the Māori voice was adequately captured. The aim was to recruit 15 Pasifika young people and 15 Māori young people and their respective aiga/whānau.

Initial contact inviting participation was made by a familiar staff member between late July and early August 2021. Of those who expressed an interest to participate, most preferred an in-person interaction. Aotearoa New Zealand moved into COVID-19 Alert Level 4 on 17 August 2021 and engagement ceased at that time. When Auckland moved to COVID-19 Alert Level 3 on 21 September 2021, participants were contacted by Māori and Pacific (Samoan) researchers contracted to CMH to ascertain if they were still interested in sharing their experiences and offering this via Zoom. Zoom enabled some conversations to happen; however, there were barriers to participation, including anxiety relating to security and confidentiality, and technological challenges including no internet access and lack of familiarity with Zoom. Some whānau/aiga did not have computers but were able to join Zoom via their smart phones. While this did support the interview taking place, it was challenging to see and connect with multiple whānau/aiga due to the small screen.

Five Māori young people and their whānau and eight Samoan young people and their aiga were able to be interviewed via Zoom. One Samoan young person and their aiga were interviewed in a socially distanced arrangement outdoors, once restrictions allowed this.

Health professional participants

Health professionals (HPs) involved in rheumatic fever care were identified by lead clinicians. This included clinicians from primary and secondary care with a range of experience and work in the area of rheumatic fever—from those working solely providing care and leadership in rheumatic fever to clinicians who may deliver...
intramuscular (IM) Bicillin as part of their broader work. Most clinicians had provision of rheumatic fever care as a small component of their employment.

Note: Some participants self-identified in more than one demographic category, which means the total numbers are more than 30 participants.

**Data analysis**

All patients and whānau/aiga interviews/hui were recorded, analysed and written up by the Māori and Samoan researchers who facilitated the interviews/hui. Health professionals’ interviews were recorded, transcribed verbatim and entered on NVivo software. Transcripts were coded and HPs’ experiences were analysed using the Braun and Clarke’s six step method for thematic analysis.\(^\text{15}\)

**Phase one—findings**

A) Patients and whānau/aiga

Three intersecting themes were identified from the Māori and Samoan interviews and focus

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**Table 1:** Interviewed patients and accompanying whānau/aiga.

<table>
<thead>
<tr>
<th>Age of the young person</th>
<th>Ethnicity</th>
<th>Whānau/aiga who participated alongside the young person</th>
</tr>
</thead>
<tbody>
<tr>
<td>12–15 years old</td>
<td>Samoan (1)</td>
<td>Samoan (4)</td>
</tr>
<tr>
<td></td>
<td>NZ Māori (2)</td>
<td>NZ Māori (4)</td>
</tr>
<tr>
<td>16+ years old</td>
<td>Samoan (7)</td>
<td>Samoan (1)</td>
</tr>
<tr>
<td></td>
<td>NZ Māori (2)</td>
<td>NZ Māori (2)</td>
</tr>
</tbody>
</table>

**Table 2:** Thirty interviewed health professional participants.

<table>
<thead>
<tr>
<th>Years of work with RF service (grouped)</th>
<th>Ethnicity</th>
<th>Professional group</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;20 years</td>
<td>NZ Māori (1) NZ European (3)</td>
<td>Doctor (3)</td>
</tr>
<tr>
<td>16–20 years</td>
<td>NZ Māori (2) NZ European (2)</td>
<td>Nurse (1) Play Specialist (1)</td>
</tr>
<tr>
<td>10–15 years</td>
<td>NZ Māori (3) NZ European (4)</td>
<td>Doctor (4) Nurse (2)</td>
</tr>
<tr>
<td></td>
<td>Samoan (1)</td>
<td>Play specialist (1)</td>
</tr>
<tr>
<td></td>
<td>Cook Island Māori (1)</td>
<td>Support worker (1)</td>
</tr>
<tr>
<td></td>
<td>Other European (1)</td>
<td></td>
</tr>
<tr>
<td>6–9 years</td>
<td>NZ Māori (1) NZ European (1)</td>
<td>Dentist (1) Pharmacist (1)</td>
</tr>
<tr>
<td>2–5 years</td>
<td>NZ Māori (1) NZ European (6)</td>
<td>Nurse (8) Pharmacist (1)</td>
</tr>
<tr>
<td></td>
<td>Samoan (2)</td>
<td>Play Specialist (1)</td>
</tr>
<tr>
<td></td>
<td>Indo-Fijian (1) Indian (1)</td>
<td>Social Worker (1)</td>
</tr>
<tr>
<td>≤1 year</td>
<td>NZ Māori (1)</td>
<td>Nurse (3) Social Worker (1)</td>
</tr>
<tr>
<td></td>
<td>Cook Island Māori (1)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Samoan (1) Tongan (1) Indian (1)</td>
<td></td>
</tr>
</tbody>
</table>
groups, and one subtheme was specific to aiga.

Whānau and aiga-centred care

Whānau is used here to reflect a Māori view of whānau, which includes relatives, friends and the community. Participants noted that aiga comprises of parents, siblings, partners, grandparents, aunts, uncles and church family.

Māori and Samoan participants stressed the importance of having their whānau and aiga involved in their healthcare at all stages. Whānau (Māori participants) and aiga (Samoan participants) acted as crucial supporters and advocates for the young people, particularly as most participants expressed that there was a lack of social support available for whānau/aiga. Māori and Pacific participants suggested opportunities to create a rheumatic fever support group as a space to connect with those who have similar lived experiences of rheumatic fever, either online or in-person. Most Samoan participants suggested that a dedicated support person for aiga was important; a support person would have a sound understanding of rheumatic fever and the care required, act as a conduit for information and provide moral support and an advocate for the young person and aiga. Peer support that involves whānau/aiga and is provided in culturally safe settings, e.g., churches or community centres, was suggested.

“She (my mum) even fought to stay the night with me, because I said to her ‘like, Mum I know I’m 21 but like I’m just, can you stay? This is weird and this is new to me, we don’t know what’s going on.’ At the time, especially waiting to have a heart scan, I was super anxious and scared” – Māori patient

“I just like the plain simple language, I like them to dumb it down for me, because I’m not going to say ‘yes, yes,’ like I know when there's big as words that I can't understand. English is not my forte, and that's all they speak out there.” – Whānau member

Whānau/aiga discussed the importance of open and clear communication so that they can be well-informed and involved in decision-making. The communication experienced by whānau/aiga was predominantly verbal, one-way (from health professional to patient) without input from whānau and aiga and they described the excessive use of medical jargon.

“I know he needs to talk to somebody because half of the time he doesn’t even know what he’s got.” – Aiga member

“Communication is what we need ... because we don’t know, all we know is [the] injection every month. That’s it, [we] don’t see it till next month. There’s no communication with what’s going on with her and that communication is what we need.” – Whānau member

Clear, open communication that supports whānau/aiga involvement in decision-making

Whānau/aiga suggested user-friendly modes of information delivery, such as the use of simple language; whānau felt that written information might be helpful, and aiga encouraged the use of simple, coloured pictures and diagrams.

“When I was in hospital, they didn’t give any information on paper or anything like that, it was all verbal ... It would have been cool to have it on paper so I could read it, and basically have what it is, to explain what it actually is in a form of not those big words, just something simple.” – Māori patient

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Māori participants varied in their desire for communications in te reo Māori. However, Samoan young people and aiga shared that it was important to have the option to translate communications into the Samoan language, particularly for their parents, grandparents and elders of the aiga for whom English may not be their first language.
“Translate it into our languages, like Samoans talking to Samoans, we understand each other. [By doing that] people can relate to each other.” – Samoan patient

Additionally, Samoan participants suggested the need for increased awareness of rheumatic fever prevention within the Pacific community. These included reaching Pacific communities (i.e., via churches, community groups and Pacific radio stations) through engagements that are Pacific-led, delivered in Pacific-specific languages, and tailored to the multi-generational make-up of Pacific communities and aiga.

“We [had] a high school programme about rheumatic fever. All these kids were there, and they were showing us what the heart looks like, and what valves are repaired when you have rheumatic fever. It was cool, so using the pictures is a good idea … A visual way of showing [little kids] would be a whole lot easier, rather than trying to explain something and not knowing how to get it across.” – Aiga member

Healthcare practices centred on patient needs rather than system needs

Issues raised included a lack of transport, the clinic location and opening hours of clinics, and that home visits were preferable as this reduced the burden on whānau/aiga to organise childcare and transport. Whānau/aiga felt regular check-ups would improve the service as they often felt anxious about their child's health. The lack of continuity of care resulted in frustration and confusion for some whānau/aiga about which person or department they should contact when they needed help. Whānau valued quality of care more than continuity of care. For most aiga, the continuity of care was critical, as it enabled rapport and trust building with health professionals, reduced the likelihood of missing information and lessened the pressure placed on young people and aiga to recall details from previous appointments and medical histories.

“I have to remember how long I've done my injection for ... My nurses are always like, ‘are you due to finish this soon?’ and I’m looking at her like ‘I don’t know. I don’t know when I’m going to finish, no one tells us, you haven’t given me any information on that.’ I have to go back and count [all the years] when I got my surgery.” – Samoan patient

“If you had that person that you feel empathised with you, and gave a damn about your son’s health, then you would feel more vulnerable to release whatever they’re wanting. There’s just a big gap between doctor and their families” – Aiga member

B) Health professional participants

Five themes emerged from the HPs’ interviews.

RF nurse specialists are invaluable supports to the wider team

Overall, RF nurse specialists were described as invaluable supports to the wider team, particularly as liaisons between primary and secondary levels of care.

Workforces should be more reflective of the community

Professionals felt that to help deliver more culturally appropriate care, the RF workforce should be more reflective of the community and culturally competent to support care and engagement of patients and their whānau/aiga.

Healthcare practices are often centred on system needs not patients’ needs

Barriers to the patient receiving equitable care included fixed clinic and lab operation hours, transportation, clinic locations and high treatment costs. Inconsistencies were found in HPs’ knowledge of care pathways, which impacted on delivery of consistent care and care planning. The broader health needs of young people, rather than their health condition alone, were often overlooked due to time constraints. Staff were keen for improved staff education and clearer treatment pathways to support staff practice focused on patient needs.

“We've got a multidisciplinary meeting happening, but we don't have a multidisciplinary approach. What I mean is, we're still working in silos.” – Pacific Nurse

“The thing that frustrates me most of all is that the RF Clinic is supposed to be a multidisciplinary clinic, it’s supposed to be
a one-stop-shop for children, adolescents and young people. That's the model for adolescent medicine. If you want to engage young people in their healthcare, then you need to make it easy to do that. They don't need to get six different appointments to go to six different places at six different times to keep themselves well." – Doctor

**Lack of appropriately resourced ARF/RHD clinical services**

High outpatient waitlist volumes, competing clinical priorities and demands from multiple clinical tasks, alongside caring for people with ARF/RHD, placed additional stress on HPs to meet the care needs of their patients.

“...The time doesn’t allow us when would like to do more for our patients.”
– RF Clinical Nurse Specialist (CNS)

“Over the years that I’ve been working in the clinic, it has become overwhelmed by the number of patients that we see, and it is nowhere as good a clinic as it used to be.” – Doctor

**Collaborative and coordinated multidisciplinary ARF/RHD services are needed**

Health professionals are mostly working in silos and have little visibility of other roles working within the ARF/RHD service. Staff recognised a lack of well-established pathways for working together. When collaboration does occur, it is often late in the patient’s care journey, which limits the ability for patients and whānau/aiga to access a range of support services that they may need. However, when multidisciplinary collaboration happens, it is considered a useful forum to get to know other ARF/RHD colleagues.

“We should come in somewhere at the beginning, but we’re asked to come in at the end part, where they’re (the patient) at high risk ... it’s like being a GI Jane to connect and re-engage them.” – RF CNS

“We act only when patients are not adhering to their medication, instead of proactively working towards preventing that from happening ... The ability for us to be able to think ahead and provide ahead of time can mean unnecessary hospital admission.” – RF CNS

**Phase two—ideation and service design**

This second phase of the project was to provide an opportunity for health professionals, patients and their whānau/aiga to review the improvement ideas and select some to prototype and test. A summary of experiences and ideas captured in phase one was synthesised and shared with the participants to generate conversations about ideas for service improvement.

**A) Young people and whānau/aiga**

The intention was for all young people and their whānau/aiga from the first phase to be invited to participate in a second workshop-style hui to review the experiences and identify ideas for service improvement. However, COVID-19 restrictions impacted on this. Two Māori young people with one whānau member each and one aiga member participated in a separate hui. Feedback included the need for age-appropriate, multi-lingual, understandable written resources that provided specific information relating to the patient’s life journey of ARF/RHD. Improvements identified by whānau/aiga related to access to clinics, which can be challenging. Ideas included the provision of plenty of notice for appointments, the provision of transportation if needed and the opportunity for home visits when that was more appropriate for whānau/aiga. It was also felt that more regular check-ups, not just when clinicians feel it is indicated, would provide helpful reassurance to whānau/aiga that their child was well. Having regular visits from the nursing team was identified as an opportunity where care beyond simply providing the Bicillin injections could be provided. Importantly, this would also build whanaungatanga and trust so that patients and whānau/aiga feel they could ask for more support if needed.

In order to facilitate whānau/aiga-centred care, improve kōrero/talanoa and reduce barriers to good healthcare, ideas included the need for a specific role or key contact person for whānau/aiga to connect with to support them to access the right care at the time they need it.

**B) Health professionals**

All health professionals that had been interviewed were invited to join one of three online workshops/hui to select ideas for initial testing.

From the health professional workshops/hui, a range of improvement ideas, many of which were
common with patients and whānau/aiga emerged. These formed into three key areas:

- **Education**—that better met the needs of patients, whānau/aiga and health professionals.
- **Systems and technology**—to allow for better streamlined information between and within services.
- **Comprehensive and coordinated care**—a broad overarching area of focus which included access to services available.

A prioritisation tool was developed to enable staff participants to identify from their perspective which ideas should be tested first. The tool (Appendix 1) enabled consideration of equity, impact to patients and whānau/aiga, impact for Māori and alignment with Te Tiriti and impact for the way clinicians care for their patients.

In addition, after these workshops, a workshop was held with CAG members to review and discuss the ideas that the health professionals had prioritised. The CAG confirmed that ideas that were important from a patient perspective had been prioritised.

**Improvement actions**

The following improvement ideas have been prototyped and tested as a result of the co-design approach to improving ARF/RHD services for young people at CMH.

1. **Better meeting the needs of patients, whānau/aiga and health professionals through connections and education.** Addressing concerns around whānau/aiga centred care, communication gaps and health professionals’ skill development.

**Peer support**

Patients, whānau/aiga and CAG had shared that ARF/RHD was often a lonely journey and they wanted to meet others with the same condition. HPs supported the idea of peer support as a way of providing support for others and empowering young people to manage their condition. Partnership with a not-for-profit organisation, Heart Kids New Zealand, was established to co-deliver a peer support evening with ARF/RHD patients from CMH. Although only a small number of young people attended, they valued the opportunity to connect, and there are plans to deliver additional events in the future.

**Patient resources**

Patients and whānau/aiga expressed the need for resources that focused on the RF journey and what their condition meant for their life, including the need for ongoing secondary prophylaxis and the ability to return to normal daily activities. This needed to be age-appropriate, informative and presented in an easy-to-understand way. Five existing resources from Aotearoa New Zealand and Australia were reviewed by young people and CAG members, who identified information that did or did not work for them. This contributed to the co-design of new resource, “My RF Journey” by clinicians, communication specialists, CAG members and young people (including those with and without ARF/RHD) to ensure that information about RF is youth appropriate and suitable for different stages of the ARF/RHD journey.

**Education videos for health professionals**

Health professionals identified differing levels of knowledge about the management of ARF/RHD patients and felt they would be better supported through access to further information resources. There is a shared recognition that adolescence is complex, cultural needs were not always met, and that the system is currently designed in a way that does not always support young people to receive the care they need.

Four short e-learning modules for health professionals to support the management of ARF/RHD patients and the provision of youth-friendly care have been co-developed—Working with young people with ARF/RHD, Youth Development, Consent and Confidentiality, and Engaging and assessing health and developmental needs of young people. These will be readily accessible by all health professionals working with young people who have ARF/RHD and are designed to be packaged with other modules already used, for example, to support HP developing skills in culturally safe practice.

2. **Systems and technology to facilitate sharing of information and better centre care on patients.**

   Addressing need for patient centred care, communication gaps and collaboration.

**Patient clinical pathways**

Health professionals’ experiences highlighted the need for better consistency of care. Patient pathways specific to the degree of RHD were developed to ensure consistency of care and to
provide clarity regarding the standard of care for patients with ARF/RHD. These were developed together with health professionals based on NZHF Guidelines on what should be the ideal standard of care at Counties Manukau for both Paediatric and Adult General Medicine wards, from admission through to completion of Bicillin. These pathways supplement national ARF clinical guidelines and provided an opportunity for health professionals to identify any gaps and opportunities for improvement to the care pathways. They are now available for health professionals to use and share with patients and whānau.

Patient dashboard

A range of health professionals contribute to ARF/RHD care, including Cardiologists, District nurses, Physicians, GPs, Pharmacists and Dentists. Having this range of professionals working in different systems leads to a lack of visibility for professionals and whānau/aiga as to what care has been provided. Health professionals shared that there was a need to improve coordination of care between services, districts and primary care services. A live electronic platform, which is currently only available to clinicians, has been developed to provide visibility of ARF/RHD patient cohort information in one place. This includes the dates they started Bicillin, their Bicillin adherence rate and clinic attendance. This platform will enable better clinical collaboration and awareness of progress with care.

3. Comprehensive and coordinated care.

Addressing concerns around lack of comprehensive and coordinated care that is developmentally and culturally appropriate.

Enhanced model of care for young people receiving Bicillin prophylaxis

Health professionals, patients, whānau/aiga and CAG experiences all highlighted the need for better continuity and connection of care to promote whānau/aiga trust and engagement with ARF/RHD services. A new nursing and case-management model of care has been piloted whereby patients are supported by a smaller team of nurses with expertise in district nursing and youth health, who provide their monthly Bicillin injections and have protected time to offer proactive, holistic wrap-around youth-centred care as needed. This model of care enables patients to build a relationship with a smaller team of nurses during their ARF/RHD journey and increases flexibility for them to receive more holistic comprehensive care alongside their monthly Bicillin.

The first six months of this pilot are being evaluated, with a view to ongoing refinement and exploration of models of care.

Strengths and limitations

The strength of this study was the inclusion of consumers, from the initial gathering of experiences to co-design of improvement ideas representative of the needs of the service users. Evaluation and modelling of the benefits is underway to understand the impact of these ideas on ARF/RHD patients and their whānau/aiga.

The COVID-19 pandemic restricted our ability to engage with patients and whānau/aiga in-person. It also limited the number of patients and whānau/aiga we were able to recruit and interview via hui or talanoa.

While our researchers attempted to contact Cook Island Māori and Tongan patients, we were unsuccessful in our engagement with these ethnic groups. Therefore, the experiences shared are not reflective of all Pacific ethnicities affected by ARF/RHD in the Counties Manukau region.

Conclusion

The experiences of ARF/RHD patients and their whānau/aiga members have highlighted the need to include the voices of our young people for effective service design. The improvements made to ARF/RHD services for young people in Counties Manukau need to be developmentally and culturally appropriate to empower patients and whānau/aiga to understand and be involved in their journey.

There is also a need for a coordinated approach to care, with health professionals working together to allow for good continuity of care, streamlining of services and timely delivery that meets the need of the patients.

Service design needs to be more inclusive of the voices of our young people, who are known to have different needs and expectations for services than their older counterparts with similar healthcare needs.
COMPETING INTERESTS
Nil.

ACKNOWLEDGEMENTS
CAG members have been engaged with the project as it continues to progress. We are grateful for their frank, open and honest feedback and sharing of personal experiences to help improve ARF/RHD services for other young people.

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REFERENCES
## Appendix 1: Idea prioritisation tool

| Achieving equity—does this have the potential to highlight and address equity issues currently experienced by patients? |
|---|---|---|
| 1= no change, equity remains an issue | 3= has potential to highlight equity issues | 5= highlights inequities and addresses them |

| Impact—is there a positive impact on patients and whānau? |
|---|---|---|
| 1= impact not noticeable by patients | 3= some impact on patients | 5= positive impact on patients and whānau |

| Te Tiriti/Māori responsiveness—what is the impact for Māori? Does this align with Te Tiriti? |
|---|---|---|
| 1= little/negative impact or insignificant | 3= some impact, makes attempt to align with Te Tiriti | 5= positive impact, aligns with Te Tiriti |

| Clinical efficacy—how does this affect the way you care for patients? |
|---|---|---|
| 1= no change to care | 3= some change/ effect on care | 5= large changes to the way care is delivered |