

## Co-design Partners in Care case study

---

# Identifying the gaps in the rheumatic fever secondary prophylaxis service and building concordance – ‘Nothing about me without me’ (Bay of Plenty District Health Board)

### Context

Rheumatic fever is considered a ‘third world’ disease, however it is a significant health issue in New Zealand, almost exclusively affecting Māori and Pacific peoples. The Ministry of Health aims to reduce the incidence of rheumatic fever and rheumatic heart disease with prevention tactics such as media advertising, throat swabbing and reducing barriers to accessing treatment.

Rheumatic fever usually starts with a sore throat, caused by the bacteria *Streptococcus A*. If the sore throat isn’t diagnosed and treated with an appropriate course of antibiotics, it can develop into rheumatic fever. Once a patient has been diagnosed with rheumatic fever they are treated with benzathine penicillin, a prophylaxis delivered by intra-muscular injection every 28 days to prevent further episodes occurring. Preventing recurrence is vital, because each new episode increases the patient’s risk of developing rheumatic heart disease (or exacerbating an existing condition).

The Bay of Plenty District Nurse Service cares for over 80 patients who require secondary prophylaxis every 28 days, however there are many barriers preventing treatment from being received on time, including social, economic, cultural, physical and educational factors.

### Aim

Our goal was to gather a range of data to better understand the challenges and opportunities for the timely delivery of the 28-day prophylaxis injections. Working closely with consumers and colleagues enabled us to identify problems within the service, allowing us to develop and implement solutions.

### Engage

We engaged with senior leaders who were very positive about the project, and were keen to understand what changes can be made to improve the secondary prophylaxis service.

We reviewed a presentation given in 2008 by Dr John Malcolm, a rheumatic fever champion at the Bay of Plenty District Health Board (BOP DHB). Dr Malcolm had identified the delays in prophylaxis treatment and attempted to make improvements to the process, which we factored into our co-design project.

We engaged four consumers who require secondary prophylaxis for themselves or for a family member, and who wanted to share their experiences. Their stories highlighted both positive and negative experiences about the delivery of care for patients with rheumatic fever and rheumatic heart disease.

Staff engagement was mixed. Most of the nurses who work with rheumatic fever patients wanted to contribute as they expressed frustration with patients failing to attend appointments, however there were other nurses who were not interested in taking part.

We created two versions of an ‘elevator pitch’ – a short explanation of what we were trying to achieve and offering the opportunity to be involved. One version was aimed at engaging consumers and the second on engaging stakeholders within the health provider system.

## Capture

We gathered organisational data to provide some context for our work.

There are 83 patients who have rheumatic fever within the (Eastern and Western) BOP DHB. This equates to a possible 1,079 benzathine penicillin injections delivered per year, if there are no ‘did not attend’ (DNA) appointments (that is, 13 injections per patient, per year).



Most days the DHB treats at least one patient with rheumatic fever.

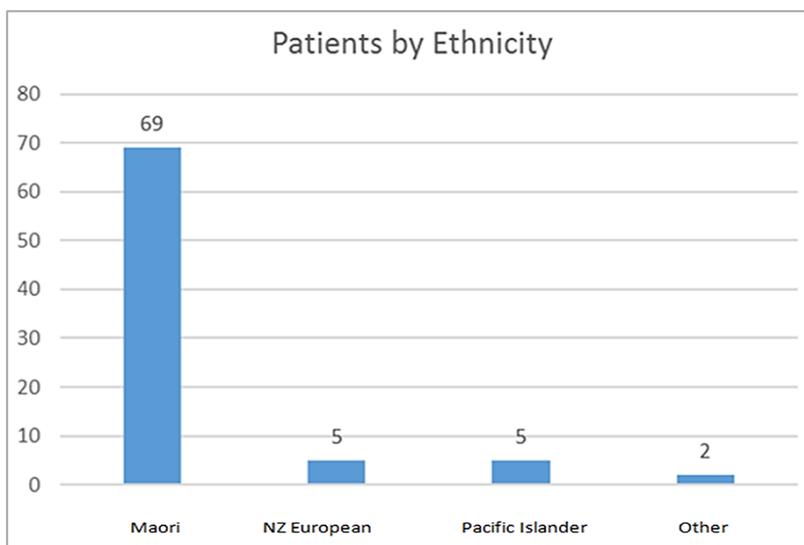


Figure 1: Patients who have rheumatic fever in the Eastern and Western BOPDHB by ethnicity.

We surveyed consumers during face-to-face sessions to understand their overall journey of care, specifically around the timeliness of the injections. We also wanted to understand their knowledge of the disease, its prevention and progression.

Questions for senior leaders focused on what was important to them, in addition to providing a high-quality service. We explored health targets and the relevance of inefficiencies, for example the DNA appointments and unproductive home visits. Paediatricians and cardiologists working with rheumatic fever patients were asked if they had identified any gaps in service delivery. Frustrations were voiced about patients not attending their outpatient appointments and about diagnoses not being made early enough to avoid rheumatic fever developing.

We asked nurses about their general experiences of providing the secondary prophylaxis programme to rheumatic fever patients and family/whānau. This included how they felt at certain points in the care delivery journey, their understanding of rheumatic fever and the disease process leading to rheumatic heart disease, and the use of distraction and analgesia techniques to reduce pain while having injections.

A clinical audit on patient notes investigated whether consumer knowledge of rheumatic fever and the social components for the person and their family/whānau had been reviewed. We looked at what education had been provided (if any) and whether key milestones/documentation had been met in the consumer journey.

## Understand

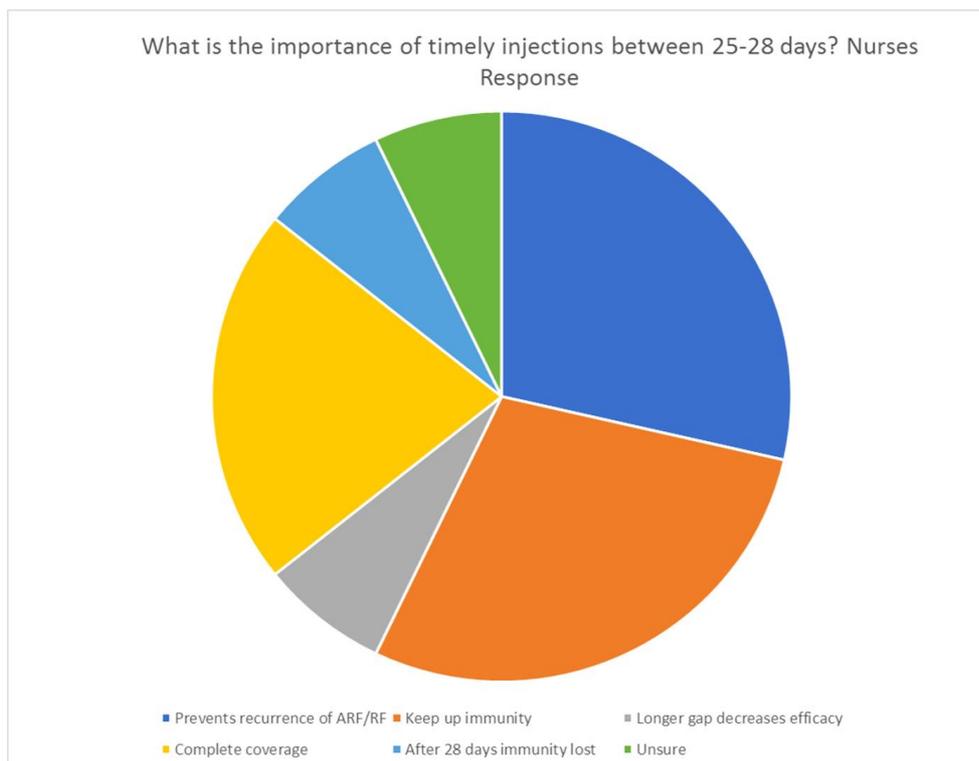
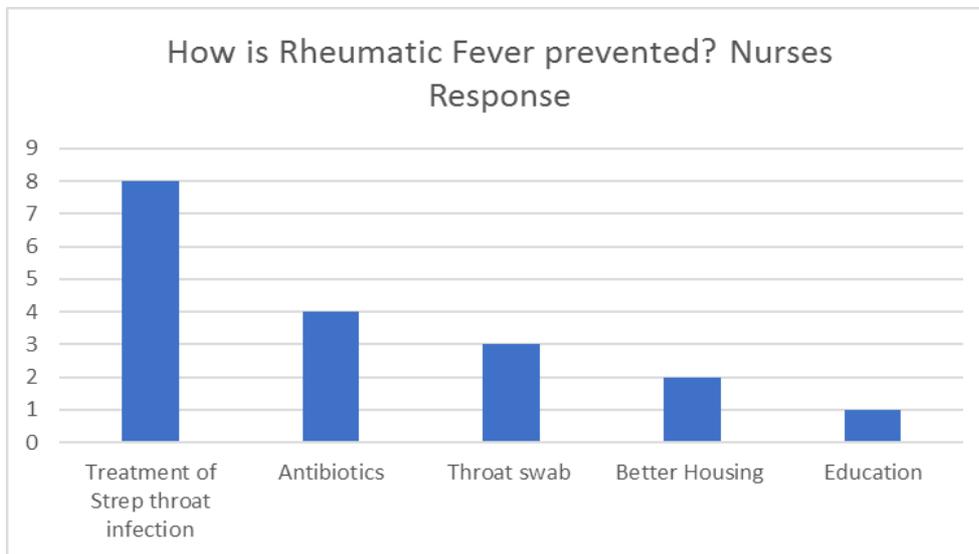
The data gathered in the capture phase provided a number of themes and insights.

The nursing survey revealed an overall feeling of frustration because of the high level of DNAs for prophylaxis injections, even if the appointment had been made at the patient's home. Nurses felt they were consistently chasing patients to provide their injections. There was little understanding of the patients' social circumstances and how it might have impacted on their actions.

The survey also highlighted a lack of knowledge amongst the nursing staff about rheumatic fever and the disease process, which limited the education able to be provided to consumers about their condition and treatment. Nurses questioned whether they were the best people to deliver educational services, suggesting that the public health nurses might be better placed to provide this.

### Nursing survey

Fifteen nurses were surveyed, with the option to choose more than one answer for each question.



## Consumer survey

The consumer survey revealed that a therapeutic relationship between the nurse and the patient is paramount to receiving appropriate and timely treatment. Continuity of care had been highlighted by many consumers as being the most important factor in care.

One consumer suggested a power imbalance, stating nurses made the rules about where treatment is given and not providing choices for the consumer. Some questioned cultural and social disconnection from the nurses, identifying there are often other priorities within their household which prevented them from being able to attend appointments (eg, no petrol/transport or unwell children). Lack of knowledge was also identified as an issue, with some consumers saying they weren't provided with appropriate/sufficient information, and many weren't offered an analgesia preference.

## Clinical notes review

Five sets of clinical notes were randomly selected for review. We wanted to find out if nurses had assessed the consumer's knowledge about rheumatic fever, whether education had been provided to the consumer and family/whānau, and if there had been discussion around Whānau Ora and social and emotional needs. We were also looking for documentation about analgesia preference, use and feedback, and what efforts were made to contact the consumer for their appointment.

We discovered there was almost no documentation about checking the consumers' understanding of rheumatic fever, limited education had been given, and there was little exploration of the social, cultural and whānau health aspects.

We identified timeliness of the injections was often delayed, which could compromise the consumer's health. There was also a startling range of appointments per injection – from two appointments and two injections through to thirteen appointments needed for just three injections.

	18 years F	30 years M	11 years M	16 years F	19 years M
Knowledge Check	No comment	No comment	No comment	No comment	No comment
Education provided	No comment	No comment	No comment	No comment	No comment
Social/ emotional comment	One comment about work	No comment	No comment	No comment	No comment
Analgesia preference offered	No comment	Pt asked ? for local	Unclear	No comment	No comment
Analgesia provided	yes	Yes	yes	Yes	Yes
Analgesia feedback	No	No	feedback provided once	No	No
Health assessment / health comment	One comment re sore back , told to go to GP or ED	One comment stated 'keeping well'	Mum commented about weight gain – no feedback whether over/ under or normal so?	One comment of 'keeping well'	No comment

	Two injections / one nurse Third at GP	Three injections Two nurses	Three injections three nurses	Three injections for three nurses	Three for one nurse
Continuity	Delayed	Delayed	Timely	Delayed	Timely
Reappoints	Delayed	Delayed	Timely	Delayed	Timely
Timeliness	Gaps 42 days and Than GP after 63 days	35 days in each of the gaps	29 days and 34 days	46 days and 44 days	Timely
Number of appointments for medication delivered	For two injections 22 apts contacts phone and texts	Three injection 6 apts	Three injections 6 apts	Three injections 13 apts	Two injection for two apts

Figure 2: Observations from clinical notes review.

Through this research we identified a need to build the quality of interactions between the consumer and the health provider/nurse. We acknowledged the importance for providers and consumers to have relevant knowledge and skills, and the value of therapeutic relationships was an important part of the experience.

### **The voice of the consumer – ‘Nothing about me without me’**

For the consumer it is important that they have control of their interaction/experience. We feel the identified goals will ultimately support timely delivery of prophylaxis treatment using a more holistic quality framework.

The theme **‘Nothing about me without me’** strengthened as we progressed.



*Figure 3: A consumer using the Buzzy Bee, to help reduce the pain during a prophylactic penicillin injection.*

## **Improve**

We are still in the early stages of this phase, however we are already working with staff and consumers to develop an educational tool that will support knowledge, social and cultural aspects linked within this specific service.

## **Measure**

We haven't reached this phase yet.

## **Working as a co-design team**

There were both positives and negatives to working as a co-design team. Our team was challenged by being geographically dispersed, and there were time constraints with members working for different organisations on different days. However, the team members were all invested in improving the process for delivering prophylaxis treatments.

Working alongside consumers outside of a provision of care setting was an interesting experience. Discussions identified concerns and challenges which were not initially what we, as health professionals, had thought they would be.

Sometimes encouragement was needed to make sure consumers let us know how they really felt about certain things within the health system. There was reluctance at times, for fear of 'telling on' specific nurses they preferred not to go to. It was important to reassure consumers that anything they said would remain in confidence.

We were grateful to have Katheryn, a medical research student studying at the University of Tasmania, included in our team. Katheryn has been involved with various rheumatic fever education, research and promotional events for the Eastern Bay Primary Health Alliance. Her role

on the project was to provide support with creating surveys, collation of data, and researching equity in regional health care evidence.

We were also very grateful to have worked closely with Joseph Ngametuangaro who shared his story and offered us advice for the future.

## Influences – the patient stories

### Joseph Ngametuangaro

- 20 years old
- Cook Island, New Zealand Māori
- Opotiki-born
- Age 8: Dad passed away from complications of Warfarin therapy
- Age 14: Diagnosed with rheumatic heart disease
- Surgery for valve repair (multiple valves)
- Age 18: Lived with his sister in Rotorua for a year; missed prophylaxis treatment
- Moved back to Opotiki; not well
- Further cardiac surgery; mum died of lung cancer while Joseph was in hospital
- Specialist commented about Joseph not making the follow-up appointment
- Messaged to say home mid-semester: 'OK to get Bicillen?'



## The project team

Name	Role	Email	Organisation
Joseph Ngametuangaro	Consumer		Massey University
Mere Pomana	Consumer		Wānanga
Whetu and Harvest Atutahi-Vernall	Consumer		Kura
Sandra Innes-Smith	District Nurse and Rheumatic Fever Clinical Lead Coordinator	<a href="mailto:Sandra.innes-smith@bopdhb.govt.nz">Sandra.innes-smith@bopdhb.govt.nz</a>	Bay of Plenty DHB and the Eastern Bay Primary Health Alliance
Leanne Ruck	Rheumatic Fever Coordinator and District Nurse	<a href="mailto:leanne.ruck@bopdhb.govt.nz">leanne.ruck@bopdhb.govt.nz</a>	Bay of Plenty DHB
Katheryn Ball	Medical Research Student	<a href="mailto:ballke@utas.edu.au">ballke@utas.edu.au</a>	University of Tasmania
Sankhala Raffel	Rheumatic Fever Register		Rotorua Area Primary Health Services