

## **Improving care for young people with Rheumatic Fever and Rheumatic Heart Disease – codesign and implementation**

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### **Background:**

Counties Manukau has the highest burden of Acute Rheumatic Fever/ Rheumatic Heart Disease (ARF/RHD) of any region in Aotearoa New Zealand, with 69 new diagnoses of ARF in 2023 and 703 patients receiving regular bicillin prophylaxis, the majority of whom are Maaori or Pacific Peoples aged between 12-24 years.

Recognising that the current system of care is complex and that young people and whaanau may struggle to navigate this and receive the care and support required, a co-design project was undertaken to understand the patient journey and experiences of patients, whaanau and staff with the current RF/RHD service and identify potential solutions for service improvement that contributes to a more youth-appropriate model of care. As a result, an enhanced youth focused model of care for young people receiving prophylaxis was piloted and evaluated.

### **Approach:**

A Consumer Advisory Group (CAG) was established to provide advice to the project team based on experiences as consumers of ARF/RHD services.

Participatory action research methods were used to gather Maaori and Pacific patient, whaanau and health professional experiences and enable them to co-design potential solutions across two phases – exploratory and ideation & solution design. Improvement ideas were prioritised by CAG, and health professionals using an equity focused prioritisation tool for testing and prototyping.

### **Outcome:**

Both Maaori and Pacific patients and whaanau shared how whaanau support and involvement is crucial to their journey, but the way care currently was delivered is often frustrating and fragmented with a lack of communication and continuity. Similarly, health professionals' experiences highlighted the need for better continuity of care, but that they are currently working in silos with little visibility of other roles or collaboration. All wanted more education to enhance understanding.

Improvements actioned include:

1) Piloting an enhanced model of care with more holistic, youth and culturally appropriate healthcare based around bicillin prophylaxis. Evaluation of the initial pilot of care delivered to 50 young people over an eight-month period was completed through analysis of quantitative information and patient, whaanau and staff interviews. Evaluation found improved satisfaction, engagement and breadth of care provided, improved cultural responsiveness, improved health literacy and empowerment of the young people and whaanau. A ongoing extension of this work is further testing and refining the model of care, trying to identify those young people who benefit the most from this more intensive model of care compared to usual services.

2) Education support for patients and whanau through a co-designed resource.

3) E-learning modules for health professionals to support the provision of youth-friendly care.

4) Systems and technology improvements to improve communication and flow of information.

**Innovation and Significance:**

The voices of young people and their whaanau have been used to inform improvements in care. Improved continuity, culturally and developmentally appropriate more holistic care together with streamlined processes have improved patient outcomes in the management of ARF/RHD.

**Disclosure of Interest Statement:**

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