Key Findings and Messages
for Improving Aboriginal and Torres Strait Islander Acute Rheumatic Fever and Rheumatic Heart Disease Care

from the '*Engaging Stakeholders in Identifying Priority Evidence-Practice Gaps and Strategies for Improvement (ESP)*' project

In most developed countries, acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are rare, but rates among Aboriginal and Torres Strait Islander people are amongst the highest recorded globally. Improving the quality of ARF/RHD care will help to remedy this inequality in health outcomes between Indigenous and non-Indigenous Australians.

The ESP project for acute rheumatic fever and rheumatic heart disease (ARF/RHD) care brought together data from 60 health centres participating in the ABCD National Research Partnership. Teams in these health centres conducted audits of ARF/RHD care (>2580 client records), and completed 80 system assessments in ARF/RHD care, over the period 2008 – 2014. The health centres include community-controlled and government managed health services, mostly in Queensland and the Northern Territory.

The research team did an initial analysis of the data. Then, though three phases of reporting and online surveys, we asked people to help interpret the clinical audit and system assessment data.

In 2014 – 2016, people in diverse health roles and organisations used the data to:

- Identify gaps in recommended ARF/RHD care that are common across health centres (>50 people)
- Share knowledge on ways to improve Aboriginal and Torres Strait Islander ARF/RHD care (>70 people).

ARF and RHD are preventable

ARF is caused by the body's response to infection with Streptococcal bacteria often found in skin sores and sore throats. ARF is common among Aboriginal and Torres Strait Islander communities. Children aged 5 to 14 are especially at risk. ARF can be prevented through improving living conditions and prompt antibiotic treatment for Streptococcal infection.

ARF can cause heart inflammation that results in permanent damage to the heart valves - which can lead to heart failure, stroke, and the need for cardiac surgery. RHD can be very dangerous for pregnant women and their babies. People who have had ARF need regular penicillin injections for at least 10 years to prevent heart complications.

Significant improvements in ARF/RHD care will be achieved by focusing on seven important 'evidence-to-practice gaps' in care delivery. These gaps in care are common across many health centres.

Key findings – Seven aspects of care were identified as system-wide priorities for improvement. The identified top priorities were: improving 1) the coverage of injections to at least 80% for clients who are prescribed benzathine penicillin G (BPG); 2) client follow-up; 3) recording of key information in client files

and master charts, and; 4) disease management planning. Better recording of; 5) ARF diagnoses and; 6) interventions, and; 7) strengthening the practice and recording of rheumatic fever education for all clients were also identified as high priorities.

The priorities were identified because they were: a) important areas of clinical care that were being recorded at low levels by most services, or b) aspects of care where there was wide variation in recorded delivery of care, or c) components of Primary Health Care (PHC) centre systems that were poorly developed compared with others.

Many health services and centres experience similar barriers to addressing the priority evidence-to-practice gaps. Overcoming these barriers involves strengthening systems for workforce recruitment and support, patient- and community-centred care, use of clinical information systems and coordination of services. Community - health centre partnerships are very important.

Key findings – People who participated in the ESP project brought experience and knowledge in Aboriginal and Torres Strait Islander health to identify the following barriers and enablers to improving ARF/RHD care:

- Systems and approaches for recruiting and retaining PHC staff, including Aboriginal and Torres Strait Islander Health Practitioners and administrative staff
- Systems to support staff to work well in teams, with advice and support from experienced colleagues
- Systems and processes to help staff understand their service populations and apply the principles of population health
- Processes to build community health literacy, expectations and leadership for quality care, and support PHC teams to work in partnership with communities
- Systems and processes to help staff understand the needs and hopes of people living in Aboriginal and Torres Strait Islander communities and provide care that is guided by patients' values
- Training in patient centred care, self-management of ARF/RHD, clinical information systems and communication technology. Teams and organisations coming together for learning
- Systems to support staff to interpret continuous quality improvement (CQI) data, plan and implement strategies for improvement
- Regionally coordinated services, partnerships and networks to strengthen ARF/RHD care across the health sector
- Systems and processes to reduce competing demands on staff, so that they can apply their knowledge of best practice ARF/RHD care

It is important to target barriers to improvement, to build on what is working well, and to work with people who bring different knowledge and views when developing solutions. These barriers and enablers are much the same as those identified in the ESP project on other aspects of PHC (e.g., chronic illness care and preventive health).

Strategies for improving ARF/RHD care include strengthening patient information systems, coordinating services across regional boundaries and between providers, and improving access to specialised services. They include dedicated resources and flexible options (including outreach services) for providing BPG injections, and ARF/RHD education in varied formats. Putting these strategies into action will have flow-on benefits in other areas of care.

Key findings – Drawing on their knowledge and experience in Aboriginal and Torres Strait Islander healthcare, participants suggested strategies that could be used to overcome the barriers and improve care in the priority areas. Action is needed at different levels of the health system.

National level strategies

- Establish a national data base of ARF/RHD patients to support BPG injection provision and disease management through better sharing of information across the health system. This would enable patients to receive care when not at their regular health service
- Add a section about ARF/RHD to the annual health assessment (MBS 715)

Jurisdiction, regional or service level strategies

- Provide options for delivery of injections - including outreach models
- Improve resources and systems for staff to be able to follow-up patients who require BPG injections
- Strengthen regional programs and partnerships to enable care for patients who move across jurisdictional boundaries
- Improve access to specialist and hospital services
- Use CQI data to inform planning and service delivery
- Advocate for housing and sanitation interventions to address the underlying causes of ARF/RHD
- Provide staff education on the importance of the injection schedule to manage ARF/RHD and best practice guidelines
- Provide staff training in social determinants of health and patient-centred care

Health centre and community strategies

- Provide community, patient and family education on the importance of receiving injections – suggestions ranged from one on one education to family focus groups and broader community education such as films in local language
- Establish a dedicated staff role with responsibility for RHD care
- Offer incentive awards for completion of injections
- Arrange an interpreter to assist in the discussions with patients as required

The ESP trend data show a small upward trend in overall delivery of ARF/RHD care for services who participated in three or more CQI cycles. Together with other evidence on the effectiveness of CQI methods, this suggests that a sustained commitment to CQI will result in improvements in the delivery of care.

The development of strategies should take account of evidence about how effective and well-suited they are in different contexts. Policy makers, funders, leaders, managers and staff across different levels of the health system need to take a coordinated approach to supporting key strategies within their levels and areas of influence. Implementing the suggested strategies to improve ARF/RHD care will strengthen other areas of care.

From messages to action: an opportunity for wide-scale improvement

Why is it important to take action on the ESP project findings and key messages for ARF/RHD care?

- They are based on the analysis and interpretation of the largest and most recent available set of CQI data for Aboriginal and Torres Strait Islander healthcare.
- They represent the work, knowledge and ideas of people working in different roles in Aboriginal and Torres Strait Islander healthcare – clinicians, managers, policy-makers, researchers, staff of health service support organisations and peak bodies representing the interests of communities and community-controlled health services.
- The findings and key messages can be used to develop system level solutions for priorities in ARF/RHD care for Aboriginal and Torres Strait Islander people and communities.

How can the findings and messages be used to improve ARF/RHD care?

ESP findings provide a focus for continuing discussions about strategies for improvement.

The findings and messages can be used by health services to plan system changes that target barriers to improvement and strengthen what is working well in ARF/RHD care.

The findings and messages can inform policy to improve local availability of services.

Strategies should be developed collaboratively across regions and jurisdictions, between health system levels, service providers and communities. They should be adapted to local settings.

What does evidence tell us about making large-scale improvements in health outcomes?

We know from international and Australian evidence that taking a system-wide approach to CQI is linked to large-scale improvements in health outcomes. Changes need to be made at different levels – the individual, the group or team, the service, and the larger environment in which services operate – to improve overall care quality.

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Download the full report here: www.menzies.edu.au/RHDfinalreport