

## Technological innovations in ARF/RHD: are we ready?

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### Introduction

RHDAustralia was established in 2009 as the National Coordination Unit to support the control of rheumatic heart disease in Australia. Funded under the Australian Department of Health's Rheumatic Fever Strategy, RHDAustralia (RHDA) is based at Menzies School of Health Research in Darwin. RHDA's aim is to reduce death and disability from acute rheumatic fever and rheumatic heart disease in Australian Aboriginal and Torres Strait Islander people by:

- supporting RHD control programs in Western Australia, Northern Territory, South Australia and Queensland
- establishing a data collection and reporting system
- disseminating evidence-based best practice guidelines
- increasing community awareness of ARF and RHD and its prevention.

RHDAustralia has recently developed two innovative, technology based resources designed to provide education and support for patients affected by acute rheumatic fever (ARF) and rheumatic heart disease (RHD), and for the health professionals who care for them.

### The issue

ARF is an autoimmune sequelae of group A streptococcal (GAS) infection mostly affecting children 5-14 years of age. Recurrent episodes of ARF can lead to cumulative heart valve damage and the development of RHD. Rheumatic heart disease is a permanent, chronic, and sometimes fatal disease that often requires heart valve surgery. It is estimated that RHD affects 15.6 million people worldwide (1). Estimating the burden of ARF and RHD in Australia is difficult because there is not a consolidated national data source.<sup>1</sup> In 2013 the Australian Institute of Health and Welfare (using register data from the Northern Territory, Western Australia and Queensland), reported (2):

- Almost all cases of ARF recorded in the Northern Territory between 2005 and 2010 were for Aboriginal and Torres Strait Islander people (98%), with 58% in 5-14 year olds.
- In the Northern Territory in 2010, the prevalence rate of RHD among Aboriginal and Torres Strait Islander people was 26 times the rate for non-Indigenous people.
- 897 deaths between 2007 and 2009 were attributed to RHD.

A timely diagnosis of the first ARF illness and subsequent use of long-term antibiotic secondary prophylaxis is the most effective method of preventing RHD. The technology-based resources developed by RHDA target two key issues contributing to the recurrences of ARF and the continued risk of children and young people developing RHD:

- the difficulties in the early and accurate diagnosis of ARF
- inadequate adherence of secondary prophylaxis.

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<sup>1</sup> RHDA has established a central data repository which will collect data from the Northern Territory, Western Australia, South Australia and Queensland RHD registers. The Data Collection System will provide mandatory KPI reports to the Commonwealth and the jurisdictions. Analysis of the data will inform quality improvement strategies within the jurisdictions.

The Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2<sup>nd</sup> edition)(3) stresses the importance of accurate diagnosis and the difficulties with diagnosis:

- There is no single diagnostic laboratory test for ARF, and while specific criteria exist to support diagnosis, it is often based on clinical judgement.
- Many clinicians have never seen a case of ARF, because they are trained in populations where ARF and RHD are virtually non-existent.

The recommended treatment to prevent recurrences of ARF (where there is no RHD) is the regular (at least every 28 days) administration of intramuscular benzathine penicillin G (BPG), for 10 years or until the patient is 21 years old. There are a number of barriers to adherence including access to and appropriateness of health services, perceived or real pain associated with administration of BPG and lack of education of causes of ARF and consequences of missing injections. Consequently, many patients do not receive the necessary doses of BPG required to prevent GAS infections and subsequent episodes of ARF.

### The resources to target these issues

RHDAustralia have developed an ARF diagnosis calculator and a Facebook application.

The **ARF Diagnosis Calculator** provides clinicians with clinical information and a simplified tool to navigate the complexities of diagnosing ARF. It is available on both IOS and Android platforms and is designed to operate offline. The Diagnosis Calculator provides a text and visual reference at each stage of the diagnosis process. The Calculator provides accurate, instant information to minimise error and inconsistency with diagnosis, referral and management of ARF. The ARF Diagnosis Calculator is an update to the pre-existing information app based on the Australian Guideline for Prevention, Diagnosis and Management of ARF/RHD (2<sup>nd</sup> Edition).

The **ARF/RHD Facebook application** is an interactive reminder service for young Indigenous people who require regular secondary prophylaxis. The tool is designed to appeal to the 13 to 25 year age group through customisable design features and attempts to address the massive challenge of engaging a patient over a treatment period of at least 10 years with injections at least every 28 days. Patients who download the app will receive regular reminders of when their injection is due. Protection of patients' privacy has been a priority in the development of the app. While Facebook is widely used in health promotion and there are a plethora of smart phone health apps, we believe this is a unique use of a Facebook application as a treatment reminder tool.

### Technological challenges

Data from Australia's RHD registers tells us the highest burden of disease is in rural and remote areas of central and northern Australia, where internet and mobile phone coverage is of varying quality and availability. So one of the challenges in developing these resources was how to take advantage of current technology and at the same time reach those most in need in areas under serviced by telecommunications networks. Although there is little data available on mobile phone ownership and usage in remote Indigenous communities, it is obvious to anyone working in communities that "remote Indigenous residents use mobile technology as their communications medium of choice for both voice calls and Internet access". (4) However, our initial desktop research and consultations with remote area health staff immediately highlighted difficulties in using a mobile app as a reminder tool. Issues included:

- lack of data on smartphone ownership
- people losing phones and therefore data
- people sharing phones (which raised privacy issues)
- digital literacy and language barriers
- limited internet access/mobile phone coverage means data is rarely backed up

This led us to the use of Facebook as an alternative platform. It has a number of advantages over a smart phone app:

- Facebook remains the most popular social media site in Australia (5) and recent market research shows usage among Indigenous Australians is higher than in the rest of the population. (6)
- It does not rely on people owning their own smartphones and keeping hold of their phones. Facebook is accessible wherever there is an internet connection (the clinic, school) and can be accessed on desktops, tablets and smart phones.
- It allows more flexibility for future development as more is learnt about the barriers/enablers for patients on secondary prophylaxis.
- A large number of people already have Facebook accounts so you are not asking them to learn new technology or download additional software, they will just need to add the app through their existing account.

There are some limitations with the use of Facebook e.g. not everyone has an account, some backlash in the community because of cyber-bullying and literacy/language barriers remain a problem. It will still not solve the problem of limited telecommunications networks and we already know that people with ARF and RHD in some of the most remote communities will be unable to access the resource.

Access issues and digital literacy issues were clearly easier to address in the development of the Diagnosis Calculator. The target audience is the health workforce, many of who are already engaging with mobile technology (the guideline information app developed previously already had 1544 downloads prior to the development of the Diagnosis Calculator). The Calculator is available off line so as long as the user has downloaded the app the resource is available regardless of mobile coverage. The questions which remain for this resource is whether at 'point of consultation' clinicians are ready to use technology to aid an improve diagnosis and if and how improved diagnosis can be evaluated.

### For discussion

These technological resources have only been recently developed, we believe they are innovative and have potential to improve outcomes for patients. Only time and evaluation will demonstrate their worth. Whether the clinicians and patients we are trying to reach are ready or able to engage with the new technology remains to be seen.

### References

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### Presenters

**Catherine Halkon** is Projects Manager at RHD Australia where she works across a number of education and training projects and is involved in operational and strategic management of the organisation. Catherine has a Masters of International Management with a focus on community engagement and not-for-profit management. She has a background in research and business management. Before joining RHD Australia in 2012, Catherine worked on a number of Indigenous education and training research projects at Charles Darwin University, including the management of a large scale literacy intervention project.

**Christian James** is the Program Manager at RHD Australia with over a ten years' experience in national and domestic rural/remote/disaster health projects with a desire to use anthropological principles to develop innovative solutions to complex health problems. Christian graduated with a B.Sc (Nursing) in 2005, after which he pursued a career in remote health in the Gibson Desert, before undertaking clinical and program management roles in Papua New Guinea, Sri Lanka. He then moved to the Middle East where he worked to redesign and manage a large remote area health service. In 2012 Christian relocated to London where he completed his MPH at Kings College London, later working with the Extreme Events Department at Public Health England and the on STEPS program at the World Health Organization.