

## Environmental health response to acute rheumatic fever and rheumatic heart disease in NSW

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### Overview

NSW Health has developed an acute rheumatic fever (ARF) and rheumatic heart disease (RHD) response protocol considering how to improve environmental living conditions in Aboriginal communities and raise awareness of the disease.

A pilot Environmental Health (EH) Response is currently being implemented in NSW. It is guided by the *Housing for Health* (HfH) Survey Fix model, which aims to ensure the house supports healthy living practices and reduces the risk of disease transmission to other family members.

We are in the early stages of piloting the implementation of a NSW-wide EH Response to ARF/RHD notification by the EH Network. This presentation will look at the process and delivery of the pilot EH Response, the challenges and barriers, and the breakthroughs.

### What are ARF and RHD?

So what are ARF and RHD?

The disease starts in children as an infection from a common sore throat and possibly infected skin sores. ARF is a rare but serious complication of an untreated throat or skin infection from group A streptococcus (GAS) bacteria, also known as streptococcal disease (strep).

Episodes of ARF can cause permanent damage to the heart valves leading to RHD. RHD can affect the heart valves, the heart muscle and its lining, and the connective tissue throughout the body.

It can end in open heart surgery, stroke, heart failure or premature death. RHD progressively gets worse, stays with those who have it for life and can end their lives. The disease is completely preventable and it has been virtually eliminated in most other developed countries.

RHD is one of the top 3 third world diseases in Australia (the other two are trachoma and otitis media), with rates in Australia among the highest in the world.<sup>1</sup> Aboriginal children and young adults are most affected by this disease. It is most common in 5-15-yr-olds, rarely occurring in those more than 35 years or less than 4 years old.<sup>2</sup>

National data indicates Aboriginal people are consistently over-represented in the ARF and RHD notification data. Aboriginal communities are suffering from shockingly high levels of RHD and early death from heart disease.<sup>3</sup> Aboriginal people are 122 times more likely to live with the life-threatening RHD than their non-Aboriginal peers.<sup>4</sup>

ARF is significantly under-diagnosed in Aboriginal communities due to the difficulty of diagnosis – multiple clinical and lab results, failure to recognise ARF and poor awareness of the disease.<sup>5</sup>

People diagnosed with ARF require long-term follow-up - including administration of benzathine penicillin G every 21-28 days for a minimum of 10 years to prevent repeat infections of strep which may lead to repeat episodes of ARF and worsening heart disease.

Take Heart has a number of Youtube videos and short films on RHD (see Take Heart video link: <https://www.youtube.com/watch?v=Prl7t8e8tKM>). Also, RHD Australia has educational resources for people with RHD, health workers and practitioners, as well as literature on the disease (refer to RHD Australia [Online]: <http://www.rhdaustralia.org.au>).

### Housing and environmental factors

It has been well established since the 1950s that a strong correlation exists between incidence of ARF and environmental disadvantage, such as poor housing, poor living conditions, inadequate infrastructure, water supplies, washing facilities, sanitation and overcrowding.<sup>6</sup>

So if socioeconomic and environmental disadvantage, in association with household overcrowding and limited access to adequate infrastructure to maintain hygiene, are the predominant drivers of ARF and RHD, the incidence of ARF may be reduced by measures that alleviate poverty and overcrowding. The causal pathway in this primordial prevention is associated with improved environmental conditions.

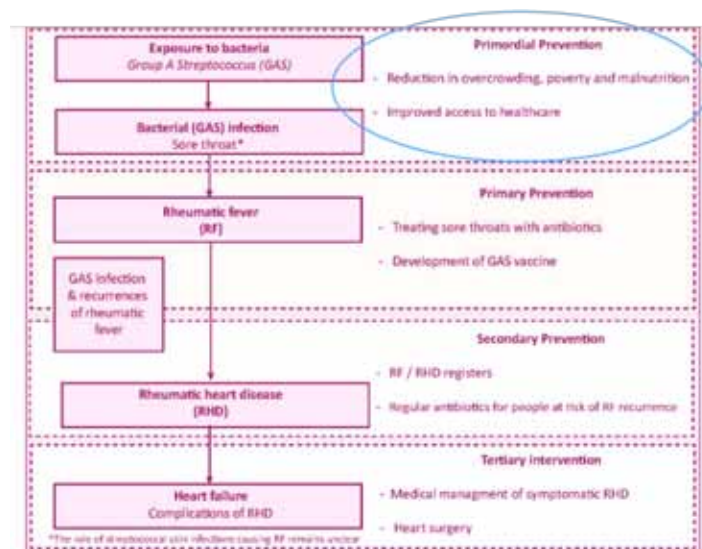


Figure 1. Causal pathway of ARF and RHD and opportunities for intervention. (Source: Wyber et al., 2014)

### ARF/RHD in NSW

In October 2015, ARF/RHD became a notifiable condition in NSW. NSW Health has established a register-based control program to enhance the clinical and public health management of ARF/RHD. The NSW Health Control Guidelines for Public Health Units (PHUs) acknowledge the need for an environmental response, stating that: "the PHU should consider involvement of the environmental health team, particularly if more than one case has occurred in a community. The environmental health team should seek to identify rectifiable environmental factors predisposing to GAS infection, and discuss the potential for a, HfH or other community-level initiative with the AEHU (if an Aboriginal community) or local council, housing provider/manager, relevant community leaders or other relevant stakeholders/service providers."<sup>7</sup>

<sup>1</sup> Australian Institute of Health and Welfare 2013; HICKIE, M. 2011.

<sup>2</sup> Australian Institute of Health and Welfare 2013.

<sup>3</sup> GRAY, C. & THOMSON, N. 2013.

<sup>4</sup> Australian Institute of Health and Welfare 2013

<sup>5</sup> CURRIE B. J. & CARAPETIS, J. R. 2001.

<sup>6</sup> HOLMES, M. & RUBBO, S. 1953; TORZILLO, P., PHOLEROS P, et. al, 2008; BAILIE, R. S. & WAYTE, K. J. 2006.

So the planning and preparation for the EH Response began, which is a collaboration between the NSW Health Aboriginal Environmental Health Unit, local health district environmental health officers and infectious disease specialists, NSW Health Communicable Disease Branch and Office of the Chief Health Officer.

We give updates and seek advice from the RHD Network (which includes local health district (LHD) RHD Coordinators, clinicians, infectious disease specialists, etc) and the Better Cardiac Care Aboriginal Advisory Group. We also seek advice from Healthabitat, which holds the license to and gives us permission to use the HfH methodology.

**Rates of ARF/RHD in NSW**

In NSW, the Rheumatic Heart Disease Co-ordinator at Health Protection NSW estimates 25-30 new cases per year, with about 50% being Aboriginal patients.

In NSW, higher rates of ARF and RHD occur in people from what are considered high-risk populations, including Aboriginal and Torres Strait Islander people, Maori and Pacific Islanders peoples and people born outside of Australia, particularly migrants from South-East Asia and Africa. Higher rates are also seen in women and in people living in disadvantaged conditions.<sup>8</sup>

Figure 2 shows data from the NSW patient data collection on ARF - between 2003-2012, the highest numbers were in the age group 5-15 years.

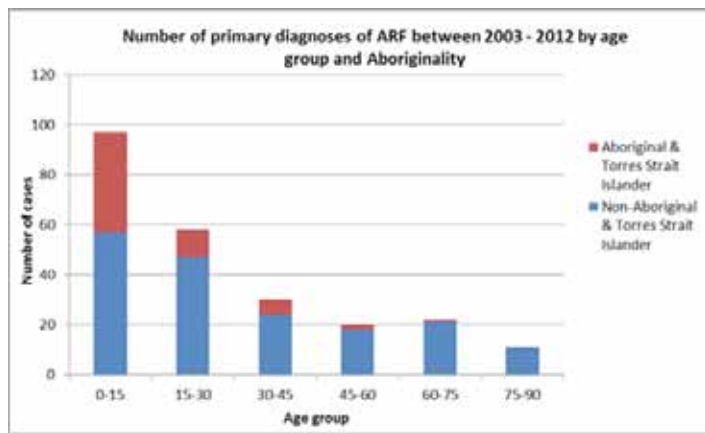


Figure 2. Data from the NSW Hospital Admitted Patient Data Collection on ARF. (Source: Health Protection NSW, 2014)

Figure 3 shows ARF/RHD notifications by age group from 2015 to 2017 and similarly shows that the highest numbers were in the age group 5-14 years.

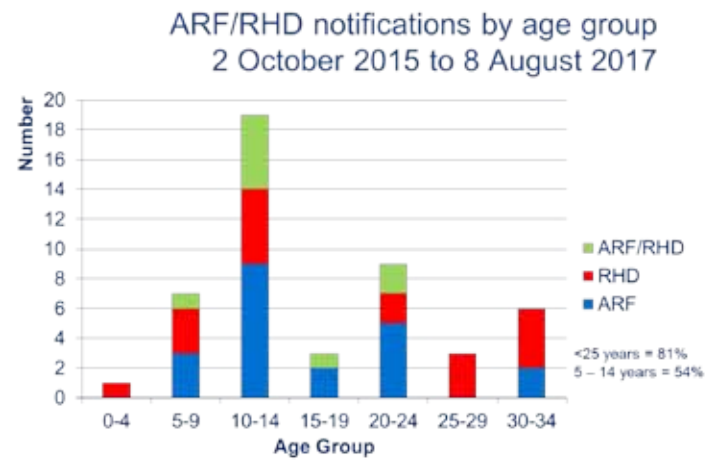


Figure 3. ARF/RHD notifications by age group - 2 October 2015 to 8 August 2017. (Source: Health Protection NSW, 2017)

Figure 4 shows that majority of cases in NSW between 2003 and 2012 by LHD were in Western NSW, Hunter New England, Western Sydney and South West Sydney.

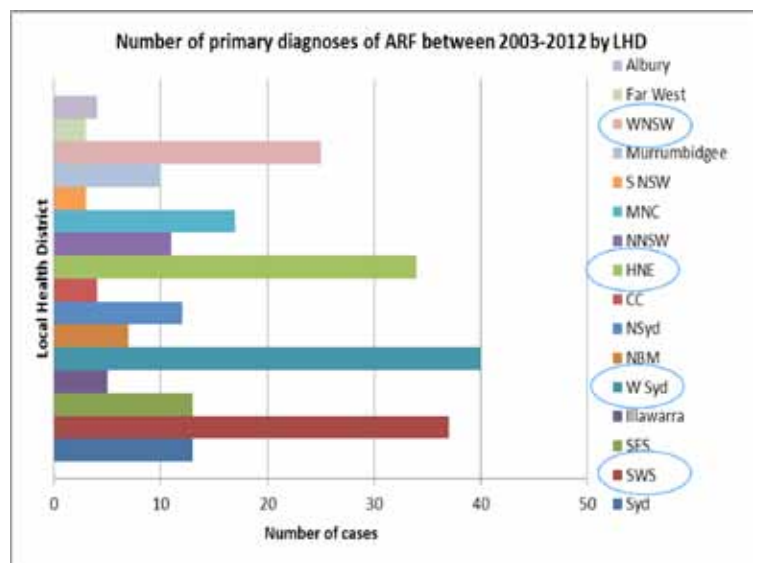


Figure 4. ARF cases by Local Health District 2003-2012 (Source: Health Protection NSW, 2014)

Figure 5 shows that, since notification, the majority of cases in NSW by LHD similarly were in Western NSW, Western Sydney and South West Sydney, but also shows a higher annual crude rate in Mid-North Coast, but four fewer cases in Hunter New England.

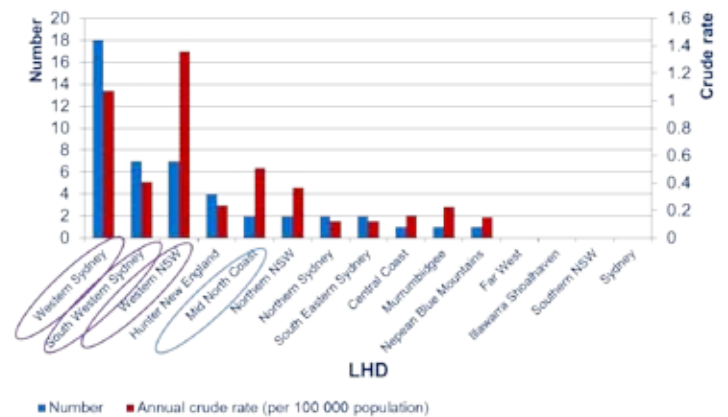


Figure 5. ARF/RHD cases by Local Health District - 2 October 2015 to 8 August 2017. (Source: Health Protection NSW, 2017)

<sup>7</sup> Acute Rheumatic Fever and Rheumatic Heart Disease: Control Guideline for Public Health Units, 2016.

<sup>8</sup> RHD Australia (ARF/RHD Writing Group) 2012.

## Pilot ARF/RHD Environmental Health Response

The pilot EH Response includes an HfH Survey Fix called a Home Assessment and Fix in the home of the patient in response to each diagnosis. Targeting EH responses, such as an HfH Survey Fix in the home of the patient will ensure the house supports healthy living practices and reduce the risk of disease transmission to other family members.

In speaking with the stakeholders to help explain the EH program, an Environmental Health Officer (EHO) has made the analogy of this EH program to that of home modification for people with physical disabilities - by adding rails, ramps and handles to bathrooms and doorways in a home modification program, which should prevent falls by providing items for the person to hang on to. By reviewing and fixing taps, showers and laundries in an EH program, we should prevent further illness by ensuring hygiene-related fixtures work to allow the person to use good hygiene practices. This analogy seems to help explain what and why quite well.<sup>9</sup>

The EH Response is designed to be carried out by a local EHO accompanied by a case manager and/or culturally appropriate health workers.

Resources have been developed to support the program, including participant information and consent forms, health education materials, health packs, and a flip chart describing the process with photos of what will be fixed. Resources also includes health promotion and education to Aboriginal health workers and the broader community.

We are in the very early stages of piloting the ARF/RHD EH Response at four sites in Far West NSW, Mid North Coast, Hunter New England and Western Sydney LHDs, starting in June/July 2017.

The NSW Health Aboriginal Environmental Health Unit runs the HfH program, which aims to improve the health status of Aboriginal people, in particular children aged 0-5 years.

HfH is an evidence-based program which has demonstrated, over a 10-year period, a 40% reduction in infectious diseases for people living in the houses that received the healthy housing intervention.<sup>10</sup> (hospital separation data only).<sup>10</sup>

The HfH program is a community-led project run for only the residents of Local Aboriginal Land Councils (LALCs) and Aboriginal Corporations (ACs) across NSW.

However, we are proposing to use the same HfH methodology; with the program to be carried out on a case-by-case basis and offered to all people with ARF/RHD, not just Aboriginal people.

### Home Assessment & Fix is based on the *Housing for Health* methodology

Home Assessment & Fix is based on the HfH Survey Fix, which is a set of standard repeatable tests to assess the safety and function of housing, focusing on repairs that will maximise health gains, particularly for children under 5 years old. It uses evidence-based health priorities called Healthy Living Practices (HLPs).

The program is a basic safety and health focussed repair program for Aboriginal housing. The program ensures houses are safe (in terms of electricity, fire, gas and sewerage), and that basic infrastructure is available to allow healthy living practices to be carried out, in particular being able to wash people (especially children), wash clothes and bedding, remove waste (i.e. a working

toilet), and being able to prepare and cook food at home. Targeting repairs to health hardware and improving the ability of the house to support healthy living practices will contribute to a reduction in the spread of infectious disease.

These are the nine HLPs the project addresses, in order of priority:

- a) Safety first
  - Electrical, fire, gas, structural
- b) Providing a healthy living environment
  1. Ability to wash people (especially children)
  2. Ability to wash clothes/bedding
  3. Removing waste
  4. Improving nutrition and food safety
  5. Reducing impact of crowding
  6. Reducing impact of pests, animals & vermin
  7. Controlling dust
  8. Temperature control
  9. Reducing trauma

} Critical

} Important

### EH Response Home Assessment & Fix priorities

The Home Assessment and Fix component of the EH Response will prioritise works as follows:

- Ability to wash people (especially children) - Being able to use functioning washing facilities reduces the spread of diseases, including, diarrhoeal disease, respiratory disease, hepatitis, and infections.
- Ability to wash clothes/bedding - Being able to regularly wash clothes and bedding can help reduce the incidence of infectious diseases, such as ARF, respiratory infections, scabies and other skin infections.
- Removing waste - Disease-causing bacteria can be transmitted if people or animals come into direct contact with wastewater or if the drinking water supply is contaminated with wastewater.
- Improving nutrition and food safety - Poor nutrition is one factor contributing to Indigenous people having high rates of obesity, diabetes, cardiovascular disease and renal disease. Poor nutrition is also a major cause of infectious diseases in children.
- Reducing impact of crowding - Crowded living conditions increase the risk of the spread of infectious diseases, such as meningococcal disease, rheumatic fever, tuberculosis and respiratory infections. In a crowded house, it can also be more difficult to access health hardware, such as a working shower, toilet, hot water and washing machines.

### Additional Home Assessment & Fix priorities

In addition to the critical HLPs, an EHO may make notes on the survey sheets to help prioritise the Home Assessment and Fix works - this could be on a case-by-case basis and may include:

- Overcrowding - look at alleviating impact of overcrowding (i.e. capacity of HWS)
- Dampness and mould - if there are issues with mould, HfH fix works may include mould removal service
- Bathroom ventilation - fixing faulty extractor fans, ensuring windows function
- Clothesline, clothes hooks, towel rails - fixing faulty/broken clothesline
- Pests and vermin - may provide pest control treatment(s)
- EHOs to leave health education materials (may include

<sup>9</sup> LAWRENCE, KERRY 2017. Email correspondence.

<sup>10</sup> NSW DEPARTMENT OF HEALTH 2010.

brochures, giveaways, healthy home kits) on: bed sharing, towel sharing, general hygiene, companion animals, smoke-free homes.

- The healthy homes kits may include the following:
  - healthy skin and hygiene packs with information about looking after skin, washing clothes, sheets and towels and the benefits of drying items in the sun
  - healthy skin packs could be taken out on surveys with the tool kit; the packs contain items to help maintain skin hygiene, such as bath towels, face washer, shower and hand wash
  - information about looking after skin, washing clothes, sheets and towels and the benefits of drying items in the sun (and fridge magnet).
  - household clean-up kits for general hygiene measures (may include dishwashing liquid, scrubber, cloths, spray and wipes, as well as general waste bin, garbage bags, dust pan, broom, bucket).

Also, each PHU has developed varied resources for healthy homes messages.

The EH Response will need to be assessed on a case-by-case basis. The EH Response will include all social housing, not just Aboriginal housing providers (LALC/AC), as well as private rental or privately owned houses. The EH Response will address all people with ARF/RHD (both Aboriginal and non-Aboriginal).

#### **Pilot EH Response challenges and barriers**

The pilot EH Response challenges and barriers to date include:

- In one pilot area, the person with ARF/RHD (case) is transient. The family moved to three different towns/homes in 3 months since notification. At this time, we are unable to determine which house to offer the Home Assessment and Fix works.
- We may have issues with getting consent from the housing provider in another pilot area because the house in which the case is living has been condemned by the community housing provider, who no longer provides repair and maintenance. Advice is to establish stronger links with the community.
- The Case Manager/RHD Coordinator in another area is unwilling to offer support until they can establish a stronger relationship with the case and family.

#### **Pilot EH Response breakthroughs - early days**

Some breakthroughs have happened with the pilot case in the Mid-North Coast. The visit to the RHD case/family went well and they have consented to proceed with the EH Response program. Also, the housing provider has been positive and supportive and has given verbal approval. We are now waiting on the formal consent letter from the housing provider before the next stage of undertaking the Home Assessment and Fix works.

Hopefully, by our next NATSIEH conference, we will have made stronger links between housing and environmental conditions and ARF/RHD and will have helped reduce the occurrences of ARF/RHD.

Thanks!

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## Glossary

AC	Aboriginal Corporation
ARF	acute rheumatic fever
EH	Environmental Health
EHO	Environmental Health Officer
GAS	group A streptococcus
HfH	Housing for Health
HLP	Healthy Living Practice
HWS	hot water system
LALC	Local Aboriginal Land Council
LHD	local health district
NATSIEH	National Aboriginal and Torres Strait Islander Environmental Health
PHU	Public Health Unit
RHD	rheumatic heart disease