

Annual Meeting Menzies School of Health Research, Darwin 11 May, 2017

Aboriginal and Torres Strait Islander Australians live with an unacceptably high burden of rheumatic heart disease (RHD). The End Rheumatic Heart Disease Centre of Research Excellence (END RHD CRE) was funded by the National Health Medical Research Council in 2014 to produce a stepwise, costed strategy to end RHD as public health priority in Australia. By 2020 this will be delivered as the RHD Endgame by the END RHD CRE.

On 11 May 2017, over 60 attendees from throughout Australia convened in Darwin, Australia for a one-day meeting to discuss progress of the research projects, national RHD advocacy and development of the final Endgame output.

The three main components of the meeting were:

- **Presentation of the thirteen END RHD CRE priority research projects.**

Investigators presented their work to the meeting attendees, including aims and objectives, current status, and expected timelines and outputs. Attendees asked questions and provided feedback to researchers.

- **Discussion of the recently formed END RHD Coalition, designed to raise the profile of RHD as a national health priority.**

The Coalition's aims include bringing together a range of stakeholders across Australia and focusing on advocacy, policy and research translation outputs. The Coalition currently has six health-sector founding partners, including the Australian Medical Association, Heart Foundation, National Aboriginal Community Controlled Health Organisation (NACCHO), RHD Australia based at Menzies School of Health Research, Aboriginal Medical Services Alliance Northern Territory (AMSANT) and the END RHD CRE based at Telethon Kids Institute.

- **The CRE's major outputs: the Endgame Strategy, Report, and Snapshot.**

The proposed format for the three sets of documents presenting the CRE's findings were discussed, ensuring they are appropriate for audiences ranging from academics and researchers, to policy makers and national peak bodies. The recommended actions will span primordial prevention both within and outside of the health sector; measures to address social determinants of RHD; detection and management of skin sores, sore throats, acute rheumatic fever and RHD; reduction of disease progression; and tertiary management of RHD. Proposed actions will be subject to ongoing open consultation with communities, researchers, collaborators, and sectorial stakeholders.



The Endgame for RHD in Australia

Structural overview of outputs from the END RHD CRE

Form and format

Intended audience

- 1 2 page summary
- 2 6 headings
- 3 Key recommendations only

- 1 Ministerial briefs
- 2 Senior government members
- 3 National peak bodies

ENDGAME
SNAPSHOT
Summary of what
should be done

- 1 Executive overview
- 2 Retain 6 key headings
- 3 Recommendation and brief review of evidence

- 1 National advisors and policy makers
- 2 Agencies involved in implementing recommendations

ENDGAME STRATEGY
Implementation focused overview of
findings and recommendations



- 1 Large technical document
- 2 6 headings
- 3 Subheadings as required
- 4 Comprehensive overview of evidence and detailed references

- 1 Academics
- 2 Researchers
- 3 Colleagues in other disease communities

ENDGAME REPORT
Outlining the evidence for the endgame



JURISDICTIONAL ANALYSIS
Review of jurisdictional specific needs



Key discussion points arising from the meeting:

- To build on the CRE's current research projects, identification of knowledge/research gaps is important, including primordial prevention and housing and environmental health.
- Effective engagement with people living with RHD, their families, and communities is essential - community consultation and partnerships will allow for tailored and appropriate interventions and effective dissemination of messages.
- Any recommendations need to work within the current health system and synergise with other disease control initiatives.

Media Coverage:

Rheumatic heart disease researchers on mission to eradicate it in Australia with new treatments

By Lucy Marks
Updated 12 May 2017, 9:06am



PHOTO: Kenya McAdams, 21, has rheumatic heart disease and has become an ambassador to raise awareness. (ABC News: Lucy Marks)

Katherine resident Kenya McAdam shared her story as part of the END RHD CRE media promotions. Diagnosed with rheumatic heart disease as a 14-year-old, Kenya underwent open heart surgery and must now endure a painful penicillin injection every 28 days for the rest of her life to prevent re-occurrence. Kenya teamed up with Telethon Kids Institute Director Jonathan Carapetis to promote the work of the END RHD CRE, speaking live on Darwin's Territory FM, being interviewed by numerous newspapers such as *The Australian* and appearing on the ABC News. Thanks to Kenya's involvement, the END RHD CRE received extensive media coverage throughout Australia.

Contact:

For more information about the END RHD CRE, please speak to Program Manager Kylie Jenkins.
Phone: +61 8 9489 7777 Email: END.RHD.CRE.SMB@telethonkids.org.au