Development Framework

2020 Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (3rd edition)

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EXECUTIVE SUMMARY

Evidence-based clinical practice guidelines are important for acute rheumatic fever (ARF) and rheumatic heart disease (RHD) since these conditions:

- are difficult to diagnose;
- are rare in the wider community, such that healthcare providers tend to lack expertise with diagnosis and management; and
- have severe consequences for the people affected.

RHDAustralia is proud to release the *2020 Australian Guideline for Prevention, Diagnosis and Management of Acute Rheumatic Fever and Rheumatic Heart Disease (3rd edition)* to support ARF and RHD prevention, diagnosis and management, and clinical policy development, in Australia.

Clinical guidelines are written to provide guidance; they do not stipulate mandatory practice and are intended to be interpreted appropriately with respect to individual clinical scenarios and local protocols.

A survey of the Australian health workforce community conducted specifically to inform these guidelines indicated that while an interactive digital platform is needed, the printed copy remains an important tool. This guideline is therefore available electronically and in printed form, and has been used to update RHDAustralia's ARF/RHD guideline smart device application. The accompanying ARF diagnosis calculator is fully aligned with the 2020 guideline.

Specifically, this guideline is:

- informed by consumer feedback and the latest research;
- developed in accordance with the NHMRC Standards for Guidelines which includes development processes focused on quality and transparency and literature review;
- developed in collaboration with an Aboriginal and Torres Strait Islander advisory group and other key stakeholders; and
- expanded to include new content and sections drawing on latest evidence and with a focus on practice that is culturally safe for Australian Aboriginal and Torres Strait Islander peoples.

CONTENTS

1 PROJECT COMPONENTS

1.1 Steering Committee

The Steering Committee was governed by Terms of Reference *(Appendix 1)*.

Members provided high level strategic direction and advice to the project and provided expert, timely support to the writing groups. Members of the Steering Committee reviewed and endorsed the final document draft prior to publication.

1.2 RHDAustralia Project Team

Rebecca Slade	RHDA Program Manager
Sara Noonan	Production Editor
Sean Rung	Communications Advisor
Diana Mosca	Senior Nurse Advisor
Vicki Wade	Cultural Advisor

1.3 Legal Matters

Copyright and Disclaimer

Copyright and Disclaimers have been determined by the Menzies Legal Department.

Intellectual Property and Moral Rights Waiver

Ownership of the Intellectual Property of the guidelines vests solely with RHDAustralia. As such, contributing authors were requested to sign a moral rights and intellectual property waiver. This letter was developed in collaboration with the Menzies Legal Department.

1.4 Stakeholder and Partners

Target Audience

The guideline is intended to support clinical, public health and RHD program staff to promote and provide best practice, culturally appropriate care to people with or at risk of ARF and RHD. The following groups were considered in all activities associated with this project:

- Aboriginal Health Workers & Practitioners
- Allied Health Staff
- Doctors, including primary practitioners and medical specialists (physicians including infectious diseases physicians and cardiologists, obstetricians, surgeons)
- Enrolled and Registered Nurses and Midwives
- Dentists
- Policy-makers

- Researchers
- RHD Program staff
- Students (health workforce)

1.5 Health Workforce Engagement

Australia's health workforce was invited to comment on content development and dissemination of the guideline. Invitations to participate in an online survey *(Appendix 2)* were sent through RHDAustralia e-media. Participation in the survey was voluntary and anonymous. The aims of the survey were to:

- identify the level of uptake of the 2012 guideline and smart phone applications;
- better understand how to most effectively deliver the future ARF/RHD guideline to relevant consumers; and
- promote stakeholder engagement around the guideline review and dissemination process.

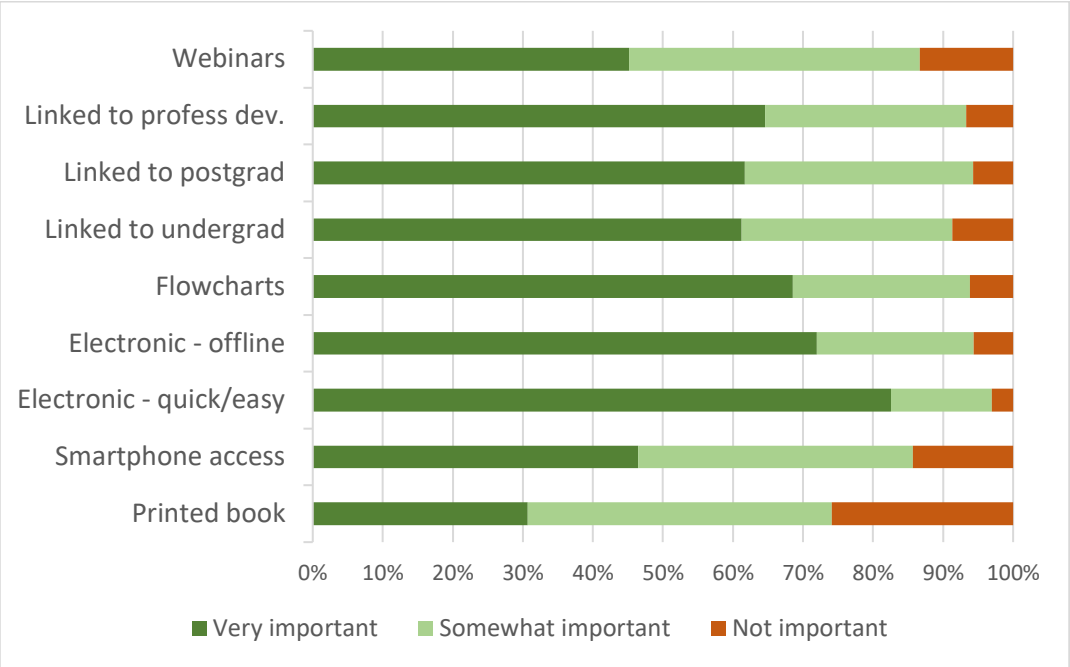
196 members of the health workforce based in urban (53%), rural (18%) and remote (29%) setting participated in the survey.

Overall, *seeking support for clinical practice* was the most common reason respondents consult disease management guidelines. Nurses and allied health staff were the groups most likely to consult guidelines for clinical support, while doctors and medical specialists were most likely to consult guidelines for professional education and/or academic reference.

The 2012 edition was available in electronic and printed form, as a full guideline and as quick references guides. The online (PDF) version of the full guideline was the resource most commonly referred to by all groups except nurses, who more commonly referred to the printed book.

Survey respondents consider a printed book to be least important for accessing information. Electronic platforms that are easy to use and available offline were the most popular important features of disease management guidelines *(Figure 1)*.

Figure 1. Health workforce feedback on preferences for dissemination



Results were collated by the RHDAustralia Project Team and disseminated to the Steering Committee and writing group members. Results were then used to inform the guideline dissemination and implementation strategy.

1.6 Guideline Endorsement

Various stakeholders were engaged about the guideline review and invited to consider the final draft and provide formal endorsement *(Appendix 3)*. They were also invited to provide their organisation logo to the document as a sign of their support. Following a 7-week consultation period, 24 organisations endorsed the guideline *(Appendix 4)*.

2 CONTENT DEVELOPMENT

The 2012 guideline was used as a platform from which to develop the third edition. Several new topic areas were developed, to a) highlight emerging themes associated with ARF and RHD, and b) frame models of care. The new content included:

- clinical practice which is culturally appropriate for Australian Aboriginal and Torres Strait Islander peoples;
- transition from adolescent to adult model of care;
- workforce education and training, with a focus on support for Aboriginal and Torres Strait Islander health staff;
- emerging technologies to prevent and manage ARF and RHD.

2.1 Development of chapter headings and writing groups

The Steering Committee determined chapter headings for inclusion and formulated appropriate expert writing groups to address each of the planned chapters. Existing chapters were expanded where indicated to allow more detail, and five additional chapters were included to address new knowledge and consumer feedback.

To prepare each chapter, writing groups were identified by the Steering Committee as representing Australasian expertise in the respective topics *(Appendix 5)*. Writing groups were convened to focus on individual topic areas. Each group included a lead author, and writers and reviewers were selected on their individual experience in the subject area. Lead authors were responsible for coordinating the writing activity and for submitting the final drafts within agreed timeframes. To support the authors, RHDAustralia provided support for meetings, coordinated drafts, and provide a platform for document management.

Authors were required to declare any potential conflicts of interest, and complete a moral rights waiver. Instructions provided to authors included to:

- review the relevant chapter from the 2012 edition (unless developing an entirely new chapter) and the accompanying reference list;
- conduct a literature review relevant to the assigned chapter to ensure inclusion of any relevant published or grey literature since the time of development of the second edition.
- follow a set template for each chapter - Changes since second (2012) edition, Key Information, Discussion;
- work together as a writing group to provide up-to-date, best practice clinical advice relevant within an Australian context.

2.2 Development of expert consensus

Several key areas for review spanned various chapters, and key proposed changes were analysed and discussed by the relevant authors, other experts and Steering Committee members. Examples include:

- definition of groups at high risk of developing ARF;
- duration of secondary prophylaxis;
- strength of recommendations for community echocardiogram screening in high risk communities.

New recommendations not firmly supported by evidence or where evidence was contentious, were discussed at length by the authors, Editors, other experts and Steering Committee members until consensus was reached, or until an acceptable majority position considering the available evidence was obtained. Discussion groups were multidisciplinary across different medical and nursing specialities, sought to be broadly inclusive, and included input from international authorities including from New Zealand where relevant.

2.3 Conflict resolution

The following escalation process was used to resolve disagreement between contributing writers.

1. The chapter lead author consulted with relevant expert Steering Committee member/s. If not resolved.
2. The issue was presented to the Steering Committee for broader discussion. If not resolved.
3. External consultant/s and/or multidisciplinary working group were engaged.

2.4 Content review

Feedback on the semi-final draft was invited from a broad range of content experts.

The semi-final draft was read in full and edited by the Editors to ensure inclusion of any recently-published or in-press literature, consistency of information across chapters, and alignment with other Australian and International guidelines where indicated.

Several relevant recommendations from other publications (e.g. American Heart Association, Australian Therapeutic Guidelines: Antibiotic) were adopted for the third edition. Several new evidence-based recommendations have also been communicated to editors of other Australian guidelines to maintain alignment ahead of their next review.

2.5 Editing and Design

A qualified copy editor was engaged to review the final drafts. Attention was directed to consistency of terminology and abbreviations, grammar, symbols, and referencing, and collating the writing styles.

2.6 Project Timeline

ACTIVITY	END DATE
Appoint project team	Apr 2018
Finalise project framework	Apr 2018
Establish writing groups	May 2018
Distribute health workforce survey	June 2018
Engage stakeholder organisations	Aug 2018
Final chapter drafts submitted	Sep 2019
Steering Committee review and endorsement	Oct 2019
Copy edit review	Oct 2019
Stakeholder consultation and endorsement	Feb 2020
Technology (app) update	Feb 2020
Guideline released	Feb 2020

Appendix 1. Steering Committee Terms of Reference

1. INTRODUCTION

1.1. Acronyms

ARF	Acute Rheumatic Fever
CRE	Centre for Research Excellence
CSANZ	Cardiac Society of Australia and New Zealand
RHD	Rheumatic Heart Disease
Menzies	Menzies School of Health Research
MCRI	Murdoch Children's Research Institute
SAHMRI	South Australian Health and Medical Research Institute

1.2. Purpose of the document

The purpose of this document is to set out the composition and operating arrangements of the Australian ARF/RHD Guideline Review Steering Committee, which will guide the Guideline review project and provide expert support to the writing groups.

1.3. Background

The Australian Government provides funding for a Rheumatic Fever Strategy. RHDAustralia (formerly the *National Coordination Unit*) is funded under the Strategy to support RHD control in Australia including review and development of national disease guidelines. RHDAustralia is operated by Menzies School of Health Research.

1.4. Steering Committee

The Steering Committee has been established to:

- Provide high level strategic direction and advice to the project;
- Provide expert, timely support to the writing groups; and
- Endorse the final document draft prior to publication.

Membership comprises of key clinical and technical experts, as well as cultural leaders and representatives from the key Partners; the Heart Foundation and the CSANZ.

2. COMPOSITION

2.1. Membership

The Steering Committee shall be comprised of:

- Members from RHDAustralia and its Partners
- Expert clinicians and researchers in ARF and RHD
- Aboriginal and Torres Strait Islander Advisors

NAME	ORGANISATION
Alex Brown	South Australian Health & Medical Research Institute
Jonathan Carapetis	Telethon Kids Institute
Cia Connell	Heart Foundation
Bart Currie	Menzies School of Health Research
John Havnen	National Aboriginal Community Controlled Health Organisation
Sara Noonan	Menzies School of Health Research
Anna Ralph	Menzies School of Health Research
Bo Reményi	NT Cardiac / Menzies School of Health Research
Rebecca Slade	Menzies School of Health Research
Andrew Steer	Murdoch Children's Research Institute
Vicki Wade	Menzies School of Health Research
Gavin Wheaton	Women's & Children's Hospital (SA)
Rosemary Wyber	The George Institute for Global Health & Telethon Kids Institute

2.2. Meeting Chair

The Chair (Director, RHDAustralia) shall convene the meetings. If the designated Chair is not available or unable to perform the duties of Chair, then the Acting Chair (Manager, RHDAustralia) shall convene and conduct the meeting. The Acting Chair is responsible for informing the Chair as to the salient points/decisions raised or agreed to at that meeting if the Chair is absent. The duties of the Chair are to:

- maintain Committee membership;
- provide leadership, strategic direction and support to Committee members;
- set meeting agenda and priorities for discussion;
- ensure the Committee functions according to these Terms of Reference;
- ensure the Committee meets as agreed and works effectively;
- monitor actions and activities arising from the meetings; and
- represent the Committee and the strategic outcomes to external stakeholders.

2.3. Meeting arrangements

A Quorum of the Committee will consist of seven (7) members, including the Chair or Acting Chair, and at least one member of the Guideline Project Team (RHDAustralia).

The Committee will meet via teleconference three (3) times each year during each year of the Project, and more frequently as part of an email conversation as required.

The Chair may call an additional teleconference meeting of the Committee if required.

Where practicable, the meeting agenda together with relevant reports and documents will be forwarded to members by email within 10 days prior to the meetings.

2.4. Conflicts of interest

Members should declare any personal interest at any meeting if it relates specifically to an issue under consideration. This declaration shall be recorded in the Minutes.

3. OPERATING PROCEDURES

3.1. Function of the Steering Committee

The Committee has responsibility for the business associated with the review and update of the Australian ARF/RHD Guideline (Project). The Committee is responsible for approving associated documents and processes, including a review of the literature, appropriate engagement of contributors, and ensuring the quality and relevance of the final product.

In practice, this means members of the Steering Committee will:

- ensure the requirements of stakeholders are met by the project's outputs;
- help balance conflicting priorities and resources;
- provide guidance to the Guideline review Project Team and contributors;
- and guide review the progress of the Project; and
- ensure that Project activities are established and conducted in line with best practice.

Members of the Committee shall nominate a proxy to attend a meeting if the member is unable to attend. The nominated proxy will be invited to provide relevant comments and feedback on behalf of the member if they are qualified to do so.

3.2. Agenda Items

Agenda items must be forwarded to the Project Coordinator by close of business, seven (7) working days prior to the next scheduled meeting.

The agenda and relevant attachments will be distributed to members at least five (5) working days prior to the next scheduled meeting.

3.3. Minutes of the Meeting

Minutes of the Meeting will be prepared by Project Coordinator. Minutes of the previous meeting and attachments will be distributed to members at least five (5) days prior to the next scheduled meeting.

By agreement of the Committee, out-of-session decisions will be deemed acceptable. Where agreed, all out-of-session decisions shall be recorded in the Minutes of the next scheduled meeting.

VERSION DATE 13 JULY 2018

Appendix 2. Health Workforce Survey

This short survey is to help RHDAustralia and its Partners understand what you might want from the upcoming third edition of the Australian ARF/RHD Guideline.

Your feedback is very important to this process, and we thank you for your time. All responses will be treated confidentially.

The survey should take about 4 minutes to complete.

1. Which best describes your primary role?
    - Aboriginal Health Worker / Practitioner
    - Allied Health
    - Doctor
    - Health Policy / Manager
    - Medical / Surgical Specialist
    - Nurse / Midwife / Practitioner
    - Researcher / Educator
    - RHD Program staff
    - Other (Please specify) [text field]

2. What is the postcode of your primary work site or base? [text field, up to 6 characters]

3. Which of the following has ever prompted you to consult disease management guidelines? (select all that apply)
    - Clinical Support (primary care / disease management)
    - Professional Education / Academic Reference
    - Program / Workforce Planning / Management
    - I do not consult disease management guidelines
    - Other (please provide details) [text field]

4. Have you ever accessed the *Australian guideline for the prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease, 2012?* (Select all that apply, or select NO)
    - Yes – hard copy Guideline (book)
    - Yes – hard copy Quick Reference Guides (books)
    - Yes – internet copy Guideline (PDF)
    - Yes – internet copy Quick Reference Guides (PDF)
    - Yes – smart phone Guideline (app)
    - Yes – smart phone ARF diagnosis calculator (app)
    - No

(Your feedback will be valuable) [text field]

5. Do you use/have you used any other guideline/s or protocol/s in relation to ARF or RHD? (Select all that apply, or select NO)
    - Australian Therapeutic Guidelines (book)
    - e- Therapeutic Guidelines (electronic)
    - CARPA Guidelines

- World Health Organisation Guidelines
- American Heart Association Guidelines
- New Zealand Guidelines for Rheumatic Fever (Update 2014)
- UpToDate
- Locally-developed guideline or protocol
- Local PHN Pathway
- No
- Other

Please provide details [text field]

6. In your opinion, how important are the following features in relation to delivering disease management guidelines?

	Very important	Somewhat important	Not very important	Not important
Delivery via smart phone applications				
Electronic – quick & easy to navigate				
Electronic - capacity for download / off-line access				
Available as a printed textbook				
Linked to undergraduate clinical education and training platforms				
Linked to professional orientation/annual skills update platforms				
Incorporated into post graduate clinical education curricula				
Flowcharts to demonstrate clinical pathways				
Presented via web-based tutorials *(e.g. Webinar)*				

7. In your opinion, how much information should clinical guidelines contain?
   - Key clinical information only
   - Key clinical information AND evidence-based discussion and rationale

8. Please provide any other feedback about how we might best support the health workforce regarding the CONTENT or PRESENTATION or DELIVERY of future ARF/RHD Guidelines. [text field]

9. Are you on the mailing list to receive e-newsletters and updates from RHDAustralia?
   - Yes
   - No
   - Unsure

If you are not on our mailing list and would like to receive e-newsletters and updates, please enter your details below, or send to info@rhdaustralia.org.au

Your Name: [text field]

Your Country: [text field]

Your Email Address: [text field]

If you have more to say, please contact us at info@rhdaustralia.org.au and address your email to **ARF/RHD Guideline Review.**

Thank you for your participation.

Appendix 3. Stakeholder Engagement Letter

[date]

[name & organisation]

RE: Review and update of The Australian guideline for prevention, diagnosis and management of acute rheumatic fever and rheumatic heart disease (2nd edition).

Dear [name]

I am writing to you as the Director of RHDAustralia, to engage [name of organisation] around the update of the Australian ARF/RHD guideline.

RHDAustralia has partnered with colleagues at the Heart Foundation of Australia and the Cardiac Society of Australia and New Zealand to conduct a review of the guideline. This project is being coordinated by RHDAustralia; a Commonwealth-funded program based at the Menzies School of Health Research in Darwin. We support control of rheumatic heart disease (RHD) in Australia through a range of activities including revision, expansion and dissemination of the national guideline.

We anticipate that review of the existing guideline will be underway for the remainder of 2018. Contributors include a wide range of clinical experts, researchers, and members of the primary care, allied health and Aboriginal health workforce. In 2019 we will focus on delivering the updated content, including integration into local guidelines and other learning platforms.

Specifically, this latest review of the Australian ARF/RHD Guideline will:

- be informed by consumer feedback and the latest research;
- be developed in accordance with the NHMRC Standards for Guidelines which includes development processes focused on quality and transparency and systematic review;
- be developed in collaboration with key stakeholders and peak Indigenous health bodies;
- be expanded to include new content and sections drawing on the latest evidence-based research and with a focus on culturally-safe practice; and
- be delivered via multimedia and new technologies in conjunction with education tools and resources, and an interactive scenario based education platform.

We will provide [name of organisation] with a final draft and invite you to consider formal endorsement. I thank you in advance for your support.

Sara Noonan has been appointed Technical Advisor to RHDA and is the lead person for the review, coordination and finalising of the 3rd edition. Sara can be contacted at sara.noonan@menzies.edu.au

Kind regards

Yours sincerely

Appendix 4. Endorsing Organisations

Australian College of Midwives (ACM)

Australian College of Rural and Remote Medicine (ACRRM)

Australian Indigenous Doctors' Association (AIDA)

Australasian Society for Infectious Diseases (ASID)

Australasian Society for Ultrasound in Medicine (ASUM)

Australasian Sonographers Association (ASA)

Australian and New Zealand Society of Cardiac and Thoracic Surgeons (ANZSCTS)

Cardiac Society of Australia and New Zealand (CSANZ)

Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)

Council of Remote Area Nurses (CRANA)

Improving Health Outcomes in the Tropical North (HOT NORTH)

Indigenous Allied Health Australia (IAHA)

Internal Medicine Society of Australia and New Zealand (IMSANZ)

Marie Bashir Institute (MBI)

Murdoch Children's Research Institute (MCRI)

National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA)

National Aboriginal Community Controlled Health Organisation (NACCHO)

One Disease

Public Health Association of Australia (PHAA)

Royal Australasian College of Physicians (RACP)

Society of Obstetric Medicine of Australia and New Zealand (SOMANZ)

South Australian Health and Medical Research Institute (SAHMRI)

Telethon Kids Institute (TKI)

The Doherty Institute

Appendix 5. Contributors

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