Australian Burden of Rheumatic Fever and Rheumatic Heart Disease

The Cost of Inaction

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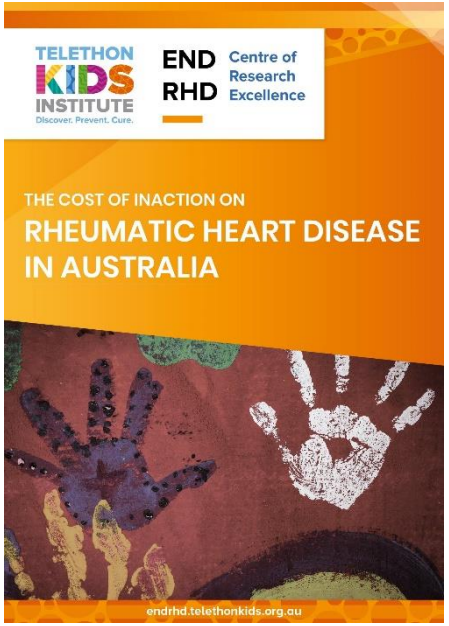
Overview

- Recent work conducted by the End RHD Centre for Research Excellence
- ‘Cost of Inaction’ report outlines the projected burden of ARF and RHD in Australia until 2031, given current levels of funding and attention



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The Endgame for RHD: Research and advocacy

Technical, clinical and research outputs

Advocacy, policy and translational outputs

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AMA

NACCHO
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AMSANT

Heart Foundation

AHCWA
Aboriginal Health Council of Western Australia

menzies
school of health research

Aboriginal Health & Medical Research Council of NSW

QAIHC
Queensland Aboriginal and Islander Health Council

Aboriginal Health Council of South Australia Ltd.
our health, our choice, our way

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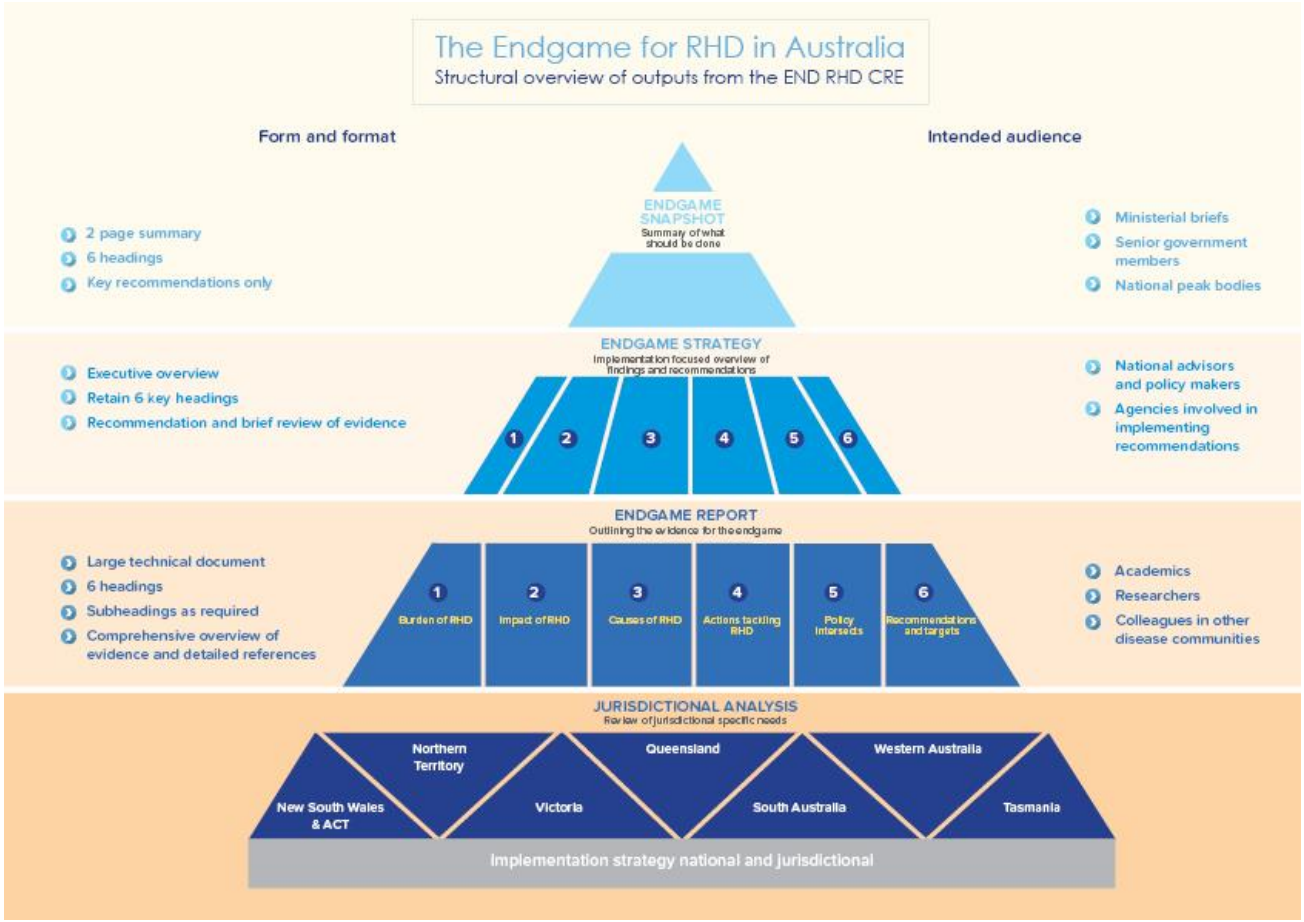

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RHD Roadmap *Planning for a rheumatic heart disease free future at a glance*

Domain	Activities	Immediate | 2019 – 2021	Medium term | 2022 – 2027	Longer term | 2028 – 2031	Destination
Structural & systems support, evaluation & monitoring	***Mechanisms for national and local decision making*** • **Guarantee** Aboriginal &Torres Strait Islander leadership by adhering to COAG's Close the Gap Refresh Implementation Principles • **Create** national and jurisdictional governance structures to strengthen partnerships and deliver results • **Resource** local community leadership and governance to ensure community-led culturally-based solutions ***Health workforce investment*** • **Align** with COAG Health Council National Indigenous Health and Medical Workforce Plan **Ensure** a sustainable on-the-ground workforce for effective environmental health including a national workforce plan • **Increase** numbers, tenure and seniority of Aboriginal and Torres Strait Islander people employed in health including dedicated positions for acute rheumatic fever (ARF) and rheumatic heart disease (RHD) case management and care co-ordination • **Enlist** the support of other education and training organisations ***Integration*** • **Focus** on improving the patient journey and system performance • **Enhance** comprehensive, responsive primary health care through systems support • **Communicate** openly with Aboriginal and Torres Strait Islander people and hear their voices to improve services ***Evaluation and monitoring*** • **Determine** accountability between partners at national, jurisdictional and local levels, and identify priority metrics for each • **Develop** a national evaluation and monitoring strategy as part of the implementation plan of the RHD Roadmap • **Ensure** incidence of ARF is recorded consistently and reported nationally at least annually	• *National RHD Steering Committee appointed with secretariat* • *High-level cross-sectoral committees or forums in high-risk jurisdictions have mandates to address social and environmental determinants* • *Jurisdictional Action Plans developed and implementation underway* • *Roadmap performance metrics including workforce requirements agreed and reporting templates finalised* • *Networks established to promote best practice in each RHD Roadmap domain*	• *Primary health care services resourced and supported to achieve quality of care metrics for Aboriginal and Torres Strait Islander populations with high rates of Strep A infections, ARF and RHD* • *Increased numbers of Aboriginal and Torres Strait Islander people in health fields including environmental health* • *Evidence reviews and clinical guidelines produced for each RHD Roadmap domain*	• *Next Implementation Plan for the National Aboriginal and Torres Strait Islander Health Plan integrates RHD Roadmap* • *ARF incidence and other priority metrics tracking according to agreed trajectory target* • *NACCHO and other peak bodies rate the level of community control as exceeding expectations*	**Aboriginal and Torres Strait Islander people and organisations engaged in sustained, genuine partnerships based on effective governance and accountability**
Primordial Prevention	***Reduce social, economic and health system inequality*** • **Achieve** whole-of-government changes to promote Aboriginal and Torres Strait Islander health within, and beyond, the health system ***Reduce the health impacts of crowded and inadequate housing*** • **Ensure** safe and sufficient housing is available in Aboriginal and Torres Strait Islander communities • **Ensure** learnings from the currently funded five Rheumatic Fever Strategy Communities are shared and inform future action • **Develop and disseminate** methods and tools to promote environmental health ***Enhance place-based primordial prevention*** • **Act** through established community organisations to plan a community-led response to factors increasing risk of ARF including access to 'health hardware' • **Use data** to identify gaps in workforce, capacity and development for response through Jurisdictional Action Plans • **Develop** national standards for safe housing, classification of urgent and priority housing repairs and assessment tools • **Produce** decision-oriented evidence reviews for communities	• *Methods to assess place-based requirements for environmental health, home maintenance and 'health hardware' advanced nationally* • *Access to local environmental health services increased in RFS Communities and results shared* • *Local community-based approaches and resources are expanded according to community need and readiness*	• *Environmental health assessments and action under strong local community governance and service monitoring* • *National standards for a safe house, classification of urgent and priority housing repairs* • *Local systems operationalize national standards* • *Local community-based approaches and resources expanded to enable all communities with high burden of Strep A to act*	• *Local partnerships achieve environmental health improvements appropriate to need that reduce rates of presentations for conditions precipitating ARF* • *Housing infrastructure, cyclical repairs and proactive maintenance specific to community need ensure appropriate service and construction investments.* • *Reduction in household crowding*	**Equity of environmental determinants of health for Aboriginal and Torres Strait Islander people**
Primary Prevention	***Community education, engagement and accountability*** • **Support** communities to learn about disease transmission, scabies, skin sores, sore throats & the risk of ARF and RHD. • **Enable** communities to evaluate the performance of local services in responding to common conditions ***High quality primary care to identify and treat Strep A infections*** • **Resource** primary health care clinics sufficiently to deliver high quality primary prevention • **Ensure** all health staff working with communities at high risk of ARF use evidence-based guidelines • **Encourage** effective CQI by local primary health care services ***Place based primary prevention priorities and innovation*** • **Support** communities to scope and begin implementing local priorities for primary prevention • **Support** from jurisdictional authorities enables whole-of-community approaches to skin sore and sore throat control ***Integrated primary prevention support by all community services*** • **Ensure** all early learning, pre-school and school policies specify soap and handwashing provisions • **Ensure** mechanisms for daily dressings of sores in education settings and referral pathways to primary health care	• *Communities have increased understanding of disease transmission and management* • *Presentations to clinic with Strep A infections increased* • *All Strep A infections appropriately treated* • *All schools have soap, skin sore and hygiene policies which are adhered to* • *ARF incidence reduced by x%*	• *Barriers to primary prevention locally identified and systematically addressed* • *Incidence of ARF reduced by x%* • *Engagement with education providers to ensure adherence to soap and hygiene policies*	• *Incidence of ARF reduced by x% to achieve no new cases of ARF* • *More than 90% of skin sores and sore throats assessed and treated within 24 hours*	**All Aboriginal and Torres Strait Islander people with a skin sore or sore throat receive timely, culturally responsive and evidence-based treatment to prevent the development of ARF**
Secondary Prevention	***Early diagnosis of ARF and RHD*** • **Improve** the diagnosis of ARF through training, improving timeliness of blood results and early echocardiography • **Improve** the early diagnosis and management of RHD by improving capacity of primary care • **Consider** a time-limited program of active case finding through echocardiography screening • **Ensure** that all people diagnosed with ARF or RHD have an actively co-designed care plan ***Support secondary prophylaxis delivery*** • **Continue** to fund all jurisdictional RHD Register-based control programmes • **Fund** primary care services to resource the full cost of delivering secondary prevention • **Elicit** community support for additional strategies to support secondary prophylaxis • **Raise** community understanding and opportunities to address low adherence to secondary prophylaxis • **Respond** effectively to community preferences for trained Aboriginal and Torres Strait Islander staff and injection delivery • **Encourage** effective CQI by local primary health care services that reinforces accountability to patients ***Guideline based care to reduce the risk of complications*** • **Ensure** services and specialist reviews are received according to agreed care plans and resolve persistent service gaps	• *Primary health workforce supported to better diagnose ARF and RHD* • *More people diagnosed ARF who are admitted to hospital* • *Increase health education and co-designed care plans for ARF/RHD* • *Proportion of people receiving 80% of their scheduled injections increased by 15% in all jurisdictions,* • *Reduce the proportion of ARF episodes which are recurrences in each jurisdiction by 5%*	• *All people diagnosed with ARF are admitted to hospital increased* • *The proportion of people receiving 80% of their scheduled injections increased to over 80% in all jurisdictions* • *Mechanism developed to identify and support individuals with poor secondary prophylaxis delivery* • *Proportion of ARF episodes which are recurrences reduced in each jurisdiction by 15%*	• *All people who need secondary prophylaxis more than 90% of prophylaxis injections* • *No recurrent episodes of ARF*	**Anyone with ARF is promptly diagnosed and has a co-designed care plan for secondary prophylaxis and other essential services**
Tertiary Care	***Medical care*** • **Improve** access to safe anticoagulation by improving access to point of care tests and primary care services • **Strengthen** capacity for primary health care services to prevent comorbidities and reduce their impact ***Surgical care*** • **Achieve** culturally responsive, timely, team-based cardiac care including fail-safe discharge planning, communication and handover • **Enhance** the patient journey including permanent care-coordination support, postoperative follow up and rehabilitation • **Build** on national health information for telehealth, discharge summaries and My Health Record ***Reproductive health*** • **Ensure** that all women diagnosed with RHD have the opportunity to discuss the implications for future pregnancy • **Ensure** all Aboriginal and Torres Strait Islander women with a murmur detected during pregnancy receive echocardiography to establish whether they may have RHD • **Ensure** all women with RHD who are pregnant receive multidisciplinary, culturally safe, antenatal and postnatal care	• *Access to specialty services and timely surgical care improved* • *All people undergoing heart surgery have a good understanding of the procedure* • *Improved support for people living with RHD in the transition from paediatric to adult care* • *Full implementation of the RHD Australia guidelines for care for women with RHD*	• *All people having heart surgery for RHD to have a clear and culturally relevant understanding of the process, medical procedure and follow up care* • *Primary health care services receive a complete discharge summary to support clinical handover after any RHD related hospital discharge*	• *Treatment services are provided ways which recognise social and cultural determinants of treatment uptake, adherence, and outcome.* • *Equitable access to appropriate tertiary services to close the gap in RHD-related cardiac mortality.* • *No person under 15 years of age dies of ARF, RHD or needs open heart surgery*	**All Aboriginal and Torres Strait Islander people with severe RHD are able to access timely assessment and culturally responsive services. Women with RHD are supported to make informed decisions about and during pregnancy**
Strategic research investments	***Consensus for national research priorities*** • **Initiate** a national dialogue involving a diversity of viewpoints and expertise to produce an agreed research strategy to accelerate evidence generation preventing ARF and managing RHD • **Produce** a National RHD research strategy that ensures research stays on track and knowledge transfer is accelerated • **Embed** Aboriginal and Torres Strait Islander leadership and partnership with ACCHSs/other parts of health system in the research journey • **Identify** leadership positions for Aboriginal researchers in specific ARF and RHD funding opportunities	• *A process to embed Aboriginal leadership and partnership with ACCHSs/other health services in strategic research is in place* • *A comprehensive national research strategy produced and fully costed* • *Biomedical research priorities fast-tracked to near completion*	• *National RHD research strategy funded and research priorities in underway* • *Demonstrable increase in the number of Aboriginal and Torres Strait Islander researchers* • *Commitments to implementing biomedical research outcomes into clinical practice once proven*	• *Effective action on social, structural, clinical and environmental determinants of ARF is accelerated through strategic research investments led by Aboriginal and Torres Strait Islander researchers*	**A reliable, responsive & productive national research effort producing evidence to address inequitable rates of ARF and RHD in Australia**

Communities celebrating success in eliminating acute rheumatic fever through empowered local decision making, effective partnerships, knowledge sharing and sustained government support for comprehensive primary health care

Centre of Research Excellence

Background

- Political momentum

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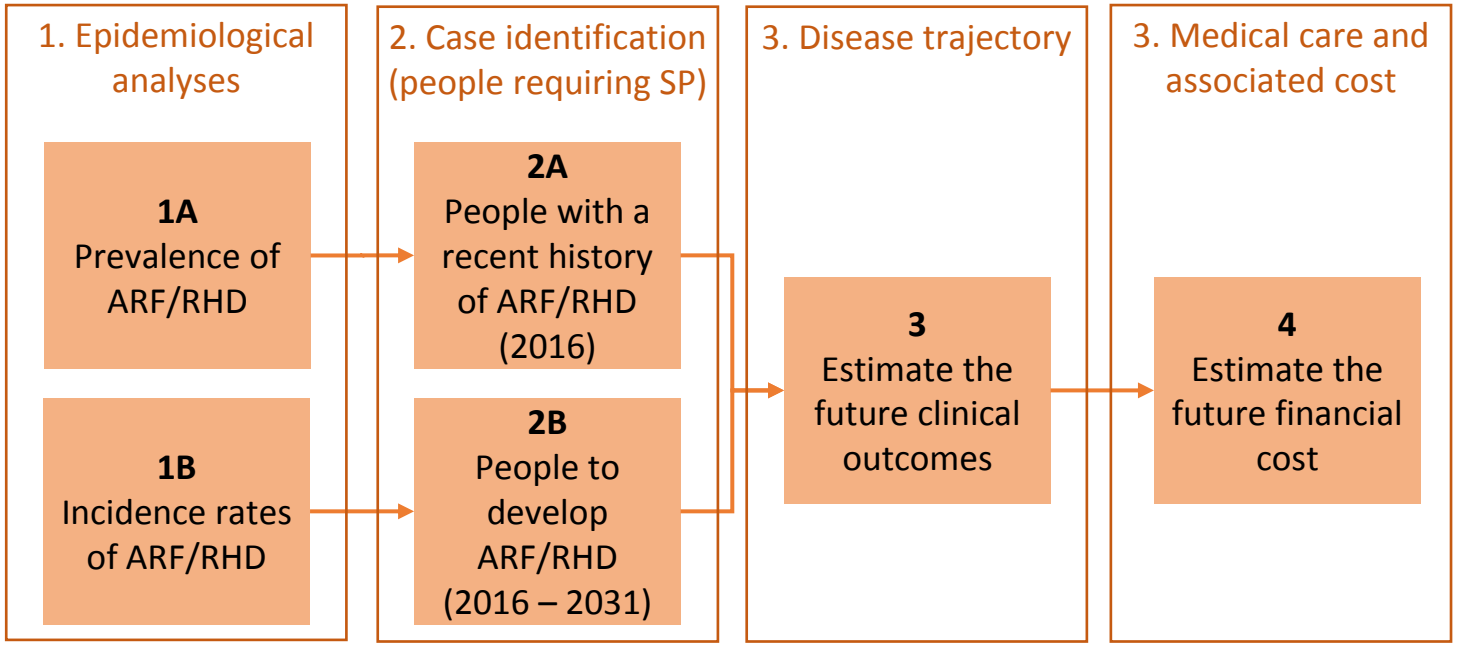
Methods



SP, secondary prophylaxis

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1. Epidemiological analysis

Linked health data 2001-16

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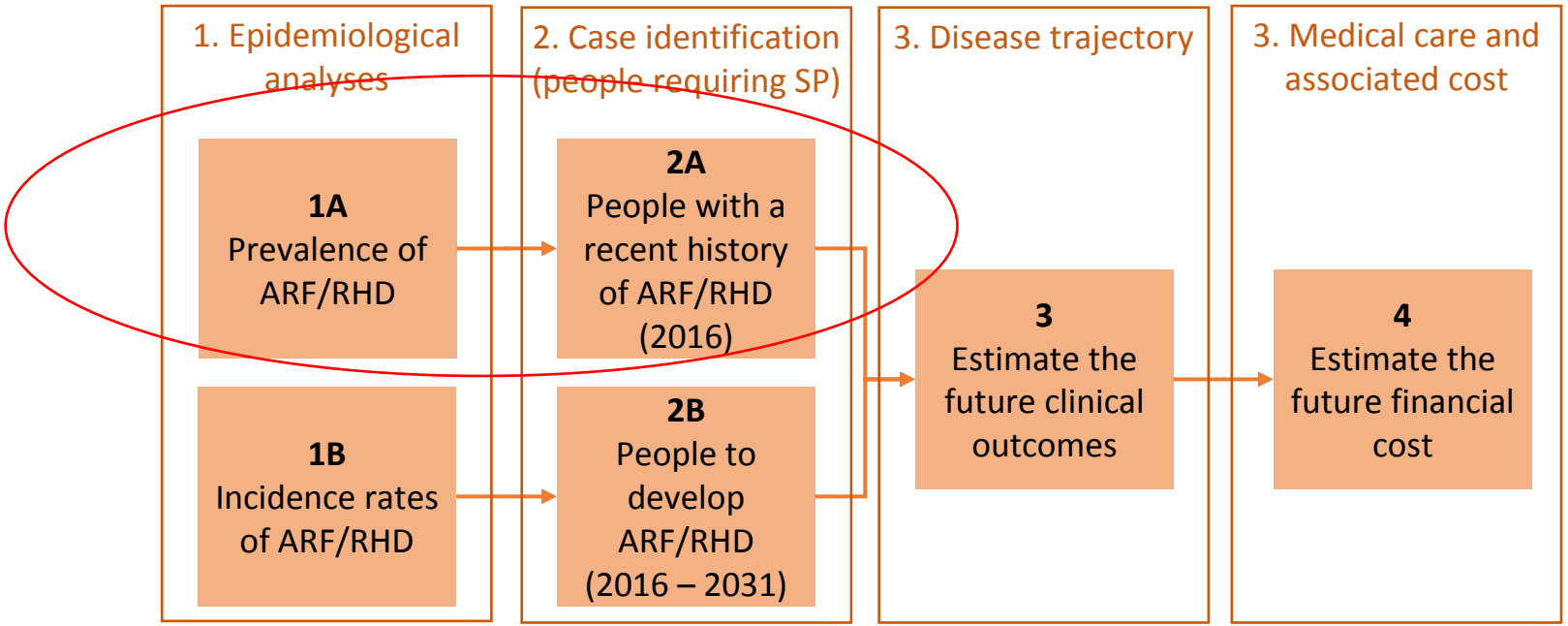
Methods: current cases



SP, secondary prophylaxis

1A. Epidemiology: prevalence

- ARF: N of people at June 30th, 2016 who were under 65 years-old and had been hospitalised for ARF, but not RHD, between 2001 and mid-2016
- RHD: N people at June 30th, 2016 who were under 65 years-old and had been hospitalised for RHD between 2001 and mid-2016

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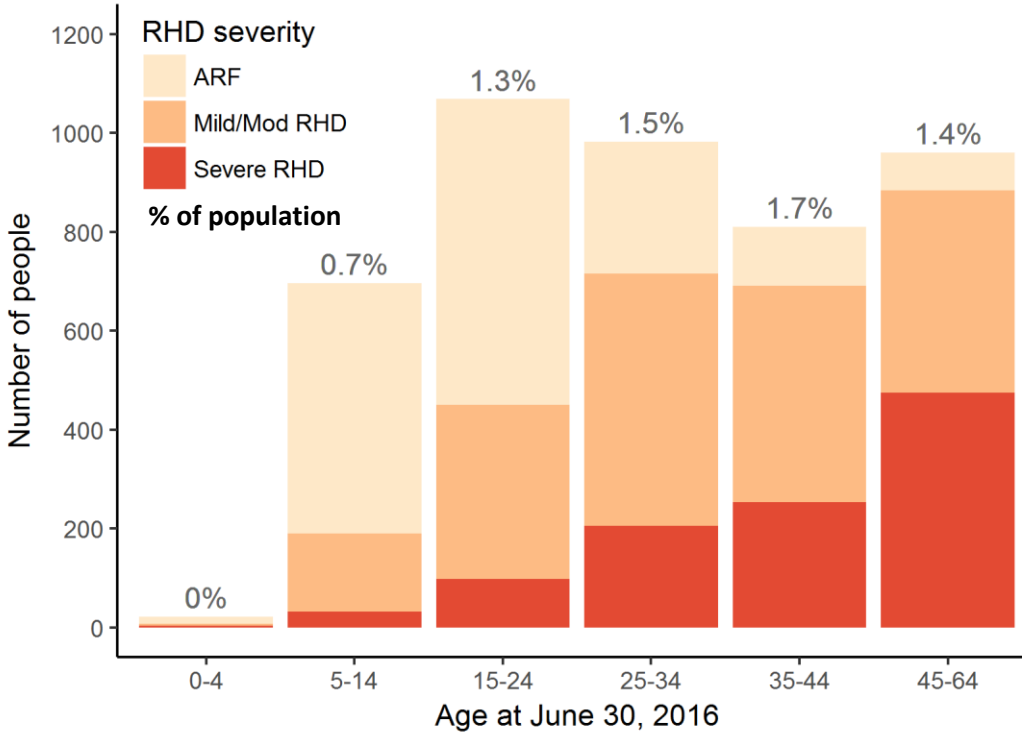
1A. Prevalence of ARF and RHD

- 4,549 Aboriginal and Torres Strait Islander people have been hospitalised with ARF and/or RHD.
- 39% were under 25 years of age
- 24% had severe RHD



2A. Recent history

- Of the 4,549 prevalent cases
  - 3,420 (75%) people were hospitalised for
  - RHD (2,156 people) or
  - ARF (1,264 people)

  less than ten years prior to mid-2016
- These people are recommended to receive secondary prophylaxis and follow-up care

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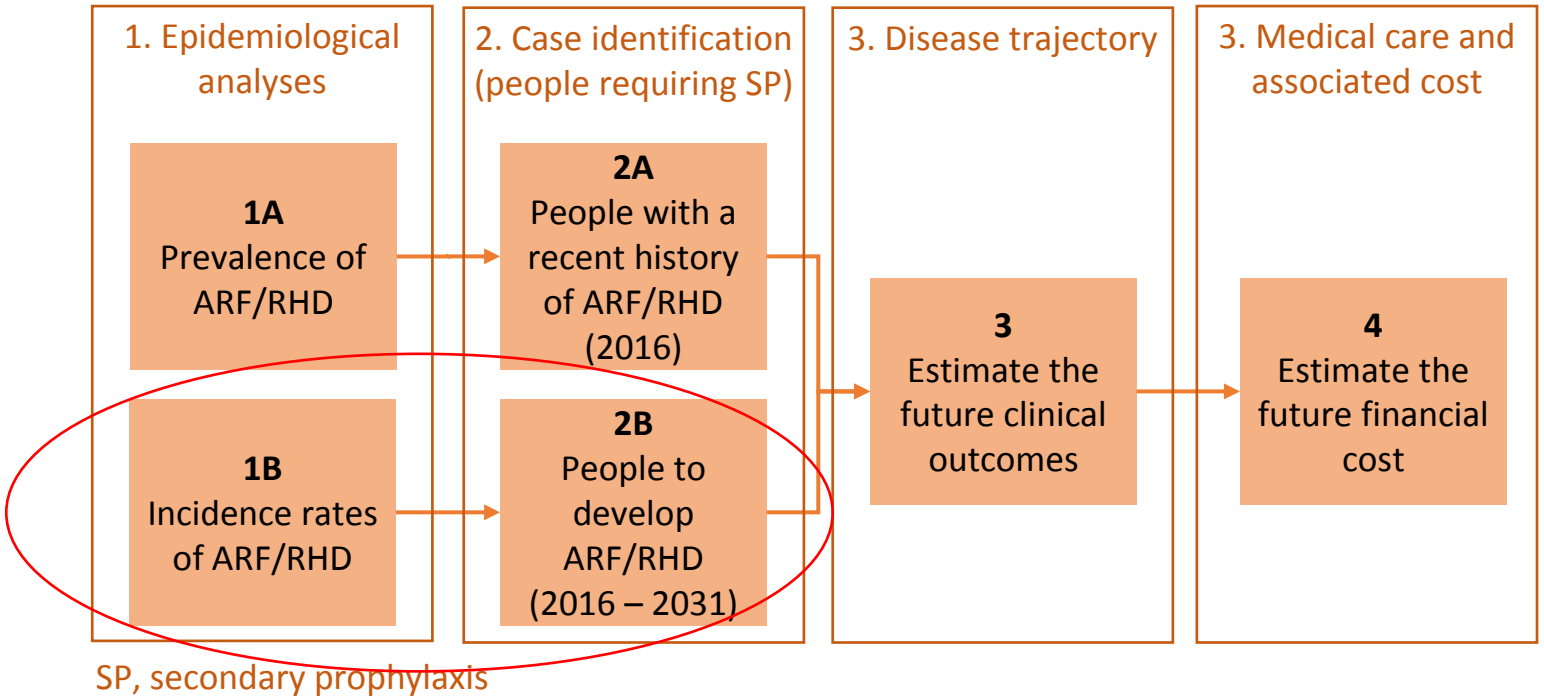
Methods: projected cases



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1B. Epidemiology: incidence rates

- ARF: N people with their first hospitalisation for ARF per calendar year
- RHD: N people with their first hospitalisation for RHD, excluding those with a history of ARF, per calendar year

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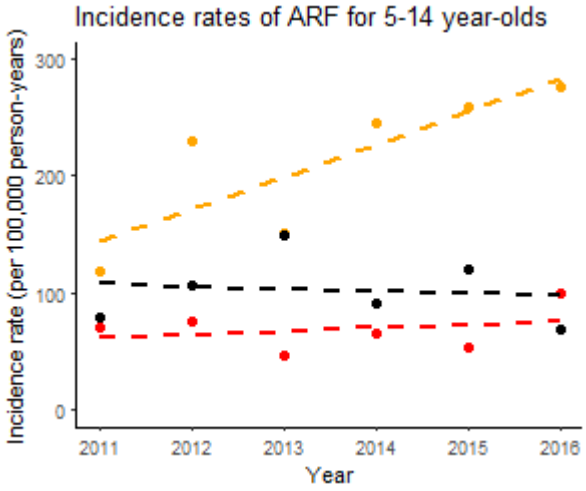
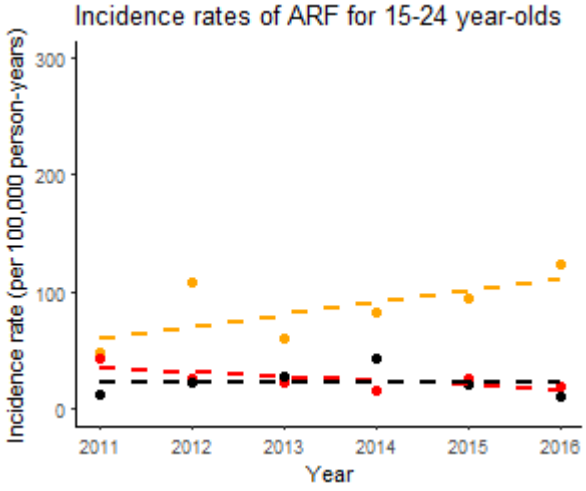
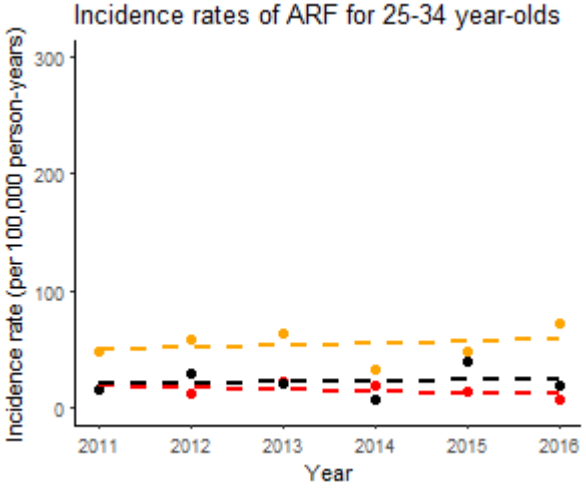
1B. Incidence rates and trends for ARF







Orange = NT and SA; Black = WA; Red = QLD

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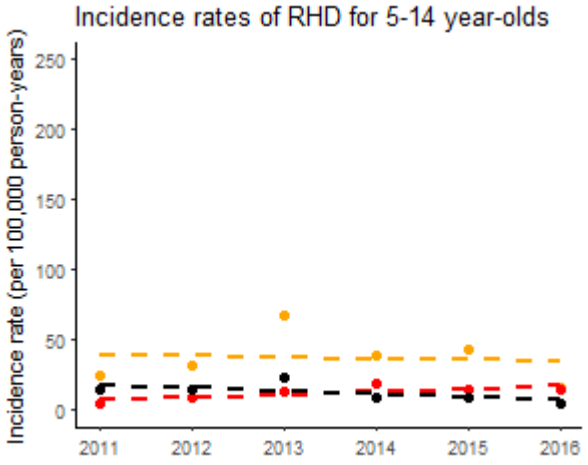
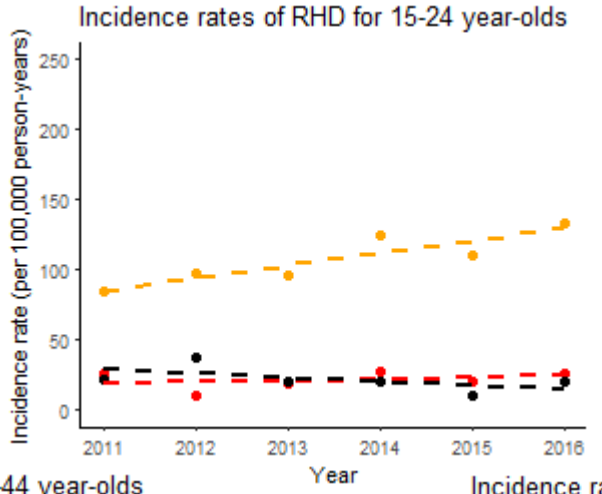
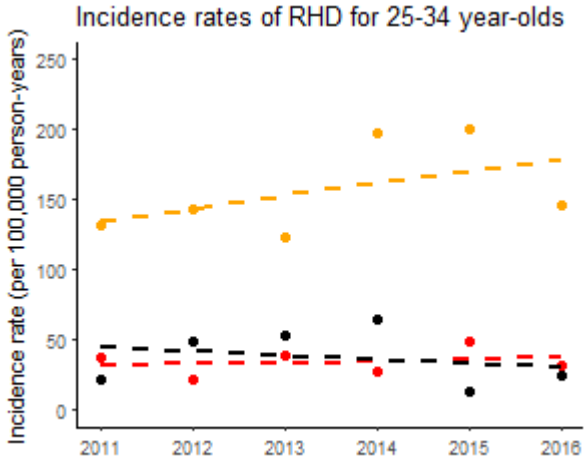
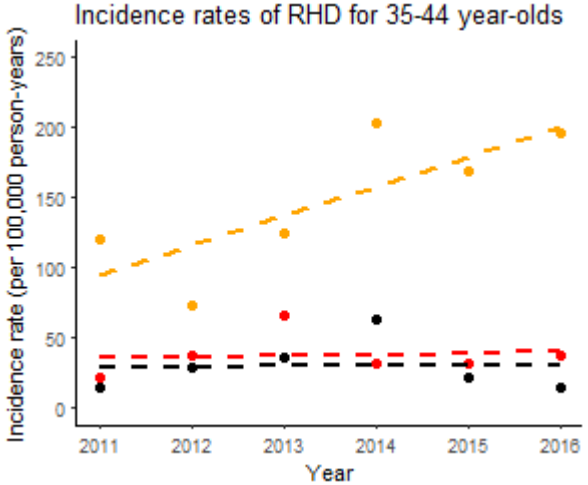
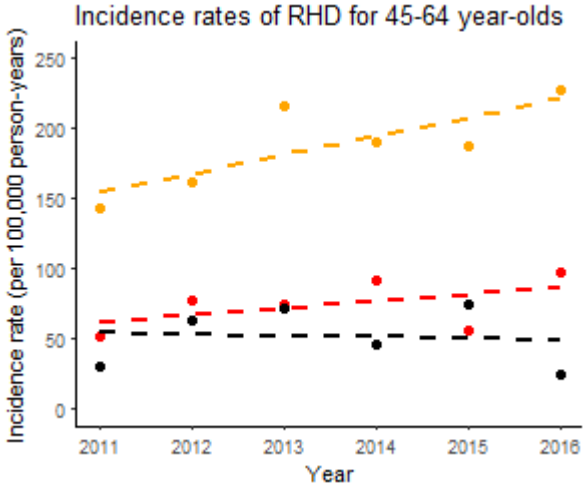
1B. Incidence rates and trends for RHD











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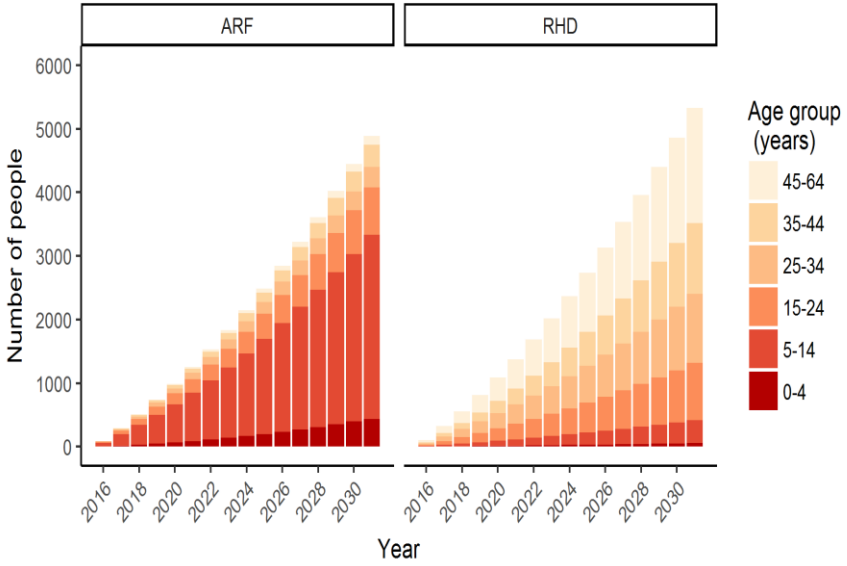
2B. Projected cases

- After extrapolating the observed trends in age-specific incidence rates:
- 4,885 people are projected to develop ARF,
- 5,326 people are projected to develop RHD with no history of ARF



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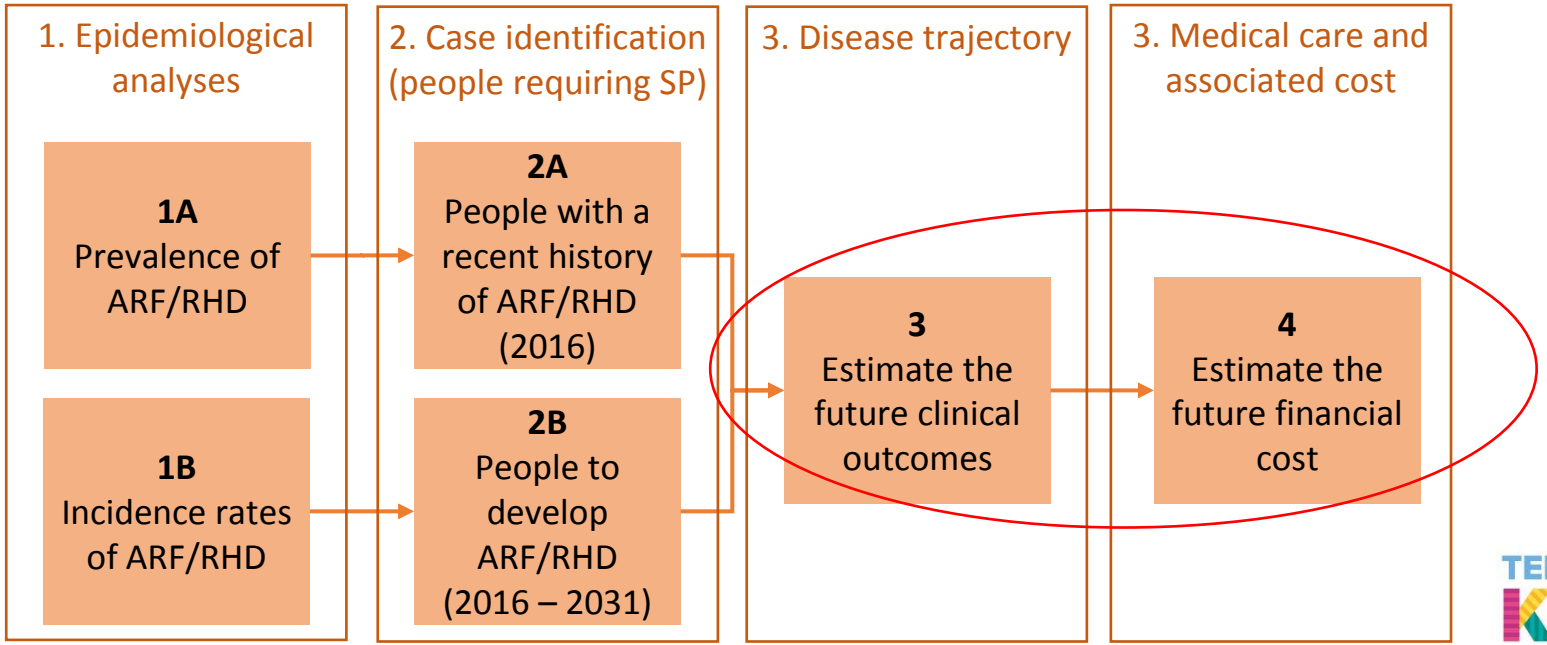
Methods: projected cases



SP, secondary prophylaxis

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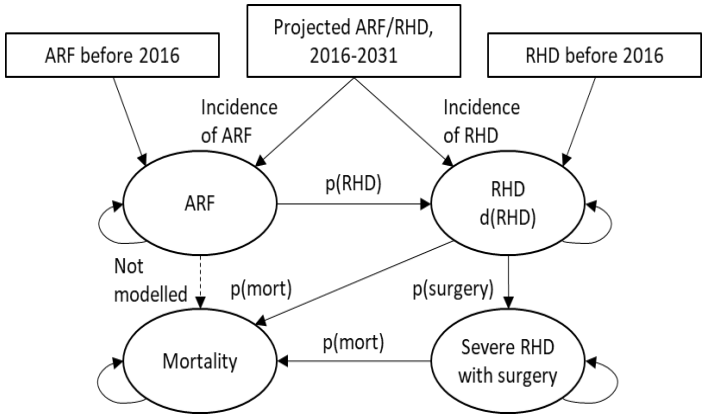
3 & 4. Disease trajectory and care

- Disease trajectory included progression from ARF to mild/moderate RHD or severe RHD, to RHD requiring surgery, and/or to death.
- Medical care was calculated for each level of severity and could include hospitalisation, surgery, and long-term management (SP and clinical reviews for 10 years).
- The likelihood of disease progression and the costs of medical care were taken from previous work.



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3. Disease trajectory: the human cost

- Current cases:
  - Recent ARF: 190 (15%) of 1,264 → RHD
  - Recent RHD: 110 (5.1%) of 2156 people → death within 10 years of hospitalisation date.

- Projected cases:
  - 7,861 additional people will experience and require medical care for RHD in their lifetime, including:
    - 2,535 people ARF (mid-2016 to 2031) → RHD
    - 5,326 people RHD with no history of ARF (mid-2016 to 2031).
  - 2,260 of this 7,861 → **severe RHD**
    - Including 1,370 people who will require valvular surgery.
  - 563 people with RHD will die

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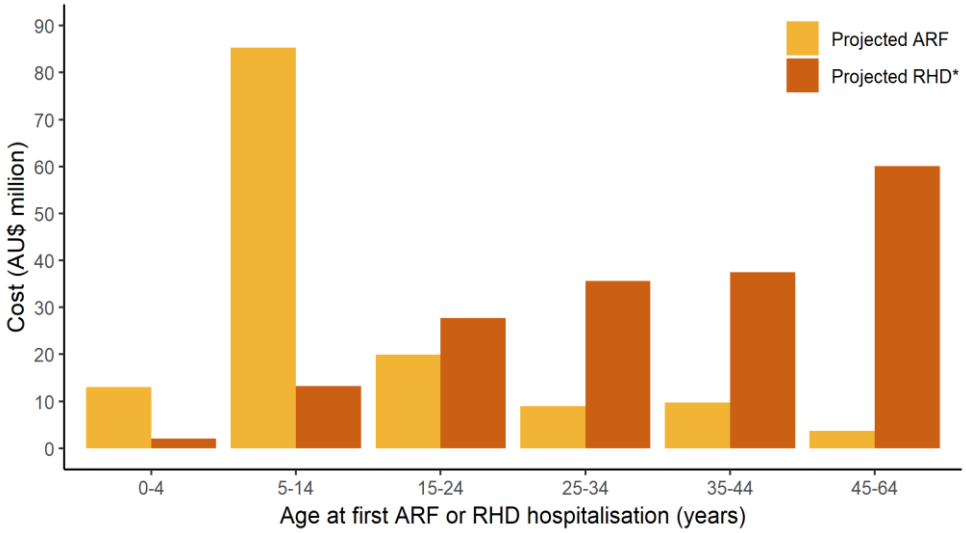
4. Medical care: the financial cost

- **$344 million:** medical care for people who have ARF or RHD or who develop the disease, comprising
  - **$27 million:** medical care for people diagnosed with ARF and RHD since 2007 and alive in mid-2016
  - **$317 million:** medical care for people who develop ARF and/or RHD from mid-2016 until 2031



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Summary


In the last ten years
3,420
were hospitalised
ARF
(1,264 people)
RHD
(2,156 people)
Future medical care will cost
$27 million
An estimated
110
of these people
with RHD will die


Who will get it?
10,212
Aboriginal and Torres Strait Islander people
are projected to develop
RHD
5327 people
and
ARF
4885 people
by 2031
$317 million
will be spent on medical care
1,370
will need heart surgery for severe RHD
563
with RHD will die

Limitations

- Hospital data do not capture cases diagnosed in outpatient or primary care settings
- Incidence based on a 10-year clearance period may not be long enough to ensure cases were truly ‘first hospitalised’ between 2011 and 2016, particularly for older age groups
- Modelled clinical outcomes were limited to a 10-year period post the date of worsening disease
- Financial costs were based on publically-funded medical care only, excluding medical and non-medical costs to patients and their family and to communities.

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