

# WORLD CONGRESS ON RHEUMATIC HEART DISEASE

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**Title:** RHEUMATIC HEART DISEASE (RHD) BURDEN IN AUSTRALIA: RESULTS AND LEARNINGS FROM USE OF PERSON-LINKED MULTI-JURISDICTIONAL DATA

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**Background & Aims:** Despite Australia's high-income status, rheumatic heart disease (RHD) remains endemic among Indigenous communities. The End RHD in Australia: Study of Epidemiology (ERASE) addresses the need for improved data to support disease surveillance, monitor outcomes, and evaluate services, policy development and advocacy. ERASE uses multi-jurisdictional person-linked administrative data from people with acute rheumatic fever (ARF)/RHD from hospital, emergency department, register, deaths, surgery and midwives databases 2002-2017. Through key results from multiple ERASE sub-studies, we report ARF and RHD burden in Australia, while illustrating six major challenges encountered producing accurate epidemiological data, how these were handled, and persisting data gaps/biases.

**Methods:** ARF/RHD cases were identified from RHD registers (clinically validated) and hospital admissions using International Classification of Disease (ICD) codes. Variation in data availability across States, varying register coverage/establishment-dates, and limited ethnic identification created challenges for harmonization and data definitions (challenge #1).

ICD coding deficiencies resulted in over-ascertainment (challenge #2), requiring a predictive algorithm for identifying ICD-coded hospital-only cases. Lack of echocardiogram results (challenge #3) meant that severity status was inferred from ICD disease/procedure codes. Under-attributed RHD deaths (challenge #4) were estimated via excess mortality methods.

**Results:** Data source comparisons found 31% and 26% of Indigenous and 76% and 10% of non-Indigenous cases <59 years missing from the register and hospital data respectively. Among patients later identified with ARF/RHD, missed diagnoses of ARF/RHD during emergency and inpatient care (identified through codes of disease mimics in 3 years prior to first diagnosis) were uncommon (3.5%).

Of 1425 ARF episodes in five Australian jurisdictions 2015-2017, 72.1% were first-ever, 88.8% in Indigenous people and 78.6% were aged <25 years. ARF rates were similar between males/females and peaked age  $\approx$ 15 years, thereafter, were higher in females than males (Figure). Age-standardized ARF episode rates were 71.9 and 0.60/100 000 for Indigenous and non-Indigenous populations respectively (age-standardized rate ratio=124.1; 95% CI, 105.2-146.3).

**Conclusions:** The ERASE sub-studies using person-linked data highlight unacceptable ethnic and regional ARF/RHD disparities in Australia. The END RHD Initiative must not stall. The plateauing male versus soaring female RHD prevalence suggests unaccounted RHD cases among adult men. Findings suggest mild/moderate RHD is under-identified among non-Indigenous people. Indigenous RHD-attributable deaths are substantially underestimated. Data challenges remain, as no single source provided comprehensive case ascertainment although underdiagnosis of ARF/RHD in ED/hospital data appeared rare. The 2017 Global Burden of Disease Australian prevalence counts were significant underestimates and may be similar for other high-resource settings, reflecting limitations in modelling and requiring data improvements.