Research, Advocacy, Action: Harnessing diverse linked data to support the control of rheumatic heart disease in Australia

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Background
Acute Rheumatic Fever (ARF) and Rheumatic Heart Disease (RHD) are endemic among Indigenous Australians. Although preventable, rates are not reducing. END RHD is a coalition of peak health-related bodies committed to ending ARF/RHD in Australia through advocating for effective strategies/policies for ARF/RHD control. Strong evidence is key but data sources are fragmented and lack inter-jurisdictional consistency. Data linkage and analytics can provide crucial information for health policy, service planning and monitoring.

Objective
Outline challenges and methods in creating the first quasi-national linked and harmonized dataset for researching ARF/RHD in Australia

Method
We derived an ARF/RHD cohort from linked RHD register, inpatient hospitalisation and death registry data (2001-2018) covering five Australians jurisdictions (85% of Indigenous people). Additional datasets (e.g. surgery registry, emergency department) were linked to the cohort to expand data utility. Given inaccuracies in hospital coding systems, complex data analytic methods were used to identify ARF/RHD cases for inclusion in analyses of disease burden, progression and outcomes.

Results
Besides the three-year wait for data, cleaning/harmonization and operationalization of definitions presented significant challenges/delays. Of 132,053 patients, 42,787 are considered true cases; only 5,454 appear in RHD registers. Compared with people on registers, the assembled cohort is older and includes proportionally more RHD patients and non-Indigenous people.

Conclusions
For the first time, estimates of ARF/RHD numbers are person-based across a range of sources. The assembled cohort balances reliable case identification with maximizing case capture and comparability across jurisdictions and over time. A range of sub-studies addresses diverse policy-relevant RHD-related research questions.