

REDCap for National Rheumatic Heart Disease Registry

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No conflicts of interest

Background: Rheumatic heart disease (RHD) is the most common cause of acquired cardiovascular disease (CVD) among young populations in low-income countries. Team Heart began performing cardiac surgical interventions in Rwanda in 2007, necessitated by the large burden of severe disease. The growing population of post-operative patients and of patients screened for RHD require a method for collecting high-quality, epidemiologic data. Disease registries have been shown to improve health outcomes, enhance disease surveillance, increase healthcare utilization, and strengthen health systems globally. We sought to create a rheumatic heart disease registry for Rwanda.

Methods: The methodology of registry development followed stages outlined by Evatt (2005). 1) *Establish goals of the registry and prepare action plan.* 2) *Selection system of data collection.* 3) *Determine data content and design data collection form.* 4) *System trainings.* 5) *Collect and analyze data.* 6) *Review the registry system.*

Discussion: The objectives of the registry are to create a centralized system for comprehensive disease data, improve healthcare access and outcomes for RHD patients, and provide a source of aggregate data to better inform policy change and further research with the goal of eradication of endemic RHD in Rwanda. With the initial surgical registry now accessible, future directions include collaborating with the Rwanda Biomedical Center (RBC) on projects and research including investigating pregnancy outcomes of post-operative patients in the context of their anticoagulation regimens.

Glossary of Abbreviations

Rheumatic heart disease.....	RHD
Cardiovascular disease.....	CVD
Non-communicable disease.....	NCD
Rwanda Biomedical Center.....	RBC
Low-to-middle-income-country.....	LMIC

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