



REDCap for National Rheumatic Heart Disease Registry

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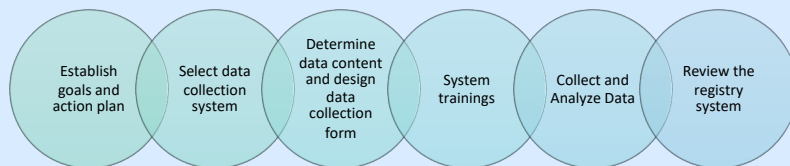
Background

Rheumatic heart disease is the most common cause of acquired cardiovascular disease among young populations in low-income countries. Team Heart began performing cardiac surgical interventions in Rwanda in 2007. The growing population of post-operative patients and of patients screened for rheumatic heart disease require a method for collecting high-quality, epidemiologic data.

Purpose

Disease registries have been shown to improve health outcomes, enhance disease surveillance, increase healthcare utilization, and strengthen health systems globally. With the growing population of post-operative patients, we sought to create a rheumatic heart disease registry for Rwanda.

Methods



State of the Registry

The registry is currently accessible through REDCap, including 10 survey forms: demographics, medical and surgical history, initial presentation, follow-up, internal follow-up, echocardiogram, electrocardiogram, INR, laboratory, and penicillin prophylaxis. Existing patient data is being entered for all surgical patients, and real time surgical data is being entered during surgical trips.

Confidential

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Demographics

Record Number _____

Patient Name _____

Patient ID _____

Check here if the patient is deceased ☐ Deceased

Date of Death _____
(Please use: DD/MM/YR or Day-Month-Year)

Reason for Death _____

Gender assigned at birth ☐ Male ☐ Female

DOB _____
(Please use: DD/MM/YR or Day-Month-Year (if only the year is known, just write the year!))

Primary Health Facility _____

Province _____

District _____

Sector _____

Marital Status ☐ Single ☐ Married ☐ Divorced ☐ Widowed

Phone number _____

Ubudehe Category ☐ I ☐ II ☐ III ☐ IV

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Discussion & Future Directions

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 on projects including investigating pregnancy outcomes of post-operative patients in the context of their anticoagulation regimens.

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