### Terms of Reference

Baylor-Malawi Children's Center
RHD RED (Remote Entry Data-capture) Registry
Mobile – Entry App for a Rheumatic Heart Disease Electronic Registry to be used in Malawi

# Collaborator Background

Amy Sanyahumbi, MD is a pediatric cardiologist with Texas Children's Hospital and Baylor College of Medicine. She is based in Lilongwe, Malawi, Africa with the Baylor-Malawi Children's center and works clinically at Kamuzu Central Hospital in Lilongwe. Her research focus is rheumatic heart disease.

# Project Background

Rheumatic Heart Disease (RHD) is the leading cause of cardiac morbidity and mortality among the world's youth, affecting 33 million people, and causing ~275,100 deaths per year [1-4]. RHD is caused by cumulative exposure to Streptococcal pharyngitis leading to acute rheumatic fever (ARF), which can result in severe cardiac valve damage [2]. RHD disproportionally affects young people in resource limited settings. Malawi has a high prevalence of RHD [5]. Secondary prevention (benzathine penicillin G (BPG) injections every 3-4 weeks to those diagnosed with ARF or RHD) has been shown to be the most successful and cost effective means to prevent severe RHD in low-resourced settings. An effective RHD register to track people with RHD and BPG injections minimizes loss to follow-up, maximizes adherence to BPG, and saves lives.

A mobile-entry RHD registry app will allow health care workers in rural or urban settings can enter information that will be synced to a central electronic registry when bandwidth is available. In addition, the app should utilize GPS and provide BPG stockout information, so stock outs will also be known in real-time, and can be addressed in a timely manner.

#### Deliverables

- Create a functioning prototype of the mobile app in CommCare consisting of:
  - o A secure mHealth App whereby RHD patient data and BPG dates can be entered.
  - Functionality should include:
    - Offline data entry (please note that the internet in Malawi is very slow so even when a connection is available, the app should be designed to use as little bandwidth as possible)
    - The ability to easily review submissions -- this data is intended to be used as a central electronic registry. Students should provide a way to easily review submissions inside CommCare HQ, potentially using custom reports, or if that is not possible, through a custom export. Students may also provide a recommendation for how to sync this data with an external registry.
    - GPS capability to allow for rapid recognition of BPG stock-outs
    - Implement (or make a recommendation if not supported) for automated alerts to notify health care personnel when a patient is overdue for BPG, or is due for yearly echocardiogram

- Generate a dashboard to summarize the data collected from the mobile app and develop a custom report of key indicators in CommCare
- Build a consulting slide deck to present the application that includes:
  - o A description of the problem
  - The proposed solution
  - A mockup of a dashboard to display information for managers from the application
- A user's guide for the application to be used to train end users
- Demonstration of the application

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