# The ADUNU Package.

## Integrated Guideline-Based Care for Rheumatic Heart Disease

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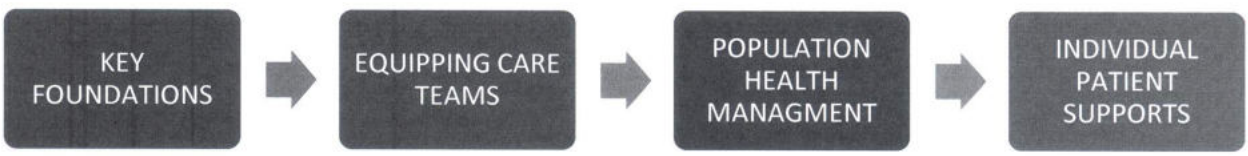
## EXECUTIVE SUMMARY

**ADUNU** (Accelerating Delivery of rheUmatic heart disease preventive iNterventions in Uganda**)** is a package of interventions built around evidence-based practice for rheumatic heart disease (RHD) designed to be delivered within the public healthcare system in Uganda by local District Health Offices (DHOs) under the guidance of the Uganda Heart Institute (UHI), the Ministry of Health (MOH)-owned tertiary facility charged with preventing and caring for cardiovascular diseases in Uganda.

ADUNU is based on two core approaches that have already proven effective in Uganda, including (1) **community-based RHD testing** using echocardiography and (2) **registry-based secondary prophylaxis.** Recommendations for implementation of these two core approaches have been structured into four aspects of programmatic design including Key Foundations, Equipping Care Teams, Population Health Management, and Individual Patient Supports.




Section 1, Key Foundations includes the rationale for the ADUNU program and outlines the essential features that must be in place to meet program objectives. This includes making guideline-based care for RHD a priority at the national, district, and HCIII level and implementing the two key programmatic elements including RHD active case finding using focused echocardiographic screening and registry-based care for those diagnosed with RHD.

Section 2, Equipping Care Teams outlines the best practice recommendations for training and evaluation of direct care staff on echocardiographic screening for RHD and on use of the mobile RHD registry (ACT platform) that currently houses the Uganda National RHD Registry. Further, this section outlines some additional trainings that providers need to care for patients with RHD and administer secondary antibiotic prophylaxis, which is the cornerstone of community based RHD care. These include administration of intramuscular benzathine penicillin G, recognizing and treating anaphylaxis, and supporting patients to improve prophylaxis adherence.

Section 3, Population Health Management, outlines strategies for implementation of the core program tenets. This includes detailed approaches for deploying echocardiographic screening in the community and ensuring those who screen positive are appropriately referred. This section also includes best practices on deploying active registry-based care, including outreach to support patient adherence, and a score-based system to help UHI prioritize patients who require surgical or catheter-based intervention. Further, we outline standardized protocols to facilitate replicable high-quality care at the district level and outline record keeping and reporting practices that will facilitate data-driven practice improvement.

Finally, Section 4, addresses the best practices in individual patient supports that can empower patients diagnosed with RHD to optimize their own care and ensure encounters with providers are informative, supportive, and collaborative.

As outlined, ADUNU is designed to shift the RHD care cascade (diagnosed, registry enrollment, retention, secondary prophylaxis adherence) from 0-0-0-0 in districts with no RHD programs to 50-90-90-90 over four years. Currently, ADUNU is a pilot program that will be deployed and studied in Amuru and Kitgum Districts, with rigorous implementation research to optimize and scale based on the pilot experiences. **Together, we will optimize ADUNU over the next 5 years to prepare for rollout as part of the Ugandan National RHD Strategy.**

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## 1.0 KEY FOUNDATION

### 1.1. MAKE GUIDELINE-BASED CARE FOR RHD A NATIONAL PRIORITY

RHD is the most common form of acquired heart disease in people between the ages of 5 and 39 living in Uganda. It is estimated that between 1-2% of all Ugandans in this age range are currently living with RHD, though few are diagnosed. RHD exerts a high toll in this age group with substantial morbidity and mortality and trickle-down effects of reduced productivity for individuals, families, and communities.

In 2018, Uganda was a key sponsor of a World Health Assembly Global Resolution to reprioritize RHD on National Health Agenda. Over the last 10 years, the Uganda Heart Institute in partnership with the Ministry of Health and global research partners, has generated evidence-based approaches to improving guideline-based care. The ADUNU program represents a culmination of this work and is a synthesis of these evidence-based strategies which are ready for pilot integration into the public health system of Uganda at scale.

Learnings from the implementation of the ADUNU Program will help shape the National RHD Strategy and refine programs that can be scaled country-wide, creating best-practices for sub-Saharan Africa and other regions where RHD remains endemic.

#### 1.1.1 Establish an ADUNU technical and quality assurance working group within the MOH

The ADUNU team will assemble a Technical and Quality Assurance Working Group (TAQA) to oversee implementation of the ADUNU program within the Ministry of Health Rheumatic Heart Disease Strategy team (led by site-PI Dr. Okello). Membership in the TAQA will consist of at least one individual from the following designations:

- MOH Department of Clinical Services (Non-communicable Diseases Division)
- MOH Department of Quality Assurance
- MOH Department of Finance and Administration
- National Drug Authority
- National Medical Stores
- District Health Office representative (1 per district participating)
- Patient representative (person living with RHD)
- ADUNU PI team (Okello, Beaton, or Watkins)

The TAQA will be tasked with providing quarterly oversight of implementation roll-out, with a focus on emerging district- and facility-level barriers that threaten patient outcomes, such as (1) uptake and efficiency of RHD testing, (2) linkage to care, retention in care, and medication adherence, and (3) adverse events among registrants; as well as recommending strategies to minimize the impact of persistent system challenges that may impede scale up, including supplies of essential medications and diagnostics (e.g., benzathine penicillin and echocardiography machines).

#### 1.1.2 Establish and track key district performance metrics

In coordination with the DHO and under the guidance of the ADUNU program, each participating district will submit an annual plan to TAQA (1.1.1) with quarterly targets areas outlined below (see 1.2.2). The ADUNU research team will assist with collection and reporting against these targets, with data reported to TAQA in "dashboard" format on a quarterly basis. Supplementing TAQA review of these data, remote and/or in-person audits and district stakeholder feedback will be used to identify emerging patient-, provider-, and facility-level barriers. TAQA meetings will occur in person or by videoconference monthly, or more frequently as needed, to develop and implement action plans and to follow up on actions taken during quarterly program oversight meetings. Quarterly meetings will be held in person, with DHO representatives rotating between involved districts.



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### 1.1.3 Develop dynamic remediation plans if metrics fall below benchmarks

Reports from these meetings and audits will be used to identify interim modifications to the implementation approach and tailor the deployment of each evidence-based intervention in the intensive and replication districts to address facility-specific emergent barriers as appropriate. Each quarter, the district strategy will also be updated, and best practices disseminated across enrollment sites. This responsive design will not only provide timely support for program delivery within the study, but will also allow ADUNU to identify effective, feasible adaptations available in response to inner and outer setting determinants of success for use by the MOH in future scale up efforts.

## 1.2. MAKE GUIDELINE-BASED CARE FOR RHD A DISTRICT PRIORITY

### 1.2.1 Establish an ADUNU district champion within each DHO

Role Summary: The ADUNU District Champion will be based at the DHO and serve as a liaison between the DHO and MOH regarding the ADUNU program. The key operational goals for the ADUNU program are to improve detection of RHD in the district through roll out of echocardiographic screening and to improve adherence to secondary antibiotic prophylaxis through implementation of registry-based care. The ADUNU District Champion will support the ADUNU Program Manager (1.2.4) in advocating for public health education, healthcare provider education, RHD active screening in the HCIIIs and through community and school outreach, and implementation of the ACT platform for RHD registry-based care.

Duties as ADUNU District Champion:

1) Provide input and leadership for ADUNU implementation, monitoring, and evaluation. Work collaboratively with local stakeholders to leverage and optimally utilize local infrastructure.

2) Chair the District RHD Advisory Group

3) Attend monthly TAQA meetings

4) Support initiatives for public education and community outreach for RHD active case finding

5) Support development of a RHD follow-up clinic at the HCIV

6) Actively monitor supplies of BPG and related supplies and provide dynamic restocking (ACT platform)

7) Establish and report against district metrics.

8) Implement monitoring reports and quality improvement processes as outlined by the TAQA.

### 1.2.2 Implement a robust monitoring system for RHD diagnosis and care delivery

The following is the proposed monitoring system, but we expect modifications when contextualizing the ADUNU program to each of the pilot districts. Additionally, prior to program launch in a district, the TAQA will co-establish benchmarks for district performance, which will be reported against monthly.

| Metric (all by age and sex) | How Collected | Frequency of Collection |
|---|---|---|
| Health center metrics | | |
| Participating health centers | | |
| Training completed | Training logs submitted to the DHO | Once |
| ACT platform updated | ACT platform review, RHD program manager | Monthly |
| Active case detection (screening) by facility, by month | Screening logs maintained by HCIIIs and outreach teams | Monthly |
| Supplies updated | ACT platform review, RHD program manager | Monthly |
| Person-level metrics | | |
| Screened (by age and sex) | Screening logs maintained by HCIIIs and outreach teams | Monthly, turned into DHO |
| Screened positive for RHD | Screening logs maintained by HCIIIs and outreach teams | Monthly, turned into DHO |

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|---|---|---|
| Confirmatory echocardiograms | Echocardiography logs, maintained by the HCIV RHD Clinic | Monthly, turned into DHO |
| Enrolled (by clinic) | ACT platform review, RHD program manager | Monthly |
| Adherence (by clinic) | ACT platform review, RHD program manager | Monthly |
| BPG + related supply stock outs | ACT platform review, RHD Program manager | Monthly |
| Adverse events | ACT platform review, RHD program manager | Monthly |

These data will be integrated into the quarterly TAQA district dashboard that will be used for ADUNU program monitoring and to guide program modifications.

### 1.2.3 Implement remediation plans, when needed, as advised by TAQA

TBD.

### 1.2.4 Hire a district ADUNU program manager

Role Summary: The ADUNU Program Manager will be a 1.0 FTE role, based at the district's highest level health facility (HCIV or regional referral hospital) and serve as a liaison between the DHO and the HCIII's and HCIV's in the district to roll out and maintain the district wide ADUNU program. The key operational goals for the ADUNU program are to improve detection of RHD in the district through roll out of echocardiographic screening and to improve adherence to secondary antibiotic prophylaxis through implementation of registry-based care. The ADUNU program manager will support the district RHD clinic, coordinate echocardiographic screening outreach, support the ACT Platform as the RHD registry, spearhead educational outreach, and provide mentorship to other providers in the district to increase competency in guideline-based care.

Desired Skills:

1) Knowledgeable and enthusiastic about RHD early diagnosis and treatment, with appropriate clinical expertise and experience. OR enthusiastic about learning these skills.

2) Competent in basic echocardiography OR enthusiastic about learning these skills.

3) Good communication skills, able to work well with others, and credible with other frontline providers.

4) Willing/able to invest time in necessary activities include development of a local RHD program, coordinating educational presentations for healthcare providers and the community at large, and promoting RHD screening in the community.

Functional and Duties as RHD Champion

1) Provide input and leadership for implementation, monitoring, and evaluation. Work collaboratively with local stakeholders to leverage and optimally utilize local infrastructure.

2) Serve on the District RHD Advisory Group

3) Develop a local approach to support deployment of district wide RHD active case finding, including screening at HCIII's and targeted outreach events for children and adults.

4) Develop a local approach for supporting patient-referral, retention, and adherence to secondary prophylaxis, and work with the HCIIIs to implement this approach.

5) Support the RHD follow-up clinic at the HCIV

6) Support echocardiography screening training and maintain and update records on certification and maintenance of certification.

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7) Develop a process for review and use of monitoring reports and tools and present these reports to the National TAQA at regular intervals.

8) Collaborate with the DHO to ensure adequate supply of BPG and related materials at all HCIIIs and HCIVs

9) Implement monitoring reports and quality improvement processes as outlined by the TAQA.

**1.2.5 Establish an advanced RHD care clinic (to be based out of the HCIV)**

Each district should identify a physician and/or clinical officer for advanced training in focused echocardiography and clinical management of RHD. This person will come to the UHI for a one-week training course, designed to provide the skills and knowledge needed to lead the clinic at the district level. This will include (1) echocardiography for RHD assessment, (2) ECG interpretation basics, (3) management of secondary prophylaxis (4) recognition and management of common RHD complications (heart failure, atrial arrythmia, stroke), and (5) recognition of the need for and management of anticoagulation. This clinical care will be supported through standardized algorithms (see 3.3).

Following training, a designated clinic should be established (recommend one full day per week). This clinic will be co-staffed by the ADUNU Program Manager and will (1) provide confirmatory echocardiograms for patients who have screened positive for RHD, (2) enroll patients confirmed with RHD into the ACT registry, (3) develop a secondary prophylaxis and care plan for patient with RHD, and (4) assign and link patients with RHD to their secondary prophylaxis clinic (HCIII). The RHD district clinic will be supported by the UHI through quarterly outreach visits by a cardiologist, who will assist with management plans for those with moderate/severe RHD.

**1.3. Make guideline-based care for RHD a HCIII priority**

**1.3.1 Designate an ADUNU champion at each HCIII**

Role Summary: Each HCIII should designate an ADUNU champion to coordinate activities alongside the District ADUNU Program Manager. The HCIII champions will play a critical role in a train-the-trainer format, where they will attend educational activities and bring materials and training back to their health center to train the remainder of the staff. This will include focused echocardiography for RHD detection and use of the ACT mobile platform.

Desired Skills:

1) Knowledgeable and enthusiastic about RHD early diagnosis and treatment, with appropriate clinical expertise and experience. OR enthusiastic about learning these skills.

2) Competent in use of technology (can turn on a tablet, use a smartphone), OR enthusiastic to learn those skills.

3) Good communication skills, able to work well with others, and credible with other frontline providers.

4) Good organizational skills, able to keep timelines, attend meetings on time.

5) Experience or enthusiasm for teaching/training peers and members of the community.

6) Willing/able to invest time in necessary activities include development of the HCIII RHD program.

Functional and Duties as RHD Champion

1) Attend all required ADUNU trainings.

2) Host trainings at home health center to educate the team using material provided at the ADUNU trainings.

3) Serve on the District RHD Advisory Group

4) Work with the ADUNU Program Manager to support deployment of district wide RHD active case finding, including screening at HCIII's and targeted outreach events for children and adults.

5) Work with the ADUNU Program Manager to develop an approach for supporting patient-referral, retention, and adherence to secondary prophylaxis.

6) Maintain or oversee maintenance of BPG stock reports in the ACT platform.

7) Oversee secondary antibiotic prophylaxis clinic(s).

8) Serve as a resource for other team members when support is needed for echocardiography or use of the ACT platform.

#### 1.3.2 Expand the RHD care team with community health workers

The ADUNU Program will develop a package of materials for use by community health workers to increase awareness of RHD and to spread the word in the community around outreach for RHD active case finding events. The HCIII champions will be responsible for coordinating with the community health workers that severe their clinics to conduct these outreaches and to help organize community events.

#### 1.3.3 Actively tract and respond to supply of guideline-based drugs

The ACT platform has a feature designed to actively predict the need for guideline-based secondary prophylaxis and related supplies. The HCIII champion or their designee will be responsible for inventorying supply on a weekly basis and updating the ACT platform so that the DHO can anticipate and respond to supply needs.

### 1.4. Implement RHD active case finding to promote early RHD identification

#### 1.4.1 Overcome high diagnostic inertia

Currently, in most Ugandan districts there are no RHD-related services and few patients who are living with RHD are aware of their diagnosis. Unfortunately, when people do learn they have RHD it is often too late to benefit from secondary antibiotic prophylaxis. Data from the Ugandan National RHD registry supports that >80% of patients present with advanced RHD, when only a surgical intervention can improve outcomes. Late presentation drives poor outcomes, and our data shows >30% of children diagnosed with RHD die within 9 months of diagnosis.

But RHD is a cumulative disease. Early detection, before people become symptomatic, affords patients the opportunity to receive regular antibiotic injections that can protect the heart and stop progression. Echocardiography, or ultrasound of the heart, has found that between 1-2.5% of Ugandans between the ages of 5-39 have early RHD and can benefit from prophylaxis.

ADUNU will overcome high diagnostic inertia for RHD diagnosis by (i) implementing an organized program to test district residents for RHD between 5-39 years of age (when risk is highest and secondary prevention is most effective), (ii) maximizing the diagnostic yield of the testing program by using four evidence-based complementary approaches, (iii) train public health nurses to do RHD testing, and (iv) coordinate district-wide RHD activities through a dedicated Program Coordinator at the district HCIV.

#### 1.4.2 Offer RHD screening and referral without a fee

A key component of the ADUNU program is that RHD active case finding be offered, at no charge, to every member of the district aged 5 to 39 years of age. These ages were chosen based on the prevalence of RHD and the window to implement secondary antibiotic prophylaxis to improve

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outcomes. We will encourage HCIIIs to offer screening to all patients (regardless of presenting complaint) at least once during the study period. We will also encourage HCIII nurses to participate in community outreach events to bring screening to the community.

### 1.4.3. Maximize the efficiency and reduce the burden of RHD screening

There are a variety of screening protocols that can be implemented to improve case detection of RHD. Those that are based on auscultation have been shown to have low sensitivity and specificity. Full echocardiographic studies are the gold standard for diagnosis of RHD but require lengthy exams and sophisticated training.

ADUNU seeks to enable efficient RHD screening, prioritizing a low time burden for healthcare workers and community members undergoing screening. Past research by our team has identified that a screening protocol utilizing a single echocardiographic view in black and white and color imaging has reasonable sensitivity and specificity for RHD diagnosis. We will implement this "single parasternal long axis view" screening for the ADUNU project. This approach typically takes <2 minutes per patient, including preparation and documentation.

### 1.5 Implement registry-based care for patients diagnosed with RHD

The ADUNU program will adopt the ACT platform, a mobile, cloud based RHD registry platform that was built through the RRCU collaborative to enable dynamic, decentralized, and connected care for patients living with RHD. The National RHD registry, headed by the UHI has already transitioned to this platform and it is currently undergoing pilot testing in HCIII's in Lira and Gulu Districts. ACT was designed with global and National stakeholders and includes four key features, considered essential for providing community based RHD Care. These features include (1) tools to improve adherence to secondary antibiotic prophylaxis, (2) tools to enable communication (i.e. remote consultations) between levels of the healthcare system, (3) tools to monitor and act on critical levels of drugs and supplies, and (4) dashboards to provide aggregate quality metrics to identify and scale best practices.

The application was built in consultation with the MOH technology working group and is compliant with all health and privacy regulatory requirements for Uganda under the approval and oversight of the MOH Health information Technical Working Group. Users will have unique logins and data will be protected in a compliant manner including audit logs.

### 1.5.1 Overcome low treatment inertia

Secondary prevention, through every 3-4 weekly intramuscular benzathine penicillin G (BPG) is the cornerstone of an RHD control program, however uptake remains poor with low case detection and inadequate retention in care as the main barriers. Among patients enrolled in Uganda's National RHD Registry, retention in care is only 57%.

The ADUNU project will overcome this low treatment inertia by addressing barriers and gaps in RHD secondary prevention in Uganda through 1) decentralizing secondary prevention from distant referral hospitals to local HCIII, which are much closer to where patients live and have more trusted relationships with providers 2) raising community, patient, and provider awareness of RHD and its risk factors to generate demand for testing services, encourage retention and adherence, and reduce stigma 3) Providing a registry based care that facilitates case management and follow-up. 4) deploying standardized guidelines for frontline workers, including best practices for minimizing pain with BPG injection 5) Tracking of BPG and essential supply stock out to reduce shortages that lead to patient frustration and unanticipated out of pocket costs.

### 1.5.2 Develop RHD treatment protocols and algorithms

ADUNU will generate and implement standardized protocols to guide frontline healthcare workers in RHD case management and appropriate recognition of when patients require referral to higher level facilities. Protocols will include 1) implementation of secondary prophylaxis for those diagnosed with RHD, 2) recognition and management of BPG related adverse events. 2) heart failure management and prevention. 3) prophylaxis, diagnosis, and treatment for endocarditis 4) oral anticoagulation for atrial fibrillation and prosthetic valves. 5) family planning and contraception, 6) management RHD during pregnancy and 7) lifestyle recommendations.

### 1.5.3 Ensure technology availability at all facilities

The ADUNU program utilized technology for RHD active case finding and registry-based care. At a minimum all HCIIIs will require a tablet, a hand-held echo machine, and WiFi or cellular service.

## 2.0 EQUIPPING CARE TEAMS

### 2.1 Train and evaluate direct care staff on echocardiographic screening for RHD

Training will be done according to protocols previously established by our team. A train the trainer model will be utilized to facilitate skills transfer and maintenance across the districts. Key components of our training program include:

1) Pre-recorded presentations and standardized hands-on educational materials for content reinforcement (facilitates replicable training)

2) Minimum number of scans completed during training (100 for those training to become trainers and 50 for those who will not become trainers)

3) Standardized competency assessment that includes demonstration of competence in use of the machine and in patient positioning and scanning technique AND a tablet-based assessment of interpretation skills including review of 20 pre-recorded scans with 90% accuracy in screen positive or screen negative required for certification.

4) Remediation sessions: Providers who do not pass the competency assessment will be invited to join a one-day remediation session with the same competency assessment to qualify for certification.

### 2.1.1 Adopt a clinical/staff training policy to train and retrain staff

To facilitate scale, we will employ a standardized curriculum and a train the trainer model, as described above. The DHO, in partnership with the District RHD Program Manager will be responsible for updating and tracking Certification of providers and Maintenance of certification.

Certification: ONLY providers who are certified as competent for screening will be able to utilize echocardiography in their clinics or in community outreach campaigns.

Maintenance of certification: To maintain certification, a minimum number of 50 scans per month averaged over each quarter (3 months) must be maintained and documented. In addition, referrals to the HCIV RHD clinic will be tracked and if the false positive rate of a screener rises above 20%, then the provider will be offered individualized remediation training to maintain certification.

### 2.1.2 Provide a standardized training curriculum for echocardiographic screening

Training curriculum development and production is underway and will include online modules, lectures, and hands on training focused on RHD and RHD echocardiographic screening.

### 2.1.3 Address adherence to proper echocardiographic screening techniques

As a measure of ongoing competency, agreement of each certified RHD testing provider and the confirmatory echocardiogram done at HC IV follow-up will be tracked. Providers that fall below 80% agreement will receive ongoing education and training and be required to re-certify prior to further independent RHD testing. In addition, the number of referrals as compared to number screened will be tracked for all providers who have been Certified. Providers with more than 10% deviation (by quarter) will undergo further review, which may include imaging review or direct observation to ensure acceptable rates of false negative and false positive scans.

### 2.1.4 Develop protocols/algorithms for referral of positive screens

After establishment of the HCIV RHD follow-up clinic, the District RHD Program Coordinator will establish a calendar of follow-up dates for use in the HCIIIs.

A standard algorithm will be developed to handle routine screen positive cases and more emergent diagnoses – to include same day referrals and remote case support from cardiologists at the UHI. A SMS based notification system will be used for the HCIII teams to communicate with the District RHD Program Coordinator. Basic information on all referrals will be sent, and a log maintained by the District RHD Program Coordinator, to support attendance at this follow-up.

### 2.2 Train and evaluate direct care staff on use of a mobile RHD registry (ACT Platform)

Direct care staff will be trained and evaluated on use of a simplified mobile RHD Registry using a standardized curriculum. Each HC III will identify super users that will undergo a prolonged training, and these will provide continued mentorship at the health center. Ongoing monitoring of fidelity to set standards for ACT platform use will be done at regular intervals and retraining done for those who fall below the set standards.

### 2.2.1 Adopt a clinical/staff training policy to train and retrain staff on RHD guideline-based care

The DHO and district RHD coordinator will organize for training of frontline health care workers in each district. Health centers with be aggregated into groups of 2-4 HCs, to allow a manageable number of health workers per training. Training will be conducted in phases, starting with one group, and progressively extending to other groups, until all health centers in the district are trained. Training will take place at a designated place that is within close range of the health centers undergoing training at a given time, and this will be identified by the DHO. The District RHD Coordinator will lead the training of frontline health workers on RHD guideline-based care that includes 1) RHD recognition, 2) prevention, and 3) treatment. Each HC IV will identify RHD champions that will undergo longer trainings at the UHI, and these will provide continued training and mentorship at the HCIV and to HCIII staff.

### 2.2.2 Provide a standardized training curriculum for registry utilization

A standardized curriculum developed by the ADUNU team will be used to train HC III/IV providers and it will include modules on 1) Basic computer literacy (if needed), 2) Basics of RHD physiology and management, 3) Best practices for BPG injection, 4) Identification of BPG-related allergy and anaphylaxis, and 5) navigation of the ACT platform. The modules will be well integrated to facilitate real-time hands-on practice. The ACT platform is designed to assist decentralization of RHD secondary prevention at the HC III and IVs. Direct care staffs will be trained on 1) entry of confirmed RHD persons into the mobile registry, 2) Entry of injections and other medications, 3) tracking of patient injections, adverse events, appointments, and follow-ups, and 4) tracking of BPG stock outs. Additionally, at least one superuser at each facility will understand ACT communication tools to facilitate referrals within and outside of the district.

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The curriculum will include pre-recorded PowerPoints, simulation of real-life case scenarios, demonstration workshops and group activities. Evaluation of direct care staff trainees will be done using test-case scenarios to ensure that providers are comfortable and facile with the system.

### 2.2.3 Address adherence to proper registry use and documentation

The District RHD Program Manager will monitor data use and registry completion in the district. This will include standard review of all new patients entered in the registry to ensure completeness, for key metrics such as RHD diagnosis, secondary antibiotic prescription, and interventional recommendations. The District RHD Program Manager will work closely with the DHO and TAQA to identify key metrics and to establish tracking systems and reporting to monitor these metrics.

## 2.3 Prepare the Care Team Beforehand for Effective RHD Management During Office Visits

### 2.3.1 Train and evaluate direct care staff on administration of secondary antibiotic prophylaxis

Direct care staff will be trained on best practices for BPG administration. The module will include RHD preventive strategies focusing on secondary prevention, precautions taken before administration of BPG, the process of reconstituting the vial of BPG, delivering the injection and observation for adverse events during and following delivery of medicine. In addition, alternative oral antibiotics will be discussed with a clear description of when they are indicated.

The curriculum will include pre-recorded PowerPoints, demonstration workshops and group activities. Evaluation will be done using a standardized pre- and post-training test assessment with a score of 80% and above in the post-training test assessment as a pre-requisite to certification. Those who score less than 80% will have remediation sessions.

### 2.3.2 Train and evaluate direct care staff on protocols for anaphylaxis

Participating HCIII and HCIV clinics will be provided standardized training in recognition and response to anaphylaxis and allergy. An emergency anaphylaxis kit will be kept on-site at all clinics administering BPG with a plan for rapid triage and transfer to the HC-IV or district hospital if anaphylaxis occurs. Standard protocols will be used to identify high risk adverse events that require alternative antibiotic prophylaxis and low risk adverse events where oral penicillin challenge may be considered.

An adverse events checklist will be used to track minor allergic and hypersensitivity reactions and will be completed prior to each scheduled BPG injection and entered into the ACT platform. Evaluation of the direct care staffs will be done using the pre-and post-training test assessment. (See above)

### 2.3.3 Ensure care team is skilled in supporting patient medication adherence

Direct care teams will be equipped with skills to support patient medication adherence that include increasing patient awareness, counselling on benefits of medication adherence, sending reminder SMS, follow-up +phone calls for missed appointments and pill count for those on oral medication. The ACT platform will help providers prioritize those at highest risk of falling below the 80% threshold of good adherence.

## 3.0 POPULATION HEALTH MANAGEMENT

### 3.1. Identify patients with potentially undiagnosed RHD

All district residents aged 5-39 (when risk of RHD is highest and secondary prevention is most effective) will be eligible for RHD testing, to be conducted through echocardiographic screening by frontline healthcare providers. Four evidence-based complementary approaches will be adopted to identify potentially undiagnosed RHD including:

1) Testing of populations already at a HCIII for other care

2) Community testing including Health Fairs, multi-disease campaigns/events to target adults, children who are not school going and adolescents

3) School testing targeting school going children

4) Reactive testing targeting First degree relatives of people living with RHD

### 3.1.1 Utilize echocardiography for routine active case detection in HCIII's

HCIIIs will be encouraged to offer RHD screening to any patient between the ages of 5 and 39 years who presents to a HCIII for other care. Patients with higher vulnerability including adolescents, pregnant women, those with cardiovascular symptoms (chest pain, shortness of breath, exercise intolerance, lower extremity edema) and those with first degree relatives or household contacts who are known to have RHD will be prioritized.

Screening logs maintained at the HCIII's will track basic demographic information about screening including refusals, screen negative exams, and screen positive exams and referrals.

### 3.1.2 Utilize echocardiography for active case detection through community events

Community testing can include events such as Health Fairs, Community Events, and/or Markets/Churches/etc. where large numbers of the community gather. These events are to ensure those who are harder to reach (men, children who are not in school, etc.) and/or do not seek routine care at HCIIIs are able to undergo screening.

To organize these events, the District RHD Program coordinator and the DHO will work together to outline a plan for adding screening into high-attendance community-based events in the district. Screening at these events will be offered to those 5-39 years of age. Community-based screening will focus on Saturdays and Sundays and will be conducted by HCIII nurses who will rotate to participate in outreach events according to need and interest.

During these events, a standardized screening log will be maintained that will track basic demographic information about screening including refusals, screen negative exams, and screen positive exams and referrals.

### 3.1.3 Utilize echocardiography for active case detection in school-based screening

The District RHD Program coordinator and the DHO and District Educational Officer (DEO) will work together to outline a plan for school-based screening in the district. School-based screening will be offered to all district students aged 5 years or older on a rotating basis. School-based screening will be conducted by HCIII nurses and/or the District RHD Program Manager who will rotate to participate in outreach events during the school week.

During these events, a standardized screening log will be maintained that will track basic demographic information about screening including refusals, screen negative exams, and screen positive exams and referrals.

### 3.1.4 Utilize echocardiography for active case detection in those with first degree relatives or household contacts of a patient newly diagnosed with RHD.

When a case of RHD is confirmed at the HCIV, the patient will be counseled that RHD screening should occur in all first-degree family members between the ages of 5 and 39 years. The District RHD Program Coordinator will work with the family to arrange a time for screening either at their local HCIII or at the HCIV clinic, depending on availability and distance from home.

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### 3.2. Utilize a registry to track and manage patients with RHD

The community based RHD registry will be utilized in 3 main ways 1) providing a clinical record system for case management and delivery of secondary prevention, 2) tracking outcomes to improve the quality-of-care delivery and identify systems problems like impending medication stockouts, and 3) archiving cases of RHD for epidemiological surveillance and research.

The ACT platform is designed as a tool to facilitate active case management in the community and to provide aggregate quality metrics and actionable alerts. Direct health care staffs will use the registry to monitor injection due dates, medication adherence, and adverse events, as well as sending out automated reminders to participants. In addition, the ACT platform will work as a liaison between primary health care workers and the cardiologists at the UHI to facilitate specialist consultation.

#### 3.2.1 Implement the ACT platform mobile RHD registry across the district

The ACT platform will be deployed across participating districts. The DHO and the district RHD program coordinator, the HC IIIs in each district will be aggregated into groups of 2-4 health centers and deployment (including training of frontline health workers and implementation at the HC III) of the platform will be done in phases starting with one group and progressively extending to involve other groups, until the whole district is included.

#### 3.2.2 Use defined processes for outreach (e.g., phone, SMS) to support adherence

The ACT-platform that will be utilized as the mobile RHD registry, has an in-built feature that is designed to send automated reminders. Defined processes to support medication adherence will include 1) Regular text messaging on motivational information or short health information that encourage adherence 2) Two-way text messages between the health care provider and the patient as reminders to show up for the monthly injections, 3) Follow-up phone calls for those with missed appointments. The ACT platform is not currently designed to send automated reminders, but this is currently being tested and if successful, this strategy could be rolled into the ACT platform to reduce the burden on frontline providers.

#### 3.2.3 Utilize urgency scores to ensure those with the highest need receive surgical prioritization

Patients will be graded according to level of disease severity to determine those with highest need for surgical prioritization. Urgency scores will be developed based on four major parameters that include 1) presence of symptoms, 2) severity of valvular disease, 3) presence of left ventricular function, 4) presence of severe of pulmonary hypertension. In general, all patients with severe valvular disease are potential candidates for surgical or catheter-based interventions, however the presence of the other 3 parameters increases the urgency for an invasive procedure. A standardized evaluation scale will be utilized at the HCIV facilities with UHI monitoring closely to assist in surgical prioritization.

### 3.3. Use clinician-managed protocols for medication adjustment and lifestyle recommendations

Clinicians based at the HC IV will be trained in RHD management and prevention and will take charge of medication prescription, adjustment, and patient counselling on lifestyle recommendations using the standardized treatment protocols and algorithms provided by our research team (see treatment protocols). These efforts will be supported by quarterly training and clinical visits provided by UHI cardiology staff to support RHD care in the districts.

#### 3.3.1 Use protocols to ensure all patients are optimized on guideline-based care

Treatment protocols and algorithms will be developed by our research team, guided by evidence. This is aimed at ensuring that all patients receive optimized guideline-based care.

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### 3.3.2 Use protocols to advise family planning recommendations

Preexisting cardiac disease significantly contributes to maternal mortality. Family planning and pre-conception counselling is a crucial part of an effective RHD care program and should be offered to all patients with RHD. Standardized protocols to guide contraceptive use will be provided. Effective contraception should be emphasized in severe valve disease patients with great emphasis on those with severe mitral stenosis, to mitigate the risk of complicated pregnancies. Patients should be advised to seek corrective procedures before considering conception.

Family planning and contraception discussions will be initiated at the HC IV RHD Clinic following confirmation of severe RHD.

### 3.4. Use practice data to drive improvement

Individual data from each HC and aggregate data from the district, on specific process and outcome metrics will be generated from the registry, analyzed at regular intervals, and utilized to drive quality improvement. Best practice from high performing HCIIIs will be studied and scaled to lower performing HCIIIs.

### 3.4.1 Determine standardized process metrics for each HCIII and district

Following training and deployment of ADUNU programs, a set of process metrics that are related to intervention adoption and implementation will be used to assess performance of each HCIII and district at regular intervals.

The process metrics for adoption of specific ADUNU programs will include:

RHD testing:

1) proportion of healthcare facilities and providers that adopt RHD testing,
2) proportion of patients screened at the health centers,
3) proportion of school-based screening and community-based screening outreaches done,
4) proportion screen positives that undergo confirmatory testing

RHD registry-based care

1) proportion of health centers and providers adopting the ACT platform,
2) proportion of those confirmed participants enrolled into the registry,
3) proportion of those confirmed prescribed secondary prophylaxis,
4) proportion of those prescribed, who receive secondary prophylaxis, with an emphasis on adherence levels (continuous days of coverage being maintained >80%)

Facility-level uptake and program fidelity:

1) proportion of healthcare providers and facilities demonstrating high fidelity in performing echocardiographic screening according to set protocols
2) proportion of healthcare providers and facilities demonstrating high fidelity in performing BPG administration, according to set protocols
3) proportion of healthcare providers and facilities demonstrating high fidelity in performing RHD registry-based management according to standardized protocols.

### 3.4.2 Regularly provide a dashboard with ADUNU goals, metrics, and performance

Using the standardized metrics and goals, a dashboard will be set up and updated at regular intervals to assess performance.

## 4.0. INDIVIDUAL PATIENT SUPPORTS

### 4.1. Support patients to maintain optimal adherence through pre-visit outreach

Adherence to secondary antibiotic prophylaxis is the only known medical intervention known to improve RHD outcomes. A central tenant of a successful RHD control program must include patient-level adherence supports.

#### 4.1.1 Contact patients to confirm upcoming prophylaxis appointments

To ensure optimal adherence, HCIII providers will be instructed in best practices to include: (1) pre-visit outreach through two-way text messages, sent 24-48 hours prior to the scheduled prophylaxis appointment, (2) phone outreach to all registrants who have missed a prophylaxis appointment by more than 24-48 hours, (3) phone outreach for registrants who have fallen below the 80% adherence threshold, with algorithmic support escalation utilizing an active interview to determine and mitigate barriers to receipt of prophylaxis.

### 4.2. Optimize patient intake to support RHD management

To ensure increased uptake of patients into registry-based care, at least 3 contact phone numbers will be obtained for all district residents who screen positive for RHD during clinical or outreach screening events. All screen positive patients will be given an appointment at the next HCIV follow-up clinic, with a sticker or card placed in the patient health card notifying them of their positive screen. Reminder calls will be made to these patients 24 hours prior to the scheduled follow-up. Three attempts will be made to reschedule residents who are screen positives but do not appear at the HC IV appointment. All RHD confirmed patients will be invited for enrolment into the district RHD registry and initiated on guideline-based care. In consultation with the patient, the HCIV clinic will assign a HCIII to each registrant, which will serve as their primary secondary prophylaxis clinic. Screening results, follow-up testing, prophylaxis recommendations, clinical care plans, and home HCIII will be recorded on a simple card for addition to the patients' individual health passport, to ensure clear documentation of their diagnosis, follow-up and medical treatment plan. These data will also be captured in the electronic registry.

#### 4.2.1 Provide patients with educational materials to help them understand RHD and its implications

All district residents who receive a diagnosis of RHD will meet with a health educator who will utilizė standardized educational materials to improve health literacy and understanding of their diagnosis. This will include an emphasis on reducing stereotypes, talking to their family and friends about their diagnosis, and in understanding the importance of secondary antibiotic prophylaxis and follow-up.

#### 4.2.2 Provide patients with tools to support their visit agenda and goal setting

Standardized RHD cards like those currently used in the National registry will be used to record follow-up clinic appointments and the monthly BPG injections. Patients will be sensitized on the optimal utilization of these cards to achieve the set goals.

#### 4.2.3 Reconcile medications patient is taking with the ACT medication list

All medications utilized by the patient will be reviewed during the HCIV follow-up clinic visits and reconciled with the ACT medication lists to avoid overdose and drug-drug interactions.

### 4.3. Optimize the patient-clinician encounter

Optimizing patient-clinician encounters will be emphasized to enable a patient centered care. Effective patient-clinician communication establishes a good interpersonal relationship between the patient and

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the clinician by building trust, ensuring adequate exchange of information between parties, and including the patient in the decision-making process. Effective communication will involve active listening, showing respect, providing a clear explanation of the clinical picture, and spending enough time with the patient. Education on these key concepts necessary for strong clinician-patient relationships will be emphasized during provider trainings.

#### 4.3.1 Use documentation templates in ACT to help capture key data such as adherence and barriers

All patient information will be entered into the ACT platform using standardized documentation templates that include but not limited to patient demographic characteristics, clinical and medical history, secondary prophylaxis, interventions and surgical procedures. This will assist in capturing key data on adherence (automatically calculated in the platform using the scheduled injection date and the actual date of injection), as well identifying barriers to optimal care.

#### 4.3.2 Use standard orders to support guideline-based care

Standard order sets that reflect current evidence-based care will be designed to reduce variation and unintentional oversight in care across spectrum of health care providers, and to enhance workflow by providing easily understood pertinent instructions.

#### 4.3.3 Use motivational interview techniques, shared plans, and "teach back" to confirm understanding

Strong provider-patient relationships have been identified as a key factor in adherence to secondary antibiotic prophylaxis in Uganda. Education of district providers will emphasize the use of motivational interview techniques, developing shared plans with patients diagnosed with RHD, and the use of 'teach-back' techniques to ensure patient understanding.

### 4.4. Support patients in self-management

Frontline healthcare workers will be empowered to support patients in self-care. All patients diagnosed with RHD will meet with a health educator. Motivational interview techniques will be utilized to help patients identify the most effective individual strategies to maintain secondary prophylaxis adherence. Strategies to increase self-management will require providing patient education and tools to increase healthy literacy on RHD and ARF care to guide daily health decisions. Patients will be encouraged to self-manage their illness by 1) adhering to the prescribed medications, 2) self-monitoring of symptoms for pharyngitis, ARF and heart failure, and 3) attending scheduled HCIV follow-up visits.

#### 4.4.1 Provide patient supports for medication adherence

Medication adherence is the center to provision of optimized evidence-based care. Efforts at the health care provider level and health care systems level will be put in place to support patient adherence. These will include utilizing a collaborative approach to involve patients in decision making, use of simplified regimen plans, using medication adherence improving aids like drug cards or medicine related information sheets, scheduling appropriate follow up, assessing adherence during consequent follow-ups using direct observation of injections, pill counts and self-reporting, identifying barriers related to adherence and addressing the problems.