ACT PROGRAM GUIDE

Active Community Case Management Tool

Version 1.0

05 August 2026

Contributors

ACT Global Network

Uganda Heart Institute

Rheumatic Heart Disease Research Collaborative in Uganda (RRCU)

Table of Contents

Overview

Rheumatic heart disease (RHD) is an acquired chronic valve disease that affects over 55 million people worldwide. The heart valve damage from RHD can increase over time, requiring lifelong care.

Disease registries play a crucial role in ensuring RHD patients receive the care they need to achieve their best outcomes. One key example is that they support patient's adherence to antibiotic prophylaxis – the only medical approach known to slow progression. Registries also help providers allocate time and resources effectively, improve equitable access to scarce treatments like cardiac surgery, and strengthen health systems by providing critical data on disease burden.

In 2023, the World Health Organization named registry-based care for RHD among its **'best buys'** for all non-communicable disease strategies. This is significant news, emphasizing the need for all providers caring for RHD patients to deliver registry-based care.

The history of the ACT platform began with the Uganda RHD Registry initially launching as a paper-based registry in 2012, which quickly shifted to an electronic database in 2015 using REDCap (Research Electronic Data Capture). In 2021, the REDCap was phased out with the introduction of the **Active Community Case Management Tool (ACT)**. Co-Developed in collaboration with global and local stakeholders, as well as the Ugandan government with guidance from the Uganda Heart Institute (UHI) and oversight by the Ministry of Health, NITA, and other government partners, ACT became a viable tool for improved RHD patient management. In 2025, ACT expanded to 5 additional institutions around the world. Today, ACT provides a scalable solution for RHD management worldwide.

ACT is a **first-in-kind dynamic mobile case manangement tool** designed to provide tools that improve care for individuals living with RHD while identifying best practices to improve global treatment and care delivery. It **addresses key barriers** in **delivering high-quality care** by connecting care settings, providing real-time data to monitor disease burden and outcomes, supporting providers in prioritizing follow-up care, improving access to surgical interventions, and empowering quality improvement initiatives.

The ACT Program Guide is **designed for global sites** that use ACT for RHD management. It provides essential **guidance and best practices** to support clinicians, nurses, and community health care workers in effectively utilizing the platform to enhance patient care, optimize clinical processes, and drive better health outcomes.

Key Objectives:

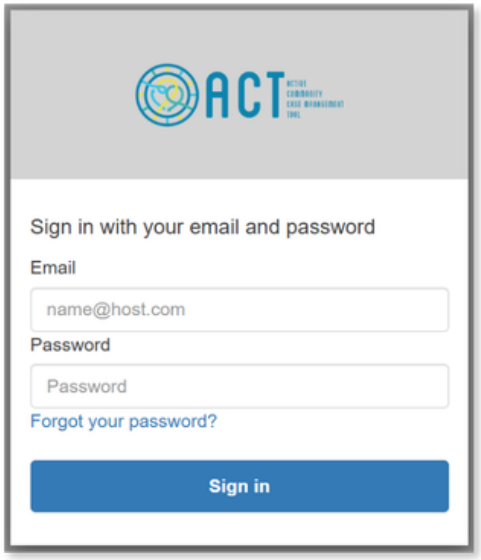
1. **Establish connected care across ACT sites and expand access to surgical interventions**
2. **Improve adherence support for secondary prophylaxis**
3. **Enhance follow-up care and improve patient outcomes**
4. **Leverage real-time data to track disease burden and monitor outcomes to drive quality improvement**

Getting Started

Any patient diagnosed with RHD or ARF should be enrolled into the ACT registry. This ensures proper follow-up and continuity of care.

ACT Account Set-up

The ACT interface can be accessed on a computer or tablet at https://multi.actregistry.org. All users must be added to the interface by an ACT Administrator and each user must have an email address to set-up have an account. ACT users will receive a unique login and be assigned appropriate user rights.



System Requirements

ACT sites will require the following necessary equipment:

- Tablet or computer
- Internet connectivity
  - Health centers without established internet access can receive monthly data through MiFi devices
- Echocardiography machine(s)
  *depending on facility level

Personnel should maintain an inventory of all supplied equipment and oversee its proper functioning at the sites.

a. **Routine Maintenance**: Conducted quarterly (every three months)
b. **Non-Routine Maintenance**: Provided upon staff reports of technical issues

All equipment will be stored in the designated lockers. Paper forms and books will also be kept in the designated locker.

Patient Enrollment

Any patient diagnosed with RHD or ARF should be enrolled into the ACT registry. This ensures proper follow-up and continuity of care.

Enrollment Process

01 Login to ACT with your unique log in credentials. Once you log in, select Registry.

02 To enroll a patient with RHD or RF in ACT, click on "Add New Patient" on the Registry page. A form will appear to complete basic patient information including first and last name, date of birth, and cardiac clinic. The cardiac clinic refers to the facility where the patient will be reviewed or receive cardiac/RHD care. Once all information is entered, select "Add" to complete the patient's enrollment.

New RHD patients should be issued the appropriate documentation e.g. BPG card (green), INR card (when necessary) with their unique RHD identifier indicated on the documents.

03 Once that patient is enrolled in ACT, you will be brought to their patient record.
The following details must be entered for the following forms:

- Patient Information
- Consultation Visit
  **Newly enrolled patients will be linked to a doctor for review on a regular basis*
- Echocardiogram (Electrocardiogram, when applicable)
  ** ALL enrolled patients must have an Echo*
- Hospital & Interventions forms, when applicable

Secondary prophylaxis should be initiated upon enrollment, unless otherwise decided upon by physician or doctor.

04 Patients should be given an appointment date for an RHD consult at a tertiary center, typically within 6-12 months depending on severity of disease.

Prophylaxis Management

What does it mean to be adherent? Why is it important?

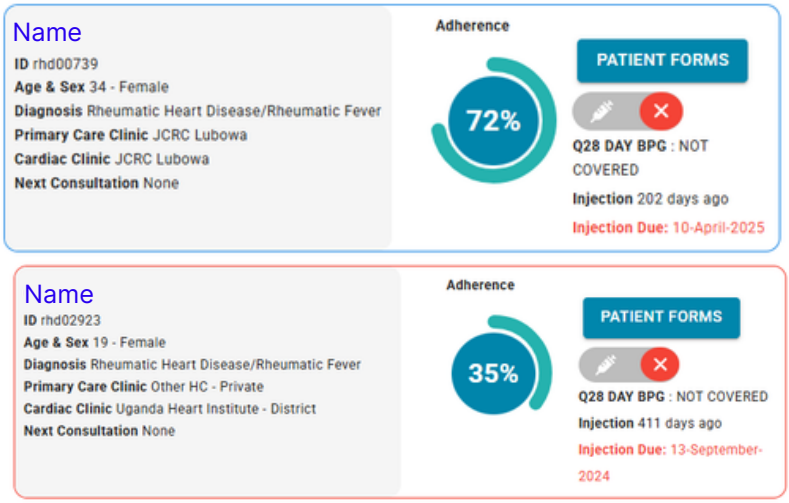
Treatment for RHD typically involves a Benzathine Penicillin G (BPG) injection every 28 days. Consistent adherence to BPG for secondary prevention significantly reduces the risk of disease progression and further heart damage. Maintaining adherence to secondary antibiotic prophylaxis is essential to preventing the worsening of RHD and improving long-term health outcomes.

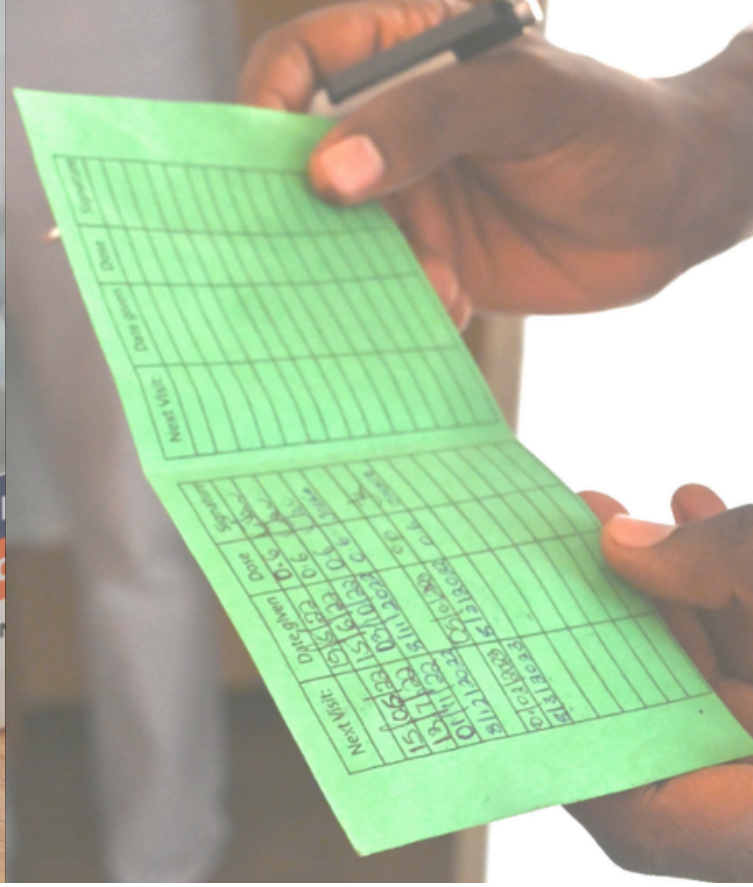
What can ACT do for you?

ACT helps clinical staff and providers support people Living with RHD by managing their patients more effectively by tracking their prophylaxis using the following features to identify patients with upcoming or missed injection dates:

- Sorting patients by "BPG Injection Status" in the 'Registry' page under a specific clinic to view patients covered, whose deadline is approaching, or not covered
- Sorting patients by "Needs Prophylaxis Data" helps track those without prophylaxis information for over 5 or 7 months. Patient cards will be highlighted in blue for those missing data for at least 5 months and in red for those exceeding 7 months.

It is important to regularly review your patient list to ensure the best care and support for RHD patients.



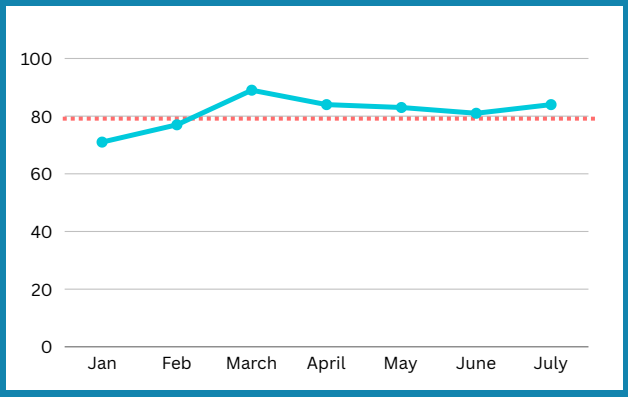


What can you do when a patient is non-adherent?

For patients who are late for an injection, follow up by phone if possible. If a patient has missed multiple injections or cannot be reached, involving a VHT can help find them and provide reminders about their appointment. Creating a supportive environment through clinic staff and community workers can significantly improve adherence by encouraging patients to return for their injections.

ACT Site Goal: Adherence

All ACT sites should **aim for more than 80% adherence** for all patients and track their site progress monthly.



Follow-up Visits & Appointment Reminders

Why do patients need regular follow-up visits?

Patients with RHD require regular annual cardiac appointments to monitor their condition and prevent any complications. These visits allow for early detection and treatment of heart issues, helping to reduce the risk of serious cardiovascular event. Patients should be called by phone one week before their scheduled appointment.

What can ACT do for you?

Using the same tools as prophylaxis management, ACT helps clinical staff and providers support people living with RHD by managing their patients more effectively by tracking their appointments in the 'Registry' page under a specific clinic and in 'Manage My Patients'.

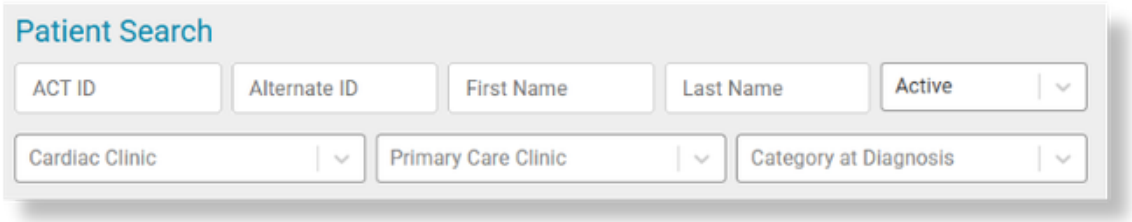
What can you do when a patient misses their appointment?

If a patient misses their appointment, it is important to follow up by phone if possible. If the patient cannot be reached after multiple attempts and some time has passed, you can work with a CHW to locate the patient and ensure they receive care.

Supporting RHD patients enhances their adherence to secondary prophylaxis, leading to improved health outcomes

Data to collect at follow-up visits

The patient's record should be reviewed since the last visit to ensure that any updates, interim history, or visit details are accurately documented. To access a patient's record, go to the 'Registry' page and search by ACT ID, first and last name, and/or a specific cardiac clinic.



Once you have located the patient's record in ACT, you can click in and select the appropriate forms on the left-hand side of the page. For a follow-up visit, a new Consultation Visit form should be added with all details from that visit and any interim history. If an ECG or Echo were performed, a new form for each should be added. If any prophylaxis information needs updating, or if injections administered since the last visit have not yet been recorded, a new BPG Delivery or Oral Prophylaxis form should be completed. Keeping patient records current and comprehensive supports effective ongoing care.

**An ECG and Echo must be performed every 12 months, and prophylaxis information should be reviewed and updated, if needed, at each visit.*

Data Security & Privacy

Patient Data Protection

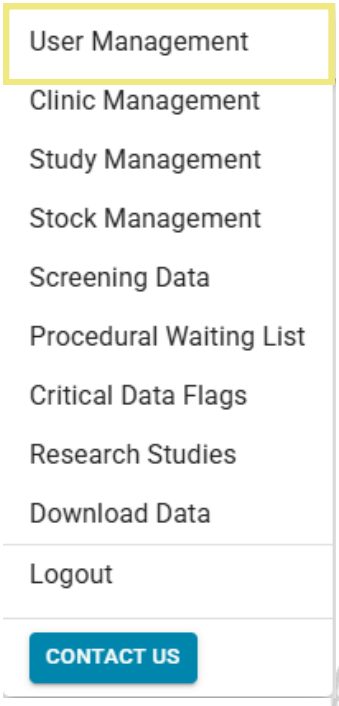
RHD ACT clinics must ensure that access to the platform complies with patient data protection standards. Staff will be assigned specific user roles to control their access to appropriate data, ensuring that information is only available based on their designated permissions.

All paper records must be securely stored and accessible only to authorized personnel, maintaining strict confidentiality and adherence to data privacy regulations.

Compliance and Quality Assurance

Users will be assigned to a specific clinic and a designated role. They will only have access to data for their assigned clinic and should only view patients under their care. Access can be monitored and tracked accordingly.

ACT administrators can manage user roles and permissions. They can grant, modify, or revoke access as needed to maintain data security and compliance. These actions can be managed through the 'User Management' page, accessible by clicking on your name in the top right corner of the page.

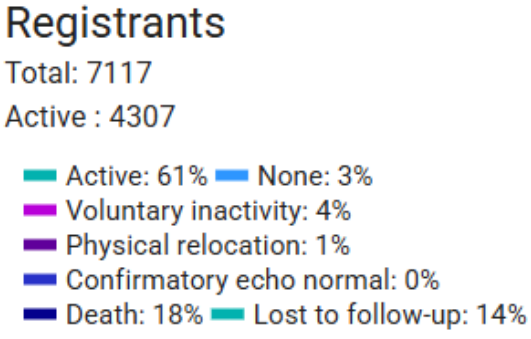


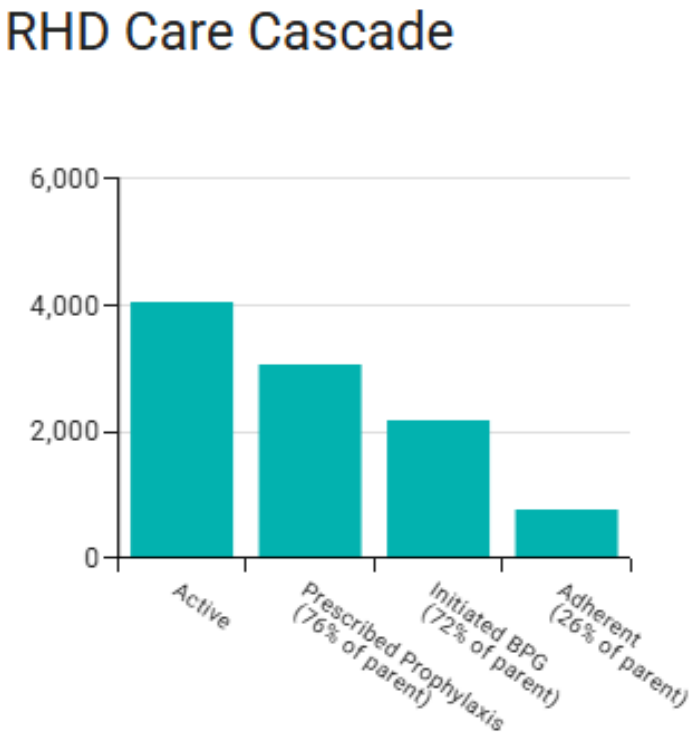
Reporting & Analytics

The Reports and Runcharts dashboards offer ACT sites valuable insights into care delivery by summarizing key metrics and visualizing performance trends. These tools help teams review site data, analyze patient populations, monitor adherence to clinical guidelines, and benchmark performance.

By leveraging these dashboards, teams can make informed decisions, track key indicators, and continuously improve care quality. These tools provide a clear view of performance, driving ongoing efforts to enhance care delivery and achieve better outcomes.

Dashboard





Quality of Care Improvement

ACT supports partner sites in delivering high-quality, patient-centered care through data, collaboration, and continuous improvement.

Using Data to Improve Care

By using ACT tools and features, providers can tailor care plans to individual patient needs, identify gaps in care, provide timely follow-up, and monitor early signs of complications. ACT allows providers to make informed decisions that improve the patient journey and overall health outcomes.

Tracking Progress with ACT

ACT is a powerful tool for monitoring care at both the individual and site level. It provides real-time data on key metrics, helping centers track patient outcomes, measure performance, and identify trends over time. As a central resource, ACT offers each site a clear reflection of progress, highlights areas for improvement, and supports informed, timely action.

ACT Support

Contact

For any questions or concerns regarding the registry, either select the icon in the top left corner of the page in ACT or contact one of the following:

McCall Miller - mccall.miller@cchmc.org
Liz Kennedy - liz.kennedy@stoprhd.org

Conclusion

Thank you to the ACT staff, clinicians, nurses, providers, collaborators, and all those involved in the ACT platform for their dedication to delivering high-quality RHD care while fostering innovation and continuous quality improvement.

Together, through ACT, we can enhance patient care, promote adherence, and reduce the burden of RHD globally, leading to better health outcomes and improved quality of life.