

# A Comprehensive Needs Assessment Tool for Planning RHD Control Programs in Limited Resource Settings



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## ABSTRACT

Rheumatic heart disease (RHD) is an important cause of disability and death in low- and middle-income countries. However, evidence-based interventions have not been implemented systematically in many countries. We present a RHD Needs Assessment Tool (NAT) that can be used at country or regional levels to systematically develop and plan comprehensive RHD control programs and to provide baseline data for program monitoring and evaluation. The RHD NAT follows a mixed-methods approach using quantitative and qualitative data collection instruments. Evidence is mapped to a conceptual model that follows a patient through the natural history of RHD. The NAT has 4 phases: 1) situational assessment; 2) facility-based assessment of epidemiology and health system capacity; 3) patient and provider experience of RHD using ethnographic methods; and 4) intervention planning, including stakeholder mapping and development of a monitoring and evaluation framework. The RHD NAT is designed to paint a comprehensive picture of RHD care in an endemic setting and to identify the major gaps to disseminating and implementing evidence-based interventions.

Rheumatic heart disease (RHD), a chronic inflammatory heart valve condition, is the most common cause of acquired heart disease in children and young adults globally. It arises from group A streptococcal (GAS) pharyngitis; in susceptible individuals, untreated GAS can lead to  $\geq 1$  episodes of acute rheumatic fever (ARF) that eventually damage the heart permanently. Individuals with RHD can develop complications such as heart failure, atrial fibrillation, stroke, and infective endocarditis, any of which can contribute to premature death. Pregnant women are particularly at risk of poor maternal and fetal outcomes [1].

RHD is a disease of disadvantage whose determinants include poor sanitation, overcrowding, malnutrition, and lack of access to health care, the latter of which can be mediated by material poverty and low educational attainment [2]. As such, among cardiovascular diseases, RHD is an especially good barometer of health inequities between and within countries. Indeed, nearly all of the 33.4 million prevalent cases and 319,400 deaths from RHD in 2015 occurred in low- and middle-income countries (LMIC), and there has been persistent neglect of RHD on global and national health agendas despite the magnitude of the problem [3-5].

A major challenge to increasing awareness of RHD at the global and national level is the lack of local country and regional data on the epidemiology of the condition and the demands it makes on the health system. Such data would ideally be used, as the World Health

Organization (WHO) recommends, to develop comprehensive disease control programs that integrate into existing efforts by ministries of health [6]. There are several evidence-based, cost-effective approaches to preventing GAS/ARF and treating RHD, and a variety of LMIC case studies have demonstrated that the burden of RHD can be rapidly and dramatically reduced with concerted efforts [7]. Yet at present, most high-burden LMIC lack the essential data on which to act.

## THE RHD ACTION NEEDS ASSESSMENT TOOL

In September 2015, the RHD Action [8] movement was launched in New York during the U.N. General Assembly. The founding partners of RHD Action were RhEACH Rheumatic Heart Disease Evidence Advocacy Communication Hope [9], the World Heart Federation [10], and Medtronic Foundation [11]. RhEACH, as the scientific and technical partner, was tasked with developing a comprehensive Needs Assessment Tool (NAT) that would support the gathering, analysis, and synthesis of GAS, ARF, and RHD information in a range of endemic settings. This NAT would outline a range of approaches that can be used to identify the major gaps in GAS, ARF, and RHD control at the local level.

This NAT is intended to serve as a critical input into the design of interventions and to provide a baseline dataset for program monitoring and evaluation. It is not intended to be a roadmap for how to conduct

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interventions (e.g., public education about sore throat). This paper outlines the rationale, design, and methods employed in the RHD NAT.

**METHODS**

**Objectives**

The overarching objective of the RHD NAT is to gather a wide range of data that collectively paint a comprehensive picture of the current state of GAS, ARF, and RHD care in a country (or region or district) of interest. The NAT employs scientifically validated methods through a variety of data collection tools (modules); because the NAT is modular in design, it can be implemented in its entirety or selectively if local resources and expertise are limited. Here we describe how the entire NAT could be implemented efficiently and in a stepwise fashion. The approach and instruments are intended to serve as a starting point for stakeholders interested in introducing RHD control programs, but they should be implemented with guidance from local practitioners who have expertise on RHD from clinical or public health perspectives.

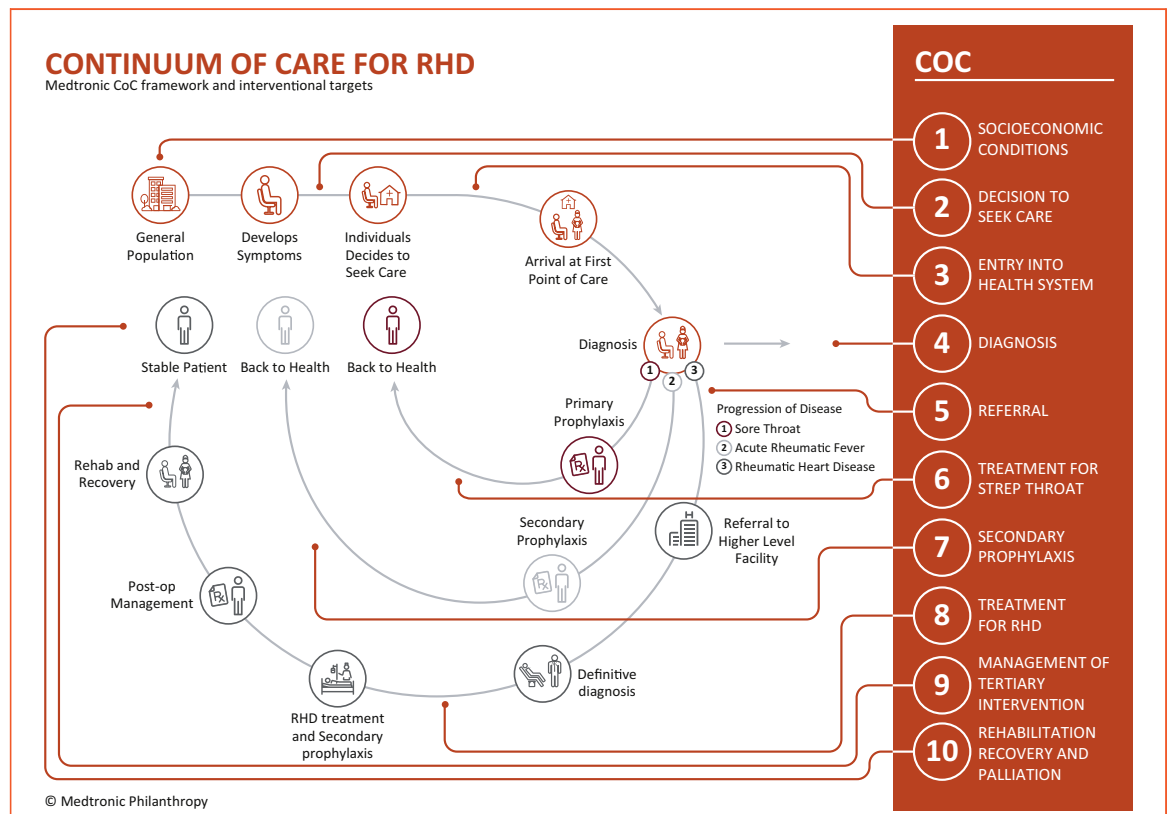
**Conceptual framework**

A guiding principle of the NAT is the central role of people living with RHD and a need to understand the “patient

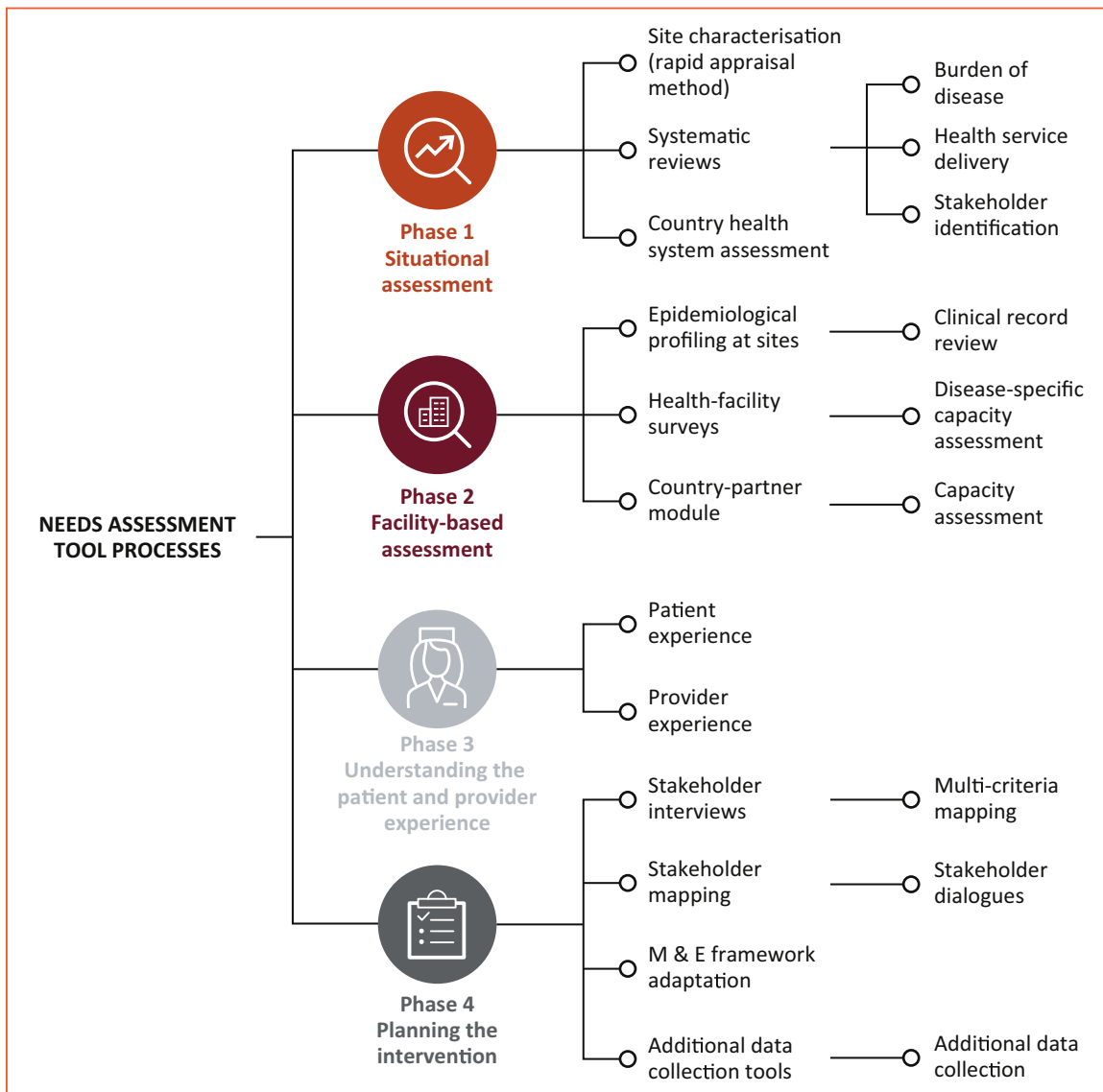
experience” of GAS, ARF, and RHD. To date, the cultural aspects of care and local determinants of care-seeking behavior and medication adherence have not received a great deal of attention by RHD researchers and practitioners [12]. Hence throughout the needs assessment process, data collection, analysis, and interpretation are guided by a conceptual model called the Continuum of Care (CoC) (Fig. 1). Initially conceived by Medtronic Foundation, CoC tracks the movement of a hypothetical patient at risk of or affected by RHD through the health system. CoC is used to synthesize all of the NAT data into 1 integrated theory of health-seeking behavior within a local context. In other words, quantitative and qualitative data collected by the NAT are “mapped” back to CoC, and the gaps and opportunities at various levels of CoC can then be addressed at a later stage by means of specific interventions such as educational programs, improvements in the quality of clinical care, and public health policies (e.g., disease notification).

**Design**

The NAT follows a 4-phase, mixed-methods approach (Fig. 2). Each phase of the NAT employs ≥1 quantitative or qualitative data collection instruments (modules) tailored to ≥1 aspects of the program-planning process (e.g., disease epidemiology, health-seeking behavior). In



**FIGURE 1. Continuum of care (CoC) for rheumatic heart disease (RHD): adapted from the Medtronic CoC framework and interventional targets. Post-op, post-operative.**



**FIGURE 2. Overall structure of the needs assessment. M&E, monitoring and evaluation.**

the fourth and last phase of the needs assessment process, information gleaned during phases 1 to 3 is synthesized and presented to stakeholders who assist in the design and implementation of the control program.

### Study setting and recruitment

The NAT usually targets/covers  $\geq 1$  “sites” defined as discrete geographic areas with endemic RHD. In the African context, for instance, subprovincial administrative districts with populations of between 100,000 to 500,000 containing  $\geq 1$  district hospital are a reasonable starting point. Interested stakeholders can choose sites based on previous experience and/or by using the site selection tool, which forms part of the phase 1 situational assessment.

After sites are selected, patients and health care providers are recruited as study participants for each of the NAT modules. Because the NAT is a form of scientific inquiry and because confidential health information will be elicited from participants, approval from the local ethics board will need to be sought prior to beginning the needs assessment, and participants will need to provide informed consent as appropriate to each of the modules.

### Workflow

If implemented in its entirety, the workflow of the NAT could proceed through 4 phases that use each of the modules in a complementary and overlapping fashion (Fig. 2). The entire process is anticipated to take between 6 and 18 months; the actual time required will greatly

depend on the number of modules used, number of sites, and resources available to collect and analyze data rapidly.

### Data collection instruments and analysis plan

#### Phase 1: situational assessment

*Site characterization.* This module draws on the rapid appraisal methodology [13]. Interviews are conducted with ~10 key informants at candidate sites to identify local health priorities, available resources, and potential barriers to an RHD program. This participatory approach seeks to gain buy-in from key decision makers at the local level from the very start of the needs assessment process. As described in previous rapid appraisal studies, participants are identified and data are analyzed using a grounded theory approach [13].

*Systematic review.* A 3-pronged systematic literature review is carried out using an existing published protocol [14]. As the published protocol presents a search filter for African countries, this should be modified to search only for literature from the user's country. The review seeks to gather all available studies (published and unpublished, quantitative and qualitative) of relevance to GAS, ARF, and RHD epidemiology, health-related behaviors (including barriers and enablers), and potential stakeholders in the country. Data are analyzed using standard meta-analysis and meta-synthesis techniques as outlined in the protocol. This allows systematic combination of relevant qualitative and quantitative study data from several selected studies to develop a unified set of conclusions.

*Country-level health systems assessment.* This brief module collects descriptive data from WHO and other sources on the general health system performance of the user's country [15]. Whereas this tool is not RHD-specific, it provides a broader health system context within which to interpret RHD-specific data that are collected in later phases. Data are analyzed using descriptive statistics such as proportions, rates, and means or medians.

**Phase 2: facility-based assessment.** At this stage, a sampling strategy should be developed for identifying health facilities (and participants) of interest at the site. Complete enumeration is recommended for sites with small populations or a limited number of facilities (e.g., ≤5). For larger sites, the following target samples are recommended:

1. All district hospitals located at the site
2. Dispensaries or pharmacies serving each district hospital: 2 to 5
3. Primary health centers serving each district hospital: 2 to 5
4. Tertiary or referral hospitals serving each site: 1 to 3

The target number of primary facilities (items 2 and 3) to be sampled will vary depending on characteristics, such as where patients typically seek care for acute childhood and adult illness (e.g., health center vs. dispensary), district size, and variation between different geographic areas within the site. The overarching aim should be, by whatever means, to capture a representative sample of facilities—and the patients they serve—at the site.

*Clinical record review.* Information on patients with GAS, ARF, and RHD is collected from clinical records using case report forms adapted to each condition and to facilities at each level of care. For simplicity and efficiency, clinical records (and participants in phase 3) are selected only from sampled health facilities. Prospective assessment of incident GAS and ARF cases (e.g., over 1 month) is recommended, whereas retrospective review (e.g., over the past year) of prevalent RHD cases is likely to be more feasible. Estimates of crude incidence, prevalence, rates of sequelae (such as heart failure and stroke), and case-fatality ratios for each condition can be analyzed separately using descriptive statistics. Record-based epidemiological studies are quite feasible and have proven incredibly useful for estimating the clinical burden of RHD, even though results may not be generalizable across the site [16].

*Health facility survey.* In parallel with the clinical record review, quantitative facility surveys to review services are conducted at all levels of care. The major needs for RHD care—from a “supply side” perspective—have been adapted from the Tools for Implementing RHD Programs manual developed by RhEACH and the World Heart Federation [17,18]. The emphasis at primary care facilities is on the availability of drugs, diagnostics, and human resources required for prevention (GAS treatment). At district and referral hospitals, the emphasis is on capacity to treat ARF, manage a secondary prevention registry, and diagnose and treat RHD, including heart valve surgery at referral facilities. As in previous modules, survey data are analyzed using descriptive statistics.

*Country partner module.* At this stage, it is recommended that key partners (clinical and public health practitioners) with expertise in RHD be engaged to complement the other facility-based data collected process. These partners are interviewed using a semistructured questionnaire that elicits their perceptions about the current policy barriers and opportunities for RHD programs. The questions center on human resources for health, policies/programs, and the presence and use of clinical care guidelines. Data are analyzed thematically and mapped to the CoC.

**Phase 3: understanding the patient and provider experience.** In this phase, the major areas of enquiry are patients' experiences of living with and receiving care for sore throat, ARF, and RHD, as well as providers'

perspectives on barriers and facilitators to care for sore throat, ARF, and RHD. It is anticipated that this phase will require significant time and resources, because it exclusively employs qualitative methods. Again, a grounded theory approach to data collection and analysis is recommended in view of the lack of previous data and the complex cultural issues that are anticipated to emerge.

Patients, primary health care providers, and specialist providers are recruited to participate in in-depth interviews and focus group discussions. These can be supplemented, as appropriate, by other ethnographic approaches, for example, photos, patient stories, and simply by observing and noting how patients and health care providers interact.

Using information collected in phase 2, the clinical record review informs the sampling of patients, while provider participants for this phase are identified from the facility surveys. Sampling occurs purposively; that is participants are not selected randomly but based on the judgment of the study leaders using pre-determined criteria. Maximum variation should be sought, including both typical and extreme cases, so as to understand the differences between those who successfully and unsuccessfully navigate the health system.

Data are collected to inform 2 higher-order themes relevant to the CoC: 1) health-seeking behavior; and 2) “gatekeepers” to care—that is, the entry points and processes to receiving care. Draft interview guides have been developed that address these themes separately. Interviews are transcribed, coded, and analyzed thematically within diseases and groups (first-order analysis). Thereafter, concepts and themes can be compared across diseases and groups (second-order analysis) and categorized as relating either to health-seeking behavior or to gatekeepers. Again, insights from this work will be mapped to the CoC and highlighted separately as “supply” or “demand” side issues.

#### Phase 4: planning the intervention

*Stakeholder interviews and stakeholder mapping.* Potential categories of stakeholders will have been identified from systematic reviews (phase 1). During phase 4, local individuals within each stakeholder category are invited to participate. They are interviewed with a focus on their perspectives on the RHD program being developed. The interviewer should be attuned to potential interactions with other stakeholders, uncertainty and agreement toward solutions, and suggestions for broadening and deepening engagement with stakeholders. Specific methods have been developed to quantify these qualitative data and to visualize interactions among stakeholders using network analysis and Venn diagrams [19]. Prior to finalizing the plans for the RHD program, stakeholder dialogues are convened to ensure buy-in to the program and continued participation and support.

*Identification of target outcomes.* The outcomes of the RHD program should focus on priority needs identified during the needs assessment process, and care should be taken that they contribute to health system strengthening

rather than fragmentation. Examples of important outcomes to consider are the following: 1) public and health care provider knowledge about GAS, ARF, and RHD; 2) proportion of sore throats appropriately given antibiotics; 3) adherence rate to the secondary prevention regimen among patients on ARF/RHD registers; or 4) rates of referral to specialist care for symptomatic RHD.

*Framework for monitoring and evaluation.* Metrics are identified for the target outcome(s) of the program, and the data collected during the needs assessment process serve as a baseline set of measures for monitoring and evaluation. These metrics are also used to build intervention-specific performance-based measures over specified time frames. Baseline data should be compared against measurable outcome target goals (both quantitative and qualitative) determined by stakeholder consensus. Best practices for monitoring and evaluation have previously been elucidated by the U.N. Development Programme and should be adopted for the RHD program [20].

*Additional data collection.* It is possible that the data gathered may need to be supplemented by focused, additional data that answer questions specifically related to determining the feasibility of intended interventions and/or assist in monitoring and evaluation. For example, suppose that antenatal screening for RHD is a particular topic of interest for a program: in this case, the NAT may need to be supplemented, first, by focus group discussions of pregnant women to assess the cultural acceptability of cardiac imaging (area 1), and second, with a quantification of rates of specialist referral during pregnancy (area 2, emphasizing improvements in patient outcomes after screening). Additional data collection plans would need to be developed in consultation with stakeholders and may require amendment of the application for ethical approval.

## DISCUSSION

### Significance

RHD persists at a high rate in LMIC, and this reflects the failure of health systems to adequately address a preventable disease that was largely eradicated from the industrialized world decades ago [21]. Our RHD NAT presents, for the first time, a scientifically rigorous approach for developing RHD programs that are responsive to local needs and challenges and that follow the comprehensive and integrated approach recommended by WHO [6].

A major objective of health systems is to improve both the level and the distribution of health in the population, that is, to improve health equity [15]. ARF and RHD are only seen in poor communities, and the prevalence of RHD is even higher in regions with high income inequality [22]. Concerted public health efforts can dramatically reduce ARF and RHD, even in poor countries and during periods of economic stagnation, as was observed in Cuba [7]. Our RHD NAT, as a first step toward eradicating RHD in



endemic countries, has the potential to catalyze great reductions in health inequities locally, nationally, and globally.

### Application in low-resource settings

This NAT is designed to be modular, and its scope can be expanded or reduced as local budgets permit. Whereas the NAT provides the richest and broadest information set when executed as a whole, in some sites it may be feasible to use a subset of the modules only. For instance, if a country has a good deal of existing epidemiological data, it may be relatively more important to conduct facility surveys and patient interviews. Similarly, if a strong program is already in place to diagnose RHD and refer patients for surgery, it may be relatively more useful to conduct a prevention- or screening-oriented assessment.

Access to scientific and technical support for RHD programs has been challenging because of barriers in accessing articles in journals that require subscription and broadband communication limitations in low-resource settings. The RHD NAT in its entirety, including drafts of all data collection instruments and protocols, will be made publicly available free of charge at RHD Action's website [8]. RhEACH is the guarantor of this work and assumes responsibility for any additional technical support or questions that end users of the NAT may have.

### Limitations

To date, the NAT has not been piloted in its entirety in any location, so the feasibility, ease of use, and true resource and time requirements are not known. A comprehensive, in-depth, and scientifically rigorous approach has been taken to the NAT, yet it is acknowledged that many countries with endemic RHD do not have the capacity to conduct this sort of work—particularly the qualitative components—easily. Furthermore, the usual limitations to starting new health programs apply: in some settings there may be large political or social barriers or competing interests that could undermine the needs assessment process or the control program. Given that implementation science is a young field, the rapidly advancing methods will likely require review and updating of each of the NAT modules.

### CONCLUSIONS

RHD is a preventable yet neglected cardiovascular disease of poverty. The scientific evidence for medical and surgical interventions that prevent and treat RHD is strong and has been available for decades. Yet the “knowledge to action” gap in RHD is wide. There is a critical need for implementation research that informs the dissemination of best practices and evidence-based interventions in the context of a strong and integrated control program led by ministries of health. A NAT, as presented here, has the potential to strengthen resource-limited health systems and reduce health inequities by building scientific and clinical capacity. As such, the NAT represents a significant advance in RHD implementation research.

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