

ORIGINAL RESEARCH

# Generating Global Priority for Addressing Rheumatic Heart Disease: A Qualitative Policy Analysis

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**BACKGROUND:** Rheumatic heart disease (RHD) poses a high burden in low-income countries, as well as among indigenous and other socioeconomically disadvantaged populations in high-income countries. Despite its severity and preventability, RHD receives insufficient global attention and resources. We conducted a qualitative policy analysis to investigate the reasons for recent growth but ongoing inadequacy in global priority for addressing RHD.

**METHODS AND RESULTS:** Drawing on social science scholarship, we conducted a thematic analysis, triangulating among peer-reviewed literature, organizational documents, and 20 semistructured interviews with individuals involved in RHD research, clinical practice, and advocacy. The analysis indicates that RHD proponents face 3 linked challenges, all shaped by the nature of the issue. With respect to *leadership and governance*, the fact that RHD affects mostly poor populations in dispersed regions complicates efforts to coordinate activities among RHD proponents and to engage international organizations and donors. With respect to *solution definition*, the dearth of data on aspects of clinical management in low-income settings, difficulties preventing and addressing the disease, and the fact that RHD intersects with several disease specialties have fueled proponent disagreements about how best to address the disease. With respect to *positioning*, a perception that RHD is largely a problem for low-income countries and the ambiguity on its status as a noncommunicable disease have complicated efforts to convince policy makers to act.

**CONCLUSIONS:** To augment RHD global priority, proponents will need to establish more effective governance mechanisms to facilitate collective action, manage differences surrounding solutions, and identify positionings that resonate with policy makers and funders.

**Key Words:** global health policy ■ health policy ■ noncommunicable diseases ■ politics ■ rheumatic heart disease

Approximately 33 million people live with rheumatic heart disease (RHD), a chronic inflammatory disease of the heart valves.<sup>1</sup> RHD is the end result of acute rheumatic fever (ARF), a consequence of untreated throat infection by group A streptococcus bacterium. It claims the lives of >300 000 people annually and is responsible for an estimated 10.5 million disability life years lost each year.<sup>2</sup> RHD is predominantly a problem for people in low- and middle-income countries (LMICs), home to 79% of people living with RHD,<sup>3</sup> as well as indigenous and other socioeconomically disadvantaged populations in high-income

countries (HICs).<sup>4</sup> It is the leading cause of cardiac disease among children in LMICs,<sup>3</sup> the third most common cause of heart failure in Africa,<sup>5</sup> and responsible for nearly 3 times the number of deaths caused by measles.<sup>6</sup>

Despite its severity, RHD receives inadequate attention and resources. ARF attracts just 0.07% of all global health research funding.<sup>6</sup> RHD receives the lowest amount of research funding relative to disease burden among a group of 15 tropical diseases.<sup>7</sup> Few national programs for RHD prevention and care exist in LMICs. There was a sharp decrease in RHD

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## CLINICAL PERSPECTIVE

### What Is New?

- We identify factors shaping recent growth but ongoing inadequacy in attention for addressing rheumatic heart disease among international organizations, donors, and national governments.
- Understanding global priority requires examining not only the nature of the disease itself and how to address it, but also *political* considerations, including those internal to the network of health professionals and scientists advocating for greater attention to the issue.
- Three linked challenges concern the following: leadership and governance, establishing institutions and champions to facilitate collective action; solution definition, generating proponent consensus on how to address the issue; and positioning, portraying the issue in ways that resonate with political leaders.

### What Are the Clinical Implications?

- To increase rheumatic heart disease global priority, proponents will need to address problems with respect to governance, solution definition, and positioning.
- There is no single “right” path for addressing these challenges; rather, those concerned with rheumatic heart disease will have to deliberate openly and inclusively to arrive at the best strategy.

## Nonstandard Abbreviations and Acronyms

<b>ARF</b>	acute rheumatic fever
<b>HIC</b>	high-income country
<b>LMIC</b>	low- and middle-income country
<b>NCD</b>	noncommunicable disease
<b>REMEDY</b>	Global Rheumatic Heart Disease Registry
<b>RHD</b>	rheumatic heart disease
<b>WHA</b>	World Health Assembly
<b>WHF</b>	World Heart Federation

research interest over the last quarter of the 20th century, after it became uncommon in HICs. In Medline indexed journals, there were an average of 516 articles per year on ARF from 1967 through 1976, but only 172 per year from 1997 through 2006.<sup>8</sup> The World Health Organization (WHO) dropped its commitment to addressing the issue in the early 2000s after coordinating a Global Rheumatic Heart Disease Control Program from 1984 to 2002.

There is, however, evidence of a measure of increased attention to RHD over the past decade. New regional and international initiatives dedicated to the issue have emerged. There is renewed commitment to addressing RHD from international institutions, including the World Heart Federation (WHF), which set a 2025 RHD reduction target. A handful of LMICs have formed national programs and advisory committees dedicated to RHD prevention and control.<sup>9,10</sup> In addition, the World Health Assembly (WHA) adopted a resolution dedicated to RHD in 2018. Challenges remain, however, and RHD global advocacy stands at a critical juncture, with the network of RHD actors and future funding in flux. We investigate the factors shaping attention to RHD, examining the reasons for recent growth but ongoing inadequacy in priority, with the aim of sparking deliberation among RHD proponents about strategy to advance global priority.

## BACKGROUND

We drew on scholarship from the fields of sociology, international relations, and policy process analysis. We considered how issue characteristics and proponent power shaped priority.

Research indicates that issues with certain features are more likely to garner attention. Policy makers are more likely to act on issues that have simple, identifiable causes, pose a significant burden, and are uncontroversial. Also, they are more likely to prioritize issues if they perceive proposed interventions to be cost-effective, inexpensive, simple to implement, and backed by scientific evidence.<sup>11</sup> In addition, issues are more likely to gain attention and resources if the affected groups are readily identifiable, viewed sympathetically by society, and are able to advocate for themselves.<sup>12</sup> Finally, issues are more likely to receive priority when they are connected to prominent developments, such as major disasters (eg, famine), discoveries (eg, cost-effective or innovative interventions), or goals and resolutions (eg, a target within the sustainable development goals).<sup>13</sup>

Research also indicates that proponent capabilities shape issue attention.<sup>14,15</sup> Three challenges are especially relevant for global health networks. The first pertains to governance—institutions for collective action, and leadership—both individual and organizational. Scholars find that the degree of formality of governing institutions needed depends on features of the network of proponents, such as the degree of trust among them.<sup>16</sup> Skillful leaders can augment issue attention by creating a unifying vision for a coalition and attracting new resources.<sup>17</sup> Leaders and proponents are most effective when they have easy access to top decision makers and maintain quality and frequent professional encounters.<sup>18</sup>

A second challenge is problem and solution definition, establishing agreement on what the problem is and how it should be addressed. Issue ascendance is more likely when proponents agree on the definition of, causes of, and solutions to the problem.<sup>15</sup> Action may be hampered when proponents disagree on or have insufficient knowledge about the nature of the problem, who or what is to blame, and the preferred strategies to address the problem.<sup>19</sup> Disagreements, when ineffectively managed, may lead to the fragmentation of networks and consequent inability to act collectively. For instance, proponents for early childhood development, fragmented across health, nutrition, education, social welfare, and social protection sectors, do not agree on the boundaries of the field, or even what age group constitutes the “early child.” Because of these persistent differences, this network has struggled to develop a coherent “ask” as a precondition of securing policy-maker attention.<sup>20</sup>

A third set of challenges pertain to positioning, portraying the issue in ways that inspire external audiences to act. Proponents are most effective in attracting attention when they create framings of the issue backed by empirical evidence and that resonate with those controlling key resources.<sup>21</sup> A tension exists between broad and narrow issue frames. Broad frames may mobilize more groups, but with lower intensity. For this reason, some advocacy coalitions use narrower framings. For example, women’s rights advocates re-framed the issue of “patriarchy” into the more specific and emotionally charged issue of “violence against women.”<sup>22</sup>

## METHODS

Given the confidential nature of the data from key informant interviews, transcripts are not available publicly.

### Literature Review

We triangulated among several data sources, including observations from a 2017 meeting on RHD in Cairo, Egypt, as well as documents collected via a literature review. The collected documents (n=173) included published peer-reviewed literature, organizational reports, and media sources. We searched Google Scholar, ProQuest, and JSTOR databases, and websites of organizations concerned with RHD. The search was restricted to literature in English, between the years 1945 and 2019. The search terms used were: “rheumatic fever” and/or “rheumatic heart disease,” in combination with “global health,” “research,” “strategy,” “advocacy,” “declaration,” “burden,” and/or “policy.”

## Interviews

We also conducted 20 semi-structured key informant interviews with actors central to RHD advocacy, research, funding, policy making, and/or clinical practice, as well as observers of global RHD control efforts concerned with global health and/or cardiovascular disease issues more broadly (Table 1). The interviews took place between January 2017 and June 2018 and were conducted by the first author. Both authors are outsiders to the RHD community. Each interview lasted on average 1 hour. All interviews were recorded and transcribed with consent from participants. In reporting interview data, we assigned each key informant a number (Table 2). We continued to interview additional key informants until reaching theoretical saturation, the point at which we obtained no new critical information from additional interviews.

We conducted 10 interviews in person at the RHD meeting in Cairo, and 10 over Skype or telephone. Using a purposive sampling strategy, we identified these individuals through our literature review and by asking interviewees whom they considered to be most centrally involved in RHD practice, research, and/or global advocacy. In line with elite interviewing protocol, we selected interviewees not with the aim of drawing a representative or convenience sample but rather to reach the most important actors involved in global policy and advocacy. Elites

**Table 1. Organizational Affiliation of Key Informants**

Organizational Affiliation of Key Informants
All India Institute of Medical Sciences
Alzaeim Alazhari University
Association of Friends of Children With Rheumatic Heart Disease
Case Western Reserve University
Children’s National Heart Institute
Institute for Health Metrics and Evaluation
Makerere University School of Medicine
Massachusetts General Hospital
Novartis Institutes for BioMedical Research
PASCAR
RHD Action
Reach (formerly RhEACH)
Telethon Kids Institute
Touch Foundation
The University of Auckland
University of Cape Town
University Hospitals Case Medical Center
University Hospitals Harrington Heart and Vascular Institute
University of Washington
Windhoek Central Hospital
World Heart Federation

**Table 2. Key Informant Information**

Key Informant No.	Organizational Type	HIC or LMIC Representation
1	Academic	LMIC
2	Academic	LMIC
3	Donor	HIC
4	Academic	LMIC
5	Academic	LMIC
6	International organization	HIC
7	Non-governmental organization	LMIC
8	Academic	HIC
9	Academic	LMIC
10	Donor	HIC
11	Academic	HIC
12	Academic	LMIC
13	Academic	HIC
14	Academic	LMIC
15	Academic	HIC
16	Non-governmental organization	LMIC
17	Non-governmental organization	LMIC
18	Academic	HIC
19	Academic	HIC
20	Academic	HIC

HIC indicates high-income country; and LMIC, low- and middle-income country.

constitute “a group of individuals, who hold, or have held, a privileged position in society and, as such, are likely to have had more influence on political outcomes than general members of the public.”<sup>23</sup> Elite interviewing seeks to glean insight into the mindset of the actors who have played a role in shaping the society in which we live and an interviewee’s subjective analysis of a particular episode or situation. One limitation of the study is that we did not extensively engage national government policy makers, the targets of these advocacy efforts. It would be valuable for future studies on global and national priority for RHD to interview these actors as a means of further interrogating our findings. The interview questions were open ended and tailored to each individual’s background. Our focus was on global rather than national or grassroots actors and debates, except in instances in which regional or national actors had influenced or been influenced by global RHD advocacy efforts. Thirty-two individuals from 17 countries were contacted for an interview. Those who accepted (63% response rate) were based in 11 countries (Australia, Egypt, India, Namibia, New Zealand, South Africa, Sudan, Switzerland, Tanzania, United States, and Zambia). They came

from HICs (36%) and LMICs (64%) and from a broad range of organizations.

## Statistical Analysis

We undertook a policy analysis, an investigation of the role of policy actors in the global agenda-setting process, how they influence and are influenced by contextual factors, and how power plays out in these processes.<sup>24</sup> We conducted a thematic analysis of the collected documents and interview transcripts, using an iterative process in developing the codes.<sup>25</sup> We originally coded (a process of “indexing or categorizing the text in order to establish a framework of thematic ideas about it”<sup>26</sup>) by 2 broad categories derived from policy frameworks that examine the determinants of political priority for global health issues.<sup>27,28</sup> These categories are (1) characteristics of the issue and (2) actions, perceptions, and strategies of the involved actors. We developed subcategories within these 2 broad categories as we collected and analyzed our data. Under the “characteristics of the issue” category, the major subcategories that emerged were: classification problems, detection difficulties, prevention and treatment complexities, inadequate research, data inadequacies, and politically weak affected groups. Under the “involved actors” category, the major subcategories that emerged were: leadership and governance challenges, solution definition complexities, and positioning.

We consulted and followed established practices for triangulating among data sources to minimize bias and validate findings,<sup>29,30</sup> comparing findings across documents and key informant interviews rather than relying predominantly on one or the other source of information. We spoke to a wide range of key informants, including researchers, clinicians, and advocates from nongovernmental, academic, and donor organizations working in both high- and low-income country settings. Also, we reviewed a wide array of documents, including donor and nongovernmental organizational reports, technical reports, peer-reviewed publications, and conference notes. We compared the information gathered from the interviews and documents to determine areas of convergence and to resolve points of divergence across these sources with respect to the historical trajectory of global attention to RHD, and to piece together a comprehensive historical narrative. Interviews provided the main sources of information pertaining to internal dynamics among proponents; documents provided the primary information on disease characteristics, prevalence, and intervention strategies. To further check the historical accuracy of the narrative, we solicited and incorporated feedback on a draft of this article from 5 interviewees, representing different regions and institutions.

We used the Standards for Reporting Qualitative Research (SRQR) guidelines to ensure comprehensive reporting of our data collection and analysis processes.<sup>31</sup> The study protocol underwent ethics review and was approved by the Institutional Review Board of American University (Washington, DC).

## RESULTS

Global priority for addressing RHD in LMICs and among disadvantaged populations in HICs has fluctuated over time and grown in recent years, but consistently been at low levels. Priority has been influenced by characteristics of the issue itself, and by strategies of RHD proponents (ie, individuals involved in RHD treatment, research, funding, and advocacy).

### Issue Characteristics

#### Classification Problems

RHD can be classified in multiple ways. It can be considered a noncommunicable disease (NCD), an infectious disease, and a neglected tropical disease. A lifelong condition, it affects people of all ages: children, adolescents, pregnant women, and older adults. Its treatment may involve pediatricians, general practitioners, infectious disease specialists, cardiologists, and public health professionals. It requires robust primary care systems, district-level facilities, and specialized tertiary care. It falls everywhere and nowhere (interviews 1, 6, 8, 15, 16, 19, and 20), “a disease that has no obvious home.”<sup>32</sup> Few health professionals and policy makers, therefore, take primary responsibility for addressing the disease.

#### Detection Difficulties

Conditions that are progressive, difficult to understand, and deemed nonurgent are less likely to attract policy maker and public attention than those that do not possess these features. RHD has all these characteristics. RHD develops over a long period and initially presents as a sore throat and/or skin sores, often perceived to be harmless (interviews 6, 7, 12, 14, 15, 18, and 19). Public awareness of RHD is minimal because pre-RHD and early RHD is difficult to recognize.<sup>33</sup> Two respondents reflected on how RHD’s features present challenges for generating attention and funding:

*“It’s insidious, it’s long term, it’s just a slow progression...the repetitive mortality that results from it is completely under the radar...it’s just been totally eclipsed by other, what appear to be, more pressing... conditions such as HIV, TB, now unfortunately Ebola recently...” (interview 12)*

*“Rheumatic fever is not sexy, it’s not scary. It’s a sore throat—it’s very difficult to catch people’s eyes with it.” (interview 6)*

### Prevention and Treatment Complexities

The disease can be difficult to prevent and address, hampering policy maker willingness to fund efforts to fight it. Streptococcal bacterial infection is more likely in crowded settings with poor sanitation, widespread malnutrition, and inadequate access to health care and good-quality antibiotics. Routine screening is difficult because populations most at risk are often located in remote areas. Fighting the disease demands addressing poverty head on (interview 18). Moreover, few centers in low-income settings treat individuals requiring cardiac surgery, and most of those that do are poorly equipped.

Beyond this, there have been global stockouts of high-quality benzathine penicillin G, a necessity for the prevention of RHD.<sup>34</sup> As of 2017, only 4 companies produced the active ingredient for penicillin. There is minimal incentive to increase production because the off-patent drug offers little profit potential. In addition, adherence to secondary prophylaxis is poor because of fear of injection pain, apprehension over the risk of a fatal allergic reaction to penicillin, minimal resources for transportation and medications, poor patient-provider communication, and insufficient availability of clinics and providers that can provide injections (interviews 1, 13, and 19).<sup>35</sup> Moreover, some RHD interventions are costly, especially valve surgery.

Improved living conditions, the use of penicillin for primary prevention, and possibly a change in the features of the bacterium stood behind the decrease in industrialized countries.<sup>36</sup> In LMICs, the disease has followed a faster and more malignant course.<sup>37</sup> One respondent notes that strategies used to eradicate RHD from the United States cannot be applied to LMICs today, especially given that overcrowding and access to quality, primary care remain significant, underprioritized problems in low-income settings (interview 15).

### Inadequate Research

There has been a growth in research on the disease over the past decade (interviews 10, 15, and 20), including investigations of its pathogenesis,<sup>38</sup> incidence and progression,<sup>39</sup> and echocardiographic screening surveys of RHD’s prevalence in schoolchildren.<sup>40</sup> In addition, there is work on developing a vaccine for RHD.<sup>41</sup> Nevertheless, understanding of ARF/RHD pathogenesis, diagnostic methods, and clinical management

remain inadequate.<sup>42,43</sup> Although it is well established that RHD is a consequence of recurrent, untreated group A streptococcus infections, the pathogenesis is incompletely understood.<sup>44</sup>

### **Data Inadequacies**

Historically, there have been insufficient and unreliable data on RHD prevalence and economic burden. As one respondent noted:

*“Data are lacking on all levels; we are in the dark.” (interview 10)*

Health authorities in many countries have relied on regional estimates of the burden of RHD, given the absence of national disease registries and underreporting or misdiagnosing of RHD.<sup>45</sup> Data on RHD prevalence remain sparse in sub-Saharan Africa, but there have been significant improvements on estimates globally and in other regions, especially on the basis of global burden of disease data (interviews 8 and 20).<sup>1</sup> Another positive development is the advancement of portable echocardiography technology (interview 19), enabling researchers to detect the disease in asymptomatic patients.<sup>40</sup>

### **Politically Weak Affected Groups**

Generating attention for RHD is challenging also because it almost exclusively affects communities that are marginalized and poor, those lacking the power to sway donors and policy makers (interview 20). For instance, indigenous Australians in the Northern Territory aged <35 years are 122 times more likely to have RHD than their nonindigenous counterparts in the same region.<sup>46</sup> ARF/RHD disproportionately affects poor and migrant children, adolescents, and pregnant women (interview 7). Virtually eradicated from high-income regions of North America and Europe by the 1980s,<sup>47</sup> RHD is predominantly a LMIC problem (interviews 6, 7, and 15).

### **RHD Proponents**

These issue characteristics shape the challenges RHD proponents face in generating attention and resources to address the disease. They confront 3 primary, linked difficulties. With respect to *leadership and governance*, the fact that RHD affects mostly poor populations in dispersed regions complicates efforts to coordinate activities and to ensure sustained donor and international organization engagement. With respect to *problem and solution definition*, the dearth of data on some aspects of clinical management, difficulties preventing and addressing the disease, and the fact that RHD intersects with several disease domains have led to

disagreements among proponents about how best to address the disease. With respect to *positioning*, an understanding that RHD is largely a problem for low-income countries, and the lack of clarity on its status as an NCD, have complicated efforts to convince policy makers to act.

### **Leadership and Governance: Progress**

Proponent initiatives have led to some growth in attention to the disease in the past several years. The number of RHD proponents, although small, has grown over the past decade. They include clinicians, researchers, and advocates who work in settings where ARF/RHD is endemic: many parts of sub-Saharan Africa and the Asia-Pacific region, poorer regions of Brazil, and among indigenous populations of Australia and New Zealand.<sup>8</sup> Most RHD proponents are from the Global South (interview 20); unlike many global health communities, this community therefore has a strong understanding of the challenges with addressing health conditions in resource-constrained settings.

RHD proponents have spearheaded several research efforts that have helped generate greater global attention to the issue. The REMEDY (Global Rheumatic Heart Disease Registry), a prospective registry that was launched in 2012 across 25 sites in 14 LMICs, is one of the largest efforts using echocardiography to collect data on disease characteristics and long-term outcomes in RHD patients.<sup>48</sup> The study strengthened ties among RHD researchers and highlighted major RHD care deficiencies (interviews 1, 4, 10, and 14). Proponents have since organized other large-scale registry and screening efforts, and there has been a surge of publications on RHD coming from LMIC investigators.<sup>49</sup>

Proponents have engaged donors as well. In 2014, the Medtronic Foundation committed \$6 million over 5 years to support global efforts to eliminate RHD and provided funding to several countries to achieve RHD reduction targets through support to RHD Action, founded by WHF and Reach (formerly known as RhEACH), a technical support and policy translation initiative for RHD (Rheumatic Heart Disease, Evidence, Advocacy, Communication, and Hope). Novartis Institutes for Biomedical Research, the funder of this study, became involved in early 2013. It produces penicillin, which is necessary for RHD's primary prevention and secondary prophylaxis. It supported the “Beat RHD” initiative in Zambia in collaboration with several partners, including PASCAR, an organization of physicians from across Africa established in 1979 involved in prevention and treatment of cardiovascular disease. Novartis has supported several RHD-related PASCAR meetings, facilitating exchange of research and best practices.

Most recently, the American Heart Association awarded a \$3.7 million grant to launch a Rheumatic Heart Disease Center, to develop innovative strategies to address RHD.

The WHF has been particularly effective at organizing RHD forums, raising awareness of the issue among Ministers of Health, and establishing mechanisms through which proponents are able to distribute information and tools (interview 20). The WHF also had a working group on rheumatic fever and RHD, although that group recently dissolved (interview 15). Many individuals affiliated with this group were central to the development of international echocardiographic guidelines for RHD<sup>50</sup> and a position statement affirming WHF commitment to a 25% reduction in premature deaths from rheumatic fever and RHD among individuals aged <25 years by the year 2025.<sup>51</sup>

The leadership of 2 individuals who strengthened regional organizations, Professor Jonathan Carapetis from Australia and the late Professor Bongani Mayosi from South Africa, was crucial (interviews 1, 3, 4, 7, 10, 13, 14, 15, 16, 17, and 19). Proponents point to their research contributions, charisma, vision, and “lead from behind leadership” (interview 10) as having propelled the field over the past decade (interviews 1, 2, 7, 10, 12, and 13). Professor Carapetis, a pediatrician and infectious disease specialist, cofounded Reach and is recognized as a leader in the Australian health field, appointed in 2018 as a Member of the Order of Australia in the Queen’s Birthday honors for his work on RHD. Professor Mayosi was a cardiologist, prolific researcher, and a leader in many global and national cardiology and RHD-specific groups. A respondent noted what made Professor Mayosi an effective leader:

*“He’s very brilliant, academically. He’s a very gifted orator. He is very engaging and passionate about his work...Everybody views him as a leader. It’s almost messiah-like...I don’t think anybody can quite command the respect that he does.” (interview 13)*

Professor Mayosi revived PASCAR in 2005, following an all-Africa workshop on ARF/RHD that he organized. In 2013, he became the organization’s president. Since the mid-2000s, PASCAR has issued several influential declarations and calls to action (interviews 1, 2, 4, 5, 10, 12, 13, 14, 16, and 17). These include the 2005 Drakensburg Declaration,<sup>52</sup> committing RHD proponents to a program to raise public and health professional awareness, establish surveillance systems, advocate for increased resources for treatment, and promote the prevention of ARF/RHD in African nations. The declaration catalyzed the initiation of RHD registries and studies demonstrating the disease’s

burden. In 2014, PASCAR members and the World Health Organization Regional Office for Africa jointly issued the Mosi-o-Tunya Call to Action to governments in endemic countries.<sup>53</sup> The call highlighted the lack of progress in establishing national prevention policies and programs and marked the first time that proponents engaged international organizations (interview 2). In 2015, RHD proponents developed the Addis Ababa Communiqué, outlining 7 priority areas for action.<sup>54</sup>

In 2014, Medtronic Foundation, WHF, and Reach founded RHD Action, a global movement to reduce the burden of the disease in at-risk populations. RHD Action has been successful in developing resources for RHD proponents (interviews 8 and 20). Some proponents (interviews 2, 6, and 20) expressed optimism in RHD Action’s potential to galvanize action on the issue:

*“I think it’s brought everyone together, so we have a joint action plan, we develop our proposals together...I think the vision of RHD Action is it can serve as an umbrella for what we do, so that we have a strong brand and communications.” (interview 6)*

### **Leadership and Governance: Challenges**

Despite these recent initiatives, leadership and governance challenges loom. One concern is that nearly all RHD proponents are clinicians, and most of them are specialists. Because of this, they have a fairly homogeneous and scientific perspective on RHD with minimal understanding on “how to translate technical interventions into action” (interview 8). Also, they are busy and often pulled in different directions because of other commitments (interviews 8, 10, 12, 13, 19, and 20), leaving insufficient time for advocacy and organizing-related activities:

*“There’s no one sitting fully outside academia who’s leading the charge and working full time to foster collective action. At least not at the senior level.” (interview 8)*

One of the biggest concerns and causes of uncertainty within the community is the recent passing of Professor Bongani Mayosi. One commented on the impact of his loss on advocacy efforts for RHD:

*“I’m not too sure who on the African continent would drive it in the same charismatic, forceful way.” (interview 12)*

The loss of his leadership is compounded by the recent passing of another central advocate from New

Zealand, Professor Diana Lennon, who initiated and led the randomized controlled trial of primary prevention of rheumatic fever with sore throat school programs, described as the most innovative rheumatic fever research for >50 years. Professors Bongani Mayosi and Diana Lennon were interviewed as part of this research study.

Also, there is minimal patient engagement (interviews 8 and 20). RHD Action initially aimed to build “a global movement,” but its commitment to patient engagement fell through early on and was never revived, and neither Reach nor WHF was provided resources for building a grassroots movement (interview 8).

There are questions, too, about the roles and sustainability of international institutions. One respondent commented:

*“The history is a little tricky [on] which organization takes leadership—it used to be WHO and then it went to WHF and WHF did a good job, but then didn’t quite do enough around certain things, perhaps around advocacy so Reach and RHD Action started.” (interview 6)*

The WHO became notably inactive on the issue from the early 2000s (interview 20). Competing health priorities, difficulties in quantifying the burden of RHD before the introduction of echocardiography, the “vertical” structure of the WHO RHD program, a lack of advocacy from WHO Member States, and a “declining sense of international camaraderie” likely contributed to WHO’s declining attention. Many RHD proponents also noted that the WHO’s disengagement roughly correlates to the period when the West was thought to have eradicated RHD (interviews 1, 3, 10, and 15).

Several respondents questioned the advocacy capacity and/or sustainability of some institutions engaged in RHD (interviews 6, 14, 15, and 20). Other respondents raised concern about the transparency and inclusivity of RHD Action, which at its creation funded country projects that were initiated by 2 HIC organizations:

*“Some people felt left out or not included... partly because of whose work was being promoted.” (interview 6)*

There is concern also among RHD proponents about the sustainability of funding by a couple of donors. One respondent expressed frustration with one of the donor’s decision to end funding for RHD:

*“In my early meetings, we [the funder and RHD proponents] were talking about eradication of RHD in Africa. That was the*

*goal. We were all motivated...[The funder was] going to try to marshal more funds to make sure it wasn’t just confined [to one country], and now it’s all being dialed back.” (interview 13)*

Many RHD proponents attribute diminished donor support to the fact that the early internal RHD champions are no longer with these organizations (interviews 6, 10, 13, and 18). Proponents are also concerned that donor funding for RHD to date has focused on either research and development or small clinical “demonstration site” programs; bilateral or multilateral agencies have offered no support for RHD control (interviews 8 and 15).

### **Problem and Solution Definition**

Proponents are unified by a belief that RHD poses a high burden and does not get the attention it deserves (interviews 1, 7, 11, 12, 13, 15, and 20). Several indicate that there is general agreement among the RHD community on how the issue should be addressed (interviews 3, 8, 15, 16, and 17), viewing differences as minor “family-style disagreements” (interview 8). However, other respondents indicate that the disagreements may be substantive, with potential to lead to fractionalization among proponents.

One disagreement concerns whether limited resources should be invested in primary prevention (to prevent development of the first episode of ARF) or secondary prevention (to prevent recurrent episodes of ARF as well as progressive heart valve damage) (interviews 2, 7, 8, 11, 14, and 20). Even among those proponents that support primary prevention, there is little consensus about best strategy. There is disagreement about the extent of energy that should be directed for vaccination development. Also, proponents disagree on how sore throat diagnosis and treatment within existing primary healthcare systems should be done.

An additional disagreement concerns the extent to which echocardiographic screening should be used and for what purpose (interviews 1, 2, 11, 12, 14, 15, and 18).<sup>55</sup> One reflects:

*“We cannot be asking the Minister of Health to invest in echo screening when he has not got enough money to operate on the kids.” (interview 2)*

Disagreements about echocardiographic screening partly stem from disciplinary differences among RHD community members. Many public health physicians believe it is unethical to screen with echocardiography if treatment cannot be offered. On the other hand, many

cardiologists and surgeons advance the need for echocardiographic screening and that doing so will better enable understanding of the disease's natural history (interview 11).

There is even disagreement among RHD proponents about whether benzathine penicillin G is effective for secondary management of RHD (interviews 7, 13, 14, and 18). Although early studies concluded that secondary preventative therapy with penicillin in individuals with a history of ARF resulted in a reduced risk of recurrent ARF and by inference RHD, some proponents argue the quality of these analyses are suboptimal because they are largely based on observational data, rather than randomized trials (interviews 14 and 18).<sup>56</sup>

Finally, there is disagreement among proponents on whether RHD should be managed via an integrated and holistic approach or a focused, vertical-program strategy (interview 12). Perspectives on this issue are influenced by professional interests, questions of feasibility because there are few clear models on how to integrate interventions for RHD in weak health systems, and disciplinary differences among practitioners.

### Positioning

There are several disagreements among proponents about how the disease should be positioned to generate policy-maker support. One point of contention concerns whether RHD should be framed as an NCD. Some proponents argue that RHD would benefit from the recent increase of attention to NCDs:

*"I see hope primarily because I think that governments in sub-Saharan Africa are interested in tackling NCDs through a comprehensive prevention strategy, and I think that RHD can easily be worked into that strategy." (interview 18)*

Others argue that RHD's integration into any NCD framework would be detrimental (interviews 1, 6, and 7). They note that RHD has not been fully embraced by the NCD community. For instance, the 2012 WHO NCD Action Plan almost exclusively focuses on the "big 4" NCDs of cardiovascular disease, diabetes mellitus, chronic respiratory disease, and cancer, and their behavioral risk factors (ie, smoking, inactivity, dietary excess, and alcohol).<sup>57</sup> None of these risk factors pertain to RHD, which involves a different set of poverty-related determinants (poor sanitation, overcrowding, and inadequate access to basic antibiotics).<sup>4,58</sup> Several proponents comment on these difficulties:

*"If we put it under NCD, it's going to be so diluted...As long as we're putting it in the ischemic heart disease and heart failures and whatever, it will not be seen." (interview 1)*

*"In our ministry, the first people I went to talk to were the NCD people and they said, 'You're not really talking about stroke, you're not talking about high blood pressure, and you're not talking about diabetes, so how is this an NCD?'" (interview 7)*

These disagreements about NCD positioning are a subset of larger tensions surrounding the fact that RHD connects with several disciplines, disease communities, and stages of people's lives. On the one hand, this wide scope offers proponents the opportunity to seek support from multiple global health communities:

*"There is discussion about is this an NCD, is this maternal health, is this primary health? It's all of those, really. You just have to find the one where there's a political focus and you can sell this issue in terms of their agenda." (interview 6).*

However, the danger of this strategy is that it poses the risk of RHD being lost amidst health issues with stronger identities and backed by more powerful advocacy coalitions.

Another tension pertains to the role of research arguments in augmenting attention to the issue (interviews 2, 5, and 6). One respondent is concerned about the community's overreliance on research to make the case:

*"We think we're successful because of all these research projects, all these publications, all these things that are happening. But success would be measured by being embedded in the ministry and by being part of the work stream of the department, and there are very few places where we have achieved that." (interview 2)*

The fact that RHD is concentrated among the poor has posed particular problems for advocacy. In late 2016, with New Zealand championing the issue, the WHO initially rejected consideration of RHD/ARF as an agenda item at the WHA, concluding that it is "not a global enough issue," because it predominately

affects the poor in Africa and Asia-Pacific (interviews 6, 7, and 19). One respondent reflected:

*"I think on a big global level, it's a disease of poverty, therefore it's not important to a lot of the world. It's in Africa. It's in India. It's 'over there'." (interview 7)*

However, after 30 months of civil society strategizing and intense diplomatic negotiation, the WHO Executive Board adopted a resolution on rheumatic fever and RHD at the 71st WHA in May 2018. Although one RHD proponent questioned whether it was worth the effort (interview 7), others are hopeful about the resolution's potential impact on national policy and action (interviews 8 and 20).

In other respects, the fact that RHD predominately affects the poor may also be advantageous for advocacy. Several proponents note how RHD may benefit from the sustainable development goals, which have catalyzed global interest in addressing poverty and the underlying social and systemic determinants of disease (interviews 1, 6, 14, and 20).

## DISCUSSION

Although there has been some growth in recent years, attention to RHD is small compared with other conditions of comparable burden. Unfavorable issue characteristics on disease classification, detection, prevention, intervention, research, data, and the social power of affected groups make advocacy for RHD difficult. These challenges underpin difficulties that proponents have encountered surrounding leadership, governance, defining solutions, and framing the issue.

Despite these challenges, there have been several developments in recent years that portend well for advocacy. LMIC investigators have produced a new wave of research. The advent of portable echocardiography has made detection easier. Pilot clinical screening programs in several LMICs have resulted in more precise estimates of prevalence and better understanding of the disease's progression. RHD proponents have issued several high-profile declarations. Leaders in Africa and Australia have emerged, as have regional and global initiatives, fostering greater collaboration among proponents. The sustainable development goals and NCD initiatives present potential grafting opportunities for advocacy. The WHA issued a resolution on ARF and RHD in 2018.

Study findings indicate that to capitalize on these opportunities, proponents will need to address 3 challenges, pertaining to governance, solution definition, and framing. Each involves tensions between breadth

and depth, being inclusive and comprehensive to appeal to a broad constituency versus being narrow and focused to ensure cohesion and specificity. Proponents will need to find the right balance between the 2.

First, proponents will need to build effective governance structures that link actors working on the issue and promote effective collective action. In the past decade, initiatives and networks dedicated to RHD have emerged, well-respected regional champions have appeared, and funders and international organizations have provided attention and resources for RHD. However, this progress is in jeopardy. The WHF's RHD working group no longer exists, institutional leadership on the issue is perceived to be transient, there is uncertainty about future leadership, especially given the unexpected passing of a central, well-respected advocate, and RHD funding from past donors is dwindling. Proponents will need to consider how to cultivate new leadership and reconstitute sustainable mechanisms for collective action. In doing so, they will need to consider: What emerging leaders exist, capable of convening RHD proponents working in LMIC and indigenous population settings? What mechanisms and platforms would most effectively facilitate the coordination of proponents in Africa, the Pacific, and other regions? And how may proponents leverage the legitimacy and experience that they hold by virtue of the fact that most are from the Global South? Another governance consideration is the diversity of the composition of involved actors. RHD proponents are largely confined to those that research, treat, and/or are affected by the disease. There is little engagement with advocates from other health and development communities. While pursuing expansion, proponents will need to consider how to manage tensions between *inclusivity* (attracting a larger, broad coalition of supporters) and *selectivity* (maintaining a tight core so as not to risk member internal cohesion and identity).

Second, proponents will need to manage internal disagreements to avoid community fractionalization. Although some do not perceive major differences on prevention and intervention strategies, this study's findings suggest otherwise. Were fractionalization to emerge, it could hamper the legitimacy and authority of the community. It could also hamper the community's capacity to develop a cohesive set of demands for policy makers, a requirement for attracting resources. This is particularly relevant as proponents determine strategies for national-level implementation of the WHA resolution. Proponents will need to ensure that that they avoid complex, overly technical jargon. They will also need to ensure that their requests balance *comprehensiveness*, accounting for the varying perspectives of proponents, as well as RHD patients, and *specificity*, clearly identifying how the disease should

be managed clinically, what strategies should be prioritized, and how detection tools should be applied.

Third, proponents will need to position RHD in ways that inspire decision makers to embrace the issue and act. Because RHD can be classified in multiple ways, proponents face a tension in crafting a framing that is *broad*, appealing to various decision makers and multiple relevant agendas, and *focused*, ensuring coherence and clarity. Each approach presents dangers and opportunities. The former strategy risks RHD getting lost among other health or development priorities that have stronger identities, but benefits from the possibility of attracting more allies and leveraging the visibility afforded when linked to multiple, powerful agendas. The latter risks losing important allies, but benefits from the likelihood of fostering greater cohesion and clarity.

## CONCLUSIONS

In sum, an understanding of RHD's recent growth in attention but ongoing inadequacy in global priority requires an understanding of the nature of the disease itself and how to address it. It also requires attention to *political* considerations, including those internal to the network of professionals and scientists advocating for greater attention to the issue. The future of global priority for RHD is uncertain because of emerging difficulties surrounding leadership, governance, and commitment from donors, international organizations, and national governments. These are not uncommon difficulties facing global health networks.<sup>20,59,60</sup> There is no single "right" path for addressing these internal challenges. What is crucial is that members of the community themselves deliberate openly and inclusively to arrive at the best strategy. Given progress over the past decade, there is no inherent reason to believe that proponents cannot surmount the governance, solution definition, and framing challenges to rekindle priority for the issue.

## ARTICLE INFORMATION

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