



RHD Action

United to End
Rheumatic Heart Disease



**WORLD HEART
FEDERATION®**

RHEUMATIC HEART DISEASE CIVIL SOCIETY SURVEY

Survey Findings – August 2016

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1. KEY MESSAGES

- The World Heart Federation carried out a survey of RHD civil society between July and August 2016 to inform decision-makers about areas in particular need of practical and policy attention.
- **166 individuals and organizations responded to the survey, representing 41 countries, 6 WHO regions, 25+ professions and over 1,500 collective years of experience in professional RHD prevention and control.**
- **The top 5 day-to-day needs of respondents were:**
 1. More funding and financial resources
 2. More support from your government
 3. Training for existing medical and non-medical staff
 4. More support from the World Health Organization
 5. More medical staff
- **The top 5 priorities identified for inclusion into an RHD Resolution were:**
 1. Acknowledgement that RHD is a public health priority
 2. Clear targets and goals to reduce the burden of the disease
 3. Pledges to invest more money into global RHD control
 4. Guidance on primary prevention
 5. Research into the epidemiology of RHD
- This preliminary analysis of the survey will be fed back to participants and should be informative to national decision-makers, the WHO and other UN Bodies as they tackle RHD prevention and control.

1 CONTEXT

- On 14 July 2016, the World Heart Federation launched a survey of civil society representatives from the RHD community.
- The survey was designed, trialed, modified and disseminated through SurveyMonkey®, an online, cloud-based survey system.
- We asked a range of one-word answer, quantitative and wider qualitative questions.
- The survey was targeted at all individuals and organizations working in RHD prevention and control around the world on behalf of civil society.
- Outreach to participants included:
 - o Invitations to participate in online newsletters, including RHD Beat (RHD Action), Members News (World Heart Federation) and Murmur (RHD Australia)



- Social media campaigns on the World Heart Federation and RHD Action Twitter accounts
- Targeted personalized emails to key individuals
- The survey closed on 04 August 2016, with a total of 166 participants.
- This document contains the general findings from the survey, focusing on both quantitative and qualitative outcomes.
- Our first priority is to communicate the survey findings back to participants, and then to advocates, policy-makers and other key global stakeholders at the WHO and United Nations.

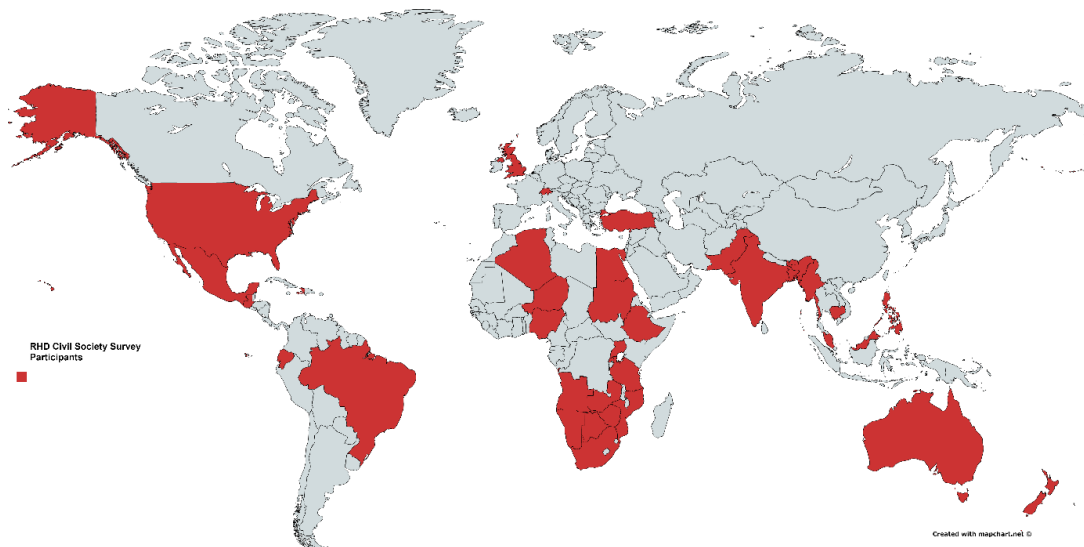
2 PARTICIPANTS

In total, **166 individuals responded**, representing **all six WHO Regions**.

41 countries were represented by our participants:

- Algeria, Angola, Australia, Bangladesh, Bhutan, Botswana, Brazil, Cambodia, Cuba, Ecuador, Egypt, Ethiopia, Fiji, French Polynesia, Guatemala, Haiti, India, Malaysia, Mexico, Mozambique, Myanmar, Namibia, Nauru, Nepal, New Zealand, Niger, Nigeria, Pakistan, Philippines, Rwanda, Samoa, South Africa, Sudan, Switzerland, Tanzania, Turkey, Uganda, UK, USA, Zambia and Zimbabwe.

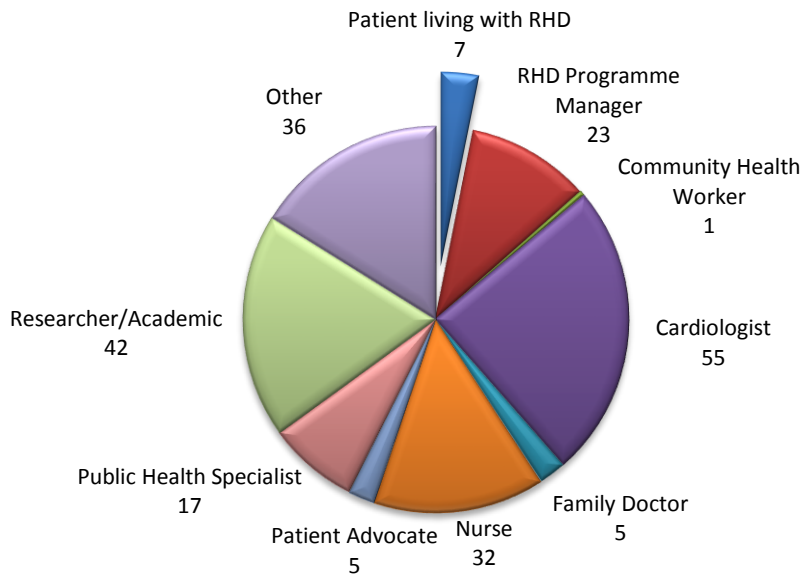
Figure 1: Map of RHD Survey Participants



- Our 166 participants spanned a **wide range of professions**, including:
 - Cardiac physicians, researchers, students, nurses, national and local programme coordinators, NGO staff (including leadership, board, gender advisors, advocates, and admin), and seven people living with RHD.
- Our 166 respondents recorded **1,579 ½ years of combined professional service** to the RHD community.
- The average (mean) length of each participant's experience in RHD prevention and control was **9 ½ years**.



Figure 2: Breakdown of participant professions



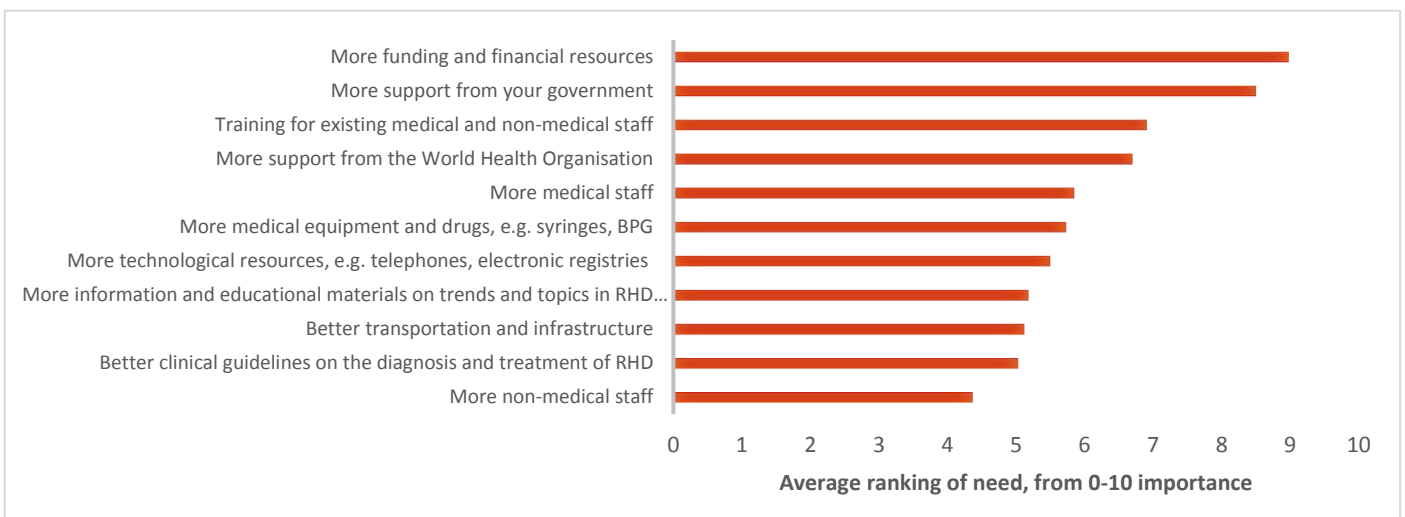
- Participants were asked to list their day-to-day areas of work – almost every participant listed more than one professional focus area, with the **top 5 areas of work** being:
 1. Clinically managing the health of PLW RHD (57.83%)
 2. Educating communities about RHD (52.41%)
 3. Engaging and supporting PLW RHD (48.19%)
 4. Supporting health workers to deliver safe, effective care (43.37%)
 5. Advocating for decision-makers to increase support for RHD (42.77%)

3 FINDINGS

NEEDS & PRIORITIES

- Participants were asked to identify and rank their day-to-day needs in order of priority.
- The World Heart Federation strongly suggests that these identified needs are addressed as priorities in the forthcoming RHD Resolution:

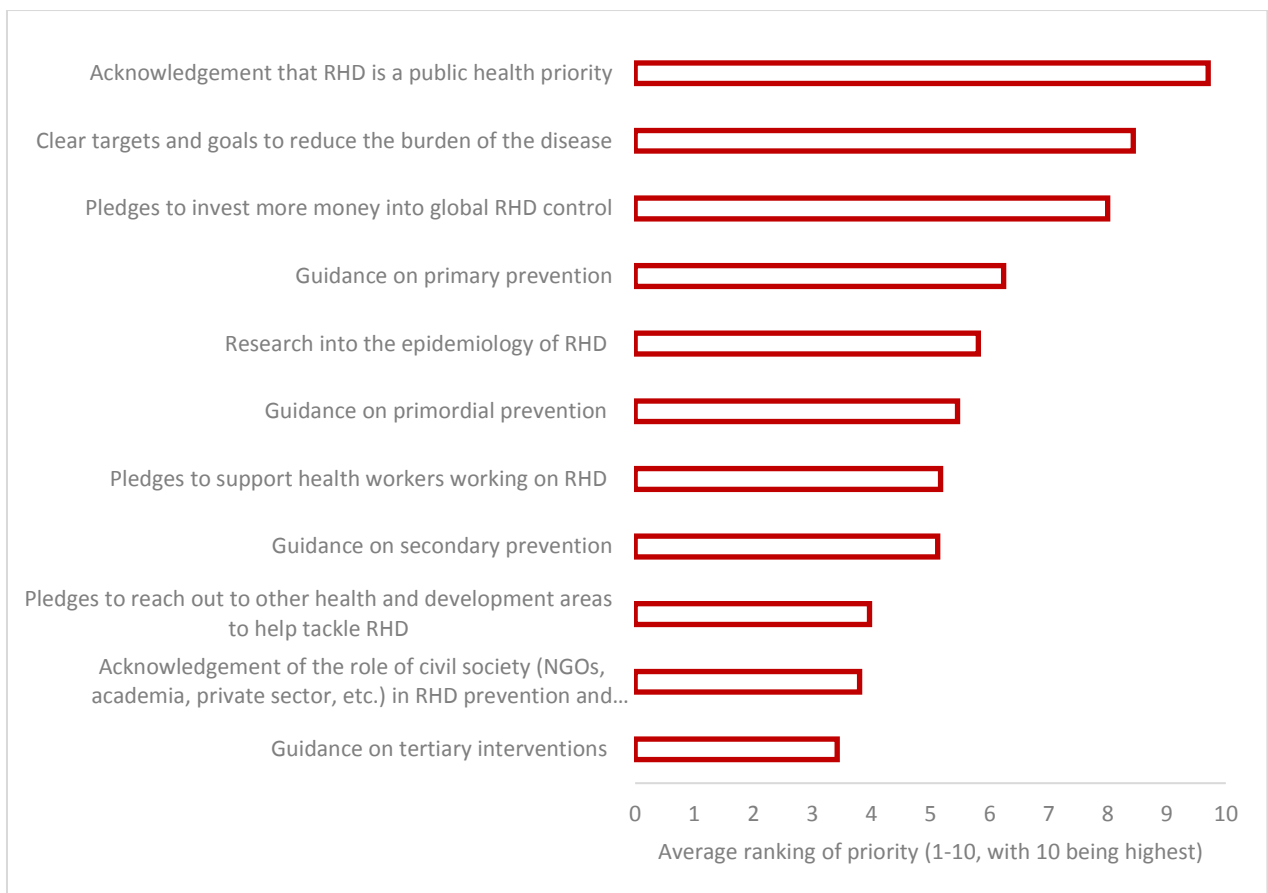
Figure 3: Day-to-day needs in RHD prevention and control, ranked in order of importance





- Respondents were then asked to identify and prioritize action areas for inclusion into the RHD Resolution text.
- Of the 121 respondents who answered this question, they prioritized the top 5 actions for inclusion:
 1. **Acknowledgement that RHD is a public health priority**
 2. **Clear targets and goals to reduce the burden of the disease**
 3. **Pledges to invest more money into global RHD control**
 4. **Guidance on primary prevention**
 5. **Research into the epidemiology of RHD**

Figure 5: Actions that should be contained in an RHD Resolution, ranked in order of priority

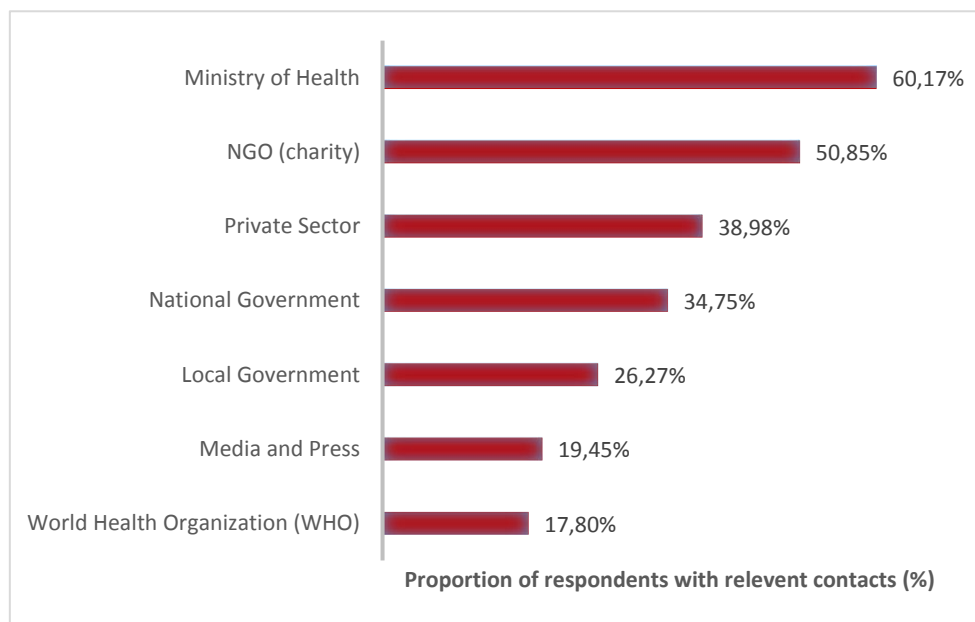


- 26 Respondents also suggested additional topics for inclusion into the Resolution, including:
 1. Acknowledgement that RHD is an easy, feasible and cost effective preventable disease
 2. Pledge to include RHD interventions (up to tertiary level) in UHC packages
 3. Stressing oral hygiene and good personal sanitation habits
 4. The importance of register-based approaches
 5. The need to focus on Acute Rheumatic Fever alongside RHD

PARTNERS & STAKEHOLDERS

- Respondents were asked to list their most common partners and stakeholders to ascertain levels of national multi-stakeholder engagement.
 - WHO was listed as the least common partners or stakeholder, ranking behind Ministries of Health, NGOs, the private sector, national government, local government and the press.
 - Only 24 participants (less than 15%) had any WHO contacts at all.
 - But more than 60% of those with no contacts at WHO said it would be valuable to their work – from this we can infer an unmet need for greater engagement, capacity building and technical support from supranational bodies on RHD issues.

Figure 4: Range of partners and stakeholders indicated by participants



CLOSING REMARKS

- Participants were asked to identify their one big ask to the WHO Director-General; the most common recommendations included:
 1. A concerted drive to raise awareness and allocate resources (human and financial) to RHD, including allocating human and financial resources to RHD staff in the WHO Secretariat.
 2. Investment and technical support in direct epidemiological measurement of global and national RHD burdens, as currently we rely on modelling estimates.
 3. A synchronized global RHD prevention and control programme, supported by a global funding source that is replenished by a coalition of global health funders and Ministries of Health.
 4. Integration of RHD prevention and control into WHO's existing child and adolescent health packages, including provision of nurses for schools.



5. Technical and financial support to improve quality, supply, access and efficacy of Benzathine Penicillin G (BPG).
- Closing comments were offered by 46 participants, including the following recommendations:
 1. “Costa Rica and Cuba have shown RHD control can be achieved over 10 years without that much money. Any resolution should be taking in account this reality.” (*Rwanda*)
 2. “RHD has crippled the lives of many innocent human beings on earth. It has hindered economic development of the nations. It is making poor nations poorer.” (*Bhutan*)
 3. “One of the main risks for contracting Strep A is poverty and overcrowding, it would be very beneficial if governments were to focus on reducing this issue.” (*New Zealand*)
 4. “RF/RHD prevention and control is feasible and cost-effective. This needs some technical and financial support, applicable training personnel and inclusion in use of available resources. This has been neglected for long time by Governments, WHO and most WHO donors.” (*Cuba*)
 5. “Tackling and eradicating RHD would represent everything [the SDGs] set out to achieve: it requires collaboration from communities such as maternal health, NCDs, vaccine research and more, with the aim of reducing the burden of disease among some of the world's poorest and most vulnerable communities.” (*Switzerland*)

4 PEOPLE LIVING WITH RHD

- Seven people living with RHD participated in the survey
- As people living with RHD have unique insights into prevention and control, some important excerpts from their responses are recorded below:
 1. “RF and RHD need to be publicized like breast cancer and heart attacks.” (*Australia*)
 2. “[We should] get every rheumatic fever and rheumatic heart disease patient around the world on a database to monitor their progress with their health.” (*Australia*)
 3. “[We need] more gatherings for people with RHD to share experiences.” (*Uganda*)
 4. “Having [a WHO] contact would help me highlight more RHD challenges in my community.” (*Uganda*)
 5. “[Engagement with WHO] will speed up our communications action and will give better credentials.” (*Fiji*)

5 NEXT STEPS

- Our first priority is to communicate these survey findings back to participants, especially the people living with RHD who contributed.
- We will be conducting communications outreach via online mailing lists, news articles, social media and personalized and targeted email.



- We will then communicate our findings to key stakeholders (governments, civil society and UN agents) in the hope that this review informs future RHD policy, especially around a proposed WHO RHD Resolution.
- For further information about this survey, please contact Joanna Markbreiter, Policy and Advocacy Manager, World Heart Federation, at: Joanna.Markbreiter@worldheart.org.