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Time to tackle rheumatic heart disease: Data needed to drive global policy dialogues

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ABSTRACT
Rheumatic heart disease (RHD) is an avoidable disease of poverty that persists predominantly in low resource settings and among Indigenous and other high-risk populations in some high-income nations. Following a period of relative global policy inertia on RHD, recent years have seen a resurgence of research, policy and civil society activity to tackle RHD; this has culminated in growing momentum at the highest levels of global health diplomacy to definitively address this disease of disadvantage. RHD is inextricably entangled with the global development agenda, and effective RHD action requires concerted efforts both within and beyond the health policy sphere. This report provides an update on the contemporary global and regional policy landscapes relevant to RHD, and highlights the fundamental importance of good data to inform these policy dialogues, monitor systems responses and ensure that no one is left behind.

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Rheumatic heart disease; rheumatic fever; global health policy; burden of disease; global development

It is time to tackle rheumatic heart disease (RHD). RHD is an avoidable condition that usually begins in childhood following rheumatic fever (RF), an abnormal immune response to a Group A streptococcal throat infection. It can lead to a range of cardiovascular complications and premature death. RHD is a disease of poverty, with roots firmly embedded in overcrowding, poor access to health services and social disadvantage. Socioeconomic development and improved medical management have seen RHD largely eliminated from high-income nations. However, it remains a cause of considerable morbidity and mortality in many low resource settings and amongst Indigenous and other vulnerable populations in some high-income countries. Globally, it is estimated that there are approximately 33 million people living with RHD and 320,000 RHD-related deaths annually (Watkins et al., 2017). Notably, whilst RHD and its social and environmental risk factors are concentrated in low resource settings, globalisation, migration, and an increasing number of protracted

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refugee crises mean that RHD is not confined to developing nations but rather is a global health problem, requiring a global policy response.

During the 1980s to early 2000s, the World Health Organization (WHO) adopted the Global Programme on Rheumatic Fever and Rheumatic Heart Disease. Implemented across 22 countries, activities included establishing disease registers, treatment programmes, health promotion, health worker education and epidemiological surveillance and research, as well as primary prevention in some settings (Carapetis, 2004; Nordet, n.d.). The initiative was disbanded in 2002, variously attributed to lack of funding, data, co-ordination and ownership (RHD Action, 2016c), and RHD faded from the global health diplomacy radar. Interest from the research community also waned over time, with a dramatic decline towards the end of the twentieth Century in the number of published studies with an RHD focus (Carapetis, 2007). Recent years have seen a resurgence in activity and interest across both the research (Carapetis, 2015) and policy (Dougherty et al., 2018; World Health Organization, 2017d) arenas. A number of initiatives and calls to action have also emerged, many of them setting targets for significant reductions in RHD burden.

Following years of relative neglect, there is now growing momentum for concerted action to end RHD (Figure 1). While timely and welcome, these calls for action also serve to highlight the paucity of reliable data available to understand the distribution and true burden of RHD and to measure progress.

Here we provide an overview of the current major global and regional policy initiatives relevant to RHD, and highlight the crucial importance of accurate, contemporary data to inform these multi-sectoral dialogues, guide policy action, measure progress and ensure that no one is left behind.

**RHD-specific global initiatives**

**Increasing global civil society advocacy and leadership**

The World Heart Federation (WHF), the leading civil society body advocating for global cardiovascular health, has a long history of engaging in and supporting efforts to tackle RHD. Formerly known as the International Society and Federation of Cardiology (ISFC), its activity in this space dates back to the early 1980s when ISFC collaborated closely with WHO on their Global Programme (World Health Organization, 2017b). Since conclusion of this initiative, WHF has assumed an increasing leadership and advocacy role, including hosting an RF/RHD Council, and since the mid-2000s providing support for regional activity in Africa and the Pacific. On the global level, side events held at the World Health Assembly in 2013 and 2015, co-sponsored by WHF and a number of governments, facilitated intergovernmental dialogues on RHD and laid the foundation for firmly embedding RHD onto the global health diplomacy agenda (Alice Grainger-Gasser, personal communication).

WHF also formally established a Working Group on RF and RHD. In 2013 this Working Group published a position statement outlining its vision and multipronged action plan towards global

*Figure 1. Global and regional RHD-specific policy activity and calls to action, 2002–2017.*
RHD control (Remenyi, Carapetis, Wyber, Taubert, & Mayosi, 2013). Aligned with the WHO’s 25 × 25 cardiovascular disease targets (World Health Organization, 2013), WHF launched its 25 × 25 < 25 campaign, calling for action towards a 25% reduction in RF/RHD mortality amongst individuals aged less than 25 years by 2025. This was accompanied by a set of health systems targets required to achieve this objective (Remenyi et al., 2013).

Recognising that reliable prevalence and mortality data would be needed to gauge progress toward 25 × 25 < 25, and that such data are sparse from many high burden settings, expert-led guidance for the echocardiographic diagnosis of RHD in endemic settings was developed, and endorsed by WHF (Remenyi et al., 2012). This provides instructions for standardised measurement, which at the population level is crucial to enable comparison of disease burden within and between settings and over time. It should be noted however, that there remains uncertainty around the clinical significance and most appropriate management of borderline cases. There is possibly a role for cheaper, hand-held echocardiographic devices facilitating early case detection and facilitating early referral to appropriate care (Sliwa & Zilla, 2012). Echocardiography screening studies have become an important source of primary data for estimates of RHD prevalence by the Global Burden of Disease (GBD) project. (Watkins et al., 2017) The role of GBD modelling as an arbiter of progress towards RHD control goals remains unclear. It is likely that a broader suite of metrics that combine local data sources and real-time updates will need to be combined with the standardised GBD methodology to understand whether progress is underway.

A series of global RHD forums held in conjunction with global cardiology and cardiac society conferences have attracted considerable interest and attention from civil society stakeholders (Johnson et al., 2015; Zuhlke, Engel, Remenyi, Wyber, & Carapetis, 2013), and mobilised a growing community from disparate sectors in global health. Operational research priorities have also been articulated, including the need to understand the burden and economics of RHD and its control (Carapetis & Zuhlke, 2011). In referring to addressing the burden of RHD there is an intentional dual meaning. Epidemiologically, the burden of disease describes incident cases of ARF and prevalent cases of RHD. Socially, the burden of RHD reflects the demands placed on the health system and the life course effects of the disease for people living with RHD. Therefore, the burden of RHD comprises both epidemiologic metrics and social impact.

To support global, regional and national operational research, policy translation and disease control efforts, RhEACH (Rhëumatic heart disease. Education. Action. Communication. Hope) was launched in 2014. Established as a collaboration between Perth, Western Australia and Cape Town, and with a satellite office in Geneva, RhEACH is a technical support and policy translation initiative to amplify RHD control efforts locally, regionally, and globally (RhEACH, 2017). Key focus areas have included documenting disease burden, collating existing knowledge to inform policy briefs and actions, and maintaining an extensive RHD resource hub and online RHD Atlas. Recognising that there is now a greater need for knowledge transfer and practical support to countries, RhEACH is evolving to fill this gap. In 2018, RhEACH transitioned to a registered not-for-profit association (NPA) in Switzerland, under the name Reach. Headquartered in Geneva, with staff in Australia, South Africa and the United States, Reach aims to meet the increasing global demand among countries for technical guidance on RHD prevention and control.

In 2015, with support from the Medtronic Foundation through their Every Woman, Every Child commitment, RhEACH and WHF joined forces as founding partners of RHD Action, a global initiative that unites and empowers the RHD community. RHD Action shares technical advice, advocacy support, and policy insights with partners and allies across the world, working to create positive change and better health outcomes for people living with RHD and their communities. Two demonstration sites were also included in the RHD Action initiative, with work in Tanzania focusing on incorporation of RHD into maternal health services, and in Uganda to strengthen RHD prevention and control activities by working through the infrastructure that had been established for HIV/AIDs services.
In 2017 RHD Action released the RHD Priorities Pyramid, outlining an activity and stakeholder engagement framework towards global RHD control (RHD Action, 2017). To guide regional and national efforts, partner organisation WHF has developed a roadmap for local adaptation, to identify and address the underlying determinants of disease and potential local roadblocks at all levels of the health care and social systems (Palafox et al., 2017).

A fundamental first step in developing a regional or national Roadmap to end RHD is conducting a situational analysis to profile the local epidemiology and health system and policy environment – development of disease control programmes and tailoring preventive initiatives requires an understanding of who and how many people live with and die from RHD, why and where. A comprehensive Needs Assessment Tool has also been published with online resources including a user guide to aid conducting of comprehensive and focussed needs assessments (RHD Action, 2016b).

Towards a global resolution on rheumatic fever and rheumatic heart disease

In June 2017, the WHO’s Executive Board met in Geneva for the 141st session (EB 141). The Government of New Zealand led an effort to have a Resolution on RHD included in the agenda. Extensive discussion among Member States culminated in the 34 governments represented on the EB recommending a Resolution on RF and RHD be adopted by the World Health Assembly. In a momentous step for the global RHD community, the World Health Assembly passed this Resolution in May 2018, representing a unified intergovernmental pledge to action and global disease control (WHO, 2018).

Amongst a suite of multi-sectoral measures, the proposed Resolution text includes a call for commitment by Member States to support regular, consistent measurement of RHD burden, and for WHO Secretariat support to Member States in using these data, including where appropriate, in the design and implementation of disease control programmes (World Health Organization, 2017c). Burden of disease data are crucial to identify disease hotspots, focus efforts, track progress and measure impact. These data are also required to help set targets towards ending RHD – the ultimate measure of success of a disease control initiative is a reduction in disease burden.

Regional RHD action

In parallel with these global efforts, the imperative to address RHD has also been recognised in several geographic regions with large populations potentially at risk, and recent years have seen numerous declarations of commitment to action. From the Pacific Islands (Aderiano et al., 2006) to Drakensberg (Mayosi et al., 2006) to Mosi-O-Tunya (Mayosi, Gamra, Dangou, & Kasonde, 2014), Addis Ababa (Watkins, Zuhlke et al., 2016), Cairo (Yacoub, Mayosi, ElGuindy, Carpentier, & Yusuf, 2017) and beyond, the consistent messages in all of these expert-led calls to action highlight that there is now generally conceptual agreement on priorities and what needs to be done to tackle RHD.

From the Pacific Islands, a call to action was issued in 2006 and further endorsed by additional expert signatories in 2008 (Aderiano et al., 2006). Regional declarations have also been strong and recurrent from Africa. In 2005, the Drakensberg Declaration pledged to support establishment and implementation of the multi-tiered A.S.A.P programme: Awareness, Surveillance, Advocacy, Prevention (Mayosi et al., 2006; Robertson, Volmink, & Mayosi, 2006). In 2014, building on lessons learned and challenges encountered in translating the A.S.A.P. principles into integrated policies and practice, the Mosi-O-Tunya Call to Action comprised a multisectoral set of recommendations from primordial prevention through to tertiary management (Mayosi et al., 2014). In 2015, African Union heads of state endorsed the Addis Ababa communiqué, which outlines seven priority areas towards achieving RHD control across the African continent (Watkins, Zuhlke et al., 2016). In 2017 the Cairo Accord was issued, outlining ten recommendations to address immediate RHD clinical, systems and research priorities globally (Yacoub et al., 2017). Across geographic regions and over time, all these
Table 1. Summary of regional and global RHD-specific calls to action.

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<td>Raising the awareness of the public and health care workers with regard to RF and RHD</td>
<td>Incorporate RHD control as an essential element in national non-communicable disease strategies</td>
<td>Reduce poverty</td>
<td>Establish prospective RHD registers at sentinel sites in affected countries to measure disease burden and track progress towards the reduction of mortality by 25% by the year 2025</td>
<td>Enhance existing databases for better understanding of the epidemiology and natural history of the disease</td>
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<td>Improving the quality of information available on the incidence, prevalence and burden of RF/RHD through epidemiological surveillance</td>
<td>Undertake assessments of the disease burden and costs of RHD in all Pacific Island countries</td>
<td>Develop integrated national programmes</td>
<td>Ensure adequate supplies of high-quality benzathine penicillin for the primary and secondary prevention of RF/RHD.</td>
<td>Provision of high-quality penicillin to endemic areas and treatment of suspected streptococcal sore throats</td>
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<td>Working together as advocates to change public policy for the improvement of healthcare facilities needed to prevent and treat the disease</td>
<td>Advocate for, establish, maintain and evaluate programmes to ensure delivery of secondary prophylaxis, good clinical care (including surgical treatment) and, where possible, institution of primary prevention measures to reduce the burden of RHD</td>
<td>Lead collaborative efforts</td>
<td>Improve access to reproductive health services for women with RHD and other non-communicable diseases</td>
<td>Accelerate the development of regional centres of excellence, linked to larger networks</td>
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<tr>
<td>Working towards the establishment of national primary and secondary prevention programmes for RF and RHD</td>
<td>Establish networks to facilitate information sharing, collaboration and co-operation to improve RHD control in Pacific Island countries</td>
<td>Build health capacity</td>
<td>Decentralise technical expertise and technology for diagnosing and managing RF/RHD</td>
<td>Enhance and coordinate global efforts to produce an effective vaccine</td>
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<td>Promote research to answer critical questions in RHD control, including clarifying the potential role of echocardiography and other new technologies in developing countries, and the development of RF vaccines</td>
<td>Create centres of excellence where surveillance, research treatment, training, and laboratory services support the prevention, control, and treatment of RF/RHD.</td>
<td>Establish national and regional centres of excellence for essential cardiac surgery for the treatment of affected patients and training of cardiovascular practitioners of the future</td>
<td>Study the genetic profile of rheumatogenic streptococcal strains and susceptible individuals.</td>
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<td>Declare national awareness events</td>
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<td>Initiate national multi-sectoral RHD programmes within NCD control programmes of affected countries</td>
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<td>Educate teachers</td>
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<td>Foster international partnerships with multinational organisations for resource mobilisation, monitoring and</td>
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<td>Study the potential role of anti-inflammatory/immunosuppressive drugs, as well as optimal drug therapy for prophylaxis against</td>
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(Continued)
declarations recognise the key role of epidemiological data and robust information systems in the
fight to tackle RHD (Table 1). Where they exist, data have also informed the content and recommen-
dations of these expert calls. Data from the Heart of Soweto Study (Sliwa et al., 2010) provided an
estimated incidence of new cases of RHD for those aged >14 years in this urban region in South
Africa of 23.5 cases/100 000 per annum. Most were black African females in child-bearing age.
The Global Rheumatic Heart Disease Registry (REMEDY) study described baseline characteristics
of people with RHD across 12 African countries, India and Yemen and identi-
fied systems gaps in
the implementation of clinical interventions (Zuhlke et al., 2015). These
findings subsequently
formed the basis of the Addis Ababa communiqué recommendations.

In addition to these expert consensus statements, there is also high-level recognition of the need
for action on RHD in other geographic regions with persistently high burden. For example, in the
Eastern Mediterranean, RHD is an ongoing health issue in some countries (Ba-Saddik et al., 2011;
El-Aroussy et al., 2013; Rizvi et al., 2004). In 2016, the WHO’s outgoing Regional Director Dr
Ala Alwan suggested that an assessment of the situation in the region was needed to identify the
magnitude and characteristics of the problem (World Health Organization Regional Office for the
Eastern Mediterranean, 2016), and with the passing of the resolution the WHO Regional Office of
the Eastern Mediterranean, in partnership with Reach and the World Heart Federation, is taking
steps towards the development of a Regional Framework for Action on RHD.

Table 1. Continued.

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<tr>
<td>Drakensberg</td>
<td>Evaluation of the programme to end RHD in Africa.</td>
<td>Thromboembolism and management of heart failure</td>
<td>Thromboembolism and management of heart failure</td>
<td>Thromboembolism and management of heart failure</td>
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<td>Drakensberg</td>
<td>Utilise champions</td>
<td>Maximise the use of valve repair procedures and dedicated training programmes</td>
<td>Maximise the use of valve repair procedures and dedicated training programmes</td>
<td>Maximise the use of valve repair procedures and dedicated training programmes</td>
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<td>Drakensberg</td>
<td>Implement surveillance</td>
<td>Accelerate efforts to develop tissue-engineered valve substitutes and affordable transcatheter valves that are easy to implant</td>
<td>Accelerate efforts to develop tissue-engineered valve substitutes and affordable transcatheter valves that are easy to implant</td>
<td>Accelerate efforts to develop tissue-engineered valve substitutes and affordable transcatheter valves that are easy to implant</td>
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<tr>
<td>Drakensberg</td>
<td>Support research</td>
<td>Echocardiographic screening programmes should be confined to research</td>
<td>Echocardiographic screening programmes should be confined to research</td>
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SOURCE/NOTES: RF rheumatic fever; RHD rheumatic heart disease.
The Americas have also seen significant activity in ARF/RHD prevention and control. Several of the earliest examples of dedicated national RHD control programmes achieving success in reducing disease burden emerged from Latin America and the Caribbean, such as those in Cuba (Nordet, Lopez, Duenas, & Sarmiento, 2008), Costa Rica (Arguedas & Mohs, 1992) and the French Caribbean (Bach et al., 1996). In South America, screening studies have recently been implemented in Peru (Spitzer et al., 2015) and Nicaragua (Paar et al., 2010), and a large-scale screening programme employing telemedicine approaches established in Brazil (Nascimento et al., 2018).

**RHD and the broader global health policy landscape**

RHD is a development issue. As a disease of poverty and inequity, with multisectoral determinants, a disproportionate impact on young people and elevated risks for women of reproductive age, RHD cuts across several of the Sustainable Development Goals (SDGs). These include SDGs 1 (no poverty), 3 (good health and wellbeing), 5 (gender equality), 10 (reduced inequalities) and 11 (sustainable cities and communities). There is a comprehensive set of agreed indicators to track progress towards the SDGs and the universal objective of leaving no one behind. Efforts to tackle RHD are directly linked with implementation and monitoring of the SDG agenda.

**RHD and universal health coverage**

Universal health coverage (UHC) refers to the ability of all citizens to access affordable and quality health care. Integral to SDG 3, WHO has recently reaffirmed its commitment to strengthening health systems and achieving UHC as an operational priority (Ghebreyesus, 2017). UHC and RHD are inextricably entangled – the populations at greatest risk of RHD are also those that typically have least access to health services. In endemic settings, integrating RHD into a universal health care package is a humanitarian imperative (RHD Action, 2015). Understanding local burden, local populations at greatest risk, and local contextual issues will aid in selection of appropriate RHD interventions for inclusion in a universal healthcare package. For this disease, which disproportionately impacts the young, a healthcare system geared towards population inclusivity and financial protection is fundamental to equitable and sustainable development. Experience has demonstrated that a strong community-based approach that focuses on supporting access to quality primary care, education and reliable access to treatment can achieve substantial reductions in disease burden (Arguedas & Mohs, 1992).

**RHD and access to essential medicines**

The injectable antibiotic benzathine penicillin G (BPG) is the mainstay of RHD prevention, which can be broadly considered as having four levels. Primordial prevention seeks to prevent Group A streptococcal infections that can lead to RF, and focuses on addressing overcrowding, poverty and the social determinants of health; primary prevention involves prompt treatment of streptococcal pharyngitis with BPG to avoid development of RF; secondary prevention requires monthly BPG administration to prevent further Group A streptococcal infections following an initial RF episode, prevent RF recurrence and avert progression to RHD; and tertiary prevention seeks to control and manage RHD symptoms once there is established disease (Palafox et al., 2017).

Primary and secondary prevention initiatives underpin RHD control efforts in endemic settings, and effective delivery of these prevention programmes requires a sufficient and regular supply of penicillin. BPG has been on the WHO’s Essential Medicines list since its inception in 1977. Essential Medicines are those that are required to meet the priority health needs of a population (World Health Organization, 2017a). Placement of a drug on the Essential Medicines list is intended to
ensure that governments prioritise availability of sufficient supplies in the correct doses and quality and at an affordable price. Recent years have seen widespread penicillin shortages (RHD Action, 2016a; Wyber, Taubert, Marko, & Kaplan, 2013). In the three year period to 2017, at least 18 countries have reported insufficient BPG supplies (Guimaraes, 2017). The drivers of stockouts are complex, variously ascribed to supply side dynamics (paucity of pharmaceutical manufacturers for the product with low profit margins) and demand barriers (with unpredictable prescribing and procurement processes) (Guimaraes, 2017).

In the context of functioning health systems, demand for BPG is driven by disease burden and the size of populations in need. Accurately understanding the global burden of RHD is therefore crucial to ensure sufficient supply of BPG and equitable access to and distribution of this essential medicine. Data are needed to inform these policy and pharmaceutical sector dialogues.

**RHD and access to appropriate medical, interventional and surgical care**

Despite high prevalence of RHD in adults in low and middle income countries, access to appropriate cardiovascular medication managing arrhythmia, heart failure, anti-coagulation and access to cardiothoracic surgery, is still essentially absent or insufficiently offered in these regions.

RHD in women is an important contributor to late maternal death (Sliwa & Anthony, 2016). In a recently published Confidential Enquiry into Maternal Deaths in South Africa (Soma-Pillay, Seabe, Soma-Pillay, Seabe, & Sliwa, 2016), complications of RHD contributed to 25.3% of cardiovascular pathology contributing to maternal death in the standard period of reporting (42 days postpartum). There is clearly a need to improve health care services for people living with RHD and a need for a coordination of global initiatives within the cardiac surgical community addressing this gap in appropriate care.

**RHD and the migrant health agenda**

Protecting and promoting the health and wellbeing of migrants is high on the agenda of the WHO and many intergovernmental and civil society organisations. In 2017, the World Health Assembly endorsed a Resolution on Promoting the Health of Refugees and Migrants. The various priorities identified in the Resolution include strengthening of health monitoring and health information systems (World Health Organization, 2017b).

In the globalisation era, and in the context of several major protracted conflicts and natural disasters resulting in mass population displacement, RHD must be considered in the migrant and refugee health agenda. Poor living conditions, overcrowding and limited access to care render many displaced populations at high risk of RHD and threaten to generate a tsunami of new cases, as was seen in Central Asia with the economic decline that followed collapse of the Soviet Union (Omurzakova et al., 2009). The risk of a burgeoning number of new cases is in addition to those with pre-existing but undiagnosed and unmanaged disease. It is estimated that approximately 10,000 of the over one million asylum seekers who arrived in Europe in 2015 could be expected to have clinical or subclinical RHD (Rossi & Lee, 2016). A Médecins Sans Frontières screening programme of refugees in Rome, Italy has reported 2.1% prevalence of subclinical definite RHD (95% CI 0.7-5.2) (De Maio et al., 2016).

On a population level, understanding disease burden among displaced populations and instigating appropriate preventive and therapeutic interventions is a humanitarian imperative, and there are urgent calls to assess the burden of RHD among refugee children (Rossi & Lee, 2016). At the individual level, ensuring that refugees are promptly integrated into health systems and have affordable access to quality care is an issue of human rights. There is also a strong economic argument for preventive action, given both the need for prolonged engagement with health services for effective secondary prevention and management of established disease, and given lost economic productivity from a disease that cuts young people down in their prime.
Data needed to inform policy dialogues

From former WHO Director-General Margaret Chan’s acknowledgement of the need to improve health data for better decision making and to close the data gaps (Chan, 2012), to the World Heart Federation’s recent Global Policy statement for improved monitoring and surveillance of cardiovascular disease (World Heart Federation, 2016), calls for improved health data to drive systems action are not new.

In the case of RHD, which has seen a marked decline in some settings but persistence among disadvantaged and vulnerable populations, serially and consistently mapping the burden of disease is crucial. There are considerable data gaps in many geographic settings (Abouzeid et al., 2017; Watkins et al., 2017). Modelling studies provide useful approximations of disease burden for data-poor countries, but they are subject to limitations and uncertainties inherent in any statistical exercise. Primary data deficits hinder accurate assessment of the true contemporary magnitude and distribution of this disease. This is compounded by the fact that the same socioeconomically deprived settings with the greatest risk of RHD are also those likely to have poorly developed health information infrastructures. Crucially, data are needed at a geographically granular level. In the absence of sub-national information, national data may obscure high-risk areas or population groups. For example, from India an apparent reduction in RHD has been reported in some studies (Nair et al., 2015) largely from the economically developing west, but the disease continues to impact large populations elsewhere across the country (Saxena et al., 2017), including in more socioeconomically deprived pockets. Subnational variation also exists in non-endemic, low burden settings – in the United States, RHD mortality varies between counties, with a hotspot belt evident in the South (Roth et al., 2017). Data deficits risk masking geographic pockets requiring focused operational efforts, with consequent policy and programmatic inertia.

Data on the cost-effectiveness of ARF/RHD prevention and control are also insufficient to provide robust advice to governments. A growing body of work is generating insights, for example exploring the cost of echo screening programmes and developing models to estimate the impact and cost of different interventions. (Roberts et al., 2017; Watkins, Lubinga, Mayosi, & Babigumira, 2016) Similarly, Watkins and colleagues reported a cost effectiveness analysis of the Cuban ARF/RHD control programme that was implemented in the 1980s. (Watkins, Mvundura, Nordet, & Mayosi, 2015) Notwithstanding, a broader base of evidence is required, particularly to guide discussion and decision-making among policymakers around prioritisation of ARF/RHD in plans and programmes.

Knowledge gaps also exist in some critical clinical domains. The clinical significance and appropriate treatment of borderline RHD diagnosed on echocardiographic screening remains uncertain. Some recent studies have addressed this important issue and others are planned to explore the effect of secondary prophylaxis in this scenario (Bertaina et al., 2017).

As the adage goes, what gets measured gets acted on. From several country settings, there are powerful examples of the importance of data in informing policy dialogues and catalysing action. For example, screening projects and intense active case finding efforts in Fiji and Samoa demonstrated high disease burden and ultimately precipitated establishment of national control programmes as part of the Pacific Rheumatic Heart Disease Control Program. Burden of disease data have also been used to drive policy and programmatic action in various settings including parts of Cuba (Nordet et al., 2008), New Zealand (Ministry of Health New Zealand, 2017) and Tunisia (Yusuf, Narula, & Gamra, 2017). Not measuring means not knowing, so it is crucial that disease burden is documented in endemic and high-risk settings.

A suite of data collection tools and guides exist. For example, RHD Action have developed a Needs Assessment Tool, comprising a range of data collection instruments to understand the state of care for Group A streptococcal infections, RF and RHD and inform development of disease control programmes within a defined geographic setting (RHD Action, 2016b). A TIPS Handbook (Tools for Implementing RHD control Programmes) also provides resources to inform and guide development of contextually relevant action; this includes an overview of systems issues, data sources...
and approaches that can be used to document RHD burden (Wyber et al., 2014). The launch of RHD Action brings the research and policy support infrastructure required to co-ordinate efforts, help fill data gaps and build in-country research and operational capacity.

Recognising the inherent difficulties in measuring RHD in some settings, the processes and outcomes of improving RHD data could also serve as a template for other conditions and generate improvements in data systems more broadly.

In addition to documenting disease burden, data are also necessary to measure progress against what the expert consensus indicates should be being done – despite repeated calls for implementation of a similar suite of recommendations, there are no sustainable and systematic means to comprehensively track activity and measure progress. A sector-supported set of RHD indicators could usefully monitor activity, identify gaps and needs, and ensure that policy efforts to tackle RHD do not stagnate in an action plan – accord – resolution stage, but rather translate into implementation and ultimately, population health gains.

**Conclusion**

Regionally and globally, there have been numerous calls for concerted action on RHD. All describe a similar suite of measures, adapted to local context, necessary to drive systems change. What is needed now is a move from rhetoric to metric: data are needed to inform decisions about the need for and types of policy and programmatic responses required in a given setting, and to gauge impact.

In implementing the global resolution on RHD, governments, researchers, international development and clinical communities must enhance efforts to document the burden of RHD and systems activity in their local contexts. Data are fundamental to ensure that the current global momentum for RHD control leads to substantive change. The lives of some of the world’s most vulnerable are at stake.

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**References**


