Rheumatic Heart Disease☆

Tools for Implementing Programmes

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The World Health Organization (WHO) has recommended register-based control programs for monitoring and management of rheumatic heart disease (RHD) from the early 1970s [1]. RHD control programs were once widespread throughout the United States and a cornerstone of global efforts to reduce the burden of the disease [2,3]. Guidelines for developing and delivering these programs were produced by a range of organizations and implementation reports were collated by WHO for a number of years [4,5].

Economic development, reduction in overcrowding, and access to health care in the 20th century dramatically reduced the incidence of RHD. Fewer group A streptococcal infections precipitated the abnormal autoimmune sequelae of rheumatic fever and subsequent RHD. The dramatic decline in rheumatic fever and RHD in high-resource settings paralleled reduced attention to the components and delivery of comprehensive RHD control programs. Yet the burden of RHD continues unabated in developing countries, which are home to 80% of people living with RHD and dying of its complications. A renewed focus on service delivery and implementation science is critical for delivering effective approaches to disease control in these settings [6].

The Tools for Implementing Programmes (TIPS) project reverses the neglect of implementation science in RHD control and provides a renewed focus on evidence-based interventions. A collaboration between the World Heart Federation and Rheumatic Heart Disease—Evidence, Advocacy, Communication, Hope (RhEACH), the TIPs project has collated 60 years of RHD control program implementation experience into a single resource. TIPs is structured around a stepwise, priority-based, conceptual framework for RHD control providing program managers and policy makers a structure for describing, planning, implementing, and evaluating interventions. The structure is not intended to be prescriptive, nor will every domain be a relevant priority in every setting. However, a comprehensive framework is important for visualizing the breadth of activities in RHD control, spanning from primordial prevention to tertiary interventions.

The content of TIPs is derived from peer-reviewed sources, "gray" literature and key informant interviews. Key themes and implementation challenges are illustrated by 8 case studies from Tonga, Nepal, Ethiopia, Egypt, and Rwanda. A synthesis of evidence and experience in RHD control highlighted common themes: the importance of burden of disease data; community education; government engagement; and health worker education. The process of compiling existing research and implementation experience also illustrated the paucity of best-practice recommendations across a number of important domains. For example, there is no standardized nomenclature to categorize people enrolled in RHD registers, no guidance on integration of RHD control into the wider health system, no system for estimating the burden of disease from routinely collected data. Many important practical lessons for engaging governments, educating communities, and supporting adherence to secondary prophylaxis remain unrecorded. Focused attention on collecting implementation data and experience is needed and should be prioritized through RHD hubs and centers of excellence [7]. In the interim, TIPs provides a "menu of options" outlining a range of possible approaches and decisions needed in the process of program development and delivery.

TIPs was launched at the World Congress of Cardiology in Melbourne on May 7, 2014. The launch event was well attended by a broad cross section of the RHD community and generated invaluable discussion about opportunities to optimize TIPs. A number of complementary resources were suggested to support dissemination, including single-page summaries for specific audiences and slide decks for regional presentations. There was a clear demand for further development of the "tools" component of TIPs, including the collation of sample resources and development of the Programme Assessment Annex into evaluation framework for RHD control programs. These recommendations are being actioned; resources are being collated or developed to be embedded into the TIPs website for download and local adaptation. Resources are expected to include samples of prophylaxis record cards, community education resources, register enrolment forms, and assessment records. A large number of attendees at the launch commented on the need for global clinical guidelines for the management of group A streptococcal, rheumatic fever, and RHD. Although clinical consensus is outside the remit of TIPs, there is strong demand for clinical bodies to provide comprehensive guidance on therapeutic interventions.

The development of TIPs has been a valuable opportunity to describe and define the components of comprehensive RHD control programs. The process has identified the relative scarcity of implementation experience data; new efforts to understand service delivery in RHD and define best practice are urgently needed. Clinicians and researchers in low-resource settings have a powerful

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opportunity to foster work in this field and the resurgence of interest in global RHD control shows tremendous promise [8]. Engaging new stakeholders is equally important; the content of TIPs should be enriched by the perspectives of governments, private partners, other disease communities, and people living with RHD. TIPs provides a framework and a foundation for these groups to coalesce and share practical steps toward disease control; this process is essential to a achieve the global goal of reducing the mortality of RHD in people under 25 years of age by 25% by 2025 [7].

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