RHD Action

*United to End Rheumatic Heart Disease*

# Needs Assessment Tool

2016

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1 SITUATIONAL ASSESSMENT
2 FACILITY-BASED ASSESSMENT
3 UNDERSTANDING THE PATIENT AND PROVIDER EXPERIENCE
4 PLANNING THE INTERVENTION

# Needs Assessment Tool

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# CONTENTS



# FIGURES

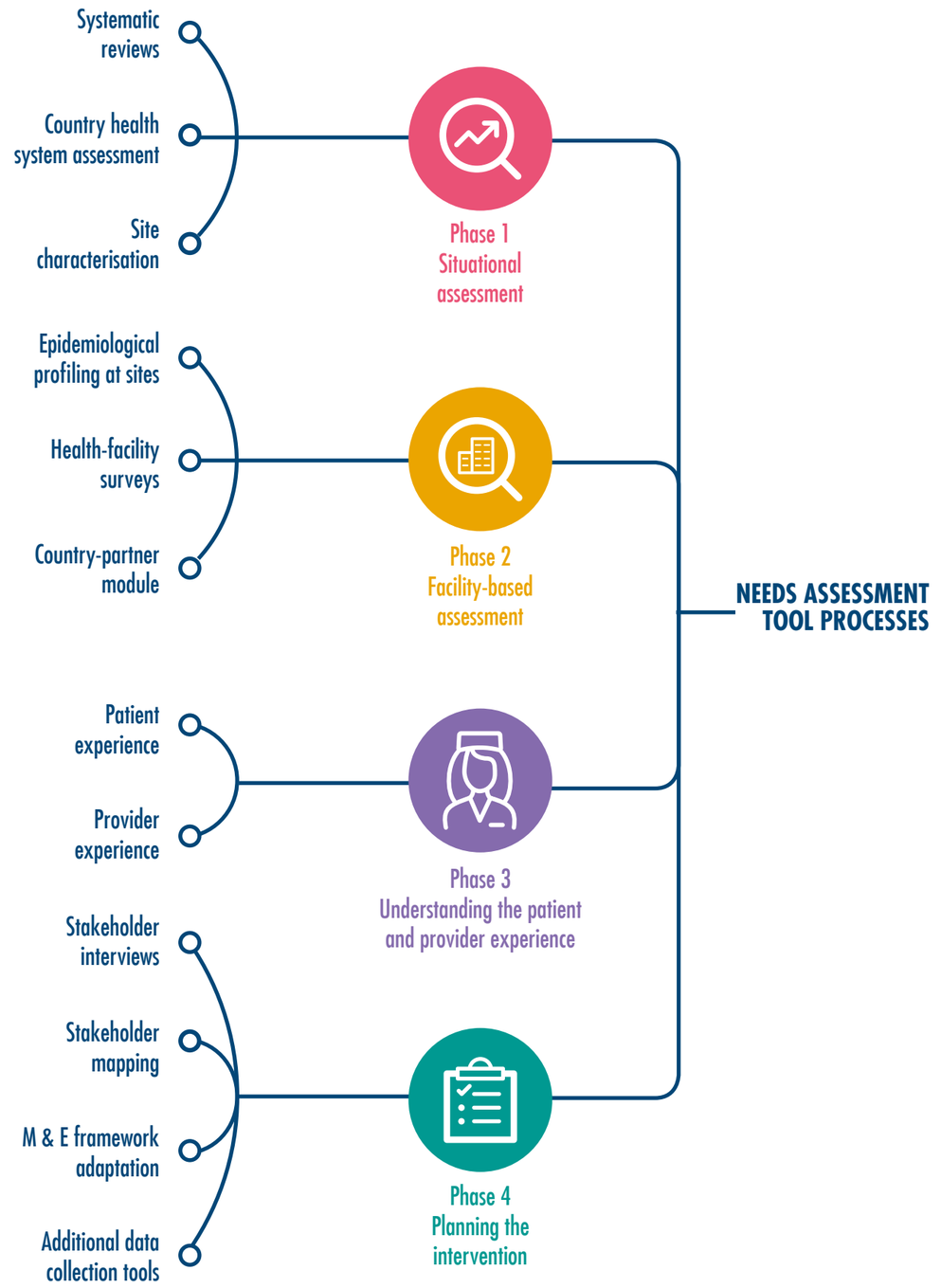
# HOW TO NAVIGATE THIS DOCUMENT?

**FORM 1.1** Systematic Review Protocol
**FORM 1.2** Health system assessment
**FORM 1.3** Suggested key informants/stakeholders
**FORM 1.4** Topic guides and interview schedules
**FORM 1.5** Existing data review

**FORM 2.1** Primary Care Sore Throat/ARF Cover Sheet
**FORM 2.2** Primary Care Sore Throat
**FORM 2.3** Primary Care ARF
**FORM 2.4** Secondary/Tertiary Facility Cover Sheet
**FORM 2.5** Secondary/Tertiary Facility ARF/RHD
**FORM 2.6** Secondary/Tertiary Facility Patient Health Services Utilisation
**FORM 2.7** Pregnancy
**FORM 2.8** Primary Care Facility Survey
**FORM 2.9** Independent Dispensary Facility Survey
**FORM 2.10** Secondary/Tertiary Facility Survey
**FORM 2.11** Interview Guide for Country Partner

**FORM 3.1** Sore Throat Patient Interview Schedule
**FORM 3.2** ARF Adult Patient Interview Schedule
**FORM 3.3** ARF Child Patient Interview Schedule
**FORM 3.4** RHD Child Patient Interview Schedule
**FORM 3.5** RHD Adult Patient Interview Schedule
**FORM 3.6** Health Care Provider Interview Schedule

**FORM 4.1** Stakeholder identification, interviews, and mapping
**FORM 4.2** Tool for Quantifying Needs and Setting Targets
**FORM 4.3** Intervention Monitoring & Evaluation Worksheet
**FORM 4.4** Summary Work Plan: Monitoring & Evaluation



# ABBREVIATIONS AND ACRONYMS

| | |
|---|---|
| ARF | Acute rheumatic fever |
| ASAP | Awareness Surveillance Advocacy Prevention |
| AU | African Union |
| BPG | Benzathine penicillin G |
| CF | Conceptual framework |
| CoC | Continuum of Care |
| CRF | Case report forms |
| FGD | Focus group discussions |
| GAS | Group A streptococcus |
| GAP | Global Action Plan |
| GBD | Global Burden of Disease |
| HSPA | Health systems performance appraisal |
| HIV | Human Immunodeficiency Virus |
| IDI | In-depth interviews |
| IHD | Ischemic Heart Disease |
| IHME | Institute for Health Metrics and Evaluation |
| LIC | Low-income country |
| LMIC | Lower-middle income country |
| M&E | Monitoring and evaluation |
| MCM | Multi Criteria Mapping |
| PASCAR | Pan-African Society of Cardiology |
| REMEDY | Global Rheumatic Heart Disease registry study |
| REA | Rapid ethnographic assessment |
| RhEACH | Rheumatic heart disease Education Advocacy Communication Hope |
| RHDA | Rheumatic Heart Disease Action |
| RHD | Rheumatic heart disease |
| RRA | Rapid Rural Appraisal |
| SAT | System assessment tool |
| ST | Sore Throat |
| TIPS | Tools for Implementing rheumatic heart disease control Programmes |
| WHF | World Heart Federation |
| WHO | World Health Organisation |

# DEFINITIONS OF KEY TERMS

### Asymptomatic RHD:
synonymous with "latent" RHD, this term refers to signs of abnormal heart valve structure or function in the absence of a history of proven ARF, symptoms or sequelae. Recent literature has frequently characterised asymptomatic RHD using echocardiography, e.g., in the context of a screening programme or RHD prevalence study.

### Forefront (healthcare worker):
refers to those individuals who are the first point of contact for a healthcare encounter. This will vary based on acute vs. chronic and inpatient vs. outpatient care. For instance, a community health worker or school nurse may be the forefront worker for outpatient sore throat care, whereas a cardiac surgeon may be the forefront worker for the care of advanced, decompensated RHD among inpatients.

### Global Action Plan:
To strengthen national efforts to address the burden of NCDs, the 66th World Health Assembly in 2013 endorsed the WHO Global Action Plan for the Prevention and Control of NCDs 2013-2020 (resolution WHA66.10). The global action plan offers a paradigm shift by providing a roadmap and a menu of policy options for Member States, WHO, other UN bodies and intergovernmental organisations, NGOs and the private sector, which, when implemented collectively between 2013 and 2020, will work towards 9 voluntary global targets, including that of a 25% relative reduction in premature mortality from NCDs by 2025.

### Primary prevention:
synonymous with "primary prophylaxis", this term refers to antibiotic treatment of acute streptococcal infection. The intention is to cure an acute episode and prevent rheumatic fever and consequently rheumatic heart disease in the first place.

### Rapid Ethnographic Assessment (REA):
This tool collects locally relevant data using qualitative methods to provide a rich understanding of social, economic, and policy factors that contribute to the root causes of poor health outcomes.

### Secondary prevention:
synonymous with "secondary prophylaxis", this term refers to the regular use of antibiotics by persons who have a history of rheumatic fever or rheumatic heart disease. The intention is to reduce carriage of the streptococcus in the throat, which prevents further attacks of rheumatic fever and worsening severity of rheumatic heart disease.

### Symptomatic RHD:
synonymous with "clinical" or "active" RHD, this term refers to typical symptoms of the condition (e.g., shortness of breath) in the presence of objective evidence of rheumatic heart valve changes and/or sequelae of RHD (e.g., stroke or heart failure).

### Rapid Rural Appraisal (RRA):
RRA provides an alternative technique for outsiders to learn quickly from local people about the realities and challenges faced in their local settings. The approach aims to incorporate the knowledge and opinions of local people, particularly in resource-poor or rural settings, in the planning and management of development projects and programme. It uses multi-disciplinary teams and a suite of visual methods and semi-structured interviews to learn from respondents.

RHD Action is the name given to the global movement to reduce the burden of RHD in vulnerable populations throughout the world. Building on commitments of the World Heart Organisation (WHO) and the World Heart Federation (WHF), the movement strives to reduce premature mortality from RHD by 25% by the year 2025 in people under 25 years of age (25x25x25).

The RHD Action Countries are a cohort of countries that have committed to achieving specific RHD targets within their geographies, while also strengthening their health systems. Strategies and tactics on the ground vary amongst countries and are dependent on existing resources and infrastructure. Aligned with national health care plans these country projects contribute to the global hub of knowledge about best practices to tackle RHD. The inaugural RHD Action Countries include Tanzania and Uganda.

### Roadmap:
In this context, the term "roadmap" refers to a policy document that is a high-level guide for reducing the burden of cardiovascular disease. Roadmaps translate existing knowledge of best practices, barriers, and solutions into practical strategies for improved cardiovascular health in these priority areas. With regards to ARF and RHD, there are currently two roadmaps:

1. The World Heart Federation has produced guides for hypertension, tobacco control, secondary prevention of ischemic heart disease, and most recently, ARF/RHD. This roadmap identifies challenges and solutions around ARF and RHD that are common across endemic regions.
2. The African Union Commission adopted a roadmap for the eradication of rheumatic heart disease in Africa during their Heads of State and Government Summit in June 2015. This resolution was developed during a consultation with the Pan-African Society of Cardiology and identifies specific challenges and solutions around ARF and RHD in Africa.

Collectively, roadmaps can serve as models, as countries meet their commitments to implement, develop, or update national non-communicable disease plans, using the framework provided by the World Health Organisation's Global Action Plan 2013-2020 (GAP).

### Sites:
refers to a defined geographical and/or political zone that is the direct target of the intended ARF/RHD intervention or programme. In most cases, the site will be a political district that is home to a population of several hundred thousand people and is served by a district hospital and several lower-level primary health care centers, dispensaries, and other health facilities.

### Tools for Implementing RHD Programmes (TIPS):
TIPS is a technical manual that was designed as an evidence-based framework for describing, prioritising, and implementing comprehensive ARF/RHD control programmes. The TIPS Conceptual Framework tracks the health system factors relevant to such programmes. Hence it forms the basis for the health facility assessment in this Needs Assessment Tool, and it can also serve as a checklist for tracking the performance of health systems in caring for and meeting the needs of people with ARF/RHD.

# INTRODUCTION AND OBJECTIVES OF THE NEEDS ASSESSMENT TOOL

## OBJECTIVE AND USES OF THIS DOCUMENT

This document outlines the processes and tools recommended in order to conduct a comprehensive needs assessment in local communities in countries where ARF and RHD are endemic. The motivation for a needs assessment in this case is the development of targeted interventions to prevent and control ARF and RHD. It utilises scientifically validated methods and is designed as a tool for public health practice. It provides technical guidance based on the experience of ARF/RHD programmes in resource-limited settings and the best level of evidence, and it focuses on the key data required for developing and monitoring ARF/RHD interventions.

However, it must be emphasised that the NAT requires adaptation to local circumstances and resources. Likewise, data collection tools should be contextualised within each setting. Furthermore, attempting to apply these instruments in different socio-cultural and ethnographic settings would require careful planning, community participation and additional refinement during implementation. The instruments suggested here serve as a foundation but must be implemented with guidance from practitioners with local expertise.

## RHEUMATIC HEART DISEASE

Rheumatic heart disease (RHD) is a chronic inflammatory disease of the valves of the heart resulting from Group A streptococcal (GAS) sore throat (i.e., "strep throat" or "pharyngitis") that has gone partially or completely untreated. The streptococcus infection stimulates an abnormal response from the immune system of infected children, which manifests as acute rheumatic fever (ARF). Recurrent and severe episodes of ARF predispose a child to RHD. Three to five percent of young people with untreated streptococcal pharyngitis develop ARF, and only a subset of those go on to develop permanent heart valve damage. RHD remains the most common cause of acquired heart disease in children and young adults globally.[1]

The most important risk factor for ARF is proximity to other people with GAS infection and colonisation. Hence, overcrowded living conditions with inadequate sanitation, such as is seen in poor urban areas, create high-risk areas. Other correlates of poverty have also been reported as ARF/RHD risk factors, e.g., inadequate nutrition, low educational attainment, and unemployment. ARF and RHD are therefore regarded as diseases of poverty.[2]

Typically, RHD becomes symptomatic during adolescence, with some people developing clinical disease between 5 and 50 years. The most common symptom is progressive shortness of breath. Studies have shown that RHD is more common in women,[3] with pregnancy being a stressful period for the heart. Unfortunately, this clinical period often arises after a long symptom-free interval – in some cases, a decade or more. This latent period creates unique barriers to screening and prevention, since affected individuals are otherwise young and often healthy, providing few opportunistic contacts with medical care and early detection. In addition, 50% of patients with a new diagnosis of RHD do not recall a history of ARF. As a result, many individuals with RHD first present to care following heart failure or with complications such as stroke (due to atrial fibrillation) or heart valve infection ("endocarditis").[4]

There is clear evidence that the burden of RHD is high in developing countries and in indigenous and marginalised communities within some high-income countries.[5] A recent review[6] argues that it would be more accurate to describe the disease burden with greater subtlety than simply as the "prevalence of RHD"; thus, the disease burden should account for the classic pharyngitis-ARF-RHD paradigm, alongside advances in scientific understanding and public health implications.[7] Such a model includes an assessment of RHD burden in two categories: 1) asymptomatic, subclinical, or latent disease, often detected upon screening, and 2) symptomatic disease or active disease, often presenting to medical care. The distinction between these two forms of RHD is critical in assessing the local burden of RHD and tailoring priorities for prevention and control.

Studies have demonstrated that penicillin treatment of streptococcal infection can reduce a subsequent episode of ARF by about 80%.[8] Furthermore, among individuals with a documented history of ARF, regular preventive (prophylactic) treatment with injectable benzathine penicillin G (BPG) can reduce the risk of recurrent ARF and RHD.[9] For individuals who already have RHD, there are a variety of open-heart surgical and heart catheter-based approaches for repair, replacement, or palliation of damaged valves. However, access to these interventions at primary, secondary, and tertiary care centers in low-resource settings globally is limited.[10] Determinants of access include limited community awareness, a lack of health literacy and health-seeking behavior ("demand"), and a lack of available, affordable, and acceptable treatment options ("supply") within a public health and policy environment that does not adequately address RHD ("context").

[1] Marijon E, Mirabel M, Celermajer DS, Jouven X. Rheumatic heart disease. *Lancet* 2012; **379**(9819): 953-64.
[2] Robertson KA, Mayosi BM. Rheumatic heart disease: social and economic dimensions. *South African medical journal = Suid-Afrikaanse tydskrif vir geneeskunde* 2008; **98**(10): 780-1.
[3] Diao M, Kane A, Ndiaye MB, et al. Pregnancy in women with heart disease in sub-Saharan Africa. *Arch Cardiovasc Dis* 2011; **104**(6-7): 370-4
[4] Sliwa K, Carrington M, Mayosi BM, Zigiriadis E, Mvungi R, Stewart S. Incidence and characteristics of newly diagnosed rheumatic heart disease in urban African adults: insights from the heart of Soweto study. Eur Heart J 2010; 31(6): 719-27.
[5] Acute rheumatic fever and rheumatic heart disease in indigenous populations. *Pediatr Clin North Am* 2009; **56**(6): 1401-19
[6] Zuhlke LJ, Steer AC. Estimates of the global burden of rheumatic heart disease. *Glob Heart* 2013; **8**(3): 189-95.
[7] Carapetis JR. Rheumatic heart disease in developing countries. *N Engl J Med* 2007; **357**(5): 439-41, 13.
[8] Robertson KA, Volmink JA, Mayosi BM. Antibiotics for the primary prevention of acute rheumatic fever: a meta-analysis. *BMC cardiovascular disorders* 2005; **5**(1): 11.
[9] Manyemba J, Mayosi BM. Penicillin for secondary prevention of rheumatic fever. Cochrane Database Syst Rev 2002; (3): CD002227.
[10] Zuhlke L, Engel ME, Karthikeyan G, et al. Characteristics, complications, and gaps in evidence-based interventions in rheumatic heart disease: the Global Rheumatic Heart Disease Registry (the REMEDY study). *European heart journal* 2015; **36**(18): 1115-22a.



## PHASES OF A COUNTRY CONTROL PROGRAMME

To date, many ARF/RHD programmes have been introduced in demonstration sites and thereafter rolled out to a larger population. A phased introduction provides an opportunity to optimise control strategies without the financial and human investment necessary to provide countrywide services.[11]

Identification of a suitable demonstration site should begin with a needs assessment approach. This needs assessment process begins with the characterisation of one or more candidate sites,[12] in which the programme can be developed and evaluated. A Site Characterisation tool is recommended as a preliminary step in order to provide key information on health status, knowledge, attitudes and behaviors in a cost-effective, timely and reliable way. This information can then be used to customise interventions according to the needs and circumstance of the communities involved.

Once a site has been decided upon, the next phase is a comprehensive needs assessment using the additional tools contained within this document. The needs assessment tool (NAT) would inform the development of the programme and would thus serve as a baseline for the monitoring and evaluation of the programme (Figure 1). Following the implementation of the intervention, we suggest that an impact assessment should be done, which would include outcomes-based monitoring and assessment as well as a health systems performance appraisal.

**FIGURE 1**
PHASES FOR COUNTRY PROGRAMMES


## A FRAMEWORK FOR EVALUATING ARF/RHD NEEDS

RHD country programmes can draw on the Medtronic Foundation Continuum of Care Framework for Health Systems (CoC©) as a conceptual framework for assessing needs relating to ARF and RHD. The CoC© as applied to ARF/RHD (Figure 2) traces a typical patient through the care process.

[11] WHO. Rheumatic fever and rheumatic heart disease. Technical Report Series No. 923. Geneva: World Health Organisation; 2004.
[12] See "Definitions of Key Terms" above.

**FIGURE 2**
MEDTRONIC CONTINUUM OF CARE © FRAMEWORK AS APPLIED TO ARF/RHD

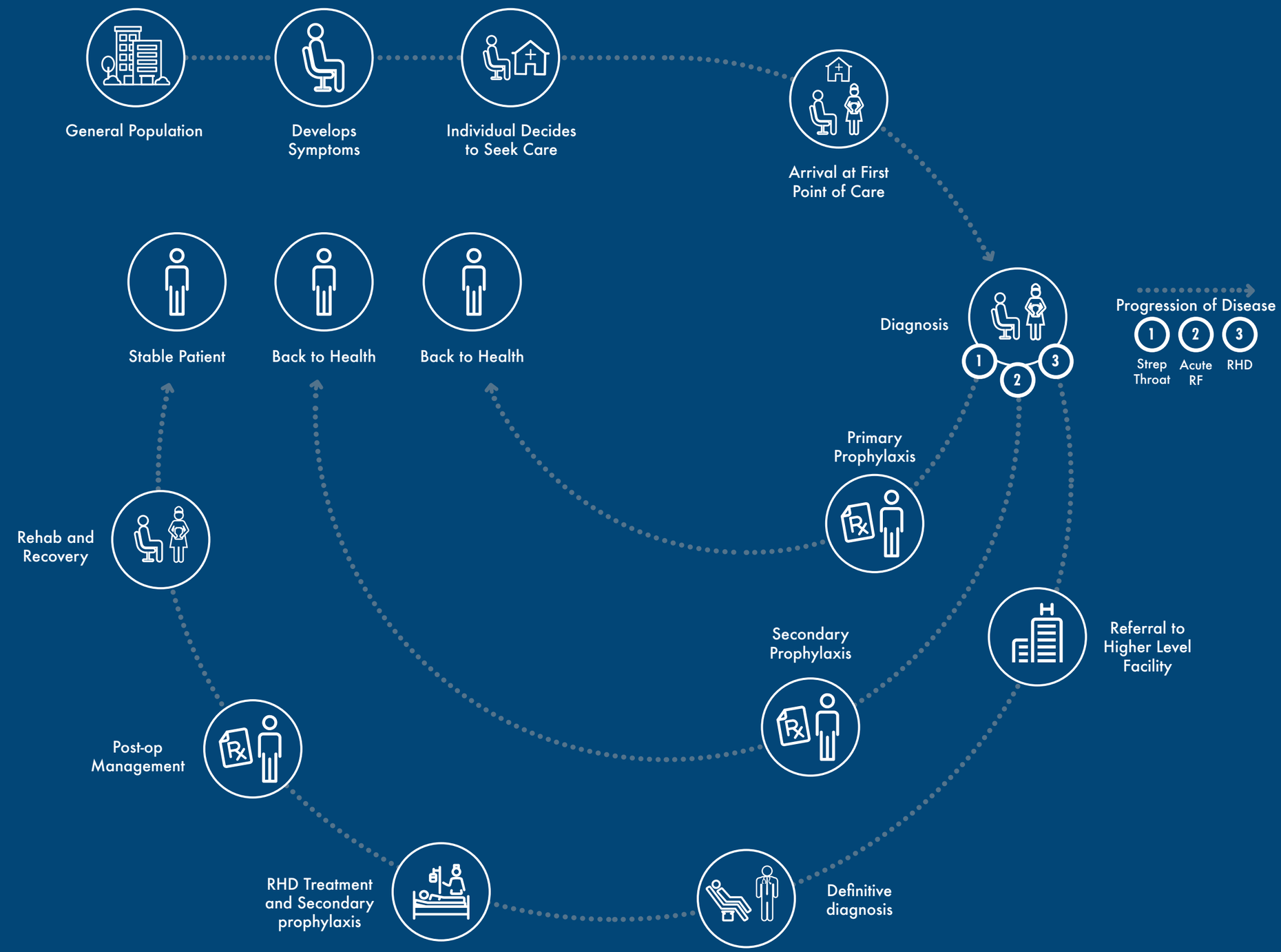
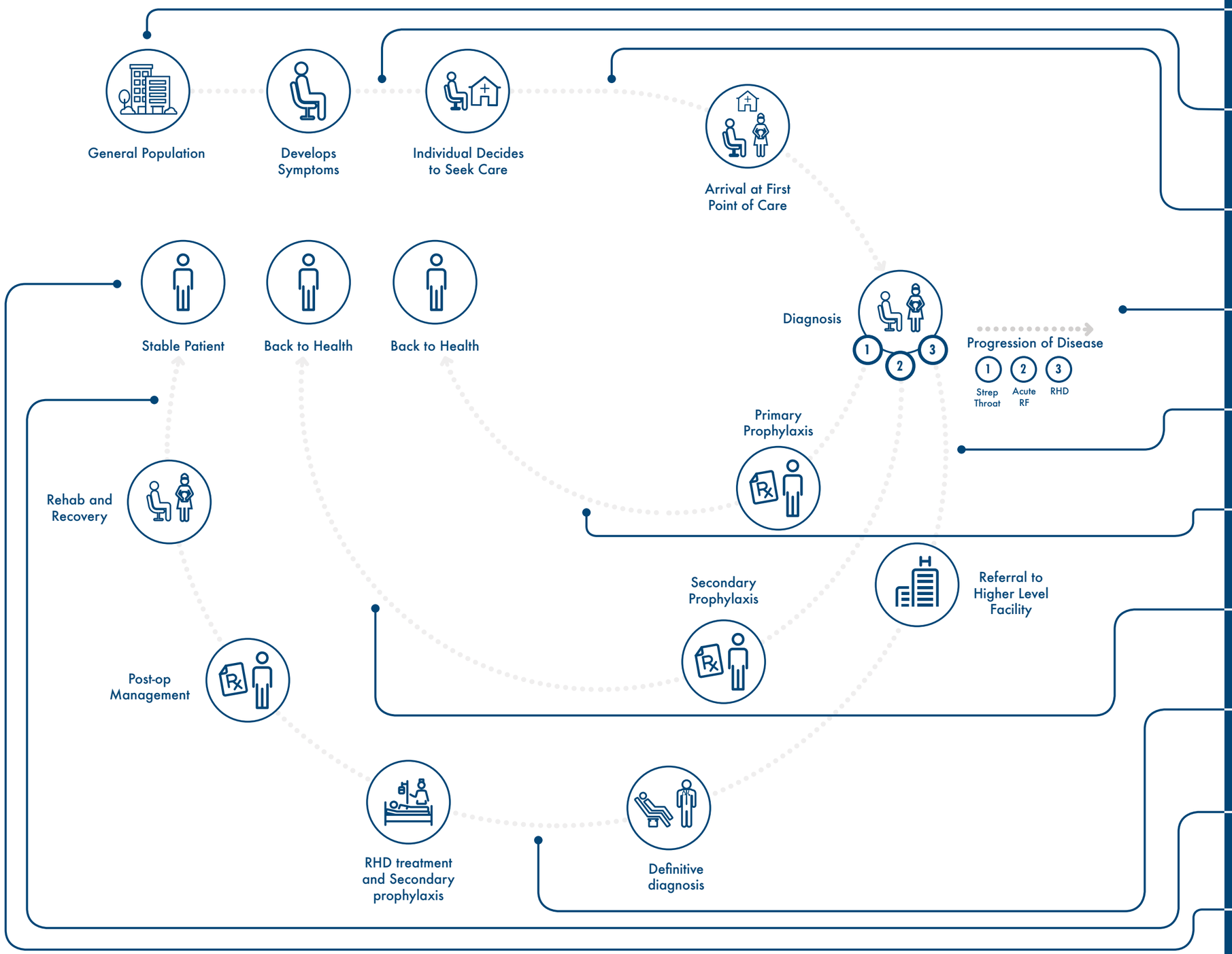


**FIGURE 3**
STEPS WITHIN THE CONTINUUM OF CARE FRAMEWORK




# COC

1. SOCIOECONOMIC CONDITIONS
2. DECISION TO SEEK CARE
3. ENTRY INTO HEALTH SYSTEM
4. DIAGNOSIS
5. REFERRAL
6. TREATMENT FOR STREP THROAT
7. SECONDARY PROPHYLAXIS
8. TREATMENT FOR RHD
9. MANAGEMENT OF TERTIARY INTERVENTION
10. REHABILITATION RECOVERY AND PALLIATION

1 SITUATIONAL ASSESSMENT
2 FACILITY-BASED ASSESSMENT
3 UNDERSTANDING THE PATIENT AND PROVIDER EXPERIENCE
4 PLANNING THE INTERVENTION

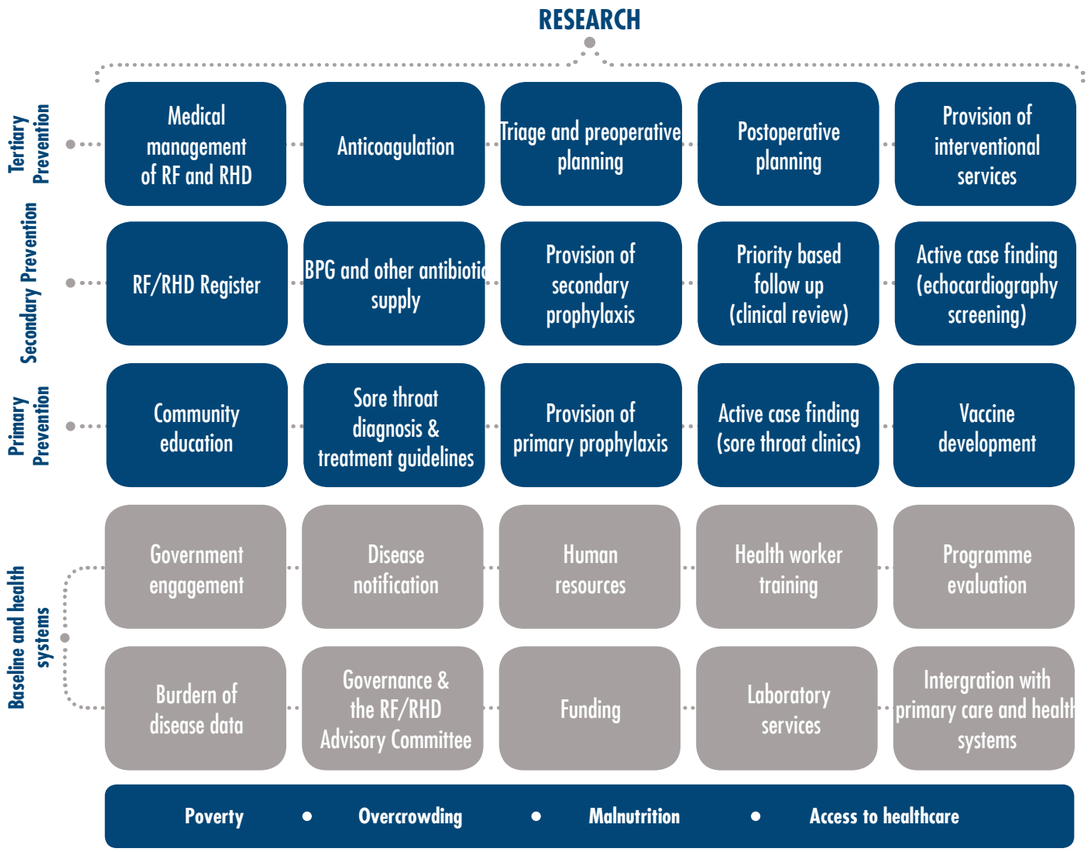
The CoC© framework helps to identify the barriers and challenges within a health system, while keeping the individual seeking care at the center of the process. As a patient-centered framework, it allows a step-by-step, comprehensive analysis of all of the challenges – whether individual, community or system-related – that prevent a person from receiving health care. The CoC© has been used in other settings, such as hypertension and diabetes, to successfully identify barriers within the demand and supply of health care for individuals, communities and health systems. Figure 2 follows the patient's journey, as he or she progresses through the community and the health system, overlaying the progression of disease so that challenges for each step of the progression can be identified. Barriers to care would present themselves at every step of the process of seeking care.

For ease of use, the CoC© has been systematically categorised into ten steps (Figure 3), based on the progression of disease (strep throat, ARF, and RHD).

This breakdown of CoC© steps in the context of GAS/ARF/RHD allows for the categorisation of the various needs (barriers) and opportunities (facilitators) at the levels of patients, providers, and the larger health system.

Tools for Implementing RHD Programmes (TIPS) is a technical manual that was designed as an evidence-based framework for describing, prioritising, and implementing comprehensive ARF/RHD control programmes. The TIPS Conceptual Framework tracks the health system factors relevant to such programmes. Hence it forms the basis for the health facility assessment in this Needs Assessment Tool, and it can also serve as a checklist for tracking the performance of health systems in caring for and meeting the needs of people with ARF/RHD.

## The TIPS conceptual framework






## COMPONENTS OF THE NEEDS ASSESSMENT

The Needs Assessment is a four-phase process (Figure 4) that involves the following:

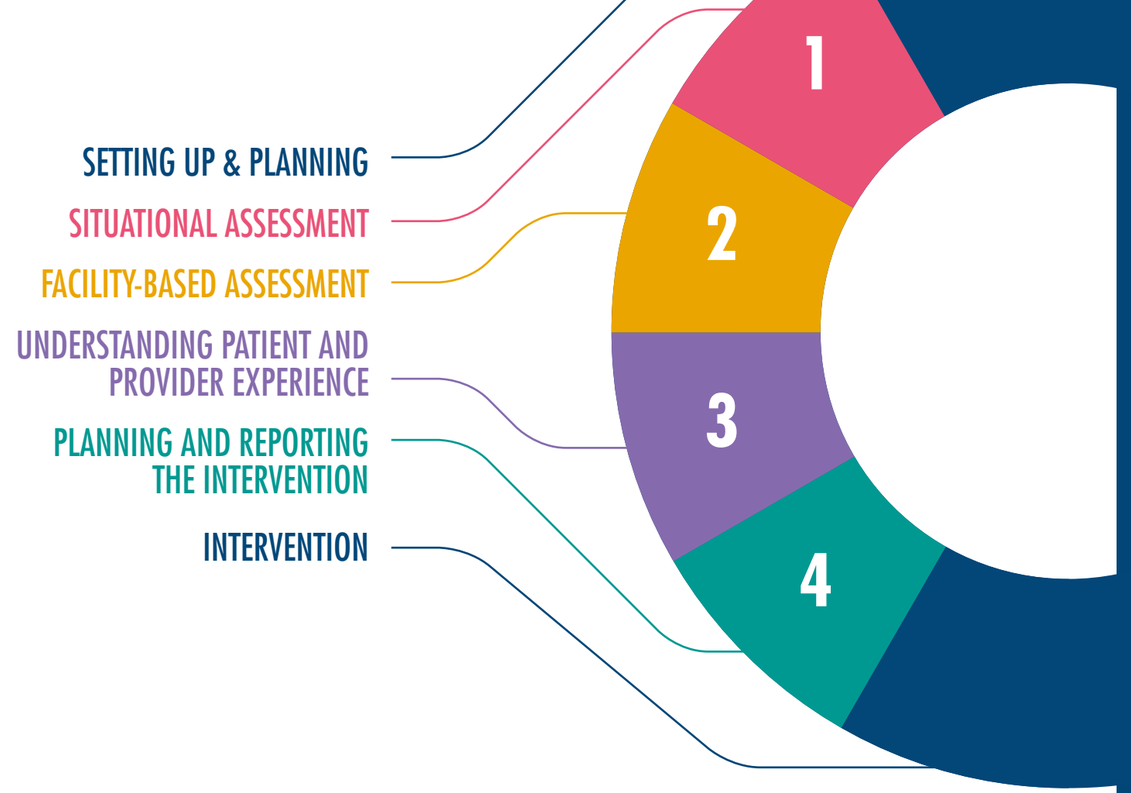
1. **Situational assessment**, which involves a systematic review of local literature around GAS, ARF, RHD and the characterisation of candidate sites.

2. **Facility-based assessment**, which includes reviewing clinical records, evaluating capacity to deliver care around GAS, ARF, and RHD in the site's health facilities, and seeking an understanding of how services around ARF/RHD integrate with the rest of the health system.

3. **Understanding the patient and provider experience**, which uses qualitative methods to understand the barriers and facilitators along the continuum of care.

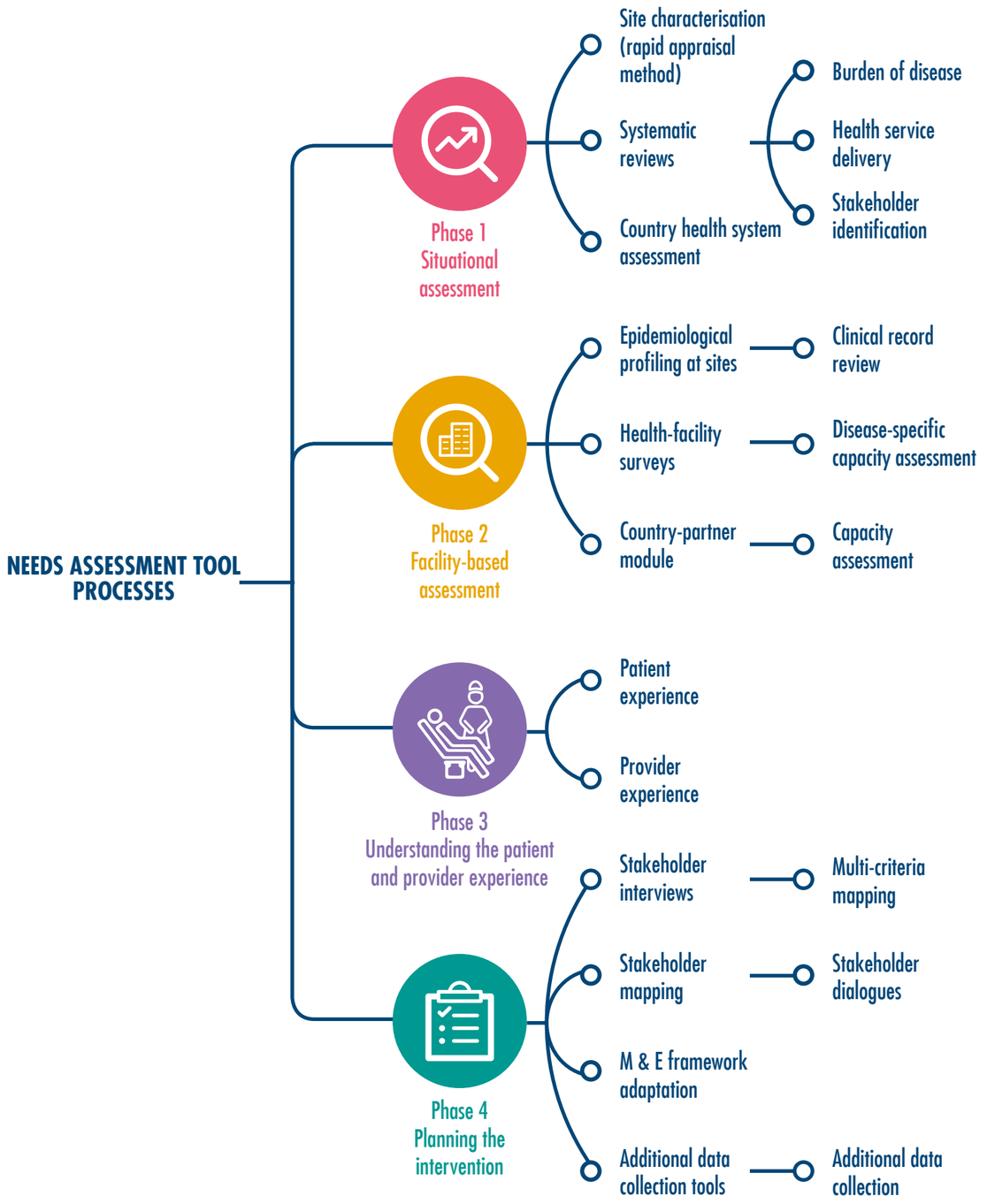
4. **Planning the intervention**, which implements a rigorous process approach to mapping and dialoguing with stakeholders and then designing the intervention as well as a monitoring and evaluation framework.

## FIGURE 4
FOUR PHASES OF THE NEEDS ASSESSMENT



The approach taken within this Needs Assessment is that of a mixed-methods assessment, with quantitative and qualitative analyses. Phase 1 includes a systematic review of existing data and a rapid appraisal of candidate sites. Phase 2 involves a detailed epidemiological assessment with quantitative assessment of new and existing data and qualitative assessment of services around GAS/ARF and RHD. Phase 3 is a detailed qualitative assessment of patients, health care professionals, key stakeholders and policy makers. Finally, in Phase 4, we introduce a monitoring and evaluation framework for selected interventions. A detailed and thorough situational analysis should include all aspects of this needs assessment and create a comprehensive representation of GAS/ARF/RHD in a particular site. These tools are presented in a step-wise package in order to facilitate its use in different situations with varied resources. Each element provides information required for RHD programmes, with the entire toolkit providing all the information required to make a detailed analysis.

**FIGURE 5**
OVERALL STRUCTURE OF THE NEEDS ASSESSMENT



# SUGGESTED RESOURCES

## KEY ELEMENTS

### In-Country Personnel

#### Phase 1

- ◯ Specialised field worker (interviewer)
- ◯ Data analysis

#### Phase 2

- ◯ Field worker: 2 workers for clinical record review
- ◯ Field worker: 2 workers for facility surveys

#### Phase 3

- ◯ Specialised field worker (interviewer): 2 workers for patient interviews and focus groups
- ◯ Specialised field worker (interviewer): provider interviews

#### Phase 4

- ◯ Specialised field worker (interviewer)

### Equipment

#### Phase 1

- ◯ 2 recording devices
- ◯ Qualitative software such as Dedoose or Atlas.ti

#### Phase 2

- ◯ 2 tablet computers for survey data entry
- ◯ Cloud-based data management software such as OpenMRS or REDCap

#### Phase 3

- ◯ 2 recording devices
- ◯ Qualitative software such as Dedoose or Atlas.ti

#### Phase 4

- ◯ 1 tablet computer for data entry
- ◯ Multi-criteria mapping software



### Services

#### Phase 1

- ◯ Transcription/translation services
- ◯ Literature screening: 2 independent reviewers for the Burden and Health Services reviews
- ◯ Literature screening: 2 independent reviewers for the Stakeholder Identification review
- ◯ Retrieval of local "grey" literature by site librarian

#### Phase 2

N/A

#### Phase 3

- ◯ Transcription/translation services: patient and provider data

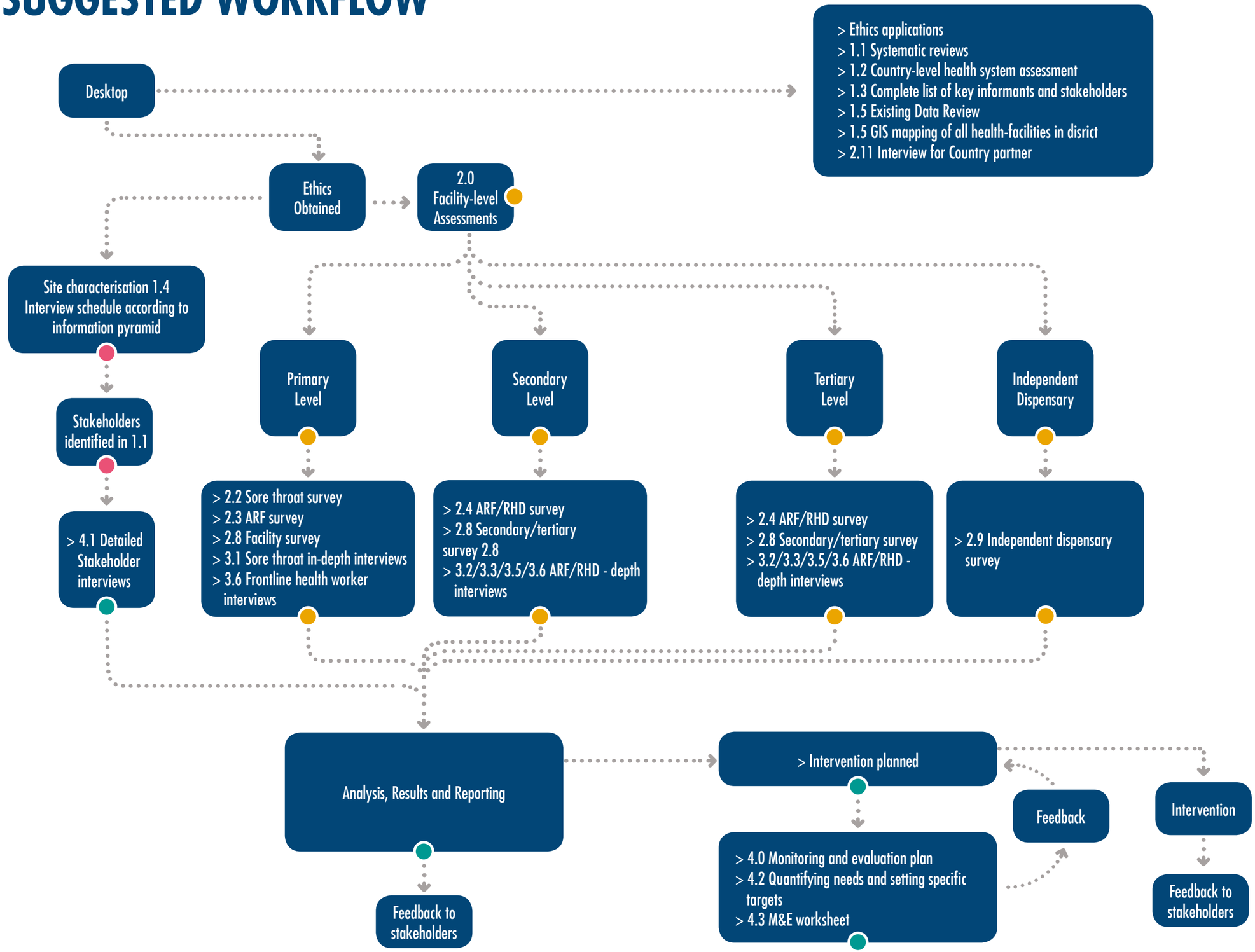
#### Phase 4

N/A

### Suggested additional notes

- "Specialised field worker (interviewer)" should be an individual who, at a minimum, has a bachelor's degree with a focus on social science and 2-3 years of experience conducting qualitative interviews. Master's students (under direct supervision) or PhD students (conducting interviews independently) are also acceptable.
- "Field worker" should be an individual who, at a minimum, has high school education and 2-3 years of experience working for an organisation that collects health-related data.
- A qualitative peer group should be constructed prior to the Site Characterisation and rapid appraisal in order to discuss and finalise research aims, objectives and methods. These will differ in each site, according to the social-economic and language settings.
- A systematic review group should be convened prior to conducting a systematic review to confirm the primary and secondary objectives and review data extraction and analyses.
- Data for health systems assessments can be obtained from the WHF and WHO and local health authorities.
- Data management platforms should be set up during the early phases of this needs assessment.

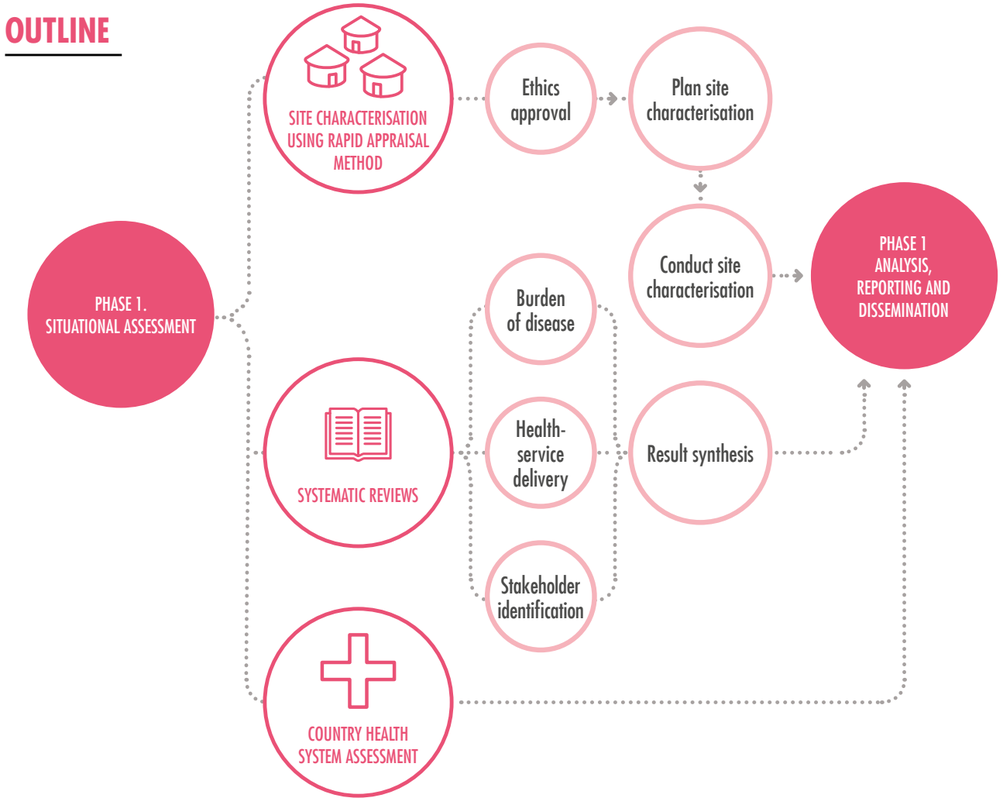
# SUGGESTED WORKFLOW



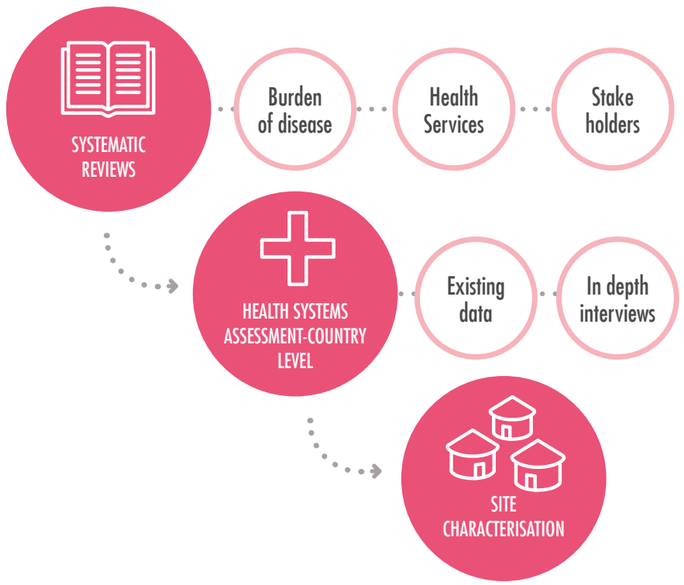
# 1

# SITUATIONAL ASSESSMENT

## OUTLINE




## ELEMENTS




## OBJECTIVES

1 SYSTEMATIC REVIEWS

- Collate and analyse existing data regarding burden of disease and epidemiology of RHD.
- Identify key stakeholders in a systematic way.
- Identify key health system delivery indicators.

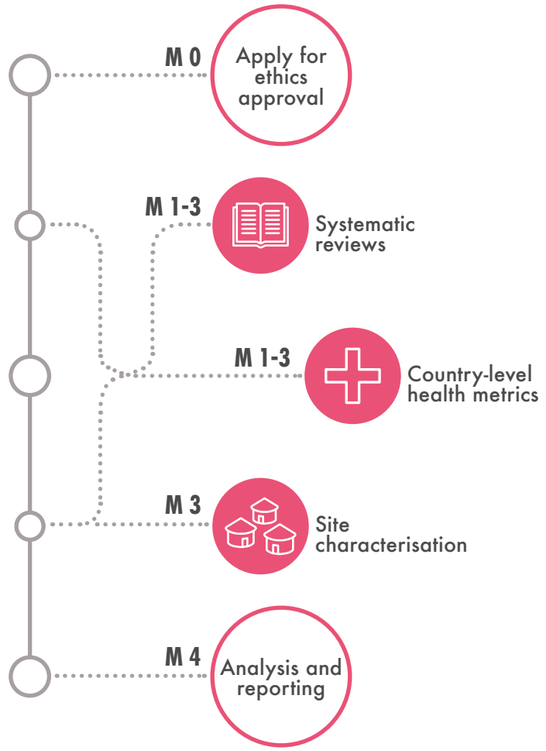
2 HEALTH SYSTEMS ASSESSMENT-COUNTRY LEVEL

- Identify and analyse country-level health system metrics.

3 SITE CHARACTERISATION

- Characterise a site using a rapid participatory method, and identify key barries, facilitators and drivers within the CoC framework.

## TIMELINE



# PHASE 1 INSTRUMENTS

# SYSTEMATIC REVIEWS

## INTRODUCTION

Planning of programmes should start with a situational assessment of the existing knowledge with regard to the barriers and challenges around GAS, ARF, and RHD. Systematic reviews are a method of comprehensively assessing the literature and synthesising all existing quantitative and qualitative data. We suggest a systematic review protocol that addresses three elements should be undertaken:

1. Epidemiological burden of GAS, ARF, and RHD
2. Issues around health service delivery for GAS, ARF, and RHD
3. Identification of stakeholders relevant to designing and implementing RHD programmes

## OBJECTIVES

1. Synthesise published estimates of incidence, prevalence, morbidity, and mortality from GAS and its sequelae (ARF and RHD)

2. Characterise the barriers and facilitators to providing care for GAS, ARF, and RHD specific to chosen countries

3. Identify the types of stakeholders who would need to be engaged when designing and implementing an RHD programme

## METHODS

We have created a series of review protocols, which are presented in this document. Systematic reviews provide a systematic method of screening existing and local "grey" literature – including unpublished data, academic theses, and government documents.

## IMPLICATIONS AND DISSEMINATION

The data gathered by means of these exercises would provide guidance on the magnitude of the RHD problem, the issues that would be encountered when prospectively assessing the Continuum of Care, and the types of stakeholders that should be engaged during Phase 4. All processes are presented according to a specific logical method to increase the methodological rigour of data and participant selection.

# 1.1
# Systematic Review Protocol

Protocol for Uganda and Tanzania

## Burden of Disease and Health Service Delivery

OBJECTIVE 1

### Define the burden of GAS, ARF and RHD

Outcomes of interest:

- Incidence of sore throat in children aged 5-15 years
- Prevalence of GAS among cases of sore throat
- Incidence of acute ARF
- Case-fatality rate from acute ARF
- Prevalence of RHD
- Mortality from RHD
- Non-fatal RHD outcomes: heart failure, stroke, infective endocarditis, atrial fibrillation, cardiac surgery and its complications

OBJECTIVE 2

### Identify key issues around sore throat, ARF, and RHD care

Outcomes of interest: barriers and facilitators in the continuum of care "matrix"

| | Patients | Health providers | Health Systems |
|---|---|---|---|
| Initial decision to seek care | ✔ | ✔ | ✔ |
| Factors influencing diagnosis | ✔ | ✔ | ✔ |
| Factors influencing treatment and/or referral | ✔ | ✔ | ✔ |
| Factors influencing adherence and retention in long-term care | ✔ | ✔ | ✔ |

OBJECTIVE 3

### To create a systematic stakeholder framework around sore throat/ARF and RHD to identify and include individual stakeholders deemed important by literature and experienced stakeholders.

Outcomes of interest:

1. Identify a relevant framework of stakeholder categories
2. Identify specific stakeholder groups
   - Begin with relevant research disciplines
   - Supplement with collaborative networks
3. Solicit feedback from expert informants
4. Presentation of a detailed stakeholder framework

Search strategy (common to both objectives):

1. Pubmed search

   Search (((((“Tanzania”[Mesh]) OR gandaa)) OR ((ganda) OR “Uganda”[Mesh]))) AND (((((“Rheumatic Heart Disease”[Mesh]) OR rheumatic heart)) OR ((rheumatic fever) OR “Rheumatic Fever”[Mesh])) OR ((((((“Pharyngitis”[Mesh]) OR pharyngitis) OR sore throat) OR strep) OR “Streptococcus pyogenes”[Mesh]) OR group a streptococcus)) Filters: Publication date from 1995/01/01 to 2015/12/31

2. Embase search

   (('group a streptococcal infection'/exp OR 'streptococcus group a'/exp OR 'group a streptococcal infection' OR 'streptococcus group a' OR 'pharyngitis'/exp OR 'pharyngitis') OR ('rheumatic fever'/exp OR 'rheumatic fever') OR ('rheumatic heart disease'/exp OR 'rheumatic heart disease')) AND ('uganda'/exp OR 'uganda' OR 'ugandan'/exp OR 'ugandans') OR ('tanzania'/exp OR 'tanzania' OR 'tanzanian'/exp OR 'tanzanian')

Supplement with grey literature searches:

- Academic theses from study country
- Government documents (especially death notification)
- Conference proceedings
- Google scholar

Also: hand-search reference lists, consult with local ARF/RHD experts in study country

Inclusion criteria:

- Studies conducted in Tanzania and Uganda
- Studies addressed one or more of the diseases of interest (GAS, ARF, RHD)
- Studies contained one or more of the objectives above
- Any epidemiological study is eligible (e.g., cross sectional, case series, case control, cohort study, intervention study)

Exclusion criteria:

- Opinion articles, case reports, reviews; systematic reviews will be retained temporarily to hand search reference lists, but ultimately excluded
- Studies prior to 1995 excluded (rationale: 1) up-to-date information desired; 2) echocardiography for diagnosis of RHD only widely used after the 1990s)

## 1 SYSTEMATIC REVIEW

### Identifying a relevant framework of stakeholder categories

This is based on an iterative search of the literature specific to ST/ARF/RHD and stakeholders/policy/mapping.

3. Pubmed search (Appendix 1)
   Search (((((“Rheumatic Heart Disease”[Mesh]) OR rheumatic heart)) OR ((rheumatic fever) OR “Rheumatic Fever”[Mesh])) OR ((((((“Pharyngitis”[Mesh]) OR pharyngitis) OR sore throat) OR strep) OR “Streptococcus pyogenes”[Mesh]) OR group a streptococcus)) Filters: Publication date from 1995/01/01 to 2015/12/31 [This could be focused on the RHDA countries or applied to all developing countries]

   ((((“policy”[MeSH Terms] OR “policy”[All Fields]) AND stakeholder[All Fields] AND mapping[All Fields]) AND (“health”[MeSH Terms] OR “health”[All Fields])) AND (“health”[MeSH Terms] OR “health”[All Fields])) AND (“developing countries”[MeSH Terms] OR (“developing”[All Fields] AND “countries”[All Fields]) OR “developing countries”[All Fields])

4. Embase search (Appendix 2)
   (('group a streptococcal infection'/exp OR 'streptococcus group a'/exp OR 'group a streptococcal infection' OR 'streptococcus group a' OR 'pharyngitis'/exp OR 'pharyngitis') OR ('rheumatic fever'/exp OR 'rheumatic fever') OR ('rheumatic heart disease'/exp OR 'rheumatic heart disease'))

   Supplement with grey literature searches:

   - Academic theses from study country
   - Government documents (especially death notification)
   - Conference proceedings
   - Google scholar

Also: hand-search reference lists, consult with local ARF/RHD experts in study country

Inclusion criteria:

- Articles focusing on the person with ST/RHD/ARF and identifying key stakeholders involved, in particular in rural and low-income settings. We will identify the relevant health stakeholders including public, policy makers and politicians and research community.
- Studies addressed one or more of the diseases of interest (GAS, ARF, RHD)
- Studies contained one or more of the objectives above
- Any epidemiological study is eligible (e.g., cross sectional, case series, case control, cohort study, intervention study)

Exclusion criteria:

- Opinion articles, case reports, reviews; systematic reviews will be retained temporarily to hand search reference lists, but ultimately excluded
- Studies prior to 1995 excluded (rationale: 1) up-to-date information desired; 2) echocardiography for diagnosis of RHD only widely used after the 1990s))



## 2 IDENTIFY SPECIFIC STAKEHOLDER GROUPS

- Begin with relevant research disciplines
- Supplement with collaborative networks

A list of relevant research disciplines will be generated using the academic affiliations of the authors of the papers from the review above and the types of journals in which they were published. We anticipate that several disciplines will be identified in this manner.

We will also add stakeholder groups related to these disciplines based on the critical literature review.

Finally we will supplement the findings with collaborative networks using internet searches, grey literature and personal communication.

## 3 SOLICIT FEEDBACK FROM EXPERT INFORMANTS

Feedback from experts will be collected to ensure that the framework reflected realities of practice and did not exclude key groups that may be missed in the literature search. A review of the framework will ensue with an iterative process to finalise the document. The key informants will include RHDA partners but also external partners to ensure a broad representation of experts.

## 4 PRESENTATION OF A DETAILED STAKEHOLDER FRAMEWORK

We will finally construct two frameworks (abbreviated and detailed), which will be utilised for key informant interviews, policy dialogues and inform the production of a detailed planning map.

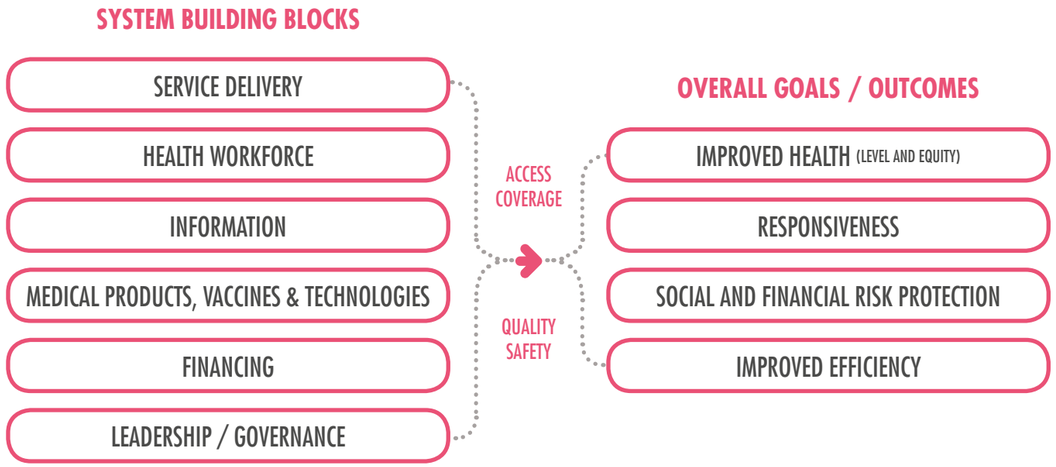
# COUNTRY-LEVEL HEALTH SYSTEMS ASSESSMENT

## INTRODUCTION

Along with a review of RHD-specific issues within a particular country, an assessment of general health system performance should be undertaken. The purpose of this separate review would be to build a foundation for health system performance appraisal during the Monitoring and Evaluation of the RHD programme. In other words, an understanding of how the RHD programme is strengthening health systems requires certain baseline information on how the health system is currently functioning.

The WHO Health System Framework (Figure 6) gives an overview of the various building blocks and goals of health systems. This framework should be used to collect and synthesise data.

**FIGURE 6**
WHO HEALTH SYSTEM FRAMEWORK




## OBJECTIVES

The objective of this assessment is to create a profile of the health system performance in each of the countries, including the identification of limitations and opportunities for improving chronic care.

## METHODS

The key sources of these data are WHF and other global organisations, such as the WHO and IHME, in order to gather relevant health system indicators and metrics. Complementing the WHO Health System Framework, the CVD-specific frameworks, tools, and approaches developed for the WHF Roadmaps can be used too, as these prioritise indicators related to chronic CVD care.

## IMPLICATIONS AND DISSEMINATION

The data gathered below would make it possible to identify systemic barriers and opportunities around RHD programmes. They would also serve as a baseline assessment of how the RHD programme might integrate with and strengthen existing health systems.

# 1.2 Health System Assessment

## A HEALTH SERVICE AT NATIONAL LEVEL

| Metric | Raw count | Rate |
|---|---|---|
| Outpatient facilities | | / 10,000 population |
| Inpatient beds | | / 10,000 population |
| Outpatient visits | | / 10,000 population per year |
| Facilities offering specific services | | / 10,000 population per year |

Comments on distribution of facilities (e.g., urban vs. rural):

| Metric | Number |
|---|---|
| General service readiness score | |
| Proportion of facilities offering specific services | |
| Specific-services readiness score for health facilities | |

Suggested data sources:

- District and national databases of health facilities. Special efforts – notably facility censuses – are often required to obtain the number of private facilities, especially if no registration system is enforced.
- Routine health facility reporting system
- Population-based surveys
- Health facility assessments

## B HEALTH WORKFORCE

| Metric | Raw count | Rate |
|---|---|---|
| Health workers | | / 10,000 population |
| Health professions graduates* | | / 10,000 population |
| Number of cardiologists | | / 10,000 population |
| Number of internal medicine specialists | | / 10,000 population |
| Number of General Practitioners | | / 10,000 population |
| Number of nurses | | / 10,000 population |
| Number of health graduates | | / 10,000 population |
| Are there any paid community health care workers | | |
| Are there any unpaid community health care workers | | |

Comments on distribution of health care workers (e.g., urban vs. rural, specialisation, gender):

Comments on differences in graduates by level and field of education:

Suggested data sources: Routine administrative records from individual training institutions. In some cases, data may be validated against registries of professional regulatory bodies where certification or licensure is required for practice.



## C HEALTH INFORMATION

*Health information system performance index:

Suggested data source: Review of national health information systems.

* As defined by the WHO

## D MEDICINES AND TECHNOLOGIES

Average availability of 14 selected (country-specific) essential medicines in public and private health facilities:

Suggested data source: existing literature. National (or sub-national) surveys of medicine price and availability are outside the scope of this tool. If no surveys exist, state so.

Median consumer price ratio of 14 selected essential medicines in:

Public health facilities:

Private health facilities:

Suggested data source: see above. If no data exist, state so.

Are there any focused surveys of BPG availability in this country?

If so, please list average availability, disaggregated if possible:

## E HEALTH FINANCING

| Metric | Number |
|---|---|
| Total expenditure on health | Gross:<br>Per Capital: |
| General government expenditure on health as a proportion of general government expenditure | |
| Ratio of household out-of-pocket payments for health to total expenditure on health | |

Suggested data sources:

- National Health Accounts
- Demographic and Health Survey
- Household expenditure and utilisation surveys

## F LEADERSHIP AND GOVERNANCE

*What is the policy index for this country?

Suggested data sources: Review of national health policies in respective domains (such as essential medicines and pharmaceutical, NCDs, other chronic diseases, TB, malaria, HIV/AIDS, maternal health, child health/ immunisation).

* As defined by the WHO

## G HEALTH TECHNOLOGIES

| Technologies | Availability within primary care (report either using categories below or % if applicable) | | |
|---|---|---|---|
| | Largely unavailable (<25%) | Generally available (25-75%) | Largely available (>75%) |
| Thermometer | | | |
| Stethoscope | | | |
| Blood pressure measurement device | | | |
| Weighing machines | | | |
| Glucometer flow meter | | | |
| Peak flow meter | | | |
| Syringes and equipment for immunisations | | | |

Nomenclature system

Is there a nomenclature system for medical devices?
Is this nationally developed?

Medical equipment: (density per million population):

Number of Computer Tomography (CT) devices per million inhabitants?
Number of echocardiogram machines per million inhabitants?
Where are Computer tomography devices located?

List of medical devices

Is there a national standard or recommended list of medical devices for different types of healthcare facilities or specific procedures?

Health technology policy

Is there a National Health technology policy in place?
Is this part of the National Health programme?
Is this an independent programme?

Procurement:

Is there a national list for approved medical devices for procurement or reimbursement?
Are these carried out on a national level?



Health information systems:

Health statistics (hospital admissions, etc.)
Surveillance system description
Regular surveys (at national and regional level)

Connectivity:

Are primary health care facilities provided with Internet connection?
Are secondary health care facilities provided with Internet connection?
Are tertiary health care facilities provided with Internet connection?

Is telemedicine available? At which levels and how are they linked?

Suggested data sources:

- WHO Global Health Observatory
- Essential Healthcare Technology Package
- Demographic and Health Survey

# SITE CHARACTERISATION

## INTRODUCTION

Rapid appraisal (RA) is an established qualitative technique used for conducting a needs assessment exercise in low-income settings. Both rapid rural appraisal (RRA) and rapid participatory appraisal (RPA) were developed in low-income settings, and they seek to provide key information on health status, knowledge, attitudes and behaviours in a cost-effective, timely and reliable way. RRA focuses more on outside learning, whereas RPA is more participatory and empowering, often enabling local people to conduct their own assessments and analyses. For this assessment, a RA can involve outside researchers, but it must involve community leaders and local stakeholders as far as possible.

Details of the RA methodology are provided in Appendix 1. Briefly, RA would select people with knowledge of the area (key informants), both to identify problems and to contribute to solutions. Informants would be queried in terms of the 10 domains of information "pyramid" (Figure 7).

In the context of the Country Control Programmes, RA would be used as an initial site characterisation tool, and as a complement and introduction, rather than as an alternative to survey-based methods. The RA approach would guide, inform the design of, and confirm findings from the comprehensive assessment.

**FIGURE 7**
INFORMATION PYRAMID USED IN RAPID APPRAISALS




## OBJECTIVES

1. Evaluate the community composition, organisation and capacity using the 10 domains within a rapid appraisal.
2. Describe the environmental factors influencing health (focusing on ST/ARF/RHD), including the physical and socioeconomic environment and the identification of disease and disability within the community.
3. Identify the services (health, education and social) services available to the community and identify key needs and barriers within these.
4. Examine the health policy components of the communities involved.
5. Prioritise needs and quantify potential barriers, solutions and interventions according to the needs and circumstances of the communities involved.

## METHODS

The site selection tool data should be derived from three major sources: existing written records, interviews, and observations. The scientific rigour and validity of this approach would depend on triangulation, with data from one source being validated or rejected after comparison with data from at least two other sources or methods of collection. Through this crosschecking process, a cohesive interpretation would be constructed.

People in the best position to understand the issues should be chosen as key informants (KIs). They would undergo semi-structured interviews, and the data would be split into the 10 separate domains. Suggested first informants would be community leaders, primary, secondary and tertiary health care workers, people living with RHD, community health care workers and parents. KIs should be chosen to represent a wide cross-section of the community, thus minimising selection bias, while considering age, gender, socio-economic status, ethnicity and religious factors.

These interviews would need to be supplemented by the collection of existing records in the community. Documents that could be used should center around health care for ARF and RHD, and the relevant forms should be completed by local partners. The rationale for this clinical focus would be to confirm that a reasonable number of cases of ARF and RHD do exist in the community and that they can be identified to be involved in any planned RHD programme.

Finally, direct observation of the community (generally) and health care facilities (in particular) would need to complement the above approaches. Trained staff members should visit community sites and make written notes on the physical appearance of the facilities, the demographics of the community and other contextual information to gain an adequate understanding of the community and in this way to build trust and partnerships with community (and health care) leaders.

Data should be collected in three phases:

**1.** 1-2 weeks, gathering and analysing people's perception of the community needs, issues and identifying community assets.

**2.** 1-2 weeks, conducting further discussions with the selected community participants and feeding back information gathered, allowing for clarification or verification and the sharing of opinions with regard to issues raised and proposed strategies. Given the time frame, participants should either meet individually or in strategically clustered employment related discussion groups.

**3.** Additional data should also be collected from existing written records about the community and field observations during this period.

Analysis of data should be done on an iterative basis. On completion of each interview, the research team should discuss findings and observations. The aim of this is to cross-check the data, identify discrepancies and ensure clarity on the side of the researcher. Detailed notes should be written at the end of each day, noting down dominant themes, interrelationships and inconsistencies. Data should be collated within the 10 areas and common themes/problems identified and priority areas discussed. Possible barriers/interventions raised by the community need to be described and recorded. Any new suggestions with regard to improvements and innovations should be reported. Observations, field notes and written data should be used to triangulate the data and create detailed thick descriptions of the data. Preliminary and final analyses should be shared among the Qualitative Peer Group, including the staff members who have collected the data.

# IMPLICATIONS AND DISSEMINATION

The data gathered in this exercise would establish community interest and investment in the subsequent intervention. Furthermore, the exercise needs to involve the community in both defining community needs and possible solutions. An important aspect is feedback to the community and the stakeholders. This could be done in feedback sessions, using visual aids and sharing a report with the involved stakeholders. One of the key elements of this method would be to produce a report (usually 25 or so pages) with an executive summary (5 or so pages), which should be widely distributed amongst the community, key stakeholders, and others.

# 1.3
# Suggested Key Informants/Stakeholders

Name of Community/District:

GPS coordinates of center of district:

Name of reviewer:

Location: Address (if available)

Longitude/Latitude:

Role:

Date: DD / MM / YYYY

Suggested Stakeholders for RRA- to be determined by countries in consultation

| Name | Position (describe in detail) | Contact details including GPS: | Person Validating Comments: |
|---|---|---|---|
| 1. Community leaders | | | |
| 2. Patients (ARF, RHD) | | | |
| 3. Forefront health worker (Primary care level) | | | |
| 4. Forefront health worker (Secondary care level) | | | |
| 5. Forefront health worker (Tertiary care level) | | | |
| 6. School teacher | | | |
| 7. School principal | | | |
| 8. Community health worker | | | |
| 9. Local NGO workers | | | |
| 10. District Chairperson | | | |
| 11. District Director of Health Services | | | |
| 12. Chief Administrative Officer | | | |
| 13. District Secretary for Health | | | |
| 14. District Health Inspector | | | |
| 15. Members of Parliament from that District | | | |
| 16. Family member of patient (ARF/RHD) | | | |
| 17. Housing Ministry representative | | | |
| 18. Representative of public works/ sanitation and built environment | | | |
| 19. Social services representative | | | |



# 1.4
# Topic guides and interview schedules

(These are guides and probes and will be adapted based on the role of the Key Informant (Stakeholder) as identified by 1.3)

### 1. Community composition

Can you describe the kinds of people who live in the area?
What is the size of the community under consideration?
What is the total population* of the community?

### 2. Community Organisation and Structure

How is the community organised?
What are the major needs?
Why do you live in this community?
Do you know of what kind of help is available for the residents of XXX?
Can you think of any other services that would be helpful to people in the area?

### 3. Community Capacity

Do you know local people who are good at getting things done?
Do you think there is a sense of community identity and/or commitment to this area?

### 4. Physical Environment

Are there any particular problems with living in the area?
How would you describe the condition of housing in XXX?
Does transport or access present you with any problems?
How safe do you feel in the neighborhood e.g. walking outside after dark, or being home alone? If not, why?

### 5. Socio-economic Environment

Do you think people manage financially?
How do people earn money in your community?
How many people live in your house?
How many people sleep in the same room as you?
Is violence/crime an issue in this community?

### 6. Diseases and Disability Profile

Is this a healthy community?
What do you think is the most important medical problem in XXX?
What kinds of things do you think affect the health of people living in XXX?
What do you think are the worst health problems in the area?
Do you know if any heart problems are a problem?
Are there many people with other important physical or health disability living in this area?
We are thinking of doing a project around rheumatic heart disease- what do you think of this?

## 7. Educational Services

Are you aware of these services locally?

- Nurseries
- Primary Schools
- Secondary Schools
- Community Centers
- Day/Evening Classes
- A place for young people?

How could these be improved?
What do you think is still needed?

## 8. Health Services

What are the health services in this community?
Describe the different services:
What is the best thing about the service and what could be better?
What do you think of the hospital services?
Have you noticed any recent changes in these services?
How would you like to see them improved?
Are primary and secondary care facilities available in the community?
Do patients have some access to referral for tertiary care (not necessarily surgical)?
Do you know about rheumatic heart disease? Do you know about heart failure?
Do you have dispensaries are in the district? If so, how many, how many public or private?
How many primary health centers are in the district?
Name of tertiary hospital serving the district:

## 9. Social services

Which social services are needed by most people in the area?
How could they be improved?

## 10. Health and Social Policy

Are you aware of government Health and Social Policy?
Have any recent changes in policy affected you?

## 11. Miscellaneous

If you could have one wish for health in your community what would it be, or what changes would you like to make in the area?



# 1.5 Existing Data Review

Name of Community/District:

GPS coordinates of center of district:

## 1. Potential RHD Burden

| | | |
|---|---|---|
| 1.1 What is the total population* of the district? | Persons: | Year: |
| 1.2 What was the number* of total ARF/ RHD cases at the district hospital? | Cases: ARF:<br>Cases: RHD: | Year: |
| 1.3 What was the number* of CV deaths** at the district hospital? | Deaths: | Year: |
| 1.4 If you have a cardiologist or other relevant specialist, what is the proportion of RHD cases among the total cases that he/she sees?*** | Number RHD / Total, (%): | Year (month): |
| 1.4 If you have a cardiologist or other relevant specialist, what is the proportion of heart failure cases among the total cases that he/she sees?*** | Number RHD / Total, (%): | Year (month): |

* Provide numbers for the most recent year that data are readily available. (If this is not available, the worksheet within the NAT may be used.)

** CV deaths = cardiovascular deaths (ICD-9 codes 390-438, ICD-10 codes I00-I79).

*** Could be calculated as number of RHD cases / Total cases seen at clinics over a defined period (e.g. in a month) or as RHD cases / Total cases as major diagnosis on echo for all echoes done over a similar defined period.

*Name:

*Role:

* Key Informant of this section

Date: DD / MM / YYYY

## 2. Health System Capacity

| | |
|---|---|
| 2.1 How many dispensaries are in the site? | |
| 2.2 How many primary health centers are in the site? | |
| 2.3 How many secondary /district hospitals serve the site? | |
| 2.4 Name of tertiary hospital serving the site: | |
| 2.5 List all GPS co-ordinates of the health facilities (Please refer to Operations Manual for instructions.) | |

*Name:

*Role:

* Key Informant of this section if different from previous section

Date: DD / MM / YYYY

## 3. Additional criteria

| | |
|---|---|
| 3.1 Is the district more than 6 hours by bus or car from a major town/city? | Yes No |
| 3.2 Has there been any recent (or ongoing) natural disaster? Comments | Yes No |
| 3.3 Have there been any recent infectious disease outbreaks? Comments: | Yes No |
| 3.4 Is the region affected by political unrest/violence or terrorism? Comments: | Yes No |



*Name:

*Role:

* Key Informant of this section if different from previous section

Date: DD / MM / YYYY

## 4. Collateral information

| | |
|---|---|
| 4.1 Are measures of poverty and housing quality in the community approximately average for values for the district? List census data used: | Yes No |
| 4.2 Is the size of the community size approximately average for the district? List census data used: | Yes No |
| 4.3 Have there been any health interventions (education campaigns, incentive payments or large research projects) which may influence health literacy or how people seek care? Discuss with local ethics committee Details : | Yes No |
| 4.4 Has there been recent environmental or other disasters creating more immediate health priorities than RHD? Details : | Yes No |
| 4.5 Are primary and secondary care facilities available in the community? | Yes No |
| 4.6 Do patients have some access to referral for tertiary care (not necessarily surgical)? | Yes No |
| 4.7 Are health care services provided to a defined, relatively geographically stable, population? (identifiable denominator). | Yes No |
| 4.8 Is there evidence of support, endorsement or interest from forefront health staff? | Yes No |
| 4.9 Do primary schools exist in this community? | Yes No |
| 4.10 Is health care delivered exclusively by international teams or agencies? | Yes No |
| 4.11 Is the size of the community between 10,000 – 30,000 people? | Yes No |
| 4.12 Is the community less than a 3-hour drive from a main center or airport? | Yes No |
| 4.13 Does the community have access to translation or language support services? | Yes No |

Other considerations

Please outline any other factors which make this community more or less suitable for inclusion as a pilot site:

# 2

# FACILITY-BASED ASSESSMENT

The secondary data analysis would be intended to provide a general sense of the magnitude of sore throat, ARF and RHD in the country in question. However, in order to design specific local interventions, a focused amount of primary local data on ARF and RHD should be collected, first to justify any interventions and, later, to evaluate their effectiveness.

Formal incidence and prevalence estimates obtained, e.g., prospective cohort or cross-sectional studies, would fall outside the scope of a needs assessment. Such research studies would typically take several years to complete and require a large amount of financial and human resources that might detract from the larger objectives of a needs assessment. The approach outlined below could be used to quantify the health system burden of ARF/RHD and serve as a foundation for tracking the intervention(s). This approach would include a review of any ARF/RHD registers within the country in addition to a review of local cases of sore throat, ARF, and RHD presenting to medical care.

## OUTLINE


## ELEMENTS




## OBJECTIVES

1 CLINICAL RECORDS REVIEW

- Collate and analyse existing data in current metrics around RHD using clinical record review.

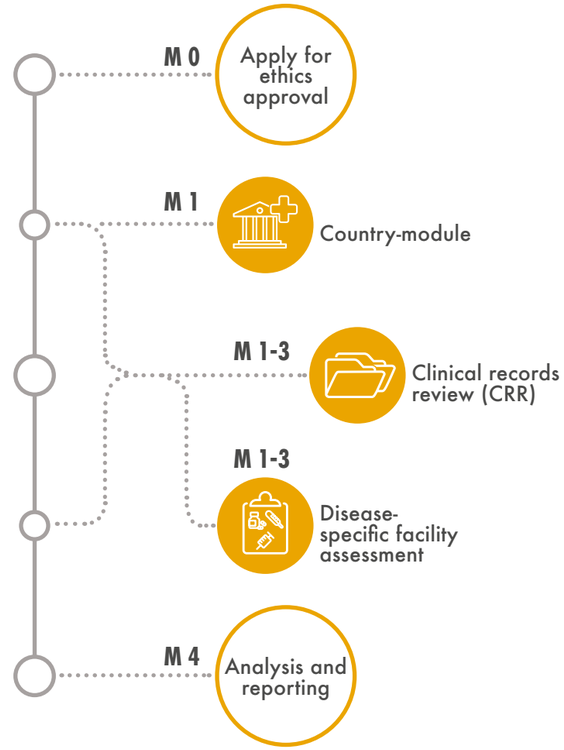
2 DISEASE-SPECIFIC ASSESSMENT

- Calculate additional metrics around the RHD continuum using facility-based survey data.

3 COUNTRY-MODULE CAPACITY ASSESSMENT

- Identify key integrators and capacity assessment within country.

## TIMELINE



# PHASE 2 INSTRUMENTS

# CLINICAL RECORD REVIEW

## INTRODUCTION

The focus of this aspect of the needs assessment is on individuals who have presented to medical care, as understanding health care utilisation provides important information about modifiable factors. This approach, despite some under-appreciation of the community-wide burden of sore throat, ARF, and RHD, allows for an assessment of the incidence and prevalence of these diseases and an appreciation of potential interventions within resource-constrained settings.

In-depth interviews of patients and providers involved in the CoC© for RHD (Phase 3 below) would supplement the quantitative data gathered in this exercise. Factors influencing seeking (or delaying) medical care should be explored as well as community and provider knowledge, attitudes, and practices. These qualitative data would provide an adequate understanding of the challenges around RHD in the community and mitigate the limitations of the approach used here.

## OBJECTIVES

1. Estimate the incidence of sore throat and ARF attending medical care at the site
2. Estimate the mortality associated with ARF and RHD at the site
3. Estimate the prevalence (total number of identified cases) of RHD at the site
4. Characterise current patterns of clinical care for sore throat, ARF, and RHD in the health facilities at the site



## METHODS

A complete enumeration of all health facilities at the site should be conducted. Cases of sore throat, ARF, and RHD would need to be defined according to local criteria (i.e., previous diagnosis by a clinician). Following this, a sample of the health facilities should be included in the prospective survey. The sampling strategy for clinical review would be as follows:

1. Up to 3 tertiary or referral hospitals at the site should be included
2. All district hospitals at the site should be included
3. A random sample of 2-5 health centers at the site should be included
4. A random sample of 2-5 dispensaries or pharmacies should be included

The total number of primary care facilities included would depend on characteristics, such as 1) where patients typically seek care for acute childhood and adult illness (e.g., health center vs. dispensary), 2) district size, and 3) geographic heterogeneity. The aim would be to capture a representative sample of primary care facilities and this might involve purposive or stratified random sampling in some cases. Data collection should take approximately 6-9 weeks.

Field workers should conduct a review of clinical records using the instruments below. Data should be stored electronically on a cloud-based server for analysis. The timeframe of sampling should be as follows:

1. One month for endemic cases of sore throat
2. One month for cases of ARF – this should be chosen as the calendar month following the month chosen above (e.g., if July is the month where GAS infection would be expected to be high at the site, then the ARF case review would involve records from August)
3. One month for cases of ARF and RHD

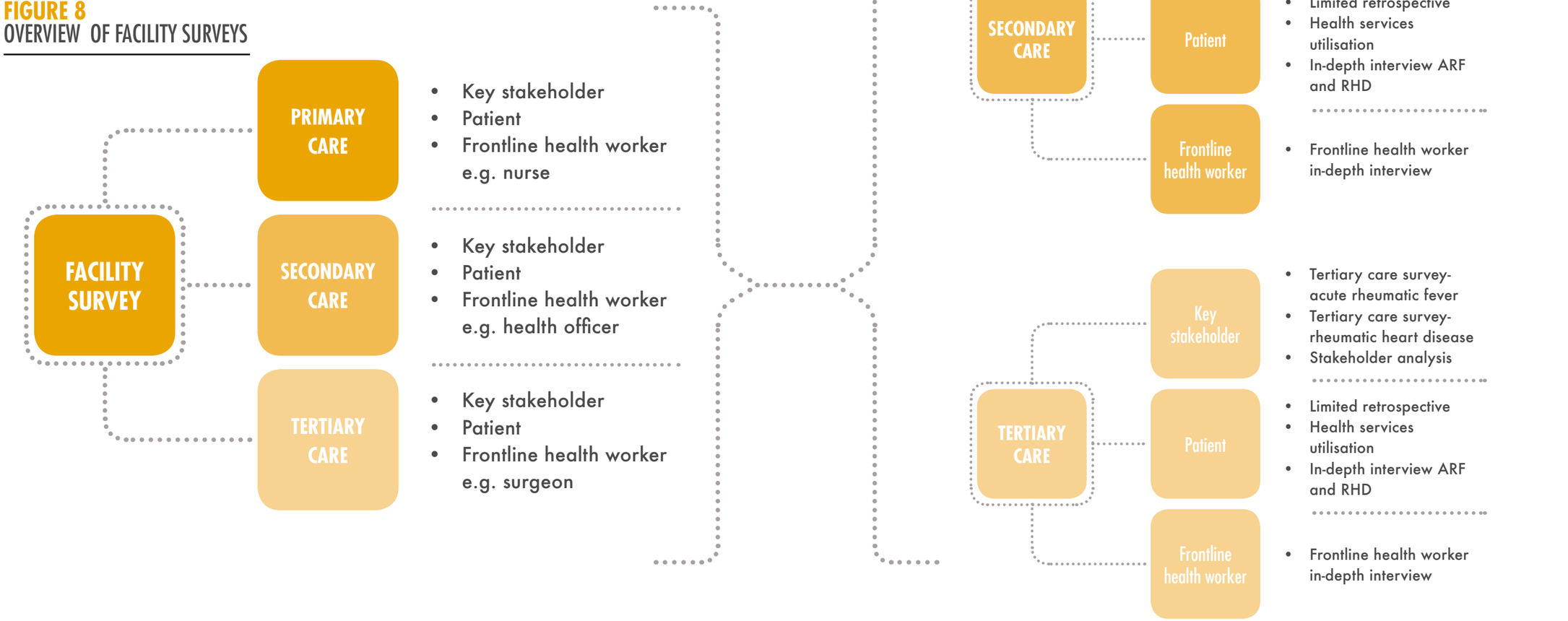
Taking into consideration the resources, training and previous experience of data collectors, the individual sites would need to adapt the clinical record review forms. If deemed necessary, additional training should be provided to capture the most robust data prior to commencing data collection. The instruments provided here aim for optimal information that could be recognised and extracted by a trained healthcare professional.

It is recommended to use a Subject ID number for clinical record reviews, either assigned sequentially from a predetermined listing, or by using some combination of subject initials and medical record number – whatever would be customary for the site and/or approved by the local Ethics Committee.

# IMPLICATIONS AND DISSEMINATION

The review of clinical records should be used to inform sites of the extent of existing burden of disease. Gathering individual records into one database should be a first step to identifying and enrolling patients in the intervention. Furthermore, the data on patient care at the individual level should be used to identify various points of intervention. For instance, an assessment of secondary prophylaxis use patterns should be developed into a "treatment cascade" that would serve to monitor where clinical care is the weakest and most amenable to intervention.

**FIGURE 8**
OVERVIEW OF FACILITY SURVEYS



# 2.1
# Primary Care Sore Throat/ARF Cover Sheet

For Primary Care Facilities

Person Conducting Records Review:

Date(s) of Records Review:

This one-month review covers the period DD / MM / YYYY to DD / MM / YYYY

Tick whichever applies
- For Sore Throat
- For Acute Rheumatic Fever (Following Month)

Please tick all that apply.

Facility Name and Country:

Facility Type
- Public/government
- Private for-profit
- Private not-for-private Philanthropic/Charity/ NGO/faith-based

Population Served (as defined by each country)
- Rural
- Urban
- Other. Please describe

Service Area
- Village
- District
- Regional
- Other, please describe

| | |
|---|---|
| IEC/IRB Approval Number and Date | |
| Name of facility personnel providing access to records: | |
| Title: | |
| Email (Primary): | |
| Alternate contact person name: | |
| Mailing Address of facility Records Department: | |
| Phone (Office): | |
| Phone (Cell): | |
| Physical Address where record review was conducted: | |
| GPS coordinates of facility: (Please refer to Operations Manual for instructions if needed.) | |
| What is the approximate catchment area/ population size served by this facility? | |



# 2.2
# Primary Care Sore Throat

Prospective Study for patients ages 3 – 15 years presenting to Clinic with Sore Throat.

Subject Initials: Medical Record No.:

Date of Birth: DD / MM / YYYY Gender:

Subject ID No:

This one-month review covers the period DD / MM / YYYY to DD / MM / YYYY

Please tick all that apply.

| Sore Throat? | | Comments |
|---|---|---|
| Date of Complaint/Visit Date | Date: | |
| Fever? If yes, temp: | No Yes Unknown/ Not Available | |
| Swollen, tender anterior cervical lymph nodes (swollen glands under the chin)? | No Yes Unknown/ Not Available | |
| Tonsillar exudate (pus on tonsils)? | No Yes Unknown/ Not Available | |
| Cough? | No Yes Unknown/ Not Available | |
| Rhinorrhea (runny nose)? | No Yes Unknown/ Not Available | |
| Final Diagnosis: | Unknown | |
| Treatment: | Unknown | |
| GAS Confirmed? | No Yes Unknown/ Not Available | |
| If yes, confirmation method? | | |
| Antibiotics Administered? | No Yes Unknown/ Not Available | |
| If yes, Type/Dosage: | | |

Source: South African clinical decision rule for evaluation of pharyngitis (Irlam et al. 2013)

Data Collector Name

Data Collection Date

# 2.3
# Primary Care ARF

Prospective Study for patients who had/have ARF during the sampling month
(One month after Sore Throat)

Subject Initials: _____ Medical Record No.: _____

Date of Birth: DD / MM / YYYY Gender: _____

Subject ID No: _____

This one-month review covers the period DD / MM / YYYY to DD / MM / YYYY

Please tick all that apply.

| ARF | | Comments |
|---|---|---|
| Date of Diagnosis: | ☐ Unknown/ Not available | |
| First diagnosis? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Diagnosed within past 12 months (i.e. not first diagnosis)? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Chronic RHD with ARF recurrence? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Referred to hospital? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| If yes, name of hospital: | | |
| Discharged to home? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Other. Please specify: | | |
| Was Revised Jones Criteria (2002) used in diagnosing ARF in the patient? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

A firm diagnosis requires that two major or one major and two minor criteria are satisfied, in addition to evidence of recent streptococcal infection.

| Required Criteria | | Comments |
|---|---|---|
| Antecedent Strep infection? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Major diagnostic criteria | | |
| Carditis? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Method of diagnosis of carditis Auscultation? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Method of diagnosis Echocardiography? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| | Major lesions: Please tick all that apply | ☐ Mitral Regurgitation ☐ Mitral Stenosis ☐ Aortic Regurgitation ☐ Aortic Stenosis ☐ Pulmonary Regurgitation ☐ Pulmonary Stenosis ☐ Tricuspid Regurgitation ☐ Tricuspid Stenosis |
| Polyarthritis? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Polyarthralgia? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Monoarthritis? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Chorea? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Erythema marginatum? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Subcutaneous Nodules? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

| Minor Diagnostic Criteria | | Comments |
|---|---|---|
| Fever? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| If yes, temp? | | |
| Arthralgia? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Acute phase reactants? [Leukocytosis, elevated erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP)] | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Prolonged P-R interval on electrocardiogram (ECG)? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Previous rheumatic fever or rheumatic heart disease? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

| Evidence of preceding streptococcal infection: Any one of the following is considered adequate evidence of infection. | | |
|---|---|---|
| Increased antistreptolysin O or other streptococcal antibodies? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Positive throat culture for Group A beta-hemolytic streptococci? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Positive rapid direct Group A strep carbohydrate antigen test? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Positive rapid direct Group A strep carbohydrate antigen test? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

| Differential Diagnoses considered: | | Comments |
|---|---|---|
| | | |
| | | |
| | | |
| ☐ Unknown/Not Available | | |

| Mortality: | | Comments |
|---|---|---|
| Did the patient die during the review period? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| If yes, please provide date and cause of death: | | |
| Date: | ☐ Unknown/ Not Available | |
| Cause of Death: | ☐ Unknown/ Not Available | |

Data Collector Name

Data Collection Date



# 2.4 Secondary/Tertiary Facility Cover Sheet

Person Conducting Records Review:

Date(s) of Records Review:

This one-month review covers the period DD / MM / YYYY to DD / MM / YYYY

Facility Name and Country:

Facility Type

- ☐ Public/Government
- ☐ Private for-profit
- ☐ Private not-for-private
- ☐ Philanthropic/Charity/NGO/ Faith-based

- ☐ Secondary
- ☐ Tertiary

- ☐ District
- ☐ Regional
- ☐ Provincial
- ☐ Other, please describe

| | |
|---|---|
| IEC/IRB Approval Number and Date: | |
| Name of facility personnel providing access to records: | |
| Title: | |
| Email (Primary): | |
| Alternate contact person name: | |
| Mailing Address of facility Records Department: | |
| Phone (Office): | |
| Phone (Cell): | |
| Physical Address where record review was conducted: | |
| GPS coordinates of facility: (Please refer to Operations Manual for instructions if needed.) | |

# 2.5
# Secondary/Tertiary Facility ARF/RHD

Prospective One month Review

Patient Initials: _____ Medical Record No.: _____

Date of Birth: DD / MM / YYYY Gender: _____

Subject ID No: _____

This one-month review covers the period DD / MM / YYYY to DD / MM / YYYY

This record is reviewed because the patient had/has:

☐ Acute Rheumatic Fever ☐ Rheumatic Heart Disease

Please tick all that apply and proceed to relevant reporting sections below.

| ARF/RHD Diagnosis | ☐ No ☐ Yes | Comments |
|---|---|---|
| Date of Diagnosis: | ☐ Unknown/ Not Available | |
| First diagnosis? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Diagnosis past 12 months? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| RHD? | ☐ No ☐ Yes | |
| ARF? | ☐ No ☐ Yes | |

| ARF | | Comments |
|---|---|---|
| Was Revised Jones Criteria (2002) used in diagnosing ARF in the patient? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

A firm diagnosis requires that two major or one major and two minor criteria are satisfied, in addition to evidence of recent streptococcal infection.

| Required Criteria | | Comments |
|---|---|---|
| Antecedent Strep infection? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Major diagnostic criteria | | |
| Carditis? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| If yes, method of diagnosis of carditis | ☐ Auscultation? ☐ Other (please list) ☐ Unknown/Not Available | |
| Method of diagnosis | ☐ Echocardiography? ☐ Other (please list) ☐ Unknown/Not Available | |

| Minor Diagnostic Criteria | | Comments |
|---|---|---|
| Fever? If yes, temp: | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Arthralgia | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Acute phase reactants? [Leukocytosis, elevated erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP)] | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Prolonged P-R interval on electrocardiogram (ECG)? Previous rheumatic fever or rheumatic heart disease? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

| **Evidence of preceding streptococcal infection:** Any one of the following is considered adequate evidence of infection: | | Comments |
|---|---|---|
| Increased antistreptolysin O or other streptococcal antibodies? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Positive throat culture for Group A beta-hemolytic streptococci? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Positive rapid direct Group A strep carbohydrate antigen test? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Positive rapid direct Group A strep carbohydrate antigen test? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

| Patient Outcome: | | Comments |
|---|---|---|
| Referred to Hospital? If yes, name of hospital: | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Discharged Home? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Other? Please specify. | | |
| Plan for secondary prophylaxis? If yes, type and dosage: | ☐ No ☐ Yes ☐ Unknown/ Not Available ☐ Unknown/ Not Available | |

| Diagnosis of Rheumatic Heart Disease | | |
|---|---|---|
| RHD? | ☐ No ☐ Yes<br>☐ Unknown/ Not Available | Comments: |
| Method of diagnosis: Auscultation-only? | ☐ No ☐ Yes<br>☐ Unknown/ Not Available | If yes,<br>☐ Screening<br>☐ Opportunistic<br>☐ Patient visit |
| Echocardiography-only? | ☐ No ☐ Yes<br>☐ Unknown/ Not Available | |
| If yes, | ☐ Screening Programme /Study?<br>☐ Opportunistic?<br>☐ Patient visit? Please describe. | |
| Method of diagnosis: Clinical examination followed by Echocardiography? | ☐ No ☐ Yes<br>☐ Unknown/ Not Available | If echo, please attach echo report |
| Per echo report, please tick all that apply: | ☐ Mitral Regurgitation | ☐ Mild<br>☐ Moderate<br>☐ Severe |
| | ☐ Mitral Stenosis | ☐ Mild<br>☐ Moderate<br>☐ Severe |
| | ☐ Aortic Regurgitation | ☐ Mild<br>☐ Moderate<br>☐ Severe |
| | ☐ Aortic Stenosis | ☐ Mild<br>☐ Moderate<br>☐ Severe |
| | ☐ Pulmonary Regurgitation | ☐ Mild<br>☐ Moderate<br>☐ Severe |
| | ☐ Pulmonary Stenosis | ☐ Mild<br>☐ Moderate<br>☐ Severe |
| | ☐ Tricuspid Regurgitation | ☐ Mild<br>☐ Moderate<br>☐ Severe |
| | ☐ Tricuspid Stenosis | ☐ Mild<br>☐ Moderate<br>☐ Severe |



# 2.6 Secondary/Tertiary Facility Patient Health Services Utilisation

Limited Retrospective Report

Subject ID Number:

Number of Clinic Visits in last 12 months:

This visit:

- ☐ Patient received outpatient services only
- ☐ Patient received inpatient services only
- ☐ Patient received both in and outpatient services
- ☐ Patient received cardiac surgical services for RHD-related condition at a referral facility. If yes, please provide details:

Number of Routine RHD Follow-up Visits in last 12 months:

- ☐ Clinic visits only:
- ☐ For medication:
- ☐ For ECG:
- ☐ For Echo:
- ☐ For Chest Xray:
- ☐ For INR (Patient on warfarin):
- ☐ For additional test:

  Please describe:

Other non-RHD-related Visits in last 12 months:

- ☐ Other Outpatient Clinic, Please describe:
- ☐ Other Inpatient Admission, Please describe:

Urgent/Emergent Care Visits in last 12 months:

1. Date: DD / MM / YYYY

   Complaint:

   Diagnosis:

2. Date: DD / MM / YYYY

Complaint:

Diagnosis:

3. Date: DD / MM / YYYY

Complaint:

Diagnosis:

4. Date: DD / MM / YYYY

Complaint:

Diagnosis:

If more than 4 visits, please provide additional information below, including dates, complaints and diagnoses.

## Secondary Prophylaxis

Is there a plan for secondary prophylaxis?

- Yes If yes, what? (Type/Dosage):
- No
- Unknown/Not Available

- BPG Injections
  - No prescribed past 12 months?
  - No received past 12 months?
- Oral Pen VK
  - No of prescriptions given past 12 months?
  - No prescriptions filled past 12 months?
- Other
  - Details:

Problems with secondary prophylaxis during the past 12 months?

Yes No Unknown

If yes, please tick all that apply

- Stock-outs
- Pain
- Bleeding
- Anaphylaxis
- Cost/No money
- Other(please describe):



If yes, is patient back on a secondary prophylaxis regime?

Yes No Unknown/Not Available

Please describe if and how the problem(s) were resolved, if known:

| RHD Past medical history | | Comments |
|---|---|---|
| History of sore throat | No Yes Unknown/ Not Available | |
| ARF | No Yes Unknown/ Not Available | |
| Stroke | No Yes Unknown/ Not Available | |
| Infective endocarditis | No Yes Unknown/ Not Available | |
| Heart failure | No Yes Unknown/ Not Available | |
| Atrial fibrillation | No Yes Unknown/ Not Available | |
| Systemic embolism | No Yes Unknown/ Not Available | |
| NYHA classification | I II III IV Unknown | |
| **Procedures:** | | **Comments** |
| Heart catheterisation? | No Yes Unknown/ Not Available | |
| If yes, procedure date: | Unknown/ Not Available | |
| If yes, facility where performed: | Unknown/ Not Available | |
| Heart valve surgery? | No Yes Unknown/ Not Available | |
| If yes, procedure date: | Unknown/ Not Available | |
| Valve repair? Detail of procedure: | No Yes Unknown/ Not Available | |
| Valve replacement? Detail of procedure: | No Yes Unknown/ Not Available | |
| If yes, facility where performed: | Unknown/ Not Available | |

| Patient Outcome: | | Comments |
|---|---|---|
| Was the patient referred to another hospital during the past 12 months? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| If yes, name of hospital: | ☐ Unknown/ Not Available | |
| Discharged Home? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Other? Please specify. | | |

| Mortality: | | Comments |
|---|---|---|
| Did the patient die during the record review period? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Cause of Death | ICD Codes for admission/ discharge | Date of Death |
| 1. | ☐ Unknown/ Not Available | |
| 2. | ☐ Unknown/ Not Available | |
| 3. | ☐ Unknown/ Not Available | |
| ☐ Unknown/ Not Available | | |
| Was patient pregnant at the time of death? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |
| Was patient within 42 days of delivery at time of death? | ☐ No ☐ Yes ☐ Unknown/ Not Available | |

Data Collector Name
Date

Data Collection



# 2.7 Pregnancy

Please attempt to complete all pregnancy and delivery outcomes.

Subject ID No.

| | |
|---|---|
| Is the patient currently pregnant? ☐ No ☐ Yes ☐ Unknown/ Not Available<br><br>Pregnant in the past year? ☐ No ☐ Yes ☐ Unknown/ Not Available | If yes, please proceed with this section of the CRF. Please attempt to complete the outcome section of this form as possible beyond the designated time period. |

| If currently Pregnant | | Comments |
|---|---|---|
| Due Date: | ☐ Unknown | |
| Delivery Date: | ☐ Unknown | |
| Para: | ☐ Unknown | |
| Gravida: | ☐ Unknown | |

| Pregnancy outcome | | Comments |
|---|---|---|
| Delivery took place in hospital<br>Name of Hospital: | ☐ No ☐ Yes ☐ Unknown | |
| Delivery took place outside of hospital<br>Please describe location: | ☐ No ☐ Yes ☐ Unknown | |
| Delivery at >38 weeks | ☐ No ☐ Yes ☐ Unknown | |
| Preterm Delivery at<br>_____weeks | ☐ No ☐ Yes ☐ Unknown | |
| Birth weight known?<br>If yes,<br>☐ >2000<br>☐ <2000 | ☐ No ☐ Yes ☐ Unknown | |
| Caesarean Section | ☐ No ☐ Yes ☐ Unknown | |
| Fetal Demise | ☐ No ☐ Yes ☐ Unknown | |
| Cause of Death:<br><br>Date: | ☐ No ☐ Yes ☐ Unknown<br>☐ No ☐ Yes ☐ Unknown | |

Other complications:
Please describe. Cause of Death:

Data Collector Name
lection Date

Data Col-

# DISEASE-SPECIFIC CAPACITY ASSESSMENT

## INTRODUCTION

Alongside the review of clinical records, a series of facility surveys should be conducted to assess current capacity to deliver care for sore throat, ARF, and RHD. Facility surveys would be an important aspect of needs assessment because they could be used to determine whether or not sufficient resources are present to deliver adequate care for RHD.

The facility surveys generally draw on the TIPS framework, which assesses GAS, ARF, and RHD care comprehensively within 25 unique domains that cover the primary, secondary, and tertiary level resources needed to deliver RHD care.

## OBJECTIVES

1. Quantify the presence (or absence) of key human resources, medications, diagnostics, and clinical guidelines and care pathways that would be required for delivering care for sore throat, ARF, and RHD
2. Identify the various resource constraints and potential opportunities to improve care at primary, secondary, and tertiary facility levels. This exercise would include a GPS mapping of all health facilities at the site

## METHODS

Similar to the clinical record review, this survey would involve the sampling of facilities. The same facilities selected for the record review should also be subject to the surveys reproduced below. Key stakeholders at each facility should be identified by the countries and by on-the-ground collaborators.

Since this review could be quite complex for some facilities, covering multiple departments in a single health facility, it is likely that more than one informant would need to be involved. The form sections are thus designed for multiple respondents.

## IMPLICATIONS AND DISSEMINATION

The review of facility capacity would be used to describe the needs around clinical care for sore throat, ARF, and RHD at the site. Resource and capacity issues are health systems issues at the local level, therefore they will also feed into the health system performance appraisal that would need to be conducted as part of intervention monitoring and evaluation. They would also, of course, be some of the key inputs, processes, and outputs for monitoring and evaluation.

Beyond the NAT, these instruments could inform the development of an RHD "scorecard" that would capture readiness to act on RHD from the point of view of a local (or regional or national) health system. This scorecard could be developed and validated in other settings and disseminated broadly to ministries of health in endemic countries.

# 2.8
# Primary Care Facility Survey

Person Conducting Interview:

Date(s) of Interview:

Facility Name and Country:

Facility Type

- Public/government
- Private for-profit
- Private not-for-private
- Philanthropic/Charity/ NGO/faith-based
- Dispensary (Chemist)

Population Served (as defined by each country)

- Rural
- Urban
- Other. Please describe

Service Area

- Village
- District
- Regional
- Other, please describe

| | |
|---|---|
| IEC/IRB Approval Number and Date | |
| Name of Person Providing Information: | |
| Title: | |
| Email (Primary): | |
| Email (Secondary) | |
| Mailing Address: | |
| Physical Address: | |
| GPS coordinates of facility: | |
| Phone (Office): | |
| Phone (Cell): | |
| Alternate Contact Person Name: | |
| Title: | |
| Email (Primary) | |
| Phone (Office) | |
| Phone (Cell): | |
| Other Comments: | |



| How much* do patients typically pay out of pocket for: | Sore throat | ARF/secondary prevention | RHD outpatient care |
|---|---|---|---|
| Clinic Visits | / visit<br>Comments:** | / visit | / visit<br>Comments:** |

| Medications | | Comments: |
|---|---|---|
| Oral penicillin tablets | /month | |
| BPG | /month | |
| Oral penicillin syrup | /month | |
| Warfarin | /month | |
| Aspirin | /month | |
| ACE inhibitor (e.g., captopril, enalapril, lisinopril) | /month | |
| Beta blocker (e.g., atenolol, carvedilol, propranolol) | /month | |
| Spironolactone | /month | |
| Furosemide | /month | |
| Digoxin | /month | |
| Comments:** | | |

| Diagnostics | | Comments: |
|---|---|---|
| Chest Xray | /test | |
| Electrocardiogram | /test | |
| Full blood count | /test | |
| INR | /test | |
| Electrocardiogram | /test | |
| Comments:** | | |

* May list in local currency or as a percentage of total costs, whichever is available.

** Please comment on any common exemptions, i.e., under-5, pregnant, HIV-positive.

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

Please describe the staffing structure at this Clinic:

- ☐ Physician
  - ☐ Full time ☐ Part-time ☐ _____ Days per week
- ☐ Clinical Officer (Mid-level Provider)
  - ☐ Full time ☐ Part-time ☐ _____Days per week
- ☐ Nurse
  - ☐ Full time ☐ Part-time ☐ _____ Days per week
- ☐ Medical/Nursing Assistant
  - ☐ Full time ☐ Part-time ☐ _____ Days per week
- ☐ Community Health Worker
  - ☐ Full time ☐ Part-time ☐ _____Days per week
- ☐ Pharmacist
  - ☐ Full time ☐ Part-time ☐ _____Days per week
- ☐ Laboratory Personnel
  - ☐ Full time ☐ Part-time ☐ _____ Days per week
- ☐ Administrative Manager
  - ☐ Full time ☐ Part-time ☐ _____ Days per week
- ☐ Administrative Personnel
  - ☐ Full time ☐ Part-time ☐ _____ Days per week
- ☐ Other. Please specify.

Clinic Days and Hours of Operation:

Number of patients seen in typical month:

Are follow-up patients given advance appointment dates and times?

☐ Yes ☐ No

Do patients typically present in this clinic for sore throat treatment?

☐ Yes ☐ No

Where else do people go for sore throat treatment?

- ☐ Government health centers
- ☐ Private health centers
- ☐ Philanthropic/Faith-based centers
- ☐ Private pharmacies
- ☐ Traditional healers
- ☐ Other. Please specify.

Who would most commonly treat sore throat?

- ☐ Community health workers
- ☐ Nurses
- ☐ Doctors
- ☐ Other. Please specify.

How common a problem is sore throat in primary care clinics for children?

Please describe any regular communications (formal or informal) between health clinic personnel and local schools on health issues.



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Diagnosis and Management of Sore Throat | |
|---|---|
| Do you have a clinic protocol for sore throat management? | ☐ yes ☐ no |
| How was the protocol or guideline developed? | |
| ☐ Developed locally | |
| ☐ Adapted from international guideline – please name: | |
| ☐ International guideline – please name: | |
| How do you identify which sort throats should receive treatment? | ☐ yes ☐ no |
| ☐ GAS throat swabs | |
| • Where are the swabs sent? | |
| • Is there a streptococcal reference laboratory? | ☐ yes ☐ no |
| ☐ Clinical criteria for identifying likely streptococcal guidelines | ☐ yes ☐ no |
| • What are the criteria? Please attach | |
| ☐ Clinical judgment, no guidelines | |
| What is the recommended treatment for GAS sore throat? | |
| ☐ Oral antibiotics | |
| • antibiotic | |
| • duration of therapy | |
| • dose frequency | |
| ☐ Intramuscular antibiotics | |
| • antibiotic | |
| • duration of therapy | |
| • dose frequency | |
| Do you give penicillin at this clinic for any indication?<br>☐ If yes, what route(s) do you administer it?<br>☐ Injection?<br>☐ Oral?<br>☐ Other? Please describe<br>What are the indications? ( please list in detail)<br>1. _____<br>2. _____<br>3. _____<br>4. _____ | ☐ yes ☐ no |
| Where are the guidelines used? | |
| ☐ Government health centers | |
| ☐ Private health centers | |
| ☐ Philanthropic centers | |
| ☐ Other, please describe: | |

Please comment on how often guidelines are used in practice:

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| | |
|---|---|
| Does this facility record cases of sore throat? | ☐ yes ☐ no |
| Do you keep a record of patients referred for further treatment? | ☐ yes ☐ no |
| Clinic Medical Record Format<br>☐ Paper Only<br>☐ Electronic Only<br>☐ Electronic and Paper<br>Additional comments: | |
| Are any Death Records recorded or maintained at this clinic?<br>If no, please describe nearest access to local death records. | ☐ yes ☐ no |
| Is there a register for ARF/RHD secondary prophylaxis at this clinic? | ☐ yes ☐ no |
| If yes, when was the register started?<br>By whom? | |
| What form is your register?<br>☐ Paper<br>☐ Electronic<br>☐ Paper and electronic in different places | |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| | |
|---|---|
| Have you received any training on identifying or treating ARF? | ☐ yes ☐ no |
| If yes, please describe what, by whom and when training was provided: | |
| What are the symptoms of ARF? | ☐ Don't know<br>_____<br>_____<br>_____<br>_____ |
| Have you seen any patients with ARF? | ☐ No ☐ Yes<br>☐ Unknown/ Not Available |
| What would you do if you saw a patient you think may have ARF? | ☐ Don't know<br>_____<br>_____ |
| Where would you send them? | ☐ Don't know<br>_____<br>_____ |



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

What happens when people:

- Move away and need to be referred to another register?
  - ☐ Don't know

  _____
- Move away and need to be referred to another register?
  - ☐ Don't know

  _____
- Can't be contacted?
  - ☐ Don't know

  _____
  - Are they removed from the register?
    - ☐ Yes ☐ No
    - ☐ Don't know

    _____
- Die?
  - ☐ Don't know

  _____
  - Are they removed from the register?
    - ☐ Yes ☐ No
    - ☐ Don't know

    _____
- Are there registers for other diseases? i.e., tuberculosis, diabetes or others?
  - ☐ Yes ☐ No
  - ☐ Don't know

  _____

  If yes, please list:

  _____

  _____

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Secondary Prophylaxis for RHD Patients | | Comments: |
|---|---|---|
| Is secondary prophylaxis for ARD/RHD usually available at this clinic?" | ☐ No ☐ Yes ☐ Don't know | |
| Do you keep a list of RHD patients who are on secondary prophylaxis? | ☐ No ☐ Yes ☐ Don't know | |
| What proportion of RHD patients are on secondary prophylaxis? (Estimate)<br>Proportion of patients on Injection Prophylaxis:<br>Proportion of patients on Oral Prophylaxis: | _____%<br>_____%<br>_____% | |
| How do people access secondary prophylaxis? | | |
| ☐ Provided by Clinic<br>• Who do you notify when more stock is needed? | ☐ No ☐ Yes | |
| ☐ Provided to patient at no charge | | |
| ☐ Purchased by patients at the health center | | |
| ☐ Purchased by patients from other pharmacies | | |
| Approximately how often do patients miss out on secondary prophylaxis because medication is out of stock? | | |
| What happens when medication is out of stock or can't be provided? | | |
| ☐ Patients told to return later | | |
| ☐ Oral alternative offered | | |
| ☐ Patients told to buy supply privately and bring in for administration | | |
| ☐ Other: please outline | | |
| Are any strategies in place to encourage adherence?<br>Please describe | ☐ No ☐ Yes ☐ Don't know | |
| Are there guidelines on the frequency of secondary prophylaxis injections | ☐ No ☐ Yes ☐ Don't know | |
| ☐ Two weekly | | |
| ☐ Three weekly | | |
| ☐ Four weekly | | |
| ☐ Other: please describe | | |
| Is the dose of Benzathine Penicillin (BPG) altered for children?<br>Please describe how | ☐ No ☐ Yes ☐ Don't know | |
| Who delivers secondary prophylaxis injections? | | |
| ☐ Community health workers | | |
| ☐ Registered nurses | | |
| ☐ Doctors | | |
| ☐ Other: please describe | | |



| Is training provided on: | |
|---|---|
| Intramuscular injection technique | ☐ No ☐ Yes ☐ Don't know |
| Diagnosis and emergency management of anaphylaxis | ☐ No ☐ Yes ☐ Don't know |
| Are any techniques used to minimise the pain of injection? | ☐ No ☐ Yes ☐ Don't know |
| Are any techniques used to encourage / incentivise attendance? | ☐ No ☐ Yes ☐ Don't know |
| Are patients also able to access secondary prophylaxis at | ☐ Don't know |
| ☐ As part of an outreach programme in homes | ☐ No ☐ Yes ☐ Don't know |
| ☐ In schools | ☐ No ☐ Yes ☐ Don't know |
| ☐ Other: please describe | |
| Are injections recorded when they are given | ☐ No ☐ Yes ☐ Don't know |
| • Where are they recorded? ☐ Don't know | |
| ☐ Patient held injection books | |
| ☐ Injection books at the clinic | |
| ☐ Notified to the register | |
| What is your most common formulation of BPG? ☐ Don't know | |
| ☐ Premixed liquid | |
| • Do you have problems with | |
| ☐ Maintaining a cold chain | |
| ☐ Anaphylaxis or adverse drug reactions | |
| ☐ Other, please describe | |
| ☐ Powder for reconstitution | |
| • Do you have problems with | |
| ☐ Difficulty reconstituting powder | |
| ☐ Breakthrough episodes of ARF on prophylaxis | |
| ☐ Intermittent supply of powdered BPG | |
| ☐ Anaphylaxis or adverse drug reactions | |
| ☐ Other, please describe: | |
| • What is the powder mixed with? What volume? | |
| Have you had any problems with reactions to penicillin | ☐ No ☐ Yes ☐ Don't know |
| If so, do you know how to deal with penicillin reactions? | ☐ No ☐ Yes ☐ Don't know |
| Do you have a supply of adrenaline to manage anaphylaxis? | ☐ No ☐ Yes ☐ Don't know |
| Has your programme had any deaths from anaphylaxis or adverse drug reaction in the last 12 months? | ☐ No ☐ Yes ☐ Don't know |
| • How many? | |
| • Please describe events, community and staff reactions in as much detail as possible | |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Additional Clinic Pharmacy Resources | |
|---|---|
| Which of these drugs are regularly stocked in your clinic? | ☐ Don't know |
| ☐ Oral furosemide | ☐ Don't know |
| ☐ IV furosemide | ☐ Don't know |
| ☐ Spironolactone | ☐ Don't know |
| ☐ Any beta blocker (e.g., atenolol, carvedilol, propranolol) | ☐ Don't know |
| ☐ Any ACE inhibitor (e.g., captopril, enalapril, lisinopril) | ☐ Don't know |
| ☐ Aspirin | ☐ Don't know |
| *Anticoagulants and vitamin K outlined in Anticoagulation section | |
| What forms of contraception are freely available? | |
| ☐ Oral contraceptive pill | |
| ☐ Intrauterine Device (IUD) | |
| ☐ Implantable subdermal implants | |
| ☐ Barrier contraception | |
| Who orders supplies of BPG? _____ | ☐ Don't know |
| Who are they purchased from? _____ | ☐ Don't know |
| Who pays for them? _____ | ☐ Don't know |
| How is stock tracked and new stock ordered? _____ | ☐ Don't know |
| What brand(s) of BPG do you use? _____ | ☐ Don't know |
| Cost of BPG per vial (to the clinic) _____ | ☐ Don't know |
| Any other antibiotics used? _____ | ☐ Don't know |
| Challenges in accessing supply? (ie transport, ordering, stock level monitoring) _____ _____ | ☐ Don't know |



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

Photographs of BPG vials, count total number, record expiry date, collect samples for analysis.

| Laboratory Services | | Comments: |
|---|---|---|
| Does your facility have access to throat swabs and culture? | ☐ No ☐ Yes ☐ Don't know | |
| Does your facility have access to rapid GAS throat swabs? | ☐ No ☐ Yes ☐ Don't know | |
| Are the swabs sent for emm typing? If so, where? | ☐ No ☐ Yes ☐ Don't know | |
| Are records of invasive streptococci kept? If yes, please describe record-keeping process. | ☐ No ☐ Yes ☐ Don't know | |

Do you have access to these other laboratory services? (Tick as many as apply)

| | | |
|---|---|---|
| ☐ Antistreptolysin O Titre (ASOT)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ C Reactive Peptide (CRP)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ Full blood count<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ |
| ☐ Anti DNase B (ADB)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ Erythrocyte Sedimentation Rate (ESR)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ International Normalised Ratio (INR)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ |

How are results communicated to clinicians?

_____

_____

Other comments:

_____

_____

_____

_____

_____

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| INR Management | | Comments: |
|---|---|---|
| How many of your clinic patients are on warfarin? | ☐ No ☐ Yes ☐ Don't know | |
| Is there access to other anticoagulants? | ☐ No ☐ Yes ☐ Don't know | |
| ☐ Aspirin | | |
| ☐ Heparin by infusion | | |
| ☐ Low molecular weight heparin (ie enoxaparin, clexane) | | |
| ☐ Thienopyridine antiplatelet agents (plavix, clopidogrel) | | |
| Do patients on warfarin have their INR monitored? | ☐ No ☐ Yes ☐ Don't know | |
| • Where can people get their INR checked? | | |
| ☐ At this clinic | | |
| ☐ Local pharmacy | | |
| ☐ Local laboratory | | |
| ☐ Local INR clinic | | |
| ☐ Only in secondary or tertiary settings | | |
| • Are the tests | | |
| ☐ Venous blood samples | ☐ No ☐ Yes ☐ Don't know | |
| • Where are blood tests sent? | ☐ Don't know | |
| • How are results reported (ie: phone, electronic, paper) | ☐ Don't know | |
| • How many days does it take for results to come back | ☐ Don't know | |
| ☐ Finger prick point-of-care machines | ☐ No ☐ Yes ☐ Don't know | |
| Who is responsible for altering the dose of warfarin? | | |
| Do you have access to Vitamin K for warfarin reversal? | ☐ No ☐ Yes ☐ Don't know | |
| Is there record book of INR results? | ☐ No ☐ Yes ☐ Don't know | |
| Do patients keep their own copy of INR records? | ☐ No ☐ Yes ☐ Don't know | |
| Do patients pay for INR testing? | ☐ No ☐ Yes ☐ Don't know | |
| • How much does one INR test cost? | ☐ Don't know | |
| Approximately how often do stable patients have their INR checked? _____ /year | ☐ Don't know | |



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

## Nearest Referral Facility

Name and address of nearest referral facility:

Distance/Travel Time to nearest referral facility:

| Nearest Facility Type | | |
|---|---|---|
| ☐ Public | ☐ Health Center | ☐ District |
| ☐ Private for-profit | ☐ District Hospital | ☐ Regional |
| ☐ Private not-for-private | ☐ Central/referral Hospital | ☐ Provincial |
| ☐ Philanthropic/Charity/ NGO | ☐ Specialty Hospital | ☐ Other, please describe |

Nearest Referral Facility Services:

- ☐ Cardiologist/Cardiology Clinic
- ☐ CT/MRI
- ☐ Echocardiography
- ☐ Cath lab
- ☐ Interventional Cardiology
- ☐ Pediatric Cardiologist/Cardiology Clinic
- ☐ Cardiac Surgery
- ☐ Intensive Care
- ☐ Screening facilities for prosthetic valves
- ☐ Other

Other comments:

| | |
|---|---|
| Are cardiac surgical follow-up services provided? | ☐ No ☐ Yes |
| Typical Bed Availability/Inpatient Bed Wait Time? | |
| Average Clinic Appointment Wait Time? | |
| Is public patient transport to referral facility available? | ☐ No ☐ Yes |
| If yes, please describe mode of transport, frequency, wait time, cost to patient. | |

## Post Cardiac Surgical Services and Follow up Care

| | |
|---|---|
| Have you provided care for anyone who has received heart surgery for RHD? | ☐ No ☐ Yes |
| Did you receive post-operative instructions and advice? | ☐ No ☐ Yes |
| Did you know who to contact if you were worried about the patient? | ☐ No ☐ Yes |

## Clinic Personnel Knowledge of Surgical Options

| | |
|---|---|
| Are you aware of a waiting list of people who would benefit from surgical intervention for RHD? | ☐ No ☐ Yes |
| Who decides which people would benefit from surgery? | |
| Please describe any clinical criteria used if known. | |

| | |
|---|---|
| What restrictions apply to someone considered suitable for surgery? (For example: adherence to previous therapy, geographic location, women of reproductive age.) | |
| Please describe the process of a patient being put on the waiting list. | |
| How many people are on the waiting list if known? As of what date? | |
| What is the estimated average time to be on the waiting list (in months)? | |
| Who decides which people would benefit from surgery? | |
| Please describe any clinical criteria used if known. | |



# 2.9 Independent Dispensary Facility Survey

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Which of these drugs are regularly stocked in your Dispensary? | Average monthly cost to patient? | Comments: |
|---|---|---|
| ☐ Oral furosemide | ☐ _____/currency ☐ Don't know | |
| ☐ Spironolactone | ☐ _____/currency ☐ Don't know | |
| ☐ Any beta blocker (e.g., atenolol, carvedilol, propranolol) | ☐ _____/currency ☐ Don't know | |
| ☐ Any ACE inhibitor (e.g., captopril, enalapril, lisinopril) | ☐ _____/currency ☐ Don't know | |
| ☐ Aspirin | ☐ _____/currency ☐ Don't know | |
| ☐ Warfarin | ☐ _____/currency ☐ Don't know | |
| ☐ Clopidrogrel | ☐ _____/currency ☐ Don't know | |
| ☐ Other anticoagulant | ☐ _____/currency ☐ Don't know | |
| ☐ Digoxin | ☐ _____/currency ☐ Don't know | |

| Do you dispense any of the below? | Average monthly cost to patient? | Comments: |
|---|---|---|
| ☐ Oral contraceptive pill | ☐ _____/currency ☐ Don't know | |
| ☐ Barrier contraception | ☐ _____/currency ☐ Don't know | |

**Penicillin**

| Which of these drugs are regularly stocked in your Dispensary? | Average monthly cost to patient? | Comments: |
|---|---|---|
| ☐ Oral penicillin tablets | ☐ _____/currency ☐ Don't know | |
| ☐ BPG | ☐ _____/currency ☐ Don't know | |
| ☐ Oral penicillin powder for reconstitution | ☐ _____/currency ☐ Don't know | |

**BPG**

| | | |
|---|---|---|
| What is your most common formulation of BPG?<br>☐ Premixed liquid<br>☐ Powder for reconstitution<br>☐ Other, please describe: | ☐ Don't know | |
| What is the powder mixed with? _____<br>What volume? _____ | ☐ Don't know | |

| | | |
|---|---|---|
| Who orders your supplies of BPG? | ☐ Don't know | |
| Who are they purchased from? | ☐ Don't know | |
| **BPG** | | |
| How is stock tracked and new stock ordered? | ☐ Don't know | |
| What brand(s) of BPG do you use? | ☐ Don't know | |
| Cost of BPG | ☐ Don't know | |
| Any other injectable antibiotics used? | ☐ Don't know | |
| **Oral Penicillin Tablets** | | |
| Who orders your supplies of Oral Penicillin tablets? | ☐ Don't know | |
| Who are they purchased from? | ☐ Don't know | |
| How is stock tracked and new stock ordered? | ☐ Don't know | |
| What brand(s) of Oral Penicillin do you use? | ☐ Don't know | |
| Cost of Oral Penicillin | _____/currency<br>☐ Don't know | |
| **Oral Penicillin for Reconstitution** | | |
| Who orders your supplies of Oral Penicillin powder for reconstitution? | ☐ Don't know | |
| Who are they purchased from? | ☐ Don't know | |
| Are there challenges with maintaining the cold chain?<br>If yes, please describe: | ☐ No ☐ Yes<br>☐ Don't know | |
| How is stock tracked and new stock ordered? | ☐ Don't know | |
| What brand(s) of Oral Penicillin Powder do you use? | ☐ Don't know | |
| Cost of Oral Penicillin | _____/currency<br>☐ Don't know | |
| Any other oral antibiotics used that have not been mentioned previously in the survey?<br>If yes, please describe: | ☐ No ☐ Yes<br>☐ Don't know | |



Pharmacy site visit:

Date: DD / MM / YYYY

Name and Title of Person in Charge:

Observations:

Photographs of BPG vials, count total number, record expiry date, collect samples for analysis.

Data Collector Name
Date

Data Collection

# 2.10
# Secondary/Tertiary Facility Survey

Person Conducting Interview:

Date(s) of Interview:

| Facility Name and Country: | |
|---|---|

Facility Type

- ☐ Public/government
- ☐ Private for-profit
- ☐ Private not-for-private
- ☐ Philanthropic/Charity/ NGO/faith-based
- ☐ Secondary
- ☐ Tertiary
- ☐ District
- ☐ Regional
- ☐ Provincial
- ☐ Other, please describe

| | |
|---|---|
| IEC/IRB Approval Number and Date | |
| Name of Person Providing Information: | |
| Title: | |
| Email (Primary): | |
| Email (Secondary): | |
| Mailing Address: | |
| Physical Address: | |
| GPS coordinates of facility: | |
| Phone (Office): | |
| Phone (Cell): | |
| Alternate Contact Person Name: | |
| Title: | |
| Email (Primary): | |
| Phone (Office): | |
| Phone (Cell): | |

| Training Programmes affiliated with this Facility: | Educational Institution Name/Location |
|---|---|
| ☐ Medical Students | |
| ☐ Specialists (Residents/Fellows) | |
| ☐ Professional Nurses | |
| ☐ Pharmacists | |
| ☐ Other. Please specify | |



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| How much* do patients typically pay out of pocket for: | ARF | Acute RHD |
|---|---|---|
| Inpatient consultations | /day<br>Comment:** | /day<br>Comment:** |

| Medications | | Comments: |
|---|---|---|
| Warfarin | /dose | |
| Penicillin (oral or benzathine) | /dose | |
| Aspirin | /dose | |
| ACE inhibitor (e.g., captopril, enalapril, lisinopril) | /dose | |
| Beta blocker (e.g., atenolol, carvedilol, propranolol) | /dose | |
| Spironolactone | /dose | |
| Furosemide (IV) | /dose | |
| Furosemide (oral) | /dose | |
| Digoxin | /dose | |

Comments:**

| Diagnostics | | Comments: |
|---|---|---|
| Chest Xray | /test | |
| Electrocardiogram | /test | |
| Full blood count | /test | |
| INR | /test | |
| Echocardiogram | /test | |

Comments:

* May list in local currency or as a percentage of total costs, whichever is available.

** As in outpatient form, please describe any important exemptions (e.g., pregnant, HIV-positive)

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Service Area: Geographic and Number Served | | |
|---|---|---|
| Number of Inpatient Beds | | |
| Number of Theatres | | |
| Number of Casualty Beds | | |
| Service: | No. of beds / Typical Occupancy (Census) | No of Medical Officers /Specialists |
| General Medical | _____ / _____% | |
| General Surgical | _____ / _____% | |
| Intensive Care | _____ / _____% | |
| Obs/Gyn | _____ / _____% | |
| Paediatrics | _____ / _____% | |
| Orthopaedics | _____ / _____% | |
| Psychiatry | _____ / _____% | |
| Other Please specify. | _____ / _____% | |
| Other. Please specify. | _____ / _____% | |
| Does the facility have an intensive care unit? | | ☐ yes ☐ no |
| ICU nurses? | | ☐ yes ☐ no |
| Echocardiography? | | ☐ yes ☐ no |
| Cath lab | | ☐ yes ☐ no |
| Screening facilities for prosthetic valves? | | ☐ yes ☐ no |
| Are there other facilities/resources available, which you feel are important in the ability to provide post-operative care?<br>Comment: | | ☐ yes ☐ no |
| Are there cardiac surgical rehabilitation programmes for patients and families? | | ☐ yes ☐ no |
| Are cardiac surgical follow-up services provided?<br>If yes, please describe | | ☐ yes ☐ no |



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Diagnosis and management of ARF | |
|---|---|
| Are guidelines or criteria for diagnosis of ARF used? | ☐ yes ☐ no |
| - Which criteria are used? (please attach a copy) | |
| ☐ Revised Jones Criteria | |
| ☐ WHO Criteria | |
| ☐ Other – please specify: | |
| - Are categories of diagnosis utilised? (for example: possible, definite, echo confirmed – please describe) | ☐ yes ☐ no |
| - What resources are available to aid diagnosis? | |
| ☐ Thermometer | |
| ☐ Stethoscope | |
| ☐ ECG | |
| - Who reads and interprets the ECG? | |
| ☐ Blood tests (see laboratory section for blood tests available) | |
| ☐ Acute access to echocardiography | |
| - Who reads and interprets the ECHO? | |
| - Are people with suspected ARF admitted to hospital? | ☐ yes ☐ no |
| - Where is the diagnosis of ARF recorded? | ☐ Unknown |
| ☐ Patient's clinical notes | |
| ☐ Patient held medical records | |
| ☐ Diagnosis book | |
| ☐ Register | |
| Are there guidelines for the management of ARF? (please attach a copy) | ☐ yes ☐ no |
| - What does management of ARF include? | |
| ☐ Bed rest | |
| - recommended for how long? | |
| ☐ Aspirin | |
| ☐ Antibiotics | |
| ☐ Steroids | |
| ☐ Other (Please describe) | |

| | |
|---|---|
| Please describe what happens when someone is diagnosed with RHD: | |
| ☐ Referral (please describe where to and how) | |
| ☐ Education (please describe any patient education undertaken/in process) | |
| ☐ Begins prophylaxis | |
| ☐ Is given a prophylaxis card | |
| ☐ Other, please describe | |
| A woman with RHD becomes pregnant: | |
| ☐ Referral (please describe where to and how) | |
| ☐ Education (please describe the education process) | |
| Someone with RHD is clinically deteriorating | |
| ☐ Referral (please describe where to and how) | |
| ☐ Admission to hospital (please describe where to and how) | |
| ☐ Added to wait list for surgery | |
| ☐ Palliative management (please describe process) | |
| Someone with RHD has symptoms of infective endocarditis | |
| ☐ Referral (please describe where to and how) | |
| - Do you have access to blood cultures | ☐ yes ☐ no |
| - Do you have access to long-term IV antibiotics? | ☐ yes ☐ no |
| Someone with RHD has symptoms of stroke | |
| ☐ Referral (please describe where to and how) | |
| - Do you have access to CT to establish whether ischemic or hemorrhagic? | ☐ yes ☐ no |
| - Do you have access to stroke rehabilitation services? | ☐ yes ☐ no |
| Someone with RHD dies. Is the cause of death recorded? | ☐ yes ☐ no |
| - Where? | |
| ☐ Death certificate | |
| ☐ Deaths book at clinic | |
| ☐ Government agency | |
| - How is the RHD register notified? | |



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Surgical/Interventional Services | |
|---|---|
| Does your facility provide interventional services? | ☐ yes ☐ no |
| ☐ Balloon valvuloplasty | |
| ☐ Valve repair | |
| ☐ Bioprosthetic valve replacement | |
| ☐ Mechanical valve replacement | ☐ yes ☐ no |
| - Can all patients have expert preoperative echocardiography locally? | ☐ yes ☐ no<br>If yes, please supply details: _____ |
| If services are referred to outside facilities, where are services delivered? | |
| Name of Referral Facility: | |
| ☐ In the same country with local surgeons | |
| ☐ In the same country with visiting surgeons | |
| How many visiting surgical providers are there? | |
| How often do they visit? | |
| ☐ Patients travel overseas for interventions (informally arranged) | |
| ☐ At regional center for excellence | |
| How many people have received cardiac surgery in the last 12 months? : | |
| Age distributions | |
| 30-day mortality | |
| 5-year mortality | |
| Morbidity | |
| Interviews with surgeons | |
| Are patients referred appropriately for surgery? Please elaborate. | ☐ yes ☐ no |
| Do you see your patients for follow-up? | |
| What are the challenges in delivering surgical care? | |

| Access to Care/Surgical Options | |
|---|---|
| Is there a wait listing of people who would benefit from surgical intervention for RHD? | ☐ yes ☐ no |
| Who decides which people would benefit from surgery? | |

| | |
|---|---|
| Please describe any clinical criteria used: | |
| What restrictions apply to someone considered suitable for surgery? (For example: adherence to previous therapy, geographic location, women of reproductive age.) | |
| Describe the process to discuss the waiting list and triage with surgical teams | |
| How many people are on the waiting list?<br>As of what date? | |
| What is the estimated average time to be on the waiting list (in months)? | |
| How is the waiting list triaged? | |
| Is there a pre-operative work up protocol? | ☐ yes ☐ no |
| - Can all patients have expert preoperative echocardiography locally? | ☐ yes ☐ no |
| - Do all patients have dental review and optimisation? | ☐ yes ☐ no |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Registers - Inpatient Admissions (Incidence and Prevalence) | |
|---|---|
| Please provide a copy of the data headings of the **Inpatient Admission Register** | |
| Does this facility record inpatient admissions by diagnosis? | ☐ yes ☐ no |
| Does this facility record inpatient discharges by diagnosis? | ☐ yes ☐ no |
| Total number of inpatient admissions over 12-month period.<br>From: DD / MM / YYYY To: DD / MM / YYYY | |
| Total number of inpatient discharges over 12-month period (if applicable).<br>From: DD / MM / YYYY To: DD / MM / YYYY | |



| Inpatient Mortality | |
|---|---|
| Does this Facility's Death Log include Cause of Death? | ☐ yes ☐ no |
| Is any information regarding deaths occurring outside of the facility captured?<br>If yes, please describe. | ☐ yes ☐ no |
| Total number of all inpatient deaths over 12-month period.<br>From: DD / MM / YYYY To: DD / MM / YYYY | |

| RHD Registers – Outpatient Services | |
|---|---|
| Please provide a copy of the data headings of the **OPD Service Attendance Register** | |
| Is a casualty/emergency department Admissions/Attendance Register maintained separately? | ☐ yes ☐ no |
| Number of people on the OPD register over 12-month period (or number of patients on Cardiac Clinic Register if provided)<br>From: DD / MM / YYYY To: DD / MM / YYYY | |
| Is there an ARF/RHD Register? | ☐ yes ☐ no |
| Is this register populated per information provided from<br>☐ Outpatient Services Only<br>☐ Inpatient Services Only<br>☐ Both In and Outpatient Services | |
| How many patients in total are on the Register?<br>Total:_____<br>ARF:_____<br>RHD:_____ | |
| What happens when people: | |
| - Move away and need to be referred to another register? | |
| - Move into the area and need to be added to the register? | |
| - Can't be contacted? Are they removed from the register? | |
| - How is 'loss to follow-up' defined | |
| - Die? Are they removed from the register? | ☐ yes ☐ no |
| Are there registers for other diseases? i.e., tuberculosis, diabetes or others?<br>If yes, please list: _____ | ☐ yes ☐ no |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Laboratory services | | Comments: |
|---|---|---|
| Does your facility have access to throat swabs and culture? | ☐ No ☐ Yes ☐ Don't know | |
| Does your facility have access to rapid GAS throat swabs? | ☐ No ☐ Yes ☐ Don't know | |
| Are the swabs sent for emm typing? If so, where? | ☐ No ☐ Yes ☐ Don't know | |
| Are records of invasive streptococci kept? If yes, please describe record-keeping process. | ☐ No ☐ Yes ☐ Don't know | |

Do you have access to these other laboratory services? (Tick as many as apply)

| | | |
|---|---|---|
| ☐ Antistreptolysin O Titre (ASOT)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ C Reactive Peptide (CRP)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ Full blood count<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ |
| ☐ Anti DNase B (ADB)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ Erythrocyte Sedimentation Rate (ESR)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | ☐ International Normalised Ratio (INR)<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ |
| ☐ Blood cultures<br>☐ Available on site<br>☐ Sent to off-site laboratory<br>Days for results: _____ | Comments: | |



Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| For Secondary/Tertiary Facilities that Provide an Outpatient Cardiology/RHD/INR Service | |
|---|---|
| Do you keep a record of all patients visiting the clinic? | ☐ yes ☐ no |
| Do you keep a record of patients referred for further treatment? | ☐ yes ☐ no |
| Do you keep a list of patients who are on prophylaxis? | ☐ yes ☐ no |
| What proportion of RHD patients are on secondary prophylaxis? (Estimate)<br>Proportion of patients on injection prophylaxis: _____%<br>Proportion of patients on oral prophylaxis: _____ % | |
| How do people access Secondary Prophylaxis? | |
| ☐ Provided by OPD Clinic or Pharmacy | |
| - Who do you notify when more stock is needed? | ☐ Don't know |
| ☐ Purchased by patients at the health center | |
| ☐ Purchased by patients from other pharmacies | |
| Approximately how often do patients miss out on secondary prophylaxis because medication is out of stock? | ☐ Don't know |
| What happens when medication is out of stock or can't be provided? | ☐ Don't know |
| ☐ Patients told to return later | |
| ☐ Oral alternative offered | |
| ☐ Patients told to buy supply privately and bring in for administration | |
| ☐ Other: please outline | |
| Are any strategies in place to encourage adherence? Please describe. | ☐ Don't know |
| Are there guidelines on the frequency of secondary prophylaxis injections | ☐ Don't know |
| ☐ Two weekly | |
| ☐ Three weekly | |
| ☐ Four weekly | |
| ☐ Other: please describe | |
| Is the dose of BPG altered for children? Please describe how. | ☐ Don't know |
| Who delivers secondary prophylaxis injections? | ☐ Don't know |
| ☐ Community health workers | |
| ☐ Registered nurses | |
| ☐ Doctors | |
| ☐ Other: please describe | |

| | |
|---|---|
| Is training provided on: | |
| Intramuscular injection technique | ☐ No ☐ Yes ☐ Don't know |
| Diagnosis and emergency management of anaphylaxis | ☐ No ☐ Yes ☐ Don't know |
| Are any techniques used to minimise the pain of injection? | ☐ No ☐ Yes ☐ Don't know |
| Are any techniques used to encourage / incentivise attendance? | ☐ No ☐ Yes ☐ Don't know |
| Are patients also able to access secondary prophylaxis at | |
| ☐ Primary health clinics | ☐ No ☐ Yes ☐ Don't know |
| ☐ As part of an outreach programme in homes | ☐ No ☐ Yes ☐ Don't know |
| ☐ In schools | ☐ No ☐ Yes ☐ Don't know |
| ☐ Other: please describe | |
| Are injections recorded when they are given | ☐ No ☐ Yes ☐ Don't know |
| - Where are they recorded? | |
| ☐ Patient held injection books | |
| ☐ Injection books at the clinic | |
| ☐ Notified to the register | |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| OPD Pharmacy Service when Associated with Secondary/Tertiary Facility |
|---|
| What is your most common formulation of BPG? |
| ☐ Premixed liquid |
| - Do you have problems with |
| ☐ Maintaining a cold chain |
| ☐ Anaphylaxis or adverse drug reactions |
| ☐ Other, please describe |
| ☐ Powder for reconstitution |
| - Do you have problems with |
| ☐ Difficulty reconstituting powder |
| ☐ Breakthrough episodes of ARF on prophylaxis |
| ☐ Intermittent supply of powdered BPG |
| ☐ Anaphylaxis or adverse drug reactions |
| ☐ Other, please describe: |
| - What is the powder mixed with? _____ |
| What volume? _____ |



| | | |
|---|---|---|
| Do you have a supply of adrenaline to manage anaphylaxis? | | ☐ No ☐ Yes ☐ Don't know |
| Has your programme had any deaths from anaphylaxis or adverse drug reaction in the last 12 months? | | ☐ No ☐ Yes ☐ Don't know |
| - How many? | | |
| - Please describe events, community and staff reactions in as much detail as possible | | |
| Which of these drugs are regularly stocked in your Outpatient/ Clinic Pharmacy? | | ☐ Don't know |
| ☐ Oral frusemide | | |
| ☐ IV frusemide | | |
| ☐ Spirinolactone | | |
| ☐ Any beta blocker | | |
| ☐ Any ACE inhibitor | | |
| ☐ Aspirin | | |
| *Anticoagulants and vitamin K outlined in Anticoagulation section | | |
| What forms of contraception are freely available? | | ☐ Don't know |
| ☐ Oral contraceptive pill | | |
| ☐ IUD | | |
| ☐ Implantable subdermal implants | | |
| ☐ Barrier contraception | | |
| | | Comment: |
| Who orders supplies of BPG? | ☐ Don't know | |
| Who are they purchased from? | ☐ Don't know | |
| Who pays for them? | ☐ Don't know | |
| How is stock tracked and new stock ordered? | ☐ Don't know | |
| What brand(s) of BPG do you use? | ☐ Don't know | |
| Cost of BPG | ☐ Don't know | |
| Any other antibiotics used? | ☐ Don't know | |
| Challenges in accessing supply? (i.e. transport, ordering, stock level monitoring) | | ☐ Don't know |
| Pharmacy site visit:<br>Date:<br>Name and Title of Person in Charge:<br>Observations: | | |
| Photographs of BPG vials, count total number, record expiry date, collect samples for analysis. | | |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Anticoagulation Criteria and Management | | Comments: |
|---|---|---|
| What are the local clinical indications for warfarin? | ☐ Don't know | |
| ☐ Mechanical prosthetic valve replacements | | |
| ☐ Atrial fibrillation | | |
| ☐ Heart failure | | |
| Is there access to other anticoagulants? | ☐ No ☐ Yes ☐ Don't know | |
| ☐ Aspirin | | |
| ☐ Heparin by infusion | | |
| ☐ Low molecular weight heparin (ie enoxaparin, clexane) | | |
| ☐ Thienopyridine antiplatelet agents (plavix, clopidogrel) | | |

| INR Management Clinic when associated with Secondary/Tertiary Facility | | Comments: |
|---|---|---|
| How many patients are on warfarin? | ☐ Don't know | |
| Do patients on warfarin have their INR monitored? | ☐ No ☐ Yes ☐ Don't know | |
| - Where can people get their INR checked? | ☐ Don't know | |
| ☐ Local primary care clinic | | |
| ☐ Local pharmacy | | |
| ☐ Local laboratory | | |
| ☐ Local INR clinic | | |
| ☐ Only in secondary or tertiary settings | | |
| - Are the tests | | |
| ☐ Venous blood samples | ☐ Don't know | |
| - Where are blood tests sent? | ☐ Don't know | |
| - How are results reported (i.e.: phone, electronic, paper) | ☐ Don't know | |
| - How many days does it take for results to come back | ☐ Don't know | |
| ☐ Finger prick point-of-care machines | ☐ Don't know | |
| Who is responsible for altering the dose of warfarin? | ☐ Don't know | |
| Do you have access to Vitamin K warfarin reversal? | ☐ No ☐ Yes ☐ Don't know | |
| Is there record book of INR results? | ☐ No ☐ Yes ☐ Don't know | |



| | | |
|---|---|---|
| Do patients keep their own copy of INR records? | ☐ No ☐ Yes ☐ Don't know | |
| Do patients pay for INR testing? | ☐ No ☐ Yes ☐ Don't know | |
| - How much does one INR test cost? | ☐ Don't know | |
| Approximately how often do stable patients have their INR checked? _____ /year | ☐ Don't know | |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Medical Records | Comments: |
|---|---|
| Inpatient and Outpatient Clinic Records are consolidated into one record? | ☐ No ☐ Yes |
| Records are kept in<br>☐ Paper only<br>☐ Both Electronic and Paper<br>Comments: | |
| Records are archived after how many years?_____<br>When are Death Records archived? _____<br>Please describe other criteria for archiving. | |
| Archived records are kept<br>For how many years? _____<br>☐ On site? Please describe location.<br>☐ At a remote location? Please describe location. | |
| Are cause of death details recorded in the Death Register?<br>Please provide data headings of this Register. | ☐ No ☐ Yes |

Name:

Role of Key Informant for this section:

Date: DD / MM / YYYY

| Morgue Operators | |
|---|---|
| Are cause of death details recorded at morgue? | ☐ No ☐ Yes |
| Is there an autopsy record book? | ☐ No ☐ Yes |

# POLICY AND CLINICAL CONTEXT: COUNTRY PARTNER MODULE

## INTRODUCTION

Reviews of records and surveys of facilities should be complemented by a general understanding of the policies and procedures around ARF and RHD in the country and at the site in particular.

Information on this "context" could be obtained by means of brief interviews of key stakeholders (Country Partners, local NGOs, academic partners, health services partners).

## OBJECTIVES

To understand, qualitatively, the key policy issues around ARF and RHD in the areas of:

1. Health systems (especially human resources for health)
2. ARF and RHD policies and programmes
3. Clinical care guidelines and practices around ARF and RHD

## METHODS

This module should be administered to the country contact, who would answer the questions outlined in the interview guide in an open-ended format. The module could also be delivered as an interview or online or paper survey, depending on the contact's preference.

The amount of data gathered would be small in volume but rich in detail. Qualitative and quantitative Peer Groups should circulate these data and incorporate them into their data analyses and interpretation. However, this module "data" would not be subject to formal qualitative data analysis.

## IMPLICATIONS AND DISSEMINATION

These focused qualitative data should fill in several important gaps in what could be otherwise obtained through surveys of facilities, records, patients, and providers.

# 2.11
# Interview Guide for Country Contacts

## A THEME

General Health System Issues

Probe: What is your sense of the issues around human resources for health at the national, regional, and local levels?

- Are there any issues unique to NCDs or ARF/RHD in particular of which you are aware?

Probe: How are healthcare workers trained in your district/region?

- Physicians
- Nurses
- Allied health care professionals
- Community health care workers
- Other relevant to your system (e.g., clinical officers)

Probe: Describe the typical referral system in your district.

- How does a patient get from a health center to the district hospital?
- If the patient needs specialised/tertiary care, how does that occur?
- Are there common barriers to the referral process (e.g., road conditions, expense of travel, waiting lists)?

Probe: What are the estimated costs to patients for care in your region and how do these work?

- At the Dispensary Level?
- At the Clinic Level?
- At the District Level?
- At the Tertiary Level?
- What happens if a patient presents for care but cannot pay?

## B THEME

ARF/RHD Policies and Programmes

Probe: What is your understanding of ARF/RHD-related policies at the national, regional, or local level? For instance, around disease notification, screening, prevention, and treatment?

- If these policies exist, how do they integrate with other policies or programmes, e.g., around infectious diseases, adult chronic care, maternal/child health, etc.?
- What is your understanding of how these policies came to be? Can you describe the process of government engagement if they were initiated outside the ministry of health?
- Are other ministries besides health, e.g., education, finance, housing/development engaged in these policies?
- If there are gaps between promulgation and implementation for these policies, what are some of the perceived barriers? Opportunities for improvement?

Probe: What sort of leadership and oversight exists within the public (or private) health care sector regarding ARF/RHD prevention and control (again, at the national, regional, or local level)?
Please compare/contrast this with...

- Infectious diseases like HIV/AIDS, tuberculosis, or malaria
- Maternal and child health issues (including obstetric care and immunisation)
- Other NCDs, e.g. hypertension and cervical cancer

Probe: Are you aware of national, regional, or local NCD strategies and policies? How would ARF/RHD integrate with other relevant NCDs?

Probe: Please describe any ARF/RHD-related public health activities (e.g., awareness campaigns) or research programmes (e.g., echocardiography screening studies) that you are aware of at a national, regional, or local level.

## C THEME

RF/RHD Clinical Care

Probe: What guidelines, protocols (e.g., Revised Jones Criteria), or resources are you aware of (again, at the national, regional, and local levels) that help providers detect and manage...

- Strep throat
- ARF
- RHD
- How do these integrate with other guidelines (e.g., IMCI)?

Probe: What is the process for reviewing cases of RHD in your district, if any?

- Do you have an ARF or RHD registry? If so, tell us a bit about it.
- If not, are there medical record systems in place to review clinical cases and determine follow-up and referral plans?
- If so, are these systems being utilised? If not, do you know why?

Probe: For patients with RHD, is there a priority system for follow-up? How are priorities classified/defined (e.g., mild, moderate, severe RHD)?

Probe: Are people with RHD given care plans or pathways, and if so, are these plans standardised (e.g., using protocols or guidelines addressed above)?

Probe: When do you decide that someone needs to be referred for follow-up of known RHD? How often do you refer patients to a more specialised unit?

Probe: Suppose an RHD screening programme were to be implemented in your district. Is there capacity to deliver advanced medical or surgical care (either within the district or via a robust referral pathway) for cases of RHD identified through screening?

# D THEME

ARF/RHD Stakeholders

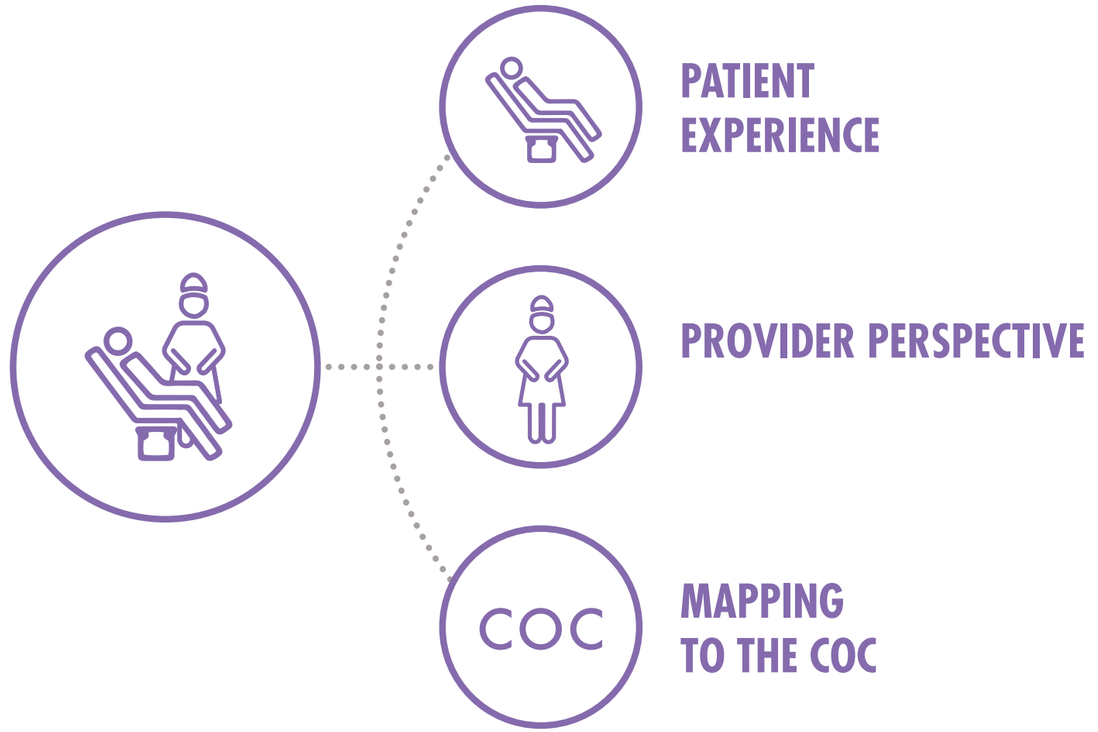
Probe: Who do you perceive to be the key stakeholders to delivering RHD care and developing public health care programmes at the...

- National level
- Regional level
- Local level

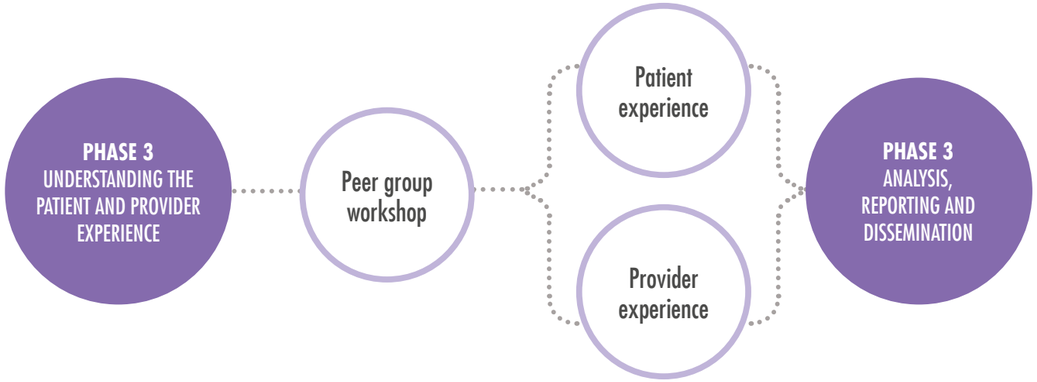
Probe: Are there other projects/NGOs that you are linking with/leveraging additional resources? If so, please explain?
Probe: To date, have any of the stakeholders you've identified been heavily involved in RHD programmes, e.g., as "champions?" If so, tell us more.

# 3

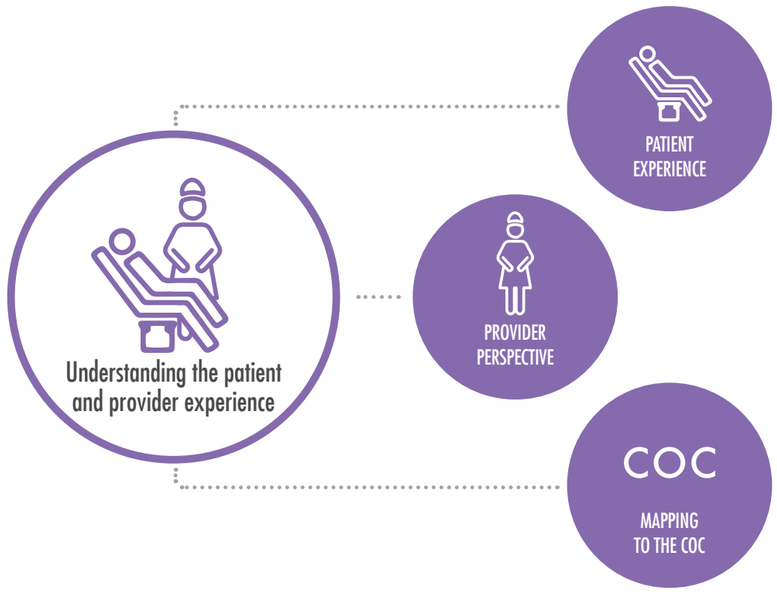
# UNDERSTANDING THE PATIENT AND PROVIDER EXPERIENCE



## OUTLINE



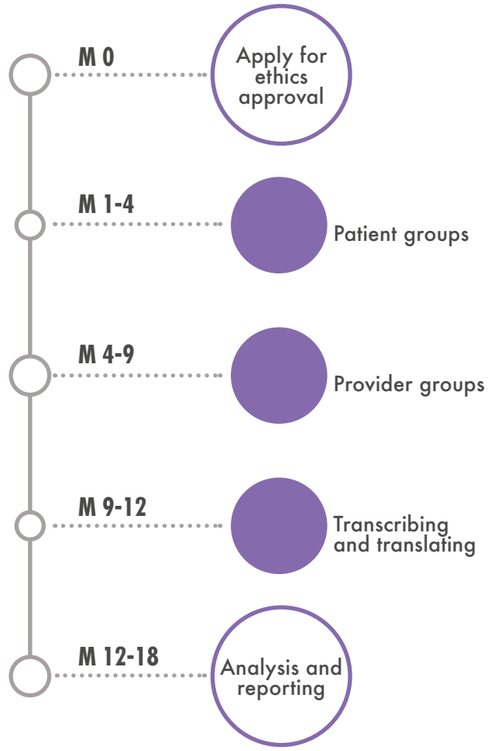

## ELEMENTS




## OBJECTIVES


- Elicit patients' experiences living with and receiving care for GAS, ARF and RHD
- Elicit providers' perspectives on barriers and facilitators to GAS, ARF and RHD care
- Map health-seeking behaviour and potential supply and demand side roadblocks onto the Continuum of Care Framework

## TIMELINE



# PHASE 3 INSTRUMENTS

# UNDERSTANDING THE PATIENT AND PROVIDER EXPERIENCE

## INTRODUCTION

The voices of patients and healthcare workers involved in strep throat, ARF and RHD care are central to the design and implementation of health system interventions. Suppliers and consumers of care would both provide important perspectives on what is working, what is not, and how it could be improved.

## OBJECTIVES

1. Elicit patients' experiences of living with and receiving care for sore throat, ARF and RHD
2. Elicit providers' perspectives on barriers and facilitators to care for sore throat, ARF and RHD
3. Map health-seeking behaviour and potential supply and demand side roadblocks onto the Continuum of Care Framework

## METHODS

This would be an entirely qualitative exercise. Patients with sore throat, ARF, and RHD, as well as primary health care and specialist providers, should be recruited to participate in in-depth interviews and focus group discussions. The participants should be recruited from the health facilities that have undergone detailed assessment during Phase 2. A local social scientist with experience in qualitative interview techniques should lead the training of field workers who would conduct the interviews and discussion groups. Two major themes should be addressed in the various interviews and discussions, namely 1) health-seeking behaviour and 2) "gatekeepers" to care. Data around these themes would be gathered by means of two separate instruments. The qualitative peer group should be able to analyse the data over 4-6 months.

## IMPLICATIONS AND DISSEMINATION

This qualitative assessment of the patient and provider experience should provide crucial information on the needs around sore throat, ARF, and RHD at the point of care, along the CoC© – particularly the bottlenecks, barriers, and challenges faced. The data would directly inform the choice of interventions in Phase 4, and they should be used as a baseline for monitoring and evaluating the impact of the intervention from the perspective of patients (participants) and their providers.

The findings of these interviews should be synthesised using standard qualitative data analysis and reporting approaches. They should form a series of vignettes, quotations, and narratives around the experience of living with ARF and RHD. The public health, advocacy, and scientific impact of this work would involve disseminating new data regarding the perceptions and attitudes of patients and health care workers on the "forefront" of RHD – a crucial gap in the literature.

**> Note:**
Local Ethics Committee Approval is required before any interview activities can take place.

# 3.1
# Sore Throat Parent and Patient Interview Schedule

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the patient if they have any questions.
- Thank the interviewee for their time and willingness to participate
- Ask the interviewee about themselves (how they are feeling etc.)

## A THEME

Reasons for Seeking Healthcare

Tell us about your child.

So your child has a sore throat, what can you tell us about his/her experience of being ill?

Probe for the following information:

- Why are you here today?
- Why did you decide to come to clinic today?
- Where you normally go for a sore throat?

## B THEME

Alternative Sources for Care

Elicit information on health-seeking behaviour prior to visiting a GP, clinic or hospital.

Probe for the following information:

- What did you do to treat your child's sore throat?
- Did you use any home remedies?
- Do you consult with your family before you seek care at a health facility?
- Did you visit any other healers
  - E.g. traditional healers, other
- What health facility do you typically go when you/your child are sick?
  - Dispensary, Duka la Dawa, clinic, district hospital, etc.



## C THEME

History of Disease in the Child

Probe for information on the child's health over time.

- When did your child start to feel ill?
- How long has he/she had the sore throat?

## D THEME

Impact on Daily Life

Understanding the impact of illness on the patients' daily lives can aid the understanding of health-seeking behaviour and adherence (or lack thereof) to long term treatment.

- Is it easy to get to a clinic?
- What was your experience at this clinic?
- How do you get to a clinic?
  - Distance: is it far?
  - Transport: is it an issue?
  - How much does it cost to get to a clinic?
  - Are you able to spend this money?

## E THEME

Theme: Awareness

Understanding what and how much patients know about their illness and RHD awareness.

- Did you know that a sore throat* can be linked with heart problems?
- Have you heard of RHD?

*we are not implying that the sore throat patient has RHD, but rather probing for awareness

Thank the parent/patient for their time and participation

# 3.2
# ARF Adult Patient Interview Schedule

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the patient if they have any questions.
- Thank the interviewee for their time and willingness to participate
- Ask the interviewee about themselves (how they are feeling etc.)

## A THEME

Disease History/Admission to Hospital

Probe for information about the patient's health over time.

There will be two possible types of patients within this group:

- Patients who have recently been diagnosed with ARF/admitted to the hospital
- Patients who were in hospital, but have since been discharged

In both instances we want to elicit information about their experiences and probe for information on the health seeking process/behaviour. Adapt questions appropriately for each type of patient i.e. pre/post hospitalisation/diagnosis.

- So you have been diagnosed with ARF, what can you tell us about your experience of being ill?
- Why were you admitted today OR why were you admitted before?
- How were you feeling before going to the clinic/hospital?
  - How long did you feel ill before going to the clinic?
  - Do you remember ever having a sore throat?
  - Did you have previous episodes of ARF before seeking care at the clinic/hospital?
- What made you decide to seek care at the clinic/hospital at that particular moment?
- What are your symptoms?
  - Probe: chorea, arthritis, skin conditions, fever, shortness of breath
- What did you think it was?
  - Probe: malaria



## B THEME

Relationships with Health Professionals & Understanding of Disease

Understanding the patient-provider relationship aids our understanding of their decisions made in relation to health-seeking behaviour as this may or may not have an influence on their disease management/knowledge.

- When you were admitted/diagnosed, what did the doctor/nurses tell you about your illness?
  - Probe: ARF, Sore Throat, relation to *RHD, knowledge on the progression of the disease
- Do you see the same doctor/nurse each time you go to the clinic/hospital?
- Did the doctor prescribe any medication?
  - Probe: secondary prophylaxis, penicillin allergies, knowledge of treatment/disease management

## C THEME

Health Seeking Behaviour

Seeks to try to identify which factors made the patient decide to seek care at this particular point in time.

- What do you do when you feel ill?
- How have you been looking after yourself until now?
  - Probe: Support Network; family and friends
- Did you use any home remedies?
- Did you see anyone else for the symptoms you had?
  - Probe: traditional healers, stigma attached to disease/symptoms (e.g. fear of speaking out because of witchcraft)
- Do you visit the clinic/hospital regularly?
  - Probe: Secondary prophylaxis

Sub-theme: Social Perceptions of Disease Characteristics
For people who described chorea-like symptoms: we want to know about the social structure of the community i.e. values, beliefs etc. factors that influence the way in which people think about disease(s). This can allow for the following probes as well as reveal further information that we did not know about prior to the interview.

- What did you think when you experienced strange movements?
- What did other people think?
  - Probe: Chorea; Witchcraft

## D THEME

Impact on Daily Life

Understanding the impact of illness on the patients' daily lives can aid the understanding of health-seeking behaviour and adherence (or lack thereof) to long-term treatment.

- Is it easy to get to the hospital?
- How do you get to the hospital?
  - Distance: is it far?
  - Transport: is it an issue?
  - Cost: can you afford to travel to the hospital?

- Finances:
  - How does this illness affect your work and income?
  - Can you afford treatment/medication?
  - How does the cost of treatment/medication affect the household?

---

## E THEME

Awareness

Understanding what and how much patients know about their illness and RHD awareness.

- Were you given info about your diagnosis?
- What else would you still like to know?
- Have you used any way of looking up facts about ARF?
- Do you use your phone or the internet?
- Did you know that a sore throat can cause ARF?
- Have you heard of RHD?
- Do you know what you can do to prevent ARF from developing into RHD?
  - Probe: penicillin; adherence to secondary prophylaxis
  - Probe: Internet, information, phone access

Thank the patient for their time and participation



# 3.3 ARF Child Patient Interview Schedule

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the patient if they have any questions.
- Thank the interviewee for their time and willingness to participate
- Ask the interviewee about themselves (how they are feeling etc.)

---

## A THEME

Disease History/Admission to Hospital

Probe for information about the patient's health.

There will be two possible types of patients within this group:

- Patients who have recently been diagnosed with ARF/admitted to the hospital
- Patients who were in hospital, but have since been discharged

In both instances we want to elicit information about their experiences and probe for information on the health seeking process/behaviour. Adapt questions appropriately for each type of patient i.e. pre/post hospitalisation/diagnosis.

So your child has been diagnosed with ARF, what can you tell us about his/her experience of being ill?

- Why has he/she been admitted today OR why was he/she admitted before?
- How was he/she feeling before going to the clinic/hospital?
  - How long did they have the fever before going to the clinic?
  - Do you remember your child ever having a sore throat?
  - Has he/she had previous episodes of ARF before seeking care at the clinic/hospital?
- What made you decide to seek care at the clinic/hospital at that particular moment?
- What are your child's symptoms?
  - Probe: chorea, arthritis, skin rash, fever, shortness of breath
- What did you think it was?
  - Probe: malaria

---

## B THEME

Relationships with Health Professionals & Understanding of Disease

Understanding the patient-provider relationship aids our understanding of their decisions made in relation to health-seeking behaviour as this may or may not have an influence on their disease management/knowledge.

- When your child was admitted/diagnosed, what did the doctor/nurses tell you about their illness?
  - Probe: ARF, Sore Throat, relation to RHD, knowledge on the progression of the disease
- Do you see the same doctor/nurse each time you go to the clinic/hospital?
- Did the doctor prescribe any medication?
  - Probe: secondary prophylaxis, penicillin allergies, knowledge of treatment/disease management

---

## C THEME

Health Seeking Behaviour

Seeks to try to identify which factors made the patient decide to seek care at this particular point in time.

- What do you do when your child feels ill?
- How have you been looking after him/her until now?
  - Probe: Support Network; family and friends
- Did you use any home remedies?
- Did you see anyone else for the symptoms your child had?
  - Probe: traditional healers, stigma attached to disease/symptoms (e.g. fear of speaking out because of witchcraft)
- Do you visit the clinic/hospital with your child regularly?
  - Probe: Secondary prophylaxis

Sub-theme: Social Perceptions of Disease Characteristics
For people who described chorea like symptoms: we want to know about the social structure of the community i.e. values, beliefs etc. factors that influence the way in which people think about disease(s). This can allow for the following probes as well as reveal further information that we did not know about prior to the interview.

- What did you think when your child experienced strange movements?
- What did other people think?
  - Probe: Chorea; Witchcraft

---

## D THEME

Impact on Daily Life

Understanding the impact of illness on the patients' daily lives can aid the understanding of health-seeking behaviour and adherence (or lack thereof) to long term treatment.

- Is it easy to get to the hospital?
- How do you get to the hospital?
  - Distance: is it far?
  - Transport: is it an issue?
  - Cost: can you afford to travel to the hospital?
- Probe around
  - Distance from nearest health facility that can provide care
  - Family support
  - Financial constraints
  - Current health system provisions to enable and facilitate entry into health system
- Finances:
  - How does having a child with ARF/RHD affect your work and income?
  - Can you afford treatment/medication?
  - How does the cost of treatment/medication affect the household?

---

## E THEME

Awareness

Understanding what and how much patients know about their illness and RHD awareness.

- Did you know that ARF is linked to the bug (use the culturally appropriate term) that causes a sore throat?
- Did you hear about RHD before becoming ill/your child becoming ill?
- Do you know what you can do to prevent ARF from developing into RHD?
  - Probe: penicillin; adherence to secondary prophylaxis

Thank the patient/parent for their time and participation

# 3.4
# RHD Child Patient Interview Schedule

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the patient if they have any questions.
- Thank the interviewee for their time and willingness to participate
- Ask the interviewee about themselves (how they are feeling etc.)

## A THEME

Disease History/Admission to Hospital

There will be two possible types of patients within this group:

- Parents of patients who present with cardiac failure at first point of care
  Probe:
  - Ask about life history and experiences of illness (we want to try understand why it is that the patient has only presented for care at this point).
- Parents of patients who have travelled through the CoC (ARF-RHD) to get to this point
  Probe:
  - Ask them to talk about the process of going through the CoC
  - Life history and experiences of illness

In both instances we want to elicit information about their experiences and probe for information on the health seeking process/behaviour. Adapt questions appropriately for each type of patient i.e. pre/post hospitalisation/ diagnosis.

So your child has been diagnosed with RHD, what can you tell us about his/her experience of being ill?

- Can you tell us about why your child has been admitted to the hospital recently?
- How was he/she feeling before going to the clinic/hospital?
  - What can you tell us about your child's health?
- Has your child been having problems with his/her heart?
  - Probe: knowledge of disease and its implications; info on valve-replacement surgery; echo examination etc.
- What made you decide to seek care at the clinic/hospital at that particular moment?
  - Has your child had previous episodes of ARF, shortness of breath, etc. before seeking care at the clinic/hospital?
- What are your child's symptoms?
  - Probe: chorea, arthritis, skin conditions, "malaria" or fever



## B THEME

Relationships with Health Professionals & Understanding of Disease

Understanding the patient-provider relationship aids our understanding of their decisions made in relation to health-seeking behaviour, as this may or may not have had an influence on their disease management/knowledge.

- When your child was admitted/diagnosed, what did the doctor/ nurses tell you about his/her disease?
  - Probe: knowledge of illness
  - Probe: ARF, sore throat, relation to RHD, knowledge of the progression of the disease
- Do you see the same doctor/nurse each time you go to the clinic/ hospital?
- Did the doctor prescribe any medication?
  - Probe: secondary prophylaxis, penicillin allergies, knowledge of treatment/disease management

## C THEME

Health Seeking Behaviour

Seeks to try to identify which factors made the patient decide to seek care at this particular point in time.

- What do you do when your child feels ill?
  - How have you been looking after him/her until now?
- Did you use any home remedies?
- Did you see anyone else for your child's symptoms?
  - Probe: traditional healers, stigma attached to disease/ symptoms (e.g. fear of speaking out because of witchcraft)
- Do you visit the clinic/hospital regularly?
  - Probe: adherence to secondary prophylaxis

Sub-theme: Social Perceptions of Disease Characteristics
Here we want to know about the social structure of the community i.e. values, beliefs etc. factors that influence the way in which people think about disease(s). This can allow for the following probes as well as reveal further information that we did not know about prior to the interview.

- Probe: Chorea; Witchcraft

## D THEME

Impact on Daily Life

Understanding the impact of illness on patients' daily lives can aid the understanding of health-seeking behaviour and adherence (or lack thereof) to long term treatment.

- Is it easy to get to the hospital?
- How do you get to the hospital?
  - Distance: is it far?
  - Transport: is it an issue?
  - Cost: can you afford to travel to the hospital?

- Finances:
  - How does having a child with RHD affect your work and income?
  - Can you afford treatment/medication?
  - How does the cost of treatment/medication affect the household?
- Does your child miss a lot of school due to being ill?

## E THEME

Awareness

Here we want to know how much the parent knows about their illness.

- Did you know that a sore throat can cause RHD?
- Had you heard of RHD before your child was diagnosed?
- Do you know what you can do to prevent ARF from developing into RHD?
  - Probe: penicillin; adherence to secondary prophylaxis

## F THEME

Future

Here we want to know about concerns for the future.

- Does your child know what they would like to do one day?
- What do most of the people in your village do?
  - Probe: future expectations (are they worried the child will get sicker, stigma about marriage prospects, economic opportunity)

Thank the parent/patient for their time and participation



# 3.5 RHD Adult Patient Interview Schedule

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the patient if they have any questions.
- Thank the interviewee for their time and willingness to participate
- Ask the interviewee about themselves (how they are feeling etc.)

## A THEME

Disease History/Admission to Hospital

Probe for information about the patient's health.

There will be two possible types of patients within this group:

- Patients who present with cardiac failure at first point of care
  Probe:
  - Ask about life history and experiences of illness (we want to try understand why it is that the patient has only presented for care at this point).
- Patients who have travelled through the CoC (ARF-RHD) to get to this point
  Probe:
  - Ask them to talk about the process of going through the CoC
  - Life history and experiences of illness

In both instances we want to elicit information about their experiences and probe for information on the health seeking process/behaviour. Adapt questions appropriately for each type of patient i.e. pre/post hospitalisation/ diagnosis.

So you have been diagnosed with RHD, what can you tell us about your experience of being ill?

- Can you tell us about why you have been admitted to the hospital recently?
- How were you feeling before going to the clinic/hospital?
  - What can you tell us about your health?

- Have you been having problems with your heart?
  - Probe: knowledge of disease and its implications; info on valve-replacement surgery; echo examination etc.)
- What made you decide to seek care at the clinic/hospital at that particular moment?
  - Have you had previous episodes of ARF, shortness of breath
  - etc. before seeking care at the clinic/hospital?
- What are your symptoms?
  - Probe: chorea, arthritis, skin conditions, malaria

---

## B THEME

Relationships with Health Professionals & Understanding of Disease

Understanding the patient-provider relationship aids our understanding of their decisions made in relation to health-seeking behavior as this may or may not have had an influence on their disease management/knowledge.

- When you were admitted/diagnosed, what did the doctor/nurses tell you about your disease?
  - Probe: knowledge of illness
  - Probe: ARF, Sore Throat, relation to RHD, knowledge on the progression of the disease
- Do you see the same doctor/nurse each time you go to the clinic/hospital?
- Did the doctor prescribe any medication?
  - Probe: secondary prophylaxis, penicillin allergies, knowledge of treatment/disease management

---

## C THEME

Health Seeking Behaviour

Seeks to try to identify which factors made the patient decide to seek care at this particular point in time.

- What do you do when you feel ill?
  - How have you been looking after yourself until now?
- Did you use any home remedies?
- Did you see anyone else for your symptoms?
  - Probe: traditional healers, stigma attached to disease/symptoms (e.g. fear of speaking out because of witchcraft)
- Do you visit the clinic/hospital regularly?
  - Probe: adherence to secondary prophylaxis

Sub-theme: Social Perceptions of Disease Characteristics
Here we want to know about the social structure of the community i.e. values, beliefs etc. factors that influence the way in which people think about disease(s). This can allow for the following probes as well as reveal further information that we did not know about prior to the interview.

- Probe: Chorea; Witchcraft

---



## D THEME

Impact on Daily Life

Understanding the impact of illness on the patients' daily lives can aid the understanding of health-seeking behaviour and adherence (or lack thereof) to long-term treatment.

- Is it easy to get to the hospital?
- How do you get to the hospital?
  - Distance: is it far?
  - Transport: is it an issue?
  - Cost: can you afford to travel to the hospital?
- Finances:
  - How does RHD affect your work and income?
  - Can you afford treatment/medication?
  - How does the cost of treatment/medication affect the household?

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## E THEME

Awareness

Here we want to know how much the patients know about their illness.

- Did you know that a sore throat can cause RHD?
- Had you heard of RHD before you were diagnosed?
- Do you know what you can do to prevent ARF from developing into RHD?
  - Probe: penicillin; adherence to secondary prophylaxis

---

## F THEME

Future

Here we want to know about concerns for the future.

- What is your occupation/what would you like to do one day?
- What do most of the people in your village do?
  - Probe: future expectations (are they worried they will get sicker, stigma about marriage prospects, economic opportunity)

Thank the patient for their time and participation

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# 3.6
# Health Care Provider Interview Schedule

While it is essential to understand the experiences of patients at first point of care and their perception of the role of health care providers, information from the perspective of the health care providers themselves is imperative as it will provide us with information on what they themselves think their role is and their knowledge about GAS, ARF and RHD.

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the interviewee if they have any questions
- Thank the interviewee for their time and willingness to participate
- Ask the interviewee about themselves (how they are feeling etc.)

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## A THEME

<u>Local Facilities</u>

By identifying the local facilities within the area it can aid our understanding of the first point of health care for patients in that particular community.

- What training have you received and what is your role where you work?
- What is the function of this particular healthcare facility?
- Generally, where do people go when they are ill?
- Who uses this particular healthcare facility?
    - Description of geographical population (age, ethnic group, gender)
    - Common health problems received in healthcare facility

---

## B THEME

<u>Knowledge of Sore Throat, ARF &RHD</u>

Understanding what and how much health care providers know about sore throat, ARF and RHD.

Scenario 1
Patient presents with a sore throat; which steps do you take to diagnose and treat them?

Scenario 2
Patient complains about the following symptoms: fever, shortness of breath, joint pain and inflammation…

Probes:

- What could be the possible diagnoses?
- What is the name of a bacterium that could be responsible for these symptoms?



What other possible symptoms could the patient have had?

*In the event that the interviewee fails to answer the above scenarios correctly, the following questions may aid the discussion.

- Can you describe the progression of disease from sore throat to RHD?
- How are these conditions treated (Streptococcal infection, ARF, RHD)?

---

## C THEME

<u>Patient Care</u>

Aim is to understand the relationship between the patient and health care provider from the perspective of the health care provider.

- What procedure is followed when patients present for care i.e. from the time they arrive at the healthcare facility to when they leave?
- Are patients generally aware/do they have knowledge about RHD?
- How do patients initially describe symptoms?
- What are the main obstacles to people attending early on in the course of the disease progression?
    - Describe the general relationship between patients and healthcare providers
    - How does that relationship impact patients' decision to seek care?
- What are challenges that you/healthcare providers face in treating sore throat, ARF and RHD?

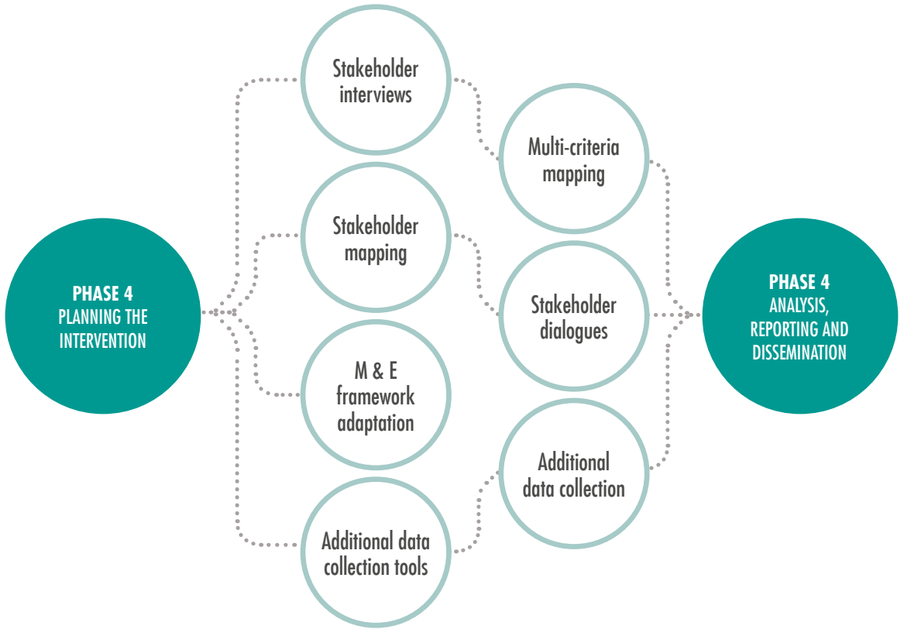
Thank the participant for their time and participation

# 4

# REPORTING THE NEEDS ASSESSMENT AND PLANNING THE INTERVENTION



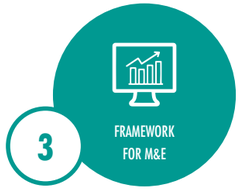
## OUTLINE




## OBJECTIVES


- To create a comprehensive framework of key stakeholders in ARF/RHD in the regions involved.
- To conduct an in-depth case study to explore interactions between stakeholders, to monitor uncertainty, agreement and solutions and to broaden and deepen stakeholder engagement.

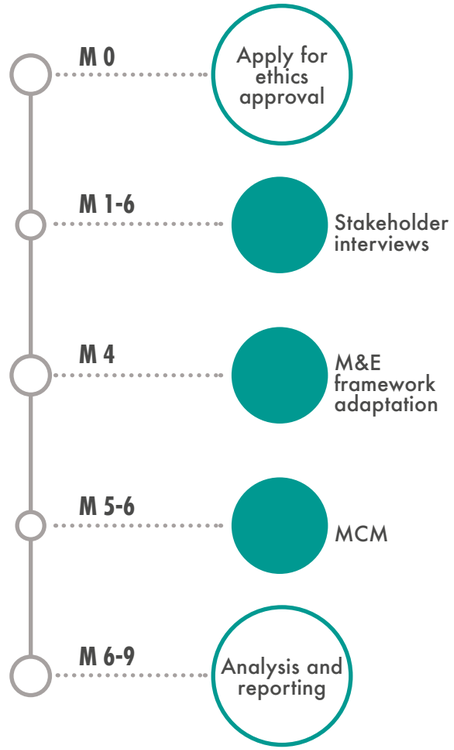

- To report the needs assessment using suggested frameworks.




- To adapt outcomes-based frameworks for evaluating performance and progress in health system strengthening as the programme develops.



## TIMELINE



# PHASE 4 INSTRUMENTS

# CREATING A COMPREHENSIVE FRAMEWORK OF STAKEHOLDERS

## INTRODUCTION

It would be critical to identify and engage key stakeholders in a community-level intervention such as RHD prevention and control. The stakeholders' engagement should be broad, transparent and far-reaching, with policy and political involvement. Currently, no data exist regarding a validated method of identifying key stakeholders within the RHD arena; to map these in a meaningful fashion would create a clearer picture of the different perspectives on key issues and choices, as well as the practical implications for decisions made. Key stakeholders would have been identified in the site characterisation phase in order to engage, empower and build collaborative relationships

## OBJECTIVES

1. Create a comprehensive framework of key stakeholders in ARF/RHD at the sites and, more broadly, at the regional and national level in the chosen country.

2. Elicit stakeholder perspectives on RHD interventions, in particular:

   - exploring interactions between stakeholders;
   - monitoring uncertainty, agreement, and solutions; and
   - broadening and deepening stakeholder engagement

## METHODS

The identification of local stakeholders would build on the process developed for the systematic review in Phase 1. Once relevant categories of stakeholders have been identified through the review process, individuals fitting various stakeholder roles in the local setting should be invited to participate in the intervention planning process.

The stakeholders should then be interviewed by trained field workers by means of semi-structured questionnaires. One of the possible aids to this process would be Multi-Criteria Mapping, which would provide a quantitative method of analysing qualitative interviews. This methodology would allow for the creation of visual aids (e.g., Venn diagrams) that represent the stakeholder space and opinions. The entire process of interviews and data analysis would require approximately 4 weeks. Qualitative researchers should lead the analysis, and the results would be used to develop a model of stakeholder engagement.

In parallel with the stakeholder interviews and data analysis, it would be important to convene stakeholder dialogues relevant to the planned interventions. These dialogues would practically apply the results of the interviews and create engagement and consensus among stakeholders.

## IMPLICATIONS AND DISSEMINATION

This approach would result in the systematic identification and assessment of stakeholder perspectives on planned RHD interventions. The practical significance of this exercise would be that it would broaden and deepen stakeholder engagement within the ARF/RHD community and at designated sites.

# 4.1
# Procedure for stakeholder identification, interviews, and mapping

Three major elements:

1. Literature review (will be completed in phase 1)
2. Creation of comprehensive stakeholder map
3. Encourage and facilitate stakeholder dialogues using the MCM method

Phase 1

1. Research assistant well-versed in systematic review and literature searches, in order to explore all categories, overseen by a senior scientist.
2. Research assistants to develop an initial framework, expand this to include all relevant research disciplines and supplement these with collaborative frameworks.
3. Social scientist to explore information and feedback from key informants.
4. Senior scientist to explore and analyse data and present a visual framework of all stakeholders.

Phase 2

1. Research assistant to use the key informants from phase 2, needs to be trained on MCM software, if used.
2. Conduct interviews with key informants.
3. Senior scientist to oversee method and analyse results.

Approaches:

Phase 1

1. Comprehensive literature review. Search using "stakeholder" AND "concept mapping" and rheumatic heart disease/ARF/GAS
2. Identify the four levels of iteration
    - Identify a relevant framework of stakeholder categories
    - Identify specific stakeholder groups including relevant research disciplines supplemented by collaborative networks
    - Solicit feedback from expert informants
    - Use a visual representation to express the stakeholders

Phase 2

1. Identify key informants based on stage one.
2. Create the checklist for semi-structured interviews with key informants (See suggested topic guide- adapt according to the different stakeholders)
3. These would be decided a priori in negotiation with country partners and stakeholders. (If using MCM software)
4. Utilise the free MCM online web-based software to create a MCM project.
5. Identify the following elements within the interview
    - Options
    - Criteria
    - Assign Scores
    - Assign weights
6. Analysis will be performed by MCM software. (If not using MCM software)
7. Detailed qualitative data analysis
8. Further interviews, policy and stakeholder dialogues may result in a further phase, based on these baseline findings.

# 4.2
# Key stakeholder interview Schedule

INTRODUCTION
(purpose of this is to make the interviewee feel comfortable)

- Introduce yourself
- Reason for interview (explain research)
- Ethics (explain consent form and any ethical issues)
- Ask the person interviewed if they have any questions.
- Thank the interviewee for their time and willingness to participate

Introductory questions

- Describe your current profession.
- What are your key responsibilities?
- What is your experience regarding the prevention and treatment of ARF/RHD?

## A THEME

General Health System Issues

Probe: What is your sense of the issues around human resources for health at the national, regional, and local levels?

- Are there any issues unique to NCDs or ARF/RHD in particular of which you are aware?

Probe: How are healthcare workers trained in your district/region?

- Physicians
- Nurses
- Allied health care professionals
- Community health care workers
- Other relevant to your system (e.g., clinical officers)

Probe: Describe the typical referral system in your district.

- How does a patient get from a health center to the district hospital?
- If the patient needs specialised/tertiary care, how does that occur?
- Are there common barriers to the referral process (e.g., road conditions, expense of travel, waiting lists)?

Probe: What are the estimated costs to patients for care in your region and how do these work?

- At the Dispensary Level?
- At the Clinic Level?
- At the District Level?
- At the Tertiary Level?



- What happens if a patient presents for care but cannot pay?
- How is the health systems financed in your country and specifically, how are ARF/RHD financed?
- What areas do you think work well in your system regarding ARF/RHD?
- How do you think you could coordinate prevention and care better? What are the biggest challenges?
- What are the key health system barriers that make it difficult to coordinate the prevention and treatment of ARF/RHD? (Probe for: Is funding a key concern for you? Or the lack of human resources, or the information system, or poor facilities, or access to care?)

## B THEME

ARF/RHD Policies and Programmes

Probe: What is your understanding of ARF/RHD-related policies at the national, regional, or local level? For instance, around disease notification, screening, prevention, and treatment?

- If these policies exist, how do they integrate with other policies or programmes, e.g., around infectious diseases, adult chronic care, maternal/child health, etc.?
- What is your understanding of how these policies came to be? Can you describe the process of government engagement if they were initiated outside the ministry of health?
- Are other ministries besides health, e.g., education, finance, housing/development engaged in these policies?
- If there are gaps between promulgation and implementation for these policies, what are some of the perceived barriers? Opportunities for improvement?
- To what extent is ARF/RHD a priority? And how has this changed over time?

Probe: What sort of leadership and oversight exists within the public (or private) health care sector regarding ARF/RHD prevention and control (again, at the national, regional, or local level)?
Please compare/contrast this with…

- Infectious diseases like HIV/AIDS, tuberculosis, or malaria
- Maternal and child health issues (including obstetric care and immunisation)
- Other NCDs, e.g. hypertension and cervical cancer

Probe: Are you aware of national, regional, or local NCD strategies and policies? How would ARF/RHD integrate with other relevant NCDs?

Probe: Can you describe the policy in terms of the health system building blocks?

Probes:

- Governance of NCD programmes (e.g. divisions, reporting structures)
- Healthcare financing (e.g. centralised/decentralised budget?)
- Health workforce (e.g who is responsible for what)
- Medical products and technologies (e.g. drugs)
- Service delivery (e.g. primary care, integrated care/coordination of care/ care continuum, acute tertiary care, intermediate/long-term care)
- Information and research (e.g. evidence base, collaborations with academia, academic health systems)
- Information technologies (e.g. electronic medical records, big data analytics for health and healthcare)
- Socio-demographic considerations (e.g. youthful population)

Probe: Please describe any ARF/RHD-related public health activities (e.g., awareness campaigns) or research programmes (e.g., echocardiography screening studies) that you are aware of at a national, regional, or local level.

## C THEME

ARF/RHD Clinical Care

Probe: What guidelines, protocols (e.g., Revised Jones Criteria), or resources are you aware of (again, at the national, regional, and local levels) that help providers detect and manage.

- Strep throat
- ARF
- RHD
- How do these integrate with other guidelines (e.g., IMCI)?

Probe: What is the process for reviewing cases of RHD in your district, if any?

- Do you have an ARF or RHD registry? If so, tell us a bit about it.
- If not, are there medical record systems in place to review clinical cases and determine follow-up and referral plans?
- If so, are these systems being utilised? If not, do you know why?

Probe: For patients with RHD, is there a priority system for follow-up? How are priorities classified/defined (e.g., mild, moderate, severe RHD)?

Probe: Are people with RHD given care plans or pathways, and if so, are these plans standardised (e.g., using protocols or guidelines addressed above)?

Probe: When do you decide that someone needs to be referred for follow-up of known RHD? How often do you refer patients to a more specialised unit?

Probe: Suppose an RHD screening programme were to be implemented in your district. Is there capacity to deliver advanced medical or surgical care (either within the district or via a robust referral pathway) for cases of RHD identified through screening?



## D THEME

Identifying the contextual factors that influence the design and implementation of ARF/RHD and NCD programmes

Probe: What are the key factors that shape your country's health system today?

Probe: What are your country's public health challenges?

Probe: What are your country's current healthcare challenges?

Closing questions

- What are your hopes for the preventing and managing ARF/RHD as it evolves?
- Before we wrap up, do you have any final thoughts that you'd like to share?

Thank the participant for their time and participation

# FRAMEWORK FOR MONITORING AND EVALUATION

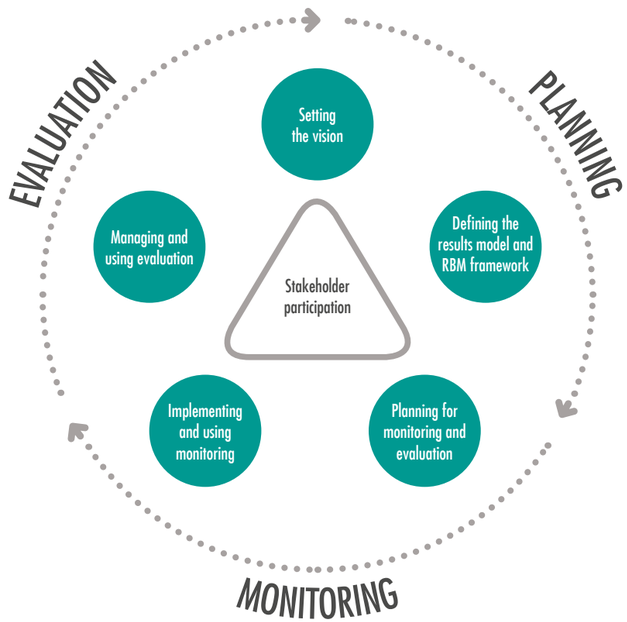
Interventions adopted by the stakeholders should be categorised according to the Medtronic Foundation CoC Framework for Health Systems ©. Planned interventions should be categorised into primary, secondary and tertiary prevention activities. Each level of prevention would require the basic building blocks of outreach and capacity building in order ultimately to improve access to care to ensure better health outcomes for individuals at risk through the lens of the CoC.

Interventions should be both quantitative and qualitative, and outcomes would focus on priority needs within RHD, while strengthening health systems at the core of all planned interventions. Priority needs within RHD have been outlined in two major documents: 1) The AU communiqué and 2) the RHD policy framework. In addition, the needs for RHD management and control programmes have previously been identified in the TIPS document. Together, these documents, with the findings from the NAT should inform the basis of robust monitoring and evaluation.

Baseline metrics collected during the needs assessment process should be used to build intervention-specific performance-based measures over specified time-frames. Baseline data should be compared against measurable outcome target goals (both quantitative and qualitative) that are determined by consensus of the stakeholders.

Best practices for monitoring and evaluation developed by the United Nations Development Programme should be adapted as the Monitoring and Evaluation (M&E) framework for this project. Figure 9 describes the process involved in a Results Based Management Approach. Note that the stakeholders are always central to this dynamic process – starting with setting the vision to managing and using the outcomes information produced by the evaluation – in a continuous system of planning, monitoring and evaluation. Through scheduled and incremental monitoring and evaluation, lessons learned can be applied to existing interventions in real time as a formative evaluation technique. A summative evaluation approach could be used to measure the performance at the end of the intervention with a more traditional quantitative pre/post intervention methodology. In total, we aim to demonstrate the impact, effectiveness, efficiency, sustainability and relevance of the intervention within the health system.

**FIGURE 9**
RESULTS BASED MANAGEMENT APPROACH






# 4.3
# Tools for Quantifying Needs and Setting Targets

Here are some examples of applying the CoC when designing interventions targeted at primary, secondary and tertiary care levels.

## For Primary Prevention Interventions:

CoC4 Diagnosis

Intervention:
Create and implement a community or facility-based RHD awareness campaign in a district and/or facility. Supplement the Awareness Campaign by providing training to Community Health Workers and/or Nursing Staff training for Sore Throat case identification. This campaign and/or training programme could be added on to an existing health awareness campaign; likewise, the RHD training material could be incorporated into an existing training curriculum.

Measurement:
How many workers were trained during the target period?
How many sore throat cases are identified post training against the number of sore throat cases identified before training?
Has the awareness campaign become part of the annual budget for health services?
Has an RHD Training/Awareness module been incorporated into the CHW and/or Nursing continuing education curriculum?

CoC6 Treatment for strep throat

Intervention:
Create and implement a programme to monitor and report the availability of medicines (including penicillin) on hand at primary healthcare facilities. Monitor the availability of penicillin during peak seasonal sore throat incidence to proactively manage stock outs.

Measurement:
How many doses of penicillin were given to sore throat cases?
How many clinics were appropriately supplied with penicillin during peak seasonal sore throat incidence periods?
Have the reports been adopted for use by local health officials to plan and monitor allocation of resources/medicines?

## For Secondary Prevention/Prophylaxis:

CoC1 Identified Socio-Economic Conditions

Intervention:
The cost of travel to a health care facility for secondary prophylaxis has been identified as being prohibitive. Clusters or groupings of RHD patients have been identified that may benefit from secondary prophylaxis delivery at outlying sites. Create and monitor a secondary prophylaxis programme that is more accessible to patients. This medicines delivery programme could serve other medical populations.

Measurement:
How many RHD patients are served by the programme?
How many RHD patients are served by the intervention that did not receive regular prophylaxis before the programme?
Have permanent staff and resources been allocated (budgeted) for this programme?
Survey to find out why some clinic patients may not be taking part in the programme.

CoC3 Entry into health system

Intervention:
Create and implement an awareness campaign in a district and/or facility on the need and benefits of secondary prophylaxis for RHD patients among Community Health Workers and/or Nursing Staff. Providing these training opportunities will increase the numbers of Community Health Workers who have been educated about the benefits of secondary prophylaxis adherence; this will facilitate entry into the health system for RHD Patients.

Measurement:
How many workers were trained during the target period?
How many new RHD patients are on secondary prophylaxis post training against the number of those on secondary prophylaxis identified before training?
Has the awareness campaign become part of the annual budget for health services?
Has an RHD Training/Awareness on the benefits of secondary prophylaxis module been incorporated into the CHW and/or Nursing continuing education curriculum?

CoC7 Secondary prophylaxis Adherence

Intervention:
Fear of anaphylaxis among front line health workers has been identified as a barrier to adherence. Provide training and supplies (kits) to front line staff for managing anaphylaxis.

Measurement:
How many front line health care workers attended the training sessions?
How many anaphylaxis kits were distributed?
Have funds for making these kits available been budgeted on a permanent basis?
Has a module on managing prophylaxis been incorporated into a front line health worker training curriculum?

## For Tertiary Prevention:

CoC9 Management of tertiary interventions

Intervention:
Introduce Point-of-Care INR machines and measure the impact of patient compliance and bleeding outcomes.

Measurement:
How many POC INR machines have been placed in the lab or outpatient clinic?
How many healthcare staff have been trained to use the machines?
How many RHD patients got POC INR testing in a given period?
How many more INR tests have been performed since their placement in the facility than over a given period prior to their placement?
Have POC INR machine purchases and distribution to lower level facilities been approved by local health officials?

CoC10 Rehabilitation, recovery and palliation

Intervention:
When surgical options are available to RHD patients, assemble a team to design, disseminate and follow-up care plans post-surgery with families. Work with the surgical team to piggy back these post op care plans with other existing protocols when possible or appropriate.

Measurement:
How many post-surgical RHD patients and/or their families received post-op care plans upon discharge to home?
Has the protocol been adopted for use by the facility?
Have personnel been allocated to deliver the post op care plans to these patients?



| | |
|---|---|
| Number of cases identified during needs assessment | |
| Number of at-risk persons in catchment area (site) | |
| Empirical "prevalence" ratio | |
| Expected prevalence ratio (based on systematic review) | |
| Expected total number of cases | |
| Targeted number of new cases to be identified and/or for outreach | |
| Number of cases identified during needs assessment | 20 persons aged 5-39 |
| Number of at-risk persons in catchment area (site) | 40,000 persons aged 5-39 |
| Empirical "prevalence" ratio | 20/40,000 = 0.0005 |
| Expected prevalence ratio (based on systematic review) | 0.00175 |
| Expected total number of cases | 0.00175 x 40,000 = 70 |
| Targeted number of new cases to be identified and/or for outreach | 70 – 20 = 50 |

Note: Consider using a range of targeted number of cases rather than point estimate. For example, the upper and lower bounds of expected prevalence ratios from the literature rather than mean estimates.

As the interventions themselves will be specific to each sites, the instruments illustrated in this section are based on example interventions to give the user some guidance for content, objectives and approaches.

# 4.4
# Intervention Monitoring & Evaluation Worksheet

Prevention Level:

Goal:

Objective:

Narrative Progress Report:

☐ Interim ☐ Final Date: DD / MM / YYYY

Use continuation pages as necessary

Narrative Description:
This intervention aims to :

Risks to Achieving Goals:

Plans for Mitigating Risks:

Indicator:

Responsible Person (s):

| Activities: Stages of Implementation | Target Completion Date: | Actual Completion Date: | Person Validating: Comments: |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

Output:

Method of Calculation and Units of Measure:

| | |
|---|---|
| Numerator: | Number of |
| Denominator: | Number of |
| Desired Outcome | Greater than __% |
| Actual Outcome | |

Qualitative Indicators:

Frequency of Performance Review/Reporting:
Monthly/Quarterly/Bi-annually/Annually (Circle one)
Report Due Dates:

Comments:



# EXAMPLE 1 - Intervention Monitoring & Evaluation

Prevention Level: Tertiary Care - Access to Care - Capacity Building
Goal: Bring more RHD patients into care by improving ARF/RHD Case Identification
Objective: Increase ARF/RHD Case Identification through use of Clinical Algorithm

Narrative Description:

This intervention aims to strengthen non-expert RHD Care at the facility through the introduction of clinical algorithms to empower non-expert healthcare workers to make accurate diagnoses and appropriate referrals for patients with cardiovascular disease.

Risks to Achieving Goals:

Plans for Mitigating Risks:

Indicator: Front line staff are qualified and trained to use an algorithm for identifying a new patient with symptoms suspicious for RHD

Responsible Person (s):

| Activities: Stages of Implementation | Target Completion Date: | Actual Completion Date: | |
|---|---|---|---|
| 1. Formulation of site-appropriate algorithm for Case ID | | | |
| 2. Identification of targeted personnel and clinical areas where they work | | | |
| 3. Development of in-service training module | | | |
| 4. Delivery of training | | | |
| 5. Assessment of training | | | |
| 6. Retrain as necessary | | | |

Output: Train at least 80% of front line staff on the use an algorithm for identifying a new patient with symptoms suspicious for RHD

Method of Calculation and Units of Measure:

| | |
|---|---|
| Numerator: | Number of front-line staff members trained on algorithm |
| Denominator: | Number of identified front-line staff members |
| Desired Outcome: | Greater than 80% |
| Numerator: | Average post training assessment score |
| Denominator: | Highest possible post-assessment training score |
| Desired Outcome: | Greater than 80% |

Qualitative Indicators:
Training curriculum has been incorporated into required annual training sessions.
Comments:

Frequency of Performance Review/Reporting:
Monthly/Quarterly/Bi-annually/Annually (Circle one)
Report Due Dates:
Comments:

Narrative Progress Report: ☐ Interim ☐ Final Date: DD / MM / YYYY

Use continuation pages as necessary

# EXAMPLE 2 - Intervention Monitoring & Evaluation

Prevention Level: Tertiary Care - Access to Care - Capacity Building
Goal: Bring more RHD patients into care by improving ARF/RHD Case Identification
Objective: Increase ARF/RHD Case Identification through Diagnostic Echocardiography

Narrative Description:

This intervention aims to strengthen non-expert RHD Care at the facility through the introduction of focused handheld echocardiography to empower non-expert healthcare workers to make accurate diagnoses and appropriate referrals for patients with cardiovascular disease.

Risks to Achieving Goals:

Plans for Mitigating Risks:

Indicator: Procurement and training on three focused hand-held echocardiography to empower non-expert healthcare workers to make accurate of diagnoses

Responsible Person (s):

| Activities: Stages of Implementation | Target Completion Date: | Actual Completion Date: | Person Validating: Comments: |
|---|---|---|---|
| 1. Procurement of three HH Echos | | | |
| 2. Identify personnel and clinical areas where equipment will be utilised | | | |
| 3. Development of training module | | | |
| 4. Delivery of training | | | |
| 5. Assessment of training | | | |
| 6. Retrain as necessary | | | |

Output: Train at least 80% of the non-expert healthcare workers on the use hand-held echocardiography equipment

Method of Calculation and Units of Measure:

| | |
|---|---|
| Numerator: | Number of non-expert healthcare workers trained on equipment |
| Denominator: | Number of identified non-expert health-care workers |
| Desired Outcome: | Greater than 80% |
| Numerator: | Average post training assessment score |
| Denominator: | Highest possible post-assessment training score |
| Desired Outcome: | Greater than 80% |

Qualitative Indicators: Training curriculum has been incorporated into required annual training sessions. HH Echos are incorporated as standard equipment and funding is allocated in the annual budget.
Comments:

Frequency of Performance Review/Reporting:
Monthly/Quarterly/Bi-annually/Annually (Circle one)
Report Due Dates:
Comments:

Narrative Progress Report: Interim Final Date: DD / MM / YYYY

Use continuation pages as necessary



# EXAMPLE 3 Intervention: Monitoring & Evaluation

Prevention Level: Primary Prevention - Outreach and Community Education
Goal: Prevent ARF/RHD sequelae through appropriate identification and treatment of Sore Throat
Objective: Deliver Educational Programmes on RHD and Significance of Sore Throat to Schools

Narrative Description:

This intervention aims to provide education about Sore Throat delivered in the school setting to encourage families and teachers of children at risk of Sore Throat to seek appropriate primary care in an effort to prevent ARF/RHD sequelae.

Risks to Achieving Goals:

Plans for Mitigating Risks:

Indicator: School personnel and learners are aware of the basic natural history and characteristics of RHD and are aware of the significance of untreated sore throats.

Responsible Person (s):

| Activities: Stages of Implementation | Target Completion Date: | Actual Completion Date: | Person Validating: Comments: |
|---|---|---|---|
| 1. Development of standardised lay presentation regarding RHD for school personnel and learners. | | | |
| 2. Identify school personnel to give permission for in-school pre-sentation | | | |
| 3. Delivery of training | | | |
| 4. Assessment of training | | | |

Output: Complete outreach activities to 80% of the community at risk for Sore Throat

Method of Calculation and Units of Measure:

| | |
|---|---|
| Numerator: | Number of school presentations delivered |
| Denominator: | Number of schools in service catchment area |
| Desired Outcome: | Greater than 80% |
| Actual Outcome: | |

Qualitative Indicators:
Community surveys post training indicate increased knowledge and awareness of RHD and the relationship to sore throat.
Comments:

Frequency of Performance Review/Reporting:
Monthly/Quarterly/Bi-annually/Annually (Circle one)
Report Due Dates:
Comments:

Narrative Progress Report: Interim Final Date: DD / MM / YYYY

Use continuation pages as necessary

# 4.5
# Summary Work Plan: Monitoring & Evaluation

Outcome: Better health outcomes by improving access to care for individuals at risk through appropriate inclusion into the Continuum of Care

| Intervention Progress Report | |
|---|---|
| Report Date: DD / MM / YYYY | |
| ☐ Interim | |
| ☐ Final | |
| Intervention: | |
| Team Leader: | |
| Objective: | |
| Input Activities: Stages of Implementation | |
| ☐ On target | |
| ☐ Completed | |
| ☐ Delayed | |
| ☐ Stalled | |
| Progress Report Narrative Comments: | Use continuation pages as necessary |
| Outputs to date | Output 1<br>Targeted Outcome<br>Actual Outcome<br>Output 2<br>Targeted Outcome<br>Actual Outcome |
| Action Plan/Remediation if Needed | (Describe challenge, plan for remediation, responsible person, new target date for completion and target date for next review) |



# ADDITIONAL DATA COLLECTION

The purpose of the needs assessment would be to inform the development of interventions for ARF/RHD. It is possible that the data gathered in the NAT may need to be supplemented by focused, additional data that 1) answer questions specifically related to determining the feasibility of intended interventions and/or 2) assist in monitoring and evaluation.

An example of the former (#1) might be an intervention around screening for antenatal RHD. The NAT in that case may need to be supplemented by focus group discussions or interviews of patients or pregnant women to determine whether cardiac imaging would be culturally acceptable in the context of antenatal services.

An example of the latter (#2) might be an intervention linking RHD care to existing HIV/AIDS treatment platforms. The NAT in that case may need to be supplemented by more detailed HIV indicators and needs than might otherwise be collected in the Health System Assessment (Phase 1), and for monitoring and evaluation, metrics around HIV care may need to be included to assess how they could be leveraged and strengthened.

This additional data collection would be developed in consultation between the local partners and relevant collaborators. Survey instruments would be developed as needed based on the goals of the intervention.

# ANALYSIS, REPORTING AND DISSEMINATION

The findings of this situational analysis would provide comprehensive data around contemporary practices, barriers and facilitators along the continuum of care for patients with GAS/ARF and RHD. Of note, is the fact that these data could in fact provide the evidence for policy dialogues with patients, key stakeholders, policy makers and national Department of Health. The final report should thus be tailored to a variety of audiences, including patients as the primary stakeholder group, as well as physicians, policy makers and health providers. A sample-reporting template is suggested, which focuses on five areas:

1. Understanding the barriers to care at each of the ten CoC© levels
2. Understanding the facilitators of care, as experienced by the patients
3. What is missing from the TIPS checklist? - This would use the TIPS framework and results from the quantitative and qualitative assessments to identify key gaps and needs.
4. Baseline Assessment: Indicators and Benchmarks. This would answer the questions: where are we, where do we want to go and how do we want to get there?
5. Stakeholders, interventions, programme and policies, which describe in detail what already exists within the community/site, as well as how these could be leveraged and what we could learn from previous programmes.

These five reporting templates summarise the findings of the Needs Assessment in a patient-centred and comprehensive manner and could be presented to all key stakeholders. In addition, they would form the basis of the choice of intervention and the baseline assessment used within a monitoring and evaluation strategy of the intervention.



## 4.6
## Understanding the barriers

| COUNTRY: | Qualitative | Quantitative |
|---|---|---|
| CoC1: Socioeconomic Conditions<br>Overarching Question: What are the socioeconomic conditions of the community? | | |
| CoC2: Decision to seek care<br>Overarching Question: What are the barriers that prevent an individual from deciding to seek care? | | |
| CoC3: Entry into the health system<br>Overarching Question: What are the barriers that prevent an individual from entering the health system? | | |
| CoC4: Diagnosis<br>Overarching Question: What are the barriers that prevent an individual from being diagnosed (whatever level of progression they're at)? | | |
| CoC5: Referral and onward progress beyond the first point of care<br>Overarching Question: What are the barriers that prevent an individual from being referred beyond the first point of care? | | |
| CoC6: Strep Throat<br>Overarching Question: What are the (individual and systemic) barriers that prevent an individual from being prescribed, getting and adhering to penicillin? | | |
| CoC7: Secondary Prophylaxis<br>Overarching Question: What are the (individual and systemic) barriers that prevent an individual from being prescribed, getting and adhering to secondary prophylaxis? | | |

| COUNTRY: | Qualitative | Quantitative |
|---|---|---|
| CoC8: covers treatment for RHD<br>Overarching Question: What are the barriers that prevent an individual from getting tertiary intervention for RHD? | | |
| CoC9: Management of tertiary interventions<br>Overarching Question: What are the barriers that prevent an individual from managing their condition long term? | | |
| CoC10: Management of palliative and rehabilitation.<br>Overarching Question: What are the barriers that prevent an individual from having optimal palliative and rehabilitative care? | | |



# 4.7
# Understanding the facilitators

| COUNTRY: | Qualitative | Quantitative |
|---|---|---|
| CoC1: Socioeconomic Conditions | | |
| CoC2: Decision to seek care | | |
| CoC3: Entry into the health system | | |
| CoC4: Diagnosis | | |
| CoC5: Referral and onward progress beyond the first point of care | | |
| CoC6: Strep Throat | | |
| CoC7: Secondary Prophylaxis | | |
| CoC8: Treatment for RHD | | |
| CoC9: Management of tertiary interventions | | |
| CoC10: Management of palliative and rehabilitation. | | |

# 4.8
# The TIPS checklist analysis

| Country: | | | | | |
|---|---|---|---|---|---|
| Tertiary Prevention | Medical Management of RF/RHD | Anticoagulation | Triage and Preoperative Planning | Postoperative Planning | Provision of Interventional Services |
| ASSESSMENT Results | | | | | |
| Secondary Prevention | RF/RHD Register | BPG and other antibiotic supply | Provision of secondary Prophylaxis | Priority based follow-up | Active case finding (echo) |
| ASSESSMENT Results | | | | | |
| Primary Prevention | Community education | Sore throat diagnosis, treatment guidelines | Provision of primary prophylaxis | Active case finding (sore throat clinics) | Vaccine development |
| ASSESSMENT Results | | | | | |
| Health Systems | Burden of disease data | Governance & RHD Advisory Committee | Funding | Lab Services | Integration with primary care and health systems |
| ASSESSMENT Results | | | | | |
| Health Systems | Government engagement | Disease notification | Human resources | Health worker training | Programme evaluation |
| ASSESSMENT Results | | | | | |



# 4.9
# Baseline Assessment: Indicators and Benchmarks

COUNTRY:
Where are we, where do we want to go and how do we want to get there?

| | Qualitative | Quantitative |
|---|---|---|
| Patient level indicators | | |
| Health system indicators | | |
| Primary Health Care Level | | |
| Secondary Health Care Level | | |
| Tertiary Health Care Level | | |
| Quaternary Health Care Level | | |

# 4.10
# Stakeholders, interventions, programmes and policies

COUNTRY:
Other interventions; what exists in the community that is already working? That can be leveraged?

| | Qualitative | Quantitative |
|---|---|---|
| Stakeholders and stakeholder mapping | | |
| Existing and leveraged interventions | | |
| Programmes, existing and planned | | |
| Policies and guidelines | | |

# APPENDICES

# APPENDIX 1
# BACKGROUND INFORMATION FOR PHASE 1

Rapid rural appraisal (RRA) is a method used to gather information and gain insight into people and their communities in order to customise interventions according to the needs and circumstance of the communities involved. It also aids in focusing questions for quantitative and qualitative surveys, refines the approach used in interventions and, most importantly, involves the community and stakeholders in the interventions from the start.

In order to select the sites, a rapid rural appraisal (RRA) method should be implemented, utilising the information pyramid in Figure 10. This is a well-validated research method used within low- and middle-income countries to provide qualitative and selected quantitative information, especially about deprived areas and communities.[13] It is based on a universal access to health philosophy and has been adapted and validated within the health care sector.[14] It uses selected people with knowledge of the area (key informants) both to identify problems and contribute to solutions.[15] The primary aims of rapid appraisal are to:

- Gain insight into a community's own perspective on its needs;
- Translate these findings into action; and
- Establish a sustainable relationship between service purchasers, providers and local communities.

**FIGURE 10**
INFORMATION PYRAMID USED IN RAPID APPRAISALS


[13] Murray SA, Tapson J, Turnbull L, McCallum J, Little A. Listening to local voices: adapting rapid appraisal to assess health and social needs in general practice. *BMJ* 1994; **308**(6930): 698-700.
[14] van Bodegom D, May L, Kuningas M, et al. Socio-economic status by rapid appraisal is highly correlated with mortality risks in rural Africa. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 2009; **103**(8): 795-800.
[15] Mazzeo J, Makonese L. Experiences of collaboration, coordination and efficiency in the delivery of HIV/AIDS home-based care in Zimbabwe. *Afr J AIDS* Res 2009; **8**(4): 443-53.



Information should be collected on all 10 areas within an information pyramid that consists of four layers (see Figure 10). The bottom layer would address the community, defining its composition, organisation and ability to act. The next would cover socio-ecological factors affecting health. The next layer would review the data on the existence, coverage, accessibility, and acceptability of services, allowing for the evaluation of current services and the identification of potential implementation and interventions. The top layer would define national, regional and local policies – in particular, any commitment from political leadership around community participation in health care programmes.

RRA methods have some important advantages over survey-based research methods: they generally involve low costs; are highly adaptable to different situations; and tend to facilitate the establishment of rapport with local communities, thus drawing attention to topics and qualitative aspects missed by closed-ended assessment tools. They also favor on-the-spot analysis with local people, enabling verification of findings and enhancing the local relevance of results. The major limitations of RRA methods are: 1) potential threats to validity, such as manipulation by informants, and 2) selection and training of field personnel, who must be familiar with the skills needed for RRA.

Hence, in the context of Country Control Programmes, RRA should be used as a site characterisation tool and as a validated method to involve the community from the outset. The RRA approach should guide, inform the design of, and confirm the findings from the larger and more comprehensive assessment. Ultimately, a combination of comprehensive and RRA methods would be the best way to ensure the quality of results.

The site selection "tool" data should be derived from three major sources: existing written records, interviews, and observations. The scientific rigour and validity of this approach would depend on triangulation, with data from one source being validated or rejected after comparison with data from at least two other sources or methods of collection. Through this crosschecking process, a cohesive interpretation would be constructed. People thought to be in the best position to understand the issues would be chosen to be "key informants".

Important considerations are:

1. **Training and selection of personnel:** It is critical for fieldworkers to be linked to persons familiar with the RRA methods, such as social scientists.
2. **Establishing contact:** This needs to be culturally and socially appropriate, and the choice of an initial contact person must be carefully considered.
3. **Timing of community interviews and sequencing of instruments.**
4. **Choice of informants:** This should be planned at the outset with purposive sampling or snowball sampling with key informant negotiation. (The stakeholder mapping process could also inform this.)
5. **Triangulation:** Triangulation refers to the comparison of data between sources to improve their validity and reliability. This is particularly critical with RRA data.

## BURDEN OF ARF/RHD

In contrast to ischemic heart disease (IHD) and many other non-communicable diseases and risk factors, very little is known about the burden of ARF and RHD at the global, regional, national, or sub-national levels.[16] There are many reasons for this knowledge gap. Episodes of ARF may be confused with other more common events such as malaria, and patients and their caregivers often do not recall attacks. Some episodes of ARF may also be subclinical (i.e., never brought to medical attention).[1] Furthermore, in most countries, ARF is not a notifiable health condition, nor is it included among the indicators of child health.[17]

[16] Zuhlke LJ, Steer AC. Estimates of the global burden of rheumatic heart disease. *Glob Heart* 2013; **8**(3): 189-95.
[17] Nkgudi B, Robertson KA, Volmink J, Mayosi BM. Notification of rheumatic fever in South Africa – evidence for underreporting by health care professionals and administrators. *South African medical journal = Suid-Afrikaanse tydskrif vir geneeskunde* 2006; **96**(3): 206-8.

Similarly, RHD in children is often – though not always – asymptomatic and only advances to symptomatic disease (i.e., heart failure and other sequelae) in adolescence or early adulthood.[1] Annual mortality is high once RHD has entered the symptomatic phase,[18] yet under-recognition of RHD as the underlying cause of death from (most commonly) heart failure or stroke can lead to inappropriately low estimates of the burden of fatal RHD at the national level.

Furthermore, the literature on the prevalence of RHD is small, and the newer echocardiography-based and the older auscultation-based clinical prevalence studies are too heterogeneous to enable direct comparisons to be made. Finally, even the highest-quality prevalence studies have not been conducted using nationally representative sampling frames. While clinicians recognise RHD as a disease of poverty, there is little evidence on how the prevalence of RHD and its sequelae vary across socioeconomic categories or between regions (e.g., urban vs. rural).

The recent Global Burden of Disease studies (GBD)[19] , led by the Institute for Health Metrics and Evaluation (IHME) at the University of Washington, have used mathematical models to estimate the age- and sex-specific prevalence of RHD at the national level for 2010 and 2013. These models incorporate more reliable data, e.g., on overall levels of sanitation or prevalence of malnutrition (usually from national health surveys), along with less reliable and sparse data (e.g., on RHD prevalence) to attempt to estimate the total number of RHD cases and deaths in each country. Accordingly, the GBD estimates are associated with wide uncertainty intervals in many countries without data, and these methods cannot at present be applied at the sub-national level (i.e., to estimate prevalence by district or province).

For the purpose of local needs assessment, we suggest conducting a secondary analysis of all available published literature on the burden of ARF and RHD in the programme country in question. A recent systematic review protocol of the burden of RHD in South Africa[20] proposed a search strategy for epidemiological studies on RHD that could be adapted to other countries.

## ARF/RHD HEALTH SERVICE DELIVERY: BARRIERS AND FACILITATORS

Very little has been written about specific issues related to health service delivery for ARF/RHD.[21] In principle, an assessment of barriers and facilitators to care for ARF/RHD could be informed, to some extent, by the literature on available health services in the country in question. This is because there are likely to be overarching issues affecting the utilisation of such health services, e.g., magnitude of out-of-pocket costs, availability of transportation to health facilities, perceived acceptability of public and private health facilities, and so on. Additionally, ARF/RHD care may be influenced by disease-specific concerns, such as health-seeking behaviour around symptoms of sore throat or shortness of breath, or relative out-of-pocket cost of laboratory and imaging tests for cardiac diseases (as compared to other conditions).

Most of the literature on RHD since 2000 has focused on echocardiographic screening or clinical epidemiology and outcomes, and thus very little is known relatively about care-seeking behaviour in endemic countries. Low awareness of ARF/RHD has been described among schoolchildren in Addis Ababa, Ethiopia[22] and various barriers and facilitators to secondary prophylaxis have been outlined in Uganda.[20] Other research in Samoa, Brazil, Australia, New Zealand and others have explored similar issues.

[18] Gunther G, Asmera J, Parry E. Death from rheumatic heart disease in rural Ethiopia. *Lancet* 2006; **367**(9508): 391
[19] Murray CJ, Vos T, Lozano R, et al. Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet* 2012; **380**(9859): 2197-223.
[20] Zuhlke L, Watkins D, Engel ME. Incidence, prevalence and outcomes of rheumatic heart disease in South Africa: a systematic review protocol. *BMJ Open* 2014; 4(6): e004844.
[21] Huck DM, Nalubwama H, Longenecker CT, Frank SH, Okello E, Webel AR. A qualitative examination of secondary prophylaxis in rheumatic heart disease: factors influencing adherence to secondary prophylaxis in Uganda. *Glob Heart* 2015; **10**(1): 63-9 e1.
[22] Oli K, Porteous J. Rheumatic heart disease among school children in Addis Ababa City: awareness and adequacy of its prophylaxis. *Ethiop Med J* 1999; **37**(3): 155-61.



## HEALTH SYSTEMS ASSESSMENT

The World Health Organisation defines health systems as "all organisations, people and actions whose primary intent is to promote, restore or maintain health."[23] This includes efforts to influence determinants of health as well as more direct health-improving activities. Health systems around ARF/RHD, then, include agents such as families affected by RHD, school educational programmes around sore throat, ARF notification systems, public and private facilities, insurance/medical aid organisations, and the like. Wide variations exist across health systems as well as with regard to their performance, and this applies particularly to RHD-endemic countries in Africa and South Asia, where health systems tend to be weaker than elsewhere.

[23] WHO 2007. Everybody business : strengthening health systems to improve health outcomes : WHO's framework for action. http://www.who.int/healthsystems/strategy/everybodys_business.pdf (accessed 01/06/2015 2015).

# APPENDIX 2
# BACKGROUND INFORMATION FOR PHASE 2

Phase 2 of the Needs Assessment centers on the provision of clinical care for GAS, ARF, and RHD, centering on 1) the analysis of existing cases and 2) understanding the supply-side constraints to delivering care. The setting for this phase are the health facilities located in the chosen sites.

The design of this phase should follow standard survey and clinical epidemiology methods. The small number of health facilities at each site implies that a stratified random sample would be required, with higher level facilities being included by default and lower level facilities being included at random. Higher level facilities should be the focus of data collected with regard to ARF and RHD, while lower level facilities should be the focus of data collected with regard to sore throat. Hence the tools for data collection should be applied to specific subsets of patients and diseases at each level of care.

The anticipated (relatively) small number of ARF and RHD cases implies that a "case series" approach may be the most appropriate for understanding current patterns of clinical care.

We propose a retrospective review of ARF and RHD cases at the district hospital and (where applicable) at referral and tertiary hospitals, and we propose a brief prospective study of sore throat management at primary health care centers. As described above, the facility capacity assessments at each of these levels of care would measure the resources needed to deliver the appropriate care. For example, a detailed assessment of penicillin use and availability could occur at primary care centers and dispensaries, whereas an assessment of echocardiography and other diagnostics could occur at the district, referral, and tertiary levels.

Individual patient data would be extracted from medical records using Case Report Forms (CRFs) relevant to each diagnosis. Facility data would be gathered through interviews and direct observation using Facility Survey instruments appropriate to each type of health facility. The content of the CRFs and facility surveys has been developed based on experience with multi-country studies of RHD in African settings.



# APPENDIX 3
# BACKGROUND INFORMATION FOR PHASE 3

## QUALITATIVE METHODS

Phase 3 uses qualitative methods to explore the experiences of people living with RHD (PLWRHD) and their healthcare providers: 1) to identify reasons why patients do or do not seek health care for sore throat, ARF and RHD, including the challenges associated with non-adherence to secondary prophylaxis for ARF. Additionally, these methods will be used 2) to investigate and document the experience and knowledge of patients and forefront healthcare providers regarding sore throat, ARF and RHD at first entry into the health system.

Qualitative methods enable the researcher to explore the feelings, experiences, social situations and phenomena as they occur in the real world and within a particular context. Patient experiences should thus be probed, in particular by identifying factors that would influence health-seeking behaviour and adherence to secondary prophylaxis. Use of qualitative methods would capture the health-seeking experience of patients starting from the initial recognition of symptoms to their first point of entry into the healthcare system and subsequent use of particular healthcare services when chronic disease is manifesting.

## RAPID ETHNOGRAPHIC ASSESSMENT

REA is an established and robust qualitative approach designed to bridge the gap between empirical research and the need for the implementation of intervention strategies.[24] REA triangulates structured surveys, semi-structured interviews, and observation[25] to elicit the most relevant information for programme planning, monitoring, and evaluation relatively quickly[26] Additional strengths of REAs are that they can identify the social structure of the community in relation to cultural beliefs and values, the role of the family in decision-making processes, and key sources of advice in relation to health-seeking practices. REAs have successfully applied traditional ethnographic methods to public health concerns in low and middle-income settings. These methods incorporate in-depth interviews (IDI) and focus group discussions (FGD), where the participants are selected via either non-probability or purposive sampling.[27]

In REAs, data collection can end, once "saturation" is reached, i.e., when enough interviews have been conducted such that no new important concepts or themes emerge with additional interviews. The levels of training and experience of the field workers in qualitative data collection are important considerations. A limitation of this methodology is the brevity of the method so that changes or developments over time cannot be observed unless the study is repeated periodically.

[24] Bull S, Farsides B, Ayele FT. Tailoring Information Provision and Consent Processes to Research Contexts: The Value of Rapid Assessments. *Journal of Empirical Research on Human Research Ethics* 2012; **7**(1): 37-52.
[25] Kengne-Ouafo JA, Millard JD, Njï TM, et al. Understanding of research, genetics and genetic research in a rapid ethical assessment in north west Cameroon. *International health* 2015.
[26] Schwitters A, Lederer P, Zilversmit L, et al. Barriers to Health Care in Rural Mozambique: A Rapid Ethnographic Assessment of Planned Mobile Health Clinics for ART. *Global Health: Science and Practice* 2015; **3**(1): 109-16.
[27] Karen Kroeger TS. Rapid Ethnographic Assessment: A tool for program improvement, community engagement, and health equity. 2012 (accessed 1 June 2015).

## HEALTH-SEEKING BEHAVIOUR OF PLWRHD

Health-seeking behaviour is part of the wider concept of health behaviour, which includes all those behaviours associated with establishing and retaining a healthy state as well as aspects of dealing with any departure from that health state. In understanding the utilisation of healthcare facilities, health-seeking behaviour is of interest, especially in the planning of health care programmes. Health-seeking behaviour does not exist in a vacuum. Intersecting biological, social, political and economic factors all influence health-seeking behaviour.[28]

Although there is a large body of information on health-seeking behaviour in general, not much is known about health-seeking behaviour in relation to sore throat, ARF and RHD in most endemic settings. Collecting qualitative evidence related to health-seeking behaviour would make it possible to identify challenges in, and opportunities for, ensuring appropriate access to health care for patients across the entire GAS/ARF/RHD spectrum. It is hoped that such qualitative evidence will complement quantitative evidence in the Continuum of Care (CoC) model by identifying the reasons why patients do or do not seek health care for sore throat, ARF and RHD in these regions and beyond.

Adherence to recommended therapy is an important aspect of health-seeking behaviour, especially among patients who have been diagnosed with ARF. All known clinical guidelines on ARF recommend secondary prophylaxis as the most effective method of preventing recurrent ARF and also of reducing the severity of RHD when present.[29] Secondary prophylaxis is effective if delivered regularly; however, poor adherence to prophylaxis regimens has been a major problem in many parts of the world.[30] In addition, recent studies show that by the time susceptible patients receive clinical attention for secondary prophylactic measures, they often have already accumulated significant valve damage from unrecognised attacks.[31]

There is a dearth of information with regard to the experiences of patients at the first point of care in relation to sore throat, ARF and RHD and how this first encounter influences future health-seeking behaviour. There is a need to investigate how well health care providers understand streptococcal infection, ARF and RHD and their link in high prevalence settings. These knowledge gaps impede the formulation and implementation of primary interventions to reduce mortality and morbidity associated with RHD. An exploration of the relationship between patients and healthcare providers at the first point of care would provide extremely valuable information for RHD control strategies.

Ultimately, this project would provide a better understanding of relationships between patients and health care providers as a key aspect in assessing the effective and efficient function of health systems that serve communities in RHD-endemic locales.

## ETHICS COMMITTEE APPROVAL AND OVERSIGHT

Local Ethics Committee approval is required to review medical records prior to any research activities taking place. Participants would provide informed consent/assent in a manner and language as approved by the Local Ethics Committee. Any audio/video taping of interviews and/or focus-group discussions would be in accordance with Local Ethics Committee approval and participant consent.

[28] Ramsey LS, Watkins L, Engel ME. Health education interventions to raise awareness of rheumatic fever: a systematic review protocol. *Systematic reviews* 2013; 2: 58.
[29] World Health Organisation. A Review of the Technical Basis for the Control of Conditions Associated with Group A Streptococcal Infections. 2005
[30] Zuhlke L, Engel ME, Karthikeyan G, et al. Characteristics, complications, and gaps in evidence-based interventions in rheumatic heart disease: the Global Rheumatic Heart Disease Registry (the REMEDY study). *European heart journal* 2015; **36**(18): 1115-22a.
[31] Veasy LG, Wiedmeier SE, Orsmond GS, et al. Resurgence of acute rheumatic fever in the intermountain area of the United States. *N Engl J Med* 1987; **316**(8): 421-7.



## SAMPLING

A qualitative research design predominantly employs non-probability sampling techniques. In particular purposive sampling would be useful for this component of the Needs Assessment. This sampling technique involves selecting a sample on the basis of the researcher's knowledge of the population, its elements and the nature of the research aims.

Participants would be drawn from a sample population comprised of three patient groups. These would be patients with sore throat, ARF and RHD, from the communities and healthcare facilities in the partner countries. Information obtained from these three patient groups would provide an understanding of health-seeking behaviour at different stages of disease progression. Information obtained from the study population regarding the first point of care, both from the perspective of the patients and that of the health care providers, would allow gatekeepers to health care to be identified and in turn help to understand the systems involved in accessing health care.

## SELECTION CRITERIA

### HEALTH SEEKING BEHAVIOUR

**Sore throat patient group** – Parents or guardians of children aged up to 15 years seeking health care for sore throat would be selected from primary health care facilities. Children would be invited to sit in for the interview. An understanding of the health-seeking behaviour of this patient group would help identify the factors that would contribute to the decision to (not) seek health care for a sore throat. Recruitment of these participants should be conducted by approaching participants sitting in hospital or clinic queues and asking them if they would be interested in participating in the study.

**ARF patient group** – Two groups of participants should be interviewed: 1) parents of children who have been diagnosed and have previously been (or are currently) admitted for treatment with ARF and 2) patients who have been diagnosed and have previously been (or are currently) admitted for treatment with ARF. These participants should be selected from secondary healthcare facilities. These patients would have already been absorbed into the health system and would help to identify the factors that influence health-seeking behaviour among ARF patients. This group would also be able to identify the factors influencing decisions to seek healthcare for sore throat.

**RHD patient group** – These are patients who first present for care with cardiac failure at a healthcare facility. This group would either not have sought treatment for sore throat, or ARF, or would likely not have received effective care and secondary prophylaxis. This may be the first diagnosis and interaction with health services, which would also provide additional useful insights. As such, this group would provide important information about health-seeking behaviour for the entire spectrum of this disease, from primary infection to chronic heart disease.

### ADHERENCE TO SECONDARY PROPHYLAXIS

**Newly on chronic medication** – These are patients who have been recently diagnosed with ARF and who have been receiving treatment for secondary prophylaxis for less than 12 months.

**Long term adherers** – These are patients who have been on secondary prophylaxis for more than a year and who are consistently (more than 85% of prescribed medication) taking their medication (i.e. going for monthly injections at the clinic/hospital).

**Non-adherers** – These are ARF patients who should be taking secondary prophylaxis but either have never taken secondary prophylaxis or have stopped taking medication after a certain period of time (i.e. these people have stopped going to the clinic/hospital for monthly injections).

Recruitment of these participants would require consulting with clinicians to identify these participants based on their interpretation of medical records in secondary healthcare facilities registers.

### FIRST POINT OF CARE/ GATEKEEPERS TO CARE

Patient Group: Parents/guardians of patients and patients seeking healthcare for sore throat, ARF and RHD would be identified through key contacts at the healthcare clinics.

Healthcare Provider Group: Doctors/Physicians, Nurses, Pharmacists, Health-care workers and any other role-players would be identified as gatekeepers at the first point of care by the patients and by other health care providers.

## DATA COLLECTION BY METHOD

There are various methods of eliciting information when using a qualitative approach. The effectiveness of the method used in collecting data is contingent on the purpose of the research.[32] Different methods of data collection may be combined to take advantage of different opportunities for data collection and to enrich our understanding of social processes.

**Interviews (Semi-structured)** – Qualitative interviews attempt to understand the world from the participant's point of view and to unfold the meaning of people's experiences. Semi-structured interviews are useful in that the researcher would make use of an interview schedule predominantly comprised of open-ended questions. This would enable the researcher to gain a detailed picture of participants' beliefs, perceptions and accounts in respect of a certain topic.

The length of the interviews would vary, depending on patient-group and participant availability. However, the maximum length for semi-structured interview would be 1.5 hours.

**Focus groups** – Focus groups are a group of people who share a similar type of experience. This data collection method would be useful in providing evidence about similarities and differences in participants' opinions and perspectives. These groups would be comprised of 8-10 participants. The ways in which participants interact within the group would contribute significantly towards the data.

With the permission of the participants, interviews and FGDs would be audio-recorded and the researcher would also take handwritten notes.

**Photo elicitation** – This technique is based on the simple idea of using photographs to facilitate the interview. It evokes information, feelings, and memories that are due to the photograph's particular form of representation.[33] Photographs could be used by researchers as a tool to expand on questions and simultaneously to provide a unique way to communicate certain dimensions of their lives. It would involve training and equipping participants with cameras to capture images they felt express their thoughts with regard to a specific topic. A follow-up discussion would be conducted with the participants, using the photographs as an interview guide. Hence this data collection method is often termed photo elicitation interviewing (PEI).[34]

The use of PEI would unlock the potential for the researcher to gain an understanding of the patient's experiences from the perspective of the participants. It would also identify opportunities for interventions, including networks and resources, with regard to the factors influencing health-seeking behaviour, and particularly obstacles to adherence. In addition, photo elicitation is an ideal methodology to engage young people and children by making the process more interesting and enjoyable. Photographs would also provide younger participants with clear and tangible prompts (ibid.).

There are two approaches to photo elicitation – using research-produced photographs and using participant-produced photographs. The former would allow for theory driven research and potentially captures aspects of participants' lives that are taken for granted. However, there is a possibility that certain important aspects could be omitted. Such cases would give the respondents an opportunity to alert the researcher to omissions and lead to further discussion on the importance of these omitted images. The second approach to photo-elicitation would entail 'autodriven' interviews in which cameras are given to participants to enable them to take their own photos, which would be later used in the interviews (ibid.).

**Interpretive biography (Unstructured interviews)** – Personal narratives illuminate the course of life over time and allow for its interpretation in its historical and cultural context. The life history approach can be used both in the generation of new theories and the testing of existing ones, and it can be used in conjunction with other methods. This method is particularly useful for providing insights into the total subjective and personal dimensions of human experience, but can also be used to focus on particular experiences and their impact on a person's life.[35]

Using an interpretive biography methodology has four important implications. Firstly, this approach creates a better understanding of the subjective reality of the individual and their everyday experience. This is an important aspect in this research, which seeks to follow the everyday experience of patients living with RHD to where they are at presently. Secondly, this method focuses on the process of changing by enabling the researcher to discover the confusions, ambiguities and contradictions that make up the everyday life experiences of the patient. Thirdly, this approach views an individual's life as a totality. This gives a holistic perspective on the experiences of the patients and allows the researcher to identify and understand the individual, social, economic and political dynamics that seem to have been most significant in shaping the life of the particular participant. Fourthly, interpretive biographies allow the researcher to move continuously between the changing biography of the individual subject and the social history of the same subject (ibid.).

Information using this method is usually gathered over a long period of time with gentle guidance from the researcher. For our purposes, this approach would consist of a number of conversations (unstructured interviews) exploring the person's experiences of living with RHD, from the moment they were first diagnosed or had their first episode of ARF.

**Observation** - Data collection may also be accomplished through observation. Observation will enable the researcher to identify the various role-players at the first point of care and to observe interactions between patients and health care providers. This would occur in the specific hospital or clinic settings that offer forefront healthcare.

[32] DeVos AS, Delport C, Fouche C, Strydom H. Research at grass roots: A primer for the social science and human professions. Pretoria, South Africa: Van Schaik; 2011.
[33] Harper D. Talking about pictures: A case for photo elicitation. *Visual studies* 2002; **17**(1): 13-26.
[34] Clark-Ibáñez M. Framing the social world with photo-elicitation interviews. *American behavioral scientist* 2004; **47**(12): 1507-27.
[35] Mouton J, Babbie E. The practice of social research. Cape Town: *Wadsworth* 2001.

# DATA COLLECTION BY PATIENT-GROUP

## HEALTH SEEKING BEHAVIOUR

**Sore throat patient-group:** Concise one-on-one semi-structured interviews would be utilised to obtain information with regard to the factors that might contribute to and the process leading up to seeking health care for a sore throat. These interviews could be conducted in the clinic, while people are waiting to see a doctor or immediately after they have seen the doctor.

**ARF patient-group:** Up to five focus group discussions (FGDs) composed of approximately 6-8 participants would be conducted, with the aim of understanding the health-seeking process/ experience of patients presenting for their first time for care with ARF. In-depth semi-structured interviews would be conducted with of up to 15 participants, with some of the patients who would have participated in the FGDs and patients who were not part of the FGDs. In-depth interviews with FGD participants would provide an opportunity to explore important and recurring topics that were brought up in the group discussions in more detail.

**RHD patient group:** Two types of interview structures would be employed for this patient group. Semi-structured interviews based on certain topic guides would be conducted to explore issues pertinent to the specific research question. In addition, a small number of (up to 5) unstructured interviews (life histories) would be utilised as a data collection tool to examine the personal narratives and disease histories of patients diagnosed with RHD.

## ADHERENCE TO SECONDARY PROPHYLAXIS

**All patient-groups:** PEI would be used as a data collection tool to identify and explore the factors that might influence adherence to secondary prophylaxis among patients diagnosed with ARF.

**Long-term adherers:** Participants in this patient group would be given disposable cameras to enable them to capture their own images of the factors that might be influencing their adherence to secondary prophylaxis. These images would be used in the follow-up interviews to discuss what these images represent for these participants, in relation to adherence.

**Non-adherers:** For this aspect of the project, local leaders of the community would be given disposable cameras to capture images that best represent the factors that might influence adherence to secondary prophylaxis. This approach would be useful for this patient group as we anticipate that these particular participants might be difficult to locate. The photographs would then be used as topic guides in the semi-structured interviews with the participants.

## FIRST POINT OF CARE/GATEKEEPERS TO CARE

**Patient-group:** Semi-structured interviews would be conducted with participants to obtain information on whom they perceive to be gatekeepers to health care for sore throat, RHD and ARF, and to hear about their experiences at this first point of care in relation to these conditions. A small number of FGDs would also be conducted with this participant group. Ultimately, this would contribute to knowledge and understanding of the interactions and relationships between patients and health care providers, particularly at the first point of care.

**Healthcare provider-group:** Use of documentary and visual data would be an innovative way to explore healthcare providers' knowledge and perceptions of sore throat, ARF and RHD. Through the use of vignettes, participants would be given an opportunity to fill in the details of a scenario to complete a story.

[13] Murray SA, Tapson J, Turnbull L, McCallum J, Little A. Listening to local voices: adapting rapid appraisal to assess health and social needs in general practice. BMJ 1994; 308(6930): 698-700.
[14] van Bodegom D, May L, Kuningas M, et al. Socio-economic status by rapid appraisal is highly correlated with mortality risks in rural Africa. Transactions of the Royal Society of Tropical Medicine and Hygiene 2009; 103(8): 795-800.
[15] Mazzeo J, Makonese L. Experiences of collaboration, coordination and efficiency in the delivery of HIV/AIDS home-based care in Zimbabwe. Afr J AIDS Res 2009; 8(4): 443-53.



# DATA ANALYSIS

Qualitative data analysis involves the transformation of data into findings. It is defined as the inductive process whereby the researcher identifies important categories, patterns and relationships in the data, so as to describe the data in ways that best capture the setting. This process continues throughout the research project. In most instances, data collection and data analysis filter into each other. Analysing data during the data collection phase also allows for the analysis of non-verbal data or other forms of evidence, which would not have been recorded as words. The topic of study, the research questions and the way in which the researcher wants to answer the questions determines what type of analysis the research team will use.

All the types of analysis that would be utilised to transform data into findings for this particular project are rooted within a grounded theory approach. For this particular project, transcripts obtained from IDIs and FGDs would be analysed by using thematic analysis.

# DATA ANALYSIS ELEMENTS

## Grounded theory approach

Grounded theory is an approach that allows us to study a relatively unknown phenomenon around which no specified theory may exist yet. In this case, not much is known about the experiences of patients and the knowledge of healthcare providers at the first point of care in relation to RHD. Crooks (2001) asserts that the grounded theory methodology is ideal for exploring integral social relationships and the behaviour of groups, where there has thus far been little exploration of the contextual factors that affect individuals' lives.[36]

## Thematic analysis

This is a multidimensional analytical technique that emphasises recognizing, examining and recording themes within the data. It is descriptive and exploratory, making it a useful tool to explore the experiences of patients and healthcare providers at the first point of care in relation to sore throat, ARF and RHD. With this type of analysis, the analyst focuses on how respondents impose order on the flow of experience in their lives and thus make sense of events and actions in which they have participated.

The **coding** strategy revolves around reading the narratives obtained from interviews or the notes from observations, and classifying them into general and consistent patterns. This allows the researcher to identify sub-themes that can be grouped together to form categories of major themes. De Vos (2011) describes the process of coding within this type of analysis as thoroughly marking passages in data using codes, numbers or highlighters, although most contemporary coding is done using computer software.[30] The identified themes can then be linked to already existing codes, or they can be classified in a way to make new codes. This type of analysis requires researchers to familiarise themselves with literature acquired on the topic prior to conducting the study, which will aid them in the process of inducing and coding categories of texts.

**Coding** entails marking different sections of the data, i.e. the line, sentence or paragraph containing material that pertains to sub-themes and theme(s) under consideration.[37] There are different ways of coding. The researcher would in this case use software programmes that aid qualitative data analysis.

[36] Crooks DL. The importance of symbolic interaction in grounded theory research on women's health. *Health Care for Women International* 2001; **22**(1-2): 11-27.
[37] Terre Blanche M, Durrheim K, Painter D. Research in practice: Applied methods for the social sciences: Juta and Company Ltd; 2006.

**Computer-Aided Qualitative Data Analysis (CAQDAS)** - CAQDAS consists of a range of software packages designed to assist in analysing qualitative data, which is generated using qualitative research methods. They allow the researcher to assign very complicated systems of codes to bits of text and images. It is important to note that such software packages are not meant to do the analysis but rather to assist the researcher in doing the analysis. This is done by helping to better organise the data according to specified codes and storing texts and images carefully.[33] Examples of commercially available software packages are Atlas.ti and Nvivo.

## REFLEXIVITY

Reflexivity is the explicit recognition and examination of the researcher's role in the research process, including the assumptions within which they operate, their identification and their possible influence on the research process. The natural development of evidence encompasses the impact of the researchers' perspectives and feelings on the way in which the evidence is produced.[38] Therefore, it is important for the research team to report how and why they think they did what they did, as this will help to determine whether or how the researchers' perspectives influenced their conclusions.

## DEVELOPMENT AND ADAPTATION OF THE TOPIC GUIDES

Topic guides specific to the two participant groups should be utilised in this project, for both IDIs and FGDs. The topic guide for the patient group would ask participants about the factors that influenced them to seek health care at the time they first presented for care, and it would explore issues relating to ongoing interactions with healthcare providers at the first point of care, for instance, in the case of ongoing warfarin blood tests. The information or data obtained from the interviews with patient groups would be incorporated into the interviews with other stakeholders.

The topic guide for the healthcare providers would consist of questions and probes that explore the experiences of healthcare providers in receiving patients with sore throat, ARF and RHD, and their knowledge of these conditions at the first point of care (to be completed once the topic guides have been prepared).

An essential first step in adapting the topic guides to the various research settings would be to pilot them with a small number of people (2 or 3) similar to the participants who would be included in the study. The purpose of the pilot would be to test whether the topic guides are helpful in eliciting useful and pertinent data, to identify concepts that are not well understood, and to scope potential interview questions. The topic guides should be amended following the pilots. All interviews and Focus Group Discussions (FGDs) should be carried out in a language with which the participants feel comfortable. This would require the topic guides to be translated into different languages.

[38] Schutt RK. Investigating the social world: Sage Publications; 2014.

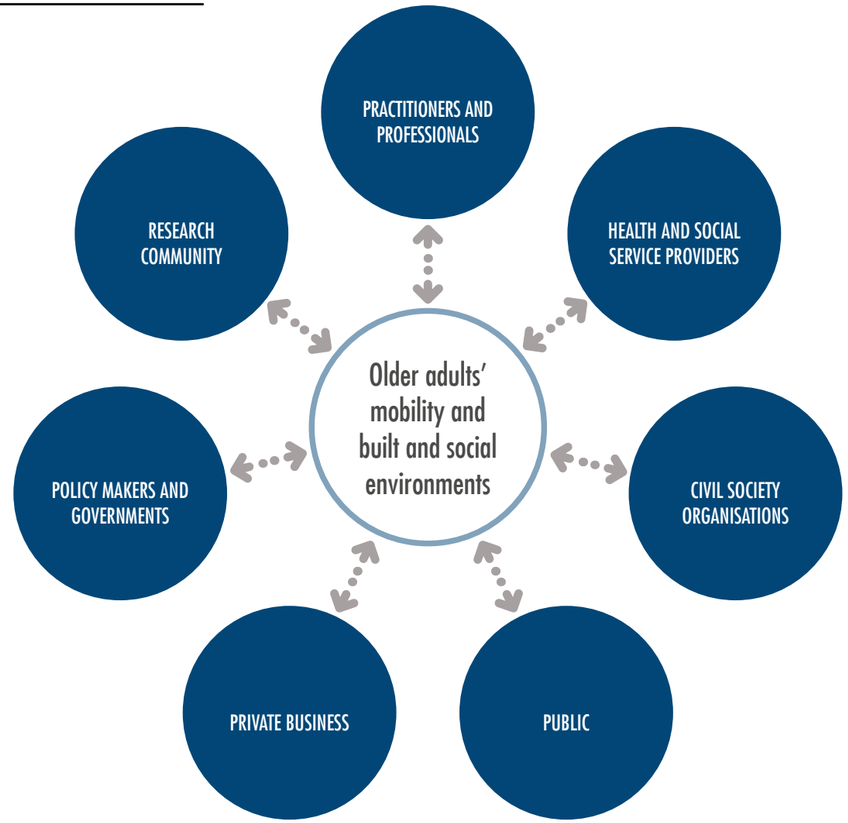


# APPENDIX 4
# BACKGROUND INFORMATION FOR PHASE 4

## STAKEHOLDER INTERVIEWS

Stakeholders are groups or individuals who can affect or are affected by an issue, in this case, ARF/RHD. Stakeholders are an important source of information in health research, and programmes and interventions rely on stakeholders not only as beneficiaries of the intervention but also as effecters or, in some cases, as obstructers. RHD is a complex interdisciplinary disease that interacts with several other sectors outside health (e.g., housing, education, finance). Stakeholders outside of the health care sector thus possess critically important insights and should play a key role in priority setting, dissemination and implementation. The main categories of stakeholders are outlined in the figures below[40].

**FIGURE 11**
FOCUSED STAKEHOLDER MAP



## FIGURE 12
DETAILED CHART OF STAKEHOLDERS

**POLICY MAKERS AND GOVERNMENTS**

- Policy networks and advisory groups
- Municipal Governments
  - Unions of municipalities
  - Municipal insurance associations
  - City councils
    - Elected officials
    - Citizen's Advisory Committees
- Departments of:
  - Legal services
  - Community services
  - Engineering and transportation
  - Human resource services
  - Sustainability
  - Parks and recreation
- Provincial Governments
  - Elected officials
  - Ministry of:
    - Children and family
    - Community and culture
    - Health
    - Social development
    - Transportation/ infrastructure
    - Energy and mines
- Health Authorities
- Federal Government
  - Elected officials
  - Ministry of:
    - Health
    - State (seniors)
    - Human resources development
    - Industry (building

**RESEARCH COMMUNITY**

- Research Centres and networks
  - Post-secondary institutions
- Health Professions
  - Medicine
  - Nursing
  - Physiotherapy
  - Occupational therapy
  - Kinesiology
  - Public health
  - Social work
  - Psychology
- Gerontology and ageing studies
- Health services
- Social inequities in health
- Architecture
- Planning
- Urban design
- Engineering
- Technology and society studies
- Transportation
- Health geography
- Environmental geography
- Social and economic policy

**PRACTITIONERS AND PROFESSIONALS**

- Inter-professional networks and advisory groups
- Health professions
  - Medicine
  - Nursing
  - Physiotherapy
  - Occupational Therapy
  - Kinesiology
  - Public Health
  - Social Work
  - Psychology
  - Pharmacology
- Gerontology and ageing studies
- Health services
- Social inequities in health
- Architecture
- Planning
- Urban design
- Building trades
- Engineering
- Technology and society studies
- Transportation
- Health geography
- Environmental geography

**PUBLIC**

- Older adults
- Families and Caregivers
- Taxpayers (community members)

**HEALTH AND SOCIAL SERVICES PROVIDERS**

- Housing and accommodations
  - Assisted living
  - Residential care
  - Sustainable housing
  - Mortgage corporations
- Health insurance providers
  - Occupational health and safety
  - Provincial medical service plans
- Disability services
- Safety and crime prevention
- Transportation
- Maintenance in public spaces

**PRIVATE BUSINESS**

- Chambers of commerce
- Health and Social service suppliers
  - Mobility aids
  - Alternative transportation
- Land use
  - Developers
  - Real Estate
- Infrastructure
  - Material manufactures
  - Construction companies

**CIVIL SOCIETY ORGANIZATION**

- Non-governmental organizations
  - Interest groups
  - Think tanks
  - Charitable organisations
    - Disease specific
    - Disability oriented
    - Community oriented
    - Sustainability orientated
- Faith-based organisations
- Indigenous/ethnic groups

Detailed chart of stakeholders, expanding framework of stakeholder catergories related to the intersection of older adult mobility with build and social environments. Adapted from Schiller *et al.*



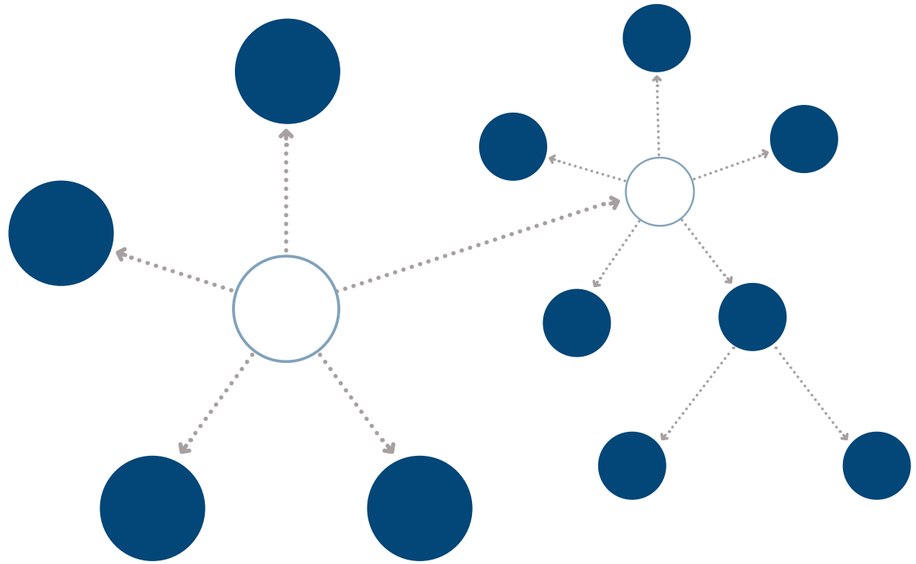
A structured literature review of policy and stakeholder mapping directed at ARF/RHD did not reveal any data in this field. Similarly, there was only one publication looking at stakeholder mapping in low-income countries, which focused on political mapping in tobacco control. Likewise, there were no data on structured frameworks around stakeholder mapping in developing countries when specifically searching for health-related frameworks.

## SCIENTIFICALLY VALIDATED MAPPING FRAMEWORKS

Concept mapping is a mixed-methods technique, which facilitates the analysis of stakeholder perspectives. As such, it is a useful tool for understanding complex phenomena in public health.[39] While mapping relies on comprehensive identification of the key stakeholders, the literature lacks systematic, practical techniques for identifying stakeholder groups and individuals. In practice, intuition and feasibility tend to guide the process, rather than structured systematic frameworks. A recent report proposed an approach that commenced with a strategic, focused literature search, with particular attention paid to the categories of health stakeholders.[40] The identified categories would thus inform a broad organisation of the stakeholder framework, populated by a spoke and wheel approach, similar to Figure 13 below. Four iterative steps can be followed to create stakeholder maps:

1. Identify a relevant framework of stakeholder categories
2. Identify specific stakeholder groups – relevant research disciplines supplemented by collaborative networks
3. Solicit feedback from expert informants
4. Use a visual representation of the stakeholders and how they relate to each other

## FIGURE 13
EXAMPLE OF VENN DIAGRAM



[39] Burke JG, O'Campo P, Peak GL, Gielen AC, McDonnell KA, Trochim WM. An introduction to concept mapping as a participatory public health research method. *Qual Health Res* 2005; **15**(10): 1392-410.
[40] Schiller C, Winters M, Hanson HM, Ashe MC. A framework for stakeholder identification in concept mapping and health research: a novel process and its application to older adult mobility and the built environment. *BMC Public Health* 2013; **13**: 428.

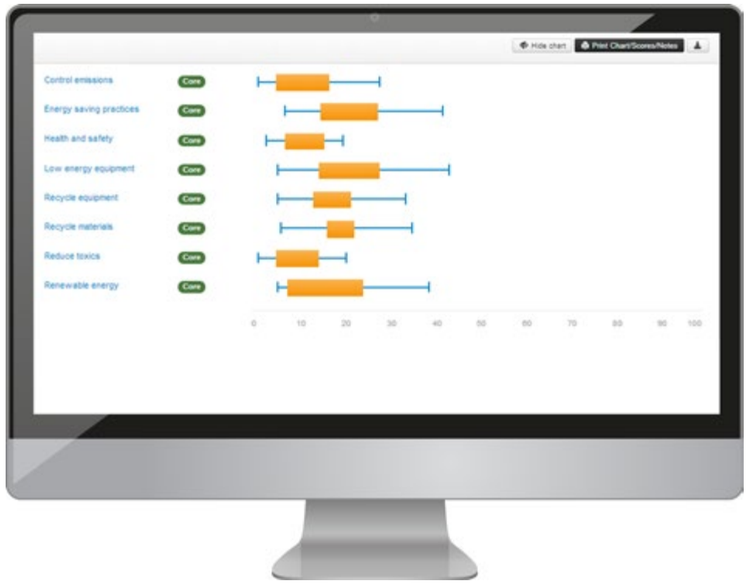
Although this approach provides a comprehensive list of key stakeholders, it does not visually depict the contributions of the different stakeholders, nor the inter-relationships between them. This is either performed by concept mapping or using a modality such as multi-criteria mapping (MCM). MCM uses a web-based, mixed-methods approach to map interviews of diverse experts and stakeholders (Figure 14 below). Users and collaborators can gain a clear picture of how and why different perspectives vary on key issues and options – as well as on the practical implications for decisions. The key benefit of MCM lies in helping to build a robust and detailed understanding of stakeholders' interactions and in monitoring and exploring changes under different views and scenarios (ibid.). The NAT will combine these two methods, first by clearly identifying all stakeholders in ARF/RHD a priori, and then by using MCM to describe the interactions between stakeholders over time.

An MCM exercise usually involves a series of one-on-one interviews with a diversity of carefully recruited 'experts' or 'stakeholders'. Special efforts are made to include all relevant perspectives and to ensure that each is content that key aspects of their view are fully and correctly interpreted.

Each participant moves through a series of four stages. Firstly, an array of alternative options e.g. the need for penicillin, reproductive services or cardiac surgery are reviewed and added to if necessary. Secondly, a set of criteria is defined, to address the issues that seem most relevant to the participant in judging how good or bad these options are. Thirdly, the participant scores their options under their criteria, expressing a range of uncertainty between pessimistic and optimistic conditions – descriptions of which are carefully recorded. Finally, each participant weighs up the different criteria to express their relative importance.

The result is a rich body of information, represented both as diagrams and text, documenting the details of the different perspectives. The web-based tool also helps analysis, exploring in flexible ways how different groupings of options, criteria or perspectives differ and what they hold in common. (See Figure 14 below for a summary diagram).

**FIGURE 14**
MULTI CRITERIA MAPPING






In the absence of a computerised programme, such as MCM, semi-structured interviews can be used together with focus groups interviews. Again, using topic guides focused on diverse perspectives.

Concept mapping will then be applied once the key themes of the interviews have been defined in order to create the Venn diagram of stakeholders and inter-relationships.

## HEALTH SYSTEM APPRAISAL/PERFORMANCE ASSESSMENT

The assessment of health systems and health system performance can be approached through several different frameworks.[41] Some of these frameworks review the four vital functions of a health system: provision of health care services, resource generation, financing and stewardship.[42] Others still have focused on health systems dimensions, such as quality, efficiency, acceptability and equity. Finally, a more reductionist approach to health system appraisal, the WHO "building blocks" model, reviews the dimensions of service delivery, health care workforce, information and research, medicines and technologies, financing, and leadership/governance. All new initiatives and programmes must be reviewed within an appraisal framework that provides a comprehensive and meaningful assessment of the relevant health system. The WHO has also promulgated a health system monitoring framework, including key indicators and their measurement strategies.[43] In addition, Murray and Frenk have defined four methods to provide a more comprehensive framework to assess health systems that includes 1) interrelations between health system components, 2) "demand-side" (consumer or "user") considerations, 3) distribution of health in a population (i.e., equity), and 4) health system functions beyond just service provision (ibid.).

Health system performance appraisal (HSPA) was the focus of two recent reports. The first, a study from Uganda, used a structured literature search approach to develop a list of six attributes for a "good" HSPA framework.[44] These were: an inclusive development process; embedding this process in the health system's conceptual model; its relation to the prevailing policy and organisational set-up and societal context; the presence of a concrete purpose, constitutive dimensions and indicators; an adequate institutional set-up; and, its capacity to provide mechanisms for eliciting change in the health system. An expert group contextualised these attributes and added one on the adaptability of the framework. The authors commented on the marked differences between the structures and contexts of frameworks from different country income categories and noted that, although HSPA developed in high-income countries are useful as a guide or checklist, it is imperative to consider the specific context of the assessment and the country concerned. Following on from this study, Swanson et al. reviewed the concept of health systems strengthening in low-income countries in the context of short-term investments that might potentially affect the long-term performance of healthcare systems.[45] This paper emphasised the importance of two key areas: firstly, the need for donors and recipient organisations to work as equal partners and, secondly, the need for strong and widely distributed leadership in low-income countries.

[41] Murray CJ, Frenk J. A framework for assessing the performance of health systems. *Bull World Health Organ* 2000; **78**(6): 717-31.
[42] Frenk J. The global health system: strengthening national health systems as the next step for global progress. *PLoS Med* 2010; **7**(1): e1000089.
[43] WHO 2007. Everybody business : strengthening health systems to improve health outcomes : WHO's framework for action. http://www.who.int/healthsystems/strategy/everybodys_business.pdf (accessed 01/06/2015 2015).
[44] Tashobya CK, da Silveira VC, Ssengooba F, Nabyonga-Orem J, Macq J, Criel B. Health systems performance assessment in low-income countries: learning from international experiences. *Globalisation and health* 2014; **10**:5

## HEALTH SYSTEM PERFORMANCE FRAMEWORKS AND STREP THROAT/ARF/RHD

The literature in this area is sparse and will be reviewed formally in Phase 1, i.e., during the systematic reviews. One existing study focused on the implementation of national best-practice ARF/RHD management guidelines at primary care level.[46] They adopted a continuous quality improvement (CQI) strategy with participatory action research methods to identify the system barriers to the delivery of high quality care. A system assessment tool (SAT) was employed to assist primary care staff in developing and implementing strategies to overcome any identified barriers, and a clinical audit was performed at baseline and annually for two further years to assess outcomes. The CQI process, which used a systems approach and a participatory action research methodology, was demonstrated to be effective. However, this was a limited study focusing only on the delivery of ARF/RHD care at sites participating in research, and it was not necessarily adaptable to a broader cohort of more diverse service providers.

Another report from Australia summarised the findings of a workshop detailing the problems, solutions and barriers within acute hospital care for indigenous people in Australia and New Zealand. Although not specifically focused on ARF/RHD, it identified critical issues within acute care delivery for indigenous people, a high-risk group for ARF/RHD.[47] These included addressing systemic racism; reconfiguring models of care to address the needs of indigenous people; cultural competence training for all healthcare professionals; increasing the participation of indigenous people in the healthcare workforce; improving information systems and facilitating communication across the health care sector and with indigenous communities. These were all clearly components of the healthcare system and represented barriers to care in this community.

This document does not attempt to provide a new or entirely comprehensive framework. Healthcare Systems Appraisal for RHD projects would focus on the key indicators and assessment points using the six WHO core components of a health care system. In order to assess the expanded view of healthcare systems, we would use a multi-method approach to identify and understand both local barriers and facilitating factors for optimal care.[48]

Based on the frameworks and tools outlined above, the health system aspects of the NAT would be addressed in three related analyses:

1. Healthcare system capacity to deliver care for GAS, ARF, and RHD
2. Healthcare system components (WHO "building blocks")
3. Healthcare system performance appraisal

## FRAMEWORK FOR MONITORING AND EVALUATION

Results Based Management (RBM) is an on-going process of constant feedback for "doing, learning, and improving"[49] Through scheduled, incremental monitoring and evaluation, lessons learned can be applied to existing interventions in real time as a formative evaluation technique. A summative evaluation approach would be used to measure the performance at the end of the intervention with a more traditional quantitative pre-/post-intervention methodology.

A Monitoring and Evaluation (M&E) point person would be designated to lead a core committee and would be responsible for the overall accountability of the process. Whenever possible, an external evaluator would also be utilised to add an unbiased member to the evaluation team. This person could be a member of the country partner organisation or an independent professional, if resources allow. Progress Reports would be distributed to designated stakeholders and formally presented and discussed at sessions at predetermined time intervals.

Successful and effective use of the RBM framework for monitoring and evaluation would require ownership beyond a select few, and it should include as many stakeholders as possible. These stakeholders should include representation from management, practitioners and patients so that there is the necessary authority to implement changes and allocate resources when necessary, and so that recommendations and lessons learned can benefit those who are responsible for results and for those who can benefit from them.

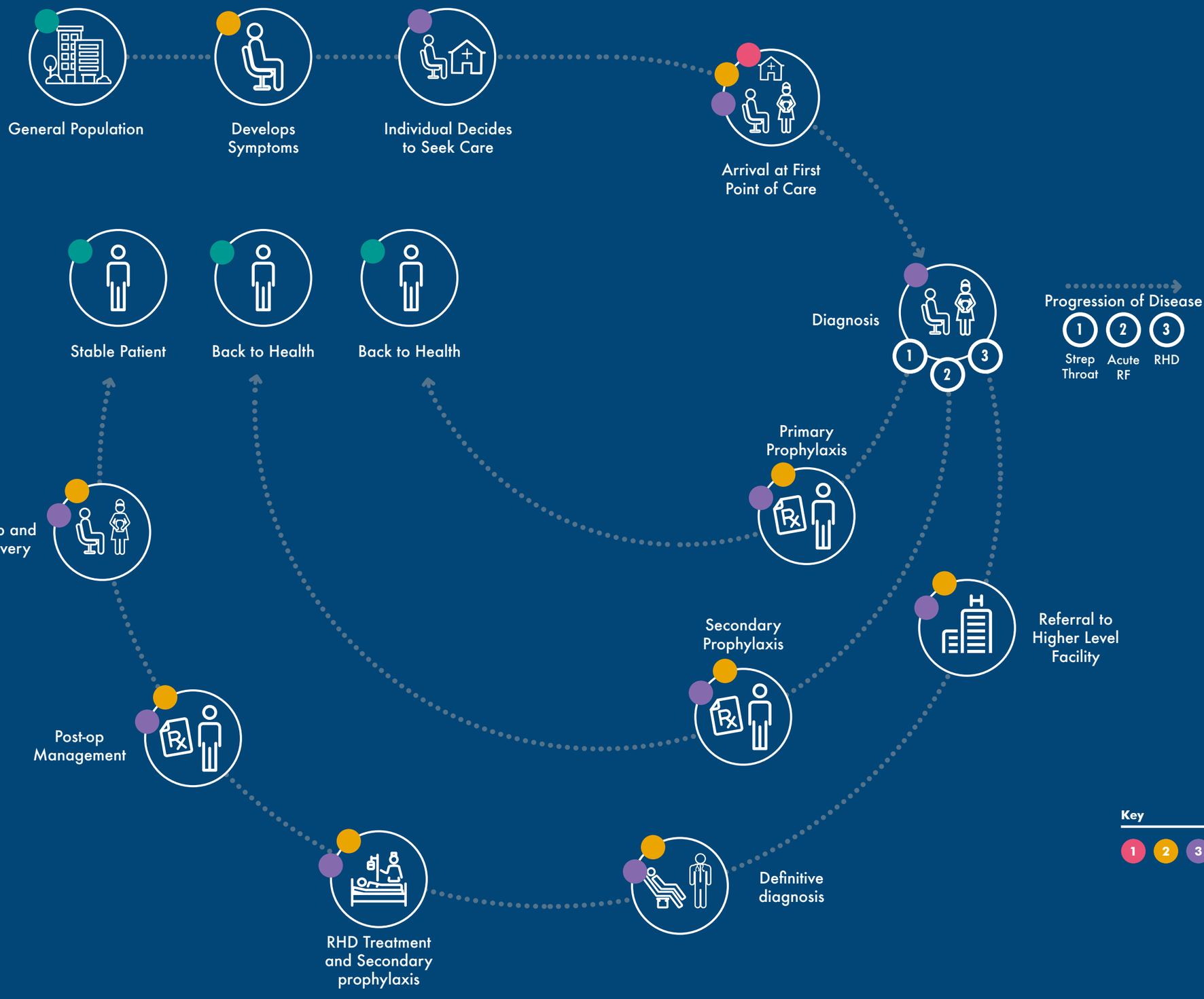
The UNDP-adapted M&E reporting methodology is comprised of three elements: the narrative, the results framework and the planning matrix for monitoring and evaluation. Potential risks/challenges to achieving the goals of the intervention and plans to mitigate those risks would also be incorporated into the reporting tool to provide a mechanism for documenting potential adjustments during the formative evaluation process. A mix of data analysis, validation and participation would be used in the M&E process and documented on standardised reporting instruments (Ibid). The progress of all planned interventions would be summarised on a facility-specific Work Plan, to support the individual intervention-specific reporting instruments.

[45] Swanson RC, Atun R, Best A, et al. Strengthening health systems in low-income countries by enhancing organisational capacities and improving institutions. *Globalisation and health* 2015; **11**(1): 5.
[46] Ralph AP, Fittock M, Schultz R, et al. Improvement in rheumatic fever and rheumatic heart disease management and prevention using a health centre-based continuous quality improvement approach. *BMC Health Serv Res* 2013; **13**: 525.
[47] Davidson PM, MacIsaac A, Cameron J, Jeremy R, Mahar L, Anderson I. Problems, solutions and actions: addressing barriers in acute hospital care for indigenous Australians and New Zealanders. *Heart Lung Circ* 2012; **21**(10): 639-43.
[48] Nolte E. McKee M. Measuring and evaluating performance. Oxford: Oxford University Press; 2012.

[49] UNDP 2009. Handbook on Planning, Monitoring and Evaluation for Development Results. http://web.undp.org/evaluation/guidance.shtml#handbook (accessed 11/06/2015).

# CONTINUUM OF CARE FOR RHD

Medtronic Continuum of Care framework, combined with the 4 phases of the Needs Assessment Tool



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