A National Rheumatic Fever/Rheumatic Heart Disease Prevention Plan for Nepal

By

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I. INTRODUCTION

A recently completed handbook for the prevention and control of rheumatic fever (RF) and rheumatic heart disease (RHD) entitled *RHD TIPS: Rheumatic Heart Disease Tools for Implementing Programs (RHD TIPS)* was written by the World Heart Federation (WHF) and RhEACH. The document is a comprehensive outline of strategies and frameworks to help guide the design and implementation of successful RF/RHD control programming. Policy-makers around the world will use it to develop RF/RHD programs for inclusion into national non-communicable disease (NCD) plans. Nepal is one of five countries tasked with piloting the handbook’s recommendations. This masters paper will use the *RHD TIPS* handbook to guide RF/RHD prevention program development in Nepal. The handbook can be thought of as a quasi-evidence-based intervention from which countries can identify priority interventions to implement from a menu of options.

At-A-Glance: Rheumatic Fever and Rheumatic Heart Disease

If left untreated, a sore throat in childhood can cause death decades later. The pathogenesis of rheumatic heart disease (RHD) begins with a pharyngeal Group A Streptococcal infection—colloquially called “strep throat”—most commonly acquired in the elementary school years. Weeks after apparent clearing of the throat infection, 0.3% to 5% of children develop acute rheumatic fever (ARF) (Irlam, 2013). As part of this inflammatory process, 30-80% of patients will develop carditis due to auto-immune-mediated destruction of valvular heart tissue (Roberts, 2013). Approximately 60% of patients will subsequently develop RHD over a ten year period (Carapetis, 2005). Of those diagnosed with RHD, between 44% and 80% will develop severe heart failure if untreated, necessitating medical or surgical treatment within 20 years (Roberts, 2013). Mortality for untreated RHD is estimated at 1.5% per year (Carapetis, 2000).
The number of individuals living worldwide with RHD is estimated at 15-20 million (Maurice, 2013). Global incidence approaches 300,000 cases per year, similar in number to the estimated RHD global mortality rate of 233,000 deaths per year (Roberts, 2013). Global incidence and prevalence estimates, however, are limited by generally poor disease surveillance systems, variability in data collection methods as well as urban bias (Marijon, 2007).

RF/RHD in Nepal

Nepal has some of the highest frequency rates of RF and RHD in the world. Based on echocardiographic screening campaigns of school-aged children in the capital city of Kathmandu and the Lalitpur district south of the city, the Nepal Heart Foundation estimates that the incidence of RF approaches 15,000 cases per year and that RHD is prevalent in the country at a rate of 2/1,000 children (Regmi & Wyber, 2013). Prevalence of RHD is likely higher in rural and poorer regions in the country, where access to health care is limited and human and resource shortages are the norm.

An RF/RHD control program already exists in Nepal. It is funded by the Nepalese Ministry of Health (MoH) and facilitated by the Nepal Heart Foundation (NHF), an organization of cardiac specialists and medical professionals founded in 1988. NHF now has 37 facilities located throughout the country. Program activities began in 2007 when NHF was granted $30,000 from the Nepalese government. Since that time, a concerted effort has been made to run RF/RHD prevention as a “diagonal” program, one in which vertical disease-specific interventions are made within the context of horizontal health systems strengthening. Core program objectives included early detection and registration of RF/RHD patients, establishment of facilities for the safe administration of antibiotic prophylaxis (secondary prevention), and the establishment of national priorities and guidelines. Baseline disease data using echocardiographic screening in school-aged children
have been collected, audits have been performed to monitor patient compliance to antibiotic prophylaxis, health workers have been trained and demand for clinical services has increased via large-scale education campaigns targeting the public. The program has also recently expanded to embrace primary prevention strategies; currently, a pilot program is being implemented in the Lalitpur district just south of Kathmandu (Wyber & Regmi, 2013). Despite the tremendous progress, Nepal still faces challenges in expanding RHD services to its entire population, integrating its RHD program into a national non-communicable disease plan, securing long-term funding and instituting monitoring and surveillance analytics to assess program outputs.

**Strategies for RF/RHD Prevention**

After over a decade of neglect and lost progress, the international community is reinforcing its efforts to combat RHD. In a major victory for RHD advocates, the World Health Organization (WHO) voted to include RHD in its *Global Action Plan for the Prevention and Control of Non-Communicable Diseases (NCDs)* in the spring of 2013. Debate exists, however, with respect to the method(s) of intervention. Because of the disease’s complex natural history, there are many potential points along the causal pathway at which to intercede.

*Primordial methods* of intervention focus on reducing socioeconomic factors that contribute to RHD development. Examples include general anti-poverty campaigns as well as programs to expand health insurance coverage, recruit physicians to urban underserved districts, promote hygiene, and improve housing conditions to prevent overcrowding.
(Webb, RF in NZ, 2011; Australia Guidelines, 2011). Creation of a vaccine against the capsular surface M-protein of GAS to prevent subsequent development of ARF can be considered primordial prevention, although some may consider vaccination as primary prevention. Unfortunately, the time frame for development of an efficacious vaccine will likely be measured in decades, not years (Carapetis, 2007; Steer, 2013).

The chief aim of primary prevention is to identify and treat symptomatic GAS pharyngitis. Primary prophylaxis is a two-step process. First, GAS sore throat must be diagnosed, but this diagnosis is tricky to make solely on clinical grounds. Only up to 30% of sore throats in the pediatric population are due to GAS and even fewer in the adult population (Irlam, 2013). Many clinical tools with varying efficacy have been developed to distinguish GAS pharyngitis from viral etiologies (Irlam, 2013; Nandi, 2002; Nordet, 2008; Arguedas & Mohs, 1992). In many developed countries, including the United States, children with clinically-suspicious GAS sore throat undergo a throat swab followed by a rapid-Strep test. Frequently, a back-up culture is grown overnight to compensate for the rapid test’s subpar sensitivity. In many parts of the world, however, this diagnostic capability is not feasible given resource constraints, making clinical diagnosis is the only viable option (Irlam, 2013). The second step is treatment after diagnosis. Fortunately, GAS remains remarkably sensitive to our most ancient antibiotic, penicillin, which can be administered both orally and intramuscularly (Kaplan 2012). Cuba and Costa Rica were both able to effectively eliminate RHD using primary prevention strategies coupled with large-scale awareness campaigns for citizens and providers (Nordet, 2008; Arguedas & Mohs, 1992). In South Africa, the use of a clinical decision rule tool coupled with injectable penicillin treatment was found to be the most cost-effective primary prevention strategy for children aged 3-15 years at $150 per QALY (Irlam, 2013).
Secondary prophylaxis involves the long-term provision of penicillin to individuals with a history of RF and/or a diagnosis of RHD. Prophylactic penicillin serves to prevent GAS pharyngitis and thus flares of RF. Frequency of RF recurrence is directly associated with severity of valvular disease and development of RHD (Bland, 1951). Monthly-administered injectable benzathine penicillin G (BPG) is preferred to twice-daily oral penicillin G due to superior efficacy and compliance (Kaplan, 2012; Mayosi, 2009). Creation of a disease registry is essential in order to monitor follow-up. Because RHD is a progressive disease, it is likely beneficial to identify individuals early in their disease process. Therefore, active screening, which can be performed by auscultation for the presence of a suggestive murmur and by echocardiography, is used to identify asymptomatic and subclinical RHD in high prevalence populations. Debate exists in the RHD community, however, regarding the clinical importance of treating asymptomatic disease (Webb, Optimising, 2011). Secondary prophylaxis is purported as the most cost-effective RHD prevention tactic in certain analyses (Australia Guidelines, 2011; Colquhoun, 2009).

### Table 1. Comparison of Primary and Secondary Prevention Strategies

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<tr>
<th>STRATEGY</th>
<th>PROS</th>
<th>CONS</th>
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| Primary prevention| - Upstream in causal pathway  
- Prevents RF (and its complications)  
- Prevents RHD  
- Effective treatment  
- Easy treatment compliance  
- ?Cost-effectiveness | - Difficult clinical diagnosis for GAS pharyngitis  
- Access to primary health care required  
- Overtreatment, both of non-GAS pharyngitis and in those with GAS pharyngitis (only 0.3-5% will develop RF anyway)  
- Expensive diagnostic tests (swabbing, Rapid test, culture)  
- Some populations have high rates of asymptomatic GAS pharyngitis (Aborigines)  
- ?Cost-effectiveness  
- Harms: anaphylaxis, inconvenience of throat swab |
| Secondary prevention| - Early detection of RHD  
- High sensitivity of echo; decent specificity  
- Effectiveness of treatment (BPG)  
- Covers populations with | - Low sensitivity and specificity of auscultation  
- High cost of echocardiography  
- Does not prevent RF (and its complications)  
- Does not prevent RHD (only worsening)  
- Poor compliance with long-term BPG |
Tertiary prevention strategies are those designed to reduce morbidity and avert complications of RHD. Interventions include medicating heart failure, anticoagulation for stroke prophylaxis and surgical repair of diseased heart valves (Australia Guidelines, 2011; Carapetis, 2007). Management of chronic RHD is exceedingly costly; paying for surgical care for one patient in many small Pacific Island countries, for example, is roughly equivalent in cost to the entire annual budget of a comprehensive national RHD prevention program (Colquhoun, 2009). In Nepal, a business case for prevention was made in order to circumvent the high costs associated with medical and surgical management of end-stage RHD (Regmi & Wyber, 2013).

**Framework for a Comprehensive RF/RHD Prevention Program**

The RHD TIPS handbook includes a framework as a way to conceptualize the various components of a comprehensive RF/RHD program at the national level. At the bottom, large social issues, which are addressed by so-called primordial prevention strategies, are shown to underlie the higher-order prevention approaches. Components are ordered in order of priority, from bottom to top and left to right. The baseline rows include components thought to be fundamental to program success. Only when baseline components have been adequately addressed is it appropriate to consider implementing more specific and complex interventions.
It will be near impossible to address every component in the framework; local context and resource availability will dictate which components are prioritized. A baseline assessment tool provided in the toolkit will help program designers identify target components for intervention. Furthermore, because the framework was conceived and generated by Western academics, the author and the chief program administrator critically analyzed the utility of the *RHD TIPS* conceptual framework in the Nepalese setting. An adapted version of the conceptual framework was generated and used to inform program design (Please see METHODS section under PROGRAM PLAN section).
II. SYSTEMATIC LITERATURE REVIEW

Introduction

A wealth of information on past and extant RF/RHD programs can be found in the literature. During the planning process for any new program, it is prudent practice to review related prior experiences in order to build upon successes and avoid failures. A comprehensive search strategy was used to identify programs relevant to RF/RHD prevention in Nepal. In subsequent pages, these programs will be analyzed systematically in order to inform the Nepalese RF/RHD prevention plan.

Methods and Search Strategy

The primary research question to be answered by this systematic review is: “What countries have implemented RF/RHD prevention programs and what can be learned from the relative successes and failures of these programs?”

I identified core references for worldwide RF/RHD programs via systematic review of the literature. EMBASE, BIOSIS and PubMed databases were searched using the terms: “rheumatic” AND (heart disease OR fever NOT arthritis) AND (control OR prevention OR prophylaxis) AND (progra* OR strateg*).” In addition, focused searches for specific components of control programs, including: “regist*,” “community education,” “training,” “anticoagulation,” “disease notification” and “surveillance” were completed. Articles published after 1952 were accepted. After this initial search, articles were first excluded based on title review. Abstracts of the remaining articles were assessed and those deemed irrelevant or unsuitable were discarded. Sentinel articles were identified and bibliographic review led to the inclusion of other references. Unpublished, informal “gray literature” was identified through review of institutional archives, including the World Heart Federation. A snowball approach was used to identify other source documents accessible through direct
contact with individuals and institutions. Participants in key informant interviews were also asked recommend other sources of unpublished gray literature.

In addition to the methods reviewed above, inclusion criteria requirements for this Masters paper included: a) the program must be designed specifically for RF/RHD prevention, b) the program must be implemented in a developing country or target vulnerable populations within developed country, and c) the program must be facilitated at the national level. Unfortunately, absence of an evaluation framework could not be considered as a reason for exclusion; to this date, only the WHO’s Global Programme for the Prevention of Rheumatic Fever and Rheumatic Heart Disease and New Zealand’s Rheumatic Fever Prevention Programme have established even a rudimentary evaluation framework. Other programs lacked a formal evaluation protocol. Importantly, the reports included in this analysis are comparative studies that use historical control groups; most programs simply compare pre- and post-implementation incidence and prevalence measurements. Thus, they are inherently limited in their ability to draw concrete conclusions unless one assumes that variables external to the intervention remain constant throughout the duration of the program. In total, five programs were selected for analysis.

**SUMMARY OF PROGRAMS**

**WHO Global Program for the Prevention of Rheumatic Fever/Rheumatic Heart Disease**

In 1986, the WHO facilitated the roll-out of RF/RHD prevention programs in sixteen countries in highly endemic regions throughout the world. The programs were managed by Ministries of Health in the participating countries.

*Description*

In a step-wise fashion, the program was rolled out in each participating country, first at a pilot site, then expanded into surrounding communities and finally scaled-up to the
national level. In exchange for technical protocols, educational materials as well as financial and moral support from WHO, countries were expected to submit semi-annual progress reports to WHO. Secondary prevention was the initial focus of the Global Programme, although after establishment of secondary prevention programs seven countries opted to develop primary prevention projects. To facilitate the formation of secondary prevention programs, WHO urged countries to create central registries for data collection and patient follow-up purposes. In order to recruit cases for the registries, active case-finding was a critical component of the program. Cases were identified by hospital record review as well as by direct questioning of school-aged students and their families for signs and symptoms consistent with a diagnosis of RF/RHD.

Awareness-raising campaigns underlay all other program activities. Program administrators preferred print media—including booklets, brochures, pamphlets and posters—to other forms of media because of their reproducibility, conciseness, ease of distribution and permanence. For example, providers can use print media guides to quickly refresh medical knowledge and RF/RHD management guidelines. Patients can refer to handouts to learn about their disease and remember follow-up recommendations. Mass media, including radio and television, were used in certain settings. Messages conveying safe hygiene practices and healthy lifestyle promotion were delivered directly to students in schools. A direct correlation was seen between the amount of education provided and the number of patients registered and compliant with secondary prophylaxis. An unstable supply of BPG, inadequate staff and weak reporting were all associated with lower rates of compliance (WHO, 1992).

Encountered challenges included follow-up for secondary prophylaxis, which requires monthly injections of benzathine penicillin G (BPG). For patients living far away, time and transportation were barriers to care. Program administrators recommended
decentralizing BPG dispensation to smaller and smaller health posts. Swabbing and culture were considered untenable for primary prevention activities because of cost and because low rates of patient return visits to clinics to receive a definitive diagnosis. Provider knowledge of RF/RHD diagnosis and management naturally wanes with time, especially with a disease like RF/RHD that is relatively rare. Providers, therefore, must be periodically reminded of clinical best practices, and print media were used as quick references resources.

Program sustainability was threatened after funding from AGFUND (Arab Gulf Programme for United Nations Development Organizations) expired. The lack of a small financial incentive was likely responsible for a reduction in country reporting rates to WHO. International camaraderie amongst Global Programme participants waned over time, further resulting in decreased country engagement with WHO. High turnover of program staff at the country level was common. Program implementers believed it was crucial for each country to have a dedicated and passionate local RF/RHD “champion” to advocate continuously to the Ministry of Health, whose support is vital in order for any program to maintain stability over time.

**Strengths**

The Global Programme set an explicit goal: to “reduce morbidity, mortality and disability caused by RF/RHD through the establishment of at least one local/regional program implementing RF/RHD measures” (WHO, 1999). Consistent with this goal, RHD prevalence rates per 1000 schoolchildren were reported in certain countries before (1986) and after implementation of the program (1998): Cuba (2.3, 0.2), Egypt (7.2, 2.3), the Philippines (1.0, 1.0), China (0.8, 0.3) and India (3.0, 1.4). WHO did monitor intermediate outcomes according to world region in the form of “activities of health education,” the number and type of health personnel trained, number of screening surveys administered,
number of cases detected and registered as well as BPG compliance and adverse reactions. Absolute numbers of pamphlets and posters distributed, radio and television programs and groups sessions were recorded. Screening campaigns throughout the world helped to provide an epidemiological baseline for burden of disease estimates. WHO provided work plan tables, intervention timelines, checklists, clinical guidelines, registry forms and diagram models for various phases of the program in an effort to standardize implementation (WHO, 1992). Some may consider standardization a weakness in this global context, however, as fidelity is prioritized over adaptability.

**Weaknesses**

The reliability of prevalence estimates is questionable, therefore compromising the internal validity of the program results. Many different methods were used for case-finding (surveys of schoolchildren, hospital retrospective case surveys and prospective detection in any clinical setting), all of which are inherently flawed and none of which approach the sensitivity and specificity of gold-standard echocardiography. It is unclear who performed the case-finding surveys (doctors, public health professionals, trained lay people, etc) and where the case finding was carried out (urban versus rural settings). Answers to these omissions may reveal further biases. Further, no data was reported on the relative strengths/weakness of the various case-finding methods and it is unclear which method(s) different countries used for detection. One can assume, therefore, that reported results reflect significant measurement bias. In addition, no formal theoretical model of program planning was used to guide program development.

**Costa Rica**

In 1968 an RF/RHD prevention program was established in Costa Rica at the National Children’s Hospital in San Jose. The program was scaled-up in 1970 and piloted in

**Description**

Primary prevention is the central focus of the program. In Costa Rica in the early 1970's, diagnosis and management of GAS pharyngitis was suboptimal. Program designers decided to eliminate throat swabbing and culture as a prerequisite for antibiotic treatment; diagnosis of GAS pharyngitis was henceforth made solely on presenting clinical signs and symptoms. This was both a practical cost consideration as well as an attempt to avoid the return visits required for swabbing/culture follow-up. In addition, the treatment modality was switched from 10-day procaine penicillin to a one-time benzathine penicillin G (BPG) injection in order to increase compliance. It was shown in a prior research study that children were only receiving, on average, 1 to 3 shots of the 10-day course of procaine penicillin. As a result, BPG was given to every patient who met the clinical criteria for GAS pharyngitis: “every patient who consulted because of fever or sore throat and whose physical examination showed halitosis, redness of the pharynx, and hypertrophy of the tonsils with a white exudate.” This intervention, led to a significant drop in the incidence of ARF and RHD in Costa Rica: in the early 1970's the incidence of RF was 90 cases/100,000 inhabitants/year; by 1990 the incidence dropped to 1/100,000/year (Arguedas & Mohs, 1992).

Ancillary program activities provided a favorable context in which the new clinical guidelines for sore throat management could succeed. At the time, the government was actively extending and improving the nation’s primary care workforce. In addition, governmental support and funding for the RF/RHD prevention program ensured the program's long-term survival. Intense and widespread awareness campaigns for the public-
at-large were carried out to increase demand for treatment of sore throat. In addition, public education campaigns stressed hygiene, nutrition and overcrowding. Clinicians, nurses and other health care workers were educated about new clinical management guidelines and were adequately supplied with BPG necessary to treat cases of suspected GAS pharyngitis. RF/RHD became part of the training curricula for health professionals in the country. Patients identified as having RF and RHD were entered into a centralized register for follow-up care.

**Strengths**

The Costa Rican program benefitted from strong governmental support, which resulted in a robust BPR procurement system and program sustainability. “Diagonal” integration into an improving primary health care system was a major component of the program that likely enhanced its effectiveness. As part of this process, decentralization of service delivery was augmented. In addition, the frequency of adverse events to penicillin was monitored and development of microbial resistance to treatment was tracked in the laboratory. Adverse events to penicillin were found to be extremely rare and always non-fatal. Likewise, GAS remained highly sensitive to penicillin throughout the program’s duration and has maintained sensitivity to this day.

**Weaknesses**

The program design was not informed by a theoretical framework. Again, there was no control group. Therefore it is theoretically possible, albeit highly unlikely, that RF/RHD rates would have decreased similarly in the absence of the program. For example, some may argue that a strengthening primary care system itself was responsible for the declines in RF/RHD rates. Lack of an evaluation framework meant that outputs were not monitored. Evaluation would have been strengthened by monitoring intermediate indicators, like
number of health care workers trained, number or newspaper articles written/pamphlets distributed/batches of BPG disbursed, among others.

**Samoa**

The Samoan Rheumatic Fever Programme has existed since 1984 (Viali, 2006). More recently, funding from NZAID (New Zealand Aid) and Vodafone foundation, as well as technical support from WHF and professionals a Menzies Research Center in Australia, has boosted Samoa’s capacity to expand their prevention program, which is focused on secondary prevention (Viali & Saena & Futi, 2011).

**Description**

Pacific Islanders exhibit some of the highest rates of RF/RHD in the world (Steer & Colquhoun & Viali, 2006). Secondary prevention, as opposed to primary prevention, was pursued in Samoa for a few reasons: 1) Samoans tend to present with late-stage RHD, suggesting that many patients are asymptomatic during GAS pharyngitis and ARF flares (Viali, 2006; Viali & Saena & Futi, 2011) and, 2) large-scale screening campaigns are considered more feasible in smaller nations, especially island nations.

The project was administered at Samoa’s National Hospital in the capital of Apia. There, a centralized electronic registry was created that collated diagnoses of both RF and RHD from centers throughout the country (Viali & Saena & Futi, 2011). Patients from throughout the country come to the National Hospital to receive secondary prophylaxis in the form of monthly BPG injections, a process facilitated by concurrent improvement in transportation infrastructure. Mobile clinics equipped with portable echocardiography are also used to reach remote populations. Since the program’s inception, compliance rates—assessed by number of injections per patient per year—have improved from <50% in the years 2001-2006 to approximately 80% in the years 2007-2009. In addition, the incidence
of RF has decreased from 30/100,000 in 2005 to 9.5/100,000 in 2009, and the prevalence of RHD has decreased from 40.2/100,000 in 2007 to 31.8/100,000 in 2009 (Viali & Saena & Futi, 2011).

Public and provider education helped scale the program’s reach. Workshops were provided for medical staff and mass media outlets, mainly in the form of TV documentaries and newspaper articles, were used to increase public demand for screening and treatment (Viali, 2006; Viali & Saena & Futi, 2011). A 2011 non-randomized qualitative study analyzed the efficacy of RF/RHD information dissemination to parent groups in Samoa using a pre/post-survey design. The study utilized theory of the Social Change Model and targeted the interpersonal level of the Social Ecological Model. Analysis revealed statistically-significant increases in knowledge exchange using this method, and the authors propose that knowledge dissemination strategies are a cost-effective way in which to reduce RF/RHD incidence (Allen, 2011).

There was a subsequent effort, in 2003, to integrate primary prevention efforts into the existing program (HRPIRD, 2003). This program, entitled the Rheumatic Fever School Program, targeted high-risk schools as identified by previous prevalence studies. The Ministry of Health and the Ministry of Education, Sports and Culture have collaborated to design a program whose core component is to use teachers to refer children with sore throat to appropriate clinical staff, in this case, local district nurses who are trained to diagnose GAS pharyngitis and administer proper treatment (Viali, 2006). Data pertaining to the effectiveness of this program is not available.

**Strengths**

Government is intimately involved with the design and funding of the program. Due to resource constraints, the government has reached out to stakeholders to supplement its efforts—foreign governments, international NGOs, IGOs and even visiting surgical teams
from abroad—resulting in a strengthened national program. Although not included in the program description above, rudimentary cost-benefit analyses have been performed by the government. Caring for end-stage RHD patient in the hospital and sending patients to New Zealand to undergo cardiac surgery was deemed unsustainable from a financial standpoint. The prevention program, therefore, is viewed as a cost-effective way in which to decrease burden of disease due to RF/RHD.

Weaknesses

The Samoan program is plagued by similar critiques already listed above. That is to say, no formal “research” has been performed to monitor or evaluate the program’s effectiveness. By its very design it is impossible to do so: there is no control group as the entire country can be considered the intervention group. Even intermediate outcomes were not reported, which may have included number of health care workers and teachers trained, number of educational materials disseminated and percentage of students screened, for example.

Rwanda

The A.S.A.P. (Awareness, Surveillance, Advocacy, Prevention) Programme approach to RHD prevention operates in a number of African countries (Robertson & Vomink & Mayosi, 2006). In Rwanda, one of the project sites is in the Gasabo district in the capital city of Kigali.

Description

In Gasabo, 10 sites were selected to generate a representative sample of both urban and rural schools. Children at these schools were screened for RHD using echocardiography in a study designed to quantify the burden of disease attributable to RHD in school-aged children in Rwanda. Prior to screening, teachers, students, parents and health workers
received RF/RHD education and print media—including a booklet for patients with RF/RHD, a protocol for BPG administration, medical management guidelines and cardiovascular disease prevention, which were distributed with the help of a grant from the World Heart Federation. Nurses at local health centers were trained in RF/RHD prevention and treatment.

The WHF echo criteria were used to diagnose RHD during the screening campaign (Remenyi, 2012). Three thousand children, aged 6-16 years old, were randomly selected from 10 schools. Plans are under way to expand the echo screening to another high prevalence region in the country to corroborate the initial findings: prevalence of 6.8/1000 in Gasabo. Children who are echo-screened positive for RHD are started on monthly BPG injections. Plans are in place to establish 6 “Points of Care” throughout the country where patients identified as having RHD, and those who have undergone surgical mitral valve repair, can receive follow-up care. At these sites patients would be seen by doctors or nurses and cardiologists would supervise them by phone or internet. It is hoped that portable echo machines become available so that these machines can be rotated between the points of care on a monthly basis. In the near future, 6 physicians will enroll in a 2-year course on echocardiography so that local dependence on foreign experts to perform screening is reduced.

Due to the collective efforts of the RHD community in Rwanda, the A.S.A.P. RHD model will be incorporated into the national strategic NCD plan. Collaboration between the RHD community and the Ministry of Education is strengthening, and progress is being made toward the inclusion of RHD in a national school health program. The school-based health care will ensure that a nurse from a local health center is responsible for providing holistic care for students in schools, including GAS pharyngitis treatment and referral of patients with symptoms of RF/RHD. Efforts are being made in tandem with the national Treatment
and Research AIDS Center to add RHD to “TRACnet,” a mobile phone-based application that is used to monitor HIV patients. Advocacy work is ongoing to establish a cardiac surgery program in Rwanda; currently RHD patients must travel internationally for surgery unless a foreign team of surgeons is visiting.

Strengths

Rwanda’s A.S.A.P. RF/RHD prevention program is still in its infancy. Before full-scale implementation of any RF/RHD program, it is important to establish baseline prevalence of disease and the program has done this in the Gasabo region. Rwanda has made partnerships with outside organizations like Team Heart based out of the United States that focuses on tertiary surgical care of end-stage RHD patients. Government involvement is increasing and the program will be integrated into the national NCD plan. Rwanda is pursuing some innovative methods by which to scale the program, including partnering with the Ministry of Education to incorporate RF/RHD prevention messages into standard educational curriculum and using mobile technology to track patients. At this early stage of program implementation, there is likely still time to include a monitoring and evaluation framework into the program design.

Weaknesses

Rwanda desperately needs to establish a functional registry if its focus on secondary prevention is to succeed. The program is not comprehensive in that it does not also allocate resources to primary prevention. No evaluation framework exists to monitor program effectiveness. Scalability and sustainability are of concern given reliance on echocardiographic screening, which is costly.
New Zealand

New Zealand’s Rheumatic Fever Prevention Programme, originally implemented in 2011, is a coordinated effort directed by the Ministry of Health. Striking geographic variability in ARF and RHD incidence rates exists in New Zealand: the northern half of the North Island possesses the highest incidence rates. Auckland, which is located in this northern region, is a microcosm of the country’s ethnic and socioeconomic divisions. South Auckland, inhabited principally by poor indigenous populations, can claim the highest measured incidence rates in the country and the world (Webb & Wilson, 2013). Even within a district, however, prevalence of RHD can vary across ethnic groups. In the Hamilton health district just south of Auckland, overall prevalence ratios of 6.5/1,000 in Maori and 0.9/1,000 in non-Maori were reported (Steer et al., 2002). Over 90% of RF cases in New Zealand occur disproportionately in the Maori and Pacific Islander children, only 36% of the total population in this demographic (Jacobs, 2014). According to government, RF/RHD is considered a “sensitive indicator” of child inequality (Liddel, 2010). A stated goal of the national RF/RHD program is to equalize incidence and outcomes of RF between indigenous and non-indigenous children (Litmus, 2013). New Zealand recognizes RF/RHD prevention as one of its top public health priorities as evidenced by its inclusion as one of the “Better Public Services” targets (Jacobs, 2014).

Description

Primordial and primary prevention strategies feature most prominently in the New Zealand Rheumatic Fever Prevention Programme. Initiatives around the country focus on one of two program prongs: “Stop It” (prevention of transmission) or “Treat It” (NZ Treasury, 2013). Initiatives falling under the "Stop It" prong are focused on primordial prevention, epitomized by the Auckland Healthy Homes Initiative, as well as community awareness raising. The housing initiative aims to equip health professionals with tools
needed to refer patients with housing-related health issues to proper welfare and housing services. The awareness-raising initiative utilizes a “door-knocking” service to deliver culturally appropriate RF/RHD educational messages to indigenous populations in Auckland. Homes, churches and community groups will all be targeted as sites of intervention. Furthermore, in early 2013, the Prime Ministers of New Zealand and Australia pledged $3 million USD in matching funds towards research to develop a vaccine for rheumatic fever (Office of John Key, 2013).

The “Treat It” prong is focused on primary prevention of GAS pharyngitis by the creation of school-based sore throat swabbing clinics and nurse-led community “drop-in” clinics. A meta-analysis of school-based primary prevention interventions showed a relative risk of 0.41 for development of ARF (95% CI 0.23-0.70, p=0.001) (Lennon et al, 2009). Furthermore, a systematic review determined that prompt diagnosis and treatment of GAS pharyngitis can reduce RF incidence in pediatric Maori and Pacific Islander populations in New Zealand (Kerdmelidis, 2010).

The Ministry of Health commissioned an implementation and formative evaluation report that was published in early 2013 (Litmus, 2013). Implementation successes were noted, including high provider dedication to the program, focus on creation of strong community links and networks, strong support from participating schools, and anecdotal evidence of high GAS detection rates. Qualitative surveys were administered to discern provider, caregiver and patient knowledge, awareness and satisfaction as well as to seek input for program recommendations. Threats to sustainability were identified: 1) growth of school-based swabbing services has outpaced awareness, especially in the primary care health system and, 2) awareness has focused on swabbing services and neglected the importance of seeking care in the primary health care system. To this point, it is believed that only 1/3rd to ½ of at-risk children undergo swabbing in schools. Evaluation consultants
recommended targeting implementation to areas with highest incidence of GAS, 
decentralizing administration to local District Health Boards, raising awareness amongst 
primary health care providers, and developing referral pathways for identified patients.

**Strengths**

The New Zealand program includes a robust evaluation framework. The evaluation 
protocol includes both qualitative and quantitative indices. Importantly, input is solicited 
from community members, staff and other stakeholders for program improvement. 
Recognition of the importance of interventions at the primordial level suggests that the 
Ministry of Health is dedicated to addressing the underlying socioeconomic risk factors of 
disease transmission. A focus on primary prevention over secondary prevention is 
inherently preferred as it not only prevents development of RHD, but also antecedent RF. 
The comprehensive nature of the plan, however, also covers secondary prevention using 
echocardiographic screening programs in schools. Government has explicitly stated that 
RF/RHD prevention is a national priority, especially given that it is considered an indicator 
of child inequalities, and has acted on this assertion by allocating adequate funds to cover 
program costs and targeting the most vulnerable populations. Innovative evidence-based 
(Lennon, 2009; Kerdemelidis, 2010) methods have been used to expand primary prevention 
services to children of school age: school-based sore throat clinics as well as "drop-in" 
clinics staffed by nurses.

**Weaknesses**

The New Zealand Rheumatic Fever Prevention Programme is the most 
comprehensive of the programs included in this literature review. Even so, the program’s 
design is not guided by theory. In addition, because the program attempts to intervene in so
many ways (likely a very good thing), it is difficult to determine the relative effectiveness of any single program component.

**Analysis and Conclusions**

The programs analyzed approach RF/RHD prevention in various ways, illustrating the many possibilities for intervention along the disease's causal pathway. Resource availability, support from government, local epidemiology and other considerations likely influence program design in different countries. Comfortingly, all programs, regardless of their prevention strategy(ies), have displayed positive results, identified mainly by reductions in RF incidence and RHD prevalence (it is too early to measure post-implementation rates in Rwanda and New Zealand, but program implementation in these countries is in and of itself can be considered a positive development). Unfortunately, the relative effectiveness of the various strategies remains unknown. Large-scale studies, including randomized-controlled trials, which compare one intervention strategy to another within or between countries do not exist. As mentioned previously, “studies” that use historical controls—like those most common in RF/RHD prevention—are inherently weaker than prospective cohort studies, including RCTs. Further, evaluation frameworks are rarely incorporated into RF/RHD prevention program design. Only the New Zealand program contains a robust evaluation framework, likely because of the country's relative wealth. Program evaluation is costly and may exceed the capacity of already-thin budgets in many developing countries. Even in New Zealand, theory was not used to guide program design. RF/RHD prevention efforts would likely benefit from a theory-based approach to program design.

A shared component in every program was education and awareness-raising. Small print media, mass media outlets and face-to-face information exchange were all used to target patients, caregivers, staff and providers. Many programs use schools as a setting for
information dissemination (Rwanda, Samoa, New Zealand). Innovative techniques are being utilized, evidenced by the use of mobile technology and remote provider consultation in Rwanda.

Implications for Nepal

The *RHD TIPS* handbook advocates for an evidence-based “comprehensive” program with elements targeting all levels of prevention. Of the programs analyzed in this review, New Zealand’s program is most representative of this ideal, but Nepal does not have the financial means to support a program as well-funded. The Nepal RF/RHD prevention program will, however, benefit from government support if political stability is maintained. In addition, a basic program infrastructure already exists in Nepal with implementation of both primary and secondary prevention measures.

Similarly to Costa Rica, the RF/RHD program in Nepal is poised to benefit from improving housing conditions and a strengthening primary health care system. Primary prevention, then, will ideally be decentralized to local clinics. In order for primary prevention to succeed at the local level, an algorithm for the clinical diagnosis of GAS pharyngitis specific to Nepal will need to be developed. A pilot primary prevention program is underway in the Lalitpur district and information gleaned from this program will guide extension into other regions. Secondary prevention using echo screening in schools can also be scaled to more regions in the country, although it is not possible in the short- to medium-term to scale nationwide as in Samoa. Not only will more children with RHD be identified and registered for secondary prophylaxis, but prevalence rates in different regions can inform program development and prioritization of resource allocation to areas with highest disease burden, as is occurring in Rwanda.
III. PROGRAM PLAN

CONTEXT

At-A-Glance: Nepal Country Profile

Nepal is a majority Hindu country located just north of India and south of Tibetan China in the heart of the Himalayas. Nepali is the native language, although English is an official state language widely spoken by those in government, business and the medical professions. Just over 30 million people live in Nepal (UN Dept. of Economic and Social Affairs, 2013) with 35% aged under 15 (WHO: Nepal Statistics Summary, 2014).

Kathmandu, the capital, is a city of just under one million inhabitants. Although urbanization characterizes overall internal migration patterns, 80% of the population is rural with a large proportion living in remote, hard-to-reach mountainous regions of the county (Wyber & Regmi, 2013). A large majority of health resources, human and infrastructural, are concentrated in the urban areas (Shrestha & Bhandari, 2012).

From 1996-2006 Nepal experienced significant political unrest due to a Maoist uprising that resulted in the internal displacement of certain sectors of the population as well as violence leading to many deaths. National elections were recently held in Nepal and the Maoist Party was roundly defeated by the more centrist Nepali Congress Party that ushered into power. Nepal is restructuring its health care system from a centralized model to one in which health service delivery and planning is increasingly made at state- and district-level; this reflects a concurrent overhaul of the structure of government in the country trending towards decentralization (HEART, 2013). Government expenditures on health care in Nepal constitute approximately 7% of GDP, but around 70% of health care expenditures are out-of-pocket payments borne by consumers (Jha, 2007). Nepal has a mixed public-private health care system.
Although great strides have been made recently to improve Nepal’s health care service and delivery mechanisms, crude health indicators—including life expectancy at birth, maternal and child mortality rates, among others—show significant room for improvement. Nepal is on target to fulfill the Millennium Development Goals (MDGs) number 4 (child survival) and 5 (maternal health), as well as MDGs related to malaria and TB. MDGs related to nutritional disease will likely not be met, however. As Nepal transitions to a more developed and urban society, non-communicable disease rates are expected to increase. Currently, the three most common preventable diseases are WaSH-related (water, sanitation and hygiene). These diseases preferentially affect children, causing respiratory and diarrheal illnesses that constitute a large majority of child deaths in Nepal (WHO|Nepal, 2013).

Nepal is still very much a developing country; its human development index is 0.48, ranking it 157th out of 187 countries, lower than the South Asian average and many sub-Saharan African countries (UNDP, 2011). Twenty-five percent of the population lives below the poverty line. Women, certain ethnic groups and the geographically-isolated are overrepresented in poverty statistics (HEART, 2013) and associated with lower rates of health literacy (Shrestha MK, 2014).

Folk beliefs regarding medicine are still widely held in Nepal. Priests and astrologers are often consulted by the ill, and numerous deities are believed to cure patients of infertility and skin diseases, for example (Wasti, 2011). Other beliefs and societal norms have made anti-retroviral adherence for HIV difficult in Nepal: the stigmatization of disease, the consideration of sex and sexuality as taboo topics, a positive valuation of shyness that creates “culture of silence” around sex, and the subordinate status of women in marital and sexual decision-making (Wasti, 2011). It is clear that the delivery of RF/RHD health care
services will occur in the context of the population’s existing health beliefs and societal norms.

**Nepalese National Health Goals and WHO Collaboration**

It will be very important for the national RF/RHD program to align with the Nepalese government’s overarching strategic goals in order to ensure its seamless integration into the health system. The program will benefit from existing health infrastructure and health systems strengthening, but will be constrained by system inefficiencies and resource constraints.

In 2010, the Ministry of Health of Nepal drafted the *Nepal Health Sector Programme II (NHSP II)*, which outlined the country's health goals for the period 2010-2015. A mid-term report completed in 2013 analyzed progress made on selected goals and outputs, which included: improved service delivery (progress), improved health sector management (progress), reduced cultural and economic barriers to accessing health care services (progress), strengthening human resources for health (limited progress), improved M&E (progress) and sustainable health financing (limited progress) (HEART, 2013). In line with the NHSP II, the WHO has identified target areas for cooperation with the Nepalese government: achieving communicable disease objectives, controlling the growing NCD burden, improving health of most vulnerable populations, health systems strengthening via an improved primary care health system, reducing consequences of natural disaster and addressing environmental determinants of health including WaSH-related disease (WHO|Nepal, 2013).

Because of the WHO General Assembly's vote to include RHD in the *Global Action Plan for the Prevention and Control of NCDs*, decisions concerning RHD programming will likely be made in the context of NCD policy-making. WHO requests that Member States
develop long-term national NCD plans. RHD will feature in these policy documents, a crucial inclusion that is likely to result in fewer funding barriers for RHD initiatives.

Stakeholders outside of government include WHF and RhEACH, among other NGOs. These organizations have given mini-grants to NHF in the past. Additionally, these organizations, along with the WHO, serve as resources for technical expertise. Foreign governments and donors are likely to fund a large percentage of the Ministry of Health budget: in 2004, 30% of the total budget for health expenditures came from overseas funding.

THEORY

The program plan will be comprehensive in that it will target multiple levels of the social ecological model and utilize many different prevention strategies—from primordial, or social, interventions to primary, secondary and tertiary interventions. Within the larger framework of the social ecological model, components of other theoretical models will be used to guide intervention design. One of these models is the RHD TIPS framework detailed above.

Individual level

At the individual level of the social ecological model, many factors related to the development of RF/RHD are not plausible targets for any intervention. Unmodifiable individual risk factors, for example, include one’s genetic code, age and race. Nutritional status, poverty status and lack of health insurance, among other factors, are all individual social determinants of health, but they are only modifiable to a certain extent by behavior change at the individual level. Often, societal level change is needed to raise the nutrition status of the population as a whole, decrease the poverty rate and provide health care access to all. However, behavior change to improve utilization of health care services and to
change attitudes regarding modern medicine, for example, can be modulated using the
Health Beliefs Model (Rosenstock, 1966). The model proposes that individual’s health
behaviors are dictated by four factors: perceived risk of disease, perceived severity of health
outcome, belief that the intervention will produce a positive outcome and perceptions
regarding barriers to seeking and obtaining care (Carpenter, 2010). Therefore, it is
important to gauge perceived personal susceptibility to RF/RHD; perceived benefits, harms
and self-efficacy of the medical management of RF/RHD; barriers to care and conditions
thought to be prerequisite to seeking care. Myths and barriers can then be addressed via
education, outreach or other higher-level interventions in order to elicit positive health
behaviors. A community diagnosis—in the form of a needs assessment survey, focus group
or other research method—will be useful in characterizing the local health beliefs and
identifying knowledge gaps. Indeed, a short-term objective of this program is to perform a
needs assessment during early implementation. Furthermore, health beliefs can be
addressed by including lay persons, patients or caregivers on advisory committees along
with other stakeholders during the program’s planning stages.

**Interpersonal level**

According to Social Learning Theory (Bandura, 1971), interpersonal and human-
environment relationships affect individual behavior and may increase or decrease risk for
any disease. RF/RHD, although categorized by the international community as non-
communicable diseases, are really manifestations of an auto-immune reaction to a
transmissible microbial infection by Group A Streptococcus. Transmissibility is influenced
by many factors, chief among them population density. The concept of “reciprocal
determinism” is enshrined in social learning theory and states that human behaviors are
shaped by interactions with other people as well as the environment, and, in turn, human
behaviors influence other beings and the environment (Bandura, 1977). Overcrowding,
therefore, is a risk factor for GAS pharyngitis and subsequent RF/RHD. This has been documented in many populations including American army recruits who lived in barracks and indigenous populations in urban New Zealand (Davis & Schmidt, 1957; Jaine, 2011). Prevention can be augmented by improved interpersonal communication: providers should recommend screening services to patients and that parents, teachers and school nurses know how to recognize symptoms of strep throat and RF/RHD. In addition to encouraging provider recommendations, outreach by community workers and patient reminders for monthly BPG injections can improve compliance with secondary prophylaxis. Specialists must also counsel patients on medication use for heart failure and the importance of strict adherence to anticoagulation regimens. With the knowledge gained after education, patients attain the “behavioral capability” necessary to make positive health choices and develop the “self-efficacy,” or confidence, to do so. Moving forward, peer support groups would strengthen relationships amongst patients at the interpersonal level.

Organizational level

Diffusion of Innovations Theory (Rogers, 2003) can serve as a model to describe how clinical guidelines will be developed and disseminated to providers. In order to facilitate uptake, guidelines must be considered an upgrade over their predecessor—termed “relative advantage”—and considered a “fit” for implementation in the clinical setting. Ease of use, scalability and observability of results will dictate the magnitude of adaptation and therefore the success of innovation diffusion. The same theory can be used to plan the expansion of echocardiography into more remote regions of Nepal. Questions that must be answered include the relative advantage of echocardiography over conventional auscultation and the “fit” of the technology into the rural health care infrastructure.

Organizational Change Theory can explain how guidelines are adopted, adhered to and institutionalized by health care professionals, their places of work and the larger health
care system. First, an organization must be willing to change and possess the capacity to transform (Weiner, 2009). Importantly, an innovation must align with the values of the instituting organization. Organizations, similarly to individuals, proceed through a step-wise process that, if completed, results in the fidelitous implementation of innovations. Stages include defining the problem, adoption/piloting, implementation and, finally, institutionalization. This theory is relevant for the RF/RHD prevention plan because in order for a register-based disease tracking system to succeed, providers must buy-in to the data collection protocol, for example. Likewise, primary care providers must adhere to a standardized referral protocol if patient transfers to specialist care are to occur seamlessly.

Community level

Efforts should be taken to involve community members in program decision-making as indicated in Community Organization Theory in order to promote empowerment, local ownership and project sustainability. The theory is similar to the health beliefs model, but instead of focusing on barriers that dissuade positive health behaviors at the individual level, attention is focused on communities and systems. A needs assessment can identify common problems relating to a health issue; these problems then become the targets for intervention. “Community competency” is another component of this theory. Education is critical in order to create and sustain community demand for clinical services relating to RF/RHD. Large-scale mass media campaigns to encourage service seeking for treatment of sore throat, for example, are necessary for primary prevention strategies to be successful. In Nepal, a documentary is frequently aired on a popular TV station, advertisements and interviews with medical professionals are broadcast on radio and celebrities are used to great effect to spread the message to large segments of the population. Smaller-scale efforts are targeted to high-risk populations like schoolchildren. RHD has been integrated in curricula and unique modes of education have been promoted, including student-produced
dramas. Print media has also been widely distributed in various venues including schools and clinics. RHD awareness increased from 8% to 48% in schoolchildren and teachers thanks in part to the “Have a Heart, Save a Heart campaign” (Wyber, Regmi, 2013). Moving forward, dissemination of knowledge by trained and respected lay persons would foster a sense of fellowship in communities.

**Policy level**

Government endorsement of a national RHD plan is crucial for program success. Not only does government ratification signal that RF/RHD prevention is a national priority, it also standardizes prevention practices across the country. An RHD plan does not exist in isolation, however. Its success is contingent on policies related to general health systems strengthening, the organization and structure of the health care system and social health insurance schemes. Even more than that, policies affecting the environment, economy, security, social welfare systems, education, housing, utilities and trash removal, occupational hazards and exposures as well as general anti-poverty campaigns, among others, will address some of the fundamental determinants of the population's health.

**METHODS**

As mentioned above, the RHD TIPS conceptual framework was used as a menu from which to identify prioritized interventions. The original framework was adapted to be more applicable to Nepalese context.

Starting from the bottom of the framework, we first added “Hygiene” to the underlying risk factors for disease. We felt that all of the Baseline and Health Systems components were relevant to the Nepalese context and no changes were made to this section of the framework.
In the Primary Prevention row a few modifications were made. First, the “Active case finding (sore throat clinics)” box was re-titled as “School-based interventions.” The rationale for this change lies in the fact that schools can be a primary site for sore throat prevention (education, messaging) and treatment activities (symptom recognition, referral to school nurse or health worker, on-site dispensing of treatment). Drop-in sore throat clinics are likely not feasible in the Nepalese context, and neither is “active case finding” via throat swabbing and culture due to high cost and other logistical prohibitions. The second modification in the Primary Prevention row was the omission of the “Vaccine development” concept box. While Nepal would certainly benefit from a vaccine should it be created, vaccine development activities will be pursued outside of country. Nepal simply does not have the financial resources or basic science facilities to sustain a vaccine development program. This concept box was changed to “TP registry” to reflect the utility of a tonsillitis-pharyngitis register as an epidemiological record, follow-up log and data collection tool for research purposes.

In the Secondary Prevention row only one substantial change was made. The “Provision of secondary prophylaxis” concept box was merged with an additional concept: “Mitigation of fear of anaphylaxis.” Anaphylaxis is so feared by practitioners and patients in Nepal that BPG is not viewed as a viable option for sore throat treatment.

“Advocacy” and “Awareness” were added to the top of the framework alongside “Research” as overarching and unifying concepts that should be considered throughout the design and implementation phases.

The concept boxes highlighted in dark red with white text represent priorities for next steps interventions. First-line priorities include securing long-term and stable funding, design of a feasible program evaluation framework, creation of a Training of Trainers course, expansion of community education and awareness-raising campaigns,
implementation of school-based prevention and treatment activities, extension of active screening with echocardiography.

Table 3. Adapted Version of RHD TIPS Conceptual Framework for RF/RHD Prevention

<table>
<thead>
<tr>
<th></th>
<th>Advocacy</th>
<th>Awareness</th>
<th>Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tertiary</td>
<td>Medical management</td>
<td>Anticoagulation</td>
<td>Triage and pre-operative planning</td>
</tr>
<tr>
<td>Secondary</td>
<td>RF/RHD register</td>
<td>Antibiotic supply (BPG and oral penicillin, erythromycin)</td>
<td>Mitigate fear of anaphylaxis</td>
</tr>
<tr>
<td>Primary</td>
<td>Community education</td>
<td>GAS diagnosis and treatment guidelines</td>
<td>Devlivery of primary prophylaxis</td>
</tr>
<tr>
<td>Baseline</td>
<td>Government engagement</td>
<td>Disease notification</td>
<td>Human resources</td>
</tr>
<tr>
<td></td>
<td>Burden of disease data</td>
<td>RF/RHD Advisory Committee</td>
<td>Funding</td>
</tr>
</tbody>
</table>

We believe that these adaptations do not threaten or lessen the integrity of the framework. In fact, by adapting the framework to be more relevant to the Nepalese setting, we believe the utility of the framework has been enhanced, and is likely better suited to guide program design and planning in developing world countries generally. An intervention must be appropriate to the setting in which it will be implemented, as cataloged in Felipe Castro’s work on the tension between fidelity and adaptation of interventions in ethnically-diverse populations (Castro, 2010).
An Adaptation Guideline Tool was created to aid program implementers in adapting evidence-based interventions to better fit their unique settings (Lesesne, 2007). This tool was used to sanction changes to the RHD TIPS conceptual framework, but a few important considerations need to be addressed: Frist, the conceptual framework is not an evidence-based intervention per se; there is no research supporting its utility in any setting, even in the Western world. It is simply a guiding framework informed by past program experiences from around the world and by prevailing attitudes and judgments among the RF/RHD technical expert community. Second, there is no agreement over which components are “core” or essential to any functional RF/RHD prevention program. In fact, as outlined in the systematic review, countries have utilized widely different strategies to reduce and/or eradicate RF/RHD (see: Costa Rica and Samoa). Therefore, adaptation of the conceptual framework should not be bound be strict rules as depicted in the Adaptation Guideline Tool. The conceptual framework is better viewed as a menu of options from which to select interventions that are most relevant to a given program’s setting.

GOALS AND OBJECTIVES

Goal: To reduce morbidity and mortality due to RF/RHD in Nepal.

Short-term Objectives:

1. *Perform local community needs assessments to identify barriers to RF/RHD care, both logistical barriers and those related to health beliefs.*

Activities: These assessments will be administered by month 3 and analyzed by month 6. Program implementers can use the information to address barriers in future program planning. Post-implementation surveys will be used to determine success of the efforts to tackle barriers. Participating patients and families should be invited to sit in on advisory committee meetings; some may even be permanent members on an advisory committee.
2. **Develop standardized curriculum to “train trainers,” or program liaisons.**

*RHD TIPS* components addressed: *Human resources, Health worker training.*

**Activities:** By year 1, Program implementers/experts will design the curriculum and lead training sessions. Educational materials will be created for trainees. Trainees will have some health care background and may include physicians, nurses or mid-level providers. Pre- and post-surveys will be used to measure trainee knowledge and skills before and after receiving education and skills training.

3. **Trainers will disseminate RF/RHD prevention knowledge and skills in their local communities.**

*RHD TIPS* components addressed: *Human resources, Health worker training, Community education.*

**Activities:** By year 3, one trained liaison will be present in each district throughout the country. They will be responsible for reporting local progress to program implementers, in this way acting as local “champions” for RHD control and prevention. In addition, they will be given necessary equipment and educational materials for dissemination into their communities.

4. **Establish “safe centers” for BPG administration of secondary prophylaxis at all 32 NHF and government-run hospitals.**

*RHD TIPS* components addressed: *Mitigate fear of anaphylaxis, Provision of secondary prophylaxis, RF/RHD register.*

**Activities:** This should be accomplished by year 1. Engage administrators at all hospitals and request dedication of one room to BPG administration. These rooms will be well-equipped with all necessary materials, including emergency kits for management of anaphylaxis. Patient compliance to secondary prophylaxis will be monitored. It is expected that
compliance will increase because wait times for patients needing injection will be dramatically reduced.

5. **Integration of RF/RHD prevention program into national non-communicable disease (NCD) plan.**

*RHD TIPS* components addressed: *Funding, Government engagement, RF/RHD advisory committee.*

*Activities:* Accomplish by year 1. Engage stakeholders in government. Ensure that the RF/RHD plan aligns with the government’s values, mission and goals. Include government representative on advisory committee. Ensure continuous, sustainable funding for RF/RHD program and investment in procurement and delivery systems for necessary clinical supplies.

**Long-term Objectives:**

1. **Decentralization of RF/RHD care and integration into primary care health system.**

*RHD TIPS* components addressed: *Integration into primary care health system, Government engagement, Human resources, Provision of secondary prophylaxis.*

*Activities:* Begin by 6 months and accomplish by year 3-5. This process will occur in a diagonal manner, alongside general improvements in the Nepalese primary health care infrastructure. Physicians will be required to recognize signs and symptoms of RF and RHD and refer to specialist care if necessary. Because RHD often becomes manifest in pregnant women, integration with perinatal services is recommended. Task-shifting can dilute the distribution of secondary prophylaxis: in rural regions, providers as well as nurses and other mid-level providers can be trained to safely administer BPG and manage anaphylaxis if it occurs. School-based interventions can also be pursued. For example, teachers can be trained how to refer students with sore throat and school-based nurses can be trained to
administer antibiotics to children with sore throat. Furthermore, primary care staff are in a unique position to form close relationships with their patients, advocate for them, educate them and address risk factors for disease like overcrowding. A robust primary care health system is prerequisite in order for scale-up of primary prevention to succeed. Integration with existing care services is likely also a cost-effective manner in which to scale RF/RHD services.

2. Expansion of echocardiographic screening to remote regions.

*RHD TIPS* components addressed: *Burden of disease data, Health worker training, Human resources, Active case-finding (echo screening)*.

*Activities:* Accomplish by years 2-5. Better prevalence estimates are needed in rural and mountainous regions. This will help to prioritize regions for future interventions. Echocardiography is preferable to auscultation for screening due to its increased sensitivity and specificity. More Nepalese must become trained users of echo machines, reducing reliance of outside experts to complete screening campaigns. More portable echo machines are required to perform screenings throughout the country, which will require significant investment.

3. Increase community awareness of RF/RHD prevention in Nepal.

*RHD TIPS* components addressed: *Community education; indirectly addresses health care service-seeking behavior related to all prevention strategies*.

*Activities:* Will occur continuously throughout duration of the program. Current awareness among students and teachers is approximately 50%, up from 8% just a few years ago thanks to large-scale awareness campaigns. Mass media (TV advertisements and documentaries, radio), print media (newspaper articles/advertisements, posters, pamphlets, brochures) and innovative techniques (plays put on by schoolchildren, songs, celebrity spokespersons)
and formal integration of RF/RHD health messaging into the national primary school curriculum—likely requiring partnership with Ministry of Education—will be employed.

4. **Continue full subsidization of secondary prophylaxis.**

*RHD TIPS components addressed: Funding, Government engagement.*

*Activities:* Will occur continuously throughout duration of the program. Ensure financial commitment from government. Extend procurement contracts.

**IMPLEMENTATION PLAN**

**Budget Proposal**

The government of Nepal launched a program to prevent and control RF/RHD in 2007. Since then, approximately 4 million Rupees ($40,854 USD) have been allocated annually to implement this program (Regmi, Program evaluation 2010). Additional grants from WHF, WHO and other NGOs and private businesses will be sought to help cover program costs, including materials and training. An estimated $10,000 USD/year will be raised. Over five years, the projected total budget is $254,270 USD.

**Short-term Goals**

1. *Perform local community needs assessments to identify barriers to RF/RHD care, both logistical barriers and those related to health beliefs.*
   
   $3,000 over first 3 months.
   
   a. Personnel: assessment developer(s), survey administrator(s) and analyst(s)
   
   b. Materials: printed surveys

2. *Develop standardized curriculum to “train trainers,” or program liaisons.*
   
   $15,000 over first year.
   
   a. Personnel: curriculum developer(s)
   
   b. Materials: course plan, workbook, reference documents
3. *Trainers to disseminate RF/RHD prevention knowledge and skills in their local communities.*

   **$30,000 from year 1 to year 3.**
   
   a. Personnel: trainers
   b. Materials: education materials
   c. Equipment: start-up kit, including reference guides, clinical decision tools, BPG kits and administration instructions


   **$38,270 over first 2 years.**
   
   a. Personnel: staff including trained BPG administrators (likely nurses)
   b. Facilities: NHF and government-affiliated clinics and hospitals
   c. Training: for BPG administration and emergency anaphylaxis reversal
   d. Equipment: BPG kits and administration instructions, anaphylaxis kits

5. *Integration of RF/RHD prevention program into national non-communicable disease (NCD) plan.*

   **$1,000 in first year.**
   
   a. Personnel: plan drafter(s), policy-makers in government

**Long-term Goals**

1. *Decentralization of RF/RHD care.*

   **$40,000 from 6 months to 5 years.**
   
   a. Personnel: primary care physicians, nursing staff, regional RF/RHD “champions,” school “champions”
   b. Facilities: capitalize on expanding primary health care infrastructure as well as Nepal Heart Foundation clinic sites; schools
   c. Equipment: BPG administration kits, oral antibiotics if necessary,
d. Materials: Print media for providers (diagnostic criteria for GAS pharyngitics and RF/RHD, referral protocol), teachers (recognition of signs/symptoms of RF/RHD), health care staff (BPG administration protocol) and patients.

2. Expansion of echocardiographic screening to remote regions. $47,000 from year 2 to year 5.
   a. Personnel: trained echocardiographers; initially, some may need to be hired from outside the country
   b. Training: curriculum development for local echocardiographers, equipment repair
   c. Equipment: portable echo machines
   d. Transportation: fuel for screening campaigns

3. Increase awareness of importance of RF/RHD prevention (seeking medical care for treatment of sore throat) in Nepal. $40,000 over all 5 years.
   a. Materials: print media (flyers, brochures, posters, newspaper columns, billboards); electronic media (radio, documentaries, TV programs)
   b. Advertising

4. Continue fully subsidized secondary prophylaxis. $40,000 over all 5 years.
   a. Financial commitment from government
   b. Materials: BPG procurement and administration equipment

**Please see Appendix A for Logic Model**

IV. EVALUATION PLAN

EVALUATION CONTEXT
The Nepalese RF/RHD prevention program represents a significant investment by the government and offers great hope to many children and young adults in Nepal living with, or at risk of, developing RF/RHD. In addition, the program, if successful, could serve as a model for countries with similar challenges related to RF/RHD. For these reasons, it is important to determine whether the plan is being implemented as planned and achieving its intended outcomes, namely a decrease in the burden of disease attributable to RF/RHD. An evaluation plan, therefore, is needed to outline the manner in which the program’s activities are yielding or not producing its desired outcomes. The evaluation plan for the Nepalese RF/RHD prevention program carefully considers the program’s priorities and financial and human resource limitations in an effort to ensure that the evaluation can be feasibly executed (CDC, 2011). Two overarching forms of evaluation are necessary to monitor implementation fidelity (process evaluation) and achievement goals (impact evaluation).

EVALUATION THEORY

Traditional research designs and evaluation methodologies are often inadequate when applied to implementation science in the realm of public health (Kellogg Foundation, 2004). All too often, evaluation efforts prioritize proving a program’s effectiveness rather than identifying ways in which a program’s activities can be improved. Mainstream evaluation methods are defined by, and inherently confined by, their ideological underpinnings rooted in the search for causality as defined by the scientific method. Programs are often multi-interventional, however, and the social contexts in which programs are implemented cannot be controlled for in the traditional sense. Because variables are not easily controlled for, traditional methods frequently can only answer whether or not a program was effective using quantitative pre/post implementation indicators; they cannot answer how or why or which components of a program were effective or not. A new, innovative form of research design called the “effectiveness-
implementation hybrid design,” however, may be applicable to assessing the Nepalese RF/RHD program. Three forms of studies exist within the hybrid design: 1) testing clinical interventions against desired outcomes while observing how the clinical care is implemented, 2) testing clinical interventions and implementation strategies simultaneously, and 3) testing an implementation strategy while observing the effects of a clinical intervention on outcomes (Curran, 2012). Although a formal research study will not be designed, evaluation of the Nepalese RF/RHD prevention program could seek to mimic the second form of study in which both clinical effectiveness of certain interventions and the implementation process are coanalyzed.

Due to the inherent deficiencies of traditional research designs as they relate to public health programs, this evaluation plan will incorporate alternative theories that focus on process measures and subjective experiences of program participants. Participatory evaluation emphasizes the importance of seeking stakeholder input from the outset and throughout the program’s implementation (Kellogg Foundation, 2004). An advisory committee composed of stakeholders from a variety of sectors—those who will actually use evaluation findings, those who are involved in program implementation and/or evaluation, and those directly served by the program—will be formed to design the evaluation plan (CDC, 2011). The evaluation plan will also be informed by a theory-based approach that requires the creation of an evaluation logic model. Based on the logic model, process indicators can be developed to monitor implementation fidelity. Program activities can then be modified in a dynamic fashion based on the data gleaned from ongoing monitoring efforts (Kellogg Foundation, 2004). The interpretivist/constructivist approach asserts that collected data should not only be quantitative; a mixed approach is preferred, and subjective program experiences should be sought from various perspectives—stakeholders, program staff and patients (Kellogg Foundation, 2004).
EVALUATION PLAN COMPONENTS

Stakeholder Involvement

Including stakeholders in the early design stages is consistent with the participatory evaluation model and increases understanding and acceptance of the evaluation process among participants, promotes participant buy-in and ensures transparency (CDC, 2011). The advisory committee for the Nepalese RF/RHD prevention program will consist of a program director, 2 program administrative staff (including 1 internal evaluator), 1 external evaluator, 1 representative from government, 1 physician who sees RF/RHD patients, 1 patient receiving long-term BPG prophylaxis and 1 patient with experience receiving primary prophylaxis treatment in the Lalitpur pilot program. Each member will bring a unique perspective to the table. Likely, the program director and government representative will take a broad, big-picture view of the successes and failures of the program. The physician, program staff and patients are likely to offer insightful subjective reports of experiences with administrative and point-of-care elements of the program, in fulfillment of interpretive/constructivist principles. Shared responsibilities may include setting goals and strategy, advocacy, fundraising, community engagement and education/advising.

It will be important to foster an open, collegial and supportive atmosphere so that members feel empowered to offer opinions and suggestions throughout the evaluation process; this becomes especially important when monitoring data reveal deficiencies in a program and constructive conversations are required to improve program effectiveness. Conflicting expectations, goals and values must be addressed and resolved. At the initial stakeholder meeting, evaluation questions and focus, intended uses and users of evaluation data, and methods of evaluation will be agreed upon. Furthermore, the advisory committee will establish individual roles and responsibilities as well as meeting protocol, including
frequency of meetings, site of meetings and expectations of communication between meetings.

**Internal/external evaluators**

Ideally, both an internal and external evaluator will be utilized to monitor program implementation and impact. As a member of program staff who may be responsible for implementing program activities, an internal evaluator has intimate knowledge of the program, direct access to data and, hopefully, is invested in program success. It is crucial that the evaluator is an individual with relevant evaluation credentials and expertise. If this is not possible, perhaps because no program staff has formal training in evaluation techniques, resources must be provided to the internal evaluator from an outside organization or expert in a technical advisory role. Evaluations performed by internal investigators are often prejudiced by bias: the evaluator may seek to “prove” that the program works and is affecting change, for example. Furthermore, the evaluator may feel overt or subtle pressure from his or her boss, in this case the program director or government representatives, to preferentially report positive over negative findings. These limitations, combined with the fact the Nepalese RF/RHD prevention program is a “high-stakes” evaluation given the government’s oversight and funding, necessitate that an external evaluator be hired to evaluate the program in an unbiased and objective manner (Calleson, lecture notes).

External evaluators do not have intimate knowledge of program implementation and delivery prior to their hiring. This naivety could be viewed as a deficiency, but it can also be valuable to have the eyes of an unbiased observer review monitoring and evaluation data; fresh insights and ideas can be offered to improve program delivery. The Nepalese RF/RHD prevention program would benefit from hiring an outside, private evaluator with a truly unbiased perspective because hiring an evaluator from government would represent a
conflict of interest as the government is funding the program. This evaluator must be an active listener in order to fully understand the goals of the program and values of program staff. Implementation is a messy business, so an evaluator must be flexible as deadlines change, staff turns over, funding streams are adjusted and unforeseen roadblocks are manifest. The evaluator(s) must be leaders so that their findings command recognition and attention (Calleson, lecture notes).

Methods

Data collection will be an all-encompassing effort at all levels of the program. Indicator data must flow from decentralized, point-of-care program staff up into a centralized platform that is easily accessed by evaluators. The Nepalese RF/RHD prevention program has many components, all of which could be monitored by many indicators using both qualitative and quantitative methods. As is it impossible from both a human resources and budget standpoint to track all relevant process and impact indicators, the advisory committee will be tasked with prioritizing which indicators to monitor as well as how often to monitor them and the manner of their collection.

Challenges

Numerous challenges must be overcome in order for evaluation activities to be successful. Importantly, political instability is the norm in Nepal. Because the Nepalese RF/RHD program is funded primarily by government monies, the program must operate under the constant threat of funding cuts. Even in the absence of political turmoil, however, budget restrictions are likely to constrain the intensity of evaluation efforts; only essential indicators are likely able to be monitored. Human resources may constitute a barrier, especially in the case of the internal evaluation. It remains to be seen if any program staff have formal training in evaluation techniques and data analysis. Furthermore, all program
staff will require training and guidance on how to collect and submit data to evaluators. Data collection resources, including reporting forms, submission protocols and survey instruments need to be developed and disseminated to program staff. Given the variety of program components and the large geographic scope of the Nepalese RF/RHD prevention program, the creation of these resources and their dissemination, the training of program staff, and the collection of data into one centralized database all constitute unique and sizeable challenges. Time is also a significant challenge. Unfortunately, program impacts are unlikely to be observed for a long time—trends in RF/RHD incidence and prevalence will likely take years, if not decades, to detect. Government allocations of funds for the RF/RHD prevention program, however, historically have been made on an annual basis. Program implementers, then, are under constant pressure to produce intermediate data showing immediate results.

STUDY DESIGN AND METHODS

Study design

The RF/RHD program’s overall design is quasi-experimental, specifically a non-randomized pre/post design without a control group, also known as a “one-group pretest/posttest” (Issel, 2014): O1 X O2. The unit of observation for this study is not the individual, but rather the population. Indicators measuring RF/RHD disease burden before implementation (O1) will be compared to the same indicators after implementation (O2) of the program plan/intervention (X). Because RF/RHD rates of disease vary between regions and program activities may not be scaled throughout the entire country, it would be prudent to focus observations and indicator measurements to regions where program activities are implemented. The local impact of program activities, then, would not be diluted by consideration of the entire Nepalese population. An ecological study design could
be used, however, to compare trends in RF/RHD rates in Nepal versus other nearby and representative countries that are not implementing RF/RHD prevention activities.

As with any study design, the pre/post design has pros and cons. A benefit of a pre/post design includes increased feasibility given the relatively low cost of administration. Many drawbacks exist, however, including an inability to control for secular trends and an inability to parse out the effects of individual interventions on the outcome(s) of interest. This is important because the Nepalese RF/RHD plan is a comprehensive plan with many interventions targeting many populations and points along the disease's causal pathway. In this way, the relative effectiveness of any particular intervention in the RF/RHD program cannot be analyzed using a pre/post study. Additionally, it is impossible to attribute changes in indicator measurements directly to program activities because the study design does not allow for strict control of external (and internal) variables, thereby compromising internal validity (Trochim, 2006).

Ideally, and if resources permit, other forms of quasi-experimental design could be utilized to evaluate components of the program. For example, an interrupted time series design could be utilized to evaluate the impact of trained liaison presence in local communities. In this design, observations are taken at regular intervals before, during and after implementation of a program component: 01 02 03 X 04 05 06 | 07 08 09 (Mercer, 2007). In this case, the intervention (X) is the insertion of a trained liaison into a community. Observations are collected prior to the insertion of this trained liaison into the community in order to collect baseline data and to control of secular trends that may independently affect outcome measurements. Observations continue to be taken at regular frequencies during and after implementation. In addition, many research designs, including some experimental designs, could be used to determine whether the creation of “safe centers” for secondary prophylaxis administration improves patient outcomes and...
population-level RF/RHD measures. For example, half of the country’s NHF hospitals (R1) could be randomized to establish safe centers (X) while the other half (R2) delivers secondary prophylaxis according to the status quo (no X): R1: \(X\) O1 O2 O3 versus R2 no X O1 O2 O3. A prospective cohort study could follow patients over time to determine if the patients receiving secondary prophylaxis from an NHF hospital with a safe center more faithfully adhere to treatment, experience fewer RF flares and have lower rates of progression to RHD.

**Methods**

Various methods for data collection will be used, including internal program document and patient record review, observation and qualitative and quantitative techniques. Program staff and evaluators will be responsible for data gathering and administering data collection instruments.

Qualitative methods will include unstructured interviews, focus groups, and written open-ended questions. Short-term goals 1-4 will be addressed using many of qualitative data collecting techniques. Program staff, health care providers as well as patients and caregivers will be participants in interviews and focus groups in order to get a holistic view of the program’s successes and/or failures. Individual experiences with the program, perceived program effectiveness, barriers to faithful implementation and suggestions for improvement will be identified during this process. Feedback from multiple sources at different points within the program will inform program activities in an iterative fashion. In this way, the program will undergo dynamic change as feedback is fed back into program design in order to improve service delivery.

Quantitative methods will include closed survey analysis, counting and frequency measurements. Counting and frequency measurements may be derived from internal review of program files, review of patient medical records and disease registries as well as
review of echocardiographic screening data, polling data and needs assessment results.

Most of the long-term goals will be assessed using quantitative data analysis, specifically, decentralization of RF/RHD care, expansion of echocardiographic screening, and awareness-raising campaigns.

**EVALUATION PLANNING TABLES**

**Short Term Objective #1:** Perform local community needs assessments to identify barriers to RF/RHD care, both logistical barriers and those related to health beliefs.

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<thead>
<tr>
<th>EVALUATION QUESTIONS</th>
<th>PARTICIPANT</th>
<th>METHODS</th>
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<tbody>
<tr>
<td>By 3 months, were community needs assessments created and administered?</td>
<td>Program staff</td>
<td>Document review</td>
</tr>
<tr>
<td>How will communities and community members know about the needs assessment?</td>
<td>Program staff</td>
<td>Documentation of print media distribution, telephone reminders</td>
</tr>
<tr>
<td>How many communities were contacted to complete needs assessment? How many communities completed the needs assessment? How many needs assessments were collected?</td>
<td>Program staff</td>
<td>Data collection and review of needs assessments</td>
</tr>
<tr>
<td>In each community, was the needs assessment completed by a member of each: program staff, physician/health care worker, patient/patient’s caregiver?</td>
<td>Program staff</td>
<td>Review of needs assessments</td>
</tr>
<tr>
<td>What were perceived barriers to administering RF/RHD care?</td>
<td>Program staff</td>
<td>Review of needs assessments Focus groups Interviews</td>
</tr>
<tr>
<td>Needs assessment participants (local health care professionals, local program staff)</td>
<td>Needs assessment participants (local health care professionals, local program staff)</td>
<td>Review of needs assessments Focus groups Interviews</td>
</tr>
<tr>
<td>What were perceived barriers to seeking or utilizing RF/RHD care?</td>
<td>Program staff</td>
<td>Review of needs assessments Focus groups Interviews</td>
</tr>
<tr>
<td>Needs assessment participants (RF/RHF patients, caregivers)</td>
<td>Needs assessment participants (RF/RHF patients, caregivers)</td>
<td>Review of needs assessments Focus groups Interviews</td>
</tr>
<tr>
<td>What suggestions did community members provide to</td>
<td>Program staff</td>
<td>Review of needs assessments Focus groups</td>
</tr>
<tr>
<td>Needs assessment</td>
<td>Needs assessment participants (local health care professionals, local program staff)</td>
<td>Review of needs assessments Focus groups</td>
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</table>
**Short-Term Objective #2:** Develop standardized curriculum to “train trainers,” or program liaisons.

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<tr>
<th>EVALUATION QUESTIONS</th>
<th>PARTICIPANT</th>
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<tbody>
<tr>
<td>By 1 year, was a curriculum devised?</td>
<td>Program staff</td>
<td>Document review</td>
</tr>
<tr>
<td>Did the program implementers meet with experts to collaboratively develop the training material?</td>
<td>Program staff Experts</td>
<td>Minutes from committee meetings Documentation of sources providing technical expertise</td>
</tr>
<tr>
<td>Was a survey created and administered to assess trainee pre-intervention knowledge and skill levels?</td>
<td>Program staff Trainees</td>
<td>Document review Training log Documentation of participants’ pre-intervention knowledge and skill level</td>
</tr>
<tr>
<td>Was a survey created and administered to assess trainee post-intervention knowledge and skill levels?</td>
<td>Program staff Trainees</td>
<td>Document review Training log Documentation of participants’ post-intervention knowledge and skill levels</td>
</tr>
<tr>
<td>Were trainees satisfied with the training? Do trainees feel prepared to serve as a program liaison in their home districts after training? What recommendations do trainees have to improve the training?</td>
<td>Program staff Trainees</td>
<td>Written open-ended questions Focus groups Interviews</td>
</tr>
<tr>
<td>Were educators satisfied with the content and structure of the training? What recommendations do educators have to improve the training?</td>
<td>Program staff Trainers</td>
<td>Written open-ended questions Focus groups Interviews</td>
</tr>
<tr>
<td>Was the training effective?</td>
<td>Program staff Trainees</td>
<td>Written open-ended questions Focus groups Interviews</td>
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</table>
Short-Term Objective #3: Liaisons will disseminate RF/RHD prevention knowledge and skills in their local communities and give regular reports to program implementers.

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<th>EVALUATION QUESTIONS</th>
<th>PARTICIPANT</th>
<th>METHODS</th>
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<tbody>
<tr>
<td>Between years 1 and 3 did liaisons disseminate knowledge and skills into their local communities?</td>
<td>Program staff Liaisons</td>
<td>Documentation of liaison presence in communities</td>
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<tr>
<td></td>
<td></td>
<td>Documentation of liaison RF/RHD promotional activities</td>
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<tr>
<td>Are program liaisons present in every district in the country?</td>
<td>Program staff</td>
<td>Documentation of liaison presence in communities</td>
</tr>
<tr>
<td>Do liaisons feel equipped to address RF/RHD needs in their districts? What were some challenges encountered with regard to starting and or scaling RF/RHD prevention efforts?</td>
<td>Program staff Liaisons</td>
<td>Written open-ended questions</td>
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<td>Interviews</td>
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<tr>
<td></td>
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<td>Focus groups</td>
</tr>
<tr>
<td>Are liaisons regularly reporting RF/RHD data from their districts to program implementers?</td>
<td>Program staff Liaisons</td>
<td>Data collection</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Documentation of reports</td>
</tr>
<tr>
<td>What techniques did liaisons use to disseminate their knowledge and skills into their home communities? Which were most effective?</td>
<td>Program staff Liaisons</td>
<td>Review of liaisons’ reports</td>
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<td></td>
<td></td>
<td>Written-open ended questions</td>
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<tr>
<td></td>
<td></td>
<td>Interviews</td>
</tr>
<tr>
<td>What was the liaison’s impact?</td>
<td>Program staff</td>
<td>Quantitative data review: # of RF/RHD referrals; # of identified RF/RH cases; # of patients receiving care; # of clinics providing RF/RHD services</td>
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Short-Term Objective #4: Establish “safe centers” for BPG administration of secondary prophylaxis at all 32 NHF and government-run hospitals.

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<th>EVALUATION QUESTIONS</th>
<th>PARTICIPANT</th>
<th>METHODS</th>
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<tbody>
<tr>
<td>By year 1 were “safe centers” established at all NHF government-run hospitals?</td>
<td>Program staff</td>
<td>Documentation of establishment of safe centers in NHF hospitals</td>
</tr>
<tr>
<td>Are safe centers properly</td>
<td>Program staff</td>
<td>Data collection</td>
</tr>
<tr>
<td>Evaluation Question</td>
<td>Participant</td>
<td>Method</td>
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<tr>
<td>equipped and staffed?</td>
<td>Local staff</td>
<td>Documentation of site-specific equipment and staffed? Interviews with local staff</td>
</tr>
<tr>
<td>Have safe centers improved efficiency of delivery of secondary prophylaxis? The cost-effectiveness of delivery?</td>
<td>Program staff, Local staff</td>
<td>Data collection: quantitative review of registry records (# of patients seen, # BPG injections administered, # of incident cases of RF/RHD in community) Interviews with local staff Review of budget, financial records</td>
</tr>
<tr>
<td>Are patients and caregivers aware of safe centers? How are they made aware?</td>
<td>Program staff, RF/RHD patients and caregivers</td>
<td>Documentation of distribution of print media Quantitative review of patient usage of safe centers</td>
</tr>
<tr>
<td>Do patients, caregivers and staff approve of the safe center approach to delivering secondary prophylaxis?</td>
<td>Program staff, Local staff, RF/RHD patients and caregivers</td>
<td>Written open-ended questions Focus groups Interviews</td>
</tr>
<tr>
<td>What innovations can be implemented to improve RF/RHD service delivery at safe centers?</td>
<td>Program staff, Local staff, RF/RHD patients and caregivers</td>
<td>Written open-ended questions Focus groups Interviews</td>
</tr>
<tr>
<td>Is it possible to scale the model to non-NHF hospitals and clinics?</td>
<td>Program staff, Local staff, RF/RHD patients and caregivers</td>
<td>Quantitative and qualitative analysis of safe center success Reconciliation of safe center cost-effectiveness and program budget Environmental scan to determine where to scale next, if determined to be feasible</td>
</tr>
<tr>
<td>What was the impact of creating safe centers?</td>
<td>Program staff, Local staff, RF/RHD patients and caregivers</td>
<td>Quantitative data analysis: % of patients regularly receiving prophylaxis; rates of RF flares among patients; rate of progression to RHD among patients</td>
</tr>
</tbody>
</table>

**Short-Term Objective #5:** Integrate RF/RHD prevention program into national non-communicable disease (NCD) plan.
<table>
<thead>
<tr>
<th>By year 1 was a RF/RHD prevention program incorporated into a national non-communicable disease plan?</th>
<th>Program staff Government</th>
<th>Documentation of integration of RF/RHD program into national NCD plan</th>
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</thead>
<tbody>
<tr>
<td>Was an advisory committee composed of government officials, program implementers, health care professionals, evaluators and patients/caregivers assembled to inform program development?</td>
<td>Program staff Stakeholders</td>
<td>Minutes from advisory committee meetings Documentation of stakeholder attendance at meetings</td>
</tr>
<tr>
<td>Were concrete goals, a budget and timeline agreed upon?</td>
<td>Program staff</td>
<td>Minutes from advisory committee meetings Review of RF/RHD program plan</td>
</tr>
<tr>
<td>What was the impact of RF/RHD integration into the national NCD plan?</td>
<td>Program staff</td>
<td>Observations: long-term funding; increased funding</td>
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**Long-Term Objective #1**: Decentralize RF/RHD care and integrate into primary care health system.

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<th>EVALUATION QUESTIONS</th>
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<tr>
<td>Are constant efforts being made to decentralize RF/RHD prevention to smaller and smaller health posts?</td>
<td>Program staff</td>
<td>Log of participating clinics and health centers Documentation of communication/outreach efforts to clinics, health centers and community leaders</td>
</tr>
<tr>
<td>Is decentralization occurring?</td>
<td>Program staff Local staff</td>
<td>Data collection Log of participating clinics and health centers</td>
</tr>
<tr>
<td>Are partnerships being sought within the expanding and improving primary health care system?</td>
<td>Program staff Partners</td>
<td>Documentation of communication/outreach efforts to clinics and health centers, schools and potential service delivery partners</td>
</tr>
<tr>
<td>Is task-shifting occurring in order to facilitate RF/RHD</td>
<td>Program staff Liaisons</td>
<td>Review of liaison reports, highlighting transfer of knowledge</td>
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prevention activities in currently underserved areas?

Are schools increasingly a site of RF/RHD prevention? Are teachers being taught to identify sore throat and RF/RHD symptoms and refer students to appropriate medical professionals? Are students taught to report sore throat to their teachers and parents?

In discussions of primary health care infrastructure in government, is RF/RHD highlighted as a disease that would benefit from increasing decentralization of care?

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<tr>
<td>By years 2 to 5 has use of echocardiographic technology been expanded into previously un-served regions?</td>
<td>Program staff</td>
<td>Data collection Documentation of screening campaigns in previously underserved areas</td>
</tr>
<tr>
<td>How many regions now have access to echocardiography? In how many regions have screening campaigns taken place?</td>
<td>Program staff</td>
<td>Data collection Documentation of screening campaigns Review of records</td>
</tr>
<tr>
<td>Are Nepalese professionals being trained as echocardiographers in order to decrease dependence on outside expertise? How many have been trained?</td>
<td>Program staff</td>
<td>Quantitative review of: # of echo training programs available to professionals, # of professionals enrolled in these programs Creation or adaption of a training curriculum</td>
</tr>
<tr>
<td>Are more echocardiographic machines available for screening campaigns?</td>
<td>Program staff</td>
<td>Product purchase records</td>
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**Long-Term Objective #2:** Expand echocardiographic screening to remote regions.
Because of screening campaigns that reveal regional RF/RHD prevalence estimates, have certain regions of the country been identified as priority regions for intervention?

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<th>EVALUATION QUESTIONS</th>
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<th>METHODS</th>
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<tr>
<td>By year 5 are awareness rates for RF/RHD prevention services and positive behaviors higher than at the program’s inception?</td>
<td>Program staff, General population</td>
<td>Survey administration, Data collection and review of survey poll results</td>
</tr>
<tr>
<td>What behaviors have been targeted? What are the primary messages delivered?</td>
<td>Program staff</td>
<td>Content review of awareness materials</td>
</tr>
<tr>
<td>What audience(s) have been targeted?</td>
<td>Program staff, Targeted populations</td>
<td>Content review of awareness materials, Evidence of tailored campaigns to different high-risk groups</td>
</tr>
<tr>
<td>How were audiences targeted? (Print media, mass media, dramas)</td>
<td>Program staff</td>
<td>Data collection, Review of different methods used to raise awareness</td>
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**Long-Term Objective #3:** Increase awareness of RF/RHD prevention in Nepal over baseline (seeking care for treatment of sore throat).

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<th>EVALUATION METHODS</th>
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<tr>
<td>Is secondary prophylaxis fully subsidized by the government?</td>
<td>Program staff</td>
<td>Review of government RF/RHD health budget</td>
</tr>
<tr>
<td>Is there political resistance to the subsidization of secondary prophylaxis?</td>
<td>Program staff, Government representatives</td>
<td>Interviews, Observation</td>
</tr>
<tr>
<td>Are long-term contracts for BPG procurement and delivery in place?</td>
<td>Program staff</td>
<td>Review of government procurement contracts</td>
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DISSEMINATION

From the outset in the design stages of the evaluation plan, it is important to consider for whom the evaluation is being conducted. In this case, the evaluation is being performed primarily for the Nepalese government as the primary funders of the program, as well as for program administrators who can use the evaluation data to change implementation strategies in a dynamic manner. Additionally, the program could be a model for other countries if successful. Therefore, the program has the responsibility to accurately collect implementation data and identify key program components that could then become part of a large, evidence-based implementation strategy for RF/RHD prevention in similar countries.

Dissemination will occur on two levels during and after implementation of the RF/RHD plan. First, during implementation recommendations from the RHD TIPS handbook will be disseminated and manifested in the program design. Awareness campaigns will also disseminate positive health messages throughout the program in order to improve health care seeking behaviors as well as general knowledge about RF/RHD. Via trained liaisons, accepted clinical and public health interventions will be spread to every region in the country. Capacity for echocardiographic screening will be enhanced and the technology disseminated to regions of the country heretofore unexposed to the screening tool. In short, the RF/RHD program itself is dissemination and implementation plan designed to improve the way RF/RHD care is delivered and expand the scope of service delivery. Second, evaluation findings will be disseminated both internally to program staff and externally to stakeholders and the general public.

Evaluation is a process by which success of dissemination and fidelity of implementation can be measured. Before evaluation even begins, it is important to consider to whom the results will be disseminated (Kellogg Foundation, 2004). In this case, process
evaluation findings will be relayed internally to program administrators. It should be a
dynamic process in which evaluation findings drive future program activities and design
(Issel, 2014; CDC 2011). Ideally, evaluators should disclose findings early and frequently so
that administrators can quickly act on the findings and so that staff and stakeholders feel
invested (Kellogg Foundation, 2004). An impact evaluation will be completed at the end of
the study and findings will be disclosed to various stakeholders, including the government,
and perhaps the public at large.

In addition, it is important to consider how the results of the evaluation will be
disseminated, both to program administrators, staff and stakeholders, as well as the
scientific community and general public if it is decided that program findings should
contribute to the general fund of knowledge. In what form will evaluations be disseminated
(Issel, 2014): reports, presentations at advisory committee meetings, peer-reviewed
journal, et cetera? Dissemination must be tailored to the targeted audience(s) (CDC, 2011).
Regardless of the format, evaluation findings should always be reported in the context of
the program’s aims and objectives.

Mechanisms must be in place to assure the quality of the evaluations (CDC, 2011).
Hiring both an internal and external evaluator is one way in which to check the accuracy of
the evaluations, especially when an unbiased evaluator is required in a “high-stakes”
evaluation as is the case with the RF/RHD program whose funding comes from outside
sources (Calleson, lecture notes). Another way to ensure evaluation quality is to develop a
strong evaluation plan with pertinent evaluation questions and a solid research design.
V. CONCLUSION

RF/RHD is a major burden of suffering, especially for children and young adults, in Nepal as well as many other countries (Maurice, 2013; Roberts, 2013; Carapetis, 2000; Carapetis, 2005). A refusal to curb RF/RHD is regrettable and immoral because it is a preventable disease. The benefits of RF/RHD prevention are numerous, ranging from decreased burden of suffering to cost savings for stakeholders. In 2013, the World Health Assembly included RF/RHD as a disease to be incorporated into national non-communicable disease plans. This development offers a wonderful opportunity for RHD advocates to bring RF/RHD to the attention of policy-makers and Ministries of Health around the world.

A systematic literature review identified past and extant RF/RHD prevention programs at the national level. Review of these model programs revealed that RF/RHD prevention can be approached successfully in a multitude of ways. Costa Rica, for example, was able to essentially eradicate RF/RHD using primary prevention interventions (Arguedas & Mohs, 1992). On the other hand, Samoa has dramatically reduced the RF/RHD burden of suffering by focusing on secondary prevention via echocardiographic screening (Viali, 2006; Viali & Saena & Futi, 2011; Steer, & Colquhoun & Viali, 2006). Local circumstances, national priorities and resource availability dictate the extent to which countries focus on specific prevention strategies: primary prevention worked in Costa Rica because of an ideological emphasis on primary health care, and secondary prevention works in Samoa because universal echo screening in a subset of school-aged children is feasible. Because of its unique situation, Nepal is likely to benefit most from a hybrid plan, one in which many strategies act synergistically to maximize RF/RHD prevention efforts. These disease-specific efforts will occur within the context of an expanding primary health care system in a so-called “diagonal” manner.
The goal of the Nepalese RF/RHD prevention plan is to reduce the burden of suffering attributable to RF/RHD. As the *RHD TIPS* toolkit recommends, various prevention strategies targeting different populations and points along the disease’s causal pathway were highlighted in this paper. Components of the adapted *RHD TIPS* conceptual framework were prioritized for intervention according to need and resource realities, and short- and long-term objectives were built around identified gaps and opportunities. In turn, the short- and long-term objectives each addressed various components of the adapted *RHD TIPS* conceptual framework.

Many levels of the Social Ecological model are targeted by the program plan, and various theories are used to inform program design at each level. For example, the Health Beliefs model will be used at the individual and community levels to identify perceived barriers to ideal service-seeking behavior and utilization of health care services. Community Organization theory will guide the solicitation of opinions and experiences of community members, patients and caregivers in the design, implementation and evaluation phases. Feedback will be fed back into the program design and improvement processes.

Evaluation of the Nepalese RF/RHD program plan is crucial for many reasons. First, it is important to know whether the interventions are being implemented faithfully. Second, it is important to know if the faithful implementation of interventions leads to improved outcomes, in this case a reduction in the burden of disease attributable to RF/RHD. Third, it is important to secure future funding and stakeholder buy-in. Fourth, because Nepal is a pilot country for the *RHD TIPS* handbook, it is important to gauge the toolkit’s utility. Fifth, results from Nepal may inform program development in other countries, therefore program implementers are responsible for collecting quality data if they believe that their program can be replicated successfully in other countries. It remains to be seen to what extent the program or its components can be turned into a research study; if resources permit, studies
could be designed to determine the fidelity of the interventions’ implementation as well as the relative effectiveness of interventions on outcomes.

Evaluation indicators were carefully selected and based on key evaluation questions, which were, in turn, informed by program goals and short- and long-term objectives. It remains to be seen whether the capacity exists to successfully carry out the evaluation using all indicators as represented in the program plan. Should resources, both financial and human, forbid the monitoring of all indicators, program implementers will be forced to prioritize which indicators to monitor.

Success is dependent on many factors, some internal to the program and other external forces. Program implementers and staff must be enthusiastic and dedicated to the program’s goals and objectives. Stakeholders must be involved in the design stage and regularly briefed during the implementation and evaluation phases in order to foster trust and program legitimacy, enhance buy-in, and keep funding streams open. Indeed, funding is crucial to any program. In Nepal, the majority of program funds will come from a politically unstable government, which may necessitate flexibility and adaptation from the implementation team. Long-term program success depends on a dependable long-term source of funding. Furthermore, human resource shortages, staff under-qualification and time constraints constitute challenges for both the implementation and evaluation components of the program.

Despite immense challenges, the Nepalese RF/RHD prevention plan provides a roadmap for the reduction of the RF/RHD-attributable disease burden in the country. In addition, the program—should it prove to be successful—may both validate the RHD TIPS handbook as an effective tool to guide program design and serve as a model program for other countries wishing to institute national RF/RHD plans. The program’s generalizability will be largely dependent on the quality of the program’s evaluation.
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ACKNOWLEDGEMENT

I would like to thank Dr. Diane Calleson and Dr. Bryan Weiner for their thoughtful comments and suggestions as well as for their steady guidance throughout the writing process. Special thanks to my mentor at WHF, Alice Grainger-Gasser, for her charisma and insightful commentaries, and my mentor at RhEACH, Dr. Rosemary Wyber, the mastermind of RHD TIPS. Dr. Regmi of the Nepal Heart Foundation was extremely open and generous during my stay in Kathmandu. He made my experience there invaluable. Seeing RHD care delivered to patients was special, and I can't thank him enough for the whirlwind tour of RHD activities in the country.
### Appendix A: Program Logic Model

**GOAL:** To reduce morbidity and mortality due to RF/RHD in Nepal.

<table>
<thead>
<tr>
<th>INPUTS</th>
<th>ACTIVITIES</th>
<th>OUTPUTS</th>
<th>OUTCOMES (1-3 YEARS)</th>
<th>OUTCOMES (3-5 YEARS)</th>
<th>IMPACT (5+ YEARS)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>People:</strong>&lt;br&gt;• Program leaders&lt;br&gt;• Health care workers at program sites (nurses, paramedics, physicians, etc)&lt;br&gt;• Local community leaders&lt;br&gt;• RF/RHD patients and their families</td>
<td>• Perform local community needs assessment to identify barriers, including health beliefs and logistical&lt;br&gt;• &quot;Trainer training&quot;: Develop standardized curriculum and train community HCW champions to disseminate RF/RHD knowledge into their communities including RF/RHD diagnosis, management, proper referral and safe injection practices for BPG administration&lt;br&gt;• Awareness campaigns: mass media, small print media and innovative techniques, like school plays: focus on elementary school teachers, students and parents&lt;br&gt;• Identify/engage local leaders/champions</td>
<td>• Report on community barriers to RF/RHD preventive care&lt;br&gt;• Increased HCW knowledge and skills needed to treat and/or prevent RF/RHD&lt;br&gt;• Increased community awareness (patients, students, teachers, parents)&lt;br&gt;• Increased involvement of local leaders, increased program legitimacy</td>
<td><strong>Short-term:</strong>&lt;br&gt;• Design of local interventions to address barriers to care&lt;br&gt;• At least 1 trained HCW in each district&lt;br&gt;• Increase in community awareness over current to 80% (currently 48%)&lt;br&gt;• At least 1 local RF/RHD &quot;champion&quot; in each district</td>
<td><strong>Long-term:</strong>&lt;br&gt;• Community awareness of importance of RF/RHD prevention approaches 100%&lt;br&gt;• RF/RHD program activities in every district in country</td>
<td><strong>Impact:</strong>&lt;br&gt;• Reduced mortality from RF/RHD&lt;br&gt;• Reduced morbidity from RF/RHD&lt;br&gt;• Reduced cost to health care system from RF/RHD&lt;br&gt;• Adequate and sustainable funding&lt;br&gt;• Amelioration of barriers to care (as identified in community surveys)&lt;br&gt;• Sustainable program design&lt;br&gt;• 100% Nepalese-run program</td>
</tr>
<tr>
<td><strong>Organizations and Partnerships:</strong>&lt;br&gt;• Nepal Heart Foundation&lt;br&gt;• Nepalese government&lt;br&gt;• Community hospitals/clinics&lt;br&gt;• Community schools&lt;br&gt;• Local public health departments</td>
<td><strong>Overarching Activities</strong>&lt;br&gt;• Form an advisory committee with members from: NHF, government, RF/RHD patients and their families, outside experts&lt;br&gt;• Progress reports to be submitted to government by NHF&lt;br&gt;• Engage school leaders for screening campaigns and school-based primary prophylaxis campaigns&lt;br&gt;• Integration of RF/RHD health messaging into elementary school curriculum (could partner with Ministry of Education)&lt;br&gt;• Continue echocardiographic prevalence studies throughout country&lt;br&gt;• Standardization of patient referral process and priority-based follow-up care&lt;br&gt;• Procure/distribute supplies to local hospitals and clinics</td>
<td><strong>Primary prevention:</strong>&lt;br&gt;• Development of RF/RHD prevention plan&lt;br&gt;• Semi-annual advisory committee meetings&lt;br&gt;• Annual progress reports&lt;br&gt;• Increase in number of schools with access to echocardiographic screening&lt;br&gt;• Creation of RF/RHD curriculum for elementary school students and teachers&lt;br&gt;• Improved epidemiologic surveillance of burden of disease&lt;br&gt;• Decrease in number of patients lost to follow-up&lt;br&gt;• Reliable and quality procurement system and supply chain&lt;br&gt;• Decentralization of RF/RHD care</td>
<td><strong>Short-term:</strong>&lt;br&gt;• RF/RHD prevention plan integrated into national NCD plan&lt;br&gt;• Increase by 3-fold the number of schools with echo screening&lt;br&gt;• Pilot RF/RHD curriculum for elementary school children and teachers in 10 representative school districts throughout country&lt;br&gt;• Epidemiologic prevalence studies in rural, mountainous regions of the country&lt;br&gt;• 100% provider understanding of referral process&lt;br&gt;• Pilot of protocol to...</td>
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<tr>
<td>Integration into strengthening primary care system</td>
<td>Increased number of functioning primary prevention programs</td>
<td>monitor quality of imported BPG</td>
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<tr>
<td>Scale Lalitpur program to other states throughout country</td>
<td>Understanding of subjective and objective successes and failures of Lalitpur pilot program</td>
<td>Establishment of at least 1 primary prevention program in rural region of Nepal</td>
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<tr>
<td>Perform post-implementation survey of Lalitpur program participants: staff, patients, parents, providers</td>
<td>Improved understanding of GAS epidemiology in Nepal</td>
<td>Report on epidemiology of GAS pharyngitis in Lalitpur</td>
<td></td>
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<tr>
<td>Perform epidemiologic studies on GAS pharyngitis presentation, incidence, natural history, RF incidence, presentation</td>
<td>CEA report on &quot;treat-all&quot; clinical approach and development of clinical diagnostic algorithm if approach is subpar</td>
<td>80% provider understanding of indications for antibiotic treatment of sore throat</td>
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<tr>
<td>Creation and maintenance of standardized tonsillitis and pharyngitis register</td>
<td>Improved patient compliance with secondary prophylaxis</td>
<td>100% provider compliance with standardized registry for GAS pharyngitis and RF</td>
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<tr>
<td>Development of GAS pharyngitis clinical diagnostic algorithm</td>
<td>Decrease in rate of anaphylactic reactions</td>
<td>&gt;95% patient compliance to secondary prophylaxis</td>
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<tr>
<td>Cost-effectiveness analysis of current &quot;treat-all&quot; GAS pharyngitis algorithm</td>
<td>Reduction in percentage of providers refusing to administer secondary prophylaxis</td>
<td>Establishment of &quot;safe centers&quot; for BPG administration in all 32 public hospitals</td>
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<tr>
<td></td>
<td>Creation of &quot;safe centers&quot; at hospitals and clinics for BPG administration</td>
<td>0% provider refusal rate to administer BPG</td>
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<td></td>
<td>Expansion of anti-anaphylaxis trainings</td>
<td>0 deaths due to anaphylaxis</td>
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<td></td>
<td>Increase in number of providers trained to use echo for RHD diagnosis</td>
<td>Decrease rate of recurrent RF by 50%</td>
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<td></td>
<td>Increase in number of echo machines</td>
<td>Training of 5 national echocardiographers to diagnose RHD</td>
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<tr>
<td></td>
<td>Increase in number of children screened for RHD</td>
<td>50% students screened with echo for RHD</td>
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</tbody>
</table>

**Secondary prevention:**
- Ensure registry compliance
- Establishment of "safe centers" for BPG administration
- Perform internal audits: cases detected, BPG administered, patient compliance rates, etc
- Anti-anaphylaxis measures: train HCWs to manage anaphylaxis, have emergency kit handy with every injection, standardize safe injection practices
- Scale echocardiographic campaigns to remote regions of the county
- Train national echocardiographers
- Purchase portable echo machines

**Funding:**
- **Annual Program Budget**
  - Lobby government to include long-term RF/RHD program funding in national NCD plan
  - Work with advisory committee members to establish a fundraising strategy
  - Assess Rotary International’s willingness to help fund scaling of primary prevention projects
  - Assess willingness of NGOs (like WHF) to fund training and education materials
- **Outside donors (Rotary)**
  - Larger, sustainable, long-term budget

**Materials and Resources:**
- **RHD TIPS handbook**
  - Use RHD TIPS handbook as a guide for program development
  - Disseminate RF/RHD programming information
  - Comprehensive RF/RHD prevention plan
  - Increase in HCW knowledge and skills
- **Long Term:**
  - Formal integration of RF/RHD health messaging into primary school curriculum (with MoE)
  - >90% provider adherence to sore throat management guidelines
  - 75% of primary school students screened
  - 100%
<table>
<thead>
<tr>
<th><strong>Data from program evaluations and screening campaigns</strong></th>
<th><strong>NHF infrastructure</strong></th>
<th><strong>Training resources</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Educational materials</strong></td>
<td><strong>Small print media</strong></td>
<td><strong>Billboards</strong></td>
</tr>
<tr>
<td><strong>Mass media: radio, TV</strong></td>
<td><strong>Innovative methods: school curriculum, plays, sufferer testimonials, etc</strong></td>
<td><strong>Mass media: radio, TV</strong></td>
</tr>
<tr>
<td><strong>Procurement systems</strong></td>
<td><strong>BPG</strong></td>
<td><strong>Anaphylaxis kits</strong></td>
</tr>
<tr>
<td><strong>Antibiotics for GAS pharyngitis</strong></td>
<td><strong>Sustainable procurement and delivery systems</strong></td>
<td><strong>Decentralization of “safe centers” for BPG administration: task-shifting BPG injections to lower-level providers</strong></td>
</tr>
<tr>
<td><strong>Using existing NHF and national primary care infrastructure</strong></td>
<td><strong>Expand RF/RHD education into communities and schools</strong></td>
<td><strong>Standardize training resources</strong></td>
</tr>
<tr>
<td><strong>Rely on existing procurement and distribution systems for clinical supplies</strong></td>
<td><strong>Use focus groups to pre-test effectiveness of various awareness-raising mechanisms</strong></td>
<td><strong>Echocardiographic screening campaigns carried out by Nepalese experts</strong></td>
</tr>
<tr>
<td><strong>Increase in general public knowledge of RF/RHD</strong></td>
<td><strong>Sustainable procurement and delivery systems</strong></td>
<td><strong>Increase in general public knowledge of RF/RHD</strong></td>
</tr>
<tr>
<td><strong>Sustainable procurement and delivery systems</strong></td>
<td><strong>Decentralization of “safe centers” for BPG administration: task-shifting BPG injections to lower-level providers</strong></td>
<td><strong>Sustainable procurement and delivery systems</strong></td>
</tr>
</tbody>
</table>
## Appendix B: Review of Literature Review Studies

<table>
<thead>
<tr>
<th>Program and Goals</th>
<th>Target Population</th>
<th>Program Description</th>
<th>Evaluation Strategy</th>
<th>Results</th>
<th>Strengths/Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>WHO Global Programme</strong></td>
<td>16 countries in highly endemic regions throughout the world.</td>
<td>Top-down: Countries provided with materials from WHO as well as modest financial backing in exchange for regular reporting to WHO. Project rolled out in 3 phases: pilot, regional, national. Focus on provider and patient education as well as secondary prevention (active case-finding using non-echocardiographic methods, registry creation, administration of BPG prophylaxis).</td>
<td>Pre-/Post-intervention RF/RHD prevalence. Intermediate outcomes: e.g. number of educational materials distributed, number of health care workers trained.</td>
<td>Variable effectiveness in different countries. Decreased incidence of RF and prevalence in most countries.</td>
<td><strong>Strengths:</strong> Long-term follow-up. Established baseline prevalence measures. Monitoring intermediate indicators. Standardization of reporting. <strong>Weaknesses:</strong> Different methods used for case-finding. Minimal country-specific information (mostly reported regionally). No theoretical framework for program design.</td>
</tr>
<tr>
<td><strong>Costa Rica</strong></td>
<td>Pediatric population (roughly ages 5-14) in Costa Rica.</td>
<td>“Diagonal” approach in which primary prevention (early detection and treatment of GAS sore throat) is delivered within a strengthening primary health care system. Focus on provider education of clinical guidelines and general</td>
<td>Pre-/Post-intervention RF/RHD prevalence. Monitoring of adverse effects to treatment and GAS resistance to BPG.</td>
<td>Rapid and sustained decline in RF incidence: from 8/100,000 in mid-1980’s to 0.5/100,000 by 1990.</td>
<td><strong>Strengths:</strong> Strong government support. “Diagonal” approach. Decentralization of care. Development of cost-effective clinical diagnostic criteria. <strong>Weaknesses:</strong> Lack of a robust evaluation procedure.</td>
</tr>
<tr>
<td>Program and Goals</td>
<td>Target Population</td>
<td>Program Description</td>
<td>Evaluation Strategy</td>
<td>Results</td>
<td>Strengths/Weaknesses</td>
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<tr>
<td><strong>Samoa</strong></td>
<td>Pediatric population and young adults in Samoa.</td>
<td>Secondary prevention focus (echocardiographic screening in schools, registry, long-term prophylaxis with BPG) with ancillary primary prevention activities (school-based; teachers refer students with sore throats to providers). Provider, patient, community education and awareness.</td>
<td>Pre-/Post-intervention RF/RHD prevalence. Intermediate indicators include: number of children screened, number of schools participating in primary prevention initiatives.</td>
<td>Decline in RHD prevalence: from 40.2/100,000 in 2007 to 31.8 in 2009.</td>
<td><strong>Strengths:</strong> Governmental support. Organized referral service. Electronic registry. <strong>Weaknesses:</strong> Lack of robust monitoring and evaluation framework. Difficult to determine which program component is responsible for decline in RF/RHD rates.</td>
</tr>
<tr>
<td><strong>Rwanda</strong></td>
<td>School-aged children in Gasabo district, soon to be scaled to other regions within the country.</td>
<td>Secondary prevention. Ancillary tertiary care services with Team Heart from USA. Provider, patient, community education and awareness. Development of mobile</td>
<td>Pre-/Post-intervention RF/RHD prevalence.</td>
<td>Unknown.</td>
<td><strong>Strengths:</strong> Establishing baseline prevalence. Collaboration with MoF and integration in national NCD plan. Innovative methods of reaching patients. <strong>Weaknesses:</strong> Lack of focus on health</td>
</tr>
<tr>
<td>Program and Goals</td>
<td>Target Population</td>
<td>Program Description</td>
<td>Evaluation Strategy</td>
<td>Results</td>
<td>Strengths/Weaknesses</td>
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</table>

**New Zealand Goals:**
1) To “achieve equity of incidence and outcomes of rheumatic fever between Māori and Pacific children, and other New Zealand children.”
2) To “contribute to the reduction of the age-standardized annual rate of rheumatic fever among Māori and Pacific peoples, other New Zealanders, and all School-aged children, especially poor and indigenous populations.”
<table>
<thead>
<tr>
<th>Program and Goals</th>
<th>Target Population</th>
<th>Program Description</th>
<th>Evaluation Strategy</th>
<th>Results</th>
<th>Strengths/Weaknesses</th>
</tr>
</thead>
<tbody>
<tr>
<td>DHB populations to 0.4 per 100,000 by 2020.</td>
<td></td>
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<td></td>
<td>Negatives: Focus on schools neglects primary health care system. Incomplete coverage of schools.</td>
<td>model to guide program design. Difficult to discern the relative contribution of each program component to decline in RF/RHD rates.</td>
</tr>
<tr>
<td>3) To “contribute to the reduction of rheumatic fever recurrence in New Zealand to five cases or fewer per annum by 2013.” (NZ MoH, 2012)</td>
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</tbody>
</table>
### Appendix C: Project Timeline

<table>
<thead>
<tr>
<th>Short-term Goals</th>
<th>Start</th>
<th>3 Months</th>
<th>6 Months</th>
<th>1 Year</th>
<th>2 years</th>
<th>3 years</th>
<th>4 Years</th>
<th>5 Years</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Perform local community needs assessments to identify barriers to RF/RHD care, both logistical barriers and those related to health beliefs.</td>
<td>Personnel: $1,500</td>
<td>Personnel: $6,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $15,000</td>
<td>Personnel: $10,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $1,000</td>
<td>$3,000</td>
</tr>
<tr>
<td></td>
<td>Materials: $1,500</td>
<td>Materials: $7,000</td>
<td>Materials: $5,000</td>
<td>Materials: $15,000</td>
<td>Materials: $10,000</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>Materials: $1,000</td>
<td>$15,000</td>
</tr>
<tr>
<td>2. Develop standardized curriculum to “train trainers” or program liaisons in rural areas.</td>
<td>Personnel: $6,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $15,000</td>
<td>Personnel: $10,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $1,000</td>
<td>$30,000</td>
</tr>
<tr>
<td>3. Trainees return to their home districts and disseminate RF/RHD prevention knowledge and skills.</td>
<td>Personnel: $7,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $18,270</td>
<td>Personnel: $12,000</td>
<td>Personnel: $22,000</td>
<td>Personnel: $22,000</td>
<td>Personnel: $1,000</td>
<td>$38,270</td>
</tr>
<tr>
<td>4. Establish “safe centers” for BPG administration of secondary prophylaxis at all 32 NHF and government-run hospitals.</td>
<td>Personnel: $8,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $18,270</td>
<td>Personnel: $12,000</td>
<td>Personnel: $22,000</td>
<td>Personnel: $22,000</td>
<td>Personnel: $1,000</td>
<td>$40,000</td>
</tr>
<tr>
<td>5. Integration of RF/RHD prevention program into national non-communicable disease (NCD) plan.</td>
<td>Personnel: $1,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $5,000</td>
<td>Personnel: $18,270</td>
<td>Personnel: $12,000</td>
<td>Personnel: $22,000</td>
<td>Personnel: $22,000</td>
<td>Personnel: $1,000</td>
<td>$1,000</td>
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<table>
<thead>
<tr>
<th>Long-term Goals</th>
<th>Total</th>
<th>Total</th>
<th>Total</th>
<th>Total</th>
<th>Total</th>
<th>Total</th>
<th>Total</th>
<th>Total</th>
<th>$254,270.00</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Decentralization of RF/RHD care.</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>Personnel: $20,000</td>
<td>$40,000</td>
</tr>
<tr>
<td>2. Expansion of echocardiographic screening to remote regions.</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>Materials: $20,000</td>
<td>$47,000</td>
</tr>
<tr>
<td>3. Awareness of importance of RF/RHD prevention (seeking medical care for treatment of sore throat) ~100% among students and teachers in Nepal.</td>
<td>BPG procurement and BPG administration equipment</td>
<td>BPG procurement and BPG administration equipment</td>
<td>BPG procurement and BPG administration equipment</td>
<td>BPG procurement and BPG administration equipment</td>
<td>BPG procurement and BPG administration equipment</td>
<td>BPG procurement and BPG administration equipment</td>
<td>BPG procurement and BPG administration equipment</td>
<td>BPG procurement and BPG administration equipment</td>
<td>$40,000</td>
</tr>
<tr>
<td>4. Continue fully-funded government-subsidized secondary prophylaxis.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>$40,000</td>
</tr>
</tbody>
</table>

**TOTAL**: $254,270.00
Appendix D: IRB Considerations

The RF/RHD program plan will include data collection activities that involve human subjects. Therefore, Institutional Review Board endorsement will be needed for ethical approval of program activities carried out by myself or other UNC personnel. Hopefully, however, local Nepalese program staff will perform the program evaluation. In Nepal, a separate entity exists for research study approval, the Nepal Health Research Council’s Ethics Review Board (NHRC ERB) (Harvard, 2006). The NHRC ERB must directly approve any projects being implemented at the national level, like the national RF/RHD plan. 

Qualitative research

Qualitative research techniques including interviews, surveys, focus groups and written open-ended questions will be used to gather data relevant to program activities throughout the study. Subjects will include program staff, health care providers as well as patients, many of whom will be under 18 years of age, and their caregivers. Human subjects will be recruited in a non-coercive manner, and informed consent will be attained via education from program staff and a study fact sheet. Participation will be strictly non-voluntary. Program aims and goals as well how evaluators use participants’ responses will be shared with participants (Calleson, n.d.c). Program staff will be assured that their responses will not affect their employment status. Avenues will be opened for study participants to contact evaluators with questions or concerns.

The risks for participants in the qualitative procedures are few because 1) there is no threat of corporal harm and, 2) the risk of psychological harm is low due to the fact that RF/RHD is not a highly stigmatized disease, there is no criminal or civil liability related to a RF/RHD diagnosis and there is no risk of damaging a participant’s employment status.

It will be difficult to assure full protection of confidentiality. It is likely that certain study participants, especially health care professionals and program staff, may be easily
indirectly identified via linked identifiers. Furthermore, it will be important to link responses in qualitative procedures to the respondents in order to analyze discrepancies in the perceptions of program implementers and beneficiaries; in this way, data cannot be de-linked from the respondent. Every effort will be made to include only relevant patient identifiers, and, as mentioned above, there is very little risk to participants even if their responses are disclosed. Only program evaluators will have access to raw data linking individual respondents to their responses; only aggregated data will be available to other program staff and stakeholders.

All survey, interview and focus group responses will be collected for internal purposes with the goal of improving program effectiveness. It is unlikely that responses will be used and published in a peer-reviewed research article. Therefore, data derived from these methods is not considered “research” because it will not contribute to the general public fund of knowledge. For this reason, it is unlikely that these qualitative instruments would require full IRB review. A fast-track exemption should be sought in this case.

*Liaison training and “safe centers” for secondary prophylaxis administration*

Pre- and post-surveys of liaison trainers and trainees will abide by the informed consent process described above. It might be prudent for the program to evaluate and report on the effectiveness of the training program, making the results open to the general public. In this way, this particular component of the program may be considered research and it is likely that study design and materials would require full IRB review. It would be necessary for evaluators to undergo Human Subjects Training, which covers consent requirements and ethical considerations, among many other competencies (UNC, 2013).

Similarly, the effectiveness of safe centers for secondary prophylaxis administration could be studied relative to the standard of care. As mentioned in the *Methods* section, many
study designs, including a prospective cohort trial, could be used to answer this study question. If program staff pursues this study, full IRB review will be required.