NEGLECTED TROPICAL DISEASE HIGH-RISK POPULATION FORMATIVE ASSESSMENT

Introduction

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Pilgrim Africa is a Ugandan NGO focused on ending diseases of poverty, particularly malaria and NTDs. We work in close partnership with the most vulnerable communities and with both government and civil society in support of Uganda's national health strategy, through large-scale program support, research and analytics, and advocacy.

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KEY DEFINITIONS

Case management neglected tropical diseases (CM-NTDs)

Neglected tropical diseases requiring diagnosis, treatment and/or supportive care at an individual level, administered through routine health service delivery.

Community-centered design

A research, intervention, or delivery design strategy that begins with community-generated ideas on barriers and access points and allows the community to take a primary role in design.

Elimination (interruption of transmission)

Reduction to zero of the incidence of a specified disease or infection caused by a specific pathogen in a defined geographical area, with minimal risk of reintroduction, as a result of deliberate efforts.

Elimination (as a public health problem)

A term related to both infection and disease, defined by achievement of measurable targets set by WHO in relation to a specific disease.

Enumeration

Systematically observing and counting the number of people – members of a high-risk population, for example – who are present during periods of high-attendance at specific venues or transit points to determine how many can potentially be accessed at each location.

Eradication

Permanent reduction to zero of the worldwide incidence of infection caused by a specific pathogen, as a result of deliberate efforts, with no risk of reintroduction.

Formative assessment

A process by which different approaches are used to collect information and summarize what is known, believed, and done in relation to a particular subject – e.g., populations at high risk of neglected tropical disease.

Gender equity and social inclusion (GESI)

Purposively identifying and addressing unique abilities, barriers, and needs of women, men, boys and girls to enable them to have the same rights to services and opportunities. It also includes identifying disadvantaged individuals or groups and covering them in prevention, control, and elimination efforts.

High-risk populations (HRPs)

Groups of people who share social, demographic, geographic, or behavioral characteristics that place them at higher risk of disease exposure and infection and/or make them difficult to reach with interventions for prevention and treatment.

Mass drug administration (MDA)

Distribution of medicines to the entire population of a given administrative setting, irrespective of the presence of symptoms or infection. Also referred to as preventive chemotherapy in the context of neglected tropical diseases.

One Health

An integrated approach to the health of people, animals, and the environment that involves collaboration among the public health, veterinary, and environmental sectors.

Preventive chemotherapy neglected tropical diseases (PC-NTDs)

Neglected tropical diseases that can be managed at the community level through mass drug administration, usually administered through vertical health campaigns.

Qualitative data

Non-numerical data that typically describe a research subject's attributes; this may include information derived from interviews, direct observation, or written documents.

Venue mapping

Identifying and listing all venues in areas where members of a specific population gather, transit, or spend time, and generating physical maps for venue-based access to services.

Water, sanitation, and hygiene (WASH)

Services and infrastructure critical for human health. Poor WASH services are implicated in the spread of several NTDs, including trachoma and soil-transmitted helminths, and many skin-related diseases.

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1. Preface

To maximize coverage of health interventions, improve health and equity, and make progress in disease control and elimination, programs must identify populations that are hardest to reach or at highest risk and appropriately tailor and target interventions for them. The Neglected Tropical Diseases High Risk Populations Formative Assessment Tool Implementation Manual is designed to assist programs in this effort.

This introduction to NTD HRP assessment serves as a companion to the implementation manual. It provides an overview of neglected tropical diseases, public health responses, and high risk population groups, as well as a background of the tool's purpose and design and comments on timing and integration with NTD program planning. Ways the tool may be used to strengthen key aspects of NTD program delivery are presented, along with descriptions of associated complementary tools.

2. Neglected Tropical Diseases

Neglected tropical diseases (NTDs) are a group of conditions caused by a range of pathogens (including viruses, bacteria, parasites, fungi and toxins) that thrive in tropical regions. NTDs affect over a billion people worldwide and can have devastating health, social, and economic consequences. While NTDs are endemic to nearly 150 countries[1], the majority of the burden is concentrated in low- and middle-income countries in Africa, Asia, and the Americas.[2] NTDs are considered "neglected" because they persist in the poorest, most marginalized and isolated communities of the world.

The World Health Organization (WHO) has prioritized 21 NTDs, categorized based on whether they can be prevented, controlled or eliminated using currently available methods **(Table 1)**. Considerable progress has been made in the fight against NTDs over the past decade, with expanded donor support, new interventions, guidelines, and partnerships. NTD interventions have been shown to be cost effective and to have a significant impact on population health and economic progress.

WHO defines five core intervention strategies to accelerate the prevention, control, elimination and ultimate eradication of NTDs:[3]

- Innovative and intensified disease management
- Preventive chemotherapy, also known as mass drug administration (MDA)
- Vector control
- Veterinary public health[3]
- Safe water, sanitation and hygiene (WASH)

Depending on the specific NTD, one or more of these strategies may be needed. Trachoma, caused by the bacterium *Chlamydia trachomatis*, is the world's leading infectious cause of blindness. Infection spreads through ocular and nasal discharge, and control is based on the SAFE strategy: **S**urgery to treat the blinding stage (*trachomatous trichiasis*); **A**ntibiotics to clear infection, **F**acial cleanliness; and **E**nvironmental improvement. SAFE combines several strategies, including: MDA with azithromycin; WASH interventions; and intensified individual case management (CM). Similarly, onchocerciasis elimination combines ivermectin MDA with black fly control and management.

NTDs that are amenable to MDA, also known as preventive chemotherapy (PC), are sometimes referred to as PC-NTDs. Both trachoma and onchocerciasis (along with lymphatic filariasis, schistosomiasis, and soil-transmitted helminthiases) fall into this category.

Some NTDs require individual case management (CM) for both detection and treatment; these are known as CM-NTDs. In addition, some NTD sufferers experience chronic pain, disease and disability and require additional health services to manage their morbidity and prevent or mitigate permanent disability.

The WHO "Roadmap for Neglected Tropical Diseases 2021-2030[2] lays out global targets for NTD control, elimination, and eradication. These include reducing NTD-related disability-adjusted life years (DALYs) by 75%; 100 countries reporting at least one NTD eliminated; and eradication of two additional NTDs worldwide.

TABLE 1

WHO recognized NTDs, control strategies, and 2030 targets

Control
Elimination as a Public Health Problem
Elimination
Eradication

NTD	Cause & vector	Control strategy	2030*
Buruli ulcer	Mycobacteria	Vector control, blood screening, case finding and treatment	**Control**
Dengue and chikungunya	Viruses, transmitted by mosquitoes	Safe water, sanitation, and health (WASH) education	**Control**
Echinococcosis	Helminths	MDA (praziquantel or triclabendazole), WASH, One Health	**Control**
Foodborne trematodiasis	Helminths	Sanitation, meat inspection, vaccination of pigs	**Control**
Leishmaniasis (cutaneous)	Protozoa, transmitted by sandflies	Integrated vector control, with a focus on personal protective measures	**Control**
Mycetoma, chromoblastomycosis and other deep mycoses	Fungi and bacteria	Case finding and treatment	**Control**
Scabies and other ectoparasitoses	Mites	MDA (ivermectin, topical scabicides); WASH	**Control**
Snakebite envenoming	Poisonous snakes	Prompt treatment with anti-venoms	**Control**
Taeniasis and cysticercosis	Helminths in pork	Case finding and treatment; food hygiene	**Control**
Chagas disease	Protozoa, transmitted by Triatominae insects	Vector control	**Elimination as a Public Health Problem**
Human African Trypanosomiasis (rhodesiense)	Protozoa, transmitted by tsetse flies	Case finding and treatment; vector control	**Elimination as a Public Health Problem**
Leishmaniasis (visceral)	Protozoa, transmitted by sandflies	To be determined, but likely to include: new diagnostics, enhanced case finding and treatment, and integrated vector control	**Elimination as a Public Health Problem**
Lymphatic filariasis	Helminths, transmitted by mosquitoes	MDA (ivermectin, albendazole), vector control	**Elimination as a Public Health Problem**
Noma	Non-specific polymicrobial organisms	Case finding and treatment; nutrition programs	**Elimination as a Public Health Problem**
Rabies	Viruses, transmitted by infected mammals	Vaccination of pets, health education on animal contact; post-exposure prophylaxis	**Elimination as a Public Health Problem**

Schistosomiasis	Trematode worms, transmitted by freshwater snails	MDA (praziquantel), vector control	**Elimination as a Public Health Problem**
Soil-transmitted helminthiases	Different species of parasitic worms	MDA (albendazole, mebendazole), health education, sanitation	**Elimination as a Public Health Problem**
Trachoma	Mites, fleas or lice	Surgery, MDA (azithromycin), WASH	**Elimination as a Public Health Problem**
Human African Trypanosomiasis (gambiense)	Protozoa, transmitted by tsetse flies	Case finding and treatment; vector control	**Elimination**
Leprosy	Bacteria	Case finding and treatment	**Elimination**
Onchocerciasis	Helminths, transmitted by blackflies	MDA (ivermectin), vector control	**Elimination**
Dracunculiaiasis (guinea worm disease)	Helminths, transmitted by water fleas	Slaughter control, WASH, treatment of dogs	**Eradication**
Yaws	Bacteria	MDA (azithromycin)	**Eradication**

The roadmap also provides a blueprint for the prevention, control, elimination, and eradication of each of the 21 prioritized NTDs, with specifics on the gaps, needs and goals associated with each **(see Table 1).**

3. NTD High Risk Populations

As an NTD nears elimination and transmission declines, cases cluster in geographic areas and among populations at higher risk of infection; these high risk populations (HRPs) often have lower coverage of interventions. Identifying and understanding the specific characteristics of populations at high risk for NTDs enables national programs to tailor interventions to their needs and engage them more effectively in solutions. Decreasing and ultimately reducing NTD transmission to zero among HRPs is essential for achieving and sustaining NTD elimination.

While NTDs disproportionately affect and are concentrated among populations living in vulnerable circumstances, some are more likely to contract NTDs than others. Sometimes, this is because they have limited access to – or are hard to reach with – prevention and treatment services. Such populations include mobile and migrant peoples and those with poor access to public health facilities and limited integration into national health systems, e.g. cross-border dwellers in remote regions. Other groups are disproportionately affected because their circumstances or behaviors expose them to greater risk. These groups may live or work in locations associated with NTD risk, including refugees from disease-endemic zones, communities without access to latrines or

clean water, and those whose domestic or work responsibilities put them in contact with vectors (e.g., daily exposure to freshwater snails puts fisherfolk at risk for schistosomiasis).

4. Introducing the NTD HRP Formative Assessment Tool

The NTD HRP Formative Assessment Tool provides step-by-step instructions on methods that programs and their partners can use to gather and analyze information to inform the delivery and evaluation of NTD interventions to HRPs. The tool helps NTD programs identify gaps in intervention delivery, treatment and diagnosis; gather evidence on risk factors and behaviors of populations likely at high risk for NTDs; adapt monitoring & evaluation (M&E) activities; track epidemiological trends in HRPs; and improve targeting of interventions. It helps programs better understand where, when and how HRPs can be reached and engaged in community solutions, and on their particular risks, behaviors, needs, and preferences.

The HRP Formative Assessment tool was originally designed for and used by malaria programs to identify and characterize populations at high risk for malaria, providing evidence to help target and tailor malaria interventions to these groups. To date, it has been used in Ethiopia, Indonesia, Lao PDR, Madagascar, Namibia, Nepal and Senegal, with documented effects on coverage and impact on malaria transmission. In Namibia, use of the formative assessment tool helped inform an intervention package tailored to the particular needs and circumstances of identified HRPs and provided in appropriate locations, at appropriate times. The effort resulted in a 57% increase in intervention coverage, and a decline in prevalence (3.5% by RDT, 7.6% PCR).[5] The findings were used to revise Namibia's national strategic plan and to inform its Global Fund and other funding proposals.

The HRP tool was adapted for use in NTDs by the Vector Borne and Neglected Tropical Diseases Division (VBNTD) of the Ministry of Health, Uganda in partnership with other NTD program managers and expert members of a technical advisory group. This collaborative, 12-month process was led by Pilgrim Africa, The University of California, San Francisco, Malaria Elimination Initiative, and WI-HER, working closely with the VBNTD program. During this time, the team also applied the tool to five HRPs at risk of trachoma or onchocerciasis in Uganda. The results of these studies are currently being used to inform elimination programming decisions for these diseases.

When should the NTD HRP formative assessment tool be used?

Though it can be used for any NTD, the NTD HRP tool is primarily focused on the NTDs targeted for near-term elimination (interruption of transmission) or elimination as a public health problem.

The tool should be used in the earliest stages of elimination program planning (six months before the deployment of activities). Using the tool at intervals during program implementation will facilitate ongoing optimization of activities, including refined targeting and additional tailoring of interventions as needed.

The specific timing and frequency should be determined based on country needs and the country's NTD Master Plan, NTD guidelines and NTD Monitoring and Evaluation Plans. Other factors to consider include planned WHO assessments, the cycle of strategic and operational planning updates, and any major shifts in population dynamics, including resettlements, displacements and rapid growth and development.

5. Use Cases

Refining Monitoring and Evaluation

Monitoring and evaluation (M&E) is needed to identify programmatic and coverage gaps, assess the impact of interventions, detect reemergence of infections and target a locally-tailored response. A formative assessment in HRPs can identify gaps in M&E. For instance, interviews with health workers in northern Uganda during an onchocerciasis HRP study using the tool identified gaps in NTD knowledge needed for case

detection. As a result, Uganda's VBNTD program is taking steps to strengthen HRP surveillance. Overall, M&E in HRPs must be informed and proactive to be effective.

Engaging the "Never Treated"

A special subset of HRPs comprises individuals or groups who have never received MDA, determined either through self-report or through MDA registers, referred to as "never treated".[6] As countries (and regions within them) move towards elimination, it becomes more feasible to identify "never treated" individuals and groups, who remain sources of transmission. Cross-border dwellers unclaimed by either country's health system, refugees, and members of remote nomadic groups may fall into this category. The NTD HRP Formative Assessment Tool can support efforts to understand and engage these individuals and groups.

Facilitating Community-Centered Design

The HRP formative assessment tool can support community-based or participatory approaches to engage underserved populations in dialogue, enabling them to be co-creators rather than passive recipients of interventions. When affected populations are empowered to play an active role in defining problems and determining locally-appropriate solutions, acceptance and uptake of interventions can increase significantly. The tool can help identify access points and barriers specific to each HRP. In Kenya, participatory approaches confirmed that the Community Health Volunteers who conduct case finding for suspected trachoma were found to be acceptable to local households, and easily able to reach them. Some nomadic pastoralist HRPs in eastern Uganda, however, prefer to gather at central locations for treatment.

Strengthening Integrated and One Health Programming

Integration of disease control programs can result in efficiencies and increase value for money. In Uganda, all NTD efforts are housed in one programme, easing implementation. HRPs often suffer from more than one NTD, and where well characterized, can be targeted with integrated programming. For example, where communities are co-endemic for lymphatic filariasis and onchocerciasis, they can be targeted for ivermectin MDA, which is effective in both cases. An HRP formative assessment can strengthen program interventions for several NTDs at once.

The One Health approach, or the joint delivery of human and animal health services, provides another example of integration. The HRP NTD formative assessment Tool can help identify which One Health approaches are most likely to succeed within a given HRP, for all NTDs whose control and elimination require them. As one example, elimination of Trypanosoma gambiense (sleeping sickness) as a public health problem in Uganda resulted from the integrated interventions of the Ministry of Health, which treated human cases, and the Ministry of Agriculture, Animal Industries and Fisheries, which controlled Tsetse flies in the West Nile sub-region.

Supporting cross-border collaboration

Many NTD HRPs are highly mobile, regularly crossing national, state or provincial borders. Others inhabit refugee camps as immigrants or live in or near borders, with frequent international movement. Many NTDs show symptoms only after many months or even years have elapsed since infection, so movement needs to be considered on a long time scale. Vectors as well as humans cross borders; the black fly responsible for transmitting onchocerciasis can fly up to 35 kilometers. Cross-border synchronization of interventions like MDA and vector control can help ensure greater impact.

Adequately addressing NTDs in refugee, migrant and cross-border dwelling populations may require cross-border, binational, or multinational initiatives, but collaboration between sovereign nations is a complex political, administrative, and logistical undertaking. It is important to identify the potential need for cross-border engagement early, and, where possible, to engage neighboring countries in planning and conducting the HRP NTD formative assessment. This should be

preceded by a mapping of border areas to define endemnicities or shared cross-border transmission zones.

Informing Microplanning

Effective microplanning, or local, "bottom-up" planning for public health interventions, ensures that NTD programs plan for and reach all beneficiaries. Microplanning processes should be community-centered and include information on HRPs, so that no one is left behind. The HRP NTD formative assessment tool will provide insights relevant to these plans, which spell out the "what, when, where, and how" of delivery in detail. The WHO Microplanning Manual is an important resource for planning NTD preventive chemotherapy.[7]

Promoting Gender Equity and Social Inclusion (GESI)

Research and field experience show that gender and social norms shape exposure and vulnerability to NTD infection as well as access to, acceptance of and uptake of NTD services. To achieve gender equitable NTD programming, national programs must identify and address the unique abilities, barriers, and needs of women, men, boys, and girls so that they have the same rights to NTD services and opportunities. For effective social inclusion, programs must identify disadvantaged individuals or groups and cover them with NTD prevention and treatment services. An HRP NTD formative assessment offers an excellent opportunity to identify entry points for GESI, and GESI factors must be considered throughout the process.

6. Related NTD Tools

Several other tools and guides can be used in conjunction with the **NTD HRP Formative Assessment Tool** to meet the needs of particular programmatic settings or groups.

The NTD NGO Network's **Resource Guide for Conflict and Humanitarian Emergencies** can assist organizations working in conflict settings. It includes a **Heightened Risk Identification Tool User Guide** developed by the United Nations High Commissioner for Refugees, which helps NGOs establish a risk rating of different groups, and could be adapted for as an accompaniment to the NTD HRP formative assessment.

A Guide to Improving MDA Using Qualitative Methods was developed by RTI to help NTD programs conduct a rapid qualitative assessment to improve coverage and increase impact of NTD MDA campaigns, but is only relevant for the PC-NTDs.

The NTD NGO Network also developed **WASH and Health Working Together: A 'How-To' Guide for Neglected Tropical Disease Programmes**, in collaboration with WHO. This is a more general guide for NTD program managers on building partnerships, mobilizing resources, and designing, implementing, and evaluating interventions based on program experience.

WI-HER has created **iDARE** (Identify, Design, Apply/Assess, Record, Expand), a five-step, results-based methodology that incorporates behavior change theory, human-centered design, and gender, equity, youth, and social inclusion to solve problems and improve quality. The methodology can be applied to any sector or program, and has been used successfully to improve health outcomes, including increasing coverage of school-and community-based MDA for NTDs. Specific to NTDs, iDARE has been used to strengthen the capacity of national, subnational and community stakeholders to devise, test, and monitor locally driven solutions to address challenges to NTD goals and outcomes. iDARE can be used in conjunction with the NTD HRP Formative Assessment Tool to help identify barriers to access, acceptance, and uptake of NTD interventions and inform agile and adaptable solutions to improve NTD program operations.

A WHO/PAHO Toolkit to address "never treatment" during MDA campaigns for PC-NTDs was developed together with the iCHORDS (Connecting Social and Behavioural Science Research to Combat NTDs) community of practice in 2024. The toolkit guides programs and partners through the identification of never

treatment levels using programmatic assessment tools and then guides users on when and how to address the problem, as well as how to communicate findings to stakeholders. It provides validated approaches to address never treatment and case studies from successful programs.

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