NTD HRP

A NEGLECTED TROPICAL DISEASE HIGH-RISK POPULATION FORMATIVE ASSESSMENT TOOL

Implementation Guide

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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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BCT
Behavior change team

CM–NTD
Case management neglected tropical disease

CMD
Community medicine distributor

FGD
Focus group discussion

GESI
Gender equity and social inclusion

HRP
High-risk population

KII
Key informant interview

MDA
Mass drug administration

NGO
Non-governmental organization

NTD
Neglected tropical disease

NS
Nodding syndrome

PC–NTD
Preventive chemotherapy neglected tropical disease

STH
Soil-transmitted helminthiasis

VHT
Village health team

WASH
Water, sanitation, and hygiene

A

OVERVIEW OF THE NTD FORMATIVE ASSESSMENT TOOL

The Neglected Tropical Disease High-Risk Population Formative Assessment Tool (NTD HRP Formative Assessment Tool) provides step-by-step instructions for implementation of a formative assessment, the goal of which is to gather, update, review, and synthesize current knowledge of neglected tropical disease (NTD) high-risk populations (HRPs), including disease transmission patterns and gaps in intervention coverage. Results of the formative assessment can directly inform targeted and tailored intervention strategies for NTD control and elimination. Formative assessment findings should be used to guide programmatic decision-making and accelerate progress toward the 2030 disease elimination and eradication goals laid out in WHO's NTD Roadmap.

The **NTD HRP Formative Assessment Tool** consists of an operational guide to help NTD programs and their partners design, implement, and interpret the formative assessment activities. In addition to a thorough planning phase, the formative assessment includes four components:

1. Review, collation, and analysis of existing evidence on HRPs for priority NTD(s).

2. Qualitative data collection to assess risk behaviors, perceptions, awareness and characteristics; existing interventions and community engagement activities; access to, acceptance, and uptake of NTD interventions; and operational information relevant for strategic planning.

3. Mapping of potential venues and access points for NTD HRPs that will help to optimize coverage and impact of interventions.

4. A framework for integrating the results from the above components to inform programmatic action and next steps.

The availability of data and programmatic knowledge of transmission dynamics will facilitate formative assessment implementation and strengthen findings and next steps. While formative assessments can be used to answer key programmatic questions in a range of NTD settings and contexts, the **NTD HRP Formative Assessment Tool** will likely be most useful for diseases close to elimination. NTD programs must have robust systems in place for data collection, analysis, and reporting to meet the stringent surveillance requirements for achieving and maintaining elimination.

Depending on programmatic priorities, the **NTD HRP Formative Assessment Tool** can be applied to NTDs controlled through preventive chemotherapy (PC-NTDs) or those requiring individual case management (CM-NTDs). Because the epidemiology, transmission routes, most-affected populations, and treatment and prevention strategies are highly variable across NTDs, illustrative examples for specific diseases are included throughout. Sample protocols, forms, and thematic guides for data collection are also provided, all of which can be adapted to suit specific diseases and local contexts.

The **NTD HRP Formative Assessment Tool** has a flexible structure and each of its components can be scaled up or down or skipped if they are not relevant for a particular setting or programmatic objective. NTD programs can implement the **NTD HRP Formative Assessment Tool** with a disease-specific approach, identifying and targeting one or more HRPs most at risk for a particular priority NTD, or they can implement with an HRP-specific approach, identifying and targeting the NTD co-endemicities that impact a particular population of interest.

Who are NTD HRPs?

HRPs are groups of people who share socio-demographic, geographic and/or behavioral characteristics that place them at higher risk of NTDs or make them hard to reach with interventions for prevention and treatment **(Figure 1)**. These shared characteristics tend to create similar access issues for a number of NTDs, and most HRPs are at risk for more than one NTD. The 12 diseases targeted for elimination and eradication are listed in **Table 1**.

FIGURE 1 Defining NTD HRPs

Groups with limited access to NTD health services and interventions due to physical/geographical, social, political, and/or economic factors. These groups are sometimes referred to as "hard to reach" because of accessibility challenges.

Groups with behaviors and/or in locations most associated with NTD risk, such as proximity to disease-transmitting vectors, inadequate access to clean water, or close contact with animals.

Groups with occupations that put them at higher risk and/or limit their accessibility, such as fisherfolk or nomadic pastoralists.

Who should conduct the formative assessment?

Formative assessments are typically conducted by national and subnational NTD program staff and their implementing partners from non-governmental organizations (NGOs), local civil society organizations, and academic research institutions. The NTD program manager and monitoring and evaluation officer are most familiar with the context and epidemiology of the priority NTD(s) in the country and are best placed to provide oversight and lead the collaboration with their subnational counterparts and implementing partners to plan for and conduct all phases of the assessment.

When should the formative assessment be conducted?

Formative assessments are critical at the early stages of program planning. Completing formative assessments 6 months prior to deploying interventions for suspected or known HRPs will allow for incorporation of formative assessment findings into future activities. For example, in mass drug administration (MDA) implementation, results of the formative assessment can assist the NTD program in scheduling an MDA cycle during seasons when certain HRP groups are more consistently accessible and available. Ideally, formative assessment results will be applied after the overall program objectives have been determined and before extensive program planning has been completed, guiding NTD programs in aligning or establishing new approaches to meet their annual goals.

Conducting the formative assessment may require 3-6 months if all components are thoroughly implemented, particularly if multiple NTDs and/or HRPs are being targeted. However, programs may shorten the implementation period, narrow their focus, and/or choose to implement a subset of the components based on available resources, existing evidence, and programmatic needs and objectives. Formative assessments may be conducted as frequently as desired based on the NTD program's available resources and goals (e.g., regular implementation to assess ongoing program progress and impact, limited implementation only when pivoting from one programmatic approach to another).

TABLE 1

NTDs targeted for elimination or eradication

Targeted for elimination as a public health problem

Chagas disease (American trypanosomiasis)
Human African trypanosomiasis (rhodesiense)
Leishmaniasis (visceral)
Lymphatic filariasis (elephantiasis)
Rabies
Schistosomiasis (bilharzia)
Soil-transmitted helminthiases
Trachoma

Targeted for elimination (interruption of transmission)

Human African trypanosomiasis (gambiense)
Leprosy (Hansen's disease)
Onchocerciasis (river blindness)

Targeted for eradication

Dracunculiasis (Guinea worm disease)
Yaws

B

REFINING THE OBJECTIVES OF THE FORMATIVE ASSESSMENT

Formative assessment activities are implemented in four phases preceded by vital preparation activities **(Figure 2).**

The overall objective of the formative assessment is to generate data that informs effective planning and implementation of prevention, treatment, management, and surveillance strategies for NTD HRPs. The scope of the formative assessment will depend on available resources, programmatic priorities, and the extent to which HRPs are already known for the priority NTD(s), all of which should be considered when refining objectives.

This section provides examples of objectives for the four components of the formative assessment that can be achieved during implementation. Specific component objectives should be adapted to the priority NTD(s) and the local context by the national NTD program and its implementing partners.

Component objectives

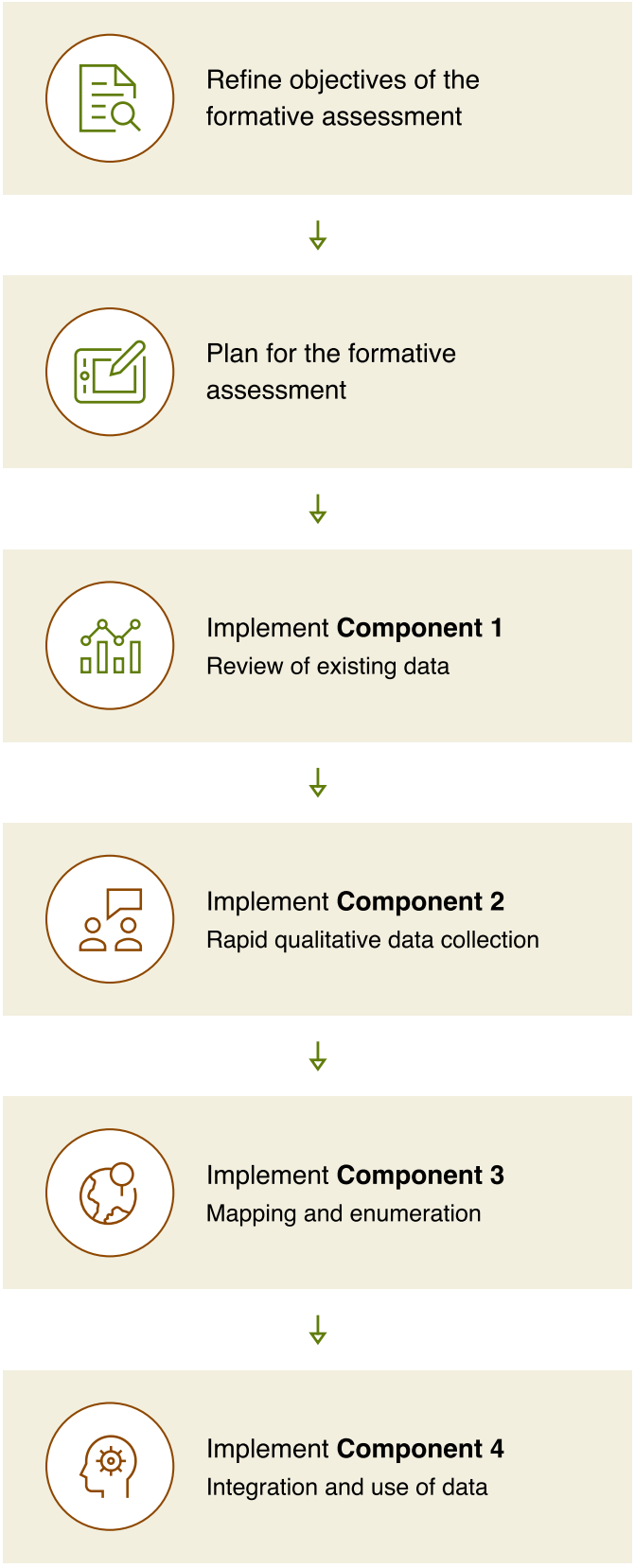
Component 1: Review of existing data

The aim of Component 1 is to define patterns of risk (in terms of person and population characteristics, time, and place) and intervention coverage for the priority NTD(s).

Specific objectives of Component 1 include:

- To identify and describe groups of people perceived or known to be at higher risk of NTDs.
- To describe and quantify the NTD burden in HRPs.
- To identify and describe gaps in access to NTD interventions, health services, surveillance and monitoring among HRPs.
- To review contextual information relevant to known or suspected NTD HRPs to better understand their exposures and risk factors, awareness and perceptions of risk, access to health care, and behavioral influences.

FIGURE 2 **Key phases of the NTD HRP formative assessment**



Component 2: Rapid qualitative data collection

The aim of Component 2 is to use qualitative research methods for rapid collection of data to inform the selection, design, and delivery strategies tailored to specific needs of HRPs for the priority NTD(s). Findings from Component 1 may be used to adjust the focus of qualitative data collection and further inform Component 2 objectives.

Specific objectives of Component 2 include:

- To identify HRPs and describe their NTD burden, intervention coverage, and organizational systems.
- To capture the unique perspectives and experiences of HRPs and community stakeholders in relation to risk factors and exposures, awareness, acceptance, access, and uptake of NTD interventions.
- To design intervention packages and delivery platforms based on NTD exposure and the factors influencing acceptability, preferences, and cultural norms of HRPs.
- To improve outreach and communication strategies to HRPs.
- To provide detailed information for national and subnational NTD program planning, targeted strategy selection, surveillance and monitoring, and operations.

Component 3: Mapping and enumeration

The aim of Component 3 is to identify and map venues and transit points where HRPs for the priority NTD(s) are most likely to be found and accessed, building on information derived in Component 2.

Specific objectives of Component 3 include:

- To develop a list of all possible venues and transit points where NTD HRPs may be accessed.
- To determine days and times when NTD HRPs are likely to be present at each location in sufficient numbers for delivery of interventions.
- To provide actionable information on where and when to target interventions for NTD HRPs.

Component 4: Integration and use of data

The aim of Component 4 is to synthesize the results from the previous components to inform programmatic action and next steps.

Specific objectives of Component 4 include:

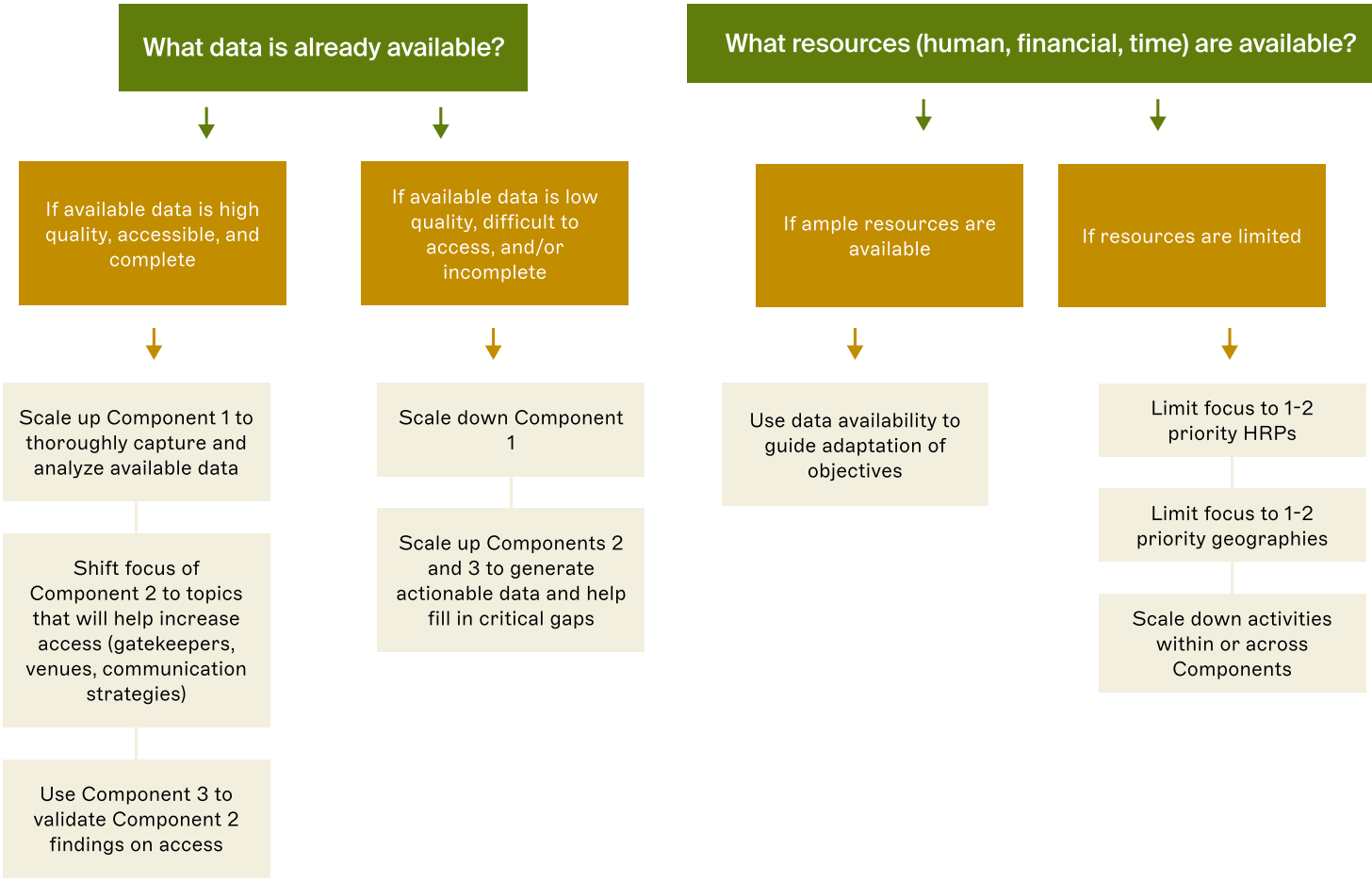
- To collate and integrate results from all formative assessment activities.
- To share findings and recommendations from the formative assessment with HRP members, community members, stakeholders, and national (and where appropriate, regional) policy makers to achieve consensus.
- To inform programmatic strategy selection, decision-making, advocacy, and resource mobilization.

Adapting component objectives

The national NTD program and its partners should adapt the specific objectives of the four components to suit the priority NTD(s) and the local context and ensure that they are relevant, useful, and realistic for meeting program needs. **Figure 3** illustrates considerations for adapting component objectives.

FIGURE 3

Considerations for adapting component objectives



C

PLANNING FOR THE FORMATIVE ASSESSMENT

Assemble the technical team

The national or, if applicable, subnational NTD program should lead the technical and operational aspects of the formative assessment. Additionally, a stakeholder mapping exercise should be conducted to identify potential and known partners with the necessary experience and expertise to join the formative assessment technical team.

The team should be made up of national and subnational NTD program staff and relevant partners at national, subnational, regional/cross-border, and international levels. Involvement of team members with expertise in social sciences, community engagement and community-centered design, gender equity and social inclusion (GESI), sustainability, capacity strengthening, and skills transfer is recommended, if possible. Experience with NTDs and/or HRPs is desirable but not essential for every partner.

Expertise may be sought from other programs within the health sector (e.g., vector-borne disease, water, sanitation and hygiene [WASH], One Health), other government sectors (e.g., agriculture, environment, veterinary, education, immigration), academia, private sector organizations, NGOs, and other national NTD programs (**Box 1**).

Engage and sensitize stakeholders

Stakeholder engagement and advocacy is essential for obtaining support from leadership at all levels and should start as early as possible. Stakeholder engagement is especially important for effective formative assessment planning due to the unique sociodemographic and behavioral characteristics of HRPs. The national NTD program should identify all relevant stakeholders and hold consultative planning meetings to build consensus on objectives, methods, logistics, and funding of the formative assessment, as well as community entry approaches within HRPs. Stakeholder engagement should be continued throughout the formative assessment to foster collaboration, trust, local ownership, accountability, and acceptance of the results.

Stakeholders will be unique to each context but may include heads of state and central government representatives, regional and district health authorities, regional and district NTD staff, community and village leaders and representatives, local employers of HRPs, and relevant NGOs or partner organizations active in selected areas.

Identify resources

Building on the partner mapping and engagement with relevant stakeholders, the national NTD program should prepare a budget and mobilize resources to conduct the formative assessment. Partners may contribute financially, in kind, or provide technical expertise. Potential funding sources may include research grants, financing from international and local NGOs, and domestic resources. Example budget items are shown in **Figure 4**.

BOX 1

Co-planning with neighboring country NTD programs

Some NTD HRPs are highly mobile and migratory, crossing national and subnational borders regularly, and may be living in refugee camps or as internally displaced people along border areas. Cross-border synchronization of interventions can increase impact in border communities and help prevent reinfection from neighboring areas once NTD elimination is achieved. It is therefore important to identify the potential need for cross-border engagement early in the planning process and to include the NTD program staff and implementing partners in both countries in planning and conducting formative assessment activities.

FIGURE 4 **Example formative assessment budget items**

Develop the workplan

Adequate planning is important to ensure achievement of objectives. The national NTD program should develop a detailed work plan to include recruitment, training, development of tools, procurement, logistics, travel and supervision. A sample workplan template is available for download.

Obtain approvals

Qualitative data collection involves engagement with human subjects and is often considered to be research. However, when conducted as a programmatic activity, the formative assessment may not require ethical review. This should be determined by the national NTD program where the formative assessment is being implemented, as well as any partner organizations with institutional review boards that are directly involved in implementation. At a minimum, informed consent is required from all individuals participating in the focus group discussions (FGDs) and key informant interviews (KIIs) to ensure their rights are respected and protected (see Component 2 and **Appendix 7**). Regardless of whether ethical approval from a review board is required, letters of approval from the relevant authorities at the national and subnational levels should be obtained.

D

CONDUCTING THE FORMATIVE ASSESSMENT

Component 1: Review of Existing Data

This section provides guidance and procedures for reviewing existing data, as well as adaptable templates for collating and organizing data. **Box 2** includes a list of key data that can be used to identify HRP characteristics, risk factors, and behaviors; select optimal methods for delivering interventions or conducting surveillance activities; identify potential cultural or structural barriers and select gatekeepers or alternative delivery approaches to overcome them; and improve outreach and engagement and encourage intervention acceptance and uptake among HRPs.

Identify key data sources and documents for review

The national NTD program should hold meetings with its partners and stakeholders to identify key data sources for the formative assessment (**Figure 5**). **Box 3** lists several questions to aid in assessing available surveillance data.

Any necessary requests to other departments or organizations for data and documentation should be made as early as possible to ensure time for approvals and obtainment.

Adapt data entry templates

Excel data entry templates for document and data review are available for download. The templates should be adapted to match the lowest level of analysis and key NTD program indicators on demographics, residence, employment, risk factors, and relevant clinical data on diagnosis and treatment, if applicable. Any variables missing from routine NTD surveillance and reporting systems should be noted.

Desk review

Following the planning meetings with the national NTD program, a desk review should be carried out that includes digital or hard copies ofall potentially relevant reports, publications, and grey literature containing the key data listed in **Box 2**.

BOX 2

Key data for planning and decision-making

- Sociodemographic, socioeconomic, and sociocultural characteristics of populations at high risk of the priority NTD(s) (e.g., age, sex, economic status, occupation).
- Known risk factors and behaviors of populations at high risk of the priority NTD(s) (e.g., migration patterns, animal contact, proximity to vector habitat, hygiene practices and access to water for washing, environmental surroundings, conflict settings, cultural and gender norms).
- Gaps in existing data collection systems and intervention coverage (i.e., how much do we know about who has been missed and why?).
- Perceptions, awareness, and uptake of NTD prevention, treatment, and/or case management.
- Barriers restricting access to NTD prevention, treatment, and/or case management measures.
- GESI-related policies and procedures impacting risk, perceptions, awareness, uptake, and/or access.
- Organizing systems that may influence HRP risk behavior and accessibility (e.g., refugee camps, schools, military barracks).
- Existing organizations working with HRPs.
- Information on security issues and other operational factors related to HRPs.
- Locations where HRPs can be reached, mode of delivery of interventions, and estimation of population size.

BOX 3

Assessing available surveillance data

How granular is the available data - is it reported individually or aggregated per administrative/evaluative unit?

If individual data are available for the intervention, are similar data available for people who did not participate, to facilitate a comparison between the two groups?

If individual case data are not available, is a registry review at health facilities or from recent interventions (e.g., surgical procedures) appropriate and/or feasible?

Are any additional data (e.g., place of residence, lifetime travel history, occupation, reason for non-participation) available through implementation surveys or at health facilities that are not reported up to higher levels?

What other data (e.g. intervention coverage) are routinely reported and at what level?

What type of active surveillance is conducted (e.g., population-based prevalence surveys, vector mapping)?

Procedure:

1. Obtain copies of reports, publications, and grey literature identified through meetings with the national NTD program and partners. NTD program staff may need to facilitate communication with other government ministries and external organizations to formally request data and documentation, provide background and context for the formative assessment, and explain how the data will be used.

2. Carry out a literature review using a search engine such as PubMed.

3. Read the relevant publications and documents found.

4. Extract data and enter into the “Desk Review” Excel template to generate a categorized summary of key findings across all referenced sources.

Passive surveillance data review

This section is applicable for CM-NTDs and should cover a 5-year period, if possible.

Procedure:

1. Gather health data extracted from HMIS, DHIS2, and other centralized data reporting systems, as well as copies of registers from community health workers

FIGURE 5 **Example data sources**

and health facilities where appropriate.

2. Enter data into each sheet of the "Passive Surveillance Data" Excel template.
3. Data entry should be as complete and at as granular a level as possible (e.g., individual-level, facility-level, village-level, district-level). Passive surveillance indicators are shown in **Table 2.** These are based on individual-level data, mainly for PC-NTDs, but they can be adapted if available data are not this granular.
4. Once data entry is complete, use the pre-formatted pivot tables on 'Sheet 3: Analysis' to summarize characteristics of positive NTD cases and negative cases (i.e., non-cases, if available) by age, sex, location, and time.

Active surveillance data review

This review should collate data collected over the past 5 years, if possible, through any active surveillance activities, including mass screening campaigns (i.e., population-based prevalence surveys), MDA campaigns, mobile outreaches, active case investigations, and/or evaluation surveys, as well as data captured in individual patient tracker apps (e.g., Hydrocele Tracker, TT Tracker, Skin NTDs). More detailed data (e.g., household demographics or residence history,) are sometimes collected during these activities and may be useful for profiling NTD cases. Active surveillance data are usually available at the individual and community levels.

Although there is no straightforward comparison group to quantify risk factors, active surveillance data can still provide information on positive NTD case characteristics and indicate suspected HRPs.

Procedure:

1. Gather data from all active surveillance activities and NTD patient tracker apps, where appropriate and available.
2. Enter data into each sheet of the "Active Surveillance Data" Excel template. Active surveillance indicators are shown in **Table 3**.
3. Once data entry is complete, use the pre-formatted

TABLE 2

Passive surveillance indicators

Age
Sex
District of residence
Population of district of residence
Sub-district of residence
Village of residence
Residence address
Nationality
Sub-district of residence
Occupation
History of travel in endemic areas (locations, dates)
History of residence in endemic areas (locations by month and year)
Prevention methods used
Date of diagnosis (MM/DD)
Year of diagnosis (YYYY)
Health facility where examined
Symptoms (in last 30 days / 6 months / 1-2 years)
Tested for NTD (where appropriate, and tests exist)
Confirmed NTD case
Clinical diagnosis, diagnostic test, symptoms + residence/travel history
District where diagnosed
Referred to higher level facility for care
Received treatment
Treated according to national policy
Health facility where treated
District where treated
Death

pivot tables on 'Sheet 5: Analysis' to summarize characteristics of NTD cases and non-cases (if available) for each type of active surveillance activity. For PC-NTDs, summarize characteristics for successfully MDA-treated cases and untreated cases.

TABLE 3

Active surveillance indicators

Type of surveillance
Type of population
Size of population
Type of site
people screened per reporting period
screened people tested per reporting period
cases detected per reporting period
treatment rounds

Conduct the analysis

Surveillance data should be analyzed by person, place, and time to identify spatial and temporal patterns of NTD infection.

Person

Analysis by person involves generating NTD case, treatment, or prevention profiles according to sociodemographic characteristics (e.g., age, sex, residence, occupation), residential history, and risk or access factors. Analysis can be done using pivot tables in the Excel templates provided with the **NTD HRP Formative Assessment Tool**, or with public-domain statistical software tools. The proportion of cases with specific sociodemographic characteristics can be compared to aggregate census data to identify whether these characteristics are likely risk factors.

Place

Case numbers and prevalence rates should be calculated for the smallest geographical area for which there is reliable population data (e.g., village, health facility catchment area). If capacity exists, geographical maps of prevalence rates can be generated and used to visually identify hotspots of disease burden and statistically evaluate correlates such as population density or proximity to sources of infection.

Time

Temporal analysis involves profiling NTD case numbers and prevalence across time (seasonally). If multiple years of data are available, base rate changes between years can be calculated to document seasonal patterns and infection trends over time.

Component 2: Rapid Qualitative Data Collection

This section provides step-by-step descriptions of how to implement rapid qualitative data collection methods to inform selection of NTD HRP interventions and surveillance and monitoring activities.

Engage with the target HRP, community members, and other stakeholders

The success of the qualitative data collection and, in a broader sense, the overall formative assessment of NTD HRPs will depend largely on community and stakeholder awareness and understanding of the project. Meetings jointly hosted by the national NTD program, national and subnational government officials, and the formative assessment team members should be held in the early

planning stages of the formative assessment and just prior to the start of data collection, and should include local health workers, village elders, religious leaders, school administrative staff, representatives of community-based organizations, and other key figures in the community. The formative assessment team should also meet with other organizations with knowledge and experience with the priority NTD(s), and organizations that have established relationships and work closely with target HRPs.

The endorsement of formative assessment qualitative data collection by community leaders should be secured before fieldwork begins. When respectfully and intentionally engaged, community leaders can be helpful resources, providing valuable insight on research questions that are most meaningful for HRP communities, facilitating access, and identifying initial participants and venues for FGDs and KIIs. The formative assessment team is responsible for clearly explaining the purpose of the qualitative data collection, data collection methods, selection of participants, and how the findings will be used. The team should also communicate the code of conduct and explain how the community can raise concerns regarding violations of this code. Any problems or concerns raised by community members must be promptly addressed and they should be encouraged to contact study teams directly to ask questions and discuss issues, particularly those they may not feel comfortable entrusting with community leaders.

Consistent and open communication and engagement with the community is critical, particularly when targeting populations with special considerations, such as illegal migrants or internally displaced persons and refugees. Data collection procedures should be adapted as necessary when working with these groups to ensure their privacy and protection. Only data that is necessary for specific research aims should be collected, and all data must be de-identified and stored safely.

Once endorsement from the community and its leaders is obtained, meetings should be held with HRP members to explain the formative assessment objectives and qualitative data collection procedures, describe the ways in which the findings will benefit the community, and solicit input on key research questions. Marketing materials such as flyers and posters can promote awareness of the assessment. These materials must be tested in advance to ensure they are respectful, culturally appropriate, and effective among the selected HRPs.

The formative assessment team should maintain close coordination and communication with community leaders and other stakeholders from both the target HRPs and the general population throughout the data collection process to foster continued awareness, support, and engagement. Planning feedback sessions with the broader community once data are analyzed is important to help identify any problems with the findings, increase participation in and support for future interventions, and strengthen the quality of the assessment.

Determine research questions

The formative assessment team should interact with the community, HRPs, and other stakeholders to collaboratively formulate key research questions that will be answered with the information derived from qualitative data collection. The formative assessment team is responsible for documenting community input, finalizing the list of research questions and ensuring they are aligned with overall formative assessment objectives, and securing approval from all stakeholders. Note that ‘research questions’ is a general term that refers to the questions the formative assessment is designed to answer, whether it is conducted as a formal research study or as a programmatic investigation.

Research questions may focus on the interaction of HRPs and potential exposure to NTD risk, or they may be designed to address traditional roles and responsibilities, gender and cultural norms, or social and political structures that guide decision-making of HRPs on whether, when, and how they access health services or NTD interventions. Prior knowledge and experiences from previous research studies, programmatic investigations, or information drawn from global-level guidance documents can be used to refine the qualitative data research questions.

ILLUSTRATIVE EXAMPLE 1

Using programmatic data to tailor interventions targeting soil-transmitted helminthiasis HRPs in Uganda

A WHO NTD Roadmap goal is to achieve elimination of soil-transmitted helminthiasis (STH) as a public health problem in children aged 1–14 years by 2030. STH is considered a public health problem when prevalence is >1%. Baseline surveys conducted in Uganda during the late 1990s and early 2000s revealed STH infection prevalence of >50% among surveyed schoolchildren. A national program of integrated MDA and health education was launched in 2003 among children aged 1–14 years, but after two decades of preventive chemotherapy, little evidence was available to show the impact of this effort. Today, despite ongoing control efforts, high prevalence of STH persists due to limited diagnostic capacity and low community awareness of how and where to access treatment and prevention services.

In 2022, in collaboration with Children Without Worms, the Uganda Vector Borne and Neglected Tropical Disease Division conducted population-based, cross-sectional household surveys in five districts to estimate the prevalence and intensity of STH. The surveys revealed high prevalence of STH among 3,000 pre-school-aged and school-aged children screened, and lack of safe water and poor sanitation were identified as key risk factors.

In response, the Uganda NTD program designed a tailored MDA implementation strategy. In two districts where prevalence was found to be >50%, the program transitioned from one round to three rounds of MDA to reduce infection intensity. In the three districts where prevalence was 10-49.9%, the program changed the treatment cycle from twice to once a year. The Uganda NTD program is also planning long-term WASH improvements and Mass Health Education in the five districts to improve sanitation and reduce exposure to unsafe water. The comprehensive surveys filled in critical surveillance gaps and allowed the program to move away from universal MDA in favor of data-driven distribution to those at highest risk, informed by strengthened monitoring and evaluation.

Adapt thematic guides

After identifying the key research questions for qualitative data collection, the next step is to develop the core themes and topic areas that will guide the development of interview and discussion questions. **Appendix 1** provides a framework for choosing themes and topics for qualitative data collection. Themes can be added or removed according to the priority research questions and availability of existing knowledge or data.

Appendix 2 provides a sample for the next step – adaptation of the thematic guides (i.e., discussion/interview guides) for FGDs and KIIs. When formulating the discussion and interview questions, it is important to take into account the sociocultural background of participants to ensure the guides are appropriate. The team should also consider how participant responses to the questions will directly inform intervention selection and delivery strategies for HRPs.

Adapt notetaker template

A standardized Notetaker Template should be adapted alongside the thematic guides (**Appendix 3**). The template will be used during FGDs and KIIs to take structured field notes for analysis.

Translate thematic guides

The adapted thematic guides should be translated into the preferred local language of the respondents. Translated

guides should then be back-translated into the original language to check if the meaning of each question was captured correctly. Any deviations from the original meaning should be corrected and the translation rechecked to confirm accuracy.

Pre-test thematic guides

Thematic guides should be pre-tested with 3-6 individuals selected from the target HRPs. Individuals who participate in the pre-test should not be included in final data collection. All pre-testing should be carried out in the language that will be used in the interviews.

Each thematic guide should be pre-tested separately to determine how well the questions are understood by the Moderator and participants and whether they are appropriate for the sociocultural context, identify redundant questions and questions that lead to multiple interpretations, determine additional questions for inclusion, and determine the time necessary to conduct each interview.

Following the pre-test, the wording of the questions should be improved, redundant questions removed, and any new questions added.

Develop data collection timeline

The timing of data collection is crucial, and the formative assessment team must take into consideration a number of factors, such as:

- When the findings are needed by the national NTD program(s), partner organizations, and/or the community to guide the planning of new interventions or the adaptation of existing ones (e.g., community mobilization activities, training of health workers, MDA campaigns).
- Events impacting the availability of participants (e.g., holidays, cultural events, elections, seasonal occupation, travel patterns).
- Number of days needed to train field teams.
- Number of FGDs and KIIs required, noting that 1-2 sessions can typically be planned per day for each team depending on participant availability.
- Number of days required to transcribe and analyze the data and complete a report.

Recruit and train field teams

Qualitative data collection is conducted by field teams made up of a Field Coordinator, Moderator(s), and Notetaker(s). The number and size of the field teams depends on available human and financial resources, data collection scope, and timeline. Male and female team members should be fairly balanced and some must be fluent in the local dialect. Field teams should be trained by experts in qualitative assessment or research methods. Trainings are typically 3-5 days and should focus on building skills in basic NTD knowledge, qualitative data collection procedures, ethical considerations, and include practice with the interview guides, forms, and audio recording equipment. **Figure 6** shows a summary of training objectives and considerations for field team members.

Field team members may need to undergo additional training, such as Good Clinical Practice, to comply with local ethical board requirements.

All field team members must adhere to ethical principles and standards while collecting data. Most importantly, they must respect and protect the privacy, confidentiality, and autonomy of participants. It is essential to identify and address with field team members any stereotypes or assumptions related to HRPs and/or GESI-related factors to ensure that these do not bias data collection and interpretation of results. Field team members must always conduct themselves in a professional manner when interacting with participants, fellow staff members, and the general public and demonstrate an understanding and respect of local customs and cultural norms. **Figure 7** describes the responsibilities of each field team member.

Implement focus group discussions

FGDs bring together a defined group of participants to investigate opinions, beliefs, or behaviors in an interactive setting. Several steps should be taken to adequately prepare for FGDs.

FIGURE 6 Training objectives for field teams

	Demonstrate	Improve	Practice
 MODERATOR	• Understanding of priority NTD(s) • Understanding of data collection ethics and processes • Understanding of qualitative data collection objectives • Literacy and fluency in local language, or ease in working with simultaneous translation	• Skills in facilitation of FGDs and KIIs • Ability to develop rapport with participants, understand group dynamics, and encourage active discussion • Data collection tools and forms through review and revision	• Listening, probing, and asking follow-up questions • Timing and pacing of discussions • Using tactics to keep discussions focused and oriented toward meeting objectives
 NOTETAKER	• Understanding and familiarity with NTD terminology • Understanding of data collection ethics and processes • Understanding of qualitative data objectives • Understanding of unbiased note-taking without interpretation	• Skills in identifying body language and non-verbal cues of participants • Ability to take thorough, detailed notes at a rapid pace	• Establishing procedures and processes for accurate note-taking, translation, and transcription • Using audio recorder and taking notes during role play discussions

Identify participants

Each FGD should comprise 6-12 participants with similar sociodemographic characteristics to promote participant comfort and encourage free sharing of ideas and perceptions during discussions. The sample size/number of FGDs per HRP to reach saturation will be determined by the formative assessment team based on local context and resources. FGDs should be held with males and females of the target HRP, as well as community health workers, community leaders, and employers of target HRPs if a sufficient number of participants per subgroup are available. Stratifying subgroups by age may be useful.

FGD participants can be selected opportunistically using snowball sampling or at gathering points. Methods for selection will depend on the specific subgroup of interest. Potential participants should be screened for eligibility upon first contact, after they agree to participate, to ensure that all individuals invited to participate in the FGD are members of the target group. **Appendix 6** contains procedures and a sample script for recruiting FGD participants.

Select a venue

The Field Coordinator should arrange for a venue to use for the FGDs in advance. The venue should be easily accessible to the participants, allow for privacy, be quiet and free from distractions, and be comfortable and well-ventilated. Potential venues for FGDs include school classrooms, community centers, district headquarters, health facilities, or church halls. The venue should be communicated to participants during the initial recruitment conversation and a reminder should be sent a day before the scheduled FGD.

Select a date and time

FGDs typically last from 1 to 3 hours. The field team should have a list of possible dates for FGDs prepared in advance. Field team members should make phone calls or field visits to the eligible participants selected for the FGDs and determine their availability, then communicate the date, time, and venue of the FGD. A reminder should be sent a day before the scheduled FGD.

FIGURE 7 Field team member responsibilities

FIELD COORDINATOR

- Daily oversight of data collection activities
- Ensuring field team members are punctual and professional
- Managing expenses
- Ensuring availability of all data collection tools and materials
- Conducting daily debriefings
- Reviewing field notes and audio recordings for quality assurance
- Addressing challenges and identifying opportunities for improvement
- Supervising and monitoring the work of field teams
- Storing documents and audio files in a safe, secure location

NOTETAKER

- Ensuring enrollment forms are completed accurately
- Creating a seating chart for FGD participants
- Operating the audio recorder
- Taking thorough, detailed notes during FGDs and KIIs
- Developing a written summary of FGDs and KIIs, including main themes and findings as well as body language and group dynamics of participants
- Participating in daily debriefing meetings
- Transcribing/translating audio recordings

MODERATOR

- Facilitating FGDs and conducting KIIs to ensure participants are engaged and high-quality information is generated
- Ensuring informed consent is obtained for all participants
- Reimbursing participants for travel expenses
- Participating in daily debriefing meetings
- Participating in completion of debrief forms and transcription/translation of audio recordings, as needed
- Organizing documents and audio files in a safe, secure location before hand-off to the Field Coordinator

Coordinate transport

The field team should work with the Field Coordinator to make sure all participants have transport to and from the venue on the day of the FGD. Transport reimbursement should be available to participants who need it. Information about transport reimbursement should be clearly communicated to the participants at the time of recruitment and a reminder should be sent on the day of the scheduled FGD.

Prepare materials

In advance of the FGD, the field team should prepare the following:

- Focus Group Discussion Guide (**Appendix 2**)
- Notetaker Template (**Appendix 3**)
- FGD/KII Debrief Forms (**Appendix 4**)
- Informed Consent Forms (**Appendix 7**) with copies for each participant
- Focus Group Discussion Enrollment Form (**Appendix 8**)
- Reimbursement Log (**Appendix 9**)
- Audio recorder
- Markers and flip chart paper
- Preprinted map of the area (if necessary)

- Name badges
- Refreshments

Prepare for participant arrival

The field team should arrive at the venue 45-60 minutes before the start of the FGD to prepare the room, materials, and refreshments. When participants arrive, field team members should welcome them in a friendly manner but be careful to avoid any conversation related to the FGD topics. The Moderator should observe the participants prior to the start of the FGD to identify behaviors or dynamics that may impact the flow of discussion (e.g., any particularly quiet or talkative participants). The seating arrangement may be adjusted to manage these dynamics.

The Notetaker should complete the Focus Group Discussion Enrollment Form (**Appendix 8**) as participants arrive and ensure that each participant has a name badge. For confidentiality purposes, participants should not use their real names on their badges; instead, they should use pseudonyms (i.e., fake names) or numbers or letters. The Notetaker should then enter each participant into the seating chart according to their self-selected name/identification.

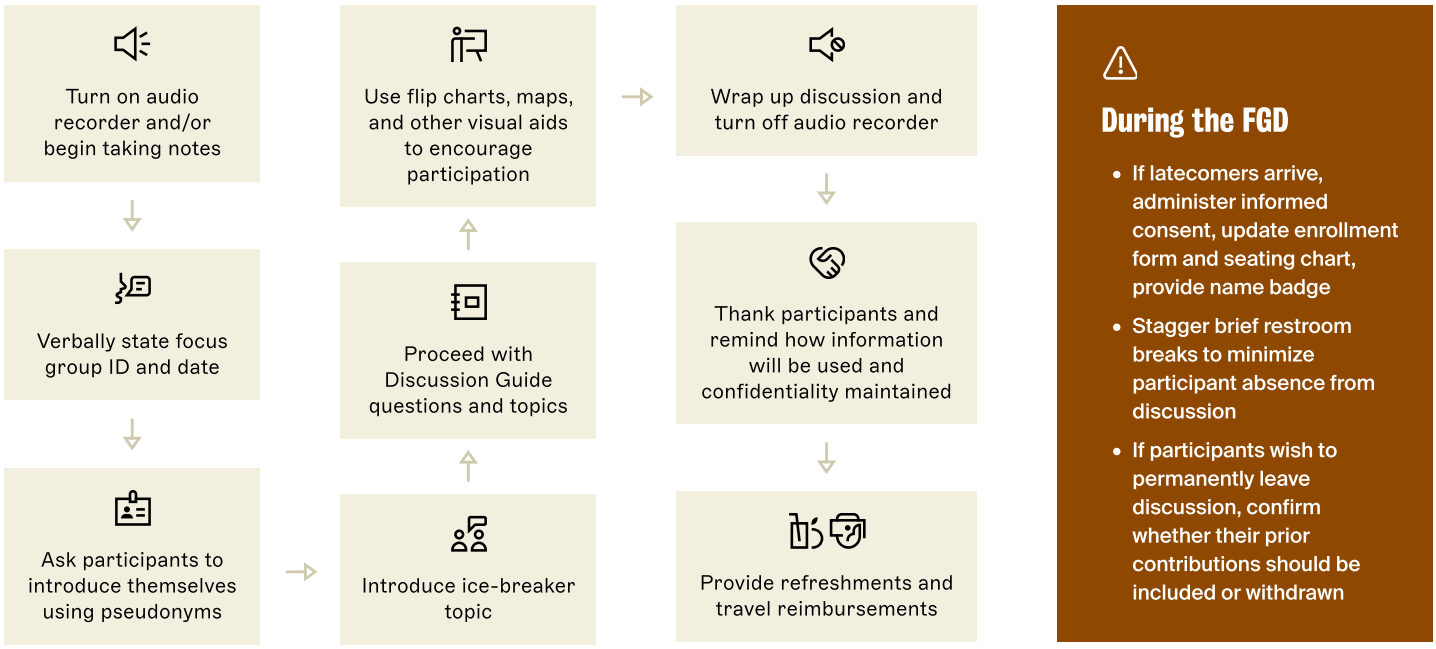
Introduce the FGD

The Moderator should provide a brief introduction of the discussion and its objectives. The Moderator should also inform the participants that the discussion will be audio recorded and explain how the recording will be used. If any participant does not want to be recorded, the Moderator should take them aside and ask whether they are still interested in participating in the FGD. If yes, the Moderator should inform the rest of the group that the discussion will not be recorded and that the Notetaker will take comprehensive notes instead, which may require more time.

The Moderator and participants should review and agree on ground rules (i.e., behavior expected for all participants) during the discussion. Examples of ground rules for FGDs include:

- One speaker at a time.
- There are no right or wrong answers.

FIGURE 8 **FGD procedures**



- Only use self-selected names/identifiers and not real names when referring to others.
- Do not share participant identities or the contents of the discussion with anyone else.

Administer informed consent

Most data collection through FGDs requires informed consent but it depends on the project and context and must be determined by the ethical review board(s) for all institutions involved in formative assessment implementation. If informed consent is required, each eligible individual invited to participate in the FGD must understand all of the procedures and how their responses will be used. Informed consent procedures are as follows:

- Explain the purpose of the FGD.
- Provide each participant with two copies of the informed consent form.
- Read the informed consent form aloud for all participants. Allow time for participants to review the form and ask questions or seek clarifications. If a participant cannot read, the Moderator should read out the form for them in the presence of a witness who will cosign the consent form.
- Answer any questions from the participants.
- Have the participants sign both copies of the informed consent form, consenting to participation in the FGD and to audio recording the discussion.
- Fill in the participant ID number and countersign both copies of the informed consent form. Return one copy to the participant and retain the second copy for study records.

Conduct the FGD

The Moderator plays a central role in directing the FGD. During the discussion, the Moderator must continually assess whether the information obtained is sufficient to answer the research questions and re-direct the conversation or follow up on contributions from participants accordingly. A well-trained Moderator should be able to recognize when a group is not communicating well and intervene as needed. **Figure 8** depicts detailed procedures to be followed during the FGD.

Implement key informant interviews

KIIs are semi-structured, one-on-one interviews with people deemed to be experts in a technical area or highly knowledgeable about the subject or HRP of interest. Key informants serve as behavioral and technical experts, offering insight into the target HRP's characteristics and behaviors that may increase NTD risk. Several steps should be taken when conducting KIIs.

Identify key informants

Key informants should include individuals important to and well-informed about HRPs in the proposed project area. They should be able to contribute to the formative assessment team's understanding of the HRPs, suggest how best to approach potential participants, and offer guidance on problems that field teams have and may encounter when implementing interventions targeting HRPs. A diverse group of key informants should be selected to meet the objectives of the formative assessment.

Examples of key informants include:

- Community leaders (e.g., elected leaders in local/provincial/state government, traditional/cultural leaders or village elders, religious leaders).
- Members of community subgroups not represented in FGDs, and/or those who would feel more comfortable in a one-on-one format (e.g., to provide insight on a disabling condition that may carry stigma within the community).
- Representatives of local organizations that have done outreach work with target HRPs.
- Community health workers, formal health workers, and other local service providers.
- Researchers familiar with target HRPs through previous studies.

ILLUSTRATIVE EXAMPLE 2

A formative assessment among onchocerciasis HRPs in the Madi Mid-North Focus of Uganda

Uganda launched an onchocerciasis elimination strategy in 2007 in 48 endemic districts based on two key interventions, semi-annual MDA with ivermectin and blackfly vector control/elimination through larviciding. As of 2024, elimination has been achieved in 36 districts and interventions continue in only 12 districts. MDA with ivermectin serves as both a preventive and curative measure; to achieve elimination, endemic communities need to take ivermectin every six months for 10-15 years, corresponding with the lifetime of the adult worm.

Despite Uganda's progress towards elimination, pockets of onchocerciasis are suspected to remain in certain key HRPs, including refugees. Many refugees originate from onchocerciasis endemic areas and may be mobile and difficult to track during MDA campaigns, and current MDA programs do not target all refugees. Uganda has an estimated 1.4 million refugees, most of whom are hosted in Adjumani district in the Madi-Mid North focus, with the majority (99%) coming from the Republic of South Sudan – a country endemic for onchocerciasis.

A qualitative formative assessment using the HRP NTD FA Tool was carried out in refugee settlements, including Adjumani district, to inform future interventions in this HRP. In 2023, MDA was conducted in April and October in these two districts. The assessment was conducted in late October 2023, just after the last round of MDA; it showed that refugees settling in Adjumani district had never been treated during the MDA rounds.

"Personally, I can say that OV is common in this settlement because back in South Sudan I was a VHT for my village called Kerepi. In Kerepi, there was a high rate of OV and we used to do MDA but that stopped when we relocated to Uganda. I'm sure it's common in Pagirinya because many people who came from Kerepi have settled here". (FGD-10, 01)

One of the gaps noted was that the NTD program did not have resources to conduct a comprehensive assessment to understand the burden of onchocerciasis amongst the refugees. This made it a challenge to understand the scope and to plan for satisfactory MDA using the available funding support. Another key challenge that emerged included limited health worker capacity to screen, diagnose, treat and routinely report on onchocerciasis.

Following stakeholder engagement meetings at the national and district levels, where the assessment findings were presented, key priority strategies to address the never-treated among the refugees were developed including: 1) conducting a baseline rapid assessment among the refugees to document the disease burden and 2) building the capacity of health workers to screen, diagnose, treat and routinely report on onchocerciasis among the refugees. These strategies have now been costed and the onchocerciasis elimination program is sourcing support to carry them out in 2025 as part of an effort to accelerate elimination of onchocerciasis in Uganda.

Typically, 3-4 interviews with key informants from each subgroup should be conducted. If possible, a conscious effort should be made to select different types of people from each subgroup so that key informants span a range of age, gender, education level, and/or specific occupation or role in the community. A list of key informant names, contact information, and key sociodemographic and occupational characteristics should be entered into the Key Informant Interview Enrollment Form (**Appendix 8**). This list can be used to track KIIs conducted and provide an overview of KII characteristics for the analysis and final report.

Schedule interviews

Field teams should contact the key informant and make an appointment for the interview. When possible, it is best to conduct the interviews in a neutral place where key informants can speak freely. If key informants will need to travel to their interview location, their transport costs should be reimbursed.

Prepare materials

The field team should prepare the following materials in advance of each KII:

- Key Informant Interview Guide **(Appendix 2)**
- Notetaker Template **(Appendix 3)**
- FGD/KII Debrief Form **(Appendix 4)**
- Informed Consent Form **(Appendix 7)** with an extra copy for the key informant
- Key Informant Interview Enrollment Form **(Appendix 8)**
- Reimbursement Log **(Appendix 9)**
- Audio recorder
- Pens and paper
- Refreshments

Make introductions

The Moderator should introduce the field team and ask the key informant to introduce themselves. The Moderator should then explain the purpose of the KII and how the information will be used, with assurance that all information shared by the key informant will be treated confidentially. It is also important to explain that their opinion is valuable and that there are no right or wrong answers.

Administer informed consent

Most data collection through KIIs requires informed consent but it depends on the context. If informed consent is required, each key informant should fully understand all the procedures and how their responses will be used.

Informed consent procedures are as follows:

- Explain the purpose of the KII.
- Provide key informant with two copies of the informed consent form.
- Read the informed consent form aloud and ask if they have questions. If a key informant cannot read, the Moderator should read out the form for them in the presence of a witness.
- Answer any questions from the key informant.
- Have the key informant sign both copies of the informed consent form, consenting to participation in and audio recording of the KII.
- Fill in the participant ID number and countersign both copies of the informed consent form. Return one copy to the key informant and retain the second copy for study records.

Conduct the KII

Similar to a FGD, the Moderator plays a key role in directing the KII and must continually assess whether the information obtained is sufficient to answer the research questions. The Moderator must re-focus the interview and ask follow-up questions of the key informant as needed. Best practices and detailed procedures to be followed during the KII are described in **Box 4**.

Data quality monitoring

Debrief sessions

Field team members should hold debrief sessions after each FGD and KII to review and summarize each discussion and interview, go over notes, and monitor data collection progress. Debrief sessions are helpful learning opportunities to identify gaps in information and points when additional questions or probes would have been useful, so that Moderators can improve their techniques in future discussions and interviews.

Data monitoring and supervisory field visits

NTD program officers and field teams should meet at least monthly to discuss progress towards the goals of the formative assessment. Meetings should include a review of the FGDs and KIIs conducted and discuss data analysis, gaps, challenges, and any other issues related to the assessment. A supervisory group comprising key stakeholders should conduct field visits for quality assurance checks. The supervisory group should meet in the first week of data collection to identify and address problems that may affect data quality.

Data analysis

Analysis of qualitative data is an ongoing process that begins as soon as data collection starts. The analysis should include a GESI lens, in which findings are considered by sex, age, disability, mobility, location, and other relevant GESI-related factors that may influence access, acceptance, or use of NTD services.

The type of analysis conducted will depend on formative assessment objectives and capacity and availability of the field team. A rapid analytical approach is described in **Box 5**. A more traditional qualitative analysis, including transcription of audio recordings, coding, and thematic analysis, may be conducted if preferred and if time allows.

BOX 4

KII best practices and procedures

Interview the key informant alone
The interview should be conducted privately. The presence of other people during an interview can prevent honest answers. To ensure both confidentiality and safety, it is good practice to choose a place for the interview that is semi-private, where others can see the key informant but cannot hear them.

Sequence questions
Begin with less sensitive questions (e.g., fact-based) and move to more sensitive ones (e.g., opinion- or judgment-based) when the key informant is more relaxed and comfortable. Alternatively, the interview may begin with questions about the present, then move to questions about the past and the future.

Use probing techniques
Encourage key informants to detail the basis for their opinions and recommendations by asking them to elaborate, clarify, or provide specific examples.

Maintain a neutral attitude
Be a sympathetic listener and avoid giving the impression of having strong views on the subject being discussed. Neutrality is essential because key informants may feel pressured to say what they think the interviewer wants to hear.

Never suggest answers to the key informant
Rather than suggest answers, probe in a way that leads the key informant to come up with a relevant answer themselves. Never read out the list of coded answers for a particular question to the key informant, even if they have trouble answering.

Wrap up
Alert the key informant that their interview is ending. Go over the main ideas from the interview to seek any clarification an allow for a few minutes of free discussion. Thank the key informant for their time, offer refreshments, and remind them that travel expenses will be reimbursed.

Component 3: Mapping And Enumeration

Mapping and enumeration activities generate a list of specific locations (i.e., venues) and times at which members of the target HRP are present, which can be used to access HRPs with interventions.

Key procedures of this component include:

- Mapping locations frequented by HRPs, leading to the development of a physical map and listing of venues.
- Identifying potential high-attendance times at these locations through FGDs and KIIs.
- Determining the number of HRP members likely to be present during high-attendance times through direct observation (i.e., enumeration).

Field teams must exercise caution when conducting mapping and enumeration, particularly in areas where there are security concerns and/or potential illegal activities taking place. Team members should not go into the field alone, and field visits must always be approved in advance in coordination with local HRP and community members. In areas where access is limited and/or unsafe for field teams, selected members of the target HRP may be trained in simple data collection methods and information-sharing techniques to help fill data gaps.

Map locations frequented by HRPs

The following types of locations and areas should be mapped by drawing on existing data, local expert knowledge including that derived from FGDs and KIIs, and direct observation:

- Locations where HRPs meet and interact with each other (e.g., village-based gathering sites like central squares, water collection points, worksites, border crossings, travel hubs, refugee camps, schools, parks, markets, bars, restaurants, places

BOX 5

Suggested steps of a rapid analytical approach

- The rapid analytical debriefing is the primary responsibility of the Field Coordinator.
- The summary reports for each site and target HRP should be reviewed and analyzed according to the predetermined themes and topics listed in the Discussion and Interview Guides (Appendix 2).
- The Reporting Summary Template (Appendix 5) can help field teams organize their ideas, identify major themes for each subgroup, and compare and contrast themes across subgroups. This template should be used to guide the rapid analytical debrief discussions.
- After each FGD/KII is completed, the Field Coordinator should host a formal debrief session with the Moderator and the Notetaker. Debriefings typically last between 1-1.5 hours.
- The Field Coordinator should ask the Moderator and Notetaker questions from the Reporting Summary Template, filling in each section based on recall as well as the notes and audio recording from the FGD/KII. Direct quotes on important points should be included in addition to topical summaries.
- After the debrief session, the Field Coordinator should review the completed Reporting Summary Template to ensure that all questions have been answered before filing it along with the corresponding notes and audio recording.
- The final output of the qualitative component of the formative assessment is a brief report with key findings for each of the predetermined and emergent themes. This report should be incorporated into the overall formative assessment report. Appendix 10 provides a suggested outline for a qualitative data collection report.

ILLUSTRATIVE EXAMPLE 3

Applying a GESI-focused behavior change approach to identify and support acceptance, access, and uptake of MDA among HRPs in Uganda

The Karamoja region in Uganda is trachoma-endemic and faces multiple challenges, including poverty, food shortage, water scarcity, high illiteracy rate, and insecurity. GESI-related barriers have hindered trachoma prevention, control, and elimination efforts in this remote area, particularly among the nomadic populations who frequently miss out on crucial information about trachoma MDA due to their constant movement. This has led to inaccurate MDA coverage data, exacerbated by illiteracy among village health teams responsible for MDA administration and tracking. WI-HER, a woman-owned small business leading GESI integration under USAID's Act to End Neglected Tropical Diseases I East (Act I East) program, in collaboration with RTI International and USAID, supported the Uganda Ministry of Health to strengthen GESI capacity at national and community levels and take a community-led approach to improve trachoma MDA coverage among nomadic populations.

A key activity was the formation of district GESI teams and local Behavior Change Teams (BCTs). Applying WI-HER's iDARE methodology, the BCTs identified root causes for people missing MDA, such as absenteeism due to gendered production activities (e.g., cattle herding, fishing, collecting firewood, selling goods in the market, cultivating gardens) and misconceptions about drug interactions, and developed and tested targeted solutions to address these challenges. BCTs integrated pre-MDA information and messages into community outreach through women's and youth groups, religious leaders, and community elders. They also promoted positive hygiene practices, engaged local leaders in door-to-door activities to share accurate information, and coordinated treatment days with people's movements.

These efforts have yielded significant results. On average, 100% of the cohort members engaged by BCTs have participated in MDA. Additionally, the support provided to district GESI teams through training and capacity strengthening has empowered them to identify and implement effective approaches to reach marginalized populations. Through community-driven strategies and partnerships, trachoma prevention barriers have been addressed, leading to improved MDA coverage and reduced trachoma prevalence in the Karamoja region.

of worship, livestock watering points, mobile livestock huts/enclosures).

- Locations where NTD health services are offered for HRPs and/or the general population (e.g., health centers, vaccination centers, school-based clinics, mobile clinics, refugee camps).
- Locations of activities held by community-based organizations that work with HRPs (e.g., religious centers, community centers, schools, markets and trading centers, refugee camps, food distribution points).
- Locations that may present potential barriers to implementation of interventions (e.g., areas off-limits due to security patrols or policing, physical/geographical barriers).

Hard copy maps, sketches, and listings of these locations can be developed, but no personal names or information related to individuals should be included. The names of roads and/or venues may be changed to protect the target HRP. If communities do not want specific locations to be mapped, that part of the venue visits can be skipped.

Verify venues

Formative assessment field teams should visit the potential venues identified to:

ILLUSTRATIVE EXAMPLE 4

A formative assessment to identify contextual factors for low uptake of Trachoma MDA in urban/peri-urban dwellers in Moroto district of Uganda

Trachoma, historically a significant public health concern in Uganda, is now endemic in 5 of the 61previously endemic districts and cities. Since 2007, Uganda has implemented the WHO- recommended SAFE strategy (surgery, antibiotics, facial hygiene and environmental improvement). Despite progress and several years of trachoma interventions, the prevalence of trachoma remains unacceptably high with a Trachomatous Inflammation – Follicular (TF) prevalence of 16.2%. Moroto district in Karamoja region of Uganda failed all the recent Trachoma Impact Surveys and is termed trachoma persistent.

Reasons for trachoma persistence include: lack of safe water, poor sanitation, and presence of HRPs, some of whom are never treated during mass drug administration (MDA). One of the HRPs in Moroto that often miss treatment are urban or peri-urban dwellers. Previous coverage evaluation surveys conducted in Moroto district indicated that health workers were the major source of MDA information among the residents.

A formative assessment was conducted in Moroto district to determine perception of trachoma and barriers to uptake of interventions, including MDA, among the urban and peri-urban communities. The findings of this assessment indicated misconceptions among urban/peri-urban dwellers regarding MDA, including beliefs that: medicines should not be taken after consuming alcohol, medicines could be harmful to them and may interfere with the fertility of women, and youth are not at risk for trachoma. It became clear that despite routine social mobilization during MDA these misconceptions still persist. Additional challenges leading to poor coverage of MDA were operational: Community Drug Distributors (CDDs) had difficulty reaching every household due to difficult terrain, medicine stock outs, insufficient time allocated MDA implementation and/or failure to return to missed households.

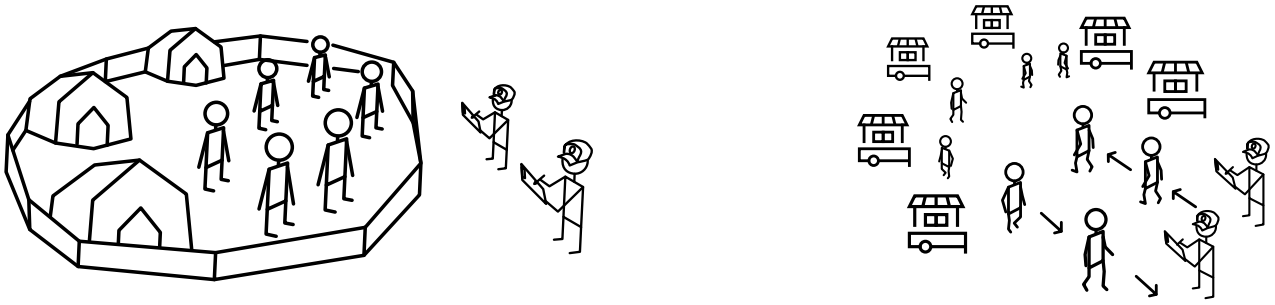
The results of the formative assessment were shared with the district health and community leadership through dissemination workshops and the following recommendations were made: (1) An increase in the number of days of MDA implementation; (2) increased medicine stocks together with sustained Social Behavior Change Communication (SBCC) after the MDA days, and (3) Improving the technical capacity of health workers through refresher trainings and provision of job aids, in order to improve trachoma services.

Strengthening MDA to address never treated populations coupled with other SAFE strategies, including improved access to safe water and sanitation, will propel Uganda towards its goal to eliminate trachoma as a public health problem by 2030.

- Confirm the location and details of how to access each site.
- Familiarize themselves with the venues and make sketch maps of the venues and their surroundings. Within the sketch map, field teams should indicate:
    - Specific areas where venue-goers will be intercepted for enumeration.
    - Discrete places at or near the venue where participants will be interviewed and NTD intervention activities will occur.
- Determine safety and accessibility of the site for conducting surveys and other NTD intervention activities.
- Meet with venue officials (e.g., venue owner, venue manager, village leader) to:
    - Confirm whether the venue is still active and establish any closure times/days.
    - Obtain permission to conduct interviews and other activities inside or outside the venues.
    - Review the map and areas where activities could take place.
    - Validate information on days and times of high attendance of HRPs.
    - Request preliminary attendance estimates that may be used to verify the numbers obtained during enumeration.

FIGURE 9

Types of enumeration



Type 1

Enumeration at venues attended exclusively by members of the target HRP. For example, if refugees are the target HRP, then an established refugee camp would fit under Type I enumeration because all individuals present are likely to be part of the refugee population. Worksites are also likely to fall under Type I. One or two field team members should count individuals attending each Type I venue during the specified high-attendance period

Type 2

Enumeration at venues with mixed attendance. For example, a public market thought to be a good place to find farmers selling their products would be a mixed venue since many people who are not farmers are also likely to be present. Ideally, two field team members will conduct Type II enumeration: one to count individuals consecutively and the other to systematically approach and briefly interview individuals to determine whether they belong to the target HRP.

- Determine any patterns in the types of individuals that tend to be present at different days and times (e.g., due to work shifts, travel patterns). This information is useful for planning interventions targeted at HRPs.

Conduct enumeration

Enumeration is the process of directly observing and counting the number of individuals present at a venue during a particular time window, generally a time when high attendance is expected. The result of enumeration is a standardized count of individuals belonging to the target HRP at the venues visited.

Enumeration should be carried out at all potential venues using the Enumeration Summary Form (**Appendix 11**) which records details about the venue, enumeration time, and number of HRPs observed at the venue. The Enumeration Summary Form can also be adapted to capture additional observations on relevant HRP characteristics (e.g., estimated age, sex, ability). There are two different standardized methods for obtaining the count of HRPs who are present at a venue in a specific time period, depicted in **Figure 9**.

It is best to conduct enumeration at all venues and from start to finish during each high-attendance period. If this is not feasible, enumeration may be conducted at a random sample of venues and/or during a portion of the high-attendance period. For example, if the high-attendance period is Wednesdays from 18:00 – 22:00 (4 hours), enumeration could be conducted for a 30- or 60-minute period during this window. To scale up the counts to estimate the number of HRPs present during the entire window, the field team will need to make a judgment based on the following considerations:

If individuals are constantly arriving and leaving, then the

observed count should be scaled up proportionally. For example, if staff enumerated for 60 minutes of a 4-hour period, then the count should be multiplied by 4.

If, for the most part, the same individuals appear to be present during the entire period, then the scale-up factor should be adjusted downward as appropriate. In both Type I and Type II enumeration, duplicate visits by the same individual should not be counted.

Lists of venues, high-attendance times, and number of HRP members expected can be used to directly inform programmatic activities. Venue notes taken during the site verification visits should be typed and compared with notes taken during the FGDs and KIIs to gain further insights into the venues where HRPs may be accessed.

Alternatives to enumeration

If direct observation is not feasible, an alternative to enumeration is to collect estimates of attendance from venue owners and collate with additional, alternative data sources such as community census registers. This may be sufficient where turnover is low or attendance records are kept (e.g., seasonal worksites, schools), but may introduce error where there is more variation in attendance across different times of the day and days of the week (e.g., bars). Locations with high attendance and high turnover (e.g., markets) should use direct observation only.

Component 4: Integration and Use of Data

This section summarizes approaches for integration of different types of data generated during the previous three components of the formative assessment and provides

FIGURE 10 **Data types, results, and integration into final formative assessment objective**

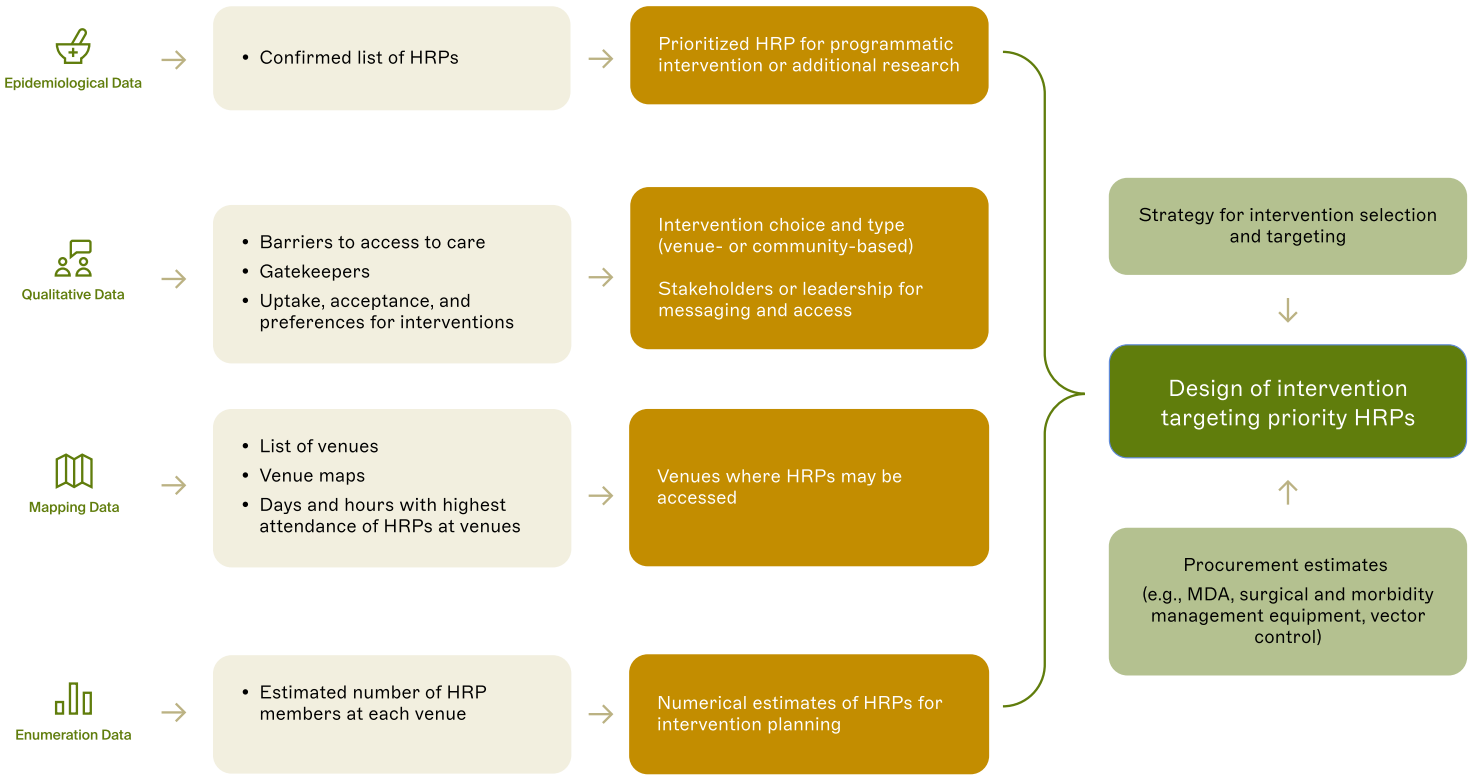


TABLE 4

Formative assessment data analysis approaches and outputs

DATA TYPE	ANALYSIS APPROACH	OUTPUT
Desk Review	Identify potential HRPs for priority NTD(s) and confirm by triangulating data from different sources. In identifying potential HRPs, define who makes up the HRP and why, and define differential characteristics, barriers, and opportunities within the HRP with a further breakdown by age, sex, location, mobility, disability, etc.	Brief report highlighting key findings according to theme*
Active and passive surveillance data	Tabulate cases by sociodemographic characteristics (e.g., age, sex, residence, location). Calculate NTD indicators (e.g., prevalence).	• Pivot tables • Prevalence maps
Qualitative data (FGDs and KIIs)	Use predetermined themes to categorize information from FGDs and KIIs. FGDs and KIIs should be representative of different communities or other groups to ensure a diversity of perspectives. Identify new and emergent themes. Review field notes, debrief forms, and individual FGD/KII summaries to categorize additional information.	Brief report highlighting key findings according to theme*
Venue mapping	List all possible venues. List high-attendance times. Identify who is using venues and at what times, and who does not have access or does not use, based on factors of sex, age, mobility, disability, location, socio-economic status, etc.	Venue maps

*The brief reports of the desk review and qualitative data should be incorporated into the main formative assessment report.

ILLUSTRATIVE EXAMPLE 5

Leaving no one behind: a pilot project to improve MDA delivery for schistosomiasis and soil-transmitted helminthiasis among street children in Kenya

Approximately 300,000 children in Kenya live on the streets, with an estimated 15,400 in Mombasa. Street children are at high risk for schistosomiasis and STH due to poor WASH habits, such as the practice of open defecation, and lack of access to health care. Most children in Kenya are given preventive treatment for schistosomiasis (with praziquantel) and STH (with mebendazole) through school-based or community-based MDA campaigns, but children living on the street are often missed in these targeted efforts, due to school absenteeism and the lack of fixed addresses. An additional challenge hindering access is the stigma associated with living on the street, which can lead community medicine distributors (CMDs) to pass over street children during MDA campaigns and/or hinder these children from approaching the CMDs for care.

In 2022, Kenya's national NTD program partnered with the Department of Children Services, ASCEND Kenya, and local NGOs working with street populations to launch a pilot project aimed at increasing access and coverage of schistosomiasis and STH MDA among high-risk street children in Mombasa. Twelve out of 30 wards had a prevalence of schistosomiasis greater or equal to 2% and were deemed eligible for MDA, and all children in these wards, including those living on the street, were targeted. The team met with county government representatives and other stakeholders to identify and map bases (the local name for groups of around 20 families living in small neighborhoods) which are often in conflict with one another over local resources. Base leaders were invited to team meetings to discuss the pilot project and secure buy-in. Eight bases were included in the pilot, and treatment was given to adults as well as to children over one year of age. The number targeted for treatment was determined in advance during a scoping exercise.

The project team adopted community-centered design principles, incorporating the input and guidance of base leaders into interventions. Base leaders suggested combining MDA with food distribution to improve coverage and requested t-shirts to signify their participation. The project team brought in CMDs to dispense food and drugs for schistosomiasis and STH; the CMDs were paired with elders and base leaders for their safety. Base leaders also mobilized the street families. A total of 2,836 street persons aged between 1-78 years were treated, more than 98% coverage of the targeted population. The success of this pilot program led the NTD program to permanently modify its MDA data collection tool to include street children in order to strengthen monitoring and awareness of this HRP. This approach – using mapping of bases, engagement of base leaders, and community-centered design – will be expanded to reach additional bases in Mombasa as resources allow.

examples of data use for planning and decision-making within the context of NTD HRPs. The data analyses conducted will depend on the type of data available, the resources and capacity available, and the needs of the NTD program.

Integrating results

Analysis of data collected during the formative assessment is based on the objectives set at the start of the project. **Table 4** summarizes the analysis approaches and possible outputs for each type of data collected, and **Figure 10** shows the different types of data that may be collected during the formative assessment and the way in which results can inform the design of an intervention targeting HRPs.

Community design workshops and stakeholder engagement

The formative assessment team should organize a workshop to present the preliminary findings to community members, partners, and stakeholders after completion of analysis, ideally within 3-6 months. Findings from each

FIGURE 11 Applications for formative assessment findings

component of the formative assessment should be presented, and ideas generated from all participants on next steps for intervention design and delivery as they discuss, critique, validate, and expand on the results. Deliberations at the workshop, including rich interpretation of the findings, will inform strategic community-centered design of new and adapted interventions and delivery strategies, and ensure that formative assessment recommendations are aligned with programmatic priorities.

A second workshop should be held to disseminate the final report of the formative assessment, incorporating the stakeholder- and community-generated input and next steps derived from the previous workshop. The target audience for this workshop should include senior management staff of the health ministry, donors, and partners who can influence funding and operational decisions to support translation of the findings into programmatic implementation.

In addition, key messages from the formative assessment report should be summarized, simplified, and passed along to community stakeholders in the local language. Suitable dissemination activities should be organized with community-level stakeholders through community meetings, workshops, or interpersonal communication with community leaders and health workers. Participants should be encouraged to create community action plans that reflect and take forward the findings and next steps in the formative assessment report, in collaboration with local leaders and NTD program representatives.

Data use

Formative assessment results can be applied in several ways to strengthen NTD program operations **(Figure 11)**.

Informed decision-making and strategic planning

Findings of the formative assessment can provide evidence-based information on gaps in NTD HRP intervention delivery strategies and surveillance and monitoring activities, as well as operational and logistical information on how and where to deliver interventions to HRPs. This data is vital for defining objectives and identifying activities required to scale up interventions among identified HRPs and make progress toward elimination. Programmatic decisions on policies, strategies, approaches, structures, and priorities must be based on the best available evidence to ensure maximum impact with available resources.

The formative assessment may also provide good baseline data to monitor and evaluate effectiveness and coverage of interventions implemented among HRPs.

Designing and improving targeted interventions

The formative assessment identifies different NTD HRPs and determinants of the NTD risks to which they are exposed (e.g., socioeconomic, behavioral, occupational, cultural, and other GESI-related factors).

Data collected from the assessment can be used to:

- Aid in the design of a last-mile elimination effort when remaining NTD transmission is concentrated among a few HRPs.
- Adapt delivery strategies and community mobilization activities to increase awareness and acceptance of NTD interventions and minimize gaps in coverage.
- Deliver interventions in specified venues where the target HRP is known to congregate (e.g., MDA for PC-NTDs at markets, fishing areas, refugee camps).
- Aid in designing specific interventions for NTDs to accelerate progress toward 2030 goals laid out in WHO's NTD Roadmap.

Data use for advocacy

Data collected from formative assessments can be used to develop social behavior change messaging to address information gaps such as lack of knowledge about NTDs. Messages tailored to the specific HRP can be developed and disseminated to the identified venues. For example, conversation starters in the form of stories are an effective method of encouraging active participation in community dialogues among HRPs to address barriers, misconceptions, and gender inequities related to NTD transmission and interventions. Findings from the formative assessment can also inform selection of effective communication channels such as community events and other strategies of raising awareness of NTD prevention, symptoms, and treatment.

Resource mobilization

Data analyzed from the formative assessment, particularly the partner and resource mapping, can inform and justify resource re-allocation and mobilization strategies for HRPs, including domestic funding. Funding will be required to initiate mapping, conduct further assessment activities, and implement targeted intervention delivery strategies among the identified HRPs. Embedding targeted approaches into existing programming is important to ensure sustainability and monitor progress towards NTD elimination.

E

APPENDICES

APPENDIX 1

Sample Themes and Topics for Qualitative Data Collection

Demographics

- Age
- Sex
- Residence
- Occupation

Residence

- Size and type of housing
- Household members
- Household amenities (e.g., running water, well, toilet facilities)
- Household communication (e.g., phone, radio, television)
- Proximity to essential services (e.g., water sources, markets, health posts)
- Proximity to international border
- Proximity to water bodies, vector-infested areas, animal enclosures, other locations associated with increased risk of exposure/transmission

Travel

- Methods of local travel (e.g., walking, bicycle, motor vehicle, public transportation)
- Methods of longer-distance travel (e.g., motor vehicle, public transportation)
- Frequency of travel
- Travel companions
- Time spent per location
- Travel origins / destinations
- Distances and times traveled
- Reasons for travel

Behaviors and practices

- Hygiene practices
- Availability of clean water for drinking/washing/bathing
- Presence of animals in sleeping areas
- Close/frequent contact with animals
- Occupation-associated risks and exposures
- Travel-associated risks and exposures
- Treatment-seeking behavior personally and for household members (e.g., is treatment sought when ill, where and from whom is treatment sought, how quickly)
- Education/knowledge-seeking behavior personally and for household members (e.g., who do you or other community members ask when advice or information is needed)
- School attendance (e.g., do older children and/or girls attend school)
- Seasonal differences in behavior or practice
- Motivation for behavior change

NTD services and interventions

- Knowledge of NTD signs and symptoms
- Knowledge of NTD transmission routes
- Knowledge of NTD prevention methods
- Perceived local burden of NTD (e.g., common, rare)
- Perceived risk of NTD personally and in community
- Attitude toward NTD personally and in community (e.g., fear, concern, indifferent)
- Perceived availability of NTD interventions
- Attitude toward NTD interventions personally and in community
- Access points and delivery methods for NTD interventions
- Reasons for NTD intervention avoidance/refusal personally and in community

Community engagement and outreach

- Needs, gaps, challenges, solutions associated with access, acceptability, uptake of NTD interventions
- Availability of education/information about NTD and NTD interventions
- Frequency, location and method of engagement and outreach activities
- Impact of engagement and outreach activities on personal knowledge, behavior
- Perceived impact of engagement and outreach activities within community

GESI considerations

- Power dynamics related to household or employer-based decision-making and access to NTD interventions
- Gendered roles and responsibilities that increase/decrease risk of NTD exposure
- Personal preference for male vs female health worker/educator/researcher
- Impact of health worker/educator/researcher gender on access, attitude, acceptance of NTD interventions
- Social stigma associated with NTD symptoms that impact treatment-seeking
- Disabilities that impact NTD risk, intervention access

APPENDIX 2

Sample Qualitative Data Collection Discussion and Interview Guides

Note: the sample shown here is for a FGD and is not an exhaustive list of questions. KIIs will involve many of the same questions as in FGDs, but should focus more on the key informants' knowledge and perception of the target HRPs rather than their personal details and experiences. KII questionnaires should also be adapted to include specific questions on their area(s) of expertise and previous interactions with the target HRP.

Sample questions by theme	Suggested follow-ups or probes
Icebreakers	
What diseases are present in this area?	Which diseases or conditions cause the most problems for people in your community?
Have you heard about [priority NTD]?	If yes, what have you heard about it? Do you know any of the symptoms or how it is spread? If no, [priority NTD] is a disease with symptoms including [list some major symptoms]. With that in mind, have you seen [priority NTD] in this area?
Demographics	
What is your age and occupation?	
Where do you live?	
Residence	
Describe the common types of housing in your community.	What materials are homes made out of? Are they roofed and screened?
Describe the layout of your neighborhood/community.	How many people live there? How close are your homes by foot?
Do you keep animals in or adjacent to the home?	What type of animals? Do they have a separate enclosure? Are they present while you and your household members sleep?
Does your home have toilet facilities? Washing facilities?	Describe these facilities in more detail.
How close is your home to a clean water source? To a market? To the nearest	How long does it take you to reach by foot/bicycle/motor vehicle?
Travel	
How frequently do you travel, and how long are your trips?	Measure in days/week/month.
Where do you go?	Provide specific names of places, distance and time to travel to each location.
What is the primary purpose of your travel?	What influences you to travel (e.g., seasons, events)?
Behaviors and Practices	
Describe your hygiene practices at home and at work.	How frequently do you wash your hands and face? Do you have access to clean water for washing?
What methods do you use to prevent insect bites at home, at work, or while	Do you use these methods every day? Why or why not?
When you or a household member feels sick, where do you go for care?	Do you go to community health worker or a health center? Do you visit a traditional healer? If you don't seek care, why not?
Do you think you are at risk for [priority NTD]?	If yes, why? If no, why do you think you are not at risk?

NTD Services and Interventions	
What are the prevention and treatment methods for [priority NTD]?	What else? (probe for additional methods)
Do you have access to these methods? Do you make use of them?	Why or why not? What do you like/dislike about them?
Where and how do you typically get access to prevention and treatment met	At a health facility? Through your work? Would you prefer other locations or methods?
What would make you or members of your community more likely to adopt [priority NTD] interventions?	Describe different delivery approaches (e.g., school-based, house-to-house, employer-sponsored, promoted by community leaders)

Community Engagement and Outreach	
Have you received any information or education on [priority NTD] within you	When and where? Who provided this education? Was it effective?
What sources of health information do you or members of your community t	Where and from whom would you most likely seek advice? Why?
How do you prefer to get information or education on health in general and [priority NTD] specifically?	Individually or in a group setting? At home, at work, or in a community setting? Via a document, a speaker, or radio/TV?
What would make you or members of your community more likely to adopt [priority NTD] interventions?	Describe different delivery approaches (e.g., school-based, house-to-house, employer-sponsored, promoted by community leaders)

GRI Considerations	
Do you prefer to receive health services or [priority NTD] education from a m	Why is that your preference?
Who in your household typically makes decisions about healthcare for yourself and your household members?	What are the reasons for this?
In your community, are there specific roles and responsibilities assigned to v	What are these roles and responsibilities? Why are they considered to be more appropriate for women or for men?
Is participation in any [priority NTD] interventions impacted by roles and responsibilities assigned to men and women?	What is the impact? Does this primarily affect women, men, or both?

APPENDIX 3

Sample Notetaker Template

Circle one: FGD KII **Focus Group ID (if applicable):** _____

Date: _____ **Start time:** _____ **End time:** _____

Venue (brief description of the location of the FGD / KII: _____

Community Engagement and Outreach	
Number of participants	
Sex (men, women, mixed group)	
Age/age range	
Profession/occupation/HRP description	
Other relevant characteristics	
Participant dynamics (group interactions and/or interactions with Moderator or Notetaker)	
Any dominant or dormant participants (FGD only)	
Participants' attitude/demeanor	
Any interruptions	
Other relevant features or observations participants(s)	

Seating chart (FGD only: draw a sketch of the group's seating plan):

Running notes of the FGD / KII

Topic Area	Notes and Observations

APPENDIX 4

Sample FGD/KII Debrief Form

(To be completed by Moderator in collaboration with Notetaker and Field Coordinator)

Focus Group ID (if applicable): _____ **Moderator initials:** _____ **Notetaker Initials:** _____

Location: _____ **Date of FGD / KII** _____ **Date of Debrief:** _____

Participant description: _____

Participant unique ID (KIIs only) or pseudonyms/self-selected names (FGDs only): _____

_____

_____

1. What were the main issues or themes that struck you during this FGD/KII?
2. How did this FGD/KII compare to previous FGDs/KIIs in this study? Was the discussion content similar or did any new topics or themes arise?
3. How would you describe the general atmosphere and level of engagement during the FGD/KII?
4. FGDs only: how would you describe the group dynamics? Did all participants contribute? Did you feel there was pressure to adhere to dominant topics or viewpoints (if so, what were those topics and viewpoints)?
5. What else was important or noteworthy about this FGD/KII?
6. Did the FGD/KII meet the specific objectives of the qualitative data collection? Are there any objectives you feel were not met? Why do you think the objectives were not met? What can we do differently in the next FGD/KII?
7. Did you experience any problems with the thematic guide (e.g., wording of questions, order of topics, missing topics) during this FGD/KII?
8. Were there any questions/themes that were not well understood by the participant(s)? Can you suggest any modifications to improve understanding of the questions?
9. Were there any questions/themes that made participant(s) hesitant, uncomfortable, and/or reluctant to respond? Can you suggest any changes in wording or approach by the Moderator that could alleviate this discomfort?
10. What were the main points made by the participant(s) (list according to the predetermined themes in the interview guide)?
11. Are there any other comments, observations, or ideas worth highlighting?

APPENDIX 5

Sample Reporting Summary Template

Target HRP: _____ **KII or FGD ID:** _____

Moderator _____ **Notetaker** _____

Note: Adapt list topics and subtopics below to match the themes and questions in the Discussion and Interview Guides. Allow plenty of space to document detailed information for each topic and subtopic.

Characteristics of participant(s) interviewed

Demographics (age, sex, occupation, residence): _____

Relationship with target HRP (applicable only to KIIs and non-HRP FGDs): _____

Travel history and travel patterns: _____

[NTD of interest] awareness/behaviors

Knowledge on [NTD of interest] signs and symptoms: _____

Attitudes/risk perceptions on [NTD of interest]: _____

Treatment-seeking behavior and uptake of health interventions: _____

[NTD of interest] services/interventions

Knowledge on methods [NTD of interest] treatment and prevention: _____

Availability/usage of [NTD of interest] interventions: _____

Reasons for avoidance or refusal of [NTD of interest] interventions: _____

Community engagement and outreach

Availability of education/information about [NTD of interest]: _____

Strategies for increasing awareness/uptake of [NTD of interest] interventions: _____

GESI considerations

Male/female preferences for health service delivery/health education: _____

Impact of gender roles and responsibilities on [NTD of interest] intervention uptake: _____

Other/additional thoughts and observations

APPENDIX 6

Procedures and Sample Script for FGD Participant Recruitment

Recruitment through snowball sampling

1. Ask a stakeholder (e.g., community leader, health worker, HRP employer) to identify a member of the target HRP. Alternatively, use NTD index cases identified through passive surveillance or MDA campaign registries to select individuals who were missed during recent MDA campaigns as a starting point for steps 2 and 3.
2. If the individual meets participation criteria, introduce the study and ask if they would like to participate in the FGD, then record their name and contact information to follow up for scheduling.
3. Ask the new participant to provide contact phone numbers or other means to identify additional individuals with similar characteristics for recruitment into the study.
4. Complete additional rounds of sampling as needed until the goal sample size for the FGD is reached.

Recruitment through gathering points

1. Ask a stakeholder to identify locations where members of the target HRP are likely to gather. For example, mobile and migrant populations may be found at bus stops or other transit points near border crossings.
2. Go to the gathering point and approach potential participants to introduce the study.

The sample script below can be used for either recruitment method. However, the sentence in bold only applies to snowball sampling and should be excluded from the script when recruiting at gathering points.

I come from [NTD program / name of institution] and I am currently working on a project examining [priority NTD(s)] risk in [location / district name] in collaboration with [partner institutions]. We are conducting a study about [priority NTD(s)] risk in association with [risk factor/HRP characteristic].

We would like to know more about how to better reach individuals who are at risk for [priority NTD(s)]. To do this, we are organizing group discussions to ask questions about experiences and opinions on [priority NTD(s)] and [priority NTD(s)] prevention, as well as activities and other factors that may increase risk. **Someone you know, [name], recently participated in this project and provided your contact information in case you would like to participate as well.** Are you interested in participating?

If so, I will ask you some simple questions now about your residence, daily roles and responsibilities, work, travel, and outdoor activities to see if you are eligible to participate. This will only take a few minutes. If you are eligible, I will schedule a time for you to participate in a group discussion with other people from the community, which will take approximately 1.5 hours. We will not pay you for participation, but we will reimburse the cost of traveling to participate and provide snacks and refreshment.

APPENDIX 7

Sample Informed Consent Form

Note: The Informed Consent Form should be adapted to suit local context, the target HRPs and priority NTD(s), and/or to meet any organizational or institutional requirements. Because of the different participant experiences and requirements, separate forms should be developed for FGDs and KIIs.

Study title _____ **Study location** _____

Study contact _____ **Study organizations** _____

Study funders _____

Introduction

Thank you for your interest in participating in this study. [Name of national NTD program and participating organizations/funders] are collecting information on people at high risk for [priority NTD(s)] in [study location] which will be used to inform future [priority NTD(s)] interventions and to design better delivery systems to your community. Before you decide whether to participate, we would like to explain the objectives of the study, tell you how the study can help you and others in your community, and inform you of any possible risks to you or others by participating in the study.

Important notes:

1. Participation in the study is completely voluntary.
2. You can decide at any time to discontinue participation.
3. If you decide not to participate, you will not lose any of the benefits that you normally receive from [name of national NTD program].

Why is this study being conducted?

[Insert background information and study objectives]. We would like to hear about your experience with [priority NTD(s)] and get your opinions on [key themes and focus areas of study]. This will help the [name of national NTD program] design interventions and delivery methods that are appropriate to your community.

How will this study be conducted?

[Insert description of qualitative data collection procedures, including study locations, priority NTD(s), target HRPs, and the categories of people selected for key informant interviews and focus group discussions]. Your participation in the study will involve answering questions [describe setting and format of FGDs or KIIs]. We are interested in hearing about your experiences and opinions, and there are no right or wrong answers. We will take notes of the ideas discussed and a recording will be made using a digital voice recorder. Afterwards, we will enter information from the interview anonymously into a computer for analysis.

What risks can I expect from being in the study?

Participation in any research study may involve a loss of privacy. Your name will not be used in any reports of the information provided. No direct quotes or other personal details arising from your participation in this study will be included in any reports, even anonymously, without your agreement. Notes and audio recordings obtained from these discussions will be secured in locked offices and only study researchers will have access to them.

How will results be disseminated?

Your information will be recorded and will be used to write reports that will be shared with [list of participating organizations and stakeholders].

If you have any questions right now, please ask the study staff administering this informed consent. If you have any questions related to the study in the future, please contact:

Principal Investigator (Insert contact info)	Principal Investigator (Insert contact info)	Principal Investigator (Insert contact info)

Do you consent to an audio recording of this study? YES, I consent ☐ NO, I do not consent ☐

Do you consent to participate in this study? YES, I consent ☐ NO, I do not consent ☐

Name (printed)

Signature or Fingerprint **Date**

Name of Study Staff Administering Consent (printed) **Position/Title**

Signature of Study Staff Administering Consent **Date**

Name of Impartial Witness **Date**

Signature of Impartial Witness **Date**

APPENDIX 8

Sample Enrollment Forms

Key Informant Interview Enrollment Form

Date	Location	Audio File	Moderator Initials	Notetaker Initials

#	Participant's Unique ID	Sex (M/F)	Age	KI Category	Community Position/Occupation	Screening Date	Enrolled in Study? Y/N	Enrollment Date	Obtained Consent? Y/N
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									

Focus Group Discussion Enrollment Form

Focus Group ID	# of Participants	Date	Location	Audio File	Moderator Initials	Notetaker Initials

#	Participant's Unique ID	Sex (M/F)	Age	Community Position/Occupation	Eligibility Screening Date	Enrolled in Study? Y/N	Enrollment Date	Attended FGD? Y/N	Obtained Consent? Y/N
1									
2									
3									
4									
5									
6									
7									
8									
9									
10									
11									
12									

APPENDIX 9

Sample Reimbursement Log

Focus Group ID: _____ **Date:** _____

Focus Group Location: _____

	Participant's Unique ID	Location Traveled From	Mode of Transport	Cost of Transport	Receipt Provided Y/N	Participant Signature or Thumbprint
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						

APPENDIX 10

Outline of the Formative Assessment Report

The formative assessment report should include the following sections:

Executive Summary

- Highlights of the key findings and recommendations from the formative assessment.

Background

- A brief description of epidemiological trends and interventions for the NTD(s) and location(s) of interest.
- A brief description of the target HRP(s).
- Objectives of the formative assessment.
- Rationale for conducting the formative assessment.

Methods

- Description of study design.
- Selection of study sites.
- Data collection tools.
- Data analysis and interpretation.

Results

- Key findings of the formative assessment by component:
  - Summary of findings from review of existing data and surveillance systems.
  - Summary of findings from FGDs and KIIs.
  - Summary of findings from mapping and enumeration.

Discussion

- Application of the formative assessment results for NTD programming, with special emphasis on design and delivery of targeted interventions and surveillance and monitoring strategies among HRPs.

Recommendations

- Key recommendations from the assessment.
- Follow-up plans and next steps.

References

Annexes

APPENDIX 11

Sample Enumeration Summary Form

	Venue Name	Address	Type of Venue	Days/Hours of Operation	Days/Hours with Highest HRP Attendance	Participant Signature or Thumbprint		Notes and Observations on Venue and/or Enumerated HRPs (Characteristics, behavior, movement patterns, etc)
						Min	Max	
1								
2								
3								
4								
5								