

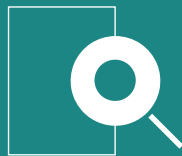


NEGLECTED TROPICAL DISEASE
NGO NETWORK

SOCIAL AND BEHAVIOR CHANGE IN NTD PROGRAMS

A quick guide

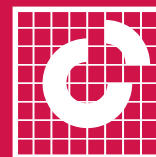
INVESTIGATE



FOCUS



DESIGN



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DISEASE SPECIFIC BEHAVIORS AND PROGRAM CONSIDERATIONS

PURPOSE

WHY NTDS AND SBC?

Neglected Tropical Disease (NTD) programs have seen enormous success in recent decades through mass drug administration campaigns, vector control programs, and disease management strategies. But we know that achieving the ambitious WHO 2021-2030 NTD roadmap goals will require increased focus on social and behavioral factors.

Behaviors underpin health in multiple ways - through the transmission of and exposure to disease, through the uptake of disease treatment and care, and through disease-related stigmatization and exclusion.

Disease prevention programs have relied for years on health education and awareness raising campaigns to influence people's behaviors. However, evidence and programmatic experience has shown that knowledge alone is not enough to impact behavior. Instead, there are multiple factors that affect a person's willingness and ability to change - such as beliefs, social pressure, access to services, and socio-economic conditions.

While behaviors are often deeply embedded in social norms and traditions, livelihoods, and personal habits, they can change.

Social and Behavior Change (SBC) is the intentional, systematic process of understanding and facilitating changes in social norms and behaviors. In this guide, SBC is an approach to design and deliver interventions to increase the adoption of healthy behaviors and influence the social norms that underpin those behaviors.

WHAT IS THIS GUIDE?

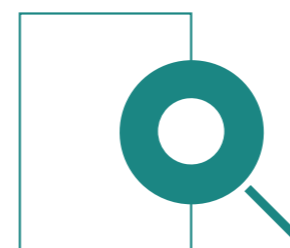
This quick guide will help organizations develop and support behavior change programs for NTD control and elimination that are effective, sustainable and appropriate. It does not offer a definitive or recommended set of interventions. Many resources, theories and approaches for the design of behavioral interventions already exist, so rather than add or replace those resources this guide will:

Provide an entry point into SBC specifically for NTDs.	Share key lessons and principles to guide SBC program design, delivery and evaluation.	Provide minimum actions recommended for all programs using SBC to improve NTD outcomes.	Provide guidance on resources necessary for SBC within NTD programs.
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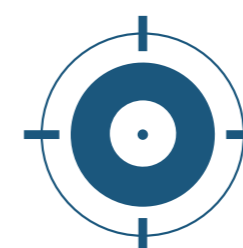
WHO IS THIS GUIDE FOR?

The guide can be used by a wide range of people - NTD program planners and implementers, their partners in broader health and development sectors, government, the private sector, civil society, and non-governmental organizations.

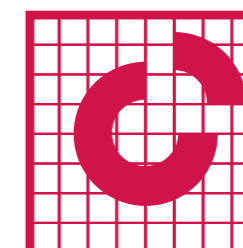
AFTER AN INTRODUCTORY SECTION, THE GUIDE IS BROKEN INTO FOUR KEY SECTIONS:



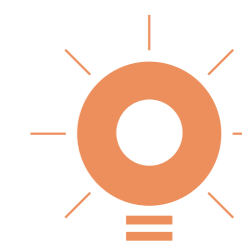
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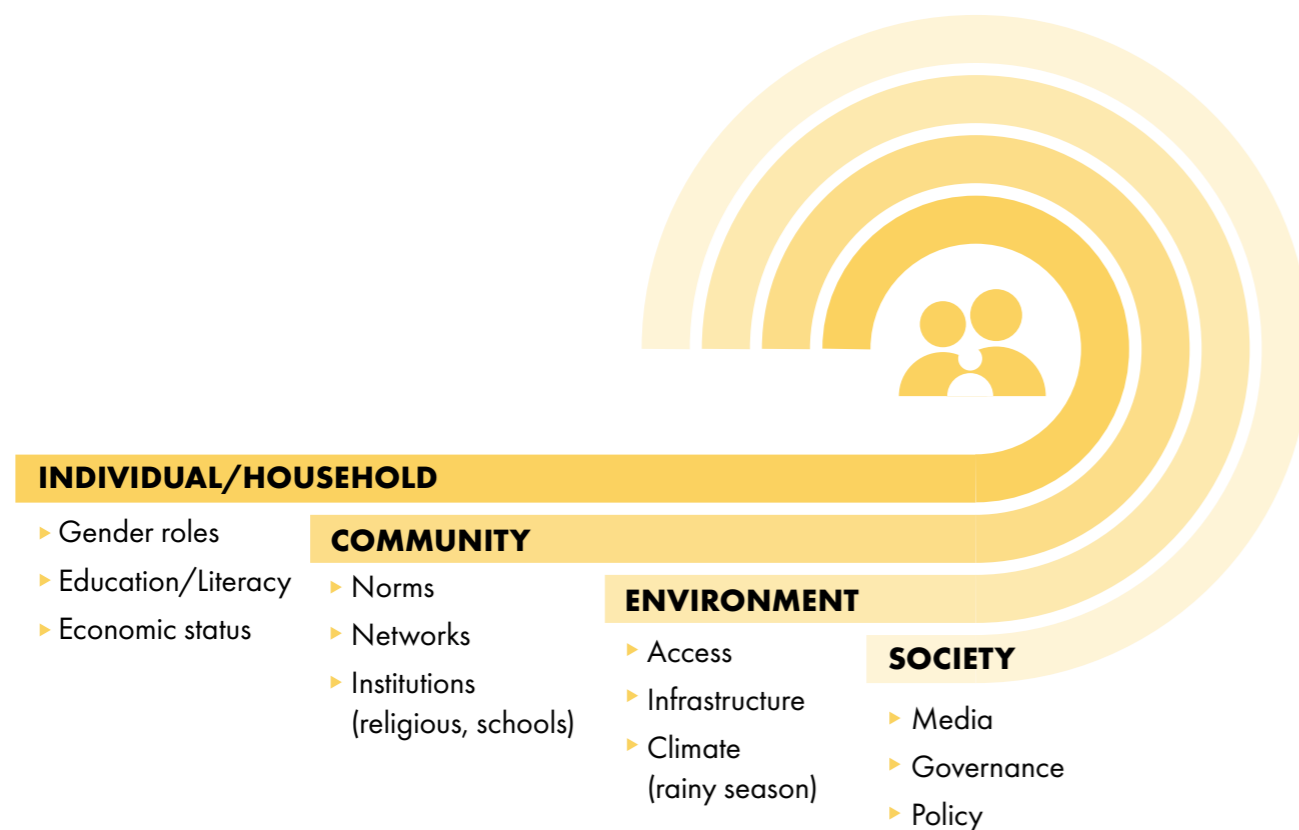
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BACKGROUND

HUMAN BEHAVIOR: THE BASICS

To understand how to design a behavior change programme, we need to first understand what influences behavior. Sustained health behavior change requires interventions at multiple levels – see Figure 1 below. While individuals perform behaviors, they do so as members of families and communities, and each individual is influenced by their environment and society. All of the conditions and expectations they experience play a role in the actions they take.

Figure 1: Socio-ecological model of selected influencers



However, while the socio-ecological model outlines the levels at which behaviors are influenced, it does not provide insights into psychological and social factors that drive change. Generally speaking, individuals are quicker to change behaviors when the new behavior is easy or convenient to perform and when there is a clear imperative to change. This could be an immediate threat, a clear immediate benefit, or when not doing so could result in punitive measures or social pressure. This is important to remember in NTD programming, since many NTDs can take years or even decades to cause severe disease or death – change can be difficult.

Remember that simply increasing people’s knowledge about a disease and how it is transmitted is unlikely to drive behavior change on its own. This means that a successful behavior change program goes beyond knowledge to address the drivers and motives of behavior.

Many development and humanitarian response efforts fail to create lasting change because they’re built on flawed assumptions about knowledge. Many do not take into account that:

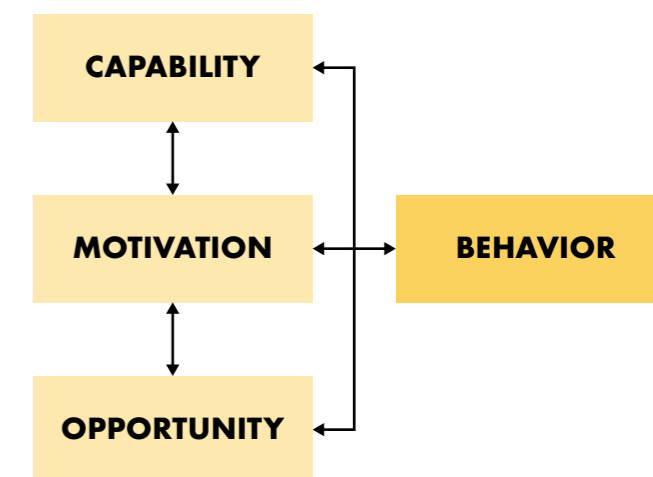
- Just because a person knows what they should do does not mean they will do it.
- Just because a person wants to adopt a behavior does not mean they can or will.
- Just because a person fears a given consequence does not mean they will take action to prevent it.
- Many of the actions people take to improve their lives are not done for the rational reasons being promoted.

While information is empowering, and facts are important, knowledge on its own is rarely enough to spur behavior change. You can probably think of a time when you wanted to make a simple change in your life - drink more water, go to bed earlier, exercise more – and knew exactly why you should make the change, but still struggled due to factors other than knowledge.

It’s because people are frequently more driven by emotion, social pressures, aspirations, habits and the surrounding environment than by information.

To help understand behavior we can also look to the COM-B model (Michie et al. 2011), and the Behavioral drivers Model (UNICEF, 2019). Both of these models offer a simplification of the many theoretical models and can serve as a tool to help practitioners to design interventions towards actions specifically aligned to the problems they are trying to solve. The COM-B model explains that three conditions are needed for a behavior to occur: the person must be capable, have the opportunity, and be motivated to do it. Behavior change interventions typically target one or more of these factors in order to bring about the desired change in behavior. The Behavioral Drivers Model takes a slightly broader approach outlining three categories of behavioral drivers; Psychology, Sociology and Environment.

Figure 2: The COM-B system: a framework for understanding behavior



THE ROLE OF BEHAVIORS IN NTDs

SBC programming related to NTDs should focus on behaviors that are easy to adopt, and that bring clear and broad benefits to people's daily lives.

In NTDs, SBC can be used to address a wide array of different behaviors. A behavior is an action that is observable, specific, measurable, and feasible, and for the purpose of designing for SBC, it should be clearly defined. A behavior is not having knowledge or understanding of something.

There are a multitude of behaviors that we try to address with SBC, so it's important to consider the unique elements of each one. Behaviors can vary in complexity, in thought required, and in effort. They also vary in the amount of investment required, if they are judged or if they are supported by the community, the level of privacy involved and if they're at the individual, household or community level.

To change a behavior, all these elements need to be considered.

Programs or interventions to address disease transmission should be based on the way in which the disease is transmitted. A **conceptual framework** of transmission and exposure pathways is a useful starting point, as it helps to better understand the processes related to transmission, exposure, severity of the disease, the associated behaviors, and the target behaviors and audiences.

SBC programs should not focus only on disease prevention, but also include considerations for disease management, disability and inclusion (DMDI), in particular:

- Persons affected by NTDs who are at risk of developing impairments as a result of the NTD, or already have impairments as a result of the NTD.
- Persons with disabilities who live in NTD affected areas – the WHO estimates that 15% of the population is disabled

Figure 3: Transmission and exposure pathways - NTD Conceptual Framework

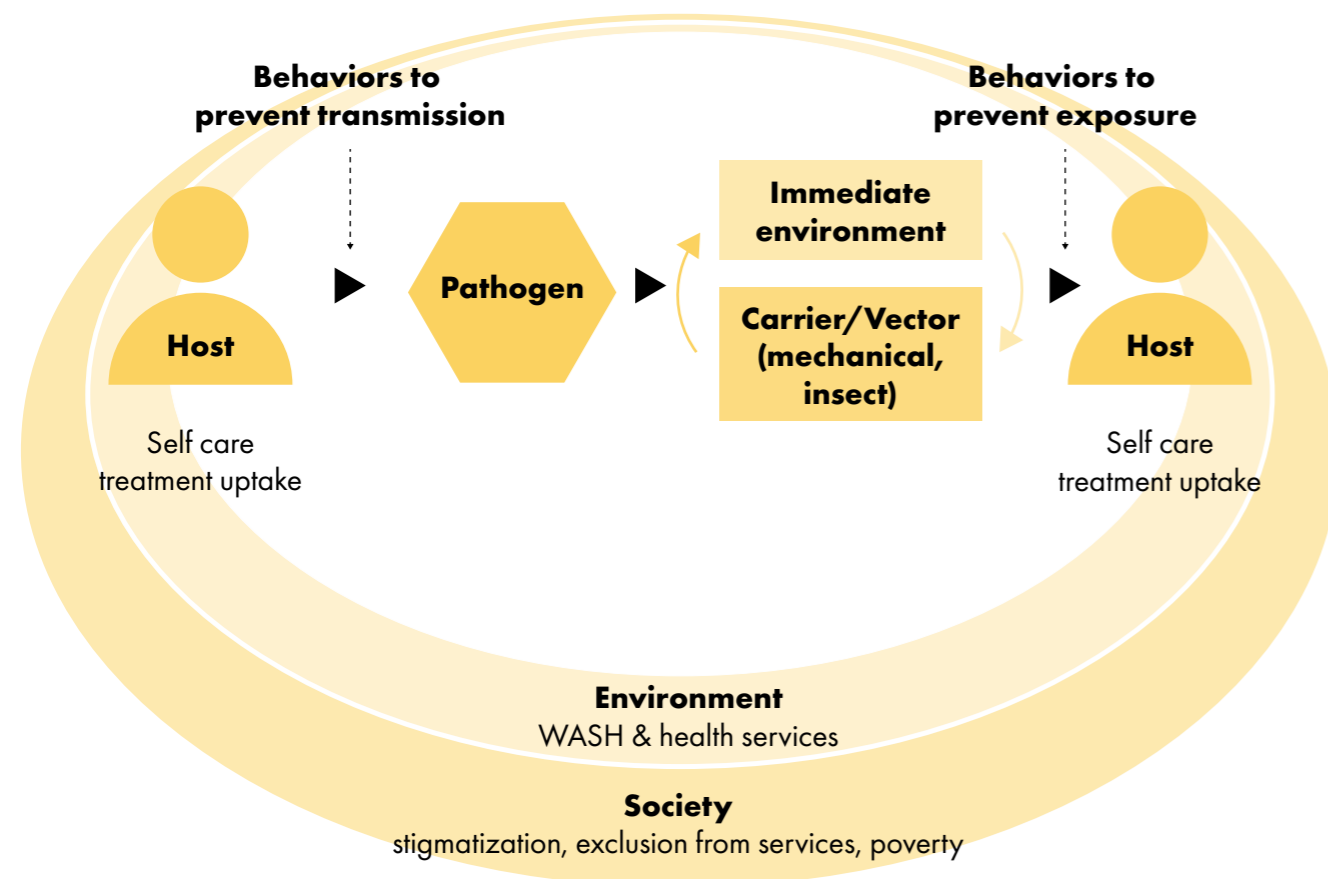


Figure 3 is an example of a basic conceptual framework, which you can adapt to any disease of interest. It shows how a pathogen is transmitted from one individual to another, between individuals/ within households and communities, through the physical environment (e.g. pathogens excreted into the soil or water and then consumed by another human host), or through vectors and other carriers (e.g. a mosquito acting as a direct vector, or objects

or household animals transporting pathogens). Transmission and exposure occur within a broader environmental and societal context. The framework can be used as a starting point to identify and prioritize behaviors.

You can find some disease specific conceptual frameworks, along with relevant behaviors, in the disease specific considerations annexes.

PRINCIPLES FOR BEHAVIOR CHANGE PROGRAMS

Before we dive into our four key sections, here is a set of proposed principles that should be upheld when planning and implementing SBC interventions:

Figure 4: Principles when planning and implementing SBC interventions



ADDITIONAL RESOURCES AND LINKS

- [The behaviour change wheel](#)
- [The Behavioural Drivers Model](#)
- [The behaviour-centred design approach](#)
- [Integrated behavioural model for WASH](#)
- [COM-B - Capability, Opportunity and Motivation influencing Behavior](#)
- [RANAS - Risks, Attitudes, Norms, Abilities, Self-Regulation](#)

1. INVESTIGATE

KEY MESSAGES

- Before designing a behavior change program it's important to understand the community context and culture, and what influences the behaviors you are targeting.
- Communities have various strengths and resources that can be drawn on to support the design and implementation of a behavior change program.
- The engagement of a diverse range of stakeholders in the design and implementation of a behavior change program can support local ownership and ensure that interventions reach the right people, at the right time, in the right way. Interventions are more likely to be successful if stakeholders are involved from the beginning.



OVERVIEW

- In this phase of program development, you will investigate and understand the community needs, context, assets and stakeholders.
- We discuss minimum actions for practice, key considerations, and resources you can draw from as you undertake your investigations.
- You may need to move back and forth between 'investigate' and 'focus'. The further you progress with your program design, the more questions will come up that may require you to gather additional information.

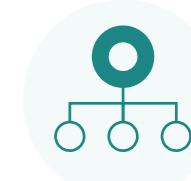


GUIDANCE AND PLANNING TOOLS

STEP 1. UNDERSTAND THE CURRENT SITUATION

Before you design your program, you will want to gather (and potentially collect) information. Developing a set of questions will help ensure this step is as efficient and targeted as possible. The following questions provide a starting point, but you may want to add to these or adjust them.

- 1. Scale.**
What is the scope of the program? Are you considering designing a program aimed at the entire country, a particular region or district, a community, or a subset of the population (for instance, school children)?
- 2. NTD prevalence and distribution.**
What is the estimated prevalence of the NTDs of interest in the program area? How has the prevalence changed over recent years? Is the disease evenly distributed, or does it affect specific places or populations? To gather this type of information at a district level you can use data portals such as the [Country Health Information Platform \(CHIP\)](#) and [ESPEN](#).
- 3. Population demographics.**
What are the demographic characteristics of the population of interest? Consider people affected by NTDs (e.g. those living with NTD-related impairments). People affected are not a homogenous population.
- 4. WASH services.**
What is the level of access to WASH services across the area, and what are the key WASH service concerns? There are a number of resources included in the [WASH and Health, Working Together](#) toolkit to help compile the data.
- 5. Health, schools, and other service coverage.**
What health services, schools, and other services - such as livelihood programs - are available to the community, and what are the key health service access concerns?
- 6. Current or recent programs.**
What NTD programs are currently in operation that may overlap with the proposed program? What programs have been conducted in the past that had a similar purpose or focus, and what was learned from these? Are there other existing programs and services, such as community-based health programs, school programs, or large-scale campaigns within which the NTD-related behavioral interventions can be integrated?





STEP 2. GATHER ADDITIONAL INFORMATION

The more reliable information you have, the higher your chances of designing an effective and impactful program.

First, building on point 6 from Step 1 above, you can draw on publicly available information such as data reports and research publications to begin to understand the local context and what interventions have been tried before. Reach out to local authorities and other organizations working in the program area. Use trusted sources for this information and take note of when and how it was collected. It is also important to gather information about people with disabilities during this step. [CBM](#) and [Sightsavers](#) offer several resources and information on collecting disability data.

You can use these existing tools to help:

- Has the NTD program completed a WASH-NTD landscape analysis? [Section F of this tool \(page 72\)](#) provides a clear template to populate SBC related data.
- Has the program done a NTDs social mobilization review exercise? [Section 1 of the Social Mobilization Toolkit](#) provides a template to populate existing social mobilization resources and strategies.

Note that if any of these already exist they may need to be updated.

Publicly available information will most likely have gaps. To understand more complex aspects or to find information that is not publicly available, you

can consider running consultative workshops or interviews. Any work should be based on your defined scope and available budget.

Second, you need to understand who the local stakeholders and influencers are. Who has power over decision-making and resource distribution? What are the main social power dynamics and structures (e.g. leadership structures) in households, schools, communities, and health facilities that influence how decisions are made and resources are allocated? What are the trusted channels for communication and social mobilization across different groups in the community? There are tools (such as [World Vision's social mapping tool](#)) that can assist you.

Third, you should consider the social environment in which people live. The Health Communication Capacity Collaborative (HC3) provides a useful [gender focused tool](#) that may help with this process.

Finally, look into what other factors influence how capable and motivated people are to engage in the behaviors you're focused on. A root cause analysis can be used to understand the underlying causes related to the identified problem ('high trachoma prevalence') or behavior of interest ('open defecation'). This can be done with stakeholder input in a consultation workshop. Several tools to conduct a root cause analysis have been developed, such as fishbone diagrams, problem trees and the 'Five Whys.' More detail on these can be found in [WASH and Health Working together](#).

STEP 3. MAKE SENSE OF THE INFORMATION YOU'VE GATHERED

Once you've gathered all the information you need, you will need to spend some time interpreting what it all means for program design. This is often best done by taking a participatory approach.

KEY ACTIONS FOR THIS SECTION

- Prior to designing your program, gather available information in order to understand the local needs and context to ensure your design is fit for context.
- Analyse existing data and conduct behavioral analysis using an SBC framework to better understand the behavior, barriers, and enablers - and how to make the change.



CONSIDERATIONS

When conducting the investigation, consider:

- **Special populations:** is there a significant population of special groups (e.g. pastoralists, migrants, internally displaced people, etc) in the project area? If yes, consult a local representative familiar with these groups, such as someone from the agricultural office in pastoralist areas or an NGO representative for displaced populations.
- **Strategic partnerships:** can any parts of the project be outsourced to the local area? For example, local creatives can support the development of materials and local colleges can potentially support data collection.

ADDITIONAL RESOURCES AND LINKS



- [NTD Inclusion Score Card \(NISC\) Tool | InfoNTD](#)
- [Access to drinking water - UNICEF DATA](#)
- [Sanitation statistics - UNICEF DATA](#)
- [Hygiene and hand washing statistics](#)
- [WASH in schools - UNICEF DATA](#)

2. FOCUS

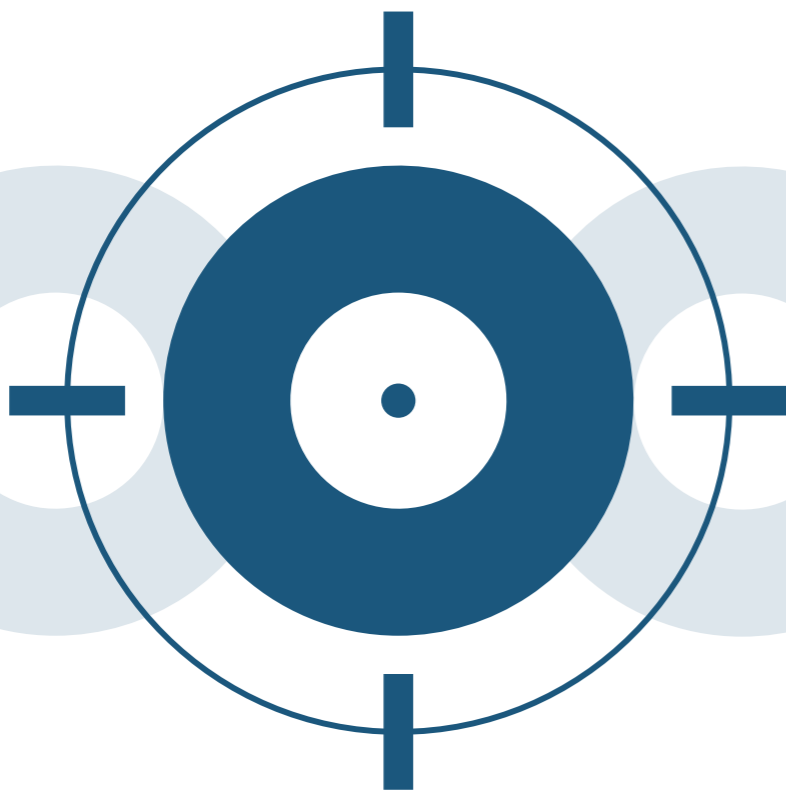
KEY MESSAGES

- There is no 'one size fits all' intervention. Interventions must respond to the context they are being delivered in and involve participation of the local community and its leaders to be effective and sustainable.
- The interventions and the way in which they will be delivered will also be influenced by the scale and scope of the program. For instance, a program delivered across an entire country will differ to one delivered in specific locations or settings or towards a specific population group.
- Effective health behavior change interventions focus on addressing the specific behaviors most directly linked to the health and disease outcomes of interest and the determinants of these behaviors.



OVERVIEW

- In this section you will identify the focus of your behavior change program.
- We discuss minimum actions for practice, key considerations, and resources you can draw from as you identify focus behaviors, drivers and barriers.



GUIDANCE AND PLANNING TOOLS

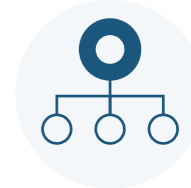
STEP 1. LIST POTENTIAL TARGET BEHAVIORS

In order to develop effective interventions, it's important to consider each potential target behavior and who it is performed by. You should also consider how frequently the behavior is performed and what resources are required to perform it.

To identify the target behaviors, you will need to identify the way in which the disease is transmitted and the behaviors that facilitate transmission and exposure. A helpful way to do this is by using a conceptual framework like Figure 3, adapted to

the disease of interest. Refer to the annex for the available disease specific diagrams (dengue, leprosy, lymphatic filariasis, rabies, schistosomiasis, soil-transmitted helminths and trachoma).

Once you've gone through this process, list everything together in a table, like the example below. Remember that when identifying who undertakes the behavior you should be as specific as possible. For example, rather than saying 'children', specify the age range of the children.



Tool 2 of the WASH & Health working together toolkit (NTD-related behaviours) provides a full list of example behaviors to draw from.

Behaviors	Who undertakes the behavior	When / how often	Resources required
Example: Washing of hands with soap	To be carried out by children aged 4 to 9 years	Before every meal	Soap and water

STEP 2. SELECT FOCUS BEHAVIORS

For each behavior, consider:

1. **Potential for impact:** which actions, undertaken by which groups of individuals, could most significantly contribute to the desired disease outcomes?
2. **Feasibility:** what actions, undertaken by which groups of individuals, will be the easiest and most cost-effective to change? Consider factors like how entrenched behaviors are and the level of investment and time that might be required to create and sustain change.

[Tool 7](#) in the WASH & Health working together toolkit (planning tool) provides a systematic process to document priority behaviors and interventions based on current programming and identified gaps.



Figure 5: Impact and feasibility

Impact
Does the intervention work to resolve the stated problem?

Feasibility
Is it possible to implement the intervention?

In terms of: funding, timeframe, governance, leadership (including personalities), human resources/skills, existing program entry points, precedent for engagement, tools (data collection and monitoring), security, etc.

3. **Equity:** what actions, undertaken by which groups of individuals, would help address disease outcome disparities experienced within and across population subgroups? This includes considering aspects of disease management and disability inclusion (DMDI); e.g. making water and sanitation services accessible to people with mobility impairments or making communication accessible to people with visual/hearing impairments or learning difficulties.

Additionally, you may have **constraints or opportunities** that will affect the scale, scope and nature of the programme:

- Level of funding you have for your project and the time you have to implement it.
 - How comprehensive does the program need to be - can it/should it target all relevant behaviors, or only the ones that have the highest potential for impact and are the most feasible?
 - What is the scale of the program - the entire country? A district? A community?
 - Are some behaviors of interest already being addressed through other existing programs or campaigns? And if so, are there opportunities to link with or amplify that program?
- A comprehensive program might hold greater potential for impact, but each component needs to be sufficiently resourced. If resources are a significant constraint, it is often necessary to be highly targeted and only select a small number of focus behaviors that are both impactful and feasible.

STEP 3. IDENTIFY THE DRIVERS AND BARRIERS TO PERFORMING THE FOCUS BEHAVIORS

Understanding what influences the behaviors you are seeking to change is crucial when designing interventions. It's important to identify the drivers and barriers associated with the focus behaviors. Here you will need to engage with available evidence or guidelines and connect with advisors and experts. In some cases, you will need to undertake some formative research. Use the socio-ecological and COM-B model presented in

Figure 1: Human behavior - the basics section of this guide to help you consider drivers and barriers from a range of different angles. For example, consider whether there are any motivational drivers the program could utilize, or if there are any barriers relating to available resources (like the availability of soap) that the program will need to address to be successful.

Behaviors	Drivers	Barriers
Children aged 4 to 9 years washing hands with soap before every meal.	Encouragement from teachers, parents and older siblings.	Access to soap.

The table presented in [Tool 3](#) of the WASH & Health working together toolkit (Understanding behavior to develop behavior change interventions) provides a good starting point for identification of drivers and potential barriers, and helps identify specific areas for further investigation.

KEY ACTIONS FOR THIS SECTION

- Identify the critical behavior or behaviors for your program.
- For each critical behavior, specify who performs it, when (and/or how often), what resources they require, and any relevant drivers and barriers to performing the behavior.



ADDITIONAL RESOURCES AND LINKS

- [TOOL2: NTD related behaviors](#)
- [TOOL 3: Understanding behavior to develop behavior change interventions](#)
- [TOOL 7: Step-by-step process to developing comprehensive and adaptive NTD programmes](#)



3. DESIGN

KEY MESSAGES

- A program is more likely to be effective if the interventions are designed for or adapted to the specific context and the needs of the target population.
- Addressing knowledge isn't enough, and it rarely drives behavior change. An effective behavior change program should try to address most (if not all) the key drivers and barriers that have been identified and these usually involve knowledge, skills, motivation, and resources.
- Changing behaviors is complex and requires time and sufficient resources. Be realistic about what you are trying to achieve, and by when.



OVERVIEW

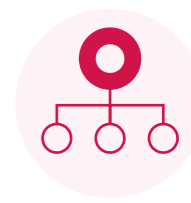
1. In this section you will go step by step through the process of designing your program.
2. We discuss minimum actions for practice, key considerations and resources you can draw from as you design your program.



GUIDANCE AND PLANNING TOOLS

STEP 1. IDENTIFY THE PROGRAM SETTING

One of the first design questions to answer is what setting or settings the program will be delivered in. Consider locations and structured environments where you are likely to find the members of the community the program is seeking to target. For example, if the program is focused on the behavior of school-aged children, the program may be school-based. Or if the program is focused on the behavior of mothers, it may be household-based or leverage social structures that mothers use at the community level.



STEP 2. IDENTIFY THE PROGRAM STRATEGY

The second design question to answer is what strategies the program will include.

See the list of strategies provided below. Select at least two of these strategies to ensure your program is tackling behavior change from more than one perspective. The root cause analysis conducted in the focus phase will help you identify the most appropriate strategy to use in light of the key barriers and drivers of behavior. For example, if a key barrier to the behavior is access to water, then you would need to ensure your program includes an approach to increasing access to water (which would be a type of ‘environmental restructuring’).

If a key barrier is motivation to wash hands, then your program could include persuasion (e.g. using religious or community leaders as influencers) and/or incentives that act to increase motivation (e.g. public/social recognition of desired behavior).



Strategies	Definition and when you'd use it	Intervention examples
Education	Increasing knowledge or understanding.	Providing information to promote participation in a mass drug administration campaign.
Training	Increasing the skills needed to perform the behavior.	Community drug distributor training to provide peer-to-peer education during mass drug administration campaign.
Persuasion	Using communication to induce positive or negative feelings (such as sadness, regret, amusement and encouragement) or stimulate an action.	Using imagery to increase empathy, respect and positive feelings towards people with lymphedema.
Incentivization	Creating an expectation of a reward, which can be financial, material or social.	Providing mirrors and stickers for families who have participated in hygiene promotion training.
Coercion	Creating an expectation of punishment or cost.	Working with local authorities to implement fines for households who don't have a family latrine or do not participate in community cleaning campaigns. Working with local authorities to support the implementation of anti-discrimination laws and sanctions.
Restriction	Using rules to reduce the opportunity to engage in the target behavior.	Laws prohibiting littering in public spaces.

Strategies	Definition and when you'd use it	Intervention examples
Modeling	Providing an example for people to aspire to or imitate.	Using TV drama scenes showing local influencers (for instance, a youth leader, singer or religious leader) modeling optimal hygiene and inclusive practices. Interviewing a famous religious leader on the radio and asking them to model and share their own experience of how face washing can prevent diseases.
Enablement	Reducing barriers to increase opportunity.	Providing braille texts in schools to facilitate access to education for students who are blind. Organizing local groups to manage WASH infrastructure and providing them with access to decision-makers.
Environmental restructuring	Changing the physical or social environment.	Placing signs and footprints between the latrine and the handwashing facility as a reminder to wash hands after using the latrine. Supporting the construction of safe, gender-segregated, disability-friendly latrines in schools.

STEP 3. INTERVENTION DESIGN OR ADAPTATION

Based on your strategy, specific interventions need to be identified. There are many tested interventions and best practices out there, so you don't need to reinvent the wheel. Before you design the program, ask: is there already a program this can be integrated into? Examples of this could be a WASH campaign that you can include NTD messages in, a mass drug administration campaign that could include SBC messaging, a national campaign, a disability inclusion program or school health or community health programs. The most important thing is to adapt the intervention to the context, the audience, and to the available budget.

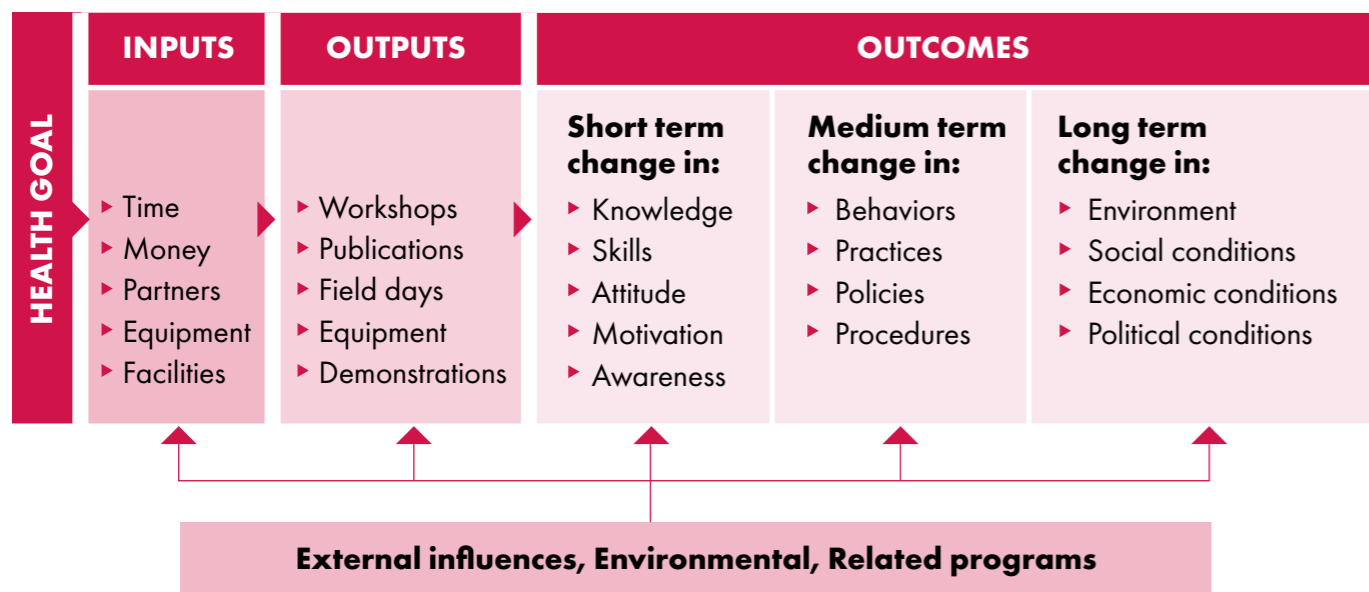
Co-creating the intervention with local stakeholders tends to result in more locally owned and relevant programs. Co-creation is a collaborative process to develop project activities and solutions together with experts, partners and stakeholders. Ideas are shared, tested and then improved together. Active and meaningful participation of representatives from the target audience, users and people with disabilities is central to this process. See [The Story of Co-Design - The Compass for SBC](#) for further guidance on approaches to co-design.

It's helpful to use a logic model to outline your intervention. A logic model is a graphic planning tool that explains the rationale behind the program design. It shows the relationship between the program resources and activities (inputs), and its results (outputs and outcomes). It's a good way to capture your project goals, objectives, activities and inputs. Ensure you're clearly outlining the problem you are trying to solve, the steps you are taking to solve the problem, and how you will know if the problem has been solved. See Figure 6 below for an example of a logic model for a NTD program.

Once you've specified the elements of the program, you will need to specify who will be responsible for delivering each activity. In many areas, community and religious leaders are a trusted source of information. Moreover, these leaders have significant reach within their communities and can mobilize resources and people. Their support is essential for community ownership.

Also consider whether there are any groups who may be marginalized or socially excluded, and how you could include them in the design of your program.

Figure 6: Inputs, outputs and outcomes



KEY ACTIONS FOR THIS SECTION

- Develop a logic model that describes the program activities and how they lead to desired outputs and outcomes.
- Include activities that address all (or most) of the drivers and barriers associated with the behavior/s you are focused on in your intervention design.
- Make sure your planning aligns with the available program budget.



ADDITIONAL RESOURCES AND LINKS

- [Designing a Social and Behavior Change Communication Strategy](#)
- [Integrating Gender Into Social and Behavior Change Communication](#)
- [WASH and Health working together toolkit: Core tool 2 \(NTD-related behaviours\)](#)
- [WASH-NTD indicators and logframe](#)
- [How to Develop a Logic Model - The Compass for SBC](#)



4. LEARN

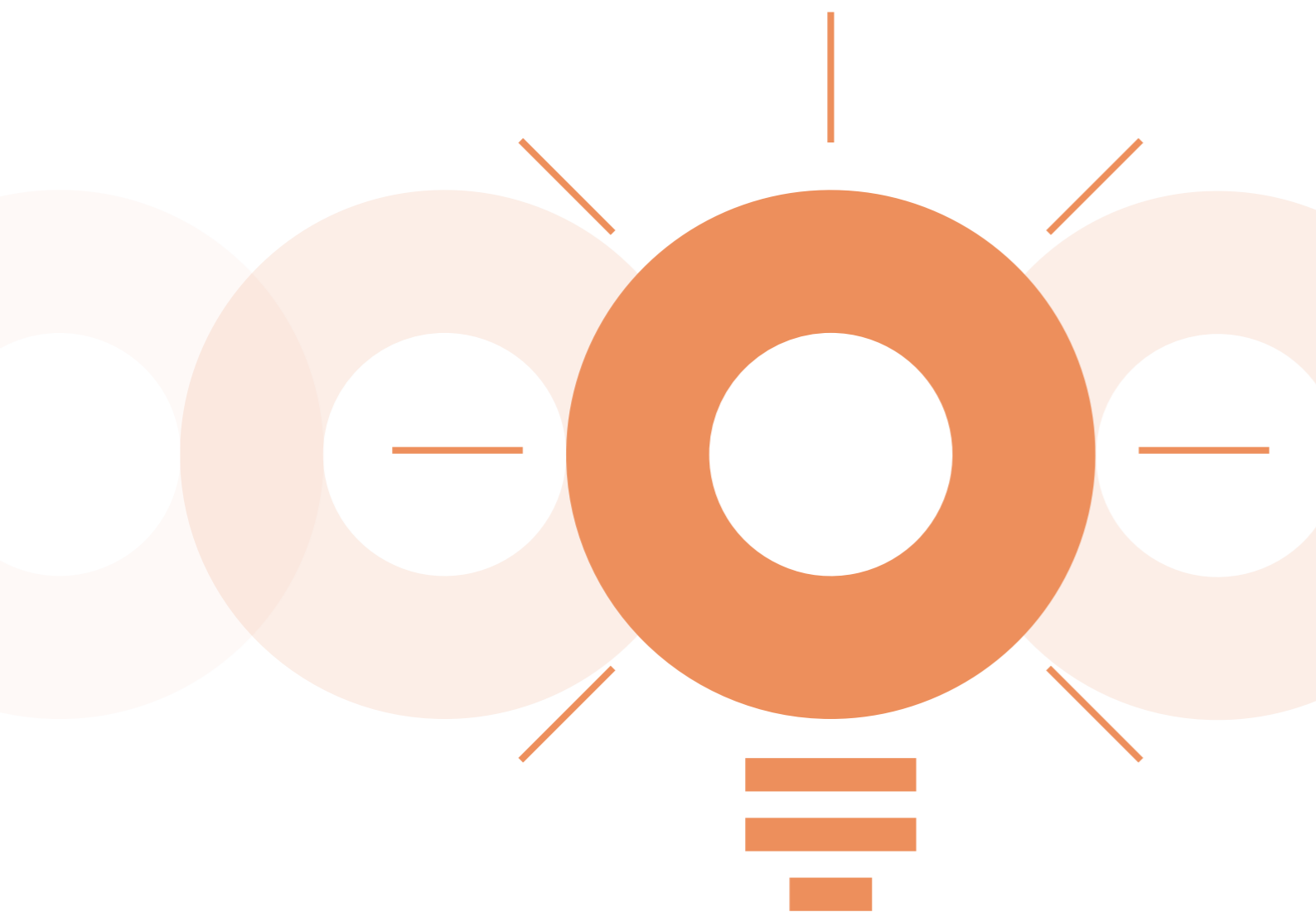
KEY MESSAGES

- Monitoring, evaluation, learning and adaptation (MELA) plays a key part in ensuring good program results.
- Ongoing reflection on what is working, and what isn't, allows you to adapt the program as it progresses.
- MELA can also be viewed as a motivating tool where implementers can see a program's vision will be realized over time.

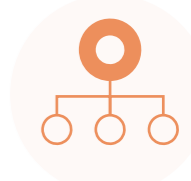


OVERVIEW

- In this section you will walk through the process of designing a MELA plan for your SBC program.
- It shares minimum actions for practice, key considerations, and resources you can draw from as you design your MELA approach.



GUIDANCE AND PLANNING TOOLS



STEP 1. IDENTIFY THE MONITORING AND EVALUATION QUESTIONS

Your monitoring and evaluation (M&E) questions will help guide what data you gather and how you present the information to key stakeholders. They help ensure you collect everything you need (and no more) and that you are able to get meaning from your data. Consider these categories of M&E questions:

- **Process.** Ongoing monitoring of activities and outputs should be conducted from the beginning to allow for rapid learning and adaptation while the program is being implemented.
- **Output.** Did your program deliver the planned outputs?
- **Drivers and barriers of behavior.** Did the activities lead to changes in the identified behavioral drivers and barriers?
- **Behavior.** Did the program lead to changes in the focus behaviors?
- **Disease outcomes.** Has the level of risk (of infection) reduced as a result of the behavior change intervention?

Measuring risk reduction would involve, for example, measuring whether a reduced level of open defecation has resulted in reduced environmental contamination.

STEP 2. IDENTIFY THE DATA YOU WILL NEED TO GATHER TO ANSWER THE M&E QUESTIONS

Ensure all major program activities are tracked with indicators. You can increase the utility of your results by using global indicators where they are available. Review existing indicators and their definitions to identify overlap. Harmonize indicators with program partners to prevent duplication.

If the SBC component of your program is part of a larger health systems strengthening plan and M&E plans already exist, you can add appropriate outcome or impact indicators and provide input into the existing M&E plan.

To see examples of indicators, see the WASH and Health Working Together toolkit, [tool 11](#) (WASH-NTD indicators and logframe).

STEP 3. DEVELOP M&E LOGICAL FRAMEWORK

This is a visual representation of the logic underlying a program's purpose and activities. It demonstrates the sequence of events through which a program may contribute to positive changes, helps justify investments, and contributes to overall accountability. It's based on the concept of cause and effect, meaning that if certain activities take place under certain conditions, certain results will be delivered.

STEP 4. IMPLEMENTATION

Quantitative methods and tools for data collection

Quantitative monitoring tends to document numbers associated with the program and involves record keeping and numerical counts. This type of information is often obtained by using quantitative methods such as service statistics and distribution records.

Quantitative methods	Quantitative tools
Reviewing SBC materials distribution	Distribution logbook
Periodic site visits	Checklist or questionnaire
Periodic review of implementation reports (e.g., peer educators' reports, supervisor's report, training reports)	Checklist, questionnaire, peer educator activity sheet, client/patient referral form

Qualitative methods and tools for data collection

Qualitative monitoring - measuring quality - asks questions about how well the elements are being carried out. This type of information and feedback is often obtained by using qualitative methods such as in-depth interviews and focus group discussions.

Qualitative methods	Qualitative tools
Focus group discussions	Focus group discussion guide
Direct observation	Observation checklist
In-depth interviews (e.g., to monitor and track changes in questions emanating from target groups and audiences during the course of project implementation)	Interview guides
Content analysis of materials	Content analysis checklist
Pre-testing of materials with target population	Pre-test checklist

STEP 5. COLLECTION AND ANALYSIS OF DATA

Baseline data

Baseline data can serve multiple purposes – identifying community needs, setting program targets, determining the type of intervention and the level of implementation, and measuring program performance and impact. Baseline data may have already been collected during the situation analysis phase or as part of formative research, but additional information might be needed to inform M&E activities. Much of this information may already exist thanks to routine national and district data collection and should be collated and analyzed to arrive at a baseline. Undertaking surveys where possible rather than using routinely collected data is an opportunity to gather additional information that is usually not captured in routine information systems.

Continuous collection of data for program adaptation

It is important to create a continuous feedback loop between data and strategy to assist with learning and adaptation during implementation. This can be done through answering the following questions:

- What should the program do more of?
- What should the program discontinue or do less of?
- What new opportunities are suggested by the findings that might be worth trying?

- Is there any need for audience re-prioritization or different segmentation?
- How might the MELA plan and its implementation be expanded, simplified, or improved?
- Are there ways to strengthen partnerships (including adding and removing partners)?
- Which activities worked well together, and which did not?
- Which activities stand out that could fuel behavior change?

Obtain and analyse endline data

Endline data will be collected at the end of the program and be compared with the baseline data to answer the following questions:

- Did the program achieve its objectives and required outcomes?
- Were there other unanticipated outcomes?
- Are behavior change measures embedded in ongoing programming to ensure sustainability?

KEY ACTIONS FOR THIS SECTION

- Have an overall M&E plan that includes behavioral indicators.
- Have clear and standardized definitions for indicators.
- Build ongoing learning mechanisms throughout the program duration.
- Demonstrate integration into broader public health and NTD program M&E structures.



CONSIDERATIONS

- It's prudent not to over-promise what data can be collected, and it's better to collect fewer data well than a lot of data poorly. Align data collection with available program staff, time, and resource costs to see what is reasonable. Make use of program partner support for data collection.
- Explore the use of any standard international, national, or donor indicators, such as those in demographic and health surveys, indicator surveys, service performance assessments, or those required by USAID, DfID, private funders, or other donors. Identify any differences between the program indicators and standard indicators to avoid duplication.
- If the start or end of a program coincides with a national survey, consider using those indicators for your baseline or endline instead of collecting them yourself (if they can be disaggregated at a level that is useful for the program).
- While observation of behaviors is considered the 'gold standard' method of behavioral monitoring, certain behaviors are prone to change if people know/think they are being observed. Also, some behaviors, particularly those related to personal hygiene, happen in private and cannot be directly observed. As such, proxy indicators could be considered. For example, the existence of a handwashing facility with soap and water.
- M&E costs money. The more involved and robust the approach, the more costly it is likely to become. e.g. existence of a handwashing facility with soap and water?



ADDITIONAL RESOURCES AND LINKS

- [WASH and Health working together: a 'how-to' guide for neglected tropical disease programs.](#)
- [HIV/AIDS Prevention Care in Resource-Constrained Settings: A HANDBOOK FOR THE DESIGN AND MANAGEMENT OF PROGRAMS.](#)
- [How to develop a Monitoring and Evaluation Plan.](#)
- [Research, Monitoring and Evaluation for Integrated SBCC.](#)
- [Getting the M&E Framework right. Geneva: World Health](#)



ACKNOWLEDGEMENTS

The Neglected Tropical Diseases (NTDs) NGO Network is a global forum for NGOs to contribute to the global control, elimination, and management of consequences of NTDs outlined within the internationally agreed World Health Organization NTD Roadmap.

The concept and contents of this resource were developed by past and present members of the Water, Sanitation and Hygiene (WASH) Working Group of the NTD NGO Network (NNN). This guide is meant to be an accompaniment to the WHO WASH and Health working together a 'how to' guide for neglected tropical disease programmes.

The following contributors are acknowledged for their contributions to the content.

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BEHAVIORS TO TARGET WITH SBC

DENGUE

The female *Aedes aegypti* lay their eggs in open containers, solid waste or uncovered water tanks with clean water.



TRANSMISSION BEHAVIORS



Bite from infected mosquito

The female *Aedes aegypti* lay their eggs in containers, surfaces or water tanks with clean water/ rain water

PREVENTION BEHAVIORS



Bite prevention (repellent, clothing, window netting, cleaning containers)

Mosquito control

Residual indoor spray

Keep areas where water accumulates clean and clear

Cover water tanks

Burn or bury rubbish

TREATMENT BEHAVIORS*



Symptom management (fever)

KEY MESSAGES

- Dengue is a viral disease that affects people of all ages. It is transmitted through the bite of an *Aedes aegypti* mosquito. It is not transmitted from person to person.
- Aedes aegypti* females lay their eggs in containers, surfaces, and tanks with water - they do not lay their eggs in puddles, lakes, swamps, rivers, or streams. This is why it's important to keep areas clean from containers that may accumulate water, properly cover water tanks and keep gutters and drains clean.
- This type of mosquito mainly bites during the first hours of the morning (dawn) and in the afternoon during the sunset. Consequently, the use of bed nets at night is not as effective in preventing bites as it is with other mosquito species
- Since there is no specific treatment for dengue, patients should seek medical advice for severe symptoms and take measures to prevent onward transmission.



PROGRAM CONSIDERATIONS

DENGUE

FOCUS

- Areas with documented presence of *Aedes aegypti* mosquitoes: some areas are endemic, with cases throughout the year; other areas are epidemic, with outbreaks depending on the movement of people from endemic to non-endemic areas with mosquito presence.
- Access to water supply services that meet all domestic needs: in case of a lack of water supply services, work on preventive messages for safe storage of water.

- Communicate preventive messages to the community on preventing mosquito breeding sites in the household, and the importance of prevention as a collaborative strategy that requires the commitment of the whole neighbourhood.
- Deliver messaging emphasizing the importance of both individual and community commitment for action.



DESIGN

- All program design and messaging must be done with community members, based on their needs, customs, and habits.
- The community needs to be engaged for a mosquito surveillance program to be effective - community participation is key.
- Given that changing habits is more feasible in children, age-appropriate educational material can be used in collaboration with the education sector to teach children about dengue so that they can take prevention measures into their own hands and share this information with other household members.

- Use information on location and degree of exposure to agree priority actions based on community preferences.
- Close collaboration with the existing acute febrile illness (AFI) surveillance system is important to guide targeted control measures in the areas surrounding the residence of a suspected case.
- Work with water supply and sanitation service providers to ensure that alternative water sources are provided.



LEARN

- Through risk stratification methodologies recommended by the WHO for arboviruses, it's possible to identify dengue 'hot' and 'cold' spots in a locality to focus surveillance activities on those areas, optimizing resources.

- Success measures should focus on the degree to which the risk of transmission of exposure has been reduced because of the intervention.
- Use qualitative methodologies to measure community uptake, participation, and satisfaction.

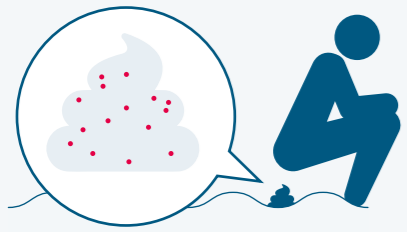


NEGLECTED TROPICAL DISEASE
NGO NETWORK

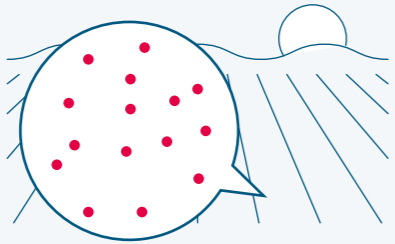
BEHAVIORS TO TARGET WITH SBC

SOIL TRANSMITTED HELMINTHS (STH)

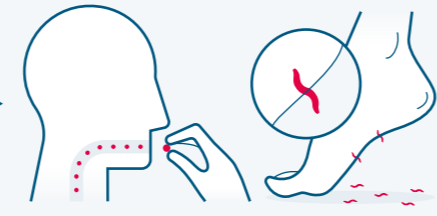
1. Eggs excreted in faeces



2. Eggs mature in soil



3. Infective larvae ingested or enter body through skin



TRANSMISSION BEHAVIORS



Open defecation

Unclean or poorly managed sanitation facilities

Use of untreated excreta/wastewater in crop fertilization/irrigation

Animals spreading human faeces

PREVENTION BEHAVIORS



Handwashing before eating/food preparation/feeding

Treating drinking water

Washing food crops

Wearing shoes

Accessible toilet construction, maintenance and cleaning

Uptake of MDA

TREATMENT BEHAVIORS



Uptake of MDA

KEY MESSAGES

- STH affect over a billion people worldwide. Five parasitic nematodes are responsible for most human infections: *Strongyloides stercoralis*, *Ascaris lumbricoides* (roundworms), *Trichuris trichiura* (whipworms), *Necator americanus* (hookworms), and *Ancylostoma duodenale* (hookworms).
- Humans get infected when they come into contact with infective stages of the parasites either through food/water (roundworms and whipworms) or walking barefoot (hookworms and *Strongyloides*). Infections affect rural or marginalized urban populations where access to safe water supply and sanitation services, and good hygiene behavior, are inadequate, insufficient, or poorly utilized.
- Preventive chemotherapy programs with albendazole/mebendazole have been largely used to control transmission. However, STH prevalence can bounce back quickly in areas where compliance with PC is sub-optimal and provision, maintenance and consistent usage of WASH services are lacking or insufficient.
- Behavioral change approaches should promote adoption of comprehensive WASH services and associated preventive behaviors.



PROGRAM CONSIDERATIONS

SOIL TRANSMITTED HELMINTHS (STH)

FOCUS

- Areas where STH prevalence remains high (20% or higher) after repeated rounds of MDA should be prioritised for WASH and SBC interventions.

- SBC efforts should focus on adoption and sustainability of safe WASH practices, as well as additional specific behaviors such as food hygiene, safe farming and animal husbandry methods, and shoe wearing.



DESIGN

- Initiate programs with cross-sectoral collaborations between service providers and end-users (communities, Health, WASH and Education Ministries) to identify needs, construct strategies and implementation plans, and develop monitoring and evaluation frameworks.
- Utilize social networks to co-construct and implement acceptable low-cost and effective strategies or interventions that ensure community ownership and sustainability.

- Ensure plans are decentralized to community levels to suit local contexts, with insights drawn from available routine programmatic data, literature, and informant interviews on STH prevalence, WASH coverage, MDA coverage, WASH coverage reports, and other factors associated with increased exposure (community dynamics, human behaviors, occupation, reasons for non-compliance with MDA).



LEARN

- Capacity building of local workforce to construct and maintain WASH infrastructure.
- Capacity building of stakeholders to regularly monitor and report WASH related behaviors using simple but comprehensive checklists.
- Other periodic community or household-based evaluation using mixed-method approaches.

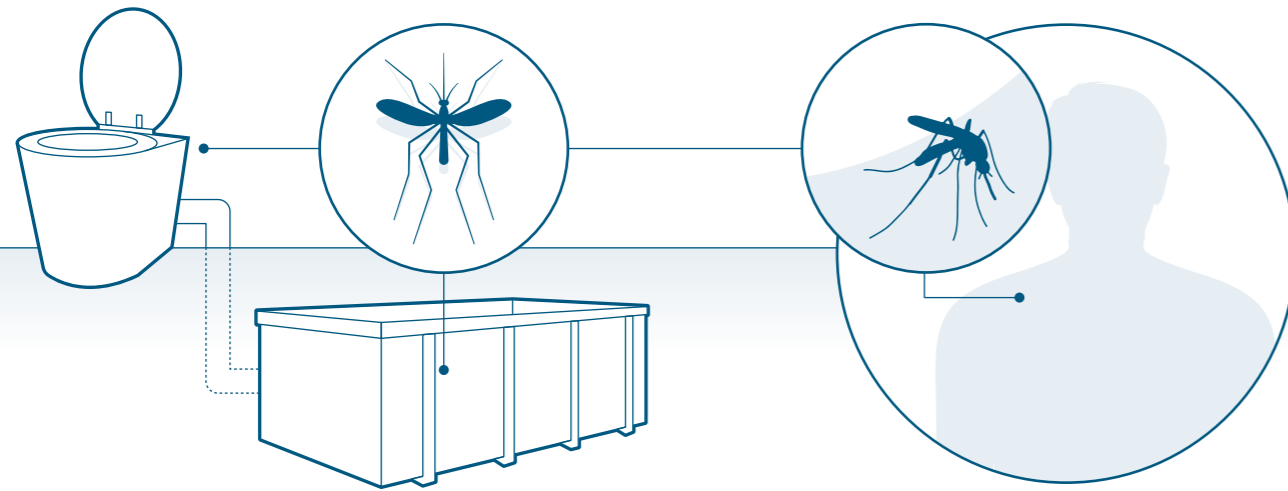
- The immediate focus on M&E should be on the proportion of households with improved access to, and use of, WASH infrastructure as a result of the intervention.
- Long-term measures of success should focus on the degree to which the risk of transmission of exposure has been reduced as a result of the intervention.



NEGLECTED TROPICAL DISEASE
NGO NETWORK

BEHAVIORS TO TARGET WITH SBC

LYMPHATIC FILARIASIS



TRANSMISSION BEHAVIORS

Bite from infected mosquito

Female mosquitos breed in uncovered drains, septic tanks, latrine pits and animal waste

PREVENTION BEHAVIORS

Drain and wastewater management

Accessible toilet construction, maintenance and cleaning

Residual indoor spray

TREATMENT BEHAVIORS

Wearing adequate footwear

Uptake of hydrocele surgery

Hygiene to reduce acute inflammatory episodes (limb washing, skin care, exercise, limb elevation)

KEY MESSAGES

- Lymphatic filariasis (LF) is an infection transmitted through mosquitoes. The vectors vary depending on the parasite responsible - mainly *Wuchereria bancrofti*, *Brugia malayi* or *Brugia Timori*.
- Water sources are important for the breeding of all the vectors and mansonioide mosquitoes; the vectors for *Brugia malayi* grow in the roots of water plants like *Pistia* so this infection is more commonly seen in waterlogged areas and those with canals and backwaters.
- The main spectrum of the LF infection/ disease includes a) asymptomatic microfilaraemia where the person affected will not have symptoms but will have microfilariae in peripheral blood and also pathological changes; b) chronic manifestations like lymphedema, hydrocele; and c) acute manifestation like acute adenolymphangitis.
- Self-care includes washing the affected limb and the unaffected limbs twice daily with clean water and then drying the limb and applying the ointments like antiseptic, antifungal, etc. Availability of accessible water source is important both at the health facility level and at home.

PROGRAM CONSIDERATIONS

LYMPHATIC FILARIASIS

FOCUS

- All LF endemic areas having people affected with lymphedema and hydrocele
- Integration of the program within the country's primary health care system
- Access to clean and safe water supply

DESIGN

- Assess the burden of people affected with lymphedema and hydrocele
- Identify at least one health facility to deliver the self-care program in each implementation unit – normally where a large number of patients are present. This health facility should have continuous access to safe and clean water
- Initially, the people affected should be brought to the health facility for training by the community
- Doctors, nurses, healthcare workers, patients and family, community members and volunteers, volunteers should be trained on self-care.
- Since domestic self-care has to be continued, water access within the domestic area should also be ascertained.

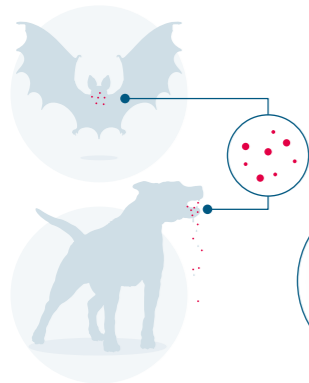
LEARN

- Monitoring of people affected should be carried out, including frequency of water usage for self-care and improvement in their condition.

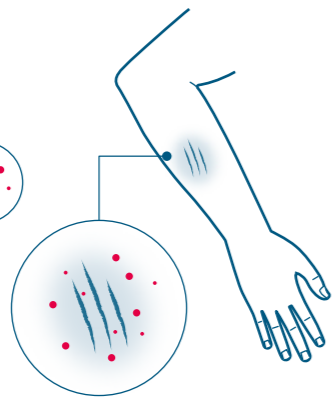
BEHAVIORS TO TARGET WITH SBC

RABIES

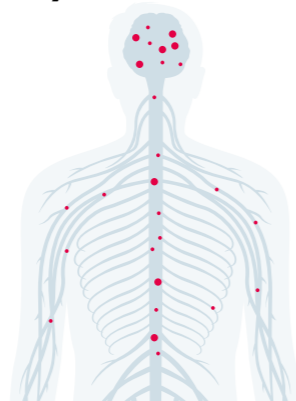
1. Virus transmitted via saliva from an infected animal.



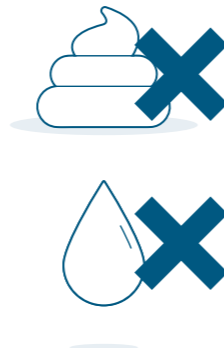
2. Bite or scratch



3. Contact with brain/nervous system tissue



4. NOT in faeces or blood



TRANSMISSION BEHAVIORS



Bite or scratch from infected animal

Contact with bats

Processing or handling of dog meat or other infected animals

PREVENTION BEHAVIORS



Vaccinating humans

Vaccinating dogs and other mammals/pets

Culling dogs

Avoidance of eating meat from animals that died of unknown causes

Learn dog behaviours to avoid bites

Safe disposal of dead animals

Safe handling and processing of raw meat

TREATMENT BEHAVIORS



Post exposure prophylaxes (PEP)

KEY MESSAGES

- Rabies is a viral disease transmitted from mammals to humans that causes severe swelling of the brain. It is transmitted through contact with saliva or brain/nervous system tissue from an infected animal through an open wound or mucous membrane.
- Dogs are the main source of rabies in humans. Other animals such as cats, hyena, bats, monkeys, and donkeys can also transmit the disease.
- Rabies is a 100% vaccine-preventable disease. Once symptoms of the disease develop it is almost always fatal. Focusing SBC interventions on preventing rabies through vaccination and avoiding exposure is critical, while also emphasizing prompt reporting and initiation of treatment after risky interactions with an animal.



PROGRAM CONSIDERATIONS

RABIES

FOCUS

- Animal and case surveillance data help to identify local hotspots of bites, confirmed cases in both animals and people, and areas to focus your program.
- Children account for about 40% of cases, so school-based programs are useful.
- As dog vaccination is one of the most strategic interventions to prevent rabies, dog owners should be considered a key population.
- Inner city/urban areas with large stray dog populations are at increased risk, as are communities where consumption of dog meat or the meat of sick animals is common.

- With use of alternative/cheaper meat sources increasing, new populations such as children who hunt, abattoir workers, dog and dogmeat market workers, food vendors, animal health workers, farmers and people who are exposed to bats are at risk. SBC for these groups should focus on self-protection from exposure.
- SBC interventions in areas lacking access to essential vaccines and/or treatment for both humans and animals should focus on keeping dogs confined, preventing dog bites, and encouraging same-day care-seeking for animal bites.



DESIGN

- Include entities working in human and animal health, surveillance, community development, agriculture and forestry, trade and entrepreneurship, drug supply-chains, mass communications and others.
- Work with government ministries and partners to harmonize existing messages and materials, provide technical expertise on essential behaviors in local contexts, and ensure that the language and format of the information are appropriate.

- Program considerations include protections when managing sick animals, proper handling and processing of raw meat, safe disposal of dead animals, and avoidance of eating or selling meat from animals who died of illness or unknown causes.
- Programs that respect cultural practices, traditional beliefs, and values around dogs, their roles, and risk of rabies are more likely to be accepted.
- Punitive measures for unconfined dogs, dog bites, and unregistered or unvaccinated animals have been shown to obstruct reporting of dog bite cases at community level.



LEARN

- Ensure that any reporting system for bites and cases in both animals and people links to national surveillance systems.
- Involve community-based monitors in capturing and reporting cases

- Monitor behavioral outcomes and determinants such as knowledge about rabies risk factors, self-efficacy to confine and vaccinate dogs in the household, and intention to seek same-day care in case of an animal bite so you can tailor interventions.



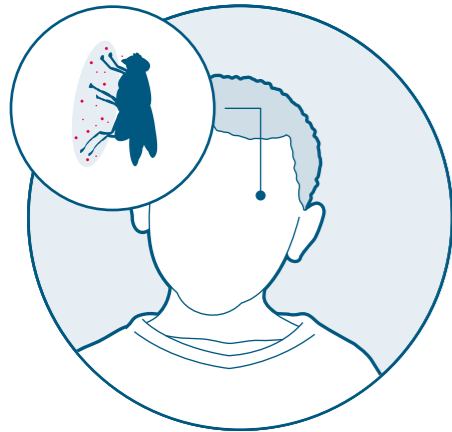
NEGLECTED TROPICAL DISEASE
NGO NETWORK

BEHAVIORS TO TARGET WITH SBC

TRACHOMA

Bacteria transferred via:

Flies



Hands/fingers



Fomites/laundry, etc



TRANSMISSION BEHAVIORS



Unclean or poorly managed sanitation facilities

Open defecation (leading to fly proliferation)

Animals kept in or close to family compounds

Unclean environment that attracts flies

PREVENTION BEHAVIORS



Washing of bedding and laundry

Hand and face washing

Reduction of flies in environment through...

Accessible toilet construction, maintenance/cleanliness

Uptake of MDA

TREATMENT BEHAVIORS*



Uptake of antibiotics through MDA

Uptake of trichiasis surgery

*Disease management and disability inclusion

KEY MESSAGES

- Trachoma is infectious, spread through repeated contact with eye discharge from an infected person via hands, towels, and eye-seeking flies.
- Trachoma thrives where there is poor sanitation and limited access to water for personal hygiene. Different behaviors therefore are performed by different groups and driven by different determinants.
- Water use behaviors are deeply embedded in people's daily lives and livelihoods (for instance, cooking, bathing, and laundry) and in settings with limited water access. A normative change strategy can be used to shift social norms and perceptions related to facial cleanliness, hygiene practices, and sanitation.
- A behavioral approach focused on promoting and sustaining behavior change at the individual, household, and community level should be prioritized.



PROGRAM CONSIDERATIONS

TRACHOMA

FOCUS

- Areas of persistent high prevalence (>30%) of trachoma prevalence despite repeated rounds of mass drug administration should be prioritized for SBC interventions.
- Endemic areas with low levels of access to safe water supply and sanitation services should be prioritized for SBC interventions.

- Environmental factors associated with more intense transmission are: inadequate hygiene, crowded households, inadequate access to water, and inadequate access to, and use of, sanitation facilities.



DESIGN

- All program design must be done with community members, based on their needs and preferences.
- Programs should be adapted to specific contexts. Tailor interventions to address the specific needs and preferences of different population groups, including marginalized and vulnerable communities.
- Utilize social networks, community influencers and role models to promote positive behavioral norms and practices within the community.

- Identify and amplify 'positive deviant' behaviors - practices that are effective in preventing trachoma but not yet widespread - in communities. Encourage individuals and households to serve as role models and catalysts for behavior change.
- Work with water supply and sanitation service providers to ensure provision of accessible, affordable, available, acceptable, high quality water supply and sanitation services.



LEARN

- Regularly monitor the uptake of key behaviors related to trachoma prevention and control. Use formative research, qualitative assessments and quantitative surveys to assess behavioral barriers, facilitators, and progress towards behavior change objectives.

- Success measures should focus on the degree to which the risk of transmission and exposure has been reduced as a result of the intervention.

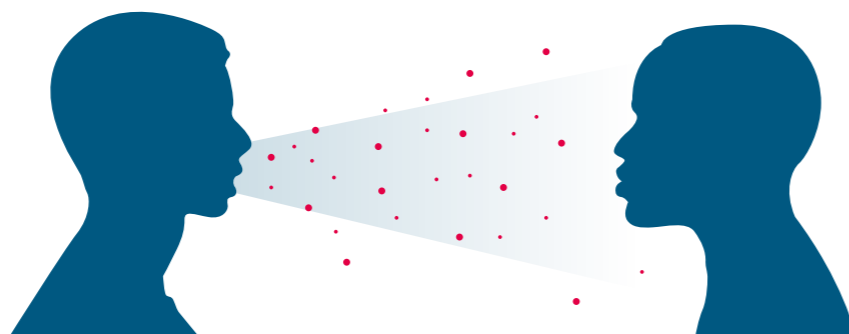


NEGLECTED TROPICAL DISEASE
NGO NETWORK

BEHAVIORS TO TARGET WITH SBC

LEPROSY

Bacteria transferred via droplets from the nose and mouth during close and frequent contact with untreated cases



*The disease is not spread through casual contact with a person who has leprosy

TRANSMISSION BEHAVIORS



Close and frequent contact with untreated cases

PREVENTION BEHAVIORS



Practice of good hygiene measures e.g. handwashing with soap

Use of improved water supply

Accessible toilet construction, maintenance/cleanliness

Emphasis on safe water and sanitation for overall good health and resistance to disease

TREATMENT BEHAVIORS



Improved hygiene to reduce severity of disease symptoms, and exclusion

Addressing social stigma and misconceptions about transmission

Ensuring affected people have access to safe water, sanitation and hygiene facilities and preventing stigma-based exclusion

Note: WASH practices do not prevent leprosy. They are critical for the self-care practice of people with leprosy disability.

KEY MESSAGES

- Leprosy is a chronic infectious disease which is caused by a type of bacteria called *Mycobacterium leprae*. The disease affects skin, peripheral nerves, mucosa of the upper respiratory tract, and eyes. Leprosy is curable and treatment in the early stages can prevent disability. Apart from the physical deformity, people affected by leprosy also face stigmatization and discrimination.
- WASH is essential for self-care in leprosy, otherwise wounds become infected leading to worsening disability and deformity, and discrimination and social exclusion for the person affected, often extending to their family.
- Deep-seated social stigma and misconceptions about transmission discourage people affected from accessing shared water and sanitation facilities both at the household and community level.
- Based on this, WASH behavioral approaches and messaging are best integrated with programs targeting other endemic WASH-related diseases and overall health promotion, both to respect affected people's privacy and minimize discrimination.
- Emphasis should be placed on all in the community having easy access to safe water, adequate sanitation, and practicing recommended hygienic behaviors.



PROGRAM CONSIDERATIONS

LEPROSY

FOCUS

- WASH must become a non-negotiable component of all leprosy programmes; understood as closely linked to decreasing transmission and preventing disability. While research suggests soil and water transmission of *M. leprae*, the emphasis on safe water and sanitation for overall good health and resistance to disease is the key consideration here.



DESIGN

- WASH education, WASH behavior change communication, and advocacy for essential water and sanitation facilities and services must be an integral component of all leprosy programs.
- WASH is a universal need of communities at risk of NTDs. Therefore, WASH program design that's done participatively with these communities will ensure inclusion without singling out affected individuals.



LEARN

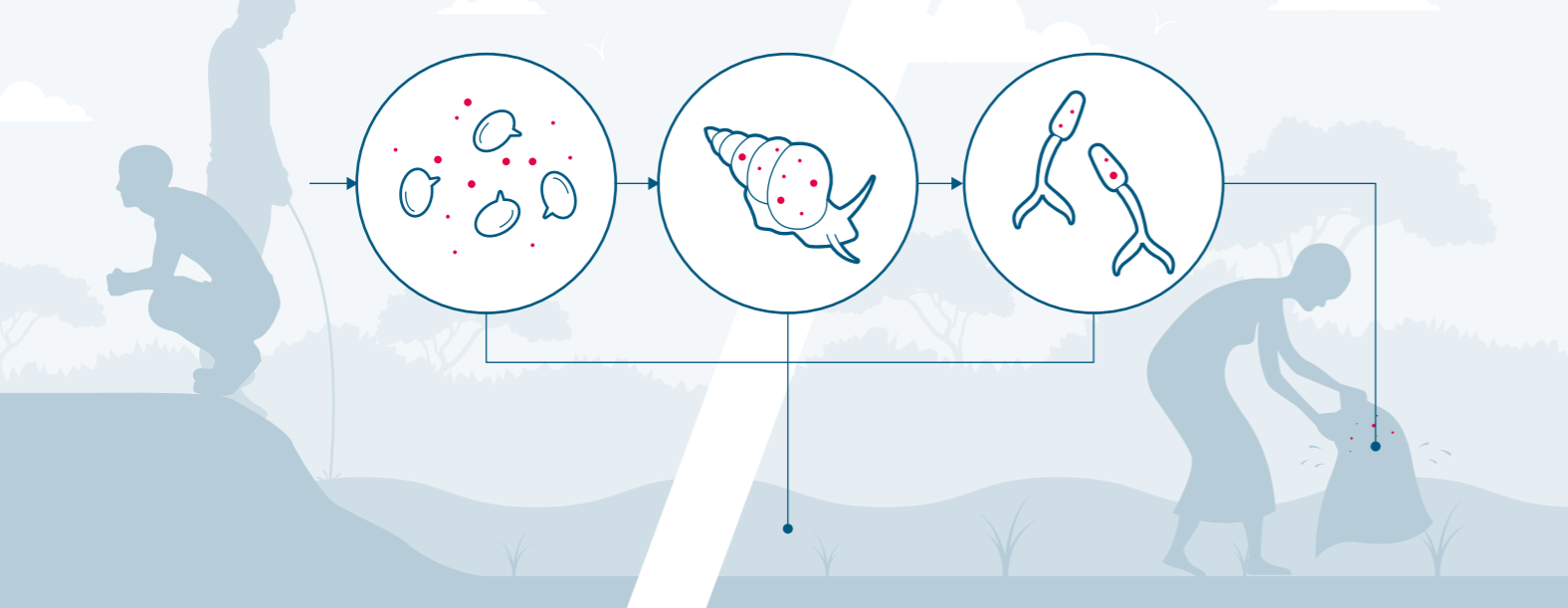
- Depending on the nature of the program, include indicators on WASH access at the level of both the community and the affected person and their household.
- Success measures can be based around the affected person having:
 - Easy access to safe water. The definition of 'easy' needs to be context-based and also take into consideration the disability.
 - Easy access to a sanitary toilet adapted to the person's disability.
 - Handwashing with soap at the recommended times.
 - Regularity of practice of recommended self-care. Lack of water and soap is not cited as the reason for irregular or non-practice of self-care.



BEHAVIORS TO TARGET WITH SBC

SCHISTOSOMIASIS

Parasite transferred via snail intermediate host



TRANSMISSION BEHAVIORS

Open defecation or urination into/near water source

Unclean or poorly managed sanitation facilities resulting in discharge/runoff of eggs into surface water

PREVENTION BEHAVIORS

Use of improved water supply

Accessible toilet construction, maintenance/cleanliness

Reduction of contact with surface freshwater sources

TREATMENT BEHAVIORS

Uptake of MDA

Healthcare seeking for morbidities and complications (e.g. genital schistosomiasis)

KEY MESSAGES

- Schistosomiasis is caused by parasitic worms of the genus *Schistosoma*, which are transmitted through contact with contaminated freshwater.
- Schistosomiasis is highly focal, with transmission and exposure varying widely depending on ecological settings, types and reasons for water contact activities. Different behaviors are performed by different groups and driven by different determinants.
- Water contact behaviors are deeply embedded in people's daily lives and livelihoods (for instance, fishing, recreational bathing, laundry) and are unlikely to change without a viable alternative option that is an obvious improvement. If primary prevention of water contamination is not possible (e.g. through universal sanitation coverage), behavior change interventions should focus on risk reduction, rather than prevention of infection. A behavioral approach that is too comprehensive or broad to take account of these specificities is unlikely to be impactful.

PROGRAM CONSIDERATIONS

SCHISTOSOMIASIS

FOCUS

- Areas of persistent high prevalence of (>50%) schistosomiasis despite repeated rounds of mass drug administration should be prioritized.
- Access to safe water supply services that should meet all domestic needs.
- In endemic areas, the extent to which people rely on water-based livelihoods, e.g. fishing and rice farming, will affect the likelihood of transmission.

DESIGN

- Program design must be done with community members, based on their needs and preferences
- Pin-point where transmission is taking place using participatory mapping - is it a specific water body or location?
- Understand the relationship of the community with the water contact site. Who is causing the transmission? Who is being exposed? Which activities are most likely to cause transmission and exposure? Are some activities more prominent than others?
- Use information on location and degree of exposure to agree priority actions. Exposure can be assessed using water contact site observations, in which data collectors spend a day at a water contact site capturing the amount of time spent in contact with water as well as the specific activities carried out. Activities can be captured using a simple checklist, and then analyzed to compare exposure across different sites and types of activities.
- Work with water supply and sanitation service providers to ensure that alternative water sources are provided and to reduce primary contamination.

LEARN

- Behavioral monitoring (such as structured observations) should be done at the water site, not at household level (unless the household is located immediately near the water).
- Success measures should focus on the degree to which the risk of transmission of exposure has been reduced as a result of the intervention.



NEGLECTED TROPICAL DISEASE
NGO NETWORK

