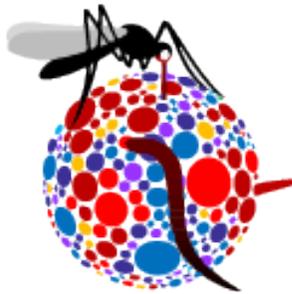# Outputs from the 2020 Meeting of the Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD)

**COR-NTD 2020**

**Virtual Meeting, November 12 – 14**

**Integrating for Impact**

Neglected Tropical Diseases Support Center, COR-NTD Secretariat – March 2021

# REPORT OVERVIEW

This document outlines the knowledge gaps and next steps identified at the annual meeting of the Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD), which took place virtually from November 12 to November 14, 2020.

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COR-NTD 2020 MEETING OUTPUTS

# LYMPHATIC FILARIASIS

## TAS to the Future: New Approaches for the Last Mile of LF

### Knowledge Gaps

**OR to improve post-treatment surveillance**
- It is unclear how concerned we should be about areas classified as non-endemic for which old or limited data are available.
- Although there is discussion about using Wb123 ELISA to detect exposure in children during post-validation surveillance (PVS) for lymphatic filariasis (LF), it is unclear what seroprevalence threshold should be used.
- It is not clear how concerned we should be about 'hotspot' villages with high prevalence in EUs that pass the transmission assessment survey (TAS).
- It is not clear which diagnostic test and which age group should be used for PVS.

**OR to improve EU formation during TAS**
- It is unclear what criteria should be used to trigger the division of an evaluation unit (EU).
- Some programs are including purposive clusters, in addition to the 30+ random clusters, in TAS 2 or TAS 3 surveys, based on the identification of positive cases in a previous TAS.  The utility and cost-effectiveness of this approach for identifying hotspots that merit program action is unclear and should be investigated.

**OR to prioritize PVS within a country**
- Clear guidelines for conducting PVS are urgently needed.
- Geostatistical models should be translated into user-friendly tools that countries can use.
- Program Managers should be engaged much more in ongoing discussions on PVS strategies.

**OR to guide hotspot response during PVS**
- Thresholds to use when defining/responding to hotspots have not been defined.
- It is unclear how to combine different diagnostics into a single model.
- It is unclear how early we can/should respond to potential hotspots. More information is needed on the dynamics of resurgence and how fast and far transmission can spread.

### Next Steps

**OR to improve post-treatment and post-validation surveillance**
- What is the programmatic value of sampling in communities where positive cases were found during TAS? When is this recommended and what should be done with the information obtained?
- It will be important to focus on utilizing already-collected data, particularly those from large seroprevalence surveys. How can data from these surveys, which may not be optimally designed for NTD program needs, be used effectively?
- It would be useful to map out an overall multi-year OR surveillance strategy with WHO and programs for buy-in from USAID and other donors.

- OR should be conducted to determine the thresholds and other characteristics below which a public health response is not needed.
- If it is determined that additional mass drug administrations (MDAs) should be conducted, what is the appropriate unit of response?
- OR should be conducted to compare the effectiveness of various PVS methods in a well-characterized population.
- Although models have the potential to be useful for answering some of the questions around PVS, the priority should be to focus on obtaining high-quality inputs to inform models.
- Additional research is needed on the kinetics of available biological markers.
- Are our population-based surveys systematically missing non-adherent individuals? How do we measure this and how do we design surveys to capture these individuals?
- What are the appropriate entomological thresholds associated with elimination as a public health problem (and elimination of transmission)?
- How can we engage communities to generate demand for surveillance?
- An economic analysis, comparing the program savings and productivity gains of being LF-free with the cost of surveillance could help to garner country buy-in.

## OR to improve EU formation during TAS
- OR focused on the criteria that should be used to trigger the division of an EU, as well as how to divide an EU, is needed.
- Will better EU formation prevent an evaluation area from passing TAS when transmission is ongoing?
- Is there a way to incorporate oversampling in potential at-risk communities? Would a pre-TAS 2 or pre-TAS 3 survey be useful?
- With some extra sampling during TAS, simulations could be run to compare what the results would have been if TAS had been conducted at the sub-EU level.

## OR to prioritize PVS within a country
- More field trials of various PVS proposals/strategies to identify priority PVS strategies
- Determine the settings where various geostatistical models are applicable
- Can geostatistical models be standardized to be usable across all country settings?
- Can other health system surveillance platforms be used to detect LF signals of ongoing LF transmission?
- How do we leverage the health system to sustain long-term post-validation surveillance?

## OR to guide hotspot response during PVS
- Are TAS data sufficient for identifying hotspots? If not the raw data, what about when combined with environmental covariates using geostatistical models? If not, should we be conducting community surveys focused on older age groups?
- What are the most effective tools and strategies to control and clear hotspots? Are targeted treatment approaches sufficient? Empiric studies should be conducted to look at these approaches and the intervention should be compared with doing nothing.
- Will some hotspots die off on their own? Will they spread if left unchecked? Longitudinal monitoring in the absence of intervention would provide insight.
- A list of steps needed to identify hotspots should be defined.

# ONCHOCERCIASIS

## Onchocerciasis – Clearing Hurdles for Elimination

### Knowledge Gaps

**Serologic threshold**
- There is some concern that the new qPCR diagnostic for black flies (which will be used to validate a serologic threshold) is more sensitive. This also implies that the current stopping threshold for black flies, which was established based on older PCR approaches, may need to be revised if a more sensitive technique is to be used. The alternative is to accept that the entomologic threshold will be more conservative when assessed via qPCR.
- We need point-of-care tests and diagnostic tools, especially for remote areas.
- We need empirical data to inform the models; particularly to relate serological prevalence with force of infection.

**Diagnostic tools**
- The lack of a sample repository is a real limitation for bringing on new tools, as is the lack of a gold standard tool against which to make comparisons.
- Current thresholds are specific to antibody tests; what happens if we select an antigen test?
- We need cross-border standards to protect program gains and encourage collaboration.
- Is a single standardized tool better than setting-specific tools or tools that adapt with the time?
- Vector identification tools are needed. For *S. damnosum* we are dealing with a big sibling species complex; adult flies cannot by typed by cytotaxonomy, advanced molecular tools are needed.

**Environmental Suitability**
- In many areas data are either missing or outdated.
- Research needs to be done to see how recent climate changes affect black fly-suitable habitats.
- It can be challenging to translate the suitability maps to practical information for the teams on the ground to find and delineate the areas.
- How does this suitability information impact our implementation unit formation? Should we be looking for transmission zones?
- Some programs require additional capacity building to leverage the software to create suitability maps.
- It would be helpful to have GPS coordinates of communities in the remote areas where onchocerciasis is endemic.
- We need to consider vector movement patterns, in addition to human movement.

## Next Steps

**Serologic threshold**
- We cannot move forward with setting the serologic threshold until we have the new qPCR methodology in place to ensure the black fly comparisons are standardized.
- There is a need to correlate the serologic threshold with entomologic data.

**Diagnostic tools**
- We should establish a sample repository for diagnostic tools.
- We need a method to set reliable cut-offs for tests.
- Diagnostic tools need to be standardized and require a set approach for establishing a Quality Assurance/Quality Control system.

**Environmental Suitability**
- Ground truthing of the models is needed.
- Ground truthing is also needed of satellite settlement predictions, as nomadic populations may have moved on.
- It would be good to explore collaboration with other sectors that have leveraged GIS technology well.
- What is the cost-effectiveness of this tool? What is the cost-effectiveness of the various tools for identifying first-line villages? There is fear that innovative tools will be expensive or that donors won't fund it.
- There is some fear that these innovations will be expensive and hard to use. User-friendly software is needed to make the maps accessible for programs and capacity building is necessary so that programs can use the information for decision making.
- There is a need to document the decision process, when it comes to making determinations of environmental suitability/non-suitability.

# SCHISTOSOMIASIS

## Developing an M&E framework for schistosomiasis and prioritizing operational research to achieve schistosomiasis elimination

Knowledge Gaps

### Monitoring and Evaluation (M&E)

*Data and tools that can help to identify optimal survey designs:*
- Secondary analysis on available age-infection-profile datasets will help determine which are the best age-group/at-risk groups to sample.
- Further fine-scale spatial species-specific data should be collected, and geostatistical analysis used to determine programmatically feasible survey designs.
- Optimal survey designs should include new and improved diagnostics which are available for programmatic use and sufficiently sensitive at lower levels of infection. In addition to this, for interruption of transmission (IoT), optimal survey designs will potentially need environment/surveillance diagnostics.
- The optimal survey design needs to be standardized, unless archetype has an influence, and produce data which identify residual foci of transmission.
- Optimal survey designs should allow for integration, where feasible, with soil-transmitted helminths.

*Data and tools to define targeted thresholds and indicators for elimination as a public health problem:*
- Secondary analysis on available data and collection of new data will be needed to determine whether we need species-specific indicators of prevalence, morbidity or intensity, as well as age- and sex-specific indicators to inform the threshold(s) for elimination as a public health problem (EPHP).
- New data analysis is needed to determine what diagnostics can be used by programs to assess whether EPHP thresholds have been met. It is likely that some of these thresholds will require improved diagnostics tools to be developed.
- Mathematical modelling can be used to determine how reaching the EPHP threshold will inform programmatic decisions.

*Data and tools that can help to determine that EPHP has been achieved and maintained:*
- Available data will need to be analysed and new data collected to determine what are the key interventions and surveillance approaches required to maintain EPHP and if this differs by archetype.
- Data analysis should address which age-groups, areas and occupations should be monitored once EPHP is achieved, and what should be the frequency of monitoring.
- New data collection and analysis is needed to determine whether active or passive, or both surveillance strategies are needed to validate that EPHP has been, and continues to be, maintained.
- New and improved diagnostic tools should be developed and used for surveillance of EPHP.
- New data collection and analysis is needed to determine how surveillance strategies can be embedded into health systems.

Next Steps

**Developing a Monitoring and Evaluation Framework**

*As we move into a new WHO NTD Roadmap for 2021-2030 we need to address the highlighted knowledge gaps and prioritize operational research to establish a stronger M&E framework in order for schistosomiasis programs to progress beyond the current, often repetitive cycle. This would be an end-to-end pathway from baseline to verification of elimination with key phases of:*

- Baseline Mapping and Attack: Appropriate survey designs that assess where schistosomiasis infection is a risk and guides required interventions.
- Achieving and maintaining elimination as a public health problem (EPHP): This is where the majority of countries with the highest burdens of schistosomiasis currently (in 2020) sit. To achieve and maintain EPHP, programs will need to sustain an appropriate level of mass drug administration (MDA) and strengthen cross-sectoral interventions.
- Surveillance and validation of EPHP: Here a program could decide to remain in this phase post-validation with a specific package of reduced interventions, or proceed to the step outlined in the next bullet.
- Achieving Interruption of transmission (IoT) with tailored micro-interventions such as focal MDA (fMDA) or focal test-treat-track (fTTT) targeted at the borough, parish or village level, coupled with effective behavior change communication (BCC), water and sanitation coordination, vector ecology management (VEM) and where required, veterinary public health (VPH). Here prevalence thresholds are required to guide decisions on when to stop large-scale MDA and start tailoring interventions to the micro-level. Once IoT has been achieved, the process of verification and surveillance will begin.
- Surveillance and verification of IoT / Maintaining IoT by surveillance-response: The verification of IoT requires a clear surveillance strategy. Once IoT has been reached in some areas or countrywide, continued surveillance will be necessary to maintain this achievement and to detect recrudescence of transmission/imported infections early. Timely and effective response mechanisms and measures need to be in place to react immediately to potential outbreaks. Such a surveillance will also be needed to build the evidence for the WHO IoT verification.

*A strong M&E framework for schistosomiasis would ensure equitable distribution of resources to communities based on need, risk, and epidemiologic phase, provide clear evidence-based programmatic decisions and would capitalize on the investments made to control and eliminate schistosomiasis.*

Knowledge Gaps

## Epidemiology

*Data and tools that can help to identify and respond to transmission hotspots:*
- Prediction models that can be used to help identify and target hotspots.
- Data analysis revealing the characteristics of hotspots.
- Improved diagnostics that can identify (re)infection levels in humans and snails (and other reservoir hosts), also shortly after treatment.
- Development and testing of intervention packages to sustainably reduce transmission in hotspots.

*Tools and strategies for effective surveillance and response, and validation of EPHP:*
- Using any available data from countries & areas that have low prevalence and intensity of schistosomiasis, modelling can be applied to explore surveillance strategies for EPHP.
- Collecting data from low prevalence areas and regions (AFRO/PAHO /WPRO) and testing out surveillance approaches using active and passive case detection and environmental surveillance.
- Data analysis can help define "early warning characteristics" for recrudescence and determine optimal response to outbreaks and recrudescence.
- Testing of strategies to determine how to address individuals with high intensity infections in low-transmission settings that are contributing to transmission.

*Tools and strategies for effective surveillance-response and verification of IoT:*
- Available data from IoT areas and data collected from near IoT areas could be used to determine how and where surveillance should be done.
- Data from active, passive and reactive case detection should be collected and analysed to determine which surveillance approach is most effective and feasible.
- Determine and define what are the diagnostic needs at different levels depending on the strategy of surveillance – Point-of-care at peripheral level? High throughput at central level? Pooling strategies? Sensitivity versus specificity? For humans and snails?
- Define what are "early warning characteristics" for recrudescence using available data and collecting new data from IoT and near IoT areas.
- Determine what cross-border surveillance is required.
- Collect data from recent outbreaks and use modelling analysis to determine what is the optimal response to outbreaks and recrudescence.
- Investigate and collect new data in settings where EPHP and IoT have been achieved to determine what is the optimal response to outbreaks and recrudescence.

## Next Steps

### Optimal survey designs for key programmatic stages

- Population-based cross-sectional survey data collected through an oversampling approach to inform geostatistical modelling, which would test survey designs.
- The optimal survey design would then be determined based on accuracy and programmatic feasibility, sample size, availability of sampling frame, and statistical/analytic expertise required to design and interpret the survey.
- Secondary analysis on available age-infection-profile datasets to determine which are the best age-group/at-risk groups to sample will help determine this.

### Identifying and addressing hotspots/non-responding communities

- Studies across multiple archetypes and countries are to assess what environmental, behavioral and socio-economic factors render a hotspot a hotspot/persistent hotpot.
- Intervention studies a to determine how transmission in hotspot areas can be effectively and sustainably reduced.
- A hotspot/non-responding communities intervention flowchart, which could include:
  - o MDA frequency for addressing non-responding/hotspot communities
  - o WASH & BCC coverage levels by archetype
  - o VEM intervention by archetype

### Defining threshold for EPHP and maintaining EPHP

- Cross-sectional surveys to be conducted across multiple archetypes to identify meaningful and measurable targets for detecting the control and elimination of schistosomiasis-related morbidity in Africa, and designed to answer the following primary evaluation questions:
  - o What are the optimal morbidity markers for *S. mansoni* and *S. haematobium* in different age groups, and how do they relate to infection indicators?
  - o What are the species- and age-specific morbidity goals for which schistosomiasis programs should be aiming for in an EPHP context?
- Further operational research to determine which optimal combination of interventions are required to maintain the EPHP threshold for which there is little, or no, new detectable schistosomiasis-associated morbidity.

### Defining threshold for IoT and determining surveillance-response approaches

- Modelling to identify surveillance/case detection strategies that are suitable to detect infected individuals that might contribute to/re-introduce transmission.
- Response interventions to react to infected individuals/contamination of environment need to be investigated for their ability to avoid recrudescence.
- Surveillance-response approaches need to be investigated for their operational feasibility, their sensitivity to detect cases, their ability to maintain IoT, and for cost-effectiveness.
- Thresholds of IoT and at what prevalence levels it is safe to move towards a surveillance-response approach need to be determined, considering the diagnostics available and recommendable.

## Knowledge Gaps

**Interventions**
- Interventions designed to achieve the goals of the specific phases of Control to EPHP to IoT are required.
- Once the goal of each phase is achieved, those gains must be maintained and a decision on the feasibility/appropriateness of moving to the next phase must be made after which the appropriate tools and interventions should be rolled out accordingly.
- What are the optimal tools for achieving and maintaining EPHP, how will EPHP validation be assessed and surveyed, and how will it be decided when and where the IoT phase should be implemented and what interventions will it entail? For each of these phases do interventions need to be tailored to the transmission archetype?
- These archetypes will need to be defined using available data.
- Modelling analysis could help answer questions on what pressure, BCC, coverage threshold for safely managed water and sanitation, effective VEM and VPH for each phase.
- Testing interventions for BCC, WASH, VEM, VPH in different archetypes and prevalence settings requires a good design and monitoring strategy to collect evidence.

## Next Steps

**Determining which interventions are required to efficiently maximize impact**
- Initially mathematical modelling could utilize existing data to explore and present how EPHP and IoT thresholds could be met in different archetypes, using different combinations of interventions to different target populations. Interventions would include:
  - Preventive chemotherapy
  - BCC
  - Safely managed water and sanitation
  - Vector ecology management
  - Veterinary public health.
- Following the modelling, operational research evaluating the impact achieved in a programmatic context by combinations of interventions would need to be conducted, including collecting data that would help to strengthen the model parameters.

# Female Genital Schistosomiasis: Using a systems-thinking approach

## Knowledge Gaps

### Prevention
- Social mobilization and sensitization strategies for community members, including men.
- Increase awareness in school-age through targeted health education.
- Determine how to most effectively utilize community health workers (CHWs) to raise awareness and support prevention of female genital schistosomiasis (FGS), which will require development of tools for training and to support the sensitization activities developed using a participatory approach.
- Adaption of the WHO WASH NTD tool for the FGS context to support integration and development of partnerships.
- Development of tools for advocacy to support government and policymaker engagement to overcome the lack of awareness amongst these key stakeholders.
- More needs to be done to understand how to tackle stigma effectively in the community, including which stakeholders to involve and how to scale up.

### Treatment and Care
- Need to integrate FGS into training for health workers at all levels.
- Country challenges in procurement of sufficient praziquantel.
- Greater understanding of the chronic morbidity associated with FGS, and of treatment and clinical outcomes.
- Determining how to reach women with praziquantel most effectively and at scale.
- Inadequacy of current diagnostics and need for point-of-care tests and rapid diagnostics.
- Need to understand what tools are effective and how the tools required may differ for different levels of the health system.

### Integration
- Further evidence on the optimal strategies to integrate and what tools will be required.
- Ability to measure the effectiveness of integration, including adding indicators for FGS into DHIS2, developing an M&E framework, measuring the number of trainings including FGS, and determining the perceptions of patients.
- Further epidemiological and clinical studies to explore:
  - Prevalence and intensity of FGS infection in relation to prevalence of schistosomiasis infection
  - Mechanisms and diagnostics to predict severity of FGS infection
  - Factors which increase vulnerability of developing FGS, for example, demographics, intensity of infection, co-infections.
  - Relationship between FGS and with other conditions
  - Associations between MGS and FGS

## Next Steps

### Prevention
- Determine most effective strategies for community sensitization (including men) and stigma reduction; for example, establishing peer support groups, or engaging CHWs.
- Develop standardized resources and information, education and communication material to support this.
- Develop standardized teaching materials and engage with Ministries of Education to incorporate FGS into the curriculum.
- Adapt existing resources to support integration and development of partnerships with HIV/AIDS, reproductive health, WASH and NTD MMDP.
- Establish networks with community organizations.
- Understand more about the epidemiology and risk factors associated with FGS.

### Treatment and Care
- Develop and evaluate training tools for health workers, including online tools and validation of the FGS competencies which have already been developed through multi-sectoral collaboration.
- Evaluate effectiveness of diagnostics at different health system levels and develop a syndromic management tool which can be used in low resource settings.
- Design and evaluate morbidity management strategies for chronic FGS and how this could be integrated into existing MMDP strategies
- Determine which platforms are most effective to reach girls and women of childbearing age with preventive chemotherapy at scale.
- Evaluate the feasibility and impact of routine screening for FGS.

### Integration
- Evaluate strategies for optimal integration of FGS into existing health services and determine how the impact of this can be measured.
- Develop tools for advocacy to support government and policymaker engagement; this will be essential to advocate for and support provision of adequate and affordable praziquantel.
- Next steps for Ministries of Health:
    - Establish reporting mechanisms for FGS
    - Embed training tools for FGS into medical curriculum at all levels of the health system and consider online training platforms
    - Establish effective monitoring, evaluation and supportive supervision of FGS management

# SOIL-TRANSMITTED HELMINTHIASIS

## STH: OR needs to sustain the gains

### Knowledge Gaps

**Integrated Hotspots**
- Poor identification of disease hotspots possibly stymies the integration of soil-transmitted helminthiasis (STH) and schistosomiasis (SCH) surveillance and intervention.
- Consequently, there is a need to reconcile these differences in the focuses of STH and SCH programs in order to identify and use integrated hotspot approaches.
- Co-sampling or spatially regulated sampling framework requires considerable statistical expertise that may not be currently accessible in endemic countries.
- It remains unclear how best to define/quantify "response" to MDA (for SCH).
- The need for capacity strengthening to improve statistical expertise for using co-sampling or spatially regulated sampling frameworks for STH and SCH surveillance was identified, as was the need for high-quality environmental and location data to enable spatially regulated sampling frameworks.

**India's Helminth Program**
- In India, deworming has historically been managed and executed at the state level; it remains to be seen how treatment can remain cost-effective in a shifting prevalence environment.
- There is a need for alternate diagnostics as prevalence drops and for drug efficacy surveys as MDA continues, over time.
- In what contexts should the national program undertake community-based surveys to determine STH prevalence and intensity?

**WASH and NTDs**
- It is not clear what kind of WASH intervention modalities might have the most impact on STH.
- WASH strategies are not currently standardized to achieve high coverage and use.
- How can we quantify the magnitude of effects of targeted interventions on STH and SCH?
- How can the NTD community think about WASH and mainstream NTD-related behaviors into WASH programming?
- Few interventions utilize behavioral-centered design; interventions often focus on addressing risk and ability factors.
- Community engagement – need a solid understanding of community ideas, needs, & priorities, in order to design effective and accepted interventions.
- Opportunities of NTD surveys to include WASH: standardization is important to ensure relevant and comparable data is collected for stronger analysis.
- Role of gender and power dynamics in uptake of WASH interventions needs further research.
- How can we help large-scale NTD programs and WASH sectors become better integrated and leverage each other's resources to reduce burden of STH and SCH?

## Next Steps

### Integrated Hotspots
- How can we extend spatially regulated sampling frameworks to community-based surveys?
- How many rounds of MDA are required before classifying an area as a hotspot?
- Can we reallocate resources from responsive to unresponsive areas in a country like Uganda where there appear to be many hotspots?
- What criteria can identify effective WASH interventions in hotspots – would WASH interventions that may be effective in hotspots for SCH also work for STH?
- How quickly is morbidity resolved for STH and SCH, and what are the differences in how morbidity is resolved in these two diseases?
- What is the applicability of the STH scoping tools/checklists for SCH?
- How can we monitor treatment areas over time to identify factors that can predict a potential hotspot?
- Are there shared reasons for why some areas become hotspots for STH and SCH?
- Is integrated surveillance for STH and SCH at the sub-district level feasible?

### India's Helminth Program
- What are the decision-making criteria to move from standard WHO state treatment frequency decisions to alternate approaches?
- What impact are WASH efforts having on STH prevalence/intensity, and how can we best target them for improved outcomes?
- How and what type of modelling can best contribute to future deworming efforts in India?
- How, when, and at what scale should drug efficacy be addressed?
- What is the best strategy to facilitate integration with other government agencies responsible for WASH, LF to enhance deworming impact?

### WASH and NTDs
- What kinds of individual WASH intervention modalities will have the most impact on STH?
- What are the minimum coverage thresholds necessary in WASH interventions to see a noticeable impact on STH?
- Is fecal egg count a good proxy for measuring impact of the effects of WASH targeted interventions on STH and SCH?
- What are the synergistic effects of WASH interventions alongside PC?
- What is the impact of sharing latrines on STH and SCH?
- What is the role of gender and power dynamics on the uptake of interventions as well as prevalence?
- How do we measure true usage of latrine and soaps?
- Does WASH influence school attendance?
- How can we standardize data collection on WASH and NTDs? How can we collect better quality data?

# TRACHOMA

## Speeding Elimination: A vs. FE – Re-assessment of the SAFE strategy

Knowledge Gaps

### Antibiotics
- Enhanced MDA strategies are often suggested for areas of persistent trachoma, but currently there is no definition for persistent trachoma. We need to define the characteristics of a community with persistent trachoma.
- Community eligibility for enhanced MDA:
    - This shouldn't only be available to areas with persistent trachoma, but we need to determine what characteristics would allow the community to be eligible.
    - There is a need to determine populations that would receive treatment (school-age children or children and immediate caretakers).
- Enhanced MDA is expensive; it would be helpful to determine if these strategies could be integrated with other programs.
- Coverage – should this measure be changed to only include children?

### Facial Cleanliness and Environmental Improvements
- How do we focus "F&E" interventions (without understanding the routes of transmission)?
- Currently, there is large variation in the definitions of measurements of WASH improvements.
    - Without these definitions – how do we guide programmatic activities and recommendations about the most effective ways to change (and measure)?
- Need tools for integration with the broader WASH sector.
- Need to focus on sustainability – how do we handover from research to programs?
- Create "positive messaging" for facial cleanliness – making sure not to marginalize any populations.
- Is it possible to create specific guidance for environmental improvements that is not regionally specific?

## Next Steps

**Antibiotics**

*Operational research is needed that would:*

- Focus on compliance over time, in particular in the potential biannual or quarterly programs.
  - Are we consistently missing the same people?
  - This more granular time series would enable insights into serial non-compliance households.
- Determine which MDA approach (twice, thrice, four times) accelerates disease reduction more rapidly measuring all indicators.

**Facial Cleanliness**

*Operational research is needed that would:*

- Determine the best ways to enhance sustained F&E-related behavior change through integration and mainstreaming.
- Identify key barriers to habit formation and help develop solutions to overcome them.
- Determine the best way of measuring facial cleanliness.
- Devise how to market clean faces.
  - How regional are effective messages about clean faces?
  - There is some discussion about "dignity" or "beauty," but will there be negative consequences in further marginalizing or shaming the poorest individuals.

**Environmental Improvements**

*Research needs include:*

- A randomized controlled trial (RCT) demonstrating impact of E on reducing trachoma/its relative contribution to achieving elimination.
  - Which "E" interventions contribute most to achieving trachoma elimination and how best can we implement them?
- Large, long-term RCTs with WASH and MDA together.
- A study to determine whether advocacy to governments leads to increased spending/implementation of E in trachoma endemic communities.
- Smaller pilot studies of specific interventions looking at behavioral outcomes as the primary outcomes (as opposed to trachoma outcomes).
- A study to determine whether WASH alone maintains elimination thresholds in hypo- or meso-endemic communities.
- Studies to determine the most effective and cost-effective strategies to behavior change to increase uptake of latrine usage and improved hygiene.
- Studies to understanding barriers to long-term maintenance and accessibility of E and how that impacts sustained elimination thresholds. Barriers could include:
  - Governance
  - Depleting ground and surface water sources
  - Maintenance of latrines and pumps

# Tackling Trachoma Endgame Challenges

## Knowledge Gaps

- Definition of persistence for deciding if enhanced strategies are needed.
    - One that defines persistence based on data from multiple surveys, encompassing "floating" persistence, "bouncing" persistence and "rebounding" persistence
    - One for areas that are just beginning treatment but are "hyper-endemic" and will likely require increased intensity of intervention
- Methods/tools to identify districts likely to take longer to reach the trachomatous inflammation – follicular (TF) elimination threshold, taking into consideration covariates such as baseline TF, MDA coverage, WASH variables, and spatial covariates.
- Methods to predict districts likely to show recrudescence.
- Tools/standardized "investigation" to facilitate the rule out quality of program delivery as a likely reason for repeat TIS with TF≥5%.
- A systematic, data-driven algorithm to assist in decision making in districts with persistent trachoma
- Established flexibility to MDA guidelines for districts with persistent trachoma.
- Grader supervision methods to ensure grader proficiency is not contributing to diagnostic error.
- Larger-scale, higher-powered data to determine which enhanced and/or targeted treatment strategies are more effective than annual MDA.

## Next Steps

**Program Investigation**
- What kind of metric can be developed to show that quality expectations for program implementation have been met?
- What universally recognized quality control measures can be developed and implemented for the supervision of graders?
- How do we contextually investigate unexpected or abnormal results – whether the TF survey result was <5% or ≥5%?

**Program Monitoring (Supplemental Indicators)**
- Should we include trachomatous inflammation (TI) in the decision making?
  - Can we grade more accurately and efficiently?
  - Can TI be consistently graded using photography?
  - How do photos compare to field diagnosis of TI?
- How can baseline TF be used as a part of the decision making and in what populations?
  - Is it possible to predict when threshold will be reached based on the trajectory of TF prevalence?
- Do we need to approach different supplemental indicators for TIS vs TSS?
- Can supplemental indicators be collected and analysed, at scale, in a timely fashion to facilitate program decision making?

**Program Monitoring (Surveys)**
- Can we predict trachoma-persistent districts?
- Could alternative evaluation designs cost effectively provide sufficient evidence to inform intervention strategies in trachoma-persistent districts?
- How could confidence intervals help us understand impact and surveillance results?

**Program Enhancement (MDA)**
- Should biannual treatment be considered and is it feasible, given:
  - Cost?
  - Coverage?
- Is it possible that the number of rounds needed for each baseline category is not adequate?
  - If so, what should the number of rounds be?
  - What do modelling results say?
- If F&E cannot be improved as quickly as desired, can the achievable level of F&E be factored into determining if the suggested number of MDA rounds is sufficient?
- What is the most effective enhanced MDA strategy to use in areas that are not responding to traditional MDA?
- How should persistence be defined in the context of deciding if a district requires an enhanced program?

# LEPROSY

## Leprosy Prevention in the Community: Exploring MDA Strategies

### Knowledge Gaps

### When to start and when to stop MDA
- It is important to agree on the last mile, to determine when to start and when to stop MDA and to have a clear understanding of the target groups.
- Mapping and testing can both be used to define what the end point will be.
- Once important stakeholders are aligned on what needs to be achieved, it becomes easier to define the necessary steps towards the endpoint.
- Having a lab measure to detect transmission would be very helpful.
- For MDA programs the following is required:
  o A clear trigger point to start
  o A defined point to end
  o A monitor system to determine whether the right points were chosen

### Availability of rifampicin
- Making rifampicin available for post-exposure prophylaxis with single-dose rifampicin (SDR-PEP) implementation is and urgent next step.
  o If any more information is needed for the pharmaceutical industry to make this happen, this needs to be given priority.
- Options to use other or additional drugs for a leprosy chemoprophylaxis regimen could be explored.
  o A combination of two or more drugs could overcome concerns around resistance.
  o However, some concerns remain about the use of critical tuberculosis drugs and feasibility issues when it comes to drug combinations or repeated administration.

### Next Steps

- A randomized control trial can help demonstrate the effectiveness of focal MDA (fMDA) for leprosy.
- Operational research is needed to gain experience with the implementation of fMDA for leprosy, in terms of feasibility, acceptability and cost effectiveness.
- Define start and end point as specified above.
- Experience needs to be gained with integrated approaches, in combination with MDA for other PC-NTDs, because these are generally preferred over single-disease approaches.
- Mapping will be needed to target fMDA. There is only limited experience with the identification of clusters.
- Surveillance for resistance needs to be set up in areas where chemoprophylaxis for leprosy is being or will be implemented, starting with the collection of baseline data.

# INNOVATIVE AND INTENSIFIED DISEASE MANAGEMENT

## IDM Diseases: What can we learn from each other?

Knowledge Gaps

### Addressing the needs of distinct patient populations of VL

- Visceral leishmaniasis (VL) in the Indian Subcontinent for HIV-negative individuals has driven disease decline, however:
  - o Both the diagnostic tools and the treatment regiments are less successful in East Africa.
  - o Treatments are not as successful for individuals who are HIV-positive.
  - o Tools to fight post-kala-azar dermal leishmaniasis (PKDL), the sequalae of VL, are limited.

### Baseline epidemiology of Chagas disease

- Because of the silent nature of Chagas disease progression, there are notable gaps in the basic epidemiology of the disease.
- To build a case for integration, baseline epidemiology of Chagas disease as well as other diseases that are asymptomatic and geographically contiguous.

### Missing metrics and data quality standards, moving goal posts

- Within the context of VL, there is an absence of data standards for consistent collections across studies and across geographic locations.
- The goal posts to abate the burden of VL are often delayed and are not necessarily aligned with the end of transmission, but rather with lower case-fatality rates.
- Moreover, there is an absence of post-validation guidelines for elimination of *L. donovani* in the Indian subcontinent, and to certify the interruption of transmission in gambiense human African trypanosomiasis (gHAT) everywhere.

Next Steps

**Definition of success metrics**
- While the WHO has set a target for the elimination of human African trypanosomiasis (HAT) by 2030 – and Chagas and VL for elimination of transmission as a public health problem by 2030 – the metrics of progress and success are not clear for all the diseases.
  - o For HAT, there are designated metrics to certify that countries have achieved HAT elimination as a public health problem.
  - o For Chagas and VL, the metrics of progress are often changing. For VL in particular, there are inconsistencies in the way that data are collected, making geographic comparisons difficult.

**Integration into the peripheral or primary health care system, aided by better diagnostics**
- It will not be sustainable to continue to perform large-scale mass screening with declining prevalence of the infection of any of these diseases.
- While vertical strategies might be easier to apply, implementation research on integration must be undertaken to demonstrate the benefits of such a system in the long run as well as the roadblocks to realization.
- For HAT, nearing elimination, promising high-accuracy serological tests on dried blood spots could be a feasible alternative. For Chagas and VL, especially VL outside of South Asia, more accurate diagnostics with same-day confirmation could ease the connection with treatment.

**Make community engagement and empowerment an integral part of the implementation process**
- Community engagement is important, but "selling" community engagement to donors is difficult.

**Develop more professional network around core activities and goals around efforts against VL, modeled after the HAT platform and the Chagas Global Coalition**
- Within the VL and CL communities, there has been some cross-country coordination of activities, but the domains of public health action are not integrated.
  - o For instance, there are separate groups pursuing treatment and control in humans and in canine reservoirs.
  - o There is one community meeting on leishmaniasis every 4 years, but there is little cross-talk across the separate parts of the community in the intervening time between meetings.
- Defining a core set of three or four goals for the community to rally around would help avoid the frustrations of large groups.

# CROSS-CUTTING

## A Multi-pronged approach to NTD Surveillance

### Knowledge Gaps

### Access to well-defined sample sets
- Integrated serosurveillance requires antigen discovery to improve assays and a repository of well-characterized sera to validate those assays.
  - This is also essential to develop STH serology further, e.g. biomarker discovery.
- Serology needs to be validated as a programmatic tool, which requires WHO recommendations and policies.

### STH serology: antibodies and assays
- We know little about STH antibody response profiles – how quickly do antibodies arise, how long are they detectable, etc.?
- We need to delve further into assay development: antigen selection/production, species-specific vs pan-STH.
  - These diagnostic tools can then be linked to program decision points.

### Xenomonitoring
- A clear definition of the epidemiology/entomology relationship is necessary and will occur only through modeling based on rigorous and high-quality data collections.
- Need for more clearly defined data interpretation framework and for a minimum set of best practice study design and data collection recommendations for all xenomonitoring studies.

### Costs of serosurveillance
- Information about cost of regular serosurveillance as a public health surveillance tool is missing.

### Next Steps

### Investment in biobanks
- A biobank of clinically defined specimens to validate new tests would accelerate progress on serological diagnosis across NTDs.

### Further studies on sampling strategies
- For integrated serosurveillance, research is needed to evaluate alternative sampling approaches to determine if they would provide useful decision-making data.
- Sampling strategies also need investigation for environmental surveillance of STH.

**Longitudinal studies of antibody responses**
- Well-designed longitudinal studies are required to understand antibody response profiles for STH serology.
- Biomarker discovery research is also essential to advance STH serology and diagnostics.

**Molecular xenomonitoring (MX) standardization**
*Research needs build along the following cycle:*
- Quality data through standardized MX methods to help us understand the epidemiology/entomology relationship.
- More complete understanding of the epidemiology/entomology relationship to facilitate pipeline development
- Development of standardized collection and processing pipelines to facilitate integration.

**Xenomonitoring implementation**
- Need to develop and agree upon xenomonitoring/integrated xenomonitoring implementation and interpretation guidelines with NTD stakeholders.
- Need for personnel capacity building for xenomonitoring at program (country) level.

**Strong protocols for integrated surveillance**
- Emphasize upfront planning requirements and also coordination and cooperation between research projects so that the benefit of collections is maximized.
- Ensure consent is sought for future unknown testing
- Material Transfer Agreement must also specify future testing for collected samples, along with storage, disposal, etc.
- Don't immediately assume that samples will need to be exported; many countries have capacity for in-country samples processing.

**Environmental surveillance**
- Need a thorough community study to validate results of the pilot study in Benin and India.
- What are the remaining questions that we need to address to make this a scalable solution?
- STH has successfully been detected in sewerage using PCR, but more work is needed to validate and interpret these assays.

**Health Information Systems**
- How can we leverage strengthened health information systems (HIS) to achieve NTDs surveillance to improve response? Could HIS play a role in the proposed multi-pronged approach for NTDs surveillance?

**Integrated surveillance**
- Need a multiplex strategy that allows us to continue to monitor for NTD pathogens in a post-validation/verification setting when the national NTD Programs are no longer in place.
- Need for longitudinal studies that combine surveillance at human, vector and environmental level.
- What about data platforms to bring surveillance together?

# COVID-19 and NTDs

Knowledge Gaps

## Building resilience into NTD programs
- There is often limited knowledge/specialization on NTD activities; how do we harness the existing skills to integrate across the NTDs?
- What do we mean by 'resilience' and how do we judge 'success'?
- How do emergencies affect resource diversion from the NTDs?
- Can we get real-time information on what is actually happening within programs?


## Impact on 2030 goals
- How effective are the models at predicting resurgence or mitigation strategies?
- How can we learn from programs that are already attempting to restart activities?
- What is the operational impact of the delays?
    - MDA supply chains
    - Sampling biases
    - Feasibility of mitigation strategies
    - Etc.
- Can COVID-19 mitigation strategies affect NTD transmission?
- What is the feasibility of resuming programs with two rounds of MDA?
- Will programs be able to resume with high levels of coverage?
- How can we verify/establish the efficacy of mitigation/catch-up strategies and how long will this take?

## Fake news and trust
- How do we identify a misinformed community/demographic?
- How should we develop and deliver messaging?
    - Do we develop messaging within the community?
    - Do we train community workers and leaders in messaging and misinformation handling?
- How do we assess if our messaging is effective and being absorbed?
    - Do we pre-test messages and messaging channels first? If so, when and how?
    - Do we assess information absorption at different levels?
    - How often do we asses messaging/communication, and who assesses it? At what stages in a program do we assess?
- How to identify resilient communities where misinformation has not spread and identify why
- What current tools/models exist that programs can use to assess and address misinformation and lack of trust issues in a community?

## Next Steps

*The following operational research priorities were defined through the session:*

- Collate and analyze information from programs at different stages of restarting.
  - Any new data/evidence should be used to validate models and update predictions.
- Assessment of strategies for integration across the NTDs, including COVID-19 and WASH activities.
- Cost-efficacy analysis of mitigation strategies
- Planning of misinformation management into both COVID-19 and NTD programs.
  - Practical tools to develop coherent messaging for communities and at-risk groups and assess if they are being absorbed or need to be changed
  - How to harness the 'infodemic' linked to the COVID crisis to strengthen communities' knowledge about NTDs and associated programs
  - How to avoid interference, multiple sources of information and confusion during field sensitization
- Identify success factors in engaging national agencies and local governments to support NTD implementation during disaster responses
- In the short term – how good practices in NTD programs can be integrated into COVID-19 operations, and how effective management of LF can be optimized during lockdown
- In the longer term – what are the mechanisms required to support integration for effective NTD prevention, control and elimination practices to maintain financial, community and political responsiveness
- Assess effectiveness of adherence to personal hygiene components of the COVID-19 responses, and identify innovative ways to support sustainable access to WASH services
- Understanding exactly how diagnosis, treatment, and prevention of COVID will divert resources of different kinds from NTD programs
- Identify the specific criteria for implementing additional or catch-up measures—where and when is this both required and feasible?
- Identify whether behavioral changes caused by COVID impact survey sampling biases

# Engaging Hard-to-reach Populations to Achieve Equity

## Gathering data on non-compliance and the reasons behind it

- How can this be done at the individual and at the community level?
    - People who don't want to participate in MDA are also unlikely to participate in data collection.
- Are technological solutions cost-effective in locating hard-to-reach groups and identifying their MDA coverage levels over time?
    - What are the potential considerations for ethics, sensitization, and complex acceptability issues among communities?
- What is the scale of the impact that hard-to-reach populations have on transmission of various NTDs, and on MDA coverage & compliance at the community level?
- What are the opportunities for integration of interventions and building local capacity, as reaching and gathering data on these populations is complex and expensive?
    - How do these groups differ across NTDs, and which ones could provide opportunities for collaboration?
    - What about other public health programs and diseases outside of NTDs?

## Targeting key risk groups

- What contextual guidance is needed, and would be most useful to target these key risk groups for interventions?
- Published case studies are needed, including:
    - What types of populations were identified?
    - How they were identified?
    - What tools and messaging were used for sensitization and mobilization?
- Both overarching guidance and compilations of specific lessons learnt would be helpful.
- Beyond MDA coverage, how can mapping, monitoring, and evaluation tools be inclusive of hard-to-reach pops?
    - What tools are needed across the program cycle and how can they be adapted to include these populations?

Next Steps

**Make data on successful intervention strategies available to program managers**
- Current data on successful intervention strategies involving hard-to-reach populations, as well as key challenges and lessons learnt, should be curated and made available to program managers.
- How can survey methodology be adapted to reflect special populations within NTD endemic districts?
    - If there are refugee or IDP camps within the district how should cluster selection be adapted to ensure they are (or not) included?
- MDA is not the only challenge in hard-to-reach populations. Mapping, and monitoring and evaluation are also big challenges. How can we provide tools to countries to address challenges on the different actions needed in the program cycle in these populations?
- How important are migrants (of different types) to on-going and recurring transmission?
- What is the appropriate geo-spatial technology that also considers movement due to livelihood patterns?

**Move beyond convincing people to take medication**
- Rather, a participatory approach – engaging the community in the scheduling and planning of MDAs and gathering their inputs when determining which groups needs more encouragement – is critical.
- More information is needed on compliance patterns within populations, namely whether these patterns change over time with control, and whether compliance is related with pre-control levels of infection.

**Determine M&E indicators**
- What indicators for routine program monitoring & evaluation could help program managers assess coverage and compliance among hard-to-reach groups?
- Are current program indicators focused on internal processes, external factors at the community level, or both?

**Integrate with other programs and sectors**
- Opportunities for collaboration across diseases and integration within health system should be sought when planning efforts to reach key risk groups.
- Also, strengthening local capacity should be built into any intervention efforts.

## How the Health Campaign Effectiveness Coalition Can Contribute to NTD Control & Elimination

### Knowledge Gaps

**Data and tools that need to be generated**
- A tool to measure and justify the value for money campaign integration.
- A system to ensure that incentives for healthcare workers are standardized and transparent to mitigate worker distrust and fatigue
- Best practices to engage the community to prevent community fatigue from multiple campaigns, distrust, and lack of involvement at the subnational level.

**Remaining questions that must be explored**
- Alignment on priorities: How can health campaign planners successfully align stakeholders on the priorities of a campaign during planning?
- Campaigns vs. primary health care (PHC): Is it possible to standardize what is considered primary health care and what is not? How can campaigns strengthen healthcare systems?
- Infrastructural changes: How can campaign planners identify the differences across countries or treatments that must be accommodated when integrating campaigns?
- Success indicators: How can campaigns demonstrate that they have been cost-effective? What constitutes "value for money" to justify the cost of integration?
- Resource availability: Resources and policies for campaign integration often differ across
- countries. A better system is needed to identify and address these differences during the planning stage. How can we identify supply chain and workforce concerns?
- Community engagement: How can campaign planners ensure community acceptance?
- Sense of loss: How can campaigns mitigate the sense of loss that comes from integration?

### Next Steps
*Research opportunities should address the following:*

**Value for money/cost savings and outcomes of campaign integration**
- This may include studies that measure the outcomes and value for money of integrating NTDs with other campaigns.

**Integration Incentives**
- A country-by-country study to determine which incentives (monetary and non-monetary) will most effectively motivate local and national governments to support integration and co-delivery, as well as the best methods for standardizing these incentives and addressing identified disincentives.

**Community engagement and fatigue**
- This includes studies that address the capacity and burden of community health workers to deliver multiple health campaigns and the implications on training, acceptability and costs/incentives.

# Integrating NTDs with other public health programs: Malaria case study

## Knowledge Gaps

### Show the gains of integration
- For advocacy purposes, more examples are needed, particularly related to cost efficiencies and programmatic advantages.
  - There are examples and case studies of where integration has improved service delivery and coverage. Dissemination of these is needed to increase political will for integration and capacity on "how to integrate."
  - These should highlight programmatic gains and/or where more was done with less resources.

### Adapt malaria tools for NTDs
- Gaps in the NTD implementation tool kit were identified. For several of these, the malaria community has tools that could be adapted to suit NTD program needs.
  - How to best approach this "matchmaking" in a way that is useful and moves the needle forward is still not fully understood.

## Next Steps

### Modify the framework for discussion between NTD and malaria programs
- Include approaches to foster deeper conversations by analysing areas of overlap and considering varying levels of endemicity, how approaches or interventions differ based on endemicity, etc.
- Make the community perspective central to the conversation from the start.
- Identify win-win opportunities for the donors.
- Include ideas on how to instigate this process or incentivize countries to integrate.

### Identify champions that provide an opportunity to use the modified framework
- Countries in Africa that have adopted the WHO 3rd edition of the Integrated Disease Surveillance and Response Technical Guidelines.
- Countries have adopted the WHO Global Vector Control Response.
- Where there is overlap with the President's Malaria Initiative (PMI) and LF endemicity.

### Further focus on additional NTD integration opportunities
- Lab capacity
- Female genital schistosomiasis and HIV/AIDS/reproductive health
- Universal healthcare essential packages
- COVID-19
- One Health
- Vector-borne Diseases

**Explore, adapt and pilot the malaria tools for NTDs**
- Treatment:
  - Supervision and social mobilization tools (including microplanning), especially those with a special focus on challenging issues, such as accurate population census, migrant populations, cross-border populations, conflict zones, and other populations who are systematically missed.
  - Supply chain monitoring of stocks and forecasting.
- Surveillance:
  - Case-based surveillance in low burden settings (e.g., China, Thailand) to support post-validation surveillance.
  - Risk-based surveillance based on foci identification.
- Integration:
  - Integration into HMIS and use of DHIS2 platforms.
  - NTD data collection through standing population-based epidemiological surveys (e.g., Demographic and Health Survey, Malaria Indicator Survey).
  - Successful cross-program/cross-government integration of malaria with other interventions (e.g., nutrition, deworming, treatment of sick children, and use of vouchers for insecticide treated nets).
- Digital:
  - Geo-spatial data with risk variable overlays (e.g., elevation, enhanced vegetation index, annual rainfall, etc).
  - Software platforms such as the Reveal Platform (piloted by Akros) for more accurate/targeted application of indoor residual spraying / long lasting insect net distribution / MDAs.

**Share malaria program entomological data**
- Species density
- Insecticide resistance
- Vector control intervention coverage and quality

# Lessons from ongoing NTD research on disability, stigma and mental health

Knowledge Gaps

**Study Design**
- No gaps were identified


**Instruments to assess stigma and mental wellbeing**
- How can we strengthen the quantitative data that we have in this area?
- Could instruments such as EQ-5D and disability-adjusted life years (DALYs) be useful in this area?


**Interventions to reduce stigma and improve mental wellbeing**
- Impact of increased communication/bringing groups together between stigmatized persons and people who may drive stigma?
- How can we provide longer term psychosocial support once physical symptoms have been treated? (Including consideration of impact of chronic and episodic pain)
- How can we effectively engage with teachers, religious leaders and explore the role of traditional healers – all of these are actors within a health system?
- Different interventions to address stigma at different levels – internal and within the community? Note: see www.stigmaguides.org
- Intervention strategies involving and integrating community – how can we best involve community in delivering stigma reduction (considering cultural settings)?
- Sustainability of services – how to strengthen referral pathways?
- What are the drivers around stigma (cultural beliefs vs disease specific, fears of contagion vs stigma of mental health – circular/double burden of stigma)?

**Study Design**
- Support wider validation of tools
- Assess feasibility/uptake of guides
- Continue to support a cross-project experience-sharing forum

**Instruments to assess stigma and mental wellbeing**
- How can we assess prevalence/incidence of post-traumatic stress disorder (PTSD), especially in conflict and fragile state?
- How can we adapt tools we are using among younger populations, children and adolescents?
- How can we calculate DALYs in relation to mental health?
- There are a lot of tools, we need to work out how we can make these available more widely and how we can help people choose the most appropriate tool

**Interventions to reduce stigma and improve mental wellbeing**
- How can we strengthen multi-sectoral collaboration?
  - How can we integrate livelihoods into NTDs programs and vice versa and linking these? Learning from tools already developed
  - Working within schools
- Learning from other sectors (disability) – how can we increase participation and inclusion of people affected in design interventions to highlight their priorities and needs?
- How to strengthen referral pathways? 2-way pathway, training community level staff/people affected linking with community and primary health system, working with people affected – particularly in low-income settings.
- Learning from cognitive behavioral therapy as an intervention in other settings
- What role can the community and other informal actors play in delivering stigma reduction interventions?
- How can we consider tools for children affected by NTDs?

# Mainstreaming and Health Systems Strengthening for Sustainable NTD Services

## Knowledge Gaps

- What can be done beyond integrating NTD indicators into HMIS to support mainstreaming of data and how can it be achieved?
- Regional coordination efforts in the presence of migratory populations require further examination: How can refugee camps be measured? How can sample frames that account for camps within disease endemic districts be collected? How does this impact the host community? How can patient follow-up in the camps be ensured?
- What is the right mix of prioritizing mainstreaming functions? Who are the right allies?
- Further research on priority setting process is needed.
- Further research on how to quantify integration is needed.

## Next Steps

### Cross-sectoral collaboration and inclusive implementation models
- How can a multi-sectoral collaboration between school feeding program, Ministry of Health, Ministry of Women Affairs, Ministry of Education and Ministry of Water Resources be operationalized to lead to improved MDA coverage, improved education, improved nutrition, and improved overall quality of life for vulnerable populations?
- Collaboration with HMIS to leverage their data entry staff, make data available through database integration to partners and develop dashboards in HMIS to convert data into information.
- Intersectional understanding of health outcomes: how do you bring an intersectional approach to NTD programs and what are the most effective strategies for reaching the most marginalized?

### Strategies for enhanced evidence-based stakeholder engagement in NTD programs
- Role of other sectors and village development committees in NTD implementation.
- NTD health outcomes are often impacted by traditional norms, cultural practices, etc. How do we introduce the knowledge that comes from science that often challenges these beliefs?

### Integration of NTDs in national human resource strategies and capacity strengthening programs
- Develop innovative supervision models and evaluate their effect on motivation and performance.
- Do NTD programs, with staffing structures that are typically made up of disease focal persons and M&E advisors, have the skills to leverage integrated data systems to promote use at national and sub-national levels or are there gaps which will hinder demand and undermine the impact of improvements in data systems?

**Optimizing existing health management information systems and tools for NTDs**
- What are the critical indicators for an integrated NTD HMIS module and associated training?

**Maintaining surgical quality after elimination has been achieved**
- Can we gather evidence on maintaining surgical quality from countries that have already eliminated?
- What promising practices exist to maintain surgeon skills, such as use of low-cost simulators and peer-to-peer learning and e-learning?

**Identification, management and reporting of TT cases after elimination has been achieved**
- From a sustainability and domestic funding perspective, the idea that a lot of resources are needed post transition makes it difficult to get commitment from government. The Malawi experience demonstrates that the numbers can be very small in reality. How can programs demonstrate to governments that the resources required post transition are limited, and can easily be handled routinely with domestic financing? And therefore, avoid policy positions, such as the need to charge for TT surgery post transition.
- The post elimination approach to managing remaining TT cases is a passive one whereby it is expected that remaining cases will self-present at a health facility based on available health information in the community.  What other approaches can be employed to determine if all remaining cases are being reached in an area district/country post elimination?
- How best do you integrate TT case identification into a weak routine eyecare system or other routine eyecare activities where they exist?

**Financing**
- How can district level ownership and accountability for NTD services be strengthened by different health financing models and better inclusion of NTDs into government budget?
- What financing or programmatic data is needed? Which Ministry needs it and when do they get it to enable increased domestic resource mobilization?
- How can lessons learned from mainstreaming other health programs into the government budget help identify and prevent key challenges to including NTDs into national budgets?

**Coordination**
- How do you move towards the integration of NTDs into primary health care and for primary care providers to deliver a more integrated approach for primary health care services (for diagnosis, referral, surveillance that includes NTDs?

# Participatory Approaches for Program Equity

## Knowledge Gaps

- The gender gap in NTD programs needs to be addressed – as we approach goals in elimination and control of NTDs, we must look to those who are left behind.
- There is a gap in the availability of standardized social science tools, particularly in relation to decision making. Frameworks are required to structure research – clear and consistent methodology aids replicability and evaluation.
- There are still significant gaps in understanding the MDA cycles, particularly related to timing – tools developed should address/uncover the barriers and challenges.
- There is a gap surrounding knowledge translation – how can we transfer information gathered through these methods into a practical report for program managers?
- There are gaps in the skill sets within the National NTD programs to utilize these methods and consider how they could be used to address equity issues.
- There is a gap in knowledge and guidance relating to conducting participatory research virtually in the times of COVID-19.
- There is a gap in understanding how to integrate participatory research in NTD programs. To what extent is the primary structure of NTD programs amenable to participatory approaches? Since programs are vertical in nature, how can we push for local-based solutions? Related to this, how can we use participatory approaches to connect the dots between communities and decision making, and imagine new ways of working? Further consideration is needed regarding how we can 'sell' participatory research to donors.

## Next Steps

- Problematize power and hierarchies to facilitate engagement from stakeholders and participants at all levels. Promote use of phrases such as 'co-researchers'
- Promote capacity building in participatory skills across different sectors.
- Address procedural challenges for participatory research such as difficulties with inflexible ethical approval processes which are more difficult to navigate for iterative approaches.
- Testing of participatory methods and tools and validating against other Monitoring and Evaluation tools.
- Develop research which investigates how to reach marginalized or hard to reach populations, particularly using visual methods. Use participatory approaches for mapping barriers to access, identify site-specific challenges, and to bring non-adherent groups into the fold.
- Integration of participatory methods into NTD programming and measuring or monitoring the impact of NTD programs.
- Address the gender gap in NTD programming and the barriers to equity.
- Develop frameworks for social science NTD research, particularly participatory research.
- Continue conducting participatory research to aid understanding of MDA and to work with local stakeholders to develop solutions.
- Work with NTD program partners to promote understanding of participatory approaches.

# Stigma Reduction and Mental Health Support for People Affected by NTDs

## Knowledge Gaps

### People affected by NTDs and/or Mental Health should be involved in design, implementation, and evaluation of interventions

- It is important to look at wider elements of well-being, such as being able to work or not, and not just look at symptom improvement as a measure of success in programs. Priorities should be determined with people affected, and can then be used as a baseline to measure interventions against
- There is a need to work with people affected to learn from their lived experience, and who can support treatment of others, advocate for change, and raise awareness
- Skills building can support building resilience and improve economic status, which can lead towards building a positive self-image.
- Self-stigma can be a barrier to seeking health care. Peer support groups can empower individuals, who can then go on to support others.

### Communities can play an important role in stigma interventions

- Trained community leaders and Community Health Workers can help identify and refer people, they have power and can therefore play a key role in reducing stigma.
- Involving community leaders is also important to make sure that human rights are protected and there is understanding of what appropriate treatment for mental health is.

### Build the capacity of the health workforce to meet patients' needs

- Stigma amongst professionals may lead to higher stigma in the population. Therefore, there is a need to work with health professions on this and raise the profile of NTDs. Working with frontline health workers to dispel myths is important, however, it may be met with initial resistance.
- Health workers can become stressed if they don't feel they have the tools and capacity to support wellbeing, so supporting their wellbeing is also quite important.

### Scale up, Policy, Funding, and Integration

- Existing evidence should be used to leverage much-needed additional funding.
- Mental health and stigma interventions are becoming increasingly important, especially as PC-NTD programs are phased out. Focus on sustainability and long-term benefits should also be used to leverage funds.
- Poverty and long distances to health facilities means there is a delay in health-seeking behaviors.
- People often work in silos, and therefore may duplicate the process.
- Specific conditions like onchocerciasis- associated epilepsy are often missed from disease management strategies.
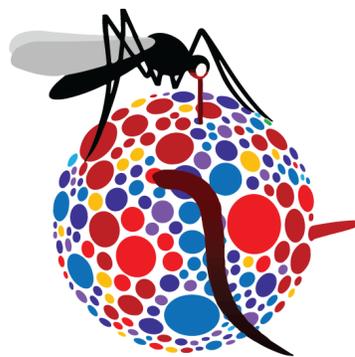
Next Steps

**Operational Research Questions**
- How can we scale up the use of existing stigma reduction strategies within health systems?
- What measurement tools are most appropriate to evaluate stigma and stigma reduction innovations?
- How can we embed gendered experience of stigma in research?
- How can we better engage different stakeholders, such as community leaders, families and carers of people affected by NTDs, non-formal health providers, and formal health providers? What role will they contribute to stigma reduction strategies?
- How can collaboration between NTD program managers and mental health providers be strengthened?
- How can we develop training packages for different levels of health system, for patients, and communities in order to improve knowledge and skills in stigma reduction and mental wellbeing?
- How can we include and/or increase the participation of people affected in research and intervention designs?
- How can we consider the mental wellbeing of health workers and how can we best build their capacity to support people affected by NTDs and provide mental health support?
- How can we safely involve volunteers in stigma reduction programs? What are the techniques, opportunities, and challenges of using volunteers?
- How can inclusive livelihoods programs be integrated with NTD mental health programs?
- How can we assess the impact/effectiveness of stigma reduction interventions?

**Actions/Next Steps**
- Develop Educational packages for different levels including:
  - Communities
  - People affected by NTDs
  - Media
  - Health workers
- Conduct a workshop to map and evaluate what tools are available and how they can be adapted and used appropriately.
- Embed initiatives, interventions, and innovations sustainably.
- Understand how drivers of social determinants can best be addressed.
- Strengthen evidence base and use this to leverage funding with donors.

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