

## Supporting Countries to Generate High-quality NTD Prevalence Data

<b>Session Date &amp; Time:</b>	Tuesday, November 19; 1:00 PM to 4:00 PM
<b>Session Location:</b>	MGM Grand Ballroom – Salon B
<b>Session Description:</b>	To ensure optimal data for decision-making, can a globally standardized methodology to collect high-quality prevalence data, which also supports countries through the continuum of the survey process, act as a blueprint across the neglected tropical diseases (NTDs)? Where are the gaps in the process and how can they be addressed?
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### KEY DISCUSSION POINTS

- In order to produce high-quality NTD prevalence data, there are four main categories to focus on: standardized training; survey methodology/design; data collection, management, and analysis; and data sharing, reporting, and use.
- Many disease-specific groups have begun to collect high-quality prevalence data, so the task now is to see how these current projects can help produce high-quality data for other NTD programs. Through this work, programs and health ministries have come across challenges, and have collaborated to address these issues with solutions or research questions.
- While each NTD has different diagnostics and methods for determining prevalence, NTD communities can still compile a standardized blueprint of the necessary key elements to produce high-quality surveys.
- There is no need to re-invent the wheel for each NTD to generate high-quality prevalence data. NTD groups need to share and collaborate across diseases, so the NTD community can continue to improve by building off the hard work already being done to produce high-quality NTD prevalence surveys.

## KNOWLEDGE GAPS IDENTIFIED

During the session key components for high-quality prevalence surveys were determined for each of the main four survey areas. After this, gaps were identified for the principles, and then solutions, recommendations, and operational research questions were determined. This work created two outputs:

- i. a checklist of important components for high-quality prevalence surveys;
- ii. future research and recommended next steps needed in the field.

Although the lists are incomplete, they provide a first draft that can built on going forwards.

Standardized Training		
Principle	Gap Identified	Solutions, Recommendations, and Operational Research Questions
Standardized training materials (e.g. manuals) <ul style="list-style-type: none"> <li>• Link training to supervision plan</li> <li>• Emphasize ethics and consent - what it means in a survey context</li> <li>• Include hands-on training (with field practice)</li> </ul>		<ul style="list-style-type: none"> <li>• Devote more training time to field training</li> <li>• Develop a facilitator manual</li> </ul>
Ensuring enough funding and time to conduct high-quality training <ul style="list-style-type: none"> <li>• Schedule training close to the fieldwork time, limiting knowledge loss</li> </ul>		<ul style="list-style-type: none"> <li>• Detailed planning required to ensure all materials are available</li> </ul>
Ability to adapt training materials to target different levels and contexts: <ul style="list-style-type: none"> <li>• Audience (National, District, CDD)</li> <li>• Group Size</li> <li>• Adult learning principles</li> <li>• Adopting training to cultural context (language, geography, photos)</li> <li>• Using the approved protocol to guide training</li> <li>• Engage local stakeholders to design participation</li> </ul>	<ul style="list-style-type: none"> <li>• Gap in engaging local stakeholders to design participation and trainings</li> </ul>	<ul style="list-style-type: none"> <li>• Standardized training materials need to be translated to the appropriate languages for the training</li> <li>• Ensure the training group is the “right” size for the target audience</li> </ul>
Review/update material regularly <ul style="list-style-type: none"> <li>• Feedback loop to guidance/protocol</li> <li>• Current scientific knowledge</li> </ul>		<ul style="list-style-type: none"> <li>• Leverage NGO/ministry of health (MOH) partnership to create change</li> </ul>

Testing of trainees' ability/knowledge		<ul style="list-style-type: none"> <li>• Providing certification for training</li> <li>• Expanding access to training on principles of study design and structure</li> </ul>
Training of trainers <ul style="list-style-type: none"> <li>• High-quality individuals with leadership capacity</li> </ul>		
Defined roles/responsibility <ul style="list-style-type: none"> <li>• Develop a chain of command</li> <li>• Recruitment criteria</li> <li>• Objectivity of data collectors</li> </ul>		
Develop and conduct refresher trainings when needed		<ul style="list-style-type: none"> <li>• Need to innovate in training outside of the classroom</li> </ul>
Creation of job aids and other reference material for technical key points		<ul style="list-style-type: none"> <li>• Compile FAQs to help anticipate problems faced in the field</li> </ul>

Survey Methodology/Design		
Principle	Gap Identified	Solutions, Recommendations, and Operational Research Questions
Survey protocols should: <ul style="list-style-type: none"> <li>• Have distinction between research-based data collection and program-based data collection</li> <li>• Be appropriate for the disease state of the area</li> <li>• Follow clear objectives that guide the design</li> <li>• Be adaptable for different contexts and special populations</li> <li>• Use the appropriate diagnostics</li> </ul>	<ul style="list-style-type: none"> <li>• Design issues for special populations (especially migratory and displaced individuals living in camps)</li> <li>• Appropriate sample size attainment (the number of households needed to achieve the correct number of age-appropriate individuals)</li> </ul>	<ul style="list-style-type: none"> <li>• A potential solution for special populations would be to use over-sampling or snowball sampling, which has been seen in the literature as a potential solution</li> </ul>
Scientific review of protocols by dedicated subject-specific epidemiologists or designated authority	<ul style="list-style-type: none"> <li>• No standardized process for protocol reviews.</li> </ul>	
Protocol conforms to WHO guidance and guidelines	<ul style="list-style-type: none"> <li>• WHO guidance on survey methodology/protocol for Schistosomiasis</li> </ul>	<ul style="list-style-type: none"> <li>• Issues of knowledge of what to do in the field should be addressed through</li> </ul>

	<p>and Soil-Transmitted Helminthiasis are not as developed as other diseases</p> <ul style="list-style-type: none"> <li>Gaps in knowledge on WHO guidance and the underpinning survey methodology, so knowledge of what to do when it deviates from the protocol in the field</li> </ul>	good and complete training
<p>Only collecting data useful for programmatic decision purposes</p> <ul style="list-style-type: none"> <li>Using auxiliary data to add richness to analysis</li> </ul>		
<p>Have a clear process for updating/changing/shifting protocols overtime</p> <ul style="list-style-type: none"> <li>Both how to make and/or communicate changes</li> </ul>		
<p>Have a record of planned methodology, and methodology implemented during fieldwork</p>		Provide sufficient documentation of methodology details in final reports

Data Collection, Management, and Analysis		
Principle	Gap Identified	Solutions, Recommendations, and Operational Research Questions
<p>Electronic data capture (EDC), with standardized data collection fields ensuring and limiting data entry errors and loss, with automatic encrypted data upload to a secure central server</p>	<ul style="list-style-type: none"> <li>Some countries are not ready for EDC, can they still generate high-quality prevalence data?</li> <li>Monitoring the fieldwork - are teams working in the correct locations?</li> <li>Standardized forms are not available for each disease</li> <li>Need training based on common field errors</li> </ul>	<ul style="list-style-type: none"> <li>Capturing GPS of the survey location can help teams ensure they are working the correct locations</li> <li>Need a feedback loop and data action framework to create a training to identify common errors</li> <li>How can map-making with external data with the elevation,</li> </ul>

		distance to water, etc can be used to incorporate into research about NTD prevalence?
Ensuring the privacy and protection of personal information of participants		
Near real-time collaborative data cleaning using automated data cleaning algorithms, facilitating feedback to teams whilst in the field		<ul style="list-style-type: none"> <li>• Data sharing agreements</li> <li>• Incorporating good data management practices into training of data collection staff</li> </ul>
Standardized data analyses using automated algorithms and/or specialist, objective data managers and one or more designated health ministry personnel	<ul style="list-style-type: none"> <li>• Sharing analysis code on Github</li> </ul>	<ul style="list-style-type: none"> <li>• Make sure all programs are sharing code with the rest of the world on sites like Github</li> </ul>
Including dashboards that allow for quality control checks for individuals with different skill set levels to make a decision		
Using a standardized reporting format for programmatic decision making and reporting as part of the database	<ul style="list-style-type: none"> <li>• Non-ESPEN countries</li> </ul>	<ul style="list-style-type: none"> <li>• What are the implications for integrated programs?</li> <li>• National NTD databases are not always updated</li> </ul>

Data Sharing, Reporting, and Use		
Principle	Gap Identified	Solutions, Recommendations, and Operational Research Questions
Prevalence results shared to inform program planning including <ul style="list-style-type: none"> <li>• Appropriate access to synthesized data in a timely manner</li> </ul>		<ul style="list-style-type: none"> <li>• Highlighting the importance of timely reports, which is essential for programmatic decision making</li> </ul>
Data used for programmatic decision making		
Protect the health ministry's data ownership		<ul style="list-style-type: none"> <li>• Working with each country to establish and understand their guidelines and</li> </ul>

		<p>regulations for data sharing</p> <ul style="list-style-type: none"> <li>• Focus on in-country expertise to help identify important research questions</li> </ul>
Protecting the confidentiality of individual and household data	<ul style="list-style-type: none"> <li>• Anonymize participant and household identifications for stored surveys</li> </ul>	<ul style="list-style-type: none"> <li>• Create a method to easily and consistently anonymize individual-level records for all surveys stored on databases</li> </ul>
Secure data storage in-country	<ul style="list-style-type: none"> <li>• What are the standards for “secure” data storage?</li> </ul>	
Capacity strengthening for effective data use	<ul style="list-style-type: none"> <li>• Trainings often focus on data collection, but there needs to be training for data management and analysis as well</li> </ul>	<ul style="list-style-type: none"> <li>• Development of training materials on data management, analysis, and data use</li> <li>• Recognizing constraints with time and resources, how best can national NTD programs’ capacity to analyse and use data be strengthened?</li> </ul>
Ensuring data reporting reaches communities which participated in the data collection, as well as the scientific community	<ul style="list-style-type: none"> <li>• Lack of support for reporting to the scientific community (e.g. – publications)</li> </ul>	Support Country capacity to publish
<p>Data reports should:</p> <ul style="list-style-type: none"> <li>• Be consistent in all reports to different stakeholders</li> <li>• Be short, salient reports with key findings, any deviations from the protocol, and next steps</li> </ul>		Explore data link with Ministry websites

## **RECOMMENDED NEXT STEPS**

- Look at the output and see how these principles can be used in each NTD program to help provide guidance to conducting high-quality prevalence surveys.
- Continue to improve existing programs collecting high-quality prevalence data for NTDs through solutions and recommendations provided above
- Collaborate between disease programs to share new solutions and insights building on current practices.