COR-NTD 2018 Meeting Outputs

Knowledge gaps and recommended next steps identified at the annual meeting of the Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD) in New Orleans, LA, Oct. 26-27, 2018.

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Glossary of Commonly Used Terms

Acronyms are defined and spelled out, wherever possible, throughout this document. They are defined again here for easy reference.

ACD	Active Case Detection
AMR	Antimicrobial Resistance
CDD	Community Drug Distributor
CDTI	Community-directed Treatment with Ivermectin
CEMAC	Central African Economic and Monetary Community (Gabon, Cameroon, Central African Republic, Chad, the Republic of Congo, and Equatorial Guinea)
DHIS2	Direct Health Information System 2
ELISA	Enzyme-lined Immunosorbent Assay
ESPEN	Expanded Special Project for Elimination of Neglected Tropical Diseases (WHO)
EU	Evaluation Unit
DOT	Directly Observed Therapy
FGS	Female Genital Schistosomiasis
FIND	Foundation for Innovative New Diagnostics
GET2020	Global Elimination of Blinding Trachoma by 2020
GIS	Geographic Information Systems
GPS	Global Positioning System
HAT	Human African Trypanosomiasis
HIV	Human Immunodeficiency Virus
IDA	Combination Therapy (for Lymphatic Filariasis) with Ivermectin, Albendazole, and Diethylcarbamazine
IDM	Intensified Disease Management
IDP	Internally Displaced Person
IU	Implementation Unit
LF	Lymphatic Filariasis
M&E	Monitoring and Evaluation
MDA	Mass Drug Administration
MEC	Mectizan Expert Committee
MIP	*Mycobacterium indicus pranii*
MMDP	Morbidity Management and Disability Prevention
MOH	Ministry of Health
MORBID	Morbidity Operational Research for Bilharziasis Implementation Decisions
MSF	Médicins Sans Frontières/Doctors Without Borders
NGO	Non-governmental Organization
NTD	Neglected Tropical Disease
OpenHIE	Open Health Information Exchange
OR	Operational Research
Ov	*Onchocerca volvulus*
PC	Preventive Chemotherapy
PCR	Polymerase Chain Reaction

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PEOPLE	Post ExpOsure Prophylaxis for LEprosy in the Comoros and Madagascar
PEP/LPEP	Post-Exposure Prophylaxis/Leprosy Post-Exposure Prophylaxis
PKDL	Post Kala-Azar Dermal Leishmaniasis
PSAC	Pre-School-Age Children
qPCR	Quantitative Polymerase Chain Reaction/Real-time PCR
RAPLOA	Rapid Assessment Procedure for *Loa loa*
SAC	School-Age Children
SAE	Serious Adverse Event
SCH	Schistosomiasis
SMS	Short Message Service
SOP	Standard Operating Procedure
STH	Soil-Transmitted Helminthiasis
STI	Sexually-transmitted Infection
TaNT	Test and Not Treat (Strategy for Onchocerciasis and Loasis Overlap)
TAS	Transmission Assessment Survey (for Lymphatic Filariasis)
TB	Tuberculosis
TCC	The Carter Center
TF	Trachomatous Inflammation–Follicular
TIS	Trachoma Impact Survey
TSS	Trachoma Surveillance Survey
TT	Trachomatous Trichiasis
U5	Under 5
UHC	Universal Health Coverage
USAID	United States Agency for International Development
WASH	Water, Sanitation, and Hygiene
WHO	World Health Organization
WRA	Women of Reproductive Age

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Lymphatic Filariasis

Generating Evidence for Moving to Elimination of LF Transmission

Knowledge Gaps

- Further research is needed to obtain an acceptable, measurable proxy for LF transmission. Years after MDA, historical infections should have cleared if transmission was interrupted.
- To verify LF elimination, we will need research on focused on the development a standard verification survey to be conducted after validation.
- Further research is required on how to enhance TAS to minimize risk of missing ongoing transmission leading to recrudescence and maximize probability of elimination of transmission.
- Further research is needed to determine whether a standardized survey, developed for implementation after validation could be used to verify elimination of transmission.
- Further research around hot spot definition, identification and response is needed
- Research on how spatial data can be used to identify and respond to hot spots is needed.
- Research to inform mathematical models and validate assumptions for stopping MDA is needed.

Recommended Next Steps

The following studies are proposed:

- Use current global program data to implement a geospatial model including environmental covariates to detect potential areas of ongoing transmission.
- Risk mapping using historical data and prospective survey data
    - Make use of risk mapping tools already available
- Population-based studies to pick up signals
    - Randomized cluster surveys
    - Conduct targeted/adaptive sampling including community/household-level studies in humans and vectors.
- Spatial overlay of diagnostic tools to define hotspots and inform surveillance strategies.
- In EUs with known, persistent low-level transmission (e.g., areas that have failed TAS), compare results from purposeful sampling, random sampling, combined purposeful/random sampling, and 2-3 diagnostic tools to determine which strategy is the most sensitive at detecting transmission.
- Use current global program data to implement a geospatial model including environmental covariates to detect potential areas of ongoing transmission.
- Risk mapping using historical data and prospective survey data
    - Make use of risk mapping tools already available
- Population-based studies to pick up signals
    - Randomized cluster surveys
    - Conduct targeted/adaptive sampling including community/household-level studies in humans and vectors.
- Spatial overlay of diagnostic tools to define hotspots and inform surveillance strategies.

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Integrating LF MMDP Activities into National Public Health Systems: Experiences Towards Universal Health Coverage

- ***Knowledge Gaps***

- Detailed community-level and sex-disaggregated data should be collected to understand the disease burden and direct sufficient resources and services to provide MMDP care.
- Reporting systems and tools to facilitate data reporting from local level to central level
- How to sustain long-term care into health systems in the absence of ongoing LF program or external funding sources?
- How can the inclusion of MMDP data collection in country-level health management information systems, such as DHIS2, play into the broader integration of MMDP into health systems? What are the challenges with integration or examples of success?
- How can people affected by chronic lymphedema develop essential community-based support networks around them?
- How can complex case management (e.g., advanced stage/grade lymphedema or hydrocele or patients with comorbidities) be integrated into the health services?

Recommended Next Steps

- There is an urgent need to improve the collection and reporting of MMDP data, including sex-disaggregated and district-level data. Data should also include psychosocial risk factors and aspects of care.
- Case studies with examples and lessons learned from successful integration of MMDP into health care services from various countries/regions should be created and disseminated.
- Determine the barriers to patients' access to MMDP services when services are available in the implementation unit.
- Examine in which countries and through which means countries are financing LF MMDP.
- Explore how LF MMDP training is incorporated into pre-service curriculum and if that knowledge is translated into quality patient care.
- Compare different service-delivery methods to determine sustainable pathways to UHC.
- Determine which service delivery strategies (e.g., patient-centered, community-centered, and mental-health focused) lead to the best long-term patient adherence.
- Explore the role of self-care groups in the long-term care of lymphedema patients, experiences, and lessons learned.
- Document which aspects of the LF MMDP minimum package of care have been included in country UHC essential care packages.
- Determine how to link community-based data collection (e.g., SMS burden estimate) and health facility MMDP data with routine reporting through HMIS systems, such as DHIS2.

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Onchocerciasis

Gaps in Our Understanding of Onchocerciasis-Associated Epilepsy

Knowledge Gaps

- A causal role of onchocerciasis in the development of epilepsy or Nodding Syndrome has not been demonstrated.
- The efficacy of once-per-year and twice-per-year ivermectin on reducing the incidence of epilepsy or Nodding Syndrome in areas with hyperendemic onchocerciasis has not been demonstrated. This should be done to determine if currently available tools might reduce the incidence of epilepsy.
- A systematic assessment of potential confounders of the relationship between onchocerciasis and epilepsy should be developed.

Recommended Next Steps

- Much of the evidence supporting an association between onchocerciasis and epilepsy is derived from weak epidemiological data. Stronger data from a prospective cohort study would provide stronger evidence. Better use of standardized diagnosis of onchocerciasis and epilepsy and more systematic evaluation for potential confounders is needed.
- Better delineation of the pathophysiological pathway for the development of Nodding Syndrome and the role of onchocerciasis in this pathway would be important in order to direct appropriate development of novel prevention strategies.
- A study comparing the impact of ivermectin treatment once per year and twice per year on the incidence of epilepsy in areas with high prevalence of both epilepsy and onchocerciasis could provide evidence to both support a causal role of onchocerciasis and to demonstrate efficacy ivermectin as it is currently used.

Threshold for Stopping MDA for Onchocerciasis: Time for a Change?

Knowledge Gaps

- Empirical data to validate assumptions of the mathematical model are needed.
- More data are needed to define optimum age group and threshold. These data should come from all age groups and use multiple diagnostic methods.
- It is not clear whether children are good sentinels for onchocerciasis transmission. It is possible that they are not exposed while adults are still infected and serve as reservoirs.
- It is not known how the efficiency of the vector can influence the appropriate stopping threshold. More entomological work to determine whether vectors vary in efficiency is needed.
- Modelling data suggest that the threshold should be lower in areas with higher baseline prevalence. Hyper-endemic areas are most prone to recrudescence. More work should be done to establish whether threshold should vary by baseline endemicity.
- Feasibility and cost data should be gathered and considered when setting a threshold.
- Entomological data paired with epidemiologic assessments could be used to determine the appropriate stopping threshold.

Recommended Next Steps

- Examination of existing data: Existing data on Ov16 seropositivity in areas where onchocerciasis has never existed (e.g., Mali) can be used to determine the background level of positive results in

the absence of infection. This can be used to determine whether the threshold of 0.1% is too low on account of background noise when using certain tests.

- Collection of new longitudinal data: Both the threshold and modeling questions could be answered by conducting a series of cross-sectional studies in Tukuyu, Tanzania (and other similar sites where the entomology is below the 0.5% cutoff but Ov16 serology exceeds 0.1%). MDA should be discontinued and studies should then monitor serology and entomology over time for recrudescence.
    - Studies should be conducted in both savannah and forest areas.
- Consideration of test-specific threshold: Additional data are needed to determine whether the threshold should vary by diagnostic test. It is possible that the optimal sampling frame could also vary by test. Comparison studies on different tests should be conducted. Cutoff values for ELISA should also be considered.
- Improving our understanding of entomology: Additional entomological studies to determine the efficiency of various vectors would be useful to determine whether this is a factor in onchocerciasis elimination.
    - Methods for determining the best places for fly catching should be refined and not based on historical data.
- Understanding the best timing for revising the threshold: The community needs to come to a consensus on whether the threshold should be revised now, or whether it is best to wait 3+ years to generate the above data before revising.

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Lymphatic Filariasis & Onchocerciasis

Can the Loascope be used successfully in the community?

Knowledge Gaps

- Are population movements important in the potential test-and-not-treat (TaNT) areas? What are the risks for patients newly arrived in the area and what are the risks for those who have lived in the area moving to a different onchocerciasis-endemic area where Loa is not co-endemic and no precautions would be taken?
- The LoaScope has become the new gold standard and the most effective tool for decision making in co-endemic areas. However, supply is extremely limited – just enough for use in field testing. When will more be available? Is it possible to conduct field operations in a meaningful way with the current stock?
- Predictive analysis points to only a short time commitment to a LoaScope TaNT strategy in each implementation unit (IU). Will this be consistent with application in the field, particularly if coverage is low?
- Estimated costs are now available. What factors would further reduce costs? Can we compare now more precisely the cost of using TaNT/LoaScope (testing all ivermectin-naïve patients) to the costs incurred in those mass drug administrations (MDAs) that are already engaged in enhanced surveillance for side effects?
- What are the factors other than fear of SAEs that influence compliance in these co-endemic settings? Can we reasonably expect a substantial increase in MDA participation if we test ivermectin-naïve individuals for Loa and prevent all/nearly all SAEs?
- How do we analyze the cost effectiveness of increased testing and management of occasional SAEs in order to reach elimination goals sooner?
- In newly identified meso- and hyperendemic foci of onchocerciasis co-endemic with loiasis (potentially in Democratic Republic of Congo and South Sudan), what is the acceptable cut-off point for prevalence at which we will continue MDA in onchocerciasis hyper-/meso-endemic communities using current MEC/TCC guidelines? Should we start with the LoaScope?
- Should the use of the LoaScope become the standard of care in newly identified onchocerciasis hypoendemic communities (prevalence of nodules <20%)?
- Assuming we have supplies, would we recommend TaNT in all Loa-endemic health districts? What would be the protocol for a “special” or “enhanced” approach to MDA with a new emphasis on community mobilization?

Recommended Next Steps

- Develop mapping protocols on how to use historical RAPLOA maps, where to use serological testing, and what is the best use of the LoaScope as a mapping tool. Can we use the predictability analyses (by Peter Diggle) to develop a convenient sampling strategy?
- Develop protocols for testing in all Loa-endemic IUs after the first round of treatment. This could include TaNT in the community for the second round, or individual patient testing at a district hospital or health center, field testing by less rigorous methods, enhanced record keeping of individual patient status, and consideration of alternative treatment in ivermectin-naïve individuals, to allow MDAs to proceed.
- Additional research questions include:
    - How many years of TaNT are needed before commencing regular community-directed treatment with ivermectin (CDTI)?

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- What are the effects on *Loa loa* microfilaremia in patients who had missed one or two rounds of Ivermectin treatment? Should they be systematically retested if they miss one round?
- What are the cultural and social factors affecting compliance (including fear of SAEs, but also other factors)?
- What are the best methods of social mobilization to maximize coverage in co-endemic areas?
- What is the effect on onchocerciasis elimination of exclusion of Loa patients from ivermectin treatment? Should they be treated with doxycycline or simply excluded?
- How does compliance change when using the LoaScope?
- In view of the prolonged treatment period and the long history of Loa SAEs, should we consider new, creative mobilization methods such as a lottery or other prize giving in order to achieve the elimination goals?

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Lymphatic Filariasis & Trachoma

How Can Current LF and Trachoma Survey Data Influence Policy?

Knowledge Gaps

- Should duration of MDA programming for LF be informed by initial prevalence of infection?
- What is the most cost-effective way to respond to "hot spots"? Should this be different than an EU-level response?
- What risk factors would emerge if results of multiple programs were analyzed together, e.g., if LF and trachoma programs were both succeeding or not succeeding in a district?
- What are the most cost-effective strategies for investigating systematic non-compliance, particularly in areas that fail pre-TAS, TAS, TIS, or TSS?
- What are the most cost-effective strategies to investigate vector-related factors after failure for LF?
- What is the half-life of antigen/antibodies? What is the relationship to historical exposure?
- Does the timing of the MDA with respect to the rainy season (or other factors affecting vector density, as well as access to the population) affect the likelihood of transmission?
- What threshold of water and sanitation and environmental improvement would achieve elimination target for TF?
- Is there a higher rate of recurrence if baseline is high?
- What is the risk to recrudescence from children found positive in TAS2 or TAS3?
- What is the role of xenomonitoring in post-validation surveillance for LF?
- How should spatial heterogeneity of transmission be considered in the survey design for surveillance?

Recommended Next Steps

- Conduct a study to determine whether duration of MDA programming for LF should be informed by initial prevalence of infection, and consider adjusting LF policy based on findings
- Consider changing requirements for reporting TAS data to the World Health Organization to include cluster-specific data, to inform more granular analyses and guidance for following up positive cases
- Conduct an analysis of TIS and TSS outcomes using data from GET2020 database, and incorporating data on WASH, socio-economic status, and population/migration, to see whether it is possible to predict areas where TIS/TSS outcomes are likely to be TF ≥5%
- Use modeling to quantify the threshold of water and sanitation and environmental improvement that would achieve elimination target for TF
- Convene experts to develop a standard definition of 'hot spots,' and conduct a study to generate evidence to guide national programs to respond to hot spots

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Schistosomiasis

Shrinking the Map for Schistosomiasis

Knowledge Gaps

- At what stage(s) of program should the SCH map be shrunk to best inform program decision-making?
- There is a critical need to use existing data to better understand focality of transmission
- Tools are required for identifying hot spots of persistent infection (e.g., ecological mapping tools)
- What programmatic interventions should be implemented for each context identified (e.g., for hot spots and foci with low prevalence e.g. behavior change interventions, molluscicide, treatment frequency, target age-groups, WASH etc.)?
- Do current World Health Organization survey designs for the mapping of schistosomiasis optimally capture spatial distribution?
- Is sampling in schools representative of the endemic population (e.g., children may travel to schools from different communities, non-attending school-age children, at-risk adults)?
- There are a lot of uncertainties around the reliability of current mapping data for schistosomiasis (e.g., how reliable were the prevalence measurements when using different diagnostics, are sample sizes adequate, etc.?).
- There is currently a lack of guidance/protocols for mapping at different implementation unit levels (e.g., district, sub-district, community, ecological area) and the subsequent programmatic decision-making and interventions required, thereafter.
- Accurate and available population data are critical to inform sampling strategy development and treatment needs.
- There is a lack of data on snail population distribution and abundance.
- There are no rapid diagnostic tests for mapping the distribution of schistosomiasis in low-prevalence/elimination settings.

Recommended Next Steps

Operational Research

- Determining the optimal survey design(s) for mapping at each critical decision-making stage of a program, dependent on program goal
- Analyses needed on the costs of treating vs. mapping at different spatial scales which determine the cost savings of sampling at a sub-district level and targeting of treatment
- Defining the optimal age-groups to be sampled for mapping and how to sample each (i.e., purposive or systematic random sampling of adults?); is there a school enrolment threshold below which you would need to do a community house-to-house survey, of **all** children <15 years?
- Identifying the optimal diagnostics to be used for mapping at each decision-making stage, per program goal
- Qualitative understanding of the operational feasibility of targeting schistosomiasis control

Actions

- Using existing multi-country schistosomiasis epidemiological data from both before and after PC within geostatistical and mathematical models to determine alternative spatial sampling strategies

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- A multi-country operational research study to test model predicted spatial sampling strategies in a range of transmission settings and their epidemiological outcomes. The results can be compared to existing sampling strategies outputs, feasibility and costs.
- To develop a standardized spatial sampling strategy, or strategies, and process to inform geographically precise schistosomiasis interventions during different program phases for national NTD programs

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Soil-Transmitted Helminthiasis

Exploring Distribution Platforms to Mainstream STH PC

Knowledge Gaps

- What are the barriers with mainstreaming PC distribution for STH, and how can those be overcome? What are the factors that a national STH program should consider when making the determination of which platform to use to reach each target group?
- Identify what phase the STH programs have reached in each country. A more mature program that is reaching 75% of each of their target populations requires different information than a less mature program. This links with the proposed tier-grouping of national STH programs.
- Identify if there is a difference between an efficient platform vs. a sustainable platform; they may not necessarily be the same.
- We need to understand what countries actually want from their STH programs, considering the epidemiological, political, and financial implications of these goals.
    - Control vs. elimination as a public health problem
    - Current model vs. mainstreaming
- We need to understand the cultural barriers to STH treatments in specific indigenous populations. With the barriers identified, next would be finding solutions to them with the help of qualified anthropologists. Context-specific approaches (e.g., little doctors in Bangladesh – children educating adults) are necessary.
- Identification of quality medicines is necessary to reach the required STH populations.
    - Donated – Availability of 600 million treatments that is limited to SAC and now PSAC
    - Government-purchased – What is the limitation of obtaining high-quality medicine for the at-risk population not covered by donation?
- Identification of whether or not STH programs should move from a coverage metric to a morbidity metric. What metric would be key for identifying success? What is the supportive evidence for each? OR is needed.
- In WRA, ideally, we should be aiming to pursue the elimination of morbidity and eventually elimination of transmission. While 75% coverage is a reasonable intermediate goal, what data is it based on? Is it high enough to achieve elimination of morbidity? OR is needed.

Recommended Next Steps

- Development and a trial of a framework that identifies the timing and process to transition to the appropriate STH platforms for the populations requiring treatment
    - The framework would begin with the development of a systematic guide to identify which questions we should be asking, and would incorporate key factors in determining appropriate alternative distribution platforms to sufficiently reach all 3 at-risk populations.
    - Pulling in qualitative researchers and anthropologists will be vital for its success.
    - Hopefully, a standardized framework would be possible that would allow countries to customize their platforms appropriately to achieve the result required by their STH programs.
- Conduct cost-effectiveness studies of the different distribution platforms, taking into consideration the target of the program, the species endemic, cost of volunteers, etc.

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- Complete studies that define or confirm estimates of when to move from semi-annual treatment to annual treatment and then to the ceasing of treatment.
- Implementation of a regional workshop to share best practices
- Determine whether modeling can be used to determine how WRA are contributing to ongoing STH infection as well as how deworming of pregnant women in antenatal care settings would impact (or not) their lifetime disease burden

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Schistosomiasis & Soil-Transmitted Helminthiasis

Identifying Non-responsive Schistosomiasis and Soil-transmitted Helminthiasis Areas Following Treatment and Determining the Causes

Knowledge Gaps

Three key knowledge gaps were identified:

1. What is the definition of a non-responsive area? Does this vary by species, location, and programmatic goal?
2. How can programs identify persistent hotspot areas? Which monitoring and sampling approaches could be used?
3. How can programs determine the cause of suboptimal response to treatment? What qualitative and quantitative tools are needed to identify the root causes of poor treatment response?

Recommended Next Steps

The following operational research questions were generated in response to the three key questions:

1. ***What is the definition of a non-responsive area? Does this vary by species, location, and programmatic goal?***
    - What "thresholds" can be tested to determine if a cluster of cases is a "hotspot" worth further investigation?
        - Using modelling and interrogation of available datasets
        - Comparison of fieldwork protocols
        - What is a reliable algorithm for determining non-responsive areas?
    - Development and testing of standardized protocols to investigate non-responsive areas, that capture:
        - *Who to test* – identifying the appropriate sampling framework, to include number, ages, design of clusters, and geographical scale
        - *How often to test* – the interval after treatment, either immediately after treatment to determine treatment failure, or prior to next treatment round to capture reinfection. Ideally, sampling at both time points could be conducted. Also, the frequency of testing
        - *Diagnostic* – the choice of diagnostic will affect the definition of non-responsive area.
        - *End point* – What is the program target – control or elimination?
        - *Cross-NTDs* – Is there scope for including other neglected tropical diseases (NTDs) in the protocol?
    - How does the starting prevalence (pre-treatment) affect the ability to reach the goal? How should this be considered when determining presence of non-responsive areas?
    - What is the evidence base for the existing thresholds for MDA?

- How does this differ between SCH and STH?
- What data are available and what additional data are required?
- Compare with MORBID study for SCH

2. ***How can programs identify persistent hotspot areas? Which monitoring and sampling approaches could be used?***

- Development of a framework for the identification of non-responsive areas
    - Use of GIS to map co-variates (e.g., WASH, temperature, proximity to water, poverty, etc.) to rule out unlikely areas and determine where field work should be focused
    - Testing of that framework to predict location of future potential non-responsive areas
- What is the correct sampling approach to detect non-responsive areas? Based on Bangladesh (STH), an option is to stratify endemic areas according to transmission risk/intensity. Conduct more extensive sampling (e.g., community-based assessments in all ages) in higher risk areas and less intensive (e.g., school-based sampling) in lower risk areas.
    - Consider matching places with similar pre-control conditions and observing how they behave under treatment
- What is the correct scale to detect non-responsive areas?
    - What level of granularity is possible (technologically and financially)?
    - What level of granularity is programmatically useful? At what scale does/will the program make decisions?

3. ***How can programs determine the cause of sub-optimal response to treatment? What qualitative and quantitative tools are needed to identify the root causes of poor treatment response?***

- Do we have a coverage/compliance gap in SCH where infection levels remain high (such as Lake Victoria)? What lessons can we take from NTD programs in Asia where directly observed treatment is less common?
- Further testing of the STH Failure Checklist/s developed by STH Coalition
- Development and testing of a SCH Failure Checklist, bringing in questions on:
    - Programmatic performance (coverage, compliance, quality of social mobilization, and supervision)
    - External factors (population migration, WASH, and water contact behavior)
    - Incorporating anthropological/qualitative research (cultural/ethnic barriers to treatment, attitudes to health workforce/government, identifying key decision makers and connectors in populations)

- Development and testing of protocols to test drug efficacy
    - For SCH and three species of STH
    - In areas of varying endemicity
    - In areas of varying treatment histories

Monitoring & Evaluation for Effective STH and Schistosomiasis Programs

Knowledge Gaps

- Standard methods for completing statistical epidemiological trend analyses are missing in the current WHO Guidelines. How can the WHO Guidelines be updated to include these critical processes?
- Current STH and schistosomiasis targets and indicators lack evidence. Research is needed to generate evidence to identify whether and how intensity should be part of the decision-making process. If more intensive mapping is needed, we may want to switch to a prevalence determination instead of an intensity determination.
- New generation diagnostics are required but as the cost of new technologies can be outside of the budget of most of countries, any new test must be affordable and field-friendly to support M&E activities.
- How can the positive impact of reducing morbidity be factored into calculations of program cost effectiveness? When calculating cost-effectiveness, researchers must also calculate the value for money in terms of the positive impact on people's lives by reducing morbidity.
- Endemic countries are in urgent need of capacity building in M&E.
- M&E frameworks should be adapted to take into consideration the characteristics of the different parasites as not all worms are created equal. Response to drugs, epidemiology, reinfection rates, etc., are different across worm species.
- Clear-cut endpoint definitions need to be agreed upon by the STH and schistosomiasis communities to assist with target setting by programs.

Recommended Next Steps

- It is recommended that STH and schistosomiasis programs develop robust M&E frameworks to guide their activities and decisions towards eliminating these diseases as a public health problem.
- Concentrated effort is required to operationalize shared tools that have been developed such as the STH Monitoring & Evaluation Framework, schistosomiasis mapping tools, and other rigorously tested tools and methods for country use, such as those used by India and Kenya.
- It is recommended that evidence is generated to support the setting of clear endpoints for programs for STH and schistosomiasis both for the control of morbidity and transition to elimination as a public health problem.
- New generation diagnostic tests are urgently needed to support the verification of endpoints for elimination, particularly when prevalence and intensity have been significantly reduced through program interventions.

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Trachoma

Challenges and Solutions for Trachoma Surveys

Knowledge Gaps

- How can graders be trained in the absence of TF without loss of survey quality?
- What alternative sampling methodologies can be used for hard-to-reach populations that may consist of small clusters or EU population sizes?
- What opportunities are there for integrated surveys (and programme implementation), including using integrated serosurveillance?
- Are there opportunities for more innovative survey methodologies or approaches to improve the efficiency of trachoma survey methodologies, in particular for small clusters as seen in Latin America?
- What might be the best approach to survey migratory/nomadic populations, to ensure the population surveyed is the population for whom decisions are applied?
- Can satellite or new technology be used to identify populations for sampling and interventions? (Identify where communities are at time of survey)
- What alternative methods (aside from a survey) are there for determining if national programmes have reached TT elimination thresholds? What are the respective roles of door-to-door case finding, TT-only surveys, and integrated case finding?
- How programmatically significant a problem is non-trachomatous trichiasis?
- What is the effect of including trachomatous scarring (TS) in TT surveys (impact on training and service delivery)?
- Can we use serology to help understand trachoma transmission dynamics? Will it help to identify areas at risk of disease recrudescence?

Recommended Next Steps

- Explore the role of assistive aids for grader training (e.g., augmented reality).
- Develop guidance on affordable post-elimination surveillance systems/methodologies.
- Validate different approaches for generating TT prevalence estimates – surveys and TT case finding (passive or active). Include an assessment of cost-effectiveness.
- Develop guidance on conducting a TT door-to-door case search as an alternative to surveys for determining if TT elimination thresholds have been reached or sustained.
- Determine the burden of non-trachomatous trichiasis and implications on training and service delivery of including TS in TT surveys.
- Complete the OR agenda identified at the “Technical Consultation on the Use of Serology for Trachoma Surveillance.”

Off-target Health Impacts of Azithromycin Mass Drug Administration

Knowledge Gaps

Current knowledge gaps regarding azithromycin as a child survival tool include:

- Which populations exact most benefit (and offset any potential risk)
- Optimal target age group. Which age group has the most significant reduction in mortality?
- Frequency of azithromycin MDA and the impact on mortality

- Duration of beneficial effect
- Optimal platforms to reach target groups
- Mechanisms of action eliciting effects observed
- Impact of seasonal transmission (specific disease entities) and timing of MDA
- The efficacy and utility of azithromycin MDA through delivery of azithromycin to mothers in labour, or children where no trachoma or yaws MDA indicated
- Impact on gut microbiome of young children given azithromycin

Current knowledge gaps related to the impact of azithromycin MDA on STIs include:

- The impact of azithromycin MDA on STIs
- Duration of any effect
- The relationship between multiple rounds of azithromycin MDA and STIs

Recommended Next Steps

Operational research required

- Further studies on azithromycin and U5 mortality from across a wide range of settings (underlying mortality rates and disease profiles) are needed, including (but not exclusive to) understanding the optimal target age group, the duration of the beneficial effect and any negative consequences including AMR.
- Evaluation of the long-term risk of azithromycin on young children through a longitudinal study evaluating the gut microbiome and possibly cardiovascular health
- Studies to evaluate the impact of azithromycin MDA on STIs
- A cost-benefit analysis of azithromycin MDA beyond trachoma; this should also take into account any potential long-term negative risks
- Azithromycin impacts on quality of life
- AMR studies across a broader range of gram negative bacteria (e.g., shigella, salmonellosis, and gonococcus)

Programmatic next steps required

- Further evaluation of routinely collected data through the health information system in countries in order to determine the feasibility of use for monitoring off-target impacts
- Need for broad guidance on what indicators would be useful for health systems to measure in regards to off-targets for azithromycin
- Support to data managers on how to analyze that data in real time or in a short timeframe

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Intensified Disease Management (IDM) Diseases

A Framework for Engaged Research to Reach Zero Leprosy

Knowledge Gaps

- Elimination as a Public Health problem has been achieved at national level in most countries, while transmission is still ongoing. How do we address this?
- How do we ensure continued support for leprosy control? What should be our next target?
- One of the main challenges of the Global Partnership is to come to action at national level.
- Undoing the elimination message is an important part of that. How can the research agenda be best formulated in order to get maximum support to work towards zero leprosy?

Recommended Next Steps

- It was suggested to identify which of the issues of the Research Agenda would need to be addressed first, before addressing others. A framework as was presented by Emily Wainwright during the plenary session showing the steps needed and indicating with green, orange, and red which steps have to be taken next when working towards the elimination of a disease.
- When formulating the research agenda, it is important to keep in mind who it will be presented to. The Global Program to Eliminate Lymphatic Filariasis has also gone through a process of formulating the research agenda. The agenda was collapsed into five key questions. This enabled the communication with major donors.

Can Kaa-azar transmission be interrupted?

Knowledge Gaps

Knowledge gaps were identified in the following domains:

- Transmission dynamics
- Active case detection (ACD)
- Vector biology and xenomonitoring
- Post Kala-Azar Dermal Leishmaniasis (PKDL)

Recommended Next Steps

The following questions merit further study:

Transmission dynamics

- Investigate factors that cause resurgence of infection in villages that had previously been below the threshold.
- Investigate foci were transmission has been absent (without resurgence) for many years
- Investigate the role of asymptomatic cases in transmission
- What is the most effective way to draw boundaries around index cases?
- What is the most accurate method in predicting location of future cases?
- What role does socio-economic development play in transmission?

ACD

- Does ACD lead to a reduction in transmission?
- What ACD methods are most sustainable?

- What other methods can be used to reduce the time to diagnosis (and hence time to treatment)?

Vector Biology and Xenomonitoring

- Calculate infection rate
- Calculate entomological inoculation rate
- What is the proportion of infected sandflies that creates risk of human disease?
- Evaluate the cost-effectiveness of xenomonitoring as a surveillance mechanism
- Develop guidelines for VL transmission endpoint assessment
- Adapt the *L. mexicana* metacyclic-specific PCR assay to *L. donovani* to measure the proportion of sandflies that are infectious
- Evaluate vector control activities for association with desired clinical outcomes
- What incidence level should trigger a vector control response?
- Can vector control strategies be expanded to target the entire transmission cycle?

PKDL

- Incidence
- What role does PKDL play in transmission?
    - Can PKDL cases serve as a reservoir of infection?
- What are the mechanisms and important determinants of PKDL development?
    - What is the relationship between primary VL treatment and development of PKDL?
    - What host factors are associated with development of PKDL?
- What VL treatment regimen is most effective in preventing PKDL?
- What is the best treatment regime for PKDL?
- Is there a way to distinguish PKDL from other skin conditions (an improved diagnostic over skin slit)?
- Are there socio-demographic factors related to PKDL?
- Are there regional differences in the association between treatment and development of PKDL?
- What are the ethical considerations of treating a disease that does not cause severe clinical manifestations with potentially toxic drugs that can cause harmful side effects?

Innovations in Leprosy Prophylaxis: Current Evidence and Upcoming Trials

Knowledge Gaps

- Better diagnostic tests are essential – not only for leprosy but for other NTDs as well.
- Molecular and genomic tools need to be refined and applied to understand networks of transmission – which will be essential for achieving zero leprosy.
- Optimization of the PEP platform is essential to maximize its impact.
- An effective vaccine is needed, and it needs to be evaluated as part of PEP (e.g., combined immunoprophylaxis and chemoprophylaxis of contacts).
- A new cadre of health workers needs to be trained to recognize and diagnose leprosy; those who had these skills previously are retiring or are no longer in the work force.
- Epidemiologic models need to be further developed to guide interventions and support advocacy efforts.

Recommended Next Steps

- Optimizing PEP: data from LPEP need to be fully analyzed; and PEP++ and PEOPLE studies should move forward in a coordinated fashion.
- Vaccine development: Phase II trials for LepVax should be initiated soon and further collaboration explored with investigators in India on the MIP vaccine.
- Diagnostics: PCR diagnostics need to be assessed across multiple laboratories to identify the best approaches and methods and develop standardized best practices.
- Diagnostics: Cadres of health workers need to be trained to diagnose leprosy.
- Diagnostics: Use of digital technology to facilitate diagnosis should be pursued.
- Mapping: Improved approaches to mapping to identify foci of transmission need to be developed and deployed (also a hot issue for other NTDs – coordinated approaches would be ideal). Epidemiologic models need to be further developed to guide interventions and support advocacy efforts.

Innovative Strategies for the Comprehensive Transmission Control and Care of Chagas Disease in Health Networks

Knowledge Gaps

- The need for access data to be in the public domain and that translation of the information systems is applicable for use in real time to tackle better access and care strategies.
- The need to integrate Chagas access and care activities with the goal of addressing the sustainable development goals and global strategies.
- The need to increase training and fostering of clinical teams to increase diagnosis.
- The need to create intensive, specialized and periodic actions to integrate mother-to-child transmission control into health interventions and structures.
- The co-creation of research questions in partnership with the community and social society. These processes should be circular versus linear and include: 1) bottom-up demand approaches, 2) prioritization according to community needs and urgent societal issues, 3) the use of appropriate tools and techniques, 4) sensitivity towards “power” relationships, cultural context, and a dialogue highlighting representativeness versus representation.
- A consensus is needed to better define how to achieve Chagas control, care, and elimination and their targets.
- The need to develop better tools or indexes for monitoring Chagas control, care, and elimination as a global public health problem.

Recommended Next Steps

- Continue to improve the vector taxonomic system and generate deep neural networks for identification purposes through the Virtual Vector Laboratory. The utility of this model can be increased by a comparison of methods, improving diagnostic accuracy, expanding the total number of species, and exploring the possibility of using smart-phone technology with georeferencing.
- Continue to give priority to the prevention of congenital Chagas – Mundo Sano to launch a global campaign called “No Baby with Chagas.”
- Expand on the topic of the integration of mother-to-child transmission control into health interventions and structures in the 2019 COR-NTD meeting.
- Disseminate and integrate the concept of practical workshops and active discussion on participatory methodologies for involving stakeholders in (i) the development of needs assessment and (ii) operational research process.
- Strengthen the tools to measure “access” impact.

- Strive to integrate operational research within all Control and Care country initiatives such that representatives from ministries of health can be more efficient in adopting any changes in policy or strategy for Chagas.
- Build more effective, scalable and sustainable partnership models – with local and regional stakeholders ensuring the inclusion of a local champion and securing political commitment.

The Role of New Technologies in HAT Elimination

Knowledge Gaps

Global monitoring

- How should the active screening algorithm be modified to target sites of infection more specifically?
- What information is needed in order to understand where infection is taking place?
- How can national programs ensure that all appropriate data are reported to them?
- How should national programs address population movements into or out of areas at risk?
- How should the global program assess what is happening outside program areas?
- Why does the disease appear in one village and not another with similar risk factors?
- How does the program confirm that zero cases means zero transmission?
- What is the impact of larger social, economic, and environmental changes on the disease (e.g., changes in climate, habitat and human behavior patterns)?

Active screening

- Digital solutions for data collection, planning, and diagnosis increase program efficiency and accuracy, but what is needed to scale them up?
- How will programs support the use of hi-tech tools in harsh and remote settings?
- Where can programs obtain reliable and accurate geographic information?
- How might the program convey to donors the strategic benefits of investing in new digital tools?
- How should programs coordinate with vector control interventions?
- How does the program increase community participation in active screening and follow up on absentees?
- How will programs serve mobile populations more effectively?

Passive screening

- In the FIND-supported projects, the facilities provided the additional services but there are examples where this does not take place without additional financial resources. What determines implementation of additional HAT services by fixed health facilities?
- What opportunities are there to save time and costs in passive screening, such as multiplex diagnostic tools?
- Are there other pressing health problems in the target areas that can be addressed jointly with HAT programming to increase efficiency and buy-in?

Recommended Next Steps

- **Scale up digital solutions in the field**
    - How can the economic and strategic advantages of digital tools be communicated effectively to donors?
    - What operational steps are needed to scale up digital data tools globally?
    - How will training and implementation be effectively scaled up across programs?

- What are the logistical challenges of managing the instruments in difficult, remote settings, and what do programs need to address them?
- How can such digital platforms be harmonized with the HAT Atlas?
- What existing sources of reliable geographic information could be leveraged by the programs (GPS coordinates, place names, and populations)?

- **Research sociocultural determinants of participation**
  - What are the daily/weekly/seasonal activities of the populations in need of active screening, and how could screening activities be organized to become more convenient and accessible?
  - What perceptions in the community cause low turnout for active screening, examining in particular the effects of stigma and perceived lack of risk?
  - What information would convince non-compliant individuals/communities to participate and how should the information be packaged and disseminated to be most effective?
  - What are the best practices for reaching refugees and IDPs?

- **Research program sustainability**
  - Research the factors affecting adoption of tools and provision of services
    i. What determines whether program staff will continue using the digital technology for program management and continue screening according to the (passive screening) protocol?
    ii. What are the appropriate time horizons?
  - Research the options currently available or in the pipeline to provide time and cost savings through:
    i. A multiplex diagnostic tool
    ii. Eliminating the need for a confirmation test
  - Research the options for combining HAT tools with tools that address other health problems that are more pressing needs in the area.

- **Assess and adapt the overall screening strategy for improved coverage**
  - What information would help programs identify and target interventions towards site of infection, such as additional indicators on patient history?
  - How should this information be collected, and how will the program operationalize this?
  - How can areas with insufficient coverage be specifically addressed? Would a global map highlighting insufficient coverage in the past five years help target interventions?
  - What is needed to develop standard recommendations/guidelines on reaching mobile populations such as refugees, IDPs, and seasonal migrants?
    i. What lessons from the FIND-supported projects (and potentially other programs) can be developed into guidelines?
    ii. Would it be useful to map mobile populations not served by existing programs but vulnerable to disease?
  - How can the current algorithm for active screening interventions be modified to:
    i. Focus more attention on site of infection
    ii. Include a standard approach to mobile populations?

- **Research transmission inside and outside program areas**

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- Why does disease appear in some places and not in others with apparently identical conditions?
- Are current methods able to predict disease based on local conditions (e.g., modelling, risk mapping)? If not, what methods can be developed?
- How can these methods help us foresee the impact of changes in conditions due to climate, economics, and human behavior?
- How is interruption of transmission confirmed?

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Cross-Cutting

Aligning NTD Programs with Universal Health Coverage – Lessons from Research

Knowledge Gaps

- NTD indicators used in UHC Monitoring reports do not include non-PC NTDs. Countries and partners should work with UHC implementers in-country to include non-PC diseases in the essential package for UHC.
- Should guidelines and related products such as training modules be integrated, to ensure integrity of the continuum of NTD services within/across delivery platforms, types of service (preventive, curative, rehabilitative, etc.), and life cycle stages?
- Might "quality" provide a useful framework by which to consider the integration of these guidelines and related products?
- What should the UHC menu of NTD interventions looks like?
- What examples/good practices can we cite of NTD mainstreaming?
- How do we demonstrate that NTD interventions are strengthening health systems across the six building blocks?
- How do we measure the contribution of NTD programmes to WHO's target of one billion more people benefiting from UHC?

Recommended Next Steps

- Conduct mapping of the 22 NTD diseases and how each links into the health system of a country and at what level. Outcome – to ascertain what is the 'smart' constellation of diseases into the health system and the UHC essential package.
- NTD programs have to understand and participate in insurance and innovative financing at country level. What are NTD priorities and how do they align with national insurance priorities?
- What is being done at country level, by whom and what are places where patients with NTDs intersect with the health system and look for synergies and missed opportunities for care?
- At country level, focus on pre-service training of medical and nursing students to alert them to key NTD policies and interventions.
- There was discussion about two distinct approaches that NTD programs and partners might take re policy. Consensus was that while carrying on as usual with donor driven PC therapy in health systems is 'easier,' the NTD community must engage UHC and participate in UHC task forces, working groups, etc. The NTD group at WHO has done this deliberately and diligently but it is unknown to what extent the NTD program at country level is a part of UHC deliberations and decision making.

Behavior Change for MDA, WHO Targets, WASH, and Morbidity

Knowledge Gaps

- How can an intervention best be introduced and maintained?
- There is need to establish an overarching framework for choosing a coordinated set of interventions that involve the patient, community, and local health system.

- There is a need to better gauge the prevalence of female genital schistosomiasis, encourage reporting, and train health workers to actively screen for schistosomiasis and to distinguish it from STIs.

Recommended Next Steps

The group devised the following operational research questions and suggested 'nudges':

- How can men be better reached during MDA? Are there alternative drug/information delivery platforms that can be used?
- How do we properly time the delivery of MDA?
- How do we improve perceived drug safety and trust?
- How do we better target children and increase their drug uptake?
- How may we increase the uptake of compostable defecation bags?
- How do we promote latrine usage?
- How do we improve the training of health professionals on aspects of FGS?
- How do we improve women's understanding of sub-fertility?
- How do we deal with hidden stigmatization of women with FGS?
  How do we reconcile differences between health systems and communities with differing views on FGS?

Community Engagement: Practices for Evolving Contexts

Knowledge Gaps

- Community Engagement – Urban areas
  - Structure – heterogeneous structure of urban areas, lack of leadership
  - Use of CDDs – urban dwellers may not trust CDDs; prefer nurse or doctor
  - Sensitization – people don't know what NTDs are, they don't believe they're sick – why should they take treatment?
  - Low risk of disease – people don't see NTDs as a high risk; urban slums may be neglected.
- How do we continue to access and engage community ownership?
  - By building trust of community through improved sensitization/strong communication strategy using modern tools
  - Recruit ambassadors to raise awareness of NTDs in urban areas (e.g., high-profile individuals such as footballers and pop culture celebrities).
- Use of CDDs
  - To address the limited number of health workers in urban areas, training CDDs and building capacity and credibility would help.
  - Government employees from other ministries, or teachers would have the credibility and trust to distribute medicines
- Community urban structures can be leveraged as central locations to improve MDA coverage as opposed to house-to-house distribution.
  - Churches, schools, community centers, the work place, and shopping centers
- Are there lessons that can be learned from HIV, malaria, Ebola, TB with regards to building and sustaining community engagement?

- These might be patient advocates, lobbying, multisectoral involvement, engagement of the informal/private sector, or working through support groups.

Recommended Next Steps

- Assessing the knowledge and awareness of community stakeholders can be conducted before and after planning to test efficacy of strategies. This research may also identify who is currently missed/needs targeting.
- Impact of microplanning (engaging communities in planning exercises) needs evaluating after longer periods to review cost effectiveness and sustainability.
- Different communication strategies should be piloted – e.g., whether educated CDDs or government workers giving back to the community would be effective leading MDA in their communities.
- Different models of MDA delivery in different contexts could be piloted for acceptability, effectiveness and cost.
- Strategies to engage communities in different contexts may require different approaches. Research is needed to look at tailoring current engagement approaches for specific contexts groups.

Discovery and Clinical Utility Testing of Biomarkers for NTD Elimination

Knowledge Gaps

- A biomarker that can recognize adult female worms (need not be exclusively females as long as adult worms can be detected) OR some other proxy that can estimate adult worm burden
- Macrofilaricide or drug to kill/sterilize adult female worms
- A test for individual diagnosis and treatment monitoring
- Target product profiles need to have extensive input from subject matter experts
    - Biomarkers for STH could be array of peptides with algorithm or analysis *OR* a more pan-helminth marker that could cover most species of interest
- Open access to shared biobanks would be beneficial to effective diagnostic development
- A searchable database of biobanks would be key (use pre-existing models)
- Need to consider incentives for different types of participants (e.g., academic vs commercial; groups with biobanks that would need to invest time and funds to prepare large sample sets)
- Need to consider protections for low- and middle-income countries wary of being taken advantage of
- Need to discuss and come to consensus on who would provide governance

Recommended Next Steps

O. volvulus

1) Support the validation of existing and newly identified biomarkers of Ov adult female for monitoring & evaluation.
    a. Demonstrate specificity
    b. Assess changes post-treatment (particularly macrofilaricidal therapies like doxycycline)
2) Support the validation of new (or newly identified) biomarkers that could be used to in making treatment stopping decisions

3) Support the validation of existing (or newly identified) biomarkers that could be used in post-treatment and/or post-elimination decision making
4) Create a virtual biobank across multiple laboratories tied to information/metadata about samples

STH

1) For all use cases, quality control/assurance programs need to be put in place for both stool-based microscopy approaches (i.e., Kato-Katz) and for qPCR
2) Biobanks (virtual or real) for post-treatment surveillance
3) Support the validation of new (or potential) biomarkers for use in post-treatment surveillance
4) Support the development of sets of SOPs for collection, storage, consent language

Engaging NTD Programs, CDDs & Communities to Improve Coverage

Knowledge Gaps

Participants worked in small groups to discuss three key thematic issues, identifying the following knowledge gaps:

1. Re-orientation of program strategies to engage for IDA rollout
   - What is the best approach to mobilizing the community so they can begin the two-year IDA poised for high coverage?
     - What might be barriers to the change?
     - What can be done to facilitate the change?
   - What are the drivers that promote and inhibit community participation in the MDA (e.g., the number of pills and side effects)? Based on these drivers, the program delivery strategy can defined.

2. Special considerations for engaging to improve coverage in urban areas
   - Identify appropriate communication strategies in increasing urban engagement in MDA. (e.g., In urban areas people are busy so you need appropriate methodology to engage them, so what is the appropriate method?)
   - What is the ideal message and who are the ideal messengers to increase coverage in (perceived?) low risk populations? (e.g., rich population, students and professionals)

3. Digital tools for engagement – opportunities and barriers
   - What would be the cost benefit ratio for developing and app for mobile phones and what would be the impact on equity? (Consideration needed for whom this would be targeted towards. e.g., CDDs or frontline health workers)

   How to determine community access to and utilization of digital tools (e.g., standard phone vs smartphone)? Many CDDs have basic mobile phones and not smart phones. We need to understand reasons they use their phone.

Recommended Next Steps

- What are the drivers that promote and/or inhibit community participation in the MDA and what are the best approaches to achieving high coverage with IDA?

- What are the appropriate communication strategies to increase urban engagement for MDA including those in perceived low risk populations (e.g. rich population, students and professionals)?
- What will be the need and cost benefit ratio for developing an app for mobile phones (for use by either CDDs and frontline health workers) and the impact on equity?

Equality and Equity of NTD Interventions

Knowledge Gaps

- Gender analysis of program data to address implementation challenges.
- Map diseases and related morbidities, as well as linkage to care.

Recommended Next Steps

- Data/Health Management Information Systems
    - Why and how does gender get removed from the joint application? How do we make we ensure that the disaggregated data are shared with programs?
    - Conduct a landscape analysis on how other sectors determine their population denominators (e.g., ethnic groups) and think how this could be applied to MDA population estimates.
- Medicine or Technology Advancement
    - Ensure that pediatric formulations of medicines are provided to appropriate populations; ensure that pregnant women are treated when eligible.
- Human Resources for Health
    - Conduct a policy review of how gender is integrated within NTD programs (e.g., looking at different levels of work force). Is there commitment from the government commitment to promote a gender balance?
    - Look at incentives for CDDs – both financial and non-financial remuneration and the relationship to equity and inclusion in the work force and performance.
    - What is the relative effectiveness of different gender mixes at different levels of the health system (focusing on peripheral health system-teachers and CDDs)?
        - Case studies
        - Quantitative studies (program performance)
- Morbidity Management/Service Delivery
    - What community-based intervention could be used to support people affected by NTDs?
    - Where do people affected by NTDs access care?
        - What is the role of the non-formal health sector?
        - What are key access points?
    - How do age, cultural norms, and gender shape MMDP care needs?
    - What impact would symptom versus disease-based management have on improving program equity?

Health Systems Strengthening Opportunities and Challenges for NTD Integration with the National Health Information System

Knowledge Gaps

- Data-sharing and use policies that lead to well-defined indicators and data sources
- SOPs for data collection, analysis, and use
- Data reflection sessions at national and sub-national level that guide data for decision making and iterate programmatic activities based on data
- Appropriate technology to storing data that facilities data sharing

- Data are collected at sub-national level for the sole purpose of reporting up (vertical flow). There is no use for the data at the level from which it is reported (horizontal flow) and there is no feedback from the national level with regards to the quality of the data or putting the data into context in the form of a report or analysis.
- What data is useful (from the field)?
- What questions are important to ask (for the modelling)?
- How can accessibility of user-friendly versions of models (e.g., web apps, spreadsheets, etc.) be increased?
- How can access to modelling outputs by non-modelers be improved?

Recommended Next Steps

- Standardized data elements, coding, and structures: NTD participation in OpenHIE to codify global standard for open data structures
- Appropriate technology: Supporting the principles of digital development (e.g., https://digitalprinciples.org/principles/), strengthening health systems through interoperability, and avoiding parallel systems and digital silos
- Embrace national health information systems: NTD partners and national NTD programs need to ensure high-quality, standardized NTD indicators are part of the national health information system. If they are not, then there needs to be support to get them added. Once added, national programs and implementing partners and donors need to rely on those data to build demand for quality.
- Data for decision making: If there were feedback (e.g., reports, meetings, other) from the national level to the sub-national (at which it is being reported), the data would be more meaningful and quality would likely be impacted positively.

Non-Compliance: Populations, Causes & Formulating a Programmatic Response

Knowledge Gaps

Participants identified knowledge gaps in the following areas:

- Epidemiology
- Social mobilization
- Selection of drug distributors
- Monitoring and evaluation

Recommended Next Steps

Epidemiology

- ***To what extent do the people we miss systematically represent reservoirs of infection? (e.g. gated communities, apartment buildings, middle aged men etc.). What are the profiles of persons often systematically missed AND who represent reservoirs of infection?
    - Questions should be addressed by disease with review articles where several papers on the topic already exist.
- What are the most common reasons for absenteeism and rejection of treatment?

Social mobilization

- ***What strategies effectively address fear of treatment and side effects?

- What rapid research methods can be used to identify barriers and facilitators of (systematic) noncompliance in settings with known challenges in this area (e.g. Nepal and Ache, Indonesia)?
    - How do barriers and facilitators of compliance vary by community and groups (e.g. urban slums, out of school children)?
- What locally owned innovative interventions, including use of different platforms, improve compliance? – Need for case studies.
- What communication methods effectively reduce noncompliance? – Need for case studies

Selection of drug distributors

- How do we identify the best people to deliver the treatment?
- *** Replicate the social networks methodology in different settings and evaluate with a randomized controlled trial.
- Would copying model programs from other health interventions that utilize *peer educators* improve compliance with MDA?
- Are more people treated when drug distributors and beneficiaries share affiliations (e.g. same family units, social support groups, workplace)? And how can this be used in selection of effective drug distributors?

Monitoring and Evaluation

- Without DOT, how do we verify ingestion of treatment? Can we revise the coverage survey so that it better captures issues around non-compliance:
    - Are we collecting the right indicators (acceptability, intentionality, systematic noncompliance) to improve programmatic reach?
    - Does the current study design reach the 'right' people?

*** *Notes the three priority questions*

NTD Capacity Building and Control in Central Africa

Knowledge Gaps

- Key regional challenges: geography, low population density, security, low capacity, low integration (French/Spanish!) – all prevent reaching MDA coverage.
- Chad – program in transition because the program manager passed away two months ago.
- Central African Republic (CAR) – insecurity and war – hard to implement.
- Few NGO partners are active in most countries except Cameroon.
- The Bill & Melinda Gates Foundation is providing resources (to cultivate the leadership) for ESPEN. Generally, institutional capacity is low but there are individuals that invest themselves to make things happen with little resources they have – identify these leaders in each country.

Recommended Next Steps

- **Time is right for this region.** Yes, it is comprised of francophone countries, many of which are experiencing civil unrest, but 35-40% of USAID-supported countries deal with this. Priority comes with disease burden. The CMAC region is dominated by Cameroon in terms of absolute numbers so to get the job done we needed to address Cameroon as the priority. Now the other countries must catch up.
- **Data**. There are still data gaps for some diseases in the region (e.g., LF).

- **Capacity building**. Congo, CAR, and Chad need capacity building to transform funding into high-quality activities on the ground. Until then, focus should be on supporting capable individuals, and encouraging NGOs to be present in the countries.
- **Collaboration and coordination.** Ministries of Health (MOH) should coordinate, strengthening leadership of NTD programs. Central coordination should be restored/built – the World Health Organization used to play this role but has more limited roles at present in several countries. Therefore, donors and actors need to coordinate.

NTD Intersections: Which Hinder Progress, and How Can We Tackle Them?

Knowledge Gaps

The groups identified areas that they thought would warrant further discussion at this workshop:

- Lymphatic filariasis + morbidity management + mental health
- Integration of mental health + disability in health system development
- Minimum mass drug administration (MDA) coverage
- Conflict settings (migration) varieties
- How conflict affects health-seeking behaviour
- Intervention packages for prevention and decreasing morbidity in conflict setting
- The foot
- NTDs + Epilepsy + childhood development.

The group divided into the areas of conflict, one health, and combined mental health/disability for further discussion.

Conflict

- Settings – varieties
- Time to intervene
- Health-seeking behavior

Mental health and disability

- When NTDs cause disability
- How to be inclusive in NTD progress
- The foot

One Health

- Lessons from NTDs
- Overlap of campaigns in animal and human health

Recommended Next Steps

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Conflict

- Research to identify if there are different strategies needed in conflict settings (for example, can we do standard MDA or do we need nuanced strategies?)
- Research to standardize the assessment of interventions approaches needed in each region
- If IDPs/refugees are from different endemicity regions, how do we conduct MDA? Do we need a survey or should we take action immediately when there is opportunity?
- What is the ideal package of NTD interventions in addition to basic health care interventions for IDPs/refugees? The NTD community should engage with other groups (e.g., MSF) on rapid assessment of these.
- Map the movement of people to, from, and within conflict regions to inform on risk.
- Where is each NTD on elimination pathway? Act quickly to prevent risks to elimination targets being achieved for disease with high capacity to outbreak quickly.
- How does conflict affect communities and behavior? This is setting dependent, but can influence priorities and health-seeking behavior.
- Can we measure and improve participation in conflict settings?

Mental health

- Review of literature of stigma for NTDs.
- Research is needed to document examples of integrating NTDs (i.e., what was done, what changed).
- Research into the impact of self-help groups, as a mechanism that could be inbuilt
- Research carried out across mental health and NTDs to ensure not reinventing the wheel
- The foot – unintentional consequences of managing footcare for diseases
- Understand better links between NTDs themselves.
- Research into how we incentivise those with diseases to seek care

One health

- Multiple layers – barriers low
- When animals are given to community community members should be educated with respect to NTDs.
- Vet services are private and paid for – map learnings of what this implies and how could be better.
- Potential to link messages around impact
- Cash transfers – swap for giving chickens
- Research needed to understand the drivers of animal health (e.g., financial, status, and how to create a demand for services)
- Research the potentials to link messages
- Map and coordinate where agricultural workers are at same places as MDA – to identify the bonus of combining services