



COR-NTD 2015

Philadelphia, PA, October 22-23

Breakout Group Summary Report

This document is intended to capture the key outputs of your breakout discussion, and to be representative of the group as a whole. Please denote your group's topic, presentations and research priorities before the start of the session, and dedicate the latter portion of your session to determining the key discussion points, knowledge gaps and recommended steps. Also, please indicate whether your group's recommendations align with the specified initial priority target. Your report will be shared on the NTD-SC website, and will inform future advisory panel discussions and donor priorities.

Section I

To be filled out before the session begins.

Breakout Topic:

2D: MMDP: What remains to be understood about the burden of NTDs?

Presentations:

After an introduction to the session given by D. Haddad and L. Fox, eight presentations were given which covered: 1) the global burden of LF morbidity (J King, WHO), 2) the global burden of trichiasis (A Solomon, WHO), 3) methodologies for assessing LF clinical burden (L Kelly-Hope, Liverpool School of Tropical Medicine and Hygiene), 4) methodologies for assessing trichiasis burden (S West, Johns Hopkins University), 5) experience from Burkina Faso's LF program on morbidity mapping for lymphedema and hydrocele (R Bouma, LF Program, Burkina Faso), 6) the global burden of mental health for NTDs (L Fox on behalf of C Mackenzie, Liverpool School of Tropical Medicine and Hygiene), 7) the economic burden of lymphedema for LF in India (E Stillwagon, Gettysburg University) and 8) integrated morbidity mapping for multiple NTDs (LF, leprosy and Buruli ulcer) (P Saunderson, American Leprosy Mission).

Research priorities to be discussed:

After the eight presentations, the group broke into three groups and addressed three different issues which included: 1) Operational research needed to determine accuracy of current survey methodologies and understanding the implications of the choice of survey methodology. Is a gold standard needed for validation of morbidity burden assessment tools? If so, what would it look like? What research needs to be done to validate it?, 2) What are the opportunities for integration of all NTD morbidity burden assessment elements in other surveys? What would this look like and what OR is necessary?, 3) How do we assess quality of care provided by morbidity management programs? What are the elements of quality care and how should they be assessed? Are there existing tools (WHO)? Both surgical and medical/nursing care?, Is there a role for operational research? Development of tools?

Form continues on the next page.



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Section II

To be filled out as the session concludes.

What were your group's key discussion points?

Breakout group (1) Burden - discussed a menu of methodologies outlined in draft WHO documents to assess the clinical burden of NTDs (list available upon request), with a focus on trichiasis, hydrocele, and lymphedema. For trachoma, the group emphasized the need to explore alternative methodologies to better determine the surgical need (i.e. trachomatous trichiasis unknown to the health system). For LF, the group recognized that house-to-house census may be a robust methodology to determine clinical case burden, but was concerned about cost and feasibility, though noted that mHealth strategies might address this. While the group focused on physical burden, it was emphasized that the number of DALYs for mental health is 2x the DALYs associated with physical burden and should be considered. (2) Integration - The group noted the potential value of integrating surveys to assess burden of disease, though experience in this area is lacking. In order to facilitate this process, each NTD should identify a limited number of key indicators that could be used as part of these surveys. The appropriateness of using school-based surveys to collect burden data was discussed. (3) Quality of MMDP services- The group emphasized patient outcomes and quality of life as important indicators of quality of services. A number of existing quality of life tools were suggested. Also, the impact that quality of services may have on the uptake of services was noted.

What knowledge gaps (if any) did your group identify?

Many gaps exist in our understanding of the global burden of NTDs, including the scope and intensity of clinical cases, as well as the economic and mental health burden of NTDs. Understanding the clinical burden of disease is critical for countries to implement target clinical interventions that will allow them to achieve global elimination goals, specifically for LF and trachoma. The availability of data on clinical disease is limited and the validity of the available data is questionable. It is also unclear how disease stigma might impact the quality of data collected during rigorous burden estimation strategies. The group also appreciated that the mental health impact of NTDs is unknown, and that the global burden of disease estimates do not include this important contributor to burden.

What next steps does your group recommend?

OR is needed to compare various sampling strategies for their ability to provide accurate clinical burden measures, with consideration to how underlying prevalence may impact these estimates. The group recommends identifying and comparing various survey designs with a 'gold-standard' house-to-house survey methodology to determine if the alternative survey methodologies can accurately approximate burden of disease. The group recommends exploring opportunities for leveraging existing data from the health system to inform burden assessments, integrating burden estimates into existing surveys or across NTDs, and identifying the role that eHealth may play in improving this process. Further, OR is needed to identify appropriate measures of availability and accessibility to MMDP services. Also, work is needed to determine which indicators will best measure patient outcomes from these programs including quality of life. Finally, economic assessments on the cost-effectiveness of MMDP programs should be expanded and mental health burden assessments are needed to inform global burden of disease estimates for other NTDs.

Do your recommended steps align with the research priorities identified on page 1?

Yes No