

Community Engagement: Practices for Evolving Contexts

Session Date: Saturday, October 27

Session Time: 1:00pm – 4:00pm

Session Location: Bacchus, 8th Floor

Session Description: As an NTD community we cannot ignore that gains made to date have relied heavily on the willingness of communities to be active participants and advocates for and within NTD programmes. As we strive toward elimination our programmes must adapt to meet their evolving needs. In this session, four presenters will explore the challenges engaging and sustaining interactions with populations in a variety of emergent contexts (urban, conflict, border, migrant), identifying how such challenges affect programme coverage and equity. They will showcase participatory research methods as a key strategy for programme implementers to develop, implement and adapt sustainable context-based solutions. In a series of round tables designed to maximize participation and amplify the experiences and inputs of different countries and contexts we will identify community engagement research questions “in common” around the contextual themes and then suggest participatory approaches to investigate and address the identified research agenda.

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KEY DISCUSSION POINTS

- **What is community?** Community is shared experience, interests, and struggles. For neglected tropical diseases (NTDs), the communities include community drug distributors (CDDs), people taking medicines, and people sharing a geographic area. These are people working collaboratively in diverse settings and diverse purposes.
- **Why engage the community?** To build trust, enlist new allies, mobilize resources, improve communication, and to help achieve NTD goals and improve health

Presentation 1: Community engagement emergent contexts.

- Engagement helps identify opportunities to engage communities in the research cycle and enrich the caliber of research through engagement of community.
- Communities serve as research participants, use research, and implement new tools and strategies that evolve from operational research (OR).
- Community plays multiple roles – problem identification, design and planning, implementation, analysis, etc.
- For example, the biggest problem is not drug supply; it's lack of infrastructure/poor roads. Are drivers and mechanics stakeholders?

- Design and planning: methodology, data collection, survey design – input is opportunity to get community buy in.
- Implementation: build awareness, implement intervention being studied, serve as data collectors or respondents, broker partnership and collaboration with community groups.
- Data analysis and interpretation (e.g., a CDD captured images to illustrate most important aspects of her role as CDD)
- Knowledge translation: post-study implementation. Community members help tailor evidence and implement strategies.
- Iteration and adaptation: communities can monitor innovation over time. Did it work?
 - Evidence based change
 - Social accountability mechanism
- Benefits to engaging the community: increases responsiveness to priority needs, improves efficiency and acceptability of the research process, facilitates complete and accurate data sets, ensures credibility of findings, creates opportunity to incorporate evidence into programming and policies to achieve public health impact

Presentation 2: Participation in research and implementation strategy and community engagement – experience in Nigeria

- Nigeria has biggest burden of NTDs (¼ of global burden)
- Baseline study/situational analysis – studies conducted in Ogun and Kaduna.
- Participatory action research cycle (PAR) – defining principle. Communities are embedded in the process.
- Participatory methods – visited communities, convened leaders and asked them to identify structures used for NTD program implementation. IEC materials in local languages would help community understanding. The sharing of information, education, and communication (IEC) needs to reflect local reality (e.g., illustrations of toilets do not help when toilets are not present).
- Other community structures can be used to engage stakeholders across the community.
- State implementers – improve capacity building by involving them in research.
- Participation ensures voices at all levels are represented and action planning is collaborative.
- Key messages: participation is key to effective research and implementation; research can be embedded in participation.

Presentation 3: Using research to inform policy

- Evidence-informed communications are needed to increase knowledge of different community groups.
- Interpersonal communication helps delivery messages in local dialects or simple English and helps ensure women are reached. Other IEC techniques can be used (e.g., radio, posters, and a variety of awareness techniques – workshops, face to face discussions, radio, and posters).
- Supervision of awareness activities to ensure all segments of the community are reached
- Ongoing awareness raising is needed to establish the links between disease and environment and the importance of medicines being distributed. Communication messaging should respond to traditional beliefs.
- Strategy development: research findings can be used to develop activities; technical working groups help refine and finalize strategy to be validated with ministry protocol and procedure.

- Collaboration revealed: socio-political factors and funding allocation, results of multi-sectoral expertise, which enabled appropriate messaging and improved understanding.

Presentation 4: Experience from Urban MDA – improving MDA Haiti example

- Lymphatic filariasis is endemic throughout Haiti in a variety of settings: heterogeneous – urban, rural, wealthy, poor, etc. Mass drug administration (MDA) coverage has declined from 2012 to 2017. Coverage surveys revealed differences between reported coverage and survey results. Why did people not take pills?
- Results led to discussion on how to strengthen MDA in urban areas in Haiti, including engaging communities in planning MDA.
- Social mobilization included redesigned IEC materials, focus groups, engaged government, stories from lymphedema patients shared via radio and television.
- The number of distribution posts were increased along with visibility of volunteers wearing badges and t-shirts. Other strategies were implemented to improve coverage many of which included community and stakeholder engagement.

Discussion

- In Haiti, microplanning sectioned the communities into smaller groups, which improved engagement and communication, which in turn facilitated information collection and resolution of issues.
- Research in Nigeria helped identify language gaps and initiated discussion on cost-effective communication strategies.
- A science-shop approach using masters level student interns in research could be used as a cost-effective way to help create and translate communication materials. This could be a mutually beneficial exercise to help link actors and it is enriching for the students to learn.
- Migrant groups represent distressed populations, who have a lack of knowledge in the community and lack of trust in people outside the community.
 - Can be reached by improved understanding of the community and mapping the community using participatory approaches
 - Informal structures in refugee communities – e.g., small churches/mosques, football clubs – can be leveraged to improve communication and engagement.
 - Community leaders should be engaged to influence communities, including prominent women who should be empowered to lead.
 - A network analysis – or stakeholders map – may be useful where there is a lack of information.
 - The use of the term ‘migrant groups’ is a very broad term that can mean commuters, cross national border migrants, cross-state/county, seasonal workers, and those living in refugee camps. Each of these sub groups might require different strategies to engage with and will have different stakeholders and community structures.

KNOWLEDGE GAPS IDENTIFIED

- 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.