



**GLOBAL
INSTITUTE ^{FOR}
~~DISEASE~~
ELIMINATION**

STAKEHOLDER ROUNDTABLE

**COMMUNITY-CENTERED
DELIVERY APPROACHES**

MEETING REPORT

15 NOVEMBER 2024

HILTON RIVERSIDE, NEW ORLEANS, LOUISIANA, USA

ACRONYMS

ASTMH	American Society of Tropical Medicine and Hygiene
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CDDs	Community Drug Distributors
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GLIDE	Global Institute for Disease Elimination
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CDTi	Community-directed treatment with ivermectin
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NTDs	Neglected Tropical Diseases
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CONTEXT

At the last mile of disease elimination efforts, it is crucial to prioritize communities most directly affected by and proximate to the vectors. The Neglected Tropical Disease (NTD) road map 2021-2030¹ highlights the critical role of community engagement in addressing NTDs and advocates for integrating community engagement and participation across all NTD activities to ensure sustainable and effective interventions. Community-directed treatment with ivermectin (CDTi) is a cornerstone strategy for mass drug administration (MDA) in African countries endemic for onchocerciasis and Lymphatic Filariasis. This approach directly involves communities in the planning of MDA, fostering local ownership and accountability. Barriers to CDTi include distrust of government entities and the process for identifying community drug distributors, fears of adverse events following treatment, low baseline knowledge and understanding of the disease, and broader community fatigue. These persistent issues pose significant obstacles to the effective delivery of MDA, contributing to high transmission areas and groups of never-treated individuals in several countries, even after decades of MDA efforts. The NTD community must pause to reflect on these persistent challenges and draw lessons from countries that have sought a deeper understanding of the root causes of ongoing transmission. Such reflections should involve learning directly from the communities themselves. As 2030 approaches—the target year for achieving the elimination goals outlined in the NTD road map—it is critical to explore how community-driven approaches can enhance elimination efforts and ensure these strategies are sustainably financed. Recognizing these challenges, the Global Institute for Disease Elimination (GLIDE) hosted a stakeholder roundtable on November 15, 2024, during the American Society of Tropical Medicine and Hygiene (ASTMH) Annual Meeting in New Orleans, Louisiana, USA. This roundtable emphasized community-centered delivery approaches, aiming to develop informed strategies for advancing onchocerciasis elimination.

The objectives of the roundtable included to:

- Highlight the crucial role of communities by emphasizing the development of community-informed strategies;
- Ensure integration of innovative strategies into elimination plans;
- Engage stakeholders to invest in community-driven elimination.

Participants and format of the roundtable:

The roundtable brought together 24 strategically selected participants, representing a diverse group of experts from NGOs, academia, funding agencies, implementation organization and national programs. This diversity ensured meaningful and multidisciplinary engagement.

The 90-minute session included presentations of country case studies, guided discussions based on tailored questions, collaboratively developed by GLIDE and the co-hosts aimed to foster engaging and targeted discussions.

¹ Ending the neglect to attain the Sustainable Development Goals: A road map for neglected tropical diseases 2021–2030

The guiding questions for this session were as follows:

- How can we ensure community voices are integrated into decision-making and empower them to translate their knowledge into policies?
- What are the key processes and pathways for co-developing community policies that inform government or stakeholder strategies for community-level interventions?
- What transferable lessons and strategies from other disease areas can be applied to onchocerciasis?
- How can we make the case for donors and stakeholders to prioritize investment in community-led initiatives?

Key insights from the roundtable discussion:

How can we ensure community voices are integrated into decision-making and empower them to translate their knowledge into policies?

Participants highlighted that integrating community voices into decision-making is essential to ensure that policies and interventions are both effective and relevant. Achieving this requires a deep understanding of community dynamics, proactive communication strategies, and a commitment to empowering key actors within the community. By addressing barriers such as misinformation, fatigue, and limited engagement, programs can foster trust and sustained participation. Below are the key insights shared during the discussion:

- 1. Understanding and engaging the community:** Participants emphasized that successfully integrating community voices into decision-making requires both understanding the evolving dynamics of communities and ensuring their active involvement at every stage. This involves not only recognizing key players and influencers within communities but also continuously reassessing their needs, challenges, and priorities. Communities today are different from what they were decades ago, and strategies must adapt accordingly to reflect these changes..
- 2. Building awareness and tailored communication:** The participants highlighted that younger populations, in particular, may lack awareness of the disease's transmission dynamics. After many years of MDA and a significant reduction in visible cases of onchocerciasis, the national onchocerciasis program became a victim of its own success. Many community members question why treatment is still necessary, underscoring the need for clear and consistent communication. Tailored and innovative messaging, such as using social media or engaging local champions, is essential for maintaining awareness and participation.
- 3. Empowering Community Drug Distributors (CDDs):** CDDs play a central role in MDA campaigns, but their effectiveness depends on trust and community involvement in their selection. Participants pointed out the need to address fatigue among both communities and CDDs after decades of treatment. A deeper understanding of these challenges and transparent communication about the ongoing necessity of MDA are crucial for sustaining engagement.

What are the key processes and pathways for co-developing community policies that inform government or stakeholder strategies for community-level interventions?

Participants emphasized that successful community-level interventions require meaningful collaboration with the communities they serve. Co-developing strategies ensure that policies and programs are rooted in local realities, making them more relevant, impactful, and sustainable. By engaging communities as active partners, stakeholders can address barriers, align priorities, and design interventions that truly reflect community needs. Below are the key processes and pathways identified during the discussion:

1. Co-designing strategies with communities: Co-designing interventions with communities ensures alignment with their specific needs, contexts, and priorities. Recognizing that not all communities are the same, participants highlighted the importance of localized designs that allow for flexibility and cultural sensitivity.

2. Aligning funders and programmatic needs: A major challenge noted was the disconnect between funders' timelines and programmatic realities. Participants discussed the discrepancy between how CDTi was initially conceptualized and how it is implemented in many countries. While the strategy emphasizes that CDDs should be selected by the community, the timing and duration of MDA are often dictated by the donation programs or donors rather than the communities themselves. Participants stressed the need for greater flexibility in funding schedules to avoid conflicts with cultural or seasonal events, such as farming periods. Similarly, it was reported that MDA are sometimes scheduled during Ramadan or other fasting periods observed by different religious communities, that complicates medication intake. This highlights the importance of aligning program schedules with community calendars to ensure the smooth implementation of interventions.

3. Establish flexible funding sources and mechanisms: By doing so, it empowers programs to adapt interventions to community-specific contexts. Such mechanisms enable local ownership, which fosters accountability and enhances sustainability.

4. Moving beyond uni-directional research: Traditional research methods often overlook community input. Participants advocated for shifting toward co-designed research that incorporates community perspectives at every stage. This approach ensures that strategies are both relevant and effective, as they are informed by the direct experiences of those impacted.

*“ Not all communities are the same,
the design must be localized ”*

What transferable lessons and strategies from other disease areas can be applied to onchocerciasis?

Participants emphasized the importance of learning from successful strategies in other disease elimination programs to enhance efforts in onchocerciasis. By leveraging synergies across public health interventions and adopting proven approaches, stakeholders can optimize resources and maximize impact. Below are the transferable lessons and strategies identified during the discussion:

1. Integration across public health interventions: Combining efforts for hard-to-reach areas: Participants highlighted the potential for leveraging multiple public health interventions in areas with low treatment and vaccination rates. For example, vaccination campaigns could be combined with MDAs to make the latter more effective. MDAs can also be used as a platform to address other aspects of disease elimination, such as incorporating morbidity management and routine surveillance. This integrated approach not only optimizes resources but also strengthens the effectiveness and long-term impact of health programs.

2. Lessons from trachoma elimination: Trachoma elimination programs have demonstrated the critical role of empowering women in driving community-level health initiatives. As one participant noted, “Trachoma is a mother and child problem; we need to select who in the community is extremely critical to empower.” By identifying and empowering key individuals within the community, such as mothers, programs can ensure more effective outreach and participation.

3. Community health councils in malaria elimination: Participants discussed the success of community health councils in malaria elimination as a model for empowering local communities. These councils have proven effective in sustaining the programs even in the absence of external funding, by fostering local ownership and accountability.

How can we make the case for donors and stakeholders to prioritize investment in community-led initiatives?

Participants emphasized that community-led initiatives are essential to achieving the last miles of disease elimination. Advocacy efforts must effectively communicate the value of these approaches to donors and stakeholders, highlighting their long-term benefits and alignment with elimination goals. A strong business case is crucial to demonstrate the cost-effectiveness, sustainability, and overall impact of community-driven strategies. Below are the key points discussed:

- 1. Building a business case for community-driven approaches:** Advocacy efforts should highlight the essential impact of community engagement on the success of elimination programs. Investments in community engagement directly enhance their effectiveness and efficiency, as well-engaged communities are significantly more likely to participate in MDA—a critical factor for achieving elimination goals.
- 2. Messaging to donors should also emphasize the financial and operational benefits of community-led strategies,** demonstrating their cost-effectiveness and ability to deliver sustainable results. Advocacy messages should include specific examples of how community-driven efforts have led to measurable successes in other disease elimination programs, such as increased treatment coverage or reduced transmission rates. Furthermore, it is crucial to communicate the risks of insufficient engagement, such as the potential for disease resurgence if participation levels are low.
- 3. Finally, advocacy must reframe community-driven approaches not as an additional expense but as an indispensable component of effective and impactful elimination strategies.** By prioritizing investments in community engagement, donors and stakeholders can ensure that resources are utilized optimally to achieve elimination targets and secure long-term health outcomes.

RECOMMENDATIONS AND NEXT STEPS

To effectively advance community-led initiatives in onchocerciasis elimination, participants proposed the following recommendations and actions:

1. Develop community-driven strategies:

- Collaborate with local stakeholders to co-design program interventions that reflect specific community needs and contexts.
- Empower communities by integrating their voices and experiences into all stages of program design, ensuring interventions are relevant, culturally sensitive, and impactful.

2. Advocate for flexible funding mechanisms and schedules

- Work with donors to establish flexible funding mechanisms that align with community calendars and priorities.
- Highlight the benefits of funding adaptability, such as improved program ownership and real-time responsiveness to emerging challenges.

3. Leverage lessons from other programs

- Apply successful approaches from other disease elimination efforts, such as trachoma and malaria, to enhance onchocerciasis strategies.

4. Leverage data into action

- Utilize information gathered through coverage evaluation surveys to derive actionable insights that can inform and improve MDA planning and execution.
- Ensure that data collected is effectively analyzed and integrated into program adjustments, optimizing resource allocation and intervention strategies.

These recommendations provide an approach to start addressing barriers through enhancing the role of communities in achieving the last miles of onchocerciasis elimination.

CONCLUSION

The roundtable underscored the critical role of community-centered approaches in achieving the last mile of onchocerciasis elimination. Participants highlighted the need for collaborative efforts, data-driven decision-making, and sustained investment to address barriers and leverage opportunities effectively. The examples provided give hope that through increased dialogue and action, community-led solutions can drive meaningful progress toward onchocerciasis elimination goals.

APPENDIX

Agenda

Presentation	Objective	Time
Opening	Welcome participants, outline the objectives of the roundtable, and set the tone for collaborative discussion.	5 min
Overview of the context	Countries case studies	20 min
Discussion with all participants	<p>Open the floor for an interactive discussion with participants.</p> <p>Potential guiding questions will include:</p> <ul style="list-style-type: none">• How can we ensure community voices are integrated into decision-making and empower them to translate their knowledge into policies?• What are the key processes and pathways for co-developing community policies that inform government or stakeholder strategies for community-level interventions?• What transferable lessons and strategies from other disease areas can be applied to onchocerciasis?• How can we make the case for donors and stakeholders to prioritize investment in community-led initiatives?	50 min
Wrap-up and Next steps	Summarize the key insights from the discussion and outline actionable next steps. Identify potential collaborations and strategies to further integrate community voices into policy and program design.	10 min
Closing		5 min

List of Participants

Bruyère Health Research Institute

Cabo Verde Ministry of Health

Catholic University of Central Africa

FHI 360

Fred Hollows Foundation

Gates Foundation

Global Institute for Disease Elimination (GLIDE)

Helen Keller International

Institute for Scientific and Medical Research (ISM)

International Center for Excellence in Research (ICER)-Mali

Kenya Medical Research Institute (KEMRI) - Wellcome Trust

Kenya Ministry of Health

Sightsavers

Task Force for Global Health

The Carter Center

The END Fund

University of Health and Allied Sciences

University of Queensland

Wi Her

World Health Organization