Evidence Brief (July 2022)

Strategies to enhance community engagement in research: The way forward for Ethiopia

Included:
- Description of problem statement and barriers for community engagement in research
- Strategies to enhance community engagement in the research process

Key messages

- Despite community is at the heart of health research, community engagement in the research addressing infectious diseases of poverty is limited in scope and depth in Sub-Saharan Africa (SSA). This is worsened when community empowerment comes to play in the research process.

- Building collaborative relationships and trust, moving away from an expert or researcher-dominated research process to community integrated and co-development of the research process (i.e. from conceptualization to translations and uptake of the findings) are critical factors to strengthen community engagement in research

- Adapting participatory research methods; working with community leaders, structures, networks, groups and community platforms; integrating research education and awareness creation; ongoing communication; adapting research techniques to fit into the local context and culture such as the use of culturally appropriate and acceptable consenting and recruitment process are all important strategies for effective and successful community engagement in research in resource-limited settings.

For whom is this evidence brief for?

Researchers, academicians, policymakers, research funding institutions, and other stakeholders with an interest in the problem addressed by this evidence brief.

Why was this evidence brief prepared?

To inform deliberations, initiate and facilitate discussions among the researchers, academicians, policymakers and other relevant stakeholders about engaging communities in research projects by providing the best available evidence on strategies to enhance community engagement in research in resource-limited settings like Ethiopia.

What is evidence brief?

Evidence briefs bring together global research evidence (from systematic reviews*) and local evidence to inform deliberations about health policies and programs

*Systematic review: A summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise the relevant research, and to collect and analyze data from this research.

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All the authors contributed to the preparation of this evidence brief.

Competing interests

No competing interest.

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Introduction

Even though research plays a crucial role in addressing the infectious diseases of poverty, the amount of health research devoted to low- and middle-income countries (LMICs) is minimal (Viergever, 2013). The existing capacity to conduct relevant health research is also insufficient in these countries (Kilmarx et al., 2020). For example, although 92% of the global disease burdens are from LMICs, only 10% of global funding for health research was devoted to addressing these persistent health challenges (Viergever, 2013). On top of limited funding and research capacity in these countries, research often do not engage the target community, which in turn limits the credibility, utility, and policy influence of research evidence to improve population health outcomes. Likewise, researchers' habits and ability to promote community engagement in the research process are weak or non-existent in most contexts (Farmer et al., 2018), calling for an urgent need to improve community engagement in the research process.

The problem

Community engagement in research can be defined as research that is done in partnership with community members, patients, health service systems, community-based organizations, and other stakeholder groups (Glandon et al., 2017; University of California, 2021). Thus, community engagement in this context is the meaningful, respectful, and fit-for-purpose involvement of the target community members in one or more aspects of the various phases of the research process, and may include engagement during the identification of the problem, defining its purpose and design, stages of implementation, analysis and interpretation, and translations of the research evidence into policy and practices (Glandon et al., 2017). The levels (depth and breadth) of community engagement in the research process may differ by the type or objective of the research and could vary from informing to empowering (WHO, 2020), where empowerment is considered the highest degree of engagement from the five levels of community engagement (i.e., inform, consult, involve, collaborate and empower).

Engaging communities in research processes have several advantages including the potential to mitigate risk to the specific community by developing appropriate protections; ensure relevance of the research; promote community-academic partnerships; ensure

accountability, transparency and equality between the partners and players of research; promote equity and gender empowerment; improve implementation of research findings and sustain a science culture; build greater trust between researchers and communities; and reach under-represented and under-served populations (National Institutes of Health, 2020; University of California, 2021). Even though engaging communities in research processes would have such benefits and implications, there remains a lack of common understanding of concepts related to community engagement and effective strategies underpinning it (George et al., 2015). Most importantly, the research efforts are poorly embedded in and linked with communities, especially in LMICs (George et al., 2015). A recent systematic review conducted by Birhanu et al revealed that there is minimal community engagement in research projects in sub-Saharan Africa (SSA) and this is even worse when community empowerment is considered (Birhanu et al., 2022). There is also a lack of in-depth accounts of what constitutes effective community engagement and is still determined largely by a combination of intuition, experience, and opinion (Birhanu et al., 2022; George et al., 2015; Vanderslott et al., 2021). Moreover, there are no studies, that reported community engagement in research addressing poverty-related diseases in the Ethiopian context (Birhanu et al., 2022).

The finding by Birhanu et al attracted our attention to why research in SSA and more specifically in Ethiopia did not engage communities and what best available evidence could inform effective community engagement in the research process? Guided by these basic questions, the authors systematically reviewed the existing evidence and prepared an evidence brief. This evidence brief summarizes the best available evidence describing the problem in resource-limited settings like Ethiopia and effective strategies to address the issue within the context.

Barriers for community engagement in the research process

Several factors that could affect community engagement in the research process in resource-limited settings have been identified. These factors include:

- ***Lack of understanding about the concept of community engagement in research***: Researchers have limited understanding of (i.e., concepts, motivations and social

processes underpinning community engagement) and experience with effective methods of engaging communities (Ahmed & Palermo, 2010; George et al., 2015). Furthermore, there is limited research communications among the communities to collaborate with and engaged in research activities (Meiring et al., 2019).

- ***Difference in expectation and interest regarding the goal of research:*** Though benefits of the research should include improved health status or services for the community within a specified period through interventions developed and agreed on by the researchers and community, this did not usually happen because communities are interested more in services than research, while the academics are interested more in research than services (Olaseha & Sridhar, 2005).

- ***Absence of shared understanding between communities and researchers:*** There is a lack of understanding by both parties of each other's needs, goals, available resources, and capacity to develop and participate in community engagement activities which might later lead to unnecessary conflicts, misunderstandings, and criticisms (Angwenyi et al., 2014; Meiring et al., 2019).

- ***Lack of representativeness (diverse perspectives and populations):*** There is no genuine and true representativeness of the community and their views in the research process which potentially leads to under-representation (Broder et al., 2020).

- ***Lack of exchanging in knowledge, experience and lessons learned among researchers:*** Research begins with and builds on community assets and strengths. However, researchers and community members often miss the opportunity to learn from each other and share expertise and knowledge regarding strategies to engage communities in the research (Pare Toe et al., 2021).

- ***Lack of trust and respect:*** Researchers should respect and follow community values, ensure that all private information from participants remains confidential and explain all aspects of the project using nontechnical language before the community agrees to participate. However, this did not usually happen and creates serious anxiety and a sense of being disrespected among communities (Ahmed & Palermo, 2010; Simwinga et al., 2016).

- ***Lack of transparency in communications and the research process:*** Communications should be bidirectional and transparent from investigators to the community and vice versa. However, researchers did not provide regular progress updates to the community. As a result, the community does not have the right information about why and how research projects are developed. This creates misconceptions, suspicions, community fatigue, and ethical dilemmas within the community (Marsh et al., 2011; Nakibinge et al., 2009).

- ***Lack of funding and sustainability after the project ends***: Researchers engage the community before, during, and after the research. However, there is a lack of funding and continuity of the projects to implement planned activities. On top of that researchers often overlook costing community engagement activities in their budget breakdown. This is happened mostly due to community needs are not always in line with funding agencies' agendas which affects the sustainability of the partnership (Ahmed & Palermo, 2010; Olaseha & Sridhar, 2005)

- ***Absence of standard frameworks for recording and reporting community engagement activities:*** Many research projects fail to report community engagement activities because there are no standard frameworks or formats to document and report community engagement activities in the research process (Birhanu et al., 2022).

Strategies to enhance community engagement in the research process

Because of the above-mentioned arrays of factors, community engagement in research is limited in resource-constrained settings. This evidence brief tried to provide effective strategies to address these factors based on the best available evidence on enhancing community engagement in research. The brief is intended to inform deliberations and promote community engagement in research in resource-limited settings like Ethiopia.

We searched for peer-reviewed scientific articles from both systematic reviews and primary research from LMICs to synthesize the best available evidence informing this brief. Accordingly, the systematic review by Zewdie et.al served as a primary source for the identification of strategies and approaches to enhance community engagement in research (Birhanu et al., 2022). In addition, we found a relevant systematic review focused on community participation in health systems interventional research in LMICs

(George et al., 2015), a scoping review on community engagement in health research to strengthen infectious disease outbreaks in SSA (Vanderslott et al., 2021), and a peer-reviewed commentary focusing on frameworks for community engagement in health research (Ahmed & Palermo, 2010). Accordingly, the following strategies are forwarded to inform researchers; research and academic institutions and research funders for considerations to develop, expand, and effectively engage communities in research.

1. **Enhancing researchers' and relevant stakeholders' understanding of concepts, processes, and values of community engagement in research:** Both parties should understand each other's needs, goals, available resources, and capacity to develop and participate in community engagement activities. The research grants should provide resources and funding to train, employ, and build the capacity of community members in all aspects of the research process (Ahmed & Palermo, 2010). The community members should be involved in all aspects of the research, from planning to the dissemination of results, and should involve and empower the community in the research process depending on the objective of the study. This helps the communities or research participants to be considered as partners in research rather than merely study subjects or eventual consumers of the interventions (Birhanu et al., 2022).

   Researchers and community should have a platform and plan to learn from each other and share expertise and knowledge. Research should begin with and builds on community assets and strengths. The community should be empowered to develop the necessary capacity to make decisions related to community health issues while the researchers should learn from the community partner how to work with communities on an individual and organizational level (Ahmed & Palermo, 2010). According to the findings, developing community trust and ownership and shifting from expert-dominated to co-development are significant factors to consider as a center of gravity for community engagement in research (Birhanu et al., 2022).

2. **Promoting and adapting community-based participatory research and collaborative relationships**: Researchers are required to move away from researcher-dominated tools and methodologies, toward participatory research approaches. Such techniques create a broader understanding through effective communication built in every stage of

the research process. Research institutions, academia and funding organizations should promote, encourage and motivate researchers to adapt participatory research tools (Birhanu et al., 2022).

A participatory research approach such as participatory action research (PAR), community-based participatory research (CBPR), and implementation research (IR) increases community understanding of the issues under study and enhances researchers' ability to understand community priorities, the importance of addressing community priorities, and the need for culturally sensitive communications and research approaches (Ahmed & Palermo, 2010). Such approaches promote a mutual learning process (Freudenthal et al., 2006; Olaseha & Sridhar, 2005), enhance collaboration between researchers and communities, help to identify the needs and resources, and empower the community members (Mabunda et al., 2016; Tarr-Attia et al., 2018). A participatory approach could also instill a sense of ownership and ensure long-term sustainability and adaption of the intervention by the community (Mabunda et al., 2016). Simultaneously, the promotion of participatory research requires strengthening researchers' capacity and skills in how to plan and execute participatory research (Birhanu et al., 2022).

Besides, researchers should aim to create strong partnership and collaboration with the communities. The collaboration should include structures and processes that facilitate sharing of information, decision-making power, and resources among partners. Researcher and community member expertise should also be explicitly incorporated in the collaboration framework and should include a formal agreement that addresses all aspects of the research, including ethics, roles, and responsibilities of all participants; data ownership; dispute resolution; and dissemination of results (Ahmed & Palermo, 2010).

3. **Ensure inclusions of diverse perspectives and populations in the research methods and fitting the methods into the local context**: All segments of the community potentially affected by the research should be represented in the spectrum of participation. Ensuring the local relevance and cultural appropriateness of the research tools and methods including methods of participant recruitment and consenting process are vital

to achieving trust and community engagement in the research process (Birhanu et al., 2022). A culturally appropriate and acceptable research strategy that respects the values and norms and is tailored to particular diversities and the marginalized population is necessary for effective engagement of communities in the research process (Ahmed & Palermo, 2010; Birhanu et al., 2022). Incorporating formative research could be one approach to ensure the local relevance and socio-cultural appropriateness of the research to the local community (Birhanu et al., 2022; Corneli et al., 2007; Folayan et al., 2019; Vanderslott et al., 2021).

4. **Exploring and using existing community structures and platforms:** Exploring and using local resources and supporting platforms such as community-level structures and networks, forums including community advisory boards (CABs); involving community gatekeepers or community leaders (traditional or formal) are found to effectively facilitate community engagement in the research process. Using such platforms can serve to represent the community voice (across research stages) and contribute to shape and ensure the contextual relevance of the research process including the adaption of locally sensitive research approaches, tools and consent process (Birhanu et al., 2022). Engaging community platforms in the research process helps to understand community structures and contexts, as well as building relationships and trust between the research team and community members. It is also necessary for continued collaboration and coordination among multiple community-level stakeholders (Birhanu et al., 2022).

   Researchers require undertaking pre-research analysis and mapping the existence or availability of such platforms and utilizing them to further engage communities in research consent and other aspects.

5. **Embedding mechanisms for accountability, transparency and responsibility in the research process**: Strengthening researcher accountability mechanisms, developing public communication monitoring tool and framework; ongoing consultations and feedback; ensuring researchers' integrity, commitment, transparency, and accountability through enforcing researcher obligations are useful points to be considered by research institutions. This requires institutional frameworks, establishing

rules of engagement, and tools (e.g., community engagement monitoring tools) that could govern the engagement of communities in the research process with appropriate implementation mechanisms.

6. **Developing standardized procedures for community engagement in research and standard reporting mechanisms**. One of the problems noted in the recent systematic review (Birhanu et al., 2022) was that many researchers often fail to report community engagement activities though their research engaged communities. This failure was attributed to researchers' lack of appreciation of community engagement, and the absence of a standard framework for engaging communities in research, documenting and reporting community engagement activities. This challenge shall be overcome by developing and ensuring access to useful practical guides on how to plan and engage communities, and document and report community engagement in the research process (Birhanu et al., 2022).

In conclusion, to ensure effective community engagement in the research process, key research stakeholders including but not limited to research institutions, academia, and funding agencies should ensure that the research process fully integrate the community into the research cycle. By doing so, communities will have an opportunity to provide meaningful input in the conceptualizations, designs, implementations, dissemination, and translations of the evidence with a clear strategy to involve, collaborate and empower communities. Likewise, researchers should aim to begin their inquiry with communities whereby treating communities as research partners. To inform policy and practice research evidence should be co-created between the researcher and the people who are affected by the problem.

The way forward for Ethiopia

In addition to the strategies addressed in the evidence brief, the following considerations are forwarded for Ethiopia to strengthen community in the research process.

- A practical guideline or working document that supports the community engagement process in the country should be developed

- There should be a responsible body or structure that ensures community engagement in the research process. There must also be an institutional arrangement that checks and monitor the balance for the desired level of community engagement in the research process

- IRBs should give emphasis in their guidelines to include community engagement in the review of protocols and follow-up. There should also be adaptations of international ethical standards and contextualization for Ethiopia

- Standard definition should be there on the common terminologies such as 'community', 'community engagement', and 'community engagement in research'

- The roles and responsibilities of the communities and the researchers should be clearly identified during the planning phase

- A prolonged engagement through the research process must be considered to define context, to understand the community culture and norms, and to contextualize the tools

- Modalities of evidence dissemination must be reconsidered including local communications of key findings translated into locally understandable language

- Engaging both formal and non-formal representatives of the community to assure there is genuine engagement in the research process

- Giving due emphasis to those research problems in which we can utilize findings through collaboration and participation is important

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How this brief was prepared?

The SURE (Supporting the Use of Research Evidence) guide was adapted for the preparation of this evidence brief. The SURE guide was developed to improve decisions about health systems by improving policymakers' access to and use of research evidence that is relevant, reliable, accessible, and timely (EVIPNet, 2014; Oxman et al., 2009). Even though the systematic review (Birhanu et al., 2022) served as the main evidence base, we searched for and utilized additional best available evidence on the topic.

The Searched electronic databases including the Cochrane Library, JBI Evidence Synthesis, Epistemonikos, PDQ Evidence, Health Systems Evidence, PubMed, and Google Scholar with a search query "Community engagement" AND "Research".

TDR, the Special Program for Research and Training in Tropical Diseases, is a global program of scientific collaboration that helps facilitate, support and influence efforts to combat diseases of poverty. It is co-sponsored by the United Nations Children's Fund (UNICEF), the United Nations Development Program (UNDP), the World Bank and the World Health Organization (WHO).
Home (who.int)

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