



Navigating the complexity of Community Engagement with health research

REAL BRIEFING FOR COMMUNITY ENGAGEMENT LEADS & RESEARCHERS | 2021

Summary

Community engagement (CE) is increasingly recognised as an essential component for improving health research where high-quality, ethical research can contribute to greater understanding of health issues and to designing contextually appropriate responses. Whilst CE approaches and activities have proliferated, there is a lack of conceptual clarity around how engagement works in practice. This potentially limits the ability of community engagement leads and researchers to engage effectively with local populations and to realize the full potential benefits of CE.

Our review on CE in malaria research trials provides new clarity about how CE works in practice,

highlighting its importance in developing long term 'working relationships' between frontline researchers, engagement staff and local populations. It is these provisional relationships, built through a range of formal and informal interactions, that lead to greater acceptance and participation in the research.

The review identifies challenges in forming and sustaining such relationships including differences of wealth and power, compounded by the broader context where research is often externally funded and controlled. The findings have implications for how those involved in CE can operate effectively and be supported to build and sustain quality relationships with local stakeholders.

This brief summarises the key findings from a review on CE in malaria trials, which provide an illustration of how CE works more generally. It highlights facilitators and challenges to engagement, and the ethical issues that are particularly relevant in low and middle income country (LMIC) settings with under resourced health systems. Based on these findings, the brief provides recommendations for researchers and those involved in community engagement to enhance their ethical engagement in health research.

What is Community Engagement?

CE is a process of collaborative work with groups of people affiliated by geographic proximity, interest or health issues, to address social and health challenges affecting those people. Definitions of CE and broader 'public engagement' or 'stakeholder engagement' overlap and are contested, with a particular critique being in relation to the degree to which there is genuine collaboration. Definitions also vary across the domains of health programmes, health-related research and international development.

Purposes of engagement The purposes of engagement, and the way engagement practices are understood to support these purposes are not always explicit or clear. A distinction is made between the instrumental goals of CE of improving quality and relevance of research and a range of ethical goals of CE. The latter include respecting stakeholders, building relationships, understanding vulnerabilities and researcher obligations and minimising risks. In practice, engagement tends to combine instrumental and ethical goals – such as in determining appropriate benefits, supporting consent processes, gaining approvals and building legitimacy for research – and these differences are rarely made explicit in planning or evaluation.

Engagement activities and strategies

Engagement activities and strategies are diverse. CE encompasses practices including: meetings with community members and representatives; information and communication activities to raise awareness and solicit support for research; community advisory boards as a conduit between researchers and local research stakeholders, and involving stakeholders in designing and implementing research activities.

1. Community Engagement enables the development of 'working relationships' between researchers and local research stakeholders

At the core of CE is the development of 'working relationships' between researchers and local stakeholders affected by the research across differences in wealth, power and culture. These provisional working relationships depend on four overarching, mutually reinforcing mechanisms as shown in Figure 1.

- ▶ Exchange and negotiation of mutual benefits from research.
- ▶ Researcher responsiveness including the degree that stakeholders feel listened to, and their concerns acknowledged.
- ▶ Contiguity (everyday interaction and familiarity) and a sense of everyday presence and accessibility of research staff, especially through research fieldworkers.
- ▶ A sense of influence over the research by stakeholders.

Figure 1: Core dynamics of and influences on engagement



Developing working relationships contributes to greater acceptance and participation in the research for stakeholders even though their motivations and understandings of what it means to participate in research might differ from researchers. Whilst researchers may aim to produce high-quality research, in countries with underdeveloped health systems, a primary motivation for local stakeholders to participate in the research is the accompanying benefit of access to health services.

Working relationships are precarious and depend on interpersonal dynamics between research staff and local stakeholders. Such relationships tend to blur across formal and informal interactions and develop over time, often beyond formal engagements linked to any one piece of research.



2. Frontline research staff play a vital intermediary role in developing and sustaining relationships

The everyday presence of locally recruited frontline research staff (often called ‘fieldworkers’) in communities helps to build relationships and facilitate responsiveness to local concerns. However, the role that fieldworkers play is often complex and under supported, and there is a danger that some of the ethical challenges of doing research in LMICs are outsourced by research initiatives to the everyday negotiations between fieldworkers and other local research stakeholders. Given the ambiguous and challenging role taken on by fieldworkers, there is a need for greater supervision and institutional support, as well as professionalization and development of related career pathways.

3. Commitment to and understanding of CE by research institutions can help to develop the relationships that sustain engagement over time

Beyond the tangible benefits and sense of reciprocity between researchers and local stakeholders, CE is enhanced by research institutions’ commitment to engagement. This commitment relies on senior researchers and research institution directors prioritising and adequately resourcing CE, ideally contributing to a culture of engagement and an expectation that it is part of the research. Examples of commitment to engagement include: dedicated roles to lead and coordinate engagement and to act as a consistent point of contact for stakeholders; drawing on technical inputs on engagement from social scientists and other experts and insights from dedicated engagement staff; investment in processes of reflection and evaluation that inform management of engagement and research; and the practice of

‘programme-wide’ engagement beyond individual research studies. Commitment is facilitated when funders make resources available for engagement at the project or institution level and have an explicit expectation that research will be preceded and accompanied by engagement.

4. External funding and control of research can undermine relationships between researchers and local populations

Health research in LMICs is predominantly funded and governed by international research partnerships and large-scale clinical trials, deployed through an international infrastructure of organisations and agencies that deal with different aspects of clinical trials. There are several characteristics of this paradigm that undermine relationships between researchers and local populations. In LMIC settings for example, research centres are often relatively wealthy local institutions with links to international networks. Where research centres are in settings of relative poverty, the exchange of health care for research participation can amount to ‘structural coercion’ rooted in the wider constraints on people’s choices. This is in spite of attempts to consider what may be a ‘fair offer’ – by ensuring that what is being proposed to potential participants is agreed by diverse reviewers as fair in terms of levels of risks and benefits for research participation.

Power differences exist, with research agendas largely funded and managed by international collaborations, limiting national governments’ interest and ability to set and follow local research agendas. It also often means, in practice, that local researchers have less decision-making power and control over research infrastructure and facilities. These factors can constrain relationships if researchers are not perceived to be easily accessible or if local stakeholders have less sense of control over the research.

5. The narrow focus of research ethics on individuals in CE overlooks wider influences on their agency and decision-making

Current research ethics frameworks, as generally applied, focus on individual autonomy and informed consent in CE, obscuring the wider influences on people's agency and decision-making such as households and local opinion. Recognition of these wider influences has resulted in attempts to strengthen procedures for meaningful input for research stakeholders to give them some say in how research is conducted. Practical initiatives such as community advisory boards and wider community consultation have been complemented by research guidelines attempting to make meaningful input more systematic¹.

However, there are limits to focusing on engagement interventions and activities; people's agency is shaped by the wider social conditions in which they live, and this may also affect how they engage with formal procedures of representation. This has led engagement scholars to advocate for careful consideration of how any procedures work in detail (paying special attention to power dynamics). However, there are limits to what CE on its own can achieve to mitigate some of the ethical challenges embedded in the contexts where research takes place. Engagement scholars suggest widening the focus of research ethics beyond individuals and immediate relationships, to consider the meso level of the facilities and institutions involved and the macro level of health systems and social, political, and economic constraints. At the same time, both the broader social impact of research and the social determinants of health should receive greater attention in research and practice for a more rounded understanding of people's health and engagement with research.



Conclusion

Greater understanding of the relational dynamics of engagement and addressing the way the wider context influences people's choices around engagement with research may be as important for developing ethical and effective engagement as the application of resources, activities, facilitation, and communication skills in engagement processes.

Community engagement should challenge rather than reproduce the global health paradigm

Whilst the development of working relationships between researchers and community stakeholders (i.e. community engagement) helps to get research done, it may also depend on: 1) suppressing formal recognition of inequalities and difference within research systems, and 2) informal mitigation of these differences through research staff interactions with research participants. In this way, the precarious relationships facilitated by CE tend to rest on ethically problematic characteristics of the dominant health research paradigm and to accommodate and reproduce them. There is a risk that CE may entrench existing inequalities if the focus remains on the immediate research encounter and the factors influencing people's agency and relationships are not addressed.

Benefits of building quality relationships

Community engagement that facilitates the development of long-term, working relationships between researchers and local stakeholders can have positive impacts beyond specific research programmes, with benefits to both research and health systems in LMIC. Strong relationships can help to broker connections between researchers and health system policy makers and managers, potentially resulting in more integrated planning of health research and health systems strengthening. They can also form the basis of collaborative partnerships that embed stakeholder decision-making into the research. This participatory approach to CE and research may help to challenge the dominant research paradigm context, enabling local stakeholders a more fundamental and equal role in knowledge production.

“Over time... there was a shift in interactions from that of formal professional to one infused with informality and relatedness. Familial titles such as daughter, son, grandchild, were used to describe the types of relationship that were evolving between fieldworkers and participants in the negotiation of study procedures.

KAMUYA ET AL, 2013. Evolving friendships and shifting ethical dilemmas: fieldworkers' experiences in a short term community based study in Kenya. *Developing World Bioethics* Volume 13 Number 1 2013

¹ UNAIDS 2011, Good participatory Practice: Guidelines for HIV Prevention Trials, Geneva: UNAIDS; UNICEF (2020) Minimum Quality Standards and Indicators for Community Engagement, Geneva: UNICEF

Recommendations

The recommendations below suggest ways that CE can be carried out by researchers and supported by institutions to build relationships with communities and enhance ethical engagement in research.

1 Focus on building quality relationships with research participants and local stakeholders

- Commit time, effort and resources towards developing quality relationships with local stakeholders through regular, programme-wide engagement beyond individual research projects.
- Programme-wide Interactions may include discussions on community priorities and concerns, and institutional goals and ways of working (including for example consent processes, ethics review processes, and ways of deciding upon study-related benefits).

2 Institutional support for local research and engagement staff and engagement capacity development

- Provide experienced-based training and supportive supervision for research fieldworkers to help staff navigate some of the relational complexities of engagement.
- Professionalise frontline research and engagement staff roles with related career pathways.
- Ensure dedicated work with researchers on their understandings and attitudes to CE at the institutional level.
- Support engagement personnel to see the sometimes invisible influence of the dominant health research paradigm on engagement, and where possible identify concrete steps to mitigate power inequities and facilitate inclusive engagement.

3 Involvement of local stakeholders in research

- Make clear where and how local research stakeholders can have input on the focus, design or implementation of particular research studies, and where there is scope to inform wider institutional policy. This could help to clarify goals of engagement and manage expectations.
- Carefully consider the time and opportunity costs involved for community members engaging with research, including engagement activities.

4 Responsive engagement activities

- Implement a range of methods for listening and responding to stakeholder concerns including formative research, dedicated spaces for raising concerns, and structured feedback from local research staff.
- Ensure that there are formal structures and processes for ensuring that community inputs are heard by power-holders in research institutions, and that issues raised are responded to, with feedback on such processes and responses fed back to stakeholders.
- During engagement activities, provide accurate information about the research. Given stakeholders' interests and concerns may be wider than specific pieces of research, this could cover information about the whole research programme and institution.

5 Planning and evaluation of engagement

- Develop explicit understandings of how engagement works, e.g., through theories of change to inform strategic planning of CE.
- Formative work to understand local decision-making processes, communication channels and preferred modes of engagement for different stakeholders should inform engagement strategies.
- Inception phases of research can facilitate partnership development, early engagement and consultation on research focus priorities and design.

6 Greater role for applied social science research on the dynamics of engagement

- Engagement practitioners should work with applied social scientists to inform engagement activities and interventions to ensure they address important relational dynamics identified locally.
- Researchers and CE practitioners should collaborate on documenting and analysing CE practice and identify priority issues for further research.
- Engagement practitioners can usefully draw on participatory methodologies to support responsive and inclusive engagement practices that help build relationships and respect.
- Biomedical research design should be informed by social science studies into the relationship dynamics of engagement, implementation studies, and the anthropology of health research.

RELATED RESOURCES

- Mesh Community Engagement online resource: <https://mesh.tghn>
- Human Engagement Learning platform for Global Health: <https://helpforglobalhealth.com>
- Everyday ethics of health systems research: <https://ethicsresource.ringsgenderresearch.org>
- NIHR webpages on Community Engagement: <https://bit.ly/3c15Ah3>



REAL RESOURCES

- ▶ Vincent R. et al (2021) Working relationships across difference: a realist review of community engagement with Malaria research, Wellcome Open Research; November 2021
- ▶ Taking relationships seriously: Building the evidence base for community engagement in health research. REAL brief; 2021
- ▶ Taking relationships seriously: Understanding community engagement with health research. REAL Animation; 2021
- ▶ Adhikari B, Vincent R, Wong G et al. A realist review of community engagement with health research. Wellcome Open Res 2019, 4:87

About REAL: REAL is a realist review of community engagement in global health research. The review aims to bring greater conceptual clarity and consistency to the field through review of the evidence around community and public engagement. The review is supported by Wellcome, UK, with additional support from KEMRI-Wellcome Trust Research Programme, Kenya and Emory University, USA (2019–20).

About the research: The research comprised a realist review of published literature on CE in malaria research trials, which highlight common current practice in CE in biomedical research in LMICs more generally, and helped focus the review to make it more manageable. It included scoping searches guided by thematic experts, whose input also helped to develop causal explanations about how CE contributes to observed outcomes – including unintended and potentially adverse outcomes – and systematic searches of the literature to refine and deepen the analysis.

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