

Taking relationships seriously

Building the evidence base for community engagement in health research



REAL BRIEFING FOR RESEARCH INSTITUTIONS & FUNDERS | 2021

Summary

Community Engagement (CE) is a critical aspect of health research because of its potential to make research more ethical, relevant, and well implemented. Many research programmes now aim to incorporate CE activities at all stages of their work and CE – also referred to as ‘public and patient involvement’ – is often a requirement in research funding applications. However, there is a lack of conceptual clarity around how engagement works, and with this, potential disregard for the complexities, context and ethical issues that shape engagement, especially within health research.

A recent review provides new clarity about how CE works in practice, highlighting its importance in facilitating precarious ‘working relationships’ between researchers and local research stakeholders, rooted in interactions around research and exchange of research related benefits. It is these provisional relationships, rather than any particular engagement activities or technical interventions, 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 review highlights issues of power and representation that have long been a concern in public health and research but given new impetus by the recent debates on decolonising global health.

Funders and research institutions have a responsibility to consider the ethical issues that arise from working in environments shaped by wealth and power differences, and to seek to challenge, rather than reproduce, existing inequalities in researcher-participant relationships. Given the importance for local research stakeholders of the access to health care that often accompanies research participation, more explicit attention to how the infrastructure of health research can strengthen health systems is one way of addressing this ethical responsibility. There is also a need for further review and research looking more closely (through reviews and empirical research) at participatory research approaches that embed stakeholder input within the research process, to better understand the dynamics and limits of greater stakeholder decision-making in research.

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 LMIC settings with under resourced health systems. Based on these findings, the brief provides recommendations for research institutions and funders to support CE and 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

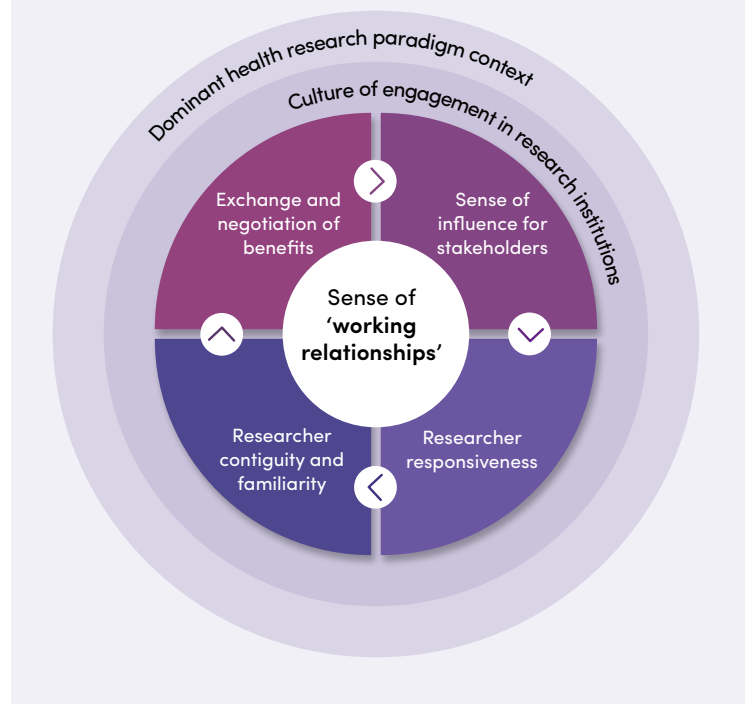
Engagement activities and strategies are diverse. CE encompasses practices including: meetings with community members and representatives; information and communication activities to raise awareness and solicit support for research; community advisory boards as a conduit between researchers and local 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. In settings with weak or under resourced health systems, a key motivation for local stakeholders to participate is the tangible benefit of access to health care and often greater quality of care, which can overcome any concerns or suspicions about the research.

What attracted us [was that] we knew our children will receive treatment for a whole year in every disease they suffer. If you have a problem and visit the people concerned, a call is made to the [principle investigator] he brings a vehicle and [the sick person] is carried away [to hospital].

(MOTHER 2, FGD 3) (MARSH ET AL 2011: 34)

Working relationships are precarious and depend on interpersonal dynamics between researchers and local stakeholders. Such relationships tend to blur across formal and informal interactions, often through the intermediary role of locally recruited research fieldworkers, whose everyday presence in communities can help build relationships and facilitate responsiveness to local concerns.

2. 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.

3. 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 can have less decision-making power and control over research infrastructure and facilities than international stakeholders, which can constrain relationships between researchers and local stakeholders.

4. 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), and also to 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.

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



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.

Integrating health research and health systems strengthening

The findings highlight the central importance of access to health care for local research stakeholders, and the fact that a primary motivation for participation in research is the use of health services and support that accompanies research participation. Taking this finding seriously, points to the need to consider how

the infrastructure of health research could pro-actively support the strengthening of health systems. Research institutions and initiatives often bring considerable resources to LMIC settings where health systems are underfunded, with impacts on health care infrastructure and personnel, levels of health care provision and health surveillance capacity. 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. However, more integrated planning of health research and health systems delivery could begin to address some of the ethical challenges of engagement in resource poor settings. There is also an opportunity to build upon the relationships developed through CE to better broker connections between health research and the strengthening of health systems.

Towards more collaborative partnerships

The findings hint at a countervailing dynamic of 'collaborative partnership' around research engagement – embedding stakeholder decision-making in research, building on existing networks and relationships and linking research to efforts to address health inequalities in LMICs – although this was not systematically explored in the current review.

A more participatory approach to CE and research may challenge the dominant research paradigm context, enabling local stakeholders a more fundamental and equal role in knowledge production. Review of the literature on participatory research approaches would further illuminate the dynamics and limits of greater stakeholder involvement in research processes. Considering the role of CE practices in the context of a wider imperative to strengthen health responses and health systems through better research and engagement, could also help build a more coherent and consistent field of theory and practice around CE.

Recommendations

The inter-related recommendations below suggest ways that CE can be supported by research institutions and funders to enhance ethical engagement in research.

1 Greater integration of health research with health systems in LMICs

- Ensure health research is planned to maximise the opportunities to strengthen health systems in the short and longer term, and minimize the danger of any unintended harms.
- Seek to expand host country ownership of health and research agendas (potentially aligning with the Council on Health Research for Development (COHRED) research Fairness Initiative).
- The above integration could be helped by greater attention to engagement with health policy and practice by both research institutions and funders.

2 Inception phases and flexibility in research funding

- Funders should explicitly consider processes to allow for budget and protocol flexibility in response to CE and in which circumstances these apply. An example is the International Development Research Centre's (IDRC) Research Quality Plus tool.
- Funded inception phases of research can facilitate partnership development, early engagement, and consultation on research focus priorities and design as is encouraged by the National Institute for Health Research (NIHR) Global Health Research Grants.

3 Broader political and ethical focus for health research engagement

CE processes will be unable to fully address the differences of wealth and power between researchers and local research stakeholders, but concrete steps can be taken to mitigate them at a range of levels:

- Compile existing guidance on provision of individual and community level research benefits and support the development of context sensitive guidance.
- Support the development of guidance for Ethics Review Board processes and for community engagement standards and processes that explicitly address the influence of wider structural factors and draw on principles of social justice.
- 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. Participatory training activities drawing on practice based case studies are valuable here.

- Consider the potential to support the recommendations outlined in our sister brief for community engagement leads and researchers.

4 Core funding to support engagement at research programme level

- Support research institutions with core funding to invest in programme-wide engagement in addition to engagement linked to individual research studies and be explicit about the purposes of providing opportunities for relationship building and stakeholder input¹.

5 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
- Dedicate work with researchers on their understandings and attitudes to CE at the institutional level

6 Clarity around engagement purposes and outcomes and the 'terms of engagement'

- Develop explicit program theories for engagement to inform responsive planning and evaluation.
- Clearly articulate the decision rights of local research stakeholders around the focus, design or implementation of particular research studies, and research institution policies.
- Develop and use clear procedural standards for community engagement to monitor levels of meaningful input and control on the part of research stakeholders.

7 Recommendations for further research

- Extend the current review to participatory research approaches to better understand the causal dynamics and limits of embedding stakeholder input and decision-making in the research process.
- Increase investment in applied social science studies on the relational dynamics of engagement, implementation studies, and the anthropology of health research.
- Support applied social science work on health systems, the social determinants of health, and international health and research governance to deepen understanding of the enablers and constraints on engagement and inform biomedical research.

1. The experience of some research centres supported long term by Wellcome, such as KEMRI, OUCRU, MLWT MORU, AHRI: <https://wellcome.org/what-we-do/our-work/programmes-and-initiatives-africa-and-asia>



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
- ▶ Navigating the complexity of community engagement with health research. REAL brief for CE leads and researchers; 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

RELATED RESOURCES

- Mesh Community Engagement online resource: <https://mesh.tghn>
- Ethics and Engagement across Wellcome Africa and Asia Programmes: <https://e-mops.ning.com>
- 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>

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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