REAL Community Engagement Realist Review

Navigating the complexity of community engagement with health research

REAL BRIEFING FOR COMMUNITY ENGAGEMENT LEADS & RESEARCHERS

August 2024 (Version 2)

Summary

Community engagement can help to improve health research by making sure it is informed by community priorities and concerns, it is done in an ethical way, and that the solutions that are developed are appropriate to the local context. Many people are engaging communities in different parts of the world, and the term 'community engagement' can mean different things in different places. This can make it hard to learn from each other's experiences and for researchers to know what steps to follow if they want to engage communities in their work.

We conducted a review on community engagement, starting with malaria research trials. We wanted to find out how it works in practice – not in theory. At the same time, we wanted to develop clearer explanations of how community engagement actually works. Highlights of our findings were that it is very important to develop 'working relationships' between researchers, staff members who interact with communities and communities themselves. Working relationships may not be 'perfect', but they allow community members and research staff to discuss research and to raise questions, concerns and ideas.

These relationships are constantly shifting and changing, but they help to get research done. They are built through informal interactions (that are not planned) and formal interactions (for example planned meetings), that have a big influence on the acceptance of research and whether people participate in it. We found that keeping these relationships going can be difficult because of the differences there can be in power, money and culture between researchers and community members. These differences can be more pronounced for research that is funded by donors based outside of the country with strict requirements for how the research is run. We hope that our findings will help promote community engagement and help researchers build and sustain important relationships with communities over time.

In this brief we summarise some of the key findings from the review about how community engagement works. We discuss what makes community engagement easier or more difficult, and some of the ethical issues involved when research is done in settings where resources are limited. We provide recommendations to support more ethical engagement with communities when doing health research.

What is community engagement?

Community engagement can be defined as interactions between researchers and other people who either: a) live in the area where the research is being conducted, b) share similar interests or health issues to those targeted in research, such as those who have experienced malaria , and c) have other special insights, for example community health workers or community based organisations. When we refer to communities in this brief we refer to people with an interest or potentially affected by research, without suggesting they all have the same attitudes or interests. Sometimes these interactions are also called 'public engagement' or 'stakeholder engagement' – but people differ on whether they feel these other types of engagement give enough attention to those who are potential participants in research. There are also different terms for community engagement whether you look at it from a health programme, research or international development perspective.

Purposes of engagement

The purposes of engagement are not always stated plainly or clearly. There is a difference between the goals of community engagement that aim at improving the quality and relevance of the research being done, which can be seen as instrumental, and ethical goals that involve doing research in a respectful way. Ethical goals include building respectful relationships, understanding the vulnerabilities of the people taking part in research, minimising the research risks and thinking about the obligations of the researchers. The way in which community engagement is typically used in health research combines these two goals (ethical and instrumental). The engagement often focusses on what the appropriate benefits for taking part in research are, making sure that consent processes are done well, and necessary approvals are in place. The different ways in which the ethical and instrumental goals influence community engagement is rarely made explicit in planning or evaluation.

Engagement activities and strategies

There are many types of engagement activities and strategies. These can include meetings with community members and representatives; information and communication activities to raise awareness and ask for support for research; setting up community advisory boards as a link between researchers and local research stakeholders; and involving different stakeholders in designing and implementing research activities.

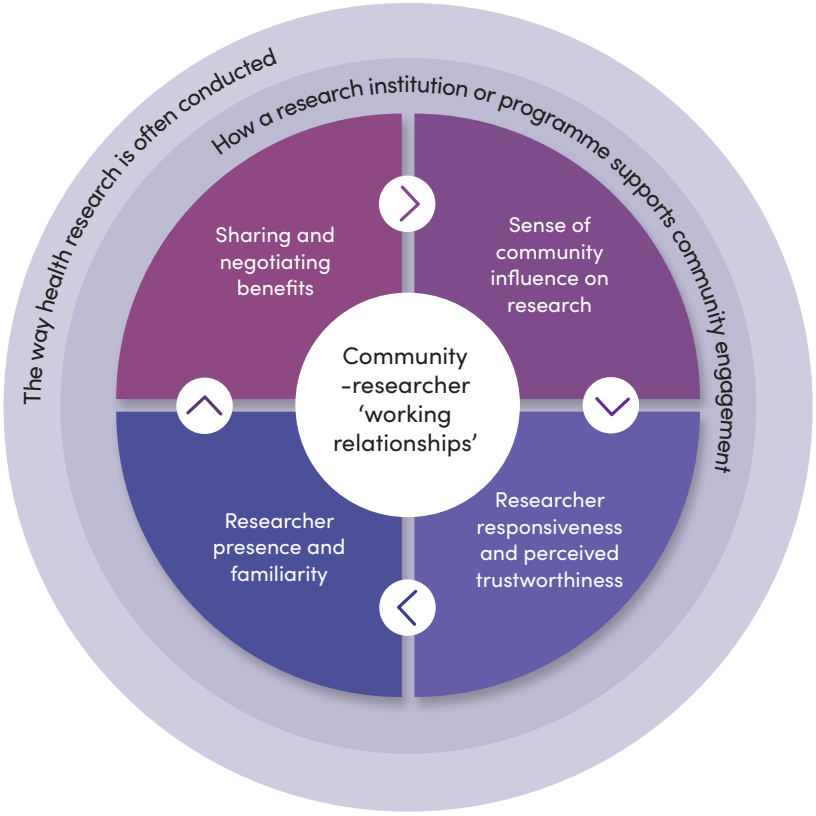
1. Community engagement helps researchers and local stakeholders develop 'working relationships'

At the core of community engagement are the 'working relationships' that develop between researchers and the different communities potentially impacted by the research. These relationships often take place across differences in wealth, power and culture. These working relationships depend on four mechanisms described in Figure 1.

- Sharing and negotiating benefits from the research for researchers and communities.
- How researchers respond to these negotiations including whether community members feel acknowledged and listened to.
- The familiarity and accessibility of research staff to communities, especially through frontline research staff.
- Whether communities feel they can influence the research.

Developing a web of working relationships between research staff and communities can help to create more acceptance and participation in research among community members. This is despite some community members having different motivations and understandings of what it means to participate in research from researchers, as well as differences among research staff. While research leads may aim to produce high-quality research, in settings with under-resourced health systems, people often participate in research because of the benefit of accessing better health services. The working relationships that develop can change over time and depend on the way research staff engage with community members, both informally (out of work and unplanned) and formally (for example planned meetings). Interactions are not always linked to a specific piece of research.

Figure 1: Core dynamics of and influences on engagement



> "Time is really important in building and maintaining relationships – we've been at it [at this research institution] for over 30 years, with relationships coming and going. There are different types of relationships: between community engagement teams and researchers, researchers and community members, Ministry of Health officials and community engagement personnel. … Being there from the outset of studies; having relationships in place influences where research is even done."
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> COMMUNITY ENGAGEMENT COLLEAGUE, KENYA.

2. Frontline research staff play an important role in developing and sustaining relationships

The everyday presence of frontline research staff (sometimes called 'fieldworkers'), who often live locally, helps build relationships and helps the broader research team be responsive to concerns of people participating in research. However, the role that these staff play is often complex and under supported. These staff need to engage in everyday negotiations that can be challenging, informal and unclear. There is therefore a danger that some of the ethical challenges of doing research in low resource settings are outsourced to frontline staff. They need more supportive supervision from their institutions and programme leads, and in some contexts may benefit from professionalization of their roles and clarity in progressing their careers.

Frontline staff need more supportive supervision

"[Frontline staff] have to bear the threats like landmines, mental health problems, and hearing the traumatic experience of the community. Mental health is very stigmatized in our culture, and not many people talk about it. But fieldworkers may be suffering. .... Community engagement fieldworkers are vulnerable and unless they are adequately valued and supported, there is no way their vulnerability is going to be mitigated."

COMMUNITY ENGAGEMENT COLLEAGUE, THAILAND

Two examples of ethical challenges faced by engagement staff in Thailand

"Close relationships also lead to development of expectations and that puts you under pressure. For example, if they ask you to employ their daughter. In our culture, denying their request can be painful ... how to deal with expectations is difficult".

"The community members invite us for food. Even the poorest communities, they tend to offer whatever they can, e.g. betel nut. That's their gesture. Sometimes it's affecting their own money they have saved for their food. The field workers accept it, and it can be offensive not to accept it. If the offering is too valuable, field workers politely decline. The offer from them also obliges fieldworkers to offer them something back. And it affects relationships and trust, what we offer them... Based on organizational code of conducts you are not allowed to gift, because it's considered bribery, but culturally, it's a norm. Fieldworkers are obliged indirectly to support them, such as by praying in church. Some exchange is prevalent."

COMMUNITY ENGAGEMENT COLLEAGUE, THAILAND

3. Commitment to community engagement by research programmes can help to develop relationships that sustain engagement over time

Community engagement depends on the support and commitment of senior researchers and directors. They need to prioritise community engagement, make sure it has enough funding, and ideally build up a culture where community engagement is a central part of how research is done. Examples of what this commitment can look like include: dedicated roles to lead and coordinate community engagement so that there is a consistent point of contact for community members; carefully evolving engagement approaches based on inputs from social scientists and engagement experts; and having processes in place from community engagement activities that inform and influence management. Doing 'programme-wide' community engagement, where this is not just for individual research studies but rather for all the research done by an institution may also useful. Commitment to community engagement is also facilitated by funders making financial and human resources available at the project or institution level. Funders should also have an explicit expectation that the research will meaningfully engage communities at the beginning and throughout the project.

The resources needed to develop and sustain relationships

"For every single step, we need more money to support travel and food costs, to invite the members of the community. Without this, it will be difficult for us to ask community members to participate.... We need to have a regular meeting with all the stakeholders to keep the activities relevant, otherwise they may forget us. We want to support them and improve the relationship with community members because we may have hurt them in the past with research. For this, we need more staff to facilitate engagement and means of transport."

COMMUNITY ENGAGEMENT COLLEAGUE, CAMBODIA

4. The way research is funded and controlled can undermine relationships between researchers and communities

Health research in many low resource settings is predominantly funded by international research partnerships and large-scale clinical trials. This is usually controlled through international organisations and agencies that deal with different aspects of clinical trials. There are several characteristics of this way of approaching research that undermine relationships between researchers and local populations. Where research centres are based in settings of relative poverty, the exchange of health care for research participation can land up being coercive– with participants feeling that they do not have a real choice about participating in the research as the overall benefits are too significant to decline. This can be despite research teams and ethics committees trying to think about what a 'fair offer' would be to people taking part in the research (i.e. when balancing the risks and benefits). Globally, there are also big differences in power, with research agendas largely being set, funded and managed by actors and institutions in high-income countries. This can limit the interest and ability of national governments to set and follow local research agendas, and undermine local researchers' decision-making power about research infrastructure and facilities. If researchers are not accessible or communities feel they lack control over research, relationships can be negatively impacted.

Sharing learning between research funders

"Perhaps funding institutions with experience of community engagement like the Wellcome Trust can share some of their insights with other large research funders in global health on the value that community engagement brings.... We've struggled with funders and programme managers that come with a specific biomedical model ... where what we were doing did not fit their template of what a 'successful' project looks like. This threatens the relationships you've built and your ability to continue important work."

A CIVIL SOCIETY ORGANISATION PERSPECTIVE, SOUTH AFRICA

5. The narrow focus in some engagement activities on individual autonomy and free choice can divert attention from community members' ability to influence the research

In drawing on research ethics guidance in community engagement activities, there is often a focus on whether a person can freely consent and make decisions about participating in research independently. That can sometimes miss the wider influences on people - such as their households and local opinion. It can also miss opportunities for getting inputs from community members on how the research is conducted and even the research questions themselves. Practical initiatives such as community advisory boards and wider community consultation can allow for more meaningful, systematic, community inputs. However, there are limits to community influences on research simply through engagement interventions and activities and engagement opportunities could also only amplify the voices of a small group of people. Often people's feelings about whether they can shape research is influenced by the wider socio-economic conditions in which they live, and this may also affect how they engage with opportunities to give input. For these reasons, more thought should be given to how procedures work in detail (paying special attention to power dynamics), and to the limits to what community engagement can achieve given the underlying socio-economic conditions. When thinking about research ethics we should widen the focus beyond individuals and immediate relationships, to consider the facilities and institutions involved in research, the health systems and social, political, and economic constraints. At the same time, the broader social impact of research and the social determinants of health should receive more attention in research and practice.

Communicating findings about research in an accessible way

"When we publish in English, it is not understandable for them, which is unfair to them. Low literacy does not mean that there are no ways to communicate."

COMMUNITY ENGAGEMENT COLLEAGUE, THAILAND

Conclusion

By better understanding how community engagement works we can see how the wider context influences people's choices around whether to engage with research. It is important to further develop ethical ways of engaging people in research, and consider what resources, activities, facilitation, and communication skills are needed to build these relationships and support meaningful engagement processes.

Community engagement should challenge rather than reproduce the way global health research is often done

While the development of working relationships between researchers and community stakeholders helps to get research done, there are some potentially harmful practices as well. This could include: 1) conducting research in ways that do not take into account inequalities and differences within research systems, and 2) placing the burden of responding to these inequities onto frontline research staff through their formal and informal interactions with community members. In these ways, ethically problematic characteristics of the way research is conducted can be continued or accommodated rather than challenged. There is a then a risk that community engagement unintentionally entrenches rather than challenges existing inequalities.

Benefits of building quality relationships

Community engagement that facilitates building long-term, working relationships between researchers and diverse community members can have positive impacts beyond specific research programmes. Strong relationships can help to build connections between researchers and health system policy makers and managers, which could in turn lead to more integrated planning of health research and to health systems strengthening. These relationships can also help embed community decision-making into collaborative partnerships. This participatory approach to community engagement and research may help to challenge the way research is done, making it more equitable by helping communities play a more fundamental and equal role in research.

Recommendations

The recommendations below suggest ways that community engagement can be carried out by researchers and supported by programmes in ways that build relationships and promote ethical practice in research.

1 Focus on building quality relationships between researchers, research participants and wider communities

- Commit time, effort and financial resources towards developing quality relationships with communities through regular, programme-wide engagement that extends beyond individual research projects where possible.
- These programme-wide interactions could include discussions on community priorities and concerns, and the ways in which these can be responded to in ways that also fulfil the needs of the research programme (including for example consent processes, ethics review processes, and ways of deciding on study-related benefits).

2 Promote institutional support for frontline staff and capacity development for engaging with communities

- Provide experienced-based training and supportive supervision for frontline research staff to help them navigate some of the challenging components of managing relationships.
- Where possible, professionalise frontline research and engagement staff roles with pathways that can help progress their careers.
- Ensure that researchers who are not doing frontline work understand the importance of community engagement and that at the research institute level there is sufficient support for it.
- Support engagement personnel to see the sometimes-invisible influence of the way research is usually done on community engagement, and where possible, identify concrete steps to mitigate power inequities and be more inclusive in the way research is done.

3 Support the involvement of local stakeholders in research

- Make clear where and how community members can have input on the focus, design or implementation of research studies, for example using participatory research methods. Planning on what stages this can be done is important. Having a wider policy for the research programme can help to clarify the goals of community engagement and manage both researcher and community expectations.
- Carefully consider the time and opportunity costs involved for community members engaging with research, including for engagement activities.

4 Ensure that research activities respond to the input of communities

- Implement a range of methods for listening and responding to community members' concerns in the local language and to – wherever possible - plan research questions and details together. Approaches could include dedicated spaces for communities to raise concerns, and seeking structured inputs from frontline staff who are often community members themselves.
- Make sure that there are formal structures and processes to feed community inputs back to power-holders in research programmes, and that the issues raised are responded to, with feedback given to communities.
- During engagement activities, provide accurate information about the research. Given that the interests and concerns of communities may be wider than specific pieces of research, this could cover open and honest discussions about what can and cannot be acted upon, and reasons.

5 Support the planning and evaluation of community engagement

- Develop explicit understandings of how community engagement is expected to work, e.g., through 'theories of change' that can inform strategic planning.
- Include specific activities early on in research planning or studies to understand local decision-making processes, communication channels and the ways that different stakeholders prefer to be engaged.
- The beginning phases of research can facilitate partnership development, and early engagement can also inform the focus of the research, its priorities and design.

6 Develop a greater role for social science research that looks at the dynamics of community engagement

- Community engagement practitioners may benefit from working with social scientists to develop engagement activities in ways that consider complex relationships and their influences.
- Researchers and community engagement practitioners should collaborate on documenting and analysing the practice of community engagement and identify priority issues for further research.
- Engagement practitioners can draw on participatory methods to support their work. This could bring interesting ideas for engagement practices that are inclusive, respond to the needs of communities and help build relationships and respect.
- Biomedical research design (for example clinical trials) should be informed by social science studies that look at 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

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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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