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Empowering *Meaningful* Community Engagement and Involvement in Global Health Research: Critical Reflections and Guiding Questions

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This resource guide was published in April 2021.

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Front cover image:
Annual review meeting in Sacatepequez Province, Guatemala

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When the first NIHR Resource Guide on Community Engagement and Involvement (CEI) was published in 2019, the world was as yet untransformed by the COVID-19 pandemic. Now, it is even clearer that global health goals are unachievable without strong relationships of trust between researchers, practitioners and the communities with whom they work (1-4). COVID-19 has also brought to the fore the importance of bringing diverse forms of knowledge to bear on complex public/global health challenges (5-8). In addition, the increased calls to build genuine equitable partnerships in global health research (9-11) have underscored the fact that meaningful community engagement and involvement is not only an ethical imperative of 'building forward differently' (6), but also a means through which global health researchers can be more accountable to those whose lives they seek to improve (12).

The word 'meaningful', when applied to CEI, reflects a range of approaches that aim to bring direct benefits to communities: to influence or hold to account public health decision-makers, to get access to improved health services and/or resources, to build capacity for direct involvement in research, and to address social drivers of ill-health (13). The terms 'community engagement', and relatedly 'community participation', are not new, and have often been used in the past to signal the beginning stage of a process when 'community buy-in' is required to move forward, or the end stage of a research process when 'expert' knowledge is conveyed to the public. For NIHR's Global Health Research Portfolio, CEI is both a mandate and a core value. The expectation is that research proposals for funding will demonstrate that CEI is not a marginalized component of an overarching research process, but instead a central component of how the research itself was conceived and delivered.

With that in mind, this learning resource offers a brief set of reflections to help guide decision-making within the context of collaborative research approaches. This text reflects a series of conversations between experienced CEI practitioners over this past year – in the first instance, through participation in the NIHR CEI Expert Advisory Committee and through consultation with NIHR staff and award holders, and later with the co-facilitators of the first learning event hosted by the IDS on 29th January, 2021: Walter Flores of CEGSS; Alex Shankland, IDS; Mieke Snijder, IDS, Tom Barker, IDS and Erica Nelson, IDS. In broad brushstrokes, we discuss CEI in design, implementation and adaptation, governance and accountability and lastly, respect for people's dignity as a core CEI commitment.

1.

Design Processes as Opportunities for Critical Reflexivity:
Getting Comfortable with Uncomfortable Truths

For those researchers more familiar with the NIHR's work on 'Patient and Public Involvement' or PPI in a UK health research context, it is important to recognize that CEI within international public health collaborations requires navigating complex dynamics of power and distinct ethical frameworks (14-15). Think, for example, about how 'communities' are referred to in global health research. Depending on how a community is defined within a given health research intervention, the boundaries of who is 'in' and who is 'out' may not map neatly on to existing social relations or take into account intersecting patterns of vulnerability and marginalization. For example, if a project were to propose that CEI processes were to target individuals within a health services catchment area, the people living within that catchment might identify themselves as belonging to distinct sets of communities that overlap with, or exist entirely separate to, the lines on a map.

To mitigate against this tendency to define 'community' membership according to pragmatic objectives, some initial questions to ask of yourself and your research team include:

1. How is community defined in this place and for the purposes of this project? Do all members of the research team understand 'the community' or 'communities' involved in the same terms?
2. In defining it this way, who is included and who might be left out? How will this shape the engagement and involvement outcomes?
3. Do you understand enough about the internal power dynamics of this particular grouping of people? Do you understand the risks your engagement potentially creates for marginalised or vulnerable individuals within the group?
4. If you don't understand these dynamics well enough, who can help you to better understand them? Have you resourced that knowledge adequately at the front end of the project?
5. Have you asked members of the community – however defined – what they would like to know? What knowledge or information do they need to resolve the problems they have identified as important to them? Have you accounted for the processes necessary to address their concerns/ unanswered questions within the research project?

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It is well known that CEI works better if the consultation process begins as early as possible (16-17). If meaningful forms of CEI are not feasible prior to the first round of proposal development, it is all the more important to think through and plan for the initial period of consultation (as required and funded by the NIHR), which may lead you to revise your research questions and amend your strategies. An important caveat here is that the feedback itself might well be contradictory (18) because of distinct positions, differing degrees of power and influence, and subsequently diverse perspectives within a given community. If a core goal of CEI is to empower marginalized and vulnerable groups, then research teams must be prepared to give up some of their own power, for example, the power to direct a research agenda, the power to determine the allocation of financial and human resources, and the power to draw attention to the needs of a given community. Building trust with interested communities must go beyond informed consent processes, and requires good listening skills, empathy, continuous checking-in to ensure that communication is clear, and a commitment to mutual learning.

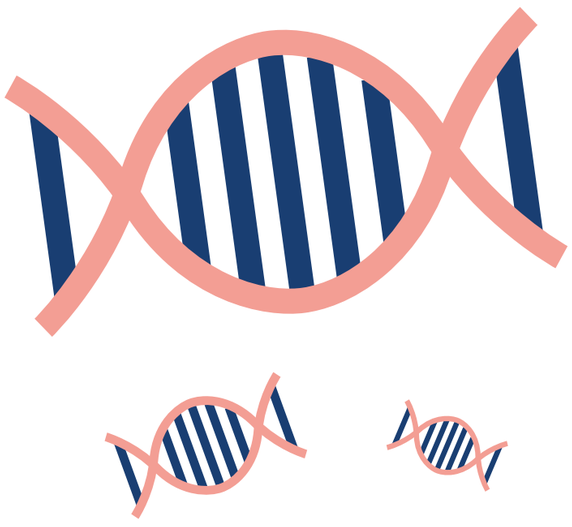
2.

Implementation and Adaptation:
Whose Knowledge Counts?

To do meaningful CEI requires more than just a multidisciplinary approach – it demands respect and openness to diverse skills and methodological practices, as well as openness to the experiential or 'lived' knowledge that team members and community members can bring to the process (19-20).

While some research designs make CEI easier to integrate and implement (for example, participatory action research), it is still possible to have meaningful CEI within any type of research collaboration. To limit 'information asymmetries' when dealing with highly technical research questions and approaches, it is crucial to account for the effort that will be required to communicate the proposed research in terms that are understandable to a diverse range of community members, and to mark off periods throughout the project cycle for feedback and dialogue. This might mean a series of participatory workshops, newsletters, radio programmes, short videos or any number of communication approaches to demystify technical language and enable community members to give constructive feedback, and for that feedback to be integrated into decision-making. The substantial contributions of time and energy that this work demands should be adequately resourced and community members should be compensated accordingly, per NIHR guidance.

The goal of CEI at the implementation stage should not be to rubber stamp the trajectory of research as envisioned by researchers, but should instead provide an opportunity to reflect on the implicit assumptions of the proposed research and make adjustments when those assumptions are challenged. To that end, it is recommended that projects adequately budget and support CEI-focussed data collection processes as either a central component of the research itself, or in ways that can inform, and even potentially shift, research outcomes.



A few key questions to consider under the category of implementation and adaptation:

1. How will you put proposed research questions (and later research findings) into formats that are community-accessible? Do you have skills within your group to do that, or do you need to allocate funds for community-based expertise?
2. How will you create the necessary flexibility and potential for adaptation within the project so that the results of CEI are incorporated, or even potentially used to change course?
3. How will diverse types of knowledge be accounted for within the research process?
4. Have you built in mechanisms to acknowledge and engage with dissent or alternative views within the CEI process?
5. How will you manage different approaches to research and to CEI within the research consortia itself? Are there plans to surface implicit biases of team members, or to address honestly as a group the challenging power dynamics that can result from diverse disciplinary allegiances?
6. When considering the proposed research, ask yourself: whose knowledge counts most? Then ask yourself: what can be done to shift that dynamic so that this research draws on and generates knowledge that reflects more fully the lived experiences and needs of marginalized and vulnerable groups?

3.

Power: Doing the Hard Work of Good Governance and Accountability

This brings us to the question of power, which shapes the contexts in which global health research is carried out, the questions that are asked, how they are answered, and the actions that follow when new knowledge is produced. There is substantial literature concerning the nature of power in global health (21-23), as well as the dynamics of power within the context of community engagement and involvement in health research (24-25). For this learning resource, Shiffmans' writings on structural power and productive power are particularly useful (22-23). Structural power in this instance means how 'we define ourselves in relationship to one another, in ways that enhance the capacities of some and limit those of others' (22, p. 297). Productive power refers to 'how we create meaning, particularly through the use of categories that lead us to think about the world in some ways but not others'. (22, p.297). When thinking about the place of CEI within a given global health research project or process, it is essential to consider how structural and productive forms of power influence the internal dynamics of a research group as well as interactions with community members.

Community leaders interview providers in rural healthcare facilities in Totonicapan and Sololá provinces, Guatemala. © CEGSS, Guatemala. All rights reserved.

Some initial questions to consider include:

1. How will you take account of unequal power dynamics within a research group, and between a research group and the communities with whom you work? What might you do to surface these power inequities and address them or mitigate them?
2. What accountability mechanisms have been put in place to hold research teams accountable to the communities you engage with and involve? (for example, a steering committee with voting power on decisions related to project design, implementation strategies, and dissemination strategies, or a community-based advisory board that has the power to suggest and implement research adaptations).
3. When analysing data and research results, how will you navigate differences in power, either within your project teams/consortia or between a research group and the engaged communities?
4. Have you put into place any processes whereby the knowledge produced by the research (data, findings) can be stored within the community so that it is accessible and useable for future use?

Just as there is no right way to do CEI within global health research, there is no right way to build trust and honest relationships through CEI. No one is an expert at this, because this kind of critical reflexive approach to power is necessarily context-specific, relational, personal and evolving. Trust-building and honesty in CEI do, however, demand respect for the dignity of communities and individual community members. With that, we turn to the last section.

4.

Respect for People's Dignity as a Core CEI Value

Global health research often involves working with marginalized and vulnerable populations, particularly if the research questions are oriented towards the health inequities that these groups experience (26). Researchers should be mindful of the fact that past international and national public health efforts have not always safeguarded the dignity of minority groups in whose lives they have intervened (20, 27). Critical self-reflection, a learning mindset and some knowledge of what groups have experienced historically vis a vis public health/ health research institutions is vital to doing CEI in a way that respects people's dignity. Regardless of the level of ambition in setting out to do CEI, it is important to pursue open dialogue with community members, to set realistic expectations, to respect any form of agreement that is reached (whether verbal or more formally contractual) and to practice cultural and professional humility.

Meaningful Community Engagement and Involvement is both a way of working and a commitment to transformative action. There is no rulebook on CEI because in practice it demands creativity, responsiveness, and the willingness to adapt and learn in ways that challenge one's previously held assumptions. We end by suggesting that while it may be ambitious to propose to do work that shifts power in global health in meaningful ways, it should be not out of reach.

Some important questions to consider include:

1. Are you being honest about the core objectives of your research with community members and what you can deliver on in terms of projected outcomes?
2. What assumptions are you/your team making about the value of community members' time and ability to contribute to decision-making? Do you need to address and shift any of these assumptions?
3. What will/can you concretely give back to the community when the project has wrapped up, and have you put into place plans to be able to follow through with such promises?
4. In what ways might your professional standing or cultural competencies influence your relationship with community members and can you bring more vulnerability and openness to your work?

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