

# Learning Brief

## Community Engagement and Involvement

This learning brief is designed for the National Institute for Health and Care Research (NIHR), NIHR partners and awardees, as well as the wider global health research and policy community. This learning is drawn from our Evaluation of NIHR's Global Health Research Portfolio, First Phase (2016/17-2020/21).



### What's the issue?

There is increasing understanding amongst global health research funders and researchers that in order for research to be relevant and to have impact, the people who will be affected by it must be involved. In a shift away from 'parachute research' and instrumental approaches of working with communities solely to gain entry and support the recruitment of research participants, community engagement (CE) approaches are increasingly geared towards involving communities in designing and implementing research. NIHR uses the terminology of 'community engagement and involvement' (CEI) to encompass the broad range of approaches undertaken in the global health context, including providing information, consultation, collaboration and co production.

Insights gained from community engagement can help researchers understand the needs, barriers and risks for different groups, including for those who are often marginalised from decision-making spaces. Well-considered CE approaches can also help researchers design better research studies with greater potential for uptake, implement more ethical research practices, and ensure a fair distribution of benefits. CE approaches also contribute to community awareness, empowerment and relationships, which in turn support communities' ability to benefit from research interventions, mobilise collectively, and influence health systems.

Funders are placing increased emphasis on community engagement. However, researchers are often constrained by funders' priorities, limited resources and short timeframes. The 'community' which tends to be understood as patients, their families, and community leaders and other members of a particular locality, can be challenging to identify and reach, particularly if they

have marginalised identities. Building trust (particularly in communities that are wary of research due to previous experiences), developing approaches that can reconcile theoretical principles of CE with realities on the ground, and embedding more deliberative models of engagement needs time, preparatory planning and flexibility, which funding processes and project cycles often do not support. Understanding context, and particularly the backdrop of structural inequalities, health inequities and under-resourced health systems is also key to developing relevant research and engaging responsibly with community expectations.

The emerging literature on CE practice in health research finds that communities are often only engaged once research priorities and questions have been decided. There is also a reliance on consultative rather than deliberative processes of gaining community feedback, such as surveys, interviews, and large meetings and working with selected community members to deliver information. Communities are often invited to provide input, but researchers retain decision-making power over whether and how that input is used. CE processes can also become dominated by gatekeepers and local elites, and while marginalised groups may be represented, they are often not supported to make their voices heard.

A key factor in effective CE is the skills of researchers in engaging with communities, as well as their commitment and openness – as individuals and institutions – to recognising, engaging with and navigating unequal power dynamics between themselves and communities. This requires contending with colonial legacies and knowledge hierarchies within global health research and developing organisational cultures and ways of working that support critical and reflexive practice.



## Key considerations from the literature

The literature on community engagement in global health research notes the lack of research and evaluations that investigate the effectiveness of different approaches in supporting successful research implementation and ethical approaches, and improving health outcomes, social participation and people's lives. The literature provides key principles that can support researchers to go beyond consultation to meaningfully involving communities, including marginalised groups, in strategic decision-making across the research cycle.

### Building deeper understanding of context

Formative research should be undertaken to understand the needs and capacities of community stakeholders, their relationships with the health system, existing systems of participation, marginalisation patterns and processes, local power dynamics and the way in which power is expressed. This can enable communities to get to know the researchers and the proposed study and support researchers to develop relevant and sustainable research and community engagement approaches.

### Valuing different forms of knowledge

Building inter-disciplinary teams that include community members and people with lived experience can ensure that research is informed by an understanding of the local area and the localised social, cultural and political factors that will shape the research and community engagement approach.

### Supporting research awareness

Communicating highly technical information about research questions, methodologies and processes requires a range of accessible dialogue and communication approaches, including training community health volunteers/ workers and holding participatory workshops. These approaches should also be used for researchers and communities to discuss research ethics and governance, and collectively agree expectations about how the research will be conducted, and which community challenges the research can respond to and to what extent. Building awareness about the health issue in question also supports communities to reflect on and articulate their needs, and actively engage in collaboration processes.

### Including diverse groups

Researchers should remain attentive to the ways in which power imbalances within CE processes can create risks for women and marginalised groups and/or inhibit their participation. This is particularly the case where there is a reliance on community leaders and gatekeepers, who can perpetuate unequal social norms and power relations, to reach and engage different groups. Involving women and marginalised groups may require working with organisations that represent them, developing methods of deliberation (venue, language, materials, ground rules, facilitation approaches) that support groups with less power to participate, and supporting alternative spaces and processes.

### People-centred ways of working

Effective community engagement requires approaches that centre people and communities within health systems. This includes ensuring that interactions are respectful and empowering, and there is an emphasis on building relational ways of working. Researchers also need to have strong facilitation and interpersonal skills, be comfortable with complexity, and be given the space to innovate without fear of failure.

### Embracing collaboration

Meaningful community engagement can shape research strategies and findings in unplanned ways, for example, by drawing attention to context, lived experience and different forms of knowledge. This should be equally valued, and researchers should be given the space and time to respond to such input.

### Supporting empowerment and social justice

It is important not to assume that communities are disempowered. However, community engagement approaches which explicitly aim to shift power and build collaborative approaches can enhance communities' ability to articulate their health needs, strengthen relationships and networks, and build skills, confidence and sustainable capacity for collective action. These changes will go beyond supporting health-related outcomes to addressing broader social justice issues of participation, accountability and responsiveness.

### Contributing to the evidence base

Building knowledge about what works, and in what conditions, requires that research projects include monitoring and evaluation approaches to understand the effectiveness, risks and impacts of CE. This is challenging as CE is a dynamic, social process that is highly contextualised, and cannot be understood as a time-bound intervention. CE approaches also vary widely, and change processes are often intangible, emergent and difficult to identify without participatory and qualitative monitoring and research. As such, tracking progress and outcomes is an evolving area with few commonly accepted monitoring and impact measurement frameworks.





## NIHR's approach

NIHR understands CEI as global health research undertaken in collaboration with communities most likely to be affected by the research outcomes. 'Collaboration' is understood as 'an ongoing partnership' where 'decisions about the research are shared', and communities are involved throughout, including in co-developing the design and research planning and being involved in implementation.

During the first phase, NIHR invested considerably in integrating CEI into funding processes. This included integrating progressively greater emphasis and guidance in Call Guidance materials and providing increasingly rigorous assessment of applicants' CEI approaches. A suite of guidance documents was also developed. NIHR-led programmes have recruited CEI specialists and people with lived experiences to their review committees and panels, training other reviewers on how to engage with the inputs of CEI reviewers. Selected programmes have also offered development and planning grants to support applicants to work with partners, policy stakeholders and communities in developing their final applications.

Sample award holders demonstrated a high level of commitment to CEI and appreciated NIHR's emphasis. Many noted that this encouraged them to engage with communities in ways they would not otherwise have done, often unlocking new understandings about community-level barriers and needs, dissemination and uptake opportunities and change pathways. NIHR's flexible approach to supporting awards' CEI journeys has enabled researchers to deploy a range of contextualised approaches that are relevant to their theme, setting and capacity, and to learn and progressively strengthen their strategies.



## Our findings

This section outlines some of the key findings on NIHR awards' approaches and practices on CEI that emerged from the evaluation of the first phase of NIHR's GHR programme.

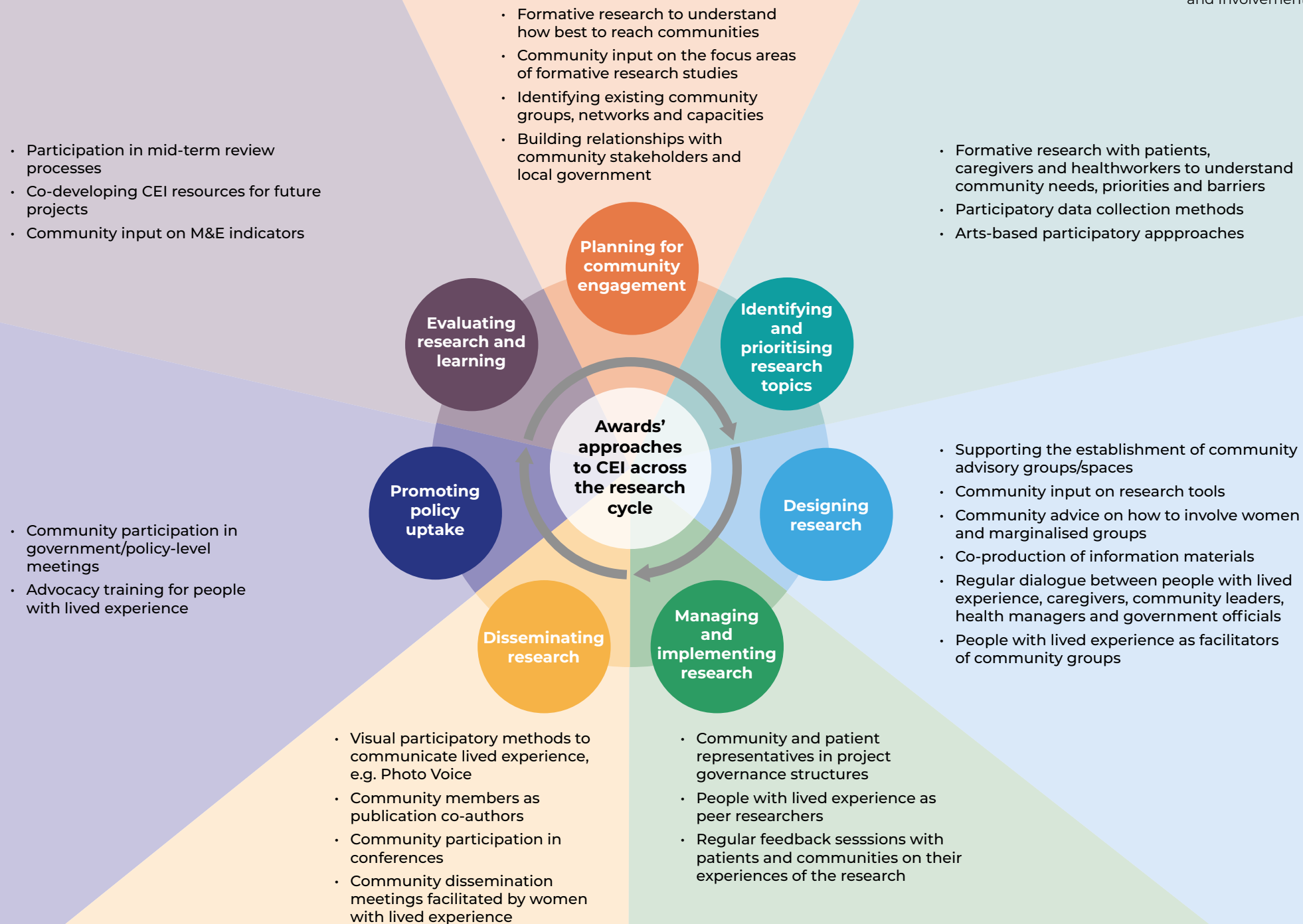
**No one-size-fits-all approach.** Various awards reported that they took time to determine how to apply CEI concepts to their context. Awards working on stigmatising health conditions, for example, took deliberative approaches to building collective understanding amongst partners about a CEI approach to issues that are rarely discussed at the community level.

**Incremental progress towards building genuine collaboration.** Awards' CEI approaches tended to evolve and mature over the lifetime of the project, or across several awards if additional funding had been achieved. This occurred as community relationships and trust became more established, awards' CEI experience and workstreams became more embedded, and communities became more actively involved. Whilst there is less evidence of the involvement of communities in priority-setting and overall design, there were various examples from more experienced awards of how community engagement had shaped the design and delivery of projects' component research interventions.

*The figure below illustrates some of the most notable approaches taken by awards to involve communities across different stages of the research cycle.*

**Providing information remains an important step.** For most awards, raising awareness about health conditions, their prevention and treatment, and the objectives of the research remained an integral part of their CEI approach, and a key starting point to more consultative and collaborative activities. Awards across the sample supported community-level dialogue, participatory research and safe spaces within which people could talk about their experiences, build confidence (particularly among women and marginalised groups), and develop a critical perspective on the relevant issues so that they could meaningfully contribute to the research.

**Reaching marginalised groups requires explicit analysis of their needs.** Beyond those awards that were focused on women's health, few from the sample assessed and responded to the needs of women and marginalised groups within their research and CEI approaches. Similarly, only a small number of awards were able to speak to the risk of community groups and CEI processes becoming dominated by people who have more knowledge, confidence, time or resources and are less able to represent the needs of lower-income or marginalised groups in the community. Whilst these issues are highlighted in NIHR's CEI guidance materials, there was limited evidence of explicit discussion amongst award holders about gender equality, intersectionality and unequal power dynamics, and how these issues shape and are shaped by CEI initiatives.



**Community representation in research governance can support researchers' openness to collaboration.**

Several awards involved community representatives in project Steering Committees and Community Advisory Groups alongside academic, policy, health management and civil society stakeholders. These groups were involved in providing community input across different stages of the research, advising on the appropriateness and feasibility of proposed activities, and designing or refining specific research outputs or processes. Some awards progressively increased the number of community representatives in Steering Committees and supported people with lived experience to chair/facilitate Community Advisory Groups.

**The progress and outcomes of CEI initiatives should be understood.**

There is emerging evidence about changes in researcher attitudes and practices on CEI, and greater confidence and empowerment amongst communities in discussing their experiences and health needs. Beyond this, sampled awards were not routinely gathering information or feedback about how community participants were experiencing the research activities, and whether the CEI activities were fulfilling participants' expectations, challenging the power asymmetries that underpin health inequalities, and contributing to empowerment and social change processes. This requires establishing ongoing feedback loops with communities and developing community-led ways of capturing and analysing information that can support collective reflection, learning and adaptation.

**Sustainability requires attention.** With some exceptions there was limited evidence that awards were considering the extent to which CEI initiatives, such as Community Advisory Groups, would be sustained. The loss of CEI initiatives creates the risk of community mistrust and disengagement (including with future projects), particularly where projects are not able to reach the point where they can demonstrate impact and clear benefits to the community. To some degree, challenges with sustainability reflect the limitations of community engagement initiatives that are implemented through time-bound projectised approaches and are thus not embedded in the existing social context. As such, researchers should plan for sustainability from the outset, including by focussing on understanding and strengthening existing systems of participation, and embedding more inclusive ways of relating and working within the health ecosystem so that communities are able to take action for themselves.



## Further reading

Brunton, G. et al, 2017, 'Narratives of community engagement: a systematic review-derived conceptual framework for public health interventions', *BMC Public Health* (2017) 17: 944

<https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-017-4958-4>

Hickey G et al, 2022, 'What Does "Good" Community and Public Engagement Look Like? Developing Relationships With Community Members in Global Health Research', *Frontiers in Public Health*, Vol 9

<https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2021.776940/full>

Nelson, E. et al, 2021, 'Empowering Meaningful Community Engagement and Involvement in Global Health Research: Critical Reflections and Guiding Questions', *NIHR/ IDS*

<https://www.nihr.ac.uk/documents/empowering-meaningful-community-engagement-and-involvement-in-global-health-research-critical-reflections-and-guiding-questions/27361>

Pratt, B., 2019, 'Inclusion of Marginalized Groups and Communities in Global Health Research Priority-Setting', *Journal of Empirical Research on Human Research Ethics*, Vol. 14, No 2

[https://journals.sagepub.com/doi/10.1177/1556264619833858?url\\_ver=Z39.88-2003&rfr\\_id=ori:rid:crossref.org&rfr\\_dat=cr\\_pub%20%200pubmed](https://journals.sagepub.com/doi/10.1177/1556264619833858?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed)

Tembo, D. et al, 2021, 'Effective engagement and involvement with community stakeholders in the co-production of global health research' *BMJ*, Vol 372

<https://www.bmj.com/content/372/bmj.n178>