Community engagement in global health
addressing power, ownership, and invisible labour

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Community engagement in global health: addressing power, ownership, and invisible labour

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Community engagement and involvement in global health research has grown since the late 1950s,[1] which reflects a wider movement toward participatory decision making and increasing awareness of health inequities. Funders have increasingly prioritised community engagement and involvement, often as a requirement for grant applications with dedicated budgets and reporting.[2] Despite abundant guidance, the origins of community engagement are predominantly rooted in high-income countries, which perpetuates coloniality in its discourse.[3-5] Frameworks developed in high-income settings are frequently applied in low-income and middle-income countries (LMICs) without adaptation or critical examination of power, thereby leading to ambiguous methods and tokenistic practices of community engagement.[6]

Amid these challenges, researchers in LMICs are pioneering context-sensitive, power-aware methods that shift community engagement and involvement from transactional participation to relational knowledge coproduction embedded in the social and ethical fabric of local health systems.[7] One 4-year UK National Institute for Health and Care Research (NIHR)-funded study in two provinces in South Africa (appendix pp 1–2) that aimed to strengthen primary health care for people with multiple long-term conditions involved five community engagement and involvement components: involvement of people with lived experience of multiple long-term conditions from proposal inception, inclusion of one community lead as a co-investigator, engagement of provincial and district primary health-care stakeholders in learning collaboratives, clinical working groups to inform clinical content (eg, a clinical decision support tool and a training package),[8] and coproduction of an advocacy academy to strengthen the personal and advocacy capacity of people with lived experience of multiple long-term conditions.

This approach enabled coproduction of knowledge but also posed numerous challenges. First, despite deliberate efforts to dismantle power imbalances, little involvement of people with lived experience occurred in spaces with policy makers. South Africa's history of structural, socioeconomic, and racial inequities has entrenched bureaucratic hierarchies and positioned policy makers as centres of power, making contributing to these spaces difficult for the public, including the people with lived experience in our study.[9] Democratising coproduction requires strategies such as facilitating parallel consultations, rotating facilitation roles, carefully considering meeting locations, and providing pre-meeting preparation to under-represented groups to ensure equitable participation and true power shifts.

Second, although people with lived experience were engaged early, some of their key concerns were difficult to incorporate into the intervention. For example, chronic pain from arthritis was a priority identified by people with lived experience and confirmed by epidemiological data,[10] but treatment options in South African primary care were few. This example illustrated how systemic constraints can lead to selective uptake of community input and risk genuine engagement. To fully realise the commitment to involving people with lived experience from early phases of research, community contributions should be transparently tracked and revisited through all research stages, incremental changes should be acknowledged, and larger systemic barriers should be addressed through the entire research process.

See Online for appendix

Third, plans to form an advocacy academy with a diverse group of civil society members from two provinces were not feasible in our case. Many of the civil society members were overcommitted, and the community lead could not genuinely engage with them. Consequently, the advocacy academy comprised women (as more women seek health care than men in the context in which our research is done) referred by the civil society organisation from the province in which the community lead resided. This challenge of recruitment of a diverse group of people with lived experience across two provinces underscored the importance of context-specific community engagement led by locally based individuals with strong networks. Local ownership is crucial for authentic and sustained engagement.

Fourth, sustaining the advocacy academy over 4 years required continuous relationship building and sensitivity to members' changing health and socioeconomic circumstances. Their life events, including the violent

death of a member and other crises, blurred personal and professional boundaries. We, as the researchers leading the NIHR study, needed to respond with care, in a culturally appropriate manner. This need highlights the invisible emotional and ethical labour of community leads and the advocacy academy. This labour requires explicit recognition and resourcing. It asks researchers to engage with humility, share power, and be reflexive about the demands placed on community collaborators, and to honour their time, knowledge, and care as equally valuable contributions.

Fifth, the study required integrated co-development, trial recruitment, evaluation, dissemination, and ongoing stakeholder engagement, which placed pressure on the time available to build relationships. Managing these timelines across two provinces with distinct health system complexities resulted in suboptimal analysis of formative data. A key lesson learned was that researchers and funders must allow flexible, context-sensitive approaches, including adapting protocols, timelines, and budgets to account for the real work of coproduction.

These challenges demand moving beyond project-bound approaches to community engagement and involvement and towards long-term, trust-based partnerships embedded within local systems. Community engagement and involvement should be understood as a long-term relational process that is rooted in trust, reciprocity, and shared responsibility, rather than a one-off procedural requirement. Although many of these lessons are not new, they remain difficult to realise in practice. Funders can play a crucial role by supporting flexible timelines, adequate resourcing, and the often-invisible labour that genuine engagement entails. Researchers should remain reflexive, transparent, and committed to sustained collaboration. In doing so, community engagement and involvement can shift from rhetoric to a continuous practice that strengthens health systems from within.

We declare no competing interests. During the preparation of this work the authors used ChatGPT in order to summarise text from original notes taken during meetings and workshops reflecting on community engagement and and involvement methods. Summary notes were used as inspiration for the authors to write parts of the Comment, and were not copied verbatim. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

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