

Assessing and Measuring Community Engagement and Involvement in Empirical Health Research – A Scoping Review of Approaches in Low and Middle-Income Countries.

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Abstract- Background: Health research widely promotes community engagement and involvement, yet no previous studies have examined approaches, operationalisation, and efficiency across disciplines and regions. **Methods:** We conducted a scoping review with Joanna Briggs Institute guidance and reported in line with PRISMA-ScR. We searched Google Scholar, MEDLINE, EMBASE and CINAHL, and sampled grey literature from relevant organisational websites. We included empirical health research and grey literature published in English (January 2015–June 2025). References were screened against the inclusion criteria, and relevant data were extracted and charted deductively against Arnstein’s Ladder of Citizen Participation. **Results:** No grey literature met the inclusion criteria. Twenty-four peer-reviewed publications were included. 16 engagement approaches were identified. Diverse, yet context-specific. There is a noteworthy overlap in approaches, designs and methods. 87.5% were qualitative, 8.3% quantitative, and 4.16% mixed-methods. 79.5% were used to report findings from a research project, and 21% were used to discuss the process and practice of community engagement itself. The evidence base was geographically concentrated in sub-Saharan Africa (n=18), with limited representation from Latin America and other LMIC regions. 87.5% have engagement consistent with “citizen power” (partnership, delegated power, or citizen control), with communities participating as partners or having substantial influence over the direction of engagement, yet tokenistic practices persist. **Conclusions:** CEI in LMIC empirical health research is feasible and often substantive, but reporting and evaluation are inconsistent, and equity gaps persist. A clearer taxonomy, transparent documentation of decision rights and resourcing, and pragmatic measures of CEI quality and impact are required.

Keywords- Health services, power imbalances, participatory research, system research, LMICs.

I. INTRODUCTION

This paper reports a scoping review of community engagement and involvement approaches in empirical health research, examining how engagement approaches are conceptualised, operationalised and measured in low and middle-income countries. Numerous reviews [1 – 9] have examined community engagement and involvement (CEI), exploring effects on research outcomes [1,3], processes across varying socioeconomic contexts [4,5], the type of intervention in which it was carried out [2] and the research settings in which it was designed [6]. Findings from these reviews established that community engagement has led to measurable gains in global health research, including improvements in school-based health outcomes [1] and long-term family planning and reproductive

health outcomes [2], among other benefits. The value of CEI in health research has therefore long been established, especially when it prioritises local literacy and epistemology. However, the literature on the practice of CEI – including its approaches, operationalisation and measurements in low- and middle-income countries is sparse [9].

We designed a scoping review to identify the available evidence [10] on CEI practice in empirical health research and to capture context-specific practices and challenges [11]. By synthesising diverse evidence, the review seeks to identify CEI approaches and their operationalisation (including power dynamics in participation). The study’s goal is to identify the breadth of available evidence on this topic, which made a scoping review a particularly suitable design, allowing for exploring heterogeneous sources and contexts, unlike

systematic reviews, which focus narrowly on effectiveness or intervention outcomes [10].

Several frameworks have been established to guide CEI practice [12–16]. This review analysed the evidence using Sherry Arnstein’s Ladder of Citizen Participation [12], which was found to be well suited to our research objectives of assessing CEI strength, gaps and equity issues. According to Arnstein, “participation without redistribution of power is an empty and frustrating process for the powerless” (p.216) [12]. Her framework describes participation as eight rungs on a ladder: from non-participation (manipulation, therapy) to tokenism (informing, consultation, placation) and citizen power (partnership, delegated power, citizen control). Each level indicates the extent to which participants can influence decision-making processes during the CEI. Other frameworks [13–16] were not considered because they did not explicitly seek to address power redistribution issues. The International Association for Public Participation framework, for example, distinguishes between informing, consulting, involving, collaborating, and empowering as different levels of participation [13] and emphasises process quality, yet does not address the underlying power dynamics that might undermine community influence in research. Arnstein’s Ladder [12], on the other hand, explicitly focuses on power redistribution between institutions and citizens; however, in this review, the focus is on research stakeholders and communities. It offers a critical lens for evaluating power dynamics in community engagement practice. To achieve the review aim, the operationalisation of CEI is broken down into strengths, gaps, and equity issues.

The review aims to answer the following research questions:

1. What CEI approaches are used in empirical health research in LMICs between 2015 and 2025?
2. What are the strengths, gaps and equity issues in CEI practice in LMICs across disciplines and regions?

Objectives:

1. Map the range of CEI approaches used in empirical health research in LMICs.
2. Assess and analyse CEI strengths, gaps and equity issues across disciplines and regions.

Examining the range of CEI approaches in the literature has both intrinsic value and instrumental importance. First, it would allow for the identification of which CEI approaches are evidently strong in and of themselves in practice; second, it would help to understand how and why researchers conceptualised and practised CEI across disciplines and regions, thereby guiding policymakers and researchers in strengthening equitable community engagement strategies in health research.

II. MATERIALS AND METHOD

Theoretical frameworks used as an analytical lens

Sherry Arnstein’s Ladder of Citizen Participation outlines eight levels of citizen engagement, from non-participation (manipulation, therapy) to tokenism (informing, consultation, placation) to citizen power (partnership, delegated power, citizen control) [12]. Arnstein’s model suggests that meaningful participation occurs only when citizens have real influence, not just symbolic involvement [2]. Over the years, this concept has been widely used in many disciplines, including global health research, to assess democratic inclusion and stakeholder empowerment [23]. Scholars have argued that its focus on power redistribution makes it a robust analytical tool, though its rigidity in addressing digital or multi-actor participation is often critiqued [24]. Despite these arguments, Arnstein’s ladder remains central to understanding participatory governance dynamics and evaluating civic empowerment frameworks. It focuses on direct measurement of power-sharing among participants, making it a useful lens for understanding the power asymmetry or lack thereof in CEI research. It reveals whether engagement practices are genuine partnerships or merely symbolic consultations. By mapping CEI activities along the model, the study can pinpoint areas where empowerment is strong and where structural or procedural barriers still limit citizen influence.

Research design

The review design followed the Arksey and O’Malley [10] methodological framework, which was enhanced by Levac [11] and the Joanna Briggs Institute guidelines [25]. Reporting was carried out in accordance with the Preferred Reporting Items for Systematic Reviews and Meta Analyses Extension for Scoping Reviews PRISMA ScR checklist [26]. A completed PRISMA-ScR checklist was submitted in the supplementary document [S2]. No protocol was prospectively published.

Inclusion and exclusion criteria

The Inclusion criteria were developed by the primary reviewer (YA) and two senior co-reviewers (LD and PA) in line with the Population Concept Context (PCC) mnemonic [25] through intensive and iterative discussion. Research was included if CEI was a central engagement approach in an empirical health research design, or if it was a relevant grey literature from government and non-governmental organisations reporting on CEI in empirical health research. Only research reported in English were included because that is the working language of the reviewers. All included research defined, described, or, where applicable, the primary reviewer (YA) understood the research as CEI based on the National Institute for Health and Care Research (NIHR) definition “An active involvement of the community throughout the research process, using participatory approaches and working in partnership with all key stakeholders” [27]. We define the PCC framework as:

The population: were CEI participants, including patients, patients' relatives or carers, the public, policymakers, community advisory boards, community health workers, civil society organisations, local stakeholders, marginalised communities, academics, healthcare providers, and research teams.

The concept: was empirical health research involving CEI as a central engagement approach, in at least one phase of the research life cycle – priority setting, design/planning, conduct/analysis, or dissemination/implementation [28]. To enable a deep dive into the CEI, only qualitative, quantitative, and mixed-method research were included.

The context: was research conducted in LMICs between January 2015 and June 2025.

Reviews, including systematic reviews and scoping reviews, were excluded. Experimental designs, including randomised controlled trials, cohort studies, and case-control studies, were also excluded. Other exclusion criteria are studies focused on high-income countries; purely theoretical, editorial, or perspective pieces without empirical data, and studies published before 2015.

Decision rule

1. CEI + LMICs + 2015 - 2025? If no → excluded.
2. CEI + Empirical health research? If no → excluded.
3. CEI + commentary tied to an empirical study? If no → excluded.
4. CEI + ≥ 1 Engagement in the Research life cycle? If no → excluded.
5. CEI + Qualitative, quantitative or mixed method? If no → excluded.

Information sources and search strategy

The choice of search terms and search strategy was discussed and listed exhaustively in one of the review meetings by the primary reviewer (YA) and the supervisory reviewers (LD and PA), covering three groups of Medical Subject Headlines (MeSH) and related terms, including 1. Community Participation/ 2. Empirical Health Research/ 3. LMICs, and a list of 108 LMICs as defined by the World Bank [29]. A complete search strategy was presented in Table 1 and submitted in the supplementary document [S1]

A comprehensive, iterative literature search was conducted by one reviewer (YA) with support from library staff. Key databases were searched for published articles, including Google Scholar, MEDLINE, EMBASE, and CINAHL. Relevant grey literature was sourced from the websites of government and non-governmental organisations, including the National Institute for Health and Care Research (NIHR), The Global Health Network, and the World Health Organisation. To

ensure a comprehensive search, reference lists of relevant literature were also searched [30]

Data charting and analysis

A data extraction form was developed iteratively over a few days following extensive discussion among the primary reviewer (YA) and the two supervisory co-reviewers (LD and PA). This process aimed to enable the review to gather appropriate information on CEI to sufficiently address the research questions and to highlight the overall themes and features of the literature. After reading the selected documents, relevant information was extracted. Data extraction was largely deductive, guided by the Population-Intervention-Comparison-Outcome (PICO) and Arnstein frameworks to identify parent study and CEI characteristics, respectively. Primary reviewer (YA) conducted the data extraction and preliminary analysis, and the senior co-reviewers (LD and PA) proofread the analysis. The extracted information is presented in Table 1 and submitted in the supplementary document 2 [S2].

III. RESULTS

Screening and selection

The literature search yielded 1447 records: 499 from Google Scholar, 457 from MEDLINE (Ovid), 380 from EMBASE(Ovid), 86 from CINAHL, and 25 from grey literature and hand searches. Of these, 714 duplicates were identified and removed by an automated reference manager, COVidence. The primary reviewer (YA) screened the remaining references against the inclusion criteria using the decision rule outlined in the 'materials and methods' section. Articles were initially included if the title and/or the abstract contained the combination of such key words as 'community engagement', 'community-led', 'community participation', 'stakeholder engagement' etc, and 'community health', 'health system', 'health services', 'hypertension', 'diabetes', 'HIV/AIDS' etc, and 'LMICs' or one of the 108 LMICs e.g 'Bangladesh', 'Nigeria', 'Brazil' etc., as classified by the World Bank [29], the research was reported in English and published between 01/01/2015 to 01/06/2025.

Resulting manuscripts were assessed for full text and included if the paper in question was specific to the operationalisation of community engagement in empirical health research and met the decision rule outlined in the 'materials and methods' section. The selection process is summarised in the PRISMA flow diagram Figure 1 and submitted in the supplementary document [S1]

Descriptive mapping and synthesis of evidence

Twenty-four peer-reviewed publications met the inclusion criteria and were charted. No grey literature was included. The evidence base is recent, with most publications in the past five

years: seven in 2023 and four in 2024. There were fewer publications in the earlier years, with only one in 2016.

The research was geographically concentrated in sub-Saharan Africa (n=18). South Africa was the most common location, with six research studies [32–34,51,52], followed by Kenya with four research studies [39,41,47,50] and other countries with one research study each, including Uganda [31], Eswatini (Swaziland) [40], and Zimbabwe [48]. Some research (n=5) were conducted in South Asia: Bangladesh [37], India [35], Pakistan [42], Myanmar [36], and Nepal [54]. Only one study was conducted in Haiti [45], North America. This distribution indicates that CEIs in health research were predominantly conducted in African LMICs, with the least representation from Latin America.



Figure 2: The CEI research distribution by world region (made from mapchart.net)

When looking at the distribution of the included research by World Bank income group, studies were distributed across the upper middle income (6 studies), lower middle income (16 studies), and low income (5 studies), noting, however, that some studies involved two or more countries from different income regions.

Table 3: Geographic distribution of included studies by World Bank income classification

Income Group	Countries	Number of Studies
Upper middle income	South Africa	6
Lower middle income	Bangladesh, India, Kenya, Tanzania, Nigeria, Ghana, Nepal, Pakistan, Myanmar, Haiti, Zimbabwe, Eswatini (formerly Swaziland)	16
Low income	Uganda, Zambia, Chad	5

Of the included studies, 87.5% [31,37–41,43,46–51,53] were qualitative, 8.33% quantitative [52,54], and 4.16% mixed method [36]. Among the qualitative studies, there is a noteworthy overlap in the use of terminologies –

interchangeable use of design, methods, process, and means – to describe approaches to engagement in CEI. Participatory action research (PAR) represents both the CEI approach and a qualitative study design in four studies [32–34,42]. It uses a reiterative process of participatory learning and action cycles to implement training, while employing a qualitative approach to data collection and analysis. Community-based participatory research (CBPR) [44], even though it was qualitative in its approach to data collection and analysis, employing key informant interviews, focus group discussions, and thematic coding, served as the CEI approach on which the participatory process was organised.

Community-based action research (CBAR) [45] followed the same pattern. One study [36] employs a mixed-method design and participatory learning approach to promote community participation in a malaria control program [36]. Here, the parent study design (mixed-methods) and the CEI approach (participatory learning and action) are treated as two distinct entities, unlike in the qualitative designs earlier described. Two studies [52,54] employ a quantitative design and use stakeholder engagement as a distinct CEI approach to identify an efficient framework for designing a national need assessment to prevent cardiovascular disease in Nepal and an integrated knowledge translation framework to advance noncommunicable disease policy and practice in South Africa.

In the included studies, community engagement was a section or process of data collection to report findings about a research project in 79% of studies, while 21% discussed the process and practice of community engagement. Among studies discussing the process and practice of community engagement, 4.2% described how it is carried out in HIV/AIDS research, 4.2% in mental and brain health research, 4.2% as an ethnography to describe what happens during CEI using a comprehensive community participation framework, and 4.2% discussed community engagement as a strategy for disease eradication.

Participants and governance structures

The populations involved in the CEIs were heterogeneous, which reflects both our inclusion criteria and the breadth of CEI practice in empirical health research [55].

Across most included studies [37,38,43,44,48], principal investigators (PIs) played a central role in selecting participants for engagement activities. However, selection also appeared to be shaped by the purpose of engagement. In some studies, participant selection appeared biased and influenced by stakeholders with greater decision-making power, as participants reported during evaluation of the CEI. This caused a loss of trust in those selected and determined whose expertise and lived experience mattered.

Participants' groups involved included:

1. donor agencies and policymakers;
2. adolescents and young women;
3. community health volunteers, village health workers, and community health workers;
4. community leaders and community advisory boards;
5. civil society organisations and local stakeholders;
6. traditional and faith healers;
7. people living with chronic diseases; and
8. academics, healthcare providers, and research teams.

In terms of governance arrangements, some studies established new advisory committees at the start of the research [34,36,39,45,46,49,50,52,54], whereas others worked through existing community structures (including community-based organisations) to support recruitment and data collection [31,32,35,42–44,51,53]. Studies that created new committees were perceived as more inclusive of vulnerable groups and people lower in local social hierarchies; however, they faced challenges in sustaining participation compared with studies that used established community structures.

Community engagement and involvement approaches

The CEI approaches reported in the included studies were wide-ranging, and the terminology used to describe them was often overlapping or inconsistent. Sixteen different terms were used across the evidence base, sometimes to describe similar engagement activities. This overlap may create confusion by blurring the distinctions among research design, engagement method, and implementation process.

Terms used to describe CEI approaches included:

1. Community engagement
2. Community participation
3. Participatory action research
4. Community-based participatory research
5. Community-led engagement
6. Community-led participation
7. Stakeholder meeting
8. Stakeholder engagement
9. Stakeholder consultation
10. Participatory learning and action
11. Radio broadcast
12. Strategies
13. Processes
14. Means
15. Methods
16. TV films

Notably, although these terms were used to describe engagement, none of the studies explicitly labelled the engagement process as a “CEI approach”. Instead, the most recognisable participatory labels were participatory action research (PAR) [32,34,36,45], community-based participatory

research (CBPR) [31,33,47,45,50], and community-based action research (CBAR) [38,43,49,52]. Across these approaches, engagement goals were generally framed in terms of co-learning, co-creation and/or co-production. Studies often support communities in identifying priorities, shaping intervention design, and participating in reflection cycles as co-researchers.

Engagement was commonly delivered through workshops, interviews and focus groups, and was sometimes guided by broader theoretical or implementation frameworks.

Depth of participation

Assessing the depth of participation helps clarify how power is shared within CEI practice. We mapped each included study to Arnstein’s ladder to examine the extent of community influence and found that participation levels often varied within the same study. In other words, empowerment and consultation could coexist, depending on who was involved in engagement activities and what roles they assumed – illustrating how social hierarchies can shape power distribution in practice.

Overall, 21 of the 24 studies (87.5%) have engagement consistent with “citizen power” (partnership, delegated power, or citizen control), with communities participating as partners or having substantial influence over the direction of engagement. However, tokenistic practices were also evident, including within some studies that demonstrated high participation. Tokenism most often appeared in decisions about who could participate and what kinds of contributions were permitted.

For transparency, we treated studies as “high participation” when they described one or more of the following:

1. Co-production of research questions or priorities;
2. Collective decision-making (shared governance) over key research processes; and/or
3. Shared control over resources or implementation decisions.

We treated studies as “tokenistic” when engagement was limited to activities such as consultation meetings or advisory committees without shared decision-making power.

Although many studies articulated an intention to make participation inclusive and meaningful, tokenism still emerged in practice. This underscores a recurring challenge in CEI: stated commitments to democratic engagement do not always translate into consistent power-sharing among all participants and across all research phases.

Arnstein's ladder and the phase of research engagement

Engagement was conducted across multiple phases of the research process. More than half of the included studies involved communities throughout the research life cycle, and several show sequential engagement (planning/design and

conduct/analysis, or planning/design, conduct/analysis and implementation/dissemination). A smaller number reported engagement in a single phase (implementation only).

Table 4: Cross-tabulation of stages of engagement with Arnstein's level of participation.

Stage of engagement	Citizen control	Delegated power	Partnership
Planning/Design	1	4	14
Conduct/Analysis	0	4	11
Dissemination/Implementation	0	1	7
Evaluation	2	2	1

Relationship between CEI and parent studies

Across the included studies, CEI was integral to achieving the parent study's aims. For example, in the PrEP ambassador study in South Africa [47], CEI mechanisms such as peer support, safe spaces and sustained engagement were linked to improved initiation of pre-exposure prophylaxis. A qualitative study of mental and brain health in Kenya [39] used CEI, spanning planning, data collection, analysis, and dissemination. Another study evaluating CEI within HIV/AIDS research shows that engagement shaped the evaluation focus and enabled the team to assess community perceptions of fairness and inclusion. Taken together, these examples suggest that CEI was used to refine objectives, strengthen recruitment and retention, enhance cultural relevance, and surface context-specific implementation barriers

Patterns, gaps and equity

Parent study or research discipline?

While there is no distinguishing pattern or evidence of variation between research disciplines, the nature of intervention or disease with respect to the CEI approach, most studies were vertical designs, addressing a single public-health issue such as HIV/AIDS [31,44,47], hypertension control [37], or mental health promotion [39]. Others adopted a more horizontal approach, seeking to address broader health-system challenges (e.g., community-led action on non-communicable diseases) [35,38,52].

Given the scope and heterogeneity of the included evidence, we avoid making strong comparative claims. However, several descriptive patterns emerged across study types and contexts. First, CEI research was concentrated in HIV/AIDS, sexual health, family planning, non-communicable diseases and mental-health programmes, with few examples in other areas such as maternal and child health, communicable diseases beyond HIV, or environmental health. Second, most studies involved adults; only a small number focused on adolescents or youth. Third, community involvement was more frequently reported during planning and implementation than during evaluation or dissemination, suggesting that communities may

be excluded from final interpretation and knowledge translation. Fourth, several studies described structural constraints—such as limited funding, administrative hurdles, or limited community capacity—that restricted the depth of engagement. Overall, these patterns point to both strengths (sustained engagement within certain topic areas) and gaps (uneven coverage across health domains and populations, later-stage exclusion, and resource constraints).

IV. DISCUSSION

This scoping review mapped how community engagement and involvement (CEI) is conceptualised, operationalised and assessed within empirical health research conducted in LMICs between 2015 and 2025. Across 24 included publications, we found substantial diversity in the labels used to describe CEI, frequent overlap among “approach”, “method”, and “study design”, and wide variation in the extent to which communities held influence over decisions. These findings mirror broader observations that community-engaged research is widely endorsed but inconsistently defined, implemented and evaluated, which can make synthesis and comparison difficult across settings and disciplines [56].

RQ1: What CEI approaches are used in empirical health research in LMICs (2015–2025)?

The included studies employed a diverse list of participatory approaches, most commonly variants of participatory action research (PAR), community-based participatory research (CBPR) and community-based action research, alongside co-design/co-creation models and stakeholder advisory structures (community advisory boards, working groups). 16 approaches were singled out. Consistent with broader syntheses, this heterogeneity reflects both contextual tailoring and the lack of agreed-upon taxonomies and reporting standards for “community engagement” in research [56]. In practical terms, our mapping suggests that CEI in LMIC empirical health research is typically enacted through combinations of activities (workshops, iterative action-reflection cycles, focus groups, community dialogues, and advisory committees) rather than through a single, distinctive method. Therefore, comparability across studies is often driven more by the underlying intent or goal of the engagement activities and where engagement sits in the research lifecycle than by the label applied to the approach. Across the mapped studies, choices about CEI activities and mechanisms are shaped by pragmatic and ethical constraints typical of LMIC research settings – such as available time and funding, the need to reduce participation burden, literacy and language considerations, and the potential for stigma in sensitive topic areas. These considerations are consistent with broader guidance that engagement methods should be selected to fit the local context and planned early to avoid late-stage “add-on” participation [57].

RQ2: What are the strengths, gaps and equity issues in CEI practice in LMICs?

A key strength of the mapped evidence base is the prominence of higher-participation models (often reaching the “partnership” end of Arnstein’s ladder in at least one research phase in up to 87.5% of included studies), with multiple studies engaging in co-learning and shared problem-solving. Across the broader literature, upstream and sustained engagement is repeatedly linked to improved relevance and acceptability of research, strengthened trust, and practical improvements in recruitment and participation – particularly when engagement shapes questions, procedures and dissemination plans rather than being limited to one-off consultation [56–58]. Our synthesis supports these claims, as many included studies positioned CEI as integral to feasibility and implementation, reporting that engagement informed priority-setting, refined intervention components, and helped identify context-specific barriers to delivery.

However, important gaps and equity concerns were also evident. First, the geographic distribution was highly uneven, with most studies located in sub-Saharan Africa and limited representation from Latin America and other LMIC regions. Second, participation was not consistently equitable across studies: although communities were often described as “partners”, decision-making power could remain concentrated among principal investigators or institutional stakeholders, creating pockets of tokenism (consultation without shared governance over priorities, resources, or interpretation). This aligns with broader critiques that involvement initiatives can stall at a tokenistic level when organisations lack strategies to share power and support diverse participation [59]. Third, engagement tended to be more common in planning and implementation than in interpretation, evaluation, and dissemination, thereby risking the reproduction of extractive dynamics in which community contributions shape delivery but not the use of findings.

A further gap concerns the assessment of CEI itself. Few studies reported systematic measurement of engagement quality, costs, or longer-term impacts on communities and systems. This is consistent with evidence that methods for evaluating citizen/community engagement vary widely and often focus on perceived respect, influence, support, and impact, with limited standardisation across projects [60]. Similarly, mapping work on community-engaged research measurement highlights that many available tools emphasise process indicators and are difficult to compare across settings or over time [61]. Strengthening CEI practice in LMIC research, therefore, requires not only deeper power-sharing but also clearer reporting of engagement aims, roles, decision rights, resourcing, and evaluation approaches.

Implications for practice, funders and research governance

Taken together, our findings reinforce that meaningful CEI is feasible in LMIC empirical health research, but it is not automatic. To move participation toward the “citizen power” end of Arnstein’s ladder, research teams should specify (and document) who has authority over 1. priority setting, 2. protocol decisions, 3. access to and interpretation of data, and 4. decisions about dissemination and implementation. Funders and institutions can enable this by providing adequate time and budget lines for engagement (including compensation and capacity strengthening), supporting long-term partnerships beyond single grants, and requiring reporting on engagement roles and decision-making processes. These actions align with recent calls for upfront, sustained and inclusive engagement as a contributor to scientific, ethical and pragmatic value in health research [57,58].

Limitations and future research

This review has limitations typical of scoping methodologies: we aimed to map concepts and practices rather than estimate effects, and the included evidence was heterogeneous in design, reporting depth and terminology. Restricting studies based on methodologies, English-language publications, and the 2015–2025 period may also have excluded relevant CEI practice reported outside these limitations. Future research should (i) expand geographic coverage (including under-represented LMIC regions), (ii) consider broader methodologies (iii) examine how power-sharing is enacted and sustained over time (including resource control and authorship/ownership of outputs), and (iv) develop and test pragmatic, context-sensitive measures for evaluating CEI quality and impact, building on emerging work in engagement evaluation and measurement [60,61].

Author contributions

Conceptualisation, LD.; methodology design, YA.; LD.; PA.; data curation, YA.; formal analysis, YA.; information search, YA.; additional resources, LD.; PA.; visualisation, YA.; writing original draft, YA.; draft review and editing, YA.; LD.; PA.; supervision, LD.; PA.;

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The authors have declared that no competing interests exist.

Ethics and consent

Ethical considerations were addressed by reviewing only publicly accessible and published materials. Any cited unpublished or internal report was used under open-access licenses.

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Paper context

Main findings: CEI was widely used in health research but described with inconsistent terminology, uneven power-sharing and tokenistic participation.

Added knowledge: The review highlights that empowerment and consultation can coexist.

Global health impact for policy and action: Funders and institutions should resource and require transparent CEI reporting (roles, decision rights, compensation, governance, and evaluation), and research teams should seek to reduce tokenism, embed early, sustained, and equitable partnerships across the research lifecycle and beyond to improve relevance, trust, and uptake.

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