Ethics Training for Community Researchers Engaged in Participatory Research in Low-Income Countries: a scoping review

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Abstract
Global shifts toward community-engagement in research emphasize the importance of ethics training for community researchers. This is particularly critical in resource-limited settings where populations can be at greater risk for research misconduct. However, current standards and frameworks for ethics training beyond the Collaborative Institutional Training Initiative (CITI) in these settings are limited. This scoping review aimed to synthesize existing literature on ethics training for community researchers engaged in participatory research in low-income countries (LICs), identify gaps, and suggest pathways toward systematic improvements. We searched MEDLINE, Embase, PsycInfo, Global Health, CINAHL, Web of Science, and Scopus, with no date or language restrictions. Data were analyzed thematically to assess the types, levels, and geographical distribution of ethics training, as well as IRB approval processes. Of 4,006 publications retrieved, 194 met inclusion criteria. A total of 44/194 (23%) studies explicitly reported ethics training for community researchers, with significant variability in training intensity. Most studies originated from Uganda (n=78), Malawi (n=35), and Ethiopia (n=20). There is a critical need for standardized, culturally appropriate ethics training frameworks for community researchers in LICs engaged in participatory research. Developing such frameworks will enhance ethical standards, promote equitable partnerships, and protect vulnerable communities from research misconduct.

Key words: ethics training, participatory research, low-income countries, community research

Introduction

As global health research aims to become more accessible and community-driven, there is a growing need to strengthen ethics training as an integral part of the structured research process for all involved, from conceptualization to publication and dissemination.[1-3] Historically, there have been too many scenarios of hierarchical research programs with power dynamics that take advantage of marginalized communities, resulting in mistrust, exploitation, and inequitable outcomes, especially among those in low-income countries.[4-5] For amenable research questions, participatory approaches to research such as community based participatory research (CBPR) aim to reconcile these power dynamics and create a culture of shared collaboration that integrates researchers and community members alike as part of the research process.[6] However, ethics training for community researchers remains fragmented, with limited guidelines beyond the standard training for academic researchers.

The Collaborative Institute Training Initiative (CITI) online ethics training modules are a common source for ethics instruction for investigators, guided globally by ethical principles for medical research outlined in the *Declaration of Helsinki,* which was established in 1964 and revised in multiple iterations in the decades since.[1,7-8] The *Declaration of Helsinki* establishes comprehensive foundational ethical principles for all human subjects research, with a focus on the duty of researchers to protect the life, health, dignity, integrity, right to self-determination, informed consent, privacy, and confidentiality of personal information of research subjects. It also stipulates that the subject's welfare must always take precedence over the interests of science and society, and it provides that allowances are needed for vulnerable research participants. Other key international research ethics guides include the International Council for Harmonization Good Clinical Practice (ICH GCP) Guidelines which pertain to clinical trials, and the Council for International Organizations of Medical Sciences (CIOMS) International Ethical Guidelines for Biomedical Research Involving Human Subjects which were designed to assist countries in defining national human subjects research ethics policies.[9-10] Some key aims of CIOMS are to reflect the needs of low-income countries and support the application of ethical standards in local circumstances, while addressing implications for multinational or transnational research.

To augment extant foundational ethics codes, guidelines for ethics training for community researchers were developed over the last two decades. However, these were developed in high-resource settings, while none exist for resource-limited settings, where populations may be at higher risk for exploitation and other vulnerabilities.[11-14] Adequate ethics training could help support community researchers and participants in roles as active collaborators in shaping research agendas.

There has been a growing emphasis on community engagement in global health research.[14-15] Community-engaged and participatory approaches have emerged as a response to past criticisms of extractive research practices, representing a movement towards the decolonization of research to ensure communities are not merely "researched on" but are actively involved as co-partners.[3, 6-8, 14-15] Participatory approaches, such as CBPR, participatory action research (PAR), and photovoice are unique forms of community-engaged research that ensure longitudinal equity in community-based research.[6] CBPR emphasizes co-creation at every stage of research; PAR adopts cyclical processes of knowledge generation and action to influence systems-level change,

and photovoice empowers individuals to share perspectives through visual storytelling across cultural and linguistic barriers.[6] These unique forms of community-based research focus on addressing health inequities and help build sustainable partnerships between researchers and communities.[6]

While these approaches have become increasingly popular, there is no standardization in ethics training for community researchers in resource limited settings. Without sufficient and standardized ethics training, participatory methodologies risk reproducing the same imbalances of power they aim to dismantle. This scoping review aimed to synthesize and map existing ethics training for community researchers engaged in participatory research in low-income countries (LICs) and identify gaps, highlight best practices, and provide insights on how ethical training can be standardized.

Methods

A scoping review was completed to identify the breadth of community ethics training for participatory researchers in LICs. A protocol was published in Open Science Framework prior to search [https://doi.org/10.17605/OSF.IO/NUY35].

Eligibility criteria

Any manuscript that mentions utilization of the philosophy/methodology of participatory research and limited to LICs. We did not include any specific dates for search.

Information sources

On February 19, 2024, we performed a comprehensive search of multiple databases: MEDLINE, Embase, PsycInfo, Global Health, CINAHL, Web of Science, and Scopus. No date or language limits were imposed on the search. All search strategies are included in Supplementary material.

Search strategy

An iterative process was used to translate and refine searches. To maximize sensitivity, the formal search used controlled vocabulary terms and synonymous free-text words to capture the concepts of "community research" and "low-income countries." The search strategy was peer reviewed by a second librarian using the PRESS standard.[16] This scoping review is based on the framework described by the Joanna Briggs Institute (JBI).[17] Additionally, the reporting of this scoping review adhered to the PRISMA-ScR: Checklist and Explanation.[18]

Selection of sources of evidence

Two independent screeners reviewed the titles, abstract, and full text of the eligible articles that met inclusion criteria. Any conflicts were resolved through consensus among the screeners.

Data extraction and data items:

After screening, results were transferred to an excel file to synthesize extracted data items. The following items were extracted: location, IRB approval site/s, description of ethics training, and type of participatory research.

Results

The final search retrieved a total of 4,006 publications, which were pooled in EndNote 21 and de-duplicated using the Yale Reference Deduplicator. This set was uploaded to Covidence for screening which identified additional duplicates, leaving 1707 for screening. After a two-stage screening process, 578 potentially relevant articles were nominated for full-text review, after which 194 studies were confirmed to meet study criteria and underwent qualitative analysis (Flow Chart in Figure 1).[19-212]

(INSERT FIGURE 1)

Geographical distribution of ethics training

Review of country-level locations of study interventions showed that most articles meeting inclusion criteria were completed in Uganda (78), Malawi (35) and Ethiopia (20). The map below (Figure 2) illustrates how many articles met inclusion per LIC, with half of all LICs having less than five articles meeting inclusion (11/22) and two countries, Togo and Guinea-Bissau, with no published articles meeting criteria.

(INSERT FIGURE 2)

Distribution of IRB Approval

Articles were analyzed based on IRB approval, comparing high- and middle-income country approval vs low-income country approval (Figure 3). Of the 194 articles, 123 specifically mentioned IRB approval (63.4%) and 71 articles (36.6%) did not report IRB approval. We found 25/123 (20%) of articles cited IRB approval in academic partners outside of LIC without reporting any local approval process.

(INSERT FIGURE 3)

Distribution of Type of Participatory Research

Articles were grouped based on the type of participatory research methods. Most of the articles used at least some standardized process of participatory research. Three main groups were identified: CBPR, PAR, and photovoice (Figure 4). PAR was revealed to be the most common form of participatory research with a total of 76 studies. CBPR was the second most common form of participatory research with a total of 28 studies. Photovoice was the third most common with 11 studies. Several articles also described applying a combination of two or more participatory research approaches. Four studies used a combination of CBPR and photovoice and an additional four other studies used a combination of PAR and photovoice. One article referenced a combination of all three forms. Of note, fifty-three articles described techniques of informal participatory research which used atypical and non-traditional participatory research methods.

(INSERT FIGURE 4)

Distribution of ethics training

Of the 194 articles, 44 specifically mentioned ethics training in their research (23%). The 144 articles were analyzed on a 5-point scale based on level of intensity of ethical training (Table 1). Level I indicated the least descriptive form of ethics training, i.e. only have the word “ethics”

referenced in their training without further description. Level II referenced ethics training with some level of detail, most commonly discussing the importance of informed consent. Level III described having a dedicated workshop as part of the research training. Level IV described having a dedicated workshop as well as ongoing conversations that carried throughout the rest of the study that involved ongoing dialogue and feedback. Level V signified the highest intensity of ethical practice in their research project, including ongoing mentorship, local involvement, and creating ethics code of conduct. Most of the articles fit level I of ethical training (27.2%). However, 8/44 (18%) of articles were found to be of the highest level of ethical considerations, well above and beyond extant ethics training requirements, and 5 of these are included as key articles below with summaries of key principles (Table 2).

(INSERT TABLE 1)

Discussion:

This review outlined the current scope of reported ethics training for community researchers engaged in participatory research in LICs and found no consistent formal framework or standardization. Furthermore, although only 44/194 (23%) of included articles reported any ethics training for community researchers, we found these had significant variability in type of training. Finally, we found a gap in local IRB approvals with at least 20% reporting no local IRB approval process and 71/194 (37%) with no mention of any IRB approval.

Medical research and training are critical components of advancing global health equity.[8, 14-15, 214-215] As medical and public health interventions are advancing and expanding across borders, so too is the demand for rigorous ethical standards in research. Ethical frameworks are a cornerstone of research, vital to safeguarding the rights and wellbeing of participants as well as strengthening trust between researchers and the communities they serve.[8, 214-215] However, current ethics training in health care research varies widely across countries, largely due to disparities in resources, infrastructure, and investment in ethics.[14-15, 216] For example, ethics training for community researchers can range from regimented CITI training to limited or no formal ethics training, depending on the location and resource investment of research. Yet, ethics is a key part of research and thus must be better incorporated into community research.[214-216] Moreover, ethics training for community researchers engaged in participatory research approaches should adhere to their core values and adapt ethics training to meet community standards and not contrariwise.[6]

Standardization of ethics training for community researchers in participatory research, however, is not a new concept. Several existing frameworks and tools have been developed for CBPR in high resource settings and set standards for IRB approval in local community-based research.[11-12, 217] *CIRTification*, a community ethics training program developed at the University of Chicago Center for Clinical and Translational Science, recognized this need over two decades ago and have since trained over 7,000 individuals and 60 partner institutions in the United States.[11] The goal of this program is to bring equitable partnership between academic-community research collaborations. Similarly, the community partnered research ethics training (CPRET) at the University of Pittsburgh, developed a database of community ethics training resources including a certification process, that is available free online.[12] CPRET has been incorporated into local IRBs outside the University of Pittsburgh with a broad intent to establish recognition

for community focused training and disseminate resources. Finally, CITI training was adapted to include modules relevant to American Indian and Alaskan Natives in a study completed in 2014.[217] Researchers evaluated acceptability and comprehension of a new culturally relevant training module, finding participants who completed the new training module not only obtained higher scores on quizzes, but also reported higher scores on perception of overall relevance of materials and satisfaction.[217] Such community-derived and responsive research ethics tools would be beneficial in LIC settings.

This review is limited by the number of available manuscripts and may underrepresent the breadth of ethics training for community researchers that may not be published. Furthermore, this review is limited by the information available in the manuscripts we reviewed. Although we found 44 articles describing variable ethics training, we do not know if the remaining articles required training for community researchers. To understand any gaps in this review, a secondary analysis to corresponding authors will be necessary.

Conclusion:

It is paramount that any type of community focused research incorporates active engagement in ethical training, and particularly with participatory approaches, where equitable research design is a core tenet. Populations living in LICs are at greatest risk to research misconduct and are vulnerable to incentives that can temporarily improve quality of life significantly and bias research. However, global health research in LICs often fails to acknowledge this potential inherent bias, assuming a written consent for IRB approval justifies a fair acknowledgment of risks and benefits. Facilitating the co-development of ethics training specific to the appropriate local culture for community researchers is a necessary step to ensure ethically responsive research, as well as bidirectional understanding of the implications of medical research. A framework and resources are necessary for community researchers in LICs to help facilitate the co-development of appropriate ethics training. This will improve IRB oversight for this type of research, provide appropriate education that ensures comprehension across cultures, and protect vulnerable communities from the historic legacy of research misconduct.

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Declaration of interest statement:

The authors report there are no competing interests to declare.

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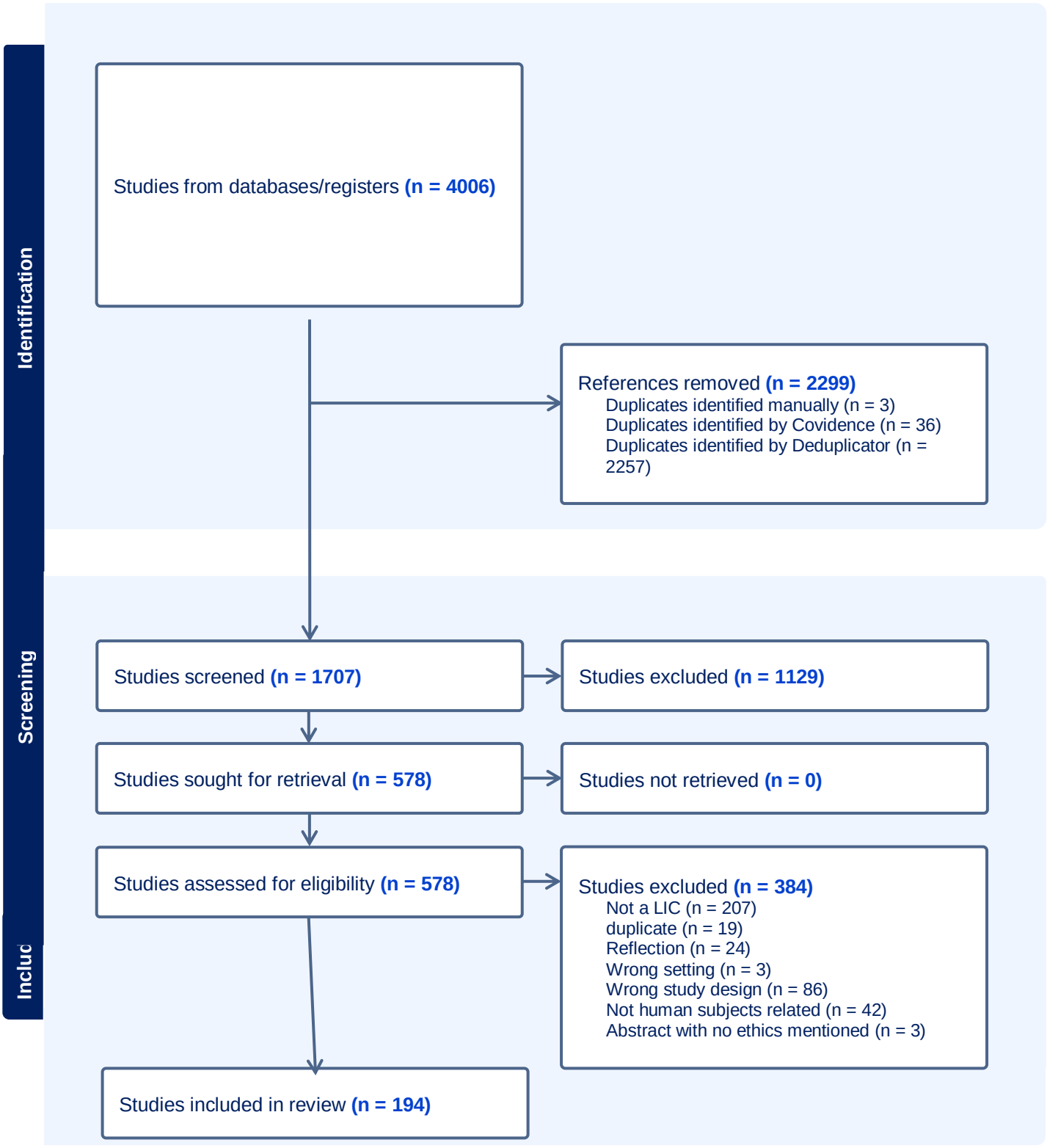
Table 1: Descriptions of 5 Point Category Scale describing ethics training

Category	Number of Articles (%)	Description
I	12 (27.2%)	Mentioned "ethics training"
II	8 (18.2%)	Specific description of ethics training (Example: written consent, etc.)
III	10 (22.7%)	Described having a dedicated ethics workshop as part of research training
IV	6 (13.6%)	Reported continuous workshops with ongoing mentorship
V	8 (18.2%)	Thorough description characterizing ongoing mentorship,

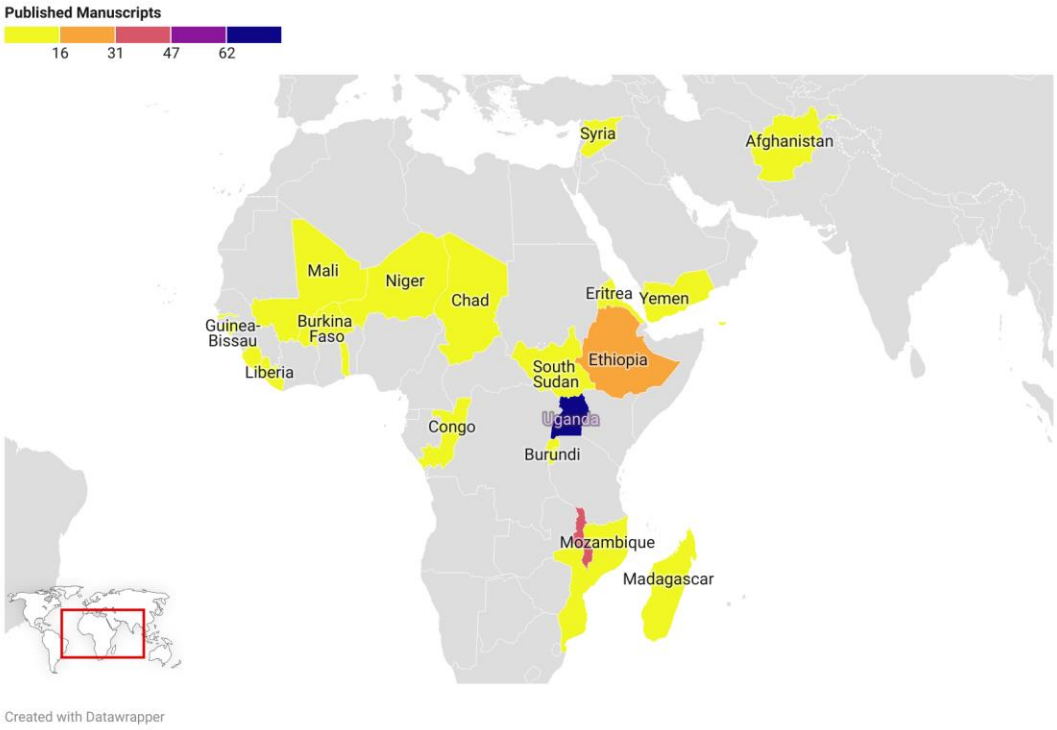
		local involvement, and creation of own ethics code of conduct
Total	44	

Table 2: Brief summary of key articles with significant ethics training

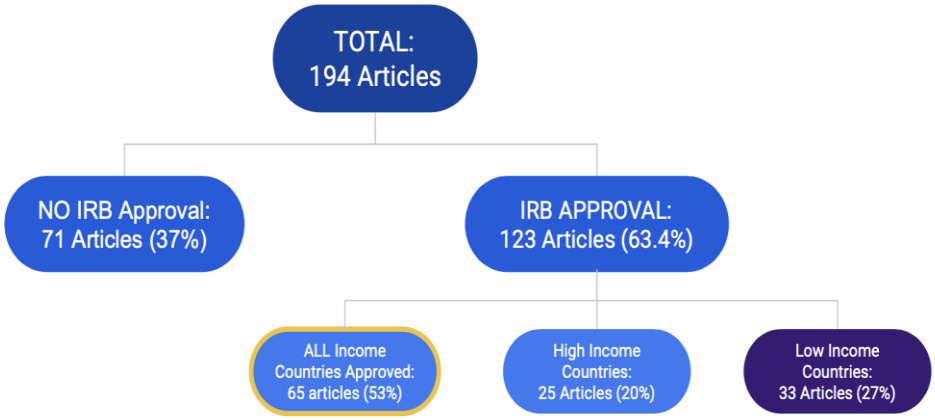
Study	Title	Location	Type of Ethical Training	Details
Ozano et al.[153]	Guiding principles for quality, ethical standards and ongoing learning in implementation research: Multi-country learnings from participatory action research to strengthen health systems	Liberia, Nigeria	PAR	Identified five additional guiding principles for quality, ethical standards and ongoing learning in PAR through analysis and reflections of existing PAR principles
Ebubedike et al. [63]	Ethics for educational research in regions of protracted armed conflict and crisis: a participatory community project in the Lake Chad region	Chad, Niger	Photovoice	Engaged in active discussion and negotiation of ethical principles at every phase of the research process Acknowledged the complexities of religion and culture in the research context Allowed community members to form their own ethics boards
Hunt et al. [96]	Ethical considerations related to participation and partnership: an investigation of stakeholders' perceptions of an action-research project on user fee removal for the poorest in Burkina Faso	Burkina Faso	PAR	Identified stakeholder perceptions and experiences through interviews to help guide the researchers' future ethical decision-making in this context
Hampshire et al.[90]	Taking the long view: temporal considerations in the ethics of children's research activity and knowledge production	Malawi, Ghana and South Africa	Informal Participatory Research	Allowed children to be involved in research process Adults facilitated trainings and workshops Children conducted their own focus groups and created their own ethical standards
Dowhaniuk et al. [61]	Setting a research agenda to improve community health: An inclusive mixed-methods approach in Northern Uganda	Uganda	CBPR	Bottom-up approach of participatory research to enable communities' members to identify their own research agenda aligned with community goals Extensive photography ethics trainings


Identification
Screening
Studies from databases/registers (n = 4006)
References removed (n = 2299)
Duplicates identified manually (n = 3)
Duplicates identified by Covidence (n = 36)
Duplicates identified by Deduplicator (n = 2257)
Studies screened (n = 1707)
Studies excluded (n = 1129)
Studies sought for retrieval (n = 578)
Studies not retrieved (n = 0)
Studies assessed for eligibility (n = 578)
Studies excluded (n = 384)
Not a LIC (n = 207)
duplicate (n = 19)
Reflection (n = 24)
Wrong setting (n = 3)
Wrong study design (n = 86)
Not human subjects related (n = 42)
Abstract with no ethics mentioned (n = 3)
Studies included in review (n = 194)

Participatory Studies in Low-income Countries



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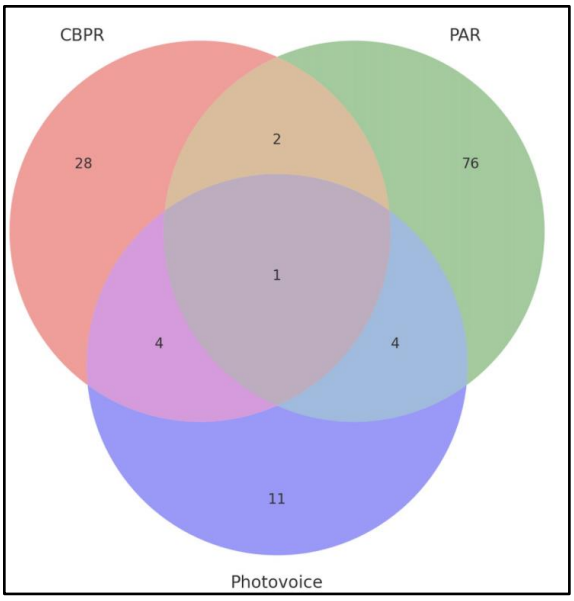


Figure Caption List:

Figure 1: Review Process

Figure 2: Geographical representation of articles that met inclusion criterion[213]

Figure 3: Distribution of IRB approval based on country income level

Figure 4: Venn Diagram outlining number of articles that used CBPR, PAR, and photovoice, or a combination of the three.