Community engagement in research in sub-Saharan Africa: approaches, barriers, facilitators, ethical considerations and the role of gender—a systematic review protocol

Claudine Akondeng,1,2 Wepnyu Y Njamnshi,1,3 Henshaw Eyambe Mandi,4,5 Valérie Ndip Agbor,6 Lucaho Engelbert Bain,4,7 Alfred K Njamnshi1,3,8

ABSTRACT

Introduction Meaningful community engagement (CE) is increasingly being considered the major determinant of successful research, innovation and intervention uptake. Community leaders, policy makers and funders have expressed the need to engage communities in research. CE in research empowers the host community to participate in addressing its own health needs and health disparities while ensuring that researchers understand community priorities. Thus, appropriate CE opens a unique way to promote coproduction, complementation and coevaluation, which may strengthen both the sense of inclusion, ownership and the effectiveness of the research life-cycle. The aim of this review is to synthesise available evidence on how to engage communities in research in a gender-sensitive, ethical, culture-appropriate and sustainable way in sub-Saharan Africa (SSA). This protocol has been developed following the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols and follows the guidance provided by the Cochrane Handbook for Systematic Reviews.

Methods and analysis A combination of key text words and medical subject headings such as ‘Community Engagement’ or ‘Community Involvement’ will be used to search 009 databases for all literature published between 1 January 2000 and 31 July 2021. Citations retrieved from database searches will be exported into EndNote X9 to remove duplicate citations and imported into Rayyan QCRI for screening. Two independent reviewers will conduct the screening and data extraction process. Disagreements between review authors will be resolved through discussions, consensus a third reviewer serving as a tiebreaker. The risk of bias will be assessed using the 10-item Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research. The three-staged process described by Thomas and Harden will be used for the thematic and narrative synthesis of findings.

Ethics and dissemination This is a systematic review which uses already collected data thus ethical approval not required. Findings will be published in an open access peer-reviewed journal and presented in relevant conferences and workshops.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Rigorous methodological and comprehensive search strategy which will be reported according to the preferred reporting items for systematic reviews.
⇒ Quality control will be ensured by using two reviewers at each stage of the study and a third reviewer as a tiebreaker.
⇒ We will conduct a study quality assessment to evaluate the credibility and transferability of the information synthesised.
⇒ Notwithstanding the strengths, the exclusion of papers not published in English and French may result in the loss of important findings.
⇒ The exclusion of commentaries might exclude some important articles.

INTRODUCTION

Community engagement (CE) in research can be defined as a process of inclusive participation that supports mutual respect of values, strategies and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest or similar situations to address issues affecting the well-being of the community of focus.1 Meaningful CE is increasingly considered the major determinant of successful uptake of research, innovation and intervention. Community leaders, policymakers and funders have expressed the need to engage communities in research.1 National and international bodies now recognise the importance of CE in research. However, CE guidelines are arguably unclear, making it difficult to implement and evaluate, potentially leading
to missed opportunities, squandered resources and poor decisions. CE in research encourages the host community to participate in addressing its own health needs and ensures that researchers understand community priorities. Indeed, existing evidence suggests that building trust and ownership of the research endeavour among stakeholders, especially the host community for the research project, is ideal to guarantee success and sustainability.

In 2009, the HIV Prevention Trials Network’s (HPTN) ethics guidance for research directly addressed CE as an ethical obligation in guidance point 3: ‘In order to ensure that HPTN research is appropriate as well as scientifically and ethically sound, relevant communities will be engaged in a meaningful process that will help guide the research from protocol development to dissemination of results.’ Thus, effective CE strategies have to be carefully integrated into the design, implementation, monitoring and sustainability phases of the research process.

Ethical CE entails upholding high ethical standards. When we engage the community, we make certain that marginalised or disempowered subgroups in the community are included in the research project. This has the potential to reduce trial attrition rates and improve uptake of trial outcomes. In addition, CE facilitates the community’s willingness to participate in future trials and other healthcare interventions. Appropriate CE promotes coproduction, coimplementation and coevaluation, which may strengthen both the sense of inclusion, ownership and the effectiveness of the research life-cycle. In contrast, an inappropriate CE strategy affects the project under investigation and jeopardizes the trust between the research team and the community in question.

Different organisations and research bodies use diverse strategies and protocols to engage communities in research activities. However, there is little information on the role gender plays in effective CE, thus justifying the need to assess gender dynamics across the entire spectrum of the research process in African communities. Gender-sensitive CE can be defined as approaches to engaging communities that promote gender equality and empowerment and respect existing context-specific gender norms. Developing guidelines of best practices to guide researchers in engaging communities in research activities in a gender-sensitive way in sub-Saharan African countries is imperative, as it stands out to be a key contribution to attaining the sustainable development goal 5 on gender equality.

The rise of community-based participatory research (CBPR) suggests that researchers are becoming more embedded in the communities they are studying and are committed to preventing harm and promoting social justice while conducting research, as well as developing caring relationships. This demonstrates the critical need for a radical rethinking of research ethics in theory and practice. Given that there are no easy answers or sets of rules that provide definitive prescriptions for action, instead of redressing ethical concerns around research, engagement activities can introduce new ethical and social challenges. Thus, an awareness of the potential complexities and conflicts and a willingness and ability among research collaborators to reflect on such ethical issues throughout the planning and conduct of CBPR are fundamental.

Culturally specific CE in research necessitates understanding the perspectives of diverse populations and disciplines and applying that understanding to the process of involving communities in a research project. For example, to be able to have a CE approach with an emphasis on cultural specificity and competency, the research team must be composed of research scientists and relevant stakeholders from that specific culture. Another critical question to consider during a culturally specific CE is whether the research questions or language used is culturally and linguistically appropriate.

Sustainable CE in research will imply engagement that does not focus solely on the research goals without developing a plan for capacity building and creating a sustainable system that will outlive the research funding period. Actively planning for and developing community capacity to ensure sustainability is especially important in research involving underserved populations and underrepresented minorities.

An example of a CE framework in research is the National Institutes of Health (NIH) Director’s Council of Public Representatives’ framework which targets investigators and communities. Its five core principles are strong community-academic partnerships, capacity building, equitable power, equitable responsibility and an effective dissemination plan. This framework proposed by the NIH intended to build public trust and create an evaluation matrix for future research.

Despite the available literature recommending CE in health research, there are still knowledge gaps in how communities might be best engaged in SSA. Indeed, CE is mentioned in published research to describe community entry, consent and study participant retention. However, the actual CE activities are generally not well documented. Also, the fact that communities are heterogenous suggests that CE activities will not produce similar results across different contexts. Particularly, in sub-Saharan African settings where there is a great community heterogeneity in terms of culture, this study proposes to synthesise available evidence across different countries in SSA on various practices for engaging communities in research and facilitators and challenges to this process. This review aims to synthesise available evidence on how to engage communities in research in a gender-sensitive, ethical, culture-appropriate and sustainable way. It will focus on health-related studies involving human subjects. We adopt the research concept as a cycle, where the available best practice guidelines shall inform how communities should be involved in the planning, execution, termination and data dissemination phases (publications and conference presentations) of the research project.
Objectives
The main objective of this review is to synthesise available evidence on how to engage communities in research in SSA. Specifically, this review aims to: (a) describe current practices in involving communities in research; (b) identify the barriers and facilitators in effectively engaging communities in research; (c) identify the ethical considerations required in engaging communities in research; (d) ascertain current trends on how gender is taken into account when engaging communities in research.

Research questions
1. What are the mechanisms and approaches used to engage communities in research in SSA?
2. What are the barriers to and facilitators in engaging communities in research in SSA countries?
3. What ethical issues should be considered when engaging communities in research?
4. What role does gender play when involving communities in research?

METHODS
This study will run from September 2021 to April 2022. We will conduct a comprehensive systematic review of available research in this domain and a qualitative synthesis of collected information towards developing a framework for CE in research in SSA. The protocol for this systematic review is developed following the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols16 (see figure 1) and follows the guidance provided by the Cochrane Handbook for Systematic Reviews.17

Eligibility criteria
In this systematic review, we will include peer-reviewed articles and grey literature. We will search for studies that include discussions and elements of CE within their research activity. While several models of CE in research exist, such as participatory research, empowerment evaluation, participatory or community action research and participatory rapid appraisal,1 we will include any study that uses any of these models. However, we will limit our search to research studies done in SSA no earlier than 2000. The rationale for restricting the search dates is that empirical research with focus on understanding engagement of communities in research is a recent phenomenon (2000 onwards). We think a 20 years search interval should be enough to provide relevant documented research findings to answer our review questions.

We will include original studies if they:
2. Contain research on CE or their research implementation involved engaging communities.
3. Include details on ethical issues involved in engaging communities.
4. Include information on the role of gender in CE.
5. Are written in English or French.

We will exclude:
1. Commentaries, personal views, letters to editors
2. Reviews and articles on CE in disciplines other than CE in community-based health research studies.

Information sources
Comprehensive systematic search
We will search MEDLINE, EMBASE, Global Health Library through OVID SP for all literature published from 1 January 2000 to 31 July 2021. Additionally, the Cochrane Library, PsychINFO, CINAHL, WHO Afro Library, WHO Global Index Medicus and the National Institute for Health Research will be searched to identify literature published from 2000 to 2021. We selected

![Image](http://bmjopen.bmj.com/) Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram illustrating the process of identification and inclusion of studies.
mostly databases that publish health-related research studies in SSA. While there are multiple health-related databases, we consider that the number of databases to be selected is comprehensive enough. A combination of key text words and medical subject headings such as ‘Community Engagement’ or ‘Community Involvement’ will be used to identify literature on CE in SSA. Moreover, we will apply a validated geographic search filter for SSA to improve the precision of our search. Table 1 shows the search strategy for MEDLINE that will be adapted to

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search other databases. Furthermore, we will scrutinise the references of selected articles for additional relevant articles missed by our search.

**Study records**

**Data management**

Citations retrieved from database searches will be exported into EndNote X9 to remove duplicate citations. The deduplicated citations will be exported to Rayyan QCRI for screening based on full-texts and abstracts. Rayyan is a mobile and web-based application that facilitates collaboration between authors involved in screening and selecting articles for final inclusion in a systematic review. Data from eligible full-text articles will be extracted using a predesigned Microsoft Office Excel Sheet.

**Selection process**

Two review authors will independently screen citations retrieved from database searches based on title and abstract. The titles and the abstracts will be screened by applying the previously stated eligibility criteria before assessing the full texts of selected articles for final inclusion in the review. Disagreements between review authors during the screening stage will be resolved through discussions and consensus. In case of non-resolution, a third reviewer will serve as a tiebreaker. Reasons for excluding references will be documented and reported in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram at the full-text assessment stage of the selection process (see figure 1). Only articles with concurrence between the two reviewers and confirmation of this concurrence by a third reviewer will be included in the review and will qualify for data extraction.

**Data item and extraction**

We will extract data into a prevalidated excel sheet which will collect data on: the surname of the first author, the language of publication, whether the article was peer-reviewed, CE reported in each article. We will extract data into a prevalidated excel sheet which will qualify for data extraction.

**Assessment of methodological quality and risk of bias**

We will conduct a study quality assessment to evaluate the credibility and transferability of the information synthesised. Two reviewers will independently assess the included full texts for methodological quality and risk of bias using the 10-item Joanna Briggs Institute Critical Appraisal Checklist for Qualitative Research. Each question in the Checklist will be attributed a score of one (if the response is ‘yes’), zero (if the response is ‘no’), and one half (if the response to the question is ‘unclear’). Thus, each study can have a maximum score of 10. Studies with scores from 3 to 5, 6–7 and 8 or over, will be classified as low-quality, moderate-quality and high-quality studies, respectively. Disagreements between review authors will be resolved by discussion and a third reviewer as a tiebreaker in the case of a non-consensus.

**Data synthesis**

The three-staged process described by Thomas and Harden will be used for the thematic synthesis of findings. First, four review authors will independently perform a line-by-line coding of aspects that are related to barriers to and opportunities of CE, ethical considerations in CE and gender-related issues to be considered in CE. The review authors will manually assess the consistency of interpretation and any disagreements will be resolved by discussion or consensus. Second, we will evaluate similarities and differences between codes through an iterative and inductive process. Finally, we will condense identified descriptives into analytical themes.

**Patient and public involvement**

No patients or members of the general public will be involved in this study.

**Ethics and dissemination**

This systematic review will not need ethical approval because it will retrieve and synthesise data from already published studies. However, appropriate public health (COVID-19) measures will be taken when accessing public spaces for grey literature. Study results will be disseminated through scientific publications in an open-access peer-reviewed journal and presented at relevant local and international scientific conferences.

**DISCUSSION**

A similar review conducted documented many health systems interventions at the community level but did not have a standard definition or reporting guidelines on describing community participation. Only a few studies in the review made references to CE definitions or frameworks. A more recent review describing patient–public engagement (PPE) strategies for strengthening health systems in SSA found that tokenism rather than actual participation is the main characteristic of PPE in SSA. Their research focused on PPE and its ability to strengthen health systems. Our review goes beyond PPE to evaluate diverse CE in community-based participatory research out of clinical settings. This study intends to describe current practices, barriers to and opportunities for engaging communities in research in SSA. In addition, we propose to create a checklist of minimum ethical issues to consider when engaging communities in research and describe specific considerations for gender-inclusive CE in research.

Generally, in research, the goals of CE are synonymous to achieving study objectives, particularly in terms of promoting study recruitment and retention. Nevertheless, in low-income contexts in particular, economic, educational and power inequalities between the research team and the host community, could serve as barriers...
and build distrust in the communities leading to study refusals and withdrawals, premature study closures, and inadequate sample sizes which cumulatively compromise the ability to generate high-quality evidence. In community research, researchers are sometimes obliged—prompted by demands from communities—to address the burden of disease that is unrelated to the area of research, which potentially diverts resources away from achieving study aims. For example, factors such as poverty, malnutrition, lack of healthcare infrastructure and high disease burden bring additional challenges which may be unrelated to the research but demanding attention during the research process. Involving communities from the design phase of the research will thus enable them to present their disease burdens and other important issues for consideration. This study will synthesise available literature in SSA on how these challenges have been overcome and identify mechanisms to facilitate CE in low-income and middle-income settings. By exploring the mechanisms that inform community and stakeholder participation in research governance and results uptake processes, it will contribute to raising stakeholder awareness on ethical and gender sensitive CE.

Meaningful CE in research aims to address ethical issues including trust and mutual respect, community benefits and risks of participation to build a better understanding of the research endeavour. It enables power-sharing, colearning, coproduction and sets realistic expectations for what a project can deliver to a community within set timelines. From this review, a few ethical concerns for CE in SSA settings will be summarised. It is important to recognise that CE occurs in settings that could either be ‘invited spaces’ with unequal power dynamics where communities are engaged on the research team’s terms, or ‘created spaces’ that emerge organically to give communities greater ownership of the research process. The purpose, however, is to create enabling environments where people can freely express themselves on the research agenda and the analyses of the research outcomes. Moreover, to varying extents, some communities may have unrealistic expectations of what benefits or compensation the community and community partners may receive. It is in these ‘spaces’ that consultative process start in the initial stages of CE to work out meaningful forms of reciprocity that researchers can offer in a time-bound project. This study will review the ethical challenges of engaging communities in research in SSA and synthesise how these challenges are overcome in different settings.

Even though there has been a lot of research on gender and CE in research, only a few studies have shown how gender plays a role in involving communities in research. The men, who are generally the household and community decision-makers, are most often consulted on whether or not their households or communities would engage in the study. In reality, decision-making is much more complicated, with many women subtly influencing the outcome. With the goal of having gender-inclusive CE in research, this study will examine current trends of gender considerations in involving communities. The findings of this study will also be useful because of the scarcity of literature on gender dynamics in engaging communities in research.

The findings of this study will guide policymakers and support researchers to improve CE planning as well as informing the design of other empirical studies to investigate gender roles in CE in research.

Strengths and limitations of the study

Strengths of the study
A key strength of this review protocol is the rigorous methodological and comprehensive search strategy that will enable us to maximise the potential of knowledge engagement in the study. In addition, this study will be innovative by synthesising the best CE strategies in research in SSA.

Another strength of the study is its effort to assess ethical and gender-inclusive CE strategies in SSA countries. This data will contribute to filling current knowledge gaps. Methodological quality assessment of the study which will enable us to evaluate the credibility and transferability of the information synthesised. Furthermore, a flexible approach to the search terms and keywords used enable a maximum number of possible studies to be identified for the review.

Limitations of the study
Notwithstanding the outlined strengths, some limitations are imminent. First, excluding commentaries, personal reports and papers that have not been published in English or French may result in the loss of important findings. Second, given the breadth and the complexity of definitions for CE and research, and the existence of a variety of community involvement in research strategies, careful considerations need to be given to ensure that best evidence is identified and included to answer the research questions.

PERSPECTIVES
The short-term impact of this project is that its results will serve as baseline data to inform stakeholders on how to engage communities in a gender-sensitive, ethical, culture-specific and sustainable way. A medium-term opportunity will be to evaluate how these strategies are being implemented in the different structures such as ethics review boards, civil society organisations and research organisations across different SSA countries.

Author affiliations
1Clinical Research Department, Brain Research Africa Initiative, Yaounde, Cameroon
2Department of programs, Cameroon National Association for Family Welfare (CANNFAW), Yaounde, Cameroon
3Education and Training department, Education and Learning for All (ELFA), Yaounde, Cameroon
4Triangle Research Foundation (TRIFT), Limbe, Cameroon
5Department of Vaccine Research Development, Coalition for Epidemic Preparedness Innovations (CEPI), Oslo, Norway
REFERENCES


