



OPEN LETTER

REVISED Multidisciplinary approach to community engagement in global public health research [version 2; peer review: 2 approved]

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Abstract

Recently, there has been a renewed interest in the role of community engagement in knowledge production and ethical issues such as 'helicopter research', indicating exploitative research activities of some researchers as well as short-term relationships with research communities especially in low- and middle-income countries. This approach is detrimental to both communities and the larger scientific community as this may breed mistrust. Major institutions such as the National Institute of Health and Care Research in the United Kingdom have highlighted the importance of community engagement as a tool to improve the reach, quality, and impact of the research by incorporating the voices and concerns of marginalized communities. Similarly, in its 2022 guidance, the American Society for Human Genetics (ASGH) highlights the need to address underrepresentation in genomics research through community engagement. Establishing ethical and meaningful long-term relationships can be challenging especially for researchers who are not members of the community or those from other countries. This article describes how 'community-engaged research' can address some ethical challenges in global public health in different cultural settings.

Keywords

Community engagement, research integrity, ethics, global health, Africa

Open Peer Review

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Any reports and responses or comments on the article can be found at the end of the article.

This article is included in the [Global Infectious Disease Ethics Collaborative \(GLIDE\)](#) gateway.

GLIDE
Global Infectious Disease Ethics Collaborative

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Author roles: **Adeagbo O:** Conceptualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Hlongwa M:** Writing – Original Draft Preparation, Writing – Review & Editing; **Tleis M:** Writing – Original Draft Preparation, Writing – Review & Editing; **Dubey P:** Writing – Original Draft Preparation, Writing – Review & Editing; **Afifi R:** Writing – Original Draft Preparation, Writing – Review & Editing; **Butali A:** Writing – Original Draft Preparation, Writing – Review & Editing

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REVISED Amendments from Version 1

We have teased out the key messages in the conclusion and added headings as suggested by the reviewers.

Any further responses from the reviewers can be found at the end of the article

Rationale for Ethical Community Engagement in Global Health Research

Community engagement (CE), defined as a participatory approach that involves communities in decision-making, planning, design, governance, and implementation of programs and interventions¹ has been studied and utilised extensively at multiple levels of health research¹⁻³. Many institutions, including the National Institute of Health and Care Research (NIHR) in the United Kingdom have highlighted the importance of CE as a tool to improve the reach, quality, and impact of the research by incorporating the voices and concerns of marginalized communities⁴. The concept of community engagement builds on existing ethical guidelines and frameworks for ethical research and participatory action research techniques, resulting in some variability in how it is defined, developed, and implemented in global public health⁵. The growing recognition of ethical considerations in research has strengthened the case for many funding institutions, international research ethics guidelines, and research institutions to begin advocating and oftentimes mandating community engagement incorporation in new studies⁴. As research progresses to reflect greater attention to ethical frameworks and the ways in which communities can be harmed or exploited in this work, CE has been a critical tool in providing insight and frameworks to navigate these challenges effectively².

Recently, there has been a renewed interest in the pivotal role of community engagement in knowledge production and addressing ethical issues such as the problematic phenomenon known as ‘helicopter research’. This term refers to exploitative research activities conducted by some researchers as well as short-term relationships with research communities especially in low- and middle-income countries (LMICs)⁶. For example, a researcher collects data from a certain community that benefits their individual career, and they never contacted the community again. Such an approach is not only detrimental to communities involved but also erodes trust within the larger scientific community. In order to rectify these concerns, many scientific institutions have advocated for a shift towards more community-engaged research (CEnR) to address underrepresentation, health disparities, research injustices, and to promote ethical partnerships and recognise collective expertise of all stakeholders throughout the research cycle⁷. For example, in its 2022 guidance, the American Society for Human Genetics (ASGH) highlighted the need to address underrepresentation in genomics research through community engagement⁷. However, establishing ethical and meaningful long-term relationships can be challenging, particularly for researchers who are not members of the community or those from other countries.

Brief Report from a Community Engagement Panel at Oxford Global Health and Bioethics 2023 International Conference

At the just concluded Oxford Global Health and Bioethics International Conference (June 26–27, 2023) organized by the Ethox Centre/Wellcome Centre for Ethics and Humanities at the University of Oxford and John Hopkins Berman Institute for Bioethics, a group lightning talk (panel session) entitled “*Community Engagement and Ethical Issues in Global Health Research*” was organized. This panel session was well attended both physically and virtually signifying the importance of CEnR among global health researchers and funders. Five speakers in the session presented CEnR from different research settings and perspectives. Facilitators and participants stimulated discussions on how ‘community-engaged research’ can address some ethical challenges in global public health, e.g., ‘helicopter’ or ‘colonial’ research, underrepresentation in genetics and genomics research, research in humanitarian settings etc. In their intervention study among young Syrian refugees living in Lebanon, Tleis *et al.* described how the formation of Community Alliance Committee (CAC) reduces power inequities and acknowledging capacity, knowledge, and expertise within community. The CAC members questioned the original plans for recruitment, provided feedback and edits to all data collection instruments, interrogated the reasoning behind intervention processes, and provided important contextual cues that guided decision making around the collection of hair to measure cortisol in this religious community. They also highlighted how the political landscape in Lebanon generated some concerns around legality/illegality of Syrian refugees/asylum seekers that eventually affected the participation of some participants in their research. Similarly, Dubey and Afifi emphasized the importance (including challenges) of ‘trust’ building with community-based organisations) in their study that explored the lived experiences of menstrual hygiene management among transgender and non-binary people in urban India. They highlighted their challenges especially the push-back they received from the community. Due to the initial decline from community members, the authors reflected on their positionality and how it affected their initial relationships with the community. Through reflexivity and positionality, *trust* was a key element in facilitating ethical and effective research in their project.

In their study of the impact of secondary findings (SF) among orofacial cleft (OFC) families in Africa, Butali and Oladayo investigated participants consent, concerns, and opportunities to access novel aspects of SF in their OFC cohort and, the role of providers and community in improving genomic education, knowledge, and utilisation using whole genome sequencing. Their presentation focused on global ethical debate in genomic research and lessons learned from their cleft cohort, providers, and community gatekeepers. Applying the *utilitarian principle*⁸ (greater good for the majority), Adeagbo explored community workers concerns about a home-based HIV testing trial that they implemented in poor communities in rural South Africa. Although HIV testing uptake increased by 55% among men (target population) due to the financial incentives

(R50[\$3] food vouchers) offered, some of the implementers (who were also community members) faced serious resentment (including verbal abuse) from participants and community members because of the financial incentive they distributed during the study. Adeagbo raised some ethical questions about ‘greater good’ in this context. Is it ‘morally right’ to ignore the safety of the implementers in this context since the financial incentive has achieved the ‘greater good for the target population’ in the community? How do we (global health researchers) ensure the safety and wellbeing of our local partners in a situation like this?

Finally, presenting data from multiple community-based HIV projects and existing literature reviews, Hlongwa and Adeagbo shed light on the scarcity of community-engaged research on pre-exposure prophylaxis (PrEP) among adolescent boys and young men (ABYM) in South Africa. Despite South Africa’s roll-out of PrEP in 2016 and growing research on this topic, there remains a concerning dearth of community-engaged research focused on PrEP and post-exposure prophylaxis among ABYM compared to similar research among adolescent girls and young women. They teased out some of the ethical challenges of one-sided research and how closing this knowledge gap is critical to addressing an important blind spot in the response to HIV. They argued that addressing this knowledge gap is critical because it hinders efforts to combat HIV/AIDS as a public health threat. Thus, to accelerate the pace towards ending HIV/AIDS as a public health threat, they argued that it is crucial to tackle the underlying reasons for the current disparities in HIV research efforts and ensure a more inclusive and equitable approach to understanding and preventing HIV transmission among ABYM.

Conclusion

In sum, the different studies presented in the panel session showed the importance of CEnR in addressing health inequities and promoting ethical partnerships. Particularly, they highlighted the benefits of ethical partnerships and collective expertise between the host community and researchers, as well as the need to magnify underrepresented or marginalised population voices through CEnR. It also flipped the narratives about who the ‘expert’ is in global health research. The shared value of expertise between researchers and the host community could facilitate trust and a sense of belonging for both parties. This could have policy implications for global public health research and partnerships. It is then safe to argue that mutual respect (including cultural humility) and benefits are key elements of CEnR to co-produce knowledge with the communities in global public health research. We call on researchers (particularly global health researchers) to conduct ethically and mutually beneficial research while involving their research communities in the research process.

Data availability

No data are associated with this article.

Author contributions

OAA wrote the first draft of this manuscript with support from MT, MH, DP, RA, and AB. OAA, MT, MH, DP, RA, and AB provided critical comments which improved the scientific quality of the manuscript. All authors approved the final draft of the manuscript for submission.

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Brenda Yankam 

University of Nigeria, Nsukka, Enugu, Nigeria

All comments have been well addressed.

Hence, the manuscript should be accepted as it is.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Community engagement, infectious diseases, HIV/AIDS, Quantitative and qualitative data analysis

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

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The revised article is okay.

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

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Thank you for the opportunity to review the open letter, Multidisciplinary approach to community engagement in global public health research.

The document provides important insights into community engagement research and the ethical issues involved therein, particularly through a multidisciplinary lens. Examples of community engagement research in Lebanon, India, South Africa and other parts of Africa were discussed.

The document is good but can be better. My suggestions on how to improve the quality of the document is as follows:

1. While the objective of the writing was clearly laid out in the abstract, this was not followed through in the body of the writing. Objective(s) of the writing should be included within the body of the writing.
2. A clear link should be established between the panel session that was mentioned in the writing and the writing. The answer to this question "Why the specific panel session and not any other?" will help to shed more light on the missing link. In other words, the importance of the panel session to the writing must be clearly demonstrated.
3. Similarly, the relationship, if any, between the five panelists and the subsequent studies that were cited should be discussed.
4. The names of the five speakers of the panel session should be mentioned in order to give more depth of meaning to the writing.

Is the rationale for the Open Letter provided in sufficient detail?

Partly

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Sociological research, Criminology and Qualitative research.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 23 Nov 2023

Oluwafemi Adeagbo

Dear Reviewer, Thank you very much for your insightful comments. We have revised the manuscript as suggested.

Thank you

Competing Interests: No competing interests were disclosed.

Reviewer Report 19 October 2023

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The open letter titled "Multidisciplinary approach to community engagement in global public health research" provides valuable insights into the importance of community engagement in research and highlights key ethical challenges.

The study addresses a highly relevant and timely topic in the field of global public health. It effectively discusses the ethical considerations related to community engagement, 'helicopter research,' and underrepresentation in research.

The inclusion of case studies from the Oxford Global Health and Bioethics International Conference adds practical depth to the discussion. These case studies illustrate the real-world application of community engagement principles, making the content more relatable and insightful.

The study adopts an interdisciplinary perspective by considering issues in genomics, HIV research, and other areas of public health. This multidisciplinary approach adds breadth to the discussion and showcases the universal relevance of community engagement.

The study does a commendable job of addressing ethical considerations in research, including the potential harm to communities, power imbalances, and the need for mutual respect and cultural humility. These discussions are crucial for ensuring ethical and responsible research practices.

My recommendations are as follows

1. While the study provides valuable information, there is room for improvement in terms of clarity and structure. The letter could benefit from a more structured approach, with clear section headings and a logical flow of ideas. This would make it easier for readers to follow the arguments and key points.
2. The letter mentions concepts like 'helicopter research,' but it would be beneficial to provide more detailed explanations and examples to ensure that readers who may not be familiar with these terms can fully grasp their significance.

Is the rationale for the Open Letter provided in sufficient detail?

Yes

Does the article adequately reference differing views and opinions?

Yes

Are all factual statements correct, and are statements and arguments made adequately supported by citations?

Yes

Is the Open Letter written in accessible language?

Yes

Where applicable, are recommendations and next steps explained clearly for others to follow?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Community engagement, infectious diseases, HIV/AIDS, Quantitative and qualitative data analysis

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 22 Nov 2023

Oluwafemi Adeagbo

Dear Reviewer, Thank you very much for your insightful comments. We have have revised the manuscript as suggested. We have also checked the manuscript for logical flows. We highlighted some of the changes made in the revised manuscript. Thank you Oluwafemi Adeagbo PhD

Competing Interests: No competing interests were disclosed.
