

The role and recognition of community health workers in research—a global survey



Community health workers (CHWs) have essential roles in the delivery of health services and have increasingly been the focus of research over the last few decades.¹ Despite this, CHWs are often excluded as authors and key decision makers in this research, typically confined to operational tasks such as data collection, with limited involvement in strategic decisions about study design, analysis, and dissemination.²

This exclusion potentially hinders the quality, relevance, and effect of CHW-related research. As trusted community members with a unique understanding of the local context, meaningful involvement of CHWs can enhance various aspects of research design, processes, and outcomes. For instance, they can facilitate the choosing of suitable methods for the context, ensure inclusion of under-represented populations, provide contextual interpretation for data analysis, and share findings within their communities in a timely manner.^{3,4} Furthermore, coauthorship serves as a significant marker of recognition, promotes equity by acknowledging diverse contributions, fosters a sense of shared ownership and responsibility, and cultivates inclusive research practices. Additionally, authorship can be leveraged by CHWs for professional development and future research opportunities. Despite this, there is no global estimate of the rates of CHW coauthorship on studies related to their profession.

We aimed to address this gap with a two-phase research approach. In phase one, a scoping review was performed to identify all publications about CHWs between Jan 1, 2018, and July 20, 2023, yielding 1894 studies. In phase two, an email survey was sent to corresponding authors of the included studies, requesting them to indicate which, if any, of the authors in their manuscript were CHWs. Ten CHWs were involved in this study, including as coauthors of this letter.

The survey received a 48% response rate (900 responses of 1875 survey invitations), consistent with the response rate in primary care literature that ranges between 10.3% and 61%.⁵ Our findings revealed that only 15% of the studies included at least one CHW as a coauthor (138 of 900). Furthermore, only 32% of the studies identified in the scoping review explicitly acknowledged CHWs in the formal

acknowledgments section (609 of 1875). Full details of the scoping review and survey method are provided in the appendix.

The low rate of CHW coauthorship on studies related to their profession suggests that traditional notions of authorship, often focused on stringent academic contributions, might not capture the diverse range of expertise and essential roles that contribute to impactful research (acknowledgment) and that CHW participation in all facets of research could be better facilitated (inclusion).

The absence of formal acknowledgment of CHWs within research is a wider challenge in global health research, which often fails to adequately recognise or involve non-academic actors.^{6,7} One potential reason might be the stringent guidelines concerning authorship attribution. The widely adopted International Committee of Medical Journal Editors (ICMJE) ascribes authorship to those who make substantial contributions to the design, conduct, and reporting of research.⁸ This statement can inadvertently exclude CHWs by prioritising scholarly contributions over technical tasks such as data collection, intervention delivery, and participant recruitment. We recommend this criterion be amended to better reflect the global health landscape and include community-based and non-academic research partners as active and important contributors, thus warranting authorship. For example, the Dialogue, Evidence, Participation and Translation for Health programme at the London School of Hygiene and Tropical Medicine has reframed its guidelines to explicitly invite non-academic partners to coauthor work through a transparent and inclusive decision-making process.⁷

Furthermore, barriers to the appropriate acknowledgment of non-academic actors exist within the academic community. For example, Cobey and colleagues⁶ found that 17% of Editors-in-Chief believed that patients involved in research should have an academic affiliation to publish, highlighting a potential bias toward scholarly research input within the editorial system.

The second challenge concerns barriers to inclusion across the research process, such as language differences, little training in research methods, and

See Online for appendix

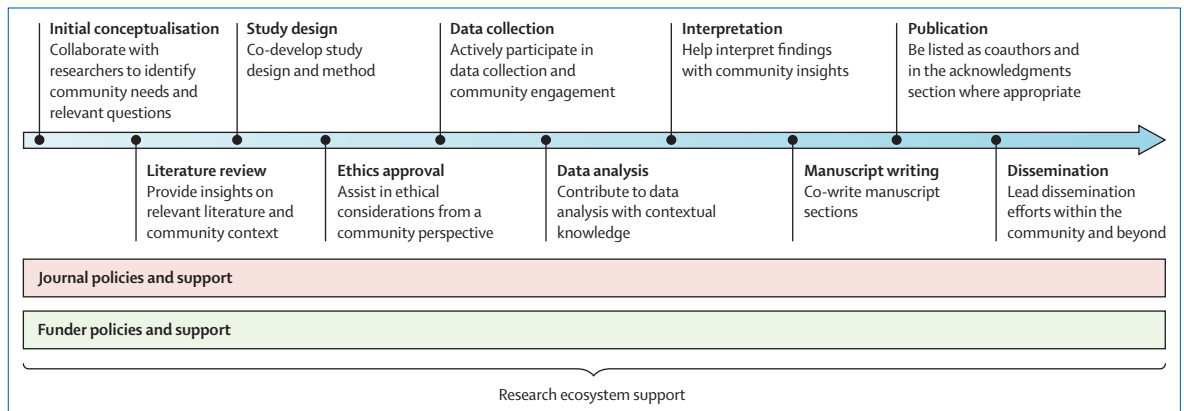


Figure: Conceptual representation of the different stages at which community health workers can be involved in the research process

power imbalances in institutional practices that prevent meaningful participation in data analysis and manuscript writing.⁹ It is crucial to address these barriers and provide opportunities for engagement, so that CHWs have the agency to choose whether or not they wish to participate and are provided with the incentive to do so, even if not all CHWs have the capacity for or interest in extensive research involvement.

Frameworks such as the Community-Based Participatory Research and the Participatory Action Research models describe how to involve community members throughout the research process. Integrating these frameworks at key stages (figure) could help to ensure that the contributions of CHWs are recognised and valued.¹⁰ Research teams should engage CHW representatives from the outset to co-develop research questions that address community needs, potentially through the formation of CHW steering committees in collaboration with university departments. Additionally, including CHW representatives in institutional review boards, offering tailored training on research methods and ethics, and providing fair compensation for their time and expertise can reduce barriers to participation. Most importantly, CHWs should have the opportunity to actively define best research practices and shape training programmes and guidelines. Additionally, it is important to think beyond authorship and understand CHWs’ perspectives on the value of traditional academic publishing, which might not be the sole or preferred method for recognising their contributions. It is, therefore, important to also explore alternative approaches and platforms to ensure equal value and visibility for the contributions of CHWs to research.

Our findings highlight the significant gap between the extensive focus on CHWs in research and their recognition as coauthors. This gap reflects both systemic power imbalances between researchers and CHWs and few opportunities for meaningful participation of CHWs. A crucial next step involves investigating the presence and effect of inclusivity mechanisms adopted by journals and funders supporting CHWs that act as gatekeepers, shaping equitable research practices. Additionally, updating and tailoring authorship guidelines, such as the ICMJE criteria, to better reflect global health research contributions from non-academic actors and developing standardised reporting guidelines for CHW involvement are crucial. Finally, exploring practical and desirable approaches to integrate CHWs into the research process is essential for creating a more equitable and effective research ecosystem capable of responding to community needs.

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