Ethics of health research priority setting

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Pecha Kucha presentation

Empowering communities in research - a model for shared decision-making and research priority setting in a rural population during a public health emergency

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Brief description of case study context

This case study examines inclusion and fair processes in health research priority setting. The COVID-19 pandemic has had a global impact, with research on prevention and treatment prioritized in well-resourced settings, leaving out rural and less-resourced settings with limited research opportunities. To address this gap, we recognized the importance of engaging communities in Siaya County, Western Kenya from 2020 to 2023 as key stakeholders in designing interventions to mitigate the pandemic in their own settings. We selected Siaya because it was one of the first rural counties to declare COVID-19 and furthermore, had long experience with Community Health Volunteers (CHVs) since the primary health care Alma Ata Declaration in 1978. There are ethical challenges in conducting research in rural settings during a public health emergency. Our priority was to engage rural community members in a population of a million people in research priority-setting. We took steps to engage the community in deciding what research to undertake, the research focus and the research questions. By involving the community, we aimed to ensure that the research prioritization was conducted in an ethical and culturally sensitive and respectful manner, for example, adopting the community's terminology for COVID-19 and masks, seeking consent for participation in the dialogue sessions and maintaining cultural sensitivities on groupings and contacts.

PRIORITY SETTING: Initially, research on COVID-19 was not a top priority in the community. However, as the severity of the disease became apparent, it quickly became a priority. We identified and approached key stakeholders who reflected the needs and interests of the community and also had influence; they included community leaders (both male and female), chiefs/assistant chiefs who represented local government, school teachers, community health volunteers and health care providers and we engaged them in several meetings based on their interest in the research topic and willingness to contribute their time and effort to the research prioritization process. Through 18 dialogue sessions over a period of two months, we engaged each group of key players in the community separately, including 43 Community Health Volunteers (CHVs) in groups of between 6 to 10 CHVs, 8 facility-based health workers, 15 community leaders in two groups, and 32 household members in 3 groups. The separate group sessions enabled in-depth discussions and exploration of participants' perspectives, opinions and suggestions. Lastly, three dialogue sessions were held with representatives from the stakeholder groups to discuss any differences in opinion and to reach a consensus on research priorities.

During the stakeholder meetings, different research priorities were mentioned due to varying views, opinions and perspectives based on each stakeholder's role and experiences. Community representatives prioritized research on prevention strategies such as health education about COVID-19, while the health workers chose research on treatment. Through open dialogue, stakeholders

were encouraged to openly express their opinions and concerns. This iterative process helped to identify common ground and potential areas of compromise. A consensus was finally reached among the different stakeholders on what was feasible within available resources. The community's prioritized research questions were: i) How did the virus spread and what were the infection prevention measures for communities to undertake? ii) Which groups (children, elderly, adults, and pregnant women) were most susceptible to severe COVID-19 infection and what protective measures could be developed for them in the community? iii) What were the available treatments for COVID-19, their effectiveness and how could they be accessed by those infected in the community? iv) How could misinformation about COVID-19 be combated within the community? In addition to prioritizing research questions, priority actions such as isolation, referral, coordination and linkage with health facilities and communities were agreed upon through the dialogue sessions.

Ethical issues

DECISION-MAKING, POWER IMBALANCES AND INEQUALITIES: Rural communities often have limited representation in research prioritization processes resulting in research that does not align to their needs. We engaged communities as partners in the research prioritization process, thus addressing potential power imbalances between researchers and rural communities. Community members contributed to research decisions by identifying the most pressing issues they faced and asking questions relevant to them. Through dialogue meetings, community members provided a first-hand perspective, and voiced their concerns and opinions which helped in prioritizing the research topics and questions. The community's involvement ensured that the research was relevant and beneficial to them and fostered a sense of ownership and commitment towards the outcomes of the research as it focused on solving their immediate problems and improving their response to the pandemic.

DECISION MAKERS ON RESEARCH: The decision-making process for research is complex and involves multiple stakeholders. In our participatory research on COVID-19 with rural communities, we consulted with community leaders, community health volunteers, and health service providers to identify specific research questions that were of priority and importance to them. We worked together to determine the most appropriate approaches to answer these questions. While the funding agency contributed to the research questions and directions, the final decision was made on the ground with a strong focus on community participation. This was because the community had specific concerns and priorities regarding how to manage COVID-19, and they were the gatekeepers for researchers to interact with them. Our goal was to produce study results that would be relevant and beneficial to the key stakeholders.

SHARING POWER IN RESEARCH PRIORITY SETTING: Research prioritization approaches that are centred around designing and conducting research with communities and health providers are preferred. Through our findings, we discovered that a participatory approach was most effective. We engaged community leaders and health providers in the research priority setting to ensure that our research was relevant and meaningful to the community. We provided each stakeholder with an opportunity to voice their concerns and priorities, utilizing participatory methods such as focus groups and community meetings. Our approach was respectful of the community's values and preferences, and our dialogue approach brought together the different stakeholders.

SHARED DECISION-MAKING AND MOVING AWAY FROM TOKENISTIC APPROACHES: Our approach of shared decision-making from the start of the research process proved to be effective as it engaged community members and stakeholders in the research design and planning stages. By incorporating inputs from the stakeholders, we built trust between ourselves and the community members, which demonstrated our responsiveness to their concerns. To ensure that we were on the right track, we held regular weekly meetings to provide feedback and evaluate the research process. We used the feedback to inform our decisions on the research process and outcomes, which helped

us to stay aligned with the community's needs and priorities and in turn helped them to stay engaged throughout the process.

Conclusions

Conducting research in rural settings during public health emergencies raises ethical issues that must be addressed through the adoption of research priority processes. It is crucial to involve all stakeholders, including the community, in the decision-making process about what research gets done. Power imbalances and inequalities that may impact the ability of certain groups to participate fully in research prioritization and benefit from its outcomes should be identified and addressed. By adopting these practices, ethical and equitable research practices can be achieved in rural communities during public health emergencies.

Recommendations

There is a need to share power with multiple stakeholders in a research prioritization process during a public health emergency. Community-based participatory research that adopts inclusive decision-making processes and co-design should be adopted as it ensures that the voices of the community are heard, and their perspectives are taken into account on research priorities. Research should be conducted in a way that is respectful of the community's values and preferences.

References

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