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Research and community engagement during the COVID- 19 pandemic in a resource-limited setting: a mixed methods study with epidemic preparedness implications

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Abstract

Background When WHO declared the SARS-CoV- 2 respiratory virus pandemic in 2020, Uganda was unprepared to prevent and control its spread or manage the COVID- 19 and non-COVID patients. A community trial to assess the efficacy of an intensive community engagement and risk communication (CERC) was contemplated. However, a baseline assessment of the existing CERC status and the challenges of conducting community research in the early months of the pandemic was necessary.

Methods A community baseline qualitative research (in-depth interviews, key informant interviews, focus group discussions, and household conversations) was implemented in 15 parishes (6 and 9 in Kawempe and Nakawa divisions respectively) of Kampala Capital City Authority, Uganda. Qualitative in-depth interviews with 20 household heads ($n = 10$ in each division), 50 household conversations ($n = 25$ in each division), and focus group discussions ($n = 10$, five in each division) were conducted during the pandemic from October 2020 to February 2021.

Results Many potential challenges to research involving CERC were identified and were categorized into three main interrelated domains: (a) implementation challenges (b) social, cultural, and political context of the research, and (c) budgetary and funding constraints.

Conclusions The three interrelated challenges identified in this study should be considered in future plans for epidemic and pandemic preparedness. The practical application of conventional concepts like CE, risk communication, qualitative research methods must be re-examined prior to epidemics and pandemics to improve their applicability and responsiveness during complex, dynamic epidemics and pandemics.

Keywords Epidemic preparedness, COVID- 19 pandemic, Community engagement, Health services research, Qualitative research, Resource-limited setting, Uganda

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Background

The emergence of the SARS-CoV- 2 in 2020 caught Uganda and the rest of the world by surprise. When the World Health Organization (WHO) declared a pandemic in March 2020 [1, 2] the world was unprepared to prevent such a highly transmissible respiratory infection or to adequately manage patients (both COVID- 19 and non-COVID). The COVID pandemic, while slow at first in Uganda compared to the global north, occurred at a time when vulnerability among poor urban communities was high. In Uganda, COVID- 19 disrupted livelihoods early on, particularly among vulnerable populations including those in the informal sector, small-scale agriculture and businesses, the elderly and people with disabilities among others living in urban and peri-urban areas. These people lost income sources following closure and bans on public transport and businesses. Citizens expressed agitation and demonstrated for relaxing of prevention and control measures to return to ordinary ways of living despite increasing imported and community-acquired reported COVID- 19 cases.

Therefore at the peak of the pandemic urban populations in Uganda were at crossroads for several reasons: (a) negative impacts to already constrained general health services including poor access to anti-retroviral drugs, immunization services, emergencies for expectant mothers and children; (b) loss of income and the disruption of livelihoods worst among low income earners for whom missing a day of work is disastrous (c) public demands for food rations from government (d) community stigmatization of COVID- 19 positive individuals, (e) worsening "infodemic"-misinformation to the public [3], and (f) the recent emergence of imported cases across Uganda's borders. Anecdotal reports in popular media particularly social media, public agencies and implementing actors revealed low risk perception of COVID- 19 in the community and increasing negative perception of mitigation measures causing low uptake among most vulnerable urban communities.

Faced with an emergency Uganda government employed a top-down approach in implementing COVID- 19 public health and social measures (PHSM), including risk communication, advocacy for social distancing, enhanced personal hygiene (hand washing and protect your cough or sneeze), lockdowns and night curfews, a ban on public and private transportation, implementation of limited laboratory COVID- 19 diagnostics, surveillance, and case management. There appeared not to be any meaningful community engagement so that individuals, households and communities would take charge of their health and social wellbeing to protect themselves and their neighbours during the pandemic. The government increasingly faced challenges in implementing the recommended social measures particularly in low resource congested communities like slum areas and peri urban communities and border communities.

Notably, during previous outbreaks such as Ebola, public health response not only recognized the need to implement community engagement (CE) to control infectious epidemics but sometimes implemented CE in control activities. The West African Ebola virus disease (EVD) outbreak from 2016 to 2020 had underscored the pivotal role of CE in achieving effective epidemic control [4, 5]. Similarly, whereas the social sciences (including anthropology and sociology) were familiar with CE, there was limited experience in implementing CE and research in communities during a COVID- 19 pandemic context characterized by stringent epidemic and pandemic preparedness and control measures. However, the SARS-CoV- 2 pandemic, characterized by respiratory transmission, presented unique challenges, compounded by absence of appropriate research guidelines [6].

This study was conducted between October 2020 to February 2021, as a baseline for a planned a randomized community trial in Uganda to assess the effectiveness of an intensive CE and risk communication (CERC) in pandemic control. Makerere University College of Health Sciences (CHS) and the College of Humanities and Social Sciences (CHUSS) prepared to conduct the randomized trial in which we hypothesized that community participation and ownership were vital for the success of pandemic control measures. However, there was no baseline data in Uganda on the challenges of conducting research in communities during COVID- 19 and on the status CERC during the early months of the pandemic. We therefore, conducted this baseline study in a sample of the anticipated trial intervention and control communities. However, the community trial did not take place due to budgetary constraints as further discussed in the findings below.

Methods

Study design

This baseline mixed-method formative study comprised both quantitative survey and qualitative research components carried out among vulnerable populations in urban and peri-urban Uganda. We aimed to identify potential challenges of conducting research in communities during the COVID- 19 pandemic and document the existing CERC status early in the phase of the pandemic and prior to implementation of a planned trial registered with the Pan African Clinical Trials Registry (PACTR202010729372570; Registration data: 20 September 2020).

Study setting

The study covered 15 parishes, including six in Kawempe division (intervention arm) and nine in Nakawa division

(control arm), two divisions within Kampala Capital City Authority.

Both Kawempe and Nakawa divisions are characterized with densely populated zones with relatively poor access to social amenities. Whereas there is some access to clean running water in some homes or within the community such as at stand pipes, and access to electricity, the neighborhoods where the most vulnerable urban populations live are severely constrained. Further neighborhood characteristics are detailed in Table 1 below.

Sampling of parishes, villages and households

We employed a multistage sampling strategy that allocated parishes and villages based on their proportional contribution to the overall intended population for the planned community trial. We used sampling frames, which contained lists of parishes and villages within the two divisions.

For each village or segment, we developed sampling frames and intervals for households in line with probability-based survey design principles. We targeted a total of 30 households per village for inclusion in the study.

Study population

Qualitative research involved in-depth interviews with 20 household heads ($n = 10$ in each division), 50 household conversations ($n = 25$ in each division), and focus group discussions ($n = 10$, five in each division). All interviews were conducted with individuals aged 18 years and above residing in urban and peri-urban areas, ensuring representation from diverse population segments. This included health workers, COVID- 19 task force members, surveillance staff, urban refugees, migrant workers, individuals with diverse livelihoods, family roles, education levels, and community roles, as well as law enforcement officials.

Sampling and participants for qualitative research

For the qualitative research, we adopted a purposive sampling approach in consultation with community gatekeepers and leaders, taking into account gender and age diversity among the participants.

Table 1 Neighborhood characteristics in study area

Neighbourhood characteristics
Very few gated structures, well planned, clean neighbourhood
Some gated structures, fairly well planned with fairly good sanitation, no congestion
Majority are not living in gated structures; semi-planned with some signs of congestion or poor sanitation
Slum dwellings with obvious signs of congestion and very poor sanitation are also quite common

Data collection

Our study employed innovative methods to implement CE and CERC. Over a period of 3 months (November 2020 – Jan 2021) several key stakeholders were oriented continuously about the project through both in-person and online meetings and presentations that were circulated upon request. Additionally, several stakeholders including Ngora parish in Eastern Uganda collaborating with ACHEST, RedCross, COVPress were visited to interact, share and learn from different experiences in community engagement relevant to COVID- 19 social contexts. Through these avenues the project was able to disseminate findings which informed policy and programming efforts for the response and preparedness effort at various local levels. This information enabled the study team to understand underlying social norms, local knowledge, community dynamics and opportunities, and people's key questions and concerns. We received responses that contributed input to the study activities, which was used to adjust data collection methods accordingly. In response to the unique challenges posed in the field by the COVID- 19 pandemic, we adopted a cross-sectional research approach that harmonized face-to-face quantitative surveys with qualitative interviews. A team of 18 highly-trained and experienced research assistants (RAs) qualified in social sciences received six weeks of rigorous training encompassing both survey and qualitative techniques. Notably, four of these RAs possessed backgrounds in social sciences and extensive experience in qualitative research methodologies. The development of the survey instrument (see Additional file 1 Quantitative_Survey_tool_English.pdf), FGD guide (see Additional file 2 FGD_Guide_English.pdf) and the HHC guide (see Additional file 3 Household conversation guide_English.pdf) was a collaborative effort, incorporating a wide array of closed and open-ended questions, iterative pretesting, and translation into Luganda-the local language widely spoken in the study setting.

For qualitative data collection we employed 10 in-depth interviews (IDIs), 10 key informant interviews (KIIs), 10 focus group discussions (FGDs) each not more than 6–8 persons to ensure adherence to public health measures and lockdown directives, and 50 household conversations (HHCs) totaling to 25 HHCs per division. FGDs were conducted outside in a place identified as convenient to allow of uninterrupted discussion given the congested nature of the setting. The interviews covered several domains, including demographics, work history, COVID- 19 beliefs, sources of information, socio-economic and cultural practices, and the impact of the pandemic on various aspects of life. Our team of 22 persons comprised investigators ($n = 3$), team supervisors ($n = 5$) and research assistants ($n = 14$). The qualitative team comprised of one supervisor and 8 RAs. Of these, 3 were

female. All RAs for the qualitative component were qualified social scientists with previous experience conducting interviews. RAs were trained on the protocol and interview tools for an extensive period of 6 weeks. RAs worked in pairs, sometimes of one male and female and in other instances of same sex. Quality control was maintained through daily debriefs and weekly team meetings, which provided a platform to address challenges and enhance problem-solving. Our qualitative study adhered to an interpretivist framework, aimed at exploring the subjective experiences of individuals within their social contexts [7]. This approach allowed us to capture context-dependent effects of the pandemic, shedding light on the intricate interplay between individuals and their communities during these trying times.

Data management and analysis

We digitized our data collection tool using Open Data Kit (ODK) and stored data on a cloud-based server. Descriptive statistics were derived from the survey data, and all qualitative interviews (IDIs, HHCs, FGDs) were audio-recorded, transcribed, and translated into English.

Our analytical approach drew from both grounded theory analysis and content analysis methodologies. This hybrid approach allowed us to develop robust coding frames and categories that captured the richness of the qualitative data. The coding process was conducted by three independent coders, each bringing a unique perspective to the analysis. To ensure the consistency and reliability of our findings, any discrepancies in coding were thoughtfully addressed through a consensus-building process among the coders. Additionally, an independent checker was engaged to provide guidance and resolve any remaining ambiguities, enhancing the validity of our interpretations.

Findings

Experiences in conducting research and community engagement during the pandemic

Throughout the research process from project planning to results dissemination, the study team encountered both challenges and opportunities. This paper focuses exclusively on the challenges encountered which are categorized into three main interrelated domains: (a) implementation challenges (b) social, cultural, and political context of the research, and (c) budgetary and funding constraints.

Implementation challenges

Research team preparation for community engagement

Equipping the research team to interact with the public during a deadly airborne disease outbreak with no available preventive vaccine or treatment posed significant challenges. Each stage, from team selection to content design, demanded extensive consultation with both medical and policy makers working with the pandemic control task forces. We held weekly consultations with the task force members who were available for consultation. Additionally, community engagement required flexibility and creativity to access the mobilizers and leaders for briefings with the team. For instance, we often tagged along the community mobilizers when they were undertaking their public health duties and that offered the opportunity to consult with them regarding our study procedures. Comprehensive and high-quality training covering a wide array of topics ranging from the specifics of the pandemic to study procedures, the rationale behind these procedures, strategies for engaging diverse populations, risk mitigation measures, and protocols for handling unforeseen circumstances became indispensable. Both theoretical and practical training required qualified trainers. Despite a rigorous six-week training period, surprises and unexpected challenges still arose in the field as discussed further below.

Methodological challenges in qualitative data collection

Qualitative data collection methods such as KII, IDIs, FGD, and HHC traditionally involve in-person, close-proximity interactions with participants. The pandemic's strict public health and social measures posed considerable challenges to these methods. While challenges in low-and-middle income countries are well-documented, certain difficulties were encountered even in high-income settings. Conventional FGDs or HHCs do not typically involve maintaining a six-foot distance between respondents and researchers. Bringing people together for community engagement proved challenging during a period when public health measures were stringent. Additionally, the fact that every household member was at home made it difficult to find quiet, private spaces for interviews, potentially constraining the openness of some respondents. Furthermore, the public health measures (PHM) introduced confidentiality challenges, as participants had to project their voices more loudly in open spaces, inadvertently compromising privacy.

Challenges to maintain ethical integrity and scientific rigor

Similar to many other regions, our Institutional Review Boards (IRBs) grappled with the formidable task of developing new research guidelines that effectively safeguarded the health and welfare of both community members and researchers. This challenge was further complicated by the imperative to expedite approval processes in order to keep pace with the rapidly evolving research landscape during the pandemic. The IRB also faced dilemmas regarding what was permissible as responsible conduct of research. This led to deliberations on various elements, including health insurance for

research team members, the content of risk management plans, and the acceptability of photography, videography, and voice recording. The strict public health measures in place, such as physical distancing, made activities like photography, videography, and voice recording ethically complex, as they raised concerns related to invasion of privacy and participant confidentiality. Consequently, the pandemic and its associated public health measures challenged the research team's ability to fully comply with some of the ethical requirements. Overcoming these challenges necessitated extra effort in the development and implementation of risk management plans.

Throughout the research process, our team diligently navigated the terrain to ensure ethical integrity and scientific rigor, focusing on several key aspects:

a) **Upholding Participant Rights**: We made it a priority to uphold participant rights, including the right to decline to answer specific questions. In instances where participants were less forthcoming during HHCs or FGDs, interviewers conducted follow-up discussions with individuals privately. The study had anticipated and prepared for such scenarios, allowing participants to engage RAs in a one-on-one setting and share additional information outside the group interview environment.
b) **Ensuring Participant Privacy**: The pandemic, in conjunction with PHM such as social distancing, amplified the challenge of preserving participant privacy during interviews. Conducting interviews while maintaining a six-foot distance between the interviewer and the participant proved particularly demanding in congested, low-income urban environments.
c) **Prioritizing Researchers' Welfare and Safety**: The pandemic placed considerable strain on the principle of ensuring the welfare and safety of researchers. Despite having a planned risk mitigation strategy, unanticipated challenges emerged. RAs who contracted the virus experienced unforeseen side effects related to their knowledge of their status, including psychological impacts. Those who remained unaffected had to shoulder additional workloads, placing them at risk even though we provided them with all the necessary protection facilities. This dynamic underscored the necessity of adaptability in the face of an evolving situation.
d) **Early collaboration and engagement with community leaders**: We recognized the limitations of earlier response efforts not collaborating with community groups, such as civil society organizations, cultural leaders, and religious leaders. In our study, we learned early that these community leaders possessed prior knowledge and experience working within the study communities. We therefore swiftly harnessed their capacity and existing networks to mobilize communities in our study setting. Additionally, the principle of respect for communities necessitates researchers to "respect communal values, protect and empower social institutions, and, where relevant, respect the decisions of legitimate communal authorities." The government-imposed movement restrictions made it challenging to locate these leaders. Nevertheless, we made concerted efforts to engage some community leaders in their individual capacities.

Social context challenges

The study unfolded amidst a dynamic social context characterized by communication and information excesses and overflow, a fluid political environment, economic strain, cultural norms and practices that carried psychological, gender, and cost related challenges for both the researchers and potential participants.

Challenges with communication channels

The pandemic introduced significant communication challenges, particularly concerning the channels through which information flowed. Social media and other communication platforms facilitated the spread of misinformation and disinformation, directly impacting the conduct of the study. In our study, most participants cited mass media platforms as their primary source of information. Person-to-person communication among friends or relatives was also prevalent (n = 791, 92·2%), followed by mainstream media such as television, radio, and newspapers (n = 624, 73·6%), and social media (n = 164, 19·3%). Notably, the majority of respondents mentioned receiving information from the president (n = 339, 40%), relatives (n = 266, 31·7%), friends (n = 252, 29·7%), government officials (n = 150, 17·7%), health workers (n = 100, 11·8%), local leaders (n = 60, 7·1%), and religious leaders (n = 33, 3·9%).

Social media and word-of-mouth played significant roles in disseminating information, contributing to COVID- 19 infodemics characterized by widespread misinformation and disinformation. The public often distrusted information from official government sources, viewing it as deceptive and intended solely to secure donor support. Participants occasionally veered off-topic to discuss allegations of corruption, challenging the study staff to address such issues and affecting the interview's focus. In the early stages of the pandemic, when the public had not yet witnessed COVID- 19 cases, community members found it difficult to believe in the existence of the pandemic. This widespread misinformation served as a real-time learning opportunity for the research team, prompting the development of measures to respond

effectively. For the study, we relied on a WhatsApp group platform to facilitate real-time communication between the research team and community leaders.

Another notable aspect of communication channels was the emergence of specialized jargon among respondents with unique knowledge, such as traditional healers and sex workers. This jargon infiltrated public communication, including daily presidential speeches on pandemic updates, reflecting a shift in language and references within the community. The translation of messages into local languages also adapted to incorporate culturally relevant terminology. Therefore, the research team needed to remain attuned to new language or references related to common concepts like 'senyiga omukambwe' (a local term for COVID- 19), masks, lockdown, quarantine, and curfew, as these were central to pandemic control activities. Additionally, some respondents utilized emerging language to discuss their pandemic experiences, reinforcing the importance of recognizing and accommodating evolving language and references during a pandemic.

Health challenges

It's important to highlight that while we had a comprehensive risk management plan (RMP) in place from the outset, which was reviewed by the IRB before ethical approval, the pandemic led to unforeseen health challenges within the research team. Several team members contracted COVID- 19, triggering the immediate implementation of the RMP. This involved halting study activities and ensuring the infected individuals received care according to Ministry of Health PHM and Uganda National Council for Science and Technology (UNCST) guidelines. The direct consequence was a reduction in available staff, as six out of 25 team members required isolation. As a precautionary measure, all research activities were suspended for eight weeks. Face-to-face activities resumed only for project staff who had tested negative for SARS-CoV- 2, resulting in increased workloads for the remaining team members. The news of infections among team members adversely affected morale and motivation. Unfortunately, while the RMP effectively addressed the outbreak within the team, it did not adequately address the social and psychological impact, particularly on the infected RAs.

Psychological effects on study participants and researchers

The pandemic affected the general community's mental well-being, with some participants expressing irritation toward COVID-related information or news. They attributed this irritation to the stress of lockdowns, absence of rapid and affordable tests, and perceived inadequacies in treatment options. Such experiences heightened panic and anxiety, exacerbated by sensational and controversial media coverage of the pandemic. Participants' anxiety related to news coverage was a notable challenge, as expressed by one respondent: "I know that the news increases my anxiety, but when I do not check it, I feel even more uncertainty." On the other hand, the researchers also faced psychological distress in part due to the exposure to the impact of COVID 19 and associated PHSMs on the communities they visited. Additionally, the leadership of the research experienced stressful moments in having to deal with the actual fieldwork and implications of the lockdown on the process/challenges. This was especially exacerbated by part of the team getting infected by COVID 19 which affected the data collection plans both in terms of limiting the personnel hours as well as increasing the costs of the study. Despite the resilience demonstrated by the leadership when dealing with these challenges it was notably a challenge that was not anticipated at the start of the study.

Research challenges related to gender norms in resource constrained settings

Our study primarily took place in low-income urban settings characterized by crowded living conditions. As a result, Household Conversations were not as private as desired. Cultural norms sometimes hindered openness among family members, particularly when discussing sensitive topics. For instance, discussions on domestic violence, income generation, or sexuality were often less informative when conducted in the presence of the household head (usually the male).

Furthermore, gender dynamics influenced the research process. Most study participants were women (n = 610, 73·05%), and participants, including men, hesitated to discuss certain topics in the presence of their spouses. Gender norms appeared to limit freedom of expression within households. Some participants were more candid after the official interview had concluded and the recorder was turned off, and the RA and usually female participant were no longer within earshot. Notably, gender-based challenges arose due to situational constraints in the research setting. For instance, when a male RA interviewed a female respondent in a private setting, it sometimes resulted in harassment and potential violence toward the RA. Conversely, some respondents preferred to be interviewed by a specific gender due to perceived power imbalances. This situation sometimes led to challenges in data collection.

To address these issues, RAs received training to apply various techniques (observation, field notes, debriefs, and follow-ups) alongside the primary data collection approach, the HC. Additionally, the research team comprised both male and female RAs to conduct HCs, helping to mitigate gender-based biases and provide support in handling security concerns. Both male and female RAs reported perceived verbal threats, sometimes of a sexual

nature, and having a partner of the opposite sex helped manage these situations.

Operational costs and budgetary (cost of research) challenges

The health challenges and other unforeseen developments substantially escalated operational costs. Collectively, these factors, including unanticipated field costs and budgetary shortfalls, impacted the study timeline and led to a 50% increase in operational costs. We brought in five volunteers to support the team, but this only partially mitigated the challenges. The blended training approach, combining face-to-face and online training, extended the training period by three weeks, 60% longer than planned, to sufficiently prepare RAs for work during the evolving pandemic. The cost of personal protective equipment (PPE) surged by up to 20% from budgeting to procurement. Identifying willing and consenting participants proved slower due to public suspicion, particularly in the months leading up to national presidential elections. Interviews took longer as participants sought to express their views to government leaders, often deviating from the main discussion points. Local guides from the communities, who possessed extensive knowledge of their environments, raised their labor costs by up to 50%, as they had no other source of daily income during lockdown. Finding suitable interview spaces became challenging due to the need for social distancing, privacy, and confidentiality in crowded, low-cost environments, with all family members present at home due to lockdown. Fuel costs rose by 30% due to a higher number of trips than initially planned. The extended data collection period by 20% necessitated hiring the team for an additional four weeks, resulting in a 30% increase in personnel costs.

Conducting research during the pandemic exposed new and unforeseen costs that were not initially anticipated and budget adjustments proved very challenging. The support of welfare and protection of team members, particularly those infected with SARS-CoV- 2 during the study, involved significant expenses. The original budget did not account for the cost of COVID tests, which amounted to USD 30 per test. Additionally, the infected team members required prolonged management, including counseling which had not been budgeted for. In addition, the study could only cover immediate care expenses, constituting approximately 10% of the total required for complete care during the study period. Some team members who contracted SARS-CoV- 2 faced stigma and required psychosocial support, which had not been fully anticipated or adequately costed.

Furthermore, there were costs related to time lost when potential study participants exhibited COVID symptoms or reported having the virus. Teams had to skip these households, which prolonged the time needed to reach the target sample size, impacting the study's overall cost.

The prolonged full lockdown provided opportunity for prolonged training prior to the start of field work to ensure the RAs were very well trained. The slow ethical approval process further delayed the start of data collection.

When a partial lockdown allowed some fieldwork, regular COVID testing became necessary during ongoing community viral transmission. The increased testing, coupled with restrictions on vehicle occupancy and curfews, raised transportation costs. Communication costs also escalated to facilitate virtual team meetings and daily debriefs. All these required data plans, phone calls, and in some cases, tablets and smartphones for team members without laptops. Finally, costs associated with covering tasks for researchers placed in isolation, including hiring new RAs while keeping the infected ones on pay, further strained the budget. Overtime pay was not feasible due to budget constraints.

Difficulty to implement CE as part of the pandemic response posed a significant challenge. The tension between the national government's desire to rapidly execute public health measures during a pandemic and the initial slow approach to mobilize and engage communities for a more effective long-term response created complications. When communities did not fully comprehend the severity of the health threat and did not embrace the proposed interventions, it resulted in community resistance and some rejection of the recommended actions.

Certain segments of society welcomed the presence of our Makerere University research team, as we provided crucial information about the pandemic. This reaffirmed the value of CERC in preparing and supporting communities to prepare them and respond to their needs and challenges in contextually appropriate ways. However, both the government and the research team faced high community expectations during the pandemic. Taking the necessary time to provide needed explanations and engage with the community slowed down the study progress and increased costs due to extended field work.

Discussion

We focus on the substantial challenges encountered and lessons learned in conducting research and CE during the COVID- 19 pandemic. Our research unfolded during a period of uncertainty and emotionally charged interactions when Uganda was preparing for presidential elections. This added a need for an extra layer of careful consideration to ensure safety measures and research rigor. Additionally, the most recent Sudan EVD outbreak in the country, though localized in three districts, from September to November 2022 also coincided with the ongoing COVID- 19 pandemic. This concurrent outbreak

underscored, yet again, the indispensable importance of effective CE during an epidemic or pandemic. It firmly reinforced the notion that community trust and collaboration are non-negotiable in the face of public health crises [6]. Notably, in EVD-affected communities, individuals exhibited reluctance to adhere to public health measures and even resorted to extreme actions, such as obstructing public health teams. The lack of successful CE can lead to community resistance and hinder response efforts [8].

Gender considerations played a role in shaping research activities. Understanding gender dynamics and addressing their impact on the practicalities of data collection and engagement proved essential. Commitment to safely engaging communities and different publics in knowledge generation remains a cornerstone to the successful conduct of quality research that informs development of policy and guidelines for control and management of a pandemic in a timely manner.

The cost and budgeting challenges experienced had no easy solutions and were a constant source of anxiety. The frequent emergence of gaps in the funder approved budget were a constant feature which could be explained by two major causes. First, the demand for both budgeted and new unforeseen and unbudgeted line-items was increasing rapidly. Secondly the supplies were erratic and uncertain and hence unpredictable due to country lock down, dwindling importations and within country transfer of commodities. Budget constraints and resource limitations influenced the implementation of activities, adding complexity to the research process. Budgeting principles like funding caps, flexibility of funders, acceptability of miscellaneous budget items in research need to be reconsidered in a pandemic situation given the challenges posed by a fluid and dynamic emergency like a pandemic. Adequate in-country expertise to undertake rapid projections would be very valuable not only to inform policies and guidelines but also inform research needs during a pandemic. Extreme PHMs and their potential implications should be very well considered before implementation.

There is need to adapt certain concepts like CE and risk communication to make them more responsive to complex and dynamic infectious disease outbreaks, epidemics and pandemics. Challenges in implementing CE during infectious disease outbreaks or epidemics, such as the West African EVD epidemic and the COVID- 19 pandemic, have been documented in previous studies [9–12]. However, limited research has addressed the specific challenges of implementing CE in the context of COVID-19 research [13]. Given that CE is recognized as a necessary ethical practice in research, its integration into research during an epidemic or pandemic may help mitigate potential challenges and negative impacts [14, 15].

Ethical challenges that may arise when planning and implementing community research during a pandemic should not be underestimated. They demand continuous attention from the planning stage throughout the research cycle, considering their variation, breadth, depth, and the extent of their impact on the well-being of the research team, study participants, and the broader society. This was very evident on the pandemic's psychological challenges to the well-being of team members and study participants and other community members. Navigating stringent public health measures that restricted movement, association, and group gatherings, as well as ensuring social distancing, warrant further discussions as part of pandemic preparedness. In future research endeavors during severe epidemics or pandemics, these ethical dilemmas may resurface as competing tensions, balancing research interests, public expectations, and the duty to protect research team members, participants, and the wider community. Conducting research is vital for providing new knowledge for epidemic and pandemic control, and management in real-time, thus contributing to preparedness for future similar occurrences. It is vital that the research is adequately resourced to ensure ethical Integrity and scientific rigor are maintained. Maintaining rigorous research standards and ethical conduct required substantial effort, and the research team continually adapted to address emerging challenges.

Engagement of the public in health research not only enhances the quality and relevance of research but also the researchers' relationships with communities, their understanding of community needs, builds community trust and confidence in the research process and findings, and ultimately may improve the translation of research outcomes [16, 17]. It is critical that efforts are made to prepare for future research and CERC as an essential component of epidemic and pandemic preparedness. Whereas our research was conceived and implemented during the pandemic, our findings are similar to those of Kroese and colleagues [18] obtained from surveying researchers who had ongoing research projects or projects which were about to start in LMICs (East, West and South Africa, Central America, South East Asia and South Asia) when the pandemic started. Additionally, there are important lessons from a study by Denegri and Starling [19] on COVID- 19 and patient engagement in health research. CERC has the potential to maximize the effectiveness of community readiness, response, and recovery to prevent and contain transmission during an epidemic or pandemic [10, 20].

Study strengths and limitations

Our study possesses both strengths and limitations:

Strengths

Engaging with communities during a pandemic has provided valuable insights into the benefits and challenges of conducting community engagement in such contexts. This experience has highlighted the importance of real-time feedback to inform policymakers, program staff, and local leaders during pandemic responses.

The study has prompted a reevaluation of how research during pandemics or other public health emergencies can be designed and executed differently. It underscores that social science research, even in a pandemic setting, is not without risks.

Limitations

It remains unknown whether our study may have inadvertently harmed the study communities, raised ethical dilemmas, increased community stress, or contributed to the spread of the disease among research team members who contracted SARS-CoV- 2. This necessitates consideration of new domains for educating, informing, and monitoring investigators' responsibilities during community-based research in pandemics.

The inability to share results with communities and policymakers in real-time hindered the timely utilization of study findings for actionable pandemic response. However, the study still holds scientific, methodological, and policy value in the context of research during epidemics and pandemics. The lessons learned can inform epidemic and pandemic preparedness efforts.

Conclusions and recommendations

Our study illustrated that implementing CE and CERC methods in response to the COVID 19 pandemic required flexibility in using conventional approaches akin to social science research and implementation data collection. In addition, we learned that budgetary implications need to be thought of carefully including aspects of human subjects and research team protection. For instance, when the RAs were infected and needed care ranging from counseling to medical care, these were unanticipated costs at the planning stages. In the end, the budgetary constraints rendered implementation of the randomized community trial impossible. Despite the challenges, the scientific and policy value of knowledge generated during epidemics and pandemics remains high. Researchers must strive to innovate and adapt conventional research methods to maximize engagement, scientific rigor, and benefits even in pandemic settings. As part of pandemic preparedness, scientists and the research community should introduce innovations and adaptations to existing formative research methods, better equipping them for research, community engagement, and mitigation programs during future pandemics. The research experiences and lessons learned from the COVID- 19 pandemic should be utilized to strengthen epidemic and pandemic preparedness. There is urgent need to review the practical application of key concepts like CE, risk communication, conventional qualitative research methods and make them more applicable and responsive during complex and dynamic infectious disease epidemics and pandemics. Additionally, the study provides evidence of the need to advocate and adopt conventional methods of qualitative data collection during times of a pandemic like COVID 19. There is need for flexibility from funders of research conducted during emergencies and we therefore refer to our study as a potential point of advocacy for researchers and provide evidence to funders who may need to consider flexibility in budgeting principles.

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

Supplementary Material 3.

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Authors' contributions

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Data availability

The data supporting the study findings are available from the corresponding author upon reasonable request, subject to privacy and ethical restrictions.

Declarations

Ethics approval and consent to participate

This study received ethical approval from the Makerere University School of Medicine Research Ethics Committee (SOMREC) REF 2020 - 144) and the Uganda National Council for Science and Technology (HS858ES). Administrative clearance to conduct the study in the two divisions of Kampala City Council was also obtained. The study adhered to the Declaration of Helsinki (https://www.wma.net/policies-post/wma-declaration-of-helsinki/). As such, each study participant provided written informed consent prior to being interviewed and was free to withdraw from the study at any time without negative consequences. Each study participant also provided consent to being audio recorded during the interview.

Consent for publication
No identifiable individual participants' data are reported in our manuscript. We have attached the consent forms that was used to seek approval to use the non-identifiable data in our publication.

Competing interests
The authors declare no competing interests.

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