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Research Article

Sustaining Community-Engaged Public Health Research during the COVID-19 Pandemic And Beyond

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Introduction

African-American, Hispanic and older individuals experience disproportionately higher rates of chronic health conditions such as hypertension and diabetes [1-3], are at increased risk for poor health [4,5], and adverse financial (e.g., employment, economic resources) impacts from the Novel Coronavirus (COVID-19) [6-8]. COVID-19's influence on the health care system poses additional challenges, particularly in routine care for non-communicable chronic health conditions [9,10]. Public health research efforts aimed at improving the health and well-being of populations with chronic health conditions have been unfortunately impacted by the pandemic with long-lasting repercussions [11,12]. The social and physical measures that protect high-risk populations from COVID-19 present unprecedented challenges to sustaining community-engaged research, critical for developing effective public health measures to address health disparities [13,14].

This brief explores the challenges of conducting community-engaged public health research with African-American adults who suffer from chronic diseases, a population at increased risk for COVID-19. Foundational to the discussion is a small qualitative study conducted by the authors during the COVID-19 pandemic. Providing discussion and hindsight gives the reader pragmatic strategic considerations for continuing research during and after the acute phase of the pandemic. We share logistical solutions that enabled our research to not only answer the original questions we posed, but also provide unexpected insights and rewards from innovative community/academic collaborations that engage individuals at high-risk of adverse health outcomes during the pandemic and beyond in the development of solutions for their improved health and well-being.

Keywords: Chronic Disease; COVID-19; Pandemic; Qualitative Research

Introduction to Our Pandemic Research Example



We built on a long-standing community/academic partnership with a major focus on improving the well-being of underserved populations. Our study population centered on underserved populations (e.g., African-American, older individuals) who were managing the challenges of chronic health conditions and, consequently, at increased risk for COVID-19. Given the increase of COVID-19 cases and mitigation strategies (e.g., social distancing guidelines, stay-at-home orders) [15,16], we transitioned this small community-engaged health study from in-person focus groups to a virtual study interacting with participants via phone, web-based tools (e.g., WebEx, Qualtrics) and mail. We coordinated participants and a multi-institutional research team predominantly located in two time zones of the United States. We developed the research focus pre-pandemic: stress resilience tools (i.e., mindfulness) and chronic health condition management. This topic assumed increased significance while the community engagement aspects presented additional challenges due to the pandemic.

Strategies

Needs Assessment

Critical to a successful transition to virtual research is a needs assessment of university policies, facilities and staffing capabilities in such areas as: Institutional Review Board (IRB), information technology, purchasing, and facilities (e.g., accessibility to biomarker labs, computing equipment). Research activities and timelines must consider the extra time, psychological and financial challenges that participants, researchers and university research support staff confront due to the pandemic. Iterative consideration of these logistics is needed to accommodate virtual work environments and rapidly changing policies due to the pandemic's fluctuations and changing prevention protocols.

Institutional Review Board

The IRB can serve as a support system for pandemic and virtual research transitions. However, balancing IRB and investigator workloads, university policies and the logistical process was challenging. At the initial stages of the pandemic, many universities imposed restrictions prohibiting in-person or contact-based human subject research [13], which may re-surface periodically until the pandemic ends and with differing challenges post-pandemic. IRB offices may experience increases in administrative burden if amendments are required from each investigator for transitioning research to reflect the changing pandemic and post-pandemic human research environment.

Using our research as a case example, the University of Maryland (UMD) IRB, notified investigators amendments would not be required to transition in-person research to virtual during the pandemic if certain conditions for minimal risk and the consent process were met. The IRB Office was thus able to remain flexible within the confines of 45CFR46 [17], while clearing investigators to continue their minimal risk work. The IRB Office prioritized transactions altering the conduct of previously approved projects from in-person to virtual, as well as initial applications studying COVID-19, and encouraged investigators to inform them of forthcoming applications meeting these criteria, allowing for efficient processing.

Multisite Collaborations

Navigating differences in research policies dependent upon variations in COVID-19 rates and the geopolitical landscape is challenging. Leveraging interprofessional collaborations between public health, nursing, information technology and community partners was vital to our success. Multisite collaborations provide advantages by allowing individual members of the team to rely on each site's strengths [18,19]. Purchasing, information technology, and other resources may be impacted by differing policies at different time periods. A multisite collaboration offers additional resource capabilities during the time of need if those at the original designated site are temporarily impeded due to the pandemic or other unforeseen challenges beyond the pandemic (e.g. natural disasters).

In our case example, the institutions involved differed by which research offices were able to respond more quickly. We were able to rely on early adoption of adaptable fiscal research policies at some institutions involved in our collaboration and early transition of research conduct policies at others. Proactive communication and engagement with all university offices involved in adapting research policies to changing pandemic conditions



was beneficial to the quick transition of our research to virtual platforms, but also resulted in long-term innovations for our post-pandemic research.

Information Technology (IT) and Data Collection Preparation

Though virtual research technology has been available, the pandemic accelerated a trend toward virtualization necessitating an increased demand for resources unlikely to be reversed post-pandemic [20]. Data can be collected via digital forms and surveys, while tele-conferencing platforms enable focus groups and interviews. Virtualized computing infrastructure allows multisite researchers to share a common, scalable platform for data storage, software, and analysis; thus, limiting the proliferation of data and code versions and limiting security risks. Early and active collaboration and communication with IT staff is crucial for establishing, accessing, and maintaining infrastructure that securely stores each piece of research data separately to protect participant anonymity and confidentiality while allowing for analysis linkages. Each member must have security training and secure access. Data security challenges are formidable for work-at-home situations, with potential for less secure networks and less private work-spaces.

From our research experience, virtual research required consideration of additional participant privacy issues which necessitated the use of audio only (versus video) interview platforms. Additionally, some participants required older technologies (e.g., phone call), and technology preferences and accessibility were not predictable by demographics or socioeconomic position. At times, researcher and/or participant technology failed, thus, flexibility for rescheduling and/or readily available alternate technologies were critical for data collection.

Study Recruitment

Recruitment efforts for community-engaged research are more challenging due to lack of in-person opportunities for relationship building [21]. Conversely, recruitment through online vehicles and social media may offer broader geographic diversity. Virtual research may attract participants with greater restrictions for traveling to research sites in-person during and post-pandemic [21,22]. Studies building on prior in-person contacts or community-academic partnerships may hold an advantage due to trust building and familiarity with the legitimacy of the research study's objectives and team.

Our study completed recruitment and data collection within six weeks, benefiting from a long-term community-academic partnership. Strong collaborations, recognized names, and established trust in the community pre-pandemic allowed our recruitment efforts to cut through the fear, stress, and overload of information during the pandemic. Feedback from participants during recruitment and interviews suggested the relevance of our topic (stress and chronic disease), social isolation and reductions in such services as chronic disease management support groups due to the pandemic may have heightened interest in participation) [21]. In addition, during the interview, we engaged each participant in a brief activity to demonstrate mindfulness stress reduction and spur discussion [23]. Multiple participants reported this exercise was stress reducing, and this immediate benefit induced them to recruit other participants.

Public Health Implications

Recognizing the importance of continuing research among underserved populations at greater risk for COVID-19 health and quality of life impacts during and post-pandemic, community-engaged public health researchers can sustain valuable efforts in in this area. We were able to accomplish this for our small multisite study by transitioning in-person research to a virtual platform. Many of the lessons we learned provide important implications for community-engaged public health research beyond the pandemic, as our world has changed irrevocably and as researchers will always confront unforeseen challenges (e.g., natural disasters). We found conducting successful community-engaged virtual research requires seeking strategic support, enhancing collaboration, and increasing our adaptability. As during and post-pandemic research environments may change quickly, important initial steps include conducting a needs assessment tailored to the situation, seeking guidance about changing policies from university research offices, and collaborating with IT staff regarding technology strengths, weaknesses and added security considerations. Multisite collaborations offer challenges due to different and changing institutional pandemic responses and recovery but also advantages. Our research greatly benefited from the combination of each institution's differing strengths. The involvement of a collaborative, committed, and highly communicative research team, perhaps larger than pre-pandemic research studies, allows adaptability



during times with less predictable schedules. Building on established community-academic partnerships enhances study recruitment efforts for virtual research. During and post-pandemic, virtual research offers advantages for recruiting and engaging geographically-diverse populations, and those with time or mobility limitations.

Despite the challenges of transitioning in-person community-engaged public health research to virtual during the pandemic, our efforts revealed unique and unanticipated benefits. Anecdotally research team members, from investigators to participants, voiced that our study afforded them beneficial human contact during the social isolation of the pandemic and particularly meaningful interactions. As one of our study participants observed, “we are going to make sure this happens...there is a broad spectrum of people who do not have the resources...we do not have to think that it just goes this way...we need to change it.” We also believe that public health researchers, through sustaining the momentum of community-engaged research, have the tools and responsibility to address the increased health and well-being needs of individuals managing chronic conditions during and post-pandemic.

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