Community-engaged Processes for Restarting Federally-funded Research in a Community-based Organization During the COVID-19 Pandemic

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ABSTRACT

Background: Birmingham AIDS Outreach (BAO) is one of three study sites partnering with the University of Pittsburgh Graduate School of Public Health (Pitt Public Health or PPH) for a National Institutes of Health-funded randomized controlled trial on a financial management intervention for people with HIV who are experiencing homelessness or housing instability. After the onset of the COVID-19 pandemic in March 2020, the study team used a community-engaged approach to adapt research protocols at this site.

Objectives: To describe a community-engaged approach to restarting NIH-funded research during the COVID-19 pandemic.

Methods: Partners at PPH and BAO developed a set of agency-wide COVID-19 policies and procedures for BAO organized around Rhodes' critical elements of community engagement.

Conclusions: The challenges presented by COVID-19 in the research sector have provided an opportunity to reevaluate study activities and increase the extent to which research is conducted in a community-centered manner.

KEYWORDS: HIV, COVID-19, Community health partnerships, Community Health Services, Power sharing

Background

Given gaps in structural interventions targeting people with HIV (PWH) with economic disadvantage (e.g., those seeking to change environments rather than behaviors), researchers at the University of Pittsburgh Graduate School of Public Health (Pitt Public Health or PPH) are conducting a National Institutes of Health (NIH)-funded randomized controlled trial (RCT) to test the effectiveness of a financial management intervention for PWH experiencing homelessness or housing instability on HIV-related outcomes.[1] The intervention is based on the representative payee program, a longstanding policy of the United States (US) Social Security Administration (SSA) in which a beneficiary of social security entitlements deemed incapable of managing their own funds is afforded a representative payee to do so on their behalf.[2] Client-Centered Representative Payee (CCRP) modifies the traditional model by emphasizing client decision-making and goal-setting while continuing to provide representative payee services to ensure clients' rent is paid and housing remains stable.[2] The CCRP intervention utilizes an organizational representative payee and a case manager, who draws from strength-based approaches, working in unison with the client to meet their financial goals. In a pilot study, investigators found that CCRP may improve adherence to antiretroviral therapy (ART) and HIV viral load.[3]

In 2019, PPH researchers formalized a partnership with a Birmingham, Alabama, community-based organization (CBO), Birmingham AIDS Outreach (BAO), as one of three CCRP study sites. Within this relationship, PPH is the awardee of the NIH grant and developed subawards with each site, including BAO. The subaward was developed by the Principal Investigator of the grant in collaboration with the financial manager at each site to ensure sufficient funding for the study responsibilities. At BAO, this included full-time coverage for a

site champion/social worker and additional effort for the site lead and financial coordinator. Recruitment at the site began in July 2019. The decision to partner with this site was made to improve recruitment outcomes and to enroll a more geographically diverse sample.

In March 2020, the World Health Organization categorized SARS-CoV-2, the novel coronavirus also known as COVID-19, as a global pandemic. Days later, COVID-19 was declared a national emergency in the US, and NIH encouraged their funded studies to "limit study visits to those needed for participant safety" on March 16, 2020.[4] The University of Pittsburgh suspended all non-essential research activities on March 20, 2020.[5] Non-essential CCRP study activities, including recruitment and enrollment of new participants, were suspended at that time. Study activities such as provision of representative payee services and data collection with current participants were considered essential activities, since halting the intervention would remove access to participants' entitlements including Supplemental Security Income. Study activities that continued through the suspension did so with significant methodological adaptation to ensure safety for participants and staff. At the same time, BAO encountered substantial challenges in their provision of services to PWH. As a CBO with a history of adapting to the evolving needs of the community, the organization swiftly modified client services, including counseling and legal services, to be completed via teleconferencing and mail, eliminating in-person contact.[6]

To adapt the study protocol in Birmingham in response to pandemic limitations and to ensure continuity of CCRP services, PPH and BAO initiated a community-engaged approach to strengthen community capacity, including problem-solving capacity, building on Rhodes' critical elements of community engagement as an organizing framework.[7] These processes expanded on the partnership's existing relationship and further increased equitability in decision-making.

Utilizing the experiences and perspectives of both NIH-funded researchers at PPH with program planning and evaluation skills and the community-based team at BAO with experience delivering client services ensured development of a responsible research restart plan.

The challenges presented by different state- and county-level COVID-19 mitigation policies, NIH and PPH guidance regarding research restart, and BAO staff safety policies (e.g., work from home) related to COVID-19 made a community-engaged approach that considered the strengths, needs, and "on the ground" realities of both partners essential to this work. Herein we describe processes used to restart research during the global pandemic guided by Rhodes's framework.[7] The shared commitment to a community-engaged approach that protects all persons at both sites provided opportunities to implement changes to organizational policies, including an NIH-approved safety protocol implemented agency-wide.

Objectives

Using the critical elements of community engagement and building on pandemic adaptations to client services already enacted by BAO, the aim of this paper is to describe a community-engaged approach to restarting NIH-funded research during COVID-19 balancing client and staff safety and community needs with university expertise and a desire to continue to advance health outcomes research. Other partnerships involving university-community collaborations may learn from our approach, whether to safely resume research activities during future pandemics or inform community-centered research planning efforts. Given community needs frequently change and evolve over time, it is imperative for research entities to have mechanisms to respond to these changing needs. Therefore, this organizing framework has utility even outside of a pandemic context.

Methods

Restarting Research under COVID-19

The process for restarting the NIH-funded CCRP study involved multiple video conference planning meetings, occurring every two weeks, with members of the academic research team at PPH and staff at BAO. During these meetings, the PPH team explained required university procedures to safely restart research activities during COVID-19, while BAO representatives described current local conditions "on the ground" and agency protocols adapted to protect the health of staff and clients. These discussions included incorporating vital input from BAO's community partner board, consisting of BAO staff and representatives from external organizations and the community including PWH, academic partners, and CBOs. During planning meetings, the university-community partnership team developed policies for research restart at BAO that fulfilled PPH and NIH requirements while aligning with BAO operational procedures. BAO and PPH representatives shared updates from their respective organizations and how the pandemic was affecting their local communities, discussed needs of study participants and ways to address those needs, and worked on adapting study procedures. The study PI also kept the team abreast of NIH and university procedures, which changed frequently. Rather than developing policies for BAO specific to the current study, university-community partners developed agency-wide COVID-19 policies and procedures that adapted and, in some cases, expanded on the university's mandates.

The process of resuming research activities for the academic and community partners was reflective of a true community-engaged process, despite myriad internal and external stressors experienced by both partners resulting from the pandemic. We describe critical elements of

community engagement[17] with examples of each element and how they pertained to the research restart process. Additional examples of each element are included in Table 1.

1. Commitment to engagement: Prioritizing ethics in human subjects research

Throughout this study and especially in the context of COVID-19 mitigation procedures, we consciously framed our work in alignment with the principle of beneficence, seeking opportunities to maximize benefits for participants and minimize risk of harm. The complex nature of the study and its involvement in managing personal finances required that the intervention continue without interruption so participants would not experience financial or emotional distress due to disruption of services, even as BAO altered operating procedures such that clients could no longer enter BAO facilities due to social distancing imperatives. Thus, while recruitment was temporarily halted, active participants continued their study visits via telephone and were mailed study surveys rather than completing them onsite. A modification was submitted to and approved by the University of Pittsburgh Institutional Review Board (IRB), the reliance Single IRB for this study, to ensure remote study activities met expectations for ethical conduct of research with human subjects. This remote arrangement continued for approximately six months until BAO determined that an exception to the "no clients in the building" rule during COVID-19 was needed for participants involved in this study, recognizing the unique ethical responsibility to clients involved in representative payee services and the enhanced need for case management.

2. Commitment to understanding and addressing participant challenges

While regular in-person contact between study participants and their CCRP case manager was central to the intervention prior to the onset of the pandemic, adherence to health and safety regulations necessitated that all study activities move to a virtual platform during COVID-19.

However, due to the limited technological access, the only feasible means of communication with most participants was telephone. Without preexisting rapport between the case manager and participants, this platform change might have been disastrous; however, the case manager had already established a strong rapport with participants. Building on this rapport, the case manager was able to continue working with clients to create budgets and complete bill payment, with community partners helping with utility assistance when bills exceeded monthly payments, and with the SSA to ensure checks were deposited in a timely manner. In addition, the case manager used CDC social distancing guidelines to provide food box home delivery to mitigate COVID risk for those without personal transportation or who were self-quarantining after an exposure. Maintaining these essential services and the case manager-client rapport upon which they are built was a research restart priority identified by our team.

3. Partner flexibility

Flexibility was central to the success of our research restart process and is perhaps the most important principle for informing our community-engaged research restart process. Changes stemming from the emergence of the pandemic were swift, requiring all study partners to be ready and willing to modify procedures rapidly. The university partners exhibited flexibility by intentionally and meaningfully integrating community partner needs into the research process, including co-creating the COVID-19 policies and procedures research restart guide in partnership with BAO. We highlight this because while intentional collaboration in keeping with Rhodes' principles is the ideal, it is not always the case in academic-community research relationships. The community partners exhibited flexibility by working to implement rigorous COVID-19 policies upheld by the entire agency, further safeguarding the health and safety of clients and staff, rather than developing separate procedures specific to the study.

Moreover, both partners viewed the COVID-19 policies we created as a living document owing to the rapidly changing nature of the pandemic and university policies, which also required a willingness to be flexible to ongoing change. This ongoing flexibility, facilitated by mutual respect and transparent communication between the university and community partners, speaks to the sustainability of this and other policies involving the PPH/BAO partnership beyond the current pandemic.

4. Leveraging resources

Study partners exhibited strong leadership while offering unique strengths. Community partners lent their expertise in forming and maintaining strong relationships with participants and contributing to the accurate dissemination of the research restart experience, while academic partners provided expertise in study fidelity and commitment to community-engaged research. In addition, community partners were able to leverage their expertise in client services by devising an innovative, tailored recruitment process when study recruitment resumed. The use of the BAO waiting room and opportunity to feature study posters on the walls became defunct once clients stopped entering the building; so curbside food box services were utilized to aid in recruitment. BAO client services staff placed IRB-approved study flyers inside food boxes so all clients receiving food boxes (comprising 99% of clients at the agency) were able to hear about the study through this alternate strategy. While prior to the pandemic we relied on "lunch and learn" sessions with community partner agencies to build participant referrals, we created virtual information sessions to align with COVID-19 mitigation policies. We also worked with BAO's existing community partner board, which met once a month via Zoom during the pandemic, to discuss innovative ways to continue recruitment.

The PPH team shared its technological resources and expertise to assist BAO in developing and implementing agency-wide COVID-19 safety procedures. PPH team members created a simple building entry survey to track staff members' movements between BAO's three separate buildings to enable contact tracing. A QR code was posted at the entrance of BAO so staff entering the building could quickly scan the code from their phones and complete a COVID-19 screening survey prior to entering. An additional QR code was placed at entrances so staff could complete short self-attestation surveys about any COVID-19 symptoms or recent exposures. PPH's resource-sharing not only served to implement and regulate COVID-19 safety procedures to ensure alignment with guidelines from PPH and NIH, but also provided BAO with increased means to protect its staff during the pandemic.

5. Participation of diverse sectors

The "pause" that COVID-19 placed on study activities also engendered opportunities for study partners to reevaluate study processes and materials. For example, after revisiting the animated recruitment video created before the pandemic, community partners from BAO's board questioned whether the video was culturally sensitive and gave feedback on how to tailor the video. After the board reviewed the video, they suggested that rather than having a White female explain the study to a Black male potential participant, which could contribute to anti-Black racism, the video should feature two culturally similar peers discussing the study. The academic partners then incorporated these changes into a new animated video voiced by culturally- and racially-matched local actors. The final version of the video was then approved by the community partner board.

6. Collaborative vision and process

PPH and BAO collaboratively established a clear and intentional mission to equitably approach the research restart process, informed by community members and building on mutual respect and a commitment to transparency. The core tenets of this approach, permeating all research restart decisions, included prioritizing flexibility and the health of clients and staff over study needs. PPH and BAO consistently met every other week (within-group meetings occurred weekly and community partner board meetings occurred monthly) to ensure that this mission directed the research restart process. While the PPH team oversaw logistical aspects of study management and ensured adherence to state and federal regulations , BAO led core implementation procedures "on the ground" and ensured that the study's ongoing implementation was informed by community members through monthly discussions with the community partner board about the needs of current and future participants. In this way, partners exerted power in their own spheres of expertise which served to enhance collaboration by averting any territoriality.

7. Adapting approaches to work through challenges and embracing conflict

One of the most significant study challenges occurred when BAO restricted clients from entering their facilities after COVID-19 was declared a pandemic (later, as previously described, study participants were the only exception to this rule and were allowed to resume in-person study activities). This directly impacted data collection, which previously occurred in-person when clients completed scheduled surveys. To adjust to the new circumstances and ensure research continuity, the study partners created a process, in tandem with appropriate IRB approvals, to obtain verbal consent to mail the surveys to participants. Once study recruitment was restarted, BAO increased its social media presence to promote the study and, as previously mentioned, placed recruitment flyers in food boxes that were distributed to clients.

8. Building a shared history

Ultimately, BAO and PPH enhanced a successful research partnership during COVID-19, informed by community voices, which may be carried forward into future collaborative endeavors. The research restart process described here, the success of which hinged on a strong partnership between all partner groups, engendered good will and a shared feeling of ownership among team members who worked together throughout to problem-solve.

Process for Manuscript Preparation and Writing

In line with the tenets of community-based participatory research (CBPR), community and academic partners were mutually involved in developing and writing the manuscript from conceptualization through the final editing stage.[8-11] Three community members representing BAO (Director of Research and Development, Director of Research Initiatives, and CCRP Lead Social Worker) and four academic researchers (including the study and site Principal Investigators, as well as the Research Coordinator and Graduate Student Researcher) met three times during the initial planning stage to outline the manuscript. To co-develop content for the manuscript, this group started with a brainstorming activity rooted in human-centered design methods known as affinity clustering.[12,13] First, each person in the group worked independently to create notes reflecting important elements of our restarting research processes. One by one, we then took turns describing a note, then placing it on a virtual mural board since all of the meetings took place remotely. As new notes were described, they were placed in proximity to similar ideas. By repeating this process, we identified patterns that aligned with the Rhodes framework and informed the content for this paper. Subsequently, specific writing assignments were allocated based on co-authors' interests. Throughout this process, the team routinely sought

input and direction on manuscript development from the BAO community partner board during monthly meetings where the work was a recurring meeting agenda item.

We applied Bordeaux and colleagues' guide for community-academic partnerships in writing manuscripts about CBPR to guide our research restart process and to ensure equitability among authors' contributions to this manuscript.[10] These guidelines describe how to equitably include community partners in each phase of the writing process and provided a framework for us to follow. Community partners were given precedence over university partners in choosing which sections to write.

Final Research Restart Organizing Framework

Academic and community partners worked together to brainstorm key elements of the research restart process, organizing our concepts around Rhodes's 12 critical elements of community engagement.[7] Rhodes's work describes a larger intervention development and implementation process generated over an extended time frame. Because our work described herein details one function of our community-based research study and this work took place over a shortened timeline, we collapsed Rhodes's 12 critical elements into eight categories (Table 1). The categorization process happened organically using affinity clustering, as described earlier.[12,13] Elements that clearly did not apply to our situation were excluded (i.e., "knowledge of and unflagging commitment to community engagement as an approach to reduce local STD disparities"), while others were combined or created to more accurately represent the research process. Table 2 illustrates how our elements compare with our Rhodes'.

Conclusions

While restarting research during the COVID-19 pandemic has presented many challenges to researchers and their community-based study partners, it has also provided opportunities to collectively reevaluate study activities while increasing the extent to which research is conducted with a community-based focus. Building on Rhodes's 12 critical elements of community engagement and adaptations put in place by BAO's client services, we described a community-engaged approach to restarting NIH-funded research during the COVID-19 pandemic, the tenets of which may inform other community-engaged research processes. Our process may be applied by other investigators in during future pandemics or any sudden changes that alter communities' health priorities, underscoring *partner flexibility*. Moreover, by balancing client and staff safety and needs with the knowledge of university and community expertise, while also engaging community members, we are able to continue health outcomes research. We believe this is the first time these critical elements of community engagement have been adapted, applied for use in a research restart setting, and described in the peer-reviewed literature. While community-engaged research is not a new concept, we believe the rapidity with which our academic and community partners united to reevaluate and retool the study protocol, while weighing national, community, and organizational regulations and staff and participant needs, is novel. Our processes were efficient especially given the extended length of time generally required for establishing strong community partnerships. An indication that our research restart methods met the needs of study participants is reflected in anecdotal evidence from individuals who expressed relief to their case managers that they could easily contact BAO staff as needed, that they remained able to access food boxes and representative payee services, and that rapport with staff was maintained even during social distancing. Multiple participants also expressed relief that COVID-19 mitigation protocols were in place at BAO, making them feel safer when they did

enter the building. Furthermore, during this process, no participants withdrew from the study, none lost housing, and rapidly returned to active recruitment once research restrictions were lifted.

Our study is not without limitations. The partnership described here includes only one community site, so elements of community engagement may not be fully transferable to multisite partnerships. Since the COVID-19 pandemic is still underway, the long-term success of this community engagement approach to research restart is still unknown. Our strategies may translate to research disruptions occurring outside of a pandemic, though here only described our community engagement experiences in restarting research during a global pandemic. Still, results suggest our strategy can withstand the multiple challenges faced by research partnerships during unusual times. Finally, while Rhodes's framework was useful for conceptualizing our research restart process, other frameworks may provide a better fit.

In conclusion, the community-academic partnership and shared commitment to a community-engaged approach offered protection to all involved in the research and provided opportunities to implement positive changes to organizational policies, including implementation of an agency-wide, NIH-approved safety protocol. Describing the ways community-engaged research may be quickly adapted to meet the evolving community health needs during a public health crisis may provide guidance for future research efforts between academic institutions and CBOs.

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Table 1. Key Elements of Community-Engaged Research

Characteristics and Values	Strategies
1. Commitment to engagement: Prioritizing ethics in human subjects research	▪ Changing the consent to match new research activities ▪ Updating the consent process ▪ Commitment to research and research ethics ▪ Necessity to continue research and intervention for participants already enrolled ▪ Strong relationship with participants ▪ Community-based organization (CBO)'s experience working with clients on the ground ▪ Balancing services with research demands at CBO ▪ Relieving fear from participants and study staff ▪ CBO's culture and investment in clients ▪ Supporting program redesign in light of the pandemic and its effects on all stakeholders
2. Commitment to understanding and addressing participant challenges	▪ Limiting face-to-face contact with participants ▪ Working with participants with limited access to resources (e.g., phone and email)
3. Partner flexibility	▪ Funding latitude afforded by NIH ▪ Adaptability of working with CBO ▪ Nature of the project's flexibility and ease of adaption ▪ Understanding that policies are a living document and may need to be changed ▪ Acting quickly when time for the study to restart ▪ Identifying innovative processes that can be used in research restart (e.g., utilizing client services for recruitment opportunities)
4. Leveraging resources	***CBO strengths:***

Kay, E.S., Creasy, S.L., Bruce, J., Olaniuan, A., Scheinert, M., Batey, D.S., Hawk, M. (2022) Community-engaged Processes for Restarting Federally-funded Research in a Community-based Organization During the COVID-19 Pandemic. *Progress in Community Health Partnerships.* (Forthcoming.)
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	▪ Organizational leadership buy-in ▪ Having research partners onsite ▪ CBO's culture and investment in clients/participants ▪ CBO's expertise and knowing what is needed for the success of the project. ▪ Strong relationship with the participants ***Research Strengths:*** ▪ Strong direction from the research team ▪ Academic resources provide shortcut to processes for CBO and guidance for research restart
5. Participation of diverse sectors	▪ Involving a CAB – the pause during the pandemic gave us a moment to revisit our process and recruitment methods ▪ Responding to and listening to the voices who needed to be at the table, i.e. CBO staff, university researchers, and NIH ▪ Turning to other programs to ensure participants had the support they needed ▪ Challenges relating to Social Security Administration (SSA) and navigating multiple systems (e.g., SSA closures and delays) ▪ Differences in state-level policies ▪ Challenges of working with multiple groups/sectors (universities, CBO, SSA)
6. Collaborative vision and process	▪ Commitment to equitable approach to research restart rather than taking a top-down or macro approach ▪ Prioritizing flexibility and creativity in applying the mandates to the community-based partner ▪ Prioritizing the health of clients and staff over study needs. ▪ Involving community partner in developing new policies (equal partnership) ▪ Open communication; sharing ideas back and forth ▪ Many positive elements of the academic-CBO partnership ▪ Working together re: university policies/timeline and CBO policies/timeline

7. Adapting approaches to work through challenges and embracing conflict	▪ Creative virtual and social distanced study activities ▪ Resuming recruitment in a new normal ▪ Data collection changes, (e.g., mailed surveys) ▪ Utilizing mail in and drop off services rather than face to face ▪ Missed surveys and lack of communication = change in data collection timelines and protocol ▪ Using technology to cut down on possible transmission routes (e.g., QR code rather than paper log) ▪ Building exit/entry & self-attestation - complement to CBO's COVID policies ▪ Staying relevant while study is in shut down
8. Building a shared history	▪ Safety protocol for entire agency to protect the health of all persons involved, not just study staff and participants ▪ Implementing changes that positively impact organization-wide policies, not just specific to research or this particular study ▪ Getting to the point of research restart in a way that felt safe for people was a success

Rhodes' Critical Element	Our Corresponding Research I Critical Element	Reasoning Behind Adaptation or I
1. Knowledge of and unflagging commitment to community engagement as an approach to reduce local STD disparities	**1. Commitment to engagement: Prioritizing ethics in human subjects research**	**Rhodes' element #1 was adapted to reflect our commitment to ethics in community-engaged human subjects research. The language around STDs was excluded as this was not the focus of our research.**
2. Commitment to understanding and addressing social determinants of health and how they relate to STDs	**2. Commitment to understanding and addressing participant challenges**	**Rhodes' element #2 was adapted to reflect our commitment to keeping study participants as safely as possible during the COVID-19 pandemic. The language around STDs was excluded as this was not the focus of our research.**

3. Partner flexibility	**3. Partner flexibility**	**N/A**
4. Talented and trusted leadership	**4. Leveraging resources**	**Our element #4 was created through a combination of Rhodes' elements #4 & #11. This more clearly fit the realities of our situation, since the resources needed to successfully restart our research processes were largely related to leadership within BAO and the PPH team.**
5. Participation of partners representing diverse sectors	**5. Participation of diverse sectors**	**N/A**
6. Collaborative establishment of a vision and mission	**6. Collaborative vision and process**	**Our element #6 was created through a combination of Rhodes' elements #6, #7, #8, & 9. We felt that each of these four elements reflected the same general intent of shared**

		and collaborative community engagement process.
7. Sharing power	**6. Collaborative vision and process**	**Our element #6 was created through a combination of Rhodes' elements #6, #7, #8, & 9. We felt that each of these four elements reflected the same general intent of shared and collaborative community engagement process.**
8. Open communication, respecting various ways of communicating, and the diversity of community voices	**6. Collaborative vision and process**	**Our element #6 was created through a combination of Rhodes' elements #6, #7, #8, & 9. We felt that each of these four elements reflected the same general intent of shared and collaborative community engagement process.**
9. Shared decision making	**6. Collaborative vision and process**	**Our element #6 was created through a combination of Rhodes' elements #6, #7, #8, &**

		9. We felt that each of these four elements reflected the same general intent of shared and collaborative community engagement process.
10. Embracing and working through conflict	**7. Adapting approaches to work through challenges and embracing conflict**	**N/A**
11. Identifying and leveraging talents, strengths, and resources	**4. Leveraging resources**	**Our element #4 was created through a combination of Rhodes' elements #4 & #11. This more clearly fit the realities of our situation, since the resources needed to successfully restart our research processes were largely related to leadership within BAO and the PPH team.**
12. Building a shared history of success	**8. Building a shared history**	**N/A**