


BRIEF REPORTS

Lessons Learned From Conducting Community-Based Research on HIV Prevention With Youth During COVID-19

Katherine LeMasters¹ ^a, Allysha Maragh-Bass², Marie Stoner³, Nivedita Bhushan⁴, John Mitchell⁵, Linda Riggins⁶, Alexandra Lightfoot⁷

¹ Department of Epidemiology, Gillings School of Global Public Health, University of North Carolina at Chapel Hill; Center for Health Equity Research, Department of Social Medicine, School of Medicine, University of North Carolina at Chapel Hill, ² FHI 360, ³ Women's Global Health Imperative, RTI International, ⁴ Center for Communication Science, RTI International, ⁵ 6. Department of Psychiatry and Behavioral Sciences, Duke University, ⁶ Cecil Sheps Center for Health Services Research, University of North Carolina at Chapel Hill, ⁷ Department of Health Behavior, Gillings School of Global Public Health, University of North Carolina at Chapel Hill; Center for Health Promotion and Disease Prevention, University of North Carolina at Chapel Hill

Keywords: PrEP, HIV prevention, Youth and young adults, Southern United States, COVID-19

<https://doi.org/10.35844/001c.38385>

Journal of Participatory Research Methods

Vol. 3, Issue 3, Youth-themed Special Issue, 2022

Mitigating HIV burden among Black youth requires true community engagement. This brief report identifies challenges, strategies, and lessons learned from transitioning our three-phased, community-engaged HIV prevention project with Black youth to a remote format during COVID-19. The project involved (1) building a community-academic partnership on youth sexual health, (2) participatory youth workshops, and (3) youth surveys and interviews about HIV prevention. Feedback from community-academic partnership, pile sorting themes, and preliminary qualitative analyses guided this report. Challenges included a disruption to in-person engagement while strategies included relying heavily on pre-existing partnerships to recruit youth for interviews. We learned that pre-existing community engagement was essential for completing phase three remotely. More education is needed to support Pre-Exposure Prophylaxis (PrEP) awareness for HIV prevention and there is a need to address structural barriers to healthcare engagement such as community violence and mental illness. Community-engaged HIV research focused on youth can adapt if anchored in community relationships. Future studies must work to more fully center youth's voices and address the structural issues that may inhibit them from engaging in HIV prevention.

Introduction

The HIV epidemic disproportionately affects Black youth (ages 13–24), particularly those in the southern United States (U.S.). Youth account for 22% of new HIV infections in the U.S. and over half of these cases are among Black youth (The Centers for Disease Control and Prevention, 2014). In addition, despite making up 37% of the U.S. population, about 45% of people with an HIV diagnosis live in the southern U.S., and Black youth bear the burden of new infections in the region (The Centers for Disease Control and Prevention, 2014, 2016). The disproportionate impact on Black youth is rooted in disparities in social and structural determinants of health (Bowleg, 2020). For example, socioeconomic status and racism are fundamental causes of health inequities that have structured the course of the HIV epidemic (Kahana et al., 2016). Structural determinants of health also adversely impact retention

^a Corresponding author:

Katherine LeMasters, Department of Epidemiology, University of North Carolina at Chapel Hill, McGavran-Greenberg Hall, CB# 7435, Chapel Hill, NC 27599; Telephone: 325-232-2090; Fax: 919-966-2089; Email: Katherine.lemasters@unc.edu).

in HIV prevention and care among youth (Kahana et al., 2016). There is a critical need to understand HIV risk among Black youth in the U.S. South to ensure that HIV prevention interventions are relevant and applicable to this population.

Pre-Exposure Prophylaxis (PrEP) is a daily pill that reduces the risk of HIV infection in people at high risk via sexual transmission by over 90% and has been approved for youth since 2018. While it is a promising approach to HIV prevention, uptake among youth—particularly Black youth—has been low due to a lack of awareness, accurate knowledge, assumptions about PrEP, perceived lack of risk, and structural factors (e.g., stigma, racism, lack of medical access and health insurance) (Eaton et al., 2015; Tanner et al., 2020). To understand the reasons for low PrEP uptake and develop strategies to increase the use of PrEP, it is critical to engage Black youth in the research process. In 2018, we began a community-engaged research project on PrEP interest and uptake among Black youth in Durham, North Carolina (NC), a city that is nearly 40% Black and has the sixth-highest rate of reported HIV infection in NC (Adams et al., n.d.).

The COVID-19 pandemic began in 2020 and its impact on Black communities has followed a similar storyline to other health conditions, such as HIV, that disproportionately affect Black communities (Bowleg, 2020). For example, Black individuals have been disproportionately hospitalized for and died from COVID-19 with Black individuals dying at 1.4 times the rate of White individuals (Price-Haywood et al., 2020). The disproportionate impacts of COVID-19 on Black communities stem from the same structural determinants of health (e.g., socioeconomic status, racism) that have shaped the course of the HIV epidemic (Bowleg, 2020). This results in communities with high proportions of people of color living in poverty, crowded housing, and high levels of racialized economic segregation experiencing high burdens of COVID-19 cases and deaths (Parolin, 2021). Given the disproportionate impact of both HIV and COVID-19 on Black communities, it is critical that HIV prevention and PrEP care remain in place during the COVID-19 pandemic. However, the HIV prevention continuum, including PrEP, has been disrupted, with disproportionate impacts patterned by structural determinants of health (Qiao et al., 2021). These disruptions are compounded for Black individuals, who already experienced more disruptions to PrEP care before the COVID-19 pandemic than others (Rowe et al., 2022), and for youth, for whom typical barriers to care (e.g., financial burdens) are heightened (Stephenson et al., 2021). The COVID-19 pandemic has disproportionately affected Black youth beyond physical health and healthcare access. Black youth are more likely than their White counterparts to experience poverty and food insecurity, to have had parents lose their jobs, and to be exposed to distance learning and school closures during the pandemic (Parolin, 2021).

Given the focus of our work on HIV prevention with Black youth, the far-reaching effects of the COVID-19 pandemic on this community, and COVID-19 restrictions on in-person meetings, we adapted our community-

engaged research approaches accordingly (e.g., from an in-person to virtual format). In this report, we identify the lessons learned from continuing our community-engaged HIV prevention project with Black youth, transitioning it to a remote setting, and pivoting to more broadly think about structural determinants of health during the COVID-19 pandemic.

Methods

Background on Community Partnerships

Project IFE (I'm Fully Empowered) was a community-academic partnership focused on long-term HIV prevention among Black women in Durham Housing Authority (DHA) communities in Durham, NC (Rimmner et al., 2022). A key finding from Project IFE's formative research with DHA residents was the need to reach youth in the community. The project discussed here was developed in response to this community concern and provided an opportunity for a group of locally-based researchers (including epidemiologists, a clinical psychologist, behavioral scientists, and experts in community engagement) to conduct community-engaged research focused on HIV prevention among youth. Our three-part project involved: 1) building an Adolescent Health Working Group (AHWG) to engage local stakeholders focused on youth sexual health; 2) conducting participatory youth workshops to understand youth perspectives; and 3) conducting surveys and interviews with youth about PrEP awareness.

The Process of Pivoting

The pandemic affected our three-part project in different ways. The majority of Parts 1 and 2 occurred prior to the COVID-19 pandemic, whereas Part 3 occurred during the COVID-19 pandemic. The AHWG, comprised of stakeholders from the DHA, LGBTQ advocacy groups, adolescent healthcare providers, community-based organizations and non-profit groups, faith leaders, Departments of Public Health, as well as parents and adolescents, met six times to provide critical stakeholder input and guidance to the project. The pandemic necessitated that our final two AHWG meetings be conducted remotely. For Phase 2, we were able to hold three participatory youth workshops using the Youth Generating and Organizing (GO)! methodology prior to the pandemic which is described elsewhere (Stacy et al., 2018). Phase 3 took place fully remotely and our team added questions on COVID-19 in the context of this adaptation.

This report discusses the overall process of transitioning our project during COVID-19. This process was shaped by feedback from the AHWG at the beginning of the COVID-19 pandemic through meetings notes and a running list of topics recommended by the AHWG members at each meeting. Our research team iteratively conducted pile sorting to organize the key themes from our AHWG feedback and subsequently revise the project (Yeh et al., 2014). Preliminary analyses from Part 3 qualitative interviews focused on COVID-19's effect on youth also shaped this process.

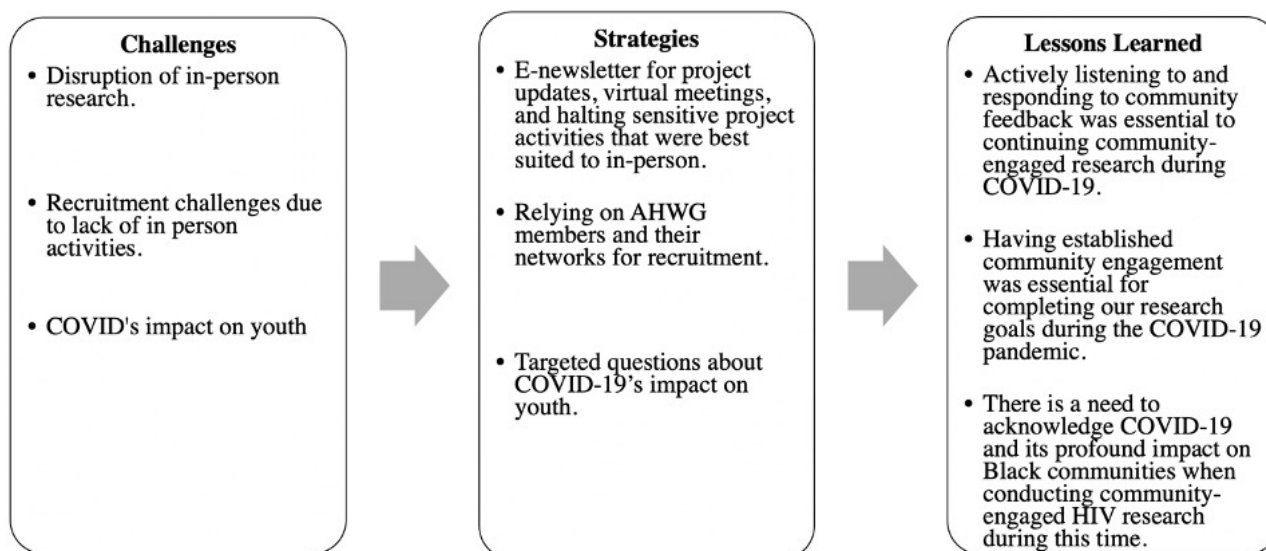


Figure 1. Challenges, strategies, and lessons learned from conducting community-based research on HIV prevention with youth during COVID-19

Results ([Figure 1](#))

Challenges

When the COVID-19 pandemic began, all in-person activities were halted. As all three parts of the project were intended to be held in person and relied on in-person community engagement, there was no clear immediate path forward. For example, the Phase 3 survey and interviews had not started prior to COVID-19 and were held entirely virtually. We began outreach in June of 2020 through Facebook advertisements and e-mailing local community listservs to reach as wide a population of youth and their parents as possible. Between June and September of 2020, we recruited only 17% of our sample target through Facebook and listserv recruitment, as these were not platforms youth themselves were regularly using. Furthermore, it was clear that the COVID-19 pandemic was having a negative impact on youth involved in the AHWG and on those participating in the participatory youth workshops via increased isolation and virtual school.

Strategies

To address the halting of in-person meetings, Phase 1's final two of six AHWG meetings were held on a virtual platform—Zoom—and guided the remaining study activities. No AHWG members expressed concern with pivoting to a virtual format and we were able to meet individuals individually in outdoor spaces to provide them with payment. Some AHWG members struggled with digital accessibility but we were able to follow-up individually with these individuals. Based on feedback from these virtual meetings, AHWG members felt comfortable expressing their thoughts in a virtual format, felt training youth in research would amplify youth voices, and that an e-newsletter could maintain community engagement while in-person gatherings were

restricted. We used feedback from this evaluation form in real-time to structure the remaining aspects of our project and in our decision to continue this piece of the project virtually.

The last Phase 2 participatory youth workshop session was not held virtually due to the sensitivity of talking about youth sexual health and youth's privacy, and the collaborative and interactive format of the participatory workshops was not conducive to a virtual environment. In September 2020, we pivoted to relying on Phase 1 AHWG community members (e.g., youth and faith community leaders) to recruit and complete enrollment targets for surveys and interviews. Using this strategy, we reached 87% of recruitment goals for interviews and surveys within 3 months. The interview guides were created at the beginning of the COVID-19 pandemic and multiple questions and prompts were added to broadly contextualize the impact of COVID-19 on Black youth in the community broadly (e.g., what is your daily life like during COVID-19). More specifically, we asked how COVID-19 intersected with HIV prevention efforts and behaviors that would put youth at risk for acquiring HIV. Interviews with youth highlighted the need to address structural barriers to healthcare engagement for HIV (e.g., community violence, mental illness), particularly during the COVID-19 pandemic. While the youth were grateful for time with family, they described "quarantine depression" due to COVID-mandated virtual schooling, physical distancing, and overwhelming racial injustices portrayed in media.

Discussion: Lessons Learned

The current study reports on a community-engaged project on HIV prevention among Black youth that was adapted in the context of the COVID-19 pandemic. The impact COVID-19 was having on Black youth in Durham, NC, required us to consider how social and structural determinants of health affect intersecting concerns like COVID-19, HIV risk, and HIV prevention. Through pivoting our project to be remote, discussing with AHWG members and youth about what aspects of the project would be appropriate to continue, and using their feedback in real-time, we developed a more holistic understanding of what was taking place in youths' lives that affected HIV prevention and health and well-being more broadly. This process points to the importance of addressing structural determinants of health and addressing overlapping health concerns when conducting community-engaged work. It is incumbent that future studies work to more fully center youth's voices and address the structural issues that may inhibit them from engaging in HIV prevention.

To address HIV prevention during 2020 among Black youth, one central lesson learned was that it was necessary to also acknowledge COVID-19 and its profound impact on Black communities. Community-engaged research provided us with the process to expand our research and to ensure our research was meaningful and attentive to the community's needs. Community engagement prior to the pandemic was also essential for completing our research goals during the pandemic and provided a platform for feedback to be

flexible in the goals of the original research plan. For example, some parts of our data collection were paused due to youths' levels of comfort with sharing virtually. At the same time, our qualitative research expanded to explore youths' daily lives and stressors related to COVID, which also affected their ability to engage in preventative health measures.

Limitations

Due to the COVID-19 pandemic quickly altering the course of our research, we were unable to solicit specific feedback on certain aspects of the project. For example, while AHWG members said that they wanted to continue with a virtual platform, we did not ask about the content of the virtual meetings (e.g., using breakout rooms). We believe that more specific feedback would have been particularly helpful in retaining youth in our AHWG. Additionally, this project was focused in Durham, NC, and youths' experiences in other regions and in more rural areas are likely widely varied. Therefore, factors that may have been relevant in adapting our research may be less generalizable in other settings. Relatedly, this project did not specifically focus on youth experiencing the greatest disparities, who may have had different experiences, and whose lives may have been impacted differently by the COVID-19 pandemic.

Conclusions

Through this process, our research team learned that the following were critical components to this engaged research: 1) actively listening to and responding to community feedback by creating an e-newsletter, halting portions of the project that would be particularly sensitive to conduct in a virtual format, and relying on Phase 1 AHWG community members for recruitment; 2) continuing to be in the community during COVID-19 via virtual Zoom meetings and one-on-one outdoor meetups; 3) centering youth's voices by regularly checking in with youth to ensure data collection strategies were appropriate for capturing their perspectives and applying to additional funding to conduct youth-focused training for participatory research; and 4) acknowledging community needs beyond HIV prevention by incorporating COVID-19-specific questions and structural barriers to care into surveys. Importantly, having established community engagement was essential for completing our research goals during the COVID-19 pandemic. It is incumbent that we continue to assess the impact of COVID-19 in partnership with this community and that we understand the trajectory of the HIV epidemic within this context.

.....

Acknowledgements

We would like to thank our partners at the Durham Housing Authority, members of the Adolescent Health Working Group and participants in the study.

Funding

Funding was provided by the Duke and UNC CFARs (UNC CFAR P30 AI50410 and the Duke CFAR P30 AI064518). KL received general and training support (T32-HD091058; T32 HS000032-33) from the National Institutes of Health.

Declaration Of Interests

The authors have no declarations of interest to report.

Submitted: May 13, 2022 EDT, Accepted: August 22, 2022 EDT



This is an open-access article distributed under the terms of the Creative Commons Attribution 4.0 International License (CCBY-4.0). View this license's legal deed at <http://creativecommons.org/licenses/by/4.0> and legal code at <http://creativecommons.org/licenses/by/4.0/legalcode> for more information.

References

- Adams, N., Barnhart, J., Cope, A., Crowley, C., Furnari, M., Maxwell, J., Samoff, E., Mobley, V., Clymore, J., & Foust, E. (n.d.). *2019 North Carolina HIV Surveillance Report*.
- Bowleg, L. (2020). We're Not All in This Together: On COVID-19, Intersectionality, and Structural Inequality. *American Journal of Public Health*, 110(7), 917. <https://doi.org/10.2105/ajph.2020.305766>
- Eaton, L. A., Driffin, D. D., Kegler, C., Smith, H., Conway-Washington, C., White, D., & Cherry, C. (2015). The role of stigma and medical mistrust in the routine health care engagement of black men who have sex with men. *American Journal of Public Health*, 105(2), e75–e82. <https://doi.org/10.2105/ajph.2014.302322>
- Kahana, S. Y., Jenkins, R. A., Bruce, D., Fernandez, M. I., Hightow-Weidman, L. B., Bauermeister, J. A., & Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2016). Structural Determinants of Antiretroviral Therapy Use, HIV Care Attendance, and Viral Suppression among Adolescents and Young Adults Living with HIV. *PLOS ONE*, 11(4), e0151106. <https://doi.org/10.1371/journal.pone.0151106>
- Parolin, Z. (2021). What the COVID-19 Pandemic Reveals about Racial Differences in Child Welfare and Child Well-Being: An Introduction to the Special Issue. *Race and Social Problems*, 13(1), 1–5. <https://doi.org/10.1007/s12552-021-09319-2>
- Price-Haywood, E. G., Burton, J., Fort, D., & Seoane, L. (2020). Hospitalization and Mortality among Black Patients and White Patients with Covid-19. *New England Journal of Medicine*, 382(26), 2534–2543. <https://doi.org/10.1056/nejmsa2011686>
- Qiao, S., Li, Z., Weissman, S., Li, X., Olatosi, B., Davis, C., & Mansaray, A. B. (2021). Disparity in HIV Service Interruption in the Outbreak of COVID-19 in South Carolina. *AIDS and Behavior*, 25(1), 49–57. <https://doi.org/10.1007/s10461-020-03013-x>
- Rimmler, S., Golin, C., Coleman, J., Welgus, H., Shaughnessy, S., Taraskiewicz, L., Lightfoot, A. F., Randolph, S. D., & Riggins, L. (2022). Structural Barriers to HIV Prevention and Services: Perspectives of African American Women in Low-Income Communities. *Health Education & Behavior*, 10901981221109138. <https://doi.org/10.1177/10901981221109138>
- Rowe, K., Theodore, D. A., Zucker, J., Cohensedgh, O., LaSota, E., Carnevale, C., Cohall, A., Olender, S., Gordon, P., & Sobieszczyk, M. E. (2022). Lost2PrEP: Understanding Reasons for Pre-Exposure Prophylaxis and Sexual Health Care Disengagement Among Men Who Have Sex with Men Attending a Sexual Health Clinic at a Large Urban Academic Medical Center in New York City. *AIDS Patient Care and STDs*, 36(4), 153–158. <https://doi.org/10.1089/apc.2022.0004>
- Stacy, S. T., Acevedo-Polakovich, I. D., & Rosewood, J. (2018). Youth GO: An approach to gathering youth perspectives in out-of-school time programs. *Afterschool Matters*, 28, 34–43.
- Stephenson, R., Walsh, A. R., Chavanduka, T. M. D., Sallabank, G., Horvath, K. J., Castel, A. D., Bonar, E. E., Hightow-Weidman, L., Bauermeister, J. A., & Sullivan, P. S. (2021). Widespread closure of HIV prevention and care services places youth at higher risk during the COVID-19 pandemic. *PLOS ONE*, 16(9), e0249740. <https://doi.org/10.1371/journal.pone.0249740>
- Tanner, M. R., Miele, P., Carter, W., Valentine, S. S., Dunville, R., Kapogiannis, B. G., & Smith, D. K. (2020). Preexposure Prophylaxis for Prevention of HIV Acquisition Among Adolescents: Clinical Considerations, 2020. *MMWR. Recommendations and Reports*, 69(3), 1–12. <https://doi.org/10.15585/mmwr.rr6903a1>
- The Centers for Disease Control and Prevention. (2014). *CDC Fact Sheet HIV among African American Youth*. <https://www.cdc.gov/nchhstp/newsroom/docs/factsheets/archive/cdc-youth-aas-508.pdf>

The Centers for Disease Control and Prevention. (2016). *Trends in U.S. HIV diagnoses, 2005-2014*.
Yeh, H.-W., Gajewski, B. J., Perdue, D. G., Cully, A., Cully, L., Greiner, K. A., Choi, W. S., & Daley, C. M. (2014). Sorting it out: Pile sorting as a mixed methodology for exploring barriers to cancer screening. *Quality & Quantity*, 48(5), 2569–2587. <https://doi.org/10.1007/s11135-013-9908-3>