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Effectively confronting the COVID-19 pandemic: Critical lessons from HIV prevention, care, and treatment and innovative strategies to conduct community-based and community-engaged research safely

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Abstract

Coronavirus disease 2019 (COVID-19) is a new infectious disease caused by the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). The COVID-19 pandemic has profoundly altered the ways in which members of communities live, learn, work, and play. Similarly, the pandemic has affected the conduct of community-based and community-engaged research, which are essential research approaches to promoting health equity, reducing health disparities, and improving community and population health. In this commentary, we outline nine lessons from HIV prevention, care, and treatment that are particularly relevant to reducing the impact of the COVID-19 pandemic. We also identify ten innovative strategies to reduce exposure to SARS-CoV-2 among teams and community members conducting community-based and community-engaged research. Implementation of these strategies will help to ensure these research approaches can safely continue during the pandemic and that communities and populations continue to benefit from research designed to promote equity, reduce disparities, and improve health.

Keywords

OVID-19; community-based research; community-engaged research; CBPR; disparities

Coronavirus disease 2019 (COVID-19) is a new infectious disease caused by the novel severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) that was not seen in humans previously (Wiersinga, Rhodes, Cheng, Peacock, & Prescott, 2020). Manifestations range from asymptomatic infection to severe complications including pneumonia, acute respiratory distress syndrome, coagulopathies, immune system dysregulation, and death. COVID-19 is highly contagious and has quickly spread globally (Cascella, Rajnik, Cuomo, Dulebohn, & Di Napoli, 2020; Shiau, Krause, Valera, Swaminathan, & Halkitis, 2020). Precautions to reduce the risk of SARS-CoV-2 transmission within communities include

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social distancing (also known as physical distancing) to avoid close contact, using face coverings to cover one's mouth and nose when around others, washing one's hands often, and disinfecting frequently touched surfaces.

SARS-CoV-2 affects people differently. Some characteristics that increase one's risk for severe illness include being older, being immunocompromised, and having serious comorbidities such as diabetes, chronic kidney disease, chronic obstructive pulmonary disease, and obesity (Clark et al., 2020). Similar to the HIV epidemic, communities and populations that are marginalized based on race/ethnicity and income also carry a disproportionate burden of COVID-19. For example, Black Americans and Native American or Alaska Native persons have COVID-19-related hospitalization rates five times that of non-Hispanic/Latinx White persons. Hispanic or Latinx persons have hospitalization rates four times that of non-Hispanic/Latinx White persons (Wilder, 2020). Furthermore, Asian Americans and Pacific Islanders have significantly higher case fatality ratios. In San Francisco, for example, Asian Americans experience a four times higher case fatality rate than that of the overall population (5.2 percent versus 1.3 percent) (Yan, Ng, Chiu, Tsoh, & Nguyen, 2020). Asian American and Pacific Islander populations and communities also face COVID-19-related discrimination and hate crimes (Dhanani & Franz, 2020; Hu, Wang, & Lu, 2020).

Community-Based and Community-Engaged Research

Community-based research and community-engaged research, are approaches to research that take place in community settings and often involve community members as partners in the design, implementation, and evaluation of research projects. Community-engaged research in particular, which includes community-based participatory research (CBPR), is designed to better understand and more effectively increase health equity, reduce health disparities, and improve community and population health through the participation of the affected community in the research process, where the community refers to any group of people affiliated by geographic proximity, special interest, or similar situations (Clinical and Translational Science Awards [CTSA] Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Committee to Review the CTSA Program at the National Center for Advancing Translational Sciences [NCATS] & Institute of Medicine, 2013; Dankwa-Mullan et al., 2010; Israel, Schulz, Parker, & Becker, 1998; Rhodes, 2014; Rhodes, Malow, & Jolly, 2010; Viswanathan et al., 2004).

There is a deeply rooted relationship between community-based and community-engaged research and HIV prevention, care, and treatment within the United States and globally (Rhodes, 2014; Rhodes, Tanner, Mann-Jackson, Alonzo, Horridge, et al., 2018). The early successes in HIV prevention, care, and treatment were very much linked to community-based and community-engaged research, and some of the most innovative and successful HIV prevention and research efforts sprang from the creativity of gay men, who were being directly impacted by the epidemic, and their allies. Formal and informal partnerships of community leaders, community members, activists, advocates, and researchers initiated educational and prevention programs; developed and provided needed care; advocated for both drug development and expedited drug trials; and developed, implemented, and evaluated prevention, care, and treatment strategies within the community. Simply, gay men and their allies provided the needed support and care to friends, neighbors, and other community members who were living with and affected by HIV (Bloom, Whittier, & Rhodes, 2014). Since those early days, much, albeit insufficient, progress has been made within HIV prevention, care, and treatment that stems in part from community-based and community-engaged research.

Commentary Purpose

In this commentary, we highlight nine lessons from HIV prevention, care, and treatment that are particularly relevant to reducing the impact of the COVID-19 pandemic and ten innovative strategies to reduce exposure to SARS-CoV-2 among research teams and community members conducting community-based and community-engaged research. These strategies are not unique to HIV research and may be applied broadly to a variety of health research arenas.

Lessons from HIV Relevant to the COVID-19 Pandemic

We are now well into the fourth decade since the identification of HIV. While we continue to face challenges in terms of HIV prevention, care, and treatment, we have made tremendous strides in preventing infections through behavior change and biomedical strategies (e.g., pre-exposure prophylaxis [PrEP] and post-exposure prophylaxis [PEP]), identifying persons with HIV, and providing access and ensuring uptake and adherence to effective antiretroviral medications that reduce the risk of transmission and prevent and reduce associated complications and diseases among persons with HIV. We outline nine lessons from HIV prevention, care, and treatment that are particularly relevant to reducing the impact of the COVID-19 pandemic (Table 1).

Accurate, Timely, and Widely Available Testing Is Fundamental

Fundamental to HIV prevention, care, and treatment is HIV testing. A successful long-term response to COVID-19 requires accurate and timely testing, both for the virus itself and for the antibodies that indicate the presence of past infection. Within HIV prevention, testing is the first step in both the prevention and care continua. Those who test negative to HIV can be provided prevention resources, such as access to PrEP and condoms, to prevent future potential exposures. Those who test positive can be linked to or reengaged in care to reduce their viral load and participate in other forms of risk reduction to reduce HIV transmission. Within the context of the COVID-19 pandemic, those who test positive can similarly be linked to care and reduce disease transmission by isolating themselves from others until it is determined that they are not infectious.

An ongoing challenge facing the COVID-19 pandemic is decreasing the turnaround time for test results. The sooner a person tested for SARS-CoV-2 can obtain test results, the sooner appropriate preventive action can occur, including isolation and contract tracing, if the person tests positive, thus reducing the risk of exposing others.

Moreover, in the United States, HIV testing is widely available: at health departments, clinics, providers, and many community organizations; and within emergency rooms.

Ensuring broad access to SARS-CoV-2 testing in the communities disproportionately impacted by COVID-19 is crucial for the identification of infections and initiation of the steps to reduce transmission and associated inequities and disparities.

Contact Tracing and Community Trust Are Essential

Contract tracing, also known as partner notification in HIV and sexually transmitted infection (STI) investigation, is a core disease control measure that has been used by public health practitioners for decades. It prevents further transmission of disease by identifying people who have (or may have) an infectious disease, such as HIV or an STI, and counseling them to reduce their likelihood of exposing others within their sexual and/or drug-using networks. Given the rapid spread of SARS-CoV-2 and high numbers COVID-19 cases, many well-trained public health personnel are needed to conduct effective contact tracing.

Furthermore, because contacts must provide accurate information about those they potentially exposed, trust in the process and the public health system is paramount. For example, contacts must trust that information provided will be kept confidential. Although trust has been a challenge facing the HIV epidemic, and the lack of trust has become a profound challenge facing the COVID-19 pandemic in the United States (Anonymous, 2020; Rhodes et al., In press), community-based and community-engaged research have been shown to increase community member trust through multiple processes, including respect, inclusion, partnership, transparency, and assets orientations (CTSA Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Committee to Review the CTSA Program at the NCATS & Institute of Medicine, 2013; Dankwa-Mullan et al., 2010; Israel et al., 1998; Rhodes, 2014; Rhodes et al., 2010; Viswanathan et al., 2004).

Clear Prevention Messages Are Needed

Early on in the HIV epidemic in 1988, the then U.S. Surgeon General C. Everett Koop published and sent to every U.S. household an eight-page brochure titled, “Understanding AIDS” about HIV transmission, including details about the ways to prevent transmission (e.g., condom use) (Bloom et al., 2014). The messaging was simple, concise, and clear. It was designed to be understandable by a wide audience. Unfortunately, messaging about the transmission of SARS-CoV-2 in the United States has not been simple, concise, and clear, and much of the U.S. population remains confused about and mistrustful of COVID-19-related guidance. An example where we have failed in COVID-19 communications is the use of the term “social distancing;” this term has been identified as confusing and not interpreted in a way that is actually necessary to reduce risks. We are not truly asking individuals to not be social. Being social is necessary for feelings of connectedness and overall well-being, feelings that are even more important during a pandemic. Rather, we are, in fact, asking individuals to practice “physical distancing” (Bergman, Bethell, Gombojav, Hassink, & Stange, 2020).

Further, although our understanding of SARS-CoV-2 and its transmission has evolved, clearly and consistently communicating what is known and what is not known prepares members of communities for emerging new and/or revised guidance over time. This type of communication considered a hallmark of effective public health communications (World Health Organization, 2017).

Ongoing Behavior Change Requires Expertise from the Social and Behavioral Sciences

HIV is intricately interwoven with individual behavior and social context, and without inclusion of social and behavioral science research and practice, HIV prevention, care, and treatment would be incomplete and less effective (Institute of Medicine, 2001). However, to date, the potentials of social and behavioral sciences have not been fully harnessed to address the COVID-19 pandemic (West, Michie, Rubin, & Amlôt, 2020). Implementing SARS-CoV-2 transmission prevention practices, such as maintaining social/physical distance and using face coverings, require changes in and the adoption of new individual behaviors as well as adaptations to social contexts. These changes can be quite complex. To reduce the impact of COVID-19, experts in social and behavioral sciences must be integrated into the promotion of preventive behaviors. Social and behavioral scientists can systematically uncover and understand the barriers and facilitators for individuals to adopt ongoing preventive behaviors; they can develop the most promising strategies to promote behavior change, including through the use of community-based and community-engaged research. Currently, however, no member of the White House Coronavirus Task Force has expertise or thorough training in critical social and behavioral sciences such as health behavior or health communications (https://en.wikipedia.org/wiki/White_House_Coronavirus_Task_Force). The absence of critical skills contributes to the challenges facing SARS-CoV-2 prevention and COVID-19 management in the United States; sadly, our prevention efforts are not as science based as they could and should be, and thus they are less effective in reducing the impact of the COVID-19 pandemic.

Harm Reduction Minimizes Risks

Within HIV prevention, harm reduction, also known as harm minimization, is designed to minimize risks, whether risks are associated with sex or drug use. The idea is that while abstinence from sex or drugs affords the greatest protection from HIV, abstinence may not be realistic. Lower-risk activities, such as mutual masturbation, limiting the number of sexual partners, and using condoms, are harm reduction strategies commonly described as “safer sex.” Advances in effective antiretroviral therapy, viral-load monitoring, the knowledge that undetectable equals untransmittable (U=U), and PrEP have changed HIV risk assessments recently and are also strategies to reduce HIV risk (Kutscher & Greene, 2020).

Within the COVID-19 pandemic, there are multiple ways to apply principles of harm reduction when the risk of SARS-CoV-2 transmission cannot be completely eliminated. For example, given that it is not realistic for all individuals to stay home at all times or avoid contact with others outside one’s household altogether, risks can be reduced through going places with substantial space and air circulation and/or at times when there will be fewer people present (e.g., visiting grocery stores during “off hours” such as early in the morning or late at night); social/physical distancing to avoid close contact, limiting group sizes, meeting outside, and using face coverings to cover one’s mouth and nose when one must be around others; washing one’s hands often; and disinfecting frequently touched surfaces.

Harm reduction also suggests that persons with COVID-19 symptoms or a recent exposure to a person with COVID-19 self-isolate or quarantine, to limit any potential further transmission.

Another example of harm reduction includes forming “pods” or “bubbles” in which two or three groupings, families, or extended families agree to socialize with one another exclusively. These groupings or families socialize, often without regard to social/physical distancing. Outside of the pod or bubble, however, they follow social/physical distancing practices.

All decisions in a harm-reduction approach must be thoughtful, intentional, and negotiated, and require the consent of all involved before any interaction to establish guidelines for safety. However, it is important to recognize that poverty, socioeconomic status, racism, social isolation, past trauma, homophobia, transphobia, sex-based discrimination, stigma, and other inequalities affect one’s vulnerability to and capacity for effectively managing risks. For example, individuals who work in service jobs often have limited choices regarding what risk they are willing to tolerate to maintain employment (Rhodes et al., In press).

Upstream Factors Require Consideration and Intervention

As with HIV, living conditions, work circumstances and requirements, childcare, and other social determinants of health, including insurance and healthcare access, as well as higher rates of comorbidities increase the risk of severe illness from COVID-19 within marginalized communities and populations. These factors are shaped by the larger context of systemic racism and inequalities (Millett et al., 2020; Rhodes et al., In press; Sanchez, Zlotorzynska, Rai, & Baral, 2020). As we work to better understand and reduce the impact of COVID-19 on communities and populations, we must not look merely at individual behavior and place blame on an individual’s action. Rather, we must also aim to understand and intervene on the upstream factors that contribute to the pandemic and its disproportionate impact on marginalized communities and populations, including communities of color and under-resourced communities.

Community Perspectives and Talent Must Be Harnessed

Another profound lesson from HIV has been the importance of partnering with community members, particularly those most affected by HIV, to better understand HIV-related phenomena and related community and population needs, priorities, and assets, and to use this more informed understanding to develop, implement, and evaluate actions (including programs, interventions, and system and policy changes) that reduce risks of transmission, and thus, the impact of HIV. Partnering with community members, including those disproportionately affected by COVID-19, can similarly ensure a better understanding of COVID-19-related phenomena and related community and population needs, priorities, and assets. This improved understanding can be applied to develop, implement, and evaluate actions (including programs, interventions, and system and policy changes) that reduce transmission, and thus, the impact of COVID-19 on communities and populations.

Community Advocacy and Empowerment Improve Health Outcomes and Reduce Health Disparities

Community advocacy and empowerment have been clearly linked to improved health through better health outcomes and reduced health disparities, and perhaps nowhere has this been illustrated more clearly than within the HIV epidemic. Advocacy by people living with and affected by HIV has been critical to the progress made in response to HIV since the beginning of the epidemic. There was little political motivation in the United States to act against HIV as the epidemic was emerging. Communities came together and identified allies and influential advocates to propel action at local, regional, and national levels (Bloom et al., 2014). Community advocacy and empowerment are needed to reduce the impact of COVID-19. Racial and ethnic minority communities, under-resourced communities, those with underlying health-compromising conditions, and older adults need targeted information and resources. These communities carry disproportionate burdens of COVID-19 and are experiencing higher rates of unemployment, housing instability, and food insecurity. Action is needed not just to understand how COVID-19 is affecting different communities but to promote change and reduce the impact of COVID-19 on marginalized and particularly vulnerable communities.

A National Strategy for Prevention Is Critical

A final lesson from HIV particularly relevant to the COVID-19 pandemic is the development and implementation of the National HIV/AIDS Strategy. Historically, the five-year National HIV/AIDS Strategy has been updated over time and outlines the vision, goals, action steps, and indicators of progress to guide our collective response to the HIV epidemic. A national strategy for preventing SARS-CoV-2 and reducing the burden of COVID-19 is needed. The U.S. National Institutes of Health (NIH) has developed a strategic plan for COVID-19 research. This plan provides a framework for accelerating the development of therapeutic interventions, vaccines, and diagnostics.

Currently, however, the United States as a nation lacks a collective response or an integrated plan (beyond that of the NIH research plan for therapeutic interventions, vaccines, and diagnostics) to gain control of the pandemic (Tanne, 2020). Efforts to understand the pandemic and approach prevention and control in an orderly fashion are fundamental to successfully reducing its impact. Without an integrated plan, COVID-19 prevention and control efforts are piecemeal and not sequential; decisions and resource allocation are not based on well-thought out priorities; the most promising strategies may be missed and/or not maximized; and the ability to measure success or failure, whether for midcourse correction of programs or for evaluating their success, is impossible.

Conducting HIV Community-Based and Community-Engaged Research Safely

Within the COVID-19 Pandemic

While HIV prevention, care, and treatment provide lessons particularly relevant to reducing the impact of the COVID-19, the pandemic poses unique challenges to the safe conduct of community-based and community-engaged research. As noted, community-based and community-engaged research have been essential to promoting health equity, reducing health disparities, and improving community and population health, and, if conducted thoughtfully and carefully, can and should continue within the context of the pandemic.

It is important to be aware that many participants in community-based and community-engaged research often are members of marginalized racial and ethnic minority and under-resourced communities, communities experiencing health inequities and disparities, communities without adequate health insurance coverage, and persons living with pre-existing health conditions, as examples. Community-based and community-engaged research activities that potentially may add to the risk of these individuals (both physical and financial) and to the overall burden of COVID-19 within already disproportionately affected communities deserve special attention. However, terminating or eliminating community-based and community-engaged research within these communities may exacerbate the profound COVID-19 and non-COVID-19 disparities they experience. For example, by excluding communities that are at increased risk for severe illness from COVID-19, we will know less about how to reduce COVID-19 disparities experienced. Similarly, if we terminate HIV community-based research designed to reduce HIV disparities because we want to reduce or eliminate COVID-19 risk, HIV disparities are certain to widen. Investigators, research teams, and community-based research partnerships face a new challenge: how to ensure the safety of community members and research teams while continuing to conduct critical research designed to reduce disparities, within the context of COVID-19.

Thus, we encourage thoughtful consideration of the risks of participation for community members and of research team members in in-person research activities, including convening of community advisory boards and steering committees, qualitative and quantitative data collection, and intervention delivery. We outline ten innovative strategies to reduce exposure to SARS-CoV-2 among teams and community members engaged in community-based and community-engaged research (Table 2). These strategies are not unique to HIV research and may be applied broadly to a variety of health research arenas.

Implement Research Activities Virtually, Including Though Smartphones

The science exploring the use and effectiveness of virtual platforms is rapidly developing, and the use of virtual platforms in community-based and community-engaged research deserves further exploration. While members of many marginalized and under-resourced communities in the United States have limited access to desktop and laptop computers, the digital divide is rapidly shrinking (Anderson & Kumar, 2019). Smartphone ownership is rapidly growing, and research suggests that smartphones are increasingly common in under-resourced households, including the working poor and the financially vulnerable. More than 96% of persons in the United States own a cellphone of some type, and the percentage who own a smart phone is over 81%, up from 35% in 2011. It is even higher among younger age groups (e.g., 96% among those ages 18–29).

Smartphones have become a “lifeline” for members of marginalized and under-resourced communities (Pew Research Center, 2019). Whereas home broadband is expensive and requires a laptop or tablet, and may be logistically difficult or impossible for those experiencing housing instability, community members commonly use smartphones as an alternative for internet access. Smartphones and basic smartphone contracts are inexpensive; furthermore, free Wi-Fi is increasingly available in public settings. Across two current community-based studies of marginalized racial and ethnic minority gay, bisexual, and other men who have sex with men, and transgender women being conducted by a CBPR partnership in North Carolina (Rhodes, Tanner, Mann-Jackson, Alonzo, Siman, et al., 2018; Rhodes, Tanner, Mann-Jackson, Alonzo, Horridge, et al., 2018), more than 97% of participants reported having a smartphone. There were no significant differences by race, ethnicity, and language use (English versus Spanish).

Given the increasing use of smartphones, technology can be used to conduct research activities virtually and reduce in-person contact. Members of marginalized and under-resourced communities may be recruited via Facebook, including project-specific Facebook pages, Facebook Live, and word-of-mouth (e.g., by Facebook users referring their friends); Instagram; and GPS-based mobile applications (“apps”) designed for social and sexual networking (e.g., A4A, Badoo, Grindr, Scruff, Growlr, and Jack’d), as examples. Members of these communities may also be able to participate in community-based and community-engaged research activities virtually. For example, Zoom and WebEx (web-conferencing platforms) can be used to host meetings of a CBPR partnership, a community advisory board, or a study steering committee. Individual interviews, focus groups, or individual- or group-level interventions can be conducted similarly.

Develop Standard Operating Procedures Inclusive of Screening for COVID-19 Symptoms

Before conducting any in-person community-based or community-engaged research activities, standard operating procedures (SOP) should be developed, and members of research teams conducting the research must understand the SOP and have the needed resources to follow the SOP while in the community. SOP may include processes for screening research team members and participants for COVID-19 symptoms, what steps to take and referrals to provide if a team member or participants screens positive, how to explain social/physical distancing and proper use of face coverings to participants, and how to handle and what to do if participants do not adhere to social/physical distancing or wearing a face covering.

Include Face Coverings and Social/Physical Distancing as Inclusion Criteria

Given the effectiveness of social/physical distancing, face coverings, and handwashing to reduce transmission (Wiersinga et al., 2020), these practices should be adhered to within in-person community-based and community-engaged research. In fact, it may be useful to include willingness to wear a face covering as an inclusion criterion for participating in studies involving in-person research activities. During one-on-one (defined as one research team member and one potential participant or participant) research activities (e.g., screenings, surveys, in-depth interviews, and individual intervention sessions) and group research activities (e.g., focus groups, community advisory board meetings, and group-level intervention sessions), each research team member present and each participant must wear a face covering throughout the entire interaction, including screening, consent, data collection, and implementation phases. The research team should have unused face coverings available for each participant in the event that they do not have one. A partnership in North Carolina has developed face coverings with project logos on them (Figure 1) to give each participant, in addition to t-shirts and other incentives. They tend to be well received. Furthermore, social/physical distancing should be practiced during in-person research activities to avoid close contact, and it may be useful to include committing to maintaining social/physical distancing as an inclusion criterion.

There is evidence that face shields may offer added benefit to reduce risks of exposure (Perencevich, Diekema, & Edmond, 2020), and thus, may be recommended when sustained close contact among participants and research team members is expected. However, this sustained close contact should only occur when it is absolutely warranted. The necessity of sustained close contact should be carefully evaluated and include risk analysis that considers local COVID-19 burden, population of participants, and potential knowledge gain.

Manage Participant Expectations

COVID-19 has dramatically changed life globally. Before any in-person research activity is initiated, a research team member should sensitively explain to participants that during the in-person activity the research team member will maintain recommended social/physical distancing and wear a face covering, and the participant will be expected to maintain social/physical distancing and wear a face covering as well. If the participant does not have a face covering, it should be explained that the research team member will provide one. Preparing a research participant for what to expect is important. Community members may feel that they are assumed to be “dirty” or infectious. Instead, messaging must be clear that the safety precautions are provided to protect the participants as well. Members of marginalized communities and populations are often stigmatized and building and maintain trust with community members requires careful consideration of their perceptions and feelings.

Reduce the Exchange of Materials

All efforts should be made to limit exchanges of all materials between research team members and participants. For example, the use of interviewer-administered data collection, in which a research team member is the only person to touch a laptop computer, tablet, or paper survey when used in data collection is a strategy to reduce risk of exposure. If exchanging materials is necessary (for example, when the participant must sign a consent form), the research team member and participant should do so in a way that allows the research team member and the participant to maintain social/physical distance throughout the entire exchange. For example, the research team member should place materials to be exchanged on a table or other location at least 6 feet away from the participant, and the participant should wait until the research team member has moved at least 6 feet away from the materials before retrieving them (and vice versa). Of course, research team members should use hand sanitizer at the start and end of every activity, and as warranted throughout the activity. Hand sanitizer should be offered to the participant as well.

Conduct In-Person Group Research Activities Only When No Alternatives Exist

In-person group research activities (e.g., focus groups, community advisory board meetings, and group-level intervention sessions) must adhere, at a minimum, to group sizes limited by state and municipal recommendations and guidelines. Group research activities may seem innocuous; after all, we are accustomed to asking participants of a focus group, for example, to adhere to certain guidelines and norms to reduce risks to other participants, such as agreeing not to share information learned about each other outside of the group. Thus, it may seem reasonable to ask participants to maintain social/physical distance precautions during the preparation and implementation phases of an in-person focus group as well. However, ensuring that participants maintain social/physical distancing throughout a group research activity can be very difficult. Participants will have their own judgements of risk; some participants may worry less about social/physical distancing than others. This can become problematic when a participant gets closer to another participant than the other would prefer; research team effort is thus spent focusing on social/physical distancing and resolving group-level challenges as opposed to the research.

If, however, it is determined that in-person group research activities must be undertaken and conducting the research virtually is impossible, research team members must have carefully articulated plans for each aspect of the activity. For example, participants should enter and leave the room using a strategy that ensures social/physical distancing from one another and from the research team members, and chairs should be arranged in a manner that ensures the maintenance of social/physical distancing among all research team members and participants throughout the research activity.

Conduct Research in Safe Settings

Often, community-based and community-engaged research activities are conducted in the local community itself, in locations that are convenient for community members (Rhodes, Alonzo, et al., 2018). In the context of COVID-19, the following locations may be appropriate places as long as social/physical distancing can be guaranteed and face coverings are worn by each research team member and participant: university, college, and institution (e.g., hospital research) spaces; health departments and clinics; community organization offices/spaces; and outside spaces. COVID-19 poses challenges for research activities in private locations, such as home-based data collection, but meeting with participants outside of these locations may be a viable alternative. For example a North Carolina CBPR partnership has had extremely high participant retention rates attributable, in part, to meeting participants at their homes for data collection (Rhodes, Alonzo, et al., 2018). However, because the cleanliness and safe airflow within private homes cannot be ensured, conducting research activities in a home is potentially no longer a safe option. Conducting research activities, such as data collection, outside the home, on a porch, for example, may be appropriate.

Furthermore, research team members should never assume a space being used for research activities is clean. Rather they should always carefully adhere to all cleaning and hand hygiene protocols to protect both themselves and participants in any space being used. Examples of proper cleaning include wiping down tables, chairs, writing utensils, keyboards, tablets, equipment, and other surfaces prior to participant arrival; using hand sanitizer at the start and end of every activity and as warranted throughout the activity; and wiping down tables, chairs, writing utensils, keyboards, tablets, equipment, and other surfaces after use, again wearing gloves and subsequently washing hands thoroughly.

Travel Separately to Community-Based Research Sites

Sometimes multiple research team members are in the community at the same time. In the context of COVID-19, it is recommended that research team members travel separately (e.g., in different cars rather than carpool) to ensure social/physical distancing among research team members.

Rethink Refreshments

Refreshments are often an important component of community-based and community-engaged research activities. Before or after a focus group, for example, a meal may be provided to participants as a sign of hospitality, an informal token of appreciation, and/or an incentive. One strategy is to eliminate refreshments and increase participant compensation to include the funds that would have been spent on refreshments. Explaining to participants, both before and during the research activity, the rationale for not including refreshments is key to this strategy.

However, another strategy is to provide a boxed meal with individually packaged forks and knives after the research activity to each participant to take offsite. We suggest that participants take their boxed meal offsite because the practice of social/physical distancing and use of face coverings (while eating) become more difficult and coupled together more risky.

Distribute Compensation for Research Participation Electronically

It is well-established that providing immediate cash compensation at the time of participation in research activities promotes community member engagement, builds community member trust in the research team and the research process, promotes long-term retention if warranted, and can reduce risks related to disclosure of study participation (Largent & Fernandez Lynch, 2017; Mitchell et al., 2018; Rhodes, Alonzo, et al., 2018; Wickliffe, Lynch, & Largent, 2020). Rather than having to meet each participant in-person to provide compensation for participation in research activities, strategies include mailing cash (or other forms of compensation) using certified mail or sending electronic compensation through mobile payment services (e.g., Cash App and Venmo). These mobile payment services are growing in popularity and use especially among certain age groups (e.g., Generation Xers and younger) (Pew Charitable Trusts, 2016) and are immediate and easy to use.

Discussion

To date, the United States has had more than eleven million cases of and 250,000 deaths from COVID-19, and the lessons from HIV prevention, care, and treatment are particularly relevant if we want to better meet the challenges of the pandemic. In this commentary, we highlight nine lessons from HIV and ten innovative strategies designed to reduce risks and facilitate the continued safe conduct of community-based and community-engaged research within the context of COVID-19.

First, testing is the cornerstone of HIV prevention, care, and treatment, and SARS-CoV-2 testing must be accurate, timely, and widely available. Furthermore, prevention messaging must be clear; we need to communicate what we know, what we do not know, and what we want community members to do to prevent and manage COVID-19. Research suggests that being open about what is not known and about changes in prevention guidelines as new knowledge is obtained facilitates uptake of revised guidelines more readily than approaches that are less forthcoming and transparent (World Health Organization, 2017).

We also need to take full advantage of the social and behavioral sciences. To date, social and behavioral science expertise has been not been included at the highest levels in the U.S. response to COVID-19, and the federal agency with expertise in the social and behavioral sciences (i.e., the U.S. Centers for Disease Control and Prevention) has been defamed and relegated to the sidelines by the White House. We also know that a national strategy to guide our country's collective response to the COVID-19 is critical; the current lack of a plan contributes to ineffective and inefficient responses that are confusing and uncoordinated.

Many of us who are engaged in science generally and community-based and community-engaged research specifically are passionate about the research questions we want to answer and communities and populations we want our discoveries to help. Our work has potential to improve the health and well-being of some of the most marginalized communities through improved understanding of health phenomena, increased health equity, and reduced health disparities. There are also a few considerations to highlight regarding the conduct of community-based research in the context of the COVID-19 pandemic. First, our passion and good intentions can cloud our judgements of both participant and research team safety. COVID-19 is now part of the context that we must consider when we consider human subject protection. We must consider how we can reduce the risks of exposure to SARS-CoV-2 in addition to reducing the risks of loss of confidentiality, data breaches, and harms to psychological well-being.

Furthermore, it often is assumed that members of marginalized and under-resourced communities do not have access to the internet and thus cannot participate in virtual research activities; thus, the argument is that research with these communities must be conducted in person. However, in the United States, while the working poor or the financially vulnerable may have lower rates of having access to a desktop and laptop in their home, they have high rates of smartphone ownership. The smartphone is, in fact, widely used and becoming a necessity in the United States among all communities and populations. The use of a smartphone to access the internet and participate in virtual research activities, however, requires research teams to help participants think through finding a quiet and private place to be and predict and eliminate potential distractions during a virtual research activity, as examples.

SOPs can help research teams prepare for the adaptations necessary for conducting research within the context of the COVID-19 pandemic. Many research teams are prepared with study protocols, but they may not have protocols that are inclusion of COVID-19 safety precautions. Because much of community-based and community-engaged research relies on relationship building and maintenance, without clear guidance, research team members may also lack the knowledge of how to assert social/physical distancing, or the confidence to assert it, for example. Moreover, including safety precautions as inclusion criteria is a simple strategy to manage expectations and ensure that research teams and community members participating in research are aligned on how to stay safe.

Finally, it is worth reiterating the importance of managing community member expectations. As we work in partnership with communities and engage with potential participants and participants, it is important to prepare them for safety precautions warranted by the pandemic. They must be reminded why we are requiring social/physical distancing and face coverings. We do not want to send messages that further stigmatize communities and community members. Clear and open communication and transparency are hallmarks of community-based and community-engaged research and should guide us while conducting research within the context of the COVID-19 pandemic.

The COVID-19 pandemic has profoundly altered the ways in which we live, learn, work, and play. Our experiences in HIV prevention, care, and treatment provide critical lessons to reducing the impact of the COVID-19 pandemic. The COVID-19 pandemic has similarly affected the conduct of community-based and community-engaged research. The innovative strategies outlined in this commentary can help to ensure that community-based and community-engaged research can continue safely within the context of the COVID-19 pandemic. Community-based and community-engaged research are critical to promoting health equity, reducing health disparities, and improving health, and the most marginalized communities and populations cannot be excluded.

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Figure 1.
Face covering with a project logo to provide to participants

Table 1.

Lessons from HIV prevention, care, and treatment particularly relevant to reducing the impact of the COVID-19 pandemic

1. Accurate, Timely, and Widely Available Testing Is Fundamental
2. Contact Tracing and Community Trust Are Essential
3. Clear Prevention Messages Are Needed
4. Ongoing Behavior Change Requires Expertise from the Social and Behavioral Sciences
5. Harm Reduction Minimizes Risks
6. Upstream Factors Require Consideration and Intervention
7. Community Perspectives and Talent Should Be Harnessed
8. Community Advocacy and Empowerment Improve Health Outcomes and Reduce Health Disparities
9. A National Strategy for Prevention Is Critical

Table 2.

Strategies to conduct community-based and community-engaged research safely within the context of the COVID-19 pandemic

1. Implement Research Activities Virtually, Including Though Smartphones
2. Develop Standard Operating Procedures Inclusive of Screening for COVID-19 Symptoms
3. Include Face Coverings and Social/Physical Distancing as Inclusion Criteria
4. Manage Participant Expectations
5. Reduce the Exchange of Materials
6. Conduct In-Person Group Research Activities Only When No Alternatives Exist
7. Conduct Research in Safe Settings
8. Travel Separately to Community-Based Research Sites
9. Rethink Refreshments
10. Distribute Compensation for Research Participation Electronically