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Author manuscript

AIDS Educ Prev. Author manuscript; available in PMC 2019 June 01.

Published in final edited form as:

AIDS Educ Prev. 2018 June ; 30(3): 243–253. doi:10.1521/aeap.2018.30.3.243.

Community-engaged research as an approach to expedite advances in HIV prevention, care, and treatment: A call to action

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Abstract

Throughout the world, we continue to face profound challenges to reducing the impact of the HIV epidemic. Community-engaged research has emerged as an approach to increase our understanding of and reduce health disparities, increase health equity, and promote community and population health. Our partnership has conducted more than 25 community-engaged research studies in the US and Guatemala, and members have identified nine themes to facilitate community-engaged research and expedite advances in HIV prevention, care, and treatment. These themes include the inclusion of multi-sectoral partners, trust building and maintenance, the alignment of partner priorities, a “can-do” attitude, capacity and desire to move beyond service and conduct research, flexibility and power sharing, empowerment and an assets orientation, the shared and timely use of findings, and a stepwise approach. To reduce HIV disparities, community-engaged research is as critical now as ever, and we desperately need to reinvigorate our commitment to and support of it.

Keywords

community-engaged research; HIV; men who have sex with men; MSM; international; gay; partnership

HIV, Gay Men, and Community Engagement

Globally, we continue to face profound challenges in preventing new HIV infections through behavioral and biomedical methods; identifying persons with HIV; and providing access and

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ensuring uptake and adherence to available and effective antiretroviral medications that reduce infectivity and the prophylaxes to prevent and reduce associated complications and diseases. Moreover, profound HIV disparities exist, particularly among racial/ethnic, sexual, and gender minority and economically disadvantaged communities, both in the United States (US) and internationally (UNAIDS, 2016).

From the beginning of the global HIV epidemic, community engagement played a critical role. Initially in the US, for example, gay communities mobilized to identify and meet the needs of their own communities (Crimp, 1988). Many community leaders, community members, advocates, activists, and researchers involved in the earliest HIV prevention and research efforts were gay themselves (Trapence et al., 2012); they were members of the communities initially most affected by HIV, and HIV was their priority. These prevention and research efforts sprang from gay men and their allies; they were developed *by, for*, and *within* gay communities. These efforts tended to be highly culturally congruent, meaningful, and thus effective for the communities they were designed to help. They also built on community assets. Naturally emerging community partnerships, comprised of community leaders, community members, advocates, activists, and researchers, organized and provided much-needed support within communities; initiated community-based educational programs; advocated for drug development, expedited drug trials, and behavioral research; and developed, implemented, and evaluated prevention strategies in communities (Altman, 1994; Bloom, Whittier, & Rhodes, 2014).

Community-engaged Research to Reduce Health Disparities and Increase Health Equity

Since these early days of the HIV epidemic, community-engaged research has emerged in public health and medicine as an approach to increase our understanding of and reduce health disparities, increase health equity, and promote community and population health. Community-engaged research is an approach to research designed to improve health through the involvement of the impacted community in research, where the community refers to any group of people affiliated by geographic proximity, special interest, or similar situations. Rather than researchers from universities, government, and/or other types of research organizations approaching and entering a community with a preconceived notion of what is best for that community, community-engaged research builds bridges among community members, those who serve communities through service delivery and practice, and researchers from universities, government, and/or other types of research organizations. In doing so, the experiences of community members, who are experts in their lived experiences and their community's needs, priorities, and assets, and of representatives from community organizations can be incorporated with sound science. Community-engaged research moves from treating community members as "targets" of research to engaging them as partners in research (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Dankwa-Mullan et al., 2010; Institute of Medicine, 2003; Kost et al., 2017; Rhodes, 2014; South & Phillips, 2014; Trinh-Shevrin, Islam, Nadkarni, Park, & Kwon, 2015; Wells, Preuss, Pathak, Kosambiya, & Kumar, 2012). This approach promotes the reduction of health

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disparities and moves toward health equity through deeper and more informed understandings of health-related phenomena and the identification of actions (e.g., interventions, programs, policies, and system changes) that are more relevant; culturally congruent; and likely to be effective, sustained, and scaled, when warranted (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Kost et al., 2017; Rhodes, Mann-Jackson, et al., 2017).

Similarly, community-engaged research ensures that study designs are more informed through the blending of multiple perspectives; thus making them more authentic to the community and to the ways that community members convene, interact, and take action. These approaches have clear advantages for researchers and communities alike. Interventions and programs, for example, can be more innovative; recruitment enrollment and retention rates can be higher; measurement can be more precise; data collection can be more acceptable and complete; analysis and interpretation of findings can be more accurate and meaningful; and sustainability and dissemination of findings is more likely (Cashman et al., 2008; Rhodes, Duck, Alonzo, Daniel, & Aronson, 2013; Wallerstein & Duran, 2006). Furthermore, by working *with* rather than merely *in* communities, partners applying community-engaged research approaches can strengthen a community's overall capacity to problem-solve through community involvement in the research process.

Community-engaged research can be imagined across a continuum that spans from (1) outreach, (2) consultation, (3) involvement, (4) collaboration, to (5) shared leadership; each point along this continuum increases the level of community involvement and participation (engagement; Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011). Community-based participatory research (CBPR) is a form of community-engaged research in which community members are equal partners sharing leadership with academic researchers throughout the entire research process (Wallerstein & Duran, 2006).

Community-engaged Research Partnership

Our established and ongoing network of partners in North Carolina and Guatemala has been collaborating to reduce health disparities, increase health equity, and promote community and population health using community-engaged research approaches for more than 16 years. We focus on identifying and understanding community needs, priorities, and assets to develop, implement, and evaluate interventions designed to reduce the burdens of HIV and sexually transmitted infections (STIs) and increase access to health services among Latinx and African Americans/Black populations; gay, bisexual, and other men who have sex with men (MSM); transgender persons; rural populations; immigrants; and persons living with HIV (Rhodes, Alonzo, et al., 2017; Rhodes, Duck, et al., 2013; Rhodes, Leichliter, Sun, & Bloom, 2016; Rhodes, Mann-Jackson, et al., 2017; Rhodes et al., 2014; Tanner et al., 2016). A representative sample of our community-engaged intervention research studies is presented in Table 1.

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Across more than 25 studies in the US and Guatemala that used community-engaged research approaches, we have identified nine critical cross-cutting themes to facilitate community-engaged research and expedite advances in HIV prevention, care, and treatment (Table 2).

Inclusion of multi-sectorial partnerships

Sound community-engaged research is facilitated by the commitment and ongoing involvement of diverse stakeholders, including community members; representatives of organizations, agencies, and businesses; clinicians; and academic researchers. Partners work together, providing perspectives, insights, and experiences (Seifer & Maurana, 2000). For example, our Centers for Disease Control and Prevention (CDC)-funded intervention known as *Impact Triad* (NU22PS005115) brings together various partners that are not typically involved in HIV and STI prevention, care, and treatment. These partners, including FaithAction International House (a community organization that serves and advocates for immigrant communities), Goodwill Industries, Guilford County Public Library, the Interactive Resource Center (a day resource center for those experiencing or at risk for homelessness or housing instability), the Regional Center for Infectious Diseases, Triad Health Project (an AIDS service organization), and Wake Forest School of Medicine, are addressing key social determinants of health that were identified through a community-engaged needs assessment as “upstream” factors affecting HIV and STI disparities among African American/Black and Latinx MSM and transgender women. These social determinants of health include employment, education, social support, and discrimination.

Trust

Trust is critical to community-engaged research. Many community members and organization representatives may not trust those from universities, academic medical centers, and/or other potential partners. To some the mere word “research” may engender distrust and fear of exploitation (Gaston & Alleyne-Green, 2013; Jones, 1993; Lynch, 2012; Thomas & Quinn, 1991), as many community members and organization representatives may feel that they have been exploited by researchers from universities and academic medical centers in the past. Furthermore, community members and organization representatives may also be hesitant to engage with each other. Relationships between community members, organization representatives, clinicians, and academic researchers may require careful development. While challenging to build, nurture, and maintain, trust is fundamental to community-engaged research. Acknowledging and discussing racism, xenophobia, homophobia, transphobia, and discrimination can support engagement. Although larger structural interventions are needed to ultimately effect change in terms of racism, at least initially, trust can built and nurtured by individuals.

Personal relationships are critical to trust. Community events such as street fairs, church gatherings, and community forums as well as parties and celebrations are ideal places for potential partners to convene and build and nurture trust. These types of opportunities show commitment and allow attendees to further know and understand one another. Participation by academic researchers in other non-research activities, such as volunteering with a community organization or serving on local health coalitions advances trust and genuine and

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mutually respectful relationships. It also may open other doors by providing further opportunities to identify others who may be committed to working together.

As an example, our community-engaged research in Guatemala is founded on multiple years of trust building, engagement, and commitment, in which the first author initially spent time visiting and listening to community members and organization representatives. He also volunteered with a Guatemalan grassroots community organization that provides HIV prevention, care, and treatment. This ongoing relationship led to expanded partnerships with community members; representatives of organizations, agencies, and businesses; clinicians; and academic researchers within Guatemala as well as North Carolina (Rhodes et al., 2015).

Alignment of partner priorities

Alignment of partner priorities, organizational missions, and research questions is also critical. Overall, our partners are committed to HIV and STI prevention and care and increased access to health services among racial/ethnic, sexual, and gender minority; rural; and economically disadvantaged communities. This alignment has been reinforced throughout our work together, but was initiated by a request for proposals from the North Carolina Department of Health and Human Services, Division of Public Health, Communicable Disease Branch, to fund behavioral HIV prevention interventions for communities at increased HIV risk, including racial/ethnic, sexual, and gender minority communities. The request for proposals required the use of evidence-based interventions included with the *CDC Compendium of Evidence-Based Interventions and Best Practices for HIV Prevention* (https://www.cdc.gov/hiv/research/interventionresearch/compendium/index.html). However, at that time, there were no efficacious Spanish-language interventions within the *Compendium*. Thus, our partnership mobilized around their first community-engaged intervention research study. We developed, implemented, and evaluated a Spanish-language community-level social network intervention for immigrant Latinx men known as *HoMBReS* (Rhodes, Hergenrather, Bloom, Leichliter, & Montano, 2009; Rhodes, Leichliter, et al., 2016; Vissman et al., 2009). As a Latinx partner noted at that time, “Latinos want and need information and help to be safe, but nothing exists that we can point to that shows promise to save the lives of Latinos living here in our community.” *HoMBReS* became the first, and to date, remains the only best-evidence community-level intervention within the *Compendium*.

Thus, overlap in community priorities, the primary focuses of community organizations, and the research strengths of academic partners is essential. Although each partner may not set HIV or STIs as a priority in its mission, each partner must recognize the mutual benefits of working together, even if through different lenses. Partners must agree on where and how to focus resources and skills through ongoing dialogue that combines local perspectives about needs and priorities with epidemiologic data. Community-engaged research relies on focusing on what is both important and changeable (Rhodes, Mann-Jackson, et al., 2017). Although much research might be needed that aligns with community priorities, focusing on priorities that are able to be effected given available interests, talents, and resources is critical.

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"Can-do" attitude

Members of our partnership are usually quite confident that we can realize our goals and aims given the successes we have experienced applying community-engaged research approaches. For example, across our studies, we have high recruitment and retention rates; this is particularly noteworthy, given that racial/ethnic, sexual, and gender minority; rural; and economically disadvantaged communities are often assumed by outsiders to be "hard to reach" or "hidden" (Rhodes et al., In press). Being considered hard to reach or hidden is purely subjective and most often refers to being hard to reach by or hidden from community outsiders, such as academic researchers. In one of our partnership's recent studies designed to test the *HOLA en Grupos* intervention, an HIV prevention intervention for Latinx gay, bisexual, and other MSM and transgender women (Table 1), we had an 100% retention rate for 304 participants at 6-month follow-up (Rhodes, Alonzo, et al., 2017).

Capacity and desire to move beyond service

Partners representing communities and community organizations must have the capacity and desire to move beyond service and be engaged in research. Service and program delivery and case management, as examples, differ from community-engaged research, in a number of ways, including timeframes, processes, and short-term objectives, even if long-term objectives (e.g., improving health outcomes) are the same. Community-engaged research is, of course, an approach to *research*. Different partners have different levels of experience with research and different types of research skills to offer, but there must be interest, willingness, and capacity to learn more about and contribute to the research process at some level. Our partners must continue to remind one another that the community-engaged research that we are conducting is innovative and can influence HIV and STIs in other parts of the world; to reach our research potentials, partners must stretch and move beyond what has been done in the past.

Flexibility and power sharing

Both partners and funders must be flexible to protocol revisions and changes during the implementation of community-engaged research studies. What was planned and seemed possible at the time of grant submission and what becomes realistic for partners as study implementation begins may differ. New information and data may emerge and even the context may change, particularly given the protracted time between developing a study, submitting a grant application, and receiving funding. For example, in our research with Latinx communities in North Carolina, changes in immigration enforcement policies could dramatically affect the ways in which potential study participants feel safe participating in studies that include government systems such as health departments and thus may require changes to study implementation and designs and/or further trust building.

It is important to recognize that those in the field (such as community members and organization representatives) are the most likely to understand the implications of any proposed changes to a study. We have witnessed uneven decision-making power within federal cooperative agreements funding community-engaged research, for example. Those most removed from the community (e.g., federal partners) have required substantial changes to peer-reviewed, well-scored community-engaged research study protocols that may not

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improve the science and may jeopardize an intervention study's outcomes and ecological validity, and/or the potential for intervention sustainability and broader uptake. Those in the field, who designed and are implementing the study (e.g., community-engaged research partnerships), may perceive to have or indeed have less power in the direction of a study. We have seen funders change study designs, modify inclusion criteria and screening processes, alter recruitment and retention strategies, adjust participant incentives and compensation, revise curricula materials, and amend evaluation procedures in ways that inhibit community empowerment and jeopardize a study's potential success and impact. Recognizing the benefits of community-engaged research may be understood by diverse stakeholders, including community members; representatives of organizations, agencies, and businesses; clinicians; and academic researchers, but may not be sufficiently appreciated by some representatives from funding sources who are far removed from the communities in which the research is taking place.

Empowerment and an assets orientation

Community-engaged research focuses on empowerment and tends to use an assets orientation to community and population health. We do not want to perpetuate a paternalistic approach to public health and medicine in which academic researchers are assumed to have the answers and communities have the problems. As examples, our *CyBER* (Rhodes, McCoy, et al., 2016; Rhodes et al., 2011), *MAP'T* (Jenkins Hall et al., 2017; Sun, Stowers, Miller, Bachmann, & Rhodes, 2015), and *weCare* (Tanner et al., 2016) interventions (Table 1) harness existing social media to promote HIV and STI prevention, screening, and treatment. While some have suggested that social media platforms, including online sites and mobile applications ("apps") that facilitate social and sexual networking (e.g., Adam4Adam, Grindr, Growlr, Jackd, and Scruff), may be contributing to increased rates of HIV and STIs, we see these settings as community assets. We harness these assets by supporting app users in multiple ways, including by building trust, offering social support, and providing HIV information and referrals that users want (and may not have access to or be open to receiving in other venues).

Shared and timely use of study findings

The timely use of findings by partners is a priority in community-engaged research. Often, the extended time between data collection, analysis, interpretation, and dissemination can be frustrating for partners who want to apply discoveries quickly. Thus, our partners often will work together to develop preliminary findings, which, for example, can be used in service grant proposals by organization representatives and other partners and can be shared with and reported back to community members and study participants (Rhodes, Mann-Jackson, et al., 2017).

Stepwise approach

Success in using and sustaining community-engaged research benefits from an approach characterized as "slow and steady". Beginning the research process modestly and incrementally building a history of success are critical to establishing a firm foundation for community-engaged research. This stepwise approach moves in a consecutive manner from formative data collection to intervention design, implementation, and evaluation and a

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partnership may adapt or build on the success of one intervention to develop the next as communities and contexts change. This must be a carefully calibrated and orchestrated process as reasonable scopes of work help to ensure early successes, which, in turn, develop capacities and help maintain enthusiasm, commitment, and involvement among partners.

Concluding Thoughts

Community-engaged research is research. Although passion can bring partners together, community engagement does not make research easier; in fact, it makes research more challenging but also perhaps more worthwhile. While traditional research using controlled, outside expert-driven approaches tends to provide guidelines related to internal and external validity, the reduction of bias, and the control of the experimental process, community-engaged research adds to the strength and value of the research. When conducted well, community-engaged research is more informed, and research is enhanced because of the diverse perspectives, insights, and experiences that are blended with sound science to inform the research.

Community-engaged research is not without challenges. Community members and organization representatives face the realities of health disparities (e.g., HIV) every day and know that something must be done for the communities we all belong to. The slow pace of securing research funding and conducting sound research is an ongoing frustration. Furthermore, community members themselves are fallible; community members and members of partnerships may hold prejudices about one another; we have seen these prejudices based on race/ethnicity, immigration status, sexual orientation, and gender identity. These prejudices must be overcome.

To further expedite advances in HIV prevention, care, and treatment, we also know that funders must affirm or reaffirm their commitments to community-engaged research by publishing funding opportunity announcements for authentic, rigorous, and innovative community-engaged research to identify and/or meet community needs and priorities while harnessing community assets. Experts in community-engaged research should also be included on funders' study sections and review panels. We need continued innovative community-engaged research. Communities must learn to work together and with academic researchers, academic researchers must listen to and learn to work with communities, and funders must be willing to acknowledge that sound and meaningful research can be conducted using community-engaged approaches. At best, community-engaged research often is conflated with behavioral and social science research; at worst it is assumed to be "touchy-feely" and lack the rigor of more controlled, outside expert-driven approaches. However, community-engaged research can add value to research and yield a more informed understanding of what is happening with communities and how to best improve community and population health (Clinical and Translational Science Awards Consortium Community Engagement Key Function Committee Task Force on the Principles of Community Engagement, 2011; Dankwa-Mullan et al., 2010; Institute of Medicine, 2003; Kost et al., 2017; Rhodes, 2014; South & Phillips, 2014; Trinh-Shevrin, Islam, Nadkarni, Park, & Kwon, 2015; Wells, Preuss, Pathak, Kosambiya, & Kumar, 2012).

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We are well into the second half of the fourth decade of the HIV epidemic, yet rates of HIV testing remain suboptimal, and significant disparities in pre-exposure prophylaxis (PrEP) uptake and adherence to antiretroviral therapy (ART) among those with HIV have been documented among some historically marginalized communities, including racial/ethnic, sexual, and gender minority; rural; and economically disadvantaged communities around the world. While we have had some successes globally, these successes have not been sufficient. In the US, for example, while overall HIV infection rates have leveled off or even declined within some communities, they have increased among gay, bisexual, and other MSM of color and those in rural communities (Schafer et al., 2017). To stem the HIV epidemic we must recommit to support community-engaged research, authentically involving community members, academic researchers, and funders.

We have provided and described nine cross-cutting themes from successful community-engaged research studies that can facilitate community-engaged research and expedite advances in HIV prevention, care, and treatment. Community-engaged research has been critical to identifying and meeting community needs in meaningful ways from the outset of the HIV epidemic, but we desperately need to reinvigorate our commitment to and support of community-engaged research going forward. To reduce HIV disparities, community-engaged research is as critical now as ever.

Acknowledgments

We thank the broader membership of the community-engaged research partnership that the authors are part of. Funding for this commentary includes CDC (TS-1023 [through a cooperative agreement with Association for Prevention Teaching and Research], U01PS005137, UR6PS000690, NU22PS005115, and U01PS001570); HRSA (H97HA28896); NIH (UL1TR001420, R01MH092932, R01MH087339, R24MD002774, R21MH082689, and R21MH079827), and the Cone Health Foundation.

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Table 1

A representative sample of our partnership's HIV-related interventions developed, implemented, and/or evaluated using community-engaged research

Intervention	Abbreviated main objective/s	Citation
ChiCAS Creando Acceso a la Salud	Increase use of PrEP and medically supervised hormone therapy among Latinx transgender women	In process
CyBER	Increase HIV testing among gay, bisexual, and other MSM and transgender persons who use social media for social and sexual networking	(Rhodes, McCoy, et al., 2016; Rhodes et al., 2011)
HOLA	Increase condom use and HIV testing within naturally existing social networks of Latinx gay, bisexual, and other MSM and transgender women	(Rhodes, Daniel, et al., 2013)
HOLA en Grupos	Increase condom use and HIV testing among Latinx gay, bisexual, and other MSM, and transgender women	(Rhodes, Alonzo, Mann, Freeman, et al., 2015; (Rhodes, Alonzo, et al., 2017)
HoMBReS Hombres Manteniendo Bienestar y Relaciones Saludables	Promote sexual health by mobilizing, organizing, and harnessing social networks of Latinx men who are members of recreational soccer leagues	(Rhodes et al., 2009; Rhodes, Leichliter, et al., 2016)

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Intervention	Abbreviated main objective/s	Citation
	Promote sexual health and social justice by mobilizing, organizing, and harnessing social networks of Latinx men who are members of recreational soccer leagues	(Rhodes, Leichliter, et al., 2016)
Impact Triad (Logo in development)	Develop, implement, and evaluate complementary strategies designed to address prioritized social determinants of health (i.e., employment, education, social support, and discrimination) and reduce STI disparities through increased prevention behaviors, screening, and treatment among young MSM and young transgender women of color	In process
	Increase HIV testing through GPS-based mobile applications used for social and sexual networking among gay, bisexual and other MSM and transgender persons	(Jenkins Hall et al., 2017; Sun et al., 2015)
	Promote sexual health among immigrant Latinas by harnessing community strengths	(Rhodes et al., 2012)

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Intervention	Abbreviated main objective/s	Citation
	Increase HIV care engagement and viral suppression of young racially/ethnically diverse gay, bisexual, and other MSM and transgender persons living with HIV through social media	(Prina, 2017; Tanner et al., 2016)

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Table 2

Cross-cutting Themes to Facilitate Community-engaged Research and Expedite Advances in HIV Prevention, Care, and Treatment

Inclusion of multi-sectoral partners
Trust
Alignment of partner priorities
“Can-do” attitude
Capacity and desire to move beyond service
Flexibility and power sharing
Empowerment and an assets orientation
Shared and timely use of findings
Stepwise approach