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What Lessons it Might Teach Us! Community Engagement in HIV Research

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Abstract

Purpose of the Review: Partnerships between academia and the community led to historic advances in HIV and paved the way for ongoing community engagement in research. Three decades later, we review the state of community engagement in HIV research, discuss best practices as supported by literature, explore innovations and identify ongoing gaps in knowledge.

Recent Findings: The community of people living with and at risk for HIV remains actively involved in the performance of HIV research. However, the extent of participation is highly variable despite long standing and established principles and guidelines of Good Participatory (GPP) and Community Based Participatory Research (CBPR). Current literature reveals that known barriers to successful community engagement continue to exist such as power differences, and poor scientific or cultural competency literacy. Several high quality studies share their experiences overcoming these barriers and demonstrate the potential of CBPR through reporting of qualitative and quantitative outcomes.

Summary: Greater time and attention should be placed on the development of community engagement in HIV research. A large body of literature, including innovative cross-cutting approaches, exists to guide and inform best practices and mitigate common barriers. However, we recognize that true growth and expansion of CBPR within HIV and in other fields will require a greater breadth of research reporting qualitative and quantitative outcomes.

Keywords

Community engagement; HIV research; Community Based Participatory Research; Good Participatory Practices

Introduction

“We condemn attempts to label us as ‘victims’, a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon

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the care of others. We are ‘People with AIDS.’” Statement from the advisory committee of the People with AIDS (The Denver Principles)¹

The accomplishments achieved in the field of HIV/AIDS are nothing short of remarkable. A fatal diagnosis is now a chronic disease, with estimates suggesting people living with HIV today may achieve a near normal lifespan². Rapid advancements in the lifesaving combination antiretroviral therapy (ART) occurred largely because vocal, credible and effective community and patient advocates demanded it and collaborated with researchers, and industry to achieve it³. Initially, HIV researchers were siloed from the community, and relationships were contentious⁴. Faced with the suffering and deaths of friends and family, activists refusing to be passive “victims” of AIDS embraced self-empowerment and effectively organized. The Denver Principles formed in 1983, served as the foundation of the activist movement and detailed how PLWH expect to be treated, how PLWH should respond to the AIDS crisis and the human rights they demand (Table 1)^{1,5,6}.

To address the ongoing outcry of activists, the National Institutes of Allergy and Infectious Diseases (NIAID) recommended including community members at AIDS Clinical Trials Group (ACTG) meetings⁷. Formalized community involvement in HIV research began soon after that with the first federally funded and mandated community advisory boards (CABs) in 1989^{8,9}. Notable contributions that community members drove were elimination of a placebo arm in indinavir efficacy studies (ACTG 320), the insistence that only combination therapy with three drugs be evaluated rather than comparisons to one or two drugs (ACTG 343), and the development of the ACTGs participant’s bill of rights, a distinct document separate from the informed consent form⁹. The role of the community in HIV research continued to expand with the HIV Cost and Services Utilization Study that welcomed community involvement in the planning and implementation of research¹⁰. Community participation in HIV research culminated with the early vaccine trials for HIV prevention. Researchers truly embraced the community and partnered with their CABs to identify potential study problems, inform recruitment practices, monitor research and ultimately disseminate study findings^{11,12}. It is widely perceived that without CAB involvement, participant recruitment and the overall quality of the research would have been compromised⁹. Today CABs are an essential component of most clinical trial networks (HIV Vaccine Trials Network, HIV Prevention Trials Network and the ACTG).

Despite this history and experience, the effectiveness of community involvement in research may be limited based on the relationship of the research team with the study’s CAB and by common misconceptions about CBPR (Table 2). Some researchers may view CABs in clinical trials as “window-dressing” or a box to be checked, or may not have the resources or training to allocate to CAB development and management⁹. Premature closure of several large-scale International biomedical HIV prevention trials¹³ due to concerns about exploitation of vulnerable persons¹⁴ demonstrated the necessity of community involvement at all stages of research to improve ethical practices around cultural, language and literacy differences¹⁵. This experience also re-demonstrated the power of advocacy¹⁶ and the importance of transparent and effective communication between researchers, participants and the community^{17,18}. As a direct result, the Joint United Nations Programme on HIV/AIDS (UNAIDS) developed a systematic framework of Good Participatory Practice (GPP)

that includes principles of community based participatory research (CBPR) and training for research teams performing biomedical HIV prevention work¹⁹⁻²². Over a decade has passed since those events and the development of GPP, yet recent community voices (particularly in the area of aging with HIV²³) suggests principles of GPP and CBPR may not be widely embraced (Table 3)^{19,24}. The purpose of this review is to a) characterize the current state of community involvement in research involving people living with and at risk for HIV, b) identify best practices towards meaningful, diverse and effective community involvement in HIV research, c) highlight innovative approaches to advance CBPR and c) identify current gaps in the literature.

Progress, but room for improvement

A recent systematic review sought to examine stakeholder (defined as an individual or group affected by the outcomes of a project) engagement in HIV clinical trials²⁵. Of 917 citations generated by literature review, 108 were included in the analysis. Most of the studies were performed in high (44.4%) and middle income (27.8%) countries. Reasons for engagement were predominantly associated with study performance (to understand factors affecting recruitment) but also included identification of barriers and facilitators to trial participation, to inform the ethical conduct of the trial, and to develop trial tools. Based on engagement by research stage, stakeholders were primarily utilized to inform trial protocol development (45.5%) and trial recruitment (43.5%). Only 13.9% of studies engaged stakeholders to participate in generating research questions, 12% in study enrollment, 15.7% in follow-up, 2.8% in interpreting results and 10.2% in trial results dissemination (Figure 1, reproduced with permission). Overall, this review revealed that the community engagement standard outlined by GPP guidelines continues to be inconsistently and incompletely applied¹⁹⁻²².

Moving beyond conventional (top-down) approaches to community engagement²⁵

Power inequities due to expert knowledge and training as well as differences in circumstances often lead to top-down engagement with the community^{26,27}. That is, an expert develops an idea, tests the idea in the community (i.e. focus groups) and ultimately implements the research. Bottom-up approaches start with the community to identify the problem (e.g., include persons living with HIV, patient advocates, clinicians and researchers), involves the community in iterative development of solutions or approaches and engages the community in the performance of research²⁸. When these approaches are blended, through a) academic and community flexibility and power sharing, b) training in community developed cultural competency and/or c) in the intentional identification of scientific leadership who are also part of the community, engagement as defined by CBPR principles can be successful²⁹. Although top-down engagement remains the predominant approach²⁵, several high quality studies were recently published that demonstrate the impact of true collaborative work³⁰⁻³². One such study evaluated a bottom up approach to improving maternal and child health services utilization in the Greater Accra and Western regions of Ghana³³. The authors engaged community groups and associations to identify gaps in service delivery in healthcare facilities across Ghana. The intervention began with

recruitment and training of facilitators that were assigned one per community group. Second, healthcare quality proxies assessed by members of the partnering community groups were gathered. These included satisfaction or disappointment with non-technical components of service delivery (i.e. staff attitude towards clients, staff punctuality etc.). Review of these scores with health managers, and other authorities to develop action plans was then regularly followed up by community quality care champions to ensure implementation of action plans. Finally, health facilities that were perceived by community members to have improved were recognized for their efforts. Ultimately this approach, compared to control facilities with no intervention, resulted in greater increases in child immunizations and HIV testing of women³³.

Bi-directional commitment, flexibility, and power sharing remain key to success

Many community members and organizations engaged by academia may be motivated by generativity or service³⁴. However at some point to be effective, the community needs to move beyond this and become engaged in research³⁵. This involves ensuring that community members are well funded and supported, understand research ethics, are able to identify potential harms to their community and are willing and able to provide feedback to researchers³⁶. Achieving this requires flexibility, power sharing (shared decision making), and education to improve science and ethics literacy for the community and CBPR and cultural competency for research teams.^{27,37} Switzer et al communicated the impact of bi-directional commitment, flexibility, and power sharing in a recent case study of substance users participating in CBPR³⁸. Feedback from the community revealed that participation in research sometimes leads to stress that results in unintended consequences for health and contributes to inconsistent engagement, prompted the researcher to seek out novel approaches to CBPR³⁹. Through collaboration, the research team provided flexibility in involvement via a “drop-in” approach and opportunities to socialize and participate in fun activities³⁸. Specifically, the research team employed diverse facilitated activities that were arts-based to guide discussion of research rather than the traditional meeting format. This ultimately resulted in expansion of opportunities for greater diversity of involvement and deeper connections between community advisors and the research team.

There is value in having difficult conversations to improve effectiveness and foster growth

As in any relationship, tensions may arise between members of the community and the research team. Several publications shared their experiences embracing “productive tensions” and their approaches to dealing with conflict and fostering difficult conversations between the community and research teams. HEADS up!, a CBPR study exploring the lived experience of HIV AIDS Neurocognitive Disease (HAND)⁴⁰ included teams of researchers, HIV providers, nurses, social workers and peer research associates. Peer research associate recruitment occurred within the clinic sites in which they received care. Tensions within the team arose, around the candid experiences of peer research associates and the clinical services they received. Tensions also arose around the diagnosis of unintended real-world

consequences of a HAND diagnosis in a participant (i.e. loss of driver's license). A separate study in South Africa relayed issues of tension around cultural differences between practices in the home and research center, and miscommunication between staff and participants²⁶. In both studies, recognizing and addressing tensions through meaningful conversations enabled the community and the research teams to move forward with stronger dynamics and relationships. The performance of CBPR may be accompanied by tensions between team members but the pursuit of meaningful dialogue based on mutual literacy and understanding may improve research effectiveness and foster growth.

Innovative approaches to enhance CBPR

Several published studies introduced innovative approaches to CBPR to improve reach to difficult to engage populations and overcome some of the innate difficulties of CBPR. Active community engagement is considered essential in the performance of culturally competent research specifically when targeting vulnerable and hard to reach persons. As such, novel approaches such as use of mobile and social media outreach are actively being explored⁴¹. Establishment of a virtual panel is one innovative way to include difficult to reach populations. The University of New South Wales (UNSW) developed a community reference panel that exists as a virtual network of persons across Australia to be engaged in research design. This panel, originally established to improve the uptake of testing and treatment of sexually transmitted infections among Aboriginal Australians, now exists to support community involvement in research that embraces populations that are difficult to engage such as persons who inject drugs, are incarcerated, and sex workers. Researchers desiring to engage with these populations use panel coordinators with established relationships with the community to engage the community⁴². Another novel approach is implementing crowdsourcing (the process where a group rather than an individual finds a solution, solves a problem, or completes a task) as bottom-up approach to facilitate research engagement⁴³. Integrating principles of CBPR with crowdsourcing recently resulted in the participation of a wide range of ages and significant representation from Black and White participants to better understand public perspectives of HIV cure-related research⁴⁴.

Innovations are also being developed around improving trust and understanding in the performance of CBPR in HIV research. One proven approach to overcoming power dynamics between researchers and the community is through enhancing understanding of the community experience using arts-based methods (digital storytelling, photography, drawing, poetry writing, or performance) or participatory visual method (PVM)⁴⁵. PVM is a collaborative process where participants and facilitators use visual methods, like art or video production, to communicate personal and potentially sensitive stories and represents a way to involve marginalized communities and enhance inclusivity^{46,47}. Utilization of this approach to impact ART adherence effectively engaged PLWH in clinic to stimulate dialogue around the treatment of HIV in South Africa⁴⁸. These examples demonstrate the importance in pursuing ongoing innovation to enhance CBPR.

Gaps in Knowledge and Key Research Priorities

Recent literature continues to demonstrate the value of academic and community partnerships but several gaps in knowledge still exist. The majority of publications on community engagement are narrative and summarize experiences and lessons learned^{27,40,49,50}. Very few evaluate true effectiveness of academic-community partnerships in the delivery of project and public health relevant outcomes that clearly communicate the added value of these partnerships, especially to researchers, funders, and difficult to reach populations⁵¹. Empirically evaluated outcomes such as improved recruitment of persons historically difficult to engage, new funding opportunities that arose directly from partnerships, enhancement/growth of the workforce, mutual gain, and changes in public health outcomes such as reduced HIV incidence^{14,30} should be evaluated to enhance collective “buy-in”³².

Researchers outside of the field of HIV are beginning to evaluate the role of human-centered design or HCD (also known as user-centered design) as a potential method to mitigate limitations of CBPR practices (specifically by optimizing the time required to build deep community trust and relationships and improving participation of minority opinions and voices)⁵². HCD originated from the field of human-computer interaction but the basic tenets embrace co-operative design (co-design), participatory design and “customer-centered design”.⁵³ Given its origins in technology development, there may be specific value in its integration into innovations evaluating the impact of technology to enhance CBPR.⁵³ Additionally, HCD acknowledges diversity in experiences and opinions of the community and as such utilizes methods (i.e. co-design workshops) that rapidly engage and target a wide-range of experiences and opinions to capture the varying experiences of PLWH. This approach may be particularly advantageous in highly heterogeneous populations such as persons aging with HIV⁵⁴ to ensure research priorities are not just influenced by the most involved and vocal but reflect the greater community. For example, PLWH who aged with HIV were exposed to longer durations of HIV viremia, more toxic ART, and significant peer losses that contribute to multi-morbidity, polypharmacy, disability and loneliness⁵⁵⁻⁵⁸. PLWH that acquire HIV in later life when immediate and safer ART are standard of care may not experience similar morbidity. Additionally, many older PLWH may not be aware that the challenges they are facing as they age are related to HIV (multi-morbidity, social isolation, treatment fatigue) and thus may be most productively engaged with methods that incorporate education. HCD at its core is inclusive and iterative and as such welcomes diverse viewpoints and experiences to ultimately deliver a refined and nuanced research agenda or intervention⁵⁹⁻⁶¹.

Lastly although principles of CBPR and GPP appear broadly embraced by the HIV prevention community, extension into other areas of HIV research is limited. We must remember that GPP were developed in the context of large-scale biomedical HIV prevention trials⁵¹. Specific areas that may benefit from greater community engagement include HIV cure-related research⁶²⁻⁶⁴, aging with HIV^{23,65} ending the epidemic^{66,67}, and emerging technologies like long acting ART because they deal with sensitive topics, or potentially vulnerable populations that may not be well understood by research teams. For example, the Last Gift study at the University of California San Diego engaged the local community

advisory board in elaborating ethical considerations for HIV cure-related research at the end of life⁶³. They discovered that the community had highly differing opinions on their specific approach, but also acknowledged PLWH as true experiential experts. The Last Gift team is utilizing the differing opinions to inform the implementation of funded research⁶⁸ and in the development of future studies specifically around controversial practices such as interruption of beneficial HIV treatment⁶⁹. Other successful efforts within the ACTG have involved community representatives as co-investigators on clinical trial protocols to understand participants' perspectives and lived experiences in HIV cure-related research and research around aging with HIV⁶⁹. As the field of HIV research continues to grow and innovate, we will need to build the capacity of biomedical researchers to value community input and communicate scientific findings in community-friendly ways.

Conclusion

History has demonstrated to us that partnerships between academia and the community are capable of accomplishing tremendous positive change. While great strides are being made in the performance of CBPR and GPP, there remains room for improvement. To truly encourage comprehensive and expansive CBPR and GPP requires ongoing robust reporting of qualitative and quantitative outcomes directly attributed to community engagement and the development of innovative communication approaches (like PVM)^{32,48}. However, meaningful and effective academic and community partnerships take time, financial resources, training in community engagement and cultural competency, infrastructure building and institutional support⁷⁰. Thus advancement of CBPR and GPP in HIV research will require the development and integration of specific community engagement standards and requirements and support to do so from funders, conferences, research journals and institutions^{23,25,53}.

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Key points

- Partnerships between the community and academia has historically resulted in critical advances and ground-breaking outcomes in the field of HIV.
- Community Based Participatory Research (CBPR) and Good Participatory Practices (GPP) established decades ago continue to be embraced in HIV research, but are often partially or incompletely implemented.
- Historical barriers to the implementation of CBPR and GPP continue to exist, and novel approaches should be pursued to overcome them.
- Future work should embrace selection and reporting of quantitative and qualitative outcomes of community engagement to enhance “buy-in” from the HIV research community at large.

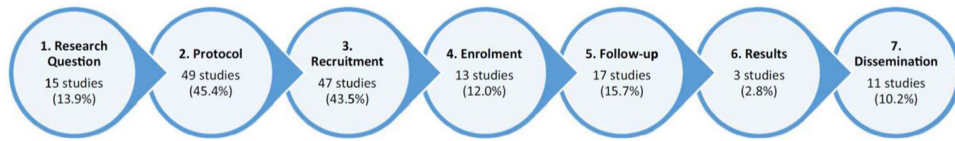


Figure 1. Summary of the purpose of stakeholder engagement by clinical research stage. Reproduced with permission ²²

Table 1:The Denver Principles¹

Statement from the advisory committee of the People with AIDS	We condemn attempts to label us as “victims,” a term which implies defeat, and we are only occasionally “patients,” a term which implies passivity, helplessness, and dependence upon the care of others. We are “People With AIDS.”
Recommendations for all people	<ol style="list-style-type: none"> 1 Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact. 2 Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.
Recommendations for people with AIDS	<ol style="list-style-type: none"> 1 Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies. 2 Be involved at every level of decision-making and specifically serve on the boards of directors or provider organizations. 3 Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge. 4 Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.
Rights of people with AIDS	<ol style="list-style-type: none"> 1 [The right] to as full and satisfying sexual and emotional lives as anyone else. 2 [The right] to quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race 3 [The right] to full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives. 4 [The right] to privacy, to confidentiality of medical records, to human respect and to choose who their significant others are. 5 [The right] to die—and to LIVE—in dignity.

Table 2:

Countering Common Misconceptions in Community Engagement

Community engagement is not recruitment for clinical research	Community engagement and recruitment are fundamentally activities and serve different purposes. Recruitment is about engaging populations of interest, screening for eligibility, and enrolling participants based on inclusion and exclusion criteria
Community engagement and community advisory boards serve related but different purposes	CABs provide input into the research process, as a sounding board, for protocol review and represent a critical safeguard in research.
Community engagement and education is not merely community service	Community engagement and education is more than community service and should be properly valued. Community engagement involves managing expectations, sharing information, meaningful dialogue and mutual literacy and understanding. Community engagement is about intentionally shifting power to the community.
Community engagement is not research or ethics	Research is systematic work that involves methods and informed consent. Ethics is the study of what ought to be done.

CABs – community advisory boards

Table 3:

Principles of Community Based Participatory Research and Good Participatory Practices

Community Based Participatory Research ²¹		Good Participatory Practices ¹⁶	
1	Recognizes community as a unit of identity	1	Respect
2	Builds on strengths and resources within the community	2	Mutual understanding
3	Facilitates collaborative partnerships in all phases of the research	3	Integrity
4	Integrates knowledge and action for mutual benefit of all partners	4	Transparency
5	Promotes a co-learning and empowering process that attends to social inequalities	5	Accountability
6	Involves a cyclical and iterative process	6	Community stakeholder autonomy
7	Addresses health from both positive and ecological perspectives		
8	Disseminates findings and knowledge gained to all partners		
9	Establish a long-term commitment to the process		

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