

Community engagement in HIV prevention trials: evolution of the field and opportunities for growth

Katie West Slevin, Morenike Ukpong, Lori Heise

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Introduction

Finding new ways and tools to prevent HIV is an urgent endeavor. An estimated 33 million people were living with HIV/AIDS in 2007, 67% of them located in sub-Saharan Africa where the majority of HIV prevention research trials take place.¹ The sense of urgency to find new prevention options, coupled with limited time and resources available to sponsors and investigators, can mean that community preparedness and engagement activities receive inadequate attention and funding. Too frequently, attention to community issues falls to the bottom of a long list of competing priorities.

The cost of this reality, however, can be severe. In three recent instances, important HIV prevention trials were either shut down or threatened due to ill-conceived or inadequate community consultation, controversies fueled by inflammatory and misleading media, and uncertainty or lack of consensus on ethical issues.²

By contrast, authentic community engagement helps ensure that trials can and will proceed smoothly. Investment in community work helps cultivate a sense of community ownership that builds trust and deepens knowledge of local realities. It can improve the quality of the data collected by ensuring that trial protocols, procedures, and strategies are acceptable to trial participants and build on locally understood languages and customs. It also optimizes the likelihood of eliciting high levels of adherence and accuracy in self-reporting.

What is community engagement and why is it needed?

Over the years, our understanding of what constitutes community engagement has evolved substantially. From its origins in early HIV treatment activism in the 1980s to the kinds of nuanced community engagement cultivated at large-scale HIV prevention trials today, community engagement in biomedical research is a developing field. Lessons are emerging continuously that inform our approaches to community engagement, our conception of who constitutes community, and our understanding of how—or *if*—true partnerships can be established in the quest to expand options to prevent HIV transmission.

Many questions arise: Who are the stakeholders in research? How do you solicit meaningful input from those stakeholders? What is needed to facilitate engagement? Who makes the decisions around who to engage in the research process and how to engage them? Is community and stakeholder engagement really a necessary part of what is already urgent, under-funded public health research?

The need for community engagement has attracted increased attention in recent years due to the highly vocal demands of HIV activists, the recognition that inclusion and transparency are ethical responsibilities, and the fact that experience shows that *not* involving communities in HIV clinical research can threaten the viability of trials.

The issue is concisely summarized in a recent paper examining the evolution of community advisory boards (CABs) and community partnerships at HIV prevention research trials:

“Research in developing countries presents distinct opportunities and challenges. The kind of complicated trials often associated with HIV/AIDS research in these regions cannot succeed without the support and cooperation of host country and affected communities. Yet, recent controversies regarding clinical trials conducted in developing countries indicate that much remains to be learned about what constitutes effective community collaboration [1-5]. Trials in developing countries have been halted or suspended for a

variety of reasons including lack of consensus on ethical issues, lack of appropriate care and treatment of participants, and lack of adequate community consultation.”³

Further, ethical guidance documents generally stress community engagement as essential to the ethical conduct of trials. *Ethical considerations in HIV biomedical prevention trials*, a document co-published by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO) notes:

“To ensure the ethical and scientific quality of proposed research, its relevance to the affected community, and its acceptance by the affected community, community representatives should be involved in an early and sustained manner in the design, development, implementation, and distribution of results...”⁴

Defining community

When discussing community engagement, it is important to arrive at a working definition of community.

A number of often-competing definitions have been used to describe what we mean when we talk about community. *Good participatory practice guidelines for biomedical HIV prevention trials (GPP)*, published by UNAIDS and the AIDS Vaccine Advocacy Coalition (AVAC), defines community as “separate and overlapping groups of people who are infected and affected by HIV in various ways”.⁵

A report from the *Microbicide Development Strategy’s Civil Society Working Group* takes a more nuanced view of community, defining it as “trial participants, their families and partners, other local stakeholders, and service providers/community groups within the geographical parameters of the clinical trial location.”⁶ While the HIV Prevention Trials Network adopts a more limited definition of community in their *Community Program FAQs* as “the group of people who will participate in, or are likely to be affected by or have an influence on, the conduct of research.”⁷

Most often, people talk about community *without* defining what they mean or to whom they are referring. The number of individuals and groups that see themselves as relevant stakeholders in HIV prevention research is also expanding. It is little wonder then that researchers find it difficult to define the boundaries of exactly who they must consult to meet evolving expectations around community and stakeholder engagement.

To help build a common paradigm around these issues, the Global Campaign for Microbicides (GCM) has proposed reserving the term “community” to refer explicitly to the specific “sub-group” (e.g., men who have sex with men [MSM] or sex workers) and/or geographic community from which trial participants will be drawn and to use the term “stakeholder” to refer to groups and individuals operating at a district, national, regional, and/or international level. Stakeholders could include political decision-makers, ministries of health, regulatory bodies, ethical review committees, national nongovernmental organizations (NGOs), civil society advocates and the media.

GCM has adopted the following tool to help define the spheres of community and stakeholder engagement in biomedical HIV prevention research and the various levels at which activities can and should occur (see Diagram 1). A similar model is outlined in the *GPP*.⁸

Diagram 1. Spheres of community and stakeholder engagement



Personal: “Trial Participants & Study Staff” refers to the women directly participating in a trial, their partners (in some instances), and the study staff working at the trial site.

Local: “Host Community” refers to the individuals living in the area of the trial, their leaders, and the community-based and non-governmental organizations (CBOs) that serve or represent them directly. This sphere can also include traditional healers and other community actors/structures such as community advisory boards (CABs).

National: “National Stakeholders” describes anyone who has a role to play in the political, scientific, and social enterprise of microbicide development at the national level. It includes political decision-makers, ministries of health (MoH), regulatory bodies, ethical review committees, national NGOs, civil society advocates, donors, and funders.

International: “International Civil Society” refers to non-profit, organized, citizen-led movements or groups interested in the goals, process, and outcomes of microbicide research and/or in the rights of communities or research participants. Civil society can include international or regional NGOs (such as the African Microbicides Advocacy Group, AVAC, GCM, or UNAIDS), networks, or the media.

Different types of community and stakeholder engagement take place at these various levels and may look very different. The activities undertaken by community education departments and community liaison officers working at research sites often focus around the “personal” and the “local” levels. These efforts typically engage trial participants, study staff, community leaders, and organizations in the area that immediately surrounds the trial site. The organization of a CAB (discussed at greater length in the section entitled *Evolving history of community engagement*) is a prime example of community engagement at this level.

The type of stakeholder engagement that occurs at the district, national, and/or regional levels is most often implemented by others in the research hierarchy such as in-country investigators, international investigators, donors, trial sponsors, or the leadership of civil society organizations. Often, research trial staff hold regular meetings with government officials to update them on the trial or convene stakeholder meetings where some of these policymakers and/or national civil society leaders are in attendance.

In recent years, groups at the “international civil society” level have also begun to view themselves as relevant stakeholders in the research process. These groups may be brought into the process to provide civil society perspectives on research decisions and/or use their international standing to advocate on behalf of more local and national groups for their greater inclusion.

Evolving history of community engagement

Traditionally, people serving as research participants and those in the communities hosting research trials have largely been absent from the research process and decision-making. Research institutions did not seek to engage them as partners in research but, instead, viewed them simply as research “subjects” and/or potential users of the end product. With the emergence of the women’s health movement in the 1970s, however, and HIV/AIDS in the 1980s, this traditional landscape was forced to undergo drastic change.

1970s—1990s

In the 1970s, women’s health advocates began to protest the inadequate inclusion of women in biomedical research and to demand a role in decision-making regarding research on contraception, pregnancy, hormone replacement therapies, and a host of other women’s health issues.⁹ In the early 1980s, this call was picked up by AIDS activists primarily in North America and Europe. Desperate to expedite the search for treatments to combat HIV/AIDS, they called for “a seat at the table.” Suddenly the biomedical research field was faced with a well-informed, energized community of activists demanding to be involved. Most of these AIDS activists were relatively affluent, well educated, and had prepared themselves for this engagement by educating themselves about HIV and scientific research.¹⁰

In response to their demands, the establishment of CABs—composed primarily of non-scientists who advise on research protocols and help to educate communities about the research taking place—became a requirement of US and European donors. It was then exported, via donor requirements, to international research sites.¹¹

Throughout the 1990s, the number of CABs in Africa and Asia expanded as the major research sponsors began requiring their use. In 2003, the Reproductive Health & HIV Research Unit, a South African research institute, conceptualized the purpose of the CAB, as follows:¹²

- To inform the community about the research study.
- To enable and increase recruitment into the study.
- To maintain enrollment levels.
- To develop strategies for the referral and support of participants who test positive for HIV.
- To solve problems arising from the study.

In recent years, this narrow concept of community engagement has largely been deemed insufficient by communities, advocates, and civil society groups. Advocates have urged a broader view of community engagement—one that encompasses and promotes community empowerment and a voice in shared decision-making, in addition to facilitating research.

The CAB strategy also ran into a number of problems when transplanted from treatment to prevention trials and from the US and Europe to the developing world.

The gay male treatment activists who first pushed for involvement were a relatively homogenous group of people living with HIV/AIDS who were motivated to make HIV treatment trials the primary focus of their activism. They had a personal and urgent interest in identifying new and better treatments that, if successful, might benefit them immediately and directly.

Conversely, the individuals and communities who participated in HIV prevention research trials comprised a much more diverse spectrum including sex workers; MSM; women; adolescents; and reproductive health, gender, and human rights advocates. These varied groups, in some instances, comprised “communities” only in the sense that they may have shared a heightened risk of contracting HIV and/or a common geography. Moreover, most large-scale HIV prevention trials took place in resource-poor countries that confronted not only a growing HIV/AIDS epidemic but a host of other health, economic, and social issues.¹³

2000s

These realities conspired to transform community engagement from an activist-led movement where individuals “pushed” for inclusion, to a researcher-led effort, where study staff worked to encourage participation and “pull” untrained, overburdened, and often marginalized individuals into relationships with Western-educated researchers.¹⁴ The nature of this shift was first articulated by individuals who participated in a GCM-sponsored consultation on community involvement held in South Africa in 2003.

Diagram 2. Expectations and challenges facing CABs	
Expectations	Realities/Challenges
Represent range of community viewpoints fairly	Dominated by political or other local agendas
Channel for communication between researchers and community	Confusion over roles: <i>should CAB members and community liaison officers help recruit?</i>
Independent advice to researchers	Can CABS really provide challenge the research when it is financially dependent on that same enterprise?
Voluntary commitment of members over time	Competing priorities in resource-limited settings
Provide input on trial design and protocol	Unclear power to influence research agenda
Oversight/watchdog for the research	Uncertain accountability of CAB to community and research enterprise to CAB

The challenge of engagement has been further complicated by disagreements about whether community engagement is really an essential part of the research endeavor, about when community input should be sought, and about what the appropriate motivations are for engaging community and stakeholders in biomedical HIV prevention research.

Participants in the 2003 consultation likewise challenged the notion that constructing a CAB—by definition—equaled adequate community engagement. They identified a number of limitations to the CAB model and described, in depth, some of the difficulties they faced when trying to implement this approach to

community engagement in their local settings (see Diagram 2).¹⁵

They proposed an alternate approach—a continuum of engagement that moved from simple information exchange, through consultation and then onto empowerment and mobilization (see Diagram 3). Using this model, most community involvement efforts occurring in 2003 could be located somewhere between information sharing and consultation.¹⁶

To document the conceptual evolution that had occurred between the 1980s and 2003, participants at the consultation then drafted an alternative list of goals for community engagement. They concluded that the aims of such efforts must shift from simply serving those associated with making research work better to a more holistic approach. Namely, community engagement should seek to:¹⁷

- Improve the ethical and scientific integrity of trials.
- Increase the transparency and accountability of the research to the community.
- Maximize benefits and minimize risks for participants and for host community.
- Strengthen local capacity and infrastructure.

To operationalize this new model, participants proposed a more flexible, multi-faceted approach to achieving these goals. Rather than rely solely on a CAB, they argued that sites should develop a “community involvement plan,” that would outline a strategy and timeline for achieving each objective of community work (see Diagram 4). The plan would draw on a wide array of tools and mechanisms, from community meetings and participatory research to street theater and creative approaches to countering rumors.

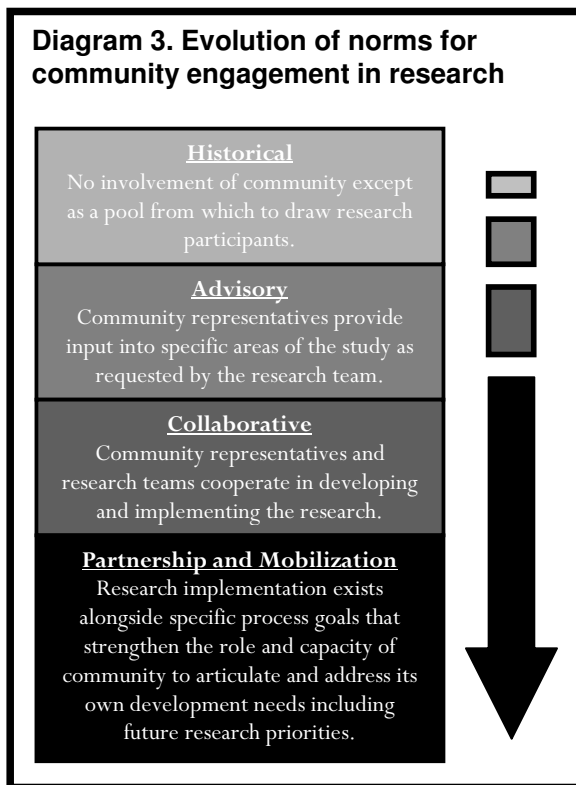


Diagram 4. Alternate objectives for community and stakeholder engagement

Objectives	Steps for Achieving the Objective
Create a conducive environment for community-research partnerships	• Identify and orient community facilitators
	• Establish relationships and build trust between research staff, facilitators, and community
	• Document community resources
	• Set goals and create opportunities for mutual learning
	• Create a monitoring, evaluation, and documentation plan
Ensure ongoing two-way information exchange, feedback, and dialogue between community and research team	• Develop communication channels with “civil society” stakeholders
	• Maintain two-way communication with the local community
	• Identify and address misinformation or concerns
Enhance scientific validity and ethical integrity throughout the trial	• Design and implement strategies to protect ethical integrity and participant and community rights
	• Design and implement strategies for maintaining scientific validity
Strengthen community capacity to articulate and address their own social and development needs	• Implement strategies that strengthen community capacity
	• Prepare for eventual introduction and access to microbicides

Current state of the field

Since 2003, the field has faced some serious controversies, most notably those arising from the oral tenofovir trials initiated in Cameroon and Cambodia. Activists in the trial countries and some international groups criticized the trials as unethical—raising concerns about how access to on-going care would be ensured to trial participants and about lack of sufficient community and stakeholder engagement. Similar but different concerns were raised by advocates in Nigeria and Thailand. Eventually activism around these issues and the ensuing media storm led the Cambodian Prime Minister to shut down the tenofovir trial before it began enrolling.¹⁸ Subsequently, the Cameroonian government suspended the trial in Cameroon, further enflaming general public mistrust of scientific research.¹⁹

These setbacks prompted a period of searching self-reflection in the HIV prevention field as donors, advocates, and scientists evaluated what went wrong and discussed what needed to change to prevent trials from being halted for political reasons in the future.

As part of this process, UNAIDS in 2005 convened a global consultation on “*Creating Effective Partnerships for HIV Prevention Trials*” to examine what had occurred in Cambodia and Cameroon and to search for a productive way forward.²⁵ Out of the consultation emerged the GPP, a product jointly developed by UNAIDS and AVAC.

The process used to develop the GPP had two goals:

- 1) To establish clear, global standards for community participation and input in HIV prevention trials.
- 2) To publish guidelines with the intent of seeking eventual endorsement by the International Council on Harmonization (ICH).²⁶

The guidelines were drafted by a diverse group of researchers, community advocates, and civil society representatives. Envisioned as a living document, the GPP aspires to set normative expectations for the field of biomedical HIV prevention research with regard to community and stakeholder engagement that are comparable to the normative documents already in place for other areas of clinical trial research such as the *Good Clinical Practice* guidelines (drafted by the ICH). Following the GPP’s



Box 1. The tenofovir case: lessons learned from Cambodia, Cameroon, Nigeria, and Thailand

In 2004 researchers embarked on a number of studies to test the safety and effectiveness of using tenofovir disoproxil fumarate as an oral pre-exposure prophylaxis (PrEP) to prevent HIV transmission. Trials commenced in five countries: Cambodia, Cameroon, Ghana, Nigeria, and Thailand.

Despite the promise of tenofovir as a potential new method for HIV prevention, trials in four of the five countries—Ghana being the exception—were prematurely closed. Of the four that closed, all of the trials suffered from what local communities and civil society perceived as a lack of meaningful community engagement. Miscommunication and the media firestorms that followed finally led the Cambodia and Cameroon trials to be closed by local governments.

While the trials in Nigeria and Thailand did not close due to controversy, advocates in these settings shared many of the concerns expressed by their counterparts in Cambodia and Cameroon. Primarily, these included issues of transparency and communication, and disagreements over certain aspects of trial implementation.²⁰

While the intricacies of each case are too complex to represent here, some of the overarching lessons learned can be summarized as follows:

- Mechanisms are needed that “ensure systematic involvement of legitimate representatives of the more affected community as partners in research.”²¹
- “Conducting an HIV prevention trial with minimal or late-stage civil society input is no longer acceptable – nor is it generally regarded as a wise or efficient approach.”²²
- The “engagement of the host community may need to start with basic ‘research literacy’ education.”²³
- Perhaps most notably, that “the people involved [researchers and communities] were coming from widely disparate cultural, social and economic viewpoints.” “Perhaps the most important lesson [to be learned]...is the cost of failing to recognize and address these disparities.”²⁴

publication, AVAC announced a call for proposals to support community consultations on the guidelines and developed a *GPP Facilitator's Guide* (available at <http://www.avac.org/gpp.htm>).

Best practices

In recent years, a number of new and creative strategies have emerged for implementing the aspirational goals outlined both by the GCM consultation and the GPP guidance. Below we highlight a number of the most promising examples of this ground-breaking work.

Best practices: The Microbicides Trials Network community engagement program

The Microbicides Trials Network (MTN) is the youngest of the six research networks sponsored by the Division of AIDS (DAIDS) at the US Department of Health & Human Services' National Institutes of Health. Its leadership works actively with the community through the Community Working Group (CWG), consisting of CAB members, community liaison officers, and civil society representatives. The CWG is actively engaged as protocol team members in all MTN protocol development processes. All CWG members, in turn, consult with their local CABs and community members to solicit input into all protocols developed by the MTN.

With the support of its partners (Family Health International and DAIDS), the MTN is able to ensure the effective engagement of the CWG by investing significant time and effort in building its members' ability to engage knowledgeably. This capacity building has taken the form of in-depth trainings on basic research concepts, specific aspects of HIV prevention research, and skills for reviewing a protocol and providing constructive feedback.

The MTN also regularly solicits the perspectives of its CWG, CAB, and community partners on a range of research-related issues including the development of research literacy and community education materials, trial product packaging, and distribution methods.

Best practices: The Microbicides Development Programme – Mwanza, Tanzania

The Microbicides Development Programme's (MDP) current trial of the candidate microbicide PRO 2000 in Mwanza, Tanzania, provides a compelling alternative to the standard CAB approach and has resulted in a substantially more inclusive and democratic strategy for community engagement.

The MDP trial in Mwanza enrolls women who work in bars, restaurants, and hotels and women who prepare food for sale or work in traditional bars preparing and selling local beer. From the outset, the study worked closely with community members, obtaining permission from managers of the various recreational facilities where the women worked to hold informational meetings and establish weekly reproductive health clinics in select hotels and guesthouses.

At the start of the trial, the community education department conducted a community mapping and held elections for representatives to sit on a city-wide community advisory committee (CAC). Among the CAC members were participant representatives—women actively enrolled in the trial—to help give voice to those most directly affected by research decisions, the trial participants themselves.

Workshops and community meetings are conducted to explore project-related concerns using a variety of participatory methods.²⁷ Study staff also use community theater performances to educate the wider public about the trial and the need for new prevention tools. In addition, MDP Mwanza holds regular community stakeholder meetings that include government officials, representatives from local care and referral facilities, and community representatives. At one such meeting, MDP

Mwanza presented its own standard of care guidelines outlining what care and prevention services should be provided to women participating in the trial. Significantly, the development of these guidelines was done in consultation with community stakeholders.

Best practices: the New HIV Vaccine and Microbicide Society, Nigeria

Partnering with civil society groups that are well-versed in research and who have ties with local communities can greatly aid community engagement efforts. The New HIV Vaccine and Microbicide Advocacy Society (NHVMAS)—formerly the Nigerian HIV Vaccine and Microbicide Advocacy Group—is one such example. Established in 2003, NHVMAS has worked collaboratively with clinical trial sites in Nigeria, including those conducting the Cellulose Sulfate and SAVVY® microbicide studies, the TMC 120 incidence study, and the HIV incidence study for HIV vaccine research.

Strategically, the organization worked with the government, journalists, community advocates, members of the institutional ethics boards, and HIV prevention trial researchers to facilitate research literacy and community support for the trials.

The researchers of the before-mentioned studies noted that the multiple media reports about microbicides helped facilitate understanding and support for the trials—something that could not have been achieved without the effective use of the NHVMAS network.²⁸

Best practices: the community of practice

While information sharing occurs within different research networks (such as DAIDS), until recently, there has been little communication on community-related issues across research networks or independent research centers. Historically, research staff at the site-level—particularly community outreach staff—have seldom had formal mechanisms for sharing their experiences, lessons learned, and best practices, or had mechanisms to help them stay abreast of developments in the wider field.

In November 2007, GCM held a meeting around issues of community engagement in research at which it was decided that GCM would help to establish and facilitate a community of practice around community engagement in HIV prevention trials.

Launched in April 2008, the Community Involvement Community of Practice (CoP) brings together community staff working at HIV prevention trial sites, community program managers, and others working on community engagement issues to share their experiences and challenges, talk about important issues, and foster a culture of sharing and collective problem-solving within the field. Over the past six months, the CoP has grown to include over 50 members from 14 countries representing civil society organizations; HIV prevention trial sites; research networks; and vaccine, microbicide, and pre-exposure prophylaxis (PrEP) trial sponsors. The CoP holds monthly calls; maintains a web-based clearinghouse; and holds annual meetings to facilitate efficient sharing of resources, information about how various community departments are structured, and strategies for engaging and soliciting input from local communities.

The way forward

While researchers have begun to think more expansively about how communities and stakeholders can be involved in the research process, more needs to be done. Below we outline some important next steps.

Establishing norms for community engagement

History has taught us that single mechanism approaches in fact are *not* one-size-fits-all and do not work in all instances. It is important to maintain a range of strategies for engaging the community

while working collaboratively as a field to establish norms around the principles and purpose for doing such work. Efforts like the GPP are a step in the right direction but more needs to be done to formalize these expectations and provide operational guidance on how to achieve the aspirational goals laid out in these guidance documents.

Beyond the CAB

CABs and other similar structures can play an important role in research. However, CABs also suffer from limitations and should not be the only mechanism used to engage and solicit input from the community. Questions regarding the extent to which a CAB can truly and actively represent the community, the perceived autonomy of an advisory body organized by the research institution, and a CAB's reliance on volunteers who have competing priorities are examples of some of these limitations.²⁹ Furthermore, "by focusing on a CAB as the primary mechanism for implementing community involvement, the whole enterprise is subject to the success or failure of one strategy."³⁰ Instead, researchers should employ a more diverse range of approaches and sponsors should require the creation and implementation of more flexible "community involvement plans" rather than rely solely on CABs.

Funding community engagement

Presently, there is little guidance on how community departments should be funded in order to achieve the level of community engagement necessary for the successful implementation of trials. New norms for community engagement must include clear guidance on reasonable budgets and these budgets should be controlled at a site level.

Early involvement

As important as the *how* to engage communities is the *when* to engage them. Involving communities in the decisions about if, where, and why research will take place helps to establish trust and a sense of ownership over the research. Early investment in the capacity of communities to engage in the research process helps to build a strong base of support and can help to avoid future misunderstandings that may threaten the viability of trials.

Planning for future access

Beyond the successful implementation of research trials, community support is vital for the successful introduction and future acceptance of study products should they prove effective. Engaging communities and stakeholders early can help ensure the strategies for introduction are contextually appropriate and acceptable to the community.

Open dialogue

Coordinated efforts to share lessons learned and best practices are vital, as are questions of how to evaluate such strategies and measure their success. The Community Involvement CoP is one important first effort. But the degree to which the field as a whole can mature will depend on donors and research institutions recognizing and supporting the importance of opportunities for professional dialogue on these issues.

Documenting evidence-based approaches

There is need for quantitative and qualitative evidence to support advocacy for increased investment in community engagement in HIV prevention trials. As new and creative strategies emerge, it will be vital for the field to document and evaluate these practices in order to build a body of evidence to inform authentic and effective community engagement.

Partnerships

In recent years, particularly in the wake of the dramatic closings of the Cambodia and Cameroon tenofovir trials, the discourse on community engagement has moved toward notions of "partnership" between community and the research entities.

While partnership is a noble goal, some of the existing language fails to acknowledge the deep power imbalances that exist between trial host communities and transnational researchers. Many community members and CABs do not have the basic tools necessary to engage constructively in debates about science and protocols. If communities are not prepared to engage, then assertions of empowerment and partnership ring hollow.

It is important to acknowledge and address issues of power in the research endeavor. Power imbalances exist across multiple lines: between principal investigators and field staff, between northern researchers and their southern counterparts, between more educated community members and those less-educated. One goal of community engagement should be to work towards reducing these power disparities and developing creative mechanisms for addressing those that are deeply entrenched (such as gender dynamics between predominantly male researchers and female trial participants). Pretending that these power imbalances do not exist can breed tokenism and mistrust.

Beyond research-based activities

As HIV prevention research focuses more and more on resource-poor communities, there is a commensurate need to provide increased support for self-motivated groups and organizations willing to help create a positive enabling environment for research. These groups exist (because the impulse to create effective community responses to HIV exists universally) but they are currently so under-resourced as to be all-but-invisible to outside eyes. Investing in them—building their knowledge, organizational capacity, and visibility—is a key commitment that the HIV prevention field needs to make. The voices in the community must be recognized, elicited, and equipped so that they can engage in an informed way in HIV prevention research.

Integration: prevention and treatment

With the advent of antiretroviral-based microbicide research and PrEP studies, the HIV prevention field will see more and more engagement of HIV treatment advocates in the HIV prevention field. The field as a whole will also increasingly engage experienced HIV treatment researchers who have learned to work successfully with HIV treatment activists. An integration of the two fields of HIV research—*treatment and prevention*—appears imminent. Thus, the field needs to proactively support this integration process within research and community and stakeholder engagement.

Conclusion

The history of community and stakeholder engagement in both the HIV treatment and prevention fields has much to teach us as we search for ways forward. Over the past several decades, vital lessons have been learned—not the least of which is how a lack of community engagement can threaten the viability of research trials—and creative approaches and novel practices have emerged. But the call for well-funded, early community and stakeholder engagement is not consistently heeded. The recommendations outlined in this paper propose a way forward as we look toward the next twenty-plus years of the epidemic.

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