Advancing Equity and Fostering Change: A Guide for Academic-Community Partnerships in the DC Center for AIDS Research

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Advancing Equity and Fostering Change: A Guide for Academic-Community Partnerships in the DC Center for AIDS Research

Martha Sichone-Cameron*, Simone Sawyer**, Marcia Ellis***, Wendy Davis**, Deanna Kerrigan**, Nina Yamanis**, David Huebner**, Maria-Cecilia Zea**, Allison O'Rourke**, Arianne Malekzadeh**, Lisa Bowleg**

*DC CFAR Community Partnership Council
**DC CFAR Social and Behavioral Sciences Core
*** DC CFAR Community Partnership Council, retired

Authors note: This document was developed and written by the coauthors and does not necessarily reflect the viewpoints and practices of all members of the DC CFAR community.

Dedication

We dedicate this guide and the collaborative process used to develop it to the brave, courageous, and compassionate spirits before and among us. Your example, stories, activism, advocacy and memories helped to define our community members' rights as full and respected partners in HIV treatment, care and research. You continue to inspire and inform us to make change that will improve all of our lives. And to those academic researchers and community partners who work towards equitable partnerships in HIV research, your efforts and example will only enhance the research and inspire others. We also dedicate this guide to you.

Purpose and Organization of this Guide

Building on the scientific literature, community expertise and practical experience, this guide aims to:

- present best practices for equitable academic-community partnerships in the DC Center for AIDS Research (DC CFAR),
- acknowledge and examine the inherent tensions that exist in building and managing a partnership
- highlight the creativity and growth inherent in this work.

Our guide is written for both academic researchers and community members in the DC CFAR. It offers a historical context, concise and focused guidance, "real world" examples, and practical tools. It is organized around key components for an equitable academic-community partnership in HIV research. Readers are invited to move through the steps in order or begin with the steps that are most relevant to their experience, needs or place in the process.

To learn more about the organization-level approaches used by the DC CFAR in the pursuit of equitable community engagement, readers are encouraged to explore the companion piece, [Building an Equitable and Sustainable Academic/Community Research Partnership: The DC Center for AIDS Research (CFAR) Example.](#)[1] This document describes the DC CFAR's evolution and commitment to meaningful and equitable academic-community partnerships with key takeaways and lessons learned.

Introduction

The Centers for Disease Control and Prevention (CDC) defines community engagement as "the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interest, or similar situations with respect to issues affecting their wellbeing".[2] Community engagement challenges the hierarchy of traditional research and medical institutions that haven't addressed community perspectives. Community engagement demands that people impacted by the health issue be involved in decision making at all steps in the process, that they be treated with dignity and respect, and that their contributions be valued and given credit equal to that of academic researchers. There is growing recognition that community engagement and community partnerships and the knowledge and expertise they represent are foundational to impactful scientific research.[3] Minkler and Wallerstein suggest that *equitable* partnerships should be the gold standard for research.[4] However, achieving equitable partnerships between community and academic researchers takes work. It requires an understanding of power, privilege, and justice and a commitment to addressing the structural barriers and norms that prevent true equity in a research partnership.

There is a well-established body of work [5,6,7] and numerous excellent resources [8-12] devoted to community-engaged HIV research. This guide reflects the experiences and perspectives of community and academic partners in the DC CFAR. Throughout the process of writing this guide, our team "walked the walk", embracing the principles outlined herein, while encountering (and overcoming) some of the inherent tensions described throughout.

Historical Context and an Introduction to Community Engagement in Research

There is growing recognition that the research enterprise, like other sectors of society, is built upon a legacy of structural racism, classism, sexism, heterosexism, and cisgenderism. [13,14,15] An important example is the story of Henrietta Lacks, a Virginia tobacco farmer and 30 year-old Black mother of five who was diagnosed with and treated for aggressive cervical cancer at the Johns Hopkins Hospital in Baltimore, Maryland in 1951. In the time that she was being treated, investigators took samples of Lacks's cancerous cells without her knowledge or consent, a common practice at that time. Investigators had been trying for decades to culture human cells without success. The cells taken from Lacks were the first to successfully grow outside of the body. Later known as HeLa cells, this cell line has become the most widely used in biomedical research, contributing to the development of vaccines, including for polio, human papillomavirus and COVID-19, and medical techniques, such as chemotherapy, gene mapping and in vitro fertilization. Lacks, who died eight months after she was diagnosed, never knew of her contribution to medical science and her family was unaware of it for more than 20 years after her death. [16,17]

The HIV/AIDS epidemic is another example of the power of these socio-structural forces. Despite the severity of the unfolding HIV/AIDS epidemic in the early 1980s, research efforts in the U.S. proceeded slowly due to the stigmatized nature of early victims. [18] Community members lobbied against these forces demanding attention and funding to address the HIV/AIDS epidemic. [18] In one instance, members of the AIDS Coalition to Unleash Power (ACT-UP) attended a meeting of the AIDS Clinical Trials Group (ACTG) uninvited, demanding that the ACTG broaden its research scope to the study of the opportunistic infections that were killing people living with AIDS. [19] Not long after, community members were allowed to attend ACTG meetings and individual ACTG sites began to consult with local community members when developing studies. [20] Ultimately, community activism led to a 1990 mandate that all National Institute of Allergy and Infectious Disease (NIAID) funded research have a community advisory board (CAB). [21]

Community activists and organizers also protested the mistreatment and discrimination of people with AIDS in the document entitled, The Denver Principles. [22] This enduring document laid the groundwork for a shift in the way researchers and clinicians would approach their research and practice in HIV/AIDS and created the foundation of the principles of Meaningful and Greater

Involvement of People with AIDS, also known as MIPA and GIPA, respectively.[23] The Denver Principles, MIPA, and GIPA remain relevant today and are the basis for what is now referred to as community engagement. The Denver Principles established the precedent of doing work with people living with HIV for people living with HIV. Despite notable progress since the Denver Principles in the breadth and extent of community engaged HIV research, socio-structural and institutional barriers persist in the pursuit of equitable partnerships in HIV research.[24] Historically marginalized populations, including Black and Latine low-income populations, sexual and gender minority people, and women of color are disproportionately affected by HIV. This can bring to the surface a host of tensions when the majority of HIV researchers are university-based, privileged in terms of race and class, and employ research strategies, techniques, tools and methods that can harm communities, position researchers and not communities as experts and privilege researchers in terms of income and prestige.[25]

Community members of the DC CFAR have experienced these socio-structural and institutional barriers and tensions first-hand. The story of Henrietta Lacks and the language of the Denver Principles resonate deeply. Community members understand that people affected by HIV, their specimens, their bodies, their intellect, are central to successful HIV research and yet that reality has not always been acknowledged nor the knowledge gained from these experiments shared with participating communities in ways that are accessible. People living with HIV, desperate for treatment and a cure, have been sought out by academic and research institutions to help in answering numerous research questions. The benefit to the community of this participation has not always been clear. And while HIV researchers are often invested in the well-being of the community, after over 40 years of personal lived experience with this disease, it has often felt that there is not adequate acknowledgment of community member 'subject matter expertise'.

As stated in the Denver Principles, community members 'reject' the labels 'victim' 'which implies defeat' or patient 'which implies passivity, helplessness, and dependence upon the care of others.'[18] Community members have dealt with trauma, disregard, and often have a sense of having 'been there, done that.' Community members look to work with academic partners who bring with them the basic human values of humility, respect, kindness, and a willingness to learn. It is well past time to evaluate the structure, roles and responsibilities of academic-community research partnerships and to acknowledge the contribution that members of the community bring to HIV research right along with academic investigators. We present this guide, to highlight the ways in which the DC CFAR has worked to partner on the research that the community believes in, in ways that are equitable and mutually beneficial to both community and academic researchers.

A Model for Academic-Community Partnerships in the DC CFAR

This guide for academic-community partnerships in the DC CFAR is organized around ten key components. At the center is the central value of equity and justice. The guide also reflects the essential principles of capacity building, resources and communication. These essential principles and our central value of equity and justice underlie and guide the six-step research process that we propose. In each section, with a color-coded heading to mark its place in the model, we define the component, offer our insights, and our recommendations and practical guidance on how to support an equitable, rigorous and innovative academic-community partnership. Within each component, we also share illustrative quotations from our collaborations and experiences. Relevant templates and other resources are included in the Resource Appendix.

Central Value
Equity and Justice in Academic-Community Partnerships
Research Process
1. **Reflexivity**
2. **Shared research interests and priorities**
3. **Funding opportunities and grant applications**
4. **Research implementation**
5. **Research updates and dissemination**
6. **Post research project sustainability**

Essential Principles
Capacity building
Resources
Communication

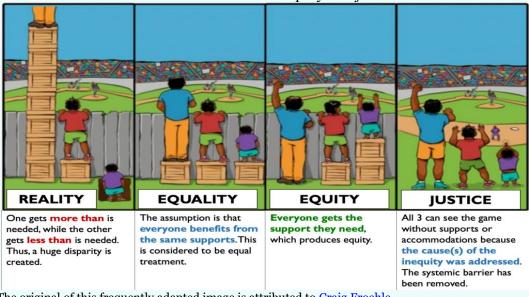**A Model for Academic-Community Partnerships in the DC CFAR**

In reviewing this model, the role and contribution of dedicated leadership on the part of both academic investigators and community members cannot be underestimated. In every step of the research process, academic researchers and community members can use their experiences in research partnerships to promote the benefits of collaborative research and advance the values of equitable partnerships to others who have not yet tried this approach. They can share the lessons that they have learned and the skills they have acquired through their experiences to demonstrate how others might proceed, thereby creating a pipeline for future academic-community partnerships. Leadership opportunities, such as the inclusion of both academic and community leaders of DC CFAR Scientific Interest and Working Groups, should be built into the organizational structure of the research entity,

Central Value
Equity and Justice in Academic-Community Partnerships

The central value of an academic and community partnership must be equity and justice. Equity in academic-community partnerships requires understanding and focusing on power, privilege, and justice and how these dynamics operate in every aspect of the partnership. In their initial conversations, academic and community partners should discuss what equity and justice look like for them in their partnership. Academic investigators should also consider and acknowledge their intersectional identities and the power they bring to the partnership. Community members may also need to consider their intersectional identities and the power and roles they have as a community representative. Ultimately, equity and justice in an academic-community partnership require a commitment to treating partners as equals, deserving of the time, financial resources, and energy it takes to ensure equity. This means equitable decision making around research topics and questions, equitable funding, and equitable leadership.[26]

The figure below illustrates what is needed to achieve equity and justice in action.

REALITY	EQUALITY	EQUITY	JUSTICE
One gets **more than** is needed, while the other gets **less than** is needed. Thus, a huge disparity is created.	The assumption is that **everyone benefits from the same supports**. This is considered to be equal treatment.	**Everyone gets the support they need**, which produces equity.	All 3 can see the game without supports or accommodations because **the cause(s) of the inequity was addressed**. The systemic barrier has been removed.

The original of this frequently adapted image is attributed to Craig Froehle.

Structural competence, or the understanding of how infrastructure and policies influence behaviors and health outcomes, can guide academic and community partners in understanding the dynamics of power, privilege, and justice. Structural competence considers the structures and processes within the social and political world and how these dynamics support or hinder individuals from achieving their desired goals.[27,28] For example, typically, in research that is funded by the National Institutes of Health (NIH), the primary investigator, the PI, must be someone who has a doctorate degree. This means that in most instances the academic investigator is going to be the principal investigator who will oversee the budget and the designated decision maker for the research project. Academic and community partners need to acknowledge these structural realities and an inherently inequitable balance of power. Individuals engaging in HIV research should also consider the historical and social contexts of people affected by HIV and their prior experiences with research and researchers. Researchers should consider how they and their research interests fit within this context. Partners must also consider:

- What does equity mean in this partnership? How can this be achieved?
- What structural barriers exist to achieving equity?
- How will the researcher commit to equalizing the partnership (e.g., collaborating on budgets?)
- How much say does the community partner have in deciding the research?
- Are partners equitably compensated for their time and expertise?
- Do meetings take place in settings and at times that are convenient and comfortable? Can meetings be made more accessible through remote options?
- Will community partners leave the research partnership with research data and findings that will empower them to better understand and advocate on behalf of their community needs?
- How can we ensure the sustainability of programs or services after a research project is completed?[29]

Academic investigators and community members must also acknowledge that engaging in equitable partnerships has an important impact on the lives of community members. It demonstrates the value of their stories and lived experiences and recognizes inequities and unmet needs. It is critical to remember that for the community partner, it is not research for the sake of research; it is often personal. Building equitable, sustainable partnerships that strengthen individual and community capacities is an important step towards putting equity into action.

A DC CFAR community member's voice

I was involved with the Planning Council and the DC Center prior to joining the DC CFAR Community Advisory Board. I appreciated that early on the DC CFAR focused time and resources on the transgender community. I consider myself a change mover and I felt that being associated with the DC CFAR would help me to effect change. I wanted to bring recognition and understanding of the transgender community to the academic researchers and community partners. Ron Simmons (DC CFAR CAB member and former Executive Director of the DC-based Us Helping Us, People into Living), was an anchor for me. He helped me build an organization and identify a space at a time when people felt that gay men had no room in their work and spaces for people of transgender experience. For my community, a priority is education and tools to help keep our community safe. Researchers need to understand these needs as well as the history and culture of the transgender community to be able to conduct meaningful research with our community.
Earline Budd, Executive Director, Empowering the Transgender Community, and CPC member

Research Process
1. Reflexivity

Using techniques from qualitative research methods, such as reflexivity, can be a valuable first step for researchers as well as community members contemplating engaging in a collaborative research partnership. Reflexivity, which "refers to the examination of one's own beliefs, judgments and practices during the research process and how these may have influenced the research" can be applied at the project initiation and revisited throughout the research process.[30,31] Academic investigators can examine their beliefs, judgments and practices (see Resource Appendix) while community partners can consider what it means to be charged with representing the needs of an entire community and how internal biases and personal priorities may inhibit their capacity to effectively and meaningfully advocate and engage.

Reflexivity is a foundational strategy to prepare for the iterative process of learning and growing with community and academic partners. It is also a good practice towards the cultural competence and cultural humility that are needed to do community-engaged work. Cultural competence has been defined as "the ability to understand, appreciate and interact with people from cultures or belief systems different from one's own"[32] with cultural humility defined as the "ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the [person].[33] In practice, cultural competency and humility require acknowledging that you aren't part of a certain culture, but that you are willing to take the time to appreciate and learn that culture and its cores values.

Cultural competence and cultural humility training can prepare researchers to recognize biases, power imbalances, and privilege and can facilitate a process that welcomes greater empathy, equity, and understanding in research. Training in cultural competence and humility can help researchers overcome entrenched norms about what constitutes research as well as traditions that position the researcher as the expert, the one in charge. It can also help academic investigators appreciate how structural racism and discrimination intersect with HIV (see Resource Appendix). Community groups that are affected by HIV are often also affected by structural racism and other forms of discrimination. Having cultural humility can practically mean avoiding research that amplifies trauma or alternatively, framing research around a resilience-focused approach.

It is also helpful to understand the culture of academic research. The academic environment is not always conducive to community-engaged research. It takes time and resources to build relationships, co-develop research questions, and sustain equitable academic-community partnerships. A commitment to cultural competence and cultural humility, to acting in accordance with core

community values can be challenging for academic researchers who are typically rewarded for the number of grants they receive, the number of papers they have published, and the number of talks they give. In those instances, where community and academic investigator goals and values do not align, the conversation may need to be respectfully suspended and perhaps resumed if and when a more productive alignment can be found.

2. Shared Research Interests and Priorities

The community of people affected by HIV is diverse, encompassing individuals of different ages, racial/ethnic groups, gender, sexual and gender minority status, and socioeconomic status with a range of experiences, needs and capacity to participate in research.[34] An important mechanism for identifying and connecting to communities who are interested in research is through academic institutions that have centers focused on HIV care and/or academic-community partnerships and affiliated CABs. For example, the DC CFAR has a strong Community Partnership Council (CPC). This group is composed of prominent members of the DC HIV/AIDS community including many senior members of DC HIV Community-Based Organizations (CBOs), HIV research CABs of participating DC CFAR partnering organizations and community clinics providing HIV services. CPC members also serve in leadership positions throughout the DC CFAR including on its Scientific Working Groups and Scientific Interest Groups and review and rate young investigator pilot grant applications on their potential for community-impact. The DC CFAR CPC serves as a resource to connect academic researchers and members of the community to build equitable research partnerships around topics of community concern.[1]

The CPC can identify viable and appropriate partners who are research champions within the community, or "population gatekeepers"[35] who know the community, have done trusted work within the community, and are viewed as leaders or individuals who have influence in their community. These connections can help researchers identify and engage parties related to their research interests, understand the community context, make introductions to individuals already working in the community, and serve as guides and resources throughout the research process. In addition to research partnerships, these connections may also help researchers identify individuals within the community who can offer insights and guidance on ethical considerations and accountability, effective advocacy and other specific expertise relevant to multiple research domains. The CPC can

help community members feel empowered to approach academic researchers in the DC CFAR with their ideas, interests, and priorities for HIV research to initiate equitable partnerships. The DC CFAR's CPC can be contacted at CFARinDC@gmail.com.

The DC CFAR's CPC can also guide researchers to other valuable local resources such as their local Eligible Metropolitan Areas (EMA) HIV planning councils. These groups are tasked with setting HIV-related service priorities and allocating funds to meet the local needs of people living with HIV.[36] Attending EMA meetings and learning about the issues that planning councils are addressing can help researchers and community members better understand local needs and build relationships with other researchers, planners, and community members who may be interested in pursuing equitable partnerships in research. Further, these groups can help researchers on the planning council identify subgroups locally, who may not be represented. In Washington, DC, the Commission on Health and HIV (COHAH) serves as the EMA HIV planning council. This group is composed of a diverse group of clinicians, community members, academics, and other stakeholders where at least one third of participants must be people living with HIV. In general, looking at the service organizations with whom local governmental entities work is an excellent way to identify potential partners.

CABs in general can be a valuable resource for academic investigators looking to engage with local community partners. CABs create a structure and guidance for leadership, partnership, activities and consultation related to research and typically consist of individuals who are highly invested in community well-being and have deep experience in fighting for equity and justice in research endeavors. They also provide opportunities for community members to express their opinions, discomfort and advice and to bring attention to processes that could be made more suitable, respectful and acceptable.

Another strategy for identifying potential partners is connecting with local CBOs. For example, monitoring a CBO's events and communications, including newsletters and press releases, will give researchers a sense of the CBO's interests, concerns and priorities and will allow the researcher to assess if there may be an opportunity for a collaboration that can be productive for both partners.

Community partners and academic investigators can also look to local HIV related data to better understand the HIV 'epidemiology' of their city or state and health disparities that may be associated with race and ethnicity, socio-economic status, violence, prejudice, stigma and discrimination (see Resource Appendix). Community members can help academic investigators appreciate the humanity that exists within a statistic and the human toll of forces such as stigma and discrimination. These data may also offer insights into which organizations are providing services to individuals affected by HIV.

An important step in establishing a relationship between a community partner and an academic partner is developing a shared understanding of the partnership's mission and purpose. This can be a critical moment for community members to review their goals for participation in the partnership. These can range from a clear path towards addressing pressing needs or concerns to participation in research that serves the greater good for individuals broadly affected by HIV and even beyond. Academic researchers and community members should discuss strengths, opportunities for growth and specific training needs as well as give insight into working and communication styles and optimal timelines. These conversations, which require honesty and vulnerability, can help ensure that everyone feels confident that they can contribute meaningfully and facilitates a process of identifying appropriate opportunities for learning and growth. Developing a detailed community partnership agreement can solidify this discussion addressing topics noted above and by clarifying roles, responsibilities and skills sets; decision-making processes and community dissemination strategies; ways to communicate about expectations; how to approach and resolve conflicts; and processes for giving honest, respectful, and transparent feedback (see Resource Appendix). The act of creating a community partnership agreement is an essential element for an equitable partnership and builds trust and durability.

A DC CFAR investigator member's voice

I was part of the DC CFAR Sexual and Gender Minorities Scientific Working Group, of which Dr. Ron Simmons was a member. He was at the time the Executive Director of the DC-based Us Helping Us, People into Living, Inc., an organization founded in 1985 to provide support for Black, gay men living with HIV/AIDS. In one of these meetings, we invited Dr. Simmons to discuss the type of research he considered important for Black men who have sex with men (MSM). He expressed interest in using altruistic attitudes to promote HIV testing among young African-American MSM. Together with Latino Health Research Center colleagues and Dr. Simmons, we developed an R21 grant application entitled "CBPR Development of an Intervention to Increase HIV Testing among Young Black MSM." We followed his lead throughout the study's conceptualization and write-up while contributing our grant-writing expertise. Dr. Simmons, who passed in 2020, frequently referred to this effort as an exemplar of true community/academic collaboration.

Maria Cecilia Zea, Co-Director, DC CFAR Social and Behavioral Sciences Core

3. Funding Opportunities and Grant Applications

When there is an opportunity of potential interest, partners can meet to determine if their research interests align with the funding announcement and if they have the capacity to pursue a specific opportunity. For example, for many NIH-funded requests for applications (RFAs), the timeline for developing an application can be just two or three months and the chances of being funded are quite low, potentially making it a less appealing option. In discussing potential opportunities, partners should be prepared to discuss:

- What are potential sources of tension in choosing either to pursue or not to pursue?
- Is there room to compromise? If so, what are expectations for future opportunities?
- Is it better to decide against participating in this current opportunity? If so, what are expectations for future opportunities?

If partners decide to pursue an opportunity, they can move forward with discussing details about the grant timeline, award amount and budget implications, developing research questions and the research protocol, identifying the skills needed to implement the research, and considering whether other partners might be needed. Of note, smaller grants and pilot awards can be a very good way to build trust and a strong collaborative relationship. Pilot awards typically include all of the elements of a larger award but are far less burdensome to develop and implement.

Defining research questions and specific aims within an equitable partnership takes time but yields a number of important benefits: it ensures that the proposed research is responsive to the funding announcement, increases scientific knowledge, meets the needs of the community, and incorporates the essential and diverse perspectives within the community context. Asking research questions that address community concerns in a way that resonates with the community an investigator hopes to engage ultimately saves time and resources as it lays a solid foundation for a proposal that is acceptable and feasible. Crafting strong research questions and specific aims is a skill that takes time to develop, even among those who receive formal training. Working on these together can strengthen the skills of academic researchers and build capacity among community partners. Academic researchers and their community partners can further refine and strengthen questions and their grant proposals overall by consulting other important resources like the DC CFAR's CPC and other community experts that they have access to, CFAR Core Directors and academic mentors, and the point of contact for the funding announcement.

As specific aims are being developed and finalized, partners can begin to work on developing the overall grant application. Developing a grant application is a large undertaking and it is essential that partners develop a detailed timeline and division of tasks (see Resource Appendix). Partners should refer back to their community partnership agreement to leverage individual and organizational strengths in the development of the proposal. For example, partners can discuss how to divide writing sections of the grant proposal, requesting letters of support, developing the budget, and reviewing and editing drafts. In some partnerships, it may make sense for one person to take the lead on writing, while the other reviews and offers feedback. In another scenario, partners might want to co-write the grant proposal but focus on specific sections. This underscores how each partnership is different and the importance of having discussions ahead of time as to how to approach the work, keeping equity at the core.

One critically important component of a grant application is the budget. Development of a budget should occur in concert with the crafting of the project's specific aims as the budget often informs what is possible in terms of a project's scope. Keeping in mind which expenses are allowable under the funding announcement, partners should discuss all of the costs associated with the research proposal and how to ensure equity in the distribution of funds. Partners should also refer to their

community partnership agreement to identify items that should be included in the budget, such as access to libraries and journals, transportation for community partners to and from key meetings or data collection sites, a hotspot for in the field data collection, resources for web design for recruitment, and funds to ensure that study findings can be shared across multiple platforms including open access journals and community-friendly fact sheets. As with a project's specific aims and grant application components, it is important to have the budget reviewed by institutional and community partners to ensure important items aren't being missed or overlooked.

Finally, partners should have realistic expectations regarding the success of a grant application. Unfortunately, a strong research idea and a well-written grant proposal do not guarantee success. In 2022, the overall success rate for NIH research grants was 20.7 %[37]. It may take several attempts before an application is successful and partners should discuss if they want to participate in a process of revision and resubmission or seek other funders for their project. Having clear expectations about the process can be helpful for academic researchers and community partners alike.

A DC CFAR investigator member's voice

It made my day, even really my year, and gave me hope and motivation for my interaction with the DC CFAR and researchers in general when a pilot award applicant followed up with me on a point I had made in his grant review, requesting my guidance and welcoming some references from me. He thoughtfully incorporated the feedback he had received from me in his ultimately successful pilot award application. I was also gratified that he shared the revised application with me and asked me to send any additional comments or suggestions I might have once I had reviewed the revision.
Martha Sichone-Cameron, Co-Principal Investigator, DC CFAR Academic Community Partnership Award and CPC member

4. Research Implementation

Congratulations! You've been funded. Partners should take a moment to celebrate this success and look for opportunities to publicize this important achievement. For example, the DC CFAR routinely announces new grants in its Weekly Update newsletter and on social media (contact CFARinDC@gmail.com). In addition to celebrating a milestone in your partnership, sharing news about your successful grant application can be viewed as a first step in disseminating information about your research and informing the broader community about work that may be of interest to them.

Researchers and community partners should meet to outline the next steps to initiate the research and begin to fulfill the requirements of the grant. This detailed conversation should reflect decisions made and documented in the community partnership agreement and should include:

- Review of the overall timeline and period of award and interim deadlines to ensure that roles, responsibilities and timelines are clear for all required tasks including for specific deliverables, such as progress reports, and any regulatory requirements and approval processes, such as IRB submissions.

- Consideration of whether partners have what they need to execute the research as during the time from application to funding things may have changed and awarded funding may not match the original budget.
- Discussion of preferred methods of communication, plans for emergency communication and schedules for standing and regular meetings so that timing and setting (e.g., virtual or in person) are convenient and accessible for all essential team members.
- Documenting and sharing of decisions made and schedules created so that these can form the foundation of an ongoing agenda and checklist for team meetings.

This is also an important moment to think through how to ensure equitable participation in the development of papers, presentations and other dissemination materials. Academic and community partners should assess each member's interest in and experience with writing and submitting research for publication, making presentations, developing fact sheets, preparing copy for community-based newsletters, etc. This creates an opportunity to reflect on each team member's priorities and to identify any skills, training or resources that might be needed to achieve those priorities. If partners agree to co-author a publication, they should proceed with the understanding that the preparation of manuscripts is an arduous process that may require significant and/or multiple rounds of revision before acceptance for publication. How to engage in the process, the division of labor, what merits inclusion as an author and authorship order, should all be discussed (see Resource Appendix).

A DC CFAR investigator member's voice

Khadijah and I are actually having a weekly 30-minute PI meeting, just for the two of us. Just to touch base because we were starting to have a lot of different emails going back and forth. And so this allows us to have 30 minutes just to have that time to touch base outside of the larger team and to make bigger decisions.

Tamara Taggart, Co-Principal Investigator, DC CFAR Academic Community Partnership Award

5. Research Updates and Dissemination

As noted earlier, academic and community partners should plan to present updates on their study progress. This can take various forms, such as social media, webinars, community meetings or presentations to scientific interest groups. For example, the DC CFAR regularly holds Research in Progress sessions and invites academic investigators and members of the community to attend. The DC CFAR also supports an annual Community Update following the Conference on Retroviruses and Opportunistic Infections (CROI), and updates have been provided on the International AIDS Society and other national and international meetings as well. These presentations provide an opportunity to learn about research that is underway, ask questions, and provide feedback. Community members can also present or participate as responders or discussants. Exchanges like this can help build capacity and trust and create the opportunity to share information and make adjustments as needed. As noted, there are multiple benefits to keeping the community and other interested parties informed about the progression of the study. It helps keep academic-community partners accountable to their

constituents while also providing opportunities and spaces for the research to have practical implications throughout the study. Sharing lessons learned, successes and challenges while the work is underway can spark innovation and new strategies even before the final results are disseminated.

Once research is completed, disseminating research findings facilitates the translation of research into practice and demonstrates to study participants and the broader community that their research participation contributed to outcomes and had meaning. Research dissemination is also an area where there may be a difference in academic expectations and community priorities. For example, publication of research is essential to an investigator's prospects for promotion and tenure and an accepted way to share innovative science or important findings with the field. Co-authorship on a publication can also have important implications for both community members and academic researchers as an established track record of published research and evidence of a successful collaboration is typically highly valued by funders. Co-presenting research findings at conferences and community symposia is another effective way to disseminate findings and demonstrate the value of equitable research partnerships, including to funders. This strategy has been used by the DC CFAR for its Annual Research Day and in the organization of the National Ending the HIV Epidemic Meeting.

Unfortunately, academic journals and conference attendance are not readily accessible to the general public, including individuals from historically marginalized groups who experience health disparities including higher rates of HIV and have the most urgent need for the latest research findings. Equitable academic-community partnerships should be sure to explore other and innovative ways to disseminate information.[24] For example, partners can plan interactive community events or produce other print or online materials including infographics, social media posts, blogs, videos, fact sheets, Op-Eds and pieces in lay, community-oriented publications[38, 39, 40] such as The Body, POZ Magazine. Partners should be sure to share research findings on the CFAR's website and with CPC membership and should consider sharing with:

- CFAR partner organizations
- The National CFAR CAB Coalition (N3C)
- relevant DC based CABs and CBOs
- NIH funded programs such as the ACTG, the HIV Prevention Trials Network (HPTN) and the Women's Interagency HIV Study (WIHS)
- local and national governmental institutions including COHAH, HIV.gov, and The President's Advisory Council on HIV/AIDS (PACHA)
- NIH affiliated offices and programs including the NIH Office of AIDS Research and the NIH HIV/AIDS Network Coordination (HANC)

- advocacy and policy groups such as Positive Women's Network (PWN), Treatment Action Group (TAG), National AIDS Treatment Advocacy Project (NATAP), The Well Project, People living with HIV Caucus, AIDS United, and the Kaiser Family Foundation

Where appropriate, dissemination opportunities might also be sought in testimonials at government hearings, and policy-briefings. Highlighting academic-community partnerships at policy-focused gatherings, for example, can increase the audience for the research and also underscore the importance of academic-community partnerships. Whatever the plan, community partners play a critical role in ensuring that the academic community research team as a whole fulfills their responsibility to share findings with communities engaged in and impacted by the research project through means that are timely, accessible, comprehensive and respectful.

Ultimately, researchers and their community partners should have honest and transparent conversations about their priorities for sharing project updates and disseminating results and how they can help each other achieve their goals. Both should acknowledge and accept that there may be times when their priorities will not be aligned. Creating a dissemination plan and budget early in the research process guarantees that findings are shared in timely and appropriate ways with essential audiences and builds equity.

A DC CFAR investigator member's voice

We are very focused on who can benefit from the findings… I care less about getting the publication and more about making sure that the findings are useful for the people that can do something with them. We tend to share findings right away with the people that need to know to move to action. And then I work on the paper or the scientific presentation… (in academia) we unfortunately, most of the time, reward the people who publish more, independent of if the information got to the people who need to make the decisions…. I do research not for my success in academia but for the communities that I work with….That facilitates also for us as a scientific group being able to use the feedback from the community and the stakeholders as we write papers. So then, we have not only the findings but the feedback from the community to integrate in the paper so that makes a better contribution to science from my perspective.
Carlos Rodríguez-Díaz, Co-Lead, DC CFAR Latina/o/x Scientific Interest Group and DC CFAR pilot award recipient

6. Post-Research Project Sustainability

At the completion of a project, academic and community partners can look at what can be learned from the project's findings and work together to determine what additional research is needed or to gain a greater understanding of how research priorities may need to evolve. Partners should evaluate and measure the success of their partnership by referring back to the original partnership agreement as well as the project's budget and dissemination plan and other planning documents. This information can provide the current research partners and future potential partnerships with insights into effective and promising strategies, as well as those that were less effective.

Ideally, successful and equitable academic-community partnerships will lead to additional research opportunities and funding. At the same time, academic researchers and community partners should be honest about what support may or may not exist after the research project is completed. They can discuss ways that their research findings can support advocacy efforts, policy development, fundraising campaigns and explore possible future collaborations that expand upon their current partnership including program grants. Partners can also work together to identify funders who have an interest in the kind of work conducted within the project.

Community partners should also be leaving the project with increased research skills and capacity. While they can remain connected to their academic partners including through CFAR events such as CFAR scientific working group and other topic specific meetings, they will also be well positioned to find other research partners and projects, engage with policy makers on research matters and to integrate research into their own work and their institution's practice.[21]

A DC CFAR investigator member's voice

My community partner and I set a long-range goal...and then we set out to get the pilot award through the CFAR as a sort of first step in that process. And we got the pilot award and then about three years later we got the larger award. But in that time in between, it wasn't radio silence, like I call and check in, see how she's doing, we've had lunch. I think a critical part of this, of how did we cultivate our relationship, is that it wasn't just about the work, like sometimes we go to lunch because we need to catch up and just see how each other is doing and this is professionally I don't mean like as friends, we are now friends because it's has been four years, but I think part of building relationship is not always having a problem you are trying to solve but rather having opportunities to come together and think together and talk together and so we did a lot of creating those opportunities. ....I've worked with her on things that she is interested in, not just on things I'm interested in applying for so sometimes I'm the lead, sometimes she's the lead....We actively manage our relationship in between.
Shawnika Hull, DC CFAR pilot award recipient

Essential Principles
Capacity Building

Capacity building, which describes the ways in which people or organizations spend time developing the resources or expertise of others to complete a desired goal, is key to pursuing equity.[41] All partners and organizations will approach new research opportunities with a range of knowledge, skills, and experiences. For partnerships to be successful, academic researchers and community partners should make an honest appraisal of the skills they possess and what is needed to complete the research. They should consider how additional training might prepare individuals and organizations for current and future opportunities. These conversations will naturally follow and draw upon a community partnership agreement and the defined roles and responsibilities. Academic-community partnerships can include in their community partnership agreement a checklist of necessary skills to determine areas of strengths and identify areas where they might benefit from

additional training, such as [The Collaborative Institutional Training Initiative](#) (CITI Program) or data collection and management techniques (see Resource Appendix).

The goal of capacity building with community partners and organizations is to prepare them for success in the research project and beyond, ensuring that they have the tools, skills, opportunities, and resources they need to improve the health and well-being of their communities. For example, research and data literacy are critical skills that can support current research opportunities and build organizational capacity and infrastructure for future opportunities[24,42] (see Resource Appendix). Further, it can provide a better understanding of research and data that can help communities improve practices, understand the root causes of issues in their communities, and apply for grant funding. Academic investigators can be instrumental and creative in linking their community partners to relevant resources for the acquisition of skills. For example, academic investigators can register community partners as university affiliates so that they can get access to university resources including on-line libraries and ask that they be included in CFAR trainings such as the DC CFAR's specific aims and grant writing sessions. They can also share in the development of conference abstracts and in preparing and making presentations.

For academic investigators, capacity building is also an ongoing exercise which includes practicing reflexivity including understanding their own layers of privilege, intentional listening, gaining cultural competence, and connecting with peers engaged in academic community partnerships to identify resources and practices that will further strengthen their partnerships. They can also benefit from the expertise of community partners who have organizational management skill sets that can be less familiar in academia including hiring a large project implementation team, and expertise engaging in advocacy and sharing data in meaningful and accessible formats.

As more academic-community partnerships develop, academic researchers and community partners may seek to work with individuals and organizations that have a track record of successful equitable partnerships. However, the challenge will be to expand the number and types of partnerships rather than rely upon the same, established partners. To accomplish this, researchers and community members with this experience can be viewed as leaders who can facilitate broader engagement and capacity building. This means that in the life cycle of building equitable community partnerships, partners find and consider other ways to build the capacity within and across communities.

Finally, as we build more equitable academic-community partnerships, we should create space for and anticipate more community-initiated HIV research.[43] Community partners and organizations should feel empowered and capable of reaching out to researchers with potential research questions and interests, building partnerships with communities leading first. Indeed, citizen or community

science, especially co-created citizen science, where individuals coming from communities experiencing health inequities collaborate with professional scientists to document and combat health inequities, is increasingly being employed across public health domains.[44]

Resources

Resources, such as funding and access to materials or technology, are needed to create and support equitable community-engaged partnerships. Time should also be considered as an important resource for both academic and community partners, because as noted, this work requires a significant investment of time to build relationships, assess community needs, plan and implement research, and ultimately evaluate and disseminate findings. Historically, contributions of time and expertise made by community members have been ignored or overlooked.[24] These contributions must be recognized and compensated.[1, 26,29] Ensuring adequate resources for academic-community partnerships is also an important way to demonstrate the value of community-engaged research and to support and sustain effective and equitable academic-community partnerships.

Budgets provide a concrete template for ensuring the equitable distribution of project resources. As noted above, development of a project budget should occur in concert with discussions around research questions and project aims. Each partner should list very specifically the resources required to fulfill their commitments to the project aims. These can include compensation for time; materials such as laptops or tablets; technology such as access to libraries, necessary software or access to platforms such as dropbox; trainings for team members; and dissemination of findings across multiple platforms and that includes both academic investigator and community partners. Budgets also offer opportunities for capacity building and partner growth. For example, academic partners should consider hiring community partners or their organizations for project research roles[18] and setting aside funds for sensitivity and cultural competence training (see Resource Appendix).

In the same way that documents such as the community partnership agreement and a publication

development template will help to ensure that roles and responsibilities are respected and maintained so too does the project's budget. Once a project has launched, budgets should be reviewed regularly by team leadership and if and when adjustments need to be made, there should be open, honest and transparent conversations about a redistribution of resources.

Communication

To ensure an equitable academic and community research partnership, communication among partners must be founded in honesty, transparency, and humility.[21,29] It must also acknowledge issues around access and ease with different technologies. In recent years, for example, many of us have become more reliant on technology to facilitate communication. Using technology has its benefits as it creates ways to engage community members who may not have been able to participate as readily in the past. At the same time, a reliance on technology uncovers disparities in access to internet-enabled devices with a reliable connection and a webcam.

While communication between partners is essential, communication to the broader community is also important. As noted earlier, this is where planning for the dissemination study results is an important step in the research process. Community members will be aware of research that is underway and they will want to know how that research impacts them and their broader community. Community engagement, when done successfully, can facilitate greater accountability for dissemination of findings and translation of research into practice. This is especially critical, as one study noted it can take up to 17 years for a small percentage, 14 percent, of original research to be implemented in policy or practice.[45] It can also help to connect HIV-focused research to larger policy issues. For example, when academic-community partners present on their HIV research addressing structural racism or unequal access to care in HIV, that research can be connected to larger policy-focused issues on housing, discrimination, immigration status, intimate partner violence, sex trafficking, Medicaid expansion, etc.

A central tenet of communication both among team members as well as when contemplating the sharing of project updates and the dissemination of results is attention to the use of destigmatizing and accessible language.[24] Because scientific and clinical research has often been conducted without the equitable partnership of community members, the language used may be triggering, stigmatizing

or patronizing to the communities affected by HIV it is meant to help. For example, transgender individuals and their providers and advocates are noting concerns about the ways in which research practices may serve to "alienate, objectify, exploit or even re-traumatize".[29]

Academic researchers and community partners should attend to the ways in which communities discuss and refer to the HIV related health issue that the partnership is researching. When presenting results, team members should be mindful that their audience may be triggered or impacted by the HIV related health issue being discussed. Working with community partners is helpful because it reminds researchers that their work is not just numbers and cases, but real people with real lives, who deserve dignity and respect. This needs to remain at the forefront in discussions about issues that can be very sensitive and personal.

In addition to using language that is respectful and demonstrates understanding of the community context, it is important for equitable academic-community partnerships to ensure that language is accessible and that the information presented gives the full picture and context. For example, when presenting findings that may be perceived as negative, are there other findings that highlight strengths within the community? Academic researchers and community members should work together to ensure that research findings are shared in a way that is dignifying to those it is meant to help. Fortunately, people first language and lists have been developed by HIV advocates and helps all in using and updating language that might be stigmatizing or disrespectful to different communities.[46] Equity and accessibility must also be considered in which languages are used to frame research questions, develop research methods and disseminate findings. Academic-community partnerships must practice language justice by ensuring that partners and community members are able to communicate about and advocate at every step of the research process in their preferred language.

A DC CFAR community member's voice

Good communication is communication that is transparent, and candid but respectful... it irritates me when folks beat around the bush...mincing words as a means to an end without appropriate attention to process. Sometimes you have to stop the process and revisit the communication to make sure that there's a baseline level of respect courtesy, collegiality and telling it like it is. I elevate the relationship, that is the first outcome. All other outcomes and deliverables and processes are contingent upon that relationship, the integrity of that relationship. Good communication is a big part of that.
Riko Boone, HIV Project Director, Treatment Action Group

Conclusion

As we contemplate how to conduct HIV research that truly hears all voices engaged in the fight to improve equity in health outcomes and justice against the drivers that stand in the way of health equity, it is important to acknowledge other essential voices in this work. Local and federal partners are critically important to helping us to adopt the central value, essential principles and approach to the research process discussed here. We applaud federal requests for funding such as those tied to the Ending the HIV Epidemic that mandate "collaboration with one or more local implementing partners" including "community- and faith-based organizations"[47] and the NIH funded Community Partnerships to Advance Science for Society (ComPASS) which aims to develop "community-led health equity structural interventions" and "a new health equity research model for community-led, multisectoral structural intervention research".[48] These significant investments in collaborative and community led research as well as our own CFAR's commitment to academic-community pilot awards are paving the way for the kinds of collaborations we hope to foster and support through dissemination of this guide. We cannot hope to achieve meaningful progress against the HIV epidemic and the marginalization and inequities that continue to drive it, without the full and equal participation of those with the knowledge, insight, expertise and capacity to innovate that is founded in first-hand experience.[49]

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