

**Building an Equitable
and Sustainable
Academic-Community
Research Partnership:
The DC Center for AIDS
Research (DC CFAR)
Example**

**By Marcia V. Ellis and George
Kerr III on behalf of the DC CFAR
Community Partnership Council**

DC CFAR Website, April 2023



From the earliest days of the HIV/AIDS epidemic, activists and advocates living with AIDS demanded a place at the research tables. The demand was part of the rights of people with AIDS, in a manifesto known as the Denver Principles of 1983. It changed healthcare forever. (Mark King, POZ Magazine, June 7, 2013) (<https://www.hivcaucus.org/resource-links/the-denver-principles-1983>)

Background

The Center for AIDS Research (CFAR) network (www.niaid.nih.gov/research/centers-aids-research) has been supported by the NIH since the late 1980's with the goals of supporting HIV research and developing the next generation of HIV investigators at approximately 20 academic sites across the U.S. Despite having some of the highest rates of HIV in the US, Washington, DC had never had a CFAR. To address this inequity, in 2009 the DC HIV/AIDS Institute, an academic consortium of HIV investigators in Washington, DC, submitted an application to the National Institutes of Health (NIH) to form a Developmental CFAR in DC. It was envisioned from the inception of the DC CFAR that community would be an integral partner along with academia and government. The DC CFAR Community Advisory Board (CAB) was formed and leaders of most of the major community groups serving the HIV affected community as well as individual advocates with broad reach and relationships throughout the community were invited to participate.

In 2010, the NIH awarded funding to establish the DC Developmental CFAR (DC D-CFAR). In 2015, the DC D-CFAR successfully competed for funding to establish a full DC CFAR and was renewed for an additional five-year period in 2020. The DC CFAR mission is to intensify its multi-institutional effort to promote and support research that contributes to ending the HIV epidemic in Washington, DC and beyond in partnership with government and community. As of this writing in 2023, the DC CFAR includes nine collaborating DC CFAR institutions: four academic institutions (George Washington, Howard, Georgetown and American Universities), two medical centers (Children's National Hospital and the Veterans Affairs Medical Center), two community-based organizations (Whitman Walker Health and Us Helping Us), and the DC Department of Health.

The Community Advisory Board

The CAB has been from its inception central to the mission of the DC CFAR and was 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 institutions, and community clinics providing HIV services. While a CAB is not a required element of a CFAR, community engagement is required and should ideally extend beyond the formation of a CAB. The CAB also included individual advocates with broad reach and relationships throughout the community, networks that serve the CFAR well. Communities represented include Persons Living with HIV (PLWH), LGBTQ, women, long-term survivors, the Latinx, African American, transgender, and faith communities. Membership is monitored to ensure that new, younger and fresh voices are brought in intentionally, while making sure that the research needs and perspectives of those who are long-term members and survivors and those living and aging with HIV are recognized and addressed.

The initial CAB members were identified and invited by CFAR Executive Committee members who drew upon their own networks, relationships, and knowledge of HIV leaders of organizations in the community who were known by them. It was a representative group from diverse communities in the DC area. The CAB then established its Bylaws which included a provision for inviting other community members onto the Board. The process involved nominating prospective new members who would be presented to the CAB for consideration. Also, in strategic planning sessions of the CAB, members considered what voices or communities are not represented. When there were members who were inactive or wished to be removed from the Board, CAB leadership could make adjustments to their membership.

Additionally, the DC CFAR Administrative Core included in its staffing a Community Research Coordinator who served as a liaison between the DC CFAR CAB and the Administrative Core and who provided guidance to the CAB. Initially, the person was an academic researcher who also acted as the CAB leader until a governance structure was put in place and a community member was selected as the CAB Chair. The CAB Chair and Members worked closely with the Community Research Coordinator on the many activities of the CAB and put in place a structure for the Community Coordinator role that followed.

The CAB Bylaws were developed and are overseen by the CAB itself, are regularly approved and adapted by the CAB membership, and lay out the governance structure and processes for the CAB.

The vision to hold Quarterly meetings primarily in community-based locations, often hosted by members at their organization's offices was a shared one between the CFAR Administrative Core, where the CAB fell organizationally, and the CAB membership. This allowed the participation of members that the organization serves and provides an opportunity for researchers to better acquaint themselves with the communities that might benefit from the research. Since the COVID-19 pandemic, however, meetings have taken place virtually by videoconference. It was important in planning community-based meetings and events to make sure to work in close coordination with the proposed meeting site to ensure that there is an understanding of what was available in terms of logistics and equipment and agree on what the CFAR would provide for the meetings. There are times when meetings were held at the CFAR offices at GW to provide the CAB members with exposure and access to CFAR offices, staff, and programs.

The CAB provides guidance to DC CFAR leadership, participates in reviewing and scoring pilot award applications, and provides community perspectives on the development and implementation of DC CFAR initiatives and activities. Below a list of CAB members' roles and responsibilities.

- 1.** Regular participation in the Pilot Award process, providing input on consultation calls with applicants; reviewing and scoring applications; serving as a resource for researchers; ensuring that community engagement tools and resources are available to applicants; participating in their research updates and presentations;
- 2.** Serving as community Co-Leads on all DC CFAR Scientific Working Groups (SWGs) and Scientific Interest Groups (SIGs), alongside the scientific investigator Co-leads;
- 3.** Reviewing and commenting on research ideas and applications;
- 4.** Participating in Executive Committee strategy and planning sessions;
- 5.** Representing the CFAR and offering a community perspective in community events and meetings, with NIH and other funders and research networks, and with other highly valued community partners;
- 6.** Serving as panelists in DC CFAR city-wide events, in community town halls, and other local and national meetings and seminars, in person or virtually;
- 7.** Being a part of writing teams for professional journals and other less academic and community accessible outlets; and
- 8.** Serving as a crucial bridge between DC CFAR investigators and communities highly impacted by HIV.

From Community Advisory Board to Community Partnership Council

As the DC CFAR matured and community engagement deepened, community members began to function more as true partners in the research process rather than only as advisors. The DC CFAR valued and relied upon the specific perspectives, insights, and professional experiences that community members brought to research. Initially, CAB members had generously contributed their time and expertise to the DC CFAR with minimal monetary support. As the responsibilities of CAB members increased, it became evident that they should be compensated for their specific tasks and contributions.

Once it was clear that the role of community had expanded, requiring more time and attention, in 2020 DC CFAR leadership and the CAB Chair/Community Coordinator developed a Compensation Plan and strategy for review by the Executive Committee. Guidance from the NIH was sought on pertinent policies and the DC CFAR implemented practices based on these policies. Although compensation for CAB members has historically been advised against due to potential bias, the NIH Grants Policy does allow for “costs of professional and consultant services rendered by persons who are members of a particular profession or possess a special skill, and who are not officers or employees of the non-Federal entity.”

https://grants.nih.gov/grants/policy/nihgps/HTML5/section_7/7.9_allowability_of_costs_activities.htm#Professional_Services_Costs) Given the large number of roles in which community members were serving, the CAB was transformed into the Community Partnership Council (CPC). Compensation was consistent with respected wages and budgeted for and provided to CPC members who elect to receive it based on their fulfillment of a detailed Scope of Work that includes the responsibilities listed above. This plan was presented to the CAB membership who were generally supportive, discussed it candidly and transparently, expressed some concerns, and asked for some revisions regarding compensation hours and rates in order to get closer to a plan that recognized the time and effort put into some of the duties.

Compensation is also provided for those who assume leadership roles such as serving as CPC Chair and Co-Leads of SWGs and SIGs. In addition, the DC CFAR allocated funds to support community-directed programming and initiatives determined by the CPC through its annual strategic planning process. The CPC Chair, in consultation with the Community Coordinator and the Administrative Director, identifies initiatives (such as developing a community guide to HIV research) which require time and effort above and beyond usual CPC participation. Scopes of work with specific start

and end dates and specific deliverables are developed and compensation is determined by the scope of work and deliverables. DC CFAR Cores and individual researchers who wish to compensate community members for their contributions to specific research projects may develop a line-item in their study budgets in accordance with their own institutional policies and NIH guidelines.

The DC CFAR provides support for and facilitates remote participation for CPC meetings and DC CFAR-wide events. The DC CFAR also encourages investigators to consider the following as they work in partnership with members of the DC CFAR CPC: 1. Provide ample orientation and lead time to community members to ensure the most meaningful input; 2. Provide acknowledgement of community contributors in papers and on posters and slide presentations; and 3. Offer opportunities to community members to co-present with lead researchers and teams.

Community Representation, Integration, and Leadership

As demonstrated above, the CPC and other community partners are integral to numerous aspects of the CFAR. Community is a voice represented in CFAR sponsored and affiliated events and integrated throughout the structure of the CFAR. Community leadership is evident throughout the CFAR and is encouraged, supported, and ongoing.

Community-Researcher relationships in the CFAR are evolving, growing in number, and improving in their effectiveness. More experienced and early researchers are intentionally seeking out and meaningfully involving community experts in conceptualizing and being involved in numerous aspects of their research. There are examples of strong relationships between researchers and the Transgender community, with women, with the drug user health community, with the DOH, and with the Latinx community. Much is being learned in those relationships about how to most effectively address the research needs and priorities in those communities. And the requirements, the challenges, and the other lessons from those relationships are being documented, shared and addressed.

CPC and other community experts have been invited to participate in the development and submission of articles for academic journals and other publications. Some community experts are writing and sharing their own perspectives and experiences through a variety of outlets. In addition, CPC members have participated in the writing and review of research funding applications. The process of writing opens another avenue for community voices who had historically been left out of

that way of sharing their expertise and experiences.

The SWGs and SIGs convene academic researchers and their community partners in ongoing dialogue about various research themes of mutual interest. In some cases, community members have initiated and advocated for SIGs and SWGs that focus on research priorities identified by those members. This is another platform for mutual sharing and learning about research needs and opportunities. Researchers are able to hear and learn from a wealth of community partners and those partners benefit from a better knowledge of the development of research questions, research aims, and pursuing funding opportunities.

Similar academic and community relationships take place on the regional and national levels through community leadership and participation in Inter CFAR working groups. These include the Social and Behavioral Sciences Research Network (SBSRN), regional hubs and networks, and through the National CFAR CAB Coalition (N3C) that the DC CFAR has supported since its beginning and provides sponsorship for selected CPC members to attend the annual N3C meetings. Large, national meetings convened by NIH and hosted or planned by the DC CFAR have included critical and substantive roles for community members in both the planning and execution of those meetings.

Community Member Joins Staff of the CFAR Administrative Core

In 2017, an important milestone occurred within the CFAR that further demonstrated the value and importance of community in the CFAR. A part time and compensated Community Coordinator position was created in the Administrative Core with GWU HR approval and support. The position added an opportunity for community members and the CFAR that was new, exciting, and responsive to community advocacy over the years.

The Community Coordinator promotes community engagement in the DC CFAR, acts as a Liaison between the CPC and the Admin Core, serves as a community resource for the Executive Committee, promotes community participation in Core, SWG, and SIG activities, and facilitates community input on investigator research, including pilot awards, grant submissions, and publications. Additionally, the Community Coordinator engages with the DC HIV community, including other CABs and partners, for input on community activities and needs, ensures the dissemination of information to and from the CPC and broader community, and promotes participation of CPC members in local and national HIV meetings, the National CFAR CAB

Coalition (N3C), and scientific conferences, webinars and seminars.

Including a community member as part of the CFAR staff provides an opportunity for more frequent and rich exchanges with CFAR staff and partners, researchers, faculty and students and allows for a better understanding of the academic environment and purpose. And those same academic partners are able to gain a deeper understanding of community needs, priorities, and assets thereby building their own competence and understanding of the importance and necessity of community in their work for greater impact and effectiveness.

The Academic-Community Partnership (ACP) Awards Program

In 2021, the CFAR launched the Academic-Community Partnership (ACP) Awards program, an activity under the Developmental Core of the CFAR. This was another bold step towards participatory and, sometimes, a community-initiated research project. And it was partially a result of a longtime community request for such opportunities, reflections around racial justice issues brewing and coming to a head in the country and what we can do about it, and the creative use of an existing mechanism and example, which in this case was the pilot award process under the Developmental Core. Again, bringing this idea to fruition required a process of discussions and input from the Developmental Core leaders, the EC, NIH, and CFAR fiscal staff.

The ACP Awards aim to provide pilot research funds to Co-Principal Investigator teams consisting of one early stage or new HIV/AIDS academic investigator and one community investigator to collect preliminary data that will lead to NIH funding in HIV/AIDS. Academic and community investigators function as Co-Principal Investigators, sharing the responsibility for conducting the research and meeting regulatory and reporting requirements. The Awards are up to \$50,000 and the funds are shared equally. The Scope of the Awards includes basic, clinical, epidemiologic, social behavioral and prevention HIV/AIDS science in the NIH high priority HIV research areas. Research topics can be developed by community members with an organizational affiliation who partner with an early-stage investigator. Applicants receive the support available through the traditional pilot award program, including an orientation, application consultations, and other developmental services.

The program has now completed its second cycle and has funded two awards, one in each cycle. The application and partnering experience will be monitored and assessed and follows the process of the Pilot Award Program of the CFAR. Following the first round, an assessment of the ACP

program took place. Ways to further support and encourage unsuccessful applicants is also a part of the pilot award process. Lessons and recommendations from that assessment were shared and addressed as part of that review process.

Academic-Community Partnering in Research Dissemination

Research dissemination is a priority for the CPC membership and the DC HIV community at large. Academic researchers also see the value and importance of disseminating their research progress and findings. Ongoing dissemination throughout the research process, not only of research findings but information about research in progress prior to the findings is an important part of engaging community. Historically, communities do not receive information on research being done that affects the lives of people in it. In the DC CFAR, the CPC and community partners, and academic researchers have tried to change that though much more needs to be done. Research dissemination is intentional and is planned with CFAR and community resources to support it. Dissemination activities include the following:

Each year following the Conference on Retroviruses and Opportunistic Infections (CROI), the CPC, the Veterans Affairs Medical Center, and other community partners organize a Community Update. The purpose is to disseminate research that is presented at CROI. The post-CROI community update has been held annually for the past 10 years. A diverse panel is formed with researchers who presented at CROI, those who can summarize major findings of interest to the community, and with community members who attended or participated in pre-CROI meetings. A person from the community is invited to present a response to the research presentations or present themselves if they attended CROI or pre-CROI meetings. These community updates are well attended and held at community locations or by videoconference. Presenters are asked to use lay or accessible language to ensure full participation. Dissemination meetings have also taken place post International AIDS Society (IAS) meetings and after other national and international conferences.

The CPC participates in CFAR organized meetings such as Citywide Seminars where they serve as panelists providing a community lens on the research theme presented. The CFAR holds twice yearly Research in Progress presentations by Pilot Awardees and in which CPC and other community partners participate. As participants in the SWGs and SIGs, community members co-present and react to research of interest to SWG/SIG members. SIG community leads have planned large events in the community that bring together HIV researchers and policy makers to engage with community. The CFAR has made provision in the CPC budgets to support dissemination

initiatives led by a CPC member. The CPC worked with the Developmental Core to ensure that dissemination is a criterion for inclusion in Pilot Award applications. Social media platforms have begun to be used to share research related information to the general public through, for example, conversations and dialog between an academic researcher and community members. Lastly, a research update is a regular part of the Agenda for the Quarterly CPC meetings providing another platform for researcher-community exchanges.

Recognition of Community Contributions

Community partners have been vital in the history of HIV. When the importance and contributions of community in research are made visible to the public on a regular basis, buy-in to the research grows. People should be recognized and their efforts should be respected and appreciated. It is the right thing to do. Community members involved in research should be highlighted and visible so that others can see who they are and what they do. In the DC CFAR, the centrality and importance of community is demonstrated first by its designation as an equal leg of the 3-legged stool along with academic and government that is fundamental in the DC CFAR mission. The DC CFAR is continuing to create an awareness of the need to respect and appreciate the necessary contributions of communities in the DC CFAR and in the DC area. It is this respect that led to the development of a compensation plan and the deliberate engagement and inclusion of community experts in virtually everything that the DC CFAR does. Researchers are reminded, where necessary, to include, incorporate, and cite community members in their research and in their publications. The DC CFAR understands the need to put resources behind efforts that include community members, and to hear and incorporate important community perspectives. Community members have a space in the DC CFAR e-newsletter, the Weekly Update, and on the DC CFAR website. In 2022, the DC CFAR held a virtual community recognition event that honored trailblazers and leaders in the community who were and are CPC members. During this event, a video that captures their stories of sacrifice, service, and compassionate care for those affected by HIV since the beginning of the epidemic was premiered and is now available on the DC CFAR website for broad public use. Certificates and plaques were presented and personal vignettes of their stories were captured and given to them. Recognition of and respect for community is a Best Practice that permeates the DC CFAR.

The Impact of COVID-19 and Mpox

When COVID-19 entered everyone's lives in a major way in 2020, its impact was immediately felt everywhere. It framed all lives and activities. People already deeply affected by poverty, health

disparities and challenges, and racism were forced to navigate another huge reality. Like everywhere else, in person work, events, and health appointments were held remotely. For people living with HIV, at risk for HIV and affected by HIV, life became more difficult. Isolation, mental health, substance use, caregiving, and intimate partner violence, became more pronounced. Those agency leaders providing services were forced to create ways to continue supporting their communities in ways that were effective and safe. The DC CFAR and CPC partnership pivoted to ensuring that the community needs were elicited, heard, and addressed. This meant making space to do community wellness checks in meetings and facilitating the continuing involvement of those who expressed their need to gather with others to help stave off feelings of isolation. Platforms were provided to discuss COVID-19, research underway and research needed on vaccines and treatment. Researchers were able to leverage some of the relationships and trust built with community to respond to community questions, suspicions and concerns. Research updates began to include both COVID-19 and HIV. At the same time, community voiced their concern for any resource shifts away from HIV and what it meant for their care. Some important research had to be paused. When Mpox hit, it triggered for many the worst times of HIV and associated stigma and caused more fear and anguish. Discussions about community needs and questions again received priority attention. Strong community advocacy drawing upon the experiences and strategies from the early days of HIV took place.

Incorporation of Community HIV Service Organizations as DC CFAR Institutional Research Partners

To further engage the community in the CFAR, the DC CFAR has included two prominent HIV service organizations in DC to become full institutional partners. These are Whitman-Walker, a leading provider of HIV prevention and care services to the LGBTQ community in DC, and Us Helping Us, People Into Living Inc., a leading provider of HIV prevention (and more recently care) services to the Black SMM community in DC. These organizations have successfully competed for NIH HIV research grants and were welcomed into the DC CFAR. They are now represented on the DC CFAR Executive Committee, investigators from these organizations can now access the full range of DC CFAR services, and early-stage investigators from these organizations are eligible to apply for DC CFAR pilot awards. In this manner, community-based HIV scientists now have equal standing with academic HIV researchers in the DC CFAR.

Conclusion

The DC CFAR example demonstrates the importance of a strong and shared vision for creating an effective researcher-community partnership with foundational principles of respect for the roles that members of the partnership play, recognition of the centrality of community needs and priorities, and shared leadership. It shows that building a partnership is dynamic and possible but requires attention, dedicated resources, and flexibility. Without the intentional and ongoing relationship building between community and academic researchers, inclusion and structural and process integration of partnership plans and strategies, and requisite resources and support for building the academic researcher and community partnership infrastructure, the role of research in ending the HIV epidemic and other public health concerns would be less effective, and equity, change, and sustainability more elusive.

Acknowledgments

The authors would like to acknowledge the NIH, the DC CFAR Executive Committee, and the DC CFAR Administrative staff members who have worked closely over the past 13 years to promote and support community engagement and participation in the DC CFAR.