

PRACTICAL TOOLS

Community Partnership Guide for Engaging with Academic Researchers

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ABSTRACT

Community engagement increases the relevance of research to underserved populations and can encourage diverse populations to participate in research. The Institute of Translational Health Sciences partnered with the Health Equity Research Community Advisory Council (an advisory group for a Clinical and Translational Science Award) to develop a community-facing Community Partnership Guide for Engaging with Academic Researchers. The Guide includes a 7-item screener to assist community organizations with deciding which requests from researchers to pursue more fully, step-by-step guidance on how to engage with academic investigators on core project elements (e.g., design, budget), and a template for Memorandum of Understanding.

KEYWORDS: Process issues, Community health partnerships, community-academic partnerships, Integrating Special Populations, Clinical and translational science award programs

ABBREVIATIONS:

ISP: Integrating Special Populations

ITHS: Institute of Translational Health Sciences

CDHE: Seattle Children's Center for Diversity and Health Equity

CAC: Community Advisory Council

Despite efforts to prioritize the inclusion of individuals from racial/ethnic minority groups in all NIH-funded research as mandated by the National Institutes of Health Revitalization Act of 1993,¹ research shows that people of color are still significantly under-represented in human subjects research in the United States, particularly in clinical trials.² Research participation in clinical trials in the United States does not reflect our growing racial and ethnic diversity.

According to 2018 census population estimates, racial/ethnic minority groups comprise 40% of the U.S. population; Black and Latinx individuals comprise 30% of the U.S. population but only account for 6% of all research participants in clinical trials.³⁻⁵

Mistrust of health and biomedical research, and the healthcare system more generally, is a key barrier to research participation. This mistrust among Black, Indigenous, and other people of color, is rooted in historical, systematic medical and research abuses toward these communities, including but not limited to the Tuskegee Study of Untreated Syphilis in African American males⁶ and the forced sterilization of Indigenous people in the United States and Canada.⁷ These racial injustices in the name of biomedical research and healthcare, were created, implemented, and supported by our own medical institutions and federal government, and are widely known among Black, Indigenous, and other people of color. These historical abuses coupled with current systemic, racist practices evident in the differential treatments of people by racial and ethnic categories in the healthcare system, as well as research studies that continue to place race as a biological factor, continue to exacerbate distrust of medical and research institutions.⁸⁻¹⁰

Community engagement in research studies is one way to increase the relevance of research to underserved populations and increase participation of more racially/ethnically diverse populations in research. Individuals from communities of color and community-based

organizations serving diverse communities can partner with academic research teams to ensure that studies are culturally responsive, and utilize a community-based research staff to recruit, enroll, and retain diverse research participants.¹¹ Community-engaged research lives on a broad spectrum, from fully community-partnered research such as community-based participatory research (CBPR), in which the community is an equal partner throughout the research process, to less community-engaged research that utilizes community input for discrete study needs (such as participant recruitment). However, at times, the goals and expectations of academic researchers do not match the needs and expectations of community partners and vice versa, which leads to reluctance from both entities to engage in research together, thus, missing an opportunity to greatly enhance research participant diversity.

Integrating Special Populations (ISP) is a program within the Institute of Translational Health Sciences (ITHS), the NIH Clinical Translational Science Award program at the University of Washington, Seattle Children's, and the Fred Hutchinson Cancer Research Center. ISP's aim is to increase engagement, enrollment, and retention of children, youth, and older adults, particularly from racially/ethnically diverse and low-income populations, in research. In collaboration with the Seattle Children's Center for Diversity and Health Equity (CDHE), ISP formed a Community Advisory Council (CAC) in 2018 to inform and guide the work of ISP and CDHE. The CAC is composed of 12 members from community-based organizations, community coalitions, and communities that serve or represent historically underserved populations, including racial/ethnic minority groups and low-income populations in the Seattle/King County metropolitan region. It is not uncommon within research to form community-based or patient-based advisory councils, but these are generally specific to an individual research project or

health condition. The CAC was formed to enable a broader perspective on how health research, particularly focused on children and older adults, more generally can adopt and implement an equity approach, not limited to one research project or condition.

Here, we describe a community-facing tool developed by the CAC, a *Community Partnership Guide for Engaging with Academic Research Teams* (henceforth, the “Guide”), to inform and guide the work of community organizations partnering with academic researchers.

Development of the Guide: *The Community Advisory Council*

Prior to the formation of the CAC, the ISP and CDHE team (henceforth “academic team”) established initial objectives for the CAC in order to facilitate recruitment of potential participants to join the CAC; these were to 1) build capacity within the community and among community-based organizations to engage in community-partnered research, and 2) advance access to health-related research for the community.

Prior to the formation of the CAC, the academic team established initial objectives for the CAC, and recruited a CAC Chair (Dr. Maxine Hayes), to facilitate potential participants to join the CAC. Dr. Maxine Hayes is a nationally known pediatrician and retired State Health Officer for Washington state with 25 years of public service. She is a founding member of the Washington State Academy of Science and a member of the National Academies of Science, Engineering, and Medicine. She has a long-standing record working with vulnerable populations throughout the Seattle/King County area and Washington State and is the recipient of many awards and honors for her work in maternal and child health.

Based on the input from existing community advisers, the academic team held two luncheons during the Summer and Fall of 2017 to engage potential community partners in conversations about their experiences with academic-community research partnerships. Following the two luncheons, we invited interested participants to join the CAC. Although diversity includes many aspects of under-representativeness, the CAC's focus is primarily on communities of color, children and youth, individuals and families living in poverty, and older adults. In January 2018, we held the inaugural meeting of the CAC.

Overview of CAC Development of The Guide

In 2018, we convened the first 4 meetings of the CAC. At the first CAC meeting, the CAC self-determined that its goal for 2018 was to create a guide to empower community-based organizations to partner with academic research teams more effectively.

During its first two meetings, the CAC discussed prior research on academic-community engagement in research, best practices by various community organizations (including their own) in partnering with academic research teams, and then identified key areas in which community-based organizations face challenges in working with academic research teams, and what tools the organizations would need to overcome these challenges. CAC members shared and discussed the processes and tools that their own organizations used in determining whether to participate in an academic research project. They came to a consensus that the processes and tools they currently used were not sufficient and that they would create concrete guidelines that community organizations could use to establish clear expectations when partnering with academic researchers. They also wanted to provide a user-friendly format for the guidelines that would be

applicable to organizations regardless of their previous experience engaging in research. The academic team summarized their input in a draft document, which was further developed and edited by CAC members in an iterative process over the next two CAC meetings.

The Community Partnership Guide for Engaging with Academic Research Teams

The CAC created the *Community Partnership Guide for Engaging with Academic Research Teams* as a tool to help empower community organizations to partner, lead, and collaborate in research. The CAC designed the *Guide* to include three steps, summarized below, along with the CAC input and feedback used to develop it:

Step One: Screening Questions

One of the main challenges to partnering with academic research teams was being able to decide which "asks" from research teams to pursue further. CAC members reported that their organizations, and others that they were aware of, often received several cold calls per week from various researchers in different institutions with various asks, from help with recruiting participants into existing studies to full partnership in a research project. The CAC reflected on their own experiences partnering with academic researchers and what questions would have been most helpful for them as they created a screening tool for organizations to quickly assess whether to further explore an opportunity to partner in research. This screening tool (Table 1) includes seven screening questions that could be easily emailed to a research team (e.g., How does the research benefit a) our organization, and b) the communities we serve; what specific resources do you need from our organization?).

Table 1. Screening Questions for Requests from Academic Researchers

1.	Why did you choose us as an organization?
2.	How does the research benefit a) our organization, and b) the communities we serve?
3.	What is your research objective, key questions, and who do you hope to enroll in the research project? Please limit your response to 3-5 sentences.
4.	Where are you in the research process?
5.	What is the timeline for this project?
6.	What specific resources do you need from our organization? (For example, staff time, data sharing)
7.	What amount funding is available for the work of our organization on this research project? What activities (if any) are you asking our organization to contribute at no cost to the study?

Step Two: Plan your Engagement

The CAC wanted to focus on the most important initial issues in the formation of the partnership to allow community organizations to evaluate their own interests and capacity to engage in research as well as the readiness of the academic partner to engage in community-engaged research. The CAC identified several points in the research process in which community organizations often did not get what they needed out of research partnerships; these were often from the experiences of CAC members working with academic researchers on behalf of their own organizations. Other CAC members provided processes that they used to determine their own organization’s engagement in a research project. This information was compiled by the academic team, and then presented for feedback and revision by the CAC. This resulted in the creation of Step 2 (Plan Your Engagement), in which community-based organizations are encouraged to consider 4 issues that the CAC proposed were critical to successful community partnership in research endeavors. The content for Step 2 of the guide provides a continuum of

engagement; the community organization selects their level of desired engagement across four key domains. Each domain has a different number of levels for engagement, ranging from 2-4 levels, and the domains are constructed so that organizations can have different levels of engagement for each domain.

a) Involvement: Determine the level of engagement to have with the academic research team, from *Outreach* only (Level 1) to true *Partnership* (Level 4).

b) Partnership Governance: Determine engagement in project governance, with a focus on how communication and decision making occurs, from the involvement of few key individuals in the organization (Level 1) to a *Project-Specific Board* with representation from the community and academic team (Level 3).

c) Budget: Determine how funding and resources will be shared in the research project, from involvement as a *Consultant* (Level 1) to having a Community-Academic Project *Collaborative Budget* (Level 3).

d) Dissemination of Findings: Determine engagement in decision-making about how the results of the research study are shared. Organizations can provide *Input on Dissemination* (Level 1), or be *Partners in Dissemination* (Level 2).

Step Three: Memorandum of Understanding

The CAC decided that it would be critical for organizations to have all decisions from Step 2 outlined in a Memorandum of Understanding (MOU) and wanted it to be easy to use, fill-in-the-

blank MOU that could be used by various partnerships across a variety of levels of community engagement in research. The CAC defined the key points needed for the MOU and provided examples of their own MOUs that had been used in the past for community-academic research partnerships. The academic team then compiled this into a template for an MOU, which was edited and revised by the CAC and included in the full Guide.

Final Product

Between CAC meetings, the CAC and academic team engaged in several iterative rounds of both substantive and presentation/stylistic revisions of the *Guide*. In response to the CAC's review and recommendation, a communications expert edited the document based on best practices for 8th-grade readability, including evaluating the number of syllables in the words and the average length of the sentences. The CAC approved a final version of the *Guide* with each section designed to be "stand-alone", and a link to download the *Guide* was distributed to CAC members, their stakeholders, and other community organizations, academic researchers affiliated with ITHS and its institutional partners, and through the listserv of the Seattle Children's Center for Diversity and Health Equity. The [Guide](#) is publicly available and free to download.

Discussion

Through the evolution of Community-Based Participatory Research, the role of the community has evolved from participants to consultants, and from advisory board members to equal partners in research. While there are strong human subjects protections in place for research participants, there are no institutional protections in place to provide oversight for these new roles for the community in research.¹² It is therefore perhaps not surprising that the CAC's first priority was

in creating resources that better empower the community and community-based organizations to engage equitably in research.

Existing tools for community-academic research partnerships can robustly measure many different aspects of a partnership, including context, process, outcome, and impact measures.¹³ We considered existing tools and ways to measure the potential for research engagement,¹³⁻¹⁵ but the CAC wanted to focus on creating a shorter, more efficient tool, that is community-facing, and allows organizations to utilize the full continuum of engagement in research, recognizing that organizations may not want to engage in full partnership for every project, or in every aspect of a project. There were no other available tools to meet this need. For example, the CBPR Readiness Toolkit developed by the Medical University of South Carolina (MUSC) and their community partners is comprehensive and important for engaging in CBPR, but as a result, is 75 pages long.¹⁴ Conversely, there are shorter tools, but their primary function is to measure than guide and are more appropriate for assessing the quality of the partnership after it is established.¹⁵

The *Guide* was designed to be community-facing and provides community organizations and researchers with specific guidance for partnered research engagement. The *Guide* was itself a form of such partnership, with the CAC developing the *Guide* based on what community-based organizations need from academic research teams to make these partnerships mutually beneficial. Through the use of this guide, community-based organizations can assess the potential benefit of the research endeavor for the communities they serve and determine their level of engagement with the research team in terms of project development, partnership governance, budget, and dissemination of findings. This is particularly relevant in that the potential benefits of biomedical and health research to communities are seldom shared in a

culturally relevant way with those communities. The Guide can also be important in efforts to empower community-based organizations to have control over their roles, time, and contributions to research. Prior studies suggest that academic-community partnerships can benefit from careful planning to avoid conflicts of interest and challenges in mutual trust.¹⁶ The *Guide* is helpful for initial consideration by community-based organizations about whether and how they want to engage in an academic partnership in research. Other existing tools and measures should be used to deepen and evaluate the quality of these relationships to sustain them once they have been established.

Community Voice

The CAC envisioned the Guide as a first step to ensuring that the community interest is protected and more inclusive research is conducted. Research teams should also seek opportunities to speak with community members who are not part of the community organization to allow for richer community input.¹⁷

Conclusion

Racial and ethnic disparities in health and healthcare will continue to persist if researchers cannot effectively engage under-represented communities in research. Community-based organizations can utilize the newly-developed *Community Partnership Guide* to more efficiently and effectively evaluate whether and how they want to work with academic research teams and achieve a more inclusive approach to research. The *Community Partnership Guide* provides guidance to community partners on how to define and achieve their preferred level of engagement in research processes.¹⁸ Future research should evaluate the validity of the

Community Partnership Guide (e.g., does it measure the critical decisions needed to form academic-community organization partnerships in research?) and its utility of it to increase diverse participation in research.

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