Engaging Underserved Urban Communities in Research: Addressing Challenges in the Context of COVID-19

GUIDE FOR COMMUNITY ORGANIZATIONS

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

◼ INTRODUCTION

In October 2020, IPFCC was selected for Eugene Washington PCORI Engagement Award funding for the project, *Engaging Underserved Urban Communities in Research: Addressing Challenges in the Context of COVID-19.* The project was intended to build an understanding of the impact of COVID-19 on communities and strengthen community organizations' capacity to actively partner with researchers. We engaged staff from Smart from the Start (Smart) to serve as members of the project team. Smart is a multi-generational family support and community engagement organization working with underserved communities in Boston, MA and Washington, DC. We also engaged Smart Family Leaders (individuals living in underserved neighborhoods in Boston and DC who have received services and completed two years of training from Smart on program and community leadership, health advocacy, child development and child advocacy, and other related topics) in all project activities.

This Guide was developed to provide insights from community members and community organizations and offer strategies to effectively connect (specifically, during COVID-19 or other public health crises) and partner with researchers on topics determined as important by the community.

◼ LEARNING FROM THE COMMUNITY

The project team engaged community members and community organizations across the project to learn from them. The following describes project activities:

Established a Workgroup to inform and collaborate with the project team across all project tasks. The Workgroup was comprised of five Smart Family Leaders and a staff member from Smart. Workgroup members received an honorarium for their participation.

Conducted focus/discussion groups with Smart Family Leaders. Family Leader Workgroup members partnered with the project team in developing the questions and protocol for the groups. Four groups were conducted with a total of 19 participants. The groups were recorded and transcripts were analyzed for themes that were used to inform the recommendations included in this Guide. The Workgroup members reviewed the themes and informed their refinement. Focus/Discussion Group participants received a stipend for their participation.

Conducted interviews with staff from community organizations. The interviews were either recorded or detailed notes were taken. Themes emerging from the interviews were reviewed with the Family Leader Workgroup members, who provided feedback. The themes informed the recommendations included in this Guide. Interviewees or their organizations (based on their preference) received an honorarium for their participation.

STRATEGIES FOR PARTNERSHIP

INITIAL STEPS TO TAKE

RECOGNIZE THE EXPERTISE THE COMMUNITY ORGANIZATION CAN BRING TO RESEARCH. It's important for community organizations to recognize the wisdom and perspectives within their staff and the community. In order for any collaboration with researchers to be successful and equitable, community organizations can begin by identifying their unique expertise and what they bring to a research project.

DETERMINE COMMUNITY PRIORITIES AND NEEDS. Traditionally, researchers reach out to community organizations with research topics and questions, and a plan for the study already developed. That approach is not reflective of authentic partnership. Community organizations can and should identify and document the community's priorities for potential research topics. This can be done in a variety of ways:

- Hold virtual town halls with community members to explore what they want to be studied

- Conduct surveys or virtual focus groups

- Use current community needs assessment findings

CREATE A SUMMARY ABOUT THE COMMUNITY. In addition to identifying the priorities of the community, a community organization can develop informational materials to provide an accurate and up-to-date picture of the community. This can include demographic information, general health statistics, community goals and accomplishments, and opportunities for improvement. Once shared, this information can ground discussions with researchers in the reality of the strengths, challenges, and needs of the community and reduce bias or preconceived views of the community.

ENGAGE PROACTIVELY WITH POTENTIAL RESEARCHERS. Community organizations shouldn't wait to be contacted by researchers. Organizations can initiate connections to researchers using a variety of strategies including:

- Identify local/regional colleges and universities that conduct research

- Identify and contact research centers or researchers focused on studying areas aligning with community priorities and needs

- Share information about the community with the researchers (see previous strategy about creating a summary on page 3)

- Hold initial "get-to-know" conversations with researchers to find out their level of interest in partnering with the organization in research

- Invite researchers to virtual or in-person community events so they get a realistic, "boots on the ground" view of the community and can build trust and relationships as the community gets to know them

- Share priorities with potential researchers about what community members want to be researched

- Ask potential researchers how they envision a research project would support and improve the community

FORM A RESEARCH WORKGROUP. An organization with little or no experience with research can start by creating a small exploratory group to partner in initial projects and obtain experience. The Family Leader Workgroup established for this engagement project provides an example of how this could be done.

The project lead reached out to the executive director of Smart from the Start (Smart), with whom she has a working relationship, to discuss the opportunity to collaborate on this engagement project. The executive director and her staff selected and invited Family Leaders (individuals living in underserved neighborhoods in Boston, MA and DC who have received services and completed two years of training from Smart) who they thought would be interested. Regular virtual meetings using Zoom were scheduled at a time that worked best for the Family Leaders. A Smart staff member was asked to be the coordinator and serve as the liaison between the project lead and the Family Leader Workgroup members. Initial meetings focused on getting to know one another and discussing the project goals and their role. The Workgroup met to develop questions for focus/discussion groups and interviews. They participated in a focus/discussion group and then helped revise the protocol. They also helped refine the summary of themes that emerged from the focus/ discussion group and interviews. At the end of the project, members received a short training in research partnerships and discussed how their participation in the Workgroup prepared them to partner in future research.

The following profiles feature the perspectives of the members and the Smart coordinator about the experience of serving on the Family Leader Workgroup.

MONIQUE DOTTSON lives in Dorchester, MA with her daughter, and has been involved with Smart from the Start since 2013. In her role as a Family Leader, she goes out into the community and encourages other family members to seek resources and help. She also provides help and support, letting parents know that they're not the only ones out there. Her interest in joining the Workgroup was to learn how research works, specifically surveys which are often done in her community. She thought it was a unique experience and liked the versatility of the group where everyone could voice their opinion, be heard, and make a change. *"It's not like your ordinary topics that you talk about with family and friends. These were real in-depth questions you want to be in on. It means a lot to the community."*

PRESTON GRAY is married with four children and lives in Washington, DC and has been with Smart for seven years. In his role at Smart, he leads a fathers' group which supports young men in building their parenting skills. He also does outreach and spreads awareness about the resources that Smart offers to community members. Preston experienced COVID and knew he could add that perspective to the Workgroup. For him the Workgroup was a *"learning experience"* and a chance to hear *"the different opinions and ideas"* shared by others. Preston joined the group after initial Workgroup meetings had been held, but felt that both the Smart Workgroup coordinator and the project lead *"welcomed him with open arms and caught him up to speed"* so he could share his voice and come up with solutions.

RONNETTA WHALEY lives in Washington, DC with her family. She became a Family Leader at Smart four years ago. In her role as a Family Leader, she says that she has strengthened her skills to be disciplined, responsible, and professional when working with other families. She is happy to help Smart when asked, including joining the Workgroup. In the group, Ronnetta enjoyed brainstorming with others and coming up with ideas about, *"…what we see that would help the situation, would make it better, not worse."* She adds that as a group, *"we don't put negativity on ideas we come up with. We hear and add on to them."*

PATRICE BARKER lives in Dorchester, MA with her three sons. She became a Family Leader at Smart three years after many years of receiving services and participating in its programs. She is an active member of her church and her community and widely shares information about Smart so that others can access the resources that Smart provides. She joined the Workgroup because she believed that the information she could share would be meaningful and improvements could be made. She appreciated the organized nature of the Workgroup, the preparation for meetings, and the open communication. As Patrice said, *"I feel like we have built up our voice to speak for others that are out there. And that's powerful."*

MATTHEW JACKSON lives in Boston, MA with his 10-year-old daughter. He has been a Family Leader since 2015 and runs a weekly fathers' group where they talk about topics such as parenting, mental and physical health, and child development. He also runs a restorative justice group. He joined the Workgroup because as he said, *"anytime I get a chance to have input or inform people that aren't from the community, on information about my community, I'm always trying to help."* Matthew appreciates that the Workgroup members' opinions are listened to and cared about. He believes that if others *"genuinely want to see change, or people get services or assisted, they got to listen to the people who's going through it."* He shared that what helped him in the Workgroup was to be kept informed, get reminders of upcoming meetings, and that time was taken to explain what the members were working on. Matthew recommended that if an opportunity came about in the future, it would be great to get children involved in a similar group.

LORI-ANNE DUFRESNE is a Program Specialist at Smart from the Start in Boston coordinating a site, leading groups, and working on grants. She served as the coordinator of the Family Leader Workgroup assisting the members in completing forms, preparing and supporting them as members, reminding them of meetings, and being the liaison between the project lead and the members. As she stated, she believes that *"…our families that we work with have so much to give to the community and it's really nice to be in the position to hear what they have to say and support their ideas. They don't often have that opportunity."* Smart has a commitment to family engagement and in her view, this project exemplified engagement. Lori-Anne recognized that while she has worked in the community for two decades, this project allowed her to continue learning from the families. *"I can never know, as much as I want to. And as much as I feel like I do, there's still a lot that it's just impossible for me to understand."*

NEXT STEPS TO TAKE

PREPARE ALL FOR COLLABORATION. Building a working, collaborative relationship takes time and effort. A key component is making sure that all have the capacity to actively and effectively partner in research. Community organizations can request that researchers provide appropriate preparation and training for staff and community members. The training should not be overwhelming but instead be just enough so that community members understand the basics of research and can get started. As they begin to engage in research, they may request additional training. The Patient-Centered Outcomes Research Institute offers helpful online resources in a special section on their website, **Research Fundamentals: Preparing You to Successfully Contribute to Research.**

Researchers also need to be prepared for collaboration. Community organizations should share information with researchers about how they engage community members, meetings are conducted, and decisions are made. Invite them to attend a virtual working meeting. Community organizations can suggest that project meetings be co-facilitated by a researcher and a staff member from the organization, demonstrating partnership and developing trust.

SET A CLEAR EXPECTATION THAT THE COMMUNITY ORGANIZATION WILL BE INVOLVED ACROSS ALL RESEARCH PHASES. When planning for authentic collaboration, there is a need to establish clear guidelines specifying how the community organization will be engaged in all stages of the research, from planning and developing research questions to converting the findings into actionable steps. The following steps will help:

- Determine and agree upon roles and decision-making process with researchers

- Request presentations from researchers prior to beginning a study so the community organization has input in determining the research focus and questions

- Develop a project plan, specific tasks, and timeline collaboratively with researchers

- Require follow up communication to the broader community about research findings and their implications and ways to involve the community in moving from findings to action/improvement

DETERMINE THE SUPPORT NEEDED FROM RESEARCHERS TO EFFECTIVELY PARTNER AND DEVELOP AN APPROPRIATE BUDGET. Partnering in research demands time and resources and community organizations should not bear the burden of engagement. Researchers should plan to support the participation of the community organization and community members and include sufficient funds in their budget. The following factors will need to be considered:

- Percent of effort for organizational staff who have responsibilities for the project and appropriate compensation to them

- Appropriate honorariums for any project committee or council members advising the project[1]

- Support for engagement of community members (e.g., technology – phone, tablets, computer, Wi-Fi or data plans; virtual or in-person meeting costs; child or adult/respite care)

- Appropriate stipends/incentives for community members who are study participants or respondents

- Employ individuals from the community to serve on the project team

[1] Guidance can be found in **PCORI's Compensation Framework**.

For more detailed information, you can access **Standard of Compensation for Involving Youth, Family, & Patient Partners** from the Children and Youth with Special Health Care Needs National Research Network.

EVALUATE THE PARTNERSHIP FROM ALL PERSPECTIVES. Understanding the experience of collaboration from all who were engaged will help identify challenges or problems to be addressed before the project is completed and improve future partnerships. Brief assessments can be done during the project for example at the end of meetings to determine any needed refinements to the meeting process or at the end of each project phase so that all feel equipped and valued before moving on to the next phase. Everyone should have the opportunity to share their perspective near the end of the project. A positive and strengths-based approach such as appreciative inquiry, can be used to conduct this evaluation. The following can be asked:

- What do you like most about the collaboration?

- What do you see as your strongest contributions?

- What do you see as the strongest contributions of others?

- How were you supported to participate as much as you wanted?

- What is one change that could be made to improve the experience?

DEVELOP A PLAN FOR FUTURE COLLABORATIONS. When you enter a partnership, think in the long-term. If the purpose is to improve and strengthen the community, consider planning next steps with the researcher. Present or co-present with researchers about the findings and how they will be acted upon to benefit the community. Ask researchers if there are funding opportunities to support research that will add on to what was learned in this project or study a new topic that is a high priority for the community. Find out if there are local, state, or national funders who will support community organizations as leaders or co-leaders in collaborative research.

ESTABLISH A COMMITTEE TO OVERSEE FUTURE RESEARCH PROPOSALS AND PROJECTS. Once a community organization has experience partnering in research it may be advantageous to establish a formal committee. For research that ultimately leads to better outcomes within a community, an organization may want to have a higher level of decision-making authority over what research is approved and how it is conducted. An effective strategy is to establish a research committee consisting of community members and organizational staff. This requires creating a selection process for members, preparing members to actively participate, establishing a process for researchers to submit proposals, developing criteria for approval, and evaluating the committee's efforts. It also requires time and resources. The profile of Mary's Center on the following page provides an example of an organization which created a research review committee.

MARY'S CENTER is a Federally Qualified Health Center (FQHC) with five clinics that serve the DC metropolitan area. It was founded in 1988 and has grown considerably since its beginning. Its model is based on a holistic and integrated model of health and well-being that Mary's Center developed called the Social Change Model. In addition to its health care services, Mary's Center provides social and educational services.

In 2015, Mary's Center established a Research Review Committee (RRC) in order for them to have decision-making authority for research projects that engage the communities they serve and with which they partner. The RRC is an interdisciplinary committee with representation from areas such as social services, mental health, and public health and meets twice per month.

They established a formal process for researchers to contact Mary's Center RRC and complete an application providing information about the research study such as methodology, expected outcomes, and how they will engage Mary's Center. The RRC developed criteria they use to determine whether an application will advance to the next stage in the process. This criteria includes how well it is aligned with Mary's Center's mission, vision, and values; how much it reflects a participant-centered approach to the research, and the financial and other benefits that would be awarded to Mary's Center. If selected, the researchers are invited to provide a full presentation of their proposal to the RRC. A rubric was created for the RRC to provide an objective means for RRC members to vote. If one or more members raise objections about a proposal, the RRC asks the researcher to respond to the concerns before making a decision.

If a research proposal is accepted by the RRC, Mary's Center has set specific expectations for the researcher to follow.

- Researcher submits official letter (signed by the researcher's department chief or other leader and then Mary's Center Chief Executive Officer)

- Project maintains alignment with Mary's Center vision, mission, and values

- Researcher engages Mary's Center as appropriate

- Findings are shared with Mary's Center and study participants

- Project provides financial award to Mary's Center

- Researchers present midpoint and final reports

As of August 2021, 98 applications have been submitted and approximately 70% of the proposals have been accepted. The types of studies approved have included clinical trials, protocol testing, focus groups, and key informant interviews.

The work of Mary's Center is guided by a set of values[2]. In all of their services and programs they maintain a commitment to those values. The RRC process is one of many ways the values come alive. Their values are:

- **Participant-centeredness:** As an organization, we use our cultural competency and compassion to promote and celebrate diversity by placing the needs of our participants and community first.

- **Accountability:** We embrace our roles, take responsibility for our actions, and are empowered to take smart risks because innovation leads to growth.

- **Respect:** We foster an honest and supportive environment free from judgement where all voices are valued.

- **Teamwork:** We actively collaborate by sharing knowledge and seeking input to effectively reach organizational goals.

[2] Source: Mary's Center website. **https://www.maryscenter.org/about-us/mission/**

"Your voice is the most powerful tool you have. It's always good to speak up for those who don't have the opportunity."

— Patrice Barker, Family Leader

■ CONCLUSION

Community organizations are essential and valuable partners in research. They are champions for the vision, priorities, goals, and needs of those that they serve. They bring the unique perspectives of the community, which ultimately will keep research grounded in what matters most to the populations being studied. They also are the bridge between community members and researchers and are instrumental in building needed trust and relationships. Community organizations can and should be proactive in connecting with researchers and exploring opportunities to serve as collaborators. They should be engaged as true partners across all stages of research and in decision-making; and should be provided the support and resources to be successful. COVID-19 or any other public health crisis should not be seen as a barrier to partnership. Over the course of this project, we witnessed how relationships and collaborations can grow and flourish in a virtual environment. We hope you find the strategies included in this Guide helpful and inspirational.

■ IPFCC PROJECT TEAM

Project Lead: Marie Abraham, Vice President, Programming and Publications
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■ ABOUT THE PROJECT

More information about the project can be found on IPFCC's **website.**

You can also learn more on the PCORI website at **https://www.pcori.org/research-results/2020/engaging-underserved-urban-communities-research-addressing-challenges-context**

An additional resource developed as part of this project, ***Engaging Underserved Urban Communities in Research: Addressing Challenges in the Context of COVID-19 – Guide for Researchers,*** can be accessed **here.**

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

The Institute for Patient- and Family-Centered Care (IPFCC) is a non-profit organization founded in 1992. IPFCC provides national and international leadership for advancing the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering partnerships among patients, families, and health care professionals, IPFCC facilitates patient- and family-centered change in all health care settings. IPFCC provides training, consulting, and technical assistance to hospitals, primary and ambulatory care practices, educational and research institutions, community organizations, and agencies at state, provincial, and federal levels. IPFCC's work is guided by the core concepts of patient- and family-centered care: dignity and respect, information sharing, participation, and collaboration. **Learn more.**

SMART FROM THE START

Smart from the Start (Smart) is a trauma-informed, multi-generational family support and community engagement organization with a mission to promote the healthy development of young children and families living in the most underserved communities of Boston and Washington, DC. The organization was founded by Cherie Craft in 2008 with support from Boston Mayor Thomas Menino. In 2012, Smart from the Start became an independent non-profit organization and expanded to Washington, DC. Many staff members, and Ms. Craft herself, grew up in the communities they serve. Smart uses a strengths-based culturally reflective approach to promote overall health and wellness of young children and families and empowers families with the tools, resources, and support they need to thrive. **Learn more.**