

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

GUIDE FOR RESEARCHERS



“The COVID-19 pandemic has increased the visibility of the value of patient engagement and highlighted the importance of ensuring greater diversity of voices in this sphere.”

— Denegri & Starling, 2021¹

■ INTRODUCTION

The Institute for Patient- and Family-Centered Care (IPFCC) partnered with Smart from the Start (Smart) in the project, *Engaging Underserved Urban Communities in Research: Addressing Challenges in the Context of COVID-19*, funded through a Eugene Washington PCORI engagement award. The project’s purpose was to identify challenges to engaging urban underserved populations in research during the time of COVID-19 and offer recommendations to address the challenges. This Guide was developed to provide insights from community members and community organizations and offer strategies to researchers for meaningful engagement.

¹ Denegri, S., & Starling, B. (2021). COVID-19 and patient engagement in health research: What have we learned? *CMAJ*, 193(27), E1048-9. doi:10.1503/cmaj.210998

■ PROCESS OF LEARNING FROM THE COMMUNITY

The IPFCC project team engaged community members and community organizations to learn from them and to inform project activities and resources. The following describes relevant 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 (individuals living in underserved neighborhoods in Boston, MA and Washington, DC who received services from and have completed training offered by Smart on program and community leadership, health advocacy, child development and child advocacy, and other related topics) 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 IPFCC project team in developing the questions and protocol for the groups. Four groups were conducted with a total of 19 participants. Groups were recorded and transcripts were analyzed for themes that were used to develop the recommendations included in this Guide. Workgroup members reviewed the themes and assisted in their refinement. Focus/discussion group participants received a stipend for their participation.

Conducted interviews with staff from community organizations. Draft questions for the interviews were reviewed with the Family Leader Workgroup members who provided suggestions for additions and changes. Community organizations in urban areas that provide services and support to underserved communities were selected for interviews. Interviewees or their organizations (based on their preference) received an honorarium for their participation.

■ ANALYSIS OF FOCUS/DISCUSSION GROUP FINDINGS

Initial themes were identified using the focus/discussion group protocol and key question categories. The IPFCC project team then reviewed and read the four focus/discussion group transcripts carefully to determine additional themes for the analysis codebook. Project staff members simultaneously applied the codes (or themes) to one transcript and then reviewed to compare their respective analyses. The codebook was further refined and finalized. Once analysis was completed, themes were summarized by code. As stated before, all themes were presented to the Family Leader Workgroup members who helped revise themes and sub-themes and refine the final summary. The protocols for the focus/discussion groups and interviews are included in the Appendix.

The following sections describe three themes—Impact of COVID-19, Family Leader Role and Outreach, and Recommendations to Researchers for Engaging Communities—and related sub-themes.

■ IMPACT OF COVID-19

COVID-19 has presented challenges in every community in the U.S. It is not surprising that families living in communities that have the lowest income level, limited access to resources, and lack of opportunities, appear to experience the greatest impact from the pandemic. Findings from the focus/discussion groups highlight how COVID-19 affected two low socio-economic, urban communities.

General

Overall, participants agreed that COVID-19 had a negative impact on their lives. Participants mentioned the impact on their social lives, mental health, and access to food, to name a few. However, the resilience of community members was observed, as one participant reported that COVID-19 *“brought out the survival mode in people”* as they started doing things they wouldn't normally do – for example, making and selling masks.

Jobs and finances

Some participants lost their jobs due to COVID-19 or had to quit their jobs in order to take care of their children who were at home either because daycare was not available or schools went virtual. As one participant reported, *“I'm not gonna lie, when everything was closed, it was tough for a lot of the dads, a lot of them, you know, lost their jobs. A lot of them was in the process of us getting them jobs, and like going on interviews, and then the world just shut down.”* However, one participant saw a positive impact, *“To every bad thing, there's always the positive side. So I definitely saw a lot of those people, you know, going out of their comfort zone, learning new things, taking tons of trainings.”*

Schools and childcare

Participants noted that COVID-19 has also impacted their children's school and daycare. Parents were frustrated because they still needed to work but there was nowhere for their children to go. One participant mentioned that their child *“did not like virtual learning at all, and he still doesn't to this day.”*

Mental health

COVID-19 has impacted the community's mental health and has added additional stress, as a participant observed, *“So it was just like, not preparing for the unknown. I guess every, the next day is just the unknown. So I'm seeing high stress levels in the community.”* With mental health challenges heightened, Smart responded by creating new programs and adding content to existing programs to provide support and *“address the stress.”*

Violence

Violence was reported by participants, specifically, shootings and unnecessary deaths they saw in their communities. As one participant reported, *“I've seen a lot of shootings in the city, a lot of deaths just because people didn't have nothing to do. They was just hanging around.”*

Food

COVID-19 has had a tremendous impact on families' ability to get food and/or obtain food stamps. This was particularly seen in families who are undocumented. As one participant observed, *“A lot of them, you know, have no papers, so they weren't getting like the food stamps.”*

“Our role is to go out, we are the frontline, we are the advocates, are the face of our other friends and parents that are in our community.”

— Focus/Discussion Group Participant

■ FAMILY LEADER ROLE & OUTREACH

The participants in the focus/discussion groups were all Family Leaders from Smart. The following describes their responsibilities and activities.

Advocating and supporting community

Smart Family Leaders described themselves as being firmly embedded in their communities. As one participant stated, *“Our role is to go out, we are the frontline, we are the advocates, are the face of our other friends and parents that are in our community.”*

Providing services and resources

Smart Family Leaders provide monthly food deliveries and facilitate supportive programs such as fathers’ and mothers’ groups, coaching, and family fun nights for children and families. In the fathers’ groups, they discuss parenting skills and help fathers obtain a GED or driver’s license and provide training that leads to certification and employment. In the mothers’ groups, they offer a variety of support as one participant shared, *“We do life coaching groups, we do self-reflection groups, therapy. We have tutoring for the kids. Just a lot of activities.”*

Spreading the word

Participants “spread the word” about the Smart program and services during food delivery and other outreach activities. Family Leaders use a variety of methods to reach the community including social media (e.g., posting on Snapchat, Facebook, Instagram), texting, as well as through email. In addition, Family Leaders share flyers during food deliveries and provide flyers to schools for distribution to families. They also use in-person opportunities to inform their community about Smart if they are at church, at a hospital or clinic, or attending community events. As one participant reported, *“I interact with the families by doing outreach, try to get as much families that I know, or that I might think needs the services we provide.”*

Connection during COVID-19

Smart Family Leaders used social media prior to COVID-19 to stay in contact with others. Use of social media increased during COVID-19. The largest shift was transitioning their programs and groups from in-person to virtual. The majority of in-person programs were moved to Zoom. Family Leaders saw that more people participated in the virtual programs, believing that it was more convenient for many. Another reason for the increase was that it was easier to participate virtually rather than in-person. It was also a matter of safety as for some it felt unsafe to travel through some neighborhoods to get to the program.

Participants thought Zoom worked well, noting *“it’s working...once we start to begin to open up more, we’re going to continue to have the offer for the Zoom. Because it’s easier for the parents to hop on with issues. If they needed a tablet or any other thing of that sort, we will provide that for them, help with the technology part.”*

“I don’t want to tell you oh this is what’s bad if you can’t relate or give me a story of your own. When I hear somebody telling me a story of their own, I say, you know, this person can relate. This person knows where I’m coming from, I feel comfortable talking to this person.”

— Focus/Discussion Group Participant

RECOMMENDATIONS TO RESEARCHERS FOR ENGAGING COMMUNITIES

Discussions from both the focus/discussion groups and the interviews yielded rich information related to partnerships among researchers and communities. The following describes the recommendations that focused on three key elements of engagement: building trust and relationships; supporting the community and community organizations; and connecting with the community.

BUILDING TRUST AND RELATIONSHIPS

Participants across the focus/discussion groups and interviews emphasized the importance of building trust and relationships with communities in order to engage authentically with them.

Be present in the community

Participants suggested that researchers be present in the community whether it is in-person or virtually. As one participant states, *“come out in the community and...show us what it is they’re trying to do or tell us,”* and *“build a bond if they’re not there physically.”*

Be relatable

Many participants expressed the desire to see researchers who looked more like community members or could relate to the community. As one participant noted, *“When you send researchers, to deal with the community, you have to send researchers out that are for that community, not necessarily meaning they have to be primarily Spanish or white or black. But they have to be like everyday people you know what I mean? They can’t be, you know, suit and tie.”* Another participant added, *“I don’t want to tell you oh this is what’s bad if you can’t relate or give me a story of your own. When I hear somebody telling me a story of their own, I say, you know, this person can relate. This person knows where I’m coming from, I feel comfortable talking to this person.”*

Build rapport/get to know the community

Participants talked about previous experiences as research subjects. They shared that they didn’t feel that researchers understood the community. As one participant stated, *“Taking the time to get to know certain individuals, or the individual you’re working with, you know. Time after time, just, you know, having a talk with them and have a better understanding with them...”* Another participant proposed that researchers show interest in community members’ perspectives, *“asking, like, community members or residents, like, what do they want to see in their community? Like, what do they feel like, is missing in their community?”*

Actively asking for the community perspective should begin before a research study is planned. Family Leaders who were members of the project Workgroup were asked about what they would like to learn more about the impact of COVID-19 through research. They shared several high interest topics related to COVID-19 including:

- Impact on social determinants of health (e.g., lack of food, housing, child care)
- Impact of lack of social interaction on children
- Impact of the lack of healthy activities for youth
- Impact of lack of access to mental health services for children
- Understanding vaccine hesitancy
- Ways to better communicate about the vaccine for children so parents can make informed decisions
- Best practices to engage people virtually (e.g., timing of virtual meetings, number of meetings)

Follow through and be consistent

Follow through and consistency was a common theme. Participants' experience with researchers has often been one-sided; researchers come in and conduct a survey and then the community members don't see them again. Participants noted researchers should *"communicate with these families. Let them know what's going on. Do follow up. Don't say you're gonna do something, ask for survey. And then we don't know where those results go. Do follow up. You want to hear how that was used or what they did with it."* Several participants said researchers need to *"be true to their word."*

Keep promises

Related to follow through was a sub-theme of the importance of researchers keeping their promises. Past experience with researchers and historical knowledge of research studies that hurt people like them remain a barrier. As one participant stated, *"I think they lost that trust way back then. And in order for them to gain it, they have to, they have to make sure whatever they're, they're putting forward, they're gonna stand by it."*

SUPPORTING THE COMMUNITY AND COMMUNITY ORGANIZATIONS

Participants across focus/discussion groups and interviews discussed the need for researchers to support the community organizations with which they are partnering.

Identify community organizations that are connected directly to the community

Interview participants pointed out the importance of identifying and selecting community organizations that are respected in the community and bring the real-life perspective of community members and not just *"representatives."* Researchers should seek out organizations that employ staff who live in the community.

Ask about the specific priorities and needs of the organization

It was thought that too often researchers come to communities with a thought-out plan for their research. Participants in both the focus/discussion groups and interviews believed that this was a barrier. One participant suggested that researchers be “*participant-centered*” by connecting with the community organization before the plan is created, provide opportunities for community members to “*share their perspectives,*” be “*led by the goals of the community,*” and “*ensure the vision for the project is aligned with the community organization.*”

Determine how the project will positively impact the community

Participants shared that research done in the community should be helpful to the community. Researchers need to be explicit about the “*benefits of the project and its intended outcomes to the organization and community.*”

Provide resources to the community organization

Participants reported that the community organization should be appropriately compensated for their effort in any partnership. Researchers should request a budget from the organization that will adequately support the organization’s engagement and this budget should be integrated into the research budget. In addition, researchers should “*invite and prepare community organization staff and community members to serve in roles on the project.*” This may include helping develop the study materials, conduct study activities (e.g, assist in enrollment, survey community members), and communicate the study findings and their implications to the community.

Compensate study participants

Participants reported that they themselves and their family and friends will participate in research if “*they get some kind of a benefit out of it, resources or something, connection to another agency, or just money or a gift card.*” The incentive should be appropriate to the effort. For instance, consider the level of engagement—compensation may vary depending on whether participants are involved in a brief, one-time survey or multiple interviews over a longer period.

CONNECTING WITH THE COMMUNITY

The COVID-19 pandemic forced a change in the way researchers could connect and involve community members as participants and as partners.

Participants described several ways to connect with the community including conducting surveys via text messages, conducting virtual focus groups or phone interviews, and using social media. As one participant offered, “*I think social media be better because I guess most people be on social media, you know, because that’s where everybody, some people be on. I think it will spread out across the world if you do it that way.*”

Participants also recommended that researchers communicate opportunities to get involved at groups led by the community organization (e.g., support groups), share information at virtual events, and post messages in various places around the community such as schools, hospitals, clinics, grocery stores, and community centers.

The participants also shared that “word of mouth” remains a powerful tool and can be done through texting and social media. If a community member trusts the researcher and believes that the study will benefit their community, they will encourage their friends and family to participate.

“I think that is cool that guys will come inside and find out what’s going on and get the input from the residents and the community leaders inside the community to help fix the problem.”

— Family Leader

■ CONCLUSION

In 2021, Goedhart and colleagues published a narrative review of 40 studies exploring the involvement of individuals living in vulnerable circumstances as collaborators in research.² Their findings are consistent with what we learned in this project from the Smart Family Leaders and the community organizations. There are a number of reasons why individuals who live in low socioeconomic neighborhoods are not engaged more frequently as research partners. These include “intrapersonal” factors such as their unfamiliarity with the research process, mistrust of researchers, and competing personal and work priorities.

As seen in the findings from the focus/discussion groups and interviews, COVID-19 has placed an increased burden on these communities. However, the pandemic or other public health crises should not be seen as an insurmountable barrier for engagement in meaningful partnerships. Findings highlight not only the negative impact of the pandemic but also the strengths within the community. The recommendations presented in this resource serve as guidance for researchers who want to build collaborative relationships with individuals and communities that are under-represented but bring critical perspectives to research. What was clear throughout this project, is that Smart from the Start and the Family Leaders who participated are resilient despite the circumstances caused by COVID-19 and remain committed to the mission to “promote the healthy development of young children and families”³ in their communities. When asked if they would be willing to partner with researchers in the future, the Family Leaders all said they would. As one Family Leader expressed why he was interested, *“I think that is cool that guys will come inside and find out what’s going on and get the input from the residents and the community leaders inside the community to help fix the problem.”*

² Goedhart, N., Pittens, C., Tončinić, S., Zuiderent-Jerek, T., Dedding, C., & Broerse, J. (2021). Engaging citizens living in vulnerable circumstances in research: A narrative review using a systematic search. *Research Involvement and Engagement*, 7(59). <https://doi.org/10.1186/s40900-021-00306-w>

³ Smart from the Start (n.d.). *Mission statement*. Retrieved from <https://smartfromthestart.org/about/>

■ APPENDIX

FOCUS/DISCUSSION GROUP PROTOCOL

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

Focus Group Outline

Time per Activity	Elapsed Time	END CLOCK TIME	Activity
4 min	4 min		Introduction / Welcome
4 min	8 min		Ground Rules
8 min	16 min		Icebreaker
10 min	26 min		Role as a Family Leader
15 min	41 min		Outreach and Connecting with Community Members
16 min	57 min		Advice for Researchers
3 min	60 min		Closing

[CONFIRM ZOOM IS RECORDING]

INTRODUCTION/WELCOME (4 min; elapsed time 4 min)

- Welcome, everyone. My name is Ushma Patel and I work for the Institute for Patient- and Family- Centered Care, also known as IPFCC.
- IPFCC and Smart from the Start have partnered together on this project to identify challenges to engaging urban underserved populations in research the time of COVID-19. We will be conducting 5 focus groups with Smart from the Start Family Leaders and Family Leaders-in-Training to understand how COVID-19 has affected their communities, and identify potential challenges in engaging in research.
- This project is funded by the Patient-Centered Outcomes Research Institute (PCORI). Results from the focus groups will be used to develop resources and tools to facilitate partnerships between researchers, community-based organizations, and community leaders that reflect challenges and opportunities associated with the COVID-19 pandemic.

- A few logistics notes before we begin:
 - If you need to go off-camera for personal reasons, please feel free to do so.
 - Please mute yourself if not actively speaking in order to minimize background noise.
 - While we hope that you will stay for the entire 60-minute group, if you feel uncomfortable or upset and feel that you need to step away at any point, please let me know.

GROUND RULES (4 min; elapsed time 8 min)

Before we get started, I would like to go over a few things about our discussion today.

- The focus group will last 1 hour and we will end promptly at _____. I want to be sure that we are able to cover all the topics we have for today and also want to be respectful of your time, so there may be times when I will need to move the conversation along.
- So that we can make the most of our limited time together, we ask that you please silence your cell phone and close out of other applications on your laptop or phone such as e-mail, text messages, and Internet browsers. If you are using your cell phone for the meeting, please refrain from taking other calls or answering text messages if possible, unless an emergency.
- We will be recording the group today to make sure we capture all of your feedback. However, all comments will be anonymous and we will not connect your name with what you say in any external documents.
- We encourage everyone to actively participate. Please be mindful of sharing time with others so that we have the opportunity to hear from everyone. Sometimes we think about this as “step up, step back.” If you feel you are speaking more than others, try to make space for other people to talk. And, if you find yourself not talking a lot, try to make an effort to contribute your comments or thoughts.
- You do not need to raise your hand or wait for me to call on you—please feel free to react and respond to each other.
- Everyone in this group will have different personal experiences and perspectives. We welcome them all. It is fine to have a different viewpoint or to disagree—we just ask that you do so respectfully.
- [All Groups except Family Leader Workgroup] Finally, as a thank you for participating, you will receive [INCENTIVE] after the focus group.
- Are there any questions before we get started?

ICEBREAKER (8 min; elapsed time 16 min)

1. First, let's start with introductions so we can get to know each other a little bit. Please briefly share with us...
 - a. Your first name
 - b. Where you live and how long you have lived there
 - c. What have you liked best about living in that area

{MODERATOR begins by answering the questions herself, then goes around the "room".}

ROLE AS A FAMILY LEADER (10 min; elapsed time 26 min)

As I mentioned, you are all here today because you have experience as a Smart from the Start Family Leader. I'd like to begin by learning a bit more about your experience, particularly during the last year's COVID-19 pandemic.

2. As a Smart from the Start Family Leader, what has been your role working with community members?
 - a. Probe: Describe your role and activities.
3. What concerns have you heard from community members about the impact of COVID-19?
4. What do you see are the effects of COVID-19 on your community?
 - a. Probe for impact on:
 - Schools
 - Access to food and basic supplies
 - Access to health services
 - Finances and job security

OUTREACH AND CONNECTING WITH COMMUNITY MEMBERS (15 minutes; elapsed time 41 minutes)

We are interested in learning more about how you have connected with community members.

5. Before COVID-19, how did you reach out to community members?
 - a. Probe for:
 - Phone
 - Mail/fliers
 - In-person
 - Social media

6. Now with COVID-19, how are you reaching out?
7. What has worked well?
8. What challenges have you experienced?
9. How do you share important information with community members?

ADVICE FOR RESEARCHERS (16 minutes; elapsed time 57 minutes)

Thank you for sharing that information. Now, I'd like to switch gears a bit. We are working with researchers who are interested in getting input from underserved communities to help inform their projects. I'd like to get your advice on how they could potentially work with community members to guide their research projects.

10. When physical access to communities and in-person meetings are restricted because of COVID-19, what are good ways for researchers to connect with community members?
11. How can researchers develop trusting relationships with community members?
12. What advice do you have for researchers who are seeking to collaborate with community members in research projects? Specifically, what should researchers consider?

CLOSING (3 min; elapsed time 60 minutes)

13. Before we conclude, is there anything you wanted to share that you did not get a chance to say?
14. Are there any questions that you have for me before we end?

Thank you very much for your time today!

INTERVIEW PROTOCOL

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

[Pre-interview: Send summary of project with invitation and interview questions]

Hello, thank you for agreeing to this interview and taking the time to speak with me. I would like to record our conversation if that is okay with you. We are partnering with Smart from the Start on this project to identify challenges to engaging urban underserved populations in research in the time of COVID-19.

- Please briefly describe your organization and how you provide outreach and support to the community.
- Overall, how has COVID-19 affected the communities you work with?
- What are you or your staff hearing from community members about their concerns and perspectives related to COVID-19?
- How has COVID-19 affected your organization's engagement and outreach activities?
 - What challenges are you or your staff facing in your engagement and outreach?
 - In what ways have you addressed those challenges?
 - Have any opportunities surfaced during COVID-19 that improved outreach and engagement efforts?

If they are not partnering with researchers, ask this question:

- How can what you have learned through your work during this pandemic be applied to facilitate partnerships between researchers and under-represented communities?

If they are partnering with researchers, ask these questions:

- How has COVID-19 affected your collaboration with researchers?
- How have you and researchers you're partnering with maintained a productive relationship?
- What strategies have been effective in helping researchers work with your community during the pandemic?
- Are there other ways or resources that would improve the connections between your organization and researchers?

Closing:

- Is there anything I haven't asked you that you would like to share?
- Do you have any questions for me?

Thank you so much for your time.

■ IPFCC PROJECT TEAM

Project Lead: Marie Abraham, Vice President, Programming and Publications

Project Coordinator: Ushma Patel, Director for Special Projects and Educational Programs

Project Advisor: Pam Dardess, Vice President, Strategic Initiatives and Operations

■ ACKNOWLEDGEMENTS

The IPFCC team would like to thank the following for their partnership in the project.

Smart from the Start Staff

Cherie Craft, CEO, Founding Executive Director

Lori-Anne Dufresne, Program Specialist

Janiya Garrett, Program Manager (DC)

Sophia Girault, Associate Director

Family Leader Workgroup

Patrice Barker

Monique Dottson

Preston Gray

Matthew Jackson

Ronnetta Whaley

■ 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 Community Organizations***, 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.](#)

This project was funded through a Patient- Centered Outcomes Research Institute® (PCORI®) Eugene Washington PCORI Engagement Award EAIN-00143.

The statements presented in this guide are solely the responsibility of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

© 2021 Institute for Patient- and Family-Centered Care®