Welcome

- Please introduce yourself in the chat box
  - Name
  - Organization (if applicable)
  - Where you are joining from

- We welcome questions and comments in the chat

- Technical issues? Chat or text:

  Natasha Reed, 646-789-1613

Creating Authentic Partnerships with Urban, Underserved Communities in Research During COVID-19

Presenters:

Marie Abraham, IPFCC

Ushma Patel, IPFCC

Janiya Garrett, Smart from the Start

Kate Boyd, PCORI

Panelists:

Lori-Anne Dufresne, Smart from the Start

Matthew Jackson, Smart from the Start

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

SMART FROM THE START

Agenda

- Overview of the project

- Overview of Smart from the Start

- Learning from the community

- Introduction to new resources

- Engaging with PCORI

Engaging Underserved Urban Communities in Research: Addressing Challenges in the Context of COVID-19
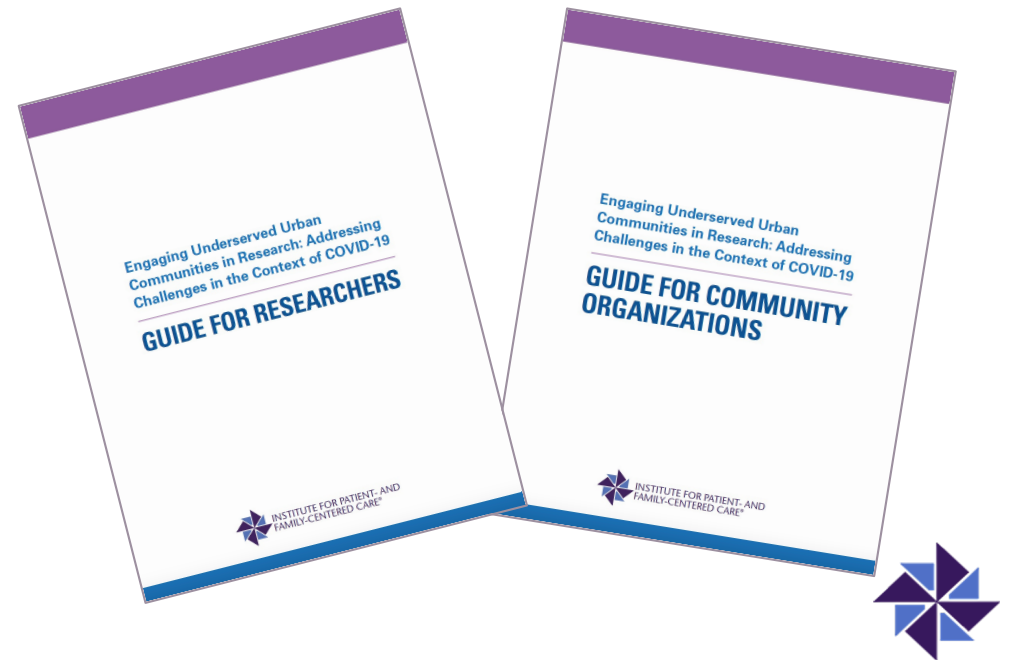
Project Overview & Purpose

- Partnered with Smart from the Start (Smart)

- Timeframe: October 2020 – January 2022

- Purpose
  - Identify challenges to engaging urban underserved populations in research during the time of COVID-19
  - Develop resources and tools to facilitate partnership between researchers, community-based organizations, and community leaders

Project Activities

- Convene a Family Leader Workgroup
- Conduct focus/discussion groups and interviews
- Develop tools and resources
- Disseminate project resources

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

GUIDE FOR RESEARCHERS

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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

Overview of Smart from the Start

A Two-Generational, Trauma- Informed Approach to Breaking Cycles and

Promoting Healthy Early Childhood Development

Cherie Craft, M.Ed, Founding CEO and Executive Director

MISSION/VISION STATEMENT

- Smart from the Start, is a multi-generational, trauma-informed family support and community engagement organization with a mission to promote the healthy development of young children and families living in under-resourced, and under-served communities.

- Smart empowers families and communities with the right com of tools, resources and support, to break cycles of chronic school under-achievement and ensuring the economic self-sufficiency of families, while encouraging and supporting community leadership.
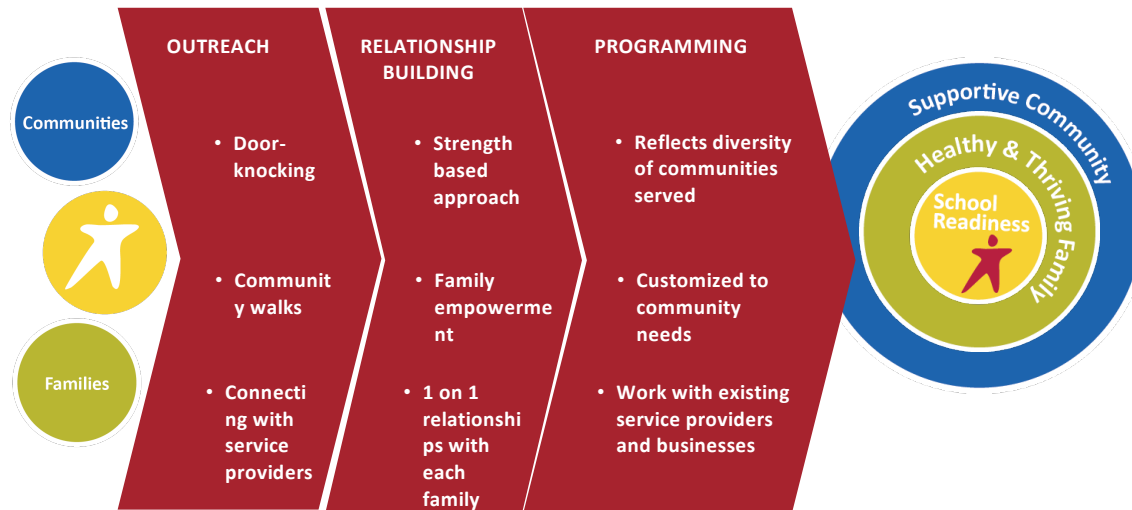
What is Smart from the Start?

- Launched in 2008 with the support of Boston Mayor Tom Menino
- Works exclusively within the lowest income, most underserved communities
- Currently serves over 2,000 children 0-6, in 38 neighborhood sites in Boston and in Southeast DC
- Programming takes place in community centers, in housing developments, homeless shelters, residential treatment facilities, and on Zoom

"Smart" in Brief.....

- Grassroots, family and community-driven
- We reflect the rich diversity of the communities we serve
- We employ a multi-cultural, multi-disciplinary team of gifted, professional and para-professional staff
- We are strengths-based and believe in the POWER of our families and communities
- We are "place-based" and embedded in the housing developments, shelters and communities where our families live
- Founded and led by a diverse team of Women of Color

Smart's grassroots approach transforms children, families, and communities

Communities

Families

OUTREACH

- Door-knocking

- Community walks

- Connecting with service providers

RELATIONSHIP BUILDING

- Strength based approach

- Family empowerment

- 1 on 1 relationships with each family

PROGRAMMING

- Reflects diversity of communities served

- Customized to community needs

- Work with existing service providers and businesses

Supportive Community

Healthy & Thriving Family

School Readiness

ALL FAMILIES WELCOME!

Smart serves a beautifully diverse population of families with various ethnic and cultural backgrounds.

Our families include single and two-parent families, grandparent and kinship-care families, teen parents, same-sex parents, foster families and more.

We serve families in 6 different languages and provide an array of culturally respectful, responsive and reflective programs and services.

Exclusively Serve......

Smart was founded to reach families others consider:

- "Impossible to engage"

- "Resistant to change"

- "Conditioned to negative lifestyles"

- "Non-compliant"

- Families raising young children who have complex challenges, but incredible untapped potential, strengths and possibilities

Best Practices

Our **early education programs** have a specially designed curriculum that includes activities, learning tools, literacy materials and experiences that honor, **and speak directly to the urban, culturally diverse population** of the little ones Smart from the Start serves.

Family Support provides parents and caregivers with amazing strengths and resiliencies the **resources and information to accomplish their short term and long term goals** and also increase each parent's confidence as **their child's first teacher.**

Our **Community Unity Initiative** takes an innovative approach to mobilizing community businesses, stakeholders and families.

SMART FROM THE
STÄRT
Families & Communities Promoting School Readiness

Programming in Brief

- ❖ Prenatal support and education
- ❖ "Smart Start" Newborn Visits
- ❖ Early educational programs for children 0-6
- ❖ Crisis intervention & family stabilization
- ❖ Parenting support and education
- ❖ Family advocacy
- ❖ Adult education and life skills
- ❖ Family leadership programs
- ❖ "Focusing on Fatherhood"
- ❖ "Address the Stress" & counseling

SMART FROM THE START

Families & Communities Promoting School Readiness

Engaging and Empowering to Inspire Lasting Change.....

www.smartfromthestartinc.org

857-308-3000

68 Annunciation Rd.
Roxbury, MA 02120

Learning from the Community

Focus/Discussion Groups

Interviews

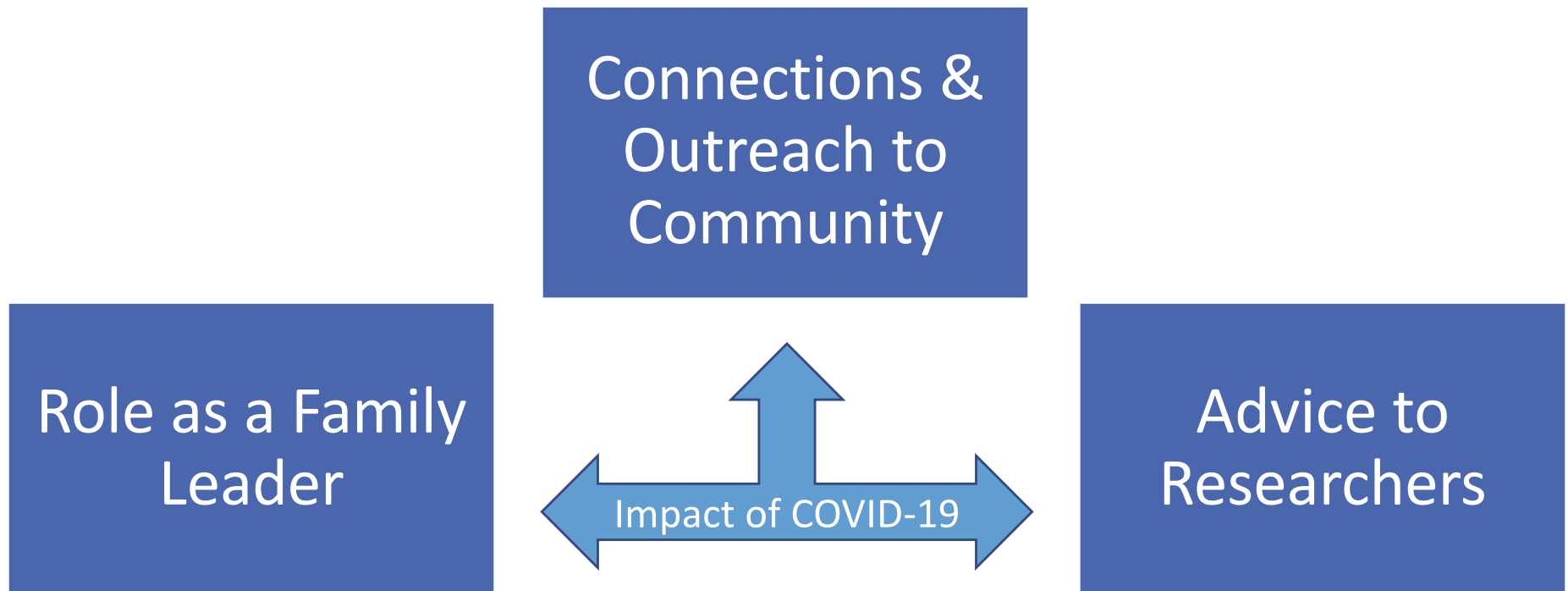Family Leader Workgroup Panel

Focus/Discussion Groups - Process

- 4 groups with a total of 19 participants
  - Smart Family Leaders from Boston and DC
- 1 hour groups held in April & May 2021
- Discussions were recorded, transcribed and analyzed
- Collaborated with Family Leader Workgroup:
  - Input on protocol
  - Review of emerging themes from the groups
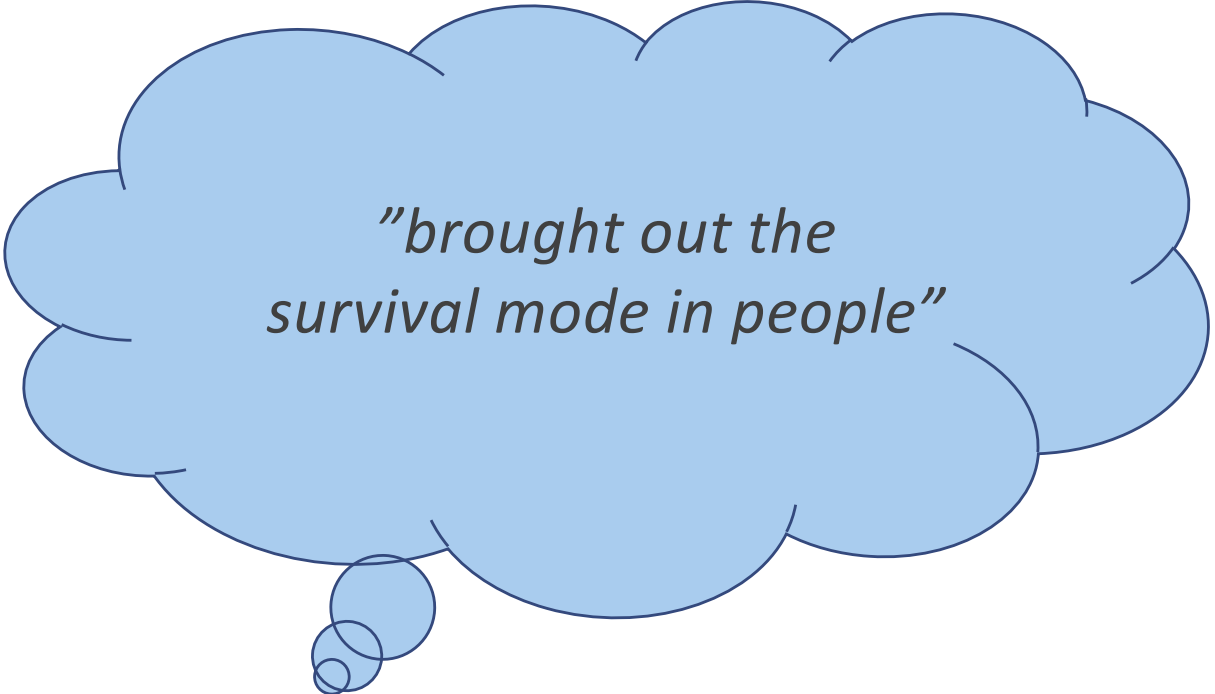- Participants received $75 stipend

Major Themes Explored

Connections & Outreach to Community

Role as a Family Leader

Impact of COVID-19

Advice to Researchers

Impact of COVID-19

- General impact
- Jobs and finances
- Schools and childcare
- Mental health
- Violence
- Food

General Impact

- Negative impact on social lives, mental health, access to food

- Resilience of community

"brought out the survival mode in people"

Jobs and finances

"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."

- Job loss due to COVID-19
- Quitting due to lack of childcare or virtual school

Schools and childcare

- Parents and children experienced frustrations around at-home & virtual learning

Mental health

"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."

- Enormous impact on mental health
- Additional stress from unknown

Violence

- Shootings and unnecessary deaths reported

"...you would just see people hanging out, people just want to get outside. 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

> *"I have more parents who's concerned about food, like, where can they go find food? They didn't have enough in the home. And I had to, like give them like resources or where to go and to go get food."*

- Ability to get food
- Obtain food stamps

Role as a Family Leader

- Advocates for their community

"we are the frontline, we are the advocates...the face of our other friends and parents..."
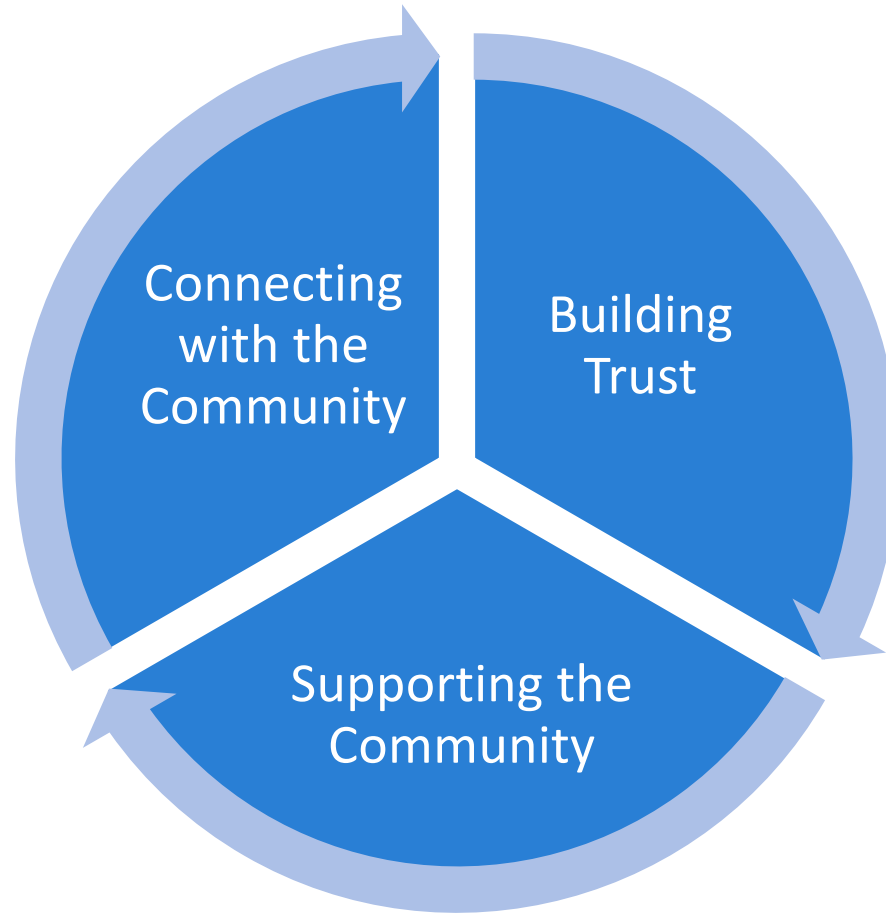
Role as a Family Leader

"We do life coaching groups…self-reflection groups, therapy…tutoring for the kids"

- Responsibilities include:
  - Distributing resources
  - Spreading the word about Smart programs and support
  - Facilitating groups for children and families (e.g., mothers' and fathers' groups)

Advice to Researchers

Focus Groups

➡️ Interviews

Family Leader Workgroup Panel

Interviews

- Four interviews with three community organizations serving populations in:
  - Urban
  - Disadvantaged
- Providing services and support in communities including:
  - Classes and support (parent, youth, mental health, school)
  - Health care
  - Connecting to community resources
  - Food and other necessities
- Strength-based and focused on engagement and empowerment
- $100 stipend provided

Interview Questions

- Two protocols developed for organizations
  - With experience working with researchers
  - With no experience working with researchers
- Questions focused on:
  - Impact of COVID-19
    - On the community
    - Provision of services and support
    - Collaboration with researchers
  - Addressing challenges due to COVID-19
  - Recommendations for facilitating partnerships with researchers

Findings

Impact on community

- Mental health
- Employment
- School/childcare
- Food and basic necessities
- Access to and skills in using technology

Impact on provision of services and support

- Home visits
- Classes/support groups
- Recruitment/enrollment
- Community events

Findings

Addressing challenges

- Transitioned programs and support from in-person to virtual
- Expanded programming as needed:
  - Mental health
  - Healthy activities
  - Job training
- Provided technology and assistance in using it
- Shifted budgets to respond to community needs
- Maintained connection through texting, phone or video calls
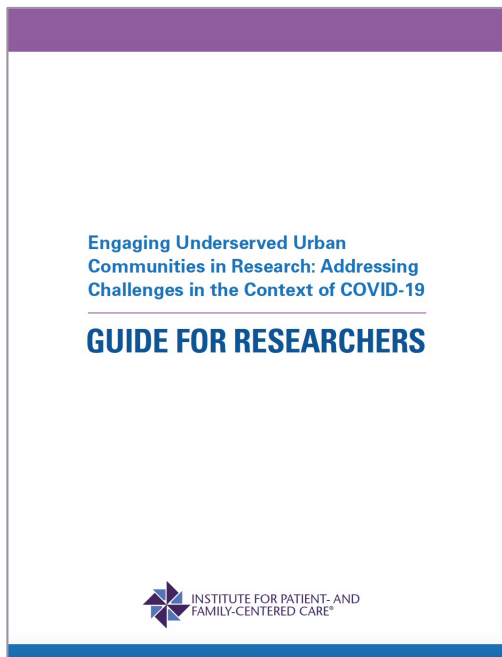- Hosted events virtually or outdoors

Focus Groups

Interviews

→ Family Leader Workgroup Panel

Resources

Guide for Researchers

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

GUIDE FOR RESEARCHERS

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

- **Describes themes and subthemes**
  - Impact of COVID-19 on the community
  - Family leader role & outreach
  - Recommendations to researchers
    - Building trust and relationships
    - Supporting the community and community organizations
    - Connecting with the community
- **Includes the protocols**

www.ipfcc.org/bestpractices/partnerships-in-research/engaging-underserved-communities.html

Build Trust & Relationships

- Be present in the community
- Be relatable
- Build rapport/get to know the community
- Follow through and be consistent
- Keep promises

Support the Community & Community Organizations

- Identify community organizations connected directly to the community

- Ask about specific priorities and needs of the organization

- Determine how the project will positively impact the community

- Provide resources to the community organization

- Compensate study participants
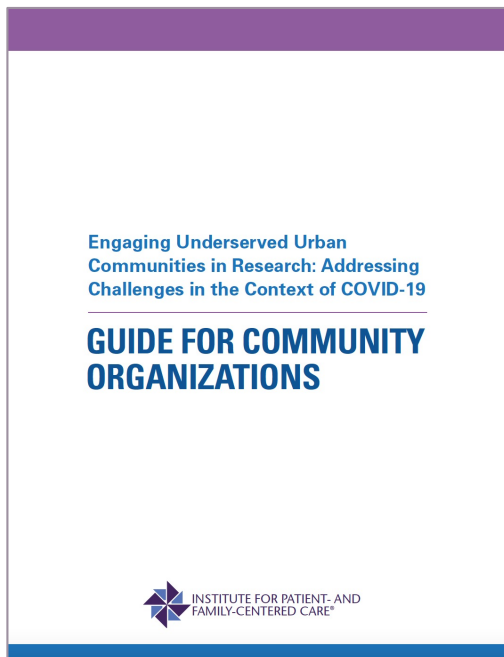
Connect with the Community

- Conduct surveys via text messages
- Virtual focus groups or phone interviews
- Use social media
- Communicate opportunities at groups/events led by community organizations
- Word of mouth – a powerful tool

Guide for Community Organizations

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®

- Describes themes
- Offers a proactive framework and strategies for research partnerships
- Provides profiles

www.ipfcc.org/bestpractices/partnerships-in-research/engaging-underserved-communities.html

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Strategies – Initial Steps to Take

- Recognize the expertise of the community organization

- Determine community needs

- Create a summary of the community

- Engage proactively with researchers

- Form a research workgroup

Strategies – Next Steps to Take

- Prepare all for collaboration
- Set expectation for involvement across all research phases
- Determine support needed to effectively partner
  - Develop an appropriate budget
- Evaluate the partnership
- Develop a plan for future collaboration
- Establish a committee to oversee future proposals and projects

Presentation Overview

- About PCORI
- The What, Why and How of Engagement
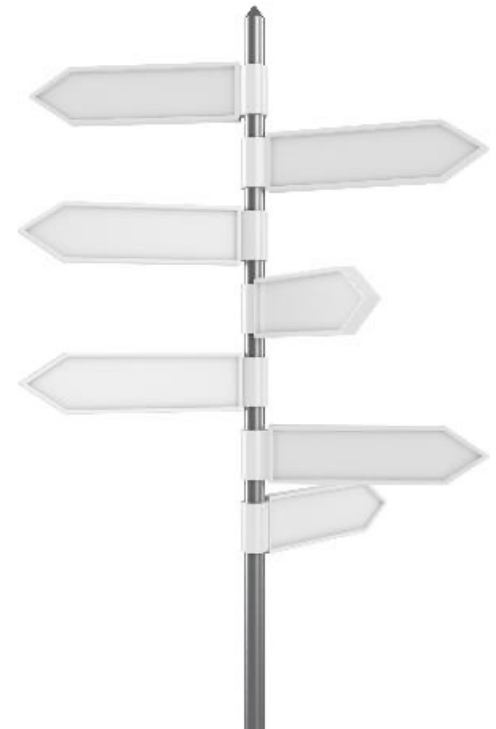- Engage with PCORI

About PCORI

- **The Patient-Centered Outcomes Research Institute (PCORI)** was authorized by Congress in 2010 and is governed by a 21-member Board of Governors representing the entire healthcare community

- PCORI funds **comparative clinical effectiveness research (CER)** that engages patients, caregivers, and other stakeholders throughout the entire research process

- What works best for **YOU**

How is PCORI's Work Different?

- We focus on **answering questions most important to patients** and those who care for them.

- We aim to produce evidence that can be easily applied in **real-world settings**.

- We engage patients, caregivers, clinicians, insurers, employers, and other stakeholders throughout the research process.

The What, Why, and How of Engagement

Core to our mission

"Patient-centeredness"

- Addresses outcomes (both benefits and harms) that are important to patients
- The interventions proposed for comparison are currently available to patients
- Study design is low-burden to participants

"Patient and stakeholder engagement"

- Patients and stakeholders are partners in research, not only "subjects"

- Can occur by building upon existing relationships, or developing new ones

- Leverages the expertise of patients, clinicians and other stakeholders for the purpose of improving study design and conduct

- Includes a range of engagement approaches: input, consultation, collaboration, shared leadership

Engagement Makes a Difference

PCORI has shown that engagement makes meaningful differences in studies'

User-Orientation & Acceptability: studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs

Feasibility: interventions, enrollment, and data collection that are more doable in real-world settings

Study Quality: study rigor, comprehensiveness, and quality of materials and products

Relevance: results applicable and important for decision-making

Engagement Scope & Quality: engagement processes are effective, and stakeholders are well equipped

Forsythe LP, Carman KL, et al. Patient Engagement In Research: Early Findings From The Patient-Centered Outcomes Research Institute. Health Aff (Millwood). 2019 Mar;38(3):359-367; PCORI Board of Governors Meeting, December 9, 2019, https://www.pcori.org/sites/default/files/PCORI-Board-Meeting-Presentation-Slides-120919.pdf, p. 32-69

Reciprocal Relationships

Roles and decision-making authority of all research partners, including the patient and other stakeholder partners, are defined collaboratively and clearly stated.

Co-Learning

The goal is not to turn patients or other stakeholder partners into researchers, but to help them understand the research process; likewise, the research team will learn about patient-centeredness and patient engagement.

Engagement Principles

Partnerships

Time and contributions of patient and other stakeholder partners are valued and demonstrated in fair financial compensation and reasonable requests for time commitment. There is commitment to diversity across project activities and demonstrated cultural competency.

Transparency, Honesty, and Trust

Major decisions are made inclusively, and information is shared readily with all research partners. Patients, other stakeholders, and researchers are committed to open and honest communication with one another.

Engagement in Research: How?

- There are a variety of approaches to engaging patient and stakeholder partners in research
  - Stakeholders can serve on ad hoc working groups to prioritize unanswered research questions or develop dissemination strategies for study results
  - They can also have more sustained involvement in a study, providing their input and guidance by serving on an advisory committee or as a co-investigator
- Much like the approaches, there is also variability with respect to level or intensity in which partners are engaged.

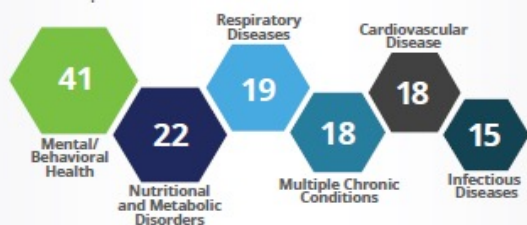# PCORI's Investment in Research Related to Addressing Disparities

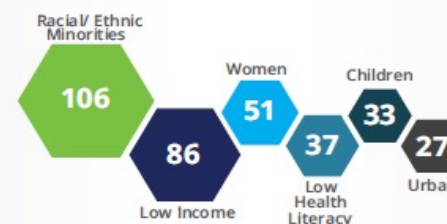As of December 2021, PCORI has awarded

$**440** MILLION TO FUND **120**

comparative clinical effectiveness research studies related to addressing disparities.

Most Studied Health Condition Disparities

- Mental/Behavioral Health: 41
- Nutritional and Metabolic Disorders: 22
- Respiratory Diseases: 19
- Multiple Chronic Conditions: 18
- Cardiovascular Disease: 18
- Infectious Diseases: 15

*A project may address more than one condition

Most Studied Populations of Interest

- Racial/Ethnic Minorities: 106
- Low Income: 86
- Women: 51
- Low Health Literacy: 37
- Children: 33
- Urban: 27

*A project may study more than one population

Getting Involved with PCORI

PCORI Engagement Awards

https://www.pcori.org/engagement/eugene-washington-pcori-engagement-awards

Other PCORI Engagement Opportunities

- **Merit Reviewers**
  - PCORI invites patients, caregivers, clinicians and other stakeholders who are passionate and committed about PCOR to serve as merit reviewers for PCORI.
  - Applications are accepted on a rolling basis.
  - Learn more: www.pcori.org/engagement/engage-us/become-merit-reviewer

- **Ambassador Program**
  - The PCORI Ambassador Program is a national, volunteer network of healthcare stakeholders aiming to shift the culture of health research to be more patient centered.
    - There are no educational or certification requirements to become a PCORI Ambassador.

Learning Packages to Support Multi-Stakeholder Research Teams

Research Fundamentals

- Provides **foundational knowledge in PCOR/CER** to **nonscientist participants** on research and other projects.
- **Free and publicly available at** https://pcori.org/research-fundamentals

Building Effective Multi-Stakeholder Research Teams

- For **new and experienced researchers and stakeholder partners**, offers **practical guidance and resources to support multi-stakeholder teams** in effectively working together.

PCORI invites you to engage with us

pcori®

Please consider expanding your commitment to engagement in health research through:

- **Eugene Washington PCORI Engagement Award Program**
- Ambassador Program
- Merit Review
- Peer Review
- Meetings and Events
- Engagement Resources
- Stay Up-to-Date!

For more information visit: www.pcori.org

Contact Information

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🌐 www.pcori.org

🐦 @pcori

f /PCORInstitute

in PCORI

v /pcori

Thank You!

Q&A

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE®

- Marie Abraham: mabraham@ipfcc.org
- Ushma Patel: upatel@ipfcc.org
- www.ipfcc.org

SMART FROM THE START

- https://smartfromthestart.org/

Patient-Centered Outcomes Research Institute:

- www.pcori.org

Thank You

Please complete the survey here:
https://www.surveymonkey.com/r/DNV8KW2