

# MEASUREMENT MATTERS

## FOCUS GROUP SNAPSHOT



Thank you for participating in Focus Groups!  
Key findings are summarized below\*

### Overview

Measurement Matters is a project funded by the Patient Centered Outcomes Research Institute (PCORI) (SOE-2022C2-28570). Measurement Matters aims to better understand what “engaged research” looks like and build a tool to measure it. We used Focus Groups as one of several methods to do this.

### Focus Group Methods

The research team engaged 34 engagement experts across six 90-minute Zoom Focus Groups. We asked focus group participants, including researchers, facilitators, and patient/partners, to respond to the following areas:

- Defining Engaged Research
- Identifying Successful Engagement Elements
- Exploring Ease and Difficulty in Implementation
- Discussing Possible Outcomes

### Participant Demographics

	Researchers	Facilitators	Patient / Partners**
<b>Participants</b>	n=12	n=12	n=10
<b>Median Age</b>	54	44	66
<b>Self-Identified Race/Ethnicities</b>	American Indian or Alaska Native (1) Black or African American (1) White (11)	American Indian or Alaska Native (1) Asian (2) White (10)	Asian (1) Black/African American (3) Hispanic or Latin(o/a/x) (2) White (5)
<b>Self-Identified Gender Identities</b>	Female (8) Male (4)	Female (9) Genderqueer (1) Male (2)	Female (9) Male (1)

\*\*Given the lower representation of patient partner voices, the research team hosted one additional focus group for patient partners reported below.

### Focus Group Findings

Focus Group Participants reviewed the following definition:

“Engaged research is the active partnership of researchers and individuals with diverse lived experience to do research that communities feel matters and is relevant to their needs. It may include partnerships in:

- identifying research priorities
- designing and implementing research
- interpreting, sharing, and acting on findings to ensure community priorities are met through research.”

Participants acknowledged the complexity of defining engaged research. They discussed the importance of defining "partnership" and using plain language.

Participants discussed their experiences with engaged research, including experiences related to:

- Engagement Phases and Levels
- Environments Ready for Engagement
- People Conducting Engagement
- Practices Important to Engagement
- Prioritizing Diversity and Lived Experience
- Outcomes of Successful Engaged Research

Participants agreed that patients and community partners should be engaged at all phases of a project. Participants also noted research environments must be well-resourced and ready to share power. In addition, participants highlighted the importance of ensuring effective communication, incentives, accessibility, and dedicated the required time and resources for engagement.

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“... *The best engagement that I've seen is engagement where the research partners and community get something out of it, even beyond the compensation for their time, where they're deriving meaning from it, or they gain information that is important to them.* ”

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Participants noted specific characteristics of the people conducting high quality engagement. This included being humble, knowledgeable, genuine, ready to share power, and okay with conflict.

Participants agreed that prioritizing diversity and lived experience is important and can be done by going directly to communities to learn from and engage community leaders and members; engaging communities as team members, and being okay with differences in thought.

Participants shared that engagement outcomes, such as improved trust, improved clinical outcomes, feeling valued, and research aligning with community priorities, are indications of successful engagement.

Participants also considered factors easy to do and hard to do in engagement that emerged from the [Consensus Methods Surveys](#). They described trust-building, seeking diversity and lived experience, power sharing, and being transparent in communication as difficult to do.

## Supplemental Focus Group

Due to slightly lower representation of patient and/or community partners voices in focus groups, the research team hosted one additional focus group for patient and community partners, including [PCORI Ambassadors](#).

## Additional Participant Demographics

<b>Participants</b>	n=8
<b>Median Age</b>	63
<b>Self-Identified Race/ Ethnicities</b>	Black or African American (3) White (5) Hispanic or Latino/Latina/Latinx (1)
<b>Self-Identified Gender Identities</b>	Female/Woman (6), Male (2)

Participants in this focus group prioritized discussions specific to:

- Practices Important to Engagement
- Prioritizing Diversity and Lived Experience
- Engagement Across All Phases
- Outcomes of Successful Engaged Research

### *Practices Important to Engagement*

**Effective Communication**, including clarity, transparency, active listening, and feedback loops

**Clarifying Roles and Responsibilities**, specifically in researcher expectations for partners

**Developing Partnerships** through accountability, honesty, and shared goals

**Investing Time** since it takes time to travel to and from meetings, to prepare for meetings, and to provide support in preparation for meetings

### *Prioritizing Diversity and Lived Experience*

**Recognizing Diversity and Lived Experience as expertise**, which means recognizing patient and community member credentials as being as important as researchers' credentials

**Avoiding Tokenism** where researchers choose participants based on their physical or racial characteristics or due to quotas rather than for their capabilities, qualifications, or personal experience

**Addressing Obstacles**, including minimal time spent thoughtfully defining research communities, funders not requiring diversity plans, and the recent anti-Diversity, Equity, and Inclusion (DEI) climate

### *Engagement Across All Phases*

**Involving Partners** at every phase of a project and ensuring ample funding for this at each phase

### *Outcomes of Engaged Research*

**Outcomes of Effective Engagement** can include improved trust in research, improved research methods, and improved clinical practices