



Measurement Matters

Focus Group Findings Report

August 2024

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Background and Methods

Background

The engagement of older adults and individuals with chronic conditions to drive research design, implementation, and dissemination is gaining increased attention among funders, policymakers, researchers, and community advocates. While numerous engagement frameworks exist to guide this work, many researchers lack clarity on how to operationalize these frameworks, creating frustrations among those who try and within the communities they seek to engage. To address this gap in knowledge, the Measurement Matters project, funded by a Patient Centered Outcomes Research Institute (PCORI) Research Award (SOE-2022C2-28570), is creating and testing a comprehensive tool to measure engagement activities and their potential impact on research outcomes. In 2024, the Measurement Matters research team worked in partnership with Technical Advisors and a Steering Committee to conduct a literature scan and implement consensus methods and focus groups to inform tool development. In 2025, the research team will test a new engagement measurement tool with researchers from the National Patient-Centered Clinical Research Network (PCORnet) – a network of diverse healthcare institutions across the U.S committed to patient-centered research. This report provides a summary of the focus group methods used for Measurement Matters and the findings that resulted from this work.

Focus Group Methods

The research team used focus groups to engage a diverse group of experts to inform measurement development. Experts, for the purpose of this study, included individuals with experience applying or participating in research engagement activities. More specifically, focus group participants were people who conduct engaged research (e.g., researchers and facilitators) and people who have been engaged (e.g., patient partners and community partners). Focus groups participants were required to live in the United States, be at least 18 years old, and complete a survey in English.

The research team partnered with [Technical Advisors](#) and [Steering Committee](#) members to inform the focus group [protocol](#) and outreach materials. Advisors provided insight into challenges presented by this methodology, identified missing or unclear concepts of data collection, and promoted meaningful integration of diversity, equity, and inclusion principles in our protocol, facilitation guide, and outreach materials.

The project’s Qualitative Research Lead facilitated focus groups using Zoom, each of which lasted up to 90 minutes. The facilitation guide addressed four priority areas: 1) the definition of engaged research; 2) key elements of successful engagement by importance; 3) elements that are easy and hard to do; and 4) possible outcomes. All participants had the option to receive a \$50 gift card in recognition of their time. The research team audio recorded the focus groups for transcription and uploaded the transcripts to NVivo Qualitative Data Analysis. Two members of the research team coded focus group transcripts. One additional research team member shadowed throughout the coding process and validated coding decisions as a mentoring opportunity.

The Qualitative Research Lead queried codes across the two coders to determine commonalities and differences, which informed the final compilation of findings and report writing. The data reflects over 1,000 data points coded across 6 focus groups,

Primary Codes	Focus Groups	Total References
Approach for Engagement	6	610
Outcomes of Engagement	6	352
People Doing Engagement	6	166
Reflections on Slides	6	171
Diversity & Lived Experience	6	118
Environment of Engagement	6	117
Phases and Levels of Engagement	6	61
Definition of Engagement	6	46



including 7 primary codes and over 300 secondary and tertiary codes.

Focus Group Selection and Participation

The research team, in collaboration with Technical Advisors, designed and disseminated the following tools to support focus group outreach and participant selection:

- An [Overview](#), targeted at our outreach partners, which briefly explains the purpose of the study, how the information will be used, and who we seek to enroll.
- An [Outreach Flyer](#), which explains our study goals, who is invited to participate, what participants will be asked to do, timeframe for participation, compensation for participation, and how to sign up.
- An [Interest Form](#), which is an electronic sign-up tool linked to the Outreach Flyer

A total of 55 people completed the focus group Interest Form over a period of three weeks. Of the 55, 42 met study criteria and were invited to participate. The research team assigned participants into one of three categories based on their primary lens and hosted a total of six focus groups, two groups for each primary lens. Of the 42 invited to participate, 34 people attended a focus group. Focus group participant characteristics are noted in **Table 1**.

Table 1: Participant Demographics

	Researchers	Facilitators	Patient / Partners
Participants (N=34)	n=12	n=12	n=10
Median Age	54 (age range 30 – 65)	44 (age range 27 – 80)	66 (age range 27 – 75)
Self-Identified Race/ Ethnicities*	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 Latino/Latina/Latinx (2) White (5)
Self-Identified Gender Identities	Female (8) Male (4)	Female (9) Genderqueer (1) Male (2)	Female (9) Male (1)
Self-Reported States Represented (17)	Florida (1), Illinois (1), Massachusetts (4), New York (1), Pennsylvania (4), Washington (1)	Alabama (1), Alaska (1), Kentucky (1), Maryland (1), Massachusetts (4), Mississippi (1), New Jersey (1), New York (1), Wisconsin (1)	California (2), Massachusetts (6), Mississippi (1), New York (1)

*Participants were able to select more than one

Supplemental Focus Group to Expand Diversity

The goal for focus group representation was to have no less than three of the focus groups represent patient partner and/or community voices, with a priority placed on individuals who have unique diversity, equity, or inclusion experiences. Given the low representation of patient partner voices in one focus group (n=2) and the minimal diversity found within the researcher and facilitator focus groups, the research team hosted one additional focus group for patient partners. The research team partnered with [PCORI Ambassadors](#) and our Technical Advisors to recruit patient partners from diverse communities for a seventh focus group. The research team modified focus group facilitation to account for lessons learned from the previous focus groups, including less emphasis on reviewing existing domains and more emphasis on sharing patient experiences with research engagement to shed light on domains' level of import and ease. This supplemental focus group was analyzed



independently of the initial six focus groups, and findings from this supplemental focus group can be found in Appendix A.

Focus Group Findings

Focus group participants provided insights into many elements of engaged research. For reporting purposes and to inform the development of a comprehensive measurement scale, findings were grouped into eight report sections, as presented below.



Within this report, many topics are relevant to more than one primary node, and because of this, some topics surface in more than one section of this report. While this may seem repetitive to a reader, this repetition of concepts remains in this report to accurately present findings and demonstrate the interconnectedness of engagement skills, practices, and environments.

Engagement Definition

The focus group facilitator presented a working definition of engaged research to participants, which was informed by PCORI's definition (2014) and findings from two consensus method surveys. The definition presented to focus group participants was:

“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.”

While participants were asked to review this definition at the beginning of each focus group, participants' reflections on this definition were delayed to the closing of each group to allow time for broader engagement discussions. When faced with this definition, participants across all focus groups recognized the complexity of



defining engaged research (6 sources, 46 references)¹. Focus group participants commented on the use of the word partnership (4, 8), the research phases described in the definition (4, 8), and the importance of plain language (4, 6) so that the definition is understood by all parties. More specifically, participants discussed using the phrase “active partnership” to represent the “balance of power within partners.” In terms of research phases, participants reflected on the importance of acting on findings to round out the engagement process. Participants also discussed the application of lived experience (3, 8). One participant recommended broadening the use of “diverse lived experience” to something like “variety of lived experiences” to simplify the definition and to allow more people to be represented.

Two of the six focus groups also discussed the importance of centering community priorities (2, 4) within the definition. Participants noted the importance of remaining flexible and learning these priorities in different settings to inform the research process. Participants also discussed the importance of operationalizing the definition (2, 2). Some participants cautioned that a definition this broad may not signal to partners that engaged research is for them if the specific focus of the research (1, 1) or outcomes expected (1, 2) are not clearly articulated.

Engagement Phases and Levels

Without specific prompts, participants within all six focus groups recognized the importance of engagement in various phases of research (6, 61). Participants from all six focus groups noted that communities should be engaged in the dissemination process (6, 15) as this is an important way to demonstrate commitment to

“... High engagement includes multiple stakeholders, multiple stakeholder groups, because if you only have the voice of one person, and that one person is representing thousands of people, it's not really engagement...When I say stakeholders, it's also at multiple levels.”

communities impacted. Participants in four focus groups discussed the importance of conducting engagement during research design, including in the design of research questions (4, 21). Participants also agreed that engaging community partners early and throughout the entire research process (4, 14) creates the most opportunities for research to be informed by communities’ priorities.

Participants within three of the six focus groups also discussed various levels in which engagement can occur (3, 11). For instance, participants discussed the importance of involving individuals, communities, community organizations, nonprofit organizations, or community leaders (2, 7). Participants also discussed the role of academic institutions in facilitating engagement (2, 3) and peer organizations in supporting outreach and diversity (2, 2).

Environments Ready for Engagement

Participants discussed environmental characteristics that can influence the existence and quality engagement (6, 117). These characteristics, which are power sharing climates, organizational buy-in and readiness for change, and funding for engagement, are described in more detail below.

¹ Figures in parentheses indicate the total number of groups and individual responses provided by theme. The first figure identifies the number of meetings in which the theme was stated out of a possible six focus groups. The second figure represents the number of times each theme or subtheme was stated across all focus groups.

“... I really liked your definition of engaged research for where we are now. And it feels like one always starts with something that's operational and you move towards aspirational...”



Power Sharing Climates

Participants across all six focus groups discussed how engagement works best in environments where people are willing to share power (6, 42). Power sharing environments reportedly value diversity and lived experience (3, 7) and prioritize trust and relationship building (4, 7). Power sharing environments also reportedly spend time carving out specific opportunities and roles for community partners to inform decision making, including informing decisions specific to the focus of research, data that will be collected, and data that will be shared (4, 14). Overall, participants point to engagement flourishing in an environment where all parties – especially those who typically sit in seats of power – stand ready to adjust to ways of doing research based on partners’ goals and interests.

Organizational Buy-In and Readiness for Change

Participants in five focus groups discussed organizational buy-in or support for engagement as factors influencing quality engagement (5, 45). Participants sometimes linked this buy-in or support to organizations’ willingness to dedicate infrastructure, staff, and resources to engagement (4, 12). Participants from three focus groups discussed how organizational ‘top-down’ approaches or an unwillingness to recognize lived experience as expertise are barriers to effective engagement (3, 9).

Similarly, participants shared that engagement often

means that organizations, including leaders and funders, have to be willing to embrace a new way of doing things in order to find success (3, 6) and be willing to hold their organization accountable (2, 3) for ensuring recommendations that come from engagement do not simply ‘sit on a shelf’ (2, 2). Participants pointed to organizations having policies and a clear plan for implementing engagement (3, 4) as indicators of leadership buy-in and accountability (3, 4).

“I think that probably the most difficult part for a lot of researchers or organizations that are trying to carry out engaged research is being humble and sort of stepping back and letting the community take charge in whatever you are doing. I think that can be really difficult and unnatural for researchers or organizations that are doing research.”

Funding for Engagement

Participants across four focus groups discussed environments where funding for engagement was allocated and the obstacles faced in engagement when money is not allocated (4, 25). Some participants discussed funders who specifically fund and value engagement, including PCORI and NIH, and how that is helpful to getting engagement off the ground (3, 8). Others spoke about inequalities in funding, sharing that larger organizations are more equipped to conduct engagement because they tend to have larger budgets than smaller, more grassroots organizations who may have closer ties to communities (1, 2). Participants mentioned that funders’ inflexible expectations can hinder engagement if funders’ goals do not align with partners’ feedback. Funders, in an ideal environment, would offer flexible mechanisms for prioritizing community engagement in projects (3, 6).

People Conducting Engagement

Frequent topics of conversation among focus group participants were the traits and behaviors they believe are important for people to have when leading engagement activities (6, 90). Specifically, participants described the importance of being genuine or authentic; ready to share power; vulnerable, appreciative, humble, and kind; culturally and linguistically competent; knowledgeable of effective meeting practices; and being OK with conflict and unknowns as characteristics associated with high quality engagement. The characteristics are further described below.



Being Genuine or Authentic

Participants across the majority of focus groups shared that engagement works well when the people running engagement activities are genuine and authentic in mindset (5, 30). When describing the importance of people being “genuine” or “authentic,” participants in five focus groups linked this descriptor to the act of being clear and transparent in communication (5, 11). Participants in three focus groups linked this descriptor to researchers being honest about the research goals and their own intentions (3, 6) as well as being able to demonstrate engagement impact (3, 7). According to one participant:

“...You need to tell people what it looks like, what it means practically, to act on that value. Otherwise, it’s just going to feel like marketing. To me, what it actually LOOKS LIKE to value diversity and lived experience is to practice cultural and linguistic competence and humility by doing things like using clear and transparent communication that takes into account the actual words and language people use in their lives...”

Being Ready to Share Power

Within four of the focus groups, participants discussed the importance of those conducting engagement (not just their organizations) being ready to share power (4, 11). Participants primarily explained ‘power sharing’ to mean leaving space for others to express themselves during engagement activities. As one participant described, power-sharing leads to healthier collaborative environments where, “I don't have to agree with you, but I hear your perspective, and I respect your perspective. And maybe then we can find mutuality and get to an outcome that works.” Some participants expressed that it takes time and resources (such as increased funding or a trained facilitator) to effectively shift the balance of power from people who have historically led research studies to those who have lived expertise.

Being Vulnerable, Appreciative, Humble, and Kind

Participants within three focus groups told us that they appreciate when people who conduct engaged research

“Just genuinely being friendly. And then also something I’ve learned through my experiences on these past projects is trying to be very human and kind in day-to-day regular communications with people and not being so corporate or research-y... opening up, sharing things about yourself, your family, and just being kind...”

are open to being vulnerable and sharing something about themselves (3, 5). One participant pointed out that community and patient partners are typically expected to share themselves in service to the research, and researchers’ willingness to open themselves on a more personal level can help balance the partnership. In addition, researchers discussed the importance of appreciating the time investment others make to a research project (1, 1). Participants indicated that researchers should be humble (2, 3), kind (1, 4), and self-reflective and aware of their own biases (1, 2). As one

participant put it, “just being kind can help you overcome a lot of the mistakes you might make along the way in engagement.”

Being Culturally and Linguistically Competent

Participants within three focus groups discussed the importance of people having cultural and linguistic competencies when conducting successful engagement (3, 9). Some participants described how cultural and linguistic competence can be demonstrated, such as through the use plain language and terms that are preferred by the group with whom they are working. Other participants used the term cultural and linguistic “humility” while describing the importance of researchers being self-reflective of positions of power and the stigma or trauma that



the communities previously experienced, which informs researchers’ steps for creating a safe and supportive environment for engagement.

Being Knowledgeable of Effective Meeting Practices

Participants within three focus groups discussed the importance of people being able to organize and run a strong meeting (3, 4). More specifically, participants discussed the importance of being able to hold meetings in spaces that are fully accessible. Participants also suggested that whoever leads engagement activities listen to how and where partners prefer to meet and design the meetings around these cues. One participant also suggested that different roles are important to ensuring an effective meeting, and it is important to know the role to which one is best suited, including leading or coordinating meetings.

Being OK with Conflict and Unknowns

Participants within three focus groups discussed the importance of people being able to embrace and navigate conflict as well as being comfortable with the unknown (3, 4). Participants shared examples from their own experiences where leaders’ ability to acknowledge and sit with differing opinions led to success because it signaled that everyone had space to express themselves, ultimately leading to a more engaged group. Additionally, one participant shared that leaders of engagement should be open to unexpected research results, noting “...we need to make sure we're not losing something because we want to get certain results... We really let the research go where it needs to go.”

People Conducting Engagement Characteristic Referenced	Number of Groups	Focus Group Lenses
Being Genuine or Authentic	5 Focus Groups	All
Being Ready to Share Power	4 Focus Groups	All
Being Vulnerable, Appreciative, Humble, and Kind	3 Focus Groups	All
Being Culturally and Linguistically Competent	3 Focus Groups	Facilitators, Researchers
Being Knowledgeable of Effective Meeting Practices	3 Focus Groups	Facilitators, Patient Partners
Being OK with Conflict and Unknowns	3 Focus Groups	Researchers, Patient Partners

Practices Important to Engagement

Participants across all six focus groups discussed practices they believe are important to doing engagement successfully (6, 610). More specifically, focus group participants discussed the importance of dedicating the time and resources needed for engagement; ensuring clear communication and accessibility; ensuring effective facilitation; providing incentives; seeking shared purpose and decision making; and providing education and training, all of which are described below.

Dedicating the Required Time and Resources

Across all six focus groups, participants discussed the importance of devoting time and resources to conduct engagement (6, 149). More specifically, participants discussed the importance of research teams having dedicated staff (6, 27) to support community partners, including to act as a primary point of contact, managing accommodations for participants, and generally serving as an advocate for community partners’ needs.

Within five of the focus groups, participants discussed the importance of compensation for community partners (5, 43). More specifically, participants noted that community partners should be compensated fairly and in a form



that they can access. For instance, one focus group participant makes a practice of “working closely with people and discussing what is a good option for them” since some may be concerned project payments could put their benefits at risk.

Within five focus groups, participants shared that engaging community partners early and often is key to successful engagement (5, 12), which takes time and resources. Namely, participants shared that engaging community partners early helps build the buy-in necessary to keep the momentum of the project up, and consistent check-ins with community partners at key decision points ensures that partners have ample opportunity to inform the research. Relatedly, participants expressed that successful engagement requires researchers spend time preparing themselves for engagement and orienting participants for their informed participation.

Ensuring Clear Communication

Across all six focus groups, participants discussed the importance of thoughtful communication practices when implementing quality engagement (6, 54). Across all six focus groups, participants noted that strong communication includes transparency from the start on roles and responsibilities, including those associated with engagement goals, time commitments, project deadlines and other details (6, 15). Participants also noted that using different modes of communication are helpful, such as one-on-one communication, in-person and virtual options, as well as modifying the approach to meet the unique styles and preferences of individual partners (4, 11).

“...Researchers and facilitators should be honest about where community/patient partners can impact decisions about the research, and where decisions are fixed due to funding or other immovable influences.”

Participants from all six focus groups also noted the importance of “closing the loop” with participants (6, 20). Focus group participants described this concept as researchers engaging partners to seek input, validate what they hear, and communicate how researchers acted upon what they heard. Closing the loop provides an opportunity to connect with partners who respond better to individual outreach. Unfortunately, participants in two focus groups said that while a feedback loop is important, it frequently does not happen (2, 2). One participant described an experience of closing the loop with quiet community partners who preferred different communication strategies:

“I thought that I was going to hear that maybe they weren't engaged, that they were confused about something or that they didn't feel comfortable participating. But to the contrary, they were just kind of quieter in meetings. They had tons and tons of fantastic ideas that they shared one-on-one that indicated that they cared very much and that they'd been paying attention to and benefiting from the conversation. They just had a different style of interacting.”

Participants also explained this closing of the loop should be timely (4, 8) and include celebration of wins (2, 3). For many participants, these strategies ensure transparency in decision making. As one researcher put it, “...it's not necessarily that you need to do everything that your research partners suggested, but if you're not going to do it, explain why that's going to happen.” Since these honest discussions often include what may not be possible, participants note that sometimes they lead to tense, but important conversations (3, 4).

Making the Process Accessible

Across all six focus groups, participants discussed accessibility as an important element in ensuring effective engagement (6, 134). When discussing accessibility, participants in five focus groups referenced the importance of using plain language (5, 37) when communicating with partners and when developing materials. More specifically, participants discussed how materials should be clear (2, 2), readable by people at different reading levels (2, 2), and easy to understand without being too academic (3, 4), exclusionary (2, 3), or riddled with jargon (2, 2). Participants also discussed the importance of making translation and interpretation available to partners to ensure language is accessible to people of different cultural backgrounds (5, 14). According to participants, translation may require dedicated staff (4, 6) and resources (2, 2), as well as educating funders of the importance of this practice. Focus group participants also noted that those conducting virtual engagement should ensure people have access to the physical hardware, Wi-Fi, and assistance needed to actively participate (2, 3).

“...[Make] sure that not only things are translated, but you have someone who’s a native speaker to really be an intermediary as well, because scientific jargon is not really accessible to a lot of folks.”

Providing Incentives

Participants in all six focus groups discussed the importance of incentives for effective engagement and meeting participation (6, 47). Participants discussed incentives that encourage attendance, such as childcare (4, 8), food (3, 5), and transportation (5, 5). Within four focus groups, participants shared that community partners should receive fair compensation for their roles in a project (4, 6) in one of a few forms, ranging from money (4, 9) and gift cards (2, 4) to scholarships, co-authorship on publications, and career benefit. We learned from focus group participants that the ability to derive meaning (5, 8) or new knowledge (2, 3) from engagement can be valued forms of compensation for some participants. Focus group participants report that researchers should expect compensation preferences to differ by person (2, 3) and that researchers should be prepared to discuss partners’ needs during the project’s development.

“... 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.”

Ensuring Effective Facilitation

Focus group participants across five focus groups discussed the importance of strong meeting facilitation strategies to support successful engagement (5, 55). In four of these focus groups, participants discussed the importance of facilitators being prepared for meeting, partnering with a co-facilitator from the target population, being a good listener, and participating with a humility that recognizes expertise of patient partners (4, 14). According to focus group participants, facilitators should also be flexible and willing to adjust (3, 11) during meetings as well as skilled at addressing conflict (3, 7) and enabling people with different perspectives to share and be heard by others (4, 6). One participant also noted the importance of facilitators taking time during meetings to acknowledge people’s contributions and to celebrate wins. Participants pointed to facilitators’ role reaching far beyond actual meetings, including assuming responsibility for distributing accessible meeting materials (3, 6) in advance of meetings, ensuring a thoughtful room set up (1, 2), and informing participants of their roles and responsibilities (3, 5).



Seeking a Shared Purpose

Within five focus groups, participants spoke about the importance of having a shared purpose or aligned goals among researchers and partners (5, 18). Researchers often have their own goals informed by their research expertise, interest, and funding mandates which may or may not align with the goals, experiences, and interests of those they seek to engage. Both parties, according to focus group participants, have an important role in working as a team (3, 5) in defining and aligning their goals for any given project, which can help minimize disagreements (2, 3) and bring people together on issues for which agreement is difficult (1, 2).

Ensuring Shared Decision Making

Within five focus groups, participants discussed the importance of having a shared decision-making process (5, 46). When discussing shared decision making, participants discussed the importance of beginning engagement early in the research process (3, 7). Participants discussed the importance of gaining consensus from partners (3, 6) rather than seeking rubber stamping approval (3, 6). Participants told us that shared decision-making is difficult to do (2, 2) and requires information sharing so partners are informed (2, 2) and able to contribute appropriately as partners to a project.

“[Projects should bring] people in from the community that you want to get information from to be part of the power group rather than simply the people that you're questioning... there's sort of an inherent snobbery at times from researchers and it's felt.”

Providing Education and Training

Participants within three focus groups spoke about the need for education and training (3, 11). Participants in three focus groups discussed the importance of training and mentoring partners on conducting research (3, 5) as well as the importance of educating academics (3, 4), funders (1, 1). Participants within two focus groups of researchers discussed how the educational experience should be bi-directional, with researchers educating those with lived experience and those with experience educating researchers in a co-learning environment. As one participant told us, “I think we need to train academics how to recognize and utilize the skills and resources and expertise of lived experience experts. And we need to train lived experience experts in the academic paradigm that they’re stepping into if they’re part of a research team.” Focus group participants described unique skills researchers must have that should be considered when conducting training, these include active listening, cultural and linguistic competence (1, 3), and clear communication and plain language skills. Focus group participants also discussed training for community partners, which included an orientation to learn the different roles of partners and mock research collection activities to ensure all parties understand what to expect with data collection.

Practices Important to Engagement	Number of Groups	Focus Group Lenses
Dedicating the Required Time and Resources	6 Focus Groups	All
Ensuring Clear Communication	6 Focus Groups	All
Making the Process Accessible	6 Focus Groups	All
Providing Incentives	6 Focus Group	All
Ensuring Effective Facilitation	5 Focus Groups	All
Seeking a Shared Purpose	5 Focus Groups	All
Ensuring Shared Decision Making	5 Focus Groups	All
Providing Education and Training	3 Focus Groups	Researchers, Facilitators

Prioritizing Diversity and Lived Experience

Prioritizing diversity and lived experience was a major theme that was discussed across focus groups (6, 118). Topics, including the importance of prioritizing diversity and helpful practices to this end, are detailed below.



Various Populations Discussed

Participants across all six focus groups highlighted diversity and lived experience within engaged research partnerships as key to effective engagement. Some participants discussed “diversity” as a general concept and noted that having differing perspectives at the table can lead to conflicting priorities, but ultimately richer research results. Some participants discussed that truly prioritizing diversity means not only ensuring that a mix of people show up to engagement activities, but that they have what they need to be active participants in discussions and decisions. To that end, participants voiced that engagement works best when the partnership is truly participatory – meaning everyone involved – engaged partners, researchers, facilitators, and others – practice sharing power equitably throughout the process.

Participants across four focus groups discussed various population groups, noted in the table below, that should be engaged in research or that they have direct experience engaging (4, 38). Often, participants defined these groups as being historically excluded from decision-making roles in research.

Table 2: Populations Referenced within Focus Groups

Populations Referenced	Number of Groups	Focus Group Lenses
Youth	3 Focus Groups	All
Older Adults	3 Focus Groups	All
People of Color	3 Focus Groups	All
People with Chronic Conditions	2 Focus Groups	Facilitators, Researchers
People who are Justice Impacted	1 Focus Group	Facilitators
People with Mental Health Conditions	1 Focus Group	Researchers
People who Use Medicare/Medicaid	1 Focus Group	Researchers
Rural Communities	1 Focus Group	Facilitators
Tribal Communities	1 Focus Group	Researchers

Helpful Practices When Prioritizing Diversity and Lived Experience

Focus group participants described helpful practices when specifically engaging diverse communities and people with lived experience as project partners (6, 76). These practices are described below.

Dedicate the Time and Resources to Ensure Accessibility. Participants in five focus groups told us that prioritizing diversity means dedicating the time and resources necessary to do it well (5, 18). This includes providing the time and materials to help orient partners. It may also include providing dedicated staff (such as translators) to support peoples’ participation in the process. One participant shared that it is good to have “...a point person who is like their guide throughout a research process... to really support our engaged partner as well so that they can continue on whether the project is long or just continue on with that partnership of your organization.”

“Consensus on every topic suggests that people aren't really embracing and feeling comfortable about fully expressing the path that they've traveled and what it means to them... if you're having too smooth [a] time, I would suggest that there may not be true representation happening.”

Be Ok with Difference Within Communities Engaged. Participants in four focus groups told us that hearing multiple and sometimes conflicting priorities when engaging diverse communities is expected (4, 10). People typically come together in engagement because of a shared interest over the research results. Still, they come to the table with differing beliefs, opinions, and life circumstances. One participant reported that conflicting priorities can at times lead to clashing and can be unconstructive while others shared that disagreement among group members is a good thing because it signals that people are passionate about the issue being researched and that they feel comfortable voicing their true opinions.

Seek Active Participation through Various Methods. Participants in four focus groups discussed the importance of ensuring not just attendance, but active participation when engaging diverse communities (4, 9). Participants shared examples of active participation, including partners asking questions, sharing their stories, and displaying enthusiasm. That said, some participants described how active participation can look different from one person to the next. Participants described how allowing engagement to occur in multiple ways, such as individually and in small groups, can allow for active participation to occur in ways that work for diverse individuals engaged.

Engaging Community Members as Team Members. Participants in four focus groups shared that people with lived experience should not only be engaged to direct or advise the research, but they should be members of the core team responsible for the conducting the engaged research project (4, 5). Others elaborated that they feel it is important that whoever recruits members of the community be reflective of that community or have already established relationships and trust with community members.

Find Ways to Share Power. Participants in three focus groups comprised of researchers and facilitators recognized the importance of not just finding ways to engage diverse communities, but to share power (3, 7). Participants talked about ways in which to encourage power sharing, such as making sure that the physical room set up or where people sit does not signify power differentials, giving people a platform to speak during meetings, and ensuring partners are credited in published papers.

“If you aren't centering power sharing and learning from your participant, then you are... not really valuing diversity and lived experience. No matter if in your heart of hearts that is important to you, you're not doing it.”

Conducting Grassroots Recruitment. Participants in three focus groups shared strategies they use when recruiting partners with lived experience (3, 3). For example, one participant shared their practice of snowball outreach, which includes identifying a core group of partners who then go out and recruit within their networks to join the partnership. Participants discussed the importance of involving different community groups, such as churches, schools, and other community-based organizations, to help outreach while others suggested going to more neutral spaces that community members frequent, such as supermarkets, to recruit. Finally, one participant mentioned the importance of being sensitive to the community's cultural norms when recruiting, such as talking with community elders or other community leaders prior to contacting broader community members. Participants within two focus groups noted the importance of researchers “doing their homework” – preparing – before recruiting others to the project. This includes learning about the community or population's history and other contextual factors.

Avoiding Tokenism. Participants within two of the focus groups discussed the importance of avoiding tokenism when engaging people with lived experience (2, 8). As one participant commented, it is important to ensure an



“equal distribution of people involved, not just a token person with lived experience so they can ‘check the box.’” Researchers also shared that tapping the same individuals repeatedly can lead to overcommitment, and as result, less active engagement (1, 2).

Helpful Practices when Prioritizing Diversity and Lived Experience	Number of Groups	Focus Group Lenses
Dedicate the Time and Resources to Ensure Accessibility	5 Focus Groups	All
Be OK with Difference within Communities Engaged	4 Focus Groups	All
Seek Active Participation through Various Methods	4 Focus Group	All
Engaging Community Members as Team Members	4 Focus Groups	All
Find Ways to Share Power	3 Focus Groups	Facilitators, Researchers
Conducting Grassroots Recruitment	3 Focus Groups	Facilitators, Patient Partners
Avoiding Tokenism	2 Focus Groups	Facilitators, Patient Partners

Outcomes of Engaged Research

Focus group participants discussed outcomes that can occur when engagement is done successfully (6, 352). The outcomes discussed most across all six focus groups were trust and relationship building, active participation of engaged communities, and identifying and prioritizing community priorities. Additionally, participants discussed the importance of partners feeling valued and improved (unspecified) clinical and community outcomes. Focus group participants often discussed how outcomes are driven by enacting the elements of successful research engagement discussed in this report.

Improved Trust and Relationship Building

When discussing outcomes of engagement, the most common topic referenced across all six focus groups was trust and relationship building (6, 111). Participants often told us that trust is most important and without it, none of the goals or outcomes of the project matter. There were numerous factors identified by participants as influencing trust as listed in the table below.

Table 3: Most Cited Factors of Trust and Relationship Building

Factors Influencing Trust and Relationship Building	
Focus Group Frequency	Reference Frequency
Noted in Five Focus Groups	
Creating a Safe Environment, Including Right to Fail	12 references
Researchers / Staff Reflect the Community	12 references
Engagement / Communication Happens Often	7 references
Noted In Four Focus Groups	
Trauma Informed / Authentic Practices	16 references
Just Having Conversations	4 references
Sharing Power	4 references
Noted in Three Focus Groups	
Dedicating a Liaison or Advocate to Process	3 references



Providing Information	3 references
Being Flexible	3 references
Collaborating	3 references
Having Clear Communication	3 references
Noted in Two Focus Groups	
Doing Your Homework	8 references
Going Into the Community	2 references
Listening Well	2 references
Noted in One Focus Groups	
Dedicating Funding	1 reference
Demonstrating Impact, Including Impact on Researcher	1 reference

Most noted concepts relevant to trust and relationship building were creating a safe environment, researchers and staff reflecting the community, and frequent communication. One participant explained the connection between trust, representation, and outcomes when stating, “...partnership is often about trust and making sure that your team looks as much like the group you want to work with as possible” because “...having connections and cultural identities that are responsive to the communities you’re trying to connect with would likely improve the ability to recruit and have good representation.” According to focus group participants, trust and relationship building is also an essential component to healing the atrocities research has committed against marginalized communities and moving both parties into a true partnership.

“...As we’re looking to engage communities and particularly communities of color or communities who have disability and even trans communities, there is a lot of trauma that has been experienced in their interactions with medical research, any of these traditional institutions...the trust and relationship building is key before the rest of these things have even taken place... which means that we are creating the environment for people to have space to speak, as opposed to looking at kids or looking at people as the problem to be fixed.”

Communities Become More Active in Research

Participants in four focus groups described the outcome of active participation (6, 56). Unlike participation in which individuals might be silent participants who sit in the audience, active participation was described by focus group participants as partners having responsibility for project outcomes and, therefore, being integral to design and implementation. One participant described an engaged research project as “horrible, horrible” because “...the people with power took their power and sat up at the front and everybody else sat in the back, which led to everyone in the back either leaving, getting off [of the project], or basically not falling in line with what people wanted.”

People Feel Valued

Participants in four focus groups described the outcome of people feeling valued (6, 35). In successful engagement, engaged partners feel they are an important part of the research project. When partners are valued, their insights and input is received, prioritized, and it becomes part of what matters most to the project. The result of valuing partners and what they bring to a project, according to participants, is that partners are willing to commit to seeing a project’s goals are met with success. As one participant described, partners are also willing to continue to contribute to a project because they feel “their comments are vital so that they’re not wasting their time.”

“A lack of feeling like, you know, we belong. You know, not always paying people for time. Inaccessible meetings, giving lip service, not seeing people with disabilities that are smart. Top-down mentality... they ask for input and yet they already have their decision made up.”

When partners feel they are not valued, it can be difficult to develop trust or any commitment to supporting the project. An important example of demonstrating lack of value, according to one participant, is to rush partners through a process because they are not on the schedule of the research team. They described that this happens “... when you try to rush the meeting along or you get a share from someone and they speak a little bit slower you know, and the group leader just rushes them along... [they] say thank you

and then go on and call the next person without making that person feel like ... their shared experience was something that was utilized or could be utilized.” An important aspect of valuing participants is not just using them in the role that is most convenient, but to also invite them into a partner role in the project where they can have an impact. One participant shared that “people with disabilities must be hired to do research, not just take part in research.” Putting people into true leadership roles is important to demonstrate the value of project partners and, overall, is essential to achieving project outcomes. The opposite of seeing partners as valuable would be relegating them to roles that were pre-determined and do not reflect how their contributions are valued by the research team.

Co-Learning Occurs Across Partners

Participants in six focus groups described the outcome of co-learning (6, 19). In successful engagement, partners come to the table with their own expertise and contributions to the project. As a result, while one partner shares their expertise, others respect that expertise and learn. There is a tendency to expect that expertise only comes through the research team and patients or community partners should expect to learn from the researchers. This perspective fails to recognize the expertise of lived experiences that partners bring and the importance of what they can teach researchers. Participants explained that engaged research projects demonstrate partnership when all parties bring expertise that is recognized, creating an environment in which all partners learn from other partners. One researcher described the outcome of having six months of meetings dedicated to co-learning within an engaged research project: “It was like I learned from the folks who were there, how I needed to change [my language] so we all understood the same terms and the same things ... because then it went into trust and relationship building and the logistics and meeting practices which came out of this co-learning.” As a result, the research team understood the importance of being more accessible and relatable, and the engaged community was better informed and prepared to be partners to the project.

Research Aligns with Community Priorities

Participants in five focus groups described the outcome of research aligning with community priorities (5, 31). In successful engagement, project outcomes are aligned with—and, when possible, derived from—community priorities. The purpose of research should be to demonstrate improvement or elimination of problems faced by the community members. According to focus group participants, if communities are engaged from the start of a project, researchers are able to learn from their expertise what goals and eventual outcomes matter most to the communities they seek to support. Thus, they will be able to ensure alignment between community priorities and the goals of the research effort.

One participant told us: “I feel like my work is in line with community priorities when a project’s done and the question is asked, ‘like, so what’s next?’... it’s sort of a source of pride that, oh, this is maybe a continued relationship in a way that I’m not always the one driving.” This comment underscores that when a project is aligned with the target community’s priorities, the community will feel some ownership of the effort and be deeply invested in seeing successful project outcomes. In some instances, a community may even take initiative in the absence of external influence or with fewer resources because they are committed to seeing an effort succeed. Aligning with

community priorities, according to participants, is to avoid a short-term effort that comes and goes without being of true benefit to that community. Rather, success in both short- and long-term project outcomes is often related to building a long-term relationship with the community and setting community improvements as the goal.

“...The point about research aligned with community priorities, I think like you might know this is working or maybe you're working towards that when like the folks you're working with are actually excited to not only like see the results, but then translate it to whatever they're doing or use the products that you're creating and then maybe even want to take it one step further.”

Clinical or Community Outcomes are Improved

Participants in four focus groups described the outcome of improved community outcomes (4, 17). Additionally, four focus groups identified the importance of clinical outcomes (4,10). In successful engagement, a research project seeks to see improved community or clinical outcomes for the community engaged to address the incidence of conditions that disproportionately affect communities of color. As one participant told us, “I think the purpose of partnership with communities as part of this work is to disrupt the inequities that they're facing, which will only be understood through

reduction in health disparities and better care and wellbeing for these communities too.”

Informing a Measurement Scale

During each focus group, we asked participants to review a slide and answer a series of questions about the content, including what is most important and least important to do and what is the easiest and most difficult to do. Sometimes, responses to these questions were not specific to one element or the other and instead led to participants asking additional questions for clarification or commenting on the complexity and interconnectivity of the elements posed (4, 4). That said, some focus group participants described what they thought was most difficult (6, 12), what were the most important elements and/or what leads to successful engagement (4, 7), and what elements are associated with low or unsuccessful engagement (3, 6). Ranking of each are provided in the table below.



Table 4: Easy, Difficult, Least Important, Most Important, Unsuccessful, and Successful Engagement

Elements Easiest to Do	Elements Most Difficult to Do
<ul style="list-style-type: none"> Dedicating Time and Resources (4,4) Logistics and Meeting Practices (3,7) Clear and Transparent Communication (2,3) Trust and Relationship Building (2,2) Valuing Diversity and Lived Experience (1,1) Collaboration, Co-Learning, Power Sharing (1,1) 	<ul style="list-style-type: none"> Trust and Relationship Building (6, 10) Valuing Diversity and Lived Experience (5,6) Clear and Transparent Communication (4,5) Collaboration, Co-Learning, Power Sharing (4,5) Dedicating Time and Resources (3,4) Logistics and Meeting Practices (2,4) Organizational Readiness (1,1)
Elements Least Important to Do	Elements Most Important to Do
<ul style="list-style-type: none"> Organizational Readiness (1,2) Collaboration, Co-Learning, Power Sharing (1,1) 	<ul style="list-style-type: none"> Trust and Relationship Building (5,8) Collaboration, Co-Learning, Power Sharing (5,6) Clear and Transparent Communication (4,7)

Elements Related to Low or Unsuccessful Engagement	Elements Related to High or Successful Engagement
<ul style="list-style-type: none"> • Power Differential/ Top Down (1,2) • Exploitation (1,1) • Feelings of Not Belonging (1,1) • Unsatisfactory Response to Input (1,1) 	<ul style="list-style-type: none"> • Valuing Diversity and Lived Experience (4,6) • Making a Difference (Outcomes) (3,5) • Dedicating Time and Resources (2,3) • Organizational Readiness (2,2) • Logistics and Meeting Practices (1,1) • Engagement Includes Multiple Methods (2,3) • Engagement Occurs in All Phases (1,1) • Collaboration, Co-Learning, Power Sharing (2,3) • Clear and Transparent Communication (2,2) • Trust and Relationship Building (Safe Space) (1,1) • Valuing Diversity and Lived Experience (1,1) • Researchers Apply What is Learned (1,1)

Closer Look at Most Difficult to Do

Trust and Relationship Building. Participants across all six focus groups cited that building trust and relationships within engagement is difficult to do (6, 10). Some shared that trust and relationship building operates differently depending on the community engaged, so it takes time to find the right approach. Others shared that trust is difficult to gain, especially among communities who have been historically either left out of or harmed by research. Finally, some shared that the ability to build relationships is a skill that not all researchers hold.

Valuing (or Seeking Out) Diversity and Lived Experience. Participants across five focus groups cited centering diversity and lived experience in engaged research as essential, but difficult to do (5, 6). Participants cited the time and effort required to outreach to diverse populations. One person talked about having to “cross geographic boundaries” and look “outside the box” to seek and engage people who are diverse. Also, welcoming diversity to the table means welcoming diversity of opinion, which participants report can lead to conflict. Finally, we heard that valuing diversity means practicing “cultural and linguistic competence,” skills not all researchers have.

Collaboration, Co-Learning, and Power-Sharing. Participants across four focus groups recognized collaboration, co-learning, and/or sharing power as concepts that don’t come easily (4, 5). Sharing power involves sharing decision making, which reportedly is not easy in most contexts where people are passionate about the research topic or may have conflicting priorities. One participant shared, “that’s probably the most difficult part for a lot of researchers or organizations that are trying to carry out engaged research, being humble and stepping back and letting the community take charge in whatever you’re doing.”

Clear and Transparent Communication. Participants in two focus groups cited clear and transparent communication as the most difficult thing to do in engagement (2, 2). Some participants noted that communication styles vary across people and making sure that everyone receives information the way they prefer takes some finesse.



APPENDIX A: MEASUREMENT MATTERS SUPPLEMENTAL FOCUS GROUP PATIENT AND COMMUNITY PARTNER VOICES

Background

In August of 2024, the Measurement Matters research team hosted a supplemental seventh focus group to ensure broader representation of patient partner voices within our focus group findings. The research team partnered with [PCORI Ambassadors](#) and Measurement Matters [Technical Advisors](#) to outreach and identify possible focus group participants. The research team modified facilitation questions to account for lessons learned from the previous focus groups, including less emphasis on reviewing existing domains and more emphasis on understanding patient experiences with engagement to then inform the refinement of domains' level of import and ease. Eight patient or community partners participated in the supplemental focus group. Participants' characteristics ranged in age, race, ethnicity, gender, geographic location, and roles in engagement projects (Table A, below).

Table A: Participant Demographics

Focus Group Participant Demographics	
Participants	N=8
Median Age	63 (age range 32 – 75)
Self-Identified Race/ Ethnicities*	Black or African American (3) White (5) Hispanic or Latino/Latina/Latinx (1)
Self-Identified Gender Identities	Female (5) Male (2) Woman (1) (as self-reported by participant)
Self-Reported States Represented	California, Georgia, Washington, Virginia, Wisconsin, Pennsylvania, Texas

*Participants were able to select more than one

Engagement Phases and Levels

Participants highlighted the importance of engagement across one or more phases of research (1, 38). Most often, participants emphasized the need for patient or community involvement in the project design phase (29). Participants noted various ways for patients or communities to be engaged during project design, including defining the underserved community of interest (6); developing a diversity plan to ensure appropriate patient or community representation (6); designing research questions (4); selecting research methods (4); and supporting grant writing (3). Participants discussed the impact funding practices have on patient and community engagement (10). For instance, participants described how researchers often are required to define their research question or study population early in a project as a condition of funding, typically before participants are engaged. When discussing other phases of research, participants discussed opportunities for patients and communities to assist with research recruitment (4) and creating research materials (2).

Practices Important to Engagement

Clear Communication

Participants highlighted communication as an important factor for successful engagement (47). Participants cited the importance of researchers communicating clearly (12) and transparently (8). Participants also cited the value of researchers being good listeners (9). Some participants proposed that research can be corrected or improved



upon (1) and gaps can be identified and addressed (1) when researchers listen to partners. Conversely, participants described feeling “frustrated” or as if they were “just not getting anywhere” when researchers did not listen (3). Several participants noted how clear and transparent communications help build trust between researchers and partners (2). Participants also noted communication “feedback loops” as essential to effective communication (11), including closing the loop on how their input was applied to research and findings (7).

Clarify Roles and Responsibilities

Participants discussed the importance of clarifying roles and responsibilities (21); specifically, the need for the research to be clear on their researcher expectations for partners (3). Participants suggested that partners do not have to be researchers to bring value to a project (2). In addition, they expressed that roles and responsibilities can evolve over time as the project needs change (1).

Develop Partnerships

Participants cited the importance of developing partnerships with researchers as another element of strong engagement (12) and described some of the specific factors that influence partnerships, including accountability to each other (3) and shared goals (3) built on understanding and established trust (1). Participants also identified open honesty and transparency as integral to establishing partnerships (2). Some participants acknowledged that establishing strong partnerships can be challenging, especially when researchers and partners have different goals, or tensions exist between partners.

Recognize Time Investment

Participants described the time investment required to partner in research (6). Participants discussed the time required to prepare for meetings (1) and to travel to and from meetings (2). Participants also discussed the time researchers need to invest in answering questions and preparing for meetings, with one participant describing how a lack of researcher preparation made the participant want to leave the project (1). Participants also advised that researchers need to be clear with patient and community partners on expectations for time investment (1), including ensuring their partners know it will take time to learn, ask questions (1), and to see progress (1). Participants also discussed the importance of financial compensation for patient and community partners, which reflect the value of their contributions to research (4). Participants also referenced the importance of dedicating time to training (5) and providing accommodations (2).

Prioritizing Diversity and Lived Experience

Defining Lived Experience

Participants consistently raised the need to prioritize diversity and lived experience when conducting engagement (50). Several participants described their own lived experience and how it should be valued as much as professional training (3). For example, one participant described being a caregiver for parents Alzheimer's Disease, which she described as “lived experience which you cannot get in any college institution.” Participants discussed how incorporating the views of those with lived experience can actually help fix research design mistakes built on bias assumptions (1) and can lead to new funding opportunities and ideas (1).

The Reality of Tokenism

Participants discussed tokenism (12) and scenarios in which they were chosen to join a study because of physical or racial characteristics or due to quotas rather than for their unique capabilities, qualifications, or personal experience (2). Participants described situations where researchers invited partners to join a study simply to check



a box or due to funding requirements (1), but refrained from incorporating the partner’s voice (2) or allowing partners to provide meaningful input (1).

Obstacles to Diverse Representation

Many participants noted obstacles to achieving diverse representation in research (11). For instance, participants described times in which researchers did not thoughtfully define their targeted communities, including the diversity that exists within the communities (7). Participants also discussed how funders do not often require diversity plans (3) as a part of their proposals. One participant recalled how she was penalized because she included a diversity plan that was not required, which was then “picked apart” by grant reviewers. Participants also discussed the recent anti-Diversity, Equity, and Inclusion (DEI) climate (1) and how this creates obstacles to supporting diversity in patient and community partners.

Outcomes of Engaged Research

Trust

Participants referenced trust as an important foundational outcome of engagement (19). They shared that engagement works well when there is “bidirectional”—or two-way trust (3). Participants described two-way trust as a “feeling that you add value” and when “trust goes both directions” between partners and researchers. Several participants agreed that trust is established over time (3). Participants shared the importance of seeing their role lead to change (e.g., in study design) as key to trust building (3). Participants also shared that trust is built when there is articulation of shared goals and vision (1), use of plain language (1), and shared experiences (1).

Tension or Conflict

Participants expressed how weak engagement can result in tensions or conflict between researchers and partners (26). Participants cited examples of feeling unseen or unheard (5), including times when there was simultaneous conversations occurring in meetings and when researchers were stuck in their ways. Participants similarly described tensions between researchers and partners due to a lack of clarity of roles (3) and different vision or goals (3), including conflict over training expectations and appropriate times for input. Participants described other causes of tension, included feeling pressured by researchers to be a methodological expert (2); disrespect among community partners; and a lack of overall progress in the project (1).

Improved Research

Participants also reported outcomes related to research process and practice (14). Participants described scenarios where partners helped researchers address gaps in research plans, identify and correct issues in a study, improve education, and streamline processes. Several participants also highlighted how their participation influenced clinical practices (3), with one participant describing how her involvement influenced a medication still used today. Participants also described how their engagement informed the writing of research grants (2), submission of publications (2) and access to programs (1).