CENTER FOR CONSUMER ENGAGEMENT
in health innovation
COMMUNITY CATALYST

November 19, 2021

VIA ELECTRONIC MAIL
Patient-Centered Outcomes Research Institute
1828 L Street, NW, Suite 900
Washington, DC 20036

Dear Sir/Madam,

Community Catalyst respectfully submits the following response to the *Science of Engagement Funding Initiative* Request for Information (RFI). We deeply appreciate the Patient Centered Outcomes Research Institute's (PCORI) commitment to advancing engagement practices within research and its commitment to seeking input on how to best pursue this essential effort.

Community Catalyst is a leading non-profit national health advocacy organization dedicated to advancing a movement for health equity and justice. We partner with local, state and national advocates to leverage and build power so all people can influence decisions that affect their health. Health systems will not be accountable to people without a fully engaged and organized community voice. That's why we work every day to ensure people's interests are represented wherever important decisions about health and health care are made: in communities, state houses and on Capitol Hill. Community Catalyst received a PCORI Engagement Award Project, Patients Lead: Identifying Meaningful Outcomes to Drive Substance Use Disorders Research and Care, a research endeavor which culminated in the April 2021 publication of Peers Speak Out: Priority Outcomes for Substance Use Treatment and Services. This project is the first national examination of treatment and recovery services outcomes prioritized by people with substance use disorders.

The Center for Consumer Engagement in Health Innovation at Community Catalyst (The Center) focuses on health system transformation and bringing the community experience to the forefront of health. The Center works directly with advocates to increase the skills and power they have to establish an effective voice at all levels of the health care system. We collaborate with innovative health plans, hospitals and providers to incorporate individuals' experience into the design of their systems of care. We also work with state and federal policymakers to spur change that makes the health system more responsive to people, particularly those who are most vulnerable.

Overall, we believe the *Science of Engagement Funding Initiative* presents a timely opportunity to advance both PCORI's and Community Catalyst's shared priority of achieving health equity. Everyone deserves a fair opportunity to achieve health regardless of race, ethnicity, income, age, gender identity, sexual orientation, disability or health status, language, or zip code. For too long, structural forms of discrimination and oppression have created and perpetuated health inequities in the United States. These powerful forces are present within the field of research, and

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disproportionately impact Black people, Indigenous people, and other people of color (BIPOC). We strongly recommend PCORI use this initiative to center efforts that reduce health inequities and advance racial justice.

Below, we provide specific responses to PCORI's Request for Information.

In reference to the Potential Topics of Inquiry to Understand the Science of Engagement, you feel these are the right topics? Are other topics or areas of inquiry missing? How would you prioritize or stage addressing these topics?

PCORI has done an excellent job identifying topics of exploration that will meaningfully grow the science of engaged research. Within the proposed topics, equity is represented as an aspect of some of the larger topics. It is our view that equity is the most important area of inquiry within the science of engaged research, and it should therefore be an essential and integral component of all of the other topics of exploration proposed by PCORI.

Community Catalyst's principles and approaches to engagement support an engagement model that aspires towards co-ownership and power-building whenever possible. While we recognize that engagement occurs across a spectrum, engagement at its core is a value-driven process centered on *transparency*, *inclusivity*, *respect, investment*, and *equity*. As such, we recommend that future PCORI projects strive towards achieving partnership with community members in all research cycles. Accordingly, ensuring communities and people with lived experience of the subject matter are engaged in ways that center their voice, promote co-ownership and share power in all research processes should also be embedded in each proposed topic.

What methods and study designs would be appropriate for producing evidence to address the areas identified in the Potential Topics of Inquiry to Understand the Science of Engagement table? Can you provide any illustrative examples?

A paradigm shift is needed in health research from short-term transactional thinking to long-term power-building in communities. This is especially true in engaged health research, which requires the development of long-standing community relationships and the empowerment of communities within health systems in order to be truly meaningful. This paradigm shift requires upfront investment from research funders in order to prioritize relationships, especially where institutional harm has occurred. This investment must be done with the intention of partnering with communities and lending institutional knowledge and tools to build skills and create ownership of the health system issues that communities feel need addressing. Without this relational focus, community knowledge is left to the wayside and institutional knowledge falls short of getting to the root cause of issues. Both communities and institutions have much to learn from each other if treated as equals in the research process. Participatory research exemplifies this approach, particularly the models of community-based participatory research and participatory action research. These value-driven research approaches center empowerment, mutual learning, and public interest; we recommend PCORI continue to fund CBPR specifically, and to use participatory research in PCORI funded projects whenever possible.

Additionally, engaged research literature reveals an alarming trend; analysis and evaluation of engagement is typically limited to the perspective of the researcher.[1] However, the people closest to the problem are the closest to the solution – without their voices meaningful change and innovation within research will not happen. In every research method or design, particular attention must be given to the experiences of the people who are directly impacted – their voices should be at the center. For example, Community Catalyst's PCORI-funded Peers Speak Out – the first research effort to identify treatment outcomes prioritized by people with substance use disorders – centered people with substance use challenges/people in recovery through forming a diverse National Peer Council to inform, guide, and shape project activities. See pages 9-11 of the Peers Speak Out report for further details on the Peer Council and other engagement of people with lived experience of substance use challenges through an online survey and focus groups. Another example is Community Catalyst's work with the Urban Institute on the Leveraging Community Expertise to Advance Health Equity project, where a consumer advisory board was engaged throughout the research cycle. An important finding from this work, is that incorporating equity and racial justice into research begins with the forming of a diverse research team. We recommend PCORI funded projects use both Child Trend's guide and Urban Institutes guide to incorporating racial equity into research.

Further, when considering research methods and design, we recommend that the planning and engagement processes prioritize the voices of people with lived experience of the research topic. These stages should be appropriately resourced in the research cycle. In addition to outcomes, the phenomenological experience of engagement for both stakeholders and researchers should be closely paid attention to and documented.

We also recommend that third-party evaluators with knowledge and expertise in engagement be involved whenever possible. This allows evaluation to be more attuned specifically to engagement while at the same time reducing the potential for conflict of interest. The use of third-party engagement experts should also be considered beyond evaluation and may prove useful in supporting stakeholders as well as researchers.

What innovations in research approaches are needed to most effectively produce the evidence needed?

Engaged research often occurs in siloes, resulting in inconsistent measurements, varying processes and challenges in generalizing findings.[2] One factor that contributes to this phenomenon is that there is no universally applicable model for engagement. This is for good reason; successful engagement requires a localized framework which focuses on co-creation and co-design with the engaged community members.[3] In order to reduce siloes while allowing for

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[1] Heckert, A., Forsythe, L. P., Carman, K. L., Frank, L., Hemphill, R., Elstad, E. A., Esmail, L., & Lesch, J. K. (2020). Researchers, patients, and other stakeholders' perspectives on challenges to and strategies for Engagement. *Research Involvement and Engagement*, *6*(1). https://doi.org/10.1186/s40900-020-00227-0

[2] Faulkner, S. D., Pittens, C. A., Goedhart, N. S., Davies, E. H., Manning, E., Diaz-Ponce, A., Jose Vicente Edo, M., Prieto-Remón, L., Husain, L., Huberman, K., Boudes, M., & Subramaniam, M. (2021). Optimising multi-stakeholder practices in patient engagement: A gap analysis to enable focused evolution of patient engagement in the development and lifecycle management of medicines. *Therapeutic Innovation & Regulatory Science*, *55*(6), 1165–1179. https://doi.org/10.1007/s43441-021-00313-9

[3] Greenhalgh, T., Hinton, L., Finlay, T., Macfarlane, A., Fahy, N., Clyde, B., & Chant, A. (2019). Frameworks for supporting patient and public involvement in research: Systematic Review and co-design pilot. *Health Expectations*, *22*(4), 785–801. https://doi.org/10.1111/hex.12888

localized approaches, Community Catalyst recommends that PCORI consider implementing learning cohorts across studies. Developing learning cohorts has the potential to create real-time networks of engagement innovation and information sharing. Learning cohorts could include engaged stakeholders connecting with their counterparts from other research projects for support, troubleshooting, and idea sharing. Similarly, researchers who are planning, implementing, and participating in engaged research could connect with fellow researchers to share lessons and promising practices.

The implementation of learning cohorts could create a more sustainable and far-reaching national network of engaged stakeholders and researchers while offering unique research opportunities. Cohorts could allow PCORI to explore using multiple studies within a study as a way to compare effectiveness. For example, a group of stakeholders and or researchers from several different studies could convene as a cohort to share knowledge, support each other and troubleshoot. In turn, outcomes, processes and experiences can then be compared and contrasted on an individual level and group level across the cohort.

What outcomes are important and appropriate for studies of engagement? What measures are most important to develop, validate, and use to quantify and to understand the quality and impacts of patient and stakeholder engagement in health research?

What is measured often gets the most attention. In terms of engagement, what is measured also needs to be directly related to why the engagement is being pursued. We suggest that engagement be pursued with the underlying goals of community empowerment and community power-building. In turn, we recommend that measures reflect how well engagement achieves these goals, including how the engaged community defines successful engagement. This latter endeavor requires that institutional knowledge and the knowledge from the collective experience of community be placed on equal footing to co-create measures. This framework also requires analysis of planning, processes, and experiences of engagement in addition to outcomes.

Process and outcome measures to assess engagement should focus on the experiences of equity, power and social justice among engaged stakeholders. Historically, measures tend to be developed from the researcher's perspective, which often does not reflect community priorities. Equity within engaged research requires measures that are co-developed with the community and people most impacted. As highlighted by our partners work at the Cultural Wellness Center, both the understanding and measurement of health must be informed by cultural "ways of knowing" and community knowledge.[4] This practice of cultural translation, is exemplified by the work of both the Cultural Wellness Center and the Community Solutions for Health Equity project at Community Catalyst. We recommend PCORI incorporate cultural translation as a process for determining outcomes within future research and that community members co-design measures.

To fully understand the experience of engagement and its impact, both quantifiable and qualitative data is needed. Community Catalyst's recommendations for measures are below:

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[4] Duke, N., & Atum, A. (2016). Creating Culturally Relevant and Responsive Health Care Models. *Journal of Community Engagement & Higher Education*, *8*(3), 53–65.

Qualitative Measures:

- Who was engaged? For example:
    - How representative is the engaged stakeholder group of the communities most impacted?
    - In terms of the different groups involved in the problem and/or the potential solution?
- What steps were taken to understand the community's needs, fears, and hopes prior to research engagement efforts? For example:
    - Establishing meaningful relationships with community members outside of the research environment.
    - Exploring the history and culture of the community and its members.
    - Being aware of previous attempts, both within the community and external to the community, to address similar issues. What went well what didn't?
    - Understanding the community's strengths.
    - Understanding areas of growth from the community's perspective.
    - Understanding how historical harms and current forces of oppression have uniquely impacted the community, and how these things are understood and talked about within the community.
- What efforts were made to prepare the research environment and researchers for successful community engagement?
    - Was an organizational culture assessment done? What did it entail?
    - What efforts were made to address areas that may make engagement challenging?
    - What efforts were made to understand stakeholders perception of what makes engagement successful?
- What were the engaged stakeholders' experience of engagement in terms of:
    - Level of trust?
    - Psychological safety?
    - Accessibility (materials, language, locations, time, etc...)?
    - Being understood, valued, and respected?
    - Level of transparency and communication?
    - Sense of ownership for the project?
    - Training and ongoing support?
- What was the transformative impact of engagement, both in those engaged and the researchers.
    - How did engagement impact stakeholders':
        - Own health?
        - Knowledge on the topic being explored?
        - Confidence/sense of empowerment in navigating research environments?
        - Willingness to be involved in further engagement and/or recommend it to people in their networks?
    - How did engagement impact researchers':
        - Understanding of the topic being explored?
        - Understanding of the community and stakeholders?
        - Willingness to be involved in further engagement and/or recommend to people in their network?

In terms of quantitative measures, there is no validated tool to measure engagement in the research cycle at this time. This initiative presents an opportunity to create an engaged research

tool analogous to the patient activation measure (PAM). The PAM identifies where on the spectrum of activation patients fall. This information can in turn can be used to tailor support, learning and organizational efforts to improve patient experience. This same idea would be helpful for researchers to get real-time feedback on how engaged stakeholders are and in turn how they need to tailor engagement efforts. Additional quantitative recommendations are below:

Quantitative Measures:

- In terms of quantitative inputs:
    - The amount of resources devoted to engagement and how they are allocated.
    - The number of engaged stakeholders and their demographics.
    - The number and type of stakeholder outreach efforts:
        - What type of efforts were used to recruit stakeholders and how frequently?
        - How many community organizations were contacted?
    - The number of engagement activities:
        - How many stakeholder meetings were there? In what format?
        - How many team-building efforts were there? In what format:
            - Among stakeholders?
            - Among stakeholders and researchers?
        - How many training sessions were offered to stakeholders? In what format?
        - What forms of current support were made available to stakeholders? How frequently were they offered? How frequently were they used?
    - The number, content, and format of stakeholder communications:
        - From the project to stakeholders.
        - From the stakeholder to the project.
    - Stakeholder input:
        - Number and thematic breakdown of issues brought up by stakeholders.
        - Number of times repeat issues were brought up across project timeline.
- In terms of quantitative outputs or outcomes:
    - Impact of stakeholder input on project direction in terms of planning, implementation, and dissemination.
        - For example, issue X was raised by stakeholders Y times and the outcome was Z.
    - Impact in terms of growth of organizational capacity to participate in engagement:
        - How many internal trainings were offered?
        - How many staff participated in these trainings?
        - Growth in infrastructure that occurred specific to engagement?
        - Addition of staffing or allocated staff time specifically for engagement?
        - Growth in funding and budgeting dedicated to engagement?
    - Impact in terms of alignment between researchers and stakeholders:
        - Shared agenda items
        - Joint meetings
        - Alignment of meetings
        - New community organizations volunteering.
        - Alignment of community/researcher's perceptions of meaningful measures.
    - Impact in terms of awareness of research among community:
        - Percentage of target audience with knowledge that research is happening.
        - Website or social media interactions.

- o Impact in terms of attitudes or beliefs:
  - Number of stakeholders understanding and valuing research.
  - Number of researchers understanding and valuing engagement.

What challenges do you foresee for *stand-alone research studies* on engagement? What award characteristics (e.g., structures, requirements, areas of flexibility), resources, or other supports would facilitate stand-alone research studies?

One of the largest challenges is ensuring that proper structure, resources and support for the engagement exist. PCORI's own research has highlighted the need for dedicated staffing, funding, and planning for engaged research. We have found these same factors are also needed for engaged organizations. In light of this evidence we recommend that intentional, value-driven and successful engagement efforts include the following components:
- o Leadership buy-in: the leadership of any research project needs to support and be involved with engagement efforts.
- o Dedicated Staff: like any other aspect of research engagement requires knowledge, intention, time, planning, and execution. Accordingly, internal, or preferably external staff, with direct reporting power to project leadership need to be dedicated to engagement**.**
- o Dedicated Budget: specific funding needs to be allocated to match all aspects of engagement activities including staffing, stipends, materials, and operations related costs.
- o Feedback Loops: clear roles and expectations need to be developed from the start, along with effective and meaningful mechanisms for clarification and communication between the research team and engaged stakeholders.
- o Recognition Programs: projects need to show appreciation and specifically lift up the contributions of engaged stakeholders.

What challenges do you foresee for *studies within a study* on engagement? What award characteristics (e.g., timing relative to parent study, requirements), resources, or other supports would facilitate studies within a study research?

The same challenges and suggested components mentioned above apply to studies within a study. However, studies within a study, in particular, will benefit from a third-party evaluator or partner with knowledge and expertise about engagement to ensure equitable and transparent evaluation. This allows for a less biased evaluation of efforts as well as external support for stakeholders and researchers. In terms of timing, successful engagement and evaluation of the engagement process requires significant planning and preparation. Studies within a study should be planned and implemented in conjunction with the parent study whenever possible.

What questions do you have about the potential development of a future funding initiative that PCORI should address as we develop materials for potential funding opportunities?

In order to facilitate equitable application opportunities, has PCORI considered funding third-party entities to assist community organizations in developing funding applications? For example, larger organizations could be assigned to provide application technical assistance to smaller organizations that have strong connections to the communities of interest.

Would you or your organization be interested in pursuing this funding initiative, including as a partner, based on the above description? Why or why not? If not, please elaborate on the reasons.

Community Catalyst would be interested in pursuing this funding initiative as a partner. Our institutional knowledge around engagement makes us particularly well suited to help guide engagement processes for institutions and provide technical assistance to community organizations. We also believe our national, state, and local partners provide us with a unique network of collaborators, including organizations that are intimately familiar with community-driven research and health system transformation among communities experiencing health inequities and systemic oppression.

What should PCORI keep in mind to ensure that these potential research opportunities (stand-alone research awards on the science of engagement, and SWAS) are inclusive of and accessible to all types of organizations and communities? How can we best support the community to ensure high-quality applications?

This is an essential question. Within engaged research, there is little information about concordance between the identities of primary researchers/awardees and the communities most impacted by the research. This includes race, ethnicity, gender identity, sexual orientation, disability or health status and primary language. Priority in funding should be given to applicants who are connected to and part of the communities the funder seeks to research. Further, within the research community, racism has resulted in exclusion and underrepresentation of BIPOC researchers[5]. To combat this trend, funders like PCORI must actively seek to prioritize BIPOC applicants. Another aspect to consider is the dissemination strategy for funding opportunities. For example, we recommend partnering with organizations from BIPOC communities, such as Unidos, NAACP, and historically black colleges and universities, in spreading awareness about the funding opportunities. This could also take the form of sub-grants to key organizations to help with recruitment.

Additionally, many smaller organizations or community groups may not have the dedicated staffing to complete lengthy applications. This is particularly true for BIPOC organizations and racial justice organizations that have historically been under-invested in by philanthropy. In turn, we recommend reducing up-front barriers to participation. For example, PCORI should consider truncating the submission requirements for the initial application, as well as accepting alternative application formats such as interviews, video or other forms of media. Language justice and accessibility should also be given particular attention to ensure groups for whom English may be a second language or groups with various educational backgrounds are able to participate. If not done so already, PCORI may want to consider increasing funding for infrastructure, minimizing reporting, and ensuring organizations get constructive feedback if their grant application is not approved. Additional approaches and information are available in the Grantmaking with a Racial Justice Lens: A Practical Guide[6]. PCORI should also require that all lead applicants submit information about how they have networked with community organizations and groups as part of their application process.

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[5] Vasquez Heilig. J., Flores, I., Souza, A., Barry, J., & Barcelo Monroy, S. (2019). Considering the Ethnoracial and Gender Diversity of Faculty in US College and University Intellectual Communities. *Hispanic Journal of Law and Policy*, *2*(1), 1-31.

[6] Community Catalyst has had success implementing some of these practices within Community Solutions for Health Equity, the Vaccine Equity and Access Program, and the Restuccia Health Justice Fellowship.

How can PCORI promote connections between organizations, communities, and qualified researchers for this potential future funding initiative if not currently available to them?

Connections with communities – especially those that have been over-researched but underserved, or who have a well-founded historical mistrust of research – requires an investment of time to listen carefully in order to build relationships of trust and respect. Accordingly, any entity seeking to connect with communities that have been historically excluded or harmed by the research community needs to meet those communities where they are with a willingness to inquire and co-create. Efforts to connect with communities can include developing relationships with trusted community members and joining community events in their own spaces. For unseasoned engaged researchers, collaboration with partner organizations that have knowledge and expertise on engagement to co-design and implement engagement efforts can create a more successful process.

PCORI can use its position to facilitate connections between seasoned engaged research institutions and those newer to engagement as well as to prioritize funding projects which help influence the research environment to be more conducive to community and organization connections. For example, projects like the Aging PCOR Learning Collaborative seek to build knowledge around engaged research while also ensuring engagement as a topic is more prominent within research training. Additionally, The Sage Resource Project is another example of generating knowledge while focusing promoting engagement among researchers which resulted in practical and usable resources for researchers which were created by CJE SeniorLife. While these above projects focus on the older adults, replicating these efforts with various communities in various locations could help stimulate connections and embed engagement in more research practices.

Additionally, PCORI should consider using its role as a funder to ensure engagement is approached in a value-based way. In turn, this will help create a research community that is conducive to engaging community members and people with lived experience of the subject matter while helping lay the foundation for more meaningful and long-term relationships. This could take the form of incorporating more explicit directives in the PCORI engagement rubric or requiring ongoing reporting from institutions in how they are engaging the community. Some principles to operationalize include:

- All stakeholders should be valued and respected.
- Stakeholders should experience timely, frequent and accessible communication, responsiveness to their concerns and questions, and their input should be listened to and understood.
- Respecting stakeholders' time also includes providing stipends for:
    - All stakeholders participation
    - Community organizations who assist with recruiting.
    - Potential funding for transportation and providing childcare.
- Take time to listen to the community and provide opportunities for researchers, organizations, and other stakeholders to get to know each other outside of the research environment.
- Historical and current forces of oppression and discrimination, especially racism, within research need to be exposed and explored:
    - Directly name past traumas caused by research and relevant fields.

- Validate the root causes of fear and mistrust between communities and researchers.
- Discuss ethics and norms of the project together.
- Have researchers and stakeholders complete racial justice learnings prior to engagement, either separately or perhaps together.

Finally, if not done already, PCORI may consider examining how its own internal structures influence connections and partnerships. For example, can relationships be forged with community members, researchers, and organizational leaders from groups historically excluded from research whose voice is needed? Can PCORI structures such as staffing, advisory panels, board members and merit reviewers be shifted to reflect and be inclusive of these communities?

Please select the stakeholder group you primarily identify with to help PCORI contextualize subsequent responses:

X Patient, caregiver, disease or condition-based advocacy organization

Sincerely,

Renée Markus Hodin
Deputy Director
Center for Consumer Engagement in Health Innovation at Community Catalyst