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Engagement in Research: Foundational Expectations for Partnerships

PCORI has developed six foundational expectations — building blocks for meaningful, effective and sustainable engagement with patients, communities and other partners in research. Researchers and partners should address each of these expectations when:

- Applying for PCORI funding.
- Developing a project plan and engagement plan for awarded projects.
- Reflecting on engagement during a project to improve and strengthen engagement over time.



The Foundational Expectations for Partnerships in Research update the 2014 PCORI Engagement Rubric and provides expectations for meaningful engagement to advance patient-centered comparative clinical effectiveness research (CER).

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Foundational Expectations Build Meaningful Engagement

The six foundational expectations promote active partnerships between researchers, patients and other partners. The expectations:

- Reflect experiences with and lessons learned from PCORI projects and other studies where patients and other partners were actively involved in shaping and influencing the research, resulting in impacts on study feasibility, study quality and the relevance of findings.[1-5]
- Put into action PCORI's Advisory Panel on Patient Engagement principles for meaningfully engaging individuals and communities in research.[6]

There is no one-size-fits-all approach to addressing these expectations. Teams should tailor their engagement approaches to meet the goals and priorities of partners, researchers and the project. Approaches also need to align with the level to which partners wish to engage.

Definitions

Meaningful engagement

An active partnership between researchers, patients, caregivers, clinicians and other partners throughout the entire research process — from planning the study to conducting the study and disseminating study results.

Engagement occurs along a continuum ranging from input to consultation to collaboration and shared leadership.[7] For PCORI, engagement practices that are limited to activities that only request input, such as conducting surveys or focus groups, are not considered meaningful engagement.

Patient partners

People with lived experience, such as patients, family members, caregivers, community members and organizations that represent the population of interest.

They are involved in planning, conducting and disseminating the research. Patient partners should not be confused with study participants.

Partners representing other perspectives

Members of groups based on professional rather than personal experience, including:

- Clinicians.
- Purchasers.
- Health insurers.
- Industry.
- Hospitals and health systems.
- Policy makers.
- Training institutions.
- Other members of the health and healthcare community.

EXPECTATION: **Representative Involvement**

Projects should include partners, organizations, researchers and other team members who reflect the range of patients and communities affected by the research topic.

Questions to ask when addressing this expectation:

- How well do the partners and researchers on the team reflect the perspectives and experiences of the groups and communities that the project will benefit?
- What efforts have been made to intentionally include the range of partners and organizations whose perspectives and experiences have not been reflected in past research?
- To what extent does the team include patients with lived experience related to the research topic as partners versus asking researchers or other team members to describe the patient perspective?

This expectation helps projects to:

- Make sure the research is relevant to and addresses the needs of those most affected by the research topic.
- Incorporate patient and other partner perspectives in project decisions.
- Create broader representation of relevant perspectives by including a range of patients or communities most affected by the area of focus, interventions and outcomes.

Quotes From Researchers and Partners

"Often the makeup of an advisory board is such that it attracts people that have child care after hours when the meetings are or don't have translation issues. And that creates a bias in terms of socioeconomics and background and empowerment and engagement."

~ Researcher

"Look at the community that you want to engage and make sure that you have a group from that community. If you're going to go out to family caregivers of people who have Alzheimer's…you have to have more than one person (who represents that perspective)."

~ Partner

EXPECTATION: **Early and Ongoing Engagement**

Projects should ensure that partners contribute early and throughout the study, including planning the study, conducting the study and disseminating study results.

Questions to ask when addressing this expectation:

- How will partners contribute to all phases of the project?
- How have partners and communities been engaged in developing the research topic, questions, approach and outcomes so that the research addresses their priorities, needs and experiences?
- How have partners helped to develop the engagement strategy, including defining their roles and responsibilities? How will partners be involved in refining their role as needed during the project?
- To what extent do partners' roles and responsibilities reflect their skills, strengths, interests and preferences?

This expectation helps projects to:

- Ensure that every phase of the project benefits from partners' contributions.
- Meet project goals and outcomes.
- Assign roles and activities based on partner preferences, skills, strengths and life circumstances.
- Build on community strengths and assets.

Quotes From Researchers and Partners

"Start early, identify the partners, build a trusting relationship, have them engaged from day one in all aspects of the project and communicate frequently with them about the process and the results."

~ Researcher

"As patient lead, I've done a lot of project management. I've helped write the grants. I've helped write abstracts. I have developed posters. I have edited and written articles. I've been involved in everything from meeting facilitation, to writing the articles, whatever needs to be done. I've gained a lot of skills from working on the PCORI (project)."

~ Partner



EXPECTATION: **Dedicated Funds for Engagement and Partner Compensation**

Projects should dedicate funds to support engaging with partners and compensate partners for their time, expertise and perspectives in a timely manner and in ways that reflect their preferences and roles.

Questions to ask when addressing this expectation:

- To what extent does the project budget compensate partners at an amount that reflects their expertise, role and contributions? To what extent is compensation fair for all partners?
- To what extent have partners been involved in determining the type, amount and frequency of compensation?
- To what extent does compensation account for out-of-pocket costs that may be barriers to participation, such as parking, transportation or child care?
- To what extent does the project budget include funds to support full partner participation such as engagement coordinators, interpreters, training and technology supports like tablets or screen readers?

This expectation helps projects to:

- Compensate partners in ways that reflect their needs and preferences, both financially and non-financially, while avoiding unintended consequences like loss of public benefits.
- Support meaningful engagement of partners in all phases of the project.

Quotes From Researchers and Partners

"It is so important to be transparent about tax implications for (community partners). By being honest about payments and what may happen — for example, changes to governmental benefits like WIC — are equally as critical as partners decide how to collaborate and what their compensation needs to be."

~ Researcher

"We need to think about how we can be fair to community-based organizations, small clinics and other small groups we want to engage so they are fairly compensated for their time. Sometimes we ask way too much of them. Their hearts are in the right place, and they want a seat at the table, but they need support — they have expenses."

~ Partner

EXPECTATION: **Build Capacity To Work as a Team**

Projects should identify skills, strengths and barriers to engagement and provide all team members with the information, training and support they need to work as a team.

Questions to ask when addressing this expectation:

- How will the team identify and build on partners' skills and strengths?
- How have barriers that affect team members' participation been identified and discussed?
- How can the team overcome barriers by offering supports or resources and building on partners' skills and strengths?
- To what extent are researchers ready to engage with patients and other partners? How will researchers develop and strengthen skills to engage with partners who bring different perspectives?
- What information and supports will help partners contribute at different stages of the project? How will ongoing needs be identified and addressed to support participation?

This expectation helps projects to:

- Meet project goals and outcomes by identifying potential challenges and building on team members' strengths.
- Address power imbalances between researchers, patients and other partners within the team and create team cohesion.
- Improve the productivity of all team members by ensuring that all have the necessary information about project topics, methods and activities to contribute effectively.

Quotes From Researchers and Partners

"For me, what makes (the project) successful is the ability to work with partner organizations or with our patient partners and sit down at the table together and say we're working on this project together, we're all invested, we're coming with a bunch of different skills and abilities. How can we use our different skills and abilities to contribute to this project in bigger or smaller ways? That has been the most important part. It's that partnership that has really been huge."

~ Researcher

"Building capacity is about everyone on the team. It's about training all team members to fully participate. Projects should look at each member to identify what they need to participate — not everyone needs the same thing. It's about supporting researchers and partners."

~ Partner



EXPECTATION: Meaningful Inclusion of Partners in Decision Making

Projects should use engagement structures and processes that include partners in decision making throughout all phases of the project, with considerations for the project's goals, scope and scale.

Questions to ask when addressing this expectation:

- How will decisions — from design to conduct to interpretation and dissemination of results — be made and communicated?
- How will the team work together to determine who is responsible for and involved in making decisions about different tasks and activities?
- How will patients and other partners influence decisions in all phases of the project?
- How do engagement structures support collaborative decision making between researchers, patients and other partners?
- How do engagement structures support the goals, purpose and scale of the project?

This expectation helps projects to:

- Ensure that partner perspectives influence decisions about study planning and conduct and dissemination of results.
- Acknowledge and address power imbalances between researchers, patient partners and other partners.
- Promote transparency about decision making and minimize conflicts that may arise among team members.
- Promote meaningful engagement, shared leadership and shared responsibility.

Quotes From Researchers and Partners

"Patients and community people don't have a true seat at the table unless they share in the top leadership, which means patients and community people need to hold themselves accountable for project outcomes as well."

~ Partner

"My attitude was pretty typical, which was, 'Let me find some patients and families that I can put on my grant and let's build a Family Advisory Council … They can tell us which of our ideas are good, which of our ideas are bad, and we'll have them meet periodically …' I really didn't understand the notion of coproduction and how do you partner with patients and families in earnest … It was immediately apparent that (the partners) had things to say and to add that we just weren't thinking about at all. It went from this notion of let's have an advisory board with some family representation to really understand that if this was going to work, they had to be central to the whole thing."

~ Researcher



EXPECTATION: **Ongoing Review and Assessment of Engagement**

Projects should gather input and feedback throughout the project to identify what is working well and what could be improved, and then adjust engagement approaches as needed.

Questions to ask when addressing this expectation:

- How and at what points will teams gather input from all team members about the process and impact of engagement, including its effect on the project and team members' relationships?
- What processes are in place to ensure that engagement-related issues and concerns are addressed respectfully and in a timely manner and that partners are involved in the process?
- What processes are in place to adjust existing engagement approaches based on assessments? How can these processes help strengthen partnerships and repair trust if needed?

This expectation helps projects to:

- Involve all team members in continuous learning to improve the process of engagement, including understanding whether engagement is occurring effectively, fairly and as intended.
- Understand the impact of engagement on the project.

Quotes From Researchers and Partners

"You need to ask how you can do better. It's almost like a quality improvement project — and then respond accordingly and then they come to trust you."

~ Partner

"We need qualitative and quantitative measures. We can understand the experience through qualitative measures and then add in empirically supported quantitative measures … For example, if you scored a 6 on this engagement tool — people aren't feeling respected. What happens next — were there improvements?"

~ Researcher

Foundational Expectations in Action

Projects can implement the foundational expectations in different ways. Teams should work together toward addressing each expectation based on their project and engagement goals and needs. During a project, engagement — and how to address each expectation — may evolve as researchers and partners learn how to work together.

Below, we highlight two PCORI-funded research projects that implemented engagement in ways that reflect the foundational expectations. These real-life examples illustrate approaches that teams took to work toward meaningful engagement within the specific context and circumstances of their projects.

Case 1: An Intentional Process of Building Trust and Relationships

Getting started: For a project that included Spanish-speaking populations, the principal investigator (PI) developed a relationship with the director of a local clinic that served patients whose first language was Spanish. The relationship began with an informal conversation where the PI and clinic director met to exchange ideas at a restaurant near the clinic. Due to previous negative experiences, clinic leadership initially did not want to be involved in research. Over the course of six months, the clinic director and clinic staff participated in ongoing discussions with the PI and other researchers, sharing information about the clinic. Because the researchers listened, spent time building relationships with the clinic and the patient community, and discussed how the study could help the clinic address existing challenges and goals, the clinic was willing to partner on the project.

Applying for funding: Researchers worked with the clinic director to plan the study and prepare the PCORI application in a way that would be feasible and mutually beneficial. Clinic leaders connected the PI with patients, who helped write the proposal. Patient and clinic partners helped to adapt the intervention to better meet the needs of the community by increasing flexibility and reducing burden and cost.

During the project: The research team — which included clinic leadership and the patient partners — hired a Spanish-speaking coordinator to lead engagement efforts. The team established a patient advisory group that was responsible for helping to plan and conduct the study. All research and engagement activities took place at the clinic, and meetings and calls were scheduled around the availability of clinic staff. The patient advisory group met every three months, and meetings were scheduled on weekends at a time that was convenient for patients. At each meeting, researchers provided a meal and child care. They also paid patient advisors for their time.

Throughout the study, researchers demonstrated respect for partners by listening, acting on their ideas and suggestions, and providing feedback when changes were not feasible. Patient advisors helped to identify outcome measures that mattered to patients, validate the main outcome measure, increase recruitment and develop dissemination strategies. Researchers also included clinic leaders in decision making at all stages of the project.

After the project: Patient advisors recommended ways to extend the intervention in a different setting. Researchers are seeking funding to support the continuation of this work. The clinic built on its participation by expanding its mission to train other organizations on how to partner in research.

How are the foundational expectations reflected in this example?

Representative Involvement

- Spent time building trust and relationships and addressing previous negative experiences with research.
- Planned study to benefit clinic and patients.
- Included patients from the community.

Early and Ongoing Engagement

Partners:

- Co-wrote proposal.
- Contributed throughout study.

Build Capacity To Work as a Team

- Scheduled activities at times and locations convenient for partners.
- Built clinic capacity for multi-site research studies.

Dedicated Funds for Engagement and Partner Compensation

- Budgeted for an engagement coordinator and for payment for advisors, meals and child care.

Meaningful Inclusion of Partners in Decision Making

- Included clinic leaders in research team meetings.
- Convened patient advisory group regularly.
- Made all study decisions collaboratively.
- Showed respect by listening and acting on input.

Ongoing Review and Assessment of Engagement

- Asked for feedback about whether approach was working.

Case 2: Pivoting Engagement To Meaningfully Include Advisors in Decision Making

Initial plans for engagement: The core research team included researchers and patient and family co-investigators. The team established a broad, geographically dispersed, 24-member advisory group. Advisors included patients, family caregivers, providers, payers, advocacy organizations and policy makers. The initial engagement plan included weekly meetings with the core team, an annual in-person meeting, quarterly telephone meetings with the core team and advisors, and quarterly updates to materials on a shared online portal.

Within the first six months, the core team realized that this well-intentioned engagement approach did not work well to meaningfully engage advisors. When the team asked for feedback, advisors said they felt disconnected from the study. Advisors wanted to do more than read materials on the online portal. They also noted challenges due to the time elapsed between meetings and the amount of information covered during them.

Pivoting the engagement approach: The team used this feedback to develop a new engagement structure that created formal connections between the core team and the advisory group. Two patient and family caregiver partners from the core team served as co-chairs of the advisory group. The team invited advisors to attend one core team meeting each month. To improve communication with advisors, the team:

- Increased the length of quarterly calls from 60 to 90 minutes, and co-chairs made sure to elicit views from everyone on the call and summarized what they heard.
- Held informal, one-on-one follow-up calls with advisors after the meetings.
- Distributed a monthly newsletter that described upcoming meetings, provided updates on study progress and shared advisor spotlights.

To identify ways to better support productive engagement and ensure that partners felt included in meaningful ways, the co-chairs developed plans for sending advisor experience surveys several times throughout the project.

Effects on the project: The new engagement structure created more opportunities for advisors to share their views and participate in shaping decisions. For example, after receiving feedback on recruitment materials from advisors, the response rate increased by 20 percent from the pilot to the main study. After debating whether it was more important for patients to understand the questions or for the questions to map to valid measures, researchers and advisors compromised on measures that could meet both needs. Formal and informal feedback loops allowed the core team to explain when and why decisions did or did not integrate advisor views.

How are the foundational expectations reflected in this example?

Representative Involvement

- Intentionally included a range of perspectives.
- Involved patients and family caregivers on the core research team and on advisory group.

Early and Ongoing Engagement

Partners:

- Helped plan study and engagement approach.
- Contributed throughout study, including helping with survey development and recruitment.

Build Capacity to Work as a Team

- Identified ways to support participation.
- Distributed a newsletter with updates.

Dedicated Funds for Engagement and Partner Compensation

- Budgeted for patient and family co-investigators, in-person meetings and virtual meetings.

Meaningful Inclusion of Partners in Decision Making

- Pivoted engagement structure to be more inclusive and collaborative.
- Included co-investigators on research meetings.
- Made decisions collaboratively, such as measures.

Ongoing Review and Assessment of Engagement

- Administered advisor experience surveys.
- Contacted advisors informally after quarterly meetings.

Foundational Expectations Build on a Growing Body of Evidence About Engagement in Research

PCORI has demonstrated the feasibility of engaging patients and other partners in hundreds of patient-centered CER projects and has generated evidence about the benefits and challenges of engagement from multiple studies of these projects.[2,3,8,9,10] Engagement improves study feasibility, acceptability and quality as well as the relevance of findings and shows promise for enhancing uptake of findings in clinical practice.[2-3] Researchers have a better understanding of patients' lives and of clinical processes and are committed to continuing engagement.[3] Patients and other partners benefit from developing skills, contributing in a positive way and improving their own health.[9] With meaningful inclusion in decision making throughout the study, researchers and partners build trusting relationships[10] that can benefit communities, community organizations and academic institutions.

Building on this practice-based evidence, PCORI undertook a collaborative and inclusive process in 2022 and 2023 to update the Engagement Rubric, which resulted in the Foundational Expectations for Partnerships in Research. This process involved:

- Collaboration with the Advisory Panel on Patient Engagement, including meetings to identify, prioritize and review expectations.
- A convening with 46 attendees, including awardees, patients and other partners, funders and thought leaders.
- A review of existing guidance related to engagement in research as well as PCORI evidence and resources on engagement.
- Focus groups with 16 PCORI awardees and 17 patient partners.
- Interviews with 24 people with expertise in research.

PCORI Engagement Resources

Guidance for the Foundational Expectations, including how to put the expectations into practice and examples for each expectation, is available at www.pcori.org/Foundational-Expectations. The guidance will be updated over time as more knowledge and evidence emerge.

Search the Engagement in Health Research Literature Explorer to find peer-reviewed articles on the Foundational Expectations at www.pcori.org/engagement/engagement-literature.

Search the Engagement Tool and Resource Repository to find PCORI-awardee developed tools and resources related to the Foundational Expectations at www.pcori.org/engagement/engagement-resources/Engagement-Tool-Resource-Repository.

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