

Engagement Policy

The experiences and perspectives of patients are an important component in network governance and decision making as well as research conducted in REACHnet. To this end, the REACHnet Engagement Policy sets forth guidelines to ensure that patients and other partners are meaningfully engaged in the research process and that the research interests of the community are being served by the research conducted. In alignment with REACHnet's partnership in PCORnet®, the National Patient-Centered Clinical Research Network, and funding from the Patient Centered Outcomes Research Institute (PCORI), the REACHnet Engagement Policy is based on the following two frameworks. We encourage all our collaborators to adhere to these principles as the minimum expectations for carrying out patient-centered research in partnership with REACHnet.

PCORI's Foundational Expectations for Partnerships in Research

The Foundational Expectations are six core principles designed to ensure meaningful, patient-centered engagement throughout the entire research process.

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.

Early & Ongoing Engagement

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

Dedicated Funds for Engagement & 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 & roles.

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 needed to work as a team.

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 consideration of the project's goals, scope, and scale.

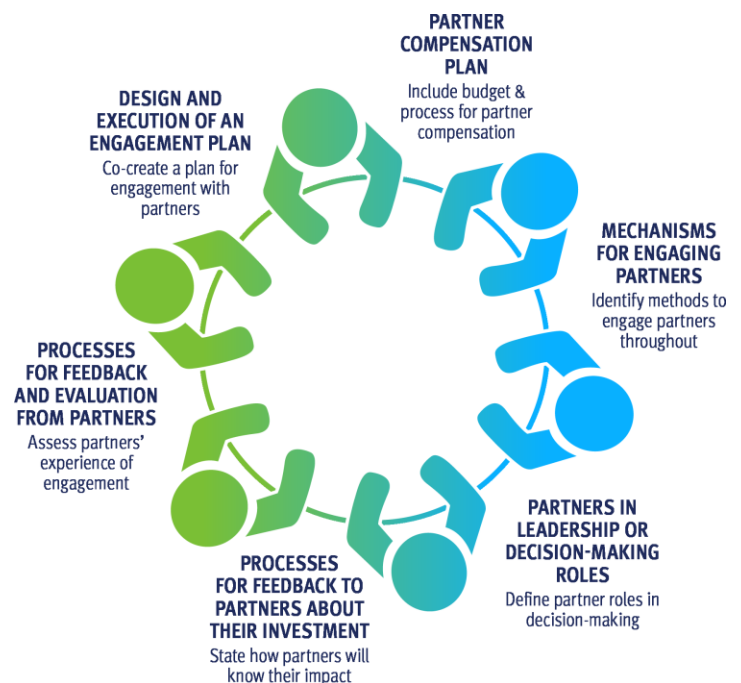
Ongoing Review and Assessment of Engagement

Projects should gather input and feedback throughout the project to identify successes and areas of improvement and then adjust engagement approaches as needed.

PCORnet® Common Engagement Model

The PCORnet® Common Engagement Model (CEM) operationalizes PCORI's Foundational Expectations for Partnerships in Research into base standards for partner engagement across all levels of PCORnet—including PCORnet® Studies, Clinical Research Networks, the Coordinating Center for PCORnet®, and PCORnet Governance.

Using the CEM elements ensures that patients, caregivers, and other partners across the healthcare community are meaningfully engaged throughout the research process—from identifying the questions that matter to disseminating research results. Each project is unique, so the engagement approach and activities will differ. Regardless of study design, studies should use the CEM to guide engagement throughout the research process, incorporating approaches that are appropriate for the study and meaningful to partners.



The following engagement guidelines and practices demonstrate how the principles and expectations set forth by PCORI and PCORnet® are operationalized in REACHnet.

Patient Partner Engagement

1. REACHnet recruits and retains Patient Partners that identify with the patient community and can draw on their lived experience to inform network decisions and activities.
2. Patient Partners serve as voting members of the REACHnet Steering Committee (SC) and have access to SC materials, attend SC meetings, and contribute to network decision-making.
3. REACHnet Patient Partners are compensated in accordance with the PCORnet® Patient and Other Partner Compensation Policy and PCORI Compensation Framework.¹
4. Patient partners are provided with access to organizational resources and information, opportunities for mutual/personal benefit (i.e. resume building, networking, and authorship), and integrated team communication.
5. Patient Partners' roles include participation in the REACHnet Engagement Team and Steering Committee, participation in engagement activities, such as Health in Our Hands (HiOH) meetings, and contribution to engagement- and network-related decision making.
6. REACHnet engages community members through Health in Our Hands (HiOH), a patient advisory group that facilitates discussion between patients and researchers on specific REACHnet projects. HiOH members are provided with compensation in accordance with the PCORnet® Patient and Other Partner Compensation Policy and PCORI Compensation Framework¹, access to organizational resources such as the HiOH Handbook and Glossary, and research fundamentals training.
7. HiOH Members sign a Community Partner Agreement² confirming that they have completed the training and orientation and understand the expectations of HiOH membership.
8. REACHnet empowers HiOH members and Patient Partners to feel confident in their skills, expertise, and opinions through readily available resources, ad-hoc research training, open communication, and one-on-one support as needed.
9. REACHnet supports the recruitment and engagement of Patient Partners in research projects by disseminating collaboration opportunities to the patient community, supporting patients in preparing proposal materials (i.e. biographical sketch and letter of support), and offering the REACHnet Patient Recruitment and Selection Toolkit as a framework for study teams to adapt and use.
10. REACHnet engages patients in periodic evaluations (i.e. 360° Engagement Assessment and HiOH Satisfaction Surveys) to assess the quality of network engagement processes and outcomes. REACHnet Patient Partners also participate in an annual evaluation led by the Coordinating Center for PCORnet.
11. REACHnet tracks progress metrics on each element in the PCORnet® Common Engagement Model and reports them annually to the Coordinating Center for PCORnet®. These metrics are used to advance network quality improvement.
12. REACHnet maintains a culture of mutual trust where all partners feel important, respected, and valued.
13. REACHnet encourages all partners to become educated on patient-centered research via PCORI Research Fundamentals training modules.³

Research Partner Engagement

1. REACHnet welcomes researchers to meet with HiOH to gather feedback from experienced community partners during the proposal or project implementation stage, ensuring early and ongoing engagement throughout the

research process. REACHnet routinely collects report-backs on changes made to research following HiOH feedback and disseminates relevant updates back to the HiOH community.

2. REACHnet supports collaboration between researchers across sites, states, and networks and can be utilized to engage with investigators, clinicians, patients, and other partners on PCORnet® Studies.
3. REACHnet offers an array of services to support research teams with engagement for funded projects.
4. REACHnet provides investigators with tools to support effective engagement for funded projects, such as the Study Meeting Agenda Template and 360° Engagement Assessment.
5. REACHnet engages researchers, clinicians, and/or project staff in periodic evaluations (i.e. 360° Engagement Assessment) to assess the quality of engagement processes and outcomes.
6. REACHnet may facilitate dissemination of research findings to relevant communities. Shared materials include pertinent and actionable information and are written with the priority audience in mind.
7. REACHnet advises researchers to compensate patient partners and advisors in accordance with the PCORnet® Patient and Other Partner Compensation Policy and PCORI Compensation Framework.¹
8. It is the responsibility of all research partners to become well-versed in patient-centered research and principles of patient engagement. Resources are available from PCORI to guide research partners in effective engagement techniques.⁴

¹ <https://www.pcori.org/resources/compensation-framework>

² <https://forms.gle/DRNpiTfrWwgrn1dT8>

³ <https://www.pcori.org/engagement-research/engagement-resources/research-fundamentals-preparing-you-successfully-contribute-research>

⁴ <https://www.pcori.org/engagement-research/tools-and-resources-support-engagement-research>