

Engagement Policy

Approved May 2019

It is key that the voice of the patient community is informing network activities, present in network supported studies, and incorporated into network governance and decision making. To this end, policies and processes need to be established to ensure transparency, promote inclusion and co-development, and support members of the patient community involved in REACHnet studies and initiatives.

REACHnet has developed a comprehensive Engagement Policy to advance the mission of PCORI to meaningfully engage patient and other stakeholders in the research process and help ensure that the research needs of the community are being served by the research that is being conducted.

The PCORI principles of engagement¹ will act as foundational guidance for REACHnet policy and processes. We encourage all our collaborators to adhere to these principles as they carry out patient-centered research in partnership with REACHnet.

Reciprocal Relationships

In reciprocal relationships, the roles and decision-making authority of all research partners, including patients and other stakeholder partners, are defined collaboratively and stated clearly.

Co-Learning

In co-learning, researchers support patient and stakeholder partners in understanding key aspects of the research process. In turn, patients and stakeholders convey their ideas, knowledge, and experience to help researchers account for all relevant perspectives.

Partnership

This principle reflects PCORI's view that the time and contributions that patients and other stakeholders give to research projects are valued and recognized by fair financial compensation as well as reasonable and thoughtful scheduling. In addition, the principle applies to projects involving priority populations, for which the research team is committed to diversity and cultural competency across all project activities.

Trust, Transparency, and Honesty

Transparency is demonstrated when all research partners share information readily and participate collaboratively in making major decisions about the project. The principles of honesty and trust are reflected by open and respectful communication in which patient/stakeholder partners and researchers recognize the value of each other's roles and contributions.

As such, the following engagement policies have been developed to provide additional guidance on how REACHnet will operationalize these foundational principles.

Inclusive Stakeholder Engagement

- 1) REACHnet strives to meaningfully incorporate the voice of the following key stakeholder groups: patients, caregivers, community health advocates, clinicians and direct-care staff, health system leaders, and research staff. Other stakeholder groups may also be identified as essential in specific network activities and initiatives.
- 2) The network will seek to develop a culture where all stakeholders feel welcome, are treated equitably, contributions are valued, and feel impactful to the network. This will be done through both formal (ex: policy, procedures, and trainings) and informal (regular communication and teambuilding techniques) mechanisms.

¹ <http://primeinc.org/pcori/rubric/5>

- 3) To ensure the network is driven by stakeholder-generated priorities and outcomes, a multi-stakeholder governance group(s) will inform network direction and key decisions.
- 4) Stakeholders will be provided with opportunities for mutual/personal benefit from their participation (i.e. resume building, networking, disease advocacy, authorship). It is the responsibility of network leadership to communicate with stakeholders to help identify these benefits and opportunities.
- 5) Conflicts of interest must be made explicit and protected. It is up to each stakeholder to disclose actual or perceived conflict of interest to the team, and wider network where appropriate.
- 6) The network will engage stakeholders and project staff in periodic evaluations to assess the quality of network engagement processes and outcomes.

Patient Partners

- 1) REACHnet will identify and hire patient partners that identify with the patient community and have the ability to draw on their lived experience to inform network decisions and activities. When at all possible, dual roles will be avoided to help ensure patient partners provide the patient perspective as their primary lens (ex: hiring a patient partner who is also a professional researcher).
- 2) Patient Partners will act as REACHnet team members; with fair compensation, access to organizational resources and information, and integrated team communication.
- 3) Patient Partners' role will go beyond consultants. They will be an integral part of the Engagement Team and be expected to fully participate in hands-on activities. As such, they will attend team meetings, contribute to engagement-related decision making, and collaborate on specific projects focused on patient engagement in research, outreach, and communication.
- 4) Patient partners will have access to the Governance Board materials (Co-PI meeting minutes and supplemental materials), be invited to attend Governance Board meetings, and contribute to discussion and decision-making related to network activities and initiatives.
- 5) The network recognizes that priorities and availability changes over time. Patient partners will review their role annually with the Engagement Director. This is a formal opportunity to discuss their experience as a patient partner, address any challenges, make changes to their role, and provide feedback for quality and process improvement to the network.
- 6) We encourage all patients (and other non-traditional stakeholders) to become educated on patient-centered research and the principles and approaches to patient engagement in research.²

Research Partners

- 1) Researchers that seek to partner with REACHnet will be required to document the project's patient-centeredness and describe their engagement plan. If no engagement was done or is planned, researchers are required to justify the lack of stakeholder engagement and how the project achieves patient-centeredness.
- 2) Researchers utilizing network resources will be required to provide the network a copy of a public facing summary³ (lay abstract) of their project. The network will use this on their website, and other public facing platforms to ensure all network stakeholders are informed of network projects.
- 3) Upon project completion, REACHnet affiliated projects are required to disseminate results back to relevant stakeholders in the community and provide the network with details about this dissemination and any supporting materials or messaging. The network has permission to further disseminate to community and other relevant stakeholders, at their discretion.
- 4) Dissemination of results back to the community should include relevant and actionable information, and be written in a way that is audience appropriate, avoids jargon, and takes into account the limited research literacy of the general public.
- 5) We encourage all research partners to become educated on patient-centered research and the principles and approaches to engaging patients and other stakeholders in the research process.⁴

² [REACHnet Patient Orientation](#)

³ Here are some guides to writing a lay abstract: [NIAA](#) ; [Academy of Medical Sciences](#)

⁴ <https://www.pcori.org/engagement/what-we-mean-engagement>