



Patient and Community Engagement in **Planning** HEAL-Funded Research

Engaging people with lived and living experience (PWLE)—patients, caregivers, and others who are affected by a condition—and communities in research requires thoughtful planning. This tip sheet outlines some key steps and considerations for planning research that engages PWLE.

Anticipating Barriers to Engagement

Effectively engaging PWLE in research can yield information that improves health care access, quality, and outcomes for underserved populations.

Planning for engagement involves anticipating potential challenges. Institutions may need to adapt their policies and practices. Investigators may need to learn new approaches. And for many PWLE, collaborating on research may be an unfamiliar endeavor.

Challenges for investigators may include:

- **Identifying patient and community partners** who have relevant experience and are a good fit with the research team.
- **Establishing relationships** with communities and PWLE.
- **Making the time** to build and sustain relationships with partners.
- **Securing funds** to support patient and community involvement.
- **Addressing logistical hurdles** such as timely securing of stipends for partners.
- **Helping partners navigate administrative processes**, such as grant submission systems, which are designed for researchers and organizational representatives.
- **Translating materials into partners' primary languages** and adapting materials to be culturally-informed.
- **Managing power dynamics** so that partners know that their role is as important as the researchers' and that their feedback is valued and incorporated.

Patient engagement is the effective involvement of people with lived and living experience throughout the research process—from selecting topics to study, through designing and conducting a study and sharing results.

Community engagement is the involvement of a range of partners who contribute to the research, including health care providers, treatment settings, and community organizations.

- **Communicating study information** in plain language to allow partners to make effective contributions.
- **Managing institutional hesitance to share authority** with those who lack academic or clinical credentials and experience.
- **Balancing scientific rigor** with responsiveness to partners' input and feedback.
- **Evaluating engagement in research** and determining what metrics should be used to measure success.

Engaging youth as partners in research brings its own considerations, such as informed consent, an acute awareness of power dynamics, and the involvement of parents or caregivers.



Challenges for PWLE and community partners may include:

- **Logistical hurdles**, such as:
 - Limited time to attend meetings or other study-related activities due to work, childcare, or other commitments.
 - Limited finances to pay for transportation to meetings and other study events, or to pay for internet access, parking, or childcare.
 - Health problems or physical limitations caused by the condition being studied or other conditions.
- **Lack of familiarity** with scientific research methods, goals, concepts, or terms.

- **Concerns over confidentiality or privacy**, such as how their individual health care experiences will be protected.
- **Mistrust of health care systems, medical research, and government agencies**, especially among communities of color that have been harmed by research in the past (e.g., in the **Tuskegee syphilis experiments** on Black and African American men in the 1930s).
- **Lack of understanding** or confidence about how they can contribute to the research team.
- **Need for training or skill development** on how to participate effectively in research.
- **Overwhelming demands from institutions** (e.g., institutional training, certification).

Removing Barriers to Engagement

Consider the following steps to address challenges for patients, community partners, and investigators:

- 1. Ask partners what they need** to successfully participate in team meetings and activities (e.g., information, translation services, childcare, technology).
- 2. Plan meetings to be convenient and accessible** for participants. Consider which meetings may not be necessary, which ones could be held in a more convenient location, and which could be held virtually. Ensure your meetings are inclusive and account for accessibility needs (e.g., wheelchair access or space for those with mobility limitations, lactation rooms, sign language interpretation, assistive listening devices).
- 3. Obtain institutional support for engagement activities.** Manage hesitance by describing **NIH's commitment to involving PWLE and community partners in research**. Emphasize the growing number of funding opportunities that require engagement of PWLE or community organizations.
- 4. Arrange campus/building security in advance** for in-person activities, if needed, to ensure that participant check-in goes smoothly.
- 5. Anticipate and plan for costs for partners**, such as transportation, parking, childcare, and time away from work.
- 6. Communicate in plain language.** Avoid scientific jargon and define any technical terms that you must use. Get **plain language writing tips** from NIH.
- 7. Provide partners with ongoing training and support in research methods.** This includes materials and glossaries of research terms in plain language. Spell out the full terms for abbreviations the first time they appear.
- 8. Set, communicate, and revisit clear goals** at the beginning of the study and throughout (e.g., through meeting agendas and summaries). See “Building Trust With Patient and Community Partners” below.
- 9. Protect personally identifiable information** and tell partners how you will do it.
- 10. Identify a liaison** on the research team to coordinate communication among team members, including partners.
- 11. Discuss partners' concerns about research methods.** These could range from objections to animal models, to concerns about the randomization approach.

Building Trust With Patient and Community Partners

Establishing trust with partners is an essential step in developing strong partnerships. Trust can:

- Reduce the chances of conflict and improve the team's ability to work through conflict when it occurs.
- Encourage partners to share their honest opinions.
- Increase their willingness to invest in another person's project or vision.

Consider the following steps to establish and maintain the trust of patient and community partners:

- 1. Build relationships with partners.** Start and sustain conversations to learn about their backgrounds, interests, and goals for the project. Actively practice **cultural humility**: a reflective process of understanding your biases and privileges as well as managing power imbalances. If you see a partner struggling with something, offer extra support.
- 2. Realize that partners are experts on their own experiences** (i.e., they aren't simply "a patient"). Recognize the power of their expertise (e.g., PWLE may have insights about the study population that help identify symptoms or experiences to measure).
- 3. Listen to their concerns and needs.** Pay close attention to partners' perspectives and show that you hear them by incorporating their suggestions. Make it standard practice for your team to invite partner feedback, even if it challenges the team's beliefs.

- 4. Communicate with clarity and honesty.**

Share intentions, how processes work, schedule changes, and other relevant topics. If something goes wrong, acknowledge and address it; embrace it as an opportunity to make positive changes.

- 5. Be consistent and reliable.** Small, consistent actions performed over time build trust. Do what you say you will, and if you can't, explain why to your partners as early as possible.

- 6. Explain the reasons behind choices or decisions (including difficult ones).** Partners are more likely to react positively when they understand how a decision was made. From the outset, ensure that all partners understand and agree on how decisions will be made and how disagreements will be resolved.

To engage PWLE and community partners effectively, investigators and institutions may need to adapt their practices. Plan for engagement by anticipating and addressing the challenges that you, PWLE, and community partners may face.

When you establish trust with partners from the start, you're much more likely to build lasting, productive relationships that inform strong science.



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