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

Pain and addiction are conditions shaped by biology, psychology, and social determinants of health. People who have lived and living experience (PWLE) with these conditions bring an important perspective to virtually all aspects of research. Their contributions can improve the scientific value, public health impact, and community acceptance of your work.

This tip sheet describes how partnering with PWLE and other community stakeholders can enrich each stage of conducting HEAL-funded research. It also provides practical tools for conducting that research.

Using Patient and Community Engagement at Each Stage of the Research Process

1. Choosing the research question(s)
Input from PWLE and community partners can fine-tune the study's priorities and increase the odds that outcomes will align with people's lived and living experiences. For example, patients' suggestions of outcome measures that are meaningful to them have included not only pain-related measures but also mood, sleep, the ability to think clearly, quality of social interactions, and quality of life.

2. Developing study materials and protocols
PWLE and community partners/advisors can contribute to the study design so that it reflects community values and interests. You may receive feedback about recruitment and retention methods, or an aspect of the protocol (e.g., randomization approach). Consider opportunities to address partners' suggestions and concerns while maintaining study rigor. Partners can also verify that written materials are user-friendly and in plain language.

3. Recruiting study participants
By collaborating with patient and community partners to promote the recruitment and retention of study participants, you demonstrate your commitment to including the perspectives of PWLE.

4. Monitoring research participant data and safety
Include patient partners on data safety and monitoring boards to increase diversity and strengthen the focus on participant safety.

5. Collecting, analyzing, and interpreting data
Involve PWLE and community partners at these stages to identify missing themes, highlight findings most relevant to the public, reduce the risk of stigmatizing language or interpretations, and influence the extent to which information is accessible to a public audience.

6. Evaluating patient and community engagement
Evaluate engagement throughout the research process to ensure that engagement is authentic and valuable for PWLE and community partners. Investigators—not partners—should be responsible for the work involved in evaluating engagement.

Use **this table** to identify the partners you want to engage at each stage of the research process.

What Do I Need to Engage the Community in my Research Project?

Personal Skills and Characteristics

To effectively include PWLE and community partners, cultivate the following skills and qualities for yourself and those on your research team:

- Conducting outreach, building relationships, and collaborating with diverse populations

- Ethically managing asymmetrical power relationships

- Practicing **cultural humility**—actively engage in ongoing self-reflection, seeking to:

  - Examine your personal history/background and social position related to gender, ethnicity, socioeconomic status, profession, education, assumptions, values, beliefs, biases, and culture, and how these factors impact your interpersonal interactions.

  - Recognize areas where you don't have all the relevant experience and expertise and demonstrate a willingness to learn from patients and communities about their experiences and practices.

- Being willing to take responsibility for mistakes

- Developing and delivering communications in plain language (learn more about **plain language**)
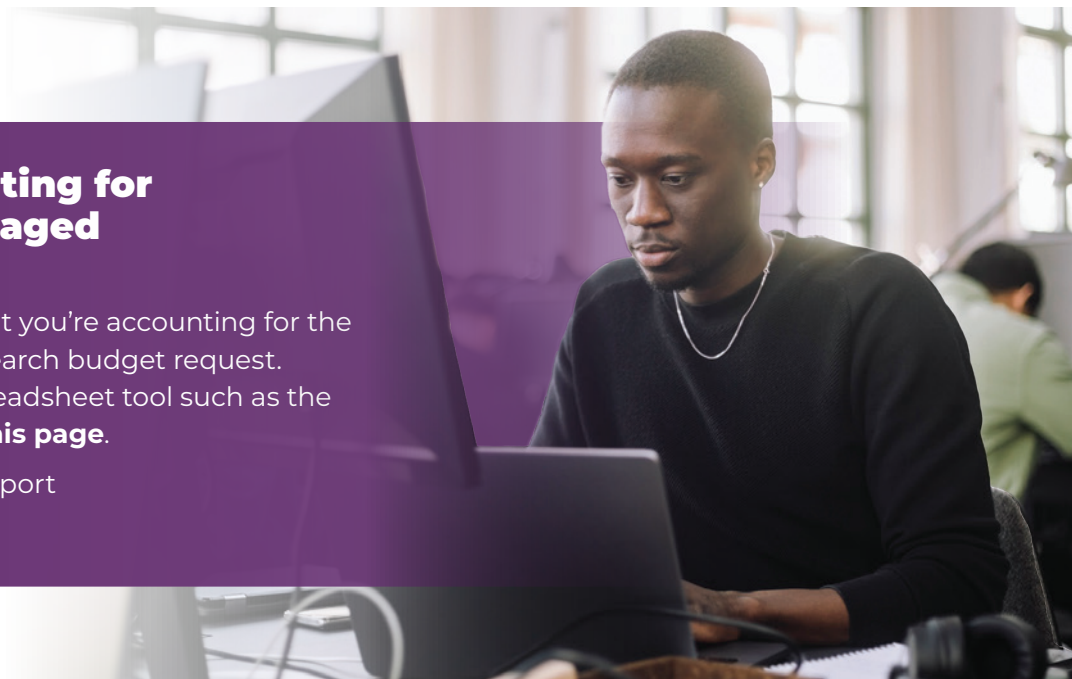
Funding

Set aside resources to establish and sustain the infrastructure you need to support engagement in research. When you plan your budget, consider costs for:

- Salary, office space, and equipment for staff dedicated to engagement

- Equitable compensation for PWLE and community partners (learn more about **best practices for partner compensation**)

- Conference fees for PWLE and community partners to participate in presentations of your research

- Interpreter/translation services and assistive devices

- Transportation, parking, and caregiving costs

- Printing and materials

- Rental for meeting venues

- Audiovisual equipment, transcription services, pens/paper, and refreshments (as allowable)

- Open-access fees for publication in peer-reviewed journals; this is **required** for HEAL-funded research.

Ready to start budgeting for your community-engaged research project?

Budgeting tools help ensure that you're accounting for the necessary resources in your research budget request. Consider using a budgeting spreadsheet tool such as the one described (and linked) on **this page**.

NIH allows certain costs to support engagement activities.

Engaging PWLE and Community Partners in Data Analysis and Interpretation

It isn't always obvious how to involve PWLE and community partners in the data analysis phase of your research, but doing so can greatly enhance the relevance and adoption of your research findings.

PWLE and communities can contribute to interpreting new data by relating results to their own lived and living experiences. They also can help you translate study findings for the communities you're hoping to reach. (**See an example.**) Finally, they can weigh in on stigmatizing language and interpretations of data.

To involve patient and community partners during data analysis:

- Keep in mind that "data" in this context can mean many things (e.g., photos, journal entries). Input on the analysis can consist of a conversation with the research team.

- If appropriate for your project, discuss any experience your partners have with statistics and determine whether training will be needed. (**See a sample training guide.**)

- Identify personnel on your research team with expertise teaching analytic concepts. As needed, invite them to join/lead meetings with patient and community partners.

- Use a variety of methods to communicate with partners (e.g., written content, video/webcast, meeting discussions).

- For some partners, interpreting data may evoke memories from their individual experiences. Have emotional supports available and make it clear that participants can take a break or stop participating at any time. Communicate the value of their lived and living experience, and avoid dismissing information shared about their individual experiences.

- Plan for enough time to review topics that may be more complex or more challenging to cover. You may need to cover these topics over multiple meetings or in person.

Special considerations for engaging partners in preclinical research

- Explain any key terms used and the role of any animal models, if appropriate.

- Create an environment where partners can comfortably opt out of discussions about research involving animals.

- Describe the pathways for transitioning from preclinical research findings to clinical research.

- Use feedback from patient partners about treatment side effects to help design research projects that will test the potential toxicity.

- Communicate how you meet ethical standards for research with animal models (e.g., Institutional Animal Care & Use Committee, veterinary requirements).

- Consider working with patient organizations or engagement coordinators to help "translate" the significance of highly technical work to PWLE.

Overcoming Challenges

Here are some common challenges in community-engaged research and tips to address each one.

CHALLENGE: Initiating a project with a community

- Understand that identifying a community to connect with and forging a relationship takes time.

- Enter the partnership with intentions for a bidirectional, long-term relationship instead of approaching the partnership to address the research team's needs for one research project.

- Draw from your network to find investigators and institutions with existing relationships.

- Understand that partnering with a community should not depend on funding. Even when you don't have specific funds for engagement, engage with partners via email or by participating in community events.

- Use plain language when you describe complex information. If you must use a technical term, define it.

- Maintain a community advisory board/panel for ongoing communication and feedback beyond formal monthly or quarterly meetings.

- Commit the staff time required to maintain active, effective community participation on the research team.

CHALLENGE: Engaging and maintaining community involvement

- Engage and seek input from a variety of community members. This distributes the burden of the work and ensures a diversity of perspectives.

- Allow extra time for building relationships and trust.

- Take the community's priorities into account.

- Communicate regularly and often with participating community organizations so that everyone knows those organizations' priorities.

- Keep engaging the community, even after you disseminate the findings, for more insights and possible involvement in your future research.

CHALLENGE: Bridging differences between academics and the community

- Build on the participating community's strengths and assets. These may include physical assets such as meeting spaces or accessibility tools, as well as skills, experiences, and relationship networks.

- Integrate the community's cultural knowledge. For example, researchers may ask for feedback on how the program or intervention being studied may be received by the community.

- Consider the pros and cons of virtual versus face-to-face meetings and choose the best option for the community. Some people may prefer virtual meetings for the flexibility, while others may prefer in-person meetings. Remember that not all meetings need to have the same format.

- Create settings for open and honest discussion and listen to all participants' input.

- Share your findings with the community. (Get **tips for disseminating findings.**)

CHALLENGE: Overcoming competing priorities and institutional differences

- Maintain transparency and honesty, and share resources across academic institutions and community groups.

- Avoid assumptions about the capabilities of a community or other institutional partner organization(s) or how they function.

- Confirm that all partners agree on all processes and timetables before you proceed.

- Keep lines of communication open until everyone involved believes that all issues are resolved.

ANTICIPATE Barriers to Engagement

Investigators conducting patient and community engagement may face unique challenges. Use the tool on **this page** to explore barriers you may face implementing engagement and map a strategy to overcome them.

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