

# Patient and Community Engagement in Disseminating HEAL-Funded Research

Sharing findings with the people with lived and living experience and communities you have engaged in your research is a core principle of community-engaged research. This step recognizes communities for all their contributions and further builds trust. It also ensures that the research directly informs changes that can improve public health. Consider these steps for disseminating your findings in the communities you've engaged.

Plan

Reach Out

Develop Content

Share Findings

Follow Up

## Plan ahead to share findings.

As you plan to share your research findings:

- **Collaborate with patient and community partners in authoring articles.** Credit these partners as coauthors on the peer-reviewed publications in which they participate. Note that people with lived and living experience (PWLE) may wish to contribute anonymously, especially those with substance use experience.
- **Build community dissemination into project aims.** In your grant proposal, include community presentations as a formal aim. NIH allows **some costs** associated with dissemination activities (e.g., open-access journal fees, travel to conferences). This may help you budget funds for additional staff and time to disseminate findings.
- **Develop a flexible plan with community members.** Collaborate on a dissemination plan with the engaged PWLE and communities. The plan may evolve as you collect community feedback or as new opportunities arise.
- **Communicate findings in a variety of formats.** Your dissemination plan may include communicating results through oral presentations or webinars, print materials, videos, email, or social media. Seek input from community partners about which formats are most useful for them. Consider developing a one-page handout that summarizes key takeaways in plain language for patient and community partners.
- **Present at standing meetings.** Presenting at meetings that already exist is often more practical than planning special events. If possible, plan to present the findings at recurring community meetings, such as educational trainings, support group meetings, staff meetings, or community forums. Whenever possible, co-present with one of your community partners.
- **Share findings with online communities.** Patient and community partners that are dedicated to the health issue addressed by the findings can help you identify the right forums and can even share the findings themselves.
- **Publish open access.** Publishing open access extends the reach of your research by eliminating costs and other barriers for community members. It helps ensure that partners who have dedicated their time and effort to the research can benefit from the results. Making publications widely accessible helps patients, community members, policymakers, and other key stakeholders translate research findings into action.

## Reach out to patient and community partners.

After you draft a dissemination plan based on partner feedback, reach out again to ask partners if they're interested in hosting presentations and distributing print and digital materials.

- **Designate a point person to coordinate dissemination outreach.** Having a specific person in charge of this task makes it easier for partners to communicate with the research team. It also helps the team address community concerns and tailor communication strategies to each audience. Ideally, this person is someone who has been working with PWLE and community members from the earliest stages of engagement.
- **Draw on established relationships.** Plan to establish relationships with community leaders before the dissemination phase. Use these contacts to find opportunities for dissemination.
- **Conduct preliminary meetings with community leaders.** Set up conversations with community partners' staff to discuss the results' possible relevance to their communities. This can help you appropriately tailor information about study findings to meet the communities' needs.

## Tailor the content to your audience.

Work with PWLE and community members to select the findings to highlight. You might ask what they think will be of most interest to community members. For oral presentations, the length of the presentation and the number of attendees and their backgrounds also may inform the content.

Follow best practices for plain language in communicating with PWLE and the community. To clearly communicate findings to nonspecialists:

- Use personal pronouns such as “I,” “you,” and “we” to connect with the audience.
- Avoid complex scientific terms and acronyms, which could confuse and alienate attendees.
- Keep sentences short, and use active voice as much as possible.
- Use **person-first language**.

## Why Share Research Findings With Study Participants and Participating Communities?

1. Patients and community partners deserve access to the knowledge they have made possible by participating or otherwise engaging in a study.
2. Community dissemination creates opportunities to explore the implications of research findings from a local and patient perspective.
3. Sharing results allows health care providers to implement findings more rapidly into clinical practice.
4. Dissemination can help inform policymakers, who may incorporate the research into policy.



Before you communicate your results, review all communication materials (e.g., slides, handouts, oral presentations) with your patient and community partners. Confirm with them that the target audiences will understand all the language.

Explore the following resources:

- Get **plain language writing tips** from NIH.
- Learn **terms to use and avoid when talking about addiction**.
- View a recorded webinar on **inclusive language, imagery, and storytelling for addiction and pain**.

## Communicating Preclinical Research Findings

While communicating preclinical findings to community members may be challenging, it is also important. When PWLE and caregivers learn about the research process, they can better understand the challenges involved in developing effective treatments, and they may become better research advocates.

Conversations with PWLE also help scientists target research questions to address the clinical needs that are most relevant to the affected communities. Yet many basic science investigators have never had the opportunity to interact with PWLE. Watch a **video testimonial** from a basic scientist about how interacting with people living with pain affected his own research.

Forging effective partnerships with PWLE enables preclinical researchers to see the power of their research to create positive change in communities. Discussing research findings with patient and community partners also may provide insights that guide basic research questions and study design. For example, a conversation with a PWLE may prompt you to consider metrics of success other than biological efficacy, such as financial cost, side effects, and quality of life.



### Share the findings.

As you disseminate the research findings, use the following strategies to engage patient and community partners and build trust:

- **Make presentations interactive.** Include community members and staff of community organizations in the presentation. Reserve time for questions and answers and active discussion with attendees.
- **Share a personal story.** You might share a story to explain how the findings have affected your own life or research. This will help to humanize the research topic.
- **Cultivate a receptive attitude toward criticism.** Receiving criticism is a part of seeking community feedback. Resist the urge to respond defensively. Adopt a receptive stance by responding in a respectful and nonconfrontational manner. Follow up by showing how the research team has incorporated their feedback into practical changes.

### Follow up and establish an ongoing dialogue.

Maintain your relationships with PWLE and community partners. This will allow you to explore how research findings impact the community long-term; it also may inform future studies. Some tips:

- **Follow up with one-on-one meetings.** Set up face-to-face meetings to strengthen relationships, and explore the implications of research findings with the engaged communities.
- **Recognize the potential value of research findings for service providers.** Community-based organizations may find the data useful in their grant proposals or in determining which aspects of their programs may be the most helpful. Develop brief reports for these collaborators.
- **Demonstrate that you integrated suggestions into further research or programs.** Be sure that PWLE and community members see how you implemented their input. By integrating feedback, you show that the discussions weren't just academic exercises, but mutual learning opportunities with tangible effects.
- **Offer your time and expertise.** Although it may not always be feasible, consider ways you could support the community you're partnered with outside the research context. If you offer support unrelated to research aims, it may help you build trust and maintain community relationships for your future research.