

## INSPIRE's Community Engagement Learning Network

Session #9: Incorporating diverse public voices throughout the research process

**Featured presenter: Christin Veasley, co-chair of the [National Institutes of Health's Engaging the Public as Partners in Clinical Research \(ENGAGE\) Working Group](#) January 2026**

Every month, the Community Engagement Learning Network will bring together a nationwide team of community engagement (CE) professionals and people with lived experience to host group discussions about improving CE efforts, present best practices for launching and maintaining CE initiatives — drawn from experts in the field, and foster community-building among participants.



### Key takeaways

- The low success rates for new therapeutics and significant amount of time for research findings to influence clinical practice are indicators of gaps in the traditional research model - characterized by researcher-driven questions, rigid timelines, and limited community influence.
- Even though benefits of engaging people with lived experience (PWLE) have been widely demonstrated, it is not standard practice, and few scientists receive training on how to incorporate engagement into their studies.

- Engaging PWLE early, before research questions are finalized, helps ensure that study priorities reflect real-world needs and prevents engagement from becoming symbolic or extractive.
- During study design, partnering with PWLE to shape methods, recruitment strategies, and data collection tools improves feasibility, relevance, and participant trust.
- Clear, shared agreements around roles, compensation, decision-making authority, and timelines support sustained engagement and reduce friction as projects move from planning to implementation.
- In the data collection phase, PWLE can play meaningful roles beyond participation, including advising on consent processes, interpreting participant feedback, and identifying unintended harms or barriers.
- Engaging PWLE in data interpretation strengthens validity by grounding findings in lived context and challenging assumptions that may not be visible to researchers alone.
- Shared ownership of dissemination—such as co-authorship, co-presenting findings, and returning results to communities in accessible formats—reinforces accountability and respect for PWLE contributions.
- Ongoing reflection and feedback throughout the research life cycle allows partnerships to adapt when conditions change and supports continuous improvement in engagement practices.



A graphic from the ENGAGE work group illustrates five key opportunities throughout the research life cycle to engage PWLE and other community stakeholders.



## Action steps

### For people with lived experience (but really, everyone)

- Ask early and explicitly how community input will shape research questions, study design, and decision-making—not just data collection
- Request clear information about roles, expectations, time commitments, compensation, and decision-making authority at the outset of the project, and revisit these agreements as the work evolves.
- Name when research processes feel rushed, extractive, or disconnected from community priorities, especially when timelines or grant requirements limit meaningful engagement.
- Advocate for involvement beyond advisory roles, including opportunities to contribute to recruitment strategies, interpretation of findings, and dissemination of results
- Name power dynamics when they affect participation—for example, when institutional language, academic norms, or funding control limit PWLE’s influence—and ask for adjustments that support equitable engagement.
- Protect your own capacity by setting boundaries around time, emotional labor, and scope of work, and by asking for support when engagement expectations are unclear or unsustainable.

### For professionals leading community-engaged research

- Engage PWLE early and often throughout the research lifecycle.
- Communicate transparently about the scope and context of the work, and constraints related to funding, timelines, IRB requirements, and institutional policies.
- Establish clear agreements around compensation, data ownership, authorship, and dissemination of findings.
- Prioritize relationship-building – both in your approach to creating new connections with PWLE and across the people in the research team
- Create feedback loops so PWLE understand how their input influenced decisions and outcomes.

---

“Equitable research partnerships don’t happen by accident—they are built through clarity, shared power, and accountability.”

---



## Resources for additional learning

- [A report of the Engaging the Public as Partners in Clinical Research Working Group](#)
- [Foundational Expectations for Partnerships in Research | PCORI](#)
- [Patient and Community Engagement in Planning HEAL-Funded Research](#)

# inspire partners

### Organizations



### People with lived experience



Alan Coker



Burt Pusch



Laura Carroll



Rebecca Esparza



Savina Makalena



Stephanie Burdick