

INSPIRE's Community Engagement Learning Network

Session #3: Connecting people with lived experience to meaningful engagement opportunities and projects

Featured presenter: [Stanford Health Care](#)

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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

- While community advisory committees and a familiar and common model for community engagement (CE), creating additional pathways for people with lived experience (PWLE) to directly support, contribute to, and co-lead projects enhances the opportunity for mutual benefit to both individuals and organizations.
- Engagement opportunities can be woven into existing advisory committee meeting agendas or they can be distinct projects conducted outside of the advisory committee meetings. Engagement opportunities can include PWLE participating in:

- Continuous improvement projects like sitting on patient safety committees and special project taskforces
- Speaking engagements such as staff training/onboarding and patient education videos
- The hiring process for new staff by sitting on interview panels

Engagement models to consider:

Consultations	• Get feedback directly from patients/caregivers via email or phone on topics like process improvement, projects, scripting, signage, etc.
Participate in Workgroups	• Invite a patient/caregiver to provide a consistent patient perspective on your workgroup or committee
Focus Groups	• Do a deep dive into a problem or process needing improvement
Understand your Data	• Get the perspective of patients in understanding and interpreting data
Conduct a Root cause Analysis	• Hear directly from patients about their perception of the problem



Action steps

For people with lived experience

- There are ways to both deepen and broaden your involvement and influence if you are already sitting on an advisory committee, but interested in doing more. This can include:
 - Speaking with staff leaders/liaisons about your personal interests and goals to identify pathways and resources the organization can provide in support.
 - Connecting with other organizations and engagement opportunities
 - A few examples: Technical Expert Panels for Medicare and Medicaid, National Patient Advocate Foundation, Condition specific foundations/organizations such as: the National Bleeding Disorders Foundation & Autoimmune Association, The PFANetwork, The PATIENTS Professors Academy
- Before accepting engagement opportunities ensure you are given all the necessary information such as:
 - What is the scope and goal of the project and what is the time commitment (how much time but also when/how are meetings held?)

- Are there specific types of lived experiences, demographic characteristics, and/or other skill sets that you will need to support the work?
- How will your input be meaningfully incorporated and acted on? (To avoid token/check-box participation)
- How will outcomes from the work be shared back with you?
- What types of training, support, or preparation will be made available to support your involvement?

For professionals leading CE

- Cultivate pathways for engagement beyond advisory board participation by considering both opportunities for PWLE to support work across your organization and community as well as models of community engagement across the CE Spectrum
- Create a process to gather relevant details that support meaningful and mutually beneficial engagement opportunities including:
 - What are the personal interest areas and goals of the PWLE you work with? (So you know which projects they may be interested in).
 - What is the scope and goal of the project and what is the time commitment (how much time but also when/how are meetings held?)
 - Are there specific types of lived experiences, demographic characteristics, and/or other skill sets that PWLE will need to support the work?
 - How will input from PWLE be meaningfully incorporated and acted on? (To avoid token/check-box participation)
 - How will outcomes from the work be shared back with the PWLE who contributed?
 - What types of training, support, or preparation will PWLE need to meaningfully engage in the work?
 - Is there compensation available, and if so, how much?
- Align on a process for how PWLE will be paired with project opportunities (e.g. an open call, do some projects require specific skill sets/types of lived experience, etc.)

“A lot of PWLE that are part of advisory committees do it because we want change within our communities, and we want to see change happening in tangible and practical ways. So when we think about these opportunities we should think 'is what you're bringing to the table tangible? Can it affect a change.’”



Resources for additional learning

- [The Spectrum of Community Engagement to Ownership](#)
- [COMMUNITY ENGAGEMENT PLANNING CANVAS](#)
- [ACT Framework — PFCCpartners](#)

inspire partners

Organizations



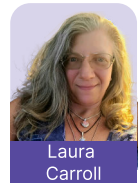
People with lived experience



Alan
Coker



Burt
Pusch



Laura
Carroll



Rebecca
Esparza



Savina
Makalena



Stephanie
Burdick