

PLEX Engagement in Research Community of Practice

Jun 2025: Engaging Patient Partners in E-Learning Design—Making Research more Participatory

This document provides a summary of engaging people with lived experience (PLEX) in the development of e-learning resources.

Key Presentation Points

- Engaging PLEX is crucial to ensure that e-learning resources are user-friendly, accessible, and relevant
- Recognize the individual abilities, strengths, and resilience of PLEX
- PLEX are the experts in what they went through and continue to experience
- Being inclusive of PLEX with diverse voices and experiences often involves working to overcome the unique intersecting circumstances that could create barriers

What did we discuss?

- **Involve PLEX across the spectrum of engagement:** PLEX can be involved in analysis, design, development, implementation, and adaptation of research outputs
- **PLEX are unique and are not a “homogenous group”:** PLEX have individual experiences that have their own nuances
- **Clear and open communication with PLEX is vital:** Keep PLEX informed on the research process including timelines and delays
- **Remain flexible when working with PLEX:** Keep an open mind in relation to adapting study designs and methods to better address questions important to PLEX
- **Families and caregivers play an important role in patient journeys:** Be mindful that families and caregivers are also PLEX and bring value to research

Relevant Resources on PLEX Engagement in Research:

1. [Participatory Research Module](#): A link to an interactive module designed to provide researchers with strategies to strengthen meaningful collaboration with patient partners and community members, particularly those from underserved or equity-denied groups
2. [NUY50](#): Dawn Barker’s movement to reshape the way that breast cancer is viewed, researched and supported within underserved communities