

Patient Engagement in Research Community of Practice

September 2023: The importance of Trauma-Informed Engagement and Critical Reflexive Practice in Patient-Oriented Research

This document provides a presentation summary about how to engage patient and family caregivers in research using a trauma-informed and critical reflexive practice approach.

Key Presentation Points

- A trauma-informed approach examines the physical, emotional, psychological, cultural and spiritual safety of people.
- It is important to distinguish between a safety zone and comfort zone. It may be okay to feel uncomfortable, but it is not okay to feel unsafe.
- Critical reflexive practice involves thinking and reflecting on the socially constructed locations each person inhabits.

What did we discuss?

- **Create safe and trustworthy environments:** Adapt physical or online spaces to be warm and welcoming, and start meetings with introductions. Provide clear and accessible information and ensure everyone understands confidentiality. Create crisis plans if people are in distress including having separate rooms or additional support and resources. Demonstrate predictable expectations and schedule consistent meetings. Be open and honest from the beginning and set realistic expectations to help manage the issue of research timelines. Schedule meetings to socialize and connect outside of the research to build relationships and trust.
- **Remove barriers:** Address barriers to engagement by providing choice and collaboration by brainstorming sessions with people with lived experience. Some strategies may include: 1) understanding people's priorities and hopes; 2) inquiring about others who they feel should be included in the engagement opportunity; and 3) using statements that make collaboration and choice explicit.
- **Provide support:** When a person with lived experience shares their story, it can be a powerful way for them to process, assert their agency over their experience, and lighten their emotional load. As researchers, it is important to listen and provide them with support. Another important part of the process is sharing affirmations by acknowledging effort and strength, offering appreciation and understanding, and recognizing success.
- **Self care for people with lived experience and research staff:** Self care can look different for people. It can be seen as having variation in your day and role, attending continuing education sessions, taking scheduled breaks throughout the day, socializing, exercising, or eating. Self-care can also look like developing a personal debriefing plan with peers or a supervisor.

Relevant Resources on Patient Engagement in Research

- [Readiness to Engage Workbook](#): A workbook that provides guidance to Research Teams and Partners planning on engaging or evaluating engagement.
- [Valuing all Voices Framework](#): A guiding framework for health research teams to make patient and public engagement more meaningful and inclusive.