

Engaging People with Lived Experience – Worksheet

Assessing readiness to engage with people with lived experience in a research setting

To conduct effective health research, researchers must be ready to engage people with lived experience (PWLE) as a part of their process. Sometimes, there is strong support and receptivity to such work; in other cases, there can be challenges. It is important to acknowledge that to be effective, a shift in thinking must occur in which PWLE are seen as active and valued participants in the research process.

Instructions: Have each member of your research team answer the following set of questions on engaging PWLE in research. These questions can be especially helpful for research team members who are new to working with PWLE; they can benefit from learning from others who have had such experiences. After everyone has completed the survey, feel free to discuss your responses as a team.

If a lack of readiness is determined, consider consulting with another research team who has successfully engaged PWLE in their work for additional recommendations and guidance.

	Yes	No	Rationale/Comments
1. Regarding engaging PWLE, I believe that they...			
a. Bring unique perspectives that will strengthen the research project			
b. Have valuable knowledge as a result of their lived experience			
c. Are able to look beyond their own experience and inform this project to impact all patients and families			
d. Believe their perspectives and opinions on planning and decision-making in the research context are as valid as those of the research team			
2. As a member of the research team, I have...			
a. Experience working with PWLE			
b. An understanding of the role and expectations of PWLE and how these may differ from other members of the research team			
c. Experience and feel comfortable delegating responsibilities to PWLE in relation to the research project			
d. An understanding that PWLE may be unable to continue engaging in the research project due to their own healthcare responsibilities			