

Planning engagement

Engagement Details	
<div>Reasons to engage</div> <div>Outline why you want to engage people with lived experience</div>	<div><input type="checkbox"/> Gathering ideas for new research areas based on patients’ needs</div> <div><input type="checkbox"/> Ensuring research is focused and relevant to the patients’ interests and concerns</div> <div><input type="checkbox"/> Ensuring transparency and accountability in research</div> <div><input type="checkbox"/> Ensuring that the methods are acceptable and sensitive to the circumstances of research participants</div> <div><input type="checkbox"/> Making the language and content of information more appropriate and accessible</div> <div><input type="checkbox"/> Increasing participation in research</div> <div><input type="checkbox"/> Collecting data by, with, and for people with lived experience</div> <div><input type="checkbox"/> Taking diverse perspectives into account when analyzing data</div> <div><input type="checkbox"/> Taking diverse perspectives into account when making decisions</div> <div><input type="checkbox"/> Increasing the dissemination and uptake of research findings</div> <div><input type="checkbox"/> Funding and supporting patient-led ideas</div> <div><input type="checkbox"/> Meeting funder requirements</div> <div><input type="checkbox"/> Acknowledging the strength of innovations led by people with lived experience</div> <div><input type="checkbox"/> Other: _____</div>
<div>Readiness</div> <div>Describe your readiness to engage people</div>	<div><input type="checkbox"/> Am aware of the need to engage people with lived experience in health research</div> <div><input type="checkbox"/> Have the desire, attitudes, and attributes to engage people with lived experience</div> <div><input type="checkbox"/> Have knowledge about the values, practices, and principles of patient engagement in research</div> <div><input type="checkbox"/> Have knowledge about the principles of cultural humility and safety</div> <div><input type="checkbox"/> Recognize and respect the strengths, values, and expertise that people with lived experience bring</div> <div><input type="checkbox"/> Have sought out training and education for my team members and for me to be able to engage</div> <div><input type="checkbox"/> Have the ability to implement, monitor, and evaluate engagement</div> <div><input type="checkbox"/> Have identified ways that I can make sure that people feel safer to engage</div> <div><input type="checkbox"/> Have reviewed the benefits that I might be able to offer patients to build reciprocal relationships</div> <div><input type="checkbox"/> Have ideas as to how to negotiate power imbalances within my project team</div> <div><input type="checkbox"/> Other: _____</div>

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<div>Partner roles</div> <div>Describe the roles people with lived experience will play in the project</div>	<div><div><input type="checkbox"/> Research team member</div><div><input type="checkbox"/> Decision-maker</div><div><input type="checkbox"/> Peer Reviewer</div><div><input type="checkbox"/> Research Knowledge Ambassador</div><div><input type="checkbox"/> Fundraising Ambassador</div></div>
<div>Engagement purpose</div> <div>Describe the purpose of engagement</div>	<div><input type="checkbox"/> Consult: To obtain lived experience feedback in certain areas</div> <div><input type="checkbox"/> Involve: To work directly with people with lived experience throughout the process</div> <div><input type="checkbox"/> Collaborate: To partner with people with lived experience in each aspect of the decision</div> <div><input type="checkbox"/> Empower: To place final decision making in the hands of people with lived experience or support them to lead a project or project component</div>
<div>Perspectives</div> <div>Outline the type of lived experience and perspectives needed on the team</div>	<div><div><input type="checkbox"/> People who have current experience with a specific condition, service, or treatment</div><div><input type="checkbox"/> People who have former experience with a specific condition, service, or treatment</div><div><input type="checkbox"/> Care partners</div><div><input type="checkbox"/> Family members</div><div><input type="checkbox"/> Community-based organizations or groups</div><div><input type="checkbox"/> Patient-led organizations or groups</div><div><input type="checkbox"/> Public</div><div><input type="checkbox"/> Other: _____</div></div> <div>Note: Consider whether a variety of people with lived experience is being engaged. Engage more than one person with lived experience. Ensure that the group of people with lived experience is diverse and representative of those experiencing the health condition, service, or treatment that is the focus of the research.</div>

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Timing of engagement State when the engagement will begin	<div><input type="checkbox"/> From generating the idea for a project</div> <div><input type="checkbox"/> Planning a grant or developing a research study design</div> <div><input type="checkbox"/> Applying for funding</div> <div><input type="checkbox"/> Developing the research team</div> <div><input type="checkbox"/> Implementing a study or specific aspect of study</div> <div><input type="checkbox"/> Sharing research results once a project is completed</div> <div>Note: Bring people with lived experience in at the very beginning and engage them throughout the research project</div>			
Method of engagement Describe how you will engage people with lived experience	CONSULT	INVOLVE	COLLABORATE	EMPOWER
	<div><input type="checkbox"/> Focus groups</div> <div><input type="checkbox"/> Surveys</div> <div><input type="checkbox"/> Interviews</div> <div><input type="checkbox"/> Opinion polls</div> <div><input type="checkbox"/> Forms</div> <div><input type="checkbox"/> Social media</div> <div><input type="checkbox"/> Forum, town hall, public meeting</div>	<div><input type="checkbox"/> Debates</div> <div><input type="checkbox"/> Panels</div> <div><input type="checkbox"/> Advisory committees</div> <div><input type="checkbox"/> Shadowing</div> <div><input type="checkbox"/> Workshops</div> <div><input type="checkbox"/> Working with existing patient groups</div>	<div><input type="checkbox"/> People with lived experience as team members</div> <div><input type="checkbox"/> Round tables</div> <div><input type="checkbox"/> Journey mapping</div> <div><input type="checkbox"/> Participatory decision making</div>	<div><input type="checkbox"/> Patient juries</div> <div><input type="checkbox"/> Patient-led research</div> <div><input type="checkbox"/> Think tanks</div> <div><input type="checkbox"/> Delegated decision making</div>

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Recruitment Describe how you will identify potential people with lived experience	<div><input type="checkbox"/> Ask your colleagues to identify potential contacts and relationships they have</div> <div><input type="checkbox"/> Connect with the PiPER office</div> <div><input type="checkbox"/> Connect with the Strategy for Patient-Oriented Research—Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit</div> <div><input type="checkbox"/> Consult existing patient advisory committees</div> <div><input type="checkbox"/> Build relationships with patient-led groups, community-based organizations, or advocacy organizations</div> <div><input type="checkbox"/> Advertise in plain language in various locations</div> <div><input type="checkbox"/> Use social media</div> <div><input type="checkbox"/> Include information about opportunities for engagement in patient-facing forms, surveys, and digital platforms</div> <div><input type="checkbox"/> Ask community members about people who might be interested in getting involved</div> <div>Note: Before recruiting, consider the engagement environment and work to address any barriers to engagement to promote diverse representation among the people with lived experience who are engaged.</div>