



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

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People with Lived Experience Roles Describe the roles people with lived experience will play in the project	☐ Research Team Member ☐ Decision Maker ☐ Peer Reviewer ☐ Research Knowledge Ambassador ☐ Fundraising Ambassador
Engagement purpose Describe the purpose of engagement	☐ Consult: To obtain lived experience feedback in certain areas ☐ Involve: To work directly with people with lived experience throughout the process ☐ Collaborate: To partner with people with lived experience on all aspects of the project or initiative, including the team’s decision making processes. ☐ Empower: To place final decision making in the hands of people with lived experience or support them to lead a project or project component ☐ Innovate: To create, design, and lead the development of new ideas, methods, therapies, and devices
Perspectives Outline the type of lived experience and perspectives needed on the team	☐ People who have current experience with a specific condition, service, or treatment ☐ People who have former experience with a specific condition, service, or treatment ☐ Care partners ☐ Family members ☐ Community-based organizations or groups ☐ Patient-led organizations or groups ☐ Public ☐ Other: _____ Note: Consider whether a variety of people with lived experience are 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.



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

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Recruitment Describe how you will identify potential people with lived experience	☐ Ask your colleagues to identify potential contacts and relationships they have ☐ Connect with the PiPER team (piper@uhn.ca) ☐ Connect with the PiPER Network of Networks ☐ Connect with the Strategy for Patient-Oriented Research—Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit ☐ Consult existing patient advisory committees ☐ Build relationships with patient-led groups, community-based organizations, or advocacy organizations ☐ Advertise in plain language in various locations ☐ Use social media ☐ Include information about opportunities for engagement in patient-facing forms, surveys, and digital platforms ☐ Ask community members about people who might be interested in getting involved 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.