Engaging People with Lived Experience in Research at University Health Network

A toolkit to support authentic engagement of patients, families, and care partners in research

PiPER ⚙UHN   Toronto General
Toronto Western
Princess Margaret
Toronto Rehab
Michener Institute

Pride in Patient Engagement in Research

Executive Summary

This toolkit is intended for routine use by University Health Network (UHN) scientists, research staff, trainees, community organizations, and people with lived experience to help plan, implement, and evaluate patient engagement in research (PER).

This toolkit describes five common roles people with lived experience may play when engaging in research. For each role, training resources are identified for UHN scientists, research staff, and people with lived experience before starting PER activities. PER planning, implementation, and financial considerations are outlined. A recommended evaluation framework is provided to evaluate the success of PER activities among research teams.

This toolkit is meant to be a living document that will help drive our vision for UHN to be a world leader in health research excellence. With the following goals for research impact, our research teams aim to address the unmet needs of the patients and communities we serve by:

- Advancing the fundamental understanding of health and disease;
- Accelerating discovery and translation to clinical practice; and,
- Training and developing tomorrow's research leaders.

We are confident that meaningfully engaging and incorporating the voice of people with lived experience into research will measurably strengthen our learning health system and the impact and reach of UHN research.

Design and layout were created in partnership with:

Patient Education

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Research at University Health Network

University Health Network (UHN) provides patient care, leads research, and administers education programs across Toronto and the country (**www.uhn.ca**). It is one of the largest hospital-based research programs in North America and the largest in Canada. UHN is made up of 10 hospital sites, the Michener Institute of Education, and 6 research institutes. UHN is fully affiliated with the University of Toronto and is a member of a network of academic hospitals and organizations affiliated with the University of Toronto called the Toronto Academic Health Science Network (**https://tahsn.ca/**).

UHN's research is led by over 1100 scientists and 3600 staff and trainees in 1 million square feet of research space across the 6 research institutes: Toronto General Hospital Research Institute, Krembil Research Institute, Princess Margaret Cancer Centre, KITE Research Institute, McEwen Stem Cell Institute, and The Institute for Education Research.

Research at UHN is funded in part by two dedicated foundations: (1) The UHN Foundation, together with donors, raises funds for research, education, and the improvement of patient care at Toronto General, Toronto Western, Toronto

Rehab, and the Michener Institute of Education; and (2) The Princess Margaret Cancer Foundation, together with donors, supports cancer-related research, education, and care.

In 2019, UHN launched the Strategic Research Plan 2019–23, with the following mission: "Together, we drive excellence in discovery and innovation to create a Healthier World". [1] The plan describes 5 priorities that will enhance our research impact and organizational excellence:

- Engage every patient to strengthen our learning health system
- Empower research teams and collaboration
- Accelerate the translation of discovery to practice
- Unleash the power of technology and innovation
- Grow research through financially sustainable structures

This toolkit is one of the key strategic deliverables related to engaging patients, families and care partners in research to strengthen our learning health system. A learning health system collects, analyzes, and uses information from practice and research in real time to help organizations continuously learn, refine processes, and grow. [2]

To learn more about UHN Research, visit **https://www.uhnresearch.ca/service/strategic-plan**

Patient Engagement at UHN

UHN is committed to a culture of engaging patients, families, and care partners. UHN has teams in the Patient Engagement portfolio that support patient engagement in patient care and program and service design at the organizational and system levels.

As experts in their own experience, patients, families, and care partners provide rich knowledge and perspectives that staff or scientists may not have. The Patient Partnerships program at UHN has developed programs that help patients, team members, and leaders work together meaningfully

toward high-quality and safe, equitable care. These programs are guided by the UHN declaration of patient values (**https://www.uhn.ca/corporate/AboutUHN/Quality_Patient_Safety/Pages/patient_values.aspx**). With the creation of the Pride in Patient Engagement in Research (PiPER) Steering Committee, we now have a mechanism to build these values into engaging patients, families, and care partners in research processes.

The PiPER Steering Committee focuses on engaging every patient in research to strengthen our learning health system. The PiPER Steering Committee's goal is to build organizational structures and technology that promote and embed the engagement of patients, families and care partners in our research. Our aim is for engagement to be authentic, accountable, transparent, and responsive. We envision a future where UHN is an international exemplar for the engagement of patients, families, care partners, and partner organizations in research. We expect that authentic engagement of people with lived experience will measurably increase the impact and reach of our research.

Traditionally, research at UHN has involved patients and their families or care partners as participants in health research. Scientists designed their studies and collected data from patients and their care partners. Increasingly, research teams are recognizing the value of engaging people with lived experience in conceiving, designing, and implementing research to improve research and care.

Many UHN organizational leaders, scientists, research staff, trainees, and current or former patients are working to understand what authentic patient engagement means and how best to promote and implement it. Authentic engagement of people with lived experience can be inspiring and rewarding and requires shared understanding, planning, and training.

This toolkit gives advice on how to build meaningful partnerships between people with lived experience and research teams at UHN. The toolkit offers information and resources for UHN scientists, research staff, trainees, community organizations, and current or future patients and care partners to help plan, implement, and evaluate patient engagement in research. The toolkit:

- Defines concepts related to patient engagement in research
- Describes the roles people with lived experience can play in research
- Identifies training resources specific to the roles that individuals can play within research projects, programs, departments, or research institutes at UHN
- Identifies tools to plan, implement, and evaluate the success of patient engagement in research

Developing this toolkit involved convening 5 working groups to focus on each one of the identified roles people with lived experience can play in research at UHN. Over 40 UHN scientists, research staff, trainees, and people with lived experience participated in a series of virtual meetings to gather perspectives around role descriptions, training requirements, and the impact of engagement over time.

This toolkit will be a living document.

Users of the toolkit are encouraged to share the toolkit with others. The toolkit may be copied freely; however, the content cannot be altered without permission from the PiPER team. Please share your experiences, your comments, and questions about the toolkit by completing a brief survey (**https://www.surveymonkey.com/r/KSM7TCS**) or by emailing us at **piper@uhn.ca**. We want you to be part of the ongoing development of the toolkit!

We will develop and link learning resources related to the toolkit internally for UHN scientists and research staff through the My Learning System and externally for people with lived experience through our website: **https://kite-uhn.com/piper**

Understanding
patient engagement in research

Throughout this toolkit, we use the phrase **"patient engagement in research"** or the short form **"PER"** to describe patients, families, and care partners engaging to plan, do, and share research. PER can take place in a variety of ways at UHN, including engaging within a research project, research program, research department, or research institute (**See Glossary**). PER is a way to bring the voice, expertise, and experience of people directly affected by research into the processes of conceiving, planning, doing, and sharing that research.

Research project

Research department

Research program

Research institute
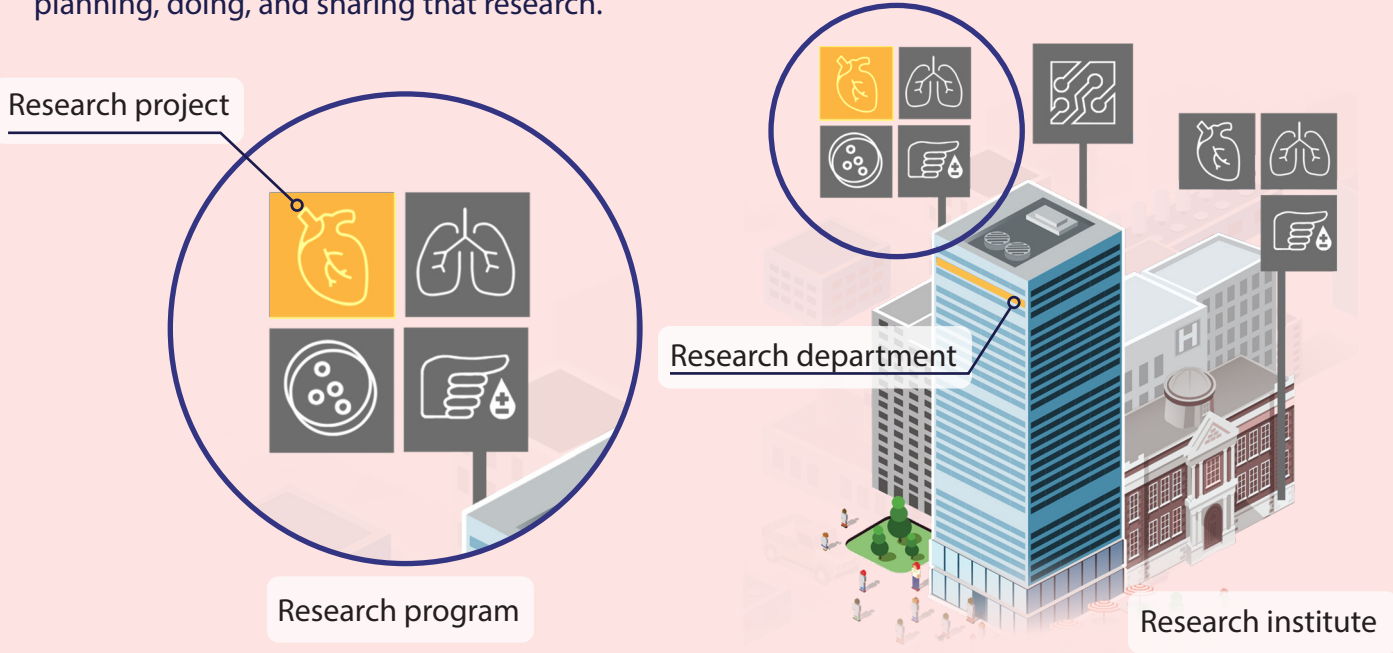
The term **"people with lived experience"** is used throughout this toolkit to refer to people who have direct experience with a health issue or with the health care system, their families, and/or their care partners. Other words can be used to describe people with lived experience, such as **"patient," "patient partner," "community member," "lived experience partners,"** among other terms. We use the term "person with lived experience" in this toolkit to cover all of these terms.

The following toolkit definitions will help to get you started:

Person with Lived Experience

A person with direct experience of a health condition or interactions with the health care system. They may be a current or former patient, a family member, or a care partner. A person with lived experience is an expert by experience.
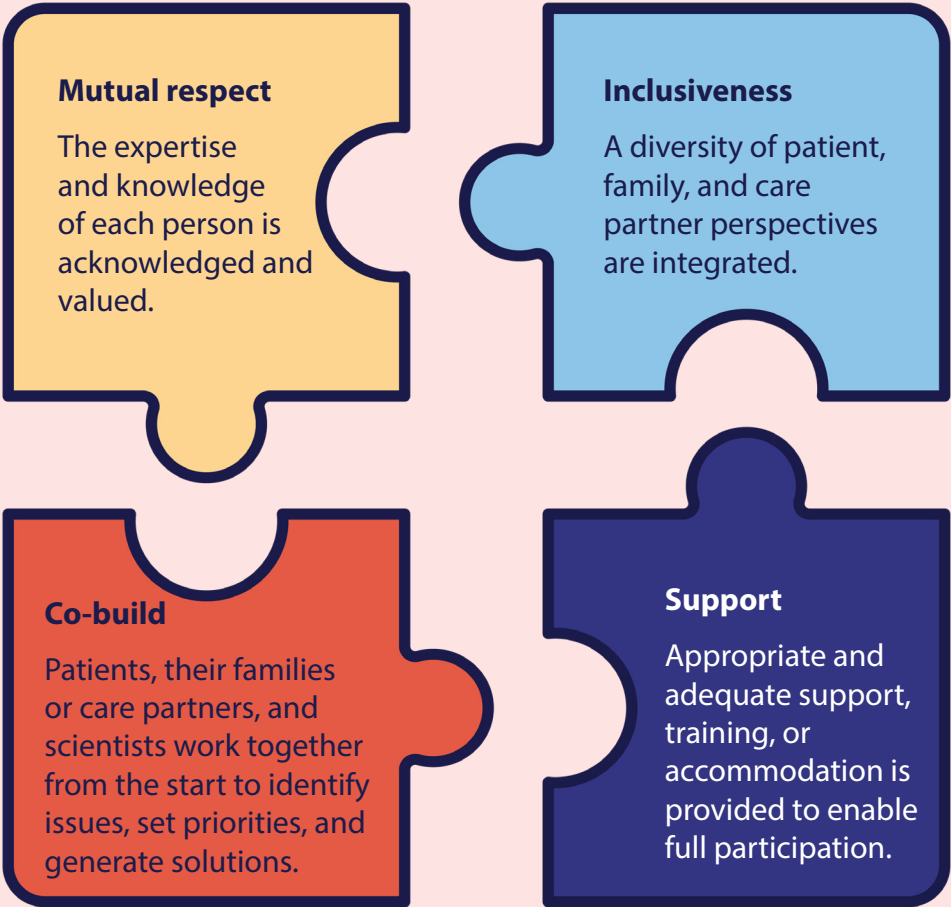
Patient Engagement in Research (PER)

The active, meaningful, and collaborative interaction between people with lived experience and scientists across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognizing their experiences, perspectives, priorities, and expertise. [3]

The term patient engagement in research does not mean:

- Patients, families, and care partners taking part in a research study as a study participants, where information is collected from or about them to help answer a research question; or
- Patients making decisions about their individual care, advising on issues related to the quality of clinical care, or reporting on their individual health care experience.

The Canadian Institutes of Health Research identifies guiding principles of PER. UHN supports these principles as follows [3]:

Mutual respect
The expertise and knowledge of each person is acknowledged and valued.

Inclusiveness
A diversity of patient, family, and care partner perspectives are integrated.

Co-build
Patients, their families or care partners, and scientists work together from the start to identify issues, set priorities, and generate solutions.

Support
Appropriate and adequate support, training, or accommodation is provided to enable full participation.

" **Patients' lived experiences** and expertise complement the medical and scientific training and knowledge of other team members—leading to insights and research being done that wouldn't otherwise be done, or done in the way it is, when patients are team members. I've seen more relevant research and research outcomes when patients are part of the team."

- Working Group Member

The value and importance of
patient engagement in research

PER benefits all who are involved. People with lived experience engaged in research can make a difference and benefit the health system or themselves and others by [4]:

- Participating in a meaningful research activity
- Learning how research results can change the health system
- Developing new knowledge and skills
- Building relationships, peer support, and their social network
- Increasing their confidence and belief in themselves
- Learning to manage their health conditions
- Advocating for research priorities that directly affects them, their family, or their community

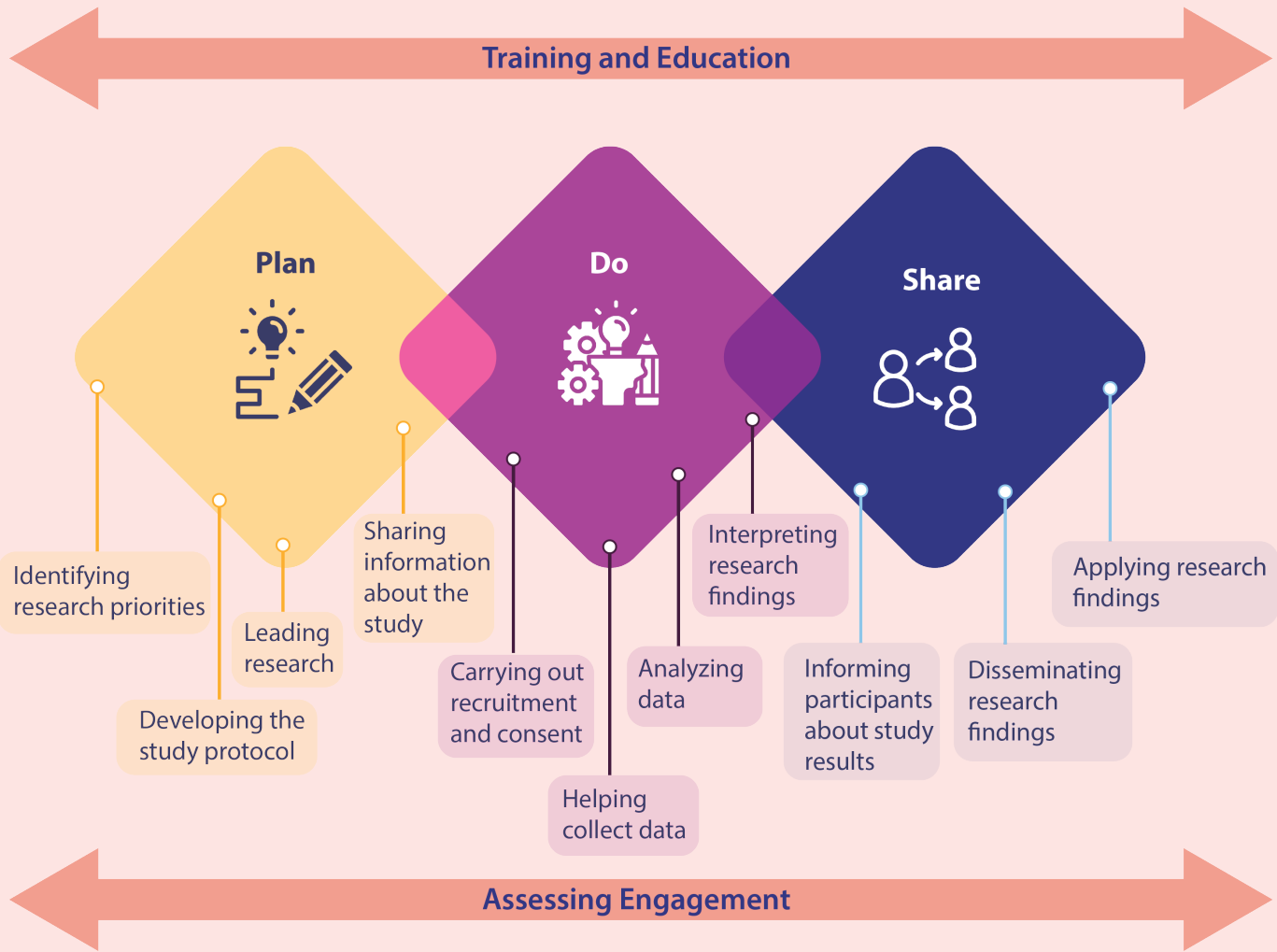Scientists engaging in PER can benefit through [5–7]:

- Better understanding of issues and research priorities based on the knowledge and perspectives of people with lived experience
- Improved responsiveness and alignment of research with the experiences, preferences, needs, and concerns of people with lived experience
- Increased participant enrollment and retention in research
- Strengthened relationships with patients
- Improved relevance, quality, and outcomes of research
- Broader impact and application of research findings

Engaging people with lived experience offers a chance to improve not only our research processes but the outcomes of our research. Doing so can lead to better health outcomes at the level of individuals and populations.

Engagement can occur across one, some, or all phases and types of research. PER can start before, during or after a research project. Figure 1 demonstrates the types of activities people with lived experience can engage in throughout research phases to plan, do, and share research.

Figure 1: Activities people with lived experience can engage in during the research process [8]

Training and Education

Plan
- Identifying research priorities
- Leading research
- Developing the study protocol
- Sharing information about the study

Do
- Carrying out recruitment and consent
- Helping collect data
- Analyzing data
- Interpreting research findings

Share
- Informing participants about study results
- Disseminating research findings
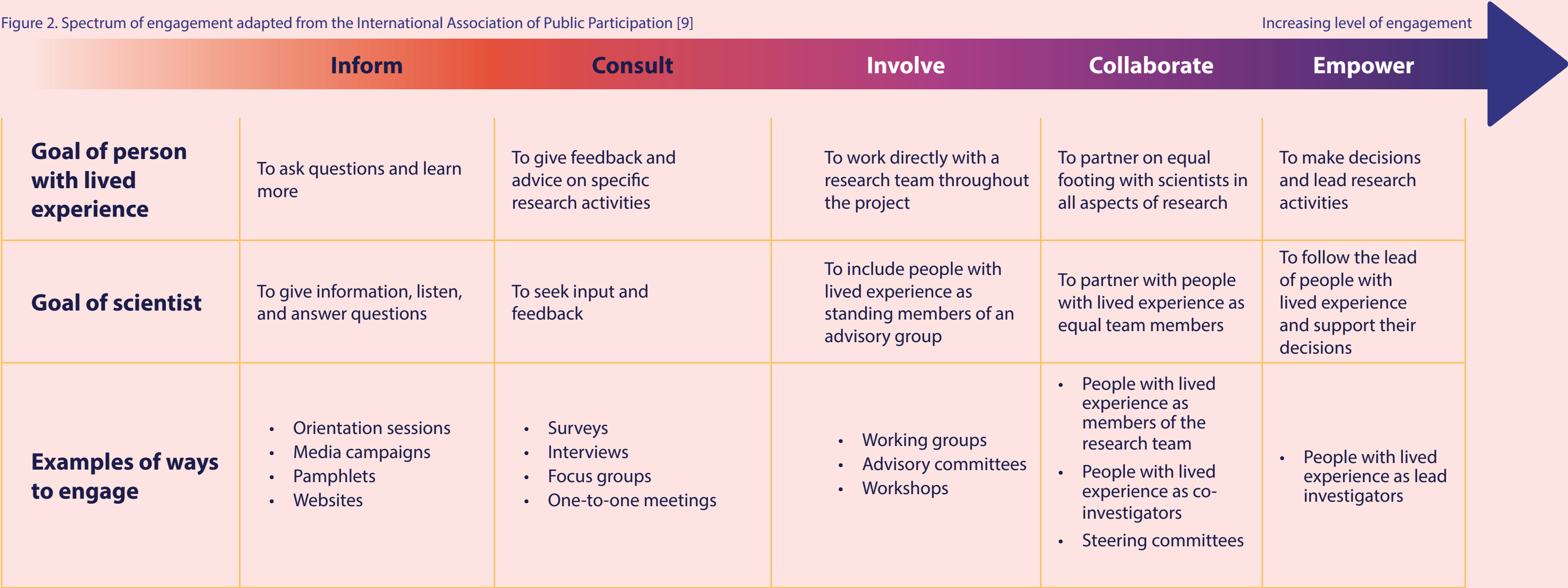- Applying research findings

Assessing Engagement

The spectrum of **engagement**

There is no "one size fits all" approach to PER. Engagement looks different depending on the type of roles people with lived experience play and their level of engagement. The level of engagement will depend on many factors, such as the goals of scientists and people with lived experience, and their time, resources, and capabilities, among other factors.

The levels of engagement can be seen as a spectrum (Figure 2): the higher the level of engagement, the more influence people with lived experience have on the research process, decision making, and outcomes. A helpful tool to understand the spectrum of engagement and potential ways to engage people with lived experience is from the International Association of Public Participation.[9] There are many ways scientists and their teams can engage people with lived experience and assure their comfort, preparation, and ability to participate in meaningful PER, so PER must be tailored to each set of circumstances and each person or group of people with lived experience.

Figure 2. Spectrum of engagement adapted from the International Association of Public Participation [9]

Increasing level of engagement →

	Inform	Consult	Involve	Collaborate	Empower
Goal of person with lived experience	To ask questions and learn more	To give feedback and advice on specific research activities	To work directly with a research team throughout the project	To partner on equal footing with scientists in all aspects of research	To make decisions and lead research activities
Goal of scientist	To give information, listen, and answer questions	To seek input and feedback	To include people with lived experience as standing members of an advisory group	To partner with people with lived experience as equal team members	To follow the lead of people with lived experience and support their decisions
Examples of ways to engage	• Orientation sessions • Media campaigns • Pamphlets • Websites	• Surveys • Interviews • Focus groups • One-to-one meetings	• Working groups • Advisory committees • Workshops	• People with lived experience as members of the research team • People with lived experience as co-investigators • Steering committees	• People with lived experience as lead investigators

Key considerations for scientists about patient engagement in research

There are several things to consider before, during, and after PER to create a process that is respectful, supportive, and authentic. The following engagement considerations can help scientists better understand how to engage people with lived in experience in research. This list of engagement considerations is a combination of information gathered from scientific articles, [10, 11] and the self-reported experiences of people with lived experience, the PiPER Steering Committee and working group members.

COMMUNICATION

Communicating clearly and consistently will help all members of the team work better together

- Assign a dedicated research staff member who will communicate with people with lived experience for support, training, and other PER-related issues
- Use plain language for written and verbal communication
- Determine with people with lived experience how they prefer to communicate: email, telephone, text message, virtual or in-person meetings
- Establish how you will communicate as a team while maintaining privacy and confidentiality
- Make sure people with lived experience have access to information
- Share materials at least 24 hours before meetings, ideally a week before
- Avoid using acronyms as much as possible. If using acronyms, provide a glossary of acronyms
- Provide information in varied or preferred formats
- Use culturally safe and inclusive language

ROLES AND RESPONSIBILITIES

Being transparent about the expectations can help misinterpretation and improve the collaboration experience.

- Discuss with people with lived experience how they would like to be identified throughout the research project and on research materials
- Agree on the roles and activities that people with lived experience will engage in during the project
- Outline the role in 'terms of reference' or a 'statement of work'. Specify the time commitment, expectations, compensation, and processes for achieving consensus and resolving conflicts
- Ensure that people with lived experience have time to give feedback
- Include people with lived experience on all published manuscripts and research products when they meet authorship criteria and choose to be identified
- Acknowledge the end of a partnership in writing with thanks

CAPABILITY

People with lived experience come to research with different skills, experiences, and familiarity with research. Having conversations about training and support helps to tailor the approach according to their needs.

- Work with people with lived experience to identify and remove barriers to participation
- Be flexible with meeting places, times, and format; ask people with lived experience when and where they feel safe to engage
- Engage in a two-way dialogue about training and support
- Identify and meet training needs for yourself and other team members
- Provide training throughout the project
- Use co-learning approaches with people with lived experience
- Provide opportunities for people with lived experience to provide peer-to-peer mentorship
- Dedicate time and space for people with lived experience to network among themselves

RELATIONSHIPS

People with lived experience bring unique and valuable perspectives to research that would otherwise be missing. Sharing this expertise requires relationships built on trust, honesty, respect, transparency, and reciprocity.

- Engage people with lived experience early, often, and throughout the research project
- Engage several people with lived experience to ensure a variety of perspectives related to the research project. Using other approaches like focus groups can add other experiences
- Integrate people with lived experience as equal collaborative research team members
- Consider and apply inclusion, diversity, equity, and accessibility principles in recruiting and retaining people with lived experience
- Distribute a list of research team members, their roles, and biographies to share ahead of meetings
- Use first names and pronouns and avoid using titles or academic credentials, wherever possible
- Add an icebreaker to the start of a meeting for introductions
- Respect confidentiality and do not share experiences with others outside of the research team without permission
- Create spaces for all members of the team to be heard
- Discuss attendee and team feedback after large events
- Demonstrate where and how input from people with lived experience was incorporated
- Celebrate accomplishments and build morale with post-event debriefs
- Schedule time for informal activities to connect around topics beyond research

FINANCIAL COMPENSATION

Compensating people with lived experience fairly for their engagement helps acknowledge their value and contributions.

- Engage people with lived experience in conversations about their expectations to ensure fair compensation and timely reimbursement of expenses
- Be transparent about the funds available, methods for, and timing of compensation
- Budget for expenses such as travel, meals, or accessibility needs (for example, attendant care)
- Use UHN tools and policies to develop PER budgets for your grants

SUSTAINABILITY

Monitoring, checking in about, and evaluating patient engagement can help research teams retain partnerships and understand what went well or how the team can improve.

- Agree on time points to check in and gather feedback for continuous learning and to identify opportunities for improvement
- Evaluate the progress and outcome of PER from multiple perspectives (for example, scientist, people with lived experience)
- Acknowledge where and how the perspectives of people with lived experience were integrated
- Provide an opportunity for people with lived experience to reflect or debrief on meetings, projects, or programs of research as appropriate
- Use established UHN tools to measure PER

Planning to engage
people with lived experience in research

Before getting started with engagement, scientists and their teams need to reflect upon their own goals, readiness, and ability to engage people with lived experience in research. Use the questions below to help you decide on your PER motivations and activities.

Should I engage people with lived experience?

- What perspective do I hope people with lived experience will bring to the project?
- What gaps will exist if people with lived experience are not engaged?
- What do I hope people with lived experience will contribute to the project?
- Will we value the perspectives of people with lived experience equally?
- What is the likelihood that the team and I will be able to listen to, fully consider, and integrate contributions from people with lived experience?
- How will I account for diversity when engaging people with lived experience, e.g., income, gender, race, age?

What role can people with lived experience play on the research or project team?
(Make a list of activities and select the most appropriate roles before proceeding—see pages 17-26)

- What types of activities or tasks will people with lived experience have in each role?
- What level of engagement is needed in each role?
- What approach can I use to engage people with lived experience?
- How many hours of work do I expect for each role?
- What will the total length of each engagement be?

Do I have the time and resources to engage people with lived experience in a meaningful way in my project?

- What are my study or project timelines?
- Do I have the budget to compensate and reimburse people with lived experience?
- How much should I budget for engagement given the nature of the work?
- What type of compensation structures are available?
- Beyond compensation, what other benefits might I be able to offer people with lived experience?
- What training do I need? What additional training do my staff need?
- Do I have staff to orient, train, and support people with lived experience during the research project?
- What training can I provide people with lived experience?
- Do I have resources to support people with lived experience in the planned role to ensure they feel safe and comfortable working with our research team?

Should I engage in the project?

- What are my priorities?
- What do I hope to gain from being engaged in the project?
- How will I communicate with the research team?
- How do I want to contribute on the research project?

Do I know what the engagement will look like?

- What roles can I play on the research team?
- What types of activities or tasks can I be engaged in?
- Do the activities in this role align with my priorities?
- What level of engagement am I comfortable with?
- What are the risks and benefits?
- What are the risks and benefits of participation?
- How many hours of work are expected from me?

Does the project team provide resources and supports?

- Who on the research team will provide me with support?
- What training do I need?
- What training is offered?
- What funds are available to cover my expenses and pay me for my work?
- Do I know when, and how, I will be reimbursed for expenses and paid for my work?
- What supports are offered to help me participate fully?

The types of engagements

Before engagement begins, scientists must consider (a) the roles people with lived experience will play; (b) the intended nature, duration, and level of the engagement; and (c) the compensation structure. Based on these considerations, people with lived experience may be engaged in contract work or time-limited and project-based employment agreements for their roles within research projects, programs, departments, or research institutes at UHN. While compensation structures can change over time, the salary paid to people with lived experience hired as UHN employees should align with the UHN research compensation guide.

Table 1. Examples of types of engagements and activities related to research team member roles

Stage of research	Research team member compensated via one-time, short-term, casual, or part-time contract	Research team member hired as a UHN employee
Planning the research	• Contribute to the design of the strategy to recruit research participants (for example, giving feedback on recruitment materials) • Give feedback on research ethics board applications or consent forms	• Implement strategy to recruit research participants • Prepare the ethics application
Doing the research	• Access summary notes and de-identified information. Do not have access to organizational infrastructure to access patient health records for study purposes	• Accesses patient health records for study purposes
Responsibilities	• Engage in research team meetings • Communicate availability and interest in various activities and participate as appropriate • Mentor people with lived experience who are new to this role to facilitate their learning	• Meet responsibilities and specific tasks outlined in job description • Engage in performance reviews with supervisor • Mentor people with lived experience who are new to this role to facilitate their learning

It is important to foster inclusive PER that engages a diversity of people with lived experience. When thinking about PER, think about the variety of considerations that make up a person, including but not limited to, race, age, gender, economic status, religious beliefs, physical abilities, geographic location, amongst others. Increasing diversity can improve research impact and outcomes.

Roles for people with lived experience in
patient engagement in research

The following sections of the toolkit describe the roles that people with lived experience can have within research projects, research programs, departments, or research institutes at UHN. The role profiles include these components:

- **Role definition**
- **Descriptions of the different types of activities that role may involve**
- **Training resources for scientists, research staff, trainees, and people with lived experience before PER**
- **Key implementation considerations**

Scientists and people with lived experience should familiarize themselves with these roles and use the role definitions, related activities, and training resources to guide their discussions with one another. We have given common examples of activities associated with each role, but the lists are not exhaustive. UHN is a rich research environment with many different kinds of research, diverse needs for support from people with lived experience, and a broad array of research impact.

Legend for Training Resources

In the following pages, these icons are used to indicate who the training resources may help on the research team: scientists, research staff/trainees, or people with lived experience. Many training resources are appropriate for more than one group. These training resources are not developed by PiPER. They have been identified by members of our working group.

Scientists

Research Staff/Trainees

People with Lived Experience

The links to the training resources for each role are available at:
https://kite-uhn.com/piper

People with Lived Experience as
Research Team Members

Can perform roles as members of a research team alongside scientists, clinicians, students, and research staff, among others. Research Team Members bring their lived expertise and perspectives (for example, health condition, social identities, environmental context) to their roles, as they engage in one or more phases of a research project. People with lived experience with prior experience in PER may mentor others who are new to the role to increase their comfort, learning, and project contributions.

Plan

- Identify the problems and priorities to be studied
- Co-create the research question
- Contribute to the design of the research plan or program
- Design the strategy to recruit research participants
- Support writing and reviewing grant application for funding

Do

- Provide feedback on participant-facing materials including recruitment materials and consent forms
- Help design the tools to collect data
- Help implement the strategy to recruit research participants
- Conduct interviews, surveys, or other data collection from research participants
- Contribute to the data analysis
- Interpret the data from the perspective of a person with lived experience
- Help define the research approach, the feasibility of implementing the results, and the research outcomes

Share

- Participate in, or contribute to, the plan to share the research results
- Help co-write or review materials that share the research results
- Share the research results in formal and informal settings
- Support the implementation of research results, including policy initiatives

Training resources

Available at: **https://kite-uhn.com/piper**

	Presentation about research basics	Glossary of language research terms	Blog about identifying and preventing tokenism	Modules about the fundamentals of research	Modules on basic research concepts	Training modules on patient engagement in research
Researcher			●	● ●	●	●
Clinician	● ●	● ●		●		● ●
Patient/lived experience	● ●	●	●	●	● ●	●

| | Tip sheet on effective communication | Tip sheet about patient partner roles on a research project | | Webpage about UHN research ethics | Decision aid for patient partners | Modules on research ethics |

Key implementation considerations

- Follow established training and onboarding processes for people with lived experience hired as UHN employees.
- Support all members to work effectively by tailoring the training plans for people with lived experience to ensure that they understand the research process and related ethical principles.

People with Lived Experience as
Research Knowledge Ambassadors

Can help create, communicate, and share materials and information about a research project and its results for a number of audiences. People with lived experience in the Research Knowledge Ambassador role contribute at the start, during, and at the end of the research project. They may monitor and check in with the research team and participants to understand the different needs for communicating and sharing the research. They often help shape the materials used to share the research with participants and audiences for whom the research was intended, or they may identify groups who may benefit from the information. People with lived experience in this role communicate and take part in collaborative conversations about the results of research and its relevance and impact.

Plan

- Determine the target audience that would benefit from knowing about the research results
- Identify the best person(s) to communicate the research results
- Build relationships with or leverage networks of organizations or individuals who might benefit from the research results
- Mentor other people with lived experience who are new to the Research Knowledge Ambassador role to facilitate their learning

Do

- Give context to the results using their own backgrounds and communities' perspectives
- Help craft and provide feedback on the main messages from a completed research project

Share

- Help develop or provide feedback on materials that share the research results in different formats
- Work with communications teams to develop and review posts on the research results for organizational or personal social media channels
- Talk with trainees, learners, or the public about research results
- Talk about how people with lived experience were engaged in the research either alone or with scientists, trainees, or research staff

Training resources

Available at: **https://kite-uhn.com/piper**

	Video about the research and publishing process	Video about publishing journal articles	Video about how to write a plain language summary	Planning template for activities to share research	Graphic about conference abstracts	Presentation about ways to share research
(researcher)			●			
(person)	●	●	●	●	●	●
(person with thought bubble)	●	●		●	●	●

Key implementation considerations

- Support people with lived experience to communicate their key messages on an equal footing with scientists.
- Prepare people with lived experience to receive and respond to critical comments around research findings.

People with Lived Experience as
Peer Reviewers

Can play a role in reviewing research, providing feedback, and evaluating future or past research activities based on their lived experiences and insights. In this role, people with lived experience contribute equally with other research team members to maintain and improve the quality and impact of research. People with lived experience may give feedback during the early stages of research to help scientists improve grant applications or before submitting results to a conference, meeting, or scientific journal. After research applications and materials are submitted for peer review, people with lived experience may take part in formal review processes with other experts in research to judge, evaluate, and determine which materials move forward or receive awards. People with lived experience who are experienced in this role may mentor others who are new to the role to help them learn the peer review process and requirements.

Plan

Give feedback that improves relevance and clarity on:

- Research ideas or concepts before they are put into a proposal or funding application
- Research applications before they are submitted for funding
- Protocol submissions and consent forms before they are sent to a Research Ethics Board

Do

Give feedback that improves relevance and clarity on:

- Reports summarizing research progress or outcomes for a funding agency
- Plain language abstracts, websites, conference or meeting summaries, articles to be published in academic journals, or the content of oral presentations
- Annual reviews of measures to understand and evaluate a research organization's overall performance
- Annual reviews of the PER activities of a UHN research institute

Share

Give feedback that determines which materials move forward:

- Applications for funding submitted to granting agencies
- Research summaries or abstracts submitted to a conference or meeting
- Articles submitted to journals for publication

Training resources

Available at: **https://kite-uhn.com/piper**

	Video about the peer review process	Video about publishing journal articles	Modules about peer review	Graphic about conference abstracts
	●	●	●	●
	●	●	●	●

Key implementation considerations

- Empower people with lived experience to share their perspectives.
- Ensure there is enough time to provide training and work through examples of the specific evaluation process that people with lived experience will be involved in. Provide context for the role of peer reviewers within the broader research process.

People with Lived Experience as
Decision Makers

Can play a role in shared decision making with scientists, clinicians, and staff members when overseeing the activities of a research organization or initiative. They participate in making research decisions with voices equal to those of other decision makers in the organization. People with lived experience provide their overall assessment and feedback, which can inform decisions at many levels of a research organization. People with lived experience can help make major strategic decisions for these organizations by taking part in formal and structured processes — for example, through independently reviewing and voting. They can also help make research decisions about day-to-day activities and plans of a research organization.

Plan

- Participate in committees with UHN scientists and research staff to review studies and engage in discussions to determine which research proposals or programs to fund

- Participate in Research Ethics Board meetings as a community member

- Advise institutes and departments about the prioritization of research activities—for example, the UHN Clinical Research Units

  Participate on committees to hire new research staff members at all levels of the organization by reviewing or providing questions for interview guides, sitting on interview panels, asking applicants questions, and identifying their preferred candidates for positions

Do

- Chair, co-chair, or participate as members of an oversight or steering committee for a research project, conference, or organizational initiative

- Engage in developing research guidelines for research institutes

- Determine the appropriateness and comprehensiveness of research staff onboarding and training

Share

- Serve as a board member on a research organization's board of directors

- Represent a larger patient group and consult with their communities to provide feedback based on their collective perspectives

- Mentor other people with lived experience who are new to the decision-maker role to facilitate their learning

Training resources

Available at: **https://kite-uhn.com/piper**

	Video about the role of community members on Research Ethics Boards	Tip sheet on participating in meetings	Checklist on chairing meetings	Guide on inclusive hiring	Guide on patient representatives on Board of Directors
		●	●		
			●	●	●
	●	●		●	●

Key implementation considerations

- Establish deliberate and transparent processes to ensure decision-making forums give equal opportunity to contribute to decision making.

- Help people with lived experience feel comfortable to share their perspectives even if they differ from those of the research team or other decision makers.

People with Lived Experience as
Fundraising Ambassadors

Can play a role in fundraising within the context of research. In this role, people with lived experience may work closely with the UHN Foundation, scientists, funders, or sponsors to provide advice on efforts to raise money for research within a research team, program, department, or institute at UHN.

Plan

- Give feedback on strategies to raise funds
- Identify what has been effective in events, campaigns, or other strategies to raise funds
- Share campaigns, events, and other strategies within their social networks

Do

- Help develop strategies to raise funds
- Share experiences, stories, and testimonials to be used as part of a strategy to raise awareness and money

Share

- Share experiences, stories, and testimonials to be used as part of a strategy to raise awareness and money
- Contribute their skills and talents to specific strategies to raise awareness and funds—for example, music or photography

Training resources

Available at: **https://kite-uhn.com/piper**

	Tip sheet on sharing your story	Tip sheet about presenting your story to different audiences	Graphic about giving a talk	Graphic about sharing your story	Policies and guidelines on Conflict of Interest
					●
	●	●	●	●	●
	●	●	●	●	

Key implementation considerations

- Ensure people with lived experience feel comfortable sharing their stories or giving input into the messaging and materials for fundraising opportunities.

Compensating people with lived experience in
patient engagement in research activities

Patient
engagement

People with lived experience may play one or more roles within specific research projects, programs, departments, or research institutes at UHN. Regardless of their role, people with lived experience should expect compensation for their engagement. Their activities, compensation, expense reimbursement and accountability will depend on whether they (a) are engaged via a one-time, short-term, casual, or part-time contract, or (b) are hired as a UHN employee.

Engagement of people with lived experience in a one-time, short-term, casual, or part-time contract

People with lived experience may be engaged in a one-time, short-term, casual, or part-time contract. The level of their engagement will depend on the scope of their role within the research project, their interests, their work hours, and the compensation model for each project. As valued members of the project team, people with lived experience should expect to receive some form of compensation and to be reimbursed for necessary expenses.

Employment of people with lived experience as employees at UHN

People with lived experience may be hired at UHN within one of the established research positions at UHN to bring their lived experience perspective to specific tasks. Their role will include having a supervisor and specific responsibilities and deliverables described in their employment agreement.

For more information about financial compensation policies and access to PER implementation resources, visit **https://kite-uhn.com/piper**

It is important to measure the meaningfulness and impact of PER from the perspective of people with lived experience, scientists, and the research community. Doing so is both an ethical responsibility and an opportunity for growth in a learning health system to foster improvements in the research process and enhance the impact of research. Measuring engagement:

- Describes people with lived experience who are or are not being engaged in research
- Highlights gaps in knowledge or gaps in engagement of people with lived experience, which could reveal opportunities for improvement
- Informs the development of PER best practices [12]
- Allows research teams and organizations to assess their performance
- Drives the development of standards to transform how research is done
- Builds research capacity among networks of people with lived experience
- Demonstrates the impact of people with lived experience on a specific project or area of research

A number of approaches and tools are available to measure the meaningfulness and impact of PER within a research project, program, department, or institute at UHN.

Recommended tools for **measuring engagement**

Table 1 gives a list of the recommended evaluation tools, the rationale for their selection, and guidance on when to use the tools depending on the phase of research, stage of project implementation, and research team member perspectives. The recommended evaluation tools were selected based on feedback from working groups on the critical indicators to measure. An indicator is information obtained from a person or group of people that points out how a project, program, department, institute, or organization is performing. [10] These critical concepts were then mapped onto existing PER evaluation tools, and each tool was assessed for its content, fit, validity, length, and ease of use.

These evaluation tools can be used to plan and evaluate PER from different perspectives at the start of, during, or at the end of the engagement. Scientists and research staff can choose how and when they want to administer these tools to all members of the research team including patients, families, and care partners; however, we recommend using the evaluation tools at the specified time points if you are new to PER or unfamiliar with the evaluation tools.

Table 1. Recommended tools for measuring engagement

Perspective	Recommended Tool	Rationale	When to use the tool
People with lived experience	Adapted UHN Patient Partner Declaration of Values – Patient Partner Experience Survey	- Addresses many considerations identified by people with lived experience, including specifics around onboarding	Beginning of the project
	Patient Engagement in Research Scale (PEIRS) [13]	- Questionnaire is specific to patient engagement in research - Has a strong underlying conceptual framework - Has been tested for internal consistency, structural validity, test-retest reliability, and construct validity	End of the project, term, or when a person with lived experience chooses to end their engagement
Scientists, research staff, or other research team members	Public and Patient Engagement Tool (PPEET), Project Questionnaire, Module A & B [14]	- Questionnaire is specific for scientists who conduct to patient engagement in research - Total score is validated	Immediately after completing the engagement component of your project

Beyond each of the tools listed, we recommend collecting a minimum data set, which includes sociodemographic and cultural information. This data set tries to capture the diversity in the perspectives of team members including people with lived experience, based on the social and environmental context, health conditions, and interactions with health systems from the perspective of the person(s) filling out and using the tools. Demographic questions include questions about our personal information such as preferred language, place of birth, race, ethnicity, disabilities, sex, gender, sexual orientation, education, housing and finances. This personal information about team members gives context to the information collected in the Patient Declaration of Values Patient Partner Experience Survey, PEIRS, and PPEET. [15] The demographic questions in the minimum data set have been developed through collaborative efforts between several Toronto-based hospitals [16] and research conducted by the SPARK team at the Upstream Lab at Unity Health. [17] When collecting this information, consider the need for shared decision-making that ensures people understand why the data is being collected and how it will be used, reflects peoples' values and preferences, protects their privacy and confidentiality, the logistics, feasibility, and any secondary intended uses of the data. [18]

patient engagement in research

Understanding the big picture: the UHN PiPER evaluation framework

Indicators or groups of indicators are combined to form an evaluation framework. Most health system and research evaluation frameworks require collecting a group of indicators. The group of indicators allows us to understand how the structures and processes of an organization influence the desired outcomes. When interpreting the data, the evaluation framework considers the diverse perspectives of people providing the indicators (minimum data set).

The indicators collected by each research project, program, department, or institute will inform the global PiPER evaluation framework.

Minimum Data Set		
Structure indicators measure the characteristics of settings in which research engagement occurs, such as material and human resources, and organizational structure. [9]	**Process indicators** measure a program's PER activities and direct inputs to assure a specific research activity. [9, 18]	**Outcome indicators** measure whether the PER program is achieving the expected effects. [18]

Measuring the progress of the PiPER initiative

The intended use of the PiPER evaluation framework (Figure 3) is to evaluate individual research projects and the global PiPER initiative. The evaluation framework is grounded in 6 guiding principles:

- Prioritize Inclusion, Diversity, Equity, and Accessibility (IDEA)
- Address power dynamics
- Build trust
- Foster reciprocal relationships
- Ensure sustainability
- Explore the research value proposition for patient engagement in research

Figure 3 shows how the structure, process, and outcome indicators will combine with the minimum data set to track our ability to support meaningful PER over time. The desired outcomes for scientists, research staff, and trainees differ from those of people with lived experience. Ultimately, this framework will help us to build a strong health system designed to learn, reflect on, and support the ongoing engagement of people with lived experience in research at UHN.

Figure 3. PiPER evaluation framework

Vision	We envision a future where UHN is an international exemplar for the engagement of patients, families, care partners, and partner organizations in research
Goal	Build organizational structures and technology that promote and embed the engagement of people with lived experience in our research. Our aim is for that engagement to be authentic, accountable, transparent, and responsive

Activities	Education and Training	Tools and Resources	Events and Learning Opportunities

Desired outcomes

Scientists, Research Staff and Trainees

Structure	Process	Outcome
Research teams complete recommended training before PER	Research teams use UHN toolkit to guide PER	Research teams implement recommended tools to evaluate PER

People with Lived Experience

Structure	Process	Outcome
People with lived experience receive recommended onboarding and training	People with lived experience feel valued and supported in PER	People with lived experience complete evaluations

Guiding principles	• Prioritize IDEA • Address power dynamics	• Build trust • Foster reciprocal relationships	• Ensure sustainability • Explore value propositions

What's next?

The practice considerations, role definitions, and training resources shown in this toolkit can help scientists and people with lived experience to plan, do, and share research. The role descriptions in this toolkit are meant to help the research community understand patient engagement in research. This toolkit is also meant to help people with lived experience learn more about the different ways they might contribute to the research. A person with lived experience may engage with a research team and play more than one role, and some role descriptions may overlap. We are collecting information to advance our understanding of the uses and usefulness of this toolkit. Please feel free to provide your feedback using this link: **https://www.surveymonkey.com/r/KSM7TCS**

The PiPER initiative is committed to supporting people with lived experience, scientists, research staff, and trainees in engagement activities. We plan to develop training resources and implementation tools to support putting patient engagement in research into practice at UHN. We welcome you to join and participate in our learning activities.

With the appropriate knowledge, structures, implementation tools, and policies, we aim to create an inclusive environment at UHN where people with lived experience can partner in meaningful and authentic ways in our research. Doing so will transform the way we lead research and enhance research impact locally and globally.

"Go ahead UHN, unleash the power of lived experience!"
- Cathy Craven, PiPER Steering Committee Lead

Engagement tools

Use the following templates to help guide the discussion on getting started with your engagement. Complete the templates as early as possible and include people with lived experience in the conversation.

The following pages have two templates:

1. Planning engagement
2. Implementing engagement

Planning engagement

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 ☐ Other: _____

Engagement Details	
Partner 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 in each aspect of the decision ☐ Empower: To place final decision making in the hands of people with lived experience or support them to lead a project or project component
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 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.

Planning engagement

Engagement Details	
Timing of engagement State when the engagement will begin	❑ 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 **Note:** Bring people with lived experience in at the very beginning and engage them throughout the research project

Method of engagement Describe how you will engage people with lived experience	CONSULT	INVOLVE	COLLABORATE	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	❑ Patient juries ❑ Patient-led research ❑ Think tanks ❑ Delegated decision making

Engagement Details	
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 office ❑ 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.

Implementing engagement

Describe how you will implement your strategy based on best practices.

Area	Description	Strategy	Strategy Details
Communication	Communicating clearly and consistently can help all members of the team to work better together	❑ Assigned staff to communicate with people with lived experience ❑ Shared information about your organization ❑ Shared information about the project ❑ Discussed preferred methods for contact and communication	**Enter any details here**
Roles and responsibilities	Being transparent about the expectations can help prevent misinterpretation and improve the collaboration experience	❑ Reviewed goals of the partnership ❑ Reviewed time commitment and expectations ❑ Discussed activities to engage in during the project ❑ Reviewed how project contributions will be acknowledged ❑ Reviewed how the partnership will end	**Enter any details here**
Capability	Having conversations about training and support helps to tailor the approach according to the individual needs of people with lived experience	❑ Identified training and support needs ❑ Provided training tailored to learning needs ❑ Provided support for physical and emotional needs ❑ Addressed barriers to engagement ❑ Provided opportunities for mentorship and peer-to-peer support	**Enter any details here**

Area	Description	Strategy	Strategy Details
Relationships	Building relationships on trust, honesty, respect, transparency, and reciprocity can allow for fuller and more meaningful partnership	❑ Discussed what mutual respect, safety, and trust should look and feel like in research setting ❑ Scheduled time for informal activities and celebrations ❑ Distributed materials ahead of meetings, including list of research team members and roles ❑ Describe a process for communicating concerns and to whom they should be directed	**Enter any details here**
Financial compensation	Compensating people with lived experience fairly for their engagement helps to acknowledge their value and contributions and advances equity	❑ Discussed needs and expectations for compensation ❑ Discussed need for expense reimbursements and eligibility ❑ Set up method and timing for compensation	**Enter any details here**
Sustainability	Monitoring, checking in, and evaluating patient engagement can help the team retain partnerships and understand what went well or how the team can improve	❑ Set up times for check-ins and feedback throughout the project ❑ Scheduled time for evaluation ❑ Provided opportunities for debriefing with people with lived experience	**Enter any details here**

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Glossary

Patient Engagement in Research (PER): The active, meaningful, and collaborative interaction between people with lived experience and scientists across all stages of the research process, where research decision making is guided by patients' contributions as partners, recognizing their experiences, perspectives, priorities, and expertise.

Person with Lived Experience: A person with direct experience of a health condition or interactions with the health care system. They may be a current or former patient, a family member, or a care partner. A person with lived experience is an expert by experience.

Research Department: Multiple research teams conducting research on a similar health condition, care experience, or service.

Research Institute: An institute that focuses on a clinically relevant program of research that spans the spectrum from basic to translational to clinical research.

Research Program: Multiple scientific undertakings that answer questions on a specific health condition, care experience, or service.

Research Project: A scientific undertaking to answer a research question.

Reflections

What can I do in the near-term to enhance patient engagement in research at UHN?

_____
_____
_____
_____

_____
_____
_____
_____

What can I do in the long-term to enhance patient engagement in research at UHN?

_____
_____
_____
_____

_____
_____
_____
_____

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