

# 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

August 2026
Version 2.0
Pride in Patient Engagement in Research (PiPER)

UHN Canada's Hospital

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Cover art by Vikkymir Shop.

# 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, share and evaluate the engagement of people with lived experience as partners in research.

The 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. Ideally, UHN scientists and research staff should review the relevant training resources before engaging people with lived experience in a research partnership. The Toolkit explains how people with lived experience and research teams can plan, do, and share their work. A suggested way to evaluate engagement is provided, so we can understand the engagement process from the views of people with lived experience, UHN researchers, and the organization.

In Version 2.0 of the Toolkit, we have expanded the spectrum of engagement to highlight the concept that people with lived experience are driving innovation, namely creating, designing, and leading the development of new ideas, methods, and devices. We have updated the Toolkit resources to reflect advancements and new ways to engage people with lived experience in research.
The Toolkit now offers practical ways for research teams to recognize the input of people with lived experience. Further, the Toolkit provides principles and links to UHN resources and policies about how people with lived experience should be paid for their expertise and how their project related expenses such as gas and parking costs will be paid back.

This Toolkit remains a living document to empower UHN research teams to lead innovation and honour the three key commitments of delivering Transformative Experiences, Solutions Beyond Boundaries, and Alignment for Impact.

To truly unleash the power of science for society, we recognize that meaningfully engaging people with lived experience in research is critical to our success.

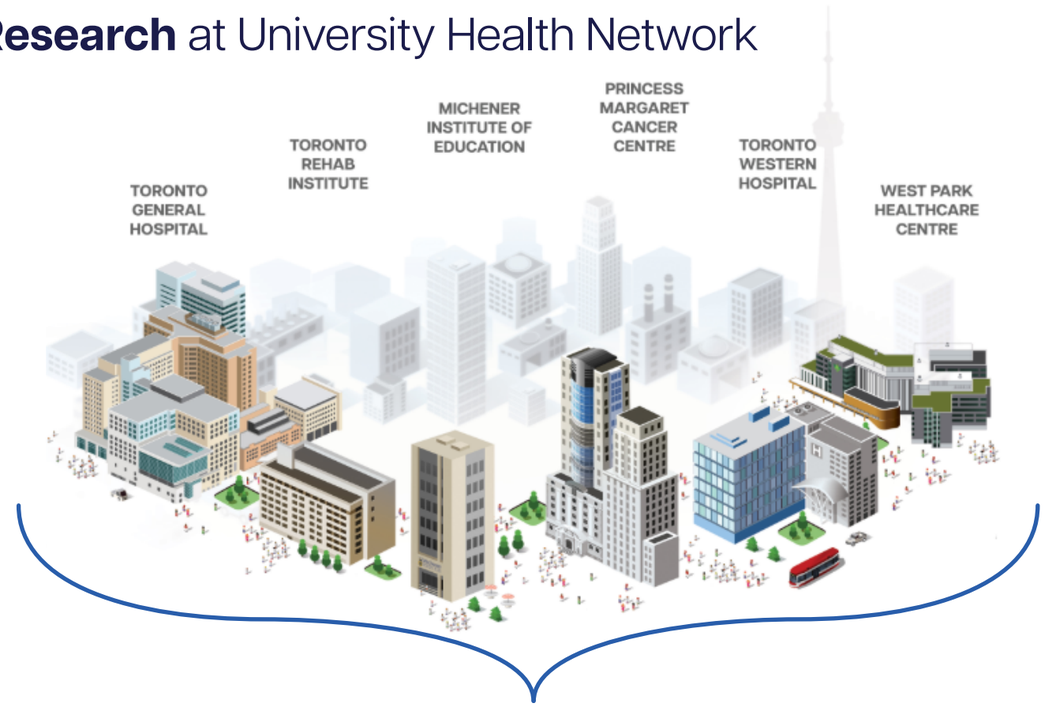
-The PiPER Team

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# About Research at University Health Network

## **Research** at University Health Network




PiPER supports all of UHN

University Health Network (UHN) provides patient care, leads research, and administers education programs across Toronto, the province of Ontario and across Canada [1] (www.uhn.ca). UHN is one of the largest hospital-based research programs in North America and the largest in Canada.

Research at UHN looks at all parts of science, from basic lab work to studies on how the health-care system works, across its research institutes and clinical programs. UHN Research is led by 1,199 scientists and 4,274 staff and trainees in over 1 million square feet of research space across the UHN Research Institutes (see diagram). UHN is fully affiliated with the University of Toronto and 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/).

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

Pride in Patient Engagement in Research (PiPER) is a strategic UHN-wide research initiative at UHN that launched in February 2022. The PiPER initiative was one of the priorities of the **UHN Research Strategic Plan** 2019-23, under the pillar "Engage Every Patient to Strengthen our Learning Health System". The renewed UHN Research Strategic Action Plan titled **Bold Resolve: Science for Society**, sets the stage for the next era of discovery, transformation, and impact. This plan emphasizes transformative experiences, solutions beyond boundaries, and alignment for impact, to guide UHN's decisions and investments over the coming years. The plan continues to feature the PiPER initiative while ensuring that UHN remains a leader in health research, creating a healthier world through innovative and inclusive solutions. To learn more about UHN Research, visit: www.uhnresearch.ca.

PiPER supports the strategic direction of "Transformative Experiences," which aims to foster an inclusive and collaborative research environment. By engaging people with lived experience as partners in research, PiPER helps to enhance research outcomes by ensuring the focus of research is relevant to those we serve and ensures the knowledge gained is shared with patients, families, caregivers, and partner community organizations.

If you are interested in joining our community or learning more about activities within the PiPER portfolio:

**Become a PiPER member:**

**Follow us on Social Media:**
LinkedIn: https://www.linkedin.com/in/piperuhn/
Blue Sky: https://bsky.app/profile/piper-uhn.bsky.social
YouTube: https://www.youtube.com/@UHNPiPER

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## **About Patient Engagement** at UHN

UHN is committed to a culture of engaging patients, families, care partners, communities and partner organizations UHN has teams in the Patient Experience 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. The PiPER Team, on the other hand, helps to build these values into engaging people with lived experience as partners in research processes.

PiPER supports the engagement of people with lived experience partners across all fields of research that exist at UHN, playing a key role in strengthening our 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 the 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.

# About This Toolkit

Traditionally, research involved community members, 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 the planning, doing, and sharing of research. 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.



Development of the first version of this Toolkit included 5 working groups to focus on each one of the identified roles people with lived experience can play in research at UHN. The first version of this Toolkit received the CIHR –Institute for Musculoskeletal Health and Arthritis Inclusive Research Excellence Prize for Patient Engagement. Over 40 people with lived experience partners, UHN scientists, research staff, and trainees participated in a series of virtual meetings to gather perspectives around role descriptions, training requirements, and the impact of engagement over time. For this second version of this Toolkit another working group with members from the original group and new members was convened to update the content to better reflect changes in the field of research engagement and evolving needs of people with lived experience, scientists, and research staff.



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, care partners, communities and partner organizations to help plan, implement, and evaluate the engagement of people with lived experience in research.

The Toolkit:

1. Defines concepts related to the engagement of people with lived experience in research;
2. Describes the roles people with lived experience can play in research;
3. Identifies training resources specific to the roles that individuals can play within research projects, programs, departments, or research institutes at UHN;
4. Describes considerations when planning for compensation and recognition of people with lived experience; and
5. Identifies tools to plan, implement, and evaluate the success of the engagement of people with lived experience in research

## 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 **below** or by emailing us at piper@uhn.ca. We want you to be part of the ongoing development of the Toolkit!

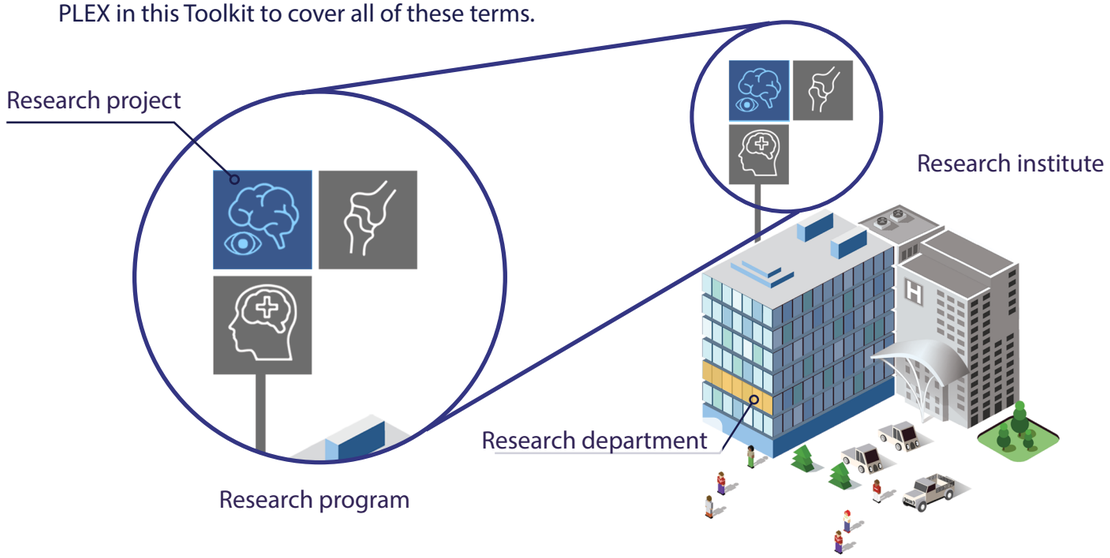
**Scan this QR code to provide feedback on the Toolkit**

We will develop and link learning resources related to the Toolkit internally for UHN scientists and research staff through the My Learning System, the **PiPER SharePoint**, and externally for people with lived experience through our website: **www.uhnpiper.ca**.

**Scan this QR code to visit the PiPER SharePoint (internal to UHN)**

# Understanding Lived Experience Engagement in Research

The term "**people with lived experience**" or "**PLEX**" 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," "partner organizations" among other terms. We use the term "person with lived experience" or PLEX in this Toolkit to cover all of these terms.




Throughout this Toolkit, we use the phrase "patient engagement in research" or the short form "PER" to describe patients, families, care partners, communities and partner organizations 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.

**The following Toolkit definitions will help to get you started:**

**Person with Lived Experience (PLEX):**

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, a care partner or member of a community or partner organization.

**PLEX 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. [2]



**The term PLEX engagement in research does NOT mean:**

- Patients, families, and care partners taking part in a research study as 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, partner organizations and scientists work together from the start to identify issues, set priorities, and generate solutions.

**Support**

Appropriate and adequate support and training are 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

Person with Lived Experience

**People with lived experience engaged in research can make a difference and benefit the health system or themselves and others by [3]:**

- 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
- Sharing research findings and impact with their communities

Engaging people with lived experience offers a chance to improve not only our research processes but also 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 ideally all phases and types of research. Engagement of people with lived experience in research can start before, during or after a research project.

Scientist

**Scientists engaging people with lived experience as partners in research can benefit through [4-6]:**

- 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, people with lived experience, and their communities
- Improved relevance, quality, and outcomes of research
- Broader impact and application of research findings

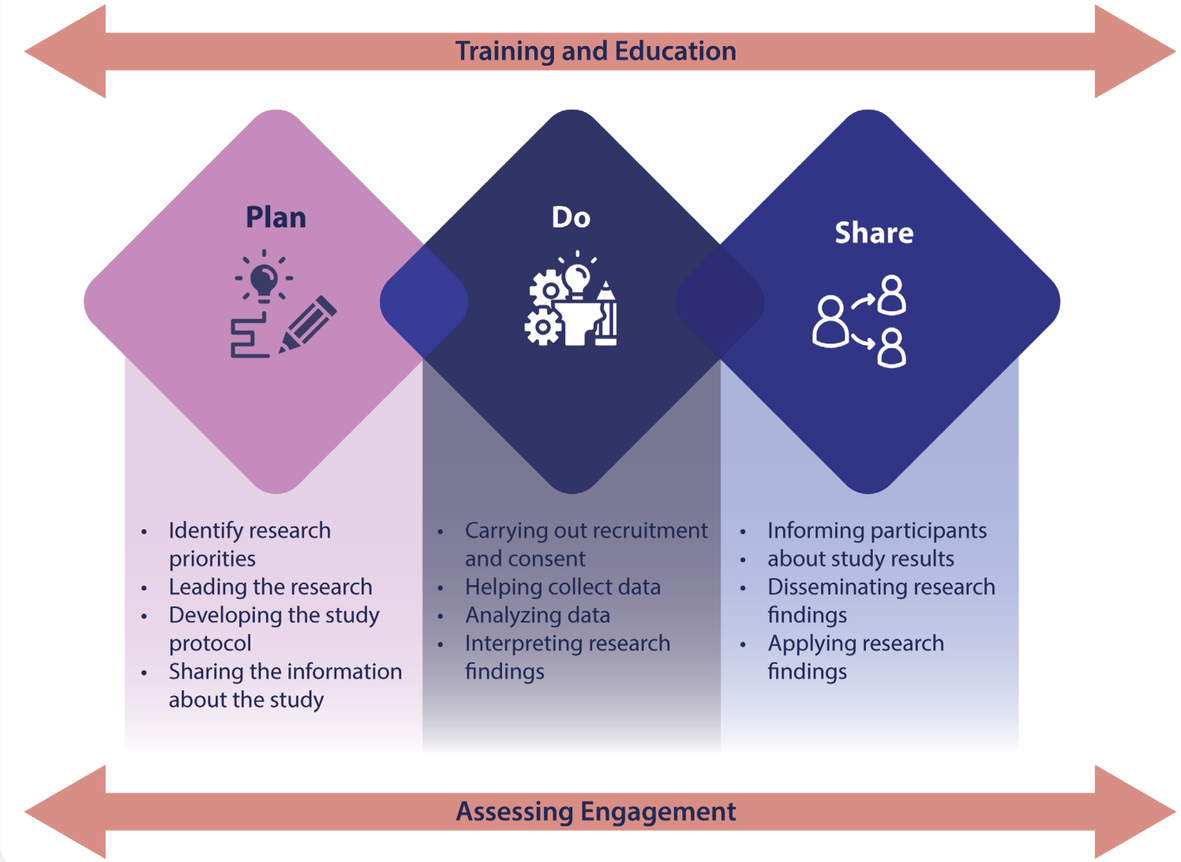



Figure 1: Activities people with lived experience can engage in during the research process [7]

# 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 (Table 1): 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 [8]. 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. People with lived experience can shift their role in the research team along the spectrum as their relationship, comfort and expertise evolve over time. If you are new to the engagement of people with lived experience in research, consider starting on the left side of the spectrum. Move towards the right side as your experiences, expertise and comfort evolves over time.

Table 1. Modified spectrum of engagement at UHN adapted from the International Association of Public Participation [8]

Increasing level of engagement

| | Inform | Consult | Involve | Collaborate | Empower | Innovate |
|---|---|---|---|---|---|---|
| **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 | To create, design, and lead the development of new ideas, methods, and devices |
| **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 | To support the generation of new ideas, methods, and devices |
| **Examples of ways to engage** | • Orientation sessions<br>• Media campaigns<br>• Pamphlets<br>• Websites | • Surveys<br>• Interviews<br>• Focus groups<br>• One-to-one meetings | • Working groups<br>• Advisory committees<br>• Workshops | • People with lived experience as members of the research team<br>• People with lived experience as co-investigators<br>• Steering committees | • People with lived experience as lead investigators | • Developing a research project idea |

# Key Considerations for Scientists About the Engagement of People with Lived Experience in Research

There are several things to consider before, during, and after engaging people with lived experience 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 experience as partners in research. This list of engagement considerations is a combination of information gathered from scientific articles, [9, 10] and the self-reported experiences of people with lived experience the PiPER Steering Committee, and working group members. See pages 41-42 to read about how to implement engagement.

| | |
|---|---|
| **RELATIONSHIPS**<br>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<br>• Engage several people with lived experience to ensure a variety of perspectives are represented<br>• Integrate people with lived experience as equal collaborative research team members<br>• Apply inclusion, diversity, equity, and accessibility principles in recruiting and retaining people with lived experience where appropriate<br>• Reduce power imbalances by using first names and pronouns rather than academic titles<br>• Distribute a list of research team members, their roles, biographies and relevant expertise to share ahead of meetings<br>• Add an icebreaker to the start of a meeting for introductions and schedule time for informal activities to get to know one another<br>• Create safe spaces for all members of the team to be heard<br>• Maintain privacy and confidentiality when sharing<br>• Discuss and incorporate feedback after meetings and events<br>• Report how, where and when input from people with lived experience was incorporated in project team documents<br>• Celebrate the contributions and accomplishments of people with lived experience |
| **CAPABILITY**<br>People with lived experience bring to research their unique experiences, skills, and familiarity with the processes of research. Having conversations about an individual's training resource and support needs helps to tailor the approach and ensure their needs are met. | • Be flexible with meeting places, times, and formats<br>• Ask people with lived experience when and where they feel safe to engage<br>• Engage in a two-way dialogue to identify, tailor, and provide training about research processes and their project role<br>• Provide opportunities for people with lived experience to provide peer-to-peer mentorship<br>• Dedicate time and space for people with lived experience to network among themselves |
| **ROLES AND RESPONSIBILITIES**<br>Being transparent about the roles people with lived experience can play in research can reduce misinterpretation and improve collaboration. | • Co-develop the role(s), responsibilities and activities people with lived experience and research team members will play during the project(s)<br>• Specify the time commitment, expectations, training, and compensation or recognition associated with the role a person with lived experience will play in a project or program of research<br>• Develop processes for achieving consensus, providing feedback, and resolving conflicts<br>• Discuss with people with lived experience how they want to be acknowledged on research outcomes (manuscripts, presentations, etc.). If appropriate, discuss if people with lived experience partners are interested in being part of the knowledge dissemination process<br>• Outline the roles and responsibilities in a 'statement of work' |



| | |
|---|---|
| **COMMUNICATION**<br>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 engagement-related issues<br>• Determine how the person with lived experience prefers to communicate: email, telephone, text message, virtual and/or in-person meetings<br>• Provide information in the preferred format<br>• Use plain language for written and verbal communication<br>• Use culturally safe and inclusive language<br>• Avoid acronyms as much as possible<br>• Provide a glossary for common terms and acronyms<br>• Maintain privacy and confidentiality when sharing<br>• Share meeting materials at least 72 hours before the meeting<br>• Send materials for review well in advance of the deadline for feedback |
| **FINANCIAL COMPENSATION AND RECOGNITION**<br>It is the research team's responsibility to offer financial compensation and/or to discuss other forms of acknowledgement with the people with lived experience prior to onboarding them. This action acknowledges the person with lived experience's value as a partner and contributor. This will be discussed in details on pages 27-28 – in brief: | • Engage people with lived experience early in conversations about their role(s) and responsibilities, current rates of compensation at UHN, the processes for payment and expense reimbursement and their desired recognition<br>• Include engagement activities, compensation and expense reimbursement for people with lived experience in grant applications<br>• People with lived experience should have the right to decline financial compensation<br>• Be transparent about the total funds available, requirements for distributing funds, and timing of financial compensation |
| **SUSTAINABILITY**<br>Evaluating the engagement of people with lived experience in research can help research teams retain partnerships, understand what went well, or identify areas for improvement. We have suggested some tools which may help you evaluate the engagement process. Before evaluating your research engagement: | • Agree on time points to check in and gather feedback<br>• Evaluate the progress and outcome of the engagement of people with lived experience in research from multiple perspectives (e.g., People with Lived Experience, Staff, Scientist etc.,)<br>• Use established tools such as the PEIRS and PPEET to measure engagement (See pages 29-30 for more details)<br>• Acknowledge where and how the perspectives of people with lived experience were integrated into the planning, conduct or sharing or research products |

# 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.

## For Scientists and Research Teams



**Should I engage people with lived experience?**

- What perspectives and contributions do I hope people with lived experience will bring to the project or research area?
- What gaps will exist if people with lived experience are not engaged?
- What is the likelihood that the team will be able to listen to, fully consider, and integrate contributions from people with lived experience?
- How will I account for inclusion, diversity, equity, and accessibility when engaging people with lived experience?

**What role can people with lived experience play on the research or project team?**

- Co-develop a list of activities and discuss the most appropriate role(s) and responsibilities with people with lived experience partners—see pages 17-26.
- What level of engagement is needed for each role and how many hours of work are expected?
- What will the total duration of each engagement be?
- How can my research team continue the relationship with our people with lived experience partners once the project is over?

**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?
- What training does my team and the people with lived experience need?
- How much should I budget for engagement in my grant given the nature of the work?
- Do I have the staff or am I willing to orient, train, and support people with lived experience during the research project?
- Do I have the budget to compensate and reimburse expenses for any person with lived experience I plan to partner with?
- Beyond compensation, what other recognitions might I be able to offer the people with lived experience partnering with my research team?



## For People with Lived Experience



**Should I engage in the project?**

- 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 to the research project?
- What level of engagement am I comfortable with?
- Do the project aims align with my values or interests?
- Does the project timeline align with my availability?
- What are the risks and benefits of participation?
- How many hours of work are expected from me?

**Will the project team provide the training and resources to support my full participation?**

- Who on the research team will provide me with support?
- What training might I be asked to do?
- How will I be paid for the work?
- What funds are available to cover my expenses?
- How and when will I be reimbursed for expenses?
- How will my work be recognized?
- What supports are offered to help me participate fully?



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 Research

The following sections of the Toolkit describe the roles that people with lived experience can have within research projects, research programs, research departments, or research institutes at UHN. People with lived experience may play more than one role based on their preferences, experience and the project needs. The next section of the Toolkit includes five potential roles people with lived can play, describing:



- **Role definitions**
- **Different types of activities each role may involve**
- **Training resources for scientists, research staff, trainees, and people with lived experience**

Scientists, research staff, 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 listed some common examples of activities associated with each role, but these lists don't include everything.

Each role features different key resources to support the onboarding, training, and activities associated with the role. To navigate the role pages, the reader should identify their role "Scientist", "Research Staff", or "Person with Lived Experience" on the left hand side of the table and read across the row to see which resources may be relevant. The reader is asked to reflect and discuss with the team members which resources may be best for your research project.

Role definitions help all team members understand the role of the person with lived experience within the project team. Research teams can use the role definitions to create engagement plans in grant proposals, create budgets, plan research implementation, and share information or lessons learned with others so they can use it to advance their health or future research.



## Legend for Training Resources

In this section of the Toolkit (Pages 17-26), these icons are used to indicate who the training resources may help on the research team: Scientists, Research staff, and People with lived experience. These freely available training resources were selected by PiPER. The training resources feature different populations (e.g., children, adults) but the PER concepts apply broadly.

Click the button  to check out each resource.



Scientists



Research Staff/Trainees



People with Lived Experience



# Research Team Members

Can perform roles as members of a research team alongside scientists and research staff. Research Team Members can contribute perspectives that reflect not only their health condition(s) but their broader life perspectives. People with lived experience with prior experience in research engagements may mentor others new to the role to increase their comfort, learning, and project contributions.

**Role in action:** John has experience in data analysis and scientific writing aside from his personal experience living with diabetes. He is hired as a Research Associate to support a diabetes research project for 6 months.

## PLAN

- Identify the problems and priorities to be studied
- Co-create the research question and study design
- Design the strategy to recruit research participants
- Support writing grant application for funding

## DO

- Provide feedback on participant-facing materials (e.g., recruitment materials, consent forms)
- Help design data collection tools
- Help implement the recruitment strategy
- Conduct interviews, surveys, or other data collection from research participants
- Contribute to data analysis and assist interpretation of the data from the people with lived experience partner's perspective
- Help determine the feasibility of implementing the results and research outcomes

## SHARE

- Contribute to the plan to share research results
- Co-develop materials that share the research results, including scientific publications, summaries for the general public, etc.
- Present the research results in formal and informal settings
- Support the implementation of research results, including policy initiatives

## Training Resources

| Role | Research Fundamentals | | Ethics and Responsible Conduct | | | | Engagement, Community and Roles | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Scientist | | | UHN research ethics webpage | Inclusion Diversity, Equity, and Accessibility Toolkit | | | CIHR PLEX Engagement in Research modules | Effective communication tip sheet | PLEX as authors article | Identifying and preventing tokenism blog |
| Research Staff | Research basics presentation | Research terms glossary | UHN research ethics webpage | Inclusion Diversity, Equity, and Accessibility Toolkit | | | Effective communication tip sheet | | PLEX as authors article | PLEX roles tip sheet |
| Person with Lived Experience | Research basics presentation | Research fundamentals module | UHN research ethics webpage | Inclusion,Diversity, Equity, and Accessibility Toolkit | | | Effective communication tip sheet | | PLEX as authors article | PLEX roles tip sheet |
| | Research terms glossary | Patient Decision Aid | Research ethics module | | | | | | CIHR PLEX Engagement in Research modules | |

**Key implementation considerations:**

- 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 and for research team members to understand best practices in engaging people with lived experience



# Research Knowledge Ambassadors

Can help create and share materials about research results. Can share project results with scientific and general audiences. People with lived experience may identify groups who may benefit from project information and co-create strategies to widen reach.

**Role in action:** Daniel has lived experience in cancer and feels comfortable talking in public. He joins a research project team as a partner, supporting the presentation of a cancer clinical trial results during a scientific conference and in community centers across the region where he lives.

## PLAN

- Determine the target audience that would benefit from knowing about the research results
- Build relationships with individuals or organizations who might benefit from the research results

## DO

- Give context to the results using their own experiences
- Co-design and provide feedback on the main messages from a completed research project

## SHARE

- Co-develop or provide feedback on materials that share the research results in different formats (e.g., videos, infographics, art)
- Work with communications teams to develop and review social media content
- Co-present with scientists and research staff at conferences and/or events
- Talk about how people with lived experience were engaged in the research either alone or with scientists, trainees, or research staff

## Training Resources

| Role | Accessible Writing | | Sharing Research | | | Academic Communication & Publishing | | | |
|---|---|---|---|---|---|---|---|---|---|
| Scientist | How to write a plain language summary video | Creative ways to share knowledge tip sheet | Sharing science on social media article | Public speaking for science article | | | | | |
| Research Staff | How to write a plain language summary video | Creative ways to share knowledge tip sheet | Sharing science on social media article | Public speaking for science article | | Research and publishing process video | | Publishing journal articles video | |
| Person with Lived Experience | How to write a plain language summary video | Creative ways to share knowledge tip sheet | Ways to share research presentation | Public speaking for science article | | Research and publishing process video | Publishing journal articles video | Activities to share research template | Conference abstract graphic |

## Key implementation considerations:

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

# 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. 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 grant 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 research funding.

**Role in action:** A research team is preparing a funding application to support their research. The team has worked with people with lived experience as partners when developing the application, but they are interested in learning if the research is meaningful to other partners and communities. The team then recruits them to act as a Peer Reviewer since they have lived experience in that area of research aside from being a long-term person with lived experience partner to other teams in the department or institute.

## PLAN

**Give feedback that improves relevance and clarity on:**

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

## DO

**Give feedback that improves relevance and clarity on:**

- Reports that explain how the research is going or what the results are, written for the group that gave the funding
- Easy-to-read summaries, websites, short reports from conferences or meetings, and published research articles
- Annual reviews of measures to understand and evaluate a research organization's overall performance

## 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

| Role | Peer Review | | | | Bias, Equity and Inclusivity | | | Academic Outputs | |
|---|---|---|---|---|---|---|---|---|---|
| Scientist | | | | | Bias in peer review module | Engaging PLEX in peer review blog | | | |
| Research Staff | Peer review process video | | Peer review for knowledge users module | | Bias in peer review module | Engaging PLEX in peer review blog | | Conference abstracts graphic | Publishing journal articles video |
| Person with Lived Experience | Peer reviewer guidance document | Peer review process video | Peer review for knowledge users module | Peer review module | Bias in peer review module | Engaging PLEX in peer review blog | | Conference abstracts graphic | Publishing journal articles video |

**Key implementation considerations:**

- 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

# Decision Makers



Can play a role in shared decision-making with scientists and research staff when overseeing the activities of a research organization or initiative. They participate in making research decisions with voices equal in weight to other decision makers in the 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 or day-to-day decisions regarding research projects.

**Role in action:** A research institute where most studies looked at how stem cells help to reduce heart attacks formed an institute-wide Advisory Committee. This committee met two times every year to discuss how the institute's research, mostly done under a microscope, could have long term impact for patients and their community. The committee invited two people with lived experience partners to join with hope of bringing lived experience feedback to the discussions.

## 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
- Participate on committees to hire new research staff members

## DO

- Chair, Co-chair, or participate as members of a 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 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

## Training Resources

| Role | Meeting Practices | Safe Spaces | | Representation and Inclusivity | | |
|---|---|---|---|---|---|---|
| Scientist | Chairing meetings checklist | Creating safe spaces document | | Guide on inclusive hiring document | | |
| Research Staff | Chairing meetings checklist | Creating safe spaces document | | PLEX representation of Board of Directors document | Guide on inclusive hiring document | |
| Person with Lived Experience | | | | Guide on PLEX representation of Board of Directors document | Role of community members on research ethics video | Guide on inclusive hiring document |

**Key implementation considerations:**

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



# 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.

**Role in action:** A donor approached the UHN Foundation, interested in funding brain injury research. A researcher and their people with lived experience partners were invited to share their experiences and the impact of the research they did together 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

- 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

| Role | Ethical Engagement | | | Communication and Storytelling | | |
|---|---|---|---|---|---|---|
| Scientist | Conflicts of interest webpage | Asking to share a story tip sheet | | | | |
| Research Staff | Conflicts of interest webpage | Asking to share a story tip sheet | | Sharing your story tip sheet | Giving a talk graphic | Sharing your story graphic |
| Person with Lived Experience | | | | Sharing your story tip sheet | Giving a talk graphic | Sharing your story graphic |

## 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 as Research Partners: Why it Matters and How to Do It Well

## Why Compensation Matters

People with lived experience bring unique knowledge to research. This expertise is valuable. Just as researchers, clinicians, and other professionals are compensated for their contributions, people with lived experience should be offered fair compensation for the time, effort, and knowledge.

Compensation shows respect for people's time, experience, and expertise. Compensation of people with lived experience can take several forms including electronic fund transfer, cheque, cash or near cash such as gift cards. Expense Reimbursement supports fairness by reducing barriers to contributing to research such as transportation costs, caregiving responsibilities, and other out-of-pocket expenses.

## Planning Compensation From the Start

Different people may have different preferences and needs when it comes to compensation. These preferences may relate to their income, pension, benefits, participation in government support programs and/or their life situation. Early discussions during project planning and grant development help research teams and people with lived experience to:

- Clarify roles and expectations to estimate time commitments
- Identify potential participation barriers
- Budget for engagement activities
- Select payment methods and payment frequency that work for all involved

UHN staff should become familiar with the internal UHN policy regarding people with lived experience compensation and check the PiPER SharePoint for updates on the compensation policy for people with lived experience partnering in research prior to developing a research budget.



## What Activities Should be Compensated?

Compensation should reflect the full range of activities people with lived experience undertake. This Toolkit outlines roles people with lived experience can play at UHN, example activities within these roles include but are not limited to:

- Completing required training or onboarding activities
- Preparing for meetings
- Participating in project meetings and advisory committees
- Helping design recruitment strategies
- Reviewing study documents, consent forms or grant applications
- Participating in day to day problem solving during research conduct
- Participating in evaluation and project close-out activities
- Contributing to knowledge translation activities like manuscript preparation, presenting at conferences or community events, drafting social media materials.

## Compensation Amount

At UHN, the compensation for people with lived experience is equal to Research Associates. This hourly rate will change over time with the cost of living. This hourly rate applies to all roles described in this Toolkit, with the exception for the Peer Reviewer role, where 10% is added to the base hourly rate due to the extra training required to do peer review.

## Choosing How to Pay People With Lived Experience

For guidance on how to process these methods of payment check the attached link to the compensation policy for people with lived experience partnering in research (only available to UHN Staff).

# Compensating People with Lived Experience as Research Partners: Why it Matters and How to Do It Well

## Common Compensation Methods Include:

**Direct deposit (e-transfer) or cheque**

These are UHN's preferred payment methods, especially for ongoing partnerships with people with lived experience. They provide clear records (i.e. tax documentation) for the organization, research team, and the individual(s) receiving compensation.

**Invoicing**

Some people with lived experience may operate as independent contractors or sole proprietors (i.e., are self-employed or run their own business) and prefer to submit invoices for their work. A cheque or direct deposit is sent once an invoice is received and processed. The related tax documentation is issued at the end of the year.

**Cash or Gift Cards**

In some situations, immediate compensation or simple payment methods may be needed. For example, some individuals may not have access to banking services to receive a direct deposit, may not have a fixed address to receive a cheque, or may be uncomfortable sharing personal information required for payroll processes. Cash payments and gift cards can be used in these cases, although no tax documentation will be issued.

## Important Compensation Considerations:

Compensation can affect an individual's tax situation and may have implications for:

- Income taxes
- Disability benefits
- Social assistance programs
- Income-tested government supports
- Housing or other financial assistance programs

People with lived experience should have the opportunity to consider how compensation may affect their circumstances, before deciding whether to accept it.

People with lived experience should have the option to decline compensation for any reason.



## Expense Reimbursement

Engaging people with lived experience often involves additional costs beyond the time spent on research activities. Research teams should consider whether people with lived experience may need support for:

- Transportation and parking
- Meals and refreshments
- Childcare, dependent care and/or personal support workers
- Accessibility supports like screen readers, closed captions, accessible transportation, etc.
- Translation or interpretation services
- Access to hardware like phones, tablets and computers
- Internet access and digital technology
- Conference travel and registration fees

Scientists and research teams are expected to cover these expenses. People with lived experience should not be expected to cover expenses and be reimbursed later, rather the research team should problem solve how to cover the expenses up front.

## Recognition Beyond Financial Compensation

Aside from financial compensation, people with lived experience may also wish to be recognized through:

- Inclusion as grant co-applicants
- Opportunities for training and professional development
- Acknowledgements on websites, publications, or project materials
- Authorship on publications, reports, and presentations
- Participation in conference presentations

# Measuring the Engagement of People with Lived Experience

Scan this QR code to access online versions of the checklists

It is important to measure and evaluate the value and impact of the engagement of people with lived experience in research from the perspective of people with lived experience, scientists, research staff, and the research community. Doing so is both a moral and ethical duty and an opportunity for learning, to foster improvements in the research process and enhance research impact. Measuring engagement:

- Describes people with lived experience who are, or are not, being engaged in research
- Highlights gaps in knowledge or gaps in the engagement of people with lived experience
- Identifies opportunities for improvement in research processes or programs
- Informs the development of best practices for the engagement of people with lived experience in research [11]
- Allows research teams and organizations to assess their performance
- Drives the development of standards
- 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 tools are available to measure the value and impact of engaging people with lived experience within a research project, program, department, or institute at UHN.

## Recommended Tools for Measuring Engagement

Table 1 shows a list of recommended evaluation tools, the rationale for tool 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 research project, program, department, institute, or organization is performing. [9] 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 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. These tools are available for use by researchers and members of TeamUHN via REDCap. For more information and access to these tools, please contact piper@uhn.ca.

Beyond each of the evaluation tools listed in Table 1, we recommend that all team members complete the About You data set at the beginning of the engagement and where appropriate after the engagement is done. This data set describes people with lived experience and TeamUHN members' sociodemographic and cultural information. This data set tries to capture the diversity of perspectives among the research team members including people with lived experience engaging in research. The data describes the social and environmental context, health conditions, and interactions with the health system from the perspective of the people with lived experience or TeamUHN members filling out and using the tools.

The personal questions in the About You Data set have been developed through collaborative efforts between several Toronto-based hospitals [15] and research conducted by the SPARK team at the Upstream Lab at Unity Health. [16] When collecting this information, ensure transparency and respect people with lived experience's values and preferences in providing some or all of their information. Ensure that people with lived experience and members of TeamUHN feel safe by helping them to understand why the data is being collected and how it will be used (including the intended use of the data). Ensure people with lived experience and members of TeamUHN know that their privacy and confidentiality will be respected [17]. Advise people with lived experience and TeamUHN members to "Answer only the questions you are comfortable with" and remind them "Taking part is your choice" while encouraging participation.

**Table 1. Recommended tools for describing your team and 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 before a project | Beginning of the project |
| | About You Data Set | • Captures the diversity in the perspectives of team members<br>• Gives context to the information collected in the other recommended tools | • Beginning of the project<br>• May be redone after a long-term project (i.e., more than three years) |
| | Patient Engagement in Research Scale (PEIRS) [12] | • Questionnaire is specific to patient engagement in research<br>• Has a strong underlying conceptual framework<br>• Has been tested for internal consistency, structural validity, test-retest reliability, and construct validity | End of the project, term, or when a partner chooses to end their engagement |
| **Scientists, Research Staff, Students and Other Research Team Members** | About You Data Set | • Captures the diversity in the perspectives of team members<br>• Gives context to the information collected in the other recommended tools | • Beginning of the project<br>• May be redone after a long-term project (i.e., more than three years) |
| | Public and Patient Engagement Tool (PPEET), Project Questionnaire, Module A & B [13] | • Questionnaire is specific for scientists and staff who conduct PER<br>• Total score is validated | After completion of the engagement component of your project |

## 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 to get a clear picture of 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 through review of the "About You" data set that tells UHN "About Us" the project team. The indicators collected by each research project, program, department, or institute will inform the global PiPER evaluation framework.

| About You | | |
|---|---|---|
| **Structure indicators** | **Process indicators** | **Outcome indicators** |
| Measure the characteristics of settings in which research engagement occurs, such as material and human resources, and organizational structures. [8] | Measure a program's PER activities and direct inputs to assure a specific research activity. [8, 17] | Measure whether the PER program is achieving the expected effects. [17] |

## Measuring the Progress of the PiPER Initiative

The intended use of the PiPER evaluation framework is to evaluate individual research projects and the global PER activities across the organization. The evaluation framework is grounded in 6 guiding principles:

1. Prioritize Inclusion, Diversity, Equity, Accessibility and Allyship (IDEAA)
2. Address power dynamics
3. Build trust
4. Foster reciprocal relationships
5. Ensure sustainability
6. Explore the research value proposition for PER

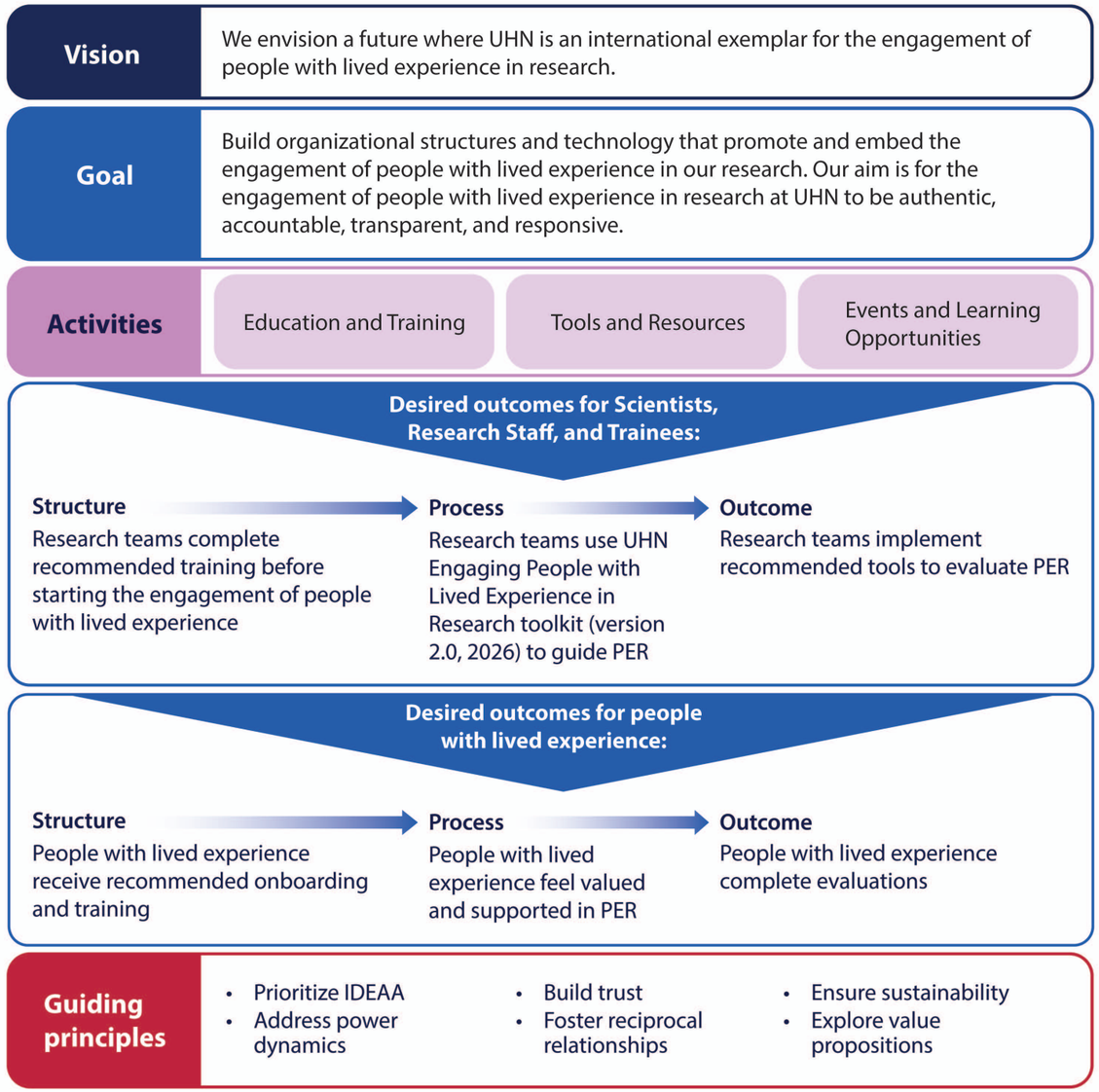



**Figure 2. PiPER evaluation framework**

# 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 and articulate the planned or intended engagement of people with lived experience 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. People with lived experience can 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 the QR code on **page 4**.

The PiPER initiative is committed to support people with lived experience, scientists, research staff, and trainees during engagement activities. We have training resources, implementation tools, policies and novel methods of engagement available on our website and internal SharePoint site to support putting the engagement of people with lived experience in research into practice at UHN. We welcome you to join and participate in our community of practice and other structured 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 Executive Lead**



# Engagement Tools

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

**1. Planning Engagement**
**2. Implementing Engagement**
**3. Before We Finish**



# Planning Engagement

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

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

# Planning Engagement

| Engagement Details | | | | | |
|---|---|---|---|---|---|
| **Timing of engagement**<br><br>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.<br>❑ From generating the idea for a project<br>❑ Planning a grant or developing a research study design<br>❑ Applying for funding<br>❑ Developing the research team<br>❑ Implementing a study or specific aspect of study<br>❑ Sharing research results once a project is completed | | | | |
| **Method of engagement**<br><br>Describe how you will engage people with lived experience | **CONSULT**<br>❑ Focus groups<br>❑ Surveys<br>❑ Interviews<br>❑ Opinion polls<br>❑ Forms<br>❑ Social media<br>❑ Forum, town hall, public meeting | **INVOLVE**<br>❑ Debates<br>❑ Panels<br>❑ Advisory committees<br>❑ Shadowing<br>❑ Workshops<br>❑ Working with existing patient groups | **COLLABORATE**<br>❑ People with lived experience as team members<br>❑ Round tables<br>❑ Journey mapping<br>❑ Participatory decision making | **INNOVATE**<br>❑ Developing a research project idea | **EMPOWER**<br>❑ Patient juries<br>❑ Patient-led research<br>❑ Think tanks<br>❑ Delegated decision making |



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

| 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<br>❑ Scheduled time for informal activities and celebrations<br>❑ Distributed materials ahead of meetings, including list of research team members and roles<br>❑ Describe a process for communicating concerns and to whom they should be directed<br>❑ Do not use formal titles and credentials to address power imbalances | 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<br>❑ Provided training tailored to learning needs<br>❑ Provided support for physical and emotional needs<br>❑ Addressed barriers to engagement<br>❑ Provided opportunities for mentorship and peer-to-peer support | 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<br>❑ Reviewed time commitment and expectations<br>❑ Discussed activities to engage in during the project<br>❑ Reviewed how project contributions will be acknowledged<br>❑ Reviewed how the partnership will end<br>❑ Co-create the role and terms of reference outlining responsibilities | Enter any details here |



| 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<br>❑ Shared information about your organization<br>❑ Shared information about the project<br>❑ Discussed preferred methods for contact and communication<br>❑ Keep people with lived experience in the loop and share how the inputs of people with lived experience have contributed to the project | Enter any details here |
| **Financial compensation and recognition** | 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<br>❑ Discussed need for expense reimbursements and eligibility<br>❑ Set up method and timing for compensation<br>❑ Be transparent about project and organizational factors | 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<br>❑ Scheduled time for evaluation<br>❑ Provided opportunities for debriefing with people with lived experience<br>❑ Communicate back to people with lived experience what was heard during the evaluation and how recommendations may be implemented | Enter any details here |

# Before We Finish

Approaching the end of a PLEX Engagement?

Ensure to plan a meeting with your PLEX partner(s) well in advance to discuss the following:

## PROCESSES

| Activity | Scientist or Research Staff | PLEX | Resource |
|---|---|---|---|
| **Evaluation** | Complete evaluation of the process using the recommended tools and invite any other questions or comments PLEX may have | Complete the evaluation and share any other questions or comments | Toolkit Evaluation Pages 31-32 |
| **End of Project Discussion** | Discuss what project aspects remain and next steps | Ask any questions regarding next steps | |
| **Sharing Project Results** | Share the project results with your PLEX partners in plain language | | PLS resources |
| **Financial Compensation and Expense Reimbursements** | Finalize compensation: Ensure all compensation or expense reimbursements processes are completed | If any financial compensation or expense reimbursement is outstanding notify the Scientist and/or Research Staff | Toolkit Compensation Pages 27-28 |
| **Storage and Data Retention** | Adhere to storage and retention of de-identified research data according to UHN policies | | Clinical Research Hub: Essential Document Templates |



| Activity | Scientist or Research Staff | PLEX | Resource |
|---|---|---|---|
| **Digital System Access** | Remove PLEX partner system access: Email lists, shared drives, platforms, where applicable | | |
| **Opportunities for Process Improvement** | Based on feedback identify opportunities for improvement on a go-forward basis and where appropriate share process improvements with the team | Provide feedback about the overall engagement process and ways the team could improve going forward | |

## MAINTAINING RELATIONSHIPS

| Activity | Scientist or Research Staff | PLEX |
|---|---|---|
| **Discuss Contributions and Impact** | Highlight the PLEX partner contributions to date | |
| **Formal Acknowledgement of Contributions** | Confirm acknowledgement and authorship preferences for contributions | Discuss how you would like to be acknowledged for your contributions (e.g., listed as an author, biography included on a report) |
| **Formal Recognition** | Consider formal recognition (e.g., writing a thank you letter, certificate, acknowledgement in team meeting, social media post, etc.) | Discuss recognition preferences |
| **Stay Connected** | Discuss ways your PLEX partner(s) can stay connected with the project team and your field of research | Discuss how you would like to stay connected with the team and the field of research |

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We would like to thank the over 50 working group members for their invaluable input and contributions throughout the creation and revision of this Toolkit. The working group members included TeamUHN, people with lived experience, our foundation, and other research institutes. Their input helped shape the plan and vision for the engagement of people with lived experience at UHN. This Toolkit was made possible through the Executive Vice President of Science and Research's vision and strategic funding from the UHN Foundation.

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**If you want to go fast, go alone.**
**If you want to go far, go together.**

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# Glossary

**Person with Lived Experience (PLEX):** 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.

**PLEX Engagement in Research (PER):** The active, meaningful, and collaborative interaction between PLEX, scientists and research teams across all stages of the research process, where research decision making is guided by PLEX contributions recognizing and acknowledging their experiences, perspectives, priorities, and expertise when co-developing, co-implementing and co-delivering research products.

**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 take away from the Toolkit?**

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

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