

Engage every patient to strengthen our learning health system.

PiPER

Pride in Patient Engagement in Research

Patient engagement or PE is meaningful and active collaboration with patients as partners in research.

It includes engaging patient partners in different ways throughout the research process so they can provide their own lived experiences, insights, and perspectives to research with the intent to improve the research and the relevance of the research results. Patient engagement is also about bringing patient partners to the team so they can contribute in ways that complement the expertise and knowledge of the other research team members.



A **patient partner** is a person with a personal experience of a health issue or a family or friend caregiver. They may provide perspectives and insights based on their 'lived experiences' of living with a health condition or having a health care system experience. Patient partners help plan, do or share the research rather than participate in the research.

UHN's Pride in Patient Engagement in Research or PiPER is a formal initiative to support PE in research efforts.

PiPER's vision is for UHN to be an international exemplar for involvement, information exchange, and participation of patient, families, and partner organizations in research. This engagement is authentic, transparent, responsive, accountable and predicated upon UHN's mission. PiPER's goals are to:

- Carry out authentic engagement
- Educate scientists, staff and partners (including patient partners)
- Renumerate patient partners for their time, skills, and expertise
- Evaluate the engagement through a framework and be transparent about the outcomes
- Contribute to a new culture that includes meaningful engagement.

You can learn more about PiPER on its [website](#), including about the team, terms used in patient engagement work, and potential patient partner roles on research teams.



PiPER Strategic Launch Workshop

On May 4, 2022, UHN researchers, clinicians, other staff, and patient partners, participated in a virtual workshop to launch PiPER. This was the first of two strategic workshops (the second will be hosted in the Fall 2022) to engage the UHN research community in celebrating and contributing to PiPER. The goals of the workshop were to:

- Share what PiPER is about
- Identify patient partner roles related to Patient Engagement including what training may be needed for each role
- Identify PE in research themes that are important principles for PiPER
- Identify volunteers who may wish to continue to be involved in further developing patient partner roles and PiPER principles.

The workshop featured speakers from UHN and outside of UHN, breakout discussions and a lunch hour yoga break tailored to all levels.

Presentations

We hope the day's speakers left attendees thinking about their own work in patient engagement, or what they might like to do in patient engagement in research. Below we've summarized key presentation points and include a quote from speakers about patient engagement or a hope they have for the PiPER initiative.

Patient Engagement for the Win! – Sue Robins

Ms. Robins encouraged researchers to stay curious and to remember that engagement is about partnering and building relationships with patients. She reminded us that patients bring wisdom and should represent who you see in the hospital. Ms. Robins stressed knowing your 'why' when engaging patient partners and being thoughtful about your 'what.' She also offered up what she seems as being the 'secret sauce' of relationships: see you, know you, like you, and trust you.

“What patients bring you is really a gift. Often we are reflecting on the worst moments of our lives – a bad experience in the health system has motivated us to try to make things better for those who come after us... we are vulnerable when we share these experiences with you to help your research be better.” — Sue Robins

Highlights from the Launch Workshop



Sue Robins
Healthcare Activist



Dr. Kristin Musselman

Scientist, KITE,
Toronto Rehabilitation Institute



Anita Kaiser

Research Trainee, KITE,
Toronto Rehabilitation Institute
Person with Lived Experience of
Spinal Cord Injury

Culture Shift in Research Engagement – Kristin Musselman and Anita Kaiser

Dr. Musselman and Ms. Kaiser reinforced Ms. Robins' thoughts about building relationships with patient partners. They also discussed the importance of language, engaging early and often, and that there are many different ways to engage. They noted the importance of creating an environment that is accessible and equitable and power imbalances are minimized (which may be facilitated by providing patient partners with training and compensation).

“*Meaningfully engaging people with lived experience as knowledge experts throughout the research process is integral to achieving high quality research that is relevant and impactful.*” — Anita Kaiser

“*Listen and learn from research team members who bring the expertise of lived experience. In my experience, this listening and learning has resulted in new research directions and more meaningful and impactful research outcomes.*” — Kristin Musselman



Dr. Andrew Boozary

Executive Director,
Population Health and
Social Medicine, UHN

Social Medicine – Andrew Boozary

Dr. Boozary emphasized the importance of recognizing a legacy of mistrust of healthcare and research in some communities. While there are some disconnects in patient engagement, including a lack of diversity of perspectives and non-representative engagement, engaging 'peer partners' or community champions is one strategy to change this and to better engage individuals you may not otherwise be able to engage. Like other speakers, he noted that engagement is partnership.



Janet Rodrigues

Disability justice advocate
living with invisible and
visible disabilities



Dr. Audrey Yap

Education Lead,
Physical Medicine and
Rehab, Sinai Health

Accessibility: Lived Experience Matters – Janet Rodrigues and Audrey Yap

Ms. Rodrigues and Dr. Yap highlighted and showed examples of some key issues to be aware of when engaging patient partners, as well as to help remove barriers brought on by these issues. Ableism, whether intended or not, sees persons with disabilities as being less worthy of respect and consideration, less able to contribute and participate, or of less inherent value than others. The medical model of disability imparts blame on the disabled person rather than considering that their social structure is the problem. Intersectionality (interconnected nature of social categorizations such as race, class, ability, sexuality, and gender regarded as creating overlapping and interdependent systems of discrimination or disadvantage) and accessibility were also discussed.

“*The way I live my life is impacted by my identities and social location which include living with visible and invisible disabilities. Any research about the illnesses I live with cannot happen in a vacuum. My arthritis’ symptoms and the way I managed them is determined by my social determinants of health. Research that focuses not just my diagnosis in a vacuum or within the biological domain, but on how the illness impact my life as a cis gender racialized immigrant woman living on a disability income may yield results that can impact my life in a practical way. One can only hope.*” — Janet Rodrigues

“*Accessibility is about shifting the medical culture to embrace the true needs of individuals living with a disability. Ramps, hearing amplifiers, and high contrast signs aren’t enough. We need to change ableist attitudes that are entrenched in medicine and our society. For a person with a disability, there are so many potential barriers to receiving equitable healthcare. My advice, ask about the feasibility of your treatment plan. My patients are truly my greatest teachers.*” — Audrey Yap



Judy Needham

Chair, Patient Representative Committee and Member, Strategic Executive Advisory Council, CCTG

Experiences, Perspectives and Insights in PE – Judy Needham

Ms. Needham shared her experiences as the Chair of the Patient Representative Committee of the Canadian Cancer Trials Group (CCTG), a cooperative academic oncology group that designs and runs clinical trials across Canada. At CCTG, patient reps team with healthcare professionals/researchers, providing input at specific points in the CCTG clinical trial lifecycle to identify potential patient barriers in trial design and improve patient outcomes. She emphasized that everyone needs training in patient engagement in research, the need to be aware of power dynamics and matching engagement needs to patient partners' strengths.

“*Patient-centred care involves encouraging patients to make informed decisions about their own health. Patient-centred services are designed around the need to understand patient unmet needs, the burden of illness, and impacts of a disease. Patient engagement in research closes the loop by including meaningful and active patient collaboration in governance, priority setting, and the patient perspective in research from basic and translational research to clinical trials.*

Because UHN umbrellas this full spectrum of patient health care and services from research through to the delivery of patient-centred health care services, it is in a unique position to enable cohesive, meaningful and active end-to-end patient engagement through the PiPER initiative. This will importantly enable the research that includes endpoints that matter to patients that in turn supports patient-centred care and services.” — Judy Needham

Breakout Discussions

The day's breakout sessions included discussions on proposed patient partner roles in patient engagement in research and themes and principles of patient engagement in research. If you volunteered to continue these discussions and this work beyond the workshop, we'll be in touch with you soon ... watch your inbox!



Next Steps for PiPER: More Opportunities to Engage

The PiPER team continues working to establish a strong foundation for UHN's PE in research efforts. Over the coming months staff will be hired; individuals who volunteered will be invited to attend additional meetings to contribute to patient partner role definitions, training and resource needs; and, preparations are underway for the second strategic workshop to be hosted in the Fall. If you wish to be engaged in next steps and haven't already let us know, please email PiPER@uhn.ca.