

Persons with Lived/Living Experience and Families Partnering in Health Research

Health research encompasses the pillars of biomedical, clinical, health services, and social/cultural/environmental/population health. All of these areas are vital for addressing the health challenges people face—research that includes patient partners translates into improved practice.

WHAT IS PATIENT ORIENTED RESEARCH (POR)?

POR involves patients, caregivers and families throughout the research cycle as partners, not participants.

BEING A PATIENT/FAMILY PARTNER (PFP):

As an active collaborator and member of a research team, your lived/living experience advises and informs at various points during a research journey. See some examples below!

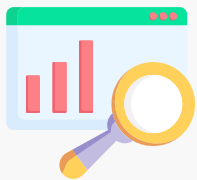
How can you engage as a patient/family partner?

START

Start with an IDEA!

Co-develop Research Question

Identify priority health topics important to patients, clarify & refine the question.



Data Collection

Assist with interviews, help conduct surveys, support writing of progress reports.



Analyze Findings

Identify themes & key messages, recommend ways to interpret data.



Share Findings

Develop communications strategies, co-present at conferences, co-author in manuscripts.

Design Research Methods

Inform & review data collection methods, identify patient/public collaboration opportunities, suggest recruitment strategies.



Submit Proposal for Funding

Review documentation, identify recognition of PFP contributions, support funding decisions.



Participant Recruitment

Promote within your network/community.

Project Starts

Review ethics applications, refine methods, ensure use of plain language in consent forms.

Implementation

Support knowledge translation and incorporation of findings into care practice.



NOTE: these are just a few ways you can collaborate in a research project. Training will be provided if needed.

Sit on advisory boards & review committees to continue advocating for the inclusion of patient/family partners in health research!

Hear from an investigator and a patient/family partner!



Dr. Lillian Hung
Founder & Head of
the UBC IDEA Lab



“ In the field of research, especially within healthcare, the inclusion of patient partners has become increasingly recognized as vital. However, despite this acknowledgment, there is a persistent challenge in truly understanding and valuing the perceptions of these patient partners. Often, their experiences, insights, and contributions remain underappreciated or misunderstood. At the UBC IDEA lab, we strive to bridge this gap by actively involving patient partners in ways that respect and reflect their preferences and contributions. Our approach is guided by the **ASK ME** framework, which ensures that patient partners are empowered to contribute meaningfully to the research process.

- A – Avoid assumptions
- S – Support people to do their best
- K – Know that the contribution will have an impact
- M – Meet regularly and stay connected
- E – Ethical sensitivity and responsibility

“ A lived experience allows a “real time” perspective in patient oriented research and I believe it gives a better understanding about the needs of the people in the delivery of medical care. Researchers and students also gain better understanding about their needs and therefore create opportunities on how to adjust academic knowledge to make them relevant in the delivery of medical care. I think it is important to have these conversations so that we can address the gaps in how care providers should treat their patients. As an advocate for people with capacity challenges, it is very satisfying whenever I see that my voice is heard and included in the research projects.



Mario Gregorio
Patient Family Partner

CHECK OUT THESE ADDITIONAL RESOURCES TO LEARN MORE ABOUT POR

BC Support Unit | <https://healthresearchbc.ca/bc-support-unit/about-us/>

Founded under Canada's Strategy for Patient-Oriented Research (SPOR), they partner researchers with patients to help improve health research and health outcomes.

- Information for Patient Partners – <https://tinyurl.com/yyye2s2r>
- Engagement Roadmap – <https://tinyurl.com/wwwp98kes>
- Patient Partner Engagement – <https://tinyurl.com/2p8dzy44>
 - Self-Assessment Readiness Tool – <https://tinyurl.com/54me7srs>
- Resource Library – <https://tinyurl.com/bdz6pwkw>

How-to Guide for Patients | <https://tinyurl.com/4zwmc57b>

CIHR SPOR Home Page | <https://cihr-irsc.gc.ca/e/41204.html>

Please contact education.award@vch.ca or CE@vch.ca if you have any questions.