

This document gives patient/caregiver partners (P/CPs) some practical tools and information around partnerships, ethics and P/CP safety during any engagement. While the focus is on research projects, much of the information may apply to non-research healthcare initiatives. The document is not a comprehensive collection nor is it a formally evaluated or ranked list; it is a starting place.

This document is the result of a collaborative effort of the Safety and Ethics Working Group, led by Kathleen Carlin. PAN thanks each member for their expertise, experience and passion shared throughout the process. Members included: Ramona Bonwick, Diana Ermel, Sandra Holdsworth, Sandy Ketler, Paula Orecklin, Ron Reddam, and Linda Riches.

We all need to be treated well and feel safe when engaging with healthcare and research partners.

P/CPs have become recognized as members of research teams, as well as project teams and working groups. Ideally P/CPs are equal members of research teams in all stages of the research process to the degree to which they are comfortable or choose to be involved. When P/CPs are authentically and meaningfully engaged, research addresses questions important to patients and results in improved patient and population health and system functioning. There may be other terms besides P/CP used, however for the purposes of this document they are interchangeable. This inclusion is key for all authentic patient engagement!

The PORLET and the IRLET and their companion guides are tools developed to help grant committees assess research applications. They also help explain patient engagement in patient-oriented research to individuals who are new to this research. Resources and references are listed at the end of this document.

Levels of engagement

Degree of influence or decision-making power the patient/caregiver partner has

Inform	Consult	Involve	Collaborate	Empower
To provide with information	To obtain feedback	To work with to develop alternatives	To partner in each aspect of decision-making	To decide

Sharing your lived experience

In discussions among P/CPs and in relevant literature one theme necessary for successful partnerships comes to the forefront again and again: Trust and respect between and among all partners on a team are essential to ensure a positive and productive partnership.

Issues that can have particularly strong impacts on trust and respect include talking about your lived experience and clear, open communication.

As a P/CP you may sometimes be asked or expected to reveal your experiences as a patient or caregiver. In deciding whether and how much to disclose, it is important to remember that you are in control as to how much you want to share.

As P/CPs come from various backgrounds and regions across the country you often hear varying terms used to reference sharing experiences and expertise gained through your involvement with healthcare and research. Often you will hear it referenced as “telling your story “ or “storytelling”. Some P/CPs are uncomfortable with that. Other references include: “sharing lived experience/expertise” or “knowledge sharing”. How you reference the sharing of your experience is up to you to decide.

If you are being asked to reveal your lived experience, or if you think it may be expected of you, here are some questions to think about:

- Am I comfortable doing this?
- Do I have the right to refuse?
- Do I feel safe refusing?
- Do I have a support person within the group?
- Do I have editorial rights?
- Am I invited for a whole meeting or just to tell my lived experience?
- Do I know how, when and where what I have shared will be used?
- Am I aware and comfortable with how and where what I have shared will be used?

Clear Communication

Clear communication is crucial to achieving trust and respect. P/CPs should:

- expect to have medical terms and acronyms that are used in research explained to them. See PERC reference for a glossary of some of them.
- Understand clearly the purpose of the study and its process
- be able to choose how they communicate, e.g., zoom, phone, email, etc.
- know who the contact person and lead researcher are, and how to contact them.
- be aware of who the project’s research ethics board and funders are.
- expect check-ins with the team.
- feel that they are able to communicate clearly and comfortably.

The rest of this guidance is in the form of questions for P/CPs to ask themselves or members during the course of a project:

Throughout engagement – relevant to all phases of the research

- Are the team’s expectations of me communicated clearly throughout the project?
- Am I listened to by other team members?
- Do I feel comfortable and safe asking questions and giving feedback to team members?
- Do I feel respected when I contribute?
- Are my unique experiences and needs recognized? Are they acted upon and considered?
- Are my insights or suggestions incorporated into the project and do I understand when they are not?
- How much decision-making power do I have?
- Am I invited to all meetings? Am I considered in schedule development?
- Is there anything going on that makes me feel uncomfortable, or that something is not right?
- Do I know the process I can follow when I feel uncomfortable?

Below are questions specific to three broad phases of research: planning, conduct and knowledge mobilization. For more detailed information on the research process, access the Patient Expertise in Research Collaboration (PERC) or the CIHR Ethics Guide which breaks research into ten stages (CIHR, p. 23)

Phases of Research

1) **Planning:** Thinking & Planning (PERC, p 22) Agenda setting, proposal, funding

- What is the researcher's experience with P/CPs?
- How does patient engagement contribute to the viability and success of the funding proposal?
- Are grants being pursued based, in part or alone, on the inclusion of patient engagement?
- Will being part of this study impact my care in any way including contact with my health care professionals?
- How far along is the project development/proposal?
- What is my role/responsibility/time commitment?
- What contributions are you expecting from me?
- Who is my contact (e-mail and phone) around my role/concerns?
- Has the project gone through Research Ethics Board (REB) and if not, will it?
- Will more than one P/CP be on the team? (Having at least 2 P/CPs on a project provides support)
- Will I be compensated, if so, how? (See CIHR compensation information document for more details.)
- What can I never share about this research outside of the team? What can I share and when?
- What constitutes a conflict of interest within this project?

2) **Conduct:** Discover, Gather & Analyze (PERC, p. 24) Carrying out the study - design and procedures, participant recruitment, data collection, data analysis

- How is the patient point of view represented in the research question? At every stage in the process?
- How are participants recruited? How will patient partners be involved in recruitment, e.g., designing posters or questionnaires?
- How is sex and gender accommodated?
- How is diversity and equity included in the study so that all Canadians are represented?
- In which areas of the research are P/CPs engaged?
- Can you share any further ways P/CPs can be involved in the project?

3) **Knowledge Mobilization:** Sharing, Impact and Dissemination (PERC, p. 25) implementation, evaluation

- Will I participate in the development and implementation of the knowledge mobilization plan?
- Will I be kept up to date as the project progresses?
- Will patient partners and advisors be given the complete results of the study, and how will that happen?
- Will my work be acknowledged officially, e.g., as a co-author?
- How will I be involved in presentations of results?
- Will results be explained in plain language?
- When can I publicly speak about the research?

Resources related to patient engagement

Alberta SPOR Support Unit. *Ethical Considerations for Partnering in Patient-Oriented Research*, <https://absporu.ca/resource/ethical-considerations-for-partnering-in-patient-oriented-research/>

PORLET and IRLET. *The Patient-Oriented Level of Engagement Tool and Indigenous Research Level of Engagement Tool*: <https://www.scpur.ca/porlet20>

PERC Advisory Board. (2019). *Patient Engagement in Research: A toolkit for Patient Partners*. A product of the INSPIRE-PHC Patient Engagement Resource Centre (PERC). Ottawa, ON. <https://perc-phc.mcmaster.ca/resources/by-perc/>

Resources related to sharing your lived experience:

PAN. Making Stories Matter Tip Sheet https://www.patientadvisors.ca/wp-content/uploads/2021/08/pan_making_stories_matter_-_advisor_tip_sheet.pdf

PAN. Making Stories Matter Requester Tip Sheet https://www.patientadvisors.ca/wp-content/uploads/2021/08/pan_making_stories_matter_-_requester_tip_sheet.pdf

OHT Engagement Learning Series – Bearing Witness to Lived Experience Workbook <https://www.mcmasterforum.org/rise/join-events/event-item/oht-engagement-learning-series---session-2-of-7-bearing-witness-to-lived-experience-and-emotions>

Sue Robins. Sharing Your Story Infographic. <https://suerobins.wordpress.com/2018/11/13/sharing-your-story/>

Resources for Effective Communication:

Communication Tips. <https://patientvoicesbc.ca/resources/tips-tricks-effective-communication/>

Resources for Planning Phase:

CIHR Ethics Guidance for Developing Partnerships with Patients and Researchers. <https://cihr-irsc.gc.ca/e/51910.html>

Engage with Impact Toolkit. <https://www.evaluateengagement.ca/CIHR>

Compensation Information. <https://cihr-irsc.gc.ca/e/51466.html>

CIHR Patient Partner Compensation Guidelines. <https://cihr-irsc.gc.ca/e/53261.html>

General Resources

Co learning commentary: a patient partner perspective in mental health care research. Linda Riches, Lisa Ridgway, Louisa Edwards <https://rdcu.be/dadUU>

Clinical Trials Ontario-Decision Aid Tool:

<https://www.ctontario.ca/patients-public/resources-for-engaging-patients/patient-decision-aid/>

Culturally Safe Engagement: What Matters to Indigenous (First Nations, Métis and Inuit) Patient Partners Pamphlet.

<https://patientvoicesbc.ca/resources/culturally-safe-engagement-what-matters-to-indigenous-first-nations-metis-and-inuit-patient-partners-pamphlet/>

Culturally Safe Engagement: What Matters to Indigenous (First Nations, Métis and Inuit) Patient Partners Companion Guide. <https://patientvoicesbc.ca/resources/culturally-safe-engagement-what-matters-to-indigenous-first-nations-metis-and-inuit-patient-partners-companion-guide/>

Audrey L'Espérance, Eleonora Bogdanova, Carolyn Canfield, Mary Anne Levasseur, Claudio Del Grande, Julia Abelson, Maman Joyce Dogba, Carol Fancott, Christine Loignon, Annette Majnemer, Marie-Pascale Pomey, Jananee Rasiah, Jon Salsberg, Maria Santana, Marie-Claude Tremblay, Robin Urquhart, and Antoine Boivin. 2023. [Learning Together : Evaluation framework for Patient and Public Engagement \(PPE\) in research](#)

Patient Engagement Learning Series:

<https://www.instituteforbetterhealth.com/portfolio-items/patient-caregiver-and-community-engagement-learning-series/>

Psychological Safety. <https://psychsafety.co.uk/the-four-stages-of-psychological-safety/>

Richards DP, Jordan I, Strain K, Press Z. *Patient partner compensation in research and health care: the patient perspective on why and how.* <https://pxjournal.org/journal/vol5/iss3/2/>

SPOR Patient Engagement Framework: <https://cihr-irsc.gc.ca/e/48413.html> (This document is being updated – current as of December 2023)

The article below was used in the development of this document:

Martineau, J.T., Minyaoui, A. & Boivin, A. Partnering with patients in healthcare research: a scoping review of ethical issues, challenges, and recommendations for practice. *BMC Med Ethics* 21, 34 (2020). <https://doi.org/10.1186/s12910-020-0460-0>