

Patient and Public Partner Engagement in Research



SPOR Evidence Alliance
Strategy for Patient-Oriented Research

Alliance pour des données probantes de la SRAP
Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research



Who are patients?

The Canadian Institutes of Health Research refers to patients with an inclusivity lens. Patients include not only those individuals who have personal experience of a health issue, yet also informal caregivers, including family and friends.¹

Who are citizens (public)?

The Canadian Institutes of Health Research defines citizen as any interested representatives of the general public, consumers of health services, patients, caregivers, advocates and representatives from affected community and voluntary health organizations.² We use citizen and public interchangeably.

What is patient and public engagement in health research?

Meaningful and active collaboration in decision-making, setting priorities, conducting research, and sharing (disseminating) research findings to ensure that the perspectives of patients and members of the public are considered in research priorities and in shaping the evidence and care they receive.

What does patient and public partnership look like?

What it is?	What it is not?
✓ Working with patient and public partners to set the research agenda	✗ Enrolling patient and public partners as a study participant to test an intervention
✓ Working with patient and public partners to conceptualize the research question and design	✗ Interviewing patient and public partners in a focus group or other qualitative study designs
✓ Working with patient and public partners to develop key messages based on the findings	✗ Observing a population to collect information on health-related outcomes

How to create a positive environment for patient and public partner engagement?

Be curious and enthusiastic	Express support
Be open	Invite others to talk
Be genuine	Keep atmosphere calm/reduce tension, and encourage others
Share information, experiences, and ideas	Listen actively
Elaborate on each others' ideas	Summarize/paraphrase to check for understanding
Acknowledge contributions	Disagree in an agreeable way

¹ Strategy for Patient-Oriented Research - Patient Engagement Framework. Available from <https://cihr-irsc.gc.ca/e/48413.html>

² CIHR Jargon Buster. Available from <https://cihr-irsc.gc.ca/e/48952.html>

Patient and Public Partner Engagement in Research



SPOR Evidence Alliance
Strategy for Patient-Oriented Research

Alliance pour des données probantes de la SRAP
Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research



What are some common barriers to keep in mind?³

Tokenism	Not setting expectations before starting an engagement
Not taking the time to build trust and respect	Being the “lonely only” patient/public on the team
Lack of understanding of each person’s motivations and perspectives	Power imbalances between researcher and patient/public
Conflicting patient/public and researcher priorities	Challenges related to ethnic, cultural, social, and organizational differences
A lack of preparation and training	

Tips for patient and public partner engagement

Communication and Relationship

- Have a main point of contact for patient and public partners
- Build trust – take time to establish mutually respectful relationships
- Be transparent – make sure everyone is aware of all the relevant information and what each person’s role is on the team
- Create a brave space – be aware of the power dynamics that exist patient and public partner engagement and work to dismantle these
- Define roles – be clear about what you are expecting/seeking from your patient and public partners, but be flexible and open to discussion and change

Provide training

- Both researchers and patient and public partners on the team will need training

Start early

- The earlier patient and public partners are engaged in the project the more they will know about the project and be able to effectively contribute

Planning

- Budget (fair compensation for patient and public partners,⁴ meeting costs, travel, etc.)
- Engage more than 1 patient/public partner: 2-3 partners will provide different insights and help support each other

³ Légaré F, Boivin A, van der Weijden T, Pakenham C, Burgers J, Légaré J, St-Jacques S, Gagnon S. Patient and public involvement in clinical practice guidelines: a knowledge synthesis of existing programs. Med Decis Making. 2011 Nov-Dec;31(6):E45-74. doi: [10.1177/0272989X11424401](https://doi.org/10.1177/0272989X11424401).

⁴ SPOR Evidence Alliance (2019). Patient Partner Appreciation Policy and Protocol. Toronto, ON: SPOR Evidence Alliance. Available from https://sporevidencealliance.ca/wp-content/uploads/2020/10/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure_2020.pdf

Patient and Public Partner Engagement in Research



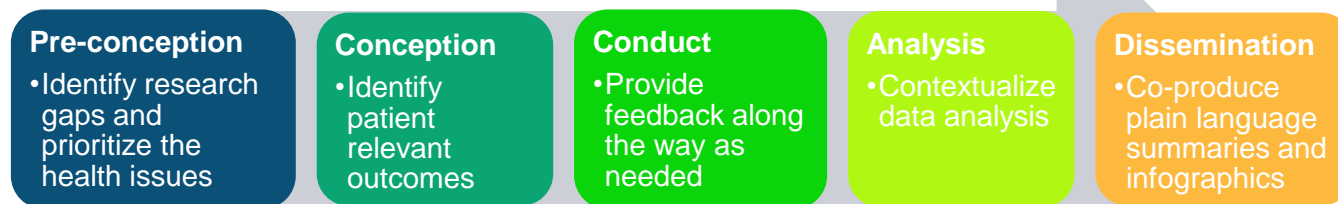
SPOR Evidence Alliance
Strategy for Patient-Oriented Research

Alliance pour des données probantes de la SRAP
Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research



What stages of a knowledge synthesis can you engage patient and public partners?



How to engage patient and public partners?⁵

Patient and public engagement in research exists along a spectrum.

	Inform	Consult	Involve	Collaborative	Empower
What	To provide easy to understand, objective, and balanced information to help them participate in the discussions.	To obtain feedback on research direction, progress, outcomes, analysis and interpretation.	To work closely throughout the research process to ensure patient/public perspectives are consistently understood and considered	Engage in each aspect of the decision in research and research-related activities	To place final decision-making responsibilities
How	<ul style="list-style-type: none"> Plain language summary Infographic 	<ul style="list-style-type: none"> 1-on-1 interviews Surveys Focus groups Workshop 	<ul style="list-style-type: none"> Working group Regular meetings 	<ul style="list-style-type: none"> Advisory committee Consensus-building Participatory decision-making 	<ul style="list-style-type: none"> Delegated decision

⁵ For more ideas, use the [Centre for Health Innovation \(CHI\): Interactive Online Engagement Tool](#)

Patient and Public Partner Engagement in Research



SPOR Evidence Alliance
Strategy for Patient-Oriented Research

Alliance pour des données probantes de la SRAP
Stratégie de recherche axée sur le patient

Strategy for Patient-Oriented Research

SPOR
Putting Patients First

Tools and Resources⁶



BUDGET

- SPOR Evidence Alliance Patient and Public Partner Appreciation Policy and Protocol. Available from https://sporevidencealliance.ca/wp-content/uploads/2020/10/SPOR-EA_Patient-Partner-Appreciation-Policy-and-Procedure_2020.pdf



PLANNING

- Workbook to guide the development of a Patient Engagement in Research (PEIR) Plan. Available from <http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf>
- Centre for Health Innovation (CHI): Patient Engagement Methods Tool. Available from <https://medium.com/knowledgenudge/how-to-use-chis-patient-engagement-methods-tool-be8014c5b355>
- Knowledge Translation Program Intersectionality Guide and Workbook. Available from <https://knowledgetranslation.net/portfolios/intersectionality-and-kt/>



COMMUNICATION

- CIHR Jargon Buster. Available from https://cihr-irsc.gc.ca/e/documents/cihr_jargon_buster-en.pdf
- Health Quality Ontario. Communicating Clearly with Patient and Caregiver Advisors. Available from <http://www.hqontario.ca/Portals/0/Documents/pe/quick-tools-checklist-communicating-clearly-pc.pdf>



EVALUATION

- Public and Patient Engagement Evaluation Tool (PPEET). Available from <https://healthsci.mcmaster.ca/ppe/our-products/public-patient-engagement-evaluation-tool>
- SCPOR Patient-Oriented Research Level of Engagement Tool (PORLET). Available from <https://www.scpor.ca/porlet>
- Patients Canada. Evaluations the Patient Partnership in Research. Available from https://ossu.ca/wp-content/uploads/EvaluationSurveysPatient_2016.pdf (for patients)
- https://ossu.ca/wp-content/uploads/EvaluationSurveysResearcher_2016.pdf (for researchers)

⁶ For more resources, visit <https://cihr-irsc.gc.ca/e/51916.html>