

Patient and Citizen Engagement in Research



Who is a patient?

The Canadian Institutes of Health Research uses patient to be inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends.¹

Who is a citizen?

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

What is patient and citizen engagement in health research?

Meaningful (*not tokenistic*) and active collaboration in governance, priority setting, conducting research, and knowledge translation to ensure patients voice and priorities play a role in shaping the evidence and care they receive.

What does patient and citizen partnership look like?

What it is?	What it is not?
✓ Working with patients and citizens to set the research agenda	✗ Enrolling patients and citizens as a study participant to test an intervention
✓ Working with patients and citizens to conceptualize the research question and design	✗ Interviewing patients and citizens in a focus group or other qualitative study designs
✓ Working with patients and citizens 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 citizen 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

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/citizen on the team
Lack of understanding of each person’s motivations and perspectives	Power imbalances between researchers and patients/citizens

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>

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).

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SPOR
Strategy for Patient-Oriented Research
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Strategy for Patient-Oriented Research
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Conflicting patient/citizen and researcher priorities
A lack of preparation and training

Challenges related to ethnic, cultural, social, and organizational differences
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Tips for patient and citizen engagement

Communication and Relationship

- Have a main point of contact for patient and citizen 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 in patient and citizen engagement and work to dismantle these
- Define roles – be clear about what you are expecting/seeking from your patient and citizen partners, but be flexible and open to discussion and change

Provide training

- Both researchers and patients/citizens on the team will need training

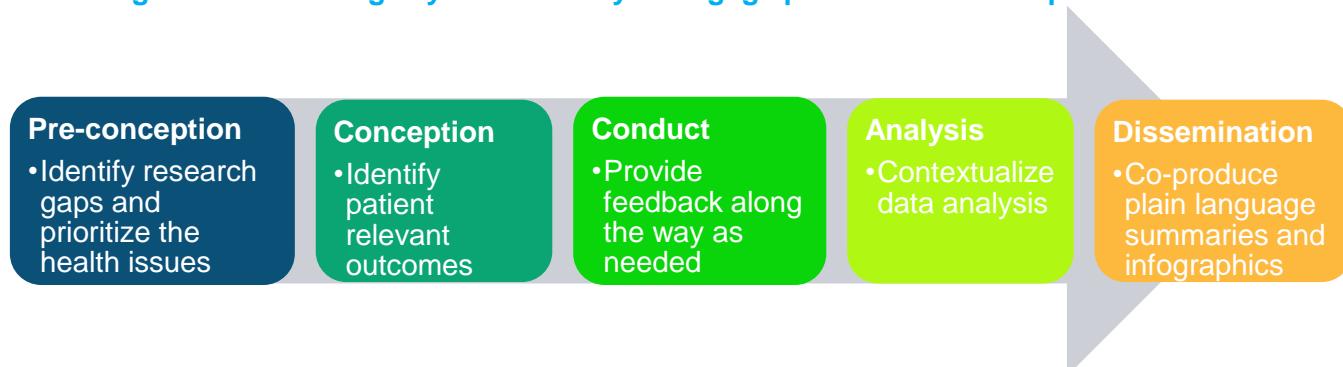
Start early

- The earlier patients/citizens 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 partners,⁴ meeting costs, travel, etc.)
- Engage more than 1 patient/citizen: 2-3 patients/citizens will provide different insights and help support each other

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



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

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How to engage patient and citizen partners⁵

Patient and citizen 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 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 summaryInfographic	<ul style="list-style-type: none">1-on-1 interviewsSurveysFocus groupsWorkshop	<ul style="list-style-type: none">Working groupRegular meetings	<ul style="list-style-type: none">Advisory committeeConsensus-buildingParticipatory decision-making	<ul style="list-style-type: none">Delegated decision

Tools and Resources⁶



BUDGET

- SPOR Evidence Alliance Patient 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/>

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

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



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)