

Patient and Public Partner Engagement in Research



SPOR
Strategy for Patient-Oriented Research
EVIDENCE ALLIANCE

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Putting Patients First

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.

How will I be engaged?

Patient and public partner engagement exists along a spectrum, which includes inform, consult, collaborative, empower.³ Each of these engagement approaches provides unique yet inclusive opportunities for patient and public engagement, as shown below.

| | Informed | Consulted | Involved | Collaborative | Empowered |
|-------------|---|--|---|---|--|
| | | | | | |
| What | Receive easy to understand, objective, and balanced information. | Provide feedback on research direction, progress, outcomes, analysis and interpretation. | Work closely throughout the research process so that your perspectives are consistently understood and considered | Engage in each aspect of the decision in research and research-related activities | Take on 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 |

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 For more details, refer to the [Centre for Health Innovation \(CHI\): Interactive Online Engagement Tool](#).

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What will I do?

You can discuss and agree on your specific role with the research team at the outset. This should take into account your interests, skills, experience, availability and preferences, as well as the research team's requirements.

Patient and Public Partner Roles

As a patient and public partner, you may opt to contribute to the research project in one or more of the following ways⁴:

During the project planning stage (the work plan or protocol)



- Help develop the research question the project will address.
- Help define the outcomes that the research should explore. This might include suggesting additional outcomes that would be of interest to patients, or selecting outcomes of greatest importance to patients.
- Provide input on how information is collected and synthesized. This might include providing feedback on whether it is appropriate to group particular symptoms, treatments or health conditions together in the synthesis.

During the report writing stage



- Provide feedback on a draft of the review results. You might be asked for specific feedback about whether you agree with how the results have been interpreted, or asked to give suggestions for what the key messages should be.
- Help develop the Plain Language Summary of the research findings. This might include you leading the writing with support from the research team.
- Comment on the plans for sharing (disseminating) the research findings. You might make suggestions to help reach the general public, or particular population groups.

Be a patient and public partner co-author



- In some instances, you can become a core member of the research project team. This would mean you will provide input throughout conduct of the research project and co-authorship will be offered as per the recommendations of the [International Committee of Medical Journal Editors](#).⁵

⁴ Adapted from Cochrane Consumer Network COVID-19 Consumer Rapid Response Group Resources. Available from <https://consumers.cochrane.org/sites/consumers.cochrane.org/files/public/uploads/covid-19-rapid-reviews-consumers.pdf>.

⁵ Defining the Role of Authors and Contributors. Available from <http://www.icmje.org/recommendations/browse/roles-and-responsibilities/defining-the-role-of-authors-and-contributors.html>.