

Patient-oriented research pathways self-assessment readiness tool

for patients

October 2019

Version 1.0

Introduction

Welcome to the *Patient-Oriented Research Pathways Self-Assessment Readiness Tool for Patients*. This tool will help you if you are a patient/ caregiver interested in learning more about participating as a partner in patient-oriented research. (For details about this research project, see the Appendix.) To start, let’s define patient-oriented research (“POR”).

Patient-oriented research is:

- Done with patient partners as research team members
- Answers questions, & measures outcomes, that matter to patients
- Aims to improve healthcare

Patients can be involved in POR in varying degrees. This diagram shows these levels of engagement. We are using the Australian National University’s language in the table to the right.¹

The most important things you **need to know** and **be able to do** (“critical competencies”) are:

- (1) Your lived experience with healthcare; and
- (2) Your interest in participating as a partner in research to make it relevant to patients.

Beyond these competencies, you will work with your research team to determine which competencies, outlined below, are desired for a project.

This Tool provides a way for patient partners to assess their readiness to participate in health research that uses a patient-oriented approach at the levels of Involve, Collaborate and Empower.

		INCREASING STAKEHOLDER INFLUENCE ON THE RESEARCH				
		INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PROMISE MADE TO STAKEHOLDERS BY RESEARCHERS	STAKEHOLDER PARTICIPATION GOAL	Researchers provide stakeholders with balanced and objective information to assist them in understanding the research process.	Researchers obtain stakeholder feedback on the research process.	Researchers work directly with stakeholders to ensure that stakeholder concerns and aspirations are consistently understood and considered in the research process.	Researchers partner with stakeholders for salient aspects of the research process.	Researchers assist stakeholders in conducting their own research.
		We will keep you informed.	We will keep you informed, listen to and acknowledge your concerns and aspirations and provide feedback on how your input influenced the research process.	We will work with you to ensure your concerns and aspirations are directly reflected in the research process and we will provide feedback on how your input influenced the research.	We will look to you for advice and innovation in designing and conducting the research process and incorporate your advice and recommendations to the maximum extent possible.	We will provide advice and assistance as requested in line with your decisions for designing and conducting your research, as well as for implementing the findings.

¹ Research-relevant modified IAP2 spectrum (Bammer G, Key issues in co-creation with stakeholders when research problems are complex. Evidence and Policy 15 (3) 423-435 <https://doi.org/10.1332/174426419X15532579188099>). [Graphic]. (2019). Retrieved October 1, 2019 from: <https://i2s.anu.edu.au/resources/stakeholder-participation-iap2-public-participation-spectrum/>

How to Use the Tool

Use the Tool by reading the competencies and determining if you have each competency or whether each is needed for your project. You can then discuss what you've learned with your research team or for your own personal/professional development, accessing the learning resources suggested. As a member of a research team, you would not be expected to be proficient in all competencies. The team would work with you to determine which of these competencies are applicable to the project. You can use the learning resources suggested in the Tool to develop competencies. There are a lot of competencies and not every patient partner needs every one.

**If you and your team elect to use the Tool, please let us know via email: bcsupportunit@healthresearchbc.ca.
We'd be pleased to hear how it's being taken up by research teams and stakeholders.**

**Patient-oriented research pathways
self-assessment readiness tool**

FOR PATIENTS

Patient Characteristics

As a patient research partner, do I have the attitudes and attributes to participate on a POR research team?

Criteria	Learning Goals
<p>Attitudes</p> <p><i>Do I have...?:</i></p> <ul style="list-style-type: none"> • an interest in research outcomes • an interest in contributing to healthcare improvement • a commitment to contributing to society • willingness to commit to long-term projects <p><i>Do I...?:</i></p> <ul style="list-style-type: none"> • value mutual benefits in collaborations • respect the complexities of a research project • respect differing skills • value the knowledge of researchers <p><i>Am I willing to...?:</i></p> <ul style="list-style-type: none"> • represent more than my personal individual experiences • commit to shared decision-making • respect differing skills 	

- value the knowledge of researchers

Personal attributes

Do others describe me as...?:

- confident
- curious
- participatory
- a good communicator
- humble
- having a constructive and positive attitude
- emotionally intelligent

Patients Competencies: Knowledge

Competency	Criteria	Learning Resources <i>Knowledge Acquisition</i>
Knowledge	<p>K1. Research Methods and Principles</p> <p><i>I know:</i></p> <ul style="list-style-type: none"> • about health research processes and methods • about participatory and community research methods • about commonly used research methods • how to be involved in the research process • how to contribute to a team developing a research question, gathering data, and analyzing findings. • where to obtain training for my contribution to a specific research project (or whom to ask). <p><i>I understand:</i></p> <ul style="list-style-type: none"> • the research method being used by my research team • the importance of research ethics • the meaning of research data, especially the data being collected by my team <p><i>I can:</i></p> <ul style="list-style-type: none"> • define and explain research approaches used by my research team. • define and use health research vocabulary 	<p>K1. Research Methods and Principles</p> <p>Basic Research Concepts Online training modules to promote an understanding of basic research concepts U.S. Department of Health and Human Service https://ori.hhs.gov/content/basic-research-concepts-brc</p> <p>Fundamentals of qualitative research methods 6 video modules covering essential topics in qualitative research, including what is qualitative research and how to use the most common methods, in-depth interviews and focus groups. Yale University, US https://www.youtube.com/watch?v=7m0LVHK8a94</p> <p>What is Quantitative Research in Sociology? - Definition, Methods & Examples Video about health research Study.com https://study.com/academy/lesson/what-is-quantitative-research-in-sociology-definition-methods-examples.html</p> <p>Training on Research Processes Online training modules about health research Canadian Depression Research and Intervention Network http://cdrin.org/lived-experience/</p> <p>Understanding Health Research A comprehensive website explaining health research University of Glasgow www.understandinghealthresearch.org</p> <p>Health Research Ethics 101 A website that briefly describes health research ethics in Alberta Health Research Ethics Board of Alberta https://hreba.ca/health-research-ethics-101/</p>

<p>K2. Participatory Approaches <i>I understand:</i></p> <ul style="list-style-type: none"> • my role within a research team and the roles of others on the team • the viewpoints and needs of other research partners • how to connect with the patient population <p><i>I can:</i></p> <ul style="list-style-type: none"> • bring a personal perspective to the research process • explain the needs of patients as respondents to research questions • help to connect with the patient population <p>K3. Cultural Competence and Context <i>I understand:</i></p> <ul style="list-style-type: none"> • the basics of cultural competence • the importance of identifying community needs, concerns, opinions and perspectives <p><i>I know:</i></p> <ul style="list-style-type: none"> • the context in which the research project is being conducted <p>K4. Logistics <i>I understand:</i></p> <ul style="list-style-type: none"> • the time required to participate in research when I make a commitment to do so <p><i>I know:</i></p>	<p>K2. Participatory Approaches <i>Patient-Oriented Research Training and Learning – Primary Health Care (PORTL-PHC)</i> Online training modules to learn about patient-oriented research PORTL-PHC is an Ontario SPOR SUPPORT Unit-funded initiative https://bcsupportunit.ca/resources/patient-oriented-research-training-and-learning-primary-health-care-portl-phc-online</p> <p>K3. Cultural Competence and Context <i>Background context on Indigenous Health Research</i> Online Modules Canadian Institutes of Health Research https://bcsupportunit.ca/resources/background-context-indigenous-health-research <i>Cultural Safety and Cultural Humility</i> Webinars First Nations Health Authority https://bcsupportunit.ca/resources/cultural-safety-and-cultural-humility-webinars <i>Indigenous Ways of Knowing</i> Online Modules University of Toronto https://www.oise.utoronto.ca/abed101/indigenous-ways-of-knowing/</p> <p>K4. Logistics <i>Public Co-Applicants in Research – guidance on roles and responsibilities</i> A document to help understand what's needed for the public and researchers to work together INVOLVE, UK https://www.invo.org.uk/posttypepublication/public-co-applicants-in-research-guidance-on-roles-and-responsibilities/</p>
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	<ul style="list-style-type: none"> the available supports and training opportunities <p>K5. Understanding Evidence and Results <i>I understand:</i></p> <ul style="list-style-type: none"> evidence and what can (or cannot) be achieved through research the meaning of the data my research team is reviewing the results of this study the expected impact of study interventions how quality in research effort and outcomes are assessed <p>K6. Knowledge About Study Topic <i>I know:</i></p> <ul style="list-style-type: none"> the study topic <p><i>I can:</i></p> <ul style="list-style-type: none"> describe my experience of the study topic <p><i>I understand:</i></p> <ul style="list-style-type: none"> needs of patients experiencing the study topic <p>K7. Priority/Agenda Setting <i>I understand:</i></p> <ul style="list-style-type: none"> how research funding priorities are set 	<p>K5. Understanding Evidence and Results <i>Making Sense of Medical Research Studies</i> A webpage about health research Canadian Women's Health Network http://www.cwhn.ca/node/40799 <i>Scientific evidence: what is it and how can we trust it?</i> A webpage about health research The Conversation Canada https://theconversation.com/scientific-evidence-what-is-it-and-how-can-we-trust-it-14716 <i>Including Patient Preferences to Assess the Balance of Benefits and Harms of Treatment Options for People with Multiple Chronic Conditions</i> A webpage about health research Patient-Centered Outcomes Research Institute https://www.pcori.org/research-results/2014/including-patient-preferences-assess-balance-benefits-and-harms-treatment</p> <p>K6. Knowledge About Study Topic <i>Public Co-Applicants in Research – guidance on roles and responsibilities</i> A document to help understand what's needed for the public and researchers to work together INVOLVE, UK https://www.invo.org.uk/posttypepublication/public-co-applicants-in-research-guidance-on-roles-and-responsibilities/</p> <p>K7. Priority/Agenda Setting <i>James Lind Alliance Guidebook</i> A training guidebook James Lind Alliance, UK http://www.jla.nihr.ac.uk/jla-guidebook/</p>
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		<p><i>James Lind Alliance: Identifying the Top 10 Canadian Research Priorities for Fibromyalgia – a Patient’s Perspective</i> A blog post recounting a patient’s involvement in priority setting Canadian Institutes of Health Research http://www.cihr-irsc.gc.ca/e/51183.html</p> <p><i>Introduction to the James Lind Alliance: A Participatory Approach to Engage Patients, Caregivers and Clinicians in Priority Setting Partnerships, part 1</i> A blog post outlining the James Lind Alliance approach Knowledge Nudge blog, Manitoba SPOR SUPPORT Unit https://medium.com/knowledgenudge/introduction-to-the-james-lind-alliance-a-participatory-approach-to-engage-patients-caregivers-94d38e4df718</p> <p><i>The James Lind Alliance: An Overview of the Process of Priority Setting Partnerships, part 2</i> A blog post outlining the James Lind Alliance approach Knowledge Nudge blog, Manitoba SPOR SUPPORT Unit https://medium.com/knowledgenudge/part-ii-the-james-lind-alliance-767a378e6b58</p>
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Patients Competencies: Skills

Competency	Criteria	Learning Resources <i>Skills Acquisition</i>
Skills	<p>S1. Research skills <i>I am able to:</i></p> <ul style="list-style-type: none"> • read and comprehend research reports • reflect patient experiences in the research questions asked • identify research gaps in knowledge from a patient perspective • help to recruit research participants • place patient stories in the research process within the context of their own life experience • work with others to establish research networks <p><i>I can:</i></p> <ul style="list-style-type: none"> • identify patient-important themes in data • participate in ethical debates <p>S2. Participatory skills <i>I am able to:</i></p> <ul style="list-style-type: none"> • create partnerships that share power and responsibility equally and fairly • collaborate in order to participate in all aspects of the study design • establish rapport with study participants, and in so doing, identify community resources 	<p>S1. Research skills Critical appraisal A tutorial to learn how to review research articles University of Exeter, UK https://libguides.exeter.ac.uk/criticalappraisalhealth</p> <p>Patient Engagement in Health Research: A How-to Guide for Patients Guidebook for patients interested in getting involved in health research Alberta SPOR SUPPORT Unit https://albertainnovates.ca/wp-content/uploads/2018/06/How-To-Guide-Patient-Version-8.0-May-2018.pdf</p> <p>Public Co-Applicants in Research – guidance on roles and responsibilities A document to help understand what's needed for the public and researchers to work together INVOLVE, UK https://www.invo.org.uk/posttypepublication/public-co-applicants-in-research-guidance-on-roles-and-responsibilities/</p> <p>S2. Participatory skills Patient Engagement in Health Research: A How-to Guide for Patients Guidebook for patients interested in getting involved in health research Alberta SPOR SUPPORT Unit https://albertainnovates.ca/wp-content/uploads/2018/06/How-To-Guide-Patient-Version-8.0-May-2018.pdf</p> <p>Twelve Lessons Learned for Effective Research Partnerships Between Patients, Caregivers, Clinicians, Academic Researchers, and Other Stakeholders Article https://bcsupportunit.ca/resources/twelve-lessons-learned-effective-research-partnerships-between-patients-caregivers</p> <p>Introduction to the James Lind Alliance: A Participatory Approach to Engage Patients, Caregivers and Clinicians in Priority Setting</p>

	<p>S3. Communication skills <i>I am able to:</i></p> <ul style="list-style-type: none"> • Compellingly express my personal experiences with the condition being studied • ask questions and probes • present my own experiences and opinions • listen to others with differing viewpoints <p>S4. Teamwork/Group Process <i>I can:</i></p> <ul style="list-style-type: none"> • define my own role in the research project • raise issues important to patients • work effectively in a group to keep a patient-centred approach at the forefront of the team’s awareness • provide feedback to the team • build relationships or teams • mentor others • mediate in the group setting • handle intense emotions with those who have differing views 	<p>Partnerships Knowledge Nudge blog, Manitoba SPOR SUPPORT Unit https://bcsupportunit.ca/resources/introduction-james-lind-alliance-participatory-approach-engage-patients-caregivers-and Patient and Stakeholder Engagement in Research: Strategies for Initiating Research Partnerships Webinar recording PCORI https://bcsupportunit.ca/resources/pcori-patient-and-stakeholder-engagement-research-strategies-initiating-research Belbin's Team Roles: How Understanding Team Roles Can Improve Team Performance Website Resource MindTools website https://www.mindtools.com/pages/article/newLDR_83.htm</p> <p>S3. Communication skills Public Dialogue and Deliberation: A Communication Perspective for Public Engagement Practitioners Guidebook Citizen Participation Network https://oliversdialogue.wordpress.com/2013/08/01/public-dialogue-and-deliberation-a-communication-perspective-for-public-engagement-practitioners/</p> <p>S4. Teamwork/Group Process Training on Research Processes for patients Online training Canadian Depression Research & Intervention Network (CDRIN) http://cdrin.org/lived-experience/</p>
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	<p>S5. Conflict/tension Management <i>I am able to:</i></p> <ul style="list-style-type: none"> • deal productively with conflicts that arise <p>S6. Evidence and Results <i>I can:</i></p> <ul style="list-style-type: none"> • support the dissemination of research results <p>Additional specific skills that may be required by individual research teams:</p> <p>S7. Research Skills: <i>I am able to:</i></p> <ul style="list-style-type: none"> • develop the research design along with other members of the team • write research goals • write consent forms, questionnaires, or interview schedules • use computers and software programs • collect data (e.g. interview study participants) • present data • collaborate in data analysis • interpret and evaluate research findings • assess risks and benefits of treatments • write and communicate using technology 	<p>S5. Conflict/tension Management Conflict management Online training University of California Irvine (US) https://www.coursera.org/specializations/conflict-management</p> <p>S6. Evidence and Results Patient Engagement in Health Research: A How-to Guide for Patients Guidebook Alberta SPOR SUPPORT Unit https://albertainnovates.ca/wp-content/uploads/2018/06/How-To-Guide-Patient-Version-8.0-May-2018.pdf</p> <p>Additional specific skills that may be required by individual research teams:</p> <p>S7. Research Skills Refer to section S1 above.</p>
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	<ul style="list-style-type: none"> collaborate with other team members to create a shared set of reliable sources of evidence <p>S8. Project Management <i>I can:</i></p> <ul style="list-style-type: none"> manage projects or aspects of the work of my research team <p>S9. Priority Setting <i>I am able to:</i></p> <ul style="list-style-type: none"> influence what is being investigated currently and in the future 	<p>S8. Project Management <i>Project management tools for researchers</i> Website with resources Vitae https://www.vitae.ac.uk/doing-research/leadership-development-for-principal-investigators-pis/leading-a-research-project/managing-a-research-project/project-management-tools-for-researchers</p> <p>S9. Priority Setting Refer to section K7 above.</p>
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Appendix: POR Pathways Project Background

Plain language summary:

Why we did this project: The Canadian Institutes of Health Research (CIHR) funded a program to change the way health research is done. The new way is called “patient-oriented research”, or by an abbreviation, “POR”. POR involves four different ‘stakeholder’ groups working together in partnership. Patients and their families/caregivers participate as equal partners on research teams. They work with researchers, people who provide care to patients, and people who make decisions about health care. Other places, like the United Kingdom, and the United States, have been doing health research this way for a number of years.

The authors work through a unit in British Columbia, Canada that was set up to help research teams and other interested people learn how to do patient-oriented research. Early on, our team members felt that we could not train people if we didn’t first understand what others had learned about which competencies (these are knowledge, skills and attitudes) were helpful to research team members working in research this way. So, we used a formal research method known as a scoping review to search the literature, that is a published record of what others have learned, to understand these things.

What we did: Our search included papers in academic journals as well as information on websites, training manuals, conference proceedings, governmental documents and statements from health organizations.

What we learned: Writers reported the usefulness of many competencies for researchers and patients doing this work. We didn’t find many for people who provide care to patients, and people who make decisions about health care. As a team, we looked at all the competencies and grouped them into themes.

We found that for researchers, the main competencies had to do with participation, communication and teamwork and conflict/tension management. For patients the main competencies had to do with research knowledge and skills, cultural competence/context and participation. For all everyone we learned that it was helpful for team members to want to work collaboratively, as part of a group, for the public good.

Our conclusions: We worked with an advisory group made up of people representing patients and their families/caregivers, researchers, people who provide care to patients, and people who make decisions about health care to review what information we found. We concluded that our competency statements can be helpful in determining what people may need to know as they join research teams generally, and there may be more specific competencies for a research project. We recommend that our lists be used as a guide for each research team and everyone to choose the competencies that are relevant to their work.

Non-plain language summary:

This project has been undertaken by the BC SUPPORT Unit, part of Health Research BC, funded by the [Canadian Institutes of Health Research \(CIHR\)'s Strategy for Patient-Oriented Research \(SPOR\)](#).

Patient-Oriented Research

Patient-oriented research (POR) refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.

Objectives of SPOR²

are to foster evidence-informed health care by bringing innovative diagnostic and therapeutic approaches to the point of care, to ensure greater quality, accountability, and accessibility of care. SPOR brings together four stakeholder groups: (1) patients, (2) researchers, (3) health care providers and (4) health system decision-makers, to actively collaborate to build a sustainable, accessible and equitable health care system and bring positive changes in the health of people living in Canada.

Patient engagement in research will improve the relevance of the research and improve its translation into policy and practice, contribute to more effective health services and products, and ultimately, improve the quality of life of Canadians and result in a strengthened Canadian health care system. Guiding principles:

Inclusiveness: *Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution— i.e., patients are bringing their lives into this.*

Support: *Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement (see CIHR's Considerations when paying patient partners in research: <http://cihr-irsc.gc.ca/e/51466.html>).*

Mutual Respect: *Researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge.*

² CIHR Strategy for Patient-Oriented Research - Patient Engagement Framework. <http://www.cihr-irsc.gc.ca/e/48413.html>

Co-Build: *Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.*

CIHR-led Training Modules

Training is also available in an in-person format through the BC SUPPORT Unit's delivery of the "Foundations in Patient-Oriented Research" workshop modules. Details: <https://bcsupportunit.ca/foundations-of-por>.

Purpose

The Patient-Oriented Research Pathway ("Pathway") articulates how individuals might progress in developing attitudes, knowledge, and skills related to patient-oriented research and research use.

Pathway Development Process

The Pathway was developed by a project team through the BC SUPPORT Unit (see section below for a list of team members). The team derived the Pathway from: (a) published literature from both peer-reviewed and grey sources; and, (b) the voice of experts represented by stakeholders from all four stakeholder groups in British Columbia, Canada, and internationally (see section below for list of expert advisors). Other countries have launched similar initiatives (INVOLVE in the UK; PCORI in the US) yet there has never been a full review of the competencies (knowledge, skills and attitudes) needed by individuals to engage in this work.

The scoping review's purpose was to summarize existing knowledge on such competencies. Our objectives were to systematically explore literature, articulate competencies necessary for POR team members, identify research gaps and provide recommendations for further research. The scoping review included peer-reviewed and grey literature. A total of 2,046 sources was retrieved through standard health databases and search methods. Data were extracted from 35 peer-reviewed papers and 38 grey literature sources. We used an iterative process to reach consensus on competency statements, which inform the Self-Assessment Readiness Tool, i.e. competencies included are based on the literature. An international group of advisors comprised of all four stakeholder groups was consulted, reviewing the findings and providing their perspectives. Our project found a dearth of information written for healthcare providers and health system decision-makers. Further research could validate these findings through a Delphi process with a panel of POR experts.

The scoping review **protocol** is available here:

Mallidou, A. A., Frisch, N., Doyle-Waters, M. M., MacLeod, M. L. P., Ward, J., & Atherton, P. (2018). Patient-Oriented Research Competencies in Health (PORCH) for patients, healthcare providers, decision-makers and researchers: protocol of a scoping review. *Systematic Reviews*, 7, 101. doi: <https://doi.org/10.1186/s13643-018-0762-1>

The scoping review **findings** manuscript is available here:

(TBA)

POR Pathways Project Team

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POR Pathways Group of Advisors

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- Healthcare Providers:
 - Agnes Black
 - Marie Westby
- Patient Partners:
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 - Sarah Fletcher
- Researchers:
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- Patient engagement, BC SUPPORT Unit: Colleen McGavin