



Patient-Oriented Research Pathways

Self-assessment

Readiness Tool

For Researchers

October 2019

Version 1.0

Introduction

The *Patient-Oriented Research Pathways Self-Assessment Readiness Tool for Researchers* was developed out of interest in uncovering competencies required to engage in [patient-oriented research](#) through a review of the literature (see the [Appendix](#) for details).

This Tool provides a way for researchers to assess their readiness to participate in health research that uses a patient-oriented approach. **A research team would not be expected to be proficient in all competencies, but rather the team would determine which of these competencies are applicable to their project and members would determine where they need to develop competencies and can use the learning resources suggested in the Tool.**

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

How to Use the Tool

Use the Tool by reading the competencies and rating yourself on a scale of 1-4. Use the results as a point of discussion on a research team or for your own personal/professional development, accessing the learning resources suggested.

		INCREASING STAKEHOLDER INFLUENCE ON THE RESEARCH				
		INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
STAKEHOLDER PARTICIPATION GOAL	STAKEHOLDER 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.
	PROMISE MADE TO STAKEHOLDERS BY RESEARCHERS	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/>

Curious about other learning resources? These BC SUPPORT Unit listings are updated regularly:

1. *Patient-Oriented Research Resources:*

<https://bcsupportunit.ca/resources>

2. *Intro to Health Research for Patients:*

<https://bcsupportunit.ca/resources/intro-health-research-patients>

3. *Resources for Researchers Working With Indigenous Communities:*

<https://bcsupportunit.ca/resources/planting-seeds-resources-working-indigenous-communities>

If you and your team elect to use the Tool, please let us know via [our online survey](#) or email: info@bcsupportunit.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 RESEARCHERS

Researcher Characteristics

As a researcher, do I have the attitudes and attributes to conduct POR research?

Criteria	Learning Goals
<p><i>Do I readily...?:</i></p> <ul style="list-style-type: none"> • participate and collaborate • establish relationships that exhibit openness and trust • commit to contributing to society, working toward the ‘greater good’ • respect community values and the lived experiences of patient partners • support the use of creative methodologies • hold a commitment to patient partners/public involvement • value research questions that are not researcher-driven • respect the ‘cultural gap’ between old and new ways of working <p><i>Am I...?:</i></p> <ul style="list-style-type: none"> • inclined toward self-reflection and professional development? • willing to be accountable to patient partners and to the community? 	

Do others describe me as...?:

- Friendly
- Accommodating
- Flexible
- Patient
- Supportive
- Encouraging
- Approachable
- Optimistic

COMPETENCY STAGE			
1 Need learning and practice	2 Knowledgeable, but need practice	3 Competent	4 Expert: can teach others

Researchers Competencies: Knowledge



Competency	Criteria	1	2	3	4	Learning Resources <i>Knowledge Acquisition</i>	Learning Goals
Knowledge	<p>K1. Research Methods and Principles <i>I know:</i></p> <ul style="list-style-type: none"> the research method being used at an expert level research approaches congruent with patient and community engagement strategies for successful participant recruitment and informed consent processes <p>K2. Participatory Approaches <i>I understand:</i></p> <ul style="list-style-type: none"> participatory approaches and methods community engagement and community involvement the need to balance patients' right to participate while ensuring patients were not overburdened or exploited 					<p>K1. Research Methods and Principles <i>Engagement Rubric</i> Guidebook for researchers Patient-Centered Outcomes Research Institute (PCORI), USA https://www.pcori.org/sites/default/files/Engagement-Rubric.pdf</p> <p><i>Public involvement in NHS, public health and social care research</i> Briefing notes for researchers INVOLVE, UK http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf</p> <p>K2. Participatory Approaches Moss, N et al. (2017) <i>Involving pregnant women, mothers and members of the public to improve the quality of women's health research</i>. BJOG: Int J Obstet Gy. 124, 3. https://doi.org/10.1111/1471-0528.14419</p>	

	<ul style="list-style-type: none"> the necessity of balancing patients' perspectives with those of others on the research team how to match people to the needs of the research approach <p>K3. Evidence and Results <i>I understand:</i></p> <ul style="list-style-type: none"> that patients require the presentation of research results in a manner that is readily understood and meaningful <p>K4. Cultural Context and Competence <i>I know:</i></p> <ul style="list-style-type: none"> the basics of cultural competence the principles of conducting work (such as obtaining informed consent) from within the cultural perspectives of the participants <p><i>I identify:</i></p> <ul style="list-style-type: none"> my own personal experiences and social contexts related to the study context <p>K5. Logistics <i>I understand:</i></p> <ul style="list-style-type: none"> there is additional time required for collaboration in the research plan 				<p>K3. Evidence and Results Plain Language Course Online training Government of BC https://www2.gov.bc.ca/gov/content/governments/services-for-government/policies-procedures/web-content-development-guides/writing-for-the-web/plain-language-guide/plain-language-course</p> <p>Program for Readability in Science and Medicine (PRISM) Online Course and Toolkit Group Health Research Institute, Seattle https://bcsupportunit.ca/resources/program-readability-science-and-medicine-prism-online-course-and-toolkit</p> <p>K4. Cultural Competence and Context Background context on Indigenous Health Research Online Modules Canadian Institutes of Health Research https://bcsupportunit.ca/resources/background-context-indigenous-health-research</p> <p>Cultural Safety and Cultural Humility Webinars First Nations Health Authority https://bcsupportunit.ca/resources/cultural-safety-and-cultural-humility-webinars</p> <p>K5. Logistics 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</p>	
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	<ul style="list-style-type: none"> • budgetary implications for involving and compensating patients <p>K6. Priority and Agenda Setting <i>I know:</i></p> <ul style="list-style-type: none"> • how research funding priorities are set • how to determine best new research ideas and future directions • how to set research priorities that are important to patients <p>K7. Understanding Patient-Oriented Research <i>I know:</i></p> <ul style="list-style-type: none"> • the relevance and benefits of patient involvement • about POR, its guiding principles and its benefits 				<p>https://www.invo.org.uk/posttypepublication/public-co-applicants-in-research-guidance-on-roles-and-responsibilities/</p> <p>K6. Priority and Agenda Setting James Lind Alliance: Identifying the Top 10 Canadian Research Priorities for Fibromyalgia – a Patient’s Perspective 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>Introduction to the James Lind Alliance: A Participatory Approach to Engage Patients, Caregivers and Clinicians in Priority Setting Partnerships, part 1 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>The James Lind Alliance: An Overview of the Process of Priority Setting Partnerships, part 2 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> <p>K7. Understanding Patient-Oriented Research Patient-Oriented Research Training and Learning – Primary Health Care (PORTL-PHC) Online training modules to learn about patient-oriented research Ontario SPOR SUPPORT Unit https://bcsupportunit.ca/resources/patient-oriented-research-training-and-learning-primary-health-care-portl-phc-online</p> <p>Embracing patient-oriented research: are you ready, willing, and able? Webinar recording BC SUPPORT Unit https://bcsupportunit.ca/resources/embracing-patient-oriented-research-are-you-ready-willing-and-able</p>	
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COMPETENCY STAGE			
1 Need learning and practice	2 Knowledgeable, but need practice	3 Competent	4 Expert: can teach others



Researchers Competencies: Skills

Competency	Criteria	1	2	3	4	Learning Resources Skills Acquisition	Learning Goals
Skills	<p>S1. Participatory Skills: <i>I am able to:</i></p> <ul style="list-style-type: none"> create a safe and respectful environment for team members attract, recruit and enroll patient and public members in the research process involve patient partners in all aspects of the study design ensure patient partners have sufficient training to participate ensure that all information given to the patient partners is comprehensive and understandable build on community strengths, 					<p>S1. Participatory Skills: <i>How to Engage Patients & Public in Health Research</i> Interactive Map Tool George and Fay Yee Centre for Health Care Innovation (CHI), Manitoba https://chimb.ca/sub-sites/1-patient-engagement?page=75-how-to-engage</p> <p><i>Engage2020 Action Catalogue</i> Online decision support tool Europe http://actioncatalogue.eu/</p> <p><i>Engaging Patients in the Research Process</i> Toolkit Can-SOLVE CKD https://www.cansolveckd.ca/wp-content/uploads/2018/07/patient-engagement-toolkit.pdf</p> <p><i>Workbook to guide the development of a Patient Engagement In Research (PEIR) Plan</i> Workbook Arthritis Research Canada http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf</p> <p><i>Patient and Public Involvement</i> Online resources NIHR Research Design London, UK https://www.rds-london.nihr.ac.uk/resources/#patient-and-public-involvement</p> <p><i>Patient Engagement: Heard and Valued</i> A handbook for meaningful engagement of patients that have not traditionally been heard in healthcare planning Canadian Foundation for Healthcare Improvement https://www.cfhi-fcass.ca/sf-docs/default-source/patient-engagement/awesome-handbook-fraserhealth.pdf?sfvrsn=2</p>	

	<ul style="list-style-type: none"> release control of the study findings to the community or population studied. <p><i>I have:</i></p> <ul style="list-style-type: none"> interpersonal skills to create and nurture partnerships that share power <p>S2. Communication Skills:</p> <p><i>I am able to:</i></p> <ul style="list-style-type: none"> communicate difficult and complex concepts and ideas in understandable language mentor others demonstrate transparency give feedback to others, ensuring differences of opinion are expressed in a productive manner prepare written documents and reports <p>S3. Teamwork – Group Process Skills:</p> <p><i>I can:</i></p> <ul style="list-style-type: none"> build trusting relationships 				<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>S2. Communication Skills:</p> <p>Plain Language Course Online training Government of BC https://www2.gov.bc.ca/gov/content/governments/services-for-government/policies-procedures/web-content-development-guides/writing-for-the-web/plain-language-guide/plain-language-course</p> <p>Program for Readability in Science and Medicine (PRISM) Online Course and Toolkit Group Health Research Institute, Seattle https://bcsupportunit.ca/resources/program-readability-science-and-medicine-prism-online-course-and-toolkit</p> <p>Guidance for researchers: feedback from researchers to patient and public involvement (PPI) contributors Tool Centre for Research in Public Health and Community Care, UK https://www.clahrc-eoe.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf</p> <p>S3. Teamwork – Group Process Skills:</p> <p>Building and managing a research team Vitae, UK https://www.vitae.ac.uk/doing-research/leadership-development-for-principal-investigators-pis/building-and-managing-a-research-team</p> <p>Leading Virtual Teams Online training Cornell University https://www.ecornell.com/certificates/leadership-and-strategic-management/leading-virtual-teams/#</p>	
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	<ul style="list-style-type: none"> • facilitate, mediate and encourage others in a group meeting • create safe/supportive team atmospheres • clarify roles for each member of the research team • manage expectations • express differences in a productive manner • handle intense emotions <p>S4. Project Management Skills: I am able to:</p> <ul style="list-style-type: none"> • create budgets for the costs of patient partners' participation • prepare written contractual and legal 				<p>Belbin's Team Roles - How Understanding Team Roles Can Improve Team Performance Mindtools website https://www.mindtools.com/pages/article/newLDR_83.htm</p> <p>Leading a productive research group University of Oxford, UK https://www.ox.ac.uk/research/support-researchers/principal-investigators/principal-investigations-blog-pis/leading-productive-research-group?wssl=1</p> <p>Building a Research Team National Association of Transplant Professionals http://www.natco1.org/research/files/BuildingaResearchTeam_000.pdf</p> <p>How to build a powerful research team Pimp Your Science website http://www.pimpyourscience.org/lesson/17/How-to-build-a-powerful-research-team.html</p> <p>Background context on Indigenous Health Research Online Modules Canadian Institutes of Health Research https://bcsupportunit.ca/resources/background-context-indigenous-health-research</p> <p>Cultural Safety and Cultural Humility Webinars First Nations Health Authority https://bcsupportunit.ca/resources/cultural-safety-and-cultural-humility-webinars</p> <p>S4. Project Management Skills: Project management tools for researchers Vitae, UK 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>Budgeting for Patient Engagement Tool George and Fay Yee Centre for Health Care Innovation (CHI), Manitoba https://chimb.ca/sub-sites/1-patient-engagement?page=79-budgeting-for-engagement</p>	
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	<p>agreements involving the conduct of research for team members</p> <ul style="list-style-type: none"> • write job descriptions • present research results in a manner that is readily understood and meaningful <p>S5. Conflict – Tension Management: I am able to:</p> <ul style="list-style-type: none"> • identify areas of potential tension and resistance within the team • prevent conflicts or misunderstandings through facilitation/mediation and conflict resolution skills • overcome tensions between differing research cultures <p>S6. POR skills: I am ready to:</p> <ul style="list-style-type: none"> • assess my own personal learning needs and 			<p>Considerations when paying patient partners in research Tool Canadian Institutes of Health Research http://cihr-irsc.gc.ca/e/51466.html)</p> <p>Peer payment standards for short-term engagements Tool BC Centre for Disease Control http://www.bccdc.ca/resource-gallery/Documents/Educational%20Materials/Epid/Other/peer_payment-guide_2018.pdf</p> <p>Should Money Come into It? A Tool for Deciding Whether to Pay Patient- Engagement Participants The Change Foundation, Ontario https://www.changefoundation.ca/patient-compensation-report/</p> <p>S5. Conflict – Tension Management: Preempting Discord: Prenuptial Agreements for Scientists National Cancer Institute, US https://www.teamsciencetoolkit.cancer.gov/public/TSResourceTool.aspx?tid=1&rid=53</p> <p>Conflict Management Specialization University of California Irvine, US https://www.coursera.org/specializations/conflict-management</p> <p>Collaboration and Team Science: A Field Guide National Cancer Institute, US https://www.cancer.gov/about-nci/organization/crs/research-initiatives/team-science-field-guide</p> <p>Tools for Preempting Discord National Institutes of Health, US http://i2sconference.digitalposter.com.au/posters-list/628</p> <p>Overton, A. R., & Lowry, A. C. (2013). Conflict management: difficult conversations with difficult people. Clinics in colon and rectal surgery, 26(4), 259–264. doi:10.1055/s-0033-1356728 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3835442/</p> <p>S6. POR skills: Ethical Conduct of Patient-Oriented Research Guide BC SUPPORT Unit https://bcsupportunit.ca/resources/ethical-conduct-patient-oriented-research-guide-researchers</p>	
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	ensure my own competence in conducting POR				<p>Patient-Oriented Research Project Planning Tool Saskatchewan Centre for Patient Oriented Research https://bit.ly/2Kyeru8</p> <p>How Patient-Oriented is Your Research? Guide BC SUPPORT Unit https://bcsupportunit.ca/resources/how-patient-oriented-your-research</p> <p>Patient and public engagement Evaluation toolkit Centre of Excellence on Partnership with Patients and the Public, QC https://nouveau.ceppp.ca/en/our-projects/evaluation-toolkit/#care</p> <p>Public and Patient Engagement Evaluation Tool McMaster University https://fhs.mcmaster.ca/publicandpatientengagement/ppeet_request_form.html</p> <p>Staniszewska S et al (2017). GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research BMJ 2017;358:j3453 http://dx.doi.org/10.1136/bmj.j3453</p>	
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Appendix: POR Pathways Project Background

This project has been undertaken by the [BC SUPPORT Unit](#), a Unit of the [BC Academic Health Science Network](#) 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. POR is defined here: <https://bcsupportunit.ca/about>.

Objectives of SPOR²

SPOR's objectives 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 <http://www.cihr-irsc.gc.ca/e/41204.html> and 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

- Decision makers:
 - Sirisha Asuri
 - Caryl Harper
- Healthcare Providers:
 - Agnes Black
 - Marie Westby
- Patient Partners:
 - Kent Cadogan Loftsgard
 - Sarah Fletcher
- Researchers:
 - Stirling Bryan
 - Caroline Sanders
- Patient engagement, BC SUPPORT Unit: Colleen McGavin