

# Patient & Community Engagement in the Design and Implementation of Research Studies

## Resource Guide

### Level 1: Learn

**Intended Audience:** The Learn level is appropriate for scientists, trainees and research staff who **have not heard of, or have very little exposure to** patient and community engagement in the design and implementation of research studies.

Many scientists, trainees and research staff have limited experience in designing (and implementing) research studies in partnership with patients and community partners, and patient and community partners may need additional assistance to fully grasp the details of the scientific methodology. However, patient and community members can contribute immensely. They can provide a wealth of information regarding lived experience, which can help in the process of designing and implementing a research study. In turn, researchers learn about the benefits, challenges, resource and other requirements to ensure an equitable, engaging and respectful dialogue.

Order	Objectives	Resources
1	Introduction	<p>Patient and clinical engagement is viewed as an important component of the research process. However, too often in preclinical research it is not considered until after experimental progress has been made and conclusions drawn. There is an evolving body of knowledge to identify that without such engagement, relevant questions and research opportunities may be missed.</p> <p>As an example, women remain vastly underrepresented in many areas of research, and respond differently to various therapies, as a priori, the fundamental research questions did not consider sex, gender and other important variables. This has two important consequences: firstly, it discriminates against members of society, and secondly, it may lead to missed opportunities to better understand the biological differences.</p> <p>The consequences of which can be significant, and may include failure to identify important therapeutic opportunities or more concerning, failure to identify potential adverse effects where therapeutics are considered. By including Patient and Community Engagement early in the design and implementation of research studies (both preclinical and clinical), these important factors may be considered and hence, potentially avoiding bias and discrimination against typically underrepresented groups and improving the relevance of the research being conducted.</p> <ul style="list-style-type: none"> <li>• <a href="#">Facilitating Public and Patient Involvement in Basic and Preclinical Health Research</a> (Maccarthy et al., 2019)</li> </ul>

		<p>An analysis of the views of preclinical researchers into the challenges regarding patient and public involvement.</p>
<p>2</p>	<p><b>Tangible/concrete benefits</b> of engaging patients and community in the design and implementation of health research studies</p>	<p><b>Pre-Clinical Resources</b></p> <ul style="list-style-type: none"> <li>• <a href="#">Patient Engagement in Preclinical Lab Research: A Scoping Review</a> (Fox et al., 2021) Engagement has been observed to enhance research in various ways including increased study relevance, improved trial recruitment and retention. Key reported benefits of patient engagement included mutual learning opportunities, establishing new collaborations, and improved research efficiency.</li> <li>• <a href="#">Engaging Patients to Improve Quality of Care: A Systematic Review</a> (Bombard et al., 2018) Patient engagement can inform patient and provider education and policies, as well as enhance service delivery and governance.</li> </ul> <p><b>Clinical Resources</b></p> <ul style="list-style-type: none"> <li>• <a href="#">Evidence Updates</a> (Patient-Centered Outcomes Research Institute) PCORI presents findings from systematic reviews* and research studies in concise, accessible formats. These updates are created and disseminated in collaboration with patient, provider, or other organizations that were engaged throughout the process. <i>*A systematic review is a study of studies. It attempts to collect all existing evidence on a specific topic in order to answer a specific research question.</i></li> <li>• <a href="#">Reported Impacts of Involvement on Research</a> (Staley, 2015) Table from the article '<a href="#">Is it worth doing?</a>' contains 9 categories of impacts identified through literature reviews that measure the impact of patient and public involvement in research.</li> <li>• <a href="#">Patient Engagement in Core Outcome Set Development</a> (COMET Initiative) This animation explains why core outcome sets are needed, what they are and how they are developed.</li> </ul>
<p>3</p>	<p><b>Definition</b> of and <b>frameworks</b> for engaging patients in the design and implementation of research studies</p>	<ul style="list-style-type: none"> <li>• <a href="#">Community-Based Research: Approach and Applications</a> (Community-Based Research Canada) A short introduction of the essentials of a community-based approach to research, including its definition, functions, phases, and applications.</li> <li>• <a href="#">Patient Engagement Framework</a> (CIHR Strategy for Patient-Oriented Research) This Framework is designed to establish key concepts, principles and areas for patient engagement to be adopted by all SPOR partners. Reviewing page 10 (Appendix 1) is specifically recommended.</li> <li>• <a href="#">Patient Engagement In Research (PEIR) Framework</a> (Arthritis Research Canada) A workbook to guide the development of PEIR Plan based on a <a href="#">research article</a> (by Hamilton et al., 2017). The PEIR Framework includes eight components that outline meaningful engagement in research from the perspectives of patient and community partners. Sample questions are provided for</li> </ul>

		each component.
4	Historical context of patient and community engagement in the design and implementation of research studies	<p><b>Overview of the History of Patient and Community Engagement in Research</b></p> <ul style="list-style-type: none"> <li>• <a href="#">Community-Based Participatory Research: Ethical Considerations</a> (The Oxford Handbook of Public Health Ethics, Buchanan, 2019)</li> <li>• <a href="#">Participatory Research: What is the History? Has the Purpose Changed?</a> (Macaulay, 2016)</li> </ul> <p><b>Historical Explanations (From Past to Present Effects)</b></p> <ul style="list-style-type: none"> <li>• <a href="#">Race and Genetics: Somber History, Troubled Present</a> (Mohsen, 2020)</li> <li>• <a href="#">Francis Galton pioneered scientific advances in many fields – but also founded the racist pseudoscience of eugenics</a> (The Conversation, 2021)</li> <li>• <a href="#">More than Tuskegee: Understanding Mistrust about Research Participation</a> (Scharff et al., 2015)</li> <li>• <a href="#">The Ideology of Racism: Misusing Science to Justify Racial Discrimination</a> (United Nations)</li> <li>• <a href="#">Now is the Time for a Postracial Medicine: Biomedical Research, the National Institutes of Health, and the Perpetuation of Scientific Racism</a> (Perez-Rodriguez et al., 2017)</li> </ul>
5	Understanding lived experience as a form of evidence and expertise	<ul style="list-style-type: none"> <li>• <a href="#">The Value of Engagement</a> (Patient-Centered Outcomes Research Institute) The lived experience as a person with an illness or injury or the caregiver or family member of such a person is incredibly valuable, and contributions of these partners should be recognized accordingly. PCORI explains what an engagement plan is and how researchers can engage patient partners.</li> <li>• <a href="#">Helping Basic Scientists Engage with Community Partners to Enrich and Accelerate Translational Research</a> (Kost et al., 2016) The introduced community-engaged research navigation (CEnR-Nav) program provides a model for successfully engaging basic scientists with communities to advance and accelerate translational science, which is aimed at translating results in basic research into results that directly benefit humans.</li> <li>• <a href="#">Community Engaged Research Practice</a> (The CTN, UBC CIHR Canadian HIV Trials Network) The CTN provides practical information on ‘why’ patient and community-engaged research is important and ‘how to’ successfully integrate people with lived experience in research teams, identification of principles for mutual learning to improve research design and execution, and building trust and support for the research enterprise.</li> </ul>
6	Knowledge about social/economic determinants of health	<ul style="list-style-type: none"> <li>• <a href="#">Social Determinants of Health and Health Inequalities</a> (Government of Canada) Includes information, tools, and resources</li> <li>• <a href="#">A Guide to Community Engagement Frameworks for Action on the Social Determinants of Health and Health Equity</a> (National Collaborating Centre for Determinants of Health)</li> </ul>

		<p>This document is intended as a reference guide for public health practitioners, who need support in adopting or revising a community engagement strategy with health equity and social determinants of health components. It is designed to make it easy for any project to be matched to a relevant framework.</p>
7	<p>Understand <b>principles and best practices</b> established in patient- and community-engaged research</p>	<ul style="list-style-type: none"> <li>• <a href="#">Patient Engagement in Health Research: A How-to Guide for Researchers</a> (Alberta SPOR Support Unit) This comprehensive resource explains the five steps of patient engagement in health research, including Why, Who, How, Engage, and Evaluate.</li> <li>• <a href="#">Methods for Patient and Public Engagement: A Guide</a> (Centre for Healthcare Innovation) This guide will help you explore options for participatory approaches and engagement methods at various stages of research, and various levels of patient and public partner involvement.</li> <li>• <a href="#">Patient and Public Engagement Planning Template</a> (Newfoundland and Labrador Support Unit) This planning template walks through a number of areas to consider when planning to engage patient and public members as part of research, including the Why, Who, When, What, and How.</li> <li>• <a href="#">Take Your Patient Partnering to the Next Level</a> (Health Quality Ontario) This short, easy to read document gives concrete advice and practical tips to overcome common challenges in partnering with patients. Created for healthcare projects, this information is transferrable to research projects.</li> <li>• <a href="#">Patient Stakeholder Engagement in Research: A Narrative Review to Describe Foundational Principles and Best Practice Activities</a> (Harrison et al., 2019) This narrative review identifies, quantifies and summarizes (a) the conceptual foundational principles of patient stakeholder engagement in research and (b) best practice activities to support these efforts.</li> <li>• <a href="#">Engage with Impact Toolkit</a> (McMaster University) The Engage with Impact Toolkit has been developed as a series of 5 modules to help scientists and organizations evaluate the impact of their patient, family and caregiver engagement programs and activities.</li> </ul>
8	<p>Role of <b>building trust in relationships between researchers and patients/community</b> in patient- and community-engaged research</p>	<ul style="list-style-type: none"> <li>• <a href="#">Community Based Research Toolkit: Resources and Tools for Doing Research with Community for Social Change</a> (Access Alliance) Developed by the Community Based Research Team at Access Alliance Multicultural Community Health Centre. Sections to consider: “Developing &amp; Maintaining Partnerships; Promoting Equitable Collaboration; pp. 41-47”</li> </ul>

9	Understanding the <b>concept of power sharing</b> and the role of <b>power and self-location</b> in patient and community engagement	<ul style="list-style-type: none"> <li>• <a href="#">Allyship in Research Toolkit</a> (UBC Kelowna Homelessness Research Collaborative) Sections to consider: “Sharing Space &amp; Power; How to Do Allyship; pp. 8-15”</li> <li>• <a href="#">Reflective Equity, Diversity and Inclusion Exercise</a> (SPOR Evidence Alliance) This exercise helps individuals explore areas where they experience advantages and/or disadvantages in their lives with an EDI lens.</li> </ul>
10	Building the <b>capacity</b> of patient or community research team members to understand and participate in research activities	<ul style="list-style-type: none"> <li>• <a href="#">Understanding Research: How and Who (including a Case Study Exercise for Researchers)</a> (Canadian Depression Research and Intervention Network)</li> <li>• <a href="#">Everyone Can Do Research: A Plain Language Guide on How to Do Research</a> (Access Alliance) This toolkit will help you understand what research is and how it is the same or different from the inquiry we do in our daily lives. The information in the toolkit will introduce you to the different phases and components of research in simple everyday language in a way that even people with low education can understand.</li> </ul>

#### Additional Resources:

- [Patient Engagement Resources](#) (Ontario SPOR Support Unit)  
OSSU provides a wide range of resources to help research teams conduct patient-oriented research, including presentations on how researchers can partner with patients, tools to evaluate the partnership experience, links to external patient-oriented tools and more.
- [Templates and Guidance for Researchers Engaging Patients in Their Research](#) (SPOR Evidence Alliance)  
SPOR Evidence Alliance works towards creating a collaborative research environment that is focused on patients and health system decision-makers as part of Canada’s SPOR initiative.
- [Patients and Partners Initiative: Engagement Tools and Resources](#) (Government of British Columbia)  
A list of resources and tools on topics such as engagement planning, related forms, engaging different populations, and success stories.
- [Engagement Resources](#) (Patient-Centered Outcomes Research Institute)  
A repository of tools and resources on various patient and community engagement topics and includes many relevant toolkits.
- [How to Involve People in Research](#) (UK National Institute for Health Research)  
Includes 10 briefing notes for researchers with practical information on how to involve members of the public in research.
- [Patient And Family Engagement: A Framework for Understanding the Elements and Developing Interventions and Policies](#) (Carman et al., 2013)  
This research article demonstrates a multidimensional framework for patient and family engagement in health and health care.
- [A Novel Patient and Community Engagement Research Method to Understand Patient and Family Experiences with Critical Care](#) (Alberta Health Services)  
One-pager example on applying PaCER (Patient and Community Engagement Research) approaches to describe the ICU experiences of critically ill patients and their families, and to identify opportunities to improve ICU care.

- [UNESCO Chair Resources on Community Based Research and Social Responsibility in Higher Education](#) (University of Victoria and the Society for Participatory Research in Asia)  
This repository is broken into three main sub-communities, which are further organized into separate categories. These categories contain a variety of resources and materials related to community-based research.
- [How to Integrate Sex and Gender into Research](#) (Canadian Institutes of Health Research)  
Tools for researchers to help them:
  - Distinguish between and define sex and gender in health research;
  - Identify sex and gender differences in the mechanism, disease or treatment under study;
  - Identify methods for integrating sex and gender variables in health research contexts; and
  - Assess a research protocol or publication based on the integration or omission of sex and/or gender.