UNITY HEALTH TORONTO

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

Level 2: Apply

Intended Audience: The Apply level is appropriate for scientists, trainees and research staff who have the **knowledge and some experience** with patient and community engagement in the design and implementation of research studies and want to **learn how to implement best practices** for engaging patients and community partners in research.

Tips on Best Practices for Community-Engaged Research (Recommended by Dr. Amanda Noble, Manager, Research and Evaluation, Covenant House Toronto)
- Develop an ongoing relationship rather than just emailing community partners to do a study and then expect them to accommodate you. We know that this is not always possible but definitely a factor in our decision to work with external researchers.
- Work collaboratively with agencies to determine what they would find helpful as opposed to going in with a set agenda that works for your own research interests.
- Avoid stigmatizing and reductive language about the people the organization serves.
- Make sure you report back the findings to the agency, but please do so in a way that does not make it sound like you are reporting something they have no knowledge of because they live and breathe it every day.
- Researchers must have a trauma informed approach to collecting data—understanding what the clients have been through, continue to go through, and work to be sensitive and understanding but not condescending.

Order	Objectives	Resources
1	Meaningfully **supporting patient and community partners in research** and related processes	• [A Rough Guide to Public Involvement](#) (National Institute for Health Research) This resource focuses on engaging patients and the community under the umbrella term "public" as defined on p. 3. **Note:** In the United Kingdom, the term public involvement is equivalent to patient engagement in Canada. • [Patient and Public Involvement in Health and Social Care Research](#) (National Institute for Health Research) This resource refers to patient and public involvement (PPI) and states that PPI is not about having patients or members of the public as research participants and defines who "patients and the public" are.

Sections to consider: "Who are Patients and the Public; p. 6" and "What do I call people who I involve in; p. 8".

- **The Six UK Standards for Public Involvement** (National Institute for Health Research)
  A framework for what good public involvement looks like. The six standards are: Inclusive Opportunities, Working Together, Support and Learning, Governance, Communications, and Impact.
- **Indigenous Community Research Partnerships** (Queen's University)
  Indigenous Community Research Partnerships is an open-access online training resource developed to educate researchers about respectful research partnerships with urban, rural or remote Indigenous communities.
- **Engaging Indigenous Patient Partners in Patient-Oriented Research: Lessons from a One-Year Initiative** (Tremblay et al., 2020)
  Section to consider: "Results: Four components of Indigenous patient engagement in research; p. 5"
- **From Tokenism to Meaningful Engagement: Best Practices in Patient Involvement in an EU Project** (Supple et al., 2015)
  An article about best practices in patient involvement, including an example from the European Union. Five key principles for the success of the patient involvement group are presented: involve early, involve deeply, have patients' feedback on project progress, include patients in dissemination and help patients convey their own story.

2	Best practices for including **people with lived experience** in research teams	**Building Meaningful Patient and Public Engagement: Resources and Tools** (Centre for Healthcare Innovation) Includes easy-to-follow guides and tools for planning, budgeting and conducting trauma-informed and inclusive patient and community engagement activities. **Resources & Style Guides for Framing Health Equity & Avoiding Stigmatizing Language** (Centers for Disease Control and Prevention)References for having an inclusive communication and avoid stigmatizing language when engaging patient and community partners. **Actively Involving Patients/Public with Trials Methodology Research: Report of Workshop** (University of Manchester, 2019) The workshop report includes learnings from a variety of methodological studies that involved patient engagement. **Patient Stakeholder Engagement in Research: A Narrative Review to Describe Foundational Principles and Best Practice Activities** (Harrison et al., 2019) Section to consider: "Foundational framework summarizing principles and best practice activities

		supporting patient stakeholder engagement in research; Fig. 2"
		• **Beyond Community Engagement: Centering Research through Indigenous Epistemologies and Peoplehood** (Huaman et al., 2019) This commentary focuses on the importance of centering the research participants instead of centering researchers (easier said than done). • **Aligning the Goals of Community-Engaged Research: Why and How Academic Health Centers Can Successfully Engage with Communities to Improve Health** (Michener et al., 2012) Sections to consider: "Authors' Suggested Strategies to Improve Working Relationships Between Academic Health Centers and Their Partners in Community-Engaged Research; Table 1" • **Engaging Youth in Research Planning, Design and Execution: Practical Recommendations for Researchers** (Hawke et al., 2018) Developed by CAMH researchers, this article provides guidelines for academic researchers to make youth engagement a key tenet of their youth-oriented research initiatives. • **Patient and Family Engagement in the Development of Core Outcome Sets for Two Rare Chronic Diseases in Children** (Vanderhout et al., 2021) Core outcome sets (COS) are lists of consensus-determined outcomes to be measured and reported in all clinical research studies within a disease area. In this paper, researchers and patient partners provide a resource for COS developers to meaningfully and effectively engage patients and families.
3	Understanding the **concept of power sharing** (role of power and self-location in community engagement)	• **Ethics Guidance for Developing Partnerships with Patients and Researchers** (Canadian Institutes of Health Research) This guidance was designed to help researchers and patients develop research partnerships in the design or conduct of research – a process known as patient-engaged research. This kind of research is similar to community-engaged participatory research. However, patient-engaged research also brings the living or lived experiences of patients to the research activity. • **Addressing Power Dynamics in Community-Engaged Research Partnerships** (Andress et al., 2020) • **Power Dynamics in Community-Based Participatory Research: A Multiple–Case Study Analysis of Partnering Contexts, Histories, and Practices** (Wallerstein et al., 2019) • **The Coin Model of Privilege And Critical Allyship: Implications for Health** (Nixon, 2019) • **We are the Researched, the Researchers, and the Discounted: The Experiences of Drug User Activists as Researchers** (Simon et al., 2021)
4	Sharing **budgets and resources** with patient and community partners	• **Patient Partner Appreciation Policy and Procedure Co-developed by Patients** (SPOR Evidence Alliance) Information on how to provide fair compensation to patient and public partners, reimburse for meeting and travel related expenses, and other costs.

		Community-Engaged Research with Community-Based Organizations (University of California San Francisco) A resource manual for researchers on conducting community-engaged and translational research. Sections to consider: Topics 9 and 13 **Building Partnerships in Community-Based Participatory Research: Budgetary and Other Cost Considerations** (Hoeft et al., 2014) A case study that provides detailed costing information about community engagement plans. Useful for planning budgets, and justifying them in grant applications. **Community Engaged Research Practice** (CIHR Canadian HIV Trials Network) Section to Consider: Compensation, p. 9
5	Ensuring a **collaborative approach to knowledge mobilization** between patient/community and researcher	**Design Thinking as an Integrated Knowledge Translation Tool** (CHI KT Platform)
6	Best practices for **creating equitable research teams** when engaging patients and community partners	**Best Practices for Equitable Research at Each Step of the Research Process** (University of Washington Institute of Translational Health Sciences) Includes best practices and strategies for integrating the value of equity into the research process. **Building Equitable Patient Partnerships during the COVID-19 Pandemic: Challenges and Key Considerations for Research and Policy** (Sayani et al., 2021)
7	Ensuring an **anti-racist, equitable and socially accountable approach** to recruitment of community members, patients, family, and people with lived experience	**Guidelines for Enhancing the Engagement of People With Lived Experience** (Human Services & Justice Coordinating Committee) This resource was developed to provide guidance on engaging people with lived experience in a meaningful and effective manner. It provides strategies and resources to help direct researchers and committees in their engagement work. **Two-Eyed Seeing** (Institute for Integrative Science & Health) Two-Eyed Seeing refers to learning to see from one eye with the strengths of Indigenous knowledges and ways of knowing, and from the other eye with the strengths of Western knowledges and ways of knowing ... and learning to use both these eyes together, for the benefit of all. **Conducting Research through an Anti-Racism Lens** (University of Minnesota) This guide shares racist research systems and practices, followed by resources for mitigating those problematic systems and practices. **Key Practices for Community Engagement in Research on Mental Health or Substance Use** (Re:searching for LGBTQ Health, University of Toronto)

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Additional Resources:

- **GRIPP2 Reporting Checklists: Tools to Improve Reporting of Patient and Public Involvement in Research** (Staniszewska et al., 2017)
  GRIPP2 (short form and long form) is the first international guidance for reporting of patient and public involvement in health and social care research. This document focuses on <u>reporting</u>, and not necessarily <u>doing</u> patient and community engagement.

- **Workbook to Guide the Development of a Patient Engagement in Research (PEIR) Plan** (University of British Columbia and Arthritis Research Canada)
  The purpose of this workbook is to facilitate high quality partnerships between researchers and patient partners undertaking research projects together by presenting guidance for research project teams to plan their activities.

- **Patient and Public Engagement Evaluation Toolkit** (Centre for Excellence on Partnerships with Patients and the Public)
  A wide range of tools to assist health system stakeholders in the evaluation of patient and public engagement initiatives, both in health research and in health care.

- **Community Engagement Framework** (Centre for Addiction and Mental Health)
  This document identifies core principles of community engagement and describes a framework for informing and supporting programs, leaders and teams in their community engagement activities.

- **Community Planning Tool: Applying a Health Equity Lens to Program Planning** (Fraser Health)

- **A Guide to Capturing and Using Patient, Public and Service User Feedback Effectively** (University of Birmingham)

- **Patient Engagement Resource Hub** (Healthcare Excellence Canada)

- **Shared Decision-Making and Health for First Nations, Métis and Inuit Women: A Study Protocol** (Jull et al.)

- **When Equity is Central to Research: Implications for Researchers and Consumers in the Research Team** (Sheridan et al.)

- **Drug Policy Training Modules** (Ontario Drug Policy Research Network)
  The ODPRN has developed training modules for students and patients new to drug policy research in Ontario. This online training aims to provide a high-level understanding of drugs, drug policy, patient-oriented research, and methodological concepts.

- **Community-Based Participatory Research for Health: Advancing Social and Health Equity** (Wallerstein et al., book)
  Sections to consider: "Chapter 1: On community-based participatory research" and "Chapter 3: Critical issues in developing and following CBPR principles"

- **Patient Partner Forums:**
  - Patient Advisors Network
  - Ontario Health Patient and Family Advisors Network
  - The Beryl Institute