UNITY HEALTH
TORONTO

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

Level 3: Transform

Intended Audience: The Transform level is appropriate for scientists, trainees and research staff who **have experience** with patient- and community-partnered research and want to deepen their understanding on how to **further advance their patient and community engagement practices with an Equity, Diversity and Inclusion (EDI) lens**. This level requires **collaborative training with patient and community partners** and ongoing practice with an assessment of competency by patient and community partners as well as academic colleagues.

Collective Principles When Embedding EDI in Patient- and Community-Partnered Research:

- Learning must be perceived as experiential and ongoing.
- Learning must take place sitting within an acknowledged place of cultural humility where individuals are open and willing to continuously learn from community and patient partners.
- Being truly versed in patient- and community-engaged research takes time, experience, the guidance of mentors (particularly those embedded in communities and community organizations with a wealth of expertise), and a lot of careful thoughts and reflection.
- An equity lens must always be applied throughout training and implementation of patient- and community-engaged research.
- Even scientists, trainees and research staff who perceive they understand patient- and community-engaged research can benefit from additional continuous training, and relationship building with patient and community partners to continuously improve their practices.
- Patient-Oriented Research (POR), Community-Based Research (CBR) and equity-focused research are not for everyone. Universal expectations can result in harms to communities. Researchers who do this work must be committed to continuous learning.
- Considerations must be made to create the unique type of training needed for researchers with lived experience of exclusion, social and health inequities who do advanced community-based research. For example, they may need training on how to navigate systemic racism and discrimination within academic/health system organizations, or how to collaborate with those who do not share EDI values, experience and expertise.
- Research administration and ethics staff should also have training to ensure they are able to support patient- and community-engaged research without causing harm.
- Ongoing assessment of learning, including self-assessment, is needed to assess development of individual competency, interactions with patient and community partners, building and sustaining collaborative relationships. Patient and community partners should be integral in this assessment and should be perceived as the key assessors.
- Recognize that community partner organizations have different levels of connection to the communities they serve. For example, there is a difference between organizations led by community members with lived experience of exclusion versus organizations with leadership and employees who are not from the communities that they serve.

- Before researchers go into a community to work with them, they should meet certain mandatory requirements in order to minimize potential harm(s) to communities. This evaluation should be from experienced researchers and patient partners.

Order	Objectives	Considerations	Resources
1	Increasing relevance, rigour and impact of research by **increasing leadership by people and communities who experience social and health inequities**	- Ensuring leadership by people with lived experience of intersections of exclusion (e.g., based on racism, sexism and ableism) - Investigating models of lived experience leadership and shared leadership in research (global and different sub-fields) - Tailoring Lived Experience Leadership to context of particular sub-fields (e.g., HIV research has more advanced use of lived experience leadership) - Strategies and Tools: - Policies and procedures for grant/publication writing/presenting with patient and community partners/collaborators - Inclusion and accommodation of people with lived experience (input from patient & community organizations/members) - Case studies	**Lived Experience Leadership Report** (Lived Experience Leadership Movement) LEx Movement is a collective impact network in UK connecting, supporting and strengthening the capacity of lived experience leaders to create systems-level change and help all our communities thrive. The Lived Experience Leadership Report compiles interviews and insights collected from LEx Elders and Leaders. **Best Practices in Research Reporting** (PLOS—open access publisher) Section to consider: Inclusivity in Global Research '**Health Equity Tourists': How White Scholars are Colonizing Research on Health Disparities** (STAT–reporting from the frontiers in health and medicine, 2021) **Writing Peer-Reviewed Articles with Diverse Teams: Considerations for Novice Scholars Conducting Community-Engaged Research** (Flicker et al., 2016) Collaborative strategies and tools relevant to scholars at multiple levels. **The Article Idea Chart: A Participatory Action Research Tool to Aid Involvement in Dissemination** (Forchuk et al., 2014) A tool for facilitating collaborative knowledge exchange **Research Involving First Nations, Inuit and Métis Peoples of Canada** (Canadian Institutes of Health Research) **Academic Citations Evolve to Include Indigenous Oral Teachings** (Eos—science news magazine)

			A librarian has developed citation templates for oral teachings shared by members of Indigenous communities. • **Building Equitable Patient Partnerships during the COVID-19 Pandemic: Challenges and Key Considerations for Research and Policy** (Sayani et al., 2021) • **Colonising Public Engagement: Revealing the "Expert–Lay" Divisions Formed by Academia's Dominant Praxis** (Esmene, 2020)
2	**Reducing/minimizing harm** to communities and patients	• Increasing understanding of what harms may ensue to community, research team, project, and/ or institution if community/patient engagement are not done well (e.g., loss of patient/community trust) • Critical analysis—examination power relationships—between academic, health system, and community organization partners with an EDI lens (e.g., composition of leadership and staff, approaches to working with community) • Understanding types of harm and their impact • Preventing harm • Addressing harm • Working with community organizations and members • Being evaluated by community organizations and members • Case studies (patient- and community-led sessions)	• **Bringing Stakeholders Together For Urban Health Equity: Hallmarks of a Compromised Process** (Katz et al., 2015) • **Supporting Peer Researchers: Recommendations from Our Lived Experience/Expertise in Community-Based Research in Canada** (Ibáñez-Carrasco et al., 2019) • **Guidelines for Inclusivity** (University of Toronto/Women's College Hospital, 2022) • **Co-Building a Patient-Oriented Research Curriculum in Canada** (Bell et al., 2019) • **A Rapid Realist Review of Patient Engagement in Patient-Oriented Research and Health Care System Impacts: Part One** (Zibrowski et al, 2021)

3	Gain practical experience through hands-on, immersive learning opportunities, partnered with community organizations and experienced research mentors	• 'Placement' of learner with a community-based organization and/or patient-led group • Ongoing evaluation and feedback from community organizations and patient partners • Resources recommended by specific community-based organizations and people with lived experience	• **Community-based Research Tools** (Access Alliance) • **GRIPP2 Reporting Checklists: Tools to Improve Reporting of Patient and Public Involvement in Research** (Staniszewska et al., 2017)

Additional Resources:
- **Equity Framework** (Ontario SPOR Support Unit)
- **Public Participation Spectrum** (International Association for Public Participation)
  The IAP2 Federation has developed the Spectrum to help groups define the public's role in any public participation process. It walks through each of the five stages: Inform, Consult, Involve, Collaborate, and Empower and the public participation goal and promise to the public for each. The IAP2 Spectrum is quickly becoming an international standard.

Next Steps:

Considering the unique nature of the Transform level, the creators of this Resource Guide recommended Research teams to collaboratively planning workshops that are focused on the following key elements:

- Problem-based working sessions, with support and advice on how one might handle commonly occurring issues in community-based research.
- Focus on equity and inclusive practices in research.
- Experiential learning where trainees are linked to a research team with substantial experience and expertise in community-based research/patient-oriented research, ideally involving community/patient partners with relevant lived experiences/expertise. Opportunities for trainees to be embedded in community organizations/communities are especially rich learning opportunities. For example, they can assist on a project and learn by doing, and the team can model appropriate practices (based on the context of the project) and evaluate the trainee.
- Discussions on how this impacts research career (and the 'usual' metrics) should be part of this training.

Session/Workshop	Leads	Evolving Resources
How to ensure leadership by people with lived experience of intersections of exclusion	Community partner, Scientist, Trainee, Peer/Lived Experience Researcher, Research Staff	• Case Study • Publications • Video • People/organizations
Models of lived experience leadership, shared leadership in research	Community partner, Scientist, Trainee, Peer Lived Experience Researcher, Research Staff	• Case Study • Publications • Video