Learning Together

AN EVALUATION FRAMEWORK FOR PATIENT AND PUBLIC ENGAGEMENT IN RESEARCH

CONTACT DETAILS

For more information on this document, please consult the CEPPP website : ceppp.ca

Email : info@ceppp.ca

Centre of Excellence on Partnership
with Patients and the Public
Centre de recherche du CHUM
850, rue Saint-Denis, Pavillon S
Montréal (Québec) H2X 0A9

ceppp.ca

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INTRODUCTION

The **Learning Together Evaluation framework for Patient and Public Engagement (PPE) in research** is a national adaptable tool, which can be used to plan and to evaluate patient engagement before, during and at the end of a project.

The **Learning Together Framework** can be used in multiple ways with the purpose of mutual learning and understanding by all partners. It is rooted in seven guiding principles of patient engagement defined by the patient-oriented research community: **Relationship building, Co-building, Equity, diversity and inclusion, Support and barrier removal, Transparency, Sustainability, and Transformation.**

This framework can be used as a guide to plan engagement strategies. Users can identify and implement best practices before the project has started, improve while the project is ongoing, and report back on the transformation their work has contributed to bring about. Users can also use the framework to build their own logic model for assessing patient engagement when conducting research. .

This tool offers a list of indicators that were highlighted by the community as essential to good engagement (" ⋆ must have") and items that pushes the engagement and its evaluation further ("+ nice to have"). Users can choose to assess either one or all of the components of the framework: the guidelines and resources that structure the foundation of their partnership (the first six dimensions represented on the pathway), the development and refinement of their partnership (the dimensions represented by the reel) and the different forms of transformation (the mountain) partnership can contribute to generate.

Ultimately, the **Learning Together framework** can serve to catalyze best practices and common strategies for PPE implementation and evaluation across the Canadian patient-oriented research community, while encouraging continuous reflection in- and on- action to sustain a learning health system that truly takes into account the needs, priorities and perspectives of patients, communities and citizens.

SECTION 1

DIVERSE PERSPECTIVES

+ Partners with different lived experiences on the research team
+ Aligning the patient partners' experience and expertise with the research project
+ Strategy to recruit various perspectives into the research project
+ Different communities' perspectives on the research team
+ Partners with different sociodemographic profiles on the research team

ROLES

☆ Understanding the part of the research project one is involved in
☆ Understanding the project potential effects on the patients and/or community
☆ Shared understanding among partners of the goals, roles, responsibilities and expectations
☆ Defining together the goals, roles, responsibilities and expectations
+ Clarity of the terms of reference
+ Existence of a terms of reference
+ Understanding of the full research project

PARTNERSHIP GUIDELINES

☆Funding opportunities for patient partnership
☆Resources allocated for patient partnership
☆Funding opportunities to support patient partnership
☆Resources allocated to support patient partnership
☆Staff dedicated to support patient partnership
☆Defining together guiding principles and values for meaningful partnership
+ Patient partners as staff within your organization
+ Awareness of policies and guidelines for patient partnership in research

SECTION 1

READINESS

+ Confidence of the partners' commitment to research partnership
+ For researchers, training in research partnership with patients
+ Confidence in preparedness of all partners for research partnership

PROJECT CO-DESIGN

☆ Choosing together the level of patient partner engagement in project planning
☆ Choosing together the level of patient partner engagement at each stage of the research project
+ Planning together the project strategy
+ Drafting together the proposal for funding
+ Defining together the ongoing evaluation of the project
+ Planning together the project activities

APPRECIATION

☆ Reimbursement of expenses
☆ Budget line for compensation of patient partners
☆ Compensation for patient partners
+ Timeliness and ease of reimbursement of expenses
+ Defining together forms of appreciation for patient partners
+ Referring to patient partner appreciation standards
+ Satisfaction with form of appreciation received

SECTION 2

>> ON THE CIRCLE

REFINING ENGAGEMENT

☆ Opportunity for patient partners to discuss, negotiate and influence the decisions
☆ Opportunity for patient partners to discuss, negotiate and influence how decisions are made
☆ Adapting to the participation needs of all partners
☆ Adapting dedicated time for patient partners to speak and contribute to the research activity
☆ Adjusting to the availability of patient partners
☆ Providing a satisfactory amount of time for all partners to speak and contribute to the research activity
+ Providing an equitable amount of time for all partners, depending on their needs, to speak and contribute to the research activity
+ Consulting the availability of patient partners
+ Level of patient partner engagement at each stage of the research project
+ Level of patient partner engagement in each research activity
+ Amount of dedicated time for patient partners to speak and contribute to the research activity

WELCOMING

☆ Ensuring respect, trust and transparency within the project team
☆ Empowering patient partners in their contributions to the project
☆ Ensuring safety for all partners
☆ Providing a safe space to share values and preferences
☆ Adapting protocols and processes to improve research partnership
☆ Respecting policies, protocols, and processes related to cultural, psychological, physical, gender and emotional safety
+ Having policies, protocols, and processes related to cultural, psychological, physical, gender and emotional safety
+ Adopting a trauma-informed approach for all partners

SECTION 2

>> INSIDE THE CIRCLE

RECOGNIZING

☆ Valuing patient expertise and lived experience
☆ Acknowledging and showcasing what has been learned from research partnership
☆ Acknowledging and showcasing patient partners' contributions
+ Expressing gratitude to all patient partners
+ Providing feedback to patient partners at each stage of research as an acknowledgement of their contributions
+ Being co-authors on publications

INCLUDING

☆ Openness toward different ideas and diverse perspectives
☆ Bringing diverse perspectives into the project team
☆ Recognition/awareness of health inequities and inherent biases
☆ Recognition/awareness of power differentials among the project team
☆ Identifying missed or absent perspectives and experiences in the research project
☆ Commitment to reflect on power imbalances and support all partners to mediate them
☆ Commitment to reflect on cross-cultural imbalances and support all partners to mediate them
+ Accommodating the cultural beliefs and practices of patient partners

COMMUNICATING

☆ Communicating in an easy-to-understand way
☆ Offering feedback about the project as it unfolds
☆ Communicating openly and frankly
+ Having access to working documents (protocol, meeting minutes, reports, etc.)
+ Offering feedback about the project at the very end
+ Determining the mode of communication (speech, writing) according to patient partner preferences

SECTION 2

INSIDE THE CIRCLE

SUPPORTING

☆ Participating in orientation, onboarding, training, education and support prior to and during the project
☆ Offering orientation, onboarding, training, education and support prior to and during the project
+ Monitoring and responding to training, education and support needs
+ Satisfaction with orientation, onboarding, training, education and support prior to and during the project
+ Assessing in advance all partners' training, education and support needs

IMPROVING PARTNERSHIP

☆ Making changes in the research partnership based on feedback
☆ Giving patient partners feedback on how their contributions influenced and shaped the research partnership
☆ Seeking feedback on the research partnership throughout the project
☆ Patient partners give feedback on their perception of researchers' contributions to the research partnership
+ Evaluating and documenting research partnership throughout the project

SECTION 3

⟩⟩ TRANSFORMATION

BUILDING CAPACITY

☆ Improved understanding of patient experiences and needs in the research subject area

\+ Improved connections through networking, relationship and community-building

\+ All partners are prepared and confident for future research partnerships

TRANSFORMING PRACTICES

\+ For researcher team members, change in research practice and behavior in a research setting

\+ For clinician team members, change in clinical practice and behavior in a clinical setting

\+ Enrichment from research partnership

REFINING RESEARCH

☆ Research relevance for patients

☆ Utilization of research results

☆ Access to the research results

\+ Overall quality of research as a result of partnership with patients

\+ Ethical appropriateness of the research

\+ Cultural appropriateness of research

\+ Scope of research

\+ Dissemination methods

SECTION 3

▶▶ TRANSFORMATION

CHANGING CULTURE

☆ Place and importance of patient-oriented research in health research
☆ Valuing and recognizing the knowledge, skills and expertise of patient partners
☆ Attitude towards and perceptions of patient partnership in research
☆ Policies and resources to promote, improve and support patient partnership in research

TRANSFORMING CARE

☆ Patient experience
☆ Quality of care
☆ Patient safety
+ Health equity
+ Quality of life
+ Services for patients and families
+ Patient journey
+ Health system
+ Healthcare provider ability to guide the patient
+ Healthcare provider knowledge

IMPROVING SYSTEMS

+ Person-centered care
+ Learning health systems
+ Healthcare system accountability

GUIDING PRINCIPES

- **Relationship building**
- **Co-building**
- **Transparency**
- **Sustainability**
- **Support and barrier removal**
- **Equity, diversity and inclusion**
- **Transformation**

LEARNING *Together*

An Evaluation Framework for Patient and Public Engagement in Research

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" TO CITE THIS FRAMEWORK

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