

# Patient Engagement in Research

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## Patient Engagement:

- Building the Team
- Strategies for Optimizing Success
- The Study
- Evaluating the Partnership

## Building Patient Engagement in a Grant:

- General Principles and SPOR PIHCI Network Requirements

**Simone Dahrouge, PhD**

**Primary Health Care Patient Engagement Resource Centre**

INSPIRE PHC and BeACCoN Webinar on Patient Engagement



# Acknowledgements

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## PERC Advisory Board Members

### Research Advisors

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### Patient Advisors

- Alies Maybee
- Karen James
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## BeACCoN Patient Partners

- Roger Stoddard
- Lynne Mansell
- Ron Beleno

## PERC Coordinator

Amélie Cardinal  
613.562-6262 ext. 2933  
[ACardinal@bruyere.org](mailto:ACardinal@bruyere.org)

# Conflict of Interest/Disclaimers

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The section of the presentation on the principles of patient engagement is intended as a guide and is NOT comprehensive.

The section on writing the grant is a representation of the author's interpretation of the PIHCl requirements and does NOT represent CIHR's views.

Simone is a co-Lead on a PIHCl grant application relating to quality improvement.

# Background

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## **Patient Oriented Research**

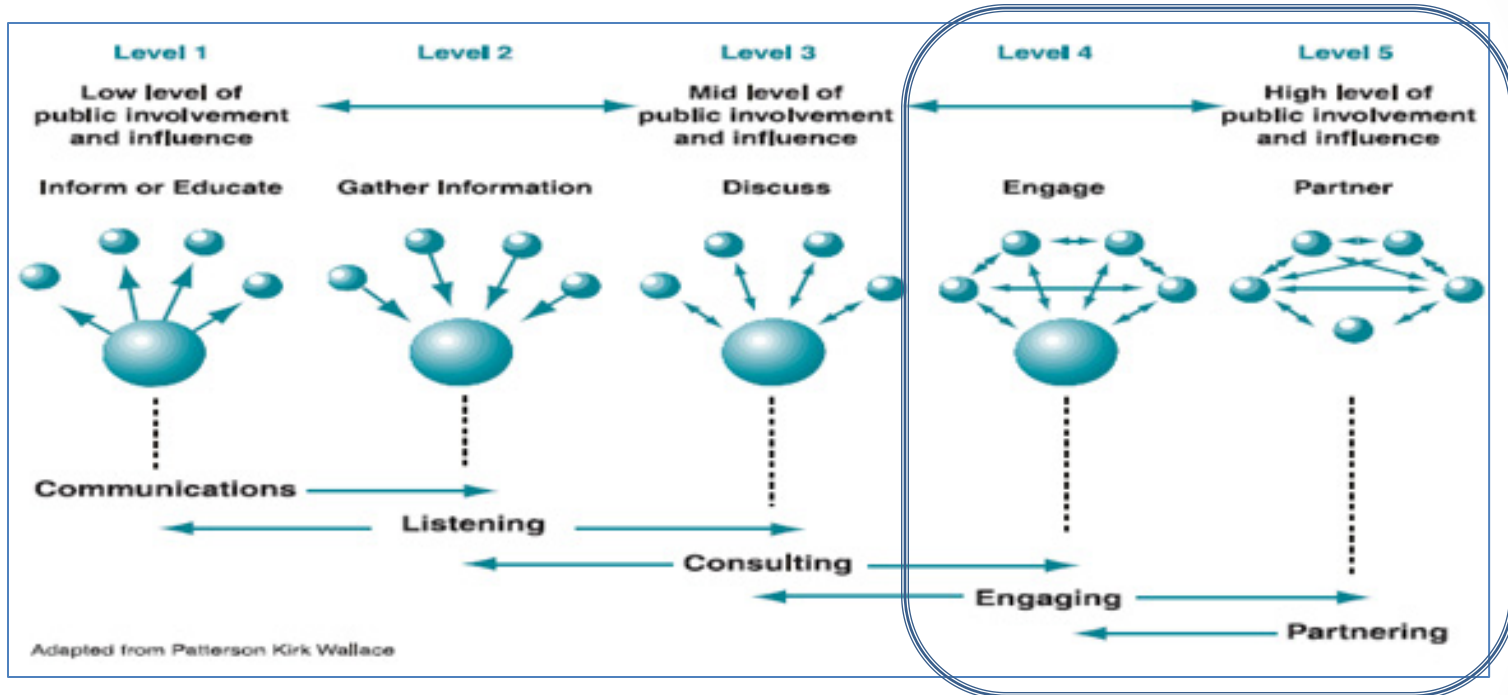
- Engages patients as partners
- Focuses on patient-identified priorities
- Improves patient outcomes.

## **Patient Engagement Guiding Principles**

**INCLUSIVENESS, SUPPORT, MUTUAL  
RESPECT, CO-BUILDING**

# Scope

## CIHR Continuum



## Collaborators/Partners

Public Forums, Informant Interviews,  
Focus Groups, etc.

# Patient Engagement Overview

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## **1. Building the Team**

- Inclusiveness
- Recruitment

## **2. Strategies for Optimizing Success**

- Values and Principles
- Clarity of Roles and Expectations
- Materials and Training Resources
- Project Management

## **3. The Study**

## **4. Evaluating the Partnership**

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# Building the Team

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## Inclusiveness

- Drawn from target study population.
- Maximize breadth of experience. Consider
  - Severity of the medical condition
  - Socio-economic profile
  - Cultural beliefs
  - Geographical setting , ...



# Building the Team

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## Recruitment

- Various strategies: Draw from existing pool, forums, organizations,...
- Assess suitability of partnership:
  - Patient Profile
  - Study needs and patient's ability to contribute
  - Researcher's Experience and Openness to PE
  - Patient's Understanding and Experience
  - etc.

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# Values and Principles

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## Foundational principles of working together

- Develop a shared Vision and Purpose
- Team values. Consider
  - Equity, honesty and transparency,
  - Appreciation of diversity, and respect for others and their view
  - Fostering of Mutual Learning
  - Co-Building

# Clarity of Roles and Expectations

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## Co-Develop Roles

- Alignment with patient preferences
- Alignment with study goals
- Clarity on:
  - Goals
  - Expectation
  - Time commitment
  - Activities
  - ...

# Materials and Training Resources

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- Identify areas requiring of training/guidance
  - Patient: Content area, Research Process, ..
  - Researcher: Approaches to PE, Strategies for optimizing PE
- Range of learning resources
  - “How-to Guides”
  - Scientific Literature
  - Webinars
  - Workshops
  - Mentorship

# Project Management

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- Timelines and deliverables
- Approach to Decision Making
  - Eliciting contribution
  - Equity and transparency of the decisions
  - Accountability
- Facilitating Participation
  - Addressing information needs
  - Creating a safe environment
  - Select adequate venue and time
  - Facilitating discussions
  - Consider barriers
  - ...

# Project Management

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## ➤ Sustaining Engagement

- Compensation
- Encouragement
- Maintaining contact during downtime

## ➤ Budget

- Translation/Printing
- Compensation/remuneration
- Out of pocket expenses
- Knowledge translation
- Project management

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# The Study

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## ➤ Planning

- Developing the Research Question
- Study Methods

## ➤ Conducting

- Recruitment and Data Collection
- Data Analyses and Interpretation

## ➤ Knowledge Translation

- Dissemination Strategy
- Dissemination Activities

# The Study - Planning

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## ➤ **Developing the Research Question**

Alignment with patient priorities

## ➤ **Study Methods**

Feasibility, Acceptability, Scalability, ... Examples:

- Enhancing recruitment
- Minimizing disruption to patients and stakeholders
- Creating relevant/appropriate study material (e.g. information sheets) Defining study outcomes, PROMs and PREMs
- Selecting/adapting tools
- Etc.

# **The Study – Conducting**

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Feasibility, Acceptability, Scalability, ...

## **Recruitment and Data Collection**

Value of relating to target community. Examples:

- Recruitment strategies and Recruitment
- Trust-Ease of contact for data collection

## **Data Analyses and Interpretation**

Valuable insight. Influence of patient experiential knowledge. Examples:

- Analytical lens
- Awareness of potential confounders/effect modifier
- Explaining variations across settings

# The Study – Knowledge Translation

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Relevance, Impact, Breadth, Uptake

## ➤ **Dissemination Strategy**

- The approach, target audience, and message
- Opportunities within patient communities

## ➤ **Dissemination Activities**

- Direct patient involvement in knowledge exchange activities
- Active roles: co-creation and ownership of data
- Consider: academic conferences, public consultations, policy forums, Public communication activities: workshops, seminars, roundtables, webinars, public lectures, etc

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# Evaluating the Partnership

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## ➤ **Formative Evaluation**

- Experience of all members in partnership
- Authenticity of engagement
- Potential areas to address
- Tools: Public and Patient Engagement Evaluation Tool (PPEET) by McMaster's University; Patients Canada, Team built,...

## ➤ **Summative Evaluation**

- Experience of all members in partnership
- Authenticity of engagement
- Impact of contribution on study conduct

# Building a Grant -Overview

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## GENERAL PRINCIPLES AND SPOR PIHCI NETWORK REQUIREMENTS

### **1. Building the Team**

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### **4. Evaluating the Partnership**

# Grounded in SPOR

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## **Patient Oriented Research**

- Engages patients as partners
- Focuses on patient-identified priorities
- Improves patient outcomes.

## **Patient Engagement Guiding Principles**

**INCLUSIVENESS, SUPPORT, MUTUAL  
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# Building the Team

Priority	Outcomes	Partnership	Inclusiveness	Support	Respect	Co-Build
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- Patients already engaged
- Demonstrate appropriateness of team profile alignment with study, breadth of experience,...

**Identify Participants:** Identifying patient applicants in [as a Knowledge User] supports SPOR's principle of patient involvement and provides formal recognition of patient applicants (e.g. acknowledgement in CIHR's funding decisions notifications) as active participants in the project

**EVALUATION** Patient engagement and partnership: a. Appropriateness of patient engagement mechanisms and the extent to which they align with the [SPOR Patient Engagement Framework](#) and **engage across diverse population groups**.

# Strategies to Optimize Success

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**EVALUATION** Patient engagement and partnership: a. **Appropriateness of patient engagement mechanisms** and the extent to which they align with the [SPOR Patient Engagement Framework](#) and **engage across diverse population groups**.

**EVALUATION** Patient engagement and partnership: b. **Strength** of stakeholder **engagement**, including the engagement of patients, policy makers and other knowledge users

**Attach Other Application Materials:** In a maximum of three (3) pages total, describe the:

- **Patient engagement plan**
- Policy Maker engagement plan
- Operational plan to ensure feasibility

# Strategies to Optimize Success

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## Values and Principles

Priority	Outcomes	Partnership	Inclusiveness	Support	Respect	Co-Build
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- Describe how the team's values and principles will support authentic patient engagement

**EVALUATION** Patient engagement and partnership: c. **Strength** of the project **team**, including the extent to which all **jurisdictions** and their representatives on the application are appropriately and meaningfully involved

# Strategies to Optimize Success

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## Clearly Articulated Roles and Expecations

Priority	Outcomes	Partnership	Inclusiveness	Support	Respect	Co-Build
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- Describe: co-creation of roles; appropriate planning and commitment from all (written documentation of roles); role and the duration of the commitment for each; alignment of role with expertise/experience, availability, and interest.
- Where applicable, demonstrate the engagement of patient partners throughout the study period.
- State explicitly how that contribution will contribute to the decision making.
- Describe the contingency plan should changes in team structure be required.

# Strategies to Optimize Success

## Clearly Articulated Roles and Expectations

Patients must play a **key role** on the research team; a minimum of one Principal Applicant or Principal Knowledge User must be a patient

### **Attach Other Application Materials:** Patient written statement

Key participants that fall in the patient/family representatives/informal care providers stakeholder group are required to provide signed written statements (**maximum two (2) pages each**) describing their relevant lived experiences that details their fit for this role in the context of the application

### **Attach Other Application Materials:** "Participant Table"

In a table format, list all key participants, the type of participant they are (NPA, PA/co-APP, PKU/KU), the sector that they are covering (research, policy or clinical (the patient participant will not have a sector) and the member network that they represent. Each participant must have a description of what each brings to and gains from the proposal.

**EVALUATION** Patient engagement and partnership: b. **Strength** of stakeholder **engagement**, including the engagement of patients, policy makers and other knowledge users

**EVALUATION** Patient engagement and partnership: c. **Strength of the project team**, including the extent to which all jurisdictions and their representatives on the application are **appropriately and meaningfully involved**

# Strategies to Optimize Success

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## Materials and Training Resources

- Explain how the training needs of the patients and the researcher undertaking patient engagement research have been assessed, the orientation provided, the resources harnessed, the training activities planned .
- Demonstrate the intent to access SPOR resources on patient engagement

Applicants are encouraged to work with the SPOR SUPPORT Units. Successful applicants are expected to engage when appropriate and possible, with other SPOR-funded entities to strengthen collaboration and maximize usage of available resources.

**EVALUATION** patient engagement and partnership: e. **Evidence of leveraging existing resources and platforms**, including SPOR SUPPORT Units.

# Strategies to Optimize Success

## Project Management

Priority	Outcomes	Partnership	Inclusiveness	Support	Respect	Co-Build
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### Approach to Decision Making

- Describe the governance structure and decision making process the team has adopted.
- Clearly demonstrate how the patient partners will contribute to the decision making process
- Explain how the process will be transparent with accountability measures built in

**EVALUATION** Patient engagement and partnership: a. **Appropriateness of patient engagement mechanisms** and the extent to which they align with the [SPOR Patient Engagement Framework](#) and engage across diverse population groups.

**EVALUATION** Patient engagement and partnership: b. **Strength** of stakeholder **engagement**, including the engagement of patients, policy makers and other knowledge users

# Strategies to Optimize Success

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## Facilitating Participation and Sustaining Engagement

- Describe the strategies co-developed to promote meaningful patient engagement throughout the study.
- Describe how communication strategies are adapted/adaptable; how the contribution will be facilitated; how known barriers pre-empted and emerging issues identified and addressed;

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**EVALUATION** Patient engagement and partnership: c. **Strength of the project team**, including the extent to which all jurisdictions and their representatives on the application are **appropriately and meaningfully involved**



# The Study

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Priority	Outcomes	Partnership	Inclusiveness	Support	Respect	Co-Build
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## 1. Planning - Explain how the project:

- Was developed with patient partners
- Addresses patient priorities
- Will make important contribution to patient outcomes

## 2. Conducting - Provide examples of how the patient partner contribution has informed specific components, e.g.:

- Recruitment strategy
- Analyses

# The Study

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## **3. Knowledge Dissemination: Explain the role of the patient partner in the planning and execution of KT**

**EVALUATION** patient engagement and partnership: a. Appropriateness of patient engagement mechanisms and the extent to which they align with the [SPOR Patient Engagement Framework](#) and engage across diverse population groups.

# Evaluating Patient Engagement

Priority	Outcomes	Partnership	Inclusiveness	Support	Respect	Co-Build
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## Partnership Evaluation Plan

- Approach and
- Tools
- Times for the assessments
- Formative evaluations
- Summative evaluation

**EVALUATION** Patient engagement and partnership: b. **Strength** of stakeholder **engagement**, including the engagement of patients, policy makers and other knowledge users

# References

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Guide in development

Patient Engagement Resource Centre (PERC)

<https://www.patientengagement-phcresearch.com/>

# Questions/Discussion