

# Competencies needed for participation in Patient-Oriented Research (POR)

Report of a Scoping Review of the Literature

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# Patient-Oriented Research (POR)

- A Canadian Initiative to support and encourage patient/public involvement in health research teams
  - Similar to the INVOLVE program in the UK, the PCORI program in the USA and other programs worldwide that seek public engagement in all phases of health research.
- As contributors to a unit supporting capacity development for POR, our team sought to learn what was published on the topic of competencies required for successful participation in POR.
- POR involves four stakeholder groups: Researchers, Patients, Health care providers and Health system decision-makers; thus our review addressed each of these groups.

# The Scoping Review

- Objectives:
  - to articulate competencies (knowledge, skills, attitudes) necessary for POR team members
  - to identify learning and competency development needs of each stakeholder group
- Searched peer-reviewed and grey literature on the topic from the time period of 1/1990 to 1/2018 using standard health databases and focusing the review on review articles.
- Uncovered 2,042 papers, and through a inclusion/exclusion extracted data from 35 peer-reviewed and 38 grey literature publications.

# Review Process: criteria

- Members of our team worked in pairs to review each paper according to established inclusion criteria:
  - Population: addressed at least one of our stakeholder groups (researchers, patients, providers, and decision makers),
  - Concepts: competencies (attitudes, knowledge or skills) to participate in POR were described or inferred
  - Context: POR or patient engagement in research
  - Language: English or French

## Reviewing process

- *Titles and abstracts were reviewed first*
  - if that reading indicated the paper might meet inclusion criteria, it was read full-text by 2 members of our team.
- *Full text reading followed.*
  - noting when competencies were provided.
- *Competency statements were recorded.*
  - data were extracted and recorded in a shared spreadsheet
- Reviews were done in two Stages

## Peer-reviewed Literature: Stage 1 search to retrieve, key papers and identify expert authors

- 11 searches were done using standard health databases
  - Retrieved a total of 100 papers
  - Papers reviewed by 2 team members
  - 8 proceeded to data extraction
    - References lists of review articles were also reviewed
    - 12 proceeded to data extraction
- Findings of Stage 1 search
  - No clear pattern of keywords were being used
  - No one journal or set of journals were used consistently
  - 7 of the 8 papers from which data were extracted were review articles

# Revision to Original Protocol

- Decision made to
  - Search for and review 'review articles' only
  - Review the references lists from all review articles selected
  - Discontinue plan for hand searching identified journals
  - Review papers from any journal issue devoted to the topic
  - Review any relevant work that might be identified

## Peer-reviewed literature: Stage 2: continuing searches

- Search of review articles through standard health databases, additional papers
  - 1,144 additional papers
  - 73 were selected for full-text review
  - 15 were selected for data extraction
- Findings from Stage 2 searches
  - Themes were emerging throughout the papers read

# Grey Literature

- Searched
  - 11 grey literature databases
  - 131 websites
  - Data were extracted from 38
- Findings from grey literature searches
  - 22 of the 38 data extraction sites were from the UK

## Results of the review

- Our team identified 42 discrete knowledge and skill competencies for researchers and 71 for patients.
- There were significantly fewer papers addressing the competences for health care providers and health system decision-makers.
- Positive attitudes toward POR and personal attributes that contribute to collaboration were also noted for all groups.
- Competencies were clustered into themes by the team through an iterative group process.

# Important Findings

- **Researcher competencies:** In addition to research competence: participation; teamwork; conflict/ tension management.
- **Patient competencies:** Research knowledge and skills; cultural competencies, knowledge of context; participation.
- **Health care provider/ Health system Decision-Maker competencies:** Understands goals of POR research projects; able to support collaboration.
- **Attitudes:** Willingness to build reciprocal relationships; valuing the notion of 'mutual good' for all parties; willingness to work for the 'greater good'.
- **Attributes:** Empathic; transparent, open with others; able to work in non-hierarchical environments.
- **All findings have implications for training and capacity development**

# Review of Findings

- Our team sent our findings from the review to our Advisory Council
  - Input from stakeholders from all 4 stakeholder groups is needed
  - Stakeholders can comment about what the literature describes:
    - Is it reasonable?
    - Does it fit with our experiences?
    - Is something left out?
  - This work is in process now.

# Meaning of the findings to Researchers

## Attributes and Attitudes:

- Values research questions that are not researcher-driven
- Respects community values and mutual relationships
- Is sensitive/empathic/caring/ flexible and open-minded
- Able to share power and control
- Knowledge:
  - Knows the principle of POR research
  - Understands participatory methods
  - Understands group processes
  - Understands cultural competence

## Skills:

- Well-developed interpersonal skills, including relationship building, conflict and tension management, leadership, and teamwork.
- Creates respectful research environments for the team
- Manages expectations and builds trust
- Manages differences

# Meaning of the findings to Patient Partners

## Attributes and Attitudes:

- Interest in contributing to society
- Valuing the notion of mutual benefits for all partners
- Willingness to represent more than own individual experience
- Has self-confidence

## Knowledge:

- Understands research methods and principles
- Understands cultural competence
- Knows community needs, concerns, opinions and perspectives

## Skills:

- Participatory and communication skills
- Ability to take on roles such as interviewer, collaborator in data analysis
- Establishes rapport with study participants and others
- Creates partnerships

# Meaning of the Findings to Providers and Decision-Makers

- Attitudes and Attributes:
  - Has interest in research outcomes
  - Values collaboration, respects differing views
  - Respects the time commitment for POR
- Knowledge:
  - Understands POR and its potential contributions to care
  - Understands the needs of all research partners
  - Understands how policy decisions are made
- Skills:
  - Collaborates with those who have differing perspectives
  - Advocates for the greater good

# BC SUPPORT Unit Role

- Training and capacity development
  - Develop a POR Self-Assessment Tool that includes learning resources for competency development
  - Provide webinars and learning sessions on selected topics
  - Collaborate with regional teams to encourage POR research
  - Provide eCoP space for any working group or research team within the province
  - Support the annual conference

# Take Home Messages from the Cochrane Colloquium

- There is a tremendous support within the Cochrane Community for patient/public involvement in research and systematic reviews
- There is interest in both quantitative and qualitative research
- There are many people worldwide engaged in work very similar to POR
- While others have addressed training needs for (mostly) patients and others engaged in POR work, no one but ourselves were discussing competencies
- There is a pervasive dispute over the definition of 'patient'
  - The broad definition is one who has a health condition and experienced health care (including family and support individuals)
  - The narrow definition that requires the 'patient' be research naive and without any professional or health background
- There is concern emerging worldwide that the evidence-based clinical practice guidelines that have emerged have created a 'burden of care' that does not address individuals, particularly elders with multiple conditions.
  
- Abstract for Cochrane presentation is available in their proceedings:  
<https://colloquium.cochrane.org/abstracts/competencies-needed-patient-involvement-patient-oriented-research-report-scoping-review>

# Questions?

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