

How to approach the conduct of patient-oriented research

Day 2, Session 1: Researchers

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OSSU Masterclass on the Conduct and Use of Patient-Oriented Research

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Objectives

1. To appreciate the components of patient-oriented research, including patient issues and patient engagement in interdisciplinary teams.
2. To understand the importance of considering that the health system needs to be guided by patients' systematically elicited needs; inviting them to comment on the system and how it can meet their needs.

Roundtable

- One example of where you have had experience in/exposure to/interest in patient oriented research (1 min each)

CIHR POR

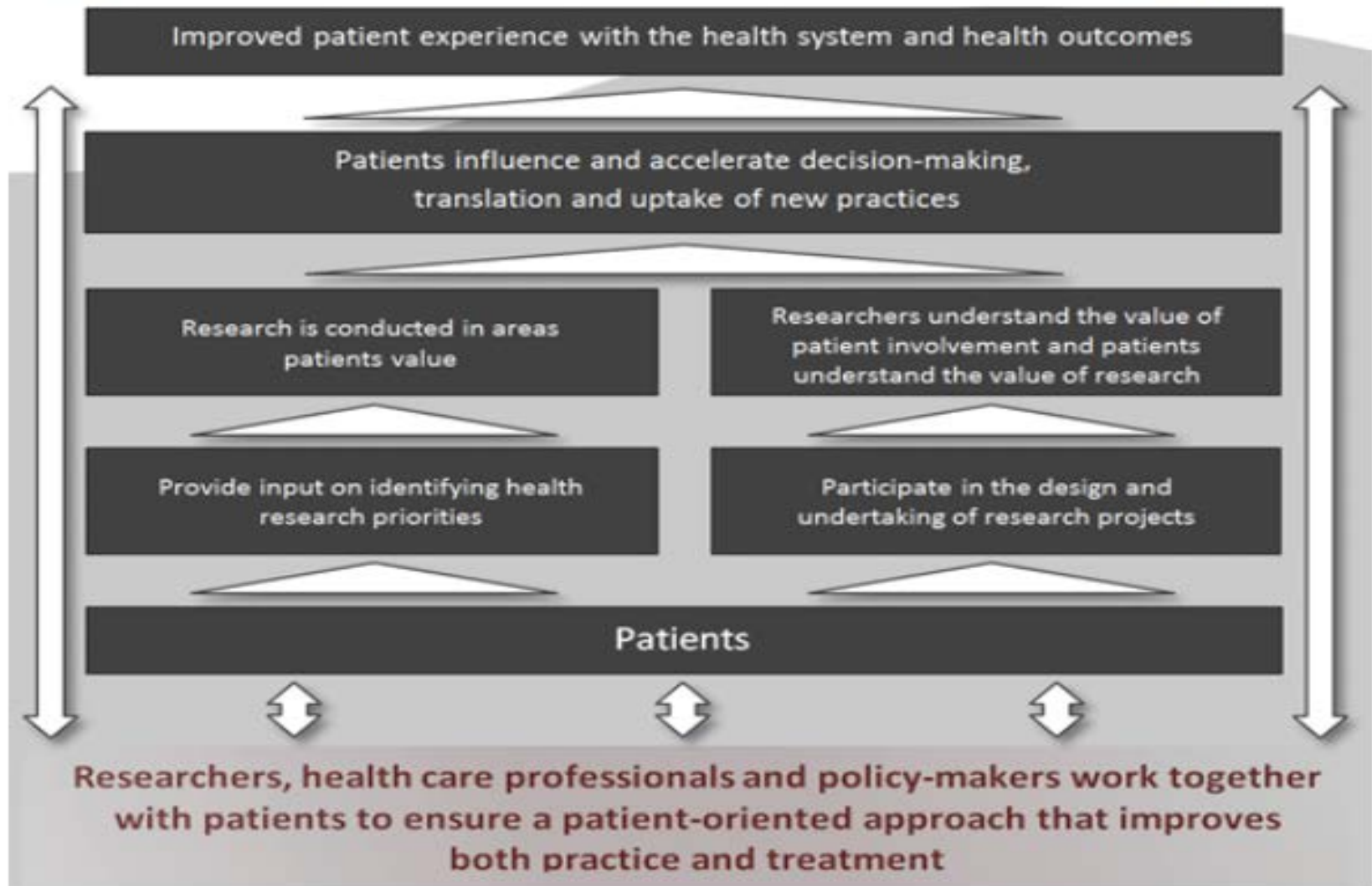
- “Canada's Strategy for Patient-Oriented Research (SPOR) is about ensuring that the right patient receives the right intervention at the right time.

Patient-oriented research refers to a continuum of research that **engages patients as partners**, focusses on **patient-identified priorities** and **improves patient outcomes**. This research, conducted by **multidisciplinary teams** in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.”

Source: CIHR, SPOR Putting Patients First

http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Figure 1: Visual Value Model for Patient Engagement



Source: CIHR, SPOR Putting Patients First http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Patient Engagement in Research - Typology

- **Minimal patient involvement**
Researcher driven
- **Consultation**
Patients provide in-depth views, share knowledge, inform aspects of the research
- **Collaboration**
Patients as partners, actively involved in all aspects of the research
- **Control**
Patient drives the research

Adapted from: Nass, Levine, & Yancy. Methods for involving patients in topic generation for patient-centered comparative effectiveness research. <http://www.pcori.org/assets/Methods-for-Involving-Patients-in-Topic-Generation-for-Patient-Centered-Comparative-Effectiveness-Research-%E2%80%93-An-International-Perspective.pdf>

Engages patients as partners

1. As research committee members, planning, designing and guiding the project as it progresses. This involvement in decision-making processes and in bringing forward priority issues for research is integral to patient-oriented research.
2. As competent patient engagement researchers.
3. As contributors to identifying the right research question, study design, recruitment, data collection, and analysis of findings. Patients can also have a role in reviewing stories to identify common threads/relevant themes. This ensures that the outcomes important to patients are supported and measured.
4. As supporters of participant-friendly research studies, improving access to patients via peer networks and accessing difficult-to-reach patients and groups.

Source: CIHR SPOR Putting Patients First

http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Patient-identified priorities

“If patient-oriented research is intended to focus on priorities that are important to patients and produce information that is truly taken up and used to improve health care practice, therapies and policies, a strong foundation for ensuring successful collaboration must be laid.”

(CIHR SPOR Putting Patients First -

http://www.cihrirsc.gc.ca/e/documents/spor_framework-en.pdf)

How to identify patient priorities?

- Organizations with a specific foci
- Patient/caregiver personal stories
- Existing research evidence
- Primary research

Organizations



A New Vision of Aging for Canada



Canadian Institute for Health Information
Better Data. Better Decisions. Healthier Canadians.

Sources on patient and caregiver experiences

Stories

Patient stories

Caregiver Stories

About Caregivers

Stories can lead to change

Connecting the dots

How patient experiences can make an impact.



Share your story

By email:

@patientscanada.ca

By phone:

(416) 900-2975

what is a patient?

Patients Canada
brochure



Design by Pivot Design Group

Source Patients Canada - http://www.patientscanada.ca/index.cfm?pagePath=Patient_Stories&id=51196

Existing Research Evidence

- Administrative databases
 - Provincial and national data holdings – e.g. ICES
 - Surveys – local, provincial, national and international
 - PREMS and PROMS– see CIHI
- Systematic or evidence reviews
 - Cochrane e.g. Cochrane Canada - www.cochrane.org
 - Evidence repositories e.g. Health Systems Evidence www.healthsystemsevidence.org
 - Research centres – e.g. McMaster Health Forum, Collaborating Centres
- Literature reviews
 - Qualitative studies
 - Quantitative studies
 - Grey literature – policy reports

Primary Research

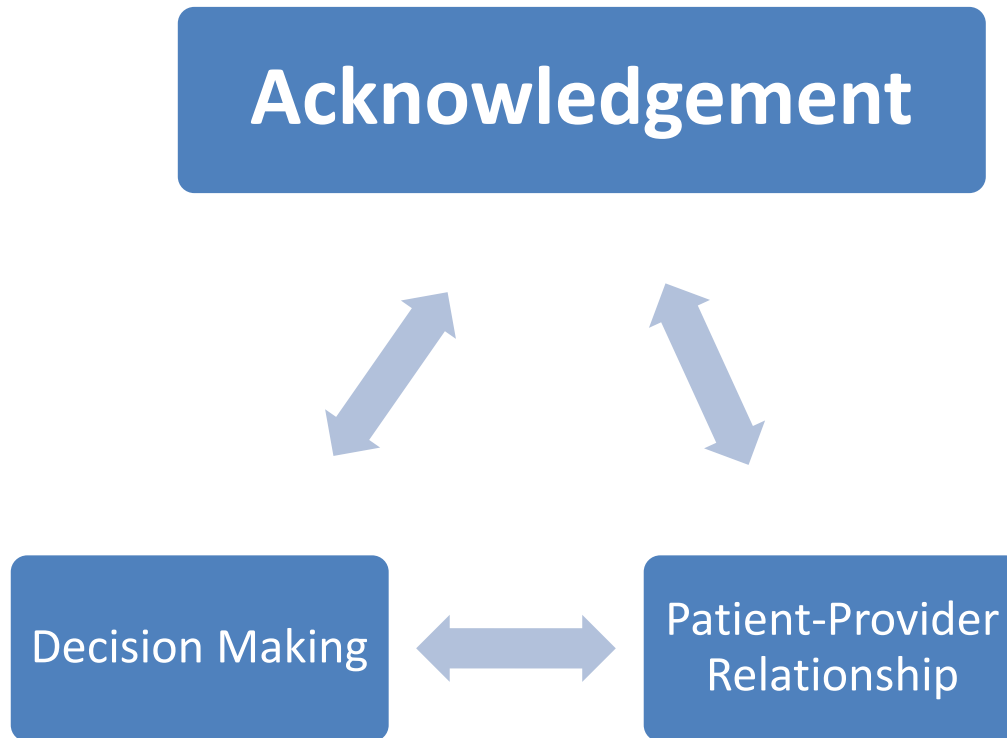
- Consultations – interviews/focus groups
- Surveys

Example – Literature Review

- **Purpose:** To describe patients' experiences of their care in primary health care settings
- **Database:** Medline OVID
- **Inclusion criteria:**
 - Qualitative methods
 - Describe experiences of care (and not experiences of illness/health) OR describe patient-identified characteristics good/poor care
 - Set in primary health care settings, including home and community care
- **Total search results:** 175
- **Total included based on inclusion criteria:** 46

Patient Experiences in Health Care

- Based on publications that used qualitative methods to describe patient experiences of primary health care



Patient Experiences in Health Care

- Continuity
 - Relational continuity & transitions of care
- Information and communication
- Access and time

Discussion

- What does the literature in your field about say about patient priorities for research?
 - Where might you find information about patient priorities?

Improves patient outcomes

Patient-oriented research is ultimately aimed at achieving benefits that matter to patients:

- Improved health
- Improved access to the health care system
- The right treatment at the right time
- Being an active and informed partner in health care
- Quality of life that is tied to patient-oriented outcomes
- Make a contribution to improving the cost effectiveness of the health care system

Source: CIHR, SPOR Putting Patients First

http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf

Identifying Outcomes

- Organizations with a specific foci
- Patient/caregiver personal stories
- Research evidence
- Primary research
- Other?

Example of POR in Research Calls: CIHR eHIPP

Person-oriented rather than technology-oriented solutions:

- The initiative will **address care gaps** and inefficiencies in particular groups where there are **substantial potential gains for patients** and the health system. Expected targets for improvement include quality, efficiencies and outcomes along the care continuum.

Objective:

- Identify **patient-oriented** eHealth solutions that will improve health outcomes, **patient experience**, and lower the cost of care along the continuum for the eHIPP priority areas.

A health-care innovation community:

- has leadership comprising a scientific lead (an independent researcher), a clinical lead (a healthcare delivery professional), a decision-maker to support adoption and scale-up of eHealth-enabled innovation services, and **patient/family representation**.

Source – CIHR. eHealth Innovation Partnership Program

<http://www.cihr-irsc.gc.ca/e/48614.html>

Example of POR in Research Calls: CIHR eHIPP

Successful e-Innovation enabled programs for care delivery are expected to achieve the following outcomes:

- Improved quality of life/well-being for patients and formal and/or informal caregivers.
- Reduced preventable emergency department visits and hospital admissions.
- Reduced admission to long term care facilities.

Source – CIHR. eHealth Innovation Partnership Program
<http://www.cihr-irsc.gc.ca/e/48614.html>

CIHR eHEALTH INNOVATION PARTNERSHIP PROGRAM (eHIPP)

- Call included specific requirements for POR
 - Outcomes linked to both patient and caregivers
 - Inclusion of patient/caregivers on team
 - Successful proposal included
 - Literature Review of Patient/Caregiver perspectives
 - Utilized pilot studies of patient/caregiver experiences – what they thought was important; what was meaningful for them; gaps about patients/caregivers in the actual pilot studies
 - Analyzed testimonials by patients
 - Patient/Caregiver focused outcomes
 - Economic analysis will include both government and societal perspectives
 - Patient/Caregiver/Provider representatives on team

Interdisciplinary Teams



Discussion

- What has been your experience working on research teams? Are they interdisciplinary?
- Have you included patients/caregivers? How?

Characteristics of Interdisciplinary Teams

- Shared values, goals and vision
- Understand, value, and respect each team member's perspective and scope of research
- Expect and accept differences
- Acknowledge and discuss diversity
- Confront conflict
- Seek an equitable and fair resolution
- Active and continuous communication
- Comfort with permeable boundaries
- Flexible
- Creativity and innovation
- Equitable distribution of responsibility, accountability, and power

Brown, JB.

http://www.uwo.ca/fammed/csfm/tutorphc/documentation/trainingpapers/TUTOR_Interdisciplinar_%20paper.pdf

Interdisciplinary Teams

How do they foster resolution?

- Open and frank communication
- Information sharing
- Evaluation
- Constructive feedback
- Listen and learn

Brown, JB.

http://www.uwo.ca/fammed/csfm/tutorphc/documentation/trainingpapers/TUTOR_Interdisciplinar_%20paper.pdf

Interdisciplinary Teams

Challenges

- Bureaucratic / Organizational
- Logistic
- Fiscal
- Turf issues
- Role blurring
- Boundary confusion
- Ambiguity of function and task
- Lack of a common framework

Brown, JB.

http://www.uwo.ca/fammed/csfm/tutorp hc/documentation/trainingpapers/TUTOR _Interdisciplinar_%20paper.pdf

Example of Interdisciplinary Team

- Transdisciplinary Understandings and Training on Research – Primary Health Care (**TUTOR-PHC**) is a one-year, pan-Canadian interdisciplinary research capacity building program that has been training primary and integrated health care researchers and decision makers from family medicine, nursing, psychology, epidemiology, social work, policy, and many other disciplines since 2003.

<http://www.uwo.ca/fammed/csfm/tutor-phc/>

Example of Interdisciplinary Team

Interdisciplinary Program Curriculum	Interdisciplinary Program Management
<ul style="list-style-type: none">- Trainees represent family medicine, nursing, epidemiology, social work, psychology, other health professions, policy, and other primary health care researchers	<ul style="list-style-type: none">- Co-investigators represent family medicine, nursing, pharmacy, interdisciplinary studies, public health, psychology, social work, and policy
<ul style="list-style-type: none">- Trainees from across Canada, UK, and NZ	<ul style="list-style-type: none">- Co-investigators located in 11 institutions across 5 provinces, from coast to coast
<ul style="list-style-type: none">- Trainees share their own research and receive feedback from the other trainees' disciplinary perspectives	<ul style="list-style-type: none">- Participate in curriculum development, program planning, trainee mentorship, and co-teach online and in-person modules
<ul style="list-style-type: none">- Trainees work as interdisciplinary teams to respond to a mock call for proposals	

Patient experience

- Patient experience on an interdisciplinary team

Researcher Experience

Discussion

Questions