



How to shape and use patient-oriented research at the individual level?

Masterclass on the Conduct and Use of Patient-Oriented Research
Day 2 (Session 3) - April 19, 2016
Toronto, ON

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Session objectives

- To develop skills in:
 - Identifying and expressing needs for information, care and support in ways that are understandable to those seeking to understand or address their needs
 - Identifying topics in research that are of concern to patients and families/caregivers



Session structure (11:15-12:30)

- Participants to identify current topics of interest and work through examples of how to effectively identify and express information, care and support needs



Scenario exercise 3 (work in groups of 4)

You are one of 2 patient members on a research team and you have been asked to gather and summarize the perspectives of patients with your condition to inform the identification of the outcomes that will be measured in a large-scale research study

- How will you approach this task?
- What resources might be helpful to you in carrying out this task?





How to shape and use of patient-oriented research at the system level?

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Session objectives

- To appreciate:
 - the different ways in which patients and families/caregivers can contribute to and use patient-oriented research at the system level through public and patient engagement opportunities
- To develop skills in:
 - identifying changes in the health system that affect their experience and know who to contact to support the change or to explain how it negatively affects them and what could be done about it

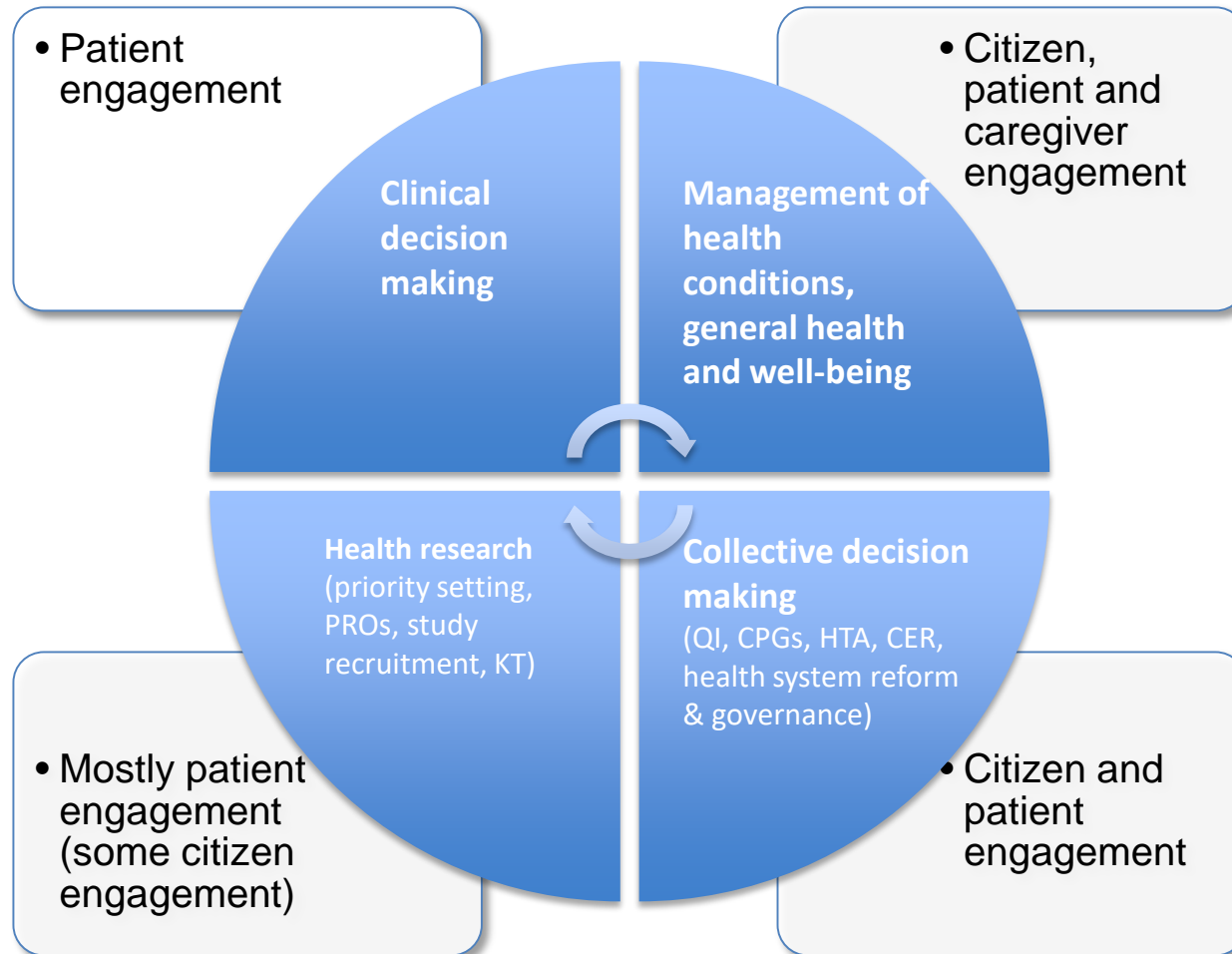


Session structure (1:30-2:45)

- Short presentation
- Small-group work guided by scenario
- Reporting back



Mapping the terrain of citizen and patient engagement



Brief history & key policy developments

1970s - early 2000s: citizen and patient involvement in...

- health care planning
- health services design
- priority setting and resource allocation
- health research
- guidelines development
- health technology assessment
- broad health system reform

Responses to:

- social activism, more informed and less deferential public, calls for greater accountability, challenges to the authority of medicine

Main vehicles used:

- public/patient representation on health councils, boards and advisory committees
- wide range of consultation exercises
- citizen dialogue and deliberation



Brief history (3)

Parallel developments

- focus on patient engagement and patient-centered health systems for health quality improvement
 - 1990s-early 2000s: Quality and patient safety agenda
 - U.S. Institute of Medicine report (Bridging the Quality Chasm)
 - Institute for Healthcare Improvement (IHI)
 - Canadian Patient Safety Institute
 - 2007: Patients as Partners (BC)
 - 2009: Patient First Review (Saskatchewan)
 - 2010: Excellent Care for All Act (Ontario)



Other important influences

- lay involvement in health research as a reflection of broader trends towards social activism, democratic accountability
Exemplars:
 - AIDS, breast cancer and rehabilitation and midwifery community calls for involvement in setting research agendas
- renewal of community-based participatory research movement
 - long tradition in public health and social sciences
 - places community at the centre of research design and conduct
- institutional commitments (primarily UK driven)
 - establishment of public and patient involvement program within the UK's National Institute for Health Research (NIHR) (1990s)
 - INVOLVE: government-funded organization, dedicated to supporting active public involvement in NHS, public health and social care research
 - *Research Involvement and Engagement*: first co-produced health research journal focused on patient and wider involvement in research



Patient Engagement in SPOR

- Patient-oriented research: continuum of research that engages **patients as partners**, focuses on **patient-identified priorities** and **improves patient outcomes**. Aims to **apply the knowledge generated to improve healthcare systems and practices**.
- Patient engagement: **meaningful and active collaboration** with patients in governance, priority setting, conducting research and knowledge translation

Strategy for Patient-Oriented Research

SPOR

Putting Patients First 

Strategy for Patient-Oriented Research

Patient Engagement Framework



Ontario's Action Plan for Health Care

Putting patients first

- Support Ontarians to make healthier choices and help prevent disease and illness.
- Engage Ontarians on health care, so we fully understand their needs and concerns.
- Focus on people, not just their illness.
- Provide care that is coordinated and integrated, so a patient can get the right care from the right providers.
- Help patients understand how the system works, so they can find the care they need when and where they need it.
- Make decisions that are informed by patients, so they play a major role in affecting system change.
- Be more transparent in health care, so Ontarians can make informed choices.



Formal arrangements for citizen and patient involvement in the health system

- Providing VOICE (and sometimes CHOICE)
 - in your care
 - Health Care Consent Act, decision aids
 - in care provision
 - complaints processes through regulatory colleges (for individual providers), individual organizations (for home, community, hospital- and long-term care organizations) and a patient ombudsman (for the health system)
 - in system monitoring
 - Excellent Care for All Act (requirement for annual public reporting on patient satisfaction)



Formal arrangements (2)

- in policy and organizational decisions
 - citizen representation on *public boards overseeing a variety of areas* (e.g., consent and capacity, payment for patient services, professional practice issues)
 - citizen and patient *advisory panels* (e.g., Ontario Citizens' Council which advises on drug policy, patient & family advisory councils at provincial agencies such as Health Quality Ontario and Cancer Care Ontario, and at some hospitals)
 - public representation on governing boards of *professional regulatory bodies*
 - *government-mandated engagement* (through Local Health Integration Networks)
 - *university-initiated citizen engagement programs* (e.g., McMaster Health Forum citizen panel program)



Informal arrangements for citizen and patient involvement in the health system

- the activities of a wide range of health care delivery organizations, professional associations, trade unions, health charities and citizen/patient organizations



Scenario exercise 4

Large group

The focus of this session is on contributing through public and patient engagement at the health system level.

- What advice would you offer to patients for applying what they have learned from dealing with problems they have faced navigating the health system to patient-oriented research or quality improvement initiatives?

