

How to conduct patient-oriented research

Day 2, Session 3: Researchers

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Objective

1. To develop skills in engaging patients in shaping a research study

Overview

1. Re-cap Concepts
2. Re-cap Available Guidance
3. Focus on Guiding Principles
4. Small Group Discussion of Enacting the Principles
5. Report Back from Small Group Discussion & Reflection
6. Tools & Steps

Re-cap Concepts

Canadian Institutes of Health Research - Strategy for Patient-Oriented Research:

- “Patient-oriented research refers to a continuum of research that engages patients as partners, focuses 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”.

<http://www.cihr-irsc.gc.ca/e/41204.html>

Re-cap Concepts

- Patient Centered Outcomes Research Institute (PCORI), “What We Mean by Engagement”:
 - “meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the research process—from topic selection through design and conduct of research to dissemination of results. We believe that such engagement can influence research to be more patient centered, useful, and trustworthy and ultimately lead to greater use and uptake of research results by the patient and broader healthcare community”

<http://www.pcori.org/funding-opportunities/what-we-mean-engagement>

Re-cap Guidance: Patient Engagement in Research

- PCORI- “Evaluation Framework”

<http://www.pcori.org/assets/2014/04/PCORI-Draft-Evaluation-Framework-042214.pdf>

- Grant Call Evaluation Criteria

OSSU IMPACT Awards

- Grant evaluation criteria for patient engagement:
 - Patients should be involved at all stages of the design and conduct of the demonstration projects:
 - As project planning team members involved in bringing forward priority issues for research
 - Having input into values and ethical considerations
 - In consideration of design and selection of patient-relevant outcomes
 - In designing recruitment strategies (where relevant)
 - In planning and delivery of knowledge translation and exchange activities
 - In evaluating the success of the project upon completion

Re-cap Guidance:

Patient Engagement in Research

- Frameworks, Discussion Documents, Research Literature
 - See Abelson, J. 2015. “Patient Engagement and Canada’s SPOR Initiative: A Resource Guide for Research Teams and Networks”. Prepared for the Ontario SPOR Support Unit.
<http://ossu.ca/2015/05/patient-engagement-and-canadas-spor-initiative-a-resource-guide-for-research-teams-and-networks/>
 - See Canadian Institutes of Health Research. “Strategy for Patient-Oriented Research- Patient Engagement Framework”.
<http://www.cihr-irsc.gc.ca/e/48413.html>

RESEARCH

Open Access

Involving patients in setting priorities for healthcare improvement: a cluster randomized trial

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Abstract

Background: Patients are increasingly seen as active partners in healthcare. While patient involvement in individual clinical decisions has been extensively studied, no trial has assessed how patients can effectively be involved in collective healthcare decisions affecting the population. The goal of this study was to test the impact of involving patients in setting healthcare improvement priorities for chronic care at the community level.

Methods: Design: Cluster randomized controlled trial. Local communities were randomized in intervention (priority setting with patient involvement) and control sites (no patient involvement). Setting: Communities in a Canadian region were required to set priorities for improving chronic disease management in primary care, from a list of 37 validated quality indicators. Intervention: Patients were consulted in writing, before participating in face-to-face deliberation with professionals. Control: Professionals established priorities among themselves, without patient involvement. Participants: A total of 172 individuals from six communities participated in the study, including 83 chronic disease patients, and 89 health professionals. Outcomes: The primary outcome was the level of agreement between patients' and professionals' priorities. Secondary outcomes included professionals' intention to use the selected quality indicators, and the costs of patient involvement.

Results: Priorities established with patients were more aligned with core generic components of the Medical Home and Chronic Care Model, including: access to primary care, self-care support, patient participation in clinical decisions, and partnership with community organizations ($p < 0.01$). Priorities established by professionals alone placed more emphasis on the technical quality of single disease management. The involvement intervention fostered mutual influence between patients and professionals, which resulted in a 41% increase in agreement on common priorities (95%CI: +12% to +58%, $p < 0.01$). Professionals' intention to use the selected quality indicators was similar in intervention and control sites. Patient involvement increased the costs of the prioritization process by 17%, and required 10% more time to reach consensus on common priorities.

Conclusions: Patient involvement can change priorities driving healthcare improvement at the population level. Future research should test the generalizability of these findings to other contexts, and assess its impact on patient care.

Trial registration: The Netherlands National Trial Register #NTR2496.

Keywords: Patient participation, Quality improvement, Health policy, Primary care, Chronic diseases, Randomized trial

Re-cap Guidance:

Patient Engagement in Research

- Organizations/Programs Focused on Patient-Oriented Research
 - Canada's SPOR and SPOR Support Units (OSSU in Ontario - <http://ossu.ca/>)
 - UK's National Institute for Health Research – INVOLVE <http://www.invo.org.uk/>
 - US's Patient-Centered Outcomes Research Institute (PCORI) <http://www.pcori.org/>

Guiding Principles

SPOR – Patient Engagement Framework

1. Inclusiveness
2. Support
3. Mutual Respect
4. Co-Build

Canadian Institutes of Health Research. Strategy for Patient-Oriented Research- Patient Engagement Framework. <http://www.cihr-irsc.gc.ca/e/48413.html>

Guiding Principles

SPOR – Patient Engagement Framework

1. Inclusiveness

- Integrates diverse patient perspectives
- Research reflects patient contributions

Canadian Institutes of Health Research. Strategy for Patient-Oriented Research- Patient Engagement Framework. <http://www.cihr-irsc.gc.ca/e/48413.html>

Guiding Principles

SPOR – Patient Engagement Framework

2. Support

- Ensure that patient participants can fully contribute
- Includes safe environments
- Implies financial compensation

Canadian Institutes of Health Research. Strategy for Patient-Oriented Research- Patient Engagement Framework. <http://www.cihr-irsc.gc.ca/e/48413.html>

Guiding Principles

SPOR – Patient Engagement Framework

3. Mutual Respect

- “Researchers, practitioners and patients acknowledge and value each other’s expertise and experiential knowledge”

Canadian Institutes of Health Research. Strategy for Patient-Oriented Research- Patient Engagement Framework. <http://www.cihr-irsc.gc.ca/e/48413.html>

Guiding Principles

SPOR – Patient Engagement Framework

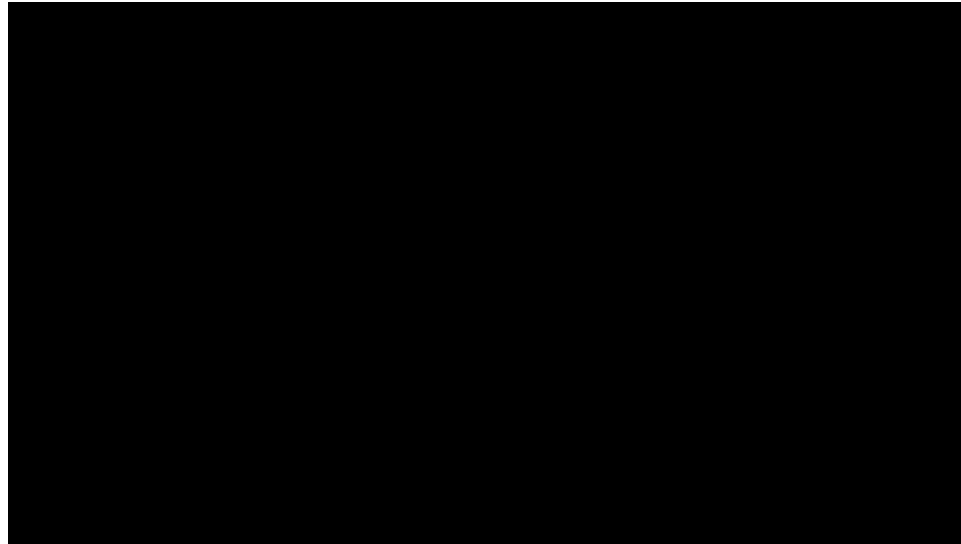
4. Co-Build

Patients, Researchers, and Practitioners together:

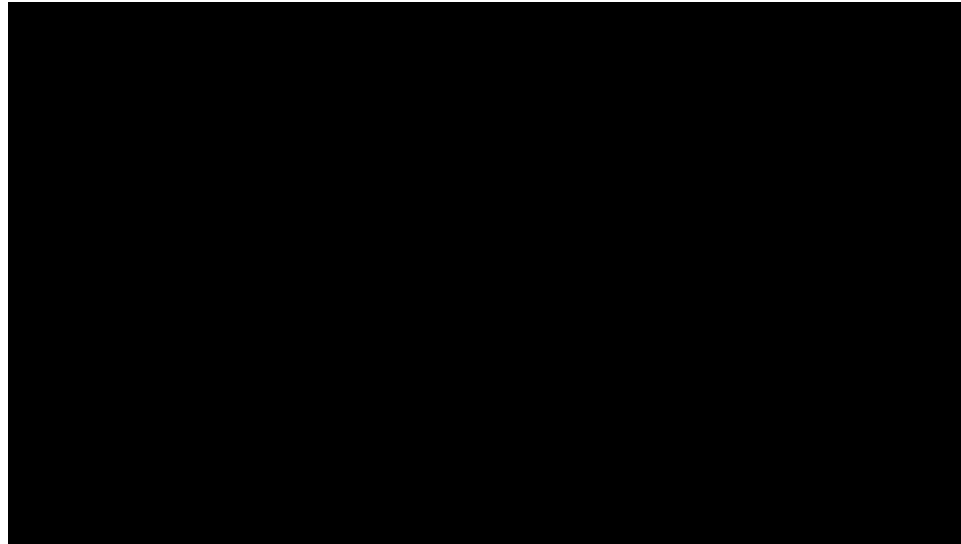
- Identify problems and gaps
- Create priorities for research
- Produce and implement solutions

Canadian Institutes of Health Research. Strategy for Patient-Oriented Research- Patient Engagement Framework. <http://www.cihr-irsc.gc.ca/e/48413.html>

Patient Engagement in Research



Patient Engagement in Research



Small Group Discussion

- Four groups – each discuss one principle
- Self-select

Small Group Discussion

- Use the following questions to guide your discussion:
 - How would you enact this principle in developing a research grant & conducting a research study?
 - What are some practical steps you could take to do this?
 - What are the barriers and facilitators you may encounter?
 - How would you know if your patient engagement work was successful?

Report Back and Reflection

Tools & Steps

See Abelson, J. 2015. “Patient Engagement and Canada’s SPOR Initiative: A Resource Guide for Research Teams and Networks”. Prepared for the Ontario SPOR Support Unit.

<http://ossu.ca/2015/05/patient-engagement-and-canadas-spor-initiative-a-resource-guide-for-research-teams-and-networks/>

Includes resources and guidance regarding:

- Recruitment Strategies
- Training
- Compensation
- Evaluation Frameworks

INVOLVE

- “Briefing Notes for Researchers: Public Involvement in NHS, Public Health and Social Care Research”

<http://www.invo.org.uk/resource-centre/>