**Citizen and Patient Engagement**

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Slide template: Bar at top. On the left, Center on Knowledge Translation for Disability and Rehabilitation Research. On the right, A project of SEDL.

Slide 0: (Title)

*Innovative KT Strategies from the Canadian Institutes of Health Research*

Citizen and Patient Engagement

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Canadian Institutes of Health Research

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Slide 1: Citizen and Patient Engagement

Canadian Institutes of Health Research

2014

Slide 2: Agenda

* Citizen and Patient Engagement
* Canada’s Strategy for Patient-Oriented Research (SPOR)
* Barriers and Facilitators
* Case Study

Slide 3: Citizen Engagement @ CIHR

At CIHR, Citizen Engagement (CE) is meant to ensure that citizens are meaningfully involved in policy or program development, from agenda setting and planning to decision-making, implementation and review.

CIHR is developing a strategy for citizen and patient engagement to identify the initiatives and mechanisms needed to realize meaningful citizen and patient engagement at our organization.

Slide 4:

“*(Citizen engagement) is essential, because patients bring a dimension to the application of research that in some ways only they can provide.”*

Image of *Vincent Dumez, Director, Bureau facultaire de l’expertise patient partenaire, Université de Montréal*

Slide 5: Citizen & Patient Engagement

***“The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, leads to better results.”*** *1*

*1 Methods for Involving Patients in Topic Generation for Patient-Centered Comparative Effectiveness Research, An International Perspective (2012), p.8*

Slide 6: Patient Engagement

Engaging patients in health research:

* Makes investments in research more accountable and transparent
* Provides new insights that could lead to innovative discoveries
* Ensures that research is relevant to patients’ concerns
* Research team work is enhanced

Slide 7: Canada’s Strategy for Patient-Oriented Research

Issue

While Canada is recognized internationally as a leader in health research, evidence shows that this does not always translate into improved health outcomes, enhanced patient experience or innovations in our health care system.

Major Barrier

Research is often too far removed from health care clinicians, policy-makers, patients, and other key stakeholders.

Slide 8: Canada’s Strategy for Patient-Oriented Research

Solution

The Strategy for Patient-Oriented Research (SPOR) represents a coalition of federal, provincial and territorial partners, including researchers, patients, provincial health authorities, academic health centres, charities, and the pharmaceutical sector, working together to generate and translate high quality, relevant research into practice.

Patient-oriented research aims to ensure that the right patient receives the right intervention at the right time

Slide 9: Patient engagement in SPOR

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.

Slide 10: Patient engagement in SPOR

A culture change and capacity development are needed

* The original impetus for patient engagement in research was an ethical and moral one – it was the right thing to do.
* Increasingly, it is being done because it has measureable impact 2:
  + improvement in the credibility of results (higher enrollment and retention)
  + directly applicable to patients (by asking pertinent questions about patient-important outcomes).

2 Domecq et al. BMC Health Services Research 2014. **14:**89

Slide 11: Patient engagement in SPOR

Image of a pencil with the words “experiential knowledge” in the middle. The pencil morphs into a tree and branches out to 4 groups. 1. Identify and recruit other patients, 2. Full members of research teams, 3. Bring the collective voice of an affected community and 4. Specific skillsets, i.e. ethics, knowledge brokers

Slide 12: Patient engagement in SPOR

* Governance and Decision-Making

Slide 13: Patient engagement in SPOR

* Governance and Decision-Making (faded out)
* Capacity building

Slide 14:

***Some researchers are concerned that while research organisations are making involvement a requirement for funding or support, not all researchers know how to do it well…..”*** *3*

*3 TwoCanAssociates Report for Mental Health Research Network (MHRN), March 2012*

Slide 15: Patient engagement in SPOR

* Governance and Decision-Making (faded out)
* Capacity building (faded out)
* Tools and resources

Slide 16: Barriers and Facilitators for Patient Engagement in Research

Barriers:

* Lack of clear roles
* Professional resistance issues
* Lack of PE performance measures
* Tokenistic involvement - limited ‘patient voice’
* Little preparation or training about the research process
* Lack of preparation, time and commitment

Facilitators:

* Research that has a patient-driven focus
* Experiential knowledge is valued as evidence
* Shared sense of purpose/outcomes
* Identifying and promoting models and approaches built on ‘partnership’
* Reimburse for time and effort

Slide 17: Motivators for Patients and Clinicians:  
source: Patient Centred Outcomes Research Institute

Patients:

* Helping others with their medical condition
* Learning about their health
* Helping the next generation
* Getting paid
* Making research more meaningful to patients

Clinicians:

* Helping patients receive better care
* Getting paid
* Contributing to scientific knowledge
* Making research more meaningful for patients
* Improving professional satisfaction
* Helping researchers decide what to study

<http://www.pcori.org/events/patient-and-clinician-views-on-cer-and-engagement-in-research-a-panel-discussion-on-new-pcori-survey-results/>

Slide 18: Case Study

Dissemination for Kahnawake Schools Diabetes Prevention Project

[http://www.cihr-irsc.gc.ca/e/42212.html#s711](http://www.cihr-irsc.gc.ca/e/42212.html)

Image of a group of teenagers playing field hocky.

Slide 19: Case Study

**What:** The Kahnawake School Diabetes Prevention Project

**Why:** This community-based participatory research project was designed to promote healthier lifestyles within the Kahnawake population. Community input was needed in order to ensure that the messages about health promotion and the research results were easily understood and would be used by the community.

Slide 20: Case Study

**Who:** The Mohawk community of Kahnawake (mostly through a Community Advisory Board)

**How:** The Community Advisory Board members were full partners to the researchers. They helped craft the messages for the rest of the community, and participated in developing and delivering presentations about the research results.

Slide 21: Case Study

* Started in 1994 as a partnership between the Mohawk community of Kahnawake (population of approximately 7,500 people), who were represented by a community advisory board, and researchers.
* Its goal is to improve healthy lifestyles to reduce the high rates of type 2 diabetes found in the community.
* In 2002, follow-up data on children in grades 1-6 showed early improved nutrition and stable physical activity levels, but increased weights.

Slide 22: Case Study

* These results were first *jointly* interpreted by the community advisory board and researchers, and were then shared with the rest of the community.
* A team of six people (including advisory board members, local nutritionists, and researchers) crafted a 20-minute presentation in lay language.

KSDPP web site <http://www.ksdpp.org/>

Slide 23: Case Study

Lessons Learned

* It takes time to build consensus.
* It can be difficult to reach an entire community.
* Test communication materials first.
* Partnership is key.

Slide 24: References

CIHR’s Framework for Citizen Engagement

[http://www.cihr-irsc.gc.ca/e/41270.html](http://www.cihr-irsc.gc.ca/e/45851.html)

The ‘Health Research in Canada and You’ booklet  
[http://www.cihr-irsc.gc.ca/e/43753.html](http://www.cihr-irsc.gc.ca/e/45851.html)

CIHR’s Citizen Engagement Handbook – a companion guide to the Framework

<http://www.cihr-irsc.gc.ca/e/42196.html>

CIHR’s Citizen Engagement in Health Casebook:   
[http://www.cihr-irsc.gc.ca/e/45358.html](http://www.cihr-irsc.gc.ca/e/45851.html)

A recently published YouTube video on the important of citizen and patient engagement in research: <http://www.cihr-irsc.gc.ca/e/47275.html>

SPOR Patient Engagement Website

<http://www.cihr-irsc.gc.ca/e/45851.html>