Patient-Oriented Research

The intersection of patient engagement and knowledge translation

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The British Columbia SUPPORT Unit

What is a SUPPORT Unit?

• Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit

• An element of Canada’s Strategy for Patient-oriented Research (SPOR)

• Multi-partner organization to support, streamline and increase patient-oriented research

Health authorities   Universities   Government

Patients/Caregivers   Research institutes, networks & foundations
But first, a quick poll

1. Which stakeholder group do you identify with, primarily?
   - Researcher
   - Health care provider
   - Health system decision-maker
   - Patient or member of the public
   - Other (please type into the chat box)
Poll question #2

2. What does the term *patient-oriented research* mean?
   a) Engages patients as partners
   b) Focuses on patient-identified priorities
   c) Improves patient outcomes
   d) Research that aims to apply knowledge generated to improve healthcare systems and practices
   e) All of the above
What is patient-oriented research?

- Engages patients as partners
- Focuses on patient-identified priorities
- Improves patient outcomes (as defined by patients)
- Aims to apply knowledge generated to improve healthcare systems and practices
Canada’s Strategy for Patient-Oriented Research (SPOR)

What is SPOR?

Canada’s strategy to ensure that the right patient receives the right intervention at the right time…
The two death valleys

Limited capacity to integrate research results into healthcare decision-making and clinical practice

Figure from: *Canada’s Strategy for Patient-Oriented Research*. Canadian Institutes of Health Research, 2011.
The proposed solution

What is SPOR?

Canada’s strategy to ensure that the right patient receives the right intervention at the right time...

...by increasing the amount of research being conducted with and by research knowledge users –

...including patients and families, health care providers, and health system decision-makers.
Patients are knowledge users too

- Patient self-manages
- Patient and care provider work together to make informed, shared decisions

Patient uses health information to make decisions

Patient engagement

Patients as partners
Knowledge Translation (KT) definitions

"Knowledge translation (KT) is defined as a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically-sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system“ (Canadian Institutes of Health Research).

“KT is the broad range of activities meant to improve the use of research evidence in practice, policy or further research” (Michael Smith Foundation for Health Research).

Or simply, “Knowledge to action”
Three main KT routes

1. Researcher push – end-of-grant
   - Publications
   - Conferences
   - Newsletters
   - Websites

2. Knowledge user pull – engages researchers to find answers to burning questions; engagement up front
   - Commission studies
   - Syntheses – analysis of multiple studies
   - Policy briefs
   - Events/forums – researchers invited to present

3. Integrated Knowledge Translation (iKT) – co-create knowledge; engagement throughout
Patient engagement in health research

SPOR definition:

“Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation.”
Meaningful and active: what does that mean?

“It’s the feeling that you’re having an impact...your voice and perspective matter and can influence decisions.”

(Patient Partner)

SPOR Patient Engagement Framework – Guiding Principles:

- Inclusiveness
- Support
- Mutual respect
- Co-build
...collaboration...

Spectrum of engagement

<table>
<thead>
<tr>
<th>Inform</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Empower</th>
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</thead>
<tbody>
<tr>
<td>To provide</td>
<td>To obtain feedback</td>
<td>To work with to</td>
<td>To partner in each aspect of decision-</td>
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<tr>
<td>with information</td>
<td></td>
<td>develop alternatives</td>
<td>making</td>
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<td>To decide</td>
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In governance...

Governance includes all those voices that contribute to decision-making re policies, funding, and operations.

Impactful roles:
- Creative outsider
- Free challenger
- Passive presence
(Crocker, J. et al. 2016)
In *priority-setting*…

Whose priorities?

- Academic researchers
- Health system decision-makers
- Health care providers
- Patients
Case in point…

**Patient priorities**

- Physiotherapy
- Surgery
- Educational and coping strategies

(Tallon, et al., 2000)

**Osteoarthritis research studies**

- Drug evaluations: 80%
In the conduct of research and knowledge translation

“...research with and by, not on, for or to” (Involve, UK)
Why patient engagement?

• The moral argument - People have a right to be involved in publicly-funded endeavours that affect them personally

• The need for greater impact on policy and practice change

• Relevance - as knowledge users, patients know what matters to them and which treatments and therapies are most likely to be acceptable to them

• Quality – Patients bring a unique perspective that complements scientific and academic expertise

• Benefits to both patients and researcher
The road less travelled
JOURNEY TO THE LAND OF EOS

START

DEATH VALLEY

DISSEMINATION

ACTION

KNOWLEDGE

ANALYSIS

DATA COLLECTION

DESIGN

PROPOSAL

FUNDING

END-OF-GRANT INTEGRATED

FINISH

CONGRATULATIONS!
Why engage patients throughout?

• Some funders require it

• The patient perspective complements the researcher perspective

• Patients can best speak to the outcomes that matter most to patients

• Better study design

• More effective communication of study results
Travel tips

• Avoid *Tokenism*

• Adopt an attitude of collaboration vs. command and control

• Connect your patient partners to other patients

• Start early, it takes time

• Budget thoughtfully

• Ask patient partners what they value about being engaged
Travel tips, continued

- Avoid *Acronyms* and *Technical Language*.
- Be mentally prepared for surprises, mostly pleasant ones!
Key messages

• Patients are knowledge users too

• Patients’ lived experience complements academic and scientific knowledge; it does not replace it.

• Patient-oriented research is where patient engagement, as defined within the context of the Strategy for Patient-Oriented Research (SPOR), and knowledge translation intersect
Thank you!

Stay in touch:

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