Integrating the Patient Voice in Health Research

The what, why and how

Colleen McGavin, Patient Engagement Lead, BC SUPPORT Unit
AllerGen NCE Webinar – March 8, 2017
Presentation goals

• Define patient engagement in patient-oriented research

• Discuss why it’s important

  We’re Trying

• Discuss how to get it right
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…

Research suggests that “[up to] 50% of patients do not get treatments of proven effectiveness, and up to 25% get care that is not needed – or potentially harmful.” (http://www.cihr-irsc.gc.ca/e/documents/fact_sheet_spor_overview_e.pdf)
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…

…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.
Why was a new strategy needed?


- Average of 17 years for research evidence to reach clinical practice (Balas & Boren (2000), Grant et al. (2003) and Wralschko (2009))

- Only 14% is believed to make it into day-to-day clinical practice (Westfall JM, Mold J, Fagan L. Practice-based research: “Blue. Highways” on the NIH roadmap, JAMA. 2007; 297:403-6.22)
The proposed solution: a new partnership

- Researchers
- Patients
- Health care providers
- Health system decision-makers

Knowledge users
Patients are knowledge users

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

Patient uses health information to make decisions
Patient-oriented research defined

Health research that:

- Is conducted in partnership, with and by patients, researchers, health care providers and health system decision-makers

- Focuses on priorities that matter to patients

- Aims to improve healthcare systems and practices
The SPOR definition of patient engagement

“Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation.”

(http://www.cihr-irsc.gc.ca/e/48413.html)
Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation

“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

Patient experience complements researcher experience; it does not replace it.
Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation

**Spectrum of engagement**

<table>
<thead>
<tr>
<th>Inform</th>
<th>Consult</th>
<th>Involve</th>
<th>Collaborate</th>
<th>Empower</th>
</tr>
</thead>
<tbody>
<tr>
<td>To provide with information</td>
<td>To obtain feedback</td>
<td>To work with to develop alternatives</td>
<td>To partner in each aspect of decision-making</td>
<td>To decide</td>
</tr>
</tbody>
</table>
Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation.

Impactful roles:
- Creative outsider
- Free challenger
- Passive presence


Governance includes all those voices that contribute to decision-making regarding policies, funding, and operations.
Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation

Whose priorities?

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

**Patient priorities**

- Physiotherapy
- Surgery
- Educational and coping strategies

(Osteoarthritis research studies

80% Drug evaluations

('Relations between the agendas of the research community and the research consumer'; Tallon et al, Lancet 2000)
Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation.

Steps in the Research Life Cycle

- Identifying and Prioritizing
- Design
- Development of the Grant Proposal
- Preparation for execution of the study
- Data Collection
- Analysing and Interpreting Data
- Dissemination
- Implementation
- Monitoring and Evaluation

(Izabella Szelest, UofSask)
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
How we’re working to support patient engagement

**Recruit**
- Where to find patient partners and others willing to work with patients?

**Train**
- How do we prepare team members to be successful?

**Support**
- What kinds of on-going mentorship and support are needed and how do you provide them?
Developing a patient engagement plan

• What stage is your project at?
• What role(s) do you envision for patients in this project?
• How will you create a safe and welcoming environment to interact in?
• How will you ensure that your patient partners feel confident in their roles? Will you provide orientation, training and/or mentorship?
• Have you budgeted for patient engagement?
• How will you evaluate whether it made a difference?
Thank you for your time!

Comments? Questions?

Colleen McGavin, Patient Engagement Lead
cmcginv@bcsupportunit.ca

More information/Sign up for email updates:
www.bcsupportunit.ca