BC SUPPORT Unit
Advancing patient-oriented research

Strategy for Patient-Oriented Research
SPOR
Putting Patients First

Patient Engagement in Research:
We're Trying
How to Get it Right
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Canada's Strategy for Patient-Oriented Research (SPOR)

What is SPOR?

Canada's strategy to improve the health of Canadians and the sustainability of the health care system 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.

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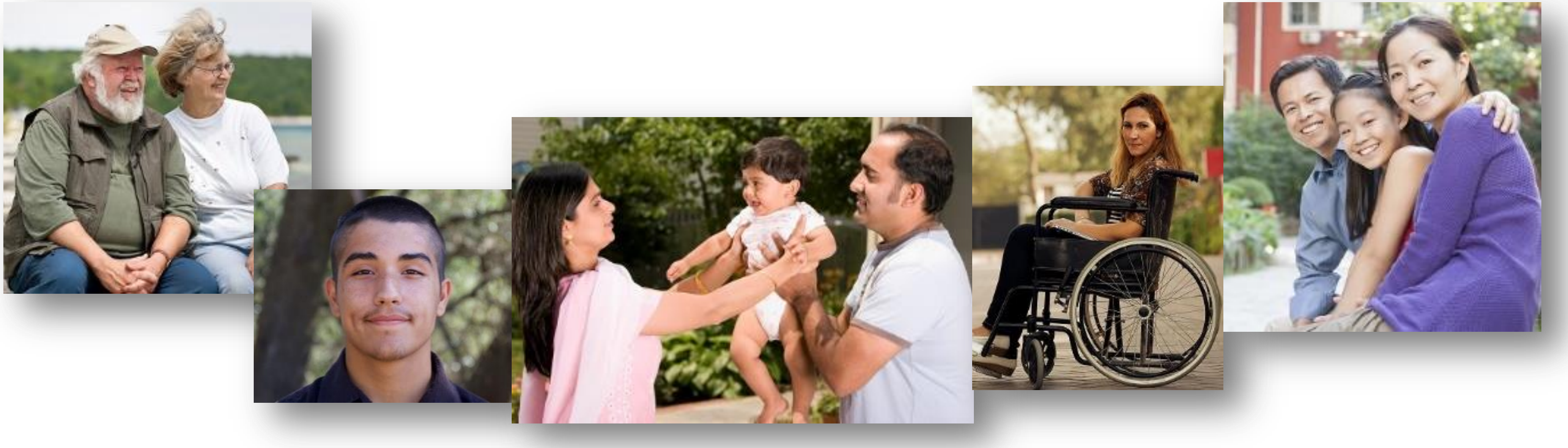
CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

Patient-oriented research

- Engages patients as partners
- Focuses on patient-identified priorities
- Improves patient outcomes
- Conducted by multidisciplinary teams in partnership with relevant stakeholders
- Aims to apply the knowledge generated to improve healthcare systems and practices



Key Messages

- Getting it right means doing your research!
- It’s possible to do rapid research in a robust and rigorous manner.
- Research shows that to ‘get it right’ we need to resolve some emergent issues.

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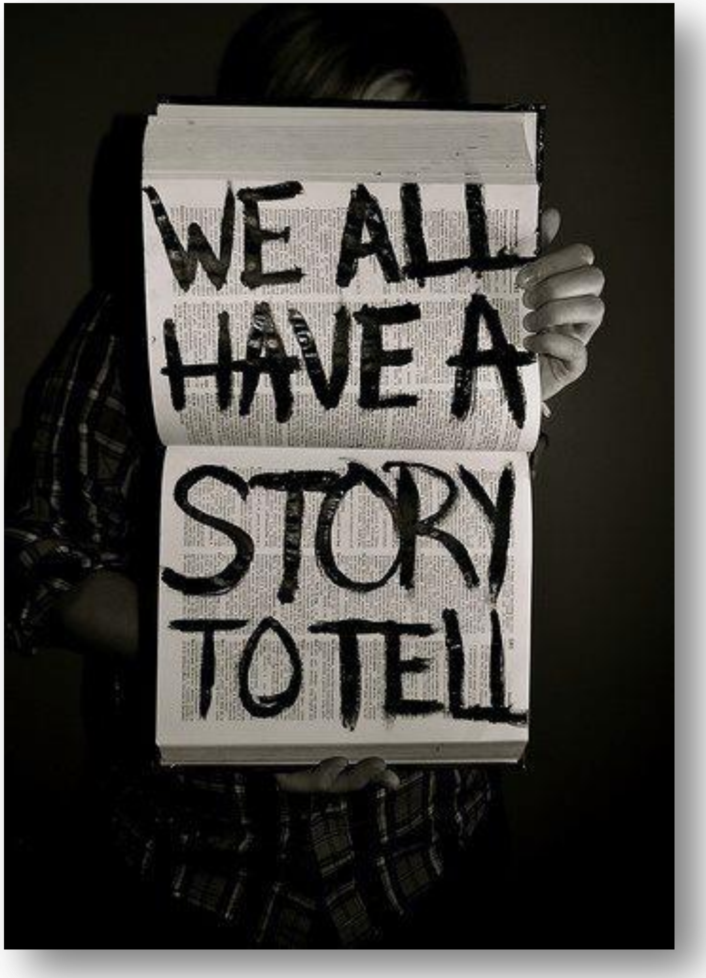
Where to start?

Stories vs. evidence



Start slowly

What we set out to learn and why

What:

- How do organizations and individuals currently recruit, train and support people to meaningfully and actively collaborate in health research? What works and what is challenging?

Why:

- To inform the BC SUPPORT Unit patient engagement strategy
- To inform training programs intended to build capacity for patient-oriented research
- To make connections and to start to build a community of practice

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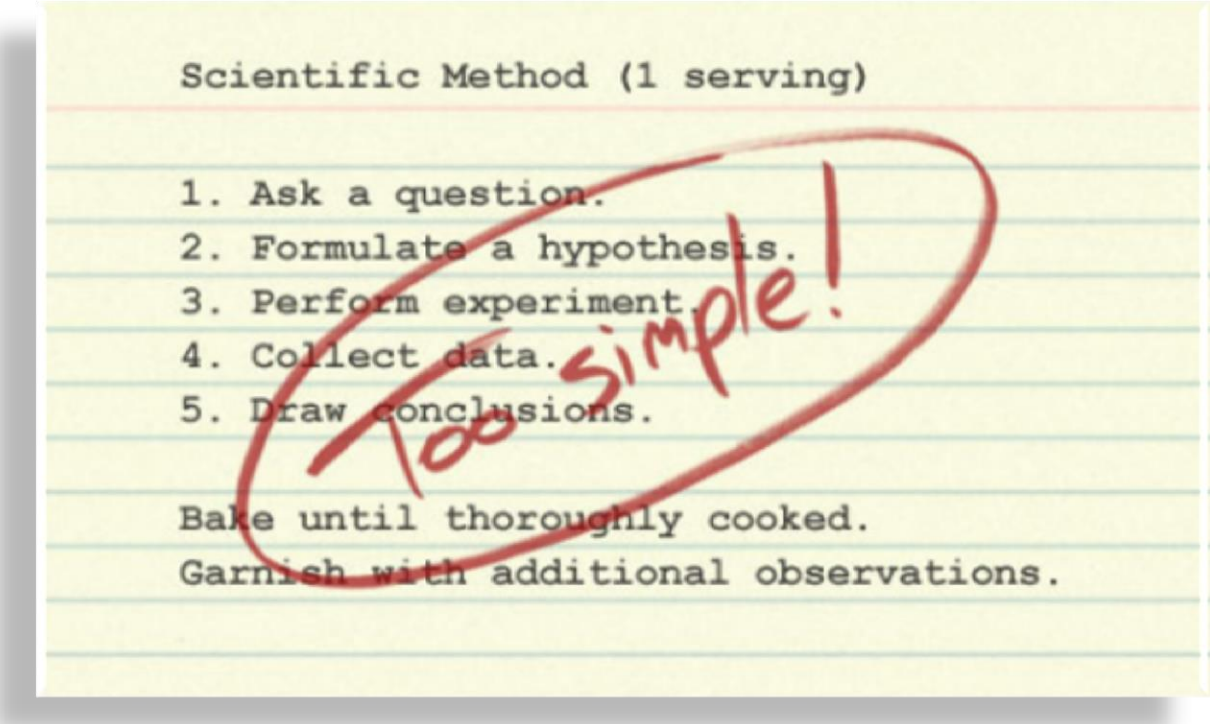
Traditional scientific method



Scientific Method (1 serving)

1. Ask a question.
2. Formulate a hypothesis.
3. Perform experiment.
4. Collect data.
5. Draw conclusions.

Bake until thoroughly cooked.
Garnish with additional observations.

Too simple!

Principles of good research

Valid

Reliable

Confirmable

Reflexive

Responsible

McLeod & Noble, 2016

How to do good research in a messy world

Valid:

- Establish a clear purpose, question and target population
- Recruit enough people to ensure diversity and to be confident in results

Reliable:

- Document research process
- Ensure transparent approach to data analysis

Responsible:

- Get consent
- Ensure accuracy and fidelity of your data

Confirmable:

- Involve participants in analysis
- Share the findings

Reflexive:

  - Be aware of potential bias when interpreting data

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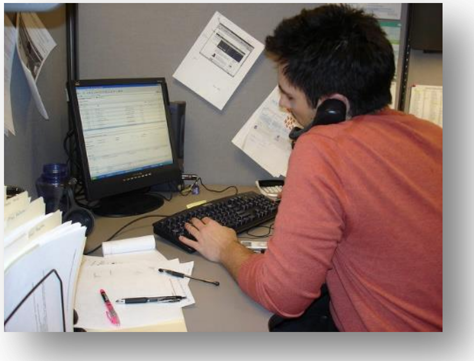
Our methods



- Convenience sampling
- Snowballing
- Telephone interviews
- 12 standardized questions
- Notes verified by study participants to ensure accuracy
- Permission to identify participants and to share notes
- Thematic analysis with opportunity for study participants to comment

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Emergent issues

- Supporting patients from vulnerable or marginalized populations to be seen as credible
- Avoiding token patient participation
- Having all parties understand the patient role/degree of influence
- A need for increased patient-oriented research training
- A need to identify the ethics of recruitment
- Ensuring fairness and equity in supporting patient partners in balance with financial sustainability

Supporting patient partners to be seen as credible

“We trial and error people and favour those who are well educated, well-spoken and don’t use their involvement as a soapbox.”

“Ability to express themselves clearly and articulate well gains them credibility.”

Interviewee
Building Momentum for Patient Engagement in Research in BC

Avoiding token patient participation/ Ensuring legitimacy

"The patient's legitimacy is limited to her personal clinical and relational experience. It would be an illogical leap to assume that the patient partner can make knowledgeable statements about every area of the hospital."

Interviewee
Building Momentum for Patient Engagement in Research in BC

Having all parties understand the patient role/degree of influence

“Power depends on the leader of the project – when the leader starts explaining in plain language, others follow; when the leader makes sure the patient has an opportunity to speak, others will follow. Also, patients hold power in that we really value their input.”

Interviewee
Building Momentum for Patient Engagement in Research in BC

A need for increased training

“More often than not, formal training in patient engagement was rare.”

“Training was done informally, on a just-in-time basis, often one-on-one.”

Colleen McGavin/Bev Holmes
Building Momentum for Patient Engagement in Research in BC

A need to identify the ethics of recruitment

For consideration:

“When patients are meaningfully and actively involved in roles other than as study subjects, the same rules (i.e., informed consent) need not apply.”

Colleen McGavin/Bev Holmes
Building Momentum for Patient Engagement in Research in BC

Fairness & equity vs. financial sustainability

“When you pay some and not others, it feels unfair. It sends a message, perhaps unintended, about whose input is valued and whose is not.”

Interviewee
Building Momentum for Patient Engagement in Research in BC

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Does this resonate with you and your work?

- What questions have you asked or do you want to ask?
- Would “rapid” research like this work for you?
- What have you already learned that could contribute to our understanding?

Thank you!

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