

Patient Oriented Research: What is it and How “Patient Research Partners” Can Help Shape the Future of Prostate Cancer Research

Vancouver Prostate Cancer Support Group | September 5, 2019
Larry Mróz, Research Navigator & Patient Engagement Coordinator

Agenda

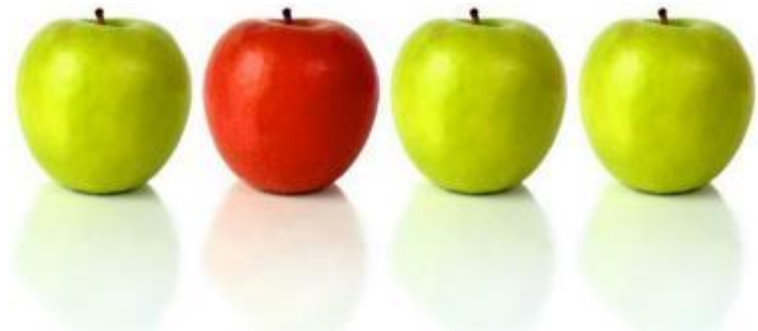
- To introduce Patient Oriented Research (POR)
- To introduce CIHR's Strategy for POR (SPOR)
- To introduce services available from the BC SUPPORT Unit

Why?



What POR isn't

- Similar but not the same as:
 - Patient-centred outcomes research
 - Patient-centred measurement (PROMs, PREMS)
 - Just including the patient perspective (qualitative research)
- Not just 'for'
 - 'With and by'



What is Patient-Oriented Research?

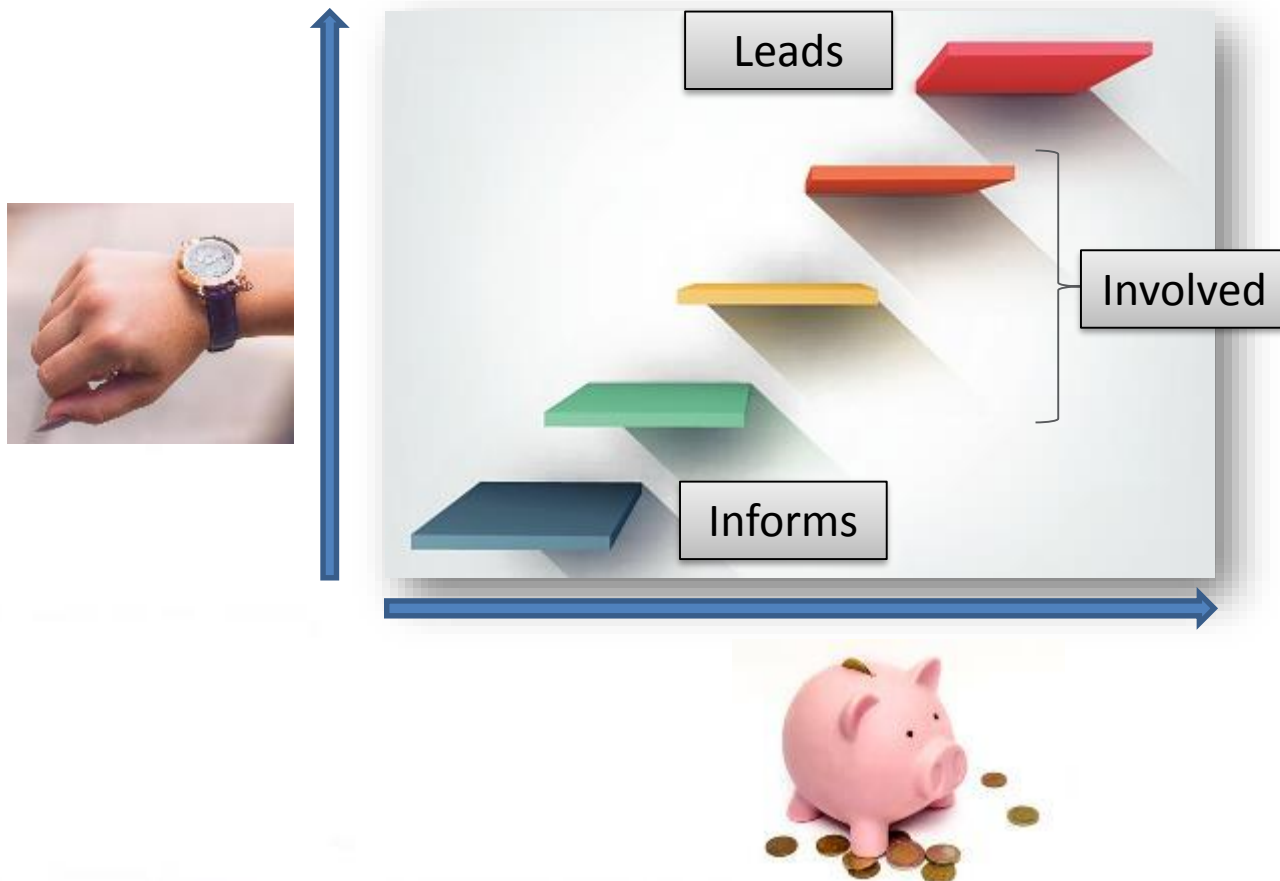
➤ Research that is:



- Done with patient *partners*
- Answers questions & measures outcomes, that ***matter*** to patients
- Aims to improve ***health care***

Level(s) of Engagement

'Patients' as Research Partners



Levels of Patient Engagement

- International Association for Public Participation (IAP2)
- One of several (widely cited)

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives and/or solutions.	To obtain public feedback on analysis, alternatives and/or decision.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision-making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.



<https://iap2canada.ca/>

Patient *Roles* in Research

‘Patients’ as Partners in Research
Their ‘lived experience’ guides research decisions

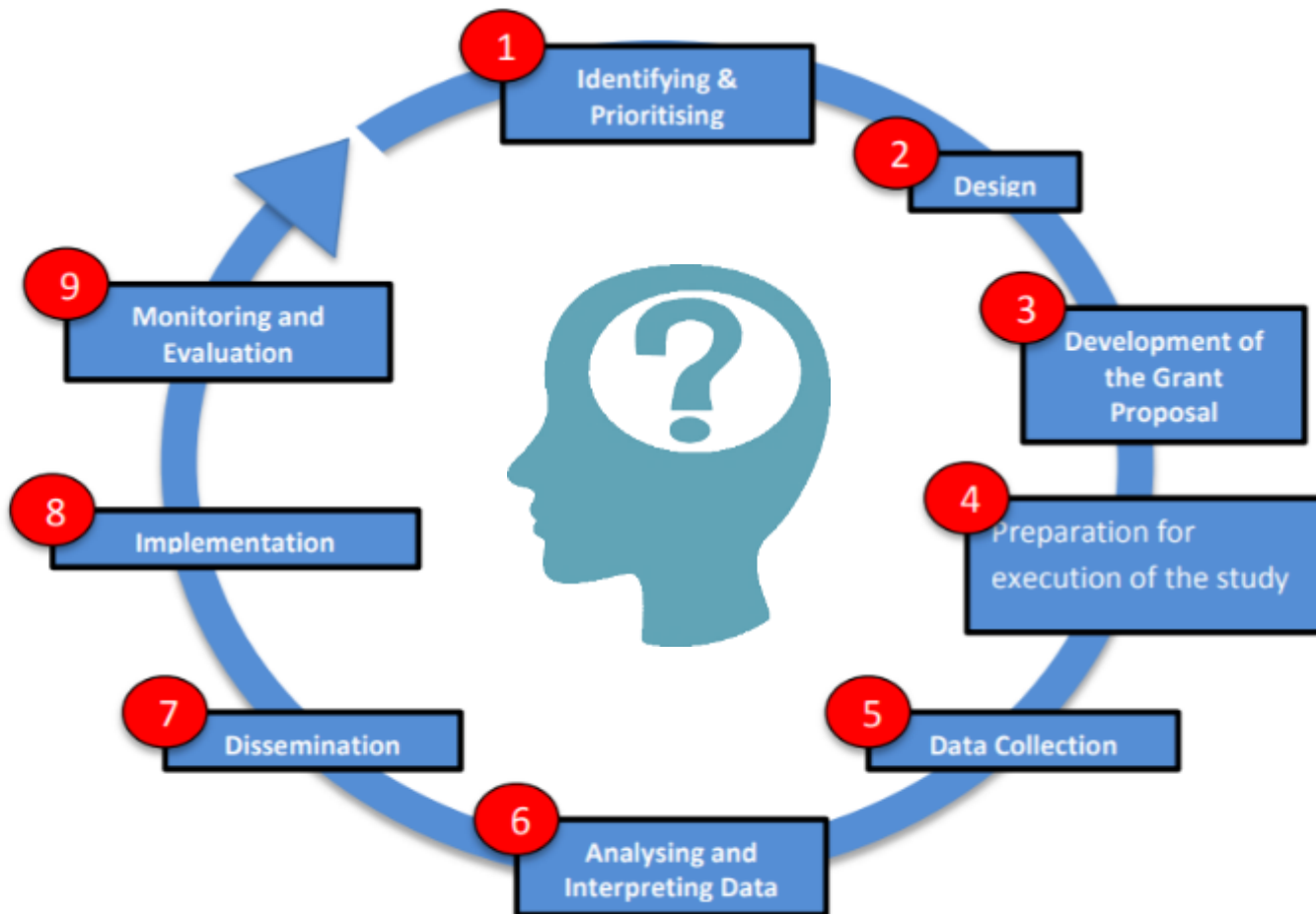
Researcher:
Needs /
Expectations



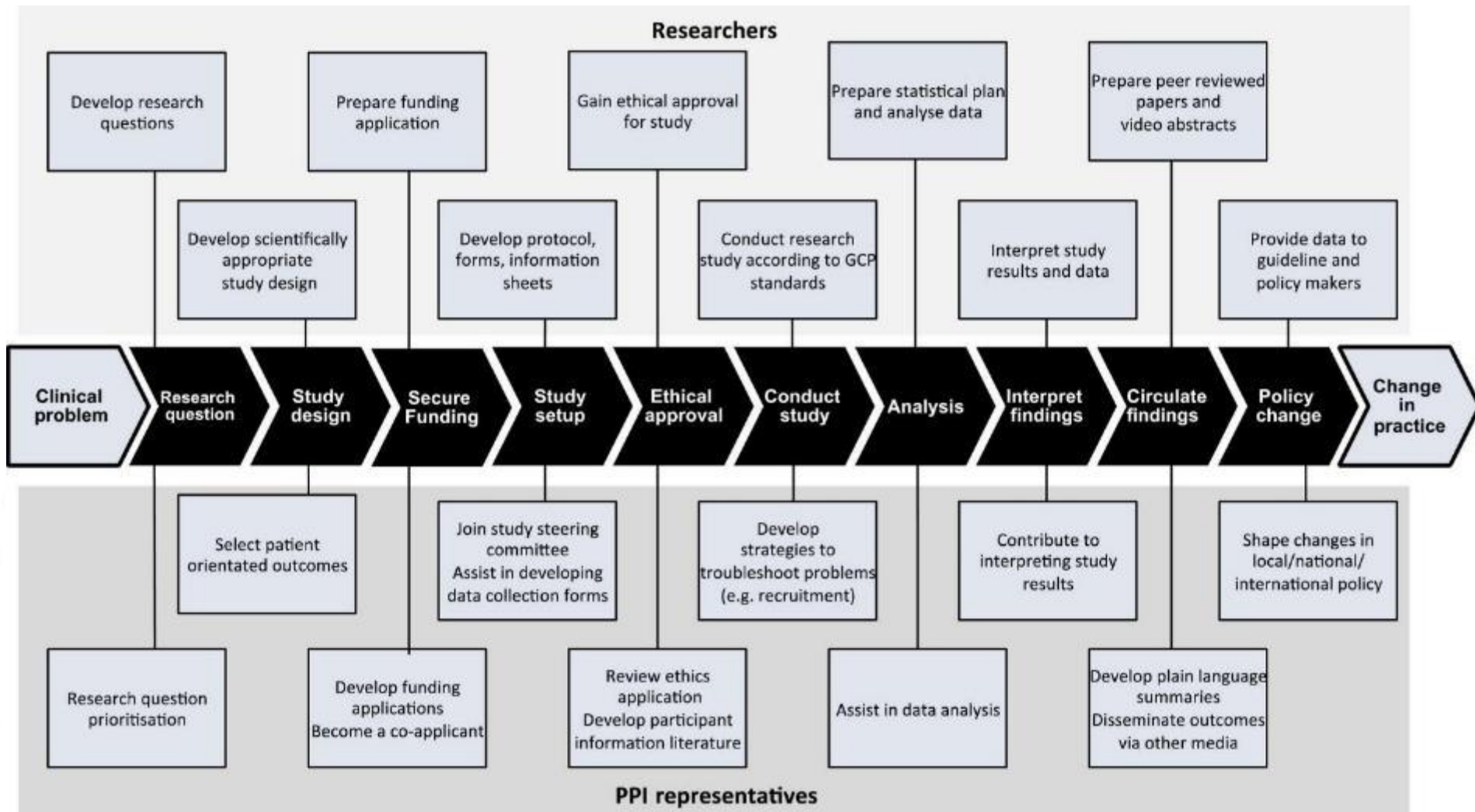
Patient:
Knowledge,
Skills & Abilities
/ Interests

Roles for Patients in Research

Source: Izabela Szelest, Research Facilitator, College of Medicine, University of Saskatchewan



Roles for Patient Partners



Source: Moss - 2017 - BJOG: An International Journal of Obstetrics & Gynaecology - Wiley Online Library
<https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/1471-0528.14419>

What to consider?

To do POR consider:

- **Levels of engagement**

- How will patient partner(s)' feedback inform decision-making?

- **Roles for patient partners**

- What will the patient partner(s) do as a research team member?

- **Phase of the research cycle**

- Where and when will patient partner(s) be engaged?

Canada's Strategy for Patient Oriented Research – 'SPOR'

- What is SPOR?
 - ***CIHR initiative 2011***
- Why SPOR?
- What is the BC SUPPORT Unit?
- What services do we offer?
- Mission: Support the conduct and implementation of high quality patient-oriented research in BC

International Organizations

'Go-To' Websites

CANADA: SPOR

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



USA: PCORI

<https://www.pcori.org/>



UK: INVOLVE

<http://www.invo.org.uk/>

INVOLVE

NHS
*National Institute for
Health Research*

Strategy for Patient-Oriented Research

SPOR

Putting Patients First



Strategy for Patient-Oriented Research

Patient Engagement Framework

Guiding
Principles
P 7 & 10

http://www.cihr-irsc.gc.ca/e/documents/spor_framework-en.pdf



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

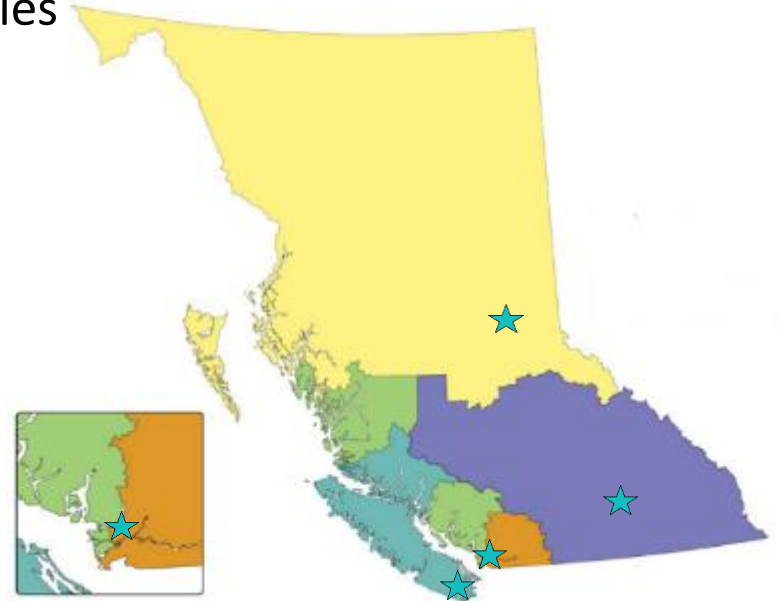
The BC SUPPORT Unit is...

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

- Health Authorities
- Universities
- Government
- Patients/Caregivers
- Research Institutes, Networks & Foundations

Regional Centres

- Each regional centre is an important part of the BC SUPPORT Unit – they're a partnership between health authorities and universities in the area.
- There are five regional centres:
 - Vancouver Island Centre
 - Interior Centre
 - Northern Centre
 - Fraser Centre
 - Vancouver Centre (Provincial Hub)



POR Training Opportunities (Vancouver)

- Annual Conference
- National Curriculum
- T4POR



Conference Wednesday November 20, 2019

**Putting Patients First 2019:
Working Together Across the Research Life Cycle**



Putting Patients First 2019

November 20 | Vancouver, BC | #PPF19

Contact Us

- E: info@bcsupportunit.ca
- W: www.bcsupportunit.ca
- W: Contact us <http://bcsupportunit.ca/hub-operations-team-contacts>
- Twitter: @bcsupportunit

Thank you for your time, attention and participation

