

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)

Strategy for Patient-Oriented Research

SPOR

Putting Patients First



CIHR IRSC

Canadian Institutes of
Health Research

Instituts de recherche
en santé du Canada

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.

Strategy for Patient-Oriented Research



Why was a new strategy needed?

- Too many discoveries sit on shelves and in journals and in books (Melanie Barwick, “Getting to Impact: Why Knowledge Translation Matters for Researchers” at <http://allergen-nce.ca/wp-content/uploads/Barwick.pdf>)
- 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

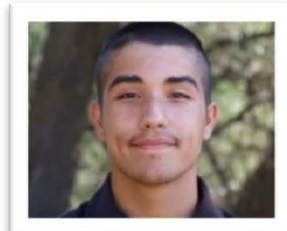


Patient-oriented research defined

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.

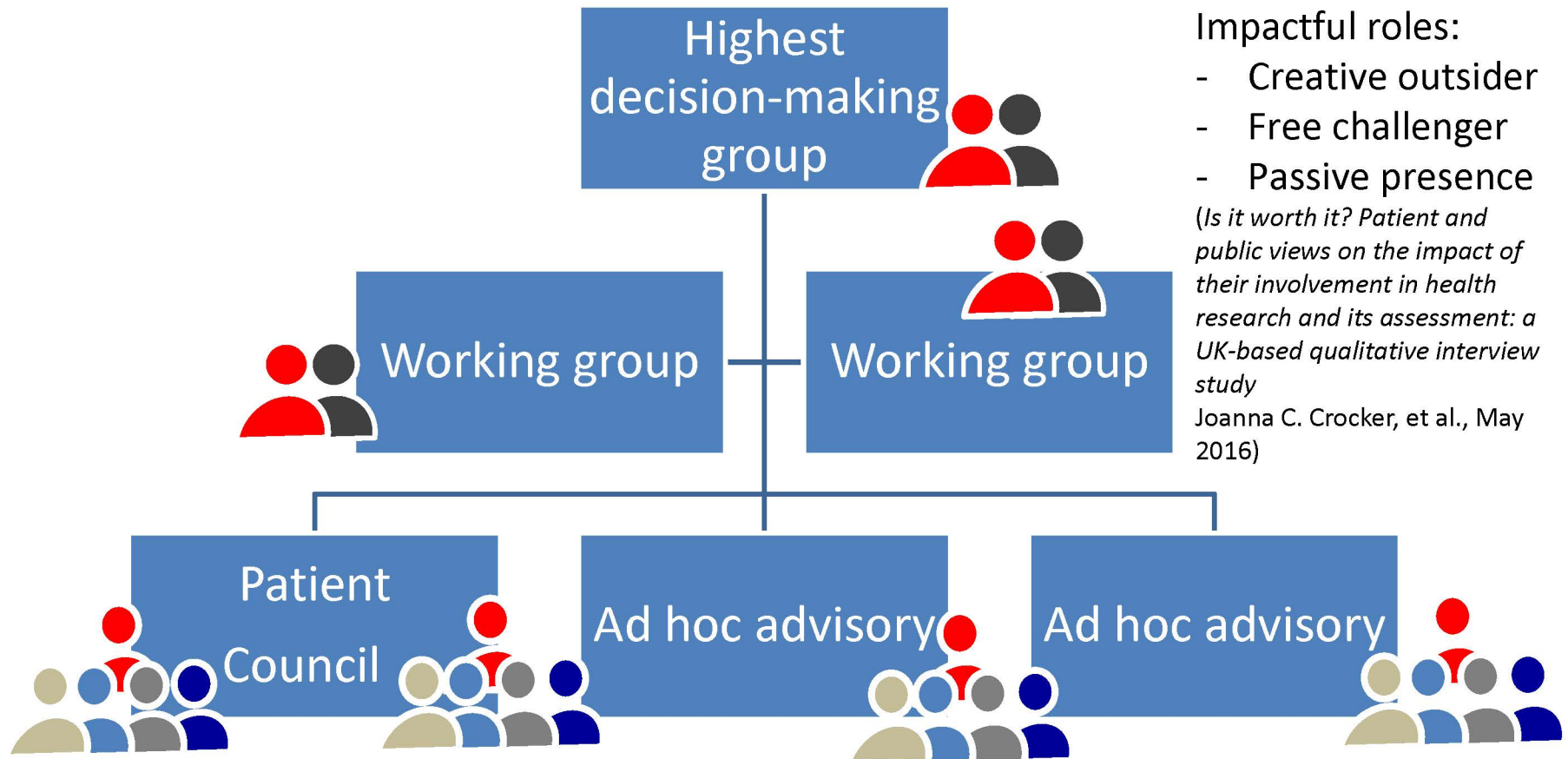
Meaningful and active **collaboration** in governance, priority setting, conducting research and/or knowledge translation

Spectrum of engagement



Inform	Consult	Involve	Collaborate	Empower
To provide with information	To obtain feedback	To work with to develop alternatives	To partner in each aspect of decision-making	To decide

Meaningful and active collaboration in **governance**, priority setting, conducting research and/or knowledge translation



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

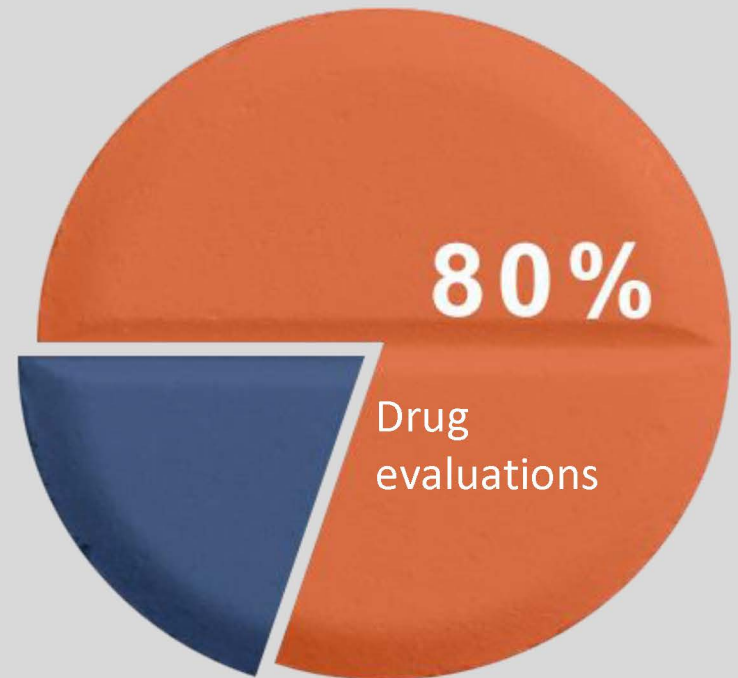
Case in point...

Patient priorities

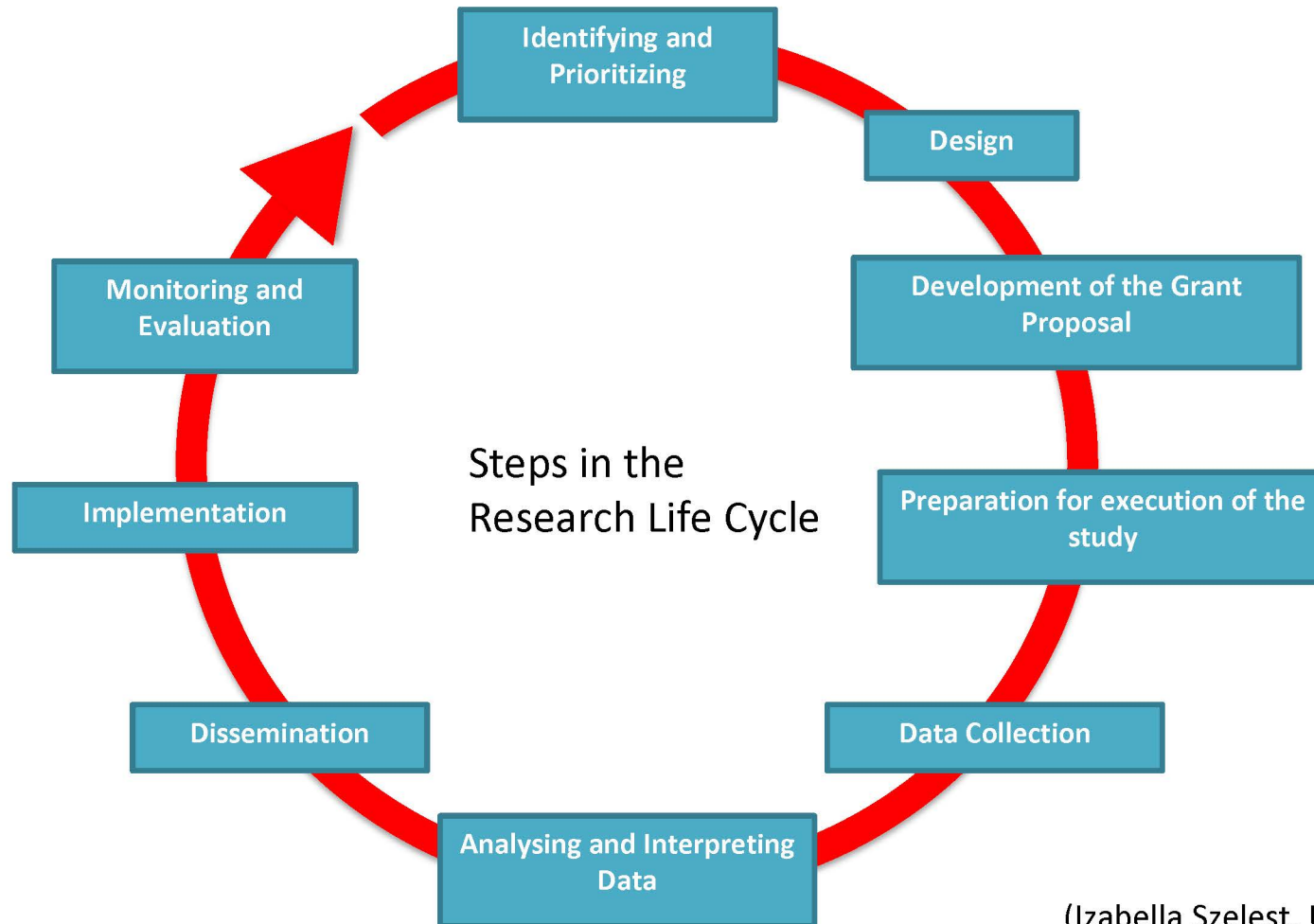
- Physiotherapy
- Surgery
- Educational and coping strategies

(‘Relations between the agendas of the research community and the research consumer’, Tallon et al, Lancet 2000)

Osteoarthritis research studies



Meaningful and active collaboration in governance,
priority setting, **conducting research and/or
knowledge translation**



(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

cmcgavin@bcsupportunit.ca

More information/Sign up for email updates:

www.bcsupportunit.ca