

Patient Engagement in Research: Sharing approaches, challenges and opportunities

AAC Consumer Coalition Workshop
October 28, 2016

Welcome!

- Our workshop speakers and panelists are:
 - Ms. Cheryl Koehn, *Founder and President, Arthritis Consumer Experts*
 - Ms. Alison Hoens, *Arthritis Patient Advisory Board, Arthritis Research Canada*
 - Dr. Beverly Holmes, *BC SPOR SUPPORT Unit*
 - Mr. Tim Murphy, *AB SPOR and Alberta Innovates – Health Solutions*
 - Dr. Sharon Straus, *Professor, Vice Chair, and Director, Division of Geriatric Medicine, Department of Medicine, University of Toronto, and many other titles*

Objectives

1. To define “patient engagement in research”
2. To share an existing approach that’s been working for 16 years
3. To share a new model based on a collaboration of arthritis consumer groups and organizations
4. To share how two SUPPORT Units are addressing patient engagement in research
5. To provide an opportunity for participants to share insights on challenges and opportunities moving forward

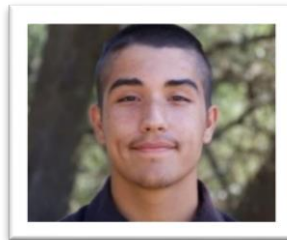
WHAT IS “PATIENT ENGAGEMENT IN RESEARCH”?

Patient engagement
in research



Patient engagement:
self-management,
health care quality
improvement, or as
study subjects

Patient engagement in research



CIHR definition:

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

Meaningful and *active*: what does that mean?

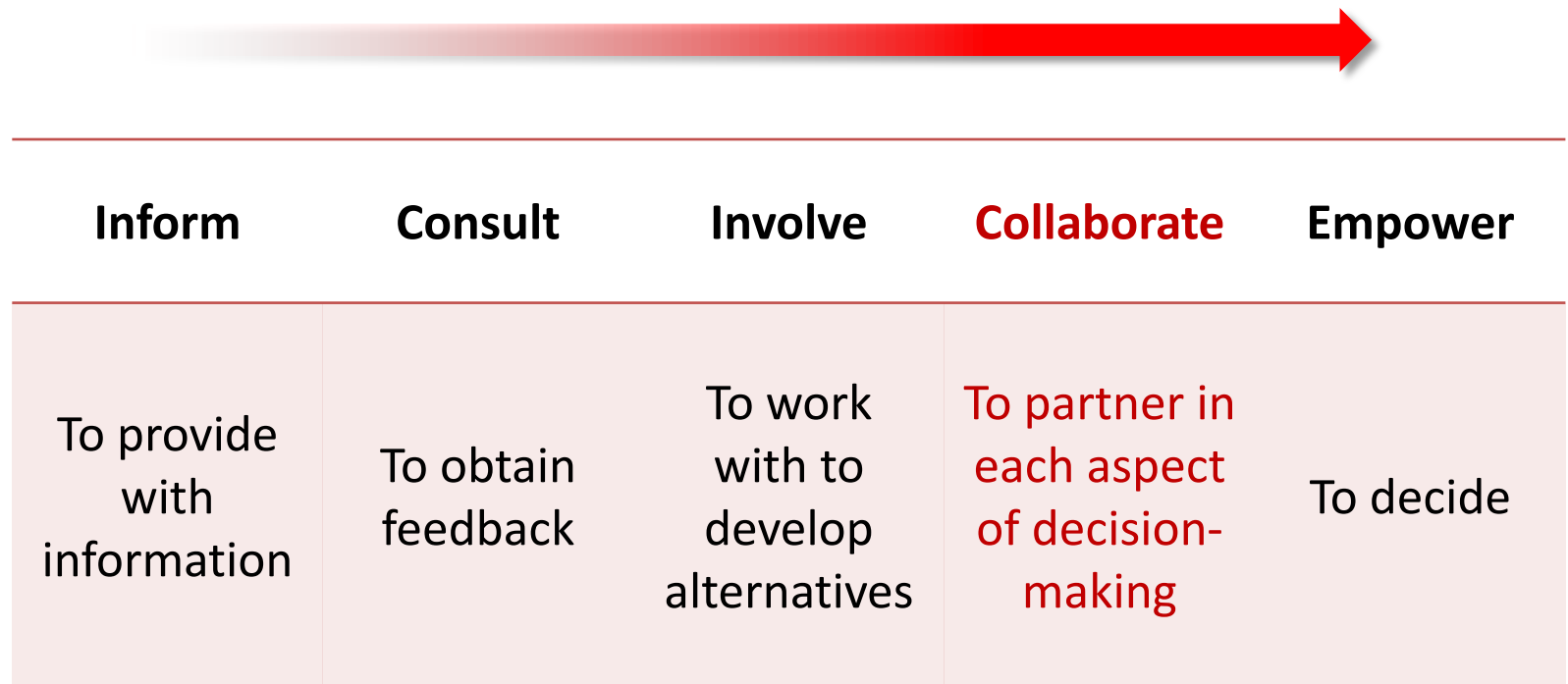
“It’s the feeling that you’re having an impact...your voice and perspective matter and can influence decisions.”

(Patient Partner)

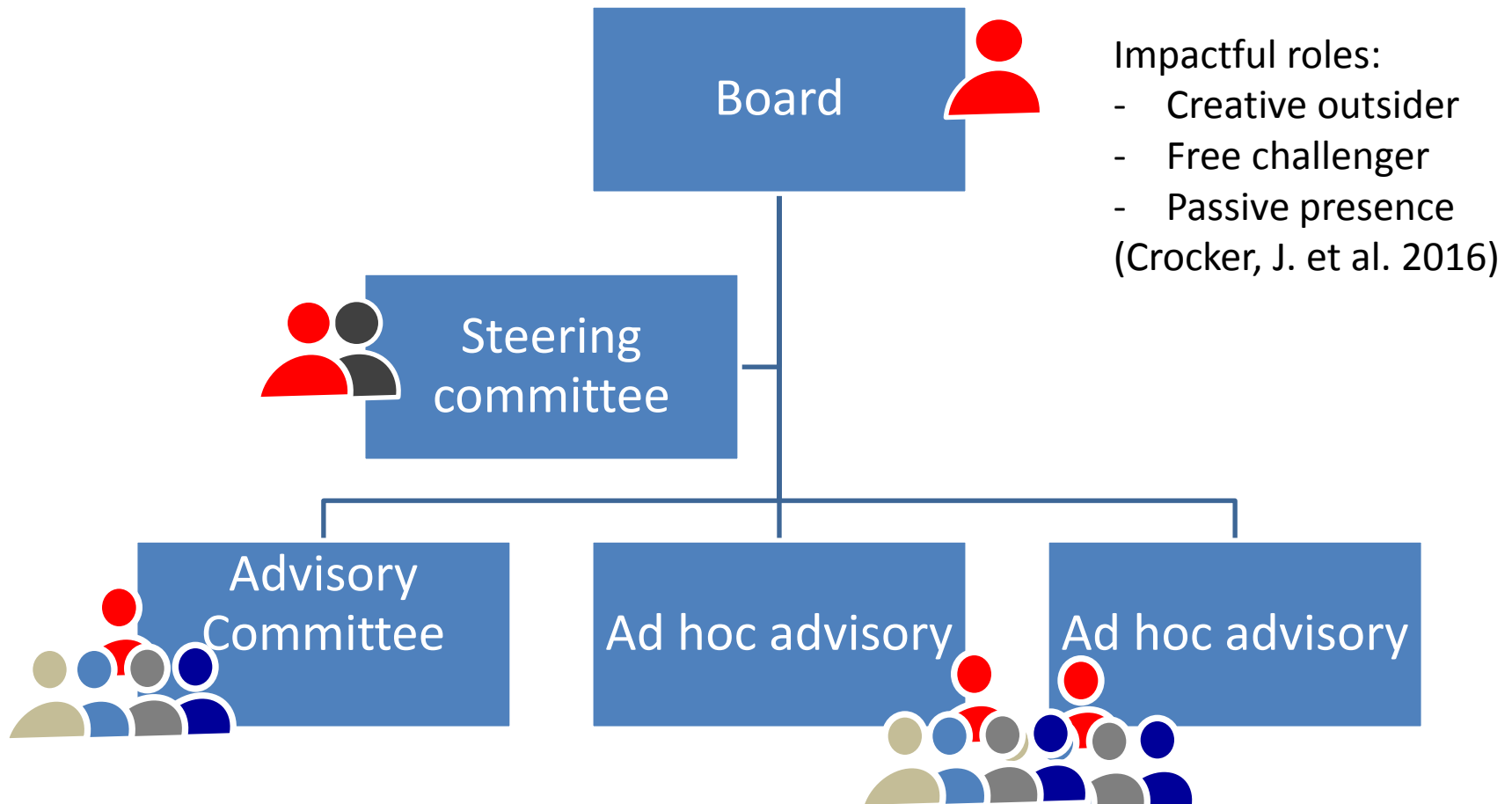
- SPOR Patient Engagement Framework – Guiding Principles:
 - Inclusiveness
 - Support
 - Mutual respect
 - Co-build

... collaboration ...

Spectrum of engagement



In governance...



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

In *priority-setting*...

- Whose priorities?
 - Researchers
 - Health system decision-makers
 - Health care providers
 - Patients

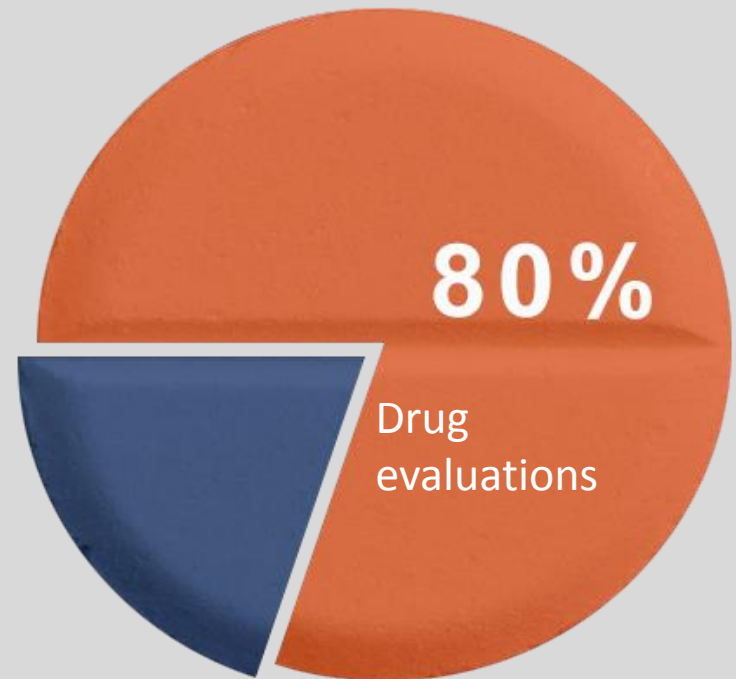
Case in point...

Patient priorities

- Physiotherapy
- Surgery
- Educational and coping strategies

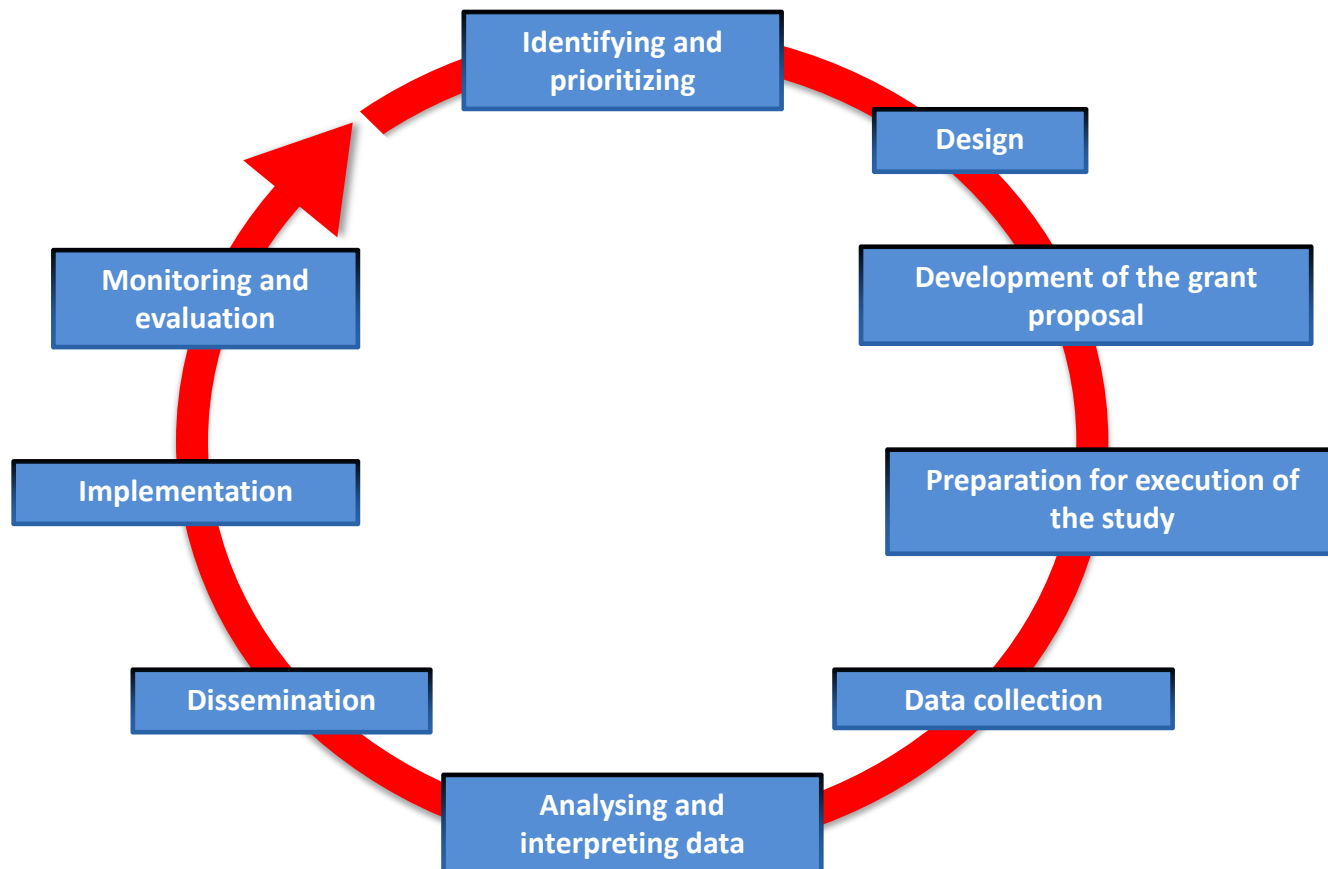
(Chalmers & Glasziou, 2009)

Osteoarthritis research studies



In the conduct of research and knowledge translation

“...research **with** and **by**, not *on, for or to*” (Involve, UK)

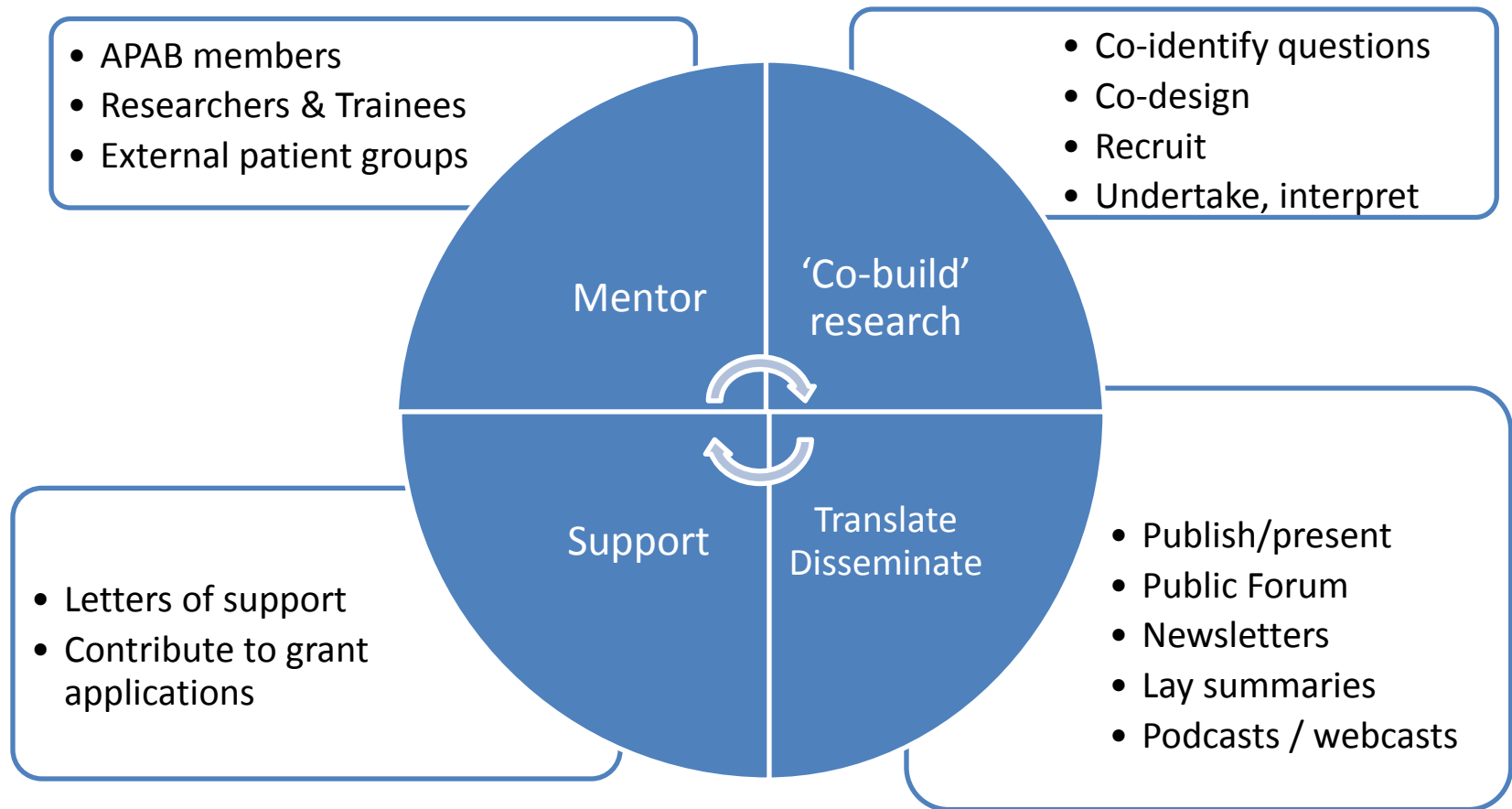


Why is patient engagement in research important?

- The moral argument
 - People have a right to be involved in publicly-funded endeavours that affect them personally
- Opportunity to do things differently and better
- Relevance - as knowledge users, patients know what matters to them
- Benefits to patients, researchers and the quality of research

AN EXISTING APPROACH: ARTHRITIS PATIENT ADVISORY BOARD (APAB)

What does the Arthritis Patient Advisory Board do?



How does the Arthritis Patient Advisory Board do it?

- “Meaningful and active collaboration in governance, priority setting, conducting research and/or knowledge translation.”
 - Meaningful
 - E.g. “About Us” research by Dr L Li & team
 - Active collaboration
 - Since inception of ARC; 16 years
 - Governance
 - Own budget; APAB member on ARC Board of Directors
 - Priority setting
 - Identifying research questions
 - Conducting research
 - All phases
 - Knowledge Translation
 - Co-publish / co-present
 - Lay summaries
 - Quarterly Newsletter
 - Annual Public Forum
 - Social media
 - Podcasts/ webcasts

A NEW MODEL: Consumer Leadership & Experience in Arthritis Research (CLEAR)

A bird's eye view of arthritis consumer-patient groups and organizations in Canada

This summary is to provide organizations advocating for patients with arthritis with a framework for identifying their degree of cooperative autonomy and thereby informing opportunities for enhanced independence and impact.



What is an arthritis consumer-patient group or organization?

A consumer or patient is a person who is living with a form of arthritis.

A consumer or patient organization or group is one that exists to further the interests of patients living with a form of arthritis or musculoskeletal disease.

A consumer-patient organization or group –

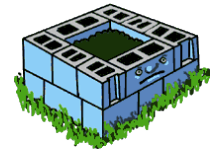
- Is comprised of patients who operate the organization in a manner that benefits all members. Benefits include support, information, education, training and advocacy, and may also include the promotion, support of, and participation in, research.
- Facilitates and encourages peer-to-peer support, mentoring and role modeling.
- Is run by people living with a form of arthritis or musculoskeletal disease, and is structured such that the boards or executive are comprised primarily of consumer-patients, who are also the key decision-makers for the organization or group.
- Is independent in decision-making, but may be affiliated with researchers, corporations and any other organization.
- Raises some or part of its funding from members, the general public, corporate partners and other organizations. It controls its own budget and can spend at its own discretion in accordance with the decisions of the board or executive committee and without influence from any other parties.
- Represents the patient perspective in all matters in which it is involved.
- That is a member of the Arthritis Alliance of Canada must have a patient representative on the AAC who is willing to participate in the business and activities of the AAC.



PATIENT ENGAGEMENT IN THE BC SUPPORT UNIT: A WORK IN PROGRESS

Key Messages

1. BC SUPPORT Unit: committed to meaningful patient engagement
2. Solid foundation to build on...
3. ...and some things to work out

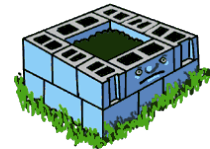


Key Messages

1. BC SUPPORT Unit: committed to meaningful patient engagement



2. Solid foundation to build on...



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BC SUPPORT Unit

Advancing patient-oriented research

Who we are and what we're doing:

A multi-sector, multi-partner organization, supporting patient-oriented research throughout BC

Main roles:

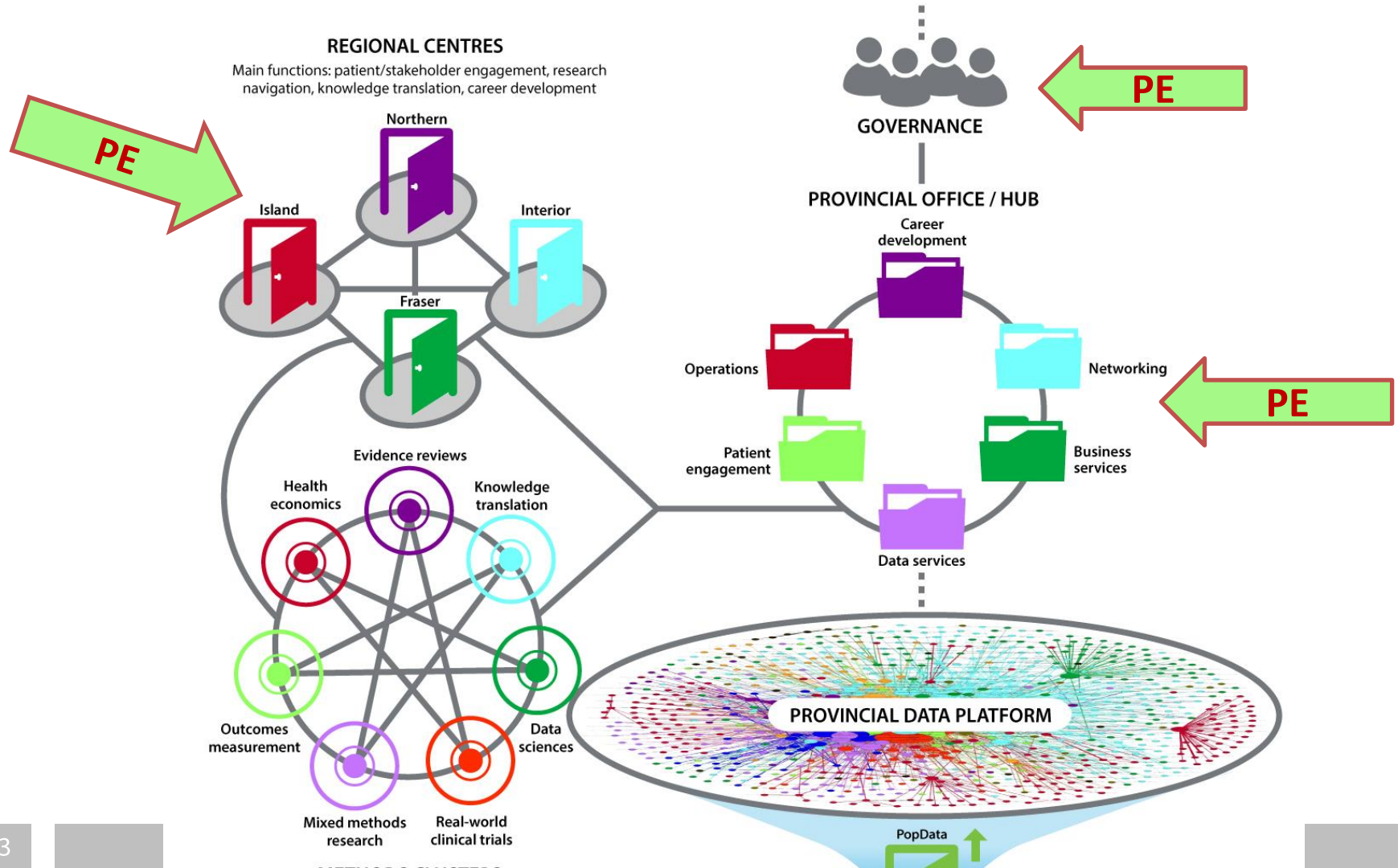
1. Providing services to researchers, patients, health care providers and health system decision makers, and
2. Facilitating initiatives identified as provincial priorities

Strategy for Patient-Oriented Research



BC SUPPORT Unit: Model*

*Some names that describe functional detail are shown in short form



BC's patient engagement framework

Recruitment

Training



Support

Facilitates PE in:

- Governance
- Priority-setting
- Conduct of research
- Knowledge translation

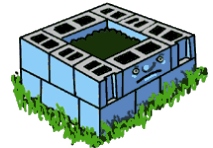


Key Messages

1. BC SUPPORT Unit: committed to meaningful patient engagement



2. **Solid foundation to build on...**



3. ...and some things to work out



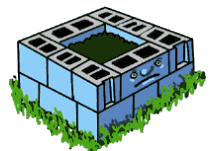
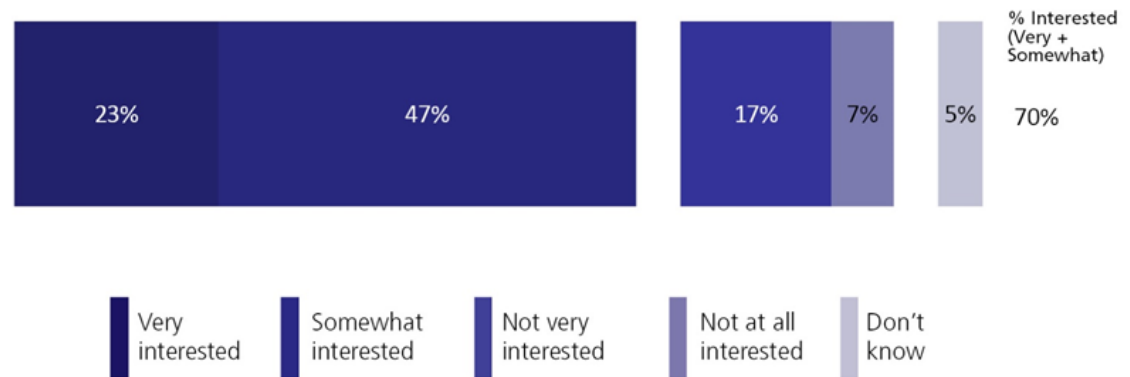
Are Canadians and British Columbians interested?

Canada Speaks 2015 public opinion poll

Poll question: How interested are you in participating in health & medical research, including helping to determine priority topics and deciding on future areas of funding?

Interest in research participation

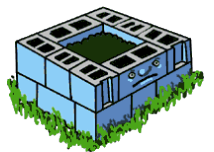
A majority of Canadians (70%) say they are interested in participating in health and medical research.



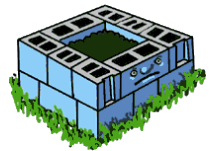
Provincially – BC

Patients as Partners | Patient Voices Network

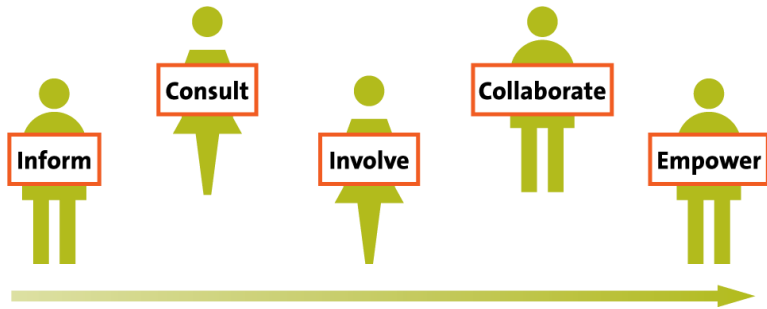
- Health authority patient advisory councils
- Individual researchers
- Consumer groups



Nationally

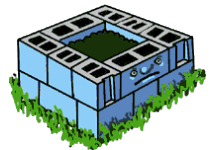


Internationally



INVOLVE

© International Association for Public Participation



Beyond borders:
An increasingly
solid research
foundation



*Engage the right people
for the right reason*



*Patient engagement needs
resources*



We have some good models



*We know some things
about the benefits*



*We know a lot about
facilitators and barriers*



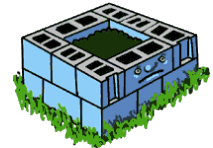
*Evaluation metrics are
coming along*



It takes a culture shift

Key Messages

1. BC SUPPORT Unit: committed to meaningful patient engagement
2. Solid foundation to build on...
3. **...and some things to work out**



To work out...



- Supporting patients to be seen as credible
- Having all parties understand the patient role/degree of influence
- A need for increased patient-oriented research training
- Working together

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

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

Working together

- Advancing knowledge about patient engagement
 - Does PE = better outcomes?
 - How do we set good goals?
 - How should we study it?
- Sharing good practice
- Finding the elephants



‘SUPPORT’ IN ALBERTA

Meaningful Patient/Public & Researcher Engagement in Patient Oriented Research

Tim Murphy

Vice President

Alberta Strategy for Patient-Oriented Research (SPOR) SUPPORT Unit &
Provincial Platforms

AIHS

Alberta SPOR SUPPORT Unit

The Alberta SPOR SUPPORT Unit has seven core areas of expertise:



PATIENT ENGAGEMENT
led by Dr. Virginia Vandall-Walker aims to support patient engagement in research.



METHODS SUPPORT & DEVELOPMENT led by Dr. Hude Quan aims to support researchers in developing innovative research methods for undertaking patient-oriented research.



KNOWLEDGE TRANSLATION led by Dr. Lisa Hartling aims to advance understanding in how to translate evidence into practice.



PRAGMATIC CLINICAL TRIALS led by Dr. Michael Hill aims to provide expertise for completing real-world clinical trials which may change health outcomes.



CAREER DEVELOPMENT jointly led by Dr. Dean Eurich and Dr. Marilynne Hebert aims to enhance training and career development in methods and health service research.



CONSULTATION & RESEARCH SERVICES led by Dr. Ross Tsuyuki aims to provide you with the tools, resources and expertise necessary for the successful completion of patient-oriented research.



DATA led by Dr. Finlay McAlister aims to provide you with the support and resources for undertaking patient-oriented research using secondary analysis of existing large datasets.

- Five platforms provide direct services to researchers.
- Two platforms, **Career Development and Pragmatic Clinical Trials**, help build capacity in Alberta's research community by providing a number of career development and training opportunities.



Accessing Services

VISIT
ABSPORU.CA

APPLY FOR
SERVICES

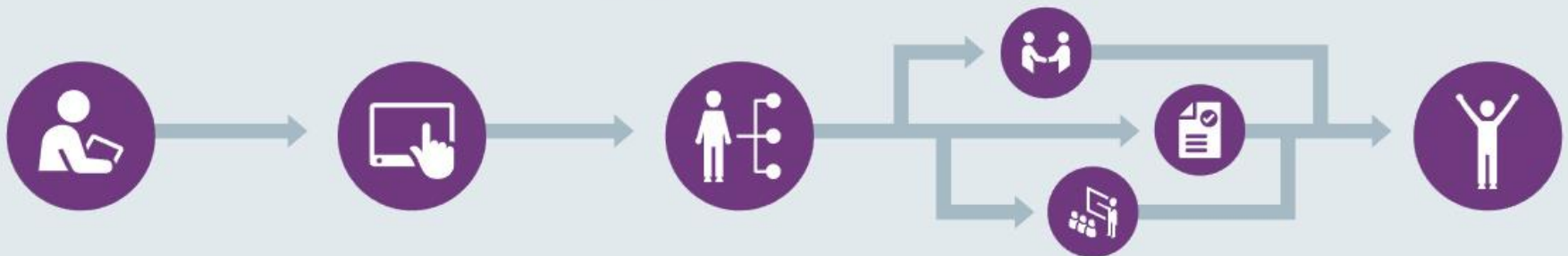
SERVICE
MATCHING

*Connecting your
project to the right
people & resources*

ACCESS
SERVICES

*Training, Expert Advice,
& Research Services*

IMPROVED
OUTCOMES



Our Impact

We've reduced the time for data
from
3 months to 3 weeks

37
data sets
available

100%
Clients find
our services
useful

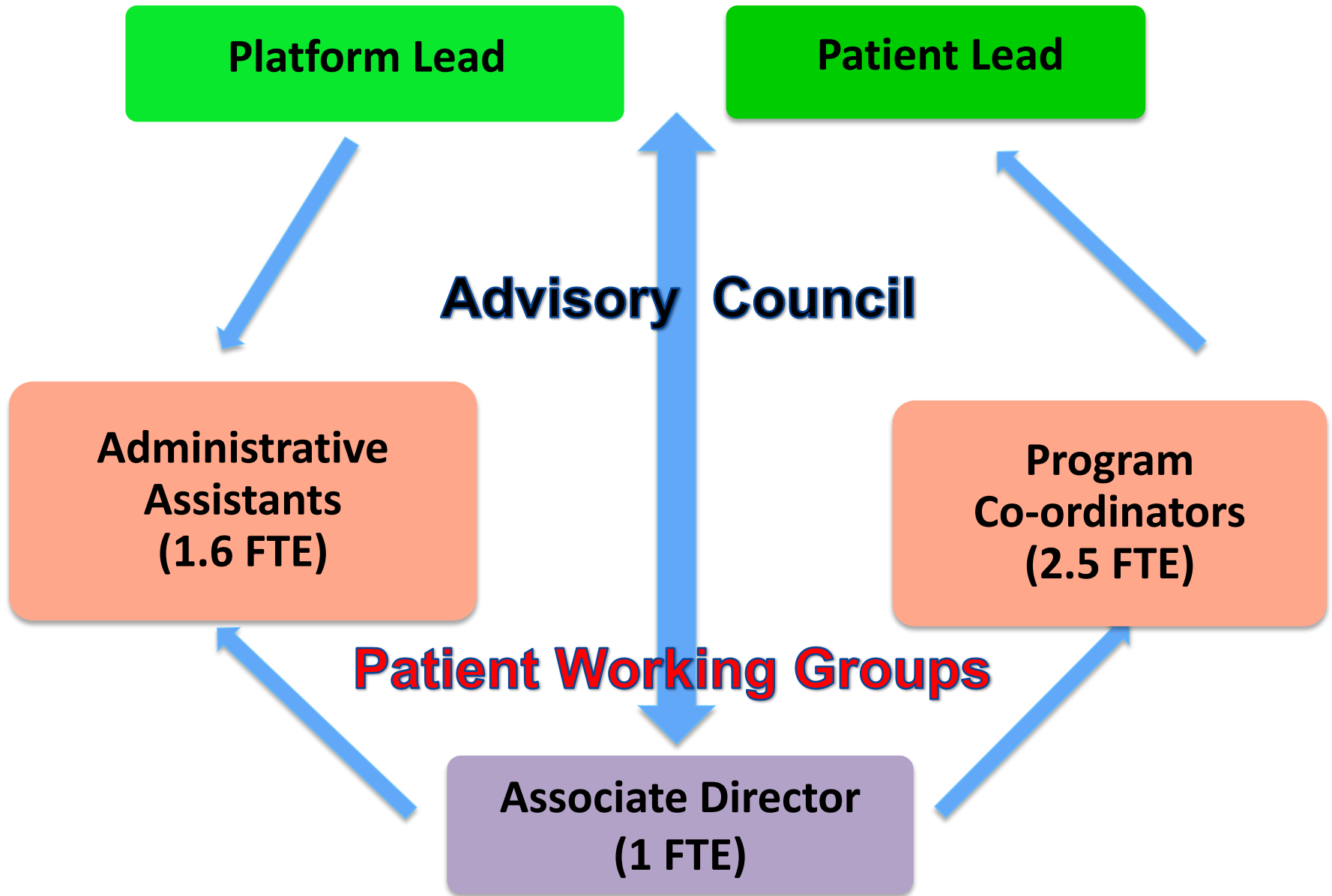
Over 1,600 people have
participated in AbSPORU training
and capacity building events

"The Alberta SPOR SUPPORT Unit is making a huge difference in our access to data which had previously been very challenging.

With the support of AbSPORU, Alberta has been the first of five provinces to provide data and analyses for a national study which will help make mental health services better for patients and families".

Dr. Carol Adair

THE PATIENT ENGAGEMENT (PE) PLATFORM



The Patient Engagement (PE) Platform Team



Top row - left to right : Ping Mason Lai, Diane Larsen, Robyn Laczy, Sennait Yohannes, Virginia Vandall-Walker, Lisa Petermann
and
Bottom row: Kiara Krawec, Gail MacKean

DEFINITIONS

ENGAGEMENT – Inclusive of patients/public AND researchers (not just patients)

PATIENT(S) - individual(s) with personal experience of a health situation & caregivers, including family & friends

PATIENT-ORIENTED RESEARCH (POR) - a continuum of research that:

- ✓ engages patients at some or all phases of research
- ✓ focusses on patient-identified topics
- ✓ improves patient outcomes

DEFINITIONS CONT'D

MEANINGFUL PATIENT/PUBLIC-RESEARCHER ENGAGEMENT

- ✓ **ACTIVE** engagement
- ✓ **Mutually beneficial & value-added for all parties**
- ✓ **Based on guiding principles of:**
 - trust, transparency, honesty
 - mutual respect
 - inclusiveness
 - Support
 - valuing reciprocal relationships, partnerships, co-learning
- ✓ **Across all research-related activity**

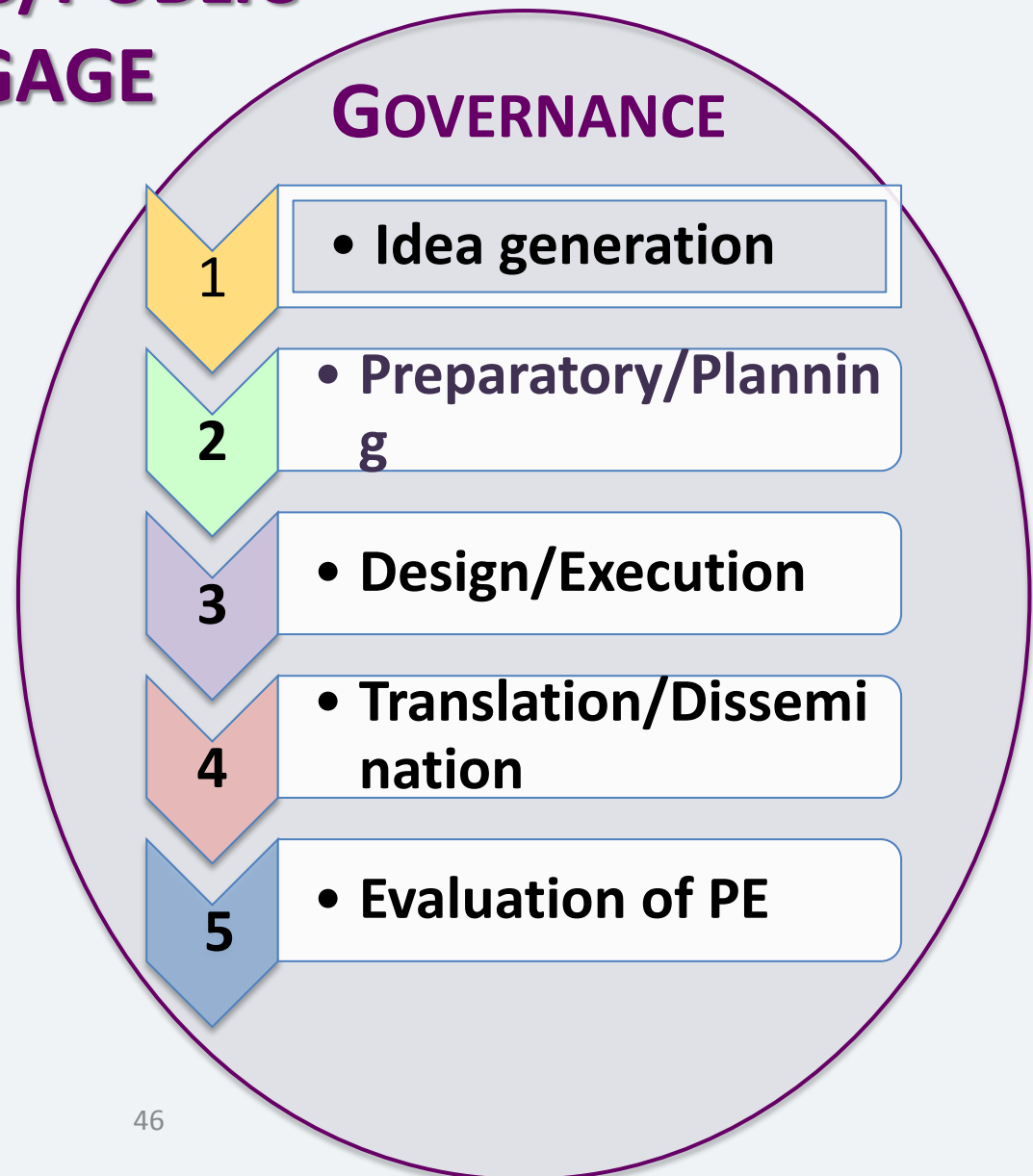


WHEN CAN PATIENTS/PUBLIC & RESEARCHERS ENGAGE

.... at any or all 4 stages and steps of the research process

+

- Governance &
- Evaluation of PE



IN GOVERNANCE



e.g. 1) PEPAC – PE Platform Advisory Council (above)

2) ICU Late Life Issues Team Grant

- ✓ Family/Public members on Project Executive Committee organized:
 - Family/Public Advisory Committee
 - Wrote terms of reference

1. IN THE “IDEA GENERATION” STAGE

e.g. Recent project in Canada found that dialysis patients/citizens rated itch as their #1 problem that needed addressing

- Researchers not aware of this concern
- Concern now communicated to researchers
- Patients/public members as **partners** on the team

2. IN THE “PREPARATORY/PLANNING” STAGE

e.g. Statement from the “BedMed” Team (2016) based on Working Group Involvement - mentored by the PE Platform

"The study plan, methods, and tools evolved with the collective experience of the Working Group. **This feedback strengthened the project design, as concepts important to patients, caregivers or potential study participants were included.** Through this process a *partnership* was established."

3. IN THE “STUDY DESIGN/EXECUTION” STAGE

“Who knew you could learn so much from your clients?”

Amirov, 2016

e.g. In 2 recent AB clinical studies patients/public members on Advisory Groups reviewed questionnaires:

-provided valuable feedback that was successfully adopted!

4. IN THE “TRANSLATION/DISSEMINATION” STAGE

e.g. AB men identified need for information about Prostate Surgery

- Involved in planning, analysis, & content

Book published!

- **print & open source**
- **in French & English**
- **> 10,000 hits!**



5. IN EVALUATING PATIENT ENGAGEMENT

✓ to add to the new **“SCIENCE” OF PATIENT ENGAGEMENT**

“What can this be?”
“Let’s inspect it and see!”
said the three blind mice.



SPECTRUM OF ENGAGEMENT IN HEALTH RESEARCH

LEVELS OF *PATIENT & RESEARCHER* ENGAGEMENT

| | LEARN/INFORM | CONSULT | INVOLVE | COLLABORATE | EMPOWER/LEAD |
|--------------------------------------|---|--|--|--|---|
| <i>Patient's Goal</i> | To suggest ideas/opinions informally To learn all I can | To more formally provide opinion/feedback | To work directly & honestly with research team | To partner on equal footing with researchers in all aspects of research | To make decisions & lead research activities |
| <i>Promise to the Patient</i> | <i>"We will respect you, hear you, & keep you informed"</i> | <i>"We will value you & seek your input"</i> | <i>"We will work directly with you"</i> | <i>"We will partner equally with you"</i> | <i>"We will follow your lead & support your decisions"</i> |
| <i>How can this be done?</i> | In an open atmosphere for sharing ideas/suggestion/knowledge | Priority-setting, cafes focus groups, working groups | Working groups, cafes, health panels | <i>Patients</i> as co-investigators & as members of Research Advisory Committees | <i>Patient</i> Advisory Committees/ <i>Patients</i> as principle investigators |

PATIENT ENGAGEMENT PLATFORM

Initiatives & Partnerships

» [Alberta Clinical Research Consortium \(ACRC\)](#)

» [Secondary Use Data Project \(SUDP\)](#)

» [Health Research Ethics](#)

» [The Alberta SPOR SUPPORT Unit](#)

» [Career Development Platform](#)

» [Consultation & Research Services Platform](#)

» [Data Platform](#)

» [Knowledge Translation Platform](#)

» [Methods Support & Development Platform](#)

» [Patient Engagement Platform](#)

» [Patient engagement resources](#)

» [Patient engagement](#)

Platform lead: [Dr. Virginia Vandall-Walker](#)

Our goal is to support meaningful engagement of patients and researchers at one or more stages across the health research process to promote patient-oriented research. The engagement of patients in health research is a growing practice in Canada. It does not refer to the inclusion of the patient as a research subject or participant, but instead is the act of patients meaningfully and actively collaborating in the governance, priority setting, conduct of research, and knowledge translation of research findings. Patients provide a unique perspective to research due to their lived experience with an illness, condition, or situation.

We are under development with a limited number of services currently available. As our capacity grows, the number of services we offer will increase.

- [Patient engagement services](#)
- [Patient engagement resources](#)

Our platform also has collaborations with:

- [The IMAGINE Project](#) – a grassroots initiative that aims to improve the healthcare system by engaging Albertans in the design and delivery of healthcare
- [Alberta Health Services](#) – recruits patient and family member advisors



Alberta
SPOR SUPPORT
Unit

[CLICK HERE TO
APPLY FOR
SERVICES](#)

Platform Initiatives



- [Patient Registry](#)
- [Alberta Depression Research Priority Setting Project](#)

More information about the Alberta SPOR SUPPORT Unit:

- [Training & events](#)
- [AbSPORU newsletter](#)
- [FAQs](#)
- [SPOR brochure](#)
- [Reports](#)
- [Platform leads](#)
- [Governance](#)

Patient/Family Registry

▼ Opportunities

| Activity | Shifts | Start | End |
|---|--------|-------|-----|
|  Communications Strategy Advisory and Working Group | 1 | | |
|  Improving Care and Outcomes of Patients with Chronic Kidney Disease | 1 | | |

Mission Statement


Welcome to the Alberta Patient/Family Registry!


Our **mission** within the Patient Engagement Platform is to promote ("spread the word!"), support ("let us help you!"), and evaluate ("are we doing this right?") patient engagement in health research in Alberta.

Our work is about building the necessary bridges together to include the patient, family and/or caregiver voice (the public perspective) in health research in Alberta.

Please fill out our **application form** (under "I would like to volunteer") in order to register with the Patient Engagement Platform. Completion of the application registers you for the Patient/Family Registry and lets us know how you want to get involved in health research in Alberta. **Signing-up with us does not obligate you to participate in research.**

I would like to volunteer

 [Fill in an application](#)

 [Log in to your account](#)

Get Social

Share this   

START ENGAGING WITH THE PE PLATFORM!

- **Web:** www.AbSPORU.ca
- **Registry:** *Your voice in health research!*
www.bit.ly/peRegistry
- **Follow Us on Social Media!**
Twitter - [@AbSPORU_PEP](https://twitter.com/AbSPORU_PEP)
Facebook - [SPOR Patient Engagement Platform](https://www.facebook.com/SPORPatientEngagementPlatform)

Final Word – A Parent's Voice

*After the briefing on the study, the answer to the question of how can I add value to the study was clear- **my voice as a parent is how I add value.** Being a part of the Letter Study makes my voice louder. It allows my voice to transcend the ears of my children's healthcare providers to ears that would otherwise never hear it; ears that have the means to create change in the delivery and management of healthcare. **Knowing that my voice is heard and can make a difference is very empowering.***

Laura Saunders, 2016

It isn't easy but it's worth it

**Great things
never came
from comfort
zones.**

ADDRESSING QUESTIONS

QUESTIONS FOR THE AUDIENCE

- What does it take for patients to see themselves as – and be seen as – “credible”?
- How can we address power imbalances?
- What types or training are needed – for whom?
- Is patient engagement threatening? To whom? What can we do about that?
- How can we work together across Canada to share knowledge and address issues?
- What other questions do you think need to be answered?