

From Patient-Oriented Research to Patient-Led Research - An Exploration from the Patient-Perspective

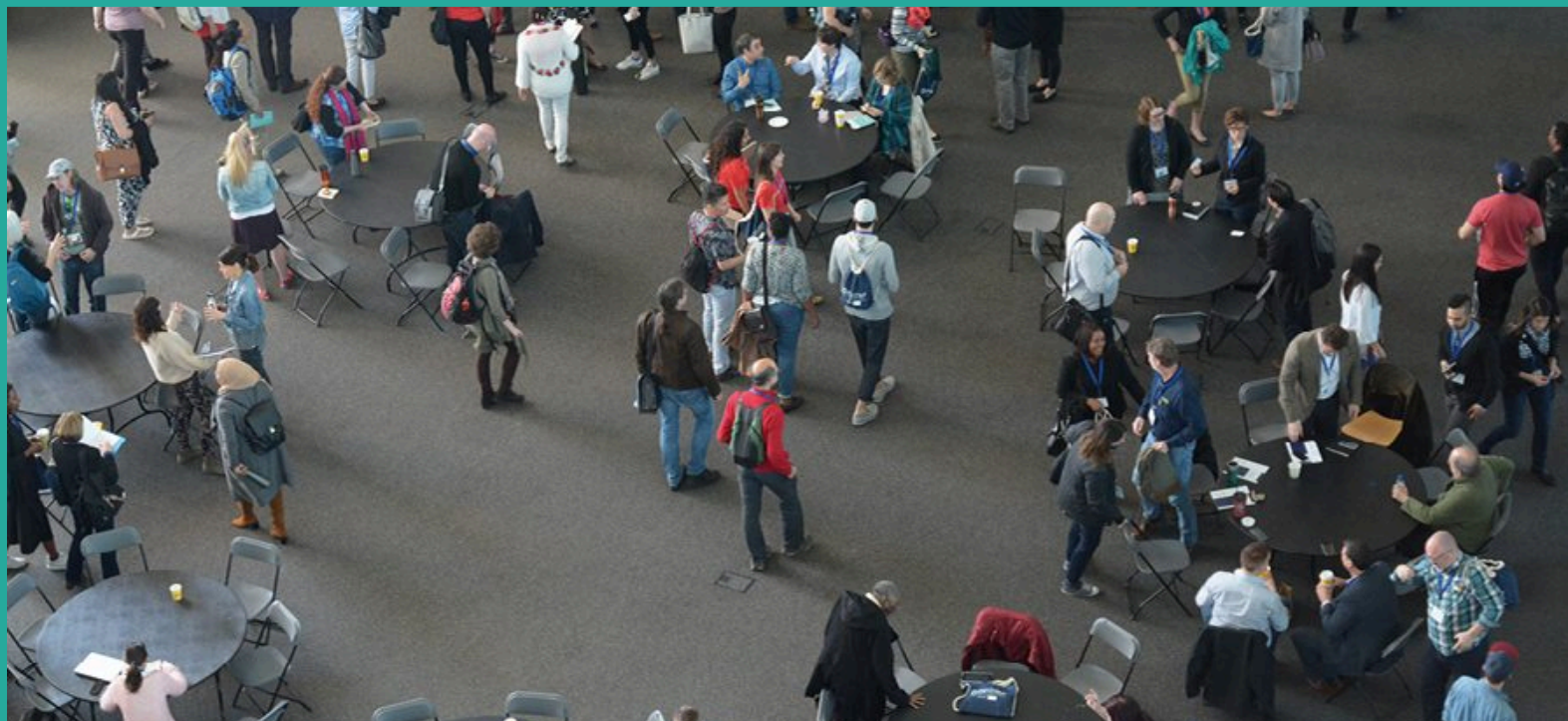
Beverley Pomeroy, May 2020

Webinar Series brought to you by
Community-Based Research Canada



Community-Based Research Canada
Recherche partenariale du Canada

About Community-Based Research Canada



www.communityresearchcanada.ca



@CbrcResearch

Presenter



Beverley Pomeroy

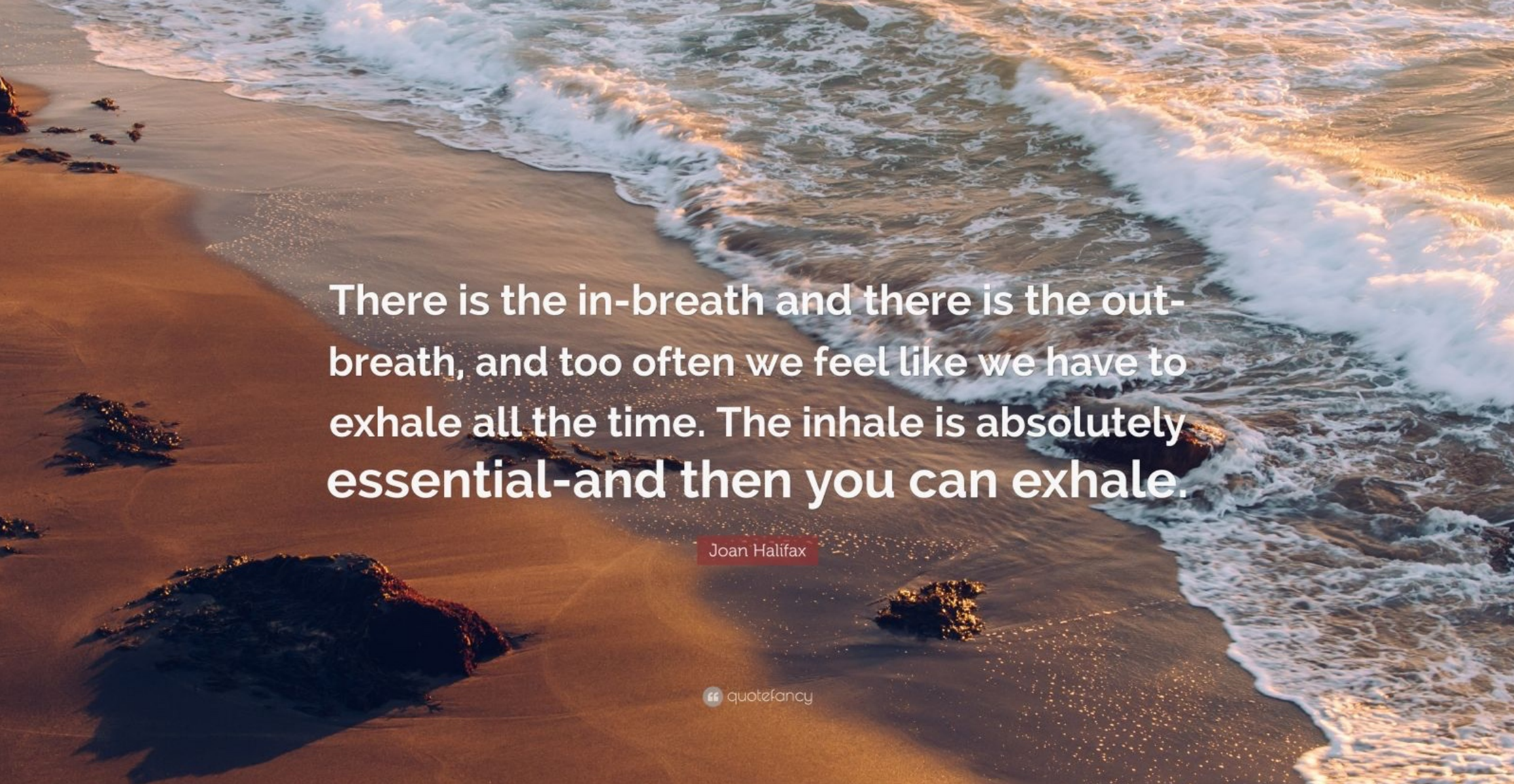
Community and Patient Engagement
Specialist and Author of Living Grief;
The Profound Journey of Ongoing Loss

Getting to know you...

1. How familiar are you with Patient-Oriented Research?
2. Do you currently collaborate with patients / public on research projects in partnership?
3. Are you here today in your professional role or as a member or patient of the community?

Today's Framework

- ▶ Personal Journey
- ▶ Patient-Oriented Research Background
- ▶ Evolution of Patient Led or Initiated Research
- ▶ Benefits
- ▶ Challenges
- ▶ Conversation



There is the in-breath and there is the out-breath, and too often we feel like we have to exhale all the time. The inhale is absolutely essential-and then you can exhale.

Joan Halifax

“ quote fancy



The Journey



The Journey



The Journey

January 1st,
2017



What is a Patient Partner

Patient Partners are community members who want to be involved in improving health care. (*Patient Voices Network / PVN*)

- Patient partners have extensive experience either as a patient, family member or caregiver
- Ideally, array of backgrounds and experiences
- Seek meaningful involvement
- All of them are passionate about improving the quality of care





Patient Partner Opportunities

Patient Partner 'Hiring' Process



Patient Engagement Movement

“**Nothing about me
without me.**”

- A moral argument that patients have the right to be involved in decisions that affect them.
- Shifting from being passive recipients of care, to active partners and informed decision makers
- Social movement considering in Canada we do have a social health care system funded by tax dollars

Patient- Oriented Research



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, caregivers, and health care providers

Foundations of SPOR



Patient-oriented research is not only about improving the way research is done but is fundamentally about improving health care policies and practices across the system, and ultimately, health outcomes. As a result, patient-oriented research requires the engagement of a wide range of stakeholders.

SPOR is the result of extensive engagement with patients and caregivers, researchers and their institutions, health professionals, policy makers, charities, and the private sector. **SPOR is about changing the culture of health care in Canada**

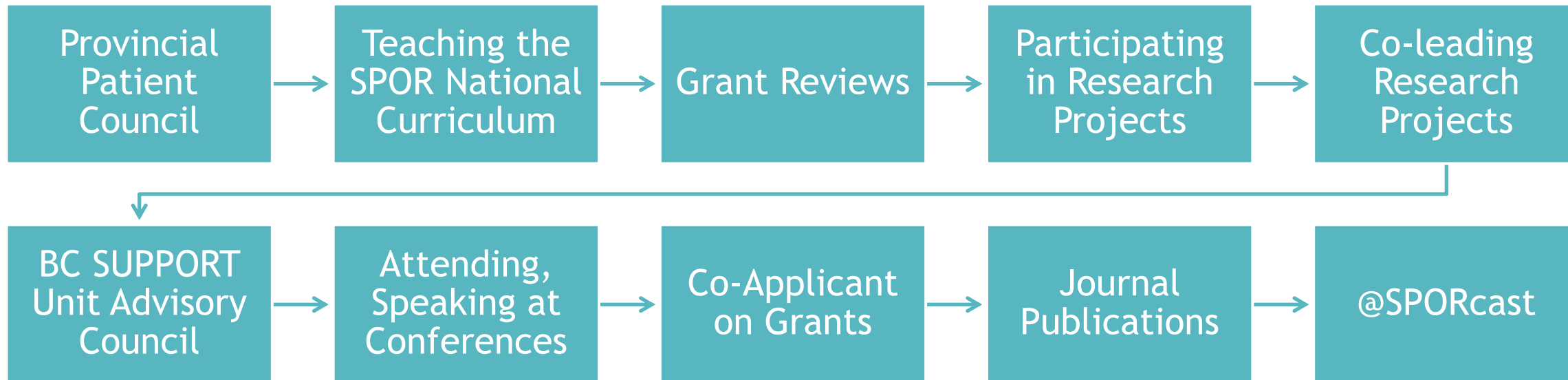
Patient-Oriented Research

- Providing services to stakeholders: patients, researchers, health care providers and health system decision makers
- Facilitating initiatives identified as provincial priorities



BC SUPPORT Unit
Advancing Patient-Oriented Research





Examples of POR Engagement

Evolution to Patient Initiated Research

Family Caregiver

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graph TD; A[Family Caregiver] --> B[Patient Partner in Healthcare]; B --> C[Patient Partner in Patient-Oriented Research];
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The diagram illustrates a three-stage evolution. It begins with 'Family Caregiver' in a teal box. A downward arrow points to 'Patient Partner in Healthcare' in a darker teal box. A second downward arrow points to 'Patient Partner in Patient-Oriented Research' in a green box. The boxes are arranged in a descending staircase pattern from top-left to bottom-right.

Patient Partner in Healthcare

Patient Partner in Patient-Oriented Research



So now what...

Intersection of Trauma and Grief



Family caregivers can experience anxiety, distress, and depression at levels greater to or equal than patients

(Huang presentation - Palos et al, 2011)



20-30% of care partners experience post traumatic stress symptoms

(Huang presentation-Posluszny, et al 2015)



Only 5% of parents who had lost their child continued to function steadily well.

(Frank J. Infurna and Suniya S. Luthar, 2017)



Bereaved parents, on average, report poorer psychological well-being even many years after child loss

(Floyd et al., 2013; Lehman et al., 1987; Rogers et al., 2008; Wijngaards-de Meij et al., 2005).

My Community Wants to Know...



What are the events or elements of care needs over the trajectory of a child with a serious illness that create a traumatic stress response in parents as caregivers.



What are the symptoms and how do we recognize and better screen for them even if those symptoms don't necessarily meet the 'diagnosis' of PTSD



What can we learn from trauma informed practice to support and intervene in ways that are accessible to parents who are parenting a complex child and / or during bereavement to assist with adapting to loss.

Fraser Health and Simon Fraser University 4th Research Pitching Day



What is the purpose of this event?

This half-day event of presentations and activities is aimed at building new research collaborations between Fraser Health, Simon Fraser University, and the community. This event is intended to bring these groups together to foster new collaborations through the presentation of research “pitches” across the divide between research, policy, and practice.

The Ask



Community Partner



Mentorship



Research Assistance



\$\$\$\$\$

The Give



MY NARRATIVE



ACADEMIC
PARTNER(S)

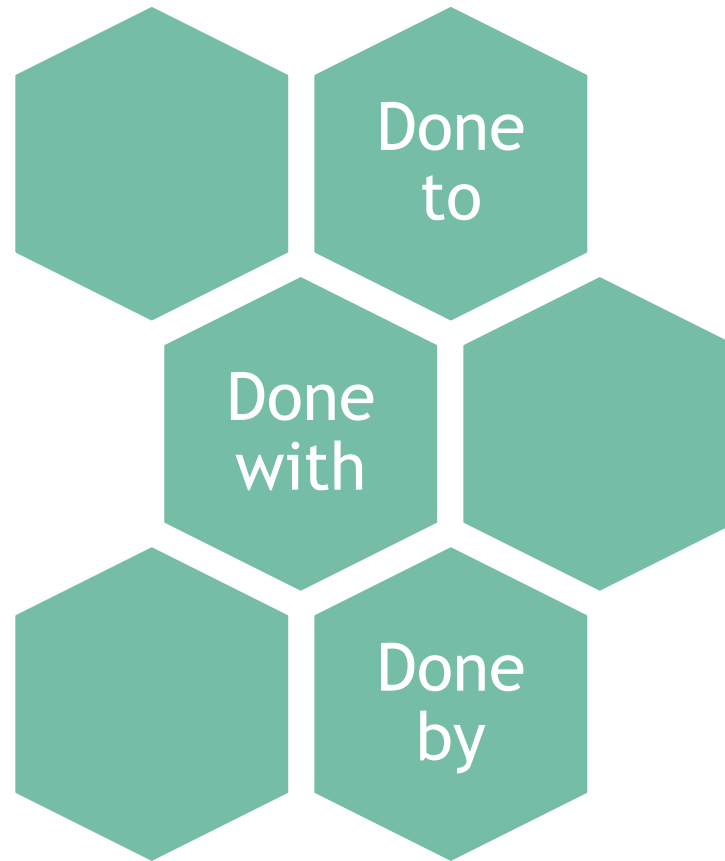


INITIAL GRANT
FUNDING OF \$5,000
(TBA SPRING 2020)

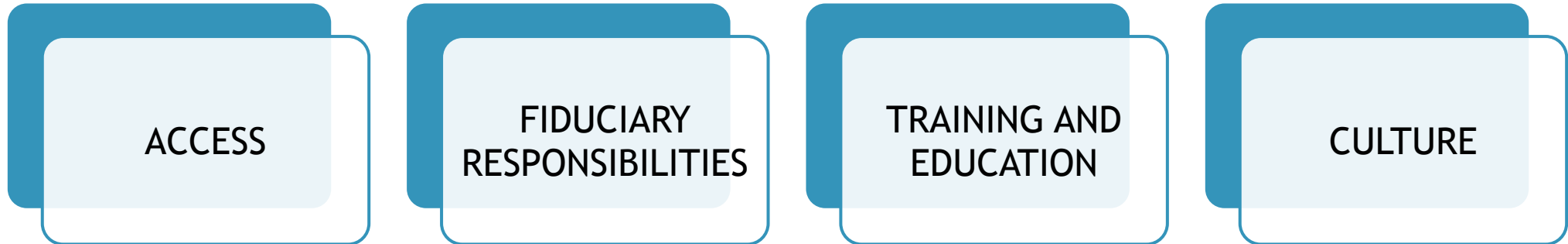


DIRECT ACCESS TO
MY COMMUNITY
(PAN-NATIONAL)

Patient Initiated Research



Patient-Initiated Research Challenges



Challenge #1: Access



Library Services

As a non-academic, no affiliation I can't get a university library card, university access
No affiliation with an NGO creates barriers (access services and supports)



Publications

Behind paywalls
BMJ just opened up their publications



REDcap, Popdata, etc

Challenge #2: Fiduciary Responsibilities



Access to Funding Grants



Holding / Dispensing Funds

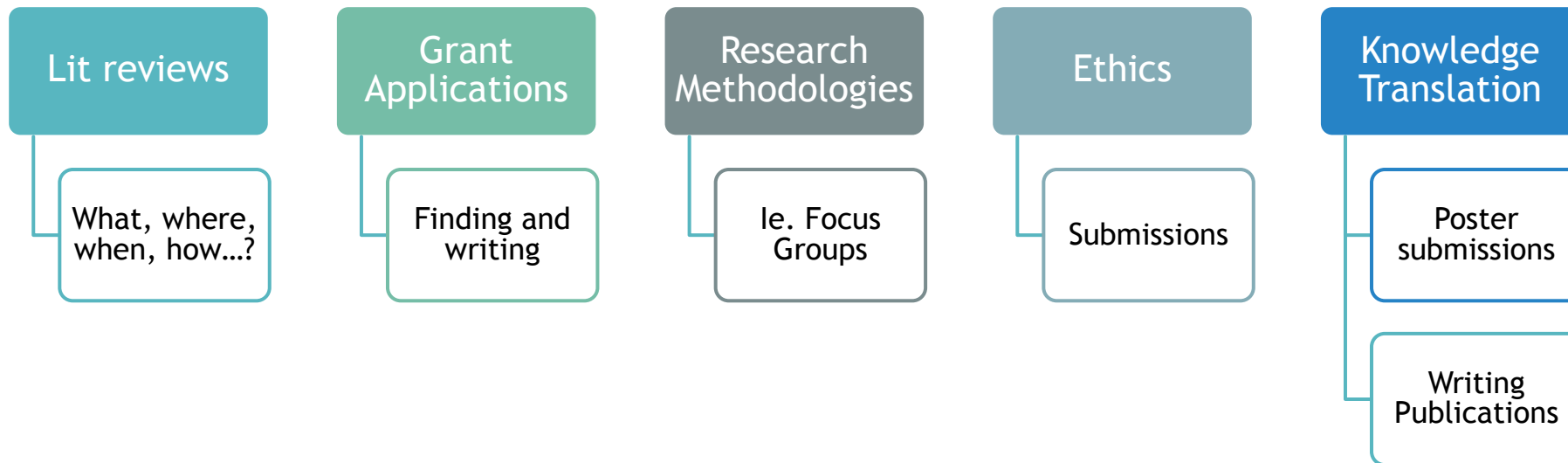


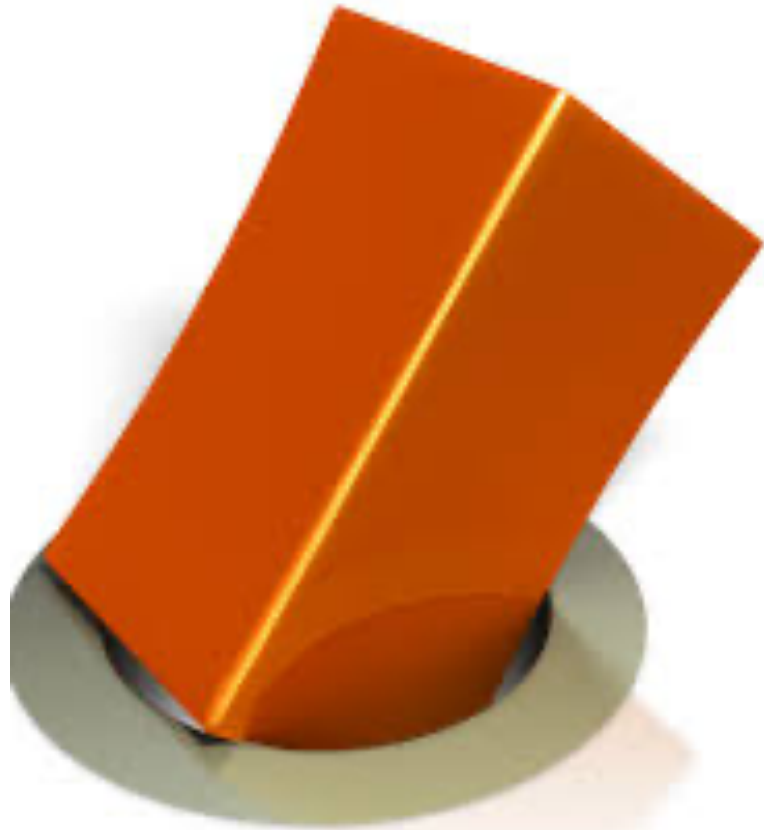
Resources to do Research (hiring a Research Assistant, paying for publications, submitting abstracts / cost of attending events, time)



Accountability (includes quality of research)

Challenge #3: Training and Education





Challenge #4: Culture

- ▶ Understanding assumptions, bias
- ▶ Power dynamics (long standing in healthcare)
- ▶ Traditional Research

Current 'Patient' Researchers

- ▶ Claire Snyman - Patient Initiated
- ▶ The impact of surgical resection on headache disability and quality of life in patients with colloid cyst





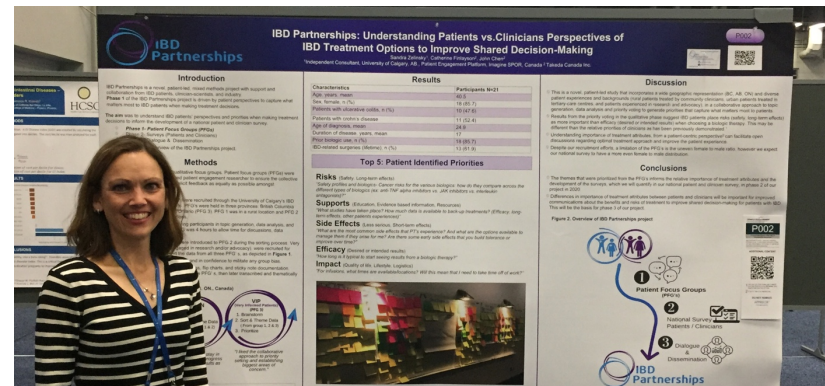
Current 'Patient' Researchers

- ▶ Lisa Ridgway and Chad Dickie - Patient Initiated
- ▶ Does SPOR Mean M.O.R.E. - More Opportunities for Research Engagement?"

Current 'Patient' Researchers

► Sandra Zelinski - Leading 3 studies

► IBD Partnerships: Understanding Patient vs. Clinician Perspectives of IBD Treatment Options to Improve Shared Decision-Making



Organizations Supporting Patient Led / Initiated Research

- Patient and Community Engagement Research (PaCER) unit at the O'Brien Institute for Public Health (University of Calgary)

PaCERs are patient researchers, citizens with a variety of health conditions trained in qualitative health research, who are creating a new collective research voice *by patients, with patients and for patients.*



Organizations Supporting Patient Led / Initiated Research

- **The Patient Led Research Hub (PLRH)**

Established in 2015 by members of the Cambridge Clinical Trials Unit ([CCTU](#)) from the University of Cambridge and the Cambridge University Hospitals NHS Foundation Trust



A decorative graphic on the left side of the slide consists of several thick, colorful ribbons in shades of yellow, pink, blue, green, red, and black, which are intertwined and knotted together. The ribbons appear to be made of a soft, felt-like material. The background of the slide is white, with blue geometric shapes on the right side and a blue vertical bar on the left.

Value of Patient Initiated Research

(anecdotal)

- ▶ Provides Sense of Purpose and Belonging (shared)
- ▶ Focuses on Patient-Identified Priorities
- ▶ Improves Patient Outcomes (as defined by patients)
- ▶ Built in Narrative
- ▶ Access to Patient Community
- ▶ Knowledge Dissemination
- ▶ Fosters Inclusivity (including shared leadership and decision-making)
- ▶ Better Engages Under-Represented / Diverse Community
- ▶ Builds Capacity
- ▶ Mitigates tokenism

Towards an Institute of Patient-Led Research

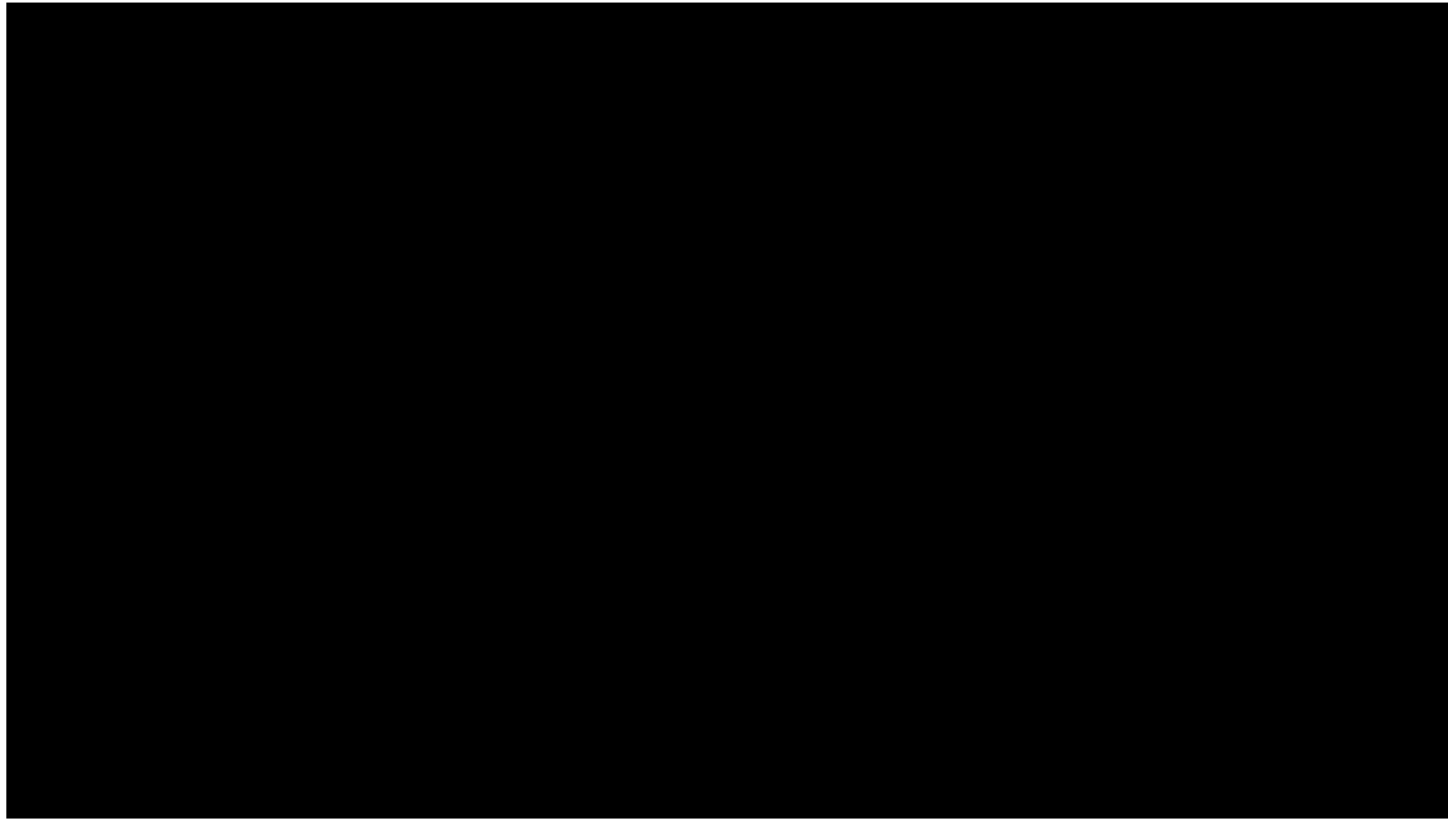
(Dr. Trish Greenhalgh)

- ▶ **Transformative involvement of patients: a question of power**
 - ▶ *transformative* involvement (to enable citizens to influence their own destiny)
 - ▶ models of patient-led research that address fundamental questions about who holds the power and sets the agenda in research.
- ▶ **A different kind of knowledge**
 - ▶ patients bring experiential knowledge—the subjective, lived-body knowledge of *what it is like to live with* a particular illness or condition
 - ▶ collective knowledge generated by online communities
- ▶ **Governing patient-led research: scientific rigour and ethics**
 - ▶ ensure that patient-led research is scientifically defensible (and hence has credibility with clinicians and policymakers)
- ▶ **The productive role of conflict**
 - ▶ conflicts generated when patients' experiential knowledge meets conventional research paradigms not only *informs* the wider research agenda but *transforms* conventional researchers into more creative scientists who prioritise different questions and study them in imaginative and flexible ways.



Where to
from here...

“The only way to discover the limits of the possible is to go beyond them into the impossible.” -Arthur C. Clarke





Thank You...

Resources Available On Request

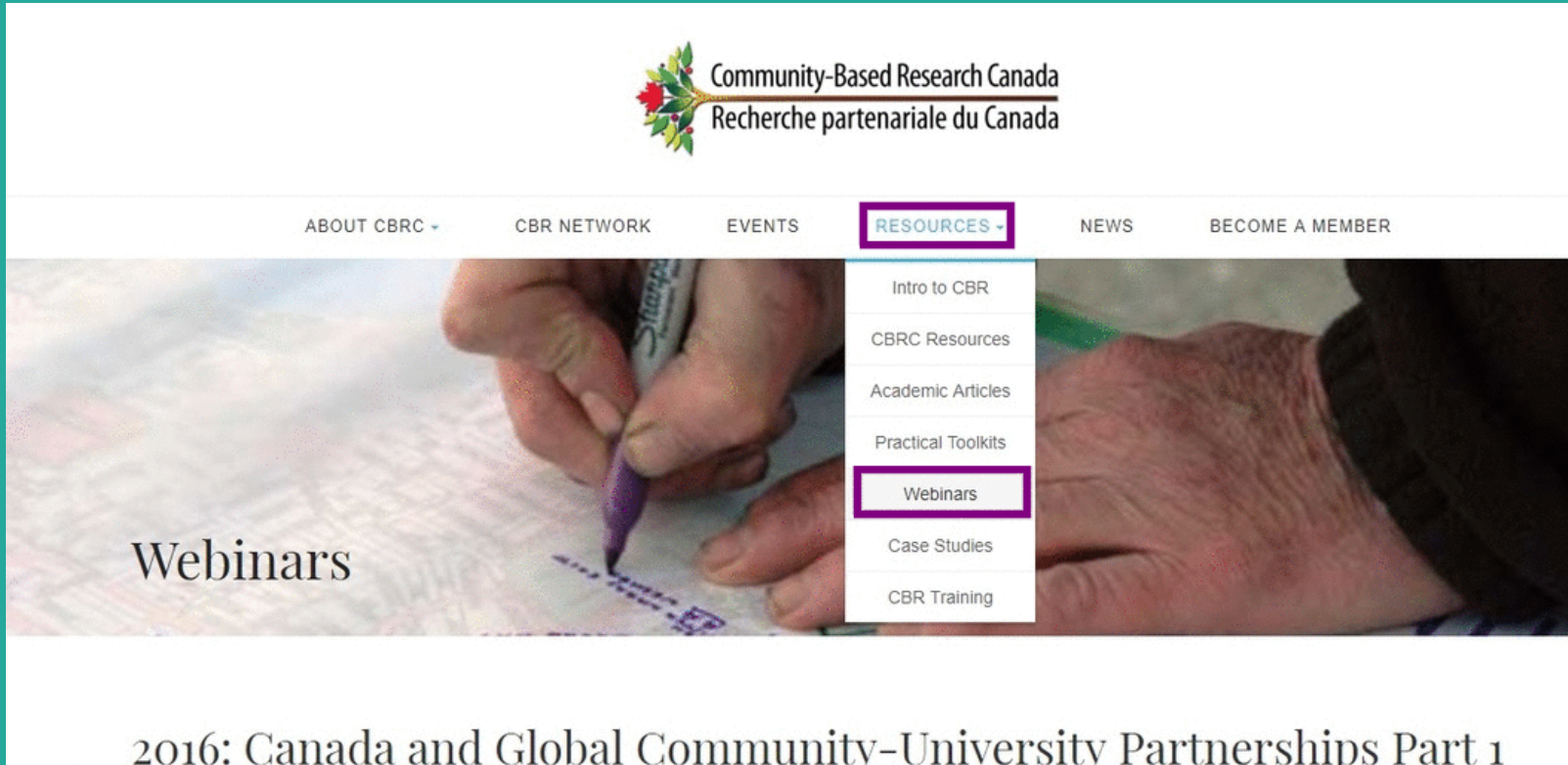
Contact: Beverley Pomeroy

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[@beverleypomeroy](https://www.instagram.com/beverleypomeroy)

Webinar Recordings



The image is a screenshot of the Community-Based Research Canada website. At the top center is the logo, which consists of a stylized tree with red and green leaves next to the text "Community-Based Research Canada" and "Recherche partenariale du Canada". Below the logo is a navigation bar with the following items: "ABOUT CBRC -", "CBR NETWORK", "EVENTS", "RESOURCES -", "NEWS", and "BECOME A MEMBER". The "RESOURCES -" item is highlighted with a purple box. A dropdown menu is open under "RESOURCES -", listing the following items: "Intro to CBR", "CBRC Resources", "Academic Articles", "Practical Toolkits", "Webinars", "Case Studies", and "CBR Training". The "Webinars" item is highlighted with a purple box. Below the navigation bar is a large banner image showing hands writing on a map. The word "Webinars" is written in a serif font on the left side of the banner. Below the banner, the text "2016: Canada and Global Community-University Partnerships Part 1" is displayed.

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ABOUT CBRC - CBR NETWORK EVENTS **RESOURCES -** NEWS BECOME A MEMBER

Intro to CBR
CBRC Resources
Academic Articles
Practical Toolkits
Webinars
Case Studies
CBR Training

Webinars

2016: Canada and Global Community-University Partnerships Part 1

www.communityresearchcanada.ca/webinars

More Ways to Get Involved With CBR Canada



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CBRC's Webinar Series CBRC's Webinar Series

CBRC Webinars

Part 1: The Canadian Perspective Part 2: The International Perspective



SFU SIMON FRASER UNIVERSITY

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you think!"



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from the Patient-Perspective

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press Enter ↵



Thank You!

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