Michael Smith Health Research BC
BC SUPPORT UNIT
Fraser Centre

Introduction to Patient-Oriented Research

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Knowledge Translation Specialist

August 2023

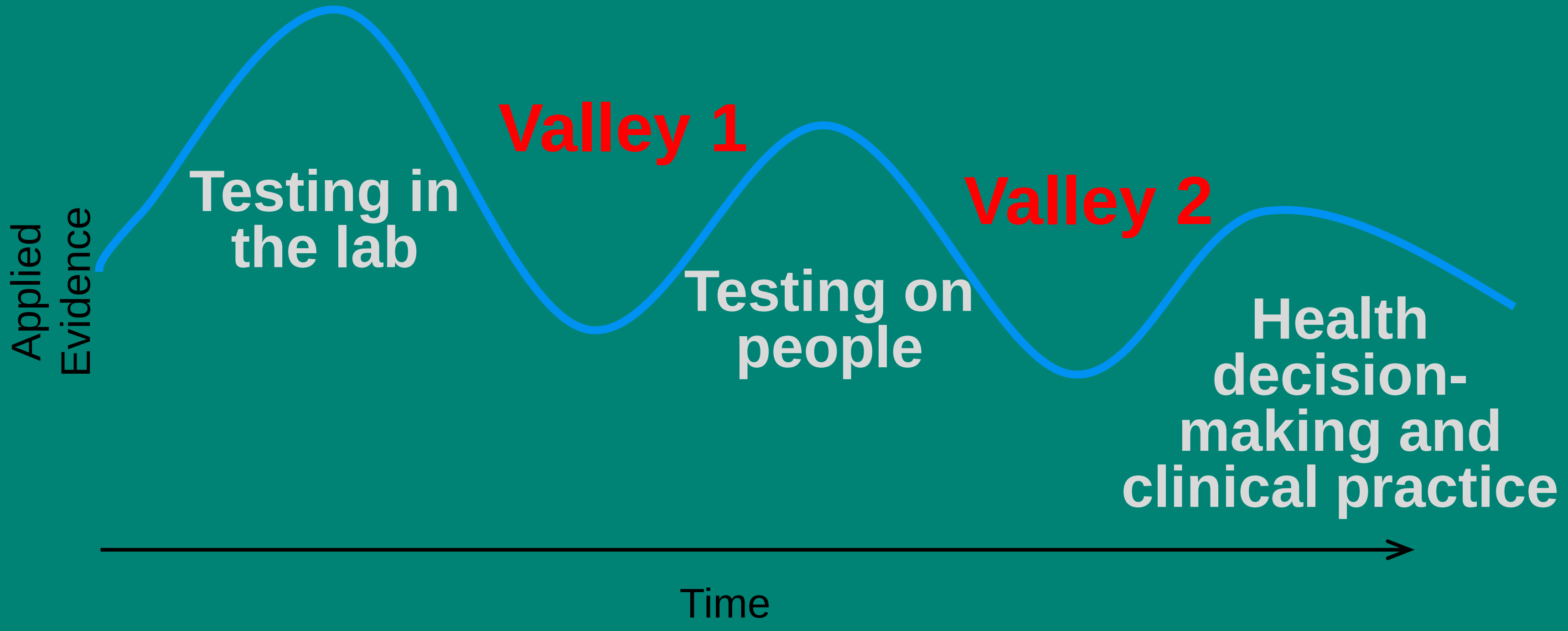
Agenda

- What is SPOR and the BC SUPPORT Unit?
- What is Patient-Oriented Research (POR)?
- Examining POR and CBPR core principles
- What is patient engagement?
- How Fraser Centre supports POR

Learning Objectives

- Acquire foundational knowledge about POR and articulate why it is beneficial to involve patients in health research
- Describe the various levels of engagement as outlined by the International Association of Public Participation (IAP2)
- Identify available tools and resources that will support conduct of POR

The health research-to-practice continuum



Valley 1

Valley 2

Testing in the lab

Testing on people

Health decision-making and clinical practice

Applied Evidence

Time

Figure adapted from: *Canada’s Strategy for Patient-Oriented Research.* Canadian Institutes of Health Research, 2011.

Which leads to…

30-45% patients don’t receive care based on scientific evidence

(Graham et al., 2006)

Strategy for Patient-Oriented Research

SPOR

Putting Patients First

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.

What is a SUPPORT Unit?

- SUPPORT (**Su**pport for **P**eople and **P**atient-**O**riented **R**esearch and **T**rials) Units are provincial elements of Canada's national Strategy for Patient-Oriented Research (SPOR)
- BC SUPPORT Unit is 1 of 10 SPOR-funded SUPPORT Units across Canada

BC SUPPORT Unit Fraser Centre

Simon Fraser University

Fraser Health

BC SUPPORT Unit: Our Work

We bridge the gap between research evidence and health care practice by:

- Providing patient-oriented research support services
- Strengthening and maintaining BC's capacity in patient-oriented research
- Engaging stakeholders as active partners in both research and its use in health care practice and policy

https://healthresearchbc.ca/bc-support-unit/about-us/

The patient engagement movement

1970s

Today

Patients as partners in their care, making informed, shared decisions

Patients self-managing their health

Patients as advisors in health system quality improvement

Communities & patients as partners in health research

Patient engagement in health research

Building on a history of community-based, participatory research

“At its core community-based research is

- ✓ collaborative
- ✓ concerned with equity
- ✓ involves community and university scholars as equal partners, and
- ✓ combines knowledge with action usually to achieve social change

The intent in CBR is to transform research from a relationship where researchers *act upon* a community to answer a research question to one where researchers *work side by side* with community members”

Community-Based Participatory Research. (2006). Examining community-institutional partnerships for prevention research group: Developing and sustaining community-based participatory research partnerships: A skill-building curriculum.

What is patient-oriented research?

- Engages patients as **partners** (*not participants*)
- Focuses on **patient-identified priorities**
- Improves patient **outcomes** (as defined by patients)
- Aims to **apply knowledge** generated to improve health care systems and practices
- Conducted by **multidisciplinary teams** in partnership with stakeholders

Who is a patient?

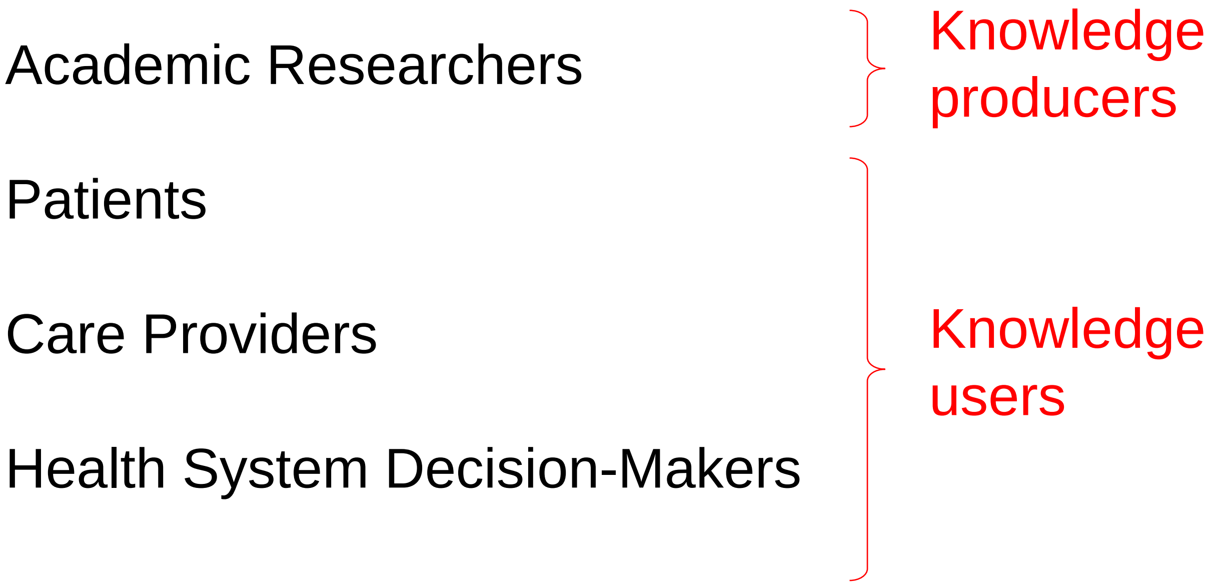
Research done **with** and **by** patients… Not **for**, **on**, or **about**.

Who's a patient?

Any person that has experienced a health care issue or the health care system, including informal caregivers, family, friends, etc.

Patient isn't always the right word!

Traditional Research Model



Academic Researchers

Patients

Care Providers

Health System Decision-Makers

Knowledge producers

Knowledge users

Patient-Oriented Research Model

Academic Researchers

Patients

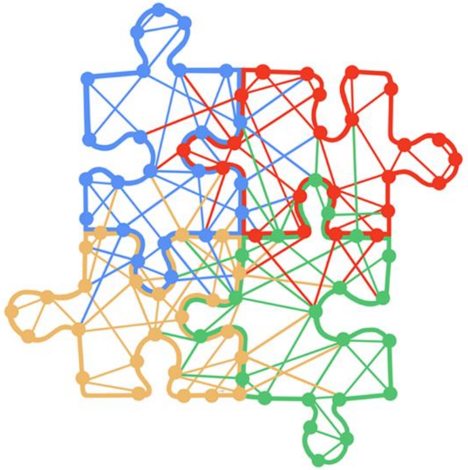
Care Providers

Health System Decision-Makers

Knowledge
producers & users

Individuals with a personal experience of a health issue relevant to the focus of the research

What Matters to Patients?



Anecdotally…

- Being heard.
- Real improvements to the health care system for those that come after them.
- Better health outcomes and experiences.

Answering questions that matter to patients is only half the battle. Patients need to see the benefit!

Why engage patients?

Benefits of patient engagement in health research

- Relevance
- Quality
- Greater impact on the lives of patients and the health care system
- Leads to more **ethical** research
- **Fostering inclusive mechanisms and processes** (including shared leadership and decision-making)
- Multi-way **capacity building**
- Multi-way **communication and collaboration**
- Experiential knowledge valued as evidence, and mobilized and translated for impact
- Patient-informed and directed research
- A **shared sense of purpose**

[CIHR, 2019]

Literature evidence for the need of patient engagement in health research

doi: 10.1111/j.1369-7625.2012.00795.x

Mapping the impact of patient and public involvement on health and social care research: a systematic review

Jo Brett MSc MA BSc(hons),* Sophie Staniszewska DPhD BSc(hons),* Carole Mockford DPhil MA BSc(hons),* Sandra Herron-Marx PhD BA DPSN RGN,* John Hughes,† Colin Tysall‡ and Rashida Suleman‡

*Royal College of Nursing Research Institute, School of Health and Social Studies, University of Warwick, Coventry, UK, †Patient Partner from UKCRC, London, UK and ‡Patient Partners from University/Users Teaching and Research Action Partnership (UNTRAP), University of Warwick, Coventry, UK

Domecq et al. BMC Health Services Research 2014, 14:89
http://www.biomedcentral.com/1472-6963/14/89
BMC
Health Services Re
RESEARCH ARTICLE Open Access

Original Research

Journal of Health Services Research & Policy
2018, Vol. 23(3) 158–167
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1355819618762960
journals.sagepub.com/home/hsr
SAGE

What constitutes meaningful engagement for patients and families as partners on research teams?

Agnes Black[1], Kimberly Strain[2], Christine Wallsworth[2], Sara-Grey Charlton[3], Wilma Chang[4], Kate McNamee[3] and Clayon Hamilton[5,6]

Abstract

Objective: There is growing emphasis on health care organizations to ensure that lay people are meaningfully engaged as partners on research teams. Our aim was to explore the perspectives of patients, family members and informal caregivers who have been involved on health care research teams in Canada and elicit their recommendations for meaningful engagement.

Methods: We conducted a qualitative study guided by thematic analysis of transcripts of focus groups and interviews of 19 experienced patient research partners in Canada.

Results: We identified four main themes: research environment, expectations, support and value, which highlight participants' combined perspectives on important factors to ensure their engagement in research is meaningful.

Domecq et al. BMC Health Services Research 2014, 14:89
http://www.biomedcentral.com/1472-6963/14/89

BMC
Health Services Research

RESEARCH ARTICLE **Open Access**

Patient engagement in research: a systematic review

Juan Pablo Domecq[1,2,5], Gabriela Prutsky[1,2,5], Tarig Elraiyah[1,5], Zhen Wang[1,5,6], Mohammed Nabhan[1,5], Nathan Shippee[1,5,6], Juan Pablo Brito[1,4,5], Kasey Boehmer[1,5], Rim Hasan[1,5,8], Belal Firwana[1,5,8], Patricia Erwin[1,7], David Eton[1,5,6], Jeff Sloan[1,5,6], Victor Montori[1,2,4,5,6], Noor Asi[1,5], Abd Moain Abu Dabrh[1,5] and Mohammad Hassan Murad[1,3,5,6*]

Patient and service user engagement in research: a systematic review and synthesized framework

Nathan D. Shippee PhD,* Juan Pablo Domecq Garces MD,†‡ Gabriela J. Prutsky Lopez MD,†§ Zhen Wang PhD,¶ Tarig A. Elraiyah MBBS,† Mohammed Nabhan MD,†,** Juan P. Brito MBBS,†† Kasey Boehmer BA,‡‡ Rim Hasan MD,§§ Belal Firwana MD,§§ Patricia J. Erwin MLS,¶¶ Victor M. Montori MD, Msc***,††† and M Hassan Murad MD, MPH***,‡‡‡

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

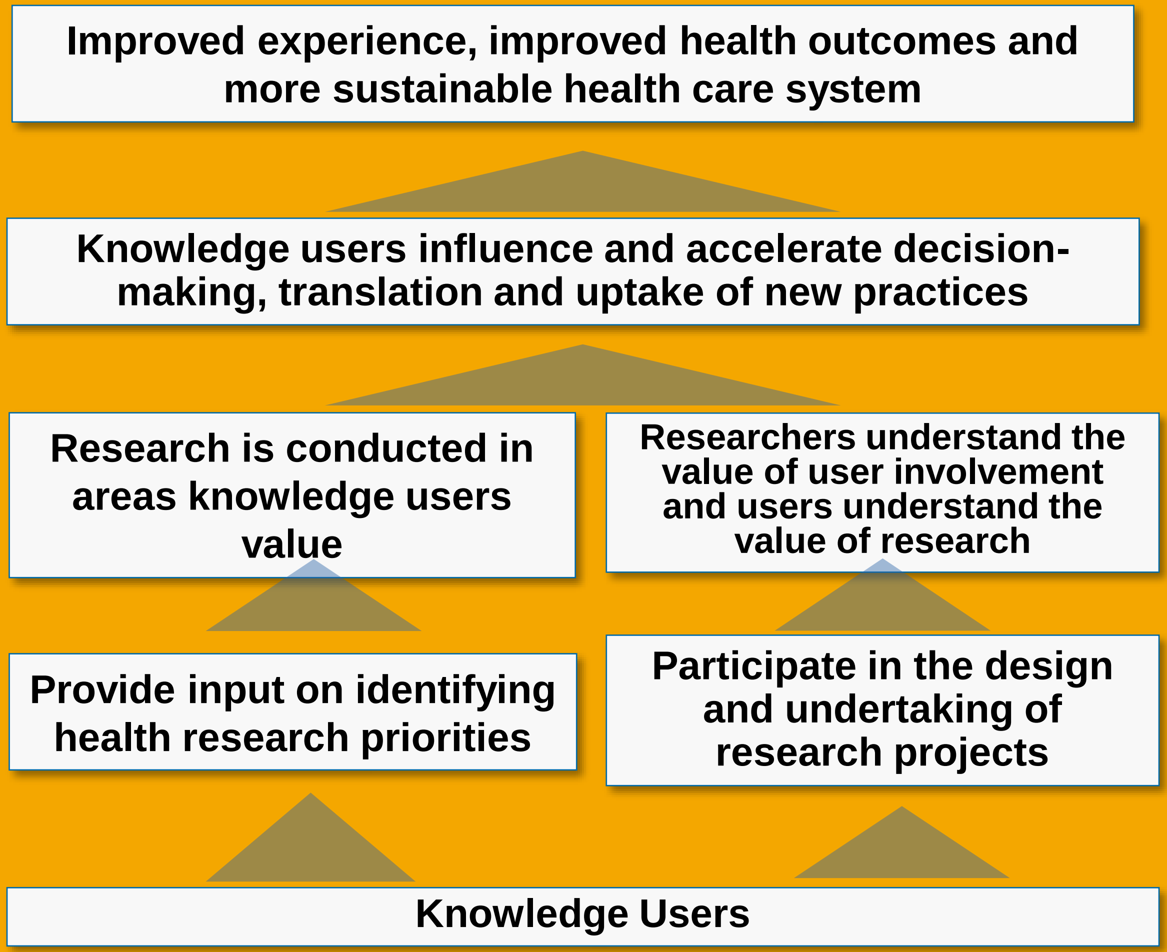
SPOR Patient Engagement Framework Guiding Principles:

- Inclusiveness
- Support
- Mutual respect
- Co-build

"It's the feeling that you're having an impact…your voice and perspective matter and can influence decisions."

Patient research partners feel equally important and are given recognition and respect.
(Hamilton CB, et al. 2017)

"It's knowing that the work we do together is going to make a real difference in the lives of patients and families."



Improved experience, improved health outcomes and more sustainable health care system

Knowledge users influence and accelerate decision-making, translation and uptake of new practices

Research is conducted in areas knowledge users value

Researchers understand the value of user involvement and users understand the value of research

Provide input on identifying health research priorities

Participate in the design and undertaking of research projects

Knowledge Users

Adapted from figure from: Canadian Institutes of Health Research website, 2014.
http://www.cihr-irsc.gc.ca/e/45851.html

For Example: Spinal Cord Injury Research

- Researcher with lived experience of a spinal cord injury (SCI)

- Majority of research focused on walking, but she knew (anecdotally) that walking wasn’t the main priority for most patients

- Surveyed ~700 people with SCI:
  - Bowel care
  - Sexual function
  - Hand function

Anderson K., 2004, ‘Targeting recovery: Priorities of the spinal Cord-Injured population’, Journal of Neurotrauma21(10), 1371–1383.

Where to start? Create an engagement plan!

WHO have you engaged with or plan to engage with?

WHY those people?

WHAT will they contribute to the project once they’re engaged?

HOW will you initiate an engagement with them?

Who to engage?

- Who is the research about? Who might find your research relevant in their life or work?
- Will anyone be personally impacted by your methods or findings?
- Who do you need on board to make sure the research happens?
- Do you need financial or in-kind support from anyone?
- Do you need access to people or data?
- Are your patient project partners representative of your population? Who’s missing?

Why engage with those people?

- Are you answering a question that matters to knowledge users?
- Are you using language that’s appropriate for your population?
- Grant applications and administrative approvals may require some level of engagement
- Feedback on feasibility, scope, timelines, etc.
- Do you need anyone to help you with recruitment and do they have capacity for your project?
- Is the population appropriate for your research question?
- Who’s missing from your recruitment strategy?

How will you engage with them?

- Different approaches for different contexts – always ask, don’t assume
- Individual team members, steering committees, advisory groups, public campaigns, etc.
- More than one patient partner is best practice

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

International Association for Public Participation

What will they contribute?

- Always describe the whole project and **ask** what interests them
- People are more than their lived experience of a certain topic
- Terms of reference and setting expectations
- Regular updates & open communication

How do we see engagement?

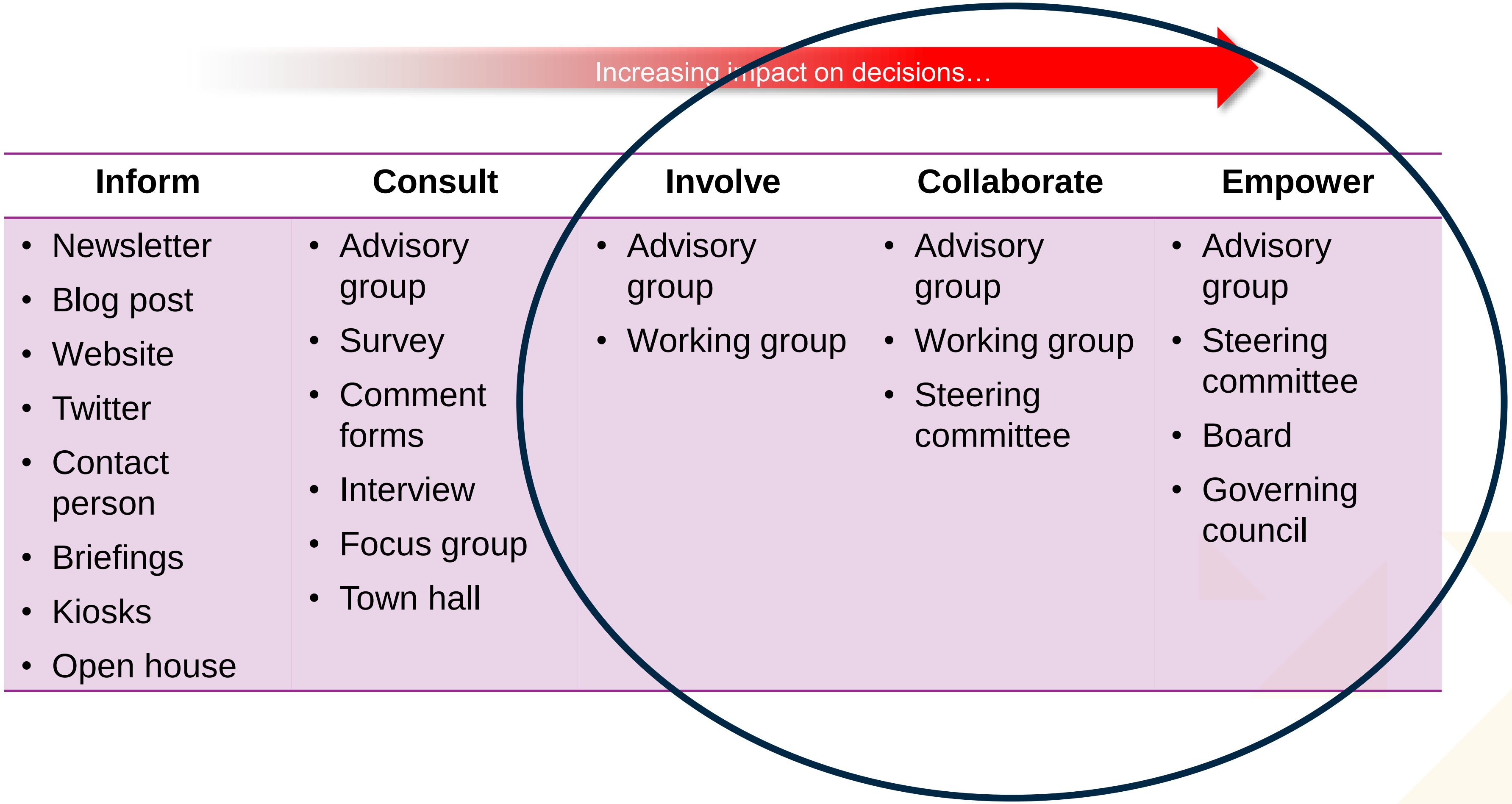
“Meaningful and active collaboration” (CIHR)

“Research done differently” (PCORI/US)

“**Research by and with…not on, for, or about**” INVOLVE/UK)

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

Methods of engagement



Increasing impact on decisions…

Inform	Consult	Involve	Collaborate	Empower
• Newsletter • Blog post • Website • Twitter • Contact person • Briefings • Kiosks • Open house	• Advisory group • Survey • Comment forms • Interview • Focus group • Town hall	• Advisory group • Working group	• Advisory group • Working group • Steering committee	• Advisory group • Steering committee • Board • Governing council

Roles & Responsibilities

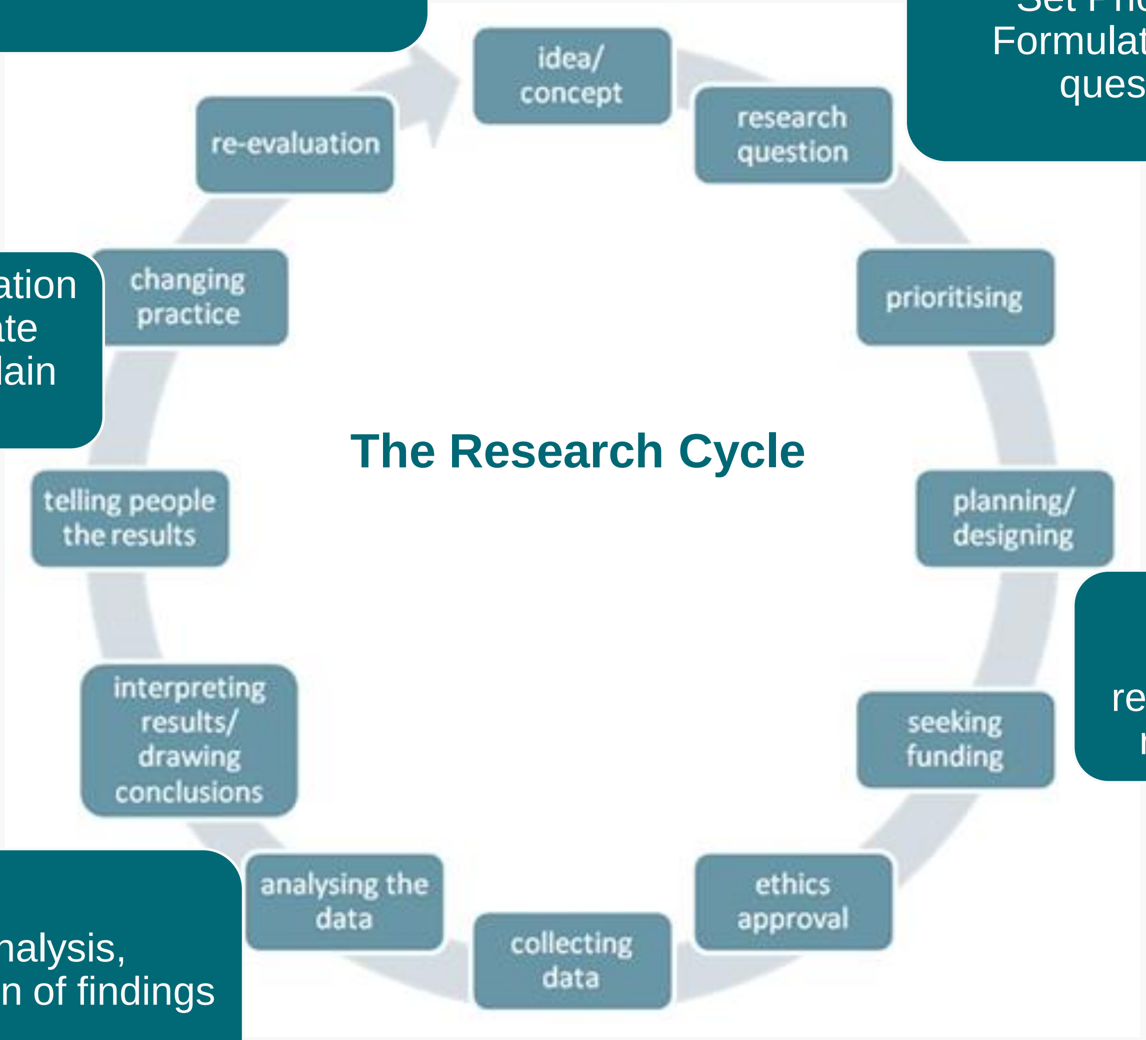
Help develop practice guidelines, evaluation

Set Priorities, Formulate study question

Design implementation activities, translate documents into plain language

Identify study population, recruitment, choosing relevant outcomes

Data analysis, Interpretation of findings



Questions to consider…

- Meet people where they are at:
  - What kind of health research knowledge or literacy?
  - What additional reading materials are needed?
  - **Do you have a point person on your team for patient partners?**
  - Preferred method of communication?
  - What are the roles and responsibilities for all team members?
  - How often do you check-in with patient partners?
  - Ongoing support and evaluation

BC SUPPORT Unit Fraser Centre has a PE Planning Template

Overcoming Challenges

Additional Resources

- Build into grants and timelines
- Reimbursement & compensation
- Engagement takes time and effort

Power Dynamics

- Built into methodological approaches for engagement (POR, CBR, co-design, etc.)
- Look to experienced mentors for support

Tokenism

- Consider WHY you are engaging
- Meaningful, culturally safe, representative engagement
- Mutual learning and collaboration

Conflict Prevention and Resolution

Prevention

- Terms of reference or partnership agreement
- Create an environment where everyone is heard and feels heard
- Open and continuous communication
- Building and maintaining relationships
- Team building exercises

Resolution

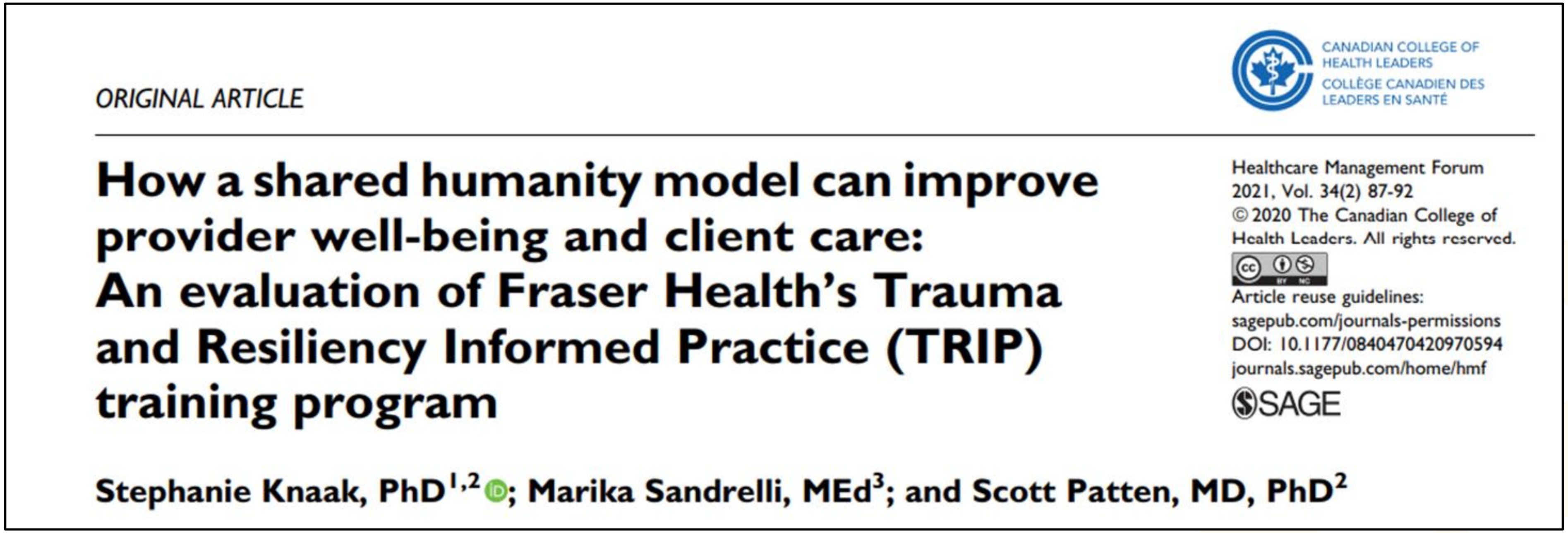
- Check in regularly to catch things before they bubble up
- Act early when an issue arises
- Go back to your terms of reference and partnership agreements
- Neutral third party to adjudicate (not your boss!)
- May need to find another opportunity for someone

Engaging with Indigenous Peoples in a Research Context

- Historical harms caused by a colonial research enterprise
- Engagement is not optional
- Research generation should come from the community, supported by others as needed
- OCAP® Principles
- BC Network Environment for Indigenous Health Research
- https://onlineacademiccommunity.uvic.ca/bcneihr/resources-1/

Trauma and Resiliency Informed Practice …in a Research Context

- Reliving trauma on a volunteer basis
- Ask about comfort level with sharing
- Dual roles – what can you share? What is data and what is not?
- Bring compassion for yourself and others



ORIGINAL ARTICLE

CANADIAN COLLEGE OF HEALTH LEADERS
COLLÈGE CANADIEN DES LEADERS EN SANTÉ

How a shared humanity model can improve provider well-being and client care: An evaluation of Fraser Health's Trauma and Resiliency Informed Practice (TRIP) training program

Healthcare Management Forum
2021, Vol. 34(2) 87-92
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DOI: 10.1177/0840470420970594
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SAGE

Stephanie Knaak, PhD[1,2]; Marika Sandrelli, MEd[3]; and Scott Patten, MD, PhD[2]

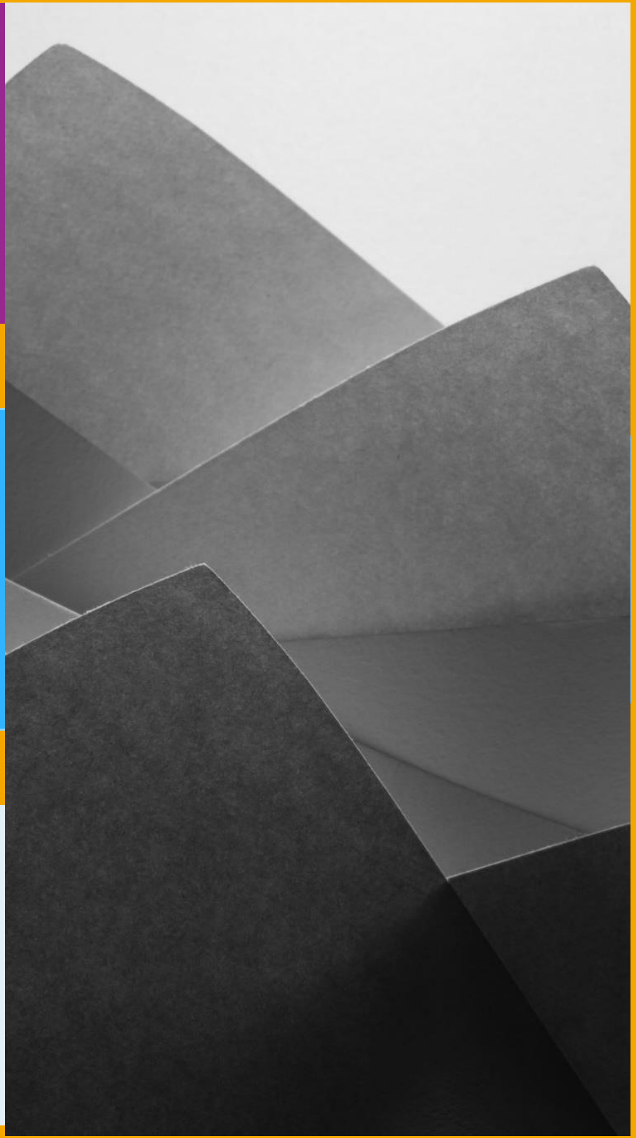
https://journals.sagepub.com/doi/pdf/10.1177/0840470420970594

Trauma & Resiliency Informed Practice is an *Approach*

- Trauma-informed approach incorporates three key elements:
  - *realizing* the prevalence of trauma;
  - *recognizing* how trauma affects all individuals involved with the program, organization, or system, including its own workforce; and
  - *responding* by putting this knowledge into practice"(SAMHSA, 2012, p. 4).

How can the research and/or evaluation experience activate, intensify or trigger the effects of trauma?

Engagement takes TIME: 3 Keys for Success



Collaboration

Curiosity

Humility

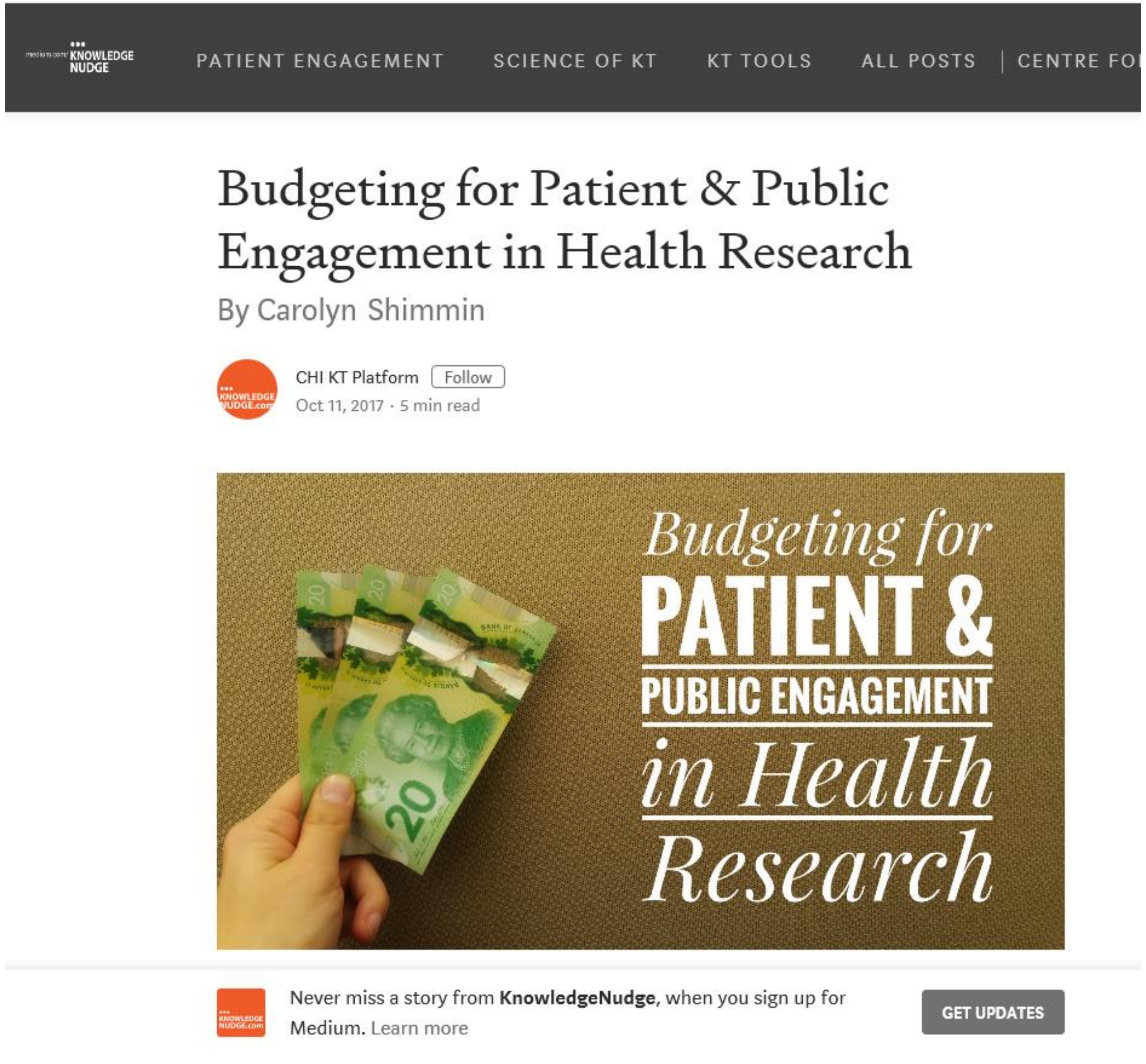
Tools and Resources

Reimbursement and Compensation

- **Reimbursement**: Repayment for out-of-pocket expenses related to engagement in an activity (e.g., childcare, parking, mileage, etc.)

- **Compensation**: Something awarded to someone in exchange for a service. This may take the form of an honorarium or in-kind gifts.
  - A voluntary payment made to a person for services for which fees are not legally or traditionally required.

Tools: Compensation and Reimbursement



Budgeting for Patient & Public Engagement in Health Research

By Carolyn Shimmin

CHI KT Platform Follow

Oct 11, 2017 · 5 min read

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https://medium.com/knowledgenudge/budgeting-for-patient-public-engagement-in-health-research-d70f5ce8fca9

Budgeting for patient and public engagement in health research (BC SUPPORT Unit): https://www.youtube.com/watch?v=4vDGCGS5544&feature=youtu.be

How to talk about compensation with patient partners: https://www.jospt.org/doi/10.2519/jospt.2020.0106

Tools: Recruitment

- Reach BC (https://reachbc.ca)
- Patient Voices Network (https://patientvoicesbc.ca/)
- Community Organizations
- Health Networks

REACHBC

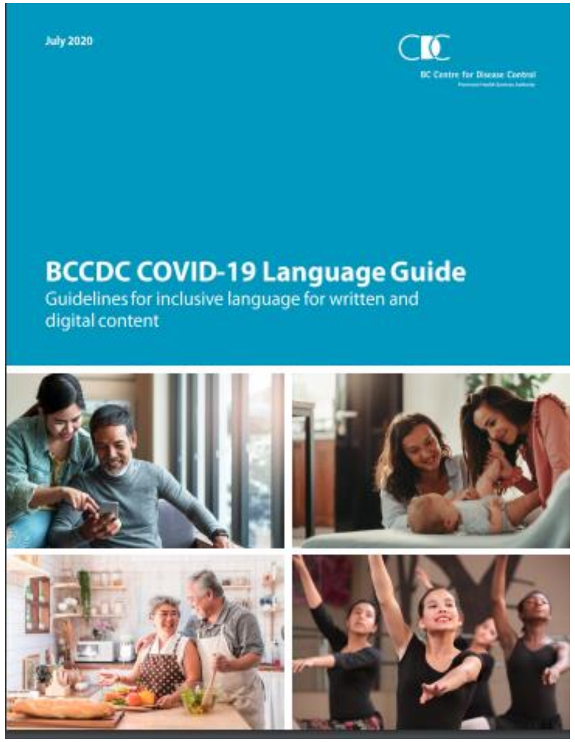
Equity, Diversity and Inclusion (EDI)

- **Dimensions Charter**: This charter is foundational to the Dimensions pilot program to foster increased research excellence, innovation and creativity within the *post-secondary sector* across all disciplines, through greater equity, diversity and inclusion (EDI)
  https://www.nserc-crsng.gc.ca/NSERC-CRSNG/EDI-EDI/Dimensions-Charter_Dimensions-Charte_eng.asp

- **BC SUPPORT Unit Island Centre**: Inclusion of EDI expectations, competencies and accountabilities for Research Department staff, aligned with Island Health's evolving strategy. Enhance equity, diversity, and inclusion in the research we conduct and support
  - https://www.islandhealth.ca/research-capacity-building/equity-diversity-and-inclusion

- **FAQs for the Fraser Health Research Community During the COVID-19 Pandemic Phase 3**
  - Fraser Health is working in partnership with the British Columbia (BC) Ministry of Health and the BC Centre for Disease Control (BCCDC) to respond to the COVID-19 pandemic. Fraser Health is focused on reducing risks for research participants, personnel, and the public
  - https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Professionals/Research-and-Evaluation-Services/COVID-19-research/20201201_FH_ResearchCommunity_FAQs.pdf?rev=e7b4adf543524176a6659d5feb6c6c16

Tools: Creating a culturally and socially safe environment

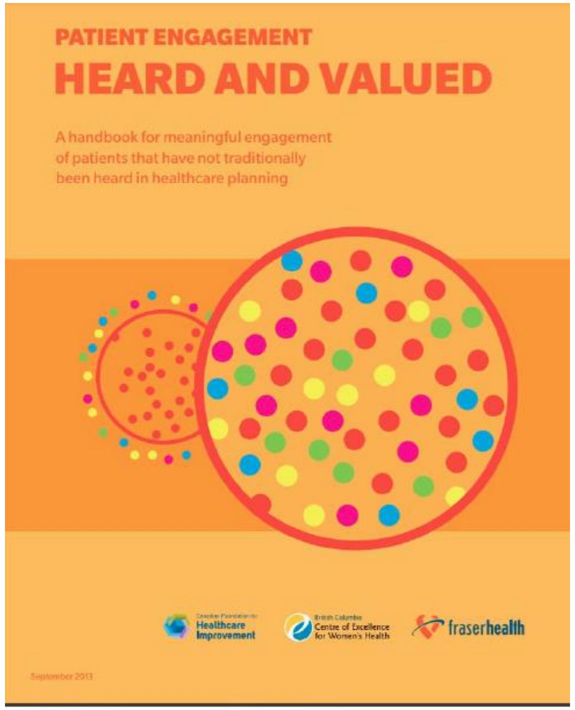


July 2020

BC Centre for Disease Control

BCCDC COVID-19 Language Guide

Guidelines for inclusive language for written and digital content



PATIENT ENGAGEMENT

HEARD AND VALUED

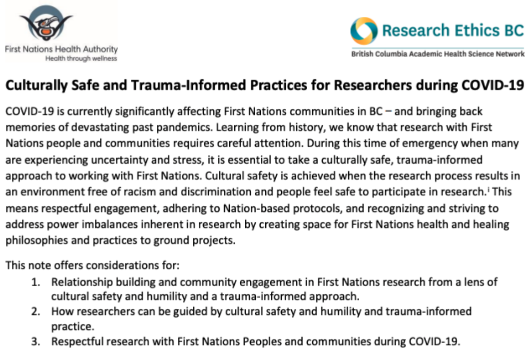
A handbook for meaningful engagement of patients that have not traditionally been heard in healthcare planning

Canadian Foundation for Healthcare Improvement

British Columbia Centre of Excellence for Women's Health

fraserhealth

September 2013



First Nations Health Authority
Health through wellness

Research Ethics BC
British Columbia Academic Health Science Network

Culturally Safe and Trauma-Informed Practices for Researchers during COVID-19

COVID-19 is currently significantly affecting First Nations communities in BC – and bringing back memories of devastating past pandemics. Learning from history, we know that research with First Nations people and communities requires careful attention. During this time of emergency when many are experiencing uncertainty and stress, it is essential to take a culturally safe, trauma-informed approach to working with First Nations. Cultural safety is achieved when the research process results in an environment free of racism and discrimination and people feel safe to participate in research.[i] This means respectful engagement, adhering to Nation-based protocols, and recognizing and striving to address power imbalances inherent in research by creating space for First Nations health and healing philosophies and practices to ground projects.

This note offers considerations for:

1. Relationship building and community engagement in First Nations research from a lens of cultural safety and humility and a trauma-informed approach.
2. How researchers can be guided by cultural safety and humility and trauma-informed practice.
3. Respectful research with First Nations Peoples and communities during COVID-19.

- https://ethics.research.ubc.ca/sites/ore.ubc.ca/files/documents/TIC-during-COVID-19-FNHA-October-2020.pdf
- https://www.cfhi-fcass.ca/docs/default-source/itr/pe-hub/awesome_handbook-fraserhealth
- http://www.bccdc.ca/Health-Info-Site/Documents/Language-guide.pdf

More tools to check out…

- BC SUPPORT Unit Resource Library: https://healthresearchbc.ca/resource-library/?resource-unit=bc-support-unit
- PCORI: Intro to Health research for patients training module https://www.pcori.org/engagement/research-fundamentals
- CIHR Jargon Buster: http://www.cihr-irsc.gc.ca/e/48952.html
- Newfoundland & Labrador Unit Patient and Public Engagement Planning Template: https://nlsupport.ca/wp-content/uploads/2022/07/Patient-and-Public-Engagement-Planning-Template.pd f
- INVOLVE UK Briefing Note on Public Involvement in Research - http://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf

Patient Engagement In Research (PEIR) Plan Workbook

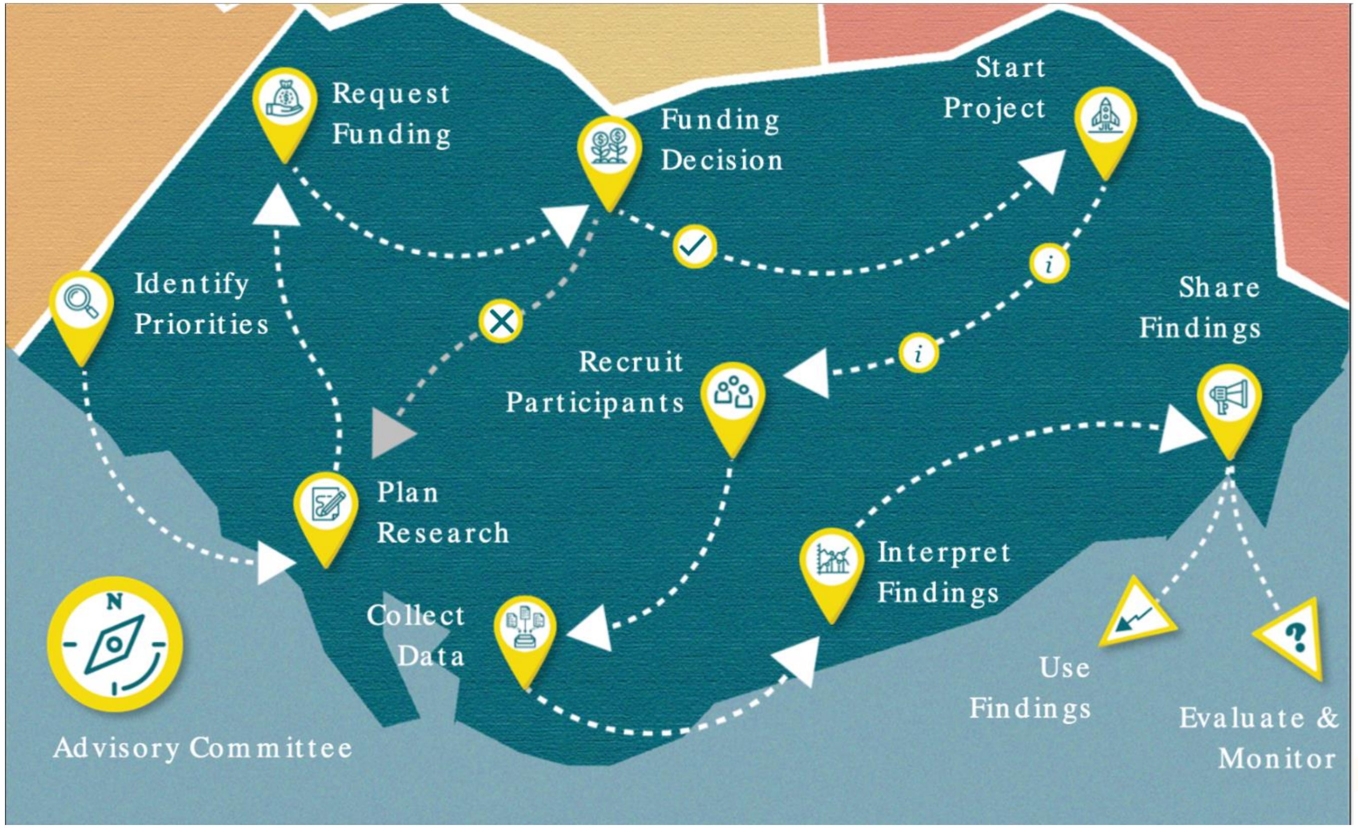
- The PEIR Framework includes eight components that outline meaningful engagement in research from the perspectives of patient partners
- Based on:
    - In-depth patient partner interviews
    - Peer-reviewed publications
    - Collective perspectives of team of patient partners and health researchers

http://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf

Patient Engagement In Research (PEIR) Framework

There are eight key components in the PEIR Framework, which collectively contribute to meaningful patient engagement in research.

A Journey through Public & Patient Engagement in Health Research: A Road Map



https://www.bcahsn.ca/research-road-map

Examples of our Work

Fraser Centre Overview

- **100+** research projects
  - 3 of these are patient-directed

- **129** patient partners engaged in research and governance activities

- **22** awards granted within the last fiscal year

- **50%** of requests for clinician-led research

- Many Fraser Health programs engaged in POR projects

Fraser Centre Governance & Operations

- Research Ready Patient Partners (R2P2)
- Core Oversight Committee
- Shared decision-making

South Asian Health Research Collaborative

- Diverse group of researchers and health providers interested in South Asian engagement in health research to improve the quantity and quality of health research for the community to inform policy and practice
  - Drafted project overview, options for convening
  - Strategy for and facilitation of goal setting activities
  - Support for initiating and facilitating a priority setting project
  - Support for knowledge dissemination activities

Fracture Liaison Service

Dr. Sonia Singh, Fraser Health

- Knowledge user identified problem
- Evidence based solution adapted to context
- Implemented & evaluated effectiveness
- Presented to decision makers with patient partner
- Sustainable program established
- Patient partner contributed to dissemination efforts (presenting at conferences, authoring manuscripts)
- Received grant to scale and spread FLS across BC
- Received grant to develop health policy for BC
- Brokered partnerships with BC Ministry of Health

Make the FIRST break the LAST

FRACTURE LIAISON SERVICES

Opioid Agnostic Treatment Project

- Fraser Health Opioid Agnostic Treatment Project
  - Trauma & Resiliency Informed Research: Emergent Promising Practices from a Patient Oriented Research Project in Response to COVID-19 and Overdose Public Health Emergencies

Training Opportunities

BC SUPPORT Unit & Fraser Centre:

- Webinars for patient partners and researchers
- Online training resources
- Methods Cluster webinars
- Annual conference
- Newsletter with updates
- See https://healthresearchbc.ca/bc-support-unit/about-us/

Contact the Fraser Centre to learn more!
frasercentre@healthresearchbc.ca

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Thank you!

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