

The background features a series of concentric circles in light gray, some solid and some dashed, creating a ripple effect. A large blue speech bubble is centered on the page, containing the main text.

Patient Engagement

Advancing the Patients as Partners Approach
in Research, Policy and Health Services

The Impetus for Engagement

- **Evidence** – results in improved quality, safety, experience, outcomes and more relevant research
- **Shifting expectations**
 - activated patients, families and communities, shared responsibility for health, self-management
 - growing “civil society” discourse; public calls for transparency and accountability from institutions
- **Mandated engagement** –government or the courts mandating engagement, accreditation standards setting expectations, research funders expecting engagement of patients (not as subjects!)

What Is Patient Engagement?

Patients as partners - patients are partners in care when they are supported and encouraged to participate: in their own care; in decision making about that care; at the level they choose; and in redesign and quality improvement in ongoing and sustainable ways

BC Ministry of Health

Nothing about me without me

Diane Pampling

An innovative approach to the planning, delivery and evaluation of health care that is grounded in mutually beneficial partnerships among health care patients, families and providers

Institute for Patient and Family Centred Care (IPFCC)

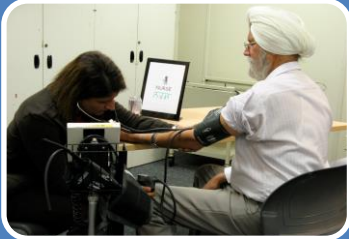
Patient-centred care = care that is respectful and responsive to individual patient preferences, needs, values and includes patient values in clinical decision making

Institute of Medicine (IOM)

Public engagement – processes by which individuals, groups and organizations have an opportunity to participate in decision-making that affects their lives

Public Health Agency of Canada (PHAC)

Three Domains



Individual care

- Activated patient – involved in their own health – self-management
- Patient –centred care – system is responsive, respectful, collaborative



Program and Service Design or Research

- Patients , families, community organizations, strategic partners engaged in design, delivery and evaluation of health care programs and services or involvement in research (from setting the research agenda to conception of projects to KT)



System and Governance

- Engagement of patients, families, communities, strategic partners in broader policy development or strategic planning
- Representation from patient, families, communities, strategic partners in governance

Engagement is not...

- A **one-way** education or communications exercise
- A way to get agreement on a pre-determined decision
- Not the only input
- Not doing to
- Not doing for
- Not one voice

The Evidence for PE

- PE enables improvement
 - Improved health outcomes
 - Improved experience for patients and providers
 - Increased sustainability of the health system
- Increased safety and quality – fewer errors
- Greater involvement enables shared responsibility for health
- Greater civic engagement, more knowledgeable citizenry, strengthened community identity, increased trust in democratic processes
- More relevant research – from the questions to the methods to KT

Mandates for Engagement



- In BC, Ministry of Health Services articulates Key Results Areas for Regional Health Authorities (including patient, family, caregiver and community engagement)
- Aboriginal people - legal duty to consult established in Canada – “First Nations are fully involved in decision-making regarding the health of their peoples” From the vision, Tripartite Health Plan

CIHR PE – Guiding Principles

- **“Inclusiveness:** Patient engagement in research integrates a diversity of patient perspectives and research is reflective of their contribution – i.e., patients are bringing their lives into this.
- **Support:** Adequate support and flexibility are provided to patient participants to ensure that they can contribute fully to discussions and decisions. This implies creating safe environments that promote honest interactions, cultural competence, training, and education. Support also implies financial compensation for their involvement.
- **Mutual Respect:** Researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge.
- **Co-Build:** Patients, researchers and practitioners work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.”



<http://www.cihr-irsc.gc.ca/e/48413.html>

CIHR - Outcomes of Patient Engagement

- Inclusive mechanisms and processes are created
- Respectful collaboration is established amongst patients, researchers and health care providers
- The experiential knowledge of patients is valued as evidence as part of the research process
- Research is informed and co-directed by patients
- Common goal of timely implementation of quality research

<http://www.cihr-irsc.gc.ca/e/48413.html>



The Spread of Engagement - International

- UK's National Health Service – legislated engagement of patients and families
- New Zealand and Australia – mandated engagement in some aspects of the system; parallel health system for Maori people (joint governance model)
- USA – Accrediting body (JCAHO) setting goals for patient engagement
- More voices in the choir – PCORI (US), Picker Institute, Institute of Medicine, Institute for Healthcare Improvement, Institute for Patient and Family Centre Care, Society for Participatory Medicine, the Institute for Public Participation...

The Spread of Engagement - Canada

- Health care organizations in most provinces adopting engagement frameworks/approaches
- BC –Patient Voices Network established as one mechanism for engaging patients, MSFHR initiatives
- Accreditation Canada measuring patient focus and involvement
- CIHR PE Framework and SPOR Funding
- Patients/families/public responding to calls for engagement

The Principles of Engagement

Dignity and Respect

- The perspectives and choices of patients, families, communities and partners will be listened to and honoured.
- The knowledge, values, beliefs and cultural backgrounds of patients and the public will be incorporated into the planning and delivery of services.

Participation

- Engagement will occur in policy and program development, implementation and evaluation, as well as in the delivery of care.

Partnership

- Engagement will be early and continuous.
- Opportunities will be sought to deepen partnerships through engagement.

The Principles of Engagement

Information Sharing

- Patients, families and the public will receive timely, accurate and complete information in order to effectively participate in decision-making.
- Complete and unbiased information will be shared with patients, families and the public in ways that are affirming and useful.

Transparency

- Communication will be clear and transparent.
- Constraints on decision-making will be shared with patients, families and the public.

Commitment

- Appropriate time and resources will be committed to ensure meaningful engagement.

The Principles of Engagement

Inclusiveness

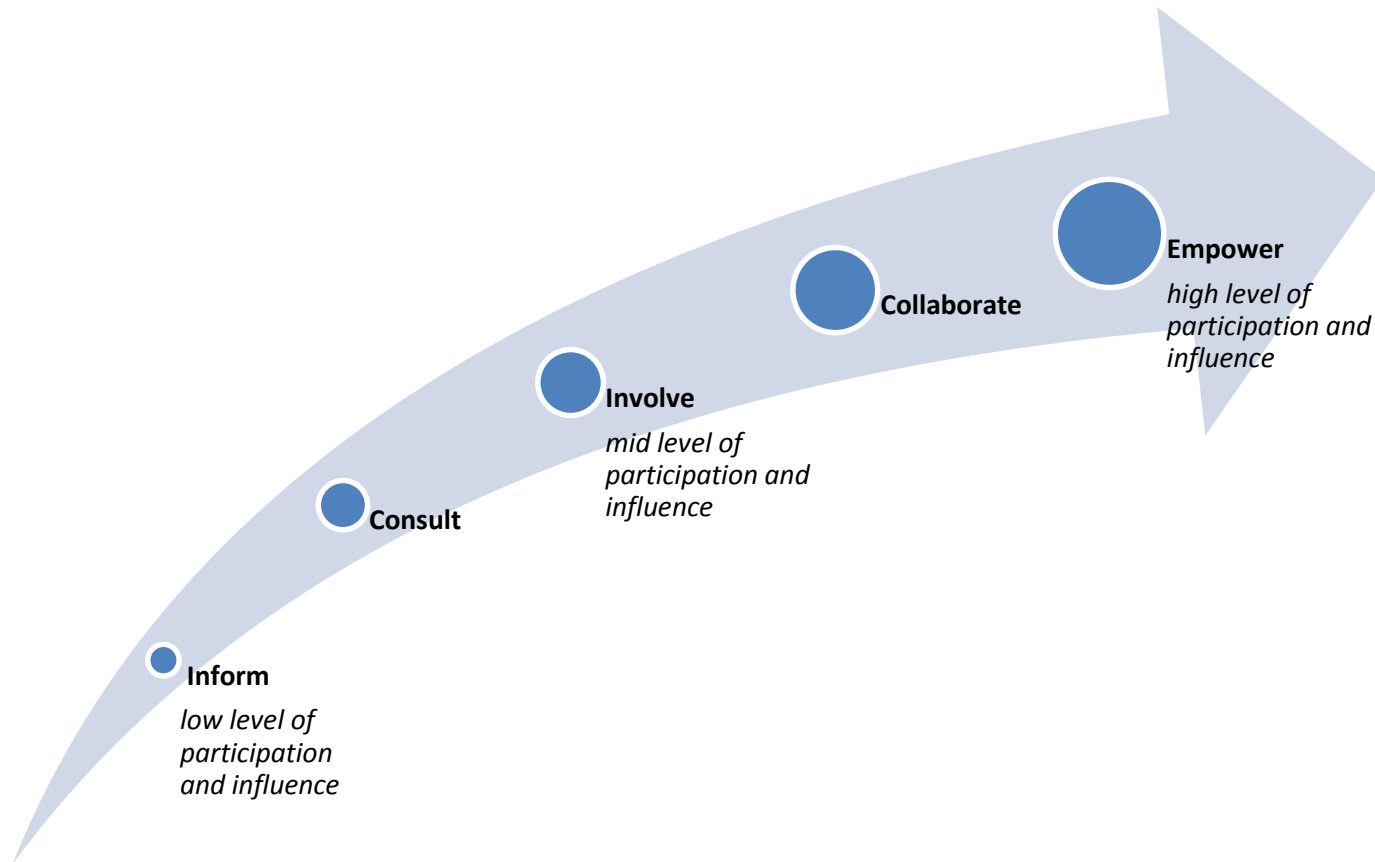
- Efforts will be made to include all affected stakeholders in the engagement process and to mitigate barriers to participation.
- Diversity of opinion will be sought.

Accountability

- Patients, families and members of the public will be informed about how their involvement affected decisions.

Integrity

- Input and concerns will be responded to in a forthright and honest manner.
- Engagement will have impact on decision-making to the level communicated at the outset.



The Spectrum of Engagement

	Inform	Consult	Involve	Collaborate	Empower
Objective	Provide balanced information to increase understanding	Solicit feedback on proposals, alternatives and/or decisions	Work with the patient to understand and consider concerns, preferences and values	Partner with the patient in each aspect of decision-making, including identifying alternatives and preferred solutions	Delegate responsibility for identifying issues, solutions and actions to the patient
Commitment	To keep the public/patient informed	To keep the patient informed, listen to concerns and acknowledge how input affected decisions	To understand patient perspectives and include them in developing options and approaches	To seek advice and innovations from patients and include these in decision-making to the fullest extent possible, acknowledging how input affected decisions	To work with the patient in a supportive role and to implement what they decide

Understanding the Spectrum

Case
Studies –
CAN

The Canadian Arthritis Research Network - 1998-2012

Included patients in Network
application, governance, priority
setting and research conduct

Patients received extensive
training and involvement grew
over the networks' existence

Informing – Case Study

Launch of a new, community-based sexual health program



Target client group:

- Multi-lingual, with representation from several ethnocultural groups, has low health literacy, experiences cultural stigma related to sexual health programming



Health Authority establishes partnership with NGO serving target community to co-develop promotional material, uses ethnic media strategically

Consulting – Case Study

Co-location of multiple, disparate services into new community health centre

Concerns over different client groups accessing services in shared location (e.g., pregnant moms, babies, street youth, mental health clients)

Some flexibility in building design but other inputs (e.g., cost, construction limitations) constraining ability to respond to input

Requires listening to varied client groups to provide information about changes and gain understanding of concerns – not all input may be acted upon

Involving – Case Study

New adult day program being developed for frail seniors
– addressing gap between home and facility care

Wide range of program options being considered by
innovative leader

Establishes an advisory group (frail seniors, family
caregivers, thought leader in elder care, Manager of
innovative program in another area) to study 4 options
and provide feedback on preferred model

After decision made, communicates results

Seeks other opportunities to involve advisory group

Collaborating
– Case Study

CIHR SPOR Chronic Pain Network

Patient Partners engaged in governance and on projects

Increasing roles in policy advocacy
– Canadian Pain Task Force

Evaluation underway – PPEET tool

Lessons learned – structure and process can limit engagement

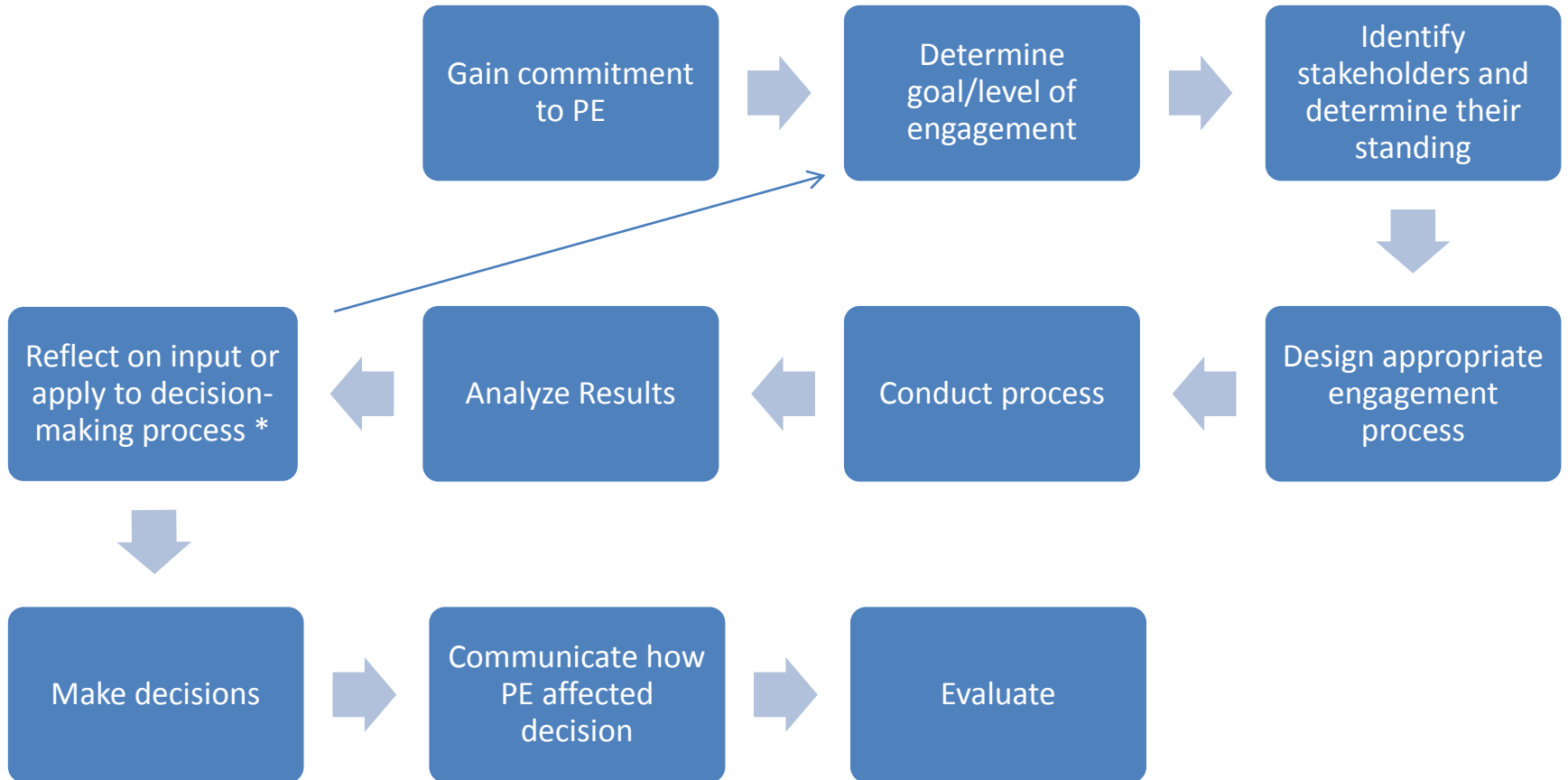
Empowering
– Case Study

New Aboriginal Health Program under development – requires tri-partite engagement, negotiation of jurisdictional issues, honouring of TCA principles

FN Community – identify program priorities and approaches, determine desired outcomes

Regional Health Authority – supports with funding transfer governed by MOU

Critical Steps in Engagement



Roles in PE

Role dependent on level of engagement



Decision-Maker/Organization

- Sets expectation of PE as required function
- Champions PE
- Supports development of organizational capacity for PE
- Provides resources for PE
- Ensures timelines accommodate meaningful PE

Researcher/Program Leader

- Listens and learns
- Designs/implements PE process
- “Neutral facilitator” or process guardian
- Supports patients or public in PE process

Patient Partner

- Listens and learns
- Communicates values, preferences, aspirations
- Provides input and advice on proposals
- Engages in deliberation on ideas, co-develops alternatives
- Identifies issues and solutions for implementation
- Engages in implementation



Moving PE Forward – What's Needed?

- Organizational commitment
 - Move beyond frameworks to influence funding, timelines and processes
- Paradigm shift among leaders, clinicians and researchers
 - Need to build capacity through development of roles and accountability for PE
 - Education and training for people with lived experience and leaders/clinicians/researchers