

Engagement 101

Translating Research Into Care

Spring 2015



Learning Outcomes

- Describe basic engagement theory
- Explain the IAP2 Spectrum of Public Participation
- Appreciate the planning process for engagement
- Identify readiness to engage
- Value patient/caregiver/stakeholder input

Agenda

- Background and context
- Foundations of engagement
- How to begin
- Words of wisdom
- Discussion-applying concepts

Background

- 2008 strategic priority at Capital Health
- 2010 engagement policy
- 2012 Patient and Public Engagement Team
- PPE team offers strategic advice, project support, training, communication, participant volunteer recruitment, evaluation, community relations, coordination and policy compliance

Context

- Patient and public engagement identified in new provincial health authority act.
- TRIC grant program requires inclusion of the patient voice in all applications.
- SPOR - The patient perspective is integrated into every step of the research process including developing research questions, defining research objectives, collecting data and evaluating results.

What is engagement?

Creates sustainable trust based relationships by involving a wide range of interests and opinions in making decisions and setting priorities.



What is public participation?

Any process that involves the public in problem solving or decision making and uses public input to make decisions.

- Identify problems and opportunities
- Developing alternatives
- Decision-making

Engagement Theory

Those affected by public decisions:

- need *accurate information*, a *voice*, and the *opportunity to participate* in how decisions get implemented
- will generally be *more supportive*, will seek ways to *improve quality* of decisions and their implementation
- will be *less likely to oppose* them if they are *given full information* and their *voices and concerns are heard and acknowledged*

IAP2 Core Values

- A say in decisions that affect their lives
- Promises that the contribution will influence the decision
- Promotes sustainable decisions
- Seeks out and facilitates participation
- Seeks input in designing the participation process
- Provides information needed for *meaningful* participation
- Communicates back how input affected the decision

Values and Guiding Principles (SPOR)

Patient engagement in research will improve the relevance of the research and improve its translation into policy and practice, contribute to more effective health services and products, and ultimately, improve the quality of life of Canadians and result in a strengthened Canadian health care system.

Principles	Description
<i>Inclusiveness</i>	Patient engagement in research integrates a diversity of patient perspectives and is reflective of their contribution – i.e., patients are bringing their lives into this.
<i>Support</i>	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.
<i>Mutual Respect</i>	Researchers, practitioners and patients acknowledge and value each other's expertise and experiential knowledge.
<i>Co-Build</i>	Patients, researchers and other SPOR stakeholders work together from the beginning to identify problems and gaps, set priorities for research and work together to produce and implement solutions.

Public participation goal

Inform

To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.

Consult

To obtain public feedback on analysis, alternatives and/or decisions.

Involve

To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.

Collaborate

To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.

Empower

To place final decision-making in the hands of the public.

Promise to the public

We will keep you informed.

We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.

We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.

We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.

We will implement what you decide.

Example techniques

- Fact sheets
- Web sites
- Open houses

- Public comment
- Focus groups
- Surveys
- Public meetings

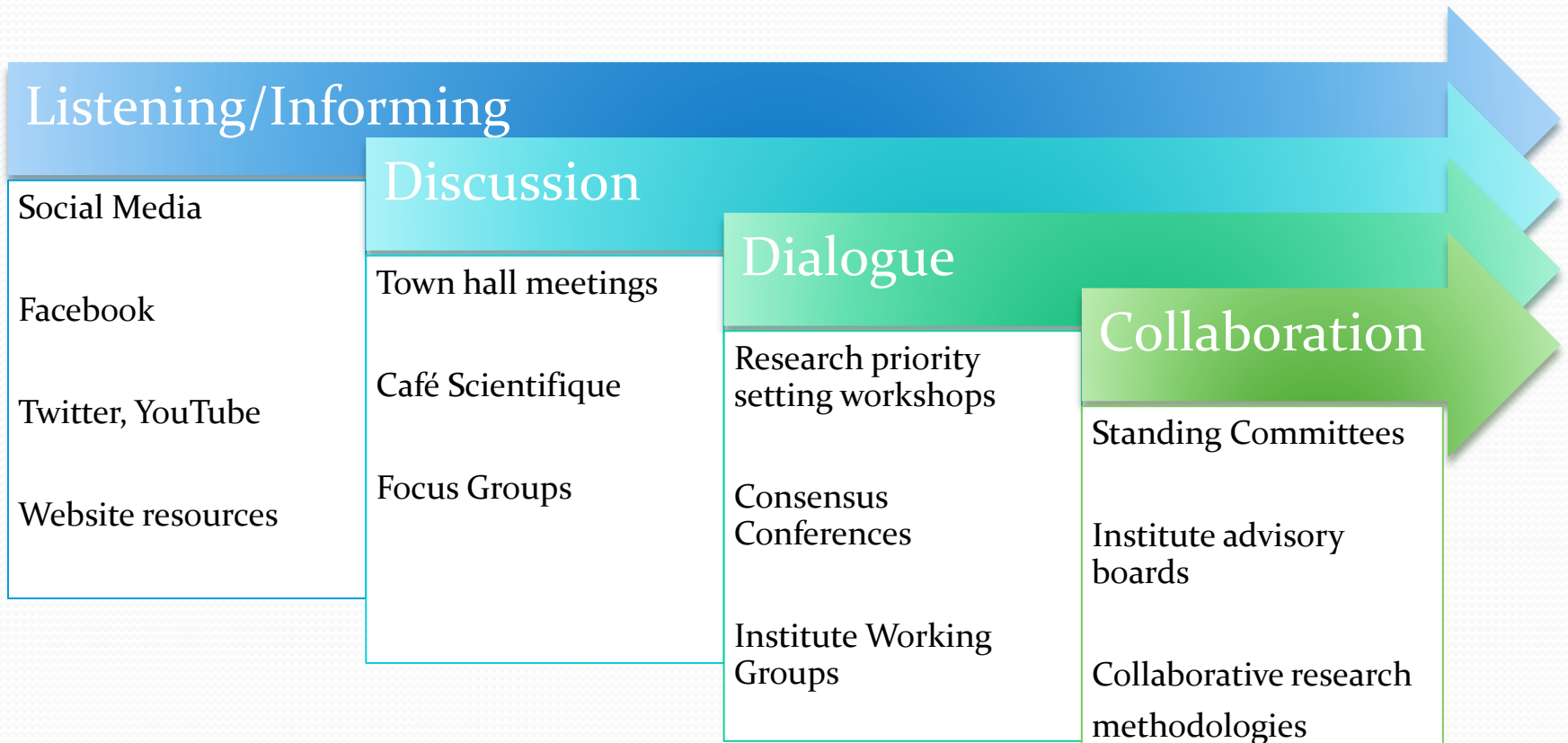
- Workshops
- Deliberative polling

- Citizen advisory committees
- Consensus-building
- Participatory decision-making

- Citizen juries
- Ballots
- Delegated decision

CIHR

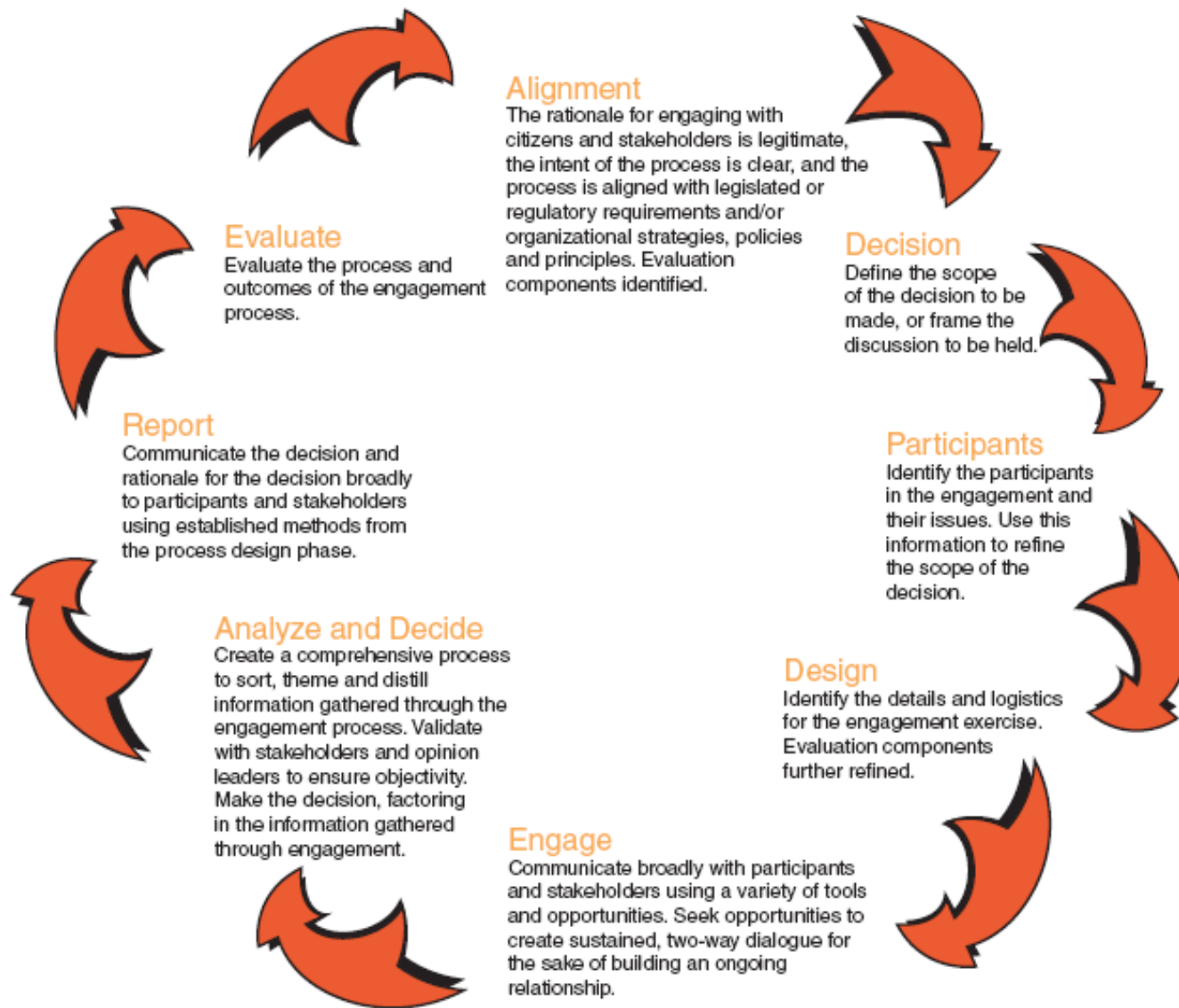
of Citizens and Patients



Jeff Latimer, PhD. Director, Platforms and Major Initiatives, Research and Knowledge Translation Portfolio. Setting the Context, An overview of the Canadian Institutes of Health Research and the Strategy for Patient-Oriented Research Presentation at the CIHR Patient Engagement Workshop, January 9, 2014

Planning is doing!!!





Intention and Readiness

- Is there a decision to be made?
- Are there any assumptions or non-negotiables?
- What is the decision?
- Who is the decision maker?
- What do you really want to know?
- Are you truly open to considering different perspectives?
- Can people contribute to the discussion?

Intention and Readiness

- Have all potential participants been identified?
- Have appropriate resources been allocated (time, budget, people)?
- Is the issue relevant to the people you want to engage?
- What information do they need to be able to contribute in a meaningful way?

Practical Ideas

- Working with research funders to prioritise research.
- Offering advice as members of a project steering group.
- Commenting on and developing research materials.
- Collecting, analyzing, and/or disseminating project information and outcomes.

Practical Suggestions

- Ensure Roles and Responsibilities are clearly understood.
- Weave research activities with teaching activities with patients and health professionals.
- Present at conferences in tandem.
- Let patients choose other patient research partners.

Words of Wisdom

- Involve patients in knowledge translation.
- Patients can help assess the impact of research, the “so what”.
- Help identify key messages, what’s important to patients/caregivers.
- Patient experience is evidence.
- Not a “one size fits all” approach.
- Benefits and challenges if researchers are also patients.
- If patients become very savvy, they can adopt a researchers mindset and lose an outside perspective.

Challenge and Opportunity

- How will engagement change your work?
- What do you need to be able to engage patients/caregivers in your research?





Stay in touch

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