

Engaging Older Adults in Healthcare Research, Planning & Decision-Making

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**Canadian
Frailty
Network**

**Réseau canadien
des soins aux
personnes fragilisées**

Acknowledgments



Outline

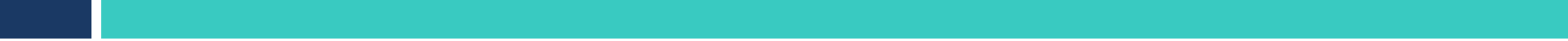
- What is engagement?
- Why should we engage older adults in healthcare research, planning, and decision-making?
- Videos
- Case Scenarios



Objectives

By the end of this presentation you will:

- Be able to describe the value and importance of patient and family engagement in health care research, planning, and clinical decision-making
- Have an understanding of patient and family engagement frameworks
- Be aware of challenges and opportunities in engaging patients and families
- Have experience working with engagement strategies by applying strategies to case scenarios



What comes to mind when you
hear the word “ENGAGEMENT”
in healthcare?

What did the older adults say?

- Experience
- Community
- Family
- Patient satisfaction
- Involvement

Patient and Citizen Engagement: In the Literature

- “Patient engagement” is used interchangeably with terms such as:
 - Client/ community/ citizen engagement
 - public involvement
 - Person/ Patient and family centered care
 - Patient experience
 - Shared decision making

Why engagement matters?

- Engagement is a current “hot topic”

- Although engagement has been recognized as critical to healthcare reform, little is known about how to actually engage older adults
 - Older adults are high users of the healthcare system (Brand et al., 2007)
 - Older adults and their families are often not engaged in decision-making and are excluded from research/planning

Engagement

- **Clinical Decision-Making:** interaction between health care provider and patient/family caregiver to make decisions about care plan
- **Research:** engagement of older adults/citizens as research team members
- **Health System Planning:** engagement of older adults/citizens on advisory boards/committees for health system planning

Importance of Engagement in Clinical Decision-Making

- Research to date has identified many potential benefits of patient and citizen engagement in health care decision-making, including:

1. improved health outcomes
2. improved patient and provider experiences
3. better care planning

(British Columbia Ministry of Health, 2011; Health Council Canada, 2011)

- Related to core concepts of Patient & Family Centered Care
 - Dignity and Respect
 - Information Sharing
 - Participation
 - Collaboration

Importance of Engagement in Research and Planning

- Healthcare Research/Planning
 - “... the people who are most affected by research have a right to have a say in what and how research is undertaken.” (Staley, 2009, p.12)

Engagement definitions and frameworks

□ Definitions:

- “ a relative term subjectively defined by individuals or groups/organizations that are planning to actively involve patients and their families in various health care advisory committees or care decision-making” (Gallivan et al., 2010 p.4)
- “Patient engagement occurs when patients meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarizing, distributing, sharing, and applying its resulting knowledge.” (CIHR definition)

Engagement Frameworks

IAP2's Public Participation Spectrum

IAP2's Public Participation Spectrum



Increasing Level of Public Impact

Inform

Public participation goal

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

Spectrum of Participation



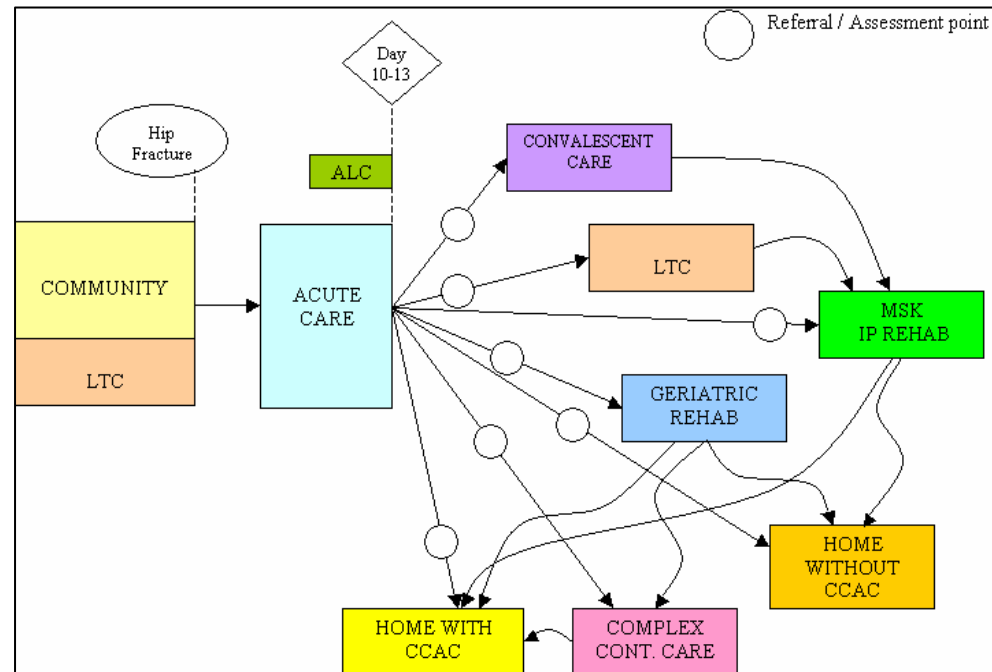
- The community needs a way of engaging patients in order to have them listened to (no one will take you seriously unless you are a formal entity)
 - New breakthroughs that involve patients like this raise expectations and then dash them because of limitations with funding and community direction mandated by ministry.
- “I can understand this model, which is important. For a diagram to work it should be intuitively comprehensible.”

Why did we become interested?

Patients and caregivers aren't engaged in decisions about their care....

You do what you're told to do, and they say 'we're going to do this' and they do it" (patient)

"They gave me a slip yesterday saying you're going to be discharged on [date]. That's it you know. The hell with you, whether you want to or not or whether you feel you're ok..." (patient)



Seniors Helping as Research Partners

Members of the SHARP network have the opportunity to:

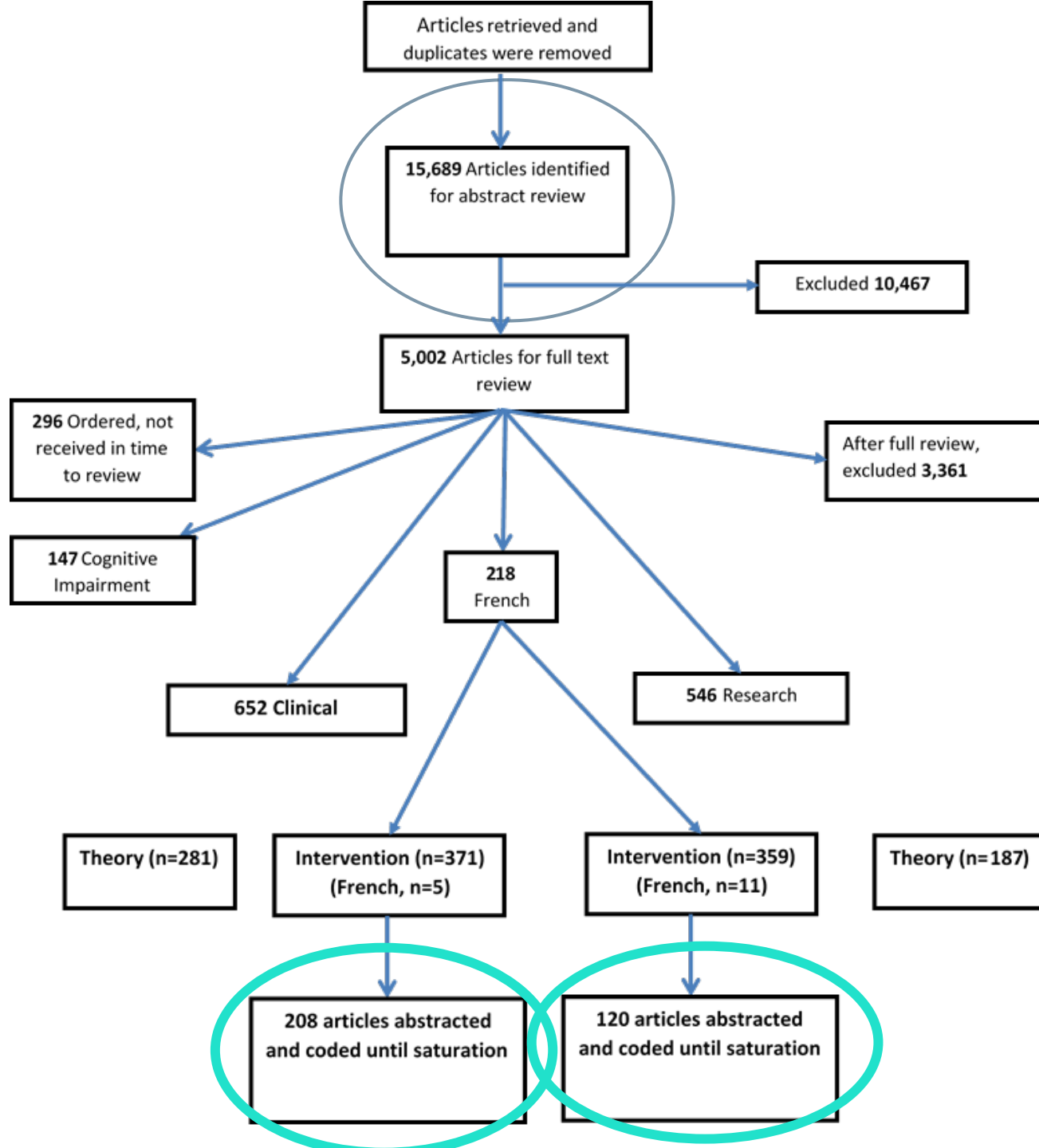
- Develop meaningful partnerships with researchers, health care providers and other key stakeholders
- Participate in various health-related research projects
- Take part in regular discussions with the SHARP research team and other stakeholders through online and community events



What did the literature tell us?

A Realist Review

1. Clarify Scope	<ul style="list-style-type: none">• Major theories and frameworks of patient engagement will be reviewed – including grey literature search• Interviews (n=2) will be conducted with key research leaders• A one day workshop with Patients Canada (n=17)
2. Search for Evidence	<ul style="list-style-type: none">• Search Strategy developed with Library Scientist
3. Appraise primary studies and extract data	<ul style="list-style-type: none">• Extraction/abstraction forms – development guided by the candidate patient engagement theories/frameworks discussed in step 1.
4. Synthesize evidence and draw conclusions	<ul style="list-style-type: none">• Search results used to “populate” the candidate theory or theories with available evidence and experience
5. Disseminate, implement and evaluate <i>*Iterative Process with Step 4*</i>	<ul style="list-style-type: none">• One day workshop with Patients Canada (n=11)• TVN Annual Conference• National and International conferences

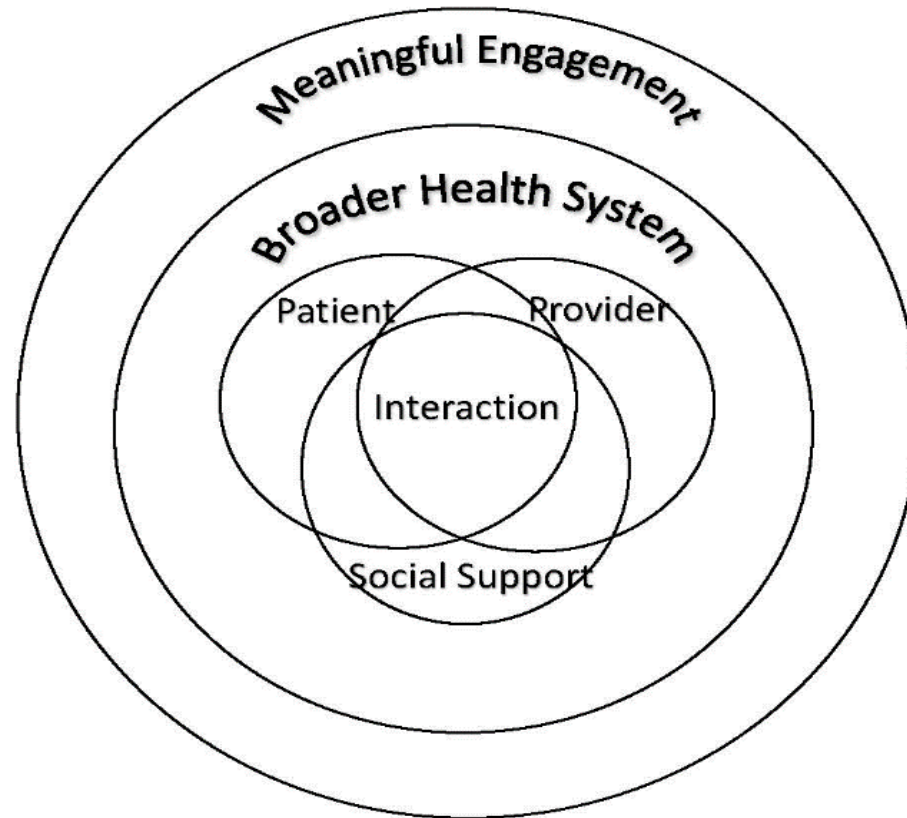




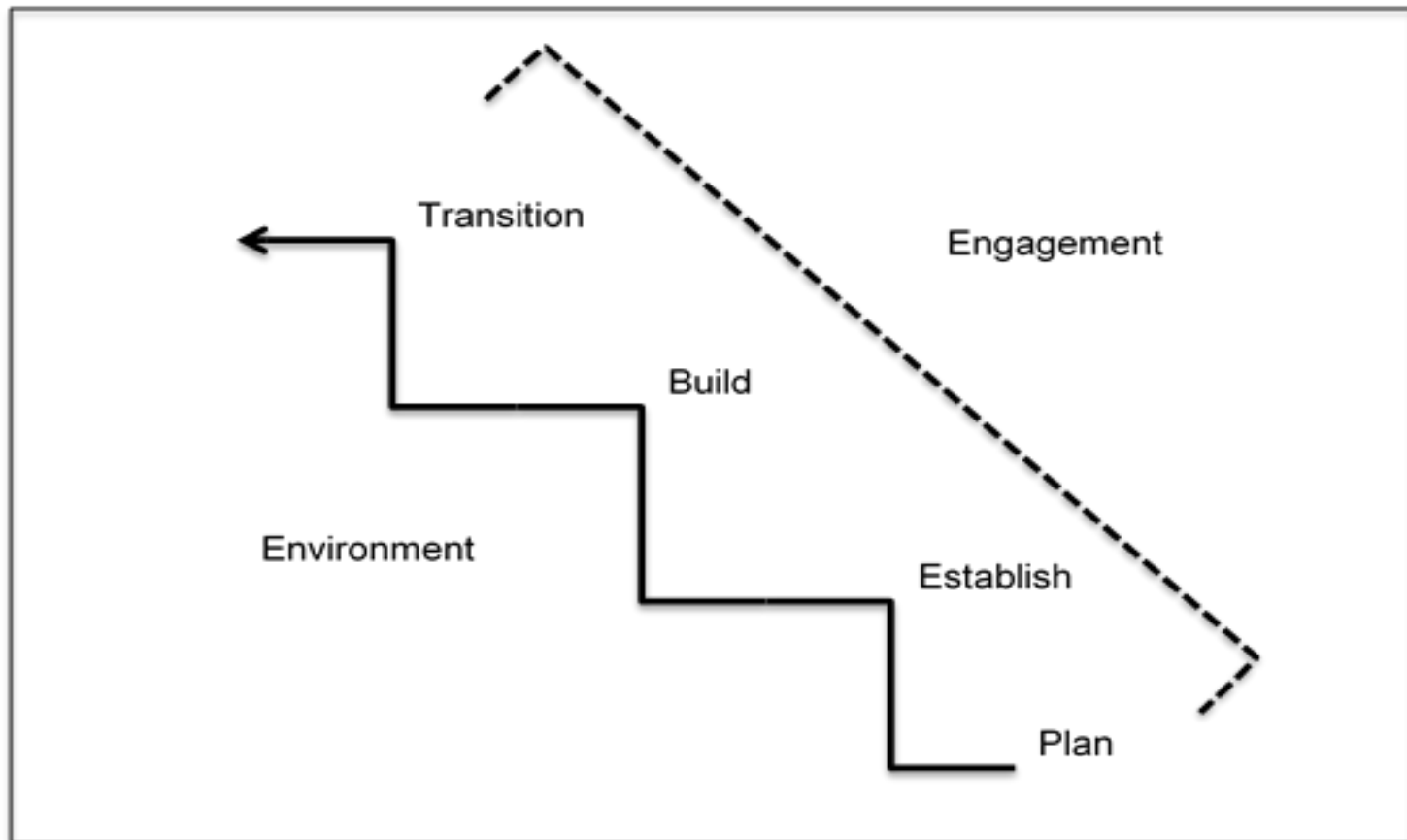
Extract data

Engagement Frameworks

Engagement in clinical decision making



Engagement in healthcare research and planning



Key Findings

- This realist synthesis has informed a ***framework for engagement in healthcare research, planning and decision-making***, and has identified a range of ***best practice guidelines and strategies*** for participants/patients, investigators/health care providers, and other stakeholders
- ***Engagement is complex*** and should be viewed as a ***dynamic relationship***
- Strategies should ***be context specific*** and need to be considered at a system level, patient/participant level, and provider/investigator level.

... More Findings

- In an engaged partnership:
 - Patients/participants should know ***they have a right to engage*** in shared decision-making and research/planning, and
 - Health care providers/investigators and patients/participants should ***outline the level of engagement*** that is appropriate for the situation (context specific).
- ***Communication is key*** to development of an open, honest, and trusting relationship
- ***Continuously evaluate level of engagement***
 - Level is fluid and evolving
 - Gain knowledge, skills, and experiences

Engaging Frail Older Adults

- Specific Considerations for Clinical Decision-Making
 - ▣ Understanding their skills and knowledge
 - ▣ Importance of caregiver involvement
- Specific Considerations for Research/Planning
 - ▣ Use of jargon/acronyms
 - ▣ Transportation
 - ▣ Technology considerations

Lived Experiences: Engaging citizens in research

Key Messages for KT from SHARP

- Confidentiality
- Advocacy
- Mutual Learning
- https://www.youtube.com/watch?v=Amd9b9I_tn0

Young Onset Dementia Video

- <https://www.youtube.com/watch?v=9jxjlxShufk>

Time to get engaged!



- Interactive portion of workshop
- Small groups
- Scenarios based on real experiences of our group

Case Scenario – Strategy Examples

Clinical	Planning & Research
<ul style="list-style-type: none">• Understand situation, patient characteristics, living situation, family involvement	<ul style="list-style-type: none">• Offer education to citizen
<ul style="list-style-type: none">• Understand skills and knowledge	<ul style="list-style-type: none">• Use plain language; avoid jargon
<ul style="list-style-type: none">• Provider should involve family if patient wishes; understand wishes and patient goals	<ul style="list-style-type: none">• Meeting times at places that are accessible; pay for transportation (if feasible)
<ul style="list-style-type: none">• Understand level patient wishes to be involved in for decision-making	<ul style="list-style-type: none">• Understand level older adult wishes to be involved in
<ul style="list-style-type: none">• Provide information – what to expect, services to access	<ul style="list-style-type: none">• Involve diverse group of older adults
<ul style="list-style-type: none">• Transfer information across health system to ensure care (hospital to LTC)	<ul style="list-style-type: none">• Provide timely feedback/knowledge translation

Engaging older adults in healthcare research, planning, and decision-making involves the creation of a **relationship** between all stakeholders involved based on **communication** to understand **situation-specific desired levels** of older adult involvement.



Other Agencies that Support Engagement Work

- Health Canada
- CIHR
- Canadian Foundation for Health Care Improvement
- Patient Voices Canada
- Alberta Health Services (and other provincial level bodies)
- McMaster University- SHARE group



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