



Meaningful Engagement: Results of the CHOICE knowledge synthesis project

Paul Stolee, Jacobi Elliott, Heather
McNeil





Getting Engaged...



■ Clinical Decision-making

- Playing an active role in healthcare decision-making can improve patients' quality of care, efficiency, and health outcomes (Coulter & Ellins, 2007; Coulter et al., 1999)

■ Healthcare Research

- "... 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)

■ Healthcare Planning

- "...as the public are both the main funders and users of the healthcare system, they are the most important stakeholders." (Born & Laupacis, 2012, p. 16)

+ Getting Engaged...

- 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
 - Older adults and their families are often not engaged in decision-making and are excluded from health care research and system planning

- + What our research on patient experience on care transitions taught us about engagement....



+ ... the patient experience across transitions of care

■ is not engagement



Meaningful Engagement?

Patients

“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)¹¹

Care Providers

“... If they want any information I’d wait for them to ask for it” (Health Care Provider)²

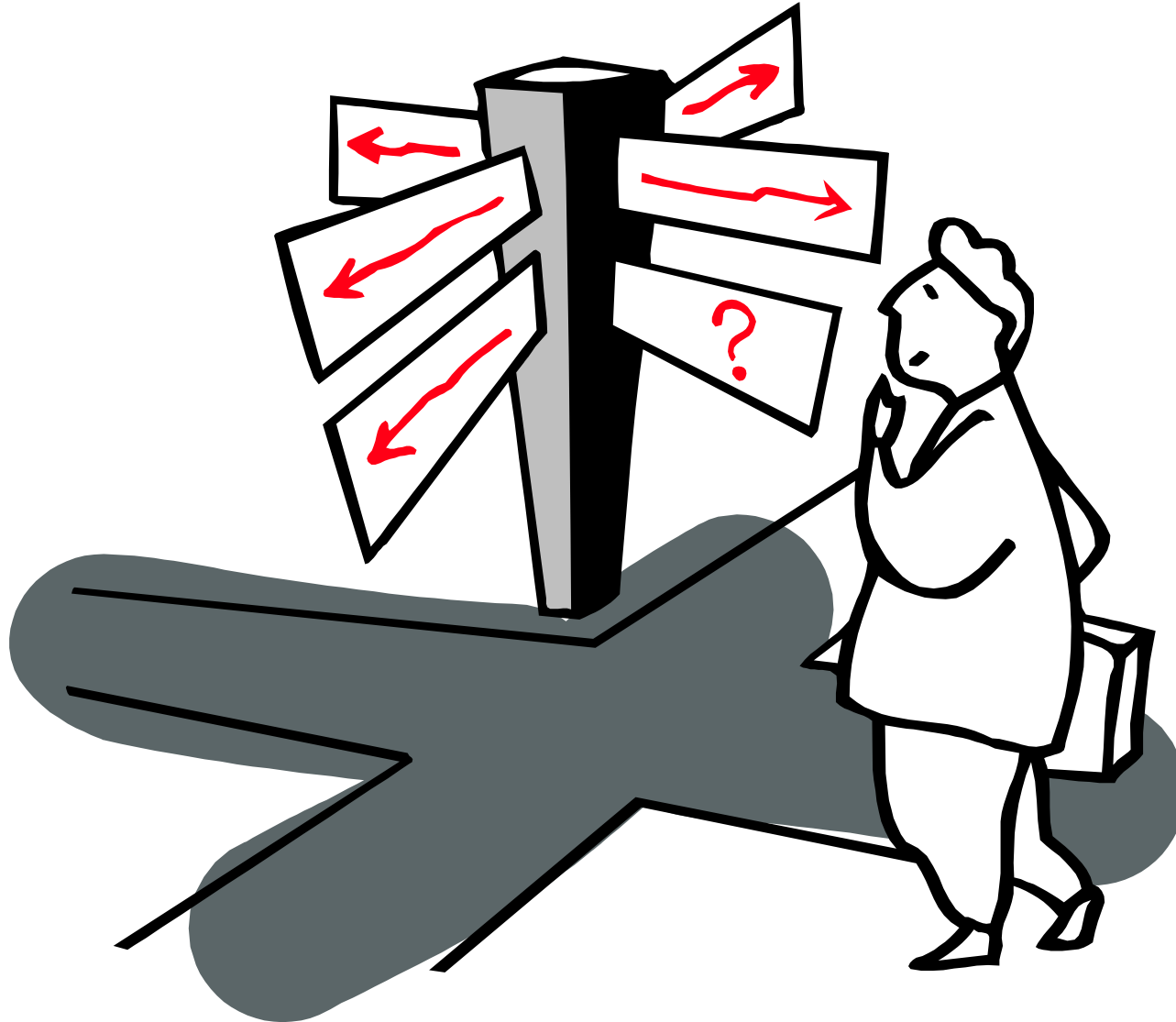
Families

“we hadn’t even heard she’d been moved...we had no idea she was being transferred” (family member)⁴

- Limited attention has been paid to how best to engage frail older adults (who are the constituency of TVN)



Where we went next....



SHARP

SENIORS HELPING AS RESEARCH PARTNERS

*“We’ve been taught, as we go along, that the doctor is always right, the doctor knows best, the doctor knows this. **The doctor does not know best**” (SHARP member)*





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*Choosing Healthcare Options by Involving Canada's Elderly: The **CHOICE** Knowledge Synthesis Project¹³*



+ The *CHOICE* Project Team



George Heckman	University of Waterloo	Co-Investigator
Veronique Boscart	Conestoga College	Co-Investigator
Sholom Glouberman	Patients Canada	Knowledge User
Maria Judd / Mireille Brosseau	Canadian Foundation for Healthcare Improvement	Knowledge User
Margaret Hedley	Community Member/ Seniors' Advocate	Collaborator
Rebecca Hutchinson	University of Waterloo	Information Scientist
Jeanette Prorok	University of Waterloo	PhD Student
Samantha Black	University of Waterloo	Coop Undergraduate Student
Kelsey Huson Jessie Ashbourne	University of Waterloo	Masters Students

The CHOICE Project: Realist Synthesis

1. Clarify Scope	<ul style="list-style-type: none">• Major theories and frameworks of patient engagement were reviewed (using a Google search)• Interviews were conducted with key research leaders• A one day workshop was held with members of Patients Canada
2. Search for Evidence	<ul style="list-style-type: none">• Search Strategy developed with Library Scientist
3. Evaluate the Evidence	<ul style="list-style-type: none">• Using the patient engagement theories and frameworks as a guide, assess the literature
4. Synthesize the information and draw conclusions	<ul style="list-style-type: none">• Use the information from the literature to draw conclusions
5. Disseminate, implement and evaluate.	<ul style="list-style-type: none">• One day workshop with Patients Canada• National and International conferences• Show up here

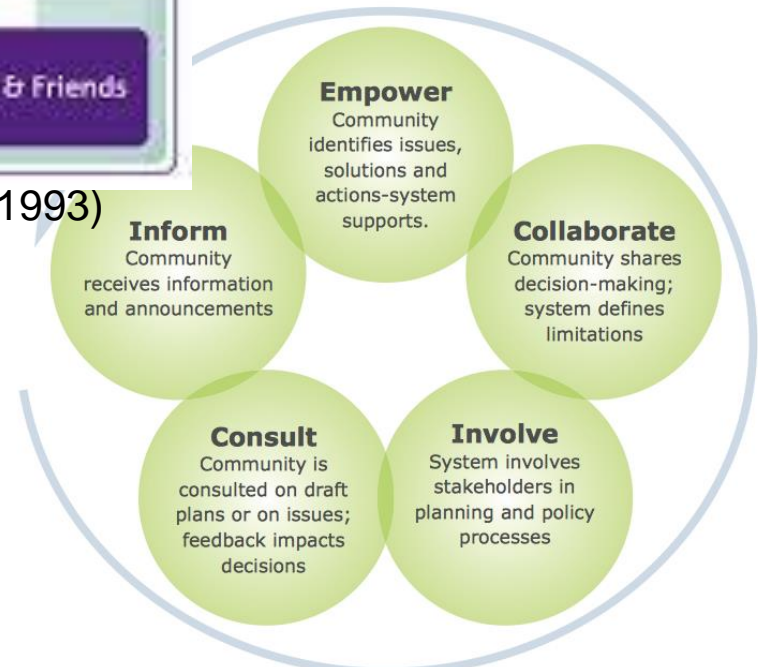
+8 Dimensions of Patient-Centered Care & Spectrum of Participation Frameworks



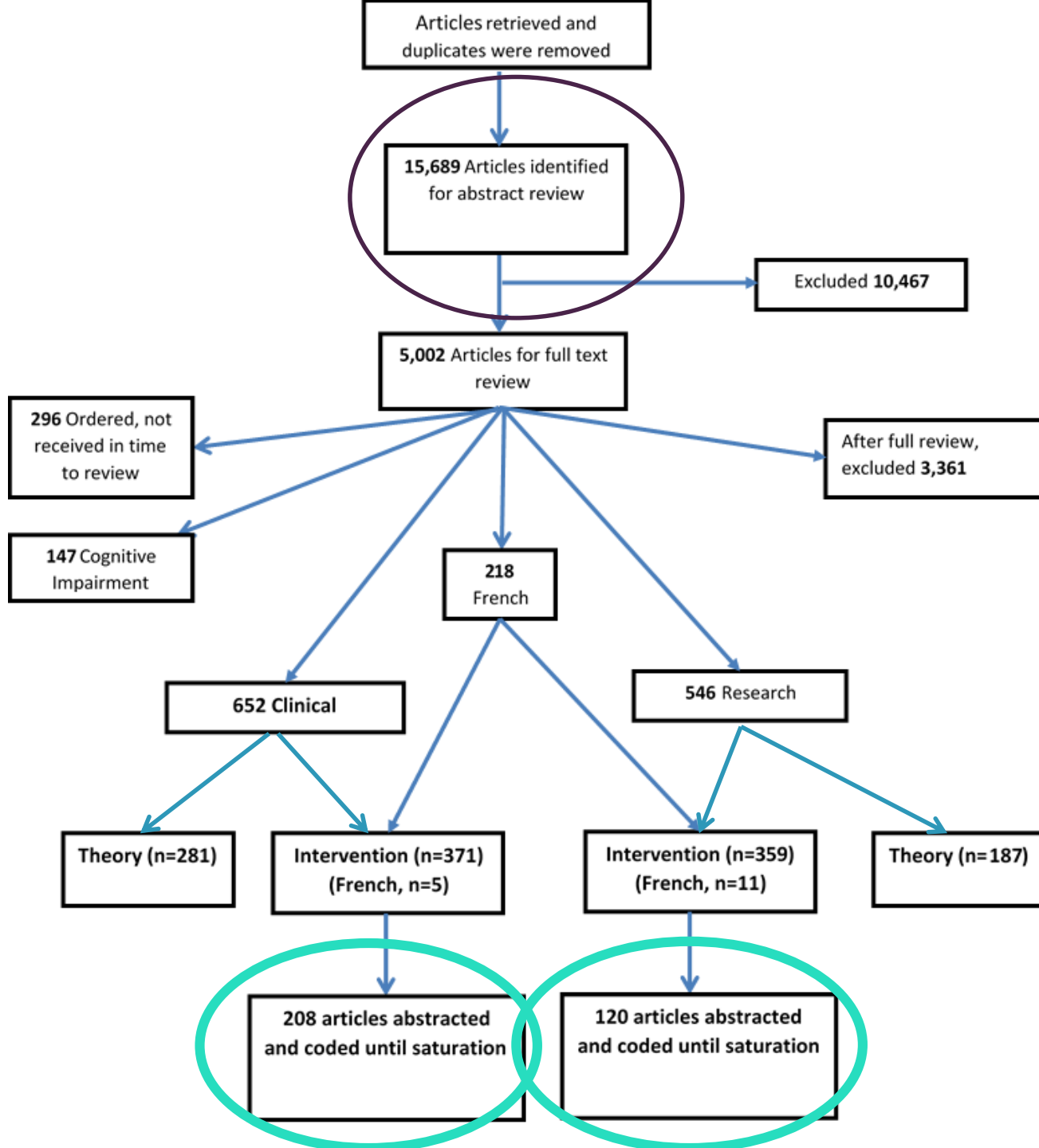
8 Dimensions of Patient-Centred Care (Picker Institute, 1993)

"I can understand this model, which is important. For a diagram to work it should be intuitively comprehensible."

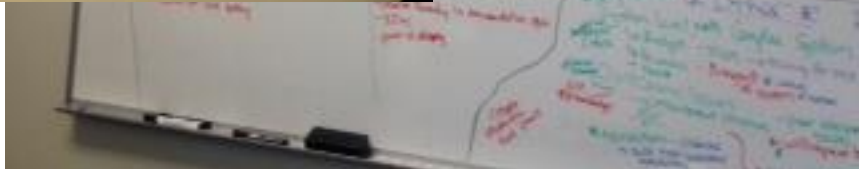
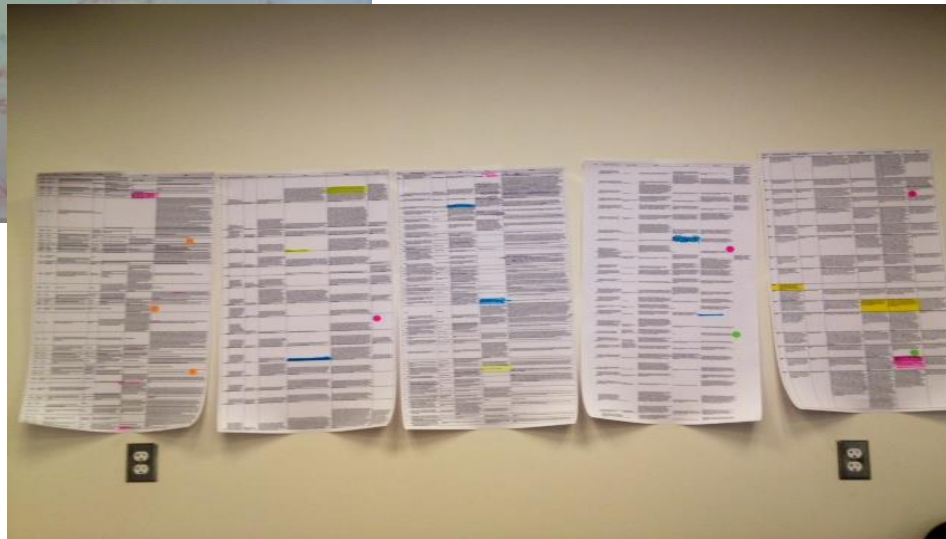
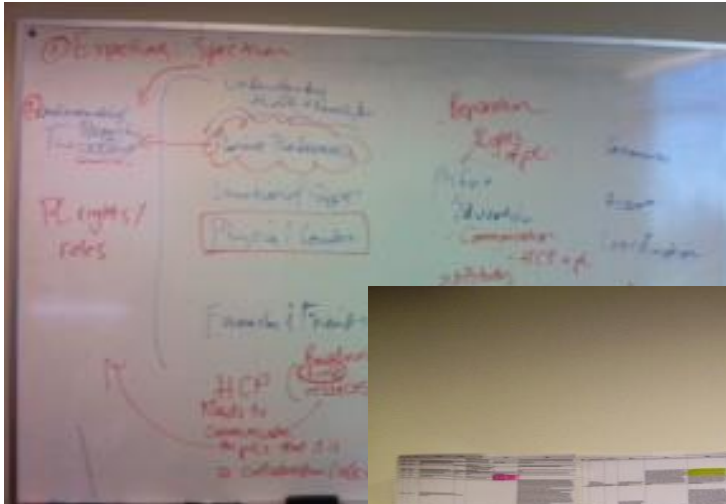
— Workshop Participant



Spectrum of Participation (IAP2, 2007; Vancouver Coastal Health, 2007)

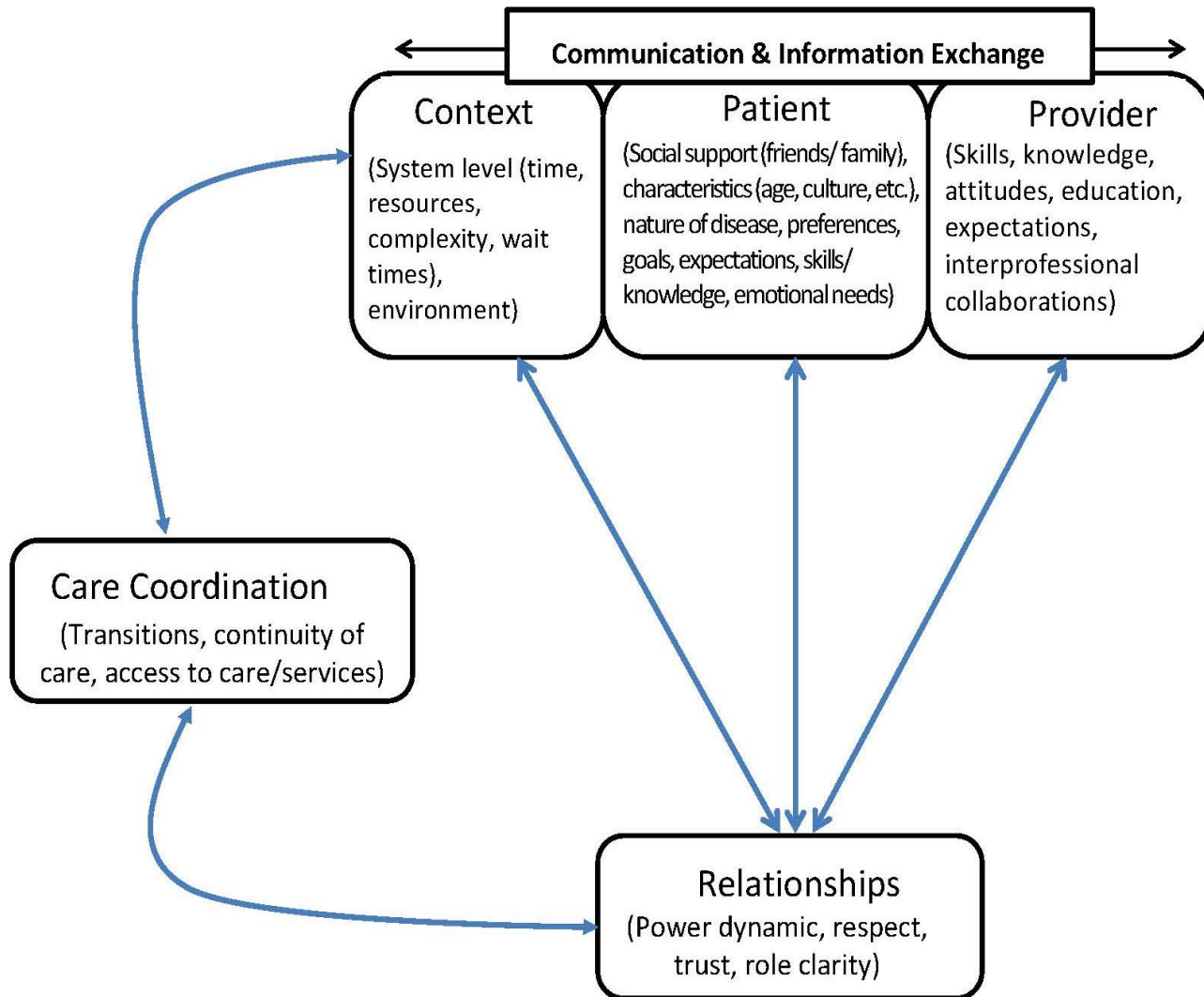


+ Highly sophisticated analyses, using latest technologies

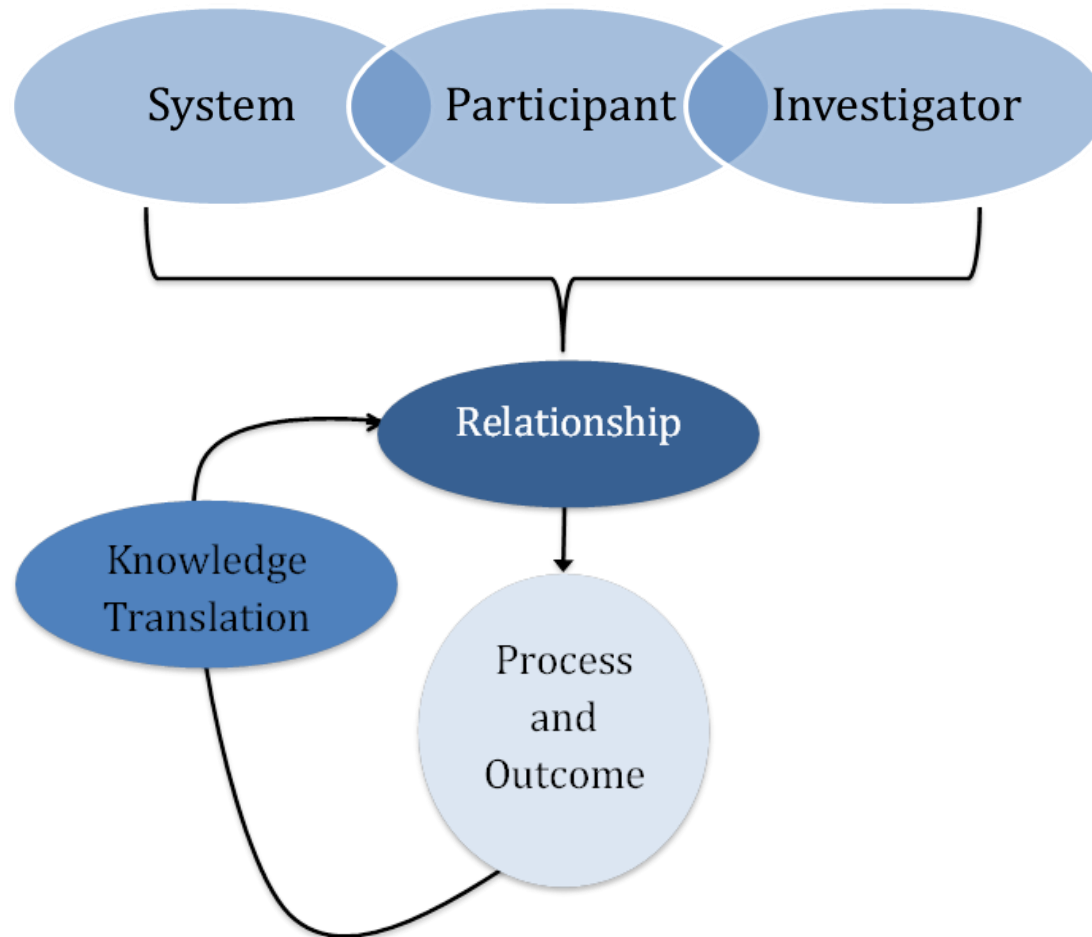




A Framework for Engagement in Clinical Decision-Making

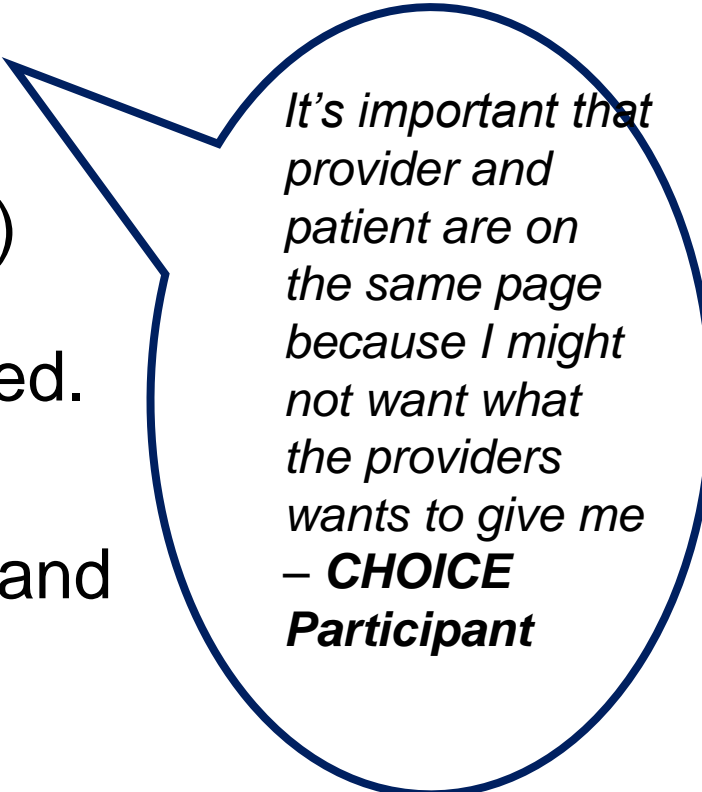


+ A Framework for Engagement in Research and Planning



+ *Some Key Findings*

- Health care providers, researchers/planners and older adults should discuss *how the person would like to be engaged* given specific situations
- The older adult's (and caregiver's) *preferences, goals, needs, and expectations* need to be discussed.
- *Communication is key* to the development of an open, honest, and trusting *relationship*



It's important that provider and patient are on the same page because I might not want what the providers wants to give me
– **CHOICE**
Participant

+ ...Getting Engaged



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Thank you!

@GHS_UW

@paulstolee

uwaterloo.ca/geriatric-health-systems-research-group/

