

CHCA Project ECHO Integrated Seniors Care

All Teach, All Learn

Bridging the Knowledge Gap in
Home and Primary Health Care



Respecting and Valuing Diverse Perspectives in Shared Decision-Making: Collaborative Care Planning for Older Adults

Subject Expert:

Dr. France Légaré, B. Sc. Arch, MD, MSc, PhD, CCFP, FCFP, Canada Research Chair in Shared Decision-Making and Knowledge Mobilization, Department of Family Medicine and Emergency Medicine, Faculty of Medicine, Université Laval

Panelists:

Dr. Yinka Akin-Deko, Family Physician, Dartmouth, NS

Wendy Gairy, RN, Care Coordinator, Ontario Health at Home

Tashani Parker, BSW, MSW, RSW, DrPH student

Host: Jennifer Campagnolo, CHCA
June 9, 2025

Land Acknowledgement



Artist Credit: Patrick Hunter

We recognize with humility and gratitude that Canada is located in the traditional, historical and ceded and unceded Lands of First Nation, Inuit and Metis Peoples. On behalf of us all, we acknowledge and pay respect to the Indigenous peoples past, present and future who continue to work, educate and contribute to the strength of this country.

Shared Decision-Making

An integrated approach to shared decision-making with older adults, their family, and healthcare team ensures:

- **Respect for cultural values, communication preferences, and lived experiences**
- **Enhanced decision-making quality**
- **Supports safe aging at home**

Ultimately, integrated shared decision-making helps ensure that care decisions are not only clinically sound but also deeply respectful of the person's identity, context, and wishes



Introductions



Dr. France Légaré

Canada Research Chair in
Shared Decision-Making and Knowledge Mobilization
University of Laval



Wendy Gairy

Care Coordinator,
Ontario Health at Home



Dr. Yinka Akin-Deko,
Family Physician, NS



Tashani Parker
Doctoral student
University of Toronto

Decision-making autonomy for older adults in the context of home care (HC) – Work focused on shared decision making in Quebec, 2007– 2025

Dre France Légaré, C.Q., BSc Arch, MD, MSc, PhD,
CCMF, FCMF
Chaire de recherche du Canada sur la décision partagée
et la mobilisation des connaissances
9 June 2025



Canada Research Chair
in Shared Decision-Making
and Knowledge Mobilization




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Objectives

- By the end of this presentation, participants will be able to:
 - Define and discuss the relevance of Shared Decision-Making (SDM)
 - Identify remaining gaps in SDM across Canada
 - Reflect on Decision-Making Needs of Seniors Receiving Home Care
 - Explore effective SDM Support Interventions for Seniors in Home Care
 - Discuss the acceptability and impact of SDM Interventions for Seniors in Home Care

Key messages

- Shared Decision-Making (SDM) = engagement of end-users in decisions about their health
- Seniors receiving home care in Canada are not engaged in decisions about their health
- Their decision-making needs are primarily related to their location of care
- Decision aids, training of clinicians, and public awareness campaigns help foster SDM
- SDM tools such as patients' decision aids and SDM training programs have been co-developed and tested



Shared Decision- Making: Definition and Relevance

Shared Decision-Making: : definition

- A **process** through which clinicians and the patient work together to make informed decisions that align with the patient's values regarding their health care.

FROM THE EDITOR-IN-CHIEF

DOI: 10.1377/hlthaff.2013.0037

Rx For The 'Blockbuster Drug' Of Patient Engagement

BY SUSAN DENTZER


Even in an age of hype, calling something "the blockbuster drug of the century" grabs our attention. In this case, the "drug" is actually a concept—patient activation and engagement—that should have formed the heart of health care all along.

The topic of this thematic issue of *Health Affairs*, patient engagement is variously defined; the Institute for Healthcare Improvement describes it as "actions that people take for their health and to benefit from care." En-



Demonstrations at Seattle-based Group Health and elsewhere have already shown that fully informed patients often choose less invasive and lower-cost treatment than their doctors recommend—and that variation in practice patterns among different physicians also narrows as a result.

But while many physicians have bought into shared decision making, others haven't. Grace Lin and coauthors describe a largely unsuccessful attempt to spread the use of decision aids—typically, brochures or videos that spell out pros and cons of various treatment options and can lay the groundwork for discussions between patients and physicians. In their case study of five primary care practices in California, the effort ran into a number of obstacles—including some physicians' reluctance to give up their traditional decision-making roles.



Shared Decision- Making : 5 Steps

1-Identify the decision that needs to be made

Ottawa Personal Decision Guide

For People Making Health or Social Decisions



1 Clarify your decision.

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice?

☐ Not thought about it

☐ Thinking about it

☐ Close to choosing

☐ Made a choice

2- Discuss the options: Evidence & Values/Preferences

2 Explore your decision.



Knowledge

List the options and benefits and risks you know.



Values

Rate each benefit and risk using stars (★) to show how much each one matters to you.



Certainty

Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0 ★ not at all 5 ★ a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0 ★ not at all 5 ★ a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer?

☐ Option #1

☐ Option #2

☐ Option #3

☐ Unsure

3-Explore the desired role

Which option do you prefer?

☐ Option #1

☐ Option #2

☐ Option #3

☐ Unsure



Support

Who else is involved?

Which option do they prefer?

Is this person pressuring you?

☐ Yes

☐ No

☐ Yes

☐ No

☐ Yes

☐ No

How can they support you?

What role do you prefer in making the choice?

☐ Share the decision with...

☐ Decide myself after hearing views of...

☐ Someone else decides...

4-Assess comfort with the decision – SURE (informed consent)

3 Identify your decision making needs.

Adapted from The SURE Test © 2008 O'Connor & Légaré.



Knowledge

Do you know the benefits and risks of each option?

☐ Yes

☐ No



Values

Are you clear about which benefits and risks matter most to you?

☐ Yes

☐ No



Support

Do you have enough support and advice to make a choice?

☐ Yes

☐ No



Certainty

Do you feel sure about the best choice for you?

☐ Yes

☐ No

If you answer 'no' to any question, you can work through steps two **2** and four **4**, focusing on your needs.

People who answer "No" to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

Measuring Informed Consent in Daily Practice Using the SURE Tool (Melbourne, Australia)



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About

11:07 5G LTE

M40.00 Consent t...

☐ Damage to close nerves, blood vessels or other structures
☐ Sub-optimal outcome
☐ All procedures carry the risk of death from surgical and/or anaesthetic complications (including dental damage)
☐ Post operative complications such as confusion, stroke, heart attack, pneumonia, delirium
☐ Anaesthetic complication
☐ Allergic reaction to equipment or materials
☐ Difficulty Passing Urine
☐ Dental damage
☐ Other

What to Expect After the Procedure
☐ Pain
☐ Scarring of your skin
☐ Driving or work restrictions
☐ Social/quality of life (medium to longer term)
☐ Other

03/2019 Page 1 of 2

Austin HEALTH
CONSENT TO ELECTIVE TREATMENT/PROCEDURE

U.R Number
Surname
Given Name(s)
Date of Birth
Address
Gender
Medicare Number

AFFIX PATIENT LABEL HERE

CLINICIAN
☐ I have explained the above procedure and risks to the patient, and I believe they have understood the information
Signature Designation/Department/Unit
First Name and Surname Unit Contact Details Date / /

SURE Test		YES	NO
Sure of myself	Do you feel SURE about the best choice for you?	<input type="checkbox"/>	<input type="checkbox"/>
Understand information	Do you know the benefits and risks of each option?	<input type="checkbox"/>	<input type="checkbox"/>
Risks-benefit ratio	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/>	<input type="checkbox"/>
Encouragement	Do you have enough support and advice to make a choice?	<input type="checkbox"/>	<input type="checkbox"/>

Consent to Procedure/Treatment
By signing this form, I acknowledge that:

PATIENT
☐ I request and consent to have the recommended procedure/treatment.
☐ I understand that I can change my mind at any time.
☐ I understand what has been explained to me regarding either my or the patient's condition, likely outcomes, risks, and alternatives to managing my condition.
☐ I have received information about the procedure and understand what is involved including blood products, anaesthetic and the risk of dental damage, if relevant.
☐ I understand that I may need extra procedures to save my life or prevent serious harm to my health.

☐ I agree to having a blood test to check for HIV/Hepatitis B/Hepatitis C in the event of accidental blood or bodily exposure (for example a needlestick injury).
Note: this is not mandatory for consent to be valid
☐ I agree to a blood transfusion, or other procedures to prevent serious harm to my health or to save my life.
Note: this will require further discussion and planning
☐ I understand that I have been given an urgency category and placed on the relevant waiting list. I will be booked for the procedure accordingly.
☐ I understand that I should tell my healthcare team if my health condition changes before the procedure.

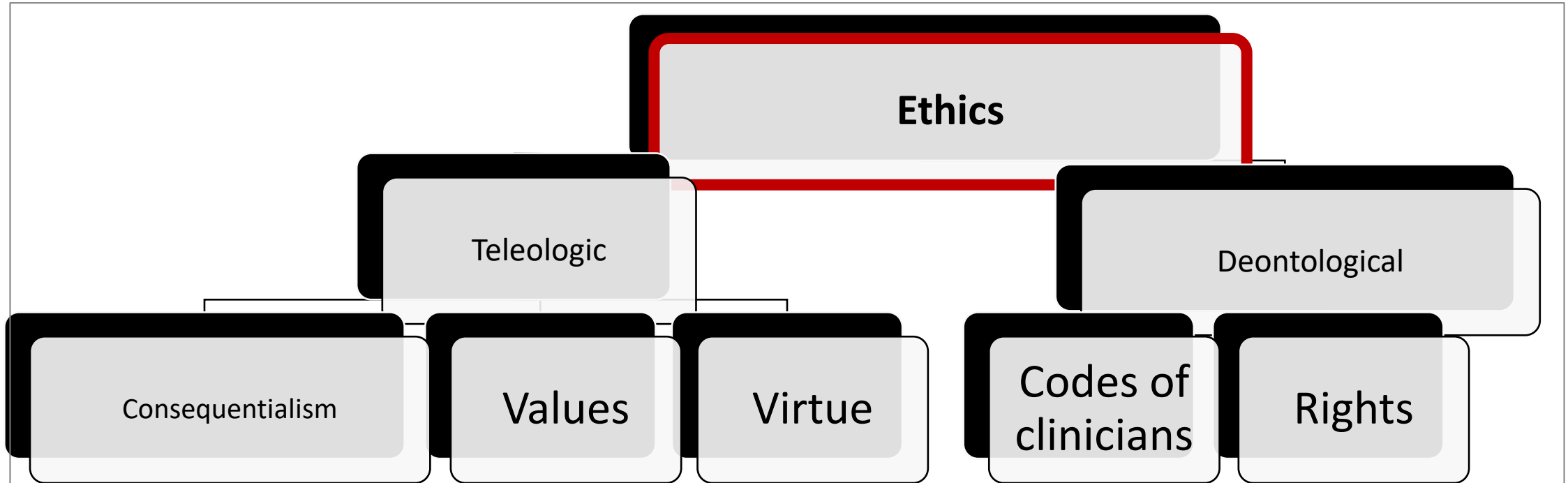
If you have answered NO to any of the above, you should consider if you need more time or information to make your decision and discuss this with your clinician.
☐ I understand that for research, education and improvement Austin Health will:
• Use my blood, tissue(s), images, and videos.
• Remove any information that could identify me.
• Make sure the right approvals are in place.

Process of Medical Treatment Decision Making Name: Signature:

5-Decide now or delay the decision



Ethical Relevance



1.1. Health Care Rights and Benefits – Federal Initiatives

a. Health Charter for Canadians

Article 4 of the bill outlines a substantial list of personal (individual) rights for users of the public health care system, including:

- (a) the right to be fully informed about one's health status;
- (b) the right to be informed about available treatment options;
- (c) the right to participate in decisions related to treatment.

Relevance for Achieving the Quintuple Aim

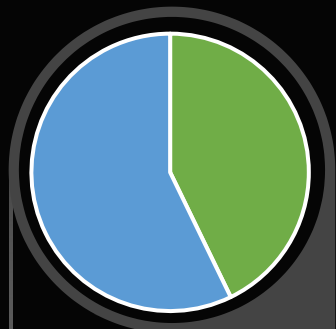




What do we
know about
the state of
SDM across
Canada?

How much are Canadians engaged in shared decision making (SDM) when facing health related decisions? A Web-based survey of 10 provinces

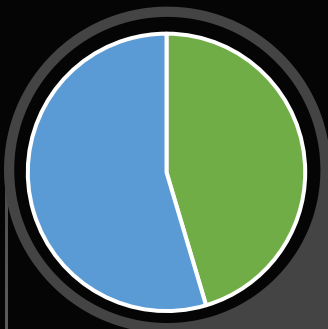
Haesebaert et al. CMAJ Open 2019



42.8 %

Choice
discussed

always/often



45.4 %

Advantages/
disadvantages
presented

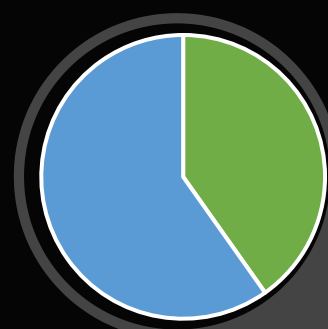
always/often



38.8%

Asked about
ideas/
preferences

always/often



40.2%

Asked about
preferred
option

always/often

Canadians (n=1591) experience a **low degree of SDM**, with variations across age, care setting, geographical area, province and ethnicity

Older people receiving home care experience the **lowest**

We know little about SDM in **indigenous populations**

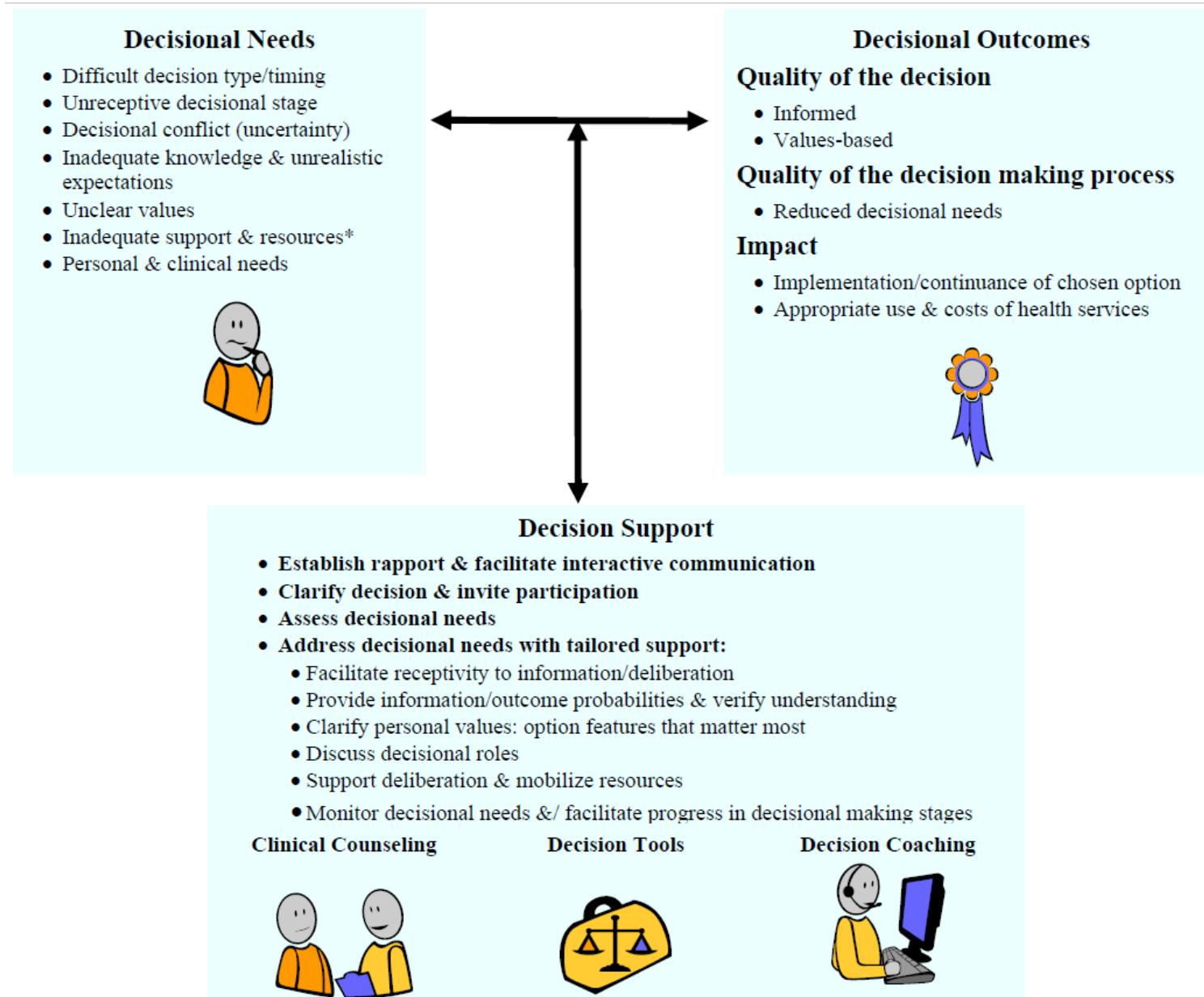


Decision- Making Needs of Seniors in Home Care

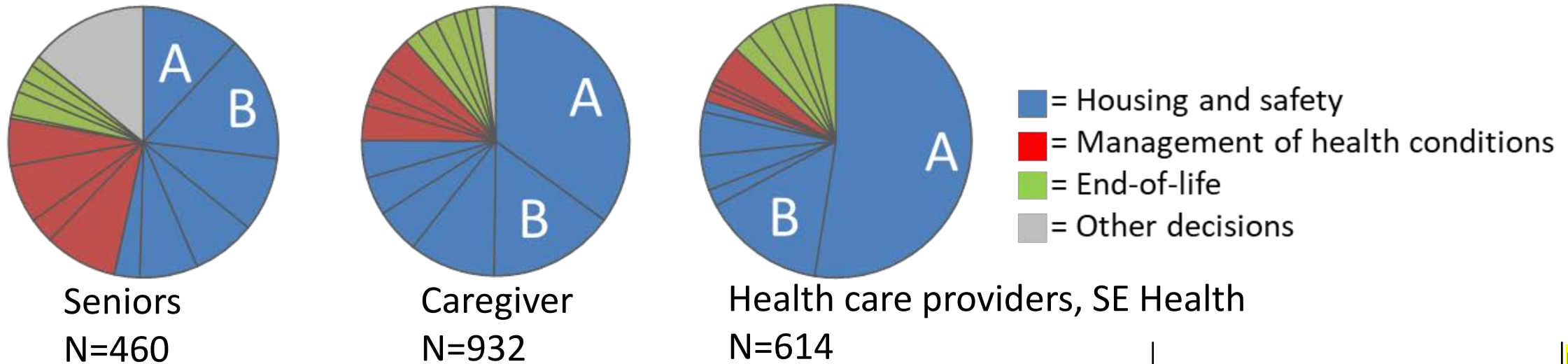
**Decision-making needs are defined
as:
the gap between a person's state
when facing a decision
and
the expected outcomes following
that decision.**

(<https://decisionaid.ohri.ca/ODST/pdf-f.php>).

The Ottawa Decision Support Framework



The types of difficult decisions are mainly those concerning the location of care (housing included)



Difficult Decisions Related to **Living Environment**:

A-Should I choose to stay at home or move?

B- What is the best option for me to stay safe at home?

What is the best option for me to prevent falls?

What is the best option for me to get care immediately?

Should I choose to receive assistance with my daily activities or not?

Should I stop driving my car or not?

Surveys			Deliberative process
N=460 Seniors	N=932 Caregiver	N=614 Health care providers	N=20 Decision-makers
2e	1er	1er	✓
1er	2e	2 ^e	✓
3e	3e	8e	
5e	4e	4e	
6e	5e	3e	✓
8e	6e	9e	

Synthèse portant sur les données probantes

Mettre à grande échelle la prise de décision partagée
en soins à domicile et en milieu communautaire au
Canada
12 décembre 2019

Deliberative Forum with Five Provinces and the Federal Level

<https://www.mcmasterforum.org/about-us/products/project/scaling-up-shared-decision-making-in-home-and-community-care-in-canada>



- Home and community care increasingly involves complex decisions, yet older adults are rarely meaningfully engaged in the process.
- There is confusion between the care needs of older adults and their decision-making needs.
- Little attention has been paid to how service providers and policymakers can support older adults' decision-making needs.
- Systemic factors further complicate efforts to meet the decision-making needs of older adults.
- Other equity-related observations relevant to this issue.

Dialogue Summary

Scaling Up Shared Decision-making in Home and Community Care in Canada

12 December 2019

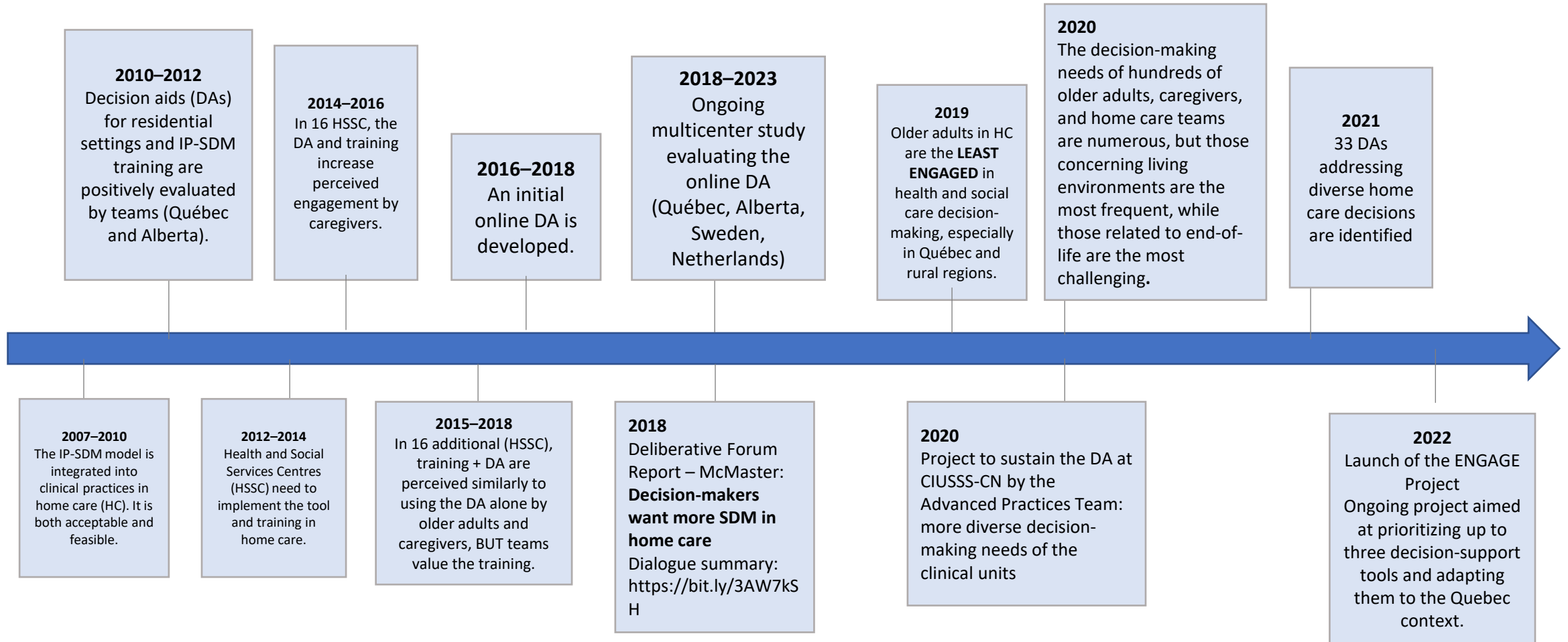


- **What do we know about the three groups of decision-making needs?**
- Group 1 — Decision-making needs that service providers could help address:
- **Service providers** could help meet certain decision-making needs of older adults regarding home and community care, such as knowing whom to turn to for understanding where and how to obtain care and assistance, where to find help in making complex decisions, or what to expect regarding the frequency and intensity of care.
- Group 2 — Decision-making needs that health policymakers could help address:
- Government health policymakers could contribute to meeting certain decision-making needs of older adults in home and community care, such as as knowing how they or their caregivers can ensure they have a say in the future direction of home and community care, how to access additional care beyond what is publicly funded, or how to determine if the care provided to people like them is adequate.
- Group 3 — Decision-making needs that policymakers in other sectors could help address:
- **Policymakers** in other sectors (e.g., finance, housing, and transportation) can help meet certain decision-making needs of older adults regarding home and community care, such as understanding what type of housing would allow them to receive an appropriate level of care, what kinds of food support are available, what transportation options they can access, or what types of financial assistance exist.



Shared Decision- Making Support Interventions

Timeline: Shared Decision-Making in Home Care (2007–ongoing)



RESEARCH ARTICLE

Open Access



Development of a decision guide to support the elderly in decision making about location of care: an iterative, user-centered design

Mirjam M. Garvelink¹, Julie Emond², Matthew Menear¹, Nathalie Brière², Adriana Freitas¹, Laura Boland³, Maria Margarita Becerra Perez¹, Louisa Blair¹, Dawn Stacey^{4,3} and France Légaré^{1,5*}

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Plain English summary

For the elderly to get the care and services they need, they may need to make the difficult decision about staying in their home or moving to another home. Many other people may be involved in their care too (friends, family and healthcare providers), and can support them in making the decision. We asked informal caregivers of elderly people to help us develop a decision guide to support them and their loved ones in making this decision. This guide will be used by health

Pour recevoir les soins et services dont j'ai besoin devrais-je rester chez moi ou déménager?



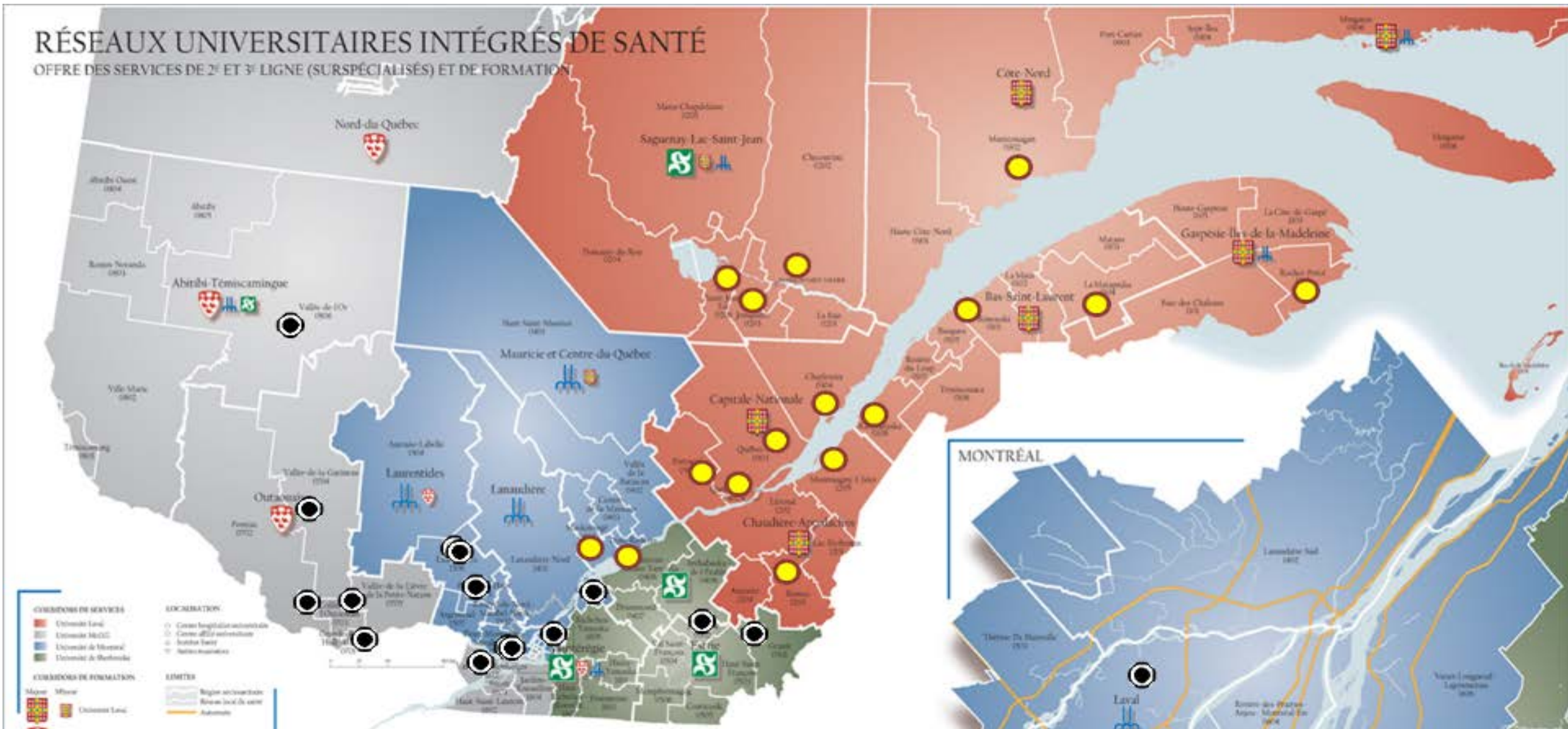
Decision aid guide

To receive the care
and services I need,
should I stay at
home or move?



RÉSEAUX UNIVERSITAIRES INTÉGRÉS DE SANTÉ

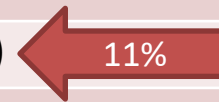
OFFRE DES SERVICES DE 2^e ET 3^e LIGNE (SURSPÉCIALISÉS) ET DE FORMATION



2014-18 Two large randomized trials: a total of 32 CSSS

More individuals took an active role in the decision to relocate a senior following training of the teams in shared decision-making and the use of a decision aid tool.

Variable n (%)	Intervention arm (n=138)	Control arm (n=158)
Role assumed in decision-making		
Active role	71 (51.5)	64 (40.5)
Collaborative role	38 (27.5)	44 (27.9)
<small>p= 0.09; ICC: 0.14</small> Passive role	28 (20.3)	50 (31.6)
No role	1 (0.7)	0 (0.0)

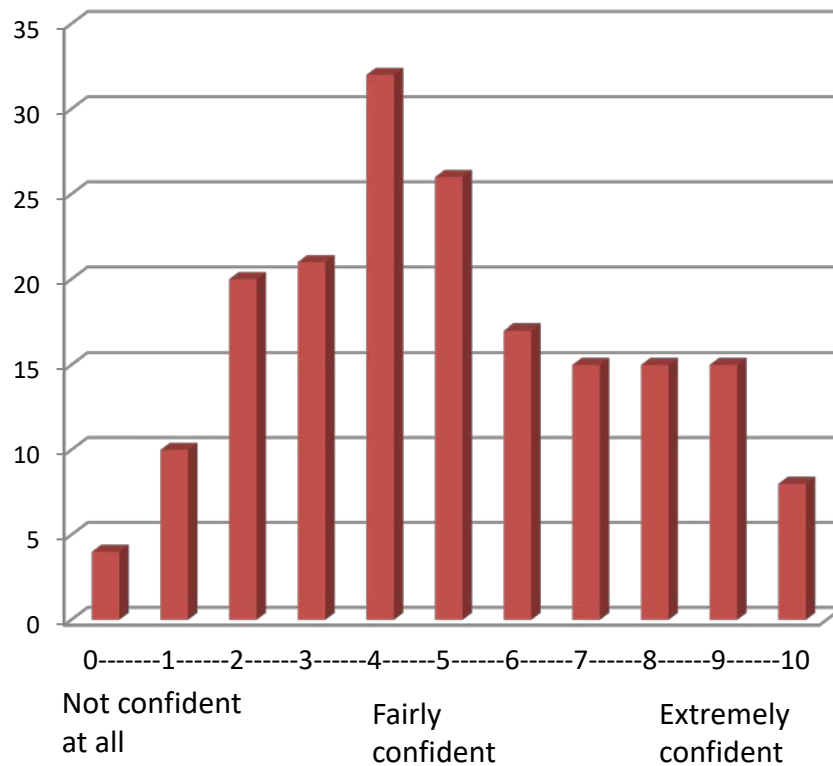


What feedback did we receive from the home care teams following the shared decision-making training?

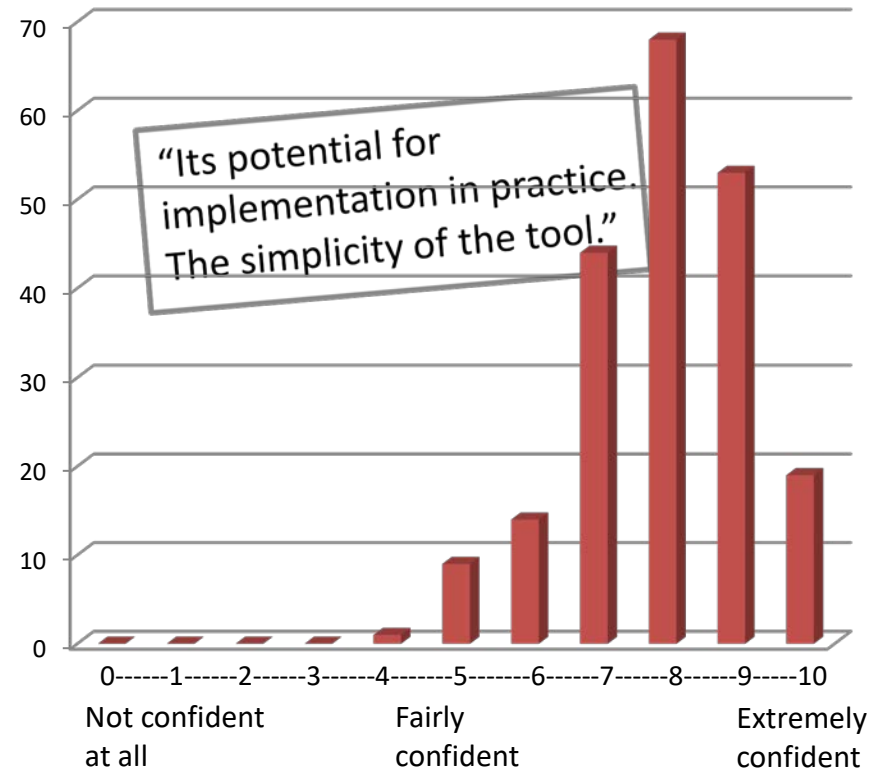


Confidence in using the patient decision aid

Before training (n=183)



After training (n=209)



Confidence that this will help seniors and their caregivers engage in the decision-making process

After training (n=209)



Impact on caregivers' involvement in decision-making: urban vs. rural settings

Variable n (%)	Intervention group (n=138)	Control group (n=158)
Decision-making role (urban/semi-urban setting)		
Active/collaborative role	40 (81.6)	13 (65)
Passive role	9 (18.4)	7 (35)
Decision-making role (rural setting)		
Active/collaborative role	69 (78.4)	95 (68.8)
Passive role	19 (21.6)	43 (31.2)

17%

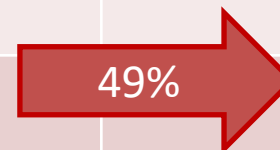
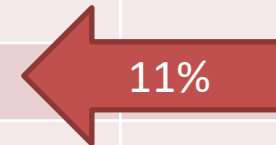
10%

The effect in urban/semi-urban settings is more pronounced than in rural areas

Adekpedjou. R. et al.

Preferred role vs. assumed role in decision-making is less discordant.

Variable n (%)	Intervention group (n=138)	Control group (n=158)
Preferred role in decision-making		
Active role	66 (47.8)	69 (43.7)
Collaborative role	52 (37.7)	61 (38.6)
Passif role	19 (13.8)	28 (17.7)
Missing data	1 (0.7)	0 (0.0)
Assumed role in decision-making		
Active role	71 (51.5)	64 (40.5)
Collaborative role	38 (27.5)	44 (27.9)
Passive role	28 (20.3)	50 (31.6)
Missing data	1 (0.7)	0 (0)
Mismatch between preferred and assumed role	13 (25.5)	38 (74.5)



STUDY PROTOCOL

Open Access

Improving Decision making On Location of Care with the frail Elderly and their caregivers (the DOLCE study): study protocol for a cluster randomized controlled trial

France Légaré^{1,2*}, Nathalie Urière³, Dawn Stacey^{4,5}, Henriette Bourassa⁶, Sophie Desroches^{1,7}, Serge Dumont^{8,9}, Kimberly Fraser¹⁰, Adriana Freitas¹¹, Louise-Paul Rivest¹² and Lise Roy³

Abstract

Background: This study aims to improve decision making on location of care for frail elderly and their caregivers.

Journal of BMC Medical Research Notes
DOI 10.1186/s13063-019-0567-7

BMC Research Notes

SHORT REPORT

Open Access

In for a penny, in for a pound: the effect of pre-engaging healthcare organizations on their subsequent participation in trials

Miriam M. Garvelink¹, Adriana Freitas¹, Matthew Mancini², Nathalie Urière³, Dawn Stacey⁴ and France Légaré^{1,2*}

Abstract

Background: Participant recruitment in clinical trials is often challenging. Building partnerships with healthcare organizations during proposal development facilitates access to the community and may influence subsequent organization participation and participant recruitment. We aimed to assess how pre-engaging decision of healthcare organizations influenced organization participation in a subsequent trial.

Findings: Reported non-enrollment in a pilot trial for a cluster randomized controlled trial involving 11 eligible health and social services agencies (HSCs). During proposal development, we asked eligible HSCs decision in a randomized to study.

Journal of BMC Medical Research Notes
DOI 10.1186/s13063-019-0567-7

Research Involvement and Engagement

RESEARCH ARTICLE

Open Access

Development of a decision guide to support the elderly in decision making about location of care: an iterative, user-centered design

Miriam M. Garvelink¹, Julie Simon^{2,3}, Matthew M. Mancini⁴, Adriana Freitas¹, Louise Blais⁵, De

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Department of Geriatrics and Long-term Care, Centre de Recherche en Vieillesse, Université de Montréal, 3800 Avenue Lacombe, Montréal, QC H3T 1J4, Canada

Plain English summary
For the elderly, the decision of where to live is often difficult. This decision affects their health and the health of their caregivers. We developed a decision guide to help elderly and their caregivers make this decision.

BMC Geriatrics

Impact of home care versus alternative locations of care on elder health outcomes: an overview of systematic reviews –Manuscript Draft–

Manuscript Number:	BGTD-D-18-00163R3
Full Title:	Impact of home care versus alternative locations of care on elder health outcomes: an overview of systematic reviews
Article Type:	Research Article
Section/Category:	Health services research
Funding Information:	Canadian Family Network (2018-2019)
Abstract:	<p>Background: Many elders struggle with the decision of where to live or where to receive care. A person's location of care can influence health and well-being. Healthcare organizations and policy makers are increasingly challenged to better support older adults and their caregivers. A summary of the evidence that examines home care compared to other care locations can inform decision making. We surveyed and summarized the evidence evaluating the impact of home care versus</p>

ENGAGING PATIENTS IN CLINICAL CARE

By Mirjam M. Garvelink, Parvati A. E. Nijman, Rhonda A. Adcock, Ndeye T. Diouf, Lutz Goh, Louise Blair, and France Légaré

AGING & HEALTH

A Synthesis Of Knowledge About Caregiver Decision Making Finds Gaps In Support For Those Who Care For Aging Loved Ones

ABSTRACT We conducted a mixed methods knowledge synthesis to assess the effectiveness of interventions to improve caregiver decision making for

DOI: 10.1186/s13063-019-0567-7
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Miriam M. Garvelink
and several other contributors
have published this article.

Journal of BMC Medical Research Notes
DOI: 10.1186/s13063-019-0567-7

Research Involvement and Engagement

REVIEW ARTICLE

Open Access

Giving voice to older adults living with frailty and their family caregivers: engagement of older adults living with frailty in research, health care decision making, and in health policy

Ilyse Holmbeck¹, Joyce Reim², Lisa Ashely³, Doris Barwick⁴, Joseph Himm⁵, Paul Hurst⁶, France Légaré⁷, Megan Mahoney⁸, Alex Maybee⁹, Heather McKel¹⁰, Gary Pulman¹¹, Richard Sawatzky^{11,12}, Paul Stolee¹³ and John Muscedere¹⁴

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Department of Geriatrics and Long-term Care, Centre de Recherche en Vieillesse, Université de Montréal, 3800 Avenue Lacombe, Montréal, QC H3T 1J4, Canada

Plain English summary

This paper discusses engaging older adults living with frailty and their family caregivers. Frailty is a state that puts an individual at a higher risk for poor health outcomes and death. Understanding whether a person is frail is important because

ENGAGEMENT OF OLDER ADULTS RECEIVING HOME CARE AND THEIR CAREGIVERS IN SHARED DECISION-MAKING WITH CLINICAL TEAMS (ENGAGE)

Funded by CIHR

Canada Research Chair
in Shared Decision-Making
and Knowledge Mobilization



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Objectives

- 1) Establish a close partnership with all knowledge users (KUs);
- 2) Assess the scalability of the 33 decision aids for older adults in home care (HC) identified through a systematic review;
- 3) Prioritize the decision aids that meet the needs of the KUs;
- 4) Lay the groundwork for adapting the prioritized decision aids to the context of the KUs, with the goal of integrating them into training for home care clinical teams;
- 5) Strengthen capacity in partnership and research related to home care and care for older adults.

Objectives

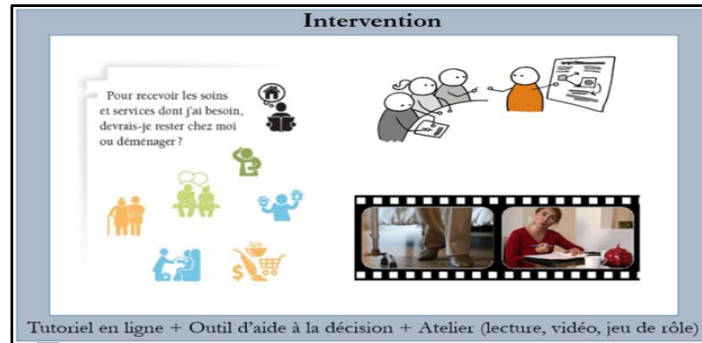
1) Scalability assessment of the tools using the ISSaQ 4.0 tool

ISSaQ 3.0	
Dimensions	Items
Health problem addressed by the innovation	2
Development process of the innovation	3
Innovation characteristics	5
Strategic, political or environmental context of the innovation	4
Evidence available for effectiveness of the innovation	2
Innovation costs and quantifiable benefits	5
Potential for implementation fidelity and adaptation of the innovation	6
Potential reach and acceptability to the target population	7
Delivery setting and workforce	3
Implementation infrastructure required for scaleup	5
Sustainability	3
n=11	n=45

2) Prioritization of tools that address stakeholders' needs (eDelphi)



3) Cultural adaptation of the prioritized tools and of a training to the quebec context



4) Partnership and capacity building in home care and aging research



Obj. 2: Prioritization of tools (eDelphi)

Results of the consensus with the steering committee to select the Delphi Decision Aids (DAs)

The tools included in the Delphi

Of the 33 tools identified in the systematic review, 10 were selected:

- **2 tools related to living environment:** maintaining independence in daily activities; deciding whether to stop driving following a memory disorder diagnosis
- **3 tools on health condition management and care:** malnutrition; options for feeding individuals with dementia; depression
- **1 tool on end-of-life care:** deciding whether to discontinue life-sustaining treatments
- **2 tools for caregivers:** acting as a substitute decision-maker for a person with loss of autonomy; options for supporting caregivers
- **2 tools for older adults with memory disorders:** maintaining cognitive abilities; options to ensure quality of life and comfort

Obj. 2: Prioritization of tools (eDelphi)

6 tools for the 2nd round

FINDING:

Among the 10 tools selected in the first round:

- 2 tools related to the living environment: maintaining independence in daily activities and deciding whether to stop driving following a memory disorder diagnosis
- ~~3 tools related to the management of health conditions and care: malnutrition; options for feeding individuals with dementia; depression~~
- 1 tool related to end-of-life care: deciding whether to discontinue life-sustaining treatments
- 2 tools intended for caregivers: substitute decision-making for a person with loss of autonomy; options to support caregivers
- 2 tools for older adults with memory disorders: maintaining cognitive abilities and options to ensure quality of life and comfort

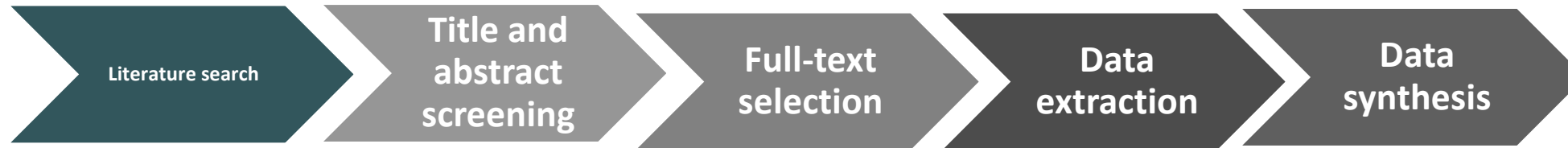
Results of the 6 prioritized tools during the 2nd round

Selection of one tool with the committee

Tool	Number of prioritized criteria (n = 6, threshold 75%)	Date of the last update	Available for adaptation
Decision aid tool for situations where a loved one is too ill to make decisions about their own health and a family member becomes the substitute decision-maker for subsequent healthcare decisions.	5 (frequency, difficulty, values + frequency and difficulty according to experience)	2008	No (tool no longer exists)
For advance care planning: Should I stop the treatments that are keeping me alive?	4 (difficulty, values + difficulty according to experience)	Nov. 2023	No (no adaptation rights)
Options to ensure the quality of life and comfort of older adults with memory and attention disorders?	4 (difficulty, values + frequency and difficulty according to experience)	Mar 2016	Yes
Options to support me as a caregiver of an older adult with memory and attention disorders.	2 (frequency, values)	Nov./Dec. 2015	Yes
Maintaining independence in daily activities.	2 (frequency, values)	May 2018 (V1) et April 2020 (V2)	Yes
<i>Deciding whether to stop driving following a diagnosis of memory and attention disorders related to aging.</i>	<i>2 (difficulty + difficulty according to experience)</i>	<i>Feb. 2016</i>	<i>Yes</i>

Update of the tool's evidence base

Devis : Rapid review



Search strategy: Launched on June 18, 2024 (systematic reviews)

Update of the tool's evidence base

Data extraction:

- 26 studies included
 - 10 effective studies covering 7 types of interventions
 - 2 interventions shared with the existing decision aid tool and 5 new interventions:
 - Cognitive stimulation
 - Art therapy
 - Mind-body therapies
 - Online cognitive intervention
 - Physical activity and cognitive training
 - Reminiscence
 - Virtual reality

Update of the tool's evidence base

- ❖ Comparison of effective interventions: those included in the existing decision aid tool and those identified through the rapid review

Types of interventions	In the existing decision aid tool	In our review
•Consultation in a specialized clinic to establish the diagnosis	✓	X
•Recovery-oriented intervention	✓	X
•Caregiver training and support	✓	X
•Cognitive stimulation	✓	✓
•Art therapy	✓	✓
•Mind-body therapies	X	✓
•Online cognitive intervention	X	✓
•Physical activity and cognitive training	X	✓
•Reminiscence	X	✓
•Virtual reality	X	✓

Key messages

- Shared Decision-Making (SDM) = engagement of end-users in decisions about their health
- Seniors receiving home care in Canada are not engaged in decisions about their health
- Their decision-making needs are primarily related to their location of care
- Decision aids, training of clinicians, and public awareness campaigns help foster SDM
- SDM tools such as patients' decision aids and SDM training programs have been co-developed and tested

Thank you!

<http://www.decision.chaire.fmed.ulaval.ca/>



Panel Discussion

Q&A



Dr. France Légaré

Canada Research Chair in
Shared Decision-Making and Knowledge Mobilization
University of Laval



Wendy Gairy

Care Coordinator,
Ontario Health at Home



Dr. Yinka Akin-Deko,
Family Physician, NS



Tashani Parker
Doctoral student
University of Toronto

Meet Mrs. Amina Khan

- **Mrs Amina** Khan is an 82 year old woman and widow who immigrated to Canada over 40 years ago and currently lives in an apartment with her adult son, who travels frequently for work.
- Her primary family support and carer is her adult daughter who lives within 30 minutes of her apartment.
- Her primary language is Urdu, and although she understands English, she prefers to speak in Urdu when discussing personal or complex matters.
- Mrs. Khan herself, played an active caregiving role within her extended family, and her own values are shaped by strong cultural values around aging and family responsibility.
- She receives publicly funded home care supports (personal care provider, medication management and currently, wound care for diabetic foot wound).

Meet Mrs. Amina Khan

Medical History (Multimorbidity):

- Type 2 Diabetes (non-insulin-dependent)
- Congestive Heart Failure (CHF)
- Hypertension
- Osteoarthritis
- Early-stage Chronic Kidney Disease (CKD)
- Cognitive decline suggestive of progression beyond Mild Cognitive Impairment (MCI); possible early-stage vascular dementia under consideration by primary care

Physical Health & Functional Status:

- Multiple chronic conditions have impacted her functional status:
- Despite diuretics she experiences shortness of breath with exertion.
- Her osteoarthritis affects mobility and grip strength, making tasks like preparing meals and personal care increasingly difficult.
- While her medications have remained stable over the past 3 months, her daughter has noted challenges with adherence and organizing her medication schedule.

Meet Mrs. Amina Khan

Current Challenges:

- Responsive behaviours are straining the home care relationship and have led to increased concern from the care team.
- Mrs. Khan has occasionally declined personal care and some visits, she has become verbally distressed, raising her voice or asking care providers to leave mid-task.
- Poor glycemic control due to missed insulin doses and irregular meals.
- Daughter is experiencing caregiver stress and considering long-term care, but Mrs. Khan strongly wishes to remain at home.
- Although Mrs. Khan lives with her adult son, he is often away for work and not consistently involved in her day-to-day care. It is unclear whether he is also experiencing caregiver stress and there are no concerns about mistreatment.
- Care coordination between the primary care team and home care is ad hoc, with no shared care plan or regular communication.
- Her daughter has requested more home support but is unsure how to coordinate services or who to speak to, highlighting gaps in system navigation and caregiver support.

Reflect on What You Heard...

Based on today's discussion what can you add or incorporate into your daily care or practices that will better support shared decision-making?

Join us next time to share and hear from others.

Upcoming TeleECHO Clinics



Integrated Seniors Care

cdnhomecare.ca/chca-project-echo

CHCA Project ECHO Integrated Seniors Care

All Teach, All Learn
Bridging the Knowledge Gap in
Home and Primary Health Care



Caring Together: Integrated Approaches to Support Responsive Behaviours in Dementia Care

June 25, 12 -1pm

CHCA Project ECHO Home-Based Palliative Care

All Teach, All Learn
Bridging the Knowledge Gap in
Home-Based Palliative Care



Holistic Spirituality and Care at End of Life

June 11, 12 – 1pm ET

