



Giving Voice to Frail Elderly Canadians

A TVN Citizen Engagement Initiative

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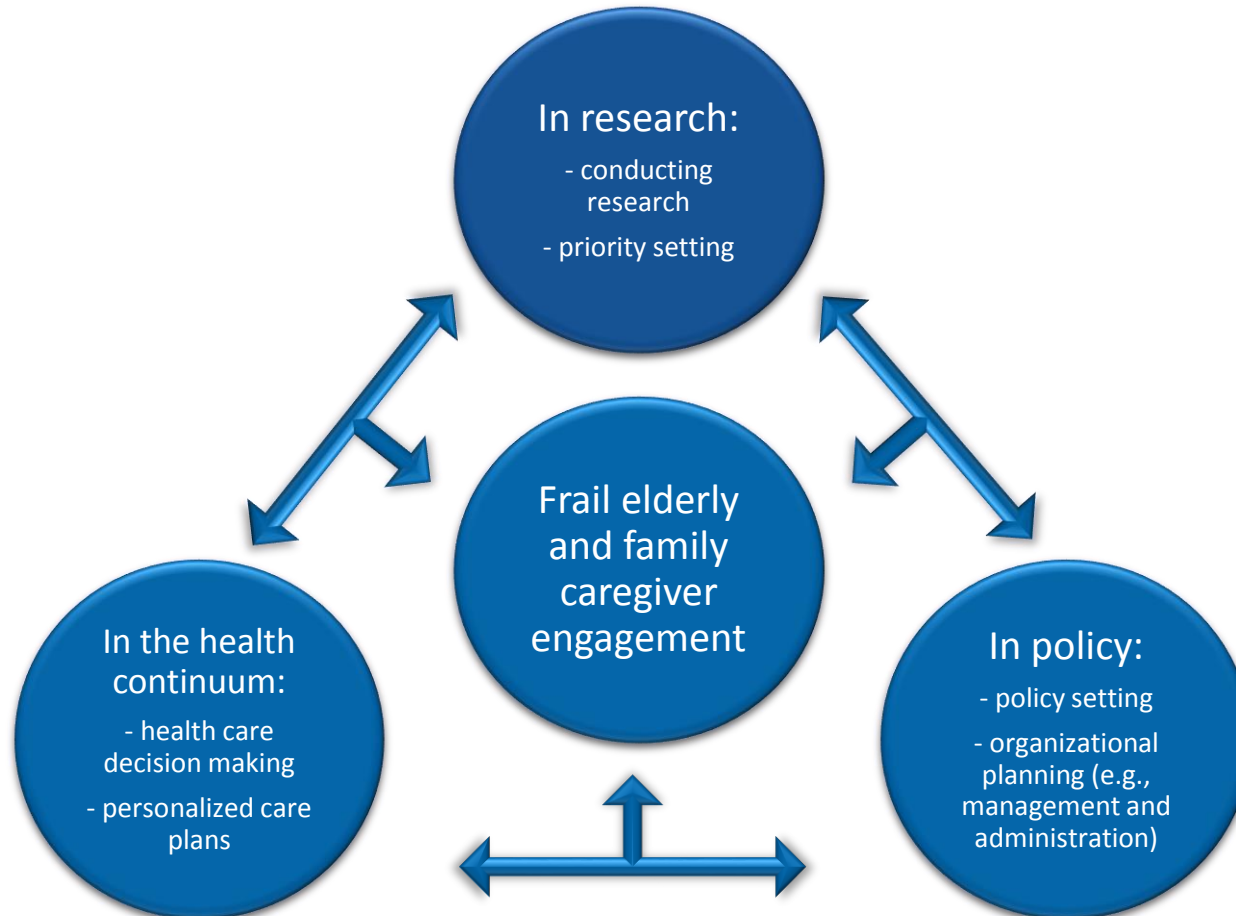
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Giving Voice to Frail Elderly Canadians Initiative

- Led by members of TVN's Citizen Engagement and Knowledge Translation committees
 - expertise in citizen engagement and knowledge implementation
 - delegates from a wide range of areas
- Tasked with engaging citizens and other stakeholders
 - Stakeholder meeting (Sept 2015)
 - Development of a white paper

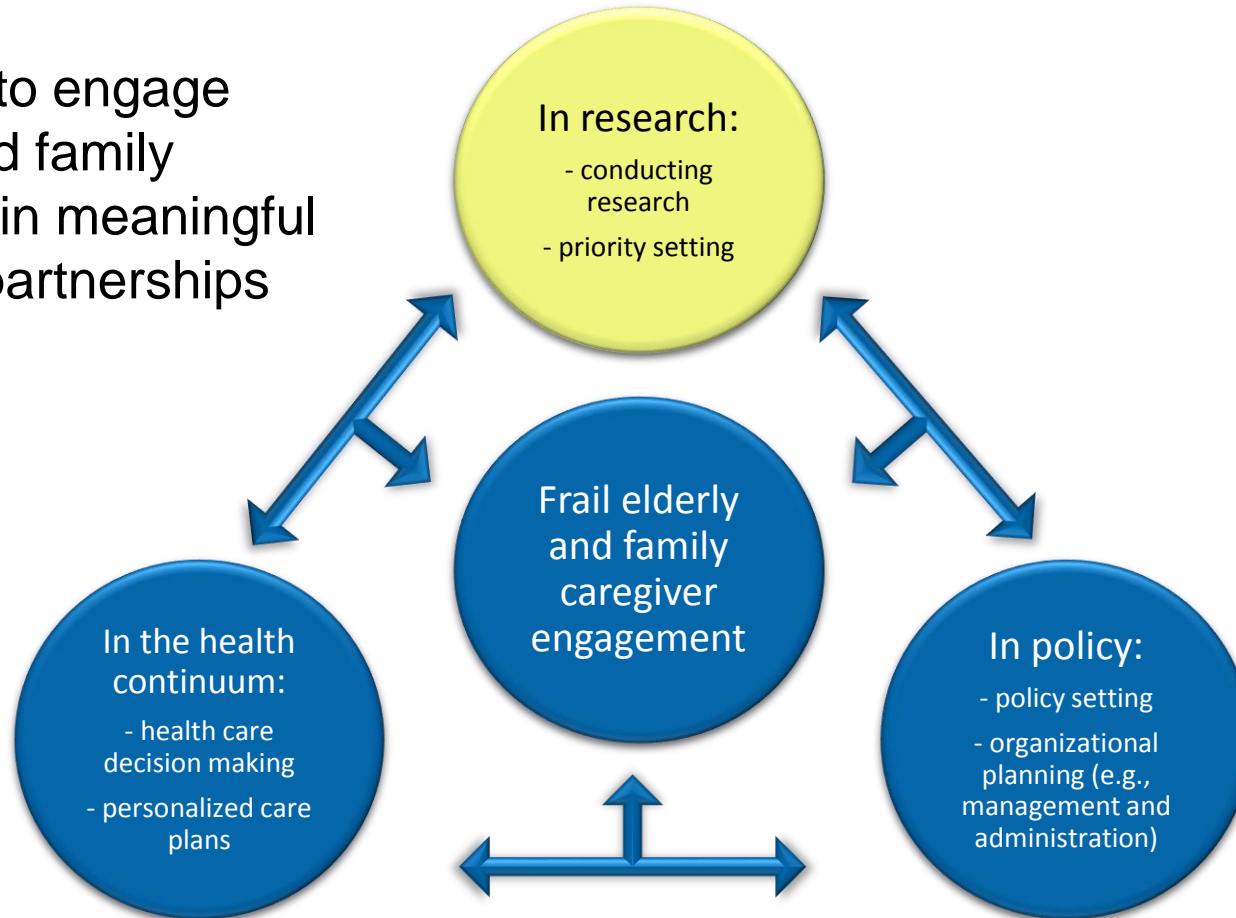


Pillars of Engagement



Pillars of Engagement

Strategies to engage citizens and family caregivers in meaningful **research** partnerships

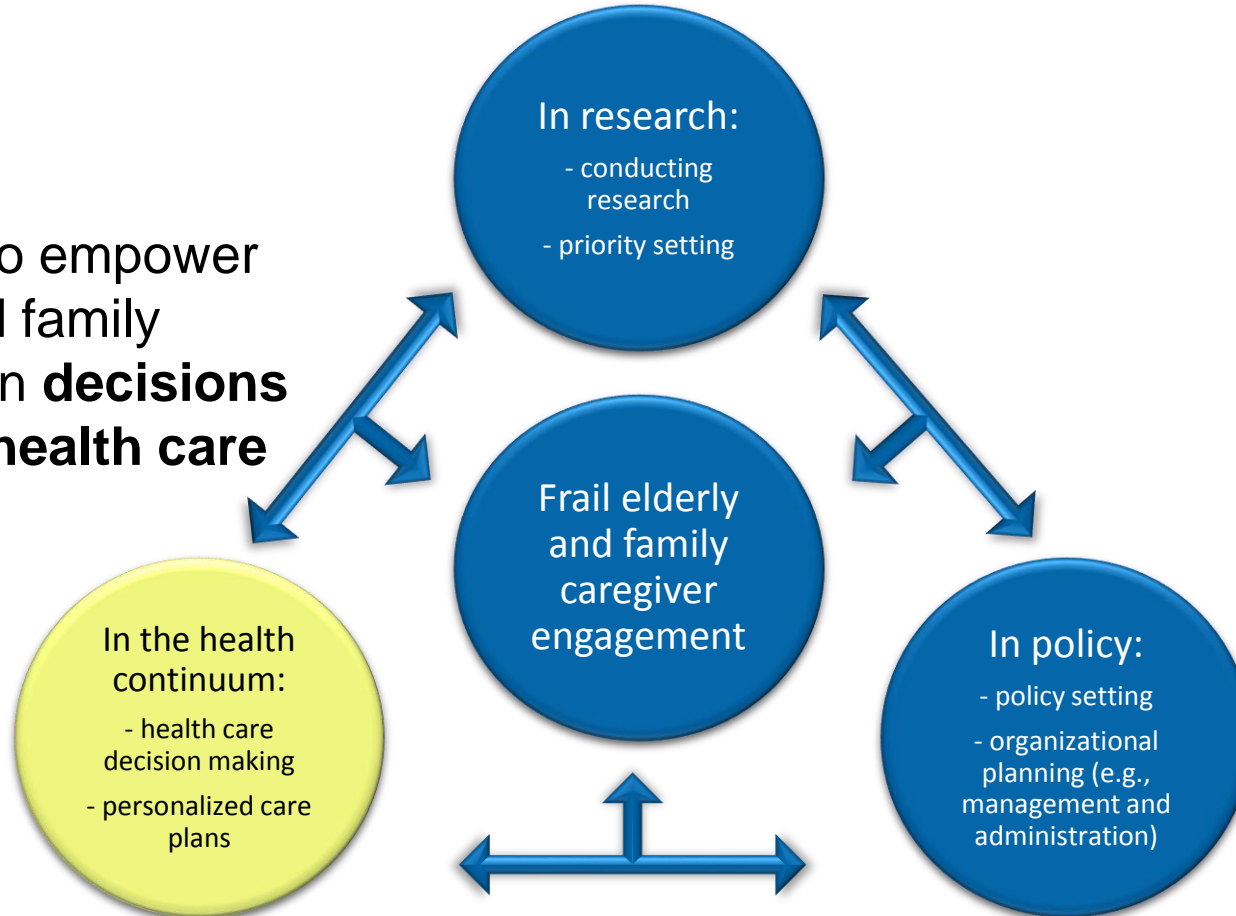


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Pillars of Engagement

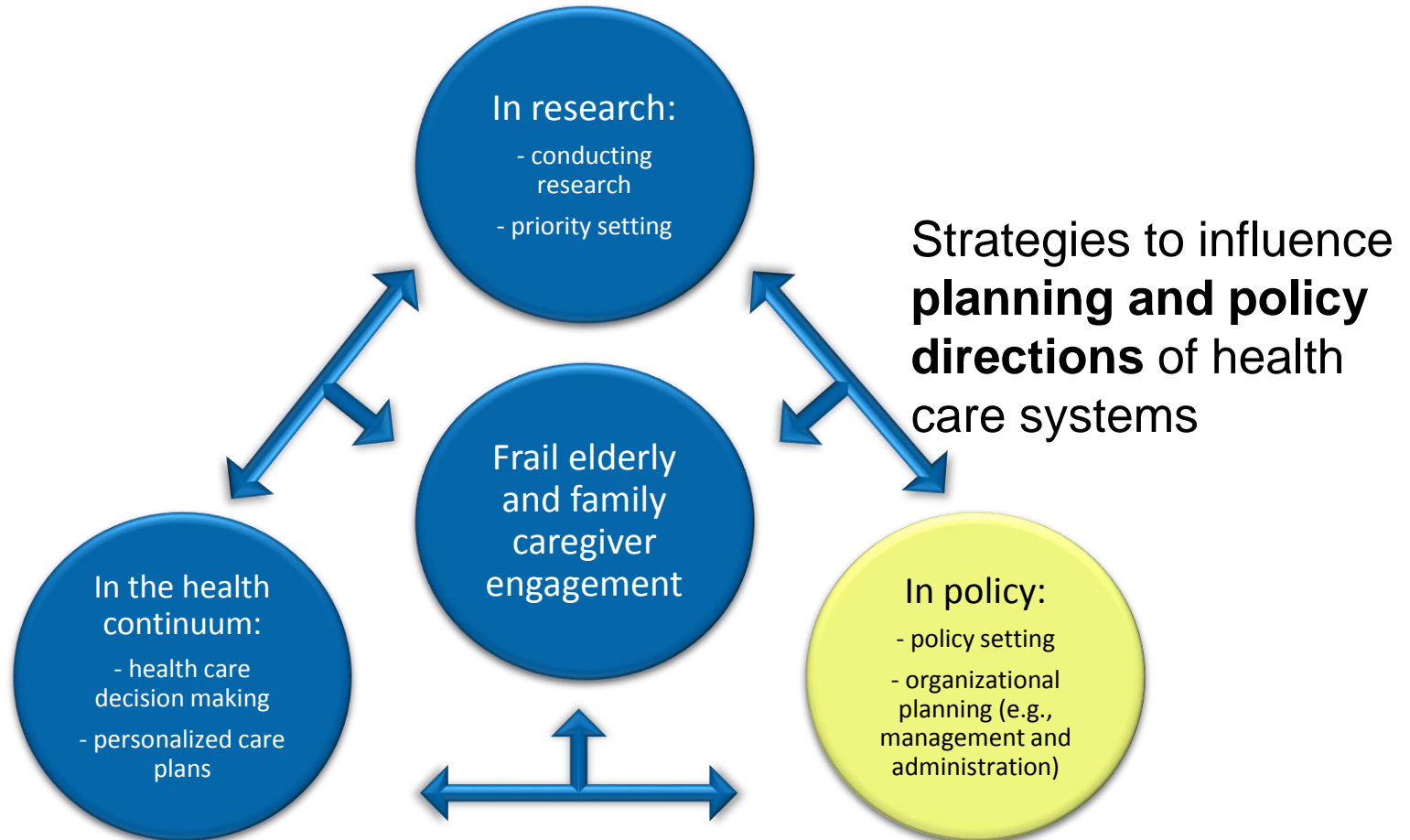
Strategies to empower citizens and family caregivers in **decisions regarding health care needs**



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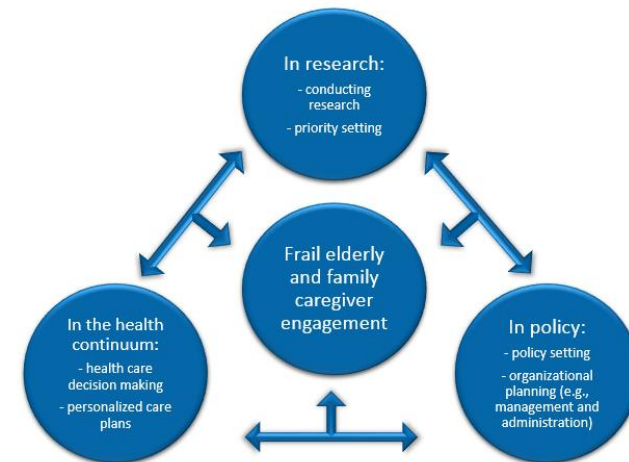
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Pillars of Engagement



Engaging our stakeholders

- **Held a world cafe-style meeting (Sept. 2015) to gain consensus on issues relating to engaging older adults living with frailty *and* their family caregivers**
- Strategies and hurdles to engagement across different settings
 - research,
 - health continuum
 - policy

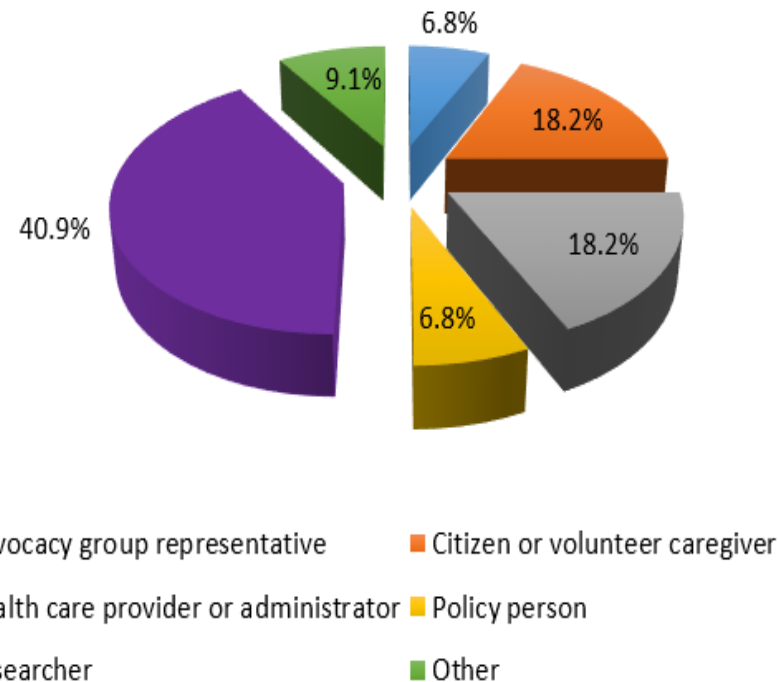


Engaging our stakeholders

Good distribution of attendees

59 attendees representing:

- Citizens, Family caregivers, Advocacy groups
- Health care providers, administrators
- Policy makers
- Researchers
- “Other” (health bloggers, federal granting agencies, industry partners)



Engaging our stakeholders

Key Issues Identified

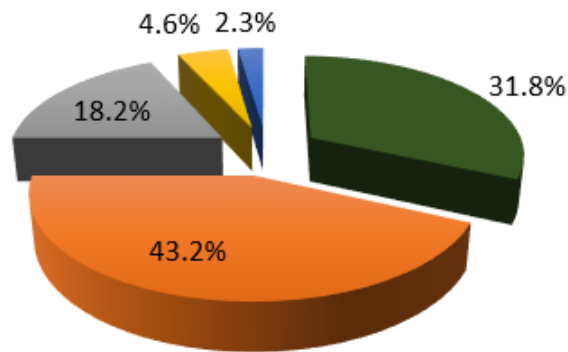
- **Citizen engagement is a necessary component** to improving care for and quality of life of older adults living with frailty
- **Flexibility** is a key to engagement
 - Timing
 - Location
 - Degrees of engagement
 - Potential solutions:
 - Travel to the citizen or family caregiver
 - Use web-based communication platforms



Engaging our stakeholders

Key Issues Identified

- Language and perception are extremely important factors
 - e.g., individuals who are living with frailty do not necessarily identify as being frail



“Frail elders do not identify as frail”

■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree



Engaging our stakeholders

Common barriers across settings

- Older adults and family caregivers expressed perceived power imbalance between themselves and researchers/health care providers
- Cognitive impairment, health literacy, cultural differences, and ageism
- Willingness and ability to engage for all parties (citizens, researchers, healthcare providers)
- Lack of appropriate incentives to engagement for all parties
- Lack of training and resources on how to engage citizens from the perspective of researchers and health care providers
- Lack of engagement opportunities in the research setting



Engaging our stakeholders

Improving engagement opportunities

- Researchers can publicize opportunities at venues where citizens may visit (e.g., libraries, seniors centers, malls)
- Make benefits of engagement in research clear to participants
- Dissemination of research findings back to citizens and to a wider audience
 - user-friendly format
 - plain-English



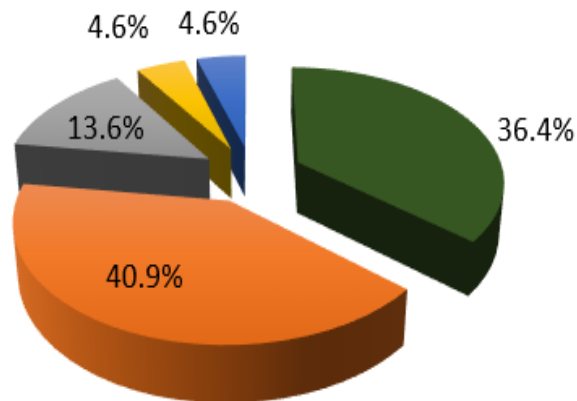
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Engaging our stakeholders

Improving engagement opportunities

- Incorporate a citizen leader on a research team who acts in the role of end-user



“Research teams should have a citizen leader in addition to a scientific leader”

■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

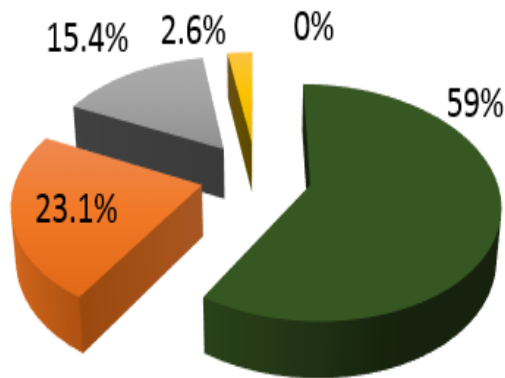


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Engaging our stakeholders

Improving engagement opportunities

- Improve health literacy by providing resources (e.g., information packages, decision aids) to educate patients on how to engage with health or social care providers, and vice versa



“Create tools and education packages for health care providers on ways to meaningfully engage frail elderly and caregivers”

■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

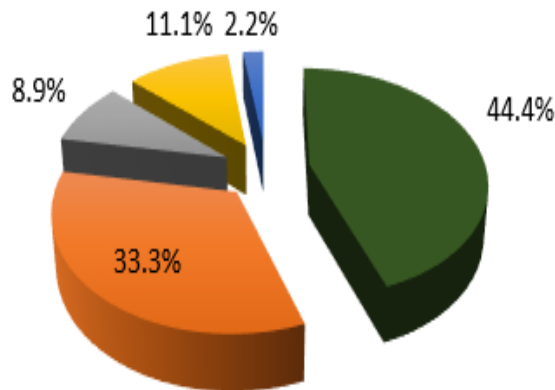


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Engaging our stakeholders

Improving engagement opportunities

- Training on how to engage directed to researchers and health providers
 - Webinars, videos, brochures, etc.
 - More research needed on how to engage this vulnerable population



“Research needed into why/how the frail elder becomes engaged in research.”

■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree



Engaging our stakeholders

Improving engagement opportunities

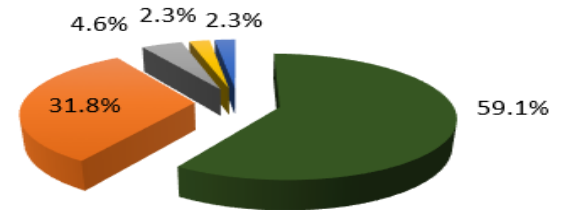
- Systematic changes that increase engagement opportunities include:
 - Adding “how to engage your patient” to health care provider education
 - Provide continuing medical education (CME) credits for engagement training
 - Use electronic medical records to document goals of care and needs of the patient, that can be accessed by the patient
 - Integrated models of care may reduce inefficiencies and financial disincentives that may allow for a more patient-centered approach



Engaging our stakeholders

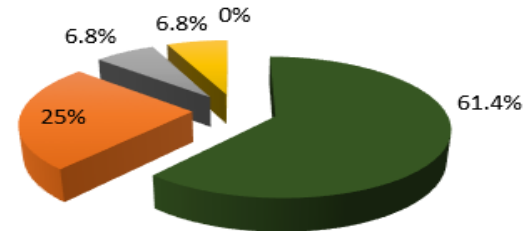
Role of TVN

- Provide guidance and support for engaging citizens and family caregivers
 - Partnerships with industry and federal/provincial health organizations
 - Resources and/or training (e.g., “how-to” manuals, or webinars)



■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

“TVN needs to play a central role in providing guidance and support for patient engagement in research”



■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

“TVN needs to provide resources to researchers that help them to effectively conduct person-centered research.”

Engaging our stakeholders

Role of TVN

- Increase awareness of TVN's mandate and the importance of understanding the frail state
- Incentivize engagement on research projects by making it a condition of funding
- Provide resources/training to research teams on how to engage older adults living with frailty and their family caregivers



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Engaging our stakeholders

Summary of findings will be:

1. Posted to the TVN website at: tvn-nce.ca/engaging-canadians
2. Linked to in the upcoming TVN newsletter



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Questions??

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