

Giving Voice to Frail Elderly Canadians

A TVN Citizen Engagement Initiative



TVN

Améliorer les soins aux aînés
dont la santé se fragilise
Improving care
for the frail elderly

SUMMARY

WORLD CAFÉ SESSION AT TVN'S MEETING ON GIVING VOICE TO FRAIL ELDERLY CANADIANS THAT TOOK PLACE ON SEPTEMBER 27, 2015.

OVERVIEW

- The morning half of the day included talks by Dr. John Muscedere, TVN Scientific Director, Dr. Jayna Holroyd-Leduc, Steering Committee Co-Chair for Giving Voice to Frail Elderly Canadians, Dr. Paul Stolee, Steering Committee member, and 5 citizens. Moderated by Dr. Tom Noseworthy, citizen speakers were: Dr. Duncan Sinclair ([via video](#)), Dr. Barry Brown, Brenda Hooper, Kelly Kay, and Paula Rudner (via audio recording). The purpose of the morning session was to introduce TVN, provide an overview of frailty, and provide an opportunity to highlight the perspectives of five citizens.
- The afternoon session was world café style where attendees had the opportunity to discuss themes relating to engaging older Canadians living with frailty and their family caregivers.

PURPOSE

- The purpose of the meeting was to engage stakeholders in a discussion about engagement of older adults living with frailty and their family caregivers. As a first step, information gathered at the meeting will be incorporated into a discussion paper "*Giving voice to frail elderly Canadians: Engaging frail elderly Canadians in research, health care settings, and in influencing health policy*" that will be published in a freely accessible journal and available on the TVN website. The meeting outcomes and corresponding discussion paper will be used to improve TVN's engagement strategies across the TVN network.

THANK YOU

We would like to give a big thank you to the meeting participants and to our meeting sponsors.



WORLD CAFÉ

- In total, 59 people attended the meeting, representing a diverse range of stakeholders including: advocacy group representatives, citizens, family caregivers, health care providers and administrators, policy makers, researchers, health bloggers, federal granting agency representatives, and industry partners (see Figure 1).
- During the first part of the world café, participants discussed engaging older adults living with frailty and their family caregivers. Following the small-group discussions we conducted a harvest in which 20 statements relating to engagement, developed from the small group discussions, were presented to the whole audience. Participants voted regarding their level of agreement with each statement, with a total of 42-46 people responding per statement.
- The following pages present a summary of the major consensus points raised during the world café discussion rounds, along with selected clicker response results to statements presented during the harvest. Bolded words or phrases represent the main ideas.

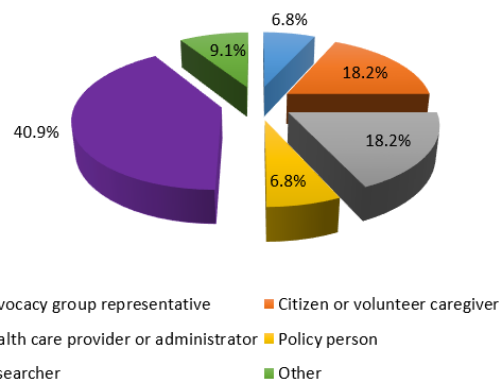


Figure 1. Pie chart showing responses to the question of “which of the following do you most closely identify as?”

OVERALL COMMENTS AND CONSIDERATIONS

- There was significant consensus that **citizen engagement is a necessary component to improving care for, and quality of life of, older adults living with frailty.**
- In general, discussion and consensus points raised during the world café paralleled and added to the points raised in the TVN citizen engagement discussion paper. **There was broad consensus regarding the topics discussed.**
- Given the burden of medical issues, limited life expectancies, and end of life issues, a key factor to engagement of older adults living with frailty and/or their family caregivers is **flexibility** (e.g., timing, location, degrees of engagement). An important factor to engagement in any setting will be asking how the engaged citizen wants to be involved. Furthermore, an additional consideration in any setting is that **family caregivers may hold different views** from that of the person living with frailty. This point should be considered when engaging, partnering with, or empowering this population across all settings of engagement.
- **Language and perception are extremely important.** Often times, individuals who are living with frailty do not necessarily identify as being frail. Note that based on comments from the world café, we have changed “frail elderly Canadians” to “older adults living with frailty”.
- A perception of some older adults living with frailty and/or caregivers is that there is a **power imbalance** between themselves and the researchers and/or health care providers. For example, there is concern that they would not have anything to contribute or do not speak the same technical/scientific/health-related language.
- Other barriers to engagement across the themes included **cognitive impairment, health literacy, cultural differences, and ageism.**

THEME 1: ENGAGEMENT IN THE RESEARCH SETTING

The overall goal of theme one was to determine ways to enable engagement and discuss possible barriers to engagement in the research setting. A second goal was to determine ways of communicating research findings back to the citizens involved and to a broader audience. Research activities were defined as determining which research questions should take priority, conducting research (e.g., development of research design and methodology, interactions with research participants), and disseminating research findings to relevant stakeholders.

ENGAGING OLDER ADULTS LIVING WITH FRAILITY AND THEIR FAMILY CAREGIVERS

1. Participants strongly supported engaging citizens in the research setting. A commonly discussed model is one where a research group partners with an **engaged citizen who acts as a citizen leader** (see Figure 2). The citizen leader would be a member of the research team, and **act in the role of end-user**. An end user team member could provide input on the choice of research measures and outcomes that are likely to be meaningful to older adults living with frailty (e.g., pain reduction, increased function and quality of life). Another suggestion was that research teams partner with more than one citizen. This will help address the recognized limitations to individual older adults with frailty participating fully, and help ensure that the citizens are clearly engaged in all parts of the research process.
2. Older adults living with frailty and their family caregivers may not be able to travel to research centres, etc. An agreed upon solution was to **travel to the citizen or family caregiver**. This may be to home, work, care setting, etc. Alternatively, **web-based communication platforms** such as Skype offer an opportunity for individuals to be involved when travel is a hurdle.
3. Oftentimes, **older adults living with frailty and family caregivers do not know about engagement or research participant opportunities**. To increase awareness and actively reach out, researchers can publicize opportunities at venues where seniors living with frailty, family or family caregivers may visit: local libraries, newspapers, shopping malls, community centres, faith-based facilities, rotary groups, acute care hospitals, and waiting rooms. Methods of outreach include oral presentations and flyers posted at these venues.
4. **Lack of incentives** are a large barrier to engagement. Both researchers and citizens require incentives to participate.
 - Researchers expressed time and cost concerns, in addition to limited support or requirements by granting agencies for engagement opportunities (see theme 4).
 - **Benefits of engagement in the research setting must be made clear** to participants. Educating citizens about the benefits of engaging in research should begin at the initial point of contact and continue through to the dissemination of results. This may include the goals of the research and possible ways that the results will be used, and how citizen engagement will improve the research.
5. Citizens should be **compensated** for any and all appropriate, approved and necessary out of pocket expenses that they incur to participate in a research/healthcare project that might otherwise impede their full engagement in a project.

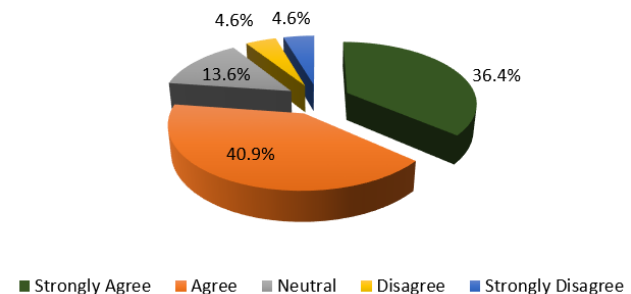
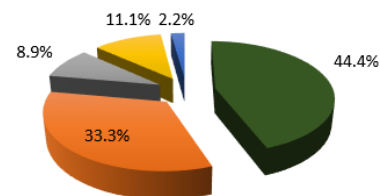


Figure 2. Pie chart showing responses to the statement, "Research teams should have a citizen leader in addition to a scientific leader."

TRAINING ON HOW TO ENGAGE

- Both citizens and researchers need to be **trained on how to engage in a research setting**. A majority of participants suggested that more research is needed into why and/or how to engage older adults living with frailty and/or family caregivers in research (see *Figure 3*).

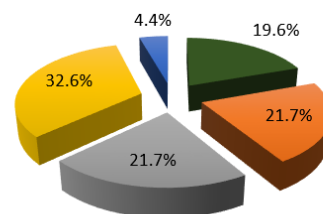


■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

Figure 3. Pie chart showing responses to the statement, “Research needed into why/how the frail elder becomes engaged in research.”

DISSEMINATING RESEARCH FINDINGS

- Summaries of research findings need to be conveyed using plain language.** One way to ensure that summaries are appropriate and understandable is to have engaged individuals (e.g., citizen leaders) give input on the final document to ensure it is written in a common language.
- Summaries of findings should include a **description of how participation in the study contributed to the research, and what is being done as a result of the study**. These were considered important factors that not only impact one’s understanding of the material, but provides motivation to read summaries about research projects (see *Figure 4*). Readability and formatting of documents is key to their uptake. When creating these documents, it is essential to have a thorough understanding on how to best distribute and convey these types of information to a broad audience (e.g., infographics vs a page of text).



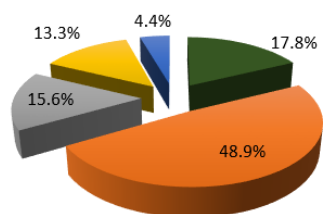
■ Strongly Agree ■ Agree ■ Neutral ■ Disagree ■ Strongly Disagree

Figure 4. Pie chart showing responses to the statement, “If I were a patient, I would read a one-page summary about research projects.”

THEME 2: EMPOWERMENT IN HEALTH AND SOCIAL CARE DECISION MAKING

The goals of theme 2 were to determine ways to empower older adults living with frailty and family caregivers in managing their health and social care needs, *and* to determine how to support health and social care professionals in empowering this vulnerable population.

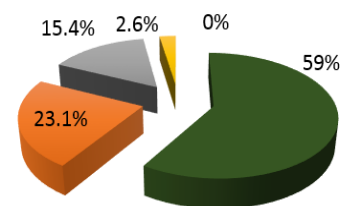
- A broad consensus during the world café was that health and social care decision making requires a shift to a **team-based approach to patient-centered care**, which includes the patient and/or family caregiver as part of the patient’s care team.
- A barrier to empowerment is that patients, caregivers, and providers may not have tools, skills, or health literacy to comprehend important information.** A solution is to provide resources (e.g., “information packages”) that educate patients on how to engage with their health and social care providers. These resources can include “questions you may want to ask your provider”, and can be placed in waiting rooms and pharmacies (see *Figure 5*). Feedback was also positive regarding having tools and education packages for health and social care providers on how to meaningfully engage seniors living with frailty and their family caregivers (see *Figure 6*).



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

Figure 5. Pie chart showing responses to the statement, “Easy to read information in waiting rooms is an effective way to communicate to patients.”

3. Similar to theme 1, **perceptions of power imbalances** may prevent some patients from reaching their desired level of engagement in the health and social care setting. Health and social care providers need to be aware of this perception, and aim for open and respectful communication with their patients.



4. **Similar documents can be disseminated to care providers.**

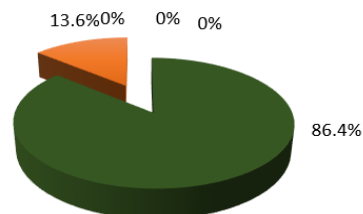
An organizational barrier is that there are currently few incentives or resources to encourage engagement. The health and social care systems are not mandated to support engagement (e.g., medical education does not include “how to engage your patient”). Solutions include: Associations (e.g., Canadian Medical Association or Canadian Nurses Association) providing continuing medical education (CME) credits for engagement training, and addition of relevant courses to the curriculum of health and social care education (e.g., medical school, nursing, social work, etc).

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

Figure 6. Pie chart showing responses to the statement, “Create tools and education packages for health care providers on ways to meaningfully engage frail elderly and caregivers.”

5. **Several frustrations were raised about the current health system.** Discussion points included:

- Need for **electronic medical records (EMR)** that can document goals of care, needs of the patient, and care plans (see Figure 7). The EMR can include a page where patients and caregivers can document questions, concerns, and comments.
- **Inefficiencies and financial disincentives** in the system mean that providers may not be able to increase time spent with patients (e.g., billing system and financial overheads).
- **Transitions of care (i.e., care coordination)** are not efficient in many provinces. Integrated Health and Social care systems may represent a model of care. **Nurse navigators** and/or allied health workers (e.g., **personal support workers**) were also suggested as additional supports to the current model and philosophy of care.



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

Figure 7. Pie chart showing responses to the statement, “Continuity of care should be supported by electronic health records and other tools to communicate decisions between care settings.”

6. Resident patients and patient councils at the facility-level setting offer the opportunity for patient and family caregivers’ input to be used to create change.

THEME 3: CITIZEN INFLUENCE ON POLICY DECISIONS AND PLANNING

The goals of theme 3 were to determine ways that older adults living with frailty and family caregivers can influence organizational planning and provincial and/or federal policy surrounding care of older Canadians living with frailty. A second goal aimed to determine how not-for-profit organizations can most effectively engage and integrate input of older adults living with frailty and their family caregivers in setting organizational policy, and advocating for provincial and federal policy change surrounding the care of older adults living with frailty.

1. Leverage policy decision making by increasing number of older adults living with frailty and family caregivers that act on committees across health and social care organizations (such as resident and family councils at hospitals, and not-for profit organizations including TVN and Patients Canada). Requiring health and social care organizations to have citizen representation on committees was also suggested (*see Figure 8*).
2. Leverage policy decision making by **encouraging the engagement of all partners and stakeholders throughout the research process** (e.g., integrated knowledge translation model).
3. **Increase awareness of the frail state** and the need for changes to health and social care by:
 - Launching a media and/or social media campaign (e.g., a collaboration between TVN and other organizations with the same goals) to attract an intergenerational audience about issues that affect older adults living with frailty. These campaigns could also be used to educate the public in general about the value, opportunities, and need for engagement and could include outlets such as print, radio, and television. Citizens could get involved, and act as the change leaders in such campaigns.
 - Continuing relationships between TVN and network partners with the federal and provincial Ministers of Health. TVN and network partners can approach policy makers with agendas that aim to improve *quality of life*, and discuss evidence that takes both economic cost and quality of life into account. Conversations with the Ministries may start small and then can be scaled up (e.g., these are the methods used in Denmark.)
 - Continuing collaborations between TVN and network partners with associations that influence policy (e.g., form one Call to Action).
4. A success story has been palliative care strategies that have effectively changed the political agenda to one that focuses on palliative care issues (e.g., advance care planning). Also, the Patient Voices network in British Columbia serves as an example of patient engagement that has resulted in polypharmacy risk reduction.

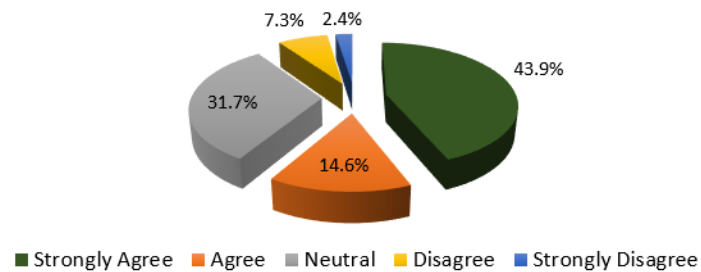


Figure 8. Pie chart showing responses to the statement, "Engagement of frail elderly in health and social care organizations should be mandated."

THEME 4: HOW SHOULD TVN IMPLEMENT THE IDEAS GAINED FROM THE WORLD CAFÉ?

Theme 4 aimed to determine how to share and implement the ideas gained from the world café discussion. Specific goals aimed to determine: 1) ways to help TVN-funded researchers and those applying for funds engage and partner with older adults living with frailty and their family caregivers, and 2) how TVN can share and implement TVN-funded research findings and/or engagement strategies and support the TVN network.

PROMOTING ENGAGEMENT IN THE TVN NETWORK

1. World café participants supported the idea of TVN playing a central role in providing guidance and support for patient engagement in research (see Figure 9). This may include:

- Providing or **partnering with groups** that include older adults that want to be engaged in research.
- **Providing resources and/or training** (e.g., “how-to” manuals or webinars) on engaging with older adults living with frailty and family caregivers. The resources could include information on how to recruit citizens, and strategies that lead to effective citizen-researcher partnerships (see Figure 10). **These resources and training outcomes would need to be flexible** to account for individual research projects and patient (and/or caregiver) populations.
- Fostering connections with various groups/organizations (e.g., hospital advisory councils, public advocacy groups).

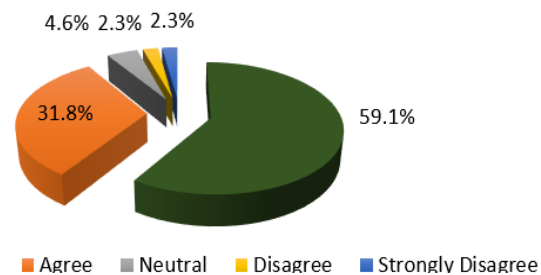


Figure 9. Pie chart showing responses to the statement, “TVN needs to play a central role in providing guidance and support for patient engagement in research.”

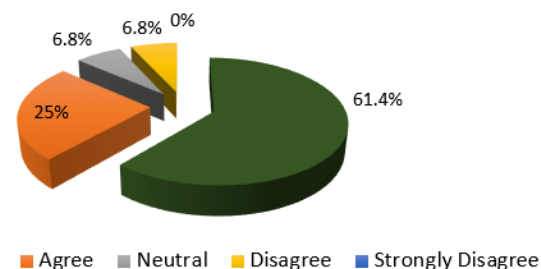


Figure 10. Pie chart showing responses to the statement, “TVN needs to provide resources to researchers that help them to effectively conduct person-centered research.”

- #### 2. One issue discussed during theme one (engagement in the research setting) and in theme four was incentives. **How do we incentivize citizen engagement?** Suggestions for how TVN could increase citizen engagement in the research setting included:
- **Making citizen engagement a condition of funding:** Incorporate granting guidelines that specify a (flexible) degree of engagement of citizen partners that is required by TVN. This would be complementary to a more rigorous evaluation of citizen engagement on funding applications for TVN grants. Inclusion of criteria for assessing grant applications based on the merit of the research group’s engagement.
 - Requiring of a certain amount of **funding dollars be directed to disseminating research results** back to all participants and relevant stakeholders.

SHARING AND IMPLEMENTING RESEARCH FINDINGS AND/OR ENGAGEMENT STRATEGIES

- #### 3. Increase the TVN network, and continue “**spreading the word**”/marketing the brand to increase ultimate influence on policy and to disseminate policy.
- #### 4. TVN can **hold focus groups and town hall meetings** with citizens and family caregivers to determine the next steps for disseminating findings and implementing data. **Avenues of disseminating research findings** include web-based research portals/hubs that post research findings, and sharing results where people were first recruited. TVN can host, or partner with an organization that maintains a database of knowledge relevant to frailty. As a way of increasing reach, TVN-funded research can also be highlighted in the newsletters of other organizations.