

# Improving Care and Support for Unpaid Caregivers in Ontario: Findings from a Citizen Panel

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## Overview (and acknowledgements)

- Citizen panels
- Our approach for convening the panel
- Key findings from the citizen brief and
- Key findings from the panel

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## Citizen Panels

- Each citizen panel brings together a group of 10 to 14 citizens for a one-day, off-the-record, dialogue that provides them with the opportunity to:
  - bring their own views and experiences to bear on an issue;
  - learn from the evidence and from others' views and experiences; and
  - share their newly informed views about the issue and how to address it.



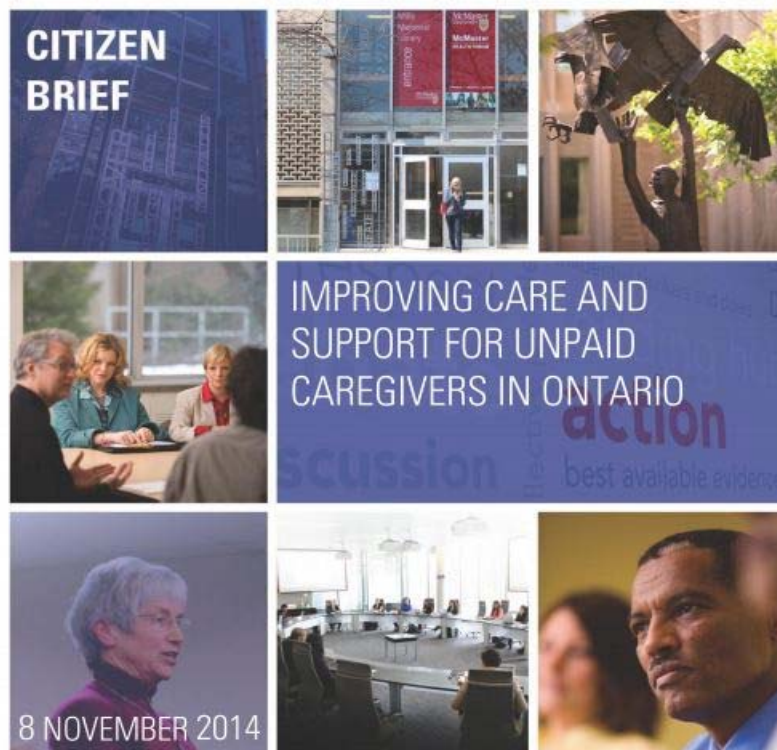
## Our Approach (1)

- Participants were recruited using explicit criteria from the AskingCanadians™ panel
- We aimed to ensure fair representation among the diversity of citizens likely to be affected by the problem:
  - 3-4 current or recent unpaid caregivers who provided care to an older adult living in the community with relatively stable needs
  - 3-4 current or recent unpaid caregivers who provided care to an older adult living in the community with increasing needs (e.g., dementia)
  - 3-4 current or recent unpaid caregivers who provided care to an older adult living in a healthcare facility (e.g., nursing home or long-term care facility)
  - 3-4 current or recent unpaid caregivers who provided care to an older adult with palliative care needs
  - Approx. 7 men and 7 women
- Secondary criteria: SES, Age, geographical region and ethnocultural background



## Our Approach (2)

- Exclusion criteria:
  - Current or past employees of healthcare organizations or healthcare professionals
  - Elected officials
  - Individuals working for market research, advertising, public media or public relations firms
  
- Two weeks before the panel, all participants were sent a “citizen brief” the described (in lay language), the problem, three options for addressing it and implementation considerations



EVIDENCE >> INSIGHT >> ACTION



## Key Findings – Citizen Brief (1)

- Providing care and support for unpaid caregivers in Ontario is challenging because:
  - An aging and diverse population has significant need for unpaid caregivers;
  - Unpaid caregivers aren't always available, are getting older, and can face demanding roles;
  - Existing programs and services often don't fully meet the values, needs and preferences of unpaid caregivers; and
  - Health-system arrangements (e.g., limited availability of financial aid) complicate the situation.



## Key Findings – Citizen Brief (2)

- **Option 1 - Addressing the economic security of unpaid caregivers**
  - This could include:
    - flexible employment arrangements;
    - government-provided income supports; and
    - supportive housing both for older adults and their caregivers to allow them to continue living at home or in the community
  - **Key findings:** Improving housing conditions can help to improve health but there is a lack of evidence about flexible employment models or income supports



## Key Findings – Citizen Brief (3)

- **Option 2 - Engaging and supporting unpaid caregivers**
  - This could include:
    - opportunities for caregivers to engage in decision-making about how care and support is organized;
    - handbooks or toolkits to help identify full range of services available; and
    - education and supports to reduce burden and help them cope/build resilience
  - **Key findings:** A range of interventions were found to be beneficial for caregivers, including:
    - engaging caregivers in decision-making about how care and support is organized;
    - providing materials that help caregivers or the individuals they provide care to make decisions about their care; and
    - providing education/training to caregivers





## Key Findings – Citizen Brief (4)

- **Option 3 - Providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions**
  - This could include:
    - programs that provide education and support that is tailored to caregivers of people with complex conditions; and
    - system navigators or coordinators that help to identify and make connections to needed care and support.
  - **Key findings**
    - Teaching coping strategies and communication skills helps to improve caregivers' psychological health, communication skills, knowledge and quality of life of people with dementia
    - Incorporating a mix of educational and supportive interventions in one package for caregivers helps to reduce their burden and stress



## Participant Characteristics (n=10)

- **Regions covered:** Hamilton Niagara Haldimand Brant (n=8); North East (n=1); and North Simcoe Muskoka (n=1)
- **Age:** 25-44 (10%), 45-64 (30%), 65 and older (60%)
- **Gender:** Men (50%) and women (50%)
- **Education:**
  - 40% completed high school;
  - 10% completed community college;
  - 40% completed a bachelor's degree/post-graduate training or professional degree; and
  - 10% completed postgraduate training



## Participant Characteristics (n=10) (2)

### ■ Employment status:

- ❑ 10% working full-time
- ❑ 20% working part-time
- ❑ 50% retired
- ❑ 10% homemakers
- ❑ 20% disabled (one participant identified their work status as both homemaker and disabled)

### ■ Income level

- ❑ 10% earned less than \$20,000
- ❑ 10% between \$20,000 and \$40,000
- ❑ 30% between \$40,000 and \$60,000
- ❑ 10% between \$60,000 and \$80,000
- ❑ 10% more than \$80,000
- ❑ 30% preferred not to disclose their income.



## Key Findings – Citizen Panel (1)

- **Four challenges were consistently raised:**
  - 1) Caregivers' heavy burden can cause anxiety about its impact on their own and other's health
  - 2) Financial and employment impacts of caregiving are substantial
  - 3) Many caregivers don't know about available services or how to access them
    - “That’s the rub - if you don’t know about it, how are you going to access it.”
    - “Everything is online because they assume you’re going online even though many older people don’t have a computer, let alone internet.”
  - 4) Caregivers' roles are not fully recognized or supported



## Key Findings – Citizen Panel (3)

- Several values-related themes emerged during the discussion about the options, with two emerging with some consistency:
  1. **competence**
    - educating and training unpaid caregivers to provide optimal care
    - also clearly defining the scope of duties of unpaid caregivers versus other healthcare providers
  2. **empowerment**
    - supporting unpaid caregivers to become strong advocates for their loved ones and for themselves
    - equipping them with practical tools to manage the complex care needs of their loved ones



## Key Findings – Citizen Panel (4)

- **Key values related to option 1 (addressing the economic security of unpaid caregivers)**
  - ❑ selflessness (e.g., need to address economic security but in a way that doesn't compromise this as a core value of caregiving);
  - ❑ inclusiveness (reach all those in need);
  - ❑ fairness (especially towards those most in need);
  - ❑ attuned to the needs of unpaid caregivers (e.g., flexible working arrangements);
  - ❑ Innovation (in terms of economic and fiscal measures); and
  - ❑ evidence-based (i.e., documenting the costs and benefits of different interventions, and building a business case).



## Key Findings – Citizen Panel (5)

- **Key values related to option 2 (engaging and supporting unpaid caregivers)**
  - Competence (education/training to provide optimal care)
    - “I will cope better if I’m trained to better manage his care.”
  - empowerment (to become strong advocates for their loved ones and for themselves)
  - holistic care (providing care to both patients and their unpaid caregivers)
  - timeliness (of information – e.g., making printed or online toolkits easily accessible)



## Key Findings – Citizen Panel (6)

- **Key values related to option 3 (providing tailored training and supports to unpaid caregivers providing care to older adults with complex conditions)**
  - ❑ compassion (most vulnerable group of caregivers –ensure they have access to all the resources they need);
  - ❑ collaboration (among caregivers, providers and organizations – need ICT, in-person supports and system navigators);
  - ❑ solidarity (trusting relationships)
  - ❑ competence (of unpaid caregivers to manage the complex care needs of their loved ones); and
  - ❑ empowerment (equipping caregivers with practical tools to manage the complex care needs of their loved ones).





## Key Findings – Citizen Panel (7)

- **Barriers** to implementation identified:
  - 1) Sustainability of a universal and equitable financial supports
  - 2) New tax measure likely face resistance from taxpayers
  - 3) Deteriorating community cohesiveness
  - 4) Too many competing demands to meaningfully engage in decision-making processes
  - 5) Lack of access to family doctors
  
- **Facilitators** to implementation identified:
  - 1) Advocacy activities targeting health system-leaders and elected officials
  - 2) Activities to promote public dialogue and support experiential learning to build sensitivity to the needs of older adults and their unpaid caregivers.



## Questions?

- **Contact:** [wilsom2@mcmaster.ca](mailto:wilsom2@mcmaster.ca)

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