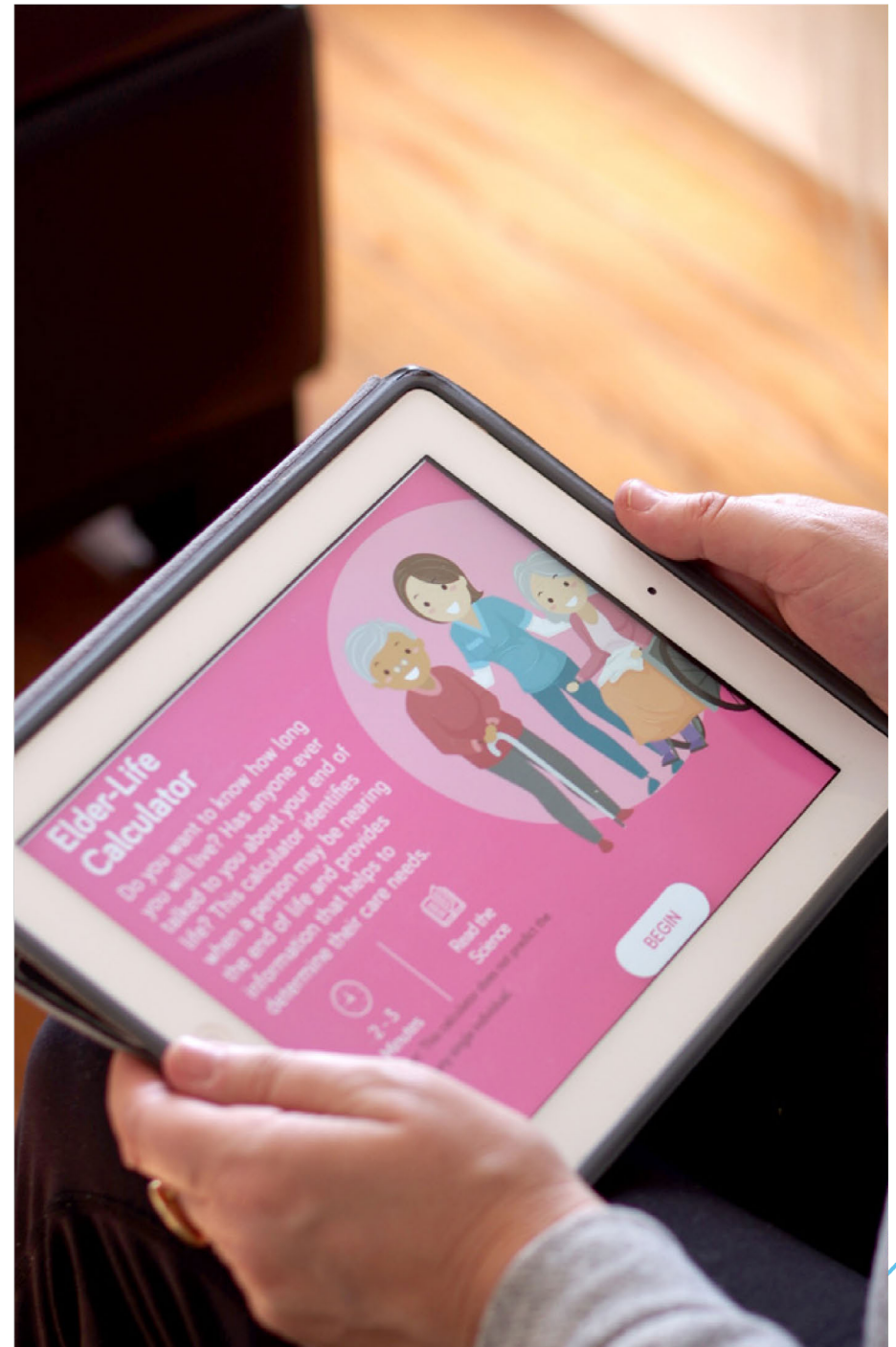


A tool using novel data approaches helps patients and caregivers **make decisions about end-of-life care**

When surveyed, **most Canadians** express a desire to die at home. However, Canada has one of the highest rates of inpatient hospital deaths among member countries of the Organisation for Economic Co-operation and Development, **with 52% of Canadians with cancer** dying in hospital compared to 22% of Americans. In Ontario, **75% of people with heart failure** die in hospital. Although recent research shows that providing end-of-life care doubles the likelihood of dying at home, only **one in three** homecare clients will receive palliative care. In the institutional setting, half of all people entering long-term care homes in Ontario will die within 18 months of admission, but doctors and families alike find talking about palliative or end-of-life care difficult.



Areas of impact:



Makes policy better



Makes health care better



Makes people healthier

ICES Research

In 2015, a team of researchers at ICES Ottawa published **a study** demonstrating the high cost of end-of-life health care, with most of the costs incurred from acute care hospitalization in the last three months of life. The study, which received **national media coverage**, highlighted the need for a prognostic tool that would help clinicians and caregivers begin a conversation with patients about palliative care. This would potentially shift care from costly acute care settings to community settings where most people prefer to be when they are dying.

In 2019, the research team led by Drs. Amy Hsu, Peter Tanuseputro and Douglas Manuel, in collaboration with health care organizations Bruyère and The Ottawa Hospital, developed a tool to predict who needs end-of-life care. The web-based calculator called **RESPECT** (Risk Evaluation for Support: Predictions for Elder-life in the Community Tool) uses big data available from ICES to develop precision health algorithms that can accurately calculate how long a person has to live based on their responses to questions about the diseases they have and their ability to care for themselves.

The researchers created the tool to be easy to use so that the results would enable patients and their caregivers to make informed decisions customized to their needs.

“We need to normalize dying and death because they are a part of life. We need to create a palliative care system that is based on a strong prognostic tool to make those who are dying as comfortable as they can be. RESPECT provides the average person with the tools they need to plan their death.”

Dr. Peter Tanuseputro, one of the ICES scientists who helped create the RESPECT calculator

How this work is having impact

- Supported by the team’s research, in 2019 the Ontario Ministry of Health introduced a Quality Improvement Plan (QIP) indicator that helps health care organizations estimate the need for palliative care among their clients and identify individuals who may benefit from a palliative care approach.
- The Windsor-Essex Compassion Care Community initiative began using the RESPECT calculator in 2019 to match more than 100 people with frailty to the community services they need.
- The Champlain Local Health Integration Network’s palliative home care program is planning a pilot project that will use the RESPECT calculator to support service delivery in retirement homes in Ottawa.
- The research team is currently working with the Champlain Long-Term Care Community of Practice, which consists of medical directors of long-term care homes in Ottawa, to use the RESPECT calculator to guide advanced care planning and goal-of-care discussions with residents and their families.
- The research team has been working with the sub-acute care sector through a pilot program in the complex continuing care setting at Bruyère.
- A **video** about the calculator was released in 2018 and has been viewed nearly 30,000 times.