



RESPECT CALCULATOR

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Research project aims to improve end-of-life care in the community

People who are approaching the end of their life can benefit from supportive care—also known as palliative care—that improves quality-of-life through treatment of pain and other distressing symptoms, as well as emotional and spiritual needs. Unfortunately, research has shown that only about half of the people who die in Canada receive any kind of palliative care in their last year of life. Drs. Peter Tanuseputro and Douglas Manuel, along with their colleagues from research institutions and clinical care teams across Ontario and Nova Scotia, believe that part of the challenge lies in identifying people in the community who are nearing the end of their life. Their team has developed a web-based tool—**THE RESPECT CALCULATOR**—to fill this need. With funding from the Canadian Institutes of Health Research, they are now consulting with patients and health-care providers to refine the tool before trial implementation in Canada.

WHAT IS RESPECT?

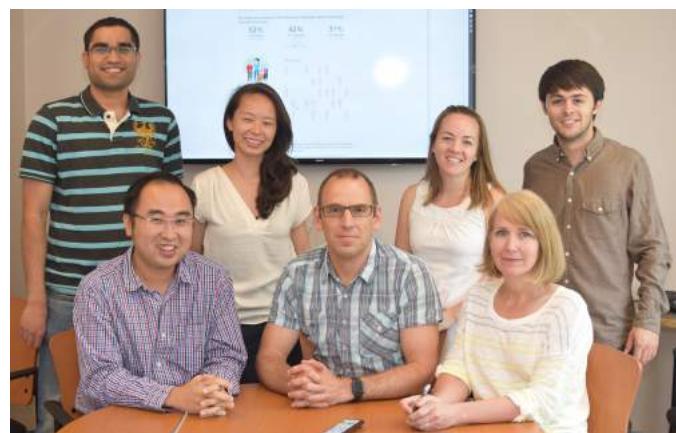
RESPECT is short for **R**isk **E**valuation for **S**upport: **P**redictions for **E**lder-life in the **C**ommunity **T**ool. Technically, it is a predictive algorithm that calculates your survival (that is, how long you will live).

"BOTH OF MY PARENTS DIED LAST YEAR. MY BROTHERS, SISTER AND I HAD CONSIDERABLE UNCERTAINTY ABOUT THEIR EXPECTED NEEDS—EVEN THOUGH I AM A FAMILY DOCTOR, PALLIATIVE CARE PROVIDER AND RESEARCHER! IT WAS ONE OF THE LARGEST BARRIERS FOR MY FAMILY TO HELP OUR PARENTS."

— DR. MANUEL
RESPECT INVESTIGATOR

WHO WILL USE RESPECT?

RESPECT is primarily for older adults who are uncertain whether they are approaching the end of their life and the family members who care for them. RESPECT can also be used by formal caregivers—such as physicians, home care staff and palliative care teams.



Members of the RESPECT Team: (L to R) Yulric Sequeira, Peter Tanuseputro, Amy Hsu, Doug Manuel, Sarah Beach, Carol Bennett, and Cameron Bell.



RESPECT Project Overview

HOW WAS RESPECT CREATED?

RESPECT was developed and validated using routinely-collected, population-level home care data from Ontario—which has more than 1.3 million home care assessment records between 2007 and 2014. The dataset contains detailed health information from the standardized Resident Assessment Instrument for Home Care (RAI-HC), which case managers and nurses use to assess the needs of home care users. During the Summer and Fall of 2016, the research team will be conducting focus groups to evaluate RESPECT for its acceptability and usefulness, as well as to improve the tool for its use in the community.

WHAT IS UNIQUE ABOUT RESPECT?

RESPECT uses a personalized and patient-oriented approach.

“Personalized” means that the questions are detailed and specific, providing calculations that are customized to each person. As well, the language and content of the questionnaire is tailored to the user.

“Patient-oriented” means the calculator is designed for people and their caregivers (as opposed to doctors or nurses). Results are presented clearly, using terms that are easy to understand. Calculations are performed in real-time as a person completes the questionnaire—giving people insight into how aspects of their health status affect their calculations.

Early results indicate that RESPECT will be the most accurate end-of-life prediction tool worldwide.

If you have feedback or questions for the research team, please contact Dr. Peter Tanuseputro at 613-798-5555 (ext. 17343) or Carol Bennett (ext. 12443).

This research has been supported by the Ontario Ministry of Health and Long-Term Care, and the Canadian Institutes of Health Research Pan-Canadian SPOR (Strategy for Patient-Oriented Research) Network in Primary & Integrated Health Care Innovations Quick Strikes Program. RESPECT is being developed by researchers at the Ottawa Hospital, Bruyère Research Institute, University of Ottawa, Dalhousie University, University of Toronto, McMaster University, Institute for Clinical Evaluative Sciences, and Windsor-Essex Compassionate Community Coalition. The project has received research ethics approval from the Ottawa Health Science Network Research Ethics Board, the Bruyère Research Ethics Board, and the University of Windsor Research Ethics Board.

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