

## **OPPORTUNITY TO PARTICIPATE IN RESEARCH PROJECT**

**Inviting adults with schizophrenia who are over 65 years old, their family members and caregivers to join our Patient and Family Advisory Committee.  
Especially those with palliative care experience**

Title: Palliative and end-of-life care for Canadians living with schizophrenia.

Principle Investigator: Colleen Webber, PhD; Senior Clinical Research Associate, Ottawa Hospital Research Institute; Affiliate Investigator: Bruyère Research Institute

Co-Investigator: John P. Hirdes, PhD FCAHS, School of Public Health Sciences, University of Waterloo

Purpose:

Researchers from Ontario and Manitoba are studying the care received by people with schizophrenia in the last year of life. We are comparing healthcare in the last year of life between people with and without schizophrenia. Our goal is to identify how to improve care.

Project Summary:

Schizophrenia is a serious chronic mental illness that affects 1% of the Canadian population. Individuals with schizophrenia often face challenges in accessing and receiving healthcare. As a result, they often have poorer health and die years earlier than individuals without schizophrenia.

The differences in health and healthcare experienced by individuals with schizophrenia may extend to the end-of-life period when healthcare needs may be at their highest. However, we have little information on the healthcare that is delivered to individuals with schizophrenia who are at the end of life; for instance, whether they receive palliative care, the role of psychiatry in end-of-life care, and where end-of-life care is delivered, such as in the hospital or home. We are also lacking information on what the end-of-life outcomes look like for this population, such as whether they die in or out of hospital. This knowledge gap is limiting our ability to develop strategies to improve the delivery of end-of-life care for individuals with schizophrenia.

In this project, we will examine healthcare use in the last year of life and end-of-life outcomes among individuals with schizophrenia who died in Ontario and Manitoba. We will identify differences in healthcare use and end-of-life outcomes between individuals who died with and without schizophrenia. Further, we will evaluate patterns of healthcare use and outcomes in the last year of life among individuals who died with schizophrenia to understand what optimal versus sub-optimal care looks like. We will also look at predictors of end-of-life healthcare and outcomes to understand who among this vulnerable population is most at risk of poor-quality care at the end of life.

This study will contribute important information on how best to meet the healthcare needs of individuals with schizophrenia who are nearing death, with findings that will help inform health system planning and policy to support this vulnerable population.

Patient-Partner Role:

The goal is to identify how to improve care for people with schizophrenia in the last year of life. We will be asking the following questions:

- What does healthcare in the last year of life look like for people with schizophrenia?
- Where do these individuals receive healthcare?
- What physicians provide care?
- What is the quality of care received?

This project will be guided by a Patient and Family Advisory Committee. This committee will help identify important questions for this project. This committee will also help us understand and communicate the results.

We are inviting adults with schizophrenia who are over 65 years old, their family members and caregivers to join our Patient and Family Advisory Committee. We are especially interested in hearing from people who have experience with end-of-life care, with lived experience with schizophrenia or caring for someone with schizophrenia.

The time commitment would be roughly 1 hour per month. This is a 4-year project. Committee members will be paid for their time.

If you are interested, please contact Colleen Webber, PhD, Senior Clinical Research Associate [cwebber@ohri.ca](mailto:cwebber@ohri.ca)