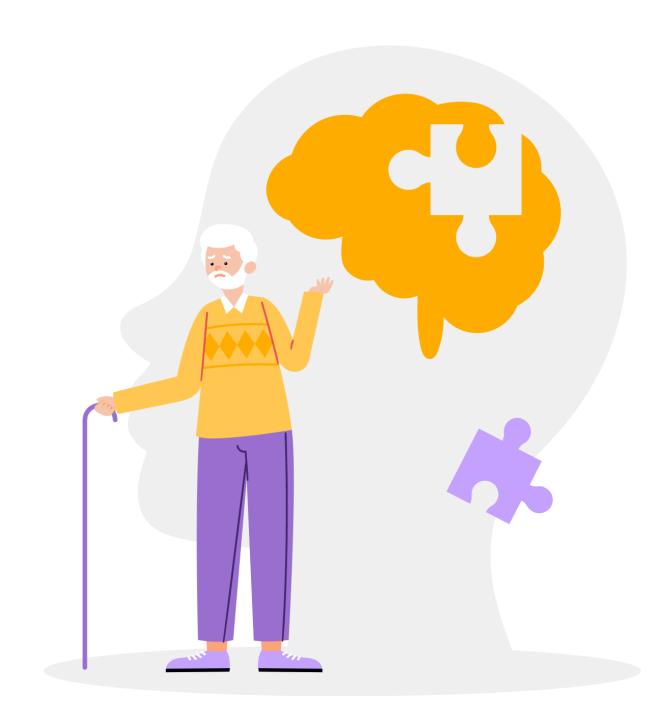
# A Dementia Registry for Canada:

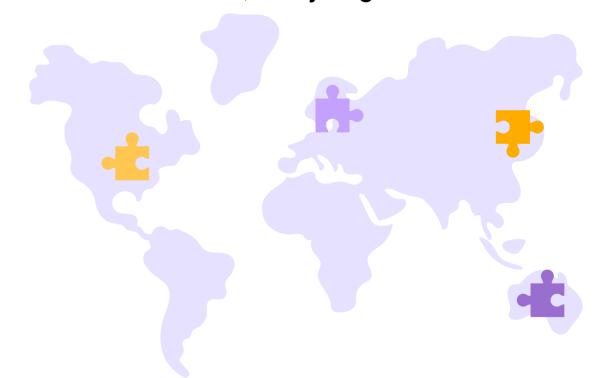
A community-driven, made-in-Ontario solution



#### Methods

#### **Jurisdictional Scan**

The Alzheimer Society of Ontario (ASO) commissioned a study of 18 surveillance and population-based dementia registries in highincome countries, analyzing 235 studies.



#### Collaboration

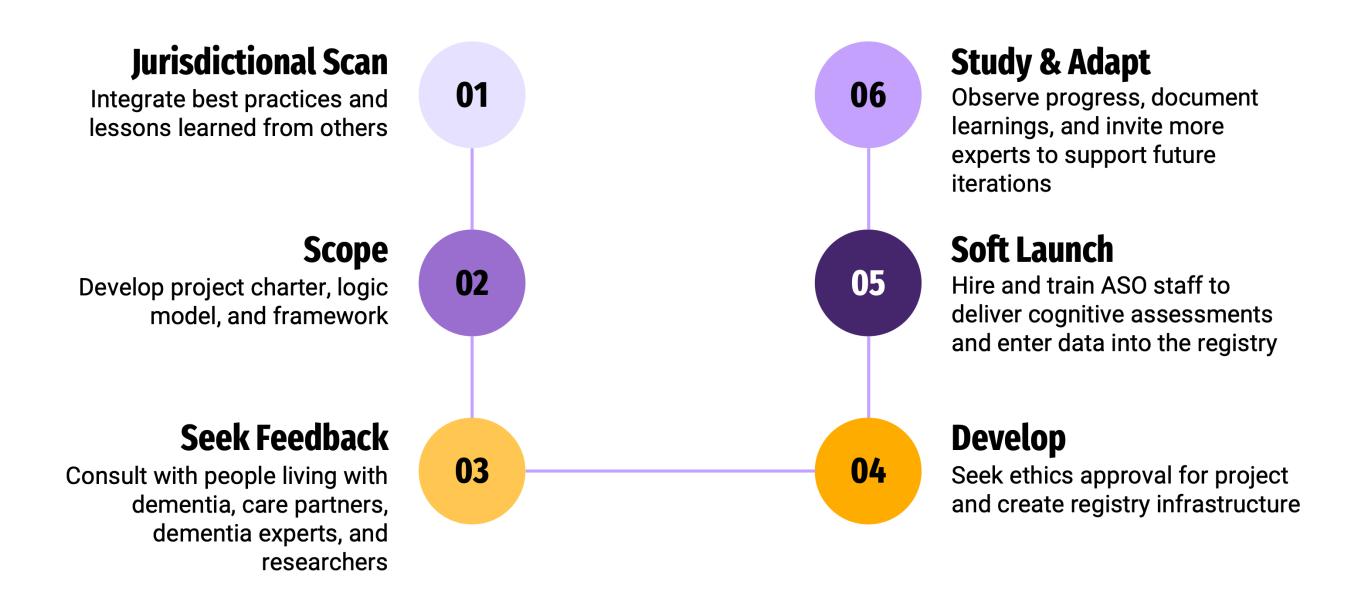
In early 2024, ASO partnered with the Ontario Brain Institute (OBI) to investigate the feasibility, design, and implementation of a dementia registry for Canada as part of a readiness strategy for DMTs.



INSTITUT BRAIN ONTARIEN INSTITUTE DU CERVEAU

Société Alzheimer Society

# **Process**



# Background

#### **DMTs are (Likely) Coming**

Two disease-modifying therapies (DMTs) for dementia are currently being reviewed by Health Canada.

#### The Registry Landscape

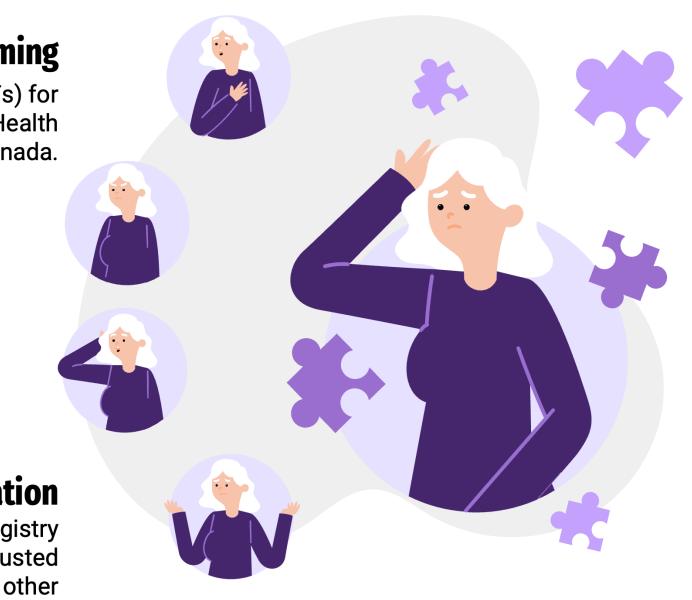
Other countries have developed a centralized repository, or dementia registry, as a requirement for approving patient eligibility for DMTs.

#### **Service Gap**

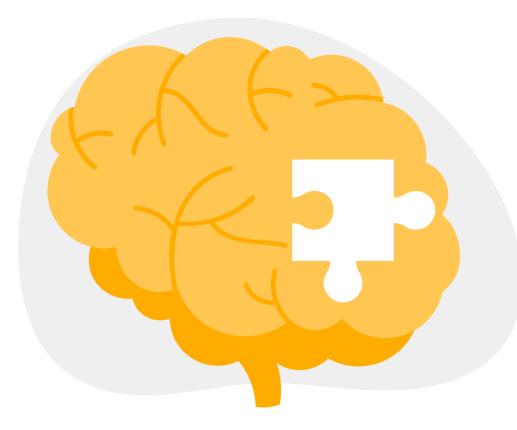
Canada does not yet have a dementia registry, but it is reasonable to assume this will be required.

#### **Opportunity for Collaboration**

Ideally, Canada should have one dementia registry that: supports DMT eligibility, provides a trusted source for data, and acts as an opportunity for other dementia technologies to be tested and leveraged.

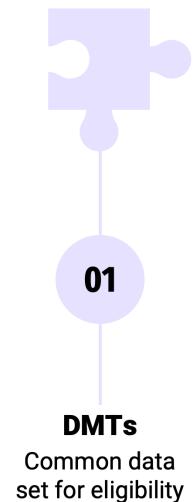


#### Results



### **Dementia Registry**

Evolving and trusted repository of realworld data about dementia in Canada that enables:



of treatments

# Research

Validation of neurotech and other solutions (e.g. digital cognitive assessments)

# 03 02

#### **Improved Health**

Inform government investments in health and social care integration

Adam Morrison | MSc, CHE | Senior Director, Public Policy & Partnerships | Alzheimer Society of Ontario | amorrison@alzon.ca

Christina Stergiou-Dayment | M.S.W., RSW | Chief Programs & Clinical Operations Officer | Alzheimer Society of Ontario | cstergiou-dayment@alzon.ca

Caitlin Siu | PhD | Program Specialist | Ontario Brain Institute | csiu@braininstitute.ca

Christa Studzinski | PhD | Director, Business Development and Partnerships | Ontario Brain Institute | cstudzinski@braininstitute.ca