

Building Capacity for Collaborations Among Researchers and People with Lived Experience of Dementia: Global Perspectives

Saturday, July 26, 2025 | 1:00 pm - 5:00 PM
Westin Harbour Castle- Pier 7&8 — Toronto, Canada
All times are in Eastern Standard Time
In-person attendance only

Overview

This workshop aims to build capacity for engaging people with lived experience in research — an approach that involves people living with dementia and care/study partners in various phases of the research process. “Patient engagement” and related concepts of “(patient and) public involvement” and “public and patient engagement” are gaining prominence internationally. For some research funding programs and organizations, patient engagement is a condition of funding. Researchers of all types are being asked to incorporate patient engagement activities into their work.

Organizing Committee

- Jennifer Bethell, PhD
- Dianne Gove, PhD
- Ana Diaz, PhD
- Carrie A McAiney, PhD
- Mary Warbelow, MA
- Ellen Snowball
- Inbal Itzhak, Ph.D,
- Iracema Leroi, MD FRCPC, MRCPsych
- Sherril B Gelmon, DrPH
- Madalena Liougas, MSc Candidate
- Karen Myers Barnett
- Diana Karamacoska, PhD
- Helen Bundy Medsger
- Emma Sheppard-Lanza
- Sarah Campill, MSc
- Jan Runar Eliassen
- Marion Tur Eliassen
- Br. John-Richard Pagan
- Juanita-Dawne Bacsu
- Robin Casey

- Myrna Norman

Target Audience

This ISTAART immersive workshop is designed for individuals at the Beginner, Intermediate, and Advanced levels in Administration, Care & Support, Research, and Lived Experience.

Learning Objectives

1. Describe examples of successful national and international initiatives that engage people with lived experience in dementia research.
2. Identify opportunities to bring together people with lived experience and researchers to collaborate in dementia research.
3. Develop tailored approaches that authentically and meaningfully engage people with lived experience in dementia research.

Registration

Educational workshops are offered for in-person attendance only. Workshops require a separate registration fee in addition to AAIC full conference registration, or they may be purchased as stand-alone events. Visit alz.org/AAIC.

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Time	Session Details	Speakers and Moderator
12:00 - 1:00 pm	Lunch (<i>Westin Metropolitan Ballroom</i>)	
1:00-1:30 pm	Welcome, Housekeeping and Introductions	Inbal Itzhak
1:30-2:30 pm	Presentations:	
	Canadian Consortium on Neurodegeneration in Aging (CCNA)	Juanita-Dawne Bacsu Carrie McAiney Karen Myers Barnett

		Robin Casey
	Global Brain Health Institute (GBHI)	Iracema Leroi Sherril Gelmon Helen Bundy Medsger Br John-Richard Pagan
	Alzheimer Europe (AE)	Sarah Campill Jan Runar Eliassen Marion Tur Eliassen
2:30-3:00 pm	Break: Refreshments will be provided	
3:00-4:00 pm	Group Activity: Attendees will be pre-assigned to a small group. The groups will be assembled to ensure diverse perspectives (i.e., including persons with lived experience, researchers, trainees, etc.).	All, with introduction by Sherril Gelmon
4:00-4:30 pm	Report Back	Ellen Snowball
4:30-4:45 pm	Personal Reflection and Session Evaluation	Emma Lanza
4:45-5:00 pm	Closing and Next Steps	Juanita-Dawne Bacsu and Myrna Norman