

Foundations For Partnering With People Impacted By Dementia In Research

Friday, July 26, 2024 | 8 a.m. – noon
Marriott (Grand Ballroom J) — Philadelphia, USA
All times are in Eastern Standard Time
In-person attendance only

Overview

The half-day ISTAART Immersive explores some of the challenges and recommendations to conduct research that is 1) truly inclusive of persons living with dementia and their closest carers, 2) representative of cultural diversities and 3) considerations when conducting research in Low- or Middle-Income Country (LMIC) settings. This ISTAART Immersive is a global and interdisciplinary perspective on 'lived experience' and co-design research.

This Immersive will offer the opportunity to engage in small group activities to apply learnings using a multi-method approach: The Immersive will start with a panel where will hear from people with dementia, their carers and researchers to un-pack how they have been involved in co-design research. We will share perspectives of individuals with lived experience from our established international networks to provide a global lens on their experiences in research. The workshop will feature presentations and roundtable discussions by co-leads on what genuine co-design is and essential skills for researchers to partner with people and communities: trust building, communication and facilitation skills, and samples of how to engage with diverse communities (people from diverse ethnic and linguistic backgrounds, and the many roles they may have during the research process).

Professional Interest Area (PIA) groups

- Partnering with Research Participants
- Diversity and Disparities

Organizing Committee

- Lupe Morales, Aging and Brain Health Advocate
- Sherril Gelmon, Oregon Health & Science University – Portland State University School of Public Health

- Sarah Walter, Alzheimer's Clinical Trials Consortium
- Helen Bundy Medsger, Lewy Body Dementia Association
- Mouna Sawan, The University of Sydney
- Diana Karamacoska, Western Sydney University
- Josefina Antoniades, National Ageing Research Institute
- Megan Zuelsdorff, University of Wisconsin, School of Nursing

Target Audience

This ISTAART Immersive workshop is targeted to attendees who are involved in research and would like to gain insights and knowledge on meaningful and equitable research partnerships with people with lived experience. The program is open to all but pitched at a foundational level.

Learning Objectives

1. Recognize the barriers and enablers to research participation encountered by those from diverse communities and with lived experiences.
2. Illustrate the challenges of conducting inclusive dementia research and develop some practical approaches to address these challenges.
3. Understand how to apply equitable and just approaches to research design.

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.

Agenda

| Time | Session Details | Speakers and Moderator |
|--------------------|-------------------------------------------------------------------------------|----------------------------------------------------------------|
| 7 – 8 a.m. | Light Breakfast | |
| 8 – 8:10 a.m. | Introduction & land acknowledgment | Megan Zuelsdorff, Mouna Sawan |
| 8:10 – 9:10 a.m. | Voices of people with lived experience panel | Moderator: Sarah Walter Speakers: Sherril Gelmon |
| 9:10 – 9:20 a.m. | Every step forward needs to be celebrated: An international case study | Sharifah Tahir |
| 9:20 – 10 a.m. | Learning Conversations: Unleashing Inclusive Imagination | Lupe Morales, Mouna Sawan |
| 10 – 10:30 a.m. | Break and Networking | |
| 10:30 – 11:15 a.m. | Partnering with people with lived experience and co-design research | Helen Bundy Medsger, Diana Karamacoska and Josefine Antoniades |
| 11:15 – 11:45 a.m. | Practical takeaways in partnering with people impacted by dementia | Sarah Walter |
| 11:45 a.m. – noon | Closing remarks | Megan Zuelsdorff |
| Noon – 1 p.m. | Lunch | |