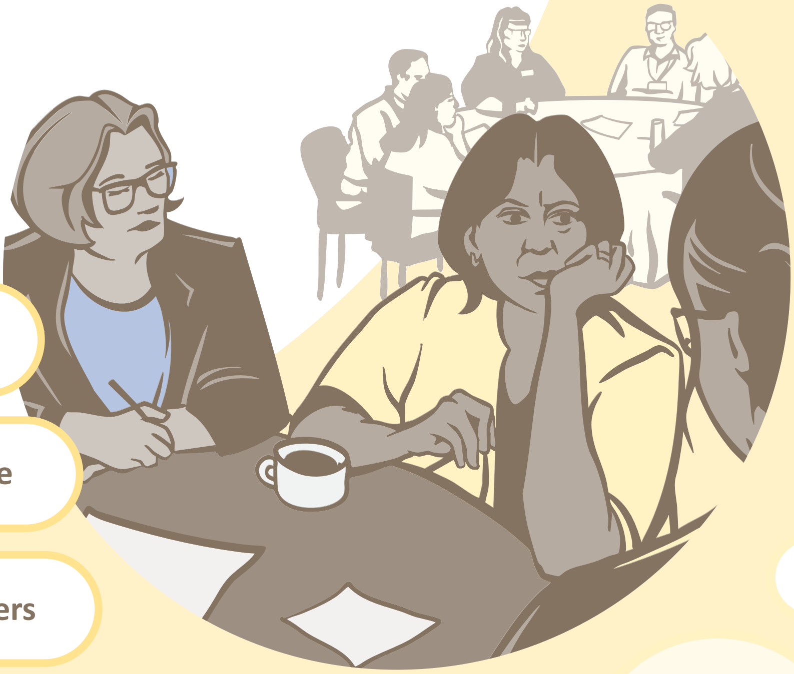
Alzheimer Society
BRITISH COLUMBIA

Research luncheons

VANCOUVER – VICTORIA – PRINCE GEORGE

In late 2024 and early 2025, the **Alzheimer Society of B.C.** hosted research luncheons in Vancouver, Victoria and Prince George, bringing together more than 115 attendees including:

- Community organizations
- People with lived experience
- Dementia-focused researchers



We explored how to meaningfully engage people with lived experience of dementia in the research process. We laid the foundation for developing resources that support researchers and people affected by dementia in making biomedical research more inclusive and accessible.

> *"I am the only one who knows how I feel."*
>
> – Lived experience panelist

> *"I am not just a name and a diagnosis."*

CALL TO ACTION

Everyone in British Columbia — regardless of cultural background or location — should have equitable access to effective risk reduction, diagnosis, treatment and support at all stages of the dementia journey.

PRINCE GEORGE

This was our first year connecting with the research community in Prince George.
Our discussions focused on the unique context of northern, rural and remote areas of the province.

KEY GAPS & CHALLENGES

- Geographic and logistical barriers to participation when research centres are typically based in urban areas (e.g., difficult and costly due to logistics, personal expense and travel time).
- Research participation does not always translate into local benefits when most data on multi-site projects are collected in urban centres.

AREAS OF SUPPORT

- Invest in northern B.C. research by ensuring funds raised in northern B.C. directly support research, training and retention of local talent.
- Foster inclusive, culturally-safe research practices through sustained relationship building, celebrating local strengths and ensuring ethical research is grounded in cultural safety.

VANCOUVER – VICTORIA – PRINCE GEORGE

In groups, attendees shared their thoughts on two questions following a lived experience panel presentation.

How could you engage people with lived experience within the type of research you do?

1 EMBRACE DIVERSE PERSPECTIVES & CONTEXTS

- ✓ Recognize cultural and language differences with regards to stigma and the understanding of dementia.
- ✓ Acknowledge the social networks of people living with dementia (e.g., families, communities).
- ✓ Understand that priorities and preferences differ between people living with dementia and care partners.

2 FLEXIBLE & STRENGTH-BASED ENGAGEMENT

- ✓ Offer multiple types of engagement that respect individual strengths, preferences and symptom variability.
- ✓ Build relationships that acknowledge vulnerability and enable meaningful, person-centered participation.
- ✓ Allow people to contribute in ways that matter to them – whether through sharing stories, testing tools or advising.

3 ETHICAL CONSIDERATIONS & INFORMED CONSENT

- Design a consent process that is ongoing, clear, dementia-friendly and inclusive.
- Be sensitive to the emotional experience of participating (e.g., diagnostic tests can be discouraging).
- Regular check-ins to update participants and manage expectations throughout the research process (e.g., once a grant is submitted, what happens?).

4 EQUITY & ACCESSIBILITY IN PARTICIPATION

- Address barriers such as technology use, transportation and the institutional nature of research spaces.
- Provide honoraria, compensate for time and ensure accessible environments.
- Advocate for decentralized and inclusive research engagement spaces.

5 RETHINKING RESEARCH OUTPUTS & METRICS

- Go beyond academic outputs to include accessible knowledge translation and storytelling.
- Ensure research feels purposeful and relevant to participants.
- Clearly communicate the “why” of the research to participants.

6 INFRASTRUCTURE, FUNDING & GRANT PROCESS

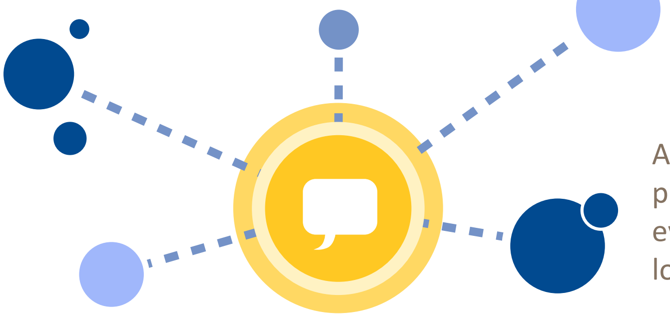
- Lack of funding to support people affected by dementia in biomedical research is a barrier.
- Need for seed grants and funding models that value lived experience engagement.
- Include people affected by dementia in grant review panels to reflect lived priorities.

7 ACCESSIBLE COMMUNITY-CENTERED RESEARCH EVENTS

- Host events with low-barrier entry (e.g., town halls, open houses).
- Make research visible and welcoming to community members, not just academics.

How can the Alzheimer Society of B.C. support you and your team in engaging with people with lived experience?

1 ACT AS A BRIDGE TO CONNECT PEOPLE



Act as a connector between researchers and people with lived experience.

Host and support events that foster trust.

Match people with lived experience with suitable projects and researchers.

Bring research into communities rather than expecting communities to come to researchers.

A consistent physical presence at community events, and partnerships with local organizations.

2 COMMUNICATION & KNOWLEDGE MOBILIZATION

- ✓ Help make research more accessible (e.g., blog posts, lay video summaries).
- ✓ Share information through public channels, including social media.
- ✓ Support translation of complex research into understandable formats for various audiences.

3 RESOURCES & TRAINING FOR RESEARCHERS

- ✓ Offer resources on engagement, consent and inclusive practices.
- ✓ Support opportunities for researchers to build and strengthen their skills in knowledge translation.
- ✓ Create and share best practices for lived experience engagement.

> *"Keep research purposeful and relevant by following-up and following-through with advocates."*
>
> – Lived experience panelist

4 EDUCATION & SUPPORT FOR PEOPLE WITH LIVED EXPERIENCE

- ✓ Help volunteers understand the research landscape and find projects aligned with their interests.
- ✓ Provide education on research roles and contributions.

5 SUPPORT FOR RESEARCH ETHICS & INSTITUTIONAL CHANGE

- ✓ Curate resources for Research Ethics Boards on dementia-inclusive practices.
- ✓ Champion integration of dementia-inclusive consent processes.

6 BUILD INTERNAL CAPACITY

- ✓ Educate Alzheimer Society of B.C. staff about research processes and the Society's role in supporting research within the province.
- ✓ Create and share best practices for lived experience engagement.

7 PRIORITIZE EQUITY, DIVERSITY & INCLUSION

Equity, diversity and inclusion are essential to the Alzheimer Society of B.C.'s research efforts. We are committed to advocating for the inclusion of people and experiences which have historically been underrepresented in research and champion the need for research which is culturally appropriate.

- **Engage underrepresented groups and identities.**
- **Understand that different communities are engaged by different approaches and mediums.**
- **Support smaller organizations working with underrepresented groups in research.**