DEMENTIA
ACTION CO-LAB
Gerontology and Dementia Research

Dementia Action Co-Lab Key Takeaways Report from Inaugural Collaborative Session

Held at the Institute on Aging and Lifelong Health, University of Victoria Campus
November 28, 2025

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Acknowledgements: The Dementia Action Co-Lab team would like to thank all the participants for their time and insight. We would further like to thank the Institute on Aging and Lifelong Health for graciously hosting the event, and those researchers, trainees, staff, people with lived experience of dementia and care partners who traveled to be with us and share their thoughts. A full list of participants and their bios can be found in Appendix A.

Executive Summary

On November 28, a diverse group of individuals—including people with lived experience of dementia, care partners, researchers, trainees, and representatives from the Alzheimer Society of British Columbia and Island Health—convened for the inaugural roundtable of the **Dementia Action Co-Lab**. Hosted at the University of Victoria, the session marked the formal launch of this community-based research hub within the Faculty of Health, founded and directed by Dr. Mariko Sakamoto. The Co-Lab is grounded in a commitment to centering the voices of people living with dementia in research, reducing stigma, fostering dementia-inclusive communities, and supporting continued engagement and quality of life.

An inspiring launch for the Dementia Action Co-Lab! So much knowledge, lived experience, and passion gathered around one table. Excited for what we'll build together moving forward.

The Dementia Action Co-Lab builds on the foundational work of the **Flipping Stigma Action Group**, a co-designed initiative led by people with lived experience of dementia and care partners. Their online stigma-reduction toolkit has been internationally recognized by the World Health Organization's Global Dementia Observatory Knowledge Exchange Platform as one of the top ten global resources for dementia diagnosis, care, support, and monitoring. Since joining the University of Victoria in 2023, Dr. Sakamoto has expanded this work through partnerships with organizations like the CARING Dementia Collaborative, Emily Carr University's Health Design Lab, and research teams across Canada, with a strong emphasis on community-based participatory and co-design methodologies.

The roundtable focused on gathering input for a proposed five-year, longitudinal qualitative study to be submitted to the Canadian Institutes of Health Research this spring. The proposed research would take place across three regions of British Columbia—Vancouver Island, the Lower Mainland, and the Fraser Valley—and aims to deepen understanding of how communities can better support people living with dementia to age in place while maintaining health, quality of life, and social connection. The study is designed to meaningfully involve people with lived experience as research partners, with interviews conducted every 18 months and community mapping activities to identify existing supports and service gaps. A national community of practice is also planned to support knowledge exchange and broader learning.

Participants provided critical guidance on study design, particularly regarding the inclusion of people living with dementia and care partners as research participants. Key considerations included whether these groups should be engaged separately to ensure both perspectives are authentically represented, the importance of language and terminology (notably distinctions between “care partner” and “caregiver”), and the potential influence of stigma on how disease progression is perceived and reported. Participants also emphasized the importance of addressing housing, social connection, stigma, spiritual needs, and end-of-life considerations within the research. In addition, there was strong support for developing centralized, accessible community resource mapping tools to reduce fragmentation and overwhelm for individuals newly diagnosed with dementia, care partners, and health-care providers. The insights generated during the roundtable will directly inform revisions to the funding application.

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1.0 Event Overview

On Friday, November 28th, a group of people with lived experience of dementia, researchers, trainees, and representatives from both The Alzheimer Society of B.C. and Island Health gathered for the inaugural roundtable session of The Dementia Action Co-Lab, a community-based research hub in the Faculty of Health at the University of Victoria founded and directed by Dr. Mariko Sakamoto. This lab centers the voices of people with lived experience in research initiatives that foster dementia inclusivity, aim to reduce the stigma around dementia, and that empower folks with lived experience to stay engaged in their communities.

2.0 Background

Dr. Sakamoto's work, and the work of her lab, was inspired by The Flipping Stigma Action Group, a team of people with lived experience of dementia and care partners, who worked together over the course of almost two years to develop an online intervention breaking down the myths and stigma society holds about dementia. This toolkit has now been recognized by the World Health Organization's Global Dementia Observatory Knowledge Exchange Platform as one of the world's top ten resources for dementia diagnosis, care, support, and monitoring. The toolkit can be found here.

Dr. Sakamoto began her research and teaching at the University of Victoria in 2023. She launched the co-lab in the fall of 2025. Her team works in partnership with a variety of other teams like the CARING Dementia Collaborative, Emily Carr University's Health Design Lab, other research teams across Canada to continuously work to improve quality of life for people living with dementia and care partners and families. They are dedicated to community-based participatory and co-design research approaches and building connections and partnerships that support dementia inclusivity.

3.0 Detailed Proceedings

3.1 Welcome

Dr. Sakamoto welcomed all the in-person and online guests, and went over some light housekeeping items, like the event's itinerary, how to participate in the online chat, and how participants could follow up after the event.

3.2 Land Acknowledgement

She then acknowledged the traditional territory on which the event was being held, paying special attention to the various territories on which guests attending online were calling in from.

3.3 Slide Presentation

Next, Dr. Sakamoto gave a slide presentation about the Dementia Action Co-Lab, it's collaborative approach to community action research, how it planned to include folks living with dementia in all research studies going forward, and what that might look like. A full collection of the slides is available in Appendix B.

3.4 Co-Lab Session

Next, Dr. Sakamoto facilitated a collaborative brainstorm session, asking participants to respond to a series of questions about a research project the Co-Lab team was proposing to the Canadian Institute for Health Research, and inviting them to be a part of the research.

The study is a five-year longitudinal qualitative study based in three regions of British Columbia: Vancouver Island, the Lower Mainland, and the Fraser Valley. The study aims to deepen understandings of how communities can become more dementia-inclusive, enabling people living with dementia to age in place, maintain their health, quality of life, and social connections. Grounded in a community-based participatory and co-design research approach, the project meaningfully involves people with lived experience of dementia as partners in identifying what communities can build upon to help better support folks living with dementia over time as their dementia progresses. The research team plans to interview study participants every 18 months to see how things are going, what needs and priorities have shifted for them, and how they think their community could best support them at each stage. The research team also plans to invite participants at two points over the course of the five years to participate in a community mapping activity that lays out where supports in community exist and identify gaps in services that could be strengthened. Lastly, the researchers plan to develop a community of practice, inviting researchers from other places across Canada to exchange knowledge and insight, further informing the project.

3.5 Key Questions

Who: Should care partners be primary study participants, or secondary information-sharers supporting people with lived experience as the primary study participants?

What: What kinds of questions could we ask study participants in our recurring interviews that would help us better understand how their needs are changing over time, and what supports might need to be amplified in their community? What areas of life could we cover, that we might not think to ask?

How: How could we best map supports, programs, and services across the regions we are interested in? What would community members gain from this activity?

3.6 Key Discussion Takeaways

Here are some of the highlights of what the group had to say…

-Several people advocated for exclusively making people living with dementia the study's primary participants

-Others suggested it would be important to include care partners *and* people with lived experience as primary participants, but in separate categories, so both voices and perspectives could be shared equally without affecting the findings of the other group

-there was a degree of concern that people living with dementia might downplay the progression of the disease from a place of self-stigma, or even concern for their care partner, and others worried care partners might lean towards the opposite perception to some degree. Keeping the reflections from these two groups separate would have important implications for policy development and even community support teams aiming to identify priorities

-The terminology of "care partner" and "care giver" came up as being a very important distinction. Some care givers felt they were no longer "partnered" with the person they support, and that the term was somewhat triggering

-Team members suggested that in their interviews, researchers could ask about issues like housing needs, stigma, social needs, and spiritual needs. They could also explore end-of-life support. As dementia progresses, it's quite common for the frequency of friend visits, for example, change and/or diminish, which is hard on a person's sense of self, and makes it increasingly hard for folks to plan their death. Keeping these components in mind is important

-In mapping supports for people with dementia, ideally it would be very helpful to organize this in such a way that someone living with dementia doesn't have to visit a myriad of distinct websites to learn what’s available to them. To have everything accessible in a centralized way would be infinitely easier. This kind of resource (which could be developed by a government organization or research team) would be beneficial not only for care partners and people with lived experience, but also for doctors and other medical professionals to give to someone they’ve recently diagnosed. It would help alleviate at least some elements of the overwhelm that comes with this diagnosis

4.0 Next Steps

Mariko and the Dementia Action Co-Lab staff would like to invite you to join us again in February 2026 to continue the valuable conversation we began in November and refine some of the ideas that came up. We will be resubmitting the funding application for this study in March and will come prepared with more specific questions for you in February. Please let us know if you’re interested in joining us, and we will share specific date and time details with you in mid-January.

5.0 Premier Film Screening

After the co-lab session concluded, special guest and film director Sam Pineda Sierra screened the premier showing of her short documentary The Now Within for all the participants. This film features three people with lived experience and their care partners talking about the experience of caring and being cared for. The film has been submitted for inclusion in a wide variety of international film festivals. Participants were deeply moved by the stories and the way they were told.

6.0 Acknowledgments

We want to thank everyone who attended the event on November 28th for taking the time to join us. The discussion was extremely helpful, and your ideas have all been incorporated into our working plans for the grant resubmission. We’d like to thank the Institute on Aging and Lifelong Health for hosting the event, UVic’s media services’ staff for facilitating a successful hybrid experience, Sam Pineda for sharing her beautiful short documentary with us all, and community members, trainees, representatives, and students for making the trip to Victoria.

7.0 Appendices

7.1 Appendix A- List of Participants

Virtual participants

Jim Mann: has served the community as a researcher and advocate for people with lived experience of dementia ever since he was diagnosed with Alzheimer's disease in 2007. He's a member of the Federal Ministerial Advisory Board on Dementia who developed Canada's National Dementia Strategy, and he served as Co-Principal Investigator on the Flipping Stigma Toolkit Project. He is currently working with Mariko and her team on the transformation of the toolkit for the Chinese community.

Cole Tamburri is a PhD student at the University of Victoria whose research focuses on the cognitive neuroscience of aging. He's been involved with investigating arts-based interventions for individuals living with dementia and their caregivers, early predictors and biomarkers of cognitive impairment and dementia risk, and innovative longitudinal statistical modeling approaches for exploring intraindividual change. Cole was a key part of the Audio Diaries project and is co-writing a paper with Dr. Mariko Sakamoto about their findings.

Cari Randa-Beaulieu is the Provincial Coordinator of Knowledge Mobilization for the Alzheimer Society of B.C. She is also a gerontologist and art therapist who worked in long-term care for years before shifting her skills into knowledge mobilization and community-engaged research. She is an avid life-long learner and artist who strives to bring creative, holistic, and person-centered approaches to the work she does.

Alice Purdey: is a caregiver to her husband Fred, who is living with dementia. She and Fred took part in a three-year arts-based research project out of UBC on what it means to live well with dementia to the end of life. She and Fred live in Burnaby with their dog Cedar and are great outdoors people. They're keen climbers and hikers, and Alice is the co-author of a book called “100 Walks in British Columbia's Lower Mainland". She's a retired master's prepared registered nurse who has worked internationally.

Debra King lives with her lifelong friend Elizabeth in Colwood, BC, where they bask in the view from their back deck when the weather is good. She moved out from Ontario after her retirement, (she worked in banking for many years), to support Elizabeth, who had been diagnosed with dementia. Debra took part in the Audio Diaries project.

In-Person Participants

Lynn Jackson: is a Vancouver Island-based dementia advocate who has been living with frontotemporal dementia for over two decades. She was Co-Lead on the Dementia Action Co-Lab's project entitled “Dementia Friendly Communities for People Living Alone”, and part of the action group that developed The Flipping Stigma Toolkit.

Amy Cameron: was diagnosed with early-onset Alzheimer's in her fifties. She lives with her husband Joe Ross and participates in Alzheimer Society of B.C. events that connect her to others with dementia. She and Joe stay very physically and socially active and take comfort in their deep connection to each other.

Joe Ross: is Amy's husband, care partner and best friend. He lives with her on Vancouver Island and advocates for more support geared towards people living with early-onset dementia.

Ashley Sharma: is a twenty-five-year-old social worker from Abbotsford and part-time caregiver to her grandmother, Devki. She was featured on the award-winning episode of *Call to Mind*, a podcast hosted by Mariko Sakamoto, recorded by caregivers of family members living with Alzheimer's and other forms of dementia.

Dr. Denise Cloutier: is a health and social geographer interested in how the places in which we live influence the experience of living with dementia. A professor in UVic's Department of Geography, as well as a research fellow with the Institute on Aging and Lifelong Health, Dr. Cloutier is also one of four members of an interdisciplinary collaborative research team at UVic called the CARING Dementia Cluster, which stands for "Community Advancing Resources and Initiative for Nurturing Generations."

Dr. Jodie Gawryluk: is a clinical neuropsychologist and associate professor in the Department of Psychology and School of Medical Sciences at UVic, specializing in neuropsychology, magnetic resonance imaging, and community-based research. She is the Director of the Institute on Aging and Lifelong Health, and one of four key members of the CARING Dementia Cluster.

Dr. Stuart MacDonald is a Professor of Psychology at the University of Victoria and is among four key members of the CARING Dementia Cluster. He is an internationally recognized scientist whose research focuses on cognitive aging and early identification of those at risk for Alzheimer's disease, paying particular attention to community-engaged lifestyle interventions that may delay or prevent changes in cognitive or functional health. Combining expertise in gerontology, cognition, longitudinal methodology, and neuroscience, Stuart's research program has been continuously funded by both Canadian and international granting agencies. He has received several career research recognitions including induction into the Royal Society of Canada's College of New Scholars, Artists and Scientists and currently holds the Mohr Research Chair in Adult Development and Aging.

Heather Strosher is a knowledge broker within Island Health's Research department, who helps to integrate research into practice, working with research teams to define who they want to engage, how to do it, and what evidence to use; she is funded through the BC SUPPORT Unit which builds capacity for Patient-Oriented Research and Learning Health Systems.

Carolyn Brandly is a PhD student at the University of Victoria who has worked with and for older adults and people with dementia for 20+ years in care and community settings – designing, implementing, and evaluating health promotion programs, and facilitating community development, knowledge translation and quality improvement initiatives and research.

Karen Terra is a PhD student in the Social Dimensions of Health program at the University of Victoria. Her research examines the intersections of arts, aging, well-being, and quality of life, with a focus on how arts-based activities can support people living with dementia.

Jaymelyn Hubert is a registered nurse with a clinical background in mental health and palliative care. In addition to her work with the Dementia Action Co-Lab, she supports the CARING Dementia Collaborative in her role as Project Coordinator.

Ka Wing (Kendall) Pun is a Registered Social Worker and Master of Social Work graduate from the University of British Columbia with extensive experience supporting children, families, and people encountering mental health challenges. As a Research Assistant on the Flipping Stigma project at the University of Victoria, she collaborates closely with people living with dementia to share their stories, challenge stigma, inspire changes, and promote inclusion through research and community engagement.

Dr. Mariko Sakamoto is the Dementia Action Co-Lab Founder and Director. She is an Assistant Professor of Nursing at the University of Victoria where she spearheads a number of exciting action research projects, like co-leading the transformation of The Flipping Stigma Toolkit for the Chinese community. She was a Postdoctoral Fellow with the Centre for Research on Personhood in Dementia and the Alzheimer Society of B.C. and is the current president of the Gerontological Nurses Association of BC. She is also one of the four key members of the CARING Dementia Cluster.

Heather Neale Furneaux is a writer and research coordinator with the Dementia Action Co-Lab. She was the Knowledge Mobilization Lead for UBC's Building Capacity Project over the past five years and works in a community engagement and knowledge translation role for UBC Okanagan's Compassionate Dementia-Inclusive Communities project. She is the author of a series of books on end-of-life decision-making for people living with dementia that is being released this winter as a free online resource through Press Books.

Paulina Santaella is a physician specializing in Pharmaceutical Medicine, holding two master's degrees: one in Health Leadership and Policy in Senior Care, and another in Social Responsibility. She is fully committed to enhancing the quality of care for older adults, particularly those living with dementia. She has been working in interdisciplinary research at institutions such as the University of British Columbia (UBC) and the University of Victoria (UVic). Her work spans projects on creating age-friendly communities, dementia care, and transforming health systems.

Haley Keenan is a master's student in the Clinical Psychology program, specializing in Neuropsychology. She completed her BSc (Hons.) at St. Francis Xavier University (StFX) in Nova Scotia, where she looked at differences in resting-state functional connectivity strength between Super Agers and Normal Agers in the Alzheimer’s Disease Neuroimaging Initiative (ADNI) database. Keenan joined the Gawryluk lab in 2024. Her research interests include aging, cognition, memory, Alzheimer’s Disease, and neuroimaging.

Samantha Pineda Sierra is a visual communication designer who works with researchers and dementia advocates to develop tools, multimedia campaigns, and visual solutions that translate concepts into effective designs. The various mediums she engages with include film, digital platforms, print, branding, animation, and more. She was a key lead member of the knowledge translation team for UBC’s Building Capacity Project over the past five years, and in addition to her role at UBC, she is also a filmmaker and the co-founder of a production company called Opia, which tells bold and original stories to elevate underrepresented voices.

Paulina Malcolm is the Community Research Coordinator for several community-based research projects focused on addressing dementia-related stigma and promoting more dementia-inclusive spaces. She works closely with people with lived experience to better understand their social landscape, co-create research priorities, and support greater project engagement. Paulina has experience working on participatory action and co-design research projects in the field of dementia and older-adult mental health. She is currently working on her Masters in Rehabilitation Science at UBC.

Kirsten Barlow lives in Nanaimo with her partner and was caregiver to her mother, Anne. Prior to taking medical leave earlier this year, Kirsten worked as a Supported Child Development Consultant at the Nanaimo Child Development Center.

Anne Barlow was an LPN at NRGH and later an OT Recreation Assistant at West Coast Occupational therapy in Vancouver, before retiring and moving to Gabriola. Anne and her daughter Kirsten bought a home in Nanaimo together and as Anne's dementia progressed, she moved from Gabriola to Nanaimo to live with Kirsten full time in 2018. In 2022, Anne received a diagnosis of Alzheimer's. She passed away in June of this year from complications of congestive heart failure.

Abby (Tegart-Barlow), who is Kirsten's daughter, also lives in Nanaimo with her partner. Abby recently started a Landscaping company and co-manages the cooperative farming program called Farm-ship. Abby was also very involved with Anne's care.

7.3 Appendix B- Related Websites and Resources

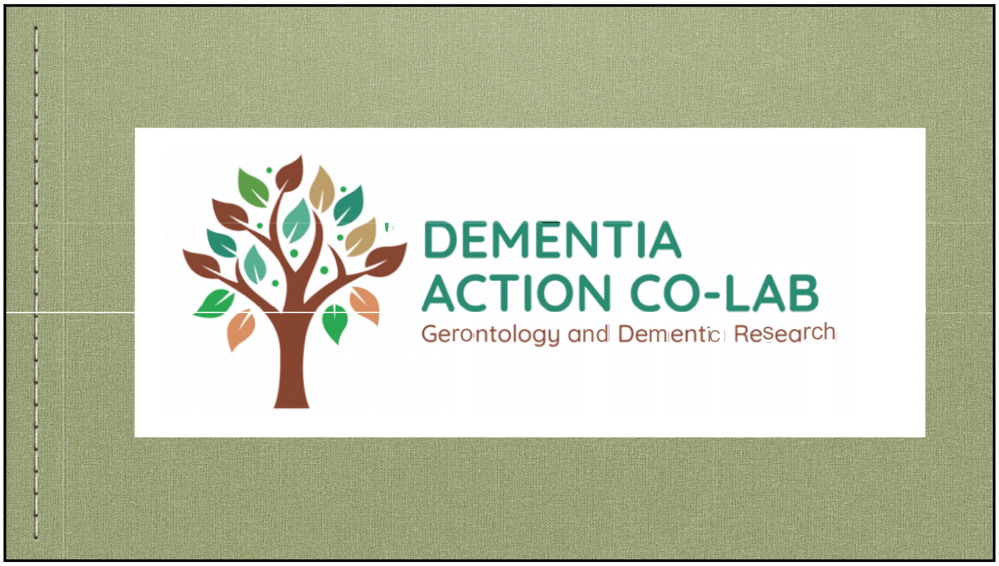
The Flipping Stigma Toolkit: flippingstigma.com

The Dementia Action Co-Lab site: https://onlineacademiccommunity.uvic.ca/actionlab

CARING Dementia Collaborative site: https://onlineacademiccommunity.uvic.ca/cdc/

Canadian Institute for Health Research: https://cihr-irsc.gc.ca/e/193.html

7.2 Appendix C- Slides from the Event



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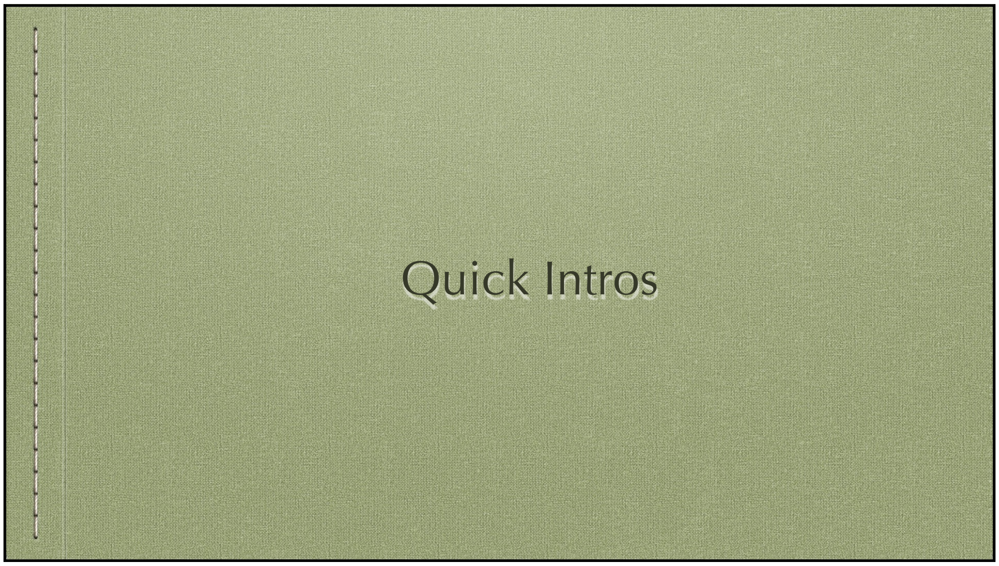
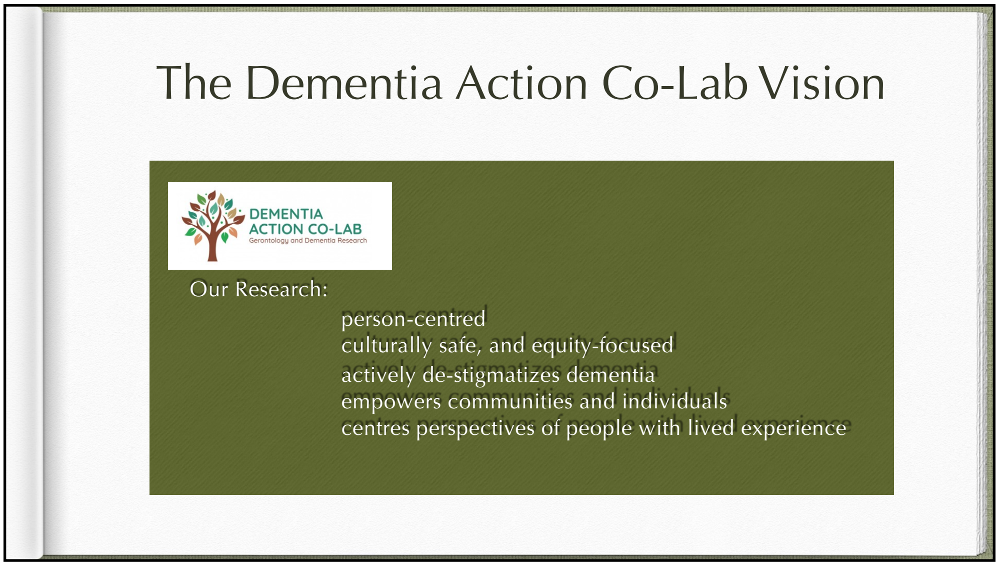
Land Acknowledgement

We acknowledge and respect the Lekwungen (Songhees and Esquimalt) Peoples, on whose traditional territory the university stands, and the Lekwungen and WSÁNEC Peoples, whose historical relationships with the land continue to this day.



Quick Intros



The Dementia Action Co-Lab Vision

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Gerontology and Dementia Research

Our Research:

- person-centred
- culturally safe, and equity-focused
- actively de-stigmatizes dementia
- empowers communities and individuals
- centres perspectives of people with lived experience

The CIHR Grant

What's the Research About?

- Longitudinal qualitative study deepening understandings of how communities can become more dementia-inclusive
- Grounded in a community-based participatory and co-design research approach

Study Objectives

- Explore the diversity of the dementia experience
- Understand how people’s needs change over time and how communities can support them
- Identify features of dementia-inclusive communities
- Share findings with the larger community and decision makers

Research-related questions

Our invitation to you for your insights and ideas

The "Who"

- Should care partners also be primary study participants or should they be secondary information-sharers who support people with lived experience as the primary study participants?

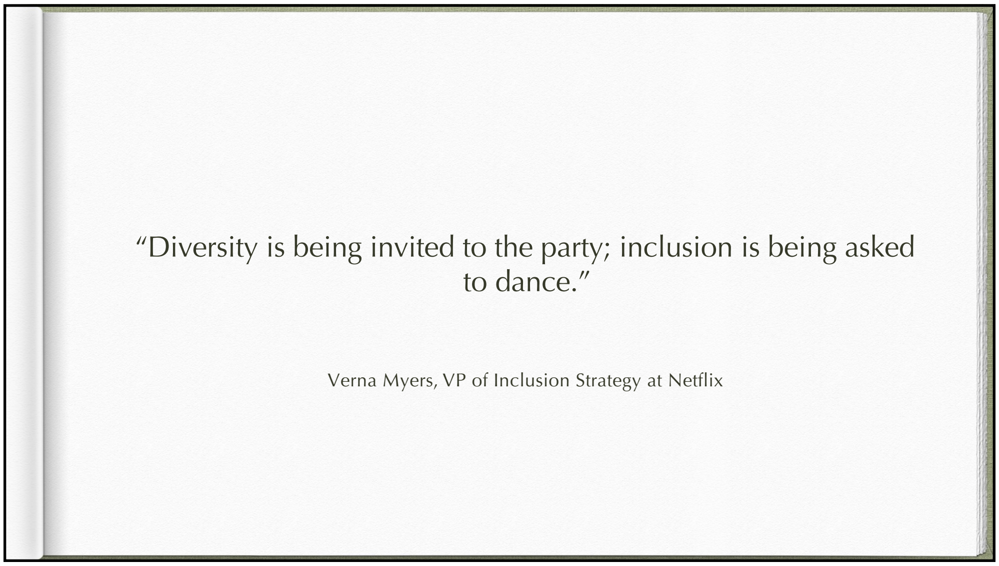
The "What"

- What kinds of questions could we ask study participants in our interviews every eighteen months?
- What areas of life could we cover? What might we not think to ask?

The "How"

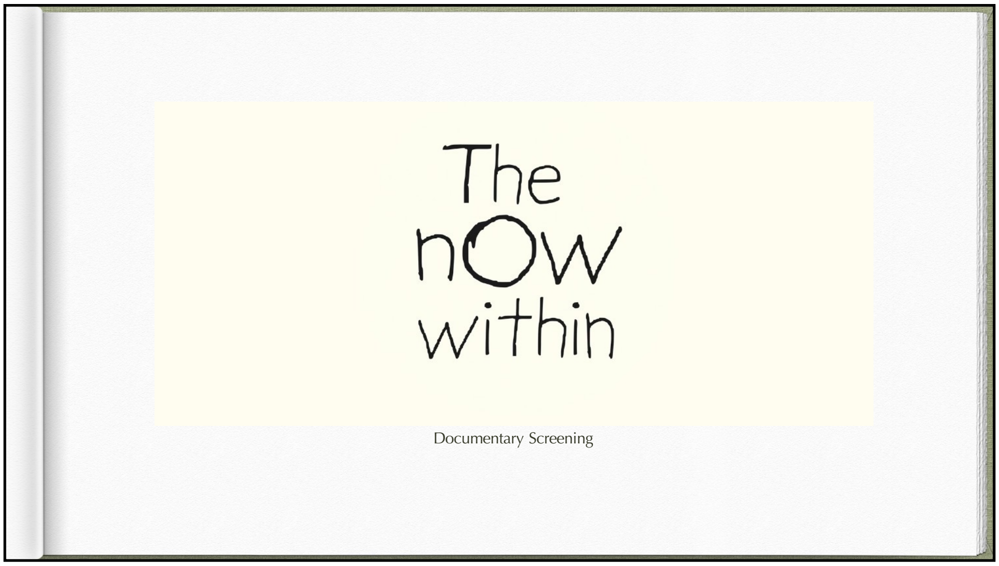
- How could we best map supports, programs, and services across the regions we are interested in?
- What would community members gain from this activity?

Debrief



“Diversity is being invited to the party; inclusion is being asked to dance.”

Verna Myers, VP of Inclusion Strategy at Netflix



The
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within

Documentary Screening