

Project Information

To help you make an informed decision regarding your participation, this letter will explain what the study is about, the possible risks and benefits, and your rights as a participant. If you do not understand something in the letter, please ask one of the investigators prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study.

TITLE OF THE STUDY: From the inside out: The integration, optimization, and promotion of inclusive approaches to supporting LGBTQI2S PLWD and their unpaid primary carers

INVESTIGATORS: This research study is being conducted by Dr. Samir Sinha, MD, DPhil, FRCPC, AGSF, Director of Health Policy Research, and Dr. Ashley Flanagan, PhD, Research Fellow, National Institute on Ageing, Ryerson University in partnership with Dr. Dai Kojima, PhD, Director of Research, and Celeste Pang, PhD(c), Senior Research Officer, LGBTQI2S Health, Aging, and Housing, Egale Canada.

This study is funded by a Public Health Agency of Canada Dementia Community Investment grant.

If you have any questions or concerns about the research, please feel free to contact the research team at dementiastudy@egale.ca or one of the project leads:

- Dr. Ashley Flanagan: akflanagan@ryerson.ca
- Celeste Pang: cpang@egale.ca

PURPOSE OF THE STUDY:

You are being invited to participate in a research study interested in exploring LGBTQI2S persons living with dementia (PLWD) and their unpaid primary carers understand and experience care and support within Canada. Recognizing the gap in current understandings of living and/or caring within the intersections of LGBTQI2S identities and dementia, this study aims to better understand the unique experiences and needs of LGBTQI2S people living with dementia (PLWD) and their unpaid carers in Canada.

This study will involve up to eight online focus groups—four focus groups with 4–6 LGBTQI2S PLWD and four focus groups with 4–6 unpaid primary caregivers—which will be led by an experienced facilitator with lived experience (e.g., regional, LGBTQI2S, caring).

In order to participate in a focus group, the following inclusion criteria are required:

- Identify as lesbian, gay, bisexual, transgender, queer, intersex, and/or Two-Spirit;
- Live with a diagnosis of dementia;
- At least 18 years of age; AND
- Have the capacity to provide consent and participate in a 2-hour focus group.

It is our hope that the insights provided by this study will positively influence LGBTQI2S PLWD and their unpaid primary carers' experiences of care and support within communities across Canada.

WHAT YOU WILL BE ASKED TO DO:

If you volunteer to participate in this study, you will be asked to do the following:

- Complete a *Recruitment Form* to indicate interest in participation;
- Participate in a 30–45 minute *Introductory Meeting* with the investigator, in which we will determine your eligibility for the study, seek informed consent, and ask some basic demographic questions; and
- Participate in a 2-hour *Focus Group* with an experienced facilitator and the investigator. During this focus group, participants will be asked to share stories about the current state of care and support in Canada, your perspectives on the aspects of care/support that are beneficial and/or detrimental, and your hopes/suggestions for enhancing care provision and support in Canada.

All engagement will take place over email, telephone, or using Tauria, an online video conferencing system. Only the focus group will be audio recorded to ensure an accurate transcript of the discussion. With your permission, anonymous quotations may be used in publications and/or presentations.

POTENTIAL BENEFITS:

We cannot guarantee that you will receive any direct benefits from participating in this study. However, there is potential for future benefits to stem from this study that will improve support for LGBTQI2S PLWD and their unpaid carers. The goal of the inquiry is to support the extension of social infrastructure (through broader public awareness, resource development, and access to inclusive spaces) to support equity and inclusion for LGBTQI2S PLWD and their unpaid carers; as well as make visible the structures that maintain barriers to equitable and inclusive support. Without these intentional efforts to address the on-going disparity in care and support, LGBTQI2S PLWD and their unpaid carers will continue to experience barriers to equitable and inclusive support within their communities. It is our hope that participation in this inquiry contributes to strengthening support within the communities of participants—as well as within communities across Canada.

WHAT ARE THE POTENTIAL RISKS TO YOU AS A PARTICIPANT:

Due to the nature of the study, we anticipate that the focus group process may present some psychological, social, and legal risks; as well as risk of personal identity being revealed. For example, as the conversation unfolds, participants will explore potentially emotional and sensitive topics of personal history, experiences, and perceptions as they relate to sexual and/or gender identity, dementia, and care and support that have the potential to be traumatic and/or triggering for some participants (e.g., previous or current experiences of neglect and/or abuse).

In the event that a participant discloses previous or current experiences of neglect and/or abuse, the subsequent duty to report to report elder abuse in Ontario is dependent upon whether the participant resides in a retirement or long-term care home. If the participant resides within a retirement or long-term care home, the researcher has a duty to report the abuse to one of the following:

- Long-Term Care ACTION Line at 1-866-434-0144 or TTY: 1-800-387-5559
- Retirement Homes Regulatory Authority at 1-855-ASKRHRA (2757472)

In either situation, in the moment of disclosure, it will be the facilitators responsibility to ensure that they respond to the participant with patience, empathy, and without judgement—which is why we are hiring experienced facilitators. Behind the scenes, it will be the researcher’s responsibility to ensure you have the time, resources, and support you need; including the provision of a list of free and affirming support services; such as Seniors Safety Line (1-866-299-1011).

Attempting to minimize the risks associated with participation in this study, focus groups will be led by facilitators who have experience in group facilitation. Further, all parties will work to create a welcoming and safe environment of mutual trust and sharing. In particular, during the *Introductory Meeting*, participants will be asked to provide some suggestions for “rules of engagement” that will be used in the focus group(s). These “rules” will be clearly laid out at the beginning of each focus group to establish openness, trust, and mutual respect within the focus group environment; as well as provide facilitator/researcher with guidelines for (re)framing discussions.

If at any point during the focus group, you become uncomfortable or distressed, you may skip answering a question or stop participation, either temporarily or permanently. In the event of this occurrence, it is the researcher’s responsibility to ensure you have the time, resources, and support you need; including the provision of a list of free and affirming support services, such as Here 24/7 at 1-844-HERE-247 (437-3247) or TTY 1-877-688-5501 (see attachment for complete list).

CONFIDENTIALITY:

While we, the research team, will respect the confidentiality of all participant’s information, we cannot promise or ensure that other participants will do the same. We will, however, ask all participants in the study to respect the confidentiality of all participants.

Identifying information will be removed from the data (e.g., replaced with pseudonyms) that is collected and stored separately on a password-protected laptop. Only the lead researchers named in this study will have access to identifying demographic data. Data will not be physically transported between members of the research team since all data will be stored on an online server that is managed by Egale Canada to enhance collaboration by the research team during analysis. Your individual responses (i.e., raw data) will be deleted after transcription and review. All transcripts will not be shared with anyone outside of the research team. Only group results (i.e., no identifying information) will be reported. You have the option of choosing or being assigned a pseudonym to be used in any future reports, presentations, or publications based on this research.

Electronic research data (e.g., transcripts, analysis files) will be retained for a minimum of 5 years on Egale Canada's secure online server—at which time they will be erased. Original audio recordings will be stored on Egale's secure online server until the transcripts have been reviewed and approved by participants—at which time they will be erased. All downloaded paper records (e.g., printed de-identified transcripts) will be stored for the duration of the analysis phase of the research project in a locked filing cabinet located in a locked personal office—at which time they will be deleted/erased and/or confidentially shredded.

INCENTIVES FOR PARTICIPATION:

You will receive a \$50 Amazon e-gift card for participation in this study; along with an *Appreciation Letter* via email when you log-on to the focus group session. Each participant will also have the opportunity to consent to be contacted after the completion of the focus group to provide additional input/feedback during the *Community Consultation Event*. At the completion of the research project, participants will have the option of receiving a summary of the key findings and future steps that have arisen from the study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

Participation in this study is completely voluntary. You can choose whether to be in this study or not. If any question makes you uncomfortable, you can decline to answer any question(s) that you do not wish to answer. You may stop participating at any time and you will still be given the full incentive described above. If you choose to stop participating, you may also choose to not have your data included in the study. You can request for your data to be removed from the study up until the de-identified focus group transcripts have been reviewed and approved by participants. Since raw audio data will be deleted at this time and it will no longer be possible to distinguish between individual contributions.

Your choice of whether or not to participate will not influence your future relations with Ryerson University, the National Institute on Ageing, Egale Canada, or the investigators involved in the research as named above.

QUESTIONS ABOUT THE STUDY:

If you have any questions about the research now, please ask. If you have questions later about the research, you may contact the research team at dementiastudy@egale.ca, Dr. Ashley Flanagan at akflanagan@ryerson.ca, or Celeste Pang at cpang@egale.ca.

This study has been reviewed and received ethics clearance through the Ryerson University Research Ethics Board (REB 2020-349). If you have questions regarding your rights or treatment as a participant in this study, please contact:



Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@ryerson.ca

CONFIRMATION OF AGREEMENT

By consenting to this agreement, you are not giving up any of your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

Title of the study: From the inside out: The integration, optimization, and promotion of inclusive approaches to supporting LGBTQI2S PLWD and their unpaid primary carers

I have read the information presented about the study conducted by Dr. Samir Sinha and Dr. Ashley Flanagan, PhD of the National Institute of Ageing at Ryerson University, in partnership with Dr. Dai Kojima, PhD and Celeste Pang, PhD(c), from Egale Canada. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that excerpts from the focus group may be included in the presentations and/or publications to come from this research, with the understanding that the quotations will be de-identified.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

I have received a copy of this agreement.

This study has been reviewed and received ethics clearance through the Ryerson University Research Ethics Board (2020-349). If you have questions regarding your rights or treatment as a participant in this study, please contact:

Research Ethics Board
c/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042
rebchair@ryerson.ca

For all other questions contact Ashley Flanagan at akflanagan@ryerson.ca or Celeste Pang at cpang@egale.ca.

I am aware the interview will be audio recorded to ensure accurate transcription and analysis. I understand how these recordings will be stored and destroyed.

YES

NO

I give permission for the use of de-identified quotations in any thesis or publication that comes of this research.

YES NO

I give permission to be contacted after the completion of this interview to provide feedback (e.g., reviewing drafts of findings) and/or additional information, if needed.

YES NO

Your consent indicates that you, with full knowledge of all foregoing, agree to participate in this focus group and keep in confidence information that could identify specific participants and/or the information they provided.

Name of Participant

Initials of Research Team Member

Date

Support Resources for Focus Group Participants

National

Call 2-1-1 or visit <https://211.ca/#service-areas> to connect to programs and services in your community

Canadian Network for the Prevention of Elder Abuse Resources: Visit <https://cnpea.ca/en/what-is-elder-abuse/get-help>

Seniors Canada: Visit <https://www.canada.ca/en/employment-social-development/corporate/seniors/forum.html>

Alberta

AB211 Help Line: Call 2-1-1 or visit www.ab.211.ca

Edmonton Pride Seniors: <http://www.epsg.ca>

- seniors@pridecentreofedmonton.ca
- Aging with Pride Telephone Group – 1st & 3rd Wednesday of each month at 4-5pm
- To join the call: 1-855-703-8985 and enter Meeting ID: 293.631.2402#

British Columbia

BC211 Help Line: Call 2-1-1 or visit www.bc211.ca

Family and Friend Caregiver Support Line: Call 1-877-520-3267 or visit www.familycaregiversbc.ca

QMUNITY Seniors & Older Adults Online Drop-in – Thursdays at 2:30pm

- Email Courtney at seniors@qmunity.ca to RSVP and for the invitation link

Seniors Abuse and Information Line: 1-866-437-1940

Office of the Seniors' Advocate BC

- Toll-free: 1-877-952-3181
- In Victoria: 250-952-3181
- info@seniorsadvocatebc.ca

Manitoba

MB211 Help Line: Call 2-1-1 or visit <https://mb.211.ca>

Klinik Crisis Line:

- Toll free: 1-888-322-3019
- Call: (204) 786-8686

Manitoba Farm, Rural, & Northern Support Services: Call toll free 1-866-367-3276 or visit www.supportline.ca

First Nations and Inuit Hope for Wellness Help Line: 1-855-242-3310

Seniors Abuse Support Line (9am-5pm; Toll free): 1-888-896-7183

For regional crisis and non-crisis contacts: Visit www.gov.mb.ca/health/mh/crisis.html

New Brunswick

NB211 Help Line: Call 2-1-1 or visit www.nbinfo.ca

Chimo Helpline: Call toll free 1-800-667-5005 or visit www.chimohelpline.ca

Morneau Shepell Crisis Support Line: 1-844-751-2133

Horizon Emergency Mental Health Services: <https://en.horizonnb.ca/home/facilities-and-services/services/addiction-and-mental-health-services/emergency-mental-health-services.aspx>

Newfoundland and Labrador

Call 2-1-1

Office of the Seniors' Advocate Newfoundland and Labrador

- Phone: (709) 729-6603
- Toll free: 1-833-729-6603
- Email: seniorsadvocate@seniorsadvocatenl.ca

Seniors NL

- Call: (709) 737-2333
- Toll free: 1-800-563-5599
- Email: info@seniorsnl.ca
- All Resources: <http://seniorsnl.ca/all-resources/>

Northwest Territories

Rainbow Coalition of Yellowknife: Call 847-444-7295 or email info@rainbowcoalitionyk.org

NWT Seniors' Society: Visit <https://www.nwtseiorsociety.ca>

- Senior Info Line: Call toll free 1-800-661-0878
- In Yellowknife: (867) 920-7444

Family Support Centre: Call 867-874-3311 or email famsnn@ssimicro.com

NWT Help Line (7pm-11pm): Call toll free 1-800-661-0844

Nova Scotia

NS211 Help Line: Call 2-1-1 or visit www.ns.211.ca

Nova Scotia Mental Health Authority: Call toll free 1-855-922-1122

Crisis Text Line: Text NSSTRONG to 741741

- Frontline workers: Text FRONTLINE to 741741

Provincial Mental Health Crisis Line: Call toll free 1-888-429-8167

Nunavut

Call 2-1-1

Nunavut Kamatsiaqtut Help Line: 1-800-265-3333

Elders' Support Line: 1-866-684-5056

Ontario

Talk4Healing (for Aboriginal women, in English, Ojibway, Oji-Cree and Cree): 1-855-554-4325

Seniors Safety Line: 1-866-299-1011

ConnexOntario Mental Health Helpline: 1-866-531-2600

211Ontario: Call 2-1-1 or visit <https://211ontario.ca/>

Seniors' INFOline

- Call toll free 1-888-910-1999
- TTY: 1-800-387-5559
- Visit: <https://www.ontario.ca/feedback/contact-us?id=25516&nid=83724>

Prince Edward Island

PE211 Help Line: Call 2-1-1 or visit <https://pe.211.ca>

Island Helpline: Call 1-800-218-2885 or visit <https://www.theislandhelpline.com>

Seniors PEI: Call 1-844-954-7433 or visit <https://seniorspei.ca>

Quebec

QC211 Help Line: Call 2-1-1 or visit <http://www.qc.211.ca>

Seniors Action Quebec:

- Call 438-386-1944
- Email: info@seniorsactionquebec.ca
- Resources: <https://www.seniorsactionquebec.ca/en/resources/online-resources.html>

Saskatchewan

SK211 Help Line: Call 2-1-1 or visit <https://sk.211.ca>

Saskatchewan Seniors Mechanism: Call toll free 1-888-823-2211 or visit <https://skseniorsmechanism.ca>

Saskatchewan Seniors Abuse & Neglect Response Line

- Prince Albert & Area Crisis Line: (306) 764-1011
- Saskatoon & Area Crisis Line: (306) 933-6200
- Regina & Area Crisis Line: (306) 757-0127

Yukon

Call 2-1-1

Let's Chat Yukon: Call toll free 1-877-321-1001

The Reach Out Support Line: Call 1-844-533-3030

All Genders Yukon: Email AGYSboard@gmail.com