

ACTING IN ALLYSHIP WITH 2SLGBTQI PEOPLE LIVING WITH DEMENTIA

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Egale

Egale is Canada's leading organization for 2SLGBTQI people and issues. We improve and save lives through research, education, awareness, and by advocating for human rights and equality in Canada and around the world. Our work helps create societies and systems that reflect the universal truth that all persons are equal and none is other.

The National Institute on Ageing is a Toronto Metropolitan University think tank focused on the realities of Canada's ageing population. Through our work, our mission is to enhance successful ageing across the life course and to make Canada the best place to grow up and grow old.



PROJECT BACKGROUND

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PROJECT BACKGROUND


- Clearly identified gap in research related to dementia and care in 2SLGBTQI communities
- Growing need for shared knowledge, resources, engagement, and critical inquiry



- Funded by a Public Health Agency of Canada Dementia Community Investment Grant

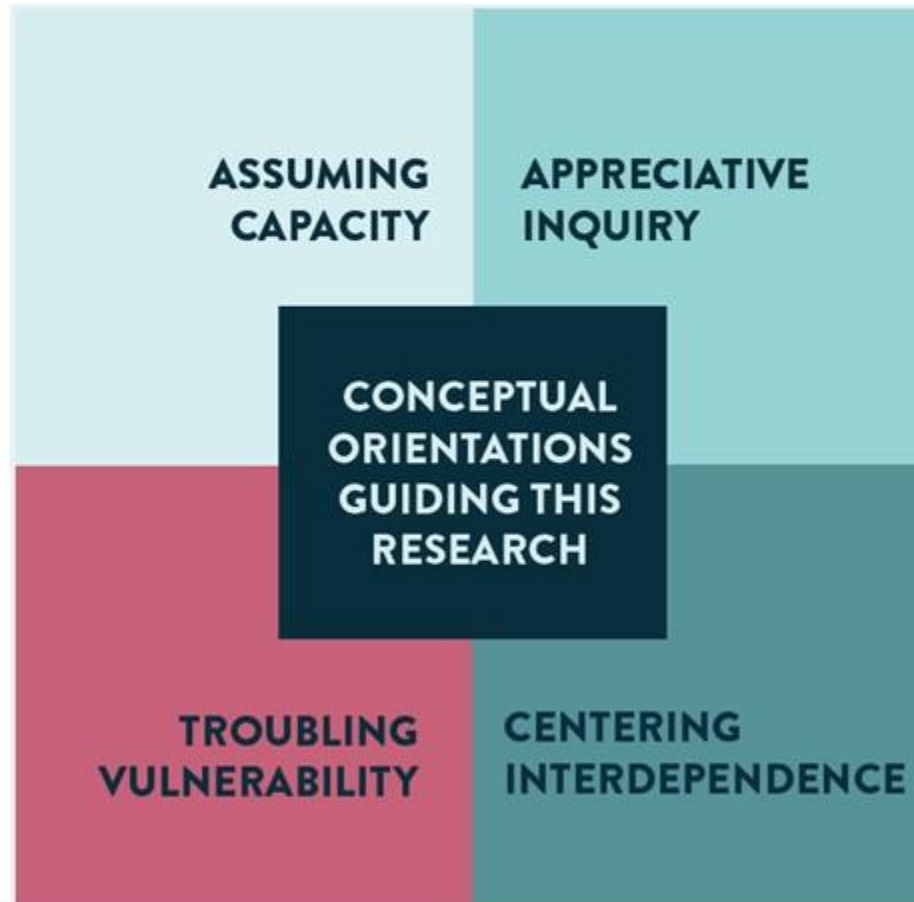
RESEARCH QUESTIONS

- What is the current state of (unpaid) care as experienced—or perceived—by 2SLGBTQI people living with dementia (PLWD) and their carers who live in Canada?
- Based on these experiences and perceptions, what can we learn about the aspects of care that are beneficial, detrimental, ignored, unfilled, imagined?
- What suggestions do 2SLGBTQI PLWD, their carers, and other key stakeholders have for enhancing care provision and support?

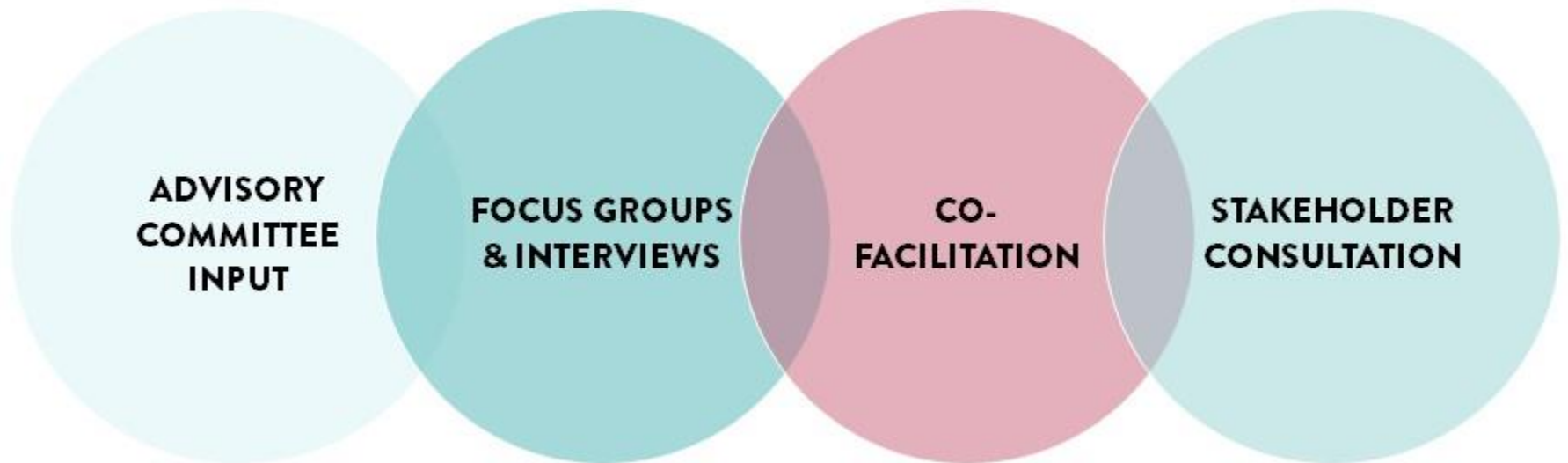
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Without greater knowledge and understanding that centres the perspectives of 2SLGBTQI people living with dementia and their primary unpaid carers within Canada, the ability of government, healthcare professionals, and others to provide equitable and comprehensive support and care is severely compromised, as is the ability to advocate for change.

RESEARCH ORIENTATION



ENGAGEMENT ACTIVITIES



PARTICIPANT DEMOGRAPHICS

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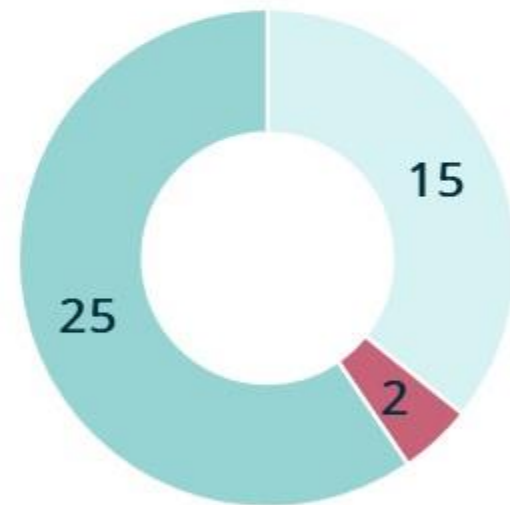
METHODS OF DATA COLLECTION

METHODS USED



- Phase I Focus Groups (5)
- Phase I Individual Interviews (2)
- Phase II Consultation Event (1)

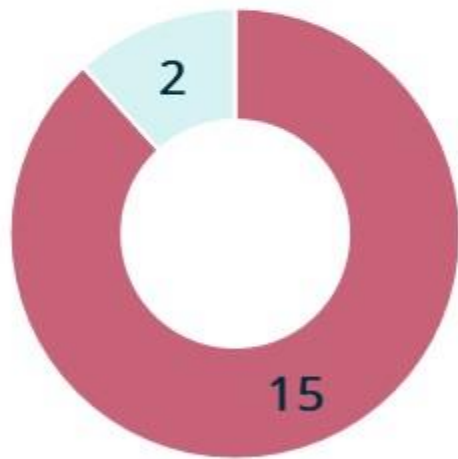
TOTAL PARTICIPATION



- Phase I Focus Groups (15)
- Phase I Individual Interviews (2)
- Phase II Consultation Event (25)

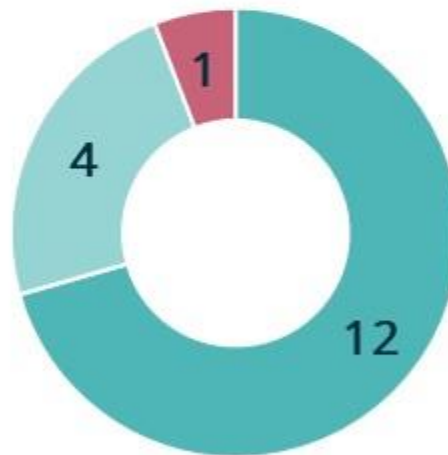
PHASE I PARTICIPANT PROFILE

RELATION TO PROJECT



- Carers (15)
- PLWD (2)

GEOGRAPHIC LOCATION



- Central Canada (12)
- Western Canada (4)
- Eastern Canada (1)

AGE



- 30-40 (3)
- 40-50 (4)
- 50-60 (2)
- 60-70 (6)
- 70+ (2)

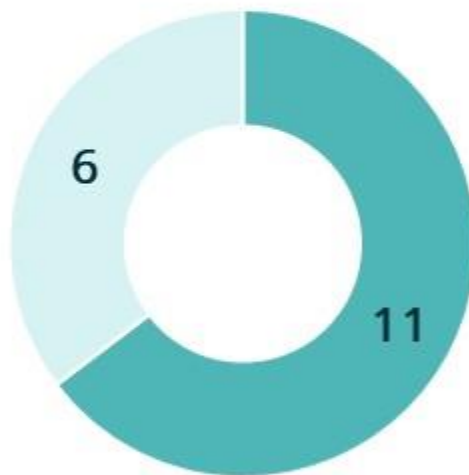
PHASE I PARTICIPANT PROFILE

SEXUAL IDENTITY



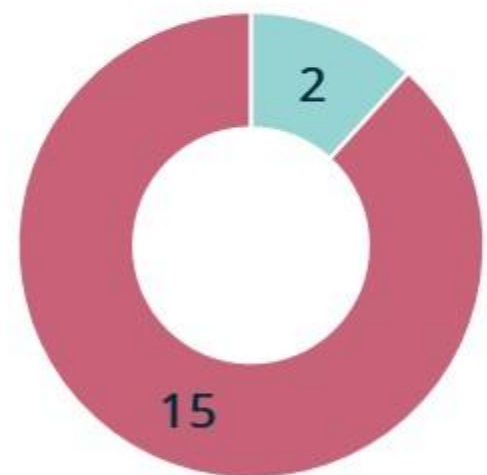
- Queer (3)
- Gay (3)
- Lesbian (5)
- Pansexual (1)
- Straight (4)
- No response (1)

GENDER IDENTITY



- Cisgender woman/female (11)
- Cisgender man/male (6)

RACIAL IDENTITY



- Racialized (2)
- white

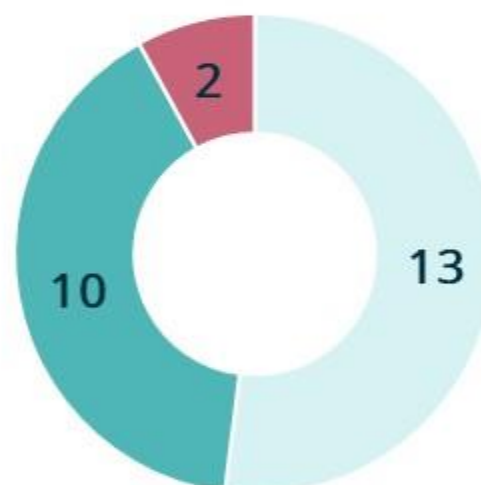
PHASE II PARTICIPANT PROFILE

RELATION TO PROJECT



- Phase I Participants (5)
- 2SLGBTQI Older Adult Group Representatives (6)
- Dementia Care Stakeholders (7)
- General Ageing Care Stakeholders (7)

GEOGRAPHIC LOCATION



- Central Canada (13)
- Western & Northern Canada (10)
- Eastern Canada (2)

FINDINGS

COMING OUT AND COMING
IN TO LIVING WITH
DEMENTIA:
Enhancing Support For 2SLGBTQI
People Living With Dementia And
Their Primary Unpaid Carers

BECOMING CARERS

- People became primary unpaid carers through a wide variety of pathways, from close pre-existing relationships to more distant ones
- Distinct from assumptions that children or spouses will be primary unpaid carers, carer participants were:
 - Caring for a spouse/primary relationship partner
 - Caring for a sibling
 - Caring for an aunt or uncle
 - Caring for community member(s)
 - Caring for friends

BECOMING CARERS



"I fell into caregiving because I said I do."
- Spouse




"I'm at the very beginning stages of this experience, I say probably about a few months in, with a community member friend of mine who is in his early 60s...I've never experienced dementia or Alzheimer's, like in my mind from watching movies, I was really like, you know, you sort of think about someone not remembering who that person is, or things like that.. And I'm still trying to figure out what happens to people when they don't have a spouse, and they don't have blood family. And I've sort of, through myself and different communities that he and I belong to here—queer community and arts community—[I've] sort of cobbled together people that I know love him. ...So just trying to figure out how to best care for someone, when in some respects, you sort of feel like it's not really your place."

- Community Member

BECOMING CARERS

- Carers brought past caring experiences forward: including from being a primary carer for other family members, community members, and friends

An illustration of two people. On the left is a man with dark hair, wearing a purple long-sleeved shirt. On the right is a woman with short grey hair, wearing glasses and a green sweater with an orange collar. They are standing side-by-side.

"Well, the biggest thing is that I've done a lot of [this since] the 80s, caretaking. Actually, dealing with dementia with much younger men, with HIV/AIDS. So... there's not a lot of surprises in how someone may act...I've volunteered, it's kind of been what I've done all my life. A lot of that because we were in [a big city] in that era. That's kind of what you did, your caretaking...So this isn't new to me."
- Partner

GRAPPLING WITH CHANGE

- Living with dementia—as a person living with dementia or a carer—also meant grappling with change.
- This included grappling with:
 - Changes in ability
 - Changes in relationships
 - Questions of recognition, and erasure

CHANGES IN ABILITY

"Well, just last year, during the pandemic, it became impossible for me to care. I never wanted to do it... [but] my partner came to the point where we were... where the cognition went right down the hill where, you know, simple things that she used to be able to do like even use a telephone, like to be able to phone somebody, like phone me at work or phone the neighbour or phone somebody, was impossible. ...The physical part started to kick in as well. So she ended up in care... in long-term care with the goal to come back home but there's no supports, there just aren't."

- Carer



"I was very active and I'm finding not only with the dementia, but my physical state has deteriorated to the point where it's very difficult for me to, number one, do what I want to do, and number two, accept the fact that I cannot do those things anymore."

- PLWD



CHANGES IN RELATIONSHIPS

"I got introduced to that concept of ambiguous grief. And, and how is that, that you are experiencing loss when the person is still sitting there right in front of your face, you know, so that has been really helpful for me to work through that."

- Carer



"I would say that the difference is vigilance in that I have to pay attention to... did she get enough to eat, did she have breakfast, did she take her pills? Did she take them at the right time?... There's a kind of vigilance that's required... And I find that I don't mind the acts of doing the things that I do, and I don't begrudge them at all. But I do find the constant having to be on your game, to pay attention, to prevent disaster. ...So that hypervigilance, I think, is exhausting."

- Carer

QUESTIONS OF RECOGNITION

"I can't tell you how many times I've been asked, Is this my mom? This is the presumption... it is the presumption at the dentist, it's the presumption at the hospital, it's the presumption everywhere. And, you know, [my partner] visually has aged dramatically in the last two years or three years. And I wasn't being asked if she was my mom five years ago. But now there's this presumption and a kind of... As a spouse, I don't feel as seen as a spouse by the medical system at all. It's bizarre. Particularly now because she is needing help."

- Carer



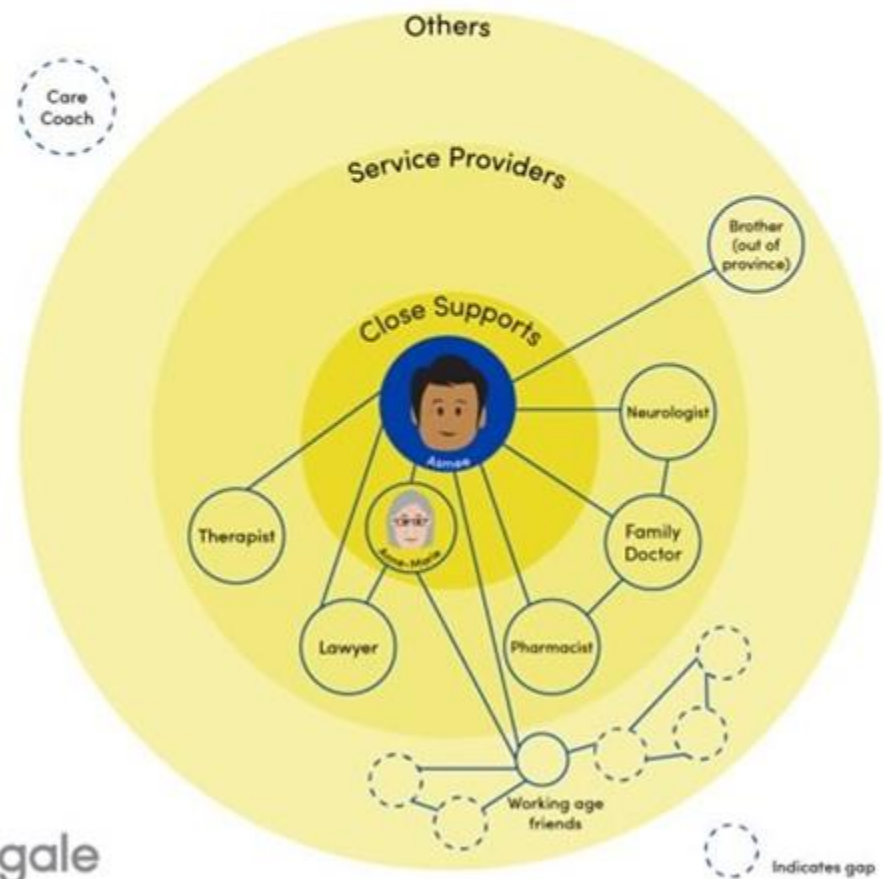
"When it comes to like her sexual orientation, we know... It doesn't affect our caregiving at all, because I don't think she has knowledge of it, she doesn't discuss it, or she doesn't, you know, she doesn't really touch base on that. It's... now her disease rules her life. And it's her actions based on that disease, like, you know, forgetfulness, being erratic, sometimes being aggressive, that kind of takes over. So, the LGBT part doesn't really affect anything that she does, our caregiving or her behaviour... Like, her sexual orientation is not the forefront of her identity for us.

That's just her personal life... We view her in terms of like her health and her situation and, you know, her mental health and physical well-being. We don't really like, discuss that."

- Carer

POWER OF SUPPORT NETWORKS

- Participants described the power of support networks, including the coming together of:
 - Family members
 - Friends
 - Community
 - Healthcare and social services



POWER OF SUPPORT NETWORKS



"I think that's what friends do for friends. They help them, you know, they help them no matter what the situation may be. Whether you're prepared for it or not. But as it was just sad, it was a beautiful experience at times, but really, really difficult at times because there's no handbook at all, and you just have to kind of do what you think is right... if you realize that a friend is at risk, and if they need that kind of support, and there's... they don't have the family or other friends that are willing to do it. You do it because it's the right thing to do. ...I was it... or nobody would have been it."

- Carer

POWER OF SUPPORT NETWORKS

- Participants also described their experiences and wishes for more inclusive healthcare and social service supports. This included:
 - Increased inclusion and safety in accessing healthcare and social services as 2SLGBTQI people and allies
 - From community organizations providing services to 2SLGBTQI people and older adults
 - Support groups geared toward 2SLGBTQI people living with dementia and their carers
 - More dementia care related supports, including in rural areas

POWER OF SUPPORT NETWORKS

"...I think that would it be wonderful, if there were more clinics that went out of their way to publicize that. To say, you know, we're experienced in dealing with the queer community and with issues of dementia, I think it would be great if that was an option."

- Carer



"There needs to be queer-specific support groups and they need to be cross-country and there needs to be access to resources for people that are living in rural areas. I think the one thing that we've learned so much since this pandemic started is that, based on what we're doing here today, these things can happen virtually. So that now that we know that those things can happen, that... they need to be put into place."

- Carer

RECOMMENDATIONS

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FUTURE RESEARCH, ADVOCACY, PROGRAMMING, AND POLICY



Build 2SLGBTQI-inclusive dementia-related services and community spaces



Increase recognition and support for primary unpaid carers of 2SLGBTQI PLWD



Enhance supports for 2SLGBTQI communities and carers through structural and systems-level change



Broaden perspectives and deepen community engagement for future critical research

8 THINGS YOU CAN DO

- **Increase** recognition of unpaid carers. **Check assumptions** about who might be an unpaid carer for a person living with dementia. **Recognize** non-familial carers. **Include** care for friends, community members, and diverse family members in your workplace leave policies.
- **Co-create** dedicated support spaces for 2SLGBTQI PLWD and their carers. **Start** a support group or resource sharing platform.
- **Increase funding** for direct services working at the intersections of dementia care and supporting 2SLGBTQI communities.
- **Expand** 2SLGBTQI inclusive dementia care and support services beyond large, urban city centres.

8 THINGS YOU CAN DO

- **Create** more services and reduce barriers to accessing dementia-related care and support for rural and small-town communities.
- **Integrate** dementia-focused discussions and education into existing 2SLGBTQI support and social groups.
- **Integrate** 2SLGBTQI histories and experiences into core course content for healthcare and social services providers, including in dementia care.
- **Enable** healthcare and social service providers to access ongoing professional development opportunities to better serve 2SLGBTQI PLWD and their carers. **Provide** training during paid time. Provide training regularly.

TIPS FOR PROVIDING AFFIRMING SUPPORT



- When setting up a referral, ask me if there is any personal or relationship information I would like passed along ahead of time to make the transition safer and more comfortable for me.
- Don't make assumptions about me or my abilities based on my identity or my diagnosis.
- Don't make assumptions about my relationships or care networks based on my sexual orientation, gender, racial or ethnic background, age, or other aspects of my identity. This includes assumptions about the level of support I have available.

TIPS FOR PROVIDING AFFIRMING SUPPORT

- Make a habit of always using inclusive and affirming language, regardless of who you are talking to.
- Share your pronouns as part of introducing yourself to others. Share them with everyone, not just some people.
- Be prepared. Keep up to date on the most recent research and information about dementia, dementia care, and 2SLGBTQI communities. This includes reading up on 2SLGBTQI history, experiences, and allyship practices.



NEXT STEPS

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KEEP LEARNING!



EL Egale Learning

2SLGBTQI Identity and Dementia: An Introduction for Healthcare and Social Service Professionals

RESUME COURSE DETAILS ▾

Find the research report, open access e-modules, and additional resources here: <https://egale.ca/egale-in-action/2slgbtqi-dementia-care/>

STAY TUNED!

- Upcoming in fall 2022:
 - Guidance document
 - Egale & NIA national resource centre on 2SLGBTQI aging
- To stay up to date on Egale and the NIA's activities subscribe here:
<https://egale.ca/get-involved/>
<https://www.nia-ryerson.ca/newsletters>

THANK YOU!

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