

Long-term care home residents shaping the place they call home

March 25, 2024



Land Acknowledgement

Together, let us now pause as we acknowledge the Indigenous Peoples of all the lands that we are on today, from wherever we are virtually participating in today's meeting. Let us take a moment to acknowledge the importance of the land we each call home.

We do this to affirm our commitment and responsibility to improving relationships between nations and to improving our own understanding of local Indigenous peoples and their cultures.

We acknowledge the ancestral and unceded territory of all the Inuit, Métis, and First Nations people who call this nation home.

Let us now join in a moment of reflection to acknowledge the harms and mistakes of the past and to consider how each of us, in our own way, can move forward in a spirit of reconciliation and collaboration.

Introductions



Jennifer Bethell

Affiliate Scientist,
KITE Research
Institute, Toronto
Rehabilitation
Institute



Jim Gilhuly

Resident Expert
Advisors and Leaders
(REAL) member and
Board Director,
Ontario Association
of Residents
Councils



Gale Ramsden

Resident Expert
Advisors and
Leaders (REAL) Go
Chair and Board
Director, Ontario
Association of
Residents Councils



Chloe Lee

Quality and
Evaluation
Specialist, Ontario
Association of
Residents' Councils

Outline

- Acknowledgements
- Introductions
- Background
- Aim 1: Scoping review
 - *Methods*
 - *Preliminary results*
- Next steps
- Intended outcomes
- More information

Acknowledgements



Canadian
Frailty
Network



Perley
Health

Centre of Excellence
in Frailty-Informed Care™



CIHR
IRSC

Canadian Institutes of
Health Research
Instituts de recherche
en santé du Canada

Introductions: The research team



Jim Gilhuly



Gale Ramsden



Devora Greenspon



Beryl Collingwood



Melissa McVie



Dee Tripp



Dr. Jennifer Bethell



Dr. Katherine
McGilton



Dr. Carrie McAiney



Julia Fineczko



Chloe Lee

Introductions: The OARC team



**Ontario
Association
of Residents'
Councils**



Background



200 000

*People living in long-term care homes across
Canada*

Background:

*Long term care (LTC)
homes and the people
who live in them*





Background:

What is resident engagement?

Adapted framework for “patient engagement” by Carman et al. (2013) recognizes three critical aspects of engagement:

- (1) engagement activities range along a continuum: consultation, involvement and partnership;
- (2) engagement occurs at different levels: direct care (resident), organizational design and governance (home), and policy making (system); and
- (3) multiple factors affect the willingness and ability of residents to engage.

Level of engagement	Continuum of engagement		
	Consultation 	Involvement 	Partnership
Direct care (Resident-level)	Residents receive information about their health and daily routines	Residents are asked about their preferences for care and daily routines	Decisions are based on resident preferences and, if applicable, family input, medical evidence and clinical judgement
Organizational design & governance (Home-level)	LTC homes survey residents about their experience in the home	LTC homes involve residents as advisors, committee members or other similar capacities	Residents as equal contributors at LTC home committees
Policy making (System level)	Public agency conducts focus groups with residents to ask opinions	Residents' recommendations about research priorities are used by public agency to make funding decisions	Residents have equal representation on agency committees that make decisions about how to allocate resources within LTC sector

Background:

Why is resident engagement important?

Many reasons. For example:

- Exercising basic right to influence decisions affecting one's life and wellbeing
- Mobilizing resources for residents
- Improving policies and activities within the home
- Collaborating to ensure resident-focused decision making
- Increasing resident satisfaction and wellbeing
- Changing attitudes (stigmas associated with aging and LTC homes)
- Facilitating transition to living in LTC
- Countering the negative effects of "institutional living"; on ongoing basis
- Enabling freedom and choice, opportunity to exercise initiative, autonomy and responsibility

Background:

A disconnect when it comes to resident engagement

On average, residents ranked the effectiveness and importance of Residents' Councils lower than Administrators and Residents' Council Assistants.



Residents' average rank of RC effectiveness



Administrators and team member average rank of RC effectiveness



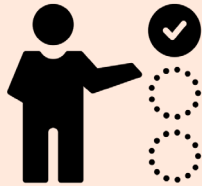
Residents' average rank of RC importance



Administrators and team members' average rank of RC importance

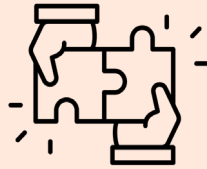
Background: *Why is this study important?*

Resident engagement in organizational design and governance



Created by LUTFI GANI AL ACHMAD
from Noun Project

A resident
identified
priority



Created by suhartono
from Noun Project

Aligns with the
culture change
movement



Created by Andi wiyanto
from Noun Project

Relevant to
updated LTC
policy



Created by Kamih Ginkaw
from Noun Project

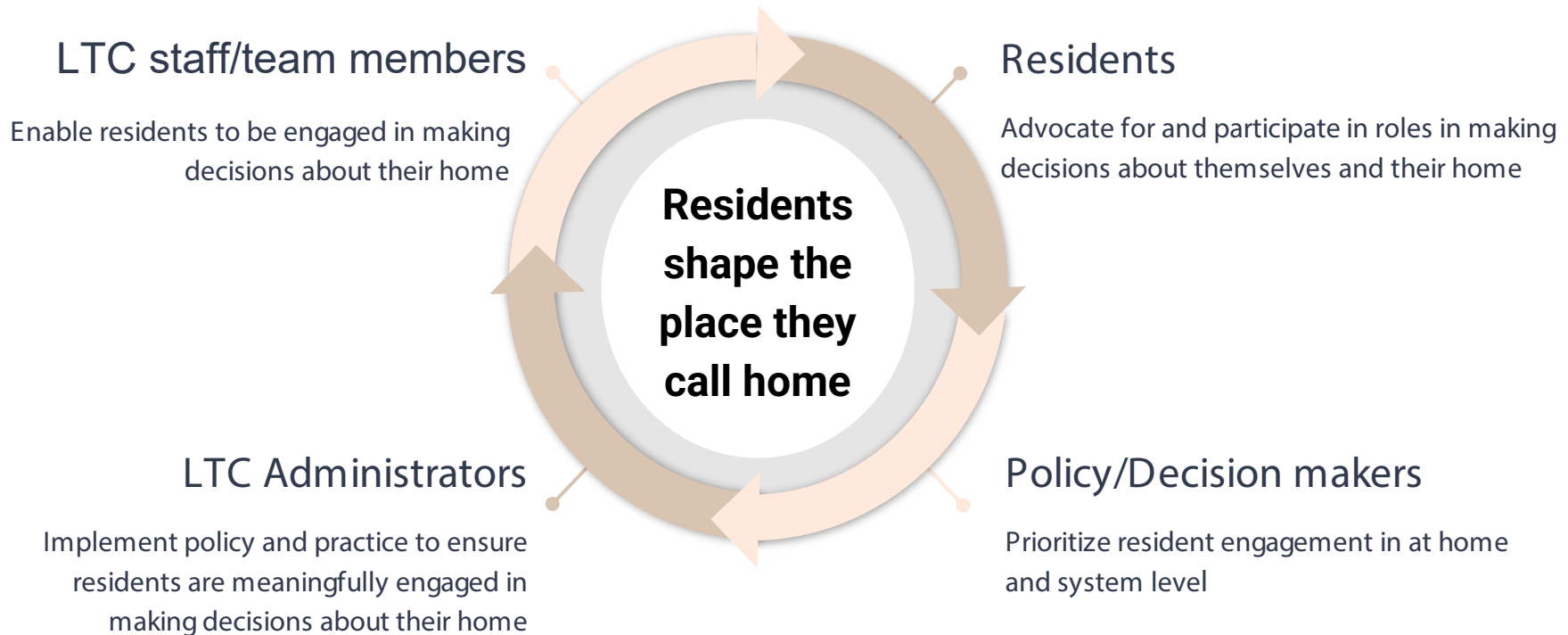
Adresses a
knowledge gap

Background:

Study aims


1. Synthesize existing knowledge on approaches to engaging LTC home residents in organizational design and governance of their LTC homes. [Scoping review]
2. Assess community capacity to implement and sustain a program to engage LTC residents in organizational design and governance of their LTC homes. [Qualitative study]
3. Codesign toolkit(s)/resource(s) to enable the engagement of LTC residents in the organizational design and governance of their LTC homes.

Background: *Study objective*

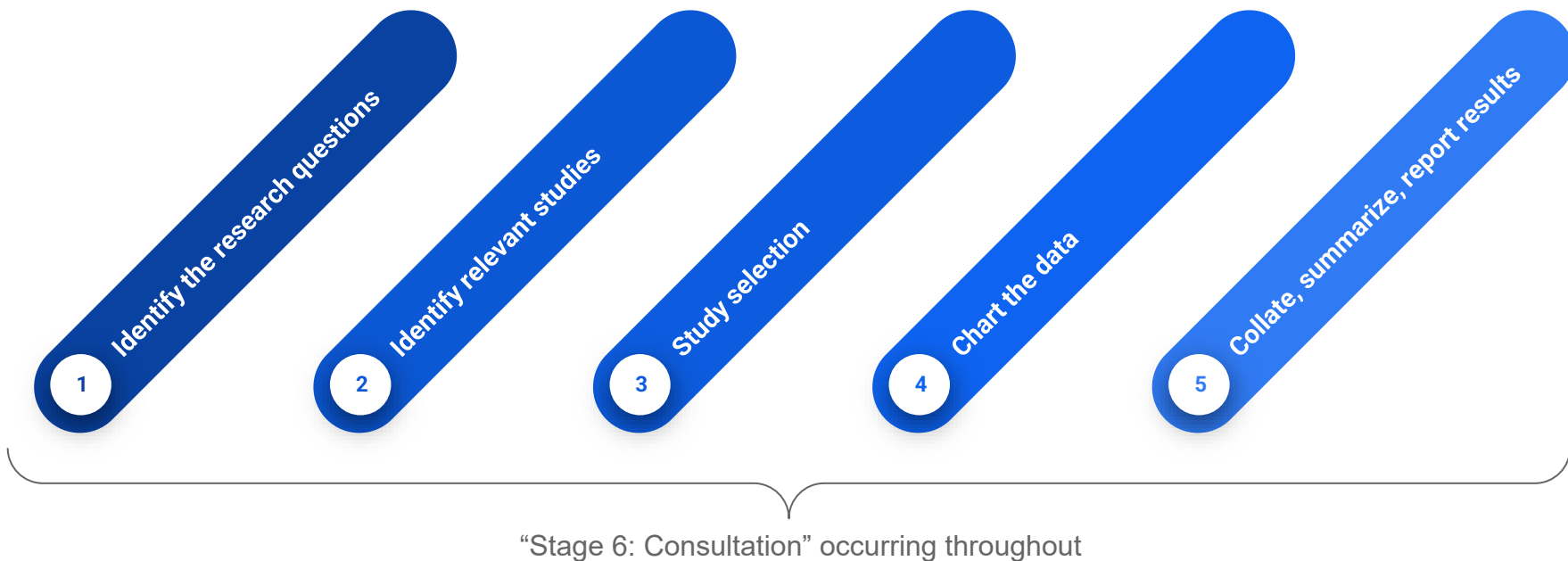


Aim 1:

Scoping review



Aim 1: Scoping review *Methods*



Aim 1: Scoping review

Research questions

1. *How have LTC residents been engaged* in the organizational design and governance of LTC homes?
2. What are the *reported barriers and enablers* to this engagement?
3. How have *considerations of diversity* (eg, related to age, gender expression and identity, culture, disability, education, ethnicity, language, religion, race, sexual orientation and socioeconomic status) been integrated into this engagement?
4. How have *considerations of dementia* and cognitive impairment been integrated into this engagement?
5. How has the impact of this engagement been *evaluated*?

Aim 1: Scoping review *Inclusion Criteria*

LTC homes and other congregate living settings

Context

Concept

Resident engagement in LTC home organizational design and governance

Excludes protocols, reviews, letters, and editorials

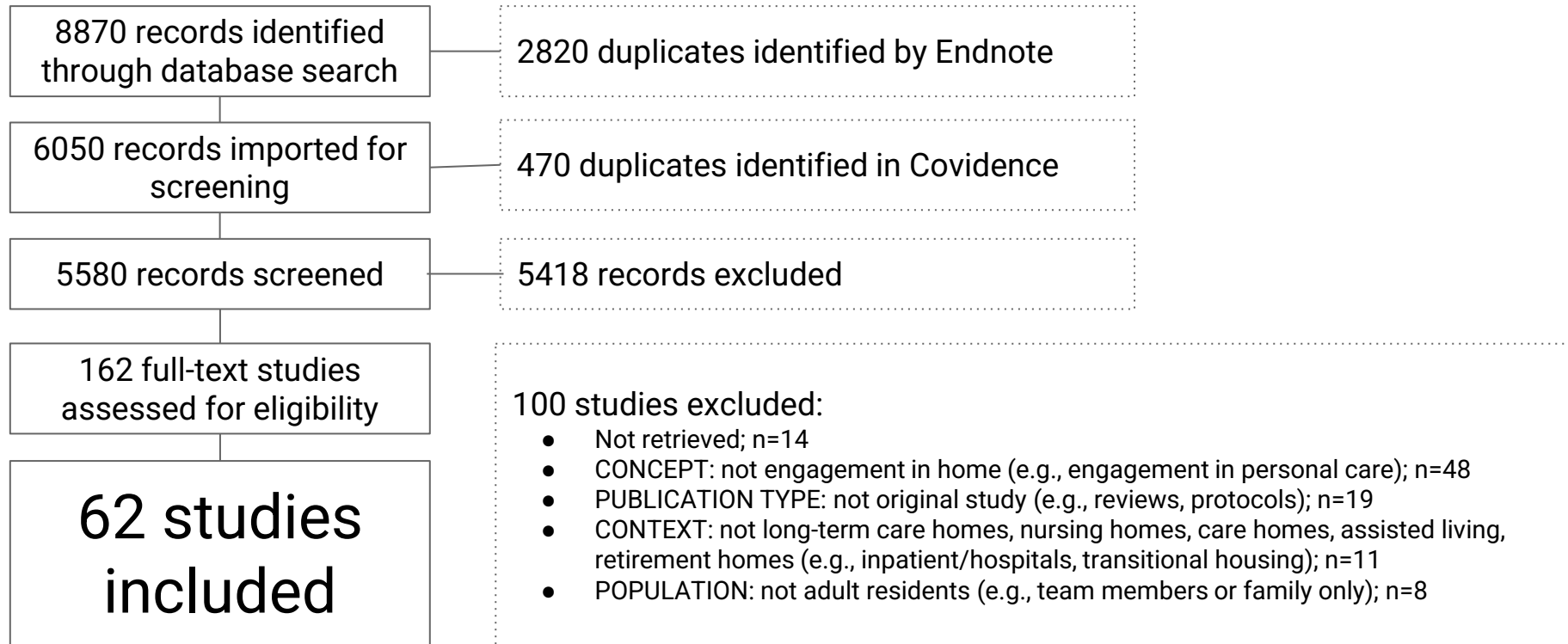
Original data

Population

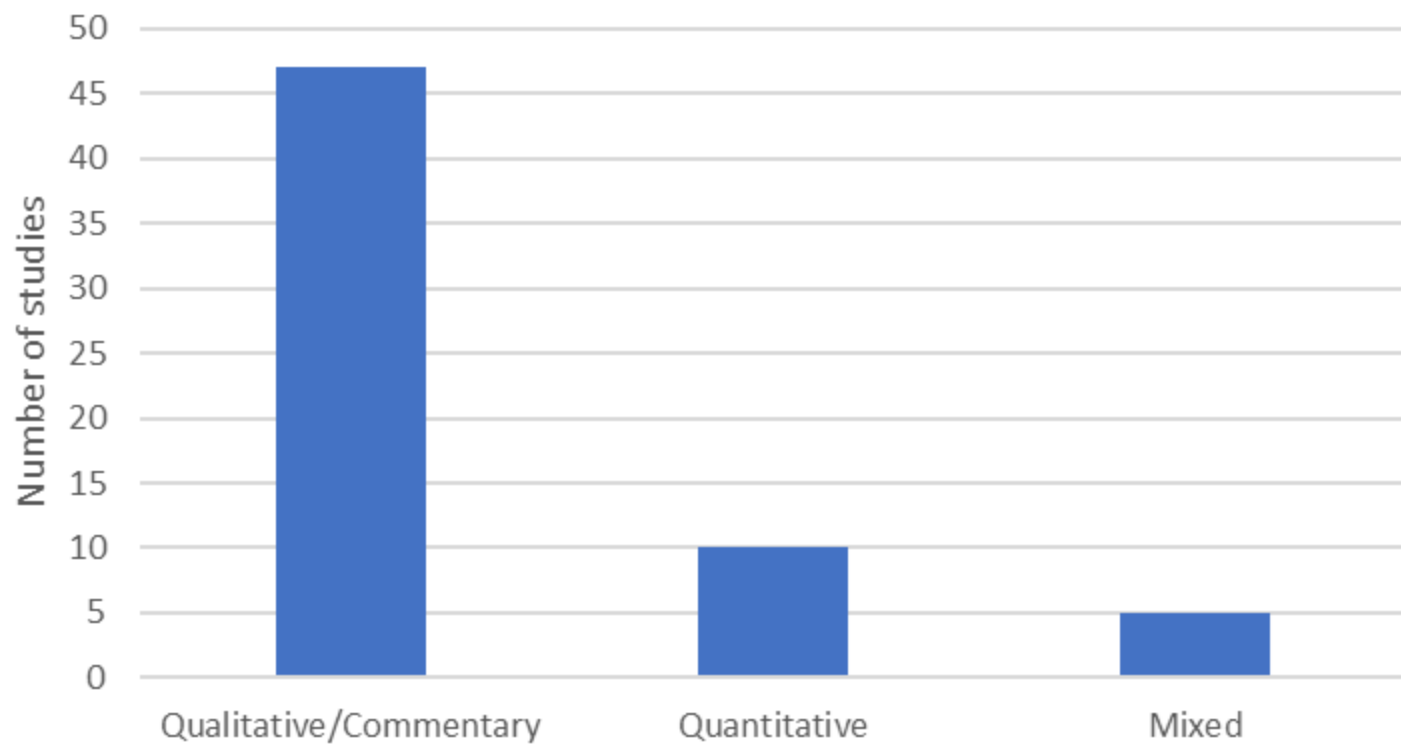
Adult LTC home residents



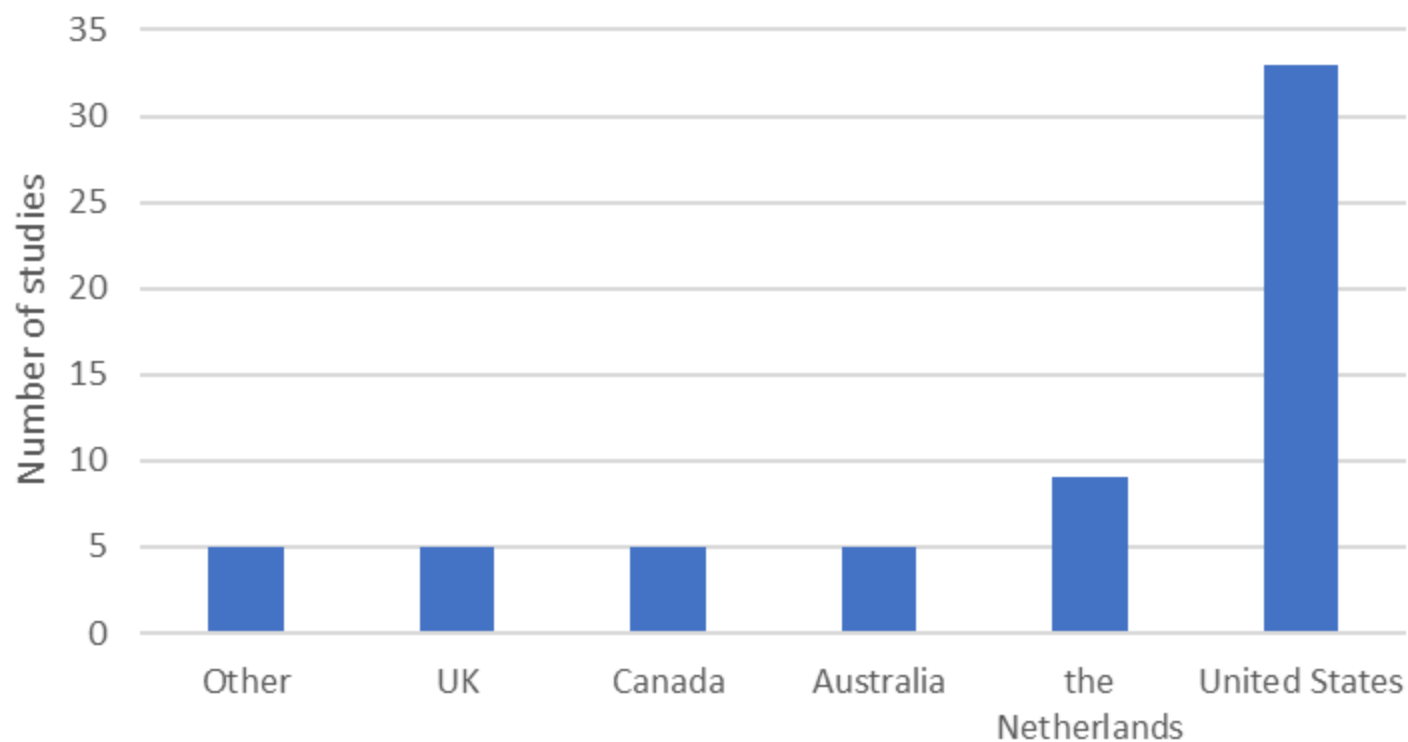
Aim 1: Scoping review *Results*



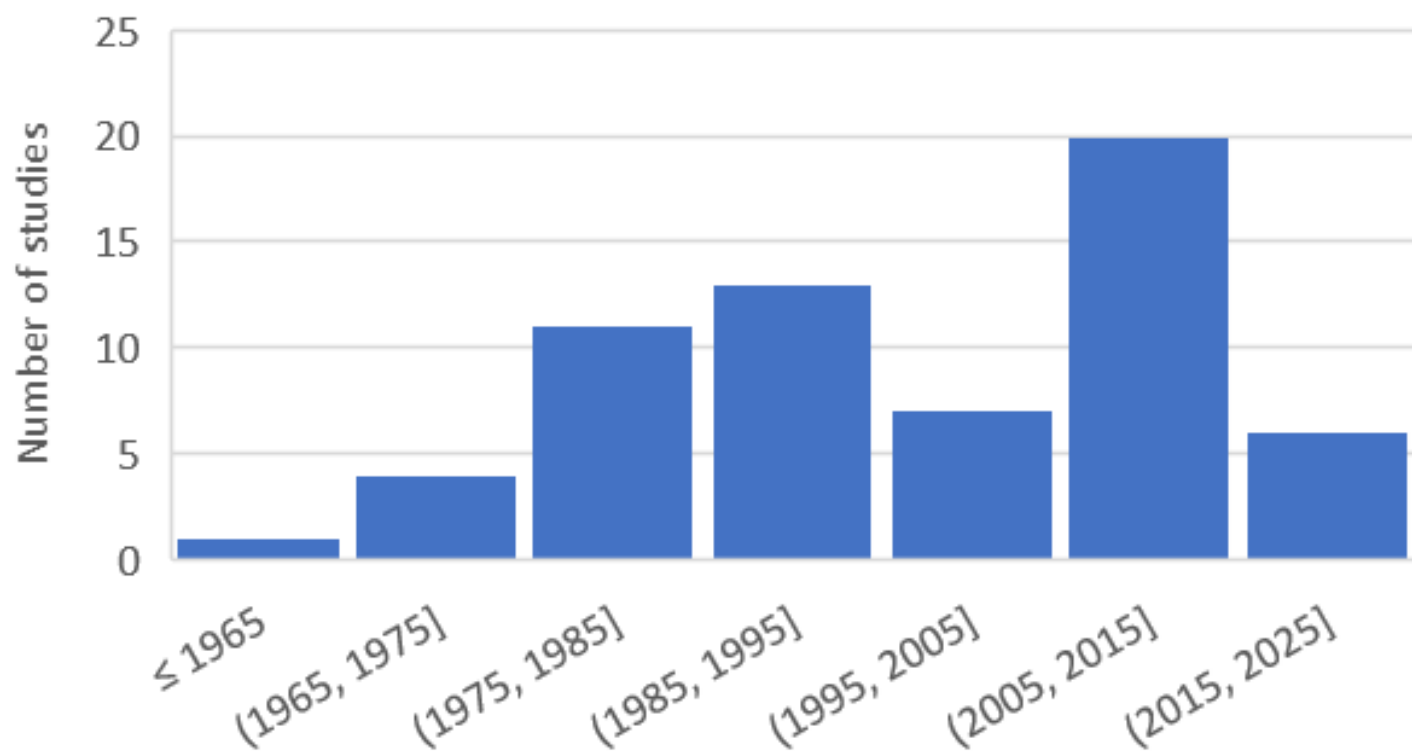
Study type



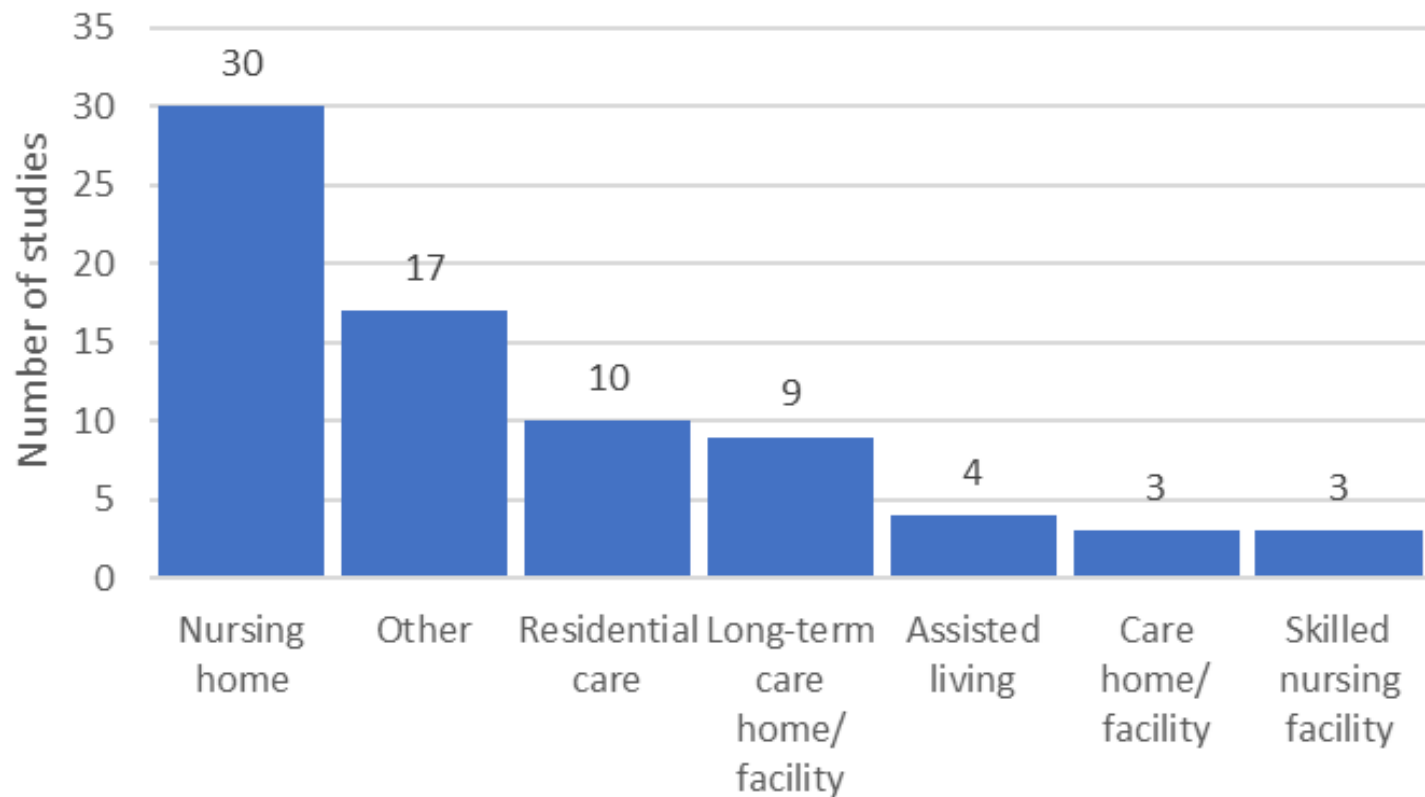
Country of studies



Year (decade) of publication



Resident engagement setting



Aim 1: Scoping review

Results- who was engaged

Few studies give information on the residents who were engaged.

For example:

- 16 (26%) reported age (e.g., range)
- Very few studies (n<5) reported information on race or ethnicity, education, other demographic characteristics

Aim 1: Scoping review

Results- how were residents identified



Created by Kieu Thi Kim Cuong
from Noun Project

Volunteered



Created by Jasfart
from Noun Project

Elected by peers



Created by Adrien Coquet
from Noun Project

Recommended by staff

Aim 1: Scoping review

Results

Studies described key roles for staff.

For example:

- Practical support
- Committee members
- Liaison with home
- Identify residents to participate

Aim 1: Scoping review

Results

1. How have LTC residents been engaged in the organisational design and governance of LTC homes?

Operationalized mostly through:

- Residents' Councils/Committees (with or without family and staff)
- Participatory action research projects (e.g., researcher involves residents in projects with intended homelevel impacts)

Aim 1: Scoping review

Results

1. How have LTC residents been engaged in the organisational design and governance of LTC homes?



Aim 1: Scoping review

Results

2. What are the reported barriers to this engagement?

Resident-level:

- Declining health/ healthrelated (e.g, vision, hearing, cognitive and mobility impairments)
- “Institutionalized” attitudes (e.g., fear of repercussions/conflict)
- Apathy, skepticism about impact
- Experience (e.g., discrepancy between desired and experienced influence and independence “powerlessness and lack of autonomy”)

Staff-/home-level:

- Staff capacity (e.g., staff shortages, workload, turnover)
- Lack of training and support
- Limited knowledge/experience
- Organizational dynamics (e.g., poor relationships between staff and administration)
- Attitudes and behaviours (e.g., limited motivation, skepticism perceived importance of resident engagement, “topdown” attitudes and approaches)

Aim 1: Scoping review

Results

2. What are the reported barriers to this engagement?

System-/Societal-level:

- Available resources (including policies, guidelines, funding, time)
- “Almost universal stigma attached to nursing homes”
- Lack of standardized measurement

Overarching:

- Sustainability (e.g., recruiting residents, encouraging participation)
- Meeting logistics (e.g., interruptions, noise, layout of meeting rooms, circulation of minutes)
- Meeting dynamics (e.g., facilitation/chairing, dominance by particular members, use as forum for personal grievances/projects, lack of communication between meetings)
- Power differential between staff and residents (e.g., lip service/ checklist mentality)

Aim 1: Scoping review

Results

2. What are the reported enablers to this engagement?

Resident recruitment:

- Should be continuous
- Host large gathering to promote the resident engagement initiative across the home

Buy-in and support across the home:

- Involve leadership (Board, administration, managers)
 - Attitude of leadership (e.g., they “must visibly support the concepts of empowerment and self determination” to foster this culture in the home)
- Promote to residents and families on move-in
- Create atmosphere to counteract “resident fear and perceived intimidation”
- Build relationships and trust

Aim 1: Scoping review

Results

2. What are the reported enablers to this engagement?

Practical support:

- Train and involve staff and volunteers (e.g., minute taking, transporting residents)
- Access outside support
- Physical accommodations to support communication (e.g., font size, using microphones)
- Address communication challenges between the home and residents

Meetings:

- Timing (e.g., timing after lunch, when residents were already congregated)
- Social atmosphere (e.g., serve refreshments)
- Formal procedures (e.g., regular date and time, system of reminders, process for circulating minutes, assigned Chair, planned agenda)
- Accessible meetings
 - Room layout (e.g., comfortable, private and ideal size)
 - Physical (e.g. font size, hearing, presentation visibility)

Aim 1: Scoping review

Results

3. How have considerations of diversity been integrated into this engagement?

4. How have considerations of dementia and cognitive impairment been integrated into this engagement?

Both:

- Families and caregivers as representatives
- Almost no discussion of specific strategies for engaging diversity of residents or residents with dementia or cognitive impairment

Diversity:

- Accessibility accommodations

Cognitive Impairment

- Other resident representatives
- Smaller group settings

Aim 1: Scoping review

Results

5. How has the impact of this engagement been evaluated?

Multiple outcomes have been described, e.g.,:

- resident empowerment, autonomy, quality of life
- staff satisfaction
- home-level initiatives and decision-making
- cohesiveness

Very few studies have assessed quantitative measures of process or outcomes, e.g.,:

- Resident Council Evaluation Tool
- Resident Control Scale
- Policy and Program Information Form
- Study-specific (e.g., ratings of perceived usefulness, influence, collaboration in quality improvement, checklist)

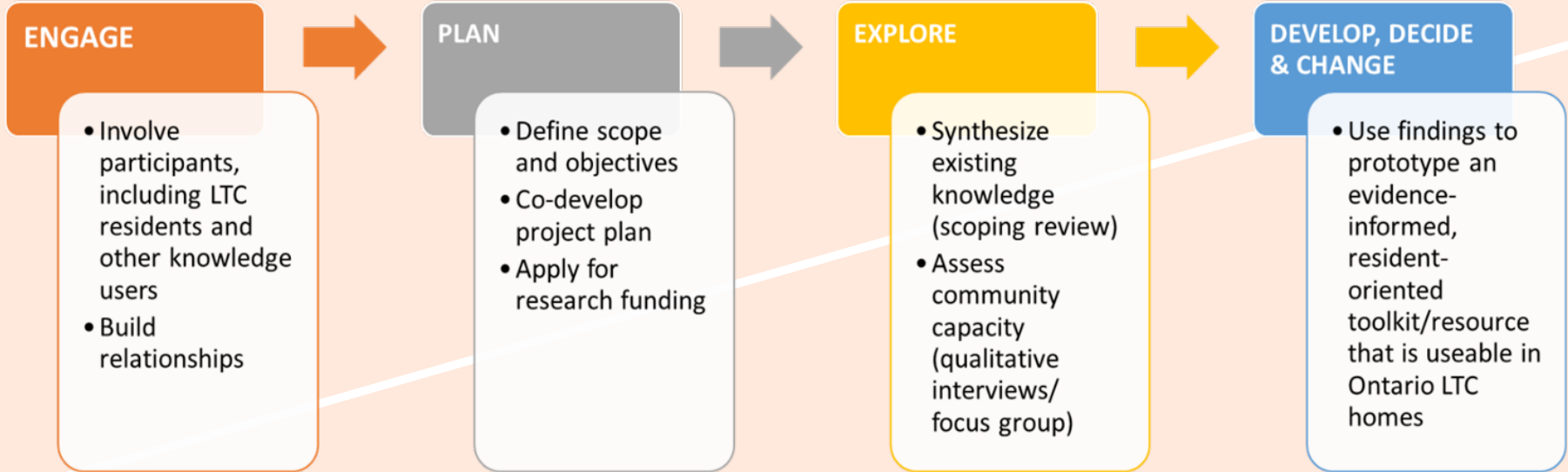
Aim 1: Scoping review

Summary

- Little is known from the literature about specific strategies for engaging residents, how to evaluate engagement or the impact it has on residents, staff and homes
- There is a body of literature, spanning decades, that describes resident engagement in LTC home organisational design and governance, and a multitude of associated barriers and enablers

**How can you support
resident engagement?**

Next steps



Next steps:

Aim 2: Recruiting for interviews (Spring 2024)

What are the perspectives of LTC residents, staff and administrators on the barriers and needs for a program to engage LTC residents in organizational design and governance of LTC homes?

Research Study: Empowering Long-Term Care Residents To Shape The Place They Call Home



We are looking for...

- People who live in long-term care homes (residents)
- People who work in long-term care homes (team-members and administrators)



We want to know...

how residents are and can be involved in influencing the way their long-term care home runs.



As a participant, you will take part in a 30-minute interview or focus group. A study team member will ask you a few questions about your experience living or working in long-term care. Participation is completely voluntary. Your decision on whether or not to participate will not affect the care you receive or your employment status.

If you are interested to participate or learn more about the study, please contact:



Thank you!

For more information,
please contact:

clee@ontarc.com

www.ontarc.com/researchand-quality/current-research.html

Scan to access our protocol paper!

Lee C, Tripp D, McVie M, Fineczko J, Ramsden G, Hothi S, Langston J, Gilhuly J, Collingwood B, McAiney C, McGilton KS, Bethell J. Empowering Ontario's long-term care residents to shape the place they call home: a codesign protocol. *BMJ Open*. 2024 Feb 6;14(2):e077791.

