



Partnering for Progress

A Guide for Meaningful Engagement of Residents and Caregivers in Long-Term Care Research



**Perley
Health**

Centre of Excellence
in Frailty-Informed Care™

Contact Information

This guide is available free for download on the Perley Health website at PerleyHealth.ca/partnering-for-progress.

For more information on this document, please consult the Centre of Excellence website at PerleyHealth.ca/centreofexcellence.

Or contact us at:



Perley Health Centre of Excellence in Frailty-Informed Care™

1750 Russell Road, Ottawa ON K1G 5Z6

centreofexcellence@perleyhealth.ca

Office: 613-526-7170 ext. 2425

The Centre of Excellence Project Team:

- **Michaela Adams**, Centre of Excellence, Perley Health
- **Jenna Henry**, Centre of Excellence, Perley Health
- **Linda Hunter**, Family Partner, Perley Health
- **Atul Jaiswal**, Centre of Excellence, Perley Health
- **Heather MacLeod**, Provincial Geriatrics Leadership Ontario
- **Sai Prashanti Mohan**, Centre of Excellence, Perley Health
- **Maya Pot**, Centre of Excellence, Perley Health
- **Benoît Robert**, Centre of Excellence, Perley Health
- **Annie Robitaille**, University of Ottawa; Centre of Excellence, Perley Health
- **Danielle Sinden**, Centre of Excellence, Perley Health

How to Cite

Perley Health. (2025). Partnering for Progress: A Guide for Meaningful Engagement of Residents and Caregivers in Long-Term Care Research. [PerleyHealth.ca/partnering-for-progress](https://perleyhealth.ca/partnering-for-progress)

Copyright

This work is licensed under the Creative Commons Attribution-Noncommercial-ShareAlike 4.0 International License.

You must provide attribution to the creator when the *Partnering for Progress: A Guide for Meaningful Engagement of Residents and Caregivers in Long-Term Care Research* is used and shared.

All attributions must be the following statement: “*Partnering for Progress: A Guide for Meaningful Engagement of Residents and Caregivers in Long-Term Care Research* © 2025 by Perley Health is licensed under Creative Commons Attribution-Noncommercial-ShareAlike 4.0 International. To view a copy of this license, visit <https://creativecommons.org/licenses/by-nc-sa/4.0/>. All rights reserved.”

It may be used for education purposes and for use in public sector organizations. The authors do not take responsibility for the improper use of this guide.



CC BY-NC-SA: This license allows reusers to distribute, remix, adapt, and build upon the material in any medium or format for noncommercial purposes only, and only so long as attribution is given to the creator. If you remix, adapt, or build upon the material, you must license the modified material under identical terms.

Continuous Improvement

Please note that we view this as a living document. Our culture of self-improvement ensures that, together, we are always striving for a higher standard of excellence. We welcome feedback from all users—residents, caregivers, researchers, staff, and administrators. Please share your experiences, comments, or questions by completing a brief survey at SurveyMonkey.com/r/N27LJMP or emailing centreofexcellence@perleyhealth.ca.

Thank you for partnering with us in progress..



Updated: June 17, 2025

Table of Contents

Contact Information2

Who We Are: About Perley Health 5

Executive Summary 6

Background.....7

Why We Need Resident and Caregiver Engagement in Long-Term Care Research 8

Barriers to Meaningful Engagement 10

What is Partnering for Progress?13

Partnering for Progress Framework for Meaningful Engagement.....14

 Section 1: Guiding Principles for Resident and Caregiver Engagement in LTC Research.....17

 Section 2: Engagement Strategies for Meaningful Engagement in LTC Research 21

 Section 3: Checklist for Resident and Caregiver Engagement..... 29

Key Takeaways.....30

Appendix A: What We Did: Brief Description of Project..... 32

Appendix B: Acknowledgement 35

Appendix C: Glossary*37

Appendix D: Resources and Tools..... 39

References.....41

Citations for Glossary:.....42

Who We Are: About Perley Health

Perley Health, located in Ottawa, Ontario, Canada, is a leading provider of long-term care (LTC), known for its innovation, compassion, and research. As one of Ontario's largest and most progressive long-term care homes, it accommodates over 600 Seniors and Veterans with a dedicated workforce of 800 employees and 400 volunteers. Perley Health is home to 450 LTC residents, many of whom are Veterans who served overseas, alongside approximately 200 seniors in 139 independent-living apartments. With a rich history dating back to 1897, Perley Health has evolved into a comprehensive care centre that offers LTC, short-stay accommodations, and specialized programs for Seniors and Veterans.

At the heart of Perley Health's mission is the Centre of Excellence in Frailty-Informed Care™, established in 2019 as a hub for innovation in research and education. The Centre of Excellence aims to set new benchmarks in senior care by facilitating applied research that drives innovation in education, best practices, and knowledge translation. Our goal is to ensure that Seniors and Veterans living with frailty receive the highest level of care both within our home and beyond.

To learn more, please visit PerleyHealth.ca/centreofexcellence.

“ Let our stories be heard. *'Meaningful'* is not just ticking boxes. Meaningful is, *'What does my engagement contribute to? What is actually going to happen with the results?'* I need to see that it leads to action. Residents are needed to ensure that the right questions are being asked.”

Executive Summary

A long-term care (LTC) home is a unique environment that houses residents with various cognitive and health-related conditions. In these homes, residents are not only care recipients but individuals with a voice, valuable insights, rich life experiences, unique perspectives, and a right to shape their home and daily lives.

In health research and the broader research field, there is a growing recognition of the critical importance of meaningful involvement of citizens in research otherwise described in terms such as citizen engagement, patient engagement, community engagement, public participation, etc. However, the voices of residents and caregivers of LTC homes remain largely excluded from meaningful involvement in research that directly impacts them. This exclusion is due to a lack of existing engagement frameworks that can be tailored to the unique realities of LTC homes. LTC homes are not just traditional healthcare facilities but **the personal living spaces of residents where care, daily life, relationships, and community intersect** alongside cognitive diversity and fluctuating health.

This Partnering for Progress guide is designed to bridge a significant gap in literature and practice by offering a structured framework for the meaningful engagement of LTC residents and their caregivers in research activities. The guide provides researchers and LTC leaders with **practical strategies, guiding principles, and concrete tools** to tailor engagement into every stage of research in LTC homes across Canada. The framework identifies **guiding principles** and outlines **practical strategies** to overcome barriers to engagement to ensure residents, caregivers, and staff are **partners, not just participants**, at every stage of the research process. Key objectives of the guide include developing a systematic approach to engaging residents and caregivers in all stages of research, ensuring research reflects the needs and values of LTC residents, improving the relevance and translation of research into practice and policy, and enhancing transparency, accountability, and trust in the research process.

This *Partnering for Progress* guide represents a significant step towards meaningful engagement of LTC residents and caregivers in research. By centering the voices and lived experiences of LTC residents, caregivers, and staff, this work aims to **advance research that is not only scientifically rigorous but also deeply relevant to the people it is meant to serve.**

Background

As of 2021, Canada has a total of 2,076 LTC homes providing 198,220 beds to 6,835,866 adults over the age of 65 ¹. There are 29 LTC beds per 1,000 Canadians aged 65 and older, with variations across the provinces and territories. In Ontario, there are nearly 626 LTC homes where roughly 78,000 adults reside ². As it is crucial to understand the unique aspects of LTC homes, it is essential to prioritize research that is deeply rooted in the lived experience of residents and caregivers ^{3,4}.

The Canadian Institutes of Health Research (CIHR) introduced “citizen engagement” in 2008 to ensure that healthcare research and policy development align with the needs and experiences of the public, thereby enhancing relevance, transparency, and trust while empowering citizens to actively participate in shaping their healthcare ⁵.

“Citizen engagement” is defined as the active involvement of citizens in identifying problems, proposing solutions, and providing meaningful input to develop healthcare policies ^{5,6}. This engagement serves as a bridge between the “citizens” or the “consumers” and healthcare research, ultimately contributing to policy development ^{5,6}. By involving citizens, research becomes more meaningful as it incorporates diverse perspectives of citizens, and research outputs are more clinically relevant ^{3,7}.

Citizen engagement in LTC involves the active participation of residents and caregivers in policy development and decision-making ^{4,5,7}. Engaging individuals with frailty and their caregivers in decision-making is both feasible and essential ⁴. It ensures that research priorities and outcomes align with the needs and experiences of those directly affected by LTC policies and practices ^{5,7}. Involving residents, caregivers, and staff in the research process provides valuable insights, leading to more relevant studies ^{3,5,7}. This engagement empowers LTC residents and caregivers by giving them a voice in shaping their care and living environments, enhancing their quality of life and improving overall care delivery ^{4,5,7}.

Although the term **“citizen engagement”** is increasingly used in research, during the development of this guide it was found to be less relatable for LTC residents and caregivers. As a result, the term **“resident and caregiver engagement”** is used throughout this guide to align more closely with the language commonly used by residents and caregivers themselves.

“LTC is not the same as a hospital—this is someone’s home. Give researchers the opportunity to understand that better.”

Why We Need Resident and Caregiver Engagement in Long-Term Care Research

Long-term care (LTC) homes are increasingly recognizing the critical importance of actively involving residents and their caregivers in an effort to improve the quality of care and life for residents⁸. The benefits of such engagement are clear—when residents and caregivers are included in decision-making, care quality improves and residents experience a higher sense of well-being^{8,9,10}. Despite this recognition, challenges persist in ensuring diverse and meaningful participation⁸. While methods such as Residents' Councils, surveys, committees, and consultations are commonly used to involve residents and caregivers, many of these efforts remain consultative rather than empowering, often leaving residents with little power in decision-making processes^{3,6,8}.

“Residents need to have a say in shaping the place they call home.”

This gap is particularly significant in LTC homes where residents, especially those with frailty or complex health needs such as dementia or sensory loss, are often the most vulnerable^{3,4,11}. Meaningful engagement can profoundly affect residents' emotional, mental, and physical health, yet several barriers—ranging from communication challenges to institutional reluctance—continue to hinder the engagement process^{3,4,10}. Overcoming these barriers is essential to improve residents' care experience and their overall quality of life^{3,8}.

While “citizen engagement” in research has demonstrated clear benefits, the involvement of residents and caregivers in LTC research remains limited³. Through the process of developing this guide, it became evident that without including the lived experience of residents and caregivers, the research outcomes remain incomplete and disconnected from the actual needs of those directly affected by LTC services^{9,10}. The primary reason for this lack of engagement is a widespread lack of understanding of the barriers to involvement and the challenges in overcoming them^{4,8,10}. In the context of LTC research, there has been no comprehensive guide to help researchers and institutions effectively engage residents and caregivers throughout the research process. This guide aims to fill that gap by providing a structured approach to maximize meaningful engagement, ensuring that residents and caregivers are not just consulted but are active contributors in shaping research that affects their lives.

“I came here to be heard, so that something can be done.”

Co-designed with residents and caregivers, this guide integrates insights gathered from a thorough review of literature, a pre-event experts' survey, and a one-day "Partnering for Progress" engagement event. This co-creation process helped identify what truly matters to residents and caregivers in terms of their involvement in research. The guide includes practical strategies, key considerations, and a framework to support effective resident and caregiver engagement in LTC research. A detailed description of the methods used to develop this guide is available in [Appendix A](#).

By embracing the active involvement of residents and caregivers, LTC research can move toward more impactful, relevant, and compassionate outcomes—ultimately transforming care for the better.

“ You must think about the difference between **‘doing to’** residents versus **‘doing with.’**”

Barriers to Meaningful Engagement

Numerous barriers to meaningful resident and caregiver engagement in LTC research were identified through this project. The barriers are systemic and at the individual level, as shown in Figure 1.

Recognizing and addressing these barriers is crucial for developing effective solutions and fostering meaningful engagement in LTC research. While we have identified some of the most significant barriers, it's important to acknowledge that additional barriers may exist, varying based on specific LTC contexts. Researchers and LTC leaders should carefully reflect on which barriers are most relevant to the LTC home where their research project will take place. This tailored approach ensures that engagement strategies are appropriately designed to overcome the unique challenges present in each setting, ultimately enhancing the quality and relevance of the research conducted

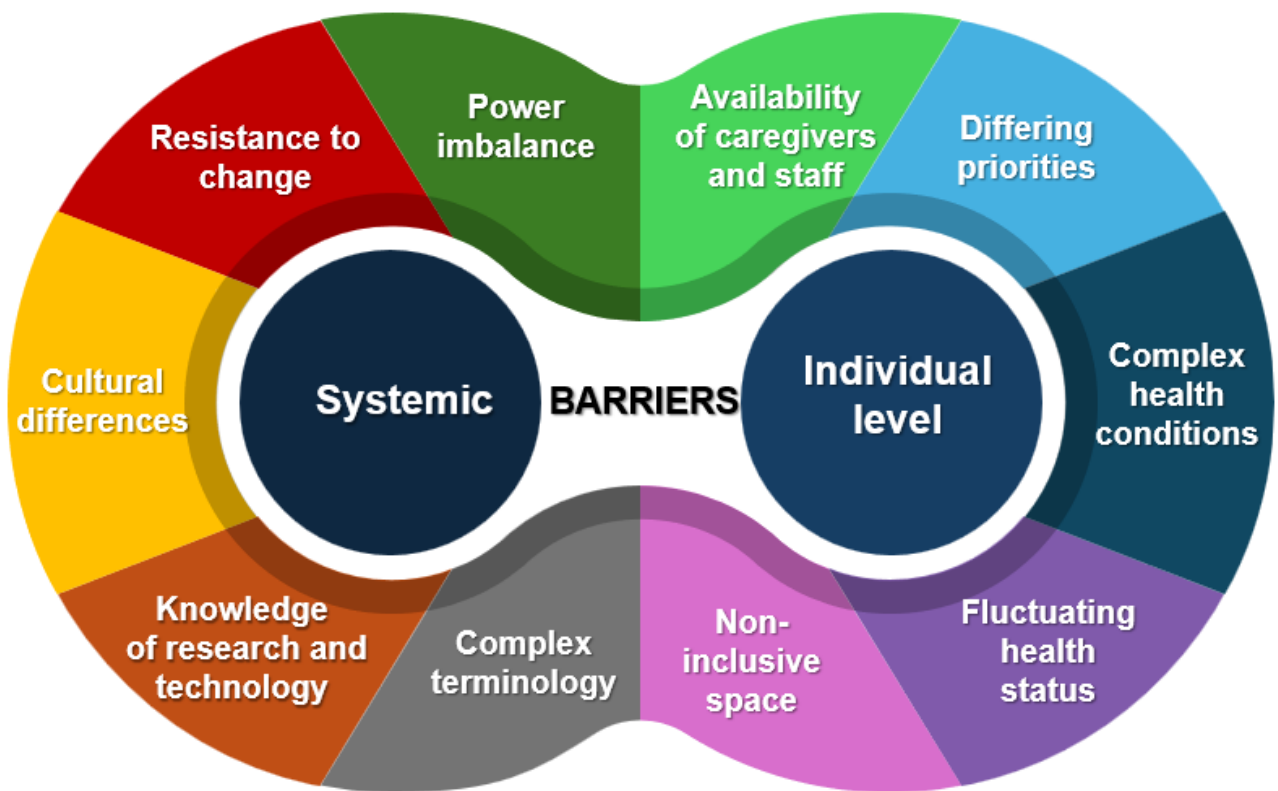


Figure 1: Barriers to meaningful engagement

1. Power imbalance

Researchers often possess greater authority than residents, which can stifle open communication and genuine collaboration. This dynamic may lead to residents and caregivers feeling undervalued and hesitant to share their insights.

2. Resistance to change

Resistance within organizations can hinder effective engagement initiatives, manifesting as a lack of support or bureaucratic obstacles. Participants may feel their contributions are merely tokenistic, undermining the authenticity of their involvement in the research process.

3. Cultural differences

Cultural differences may not be adequately accommodated. For example, cultural values that emphasize privacy can lead to discomfort or reluctance among some residents in sharing their stories. The research process may not adequately address language needs, creating barriers for residents who speak different languages.

“Some cultures are very private and don’t encourage sharing.”

4. Knowledge of research and technology

A lack of sharing of clear, complete, and understandable information about the research project can leave residents feeling confused or intimidated, discouraging them from participating or sharing of their opinions. Appropriate technological support may not be always available for all residents and caregivers, which limits their ability to participate in any digital aspects of the research process.

5. Complex terminology

The use of scientific terms and complex language can overwhelm or intimidate participants, leading to reduced engagement. This may also contribute to a sense of power imbalance or lack of trust between residents and researchers.

6. Non-inclusive space

Accessibility barriers in LTC homes, such as narrow doorways, inadequate seating, or a lack of maneuvering space for wheelchair use, significantly restrict residents' mobility and access to meeting spaces, hindering their ability to engage meaningfully in research processes.

7. Fluctuating health status

Limited understanding and support for residents' varying health conditions can make participation challenging. A resident's health status often fluctuates due to advancing medical conditions associated with age, complicating consistent involvement.

“ The word ‘research’ itself can be a barrier. Some people may wonder what it means. Researchers are often in their own corner of the world, unable to understand how simple or complicated this can be for others to grasp.”

8. Complex health conditions

Inadequate support for residents with cognitive challenges (e.g., dementia), mobility difficulties, or invisible disabilities (e.g., sensory loss) can make it difficult for the residents to fully participate, limiting their engagement and contribution.

9. Differing priorities

The goals and priorities of the research team, residents, caregivers, staff, and the organization can differ in areas such as research ideas, intended outcomes, and processes. Failure to recognize and address these differing priorities can limit interest and engagement in the research.

10. Availability of caregivers and staff

Family members' participation in research may be limited due to personal schedules and responsibilities. A lack of accommodations (e.g., flexible scheduling) makes it difficult for their own engagement (i.e., providing their perspective) and reduces the support available for meaningful engagement of residents. Moreover, not all residents may have family members to support them.

Caregivers and frontline LTC staff have busy schedules and may be unable to take time off work or time away from their regular duties, limiting their participation in research. Additionally, staff turnover can hinder consistent support for resident involvement in research activities.

“ You might have plans to conduct interviews all day, but a caregiver could be very exhausted, so you shouldn't proceed with the interview. Sometimes researchers focus so much on their work that they forget to consider the people they are connected with.”

What is Partnering for Progress?

Partnering for Progress calls for a transformative approach and shift in thinking about long-term care (LTC) research, emphasizing the importance of viewing LTC as the home of residents rather than service institutions responsible for caring for residents. This engagement approach challenges traditional research methods by actively involving residents and caregivers as co-creators and partners in the research process through creative, flexible, and non-traditional practices.

By changing the language and conceptualization of engagement, the framework enables and empowers LTC residents and their caregivers to shape the places they call home. This approach recognizes the value of lived experiences and promotes a more holistic understanding of LTC environments. This shift promotes collaborative engagement, repositions residents as experts in their own care, and creates a more inclusive, person-centred research environment that can drive meaningful improvements in LTC quality and understanding.

Below, we present the framework and associated tools for resident and caregiver engagement in LTC research.

Partnering for Progress Framework for Meaningful Engagement

Section 1: Guiding Principles for Resident and Caregiver Engagement in LTC Care Research

Section 2: Strategies for Meaningful Engagement at Various Stages of Research

Section 3: Checklist for Meaningful Engagement

Partnering for Progress Framework for Meaningful Engagement

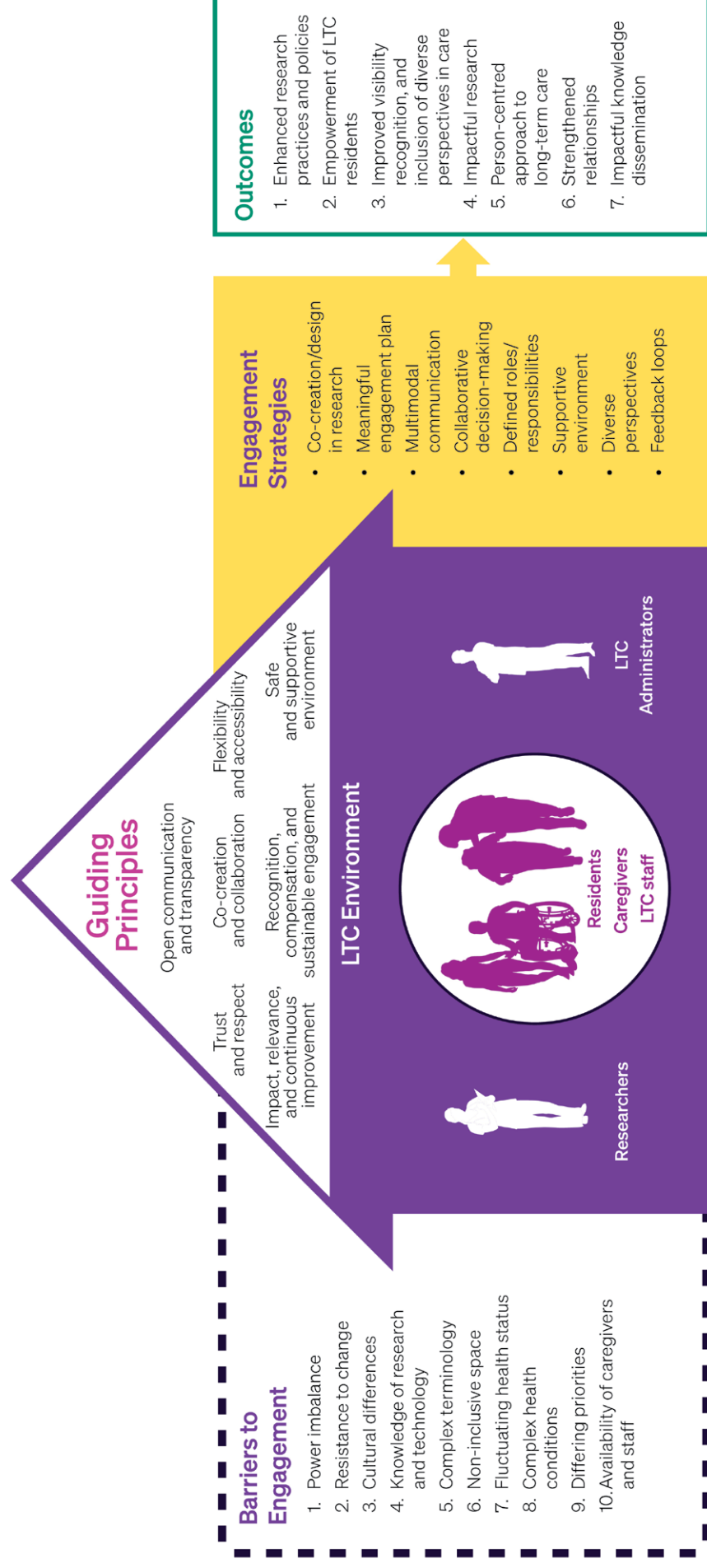
The Partnering for Progress framework represents a participatory approach to involving residents, caregivers, and stakeholders in shaping the future of LTC. This innovative framework recognizes the critical importance of engaging those directly impacted by LTC policies and practices in the research process.

The framework is rooted in seven guiding principles:

1. Open communication and transparency
2. Co-creation and collaboration
3. Trust and respect
4. Flexibility and accessibility
5. Safe and supportive environment
6. Recognition, compensation, and sustainable engagement
7. Impact, relevance, and continuous improvement

The framework serves as a guide to plan engagement strategies in LTC research and can be used in multiple ways, with the purpose of mutual learning and co-creation of research outcomes that are not only scientifically rigorous but also relevant and beneficial to LTC residents and their communities.

Partnering for Progress Framework for Meaningful Engagement



This illustration is a visual representation of the Partnering for Progress framework for meaningful engagement in LTC homes in which all elements are structured around the core of the framework: residents, caregivers, and LTC staff.

The framework identifies the researchers and LTC administrators within the LTC environment but external to the core. The framework acknowledges the barriers to engagement with residents and caregivers in LTC research.

The framework highlights the guiding principles of meaningful engagement, such as trust and respect, collaboration, flexibility, and impact-driven research, that provide its foundational values.

The engagement strategies build off the principles and aim to overcome the identified barriers to ensure residents and caregivers are given the resources and support to be involved throughout the research stages.

Finally, the engagement strategies lead to the expected outcomes of this framework, such as enhanced research practices, empowerment of LTC residents, and improved care.

We hope that using this framework can lead to enhanced research practices and outcomes, better-informed decisions, increased accountability, and more effective solutions to complex challenges in the LTC sector in Canada and beyond.



Tip

Regular check-ins with the project team (including residents and caregivers) are important to keep everyone informed and help people feel included.



Tip

Provide regular updates to all those involved about the research process—what has happened, what is happening now, and what the next step is. Don't just wait until you have results.



Section 1: Guiding Principles for Resident and Caregiver Engagement in LTC Research

The guiding principles for meaningful engagement in LTC research are essential to creating a collaborative and inclusive environment that respects and values the contributions of all residents and caregivers. These principles apply to the overall research process and help guide and facilitate meaningful engagement of residents and their caregivers.

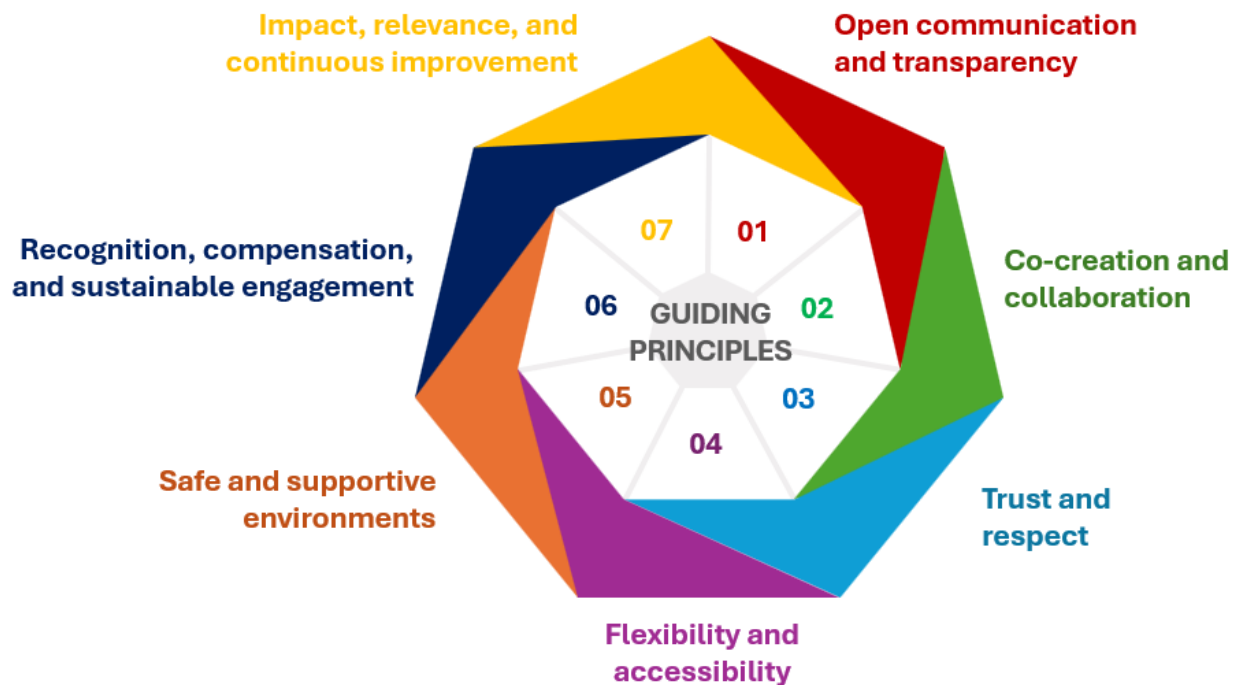


Figure 2. Guiding principles for meaningful engagement

Meaningful engagement requires:

1. **Open communication and transparency.** Ensure honest, transparent dialogue and open information sharing, creating an environment where residents and caregivers feel fully informed about the entire research process. Use enabling language to facilitate engagement and document research, emphasizing how the process supports and empowers participation.
2. **Co-creation and collaboration.** Encourage active participation and joint decision-making, valuing the contributions of all residents and caregivers in developing research approaches and outcomes.
3. **Trust and respect.** Build a foundation of mutual understanding and appreciation, recognizing the inherent dignity and worth of each resident and caregiver's experiences and perspectives.
4. **Flexibility and accessibility.** Adapt research methods to accommodate diverse needs, ensuring that participation is possible for individuals with varying abilities and circumstances. Accessibility of physical environment is an important factor.

5. **Safe and supportive environment.** Create a welcoming space where residents and caregivers feel secure, valued, and comfortable expressing their thoughts without fear of judgment or negative consequences.
6. **Recognition, compensation, and sustainable engagement.** Acknowledge the time, effort, and expertise of residents and caregivers through appropriate compensation and ongoing appreciation of their contributions.
7. **Impact, relevance, and continuous improvement.** Focus on ensuring that research remains meaningful, is responsive to residents and caregivers needs, and continuously evolves based on ongoing evaluation, feedback, and emerging insights on engagement.

These guiding principles for LTC residents, caregivers, researchers, and LTC staff emphasize person-centred care, collaboration, and respect for diverse perspectives. These principles aim to create a supportive and inclusive environment in LTC homes, promoting the well-being of residents and their caregivers.

Table 1 on next page provides engagement strategies tailored for residents, caregivers, researchers, staff, and administrators, based on each guiding principle.



Tip

There should be an open-door policy—a bulletin board outside the research area that has a keynote section.

“Researchers should come with a flexible agenda, flexible timelines, extra helping hands, and a true commitment to knowledge mobilization.”

Table 1 – Guiding principles of engagement for LTC residents, caregivers, LTC staff, and administrators

Guiding principles	LTC residents	Caregivers	LTC Staff and administrators
Open communication and transparency	<ul style="list-style-type: none"> • Be open to sharing experiences and input. • Communicate needs and required supports for engagement. 	<ul style="list-style-type: none"> • Facilitate residents' communication without speaking on their behalf. • Encourage and support residents' voices. 	<ul style="list-style-type: none"> • Ensure communication channels are free of power dynamics (e.g., avoid titles). • Ensure information is communicated clearly.
Co-creation and collaboration	<ul style="list-style-type: none"> • Actively participate in discussions and decision-making. 	<ul style="list-style-type: none"> • Support residents in co-creation while ensuring their autonomy is respected. 	<ul style="list-style-type: none"> • Facilitate opportunities for residents and caregivers to share ideas. • Identify barriers to engagement in LTC home and co-create solutions.
Trust and respect	<ul style="list-style-type: none"> • Be open and honest. • Trust that contributions are valued. 	<ul style="list-style-type: none"> • Respect residents' autonomy, choices, and participation. 	<ul style="list-style-type: none"> • Be respectful, inclusive, and culturally sensitive.
Flexibility and accessibility	<ul style="list-style-type: none"> • Don't hesitate to communicate accessibility needs and request flexibility. 	<ul style="list-style-type: none"> • Support and facilitate accommodations. • Support the creation of inclusive spaces. 	<ul style="list-style-type: none"> • Be attentive to fluctuating health. • Facilitate accommodations. • Create and provide support for inclusive spaces.
Safe and supportive environment	<ul style="list-style-type: none"> • Express comfort or discomfort. 	<ul style="list-style-type: none"> • Help create a supportive and encouraging atmosphere and space. 	<ul style="list-style-type: none"> • Create safe and supportive spaces. • Maintain confidentiality.
Recognition, compensation, and sustainable engagement	<ul style="list-style-type: none"> • Recognize the importance of engagement. 	<ul style="list-style-type: none"> • Help celebrate and share residents' contributions. 	<ul style="list-style-type: none"> • Help coordinate fair compensation. • Acknowledge value contributions.
Impact, relevance, and continuous improvement	<ul style="list-style-type: none"> • Provide honest feedback. 	<ul style="list-style-type: none"> • Encourage residents to provide feedback and insights. 	<ul style="list-style-type: none"> • Help document feedback. • Help monitor impact of engagement.

Table 2: Guiding principles of engagement for researchers

Guiding principles	Researchers
Open communication and transparency	<ul style="list-style-type: none"> Continually share information and engage with participants (from start to finish). Have honesty, openness, and transparency guiding all communication. Tailor communication to meet different needs and preferences.
Co-creation and collaboration	<ul style="list-style-type: none"> Implement an organizational culture of research that prioritizes collaboration. Co-design, co-lead, and co-create the project. Invest time in co-education and learning for researchers and participants.
Trust and respect	<ul style="list-style-type: none"> Treat all participants with respect by valuing and acting on their input. Be mindful of, aware of, and sensitive to cultural and ethnic diversity. Foster and value relationships.
Flexibility and accessibility	<ul style="list-style-type: none"> Be flexible and adapt to participants' needs (e.g., use multiple modes of engagement including virtual and in-person, provide translators/interpreters, provide technological support, etc.) Create accessible physical environments for residents with wheelchairs. Be mindful of fluctuating health conditions, schedules, time logistics, and resources.
Safe and supportive environment	<ul style="list-style-type: none"> Create a safe and supportive environment that instills confidence in participants. Assess and respect comfort levels. Maintain confidentiality.
Recognition, compensation, and sustainable engagement	<ul style="list-style-type: none"> Recognize resident and caregiver contributions and empower them in the process. Provide fair compensation for residents' and caregivers' time. Value contributions and the different strengths that people bring.
Impact, relevance, and continuous improvement	<ul style="list-style-type: none"> Prioritize relevant and impactful topics. Give importance to participant feedback. Regularly assess impact of engagement for all parties.



Section 2: Engagement Strategies for Meaningful Engagement in LTC Research

In alignment with the guiding principles, we present the list of key engagement strategies for meaningful engagement of residents and caregivers in LTC research.

1. **Co-creation/design in research:** Involve residents and caregivers as active collaborators in research design, ensuring their lived experiences and perspectives shape the study's objectives, methods, and outcomes. This participatory approach enhances relevance and fosters ownership of the research process.
2. **Meaningful engagement plan:** Develop a structured plan that outlines clear goals, timelines, and strategies for engagement, accommodating the unique needs of LTC residents and caregivers. This ensures inclusivity and maximizes participation throughout all research stages.
3. **Multimodal communication:** Utilize diverse communication methods, such as newsletters, videos, seminars, or interpreters, to cater to varying preferences and abilities. This ensures accessibility and keeps participants informed while fostering engagement.
4. **Collaborative decision-making:** Facilitate shared decision-making by involving residents and caregivers in key research decisions. This approach respects their autonomy and ensures that their insights directly influence the study's direction.
5. **Defined roles/responsibilities:** Clearly define roles for all participants to ensure accountability and streamline collaboration. Tailoring responsibilities to individual strengths promotes active involvement and enhances the efficiency of the research process.
6. **Supportive environment:** Create a safe and respectful environment by addressing physical, cognitive, and emotional needs. Providing adequate resources, training, and flexibility ensures meaningful participation while reducing barriers.
7. **Diverse perspectives:** Incorporate cultural, ethnic, and experiential diversity into the research process to ensure inclusivity. Recognizing varied backgrounds enriches the study's findings and promotes equitable representation.
8. **Feedback loops:** Establish continuous feedback mechanisms to gather input from participants at every stage of the research. Transparent communication builds trust, validates contributions, and ensures iterative improvements in engagement strategies.

Strategies for Resident and Caregivers Engagement at Various Stages of Research

The research process is commonly broken down into eight distinct stages: 1. Problem identification, 2. Literature review, 3. Grant writing, 4. Study design, 5. Data collection, 6. Data analysis, 7. Report writing, and 8. Knowledge dissemination.

Below, we present engagement strategies for each group at each stage of research.

Stages of Research	Residents and caregivers	LTC staff and administrators	Researchers
1. Problem identification	<ul style="list-style-type: none"> Actively participate in regular meetings to understand potential research projects and share your unique perspectives and experiences. Communicate problems and opinions openly, understanding your input directly shapes beneficial research. Support and encourage fellow residents to attend meetings, ensuring diverse representation. Engage directly with research teams, recognizing the equal value of all shared perspectives. Maintain a personal journal of daily experiences, challenges, and ideas to bring well-thought-out contributions to discussions and help prioritize research focus areas. Support residents' participation by facilitating meeting attendance and ensuring their voices are heard in the engagement process. 	<ul style="list-style-type: none"> Communicate institutional values and research goals clearly, emphasizing stakeholder importance in improving care. Provide accessible venue and resources (e.g., transportation, interpreters, meeting spaces) for inclusive, regular discussions on research topics. Participate actively in meetings, sharing staff insights while encouraging residents and caregivers to freely share their experiences and opinions. Support stakeholders during meetings (e.g., note-taking, clarifying topics) to ensure all voices are heard and accurately represented Foster a safe, non-judgmental environment where residents and caregivers feel comfortable expressing concerns, leading to more authentic problem identification. 	<ul style="list-style-type: none"> Use language that places emphasis on the structural arrangements and resources to facilitate engagement. Align research proposals with the organization's values and mission and clearly communicate how they benefit residents and caregivers. Organize collaborative brainstorming sessions using inclusive language to define project scopes and emphasize the value of resident and caregiver input. Foster a welcoming, accessible, inclusive environment that actively engages participants and ensures all voices are heard and respected. Be mindful of barriers in the physical environment for residents with wheelchairs and try to overcome them at venue for meetings. Establish and share a clear project timeline with multiple opportunities for resident and caregiver involvement. Partner with community organizations to expand reach, using enabling language to create supportive structures for meaningful engagement.

2. Literature review	<ul style="list-style-type: none"> • Suggest diverse literature sources, including personal narratives and community experiences. • Collaborate with researchers in identifying and evaluating relevant sources. • Ask questions and provide feedback and suggestions. • Participate in the literature review process at your comfort level by sharing your perspectives. • Communicate preferred methods for receiving and engaging with research summaries. 	<ul style="list-style-type: none"> • Align reviewed literature with organizational values and mission, ensuring it reflects resident-centred priorities. • Support and provide access to literature in the preferred mode requested by residents. • Support residents in suggesting and reviewing diverse literature sources, including lived experiences. • Empower resident participation in literature evaluation through guided, supportive processes 	<ul style="list-style-type: none"> • Broaden the literature definition to include diverse sources such as resident journals, caregiver testimonials, and community narratives, enriching the review with lived experiences. • Actively involve residents in the literature review process, inviting source suggestions and collaborative analysis. • Create and present accessible, clear summaries of scientific information using plain language and visual aids. • Develop resident-researcher partnerships to co-create search strategies and review criteria.
3. Grant writing	<ul style="list-style-type: none"> • Participate in the grant writing process at your comfort level, offering your unique perspectives. • Take on a leadership role in the grant writing process in accordance with your comfort level. • Share personal insights and provide feedback on research objectives and grant proposals. • Request the time and resources to understand the grant requirements and potential research impact. • Advocate for resident and caregiver voices in research priorities and grant development. 	<ul style="list-style-type: none"> • Collaborate with the research team to understand their expectations, funding requirements, and how the grant aligns with institutional goals and resident priorities. • Provide realistic budget and resource allocation for grant development. • Facilitate opportunities for residents and caregivers to co-lead and share their insights and feedback, ensuring their perspectives are incorporated into the grant proposal. • Support co-creation and facilitate meaningful engagement between the research team and residents regarding the grant process. 	<ul style="list-style-type: none"> • Align project objectives with the LTC home's mission and resident needs, clearly communicating these priorities to funding bodies. • Engage residents and caregivers throughout grant writing, offering co-leadership roles and providing ample time and resources for meaningful co-creation. • Share funding information and grant expectations with residents, ensuring transparency and understanding. • Recognize and acknowledge resident and caregivers' contributions to the grant writing process.

4. Study design	<ul style="list-style-type: none"> • Actively participate as co-leads or integral team members, sharing personal insights to shape the study design. • Attend resident council meetings to voice ideas and inputs. • Ask questions freely and provide feedback after reviewing project summaries, ensuring your perspective is clearly understood and incorporated. • Engage consistently in discussion groups, offering inputs in the study design process. 	<ul style="list-style-type: none"> • Facilitate resident council meetings and brainstorming sessions to amplify resident voices. • Allocate resources to support meaningful engagement in study design, such as providing accessible meeting spaces, materials in appropriate formats, and staff support. • Create opportunities for residents to review and provide study design feedback. • Ensure study designs align with resident-centred institutional values. 	<ul style="list-style-type: none"> • Collaborate and create opportunities for residents and caregivers to co-design the project, fostering genuine partnership and shared decision-making. • Hold regular meetings with resident councils to gather inputs and ideas on study design considerations, ensuring ongoing engagement. • Provide accessible lay summaries of the project and empower participants to contribute to study design selection. • Facilitate workshops or focus groups where residents and caregivers can actively participate in shaping research methods and approaches.
------------------------	--	--	--

5. Data collection	<ul style="list-style-type: none"> • Actively participate in data collection activities, sharing personal experiences and insights about life in the LTC homes • Encourage fellow residents and caregivers to share their stories, challenges, and perspectives during data collection activities • Attend scheduled meetings and data collection sessions, contributing to meaningful discussions and providing valuable input • Offer feedback on the data collection process, suggesting improvements or alternative methods that might better capture resident experiences 	<ul style="list-style-type: none"> • Actively support the data collection process by facilitating communication between researchers, residents, and caregivers to ensure smooth collaboration. • Provide logistical assistance to expedite data collection, such as scheduling interviews or focus groups and coordinating resources. • Create a supportive environment for residents and caregivers by addressing any concerns or questions about the data collection process. • Encourage participation by ensuring flexibility in scheduling and accommodating residents' and caregivers' preferred methods of communication. 	<ul style="list-style-type: none"> • Provide clear, accessible descriptions of the study topic, outcomes, methods, and implementation, offering various engagement options and allowing participants to choose their preferred level of involvement. • Ensure transparency by providing appropriate access to data, keeping participants informed and motivated throughout the data collection process. • Offer flexible data collection methods, accommodating participants' preferred modes of communication and participation to enhance engagement. • Organize small focus groups to create comfortable environments where residents can freely share their experiences and insights. • Be mindful of barriers in the physical environment for residents with wheelchairs and try to overcome them at the venue for data collection.
---------------------------	--	--	---

<p>6. Data analysis</p>	<ul style="list-style-type: none"> • Actively participate in data analysis sessions, offering insights based on lived experiences to interpret and contextualize findings. • Provide input on preliminary analysis results, helping researchers understand the real-world implications of the data. • Seek opportunities to learn about basic data analysis concepts to better engage in discussions and contribute meaningful perspectives. • Collaborate with researchers to identify themes or patterns in the data that resonate with resident and caregiver experiences. 	<ul style="list-style-type: none"> • Facilitate resident/caregiver meetings to review and contextualize data analysis. • Provide accessible summaries to help residents and caregivers understand the process and contribute meaningfully. • Encourage collaborative workshops where residents and caregivers can actively participate in identifying themes or patterns in the data. • Acknowledge the contributions of residents and caregivers, ensuring their input is valued and reflected in the final analysis. 	<ul style="list-style-type: none"> • Conduct collaborative data analysis sessions with residents and caregivers, ensuring their perspectives are integrated into the interpretation process. • Develop and distribute a user-friendly glossary of data analysis terms to facilitate understanding and engagement in the analysis process. • Explain the nature of the data (qualitative or quantitative) and provide accessible education on key aspects of the data analysis. • Use visual aids to present data and gather feedback on interpretations.
--------------------------------	---	--	--

<p>7. Report writing</p>	<ul style="list-style-type: none"> • Actively participate in co-writing sessions, contributing personal experiences and insights to enrich the report's content. • Provide constructive feedback on draft sections, ensuring the report accurately reflects resident and caregiver perspectives. • Collaborate with team members to articulate ideas clearly, helping to translate lived experiences into impactful written content. • Review and suggest improvements for the report's accessibility, ensuring it's understandable for a wide range of readers. 	<ul style="list-style-type: none"> • Actively engage residents and caregivers in the report writing, providing support to ensure their insights are accurately captured. • Organize collaborative writing sessions where residents, caregivers, and staff can contribute their perspectives. • Create a structured feedback system for residents and caregivers to review report drafts. • Facilitate interdepartmental meetings to ensure comprehensive input from all relevant stakeholders, including residents and caregivers, in the final report. 	<ul style="list-style-type: none"> • Collaborate with residents and caregivers to co-write sections of the report, ensuring the language represents their perspectives. • Create multiple versions of the report tailored to different audiences, including an accessible version for residents and caregivers. • Organize review sessions where residents and caregivers can provide feedback on draft reports, ensuring accuracy and relevance of findings. • Involve residents and caregivers in developing recommendations based on the study results, linking findings to practical improvements in LTC.
---------------------------------	--	---	---

8. Knowledge dissemination	<ul style="list-style-type: none"> • Co-present research results with researchers at conferences and events, showcasing the rich lived experiences of LTC residents. • Share findings peer-to-peer at resident council meetings, facilitating discussions and insights among fellow residents. • Participate in creating accessible materials (e.g., newsletters, posters) to disseminate results within the LTC community. • Engage in media interviews or public forums to share personal stories that illustrate the research findings and their impact 	<ul style="list-style-type: none"> • Collaborate with researchers to organize knowledge dissemination events, ensuring accessible venues and formats for resident and caregiver participation. • Distribute invitations to residents and caregivers in their preferred format (print or email) and utilize the LTC home's email list to promote the news. • Encourage other LTC administrators to attend and see the project's impact. • Support residents and caregivers in preparing for and participating in knowledge dissemination activities. 	<ul style="list-style-type: none"> • Create opportunities and co-present results with residents and caregivers at knowledge dissemination events, showcasing their integral role in the research process. • Utilize diverse platforms (e.g., social media, podcasts, webinars) to share results, ensuring accessibility for various audiences. • Organize on-site knowledge dissemination events in the LTC homes, inviting other homes to witness firsthand the impact and implementation of findings. • Develop user-friendly materials (e.g., infographics, short videos) with resident and caregiver input for wider dissemination of results.
-----------------------------------	--	---	--

Note: While we have endeavoured to provide a comprehensive list of engagement strategies, it is important to acknowledge that not all the strategies may be feasible and additional strategies may exist, based on specific LTC home context. Researchers and LTC leaders are encouraged to carefully consider which strategies will be most relevant and effective for the LTC home where the research project will take place. The dynamic nature of LTC environments may necessitate adaptations or the development of novel engagement strategies to best suit individual circumstances.

“ If we are invited to participate in something, you need to tell us when the results should be expected. You need to loop back with the results. Ensure you are not just engaging to check off a box/requirement.”

Tip

Customize forms of communication to meet individual resident needs.
For example, provide printed copies as needed (considering large font).

Section 3: Checklist for Resident and Caregiver Engagement

1. ☐ Engage residents and caregivers from the inception of the project.
2. ☐ Encourage participation at any and every stage of research.
3. ☐ Identify barriers to engagement and co-create solutions in the LTC home.
4. ☐ Establish advisory boards for research projects.
5. ☐ Establish a point of contact from the research team for continuous flow of information.
6. ☐ Prioritize relevant topics by regular consultation, dialogue, and feedback.
7. ☐ Use clear language and accessible formats throughout the research (e.g., avoid abbreviations or scientific terminology, use large fonts, and add a glossary of terms).
8. ☐ Offer educational support for participants on research and technology use.
9. ☐ Give participants the anticipated practical impacts of the project.
10. ☐ Instill participants' confidence by sharing documents ahead of time for preparation.
11. ☐ Use residents' preferred communication modes for project updates.
12. ☐ Recognize and accommodate diverse accessibility needs, including physical, cognitive, and invisible disabilities, such as hearing impairments and dementia.
13. ☐ Ensure adequate time is allotted for meaningful discussions.
14. ☐ Choose data collection methods based on participants' preference (e.g., paper surveys versus online surveys, interviews versus focus groups).
15. ☐ Incorporate participant feedback or provide rationales for when you can't.
16. ☐ Assess participants' comfort levels to create safe space (e.g., preferred location, ground rules for meetings).
17. ☐ Ensure participants' confidentiality and disclose exceptions (e.g., in focus groups).
18. ☐ Take participants' cultural and ethnic diversity into consideration and understand the underlying differences.
19. ☐ Work around residents' and/or caregivers' schedules as much as possible.
20. ☐ Accommodate residents' fluctuating health with flexible engagement options and supports (e.g., virtual or in-person, translators/interpreters, technological support).
21. ☐ Offer appropriate compensation for participant time and contributions (e.g., physical versus digital gift cards, amount).

Key Takeaways

The **Partnering for Progress** framework's development involved continuous reflection, collaboration, and adaptation, culminating in valuable insights and key lessons tailored to the unique context of LTC. Research conducted in an LTC home requires a distinct approach, recognizing that these settings are primarily the residents' homes rather than traditional healthcare or institutional environments. Here, we list some of the key takeaways for LTC residents, caregivers, LTC staff, administrators, and researchers that may help other LTC homes in developing a guide of a similar nature for their respective homes.

LTC Residents

- **Active participation:** Engage in regular meetings and discussions to share living or lived experiences and highlight problems faced in LTC, ensuring research addresses high-priority issues.
- **Comfortable communication:** Feel safe sharing thoughts without repercussions to care, fostering open dialogue and trust in the research process.
- **Influence on research direction:** Considering one's health and life situation, contribute to as many stages of research as possible, from literature review to report writing, to ensure the research remains relevant and impactful.

Caregivers

- **Supportive role:** Assist and support residents in participating in research, providing valuable insights and guidance to the research team.
- **Active engagement:** Interact regularly with researchers to ensure their perspectives are considered and integrated into the research process.
- **Collaborative problem-solving:** Work with researchers to identify and address problems faced by residents, leveraging their unique understanding of resident needs.

LTC Staff

- **Collaborative environment:** Foster a supportive environment that encourages resident and caregiver participation in research, promoting a culture of collaboration and trust.
- **Flexibility and adaptability:** Be adaptable to the changing needs and health status of residents, ensuring research processes are flexible and responsive.
- **Empathy and understanding:** Approach research with empathy, recognizing the unique context and challenges of LTC settings.

LTC Administrators

- **Institutional support:** Provide a supportive environment, resources, and space for research activities, ensuring alignment with institutional values and priorities.
- **Resource allocation:** Manage budgets effectively to support research projects, ensuring substantial resources are allocated while staying within budget constraints.
- **Communication and engagement:** Facilitate communication and engagement by providing access to institutional newsletters to advertise research events and maximize engagement in research activities.

Researchers

- **Collaborative problem identification:** Engage residents and caregivers in identifying research problems, ensuring topics are relevant and meaningful to the LTC community.
- **Flexible and adaptive approach:** Adopt a flexible approach to accommodate the unique needs of residents and caregivers, fostering trust and meaningful engagement.
- **Open communication and co-creation:** Foster open communication and co-creation with residents and caregivers by establishing clear timelines, project priorities, engagement plans, funding application, feedback mechanisms, and other solutions to address specific barriers to engagement in the LTC home.
- **Empowering language:** Use language that empowers residents and caregivers throughout the research process, valuing their insights and feedback to drive impactful solutions.

Appendix A: What We Did: Brief Description of Project

Embracing the principles of co-design, the Centre of Excellence project team identified stakeholder groups, including residents, caregivers, and LTC professionals and researchers to join the “Advisory Committee” (the Committee) for this project in 2023. Members were recruited, and meetings were organized to discuss the plan for the study. The project began with a literature review to inform the committee about the current evidence on resident and caregiver engagement. Based on this review, the committee developed a plan proposing a two-phase study: first, a survey to assess existing knowledge about resident and caregiver engagement, and second, a one-day in-person “Partnering for Progress” engagement event with residents, caregivers, researchers, administrators, and sector leaders. This collaborative approach ensured that the project was grounded in evidence while incorporating valuable diverse perspectives.

Phase 1: Survey

A cross-sectional survey was conducted, focusing on three important questions:

- i. What are key elements of the successful engagement of residents?
- ii. What are some challenges to successfully engaging residents of LTC homes as partners in research?
- iii. How can these challenges be overcome?

For survey distribution, we collaborated with CanSPARK LTC to distribute the survey through their network. In addition, surveys were sent to 90 potential participants using the email network of Perley Health. Research team members participated in two resident council meetings and one Family and Friends Council meeting, advertised in the resident newspaper, and presented to senior leadership to promote the survey.

A total of 33 LTC residents, caregivers, researchers, and organizations within the LTC sector completed the survey. (See Figure 3 for survey participant demographics.)

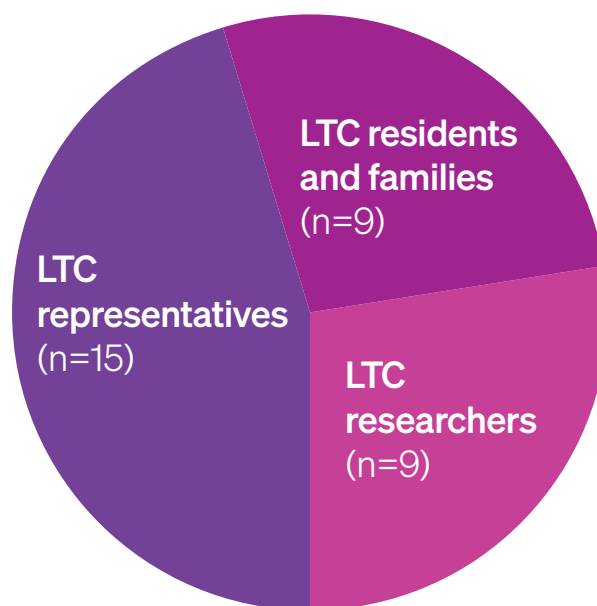


Figure 3: Survey participant demographics

The research team collated and cleaned survey responses to ensure completeness and remove redundancy. Specific themes were assigned to each response to increase clarity. The raw data was then transcribed into accessible language and was later presented at the advisory committee meetings. The analyzed data was compared to existing literature to highlight any gaps in knowledge and inform the development of the one-day engagement session topics.



Phase 2: Partnering for Progress engagement event

The Centre of Excellence Project team hosted a **“Partnering for Progress”** engagement event on May 29, 2024, attended by over 30 residents, caregivers, researchers, and LTC staff. The event aimed to integrate resident and caregiver perspectives on their meaningful engagement in LTC research and inform the development of an engagement framework and associated implementation tools. This in-person event encouraged residents and their caregivers to share their experiences ([*Perley Health Centre of Excellence Newsletter, June 2024*](#)).

Roundtable discussions were organized with residents, caregivers, researchers, and LTC representatives. Two facilitators were placed at each table—one to moderate the discussion and another to take meeting notes. Careful consideration was given by the project team to seating placement, ensuring each table had equal representation from diverse perspectives. Discussions focused on the topics of making residents comfortable sharing perspectives, addressing engagement barriers, and involving residents and caregivers in research stages.

The project team organized and refined the engagement event data to ensure completeness and eliminate redundancy, organizing the responses by theme for clarity. The data was transcribed and later presented at the committee meetings. Subsequently, the project team combined data from both phases to develop the framework and associated guide for the LTC sector.



Unique elements of our project

One of the important design elements of both phases was to gather real-time input from residents and caregivers about their living or lived experiences.

Both phases highlighted key factors influencing meaningful engagement in LTC, such as barriers to engagement, guiding principles of engagement applicable to the overall research process, and strategies for engaging residents in research process. The data collected from these activities allowed us to identify crucial aspects of resident engagement directly from the participants.

This approach was essential for achieving our objective of maximizing engagement by involving residents and their caregivers at every step. Practical strategies used for resident and caregiver engagement included effective advertising, continuous discussion in resident meetings, wheelchair accommodations, and flexible participation options for residents with fluctuating health conditions. This approach helped our project achieve the overall objectives of meaningful resident and caregiver engagement by directly involving residents and their caregivers throughout every step of this project.

Appendix B: Acknowledgement

We would like to sincerely thank and highlight the contributions of our advisory committee members for providing expert advice throughout the development of this guide on meaningful engagement.

Gail Fugère, Resident Partner and Advisory Committee Member, Perley Health

Heather MacPhee, Family Partner and Advisory Committee Member, Perley Health

Colin Martell, Resident Partner and Advisory Committee Member, Perley Health

Louise Mulitze, Family Partner and Advisory Committee Member, Perley Health

Michael Mulitze, Resident Partner and Advisory Committee Member, Perley Health

Gale Ramsden, Resident Partner and Advisory Committee Member, Perley Health

Brenda Thompson, Resident Partner and Advisory Committee Member, Perley Health

We would also like to thank the project participants who contributed to the project's planning, consultation, reviewing, and additional engagement.

Sheila Bauer, LTC, City of Ottawa

Ron Beleno, Caregiver Advocate (Toronto)

Stephanie Conrad, CanSPARK LTC Network, Bruyère Health

Sue Davies, Caregiver Advocate (Toronto)

Jennie Day, University of Ottawa

Cathleen Edwards, Family Councils Ontario

Michelle Fleming, Ontario CLRI at Bruyère Health

Carole Green, Dementia Society of Ottawa and Renfrew County

Devora Greenspon, Resident Partner, Hillel Lodge

Sam Greenspon, Care Partner, Hillel Lodge

Amanda Kutenski, University of Ottawa

Heather Lannon, The Ontario Caregiver Organization

Heather Lintell, Care Partner, Perley Health

Dianne Leclerc, Care Partner, Perley Health

Rachel Lithopoulos, Ontario CLRI at Bruyère Health

Leslie McCormick, Care Partner, Perley Health

Sandra McDonald, Resident Partner, Hillel Lodge

Claudia McKeen, Care Partner

Heather Moxley, Family Council Representative, Perley Health

Stuart Nicholls, Ontario SPOR, Ottawa Hospital Research Institute

Chris Pugh, Ontario Long Term Care Association

Grace Welch, Champlain Region Family Council Network

We warmly thank all the partner organizations leads and LTC experts for helping our team at various stages of this project.

Funding support: We thank the Canadian Institutes of Health Research (CIHR) Institute of Aging for financially supporting this initiative through the knowledge dissemination grant. (Funding reference number PCS # 190992.)

Appendix C: Glossary*

Activities of Daily Living	A term used to collectively describe fundamental skills required to independently care for oneself, such as eating, bathing, personal hygiene, dressing, transfers/bed mobility, locomotion, and bowel and bladder control. ¹
Canadian Institutes of Health and Research (CIHR)	Canada's federal funding agency that supports research and innovations in the field of healthcare with the aim of improving the healthcare system. ²
Canada Supporting Partnerships, Advancing Care and Knowledge in Long-Term Care (CanSPARK LTC)	A collaborative network in Canada supporting partnerships to cultivate a pan-Canadian learning ecosystem driving continuous learning, research, timely data, innovation, and coordination of existing and emerging efforts with an inclusive community of all interested partners.
Caregiver	They are essential visitors, designated by a resident or their substitute decision maker, to provide support or assistance to residents. Caregivers can be family members, friends, or people of importance to a resident, including privately hired caregivers, paid companions, translators, etc. ³
Citizen	Interested representatives from the general public, consumers of health services, patients, caregivers, advocates, and representatives from affected community and voluntary health organizations. ⁴
Citizen engagement	Meaningful involvement of individual citizens in policy or program development, from agenda setting and planning to decision-making, implementation, and review. This "meaningful involvement" can take place at a variety of stages in the research, planning, or implementation phases of a project. ⁴
Cognitive disorders	Disorders that affect the intellectual abilities of an individual, including thinking, learning, memory, reasoning, perception, and problem-solving.
Consultations	The techniques involving a two-way flow of information that offers options for consideration and encourages feedback, such as additional ideas or options, from the public. ⁴
Co-creation	A co-operative approach to problem-solving that involves diverse stakeholders at every stage of a project. It fosters value creation by actively engaging stakeholders in identifying issues, developing solutions, and assessing their effectiveness. ⁵
Co-design	Engaging stakeholders in joint solution design, fostering citizen participation to address and enhance specific issues. ⁵

Family council	A group formed of family and friends of LTC home residents that focuses on improving residents' quality of life and care, while providing support to one another. ³
Lived/living experience	Personal knowledge about the world gained through direct, firsthand involvement in everyday events rather than through representations constructed by other people (e.g., living in a LTC home or caring for someone who lives in LTC home is lived/living experience; a person with lived/living experience is an expert by experience). ⁶
Long-term care (LTC)	Long-term care homes provide accommodation, nursing, and personal support services to adults who need 24-hour care, seven days a week (24/7). ⁷
LTC staff	Any employee of the LTC home. It may include doctors, nurses, personal support workers (PSWs), and allied healthcare and recreation staff. ³
Person-centred care	Person-centred care is a philosophy that recognizes individuals have unique values, personal histories, and personalities and that each person has an equal right to dignity, respect, and the ability to participate fully in their environment. ⁸
Research	A detailed study of a subject, especially to discover new information and/or reach a new understanding.
Resident council	A group of LTC residents who meet to provide advice, feedback, and recommendations on what residents would like to see done to improve care or the quality of life in the home. ³
Stakeholder	An individual, group, or organization having a "stake" in an issue and its outcome. ⁴ In LTC, this includes residents, families, staff, management, healthcare providers, policymakers, and researchers.

***Citations used in the glossary are listed in the References section**

Appendix D: Resources and Tools

Here are some resources and tools that could be helpful and applied to residents and caregiver engagement.

Alberta SPOR SUPPORT Unit (2018) - Patient Engagement in Research: A How-to Guide for Researchers

Link: <https://absporu.ca/wp-content/uploads/2020/05/How-To-Guide-Researcher-Version-8.0-May-2018-1.pdf>

Key feature: Step-by-step guide for researchers, including tools, strategies, and checklists for patient engagement in research process.

CIHR (2020) - Ethics Guidance for Developing Partnerships with Patients and Researchers

Link: https://cihr-irsc.gc.ca/e/documents/ethics_guidance_partnerships-en.pdf

Key feature: Ethical guidance for research partnerships between patients and researchers.

Healthcare Excellence Canada (2024) - Guiding Principles of Engagement

Link: https://www.healthcareexcellence.ca/media/d5koz5cf/20230511_pe_guidingprinciples_v4_en.pdf

Key feature: Guiding principles of engagement across the organization.

Health Quality BC (2024) - A Guide to Authentic Patient Engagement

Link: <https://healthqualitybc.ca/resources/a-guide-to-authentic-patient-engagement/>

Key feature: Step-by-step framework, principles, and resources, including sections on diversity, equity, and inclusion; Indigenous cultural safety.

Health Quality Ontario (2017) - Ontario's Patient Engagement Framework

Link: <https://www.hqontario.ca/portals/0/documents/pe/ontario-patient-engagement-framework-en.pdf>

Key feature: Framework that guides planning, implementation, and evaluation of patient engagement activities across all levels of the health system.

MIRA Collaborative for Health & Aging & Julia Abelson, Rebecca Ganann, McMaster University (2020) - Partnering Principles and Strategies: A Guidance Document

Link: <https://mira.mcmaster.ca/news-events/partnering-principles-and-strategies-a-guidance-document-for-researchers-patients-and-caregivers/>

Key feature: Actionable principles and strategies to plan for and involve Patient, Caregiver, and Public Research Partners.

PEIRS Project Team (2018) - Workbook to guide the development of a Patient Engagement In Research (PEIR)

Link: <https://www.arthritisresearch.ca/wp-content/uploads/2018/06/PEIR-Plan-Guide.pdf>

Key feature: Reference for workbook and practical tools to guide the development of plan for patient engagement in research.

PERC Advisory Board (2019) - Patient Engagement in Research: A toolkit for Patient Partners

Link: <https://perc-phc.mcmaster.ca/app/uploads/2022/01/Patient-Engagement-in-Research-A-toolkit-for-Patient-Partners.pdf>

Key feature: Reference for step-by-step guidance, practical tools, and tips to engage patient partners in research.

Peterborough Public Health (2018) - Community Engagement Planning Toolkit

Link: https://www.peterboroughpublichealth.ca/wp-content/uploads/2019/09/PPH-CE-Planning-Toolkit_2018.pdf

Key feature: Reference for customizable worksheets and step-by-step guidance to plan, implement, and evaluate community engagement activities.

PPEET Research - Practice Collaborative & Julia Abelson. McMaster University (2018) - Public and Patient Engagement Evaluation Tool (PPEET) Version 2.0

Link: https://ppe.mcmaster.ca/wp-content/uploads/2023/04/PPEET_Version-2.0_Full-Set.pdf

Key feature: Reference for comprehensive set of three distinct questionnaires-targeting participants, project leads, and organizations-to rigorously evaluate the context, process, and impact of public and patient engagement activities.

University Health Network (2023) - Engaging People with Lived Experience in Research

Link: <https://perc-phc.mcmaster.ca/app/uploads/2023/12/piper-tool.pdf>

Key feature: Reference for information and training resources to help plan, implement, and evaluate patient engagement in research, with emphasis on meaningful involvement of people with lived experience as research partners.

University of Manitoba Centre for Healthcare Innovation (2020) - Methods of Patient & Public Engagement: A Guide

Link: <https://umanitoba.ca/centre-for-healthcare-innovation/sites/centre-for-healthcare-innovation/files/2021-11/methods-of-patient-and-public-engagement-guide.pdf>

Key feature: Reference for stage-specific guidance on participatory methods for engagement during research.

References

1. Canadian Institute of Health Information. How many long-term care beds are there in Canada? 2021. Available from: <https://www.cihi.ca/en/how-many-long-term-care-beds-are-there-in-canada>
2. Financial Accountability Office of Ontario. Long-Term Care Homes Program: A review of the plan to create 15,000 new long-term care beds in Ontario. 2019. Available from: <https://www.fao-on.org/en/Blog/Publications/ontario-long-term-care-program>
3. McArthur C, Alizadehsaravi N, Quigley A, Affoo R, Earl M, Moody E. Scoping review of methods for engaging long-term care residents living with dementia in research and guideline development. *BMJ Open*. 2023;13(4): e067984. doi:10.1136/bmjopen-2022-067984
4. Leduc JH, Holroyd-Leduc J, Heyland D, Keller H, Sinha S, Muscedere J, et al. Giving voice to older adults living with frailty and their family caregivers: engagement of older adults living with frailty in research, health care decision making, and in health policy. *Res Involv Engagem*. 2016;2(1):23. doi:10.1186/s40900-016-0038-7
5. Canadian Institutes of Health Research. CIHR's framework for citizen engagement. 2010. Available from: <https://cihr-irsc.gc.ca/e/41270.html>
6. Tittlemier BJ, Cooper J, Steliga D, Woodgate RL, Sibley KM. A scoping review to identify and describe the characteristics of theories, models and frameworks of health research partnerships. *Health Res Policy Syst*. 2022;20(1):69. doi:10.1186/s12961-022-00877-4
7. Chudyk AM, Horrill T, Waldman C, Demczuk L, Shimmin C, Stoddard R, et al. Scoping review of models and frameworks of patient engagement in health services research. *BMJ Open*. 2022;12(8):e063507. doi:10.1136/bmjopen-2022-063507
8. Lynch B, Ryan AA, O'Neill M, Penney S. The factors that influence care home residents' and families' engagement with decision-making about their care and support: an integrative review of the literature. *BMC Geriatr*. 2022;22(1):873. doi:10.1186/s12877-022-03503-8
9. Krist AH, Tong ST, Aycock RA, Longo DR. Engaging patients in decision-making and behavior change to promote prevention. *Stud Health Technol Inform*. 2017; 240:284-302. Available from: <https://pubmed.ncbi.nlm.nih.gov/28972524/>
10. Registered Nurses' Association of Ontario. Engaging Persons with Lived Experience. [Internet]. Available from: <https://rnao.ca/bpg/leading-change-toolkit/engaging-persons/engaging-persons-with-lived-experience>
11. Armstrong MJ, Mullins CD, Gronseth GS, Gagliardi AR. Impact of patient involvement on clinical practice guideline development: a parallel group study. *Implement Sci*. 2018;13(1):55. doi:10.1186/s13012-018-0745-6

Citations for Glossary:

1. Katz S. Assessing self-maintenance: activities of daily living, mobility, and instrumental activities of daily living. J Am Geriatr Soc. 1983;31(12):721-7. <https://doi.org/10.1111/j.1532-5415.1983.tb03391.x>
2. Canadian Institutes of Health Research. About us. [Internet]. Available from: <https://cihr-irsc.gc.ca/e/37792.html>
3. Ontario Ministry of Long-Term Care. Living in a long-term care home. [Internet]. Available from: <https://www.ontario.ca/page/living-long-term-care-home>
4. Canadian Institutes of Health Research. CIHR's framework for citizen engagement. 2010. Available from: <https://cihr-irsc.gc.ca/e/41270.html>
5. Vargas C, Whelan J, Brimblecombe J, Allender S. Co-creation, co-design and co-production for public health-a perspective on definitions and distinctions. Public Health Res Pract. 2022;32(2): e3222211. <https://doi.org/10.17061/phrp3222211>
6. University Health Network. Engaging people with lived experience in research: a guide. 2023. Available from: <https://perc-phc.mcmaster.ca/app/uploads/2023/12/piper-tool.pdf>
7. Office of the Auditor General of Ontario. Long-term care homes: delivery of resident-centred care. 2023. Available from: https://www.auditor.on.ca/en/content/annualreports/arreports/en23/AR_LTCresidential_en23.pdf
8. Alzheimer Society of Canada. What is person-centred care? [Internet]. Available from: <https://alzheimer.ca/en/help-support/im-healthcare-provider/providing-person-centred-care>

Notes

[illegible]

Support the Centre of Excellence

There are many ways to support the Centre of Excellence in Frailty-Informed Care™ as Perley Health aspires to double the number of Seniors and Veterans served by 2035.

Your support can take various forms:

- 1. Participate:** Embrace the opportunity to be directly involved in transforming care for Seniors and Veterans. Participate in research studies, ensuring that the voices and experiences of members of the Perley Health community inform and guide our work. We encourage residents, tenants, families, caregivers, clients, staff and volunteers to engage to help ensure our community's needs are represented.
Read about our projects:
[PerleyHealth.ca/ongoing-research-projects](https://perleyhealth.ca/ongoing-research-projects)
- 2. Learn:** Expand your knowledge and understanding on a variety of topics related to aging, frailty and long-term care, by attending our monthly webinars. Subscribe, participate, and learn alongside experts for leading-edge information about frailty-informed care.
Register here: [PerleyHealth.ca/collaboration](https://perleyhealth.ca/collaboration)
- 3. Connect:** Keep informed on the latest developments, read about the impact of our ongoing research projects in our newsletter and our social media channels.
Access our newsletter and recent media coverage: [PerleyHealth.ca/newsletter](https://perleyhealth.ca/newsletter)
- 4. Collaborate:** We welcome inquiries to partner with researchers, healthcare professionals, industry, organizations and local groups to strengthen our outreach and impact.
Contact us:
centreofexcellence@perleyhealth.ca
- 5. Donate:** Your donations to the Perley Health Foundation support innovative projects and help to transform care for Seniors and Veterans.
Donate here: [PerleyHealthFoundation.ca](https://perleyhealthfoundation.ca)

Contact Information

If you are interested in participating or would like to learn more about a particular project, please contact:

Michaela Adams
Research Associate,
Centre of Excellence in Frailty-Informed Care™
Office: 613.526.7170 ext. 2425
madams@perleyhealth.ca

Thank you to Commissionaires Ottawa for their ongoing support of the Centre of Excellence in Frailty-Informed Care™.



Contact Information

Danielle Sinden
Director, Centre of Excellence
and Research Operations
Office: 613.526.7170 ext. 2424
dsinden@perleyhealth.ca



1750 Russell Road, Ottawa ON K1G 5Z6
centreofexcellence@perleyhealth.ca

[PerleyHealth.ca/centreofexcellence](https://perleyhealth.ca/centreofexcellence)