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What We Heard Report #3

Findings from HSO's Public Engagement in the Development of a New National Long-Term Care Services Standard (CAN/HSO 21001:2023 Long-Term Care Services)

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About Health Standards Organization (HSO)

Health Standards Organization (HSO) develops evidence-informed health and social services standards, assessment programs, and quality improvement solutions. Recognized as a Standards Development Organization by the Standards Council of Canada, we work with leading experts and people with lived experience from around the world, using a rigorous public engagement process, to co-design standards that are people-centred, integrated, and promote safe and reliable care. We are a registered non-profit headquartered in Ottawa, Canada. For more information visit www.healthstandards.org.

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This report summarizes findings from the Public Engagement activities that supported the development of HSO's National Long-Term Care (LTC) Services Standard. HSO heard from over 18,800 Canadians in 2021 and 2022 through the Public Engagement activities. All engagement participants gave consent for their information to be used for the development of the standard. In accordance, all responses have been treated in confidence and have been anonymized in this report.

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Executive Summary

In light of the long-term care crisis that surfaced during the COVID-19 pandemic, HSO developed a new National Long-Term Care Services Standard (CAN/HSO 21001:2023 Long-Term Care Services) that provides clear requirements and accountabilities to enable LTC home teams, leaders, governing bodies, and other stakeholders to work together towards a common vision for high-quality, safe, resident-centred care. A series of engagement activities over three phases (between March 2021 and June 2022) were undertaken to ensure insights and feedback from Canadians were at the forefront of the development of a new LTC Services standard.

What We Heard Report #3 builds on the feedback provided by the over 18,000 Canadians who participated in HSO's Phase One (Inaugural National Survey on Long-Term Care) and Phase Two (Consultation Workbooks and Town Halls) Engagement activities. In particular, the Phase Three Engagement activities aimed to facilitate deeper engagement with LTC home residents and other key stakeholders about their experiences with and perspectives on key areas in the provision of long-term care in Canada. To gain these additional insights and information, HSO solicited greater input through three activities:

1. Virtual Visits with LTC home residents from across Canada;
2. An additional series of five Town Halls; and
3. A Public Review of the draft standard.

Many of the overarching themes and core sentiments that were shared in previous What We Heard Reports remain true and resonate among the key themes that have emerged from the Phase Three Engagement activities. With that in mind, in this report we begin by providing a recap of the key takeaways from *What Heard Report #1* and *What We Heard Report #2*; as well as an overview of the demographic profile of the 18,856[1] individuals and groups who provided feedback to help HSO's National LTC Services Technical Committee develop the new National LTC Services Standard—which was released alongside this report in early 2023.

What We Heard During Phase Three Public Engagement Activities

Next, we present an overview of the demographic profile of the individuals who participated in Phase Three Engagement activities by language, age, gender, geographic location, race, ability, and relationship to long-term care.

In the body of the report, we present key themes that were shared by the almost 800 individuals and groups who participated in HSO's Phase Three Engagement activities in 2022.

[1] While the total number of responses on record for all Public Engagement activities is 18,856, this number is an underrepresentation of participation as some groups who completed Roundtable Consultation Workbooks or participated in the Public Review did not report how many individuals participated.

When asked whether HSO's draft standard appropriately addressed concerns regarding the provision of high-quality long-term care, participants reinforced the key messaging from *What We Heard Report #2*—that providing excellent long-term care is a careful balancing act that requires long-term care homes to prioritize residents' rights. Further, many Phase Three Engagement participants identified the need to revisit and reshape the current perception of long-term care in Canada. In particular, working to shift the historically institutional culture and re-situating relationship-centred care as the foundation of safe, reliable, and high-quality long-term care. To demonstrate the impact that systemic transformation will have on the day-to-day experiences of residents living in Canadian LTC homes, we share three fictionalized[2] resident profiles which highlight both current day-to-day (Márcia and Henry) and transformed (Patrick) experiences based on Virtual Visits conducted with LTC home residents.

When it comes to enabling the provision of high-quality care in LTC homes across Canada, Phase Three Engagement participants offered a range of suggestions that could transform care experiences—for residents, family members, and also the workforce, including: embracing a true continuum of care which includes palliative care; emphasizing resident autonomy and choice; embracing an interdisciplinary and collaborative team approach to care; engaging essential care partners more in care teams; and creating a home-like environment.

When discussing how to best enable good communication (including the use of information technology) within LTC homes, many participants stressed the importance of both interpersonal communication (e.g., offering interpretation and translation services, utilizing available strategies, tools, and devices, connecting with external specialized services) and organizational communication (e.g., clear protocols, engaged leadership, public reporting) as foundational in the provision of high-quality care.

When discussing how to best support the LTC workforce, many Phase Three Engagement participants called attention to the inequities that permeate the day-to-day experiences of the individuals who comprise the LTC workforce. In particular, participants would like to see direct action to address job security, staffing concerns, and education and learning opportunities.

When asked about the feasibility of requirements for governance and leadership, Phase Three Engagement participants sought additional clarity on accountabilities and responsibilities (e.g., resource allocation, evaluation/assessment). When it comes to governance at the home-level, participants felt that it is the responsibility of an LTC home's leadership to establish clear mission and vision statements, clear hiring criteria, clear mechanisms for keeping up with regulations and reporting, clear mechanisms for communicating with residents' and family councils, and education opportunities for all stakeholders in the provision of care.

Next, we provide a summary to highlight the significant changes that occurred to the LTC Services standard as a result of the Public Review period and insights that were captured during the Phase Three Engagement activities.

Similar to feedback received in the Phase One and Phase Two Engagement activities, there was some extensive and rich feedback that are key enabling factors for supporting the meaningful implementation of the standard; however outside the scope of HSO's new National LTC Services Standard.

[2] It is important to note that, while fictionalized, the resident profiles presented herein are composite narratives that are rooted in the lived experiences reported by LTC home residents during Virtual Visits conducted with LTC home residents from across Canada.

Moving Forward

Throughout all phases of public engagement in the development of HSO's new National LTC Services Standard, Canadians have been consistent in voicing what they want to see when it comes to the future of long-term care services in Canada. As we look to the future, we are confident that HSO's new National LTC Services Standard truly reflects Canadians' views on what an optimal future state of LTC ought to look like in Canada. With that in mind, we conclude this report by highlighting the key values—Care, High quality, Integrity, Respect, and Community – that exemplify what Engagement participants feel is integral for facilitating a paradigm shift in the perceptions, delivery, and experience of long-term care in Canada.

Introduction

Considering the existing crisis in LTC homes, and in response to the federal government's commitment in 2020 to improve the provision of LTC across Canada, the Standards Council of Canada (SCC), Health Standards Organization (HSO), and the Canadian Standards Association (CSA Group) agreed to work collaboratively on the development of two new complementary national standards for long-term care (LTC). The standards have been shaped by the needs and voices of Canada's LTC home residents, substitute decision makers, essential care partners, the workforce, local communities, and members of the public.

About HSO's Standards and How They are Used

Standards exist in every aspect of Canadian life. They are the "invisible infrastructure" that allows us to live and work safely and to thrive. Standards can become the basis of government legislation, policy, regulations, and accreditation programs.

HSO is an independent, non-governmental, not-for-profit organization recognized by the Standards Council of Canada (SCC) as a Standards Development Organization (SDO), which develops National Standards of Canada (NSC). HSO is the only SDO in Canada that is solely dedicated to health and social services and has developed standards that are currently being used in over 15,000 locations, across 38 countries. In light of the COVID-19 pandemic, HSO developed a new National LTC Services Standard (CAN/HSO 21001:2023 Long-Term Care Services) that provides clear requirements and accountabilities to enable LTC home teams, leaders, governing bodies, and other stakeholders to work together towards a common vision for high-quality, safe, resident-centred care.

HSO's National LTC Services Standard provides LTC home teams, leaders, and governing bodies with guidance on:

- Providing evidence-informed, resident-centred care that values compassion, respect, dignity, trust, and a meaningful quality of life.
- Working in a team-based way to deliver high-quality care that is culturally safe and trauma-informed to meet residents' goals, needs, and preferences;
- Enabling a healthy and competent LTC home workforce and healthy and safe working conditions.
- Upholding strong governance practices and a culture that is outcome-focused and committed to continuous learning and quality improvement.

LTC homes, also referred to as continuing care, personal care, or nursing homes, are settings where people with complex health care needs live. LTC homes are formally recognized by jurisdictions with a licence or permit and are partially funded or subsidized to provide a range of health and support services, such as lodging, food, and personal care for their residents 24 hours a day, 7 days a week (Canadian Institute for Health Information, 2021).[3]

[3] Canadian Institute for Health Information. (2021). Long-term care homes in Canada: How many and who owns them? https://www.cihi.ca/en/long-term-care-homes-in-canada-how-many-and-who-owns-them

About the National LTC Services Standard Development Process

The following timeline outlines the various milestones of the development process for the National LTC Services Standard:

March 2021

- Public announcement of the development of two new complementary national standards for long-term care
  - HSO's LTC Services Technical Committee – to address the delivery of safe, reliable, and high-quality long-term care services
  - CSA Group's Standard for Long-Term Care Home Operations and Infection Prevention and Control – to address the design, operation, and infection prevention and control practices in long-term care homes
- Launch of member recruitment for HSO's LTC Services Technical Committee
- Launch of Inaugural National Survey on Long-Term Care

May 2021

- LTC Services Technical Committee formed

July 2021

- Joint HSO & CSA Group Government Advisory Table for LTC Standards formed
  - Purpose: To provide provincial, territorial, and federal level officials an opportunity to remain engaged throughout the development of HSO and CSA Groups's new national standards for long-term care
  - 10 subsequent meetings held throughout the development of the standards
- Inaugural National Survey on Long-Term Care closed

August 2021

- Consultation Workbooks launched

September - December 2021

- Phase 1 Town Halls hosted (9 Town Halls)

October 2021

- *What We Heard Report #1* released

December 2021

- Consultation Workbooks closed
- Received consensus from the LTC Services Technical Committee to release the draft standard for public review

January 2022

- Launch of draft National LTC Services Standard for 60-day Public Review
- *What We Heard Report #2* released

March 2022

- Phase 2 Town Halls hosted (5 Town Halls)
- Public Review closed

March 2022 - June 2022

- Virtual Visits with LTC home residents hosted

December 2022

- Received consensus from the LTC Services Technical Committee to release final standard for publication

January 2023

- Final National LTC Services Standard released – incorporating feedback from HSO's Public Review and other engagement activities
- *What We Heard Report #3* released

About HSO's Public Engagement Activities

HSO's National LTC Services Standard brings the voices of residents, families, and the LTC workforce to the forefront of designing and developing how LTC homes and LTC teams can use evidence-informed practices and work collaboratively to ensure safe, reliable, and high-quality care.

An integral component of designing and building the new standard was hearing what matters most to Canadians when it comes to long-term care. From March 31, 2021 to June 7, 2022, HSO invited Canadians to participate in a series of Public Engagement activities to get a better sense of their views on what an optimal future state of LTC ought to look like in Canada. In total, 18,856[4] individuals and groups provided feedback to help HSO's National LTC Services Technical Committee develop the new National LTC Services Standard—which was released alongside this report in early 2023.

Who We Heard From: An Overview

The insights, needs, experiences, and hopes shared by Canadians informed HSO's National LTC Services Technical Committee's work to develop the new National LTC Services Standard.

Throughout the three phases of engagement[5] we heard from a variety of people from across Canada.

- **30%** of participants who were asked about their age reported they were 65 years of age or older.
- **67%** of participants who were asked about their gender self-identified as female.
- **2%** of participants who were asked about Indigenous identity indicated that they were First Nations, Métis, or Inuit.

[4] While the total number of responses on record is 18,856, this number is an underrepresentation of participation as some groups who completed Roundtable Consultation Workbooks or participated in the Public Review did not report how many individuals participated.

[5] Please note that while we received a total of 18,856 responses, not all participants chose to respond to all demographic questions nor were all demographic questions included in all Engagement activities in order to best ensure participant anonymity. Thus, the percentages reported herein were calculated based on the total number of responses received for each individual question (versus total responses received across engagement activities).

- **9%** of participants who were asked about racial identity self-identified as being a visible minority.[6]
- **7%** of participants who were asked whether they were living with a disability self-identified as living with a disability.
- **90%** of participants answered in English.
- **55%** of participants who were asked about their geographic location reported living in Ontario.
- **26%** of participants self-identified as a Family Member, Friend, or an Essential Care Partner to an LTC Home Resident; while **21%** of participants self-identified as being part of the LTC Workforce and **2%** of participants self-identified as being an LTC Home Resident.

A full breakdown of the demographic profile of participants from each phase of Engagement activities can be accessed by clicking on the following links:

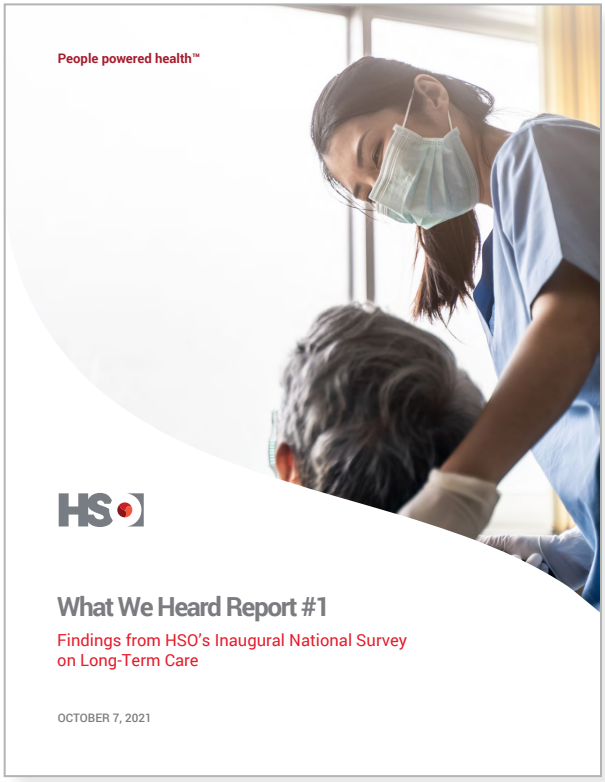
- Phase One: *What We Heard Report #1*
- Phase Two: *What We Heard Report #2*
- Phase Three: Appendix A

[6] We acknowledge the growing sense that the term "visible minority" is outdated—and even discriminatory in some instances. Instead, the term "people of colour" is now more commonly used to reflect shifts in population demographics.

The following sections provide an overview of what we have heard from Canadians over Phase One and Phase Two of the Public Engagement activities. From there, we shine a light on who we heard from, and what they shared in our final phase of Public Engagement activities in 2022, which included: Virtual Visits with LTC home residents across Canada, Phase Two Town Halls, and Public Review feedback on the draft National LTC Services Standard.

What We Heard

This section presents key themes that were heard through HSO's Phase Three Engagement activities in 2022. Many of the overarching themes and core sentiments that were shared in both *What We Heard Report #1* and *What We Heard Report #2* remain true and resonate among the key themes that have emerged from the Phase Three Engagement activities. With that in mind, this section begins with a brief recap[7] of the key takeaways from *What Heard Report #1* and *What We Heard Report #2*.



[7] In order to avoid duplicating the discussion contained in *What We Heard Report #1* and *What We Heard Report #2*, the discussion herein highlights the most salient points from the Phase Three Engagement activities.

Recap of Where We've Been

What We Heard Report #1

In spring 2021, HSO invited Canadians to complete the Inaugural National Survey on Long-Term Care to get a better sense of their views on what an optimal future state of LTC ought to look like in Canada. *What We Heard Report #1* provides highlights from the 16,093 responses that were received between March 31 and July 31, 2021. The insights were used to help HSO's 32-member National LTC Services Technical Committee develop the new National LTC Services Standard.

When asked about the most important issue to address within LTC, survey participants reported the following key issues: ensuring the provision of high-quality care; ensuring the safety of LTC home residents and staff, while respecting the rights of residents; ensuring a well-supported, strong, and capable LTC workforce; ensuring appropriate LTC funding exists to support the provision of high-quality care; ensuring greater transparency and accountability; and reconsidering the provision of for-profit LTC care.

79.5% of survey participants were aware that standards are currently being used in long-term care in Canada, and 67% of survey participants did not feel that LTC homes in Canada were providing safe, reliable, and high-quality care.

When asked what was most important when it comes to ensuring "resident- and family-centred care practices that value the importance of respect, dignity, trust, and quality of life" in LTC homes, survey participants emphasized: prioritizing the rights, needs, and satisfaction of residents; caring, compassionate, and competent interprofessional care teams; and an environment that upholds the qualities of home.

When asked what was most important when it comes to ensuring "safe, reliable, and high-quality care" in LTC homes, survey participants called for: the reimagining of long-term care as a true continuum of care; adequate funding; responsible national standards and governance; and enhanced organizational accountability and transparency.

When asked what was most important when it comes to maintaining a "healthy and competent workforce" in LTC homes, the key themes that emerged from survey participants included: job security; prioritizing the health and safety of the LTC workforce; an affirming, positive, and supportive work environment; and education and licensing standards.

When asked what was most important when it comes to the environment, operations, and maintenance of LTC homes to improve the quality of life of residents and families, survey participants answered: aiming to enhance resident quality of life; ensuring safety and security of residents and staff; and striving for the highest standards of cleanliness and maintenance.

Finally, 99.4% of survey participants felt LTC homes should be required to meet standards.

For a more comprehensive look at what we heard during Phase One Engagement activities, check out the full *What We Heard Report #1*.

What We Heard Report #2

Building on the feedback from the Inaugural National Survey on Long-Term Care (Phase One Engagement), HSO invited Canadians to provide more specific input to support the development of the National LTC Services Standard. Specifically, the Phase Two Engagement activities aimed to facilitate deeper engagement and welcome additional perspectives on what an optimal future state of LTC ought to look like in Canada. *What We Heard Report #2* provides highlights from the 1,984 individuals and groups that participated in the Consultation Workbooks and Phase 1 Town Halls between August 1 and December 1, 2021.

When asked what the future of long-term care should look and feel like, engagement participants felt that high-quality care is the outcome of providing safe, reliable, and compassionate care. However, they also noted that ensuring and achieving this requires a careful balancing act between people, values, and priorities. For residents, what's key is a home-like environment and individualization. For families, what's important is transparency and trust. And for the LTC workforce, what's key is having the time to provide care and feeling valued and supported.

Another important contributor to safe, reliable, compassionate, and high-quality care shared by participants is an LTC home's ability to exemplify the qualities of "home" and also provide a "positive, supportive, and caring work environment." In particular, the need to balance the duality of LTC homes as both a home (e.g., daily activities, relationships, and spaces) and a workplace (e.g., leadership, workplace culture, and hiring practices) was highlighted.

One of the most important contributors to safe, reliable, compassionate, and high-quality care that participants highlighted is the need to respect the rights and quality of life of residents. The need to respect the rights of individuals (e.g., fostering and maximizing independence, respecting a resident's right to live with risk, and clearly articulating the "boundaries" of individual rights) and the collective (e.g., free from harm, and health and safety regulations) were of particular importance for balancing the rights and safety of residents.

Finally, participants shared that some of the most important contributors to safe, reliable, compassionate, and high-quality care are ensuring the provision of resident-centred care and an unwavering commitment to consistency and quality of care. In particular, the need to strike a balance between calls for individualized approaches to care and calls for standardization in the provision of high-quality care was emphasized.

Engagement participants also provided ideas and insights for enabling immediate system change (e.g., evidence-based practices, staffing, funding, and accountability) and system transformation (e.g., addressing the stigma associated with LTC, building collaborative networks of care, and acting on the criteria included in HSO's National LTC Services Standard).

For a more comprehensive look at what we heard during Phase Two Engagement activities, check out the full *What We Heard Report #2*.

What We Heard During Phase Three Public Engagement Activities

Phase Three Engagement activities focused on building on the feedback from the over 18,000 Canadians, including over 350 LTC home residents, who participated in the Phase One (Inaugural National Survey on Long-Term Care) and Phase Two (Consultation Workbooks and Town Halls) Engagement activities. In particular, the Phase Three Engagement activities aimed to facilitate deeper engagement with LTC home residents and key stakeholders about their experiences with and perspectives on key areas in the provision of long-term care in Canada. To gain these additional insights and information, HSO solicited greater input through three activities:

1. Virtual Visits with LTC home residents from across Canada;
2. An additional series of five Town Halls; and
3. A Public Review of the draft standard.

The following sections discuss who we heard from in our Phase Three Engagement activities followed by the key themes that were shared by participants.

Who We Heard From: Phase Three Public Engagement Participants Overview

Through our Phase Three Engagement activities, we heard from an additional 779 individuals and groups from across the country. Their insights, experiences, needs, and hopes have not only reinforced what we have previously heard from Canadians, but also highlight the importance of standards for facilitating a paradigm shift within the provision of long-term care in Canada.

Virtual Visits with LTC Home Residents

We were honoured to have the opportunity to speak one-to-one with 63 residents, who shared their experiences and perspectives in response to questions that were developed to gain deeper insight into daily life within Canadian LTC homes.

- **59%** of residents self-identified as female.
- **81%** of residents were 65 years of age or older.
- **49%** of residents reported living in Nova Scotia.
- **4%** of residents self-identified as being First Nations, Métis, or Inuit.
- **13%** of residents self-identified as being from a visible minority.
- **70%** of residents self-identified as living with a disability.

Town Halls

We heard the perspectives of 134 people from across the country through our second series of virtual Town Halls.

- **14%** of Town Hall participants participated in French.
- **55%** of Town Hall participants reported living in Ontario.
- **22%** of Town Hall participants self-identified as being a Family Member, Friend, or an Essential Care Partner to an LTC Home Resident, while 36% self-identified as being an LTC Organization Representative and 22% self-identified as being an LTC Health Care Provider.

These sessions were designed to gain additional input in the following areas:

- Engaging essential care partners in resident-centred care for LTC home residents.
- Supporting the educational needs of the LTC workforce.
- Enabling palliative care and advance care planning in LTC homes.
- Supporting governance and accountability for LTC homes.
- Enabling good communication in LTC homes and the use of information to support it.

Public Review

Launched on January 27, 2022, the 60-day Public Review for the draft National LTC Services Standard received 3,637 comments from over 582 individuals and groups from 12 of Canada's provinces and territories, as well as comments from four other countries.

- **90%** of comments were submitted by individual participants.
- **38%** of comments were from participants who reported living in Ontario.
- **31%** of comments were received from participants who self-identified as being a Family Member, Friend, or an Essential Care Partner to an LTC Home Resident, while **22%** self-identified as being an LTC Health Care Provider and **16%** self-identified as being an LTC Organization Representative.

A more detailed breakdown and description of the demographic profile of participants in Phase Three Engagement activities is provided in Appendix A.

Transforming the Delivery of Long-Term Care in Canada

When taken together, residents' stories of the day-to-day experiences of living in an LTC home and other stakeholder perspectives (from both the Town Halls and Public Review) on whether HSO's draft standard appropriately addresses concerns regarding the provision of high-quality long-term care reinforced the key messaging from *What We Heard Report #2*—that providing excellent long-term care is a **careful balancing act** that requires long-term care homes to prioritize residents' rights. In fact, many of the key themes shared in both *What We Heard Report #1* and *What We Heard Report #2* were prominent in conversations with both residents and other key stakeholders, as well as feedback responses collected, during the Phase Three Engagement activities.

While discussing the key areas of provision of care, staffing considerations, education, communication, and governance and accountability, many Phase Three Engagement participants identified the need to revisit and reshape the current image—or perception—of long-term care in Canada. In particular, working to shift the historically institutional culture and re-situating relationship-centred/relational care as the foundation of safe, reliable, and high-quality long-term care. To facilitate this paradigm shift, participants wanted to see more emphasis placed on sharing positive stories about the day-to-day experiences of living and working in LTC homes. For example, one LTC home resident shared:

> *In terms of the home that I'm in, they really support me. They get me up in the morning, the food is good, and the activities are good. So far, it's been a pretty good experience and I do like the nurses. They're really nice. All that makes such a difference. They work hard, but they're nice. They know who I am because I keep teasing them all the time. They do pull a few tricks on me, but I know it's just a joke of course.*
>
> *– LTC Home Resident*

Various participants expressed that sharing more positive stories about living and working in LTC homes is important for balancing and shifting the existing perception of long-term care. Many participants felt that focusing on enhancing communication alongside education were two key areas for facilitating this paradigm shift–each of which will be unpacked further.

In addition, as we work to reshape the perception (and, ultimately, the delivery) of long-term care services in Canada, one of the outcomes highlighted by participants is the transformation of the provision of care within LTC homes into a highly sought after, competitive, and specialized career. In other words, the recognition that the provision of long-term care is a specialized role that requires a specialized set of skills.

A Day in the Life of LTC Residents

Stories keep us grounded as we reflect on what it's like, what's needed, and what it will take to transform the quality and experience of LTC care into the future. The following two fictionalized[8] resident profiles of "Márcia" and "Henry" illustrate and centre examples of the current day-to-day experiences of residents (with varying care needs) living in Canadian LTC homes.

	Márcia: Living with minimal care needs	Henry: Living with high physical care needs
Morning	In a shared room with a curtain dividing Márcia and her roommate, Márcia starts off her morning quietly by checking the news on her phone. Her son Tomás comes in this morning to visit, and to translate his mother's comments for us as we follow her for the day. Tomás tells us that his mom moved in around a year ago and was a previously very active volunteer in the local Latino community. As Márcia's first language is not English, Tomás shares the frustrations they both have faced since Márcia moved into the LTC home: "*I always make sure I'm here for any appointments my mom has with staff, especially medical ones. It's hard enough for me to understand the technical, medical terms. How can they expect my mother, who is still learning English, to understand what is going on? I'm probably here two to three times each week to support my mom. Because regular translation services are so hard to get a hold of, I need to actively make sure my mom's concerns are not going unheard or unaddressed*." At around 10am, our conversation with Márcia and Tomás is interrupted when a health care aide comes in to help Márcia put on her compression stockings. Afterwards, Márcia tells us (with her son translating) that she didn't want to miss her opportunity with the health care aide: "*I'm actually very grateful that the staff are accommodating, with me waking up and getting ready a bit later than everyone else. But apart from that, it feels like the home runs a very tight ship that's on a very tight schedule. If I miss the health care aides in the morning, then I might need to wait an hour or longer before they can come back in again*."	An early riser, Henry has been awake since 5am. He does some early morning reading, with the help of his iPad. At 6:45, he tells us about how the nurses are running late again, "*They're pretty short-staffed here, so it's not really up to me on when I'll get ready for the day. To be honest, we're all used to waiting up to an hour after calling for service before anyone comes to check in on us*." At 7:15am, a health care aide comes in and assists Henry with washing and dressing. After a brief 20 minutes of Henry providing instructions and directing the health care aide, they are off to assist another resident in getting ready for the day. Henry comments on how he had never met that health care aide before and would like to see the same staff each morning, "*I've probably seen around 60-70 aides now, just for my mornings. It's hard to keep conversation and get to know them, because I know they are so busy, and I probably won't be seeing them again*."

[8] It is important to note that, while fictionalized, the resident profiles presented herein are composite narratives that are rooted in the lived experiences reported during Virtual Visits conducted with LTC home residents from across Canada.

Lunch

We follow Márcia as she makes her way to the dining hall for lunch. Today's menu consists of egg salad sandwiches, bean salad, and an ice cream sandwich. Tomás notes that he and his mother used to love cooking together at home, so adjusting to a very limited menu in long-term care has not been the easiest — even after a year. Márcia tells us that while she doesn't think negatively of the food, she wishes there was a bit more variety in the cultures and types of food options available. Márcia also tells us of the difficulties with accessing services around food: "*I've tried many times to access a dietician, but their availability makes it pretty hard to get a hold of them. I think it's likely because so many of them work across multiple homes at once. I think in the time I've lived here I've only seen her with other residents a handful of times*."

Around noon, a health care aide brings a lunch tray into the room for Henry. The tray consists of sliced peaches, boiled peas, potato wedges, and a slice of meatloaf. We ask Henry what he thinks of the day-to-day menu. "*You know, they cook the food first, then they keep them in steamers, then they put them in a heater to keep everything warm. So, the food is cooked about 3-4 times and very overcooked before they get it to us. But then they manage to put them on cold plates so that you have overcooked food that is cold*." He points to the sliced peaches, "*It's pretty rare too to see fresh fruit. It's a nice treat to see once in a while*."

Afternoon

Shortly after having lunch, Tomás takes us along the process of arranging for his mom to visit the local mall, from booking transit services to getting assistance to rallying the health care aides to assist with getting ready. For Márcia, the ability to come and go as she wants is very important to her. We ask her if other residents have a similar experience in regard to outings, daytrips, and accessing the community: "*I've been very fortunate to be able to get around when I want, especially for shopping or seeing my old friends. My son has been so helpful in arranging this each time I go out. But there are plenty of residents here who I've never seen leave their rooms. It's already been hard enough not having visitors during the pandemic, so I do worry about the other residents from time to time, especially those who may not have family visiting or taking them out into the community*."

Márcia also adds why she feels so strongly about going out: "*Being able to leave to see my family and friends has really helped me adjust to living here. Some of the activities here have been great for other residents, but it's hard for me to attend because they're always in English and the staff always speak so fast. So, getting out is another way for me to feel like I'm spending my afternoons in a meaningful way*."

After lunch, a recreation coordinator drops in to tell residents that there will be a music listening activity happening in the main dining room. We offer to attend with Henry, but he declines: "*To be honest I haven't really been able to go to most activities or social events here. It's frustrating, because as a person who is hard of hearing, they always seem to pick activities that don't accommodate me very well. Without the option to join any activities, it really feels like some days there isn't much going on here*."

We spend the rest of the afternoon with Henry, as he browses his iPad and shows us photos of his family. Later on, we join Henry as he goes for a small excursion around the home using his power wheelchair. However, getting around the home isn't always easy for Henry: "*Sometimes the accessories the home gives us aren't the best. If a health care aide uses the wrong seat cushion or I'm not seated properly on the wheelchair, it can get very uncomfortable and even painful sometimes. Getting help to be readjusted can be hard, especially since staff are already so busy. The other thing is that the size of my room and bathroom make it so hard to move about in my power chair, even with the aides helping me. I feel like as my mobility gets worse, I just get more and more anxious about being able to navigate safely around home in my chair*."

Evening	In the evening, Márcia is joined by her neighbour, Mei, in the community room for a round of cribbage. Despite having a language barrier, the two have formed a close friendship over the past year as they both moved in around the same time. The room is fairly small but has a television and a few photos hanging on the wall. Mei tells us that while it isn't exactly like a living room, having a space to visit with Márcia does help make it feel more like a home: "*It's probably the only space in here that has helped us all settle in. Having a room like this for games and tea makes all the difference. Before the pandemic, staff would join us for a few rounds of cards here and have some tea with us too. But now it feels like they are strangers, always coming in and out. The health care aides are so busy and short-staffed that they don't have time to talk with us anymore. Everyone is always avoiding chit-chat and hurrying to the next resident, and that rushed atmosphere is not very good to have in your own home every day.*"	Henry's daughter, Isabella, comes in for a visit and has brought dinner for him. We notice that she does seem a bit frustrated with the staff, so we ask her how her experience as a visitor has been so far: "*Each time I visit, I ask the staff if we can use the visiting room. But they never say yes. It's because then they'd need to set up the room and get my dad all ready to be moved. It's not ideal because I do want my dad to feel comfortable with hosting visitors and having company in a space that feels like a home. But instead, we have to have visits in his room, which feels very much like a hospital. And we don't have much privacy with staff coming in and out of the rooms either. Whenever I advocate for my dad's care, it's like they don't take me seriously.*" We offer to help raise Isabella's concerns to staff, but she declines, "*It's alright. I know the staff are already short-staffed and busy enough, and I'm just happy to be able to visit again since the pandemic began.*"
Night	As Márcia winds down her day, we ask if she has any final suggestions: "*Today was a pretty good day, especially having gone into town and gotten a few errands done. But I do think it would be great to see more recognition of the different cultural backgrounds of residents. My friend Mei and I both come from different cultures, with our own separate traditions and celebrations. And it can be really comforting being able to hold on to your culture and having it celebrated in your own home. We're all residents here, yes, but we still each have unique backgrounds, and I would love to see this recognized or celebrated more. Maybe something as simple as letting us add our celebrations and holidays to the recreation calendar?*"	As Henry gets ready for the evening, he tells us about his overnight experiences at the care home: "*It's not unusual here for me and other residents to share a floor with residents who have dementia. Most folks here agree that the decision to have everyone living together on the same floor or unit is a good thing. However, I just don't think the home understands the day-to-day realities of such sweeping decisions, and they certainly aren't prepared to accommodate the needs of residents without dementia at night. It seems they just paint us residents all with the same brush as an excuse to keep procedures simple and avoid listening to our concerns. There aren't any locks on the doors here, so sometimes I'll wake up in the middle of the night to someone who has wandered into my room. I've had people come in here overnight and take my picture frames and books with them too. It's really quite unsettling and I wish something could be done for everyone's sake.*"

Key Considerations for Transforming the Delivery of Long-Term Care in Canada

Key areas for ensuring the delivery of safe, reliable, and high-quality long-term care across Canada that were emphasized by Phase Three engagement participants included:

- Improving care experiences
- Enhancing communication
- Supporting the LTC workforce
- Enabling good governance

Improving Care Experiences

Phase Three Engagement participants expressed feedback that the draft standard placed too much emphasis on leadership and workforce, rather than placing emphasis on the rights and quality of life of residents and family members.

To this end, participants offered a range of suggestions that could transform care experiences for residents, family members, and also the workforce. In particular, participants would like to see the provision of long-term care that:

- Embraces a true continuum of care which includes palliative care;
- Emphasizes autonomy and choice;
- Embraces an interdisciplinary and collaborative team approach to care;
- Engages essential care partners more in care teams; and
- Exemplifies the qualities of home.

> *If they wish to read up about me before they come into the room, that information is all available. So, they have a plan of care, but that's what it is, a plan. It sits on the table and doesn't really help provide the care that I need. And then I'm concerned, because [my co-resident/neighbour] and I have a voice, we can tell [staff] what we need done. Whereas there are a lot of people in here who haven't got a voice for themselves.*
>
> *– LTC Home Resident*

Embracing a true continuum of care which includes palliative care

Building from participant responses shared in *What We Heard Report #1* that called for the reimagining of long-term care as a true continuum of care (see Box 1 for recap), Phase Three Engagement participants also highlighted the need to integrate palliative care—or, rather, a palliative approach to care—into the provision of long-term care.

When asked about the provision of palliative care and advance care planning in LTC homes, participants noted that some individuals and families may be resistant to discussing a palliative approach to care, but stressed the importance of:

- Enhancing understandings of what palliative care and advance care planning are (e.g., separate concepts, purposes, processes).
- Focusing on goals of care (vs. advance care planning) and enhancing quality of life (vs. focusing on the end-of-life).
- Having a palliative care champion to facilitate the distribution of information and knowledge regarding palliative approaches to care.
- Ongoing consent and assessments by appropriate care professionals until end-of-life.
- Clearly articulating the legal aspects of palliative care.

When it came to discussions of "how" to integrate palliative care into the provision of long-term care, participants offered some suggestions that could help to enhance access to palliative care in LTC homes:

- Enhance and leverage internal resources (e.g., staff training, reallocating funding).
- Implement a consultant model to bring external expertise into the LTC home.
- Establish processes for transferring residents to hospice or palliative care settings.

Another important component of the discussion was the question of whether or not MAID (Medical Assistance in Dying) should be associated with palliative care and advance care planning–especially in light of ongoing debates and the religious affiliations/origins of many LTC homes.

Box 1. Excerpt from *What We Heard Report #1* (p. 17)

To achieve "safe, reliable, and high-quality care" in LTC homes, survey participants called for the re-imagining of long-term care as a true continuum of care that:

- Provides equitable care for all (e.g., choice, access, cost) across jurisdictions (e.g., geographic location, ownership). As one LTC Home Staff Health Care Provider from Ontario stated, "[We need] a financially sustainable system with the structure geared towards equitable access for the majority of patients."
- Prioritizes continuity in care (e.g., same staff providing care to build rapport).
- Respects and values the workforce (e.g., staffing, workplace conditions).
- Asserts zero tolerance for neglect (e.g., timely personal care) and abuse of residents (e.g., physical, sexual). For example, one LTC Home Resident from Ontario shared that LTC homes should be a place "Where you can receive care in a timely fashion, and you don't have to worry about it not coming."
- Is integrated into the broader health care system (e.g., medical records, access to medical care).
- Includes options for ageing in place (e.g., home care). For example, one survey participant from Ontario shared an idea, "Pay family caregivers to provide assistance to prevent institutionalization. Institute a 'Money Follows the Person' initiative so people can purchase their own care in the community."

Emphasizing autonomy and choice

> *Having a say is important to me, but sometimes the staff aren't the best at listening. Last week one of the care aides came in to help me wash up. I didn't want my nails clipped but she went ahead anyways and did it. Occasionally you get rude staff like that who rush. It makes everyone feel like an inconvenience.*
>
> *– LTC Home Resident*

When sharing their care experiences, some participants who were living in an LTC home felt supported in decision-making and directing their care, and, overall, felt that their medical and personal care needs were being met. On the other hand, there were also many participants who echoed previous calls to involve residents and their family members more in care planning, as well as to recognize the varying abilities and unique needs of residents in ways that emphasize autonomy and choice. As one LTC home resident shared, "Management tends to act as if everyone here is living with dementia. I'm not really ever informed of any activities or even provided updates on what is going on."

Embracing an interdisciplinary and collaborative team approach to care

Echoing sentiments highlighted in *What We Heard Report #1* and *What We Heard Report #2*, Phase Three Engagement participants also highlighted the importance of building inclusive and interdisciplinary care teams with open communication (discussed in the next section). When asked about "who" should be included in care teams, participants offered the following suggestions for additional team members:

- Physicians
- Social Workers
- Speech-Language Pathologists
- Audiologists
- Professional Interpreters (when needed)
- Communication Specialists
- Dental Hygienists
- Essential Care Partners
- Physiotherapists
- Occupational Therapists
- Registered Dietitians

While participants called for interdisciplinary and collaborative care teams, they also recognized that there may be situations that require access to existing or established external resources and support to supplement staff responsibilities.

Engaging essential care partners in care teams

> *In terms of families, families are partners in residents' care. We are not support - that puts us in a lower level within the LTC home. The LTC home is a unique institution that provides a unique care and service to residents. Residents are not patients but rather residents with very high needs and such need a number of people collaborating in providing care and meeting the needs of residents. Families and friends are a part of their lives and if we have learnt anything from the pandemic, it is that families are partners. So, I would recommend emphasizing that partnership and including families as a partner.*
>
> *– Town Hall Participant*

With respect to engaging essential care partners in resident-centred care for LTC home residents, an overwhelming majority of Phase Three Engagement participants did not resonate with the term *Designated Support Person*, which was used in the draft standard. Subsequently, they felt that the draft standard did not appropriately recognize the importance of this group in the provision of high-quality care. Instead, participants suggested the adoption of the term *Essential Care Partner,* as used by Healthcare Excellence Canada, since it better reflects the range of caring relationships that are integral to enhancing a resident's day-to-day care experiences.

Beyond shifting terminology, participants also wanted to call attention to the need to explicitly name and include essential care partners as important members of care teams. In line with this, participants highlighted the importance of recognizing the dynamic nature of relationships and respecting resident wishes when it comes to the designation of essential care partners (e.g., expanding definitions beyond biological kin).

> *It is friendship that makes the difference… My family don't live close by and they're not the most supportive. I have a friend who is almost like a son to me, and I would definitely say he is 'essential'. But it's been so difficult to get the home to let him visit or to take him seriously when it comes to planning my care.*
>
> *– LTC Home Resident*

Creating a home-like environment

> *They're still running on hospital models that were created back when nursing homes first appeared. We have hallways lined with carts of dirty linens with lifting machines. And standing lifts with blood pressure machines. It's a hospital ward. The rooms are designed as hospital rooms. I had a better room actually in rehab at the hospital than my room is here.*
>
> *– LTC Home Resident*

Recognizing current policies, practices, and procedures within LTC homes focus on risk management, Phase Three Engagement participants echoed earlier calls for LTC homes to exemplify the qualities of home. In particular, participants shared a number of suggestions that could help their rooms feel more "home-like," such as: being able to hang personal effects (e.g., photos, posters), having shelves to showcase meaningful items from home (e.g., books, hobby supplies), having pets or companion animals, and having access to their own window (which is often limited beyond single-occupancy rooms). To further enhance the feeling of home, participants requested more recreational opportunities, as well as enhanced choice with respect to their diet and mealtimes.

Enhancing Communication

> *Clarity is very difficult [at the home]. I have the best hearing aids out there, but they're not doing that much. For instance, when we go to the dining room for our meals, the staff will start talking to the person to the right of me, and she will often translate. But they don't understand how to talk to me. And the background loud noise is painful. You know, if they shout at me, that's painful. So, they don't mean to shout.... I don't think they have any training that I know of in that respect.*
>
> *– LTC Home Resident*

When discussing how to best enable good communication (including the use of information technology) within LTC homes, many participants stressed the importance of communication as foundational in the provision of high-quality care–which many participants also identified as important for facilitating a paradigm shift in the provision of long-term care in Canada.

As participants shared their experiences, needs, and suggested ways forward with respect to communication, two overarching areas of discussion emerged: *interpersonal communication* and *organizational communication*.

Interpersonal Communication

With respect to enabling good interpersonal communication, participants stressed the importance of starting from the understanding that *everyone can communicate*. By beginning with this underlying premise, we can better position ourselves to seek a proper (and ongoing) assessment of residents' communication abilities, needs, and preferences and use available resources to support the communication needs of residents, family members, and the workforce (or acquire external support, when needed). For example, some participants called for an explicit focus on enhancing in-home accessibility supports and resources in order to facilitate clear and effective communication. Some key considerations shared by Phase Three Engagement participants included:

- Offering interpretation and translation services (e.g., language, medical jargon)–and not relying on family members to act as translators.
- Working with each resident to meet their communication needs (e.g., ongoing assessments) using available strategies (e.g., Gentle Persuasive Approach), tools (e.g., sign language, captioning, speech detection technology), and devices (e.g., hearing aids, iPads).
- Creating physical environments that are conducive to effective communication (e.g., minimizing loud noises, hallway traffic).
- Connecting with external specialized services (e.g., accessibility consultants, speech-language pathologists) when needed—which participants also recognized may be a challenge depending on geographic location (in which case, additional funding should be reserved to facilitate access).

> *I'm looking in the elevator and there's a couple notices there that I can't read because I'm confined to a wheelchair and the angle is not right. So, I went down and talked to the guy in the office who is in charge of risk and asked about this. He got back to me yesterday and said that they're going to bring in an outside group, but with direct experience in accessibility and posting of signs so that information will be at a level where everybody can see and read it.*
>
> *– LTC Home Resident*

Organizational Communication

> *I feel like I'm misinformed and not listened to. No one really knows what's going on.*
>
> *– LTC Home Resident*

Phase Three Engagement participants also shared and offered suggestions for enabling good organizational communication. In particular, participants called for clear and concrete plans/processes (with accompanying accountability measures) that create the conditions for open and collaborative communication between all stakeholders (including the broader public)—without fear of reprisal. Some of the suggestions provided by participants included:

- Clear protocols and protections for stakeholders (e.g., residents, family, staff) to submit concerns and/or complaints (e.g., whistleblower protection).
- An engaged leadership team who takes the time to be present and listen to frontline staff.
- Public reporting on staffing levels, percentage of hours worked by full-time employees, and hours worked by agency staff.

Ultimately, participants felt that communication is foundational to not only the provision of high-quality care, but also to building trust between stakeholders and enabling informed decision-making.

> *I'm still not aware of what's going on and I'm really annoyed. I have spoken to the administrator more than once and now they are finally sending me copies of what they send home [to my family], but I still don't know about the directives.*
>
> *– LTC Home Resident*

COVID-19 Spotlight

When reflecting on the impact of COVID-19 on their experiences of living in LTC homes, some residents recounted how the public health measures and restrictions exacerbated existing communication challenges. As one participant shared:

> *We're still cohorted here and I don't know when they're going to let us mingle. I haven't been able to find the [LTC home] director or the administrator to find out what's going on. I feel that as a resident leader, I should have been told exactly what they plan to do.*
>
> *– LTC Home Resident*

Another participant shared:

> *If I'm wearing a mask, she [another resident] cannot understand me. The mask is an impediment. There are now masks that have a clear window, so she can see your lips. They show them clearly, so it enables her to understand others much better.*
>
> *– LTC Home Resident*

Supporting the LTC Workforce

> *Most of the workforce is female, a significant proportion has English as a second language, most are paid below the living wage, and struggle to manage their paid care work and their unpaid care work at home. In my experience, and the literature can back this up, many of the problems between staff (unregulated vs regulated vs management) are based on gender equity issues.*
>
> *– Public Review Participant*

When discussing how to best support the LTC workforce, many Phase Three Engagement participants called attention to the inequities that permeate the day-to-day experiences of the individuals who comprise the LTC workforce. In particular, participants would like to see direct action to address job security, staffing concerns, and education—all of which can be linked to gender inequity as highlighted in the above quote.

Job Security

> *The growing precarity and casualization of work in addition to the poor work conditions and compensation in the LTC sector has resulted in workers leaving the sector and deterring new entrants. Job precarity and poor compensation have often led to many LTC workers needing to take on multiple jobs at different work sites to piece together a living. Offering full-time work at one LTC home was one of the key interventions by public health authorities to curb transmission rates in the first year of the pandemic.*
>
> *– Public Review Participant*

Job security refers to full-time, permanent employment that is equitably compensated (e.g., wages, benefits, pension, paid time off) for expertise and skills. In addition to equitable wages and benefits, participants would like to see improved access to well-being supports (e.g., counselling, Employee and Family Assistance Programs, work/life balance initiatives) and opportunities for career advancement.

Many participants felt that by guaranteeing job security, LTC homes would be better positioned to retain staff and ensure continuity in care for residents by enhancing opportunities for full-time employment in one establishment.

Staffing Concerns

> *Over three and a half years, I found that gradually there have been more and more things put on I think everybody's shoulders who work here. And I think it's just getting to a tipping point. I have been concerned, [especially about] nurses too. The nurse management here said, 'I am really concerned that if we don't get any extra staff, something is going to happen somewhere.' Because when people are thinking about the next jobs they have to do, trying to get their morning sorted out… I don't know how they do it.*
>
> *– LTC Home Resident*

In order to provide high-quality long-term care, participants across engagement activities called for immediate action to address the staffing crisis within LTC homes in Canada. Some specific examples provided by participants included:

- Ensuring appropriate staffing levels that reflect the resident demographics to best ensure the delivery of high-quality resident-centered care.
- Ensuring consistency in staff by offering more full-time permanent employment that is not only equitably compensated for expertise and skills, but is in alignment with rates of compensation offered across the country. The following quote from an LTC home resident exemplifies resident perspectives on staffing consistency: "*Weekends seem to be fairly difficult for staffing. I don't usually recognize any of them that are coming in*."
- Embracing a collaborative and interdisciplinary approach to care, including examples of who (e.g., level of family and resident involvement) should be included in care teams as guidance currently varies by jurisdiction.
- Focusing on improving workplace culture by modeling the principles of psychosocial care for the workforce, as well as residents–as shared by one resident, "*There's a few certain staff members who I really look forward to seeing. They really brighten my day because they are so good at lifting everyone up, and they are what I think of when someone mentions patient-centered care*."
- Increasing the amount of time that staff are able to spend interacting with residents (e.g., at least 4.1 hours per resident per day). As one LTC home resident shared,

  "*We only have 3.6 hours allotted for each person for their needs. And because 20 years ago people came to nursing homes as they're just getting old and feeble, and some needed more care. But I think now people are coming in with a lot more needs because they are able to stay at home for longer. Part of the frustration that you would have is the added workload nowadays for the staff and having them kind of juggle all the needs of the residents that they have to look after for that.*"

> *Well, I think we all wish as residents here that the staff had a tiny bit more time to speak to us individually, which I know they don't have as the care has to come first. You know, we care about them as people and I'm sure they feel the same about us. But there's no time to have just a word or two. It can really make a difference.*
>
> *– LTC Home Resident*

Education and Learning Opportunities

> *[We need] more training for these people. Not just staff [roles] but the broader perspective. Those interactions, more training and around what is respect and how to have a respectful interaction with someone.*
>
> *– LTC Home Resident*

With respect to how to best support the educational needs of the LTC workforce, many participants viewed education as "the key" to the provision of high-quality care–which many participants also identified as important for facilitating a paradigm shift in LTC homes. Some of the most prominent calls focused on:

- Implementing minimum educational standards for all levels of care and support—including leadership and family members. This could be further complemented by standards for percentages of staff with training in specific and/or specialized areas (e.g., wound care, palliative care).
- Providing skill-based knowledge and education that is rooted in evidence-based best practices (while recognizing jurisdictional variation in practice expectations).
- Providing ongoing (e.g., at regularly scheduled, consistent intervals) training and assessment opportunities beyond the onboarding process for new staff. This should include offering a range—or continuum—of opportunities for continuing education, hands-on training, and support of increasing credentials.
- Recognizing the importance of strong mentoring relationships and skills for supporting ongoing training.
- Addressing the existing disconnect between clinical, task-based training and recent shifts toward the provision of relational care.
- Using appropriate platforms to deliver education and training (e.g., Surge Learning).

Including education and training in specific areas, as well as continuously assessing core competencies Some suggested areas of focus included:

- Geriatric care (including specific focus on working with residents who are deaf, blind, etc.).
- Palliative approaches to care and techniques.
- Dental care and oral health.
- Exploring biases (e.g., ageism, racism, homophobia, transphobia).
- Non-verbal communication and behaviours.
- Mental health (including resident care and self-care).
- Relational/relationship-centred/person-centred care.
- New technologies and up-to-date best practices.
- Interpreting and adhering to public health and ministry guidelines.

While participants felt that placing more emphasis on the educational needs of the various stakeholders in the delivery of high-quality care is necessary, they also acknowledged that high rates of staff turnover often create difficulty in offering ongoing training opportunities. However, it is reasonable to assume that providing clear guidance inspired by the suggestions for addressing identified gaps in educational standards included herein (as well as in *What We Heard Report #1* and *What We Heard Report #2*) will positively contribute to the transformation of the provision of long-term care in Canada.

Enabling Good Governance and Leadership

> *The administrators or CEOs feel that they have a job to run the home. And I would challenge them to say, 'Instead of you thinking your job is to run the home, should it not be the residents that are at the forefront? Should it not be that everything you do should be prefaced by the question: what would be the best for the residents? As opposed to you sitting in your office making all these decisions and controlling what goes on.' I'm not saying the residents should run the home, but the residents' needs and desires and wants and way of life should be what runs the home.*
>
> *– LTC Home Resident*

When asked about the feasibility of requirements in the draft standard for governance and leadership, Phase Three Engagement participants sought additional clarity on where the accountabilities and responsibilities lie with respect to governance (e.g., resource allocation, evaluation/assessment): Do they lie at the home-level? Provincial-level? Federal-level? As one Public Review participant shared, "The HSO standard is directed to 'governing bodies', which it defines as including a board of directors, a council, a Chief and Council, or another decision-making body. It is unclear how this list would apply to the owners of a fully private or for-profit entity, or even a government-run home. Who can residents and their families turn to if the conditions of care are unsatisfactory?"

As participants discussed who is responsible for governance, they identified the role of the federal government as providing clear support (e.g., allocating funding through the Canada Health Act) and specific forms of guidance that can support leaders at the home-level. In addition to providing guidance, participants also wanted to see opportunities for LTC homes to contextualize and operationalize standards to meet the unique needs of their community, as well as to focus on reward/recognition for great work (vs. punitive measures). With respect to governance and leadership at the home-level, participants felt that it is the responsibility of an LTC home's leadership to:

- Establish clear mission and vision statements.
- Establish clear expectations and criteria for hiring and evaluating leadership (e.g., including resident and family representation on the Board).
- Establish mechanisms to support homes/organizations in keeping up with regulations (e.g., concrete examples of how to meet criteria) and reporting–regardless of funding model.
- Establish clear mechanisms for connecting to and communicating with residents' and family councils.
- Lead continuous quality improvement efforts (which include input from residents and family members).
- Ensure education opportunities are available for all stakeholders in the provision of care, including training for Board members on how to govern.

> *I attended [the residents' council] a couple of times and I couldn't hear well what the questions were that the leader would tell me. They were mundane questions generally, yeah. 'Why do we have to have green beans so often?', and things like that. So, I've gone back twice, but the coordinator tries hard, you know, she tries to slow down… I've not gone more than 2-3 times and I don't feel that there is much that goes [in terms of] action on things you know they'll look into. There are complaints about the odd little thing, but I just don't feel that it's worth trying to go to the meetings and fight the noise coming at me that I'm not hearing it right.*
>
> *– LTC Home Resident*

Words Matter: The Importance of Language

Throughout each of the Phase Three Engagement activities, participants repeatedly emphasized the importance of language in not only shaping the current perception of long-term care but also in ensuring that the standard is clear and actionable.

As several Public Review participants shared, "the devil is in the details."
When thinking about the impact that language used may have on expectations for implementation of the standard, several participants questioned the intended scope of the standard since much of the language felt aspirational rather than actionable or implementable.

In order to shift from aspiration to implementation, participants would like to see clearly defined, actionable, and reportable terms alongside guidance and clarifying examples on how to meet—or exceed—the standard.

Some of the terms that participants suggested required further context or definition included:

- Advance care planning
- Communication support
- Competent; competency
- Essential Care Partner
- High-quality
- Palliative care; palliative approach to care
- Team
- Timely
- Trauma-informed approach
- Workforce

> *If we want quality of life, family must be mentioned. If we are talking about designated support person, families in most cases are designated support persons. When we speak about governance, family councils need to be mentioned. And if we are talking about safety, and there was a lot of discussion around safety in the standard, families are crucial in oversight of safety and picking up on sudden changes in residents in order to report to the LTC home.*
>
> *– Town Hall Participant*

A Transformed Day in the Life

The following resident profile – Patrick -- is a fictionalized[9] narrative representation based on the suggestions and recommendations shared by residents through Virtual Visits. It illustrates how improving care experiences, stronger and trusting communication, support for the LTC workforce, and good governance and leadership practices can transform the day-to-day experiences of LTC home residents across Canada.

	Patrick: Living with high care needs
Morning	Patrick got up at 9am today, sleeping in a bit later than usual. After some light morning reading and checking the news, he calls for assistance with getting ready for the day. A few moments later Emily, the health care aide who has supported Patrick consistently for over 6 months now, knocks on the door before entering to assist. Not only is Emily familiar with Patrick's care preferences, she also has kept written reminders from his daughter, Angela, on file to ensure nothing is missed. The two share a friendly chat as Emily goes about her duties. Patrick shares his thoughts on his morning routine with us: "*Being able to have a say in when I get ready and what they assist me with really makes a good start to the day for me. Having the same faces greet you each time you wake up makes such a difference. People don't realize the impact of having continuity in staff, to be able to have nurses and health care aides who know you by name and thoroughly know your personal care needs. I don't have to stress anymore about repeating instructions to a different person each morning.*"
Lunch	A health care aide comes into Patrick's room around noon and asks if he would like to have lunch in his room or in the dining room today. Patrick tells the aide that he has plans to meet his friend, Larry, for lunch in the dining room and the health care aide assists Patrick into his wheelchair and brings him to meet Larry. Lunch today consists of tomato soup, a tuna-melt sandwich, fresh garden salad, and sliced watermelon. Patrick isn't the fondest of watermelon, so he asks if the staff have anything else. They offer him some fresh strawberries instead, which Patrick happily accepts as he tells us, "A good menu item can really make a good day. If I don't prefer the lunch they have for a day, having different choices or alternatives really makes a big difference too." We ask Patrick if there is anything that he thinks would further enrich his mealtime experiences, he thinks for a few moments before responding, "*I would love the idea of having a small kitchen available on the floor for us residents to use if we want. We already have a shared pantry that is regularly stocked by the staff. Why not go a little further and let us do a little bit of cooking sometimes?*"
Afternoon	In the afternoon, Patrick participates in a drawing class with his friend Larry. The recreation coordinator has worked diligently to make sure Patrick is sitting at the front so that he can hear more easily, as well as turned off the television next door and minimized any other background sounds that might interfere with Patrick's hearing aids. After the class, Patrick proudly shows us the lighthouse that he has sketched. "*I've been really enjoying coming to this drawing group. It's always so rewarding being able to not only have a finished product at the end of the day, but also to know that I've learned something different or picked up a new skill. That sense of accomplishment really brightens my day. Also, as someone who is a little younger than the other residents and not living with dementia, I do appreciate that there are a little more mentally stimulating activities offered too. The program staff really do go out of their way to make sure there are things available for everyone to do, of all ages and activity levels.*"

[9] It is important to note that, while fictionalized, the resident profiles presented herein are composite narratives that are rooted in the lived experiences reported during Virtual Visits conducted with LTC home residents from across Canada.

Evening

Patrick is attending the Residents' Council meeting tonight. He raises his concern about the home's accessibility challenges for wheelchair users, which is echoed by a couple other residents–prompting an engaging discussion. The staff do an excellent job in making sure the discussion happens in plain, jargon-free language to ensure everyone understands what is being discussed, and that everyone who would like to speak has an opportunity to. One of the home's board members and the administrator who are in attendance tonight for the discussion offer to relay feedback to the rest of the home's leadership team.

As the meeting comes to an end, staff remind attendees that they are always welcome to raise concerns outside of the Residents' Council meetings as well. Patrick shares a bit about why he keeps attending: "*To be honest the Residents' Council meetings usually have lower turnout, with maybe only 8-9 of us from the entire building going. Most of my neighbours don't have an interest, or don't feel that going will make a difference in the way things are run here. There were a lot more people here tonight, and I think that's because the new administration has been trying extra hard lately to make the meetings meaningful, and to rebuild a lot of that trust with residents. People will only speak up if they feel they will be heard. I also keep attending because I feel it's important to speak up for the many residents here who are unable to. There are many residents who may not be able to leave their rooms or who struggle with speaking*."

Night

To wind down the day, Patrick has a care aide assist in his nightly routine to get ready for bed. He shares with us a glimpse into how nights usually are in this care home, noting how most nights, disturbances to his sleep are fairly rare and he gets very good rest. He attributes this to the excellent staffing, noting how multiple staff work through the nights to ensure the safety and well-being of residents with dementia, or anyone else who may accidentally wander out of their rooms during the late hours. We ask if this has always been his experience, having previously moved from another LTC home: "*In the last home, directors and managers would treat everyone as if they weren't competent. Their policies, procedures, and programs were really focused on whatever worked for the most people. They didn't take into account that there is such a diverse range of abilities, preferences, and care needs among us folks who live in long-term care homes. Management at this home has been the exact opposite. They've really stepped up to make sure residents with dementia are taken care of, and that they prioritize the well-being of us few residents without dementia just as equally. I think this type of individual, personalized approach, whether it's in the personal care I get, or the new policies announced, has really made a difference in helping me feel at ease here and to call this place home*."

What's New Following HSO's Public Review of the Draft National LTC Services Standard?

While all of the feedback collected during the Public Engagement activities has guided the development of the new National LTC Services Standard, the following discussion highlights the significant changes that occurred to the standard as a result of the feedback received during the Public Review and insights that were captured during the Phase Three Engagement activities.

Each of the 3,637 comments that were received from participants during HSO's Public Review was analyzed and subsequently actioned appropriately. In alignment with the key considerations for transforming the delivery of long-term care in Canada outlined above, the resulting changes to the standard included:

Improving Care Experiences

- Further emphasizing the importance of trauma-informed, resident-centred care in improving the day-to-day care experiences of LTC home residents.
- Ensuring comprehensive assessments of residents' goals, needs, and preferences.
- Ensuring safety incidents are addressed.

Enhancing Communication

- Ensuring there are open channels to receive feedback from residents, essential care partners, and the workforce through a variety of mechanisms.
- Ensuring complaints from residents and essential care partners are addressed.

Supporting the LTC Workforce

- Ensuring an emphasis on a team-based approach to care that values the role of all members of the team.
- Ensuring concerns from the workforce are addressed.

Enabling Good Governance

- Ensuring the governing body and LTC home leaders have the required competencies and access to appropriate training.
- Ensuring environmental stewardship is embedded within the LTC home.

We also worked to add more clarity with respect to the language and content of the standard, including:

- Revising the terminology of designated support person to essential care partner.
- Adding new definitions based on gaps identified in terminology (e.g., communication, palliative care, quality of life, evidence-informed approach).
- Further building out definitions of some existing terms (e.g., decision-making, essential care partner).
- Refining criteria to ensure the accountability, action, and intent are clearly articulated.
- Building out guidelines with more details on how each criterion can be met.
- Adding cross-referencing to the complementary CSA standard to provide clarity on how the two standards fit together.

Areas of Feedback That Remain Out of Scope

Many of the key issues that were identified as important for facilitating a paradigm shift in the provision of long-term care in Canada, in both *What We Heard Report #1* and *What We Heard Report #2,* remained top of mind for Phase Three Engagement participants. In particular:

- Funding;
- Building infrastructure;
- Ownership; and
- Enforcement and transparent performance accountability.

While these important issues are outside of the scope of HSO's National LTC Services Standard, we do want to acknowledge public calls for change and highlight how important they are to enabling the provision of safe, reliable, and high-quality long-term care.

We encourage jurisdictional awareness and attention to these key issues and have included examples of participant sentiments here.

Funding

> *I think [the government] has to find a way to attract more [staff] into [long-term care] and somehow get the money together. They seem to be able to distill money everywhere else. Why not to us?*
>
> *– LTC Home Resident*

Participants raised the need for appropriate funding and advocated for the federal government to demonstrate the prioritization of delivering high-quality care through increased funding (e.g., ensuring access for older adults with limited financial resources). Further, some participants would like to see increased funding to support LTC homes in meeting and/or exceeding standards (e.g., education, on-the-job training, resources, infrastructure). While participants felt that funding was an essential and necessary component for meeting standards, they also called for accountability measures to ensure funds are used appropriately.

> *The governing body cannot meet this criterion if the provincial/territorial authority responsible for their respective LTC system does not allocate sufficient resources. A national standard for an LTC Home will not be effective without corresponding sufficient federal/provincial/territorial funding allocations that are systemic and sustainable to meet the forecasted level of demand for services. Many of the criteria relating to other identified objectives in the standard (e.g., resident quality of care and quality of life, appropriate technology, equipment, and supplies) will not be met without the assurance of these funding allocations.*
>
> *– Public Review Participant*

Building Infrastructure

When it comes to considerations of the environment, operations, and maintenance of LTC homes, many participants highlighted that specific attention must be paid to infrastructure and maintenance in ways that:

- Offer a mix of private and public spaces for visiting with family and friends (both indoors and outdoors).
- Focus on accessible (e.g., elevators, automatic door openers, wide hallways), comfortable (e.g., private rooms, own furnishings), and aesthetically pleasing (e.g., décor, paint) spaces.
- Ensure safety and security for residents and staff (e.g., routinely updating emergency preparedness plans, physical equipment in proper working order).
- Strive for the highest standards of cleanliness and maintenance (e.g., dedicated staff positions for cleaning, groundskeeping, and maintenance).
- Ensure highest levels of air, light, and sound quality (e.g., updating HVAC systems, minimizing noise of day-to-day operations).
- Embrace best practices in design (e.g., low-density buildings) and technology (e.g., wi-fi-enabled) from across the world.

These areas are within the scope of CSA Group's complementary National Standard for *Long-term care home operations, design, and infection prevention and control*.

Ownership

> *For-profit homes in this regard are seriously problematic - why spend dollars on fulsome training when patients can be 'managed and warehouse' with fewer fiscal inputs leading to greater profits. I have seen nothing to convince me that for-profit homes are a good idea.*
>
> *– Public Review Participant*

In alignment with calls to address the ownership of LTC homes that have emerged in response to the treatment of LTC home residents during the COVID-19 pandemic, many Phase Three Engagement participants echoed ongoing calls to abolish for-profit ownership in Canadian LTC homes. In particular, participants—and the Canadian public more broadly—have drawn a direct connection between for-profit ownership models and substandard provision of care that undermines the quality of life and working conditions within LTC homes.

> *LTC homes and care provisions were systematically diminished from decades of underfunding, understaffing, poor working conditions and the increase of for-profit LTC homes that put profits before the care of residents. This broken LTC system was brought to the brink of collapse when the COVID-19 pandemic hit. As a result, Canada witnessed the tragedy of a great number of residents and workers losing their lives in LTC homes, especially in for-profit LTC homes. Studies[10] have shown that during the pandemic, compared to non-profit and public LTC homes, for-profit LTC homes: had the highest resident fatalities; provided the least hours of direct care per resident per day; and had worse care outcomes. LTC homes have increasingly become reliant on high levels of casualization of employment, intensification of work, and poor wages and benefits of the LTC workforce; this is especially true for for-profit homes. To provide safe, reliable, and high-quality care, LTC must be part of the public health care system, and for-profit LTC homes and operations must be removed from the sector.*
>
> *– Public Review Participant*

[10] The following references have been added to this statement provided by a Public Review participant:

- Akhtar-Danesh, N., Baumann, A., Crea-Arsenio, M., & Antonipillai, V. (2022). COVID-19 excess mortality among long-term care residents in Ontario, Canada. PLOS ONE, 17(1), e0262807. https://doi.org/10.1371/journal.pone.0262807
- Canadian Institute for Health Information. (2021). COVID-19's impact on long-term care. https://www.cihi.ca/en/covid-19-resources/impact-of-covid-19-on-canadas-health-care-systems/long-term-care
- Stall, N.M., Jones, A., Brown, K.A., Rochon, P.A., & Costa, A.P. (2020). For-profit long-term care homes and the risk of COVID-19 outbreaks and resident deaths. CMAJ, 192(33), E946-E955. https://doi.org/10.1503/cmaj.201197

Enforcement and Transparent Performance Accountability

> *How do you make it [change] happen when there isn't a state of readiness in the system, and it [accountability] falls back into the provincial system as well. And the fact that if there isn't a political willingness to make it work, then ongoing issues [e.g., staffing shortages] will still be a problem.*
>
> *–Town Hall Participant*

Thinking about the potential impact that the standard may have on the day-to-day experiences of residents living in LTC homes, Phase Three Engagement participants – echoing calls made in *What We Heard Report #1* and *What We Heard Report #2* – noted the need for greater enforcement and accountability. In particular, participants stated that such measures were required to:

- Ensure clear understanding of expectations and how to address issues;
- Ensure alignment with existing legislation (e.g., occupational health and safety);
- Maintain licensing and/or accreditation;
- Ensure organizational follow-through after monitoring and reporting; and
- Enforce compliance with standards.

> *The standard must be open, transparent, and measurable to the public in order to restore confidence in long-term care in Canada.*
>
> *– Public Review Participant*

COVID-19 Spotlight

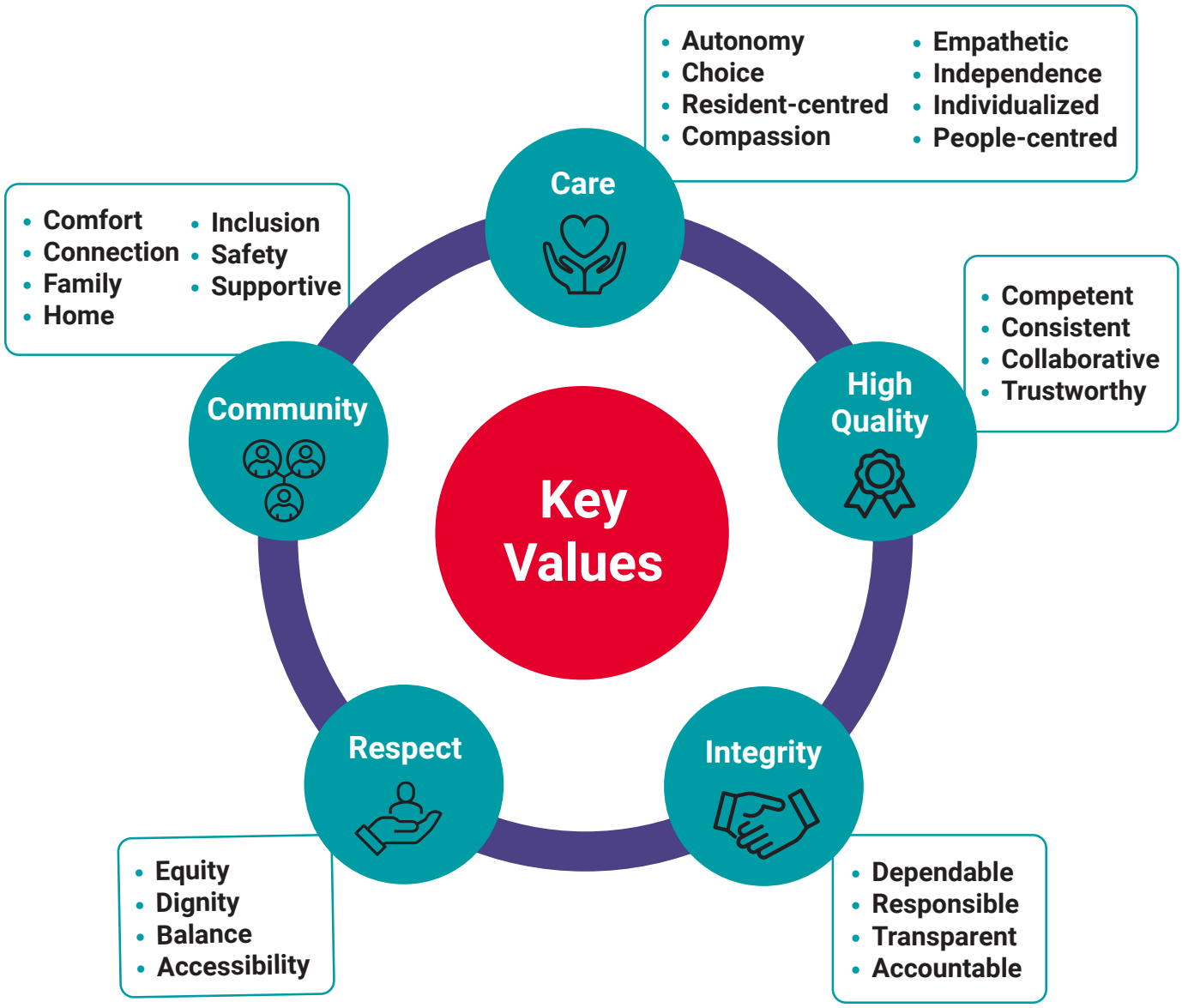
When reflecting on the impact of COVID-19, one resident commented on the lack of accountability surrounding how public health measures and restrictions have impacted residents living in Canadian LTC homes:

> *I don't think [the government] has had any idea of the effects that some of the rules that they've imposed on us has been. As we've progressed through this, we've come to realize, or recognize, or acknowledge, that, 'oops, maybe we've created situations where isolation and depression and under-stimulation and those kinds of things have occurred as a direct result of what you have done.' Nobody's actually said that, but that's where it came from. So, as we've come to the point where we are, my hope would be that we would resolve some of those things going forward. But that's not happened. We continue to be controlled by the same lack of understanding of what the effects of what you're imposing are, and that frustrates me to no end.*
>
> *– LTC Home Resident*

Moving Forward

Throughout all phases of Public Engagement to support the development of HSO's new National LTC Services Standard, Canadians have been consistent in voicing what they want to see when it comes to the future of long-term care in Canada.

As we look to the future, we are confident that HSO's new National LTC Services Standard reflects Canadians' views on what an optimal future state of LTC ought to look like in Canada. With that in mind, we conclude this report by highlighting the key values that exemplify what Public Engagement participants feel is integral for facilitating a paradigm shift in the delivery of long-term care in Canada.

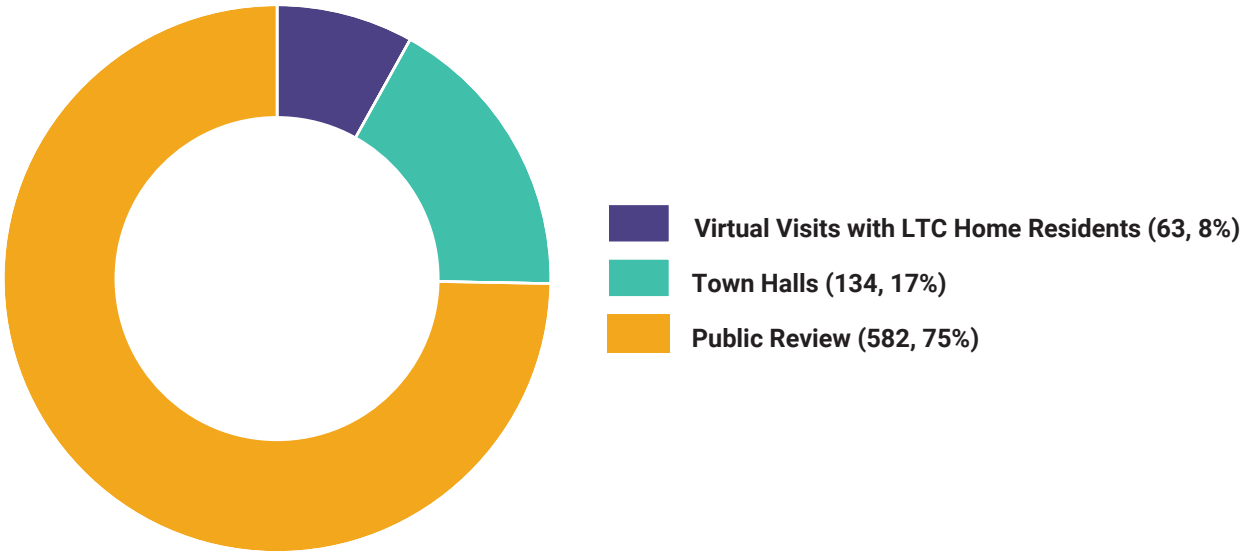


Appendix A – Phase Three Public Engagement Participant Demographics

In what follows, we provide a breakdown and analysis of the demographic profile of Canadians who participated in HSO's Phase Three Engagement activities. Please note that while we engaged with almost 800 individuals and groups, some participants were not asked certain demographic questions (depending on the activity) while others (when asked) chose not to provide responses to all demographic questions – as indicated by "Prefer not to answer/No response" in the following charts.

Total Participants

In HSO's Phase Three Engagement activities, we heard from a total of 779 participants from across the country. Specifically, 63 LTC home residents (8%) participated in a Virtual Visit, 134 (17%) key stakeholders participated in a Town Hall, and 582 (75%) individuals and groups provided comments during Public Review –as illustrated in the chart below.

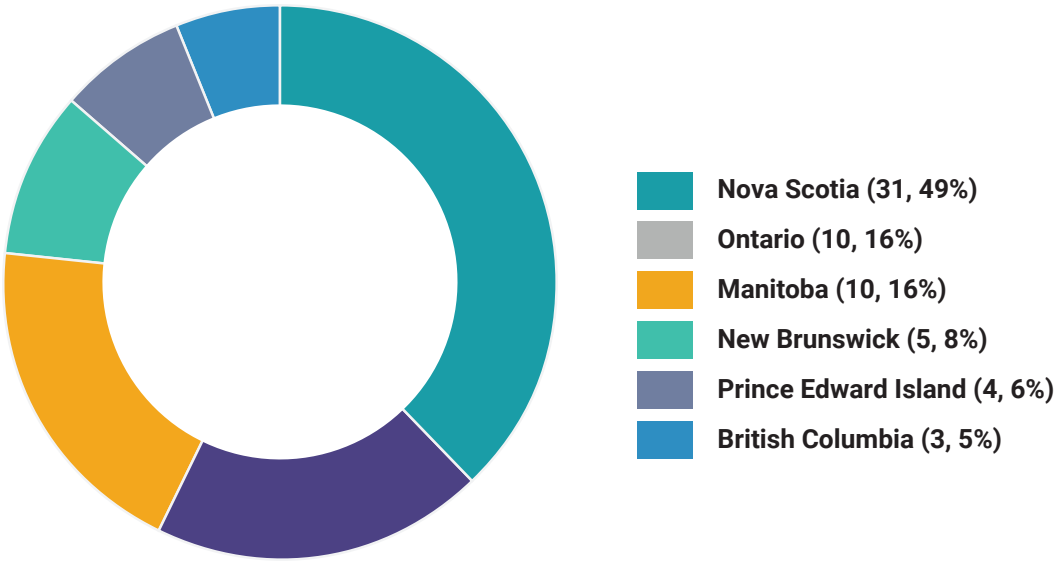


Virtual Visits with LTC Home Residents

In this section, we break down the demographic profile of HSO's Phase Three Engagement participants who participated in Virtual Visits.

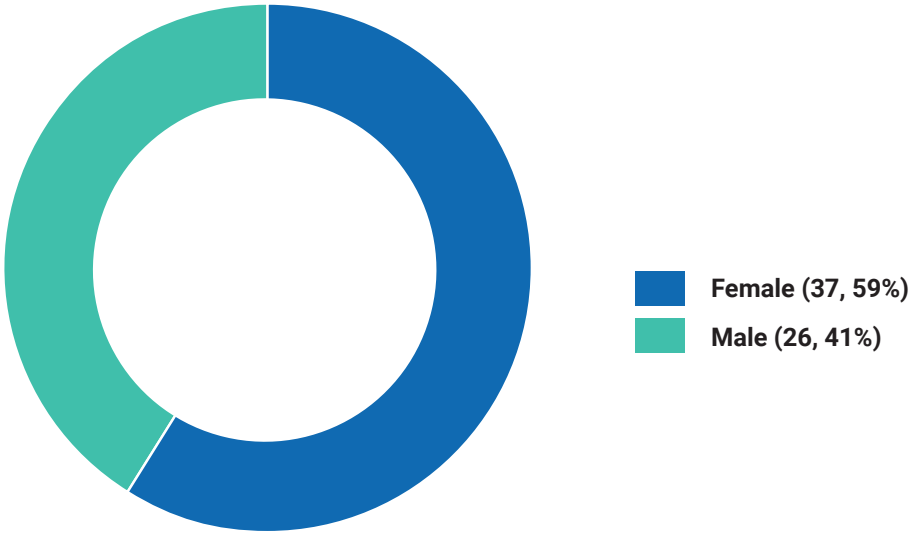
Geographic Location

The majority (49%) of residents identified as living in Nova Scotia, with additional representation from Ontario (16%), Manitoba (16%), New Brunswick (8%), Prince Edward Island (6%), and British Columbia (5%).



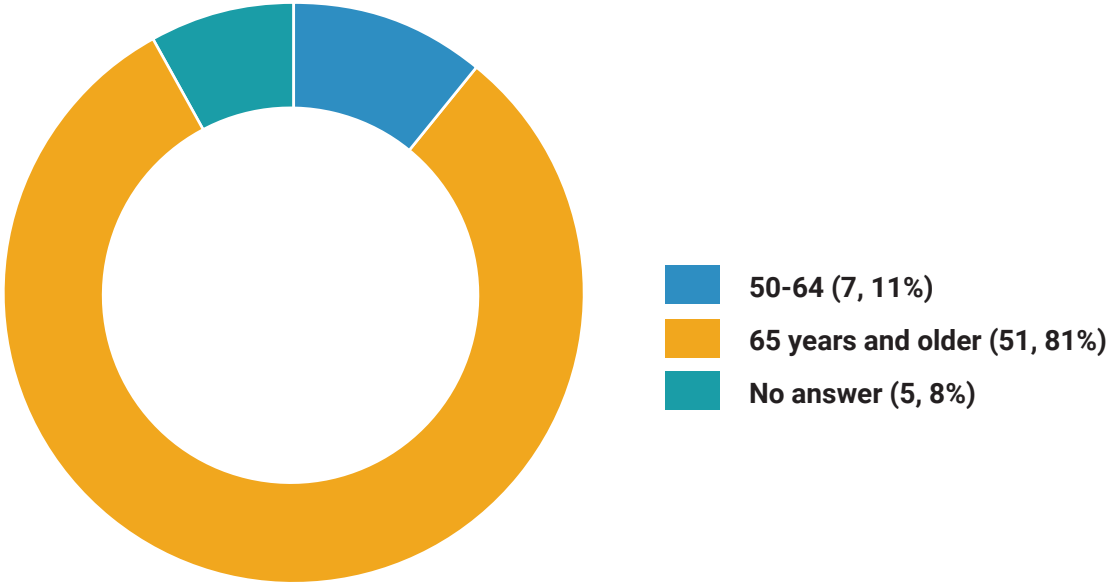
Gender

While the majority of residents (59%) who participated in a Virtual Visit indicated that they identify as female, we also saw a greater percentage (41%) of participants who identified as male compared to previous Engagement activities.



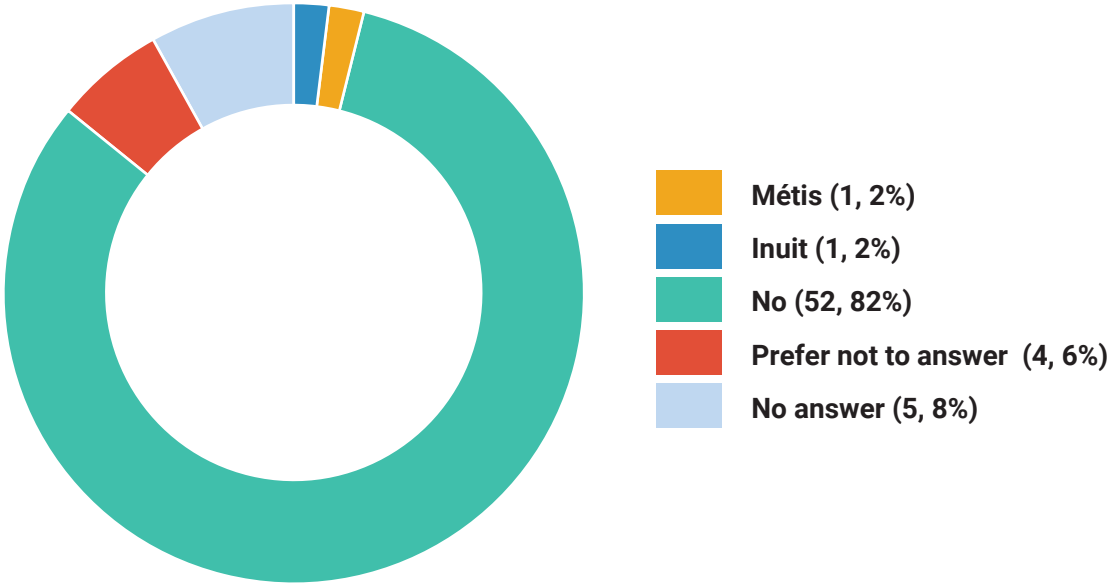
Age

The overwhelming majority (81%) of residents who participated in a Virtual Visit indicated that they were 65 years of age or older, while 11% were between 50-64 years of age.

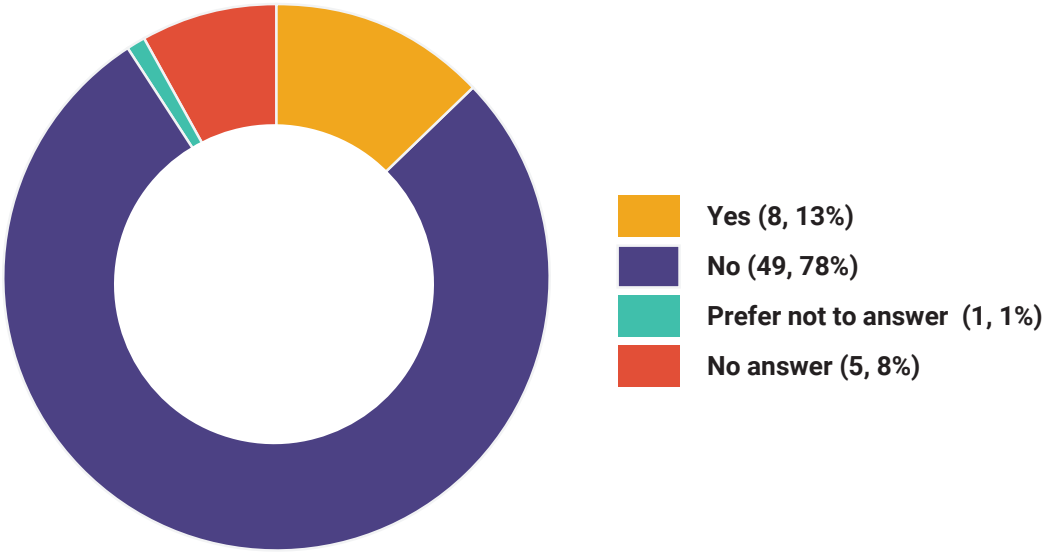


Race

4% of residents who participated in a Virtual Visit indicated that they were First Nations, Métis, or Inuit.

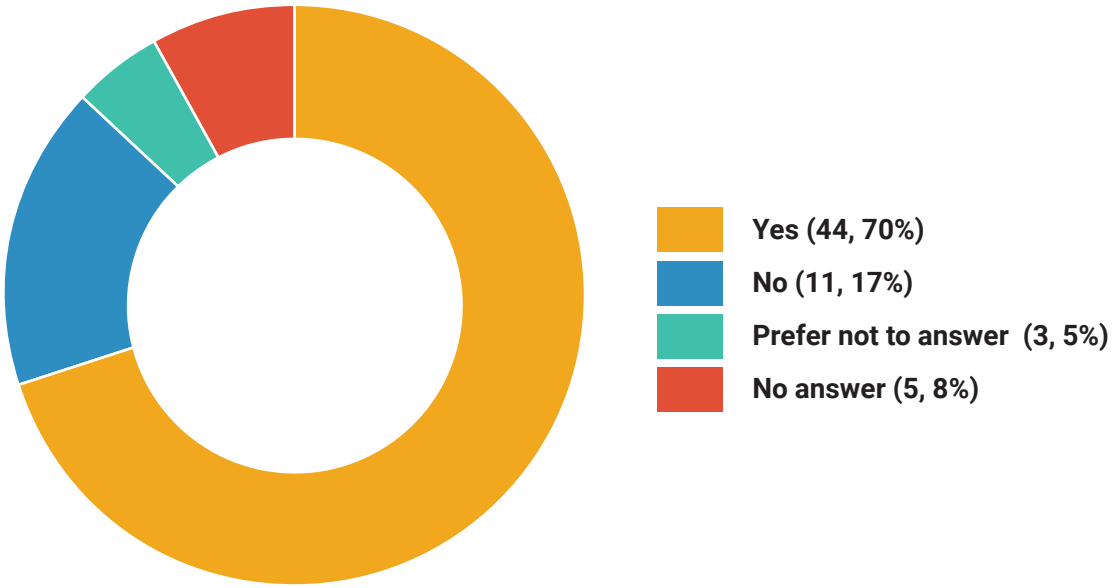


Of all the residents who participated in a Virtual Visit, 13% identified as being from a visible minority.



Ability

Of the residents who participated in a Virtual Visit, 70% identified as living with a disability.

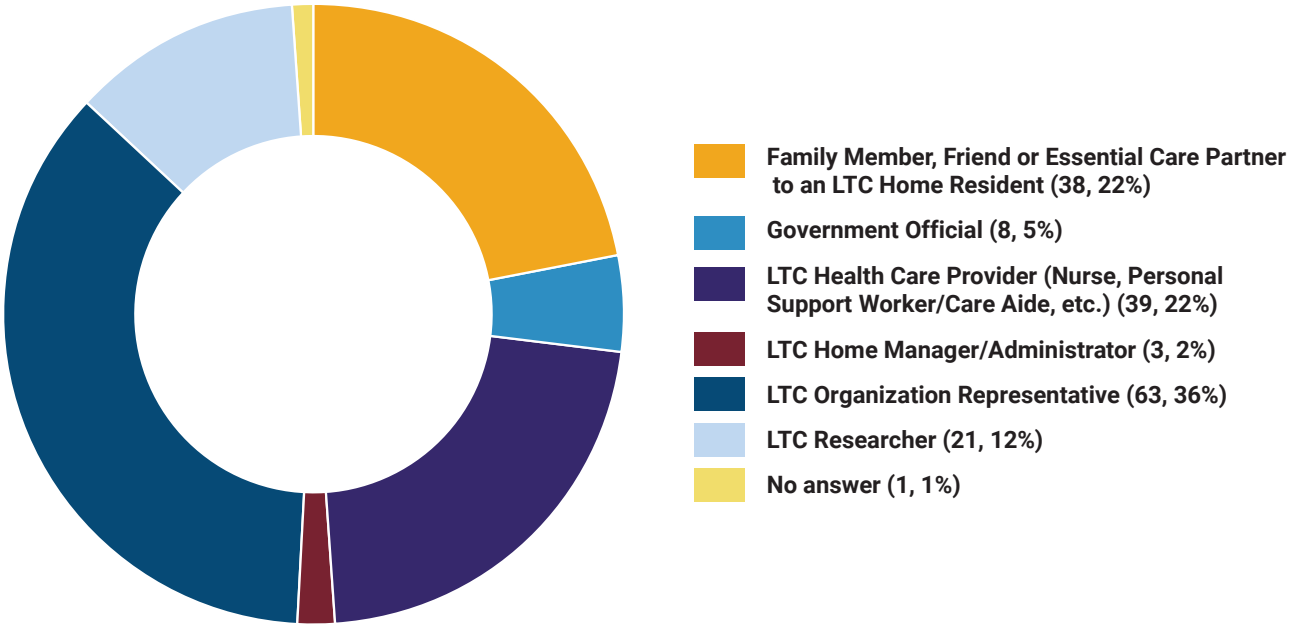


Town Halls

In this section, we break down the demographic profile of HSO's Phase Three Engagement participants who participated in a Town Hall. It is also important to note that we collected limited socio-demographic information due to the public nature of the Town Halls.

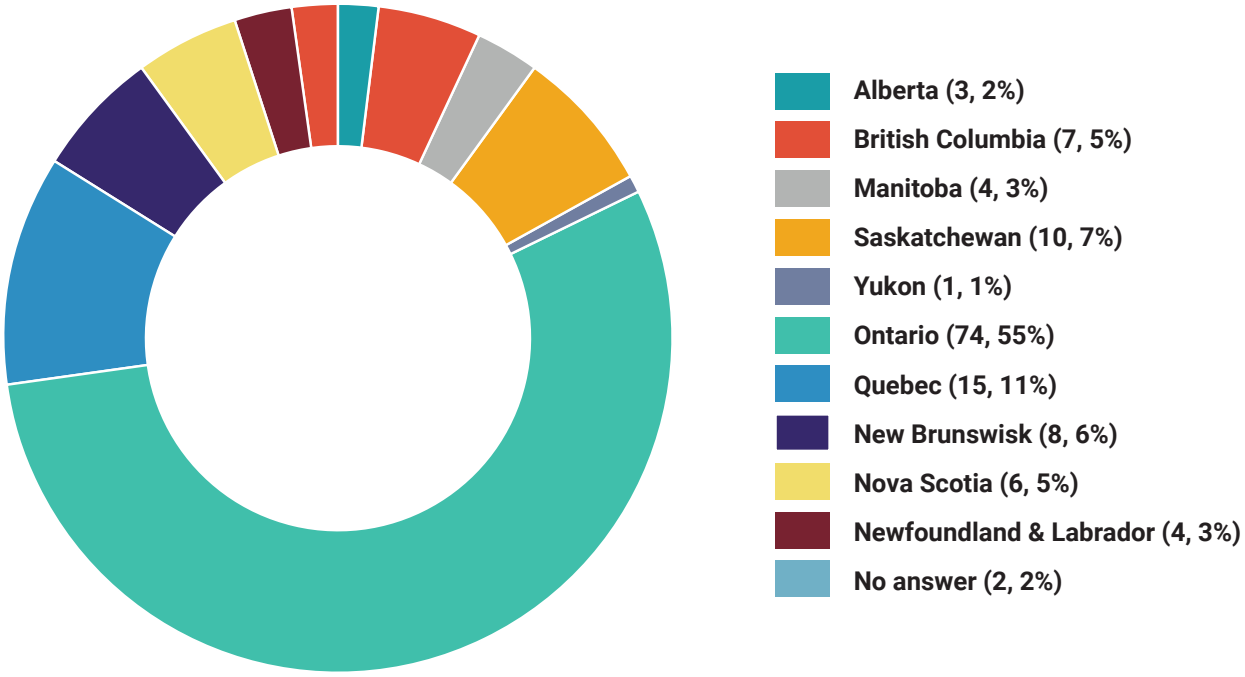
Relationship to LTC

The Town Halls were an opportunity to engage with specific stakeholder groups who have experience with long-term care. The breakdown of the participants from each Town Hall in relation to the total number of Town Hall participants is illustrated below.



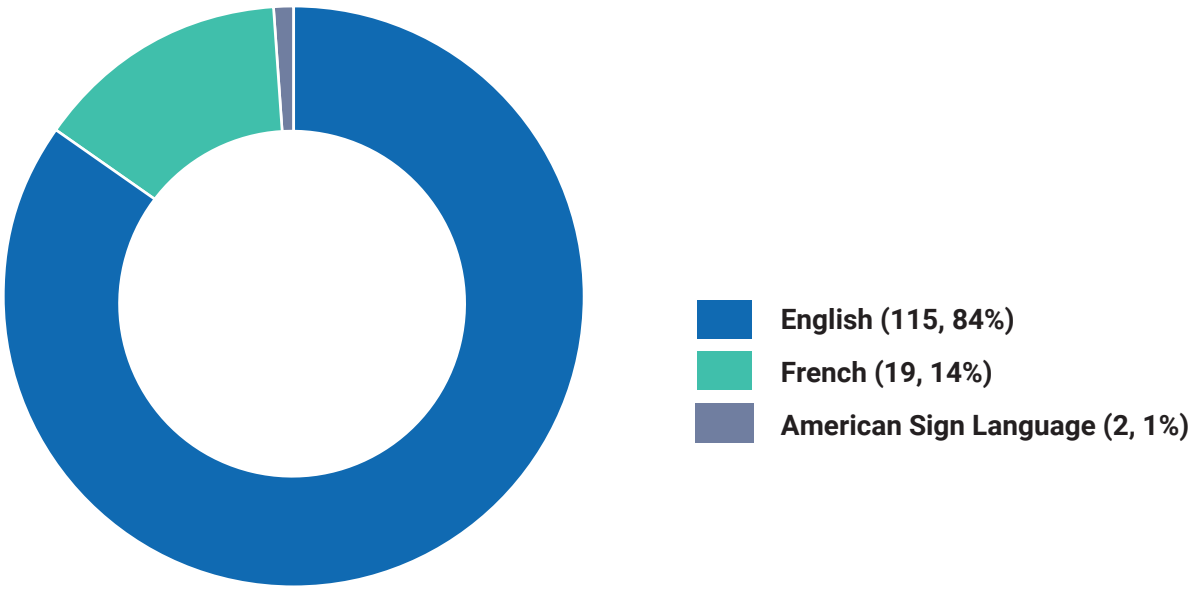
Geographic Location

The majority (66%) of Town Hall participants reported living in Central Canada (Ontario – 55%; Quebec – 11%), followed by 17% from Western Canada (Alberta – 2%; British Columbia – 5%; Saskatchewan – 7%; Manitoba – 3%), 14% from Eastern Canada (Nova Scotia – 5%; Newfoundland and Labrador – 3%; New Brunswick – 6%), and 1% from Northern Canada (Yukon – 1%).



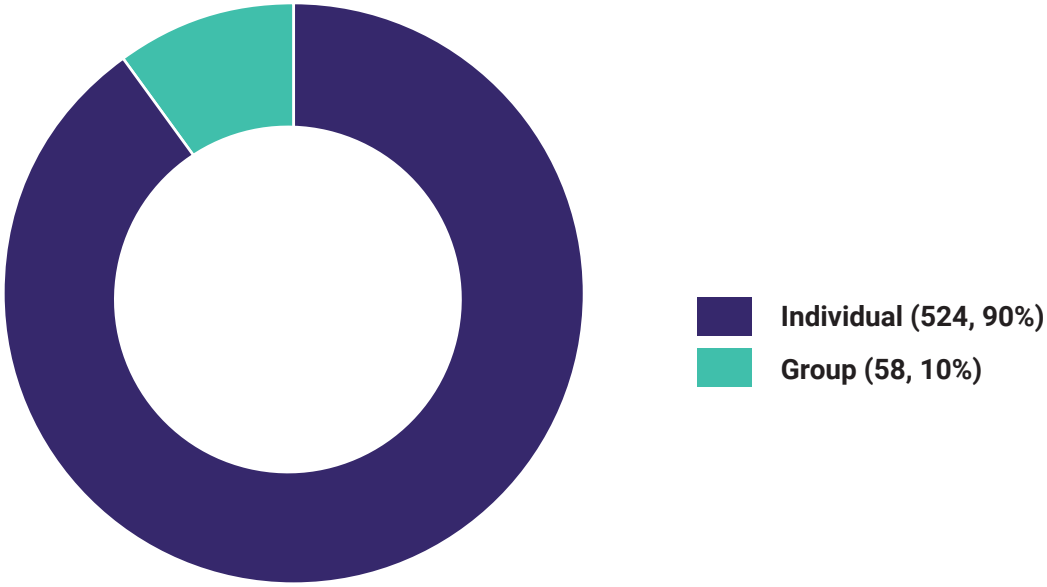
Language

The majority (86%) of Town Hall participants shared their feedback in English, while 14% responded in French—which is a significant increase from Phase Two Engagement activities.

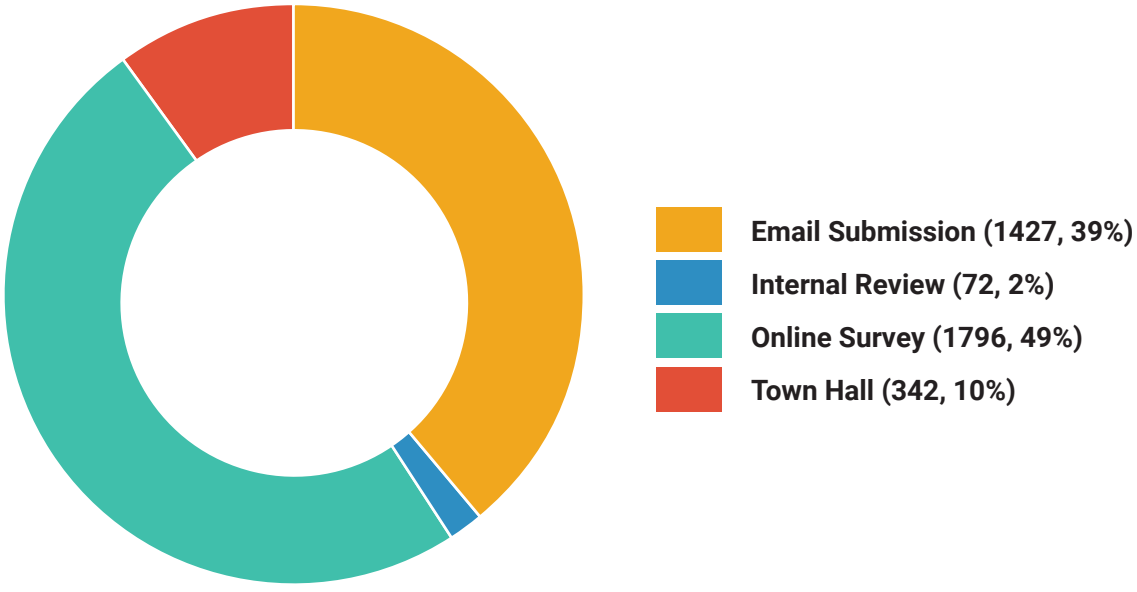


Public Review

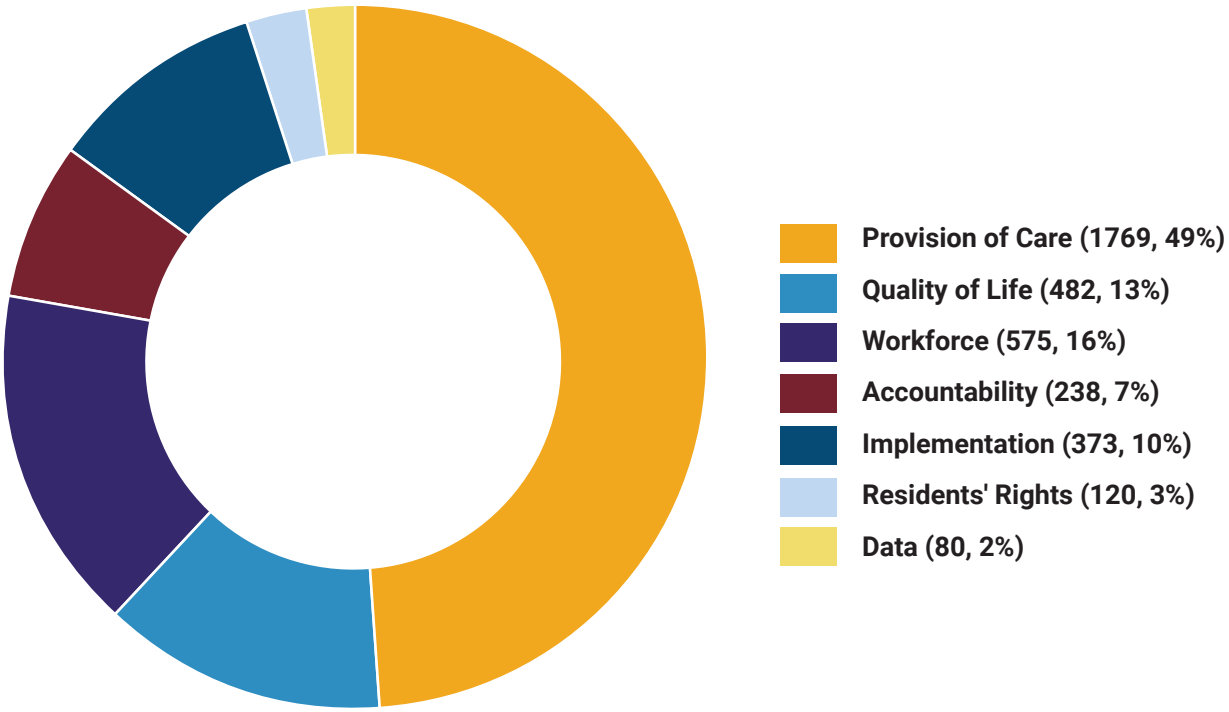
In this section, we break down the demographic profile of HSO's Phase Three Engagement participants who participated in the Public Review of the draft standard. In total, 3,637 comments were received from 582 participants from across the country. Of these 582 participants, there were 524 (90%) individual participants and 58 (10%) group participants—as illustrated in the chart below.



The comments received during Public Review can also be broken down by source. Specifically, the majority (49%) of comments were received via online survey, while 39% were received by email submission, 10% through a Town Hall, and 2% through an internal review conducted at HSO.

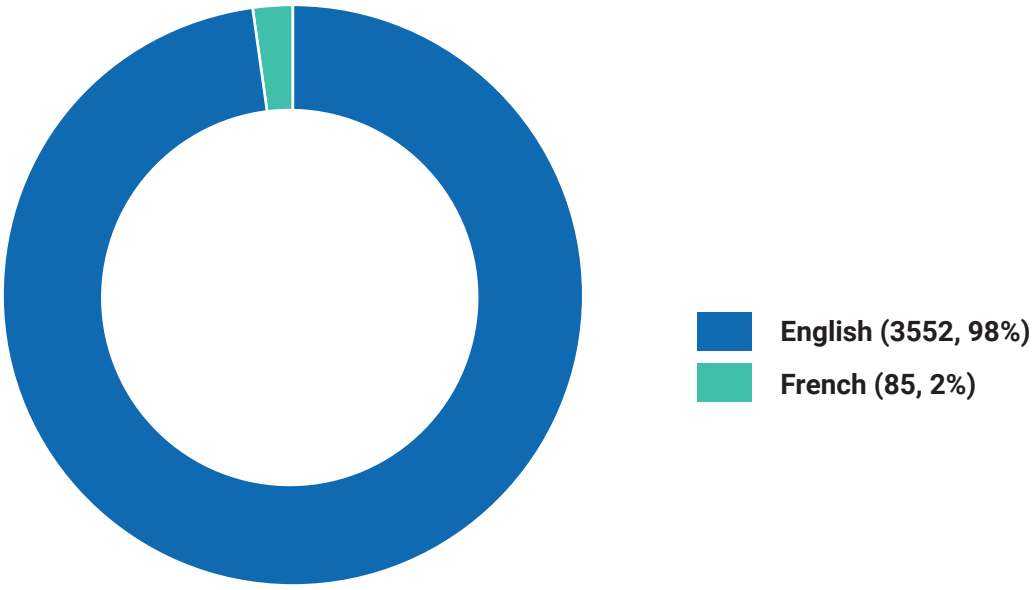


Each of the comments received during Public Review were categorized by theme. In particular, the majority (49%) of comments pertained to “Provision of Care”, while 16% pertained to “Workforce”, and 13% pertained to “Quality of Life.”



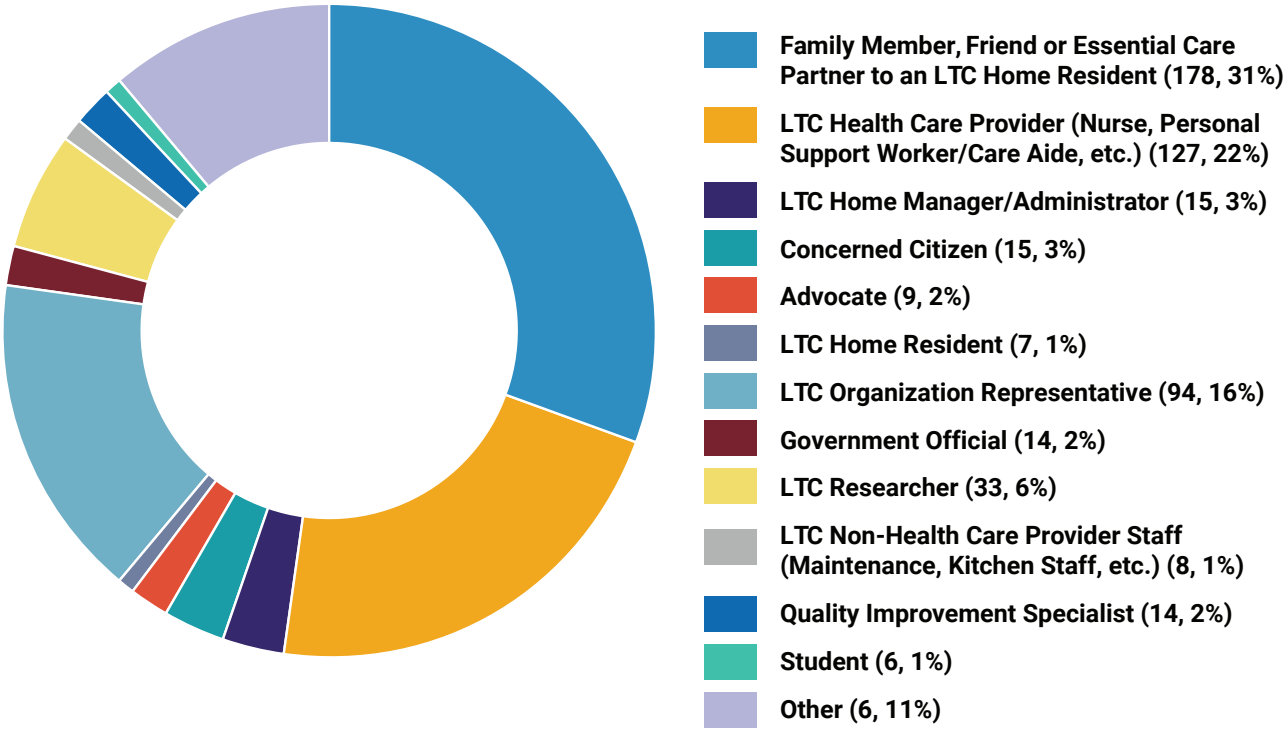
Language

Breaking down the total Public Review comments by language, 95% (371) of submissions were completed in English.



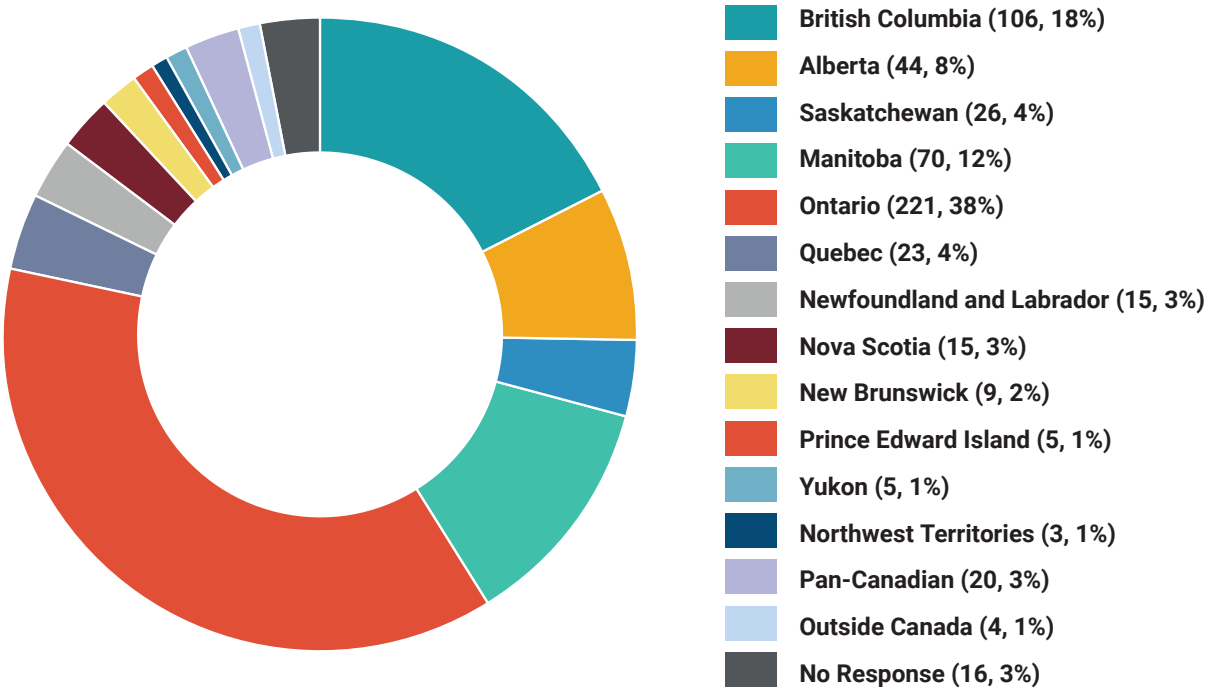
Relationship to LTC

The largest proportion of Public Review comments (31%, 178) were received from participants who identified as a Family Member, Friend, or an Essential Care Partner to an LTC Home Resident, followed by comments from participants who identified as being part of the LTC workforce (23%, 135).



Geographic Location

The majority (84%) of Public Review participants reported living in Central Canada (Ontario – 38%; Quebec – 4%) and Western Canada (Alberta – 8%; British Columbia – 18%; Saskatchewan – 4%; Manitoba – 12%), 8% from Eastern Canada (Nova Scotia – 3%; Newfoundland and Labrador – 3%; New Brunswick – 2%; Prince Edward Island – 1%), and 2% from Northern Canada (Yukon – 1%; Northwest Territories – 1%).



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