

People powered health™



What We Heard Report #2

Findings from HSO's National LTC Standard
Consultation Workbooks and Town Halls

JANUARY 27, 2022

About Health Standards Organization (HSO)

HSO stands for Health Standards Organization. Formed in February 2017, our goal is to unleash the power and potential of people around the world who share our passion for achieving quality health services for all. We are a registered non-profit headquartered in Ottawa, Canada.

Mailing Address

Health Standards Organization
1150 Cyrville Road
Ottawa, ON, Canada
K1J 7S9

© THIS DOCUMENT IS PROTECTED BY COPYRIGHT

Copyright © 2022, Health Standards Organizations (HSO) and/or its licensors. All rights reserved.

Key Contributors

Engagement Development

HSO's Phase Two Engagement strategy was developed by:

Dr. Kaye Phillips

Executive Director, Global Programs,
Health Standards Organization

Dr. Samir Sinha

Director of Geriatrics, Sinai Health and
University Health Network in Toronto
Chair, HSO's National Long-Term Care (LTC)
Services Technical Committee

Dr. Louise Clément

Executive Director, Clinical Partnerships,
Health Standards Organization

Emma Park

Project Manager, Long-Term Care Engagement
Project, Health Standards Organization

Research Team

This report was developed by:

Dr. Ashley Flanagan

Research Fellow,
National Institute on Ageing

Weni Chen

Research Assistant,
National Institute on Ageing

This report summarizes findings from HSO's Phase Two Engagement in the development of the new National Long-Term Care Services Standard—specifically, Consultation Workbooks and Town Halls. 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.

Table of Contents

About Health Standards Organization (HSO)	2
Key Contributors	3
Table of Contents	4
Executive Summary	5
Introduction	7
About HSO's Standards and How They are Used	8
About HSO's Phase Two Engagement	9
What We Heard: Providing Excellent Long-Term Care is a Careful Balancing Act	11
Balancing the Duality of the LTC Environment: A Home and Workplace	12
Balancing Rights and Safety: Individual and Collective	16
Balancing Approaches to Care Provision: Individualization and Standardization	21
Suggested Ways Forward	24
Where Do We Go From Here?	28
Appendix: Who We Heard From	29
References	38

Executive Summary

Building on the feedback from HSO’s 2021 Inaugural National Survey on Long-Term Care (Phase One Engagement), HSO invited Canadians to provide more specific input to support the development of HSO’s National Long-Term Care Services Standard. Specifically, the Phase Two Engagement aimed to facilitate deeper engagement and welcome additional perspectives on what an optimal future state of long-term care (LTC) ought to look like in Canada. The following report provides highlights from the 1,984* responses that were received between August 1 and December 1, 2021 through the Consultation Workbooks and Town Halls to help HSO’s National LTC Services Technical Committee develop the new National LTC Services Standard.

What We Heard: Providing Excellent Long-Term Care is a Careful Balancing Act

We begin the report by providing an overview of the demographic profile of the individuals who participated in our Phase Two Engagement activities (Consultation Workbooks and Town Halls) by language, age, gender, geographic location, race, ability, and relationship to long-term care.

Next, we present the key themes—or the primary challenges and opportunities—that were shared by engagement participants.

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 the key contributing factors differ depending on one’s relationship to the provision of LTC: residents (Home and Individualization), families (Transparency and Trust) and LTC workforce (Having Time to Provide Care and Feeling Valued and Supported).

The remainder of the report unpacks the multifaceted considerations brought forward by engagement participants who felt that ensuring safe, reliable, compassionate, and high-quality care in a long-term care home is a careful balancing act.

We heard that some of the most important contributors to safe, reliable, compassionate, and high-quality care are long-term care homes that exemplify the qualities of “home” and also provide a “positive, supportive, and caring work environment.” In particular, the responses shared by engagement participants highlighted the need to balance duality of long-term care homes as both a home (e.g., daily activities, relationships, and spaces) and a workplace (e.g., leadership, workplace culture, and hiring practices).

We heard that one of the most important contributors to safe, reliable, compassionate, and high-quality care is the need to respect the rights and quality of life of residents.

* While the total number of participants on record is 1,984, this number is an underrepresentation of participation as some groups who completed Roundtable Consultation Workbooks did not report how many participants were present.

In particular, the responses shared by engagement participants highlighted the individual (e.g., fostering and maximizing independence, respecting a resident’s right to live with risk, and clearly articulating the “boundaries” of individual rights) and collective (e.g., free from harm, and health and safety regulations) considerations for balancing the rights and safety of residents.

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

As we consider the future of long-term care in Canada, specifically how to best balance the key considerations outlined by participants in HSO’s 2021 Phase Two Engagement Activities, we conclude this report by providing some of the ideas and insights suggested by engagement participants 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).

Where Do We Go From Here?

We conclude by offering an overview of the next steps in HSO’s public engagement that will inform the development of HSO’s new National LTC Services Standard—which will be released for public review in early 2022 with a final version published in the fall of 2022.

Introduction

In response to the federal government's commitment to improve the provision of long-term care across Canada, the Standards Council of Canada (SCC), Health Standards Organization (HSO), and Canadian Standards Association (CSA Group) are aligning on the development of two new complementary National Standards for Long-Term Care (LTC) that are being shaped by the needs and voices of Canada's LTC home residents, workforce, and local communities, as well as 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 allow 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 is developing a new National LTC Services Standard that will provide clear requirements and accountabilities to enable long-term care home teams, governing bodies, and stakeholders to work together towards a common vision for resident-centred, high-quality care.

HSO's National LTC Services Standard will provide LTC home residents, teams/workforces, organizational leaders, and governing bodies with guidance on:

- Providing evidence-informed resident-centred care practices that value 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 appropriate to the diverse needs of residents, the workforce, and the broader team involved in the life of a LTC home.
- Enabling a healthy, competent, and resilient workforce and healthy working conditions.
- Upholding strong governance practices and operations and a culture that is outcomes-focused and committed to continuous learning and quality improvement.

LTC homes, also referred to as residential, continuing, personal care, or nursing homes, are residential settings where the majority of residents often live with complex health care needs. LTC homes are formally recognized by jurisdictions (i.e., are licensed and/or permitted) and are partially funded or subsidized to provide a range of professional health services, lodging, food, and personal care (e.g., assistance with everyday activities) for their residents 24 hours, 7 days a week.

Engaging with Canadians on what matters most to them when it comes to the delivery of long-term care has been, and will continue to be, a priority for the HSO LTC Services Standard Technical Committee – the group leading the development of this new national standard. Learn more about the National LTC Services Technical Committee: www.longtermcarestandards.ca/technical-committee.



About HSO's Phase Two Engagement

Building on the feedback from HSO's 2021 Inaugural National Survey on Long-Term Care (Phase One Engagement), HSO invited Canadians to provide more specific input to support the development of HSO's National LTC Services Standard. Specifically, the Phase Two Engagement aimed to facilitate deeper engagement and welcome additional perspectives on what an optimal future state of LTC ought to look like in Canada. During this phase, HSO solicited input through Consultation Workbooks and Town Halls.



Who We Heard From: An Overview

Through our Phase Two Engagement activities, we heard from the 1,984[†] Canadians from across the country. The insights, needs, experiences, and hopes shared by Canadians informed the HSO's National LTC Services Technical Committee's work to develop the draft standard to be released for public review in early 2022. Following the incorporation of feedback generated during the public review and other engagement, the final standard will be published in the fall of 2022.

Consultation Workbooks

We are honoured to have received 392 submissions of our Consultation Workbooks, from 1,805 people, responding to more specific consultation questions that were developed based on what we learnt from the 16,093 responses received to our Inaugural National Survey on Long-Term Care.

Individual Workbook Submissions

- ✓ **95%** of workbook respondents answered in English.
- ✓ **38%** of workbook respondents were 65 years of age or older.
- ✓ **78%** of workbook respondents self-identified as female.
- ✓ **48%** of workbook respondents reported living in Ontario.
- ✓ **2%** of workbook respondents self-identified as being First Nations, Métis, or Inuit.
- ✓ **8%** of workbook respondents self-identified as being from a visible minority.
- ✓ **12%** of workbook respondents self-identified as living with a disability.
- ✓ **44%** of workbook respondents self-identified as being part of the LTC workforce; while **42%** self-identified as a Family Member, Friend, or Unpaid Caregiver to a LTC Home Resident and **4%** self-identified as being a LTC Home Resident.

Roundtable Workbook Submissions

- ✓ **21%** of workbook respondents reported living in Ontario.
- ✓ **22%** of workbook respondents self-identified as being part of the LTC workforce; while **16%** self-identified as a Family Member, Friend, or Unpaid Caregiver to a LTC Home Resident and **8%** self-identified as being a LTC Home Resident.

[†] While the total number of participants on record is 1,984, this number is an underrepresentation of participation as some groups who completed Roundtable Consultation Workbooks did not report how many participants were present.

Town Halls – Fall 2021

In Fall 2021, we spoke to 179 people from across the country through our virtual Town Halls—designed to gather additional input from:

- Long-term care residents and their families
- The long-term care workforce
- Indigenous persons with experience in long-term care
- Francophones and persons from Quebec with experience in long-term care
- Individuals providing perspectives related to equity, diversity, and inclusion in long-term care
- Leaders and administrators of long-term care homes

A more detailed breakdown and analysis of the demographic profile of Consultation Workbook and Town Hall participants is provided in the [Appendix](#).

What We Heard: Providing Excellent Long-Term Care is a Careful Balancing Act

The following discussion presents the key themes—or the primary challenges and opportunities—that were shared by the 1,984[‡] participants in HSO’s Phase Two Engagement activities.

When asked what the future of LTC should look and feel like, individuals who shared their perspectives through the Consultation Workbooks and Town Halls felt that the high-quality care is the outcome of providing safe, reliable, and compassionate care.



While engagement participants clearly felt this formula is at the core of high-quality care, they also noted that the key contributing factors differ depending on one’s relationship to LTC.

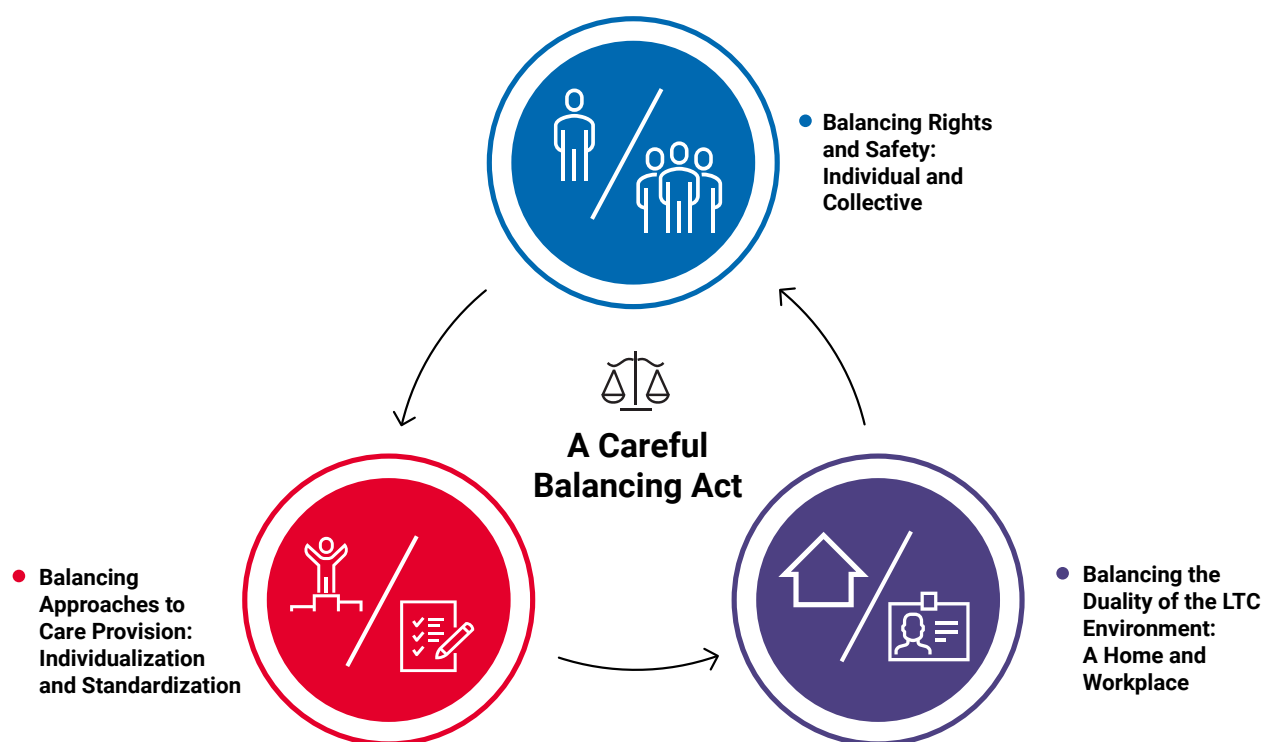
- For residents, the key factors that contribute to high-quality care within LTC are: **Home** and **Individualization**. When it comes to home, many engagement participants felt that an important component of high-quality care is acknowledging and respecting that the long-term care home is, in fact, a resident’s home. Hand in hand with emphasizing the “home” in “long-term care home” is the importance of being able to receive individualized care and support. For engagement participants, individualization is at the heart of high-quality care as it places the residents’ wants, needs, and desires at the centre of care.
- For families, the key factors that contribute to high-quality care are: **Transparency** and **Trust**. Transparency, for engagement participants, looked like open channels of communication between families and care teams (including leadership) with respect to the care of their loved one(s). Beyond direct communication, transparency also refers to public reporting by long-term care homes/organizations. Alongside transparency, engagement participants also felt that a key component of high-quality care is trust. In particular, families should be able to trust that their loved one(s) are safe and being supported.

[‡] While the total number of participants on record is 1,984, this number is an underrepresentation of participation as some groups who completed Roundtable Consultation Workbooks did not report how many participants were present.

- For the LTC workforce, the key factors that contribute to high-quality care are: **Having Time to Provide Care** and **Feeling Valued and Supported**. According to engagement participants, individuals who are part of the LTC workforce require more time to provide safe, compassionate, and resident-centred care. An additional key component in the provision of high-quality care is ensuring that the LTC workforce feels valued and supported through equitable salaries and benefits, employee appreciation initiatives, and opportunities for career advancement.

As demonstrated by the above discussion, which shows how perceptions of the key factors that contribute to high-quality care differ depending on one's relationship to the provision of long-term care, engagement participants clearly felt that ensuring safe, reliable, compassionate, and high-quality care in a long-term care home is a careful balancing act.

The following discussion summarizes the perspectives shared by engagement participants as it exemplifies the multi-faceted considerations that are pertinent for the future provision of long-term care in Canada.



Balancing the Duality of the LTC Environment: A Home and Workplace

In HSO's Inaugural National Survey on Long-Term Care we heard that some of the most important contributors to safe, reliable, compassionate, and high-quality care are long-term care homes that exemplify the qualities of "home" and also provide a "positive, supportive, and caring work environment." Digging deeper into these perspectives, responses shared by participants in Phase Two Engagement activities highlighted the need to balance duality of long-term care homes as both a home and a workplace.



Home



"Homes not warehouses."

– Individual Workbook Participant from Yukon

When asked about what would make a long-term care home "feel more like a home" (rather than a hospital or institution), engagement participants talked about the necessity of focusing on enhancing residents' quality of life and care (over profits). The key qualities that contribute to quality of life—as shared by participants—fall within three categories:

● Daily Activities

For engagement participants, one of the most important qualities of home is having flexibility. Flexibility in the context of providing long-term care could look like breaking down rigid routines related to personal care and mealtimes. For example, engagement participants would like to see resident-directed schedules that support their choice in when to eat (e.g., timing, options), sleep (e.g., timing, amount), and bathe (e.g., frequency). In essence, engagement participants felt that care and support should be available to them when needed.

● Relationships

Building from embracing flexibility within their daily activities, engagement participants also talked about the importance of maintaining their existing relationships and facilitating opportunities to form new relationships. For example, engagement participants called for unrestricted visiting to better enable residents to maintain connections to their loved ones and communities. To facilitate building new relationships, engagement participants would like to see more activities that foster meaningful engagement and connections with others; as well as mealtime experiences that bring residents together in conversation and community.

● Spaces

Engagement participants also talked about important considerations that make the spaces within a long-term care home feel like a home. With respect to the overall structural environment, participants expressed that low-density structures that feel warm and inviting (e.g., paint colours, furnishings, décor) while also offering privacy (e.g., single or double occupancy rooms, private bathrooms) are essential. When it comes to resident spaces, engagement participants emphasized the importance of being able to personalize one's living space. For example, being able to hang pictures on the walls, bring in their own furniture, and choose their own wall colours.



Workplace



“As with all workplaces/establishments, good leadership is key. They set the tone and standards for what goes on in the workplace. They should be approachable by all parties and the latter should feel acknowledged, supported and a sense of fairness. There is no place for lip service or arrogance.”

– Individual Workbook Participant from British Columbia

On the other hand, engagement participants also talked about the importance of recognizing that long-term care homes are also workplaces. When asked what would make a long-term care home a more “positive, supportive, and caring work environment,” engagement participants talked about the importance of leadership, workplace culture, and hiring practices.

● Leadership

For engagement participants, a positive, supportive, and caring work environment starts with actively engaged leadership. Engagement participants felt that a long-term care home's leadership needs to be “on the floor” on a daily basis to see and hear the challenges faced by staff and residents alike. For one Individual Workbook Participant from New Brunswick, actively engaged leadership is ready to “roll up sleeves and help when short-staffed.” By being embedded within the daily activities of the long-term care home, leadership is better able to provide organizational support and guidance.



Workplace Culture

In addition to ensuring actively engaged leadership, engagement participants felt that a respectful and collaborative workplace culture was important for ensuring a positive, supportive, and caring work environment. To facilitate a respectful and collaborative workplace culture, engagement participants talked about the importance of ensuring that the contributions of each team member are recognized and appreciated. Additionally, engagement participants also emphasized the importance of collaboration and positive reinforcement (rather than retribution). A collaborative workplace focuses on sharing ideas and ongoing learning in order to provide the best possible care.



Hiring Practices

Another important aspect for ensuring a positive, supportive, and caring work environment are hiring practices. For engagement participants, hiring practices—or “screening of staff to ensure they are suited for the job” as one Individual Workbook Participant from Saskatchewan stated—are an important component in facilitating strong team cohesion and ensuring high-quality care. When rethinking the hiring process, engagement participants would also like to see resident and family input into who is being hired to provide care.



Defining Terms: Home vs. Home-like

When thinking about how to best balance the duality of the environment within long-term care homes, the language used in these discussions is important. There is opportunity to balance the reality that long-term care homes are both a home and a workplace by shifting the language depending on the context. For example, when talking about resident-specific experiences and spaces, the term “home” may be more appropriate; while “home-like” may be more appropriate when specifically addressing the workplace—or environments in which people both work and live. The caveat, however, is that in order for a long-term care setting to genuinely become homes for residents, significant work must be done to transform the experiences of daily life within Canada’s long-term care homes—as noted above.

Balancing Rights and Safety: Individual and Collective

In HSO's 2021 Inaugural National Survey on Long-Term Care we heard that one of the most important contributors to safe, reliable, compassionate, and high-quality care is the need to respect the rights and quality of life of residents. Digging deeper into these perspectives, responses shared by participants in Phase Two Engagement activities highlighted the individual and collective considerations for balancing the rights and safety of residents.



Individual: Resident's Rights



"I think it needs to come with a really big culture shift, where people are not just seen as the embodiment of tasks for staff to get done, and where social, emotional, and spiritual needs are just as prioritized as physical needs. In order to do this, there would need to be staffing ratios and culture change that supported it. I think a good starting place would be to really foster critical thinking and person-centered care among staff."

– Individual Workbook Participant from Ontario

When asked to share their perspectives on how to balance and respect the rights and quality of life of residents, with the need to keep them safe, engagement participants clearly articulated that residents have the same rights as any other Canadian citizen, including: fostering and maximizing independence, respecting one's right to live with risk, and clearly articulating the "boundaries" of an individual's rights.

● Fostering and Maximizing Independence

Engagement participants agreed that residents have the right to be supported in maximizing autonomy and independence. For example, residents have the right to:

- Access physiotherapy and occupational therapy services;
- Appropriate mobility aids;
- Adequate pain management; and
- Care that builds from the resident's abilities.

In fact, engagement participants underscored the necessity of recognizing that individuals enter long-term care to receive additional support (e.g., assistance with activities of daily living); not to have their independence stripped for the sake of expediency in care provision.



Respecting a Resident's Right to Live with Risk

Recognizing that environments supported by health care professionals are inherently risk averse, engagement participants clearly stated that a resident's autonomy and decision to live with risk must be respected. Some specific examples included:

- Continuing to eat foods and drink fluids that one enjoys despite risk of choking and/or aspiration.
- Continuing to walk independently (e.g., without mobility aid) despite the risk of falling.
- Continuing to visit freely during the COVID-19 pandemic despite public health guidelines to limit close contacts.

Drawing on residents' experiences during the COVID-19 pandemic, engagement participants also talked about the implications of restricting residents' rights, such as declining health, wellbeing, quality of life, and increased isolation).

Clearly Articulating the Boundaries of Individual Rights

Engagement participants felt that a key component of balancing a resident's rights and the need to keep them safe was clearly articulating the "boundaries" of an individual's rights within a long-term care home (e.g., implications for the collective). Some suggestions offered by engagement participants for facilitating such discussions included:

- Focusing on informed consent and decision-making;
- Education with families and staff around an individual's right and choice to live with risk;
- Engaging with residents and their families in establishing a ethical guidelines/protocol/framework for minimizing collective risk; and
- Building trust through engagement with all stakeholders.

This discussion may begin as part of the orientation process for incoming residents and their families, as well as members of the workforce.

When talking about individual rights, engagement participants also talked about the importance of all individuals living, working, and visiting within long-term care homes having a clear understanding about their personal responsibility for the safety of the collective. The most cited example of this was with respect to mandatory COVID-19 vaccination requirements for all family members, visitors, and workforce (including leadership and administration).



Defining Terms: Quality of Life vs. Quality of Care (Impact of COVID-19 on LTC Homes)

It is no secret that residents in Canada's long-term care homes have been disproportionately impacted by COVID-19—with over 57,000 residents and 29,000 staff in Canada's LTC and retirement homes infected with COVID-19, resulting in more than 15,700 deaths among residents and staff.¹ While the number of infections and deaths clearly illustrates the devastating impact of COVID-19 on long-term care settings in Canada, the response strategy to ensure physical safety had consequences for the mental and emotional wellbeing of residents and staff. As shared by Roundtable Workbook Participants from Saskatchewan,



"Let us be blunt. What was done to LTC residents and families during this pandemic in the name of 'safety' has wreaked havoc, led to the premature deaths of over 14,000 residents and COVID-19 infection for many more. Residents have been isolated, medical services greatly reduced, recreation programs cancelled, and families excluded to the detriment of care, safety, and quality of life. What we have observed in LTC was not caused by the pandemic, rather the pandemic revealed challenges already present in the sector."

In other words, collective efforts to maintain and ensure quality of care through strict regulation and restriction had—and continues to have—a drastic impact on the quality of life of residents, families, and staff in long-term care homes across the country.

"Existence is not quality of life; you need more than that."

—Roundtable Workbook Participants from Newfoundland and Labrador



Collective: Ensuring Resident and Workforce Safety



“When it comes to implementing strong infection prevention and control practices, the safety of the many comes before the safety, autonomy or choice of the one individual. Someone infectious does not have the right to deliberately or unintentionally (if they lack insight to stay away from others such as with an advanced demented patient who wanders and cannot comprehend they may hurt others) infect (and with COVID-19 as we saw) cause the deaths of other patients.”

– Individual Workbook Participant from British Columbia

While engagement participants clearly articulated the importance of respecting a resident’s rights and autonomy (i.e., individual rights are paramount), participants also felt that “the needs for safety of the residents as a collective supersedes individual rights”—as stated by one Individual Workbook Participant from Ontario. Some engagement participants felt that living in community with others means that one must respect community standards that enable a good environment for all—especially when it comes to infection prevention and control (IPAC). In fact, engagement participants talked about the need to ensure environments that are free from harm (vs. free from risk) and comply with health and safety regulations.

Free from Harm

Engagement participants distinguished between creating and maintaining a long-term care home as an environment that is “free from-harm” as opposed to “free from risk”—which may more directly undermine resident autonomy and rights. When defining what an environment that is free from harm looks like, engagement participants emphasized the importance of a physically and emotionally non-threatening environment that is proactive in preventing resident-to-resident aggression and violence, as well staff-to-resident (and vice versa) harassment and abuse.

Health and Safety Regulations

When it comes to health and safety regulations, engagement participants distinguished between personal hygiene (i.e., choice) and infection prevention and control protocols (i.e., mandatory). In the case of a long-term care home, IPAC protocols encompass hand hygiene, personal protective equipment, respiratory protection, cleaning and disinfection, etc. In fact, some engagement participants stated that resident decisions should not compromise the safety and/or professional standards of the workforce. However, engagement participants also recognized that there is a fine line between infection control and solitary confinement—as was seen in response to COVID-19 in a number of long-term care homes.



Defining Terms: Safety vs. Security

When talking about safety and risk within the context of long-term care homes, there are often calls to implement more rigid safety protocols (e.g., safety bars, bed alarms) and enhance security through the installation of security systems (e.g., surveillance cameras, entry codes). While one motive driving such calls is the protection of residents and staff; however, the underlying driver is most often a lack of trust. In fact, when people do not trust, the tendency is to lean into security/surveillance measures in order to put minds at ease (i.e., constant supervision to prevent wrongdoing). While enhanced security may, in some instances, link to safety, the more common outcome is a toxic environment. Individuals under surveillance (i.e., frontline staff) are more likely to have direct connections to the harm and injustice of historical hyper-surveillance of people of colour, immigrant, and 2SLGBTQIA+ communities—which, ultimately, impacts the provision of relational and high-quality care. The answer is to place emphasis on safety; specifically unpacking and defining what safety means for individuals (e.g., residents and staff) and communities (e.g., LTC homes as collectives), in order to best ensure the provision of high-quality care. If we work collaboratively create more safe environments in LTC homes, the calls for enhanced security will abate.

Balancing Approaches to Care Provision: Individualization and Standardization

In HSO's 2021 Inaugural National Survey on Long-Term Care we heard that some of the most important contributors to safe, reliable, compassionate, and high-quality care are ensuring the provision of resident-centred care alongside calls for an unwavering commitment to consistency and quality of care. Digging deeper into these perspectives, responses shared by participants in Phase Two Engagement activities highlighted the need to strike a balance between calls for individualized approaches to care and calls for standardization, to facilitate greater continuity, transparency, and accountability in the provision of high-quality care.



Individualization



"Ultimately, any new standards need to put an emphasis on resident choice. PSW training, for example, should include choice-centric ways of interacting with a resident: in the morning, a PSW should be trained not to rouse a resident at a particular time no matter what, but to ask them if they would like to get up now or later. People's choices change from day to day and building in approaches that recognize this will help empower the rights of residents while keeping them safe."

– Roundtable Workbook Participants from Ontario

When asked about what "safe, reliable, compassionate, and high-quality care" in a long-term care home looks like for residents, families, and staff, the most commonly shared responses called for an individualized approach care. As one engagement participant (57) stated, "A place where residents are made to feel like PEOPLE and not just tasks to be completed."

According to engagement participants, an individualized approach to care places the needs, wishes, and desires of the resident at the centre of care decisions—also known as resident-centred care. Shifting our focus on the provision of culturally safe and appropriate care places emphasis on:

- Resident voice and choice to not only maintain but enhance independence and autonomy.
- Viewing residents holistically by attending to their physical, mental, spiritual, and social needs.
- Trauma-informed approaches that recognize and acknowledge the lived and living experiences that residents carry with them, and harm-reduction approaches that respect and value residents' right to live with risk.
- Involving residents in the day-to-day operations (e.g., meal prep/planning) of the long-term care home, which will also enhance one's sense of purpose.



- Engaging in activities that are tailored to the individual and collective interests of residents (rather than pre-packaged, generic programming that is outdated).
- Collaboration as residents, families, and staff work together to provide the best care.

For staff to better support and provide resident-centred care, engagement participants shared that staff must be supported to spend time getting to know each resident. Within the current long-term care home context, staff have very little to no time to engage with residents outside of providing direct care. The lack of time—which is a direct consequence of under-staffing and under-valuing care work—seriously limits the capacity and ability to provide resident-centred care.



Standardization



“‘Safe’ LTC is such that both individual residents and the collective group of residents have their daily needs met in a manner that is at or above nationally and provincially mandated standards for people of their age, medical reality, frailty, and state of mental health; that such care and attention is provided in an atmosphere which is physically and emotionally non-threatening within reasonable bounds for staff working in LTC; and is likewise for family and friends who visit residents in such [settings].”

– Individual Workbook Participant from Alberta

On the other hand, engagement participants also talked about the need for a standardized approach to care. In particular, engagement participants want to see:

- Consistent levels of care (e.g., same level of care, every day);
- Continuity in staff across shifts and days of the week (e.g., full-time, permanent positions);
- Mandated expectations for education and licensing (e.g., specialized training in geriatric and culturally safe care);
- Collection and utilization of sociodemographic data from residents and workforce (e.g., race-based data);
- Established channels of communication (e.g., updates and feedback on care); and
- Well-maintained and clean environments.

However, engagement participants also added the caveat that standardization should not mean a top-down approach nor the provision of highly regimented care in sterile environments where care interactions are viewed as series of tasks to be “checked off a list”. Instead of viewing standardized approaches to care in opposition to calls for individualized care, some engagement participants view standardization (e.g., hours of direct care, staffing levels) as a facilitator towards providing high-quality resident-centred care. When staff have the necessary time and resources to provide consistent care, engagement participants felt that there would be more opportunities for meaningful engagement and enhanced familiarity—which would translate into greater trust.



Defining Terms: Cultural Safety

Cultural safety is an outcome of respectful engagement, based on recognizing and working to address inherent power imbalances in the health system. It results in an environment free of prejudice, discrimination, and harassment based on an individual’s various interconnecting social identities (e.g., age, race, ethnicity, gender identity, sexual identity, etc.). It is a space where people feel safe when receiving and providing care, and when interacting with the health system.²

Within the context of long-term care settings, cultural safety flourishes when the values of empathy, respect, and collaboration are embedded within all aspects of care—especially pertinent when working with Black, Indigenous, and other People of Colour, as well as 2SLGBTQIA+ communities and members of other equity-deserving communities. Cultural safety is the outcome of providing culturally appropriate and sensitive care.



“Safe care, training, and skills: LGBTQ + populations are almost completely invisible in LTC [homes] (residents and caregivers), even if the population is at least 10% of the Canadian population. It takes a big hit on mental health. So, more training needed to be able to provide truly safe care. The socio-cultural background of LGBTQ + residents must be understood.”

–Town Hall for Family Caregivers of LTC Residents

Suggested Ways Forward

As we consider the future of long-term care in Canada, specifically how to best balance the key considerations outlined by participants in HSO’s 2021 Phase Two Engagement activities (and summarized above), we conclude this report by providing some of the suggested steps. These ideas and insights can help move Canada forward, towards a reimagined future of resident-centred long-term care in Canada.

Enabling Factors for Immediate System Change

When considering pathways to immediate change within long-term care settings, engagement participants noted several key enabling factors that are necessary for striking balance as we plan for the future of long-term care:

- Evidence-based practices;
- Staffing;
- Funding; and
- Accountability.

Evidence-Based Practices

Citing the numerous studies and reports that exist regarding evidence-informed best practices in long-term care settings, engagement participants talked about the importance of being guided by evidence in order to ensure the provision of “safe, reliable, compassionate, and high-quality care” in Canada. Some specific examples provided by engagement participants included:

- Ethical framework for decision making with respect to safety and risk;
- Models of care that reflect best practices from around the world; and,
- Infection prevention and control protocols that align with public health guidance.

Promising Models of Care

Two of the most commonly cited models of care by engagement participants were: the Butterfly Model of Care and the Green House Project.

The Butterfly Model of Care³

The Butterfly Model of Care focuses on delivering emotion-focused care that connects with people in a dignified, human way. It addresses the holistic needs of the individuals and supports quality of life for each person across the whole of their lived experience.

The key components of the Butterfly Model of Care are focused upon:

- Small households (with front doors) of 8-12 people;
- Housekeepers who are at the heart of the home;
- Emphasizing the quality and value of close relationships that focus on real, positive, social, and shared connection;
- Mealtime experiences (including food preparation, visual choices) are key opportunities for social interaction in the day;
- Grouping people together who are at a similar point of experience
- Providing flexibility in routines;
- Opportunities to reminisce, touch, feel, carry objects, and be engaged in the daily life of the home; and,
- Training on the meanings behind behaviours.

The Green House Project⁴

The Green House Project aims to develop small-scale, self-contained, and self-sufficient long-term care settings that put residents at the centre of what they do. Each home includes private rooms and bathrooms for each resident, a living room with a fireplace, a kitchen where meals are prepared, and outdoor spaces that are easy to access and navigate.

Each home is guided by the Green House core values:

- Meaningful Life: Deep knowing, autonomy and control, and purposeful, meaningful engagement are key.
- Empowered Staff: Radical organizational redesign where care teams thrive on collaborative coaching culture and shared decision making.
- Real Home: Intentional communities of belonging that leverage the power of deinstitutional living and convivium (the sharing of good food in good company).

Staffing

In order to provide “safe, reliable, compassionate, and high-quality care,” engagement participants called for immediate action to address the staffing crisis within long-term care settings in Canada. Some specific examples provided by engagement participants included:

- Ensuring full-time, permanent employment that is equitably compensated (e.g., wages, benefits, pension, paid time off) for expertise and skills.
- Ensuring appropriate staffing levels (e.g., MDs/NPs, RNs, RPNs, PSWs, etc.) and ratios.
- Ensuring access to adequate physical resources (e.g., proper equipment, sufficient hygiene products), as well as increased time to provide care (e.g., increase direct care allocations, decrease amount of documentation/paperwork).

Funding

One of the most frequently stated factors for enabling the provision of “safe, reliable, compassionate, and high-quality care” was funding. Engagement participants felt that increased funding from federal and provincial/territorial governments was absolutely necessary. In particular, engagement participants talked about the importance of funding to provide:

- Adequate care resources (e.g., wages, equipment and supplies).
- Ongoing on-the-job training (e.g., IPAC, care practices).
- Renovating existing or building new infrastructure (e.g., single rooms with private washrooms).

Accountability

Alongside calls for funding, engagement participants also noted the need for greater accountability within the long-term care sector. Specifically, engagement participants want to see:

- Implementation of third-party oversight (e.g., national governance body).
- Enforcement (e.g., inspections, accreditation) of mandated minimum standards of care for all long-term care homes—regardless of ownership.
- Transparent public reporting and ongoing review of documentation.

Suggestions for System Transformation

Beyond the considerations for enabling the balancing act of LTC discussed above, engagement participants also offered some suggestions—or ways forward—for facilitating the transformation of long-term care as we know it within Canada:

- Addressing the stigmas associated with LTC;
- Building collaborative networks of care between all care sectors; and
- Acting on the criteria included in HSO’s National Long-Term Care Services Standard.

Addressing the Stigma Associated with LTC

In order to truly transform the way long-term care is provided in Canada, engagement participants felt that addressing the stigma associated with the provision of long-term care was of the utmost importance. Rooted in widespread societal ageism, engagement participants felt that addressing this stigma could help to change public perceptions of long-term care and care for older persons to:

- The reward for a life well-lived—or as Roundtable Workbook Participants from Saskatchewan shared, their vision for the future is one where moving into a long-term care home is “not seen as an adverse event, but some soft space to land”.
- A highly competitive specialization for healthcare providers.

Addressing the stigma associated with both ageing and long-term care would help to rebuild trust in the provision of long-term care within Canada.

Building Collaborative Networks of Care

When thinking about the future provision of long-term care in Canada, engagement participants advocated for building collaborative networks of care. In particular, engagement participants want to see the creation of a system that will support what people want (i.e., the right care, in the right place, at the right time, by the right provider). In this system, long-term care homes will be connected with each other and other care organizations (e.g., hospitals, home care, hospice), as well as embedded within their local communities. By creating a network of care, engagement participants felt that care provided in long-term care homes would be one possibility in an array of options for support in ageing (i.e., a true continuum of care).

Acting on the Criteria Included in HSO’s National Long-Term Care Services Standard

Engagement participants were tired of empty promises and long-standing inaction with Canada’s long-term care sector. They want to see action. In fact, many engagement participants viewed HSO’s new National Long-Term Care Services Standard as a “catalyst for change” that would help to move the dial from small tweaks (with minimal impact) towards system transformation. For example, engagement participants want to see daily experiences of care that not only align with, but exceed the guidance laid out in HSO’s new National LTC Services Standard.



The sheer number of deaths heightened the public’s awareness of the dire plight of the long-term care system and the need for reform. Various changes have been suggested including single rooms in nursing homes, paying higher wages to care staff, eliminating for-profit care homes, improving working condition, nationalizing long-term care standards, and better oversight. While these changes may be part of the solution, in order to make significant and sustainable improvement, the entire health system must change and the country must revisit the way we support elders in their final years. Every system was perfectly designed to get the results that it gets. If we want different performance, we must think in a fundamentally different way. Our focus on supporting the aging population must be on adding life to remaining years rather than years to remaining life.

– Individual Workbook Participant from British Columbia

Where Do We Go From Here?

The feedback received through HSO's Phase Two Engagement—when taken alongside the responses from HSO's 2021 Inaugural National LTC Standards Survey—have helped HSO's National LTC Services Standard Technical Committee better understand what is important to Canadians when it comes to the future provision of long-term care in Canada. The feedback collected through our engagement activities to date (i.e., 2021 Inaugural National Survey, Consultation Workbooks, Town Halls) will directly inform the development of HSO's new National LTC Services Standard.

Moving forward, we welcome your feedback on the draft National LTC Services Standard—which will be released for public review in early 2022. We will also be inviting groups and individuals from across the country to participate in an additional series of Town Halls. Please contact engagement@healthstandards.org for more information.

After incorporating the feedback generated from the public review and other engagement in early 2022, the final National LTC Services Standard will be published in the fall of 2022.

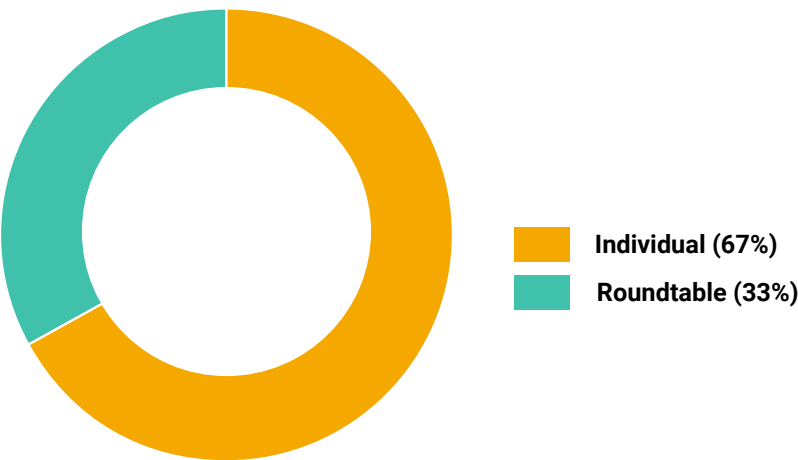
For more information and to follow HSO's standard development and engagement activities, go to: www.longtermcarestandards.ca.

Appendix: Who We Heard From

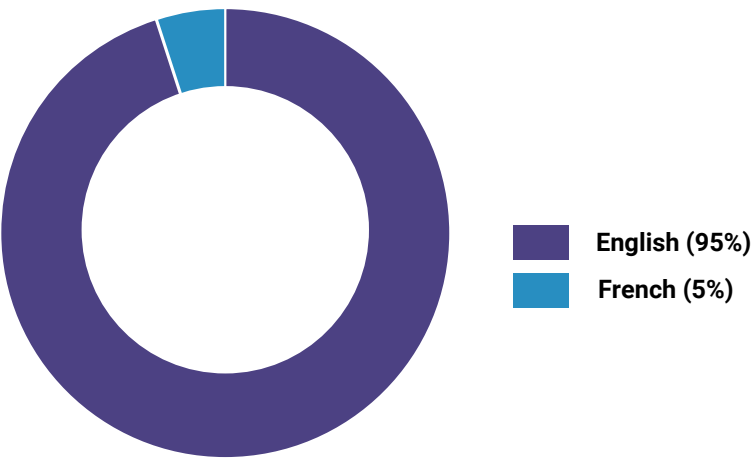
In what follows, we provide a breakdown and analysis of the demographic profile of Canadians who participated in HSO’s Phase Two Engagement. Please note that while we engaged with 1,984[§] Canadians, not all participants chose to provide responses to all demographic questions –as indicated by “Prefer not to answer/No response” or “Did not report” in the following charts.

Workbooks

In HSO’s Phase Two Engagement, a total of 392 Consultation Workbooks were received from participants from across the country. Of these 392 submissions, there were 264 (67%) Individual Workbooks and 128 (33%) Roundtable Workbooks—as illustrated in the chart below.



Breaking down the total Consultation Workbook submissions by language, 95% (371) of submissions were completed in English.



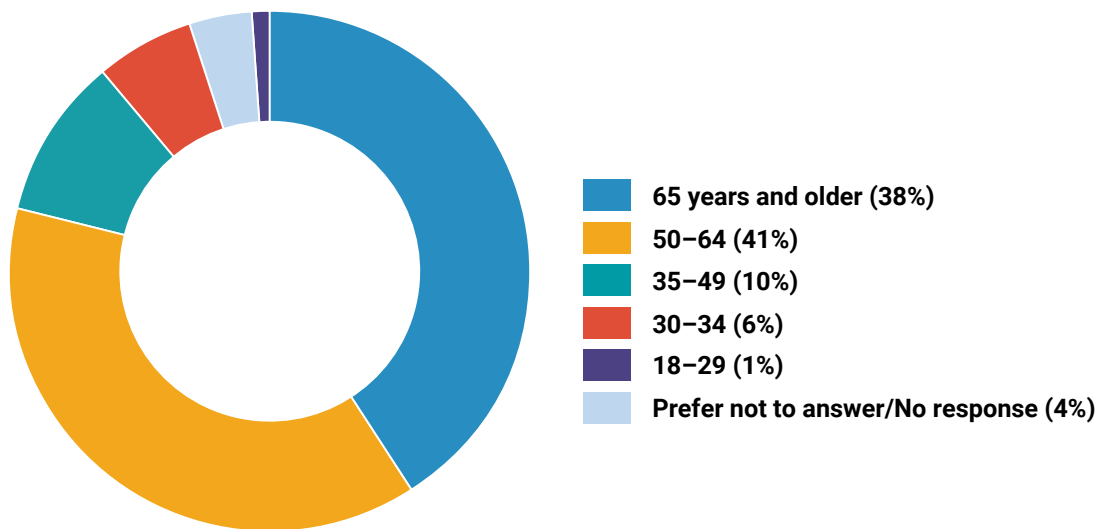
[§] While the total number of participants on record is 1,984, this number is an underrepresentation of participation as some groups who completed Roundtable Consultation Workbooks did not report how many participants were present.

Individual Submissions

In this section, we will breakdown the demographic profile of HSO’s Phase Two Engagement participants who submitted Individual Consultation Workbooks.

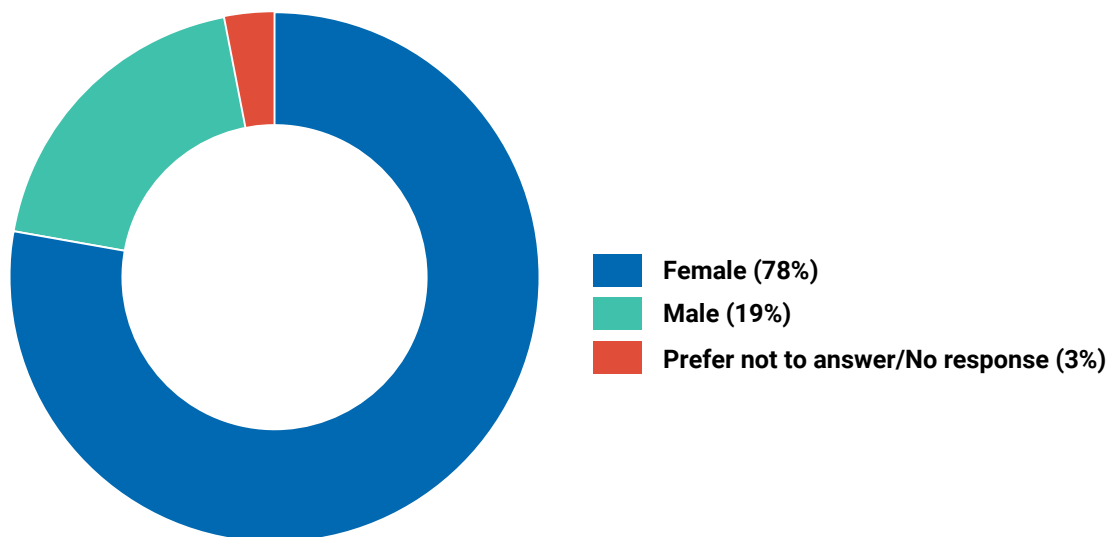
Age

The majority of participants who submitted an Individual Workbook indicated they were over the age of 50. Specially, 38% (100) identified as being 65 years and older, while 41% (108) identified as being between the ages of 50 and 64. Similar to participants in HSO’s 2021 Inaugural National Survey on Long-Term Care, the overwhelming response from Canadians over the age of 50 demonstrates that these issues are closer to home for older Canadians.



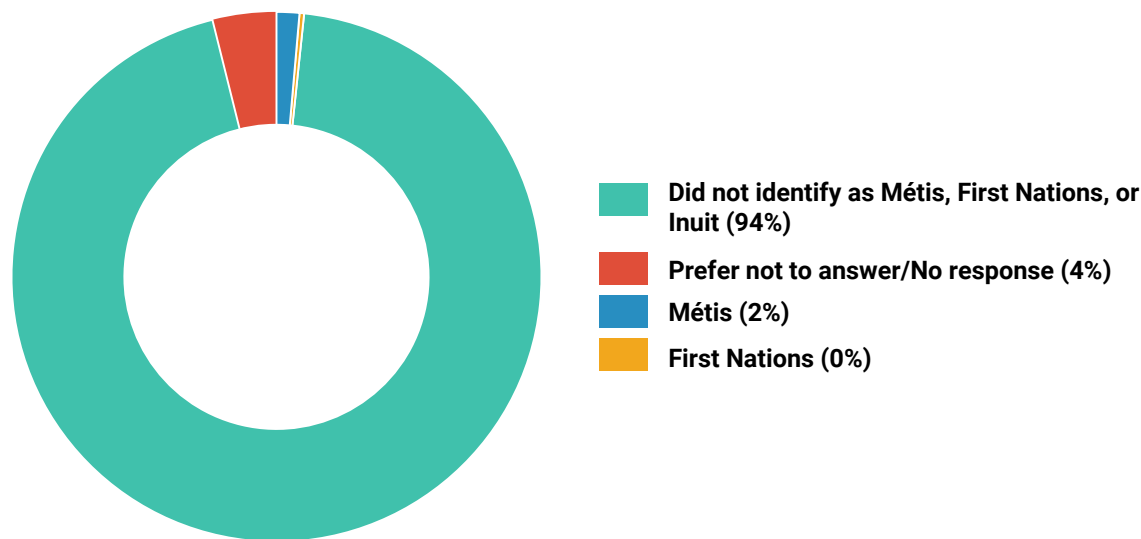
Gender

The overwhelming majority of participants (78%, 207) who submitted an Individual Workbook indicated that they identify as female—which is significantly higher than Canadian population averages, where 50.6% of people over the age of 18 in Canada are female.⁵

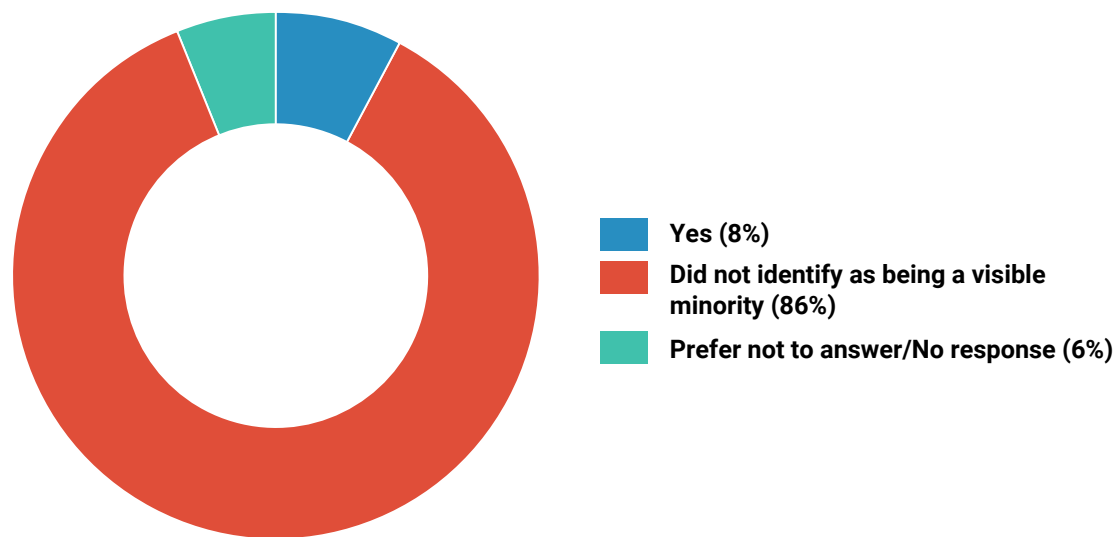


Race

While Indigenous peoples comprise 4.9% of the total population in Canada, only 2% (5) of individuals who responded to this question indicated that they were First Nations, Métis, or Inuit.⁶

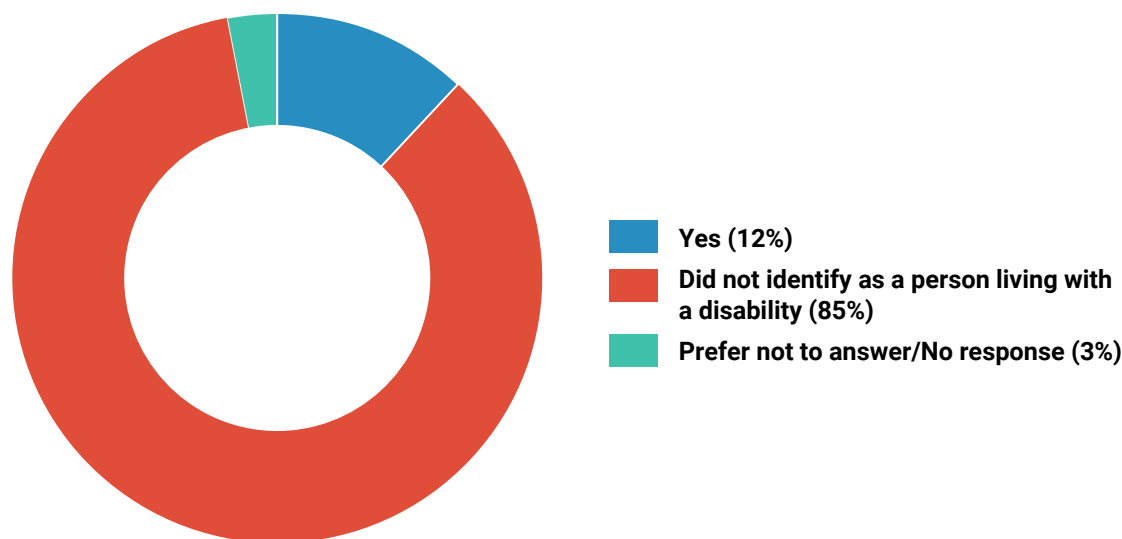


Of the individuals who submitted an Individual Workbook, 8% (21) identified as being from a visible minority—which is significantly less than the 22.3% of the total Canadian population who identify as being from a visible minority.⁷ In alignment with The Employment Equity Act, visible minority was defined as “persons, other than Aboriginal persons, who are non-Caucasian in race or non-white in color.”^{8,9}



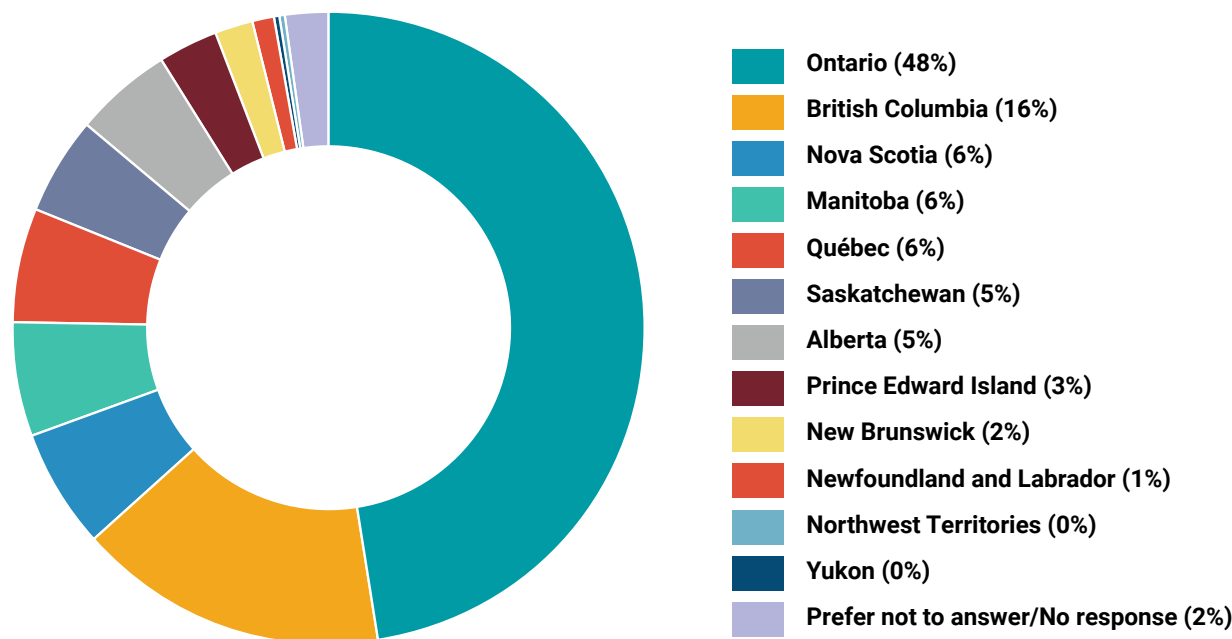
Ability

Of the individuals who submitted an Individual Workbook, 12% (31) identified as living with a disability—compared to 22% of the total population in Canada.¹⁰



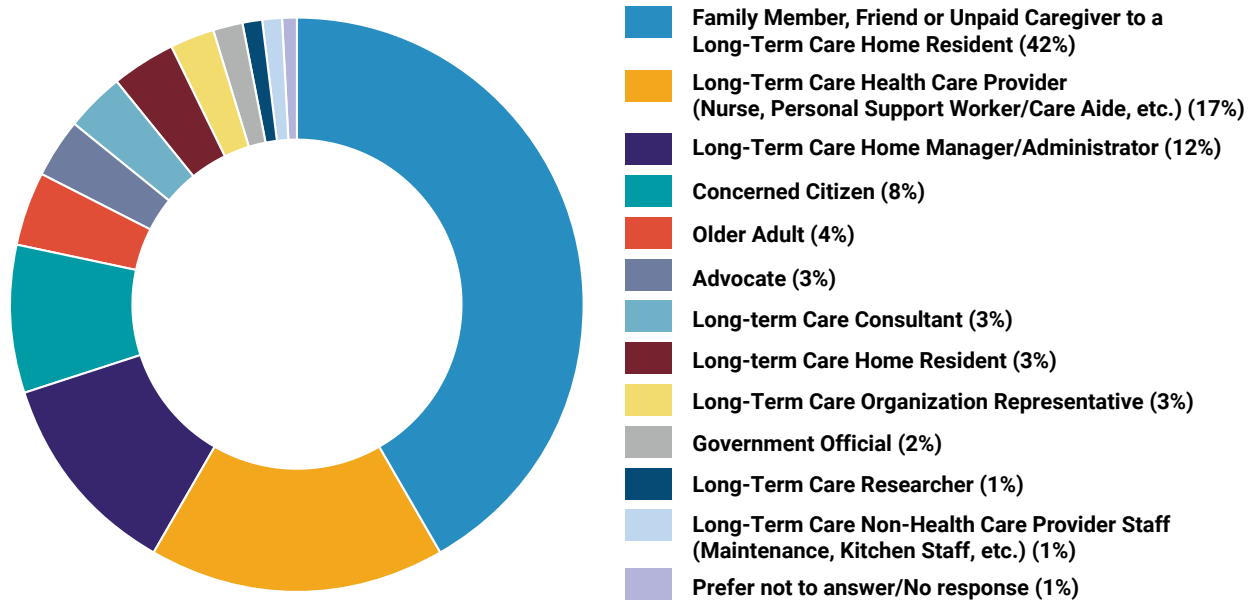
Geographic Location

While the majority of participants who submitted an Individual Workbook identified as living in Ontario (48%, 126), we saw increased representation from across Canada when compared to response rates to HSO’s 2021 Inaugural National Survey on Long-Term Care (as illustrated below).



Relationship to LTC

The largest proportion of Individual Workbooks (42%, 110) were received from participants who identified as a Family Member, Friend, or Unpaid Caregiver to a LTC Home Resident, followed by submissions from participants who identified as being part of the LTC workforce (18%, 47), while only 3% (9) of participants identified as being a LTC Home Resident.

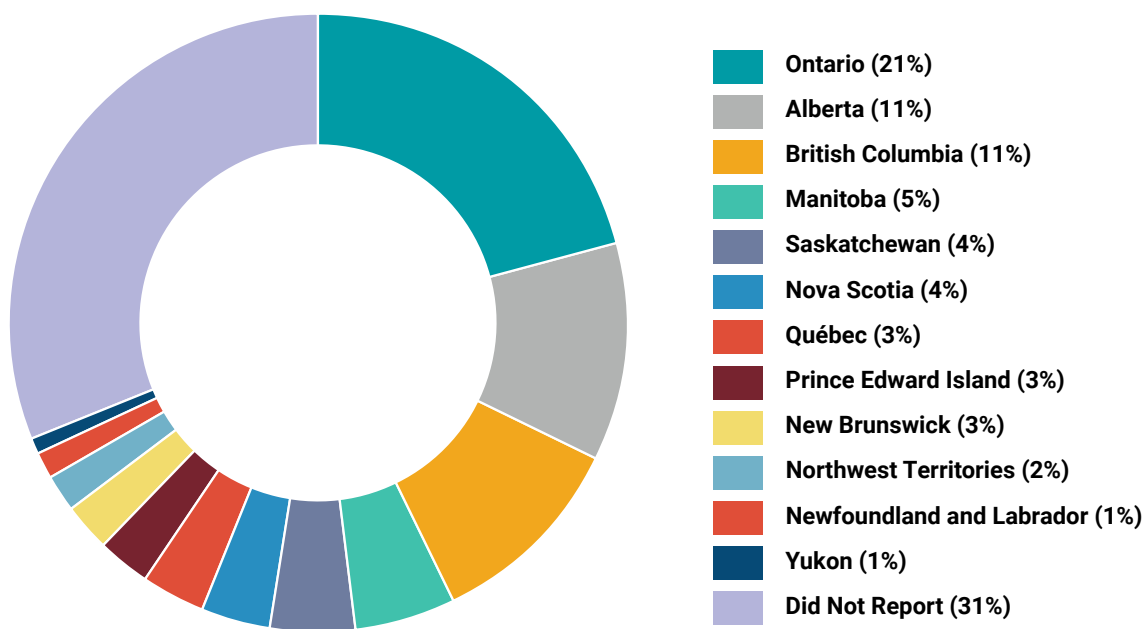


Roundtable Submissions

In this section, we will breakdown the demographic profile of HSO’s Phase Two Engagement participants who submitted Roundtable Consultation Workbooks.

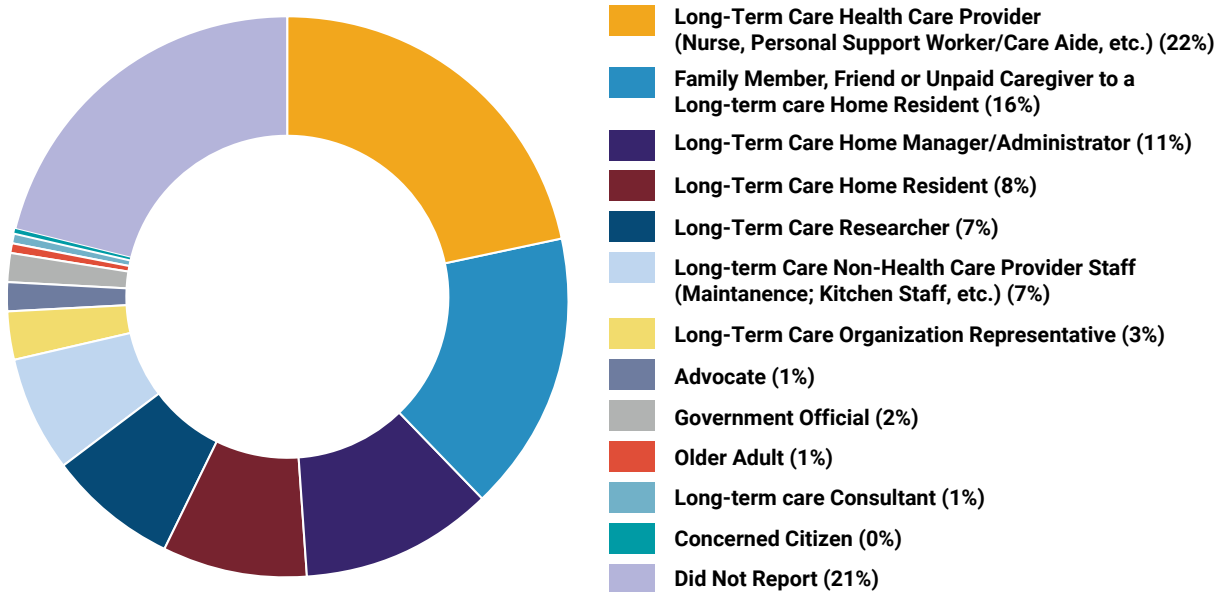
Geographic Location

In contrast to participation in HSO’s 2021 Inaugural National Survey on Long-Term Care, the majority (31%) of participants who participated in a Roundtable Workbook discussion identified as living in Western Canada (Alberta – 11%, 36; British Columbia – 11%, 33; Manitoba – 5%, 16; Saskatchewan – 4%, 14); versus 24% of submission from Central Canada (Ontario - 21%, 66; Quebec – 3%, 10). However, 31% (97) of survey respondents preferred not to identify their geographic location—which most likely reflects concerns participants held about data usage and the potential of being identified by their responses.



Relationship to LTC

The largest proportion of participants who participated in a Roundtable Workbook discussion (29%, 89) reported being part of the LTC workforce; while 16% (51) identified as a Family Member, Friend, or Unpaid Caregiver to a LTC Home Resident and 8% (23) as being a LTC Home Resident

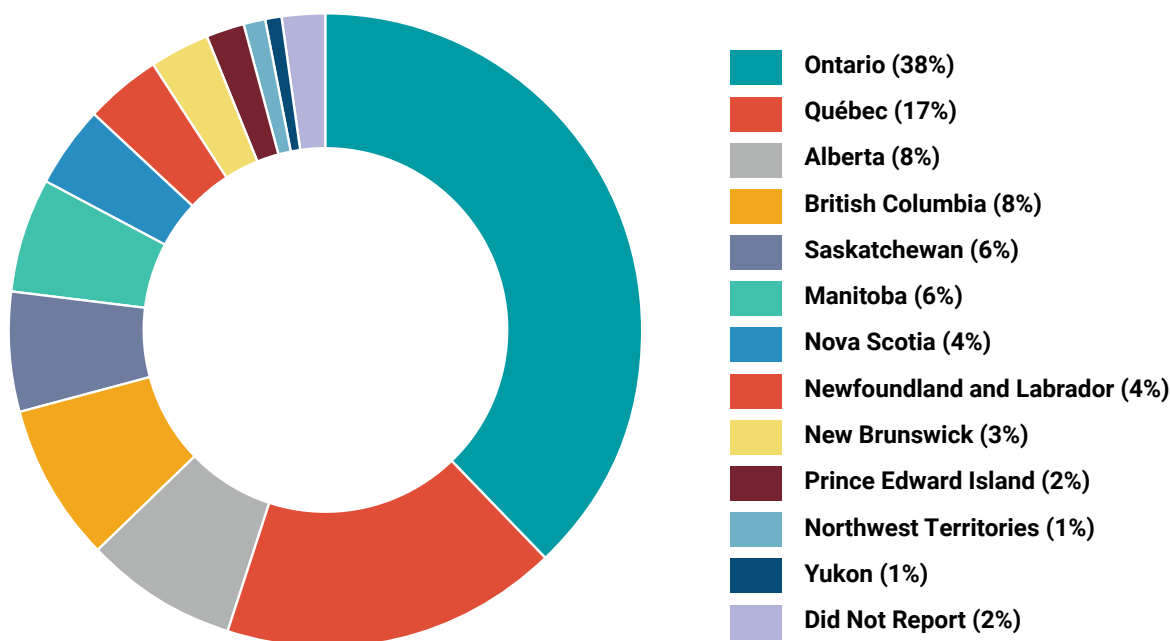


Town Halls

In this section, we will breakdown the demographic profile of HSO’s Phase Two Engagement participants who participated in a Town Hall. It is also important to note that we collected limited sociodemographic information (i.e., geographic location, relationship to LTC) due to the public nature of the Town Halls.

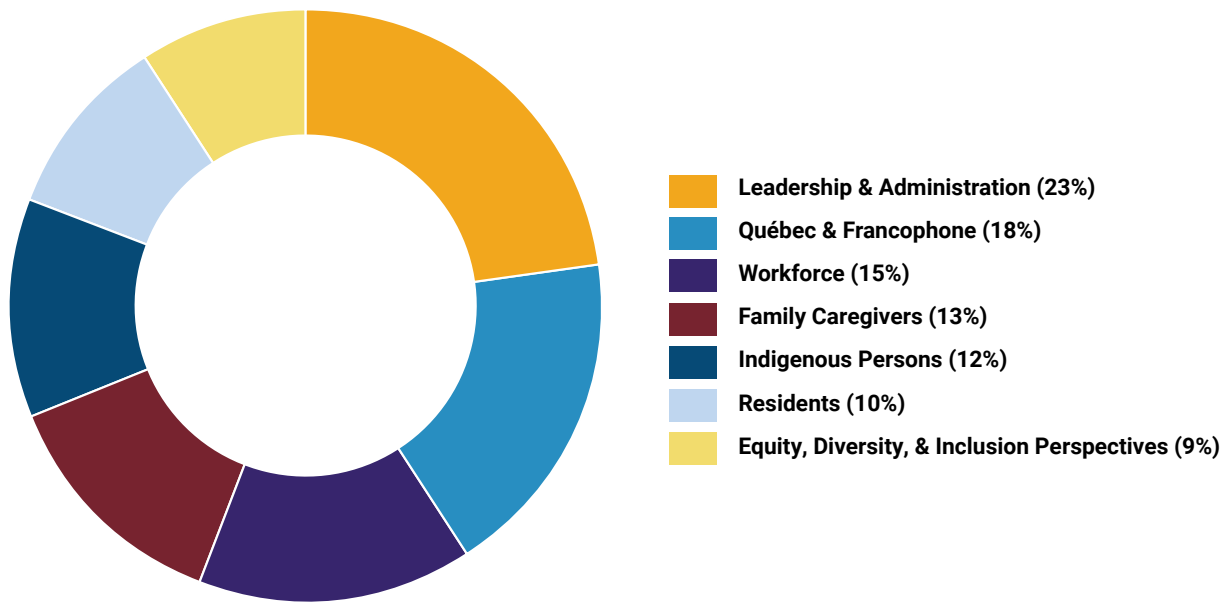
Geographic Location

The majority (55%) of Town Hall participants reported living in Central Canada (Ontario – 38%, 69; Quebec – 17%, 31), followed by 27% from Western Canada (Alberta – 8%, 14; British Columbia – 8%, 14; Saskatchewan – 6%, 11; Manitoba – 6%, 10), 14% from Eastern Canada (Nova Scotia – 4%, 8; Newfoundland and Labrador – 4%, 7; New Brunswick – 3%, 6; Prince Edward Island – 2%, 4), and 1% from Northern Canada (Northwest Territories – 1%, 1; Yukon – 1%, 1).



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 participants is illustrated below.



References

- ¹ 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?fbclid=IwAR1DaGluCN7FXIYJ0jDf1IS7jlnwDPT9Tr4bisrhn32QyvnAC56u0DjtfFE#refi>
- ² First Nations Health Authority. (2021). Cultural safety and humility.
<https://www.fnha.ca/wellness/wellness-and-the-first-nations-health-authority/cultural-safety-and-humility>
- ³ Primacare. (2020). Innovations in care: Butterfly model of care.
<https://www.primacareliving.com/butterfly-model-of-care>
- ⁴ The Green House Project. (2021). The Green House Project: Nursing homes made for this moment.
<https://thegreenhouseproject.org/>
- ⁵ Statistics Canada. (2017). Table 17-10-0005-01 Population estimates on July 1st, by age and sex [Data table]. <https://doi.org/10.25318/1710000501-eng>
- ⁶ Statistics Canada. (2017). Aboriginal peoples in Canada: Key results from the 2016 Census [The Daily].
<https://www150.statcan.gc.ca/n1/daily-quotidien/171025/dq171025a-eng.htm>
- ⁷ Statistics Canada. (2017). Census Profile: Canada [Country] and Canada [Country] (Data table). <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/prof/details/page.PR&Code2=01&Data=Count&SearchText=Canada&SearchType=Begins&SearchPR=01&B1=Visible%20minority&TABID=1>
- ⁸ Catalyst. (2020). People of Colour in Canada (Quick Take).
<https://www.catalyst.org/research/people-of-colour-in-canada/>
- ⁹ Statistics Canada. (2017). Visible minority and population group reference guide, Census of the Population, 2016 [Reference materials].
<https://www12.statcan.gc.ca/census-recensement/2016/ref/guides/006/98-500-x2016006-eng.cfm>
- ¹⁰ Morris, S., Fawcett, G., Brisebois, L., & Hughes, J. (2018). A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017. Canadian Survey on Disability Reports, 89-654-X.
<https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm>

People powered health™

