

Background

- On 3 October 2025, a diverse group of 10 citizens – a mix of long-term care (LTC) residents, their families and caregivers, and those with experience as staff – brought their unique perspectives to deliberate about helping LTC homes in Ontario protect residents and staff during infectious disease outbreaks. The virtual panel was informed by a pre-circulated citizen brief and had three main objectives: 1) to gather insights on the challenges LTC residents, their families and caregivers, and staff face during outbreaks, particularly as they navigate efforts to reduce the spread of infections; 2) to explore potential approaches that could help homes adopt mandated infection prevention and control measures, co-develop context-specific responses, and strengthen learning and improvement cycles; and 3) to identify barriers and facilitators that could influence whether and how these approaches are implemented. Box 1 provides a summary of the main features of the virtual panel.
- The views and experiences shared by panellists were used to inform a provincial stakeholder dialogue on the same topic, bringing together government policymakers, system and organizational leaders, professional leaders, leaders from citizen-serving NGOs or organizations, and research leaders to deliberate about the problems, elements of a potentially comprehensive approach for addressing them, and implementation considerations. This document summarizes the key themes that were raised by participants at the citizen panel.

Summary of the deliberation about the problem

In discussing the problem and its causes, participants mostly agreed with the points as they were framed in the pre-circulated citizen brief (see visual below). The main points they raised often reinforced what was covered by the citizen brief, and in many instances, participants added additional insights based on lived experience, which are summarized in the sections that follow.

Panel Summary

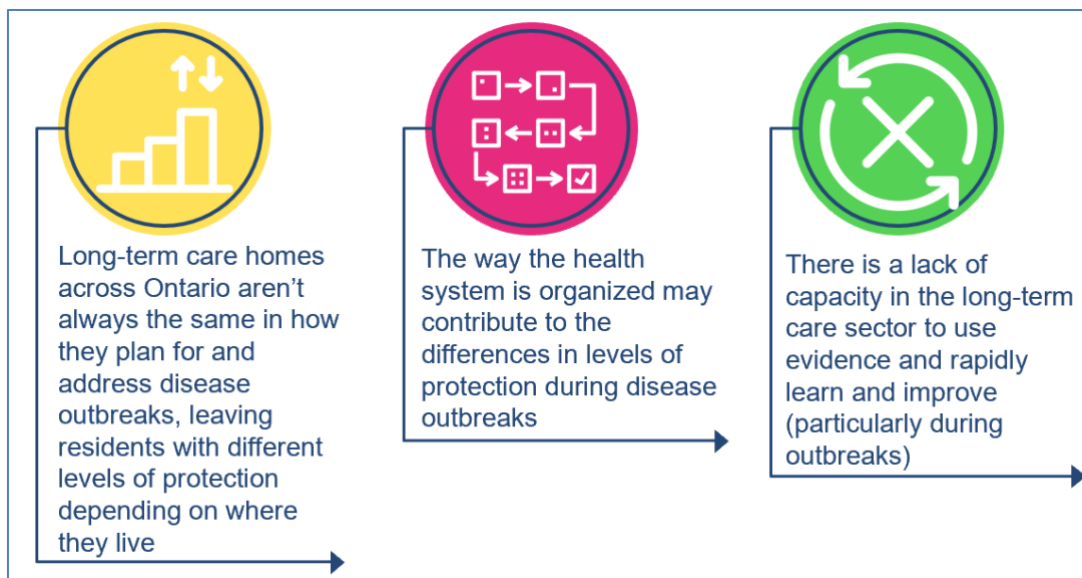
Helping long-term care homes in Ontario protect residents and staff during infectious disease outbreaks

3 October 2025

Box 1: About this panel

This virtual panel had the following 11 features:

- it addressed a high-priority issue in Canada
- it provided an opportunity to discuss different features of the problem
- it provided an opportunity to discuss solutions for addressing the problem
- it provided an opportunity to discuss key barriers and facilitators to move forward
- it provided an opportunity to talk about who might do what differently
- it was informed by a pre-circulated, plain-language brief
- it involved a facilitator to assist with the discussions
- it brought together participants affected by the problem or by future decisions related to the problem
- it aimed for fair representation among the diversity of participants involved in or affected by the problem
- it aimed for open and frank discussions that preserved the anonymity of participants
- it aimed to find both common ground and differences of opinions.



Long-term homes across Ontario aren't always the same in how they plan for and address disease outbreaks, leaving residents with different levels of protection depending on where they live

Most participants described the inconsistencies they experienced with respect to the use of infection prevention and control (IPAC) measures in LTC homes, with specific examples related to personal protective equipment (PPE) being better in some settings than in others, and ventilation systems that weren't always functional. Participants also described several factors that they said contribute to variation across homes:

- Some participants noted that they understood the inconsistent use of IPAC measures to be shaped by a mix of factors such as:
 - geography, such as the difference between how homes function in urban compared to rural settings
 - health-system factors, including different levels of funding, management capacity, and infrastructure across LTC homes, as well as staffing – which was also discussed extensively in relation to the second component of the problem (covered in the next section).
- Many participants also focused on the role the poor communication played in driving variation in how IPAC measures are used across LTC homes in Ontario, explaining that in their experience:
 - residents, families and caregivers, and staff often receive conflicting and unclear information during disease outbreaks (especially during crises like the COVID-19 pandemic), and this can create confusion, leading to a loss of trust and confidence
 - communication among LTC home staff and managers appears inadequate and fragmented, with inconsistent information-sharing during shift changes and limited access to shared records.
- In addition to discussing variations and inconsistencies, during this part of the deliberation many participants voiced concerns about the downsides of IPAC measures for residents, families, and caregivers, discussing the negative impacts – including isolation, emotional harm, depression, and anxiety (especially during the COVID-19 pandemic) – that resulted from the use of restrictive visitation policies. Specific examples provided by participants included mask-related communication barriers, reduced social contact due to distancing, and limited support for navigating technology for virtual visits.
- A few participants also noted that there are ethical concerns associated with aspects of the COVID-19 pandemic response that need to be considered because they further erode trust in decision-makers, such as:
 - focusing narrowly on disease control without respecting residents' autonomy, dignity, and quality of life
 - deploying the military into what should be respected as residents' homes
 - decision-makers failing to be transparent about trade-offs during crises.



The way the health system is organized may contribute to the differences in levels of protection during disease outbreaks

Participants also discussed how health-system arrangements shape the way IPAC measures are used in response to disease outbreaks in LTC homes. They spent most of the time during this part of the panel sharing their views about challenges in three areas: accountability, fragmented communication, and staffing.

- Participants discussed a lack of accountability at two levels:
 - At the level of the LTC sector, participants identified the following challenges with respect to accountability for decision-making related to IPAC:
 - too many decision-making authorities with overlapping or unclear roles
 - poor coordination between levels of government, and overly complex decision-making processes that discourage participation by residents, their families and caregivers, and staff
 - a lack of engagement of residents, their families and caregivers, and staff in how IPAC rules are developed and implemented.
 - At the level of LTC homes, participants described contributors to a lack of accountability for adhering to mandated IPAC measures, including:
 - irregular and inconsistent inspections narrowly focused on compliance, inconsistent enforcement of rules, and limited transparency
 - few opportunities for residents, their families and caregivers, and staff to provide feedback during inspections, meaning experiences were not used to learn and improve.
- When discussing fragmented communication, participants focused on challenges related to:
 - information flowing from multiple unaligned sources
 - a lack of mechanisms to keep all groups up to date across the system
 - media contributing to confusion and misalignment between system-level messaging and residents' lived experience inside homes.
- Within conversations about staffing, participants focused on shortages and a lack of capacity among existing staff in LTC homes as major contributors to the problem. The following examples were also provided as factors that make the situation worse:
 - recruitment that prioritizes the wrong individuals, such as those without a real interest in working in the LTC sector, and those who were 'rushed' through training and licensure processes to fill vacancies (which can lead to staff who are unqualified or underprepared for implementing IPAC measures)
 - a lack of proper onboarding and ongoing learning opportunities to help build a workforce that is capable of adapting to evolving IPAC measures
 - low wages for those working in LTC, forcing many workers to hold multiple jobs, which increases their workload (and risk of burnout)
 - challenges associated with persistent burnout among those working in LTC homes (particularly since the COVID-19 pandemic), with staff seeming chronically overwhelmed, tired, emotionally exhausted, and unable to function in ways that support the delivery of high-quality, personalized care consistently to residents.

During these discussions, some participants noted that their loved ones lacked basic supports as a result of staffing challenges during disease outbreaks, such as brief/incontinent product changes and bathing, and expressed their concern that this led to worsening or new health problems.



There is a lack of capacity in the long-term care sector to use evidence and rapidly learn and improve (particularly during outbreaks)

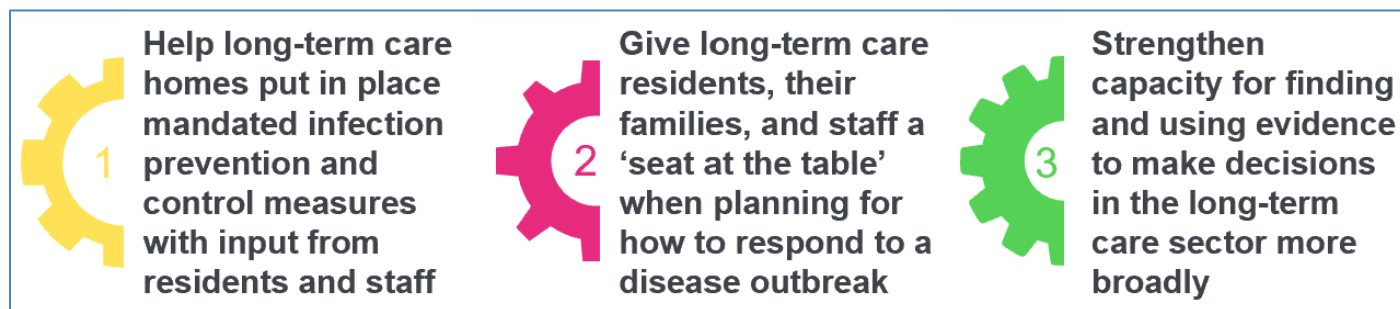
Participants highlighted challenges related to communication, feedback, and decision-making that limit opportunities for using evidence and for learning and improvement during outbreaks.

- Participants highlighted the lack of mechanisms for feedback and two-way communication that could be used to raise problems in LTC homes, including:
 - few opportunities or mechanisms that enable residents and their families and caregivers to communicate with staff and managers
 - fear among residents and their families and caregivers about providing honest negative feedback

- lack of accommodations to enable feedback from people with varying communication needs (e.g., vision or hearing impairments).
- Participants also noted that:
 - the absence of transparent, evidence-informed processes for weighing trade-offs hindered the sector’s ability to learn and improve during rapidly evolving conditions
 - harms related to isolation and emotional well-being did not appear to be adequately incorporated into decision-making during the COVID-19 pandemic, signalling gaps in how emerging lessons learned were documented and used to inform efforts to improve the situation.

Summary of the deliberation about solutions

Participants raised several issues when discussing each solution as they were framed in the brief (see visual below) and focused on how each could work in practice. They suggested ways to adapt or deepen them based on their experiences in long-term care homes, which are summarized in the sections that follow.



Help long-term care homes put in place mandated infection prevention and control measures with input from residents and staff

When discussing element 1, participants voiced support for implementing mandated measures consistently, while reflecting resident and staff perspectives. They suggested several approaches that could be adopted to support this aim, which included:

- clear communication from decision-makers to LTC residents, their families and caregivers, and staff about which measures are mandated (versus those that can be adapted locally)
- guidance and tools that advise on how local factors, including residents’ risk levels, health conditions and care needs, and those related to settings (e.g., rural or urban), can be built into implementation plans, as well as the trade-offs that need to be considered (e.g., short-term expenses that may have long-term benefits for the health and well-being of residents and staff)
- advisory boards or councils in each LTC home that include LTC residents, their families and caregivers, and staff to guide the interpretation and implementation of mandated measures
- mechanisms to facilitate structured, ongoing feedback about the implementation of mandated IPAC measures (e.g., morning briefings, shift turnover meetings, meal-time discussions, or during home inspections), in ways that empower residents and staff – including efforts to ensure that such a mechanism is accessible to everyone (e.g., accounting for different language needs and hearing and vision impairments).



Give long-term care residents, their families, and staff a ‘seat at the table’ when planning for how to respond to a disease outbreak

During discussions related to element 2, all participants emphasized the importance of meaningful involvement of LTC residents, their families and caregivers, as well as staff in decision-making about disease outbreaks. They noted that this type of engagement should:

- occur early, when potential outbreaks are being monitored, not after decisions have already been made
- be driven by permanent advisory boards or councils that engage LTC residents, their families and caregivers, and staff (and that facilitate co-governance and collaborative decision-making), ideally through regular meetings, such as morning check-ins and staff/resident discussions
- include mechanisms that foster safe and confidential feedback from residents and their families and caregivers so concerns can be raised without fear of retaliation (or worse care), and that includes communication about how concerns are being addressed.

Participants also expressed the importance of several principles (which often overlapped with key themes raised when discussing element 1), such as:

- inclusivity (e.g., ensuring diverse health and social needs as well as perspectives are embedded in the process)
- transparency (e.g., clear communication about trade-offs considered)
- accountability (e.g., feedback mechanisms that are clear about how challenges raised by residents, their families and caregivers, and staff are being addressed)
- flexibility (e.g., multiple 'ways in' for resident inputs)
- commitment to collaboration and continuous learning and improvement.



Strengthen capacity for finding and using evidence to make decisions in the long-term care sector more broadly

When discussing element 3, participants highlighted the value of building stronger mechanisms for learning and improvement, with many stating that better support for learning and improvement could help LTC homes respond more effectively to outbreaks. They also pointed to several specific approaches that could be adopted now to improve how evidence is gathered, shared, and used in decision-making about outbreaks, such as:

- building on lessons learned from previous outbreaks and making 'what works' the new normal
- creating (or building on existing) centralized data collection and tracking systems, ensuring that LTC residents, their families and caregivers, and staff can provide input on what is being measured and what targets and goals are being set for their home
- building processes for transparent reporting of progress in ways that are accessible to LTC residents, their families and caregivers, and staff
- building 'feedback loops' that can accommodate varying preferences for providing input, with one participant suggesting home inspections could be leveraged to collect structured feedback from LTC residents and staff to inform how standards evolve over time and how future policies are shaped
- facilitating opportunities for cross-sector and cross-jurisdiction learning, including learning from acute care or home care, or from other provinces, territories, or countries.

Summary of the deliberation about barriers and facilitators to moving forward

After discussing the three solutions, participants examined potential barriers to and facilitators of moving forward.

- Participants identified three barriers that could affect the implementation of the three elements, including:
 - 1) financial constraints, with participants noting that limited resources make it difficult for homes to hire qualified staff, support training, and update communication systems
 - 2) staff shortages
 - 3) communication gaps and unclear responsibilities across the many decision-making authorities involved in LTC.
- Participants also identified four facilitators, including:
 - 1) many staff are deeply committed to residents' well-being, which can help drive improvements when supported by strong leadership within homes and across the sector more generally
 - 2) LTC residents and their families and caregivers want to be more actively involved in planning, which could strengthen trust, improve transparency, and lead to more responsive decision-making in homes

- 3) there are simple, consistent practices that are already in place that could be leveraged to improve engagement and drive learning and improvement (e.g., regular team meetings, structured opportunities for residents and families to share feedback, and clearer communication about goals)
- 4) there are lessons available from other sectors and other jurisdictions that can serve as a starting point.

Ali A, Dass R, Whitelaw H, Moat KA. Panel summary: Helping long-term care homes in Ontario protect residents and staff during infectious disease outbreaks. Hamilton: McMaster Health Forum; 3 October 2025.

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