McMaster University | Health Forum

Citizen Brief

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

3 October 2025

Context

Background

People living in long-term care can be at greater risk of becoming sick when there are infectious disease outbreaks in the places they live. Staff working in these settings also risk becoming sick during disease outbreaks. This brief is focused on how to help ensure long-term care homes in Ontario can protect residents and staff during such outbreaks and will provide an overview of several aspects of the issue as an input into a citizen panel (see Box 1).

Some of the diseases of public health significance that pose the greatest risk to residents in long-term care homes include:
- respiratory infections (such as COVID-19 and influenza)
- gastroenteritis
- clostridioides difficile (commonly referred to as 'C.diff' for short)
- candida auris.

Residents of long-term care homes are typically older and include people living with multiple health conditions. For example, 75% of residents entering long-term care homes have three or more medical conditions (including hypertension, dementia, arthritis, diabetes, and cardiovascular disease), which makes them more vulnerable in the face of disease outbreaks.

While this has always been the reality for long-term care residents, many Ontarians only became aware of this risk during the COVID-19 pandemic. In Canada, over 80% of COVID-19 deaths during the first pandemic wave occurred in long-term care homes, and in Ontario, 13 times more long-term care residents over the age of 69 died compared to those over 69 living in the community.(1; 2)

To keep residents, staff, and visitors in long-term care as safe as possible during disease outbreaks infection prevention and control efforts are an important tool. For example, in Ontario such efforts were used in long-term care homes during the pandemic – including mask wearing, testing, and screening – and were shown to reduce the spread of illness among residents and staff before the availability of vaccines.(1)

Box 1: About this citizen brief

This document was produced to inform a citizen panel with citizens – including long-term care residents – from across Ontario. The panel will bring together 14–16 participants to share their ideas and experiences regarding the issue and learn from research evidence and from the views of others. The panel will help us to understand the values that participants feel should inform future decisions about the issue, as well as to reveal new understandings and get ideas about how it should be addressed.

The insights and lessons learned from the panel discussion will inform an upcoming dialogue on this topic in November 2025. This dialogue will bring together government policymakers, system and organizational leaders, health professionals, researchers, members of the public, and other interest holders from across Ontario.

We used three mechanisms to collect the information presented in this document:
- we consulted the committee leading this project
- we interviewed people who know the issue very well
- we examined what is known from the best-available evidence documents on the issue.

Throughout the document, we provide spaces for you to write down your thoughts ahead of the panel discussion. At the end of the document, we also provide a glossary of some of the key terms used throughout the document, as well as a list of all the references we cited in the document.

Why is this issue important?

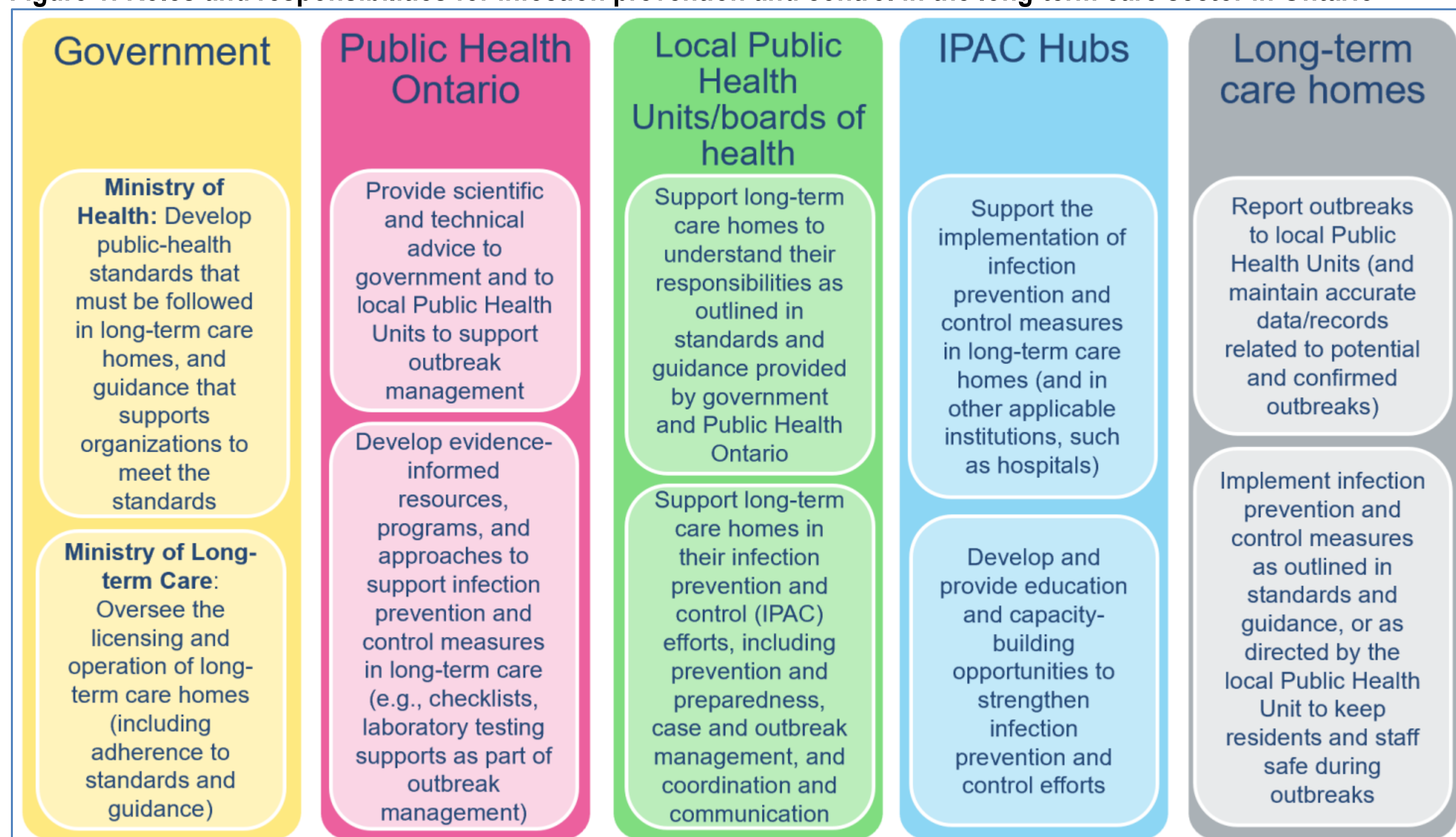
The long-term care sector in Ontario is large, with 76,000 resident spaces across 609 licensed long-term care homes. These homes include a mix of publicly and privately owned organizations, with privately owned homes made up of both for-profit and not-for-profit organizations. Long-term care homes are unique because, while they are places people receive care and support, they are peoples' homes first and foremost.

There are also many organizations (including government) with important roles to play in identifying and responding to disease outbreaks in long-term care homes (**see Figure 1**). These organizations function at different levels of the long-term care system, and some may have a better understanding than others about the 'day-to-day' realities of what happens in long-term care homes This can make it challenging to coordinate approaches across the province. Studies have shown that there can be large differences in how different homes have responded during past disease outbreaks, such as during the COVID-19 pandemic.(3; 4) Some of these differences may be necessary or expected, but they could also mean that residents and staff aren't equally benefitting from best practices, which could lead to differences in their health and well-being. It could also mean that not all residents are enduring the same challenging adjustments to their daily living when infection prevention and control measures have downsides.

In the sections that follow, the brief will provide you with a description of some of the problems that could be driving this issue, potential solutions for addressing them, as well as the barriers and facilitators that will influence whether and how those solutions are adopted.

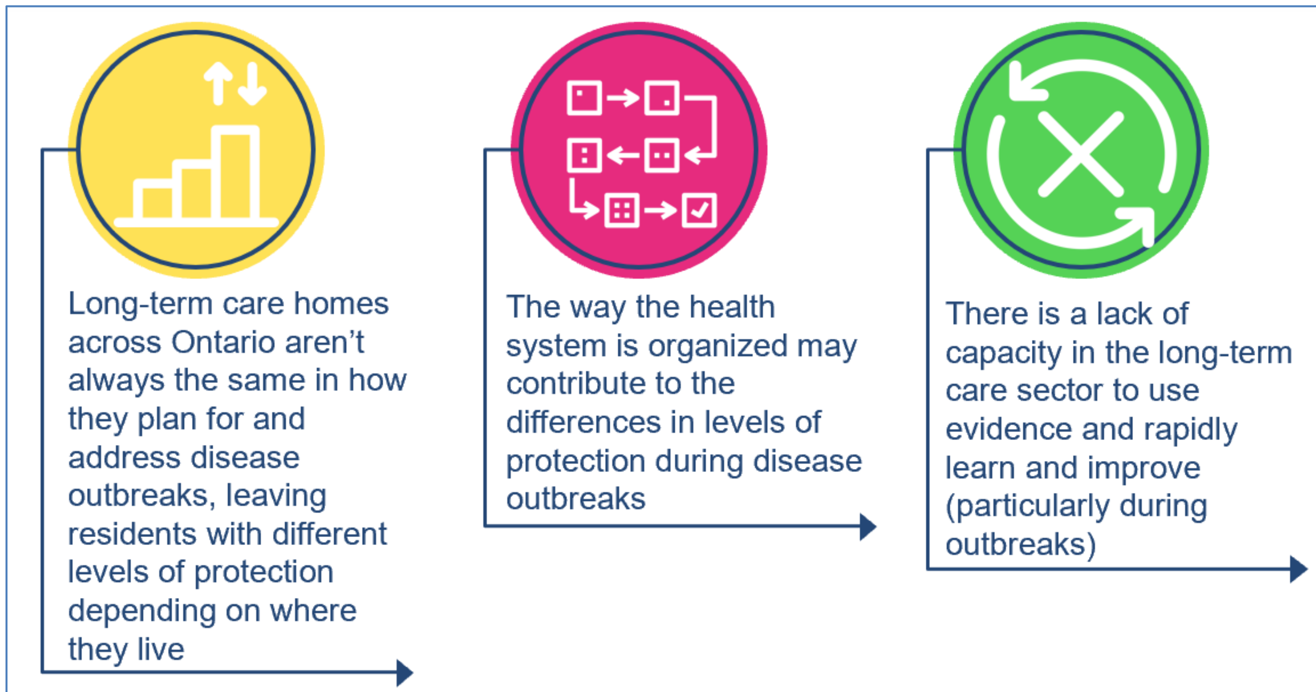
Each section includes questions that citizens may want to consider as preparation for the citizen panel discussions. We also provide a glossary at the end of the document, which defines important terms used throughout this brief.

Figure 1: Roles and responsibilities for infection prevention and control in the long-term care sector in Ontario



Exploring the problem

We have identified three aspects of the problem, which are outlined in the visual below and discussed in the sections that follow.



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

Ontario has 609 licensed long-term care homes spread across many different communities. Because of this diversity, it's natural that each home might operate a little differently. But when it comes to stopping the spread of diseases of public health significance, all homes are expected to follow the same best practices. These are outlined in the Ontario Public Health Standards and supported by resources to help homes meet these best practices, such as the checklists developed by Public Health Ontario.(5; 6)

Researchers have found that during the COVID-19 pandemic, long-term care homes in Ontario didn't always follow public-health rules in the same way – even within the same region.(3; 4) For example, in Southeastern Ontario, the rules for visitation from family and friends and for recreational activities wasn't always the same across homes.(3; 4) These differences mean that residents living in homes that didn't put the rules in place as directed may have been at higher risk of infection. However, it's also true that residents living in these same homes may have been less negatively impacted by pandemic restrictions that have been documented in Ontario and in other jurisdictions as negatively affecting health and well-being.(7-11)

There are at least four reasons why long-term care homes might vary in how they respond to disease outbreaks:

1) homes are owned and operated in various ways in Ontario, with some being owned publicly, and others run by private corporations
2) homes don't all have the same approach to applying public-health rules and this is especially true when those rules change quickly or when they allow for local flexibility (which requires decision-makers to make their own judgements)
3) the risk to the community and to those living in a long-term care home may change depending on where you are in the province, with dense urban communities needing to take different factors into account than rural ones
4) the make-up of residents varies across homes with respect to their health and social needs, meaning some homes have a greater number of residents with complex health conditions that can put them at greater risk during an outbreak, or

have a more culturally diverse mix of residents which may affect how different infection prevention and control measures are received.

Studies showed that some of these factors affected things like COVID-19 positivity rates. For instance, rates were higher in Central Ontario than in Northern Ontario, and higher in municipally owned homes than in for-profit ones.(12)

Two other factors may also contribute to differences in how long-term care homes respond to disease outbreaks in Ontario:
1) public health messaging comes from multiple sources, which may create confusion, especially if the messaging is changing or evolving (as it did during the COVID-19 pandemic)
2) the staff responsible for implementing infection prevention and control measures need to balance the safety, emotional well-being, and comfort of the residents they care for, which can be especially tough when residents have different health and social needs.

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

Several issues in how the long-term care system is governed, funded, and delivered are making it harder for homes to follow infection prevention and control rules during outbreaks of diseases.

Three main governance issues affect how long-term care homes respond to outbreaks:
1) The laws and regulations developed may clash with the day-to-day realities of long-term care homes. For example, during the COVID-19 pandemic, the passing of the *Reopening Ontario Act* (2020) meant staff could only work at one home to stop the spread of COVID-19. But this made it hard to ensure there were enough staff present to care for residents, and hurt workers who relied on multiple jobs to earn a living.
2) The instructions received by long-term care homes can be hard to interpret and implement because it includes a mix of public health standards that must be complied with by law and guidance about best practices that may be ideal but not necessary, and these are communicated by various groups including government and local Public Health Units, Public Health Ontario, and IPAC Hubs.
3) Different ownership models (e.g., for-profit vs. not-for-profit) may create variability between long-term care homes in the resources devoted to infection prevention and control and responding to disease outbreaks. During the pandemic, some studies found that for-profit homes had more deaths per bed, especially in areas with big outbreaks (e.g., Peel, Durham, Toronto, Ottawa), showing how different operating models may affect resident health and well-being.(13)

Two main issues related to how the long-term care system is funded (including how staff are paid) affect homes' capacity for responding to outbreaks:
1) long-term care homes have historically received less funding than hospitals, making it harder to build strong infection prevention and control systems
2) staff are paid less than in other healthcare sectors, making it hard to keep workers, and many staff work multiple jobs to make ends meet, which complicates rules like only working in one home to prevent disease spread.

Lastly, three delivery-related issues also contribute to the problem:
1) Some long-term care homes are based in older buildings or have limited space, which can make it tougher for them to adjust to new infection prevention and control rules, such as physical distancing requirements during visits and meals.
2) The long-term care sector is characterized by high staff turnover, burnout, and unfilled positions, which was made worse by the COVID-19 pandemic,(14) and this makes it challenging to train staff on infection prevention and control measures and build a strong culture supportive of these measures.
3) There is inconsistent in-home leadership for infection prevention and control, with some homes staffing highly trained specialists as infection prevention and control leads, while others experience challenges filling the role with qualified candidates. Furthermore, not all IPAC Hubs in Ontario have strong relationships with the long-term care homes operating in their region, which means support from them can vary across the province.

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

To improve how long-term care homes respond to disease outbreaks and implement infection prevention and control measures, it's important that everyone involved – government officials, healthcare leaders, staff, and long-term care residents – can access and use the best available data and research when making decisions. This idea is called an "evidence-support system," and while it's hard to build in any sector, it's especially lacking in long-term care, despite there being many 'assets' that could contribute to building such a system, including Public Health Ontario, IPAC Hubs, and local Public Health Units.

Some reasons that may contribute to this problem include:

- decision-makers in long-term care are often dealing with one urgent issue after another, leaving little time to focus on long-term improvements
- most research on disease outbreaks comes from hospitals, not long-term care homes, making it hard to apply directly
- long-term care homes often lack the tools and support needed to understand and use research effectively
- compared to hospitals, many long-term care homes don't have the same capacity for using data and research to guide decisions.

Without a strong system to support evidence-based decisions, it's hard for long-term care homes to learn from challenges and improve over time. Ideally, problems would be spotted early, solutions would be developed with input from staff and residents, and successful changes would become standard practice.

Questions about the problem

- What do you think of the challenges presented above?

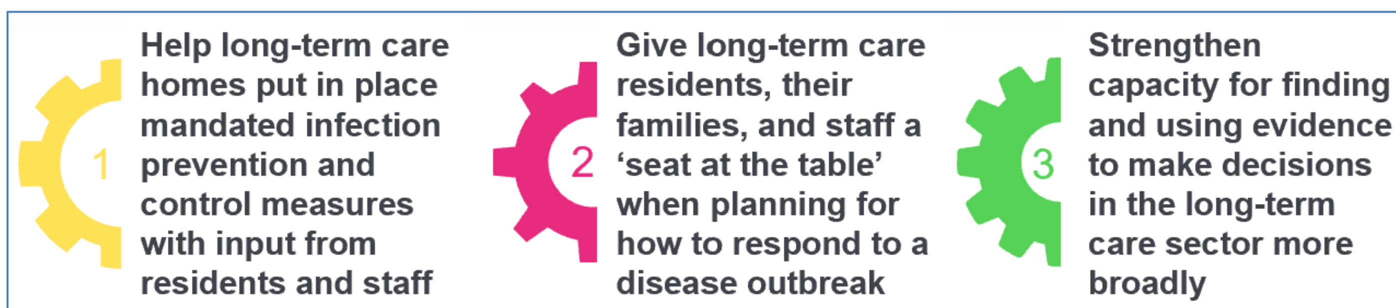
- What additional challenges do residents of long-term care, their family/caregivers, and staff face during disease outbreaks? How does this affect their health and well-being?

- From your perspective, what is the biggest challenge facing long-term care homes when responding to disease outbreaks?

- What gives you hope that we can bring about change?

Discussing solutions

We identified three potential solutions to address the problems outlined above. These solutions are outlined in the visual below and discussed in the sections that follow. The solutions are meant as a jumping off point for discussion, and can be considered separately, as a combination, or alongside an entirely new set of solutions.



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

This element would aim to make it easier for long-term care homes to implement mandatory public-health measures during disease outbreaks. Some of the approaches that would be included are:

- establish a unified approach for supporting long-term care homes to put infection prevention and control measures in place, with particular focus paid to helping them to identify and overcome issues that might get in the way
- make it clear for long-term care homes which resources and organizations can be relied on for support
- do a better job of engaging long-term care residents and staff in planning for how public-health rules are introduced in homes.

What evidence can inform this solution?

In our searches for the best-available evidence, we found evidence documents that showed the importance of:

- encouraging regular communication and coordination between those helping to create public-health rules and those responsible for putting them in place, such as long-term care operators, staff, and residents (as well as families and caregivers) (15-29) (32-34)
- engaging families as part of the infection control team (30-32)
- making tools and resources available that can help homes react quickly when infection prevention and control measures change during disease outbreaks and that make it easier to overcome the downsides of certain public-health rules, such as digital technology that can help to reduce residents' feelings of isolation.(15; 16; 18; 19; 27) (21-23; 26; 28; 33; 34)

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

This element would focus on enabling long-term care residents, caregivers, and front-line staff to shape how their home responds to a disease outbreak in their own setting, especially when there is flexibility in how they do so. Components of this approach include:

- prioritize engaging residents, their families, caregivers, and long-term care home staff in identifying problems and finding solutions to them in real time
- create a process that helps long-term care homes balance best practices with the unique needs of their residents
- create stronger ties between individual long-term care homes and the full range of individuals and organizations in place to support them in their efforts to respond to disease outbreaks.

What evidence can inform this solution?

In our searches for the best-available evidence, we found evidence documents that showed the importance of:

- establishing strong governance structures, leadership, and supervision (42; 45; 47-51), as well as regular communication and opportunities for 'two-way' discussion to build trust (15; 35-42)
- involving the full range of long-term care stakeholders (15; 40; 41; 43-48)
- learning from the lived experience of residents, their families and staff as part of decision-making,(40-42) and planning in advance for overcoming the downsides of infection prevention and control measures.(15; 41; 46; 52-56)

The evidence we identified also found that it is important to make sure the unique needs of certain residents are considered, such as for those with conditions like dementia (56-59) or in need of supports that are culturally appropriate.(39; 44; 52; 60; 61). The realities of the system should also be planned for, including how homes are built and designed and staffing levels.(43; 47; 52; 54; 58; 62-64)

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

This element focuses on strengthening the systems in place to ensure those working and living in long-term care homes (and the many organizations supporting them) can easily 'reach into the research world' to rapidly get the evidence-based answers they need to address the full range of problems they may face. It would also help them to take the lessons they're learning and change course when things aren't working, or make an approach the 'new normal' if it is working. Specific approaches could include:

- create a map of researchers, decision-makers, and those who specialize in making connections between these groups
- build timely 'ways in' for the best evidence in decision-making processes in long-term care homes and at all levels of decision-making
- help to build a culture of evidence use in long-term care homes.

What evidence can inform this solution?

In our searches for the best-available evidence we found evidence documents that showed the importance of:

- investing in research and building capacity for data collection and monitoring (14; 41; 46; 47; 55; 65; 66) (67)
- creating and providing the needed resources to teams that can test new approaches and that support promising practices (41; 68)
- taking steps to align how different research studies are designed across different settings, which makes findings easier to compare and learn from across the entire system (55; 66; 69)
- finding opportunities to make use of digital innovations, such as dashboards and capacity trackers, to help improve evidence-informed decision-making.(41; 66)

Questions to consider about solution 1:

- What role should residents (and their family/caregivers) and staff play in planning for how their home implements public-health guidance provided by government (e.g., the Ministry of Long-Term Care) and other public-health agencies (e.g., local Public Health Units)?

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- In your view, what level of implementation planning would residents (and their family/caregivers) and staff be most interested in contributing to during disease outbreaks? For example, would they be most interested in:
    - planning for changes in how the long-term care system is organized
    - planning for changes in how long-term care homes operate
    - planning for changes in how the care providers in long-term care homes deliver supports and services
    - planning for changes in how the residents or long-term care homes go about their daily lives?

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- What would an ideal process for engaging residents (and their family/caregivers) and staff in these discussions look like?

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Questions to consider about solution 2

- What role should residents (and their family/caregivers) and staff play in planning new responses to disease outbreaks?

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- What types of information would be most useful to inform residents' (and their family/caregivers') and staff members' roles in planning new responses to disease outbreaks (e.g., data, research evidence, resident values, experiences from other provinces, territories, or countries)?

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- What would an ideal process for engaging residents (and their family/caregivers) and staff in these discussions look like? How might this change in times of emergency, or during public-health crises when decision-making happens rapidly?

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Questions to consider about solution 3

- What roles could residents (and their family/caregivers) and staff play to help the long-term care system learn and improve rapidly? For example, could their roles include:
  - identifying problems related to disease outbreaks in long-term care that need to be addressed
  - designing solutions to address problems (drawing on evidence)
  - planning for the implementation of solutions
  - monitoring progress towards addressing problems?

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- What types of mechanisms could be put in place to engage long-term care residents (and their family/caregivers) and staff in efforts to help the system learn and improve (e.g., social media, online or telephone surveys, group discussions)?

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- How can we make sure everyone who wants to can make their voice heard as part of this process?

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Identifying barriers and facilitators moving forward

Solutions are great, but only if they can be put into action. There are often barriers in the way. Some of these barriers can be overcome. On the other hand, different things may facilitate the implementation of a solution. For example, a news story, a crisis, a new public opinion poll, or an upcoming election can bring an issue into the forefront. This may encourage people to pay attention to a problem and to implement a solution to address it. We have outlined some potential barriers and facilitators below.

Barriers

The long-term care sector lacks the resources and capacity to focus on system-wide changes in how IPAC measures are implemented

Residents' needs will continue to be diverse and complex, and this will only become more challenging as Ontario's population ages

Relationships between IPAC specialists and decision-makers in long-term care aren't as strong they are in other sectors

Facilitators

Residents and staff in long-term care are resilient and eager to have their voices heard during future disease outbreaks

The COVID-19 pandemic showed that it is possible for collaborative and timely evidence-based decision-making to work in Ontario

Ontario learned a lot of lessons about IPAC in the long-term care sector during the pandemic, creating new evidence that can now be built upon

Questions to consider about implementing the solutions

- What might be the biggest barrier to the three solutions discussed earlier?

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- What might be the largest facilitator of these solutions?

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Glossary of key terms

Term	Description
congregate living settings	Congregate living settings refer to a range of facilities where people (most or all of whom are not related) live or stay overnight and use shared spaces (e.g., common sleeping areas, bathrooms, kitchens) including shelters, group homes, correctional facilities, children or youth residential settings [source]. Long-term care homes are considered congregate living settings.
Crown agency	In Ontario, a Crown agency is a government organization, like a board, commission, or company, that is owned, controlled, or operated by the Government of Ontario or the Lieutenant Governor in Council. These entities are essentially agents of the Crown and are responsible for delivering public services or managing public assets [source].
diseases of public health significance	A list of diseases designated by the Government of Ontario in the *Health Promotion and Protection Act* (1990) as reportable to Public Health Ontario [source]. Most of these diseases can be passed from one person to another.
disease outbreak	While the precise definition of an outbreak depends on the disease being considered under the Ontario Public Health Standards, it generally refers to one or more patients/clients/residents and/or staff/other visitors in a home with a confirmed case of a specific disease, when the cases are linked and when there is the potential for it to spread to others living, working, or visiting the home [adapted from the following source].
health and well-being	Health and well-being is defined as a state of complete physical, mental, and social well-being, not merely the absence of disease or infirmity, and encompasses joy, happiness, and wellness. It is essential for achieving life goals and is influenced by factors such as background, economic status, and access to healthcare services [source].
infection prevention and control	Evidence-based practices and procedures that, when applied consistently in the long-term care home, can prevent or reduce the risk of transmission of microorganisms to healthcare providers, clients, patients, residents, and visitors [adapted from the following source].
Infection Prevention and Control Hubs (IPAC Hubs)	IPAC Hubs are local teams of infection prevention and control experts dedicated to supporting congregate living settings – including long-term care homes and hospitals – in implementing best practices. They work closely with those staff who have responsibility for preventing and controlling disease outbreaks to support them in adopting best practices, providing specialized guidance, networking opportunities, coaching, mentoring, training, and education. Additionally, they may assist with the implementation of outbreak measures in conjunction with local Public Health Units [source].
infection prevention and control leads	Infection prevention and control leads are responsible for managing a long-term care home's infection prevention and control program [adapted from the following source].
local Public Health Unit	There are 29 local Public Health Units in Ontario, each of which is accountable to a local board of health and responsible for offering healthy living and disease prevention information and programs to their communities. At the local level, they lead programs focused on the prevention and control of communicable diseases, including monitoring local data to tailor their programs to what is happening in their community. They also provide information about and programs to encourage healthy lifestyles, including sexual health, vaccinations, substance use, mental health, and healthy growth and development. Public Health Units are led by a medical officer of health [source].
long-term care stakeholders	All of the organizations and people who are involved in or affected by decisions related to long-term care. This includes government ministries, Crown agencies, organizational leaders and, most importantly, residents, their family/caregivers, and staff.
Ministry of Health	The Ministry of Health is responsible for administering the healthcare system and providing services to the Ontario public through such programs as health insurance, drug benefits,

	assistive devices, care for the mentally ill, long-term care, home care services, community and public health, health promotion, and disease prevention. It also regulates hospitals, operates psychiatric hospitals and medical laboratories, and coordinates emergency health services [source].
Ministry of Long-term Care	The Ministry of Long-Term Care oversees long-term care in Ontario, including: 1) supporting the building of new homes and upgrading outdated homes; 2) setting the legislation, regulations, and policies that all homes must follow; 3) developing programs to attract and retain workers; and 4) inspecting homes and ensuring standards are met [source].
Public Health Ontario	Public Health Ontario is a Crown agency that works closely with partners in government, public health, and healthcare to prevent illness and improve health. Its role is to provide the scientific evidence and expert guidance that shapes public health policies and practices [adapted from the following source].

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