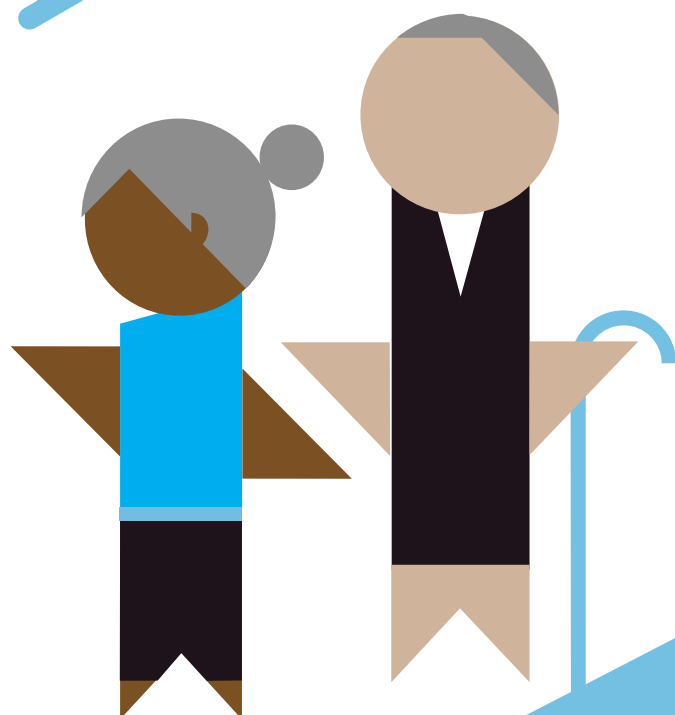


Counting COVID-19 in Canada's Long-Term Care Homes: NIA Long-Term Care COVID-19 Tracker Project Summary Report



National Institute on Ageing

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About the National Institute on Ageing

The National Institute on Ageing (NIA) is a public policy and research centre based at Toronto Metropolitan University (formerly Ryerson University). The NIA is dedicated to enhancing successful ageing across the life course. It is unique in its mandate to consider ageing issues from a broad range of perspectives, including those of financial, psychological and social well-being. The NIA is focused on leading cross-disciplinary, evidence-based and actionable research to provide a blueprint for better public policy and practices needed to address the multiple challenges and opportunities presented by Canada's ageing population. The NIA is committed to providing national leadership and public education to productively and collaboratively work with all levels of government, private- and public-sector partners, academic institutions, ageing-related organizations and Canadians.

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Background and Context

In March 2020, as the COVID-19 pandemic began to intensify around the world, experts and front-line workers sounded the alarm about its potential impact on older populations. The NIA reacted quickly by establishing the Long-Term Care COVID-19 Tracker Open Data Working Group and developing the NIA Long-Term Care COVID-19 Tracker: a web-based mapping system that could track outbreaks across 6,029 long-term care (LTC) and retirement homes in every Canadian province and territory, including the number of cases and deaths among staff and residents.¹

This publicly accessible, online tracking map was launched in April 2020. It was built in collaboration with Empower Health, and was created to compile the best available data from multiple sources. These included public health units, government reports and dashboards, news media, public statements from the homes themselves, and sometimes communications from individual homes shared with residents, families and staff. The NIA became Canada's first and only organization to track COVID-19 outbreaks in LTC and retirement homes — as well as resident and staff cases and deaths — in a consistent, reliable and timely way.

From the project's early days in March 2020, there have been challenges to compiling this data in a consistent way, given the number of possible data sources. Not all of Canada's provinces or territories were readily sharing their data on LTC and retirement home resident and staff cases or deaths, publicly or otherwise (Rankin, 2020). Nevertheless, the NIA worked to develop data-sharing agreements with Alberta, New Brunswick and Ontario, and supplemented the official available figures with additional verifiable information from the news media, LTC homes' websites and other open-source data. At one point in the first wave, it took seven researchers and volunteers at the NIA and Sinai Health's Healthy Ageing and Geriatrics Program working full-time to gather and process this data.

¹ The tracker can be found online at ltc-covid19-tracker.ca.

Generating Data-Driven Pandemic Insights

The NIA, in turn, has readily provided its data cost-free to other institutions to help inform their reports and policy decisions. The NIA's Long-Term Care COVID-19 Tracker Open Data Working Group became the principal supplier of comprehensive and accurate data on COVID-19 in Canadian LTC and retirement homes to the Canadian Institute for Health Information (CIHI), and the Public Health Agency of Canada (PHAC), the LTC COVID international research consortium based at the London School of Economics and Political Science, and other agencies, institutes, researchers and journalists looking to better understand what was happening across Canadian LTC and retirement home settings.

The NIA's Long-Term Care COVID-19 Tracker data helped to inform several seminal reports, including CIHI's "Pandemic Experience in the Long-Term Care Sector: How Does Canada Compare With Other Countries?" (CIHI, 2020) and "The Impact of COVID-19 on Long-Term Care in Canada: Focus on the First 6 Months" (CIHI, 2021), and Healthcare Excellence Canada's "Reimagining Care for Older Adults: Next Steps in COVID-19 Response in Long-Term Care and Retirement Homes" (HEC, 2020). The data was also used in NIA's evolving guidance document, "The NIA's Recommended 'Titanium Ring' for Protecting Older Canadians in Long-Term Care and Congregate Living Settings" (NIA, 2021), and its subsequent reports and articles done in collaboration with the LTC COVID international research consortium (Low et al., 2021).

The NIA also published "A Comparison of COVID-19 Mortality Rates Among Long-Term Care Residents in 12 OECD Countries" in the *Journal of the American Medical Directors Association* in November 2020 (Sepulveda, Stall and Sinha, 2020). This academic paper helped establish how at the time, Canada's LTC resident deaths accounted for 78.4 per cent of the country's overall COVID-19 deaths, compared to an average of 47.3 per cent for 12 countries in the Organization for Economic Co-operation and Development (OECD). Canada also had the highest reported ratio of LTC resident deaths compared to deaths of community-dwelling older persons at 73.7, compared to the OECD 12-country average of 25.5. These widely cited findings helped encourage Canada's federal government to announce the creation of new National LTC Services Standards in the 2020 throne speech (Government of Canada, 2020; HSO, n.d.). The NIA has played a key role in the subsequent development of those standards (HSO, 2021).

Data from the LTC COVID-19 Tracker has been referenced in hundreds of media articles, reports and journal articles. Ultimately, this data helped fill gaps in our collective understanding of the pandemic's effects on Canada's LTC and retirement homes. We learned the full extent to which these settings were affected by large numbers of COVID-19 outbreaks, leading to many cases among both residents and staff, as well as a

disproportionate number of deaths. As of July 1, 2022, the NIA's LTC COVID-19 Tracker Open Data Working Group was reporting that 245 of Canada's 6,029 LTC and retirement homes were experiencing active COVID-19 outbreaks. In total, the Working Group has recorded COVID-19 outbreaks across 3,820, or 63 per cent, of Canada's LTC and retirement homes. A total of 107,461 resident cases and 58,715 staff cases have been identified across these settings, along with 17,177 resident and 32 staff deaths, accounting for a staggering 43 per cent of Canada's overall COVID-19 deaths (See Table 1).

While vaccinations have led to fewer serious or fatal cases of COVID-19 in residents, these settings have remained highly affected by both outbreaks and visitor restrictions that have continued through the additional waves of the pandemic. Indeed, LTC and retirement home residents have suffered disproportionately not just from COVID-19 infections and deaths, but also from social isolation and changes to their care, including reductions in staffing and limits on visitors and essential care partners.

In addition to allowing us to monitor what was happening at a regional or provincial/territorial level, the LTC COVID-19 Tracker also helped uncover differences between provinces or territories that may have been related to their different approaches to managing various stages of the pandemic. The NIA's academic independence allowed it to remain an objective source of information throughout the pandemic, even as data collection efforts became increasingly politicized over the course of the pandemic.



Table 1: Final Update: NIA Long-Term Care COVID-19 Tracker as of July 1, 2022

Canadian Jurisdiction	Total Number of Cases	Total Number of Deaths	Total Number of LTC and Retirement Homes	Total Number of Homes Affected	% of Homes Affected	Homes Currently in Outbreak	Total Number of Resident Cases	Total Number of Staff Cases	% Staff + Resident Cases out of Total Cases	Total Number of Resident Deaths	Total Number of Staff Deaths	Resident Case Fatality Rate	% Staff + Resident Deaths out of Total Deaths
AB	583,112	4,558	578	529	92%	55	2,1299	12,778	6%	1,831	6	9%	40%
BC	363,302	3,147	392	278	71%	2	7,599	3,139	3%	1,085	0	14%	34%
MB	140,931	1,792	261	110	42%	2	3,589	1,439	4%	585	0	16%	33%
NB	62,148	399	468	84	18%	0	1,417	1,373	4%	145	1	10%	37%
NL	44,345	165	125	34	27%	1	78	68	0%	7	0	9%	4%
NT	11,919	22	9	1	11%	0	0	0	0%	0	0	N/A	0%
NS	85,999	313	134	52	39%	0	3311	329	4%	145	0	4%	46%
NU	3,531	7	5	0	0%	0	0	0	0%	0	0	N/A	0%
ON	1,278,579	12,923	1,396	1,267	91%	80	40,958	31,005	6%	5,030	14	12%	39%
PE	35,433	26	39	27	69%	1	610	468	3%	25	0	4%	96%
QC	1,045,832	15,036	2,215	1,216**	55%	91	28,093**	7,850*	3%	8,170**	11	29%	54%
SK	136,027	1,312	402	220	55%	13	507	266	1%	154	0	30%	12%
YT	4,226	25	5	2	40%	0	0	0	0%	0	0	N/A	0%
CANADA	3,795,384***	39,725***	6,029	3,820	63%	245	107,461	58,715*	4%	17,177	32	16%	43%

* Quebec's staff case numbers are not readily reported and therefore what is presented are likely significant underestimates of their actual staff case counts.

** These numbers are an underestimation as the Working Group is currently retroactively cleaning this data due to the record number of outbreaks during the Omicron wave.

*** These numbers are an underestimation because the source used, <https://art-bd.shinyapps.io/covid19canada/>, has been temporarily suspended since May 3, 2022, as it transitions to a new dataset. This may also affect the case fatality rates that are presented.

Last updated: July 1, 2022

Managing Inconsistent Definitions and Evolving Sources of Data

When the COVID-19 pandemic first began in 2020, the definition of an LTC home “outbreak” was generally consistent across the country: only one case among either a resident or worker was required to declare an outbreak. As the pandemic progressed and vaccinations were deployed in these settings, the definitions of what constituted an “outbreak” quickly began to change across the country. Most provinces and territories moved toward a definition that required two or more cases that were likely to be linked and likely to have been spread in the home. This shift began around April 2021 in Ontario and Manitoba, before other provinces and territories followed, including Alberta, Saskatchewan, Yukon, Newfoundland and Labrador, Northwest Territories, New Brunswick, Nova Scotia and Prince Edward Island (Government of Ontario, n.d.; Gowriluk, 2021; Government of Alberta, 2021; Government of Saskatchewan, 2022; Yukon Communicable Disease Control, 2022; Provincial Infection Control-Newfoundland Labrador, 2022; Government of N.W.T., 2022; N.B. Department of Social Development, 2022; Patil, 2022; P.E.I. Health and Wellness, 2022). British Columbia changed its definition in February 2022 to leave it up to the local medical officer of health, based on new guidance stating: “A COVID-19 outbreak will not be declared solely on the basis of cases diagnosed among residents or staff.” (BCCDC, 2022)

During the first three waves of the pandemic, the news media became a reliable source of information for jurisdictions where official data was not always publicly accessible. Data was also made readily available on the websites of many LTC and retirement homes. When homes were owned by a larger chain, there often was a central repository of data presented on the main company website. However, the type of data made available varied greatly. For example, some provided only the names of their homes in outbreak with no specific data about the number of cases and deaths, while others provided more detailed information including the number of cases, deaths and dates of outbreaks. Independent homes often provided information directly on their websites or social media channels. However, one difficulty was determining who each home considered to be “staff” — i.e., only people employed by the home directly versus third-party contractors who entered the home. Definitions of staff cases, therefore, often differed between homes and local public health units that tended to report higher staff case counts.

As the pandemic moved into its fourth wave in August 2021, most LTC and retirement home residents had been fully vaccinated, which helped reduce the worst outcomes — including hospitalizations and deaths — previously seen in these settings. However, this corresponded with less reporting on homes in outbreak.

When the NIA's LTC COVID-19 Tracker Open Data Working Group first began to collect data, the NIA shifted its priorities and employee and volunteer time toward data collection. In the early stages of the pandemic when the group was doing daily data collection, it took seven researchers at the NIA and Sinai Health's Healthy Ageing and Geriatrics Program working full-time to gather and process the data. As the number of outbreaks and cases decreased, the group was able to reduce collection, first to twice per week at the end of July 2020 and then ultimately to once per week in July 2021.

Then in December 2021, the Omicron variant brought record numbers of homes in outbreak across the country, with almost 2,000 of the 6,029 homes being followed found to be actively in outbreak in January 2022. The record number of outbreaks made it extremely challenging to stay on top of data collection, but the group persevered.

However, since the beginning of 2022, the majority of Canada's provinces and territories have been sharing less data about outbreaks and cases within LTC and retirement homes (Neatby, 2022). Even as case numbers have risen again across the country, it has become increasingly difficult to source timely, accurate and comparable data, and without that, the NIA's LTC COVID-19 Tracker Open Data Working Group no longer feels confident that it can provide the quality of data needed to make this a useful, reliable source of information. A tool like this is only as useful as the data it's based on, and without consistent and accurate data, the NIA can no longer guarantee a consistent and accurate LTC COVID-19 Tracker.



Wrapping Up and Next Steps

The NIA made the difficult decision to pause its NIA Long-Term Care COVID-19 Tracker Project, effective July 1, 2022. The timing is not ideal: as of July 2022, Canada and its LTC and retirement homes are struggling to cope with the seventh wave of this pandemic (Pasioka, 2022), and more limited public health data suggests cases are surging once again in LTC and retirement homes (Public Health Ontario, 2022).

The NIA's LTC COVID-19 Tracker Open Data Working Group is pausing data collection efforts not because the pandemic and its threat to LTC and retirement homes has ended. Rather, the pause is occurring because many of Canada's provincial and territorial governments and public health authorities are no longer providing enough of the reliable, timely data the Working Group needs to ensure its LTC COVID-19 Tracker can remain a highly accurate source of information.

Looking back, the NIA was able to quickly adapt to the unknown nature of COVID-19 in March 2020, and in collaboration with Empower Health, created a timely resource that provided comprehensive and transparent data on outbreaks in LTC and retirement homes across the country. The NIA accomplished its goal of not only providing this data publicly, but by partnering with organizations such as CIHI, PHAC and Healthcare Excellence Canada, it was also able to use this data to inform key observations, recommendations and policy decisions that will work to improve long-term care in Canada.

Even though the Working Group has had to end its weekly data collection for the NIA's LTC COVID-19 Tracker, it is hopeful that the lessons learned from this project can be useful for other researchers and organizations taking on this kind of data collection work in the future. There is now a framework and system that has shown how this work can be done and why it is needed. The Working Group will also be able to resume data collection and sharing quickly the next time there is a need for an effort like this. As of July 1, 2022, the NIA's LTC COVID-19 Tracker will continue to display its entire set of archived data up until that point as an ongoing reference document.

Finally, the NIA continues to recommend that Canada's provincial, territorial and federal governments continue collecting and releasing data on COVID-19 cases and deaths in Canada's LTC and retirement homes. This data plays an important role in both understanding past actions and informing future actions to better support those living and working in these settings. In order to do so effectively, Canada's provinces and territories should come to an agreement on common data collection and reporting definitions and standards, along with a mechanism to regularly report this data to a central organization such as CIHI with a mandate to organize and share the data, as it currently does with other LTC data. Unless we find a path forward together, we will likely lose a valuable opportunity to further understand how COVID-19 continues to affect Canada's LTC and retirement homes.

Appendix

Overview of the Variable and Evolving COVID-19 LTC and Retirement Home Data Reporting Methods by Canada's Provinces and Territories

Province/ Territory	Official Data Information Sources
<p>Alberta</p> 	<ul style="list-style-type: none"> • Alberta publicly provided a list of names of homes in outbreak on its provincial website (Government of Alberta, n.d.). • The NIA created a data-sharing agreement with the Government of Alberta to ensure the accurate reporting data for each LTC and retirement home in outbreak. The Working Group received weekly summaries for all homes in outbreak. As of the end of March 2022, Alberta began providing monthly summaries.
<p>British Columbia</p> 	<ul style="list-style-type: none"> • Many B.C. public health authorities reported information about the names of homes in outbreak in their regions. • On Jan. 7, 2021, the BC Centre for Disease Control began to release detailed updates on outbreaks across the province (BCCDC, 2022b). This included the start and end dates of outbreaks, and the number of cases and deaths of both residents and staff for each home outbreak. In the release of its first report, the BCCDC retroactively provided information on the outbreaks that had happened up until that point. • As of July 2022, the BCCDC continues to release weekly outbreak reports.
<p>Manitoba</p> 	<ul style="list-style-type: none"> • In January 2021, Manitoba developed a COVID-19 dashboard that was updated daily and provided detailed information on outbreaks across the province. This included resident cases and deaths, and staff cases at each home. The government also released news reports that provided additional information on when the outbreaks began and ended at each home. • On March 24, 2022, Manitoba announced it would no longer be updating its COVID-19 dashboard and moved to weekly epidemiological reports in which the names of homes in outbreak were listed, but detailed breakdowns of the number of cases and deaths associated with each outbreaks were no longer made available (Manitoba Government, 2022). • The Winnipeg Regional Health Authority continues to list the names of homes in outbreak in the region, but no additional details are being provided. (WRHA, n.d.)



<p>Newfoundland and Labrador</p> 	<ul style="list-style-type: none"> • No publicly accessible dashboard was made available in Newfoundland and Labrador with information regarding outbreaks. • The Working Group relied on information provided by health authorities, media reports or the homes themselves.
<p>New Brunswick</p> 	<ul style="list-style-type: none"> • No publicly accessible dashboard was made available in New Brunswick with information regarding outbreaks. • The NIA was able to work with the government to verify information during the first few waves of the pandemic, until Omicron brought challenges with their ability to support further verification work due to the large number of outbreaks experienced.
<p>Northwest Territories</p> 	<ul style="list-style-type: none"> • The N.W.T. reported outbreaks through government news releases, but no specific details were ever provided, which may have been due to confidentiality given the small population of the homes.
<p>Nova Scotia</p> 	<ul style="list-style-type: none"> • Nova Scotia provided updates on new outbreaks in LTC homes through government news releases. These news releases often provided the initial information about the outbreak (i.e. how many cases there were at that time) and sometimes provided follow-up information as the outbreak evolved. • On March 10, 2022, Nova Scotia moved to releasing weekly epidemiological summaries, and then by July 2022, monthly summaries (Government of Nova Scotia, 2022b). These reports presented total cases and deaths among LTC residents in each wave. They do not specify staff cases at the same level. The new summaries also do not provide the names of the homes in outbreak.
<p>Nunavut</p> 	<ul style="list-style-type: none"> • No publicly accessible dashboard was made available in Nunavut with information regarding outbreaks. • There were media reports that covered some outbreaks (Venn, 2022a; Venn, 2022b; CBC News, 2022).

Ontario



- Ontario's Ministry of Long-Term Care provided information on outbreaks in long-term care homes, including resident and staff cases and deaths, on its website. There was no reporting on the exact number of cases in homes with fewer than five cases, which meant that the Working Group could not enter this data into its system. Furthermore, the Ministry only reported active cases, making it hard to determine the total cumulative number of cases that occurred during an outbreak. As of June 17, 2022 when Ontario moved to weekly reporting, this dashboard is no longer updated
- In September 2020, Ontario's Retirement Homes Regulatory Authority (RHRA) created a dashboard reporting active outbreaks in retirement homes (RHRA, 2022). The Working Group found similar data challenges in that they would not specify numbers when less than five cases were reported. While the RHRA did report cumulative cases for each outbreak, once an outbreak was removed from the active outbreaks list, the resident case numbers were no longer available, only the resident death numbers.
- The NIA created a data-sharing relationships with the RHRA and the MLTC to help verify its collected data and to resolve data discrepancies that the Working Group encountered.
- Some Ontario public health units provided (and continue to provide) detailed information, including case data, for each outbreak in their jurisdiction: Ottawa, Peel, Hamilton, Region of Waterloo, Brant, Southwestern, Windsor-Essex, York, Wellington-Dufferin-Guelph and Huron-Perth. Lambton provided detailed information, but did not include specific case numbers for fewer than five cases. However, not all public health units provided outbreak end dates, which made it difficult to know definitively when their outbreaks were declared over.
- Chatham-Kent and North Bay Parry Sound Public Health Units provide total case numbers only, not breakdowns of staff versus resident cases.
- Renfrew County and District Health Unit, Haldimand and Norfolk Health Unit and Northwestern Health Unit only provided the total number of current outbreaks, but no specific information on the homes in outbreak.
- The following public health units only provided the name of the homes in outbreak and the start/end dates of the outbreaks: Peterborough; Haliburton, Kawartha, Pine Ridge District Health Unit; Leeds, Grenville, & Lanark District Health Unit; Eastern Ontario Health Unit; Timiskaming Health Unit; Algoma Health Unit; Sudbury & Districts Public Health; Simcoe Muskoka District Health Unit; Thunder Bay District Health Unit; Middlesex-London Health Unit; Hastings Prince Edward Public Health; Porcupine Health Unit; and Grey Bruce Health Unit.

<p>Ontario (Continued)</p>	<ul style="list-style-type: none"> • Niagara Region provided only the names of the homes currently in outbreak and a start date, then removed the information when the outbreak was over. • Halton Region, Kingston and Durham Region originally provided detailed information (i.e. start/end dates, resident and staff cases and deaths) for each outbreak. All three regions have stopped providing detailed case counts, with Halton Region and Kingston only listing homes in outbreak and the start date of each outbreak, while Durham has continued to provide end dates. Therefore, the Working Group had to turn to other sources (i.e. Ministry or RHRA) to try to fill in these gaps if possible. • Toronto Public Health at first provided data for each of its long-term care and retirement homes. Around May 2020, it began to refer to the Ministry website for LTC homes, but they continued to provide information on retirement homes (included start/end dates, and resident/staff cases and deaths).
<p>Prince Edward Island</p> 	<ul style="list-style-type: none"> • P.E.I. initially released public health updates when outbreaks occurred, but did not always include specific details. In January 2022, P.E.I. announced it would no longer report on outbreaks in LTC homes. • In March 2022, it resumed reporting on current outbreaks. It does not report less than five cases and it provides a total number of resident deaths, but does not associate them with a specific home. It provides the number of staff and resident cases associated with each home currently in outbreak. It also has reports for past outbreaks, summarizing the start and end dates and the number of cases, but not the number of deaths (P.E.I. Health and Wellness, n.d.).
<p>Quebec</p> 	<ul style="list-style-type: none"> • Quebec provided information on the homes in outbreak separated out as CHSLDs (long-term care homes) and RPAs (retirement homes) (Gouvernement du Québec, 2022). Quebec never provided information on staff cases, as this was not being readily collected, and thus only reported resident cases and deaths. The Working Group’s staff totals were based on occasional estimates that were released by the Ministry, but likely are a significant undercount. Quebec also only provided information on active cases and new cases in the past 24 hours. Originally, reports were updated daily, but then eventually only on weekdays. • There were a few extended periods of time when Quebec switched its processes of reporting or conducted data cleaning, during which it would not release any new reports. It was unclear whether all the data associated with these periods was included in future reports.

<p>Saskatchewan</p> 	<ul style="list-style-type: none">• Saskatchewan provided updates on homes in outbreak and total numbers for both resident and staff cases associated with an outbreak (Government of Saskatchewan, 2022b). As the NIA's tracking system was developed to distinguish resident and staff cases, it was often hard to determine staff and resident case numbers. Sometimes media reports were able to provide information identifying staff and resident numbers, which was used to further determine case totals, but the Working Group could not always associate these totals with individual homes.• As of early 2022, Saskatchewan stopped providing those additional details and only provided the names of homes in outbreak (Government of Saskatchewan, 2022b).
<p>Yukon</p> 	<ul style="list-style-type: none">• The Yukon released news releases of outbreaks, but did not always include specifics about the number of cases in each home (i.e. Government of Yukon, 2022).

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