

BC COVID-19

STRATEGIC RESEARCH
ADVISORY COMMITTEE

LONG-TERM CARE WORKING GROUP

**Building a Knowledge Enterprise for Long-
Term Care in British Columbia**

March 22, 2021

Building a Knowledge Enterprise for Long Term Care in British Columbia

Long-term care (LTC) homes provide a range of nursing, medical, and social care to meet the cognitive, socio-emotional and physical needs of people, primarily older adults, who are no longer able to live independently in the community. Individuals moving to LTC have a much higher level of care needs than in the past, and as their average length of stay is just over two years¹, LTC is also an important site for palliative and end-of-life care.

The delivery of LTC in British Columbia (BC), like other provinces in Canada, is a mix of public, private-for-profit, and private non-profit LTC homes; and, as a healthcare sector, it is large. Approximately **28,000 BC residents are served by at least that many staff in 293 LTC homes**. One hundred and eighty-two (62%) of these home are privately owned: 34% of which are for-profit and 28% are not-for-profit², with the remainder being owned and operated by Health Authorities.

LTC is a gendered and racialized workforce. While direct care staff also comprises RNs, LPNs, allied health staff (e.g., recreation, dieticians), and support staff (e.g., housekeeping, food services, dietary), **90% of the direct care workforce are health care aides**, who are generally middle-aged women, speak English as their second language, and have a high school diploma³. These staff are generally the lowest paid, and many hold multiple jobs. LTC is also a place where care provided by family members and friends continues. That is, family members adopt important roles within the LTC environment to support their relative's overall physical and psychosocial wellbeing⁴.

COVID-19 has brought into sharp focus the vulnerability of LTC residents and the care staff and families who support them. In Canada, 85% of COVID-19 deaths were LTC residents – the highest among 14 countries⁵. The implementation of restrictions to minimize the risk of harm to residents has resulted in unintended consequences significantly compromising quality of care and quality of life in long-term care. Residents have experienced adverse impacts such as cognitive decline and physical deconditioning due to the lack of activity and stimulation, meaningful programming, and loneliness. The impact of steps taken to reduce the risk of transmission of COVID-19 has resulted in an altered concept of LTC as the residents' 'home'; residents referring to themselves as "inmates" and staff and family reflecting that residents' "free will has been taken away."

For decades, researchers, healthcare providers and policy makers in the sector, residents, families, and staff alike have identified issues - and potential solutions - to the challenges in the LTC sector across Canada⁶. Despite the research evidence, the LTC sector nationally has changed little – issues identified over three decades ago continue to plague the sector. The pandemic has shone a light on these deep, long-term systemic deficiencies⁷⁻⁹.

It is long past time to make purposeful, thoughtful and significant change if we are to understand the impact of COVID-19, prepare for the inevitable pandemics of the future, and **take steps to address the systemic issues that made it possible for this pandemic to so significantly impact the lives of seniors in BC**.

The role of the COVID-19 Strategic Research Advisory Committee (SRAC) Long-Term Care (LTC) Working Group (Appendix 1) was to advise on the best path forward for LTC research in BC in the context of COVID-19. What are the most critical questions we need research to address based on our experience with COVID-19 in LTC in BC? How has the pandemic further illuminated the existing structural issues and inequities in care? In the implementation of existing evidence? What are the strengths and opportunities in BC that we can build on? How do we take a resident-focussed approach that recognises the well-known determinants of health?

This paper summarizes some key research priorities and identifies important research questions to be addressed (Appendix 2). A rapid analysis of research that is currently being conducted in BC (Appendix 3) was completed. Importantly, Working Group deliberations also identified key system challenges related to research capacity in LTC in BC. **These challenges, if not addressed, will ensure that despite strong individual research efforts, the multiple systemic and structural barriers that impede the conduct of rapid, timely, coordinated and impactful research will continue to impede the development of new evidence for LTC, and its translation into policy and practice.**

Reimagining Long Term Care Research in the Context of COVID-19

British Columbia has extraordinary strengths in the LTC sector. Our LTC administrators and staff are deeply committed to improving the quality of life and quality of care for BC LTC residents. Family members – essential to this aim – are often intimately involved in the everyday life and work in LTC facilities, and are a voice for the importance of change in the sector.

BC and Canada have extensive research talent and researchers who are already embedded and poised to work within the sector to address some of the long-standing issues and research priorities in LTC and address the urgent ones arising as a result of COVID-19.

Decades of evidence exists to inform solutions to the enduring problems in LTC that may have helped minimize the unintended consequences and heartbreaking deaths related to COVID-19.

As a province, we need to harness the available evidence and generate new knowledge to understand the impact of COVID-19 and prepare for the inevitable pandemics of the future.

- What if there was a robust learning system in place in BC with trained researchers embedded in LTC who were poised to rapidly respond to the emergent pandemic crisis in LTC?
- What if we had a more fulsome understanding of the characteristics of BC's LTC homes that excelled with infection control on an everyday basis? Or, of LTC homes that championed balancing resident safety with residents' rights to agency and living at risk?
- What would a robust learning system in LTC have done for us in terms of our response to, and our understanding of, the consequences – both intended and unintended - of the policies and practices that resulted from the pandemic?
- How could a robust learning system prepare us for the next pandemic?

Based on deliberations of our expert Working Group, building a robust learning system for LTC in BC will require us to **develop and implement a sustainably funded interdisciplinary knowledge enterprise in BC, guided by a provincial framework for research in LTC**. Key attributes of this LTC Knowledge Enterprise would include:

- Demonstrated evidence of generating and facilitating applied and translational research in the LTC sector;
- Respected partnerships with pan-Canadian and international research partners, and with residents, family members, LTC staff, and healthcare providers and policy makers in the sector;
- Established capacity to promote, disseminate and mobilize knowledge related to aging and LTC; and
- Demonstrated capacity to deliver high-quality research training and mentorship opportunities to build capacity for LTC research in BC.

The Knowledge Enterprise would bring together leading researchers from BC and across Canada, LTC sector stakeholders, residents, family members, and LTC staff to build support for ongoing LTC research as a component of pandemic preparedness, a learning health system that recognises the strengths and gaps in the LTC research environment in BC, and that addresses priority research areas identified by the Working Group (see Appendix 2 for the full, but not exhaustive, list of suggested research questions). The following thematic areas were identified in discussion at the Working Group level:

- 1) **Resident wellbeing:** Questions relate to the impact of infection control policies on resident quality of life, the impact on different diagnosis (e.g., those with dementia), genders, ethnicities, and illness trajectory (e.g., palliative care) as well as impacts on residents' rights to live at risk.
- 2) **Operational and organizational issues:** Questions relate to staffing models, the role of the built environment, infection control preparedness, and LTC home organizational characteristics (e.g., ownership, size, geographical area).
- 3) **Interpretation and implementation of COVID-19 policy.** Questions relate to understanding the intended and unintended consequences of how the various Public Health Officer orders were interpreted, implemented, and translated.

- 4) **Health and human resource impact:** Questions relate to understanding the impact on individuals working in this sector, staff retention, impact of Single Site and Wage Levelling orders, and how medical services were provided during the pandemic.
- 5) **Implementing, evaluating, and monitoring best practices.** Questions relate to understanding the mechanisms of implementing best practices, including the use of technology and localized innovation, and how well these interventions met the needs of residents, families, staff, and the public.
- 6) **Risk communication.** Questions relate to information sharing with residents, families, staff, and volunteers and the communication structure required to ensure consistent information.

What Would a Knowledge Enterprise Accomplish?

Connecting key LTC stakeholders from communities and institutions across BC, the Knowledge Enterprise would bring together multiple perspectives to address salient questions facing the LTC sector. The LTC Knowledge Enterprise would look at ways to address the challenges to conducting research in BC. It would **build pathways for evidence to make significant change in this sector – through knowledge syntheses and high quality, rigorous research.** It would help the sector engage in large-scale projects that have the capacity to make significant shifts to the system. It would play a role in monitoring that research is completed, collect research products, and contribute to building a knowledge database of research completed in BC.

Development and implementation of a sustainably funded LTC Research Enterprise in BC would create opportunity to address the current challenges (see Table 1 below) identified in conducting research in the sector and propose possible solutions.

The British Columbia Long Term Care Knowledge Enterprise would **inform policy and decision-making**, and respond to questions or issues of importance to government, health authorities, and the LTC sector. It could advise research funding agencies on research priorities. It would be a model 'learning health system' for Canada and internationally in terms of the LTC sector, and support knowledge integration across the sector.

This is British Columbia's opportunity to step into a leadership role in Long-term Care on a national level, and to drive quality of care, quality of life and quality of service that will forever change the face of long-term care in Canada.

Table 1. Challenges and Possible Solutions

Challenges	Possible Solutions
<p>A lack of operational infrastructure in LTC homes to conduct, engage, or partner in research. Leadership support for research in LTC is fragmented, as is knowledge of how to partner effectively with researchers. Stretching limited resources to effectively take part in research and partner with researchers deters many providers from participating in research.</p>	<ul style="list-style-type: none"> • Develop strategies to enable LTC leadership to effectively participate in research • Engaging LTC leaders in opportunities to develop partnerships with researchers. • Funding calls shaped to recognize the need for LTC leader partnership and engagement in research aligned with priority areas identified by LTC partners, including residents and families.
<p>Grant application processes do not recognize the time and resources required to engage in relationship and engagement processes necessary to conduct research in LTC.</p>	<ul style="list-style-type: none"> • Develop <i>LTC-specific</i> funding calls that recognize the value of a collaborative approach to research in long-term care • Employ a merit-based review process alongside peer review, and support formative and longitudinal research in this sector.
<p>Despite a growing wealth of sources of data in BC there is a lack of a coordinated approach to the ongoing acquisition, access, and use of these data for meaningful analyses. Questions of data access and quality, inadequate metadata and the lack of readily accessible opportunities for linkage significantly impact researchers' ability to effectively access data and dissuades new researchers from engaging in research in this area.</p>	<ul style="list-style-type: none"> • Integrate provincial administrative data sets in a data infrastructure reflecting BC's LTC system. • Ensure opportunities for research and evaluation in LTC utilizing this database. Ongoing maintenance of data platforms and analyses that could rapidly and robustly inform decision making in the context of COVID-19 and beyond
<p>Navigating research ethics and operational approval processes across multiple health authorities is extremely challenging and time-consuming, which creates barriers to conducting large-scale studies.</p>	<ul style="list-style-type: none"> • Develop partnerships with BC SUPPORT units across the province and Research Ethics BC to develop LTC-specific research ethics guidance for REBs, including the inclusion of people with dementia in research.
<p>Lack of targeted trainee funding.</p>	<ul style="list-style-type: none"> • Develop specific trainee opportunities in LTC to help build future researchers specializing in this sector.
<p>There is great variation in institutional and organizational support for researchers across BC based universities and institutions. This can lead some researchers to continue to float from small grant to small grant with unstable funding, impacting their capacity to further scale studies.</p>	<ul style="list-style-type: none"> • Target funding to targeted scale-up projects or projects that focus on inclusion of researchers from multiple regions across the province.

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- ⁹ Chief Science Advisor of Canada (2020). *Long-term care and COVID-19*. Report of a special task for prepared for the Chief Science Advisor of Canada.

Appendix 1: Long-Term Care Working Group Membership

Committee Co-Chairs	
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Gita Rafiee Clinical Nurse Specialist Fraser Health Authority	Breanna Horne Administrative Assistant University of Victoria

Appendix 2: Key Research Priorities

Key research priorities emerging from the COVID-19 LTC Working Group are outlined below, along with research question suggestions (not an exhaustive list). The priority areas have been mapped to the BC COVID-19 Strategic Research Advisory Committee's (SRAC) *Framework for Research and Action in an Emerging Disease*¹.

Priority One: Resident wellbeing

(Evaluation of programmes, evaluation of health services, analysis of vulnerabilities and resiliencies and structural issues contributing to these)

- 1) How do residents define acceptable health risk? How has the pandemic impacted end-of-life decision making? Many residents are reaching the end of life yet are not able to determine what constitutes acceptable risk to them. It may be that COVID-19 is less frightening than being separated from family at this stage of life.
- 2) Residents' choice and freedom of movement within and outside LTC homes has been curtailed. How has this impacted their experience of 'home', quality of life, and loneliness? What is needed to prevent the negative health impacts of immobility?
- 3) How did changes in programming, including changes in recreation programming, affect resident quality of life and quality of care? What should the role of recreation therapy be during a pandemic?
- 4) What were the experiences with COVID-19 in LTC homes, and how did they vary, across minority groups? Ethnic groups? Genders? Special populations (e.g., young persons with brain injury, those with mental health disorders)?
- 5) Family care partners provide much needed IADL and ADL assistance and emotional and social support in LTC. How has visiting restrictions and the Essential Visitor Policy impacted residents' physical, cognitive, and emotional health? What strategies were implemented to reduce the impacts of loneliness? What demonstrated greatest effectiveness?
- 6) How were group mealtimes affected? How was nutrition affected?
- 7) How did COVID-19 impact residents with dementia? How has dementia affected the implementation of infection control practices for residents with COVID-19. For example, how does the act of staff wearing PPE impact behaviours in residents with dementia?
- 8) What is the impact of the Essential Visitor policy on residents' psychological wellbeing?
- 9) How was palliative care for COVID-19 and unrelated conditions provided in LTC during the pandemic?
- 10) How do palliative end-of-life standards in LTC meet the evidence-based standards in the literature? How did COVID-19 impact the provision of palliative end-of-life care in LTC?
- 11) How did COVID-19 impact persons on waiting lists for LTC? What were the experiences of those who newly entered LTC during the pandemic? What were the effects of mandatory quarantine period for newly admitted residents? What were the effects for persons who were discharged from LTC back to community (e.g., family took them home, they voluntarily left etc.)?

¹ BC COVID-19 SRAC. Framework for Research and Action in an Emerging Disease. Available from: <https://www.msfrh.org/sites/default/files/APRIL%2027%202020%20FRAMEWORK%20ISSUE%201.pdf>

Priority Two: Addressing broader LTC challenge in relation to learnings from a pandemic

(Evaluation of programmes; evaluation of health services)

- 1) What staffing model changes are required in LTC (e.g., the need for leadership, RN vs. LPN)? Do the staffing models in BC achieve evidence-based best practises that have been identified for the current LTC populations and subpopulations? Given pre-pandemic staffing shortages, what strategies are required to effectively recruit sufficient, qualified staff?
- 2) There is a significant gap in understanding the role the built environment plays in preventing, reducing or shortening outbreaks and infectious diseases (e.g., the behaviour of bio aerosols) in LTC. What facility design characteristics do, or could reduce the impact of a pandemic? How do measures taken by staff to prevent the spread of COVID-19 need to differ for each environment type (e.g., 4-bed rooms with shared bathrooms vs. single occupancy rooms)? How should these differences be reflected in policy?
- 3) How well do the licensing standards support outcomes for residents? How are these standards for care/quality and service interpreted, measured and evaluated? How is risk determined when these minimum standards are not met? How well are standards understood in settings where the current licensing regulations do not apply (hospital based LTC, assisted living)?
- 4) How have infection control measures impacted meaningful culture change in LTC? What system-level changes have been, or need to be, made to improve infection control preparedness in LTC? For example, LTC facilities can hire a different housekeeping company for their services. Each company has their own policies that dictate the standards of cleanliness that should be achieved. There should be a policy that unifies cleaning standards across all sites.
- 5) Were there differences in outcomes and experience between different types of settings (licensed care of various sizes, hospital-based)? Geographical area (rural vs. urban, north vs. south vs. island)? Differences in outcomes based on public versus private ownership and management. Do previously identified parameters of quality correlate with outcomes during the pandemic?
- 6) What future pandemic planning is required? For example, ensuring that tabletop or simulation exercises are conducted for/with the LTC sector.

Priority Three: Interpretation and implementation of policy related to the pandemic

(Evaluation of programmes; evaluation of health services; impact of disease, treatment, and control measures; analysis of vulnerabilities and resiliencies and structural issues contributing to these)

- 1) What are the intended and unintended consequences of how Public Health Officer orders are interpreted, implemented, or translated across the province, between Health Authorities or between LTC homes and assisted living? In what ways are guidelines, orders directions and policy recommendations communicated to residents, families, staff, and LTC home operators? Are there similarities/differences in interpretations? For example, how are family visit orders interpreted and enacted? How is the definition of an 'essential visitor' applied or understood?
- 2) Were residents and families involved in the interpretation and implementation of policies? If so, in what way? Were they part of the process or just receivers of the policies?

- 3) Once an outbreak has been declared, long-term care homes have received differing direction from experts intending to support the long-term care home. This has resulted in confusion for staff, residents and families about the management of COVID-19 in long-term care. As such, there is a need for clear, consistent messaging, provided consistently. What factors contributed to misinformation and breakdowns in communication? How has communication during a COVID facility outbreak differed from communication when there were other infectious outbreaks, or when the facility was not experiencing an outbreak? How are inconsistencies in interpretations of guidelines, orders or policies prevented? Is it possible to allocate SWAT resources in a way that ensures consistency (e.g., one SWAT team to a particular number of LTC homes)? This would promote more engaged conversation and a deeper understanding of the nuances of each site, and perhaps do much to reduce staff, resident and family anxiety.

Priority Four: Health and human resource impact

(Evaluation of programmes, evaluation of health services, impact of disease, treatment, and control measures, analysis of vulnerabilities and resiliencies and structural issues contributing to these)

- 1) What is the impact on individuals working in this sector; for example, their experience of moral distress?
- 2) Given the varied models of medical care in LTC settings, were outcomes and experiences during the pandemic influenced by the configuration of medical care (nurse practitioner, dedicated medical staffing, care by community-based physicians)? What were the patterns (numbers, frequency, appropriateness) of direct medical care services (for both COVID-19 related and unrelated issues) provided to residents in facilities experiencing outbreaks and those that did not?
- 3) How has outbreaks/infection control protocols and changes in policies affected staff and volunteer retention, access to PPE, education and awareness of infection control measures?
- 4) Given the grim picture painted of long-term care homes in the public eye regarding quality of care and service, and quality of life, how has that impacted staff recruitment? Waitlists for long-term care? Public opinion about long-term care? Staff's perspective of the importance of their work? Staff commitment to continuing to work in long-term care?

Priority Five: Implementing, evaluating, and monitoring best practice: Scaling up local innovation

(Evaluation of programmes; evaluation of health services; analysis of vulnerabilities and resiliencies and structural issues contributing to these)

- 1) While best practices in infection control has been identified, what happens when facilities are challenged to communicate and/or maintain best practices? What are the most effective mechanisms by which residents and family can raise their concerns and avoid being labelled as troublemakers? What policy or processes need to be refined? In what way? Why?
- 2) How has technology mitigated the challenges with COVID-19? For example, how has the addition of technology for family visits impacted resident wellbeing? How has this impacted care staff? Are other care duties being missed to accommodate linking residents and families? Which technology introduction is identified as the most acceptable – to staff? To families? To residents?
- 3) The pandemic has prompted localized innovations (e.g., front-door ambassadors; connecting with family via Zoom). What can be learned from these practices? Are they sustainable? Can they help prepare LTC for future crises?

Priority Six: Risk communication

(Evaluation of programmes)

- 1) What information do families, staff and residents want to know? Need to know? What communication structure is required to ensure consistent information throughout all LTC?
- 2) What strategies for exchanging information have proven most beneficial? Timely? Responsive?
- 3) Some care staff have expressed fear in working with residents who have COVID. How has risk of transmission been communicated to care staff? From the perspective of care staff, what are acceptable risks? What supports are needed to enable care staff to continue to work in the sector?

Appendix 3: Current COVID-19 research in LTC in BC

Scan for Current Research Relevant to COVID-19 response in LTC in BC

Scanned: Dec. 15, 2020; Dec. 23, 2020

Methods: AHSN database exported to Excel. Search terms included: “LTC”, “long-term care”, “nursing home”, “residential care aides”, “assisted living”, and “AL” across all columns and rows. Eight studies were extracted. Given that the AHSN database reflects research projects voluntarily submitted and therefore does not capture all research occurring within BC, hand searches for additional research projects were also conducted. All study descriptions (if available) were scanned and categorized according to bucket issues identified by the LTC working group.

Bucket Issues (#) corresponds to priority issue identified in App.2	Summary	Research Lead	Source
HIGH RELEVANCE: LTC research that can be used to inform key research questions			
Health and human resource impact (4)	Evaluation of rapid redesign on (a) the quality and safety of care delivery and (b) staff, residents and their families.	Farinaz Havaei	AHSN
Health and human resource impact (4) & Resident wellbeing (1)	Staying Apart to Stay Safe: The Impact of Visit Restrictions on Long-Term Care and Assisted Living Survey	Office of Senior’s Advocate, Office of Patient Centred Measurement	Senior’s advocate
Health and human resource impact (4)	Impact of COVID-19 on the wellbeing of frontline health-care workers in the home care and LTC in BC.	Bala Nikku	AHSN
Health and human resource impact (4) & Resident wellbeing (1)	Impact of infection, prevention, and control (IPC) measures on culture change in LTC.	Amy Salmon	University seed grant proposals
Health and human resource impact (4)	Implementation of “one high risk site” staffing policy, prohibiting LTC staff from employment in more than one facility.	Joanie Sims Gould	MoH/MSFHR funding partnership
Family caregiving	The effects of visit restrictions on family caregivers in DSL/AL; whether changes in care patterns differ across characteristics of family caregivers, residents, and DSL/AL	Jennifer Baumbsuch	AHSN

Bucket Issues (#) corresponds to priority issue identified in App.2	Summary	Research Lead	Source
Implementing best practices (5) (Pandemic preparedness)	A resident/family-centred, team-based virtual quality improvement collaborative approach to comprehensive pandemic preparedness in LTC.	Akber Mithani	MoH/MSFHR funding partnership
Implementing best practices (5) (Technology)	Expand the use of video and audio technologies for the virtual work environment and test the use of robots in long-term care and clinic settings using 4G/5G networks and digital medical tools such as digital stethoscopes and biometric monitoring.	Kendall Ho, Karon MacLean	AHSN
Implementing best practice (5) (Technology)	Case study for the implementation of a Portable 3D printed Mechanical Ventilator to Fight COVID-19 in long term care homes	Woo Soo Kim, Lillian Hung	University seed grant proposals
Addressing broader LTC challenges (2)	Facility ownership and organizational (e.g., staffing) characteristics associated with outbreaks of Covid-19	Margaret J. McGregor	AHSN
Health and human resource (4)	(1) Health resource utilization and medical costs for patients with mild, moderate, and severe COVID. (2) How hospitalizations, physician's services, home care, long term care, and other resources have changed in patients without COVID.	Kimberlyn McGrail, Stuart Peacock	AHSN
COVID-19 transmission, genetic diversity & evolution	Advancing real-time SARS-CoV-2 genomic analysis to enable rapid action in healthcare-related SARS-CoV-2 outbreaks	Chanson Brumme	University seed grant proposals
COVID-19 transmission	Reduce spreading of Covid-19 by using antiviral coatings in senior care homes and hospitals	Rizhi Wang	UBC

Bucket Issues (#) corresponds to priority issue identified in App.2	Summary	Research Lead	Source
MEDIUM RELEVANCE: research that includes LTC in sample			
Health and human resource (4)	Impact of pandemic on nurses' psychological health and safety and how this has changed after the pandemic.	Farinaz Havaei	AHSN
LOWER RELEVANCE: research that is related to aspects of LTC (e.g., health and human resource) though sample may not include LTC directly.			
COVID-19 exposure	Factors impacting exposure to COVID-19 for healthcare workers (HCWs) in Vancouver Coastal Health (VCH).	Annalee Yassi	AHSN