Through the Looking Glass

The Impact of COVID-19 Isolation on Long-Term Care Facility Residents — A Visitor's Perspective

A Patient-Initiated Research Project in Newfoundland and Labrador's Eastern and Western Health Zones (formerly Eastern Health and Western Health)

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Letter from The Patient and Public Partners

Isolation killed my mother; she died of a broken heart. The chance to never say goodbye to a loved one is very difficult. We have to live with the guilt of never being there for her in the last few months of life.

— Survey Respondent

Our survey echoed many of the key themes we heard from friends and family during the COVID-19 pandemic in Newfoundland and Labrador (NL) in the spring and summer of 2020. As Patient and Public Partners on NL SUPPORT's Patient and Public Advisory Council, we also heard concerns about the impact visitor restrictions were having on residents in long-term care facilities. These concerns led to the study outlined in this report. This study is a Patient Partner-Initiated Research Study, with two Patient Partners volunteering to be full members of the research team. The goal of this study was to determine the impact of COVID-19 restrictions on visitors and residents of long-term care facilities in Eastern and Western Health.

This study involved the development of a visitor survey and its promotion to community members. We would like to thank all those who took the time to complete our survey, as well as those who helped with its promotion. We appreciate that for many visitors it was difficult to answer the survey questions, as they sparked many deep emotions. We thank all those who responded for giving a voice not only to their own experiences but for speaking for their resident(s) in long-term care whom we could not include in this study.

While many themes emerged from the research outlined in this report, as Patient Partners the most important theme to us was loss. As seniors (and Patient Partners) we felt an overriding sense of loss—sometimes unbearable loss. Loss of time with loved ones, loss of day-to-day activities, loss of confidence in the residents' well-being, loss of daily communication, loss of trust in the system, and sometimes the unbearable loss of losing a loved one without the chance to say goodbye. Certainty was often replaced with worry and confusion as restrictions on visitation, masks, and distancing constantly changed.

Health authorities and long-term care facilities were doing their best to keep up with the evolving science and changes in patient care while waiting for a COVID-19 vaccine to become available. The focus was on safety, and this trumped other concerns, such as the impacts of isolation and loneliness on residents in long-term care. Some visitors felt that the benefits of visits from family and friends far outweighed the risk of contracting COVID-19, highlighting the important role that visits play in a resident's quality of life. This study provides insight into important lessons that society can take away and makes recommendations that we hope policy-makers will consider as we move forward in developing long-term care policies and pandemic preparedness plans. These recommendations are listed on page 31 of the report.

From our point of view, the recommendations boil down to one thing: put the residents and their families first. Consider their needs and build a better system to address them. Create change from the bottom up—keep what is working while building new procedures and policies that follow a resident-centred approach. One size does not fit all, as long-term care facilities manage residents with a wide variety of cognitive and physical impairments, such as dementia, hearing loss, and mobility issues. To do this, we will require a willingness to act from our leaders, as well as their understanding and compassion.

For seniors like us, the experience of long-term care residents during COVID-19 lockdowns sparked fear for our future, with concerns for our well-being and the quality of care we will receive. The question at the top of our minds is: where are we going to go when we can no longer take care of ourselves? With the well-publicized reports of the crisis and mortalities in long-term care facilities during COVID-19, seniors are reconsidering their options. They want control of their health care choices and the ability to make decisions regarding their care. Living in long-term care should not mean a relinquishing of control of one's life or one's willingness to live at risk.

This project has been a labour of love. We have devoted many volunteer hours to its completion over the past three years. As patient and public partners, we have had many rewarding challenges working for the first time with an experienced research team, and there is much we hope to share with patients eager to get involved in our health care system and policy-making at the ground level. Engagement of all Newfoundlanders and Labradorians in creating change is essential. We encourage those who are interested in getting involved in research as a patient partner to participate in groups such as the NL SUPPORT Patient and Public Advisory Council. We thank the research team for investing their time and energy into this project, NL SUPPORT's Patient and Public Advisory Council for its feedback, and NL SUPPORT for providing the funding to make this project possible. Together we can improve the quality of life for residents in long-term care and for our province's aging population.

Cris Carter *is a patient and public partner and volunteer in the health care sector working to improve health care outcomes for seniors through various research and health care initiatives.*

Rosemary Lester *is a patient and public partner and advocate for the rights and protection of older persons. She successfully sought support for a number of initiatives designed to improve the lives of seniors in Newfoundland and Labrador.*

Hopefully policymakers have learned, as we all have, from COVID. It's tough to find that middle ground but that is their job. Restrictions in future will need to find a better balance. Loneliness will kill as well.

— Survey Respondent

Letter from The Clinical Lead

March, 2024

Reading this report will leave you questioning what we could have done differently for the residents of long-term care facilities during the COVID-19 pandemic. Many of the quotes from visitors and family members of the residents are raw and emotional, showing the depth of feeling they experienced. Despite this, I am delighted that NL SUPPORT was able to support Patient and Public Partners in taking this project forward, as the experiences of visitors and family members of residents needed to be told. This work highlights important lessons learned, as well as the vital insights patient and public partners can provide to health care research and evaluation.

This project represents a further step in the work of the NL SUPPORT Unit. While it has supported patient-oriented research in many forms since its inception in 2014, this project is the Unit's first patient-initiated research project, or research led by Patient and Public Partners. Everyone involved in this project has learned a great deal from this process, and are proud to present the research findings in this report.

This project was an ideal fit for patient-initiated research because the topic was identified by members of NL SUPPORT's Patient and Public Advisory Council as one of concern early in the COVID-19 pandemic and one of personal importance. Given the personal relevance of the topic and NL SUPPORT's Patient and Public Partners' enthusiasm, we felt this was an opportunity to support them in embarking on a patient-initiated research project.

A key component of patient-oriented research is selecting topics that are of importance to people directly affected by an issue. In listening to reports from visitors and families, it was clear that this topic was of great concern to many people in Newfoundland and Labrador who were looking to balance safety and quality of life for those living in long-term care facilities. The knowledge generated from this study adds further weight to the importance of conducting patient-oriented research.

The research team was encouraged by the willingness of the Regional Health Authorities (now referred to as NL Health Services) to participate in this work, despite the tremendous additional pressure placed on them

by the realities of the pandemic. This willingness demonstrates a desire to learn from the experiences of the pandemic to help better prepare for the future and provide the best care possible to residents of long-term care facilities. This desire for systems improvement also aligns with NL SUPPORT's work on developing and supporting a learning health and social system in the province. A learning health and social system works to continuously improve by taking in information on system performance and using it to adapt and adjust service provision. As is apparent from the findings of this project, there is much to learn from this experience that can be used by the system to adapt and adjust for a better future. The research team is grateful to the directors in NL Health Services (formerly Eastern and Western Health) who encouraged this endeavor and the staff who facilitated this work within their facilities.

We thank the participants who took the time to complete the survey and contribute to this work. It is very clear from the responses that reflecting on their experiences was difficult for many respondents and the team is grateful for the time they took to share their experiences. These stories are incredibly impactful and allow the reader to understand the impact that provincial policies have on the lives of those in long-term care.

NL SUPPORT thanks its Patient Partners, Rosemary Lester and Cris Carter, for their tireless dedication to completing this project and ensuring the patient and caregiver voice is front and center in the information shared with decision-makers. After all, it is the patients' and caregivers' lives that are directly impacted by the policies decided upon by decision makers. The commitment of Rosemary and Cris to this work is a demonstration of the important role that patients play in all aspects of the health care system.

The world has now moved towards the "new normal" of living with COVID-19 and we are tasked with determining how best to apply learnings from the acute lockdown phase to the future. Readers of this report are encouraged to pay attention to the role of connection in the stories shared and remember that even in the midst of crisis, it is human connection that residents and visitors in long-term care facilities value. In the spirit of a learning health and social system, NL SUPPORT hopes that by sharing these research findings it can help residents and visitors shape system changes to come.

Dr. Brendan Barrett
NL SUPPORT Clinical Lead

Abbreviation Index

PPAC – Patient and Public Advisory Council

NL SUPPORT – Newfoundland and Labrador Support for People and Patient-Oriented Research and Trials (one of eleven units across the country as part of the Canadian Institutes of Health Research Strategy for Patient-Oriented Research)

SPOR – Strategy for Patient-Oriented Research (funded by the Canadian Institutes of Health Research)

NL – Newfoundland and Labrador

LTC – Long-term care

WHO – World Health Organization

OECD – Organisation for Economic Co-Operation and Development (intergovernmental organisation with goal of stimulating economic progress and global trade)

QCNL – Quality of Care Newfoundland and Labrador

RAI-MDS 2.0 – Resident Assessment Instrument – Minimum Data Set (a standard data reporting tool used in continuing care settings across the country)

CIHI – Canadian Institute for Health Information

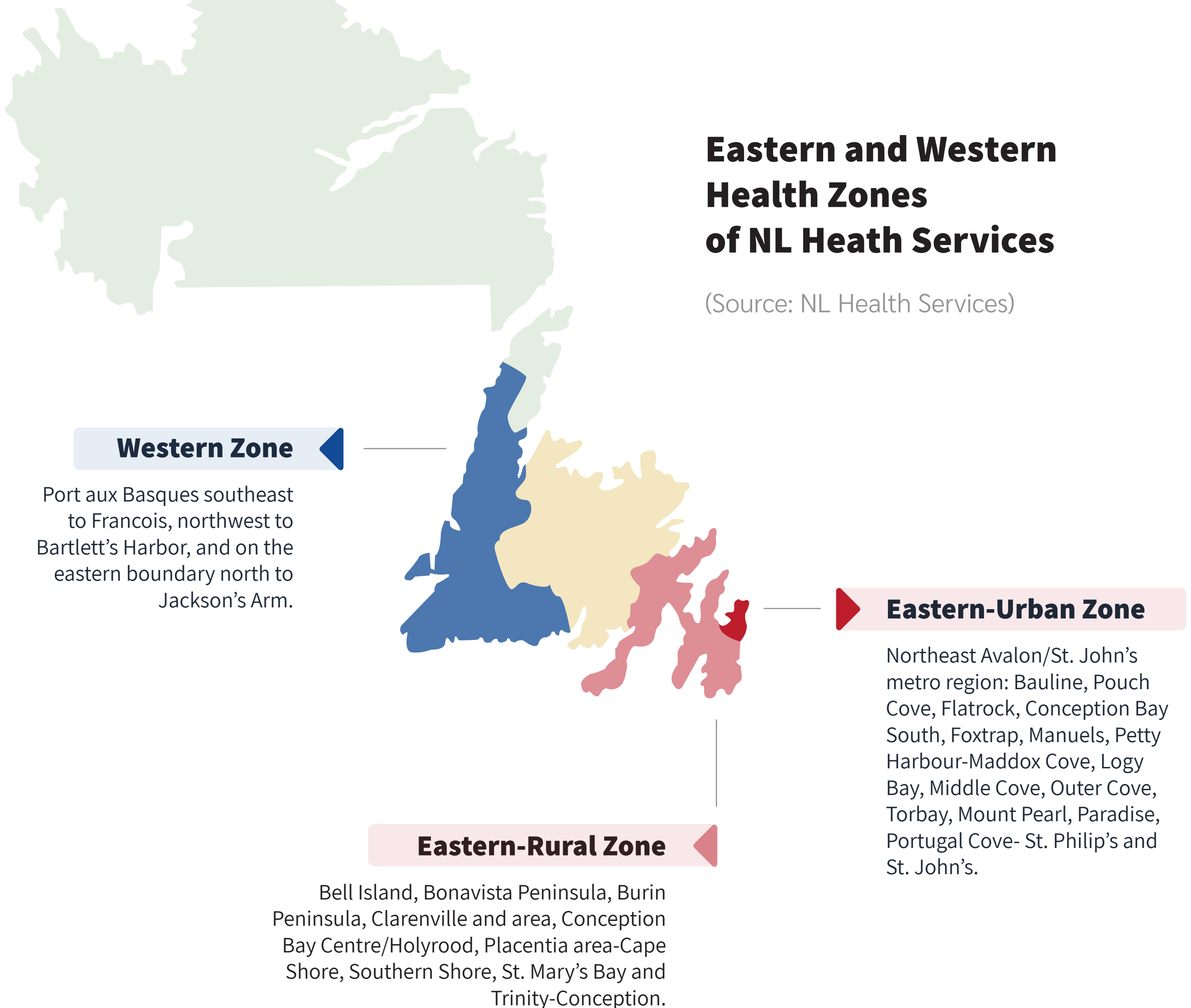
OSA – Office of the Seniors Advocate

HSO – Health Standards Organization

Executive Summary

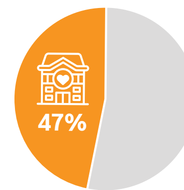
In long-term care facilities, visitors play a crucial role in the circle of care for residents. The COVID-19 pandemic unfortunately enforced tight restrictions and at times the complete removal of visitors which resulted in a significant increase in isolation for residents. Prolonged social isolation raised concern for residents' mental and physical health and overall well-being. In the fall of 2020, members of the Patient and Public Advisory Council of Newfoundland and Labrador's SPOR SUPPORT Unit (NL SUPPORT) expressed concerns regarding the impact of these restrictions on residents and their families. These concerns led to a research project investigating the effect of restrictions on the mental and physical well-being of residents and their visitors. This research project focused on the completion and analysis of a survey of visitors of long-term care facility residents during the COVID-19 pandemic. The survey was only completed by those who would have been visitors as many residents would have required unavailable assistance to provide their own perceptions.

A total of 184 respondents completed the survey. Survey respondents were from the Eastern and Western Health Zones of NL Health Services (formerly Eastern Health and Western Health).



Survey results showed:

47% of survey respondents reported that the resident they visited was residing in a long-term care facility prior to the start of the COVID-19 pandemic (March 2020)



These survey responses can be compared to data from the Resident Assessment Instrument – Minimum Data Set (RAI-MDS 2.0)* that is reported on all residents of long-term care in the province. Health care employees engaged in the residents' care complete the RAI-MDS 2.0 quarterly on all residents. It is included in this report to give a clinical interpretation that represents all residents of long-term care at the time and not just those represented by visitors in this survey. Comparing the **RAI-MDS 2.0 data points** from Mar 2020–Nov 2022 (the same period included in our survey) for all long-term care residents in Newfoundland and Labrador to before the pandemic (prior to March 2020), **we see some similarities and differences to the survey responses**:

Survey respondents reported that during COVID-19 pandemic restrictions:

20% of visitors reported that a resident **passed away**

60% of visitors reported that the **overall health of the resident they visited worsened**

62% of visitors reported that the resident's **cognitive function worsened**

5% of visitors reported that a resident **passed away in the first year** (Mar 2020–Apr 2021)

53% of visitors reported that the resident's **physical mobility worsened**

60% of visitors reported that the resident's **overall mood and well-being worsened**

69% of visitors reported the **quality of care** provided to residents was **very good**

41% of visitors reported **their own mental and emotional well-being worsened**

RAI-MDS 2.0 Data Points

During the COVID-19 pandemic restrictions:

21% of residents **passed away**#

28% of residents' **overall health** worsened, **53%** stayed the same, and **18%** improved

24% of residents' **cognitive function** worsened, **64%** stayed the same, and **11%** improved

24% of residents **passed away in the first year** (Mar 2020–Apr 2021)

25% of residents' **physical mobility** worsened, **65%** stayed the same, and **9%** improved

26% of residents' **mood and well-being** worsened, **55%** stayed the same, and **18%** improved

#Zero deaths due to COVID-19 were reported in the study period

*RAI-MDS 2.0 stands for Resident Assessment Instrument-Minimum Data Set. This is a data-reporting tool that is used in continuing care settings across the country. Data are regularly submitted to the Canadian Institute for Health Information (CIHI). According to CIHI submitted data are used to "plan and monitor care, understand populations, improve quality, and allocate resources".

Two major themes arose from respondents when given the opportunity to share their own thoughts and stories during the pandemic:

1. Restrictions had a negative impact on the mental health of residents. There were feelings of loneliness, isolation, confusion, and abandonment, particularly for residents with cognitive impairments such as dementia. Visitors identified the importance of social connection as a key focus area for decision-makers to consider when creating or amending policies that affect quality of life. Using social connection as a lens will ensure that polices will improve quality of life.

2. Negative feeling about provincial policies regarding restrictions in LTC facilities and the need to carefully weigh the harms and benefits of restrictions in place.

> *Because we were not allowed in to see my mother, her condition worsened. She could not understand why we were not permitted to see her. Mentally this was too much for her.* ***3 months and no visit from her family at 95 years old was the cruellest punishment inflicted on her.***
>
> — Survey Respondent

In careful review of the survey responses and of recent reports, the project team is making five major recommendations:

1. Always allow for at least one visitor in LTC facilities to support the quality of life of the resident. Permit alternative designated visitors to reduce the burden on the designated visitor.

2. Place priority on socialization and connection between residents. In addition, minimize the restriction on regular extracurricular, physical, social and routine activities.

3. Improve mechanisms of communication between facilities, staff, visitors and residents, specifically in relation to policies and decision-making processes regarding residents' physical and mental care.

4. Consider the different needs and circumstances of residents when developing policies and making decisions around restrictions (e.g. those with cognitive impairment, those in protective care units and those receiving palliative care).

5. Provide a method of communication available to residents that they know how to use or that they can be assisted to use with the support of staff, volunteers, and visitors.

Background

On March 11, 2020 the World Health Organization (WHO) declared COVID-19 a global pandemic (1). Across Canada, provincial governments focused their initial efforts on hospitals and consequently did not prepare to mitigate the impact of infections in the long-term care sector, resulting in a significant number of deaths. During the first wave of COVID-19, which occurred from Mar 2020–Aug 2020, Canada reported the highest proportion of all deaths occurring in LTC (**84%**) amongst all Organisation for Economic Co-operation and Development (OECD) countries. The majority of these deaths were within Ontario and Quebec (2).

On March 23, 2020, the Newfoundland and Labrador Government's Department of Health and Community Services announced that all LTC facilities across NL were closed to all visitors—this occurred just five days after declaring a Public Health State of Emergency (Figure 1). The NL Government stated this action was taken "to protect elderly residents and those with weakened immune systems or underlying medical conditions who are at higher risk of developing complications from COVID-19" (3). The increased vulnerability of LTC residents propelled the implementation of strict public health infection control protocols in facilities to reduce spread of the virus among residents during the first wave of the COVID-19 pandemic.

In an effort to reduce additional harms to those living in LTC, more restrictive visitor policies were implemented in LTC facilities across Canada. No deaths from COVID-19 occurred in LTC facilities in NL between Mar 1 2020–Aug 15 2021 (4). The restrictions and guidelines that were put in place over the course of the pandemic, either eliminating visitations or enforcing tight restrictions around them, may have contributed to lack of deaths from COVID-19 in LTC.

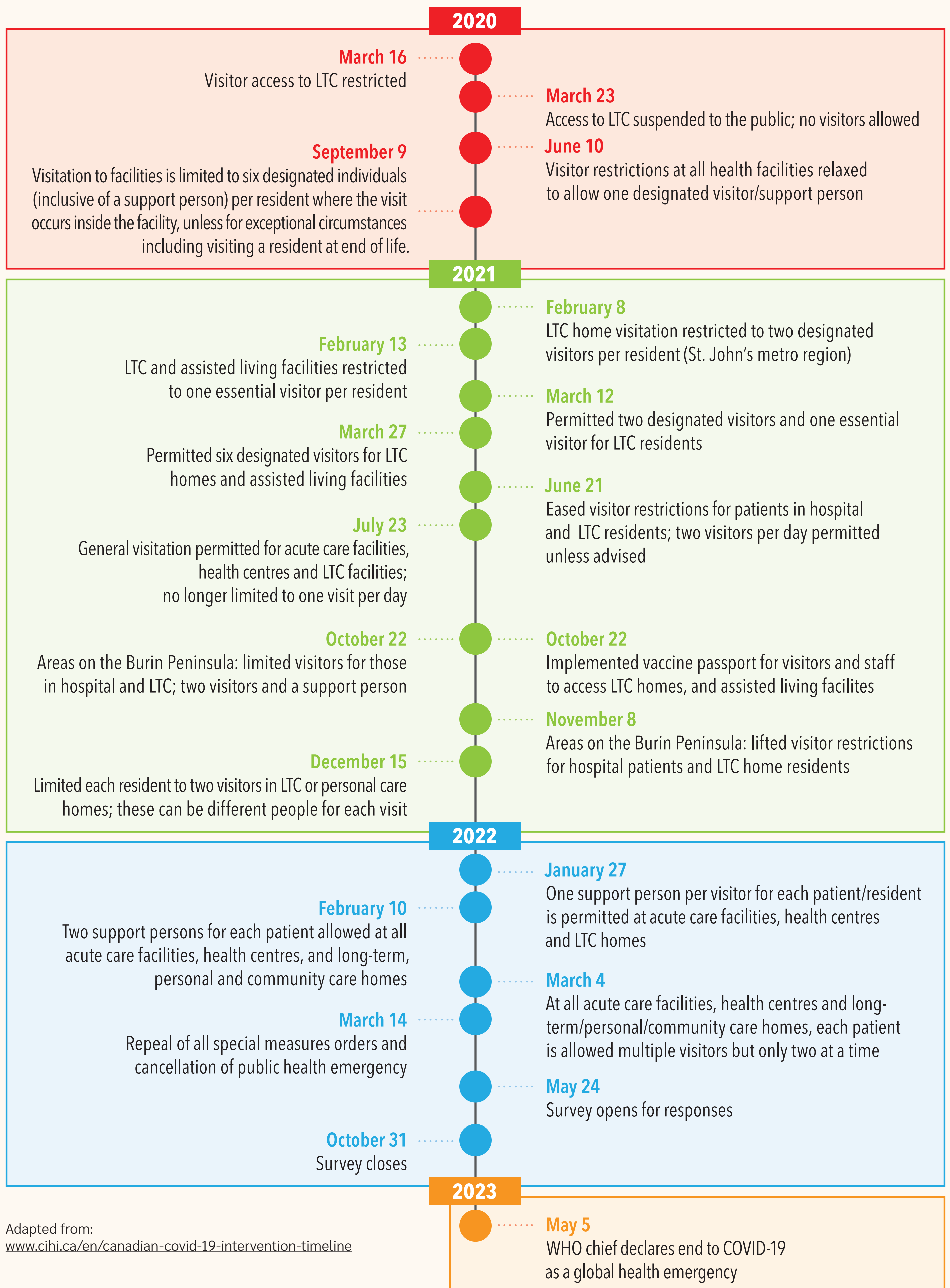


Figure 1. Timeline of Interventions Pertaining to Long-Term Care in NL

In LTC facilities, visitors are integral to residents' care teams as supplementary care providers and advocates for the residents they visit as they are in a unique position to understand the full needs of the resident in care (5). Family members and visitors act as care coordinators and help choose care options that require shared decision-making, or act as surrogate decision-makers when their resident in care is cognitively unable to do so (5). The lockdowns in LTC facilities and resulting removal of visitors from the care team can significantly increase the care burden on staff. Aside from the physical effects of staffing shortages, elderly people also suffer from increased ill health and death because of the removal of social interaction and mental stimulation (6). Despite government rules and facility practices, aging research and policy experts advocated for the protection of meaningful connections during the COVID-19 pandemic to prevent this increased death rate (5).

Furthermore, stories from family members, visitors, and seniors' advocates across the country point to negative impacts of prolonged social isolation on residents' mental and physical health (7). Social isolation is the objective state of having few social relationships or infrequent social contact with others while isolation contributes to the subjective feeling of loneliness. These are serious yet underappreciated public health risks that affect a significant portion of the adult population. Declines in residents' mental and physical health may be caused by worsened feelings of loneliness and isolation, as well as impacts of the lockdown on availability and quality of care (6, 8, 9).

Isolation may trigger responsive behaviours, particularly in those with dementia who may then be administered multiple sedative or antipsychotic medications (10). In 2019–2020, **23.1%** of residents of LTC facilities in NL were potentially inappropriately prescribed antipsychotics. During the first year of the pandemic (Apr 2020–Mar 2021), it was **22.1%** and increased to **26.4%** in 2021–2022 (11).

NL SUPPORT is Newfoundland and Labrador's SPOR SUPPORT Unit. SPOR is the Canadian Institutes of Health Research-funded Strategy for Patient-Oriented Research. NL SUPPORT provides supportive services in areas such as research methodologies, knowledge translation, patient engagement, and patient-oriented research. This Unit also includes the research and evaluation program Quality of Care NL (QCNL).

In fall 2020, members of the NL SUPPORT Patient and Public Advisory Council (PPAC) expressed concern about COVID-19 restrictions in LTC facilities. The PPAC is a patient/public volunteer group offering advice and guidance to NL SUPPORT and QCNL for patient-oriented research priorities, engagement of patients/public in research projects, and public outreach activities. Discussions led to an agreement within the PPAC to initiate a research project to study the impact of COVID-19 restrictions on visitors and residents in LTC facilities in Newfoundland and Labrador. The goal was to investigate the effect of restrictions on the residents' and the visitors' mental and physical well-being.

In response, NL SUPPORT established a research team to work with patient partners to investigate the problem. The team conducted an environmental scan of similar work on this topic. Through this, the team consulted with the Office of the Seniors Advocate of British Columbia who had published a report titled "Staying Apart to Stay Safe: The Impact of Visit Restrictions on Long Term Care and Assisted Living Survey". In this report, they share findings of a five-week survey about the impact of COVID-19 related visitor restrictions at long-term care and assisted living homes. The survey was answered by residents, their family members, and the general public. https://www.seniorsadvocatebc.ca/osa-reports/staying-apart-to-stay-safe-survey/. With permission, our team adapted the survey developed by Office of the Seniors Advocate of British Columbia to reflect the LTC population in NL. This report is the result of our team's work.

The Survey

Background

In this study, a survey (Appendix B) was used to examine the effect of COVID-19 restrictions on visitors and residents in LTC facilities in NL. The survey was open for responses from May 24 2022–Oct 31 2022 and could be completed online or by mail. The survey was advertised and open to visitors# of residents living in LTC facilities in the former Eastern and Western Health Authorities in NL (**24** total facilities). This represented a wide variety of facility sizes from under 25 beds to over 450 beds. A total of **224** surveys were collected, of which **184** provided usable data and **40** were excluded due to incompletion. Due to pandemic-related capacity constraints in Central and Labrador-Grenfell Health, the research team chose to survey only Western and Eastern Health. The inclusion of RAI-MDS 2.0 data* from all LTC facilities across the province allowed for some evaluation of all regional health authorities without creating additional burden on the system. A resident survey was not included in the study design due to the high number of residents that would have required support from staff in order to complete the survey.

The survey contained both multiple choice and short answer questions. Key findings are included below. The text boxes in each of the following sections include additional information to supplement the data provided. Quotes were selected from open-ended survey responses for that section and the data points reference RAI-MDS 2.0 data* that are collected by each LTC facility on all residents in the province. RAI-MDS 2.0 data points were added to provide additional context to the information collected in the survey. The survey collected responses from a relatively small number of individuals in two regions of the province. The RAI-MDS 2.0 data are regularly reported on all residents of LTC in the province and so provide a more complete picture of changes in resident health and well-being during the time period of the study.

Who Responded

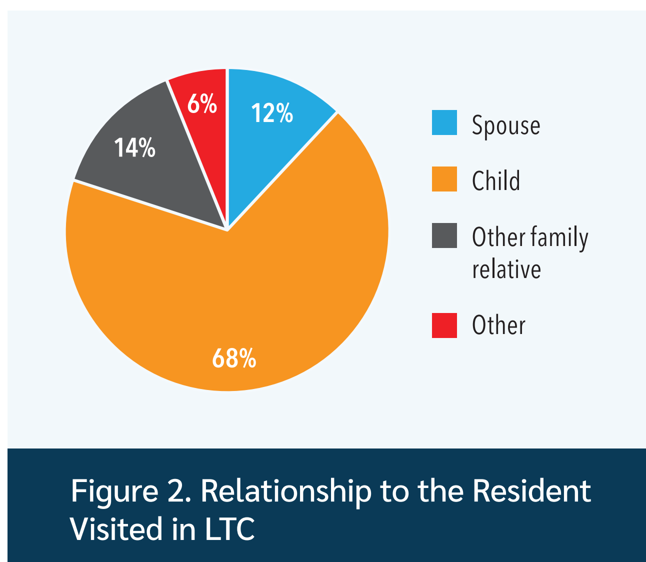


Figure 2. Relationship to the Resident Visited in LTC

68% of respondents were a child of a LTC resident, **14%** were relatives (i.e. cousin, aunt, sibling), and **12%** were a spouse (Figure 2)

81% of respondents were female and **19%** of respondents were male (**one** respondent identified as non-binary)

Average age of respondents was **60 years old**

20% of respondents had to travel more than an hour to arrive at the LTC facility in which the resident resided

#visitors refers to any person entering a LTC facility/nursing home for the purposes of visiting a resident of the facility or volunteering with residents of the facility. Visitors of residents who had passed away during the restrictions were also invited to participate.

*RAI-MDS 2.0 stands for Resident Assessment Instrument-Minimum Data Set. This is a data-reporting tool that is used in continuing care settings across the country. Data are regularly submitted to the Canadian Institute for Health Information (CIHI). According to CIHI submitted data are used to “plan and monitor care, understand populations, improve quality, and allocate resources”.

The Residents

Survey respondents reported that:

The average age of residents (who received visitors) was **84 years old**

69% of residents were female (Figure 3)

20% (33) of residents passed away during the course of the pandemic (see Figure 1 for pandemic timeline)

- Of those, **nine** residents passed away in the first year (Mar 2020–Feb 2021)

47% of residents were admitted to a LTC facility prior to the pandemic

68% of residents resided in NL's Eastern Health Zone and **32%** of residents resided in NL's Western Health Zone

64% of residents resided in a private room, **29%** of residents shared a room with one person, and **7%** of responses indicated "other living arrangements"

52% of residents did not have a private phone or access to a mobile phone

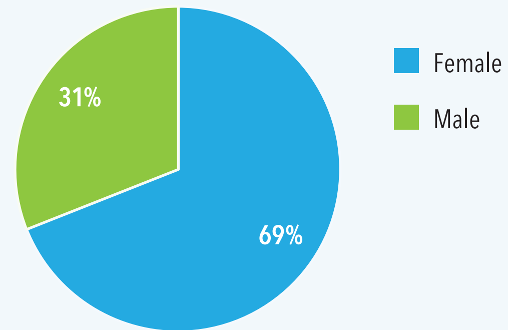
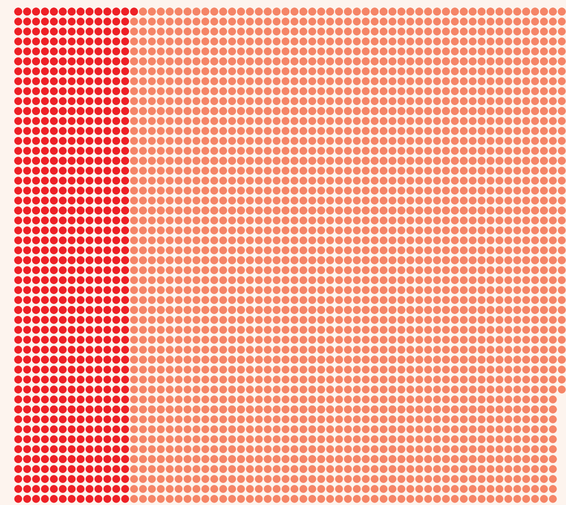


Figure 3. Gender of the Resident as Reported by Survey Respondents

RAI-MDS 2.0 Data Point



A total of **651 out of 3139** residents **(21%)** passed away during the course of the pandemic in all LTC facilities in NL.

> *They were transferred alone in a taxi and placed in isolation with no phone for about 26 days. We were told the room didn't have a phone jack and our only option was a cell phone, which our mother was unfamiliar with. We had a hard time with all that, but not nearly as hard a time as our mother had with the sense of neglect.*
>
> — Survey Respondent

Dad uses a laptop and regularly uses iMessages and Facetime

— Survey Respondent

Communication with Residents

Survey respondents reported that since the start of the COVID-19 pandemic:

55% of residents always required assistance from staff or volunteers when making a call via video or phone

Phone calls (Figure 4)

27% reported an increase in the number of visitor-resident phone calls

17% reported no change in the number of visitor-resident phone calls

19% reported a decrease in the number of visitor-resident phone calls

37% reported that the resident does not talk on the phone

Video calls

33% reported an increase in the number of visitor-resident video calls

11% reported no change in the number of visitor-resident video calls

7% reported a decrease in the number of visitor-resident video calls

46% reported that they did not use video calling to communicate with the resident

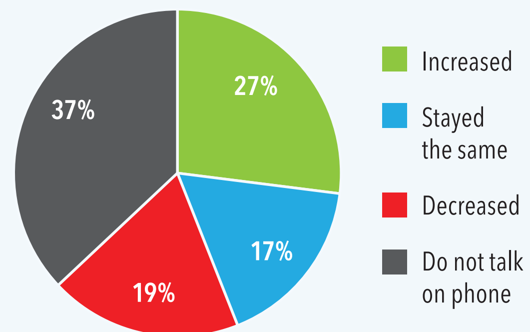
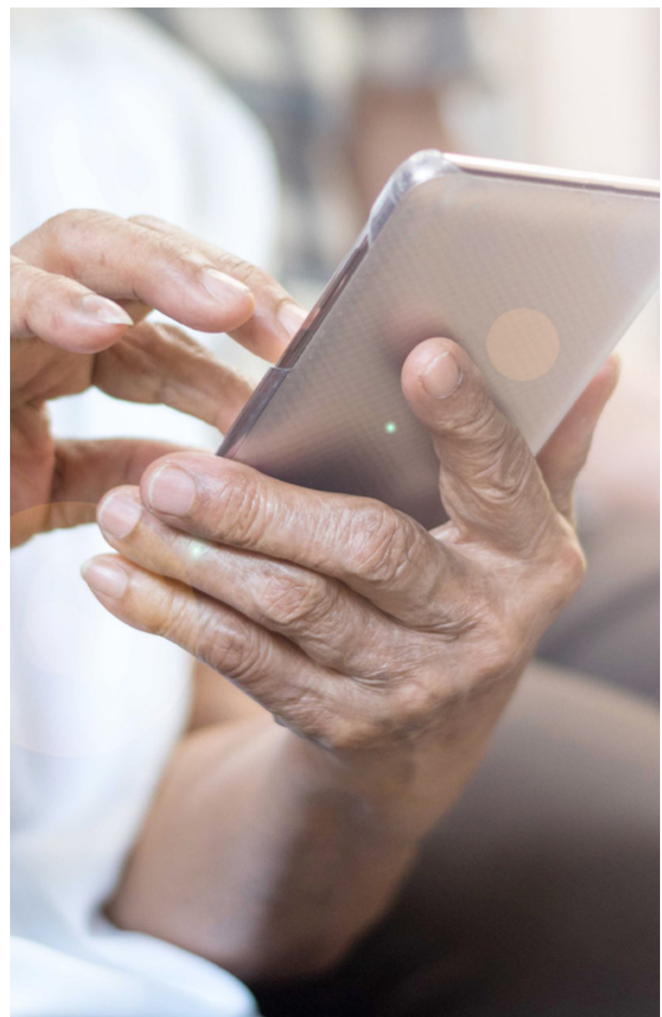


Figure 4. Number of Phone Calls During the Pandemic Compared to Before



Additional Services

Additional Services are provided either in or outside of the LTC facility. Additional Services include but are not limited to a paid companion, podiatrist, physical therapist, or hairdresser.

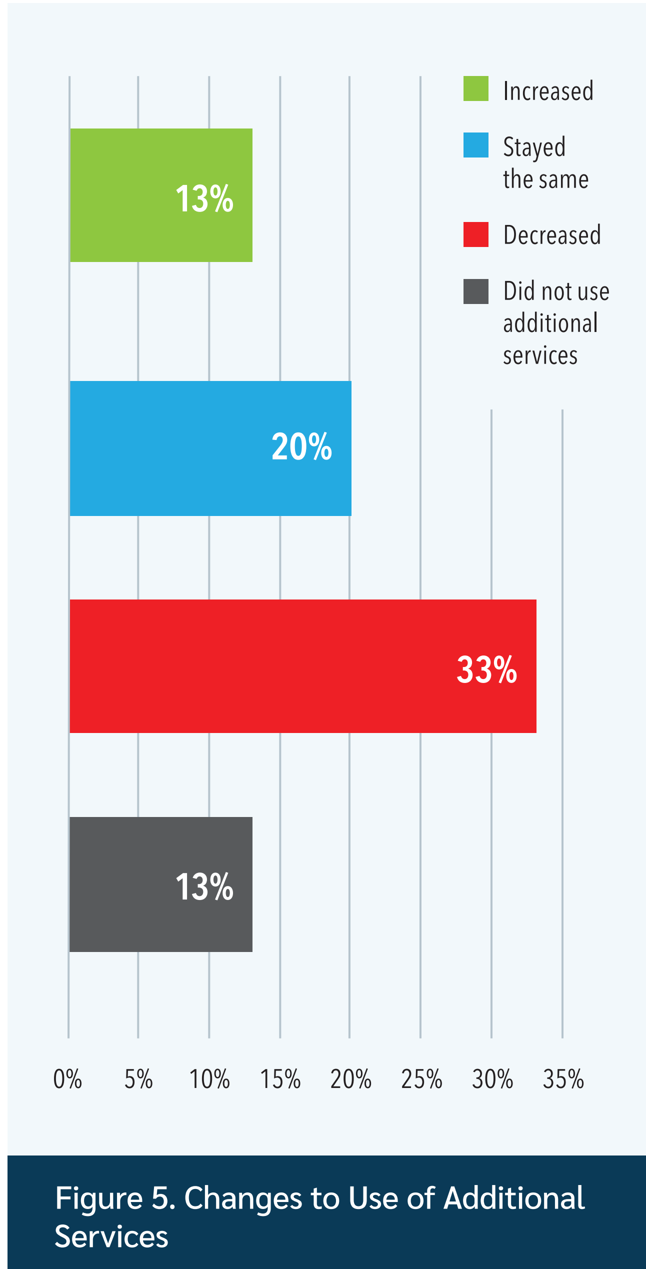


Figure 5. Changes to Use of Additional Services

Survey respondents reported that compared to before the pandemic (Figure 5):

33% reported that additional services decreased for the resident

13% reported that additional services increased for the resident

20% reported that where was no change in additional services for the resident

13% reported that they did not use additional services

> *Although Mom received good care there was a shortage of staff on a regular basis. This would mean that Mom spent more time in her room than she normally would.*
>
> — Survey Respondent

> *I make it a girls' day for haircut day. Normally this happens every 8 weeks. It decreased for a while.*
>
> — Survey Respondent

Health and Well-Being of Residents

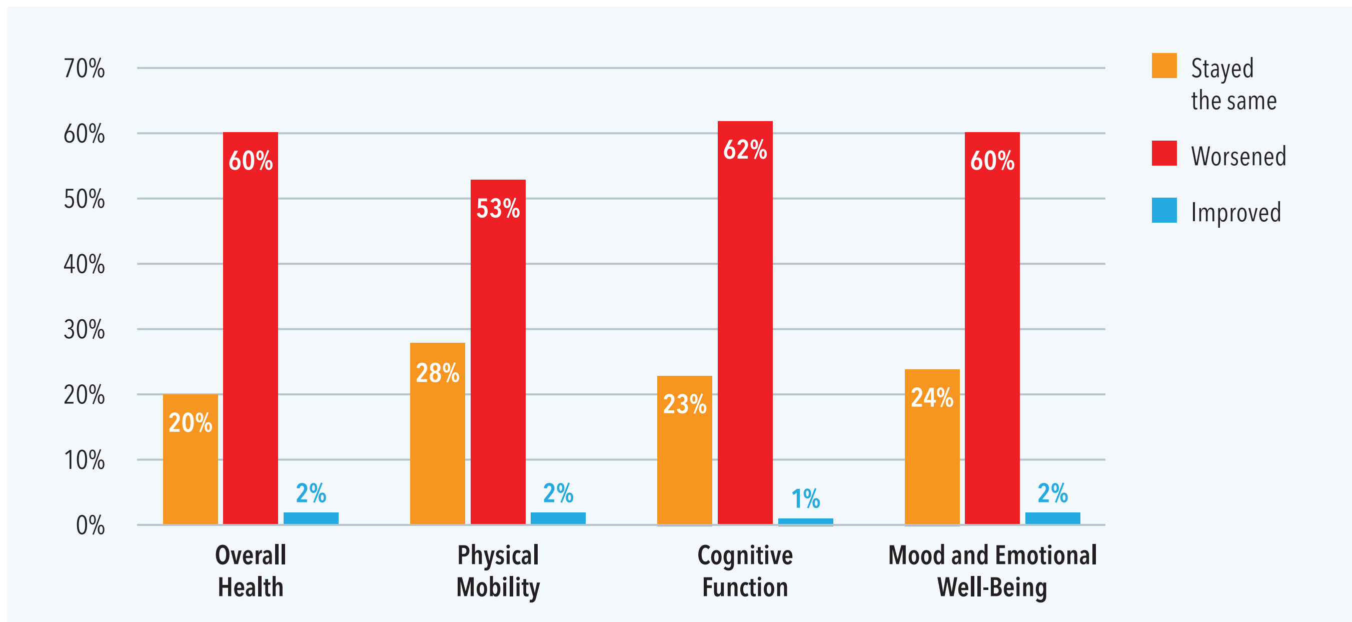


Figure 6. Health and Well-Being Changes of Resident During Pandemic as Reported by Survey Respondents

RAI-MDS 2.0 Data Point

Changes in health and well-being of residents between pre-pandemic (Apr 2019–Mar 2020) and during pandemic (Apr 2020–Mar 2021)

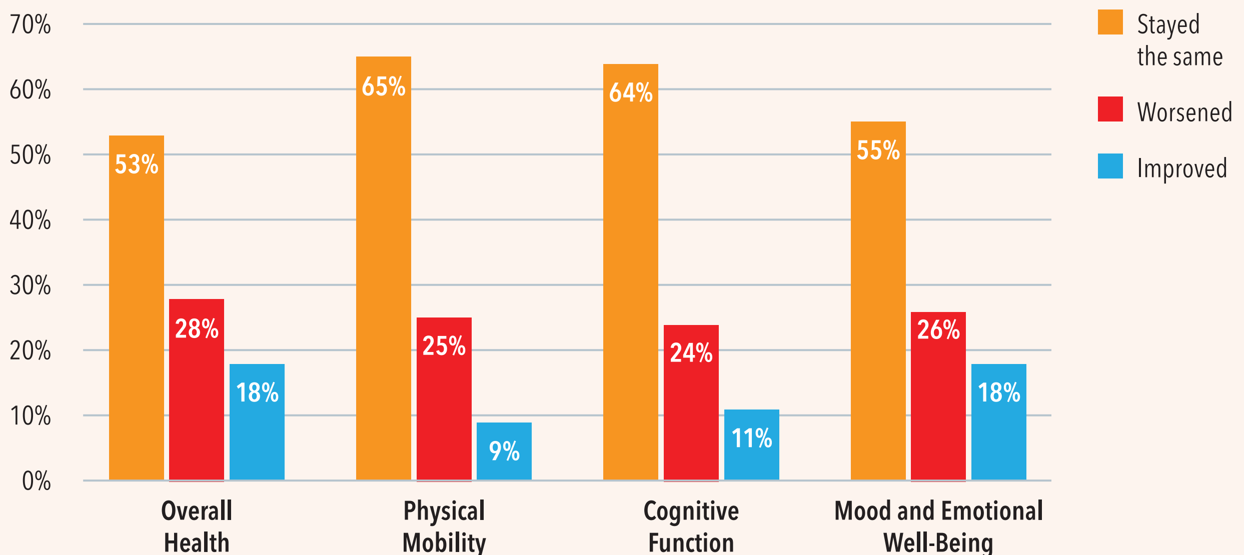


Figure 7. Health and Well-Being Changes of Resident During Pandemic as Reported in RAI-MDS 2.0

Survey respondents reported that compared to before the pandemic (Figure 6):

Overall health

60% reported that the resident's overall health worsened

20% reported no change in the resident's overall health

2% reported that the resident's overall health improved

Physical mobility

53% reported that the resident's physical mobility worsened

28% reported no change in the resident's physical mobility

2% reported that the resident's physical mobility improved

Cognitive function

62% reported that the resident's cognitive function worsened

24% reported no change in the resident's cognitive function

1% reported that the resident's cognitive function improved

Overall mood and well-being

60% reported that the resident's overall mood and well-being worsened

24% reported no change in the resident's overall mood and well-being

2% reported that the resident's overall mood and well-being improved

RAI-MDS 2.0 Data Points

Compared to before the pandemic (Figure 7):

Overall health

28% of residents' overall health worsened

53% of residents' overall health stayed the same

18% of residents' overall health improved

Physical mobility

25% of residents' physical mobility worsened

65% of residents' physical mobility stayed the same

9% of residents' physical mobility improved

Cognitive function

24% of residents' cognitive function worsened

64% of residents' cognitive function stayed the same

11% of residents' cognitive function improved

Overall mood and well-being

26% of residents' mood and well-being worsened

55% of residents' mood and well-being stayed the same

18% of residents' mood and well-being improved

Communication with LTC Facility

Survey respondents reported that since the start of the COVID-19 pandemic:

Types of visitor-facility communication

48% reported that they received an email or text message about visitor restrictions

24% received a phone call

4% received correspondence by mail

8% used website postings

6% reported that they were not informed

Visitor satisfaction with facility communication (Figure 8)

61% reported that they always knew who to contact at the LTC facility

51% reported that they were satisfied with the communication they received from the LTC facility

30% reported that they were dissatisfied with the communication they received from the LTC facility

8% reported that they were neither satisfied or dissatisfied with the communication they received from the LTC facility

Visitor involvement in LTC facility decision making about resident care

58% of respondents either felt involved with decisions all of the time or sometimes

while **28%** rarely or never felt involved

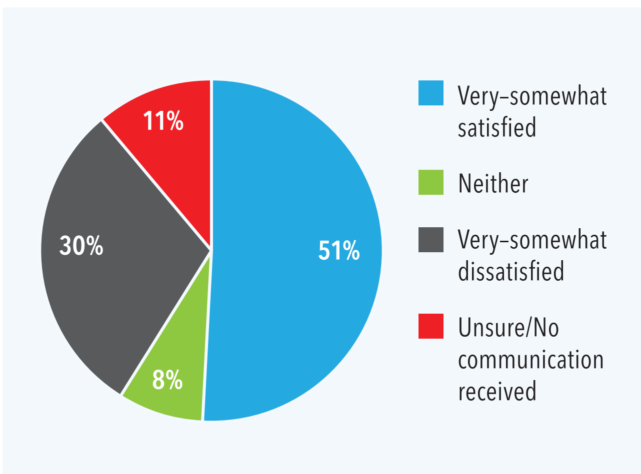


Figure 8. Satisfaction with Communication from the Facility During the Pandemic

Visitor Restrictions within the Facility

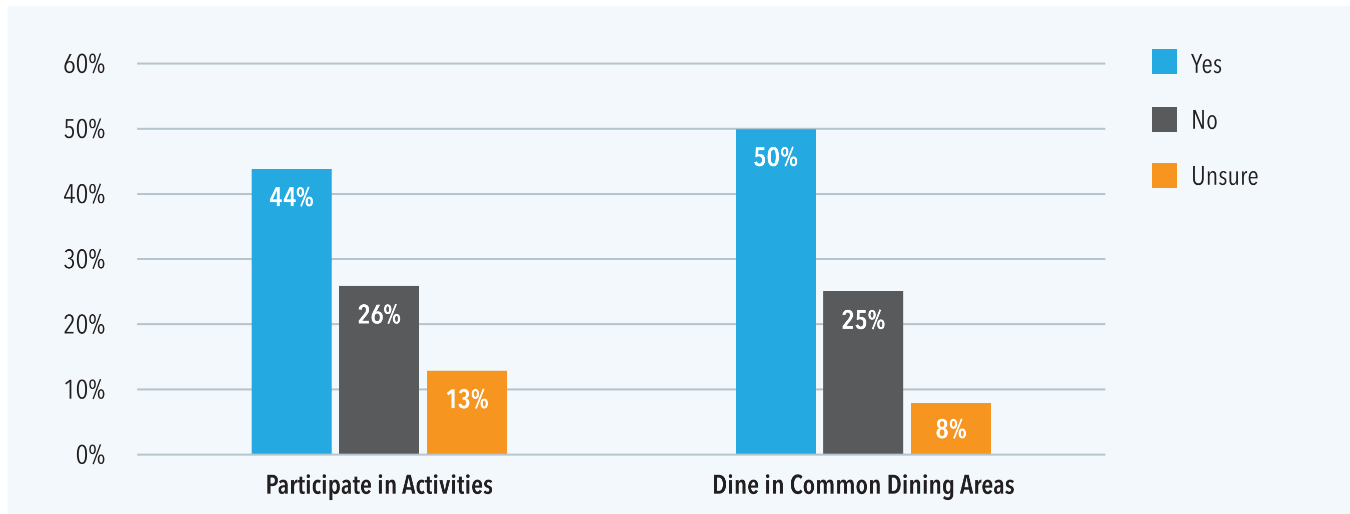


Figure 9. Reported Socialization Opportunities for Residents Within the Facility

Survey respondents reported that in terms of socializing within the facility (Figure 9):

44% reported that the resident **was allowed** to participate in activities

50% reported that the resident **was allowed** to dine in common dining areas

26% reported the resident **was not allowed** to participate in activities

25% reported the resident **was not allowed** to dine in common dining areas

> *I believe many of the activities were curtailed as a result of public health restrictions. I further believe the staff did the best they could within the associated public health directions.*
>
> — Survey Respondent

> *This varied but was very restrictive and staff dependent.*
>
> — Survey Respondent

Visits During Pandemic

Survey respondents reported that during the pandemic (Figure 10):

64% reported that at the first visit with the resident (once they were permitted to visit), the resident's condition seemed worse (Figure 10)

34% reported that at the first visit with the resident (once they were permitted to visit), the resident seemed the same.

On average, respondents reported **four designated visitors** having visited the resident during the pandemic.

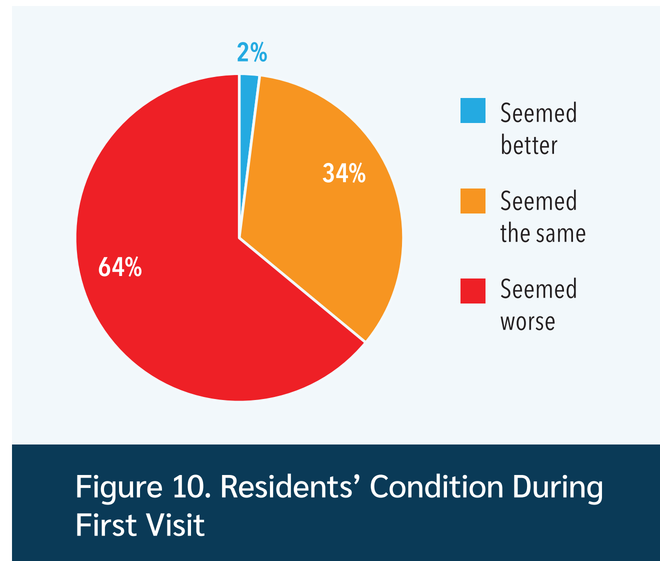


Figure 10. Residents' Condition During First Visit

Frequency of visits:

41% reported they would visit several times a week

19% reported a daily visit

Length of visits:

19% reported visiting for 30 minutes to an hour

41% reported visiting for 1–2 hours

19% reported visiting for 2–4 hours

I was with loved one every day. If I wasn't there somebody else visited.

— Survey Respondent

Location of visits:

53% reported that visitations occurred in the resident's room

14% reported that visitations occurred outside the resident's room

13% reported that visitations occurred in a designated area

20% reported that visitations occurred through a window

Visit rules:

35% reported that a staff member was always observing visits

57% reported there was no observing by staff members

55% reported that they were allowed to hug or touch the resident they visited

Quality of Care

Survey respondents reported on the quality of care provided by the facility during the pandemic:

Satisfaction with care (Figure 11):

17% reported that the overall quality of care and services was excellent

52% reported that the overall quality of care and services was very good to good

27% reported that the overall quality of care and services was not very good or poor

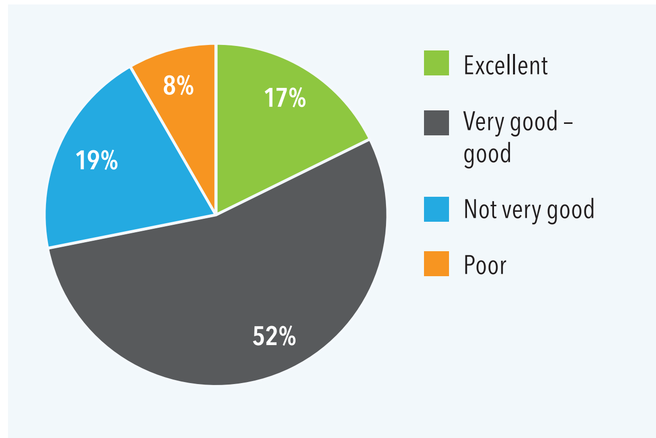


Figure 11. Respondents' Rating to the Quality of Care Provided by Facility

Resident safety:

49% were moderate to extremely confident that the restrictions put in place kept the resident from getting COVID-19

19% were not confident that the restrictions put in place kept the resident from getting COVID-19

37% were extremely worried about the resident getting COVID-19

9% were not worried about the resident getting COVID-19

Facility management of restrictions:

55% reported that the restrictions were either exceptionally well or very well managed

17% of respondents reported that the restrictions were poorly managed

Consideration of removal from LTC facility:

27% of respondents considered removing the resident from the LTC facility

2 visitors reported removing a resident from the LTC facility

Mental and Emotional Well-Being of Respondents

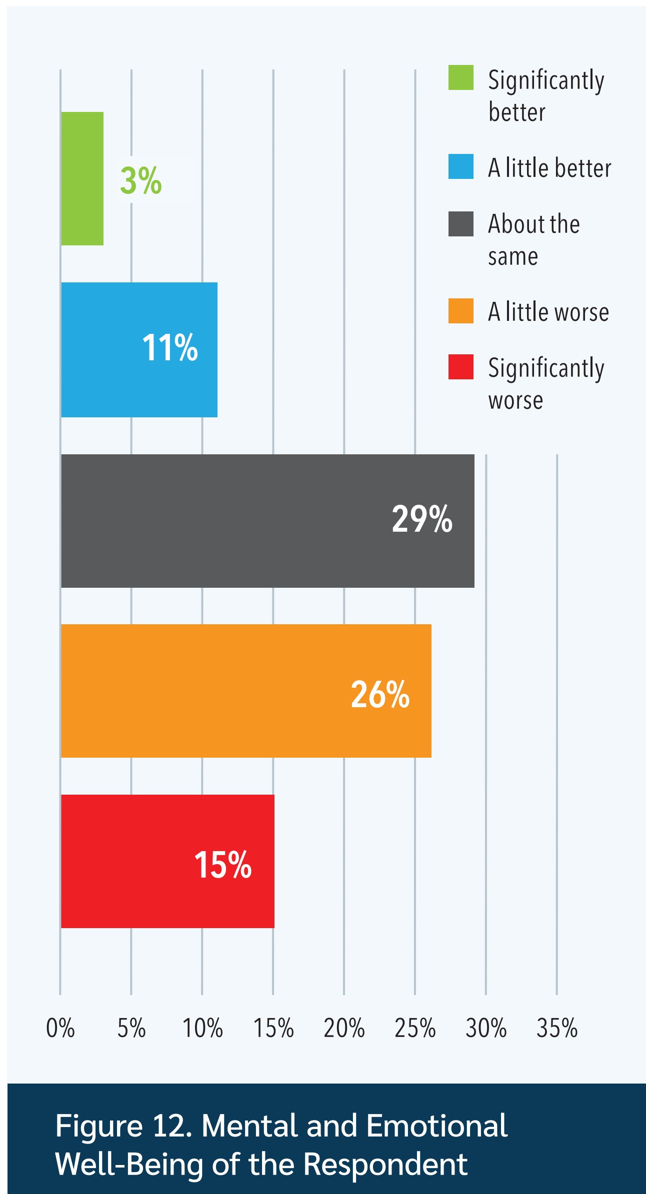


Figure 12. Mental and Emotional Well-Being of the Respondent

Survey respondents reported that compared to before the pandemic (in response to visitor restrictions) (Figure 12):

14% reported that their mental and emotional well-being was better

29% reported that there was no change to their mental and emotional well-being

41% reported that their mental and emotional well-being was worse

Other than not being able to see my dad I felt relieved and confident he was in the best place with the best staff with wonderful care.

— Survey Respondent

Watching my loved one decline over a phone or iPad screen was heart wrenching. Just being allowed to visit freely once [the resident was] deemed palliative was beyond sensible. It was too late! I have never experienced such a traumatizing event in my lifetime.

— Survey Respondent

Priorities for Future Policy

When asked about the potential for future health crises, the majority of respondents agreed that ensuring resident and staff safety, increasing staffing level to support residents, strong infection prevention control, increasing interaction between residents, access to additional visitors, and access to outside recreation opportunities are important priorities.

- Respondents identified ensuring resident and staff safety as having the greatest importance with 100% in agreement, while access to outside recreation opportunities was of lesser importance to respondents with only 77% in agreement (Figure 13).

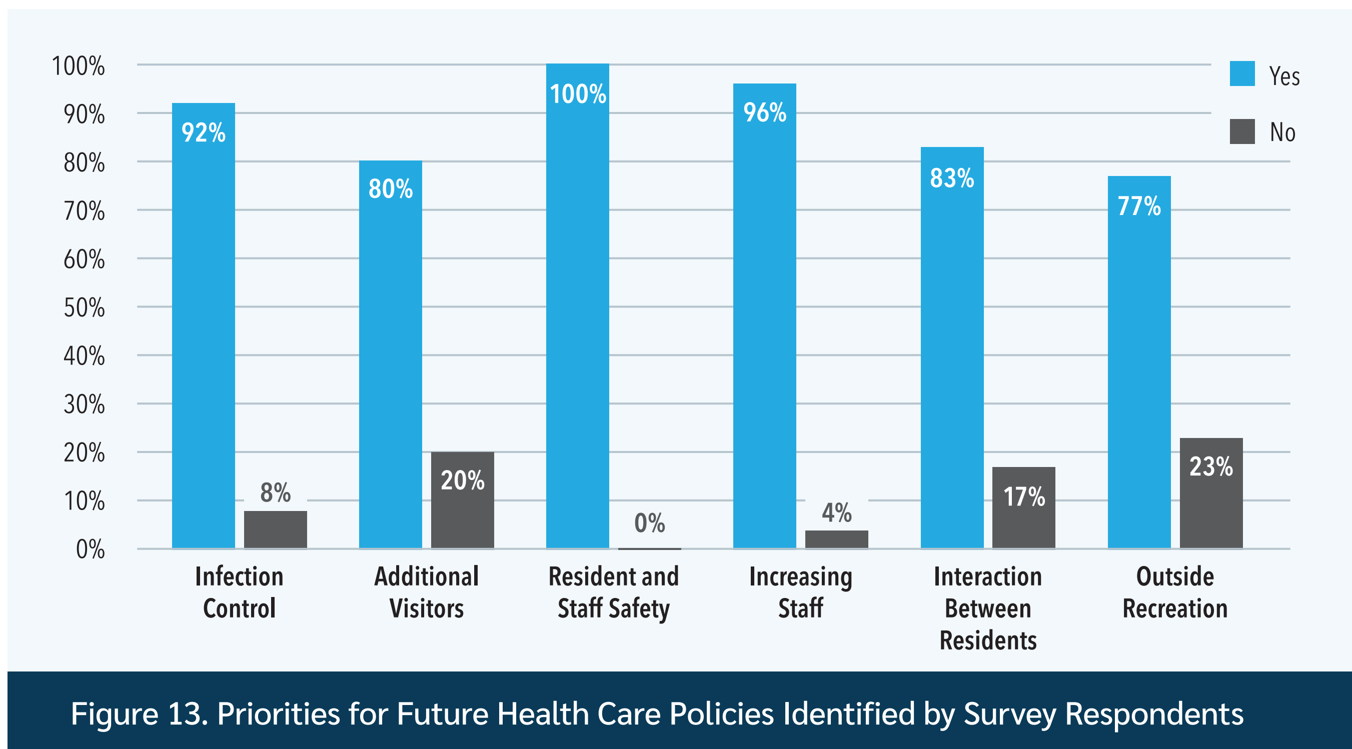


Figure 13. Priorities for Future Health Care Policies Identified by Survey Respondents

Respondents’ Thoughts (Short Answer Questions)

The survey used in this study contained three short answer questions, giving respondents an opportunity to share their stories and provide additional information that they felt was important. **The three questions were:**

Do you agree with the right of residents to live with a certain degree of risk? (i.e. less restrictions during the COVID-19 pandemic) as referenced in the draft LTC Services Standards.*

Is there any other information you would like to share about the impact COVID-19 visitor restrictions have had on you or the resident you visit(ed)?

Are there any recommendations you would like to share with policy-makers that would improve the quality of life for residents and visitors in a future pandemic?

*The Health Standards Organization (HSO) LTC Services Standard was finalized in 2023. Information about the updated standard can be found at https://healthstandards.org/standard/long-term-care-services-can-hso21001-2023-e/.

A review of the answers to those questions revealed 27 themes (see Appendix E for list of themes, referred to as 'codes'). Two themes occurred frequently in the responses, suggesting they were important to many of the survey respondents. The first was the resident's quality of life: mental health, which was defined as "any elements related to the quality of life for the resident (mental, emotional)". The second was negative feelings related to policies, which was defined as "elements relating to respondents' opinion of policies in a negative way (too restrictive, harms related to isolation did not outweigh benefits of possible reduced risk of contracting COVID-19 etc.)".

Resident's Quality of Life: Mental Health

Respondents reported that COVID-19 restrictions had a negative impact on the mental health of the residents they visited. These impacts included the development of symptoms of depression, as well as feelings of loneliness, isolation, and confusion. Respondents also reported that residents felt forgotten and abandoned by their family, friends, and loved ones, particularly for residents with cognitive impairments such as dementia. Respondents were clear that residents should have access to at least one visitor at all times. Respondents also described the challenges associated with periods of restriction that permitted only the same visitor to visit.

The impact of restrictions on the mental health of the residents was a key reason for supporting the right of residents to live with a certain degree of risk. Respondents felt that the benefits of visits from family and friends far outweighed the risk of contracting COVID-19, noting that residents deserve the best quality of life possible for the remainder of their lives and that visits play an important role in quality of life. It is important to note that these are respondents' perceptions and thoughts related to residents living at risk. Additionally, while **63%** of respondents agreed with the right for residents to live at risk, **22%** did not agree, and **15%** were unsure.

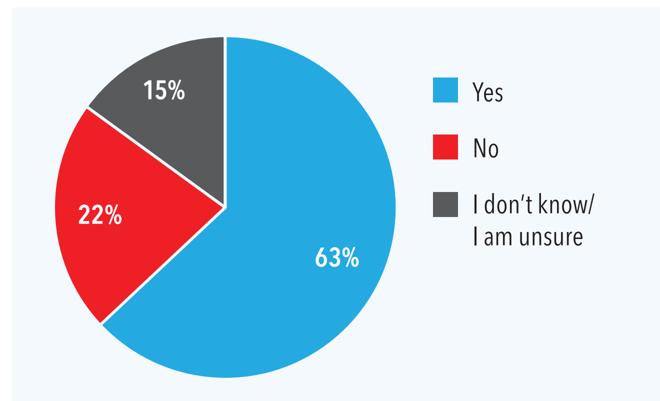


Figure 14. Respondent Support of Residents Right to Live with a Certain Degree of Risk

My mother was unable to see her husband, children, and grandchildren. Then she passed away during a lockdown in Jan 2022 and a month later they lifted all restrictions. My husband who has been in her life for over 20 years wasn't even allowed in the facility to say goodbye. It was traumatic for all involved. The treatment of my family and my mom will never be fully erased from our memories. Life is about family. That's it. End of story.

— Survey Respondent

The importance of socialization and connection with visitors was identified as a key area for policy-makers to consider when looking to improve the quality of life of residents and visitors in a future pandemic scenario. Lack of socialization and connection with visitors was particularly distressing for residents who had difficulty with alternatives like telephone calls and virtual visits due to cognitive or hearing impairments and challenges with staff availability.

> *It is nearly impossible to eliminate all risk. Staff must interact with the general public when not at LTC and visitors also pose risk. But residents' mental health and ability to interact with loved ones is equally important for overall health and to help prevent cognitive, mental and physical decline. It is impossible to have these without some degree of risk*
>
> — Survey Respondent

Negative Feelings about Policy:

Respondents reported that COVID-19 restrictions and resulting polices had a negative affect on both residents and visitors. A common concern among respondents was the degree of restriction, particularly in early stages of the pandemic, and the need to weigh harms and benefits of the policies put in place to keep residents safe. Comments that fell under this theme highlighted that respondents felt policies were overly restrictive and made it difficult for visitors to provide support to residents (e.g., assisting in care, supporting emotional well-being, etc.). Respondents also expressed frustration with the lack of flexibility and the slow speed of change in policies as the risk of COVID-19 changed through the course of the pandemic.

Some respondents stated that the effects of the policies on the residents, both mentally and physically, were worse than COVID-19 itself and that residents expressed this view to them. Hence, risks of the restrictions far outweighed the benefits. They felt it was important for decision-makers to understand the impact of the restrictions with the hope that this information could inform future decision-making with better outcomes for residents and visitors.

> *There was no collaboration (between) residents and family caregivers... Listen to families. We are already devastated by the lack of standards and terrible shortages of staff. The only comfort is being a constant presence and that was completely taken away. There needs to be a true patient/family centered approach to care that respects the rights of residents and those they entrust to keep them safe (i.e. family).*
>
> — Survey Respondent

Summary

A total of **184** visitors of residents to long-term care completed the survey from the Eastern and Western Health Zones of NL Health Services (formerly Eastern Health and Western Health). Survey responses show that **60%** of respondents reported that the overall health, cognitive function, and overall mood and well-being of the resident they visited worsened, **53%** reported worsening of general physical mobility and **62%** reported worsening of cognitive impairment of the resident they visited compared to before the pandemic. However, RAI-MDS 2.0 data showed a **28%** increase in the worsening of overall health, **25%** increase in worsening of physical mobility, **24%** increase in the worsening of cognitive function, and **26%** increase in the worsening of mood and well-being of residents in NL LTC during the pandemic. We noted a difference in the respondents' perception of the change in residents and the clinical assessment data from the RAI-MDS 2.0. Respondents also said they saw an increase in dementia, physical decline, and palliative care status during the period of visitor restrictions and saw visible improvements in those areas once restrictions were lifted.

Respondents were mixed in their perspective of the quality of care and services residents received. **17%** of respondents felt it was excellent, **52%** felt it was good or very good, and **27%** felt it was not very good or poor. Many respondents noted that staffing shortages, along with COVID-19 protocols, caused an increase in staff workload, which in turn affected the quality of care residents received and had a negative impact on residents both mentally and physically.

The survey also showed that many residents resided in private rooms and did not have access to a private phone (landline or mobile), likely contributing to limited social interactions. Over **50%** of respondents indicated that residents always required assistance to participate in video and phone calls. While video and phone calls were reported to have increased for almost **30%** of respondents, it is likely staff were not always able to provide assistance when desired due to the staffing challenges and additional care burden experienced by staff during the pandemic. The survey found that over **30%** of residents also had a decrease in outside services (like a paid companion, hairdresser, and physical therapy). Respondents suggested the decrease in outside care, extracurricular activities, and social engagement further contributed to a decline in the resident's physical and mental health.

Many respondents commented on their frustration with the lack of communication between the staff and caregivers. Results from the survey showed that **30%** of respondents were dissatisfied with the communication they received from the LTC facility and **28%** rarely or did not feel involved with decisions about the care of the resident they visited. **51%** were satisfied with the communication they received from the LTC facility and **58%** felt involved with decisions about the care of the resident all or some of the time.

Survey responses showed that over **40%** of respondents reported their own mental and emotional well-being was worse than before the pandemic while almost **30%** felt it was the same and **14%** reported that it was better. Comments from respondents highlighted the guilt of missing special occasions, such as birthdays and Christmas celebrations. Others reported living with the fact they were not able to say goodbye or hold the hand of the resident in their last moments before their loved one passed. Respondents expressed frustration with the health care system in allowing strict restrictions and felt powerless to change anything about the quality of life residents were experiencing.

Answers to the short answer questions in the survey were analyzed and coded into **27** themes with two themes occurring frequently in the responses, suggesting they were important to many of the survey respondents:

1. **Quality of life: mental health.**
   Respondents reported that COVID-19 restrictions had a negative impact on the mental health of the residents they visited. These impacts included the development of symptoms of depression, as well as feelings of loneliness, isolation, confusion, and abandonment. These symptoms were worse for residents with cognitive impairments such as dementia. Respondents identified the importance of social connection as a key focus area for decision-makers to consider when creating or amending policies that affect quality of life. Using social connection as a lens will ensure that polices will improve quality of life.

2. **Negative feelings related to policies.**
   Respondents reported that COVID-19 restrictions and resulting polices had a negative effect on both residents and visitors. Concerns centred on the degree of restriction which made it difficult for visitors to provide support to residents (e.g., assisting in care, supporting emotional well-being, etc.). Respondents identified the need to weigh harms and benefits of the policies put in place to keep residents safe.

Recommendations

The COVID-19 pandemic shone a spotlight on our health care system—in particular long-term care—identifying major gaps. These gaps have provided us with an opportunity to learn how we can make our health and social systems better for everyone—the people, patients, and residents who use them.

In careful review of the survey responses and of recent reports, the project team is making five major recommendations:

1. Always allow for at least one visitor in LTC facilities to support the quality of life of the resident. Permit alternative designated visitors to reduce the burden on the designated visitor.
2. Place priority on socialization and connection between residents. In addition, minimize the restriction on regular extracurricular, physical, social and routine activities.
3. Improve mechanisms of communication between facilities, staff, visitors and residents, specifically in relation to policies and decision-making processes regarding residents' physical and mental care.
4. Consider the different needs and circumstances of residents when developing policies and making decisions around restrictions (e.g. those with cognitive impairment, those in protective care units and those receiving palliative care).
5. Provide a method of communication available to residents that they know how to use or that they can be assisted to use with the support of staff, volunteers, and visitors.

Final Thoughts

We were seeking to understand the experiences of residents and their visitors with this project and we feel that the survey enabled visitors to speak on behalf of themselves and the residents they visited. While this report reflects the visitor perspective, we wish to acknowledge that patient, family, and caregiver voices are a key component in the delivery of health care, as well as health care decision-making processes. We hope that by sharing our research findings in this report, we can help the voices of LTC residents (through their visitors) reach decision-makers and positively influence future LTC policies.

We would also like to commend the people who worked in LTC and public health during the pandemic. We know many difficult decisions were made balancing the best interests of the residents, staff and public. Acknowledgement of the challenges decision-makers faced and gratitude for the work of all in the sector was also shared by the survey respondents and can be found in quotes in Appendix F.

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Appendix A: Methodology

NL SUPPORT launched the survey on May 24, 2022 and it closed October 31, 2022. Respondents could choose to complete the survey online or by mailing in a paper copy upon request. The survey was open to all visitors speaking for residents of all LTC facilities in the former Eastern and Western Health Regions (due to the strain of the pandemic on the health care system and workforce, Central Health and Labrador-Grenfell Health could not commit to participating in the survey). Visitors of residents who had passed away during the restrictions were also invited to participate. A total of **224** surveys were obtained with **184 (82%)** providing valid information. **40** surveys were excluded from the final analysis because they were deemed incomplete.

Design

The design of the study was carried out by the core members of the Research Team (p 32). Through jurisdictional scans and consultations across the country, the design of "Staying Apart to Stay Safe" a survey conducted by the Office of the Seniors Advocate (OSA) in the province of British Columbia was the one that resonated with the team and aligned with the objectives of the study. With permission from the OSA, their survey was used as a template, and modified to the current pandemic timeline, long-term care structure, and population in Newfoundland and Labrador.

The survey was designed in Qualtrics, a web-based tool used to create, share and analyze surveys. It was then advertised through information letters that were made available at facility masking stations and through NL SUPPORT and QCNL's social media platforms such as Facebook, Twitter, and websites.
To increase awareness, several news articles and radio interviews were conducted by team members showcasing the importance of the research.

Appendix B: The Survey

Included in this package is an information letter with details about the study, the survey, and consent information. It is important you read this letter to understand the study, the survey, and the consent information. **Completing and submitting the survey implies your consent to participate in this research study.**

This survey asks about your visits to a long-term care (LTC) facility before and during the COVID-19 pandemic. In this survey "before the pandemic" refers to before March 2020. We want to know what type of activities you did during your visits and what the health and well-being of the resident you visit(ed) was like.

It is your choice to take part in this study. ***You may take part in the study if the individual you have visited has passed away during the pandemic as the information you provide is still extremely valuable.*** Participation is voluntary and your responses are completely anonymous. You can change your mind at any time during the research study. If you choose not to take part in this study or if you decide to withdraw from the study once it has started, there will be no impact on the care the LTC resident you visit receives, now or in the future.

There will be approximately 5 questions (single choice or open text) on each page. Throughout the survey, you can choose to not answer any question that makes you uncomfortable. The survey will take approximately 30-40 minutes to complete. Responses will be combined, so your individual responses will not be reported. No identifying information will be present in the reports.

This survey will close on October 31st, 2022.

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Long-Term Care COVID-19 Survey

1. What is/was your relationship to the resident that you visit(ed) in long-term care?

◯ Spouse

◯ Parent/Guardian

◯ Child

◯ Grandchild

◯ Other family relative. Please specify.____

◯ Friend

◯ Paid companion

◯ Spiritual advisor (e.g., Reverend, Priest, Rabbi)

◯ Other ____

2. What gender do you identify with?

◯ Male

◯ Female

◯ Non-binary

◯ Choose to self-identify ____

3. What gender does/did the resident you visit(ed) identify with?

◯ Male

◯ Female

◯ Non-binary

◯ Choose to self-identify ____

4. What is your age in years?

____

5. What is the current age of the resident you visit? If the resident you visited is deceased, what was their age when they passed?

____

6. If the resident you visited passed away during the pandemic, when did they pass away? ***(Please note: Even if the resident you visited has passed away, please continue with the survey as the information you provide is still extremely valuable).***

- ◯ Insert month/year: ____
- ◯ Unsure of date
- ◯ Not applicable

7. When was the resident who you visit(ed) admitted to the long-term care facility?

- ◯ Insert month/year: ____
- ◯ Unsure of date

8. How long does/did it take to travel from where you live to the long-term care facility?

- ◯ Less than 30 minutes
- ◯ 30-60 minutes
- ◯ More than 1 hour

9. Which health region does/did the resident you visit(ed) live in?

- ◯ Eastern Health
- ◯ Western Health

10. Does/did the resident you visit(ed) live in:

- ☐ A private room
- ☐ A shared room with one other person
- ☐ A shared room with more than one other person
- ☐ Other, please explain

____

11. Does/did the resident you visit(ed) have a private phone line in their room or have access to a mobile phone?

- [ ] Yes
- [ ] No
- [ ] I don't know/I am unsure
- [ ] Other, please explain ______________________________

12. Compared to before the pandemic (i.e., March 2020), have/did the number of phone calls between you and the resident:

- ○ Increased
- ○ Stayed the Same
- ○ Decreased
- ○ I don’t know/I am unsure
- ○ We do not talk on the phone

13. Compared to before the pandemic, have/did the number of video-calls between you and the resident:

- ○ Increased
- ○ Stayed the Same
- ○ Decreased
- ○ I don’t know/ I am unsure
- ○ We do not use video calling

14. Does/did the resident you visit(ed) need help from staff or volunteers to use video-calling or to talk on the phone?

- Always
- Sometimes
- Rarely
- Never
- We do not use phone or video-calling

15. Compared to before the pandemic, has/had the number of additional people that provide(d) care or services to the resident, either in or out of their long-term care facility: (For example: a paid companion, podiatrist, physical therapist, or hairdresser)

- Increased
- Stayed the Same
- Decreased
- I don't know/I am unsure
- The resident does/did not use additional services
- Additional Comments:

16. Compared to before the pandemic, has/had the overall health of the resident who you visit(ed):

- Improved
- Stayed the same
- Worsened
- I don't know/I am unsure
- Additional Comments:

17. Compared to before the pandemic, has/had the resident's general physical mobility (the resident's ability to move around in the long-term care facility on their own):

- [ ] Improved
- [ ] Stayed the same
- [ ] Worsened
- [ ] I don't know/I'm not sure
- [ ] Additional Comments: ______________________________

18. Compared to before pandemic, has/had the resident’s general cognitive function (the resident's ability to understand new information, memory, attention span, decision making):

- [ ] Improved
- [ ] Stayed the same
- [ ] Worsened
- [ ] I don’t know/I’m not sure
- [ ] Additional Comments: ______________________________

19. Compared to before the pandemic, has/had the resident’s general mood and emotional well-being:

- [ ] Improved
- [ ] Stayed the same
- [ ] Worsened
- [ ] I don’t know/I’m not sure
- [ ] Additional Comments: ______________________________

20. Throughout the pandemic, how were you informed about visitor restrictions? Check all that apply.

- ☐ I received an email and/or text message from the long-term care facility
- ☐ I received a phone call from the long-term care facility
- ☐ I received a letter sent by regular mail from the long-term care facility
- ☐ A notice was posted on the long-term care facility's website
- ☐ Other
- ☐ I was not informed by the long-term care facility

21. During the pandemic, how satisfied were you with the communication you received from the long-term care facility about the overall general and physical health of the resident you visit(ed)?

- ○ Very satisfied
- ○ Somewhat satisfied
- ○ Neither satisfied nor dissatisfied
- ○ Somewhat dissatisfied
- ○ Very dissatisfied
- ○ I did not receive any communications
- ○ I don’t know/I am unsure

22. During the pandemic, did you know who to contact at the long-term care facility to get information about the resident you visit(ed)?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

23. During the pandemic, did you feel you were involved as much as you wanted in decisions (e.g. Health Care decisions, Day to Day Decisions such as grooming, physical activity) about the resident you visit(ed)?

- Always
- Sometimes
- Rarely
- Never
- I don't know/I am unsure

24. During the pandemic was the resident you visit(ed) restricted to their room within the long term facility for any length of time?

- Yes, please round up to the total number of weeks____
- No
- I don't know/I am unsure

25. During the pandemic, was the resident you visit(ed) allowed to participate in activities within the long-term care facility?

- ☐ Yes, always
- ☐ Yes, sometimes
- ☐ No
- ☐ I don't know/I am unsure
- ☐ Additional Comments:

____

26. During the pandemic, was the resident you visit(ed) allowed to dine in common dining areas?

- [ ] Yes, always
- [ ] Yes, sometimes
- [ ] No
- [ ] I don't know/I am unsure
- [ ] Additional Comments:

____

27. When you first saw the resident after you were allowed to visit, what was your overall first impression? Please select one.

- ○ They seemed better than when I last saw them
- ○ They seemed about the same as when I last saw them
- ○ They seemed worse than when I last saw them
- ○ I don't know/I am unsure
- ○ Not applicable

28. Since visitor restrictions have been lifted, how many total designated visitors have visited the resident including yourself?

- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ 5
- ○ 6
- ○ I don’t know/I am unsure
- ○ Not applicable

29. Since visitor restrictions have been lifted, on average how often do/did you visit? (This includes taking the resident out of the facility)

- ☐ Daily
- ☐ Several times per week, but not always daily
- ☐ Weekly
- ☐ Every other week
- ☐ Monthly
- ☐ Other
- ☐ I don’t know/I am unsure
- ☐ Not applicable
- ☐ Additional Comments:

____

30. Since visitor restrictions have been lifted, on average how long are/were your visits? (This includes taking the resident out of the facility)

- ☐ 30 minutes or less
- ☐ 30 minutes to one hour
- ☐ One to two hours
- ☐ Two to four hours
- ☐ More than four hours
- ☐ I don't know/I am unsure
- ☐ Not applicable
- ☐ Additional Comments: ________________________________

31. During the pandemic, where were you allowed to visit? Please check all that apply.

- ☐ Outside
- ☐ In a designated common area within the long-term care facility
- ☐ In the resident’s room
- ☐ Through a window

32. Are/were there staff from the long-term care facility observing you during visits?

- ◯ Yes, always
- ◯ Yes, sometimes
- ◯ No
- ◯ I don't know/I am unsure

33. Are/were you allowed to hug or touch the resident you visit(ed) anytime during the pandemic?

- ◯ Yes
- ◯ No
- ◯ I don't know/I am unsure
- ◯ Not applicable

34. Since the COVID-19 pandemic was declared, how would you rate the overall quality of the care and services provided by the long-term care facility to the resident you visit(ed)?

- ◯ Excellent
- ◯ Very good
- ◯ Good
- ◯ Not very good
- ◯ Poor
- ◯ I don't know/I am unsure

35. How confident are you that the restrictions that were put in place during this pandemic kept the resident you visit(ed) from getting COVID-19?

- ◯ Extremely confident
- ◯ Moderately confident
- ◯ Somewhat confident
- ◯ Not at all confident
- ◯ I don’t know/I am unsure

36. Given what we now know about the virus and our experience over the past two years, how worried were you about the resident you visit(ed) getting COVID-19?

- Extremely worried
- Moderately worried
- Somewhat worried
- Not at all worried
- I don’t know/I am unsure

37. How well do you feel that visitor restrictions were managed by the long-term care facility you visit(ed)?

- Exceptionally well managed
- Very well managed
- Somewhat well managed
- Not well managed
- Very poorly managed
- I don’t know/I am unsure

38. At any point during this pandemic, did you consider removing the resident you visit(ed) out of the long-term care facility to be cared for elsewhere?

- Yes
- No
- I don't know/I am unsure

39. Did you remove the resident you visit(ed) out of the long-term care facility?

- Yes
- No
- Not Applicable

40. Compared to before the pandemic, and more specifically in response to the visitor restrictions, do you feel your mental and emotional well-being is:

- ☐ Significantly better
- ☐ A little better
- ☐ About the same
- ☐ A little worse
- ☐ Significantly worse
- ☐ I don't know/I am unsure
- ☐ Additional Comments: ______________________

41. Given your experience over the past two years and thinking about the potential for future public health crises, are the following priorities important to you?

	Yes	No
Strong infection prevention controls	○	○
Access to additional visitors	○	○
Ensuring resident and staff safety	○	○
Increasing staffing level to support residents	○	○
Increasing interaction between residents (example: communal dining)	○	○
Access to outside recreation opportunities (example: bus rides, going to a park)	○	○

42. Do you agree with the right of residents to live with a certain degree of risk? (i.e. less restrictions during the COVID 19 Pandemic) As referenced in the draft Long Term Care Services Standards. (For more information on Standards click here: https://healthstandards.org/general-updates/health-standards-organization-hso-launches-public-review-new-draft-national-long-term-care-services-standard-releases-heard-report-2/)

○ Yes, please explain: ____

○ No, please explain:____

○ I don't know/I am unsure, please explain:____

43. Is there any other information you would like to share about the impact COVID-19 visitor restrictions have had on you or the resident you visit(ed)?

____

____

____

____

____

44. Are there any recommendations you would like to share with policy makers that would improve the quality of life for residents and visitors in a future pandemic?

____

____

____

____

____

You have reached the end of the survey.
THANK YOU very much for your participation.

If completing this survey has brought up challenging feelings for you, please see the following list of mental health supports that are available to you:

Eastern Health:
• Doorways (709) 752-4903
• Mobile Crisis Response Team (709) 737-4668
• Adult Central Intake (709) 752-8888

Western Health:
• Doorways (drop-in or call-in counselling, no waitlist) https://westernhealth.nl.ca/doorways/ for the office nearest to you
• Mental Health Crisis Line 1-888-737-4668

Across the province:
• bridgethegapp.com
• Any Hospital Emergency Room
• HealthLine 811

Appendix C: Media Coverage

1. CBC Newfoundland Morning with Bernice Hillier, Martin Jones – Sep. 14, 2022: No visitors allowed. Link no longer available.

2. Clinical Lead with NL SUPPORT, Dr. Brendan Barrett. Oct 13, 2022

   https://soundcloud.com/vocm/thursday-oct-13th-clinical-lead-with-nl-support-dr-brendan-barrett

3. NL SUPPORT Conducting Survey on Impact of Pandemic Restrictions on Long-Term Care Facilities. Oct 22, 2022

   https://vocm.com/2022/10/22/nl-support-conducting-survey-on-impact-of-pandemic-restrictions-on-long-term-care-facilities/

Appendix D: Newfoundland and Labrador COVID-19 Timeline

Date	Description
16-Mar-20	Visitor access to long-term care restricted
23-Mar-20	Visitor access to long-term care suspended
10-Jun-20	Visitor restrictions at all health facilities relaxed to allow one designated visitor/support person
08-Feb-21	Long-term care home visitation restricted to two designated visitors per resident (St. John's metro region)
13-Feb-21	Long-term care and assisted living facilities restricted to one essential visitor per resident
13-Feb-21	Long-term care and assisted living facilities restricted to one essential visitor per resident
27-Feb-21	All regions (except Avalon) had some health care services resumed
12-Mar-21	Permitted two designated visitors and one essential visitor for long-term care residents
13-Mar-21	Avalon had some health care services resumed
27-Mar-21	Permitted six designated visitors for long-term care homes and assisted living facilities
21-Jun-21	Eased visitor restrictions for patients in hospital and long-term care residents; two visitors per day permitted unless advised
01-Jul-21	Eased visitor restrictions at Eastern Health facilities; visitors from outside Atlantic Canada allowed if not self-isolating or with COVID-19 symptoms
23-Jul-21	General visitation permitted for acute care facilities, health centres and long-term care facilities; no longer limited to one visit per day
22-Oct-21	Implemented vaccine passport for visitors and staff to access long-term care homes, assisted living facilities
22-Oct-21	Areas on the Burin Peninsula: limited visitors for those in hospital and long-term care; two visitors and a support person
08-Nov-21	Areas on the Burin Peninsula: lifted visitor restrictions for hospital patients and long-term care home residents
15-Dec-21	Limited each resident to two visitors in long-term care or personal care homes; these can be different people for each visit
20-Dec-21	Facilities in Badger, Gander, Grand Falls-Windsor and Twillingate or in Central Health sites with outbreaks: limited to one constant designated visitor per patient/resident
27-Jan-22	One support person/visitor for each patient/resident is permitted at acute care facilities, health centres and long-term care homes
10-Feb-22	Two support persons for each patient allowed at all acute care facilities; health centres; and long-term, personal and community care homes
04-Mar-22	At all acute care facilities, health centres and long-term/personal/community care homes, each patient is allowed multiple visitors, but only two at a time

Appendix E: Qualitative Analysis Coding Framework and Analysis

<table>
<tr><th colspan="2">Code</th><th>Description</th></tr>
<tr><td colspan="2">Quality of Life - Mental (Resident)</td><td>Any elements related to the quality of life for the resident (mental, emotional)</td></tr>
<tr><td colspan="2">Quality of Life - Mental (Visitor)</td><td>Any elements related to the quality of life for the visitor (mental, emotional)</td></tr>
<tr><td colspan="2">Isolation</td><td>Any mention of isolation and its effects (mental or physical)</td></tr>
<tr><td colspan="2">Loneliness</td><td>Any mention of feelings/experiences of loneliness and its effects</td></tr>
<tr><td colspan="2">Family Member/ Outside Care</td><td>Any mention of the care of residents by families or outside paid caregivers—respite, personal hygiene, exercise, feeding support, friendly visiting, activities, reduce demands on staff, etc.</td></tr>
<tr><td colspan="2">Quality of Life - Physical</td><td>Any elements related to the quality of life for the resident (physical)</td></tr>
<tr><td colspan="2">Guilt related to missing significant events</td><td>Any mention of important events missed (e.g. resident passing away without family present; holidays, birthdays, etc. missed)</td></tr>
<tr><td colspan="2">Deteriorating health</td><td>Any mention of major changes in health status during restrictions (e.g. significant mobility loss, dementia progression)</td></tr>
<tr><td colspan="2">Extracurricular Activities</td><td>Any mention of physical or social engagement</td></tr>
<tr><td colspan="2">Safety</td><td>Any elements related to risk to residents, caregivers, or staff (e.g. mask wearing, exposure through staff).</td></tr>
<tr><td colspan="2">Right to live at risk (for)</td><td>Related to question 42, any mention of residents' right to live at risk</td></tr>
<tr><td colspan="2">Right to live at risk (against)</td><td>Related to question 42, disagreement with right of residents to live at risk (e.g. residents should be kept as safe as possible no matter what)</td></tr>
<tr><td rowspan="2">Policies</td><td>Positive Feelings</td><td>Elements relating to respondents' opinion of policies in a positive way (benefit of them, kept resident safe, etc.)</td></tr>
<tr><td>Negative Feelings</td><td>Elements relating to respondents' opinion of policies in a negative way (too restrictive, harms did not outweight benefits, etc.)</td></tr>
<tr><td colspan="2">Staffing</td><td>Any mention of staffing as it relates to resident and visitor experience (e.g. workload for staff, staffing numbers, morale, management)</td></tr>
</table>

<table>
<tr><th colspan="2">Code</th><th>Description</th></tr>
<tr><td rowspan="2">Communication</td><td>Communication with Facility</td><td>Any form of communication between caregiver and Staff
(e.g. information about changing restrictions, change in resident care)</td></tr>
<tr><td>Resident Communication</td><td>Any form of communication between:

• Resident and caregiver (e.g. phone call/virtual/in person visits)
• Resident and staff
• Between residents</td></tr>
<tr><td colspan="2">Communication between management and staff</td><td>Any form of communication between facility management and staff around policy implementation</td></tr>
<tr><td colspan="2">Unique Needs</td><td>Any mention of unique considerations in relation to facility or residents (e.g. hearing loss, wheelchair)</td></tr>
<tr><td colspan="2">Dementia</td><td>Any mention of dementia/Alzheimer’s and experience of restrictions</td></tr>
<tr><td colspan="2">End of life</td><td>Any mention of end of life/palliative care and experience of restrictions</td></tr>
<tr><td colspan="2">Lack of care</td><td>Any mention of lack of care related to the resident or facility (e.g. personal care, exercise routines, room/facility cleaning)</td></tr>
<tr><td colspan="2">Abandonment</td><td>Any mention of confusion around restricted visiting and resident feelings of being abandoned, visitors not caring about resident anymore</td></tr>
<tr><td colspan="2">Visitation</td><td>Any mention of the need for residents to have at least one visitor at all times</td></tr>
<tr><td colspan="2">Influence over LTC facility restrictions</td><td>Any mention of involving residents and family members in decisions related to pandemic related changes within the LTC facility</td></tr>
</table>

Appendix F: Additional Comments and Personal Stories

From those who agreed with the right of residents to live with a certain degree of risk

- "It's my opinion the lack of interaction and seclusion from friends and family members posed a greater risk with health decline of my family member than COVID would have caused.. It led to rapid health decline. I think the level of risk that would result from being able to visit would have been well worth it. In my opinion many families lost loved ones during the pandemic, not as a result of actually getting the virus but rather as a result of lack of family oversight, intervention and contact. The isolation may be a bigger contributor to health decline and death than the Virus, however unsure how that can ever be quantified."

- "I believe that the isolation of residents could be a little less restrictive going forward. With updated and current COVID vaccinations and boosters and influenza vaccinations available, we need to compare the risk of isolation and the well-being of residents, to the detrimental and devastating effects on them being isolated from family and close friends. Many of those in care do not understand the reasons why they have no visitors … especially their family. Understandably, we must continue to keep them safe and healthy, but we must also focus on their mental health. Isolation and loneliness can have devastating effects on them as well as family members who cannot be with them."

- "It is nearly impossible to eliminate all risk. Staff must interact with the general public when not at LTC (Long-Term Care) and visitors also pose risk. But residents' mental health and ability to interact with loved ones is equally important for overall health and to help prevent cognitive, mental and physical decline. It is impossible to have these without some degree of risk."

- "My mother- in-law was placed in (a home) in June 2021 due to Alzheimer's. She was exit seeking and at risk of harming herself or her husband. She was there about 4 weeks when the province went into lock down. During that time (lockdown) she was placed in adult diapers, became much more aggressive and had forgotten most of her family members by the time we were allowed to see her again. Alzheimer's and dementia patients need their family regardless of COVID risks."

- "My mother is in a protective care/locked unit with 19 other residents. They are always together like a big family. They do not have the cognitive ability to understand they need to socially distance or wash their hands. I agree with visitors wearing masks (even though it makes them more confused), but let the residents eat together, have recreation activities together, go outside together. Try to keep everyday life for them as normal as possible."

- "My mother was unable to see her husband, children, and grandchildren. Then she passed away during a lockdown in Jan 2022 and a month later they lifted all restrictions. My husband who has been in her life for over 20 years wasn't even allowed in the facility to say goodbye. It was traumatic for all involved. The treatment of my family and my mom will never be fully erased from our memories. Life is about family. That's it. End of story."

- "Given the degree of limitations that my mother had at the time, she was completely cut off from the outside world (unable to talk on the phone) and unable to control her immediate surroundings (couldn't

feed herself or turn on the tv or get out of bed), the damage done by not allowing visitors for those few months far outweighed any risk introduced by allowing limited and controlled visitation."

- "The risk of exposure against the decline of the residents mental and physical well-being is a question that needs to be addressed. The past three years of my mother's life was not great. Many times she was in complete isolation and then only my 91 year old father was the only person allowed to visit. The decline in her mental acuity and physical health was quite evident. Protecting against the illness was terrible for the senior population."

- "The complete isolation of residents was wrong. Residents confined to rooms, unable to interact, with no outside visitation allowed. It was easier to enter the penitentiary than to see a loved one in LT Care facility. The complete isolation was criminal."

- "Residents should not be totally isolated. This is bad for their emotional well-being. Not much good to have them totally restricted only to have them slowly wasting away because of loneliness and thinking that no one cares. Interaction with your family and loved ones is just as important as access to nursing care."

- "My father has said many times that he would rather die of COVID than loneliness."

- "Residents, although considered a vulnerable population, have basic rights. Isolating them from loved ones is not acceptable and had devastating impacts on them and family members. No one cares more about these people than their loved ones, and the loved ones would not put them at increased risk. In recent months COVID has been present in many facilities, and in many cases, it was staff as much or more, that brought the virus to the facility. If staff can come and go, then loved ones should be able to as well. This will also help with the care and lighten the load on staff."

- "I think it's a personal choice. No one should visit if ill (common sense) but denying elderly the choice to see family is detrimental to their physical and mental health. And you lose precious time that you can never get back (as we did)."

- "When you look at the context in which residents find themselves (near the end of life), I believe that when you weigh the risk of exposing residents to COVID (or any virus), versus social interaction and enhanced care by family members, it's more important to focus on the latter, which is really an issue of quality of life. My father was cut off from his primary caregiver/support worker (myself), as well as a hired caregiver. Without us there to help feed him, change him, as well as other personal care, I believe he suffered in some shape or form (physically/emotionally) on a daily basis. The staff does not have the time to attend to all of the physical and emotional needs and therefore, the role of the visitors/ caregivers outside of the institution are paramount. If we had been granted access and my father had gotten COVID, for example, at least his quality of life would have been significantly improved. As it turns out, he got the residents responding directly and we did not. COVID anyway. So all of the measures to keep him (and other residents safe from the virus) were meaningless. The only thing compromised was his quality of life."

- "It is a very difficult balance to protect the health of residents living in long-term care, especially those with dementia like my father, with the need for social interaction and visitation from loved ones, family and friends. Although I would not want to see anyone living in a home be in any danger, to live in isolation for lengths of time, in my opinion, is more dangerous than any virus."

From those who disagreed with the right of residents to live with a certain degree of risk

- "My Dad was in end stages of Alzheimer's and I wanted his risk to be as little as possible and if that meant being confined to his room and us not being able to visit I was ok with that. It was hard on all of us but the thought that I could bring Covid-19 or any illness to a resident of a long-term care home made the restrictions easier to follow."

- "Overall I think that the restrictions were necessary and helped to prevent spread."

- "The restrictions in place helped keep the spread of the virus to a minimum at the LTC facility."

- "I believe the staff and managers made the best decisions for my mother. I would have liked to have seen my mother more often but did not want to compromise the health of any of the other residents."

- "There definitely should be restrictions when considering the well-being of our seniors in LTC."

From those who were not sure about the right of residents to live with a certain degree of risk

- "I struggle with this as I know that in a group setting, the collective well-being of residents must be considered at all times. Likewise, staff have to feel safe and be adequately supported to do their jobs to the best of their ability. I would like to see the staffing shortages addressed."

- "My son is in a unique situation as he is nonverbal and confined to a wheelchair. He completely relies upon others for his every need. I don't think I have enough trust in others to be as careful as I am with respect to my son's health and safety."

From visitors on the impact COVID-19 visitor restrictions had on them and the residents they visited

- "I feel my mom was traumatized by the lock downs with no visitation- only window visits & talking by phone (she is extremely hard of hearing). When lock downs were lifted she was terrified that there would be further lock downs."

- "In June 2018 my mother at the age of 99, living independently in her own home, with the help of some home care, fell and broke her hip. She spent time in the hospital then to Long-Term Care and was doing rehab. She was a very determined woman and in relatively good health and of very sound mind. She was rehabilitating and was up walking with some assistance of a walker..... By the time the pandemic struck she had passed her 100th birthday. Then the lock down occurred in March of 2019. After this I phoned the ward daily to try to get access to visit her but was denied. I made many calls to her doctor and to her nursing caregivers on the floor over the next three months to inquire about her health and in attempts to see her. The rehab activities ceased once lock down occurred as did her daily walks. By the time I was allowed to visit 3 months later, she was considered Palliative and she passed away 3 days after that visit... The change in her condition over a 3-month period was beyond belief. I am haunted by it and firmly believe that she is also an unknown and uncounted victim of the pandemic. I also firmly believe my mother would have lived much longer had family been there to oversee daily activities, to monitor her care and to provide companionship and comfort."

- “Not being able to visit the resident meant that we were not able to monitor overall mental, cognitive and physical health regularly. Important items such as clean clothing, proper footwear, wearing own glasses, having foot care and proper bathing were not able to be monitored by friends/family and therefore there was a certain degree of physical neglect observed. Regular visits by friends/family and regularly calling staff to task on items that need to be addressed is unfortunately essential at the long-term facility where the resident is housed. The fact that friends/family were not able to regularly arrange care, whether by family/friends or by outside service providers, meant that there were physical issues that fell into a certain amount of decline. We are still addressing those issues.”

- “My mother had Alzheimer’s and was bedridden. She did not understand why I could not visit her… My mother passed away two months after COVID started. She passed away as a result of COViD. Not the virus itself but the effects of no visits. She became depressed and just gave up. In essence she died of loneliness. I have great sorrow I never even got to see her before she passed away and she died alone. Not the end anyone should have and my mother was my world and it still haunts me.”

- “Any resident in LTC should always have access to one family member or loved one. The family may have to be immunized and wear a mask, but they should never be prohibited from visiting LTC. These people are so vulnerable, they need to be in contact with those who love them, and those who love them need to be able to see that they are doing ok, in person.”

- “It’s hard to measure the impact of Covid-19 visitor restrictions on my father as he is unable to communicate. On my part, I can say without hesitation that it affected his quality of life. If the facilities were well staffed and the workers had the time to spend with each resident, fulfilling both their social and emotional needs, I would not be concerned. However, it is widely known that staffing shortages, particularly of the PCAs and LPNs - those who have all of the contact with the residents resulted in the residents not receiving proper care. To enforce visitor restrictions knowing that the staff is not able to care adequately for the residents, is at the very least, unethical.”

- “It was an extremely difficult period for seniors in long-term care facilities and I believe it took a toll on many residents… If they or another resident tested positive, it was heartbreaking to watch. Trying to communicate through a glass window, not on (the) ground floor, was next to impossible. A very sad time for all…and I know difficult for staff also.”

- “Lack of staff and staff not being knowledgeable about the pandemic was a big concern. Leaving residents in their rooms for hours on hours and days on days was unacceptable. The lady I visited slowly died. She caught covid, chest infection and the stomach bug all in months of each other. All residents at one point had all of these illnesses! It was a terrible situation to be in for both residents and visitors!”

- “There was no collaboration (between) residents and family caregivers… Listen to families. We are already devastated by the lack of standards and terrible shortages of staff. The only comfort is being a constant presence and that was completely taken away. There needs to be a true patient/family centered approach to care that respects the rights of residents and those they entrust to keep them safe (ie family).”

- “Isolation killed my mother; she died of a broken heart. The chance to never say goodbye to a loved one is very difficult. We have to live with the guilt of never being there for her in her last few months of life.”

- “The restrictions really impacted my dad’s health and mobility. Prior to COVID, he was a healthy, agile male with no health problems other than declining dementia. With the COVID restrictions, he declined rapidly and there was very little support from staff. When family was permitted to visit again, only one

family member, he had totally forgotten who I was and prior to COVID he knew everyone. All activities for seniors were shut down, they were treated like prisoners...They wouldn't even let a hairdresser cut my dad's hair... for quite a period of time... Communications with parents/guardians was poor... My dad's health declined rapidly; he had no idea why family were no longer visiting him. He was upset and lonely a lot of the time."

- "It has been extremely heartbreaking to watch a couple that have been married for 63 years (become) unable to see or communicate with each other for such a long duration. It has taken a physical and mental toll on both"

- "We are a large family and are very close. My father had cancer and died just 3 weeks after my mom. He went weeks to months without seeing my mother even though he was just as protected at home and just as vulnerable as she was. A close family was very much separated by this pandemic. My mom would spiral into depression without visitors. Therefore, as the often only allowed visitor I tried to be with her as often as I could and for as long as I could. I do not think that the emotional and mental well-being of the residents of long-term care was adequately considered during this pandemic. Or that of their support person."

- "It was extremely frustrating. I felt so helpless and worried about my mother. Having her eat alone and spend so much time alone. Especially when she can't understand what is going on, or why no one is coming to see her. There was also worry about the level of care she was receiving with no one from the outside able to visit."

- "For residents with Alzheimer's/Dementia, visitors wearing masks is very confusing and very detrimental. The only person my mother still knew prior to Covid is no longer recognizable to her. I know that some of that is progression of the disease, but I truly feel that some (of it) is from not seeing the faces for 2 years. I do understand the need (for) a mask, but it really does make a difference in these people... Also, having patients on Protective care only having visitors in a closed bedroom is also very difficult for them. They need to wander."

Recommendations to policy-makers for future pandemics

- "Consider more than one designated visitor. It is hard to be the only one expected to visit daily. Hard on visitor mental and emotional well-being."

- "I do understand that there must be precautions taken to ensure the safety of a very vulnerable population but am of the belief that lockdown is not the answer. Residents need their families. They need them to ensure they are being treated properly, to give them a voice, to give them support, to give comfort and companionship. Also recreational activities need to be continued as do activities such as physiotherapy. I also feel additional staff resources need to be put to bear, notably for LTC during any future pandemic."

- I believe that long-term care residents should continue to be on the priority list for vaccinations and boosters. It is imperative that we care for our seniors and give them (the) quality of life they truly deserve. I and my family are thankful and grateful for the direction that Eastern Health has guided us through during the pandemic."

- “Ensure additional staff are made available to keep the mental, physical and cognitive health of residents a priority during times such as these. Find a safe way to allow families to visit with family members to ensure there is still a feeling of ‘family’ even if dementia is present. Don’t keep families away when a loved one is ill and needs family supports. Engage residents in the day-to-day activities of the facility so that they are feeling they have a purpose. Encourage interactions with friends/family using social media and/or technology on a regular basis, not just during the pandemic situations.”

- “More communication between staff and family members.”

- “Please don’t lock up our seniors. Give them the quality of life they deserve in the years they have left.”

- “Always allow at least one designated family member to visit. Allow family member to drop off special snacks, gifts, and things to help with loneliness.”

- “As a family member it would be nice if families of the residents had some input into what is happening. Also, when the resident has a living spouse, who is not in the home, they should be allowed to visit all the time and another person as well be designated to help. It is very hard on an elderly partner to visit daily and help keep up the resident’s emotional spirits. Some of the restrictions were too wide and each long-term care home should be able to make exceptions for the residents that are in the home that are safe and healthy for all of the family.”

- “Train your managers and administration in compassion and empathy for both their residents and family care givers. Create a more collaborative decision-making approach for residents that include family... Family members know their family member better! Listen more. Don’t shut family members out.”

- “I feel staff following these policies need to be educated and able to explain the rationale behind the rules, also each facility should follow the exact same policies and not make up their own which I am convinced happened in my situation. The biggest frustration and effect on both my family and my mom’s mental health was the changing rules, the inconsistencies and again lack of common sense and rationale.”

- “Resident/family centered care. True collaboration not just lip service in family councils. Family as active participants in decision making around infection prevention and control and pandemic and pandemic planning and emergency preparedness. Safely ensuring family visitation standards of care for LTC with independent oversight and monitoring. Transparency and government at arm’s length from oversight. Have family members as part of independent inspections.”

- “Increased staff, particularity PCA’s who deal with the basic care of the residents. They are the people who provide support, empathy. Compassion and love (are) all elements necessary for psychological stability. Furthermore, they are responsible for cleanliness and feeding, providing the basic needs for the residents. These staff members are the most critical component within LTC, yet LTC seems to be top heavy with management, who ultimately know very little about the residents, yet they make decisions for the residents. This NEEDS to change. It’s an issue about quality of life.”

- “Always allow one essential caregiver. If a resident is required to isolate in their own room there must be policies in place that prevent undue stress to the resident. This should include no new restraints, a socialization plan, a physical activity plan, a metal health plan. All LTC facilities should have a full-time therapist on staff. Increase staffing. Have minimum recreation plan each day.”

- "A couple of suggestions: 1. Sit residents in the doorway of their rooms, facing the hallway, to ensure proper social distancing and conduct mentally and socially engaging activities, such as bingo, singsong, etc. 2. Access to a support animal. Studies show that animals (dogs/cats) provide emotional stimulation and improve overall wellness. These animals can visit residents even during a pandemic but I would argue they should be integrated into all facilities on a regular, permanent basis. 3. More IPads !!! This would enable residents to contact family on a regular basis."

- "Please never let this happen again to patients. Family is the most important thing to a patient in need, especially the elderly."

- "Let "Quality of Life" be a strong guidepost and lessen "Risk Aversion" as primary guidepost. People want to "Live" their lives; we are a relational species. Provide much more space for socializing and recreational opportunities."

- "Hopefully policymakers have learned, as we all have from COVID. It's tough to find that middle ground. But that's their job. Restrictions in future will need to find a better balance because loneliness will kill as well. Both the family members inside and outside of the facilities."

- "Instead of reacting it is time that management became proactive on how things should play out next time. .. If there are to be lockdowns there should be visitor restrictions but immediate family members or an alternate should be allowed to visit. More concentration should be put on recreation and what can be done to keep residents both mentally and physically active... Staffing needs to increase and nurses and PCAs should not be mandated to work more than their 12-hour shift... Management is top heavy and they seem to be having repetitive meetings and never solving issues... To improve policies, management has to be downsized and deadlines need to be given to deal with issues. Quality of life is ..most important for our seniors. This is the last stage. We warehouse our elderly without regard for their mental well-being. According to my father, this past two years have been preparation for help"

- "Increase nursing staff. The staff were overworked. Staff were working constantly in masks and protective gowns which made it more difficult to move around. Most clients were more emotional due to lack of visitors and staff were trying their best to give more one-on-one care. I would like to throw a bouquet to the nursing staff. They went above and beyond on my mother's unit, in such a stressful time. More staff is required."

- "There should have been more communication between LTC facilities and family members. It would take weeks before you could even speak or hear from the health care providers, if they decided to get hold of you at all. Phone calls and emails were not answered until a family member said they were going to speak to someone higher than the person you were trying to get hold off."

- "Absolutely ensure that our seniors have everything that they need to survive and prosper... I realize that staff were busy and there may have been cuts made but that doesn't mean that our family members should be pushed to the side and have to wait on anything, especially in the absence of their loved ones... You can't lock them away for over two years and not expect to have consequences. At one point, we were not even allowed to drop anything off to our loved ones, nothing. It has been a sad time for all. Time that they will never get back."

- "There needs to be more accommodation for those with cognitive issues who could not understand why they could not see their families for months at a time. Also, residents were not allowed outside, even in the restricted garden areas of the facility. This made little sense at any point of the pandemic."

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