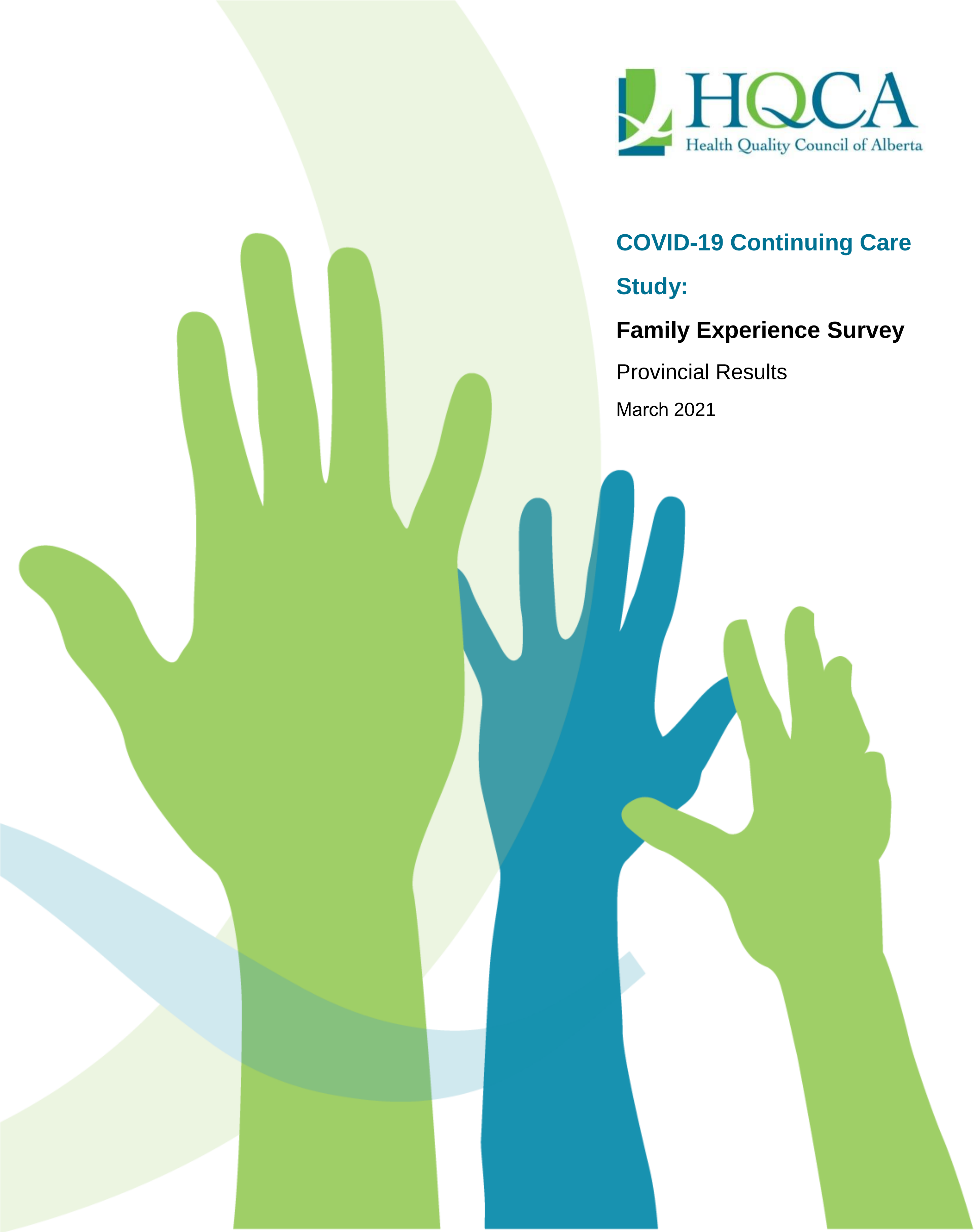
HQCA
Health Quality Council of Alberta

COVID-19 Continuing Care Study:

Family Experience Survey

Provincial Results

March 2021



Promoting and improving patient safety, person-centred care, and health service quality throughout Alberta

The Health Quality Council of Alberta is a provincial agency that has a legislated mandate to promote and improve patient safety, person-centred care, and health service quality for Albertans. We engage with Albertans to gather information about their experiences and collaborate with Alberta Health, Alberta Health Services, and other stakeholders to identify and drive actionable improvements. Our responsibilities are set forth in the *Health Quality Council of Alberta Act.*

Health Quality Council of Alberta. COVID-19 Continuing Care Study: Family Experience Survey. Provincial results. Calgary, Alberta, Canada: Health Quality Council of Alberta; March 2021.

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EXECUTIVE SUMMARY

The 2020 coronavirus pandemic, known as COVID-19, presents a rapidly changing and tremendously challenging time. In order to control the spread of COVID-19, public health orders were implemented March 20, 2020[1] that restricted visits to all healthcare facilities, including continuing care sites (i.e., licensed supportive living and long-term care sites). This *Restricted Access* approach allowed only individuals regarded as "essential visitors" to enter sites and only for the purposes of providing essential care needs for the resident, or if a resident was at end-of-life. The province subsequently moved from the *Restricted Access* approach to a *Safe Access* approach starting on July 23, 2020, which relaxed restrictions and allowed for greater connection between family members and residents.

> *"[The resident] has always said they would choose quality of life over length of days…I would rather that [the resident] was feeling loved and cared for by her family than closing her off completely and locking her up."*

Finding a balance between public health and safety, and resident quality of life can be difficult.[2] Currently, there is a knowledge gap in understanding the impact of the public health orders on the quality of life of residents and their family members in Alberta's continuing care sector. Family member experiences are particularly important: they are essential caregivers and partners in the resident care team[3], and are advocates for the experiences of residents particularly in situations where the resident is unable to speak for themselves. Through understanding and learning from resident and family experiences from March 20 – July 23, 2020, prior to the relaxation of the access restrictions, this can inform a person-centred approach to public health orders that balance health and safety with resident quality of life.

The COVID-19 Continuing Care Study

In partnership with Alberta Health and Alberta Health Services, the Health Quality Council of Alberta (HQCA) conducted the ***COVID-19 Continuing Care Study***. The ***Study*** has several components[4]; this report focuses on the findings from **the COVID-19 Continuing Care Family Experience Survey in Designated Supportive Living (DSL) and Long Term Care (LTC).** The online-only survey was constructed and subsequently delivered to family members via email between August 24 and October 30, 2020. Overall, 9,625 family members responded across 308 LTC and DSL sites across the province.

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[1] Chief Medical Officer of Health order 9

[2] Finding the right balance: An Evidence-informed Guidance Document to Support the Re-Opening of Canadian Long-term Care Homes to Family Caregivers and Visitors during the COVID-19 Pandemic.

[3] Caregiver-Centered Care Competency Framework© (seniorsnetworkcovenant.ca)

[4] The Study also comprises a Resident Survey in Continuing Care, a Resident and Family Survey in Seniors Lodges, and Resident interviews in Continuing Care.

What did we learn?

We asked family members about their experiences at the site their loved one resided from March to July 2020 of the pandemic**.**

1. Family member perceptions of site restrictions were polarized, and many felt an imbalance between infection prevention and quality of life.

Overall, family members rated their own site's overall response to the pandemic from 0 which is the worst and 10 which is the best. Provincially, the average rating was 8.7 out of 10. Furthermore, 67% reported that the restrictions placed on DSL and LTC sites struck a good balance. Similarly, 66% reported that the relaxing of restrictions on July 23 also struck a good balance.

While many family members thought restrictions struck a good balance, many other family members thought restrictions were imbalanced. In particular, 29% felt restrictions went too far[5], with family members describing residents as being treated like "inmates" because restrictions and safety measures had turned their loved one's home into a "prison". On the other hand, some family members felt that restrictions were not strict enough. They expressed worry about visitors, staff, and residents bringing COVID-19 into their loved one's home, and were concerned of inadequate implementation and enforcement of safety measures, such as mask wearing, sanitization, and physical distancing.

From the family member's perspective, resident mental, physical, emotional, and spiritual health suffered significantly during the pandemic. From the survey, 41% of family members reported that their loved one's physical health worsened, and 57% reported that their loved one's mental health worsened. Family members described the cascading consequences of restrictions from staffing and lack of family caregiver support, on the delivery of care and services and ultimately to the resident's quality of life. Family members want to have continued access to their loved one's homes to help provide care and support that they felt is essential and that only they can provide given their knowledge and relationship with their loved one. Family member's see themselves as part of the solution in providing care and ensuring good quality of life, rather than a potential source of COVID-19 transmission.

Overall, family members felt that policy decisions generally ignored resident quality of life, or felt that quality of life was not considered equitably with infection prevention.

2. Family members had confidence in their site's ability to control the spread of COVID-19, but had concerns about resident safety overall.

Family members rated their confidence in their site's prevention of the spread of COVID-19 from 0 to 10, where 0 is the least confident and 10 is the most confident. Family confidence ratings were 8.8 out of 10 in preventing visitors and designated support persons from contracting COVID-19, and 8.9 out of 10 in preventing residents from contracting COVID-19. Survey results suggest that family members had confidence in sites preventing the spread of COVID-19 among residents, families, and designated support persons; however, the proportion of family members who felt their loved one was always safe at the site was not as positive. Only 58% felt their loved one was always safe at the site, and was lower at outbreak sites (50%) vs. non-outbreak sites (60%). Family members commented that family members'

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[5] Responded with "a bit too far" or "much too far"

safety concerns not only included sites and site staff, but also resident and visitor adherence to protocols and guidelines. Family members also reported that the unintended consequences of public health restrictions in some cases lead to neglect in care and quality of life.

3. Visiting experiences were challenging, lacked meaningful engagement, were inflexible to family members, and did not accommodate for the abilities of residents.

Only 25% of family members were completely satisfied with the way sites assisted them in connecting with their loved one, and 42% were very satisfied. In addition, 24% reported having some difficulty in connecting with their loved one virtually (e.g., phone or video calls). Family members reported challenges with technology, and that there was a lack of options, or not enough options, to connect virtually that also considered resident ability (e.g., hearing, vision, and cognitive impairments). They also felt that sites implemented public health orders in ways that did not accommodate for the schedules and realities of family member's lives, for example only opening for visits during business hours which was difficult for families.

4. Communication with family members about the site's pandemic response and how loved ones are doing could be improved.

From the survey, when asked about receiving information about the site's response to the pandemic or information about their loved one, less than half of family members felt: (1) they were always satisfied with the information that they received, (2) always received enough information, (3) or that the information received was very easy to understand. Through comments, family members cited staff availability as the reason for the lack of responsiveness to their phone calls and emails. Family members reported having difficulty reaching staff at the site, which led to feelings of anxiety and concern for their loved ones as they did not have other means to contact the resident at the site.

What are the opportunities for improvement?

> *"[Residents] believe that their dignity is at stake and they feel capable of playing a part in a decision that so profoundly involves them. […] they are not children and have managed a century of war, depression, etc., and profound change. […] I wish those making all these challenging decisions all the best and appreciate all the efforts to date."*

Family members' perceptions of, and experiences with, the *Restricted Access* and *Safe Access* approaches suggest that an opportunity exists for Alberta Health, Alberta Health Services, and continuing care operators to better balance residents' quality of life with protecting residents from COVID-19, as they continue to navigate and respond to the pandemic. Family members expressed concern about the *Restricted Access* approach; they described the harmful consequences these restrictions had on their loved one's quality of life, and felt these restrictions did not align with their values and preferences. For these reasons, many families welcomed the shift to the *Safe Access* approach, which allowed them to see more of their loved ones in-person, for example.

The following four improvement opportunities were determined through an analysis of the survey questions that were strongly associated with family members thinking the restrictions went too far (**bolded** questions below), as well as analysis of over 4,000 family member comments.

While some of these elements are present in public health orders that comprise the *Safe Access* approach, family members in this study conveyed that room for improvement exists in how sites implement these orders; particularly when they are perceived to be more restrictive than what family's desire.

Acknowledge the impact of restrictions on family members, and engage family members/support persons as essential care partners.

Provincially, 69% of family members felt negatively impacted by visiting restrictions.[6] **Furthermore, 75% of family members felt stress, anxiety, or depression related to not being able to visit.**[7] Family members spoke of their heartbreak, sadness, devastation, and frustration over not seeing their loved ones.

Relatedly, through comments, family members discussed the decline in quality of care being provided to their loved one because they were restricted from visiting. Essential care tasks they previously supported their loved one with were left to staff to undertake. This, compounded by no additional staff and new tasks related to safety measures and protocols as a result of the pandemic, left staff overworked, exhausted, and unable to meet the essential needs of residents. As a result, family members felt resident care and quality of life suffered.

To acknowledge the impact of restrictions and engage family members as essential care partners[8] , the following suggestions are based on family member comments:

- Expand access to include multiple individuals important to the resident, for example designated family/support persons as essential care partners and non-essential care partners. This may include, for example, greater ease and flexibility for residents and care partners to modify the list of designated family/support persons and/or non-essential care partners.

Improve visit experience by being more flexible in the scheduling of visits (virtual or in-person), and expand and support visit options particularly for those with vision, hearing, or cognitive impairments.

Only 25% of family members were completely satisfied with the way site staff assisted them to connect or visit with their loved one. Furthermore, 24% reported difficulty in connecting with their loved one virtually. Family members' concerns about the lack of flexibility in visiting highlighted that visits did not meet residents' needs. Family members commented that challenges exist with virtual

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[6] Responded with "Definitely" or "Somewhat" negatively impacted.

[7] Responded with "Definitely" or "Somewhat" feeling stress, anxiety, or depression related to not being able to visit

[8] For guidance on how to reintegrate essential care partners please see the Policy Guidance for the Reintegration of Caregivers as Essential Care Partners report, located at: https://www.cfhi-fcass.ca/docs/default-source/itr/tools-and-resources/policy_guidance_en.pdf?sfvrsn=292a980e_4

visits, including lack of virtual visit options that accommodate the physical and cognitive abilities of the resident, and family members' time.

To improve the visit experience for both residents and families, the following suggestions are based on family member comments:

- Visit restrictions should continue to be tailored to site-specific contexts; for example, outbreak status, the site's risk tolerance, and to the abilities of the resident (e.g. visit challenges related to resident impairments in vision, hearing, or cognition).
- Make WiFi available to all residents and families at the site.
- Increase access to technology and devices (e.g., larger screens, speakers, etc.).
- Consider ways to support safe indoor visiting during winter and inclement weather, such as designated visiting rooms with appropriate barriers mimicking a window visit.

Promote resident quality of life by allowing greater resident access to designated family/support persons who provide essential support for the resident's mental, physical, emotional, and spiritual health. Special attention must be given to residents living with dementia, where the impact of restrictions on quality of life is more severe.

Provincially, 57% of family members reported a worsening of their loved one's mental health (Q4 above).

Relatedly, 41% of family members reported a worsening of their loved one's physical health. Quality of life was a frequently discussed topic by family members in their comments. Family members characterized "quality of life" as holistic, including mental, physical, emotional, and spiritual health, and felt resident's quality of life worsened because of the pandemic. Specifically, they observed a decline in their loved one's physical and mental health, and increased social isolation and loneliness.

To improve the quality of life of residents, the following suggestions are based on family member comments:

- Reduce restrictions on designated family/support persons so they can provide essential physical, mental, and emotional support.
- Re-institute recreation programming at sites that discontinued them, and/or support sites to enable recreation programming to continue. Ensure residents have access to these activities in order to address social isolation, declines in mobility, and lack of stimulation.
- Increase COVID-19 testing to reduce isolation time of residents in instances where residents are required to isolate.
- In consultation with families and residents, Alberta Health and the Chief Medical Officer of Health to review the definition of quality of life as it relates to current COVID-19 restrictions. The definition should identify specific activities that promote quality of life. Specifying activities will ensure that essential activities important and necessary to residents' quality of life are emphasized and promoted, while also ensuring consistency in the activities offered by all sites across the province.

Improve communication with family members by being more timely and clear with information, and being more responsive to family requests.

Less than half, 45%, of family members were always satisfied with the information from the site about their loved one. Relatedly, 42%, of family members were always satisfied with the information from the site about the site's pandemic response.

To improve communication, the following suggestions are based on family member comments:

- Sites to improve communication with family and residents by being more clear and transparent regarding site-level decisions about restrictions, particularly in situations where restrictions at the site are stricter than current public health orders.
- Public health orders to include more information to reduce inconsistencies in site interpretation. For example, visits intended to promote quality of life were added in previous public health orders, but did not include a detailed description of what activities 'quality of life' encompasses.
- Consult with residents and family members regarding site-specific decisions on restrictions.
- Provide more regular updates about the resident to family members, particularly in situations of increased site restrictions.

Site characteristics

The impact of site characteristics on family experience, such as level of care, geography, size, operator type, and outbreak status, were also explored. These results can be found in the body of the report.

1.0 BACKGROUND

1.1 Introduction

The COVID-19 pandemic presents many challenges for Alberta's health system and continuing care providers and has required public health orders to help control the spread of the virus. Public health orders, early in the pandemic, were characterized by a *Restricted Access* approach to limit adverse outcomes among continuing care residents. This approach began in March, 2020 and included a wide range of orders about visiting, cleaning, hand hygiene, mask wearing, social distancing, symptom identification, capacity of shared spaces, isolation requirements, and staff assignments to single sites. Continuing care sites were expected, at minimum, to follow these orders, and were also able to increase restrictions beyond the order based on need.[9] Throughout the summer several other public health orders were introduced (e.g., the addition of quality of life), most significantly the province shifted to a *Safe Access* approach.[10] This approach allowed more visitors and site-level decision making so that restrictions could be responsive to site context and the local community. Each of these approaches is characterized by a suite of orders that have impacted routines and processes at the site level, as well as, the lived experiences of residents in designated supportive living (DSL) or long-term care (LTC) sites and their family members.

HQCA's COVID-19 Continuing Care Study

The Health Quality Council of Alberta (HQCA) partnered with Alberta Health and Alberta Health Services to conduct the *COVID-19 Continuing Care Study*. The purpose of this study was to understand residents and family members' experiences and perceptions regarding the public health orders and their implementation by the sites. The *Study* has several components. This report focuses on the results of a survey of family members with a loved one living in DSL or LTC. The purpose of this survey was two-fold:

a) to develop a better understanding of family members' experiences and perceptions during the *Restricted Access* period of the pandemic, from March 20 to July 23, 2020, as well as perceptions regarding the relaxing of these restrictions (*Safe Access* – beginning July 23, 2020); and

b) to identify suggestions from family members about how to improve the system's response to the pandemic specifically as it relates to continuing care.

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[9] CMOH Order 09-2020

[10] (starting July 23 2020) CMOH Order 29-2020

2.0 SURVEY PROCESS AND METHODOLOGY

2.1 Survey development

A survey was developed by the HQCA in consultation with the HQCA's Patient & Family Advisory Committee and external partners, which included (1) Alberta Health – Continuing Care Branch; (2) Alberta Seniors and Housing; (3) Alberta Seniors Communities & Housing Association; and (4) Alberta Health Services Quality Management Teams and Zone Leaders.

The survey was built using questions from existing HQCA surveys to leverage established question reliability and validity. These surveys include:

- Long-term Care Family Experience Survey
- Designated Supportive Living Resident Experience Survey
- Designated Supportive Living Family Experience Survey
- COVID-19 Experiences and Impacts Survey

From these surveys, questions were selected and then modified to fit the context of the study and align with topics important to stakeholders including: (1) visiting restrictions and their impact on families, (2) communication by sites to families, (3) perceived adequacy of care and staffing, (4) trust in the provision of care, (5) perceptions of resident safety and infection control, and (6) opportunities to connect residents with family members, and how sites supported or enabled this (e.g., virtual visits).

In addition, questions were written to assess family member's perceptions about the *Restricted Access* approach to the pandemic (from March 20 to July 23, 2020) and to assess family member's perceptions about the relaxing of these restrictions. The latter was important given that the system's response was shifting to the *Safe Access* approach during survey development.

An open-ended question was also included in the survey for family members to answer:

> *Do you have any suggestions for how the province, Alberta Health Services or [your site] could improve their response to the pandemic? If so, please explain.*

2.2 Survey protocol and sampling

In collaboration with AHS, publicly funded DSL and LTC sites were contacted and informed about the study. In total, 308 sites out of a possible 354 sites participated in this study. Family member and/or designated family/support persons email addresses were requested from sites so that a web-based online survey could be delivered to respondents. While we recognize that designated family/support persons could extend beyond family, this report refers to survey respondents as "family members."

Data collection for the online-only survey occurred from August 24 to October 30, 2020. The survey response rate was 48 per cent; 9,625 out of a possible 20,056 eligible family members completed and returned the survey. The chart below details important characteristics about the sample. More details about the methodology can be found in the *COVID-19 Continuing Care Study: Appendices*, such as a further breakdown of responses by AHS Zone (Appendix II) and full question level results by AHS Zone (Appendix III).

Each participating site with five or more respondents received a customized report of the results from family members for their site.

SITE AND RESPONDENT DESCRIPTIONS:

308	9,625	4,071
Sites participated	Family members	Comments from family members

FAMILY MEMBERS WHO RESPONDED WERE:

71%	73%	79%	47%
Between 55-74 years of age	Identify as a woman	Able to connect with their loved one (virtual or in-person visit)	Connected with loved one in-person (including window and outdoor visits)

2.3 Reporting of results and analytics

Family members were asked in the survey to respond based on their experiences from March 20 to July 23, 2020. This time period is referenced in this report as *Restricted Access*. *Safe Access* was used to reference the time period after July 23 during the relaxing of some restrictions. Questions that require the presence of families at the site (such as observations of staffing levels and site PPE use) were only asked of family members who reported they were able to visit the site in-person during the *Restricted Access* period to ensure accurate and reliable responses to these questions.

In response to the open-ended survey question, family members provided suggestions for improvement in addition to describing their concerns with the system's response to the pandemic. Their feedback provides rich reflections about their experiences during the pandemic. Given that the survey was in the field from August 24 to October 30, it is important to note that family members may have reported on their experiences at any time during the pandemic, including after July 23.

The findings integrate survey results with family member comments where applicable, and were informed by themes generated from: a) topics identified by stakeholders prior to survey rollout and reflect the purposes of the survey (e.g., perceptions on restrictions), b) key findings from family member comments, and c) statistical modelling approaches that identified key survey questions that were strong factors in family member experiences about site restrictions. For more information on methodology, see Appendix II.

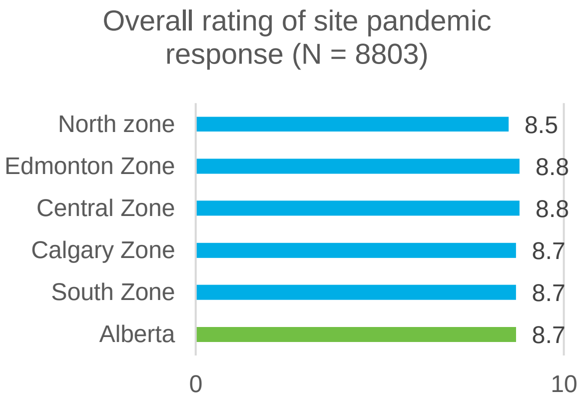
As a result, this report is organized into five key sections:

1. Perceptions about overall pandemic response and public health restrictions
2. Staffing, care and services, and the impact on resident quality of life
3. Impact of restrictions on family members
4. Communication
5. Concerns about safety and adherence to protocols and guidelines

3.0 FINDINGS

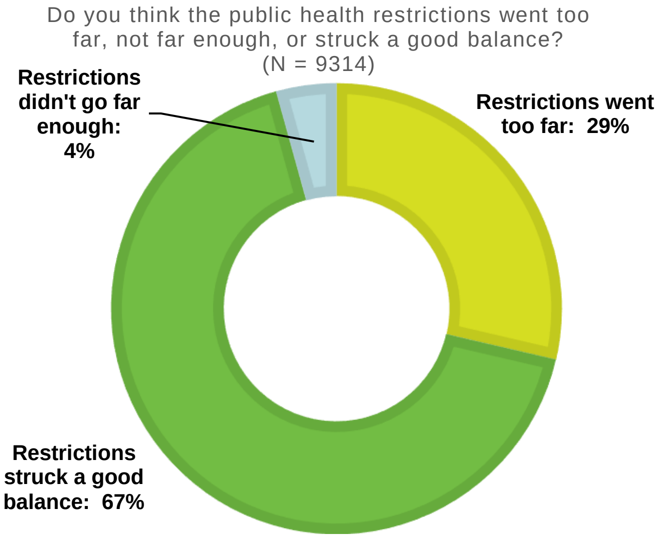
3.1 Perceptions about overall pandemic response and public health restrictions

Family members rated the site's overall response to the COVID-19 pandemic from 0, which is the worst, to 10 being the best. Family members rated the overall response to the pandemic at **8.7 out of 10**, with outbreak sites significantly lower at **8.4 out of 10 compared to non-outbreak sites at 8.8 out of 10**.



Family members were asked questions about the public health orders in place from March 20 to July 23, 2020. When reflecting on this time period, family members reported that they were knowledgeable about these restrictions, with **less than 1% reporting that they were not at all familiar with these restrictions.**

Overall, **67% of family members reported that the restrictions struck a good balance.** There were no differences between AHS Zones, provider type, or between outbreak and non-outbreak sites.



However, **29% of family members felt the restrictions went too far**. These family members were more likely to be younger, identify as a woman, and higher educated. Furthermore, they also reported poorer communication with sites, and were more likely to report feeling stress, anxiety, and depression about not being able to visit their loved ones.

Comments by family members support the finding of polarized perceptions existing about restrictions. On one hand, family members felt that the restrictions went too far. Residents were being treated like "inmates" because restrictions and safety measures had turned their loved one's home into a "prison". Family members said residents were "confined" to their rooms and unable to access fresh air, supplies, social engagement, and physical connection with family members. For all of these reasons, family members expressed concern about the well-being of their loved one, and felt that violations of their rights, independence, and dignity occurred.

> *"He described the 'lockdown' like being in prison with no mobility within the facility, reduced recreation, very limited visits, etc."*

> *"I did not agree with confining seniors in their rooms denying them fresh air and cutting them off from their families."*

> *"Residents felt like caged prisoners because they couldn't go outside; … have their loved ones visit; …[receive] items and supplies that they counted on … and were also deprived of any social engagement because their routines were destroyed when all activities got cancelled. Loved ones were involuntarily stripped of their rights to be with their family members, especially at a time when they were needed most to be there with them for comfort. Even worse, were those who were forcefully prevented from being able to say goodbye before death."*

> *"[Residents] believe that their dignity is at stake and they feel capable of playing a part in a decision that so profoundly involves them. […] they are not children and have managed a century of war, depression, etc., and profound change. […] I wish those making all these challenging decisions all the best and appreciate all the efforts to date."*

On the other hand, some family members felt that restrictions were not strict enough. They expressed worry about visitors, staff, and residents bringing COVID-19 into their loved one's home, and were concerned about inadequate implementation and enforcement of safety measures, such as mask wearing, sanitization, and physical distancing.

> *"[The site] needs to implement more strict and more limited family visits, as the COVID-19 infection is easily transmittable from visitor to residents/staff. Similarly, if there are any positive cases of residents/staff then the visitation should be suspended to prevent infection transmission to family visiting."*

> *"Enforce the lockdown. Residents were leaving the facility by their own cars to visit friends, get haircuts and go to family dinners. Upon entering the car parkade and the facility there were no checks or sanitization procedures followed and still are not. … Smokers were allowed to come and go without proper checks, and allowed to smoke just outside the entrance and in the visiting area. This continues today. Kitchen staff did not wear masks until well into the lockdown and then were not worn properly."*

Visiting and virtual visits

Early in the *Restricted Access* approach, only one essential visitor per resident was allowed and only if it was identified that a resident had essential needs that could not otherwise be met by staff.[11] Later, this order was updated to include quality of life,[12] and on July 23 (*Safe Access*) visits could occur with two designated support persons.

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[11] Order 03-2020 and implemented on March 20, 2020.

[12] CMOH Order 14-2020 (April 28, 2020)

Both survey results and family comments identify challenges related to visiting generally and virtual visits. From the survey, **68% of family members reported they visited much less than they did before the pandemic, and only 42% felt they were always involved in decisions about their loved one's care.**

Family members felt they were essential members of the care team. Through comments, family members described their knowledge of the residents' needs that they provided, and which they considered essential. As a result, they expressed frustration when the sites refused to allow them access. Family members were frustrated when there was no flexibility around who could be named as the essential visitor, specifically because the person identified could not be changed. They acknowledged that limiting the number of visitors is important, but expressed their exhaustion at being the only family member permitted into the site to provide care. They felt the number of visitors should expand or provide sites guidance to distinguish between types of visitors (e.g., designated family/support persons vs. non-essential visitor), and separate visiting policies should be implemented for each.

In response to the survey question about the *Restricted Access* period, only **25% of family members were completely satisfied** with the ways sites assisted them to connect with their loved one, and **42% were very satisfied**.

In addition, a common topic in the comments overall was about visiting and the many challenges family member's experienced. Family members' comments provide insight into their experiences on how sites implemented the designated family/support person or essential visitor policy.

With respect to virtual visits, while some family members said these visits helped them stay connected to their loved ones, many reported challenges with the quality of the visits and this prevented families from having meaningful visits. When asked in the survey about virtual visits, which included video and telephone calls, **24% reported having some difficulty in connecting with their loved one virtually**. Family members specified what these challenges were including: (1) no options or not enough options to connect virtually (n = 325), and (2) limitations due to resident capacity (n = 468, e.g. dementia, cognitive impairment, and auditory and visual impairment, etc.).

> *"I would suggest getting proper internet so that when and if we want to video chat that there is a service that does not cut out. The current service made it almost impossible to have a proper visit."*

> *"We were told that staff were using their own phones and data to make calls."*

In their comments, family members identified other challenges they encountered during both the *Restricted* and *Safe Access* approach. They expressed concern about outdoor visits as the weather and physical distancing were challenging for their loved ones. They also felt sites implemented public health orders in ways that did not accommodate for the schedules and realities of family member's lives, for example only opening for visits during business hours which can be difficult for working families.

> *"Visiting when only outdoor visits were allowed was extremely difficult. My family member is frail and even when the temperature was breezy and 20 degrees Celsius, being outside was cold and uncomfortable (even in a winter jacket). … Having the option to meet indoors (the auditorium) was temporarily available for bad weather days, would have been greatly appreciated."*

> *"Visitations when restarted outdoors were randomly assigned, only on one day per floor and made no allowances for caregivers who work during the day. They should have scheduled more visits, allowed for visits during lunch or later in the day to allow family to get from work to [the site]."*

> *"More shaded areas need to be provided during summer months for outdoor visits. The [patio] which has a high fence could have easily modified to facilitate visits by adding a plexiglass window."*

Family members whose loved ones are living with dementia or who have other unique needs, expressed additional frustration with the visit limitations. Family members found virtual visits to be unsatisfactory because families relied on physical touch to connect in light of memory, visual, and auditory impairments. When in-person visits were available, mask usage prevented their loved ones from recognizing them, and prevented residents from being able to respond to "visual facial cues." Ultimately, family members desired visiting protocols to be more responsive to the communicative requirements of residents with dementia along with hearing and visual impairments.

> *"[The resident] has severe dementia and doing virtual visits do not work. Even visiting with a mask and at a 6 foot distance is a challenge because she feeds off of visual facial cues and responds to touch. She is [age] with dementia and I fear I will never be able to have a physical, and meaningful visit with [the resident] ever again."*

> *"I am still quite concerned considering the later stage of dementia that [the resident] is in that has no touch or closeness to me or other family members. She has no language skills and doesn't know me so touch is all that is left to give her. Being 5 feet away from her has no value as she doesn't have the cognition. To hold her hand or stroke her hair is so important in this later stage and yet we aren't allowed to do so. This seems so inhumane. [The resident] has always been there to support her family and many others and here in her later life no one can support her in the way that she needs."*

> *"I think provisions need to be made for residents who are hard of hearing. Window visits and cyber visits were very difficult. A glassed in visitation booth with microphones and speakers would be a good idea when considering facility design to be used during COVID and other lock down periods."*

Concern about isolation of residents in their rooms

Family members also reported their concerns about the policies of isolating residents in their rooms. Family members discussed their loved ones having pre-existing medical conditions with symptoms similar to those of COVID-19 (e.g., cough, runny nose, etc.), which resulted in unnecessary isolation periods, sometimes on numerous occasions. They also discussed their loved ones who were hospitalized for concerns unrelated to COVID-19 and then had a mandatory 14-day isolation upon return to the site. Family members' concerns centred on the negative impact they believe this isolation had on residents. Their perception was that the resident's condition deteriorated significantly in isolation, their care was neglected, and the inability to visit their loved ones further negatively impacted the residents' health and wellbeing.

> *"[T]here is quarantine within the quarantine, when they are not allowed to leave their rooms, so they sleep all day. How do they get their proper intake of fluids when sleeping all day?"*

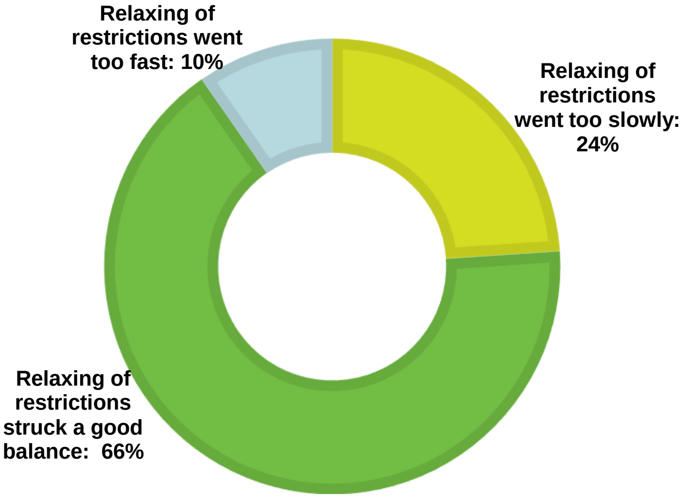
> *"Residents with pre-existing conditions such as [medical conditions] can develop symptoms such as coughs and fevers that resemble COVID symptoms. There should be a separate set of criteria to determine when symptoms are caused by factors other than COVID so these residents are not placed in quarantine unnecessarily."*

> *"[The resident] has had to go into isolation three times because her roommate has had COVID symptoms. I would really like her to have her own room, but there are non available. There needs to be more single rooms available especially during a pandemic."*

Relaxation of restrictions: A move from *Restricted Access* to *Safe Access*

Family members were asked about their perceptions on the relaxing of visiting restrictions that went into effect July 23, 2020, known as *Safe Access*.[13] This approach involved expanding the designated family/support persons' criteria and the opening of common areas. The majority of family members **(66%) reported that the relaxing of restrictions struck a good balance,** whereas **24% felt the relaxing of restrictions moved too slowly**. Furthermore, only **62% of families reported they were consulted about the site's safe visiting policy**.

To what extent do you feel that Safe Access (i.e., the lifting of some restrictions on July 23rd) moved too fast, too slowly, or strikes a good balance?



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[13] CMOH 29-2020

In the comments, family members provided insights about their concerns regarding the easing of restrictions. On one hand, some family members were "disappointed" and "stressed" about the change in restrictions feeling that expanding the visiting criteria was risky for their loved ones. On the other hand, some family members were pleased about changes that allowed them more access to their loved one, but felt it was still limited, wanting for example longer and more frequent visits. Other family members expressed concern regarding how they perceived sites to be implementing the *Safe Access* approach.

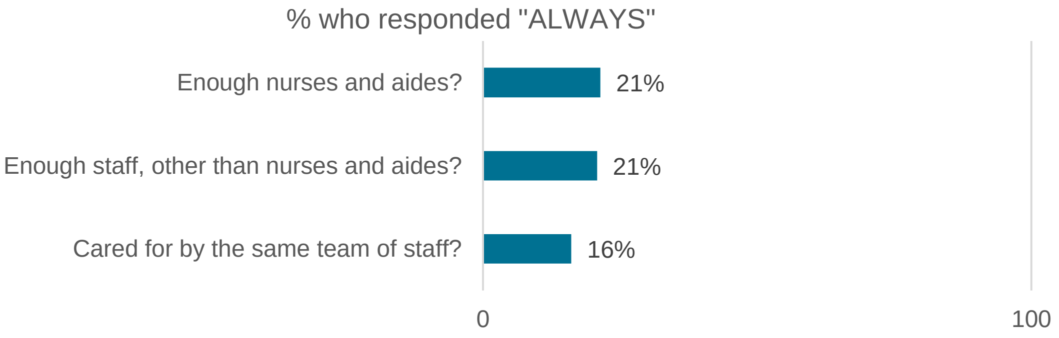
> *"I am very concerned and stressed over the decision by AHS to relax visitation protocols at [site 1] or [other sites]. Firstly the people in these facilities are counting on AHS for their safety and well being. …The safety of the residents and the caregivers should be the primary goal! I am very concerned and disappointed that [site 1] and all the other senior centers have not become more restrictive (locked down) when considering the surge in infection and death toll rates in the senior care centers."*

3.2 Staffing, care and services, and the impact on resident quality of life

This section presents survey findings that reflect issues family members had with staffing levels, care and services, and the trust and confidence they had in care provision. Through comments, family members described making connections with limited staff, the resulting limitations to care provision, and ultimately the impact on resident quality of life.

Staffing

Only **21% of family members reported there were always enough nurses and aides, and only 21% reported there were always enough staff other than nurses and aides.**



Percentage of family members who thought there were ALWAYS enough nurses and aides

21%	23%	18%
2020 COVID-19 Family Experience Survey in DSL and LTC	2019 Family Experience Survey in DSL	2017 Family Experience Survey in LTC

The proportion of family members who felt there were always enough nurses and aides is consistent with findings from previous HQCA family surveys in both LTC and DSL. In the comments; however, family members reported that pandemic related circumstances and associated restrictions exacerbated staffing concerns by creating new and additional tasks for staff with no *additional* support. They observed staff taking on new roles, such as the coordination of visits, screening for COVID-19 symptoms, and cleaning. Specific examples included concerns over recreation staff being re-assigned to some of these roles, resulting in the cancellation of recreation activities. Family members worried about staff taking on new tasks because they knew it was reducing the quality of care provided by health care aides and limiting residents' access to activity and social engagement, thereby impacting their quality of life.

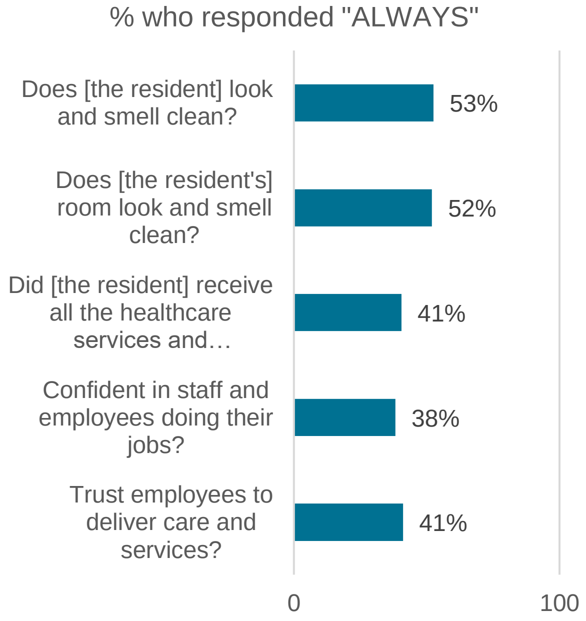
> *"Most of the roadblocks to visitation or assistance with meals, etc. have been due to insufficient dedicated staffing being devoted to those activities, including scheduling, controlling movement within the facility, etc. Existing staff, whom were already fully engaged and at times short staffed, were stretched with additional requirements due to COVID-19 protocols and are hard pressed to take on these additional coordinating role."*

> *"There should be designated cleaning staff for the residents rooms and not put that responsibility on the health care aides. They do not have ample time to do a reasonable job and then they are expected to go and give meds and serve dinner. They were very busy during the pandemic keeping the residents' safe which was more important."*

Care and services

Family members who visited in-person or virtually were asked questions about the care and services their loved one received at the site. They attributed declines in care quality to insufficient staffing levels that the pandemic exacerbated, staff that were overwhelmed by pandemic-related tasks, and their inability to visit as they normally did to supplement the care provided by staff, for example, at mealtimes.

For family members who reported visiting, **approximately half felt the resident's themselves always looked and smelled clean**



(53%) and that the rooms (52%) always looked and smelled clean.[14]

Furthermore, **41% always trusted that employees and staff were providing all of the needed care and services to their loved one,** and this also differed between outbreak and non-outbreak sites, with **42% of family members of non-outbreak sites *always* trusting the employees to deliver needed care and services, whereas this percentage was only 37% among outbreak sites**.

Only **41% said the resident always received all the healthcare services and treatments they needed. This percentage is lower in outbreak sites (37%) compared to non-outbreak sites (42%).** Family members witnessed or heard from residents about needs not being met. This included: untrimmed nails, teeth that had not been brushed, dirty and ungroomed hair, few to no showers for extended periods (weeks to months), lack of access to medical care (e.g., specialists, physiotherapy), unmet dietary needs, and delayed support using the bathroom.

> *"I was surprised that [the site] stopped giving showers/baths to the residents. This is not acceptable, how would you like to go without a shower or bath for months!!!"*

> *"[The resident] (unable to move) lost her private physiotherapist visits and these were not replaced with additional staff treatments."*

Quality of life

Through comments, family members characterized "quality of life" as holistic, including mental, physical, emotional, and spiritual health. Public health orders also recognized the importance of quality of life and were set to enable sites to consider the promotion of resident quality of life where appropriate in the context of current visiting restrictions.[15] However, public health orders did not include a detailed description of what specific activities or themes 'quality of life' encompassed.

While family members acknowledged and appreciated the efforts made to protect their loved ones from COVID-19 (See Section 4.5), they questioned the measures taken to do so and the consequences to resident quality of life. Family members reported a decline in their loved one's quality of life during the pandemic, including negative impacts to mental health and socialization, in addition to or resulting in, negative impacts to resident physical health (e.g. loss of mobility).

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[14] Of note, many family members commented that they could not accurately answer questions about resident hygiene and care because their visits were limited to physically distanced outdoor or window visits. The result of 52% reporting the room always looked and smelled clean was limited to those who reported they visited the room.

[15] Chief Medical Officer of Health (CMOH) Order 14-2020

41% of family members reported that their loved one's physical health worsened and 57% reported that their loved one's mental health worsened.

Through comments, family members cited various factors contributing to the negative impact on residents' quality of life including: a) the lack of support from family caregivers, b) limitations on staffing and quality of care, and c) the cancellation of recreational programs. Family members felt there was an overall lack of consideration to their loved ones' mental health and overall wellbeing during the pandemic.

Family members felt knowledgeable about residents' needs and that the care they provided regularly before the pandemic was essential (e.g., ensuring residents had enough water or food, doing their laundry, doing memory exercises, and providing social and emotional support). From their perspective, neglect was occurring because policies restricted these caregiving tasks they felt were essential.

They also felt that public health orders and their implementation had brought about too little social engagement and recreation. Although public health orders stated in the *Restricted Approach* that recreation could continue with groups of five residents or less, some family members conveyed that no recreation activities were occurring at sites.[16]

> *"Although the ruling stated that family members should be allowed to assist with care if staff could not complete it, I was not allowed in. [The resident] lost 25 pounds over that time, at least some of that can be accounted to the fact that staff did not have the time to feed him (he sometimes takes a long time to eat). … [W]hen I finally saw him in an outdoor visit I noticed how skinny he looked. Then I initiated a call and asked for his monthly weight over the past [number of] months and discovered the drastic loss."*
>
> *"[The site] could improve the response by putting options in place for residents to maintain their mobility such as scheduled walks in the hallway much sooner in the process. We feel that [the resident's] lack of opportunities to exercise, walking in particular, may have contributed to his subsequent fall and hospitalization."*
>
> *"During the time of restricted visits [the resident's] health had declined to the point where her doctor recommended moving her goals of care to C1 (comfort care only) because she had suffered several [medical conditions]. Additionally, her overall mental and physical health had declined to the point where her cognitive ability had greatly declined, she needed a wheelchair, and slept much of the day. Since she has been allowed visitors using the end of life guidelines, her cognitive ability has recovered to a pre-COVID level and her physical health has improved somewhat. There have been no further [medical conditions] since she has been allowed more visitors. This is an example of how resident health has been negatively impacted by the restrictions implemented because of COVID."*

Family members also highlighted that their loved ones were nearing end of life and therefore quality of life was of utmost importance. Family members reported their concerns that the restrictions were taking away residents' ability to live the rest of their lives the way they would choose to. Family members requested that decisions and policies be made with compassion, and their feedback reflects the severe impact the restrictions had on resident quality of life. Overall, family members felt the

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[16] CMOH order 06-2020 : 2020 COVID-19 response (alberta.ca)

response to the pandemic emphasized *quantity* of life rather than *quality* because they prioritized physical safety from COVID-19 at the expense of allowing for care provision that attended to the mental health and overall wellbeing of residents.

> *"[The resident] has always said they would choose quality of life over length of days …I would rather that [the resident] was feeling loved and cared for by her family than closing her off completely and locking her up."*

> *"Let residents enjoy quality of life rather than quantity. … Her mental and spiritual health has declined leading to a physical decline with less stimulation. … I'm very disappointed in her quality of life."*

While family members whose loved ones were living with dementia reported many of the same concerns as other family members including decreased quality of care, decreased quality of life, and worsening mental health, these family members also emphasized that the experiences were more negative and more severe for those living with dementia. Although the survey did not ask specific questions about the experiences of residents living with dementia, or a significant cognitive impairment, many family members, in the comments, felt that accelerated disease progression was occurring due to social isolation and the lack of stimulation. They also argued that while it is important to find ways to keep people physically safe from COVID-19, restrictions need to be responsive and consider "all other aspects of health" and the specific needs of "sense-impaired non-verbal residents." For instance, they suggested that frequent in-person visits were necessary to check in and to advocate for persons with dementia, given that their loved ones could not tell them how they were doing on the phone or during a virtual visit.

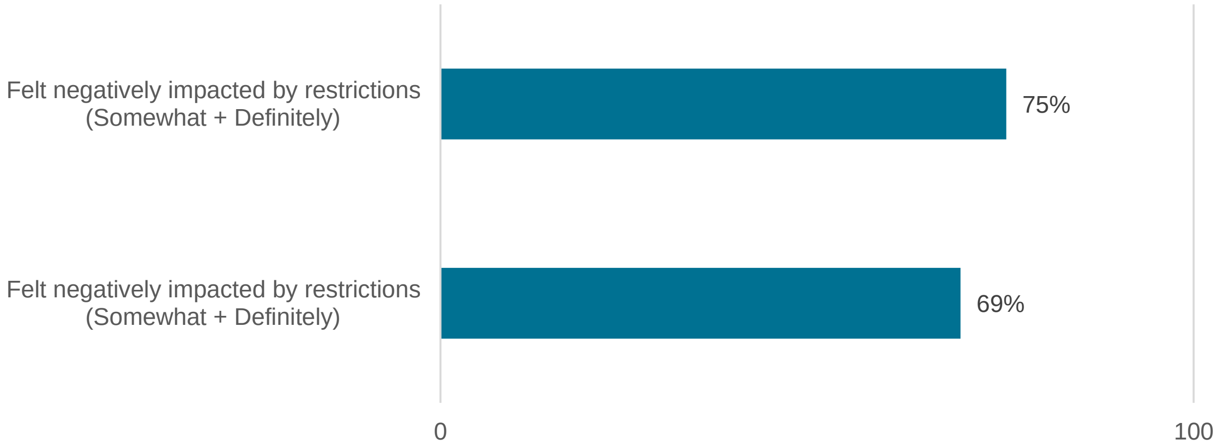
> *"[The resident] suffers from Dementia/Alzheimer's. The total and complete shut down of visitation during the COVID-19 response worsened his condition. I agree with shutting down the facility to visitors to a degree; however, [the resident] no longer knows who we are. We are strangers to him. He used to look forward to our visits and we could come [a number of] times a week. Now he has no idea who we are. Was it inevitable? Perhaps, but not being able to see him quickened his total memory loss of who we are."*

> *"I understand that infection control safeguards are needed, but these should not compromise all other aspects of health or lead to questions whether life is even worth living in the strict isolation that is all the harder on cognitive and sense-impaired non verbal residents."*

> *We were not allowed in the facility until after [date]. This was outrageous. [The resident] has dementia. I had no idea what kind of care she was getting because she could not tell me."*

3.3 Impact of restrictions on family members

Provincially, **69% of family members felt negatively impacted** by visiting restrictions, **and 75% felt stress, anxiety, or depression with not being able to visit**. These proportions were even higher among family members who felt the restrictions went too far.



The impact on family members came through in their comments as they expressed their concerns and worries for their loved ones and commented on how separation from their loved ones made them feel heartbroken, sad, devastated, and frustrated. Family members described mental anguish, losing sleep, and excessive worry as they tried to ensure their loved ones were doing well and receiving adequate care.

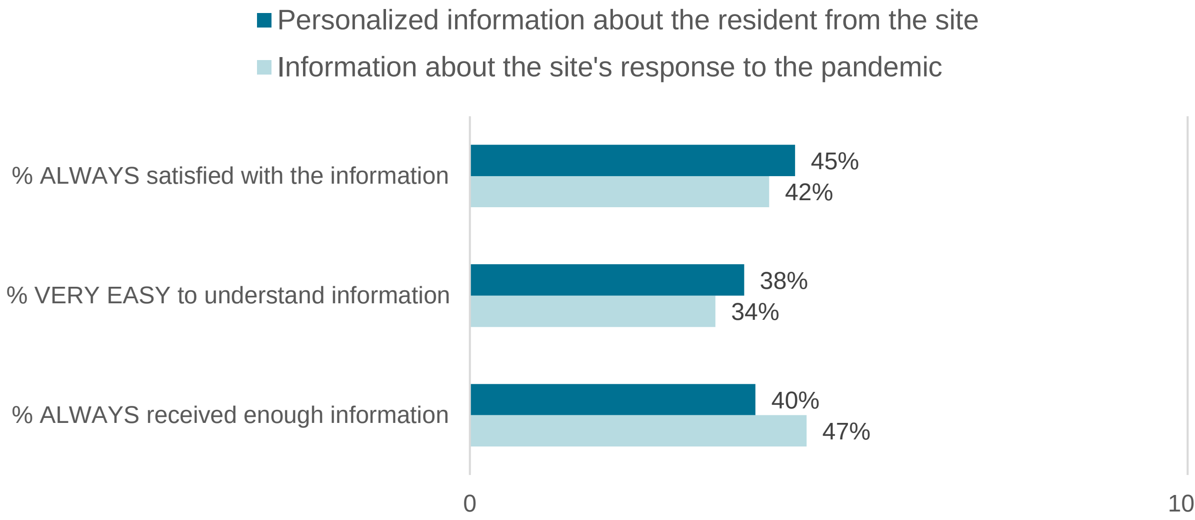
The comment below illustrates how public orders and the implementation of these orders by sites dramatically impacted the quality of life and mental well-being of both family members and residents. The comment reflects the effort required of a family member to become declared a designated visitor, and the impact of poor site communication. Moreover, this comment illustrates the anguish that family members experience when they are unable to visit and have 'meaningful interactions' with their loved ones, to the point that they are motivated to find another "solution" for care such as transferring the resident out of the site.

> *"Before the pandemic, I was with him every day. After the pandemic hit I suddenly was not able to see him at all. After numerous calls and emails and after contacting AHS, on [date] I was finally allowed to be a designated visitor. On the [date], the doors were shut to me again without proper explanation. All we were told is that someone in the building had received an infection. A few days later we were told that it was not due to COVID-19. Yet, the doors never opened again and ever since then my family and I have been totally shut out. … This is extremely cruel. [My family member] and I cry ourselves to sleep many a night. We are full of anxiety and mourn the fact that [the resident] is not allowed to have any meaningful interaction with us and his family. [The site] is aware of our situation, but tells us that they cannot make an exception with us. They are not concerned sufficiently about his mental and spiritual well-being. We are very much afraid that he will become very depressed and be unmotivated to live. … [He} is left without hope. And so are we. We are desperately seeking another solution for his care. We are quite upset because of this situation. … Why doesn't anybody care enough?"*

3.4 Communication

Family members who engaged with the resident either in-person or virtually (79% of respondents) were asked whether they received any information from the site about the site's pandemic response. Among those that said **yes**, respondents were asked questions about the information they received about: (1) the site's response to the pandemic, or (2) information about the resident. Through comments, many family members further elaborated on survey findings, noting need for improved communication and where these opportunities for improvement exist.

When asked about receiving information about the site's response to the pandemic or information about their loved one, less than half of family members felt they were **always satisfied with the information they received.**



Only 34% felt the information received about site actions was very easy to understand. Family member comments compliment this finding, with family members expressing that communication from sites was policy heavy or full of jargon and legalese, and at times, too much and fragmented (e.g., multiple emails in a short period of time), which was overwhelming and confusing.

Only 47% felt they always received enough information about site actions. Family members also reported wanting to receive more information on the protocols being used to ensure safety, such as sanitization procedures in shared spaces and how items were cleaned that were brought into a site. They also felt insufficiently informed by sites about the public orders and how sites were responding to the orders in relation to visiting, and felt a lack of transparency. Even after the shift to the *Safe Access* approach, some family members were not aware they could visit their loved one because the site failed to communicate this information. Instead, they discovered this information by reading the public health orders themselves or by completing the HQCA survey.

> *"Early in the COVID shutdown, while I received emails from every grocery chain, cell provider, bank, etc. about their COVID response, not a word had come from [the site]. After contacting them regarding an issue with my family member and pointing out the lack of communication, an email was eventually received. This didn't instill much confidence on how family members were being cared for during this crisis."*

> *"After much frustration, we dug into the act and found out that I could have access to [the resident] as a designated visitor as the only living relative. No one at [the site] told me about this – that is alarming and causes mistrust for sure. If I had kno[wn] I could [have] seen [the resident] a lot sooner."*

Only 40% felt they always received enough information about their loved ones. Family member comments revealed difficulty with receiving answers to phone calls and emails, which heightened their anxiety when they had no other way to contact or get information about their loved one. Family members cited that communication from sites was general and provided information on policies and changes to rules, but often no regular personal updates on the wellbeing of their loved ones.

> *"The communication we did receive was very general and felt like the person that called was not really aware of how our loved one was doing."*

> *"Better communication with how our family member was doing. Had no idea if they needed anything. The communication we did receive was very general and felt like the person that called was not really aware of how our loved one was doing."*

Only 37% of family members reported that the people in charge were always available to talk with. In the comments, family members further elaborated on their concerns with management. In their experience, they felt that leadership was lacking and contributing to poor communication overall. Family members commented that communication between staff caused disorganized and inconsistent resident care. Family members also explained that, from their perspective, management decisions appeared to prioritize "liability" rather than the interests of residents and families, which made them feel distrustful of leadership and their decision-making. Family members desired greater transparency from leadership overall, which included more information about why certain decisions were made, and consulting with family members before making decisions that impacted them and the quality of life of their loved ones.

> *"[To] be denied access to even sit outside [the resident's] window while she was in isolation so she wouldn't be along and there would be eyes on her if she fell! Her window happens to be within an outdoor courtyard considered by [the site] to be a 'common area' and therefore it was too great a liability for them if I sat outside said window. Liability trumped common sense, reason and compassion."*

Sites under outbreak and family member knowledge

Through comments, family members expressed a desire for sites to communicate more frequent information about case numbers and outbreaks, whether the cases existed among staff and/or residents, and where transmission had occurred. They wanted this information directly from the site rather than learning about it through the media.

> *"When there was news of outbreaks at seniors' facilities in [city] we were left wondering if there were any at [the site]. It would have been good to get a quick note (or web link) saying all clear at her facility on a regular basis to ease the worry."*

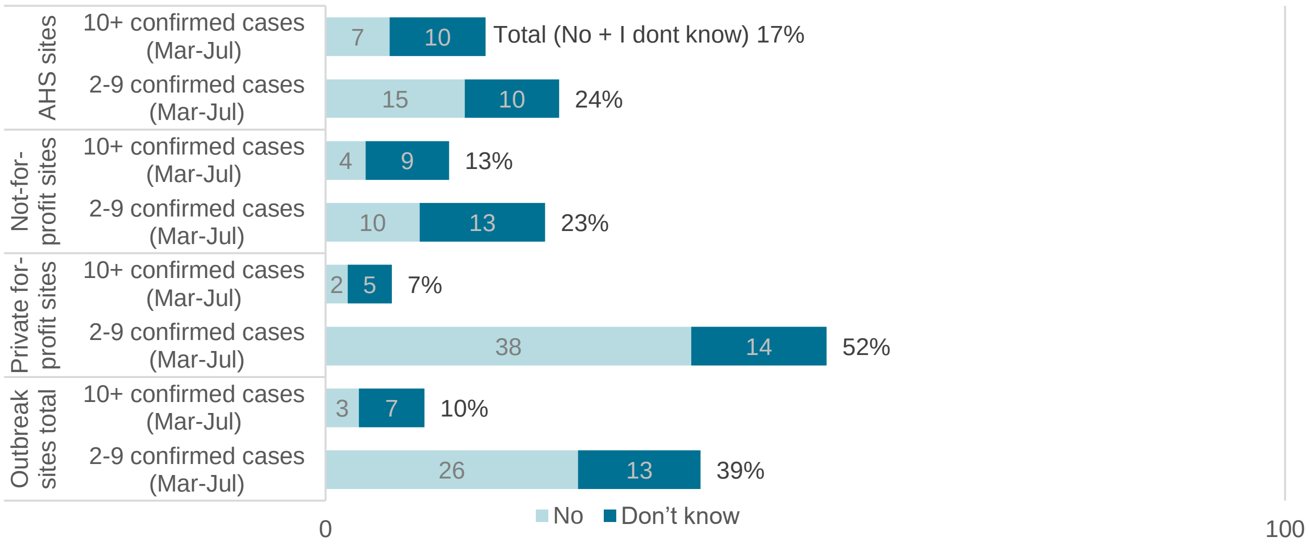
> *"Management of [the site] did communicate relatively openly with families, although once the case in a resident was confirmed (and passed away), this was learned from the news and from friends rather than directly from [the site]."*

Public health orders[17] as early as mid-April 2020 required operators to disclose to family members, residents, and staff about a probable or confirmed COVID-19 outbreak, but did not specify the content of the information to be disclosed, other than the outbreak status.

The survey asked family members about the outbreak status of their site. Among sites who had an outbreak during the survey period (i.e., two or more confirmed cases between March 20 and July 30), **29% of family members reported there was no outbreak or they did not know about an outbreak at the site.** Furthermore, the degree of the outbreak was found to be a contributing factor to family member awareness, in that **10% of family members did not know of an outbreak** at a site when there were 10 or more cases, compared to **39% among sites who had two to nine cases**.

There were also provider type differences found in outbreak awareness when there were less than 10 cases, with **51% of family members unaware or unsure** of a site's outbreak status among privately owned sites, compared to **24% and 23% among AHS and not-for-profit sites**.

It's important to note that differences between sites and/or types of sites in how they communicate outbreak status may vary for different reasons, including their resourcing capacity to effectively communicate information, and the terminology used by sites to convey outbreak status.



Has an outbreak ever occured at your site?
"No" + "Dont know" responses

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[17] CMOH Order 10-2020

3.5 Concerns about safety and adherence to protocols and guidelines

Family members rated their **confidence in sites preventing the spread of COVID-19** from 0 to 10, where 0 is the least confident, and 10 is the most confident. Family confidence ratings were:

8.8 out of 10 in preventing **visitors and designated support persons** from contracting COVID-19

8.9 among non-outbreak sites

8.6 among outbreak sites

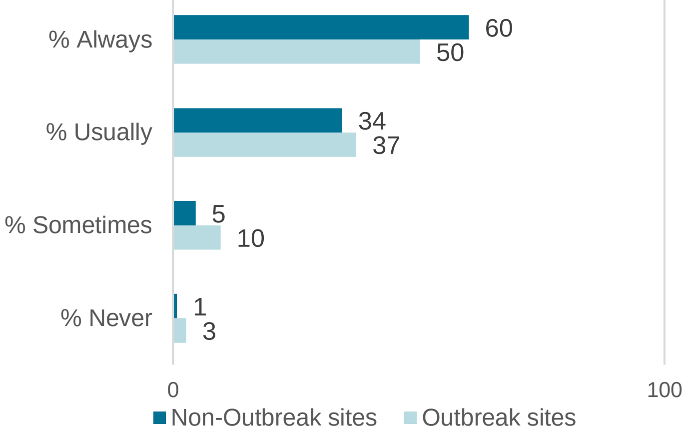
8.9 out of 10 in preventing **residents** from contracting COVID-19

9.0 among non-outbreak sites

8.6 among outbreak sites

Although survey results suggest that family members had confidence in sites preventing the spread of COVID-19 among residents, families, and designated support persons, the proportion of family members who felt their loved one was **always safe** at the site was only **58%.** This percentage differed between outbreak and non-outbreak sites, with **50% of families at outbreak sites** reporting they felt their loved one was **always** safe, whereas at **non-outbreak sites this percentage was 60%**.

How often did you feel your loved one was safe at the site?
(N = 8208)



Analysis of family member comments provide additional context, as family member' safety concerns not only included sites and site staff, but also resident and visitor adherence to protocols and guidelines.

Family members reported witnessing staff either not wearing masks, gloves, and gowns, wearing PPE inappropriately (e.g., masks worn around the chin or under the nose), and a lack of physical distancing. They also observed and experienced inconsistency with respect to isolation practices, the screening of visitors, the use of hand sanitizer by visitors, and variable enforcement of public health measures by staff while visiting loved ones. Observations about lack of adherence to safety protocols contributed to the worry that staff may also have a "relaxed attitude" about safety outside of work and introducing risk into the lives of their loved ones.

> *"Their PPE was locked in storage, staff and residents traveling throughout the building cross contaminating, there was inconsistent isolation practices for query COVID and influenza symptoms, staff went between rooms with no gowns on and masking was inconsistent."*

> *"I believe a lot of the challenges care residences faced came from the relaxed attitude and not being mindful of what staff members were doing outside of their work. Then coming to work and bring the virus into the care residences."*

> *"As the designated visitor, I completed the self-identification and my temperature was noted before our outside visit with [the resident]. I was accompanied by another family member to visit the resident and their information and temperature was not taken."*

Family members also had concerns about visitor and resident adherence to the guidelines. They described situations where residents and family members took off their masks or did not wear masks when they should have, touched one another, or broke physical distancing guidelines. They worried that lack of adherence to the protocols was putting their loved ones at risk and threatening their ability to visit. As such, family members suggested that sites more strongly enforce compliance or supervise visits when non-compliance was an issue. Family members also felt that residents needed more awareness and reminders about how the measures were intended to keep them safe.

> *"I know that it is very difficult to enforce masking requirements with visitors but I have noted more than a few visitors with masks worn incorrectly or who frequently remove them when speaking with loved ones."*

> *"My family members and I were never made aware that residents were allowed to go to nearby stores and be out in public, while we were still social distancing outside wearing masks. I am aware that [the site] can't restrict residents, but as a family we were worried about possible exposure of our resident which could have ended up affecting all other residents and our family as well."*

> *"While I see the general [the site] operations functioning with fairly stringent and good precautions which are working (thank you), it seems the residents themselves are not reminded of the necessity for social distancing. As they are elderly, it could be they do not understand, do not remember or do not care to keep each other safe. Residents are often clustered together or chatting in very close proximity with those who are dining, or near the front entrance. If the rule is two to a table, for instance, then two more should not be standing over them chatting. … This is especially worrisome now that the restrictions are lifting and the residents are leaving the building for appointments, etc. thereby being exposed to more opportunities for contamination."*

4.0 SITE CHARACTERISTICS

This section reviews the impact of site characteristics, such as level of care, geography, size, operator type, site age, and outbreak status, on the survey questions. Analyses were conducted at the respondent level, and all site characteristics were considered simultaneously in order to adjust for confounding effects. Family member characteristics of age, gender, and financial stability were also considered in the analysis.

4.1 Outbreak vs. Non-outbreak

A site was defined as under "outbreak" if it had two or more confirmed cases of COVID-19 between March and July 2020. Some differences in experiences and perceptions between outbreak and non-outbreak sites were found and include:

- Ratings of confidence in preventing the spread of COVID-19 among **visitors** were higher by family members in **non-outbreak sites** (8.9 out of 10) than **outbreak sites** (8.6 out of 10).
- Ratings of confidence in preventing the spread of COVID-19 among **residents** were higher by family members in **non-outbreak** sites (9.0 out of 10) than **outbreak sites** (8.6 out of 10).
- Ratings of **overall pandemic response** by the site were rated higher by family members among **non-outbreak** sites (8.8 out of 10) than **outbreak sites** (8.4 out of 10).
- The proportion of family members who **ALWAYS felt their loved one was safe** at the site were **higher among non-outbreak sites** (60%) compared to **outbreak sites** (50%).
- The proportion of family members who **ALWAYS trusted** that employees and staff were providing all of the needed care and services to their loved one was **higher among non-outbreak sites** (42%) compared to **outbreak sites** (37%).
- More family members at **outbreak sites** (24%) reported that their loved one shared a room with another resident, compared to **non-outbreak sites** (17%).
- The proportion of family members who felt their loved one ALWAYS looked and smelled clean was **higher among non-outbreak sites** (54%) compared to outbreak sites (47%).

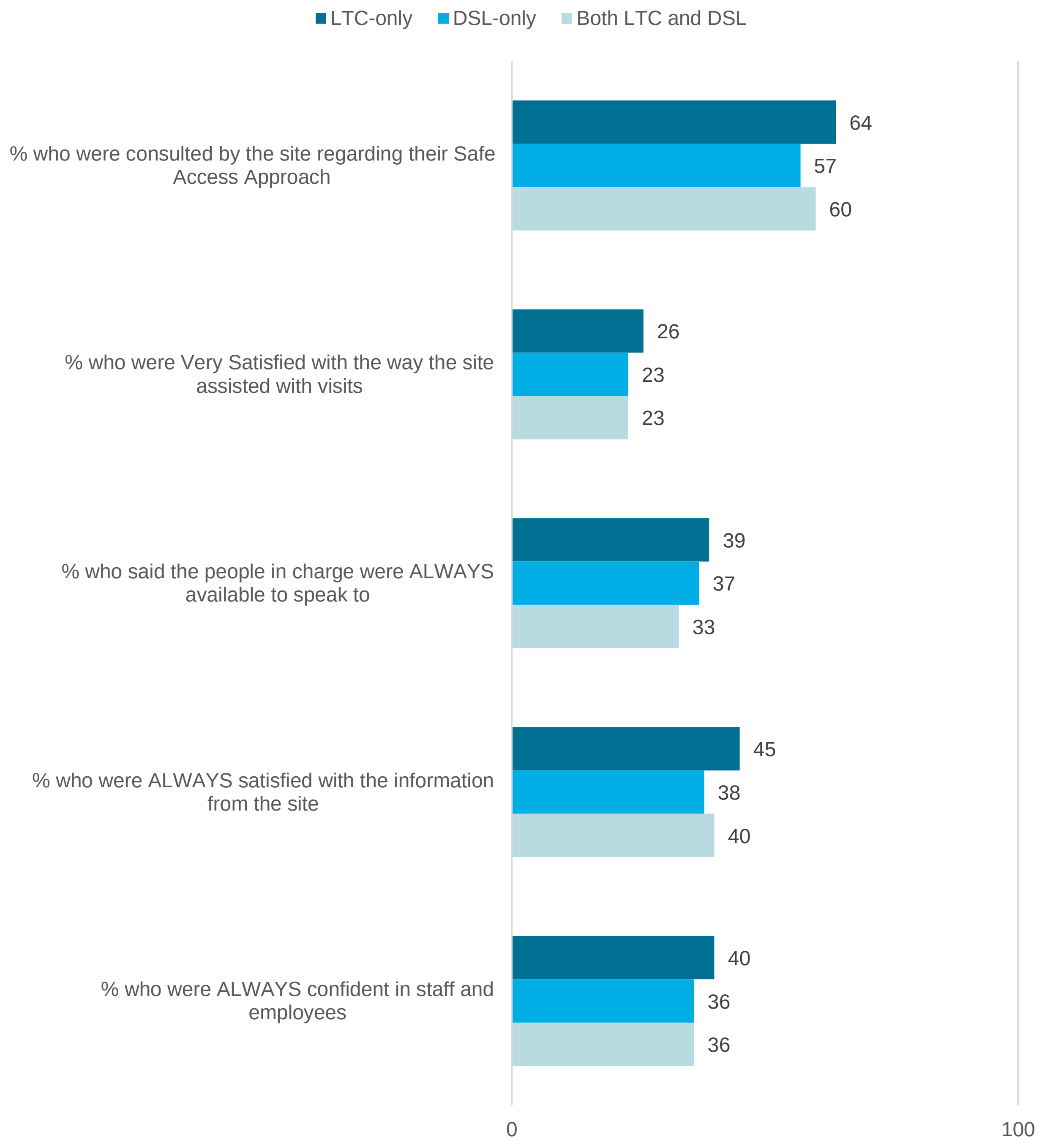
4.2 Geography: Urban versus rural

Geography, i.e., urban and rural location, was defined using the postal code of the site. Therefore, results reflect where the site was located; not the location of the family member respondent. In general, when considering other site factors such as site size and level of care, no significant differences were found between urban and rural sites.

4.3 Level of care

Responses from family members who have a loved one living in a LTC site, a DSL site, or a site with both LTC and DSL were compared. Generally, responses from family members with a loved one at a solely LTC site were more positive than responses from family members with a loved one at a DSL site.

Select results include:

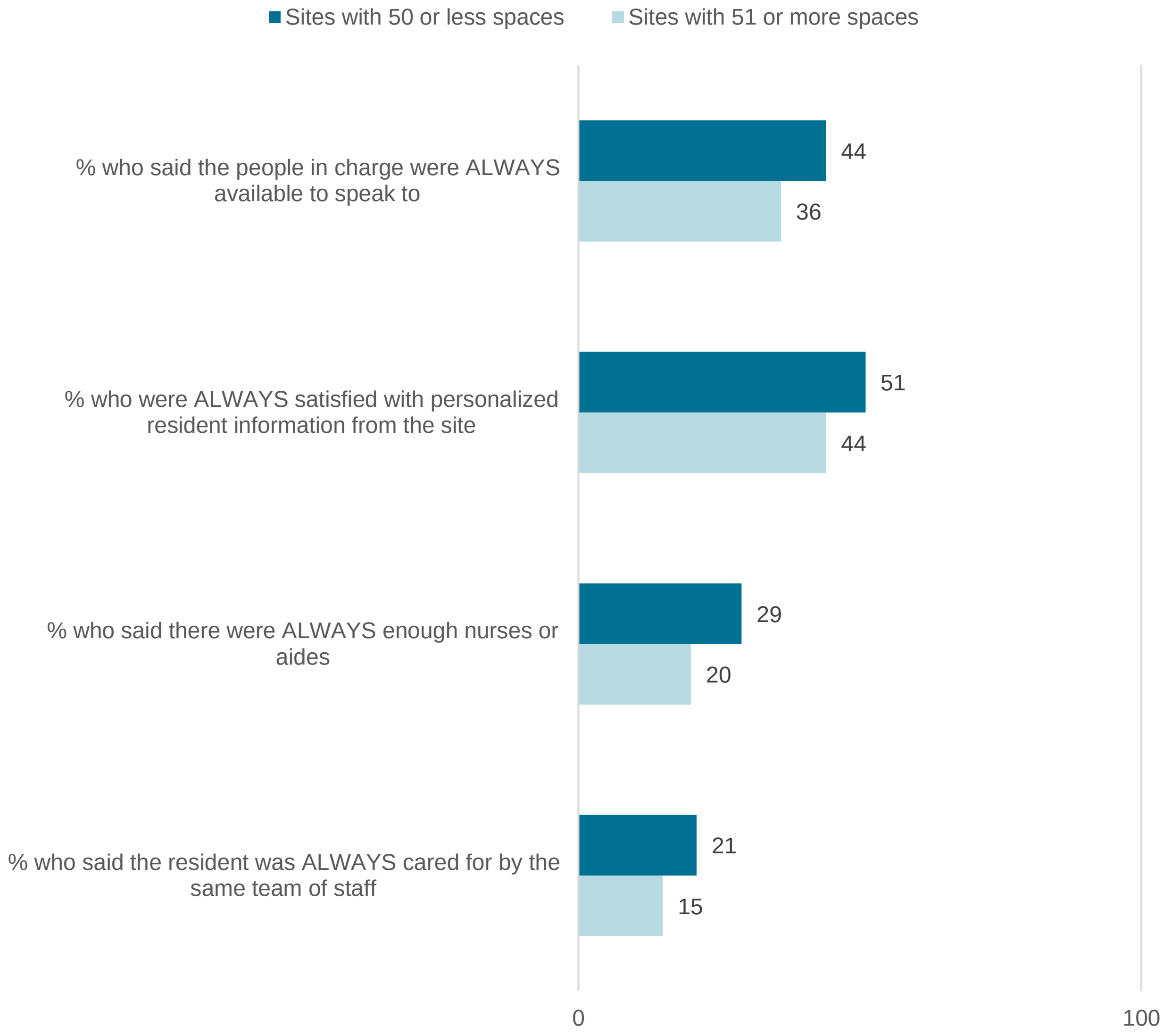


4.4 Site size: Number of spaces

Site size was defined as the number of beds or spaces at a particular site. Based on (1) current survey data, (2) knowledge of previous survey results conducted in continuing care, and (3) feedback from AHS, results were stratified in accordance to the binary category of small sites (50 or less spaces) vs. medium-to-large site (51 or more spaces).

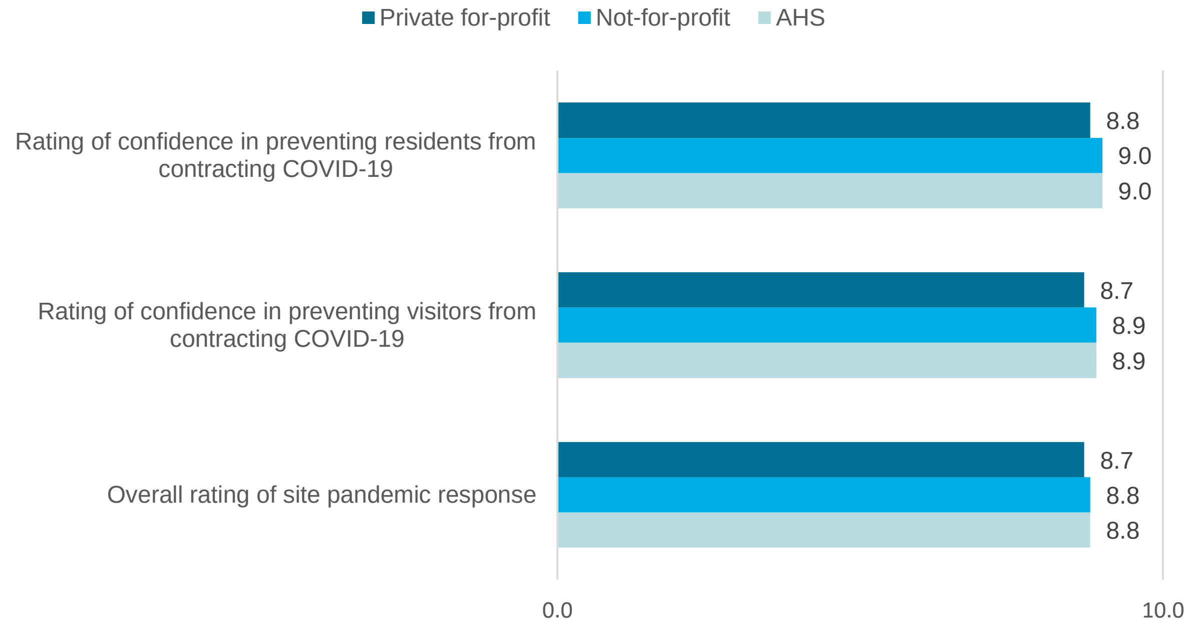
Generally, responses from family members with a loved one at a small site were more positive than responses from family members with a loved one at a medium-to-large. For example, when family members rated the site's overall response to the pandemic from 0 to 10, where zero is the worst and 10 is the best, family members who have a loved one in a small site rated the site's overall response to the pandemic at 8.9 out of 10, whereas those at a medium-to-large site rated the site response at 8.7 out of 10.

Other select results include:

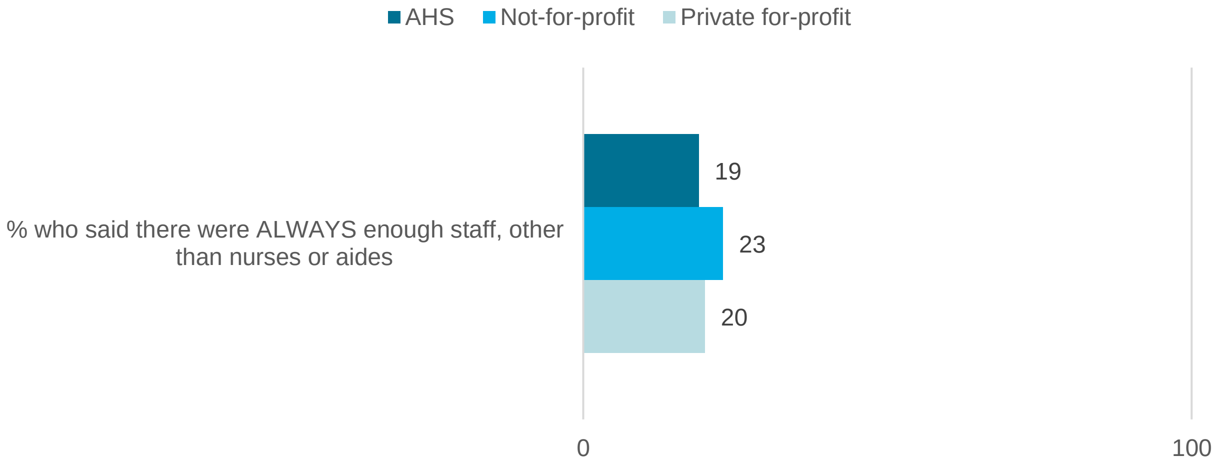


4.5 Operator type

Operator type was defined as whether the site was operated by AHS, a not-for-profit organization, or a private for-profit organization. Few differences were found between operator types, and include for example, questions about overall pandemic response and confidence in preventing infection spread. For these questions responses from family members at private sites had less positive ratings compared to AHS and/or not-for-profit sites.



When questions about perceived staffing levels of nurses and aides were considered, responses from family members at AHS sites had less positive responses compared to private sites and not-for-profit sites.



5.0 LIMITATIONS

In interpreting results, there are several important limitations to consider:

1. **The effect of email modality.** The survey was delivered to family members who have an email address and were able to respond to the survey online. Family members who did not have email and/or did not have access to the internet to complete the survey may be different and could have different perspectives from those that are able to complete the survey, and as a result their experiences may also be different.
2. **Limitations of open-ended comments.** Family members shared a wide variety of perspectives and opinions in their responses to the open-ended question at the end of the survey. However, a significant limitation is the inability to gain further information or clarify points identified by family members. It is also difficult, at times, to determine whether their suggestions are specific to the *Restricted Access* approach or *Safe Access* approach, given the length of time the survey was in the field.
3. **Survey topics.** Through the analysis of the survey and comments, we identified topics that were important to family members that were not covered in this survey that could be considered in a future version of the survey. For instance, an important topic that was not covered was cognitive impairment/dementia and family members' perceptions of risk and risk tolerance in this context.
4. **Other perspectives.** It is important to note that family experience is not the only source of information to assess performance, other quality measures such as those derived from the *Resident Assessment Instrument* (RAI), complaints and concerns, accreditation results, and *Continuing Care Health Service Standards* compliance should also be considered. In addition, the perspectives of site staff, and administrators could also provide important insights about family member and resident experiences.
5. **Reporting on in-person visits.** There were three questions in the survey that asked whether a respondent visited the site in-person and/or virtually that preceded sections of the survey. In some cases, reporting of whether a family member respondent visited in-person is inconsistent across these questions and sections.

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