



**LONG TERM CARE  
FAMILY EXPERIENCE  
SURVEY**

**Methodology**

October 2019



Promoting and improving patient safety and health service quality across Alberta

The Health Quality Council of Alberta is a provincial agency that pursues opportunities to improve patient safety and health service quality for Albertans. It gathers and analyzes information, monitors the healthcare system, and collaborates with Alberta Health, Alberta Health Services, health professions, academia, and other stakeholders to drive actionable improvements. Our responsibilities are set forth in the *Health Quality Council of Alberta Act*.

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## BACKGROUND

The Health Quality Council of Alberta (HQCA) is an independent organization legislated under the *Health Quality Council of Alberta Act*, with a mandate to survey Albertans on their experience and satisfaction with patient safety and health service quality.

Alberta's continuing care system provides Albertans of advanced age or disability with the healthcare, personal care, and accommodation services they need to support their daily activities, independence, and quality of life. There are three streams of continuing care in Alberta tailored to individuals' level of need and/or limitations: home care, supportive living, and facility living (Figure 1). The focus of this Methodology Report is long term care.

**Figure 1:** Three streams of the continuing care system

Three Streams of the Continuing Care System					
Home Care	Supportive Living				Facility Living
Independent Living (e.g., House, Apartment and Condominium)	A congregate setting that combines accommodation services with other supports and care				
	<b>Non-Designated Supportive Living</b> (e.g., Lodges, Group Homes and Congregate Settings)	<b>Designated Supportive Living (DSL)</b>  A congregate setting that provides additional support with on-site health care staff			<b>Long Term Care (LTC) Facility</b> (i.e., Nursing Homes and Auxiliary Hospitals)
Publicly funded health care is provided through the Home Care Program	Publicly funded health care is provided through the Home Care Program	<b>DSL- 3</b>	<b>DSL- 4</b>	<b>DSL 4-Dementia</b>	24-hour on-site health care services provided by a diverse mix of health care professionals** and health care staff
		24-hour on-site care provided by health care staff*	24-hour on-site care provided by health care staff*	24-hour on-site care provided by health care staff* in a therapeutic environment	

Figure courtesy of Alberta Health.

\*Health care staff in DSL 3, 4 and 4D may include Health Care Aides, Therapy Assistants and Licensed Practical Nurses.

\*\*Health care professionals in LTC may include Registered Nurses, Licensed Practical Nurses, Health Care Aides, Occupational and Physical Therapists and Physicians.

Long term care facilities (sometimes referred to as nursing homes, auxiliary hospitals, or continuing care facilities) are available for people who are not able to safely cope in their own home or in a lower level living option with or without formal support. These individuals are assessed to have complex and/or unpredictable medical needs that are cared for under the direction of a family physician, 24-hour on-site registered nurses who supervise care with support from licensed practical nurses, healthcare aides, and other healthcare providers.

## FAMILY EXPERIENCE

### The Long term care Family Experience Survey

Feedback from family members about the quality of care and services that residents received at long term care facilities across Alberta was collected using the *Long term care Family Experience Survey* in collaboration with Alberta Health Services (AHS) and Alberta Health (AH). Survey results are used to describe the current state of long term care from the family members' perspective and to provide facilities and other stakeholders with information that can be used for ongoing monitoring and quality improvement.

The main body of questions in the *Long term care Family Experience Survey* was adapted from the CAHPS® *Nursing Home Survey: Family Member Instrument*. This survey is a 64-question self-reported assessment that assesses a family member's overall experience (i.e., Global Overall Care Rating) with the facility and was used with the permission of the Agency for Healthcare Research and Quality.

The questionnaire was delivered to, and answered by, family members (respondents).

The CAHPS® survey consist of four subscales (i.e., Dimensions of Care) that contain multiple questions on a similar theme:

1. Staffing, Care of Belongings, and Environment
2. Kindness and Respect
3. Providing Information and Encouraging Family Involvement
4. Meeting Basic Needs

Survey questions, within each subscale, were followed by a two-option *Yes or No* response or a four-option response: Always, Usually, Sometimes, and Never.

Questions that addressed the following topics were also included in the CAHPS® survey:

- Improvement suggestions for the care and services provided at the long term care facility (open-ended question).
- Family member rating of food (Food Rating Scale).
- Willingness to recommend the long term care facility (Propensity to Recommend).
- Medications.
- Resident and respondent (family member) characteristics.
  - Some questions from the CAHPS® survey were removed, modified, or added to improve their relevance in an Alberta context or to meet the information needs of stakeholders.

## SURVEY SAMPLING DESIGN, RECRUITMENT, AND (FAMILY MEMBER) RESPONSENT INCLUSION/EXCLUSION CRITERIA

The survey was conducted as a census approach of all eligible participants for whom contact data was available. Given the small size of long term care facilities, random sampling techniques were not required and would have added little value at the expense of increased complexity for a few larger facilities where random selection might have been justified.

Eligible respondents (family members) were identified with assistance from a liaison at each long term care facility. Liaisons were asked to provide contact information of the most involved family member or person of a resident. Exclusion criteria included:

- Contacts of new (< 1 month) or transitional residents.
- Residents who had no contact person (family member), or whose contact person resided outside of Canada.
- Contacts of deceased residents or residents no longer living at the facility.
- Contacts of residents who were listed as a public guardian (i.e., non-family member or friend).

Family members of residents who were deceased subsequent to survey rollout were given the option to complete the survey and to provide responses that reflected the last six months the resident resided in the facility.

The following three-stage mailing protocol was used to ensure maximum participation rates:

- Initial mailing of questionnaire packages.
- Postcard reminders to all non-respondents.
- Re-mailing of the questionnaire package with a modified cover letter to all non-respondents.

## REPORTING OF FACILITY-LEVEL RESULTS

To maximize the reliability of facility-level results and to maintain respondent anonymity, data from an individual facility was included in facility-level analyses only if:

- The facility yielded five or more respondents **AND**
- The facility response margin of error was equal to or less than 10 per cent and/or the facility had a response rate of over 50 per cent among eligible respondents.

## COMPARISON GROUPS

Three comparison groups are used to organize experience survey results on the FOCUS on Healthcare website. These include: site size<sup>1</sup>, geography, and operator type. These comparison groups are defined as follows.

### Zone

AHS is organized into five geographic zones (i.e., South, Calgary, Central, Edmonton, and North), with each site located in one of these zones. Survey results on the FOCUS on Healthcare website are organized using zone as a comparator group.

### Site size

Site size was measured by the number of long term care beds at each facility.<sup>2</sup> This data was collected from AHS at the time of survey rollout. Survey results on the FOCUS on Healthcare website are organized using the following categories of site size:

- **Less than 25,**
- **25 to 50,**
- **51 to 100, and**
- **101 or more.**

### Geography

Geography was based on the site's postal code, and is defined as:

- **Urban areas:** Includes the cities of Calgary and Edmonton proper and surrounding commuter communities, and other major urban centres with populations greater than 25,000 and their surrounding commuter communities.
- **Rural areas:** Includes populations less than 25,000 and/or greater than 200 kilometres away from an urban centre.

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<sup>1</sup> The HQCA's *Long term care Family Experience Survey* uses the term facility to describe this type of continuing care accommodation. Through the stakeholder engagement work done to develop FOCUS on Long term Care, it was decided to use the word site to describe this living environment, which was preferred by residents, family members, and those working in long term care.

<sup>2</sup> Data was obtained from AHS's bi-annual bed survey. In total, 146 facilities were included in the HQCA's analysis and ranged in bed numbers from 10 to 252.

## Operator type

Operator type was based on the four categories or models of care providers that AHS uses to classify facilities. These include:

- **AHS (public):** a site that is operated by or wholly owned subsidiary of AHS.
- **Private:** a site that is operated by a private for-profit organization.
- **Non-Alberta regional health authority (RHA):** a site that is present in a RHA outside of Alberta, such as Saskatchewan Health Authority.
- **Not-for-profit:** a site is operated by a not-for-profit or faith-based organization.

Other ownership models may exist (for example, private not-for-profit housing bodies), but the AHS categories and definitions were used for reporting.

## APPENDICES



## THE RESIDENT

**1. The resident of the nursing home and the person named on the cover letter is your...?**

- <sup>1</sup> ☐ Spouse/Partner
- <sup>2</sup> ☐ Parent
- <sup>3</sup> ☐ Mother-in-law / Father-in-law
- <sup>4</sup> ☐ Grandparent
- <sup>5</sup> ☐ Aunt / Uncle
- <sup>6</sup> ☐ Sister / Brother
- <sup>7</sup> ☐ Child
- <sup>8</sup> ☐ Friend
- <sup>9</sup> ☐ Other (specify) \_\_\_\_\_

**For this survey, the phrase "family member" refers to the resident named in the cover letter.**

**2. Is your family member now living in the nursing home listed in the cover letter?**

- <sup>1</sup> ☐ Yes → if Yes, go to question 4
- <sup>2</sup> ☐ No

**3. Was your family member discharged from this facility, moved to another facility or are they deceased?**

- <sup>1</sup> ☐ Discharged      If your family member was discharged or moved to another home please stop and return this survey in the postage-paid envelope.
- <sup>2</sup> ☐ Moved to another facility

- <sup>3</sup> ☐ Deceased      If your family member is deceased, our condolences. We understand that you may not want to fill out a survey at this time. Please check the box indicating that your family member is deceased and return the survey in the enclosed envelope. If you would like to do the rest of the survey, we would be very grateful for your feedback. Please answer the questions about your family member's **last six months** at the nursing home. Thank you for your help.

**4. Do you expect your family member to permanently live in this nursing home?**

- <sup>1</sup> ☐ Yes
- <sup>2</sup> ☐ No
- <sup>3</sup> ☐ Don't know

**5. In the last 6 months, has your family member ever shared a room with another person at this nursing home?**

- <sup>1</sup> ☐ Yes
- <sup>2</sup> ☐ No

**6. In the last 6 months, how often was your family member capable of making decisions about his or her own daily life, such as when to get up, what clothes to wear, and which activities to do?**

- <sup>1</sup> ☐ Never
- <sup>2</sup> ☐ Sometimes
- <sup>3</sup> ☐ Usually
- <sup>4</sup> ☐ Always

## YOUR VISITS

**Please answer the following questions for only yourself. Do not include the experiences of other family members.**

**7. In the last 6 months, about how many times did you visit your family member in the nursing home?**

- <sup>1</sup> ☐ 0 - 1 times in the last 6 months → **go to question 59 on page 7**
- <sup>2</sup> ☐ 2 - 5 times in the last 6 months
- <sup>3</sup> ☐ 6 - 10 times in the last 6 months
- <sup>4</sup> ☐ 11 - 20 times in the last 6 months
- <sup>5</sup> ☐ More than 20 times in the last 6 months

**8. In the last 6 months, during any of your visits, did you try to find a nurse or aide for any reason?**

- <sup>1</sup> ☐ Yes
- <sup>2</sup> ☐ No → if No, go to question 10

**9. In the last 6 months, how often were you able to find a nurse or aide when you wanted one?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**10. In the last 6 months, how often did you see the nurses and aides treat your family member with courtesy and respect?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**11. In the last 6 months, how often did you see the nurses and aides treat your family member with kindness?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**12. In the last 6 months, how often did you feel that the nurses and aides really cared about your family member?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**13. In the last 6 months, did you ever see any nurses or aides be rude to your family member or any other resident?**

- 1 ☐ Yes  
2 ☐ No

**14. In the last 6 months, during any of your visits, did you help your family member with eating?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 16

**15. Did you help your family member with eating because the nurses or aides either didn't help or made him or her wait too long?**

- 1 ☐ Yes  
2 ☐ No

**16. In the last 6 months, during any of your visits, did you help your family member with drinking?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 18

**17. Did you help your family member with drinking because the nurses or aides either didn't help or made him or her wait too long?**

- 1 ☐ Yes  
2 ☐ No

**18. "Help toileting" means helping someone get on and off the toilet, or helping to change disposable briefs or pads.**

**In the last 6 months, during any of your visits to the nursing home, did you help your family member with toileting?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 20

**19. Did you help your family member with toileting because the nurses or aides either didn't help or made him or her wait too long?**

- 1 ☐ Yes  
2 ☐ No

**20. In the last 6 months, how often did your family member look and smell clean?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**21. Sometimes residents make it hard for nurses and aides to provide care by doing things like yelling, pushing or hitting. In the last 6 months, did you see any resident, including your family member, behave in a way that made it hard for nurses or aides to provide care?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 23

**22. In the last 6 months, how often did the nurses and aides handle this situation in a way that you felt was appropriate?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

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**YOUR EXPERIENCE WITH  
NURSES AND AIDES**

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**23. In the last 6 months, how often did the nurses and aides treat you with courtesy and respect?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**24. In the last 6 months, did you want to get information about your family member from a nurse or an aide?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 26

**25. In the last 6 months, how often did you get this information as soon as you wanted?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**26. In the last 6 months, how often did the nurses and aides explain things in a way that was easy for you to understand?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**27. In the last 6 months, did the nurses and aides ever try to discourage you from asking questions about your family member?**

- 1 ☐ Yes  
2 ☐ No

**28. In the last 6 months, how often is your family member cared for by the same team of nurses and aides?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**29. In the last 6 months, how often did you feel confident that nurses and aides knew how to do their jobs?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

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**THE NURSING HOME**

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**30. In the last 6 months, how often did your family member's room look and smell clean?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**31. In the last 6 months, how often were you able to find places to talk to your family member in private?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**32. In the last 6 months, how often did the public areas of the nursing home look and smell clean?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**33. In the last 6 months, did you ever see the nurses and aides fail to protect any resident's privacy while the resident was dressing, showering, bathing, or in a public area?**

- 1 ☐ Yes  
2 ☐ No

**34. Personal medical belongings are things like hearing aids, eye-glasses, and dentures. In the last 6 months, how often were your family member's personal medical belongings damaged or lost?**

- 1 ☐ Never  
2 ☐ Once  
3 ☐ Two or more times

**35. In the last 6 months, did your family member use the nursing home's laundry services for his or her clothes?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 37

**36. In the last 6 months, when your family member used the laundry service, how often were clothes damaged or lost?**

- 1 ☐ Never  
2 ☐ Once or twice  
3 ☐ Three times or more

**37. At any time in the last 6 months, were you ever unhappy with the care your family member received at the nursing home?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 41

**38. In the last 6 months, did you talk to any nursing home staff about this concern?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 40

**39. In the last 6 months, how often were you satisfied with the way the nursing home staff handled these concerns?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**40. In the last 6 months, did you ever stop yourself from talking to any nursing home staff about your concerns because you thought they would take it out on your family member?**

- 1 ☐ Yes  
2 ☐ No

#### **CARE OF YOUR FAMILY MEMBER**

**41. In the last 6 months, have you been involved in decisions about your family member's care?**

- 1 ☐ Yes  
2 ☐ No → if No, go to question 43

**42. In the last 6 months, how often were you involved as much as you wanted to be in the decisions about your family member's care?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**43. A care conference is a formal meeting about care planning and health progress between a care team and a resident and his or her family.**

**In the last 12 months, have you been part of a care conference, either in person or by phone?**

- 1 ☐ Yes → if Yes, go to question 45  
2 ☐ No

**44. Were you given the opportunity to be part of a care conference in the last 12 months either in person or by phone?**

- 1 ☐ Yes  
2 ☐ No

#### OVERALL RATINGS

**45. Using any number from 0 to 10 where 0 is the worst care possible and 10 is the best care possible, what number would you use to rate the care at the nursing home?**

- 1 ☐ 0 Worst Care Possible  
2 ☐ 1  
3 ☐ 2  
4 ☐ 3  
5 ☐ 4  
6 ☐ 5  
7 ☐ 6  
8 ☐ 7  
9 ☐ 8  
10 ☐ 9  
11 ☐ 10 Best Care Possible

**46. If someone needed nursing home care, would you recommend this nursing home to them?**

- 1 ☐ Probably no  
2 ☐ Definitely no  
3 ☐ Probably yes  
4 ☐ Definitely yes

**47. In the last 6 months, how often did you feel that there were enough nurses and aides in the nursing home?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

#### OTHER ISSUES

**Please remember the questions in this survey are about your experiences. Do not include the experiences of other family members.**

**48. In the last 6 months, how often did you feel like your family member is safe at the facility?**

- 1 ☐ Never  
2 ☐ Sometimes  
3 ☐ Usually  
4 ☐ Always

**49. In the last 6 months, did you help with the care of your family member when you visited because nurses or aides either didn't help or made him or her wait too long?**

- 1 ☐ Yes  
2 ☐ No

**50. Using any number from 0 to 10 where 0 is the worst food possible and 10 is the best food possible, what number would you use to rate the food at this nursing home?**

- 1 ☐ 0 Worst Food Possible  
 2 ☐ 1  
 3 ☐ 2  
 4 ☐ 3  
 5 ☐ 4  
 6 ☐ 5  
 7 ☐ 6  
 8 ☐ 7  
 9 ☐ 8  
 10 ☐ 9  
 11 ☐ 10 Best Food Possible

**51. In the last 6 months, how often did your family member receive all of the healthcare services and treatments they needed?**

- 1 ☐ Never  
 2 ☐ Sometimes  
 3 ☐ Usually  
 4 ☐ Always

**52. In the last 6 months, how often did you have concerns about your family member's medication?**

- 1 ☐ Never → if Never, go to question 55  
 2 ☐ Sometimes  
 3 ☐ Usually  
 4 ☐ Always

**53. Did you talk with any nursing home staff about these medication concerns?**

- 1 ☐ Yes  
 2 ☐ No → if No, go to question 55

**54. In the last 6 months, how often were your concerns about your family member's medication resolved?**

- 1 ☐ Never  
 2 ☐ Sometimes  
 3 ☐ Usually  
 4 ☐ Always

**55. In the last 6 months, did you ask the nursing home for information about payments or expenses?**

- 1 ☐ Yes  
 2 ☐ No → if No, go to question 57

**56. In the last 6 months, how often did you get all the information you wanted about payments or expenses?**

- 1 ☐ Never  
 2 ☐ Sometimes  
 3 ☐ Usually  
 4 ☐ Always

**57. A resident and family council is a group of residents or family from the same nursing home that meets on a regular basis to improve the quality of life of residents and to identify and address concerns.**

**Does your family member's facility have a resident and family council?**

- 1 ☐ Yes  
 2 ☐ No  
 3 ☐ I don't know

**58. In the last 6 months, how often were the people in charge available to talk with you? (Such as managers, supervisors, administration)**

- 1 ☐ Never  
 2 ☐ Sometimes  
 3 ☐ Usually  
 4 ☐ Always  
 5 ☐ I did not need this

## YOU AND YOUR ROLE

### 59. What is your age?

- ☐ 18 to 24  
☐ 25 to 34  
☐ 35 to 44  
☐ 45 to 54  
☐ 55 to 64  
☐ 65 to 74  
☐ 75 or older

### 60. Are you male or female?

- ☐ Male  
☐ Female

### 61. What is the highest grade or level of school that you have completed?

- ☐ Grade school or some high school  
☐ Completed high school  
☐ Post-secondary technical school  
☐ Some university or college  
☐ Completed college diploma  
☐ Completed university degree  
☐ Postgrad degree (Master's or Ph.D.)

### 62. What language do you mainly speak at home?

- ☐ English  
☐ French  
☐ Other

### 63. Considering all of the people who visit your family member in the nursing home, are you the person who has the most experience with his/her care?

- ☐ Yes  
☐ No  
☐ Don't know

### 64. Do you have any suggestions how care and services at this nursing home could be improved? If so, please explain. (Feel free to attach additional pages).

***Thank you for completing this survey.  
Your opinions are important to us.***

***Please return the completed survey  
in the postage-paid envelope.***

If you have a concern about the care and services your family member is receiving, please see next page for further instructions.

If you have a concern about the care and services your family member is receiving at your facility you should contact your facility manager directly.

Or you can contact the Alberta Health Services Patient Relations Department at

Phone: 1-855-550-2555, Fax: 1-877-871-4340,

Mail: Patient Concerns Officer and Executive Director, Patient Relations. Suite 300, North Tower  
Seventh Street Plaza, 10030-107th Street, Edmonton Alberta T5J 3E4 or

On-line: <https://www.albertahealthservices.ca/about/Page12832.aspx>

If you would like the HQCA to submit your concern to Alberta Health Services (AHS) on your behalf,

please check here →

☐ 1

Please note that if you check the box above the HQCA will share with AHS 1) your name, 2) your family member's name and facility, and 3) your written concern as you have written below, in order for AHS to respond to your concern.

**However, all other survey responses will remain confidential.**

Please write down your concern in the box below. Only information recorded in the box below will be forwarded to AHS.





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