A·C·C·E·S
Alberta Continuing Care
Epidemiological Studies

DESIGNATED ASSISTED LIVING (DAL) AND LONG-TERM CARE (LTC) IN ALBERTA:

ALBERTA CONTINUING CARE EPIDEMIOLOGICAL STUDIES (ACCES) METHODOLOGY

June 2011

Prepared by:
Deanna Wanless, Laurel A. Strain, & Colleen J. Maxwell
On behalf of the ACCES Research Group

DESIGNATED ASSISTED LIVING (DAL) AND LONG-TERM CARE (LTC) IN ALBERTA:

SELECTED HIGHLIGHTS FROM THE ALBERTA CONTINUING CARE EPIDEMIOLOGICAL STUDIES (ACCES)

Deanna Wanless, MA
ACCES Study Coordinator

Laurel A. Strain, PhD
ACCES Co-Principal Investigator
Professor
Department of Sociology
University of Alberta

Colleen J. Maxwell, PhD
ACCES Co-Principal Investigator
Professor
Department of Community Health Sciences
University of Calgary

Wanless, D., Strain, L.A., & Maxwell, C.J. (2011). *Designated Assisted Living (DAL) and Long-term Care (LTC) in Alberta: Alberta Continuing Care Epidemiological Studies (ACCES) Methodology*. Edmonton, AB: ACCES Research Group, University of Alberta.

This report is also available in PDF format.

For further information about the ACCES methodology, contact Dr. Laurel Strain at lstrain@ualberta.ca or call 780-492-2214 or Dr. Colleen Maxwell at maxwell@ucalgary.ca.

EXECUTIVE SUMMARY

The **Alberta Continuing Care Epidemiological Studies (ACCES)** program focused on designated assisted/supportive living (referred to as DAL) and long-term care (LTC) in Alberta.[1] This **methodology report** provides information regarding ACCES facilities, residents and family caregivers, with particular attention to sample selection and data collection methods.[2]

ACCES was a **large-scale longitudinal study** that relied on numerous data sources (Table 1). From 2006-2009, comprehensive **baseline** and **1-year follow-up assessments** were conducted with **1089 residents** in **59 DAL facilities** and **1000 residents** in **54 LTC facilities** across Alberta. Data were also collected from **family/friend caregivers** and **facility representatives**.

TABLE 1. ACCES STUDY COMPONENTS AND SAMPLE SIZES

	Sample Size		
Study Component	**DAL**	**LTC**	**TOTAL**
ACCES Facilities			
Facility Surveys with Administrators	59	54	**113**
ACCES Residents			
Baseline Resident Assessments	1089	1000	**2089**
1-Year Follow-up Resident Assessments	892	691	**1583**
Baseline Views of Residents Survey	704	N/A	**704**
1-Year Follow-up Views of Residents Survey	464	N/A	**464**
ACCES Family Caregivers			
Baseline Family Caregiver Interviews	974	917	**1891**
1-Year Follow-up Family Caregiver Interviews	791	609	**1400**
Discharge Interviews with Family Caregivers	199	38	**237**
Decedent Interviews with Family Caregivers	148	273	**421**

Ethical approval was obtained from the University of Calgary Conjoint Health Research Ethics Board, the University of Alberta Health Research Ethics Board – Panel B, and the University of Lethbridge Human Subject Research Committee. Administrative approvals from the health regions and/or facilities were also obtained.

---

[1] At the time of the study, designated spaces in Alberta were referred to as designated supportive living (DSL), designated supportive housing (DSH), enhanced lodge (EL), designated assisted living (DAL) and enhanced designated assisted living (E-DAL). The term 'DAL' is used in this study to incorporate all these types of spaces.

[2] For selected study findings, see *Designated Assisted Living (DAL) and Long-term Care (LTC) in Alberta: Selected Highlights from the Alberta Continuing Care Epidemiological Studies (ACCES)* (Strain, Maxwell, Wanless & Gilbart, 2011).

DAL and LTC Facilities

- ACCES began with the selection of DAL and LTC facilities. A DAL/LTC facility was **eligible** for consideration in ACCES if:
  - it had been in operation for at least 6 months;
  - there were four or more residents aged 65 years or older in smaller facilities and 10 or more in larger facilities; and,
  - it did not primarily serve clients with a mental illness or developmental disability.

- 60 DAL facilities across 5 of the former Alberta health regions met the eligibility criteria. One facility refused participation. The remaining **59 DAL facilities** were involved in ACCES.

- Given the larger number of LTC facilities in Alberta, it was not possible to include all LTC facilities that met the eligibility criteria. Within each region, facilities were divided in small versus large facilities based on the median bed size for the region. A random sample of facilities was then selected within each group for each region. A total of **54 LTC facilities** were involved in ACCES.

- A **facility survey** was completed in person or via telephone with a facility representative. This representative was the facility administrator, manager, or director of care who was familiar with the facility and had direct knowledge about the residents. Questions focused on location, ownership, type and size of the facility, admission and retention criteria, staffing, health and wellness services, hospitality services, the physical and social environment, fees, and issues/challenges facing DAL or LTC. Some questions were modeled on those used in a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000) while other questions were developed specifically for ACCES and the Canadian context.

DAL and LTC Residents

- A DAL or LTC resident was considered **eligible** for ACCES if s/he:
  - was 65 years of age or older;
  - had lived in the facility for at least 21 days;
  - was not a short-stay/temporary resident; and
  - was not currently palliative.

- All 1510 DAL residents who met the eligibility criteria were invited to participate in ACCES. **1089 DAL residents** were assessed at baseline (2006-2007), for a response rate of 72%. These individuals were followed over a 1-year period, with **892 DAL residents** assessed at follow-up. Residents who moved to a new setting such as LTC were assessed in that setting. If a resident died in the year following the baseline assessment and their family caregiver had been interviewed at baseline, attempts were made to briefly interview the caregiver again. Decedent interviews with family caregivers were completed for **148 DAL residents.** There were **199 DAL residents** who moved to another location and for whom a discharge interview was completed with the family caregiver.

- When ACCES began, there were 5785 residents in the 54 LTC facilities. A random sample of residents within each facility was selected. Of the 1731 eligible LTC residents randomly selected, assessments were completed with **1000 LTC residents** at baseline (2007-2008), for a response rate of 58%. 1-year follow-up assessments were conducted with **691 LTC residents**. Decedent interviews with family caregivers were completed for **273 LTC residents**. Discharge interviews with family caregivers were completed for **38 LTC residents**.

- Trained study nurses (RNs) administered the **Resident Assessment Instrument for Assisted Living (interRAI-AL)** with DAL residents and the **Resident Assessment Instrument for Long-term Care Facilities (interRAI-LTCF)** with LTC residents, at baseline and at follow-up. These comprehensive, standardized assessments provide information on the residents' sociodemographic characteristics, physical and cognitive status, health conditions, behavioural problems, social relationships, and use of medications and services. The interRAI tools draw on multiple sources of information including the resident, staff, family members, and chart reviews (for further information, see www.interrai.org). Guided by the assessment manual, the study assessors used their clinical judgement to determine the best source of information for each item. Many items are the same in the interRAI-AL and interRAI-LTCF tools although some are setting-specific. These tools are the most recent interRAI tools available; key domains are the same as those covered in the MDS 2.0 and RAI-Home Care tools.

- In conjunction with the interRAI assessment, a short **Views of Resident Survey** was conducted with the DAL residents only. This survey was a modified version of the Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAHPS) survey developed by the Agency for Healthcare Research and Quality (AHRQ) in the United States (Sangl et al., 2007; for further information on CAHPS, see www.cahps.ahrq.gov). In consultation with an ACCES decision-maker partner, only items deemed relevant to the DAL population were retained. At baseline, **704 DAL residents** completed the survey while **464 residents** did so at follow-up.

DAL and LTC Family Caregivers

- An attempt was made to complete an interview with a family/friend caregiver of each DAL and LTC resident in ACCES (referred to as family caregivers). A family member, friend, or volunteer was considered **eligible** for ACCES if s/he:
  - Was an informal/unpaid caregiver of a DAL or LTC resident in the ACCES cohort, and,
  - Was identified as the person most involved in the care and/or most informed about the resident.

- This individual was identified by the resident and/or the facility. If the resident had no one who met these eligibility requirements or if the resident requested that their caregiver not be contacted, an interview was not completed.

- In total, interviews were completed with **974 family caregivers of DAL residents** (90% response rate) and **917 family caregivers of LTC residents** (93% response rate) at baseline.

- Follow-up interviews were completed with **791 DAL caregivers** and **609 LTC caregivers**.

- The caregiver interview focused on assistance provided to the resident, the resident's health and use of services, the effects of caregiving on employment, caregiver burden, knowledge and views about the facility's services/policies, and costs related to care. Some questions were drawn from the Canadian/Manitoba Study of Health and Aging (C/MSHA) (MSHA Research Group, 1998) and from a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000) while other questions were selected/developed specifically for ACCES.

- As noted above, if a resident died during the 1-year period, their caregiver was asked to complete a short **decedent interview**. In addition, if a resident moved during the year, their caregivers were approached to complete a brief **discharge interview about the move**.

Administrative Health Data

- Consent to access the residents' health service utilization data was obtained from 98% of the residents or their surrogate decision-makers.

- Data on inpatient hospitalizations, emergency room visits, and day procedures were obtained.

Overall, this report provides detailed information about the ACCES methodology. Further information is available upon request.

ACKNOWLEDGEMENTS

Numerous individuals have provided invaluable assistance to this research program. Residents, family caregivers, and facility staff willingly answered our many questions. The staff in the DAL and LTC facilities and Home Care/Supportive Living welcomed us and facilitated recruitment and data collection. Our study nurses collected a wealth of information in a timely manner with their thorough assessments and interviews and a number of research assistants were involved in the data entry and cleaning. Our study coordinators assisted in various aspects of the research, including the development of the data collection tools, recruitment, coordination of data collection and data entry, and interviewing participants. Our research associates have been involved in study design and data analysis. Our co-investigators and our decision-making partners provided important insight into issues related to DAL and LTC and identified important questions to be answered. Dr. Catherine Hawes and Dr. Charles Phillips who conducted a U.S. national study of assisted living generously shared their reports, tools and expertise with us and assisted in the first training session for our study nurses. The success of ACCES reflects the commitment of all these individuals to this initiative.

ACCES Research Group Members

Co-Principal Investigators:
Dr. Colleen Maxwell, University of Calgary
Dr. Laurel Strain, University of Alberta

Co-investigators:
Dr. Misha Eliasziw, University of Calgary
Dr. Brad Hagen, University of Lethbridge
Dr. David Hogan, University of Calgary
Dr. Jean Parboosingh, University of Calgary
Dr. Heidi Schmaltz, University of Calgary
Dr. Gary Teare, Health Quality Council of Saskatchewan
Dr. Walter Wodchis, University of Toronto
Dr. David Zimmerman, University of Wisconsin

Partner organizations involved in initial application:
Alberta Health & Wellness
Alberta Seniors & Community Supports
Calgary Health Region
Capital Health
Chinook Health Region
David Thompson Health Region
East Central Health Region
The CAPITAL CARE Group
The Good Samaritan Society

Study Coordinators:
Anna Charlton
Allyson Link
Cheri Komar
Deanna Wanless

Research Associates:
Dr. Joseph Amuah
Elizabeth Freiheit
Dr. Erin Gilbart
Shannon Otsuka
Andrea Soo
Tyler Williamson

Research Assistants:

Kendra Bradford
Kim Chapman
Nicole Dalmer
Allison Dolan
Elisabeth Gallant
Bethany Huybregts
Laura MacKinnon
Anna Urban

Study Nurses:

Elsie Bargen
Rose Bateman
Joanne Berg
Elsie Bulva
Patti Child
Linda Derkach
Katy Edmundson
Marlene Gerig
Nancy Giles
Donna Gravistin
Jeanette Hallgren
Dollie Hendrickson
Sharon Hirsche
Peggy Hudson
Vivian Hughes
Sally Jones
Heather Kennedy
Kathy Kirkwood
Sue Kyllo
Melody Lenz
Annette Malan
Monica O'Gorman
Christine Osborne
JoAnne Plested
Kathy Rasmussen
Dawn Robinson
Carol Salisny
Gail Sinclair
Vicky Smith
Yvonne Spornitz
Rita Talen
Kim Tomlin
Marlyn Wall
Myrna Wallis
Margaret Woolley
Kendy Zsombor

Funding was provided through grants from Alberta Innovates: Health Solutions (Alberta Heritage Foundation for Medical Research #200400893) (PIs: Maxwell and Strain); the Canadian Institutes of Health Research's Institute of Aging and the Rural and Northern Health Research Initiative (HAS-63179) (PI: Strain); the Canadian Institutes of Health Research (MOP 81216) (PI: Maxwell); and Alberta Health Services and Alberta Seniors and Community Supports as part of the Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities (PI: Maxwell). The support of all sources is gratefully acknowledged. The results and conclusions are those of the authors and no official endorsement from the funding agencies is intended or should be inferred.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

INTRODUCTION

The **Alberta Continuing Care Epidemiological Studies (ACCES)** program focused on designated assisted/supportive living (referred to as DAL) and long-term care (LTC) in Alberta.[3] The objectives of ACCES were:

(1) to examine the health, social needs, and quality of care of older adults living in DAL and LTC facilities in Alberta;
(2) to identify the mix of services provided to these residents, including assistance from family caregivers; and,
(3) to examine health outcomes across settings, taking resident and facility characteristics into account.

This methodology report provides information regarding ACCES facilities, residents and family caregivers.[4] Attention is given to sample selection and data collection methods used in the study.

Study Components and Sample Sizes

ACCES was a large-scale longitudinal study that relied on numerous data sources (Table 2). Between 2006 and 2009, comprehensive baseline and 1-year follow-up assessments were conducted with 1089 residents of 59 DAL facilities and 1000 residents in 54 LTC facilities across Alberta. Data also were collected from family/friend caregivers and facility representatives.

TABLE 2. ACCES STUDY COMPONENTS AND SAMPLE SIZES

	Sample Size		
Study Component	**DAL**	**LTC**	**TOTAL**
ACCES Facilities			
Facility Surveys with Administrators	59	54	**113**
ACCES Residents			
Baseline Resident Assessments	1089	1000	**2089**
1-Year Follow-up Resident Assessments	892	691	**1583**
Baseline Views of Residents Survey	704	N/A	**704**
1-Year Follow-up Views of Residents Survey	464	N/A	**464**
ACCES Family Caregivers			
Baseline Family Caregiver Interviews	974	917	**1891**
1-Year Follow-up Family Caregiver Interviews	791	609	**1400**
Discharge Interviews with Family Caregivers	199	38	**237**
Decedent Interviews with Family Caregivers	148	273	**421**

---

[3] At the time of the study, designated spaces in Alberta were referred to as designated supportive living (DSL), designated supportive housing (DSH), enhanced lodge (EL), designated assisted living (DAL) and enhanced designated assisted living (E-DAL). The term 'DAL' is used in this study to incorporate all these types of spaces.

[4] For selected study findings, see *Designated Assisted Living (DAL) and Long-term Care (LTC) in Alberta: Selected Highlights from the Alberta Continuing Care Epidemiological Studies (ACCES)* (Strain, Maxwell, Wanless & Gilbart, 2011).

Five of the former 9 Health Regions (Calgary, Capital, Chinook, David Thompson and East Central) participated in ACCES. These regions represented a mix of urban and rural settings (see Appendix A for number of facilities, residents and family caregivers by region).

Ethical Approval

Ethical approval was obtained from the University of Calgary Conjoint Health Research Ethics Board, the University of Alberta Health Research Ethics Board – Panel B, and the University of Lethbridge Human Subject Research Committee (see Appendix B for copies of the initial approvals). Administrative approvals from the health regions and/or facilities were also obtained.

Organization of the Methodology Report

This methodology report provides information about ACCES sample selection and data collection and is organized as follows:

- **ACCES Facilities**
    - Selection of facilities
    - Facility surveys
- **ACCES Residents**
    - Selection of residents
    - DAL & LTC resident assessments
    - Resident interviews – views of residents
- **ACCES Family Caregivers**
    - Selection of family caregivers
    - DAL & LTC family caregiver interviews
    - Discharge & decedent interviews
- **Administrative Health Data**

ACCES FACILITIES

In total, 113 facilities (59 DAL and 54 LTC facilities) participated in ACCES. The selection of facilities (including information on eligibility and refusals) and information about facility surveys conducted with a facility representative are detailed here.

Selection of Facilities

ACCES began with the selection of DAL and LTC facilities. Due to the relatively low number of DAL facilities in the participating regions when the study began, all DAL facilities that met the eligibility criteria were approached to participate. The large number of LTC facilities necessitated a random selection of facilities within each of the 5 participating health regions.

Eligibility Requirements

- A DAL/LTC facility was eligible for consideration if:
    - it had been in operation for at least 6 months;
    - there were four or more residents aged 65 years or older in smaller facilities and 10 or more in larger facilities; and,
    - it did not primarily serve clients with a mental illness or developmental disability.

  These criteria were employed to ensure the selection of facilities that had some degree of stability in care processes and to maximize efficiency in enrolling older subjects.

DAL Facilities

- An attempt was made to include all eligible DAL facilities in the 5 health regions at the time ACCES began.
- 11 facilities were considered as ineligible (total bed size = 329).
    - 4 facilities were excluded as they had been in operation for less than 6 months (total bed size = 125).
    - 4 facilities were excluded due to the low number of residents aged 65 or older (total bed size = 64).
    - 3 facilities were excluded as they primarily served clients with mental illness or developmental disability (total bed size = 140).
- 1 facility refused participation (total bed size = 20). No reason for refusal was provided.
- 59 DAL facilities participated in ACCES. Table 3 provides a breakdown by region.

TABLE 3. FACILITIES BY REGION

	DAL Facilities (n=59)	LTC Facilities (n=54)	Total Facilities (n=113)
Calgary	22.0% (n=13)	25.9% (n=14)	23.9% (n=27)
Chinook	18.6% (n=11)	14.8% (n=8)	16.8% (n=19)
David Thompson	20.3% (n=12)	18.5% (n=10)	19.5% (n=22)
Capital	23.7% (n=14)	25.9% (n=14)	24.8% (n=28)
East Central	15.3% (n=9)	14.8% (n=8)	15.0% (n=17)

LTC Facilities

- Given the large number of LTC facilities and spaces in 2006, it was necessary to obtain a random sample of LTC facilities. When the study began, there were 132 LTC facilities in the 5 health regions (Calgary = 42, Chinook = 11, David Thompson = 25, Capital = 36, East Central = 18).
- As bed size has been shown to be related to both facility characteristics, quality of care, and outcomes, facilities were initially stratified by small vs. large bed size, using the median within each region as the cut-point. This resulted in 10 strata, defined by the 5 regions and 2 bed sizes.
- A random sample of facilities was selected within each of the 10 strata.
- 5 facilities were considered as ineligible (total bed size = 319):
    - 1 facility was excluded due to low number of residents aged 65 or older (total bed size = 147).
    - 2 facilities were excluded as they served an English as a Second Language (ESL) population, causing a language barrier to assessments and interviews (total bed size = 154).
    - 2 facilities were excluded due to travel distance (total bed size = 18).
- 5 facilities refused participation (total bed size = 549).
    - 3 refused due to staff demands and shortages (total bed size = 282).
    - 2 did not provide a reason for refusal (total bed size = 267).
- 54 LTC facilities participated in ACCES. Table 3 provides a breakdown by region.

Facility Surveys

Facility surveys were completed with a representative of each participating facility. Interviews were conducted with the facility administrator, manager or director of care (i.e., familiar with the day-to-day operation of the facility and had direct knowledge about the residents). This individual preferably had been in this position for at least 6 months. Questions focused on location, ownership, type and size of the facility, admission and retention criteria, staffing, health and wellness services, hospitality services, the physical and social environment, fees, and issues/challenges facing DAL or LTC. Some questions were modeled on those used in a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000) while others were developed specifically for ACCES. See Appendix C for more information the facility survey.

Completed Facility Surveys

- Facility surveys were completed for all 113 participating facilities (DAL=59; LTC=54).
- Surveys were to be conducted between the baseline and follow-up assessments at each facility. DAL facility surveys were completed between November 2006 and October 2007. LTC facility surveys were completed between January 2008 and January 2009.
- Interviews were conducted in person unless the respondent or situation required otherwise.
    - 87.6% (n=99) were completed in person (DAL=81.4%, n=48; LTC=94.4%; n=51)
    - 8.0% (n=9) were done via phone (DAL=10.2%, n=6; LTC=5.6%; n=3)
    - 4.4% (n=5) required both in-person and phone contact (DAL=8.5%, n=5)
- The average length of time to complete the DAL facility surveys was 106 minutes (range: 55 – 195; mode: 165). The average length of the LTC facility surveys was 105 minutes (range: 50 – 190; mode: 120).
- Most surveys were completed in one sitting. Only 6 DAL facility surveys were completed in 2 parts while 1 required 3 sittings.
- Interviews were conducted by 3 study coordinators and 2 study assessors/interviewers (Table 4) (see Appendix D for information on assessors/interviewers). One study coordinator completed all DAL and LTC interviews in three regions (David Thompson, Capital, and East Central), representing 59% of all interviews. One study nurse completed all LTC interviews in the remaining two regions.

TABLE 4. COMPLETED FACILITY SURVEYS BY INTERVIEWER

Assessor/ Interviewer ID #	DAL Facility Surveys Completed (n=59)	LTC Facility Surveys Completed (n=54)	Total Facility Surveys Completed (n=113)
03	3.4% (n=2)	---	1.8% (n=2)
05	6.8% (n=4)	40.7% (n=22)	23.0% (n=26)
07*	11.9% (n=7)	---	6.2% (n=7)
12*	18.6% (n=11)	---	9.7% (n=11)
51*	59.3% (n=35)	59.3% (n=32)	59.3% (n=67)

* indicates a study coordinator.

FACILITY SURVEY RESPONDENTS

- 89.4% of the interviews were conducted with only one person (n=101; DAL=84.7%, n=50; LTC=94.4%, n=51). In the remaining 12 facilities, two individuals provided information (10.6%, (n=12; DAL=15.3%, n=9; LTC=5.6%, n=3). Six of the 12 interviews were completed with both respondents at the same time while 6 were completed with the two respondents at different times (e.g., the Director completed the survey for multiple facilities at a system-wide level and then the facility manager completed the survey with facility specific information). In total, there were 125 respondents (DAL n=68; LTC n=57).

- The type of position held by the respondents is detailed in Table 5.

TABLE 5. POSITION OF FACILITY SURVEY RESPONDENTS

Relationship	DAL Respondents (n=68)	LTC Respondents (n=57)	All Respondents (n=125)
Executive Director/Administrator	19.1% (n=13)	10.5% (n=6)	15.2% (n=19)
Manager/Assistant Director	42.6% (n=29)	31.6% (n=18)	37.6% (n=47)
Supervisor-in-charge/Director of Care	27.9% (n=19)	42.1% (n=24)	34.4% (n=43)
Other			
Care Manager/Coordinator	2.9% (n=2)	7.0% (n=4)	4.8% (n=6)
Program/Home Support Manager	1.5% (n=1)	3.5% (n=2)	2.4% (n=3)
Team Leader	2.9% (n=2)	---	1.6% (n=2)
Social Worker	---	3.5% (n=2)	1.6% (n=2)
Administrative Support	1.5% (n=1)	1.8% (n=1)	1.6% (n=2)
Assistant Manager	1.5% (n=1)	---	0.8% (n=1)

- Four respondents completed more than 1 interview as they managed more than 1 site. More specifically, 3 respondents each completed DAL facility surveys for 3 facilities while 1 respondent did so for 1 DAL and 1 LTC facility.

ACCES RESIDENTS

In total, 2089 residents (1089 DAL and 1000 LTC residents) participated in ACCES. Presented here is information regarding the selection of residents (including eligibility and refusals), the consent process, the 1-year follow-up status of residents, and the interRAI assessments. The Views of Residents Survey completed with the DAL ACCES cohort is detailed, including information about eligibility, participating residents, 1-year follow-up surveys, and the survey instrument.

Selection of Residents

Within the ACCES facilities, attempts were made to assess all DAL residents who met the eligibility criteria. Due to the large number of LTC residents, there was a random selection of residents within the selected facilities. The processes used in each setting are described below.

Eligibility Requirements

- A DAL or LTC resident was considered eligible for ACCES if s/he:
    - was 65 years of age or older;
    - had lived in facility for at least 21 days;
    - was not a short-stay/temporary resident; and,
    - was not currently palliative (i.e., death was imminent/expected within the next 6 months) and/or facility staff or caregiver felt an assessment would be inappropriate.

Consent Process

The consent process involved an initial approach by the facility/Home Care staff followed by an approach by study team members.

FACILITY APPROACH

- In order to meet the Freedom of Information and Protection of Privacy (FOIPP) requirements, the facility or Home Care staff had to obtain approval from the resident or surrogate decision-maker to provide the study coordinators with the name and contact information and an indication of a willingness to be approached for consent to participate in the study. The specific process of obtaining this initial approach was determined in consultation with the regions/facilities. It involved either a verbal approval or an on-site/Home Care person mailing or hand-delivering the consent form and a letter directly to the surrogate decision-maker.

- Facility/Home Care staff members were provided with a script to use when approaching residents or surrogate decision-makers (see Appendix E for example).

STUDY APPROACH: RESIDENT CONSENT

- After the initial approach by the facility, residents who the facility representatives considered capable of making their own informed decision or who did not have an enacted personal directive were approached by a study nurse directly. She gave the resident a copy of the consent form, explained the study and the form, and answered any questions regarding participation (see Appendix F for a sample of the consent form).

- Written consent was obtained from the residents. In instances where the resident was unable to sign due to health problems, a facility or study staff member served as a witness and verbal consent was obtained.

STUDY APPROACH: SURROGATE CONSENT

- Surrogate decision-makers had to provide consent for some residents.
    - Consent from surrogate decision-makers was required for those residents who had moderate to severe cognitive impairment as determined by the facility representatives or where there was an enacted personal directive.
    - The surrogate was a key contact identified by the facility as the person responsible for making care decisions on behalf of the resident.
    - If the resident had been legally declared to not have capacity for decision making by a court and a guardian had been appointed, the appointed guardian had to sign the surrogate consent form on behalf of the resident.
    - If the resident had some impairment and reduced capacity but had NOT been legally declared to lack capacity for decision making by a court, attempts were made to obtain signed consents from both the resident and their noted guardian, even though the latter was not legally appointed by the court.

- After the initial approach by the facility, the facility staff or the study coordinator mailed out a consent package to the surrogate for their review. Alternatively, the study coordinator telephoned to explain the study and inquire about their consent for the resident's participation. If speaking with the surrogate on the telephone, verbal consent was obtained if possible, and a request to sign and return the consent form was made. The verbal consent was recorded (with permission) and then witnessed by a second party at a later date.

PERSONAL HEALTH INFORMATION CONSENT

- Residents or surrogate decision-makers were asked for separate consent for access and data linkage to personal health information to be obtained from the health region or Alberta Health and Wellness (see Appendix F for a sample of the consent form).

- The resident or surrogate decision-maker could refuse access and data linkage to selected personal health information, but still consent to being in the study.

DAL Study Participants and Non-Participants

At the time ACCES began, there were 1801 spaces at the 59 eligible DAL facilities. Figure 1 provides a flowchart that outlines study recruitment while Table 6 gives a breakdown according to health region. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-1).

FIGURE 1. DAL RESIDENT BASELINE FLOWCHART

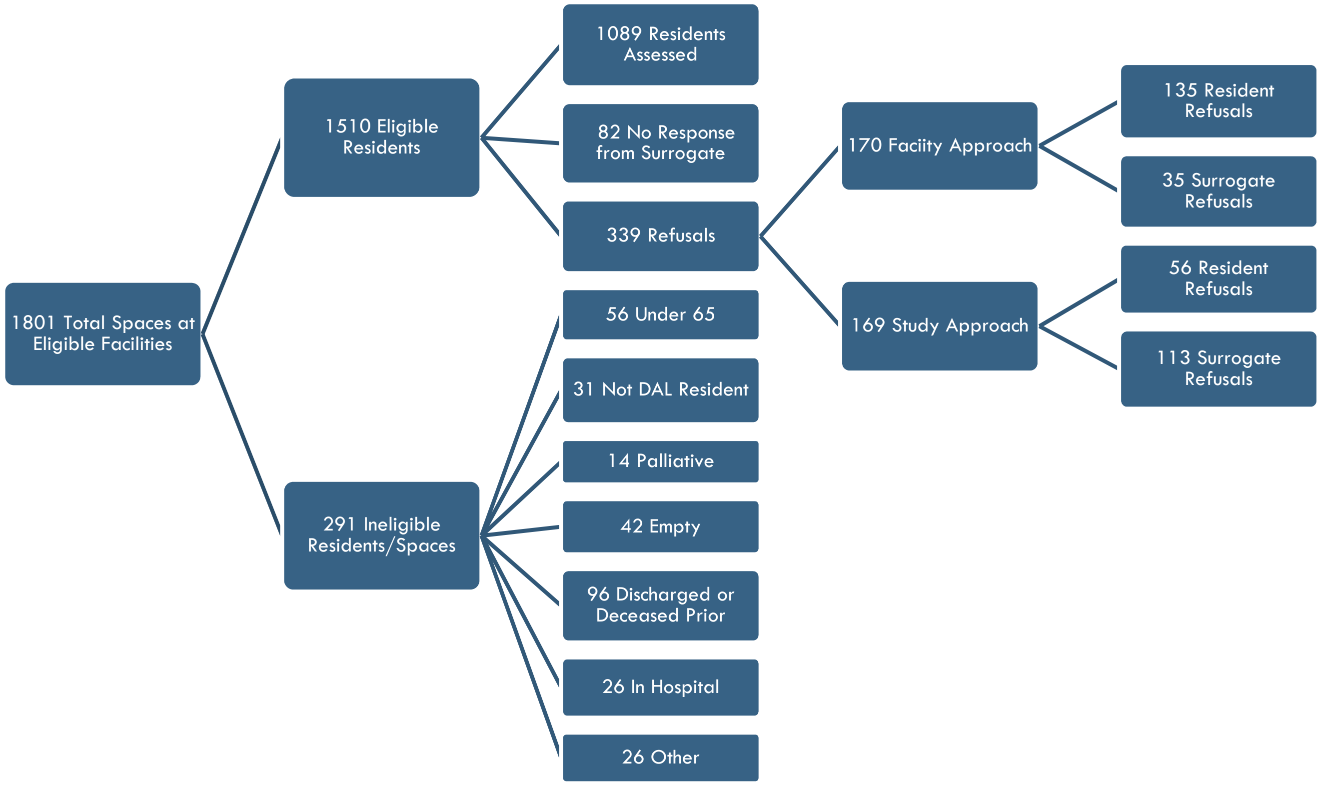


TABLE 6. OVERVIEW OF RECRUITMENT: DAL RESIDENTS

Region	Total Spaces	Ineligible Residents/ Spaces	Refusals at facility approach	Refusals at study approach	No Response from Surrogate	Total Number of Residents Assessed	% of Spaces Assessed[1]	% of Eligible Spaces[2]
Calgary	450	34	42	57	6	311	69.1%	74.8%
Chinook	452	130	27	30	31	234	51.8%	72.7%
David Thompson	248	34	25	25	9	155	62.5%	72.4%
Capital	481	66	61	41	32	281	58.4%	67.7%
East Central	170	27	15	16	4	108	63.5%	75.5%
TOTAL	**1801**	**291**	**170**	**169**	**82**	**1089**	**60.5%**	**72.1%**

[1] Calculated as total number of residents assessed divided by total number of spaces.

[2] Calculated as total number of residents assessed divided by the number of eligible residents/spaces (i.e., total number of spaces – number of ineligible residents/spaces).

- 83.8% (n=1510) of the 1801 spaces were occupied by eligible residents.
- Of the 1510 eligible residents at baseline,
    - 22.4% (n=339) refused participation in the study.
    - 5.4% (n=82) required consent from their surrogate decision-makers who did not respond to the study requests for participation.
    - 72.1% (n=1089) of the eligible residents participated in the study.[5] These participants accounted for 60.5% of all DAL spaces in the 59 facilities.
- Of the 1089 participants who participated in ACCES at baseline,
    - 61.5% (n=670) gave their own consent to participate while surrogate consent was required for 37.2% (n=405). Only 1.3% (n=14) of the consents were from both the resident and surrogate.
    - 98.2% (n=1069) of DAL residents/surrogates provided consent for linkage to the resident's personal health information.

INELIGIBILITY: DAL RESIDENTS

- Among the 291 residents/spaces considered as ineligible,
    - 33.0% (n=96) were discharged or had died prior to assessment/consent.
    - 19.2% (n=56) were under the age of 65.
    - 14.4% (n=42) were empty spaces.
    - 10.7% (n=31) were not DAL residents (e.g., Private Assisted Living (PAL) resident).
    - 8.9% (n=26) were in hospital at the time of data collection.
    - 4.8% (n=14) were residents who were considered palliative.
    - 8.9% (n=26) were ineligible for other reasons (surrogates were uninvolved and did not respond to the facility (n=3), no surrogate available (n=4), resident had been in the facility for less than 3 weeks (n=3), language barrier with surrogate (n=2), resident in rehabilitation hospital (n=1), resident in process of moving from DAL (n=1), already assessed in another DAL (n=1), and no reason provided (n=11)).

---

[5] Included are 2 residents who were within 6 months of their 65th birthday and 2 residents who were assessed although they had been in the facility less than 3 weeks (1 for 6 days and 1 for 18 days).

REFUSALS: DAL RESIDENTS

- Among the 1510 eligible residents,
    - 11.3% (n=170) residents or their surrogates refused when approached by the facility for initial consent.
    - 11.2% (n=169) refused when approached by the study for consent to participate. There were seven cases where consent was initially given but then withdrawn in the process of or after the completion of the assessment.
- Among the 339 refusals,
    - 55.5% (n=188) were resident refusals.
    - 43.7% (n=148) were surrogate refusals.
    - 0.9% (n=3) were combined resident & surrogate refusals (included as resident refusals in Figure 1).
- The most frequent reason for refusal was “not interested/does not want to participate” (34.5%, n=117) (Table 7). 37.2% (n=126) of refusals did not provide a reason for the refusal.

TABLE 7. REASONS FOR REFUSAL: DAL RESIDENTS

Reason for Refusal	Facility Approach (n=170)	Study Approach (n=169)	All Refusals (n=339)
Not interested/doesn’t want to participate	42.9% (n=73)	26.0% (n=44)	34.5% (n=117)
Too sick/old/tired/sad	12.4% (n=21)	11.2% (n=19)	11.8% (n=40)
No time/not a good time	8.8% (n=15)	4.7% (n=8)	6.8% (n=23)
Too upsetting/shy	2.9% (n=5)	10.7% (n=18)	6.8% (n=23)
Language issues/barriers	1.2% (n=2)	1.2% (n=2)	1.2% (n=4)
Public guardian office policy	1.8% (n=3)	---	0.9% (n=3)
Moved before assessment completed (Incomplete)	N/A	1.2% (n=2)	0.6% (n=2)
Proxy/Family member uninformed about resident’s situation	0.6% (n=1)	---	0.3% (n=1)
No reason given	29.4% (n=50)	45.0% (n=76)	37.2% (n=126)

AGE AND GENDER COMPARISON OF DAL PARTICIPANTS AND NON-PARTICIPANTS

- Attempts were made to obtain information on the age and gender of eligible residents who did not participate in the study.
    - Of the 421 eligible residents who did not participate in the study (339 refusals and 82 surrogate non-responses), information was available on both age and gender for 364 residents, gender only for 35 residents, and age only for 2 residents. There was no information on age and gender for 20 residents.
- As illustrated in Table 8, the age and gender compositions are comparable for the study sample and the non-participants in the DAL cohort.

TABLE 8. DAL BASELINE RAI ASSESSMENTS: COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

	Participants	Non-Participants
Age Group[1]		
65-69	3.8% (n=41)	1.6% (n=6)
70-74	6.8% (n=74)	7.9% (n=29)
75-79	14.4% (n=157)	14.2% (n=52)
80-84	20.0% (n=218)	24.0% (n=88)
85-89	28.8% (n=314)	28.1% (n=103)
90-94	20.5% (n=223)	17.8% (n=65)
95-99	4.9% (n=53)	4.9% (n=18)
100+	0.8% (n=9)	1.4% (n=5)
Age (continuous)[1]		
Range	64-103	66-105
Mean	84.43	84.36
Median	85	85
SD	7.31	7.08
Gender[2]	76.7% (n=835) female	73.9% (n=295) female

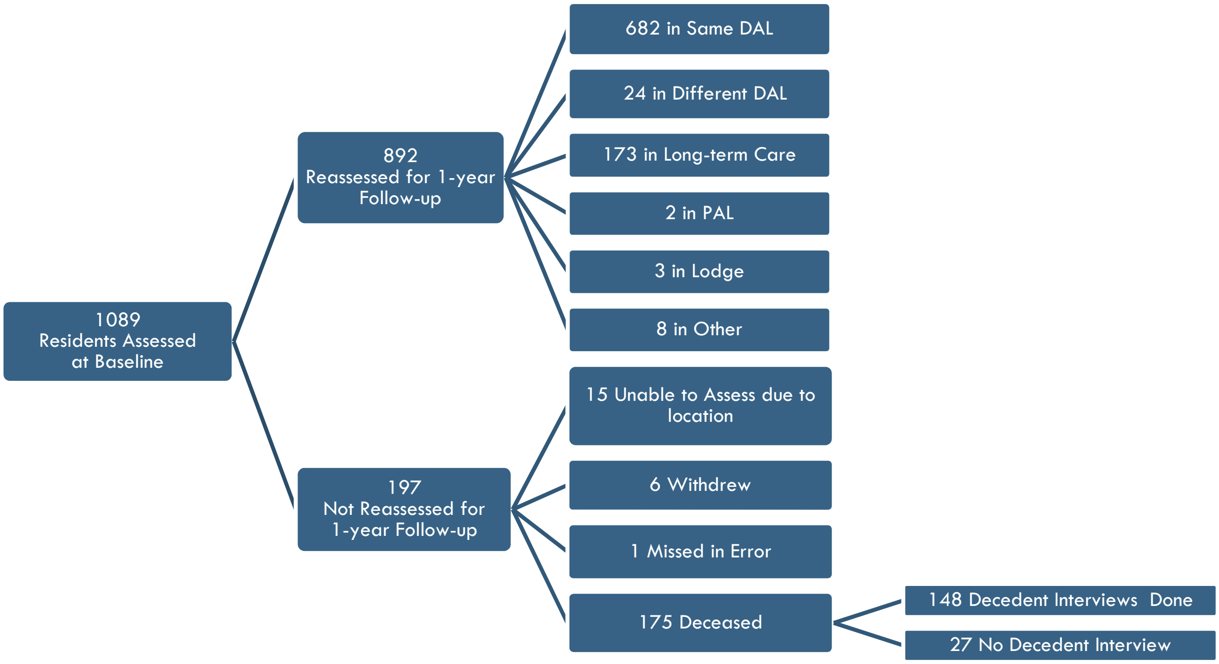
[1] n=1089 participants and 366 non-participants. Excludes 55 non-participants for whom no information on age was available. Note that two residents within 6 months of their 65th birthday were included in the study.

[2] n=1089 participants and 399 non-participants. Excludes 22 non-participants from whom no information on gender was available.

DAL 1-YEAR FOLLOW-UP STATUS

Figure 2 details follow-up data collection. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-1).

FIGURE 2. DAL RESIDENT FOLLOW-UP FLOWCHART



- Among the 1089 DAL participants at baseline, their status at the 1-year follow-up[6] was as follows:
  - 62.6% (n=682) were still in the same DAL facility.
  - 16.1% (n=175) had died.
  - 15.9% (n=173) had moved to a long-term care facility.
  - 2.2% (n=24) had moved to a different DAL facility.
  - 1.2% (n=13) had moved to another setting (private home (n=4 including 1 alone, 1 with friend, 2 with daughter); lodge (n=3); PAL (n=2); own apartment (n=1); independent living (n=1); private LTC (n=1); geriatric psychiatric facility (n=1)).
  - 1.4% (n=15) were in settings where an assessment was not possible (acute care (n=8); hospice/palliative care (n=2); rehabilitation facility (n=1); transition bed (n=1); out of province (n=2); health region other than the 5 regions in the study (n=1)).
  - 0.6% (n=6) withdrew from study at follow-up.
  - 0.1% (n=1) were missed at follow-up.
- Outcome of 1-year follow-up:
  - 892 assessments completed:
    - 717 interRAI-AL assessments
    - 175 interRAI-LTCF assessments (used in LTC and geriatric psychiatric facilities)
  - 197 DAL residents were not reassessed at follow-up:
    - 149 had a caregiver interview (but not a resident assessment) completed related to 1-year status.
      - 1 resident withdrew but a follow-up caregiver interview was completed.
      - 148 had died and a decedent interview was completed.
    - 48 had no caregiver interview done related to 1-year status.
      - 15 were unable to be assessed due to location.
      - 5 withdrew and no follow-up caregiver interview was completed.
      - 1 was missed at follow-up.
      - 27 had died and no decedent interview was completed.

---

[6] These numbers represent resident location at the 1-year follow-up assessment. As several transitions may occur over the year, sample sizes for specific analyses will depend on the research question. For example, the number who moved to a higher level of care over the year may include those who moved but died by 1-year as well as those who moved and were still living.

LTC Study Participants and Non-Participants

At the time ACCES began, there were 5785 spaces at the 54 selected LTC facilities. Of those, 1958 spaces were randomly selected for participation. Figure 3 provides a flowchart that outlines study recruitment while Table 9 gives a breakdown according to health region. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-2).

FIGURE 3. LTC RESIDENT BASELINE FLOWCHART

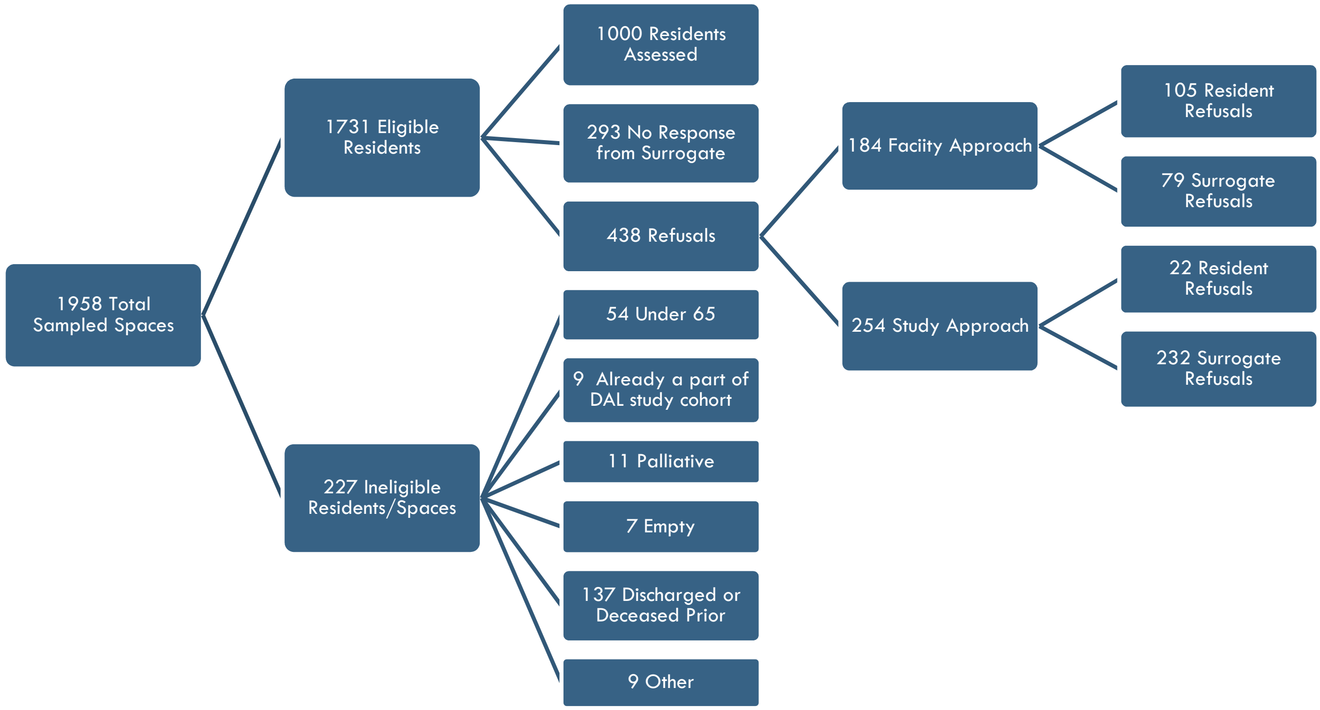


TABLE 9. OVERVIEW OF RECRUITMENT: LTC RESIDENTS

Region	Total Spaces	Ineligible Residents/ Spaces	Refusals at facility approach	Refusals at study approach	No Response from Surrogate	Total Number of Residents Assessed	% of Spaces Assessed[1]	% of Eligible Spaces[2]
Calgary	576	41	12	101	126	296	51.4%	55.3%
Chinook	475	81	54	55	79	206	43.4%	52.3%
David Thompson	257	33	27	33	15	149	58.0%	66.5%
Capital	476	57	79	47	54	239	50.2%	57.0%
East Central	174	15	12	18	19	110	63.2%	69.2%
TOTAL	**1958**	**227**	**184**	**254**	**293**	**1000**	**51.1%**	**57.8%**

[1] Calculated as total number of residents assessed divided by total number of spaces.

[2] Calculated as total number of residents assessed divided by the number of eligible residents/spaces (i.e., total number of spaces – number of ineligible residents/spaces).

- 88.4% (n=1731) of the 1958 spaces sampled were occupied by eligible residents.
- Of the 1731 eligible residents at baseline,
    - 25.3% (n=438) refused participation in the study.
    - 16.9% (n=293) required consent from their surrogate decision-makers who did not respond to the study requests for participation.
    - 57.8% (n=1000) of the eligible residents participated in the study.[7] These participants accounted for 51.1% of all LTC spaces sampled in the 54 facilities.
- Of the 1000 LTC residents who participated in ACCES at baseline,
    - 29.6% (n=296) gave their own consent to participate while surrogate consent was required for 69.8% (n=698). Less than 1% (n=6) of the consents were from both the resident and surrogate.
    - 98.0% (n=980) of LTC residents/surrogates provided consent for linkage to the resident's personal health information.

INELIGIBLITY: LTC RESIDENTS

- Among the 227 residents/spaces considered as ineligible,
    - 60.4% (n=137) were discharged or had died prior to assessment/consent.
    - 23.8% (n=54) were under the age of 65.
    - 4.8% (n=11) were residents who were considered palliative.
    - 4.0% (n=9) were residents who were already in ACCES as a DAL resident.
    - 3.1% (n=7) were empty spaces.
    - 4.0% (n=9) were ineligible for other reasons (no decision-maker available (n=4), language barrier (n=1), decision-maker uninvolved and didn't respond to facility (n=1), temporary placement (n=1), and no reason provided (n=2).

REFUSALS: LTC RESIDENTS

- Among the 1731 eligible residents,
    - 10.6% (n=184) residents or their surrogates refused when approached by the facility for initial consent.
    - 14.7% (n=254) refused when approached by the study for consent to participate. There were five cases where consent was initially given but then withdrawn in the process of or after the completion of the assessment.

---

[7] Included 1 resident who was within 6 months of his/her 65th birthday.

- Among the 438 refusals,
    - 28.1% (n=123) were resident refusals.
    - 71.0% (n=311) were surrogate refusals.
    - 0.9% (n=4) were combined resident & surrogate refusals (included as resident refusals in Figure 3).
- The most frequent reason for refusal was "not interested/does not want to participate" (21.0%, n=92) (Table 10). 51.4% (n=225) of refusals did not provide a reason for the refusal.

TABLE 10. REASONS FOR REFUSAL: LTC RESIDENTS

Reason for Refusal	Facility Approach (n=184)	Study Approach (n=254)	All Refusals (n=438)
Not interested/doesn't want to participate	32.6% (n=60)	12.6% (n=32)	21.0% (n=92)
Too sick/old/tired	8.7% (n=16)	12.2% (n=31)	10.7% (n=47)
No time/not a good time	13.6% (n=25)	3.9% (n=10)	8.0% (n=35)
Too upsetting/shy	1.1% (n=2)	5.5% (n=14)	3.7% (n=16)
Language issues/barriers	3.3% (n=6)	0.8% (n=2)	1.8% (n=8)
Public guardian office policy	1.1% (n=2)	2.0% (n=5)	1.6% (n=7)
Proxy/family member uninformed about resident's situation	1.6% (n=3)	0.8% (n=2)	1.1% (n=5)
Study nurse error (incomplete assessment)	N/A	0.8% (n=2)	0.5% (n=2)
Moved before assessment completed (incomplete)	N/A	0.4% (n=1)	0.2% (n=1)
No reason given	38.0% (n=70)	61.0% (n=155)	51.4% (n=225)

AGE AND GENDER COMPARISION OF LTC PARTICIPANTS AND NON-PARTICIPANTS

- Attempts were made to obtain information on the age and gender of eligible residents who did not participate in the study.
    - Of the 731 eligible residents who did not participate in the study (438 refusals and 293 surrogate non-responses), information was available on both age and gender for 665 residents, gender only for 47 residents, and age only for 2 residents. No information on age and gender was available for 17 residents.
- As illustrated in Table 11, the age and gender compositions are comparable for the study sample and the non-participants in the LTC cohort.

TABLE 11. LTC BASELINE RAI ASSESSMENTS: COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

	Participants	Non-Participants
Age Group[1]		
65-69	4.3% (n=43)	3.0% (n=20)
70-74	6.0% (n=60)	7.0% (n=47)
75-79	12.8% (n=128)	13.6% (n=91)
80-84	20.1% (n=201)	23.7% (n=158)
85-89	27.1% (n=271)	24.7% (n=165)
90-94	21.3% (n=213)	18.3% (n=122)
95-99	7.5% (n=75)	8.1% (n=54)
100+	0.9% (n=9)	1.5% (n=10)
Age (continuous)[1]		
Range	64-104	65-104
Mean	84.92	84.66
Median	86	85
SD	7.63	7.48
Gender[2]	65.7% (n=657) female	67.3% (n=479) female[2]

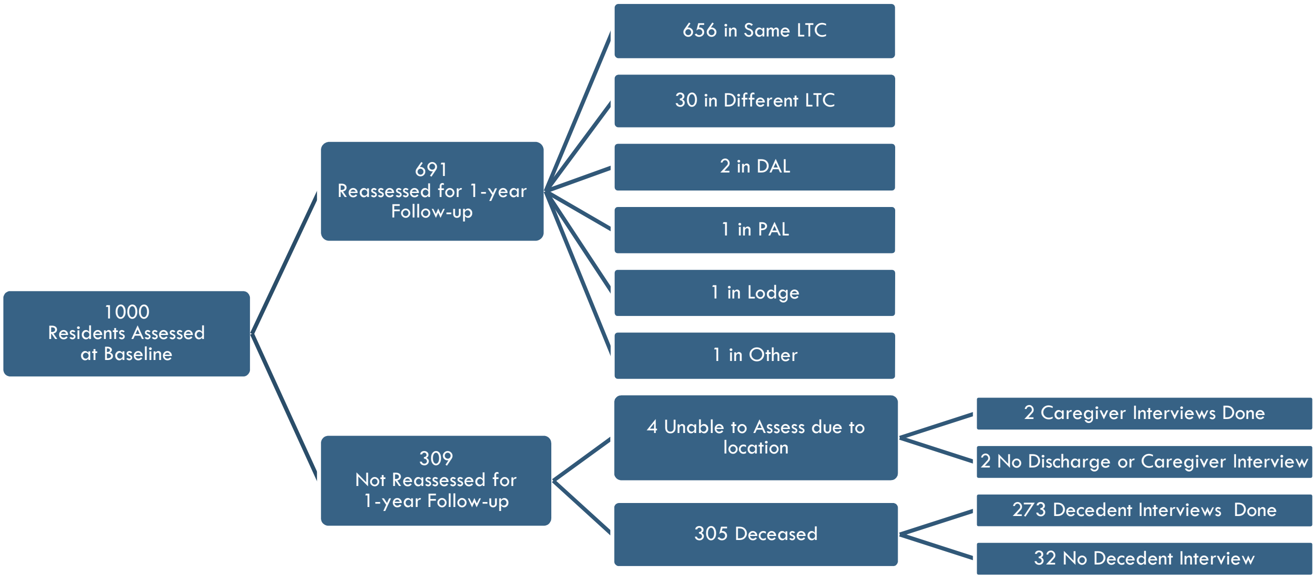
[1] n=1000 participants and 667 non-participants. Excludes 64 non-participants for whom no information on age was available. Note that one resident within 6 months of his/her 65th birthday was included in the study.

[2] n=1000 participants and 712 non-participants. Excludes 19 non-participants for whom no information on gender was available.

LTC 1-YEAR FOLLOW-UP STATUS

Figure 4 details follow-up data collection. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-2).

FIGURE 4. LTC RESIDENT FOLLOW-UP FLOWCHART



- Among the 1000 LTC participants at baseline, their status at the 1-year follow-up[8] was as follows:
    - 65.6% (n=656) were still in same LTC facility.
    - 30.5% (n=305) had died.
    - 3.0% (n=30) had moved to a different LTC facility.
    - 0.2% (n=2) had moved to a DAL facility.
    - 0.3% (n=3) had moved to another setting (lodge (n=1); PAL (n=1); geriatric psychiatric facility (n=1)).
    - 0.4% (n=4) were in settings where an assessment was not possible (out of province (n=2); out of country (n=1); distant community (n=1, not assessed due to travel costs for 1 assessment)).
- Outcome of 1-year follow-up:
    - 691 assessments completed:
        - 687 interRAI-LTCF assessments
        - 4 interRAI-AL assessments
    - 309 LTC residents were not reassessed for follow-up:
        - 275 had a caregiver interview completed (but not a resident assessment) related to 1-year status.
            - 2 were unable to be assessed due to location but a follow-up caregiver interview was completed.
            - 273 had died and a decedent interview was completed.
        - 34 had no caregiver interview done related to 1-year status.
            - 2 were unable to be assessed due to location.
            - 32 had died and no decedent interview was completed.

---

[8] These numbers represent resident location at the 1-year follow-up assessment. As several transitions may occur over the year, sample sizes for specific analyses will depend on the research question. For example, the number who moved to another level of care over the year may include those who moved but died by 1-year as well as those who moved and were still living.

DAL and LTC Resident Assessments at Baseline and 1-Year Follow-up

At baseline and follow-up, trained research nurses (RNs) administered the Resident Assessment Instrument for Assisted Living (interRAI-AL) with DAL residents and the Resident Assessment Instrument for Long-term Care Facilities (interRAI-LTCF) with LTC residents (see Appendix D for information about ACCES assessors/interviewers). These comprehensive, standardized assessments provide information on the residents' sociodemographic characteristics, physical and cognitive status, health conditions, behavioural problems, and use of medications and services. Many measures are the same across the interRAI-AL and interRAI-LTCF tools although some are setting-specific. These two tools are from the most recent interRAI suite of tools but key domains covered in the MDS 2.0 and RAI-Home Care are addressed in the new tools. Additional items were added to the interRAI-AL for a sub-study examining frailty. See Appendix H for more information about the interRAI tools and key measurements.

The interRAI tools draw on multiple sources of information (i.e., the resident, facility charts & staff, Home Care charts & staff, family members). Guided by the assessment manual, the study assessors used their clinical judgement to determine the best source of information for each particular item. In situations where the resident did not feel they could answer the questions or the surrogate requested that the assessor not speak with the resident but gave consent to participate, the assessment was completed based mainly on information from charts, staff and family. In situations where residents did not speak English, attempts were made to have a family member or staff translate for the resident.

Completed Baseline Assessments

- DAL baseline assessments were conducted between March 2006 and November 2007. The majority (97.4%, n=1061) were completed between March 2006 and April 2007.
- LTC baseline assessments were conducted between January 2007 and April 2008.

Completed 1-Year Follow-up Assessments

- DAL follow-up assessments were completed between May 2007 and December 2008.
- LTC follow-up assessments were completed between February 2008 and April 2009.
- At 1-year follow-up, the appropriate interRAI assessment for the current setting of the resident was completed (i.e., the interRAI-AL was completed for residents in DAL, lodge, PAL, or a private homes while the interRAI-LTCF was completed for residents in LTC or a geriatric psychiatric facility).

Timing of the 1-Year Follow-up

- The intent was to complete the follow-up interRAI assessment 12 months after the baseline assessment. A time frame of 2 weeks prior to the due date and up to 4 weeks after the due date (i.e., a 6 week window) was set. For those residents in settings where assessment was not possible within this time fram (e.g., hospital, rehabilitation, transition care, palliative care), an additional 4 weeks after the due date (8 weeks total) were given to allow extra time for the resident to be placed in a setting where the assessment could be completed.

DAL 1-YEAR FOLLOW-UPS

- 85.3% (n=761) of the 892 DAL follow-up assessments were completed within the desired 6 week time frame.
- The remaining 14.7% (n=131) were not completed within this time frame.
    - 2.2% (n=20) were done past the desired time period due to the resident's location.
    - 12.0% (n=107) were done past the desired time period due study assessors' competing demands or error.
    - 0.4% (n=4) were completed one day before the desired time period due to assessor availability or error.

LTC 1-YEAR FOLLOW-UPS

- 95.7% of the 691 LTC follow-up assessments were completed within the desired 6 week time frame.
- The remaining 4.3% were not completed within this time frame.
    - 0.4% (n=3) were done past the desired time period due to the resident's location.
    - 2.5% (n=17) were done past the desired time period due study assessors' competing demands or error.
    - 1.4% (n=10) were completed before the desired time period due to assessor availability or error.

Views of Residents Survey

For the DAL ACCES cohort only, a **Views of Residents Survey** was completed with eligible residents, in order to ascertain their views about the facility and the care they received. No attempts were made to conduct this survey with LTC residents due to cognitive impairment levels among residents as well as a study on LTC satisfaction being conducted by other researchers at the same time.

Eligibility Requirements

- A DAL resident who was part of the DAL cohort was considered eligible for the survey if s/he:
    - was not in a dementia space/unit (as indicated by the facility/health region), and/or,
    - scored below a 4 (severely impaired) on item F1(Cognitive skills for daily decision making) on the interRAI assessment.

Baseline Views of Residents Survey

- Of the 1089 DAL residents,
    - 27.1% (n=295) were deemed ineligible for the Views of Residents Survey.
    - 3.9% (n=42) met the eligibility criteria but a study nurse deemed the resident as unable to complete the survey, based on their clinical judgment.
    - 4.4% (n=48) were eligible but refused. The reason for refusal was not recorded.
    - 64.6% (n=704) completed the survey.

AGE AND GENDER COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

- As illustrated in Table 12, the age and gender compositions of those who completed the survey and the non-participants (both the ineligibles and refusals) were comparable.

TABLE 12. DAL VIEWS OF RESIDENTS SURVEY: COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

	Participants (n=704)	**Non-Participants (n=385)**
Age Group		
65-69	4.1% (n=29)	3.1% (n=12)
70-74	7.8% (n=55)	4.9% (n=19)
75-79	15.8% (n=111)	11.9% (n=46)
80-84	18.3% (n=129)	23.1% (n=89)
85-89	29.4% (n=207)	27.8% (n=107)
90-94	18.8% (n=132)	23.6% (n=91)
95-99	5.1% (n=36)	4.4% (n=17)
100+	0.7% (n=5)	1.0% (n=4)
Age (continuous)		
Range	64-103	65-102
Mean	84.03	85.15
Median	85	86
SD	7.50	6.89
Gender	76.0% (n=535) female	77.9% (n=300) female

1-Year Follow-up Views of Residents Survey

- Of the 712 DAL residents residing in a DAL, PAL, lodge, or independent living setting at the 1-year follow-up,
    - 26.0% (n=185) were deemed ineligible for the Views of Residents Survey.
    - 1.5% (n=11) met the eligibility criteria but a study nurse deemed the resident as unable to complete the survey, based on their clinical judgment.
    - 7.3% (n=52) were eligible but refused. The reason for refusal was not recorded.
    - 65.2% (n=464) completed the survey.

FOLLOW-UP AGE AND GENDER COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

- As illustrated in Table 13, the age and gender compositions of those who completed the survey and the non-participants (both the ineligibles and refusals) were comparable.

TABLE 13. DAL FOLLOW-UP VIEWS OF RESIDENTS SURVEY: COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

	Participants (n=464)	**Non-Participants (n=248)**
Age Group		
65-69	3.7% (n=17)	3.6% (n=9)
70-74	7.8% (n=36)	6.9% (n=17)
75-79	14.4% (n=67)	10.9% (n=27)
80-84	18.5% (n=86)	19.8% (n=49)
85-89	25.2% (n=117)	32.7% (n=81)
90-94	22.4% (n=104)	20.2% (n=50)
95-99	7.3% (n=34)	5.6% (n=14)
100+	0.6% (n=3)	0.4% (n=1)
Age (continuous)		
Range	65-101	65-103
Mean	84.60	84.83
Median	86	85
SD	7.63	7.13
Gender	77.2% (n=358) female	79.0% (n=196) female

Views of Residents Survey Methodology

- This survey was a modified version of the Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAHPS)[9] survey. In consultation with one of the ACCES decision-maker partners, only items deemed relevant to the DAL population were retained. See Appendix H for more information about the design of the Views of Residents Survey.

- The survey was conducted at the same time as the inter*RAI* assessment.

---

[9] More information on the NH-CAPHS and other surveys in the program is available at https://www.cahps.ahrq.gov

- The survey was designed to be self-administered but could be interview-administered if health problems made self-completion difficult or if the resident requested assistance from the nurse assessor.

- A self-administered survey and a self-sealing envelope was left with the resident. The assessor later returned to retrieve the completed sealed survey.

DAL BASELINE SURVEY METHODS

- Of the 704 completed surveys at baseline,
  - 17.5% (n=123) were self-administered.
  - 82.5% (n=581) were interviewer-administered.
- The reasons for 581 interviewer-administrated surveys are detailed in Table 14.

TABLE 14. REASON FOR INTERVIEW-ADMINISTERED VIEWS AT BASELINE

Reasons Interviewer-administered	**(n=581)**
Resident or nurse chose interview-administered	50.4% (n=293)
Due to vision problems	20.5% (n=119)
Due to other health problem(s)[1]	9.5% (n=55)
Due to arthritis	4.0% (n=23)
Other reason(s)[2]	3.6% (n=21)
Multiple Reasons	12.0% (n=70)
Vision & Choice of resident/nurse	30.0% (n=21)
Choice of resident/nurse & Other health problem(s)[1]	18.6% (n=13)
Vision & Other health problem(s)[1]	15.7% (n=11)
Vision & Arthritis	14.3% (n=10)
Arthritis & Choice of resident/nurse	8.6% (n=6)
Arthritis & Other health problem(s)[1]	4.3% (n=3)
Choice of resident/nurse & Other reason(s)[2]	2.9% (n=2)
Vision & Other reason(s)[2]	1.4% (n=1)
Vision, Arthritis & Other health problem(s)[1]	1.4% (n=1)
Vision, Arthritis & Choice of resident/nurse	1.4% (n=1)
Vision, Arthritis & Other reason(s)[2]	1.4% (n=1)

[1] Other health problem(s) (n=83) included problems with hands/arms (including unspecified tremors) (n=29); dementia/memory problems/confusion (n=21); neurological problems such as CVA, Parkinson's disease, and MS (n=15); too tired/unwell (n=10); cardiac/respiratory problems (n=3); infections (n=2); anxiety (n=1); and unknown (n=2).

[2] Other reason(s) (n=25) included language difficulties (n=12), difficulty reading (n=6), and comprehension difficulties (n=7).

DAL FOLLOW-UP SURVEY METHODS

- Of the 464 completed surveys at follow-up,
  - 15.3% (n=71) were self-administered.
  - 84.7% (n=393) were interviewer-administered.

- The reasons for 393 interview-administrated follow-up surveys are detailed in Table 15.

TABLE 15. REASON FOR INTERVIEW-ADMINISTERED VIEWS AT FOLLOW-UP

Reason Interviewer-administered	**(n=393)**
Resident or nurse chose interview-administered	59.0% (n=232)
Due to vision problems	18.1% (n=71)
Due to other health problem(s)[1]	9.2% (n=36)
Due to arthritis	3.3% (n=13)
Other reason(s)[2]	2.0% (n=8)
Multiple Reasons	8.4% (n=33)
Vision & Choice of resident/nurse	39.4% (n=13)
Vision & Other health problem(s)[1]	18.2% (n=6)
Arthritis & Other health problem(s)[1]	9.1% (n=3)
Choice of resident/nurse & Other health problem(s)[1]	9.1% (n=3)
Vision & Other reason(s)[2]	6.1% (n=2)
Choice of resident/nurse & Other reason(s)[2]	6.1% (n=2)
Vision, Arthritis & Other health problem(s)[1]	6.1% (n=2)
Vision & Arthritis	3.0% (n=1)
Other health problem[1] & Other reason(s)[2]	3.0% (n=1)

[1] Other health problem(s) (n=51) included problems with hands/arms (including unspecified tremors) (n=16); dementia/memory problems/confusion (n=18); neurological problems such as CVA, Parkinson's disease, and MS (n=13); too tired/unwell (n=3); and cardiac/respiratory problems (n=1).

[2] Other reason(s) (n=13) included language difficulties (n=8), difficulty reading (n=1), and comprehension difficulties (n=4).

ACCES FAMILY CAREGIVERS

In addition to obtaining information about residents, interviews were conducted with family members, friends or other individuals who were involved in the lives of the residents. In total, 1891 family caregivers (974 DAL and 917 LTC caregivers) participated in ACCES at baseline. Presented here is information on the selection of family caregivers (including eligibility and refusals), the consent process, and the follow-up status of the caregiver/resident. Details are also provided regarding the completed caregiver interviews, including characteristics of the participating caregivers (e.g., relationship to the resident), timing of the interviews, and the interview methodology.

Selection of Family Caregivers

An attempt was made to complete an interview with an informal caregiver of each DAL and LTC resident in the ACCES study (referred to hereafter as family caregiver interviews).

Eligibility Requirements

- A family member, friend, or volunteer was considered eligible for ACCES if s/he:
    - Was an informal/unpaid caregiver of a DAL or LTC resident in the ACCES cohort.
    - Was identified as the person most involved in the care and/or most informed about the resident.

This individual was identified by the resident and/or the facility. If the resident had no one who met these eligibility requirements or if the resident requested that their informal caregiver not be contacted, an interview was not completed.

Consent Process

- Each family caregiver was contacted by a study nurse and invited to participate in the study. The study nurse provided a copy of the consent form, explained the study and the form, and answered any questions regarding participation (see Appendix I for a sample of the caregiver consent form).
- Written consent was obtained from the family caregivers. In instances where the consent was provided via telephone, a witnessed verbal consent was obtained.

DAL Family Caregiver Participants and Non-Participants

Figure 5 provides a flowchart that outlines the family caregiver recruitment process, while Table 16 gives a breakdown according to region. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-3).

FIGURE 5. DAL FAMILY CAREGIVER BASELINE INTERVIEW FLOWCHART

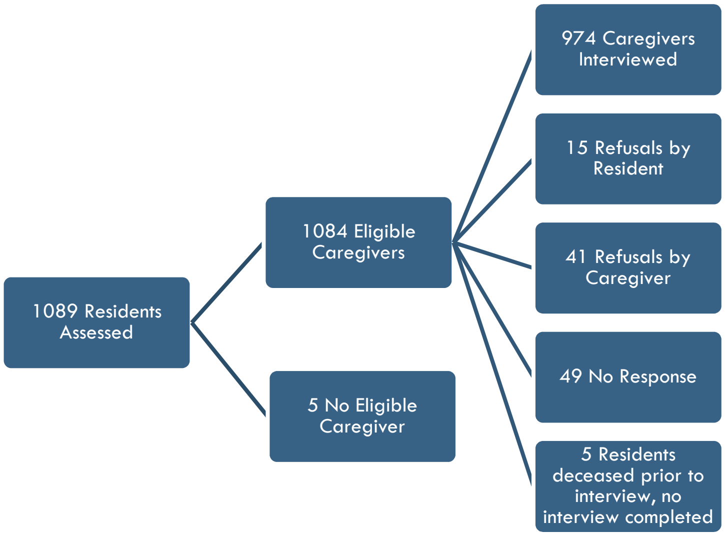


TABLE 16. OVERVIEW OF RECRUITMENT: DAL FAMILY CAREGIVERS

Region	Total Residents	No Eligible Caregiver	Resident Refusals	Caregiver Refusals	No Response	Resident Deceased Prior	Total Caregivers Participating	Participation Rate
Calgary	311	3	6	16	11	1	274	88.1%
Chinook	234	0	5	14	26	1	188	80.3%
David Thompson	155	0	2	4	1	1	147	94.8%
Capital	281	2	0	5	7	0	267	95.0%
East Central	108	0	2	2	4	2	98	90.7%
TOTAL	**1089**	**5**	**15**	**41**	**49**	**5**	**974**	**89.4%**[1]

[1] Response Rate = 89.8% (calculated as total number of caregivers participating divided by the number of residents with an eligible caregiver (i.e., total residents – number with no eligible caregiver)

- For 89.4% (n=974) of the 1089 DAL residents, a family caregiver completed the interview.
- The remaining 10.6% (n=115) of the DAL residents did not have a family caregiver who completed the interview.
    - 0.5% (n=5) had no eligible family caregiver.
    - 1.4% (n=15) refused to have their family caregiver interviewed.
    - 3.8% (n=41) identified family caregivers who subsequently refused participation.
    - 4.5% (n=49) had family caregivers who did not respond to study requests for participation.
    - 0.5% (n=5) were residents who died prior to the family caregiver interview and an interview was not completed.

- Among the 56 refusals, 26.8% (n=15) were resident refusals and 73.2% (n=41) were caregiver refusals. The most frequent reason for refusal was that the family caregiver was not interested/did not want to participate (Table 17).

TABLE 17. REASONS FOR REFUSAL: DAL FAMILY CAREGIVERS

Reason for Refusal	Caregivers (n=56)
Not interested/doesn't want to participate	33.9% (n=19)
Resident request	26.8% (n=15)
No time/not a good time	21.4% (n=12)
Proxy/Family member uninformed about resident's situation	10.7% (n=6)
Too upsetting/shy	3.6% (n=2)
Too sick/old/tired	1.8% (n=1)
No reason given	1.8% (n=1)

AGE AND GENDER COMPARISON OF DAL FAMILY CAREGIVER PARTICIPANTS AND NON-PARTICIPANTS

- Of the 105 eligible family caregivers who did not participate (56 refusals and 49 non-responses), information on gender was available for 102 family caregivers. Age of the non-participants was not available.

- 70% of the participants were female compared to 53% of the non-participants (Table 18).

TABLE 18. DAL BASELINE FAMILY CAREGIVER INTERVIEWS: COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

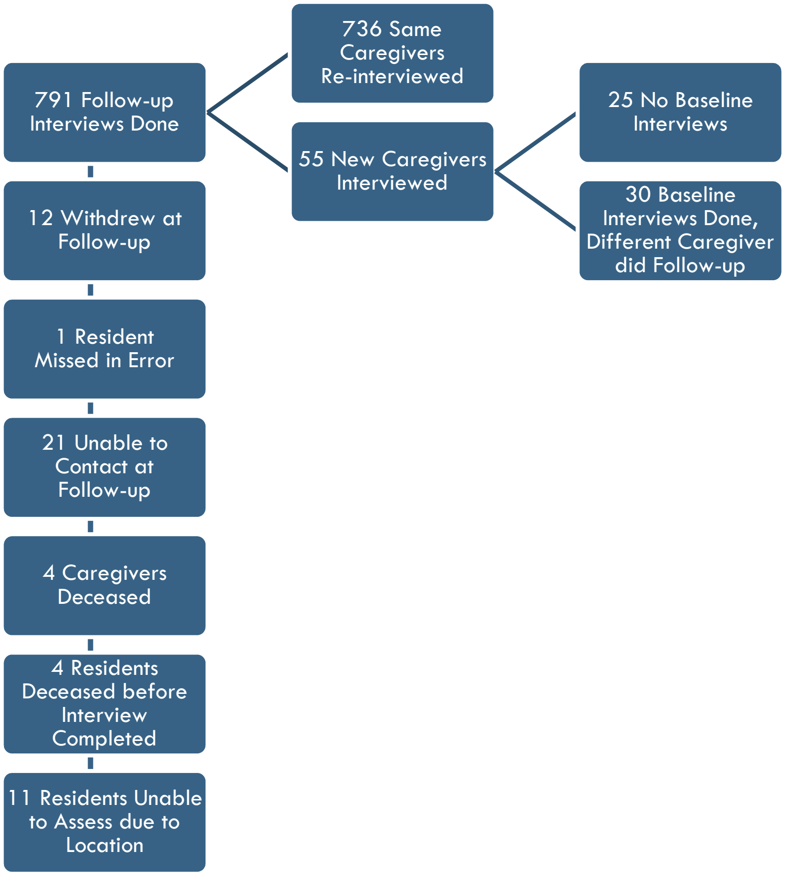
	Participants (n=974)	Non-Participants (n=105)
Age Group		Not Available
<50	20.3% (n=198)	
50-64	55.7% (n=543)	
65+	23.2% (n=226)	
Refused	0.7% (n=7)	
Age (continuous)		Not Available
Range	22-91	
Mean	57.69	
Median	57	
SD	10.53	
Gender	70.3% (n=685) female	52.9% (n=54) female[1]

[1] Excludes 3 non-participants for whom information on gender was not available.

DAL FAMILY CAREGIVER FOLLOW-UP STATUS

Figure 6 provides a flowchart that outlines the family caregiver status at the 1-year follow-up of the resident. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-3). It is important to note that the follow-up with the family caregiver is linked to the follow-up with the resident and therefore may not occur at precisely 1-year after the baseline family caregiver interview.

FIGURE 6. DAL FAMILY CAREGIVER FOLLOW-UP INTERVIEW FLOWCHART



- For 86.5% (n=791) of the 914 residents alive at the 1-year follow-up, a family caregiver completed the interview.

- The remaining 13.4% (n=123) of the DAL residents did not have a family caregiver who completed the follow-up interview.
    - 7.4% (n=68) had caregivers who refused or were unable to be contacted at baseline (not shown in Figure 6).
    - 2.3% (n=21) had caregivers who were unable to be contacted at follow-up.
    - 1.3% (n=12) had caregivers who withdrew from participation (not interested (n=5), had no time (n=4), and felt interview was too upsetting (n=3)).
    - 1.3% (n=12) of residents were unable to be assessed due to location/missed in error, and no family caregiver interview was done.
    - 0.4% (n=4) had caregivers who were interviewed at baseline but had died, and no other caregiver was available or willing to participate.

    - 0.4% (n=4) of residents died before the family caregiver interview could be completed.
    - 0.2% (n=2) had no eligible caregiver identified at baseline or follow-up (not shown in Figure 6).
- Among the 791 family caregivers interviewed at follow-up,
    - 634 family caregivers were involved with residents still in DAL or an equivalent level of care ("In DAL" interviews).
    - 157 family caregivers were caring for residents who had moved to LTC or an equivalent level of care ("In LTC" interviews).
- Of the 791 completed follow-up interviews, 7.0% (n=55) were with new family caregivers.
    - For 7 residents, the family caregiver interviewed at follow-up had been present for the baseline interview but was not the primary respondent.
    - For 23 residents, the family caregiver interviewed at follow-up was a different caregiver than the one interviewed at baseline.
        - 7 caregivers interviewed at baseline were no longer involved with the resident.
        - 4 caregivers were approached due to a study nurse error (confusion about who was interviewed at baseline).
        - 3 caregivers interviewed at baseline were deceased.
        - 2 caregivers interviewed at baseline were not willing to participate further.
        - 2 caregivers interviewed at baseline felt they were too busy at follow-up.
        - 2 caregivers interviewed at baseline suggested an alternate caregiver should complete the follow-up interview.
        - 1 caregiver interviewed at baseline was too ill to complete follow-up interview.
        - 1 caregiver interviewed at baseline was away for an extended period of time.
        - 1 caregiver interviewed at baseline was less involved with the resident than the new caregiver.
    - For 25 residents, no family caregiver completed a baseline interview but an interview was done at the time of follow-up.
        - 17 caregivers could not be reached at baseline but were successfully contacted at follow-up.

- 4 residents had no eligible caregiver at baseline but at follow-up a new caregiver who was now involved or had been previously unidentified agreed to be interviewed.
- 3 caregivers refused at baseline but were willing to participate at follow-up.
- 1 caregiver was not interviewed at baseline due to study nurse error.

LTC Family Caregiver Participants and Non-Participants

Figure 7 provides a flowchart that outlines the LTC family caregiver recruitment process, while Table 19 gives a breakdown according to region. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-4).

FIGURE 7. LTC FAMILY CAREGIVER BASELINE INTERVIEW FLOWCHART

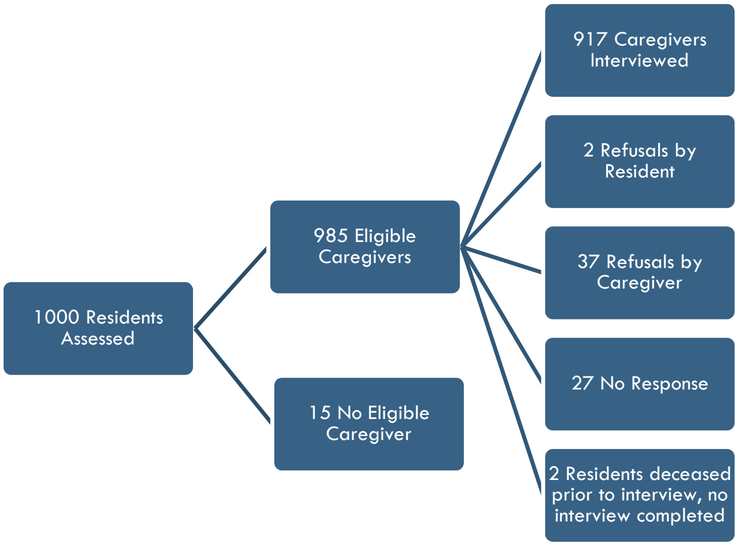


TABLE 19. OVERVIEW OF RECRUITMENT: LTC FAMILY CAREGIVERS

Region	Total Residents	No Eligible Caregiver	Resident Refusals	Caregiver Refusals	No Response	Resident Deceased Prior	Total Caregivers Participating	Participation Rate
Calgary	296	5	0	11	9	1	270	91.2%
Chinook	206	5	2	14	6	1	178	86.4%
David Thompson	149	2	0	1	2	0	144	96.6%
Capital	239	3	0	6	9	0	221	92.5%
East Central	110	0	0	5	1	0	104	94.5%
TOTAL	**1000**	**15**	**2**	**37**	**27**	**2**	**917**	**91.7%**[1]

[1] Response Rate = 93.1% (calculated as total number of caregivers participating divided by the number of residents with an eligible caregiver (i.e., total residents – number with no eligible caregiver)

- For 91.7% (n=917) of the 1000 LTC residents, a family caregiver completed the interview.
- The remaining 8.3% (n=83) of the LTC residents did not have a family caregiver who completed the interview.
    - 1.5% (n=15) had no eligible family caregiver.
    - 0.2% (n=2) refused to have their family caregiver interviewed.
    - 3.7% (n=37) identified family caregivers who subsequently refused participation.
    - 2.7% (n=27) had family caregivers who did not respond to study requests for participation.
    - 0.2% (n=2) were residents who died prior to the caregiver interview and an interview was not completed.
- Among the 39 refusals, 5.1% (n=2) were resident refusals and 94.9% (n=37) were caregiver refusals. The most frequent reason for refusal was that the family caregiver was not interested/did not want to participate (Table 20).

TABLE 20. REASONS FOR REFUSAL: LTC FAMILY CAREGIVERS

Reason for Refusal	**Caregivers (n=39)**
Not interested/doesn't want to participate	28.2% (n=11)
No time/not a good time	23.1% (n=9)
No reason given	15.4% (n=6)
Proxy/Family member uninformed about resident's situation	10.3% (n=4)
Too upsetting/shy	10.3% (n=4)
Resident request	5.1% (n=2)
Too sick/old/tired	5.1% (n=2)
Had done enough	2.6% (n=1)

AGE AND GENDER COMPARISON OF LTC FAMILY CAREGIVER PARTICIPANTS AND NON-PARTICIPANTS

- Of the 66 eligible family caregivers who did not participate (39 refusals and 27 non-responses), information on gender was available for all 66 family caregivers. Age of the non-participants was not available.
- 69% of the participants were female compared to 59% of the non-participants (Table 21).

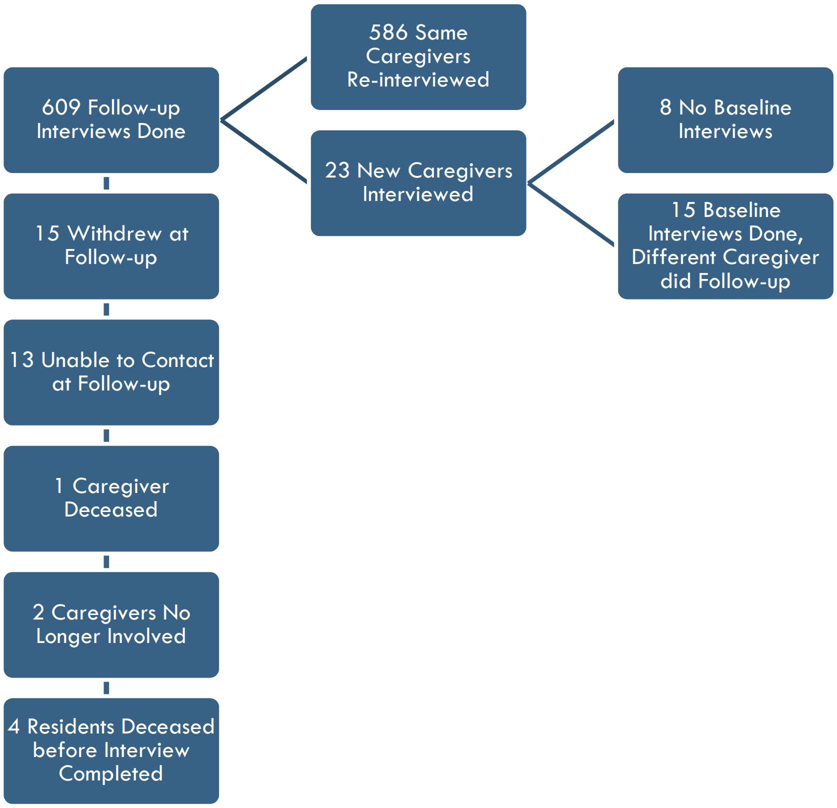
TABLE 21. LTC BASELINE FAMILY CAREGIVER INTERVIEWS: COMPARISON OF PARTICIPANTS AND NON-PARTICIPANTS

	Participants (n=917)	Non-Participants (n=66)
Age Group		Not Available
<50	14.4% (n=132)	
50-64	47.0% (n=431)	
65+	37.9% (n=348)	
Refused/Missing	0.7% (n=6)	
Age (continuous)		Not Available
Range	24-95	
Mean	61.73	
Median	61	
SD	12.28	
Gender	69.1% (n=634) female	59.1% (n=39) female

LTC FAMILY CAREGIVER FOLLOW-UP STATUS

Figure 8 provides a flowchart that outlines the family caregiver status at the 1-year follow-up of the resident. See Appendix G for a detailed flowchart of baseline and follow-up (Figure G-4). It is important to note that the follow-up with the family caregiver is linked to the follow-up with the resident and therefore may not occur at precisely 1-year after the baseline family caregiver interview.

FIGURE 8. LTC FAMILY CAREGIVER FOLLOW-UP INTERVIEW FLOWCHART



- For 87.6% (n=609) of the 695 residents alive at the 1-year follow-up, a family caregiver completed the interview.
- The remaining 12.4% (n=86) of the LTC residents did not have a family caregiver who completed the follow-up interview.
    - 5.8% (n=40) had caregivers who refused or were unable to be contacted at baseline (not shown in Figure 8).
    - 2.2% (n=15) had caregivers who withdrew from participation (not interested (n=3), had no time (n=8), were too sick (n=2), felt interview was too upsetting (n=1), and felt uninformed about the resident and their situation (n=1)).
    - 1.9% (n=13) had caregivers who were unable to be contacted at follow-up.
    - 1.6% (n=11) had no eligible caregiver identified at baseline or follow-up (not shown in Figure 8).
    - 0.3% (n=2) had caregivers who were no longer involved with the resident or their care at follow-up.
    - 0.1% (n=1) had caregivers who were interviewed at baseline but had died, and no other caregiver was available or willing to participate at follow-up.
    - 0.6% (n=4) of residents died before the caregiver interview could be completed.
- Among the 609 family caregivers interviewed at follow-up,
    - 606 family caregivers were involved with residents still in LTC or an equivalent level of care ("In LTC" interviews).
    - 3 family caregivers were caring for residents who had moved to DAL or an equivalent level of care ("In DAL" interviews).
- Of the 609 completed follow-up interviews, 3.8% (n=23) were completed with new family caregivers.
    - For 2 residents, the family caregiver interviewed at follow-up had been present for the baseline interview but was not the primary respondent.
    - For 13 residents, the family caregiver interviewed at follow-up was a different caregiver than the one interviewed at baseline.
        - 4 caregivers interviewed at baseline were no longer involved with the resident.
        - 4 caregivers interviewed at baseline were deceased.
        - 2 caregivers interviewed at baseline indicated that they were too busy at follow-up.

        - 2 caregivers interviewed at baseline were too ill to complete the follow-up interview.
        - 1 caregiver was approached due to a study nurse error (confusion about who was interviewed at baseline).
    - For 8 residents, no family caregiver completed a baseline interview, but an interview was done at the time of follow-up.
        - 5 caregivers could not be reached at baseline but were successfully contacted at follow-up.
        - 2 residents had no eligible caregiver at baseline but at follow-up a new caregiver who was now involved or had been previously unidentified agreed to be interviewed.
        - 1 caregiver refused at baseline but was willing to participate at follow-up.

DAL and LTC Family Caregiver Interviews at Baseline and Follow-up

In the family caregiver interview, information on the assistance provided to the resident, an assessment of the resident's health and use of services, the effects of caregiving on employment, caregiver burden, knowledge and views about the facility's services/policies, and costs related to the resident's care was gathered (see Appendix D for information on study assessors/interviewers). Some questions were derived from the Canadian/Manitoba Study of Health and Aging (C/MSHA) (MSHA Research Group, 1998) and from a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000) while other questions were selected/developed specifically for ACCES. See Appendix J for more information about the design of the caregiver interviews and key measurements.

Completed DAL Family Caregiver Baseline Interviews

- DAL baseline family caregiver interviews were conducted between March 2006 and December 2007. The majority (97.2%, n=947) were completed between March 2006 and April 2007.
- Attempts were made to complete the family caregiver interview within one month of the resident assessment. 84% of the interviews were completed within this time frame (Table 22).

TABLE 22. TIME DIFFERENCE BETWEEN DAL BASELINE RESIDENT ASSESSMENT AND FAMILY CAREGIVER INTERVIEW

Time Difference (n=974)	
Prior to assessment	1.0% (n=10)
Within 1 month (0 to 31 days post)	84.1% (n=819)
32 to 56 days post assessment	8.7% (n=85)
57 to 84 days post assessment	3.2% (n=31)
85 or more days post assessment	3.0% (n=29)
Range	5 days prior to 202 days post
Mean	16.9 days post assessment
Median	8 days post assessment
Mode	0 days post assessment

- Baseline interviews were to be conducted in-person whenever possible. The majority of interviews (91.2%) were completed in-person.

- The location of the interview was chosen by the family caregiver and/or study nurse.
    - 45.2% (n=440) in the facility
    - 30.7% (n=299) in respondent's home[10]
    - 9.1% (n=89) in a public place
    - 8.8% (n=86) via telephone
    - 5.1% (n=50) at the respondent's workplace
    - 1.0% (n=10) at someone else's home

- The average length of the interview was 93 minutes (range from 25 minutes to 3.5 hours). The most frequent length was 1 hour.

- 968 interviews (99.4%) were completed in one sitting; 6 were completed in two parts.

- The average age of the family caregivers was 57 (Table 23).

TABLE 23. AGE OF FAMILY CAREGIVERS: DAL BASELINE

	DAL Family Caregivers (n=974)
Age Group	
<50	20.3% (n=198)
50-64	55.7% (n=543)
65+	23.2% (n=226)
Refused	0.7% (n=7)
Age (continuous)	
Range	22-91
Mean	57.69
Median	57
SD	10.53

- 70.3% (n=685) were female caregivers.

- 73.7% of caregivers were the residents' children (Table 24). Four respondents (all spouses) lived at the same facility as the resident (either in the same or a separate room).

---

[10] Two interviews were started in the respondent's home and finished by phone and one was finished in a public place.

TABLE 24. FAMILY CAREGIVER RELATIONSHIP: DAL BASELINE

Relationship to Resident	DAL Family Caregivers (n=974)
Daughter	50.8% (n=495)
Son	22.9% (n=223)
Daughter/Son-in-law	4.5% (n=44)
Niece/Nephew	4.1% (n=40)
Sibling	3.9% (n=38)
Wife	3.6% (n=35)
Friend	3.3% (n=32)
Husband	2.2% (n=21)
Grandchildren	2.0% (n=19)
Step-relative	1.1% (n=11)
Niece/Nephew-in-law or Great-Niece/Nephew	0.8% (n=8)
Other relatives (sister-in-law, aunt, cousin)	0.8% (n=8)

- 16 family caregivers completed two interviews as they were the identified caregiver for two residents (married couples). These caregivers were their children (n=13), daughter-in-law (n=1), niece (n=1), or friend (n=1). All but 1 of the 16 completed the interviews for both residents either simultaneously or consecutively.

- Three “combination decedent/family” interviews were completed. These contained the complete decedent interview and a portion of the family caregiver interview. These interviews were completed as the resident died prior to the interview completed, contact with the caregiver had been made, and the caregiver was willing to do the interview.

Completed DAL Family Caregiver Follow-up Interviews

- The location of the 791 residents (at the time of their resident assessment) and whether the same or a new caregiver was interviewed is detailed in Table 25.

TABLE 25. RESIDENT LOCATION AND DAL FOLLOW-UP FAMILY CAREGIVERS

Location of Resident at Time of Assessment	Same Caregiver as Baseline (n=736)	New Caregiver (n=55)	All Caregivers (n=791)
Same DAL facility	76.6% (n=564)	69.1% (n=38)	76.1% (n=602)
Long-term care facility	19.0% (n=140)	27.3% (n=15)	19.6% (n=155)
Different DAL facility	3.0% (n=22)	N/A	2.8% (n=22)
Another setting[1]	1.4% (n=10)	3.6% (n=2)	1.5% (n=12)

[1] Includes private home (n=4 including 1 alone, 1 with friend, 2 with daughter), lodge (n=3), PAL (n=1), own apartment (n=1), independent living setting (n=1), private LTC (n=1), and geriatric psychiatric facility (n=1).

- DAL follow-up family caregiver interviews were completed between May 2007 and December 2008.

- Attempts were made to complete the family caregiver interview as soon as possible after the resident assessment was completed (Table 26).

TABLE 26. TIME DIFFERENCE BETWEEN DAL FOLLOW-UP RESIDENT ASSESSMENT AND FAMILY CAREGIVER INTERVIEW

Time Difference (n=790)[1]	
Prior to assessment	1.4% (n=11)
Within 1 month (0 to 31 days post)	83.7% (n=661)
32 to 56 days post assessment	9.1% (n=72)
57 to 84 days post assessment	2.5% (n=20)
85 or more days post assessment	3.3% (n=26)
Range	70 days prior to 141 days post
Mean	17.0 days post assessment
Median	8 days post assessment
Mode	0 days post assessment

[1] Excludes one case where the resident withdrew from the follow-up but the follow-up caregiver interview was completed.

- The follow-up interview was done in conjunction with the resident assessment rather than one year following the baseline family caregiver interview. The length of time between the baseline and follow-up caregiver interviews is shown in Table 27. Some delays reflect caregiver or study nurse availability at either baseline or follow-up.

TABLE 27. LENGTH OF TIME BETWEEN DAL BASELINE AND FOLLOW-UP FAMILY CAREGIVER INTERVIEWS

Length of Time (n=766)[1]	
219 days to 364 days apart	23.6% (n=181)
365 days to 399 days apart	54.0% (n=414)
400 days to 449 days apart	18.7% (n=143)
500 days to 608 days apart	3.7% (n=28)
Range	219 days to 608 days apart
Mean	381.9 days apart
Median	382 days apart

[1] Excludes 25 cases where no baseline interview was done.

- The follow-up interviews were to be conducted via telephone unless the respondent or situation required otherwise; 90.1% were completed by phone.

- The location of the interview was chosen by the family caregiver and/or study nurse.
    - 90.1% (n=713) via telephone
    - 5.9% (n=47) in the facility
    - 2.1% (n=17) in respondent's home
    - 0.9% (n=7) at the respondent's workplace
    - 0.6% (n=5) in a public place
    - 0.3% (n=2) at someone else's home

- The average length of the interviews was 48 minutes (range from 20 minutes to 2.3 hours). The most frequent length was 45 minutes.
- 780 interviews (98.6%) were completed in one sitting; 11 were completed in two parts.
- The average age of the family caregivers was 58 (Table 28).

TABLE 28. AGE OF FAMILY CAREGIVERS: DAL FOLLOW-UP

	DAL Family Caregivers (n=791)
Age Group	
<50	18.0% (n=142)
50-64	55.0% (n=435)
65+	24.9% (n=197)
Refused/Missing	2.1% (n=17)
Age (continuous)	
Range	22-89
Mean	58.22
Median	58
SD	10.39

- 70.0% (n=554) were female caregivers.
- 73.5% of respondents were children (Table 29). Four respondents (spouses) lived at the same facility as the resident (either in the same or a separate room). Three residents lived with the respondent in their own personal home.

TABLE 29. FAMILY CAREGIVER RELATIONSHIP: DAL FOLLOW-UP

Relationship to Resident	DAL Family Caregivers (n=791)
Daughter	49.7% (n=393)
Son	23.8% (n=188)
Daughter/Son-in-law	4.9% (n=39)
Niece/Nephew	4.6% (n=36)
Sibling	3.8% (n=30)
Wife	3.3% (n=26)
Friend	3.0% (n=24)
Husband	2.1% (n=17)
Grandchildren	1.8% (n=14)
Step-relative	0.8% (n=6)
Niece/Nephew-in-law or Great-Niece/Nephew	0.8% (n=6)
Other relatives (sister-in-law, aunt, cousin)	1.5% (n=12)

- 11 family caregivers completed two interviews as they were the identified caregiver for two residents (married couples). Most often the caregivers were their children (n=8), daughter-in-law (n=1), niece (n=1), or friend (n=1). All but 2 of the 11 completed the interviews for both residents either simultaneously or consecutively.

Completed LTC Family Caregiver Baseline Interviews

- LTC baseline family caregiver interviews were conducted between February 2007 and July 2008. The majority (96.0%, n=880) were completed between February 2007 and April 2008.

- Attempts were made to complete the family caregiver interview within one month of the resident assessment. 83% of the interviews were completed within this time frame (Table 30).

TABLE 30. TIME DIFFERENCE BETWEEN LTC BASELINE RESIDENT ASSESSMENT AND FAMILY CAREGIVER INTERVIEW

Time Difference (n=917)	
Prior to assessment	1.9% (n=17)
Within 1 month (0 to 31 days post)	82.7% (n=758)
32 to 56 days post assessment	9.7% (n=89)
57 to 84 days post assessment	4.1% (n=38)
85 or more days post assessment	1.6% (n=15)
Range	22 days prior to 174 days post
Mean	15.8 days post assessment
Median	7 days post assessment
Mode	0 days post assessment

- Baseline interviews were to be conducted in-person whenever possible. The majority of interviews (88.5%) were completed in-person.

- The location of the interview was chosen by the family caregiver and/or study nurse.
    - 54.6% (n=501) in the facility[11]
    - 24.0% (n=220) in respondent's home
    - 6.8% (n=62) in a public place
    - 11.5% (n=105) via telephone
    - 3.1% (n=28) at the respondent's workplace
    - 0.1% (n=1) at someone else's home

- The average length of the interview was 78 minutes (range from 20 minutes to 4 hours). The most frequent length was 1 hour.

- 903 interviews (98.5%) were completed in one sitting; 14 were completed in two parts.

- The average age of the family caregivers was 62 (Table 31).

---

[11] One interview was started in the facility and finished in another person's home.

TABLE 31. AGE OF FAMILY CAREGIVERS: LTC BASELINE

	LTC Family Caregivers (n=917)
Age Group	
<50	14.4% (n=132)
50-64	47.0% (n=431)
65+	37.9% (n=348)
Refused/Missing	0.7% (n=6)
Age (continuous)	
Range	24-95
Mean	61.73
Median	61
SD	12.28

- 69.1% (n=634) were female caregivers.

- 58.6% of caregivers were children (Table 32). 19% of respondents were the resident's spouse, which is higher than the 6% of DAL respondents. One respondent (a spouse) lived at the same facility as the resident (in the same room).

TABLE 32. FAMILY CAREGIVER RELATIONSHIP: LTC BASELINE

Relationship to Resident	**LTC Family Caregivers (n=917)**
Daughter	39.8% (n=365)
Son	18.8% (n=172)
Wife	12.1% (n=111)
Husband	6.9% (n=63)
Sibling	5.2% (n=48)
Daughter/Son-in-law	4.3% (n=39)
Friend	3.9% (n=36)
Niece/Nephew	3.7% (n=34)
Step-relative	1.6% (n=15)
Grandchildren	1.5% (n=14)
Niece/Nephew-in-law or Great-Niece/Nephew	0.8% (n=7)
Other relatives (sister-in-law, cousin, grandson-in-law)	1.4% (n=13)

- 5 family caregivers completed more than one interview as they were the identified caregiver for multiple residents (married couples or religious sisters). Of these, 4 completed the interview for 2 residents while 1 completed it for 3 residents (for a total of 11 residents). Most often the caregivers were the residents' children (n=3), cousin (n=1), or friend (n=1). All 5 completed the interviews for both residents either simultaneously or consecutively.

Completed LTC Family Caregiver Follow-up Interviews

- The location of the 609 residents (at the time of their resident assessment) and whether the same or a new caregiver was interviewed is detailed in Table 33.

TABLE 33. RESIDENT LOCATION AND LTC FOLLOW-UP FAMILY CAREGIVERS

Location of Resident at Time of Assessment	Same Caregiver as Baseline (n=586)	New Caregiver (n=23)	All Caregivers (n=609)
Same LTC facility	95.2% (n=558)	82.6% (n=19)	94.7% (n=577)
Different LTC facility	4.1% (n=24)	17.4% (n=4)	4.6% (n=28)
DAL facility	0.2% (n=1)	---	0.2% (n=1)
Another setting[1]	0.5% (n=3)	---	0.5% (n=3)

[1] Includes lodge (n=1), PAL (n=1), and geriatric psychiatric facility (n=1).

- LTC follow-up family caregiver interviews were completed between February 2008 and May 2009.

- Attempts were made to complete the family caregiver interview as soon as possible after the resident assessment was completed (Table 34).

TABLE 34. TIME DIFFERENCE BETWEEN LTC FOLLOW-UP RESIDENT ASSESSMENT AND FAMILY CAREGIVER INTERVIEW

Time Difference (n=607)[1]	
Prior to assessment	0.7% (n=4)
Within 1 month (0 to 31 days post)	88.8% (n=539)
32 to 56 days post assessment	8.9% (n=54)
57 to 84 days post assessment	1.3% (n=8)
85 or more days post assessment	0.3% (n=2)
Range	1 day prior to 99 days post
Mean	11.6 days post assessment
Median	6 days post assessment
Mode	0 days post assessment

[1] Excludes 2 cases where the resident was unable to be assessed due to location, but the follow-up caregiver interview was completed.

- The follow-up interview was done in conjunction with the resident assessment rather than one year following the baseline family caregiver interview. The length of time between the baseline and follow-up interviews is shown in Table 35. Some delays reflect caregiver or study nurse availability at either baseline or follow-up.

TABLE 35. LENGTH OF TIME BETWEEN LTC BASELINE AND FOLLOW-UP FAMILY CAREGIVER INTERVIEWS

Time Difference (n=601)[1]	
200 days to 364 days apart	44.8% (n=269)
365 days to 399 days apart	47.8% (n=287)
400 days to 464 days apart	7.5% (n=45)
Range	200 days to 464 days apart
Mean	366.2 days apart
Median	368 days apart
Mode	358 days apart

[1] Excludes 8 cases where no baseline interview was done.

- The follow-up interviews were to be conducted via telephone unless the respondent or situation required otherwise; 74.4% were completed by phone.
- The location of the interview was chosen by the family caregiver and/or study nurse.
    - 74.4% (n=453) via telephone
    - 21.5% (n=131) in the facility
    - 2.1% (n=13) in respondent's home
    - 1.6% (n=10) in a public place
    - 0.3% (n=2) at the respondent's workplace
- The average length of the interviews was 52 minutes (range from 10 minutes to 3.75 hours). The most frequent length was 1 hour.
- 602 (98.9%) of the interviews were completed in one sitting, 6 were completed in two parts and 1 was completed in three parts.
- The average age of the family caregivers was 62 (Table 36).

TABLE 36. AGE OF FAMILY CAREGIVERS: LTC FOLLOW-UP

	LTC Family Caregivers (n=609)
Age Group	
<50	11.5% (n=70)
50-64	48.1% (n=293)
65+	39.4% (n=240)
Refused/Missing	1.0% (n=6)
Age (continuous)	
Range	28-96
Mean	62.57
Median	61
SD	12.08

- 68.5% (n=417) were female caregivers.
- 57.6% of caregivers were children (Table 37) and 18.6% were the resident's spouse. One respondent (a spouse) lived at the same facility as the resident (in a different room).
- 2 family caregivers completed two interviews as they were the identified caregiver for two residents (1 married couple and 1 pair of religious sisters). One was a child while the other was a friend. One of the two completed the interviews for both residents consecutively.

TABLE 37. FAMILY CAREGIVER RELATIONSHIP: LTC FOLLOW-UP

Relationship to Resident	**LTC Family Caregivers (n=609)**
Daughter	39.9% (n=243)
Son	17.7% (n=108)
Wife	11.5% (n=70)
Husband	7.1% (n=43)
Sibling	5.1% (n=31)
Daughter/Son-in-law	4.9% (n=30)
Niece/Nephew	4.3% (n=26)
Friend	3.8% (n=23)
Step-relative	2.5% (n=15)
Grandchildren	1.0% (n=6)
Niece/Nephew-in-law or Great-Niece/Nephew	0.7% (n=4)
Other relatives (sister/brother-in-law, cousin)	1.6% (n=10)

Discharge & Decedent Interviews

Discharge to higher levels of care (e.g., a move from DAL to LTC) and death were considered outcomes of interest for ACCES. As such, attempts were made to interview a family caregiver after these transitions. In this section, information regarding the tracking of discharge/deaths, the interviews, and the respondents is provided.

Tracking Transitions

A discharge tracking form for each participating resident was left with the facility and/or Home Care (see Appendix K for a sample form). At the time of any discharge (i.e., discharged from the facility and not returning) or death, these forms were to be filled out and faxed to the study coordinator who then arranged for a discharge or decedent interview to be completed with the family caregiver. These forms were to be sent in until all follow-up assessments at a facility had been completed.

Discharge Interviews

In the event of a discharge from the baseline facility (with no expectation of return), study assessors/interviewers/co-ordinators attempted to complete a discharge interview with the resident's family caregiver. See Appendix D for information on study assessors/interviewers and Appendix J for information about the design of the discharge interviews and key measurements.

- By the 1-year follow-up, 16.1% (n=336; DAL=26.2%, n=285; LTC=5.1%, n=51) of residents had been discharged from their baseline facility. Of these, 71 (DAL=59, LTC=12) subsequently died.
- Of these 336 residents who moved, discharge interviews were completed for 70.5% (n=237; DAL=199; LTC=38).
- The remaining 29.5% (n=99; DAL=86; LTC=13) of discharged residents did not have a family caregiver complete the discharge interview.
    - 10.4% (n=35; DAL=30; LTC=5) of residents died prior to the discharge interview being completed (a decedent interview was then attempted).
    - 6.3% (n=21; DAL=21) were due for their follow-up assessment in less than 1 month and the discharge interview was not completed (instead a "moves addendum" was completed as part of the follow-up caregiver interview to get information about the moves).
    - 5.7% (n=19; DAL=15; LTC=4) had no baseline caregiver interview and an attempt to complete the discharge interview was not made (caregiver refused or was unable to be contacted or the resident died prior to the baseline caregiver interview).
    - 4.8% (n=16; DAL=14; LTC=2) had caregivers who were unable to be contacted for the discharge interview.
    - 1.2% (n=4; DAL=2; LTC=2) were not completed due to study coordination error.

  - 0.6% (n=2; DAL=2) had caregivers who withdrew from participation (1 was not interested and 1 had no time).
  - 0.3% (n=1; DAL=1) had caregivers who were interviewed at baseline but had died, and no other caregiver was available or willing to participate.
  - 0.3% (n=1; DAL=1) had no eligible caregiver identified at baseline or follow-up.

- Of the 237 completed discharge interviews, 3.4% (n=8; DAL=6; LTC=2) were completed with new family caregivers.
  - For 2 residents, the caregiver interviewed at follow-up had been present for the baseline interview but was not the primary respondent.
  - 3 caregivers interviewed at baseline were no longer involved with the resident.
  - 2 caregivers interviewed at baseline were not willing to participate further.
  - 1 caregiver interviewed at baseline was away for an extended period of time during follow-up.

- The location of the 237 residents (at the time of their discharge interview) is detailed in Table 38.

TABLE 38. RESIDENT LOCATION AT THE TIME OF THE COMPLETED DISCHARGE INTERVIEWS

Location of Resident	**DAL Residents (n=199)**	**LTC Residents (n=38)**	**All Residents (n=237)**
Long-term care facility	65.3% (n=130)	84.2% (n=32)	68.4% (n=162)
DAL or Residential facility	13.1% (n=26)	5.3% (n=2)	11.8% (n=28)
Acute Care	13.1% (n=26)	2.6% (n=1)	11.4% (n=27)
Rehab Facility or Subacute Unit	3.5% (n=7)	-----	3.0% (n=7)
Private Assisted Living	1.5% (n=3)	5.3% (n=2)	2.1% (n=5)
Private Home/Apt	2.0% (n=4)	-----	1.7% (n=4)
Hospice or Palliative Care	1.0% (n=2)	-----	0.8% (n=2)
Private LTC	0.5% (n=1)	-----	0.4% (n=1)
Psychiatric Hospital/ Unit	-----	2.6% (n=1)	0.4% (n=1)

- DAL discharge interviews were completed between June 2006 and October 2008. LTC discharge interviews were completed between April 2007 and April 2009.
- Attempts were made to complete the discharge interview within two to four weeks of the discharge. 28% of the interviews were completed within the 4 week time frame (Table 39). This time frame often was not feasible due to various circumstances (not being informed of the discharge in a timely fashion or until it was discovered when the follow-up assessment was attempted, difficulty reaching caregivers, nurse availability, etc.).

TABLE 39. TIME DIFFERENCE BETWEEN DISCHARGE FROM FACILITY AND DISCHARGE INTERVIEW

Time Difference	DAL (n=199)	LTC (n=38)
Within 1 month of discharge (0 to 31 days post)	31.7% (n=63)	7.9% (n=3)
32 to 56 days post discharge	26.1% (n=52)	21.1% (n=8)
57 to 84 days post discharge	17.1% (n=34)	18.4% (n=7)
85 or more days post discharge	25.1% (n=50)	52.6% (n=20)
Range	3 to 333 days post	23 to 309 days post
Mean	71.9 days post discharge	113.2 days post discharge
Median	49 days post discharge	89 days post discharge
Mode	26 days post discharge	Multiple modes

- The discharge interviews were to be conducted via telephone unless the respondent or situation required otherwise; 97% were completed by phone.

- The location of the interview was chosen by the family caregiver and/or study nurse.
    - 97.0% (n=230; DAL=98.5%, n=196; LTC=89.5%; n=34) via telephone
    - 1.3% (n=3; DAL=1.0%, n=2; LTC=2.6%; n=1) in respondent's home
    - 0.8% (n=2; DAL=0.5%, n=1; LTC=2.6%; n=1) in the facility
    - 0.8% (n=2; LTC=5.3%; n=2) in a public place

- The average length was 21 minutes for the DAL discharge interviews and 22 minutes for the LTC discharge interviews. The interviews ranged from 10 minutes to 1 hour and the most frequent length was 15 minutes.
    - 36 (15.2%) of the discharge interviews were completed together with the baseline or follow-up caregiver interview. Two (DAL) interviews were done in conjunction with the baseline and 34 (23 DAL, 11 LTC) were completed with the follow-up interview. As these two interviews were completed consecutively, some of the interview lengths actually reflect the total time to complete both interviews.

- 234 discharge interviews (98.7%) were completed in one sitting; 3 were completed in two parts.

DISCHARGE INTERVIEW RESPONDENTS

- The average age of the family caregivers who completed the discharge interview was 59 (Table 40).

- 71.7% (n=170; DAL=70.9%, n=141; LTC=76.3%, n=29) were female caregivers.

TABLE 40. AGE OF FAMILY CAREGIVERS: DAL AND LTC DISCHARGE INTERVIEW

	DAL Family Caregivers (n=199)	LTC Family Caregivers (n=38)	All Family Caregivers (n=237)
Age Group			
<50	14.6% (n=29)	5.3% (n=2)	13.1% (n=31)
50-64	56.3% (n=112)	60.5% (n=23)	57.0% (n=135)
65+	26.1% (n=52)	28.9% (n=11)	26.6% (n=63)
Refused/Missing	3.0% (n=6)	5.3% (n=2)	3.4% (n=8)
Age (continuous)			
Range	38-91	37-87	37-91
Mean	58.58	61.97	59.11
Median	57	60	58
SD	9.36	12.09	9.88

- 72.6% of respondents were children (Table 41).

TABLE 41. FAMILY CAREGIVER RELATIONSHIP: DAL AND LTC DISCHARGE INTERVIEW

Relationship to Resident	DAL Family Caregivers (n=199)	LTC Family Caregivers (n=38)	All Family Caregivers (n=237)
Daughter	52.8% (n=105)	34.2% (n=13)	49.8% (n=118)
Son	24.1% (n=48)	15.8% (n=6)	22.8% (n=54)
Daughter/Son-in-law	4.0% (n=8)	10.5% (n=4)	5.1% (n=12)
Niece/Nephew	5.0% (n=10)	2.6% (n=1)	4.6% (n=11)
Sibling	4.5% (n=9)	2.6% (n=1)	4.2% (n=10)
Wife	1.5% (n=3)	10.5% (n=4)	3.0% (n=7)
Friend	2.5% (n=5)	5.3% (n=2)	3.0% (n=7)
Step-relative	1.5% (n=3)	5.3% (n=2)	2.1% (n=5)
Husband	0.5% (n=1)	7.9% (n=3)	1.7% (n=4)
Grandchildren	0.5% (n=1)	2.6% (n=1)	0.8% (n=2)
Niece/Nephew-in-law or Great-Niece/Nephew	1.0% (n=2)	-----	0.8% (n=2)
Other relatives (sister-in-law, cousin)	2.0% (n=4)	2.6% (n=1)	2.1% (n=5)

- 4 family caregivers completed two discharge interviews as they were the indentified caregiver for two residents (married couples). All four were daughters. Two of the four completed the interviews for both residents either simultaneously or consecutively.

Decedent Interviews

When a resident died prior to the 1-year follow-up assessment, attempts were made to complete a decedent interview with a family caregiver. In some instances, the facility informed the study coordinator about the death when it occurred, while in other instances, a death was noted when the coordinator was doing a check on the residents' status. Prior to contacting the family caregiver, a sympathy card/letter was sent. See Appendix D for information on study assessors/interviewers and Appendix J for information about the design of the decedent interviews and key measurements.

- By the 1-year follow-up, 23% (n=480; DAL=16.1%, n=175; LTC=30.5%, n=305) of residents had died.
- Of these 480 residents who died, decedent interviews were completed for 87.7% (n=421; DAL=148; LTC=273).
- The remaining 12.3% (n=59; DAL=27; LTC=32) of deceased residents did not have a family caregiver complete the decedent interview.
    - 9.2% (n=44; DAL=20; LTC=24) had no baseline caregiver interview and an attempt to complete the decedent interview was not made (caregiver refused or was unable to be contacted or the resident died prior to the baseline caregiver interview).
    - 1.7% (n=8; DAL=5; LTC=3) had caregivers who were unable to be contacted for the decedent interview.
    - 1.5% (n=7; DAL=2; LTC=5) had caregivers who withdrew from participation (4 were not interested, 2 had no time, and 1 felt it was too upsetting).
- Of the 421 completed decedent interviews, 1.2% (n=5; DAL=2; LTC=3) were completed with new family caregivers.
    - For 2 residents, the caregiver interviewed at follow-up had been present for the baseline interview but was not the primary respondent.
    - 2 caregivers interviewed at baseline were deceased.
    - 1 caregiver interviewed at baseline was away for an extended period of time during follow-up.
- DAL decedent interviews were completed between April 2006 and September 2008. LTC decedent interviews were completed between March 2007 and April 2009.
- Attempts were made to complete the decedent interview within four to six weeks of the death. Only 9.5% of the interviews were completed within this 6 week time frame (Table 42). The time frame often was not feasible due to various circumstances (not being informed of the death in a timely fashion or until it was discovered when the follow-up assessment was attempted, difficulty reaching caregivers, nurse availability, etc.).

TABLE 42. TIME DIFFERENCE BETWEEN DEATH AND DECEDENT INTERVIEW

Time Difference	**DAL (n=148)**	**LTC (n=273)**
Within 6 weeks of death (0 to 42 days post)	13.5% (n=20)	7.3% (n=20)
42 to 56 days post death	22.3% (n=33)	13.2% (n=36)
57 to 84 days post death	19.6% (n=29)	33.7% (n=92)
85 or more days post death	44.6% (n=66)	45.8% (n=125)
Range	0 to 461 days post death	9 to 371 days post death
Mean	110.7 days post death	101.3 days post death
Median	79 days post death	80 days post death
Mode	54 days post death	Multiple modes

- The decedent interviews were to be conducted via telephone unless the respondent or situation required otherwise; 99% were completed by phone.

- The location of the interview was chosen by the family caregiver and/or the interviewer.
    - 99.3% (n=418; DAL=99.3%, n=147; LTC=99.3%; n=271) via telephone
    - 0.5% (n=2; DAL=0.7%, n=1; LTC=0.4%; n=1) in respondent's home
    - 0.2% (n=1; LTC=0.4%; n=1) in the facility

- The average length was 21 minutes for the DAL decedent interviews and 20 minutes for the LTC discharge interviews. The interviews ranged from 5 minutes to 2.5 hours and the most frequent length was 15 minutes.
    - 5 (1.2%) of the decedent interviews were a "combination decedent/family" interview. These were used when the resident died prior to the baseline interview being completed and consisted of the completed decedent interview and a shortened caregiver interview. These interviews constitute all 3 decedent interviews recorded as being more than 1 hour in length.

- 420 decedent interviews (99.8%) were completed in one sitting; 1 was completed in two parts.

DECEDENT INTERVIEW RESPONDENTS

- The average age of the family caregivers who completed the decedent interviews was 62 (Table 43).

- 71.3% (n=300; DAL=73.6%, n=109; LTC=70%, n=191) were female caregivers.

TABLE 43. AGE OF FAMILY CAREGIVERS: DAL AND LTC DECEDENT INTERVIEW

	DAL Family Caregivers (n=148)	LTC Family Caregivers (n=273)	All Family Caregivers (n=421)
Age Group			
<50	13.5% (n=20)	11.7% (n=32)	12.4% (n=52)
50-64	52.7% (n=78)	44.7% (n=122)	47.5% (n=200)
65+	32.4% (n=48)	42.5% (n=116)	39.0% (n=164)
Refused/Missing	1.4% (n=2)	1.1% (n=3)	1.2% (n=5)
Age (continuous)			
Range	39-92	24-91	24-92
Mean	60.44	63.16	62.21
Median	59	62	62
SD	10.52	12.63	11.99

- 66.1% of respondents were children (Table 44). 14.2% were the spouse of the resident.

TABLE 44. FAMILY CAREGIVER RELATIONSHIP: DAL AND LTC DECEDENT INTERVIEW

Relationship to Resident	DAL Family Caregivers (n=148)	LTC Family Caregivers (n=273)	All Family Caregivers (n=421)
Daughter	51.4% (n=76)	41.0% (n=112)	44.7% (n=188)
Son	23.0% (n=34)	20.5% (n=56)	21.4% (n=90)
Wife	6.1% (n=9)	12.5% (n=34)	10.2% (n=43)
Daughter/Son-in-law	4.7% (n=7)	4.0% (n=11)	4.3% (n=18)
Husband	1.4% (n=2)	5.5% (n=15)	4.0% (n=17)
Friend	4.1% (n=6)	4.0% (n=11)	4.0% (n=17)
Sibling	1.4% (n=2)	5.1% (n=14)	3.8% (n=16)
Niece/Nephew	2.7% (n=4)	3.3% (n=9)	3.1% (n=13)
Grandchildren	1.4% (n=2)	1.8% (n=5)	1.7% (n=7)
Step-relative	2.7% (n=4)	-----	0.9% (n=4)
Niece/Nephew-in-law or Great-Niece/Nephew	0.7% (n=1)	1.1% (n=3)	0.9% (n=4)
Other relatives (sister-in-law, cousin)	0.7% (n=1)	1.1% (n=3)	0.9% (n=4)

Discharge/Death Outcome Information

Since the discharge/decedent interviews were based on the memory and knowledge of the family caregiver, causes of deaths and exact dates were often unknown. As a result, an Outcome Dates Summary File which tracked all discharges and deaths was created. It was based on the information from the Discharge Tracking form, the discharge/decedent interviews, and the Moves Addendum (a short addition to the follow-up family caregiver interview that included information on all moves occurring between baseline and follow-up) for all residents who moved/died (regardless of whether or not a discharge/decedent interview was completed).

This summary file includes the most comprehensive information available about the transitions, including the date and cause of death, date of first move out of the baseline facility, date of initial LTC placement, date and information about all moves, etc. The information received from the facility/Home Care was considered the best source of information. Information from the discharge/decedent interviews or moves addendums with the family caregivers were only used if there was missing information on the tracking form or if there were inconsistencies and the information from family caregivers was deemed more accurate. In addition, information is available for those who did not have a discharge/decedent interview completed. As such, when examining these transitions of care and the dates and causes associated with them, the Outcome Dates Summary File should be used instead of the information collected in the discharge/decedent interviews.

ADMINISTRATIVE HEALTH DATA

Consent to access residents' health service utilization (hospitalizations, emergency room visits, and day procedures) information was provided for 2049 residents (1069 DAL, 980 LTC), by either the resident or their surrogate decision-maker, representing 98% of the study population (see Appendix F for a sample consent form). Data were obtained from data custodians from Alberta Health and Wellness and the former Regional Health Authorities. The data can be linked with other components of ACCES to examine factors associated with health service use and health outcomes.

Episode of care data for all inpatient hospitalizations in the province (core data elements abstracted from the Alberta Discharge Abstract Database (DAD)) included:

- admission and discharge dates;
- most responsible diagnosis (and ICD-10-CA code);
- additional diagnoses (ICD-10-CA codes, up to 24 additional diagnoses may be listed) with associated codes for diagnoses types and prefixes;
- intervention/procedures and dates (CCI codes, up to 20 may be listed);
- institution admitted from and transferred to; and
- total length of stay (LOS) (includes acute LOS and Alternate Level of Care or ALC and non-acute LOS).

Additional data elements available from the Ambulatory Care Classification System (ACCS) Database for emergency and day procedures included:

- visit date;
- mode of visit (face to face, off site, etc.);
- provider type(s);
- main diagnosis and up to 9 secondary diagnoses (ICD-10-CA codes), with additional diagnostic elements (diagnosis prefix);
- main intervention/procedure and up to 9 other interventions (CCI codes);
- whether admitted by ambulance;
- institution admitted from and transferred to; and
- disposition (service recipient's type of separation from ambulatory care service).

REFERENCES

Hawes, C., Phillips, C.D., & Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly: Final Report*. Beachwood, OH: Myers Research Institute, Menorah Park Center for Senior Living.

MSHA Research Group. (1998). *Follow-up to the Manitoba Study of Health and Aging (MSHA-2): Methodology*. Winnipeg, MB: Centre on Aging, University of Manitoba.

Sangl, J., Buchanan, J., Cosenza, C., Bernard, S., Keller, S., Mitchell, N., Brown, J., Castle, N., Sekscenski, E., & Larwood, D. (2007). The development of CAPHS® Instrument for Nursing Home Residents (NHCAHPS). *Journal of Aging & Social Policy, 2*, 63-82.

Strain, L.A., Maxwell, C.J., Wanless, D., & Gilbart, E. (2011). *Designated Assisted Living (DAL) and Long-term Care (LTC) in Alberta: Selected Highlights from the Alberta Continuing Care Epidemiological Studies (ACCES)*. Edmonton, AB: ACCES Research Group, University of Alberta.

APPENDIX A: SAMPLE SIZES BY HEALTH REGION

Five former Alberta Regional Health Authorities (RHAs) participated in ACCES. The sample sizes of DAL and LTC facilities, residents, and family caregivers are presented below.

TABLE A-1. SAMPLE SIZE: FACILITIES

Region	**DAL Facilities (n=59)**	**LTC Facilities (n=54)**
Calgary Health Region	22.0% (n=13)	25.9% (n=14)
Chinook Health Region	18.6% (n=11)	14.8% (n=8)
David Thompson Health Region	20.3% (n=12)	18.5% (n=10)
Capital Health	23.7% (n=14)	25.9% (n=14)
East Central Health	15.3% (n=9)	14.8% (n=8)

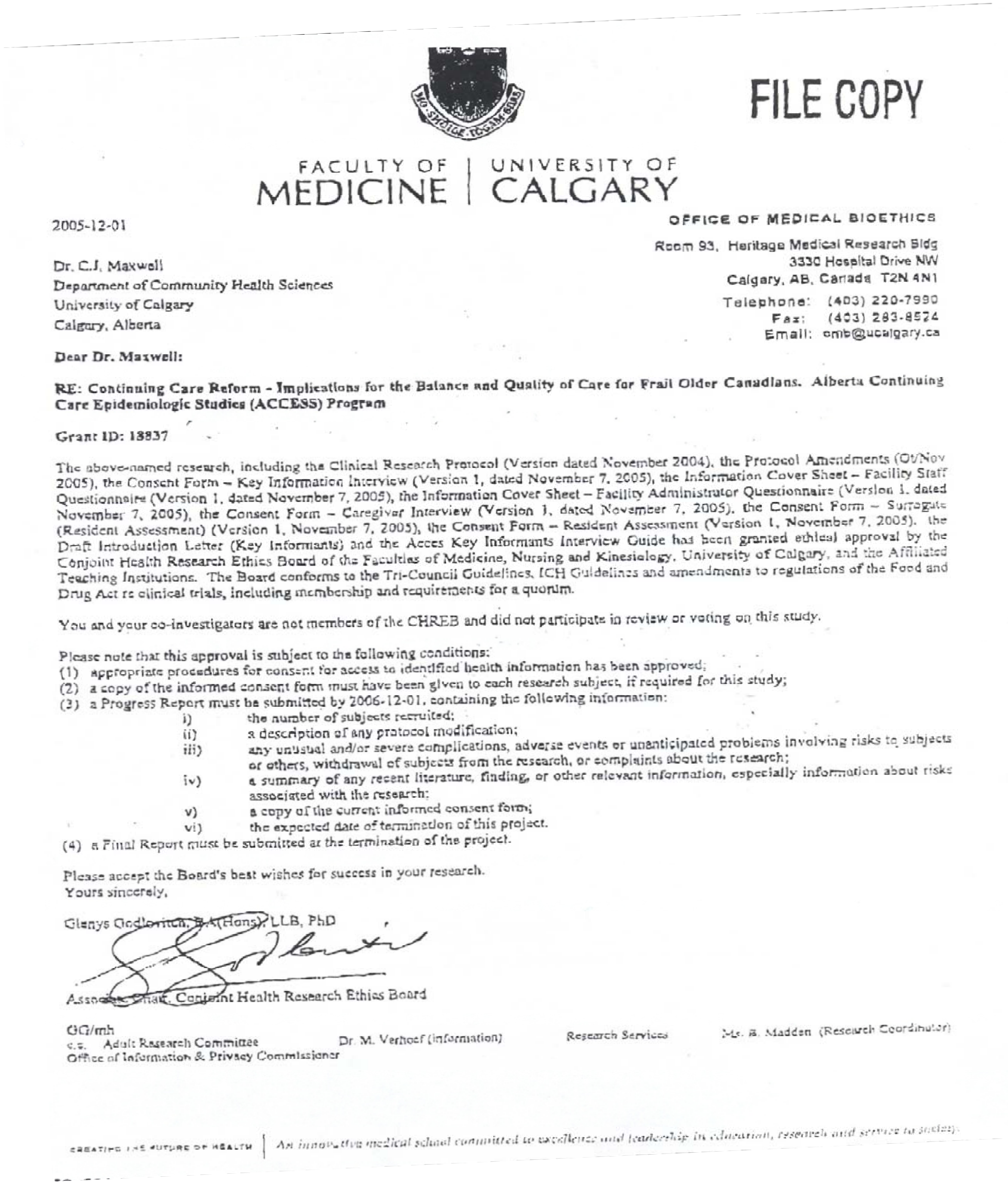
TABLE A-2. SAMPLE SIZE: RESIDENTS

	DAL Residents		**LTC Residents**	
Region	**Baseline (n=1089)**	**Follow-up (n=892)**	**Baseline (n=1000)**	**Follow-up (n=691)**
Calgary Health Region	28.6% (n=311)	30.0% (n=268)	29.6% (n=296)	30.7% (n=212)
Chinook Health Region	21.5% (n=234)	19.4% (n=173)	20.6% (n=206)	19.8% (n=137)
David Thompson Health Region	14.2% (n=155)	14.3% (n=128)	14.9% (n=149)	13.7% (n=95)
Capital Health	25.8% (n=281)	26.9% (n=240)	23.9% (n=239)	23.9% (n=165)
East Central Health	9.9% (n=108)	9.3% (n=83)	11.0% (n=110)	11.9% (n=82)

TABLE A-3. SAMPLE SIZE: FAMILY CAREGIVERS

	DAL Family Caregivers		**LTC Family Caregivers**	
Region	**Baseline (n=974)**	**Follow-up (n=791)**	**Baseline (n=917)**	**Follow-up (n=609)**
Calgary Health Region	28.1% (n=274)	30.1% (n=238)	29.4% (n=270)	31.7% (n=193)
Chinook Health Region	19.3% (n=188)	18.2% (n=144)	19.4% (n=178)	18.4% (n=112)
David Thompson Health Region	15.1% (n=147)	15.2% (n=120)	15.7% (n=144)	14.3% (n=87)
Capital Health	27.4% (n=267)	26.8% (n=212)	24.1% (n=221)	23.2% (n=141)
East Central Health	10.1% (n=98)	9.7% (n=77)	11.3% (n=104)	12.5% (n=76)

APPENDIX B: ETHICAL APPROVAL



FILE COPY

FACULTY OF MEDICINE | UNIVERSITY OF CALGARY

OFFICE OF MEDICAL BIOETHICS
Room 93, Heritage Medical Research Bldg
3330 Hospital Drive NW
Calgary, AB, Canada T2N 4N1
Telephone: (403) 220-7990
Fax: (403) 283-8524
Email: omb@ucalgary.ca

2005-12-01

Dr. C.J. Maxwell
Department of Community Health Sciences
University of Calgary
Calgary, Alberta

Dear Dr. Maxwell:

RE: Continuing Care Reform - Implications for the Balance and Quality of Care for Frail Older Canadians. Alberta Continuing Care Epidemiologic Studies (ACCESS) Program

Grant ID: 18837

The above-named research, including the Clinical Research Protocol (Version dated November 2004), the Protocol Amendments (01/Nov 2005), the Consent Form – Key Information Interview (Version 1, dated November 7, 2005), the Information Cover Sheet – Facility Staff Questionnaire (Version 1, dated November 7, 2005), the Information Cover Sheet – Facility Administrator Questionnaire (Version 1, dated November 7, 2005), the Consent Form – Caregiver Interview (Version 1, dated November 7, 2005), the Consent Form – Surrogate (Resident Assessment) (Version 1, November 7, 2005), the Consent Form – Resident Assessment (Version 1, November 7, 2005), the Draft Introduction Letter (Key Informants) and the Acces Key Informants Interview Guide has been granted ethical approval by the Conjoint Health Research Ethics Board of the Faculties of Medicine, Nursing and Kinesiology, University of Calgary, and the Affiliated Teaching Institutions. The Board conforms to the Tri-Council Guidelines, ICH Guidelines and amendments to regulations of the Food and Drug Act re clinical trials, including membership and requirements for a quorum.

You and your co-investigators are not members of the CHREB and did not participate in review or voting on this study.

Please note that this approval is subject to the following conditions:
(1) appropriate procedures for consent for access to identified health information has been approved;
(2) a copy of the informed consent form must have been given to each research subject, if required for this study;
(3) a Progress Report must be submitted by 2006-12-01, containing the following information:
    i) the number of subjects recruited;
    ii) a description of any protocol modification;
    iii) any unusual and/or severe complications, adverse events or unanticipated problems involving risks to subjects or others, withdrawal of subjects from the research, or complaints about the research;
    iv) a summary of any recent literature, finding, or other relevant information, especially information about risks associated with the research;
    v) a copy of the current informed consent form;
    vi) the expected date of termination of this project.
(4) a Final Report must be submitted at the termination of the project.

Please accept the Board's best wishes for success in your research.
Yours sincerely,

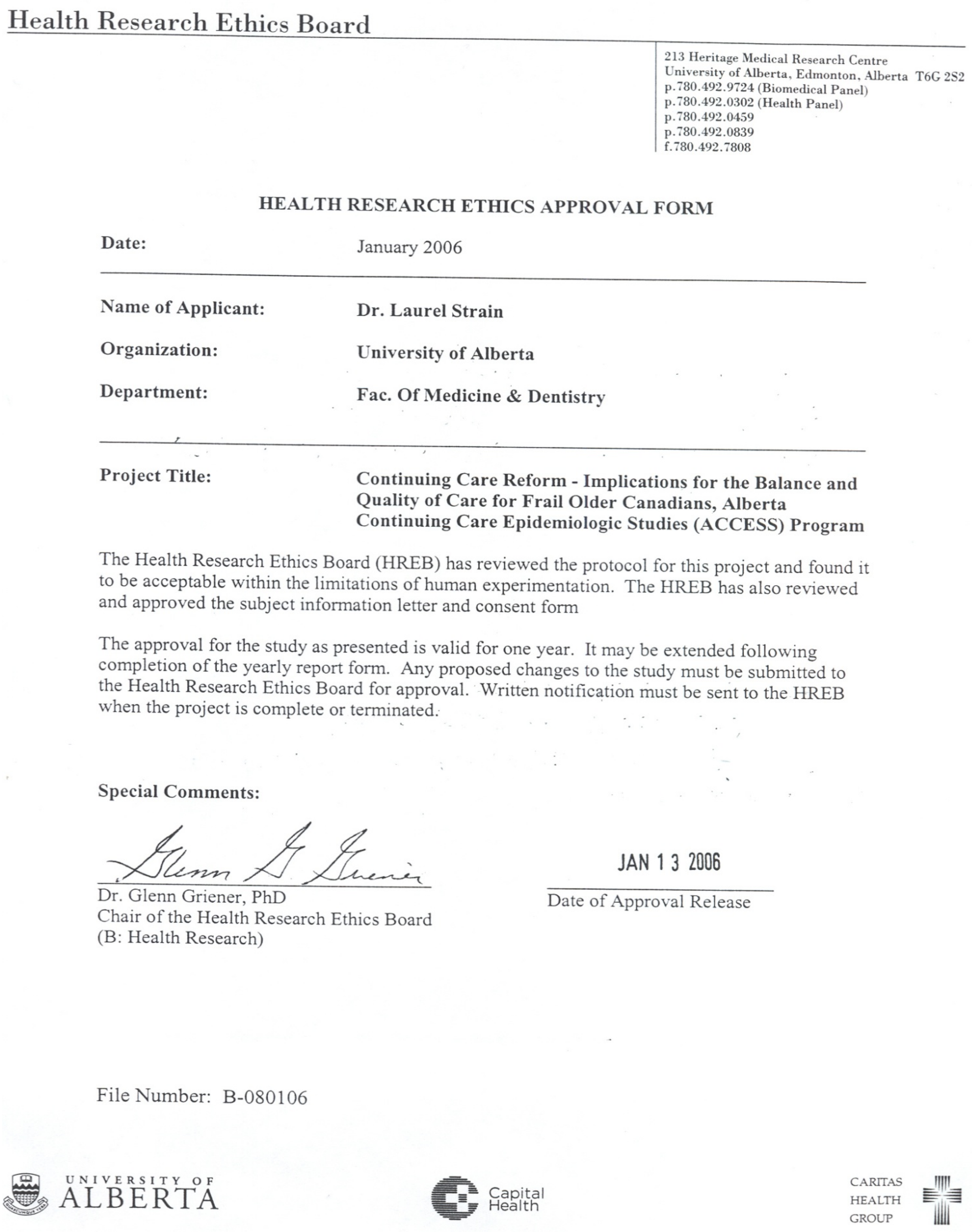
Glenys Godlovitch, B.A.(Hons), LLB, PhD

Associate Chair, Conjoint Health Research Ethics Board

GG/mh
c.c. Adult Research Committee Dr. M. Verhoef (information) Research Services Ms. B. Madden (Research Coordinator)
Office of Information & Privacy Commissioner

CREATING THE FUTURE OF HEALTH | *An innovative medical school committed to excellence and leadership in education, research and service to society.*

Appendix B: Ethical Approval



Health Research Ethics Board

213 Heritage Medical Research Centre
University of Alberta, Edmonton, Alberta T6G 2S2
p.780.492.9724 (Biomedical Panel)
p.780.492.0302 (Health Panel)
p.780.492.0459
p.780.492.0839
f.780.492.7808

HEALTH RESEARCH ETHICS APPROVAL FORM

Date:	January 2006
Name of Applicant:	**Dr. Laurel Strain**
Organization:	**University of Alberta**
Department:	**Fac. Of Medicine & Dentistry**
Project Title:	**Continuing Care Reform - Implications for the Balance and Quality of Care for Frail Older Canadians, Alberta Continuing Care Epidemiologic Studies (ACCESS) Program**

The Health Research Ethics Board (HREB) has reviewed the protocol for this project and found it to be acceptable within the limitations of human experimentation. The HREB has also reviewed and approved the subject information letter and consent form

The approval for the study as presented is valid for one year. It may be extended following completion of the yearly report form. Any proposed changes to the study must be submitted to the Health Research Ethics Board for approval. Written notification must be sent to the HREB when the project is complete or terminated.

Special Comments:

Glenn G. Griener

Dr. Glenn Griener, PhD
Chair of the Health Research Ethics Board
(B: Health Research)

JAN 13 2006

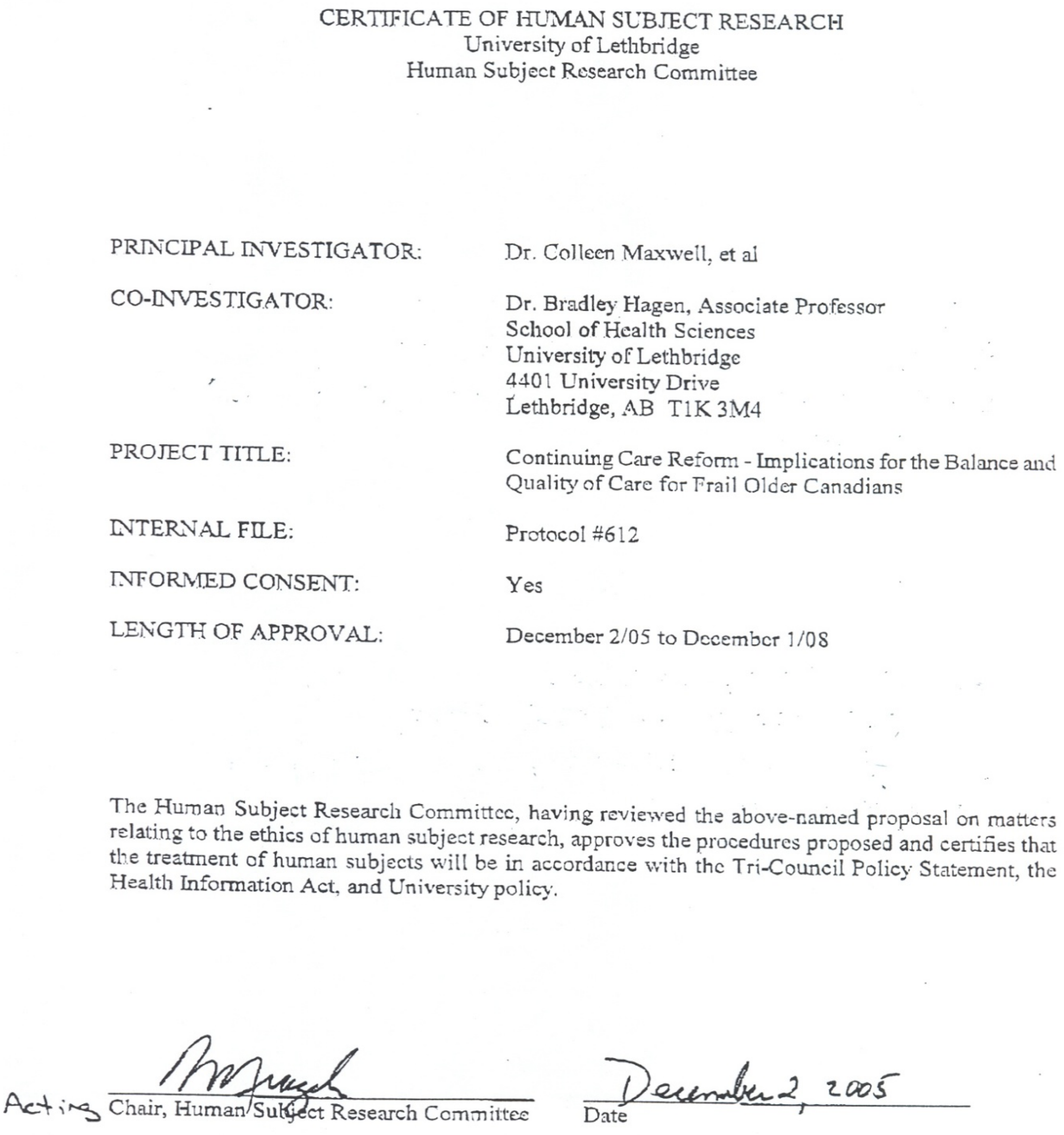
Date of Approval Release

File Number: B-080106

UNIVERSITY OF ALBERTA

Capital Health

CARITAS HEALTH GROUP



CERTIFICATE OF HUMAN SUBJECT RESEARCH
University of Lethbridge
Human Subject Research Committee

PRINCIPAL INVESTIGATOR:	Dr. Colleen Maxwell, et al
CO-INVESTIGATOR:	Dr. Bradley Hagen, Associate Professor School of Health Sciences University of Lethbridge 4401 University Drive Lethbridge, AB T1K 3M4
PROJECT TITLE:	Continuing Care Reform - Implications for the Balance and Quality of Care for Frail Older Canadians
INTERNAL FILE:	Protocol #612
INFORMED CONSENT:	Yes
LENGTH OF APPROVAL:	December 2/05 to December 1/08

The Human Subject Research Committee, having reviewed the above-named proposal on matters relating to the ethics of human subject research, approves the procedures proposed and certifies that the treatment of human subjects will be in accordance with the Tri-Council Policy Statement, the Health Information Act, and University policy.

Acting Chair, Human Subject Research Committee

December 2, 2005
Date

APPENDIX C: FACILITY SURVEY MEASURES

The facility surveys included some questions from a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000) while other questions were selected/developed specifically for ACCES. Questions were modified or developed to fit the Alberta continuing care context (see Table C-1 for topics and coverage for DAL and LTC).

TABLE C-1. FACILITY SURVEY QUESTIONS

	DAL	LTC
Respondent Background		
- position[1]	✓	✓
- length of time in current position[1]	✓	✓
- professional qualifications[1]	✓	✓
- prior work in health care sector[1]	✓	✓
Facility Ownership and Size		
- ownership status[2]	✓	✓
- part of chain of facilities[2]	✓	✓
- length of operation[3]	✓	✓
- number of DAL/LTC spaces available/occupied	✓	✓
- distribution of DAL/LTC beds among units	✓	✓
- Alzheimer's/dementia spaces[1]	✓	✓
- specially designated LTC spaces	---	✓
- waiting list[2]	✓	✓
- other levels of care/housing on site and number of spaces[3]	✓	✓
Staffing	✓	✓
- PCA/LPN/RN coverage on-site and on-call	✓	✓
- multi-skilled PCAs[2]	✓	✓
- PCA/LPN/RN affiliation (facility, Home Care or contract staff)	✓	✓
- LPN/RN tasks	✓	✓
- PCA/LPN/RN staff shift information	✓	✓
- PCA/LPN/RN non-shift hours of care information	✓	✓
- PCA/LPN/RN approved FTE and staff-to-resident ratios	✓	✓
- PCA/LPN/RN annual turnover[2]	✓	✓
- PCA/LPN/RN part-time, full-time and casual staff numbers	---	✓
- training/orientation for direct care staff[1]	✓	✓
- cross-training of staff[1]	✓	✓
- crossover of acute care and LTC staff	---	✓
- % of direct care staff ESL	✓	✓
- other health/care professionals staff members or consultants[2]	✓	✓
- physician affiliation	✓	✓
- challenges to adequate staffing[4]	✓	✓
- options to cover shifts when staff shortages exist	✓	✓

	DAL	LTC
Facility Services and Policies		
- who administers/stores prescription medications[1]	✓	✓
- storage of prescription medications	✓	✓
- medication review process	---	✓
- meal times[2]	✓	✓
- common dining area & expectation of residents to walk/wheel self	✓	✓
- ability to meet special dietary requirements and preferences	✓	✓
- residents able to store & cook food in rooms, have meals delivered to rooms	✓	✓
- residents able to bring personal furniture[2]	✓	✓
- residents able to physically change rooms	✓	✓
- residents able to have pets[2]	✓	✓
- facility pets[2]	✓	✓
- visiting pets allowed	✓	✓
- options for overnight guests	✓	✓
- spousal suites	✓	✓
- visiting hours/restrictions[2]	✓	✓
- dress code for common areas	✓	✓
- outside amenities	✓	✓
- if facility has dementia spaces, is there a secure outside area for residents to use	✓	✓
- services provided or arranged by the facility and if part of base fee or extra charge[2]	✓	✓
- lowest and highest base rate[3]	✓	✓
- variations in monthly charge	✓	✓
- usual practice if resident is ill and requires nursing care beyond capability of facility[1]	✓	✓
- does staff perform CPR	✓	✓
- under which conditions would a resident be sent to an ER	✓	✓
- admission/retention criteria[1]	✓	✓
- impact of new provincial standards for care and accommodation	---	✓
- challenges & strengths of DAL/LTC for residents, family, staff, management and regional health authority	✓	✓
- changes would like to see in DAL/LTC in next 3 years	✓	✓

Questions taken or modified from:

[1] Hawes, C., Phillips, C., & Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly*. Beachwood, OH: Myers Research Institute, Memorah Park Center for Senior Living. Questions from Operator In-person Interview.

[2] Hawes, C., Phillips, C., & Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly*. Beachwood, OH: Myers Research Institute, Memorah Park Center for Senior Living. Questions from Operator Supplement (Self-Administered).

[3] Hawes, C., Phillips, C., & Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly*. Beachwood, OH: Myers Research Institute, Memorah Park Center for Senior Living. Questions from Facility Screening Questionnaire.

[4] Nova Scotia Nursing Home Provincial Survey, 2001 (Research and Recommendations of the Task Force on Resident/Staff Ratio in Nursing Homes, February 2002, http://www.gov.ns.ca/health/reports/pubs/taskforce_report_nursing_homes.pdf).

APPENDIX D: ACCES ASSESSORS/INTERVIEWERS

Over the data collection period, a total of 36 assessors/interviewers and 4 study coordinators were employed. Due to the complexity of ACCES assessments and interviews, it was important to hire RNs who had prior continuing care and/or Home Care experience as these nurses had an existing knowledge of the clientele in DAL and LTC. This proved challenging due to an employee shortage throughout the province. Several individuals hired as ACCES assessors/interviewers were retired or semi-retired and many were not interested in or able to work full-time, which led to delays in data collection to some extent. While some individuals were employed for the entire study duration, others worked for a shorter period of time for various reasons (i.e., quit as they did not enjoy the work or had other time commitments; were let go as not enough work for all assessors/interviewers; hired later in data collection; etc.).

Training

All assessors/interviewers and study coordinators received extensive training. An initial training session on the interRAI-AL (led by two designers of the tool), the Views of Residents Survey and family caregiver interviews (conducted by the designer of the family caregiver interview) was held in Calgary with an initial group of assessors/interviewers and two study coordinators. After that, training was held as data collection began in each of the remaining four health regions, and was conducted by a principal investigator and study coordinator. Similar training sessions were held prior to beginning the LTC baseline assessments/interviews (including training on the interRAI-LTCF tool) and the DAL and LTC follow-up assessments/interviews. After these training sessions, any newly hired assessors/interviewers were trained in a one-on-one session with the study coordinator. In addition, individuals conducting discharge/decedent interviews or facility surveys were trained to do so by a study coordinator.

Number of Assessments/Interviews by Assessor/Interviewer

The number of assessments/interviews completed by each study assessor/interview or coordinator is provided for the facility survey (Table D-1), the interRAI assessments (Table D-2), the Views of Residents Survey (Table D-3), the family caregiver interviews (Table D-4), and the discharge/decedent interviews (Table D-5).

TABLE D-1. COMPLETED FACILITY SURVEYS BY ASSESSOR/INTERVIEWER

Assessor/Interviewer ID #	DAL Facility Surveys Completed (n=59)	LTC Facility Surveys Completed (n=54)	Total Facility Surveys Completed (n=113)
03	2	---	2
05	4	22	26
07*	7	---	7
12*	11	---	11
51*	35	32	67

* = study coordinator

TABLE D-2. COMPLETED RAI ASSESSMENTS BY ASSESSOR/INTERVIEWER

Assessor/ Interviewer ID #	Baseline DAL RAIs Completed (n=1089)	Follow-up DAL RAIs Completed (n=892)	Baseline LTC RAIs Completed (n=1000)	Follow-up LTC RAIs Completed (n=691)	Total RAIs Completed (n=3672)
01	15	---	---	---	15
02	22	---	---	---	22
03	54	136	133	99	422
04	7	---	---	---	7
05	129	139	165	125	558
06	---	---	---	---	---
08	44	---	---	---	44
09	33	---	---	---	33
10	33	26	14	---	73
11	81	76	86	92	335
12*	19	4	22	---	45
13	42	6	10	---	58
14	19	15	---	---	34
15	7	---	---	---	7
16	3	---	---	---	3
17	20	5	---	---	25
18	15	---	---	---	15
19	---	1	1	---	2
20	---	---	32	20	52
21	2	20	21	---	43
23	---	12	18	14	44
52	41	---	---	---	41
53	2	---	---	---	2
54	19	---	---	---	19
55	6	---	---	---	6
56	41	---	---	---	41
57	113	---	10	---	123
58	5	---	---	---	5
59	62	110	33	76	281
62	68	64	35	24	191
63	44	34	25	19	122
64	31	62	50	34	177
65	71	137	49	55	312
66	41	34	59	39	173
67	---	7	85	47	139
68	---	1	77	47	125
69	---	3	75	---	78

* = study coordinator

TABLE D-3. COMPLETED VIEWS OF RESIDENTS BY ASSESSOR/INTERVIEWER

Assessor/ Interviewer ID #	Baseline Views of Residents Completed (n=704)	Follow-up Views of Residents Completed (n=464)	Total Views of Residents Completed (n=1168)
01	13	---	13
02	13	---	13
03	49	75	124
04	4	---	4
05	83	63	146
08	34	---	34
09	17	---	17
10	21	16	37
11	56	48	104
12*	8	1	9
13	19	4	23
14	15	9	24
15	4	---	4
16	3	---	3
17	16	3	19
18	11	---	11
21	2	16	18
23	---	4	4
52	29	---	29
53	2	---	2
54	19	---	19
55	6	---	6
56	23	---	23
57	37	---	37
58	4	---	4
59	50	69	119
62	48	33	81
63	30	24	54
64	20	21	41
65	38	55	93
66	30	23	53

* = study coordinator

TABLE D-4. COMPLETED FAMILY CAREGIVER INTERVIEWS BY ASSESSOR/INTERVIEWER

Assessor/ Interviewer ID #	Baseline DAL Caregiver Interviews (n=974)	Follow-up DAL Caregiver Interviews (n=791)	Baseline LTC Caregiver Interviews (n=917)	Follow-up LTC Caregiver Interviews (n=609)	Total Caregiver Interviews (n=3291)
01	10	---	---	---	10
02	6	---	---	---	6
03	52	112	128	94	386
04	6	---	---	---	6
05	101	117	148	111	477
06	32	20	5	---	57
08	34	---	---	---	34
09	27	---	---	---	27
10	23	14	10	---	47
11	80	75	92	77	324
12*	5	3	1	---	9
13	22	2	5	---	29
14	15	5	---	---	20
15	19	---	---	---	19
16	2	---	---	---	2
17	22	2	---	---	24
18	9	---	---	---	9
19	---	1	1	---	2
20	---	---	26	17	43
21	1	13	14	---	28
23	1	17	24	7	49
52	24	---	---	---	24
53	2	---	---	---	2
54	18	---	---	---	18
55	3	---	---	---	3
56	41	---	---	---	41
57	108	---	10	---	118
58	2	---	---	---	2
59	50	94	29	63	236
62	44	62	29	22	157
63	47	32	27	17	123
64	26	57	42	30	155
65	63	124	52	44	283
66	48	32	57	37	174
67	31	7	75	46	159
68	---	1	71	44	116
69	---	1	71	---	72

* = study coordinator

TABLE D-5. COMPLETED DISCHARGE AND DECEDENT INTERVIEWS BY ASSESSOR/INTERVIEWER

Assessor/ Interviewer ID	Discharge Interviews Completed (n=237)	Decedent Interviews Completed (n=421)	Total Discharge & Decedent Interviews Completed (n=658)
01	1	---	1
03	8	42	50
05	34	78	112
06	7	---	7
07*	1	13	14
11	8	1	9
12*	8	3	11
15	16	1	17
19	7	79	86
51*	6	8	14
52	---	1	1
59	5	---	5
62	7	---	7
63	2	---	2
64	2	---	2
65	112	143	255
66	4	---	4
67	8	52	60
69	1	---	1

* = study coordinator

APPENDIX E: FACILITY APPROACH CONSENT SCRIPTS

Resident

The University of Alberta is doing a project about the health and care of the residents at (name of facility). A study nurse would like to talk to you about the project. Can I give her your name so that she can come and tell you more about this? You can decide after you talk to her if you want to be involved.

Surrogate

The University of Alberta is doing a project about the health and care of the residents at (name of facility). A study nurse would like to talk to you about the project. Can I give the study your contact information and (resident)'s name so that you can learn more about this? They will explain the study and answer any of your questions. You will be asked at that time whether or not you and (name of resident) want to participate.

APPENDIX F: SAMPLE RESIDENT CONSENT FORM

Consent Form – Resident Assessment

TITLE: Continuing Care Reform ~ Implications for the Balance and Quality of Care for Older Canadians.
Alberta Continuing Care Epidemiologic Studies (ACCES) Program

SPONSORS: Alberta Heritage Foundation for Medical Research (AHFMR)

INVESTIGATORS:
Dr. Colleen J. Maxwell and Dr. Laurel Strain (Co-Principal Investigators)
Dr. David B. Hogan, Dr. Gary Teare, Dr. Brad Hagen, Dr. Jean Parboosingh, Dr. David Zimmerman, Dr. Michael Eliasziw

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

You are being asked to take part in a study to examine the health and quality of life of residents in assisted living and long-term care in the province. Many types of care services are now available for older adults, yet we know very little about the mix of services that best fit the changing medical and social care needs of seniors. Your involvement in this study will help us better understand ways to improve the quality of care and quality of life of residents in these settings.

Your participation will require that you receive a health and functional assessment performed by a trained research nurse at the start of the study and again at about 12 months following your first assessment. The assessment will take place in your facility residence. At both assessment times, you will also receive a quality of care satisfaction survey which you may complete on your own time and then send back to us.

Most of the assessment will be very similar to that you normally receive as part of your routine care (e.g., similar to a home care assessment). For example, the study nurse will assess your health conditions and ability to perform daily activities, the help you receive and your use of health services and medications. The entire assessment may last up to 1 hour, with additional time for breaks if necessary.

The study will also involve a 45 minute interview with a close relative or friend who you identify as being well-informed about your care and health (primary caregiver). The caregiver interview will include details about your medical and social support needs and the quality of services provided to meet your needs. The interview with your caregiver will be conducted at 2 time periods, close to your first assessment and around the time of your 12 month follow-up.

We wish to emphasize that all your information and responses as well as your caregiver's information will be kept strictly confidential and stored in locked file cabinets. All your personal contact information (e.g., name) will be deleted from all forms and records and you will be given a unique study ID number to protect your identity. Only the members of the research team and affiliated study coordinators/assessors will have access to the information collected. Also, your personal contact information will be stored separately from your health information.

If you agree to participate in this study, there may or may not be a direct medical benefit to you. Your health and functional status may be improved during the study but there is no guarantee that this research will help you. The information we get from this study may help improve the future quality of life and quality of care for older adults requiring continuing care assistance. No painful procedures will be involved and there are no risks associated with the assessments.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. Your participation is voluntary and you are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Laurel A. Strain (780) 492-2214 / Dr. Colleen J. Maxwell (403) 220-6557
Or
Deanna Wanless, Project Coordinator (780) 492-7733

If you have any questions concerning your rights as a possible participant in this research (B-080106), please contact Charmaine Kabatoff, Administrative Coordinator, Health Research Ethics Board (Panel B), University of Alberta, at (780) 492-0302.

Resident’s Name	Signature and Date
Investigator/Delegate’s Name	Signature and Date
Witness’ Name (if available)	Signature and Date

The University of Alberta Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

Consent to the Disclosure of Individually Identifying Health Information

We would also like to collect information on your use of health care services during the 2-year period following your first assessment (this would include your in-patient hospitalizations, emergency room visits, home care service use and admission to care facilities). To obtain this information, we will have to use your personal health care number.

However, after obtaining this information, your health care number and all other personal contact information (e.g., name) will be deleted from all forms and records and you will be given a unique study ID number to protect your identity. All your information will be kept strictly confidential and stored in locked file cabinets. Only the members of the research team and affiliated study coordinators/assessors will have access to the information collected. Also, your personal contact information will be stored separately from your health information. You may say NO to the use of your PHN and still remain a participant in the health assessment part of the study.

I ________________________________, authorize individually identifying registration and diagnostic, treatment and care information of myself to be disclosed by Alberta Health and Wellness or by the Health Region Corporate Database in accordance with section 34 of the *Health Information Act* to Drs. Colleen Maxwell and Laurel Strain, for the following purpose(s): *To allow the researchers to examine my key health outcomes (e.g., in-patient hospitalizations, emergency room visits, home care service use and admission to care facilities) during a 2-year period following my first study assessment.* I understand why I have been asked to disclose my individually identifying health information, and am aware of any potential risks or benefits of consenting, or refusing to consent, to the disclosure of my individually identifying health information. I understand that I may revoke this consent at any time.

____________________	____________________
Resident's Name	Signature and Date
____________________	____________________
Investigator/Delegate's Name	Signature and Date
____________________	____________________
Witness' Name (if available)	Signature and Date

The University of Alberta Health Research Ethics Board has approved this research study. A signed copy of this consent form has been given to you to keep for your records and reference.

FIGURE G-1. DAL RESIDENT BASELINE & FOLLOW-UP FLOWCHART

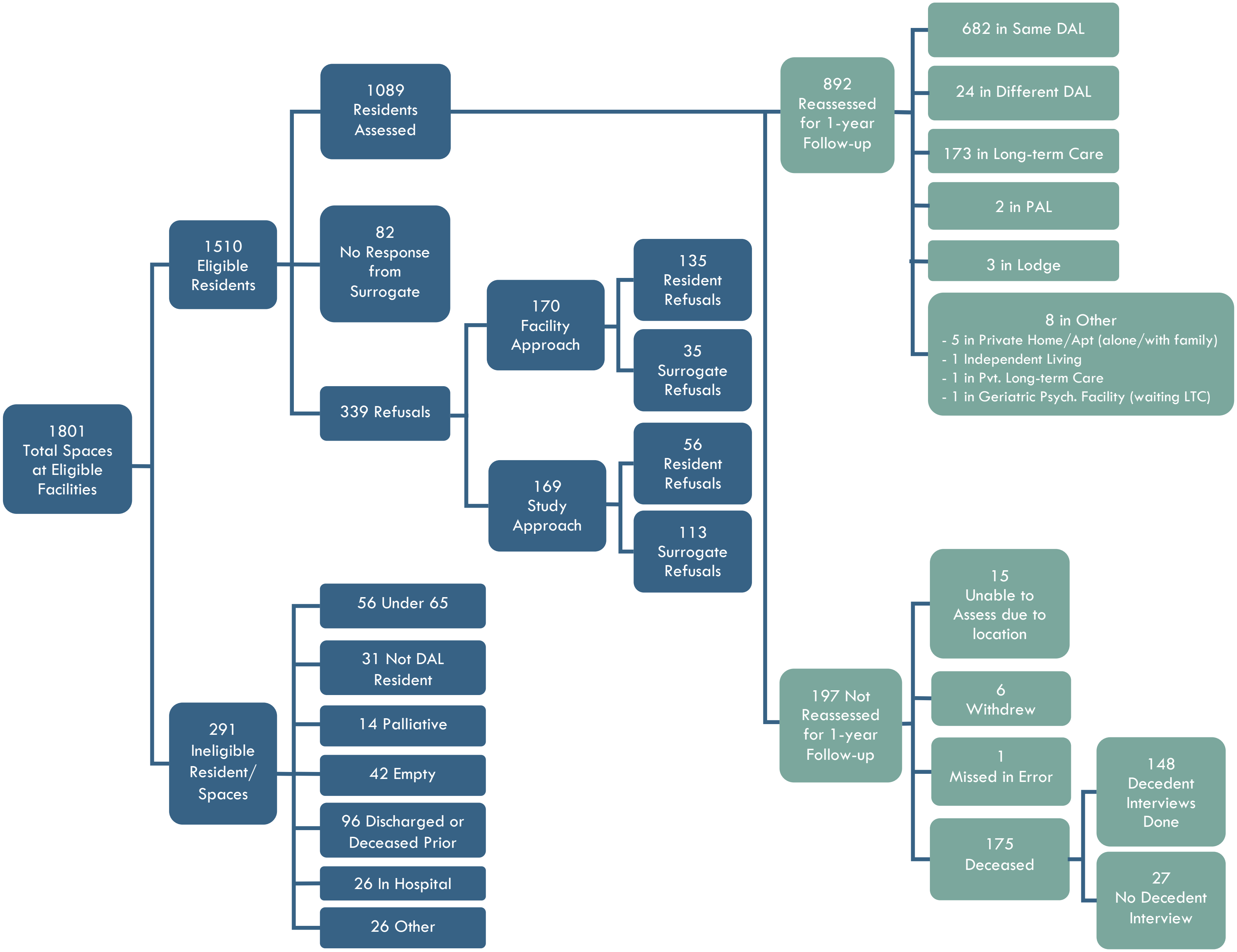


FIGURE G-2. LTC RESIDENT BASELINE & FOLLOW-UP FLOWCHART

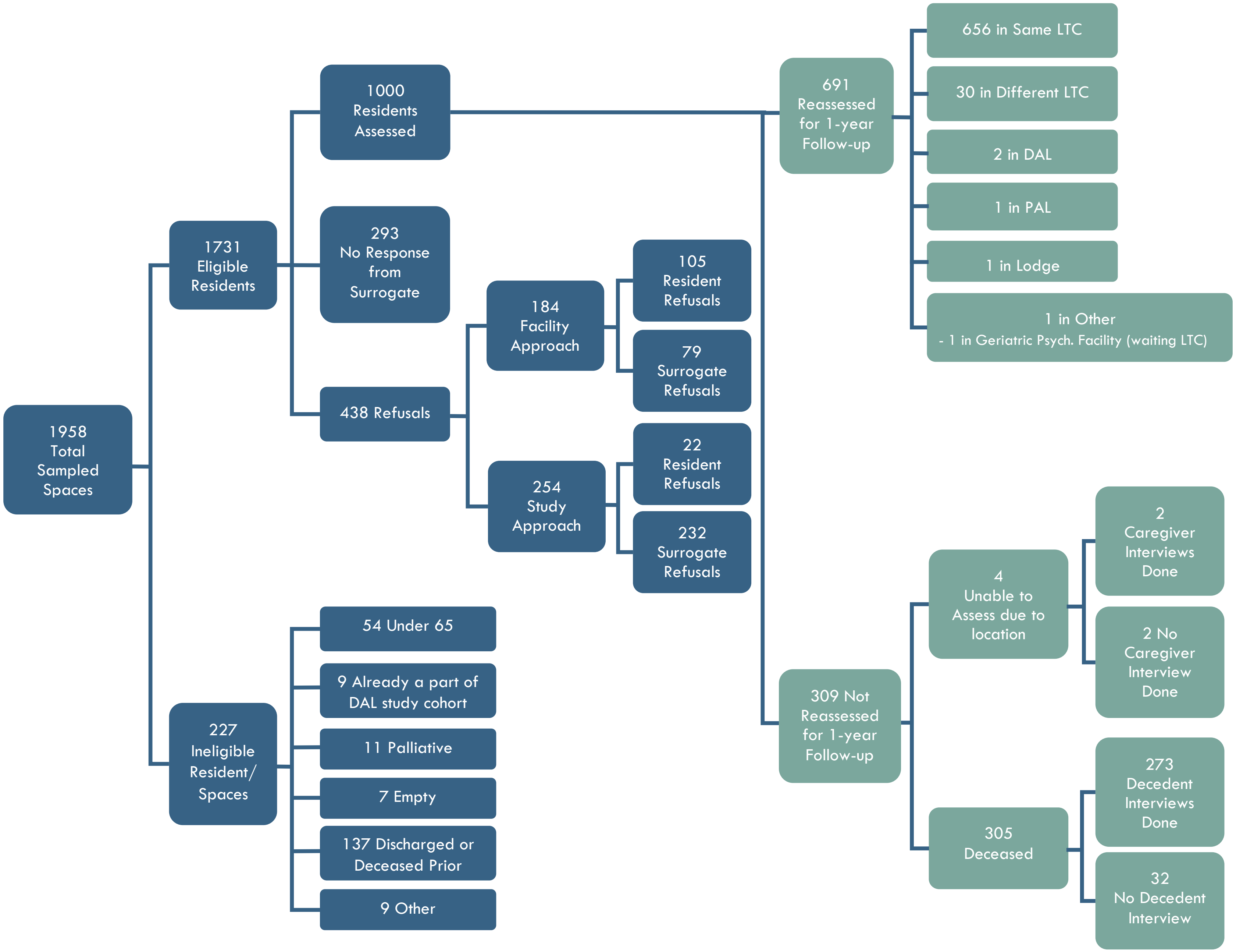
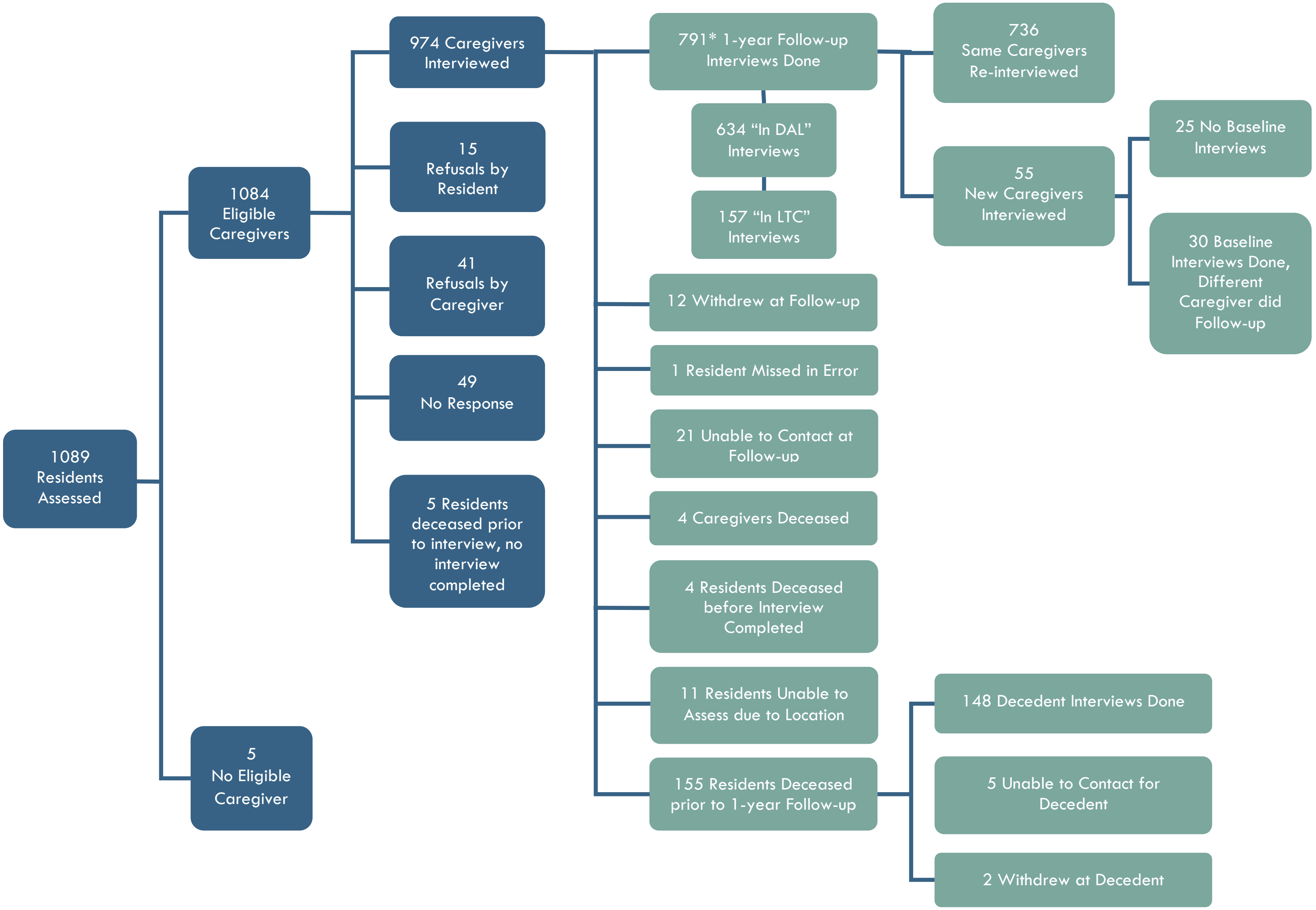
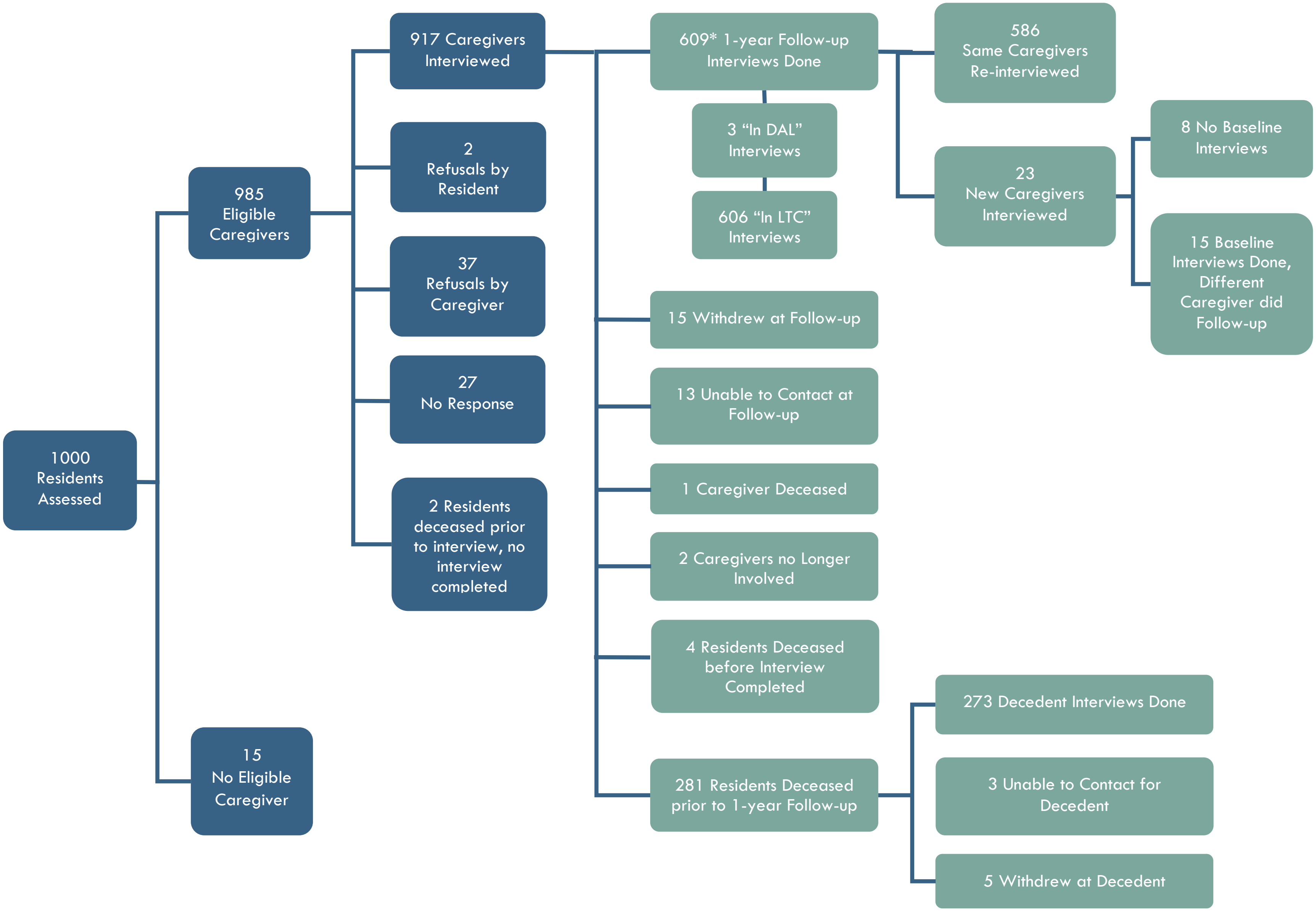


FIGURE G-3. DAL FAMILY CAREGIVER BASELINE & FOLLOW-UP FLOWCHART



*This includes 25 Residents for whom a Caregiver was interviewed for the first time at follow-up, in addition to the 974 interviewed at baseline.

FIGURE G-4. LTC FAMILY CAREGIVER BASELINE & FOLLOW-UP FLOWCHART



*This includes 8 Residents for whom a Caregiver was interviewed for the first time at follow-up, in addition to the 917 interviewed at baseline.

APPENDIX H: RESIDENT ASSESSMENT/INTERVIEW MEASURES

interRAI-AL and interRAI-LTCF

The interRAI-AL and interRAI-LTCF tools consist of the following sections (see www.interrai.org for additional information):

- Identification Information
- Intake and Initial History
- Psychosocial Well-being
- Mood
- Activities
- Cognition
- Communication and Vision
- Functional Status
- Continence
- Disease Diagnosis
- Health Conditions
- Behavior Symptoms
- Skin Condition
- Nutritional Status
- Medications
- Treatment and Procedures
- Responsibility and Directives

Some specific items are not available on both tools, reflecting setting differences. Some items were modified to reflect the Canadian scene (e.g., payment sources, ethnicity).

Frailty measures were added to the interRAI-AL tool in order to address questions for a frailty sub-study. These included:

  - Participation in a number of exercise and leisure activities (including frequency in the last 2 weeks and average duration of each session)
  - Self-reported fatigue (3 items)
  - Self-reported weight loss in last year
  - Timed 3-meter walk
  - Hand grip strength test (using a hand dynamometer)

interRAI Scales

Items on the interRAI tools can be used to create a number of established interRAI scales. These include:

- **Changes in Health, End-stage Disease and Symptoms and Signs (CHESS)**
  - Higher CHESS scores have been associated with adverse outcomes including mortality, acute hospitalization, and pain.

  - Hirdes, J.P., Krijters, D., & Teare, G.F. (2003). The MDS-CHESS Scale: A new measure to predict mortality in institutionalized older people. *Journal of the American Geriatrics Society, 51*, 96-100.

- **Pressure Ulcer Risk Scale (PURS)**
  - Identifies individuals at risk for developing a pressure ulcer.
  - Poss, J., Murphy, K.M., Woodbury, M.G., Orsted, H., Stevenson, K., Williams, G., MacAlpine, S., Curtin-Telegdi, N., & Hirdes, J.P. (2010). Development of the interRAI Pressure Ulcer Risk Scale (PURS) for use in long-term care and home care settings. *BMC Geriatrics, 10, 67.*

- **Pain Scale**
  - Takes pain frequency and intensity into account.
  - Fries, B.E., Simon, S.E., Morris, J.N., Flodstrom, C., & Bookstein, F.L. (2001). Pain in U.S. nursing homes: Validating a Pain Scale for the Minimum Data Set. *The Gerontologist, 41*, 173-179.

- **Activities of Daily Living Self-Performance Hierarchy Scale**
  - Measures ADL performance according to early, middle and late stages of loss using four ADLs (personal hygiene, toilet use, locomotion and eating).
  - Morris, J.N., Fries, B.E., & Morris, S.A. (1999). Scaling ADLs within the MDS. *Journal of Gerontology: Medical Sciences 54A*, M546-M553.

- **Cognitive Performance Scale (CPS)**
  - Considers skills for daily decision-making, short-term memory, making self understood, and eating impairment.
  - Morris, J.N., Fries, B.E., Mehr, D.R., Hawes, C., Phillips, C., Mor, V., & Lipsitz, L. (1994). MDS Cognitive Performance Scale. *Journal of Gerontology: Medical Sciences, 49, M174-M182.*
  - Hartmaier, S.L., Sloane, P.D., Guess, H.A., Koch, G.G., Mitchell, C.M., & Phillips, C.D. (1995). Validation of the Minimum Data Set Cognitive Performance Scale: Agreement with the Mini-Mental State Examination. *The Journals of Gerontology, Series A: Medical Sciences, 50*, M128-M133.

- **Depression Rating Scale (DRS)**
  - Higher values indicate a greater number and/or frequency of symptoms. A score of 3 or higher indicates clinically important depressive symptoms.

  - Burrows, A.B., Morris, J.N., Simon, S.E., Hirdes, J.P., & Phillips, C. (2000). Development of a Minimum Data Set-based Depression Rating Scale for use in nursing homes. *Age & Ageing, 29*, 165-172.

- **Aggressive Behaviour Scale**
  - Takes four behaviors (verbal abuse, physical abuse, socially inappropriate or disruptive behavior, and resists care) into account.
  - Perlman, C.M., & Hirdes, J.P. (2008). The Aggressive Behaviour Scale: A new scale to measure aggression based on the Minimum Data Set. *Journal of the American Geriatrics Society (JAGS), S6,* 2298-2303.

interRAI CAPS

The interRAI Clinical Assessment Protocols (CAPs) are designed to focus on key common/severe issues identified during the assessment process, so that evidence-based decisions can be made to improve resident care planning. CAPs are triggered to indicate "the possibility of problem resolution, reducing the risk of decline or increasing the potential for improvement" (Canadian Institute for Health Information (CIHI), 2008, p.1). The following CAPs can be calculated based on the interRAI assessments, using CIHI guidelines.

- **Clinical CAPs:**
  - Falls CAP
  - Pain CAP
  - Pressure Ulcer CAP
  - Cardio-Respiratory CAP
  - Prevention CAP
  - Appropriate Medication CAP
  - Tobacco and Alcohol Use CAP
  - Urinary Incontinence CAP
  - Bowel Conditions CAP
  - Under Nutrition CAP
  - Feeding Tube CAP (interRAI-LTCF only)
  - Dehydration CAP (interRAI-LTCF only)

- **Physical Function CAPs:**
  - Physical Activities Promotion CAP
  - Instrumental Activities of Daily Living CAP (interRAI-AL only)
  - Activities of Daily Living CAP
  - Institutional Risk CAP (interRAI-AL only)
  - Physical Restraints CAP

- **Cognitive Function and Mental Health CAPs:**
    - Cognitive Loss CAP
    - Delirium CAP
    - Mood CAP
    - Communication CAP
    - Behaviour CAP

- **Social Life CAPs:**
    - Activities CAP
    - Social Relationship CAP

Reference:

Canadian Institute for Health Information (CIHI). (2008). *interRAI Clinical Assessment Protocols (CAPs) - For Use with interRAI's Community and Long-Term Care Assessment Instruments*. Ottawa, ON: CIHI. (An Errata "Revisions to the interRAI Clinical Assessment Protocols Manual" was published July 2009.)

Views of Resident Survey

The Views of Resident survey was conducted with DAL residents only at baseline and with those still in DAL or in a lodge, PAL, etc. at follow-up. This survey was a modified version of the Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAHPS) survey developed by the Agency for Healthcare Research and Quality (AHRQ) in the United States (Sangl, Buchanan, Cosenza, Bernard, Keller, Mitchell, Brown, Castle, Sekscenski, & Larwood, 2007; for further information on CAHPS, see www.cahps.ahrq.gov). In consultation with an ACCES decision-maker partner, only items deemed relevant to the DAL population were retained. Questions included:

- Answered on a scale of 0 to 10 with 0 being the worst possible and 10 the best possible:

    1. What number would you use to rate the food here?
    2. When you eat in the dining room, what number would you use to rate how much you enjoy mealtimes?
    3. What number would you use to rate how comfortable the temperature is in the facility?
    4. What number would you use to rate how clean the facility is?
    5. What number would you use to describe how safe and secure you feel here?
    6. What number would you use to rate how quickly the staff come when you call them for help?
    7. Do the staff help you get dressed, take a shower or go to the toilet? If yes, what number would you use to rate how gentle the staff are when they're helping you?
    8. What number would you use to rate how respectful the staff are to you?
    9. What number would you use to rate how well the staff listen to you?
    10. What number would you use to rate how well the staff explain things in a way that is easy to understand?
    11. Overall, what number would you use to rate the care you get from the staff?
    12. Overall, what number would you use to rate this facility?

- Answered with yes, no or sometimes:

    13. Is the area around your room quiet at night?
    14. Are you bothered by noise in the facility during the day?
    15. If you have a visitor, can you find a place to visit in private?
    16. Do the staff make sure you have enough personal privacy when you dress, take a shower or bathe?
    17. Can you choose what activities you do here?
    18. Are there enough organized activities for you to do on the weekends?
    19. Are there enough organized activities for you to do during the week?

- Answered as definitely no, probably no, probably yes or definitely yes:

    20. Would you recommend this facility to others?

The CAHPS group recommends using 3 category groupings for the 0 to 10 scale responses.[12] Two possible groupings are suggested: (1) 0-6, 7-8, and 9-10 and (2) 0-7, 8-9, and 10. The latter grouping is recommended for situations where the mean rating is quite high. Given that the mean ratings for the ACCES DAL residents are relatively high, the recommended grouping for ACCES is 0-7, 8-9 and 10.

Reference:

Sangl, J., Buchanan, J., Cosenza, C., Bernard, S., Keller, S., Mitchell, N., Brown, J., Castle, N., Sekscenski, E., & Larwood, D. (2007). The development of CAPHS® Instrument for Nursing Home Residents (NHCAHPS). *Journal of Aging & Social Policy, 2*, 63-82.

---

[12] https://www.cahps.ahrq.gov/content/cahpsOverview/faqanswer.asp?faq_id=128&showanswer=1&viewall=0&current_cat_id=18&cat_id=18&keyword=&hassub=0#b_128

APPENDIX I: SAMPLE CAREGIVER CONSENT FORM

Consent Form – Caregiver Interview

TITLE: Continuing Care Reform ~ Implications for the Balance and Quality of Care for Frail Older Canadians.
Alberta Continuing Care Epidemiologic Studies (ACCES) Program

SPONSORS: Alberta Heritage Foundation for Medical Research (AHFMR)

INVESTIGATORS:
Dr. Colleen J. Maxwell (Co-PI)
Dr. Laurel A. Strain (Co-PI)
Dr. David B. Hogan, Dr. Gary Teare, Dr. Brad Hagen, Dr. Jean Parboosingh, Dr. David Zimmerman, Dr. Michael Eliasziw

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

Your relative (or friend), ________________________ has consented to participate in a study to examine the health and quality of life of residents in assisted living and long-term care facilities. She/He has identified you as a person close to her/him who could be interviewed as part of this study.

The interview will be conducted in person by a trained interviewer and will include questions regarding the medical and social support needs of your relative (or friend) and the impact of care provision on your well-being. You will also be asked about your perceptions of, and satisfaction with, the quality of care and services provided in the facility. The interview will last approximately 30-45 minutes and will be conducted at 2 time periods, within 1 month of your relative (or friend's) initial assessment and at a 12-month follow-up period (this follow-up may also be conducted by telephone). A brief telephone interview to assess any recent changes in the health or care received by your relative (or friend) may also be conducted during follow-up.

All information obtained will be kept strictly confidential and no results will be released in any way that could identify _________________________ or you personally. All personal contact information (e.g., name) will be deleted from all forms and records and you will be given a unique study ID number to protect your identity. Only the members of the research team and affiliated study coordinators/assessors will have access to the information collected during the interview and all information will be stored in locked file cabinets. Your personal contact information will be stored separately from your interview information.

The information from this research program is expected to help in the development of effective continuing care policies and programs to improve the quality of life and quality of care of seniors residing in assisted living and long-term care facilities in the province. It is also hoped that this study will identify opportunities to improve the health and well-being of caregivers involved in providing care and assistance in these settings.

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time without jeopardizing your health care. If you have further questions concerning matters related to this research, please contact:

Dr. Laurel A. Strain (780) 492-2214 / Dr. Colleen J. Maxwell (403) 220-6557
Or
Deanna Wanless, Project Coordinator (780) 492-7733

If you have any questions concerning your rights as a possible participant in this research (B-080106), please contact Charmaine Kabatoff, Administrative Coordinator, Health Research Ethics Board (Panel B), University of Alberta, at (780) 492-0302.

Caregiver’s Name	Signature and Date
Investigator/Delegate’s Name	Signature and Date
Witness’ Name (if available)	Signature and Date

The University of Alberta Health Research Ethics Board has approved this research study.

A signed copy of this consent form has been given to you to keep for your records and reference.

APPENDIX J: CAREGIVER INTERVIEW MEASURES

Baseline and Follow-up Caregiver Interviews

Family caregivers were asked a series of questions at baseline and follow-up to ascertain the resident and caregiver status/health, caregiver burden, effects of caregiving on employment, service use, knowledge and views of the facility's services/policies, costs related to care, etc. (see Table J-1 for topics and coverage at each time-point). Follow-up interviews excluded some questions asked at baseline and included new questions to assess change since baseline.

Some questions were derived from the Canadian/Manitoba Study of Health and Aging (C/MSHA) (MSHA Research Group, 1998) and a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000), with some modified for ACCES. Other questions were selected/developed specifically for ACCES.

TABLE J-1. CAREGIVER INTERVIEW QUESTIONS

	DAL Baseline	DAL Follow-up	LTC Baseline	LTC Follow-up
Caregiver Socio-demographic Characteristics				
- gender	✓	✓	✓	✓
- relationship to resident[1]	✓	✓	✓	✓
- date of birth[2]	✓	✓	✓	✓
- marital status[1]	✓	✓	✓	✓
- education[2]	✓	✓	✓	✓
- ethnic background[1]	✓	---	✓	---
- employment status[1]	✓	✓	✓	✓
- yearly income (categories)[2]	✓	---	✓	---
Caregiver's/Resident's Potential Network				
- # of members in caregiver's household[1]	✓	✓	✓	✓
- # of caregiver's children, other close relatives[1]	✓	✓	✓	✓
- # of resident's children, close relatives, close friends[1]	✓	---	✓	---
- others who provide help to resident[3]	✓	✓	✓	✓
- potential helpers (who would take over) [1]	✓	✓	✓	✓
Caregiver Visiting/Helping Tasks				
- frequency of visiting[1]	✓	✓	✓	✓
- change in visiting frequency in last year	---	✓	---	✓
- distance[3]	✓	✓	✓	✓
- mode of transportation[3]	✓	---	✓	---
- travel time[3]	✓	---	✓	---
- length of visit[1]	✓	✓	✓	✓
- activities while visiting[4]	✓	✓	✓	✓
- help provided out of facility[1]	✓	✓	✓	✓

	DAL Baseline	DAL Follow-up	LTC Baseline	LTC Follow-up
Caregiver Burden/Stress				
- Caregiver Reaction Assessment[5]	✓	✓	✓	✓
- rating of caregiving experience[3]	✓	✓	✓	✓
- positive aspects of caregiving[3]	✓	✓	✓	✓
- impact on employment[1]	✓	✓	✓	✓
Caregiver Health				
- self-rated health[2]	✓	✓	✓	✓
- depression (11-item CES-D)[6]	✓	✓	✓	✓
Resident Health				
- resident ADL/IADL capacity (from OARS)[1]	✓	✓	✓	✓
- if caregiver or other family help with ADL tasks[1]	---	4 of 5 regions	3 of 5 regions	✓
- resident's memory (from CAMDEX)[1]	✓	✓	✓	✓
Medical Care				
- doctor visits[1]	✓	✓	✓	✓
- emergency room visits[1]	✓	✓	✓	✓
- hospital visits[1]	✓	✓	✓	✓
Resident's Income				
- primary source[3]	✓	if changed	✓	if changed
- yearly amount (categories)[2]	✓	if changed	✓	if changed
Move to Facility				
- reasons for move[1]	✓	---	✓	---
- if this facility is first choice	✓	---	✓	---
- waited to move into this facility	✓	---	✓	---
- important features[7]	✓	---	---	---
- control of decision[7]	✓	---	✓	---
Family Involvement				
- has facility created opportunities to be informed/involved	✓	✓	✓	✓
- Family Involvement[8]	---	✓	✓	✓
Services Provided[1, 7]				
- who provides[1]	✓	---	✓	---
- if received/used in last month	✓	✓	✓	✓
- satisfaction with quantity and quality[1]	✓	✓	✓	✓
Facility Policies				
- comfort at expressing concerns[7]	✓	---	✓	---
- awareness of policies[7]	✓	---	✓	---
- expectations about discharge[7]	✓	---	✓	---

	DAL Baseline	DAL Follow-up	LTC Baseline	LTC Follow-up
Payment/Costs				
- base rate, regular extra monthly costs[7]	✓	✓	✓	✓
- clarity/expectation of charges[7]	✓	✓	✓	✓
- costs in last month[7]	✓	✓	✓	✓
- one-time costs in last year[3]	✓	✓	✓	✓
General Views about Facility				
- rating of cleanliness, care and overall rating of facility[9]	✓	✓	✓	✓
- would recommend facility[9]	✓	✓	✓	✓
- advantages/disadvantages to family[10]	✓	✓	✓	✓
- observed changes in last year to staffing, accommodation, activities, medication assistance, personal care, other	---	“Still in DAL” interview	---	“Still in LTC” interview

Questions taken or modified from:

[1] Canadian/Manitoba Study of Health and Aging (C/MSHA). Questions were used in the national study but are taken from the Manitoba Caregiver Interview, Version 3 (subject in institution) and Version 1 (subject in community). For further information on CSHA, see http://www.csha.ca/default.asp. See Note #3 regarding MSHA.

[2] Statistics Canada. General Social Survey, Cycles 16 (2002) and 17 (2003).

[3] Manitoba Study of Health and Aging (MSHA). Questions were used in Manitoba version only (see Note #1). For further information on MSHA, see Manitoba Study of Health and Aging Research Group. (1998). *Follow-up to the Manitoba Study of Health and Aging (MSHA-2): Methodology*. Winnipeg, MB: Centre on Aging, University of Manitoba.

[4] Based on review of literature, including 3 items from Shuttlesworth, G. E., Rubin, A., & Duffy, M. (1982). Families versus institutions: Incongruent role expectations in the nursing home. *The Gerontologist, 22*(2), 200-208.

[5] Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health, 15,* 271-283. [Use approved by the Family Care Research Program, Michigan State University].

[6] Kohout, F.J., Berkman, L.F., Evans, D.A., & Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D depression symptoms index. *Journal of Aging and Health, 5*(2), 179-193.

[7] Hawes, C., Phillips, C., & Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly*. Beachwood, OH: Myers Research Institute, Memorah Park Center for Senior Living. Questions from Assisted Living Resident Interview (R) and Family Member Telephone Interview (FM) and Assisted Living Resident Discharged Interview (R-Discharge).

[8] Reid, R.C., Chappell, N.L., & Gish, J.A. (2007). Measuring family perceived involvement in individualized long-term care. *Dementia, 6*, 89-104. [Use approved by Reid and Chappell].

[9] NHCAHPS (Nursing Homes Consumer Assessment of Healthcare Providers and Systems). Developed by the U.S. Agency for Healthcare Research and Quality (AHRQ). Sangl, J., Buchanan, J., Cosenza, C., Bernard, S., Keller, S., Mitchell, N., Brown, J., Castle, N., Sekscenski, E., & Larwood, D. (2007). The development of CAPHS® Instrument for Nursing Home Residents (NHCAHPS). *Journal of Aging & Social Policy, 2*, 63-82. [Instrument provided by Sangl].

[10] Adult Day Care Research Group. (1997). *An Evaluation of Adult Day Care in Manitoba*. Winnipeg, MB: Centre on Aging, University of Manitoba.

Discharge Interviews

In the event of a discharge from the baseline facility (with no expectation of return), an attempt was made to complete a discharge interview with the resident's family caregiver. The intent was to ascertain information about the resident's move(s) and the reason for/impact of the move, the resident's health status in the month prior to the move, and the caregiver's perceptions about the baseline facility and its policies (see Table J-2).

TABLE J-2. DISCHARGE INTERVIEW QUESTIONS

Caregiver
- gender
- relationship to resident[1]
- frequency of visiting[1]
Resident Health
- resident ADL/IADL capacity (from OARS)[1]
- resident's memory (from CAMDEX)[1]
Move from Facility
- date moved[2]
- currently staying[2]
- length of time at current place
- move anywhere in between [2]
- where went between[2]
- reasons for move[2]
- whose decision to move[2]
- control of decision to move[2]
- difficulty of move
- resident better or worse since move
Facility Policies
- awareness of policies[2]
- feelings about actual length of stay[2]
Payment/Costs
- knowledge of charges[2]
- cost increases, extra costs[2]
- rate performance in meeting cost expectations[2]
General Views about Facility
- rating of facility's performance[2]
- features better or worse than expected[2]
- feelings about experience[2]
- would recommend facility[2]

Questions taken or modified from:

[1] Canadian/Manitoba Study of Health and Aging (C/MSHA). Questions were used in the national study but are from the Manitoba Caregiver Interview, Version 3 (subject in institution) and Version 4 (subject deceased). See Notes 1 & 3, Table J-1 for additional information about C/MSHA.

[2] Hawes, C., Phillips, C., & Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly*. Beachwood, OH: Myers Research Institute, Memorah Park Center for Senior Living. Questions are from the Assisted Living Discharge Resident Proxy Interview (Discharge – FM)

Decedent Interviews

When a resident died prior to the 1-year follow-up assessment, attempts were made to complete a decedent interview with the family caregiver. Questions were asked about the location and cause of death, the resident's health status in the month prior to death and, if the resident was in a care facility, the caregiver's perceptions about that facility (see Table J-3).

TABLE J-3. DECEDENT INTERVIEW QUESTIONS

Caregiver
- gender
- relationship to resident[1]
Resident Health
- resident ADL/IADL capacity (from OARS)[1]
- resident's memory (from CAMDEX)[1]
- anything else about resident's health prior to death
Death
- date of death[1]
- cause of death[1]
- location of death[1]
- places lived between baseline facility and death[2]
Facility
- how did staff assist at time of death (if in DAL/CCC at time)
- rating of facility's performance (if in DAL/CCC at time)[2]

Questions taken or modified from:

[1] Canadian/Manitoba Study of Health and Aging (C/MSHA). Questions were used in the national study but are from the Manitoba Caregiver Interview, Version 3 (subject in institution) and Version 4 (subject deceased. See Notes 1 & 3, Table J-1 for additional information about C/MSHA.

[2] Hawes, C., Phillips, C., & Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly.* Beachwood, OH: Myers Research Institute, Memorah Park Center for Senior Living. Questions are from the Assisted Living Discharge Resident Proxy Interview (Discharge – FM)

Scales

Resident's Activities of Daily Living (ADLs)

Family caregivers were asked to assess the assistance residents required with activities of daily living, drawing on the 14-item Older American Resources and Services (OARS) Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) Scales used in C/MSHA. In ACCES, only 7 ADLs (eating, dressing, personal appearance, walking, getting in and out of bed, bathing, and toileting) and 1 IADL (taking medications) were included. Response categories were on a 5-point scale (1-without any help, 2-some help from a device only, 3-some help from a person only, 4-some help from a person & device, and 5-unable to do it) used in MSHA. Higher scores indicate a higher level of dependence.

Questions on whether or not the caregiver or other family members helped the resident with the ADLs were asked in the DAL Follow-Up interviews in 4 of 5 regions, LTC Baseline interviews in 3 of 5 regions, and all LTC Follow-up interviews. For each activity scoring a 3 or higher (indicating at least some help was received from a person), caregivers were asked "Do you help with this?" and "Do other family members help?" (no/yes).

- Included on all caregiver interviews (including discharge/decedent interviews).
- Fillenbaum, G.G. (1988). *Multidimensional Functional Assessment of Older Adults: The Duke Older American Resources and Services Procedure*. Hillsdale: Lawrence Erlbaum Associates.
- Fillenbaum, G.G., & Smyer, M.A. (1981). The development, validity, and reliability of the OARS Multidimensional Functional Assessment Questionnaire. *Journal of Gerontology, 36,* 428-434.

Resident's Memory

Family caregivers were asked about the degree of difficulty the resident has with various actions, such as "Does he/she have difficulty remembering recent events?" and "Does he/she have difficulty finding the way about the facility?". The five items were from the memory section of the Cambridge Mental Disorders of the Elderly Examination (CAMDEX) that was used in C/MSHA. Responses were on a 3-point scale (0-No difficulty, 1-Slight difficulty, and 2-Great difficulty).

- Included on all caregiver interviews (including discharge/decedent interviews).
- Roth, M., Huppert, F.A., Tym, E., & Mountjoy, C.Q. (1988). *CAMDEX: The Cambridge Examination for Mental Disorders of the Elderly*. Cambridge: Cambridge University Press.

Caregiver Reaction Assessment (CRA)

The Caregiver Reaction Assessment asked caregivers to indicate their feelings in the last month regarding 24 statements related to caregiving. There are 5 subscales which measure the impact of caregiving on the health of the caregiver, the caregiver's self-esteem, their schedule, finances, and support from family members. Responses were on a 5-point scale (1-strongly disagree, 2-disagree, 3-neither disagree nor agree, 4-agree and 5-strongly agree). Higher scores indicate higher levels of caregiver burden (5 items are reverse scored). Examples of statements include "I feel privileged to care for (___)", "It is very hard to get help from my family in taking care of (___)", and "My activities are centered around care for (___)".

- Approval to use the CRA was received from the Family Care Research Program at Michigan State University.
- Included on all baseline and follow-up caregiver interviews (not on discharge/decedent interviews).
- Given, C.W., Given, B., Stommel, M., Collins, C., King, S., & Franklin, S. (1992). The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health, 15,* 271-283.

Caregiver Depression (11-item CES-D)

To identify depression among the ACCES caregivers, an 11-item version of the Center for Epidemiological Studies Depression Scale (CES-D) was used. This shorter version of the standard 20 item CES-D was developed to reduce the response burden on older respondents. Respondents were asked 11 statements and indicated the frequency they felt that way in the last week on a 3-point scale (0-Hardly ever or never, 1-Some of the time, and 2-Much or most of the time). Higher scores indicate higher prevalence of depressive symptoms (2 items are reverse scored). Examples of statements include “I felt depressed”, “I was happy”, and “People were unfriendly”.

- Included on all baseline and follow-up caregiver interviews (not on discharge/decedent interviews).
- Kohout, F.J., Berkman, L.F., Evans, D.A., & Cornoni-Huntley, J. (1993). Two shorter forms of the CES-D depression symptoms index. *Journal of Aging and Health, 5*(2), 179-193.

Perceived Family Involvement

The Perceived Family Involvement Scales were developed for dementia care in long-term care, in order to assess whether or not family members perceive that the facility provides opportunities for family involvement and whether or not that is important to them. Two individual scales (family perceived involvement and family assessment of importance of their involvement) were created by summing the scores for 20 individual statements. For each statement, the family member indicated if it describes the facility (1-strongly disagree, 2-somewhat disagree, 3-somewhat agree, and 4-strongly agree) and its importance to them (1-unimportant, 2-somewhat important, 3-quite important, and 4-extremely important). Higher scores indicate a higher perceived involvement and higher importance. Examples of statements include “I have been asked about my family member’s personal history”, “I am informed about changes in my family member’s care plan”, and “I trust the staff members at this facility”.

For the purposes of the ACCES caregiver interviews, 8 of the 20 items were selected (in consultation with the creators of the scale) for inclusion in a shortened family involvement scale.

- Approval to use the shortened Perceived Family Involvement Scales was received from Drs. Reid and Chappell.
- Included on LTC baseline and all follow-up caregiver interviews (not on DAL baseline or discharge/decedent interviews).
- Reid, R.C., Chappell, N.L., & Gish, J.A. (2007). Measuring family perceived involvement in individualized long-term care. *Dementia, 6*, 89-104.

APPENDIX K: DISCHARGE TRACKING FORM

Today's date: _____/_____/_____
DD MM YYYY

Facility Name: ____
Resident Name: Mr.
Mrs. _____________/ _____________/ _____________/ _____________
Ms. First Middle Surname Maiden

Reason for Discharge:

(i) Transferred

Date of transfer: _____/_____/_____
DD MM YYYY

Transferred to (**please circle**):

1 Acute care hospital
2 Psychiatric hospital or unit
3 Mental health residence (e.g., psychiatric group home)
4 Hospice facility / palliative care unit
5 Nursing home/long term care facility
6 Rehabilitation facility or subacute care unit
7 Another residential facility or assisted living facility
8 Own home or apartment
9 Home or apartment of a relative
10 Some other place (SPECIFY)_______________

Primary Reason for transfer:____

New Address: ____

_____________ _______________ _________
City/Town Province Postal Code

(ii) Deceased

Date of death: _____/_____/_____
DD MM YYYY

Location of death (**please circle**):

1 This facility
2 Acute care hospital
3 Psychiatric hospital or unit
4 Hospice facility / palliative care unit
5 Nursing home/long term care facility
6 Home or apartment of a relative
7 Some other place (SPECIFY)_______________

Primary Cause(s) of death: ____

PLEASE FAX THIS FORM TO ACCES STUDY CO-ORDINATOR (DEANNA WANLESS) OR PRINCIPAL INVESTIGATOR (DR. LAUREL STRAIN) FAX: 780-492-3190