



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



A NATIONAL STUDY OF ASSISTED LIVING FOR THE FRAIL ELDERLY:

DISCHARGED RESIDENTS TELEPHONE SURVEY DATA COLLECTION AND SAMPLING REPORT

October 1999

Office of the Assistant Secretary for Planning and Evaluation

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**A NATIONAL STUDY OF ASSISTED LIVING
FOR THE FRAIL ELDERLY:
Discharged Residents Telephone Survey Data
Collection and Sampling Report**

Research Triangle Institute
Survey Research Division

October 1999

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Office of Disability, Aging and Long-Term Care Policy
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The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

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INTRODUCTION

Research Triangle Institute (RTI) conducted the Discharged Residents Survey for the Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services through a subcontract with Myers Research Institute (MRI). The survey was administered during June and July 1999. This report documents the data collection activities undertaken by RTI for the survey. It describes procedures we used to identify and locate discharged residents, train staff, conduct and monitor data collection, and prepare the data file. It also includes a report on response rates and non-response weight adjustment calculations.

The Discharged Residents Survey represents the fourth and final data collection activity RTI has undertaken for the National Study of Assisted Living for the Frail Elderly. The first was a screening survey in early 1998 to identify and categorize a sample of assisted living facilities across the country. As a result of this screening survey, we classified facilities into "tiers," according to the level of care and the amount of privacy they provided. The second data collection activity was a field survey of residents, staff and administrators of 300 "Tier 3" assisted living facilities. The "Tier 3" study also included telephone interviews with family members of residents who were unable to respond for themselves. The third was the "Tier 2" telephone survey of 204 facility administrators. The Tier 2 and Tier 3 surveys were both conducted during the Summer and Fall of 1998.

The Discharged Residents Survey provides data to support the Assisted Living Study's analysis of issues such as resident satisfaction, autonomy, and length of stay at assisted living facilities. The basis for the survey sample was the list of 1581 respondents from 293 facilities that participated in the Tier 3 survey.¹ The survey eligible population consisted of the Tier 3 respondents who had been discharged from their facility since their Tier 3 interview. The respondents to the survey were the discharged resident or, if he or she was physically or cognitively unable to participate, a family member who could serve as a proxy for the former resident.

¹ At seven of the 300 facilities that participated in the Tier 3 survey, no interviews were conducted with a resident or proxy.

SCREENING TIER 3 RESPONDENTS

Lead materials. RTI sent an advance packet to each of the 293 facilities in which residents (or their proxies) had participated in the Tier 3 survey. The cover letter from the Principal Investigator, Dr. Hawes, reminded the administrators of their previous participation in the study and explained that an RTI staff member would be calling to ask which of the residents we interviewed at their facility had been discharged. We enclosed a project brochure with additional details about the study. We also enclosed a list of the residents we had interviewed at the facility. At those facilities where the same administrator was the contact person for more than one section of the facility that participated in the study, we enclosed separate lists for each of the relevant sections. A sample of each document in the advance packet is provided in **Exhibit 1, Exhibit 2 and Exhibit 3.**

The list of residents we enclosed with the letter was printed on a *Discharged Residents Form (Exhibit 3)*, which was designed so that facility administrators could simply fill in the information we needed and either fax it back to us or wait to provide it over the phone. It provided spaces to record the following information:

- the resident's name,
- the resident's phone or room number, and
- the name and contact numbers for a family member.

We filled in the contact information we had collected during the original interview for the administrator's reference, and asked that the administrator provide us with an update. The *Discharged Residents Form* also provides a space to record whether the resident had been discharged from the facility.

Staff Training. We trained 8 telephone interviewers and 2 telephone supervisors from RTI's Telephone Survey Unit (TSU) to contact the assisted living facilities to obtain information on the discharged residents. Training took place on June 9, 1999, and was based on the material presented in the *Discharged Residents Survey Telephone Interviewer Manual* (RTI: 1999). It included a discussion of assisted living facilities and the Assisted Living Study, and the interviewer's role in the Discharged Residents Survey. Training techniques focused on hands-on practice, using role playing and mock scripts to guide the trainees through various scenarios they might encounter. The manual is provided as a companion document to this report.

Facility Script. We developed a brief but detailed script for the TSU staff to follow in their contacts with the assisted living facilities (see **Exhibit 4**). The script leads the interviewer through the interaction with the receptionist and provides two alternatives for the initial contact with the facility administrator. The first alternative is for cases where the current administrator is the same person with whom we had contact during the Tier 3 survey. The script in this case is for the interviewer to be prepared simply to remind the administrator of the facility's previous involvement. The second alternative is for

cases where the current administrator is new to the facility or is not familiar with the study. In this case, the script includes additional information about the purpose of the study.

On the Discharged Residents Form, we printed the name of the administrator during the time of the Tier 3 survey so that the interviewer would know which of the two script alternatives was appropriate to use.

Data Collection Materials. In addition to the Discharged Residents Form, TSU staff were given a *Resident Information Sheet* on each of the 1581 residents in the sample. A sample of this form is provided in **Exhibit 5**. This document provides information on each resident individually, and includes facts that were not printed on the Discharged Residents Form, including:

- the final Tier 3 survey status (whether the resident completed the interview or a proxy was required)
- the resident's Medicare number, and
- the resident's birth date.

For discharged residents who had a proxy for the Tier 3 survey, our approach was to again seek a proxy interview for the Discharged Residents Survey. In each case, we first consulted with the administrator to determine whether a proxy was still appropriate. Similarly, for those who completed the Tier 3 interview themselves, we sought to determine from the administrator whether the resident was still the best person to interview or whether a proxy would be more appropriate. Knowing the resident's Tier 3 survey status (complete or proxy) alerted the telephone interviewer about how this question should be asked of the administrator.

In many cases, residents were identified in our files only by first name and last initial; in 58 cases, no name was recorded at all. When available, we provided each resident's Medicare number and birth date on the *Resident Information Sheet* to help the administrator and interviewer identify the correct resident. In 54 of the 80 cases for which only the resident's first name was known, we were also able to use a family member's name to help identify the resident. With the help of the family information and birthdate, we were able to determine the name of 8 of the 58 residents for whom we had no name recorded at all. In the other 50 cases, administrators reported that they did not keep records in a form that allowed them to easily locate residents by Medicare number or birth date.

The Resident Information Sheet also serves as the data collection form for the screening process. Spaces are provided to record administrator's answers to questions about the residents regarding:

- the resident's current status (discharged or not)
- the date of discharge, if applicable
- whether the resident has died or, if not,

- the place to which the person was discharged,
- the identity of the best person to contact for an interview (the resident or a family member or friend), and
- the contact numbers for the resident and a family member or friend who is familiar with the resident's care.

Interviewers were instructed to obtain family member contact information even for those discharged residents whom administrators thought could themselves serve as respondents to the Discharged Residents Survey.

Procedures. Our data collection procedure was designed to take no more than five minutes of the administrator's time. We waited a week after sending the lead letter before starting to call the facilities. This allowed the administrators time to read the letter, and for many of them to fax back the information we needed without being prompted by our phone call.

Forty-six of the 293 administrators eventually faxed the information we needed back to us. Over half of these (27) sent the fax within the first week of survey operations. The rest sent in their faxes after having been prompted by a phone call from RTI. All faxed forms were reviewed by project staff to determine if additional information was needed from the facility. We called those administrators from whom additional information was required.

Telephone interviewers called the facility number provided on the Discharged Residents Form, and asked to speak with the administrator. In those cases where the administrator was new, the interviewer sought to speak with the new administrator and explain the purpose of the call. Interviewers were also instructed that they could ask to speak to someone else who could help if the administrator was too busy to help or could not provide the information we requested.

Results. Altogether, 279 of the 293 facilities (96 percent) responded to our request for information. Of the 293 facilities that participated in the Tier 3 survey, only 13 (4 percent) failed to provide information regarding their discharged residents. In addition, we were unable to contact one of the facilities. In this case, the phone number was no longer a working number and directory assistance was unable to provide a different one in the area.

The screening information we received from the 279 facilities resulted in a list of 281 discharged residents. This represents 19 percent of the 1483 residents about whom we were able to determine current status.

One notable result of this screening process is how seldom administrators recommended the resident as the best respondent for the Discharged Resident interview. If the resident had been the original respondent, we asked the administrator whether the respondent was still the best person to interview. If a proxy had been interviewed in the original survey, we asked the administrator if a proxy was still the best

person to interview. In those cases where the administrator indicated a proxy ought to be interviewed, the interviewer was trained to verify this judgment with the family proxy and the reason for the proxy. Among the 246 discharged residents for whom administrators were able to answer this question, only 35 (14 percent) were judged to be the best respondent for the survey. In another 35 cases, the administrator was unable to answer the question. In each of these 35 cases, the original respondent was the resident.

CONDUCTING THE INTERVIEWS

Data Collection Instruments. Two survey instruments were designed by Dr. Hawes to collect the information for the Discharged Residents Survey. One is the *Assisted Living Discharged Resident Telephone Interview*, which was designed to take an average of 10 minutes to administer. The second is the *Assisted Living Discharged Resident Proxy Respondent Telephone Interview*, which was designed to take an average of 12 minutes. Each of these instruments is provided in **Appendix A and Appendix B** of this report.

Staff Training. We trained four day-shift telephone interviewers and six evening-shift interviewers and their supervisors to conduct the Discharged Resident and Proxy Interviews. Several of the selected staff had participated in previous data collection efforts for the Assisted Living Study. The training took place one week after the facility contacts had begun, and was based on the *Discharged Residents Survey Telephone Interviewer Manual* (RTI:1999). The training incorporated information we had gathered through debriefings of the telephone interviewers who were contacting the assisted living facilities. It was clear from the first week of operations, for example, that the vast majority of interviews would be sought with family member proxies, so we added additional staff to the evening shift and devoted additional time to discussing potential issues which could arise with the proxy respondents. Training covered the purpose of the project and the previous data collection efforts connected with it, and included mock interviews and role-playing.

Procedures. Telephone staff began contacting discharged residents and their family proxies immediately after training. Each assignment packet included a copy of the questionnaire with the resident's ID label and the Resident Information Sheet on the discharged resident. On the lower half of the Resident Information Sheet is a Record of Calls form for the interviewer to record pertinent information about calls that were made to reach the respondent. Once contact was established, the interviewer explained the purpose of the call and obtained the respondent's informed consent before beginning the interview.

In those 35 cases where the administrator had been unable to tell us whether the original respondent was still the best person to interview, the telephone interviewer was instructed to call the resident's phone number first and attempt to interview the discharged resident. In all except two of these 35 cases, we determined that a proxy was required for the interview. In several cases, the discharged resident was living in a nursing home, and a nurse or other staff told us it would be better to interview someone else. In five of the 35 cases, we had only a family member's phone number, and that person informed us that it was not appropriate to interview the discharged resident.

Quality control of the telephone interviews consisted of monitoring, supervision, quality control circle meetings, and post-interview editing. RTI's Telephone Survey Unit (TSU) is equipped with silent monitoring rooms in which monitors can listen in on any

on-going telephone interview. Project staff regularly monitored on-going interviews throughout the data collection process. Supervisors were available at all times to answer questions and help solve data collection problems. Project staff met with TSU interviewing and supervisory staff once a day during the first two weeks of data collection to discuss special issues and debrief the interviewers. These meetings allowed project staff to discuss alternative approaches to locating difficult-to-find respondents and converting initial refusals. The completed interviews were also edited for quality.

Problems Encountered. The first step in conducting the interviews was to contact the potential respondent. However, administrators were not always able to tell us the current address or phone number of the residents they identified as discharged. Many did not have a current phone number for a family member or friend to contact. Among the 281 discharged residents, we were given no contact information at all for 29 residents. For these cases, we took several steps to trace the residents. We began with directory assistance, then continued by searching online directories and national databases such as the Postal Service's National Change of Address System. This effort eventually resulted in useful contact information for 21 of the 29 residents or their family proxies. In 10 of these 21 cases, the administrator had been unable to tell us who would be the best respondent for the survey. In all 10 cases, we concluded from our conversations with the contact that a family member was the most appropriate respondent.

Refusal Conversions. Forty-six (46) family members initially refused to participate in the survey. In each case, the telephone interviewer attempted to ascertain the reason for the refusal before ending the contact. In four cases, family members reported that their relative had recently died and they were too busy to respond to an interview. We placed these cases in a delayed call-back status, and waited until the last week of data collection before attempting to contact them again. By the end of the data collection period, we were able to convert three of these four family members, and to complete interviews with them. In most of the other cases of initial refusal, we waited only a few days, then assigned one of our most experienced and successful interviewers to recontact the family member. Our interviewers were able to produce an additional 18 refusal conversions as a result of these recontacts.

Completions. We completed interviews with a total of 248 people (representing 88 percent of the 281 discharged residents). The completed interviews included 232 proxy interviews and 16 resident interviews.

Of the 1581 resident/proxy interviews we conducted for the Tier 3 baseline study, we were unable to determine the status of 98. The reasons for these incomplete screenings were:

- 6 due to refusal of the facility to provide information (one facility refused to participate);

- 63 due to other nonresponse by facility (12 facilities refused to come to the phone or return our calls); for 26 of these 63, we also had incomplete resident information.
- 25 due to incomplete resident identification information (14 facilities)
- 4 due to the facility having closed (1 facility).

Of the 1483 residents for whom discharge status was determined, 281 residents were found to have been discharged. We interviewed directly or by proxy 248 of these former residents. There were 33 nonresponses among this group of 281 discharged residents. We were unable to locate 8 proxies, and 25 proxies refused to participate.

From anecdotal evidence provided by the telephone staff, the shortness of the interview seems to have helped boost the response rate for this survey.

DATA EDITING, CODING AND KEYING

All completed questionnaires were routed from the Telephone Survey Unit to RTI's Data Preparation Unit (DPU) for processing. DPU staff first verified that each document had an ID number then registered the receipt of the document on the electronic data processing control system.

The questionnaires were edited by a trained staff of editors, following the specifications described in the *Discharged Residents Survey Edit Specifications* guide (see **Appendix C**). Data Editors were trained by project staff to follow the specifications, record the results of the edits, report edit problems and resolve discrepancies before routing the questionnaires to be keyed.

The editing supervisor conducted quality control checks of each editor's work. Problems that arose were recorded and sent to project staff for resolution. To ensure that procedures were being followed correctly, quality control checks were conducted of 100 percent of the first two batches of documents edited by each editor. If the supervisor was satisfied with the editor's performance, a 10 percent sample of the editor's remaining work was selected for quality control.

Data editors used the following consistency codes: Not Applicable = - 3; Don't Know = - 4; Refused = - 7; and Blank = - 8.

DPU staff also coded open-ended questions such as those with the response category: "Other (Specify)." Data editors converted these alphanumeric responses to numeric codes. As instruments were edited and coded, the editing staff maintained a list of codes developed for each of the items on each of the questionnaires. These codes are provided in the *Discharged Residents Survey Resident and Proxy Questionnaire Codes* contained in **Appendix C**.

Edited and coded questionnaires were converted to computer-readable form through program controlled, key-to-disk data entry operation. A data entry program was written that included an edit program that was executed interactively during keying to perform immediate data checks. The edits that were designed into the system included:

- checks of data type (alpha, numeric, or alphanumeric)
- specific value checks for categorical variables
- range checks for continuous variables, and
- check-digit verification of questionnaire ID numbers.

The data entry screen was designed to provide a means of displaying fields for the key entry of data and were designed to replicate hardcopy questionnaire pages. Program logic was implemented as checks of variables at the time of data entry and was based on criteria identified in the corresponding questionnaire codebooks.

After development and testing, the data entry program was reviewed by project and data processing staff before being finalized. Once the programs were finalized, we selected experienced data entry keyers to enter the data. The keyers were trained by the data entry programmer. Data entry began immediately after training.

Quality control consisted of a blind, 100 percent rekey of all questionnaires by a keyer other than the original keyer. The second keyer resolved discrepancies between the two keyings.

FILE PREPARATION

Codebooks were developed for both questionnaires to define data entry program specifications. Codebook definitions included the following characteristics for both questionnaires:

- variable name (8 or fewer unique characters)
- variable type indicator (A=alpha, N=numeric)
- variable field width
- variable description (40 characters or less with the first characters identifying the item number)
- variable levels and definitions, if applicable (e.g., 01 = yes)
- variable ranges, if applicable (e.g., Range = 01-40).

Keyed data were transmitted to a master ALS directory and checked for completeness, ID validity, duplication and key verification. Data were then archived by form type into subdirectories in SAS data sets.

NON-RESPONSE WEIGHT ADJUSTMENTS FOR DISCHARGED RESIDENTS

All *Tier #3* Resident respondents who had been discharged since responding to the *Tier #3* Resident, Resident Proxy or Family Member Questionnaire were eligible for the Discharged Resident Questionnaire. However, the status of whether or not a resident had been discharged was determined for 1,483 of the 1,581 *Tier #3* Resident respondents. Of the 1,483 residents with known discharge status, only 281 (19%) residents had been discharged since responding to one of the *Tier #3* Resident Questionnaires. A discharged resident was considered a respondent if we received a completed Discharged Resident or Discharged Resident Proxy Questionnaire. There were no partial interviews or cases where the interview had ended prematurely. At the conclusion of data collection we had received 16 Discharged Resident Questionnaires and 232 Discharged Resident Proxy Questionnaires, for a combined total of 248 Discharged Resident Respondents.

In order to calculate the non-response weight adjustments for the discharged residents, we assigned the following indicators to each of the 1,581 *Tier #3* Resident respondents, where m is the resident in facility k in location j in PSU i :

$$RF_{cijkm} = \begin{cases} 1 & \text{if the discharge status of resident}_{cijkm} \text{ was determined,} \\ 0 & \text{Otherwise} \end{cases}$$

RF_{cijkm} was set to one for 1,483 residents and to zero for 98 residents.

$$RE_{cijkm} = \begin{cases} 1 & \text{if resident}_{cijkm} \text{ was discharged,} \\ 0 & \text{Otherwise} \end{cases}$$

RE_{cijkm} was set to one for 281 residents and to zero for 1,300 residents.

$$RD_{cijkm} = \begin{cases} 1 & \text{if resident}_{cijkm} \text{ was a respondent,} \\ 0 & \text{Otherwise} \end{cases}$$

RD_{cijkm} was set to one for 248 residents and to zero for 1,333 residents.

We used the above indicators to compute the non-response adjustment factor for each weighting class c , where c is the same weighting class, determined by the privacy, service and size levels for facility from which the resident was discharged, that was used in the *Tier #3* Resident weight adjustments. The weight adjustments were calculated by:

$$ADJK_c = \sum_{ijkm \in c} RESWT_{ijkm} / \sum_{ijkm \in c} RESWT_{ijkm} \cdot RF_{ijkm}$$

$$ADJD_c = \sum_{ijkm \in c} RESWT_{ijkm} \cdot RE_{ijkm} / \sum_{ijkm \in c} RESWT_{ijkm} \cdot RD_{ijkm}$$

where $RESWT_{ijkm}$ is the final analysis weight for the *Tier #3* Residents. The final discharged resident analysis weights were calculated from the *Tier #3* Resident weights as follows:

$$DISTATWT_{ijkm} = RESWT_{ijkm} \cdot ADJK_c \cdot RF_{ijkm}$$

$$DISRESWT_{ijkm} = DISTATWT_{ijkm} \cdot ADJD_c \cdot RD_{ijkm}$$

DISTATWT is useful for estimating discharge rates among various subpopulations of residents. For example, the estimated discharge rates among eligible residents are shown by weighting class in **Table 1**. DISRESWT is the analysis weight for estimating population characteristics of discharged residents.

TABLE 1. Estimated Discharge Rates by Weighting Class				
Weighting Class			Total Residents ²	Estimated Discharge Rate ³ (%)
Level of Privacy	Level of Service	Size ¹		
High	High	Medium	221	23.0 +/- 6.9
High	High	Large	263	15.8 +/- 3.9
High	Low	Medium	392	22.6 +/- 6.9
High	Low	Large	242	19.1 +/- 5.5
Low	High	Medium	163	20.3 +/- 6.3
Low	High	Large	202	16.3 +/- 6.9
Total			1,483	19.0 +/- 2.5

1. Size categories: Medium = 11 to 50 beds; Large = 51+ beds.
2. Total number of residents who were Tier #3 respondents with known discharge status.
3. Estimated discharge rate with 95% confidence bounds.

Table 2 shows the weighted and unweighted response rates for the discharged residents by weighting class. The discharged resident response rates are the product of the corresponding Tier#3 facility and discharged resident participation rates.

TABLE 2. Discharged Resident Response Rates								
Weighting Classes			Tier #3 Facilities		Discharged Residents		Response Rates ²	
Level of Privacy	Level of Service	Size ¹	Eligible	Respond	Eligible	Respond	Unweighted	Weighted
High	High	Medium	51	49	56	49	84%	80%
High	High	Large	42	40	36	33	87%	87%
High	Low	Medium	76	72	78	69	84%	82%
High	Low	Large	50	45	47	39	75%	78%
Low	High	Medium	31	31	35	32	91%	86%
Low	High	Large	43	42	29	26	88%	85%
Total			293	279	281	248	84%	82%

1. Size categories: Medium = 11 to 50 beds; Large = 51+ beds.
2. Response rates are the product of the facility and resident response rates.

Expected Statistical Power. We estimated the probability or power to detect pairwise percentage differences for outcomes related to the discharged residents by the level of privacy and level of service for the facility from which the resident was discharged. We based the power calculations on the expected (or average) design effects for each combination of privacy and service shown in **Table 3**. The effective sample size shown in the table is the number of Discharged Resident respondents associated with the difference divided by the associated design effect.

TABLE 3. Expected Detectable Differences ¹ for Comparing Percentage Estimates between Discharged Residents in Facilities with Various Combinations of Privacy and Service			
	Design Effect	Effective Sample Size	Expected Detectable Difference
Interactive Comparisons			
High Privacy & High Service vs. High Privacy & Low Service	1.38	138	21.0%
High Privacy & High Service vs. Low Privacy & High Service	1.44	97	24.9%
High Privacy & Low Service vs. Low Privacy & High Service	1.40	119	23.6%
Main Effects Comparisons (Assuming no interactions)			
High Privacy vs. Low Privacy	1.4	177	22.0%
High Service vs. Low Service	1.42	175	18.5%

1. True differences between two facility-level percentages in the mid-range (i.e., 40% to 60%). The detectable differences listed are expected to be significant with 80% power at the 0.05 (one tail) level of significance. Smaller differences will be detected with the same power when both percentages are either above 60% or below 40%.

EXHIBIT 1. LEAD LETTER

Dear [ADMINISTRATOR NAME]

I would like to thank you for your facility's recent participation in the *National Study of Assisted Living for the Frail Elderly*. I appreciate you taking time from your busy schedule to participate in this important project. The information provided by hundreds of facilities such as yours will be used to develop a national profile of the assisted living industry for the Department of Health and Human Services (DHHS). This information will be beneficial not only to DHHS, but also to providers and developers within the assisted living industry.

To complete this profile, we are collecting information on resident discharges from the facilities that are participating in the study. You will be receiving a telephone call about this in the coming weeks. This call will take no more than **5 minutes** of your time.

In each of the several hundred facilities participating in the study, we selected up to six residents. For each of the selected residents, we sought consent to participate from the resident or their legal guardian or responsible family member. Only those who consented were interviewed. If a resident was too physically ill or cognitively impaired to respond to the interview, we interviewed a staff member who was a direct care giver and a family member. We also sought and received the consent of all participating residents and family members to recontact them in a few months. That will be the purpose of our call to you.

We will be calling you to ask you to identify those residents among our sample of up to six in your facility who have died or permanently left the facility since we interviewed them (i.e., not someone who is now in the hospital but is expected to return to your facility). Enclosed is a form with the names and other identifying information of the residents who participated in the study from your facility. If you wish, you may simply fill out the information we need and fax it back directly to Michelle Major at (919) 541-1261. Otherwise, we will call you in a few days.

If you know the resident is deceased, it would be helpful if you would tell us that, since we would seek to interview the next-of-kin rather than the resident. In addition, if you have contact information, particularly a name and phone number, that can help us locate a resident or a relevant family member, that would be very helpful. If the resident is discharged, please indicate the date of discharge. The information you provide will be kept confidential and will be used only by RTI project staff to request an interview.

Again, I would like to thank you for your assistance in this important national data collection effort. If you have any questions about the upcoming telephone call, or if you would like to be placed on the mailing list for the final report, you may call Michelle Major at the Research Triangle Institute at (919) 541-6921 or Kristina Ahlen at (919) 485-7722. If you are a new administrator and you are unfamiliar with this study or your facility's participation, please take a moment to read the enclosed brochure.

Yours truly,

Catherine Hawes, Ph.D.
Senior Research Scientist and Study Director

EXHIBIT 2. PROJECT BROCHURE

NATIONAL
STUDY
OF
ASSISTED
LIVING
FOR THE
FRAIL
ELDERLY



Information for
residents in residential care
and assisted living facilities

NATIONAL STUDY OF ASSISTED LIVING

This study is funded by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE). Additional funding has been provided by the National Institute on Aging, the Administration on Aging, and the Alzheimer's Association.

About The Study...

Why Is This Study Being Done?

DHHS is sponsoring this study to learn about the roles that assisted living and residential care facilities play in meeting the needs of older adults in the U.S.

Who Supports This Study?

Major associations such as the Assisted Living Federation of America, the American Health Care Association, and the National Center for Assisted Living support this study. We have also informed the licensing agency in your state about the study. And we have already seen high interest in this study from states and from members of Congress.

Who Is Conducting The Study?

Research Triangle Institute (RTI) and Myers Research Institute are conducting the study on behalf of DHHS. RTI is a not-for-profit, research organization associated with the University of North Carolina, Duke University, and North Carolina State University. Myers Research Institute is a division of Menorah Park Center for the Aging, a not-for-profit long term care system providing care and services to frail elders in Cleveland, Ohio, since 1906.

Who Is Being Asked To Participate? Why Was I Chosen?

Participants were randomly chosen from facilities in 27 states across the U.S. About 600 assisted living facilities will participate. The administrator, up to six residents, and up to two staff from your facility will be selected to participate.

Who Will Interview Me?

An interviewer from your local area will arrive at your facility and speak with the

administrator. The administrator or another staff person from your facility will help set up the interview. The interview will take place at your convenience, at any location you prefer. All interviewers will be extensively trained before coming to your facility. They will present identification upon arrival. They are not representatives of any government agency.

About Your Participation....

Do I Have To Participate?

Participation in the study is voluntary. However, assisting in the study gives you the opportunity to contribute to the first national study of assisted living. DHHS wants to know how residents of assisted living facilities feel about this type of care. Your opinions and ideas are very important.

How Long Will The Interview Take?

Your interview will last about 30 minutes.

WHAT KIND OF QUESTIONS WILL I BE ASKED?

You will be asked basic questions about your health and background. You will also be asked about the help you receive from staff and the kind of activities in which you are involved. You will be asked about your reasons for choosing this facility and your views about your experiences here. Also, a staff member may be asked to provide information about your medications. You may refuse to answer any question, but your opinions are very important and everything you say will be kept confidential.

IS THE INFORMATION I GIVE CONFIDENTIAL?

All information you or others provide will be used for research purposes only. Your name will not be associated with your responses. Your answers will not be revealed to ANYONE including the staff at this facility, except at your request. Your information is confidential and is protected by the Federal Privacy Act.

Research Sponsored By:

The U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation
<http://aspe.os.dhhs.gov/daltcp/home.htm>

To request reports:

Ms. Tammy Bailey
DHHS, ASPE/DALTC
200 Independence Ave., SW, Room 424E
Washington, DC 20201

Research Conducted By:



Research Triangle Institute
3040 Cornwallis Road
Post Office Box 12194
Research Triangle Park,
NC 27709-2194

AND

Myers Research Institute
at Menorah Park Center for the Aging

**For More Information,
Please call Michelle Major at
Research Triangle Institute
at 1-800-334-8571, ext. 6921
Monday-Friday, 8:30 a.m.-4:30 p.m.
Eastern Time**

EXHIBIT 3. DISCHARGED RESIDENTS FORM

Facility _____ Administrator/Director _____

DISCHARGED RESIDENTS

1. Please indicate in Column (c) if any of these residents have been permanently discharged (and when) and specify if deceased
2. Please update our contact information in the space directly below printed information. (Please PRINT or TYPE)
3. Fax this completed sheet to Michelle Major at (919) 541-1261 or provide the information to our staff when they call.

(a) For Office Use Only Resident ID	(b) Resident Name & Current Phone Number (If discharged, please provide current address)	(c) Date resident was discharged (Specify if deceased) N.A. = Not discharged	(d) Who is best person to interview about this resident? (Resident or another?)	(e) Name of Family Member or Contact Person to Interview about the Resident	(g) Family/Contact Phone (Include area code)
UPDATE ⇄					
UPDATE ⇄					
UPDATE ⇄					
UPDATE ⇄					
UPDATE ⇄					

EXHIBIT 4. DISCHARGED RESIDENTS SURVEY: SCREENING SCRIPT

Discharged Residents Survey: Screening Script

Step 1: Study the Discharged Resident Form and the Resident Information Sheets. Note how many residents participated in the original survey. Note which ones required a proxy respondent.

GETTING THROUGH THE GATEKEEPER

Hello, may I speak to _____ [NAME / "THE ADMINISTRATOR"] ?

RECEPTIONIST / GATEKEEPER
WANTS INFORMATION

My name is _____. I'm calling from the Research Triangle Institute in North Carolina

The _____ [FACILITY] participated a few months ago in the National Study of Assisted Living for the Frail Elderly. I'm calling in reference to a letter Dr. Catherine Hawes recently sent to _____ [NAME / "THE ADMINISTRATOR"]. He/she should be expecting my call.

ADMINISTRATOR / ORIGINAL
RESPONDENT NO LONGER AT
FACILITY

Who is the current administrator? [RECORD NAME ON CONTACT SHEET]

May I speak to _____ ?

GATEKEEPER RELUCTANT TO
GIVE NAME

My name is _____. I'm calling from Research Triangle Institute in North Carolina. The _____ [FACILITY] participated a few months ago in the National Study of Assisted Living for the Frail Elderly and I am making a follow up call regarding that study. Dr. Catherine Hawes recently sent a letter to _____ [NAME / "THE ADMINISTRATOR"]. The new administrator may have been forwarded the letter and may be expecting my call. May I speak with her/him?

ADMINISTRATOR NOT
AVAILABLE
NEED TO LEAVE A MESSAGE

He/She can call us at 1-800-###-####. Please tell him/her that I am calling in reference to a letter Dr. Catherine Hawes recently sent to _____. When he/she calls, he/she should ask to be connected to _____.

OR

When would be a more convenient time to call?

SPEAKING WITH THE ORIGINAL ADMINISTRATOR

My name is _____. I'm calling from the Research Triangle Institute in North Carolina. Dr. Catherine Hawes recently sent you a letter about a study your facility participated a few months ago called the National Study of Assisted Living for the Frail Elderly.

Have you had a chance to read this letter?

YES

As you may know from Dr. Hawes' letter, I am calling to find out about the current status of the residents who participated in this study. One of our interviewers visited _____ [FACILITY] and interviewed _____ [NUMBER] of your residents (or their family members). At that time the people we interviewed agreed we could contact them again. I would like to find out the current status of each of those residents. It should only take about 5 minutes of your time.

NO

In her letter, Dr. Hawes sent her thanks to you for participating a few months ago in this national study. She also wrote that I would be calling to ask for your help in completing the study. One of our interviewers visited _____ [FACILITY] and interviewed _____ [NUMBER] of your residents (or their family members). The people we interviewed agreed we could contact them again. I would like to find out the current status of each of those residents. It should only take about 5 minutes of your time.

- | | | |
|---|----------|---|
| <input type="radio"/> Yes, okay | → | GO TO FINAL SECTION |
| <input type="radio"/> I don't have time | → | Is there someone else there who could help, or would you prefer that I call back at another time?
SET UP APPOINTMENT TO CALL AGAIN |
| <input type="radio"/> Not interested/Refuse | → | RECORD STATUS ON RESIDENT INFORMATION SHEET |
| <input type="radio"/> I already faxed the information to RTI | → | We don't seem to have received it yet, but I will check. When did you send it? Could you confirm which fax number it was sent to? Perhaps it would be easier to simply read the information to me. Would you do that?
RECORD ON RESIDENT INFORMATION SHEET |

YOU ARE SPEAKING TO A NEW ADMINISTRATOR

My name is _____. I'm calling from the Research Triangle Institute in North Carolina. Dr. Catherine Hawes recently sent _____ [ADMINISTRATOR] a letter concerning the National Study of Assisted Living for the Frail Elderly. _____ [FACILITY] participated in this study a few months ago. Was this letter forwarded to you? Have you had a chance to read it?

YES (to both questions)

As you may know from Dr. Hawes' letter, I am calling to find out about the current status of the residents who participated in this study. The study is about the roles that assisted living and residential care facilities play in meeting the needs of older adults in the U.S. As part of this study, one of our interviewers visited _____ [FACILITY] last year and interviewed _____ [NUMBER] of your residents (or their family members). At that time, the people we interviewed agreed we could contact them again. I am calling today because we would like to find out the current status of each of those residents. It should only take about 5 minutes of your time.

NO (to either or both questions)

In her letter, Dr. Hawes sent her thanks for your facility's participation a few months ago in this national study. She also wrote that I would be calling to ask for your help in completing the study. The study is about the roles that assisted living and residential care facilities play in meeting the needs of older adults in the U.S. As part of this study, one of our interviewers visited _____ [FACILITY] and interviewed _____ [NUMBER] of your residents (or their family members). At that time, the people we interviewed agreed we could contact them again. I am calling today because we would like to find out the current status of each of those residents. It should only take about 5 minutes of your time.

- Yes, okay** → GO TO FINAL SECTION
- I don't have time** → Is there someone else there who could help, or would you prefer that I call back at another time?
SET UP APPOINTMENT TO CALL AGAIN
- Not interested/Refuse** → RECORD STATUS ON RESIDENT INFORMATION SHEET
- I already faxed the information to RTI** → We don't seem to have received it yet, but I will check. When did you send it? Could you confirm which fax number it was sent to? Perhaps it would be easier to simply read the information to me. Would you do that?
RECORD ON RESIDENT INFORMATION SHEET

OBTAINING RESIDENT INFORMATION

(ADMINISTRATOR AGREES TO PROVIDE INFORMATION)

I have a list of the people who participated in the original study. I'll go through each person, and you can tell me whether he or she has been discharged.

IF FIRST AND LAST NAMES FOR ALL RESIDENTS ARE NOT AVAILABLE ON THE INFORMATION SHEET:

As researchers, we are required to follow strict confidentiality rules, so our information on these residents is limited in some cases. I may need your help in identifying some of them.

The first of the __ [NUMBER] people on our list is _____ [RESIDENT'S NAME].

Has _____ [RESIDENT'S NAME] been discharged from your facility? [ASSIST AS NECESSARY WITH OTHER AVAILABLE INFORMATION SUCH AS FAMILY MEMBER'S NAME, OR RESIDENT'S MEDICARE NUMBER OR BIRTH DATE.]

YES → What was the date of discharge? [RECORD ON RESIDENT INFORMATION SHEET]

Where is _____ [RESIDENT] now? [RECORD ON RESIDENT INFORMATION SHEET]

- HOME OR WITH FAMILY/FRIENDS
- HOSPITAL/REHABILITATION FACILITY
- NURSING HOME
- AT ANOTHER ASSISTED LIVING OR RESIDENTIAL CARE FACILITY
- PSYCHIATRIC CARE FACILITY
- OTHER _____ (SPECIFY ON RESIDENT INFORMATION SHEET)
- DON'T KNOW
- REFUSED

DECEASED → VERIFY OR OBTAIN CONTACT INFORMATION FOR FAMILY MEMBER OR OTHER:

FAMILY MEMBER OR FRIEND'S NAME IS KNOWN →

The information we have is that _____ [RESIDENT] can also be contacted through _____ [FAMILY NAME]. Is that still correct as far as you know?

FAMILY MEMBER PHONE KNOWN →

Could you tell me if our phone number for _____ [FAMILY NAME] is still correct? [READ NUMBER AND VERIFY OR CORRECT ON RESIDENT INFORMATION SHEET]

FAMILY MEMBER PHONE NUMBER UNKNOWN →

Could you give me _____ 's [FAMILY NAME] phone number and address?

FAMILY MEMBER NAME & PHONE UNKNOWN →

Could you give me the name and phone number of the best person for us to contact about _____ [RESIDENT'S NAME] ?

GO TO NEXT NAME

NO → GO TO NEXT NAME [The next name on the list is.....]

APPENDIX A: ASSISTED LIVING DISCHARGED RESIDENT TELEPHONE INTERVIEW

OMB Number: 0990-0217
Expires: _____

ASSISTED LIVING DISCHARGED RESIDENT TELEPHONE INTERVIEW

Respondent ID Label

Facility Name: _____

Interviewer Name: _____ Interviewer ID # _____

Date of Interview: ____/____/____
Month Day Year

Start Time: ____:____ am/pm

End Time: ____:____ am/pm

Paperwork Reduction Act Statement

A federal agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Public reporting burden for this collection of information is estimated to average 10 minutes per response, including time for reviewing instructions, searching existing data sources, gathering and maintaining the necessary data, and completing and reviewing the collection of information. Send comments regarding the burden estimate of any other aspect of this collection of information to the OS Reports Clearance Officer, ASMB/Budget/PIOM, Room 503H HHH Bldg., 200 Independence Avenue, SW, Washington, DC 20201.

INTERVIEWER INSTRUCTIONS:

Unless you know that the resident is deceased, ask to speak with the resident.

If the resident is deceased, ask to speak with a family member who has the most information about the resident's experience in the assisted living facility/residential care home and use the Discharged Resident Proxy Interview Form.

Read introduction/consent below before you begin with the questions.

INTRODUCTION

You are being asked to participate in a national study of assisted living and residential care for the frail elderly. About six months ago, we interviewed you in-person while you were a resident at _____. This is a follow-up interview for all residents in the study who subsequently left any of the several hundred facilities in the study.

As you may remember, this study is being conducted for the U.S. Department of Health and Human Services to learn more about the role that assisted living and residential care facilities can play in meeting the needs of older persons. Determining the experiences of residents who have left such facilities will help the government understand the role such facilities play in providing long-term care for older persons.

The follow-up study is being conducted for the government by Research Triangle Institute (RTI). RTI is a nonprofit university-affiliated research organization in North Carolina.

As before, your participation is voluntary. You may refuse to answer any question we ask. In addition, all your responses are confidential and will not be disclosed except as required by law. The information you provide will not be reported in any way that identifies you or the facility. This interview will take about 10 minutes. It asks about your experience and views, including why you left the facility.

We hope you will agree to participate, since your views and experiences are important in helping us learn more about how to provide good care for older persons.

1. On what date did you leave _____ ?

 /___/ /___/ /___/___/___/
 MO DAY YR

2. Which of the following best describes the place where you are currently staying?

- Acute care hospital 01
- Nursing home 02
- Rehabilitation facility or subacute care unit 03
- Another residential care or assisted living facility 04
- Own home or apartment 05
- Home or apartment of a relative 06
- Some other place (SPECIFY) _____ 07

3. Did you go anyplace else between leaving _____ [FACILITY] and where you currently are staying?

- YES 01
- NO 02 (SKIP TO Q. 5)

4. Which of the following best describes the place (*or places*) you went between leaving _____ [FACILITY] and where you are currently staying? (CIRCLE ALL THAT APPLY)

- Hospital (*acute care hospital*) 01
- Nursing home 02
- Rehabilitation facility or subacute care unit 03
- Another residential care or assisted living facility 04
- Own home or apartment 05
- Home or apartment of a relative 06
- Some other place (SPECIFY) _____ 07

5. Which of the following best describes the decision to leave the facility? Would you say the decision was:

- Mainly mine or my family's decision 01
- Mainly the facility's decision 02
- Mutual 03
- DK 04

6. All in all, how much control did you have over the decision to leave _____ [FACILITY]?
Would you say you had....

- Complete or almost complete control 01
- Some control 02
- Little or no control 03

7. Please tell me which of the following statements describe the reasons you left ____ [FACILITY]:
(CIRCLE ALL THAT APPLY)

- Required hospital care 01
- Needed nursing home care 02
- Required more care than the facility could provide 03
- Preferred location closer to family or friends 04
- Exhausted my resources and had to leave because of money .. 05
- Dissatisfied with the quality of care 06
- Dissatisfied with the price or charges 07
- Dissatisfied with some other aspect of the Facility 08
- It was the facility's request for unknown reason 09
- Is there any other reason not mentioned here?
(SPECIFY)_____ 10

8. Which of the following statements best describes your feeling about the timing of your departure from _____ [FACILITY]?

Wish I had left sooner 01

Wish I had been able to stay there longer 02

Left at just the right time 03

9. When you moved into ____ [FACILITY], did you expect that you would be able to remain in that facility as long as you wanted to? Sometimes this is called being able to “age in place.”

YES 01

NO 02

10. When you entered _____ [FACILITY], did someone discuss with you the conditions under which you would be asked to leave or when the facility would NO longer be able to meet your care needs?

YES 01

NO 02 (SKIP TO Q. 12)

DK -4 (SKIP TO Q. 12)

11. Which of the following best describes the facility’s policies about discharge?

Very unclear - what the facility promised and what it actually did were very different 01

Unclear - you didn’t know what to expect because the terms were very vague 02

Adequate - you had a general idea of what to expect 03

Very Clear - facility policies were clear, and the facility lived up to what it promised 04

12. Use any number on a scale from 0 to 10, with 0 being the worst and 10 being the best. How would you rate the facility’s performance in terms of meeting your need for personal assistance or health care?

_____ Score

DK -4

13. Use any number on a scale from 0 to 10, with 0 being the worst and 10 being the best. How would you rate the facility's performance in terms of meeting your expectations about how much it would cost on a monthly basis?

_____ Score

DK -4

14. Think back to when you moved in to _____ [FACILITY]. Which of the following were important to you? (CIRCLE ALL THAT APPLY) *(The facility selected may not have had all the things the resident wanted, but the responses should reflect preferences.)*

YES NO

Having a private bedroom 01 02

Having a private bathroom 01 02

Being able to bring your own furniture to the facility 01 02

Having access to a place to store and cook food 01 02

The attractiveness and amenities of outside areas 01 02

The attractiveness and amenities of the indoor public spaces 01 02

The availability of monitoring, for example if you fell or needed help with medications 01 02

The quality of the direct care staff (knowledge, training, attitudes, staffing level) 01 02

Whether the facility had a Registered Nurse on staff 01 02

The ability of the facility to provide more or different services if your needs changed 01 02

The availability of a nursing home on the same campus 01 02

The activities that were available 01 02

Location 01 02

Price 01 02

NONE OF THE ABOVE 77

15. Did your opinion of what was most important to you change over time, as you lived in the facility?

YES 01

NO 02 (SKIP TO Q. 17)

16. Which of the following became *MORE* important to you as you lived at _____ [FACILITY]?
(CIRCLE ALL THAT APPLY) (If the facility did not offer something but the resident wanted it or needed it, the response for that item should be a "YES.")

YES NO

Being able to have a private bedroom 01 02

Being able to have a private bathroom 01 02

Being able to bring your own furniture to the facility 01 02

Having access to a place to store and cook food 01 02

The attractiveness and amenities of the outside areas 01 02

The attractiveness and amenities of the indoor
public spaces 01 02

The availability of monitoring, for example if you fell or
needed help with medications 01 01

The quality of the direct care staff (knowledge, training,
attitudes, staffing level) 01 02

Having a Registered Nurse on staff 01 02

The ability of the facility to provide more or different
services if my needs changed 01 02

The availability of a nursing home on the same campus 01 02

The activities that were available 01 02

Location 01 02

Price 01 02

NONE OF THE ABOVE 77

17. Did you find that charges at ____ [FACILITY] increased at a faster rate than you expected or that there were additional, unexpected charges, over and above the monthly rate?

YES 01

NO 02

18. Which of the following were better than you expected at _____ [FACILITY]? (CIRCLE ALL THAT APPLY)

The accommodations 01

The price 02

The activities 03

The transportation that was offered 04

The staff (quality and number) 05

The availability of services or assistance you needed 06

19. Which of the following were worse than you expected at _____ [FACILITY]? (CIRCLE ALL THAT APPLY)

The accommodations 01

The price 02

The activities 03

The transportation that was offered 04

The staff (quality and number) 05

The availability of services or assistance you needed 06

20. Overall, which of the following statements best describes your experience at _____ [FACILITY]? Would you say it was

Better than you expected 01

Worse than you expected 02

About the same as you expected 03

21. Would you recommend this facility to a friend who had the same type of needs and interests you had?

YES 01

NO 02

END

Thank you for your assistance in helping us understand the role of assisted living and other residential care settings in providing care to older persons.

PROBLEM SHEET

Item	Comments

APPENDIX B: ASSISTED LIVING DISCHARGED RESIDENT PROXY RESPONDENT TELEPHONE INTERVIEW

OMB Number: 0990-0217
Expires: _____

ASSISTED LIVING DISCHARGED RESIDENT PROXY RESPONDENT TELEPHONE INTERVIEW

Respondent ID Label

_____ Facility Name:

Name of Discharged Resident: _____

Interviewer Name: _____

Interviewer ID # _____

Date of Interview: ____/____/____
Month Day Year

Start Time: ____:____ am/pm

End Time: ____:____ am/pm

Public Reporting Burden Statement

A federal agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Public reporting burden for this collection of information is estimated to an average of 12 minutes per response, including time for reviewing instructions, searching existing data sources, gathering and maintaining the necessary data, and completing and reviewing the collection of information. Send comments regarding the burden estimate or any other aspect of this collection of information to the OS Reports Clearance Officer, ASMB/Budget/PIOM, Room 503H HHH Bldg., 200 Independence Avenue, SW, Washington, DC 20201.

INTERVIEWER INSTRUCTIONS:

Unless you know that the resident is deceased, ask to speak with the resident and use the Discharged Resident Interview.

If the resident is deceased or too physically ill or cognitively impaired to respond, ask to speak with a family member who has the most information about the resident's experience in the assisted living facility/residential care home.

Read introduction below before you begin with the questions.

INTRODUCTION

You are being asked to participate in a national study of assisted living and residential care for the frail elderly. About six months ago, we interviewed one of your family members, _____ [RESIDENT]. This is a follow-up interview about all residents in the study who have left the facility or who are deceased.

This study is being conducted for the U.S. Department of Health and Human Services. This agency is sponsoring the study to learn more about the role that assisted living and residential care facilities can play in meeting the needs of the elderly. Determining the experiences of residents who have left such facilities or who died while a resident there will be very helpful in understanding the role such facilities play in providing long-term care to elders. Research Triangle Institute (RTI) is conducting the study on behalf of the government. RTI is a nonprofit university-affiliated research organization in North Carolina.

Your participation is voluntary, and you may refuse to answer any question we ask. In addition, all your responses are confidential and will not be disclosed except as required by law. Your responses will also not be reported in any way that identifies you or your family member. This interview will take about 12 minutes. It asks about the experience of your family member in the facility and your views of the care HE/SHE received.

We hope you will agree to participate, since your views and experiences are important in helping us learn more about how to provide good care to elders.

1. What is/was your relationship to _____ [RESIDENT]? Are you his/her...
- Spouse 01
 - Child 02
 - Child-in-law 03
 - Sibling 04
 - Grandchild 05
 - Niece/nephew 06
 - Other (SPECIFY) _____ 07

2. Reason for not conducting the interview with resident?

(IF POSSIBLE, CODE WITHOUT ASKING BASED ON INFORMATION PROVIDED BY TELEPHONE SURVEY LOCATORS)

- Resident had proxy respondent in original interview 01
- Resident is deceased 02
- Resident is too cognitively impaired to respond 03 (SKIP TO Q.3)
- Resident is too physically ill to respond 04 (SKIP TO Q.3)
- Resident is too hard of hearing to respond to a telephone interview 05 (SKIP TO Q.3)
- Other (e.g., language) (SPECIFY) _____ 06 (SKIP TO Q.3)

2a. On what date did _____ [RESIDENT] die/pass on?

/_/_/ /_/_/ /_/_/_/_/

 MO DAY YR

2b. Did _____ [RESIDENT] die/pass on at _____ [FACILITY]?

- Yes 01 (SKIP TO Q. 2e)
- No 02

2c. On what date did _____ [RESIDENT] leave _____ [FACILITY]?

/_/_/ /_/_/ /_/_/_/_/

 MO DAY YR

2d. Which of the following describe where _____ [RESIDENT] went between leaving _____ [FACILITY] and when he/she died? (CIRCLE ALL THAT APPLY)

- Hospital (*acute care hospital*) 01
- Nursing home 02
- Rehabilitation facility or subacute care unit 03
- Another residential care or assisted living facility 04
- Own home or apartment 05
- Home or apartment of a relative 06
- Some other place (SPECIFY) _____ 07

2e. Did he/she receive hospice care while living at _____ [FACILITY]?

- Yes 01 (SKIP TO Q. 9)
- No 02 (SKIP TO Q. 9)

3. On what date did _____ [RESIDENT] leave _____ [FACILITY]?

 / / / / / / / /
 MO DAY YR

4. Which of the following best describes the place where _____ [RESIDENT] is currently staying?

- Hospital (*Acute care hospital*) 01
- Nursing home 02
- Rehabilitation facility or subacute care unit 03
- Another residential care or assisted living facility 04
- Own home or apartment 05
- Home or apartment of a relative 06
- Some other place (SPECIFY) _____ 07

5. Did _____ [RESIDENT] go anyplace else between leaving _____ [FACILITY] and where he/she is currently staying?

- YES 01
- NO 02 (SKIP TO Q. 7)

6. Which of the following best describes the place (or places) he/she went between leaving _____ [FACILITY] and where you are currently staying? (CIRCLE ALL THAT APPLY)

- Hospital (*acute care hospital*) 01
- Nursing home 02
- Rehabilitation facility or subacute care unit 03
- Another residential care or assisted living facility 04
- Own home or apartment 05
- Home or apartment of a relative 06
- Some other place (SPECIFY) _____ 07

7. Which of the following best describes the decision to leave the facility? Would you say the decision was:

- Mainly relative or our family's decision 01
- Mainly the facility's decision 02
- Mutual 03
- DK 04

8. Please tell me which of the following statements describe the reasons your relative left ____ [FACILITY]: (CIRCLE ALL THAT APPLY)

- Required hospital care 01
- Needed nursing home care 02
- Required more care than the facility could provide 03
- Preferred location closer to family or friends 04
- Exhausted his/her resources and had to leave because of money 05
- Dissatisfaction with the quality of care 06
- Dissatisfaction with the price or charges 07
- Dissatisfaction with some other aspect of the facility 08
- It was the facility's request for unknown reason 09
- Relative died/passed on 10
- Is there any other reason not mentioned here? (SPECIFY) _____ 11

9. When _____ [RESIDENT] moved into ____ [FACILITY], did you expect that he/she would be able to remain in that facility as long as you wanted to? Sometimes this is called being able to "age in place."

- YES 01
- NO 02

10. When your relative entered _____ [FACILITY], did someone discuss with you the conditions under which he/she would be asked to leave or when the facility would no longer be able to meet his/her care needs?

- YES 01
- NO 02 (SKIP TO Q. 12)
- DK -4 (SKIP TO Q. 12)

11. Which of the following statements best describes the facility's policies about discharge?

- Very unclear - what the facility promised and what it actually did were very different 01
- Unclear - you didn't know what to expect because the terms were very vague 02
- Adequate - you had a general idea of what to expect 03
- Very Clear - facility policies were clear, and the facility lived up to what it promised 04

12. Which of the following statements best describes your feeling about the length of your relative's stay in _____ [FACILITY]?

- Wish he/she had left sooner, for example to go to a nursing home 01
- Wish he/she had been able to stay there longer 02
- Left at just the right time 03

13. Use any number on a scale from zero to ten, with zero being the worst and 10 being the best. How would you rate the facility's performance in terms of meeting your relative's need for personal assistance or health care?

- _____ Score
- DK -4

14. Did you help your relative select _____ [FACILITY]?

- YES 01
- NO 02 (SKIP TO Q. 18)

15. Think back to when your relative moved into _____ [FACILITY]. Which of the following were important to you? (CIRCLE ALL THAT APPLY) *(The facility selected may not have had all the things the family member or resident wanted, but the responses should reflect preferences.)*

	Yes	No
Private bedroom	01	02
Private bathroom	01	02
Ability to bring his/her own furniture to the facility	01	02
Having access to a place to store and cook food	01	02
The attractiveness and amenities of the outdoor areas	01	02
The attractiveness and amenities of the indoor public spaces	01	02
The availability of monitoring, for example if your relative fell or needed help with medications	01	01
The quality of the direct care staff (knowledge, training, attitudes, staffing level)	01	02
Whether the facility had a Registered Nurse on staff	01	02
The ability of the facility to provide more or different services if your relative's needs changed	01	02
The availability of a nursing home on the same campus	01	02
The activities that were available	01	02
Location	01	02
Total Cost (Price plus any extra charges)	01	02
All were equally important	77	

16. Did your opinion of what was most important change over time, as your relative lived in the facility?

- YES
- NO

17. Which of the following became *MORE* important to you over time? (CIRCLE ALL THAT APPLY)

Yes No

- Private bedroom 01 02
- Private bathroom 01 02
- Ability to bring his/her own furniture to the facility 01 02
- Having access to a place to store and cook food 01 02
- The attractiveness and amenities of the outdoor areas 01 02
- The attractiveness and amenities of the indoor public spaces 01 02
- The availability of monitoring, for example if your relative fell or needed help with medications 01 01
- The quality of the direct care staff (knowledge, training, attitudes, staffing level) 01 02
- Whether the facility had a Registered Nurse on staff 01 02
- The ability of the facility to provide more or different services if your relative's needs changed 01 02
- The availability of a nursing home on the same campus 01 02
- The activities that were available 01 02
- Location 01 02
- Total cost (Price plus any extra charges) 01 02
- NONE OF THE ABOVE, All were equally important 77

18. In the two months before your relative left the facility/dies, how often were you able to go to ____ [FACILITY] and visit?

- Daily 01
- Several times a week (3 or more times) but not daily 02
- 1-2 times a week 03
- 2-3 times a month 04
- Once a month or less 05

19. Did you have any knowledge about the charges at ____ [FACILITY]?

- YES 01
- NO 02 (SKIP TO Q. 22)

20. Did you find that charges at ____ [FACILITY] increased at a faster rate than you expected or that there were additional, unexpected charges, over and above the monthly rate?
- YES 01
- NO 02
21. Use any number on a scale from 0 to 10, with 0 being the worst and 10 being the best. How would you rate the facility's performance in terms of meeting your expectations about how much it would cost on a monthly basis?
- _____ Score
- DK -4
22. Which of the following were better than you expected at _____ [FACILITY]? (CIRCLE ALL THAT APPLY)
- The accommodations 01
- The price 02
- The activities 03
- The transportation that was offered 04
- The staff (quality and number) 05
- The availability of services or assistance you needed 06
- None of the above 07
23. Which of the following were worse than you expected at _____ [FACILITY]? (CIRCLE ALL THAT APPLY)
- The accommodations 01
- The price 02
- The activities 03
- The transportation that was offered 04
- The staff (quality and number) 05
- The availability of services or assistance you needed 06
- None of the above 07
24. Overall, which of the following statements best describes your feelings about your relative's experience at _____ [FACILITY]? Would you say it was
- Better than you expected 01
- Worse than you expected 02
- About the same as you expected 03

25. Would you recommend this facility to a friend who had the same type of needs and interests that your relative had?

YES 01

NO 02

END

Thank you for your assistance in helping us understand the role of assisted living and other residential care settings in providing care to older persons.

PROBLEM SHEET

Item	Comments

APPENDIX C: DISCHARGED RESIDENTS SURVEY EDIT SPECIFICATIONS AND DISCHARGED RESIDENTS SURVEY RESIDENT AND PROXY QUESTIONNAIRE CODES

Discharged Residents Survey (RTI Project 7410) Edit Specifications

1. Assisted Living Discharged Resident Proxy Respondent Telephone Interview

Editing

- Check that all documents have an 8-digit ID number on the front cover.
- Check all instruments for legibility and illegal multiple responses only. Multiple responses are allowed for the following questions:
 - Q.2d
 - Q.6
 - Q.8
 - Q.15
 - Q.17
 - Q.22
 - Q.23
- Verify that the answers to the following questions are single, whole numbers between 0 and 10. Round fractions if necessary.
 - Q.13
 - Q.21
- Make corrections in red ink. Record editor's initials in the upper left hand corner of the first page.

Coding

Develop supplemental codebook for the following questions:

Q.1
Q.2
Q.2d
Q.4
Q.6
Q.8

Event Keying & Batching

Batch in groups of 20 with a sequential batch number assigned to each batch.

Routing to Data Entry

Route edited, coded and batched questionnaires to Data Entry.

2. Assisted Living Discharged Resident Telephone Interview

Editing

- Check that all documents have an 8-digit ID number on the front cover.
- Check all instruments for legibility and illegal multiple responses only. Multiple responses are allowed for the following questions:
 - Q.4
 - Q.7
 - Q.14
 - Q.16
 - Q.18
 - Q.19
- Verify that the answers to the following questions are single, whole numbers between 0 and 10. Round fractions if necessary.
 - Q.12
 - Q.13
- Make corrections in red ink. Record editor's initials in the upper left hand corner of the first page.

Coding

Develop supplemental codebook for the following questions:

- Q.2
- Q.4
- Q.7

Event Keying & Batching

Batch in groups of 20 with a sequential batch number assigned to each batch.

Routing to Data Entry

Route edited, coded and batched questionnaires to Data Entry.

Discharged Residents Survey Resident and Proxy Questionnaire Codes

PROXY QUESTIONNAIRE CODES

Question # 1

- 08 Friend
- 09 In - laws (Mother and Father)
- 10 Cousin
- 11 Step - Father
- 12 Client/Administrator
- 13 Brother - in - law
- 14 Sister - in- law
- 15 Guardian
- 16 Pastor/Power of attorney
- 17 Aunt's Husband
- 18 Foster Son
- 19 Conservator

Question # 2

- 07 Wants another family member to respond on their behalf

Question # 4

- 08 Group Home
- 09 Personal Residence for Seniors

DISCHARGED RESIDENTS TELEPHONE INTERVIEW CODES

Question # 11

- 11 The desire to live on his/her own

CONSISTENCY CODES

- NA = - 3
- DK = - 4
- Refused = - 7
- Blank = - 8

NOTE:

- 4 was used if 00 was entered for the days in any of the dates..
- 8 was used if the day was missing in any dates.

To obtain a printed copy of this report, send the full report title and your mailing information to:

U.S. Department of Health and Human Services
Office of Disability, Aging and Long-Term Care Policy
Room 424E, H.H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C. 20201
FAX: 202-401-7733
Email: webmaster.DALTCP@hhs.gov

RETURN TO:

Office of Disability, Aging and Long-Term Care Policy (DALTCP) Home
[\[http://aspe.hhs.gov/office_specific/daltcp.cfm\]](http://aspe.hhs.gov/office_specific/daltcp.cfm)

Assistant Secretary for Planning and Evaluation (ASPE) Home
[\[http://aspe.hhs.gov\]](http://aspe.hhs.gov)

U.S. Department of Health and Human Services Home
[\[http://www.hhs.gov\]](http://www.hhs.gov)

NATIONAL STUDY OF ASSISTED LIVING FOR THE FRAIL ELDERLY

Reports Available

A National Study of Assisted Living for the Frail Elderly: Discharged Residents Telephone Survey Data Collection and Sampling Report

HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/drtelesy.htm>
<http://aspe.hhs.gov/daltcp/reports/drtelesy.pdf>

A National Study of Assisted Living for the Frail Elderly: Final Sampling and Weighting Report

HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/sampweig.htm>
<http://aspe.hhs.gov/daltcp/reports/sampweig.pdf>

A National Study of Assisted Living for the Frail Elderly: Final Summary Report

HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/finales.htm>
<http://aspe.hhs.gov/daltcp/reports/finales.pdf>

A National Study of Assisted Living for the Frail Elderly: Report on In-Depth Interviews with Developers

Executive Summary
HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/indpthes.htm>
<http://aspe.hhs.gov/daltcp/reports/indepth.htm>
<http://aspe.hhs.gov/daltcp/reports/indepth.pdf>

A National Study of Assisted Living for the Frail Elderly: Results of a National Study of Facilities

Executive Summary
HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/facreses.htm>
<http://aspe.hhs.gov/daltcp/reports/facres.htm>
<http://aspe.hhs.gov/daltcp/reports/facres.pdf>

Assisted Living Policy and Regulation: State Survey

HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/stasvyes.htm>
<http://aspe.hhs.gov/daltcp/reports/stasvyes.pdf>

Differences Among Services and Policies in High Privacy or High Service Assisted Living Facilities

HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/alfdiff.htm>
<http://aspe.hhs.gov/daltcp/reports/alfdiff.pdf>

Family Members' Views: What is Quality in Assisted Living Facilities Providing Care to People with Dementia?

HTML
PDF

<http://aspe.hhs.gov/daltcp/reports/fmviews.htm>
<http://aspe.hhs.gov/daltcp/reports/fmviews.pdf>

Guide to Assisted Living and State Policy

HTML <http://aspe.hhs.gov/daltcp/reports/alspguide.htm>
PDF <http://aspe.hhs.gov/daltcp/reports/alspguide.pdf>

High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey

Executive Summary <http://aspe.hhs.gov/daltcp/reports/hshpes.htm>
HTML <http://aspe.hhs.gov/daltcp/reports/hshp.htm>
PDF <http://aspe.hhs.gov/daltcp/reports/hshp.pdf>

National Study of Assisted Living for the Frail Elderly: Literature Review Update

Abstract HTML <http://aspe.hhs.gov/daltcp/reports/ablitrev.htm>
Abstract PDF <http://aspe.hhs.gov/daltcp/reports/ablitrev.pdf>
HTML <http://aspe.hhs.gov/daltcp/reports/litrev.htm>
PDF <http://aspe.hhs.gov/daltcp/reports/litrev.pdf>

Residents Leaving Assisted Living: Descriptive and Analytic Results from a National Survey

Executive Summary <http://aspe.hhs.gov/daltcp/reports/alresdes.htm>
HTML <http://aspe.hhs.gov/daltcp/reports/alresid.htm>
PDF <http://aspe.hhs.gov/daltcp/reports/alresid.pdf>

State Assisted Living Policy: 1996

Executive Summary <http://aspe.hhs.gov/daltcp/reports/96states.htm>
HTML <http://aspe.hhs.gov/daltcp/reports/96state.htm>
PDF <http://aspe.hhs.gov/daltcp/reports/96state.pdf>

State Assisted Living Policy: 1998

Executive Summary <http://aspe.hhs.gov/daltcp/reports/98states.htm>
HTML <http://aspe.hhs.gov/daltcp/reports/98state.htm>
PDF <http://aspe.hhs.gov/daltcp/reports/98state.pdf>

Instruments Available

Facility Screening Questionnaire

PDF <http://aspe.hhs.gov/daltcp/instruments/FacScQ.pdf>