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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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. 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.
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:
where $RESWT_{cijkm}$ 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:

\[
ADJK_c = \sum_{ijkm \in c} RESWT_{cijkm} / \sum_{ijkm \in c} RESWT_{cijkm} \cdot RF_{cijkm}
\]

\[
ADJD_c = \sum_{ijkm \in c} RESWT_{cijkm} \cdot RE_{cijkm} / \sum_{ijkm \in c} RESWT_{cijkm} \cdot RD_{cijkm}
\]

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>
<thead>
<tr>
<th>Weighting Class</th>
<th>Total Residents</th>
<th>Estimated Discharge Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>High High Medium</td>
<td>221</td>
<td>23.0 +/- 6.9</td>
</tr>
<tr>
<td>High High Large</td>
<td>263</td>
<td>15.8 +/- 3.9</td>
</tr>
<tr>
<td>High Low Medium</td>
<td>392</td>
<td>22.6 +/- 6.9</td>
</tr>
<tr>
<td>High Low Large</td>
<td>242</td>
<td>19.1 +/- 5.5</td>
</tr>
<tr>
<td>Low High Medium</td>
<td>163</td>
<td>20.3 +/- 6.3</td>
</tr>
<tr>
<td>Low High Large</td>
<td>202</td>
<td>16.3 +/- 6.9</td>
</tr>
<tr>
<td>Total</td>
<td>1,483</td>
<td>19.0 +/- 2.5</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Weighting Classes</th>
<th>Tier #3 Facilities</th>
<th>Discharged Residents</th>
<th>Response Rates(^2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level of Privacy</td>
<td>Level of Service</td>
<td>Size(^1)</td>
<td>Eligible</td>
</tr>
<tr>
<td>High</td>
<td>High</td>
<td>Medium</td>
<td>51</td>
</tr>
<tr>
<td>High</td>
<td>High</td>
<td>Large</td>
<td>42</td>
</tr>
<tr>
<td>High</td>
<td>Low</td>
<td>Medium</td>
<td>76</td>
</tr>
<tr>
<td>High</td>
<td>Low</td>
<td>Large</td>
<td>50</td>
</tr>
<tr>
<td>Low</td>
<td>High</td>
<td>Medium</td>
<td>31</td>
</tr>
<tr>
<td>Low</td>
<td>High</td>
<td>Large</td>
<td>43</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td></td>
<td>293</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th></th>
<th>Design Effect</th>
<th>Effective Sample Size</th>
<th>Expected Detectable Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interactive Comparisons</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Privacy &amp; High Service vs. High Privacy &amp; Low Service</td>
<td>1.38</td>
<td>138</td>
<td>21.0%</td>
</tr>
<tr>
<td>High Privacy &amp; High Service vs. Low Privacy &amp; High Service</td>
<td>1.44</td>
<td>97</td>
<td>24.9%</td>
</tr>
<tr>
<td>High Privacy &amp; Low Service vs. Low Privacy &amp; High Service</td>
<td>1.40</td>
<td>119</td>
<td>23.6%</td>
</tr>
<tr>
<td>Main Effects Comparisons (Assuming no interactions)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High Privacy vs. Low Privacy</td>
<td>1.4</td>
<td>177</td>
<td>22.0%</td>
</tr>
<tr>
<td>High Service vs. Low Service</td>
<td>1.42</td>
<td>175</td>
<td>18.5%</td>
</tr>
</tbody>
</table>

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
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:

/RTI/
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
### DISCHARGED RESIDENTS

<table>
<thead>
<tr>
<th>Facility</th>
<th>Administrator/Director</th>
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</thead>
</table>

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.

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

| UPDATE | | | | | |
| UPDATE | | | | | |
| UPDATE | | | | | |
| UPDATE | | | | | |
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.

○ 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
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
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.

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.....]
### EXHIBIT 5. RESIDENT INFORMATION SHEET

<table>
<thead>
<tr>
<th>Resident Information Sheet</th>
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<tbody>
<tr>
<td>Resident (Resident ID #)</td>
<td></td>
</tr>
<tr>
<td>Name:</td>
<td></td>
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<td>Phone Number:</td>
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<td>Mailing Address:</td>
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<tr>
<td>Field Survey Final Status:</td>
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<td>Medicare Number:</td>
<td></td>
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<td>Date of Discharge:</td>
<td></td>
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<tr>
<td>Resident (Discharged):</td>
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<td>Resid. (Deceased):</td>
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<td>Best Person to Interview:</td>
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<td>Pending Status Code:</td>
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<td>Result of Call/Notes:</td>
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<tr>
<td>Record of Calls:</td>
<td></td>
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<tr>
<td>Person Contacted:</td>
<td></td>
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<td>Date/Time:</td>
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</tbody>
</table>
APPENDIX A: ASSISTED LIVING DISCHARGED RESIDENT TELEPHONE INTERVIEW

ASSISTED LIVING DISCHARGED RESIDENT TELEPHONE INTERVIEW

Respondent ID Label

Facility Name: 

Interviewer Name: 

Interviewer ID #: 

Date of Interview: ____/____/____ Start Time: _____:_____ am/pm

Month Day Year

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 anywhere 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.
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<tr>
<th>Item</th>
<th>Comments</th>
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APPENDIX B: ASSISTED LIVING DISCHARGED RESIDENT PROXY RESPONDENT TELEPHONE INTERVIEW

ASSISTED LIVING DISCHARGED RESIDENT PROXY RESPONDENT TELEPHONE INTERVIEW

Respondent ID Label

Facility Name:

Name of Discharged Resident:

Interviewer Name: 

Date of Interview: __/__/____

Month Day Year

Interviewer ID #: 

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 HHHH 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. 2c)
   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 anywhere 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.)

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

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

YES | .01 |

NO | .02 (SKIP TO Q. 18)
17. Which of the following became MORE important to you over time? (CIRCLE ALL THAT APPLY)

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private bedroom</td>
<td>01</td>
</tr>
<tr>
<td>Private bathroom</td>
<td>01</td>
</tr>
<tr>
<td>Ability to bring his/her own furniture to the facility</td>
<td>01</td>
</tr>
<tr>
<td>Having access to a place to store and cook food</td>
<td>01</td>
</tr>
<tr>
<td>The attractiveness and amenities of the outdoor areas</td>
<td>01</td>
</tr>
<tr>
<td>The attractiveness and amenities of the indoor public spaces</td>
<td>01</td>
</tr>
<tr>
<td>The availability of monitoring, for example if your relative fell or needed help with medications</td>
<td>01</td>
</tr>
<tr>
<td>The quality of the direct care staff (knowledge, training, attitudes, staffing level)</td>
<td>01</td>
</tr>
<tr>
<td>Whether the facility had a Registered Nurse on staff</td>
<td>01</td>
</tr>
<tr>
<td>The ability of the facility to provide more or different services if your relative’s needs changed</td>
<td>01</td>
</tr>
<tr>
<td>The availability of a nursing home on the same campus</td>
<td>01</td>
</tr>
<tr>
<td>The activities that were available</td>
<td>01</td>
</tr>
<tr>
<td>Location</td>
<td>01</td>
</tr>
<tr>
<td>Total cost (Price plus any extra charges)</td>
<td>01</td>
</tr>
<tr>
<td>NONE OF THE ABOVE, All were equally important</td>
<td>77</td>
</tr>
</tbody>
</table>

18. In the two months before your relative left the facility/died, 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.
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

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]

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

U.S. Department of Health and Human Services Home  
[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 http://aspe.hhs.gov/daltcp/reports/drtelesy.htm
PDF http://aspe.hhs.gov/daltcp/reports/drtelesy.pdf

A National Study of Assisted Living for the Frail Elderly: Final Sampling and Weighting Report
HTML http://aspe.hhs.gov/daltcp/reports/sampweig.htm
PDF http://aspe.hhs.gov/daltcp/reports/sampweig.pdf

A National Study of Assisted Living for the Frail Elderly: Final Summary Report
HTML http://aspe.hhs.gov/daltcp/reports/finales.htm
PDF 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 http://aspe.hhs.gov/daltcp/reports/indpthes.htm
HTML http://aspe.hhs.gov/daltcp/reports/indepth.htm
PDF 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 http://aspe.hhs.gov/daltcp/reports/facreses.htm
HTML http://aspe.hhs.gov/daltcp/reports/facres.htm
PDF http://aspe.hhs.gov/daltcp/reports/facres.pdf

Assisted Living Policy and Regulation: State Survey
HTML http://aspe.hhs.gov/daltcp/reports/stasvyes.htm
PDF http://aspe.hhs.gov/daltcp/reports/stasvyes.pdf

Differences Among Services and Policies in High Privacy or High Service Assisted Living Facilities
HTML http://aspe.hhs.gov/daltcp/reports/alfdiff.htm
PDF 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 http://aspe.hhs.gov/daltcp/reports/fmviews.htm
PDF http://aspe.hhs.gov/daltcp/reports/fmviews.pdf
Guide to Assisted Living and State Policy
- HTML: http://aspe.hhs.gov/daltcp/reports/alspguide.htm

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

National Study of Assisted Living for the Frail Elderly: Literature Review Update
- Abstract HTML: http://aspe.hhs.gov/daltcp/reports/ablitrev.htm
- HTML: http://aspe.hhs.gov/daltcp/reports/litrev.htm

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