

**SUPPORTING STATEMENT**

**Part A**

Pre-test of an Assisted Living Consensus Instrument

**Version: November 10, 2011**

Agency for Healthcare Research and Quality (AHRQ)

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## **A. Justification**

### ***1. Circumstances that make the collection of information necessary***

The mission of the U.S. Agency for Healthcare Research and Quality (AHRQ) set out in its authorizing legislation, The Healthcare Research and Quality Act of 1999 (see Attachment A), is to enhance the quality, appropriateness, and effectiveness of health services, and access to such services, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health systems practices, including the prevention of diseases and other health conditions. AHRQ shall promote health care quality improvement by conducting and supporting:

1. research that develops and presents scientific evidence regarding all aspects of health care; and
2. the synthesis and dissemination of available scientific evidence for use by patients, consumers, practitioners, providers, purchasers, policy makers, and educators; and
3. initiatives to advance private and public efforts to improve health care quality.

Also, AHRQ shall conduct and support research and evaluations, and support demonstration projects, with respect to (A) the delivery of health care in inner-city areas, and in rural areas (including frontier areas); and (B) health care for priority populations, which shall include (1) low-income groups, (2) minority groups, (3) women, (4) children, (5) the elderly, and (6) individuals with special health care needs, including individuals with disabilities and individuals who need chronic care or end-of-life health care.

Using a consensus-based process and in partnership with the Center for Excellence in Assisted Living (CEAL), AHRQ has developed a data collection tool that will collect uniform information about individual assisted living facilities (ALFs) in the United States to increase the value of healthcare for consumers by helping them make informed choices when selecting an ALF. Included in the development process was a voluntary committee of national representatives of Assisted Living (AL) consumers and researchers (Attachment B).

AL is a relatively new long-term care option that currently serves approximately one million older and dependent Americans. Unlike skilled nursing facilities which are federally regulated and relatively uniform from state to state, ALFs vary from state to state, as well as within each state, reflecting various core values that embrace consumer choice and provider diversity.

Most states mandate a set of basic services that an ALF must offer, such as meals and housekeeping. The upper limits of allowable services are also often proscribed. However, within the range of services required and allowed, ALFs in most states are given some

latitude as to who they choose to serve and what services they choose to provide. Further, the choice of services is not always confined by geography; that is, given the widespread dispersion of families, potential AL residents may be looking to choose among assisted living properties in different states, thereby widening the choices available.

While some ALFs are equipped to serve a wide range of resident needs, it is more common that an ALF will address a particular “market niche.” There are many ways in which ALFs offer diversity – in the religious or cultural affiliations of their target market; in the house rules that influence expectations about dress and behavior in the dining room; in the admission and discharge criteria in place; as well as in the range of services provided. Major variation is found in the extent to which a particular ALF is able and willing to serve those with dementia. While most ALFs admit and retain residents with mild cognitive impairment, those without a specialized dementia program may have difficulty serving residents with common symptoms such as a lack of safety awareness, wandering, sleep disturbances and agitation. To some extent, admission and discharge criteria are dictated by the laws and regulations of the state in which a particular ALF operates. Beyond this, ALFs have considerable latitude (even considering the requirements of the Fair Housing and Americans with Disabilities Acts) in assessing individuals whom they will admit and retain in their facilities.

In addition to the assessment of needed services in relation to the services that are available, the ability to pay for services is a critical factor for both the consumer and ALF decision-making about whether and when an individual moves into and out of a particular ALF. Approximately ten percent of AL residents receive subsidies through State Medicaid Waiver or State Plan programs, and fewer than three percent are covered by long-term care insurance. Thus, a substantial percentage of AL consumers use savings and other assets, including proceeds from the sale of their homes, to pay for their stay in an ALF. In choosing an ALF, consumers need to consider whether a particular facility is able to accept Medicaid or other third party payments, both now and in the future, should their assets become depleted.

This research has the following goals:

- 1) Refine the data collection tool, known as *The Assisted Living Provider Information Tool for Consumer Education*, through pre-testing with a sample of ALFs; and
- 2) Make the data collection tool publically available through the AHRQ website so that consumer intermediaries (e.g., state regulators, aging agencies, provider trade groups, etc.) can use the tested tool to obtain (and ultimately make available) standardized information on all ALFs in an area – thus enabling consumers to better chose an ALF that meets their needs.

To achieve the goals of this project the following data collection will be undertaken:

- 1) Telephone verification (Attachment C). The purpose of the telephone verification is to ensure that the most current mailing address of each ALF is utilized for the survey pre-test, and to obtain the name of the current Administrator or Executive Director of the ALF so the mailed pre-test survey can be addressed directly to that person; and
- 2) Pre-test of the *Assisted Living Provider Information Tool for Consumer Education* (Attachment D). The data collection will include information on several topics of interest to consumers including services available in ALFs and costs of those services, criteria for moving into and out of an ALF, resident's rights, house rules, life safety features, staffing within the ALF, and the availability of dementia care services within the ALF. The purpose of the pre-test is to assess the utility of the data collection tool as well as the feasibility for its implementation.

This study is being conducted by AHRQ through its contractor, Abt Associates Inc., pursuant to AHRQ's statutory authority to conduct and support research on healthcare and on systems for the delivery of such care, including activities with respect to the quality, effectiveness, efficiency, appropriateness and value of healthcare services and with respect to quality measurement and improvement. 42 U.S.C. 299a(a)(1) and (2).

## **2. Purpose and Use of Information**

This is a one-time data collection. The data that will be collected through this effort will be used to make final refinements to the *Assisted Living Provider Information Tool for Consumer Education* and to make adjustments to the recommended processes for implementing a similar data collection effort on a broader basis.

## **3. Use of Improved Information Technology**

When this data collection is implemented nationally through State agencies or other AL entities, it is likely that data collection will be conducted via a mailed paper survey. Therefore, our data collection effort centers on the process of a mail survey and does not involve the use of electronic data collection methods.

## **4. Efforts to Identify Duplication**

A thorough review of the existing literature did not reveal any similar efforts. While there is some existing literature that describes ALFs, that literature does not address the goals of this data collection effort (i.e., to develop, via consensus, a tested instrument that can be used by consumer intermediaries to obtain/make available standardized information on a census of ALFs).

There are some similarities between this pre-test and the recent National Survey of Residential Care Facilities (NSRCF) conducted by the National Center for Health Statistics. Both efforts use the same conceptual definition of a residential care facility (referred to as "assisted living" here)(with the minor exception that the NSRCF's

includes facilities with 4 or 5 beds, and these are excluded from this pre-test). Both use similar methods to construct the sampling frame (see “National Survey of Residential Care Facilities: Sample Frame Construction and Benchmarking Report, 2010”). The major difference between the two is that the NSRCFs is a multi-purpose research survey, while this effort is a large scale test of an AL provider tool designed to (ultimately) collect information for an area’s census of ALFs.

### **5. Involvement of Small Entities**

Some of the ALFs involved in this research may be considered to be small businesses. The data collection tools have therefore been designed to minimize the burden to all participating ALFs.

### **6. Consequences if Information Collected Less Frequently**

This is a one-time data collection.

### **7. Special Circumstances**

This request is consistent with the general information collection guidelines of 5 CFR 1320.5(d)(2). No special circumstances apply.

### **8. Federal Register Notice and Outside Consultations**

#### **8.a. Federal Register Notice**

As required by 5 CFR 1320.8(d), notice was published in the Federal Register on May 11<sup>th</sup>, 2011 for 60 days and again for 30 days on July 27<sup>th</sup>, 2011 (see Attachment E). No comments were received.

#### **8.b. Outside Consultations**

1. The *Assisted Living Provider Information Tool for Consumer Education* (the pre-test instrument) was developed by AHRQ through a voluntary consensus process with the Center for Excellence in Assisted Living and representatives of national organizations that represent AL providers, consumers and researchers (collectively called the AL Disclosure Collaborative). The following organizations were voting members of the AL Disclosure Collaborative:

- AARP
- Agency for Healthcare Research and Quality
- Alzheimer's Association
- American Association of Homes and Services for the Aging
- American College of Health Care Administrators
- American Seniors Housing Association
- Assisted Living Federation of America
- Commission on Accreditation of Rehabilitation Facilities-Continuing Care Accreditation Commission

- Consumer Consortium on Assisted Living
- Gerontological Society of America Assisted Living-Special Interest Group
- National Association of State Ombudsman Programs
- National Association of State Units on Aging
- National Association of Social Workers
- National Association of Professional Geriatric Managers
- National Center for Assisted Living
- NCB Capital Impact
- Pioneer Network

2. The AL Disclosure Collaborative also consisted of representatives from three operative divisions of the US Department of Health and Human Services:

- National Center for Health Statistics, Centers for Disease Control
- Office of the Assistant Secretary for Planning and Evaluation, Office of the HHS Secretary
- Administration on Aging

These representatives reviewed the instrument during the development process.

3. The AL Disclosure Collaborative was composed of 96 individuals who served as expert consultants (Attachment F). All of these persons contributed to the development of the *Assisted Living Provider Information Tool for Consumer Education*.

4. An informal dialogue (focus group) was held with nine ALF Administrators (the target respondents for the instrument).

5. Two rounds of cognitive interviewing were also conducted with nine additional ALF providers.

6. The following AHRQ contractor staff also contributed to this project:

- Sheryl Zimmerman, Ph.D.  
Cecil G. Sheps Center for Health Services Research  
University of North Carolina, Chapel Hill
- Philip D. Sloane, MD, MPH  
UNC School of Medicine  
University of North Carolina, Chapel Hill
- Joan Hyde, PhD  
Ivy Hall Senior Living and  
Gerontology Institute, Wheatley Hall  
University of Massachusetts
- Allison Muma, MHA  
Abt Associates

Durham, NC

### **9. Payments/Gifts to Respondents**

No incentives or gifts will be offered to survey respondents.

### **10. Assurance of Confidentiality**

Individuals and organizations will be assured of the confidentiality of their replies under Section 934(c) of the Public Health Service Act, 42 USC 299c-3(c). They will be told the purposes for which the information is being collected and that, in accordance with this statute, any identifiable information about them will not be used or disclosed for any other purpose. In instances where respondent identity is needed, the information collection will fully comply with all respects of the Privacy Act.

Respondents will be informed in the introduction of the mailed paper survey that their answers will be kept confidential to the extent permitted by law. Participation will be entirely voluntary, and the study will conform to the requirements of the Privacy Act by omitting individuals' names, addresses, telephone numbers and other personal identifiers in the final data file.

The firm that will conduct the data collection -- Abt Associates Inc. -- has conducted numerous projects and surveys involving both sensitive and non-sensitive information; consequently, processes and procedures have been developed to maintain respondent confidentiality. All Abt Associates project staff will sign confidentiality agreements (Attachment G) specifying that no identification of respondents or their answers will be revealed to other persons who are not specifically involved with this project as an employee. All databases will be password protected, with only the data administrators having write authority over files. If electronic data transfer is necessary, the data will be transferred via diskette or CD-ROM to clients in an encrypted and password-protected format before shipping via a bonded courier.

Abt Associates emphasizes the importance of protecting the data while it is stored in their facilities. Abt Associates frequently maintains and manages large datasets, which frequently include highly sensitive information. In over a decade of conducting surveys on sensitive topics, Abt Associates has never suffered a breach of any respondent's privacy.

### **11. Questions of a Sensitive Nature**

The data collection tool does not contain any questions concerning sexual behavior and attitudes, religious beliefs, or other matters that are commonly considered private.

### **12. Estimates of Annualized Burden Hours and Costs**

Exhibit 1 shows the estimated annualized burden for the respondents' time to participate in this project. The telephone verification will be completed by 285 AL providers and will take approximately one minute to complete. The pre-test of the *Assisted Living*



*Provider Information Tool for Consumer Education* will be completed by 191 ALFs and will require approximately 25 minutes to complete. The total annual burden is estimated to be 85 hours.

Exhibit 2 shows the estimated annualized cost burden associated with the respondents' time to participate in this project. The total annualized cost burden is estimated to be \$3,576.

**Exhibit 1. Estimated annualized respondent burden hours**

Form Name	Number of respondents	Number of responses per respondent	Hours per response	Total burden hours
Telephone verification	285	1	1/60	5
Pre-test	191	1	25/60	80
<b>Total</b>	476	na	na	85

**Exhibit 2. Estimated annualized cost burden**

Form Name	Number of respondents	Total burden hours	Average hourly wage rate*	Total cost burden
Telephone verification	285	5	\$15.37	\$77
Pre-test	191	80	\$43.74	\$3,499
<b>Total</b>	476	85	na	\$3,576

\*Based upon the mean of the average wages reflected in the *National Compensation Survey (May 2009)* U.S. Department of Labor, Bureau of Labor Statistics. Wage categories used: phone verification - office and administrative support workers; pre-test - medical and health services managers in the United States.

**13. Estimates of Annualized Respondent Capital and Maintenance Costs**

There are no direct costs to respondents other than their time to participate in the study.

**14. Estimates of Annualized Cost to the Government**

The total cost of this contract to the government is \$439,552. The project extends over four years, but this request is for a one year OMB clearance, which covers the data collection period. Exhibit 3 shows a breakdown of the total cost as well as the annualized cost.

### Exhibit 3. Total and annualized cost burden to the government

Cost Component	Total Cost	Annualized Cost
Project Development	\$125,000	\$31,250
Data Collection Activities	\$90,000	\$22,500
Data Processing and Analysis	\$30,000	\$7,500
Reporting of results	\$30,000	\$7,500
Project Management	\$ 164,552	\$ 41,138
TOTAL COSTS	\$ 439,552	\$ 109,888

#### 15. Changes in Hour Burden

This is a new collection of information.

#### 16. Time Schedule, Publication and Analysis Plans

##### Time Schedule:

Phase I of this project (not to be confused with the first phase of sampling described in Supporting Statement B) began in May 2008 and ended in April 2010. During Phase I, the *Assisted Living Provider Information Tool for Consumer Education* was developed through a national, voluntary consensus process involving approximately 12 voting member organizations and nearly 100 individual representatives from those organizations. Phase I of the project involved no data collection. Phase II of the project began in September 2009 and will run through approximately Spring 2012. Phase II includes small scale testing via cognitive interviewing with nine AL providers, and large scale pre-testing via a mail survey with a target of 191 completed responses from ALFs, as described in this Supporting Statement. We anticipate beginning large scale pre-testing in Winter 2012 and completing data collection within three months, with analysis and reporting beginning directly thereafter. Phase III of the project involves the dissemination of the finalized provider tool to consumer intermediaries by the AL Disclosure Collaborative. AHRQ, as a member of the AL Disclosure Collaborative, will participate in Phase III planning (in the initial stages now) and tool dissemination (commencing during the Summer of 2012). Phase III efforts will not involve any Federal Government data collection activities.

##### Publication Plan:

Results of the small and large scale testing will be provided to AHRQ by Abt; AHRQ will then make the final *Assisted Living Provider Information Tool for Consumer Education* available to the public via the AHRQ website.

**Analysis Plans:**

The data analysis is intended to assess the completeness of questionnaire responses from a pre-test of the *Assisted Living Provider Information Tool for Consumer Education*, and to identify questions or areas in which the target audience may have difficulty responding. It is not intended to collect nationally representative data for analysis or research. As such, our analysis plans center on descriptive statistics for the survey items. Specifically, we will examine the following:

1. disposition of the surveys with respect to the number of completed surveys, partial surveys, and non-responses;
2. distributions, including missing data, by survey item;
3. disposition of surveys and distribution of responses by characteristics of the sample, including ALF location, size, profit status, affiliation with another level of care, and presence of a dementia care neighborhood;
4. instances of when the survey items were completed incorrectly (e.g., more than one answer/item, incorrect skip); and
5. logic checks.

In addition to the item specific analysis, analytic plans include the modeling of unit non-response. Depending upon the results of the pre-test item response modeling may be undertaken to access item-specific response.

Attachment H contains all of the materials survey participants will receive as part of the pre-test process, including a recruitment/reminder letter to sampled ALFs, the ALC brochure, and reminder post cards.

**17. Exemption for Display of Expiration Date**

AHRQ does not seek this exemption.

**List of Attachments:**

Attachment A: Healthcare Research and Quality Act of 1999

Attachment B: Organizational Participants of the AL Disclosure Collaborative (ALDC)

Attachment C: Telephone Verification Script

Attachment D: Assisted Living Provider Information Tool for Consumer Education

Attachment E: Federal Register Notice

Attachment F: Individual Participants of the AL Disclosure Collaborative (ALDC)

Attachment G: Confidentiality Agreement for Contractor Staff

Attachment H: Recruitment Letter, Brochure & Followup Postcards

