

# Understanding How Families Access and Use Long-Term Care Services

ASPE Generic Information Collection Request  
OMB No. 0990-0421

## Supporting Statement – Section A

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### **Program Official/Project Officer**

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## Section A – Justification

### 1. Circumstances Making the Collection of Information Necessary

#### Background

Long-term care is assistance with daily activities provided to people with functional limitations because of physical, cognitive, or mental disability. These services include health and social services that may be provided in a number of settings including at-home, in adult day care centers, residential care settings, and nursing homes. Although the majority of long-term care is provided informally by family members and friends, this project will focus on paid supports. Most paid long-term care is financed by Medicaid, which provides coverage for people who have limited financial resources and have a significant level of disability. However, almost one-quarter of long-term care for older adults is paid out-of-pocket.

Individuals and their families may turn to many places for information, including friends, geriatric case managers, hospital discharge planners, or providers. Long-term care decisions are complex and multi-layered (Maloney & Finn, et al, 1996), involve numerous cost and quality assessments (Castle, 2003) and are often made at a time of crisis with little advance thought to preferences (Kane & Kane, 2001). Consequently some researchers have concluded that consumers are decidedly at a disadvantage when it comes to choosing a long-term care setting that best meets their needs (Lubalin and Harris-Kojetin, 1999, Hibbard and Peters, 2003).

The federal government provides some information and resources on long-term care. The Administration on Aging (AOA) within the Administration for Community Living (ACL) supports a national network of area agencies on aging (AAAs) that are designed to provide information on services and supports available in each community and assist in decision making. The [Eldercare Locator](#) can help families find the nearest AAA. Information on nursing facilities or home healthcare agencies, including information on the quality of services, is available from Center for Medicare and Medicaid Services' [Nursing Home Compare](#) or [Home Health Compare](#) websites.

In 2005, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) undertook a study to understand how families choose a nursing home. The resulting study (available at: <http://aspe.hhs.gov/daltcp/reports/2006/choose1.htm>) found that location is the most important factor families consider when searching for a nursing home for a loved one. Additional important factors include experiences of family and friends, cost, and appearance of the facility.

Little is known, however, about the processes that families and older adults go through to gather information, make decisions, and access long-term care generally when a loved one needs assistance. The purpose of this study is to examine where families gather information, how they make decisions, and how well these arrangements work. Findings from the proposed data collection described in this Generic Information Collection package will address four main research questions, listed below:

1. How do people find information on long-term care?
2. What is the process that families go through to gather information and make decisions about long-term care?
3. What public and private sources of information on long-term care do people use?
4. How useful are federal resources and how can they be improved to better understand the needs of older adults and their families?

This data collection is being conducted using the Generic Information Collection mechanism in the Office of the Assistant Secretary for Planning and Evaluation (ASPE) – OMB No. 0990-0421. The data will be collected through electronic focus groups. Participants will include members of the KnowledgePanel®, a sample of people maintained by GfK, who have indicated that they have a family member who has used long-term care.

This data collection is authorized by Section 301 of the Public Health Service Act (42 U.S.C. 241).

### **Privacy Impact Assessment**

Overview of the Data Collection System – The data collection will be conducted through four moderated online focus groups. The online focus groups will be structured with a session moderator posing open-ended questions to the participants, and participants will be invited to respond. Participants will also be asked to participate in instant polls that are relevant to the discussion. Participation in the focus groups (and subsequent information provided by participants) will be completely voluntary. No personal identifying information will be collected. The questions to be posed by the moderator have been developed and revised prior to the session (see Attachment A) by ASPE staff. The ASPE federal project officer is a subject matter expert and will serve as the moderator. Other ASPE staff will assist her by providing additional probing questions or asking for details on the information provided by the participants as needed. The data will be collected qualitatively from the transcript of the online focus groups. After the focus groups, ASPE staff will analyze the data qualitatively by reviewing the transcript and any notes, and identifying the main themes from the discussion. ASPE staff will note if particular issues (for example, challenges in finding information on home health aides) seemed to be raised more often, or of greater importance, to the focus group participants.

The findings from the focus groups will not be generalizable. The method of data collection was chosen due to the exploratory nature of this inquiry. Through the focus groups, the ASPE staff will be able to collect nuanced and detailed information about the on-the-ground experiences and challenges to accessing long-term care.

### Items of Information to be Collected –

- No personally identifiable information will be collected.
- What is impetus for families beginning to look for services and supports for their loved one?

- Where/from whom do families first seek information on these services?
- What is the process that families go through in determining what services to use? Who is involved or assisted in the decision making?
- What are the key pieces of information that consumers use when making decisions about services and supports?
- How useful and relevant was the information available from government (i.e., federal, state, and local sources) and non-government organizations when making decisions?
- What additional information would be useful when families are evaluating long-term care options?
- How could the process of looking for long-term care be improved?

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

There are currently no federal efforts underway that focus on understanding how families gather information, make decision, and access long-term care. The purpose of this project is to examine where families gather information, how they make decisions, and how well these arrangements work. Specifically, research questions for this current project include, but are not limited to:

1. How do people find information on long-term care?
2. What is the process that families go through to gather information and make decisions about long-term care?
3. What public and private sources of information on long-term care do people use?
4. How useful are federal resources and how can they be improved to better understand the needs of older adults and their families?

The current Generic Information Collection request will address the above questions. The data collection will be conducted through four moderated online focus groups. The online focus groups will be structured with a session moderator posing open-ended questions to the participants, and participants will be invited to respond. Participants will also be asked to participate in instant polls that are relevant to the discussion. Participation in the focus groups (and subsequent information provided by participants) will be completely voluntary. No personal identifying information will be collected. The questions to be posed by the moderator have been developed and revised prior to the session (see Attachment A) by ASPE staff. The ASPE federal project officer is a subject matter expert and will serve as the moderator. Other ASPE staff will assist her by providing additional probing questions or asking for details on the information provided by the participants as needed. The data will be collected qualitatively from the transcript of the online focus groups. After the focus groups, ASPE staff will analyze the data qualitatively by reviewing the transcript and any notes, and identifying the main themes from the discussion. ASPE staff will note if particular issues (for example, challenges in finding information on home health aides) seemed to be raised more often, or of greater importance, to the focus group participants.

The information will be used to inform future ASPE research projects. Longer term, the findings might impact how federal sources of information are publicized.

#### Privacy Impact Assessment

All information or data collected will be kept secure and will be used only to inform the overall findings of the project. No personally identifiable information will be collected.

### **3. Use of Improved Information Technology and Burden Reduction**

Data will be collected via online focus groups. Respondents are members of the KnowledgePanel® who have previously indicated that they have a family member who used long-term care and who consent to participate in one of these focus groups. Therefore, the sample for this data collection will be a sample of convenience. This method was chosen to reduce the overall burden on respondents and to gather as many perspectives as possible in the shortest amount of total time. The benefit of the online focus groups is that there is potential to have greater geographic representation than in-person focus groups. However, this is a convenience sample so there is no guarantee that there will be geographic diversity.

### **4. Efforts to Identify Duplication and Use of Similar Information**

Over the past year, ASPE staff has scanned the literature and met with experts in the field to understand what information is available on how families access long-term care. No other similar efforts were identified.

This data collection will build on information gathered in separate research efforts, but will not duplicate past work. In 2005, ASPE undertook a study to understand how families choose a nursing home. The resulting study (available at: <http://aspe.hhs.gov/daltcp/reports/2006/choose1.htm>) found that location is the most important factor families consider when searching for a nursing home for a loved one. Additional important factors include experiences of family and friends, cost, and appearance of the facility. This study will uniquely take a broader focus on all paid long-term care and will examine how families gather information, make decisions, and access long-term care.

### **5. Impact on Small Businesses or Other Small Entities**

No small businesses will be involved in this data collection.

### **6. Consequences of Collecting the Information Less Frequently**

This request is for a one time data collection. There are no legal obstacles to reduce the burden. Without this information, the Department of Health and Human Services would have very limited information about the processes that families go through, including the challenges they face, when looking for long-term care.

### **7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5**

There are no special circumstances with this information collection package. This request fully complies with the regulation 5 CFR 1320.5 and will be voluntary.

**8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency**

This data collection is being conducted using the Generic Information Collection mechanism through ASPE – OMB No. 0990-0421.

**9. Explanation of Any Payment or Gift to Respondents**

Focus Group participants will be offered a small noncash incentive by GfK to complete the focus group. GfK uses a “points”-based incentive system to thank panel members for completing surveys and focus groups of any length. For these focus groups, each panelist will be provided 50,000 points, the monetary equivalent of \$50. This honorarium is intended to recognize the time spent by participants in participating in this focus group, encourage their cooperation, and convey appreciation for contributing to this important study.

**10. Assurance of Confidentiality Provided to Respondents**

The Privacy Act does not apply to this data collection. Participants will not be asked about, nor will they provide, individually identifiable information.

This data collection is not research involving human subjects.

**11. Justification for Sensitive Questions**

No information will be collected that are of personal or sensitive nature.

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

The estimate for burden hours is based on a 60 minute focus group discussion with up to 10 participating individuals in each of the four focus groups.

Estimates for the median hourly wage for respondents are based on the Department of Labor (DOL) 2014 estimates for all occupations: [http://www.bls.gov/oes/current/oes\\_nat.htm#00-0000](http://www.bls.gov/oes/current/oes_nat.htm#00-0000). The average hourly wage rate in 2014 of \$22.71 was used as an hourly wage estimate for or all 40 respondents. Table A-12 shows estimated burden and cost information.

**Table A-12:** Estimated Annualized Burden Hours and Costs to Respondents

Type of Respondent	No. of Respondents	No. of Responses per Respondent	Average Burden per Response (in hours)	Total Burden Hours	Hourly Wage Rate	Total Respondent Costs
Focus Group Participants	40	1	1	40	22.71	\$908.40
<b>TOTALS</b>	40	40		40		<b>\$908.40</b>

**13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers**

There will be no direct costs to the respondents other than their time to participate in the data collection.

**14. Annualized Cost to the Government**

**Table A-14:** Estimated Annualized Cost to the Federal Government

Staff (FTE)	Average Hours per Collection	Average Hourly Rate	Average Cost
Social Science Analyst, GS 14	4	56.57	\$226.28
Social Science Analyst, GS 12	4	43.92	\$175.68
<b>Estimated Total Cost of Information Collection</b>			<b>\$401.96</b>

**15. Explanation for Program Changes or Adjustments**

This is a new data collection.

**16. Plans for Tabulation and Publication and Project Time Schedule**

The qualitative information gathered from the focus groups will be summarized by ASPE staff who will identify common themes, common processes, and unique situations. This information will also be shared with the contractor for a future ASPE project (expected to begin September 2015) that will examine the processes in four communities.

**17. Reason(s) Display of OMB Expiration Date is Inappropriate**

We are requesting no exemption.

**18. Exceptions to Certification for Paperwork Reduction Act Submissions**

There are no exceptions to the certification. These activities comply with the requirements in 5 CFR 1320.9.

**LIST OF ATTACHMENTS – Section A**

- A. Understanding How Families Access and Use Long-Term Care Services Discussion Guide (in a separate attachment as instructed)