DOCUMENTATION FOR THE GENERIC CLEARANCE
FOR THE COLLECTION OF QUALITATIVE RESEARCH & ASSESSMENT

TITLE OF INFORMATION COLLECTION: Understanding How Families Access and Use Long-Term Care Services

[ ] INTERVIEWS
[ ] SMALL DISCUSSION GROUPS
[X] FOCUS GROUPS
[ ] QUESTIONNAIRES
[ ] OTHER (EXPLAIN)

DESCRIPTION OF THIS SPECIFIC COLLECTION

1. Intended purpose

Little is known about how families and older adults gather information, make decisions, and access long term care when a loved one needs assistance. The purpose of this project is to gather qualitative information about how and where families gather information, how they make decisions about specific services and providers, how well these arrangements work, and how useful government resources are in these processes. This project also explores the community-specific dynamics regarding both the public and private sector resources that have an impact on families' experiences with identifying and meeting care needs.

2. Need for the collection

The federal government provides some information 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.

This data collection is needed for a few reasons. First, it will provide information that is not otherwise available on where families go for long term care information for all types of long term care, not just facility care (e.g., home health, caregiver supports, assisted living, etc.). This is important since the use of alternatives to facility care and to nursing home care in particular is growing rapidly. Second, it will help us understand how useful existing federal resources are and how they can be improved to better meet the needs of older adults and their families. By focusing in depth on adults carefully chosen based on key demographic and care need characteristics and within three very different communities, we will gain vital insights into environmental and demographic factors that influence the nature of the care-seeking experience.

3. **Planned use of the data**

   The focus group findings will be used to identify predominant themes with regard to factors that facilitate or impede the process of finding long term care for consumers, examining in particular community and demographic factors that play important roles in the process. The information will be used to inform future ASPE research projects.

4. **Date(s) and location(s)**

   Four in-person focus groups will be conducted in three communities within Pennsylvania: Pittsburgh, Philadelphia, and Scranton. Two groups will be conducted in the Greater Philadelphia area, and one each in Pittsburgh and Scranton. Participants will be recruited so that they represent a balance of geographic and demographic criteria within each of the three communities. The groups will be conducted by a trained moderator with extensive expertise in long term care as well as working with ASPE. The groups are anticipated to take place during the first two weeks in June 2016.

5. **Collection procedures**

   The data will be collected by digital video capture (for the first focus group), and by audio and written transcripts for all four of the groups. The Zacharias Group is a subcontractor to Truven and is responsible for all logistics around data capture. A copy of both the audio and written transcripts will be provided to ASPE.

   The focus groups will be informal, moderated discussions where participants will be offered the opportunity to respond to various topics in a group environment.

6. **Number of collections (e.g., focus groups, surveys, sessions)**

   There will be four focus groups with 10 participants each.

7. **Description of respondents/participants**

   ASPE will work with Truven Health and the Zacharias Group to identify participants between the ages of 40 and 70 who have previously indicated that they had an adult family member who used long term care. Participants will be screened so that only those who sought long term care in the past two years will be included. This will facilitate accurate and detailed recollection.

8. **Description of how results will be used**
   The information will be used to inform future ASPE research projects, and better understand how federal resources are being used.

9. **Description of how results will or will not be disseminated and why or why not**

   Findings will be shared with leadership in ASPE, ACL, and CMS. The focus group transcripts will not be made public.

AMOUNT OF ANY PROPOSED STIPEND OR INCENTIVE

Focus Group participants will not be offered any incentive payment for participation. We believe this will have a detrimental effect on participation.

BURDEN HOUR & COST COMPUTATION *(Number of responses (X) estimated response or participation time in minutes (/60) = annual burden hours):*

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	2	80	22.71	$1,816.80
TOTALS	40	40		80		**$1,816.80**

<u>OTHER SUPPORTING INFORMATION</u>

REQUESTED APPROVAL DATE: April 20, 2016

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DEPARTMENT/OFFICE/BUREAU: HHS /ASPE