
Supporting Statement A for Hospice Experience of Care Survey

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RAND Project Director/Principal Investigator
Karl Lorenz

RAND Co-Project Director/Co-Principal Investigator
Rebecca Anhang Price

RAND Corporation
1776 Main St.
P.O. Box 2138
Santa Monica, CA 90407-2138

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Lori Teichman/Debra Dean-Whittaker,
Project Officers



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SUPPORTING STATEMENT HOSPICE EXPERIENCE OF CARE SURVEY

Introduction

The Centers for Medicare & Medicaid Services (CMS) requests a one-year clearance from the Office of Management and Budget (OMB) under the Paperwork Reduction Act of 1995 to implement the Hospice Experience of Care Survey.

Under Contract Number HHSM-500-2012-00126G, the project team will develop, field test, and analyze a hospice experience of care survey for bereaved family members or close friends of patients who died while receiving hospice care. Specifically, the Centers for Medicare and Medicaid (CMS) will conduct a field test of a survey to collect data on experiences of hospice care. The survey will include bereaved family members or close friends of hospice patients who died while in hospice care at home, in nursing homes, or in inpatient settings, including acute care hospitals and freestanding hospice inpatient units. Field test findings will be used to refine survey content and implementation procedures in advance of CMS' planned national implementation of a hospice survey.

A. Justification

A1. Necessity of Information Collection

The Centers for Medicare & Medicaid Services (CMS) has already implemented patient experience surveys in a number of settings including Medicare, Medicare Advantage, and Part D Prescription Drug Plans, hospitals, and home health agencies. Other Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys exist for hemodialysis facilities, nursing homes, and physician practices. As the environment and patient population of hospice care are unique, existing patient experience instruments designed for other settings are only partially relevant for capturing hospice care experiences. The hospice survey differs from most other CMS patient experience surveys because its target population is bereaved family members or close friends of patients who died in hospice care. Family members and friends are the best source of information regarding the entire trajectory of hospice care. In addition, many hospice patients are very ill and unable to answer survey questions.

A rigorous, well-designed hospice survey will allow us to understand experiences of both hospice patients and their family members or friends, as reported by family members and friends. This information will ultimately be used to help improve the quality of care patients and their families and friends receive in hospice.

Hospice serves approximately 42 percent of dying patients in the United States (Analysis of Medicare claims data). To date, no single survey has been systematically administered by all hospices across the country to assess experiences of care with hospice. The proposed survey will enhance Medicare's capacity to evaluate hospice care and assess the value of hospice services to patients and their families. The field test for which this

Supporting Statement requests clearance is a required part of the process for certification of an experiences of care survey as a CAHPS survey, and ensures that items in the instrument perform well under real-world survey administration conditions and are appropriate for making objective comparisons between hospices across the U.S.

A2. Purpose and Use of Information

This survey supports the National Quality Strategy developed by the U.S. Department of Health and Human Services (HHS) that was called for under the Affordable Care Act to create national aims and priorities to guide local, state, and national efforts to improve the quality of health care. This strategy has established six priorities that support a three-part aim focusing on better care, better health, and lower costs through improvement. The six priorities include: making care safer by reducing harm caused by the delivery of care; ensuring that each person and family are engaged as partners in their care; promoting effective communication and coordination of care; promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease; working with communities to promote wide use of best practices to enable healthy living; and making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models. Because the hospice survey focuses on experiences of care, implementation of the survey supports the following national priorities for improving care: engaging patients and families in care and promoting effective communication and coordination. In addition, upon national implementation and public reporting of hospice survey results, the survey will provide data on experiences with hospice care that enable consumers to make meaningful comparisons between hospices across the nation.

A3. Technological Collection Techniques

The survey vendor will collect the data via a mixed mail/telephone data collection strategy for bereaved family members or close friends of patients who died while receiving hospice care (1) at home, (2) in a nursing home, and (3) an inpatient setting (i.e., freestanding inpatient unit or acute care hospital). Separate, but similar, versions of the survey will be administered for each of these three hospice care settings. The bereaved family member or close friend for each patient, identified as the patient's primary informal caregiver in hospice records, will receive one prenotification letter and one survey mailing, followed by telephone interviews. The mailed survey will be formatted for data scanning, and data from all returned surveys will be scanned into an electronic data file. Computer Assisted Telephone Interviewing (CATI) will be used for the secondary mode of data collection for non-responders to the mailed request to complete the survey.

A4. Identifying Duplication

The hospice experience of care survey consists largely of a set of newly developed or substantially revised existing items specific to the domains of experience in hospice care. A call for input on topics was published in Federal Register Volume 78, Number 17

(Friday, January 25, 2013). Items addressing communication, shared decision making, and overall rating are adapted from Nursing Home, Home Health and the Clinician and Group CAHPS item sets; they are edited for wording specific to hospice care. Items addressing symptom management and emotional and spiritual support are adapted from the Family Evaluation of Hospice Care survey; these items are edited for wording and response scales specific to CAHPS survey design principles. The survey is being designed to gather only the data that CMS needs for assessing experiences with hospice care.

Though hospices and vendors may use the Family Evaluation of Hospice Care, the Veterans Health Administration Bereaved Family Survey, or other site-specific surveys to collect data on experiences with hospice care, to date, no standardized instrument has been used to collect such data from all hospices across the country for the purposes of comparability and accountability.

A5. Impact on Small Businesses

No small businesses or other small entities are impacted by this information collection.

A6. Consequences of Less Frequent Data Collection

This Supporting Statement requests clearance for a one-time data collection.

A7. Special Circumstances

There are no special circumstances associated with this information collection request.

A8. CMS Federal Register Notice

The 60-day Federal Register notice published on April 4, 2013 (78 FR 20323). No comments were received.

Nonsubstantive changes have been made to the Home Survey since the publication of the 60-day FR notice. Changes include adding the word “letter” on several occasions, revising several questions into active voice, skipping several landing locations, and adding instruction for item 49. CMS has also added item 48 to see whether hospice team was available as soon as needed after the death.

A9. Respondent Payments or Gifts

This data collection will not include respondent incentive payments or gifts.

A10. Assurance of Confidentiality

Individuals contacted as part of this data collection will be assured of the confidentiality of their replies under 42 U.S.C. 1306, 20 CFR 401 and 422, 5 U.S.C. 552 (Freedom of Information Act), 5 U.S.C. 552a (Privacy Act of 1974), and OMB Circular A-130.

A11. Sensitive Questions

As this survey requests information from bereaved family members or close friends of a deceased patient, the potential for distress is possible; however, the extensive experience of the Department of Veterans Affairs with the Bereaved Family Survey and the National Hospice and Palliative Care Organization with the Family Evaluation of Hospice Care survey over the past nine years indicates that this is a very rare event. The cover letter accompanying mailed surveys will include a toll-free number which respondents may use for questions or concerns; should a respondent experience distress significant enough for him or her to request additional support, project staff manning the toll-free number or administering the telephone survey will put the respondent in contact with the appropriate local resource (generally a bereavement counselor or social worker on the hospice team that provided care to their family member or friend). This visit and support groups for bereavement are part of the services covered under the Medicare Hospice Benefit.

A12. Burden of Information Collection

Table 1 shows the estimated annualized burden for the respondents' time to participate in this data collection. The hospice experience of care survey will be administered to 730 individuals in 2013. There are three versions of the survey: one for bereaved family members and close friends of decedents who received hospice care at home (Attachment A), one for bereaved family members and close friends of decedents who received hospice care in nursing homes (Attachment B), and one for bereaved family members and close friends of hospice patients who received hospice care in inpatient settings, including acute care hospitals and freestanding hospice inpatient units (Attachment C).

The home version of the survey contains 72 items and is estimated to require an average administration time of 15.8 minutes in English (at a pace of approximately 4.5 items per minute) and 18.9 minutes in Spanish (assuming 20 percent more words in the Spanish translation), for an average response time of 15.9 minutes or 0.266 hours. The nursing home version of the survey contains 65 items and is estimated to require an average administration time of 14.4 minutes in English and 17.3 minutes in Spanish, for an average response time of 14.6 minutes or 0.243 hours. The inpatient version of the survey contains 67 items and is estimated to require an average administration time of 14.9 minutes in English and 17.9 minutes in Spanish, for an average response time of 15.0 minutes or 0.251 hours. These burden and pace estimates are based on CMS' experience with surveys of similar length that were fielded with Medicare beneficiaries. As indicated below, the annual total burden hours are estimated to be 184.6 hours.

Table 1. Estimated annualized burden hours

Survey Version	Number of Respondents	Number of Responses per Respondent	Hours per Response	Total Burden Hours
Home	219	1	.266	58.2
Nursing Home	219	1	.243	53.2
Inpatient	292	1	.251	73.2
Total	730	1	.253	184.6

Table 2 shows the survey participants' cost burden associated with their time to complete a survey. The annual total cost burden is estimated to be \$4,082.86.

Table 2. Estimated annualized cost burden

Form Name	Number of Respondents	Total Burden Hours	Average Hourly Wage Rate*	Total Cost Burden
Hospice experience of care survey	730	184.6	\$22.77	\$4,203.30
Total	730	184.4	\$22.77	\$4,203.30

*Based upon mean hourly wages, "National Compensation Survey: All United States December 2009 – January 2011," U.S. Department of Labor, Bureau of Labor Statistics.

A13. Capital Costs

There are no capital, start-up, operation or maintenance costs. Cost estimates are not expected to vary widely. The only cost is that for the time of the respondent. There is no anticipated recordkeeping burden as respondents are not required to keep a copy of the survey.

A14. Cost to the Federal Government

The total cost to the Federal Government is \$1,003,129 for the period of 9/24/2012 to 3/23/2014.

A15. Program Changes or Adjustments to Annual Burden

This is a new information collection request.

Nonsubstantive changes have been made to the Home Survey since the publication of the 60-day FR notice. Changes include adding the word “letter” on several occasions, revising several questions into active voice, skipping several landing locations, and adding instruction for item 49. CMS has also added item 48 to see whether hospice team was available as soon as needed after the death. The burden has not been adjusted.

This request seeks approval of 184.6 hours of respondent burden to assess experiences of care with hospice reported by bereaved family members or friends of patients who died while receiving hospice care. These hours are required to (1) assess experience of care at the respondent level; (2) allow for a comparison of care experiences across settings of hospice care; and (3) test the psychometric properties of core survey items applicable to all settings of care, and setting-specific survey items applicable to the home, nursing home, or inpatient setting only.

A16. Tabulation and Publication of Results

We anticipate that the analysis plan will include analyses needed to refine the survey instrument and those to support improved sampling, implementation, and data collection processes. Such analyses fall into the following fundamental categories: psychometric analysis; weighting; case mix adjustment; and analyses of data quality and composite development.

(1) Psychometric Evaluation. Analyses will include evaluation of item missing data, item distribution (including ceiling and floor effects), and assessment of hospice-level reliability of items. We will compute these statistics overall, and separately by setting, and language, computing mean scores for composites and global rating items.

(2) Weighting. Analyses will include the calculation of (a) *Sampling weights* to reflect the probability that each bereaved family member or close friend is selected for the survey; (b) *nonresponse weights* to reflect the probability that a sampled bereaved family

member or close friend responds to the survey; and (c) *poststratification* weights to make the characteristics of the respondent sample more similar to the overall population.

(3) Case-mix adjustment and nonresponse. In consultation with CMS, we will consider mixed effect regression models of performance measures for hospice care. This approach uses linear models in which the dependent variable is a survey score and the independent variables are case-mix adjusters, with controls for unit (e.g., hospice) effects. These models would include fixed effects for case-mix adjusters, such as age, education, and primary diagnosis.

Publication of Results: CMS may confidentially share hospice-level estimates with hospice administrators for quality improvement purposes. However, hospice-level data from this survey will not be made publicly available to Medicare beneficiaries or the general public because the results are from a field test of the survey instrument.

A17. Display of OMB Expiration Date

The expiration date for OMB approval of this information collection will be displayed on the survey.

A18. Exceptions to the Certification Statement

There are no exceptions to the certification statement identified in item 19 of OMB Form 83-I associated with this data collection effort.