
Supporting Statement Part A Field Test of A
Survey of End-of-Life Care – 0935-0124

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SUPPORTING STATEMENT: Field Test of a Survey of End-of-Life Care

Introduction

The Agency for Healthcare Research and Quality (AHRQ) requests clearance from the Office of Management and Budget (OMB) under the Paperwork Reduction Act of 1995 to field test a survey entitled, “Survey of End-of-Life Care.”

Producing evidence to make health care safer, higher quality, more accessible, equitable, and affordable is part of AHRQ’s mission. Sponsored by AHRQ, the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Program is purposed with advancing the scientific understanding of the patient experience of care, including the development and testing of new surveys and/or approaches to data collection to promote or improve the collection of consumer reports and evaluations of their experiences with health care.

The proposed field test of a survey of bereaved caregivers regarding their family member or friend’s end-of-life care experiences fulfills AHRQ’s mission by addressing a critical priority identified by the National Academy of Sciences, Engineering, and Medicine (2017): integrating the patient and caregiver voice into assessments of the quality of serious illness and end-of-life care. The field test furthers the purpose of AHRQ’s CAHPS Program by finalizing a reliable and valid survey instrument that can assess care experiences across care settings and provide a comprehensive picture of care experiences at the end of life. The field test’s scientific design will assess both the feasibility of conducting a survey of bereaved family members or friends regarding care experiences across settings, and the measurement properties of proposed survey items and composite measures.

A. Justification

A1. Necessity of Information Collection

Standardized surveys and administration procedures are central components of CAHPS surveys. The CAHPS survey items address aspects of care that consumers value and for which they are the best source of information. The CAHPS suite of surveys is extensive and includes items to evaluate provider care in an ambulatory care setting (e.g., accountable care organizations--ACOs, clinicians/groups, patient-centered medical homes--PCMHs, American Indian), and institutional care (hospital, nursing home, hemodialysis, outpatient and ambulatory surgery centers). CAHPS survey data are used as a component of provider quality payments, including pay-for-reporting by hospices under the Hospice Quality Reporting Program, hospital value-based purchasing payments, quality bonus payments for Medicare Advantage Plans, and dialysis center value-based purchasing payments.

The Survey of End-of-Life Care is distinct from existing CAHPS surveys in that it assesses experiences across a variety of different care settings (e.g., hospice inpatient unit, nursing home, acute care hospital, other care facility, or at home).

The Survey of End-of-Life Care directly addresses a stakeholder need to assess the full episode of end-of-life care, capturing experiences of care in all settings, and including transitions across care settings, which can be particularly burdensome to patients.

A2. Purpose and Use of Information

This data collection effort is a one-time field test to be completed in 2021— 2022. The field test will select caregivers of patients who died while receiving care from a large integrated health system operating in multiple regions in the United States (e.g., Kaiser Permanente) to receive the Survey of End-of-Life Care for the following purposes:

- a. Assess overall response rate. We will assess the overall response rate to the survey and examine variation in response rate by patient characteristics (e.g., use of palliative or hospice care).
- b. Assess item-level response rates. We will review item-level response rates to assess the extent of missing data overall and across patient subgroups of interest (e.g., between those with cancer versus other diagnoses).
- c. Assess measurement properties. We will examine the distribution of responses to each survey question, including whether questions exhibit ceiling or floor effects (i.e., nearly all respondents give the highest or lowest score).
- d. Analyze psychometric properties. We will calculate internal consistency reliability of multi-question composites or scales and assess correlations between reports of care experiences and overall ratings of care.

The result of these analyses will inform which survey items will be included in the Survey of End-of-Life Care, and the composition of care quality measures based on results of that survey.

A3. Use of Information Technology

The field test will be conducted using mixed mode survey administration, including mail with telephone follow-up for non-responders. This is a standard mode for the conduct of CAHPS surveys.

A4. Identifying Duplication

The proposed information collection does not duplicate any other effort and the information cannot be obtained from any other source. While the CAHPS Hospice Survey evaluates the care experiences of individuals who have received hospice services at the time of death, no currently existing survey instrument evaluates the care experiences of individuals who die without hospice care or allows for comparison between individuals who have received hospice care and those who have not.

A5. Impact on Small Businesses

Survey respondents are informal caregivers of patients who received care from health care providers within the integrated health system. The field test will employ a standard CAHPS mixed mode survey protocol (mail with telephone follow-up), which is designed to minimize burden on survey respondents. Small businesses or other small entities will be not significantly impacted by the field test.

A6. Consequences of Less Frequent Data Collection

This is a one-time field test.

A7. Special Circumstances

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

A8. CMS Federal Register Notice

This proposed information collection is being submitted under AHRQ's generic clearance (OMB No. 0935-0124). Therefore, publication in the Federal Register is not required.

A9. Respondent Payments or Gifts

This data collection does not include any respondent payments or gifts.

A10. Assurance of Confidentiality

Survey respondents will be told that the survey is voluntary.

Comments provided by caregivers responding to the survey will be provided to the integrated health system, so they may follow up with respondents for purposes of quality improvement. Therefore, an assurance of confidentiality will not be provided. Instead, the letter that accompanies the survey instrument will be printed with the following statement:

Your Participation is Voluntary. Your answers may be shared with [NAME OF INTEGRATED HEALTH SYSTEM] for purposes of quality improvement.

Informed consent from caregiver survey respondents will be implied by their completion of the survey. Caregivers in the survey sample will receive additional informed consent via the telephone script for the telephone survey (See Attachment A for English language survey materials, and Attachment B for Spanish language survey materials).

The study will have a Data Safeguarding Plan to ensure the safeguarding of respondent and survey information at RAND. In addition, RAND will transmit and store data files

and files containing contact information for data collection following procedures reviewed and approved by RAND's Human Subjects Protection Committee (its Institutional Review Board).

RAND will execute a data use agreement with the integrated health system to receive consumer contact and provider information as part of the sample. (See Part B for more details of survey procedures.)

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 RAND team's experience with this through contracts supporting the Centers for Medicare & Medicaid Services' national implementation of the CAHPS Hospice Survey indicates that this is a very rare event. The cover letter that accompanies 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, RAND's Survey Research Group telephone staff will put the respondent in contact with an appropriate resource provided by the integrated health system.

A12. Burden of Information Collection

Table 1 shows the estimated annualized burden and cost for survey respondents' time to participate in this data collection.

The length of the Survey of End-of-Life Care is estimated at 0.19 hours (11.43 minutes). The estimates are based on tests of the survey conducted on nine or fewer persons and on prior work that established guidelines for estimating survey completion time (Berry, 2009).

The May 2020 National Employment and Wage Estimates reported by the Bureau of Labor Statistics indicate an average hourly wage of \$27.07 across the 50 U.S. states and the District of Columbia. We have used the national average to estimate the wages of survey respondents.

Table 1. Estimated annualized burden hours and cost

Collection Task	Number of Respondents	Number of Responses per Respondent	Hours per Response	Total Burden hours	Average Hourly Wage Rate*	Total Cost Burden
End-of-life Care Survey	510	1	0.19	96.9	\$27.07	\$2,623.08
Total		1	0.19	96.9		\$2,623.08

*Based upon mean hourly wage, “May 2020 National Occupational Employment and Wage Estimates United States,” U.S. Department of Labor, Bureau of Labor Statistics, retrieved at https://www.bls.gov/oes/current/oes_nat.htm#00-0000

As indicated in Table 1 above, the annual burden hours are estimated to be 96.9 hours in total for 510 caregivers responding to the Survey of End-of-Life Care.

A13. Capital Costs

Capital and maintenance costs include the purchase of equipment, computers or computer software or services, or storage facilities for records, as a result of complying with this data collection. There are no direct costs to respondents other than their time to participate in the study.

A14. Estimates of Annualized Cost to the Government

Funding for the one-time data collection is from AHRQ award number U18HS025920 to RAND. The cost of the data collection is estimated to be \$155,530. As shown in Table 2, we estimate an additional cost of about \$12,590 for AHRQ agency staff to oversee the effort. Therefore, the total annual cost to the government is estimated to be \$168,120.

Table 2. Estimated Cost of AHRQ Agency Staff to Oversee Data Collection

AHRQ position	% time	Annualized Cost*
GS-15, Step-5	3%	\$4,900
GS-14, Step -5	3%	\$4,165
GS-13, Step- 5	3%	\$3,525
Total		\$12,590

*Based upon “Pay & Leave Salaries & Wages,” U.S. Office of Personnel Management, retrieved at <https://www.opm.gov/policy-data-oversight/pay-leave/salaries-wages/salary-tables/21Tables/html/DCB.aspx>

A15. Program Changes or Adjustments to Annual Burden

This is a new information collection request.

A16. Time Schedule, Tabulation and Publication of Results

For planning purposes, we anticipate data collection will begin as early as October 2021 and no later than January 2022. Table 3 provides an approximate timeline for survey tasks including tabulation of data following review and approval of this field test.

Table 3: Time Schedule of Survey Tasks

Activity	Proposed Timing of Activity
Prepare field materials	Months 1 and 2
Identify target respondent	Months 2 and 3
Collect survey data	Months 4 through 6*
Analyze data	Months 7 and 8
Revise Survey	Month 9

* Data collection will begin as early as October 2021 and no later than January 2022.

Results of the field test, including a description of overall and subgroup response rates, and measure and psychometric properties, may be published in a peer-reviewed journal, and disseminated via conferences.

A17. Display of OMB Expiration Date

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

References

Berry, S. (2009). How To Estimate Questionnaire Administration Time Before Pretesting: An Interactive Spreadsheet Approach. *Survey Practice*, Vol 2(3).

National Academies of Sciences, Engineering, and Medicine. (2017). Integrating the patient and caregiver voice into serious illness care: Proceedings of a workshop. Washington, DC: The National Academies Press. doi: <https://doi.org/10.17226/24802>.

Attachment A – Survey

Attachment B – Survey Cover Letter and Telephone Interview Introduction