***SUBMISSION OF INFORMATION COLLECTION UNDER THE***

***Request for Approval under AHRQ’s Generic Clearance “Questionnaire and Data Collection Testing, Evaluation, and Research for the Agency for Healthcare Research and Quality” (OMB Control Number: 0935-0124)***

***DATE OF REQUEST:*** September 15, 2021

***SUB AGENCY (I/C):*** HHS/AHRQ

***TITLE:*** Field Test of Survey of End-of-Life Care

***GENERIC CLEARANCE UNDER OMB#:*** 0935-0124 ***EXP. DATE:*** 01/31/2024

***ABSTRACT:***  Integrating the patient and caregiver voice into assessments of the quality of end-of-life care is a critical priority identified by the National Academy of Medicine. The AHRQ 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. As part of the CAHPS Program, we propose to field-test a survey of bereaved caregivers regarding their family member or friend’s end-of-life care experiences. The goal of the field test is to finalize a reliable and valid survey instrument to 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 allow for assessment of 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.

The proposed 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 to receive the Survey of End-of-Life Care. We will use these survey data to:

1. 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).
2. Review item-level response rates to assess the extent of missing data overall and across patient subgroups of interest.
3. Examine the distribution of responses to each survey question, including whether questions exhibit ceiling or floor effects (i.e., a substantial number of respondents select the most positive or negative response option).
4. Analyze psychometric properties 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.

***TOTAL ANNUAL BURDEN APPROVED: RCO 8900***

***BURDEN USED TO DATE:*** ***1180.***

***BURDEN THIS REQUEST:*** 96.9 hours.

***FEDERAL COST:*** The estimated annual cost to the government is $168,120.

***IS RACE AND ETHNICITY DATA COLLECTED AS REQUIRED?***

\_\_\_X\_\_\_YES \_\_\_\_\_\_ NO \_\_\_\_\_\_ N/A

***OBLIGATION TO RESPOND:***

 \_\_\_X\_\_VOLUNTARY

\_\_\_\_\_\_ REQUIRED TO OBTAIN OR RETAIN BENEFITS

\_\_\_\_\_\_ MANDATORY

***HOW WILL THIS SURVEY BE OFFERED?***

\_\_\_\_\_\_ WEB SITE

\_\_X\_ TELEPHONE INTERVIEW

\_\_X\_\_\_ MAIL RESPONSE [email]

\_\_\_\_ IN PERSON INTERVIEW

\_\_\_\_\_ OTHER: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

***CONTACT INFORMATION:***

NAME: \_\_\_\_\_ Caren Ginsberg \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

TELEPHONE NUMBER: \_(301) 427-1894\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

EMAIL ADDRESS: \_\_\_ Caren.Ginsberg@ahrq.hhs.gov \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_