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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Medicare & Medicaid Services

[CMS-4172-NC]

Medicare Program; Request for Information to Aid in the Design and Development of a Survey Regarding Patient and Family Member/Friend Experiences with Hospice Care

AGENCY: Centers for Medicare & Medicaid Services (CMS), HHS.

ACTION: Request for information.

SUMMARY: This document is a request for information regarding patient and family member or close friend experiences with hospice care.

DATES: The information solicited in this notice must be received at the address provided below by [insert date 60 days after date of publication in the **Federal Register**].

ADDRESSES: In responding to this solicitation, please reply via e-mail to HospiceSurvey@cms.hhs.gov or by postal mail at Centers for Medicare and Medicaid Services, Attention: Debra Dean-Whittaker, Mailstop C1-25-05, 7500 Security Boulevard, Baltimore, MD 21244-1850.

FOR FURTHER INFORMATION CONTACT:

Debra Dean-Whittaker, 410-786-0848

SUPPLEMENTARY INFORMATION:

I. Background

In accordance with section 3011 of the Affordable Care Act, the Department of Health and Human Services (HHS) developed the National Quality Strategy to create national aims and priorities to guide local, state, and national efforts to improve the

quality of health care. The National Quality Strategy established three aims supported by six priorities.

The three aims are as follows:

- Better Care: Improve the overall quality, by making health care more patient-centered, reliable, accessible, and safe.
- Healthy People/Healthy Communities: Improve the health of the U.S. population by supporting proven interventions to address behavioral, social, and environmental determinants of health in addition to delivering higher-quality care.
- Affordable Care: Reduce the cost of quality health care for individuals, families, employers, and government.

The six priorities are: "(1) making care safer by reducing harm caused by the delivery of care; (2) ensuring that each person and family are engaged as partners in their care; (3) promoting effective communication and coordination of care; (4) promoting the most effective prevention and treatment practices for the leading causes of mortality, starting with cardiovascular disease; (5) working with communities to promote wide use of best practices to enable healthy living; and (6) making quality care more affordable for individuals, families, employers, and governments by developing and spreading new health care delivery models."

The survey, now under development, hereinafter referred to as the "Hospice Survey" supports the National Quality Strategy goal of Better Care and the priorities of--

- Ensuring that each person and family are engaged as partners in their care (priority #2); and
- Promoting effective communication and coordination of care (priority #3).

The Centers for Medicare & Medicaid Services (CMS) has previously implemented national surveys called Consumer Assessment of Healthcare Providers and Systems (CAHPS[®]) surveys in both in-patient and out-patient settings and for different services. Specifically, CMS has implemented CAHPS[®] surveys for Medicare health and drug plans, inpatient hospitals, and home health agencies. CMS and the Agency for Healthcare Research and Quality (AHRQ) have also developed CAHPS[®] surveys for in-center hemodialysis facilities, nursing homes, and clinician and group practices. None of these CAHPS[®] surveys address experiences with hospice services.

Hospice focuses on caring for patients at the end of their lives and on helping their families. In the **Federal Register** we have defined hospice and hospice care as follows:

Hospice means a public agency or private organization or subdivision of either of these that is primarily engaged in providing hospice care as defined in this section.

Hospice care means a comprehensive set of services described in section 1861(dd)(1) of the Act, identified and coordinated by an interdisciplinary group to provide for the physical, psychosocial, spiritual, and emotional needs of a terminally ill patient and/or family members, as delineated in a specific patient plan of care.¹

The Hospice Foundation of America is one of many private organizations that agree with the following statement:

Hospice is a special concept of care designed to provide comfort and support to patients and their families when a life-limiting illness no longer responds to cure-oriented treatments.²

1 42 CFR 418.3 Accessed November 19, 2012 <http://www.gpo.gov/fdsys/pkg/CFR-2011-title42-vol3/xml/CFR-2011-title42-vol3-part418.xml#seqnum418.3>

2 Hospice Foundation of America, accessed November 2, 2012 <http://www.hospicefoundation.org/whatishospice>

The National Hospice and Palliative Care Organization (NHPCO), a leading organization for hospice providers, describes hospice care as follows:

The focus of hospice relies on the belief that each of us has the right to die pain-free and with dignity, and that our loved ones will receive the necessary support to allow us to do so.³

The planned CMS Hospice Survey differs from other CMS patient experience surveys because the target population for the Hospice Survey is bereaved family members or close friends of patients who died in hospice care. The reasons for focusing on family members/friends are that the patient is not the best source of information for the entire trajectory of hospice care, and that many hospice patients are very ill and unable to answer survey questions.

Given the unique environment and patient population of hospice care, existing patient experience instruments designed for other settings are only partially relevant for capturing hospice care experiences. A rigorous, well-designed Hospice Survey will allow us to understand: (1) patient experiences throughout their hospice care, as reported by their family members/friends; and (2) the perspectives of family members/friends with regard to their own experiences with hospice. This information will ultimately be used to help improve the quality of care patients and their families and friends receive in hospice.

We are in the process of reviewing potential topic areas, as well as publicly available instruments and measures, for the purpose of developing a Hospice Survey that will enable objective comparisons of hospice experiences across the country. This survey will be used to help consumers make more informed decisions about providers, as well as provide information to drive improvements in the quality of hospice care. The principal

³ Caring Connections, accessed November 1, 2012
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3356>

focus of this effort is to develop a survey of family members or friends who are 18 years of age and older and who are knowledgeable about the care provided to the person enrolled in hospice.

II. Solicitation of Information

We are soliciting the submission of suggested topic areas (such as "communication with providers," "pain control" or "non-pain symptom management," as well as publicly available instruments for capturing family members' or friends' experiences with hospice care. We are interested in instruments and items that can measure quality of care from the family member/friend's perspective, including all potential hospice settings (for example, home, nursing home, hospital, and free-standing hospice) and instruments that track changes over time.

We are looking for suggested topic areas and publicly available instruments in which the information was identified by family members/friends as important to them in evaluating hospice care. Existing instruments are preferred if they have been tested, have a high degree of reliability and validity, and report evidence of wide use.

The following information would be especially helpful in any comments responding to this request for information:

- A brief cover letter summarizing the information requested for submitted instruments and topic areas, respectively, and how the submission will help fulfill the intent of the survey.

- (Optional) Information about the person submitting the material for the purposes of follow up questions about the submission which includes the following:

++ Name.

- ++ Title.
- ++ Organization.
- ++ Mailing address.
- ++ Telephone number.
- ++ Email address.
- ++ Indication that the instrument is publicly available.

- When submitting topic areas, we encourage including to the extent available the following information:

- ++ Detailed descriptions of the suggested topic area(s) and specific purpose(s).
- ++ Relevant peer-reviewed journal articles or full citations.

- When submitting publicly available instruments or survey questions, we encourage including to the extent available the following information:

- ++ Name of the instrument.
- ++ Copies of the full instrument in all available languages.
- ++ Topic areas included in the instrument.
- ++ Measures derived from the instrument.
- ++ Instrument reliability (internal consistency, test-retest, etc) and validity (content, construct, criterion-related).
- ++ Results of cognitive testing (one-on-one testing with a small number of respondents to ensure that they understand the questionnaire.)
- ++ Results of field testing.

++ Current use of the instrument (who is using it, what it is being used for, what population it is being used with, how instrument findings are reported, and by whom the findings are used).

++ Relevant peer-reviewed journal articles or full citations.

++ CAHPS[®] trademark status.

++ National Quality Forum (NQF) endorsement status.

++ Survey administration instructions.

++ Data analysis instructions.

++ Guidelines for reporting survey data.

CMS is developing this survey and plans to submit it to AHRQ for recognition as a Consumer Assessment of Healthcare Providers and Systems (CAHPS[®]) survey. The survey will be developed in accordance with CAHPS[®] Survey Design Principles and implementation instructions will be based on those for CAHPS[®] instruments (<https://www.cahps.AHRQ.gov/About-CAHPS/Principles.aspx>).

(Catalog of Federal Domestic Assistance Program No. 93.773, Medicare--Hospital Insurance; and Program No. 93.774, Medicare--Supplementary Medical Insurance Program)

Dated: December 5, 2012

Marilyn Tavenner,
Acting Administrator,
Centers for Medicare & Medicaid Services.

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