DEPARTMENT OF HEALTH AND HUMAN SERVICES

Agency for Healthcare Research and Quality

Request for Measures of Patient Experiences of Cancer Care

AGENCY: Agency for Healthcare Research and Quality, HHS.

ACTION: Notice of request.

SUMMARY: The Agency for Healthcare Research and Quality (AHRQ), in collaboration with the National Cancer Institute (NCI), is soliciting voluntary submission of survey items and instruments. AHRQ is seeking these items and measures from researchers, survey firms, cancer care providers, patient advocacy groups, individual cancer patients, and other stakeholders who are interested in the development of survey measures of patient experiences of cancer care. To be as inclusive as possible, AHRQ is requesting such instruments and individual items, along with any available documentation of their validity and reliability and descriptions of survey methods for using them.

In addition to the patient perspective on the care they receive, the PCC instruments will address communication from the perspective of the treating clinicians.

AHRQ will consider all submitted instruments and items for inclusion in the final survey instruments under development. Submitters will not be identified with specific items in the final instrument, but will be included in a list of those who contributed candidate instruments and items if so desired. Please include a statement with your submission indicating whether or not you wish to be identified as a contributor.

DATES: Please submit instruments and supporting information to Dr. William Lawrence (see address below) on or before April 2, 2010.

ADDRESSES: Submissions should include a brief cover letter, a copy of the instrument or items for consideration and supporting information as specified under “Submission Criteria” below. Submissions may be in the form of a letter or e-mail, preferably with an electronic file in a standard word processing format on a CD or as an e-mail attachment. Electronic submissions are encouraged. Please do not use acronyms unless clearly defined.

Responses to this request should be submitted to: Dr. William Lawrence, Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, Phone: (301) 427–1517, Fax: (301) 427–1520, E-mail: william.lawrence@AHRQ.hhs.gov. To facilitate handling of submissions, please include full information about the instrument developer, any copyright holder and person to contact: (a) Name, (b) title, (c) organization, (d) mailing address, (e) telephone number, (f) fax number, and (g) e-mail address. A copy or citation of relevant peer-reviewed journal articles is also desirable, but not required. For citations, please include the title of the article, author(s), publication year, journal name, volume, issue, and page numbers where the article appears and/or other applicable evidence to support the value of the instrument or items for measuring patients’ experience (or the clinicians experience for the PCC initiative) of cancer care.

All submissions must include a written statement granting AHRQ the right to use and authorize others to use the submitted instruments, items, and their documentation for the above-described purposes. Thus, this statement must indicate whether you are interested in submitting the items or instruments for use in the first initiative (CAHPS® Survey for Cancer Care), the second initiative (PCC Surveys), or both. This statement must be signed by an individual authorized to act for any holder of copyright on each submitted measure or instrument. The authority of the signatory to provide such authorization should be described in the letter. Submitters’ willingness to grant to AHRQ the right to use and authorize others to use their instruments, items, and measures means that AHRQ will have a license to grant free access and rights to use all elements of the early and final versions of the CAHPS® and/or PCC instruments, in accordance with the instruments’ supporting administration information and instructions.

FOR FURTHER INFORMATION CONTACT: William Lawrence, MD, MS, from the...
In addition, a description of how extensively the survey has been fielded should also be included in the submission materials. Measures that have been tested or implemented in just one or two research studies would have more limited value than those tested or implemented more widely, but measures will be considered on an individual basis when evaluating the measures needing further testing as a prerequisite to their inclusion in CAHPS® or PCC draft and final survey tools.

Submission of copies of existing report formats developed to disclose findings to consumers and providers is desirable, but not required. Additionally, information about existing database(s) for the instrument(s) submitted is helpful, but not required for submission. Evidence of meeting the validity, reliability, and other criteria may be demonstrated through submission of peer-reviewed journal article(s) or through the best evidence available at the time of submission.

SUPPLEMENTARY INFORMATION:

Background

AHRQ is a leader in developing and testing instruments for quantitative measurement of consumer experience within the healthcare system of the United States as evidenced by the development and widespread use of CAHPS® survey products. The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) program is a public-private initiative to develop standardized surveys of patient experience of care received in ambulatory and facility settings. Standardization of measures is essential for meaningful comparison of performance across providers and settings. While CAHPS® instruments have been highly regarded within the industry and provide valuable information, until now, no CAHPS® condition-specific surveys have been developed. Use of a standardized measurement instrument for cancer care will provide several benefits including: Comparable information across cancer care providers for the public about the quality of care; data-based recommendations for quality improvement efforts and a data base to stimulate further research in this area. AHRQ, through a collaborative process with NCI and other stakeholders, has initiated the process for this project.

The steps to advance this initiative are described below:

• Survey Development and Testing: The process by which measures will be defined and the most useful instruments or measures identified is as follows:

Instruments submitted will be evaluated by the project team in consultation with AHRQ and NCI staff to determine if they meet high priority or common measurement needs and to identify whether additional measure development is required. Additional measure development will be done as needed.

Until the trademarked versions or each instrument are available, access to and use of draft versions will require explicit written permission from AHRQ and sharing of testing results with the CAHPS® team. testing.

• Implementation Plan: The final tools and a description of the survey process as well as instructions for implementing of the final standardized CAHPS® and PCC cancer care instruments will be made available at no cost to the public on AHRQ and NCI Web sites and will include requirements and information related to their use in future data collections, analysis, and public reporting.

Carolyn M. Clancy,
Director, AHRQ.

[FR Doc. 2010–4387 Filed 3–3–10; 8:45 am]

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