The case for systematically measuring patient experiences with cancer care

Cancer is multifaceted and complex. In 2013 alone, 1.6 million new cases were diagnosed and there are more than 14 million cancer survivors alive today. Cancer can be complicated to treat and cancer and its treatment often result in a profound physical and psychosocial burden on both the patient and their families. To comprehensively assess and improve the quality of care delivered to cancer patients, it is critical that we systematically assess cancer patients’ care experiences. The CAHPS for Cancer Care survey can be used by organizations providing cancer care to assess quality of care from the patient’s perspective for the purpose of identifying ways of improving that care. The results from this survey also can be used by patients and families to inform decisions about how they choose and manage their care.

Activities to Date

The Agency for Healthcare Research and Quality, the National Cancer Institute, and the California HealthCare Foundation supported the initial development phase of the survey. Activities to date include:

- **Literature review and database of existing measures.** The survey development team identified 71 surveys containing a total of 1,563 questions.
- **Call for measures in the Federal Register.** On March 4, 2010, AHRQ published a call for measures in the Federal Register. No measures were submitted.
- **Focus groups.** The survey development team conducted 14 focus groups with patients who varied by stage of cancer, type of cancer, type of treatment facility used, and primary language. Two focus groups were conducted with patient caregivers.
- **Stakeholder interviews.** Meetings with major stakeholders were held across the country to understand their needs for a survey and reporting.
- **Draft survey.** The initial set of survey items were drafted between July 2010 and January 2011.
- **Technical expert panel (TEP).** The TEP reviewed candidate items and composites during a webinar held in January 2011.
- **Cognitive testing of the draft survey.** The survey development team conducted two rounds of cognitive testing with consumers in June and August 2011 to assess comprehension of the survey questions.
- **Survey refinement.** The survey was further reviewed, refined, and finalized for the field test in March 2012.
- **Field test with six sites.** The field test was conducted at three academic facilities, one large community-based cancer center, one small community-based cancer center, and one health care system in which the cancer center was spread over five locations within a substate region. Geographic regions included the West Coast, Midwest, South, Northeast, and Southeast. Our initial sample size goal was 750 cancer patients with any type or stage of cancer distributed equally among the three main cancer treatment

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**What does the CAHPS for Cancer Care Prototype Survey Cover?**

The survey covers five topics:

1. Cancer care team communicates well with patients
2. Cancer care team engages patients in decisions about cancer treatment
3. Cancer care team explains your cancer and cancer treatment
4. Cancer care team supports patients in coping with their cancer
5. Cancer care team provides care and information when needed

Patient safety is a 6th topic can be addressed using items from the other 5 topics.
modalities: medical, radiation, and surgical oncology. Our goal was a 40 percent response rate or 300 completions per site. Data were collected by the Mayo Clinic Survey Research Center.

- **Analysis of the field test data.** The analysis team conducted psychometric testing of the pilot data using factor analysis, multitrait analysis, and statistical models to evaluate the ability of quality scores to detect differences in cancer centers (center-level reliability). The psychometric results support the reliability and validity of five composite measures (as shown on the box in the first page), and included testing the feasibility of specifying a separate patient safety composite made up of items drawn from three of the five recommended composites. Two single item measures regarding care coordination are included in the final recommended measure set. The patient safety composite has good properties – its internal consistency reliability is over 0.70, it is strongly correlated with the global rating of the treatment team, and has very low ceiling and floor effects. However, its relatively low unit-level reliability could make discriminating patient safety performance among cancer treatment sites difficult. The field test data did support the use of the patient safety composite to track performance change in quality improvement projects over time by a single cancer center and as a measure of patient safety performance in evaluation studies. Evaluation of the precision with which the five other composites distinguished among cancer centers indicated that acceptable center-level reliability could be obtained with approximately 150 to 300 completed surveys per center. Analysis of center reliability separately by treatment modality indicated that reliability of the composites varied by modality. In addition to the psychometrics, the team conducted a nonresponse analysis to identify factors associated with the decision of sample members to respond. The team also conducted randomized experiments to compare telephone versus mail administration and to assess two alternative measures of health status for case mix adjustment.

The CAHPS Consortium has requested additional testing before the CAHPS trademark is awarded. The term CAHPS for Cancer Care is used with permission of the Consortium, but the survey remains a prototype pending completion of the additional testing.

**Current Activities**

Currently, the National Cancer Institute and the Agency for Healthcare Research and Quality are supporting the development and cognitive testing of a Spanish version as well as the testing of the composite labels for use when the data are publicly reported. In addition, the California Healthcare Foundation has provided a modest amount of funds to conduct an additional field test with a variety of cancer centers to test the survey.

**What is needed for additional testing?**

The use of only six hospital-based cancer centers in the 2012 field test represents a limitation on the generalizability of our findings and on our ability to evaluate the degree to which the survey discriminates among cancer centers. The next steps include obtaining survey data from additional hospital-based cancer centers and from group oncology practices that are not based at hospitals to verify that the composite measures derived from the 6-site field test can be generalized to other centers, to determine the ability of the measures to discriminate among a larger group of centers, and to determine if the measures derived from hospital-based centers are reliable for group practices. Data from a more heterogeneous group of cancer centers would enable us to better evaluate center-level reliability and to identify and evaluate patient-mix adjusters.
A larger field test would also support further investigation of sampling frames. Tumor registries, which are common to all accredited cancer centers, were not useful as sampling frames because their enrollment timeframe did not match the requirements of enrollment in our field test. The tumor registries are required to enroll only new cases within six months of diagnosis or initial treatment. Based on stakeholder interviews, we decided to include episodes for recurring cancer and cancers diagnosed elsewhere in the patient population from which performance would be measured. Once we determined that it was important to sample and assess care by treatment modality, we also decided on a three-month reference period for treatment items to minimize the frequency with which patients would have multiple treatment modalities during the reference period and improve their recall about the modality they were being asked to assess. Work is underway at the Commission on Cancer to evaluate the feasibility of rapid registration, which suggests that using tumor registries as the sampling frame might become feasible in the future. A substantially larger field test would enable further investigation of the use of tumor registries and other potential sources of sampling frames. Additional funding from other funders will be needed in order to successfully meet the requirements for CAHPS trademark and NQF endorsement.

For More Information

For additional information about or to use the Cancer Care Experience Survey, please contact the following individuals.

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