

THE NATIONAL QUALITY FORUM

NQF Steering Committee Meeting

Standardizing Quality Measures for Cancer Care Summary Report

Overview

Approximately 1.2 million Americans are newly diagnosed each year with cancer and more than 8 million Americans each year require care for new or recurrent cancers. Persons with cancer do not always receive care that is known to be effective; mechanisms to consistently measure the provision of effective and high-quality care do not exist. Systematic improvements in cancer care quality must rely on ways to distinguish high-quality care.¹ Despite much progress in developing ways to assess the quality of care for particular cancer types and in cancer care delivery in general, this progress has not yet been translated into commonly accepted ways that: 1) inform patients and families so they can make decisions about where to seek care; 2) identify opportunities where healthcare professionals can pursue quality improvement in cancer care; and 3) provide information that allows researchers to evaluate which interventions result in better care.

In April 2002, the National Quality Forum (NQF), with support from the National Cancer Institute (NCI), undertook a project to address the need for national voluntary consensus standards for measuring quality of care that would result in information useful to patients, providers, and other stakeholders. The initial step in this project consisted of planning and convening the first meeting of the project's Steering Committee (attachment 1) in order to discuss a basic framework for cancer quality measurement and a work plan for the full project.

The meeting of the NQF "Cancer Care Quality Measures" Steering Committee was held on September 4-5, 2002, in Washington, DC (attachment 2). More than forty members of the public attended this meeting (attachment 3). This report summarizes the discussion and outcomes of that meeting.

The NQF's President and Chief Executive Office, Kenneth W. Kizer, MD, MPH, opened the meeting by outlining the objectives of the Steering Committee:

1. To reach agreement on the purpose for the Cancer Care Quality Measure Project;
2. To reach agreement on criteria for selecting priority focus areas for the cancer care quality measure set; and

¹ Institute of Medicine (IOM) and National Research Council (NRC). 1999. *Ensuring the Quality of Cancer Care*. Hewitt, M., Simone, J.V. Washington, D.C.: National Academy Press.

3. To reach agreement on priority areas that will be the initial focus of the measure set.

As envisioned, the full Cancer Care Quality Measures project will include the identification and evaluation of existing measures for quality of cancer care, and endorsement of measures as voluntary consensus standards for measurement via the NQF's Consensus Development Process (CDP). This voluntary consensus process enables the federal government to participate in the private-sector development of voluntary consensus standards and then preferentially use these standards in federal programs (as long as the standard setting process meets the criteria specified in the National Technology Transfer Advancement Act.², including transparency).

Following this first Steering Committee meeting, it is anticipated that technical advisory panels (aka expert panels or workgroups) will be organized around each of the priority focus areas (subject to the availability of funding). Each workgroup will identify candidate measures based on the suggestions of the Steering Committee, NQF, a systematic review by experts in such reviews (such as the Agency for Healthcare Research and Quality's Evidence-based Practice Centers) and other sources. The workgroups will assess these candidate measures for suitability as part of a cancer care quality measure set and their relevance to the purpose of the measure set, as recommended by the Steering Committee. The Steering Committee will review the measures recommended by the workgroups in each of the focus areas and make a recommendation to NQF on whether all or part should be endorsed as voluntary consensus standards for measuring the quality of cancer care. If no valid measures exist in a particular domain within a focus area, workgroups and the Steering Committee may also make recommendations for research and development priorities.

The measure set recommended by the Committee will then be vetted through the NQF's CDP. Following NQF member and public review, members will vote on the measures; formal endorsement by the Board of Directors, after member council approval, completes the process.

In addition to the measures themselves, the project also will address strategies to update the set of standards for measurement to ensure that the set reflects current science. Also addressed will be strategies for implementation of the final set of voluntary consensus standards for measurement.

To ensure the utility and validity of the resulting measure set and research recommendations, the workgroups will consist of representatives of key stakeholder groups. These groups include those in patient advocacy, practicing healthcare professionals (including medical, radiation and surgical oncologists), health services

² Complete information on the NTTAA can be found on the website:
<http://ts.nist.gov/ts/htdocs/210/nttaa/nttaa.htm>

researchers, purchasers, and other key stakeholders who have knowledge of quality improvement methodologies and/or understand the relevance these measures may have for consumers and patients, as they go through decision-making processes.

It is anticipated that phase II of the full project will take approximately 18 months to complete.

Discussion 1: Purpose of Cancer Quality Measures Core Set

Development of a purpose statement was the first item considered by the Steering Committee. This discussion centered on recommending the primary intended uses of the measure set that would guide subsequent efforts related to identifying and evaluating measures in the set. To provide some context to this discussion and those that followed, the NCI provided two commissioned papers from the RAND Corporation, *Applying the Strategic Framework Board's Model to Selecting National Goals and Core Measures for Stimulating Quality for Cancer Care*. (McGlynn)³ and *Selecting National Goals and Core Measures of Cancer Quality* (McGlynn E & Malin J)⁴.

Prior to this meeting, Steering Committee members were asked to complete a survey (attachment 4) in which they rated the uses of a standardized set of cancer care measures. In the survey, uses were categorized as either for quality improvement or accountability, in line with the NQF national framework of quality measurement and reporting⁵. This exercise had the function of providing NQF with each Steering Committee member's view on priorities before any group discussion as a means of getting the broadest base for beginning discussions. NQF staff drafted a purpose statement for the Committee (attachment 5) based on the aggregate ratings designated by the survey analysis. Based on the response of 14 Committee members the priorities were rated as follows:

³ McGlynn E. *Applying the Strategic Framework Board's Model to Selecting National Goals and Core Measures for Stimulating Improved Quality for Cancer Care*. Santa Monica; RAND. August 2002

⁴ McGlynn E and Malin J. *Selecting National Goals and Core Measures of Cancer Care Quality*. Santa Monica: RAND; August 2002

⁵ National Quality Forum. *A National Framework for Healthcare Quality Measurement and Reporting: A Consensus Report*. Washington, DC: National Forum for Healthcare Care Quality Measurement and Reporting; 2002

Ratings of the Uses of Cancer Performance Measures

	High Priority	Mid-Level Priority	Low Priority
I. Public Accountability Purposes			
Consumer selection (e.g., of plans)		✓	
Patient selection (e.g., of institutions, clinicians, treatments)	✓		
Purchaser selection (public and private)		✓	
Regulator oversight			✓
Health plan selection to include provider in network		✓	✓*
Referring clinician selection	✓		
Tracking national progress toward cancer quality goals	✓		
II. Improvement Purposes			
Institutional quality improvement	✓		
Individual provider quality improvement	✓		
Stimulate rapid translation of research into practice			✓

*Rating for this use was tied.

Note:

High Priority = majority of responses rated this topic 1 or 2 (1= highest priority)

Mid Level Priority = majority of responses rated this topic 3, 4, or 5

Low Priority = majority of responses rated this topic 6 or 7

Included in this discussion was the consideration of how the group would define **cancer** (e.g., does this project include benign conditions?) and **care** (e.g., across the continuum of care or only at specific points of care?). The definition of these concepts would have bearing on the project's scope, which should be reflected in the purpose statement. After several iterations of the initial draft statement, the Committee agreed on the following working purpose statement:

The purpose of the cancer care quality measurement and reporting system (which includes a core set of measures) is to inform the public, payers, providers, purchasers and researchers about the quality of cancer prevention and treatment activities, including the patient experience across healthcare delivery systems, and to identify opportunities to improve these activities in order to reduce death, disability, suffering, and economic burden caused by cancer.

Major points raised during the discussion that were considered as the statement was developed were:

- Prevention should be within the scope of this project. The phrase “cancer care” implies that the project only addresses quality improvement issues after a diagnosis of cancer. For example, screening for colorectal cancer, is where quality improvement could have the greatest positive impact as early detection often

results in “cure.” However, public perception of “cancer care” may not include prevention and screening and this should be considered as this core set is primarily for the public.

- Patient experience along the continuum of cancer care is a key quality-of-care and service issue that should be reflected in the purpose.
- Measures should be feasible, scalable, and durable. At least some measures in the set should be useful to track quality improvement at national and sub-national levels (e.g., regional, state, local). Additionally, some measures in the set must be useful in measuring and improving care at the levels of the local health system and the individual health professional.
- The measures should be useful for aligning provider reimbursement with quality outcomes. Rewarding providers who are of high quality provides an incentive to improve quality.
- Reduction of social and individual economic burden related to low quality cancer care is an important long-term purpose along with reduction in death, disability and suffering.
- Purchasers, as well as other payers, are important users of quality measurement data.
- The purpose statement should capture the idea that measures are used for patient selection of care options (informed decision-making) as well as selection of providers.

Public comments on the purpose statement discussions included:

- Specific guidance in the area of safety and the patient experience is needed for small hospitals and would be beneficial.
- Research to advance the agenda for evidence-based medicine should be reflected in this statement as an important purpose of this project.

The Committee agreed on the statement above, which takes into account the concerns and recommendations voiced during discussions. However, there was the stipulation that further revisions could be made when the meeting summary document is reviewed.

Discussion 2: Criteria for Selecting Focus Areas for Measurement

Before identifying focus areas for measurement, the Committee discussed and chose criteria to apply to focus areas being considered. To guide this discussion, NQF staff presented an overview of the criteria recommended in the NCI commissioned background paper, *Selecting National Goals and Core Measures of Cancer Quality (McGlynn E & Malin J.)* as well as NQF developed criteria that were potentially useful (attachment 6). In addition, the Committee was asked to consider whether weighting or prioritizing criteria would be appropriate and necessary.

Using these suggestions as points of discussion, the Steering Committee recommended the following criteria be used for selecting focus areas for this project:

- 1) Consistent with broad-based national goals
- 2) Important as defined by:
 - impact on outcomes (survival, quality of life, patient preferences, costs)
 - burden of disease, including costs
- 3) Represents a dimension of the patient-centered care experience
- 4) Improvement is possible (variability, malleability)
- 5) Disparities/serious quality problems exist

Key points raised by the Steering Committee members during the discussion of potential criteria included the following:

Consistent with broad-based national goals: Several Committee members questioned how “consistent with national goals” is defined. *Healthy People 2010* goals were discussed as examples. It was further clarified that focus areas need not use the same measures as these and other similar efforts but the measures should be compatible with the quality improvement goals.

Importance: The Committee agreed that “importance” should capture the concept of a substantial impact on a significant number of people. Survival rates are an important component of this criterion, but not the only one. Importance in reducing morbidity, suffering and economic burden should be viewed as significant as survival rates. Patient safety is a component of quality improvement and is inherent in all the criteria. Targeted safety issues are better discussed along with measure recommendations rather than as a selection criterion.

Patient-centered Care: Patient experience should be a criterion that is separate from other aspects of “importance”, to emphasize that this aspect of quality care is a distinct focal point of this quality improvement activity.

Improvement is possible: This criterion addresses unnecessary variability in practice, as well as opportunities to effectively change practice (malleability).

Disparities: This criterion includes demonstrated differences in patterns of care by race, ethnicity, gender, age, socio-economic status, and geographic location (e.g., rural versus urban) that may reflect differences in the quality of care. The disparities criterion was kept as a separate criterion to emphasize its importance for focusing quality improvement efforts in cancer care.

Discussion 3: Identification of Potential Initial Focus Areas for Measurement

Steering Committee members applied the criteria to data presented in background materials and their own knowledge and expertise to identify potential focus areas for measurement.

A three-step process was used for selecting the potential focus areas:

1. Proposing a list of candidate areas for discussion based on background materials and personal knowledge;
2. Rating the list of candidate areas; and
3. Agreeing on a cut-off point for the initial focus areas to ensure a feasible work plan.

Included in the background materials the Steering Committee received prior to the meeting were examples of data (attachment 7) to demonstrate the many ways selection criteria could be used to choose focus areas and to prioritize these areas. The Committee’s initial approach was to select broad cross-cutting focus areas of relevance to any cancer type, along with tumor specific areas. Three questions were considered: 1) Can the criteria be applied to all of these focus areas? 2) Would the criteria help in differentiating the more important areas? 3) Should less common focus areas be selected as well as the common ones?

The first round of suggesting topics resulted in the following candidate focus areas proposed for further discussion and Steering Committee vote:

Proposed Potential Cross-cutting Areas for Measurement

- Volume/Outcome
- Symptom Management
- Access
- Medical Specialty
- Pain Control
- Communications/Education
- Coordination of Care
- Screening/Surveillance
- Pathology/Staging

Major points raised during the discussion of these potential focus areas included:

- *Volume/Outcome:* Health services research literature has demonstrated that better outcomes of complex invasive procedures are sometimes associated with the volume of those procedures performed at an institution. Volume/outcome relationships would not be relevant in specific tumor types if the most prevalent cancers were chosen because those tumor types are not ones in which volume/outcome relationships have been demonstrated. The data may be useful for procedures involving esophageal, pancreatic and certain lung cancers; however, aggregate findings have been inconclusive. The relationship between institutional and clinician volume, and the impact that each has, separately and jointly, on outcomes is not known.
- *Symptom Management:* Management of symptoms such as pain, nausea/vomiting, fatigue and other similar symptoms is related to treatment and/or the course of the disease and is important from initial diagnosis and treatment through the end of life. This is an important crosscutting issue relevant to all cancers, at all stages of disease and of special importance to cancers where curative treatment is limited such as for lung, pancreas and esophageal. These symptoms, for example, pain, go directly towards quality of life and are often not treated optimally.
- *Access:* This is an important issue for all cancers in terms of access to specialists, to information on appropriate treatment options, to screening and early diagnosis, to supportive care and to culturally competent care and services. Access to clinical

trials is also included in this category. This criterion excludes issues of insurance because these issues are not under the control of health care institutions or practitioners.

- *Medical Specialty*: Evaluating key practices in the main areas may be a way to get at the quality improvement need across all cancers. However, identifying the specific practices related to surgery, radiotherapy, oncology nursing and medical oncology that are applicable across all cancer types is probably not feasible.
- *Pain Control*: Members agreed that this was an important issue that should be placed under “symptom management” as a specific management issue.
- *Communications/Education*: Assessment of patient/doctor and other healthcare professional communication issues, as well as information that is culturally and linguistically appropriate, would be important areas for measurement because they have significance for patient-centered care.
- *Coordination of Care*: Coordination of care could encompass the full spectrum of care, from screening to end of life care. Communication can also be considered an aspect of coordination of care.
- *Screening/Surveillance*: Adherence to guidelines for appropriate cancer screening (for example, guidelines recommended by the United States Preventive Services Task Force) is a cross-cutting measure of importance to many cancer types. Screening and surveillance are also scalable measures that can be applied from the individual practitioner up to the national level (the concept of scalability was considered important during the discussion of the purpose statement).
- *Pathology/Staging*: Incorrect or inaccurate pathology reports result in wrong treatment plans. There is a good opportunity to improve this critical step in the process. Criteria for appropriate assessment developed by the American College of Pathologists would be useful if this is selected as a high priority area.

In addition to the candidate focus areas, the area of pediatric oncology was discussed. Steering Committee members noted that children with cancer most often go to specific cancer centers for care. Almost without exception, children are treated at centers that specifically treat children. In general, there is a national system for quality in pediatric oncology; for example, it is rare for a child with cancer not to be treated by an oncologist. This is different than in the adult population. It was felt that the opportunities for immediate substantive improvement in care through focusing on patient-centered measures of quality are greater in the adult population. However, the Committee did acknowledge that in the pediatric population cross-cutting areas such as symptom management, communication and end of life care are important.

Proposed Tumor -Specific Cancer Areas for Measurement

- Breast
- Prostate
- Ovarian
- Lung
- Lymphoma/Hodgkin's Disease
- Other gynecological cancers

Major points raised during the discussion included:

- The most common cancer sites comprise approximately 55% of new cancer diagnoses in this country according to the American Cancer Society (ACS)⁶. For the 45% of cancers that are not as common or do not have clear treatment guidelines, cross-cutting measures may be effective in addressing the quality of care issues often related to such cancers.
- The Steering Committee should provide the workgroups with guidance on the aspects unique to tumor specific cancers that should be measured to avoid duplication with cross-cutting areas like symptom management, patient experience, or end-of-life care.

Public Comments

- Access to research is an important cross-cutting measure. Appropriate staging for lung cancer, which is also an important issue, could be captured in the crosscutting measures.
- Information technology and data system issues should be considered for inclusion under "Communication and Coordination of Care."
- Surveillance should be considered along with screening.
- Thinking "bigger" and not merely doing what is most practical will be most effective for this project.
- Pathology is rightfully on the list since incorrect and/or incomplete reports render the entire treatment plan useless.

⁶ American Cancer Society. *Cancer Facts and Figures 2002*

- Focus areas identified by the Steering Committee are not comprehensive. Other important areas exist that are not reflected here.

Steering Committee members agreed to rate the focus areas discussed during this session using the selection criteria they agreed upon earlier in the day. Each member rated the areas on a scale of one to seven. Number one (1) indicated that in their assessment an area was not rated high on that criterion and seven (7) indicated a high correlation rating on that criterion (attachment 8).

Discussion 4: Recommendations for Potential Focus Areas for Measurement

Based on the Steering Committee's individual ratings and subsequent discussion, the following focus areas emerged as the priority areas for measure identification and/or recommendations for research and development (again, subject to available funding):

Recommended Potential Focus Areas*

- Access/Cultural Competence/Clinical Trials
- Breast Cancer
- Colorectal Cancer
- Communication and Coordination of Care (including information technology issues)
- Prevention/Screening
- Prostate Cancer
- Symptom Management/End-of-life Care

**The seven focus areas are not listed in priority order*

Addressing Lung, Gynecological, Brain, Lymphomas and Other Cancers:

Several types of prevalent and important tumors with significant issues of morbidity, suffering, and economic burden were discussed at length by the Steering Committee. Since this list of initial focus areas for voluntary consensus standards for measurement would not explicitly address them, the Committee recognized their importance and noted that for tumors such as lung, gynecological, lymphomas and brain cancers, the greatest impact on quality improvement for the greatest number of patients is through the cross-cutting measures that are applicable to all cancers. Areas such as prevention, access to clinical trials, symptom management, and coordination of care are areas of care that are often inadequate even though strategies for improvement are known to

exist. For example, lung cancer was the source of considerable discussion as it places an enormous burden on society. However, the variability and opportunity to improve outcomes was not viewed as being as strong in the three tumor sites included. After much discussion, the Committee recommended that smoking was the primary target quality improvement in the prevention of lung cancer and that measurement standards should be addressed through the work of the prevention/screening workgroup.

Pathology and staging of disease also were noted to be areas with potential opportunities for significant improvement. Although this topic did not appear on the final list of focus areas, Committee members recommended that this area receive particular attention when workgroups search for measures

RECOMMENDED FOCUS AREAS WITH COMMENTS

Recommended Focus Area	Examples of Specific Measurement Areas and Related Expertise
Access to Care, Clinical Trials, and Cultural Competence	<p>Geographic variability including type of providers available; transportation and issues of rural versus urban disparities; access to information in appropriate language and reading level; patient choice of providers; ability to navigate through the healthcare system; access to appropriate clinical trials; timeliness of referrals</p> <p><i>Relevant expertise includes:</i> Cultural competency experts, oncology specialists, primary care practitioners, representatives of rural health organizations, patient advocates</p>
Breast Cancer	<p>Post-lumpectomy radiation; disparities in treatment options offered related to age; sentinel node biopsy; estrogen/progesterone receptor status; pathology results; surgical margins; chemo-prevention; management of ductal carcinoma in situ (DCIS); reconstructive surgery</p> <p><i>Relevant expertise includes:</i> Pathologists, surgical, medical and radiation oncologists, breast cancer advocates, quality of care researchers</p>
Colorectal Cancer	<p>Diagnosis; pathology/staging; adjuvant care offered vs. provided; function after surgery (e.g., permanent colostomy); follow-up care; symptom management</p> <p><i>Relevant expertise includes:</i> Surgical oncologists, primary care providers, pathologists, disparities researchers</p>

Recommended Focus Area	Examples of Specific Measurement Areas and Related Expertise
Communication and Coordination of Care	<p>Patient satisfaction; communication issues between physician and patient, physician and physician, and among health plans and facilities (e.g., health plan, hospital, laboratories); offered versus received care; time between diagnosis and treatment; efficiency and effectiveness of data systems; patient compliance; pathology/staging accuracy</p> <p><i>Relevant expertise includes:</i> Communication and education experts, providers, practitioners, consumer advocates, experts in cultural competence; oncologists and patient advocates.</p>
Prevention/Screening	<p>Smoking cessation, physician/patient communication; advice on diet, exercise for reducing certain risks; clinical preventive services, patient evaluation of screening; management of patients at high at risk (e.g., lung, ovarian); informed decision making.</p> <p><i>Relevant expertise includes:</i> Geneticists, experts on informed decision-making, pathologists, patient advocates</p>
Prostate Cancer	<p>Coordination of care (among primary care, urology and oncology specialists); communication of risks related to treatment options; quality of life; surgical, radiation and medical treatment outcomes</p> <p><i>Relevant expertise includes:</i> Surgical, radiation and medical oncologists, urologists, patient advocates</p>
Symptom Management and End-of-life Care	<p>Pain; fatigue, psychosocial aspects (e.g., depression, stress, body image issues); quality of life; activities of daily living; consideration of curative versus palliative treatment (e.g., overuse of chemotherapy in lung cancer patients); documentation of do not resuscitate (DNR) orders</p> <p>Note: The Committee also noted that even though symptom management and end-of-life care have been clustered together, the management of symptoms is not solely related to the end of life, but to all cancer patients from time of diagnosis.</p> <p><i>Relevant expertise includes:</i> Nurse specialists, psychologists, oncologists, social support services, patient advocate groups with expertise in using quality measurement for selection of care and service</p>

The Steering Committee also noted that for areas where there may be an overlap in issues—e.g., measures for communication of treatment risks, disparities—the workgroups should be given clear guidance on what to analyze so as to avoid

duplication of efforts. Where coordination of effort would be efficient, the Steering Committee would provide that guidance as well.

The Committee also agreed that if funding did not permit including the complete list of initial focus areas that they would reconvene to discuss which issues should receive initial attention. If funding is unable to support the seven focus areas, then the configuration of the areas may also change, for example, placing screening with specific tumor sites instead of keeping it as a separate focus area.

Public Comment

- Consult with nurses who provide direct patient care, and their professional organizations as well.
- Raise the profile of this project in the cancer community.
- Variation in breast cancer treatment should be addressed by this project, especially under-utilization.
- Long-term follow-up of breast cancer patients, and what should be done in these visits with regards to testing, also should be considered for measurement. Variation in medical practice related to breast cancer between the specialists and the primary physician is an issue for quality improvement. Specialists (e.g., surgeons) have a higher follow-up rate.
- *A National Framework for Healthcare Quality Measurement and Reporting* is a useful framework and should be made available for wider distribution, since it provides a good background on the mission and goals of the NQF.
- The continuum of care from primary care providers to specialists is a good aspect of this project. The breast cancer workgroup should include expertise from different sides of healthcare, such as those in measurement, breast centers, private clinics, and others settings to ensure that all aspects of coordination of care is addressed.
- Include attention to treatment planning and navigation of the system as important topics for the breast cancer workgroup. The Centers for Disease Control and Prevention has written about patient navigation issues. California has funded breast cancer treatment studies looking at coordination of care by nurses and social workers. Also include assessment of new technology and emerging implications for staging and treatment planning as potential measurement areas for this group.

Discussion 5: Methods for Identifying and Evaluating Measures

A primary task for each workgroup will be to identify existing measures in the particular focus area. The Steering Committee recommended that, where possible, the workgroups should give highest priority to identifying relevant measures in the public domain. However, the Committee recommended that a national call for measures would be important for identifying measures that may be available, but not in the public domain or simply not well known. Along with the public call for measures, the workgroups should consult with relevant organizations involved in quality measurement, including but not limited to:

- Agency for Healthcare Research and Quality National Quality Report (will contain cancer measures such as screening)
- American Academy of Family Practitioners
- American College of Radiology
- American College of Surgeons
- American Society for Clinical Oncology
- College of American Pathologists
- Foundation for Accountability (FACCT) (has measures on patient experience with breast cancer treatment)
- Joint Commission on Accreditation of Healthcare Organizations
- Kaiser Permanente, Group Health of Puget Sound, and other private organizations that may have developed measures. If, however, any of these measures are proprietary, there may be some restrictions on the analytical methods used that would raise problems of transparency and so limit the measures' usefulness and/or the willingness of NQF Members to endorse them as voluntary consensus standards.
- National Committee for Quality Assurance
- Nursing organizations that are focused on cross-cutting areas in cancer

In addition to directly contacting groups, a broad-based general call for measures might be worthwhile, because this may provide additional opportunity to contact researchers and measure developers.

Once identified, candidate measures must be evaluated by the workgroups for suitability for the measure set. The Steering Committee recommended that measures be evaluated for: 1) relevance; 2) scientific soundness; 3) usability; and 4) feasibility. Greg Pawlson, MD, MPH from the National Committee for Quality Assurance (NCQA) suggested a list of criteria for use in evaluating measures (attachment 9). Steering Committee members recommended reviewing the evaluation criteria more closely during the next phase of project.

Levels of Evidence

The Steering Committee reviewed materials concerning evaluating evidence based on NQF's Strategic Framework Board report and NQF's hospital measurement draft framework (attachment 10). The Steering Committee briefly discussed the types of evidence useful to consider during measure evaluation. During this discussion the Committee reached three conclusions:

- 1) The workgroups will need to determine what level of evidence is adequate when selecting measures. Face validity may need to be used in some cases since not all evidence will be of the highest level (e.g., randomized clinical trials);
- 2) There will need to be a consistent approach to the evaluations across the workgroups; and
- 3) Given the likely uneven quality and quantity of the evidence linking provider performance and outcome (i.e. the quality of the outcome may be more a result of the idiopathic nature of a disease rather than physician intervention), it may be difficult to draw statistically valid distinctions about the quality of care at the individual provider level.

It is anticipated that each workgroup will receive a report from an evidence-based research group on measures and the evidence supporting its use. Using that report and experience, the workgroups will assess the evidence for measures and make recommendations to the Steering Committee about measures that are ready for adoption and implementation, those that need more research before adoption, and areas where measures do not exist but are a priority for development. It is important that the workgroups be informed of the urgency to identify and implement this project in a timely manner. Without methods for screening measures, the length of time to sort through measures may be detrimental to the entire project.

Next Steps

NQF staff will produce a summary report of the meeting as per its contract with the Department of Health and Human Services. In addition, the meeting report will be submitted for public comment and NQF member review; these comments will be considered in the final work plan for the project.

THE NATIONAL QUALITY FORUM
Cancer Care Quality Measures Steering Committee

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Washington, DC

Rodger Winn, MD (Co-Chair)
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THE NATIONAL QUALITY FORUM

Meeting of the Cancer Care Quality Measures Steering Committee

September 4–5, 2002

West End Ballroom A-B-C
Washington Marriott
1221 22nd Street, NW
Washington, DC

AGENDA

September 4, 2002

- 9:00 a.m. Executive Session
- 9:30 a.m. Welcome and Introductions
Kenneth W. Kizer, MD, MPH, NQF President and CEO
Nancy-Ann DeParle, Esq., Co-Chair
Rodger Winn, MD, Co-Chair
- Overview of NQF Process
- Overview of Project Goals
- 10:15 a.m. Break
- 10:30 a.m. Purpose of Cancer Quality Measures Core Set
- Public accountability (e.g., patient selection of providers, etc.)
 - Quality improvement
- 11:30 a.m. Public Comment
- 12 noon Lunch
- 1:00 p.m. Criteria for Selecting Focus Areas For Measurement
- Consistency with national framework
 - Importance to patients and society
 - Potential for quality improvement
 - Other
- 2:30 p.m. Break
- 2:45 p.m. Identification of Tentative Potential Focus Areas for Measurement
- 4:30 p.m. Public Comment
- 5:00 p.m. Recess

FINAL SUMMARY

September 5, 2002

- 8:30 a.m. Review of Day One
- 9:00 a.m. Recommendations of Potential Focus Areas for Measurement
- 10:00 a.m. Issues in Identifying and Evaluating Potential Core Measures
- Prioritization of selected focus areas
 - Methods for identifying measures
 - Criteria for evaluating measures
 - Consideration of evidence
 - Role of technical advisory panels
 - Role of liaison/other panels
- 11:30 a.m. Public Comment
- 12 noon Lunch
- 1:00 p.m. Issues in Identifying and Evaluating Potential Core Measures (continued)
- 2:15 p.m. Next Steps
- 2:40 p.m. Executive Session
- 3:00 p.m. Adjourn

THE NATIONAL QUALITY FORUM

Cancer Care Quality Measures Steering Committee Meeting: List of Attendees

Name	Organization
Kelley E	Agency for Healthcare Research and Quality
Dubow J	American Association of Retired Persons
Billings T	American Cancer Society
Cameron B	American Cancer Society
Bjork S	American College of Radiology
Naierman N	American Hospice Foundation
Nelson M	American Hospice Foundation
Munley-Gallagher R	American Nurses Association
Ingram J	American Society for Clinical Oncology
Simonson K	American Society for Therapeutic Radiology & Oncology
Riese Daly N	American Society for Therapeutic Radiology and Oncology
Taylor J	American Society of Clinical Oncologists
Patyk J	Association of American Medical Colleges
Walsh C	Cancer Center of Virginia
Lee N	Centers for Disease Control & Prevention
Goldfarb J	Centers for Medicare and Medicaid Services
MacTaggart P	Centers for Medicare and Medicaid Services
Coleman C	Coleman Breast Center Consultation Services
Mitchell C	College of American Pathologists
Demakis J	Department of Veterans Affairs
Coleman P	Health Resources and Services Administration
Rollins R	Health Resources and Services Administration
Lothschuetz Montgomery	Health Strategies, LLC
Eden J	Institute of Medicine - National Academy of Sciences
Herdman R	Institute of Medicine - National Cancer Policy Board
Shockney L	Johns Hopkins Breast Cancer Ctr & the Nat'l Consortium of BC
Sprenger S	Joint Commission on Accreditation of Healthcare Org.
Schrag D	Memorial Sloan-Kettering Cancer Center
Collina S	National Breast Cancer Coalition
Hain C	National Breast Cancer Coalition
Clauser S	National Institutes of Health -National Cancer Institute
Donaldson M	National Institutes of Health -National Cancer Institute
Lipscomb J	National Institutes of Health -National Cancer Institute
Miller N	National Institutes on Health
DeSpain-Magoffin C	National Pharmaceutical Council
Renner P	Nat'l Committee for Quality Assurance
Potsky A	NCI
Graham J	New York Presbyterian Hospitals
Gabig T	North Shore-Long Island Jewish Health System
Pfleeger J	Office of Personnel Management
Stack P	Robert Wood Johnson Univ. Hospital
Reed T	The Medstat Group, Inc.

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Cancer Care Quality Measures Steering Committee Pre-Meeting Survey Tool

Please rank this listed purposes for both Public Accountability and Improvement:

I. Public Accountability Purposes	Rank 1-7: 1 is most important
Consumer selection (e.g., of plans)	
Patient selection (e.g., of institutions, clinicians, treatments)	
Purchaser selection (public and private)	
Regulator oversight	
Health plan selection to include provider in network	
Referring clinician selection	
Tracking national progress toward cancer quality goals	
Other _____	

II. Improvement Purposes	Rank 1-3 (1 is highest)
Institutional quality improvement	
Individual provider quality improvement	
Stimulate rapid translation of research into practice	
Other _____	

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Cancer Care Quality Measures Steering Committee Meeting: Initial Draft Purpose Statement for Steering Committee Discussion

The essential purpose of the core set of cancer care quality measures is to provide information to help patients with cancer select cancer care providers at the time of need. These measures must also be useful in helping health plans and cancer care providers improve their performance. In addition, the measure set should permit assessment of progress towards national cancer quality goals, provide information for selection of cancer care providers by purchasers and referring healthcare professionals, and be useful to others seeking to assess and improve the quality of cancer care.

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Cancer Care Quality Measures Meeting: Proposed Criteria for Discussion

McGlynn and Malin proposed criteria:

The paper proposes that focus areas for measurement should be selected based on their relative importance in addressing each of the following criteria:

- Consistent with other national quality measurement and improvement efforts
- Significant impact on health and functioning
- Significant impact on individual or societal costs
- Represent an important dimension of the patient care experience
- Areas where improvement is possible (e.g., strategies known to be effective in improving care exist but are not widely implemented).

Other potential criteria:

Additional or alternative criteria that have been suggested from Committee members and other sources include:

- Areas of known disparities in care across population, or serious demonstrated overall quality problems
- Areas of high importance to patients, families, consumers and the general public
- Significant patient safety issue
- High profile areas – media and/or legal attention.

In addition to the criteria above, the Steering Committee may also wish to consider the following issues in its discussion on criteria and focus areas.

Applicability of measures across the population:

Does the focus area have the potential to “touch” everyone? That is, if this focus area were populated with measures of the quality of care in that area, is there the potential for every cancer patient to find at least some measures in that focus area that are relevant to himself or herself? Alternatively are there at least some focus areas relevant to all patients regardless of demographic group:

- Age (child, adolescent, adult, senior)
- Gender
- Race/ethnicity
- Primary language (limited English proficiency)
- Geographic location (rural, vs. urban, resources available)

Level of analysis: Many levels of the healthcare system are involved in the management of a person with a diagnosis of cancer or is at risk for the disease. In selecting and applying criteria, the Steering Committee may want to consider the different levels of the health delivery system, and whether there is potential for measures in this focus area to address each relevant level. Addressing the appropriate level of analysis for measurement and accountability assures that the right group will have the capability of improving that area of quality. Examples include:

- Hospital (inpatient/outpatient services)
- Health plan
- Independent lab or radiology facility
- Individual healthcare professional practice
- Cancer center
- Infusion center
- Home health agency
- Pharmacy
- Social support services

Cohesive group of topics: Does the group of topics represented collectively by the focus areas make sense? Will a public report of measures of these focus areas have the potential to tell an understandable story about the quality of cancer care that is:

- Useful to patients, referring clinicians, and purchasers;
- Fair to healthcare providers; useful for stimulating and focusing quality improvement activities by providers; and
- Sufficiently complete within its scope to be useful to policymakers?

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Cancer Care Quality Measures Steering Committee Meeting: Examples of Data for Selection Criteria

Comparison of criteria, “significant impact on health and functioning” and “significant impact on individual or societal costs”

Comparison of Long-term Costs of Cancer Care (Kaiser Permanente-Northern California)

SITE	COSTS FROM DIAGNOSIS TO DEATH OR 15 YEARS
Ovarian	\$64,000
Rectum	\$51,000
Non-Hodgkin's Lymphoma	\$48,000
Colon	\$42,000
Breast	\$35,000
Lung	\$33,000
Prostate	\$29,000

Source: Fireman BH, Quesenberry CP, Somkin CP et al. Cost of care for cancer in a health maintenance organization. *HealthCare Finance Rev 1997;18(4):51-76.*

Disability Adjusted Life Years Estimates for Selected Cancer Sites, CDC Estimates 1996

SITE	DISABILITY ADJUSTED LIFE YEARS
Lung	16
Breast	6
Colorectal	6
Prostate	3
Non-Hodgkin's Lymphoma	3
Leukemia	3
Pancreas	3
Brain	2
Skin	2
Ovarian	2

Source: Brown, Lipscomb, Snyder 2001.

**THE NATIONAL QUALITY FORUM
Cancer Care Quality Measures Steering Committee Focus Area Rating Tool**

CRITERIA

1. Consistent with broad-based national goals
2. Important
 - impact on outcomes (survival, QoL, pt. preferences, costs)
 - burden of disease including costs
3. Represents a dimension of patient-centered care experience
4. Improvement is possible (variability, malleability)
5. Disparities/serious quality problems exist

	CRITERIA				
	1	2	3	4	5
Colorectal					
Breast					
Prostate					
Lung					
Lymphoma/Hodgkin's					
GYN Cancers					
End of Life					
Symptom Management					
Communication (including IS & IT)					
Coordination of Care/Cultural Competence					
Access to Care (including clinical trials)					
Pathology/Staging					
Screening/Surveillance					

**Example Criteria for Review of
Measures for Discussion (Submitted by G. Pawlson)**

- 1) Measure is available in public domain
- 2) Measures developed using standard criteria that include consideration and documentation of:
 - Importance
 - Scientific Evidence
 - Feasibility
- 3) Measures were developed by a process that includes formal review by groups outside of the group developing the measure
- 4) Measures have been field tested and result of field test are available
- 5) Measures have been used and the data are available on the “performance” of the measure’s widespread quality evaluation and/or improvement activities.

In order of strength the following rankings for measures are recommended:

- Level I - All the criteria above have been met
- Level II- Criteria 1 through 4 have been met
- Level III - Criteria 1 through 3 have been met
- Level IV – At least one criteria has been met

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Cancer Care Quality Measures Steering Committee Meeting Background Document: Considering Evidence

A core measure set for cancer care must be evidence-based. Evidence for relationships of performance measurement to quality is not limited to the scientific and clinical research areas. Qualitative health services research, real-world quality improvement activities, formal professional consensus, face validity, expert opinion, case reports, and theory are all types of evidence that should be considered. Outside of clinical research, however, standardized rating systems for judging the levels of evidence have not been well established.

The Steering Committee may wish to suggest directions or approaches for how evidence should be considered by technical panels as they evaluate candidate measures in their respective focus areas. The following information summarizes some different categories of evidence that are likely to be relevant to measure evaluation. This approach to considering evidence is based on the work of the NQF's Strategic Framework Board (SFB), as described in Draft Report of the NQF Strategic Framework Board, April 2001.¹

I. Empirical Clinical Research

This is the most common and well-known type of evidence that has an existing rating system.

Treatment

The PDQ Editorial Board for NCI's cancer information regarding cancer treatment studies uses the following system based on 1) strength of the study design and 2) strength of the end-points.

Study Design (descending order of strength)

1. Randomized controlled clinical trial(s) (RCTs)
 - a) Double-blinded
 - b) Non-blinded
2. Nonrandomized controlled trial(s)
3. Case series
 - i) Population-based, consecutive series
 - ii) Consecutive cases (not population-based)
 - iii) Nonconsecutive cases

End Points (descending order of strength)

1. Total mortality (or overall survival from a defined point in time)

¹ Although the specific recommendations were approved by the NQF as a consensus product, the approach to considering evidence was not part of the final consensus product to preserve the SFB's interest in publishing the complete work in the peer-reviewed literature. Notwithstanding this, the approach to evidence was discussed with the NQF Board at several Board meetings, and the Board indicated its general approval.

2. Cause-specific mortality
3. Carefully assessed quality of life
4. Indirect surrogates
 - a) Disease-free survival
 - b) Progression free survival
 - c) Tumor response rate

Screening

For screening, the evidence is evaluated somewhat differently because “it is not always practical to conduct such a trial to address every question surrounding the field of screening.” The five levels in order of strength of evidence are:

1. Evidence obtained from at least one well-designed and conducted RCT
2. Evidence obtained from well-designed and conducted nonrandomized controlled trials
3. Evidence obtained from well-designed and conducted cohort or case-control studies
4. Evidence obtained from multiple-time series with or without intervention
5. Opinions of respected authorities based on clinical experience, descriptive studies or reports of expert committees.

II. Empirical organizational, social science or health services research

To date, rating systems for studies in the health services, social science, and organizational literature have not been developed. Quality measurement and reporting, however, involves disciplines outside of clinical management. Research on organizational behavior, studies on the reasons for failing to implement best practices in medicine, exploration of the most effective mechanisms for encouraging changes in behavior, and studies of cognitive processes that inform us how people make decisions are important evidence in quality measurement and reporting.

III. Findings from learning laboratories

“Learning laboratories” are real-world activities (as opposed to formal research) that engage in processes within the context of continuous feedback and collect information about what does and does not work. Many of these activities are not published in the peer-reviewed or other literature, but are simply a result of day-to-day provision of healthcare services.

IV. Formal professional consensus

Collective professional opinion can be evaluated by various criteria that may include selection of an expert panel, level of agreement within the panel, use of voting techniques vs. consensus, number of panelists, number of panels reaching same or similar conclusions.

V. Theory

There are a variety of theories related to human behavior, organizational behavior, transmission of innovations and cognitive functioning that provide a context for assessing the likelihood that a proposed approach to a problem will work. This type of evidence may be graded as follows:

1. Theory for which empirical evidence in support of the theory exists
2. Theory for which empirical evidence finds mixed or no support
3. Theory that has not been empirically tested.

