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Delivering High-Quality Cancer Care: The Critical Role of Quality Measurement

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Abstract

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In 1999, the Institute of Medicine (IOM) published *Ensuring Quality Cancer Care*, an influential report that described an ideal cancer care system and issued ten recommendations to address pervasive gaps in the understanding and delivery of quality cancer care. Despite generating much fervor, the report's recommendations—including two recommendations related to quality measurement—remain largely unfulfilled.

Amidst continuing concerns regarding increasing costs and questionable quality of care, the IOM charged a new committee with revisiting the 1999 report and with reassessing national cancer care, with a focus on the aging US population. The committee identified high-quality patient-clinician relationships and interactions as central drivers of quality and attributed existing quality gaps, in part, to the nation's inability to measure and improve cancer care delivery in a systematic way. In 2013, the committee published its findings in *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, which included two recommendations that emphasize coordinated, patient-centered quality measurement and information technology enhancements:

- Develop a national quality reporting program for cancer care as part of a learning health care system; and,
- Develop an ethically sound learning health care information technology system for cancer that enables real-time analysis of data from cancer patients in a variety of care settings.

These recommendations underscore the need for independent national oversight, public-private collaboration, and substantial funding to create robust, patient-centered quality measurement and learning enterprises to improve the quality, accessibility, and affordability of cancer care in America.

Background of the Report

Cancer patients deserve the best care possible, yet many obstacles render timely, efficient, safe, and affordable cancer care an elusive goal, even in the 21st century. Since the 1990s, the Institute of Medicine (IOM) has directed attention to these quality issues. Most recently, the IOM assembled the *Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population* (“Committee”) in 2012 to revisit prior analyses and recommendations for the nation's cancer care delivery system, examining what had changed, what challenges remained, whether new problems had arisen, and how health care reform might affect quality of care—with a specific focus on the aging US population. Examining the current delivery system from the six IOM aims for improvement (safety, timeliness, efficiency, effectiveness, patient-centeredness and equity),² the Committee identified many quality gaps and published its findings in *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*.¹ This report takes a fresh look at today's obstacles to high-quality cancer care and recommends solutions for major stakeholders. Patient-clinician relationships and interactions—universal elements of the health care system—are a central focus of its recommendations and conceptual framework, since high-quality interactions are critical to delivering high-quality cancer care.

This report builds upon a 1999 IOM report, *Ensuring Quality Cancer Care*, which outlined ten recommendations to improve the quality of cancer care, including two recommendations to develop, collect, and disseminate a core set of cancer quality measures.³ Unfortunately, many objectives outlined in *Ensuring Quality Cancer Care* remain unfulfilled, and the status of quality measures and data systems remains remarkably unchanged. Then, and now, the IOM associated many quality gaps with an inability to measure performance and improve it in a systematic fashion. Thus, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* highlights the key role that quality measurement plays in improving the quality of cancer care. This review describes deficiencies in the nation's quality measurement system and a path forward to improve the quality of cancer care in America.

The Conceptual Framework

The report outlines six components of a high-quality cancer care delivery system: 1) engaged patients; 2) an adequately-staffed, trained, and coordinated workforce; 3) evidence-based cancer care; 4) a learning health care information technology (IT) system; 5) translation of evidence into clinical practice, quality measurement, and performance improvement; and, 6) accessible, affordable cancer care.¹

Quality measures are integral to this conceptual framework, providing an objective means for patients and their families to identify high-quality cancer care, for providers to standardize care practices, and for payers to incentivize higher quality care through alternative reimbursement mechanisms. Additionally, quality measures allow providers and payers to determine whether performance improvement initiatives and new payment models improve the quality, accessibility, and affordability of cancer care. The act of measuring performance can motivate clinicians to improve care delivery, either out of the desire for self-improvement or to provide comparable or better care than their colleagues.⁴ Thus, to build and sustain a high-quality cancer care delivery system, its members must be able to measure and assess progress in improving cancer care delivery, to report that information publicly, and to develop innovative strategies for further performance improvement. In the Committee's conceptual framework for this system (Figure 1), quality measurement is part of a cyclical process. The system measures the outcomes of patient-clinician interactions (including health care outcomes and costs), which inform development of performance improvement initiatives and implementation of new payment models. These, in turn, lead to improvements in the quality, accessibility, and affordability of cancer care.

Quality Measurement Challenges

The Committee's conceptual framework provides a solid basis to improve the quality of cancer care. Foundational measures evaluate the quality of care across the treatment cycle—prevention and early detection; diagnosis and treatment; and, survivorship or end of life—and along important dimensions of care, including access to care and quality of life.^{5,6} Disease-specific measures assess adherence to screening and treatment guidelines and complement broader, cross-cutting cancer measures. Several specialty-focused quality measurement registries facilitate standardized reporting of these types of measures, as summarized in Table 1. Despite these efforts, continued deficiencies in cancer-focused

quality measures, including measurement gaps and overlapping, duplicative, or competing measures, undermine efforts to measure and improve performance systematically. Figure 2 summarizes key measurement gaps, and factors contributing to these deficiencies are described below.

Inadequate Consideration of Patient Perspectives

Historically, public reporting has focused on clinical quality measures from institutional administrative data (e.g., readmissions), which lack meaning for patients and are misinterpreted frequently,⁷ contributing to erroneous conclusions about health care quality. Patients use these data minimally when choosing providers,^{8–10} despite their strong interest in health care quality information.¹¹ This non-consumer-oriented approach ignores patient information needs and preferences, despite well-intentioned efforts to increase transparency in health care.

Additionally, most cancer quality measures evaluate provider adherence to evidence-based guidelines, giving minimal consideration to patient preferences regarding care, and, in particular, to the patient-reported outcomes associated with particular treatment plans. Clinical and psychosocial factors influence patient treatment preferences and should inform providers' treatment recommendations. In certain cases, a personalized approach may yield better outcomes than strict guideline adherence.^{12,13} Thus, quality measures should allow providers to respect individual patient preferences, needs, and values in delivering cancer care without penalty.

Measure Fragmentation

Cancer patients move between multiple oncology and non-oncology care settings throughout their care. Accordingly, health care outcomes, costs, and patient experience are influenced by multiple providers and should be measured using an integrated approach that traverses care settings. Instead, most cancer quality measures mirror existing fragmentation in health care delivery and focus on the clinician, medical subspecialty, or care setting, rather than the patient. Several problems contribute to this fragmented state: independent measure development and reporting efforts; lack of national oversight; failure to develop appropriate collective attribution methodologies for health care outcomes and costs; and, reporting programs that operate without clear goals and a strong measurement framework.

Thus, overlapping quality measures with slight, but meaningful, differences co-exist with pervasive gaps in cancer measures. This dichotomy weakens efforts toward shared accountability, care coordination, and patient-centered care. Organizations, such as the National Quality Forum (NQF), encourage measure developers to harmonize similar measures to reduce measure fragmentation. However, their efforts have yielded minimal success due to the non-binding nature of their recommendations.

Challenging Measure Criteria

Measure developers face significant challenges in translating measure concepts into validated quality measures. Measures that support broader comparisons across diseases or practice settings often fail the rigorous technical standards established by organizations,

including the NQF. Thus, many validated measures are highly specific—incorporating complex inclusion/exclusion criteria and applying to small patient populations. Some measures are so specific that they produce small sample sizes that cannot be validated through traditional statistical testing methods. Thus far, measure developers and endorsing organizations have failed to strike a balance between satisfying the technical criteria that are important for validating measures, the need to fill critical measurement gaps, and the need to measure health care in a broader, more coordinated fashion.

Scientific Evidence Gaps

Since clinical research provides the foundation for measure development, many cancer measurement gaps derive from associated clinical research gaps. For example, elderly cancer patients are underrepresented in quality measurement for cancer care due primarily to their underrepresentation in clinical trials.^{14–17} Hence, existing quality measures may not apply directly to older adults, even though most new cancer diagnoses occur in this population.¹⁸ This omission is reflected in treatment- and screening-related disparities among the elderly.^{19–25} Additionally, because most clinical research evaluates the technical aspects of anti-cancer therapies, there are significant gaps in necessary research for oncology-focused measures of care coordination, quality of life, patient/family engagement, and costs of care. Inadequate national funding and direction for this research are contributing factors.

Inadequate Data Systems

In contrast to major technical advances in health care technology, minimal progress has occurred in producing timely and actionable performance data to support quality measurement and performance improvement. Many measures utilize administrative claims data. However, these data were not intended for this purpose, and, therefore, have limited ability to provide meaningful insights into care. Health care legislation and regulations have triggered increased use of electronic health records (EHR), but these systems require further enhancements and are limited by the completeness and accuracy of the data that are captured routinely by providers. Unsuccessful efforts to implement EHR-based quality measurement through the Meaningful Use program have frustrated some providers, suggesting the need for additional strategic and technical enhancements for the program.²⁶ Presently, manual chart abstraction is the most reliable data collection method for quality measurement, but its significant resource requirements and time delay make it a poor choice to support long-term quality measurement efforts.

A Path Forward – Two Major Policy Recommendations

The Committee proposed major changes—both in the IT systems used to collect patient information and in the kind of measures that are collected and reported—for quality measurement to yield significant improvements in the quality of cancer care for Americans. Two of the ten recommendations in the report target the quality measurement issues described previously. The first recommendation addresses IT issues, and the second recommendation addresses quality measures. These recommendations are discussed below.

A Learning Health Care IT System in Cancer Care

Recommendation 7: A Learning Health Care IT System in Cancer Care

Goal: Develop an ethically sound learning health care information technology system for cancer that enables real-time analysis of data from cancer patients in a variety of care settings. To accomplish this:

- Professional organizations should design and implement the digital infrastructure and analytics necessary to enable continuous learning in cancer care.
- The Department of Health and Human Services should support the development and integration of a learning health care IT system for cancer.
- The Centers for Medicare & Medicaid Services and other payers should create incentives for clinicians to participate in this learning health care system for cancer, as it develops.¹

Implementing a learning health care IT system would enhance existing cancer quality measurement and reporting efforts. This system would streamline provider collection of essential data for performance improvement and public reporting on a real-time basis by:

- Integrating provider-collected data with patient-reported outcomes gathered from online surveys and tablet-based applications;
- Using facile data repositories for collecting, storing, analyzing, and reporting large datasets; and,
- Aggregating and reporting designated measures to various agencies and registries for purposes of public reporting and for more generalized performance improvement.

Existing reporting programs may be leveraged in this effort, but not without challenges. For example, as Table 1 describes, the American Society of Clinical Oncology (ASCO) is migrating its Quality Oncology Practice Initiative (QOPI) to an automated data abstraction system (eQOPI) as part of its CancerLinQ rapid health learning system. Recent experience suggests that several QOPI measures are not readily computable and that nontrivial interpretation differences occur during manual chart review, raising concerns regarding measure validation in an electronic environment.²⁷ These technical hurdles, coupled with the voluntary and independent nature of existing quality reporting programs, highlight the need for continued IT enhancements to advance the implementation of this recommendation.

Quality Measurement

Recommendation 8: Quality Measurement

Goal: Develop a national quality reporting program for cancer care as part of a learning health care system.

To accomplish this, the Department of Health and Human Services should work with professional societies to:

- Create and implement a formal long-term strategy for publicly reporting quality measures for cancer care that leverages existing efforts.
- Prioritize, fund, and direct the development of meaningful quality measures for cancer care with a focus on outcome measures and with performance targets for use in publicly reporting the performance of institutions, practices, and individual clinicians.
- Implement a coordinated, transparent reporting infrastructure that meets the needs of all stakeholders, including patients, and is integrated into a learning health care system.¹

The complexity and costs of cancer care, along with its prevalence, necessitate a unified strategy and a well-developed framework for measuring and improving the quality of cancer care. This is reflected in the Committee's recommendation to develop a national quality reporting program for cancer care as part of a learning health care system. A broad stakeholder group, including professional societies and patient advocates, must be engaged in this effort. Their familiarity with complex cancer care delivery systems provides an essential perspective for creating and implementing a formal long-term strategy for public reporting. Additionally, measure development should focus on measures that are meaningful to patients and their families—measures that focus on important outcomes (e.g., survival and treatment toxicities) and costs—and on reporting these measures in an understandable way for patients and other stakeholders. This outcomes-focused reporting program may influence the choice and type of therapy while simultaneously informing quality improvement efforts in various care settings, thereby improving the quality of care throughout the health care system.

The IOM recommends implementation of a coordinated, transparent reporting infrastructure that meets the needs of all stakeholders and that is integrated with a learning health care system. This reporting program could accelerate progress toward a high-quality cancer care delivery system by making the outcomes, processes, and costs of cancer care more transparent to promote patient engagement and delivery of evidence-based care and to discourage wasteful and potentially harmful treatments.

Implementing the Recommendations—The current landscape contains the necessary foundational knowledge, support, and technology to construct the learning health care system and national reporting program described in the report. These factors comprise a solid platform on which to develop a national reporting program. However, additional transformation and leadership—in the form of funding, coordination, and oversight—are necessary to implement the Committee's recommendations. Additionally, providers and other stakeholders will have to adjust to a more patient-centered cancer care delivery model, where high-quality patient-clinician relationships and interactions are central drivers of quality and quality is measured and improved in a systematic way. Within this model, responsibility for the outcomes and costs of care is shared across providers, traditionally

proprietary health care cost data are more transparent, and patients, as integral members of health care teams, share responsibility for their outcomes of care. Specific recommendations for leadership, key tasks, and reducing disparities are described below.

Leadership

The Committee identified the Department of Health and Human Services (HHS) as the logical convener to lead implementation. The success of the Office of the National Coordinator for Health Information Technology (ONC) in accelerating nationwide adoption of health IT through the Meaningful Use program has direct relevance for creating a learning health care system for cancer. HHS could leverage the ONC model to create an Office of the National Coordinator for Health Care Quality to design and implement a robust national reporting program for cancer care, including initiating and funding projects to develop patient-centered measures to fill critical measurement gaps. With proper funding and authority and with multi-stakeholder collaboration, the national quality coordinator could reinvigorate cancer quality measurement and reorient existing activities in a more coordinated, patient-centered direction. Numerous payers, professional organizations, providers, patient advocacy groups, and public agencies share a vested interest in improving the quality and transparency of cancer care and should be involved. Designating the Centers for Medicare & Medicaid Services (CMS) and the NQF as key partners would further enhance implementation of the IOM's recommendations, as described below:

- **CMS:** As the principal payer for most newly diagnosed cancer patients and cancer survivors, CMS has a substantial interest in the quality of cancer care in America. CMS has the regulatory and legislative authority to enforce a mandatory quality measurement program, but its timelines are too brief and its focus on the Medicare population is too narrow to implement an effective and influential national reporting program for cancer care. CMS could support implementation of the IOM's recommendations by leading payers in linking reimbursement to outcomes and by offering financial incentives to providers that participate in a learning health care system and in a national quality reporting program for cancer care. CMS could adopt a simplified version of the pay-for-reporting incentive/penalty model of the Physician Quality Reporting System (PQRS) for this purpose. The Center for Medicare & Medicaid Innovation (CMMI) should fund demonstration projects to test appropriate pay-for-performance models for this program.
- **NQF:** The NQF holds the federal contract to endorse health care quality measures for use in public reporting²⁸ and has expended significant effort to expand cancer quality measurement.^{29–33} However, it lacks the authority to enforce its recommendations and the resources to fund measure development. The NQF is exploring opportunities to expedite filling key measurement gaps, such as through a virtual “measure incubator” that connects measure developers with potential funders, EHR vendors, and other key stakeholders.³⁴ A mechanism like this could accelerate the timeline and reduce the cost of developing patient-centered oncology measures. Similarly, ongoing efforts to streamline the NQF's measure endorsement process could hasten implementation of these measures.³⁵

Key Tasks

Specific tasks for implementing the IOM's recommendations are described below:

- **Strategy Development:** Create and enforce a formal long-term strategy (with shorter-term milestones) for developing and publicly reporting cancer measures, aligned with the aims and priorities of the National Quality Strategy³⁶ and informed by the work of organizations, such as the IOM, the RAND Corporation, the NQF, and the NQF-convened Measure Applications Partnership.
- **Research Funding:** Fund health services research and clinical trials focused on the non-technical dimensions of cancer care, including: access and care coordination; patient and family engagement; managing complex comorbidities; quality-of-life issues during and after treatment; reintegration into society (i.e., return to work and managing personal obligations); and, the costs of care. Older cancer patients should be well-represented in this research.
- **IT Enhancements:** Enhance EHRs to address known workflow, usability, interoperability, and data management issues.²⁶ Modify data structures to capture and report patient-reported data, to integrate structured, unstructured, and semi-structured data, to support robust data analytics and real-time decision making support, and to support data sharing, public reporting, and care coordination.³⁷ The ONC should integrate the principles of a learning health care system for cancer in the criteria for future Meaningful Use stages to ensure that the IOM's recommendation is implemented. Table 2 compares the IOM's ten recommendations to accelerate progress toward a learning health care system with Meaningful Use Stage 2 objectives.
- **Measure Development:** Fund and direct the development of cancer-focused measures that are meaningful for all stakeholders, focusing on: gaps in outcome measures, in cross-cutting, non-technical measures, and in measures for rarer cancers; measures that promote shared accountability (across providers *and* including patients) and that reduce disparities in coverage and access to care; and, measures with a well-defined cost-benefit relationship. Engage multidisciplinary provider teams with clinical and quality expertise and patient representatives in all stages of measure development. Develop a formal tool to assist with prioritizing measure development,³⁸ with highest priority given to patient-centered outcome measures.
- **Public Reporting:** Implement a reporting infrastructure (including IT and reporting methodologies) that meets the information needs of all stakeholders (patients and caregivers, providers, payers, and state and federal agencies), that emphasizes transparency, and that presents data in a way that guides patients and caregivers in health care decision-making.

Reducing Disparities

Accessible, affordable cancer care is a key component of high-quality cancer care delivery in the Committee's conceptual framework. A central goal of the framework is that quality of

care should not depend on the care setting (e.g., academic cancer centers vs. community cancer centers).¹ Several ongoing activities are designed to reduce disparities in patients' access to cancer care. The Affordable Care Act of 2010 (ACA) is expected to provide 25 million people with insurance coverage by 2023.³⁹ It also includes several provisions designed to improve care for vulnerable and underserved populations, through improved primary care, preventive services, and patient navigators. Additionally, several promising public and private efforts are underway to address disparities in cancer care, such as patient navigation programs sponsored by the National Cancer Institute (NCI) and C-Change. A national quality reporting program for cancer care should measure the effectiveness of these efforts in improving access and reducing disparities at provider-, community-, state-, and federal levels.

Significant financial resources are needed to ensure that institutions that care for vulnerable and underserved populations have the infrastructure and staffing to participate in a national quality reporting program and a learning health care system for cancer. A recent IOM report estimated that more than \$750 billion of health care costs are wasteful,⁴⁰ including inefficient care delivery, overuse of care, and excessive administrative costs. By eliminating waste, the cancer care delivery system could redirect the savings to attenuate disparities in access and care delivery. Additional grant funding is necessary to ensure that providers that care for vulnerable and underserved populations can take full advantage of EHRs and other health IT. Over time, cost savings associated with a healthier American population should offset a portion of the public's investment in this technology.

Conclusion

For more than a decade, the IOM has directed public attention to significant quality gaps in national cancer care delivery. Throughout, the IOM advocated creating a national quality reporting program for cancer care and the necessary technical infrastructure to support this program as an effective means of assessing and improving cancer care delivery. Several organizations have attempted to fill these voids, but their efforts lacked the breadth, magnitude, coordination, and sustainability to transform cancer care across the nation. Thus, despite public and private efforts to develop cancer quality measures and the IT systems to capture and report these measures, this national reporting program does not exist today.

In *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, the IOM took a fresh look at cancer care in America and, again, identified unified, patient-centered cancer quality measurement as a necessary element of a well-functioning cancer care delivery system. The report includes two recommendations targeting the nation's inability to measure and improve cancer care delivery in a systematic way:

- Develop a national quality reporting program for cancer care as part of a learning health care system; and,
- Develop an ethically sound learning health care information technology system for cancer that enables real-time analysis of data from cancer patients in a variety of care settings.

National oversight, public-private collaboration, and a patient-centered approach are fundamental to creating the robust learning system and national cancer quality measurement program described in the report. By providing specific performance goals and measurements of care, by incorporating the perspectives of all stakeholder groups, by unifying existing, independent measure development activities, and by reporting this information in a way that supports patient decision-making, this patient-oriented reporting program for cancer care would transform the way that patients, providers, payers, and regulators evaluate cancer care and health care, in general. With proper national oversight, funding, and coordination, it will accelerate improvements in cancer care where other programs have failed.

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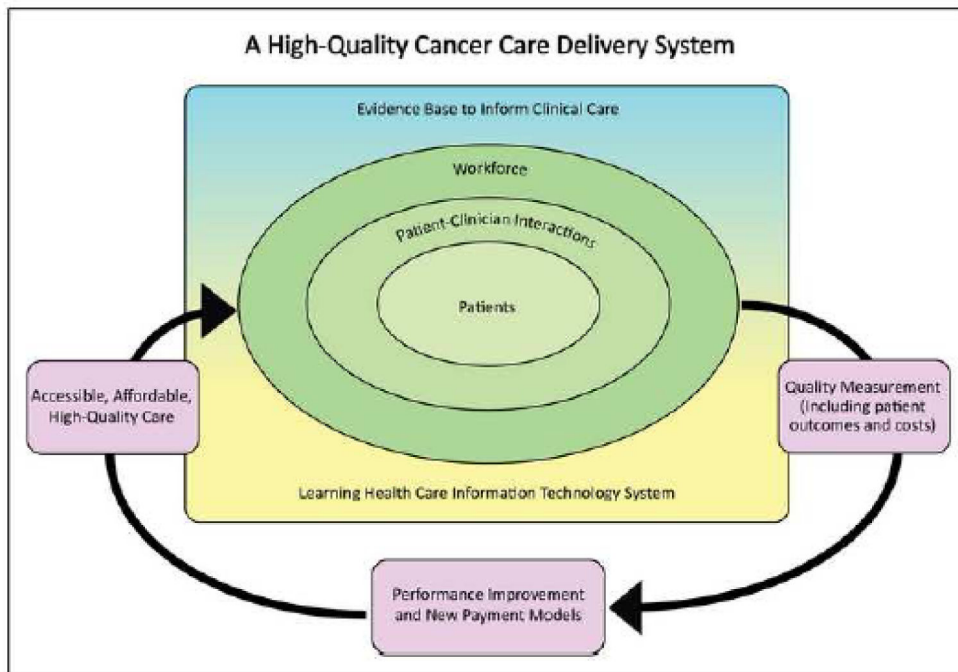


Figure 1. A High-Quality Cancer Care Delivery System

Figure 1 represents the committee's conceptual framework for improving the quality of cancer care. Quality is achieved through the cyclical process of measurement, improvement, and integration into the system. The system should be accessible and affordable to all patients with a cancer diagnosis. Reprinted with permission from *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, 2013 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, D.C.

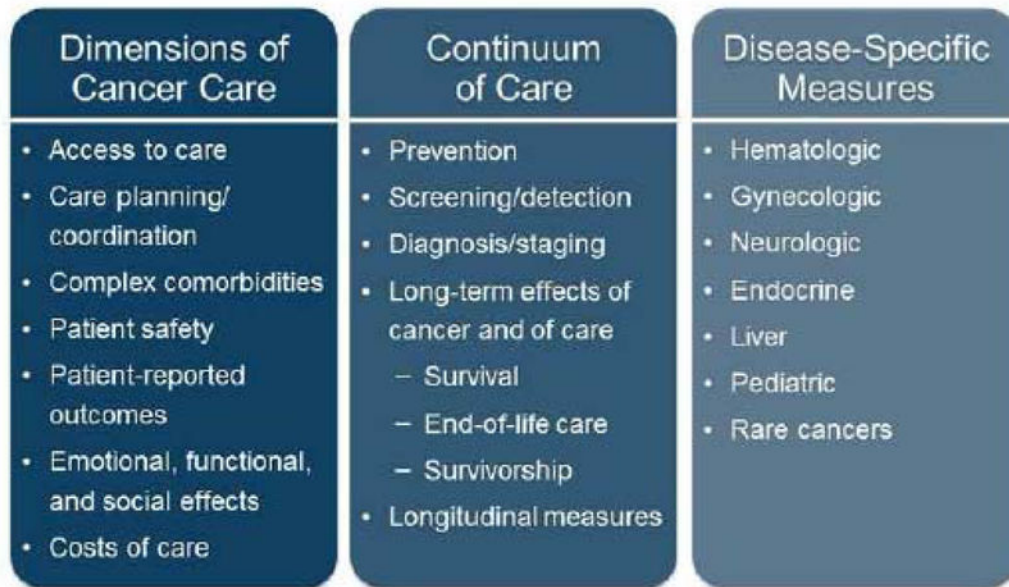


Figure 2. Key Gaps in Cancer-Specific Quality Measures

Figure 2 lists significant gaps in existing cancer-specific quality measures, including gaps in measures that assess important dimensions of cancer care, gaps throughout the continuum of cancer care, and gaps in disease-specific measures.

Table 1
Specialty-Focused Quality Measurement Registries

Table 1 provides an overview of three specialty-focused quality measurement registries for cancer care.

<p>American Society of Clinical Oncology Quality Oncology Practice Initiative Program</p> <ul style="list-style-type: none"> • Background: Administered by the American Society of Clinical Oncology (ASCO) as a voluntary practice-based quality program since 2006, the Quality Oncology Practice Initiative (QOPI) provides tools and resources for quality measurement, benchmarking, and performance improvement in the outpatient setting.^{41,42} QOPI is based on retrospective, manual chart review and evaluation with specific practice-level feedback.⁴³ • Benefits: Participation is associated with measurable improvement—with the greatest improvement observed among practices with low baseline performance and in measures associated with new clinical guidelines.^{41,43} Though voluntary, its membership increased when the QOPI certification program was introduced and when the program was adopted by third-party payers.⁴⁴ • Limitations: QOPI measures are process-based and do not evaluate the outcomes of care. Data abstraction and submission are time-consuming, and program costs are absorbed by participating practices (except for an innovative program in Michigan⁴⁵). QOPI's voluntary nature limits widespread participation. • Recent Developments: ASCO is developing eQOPI to automate QOPI data abstraction, as part of its CancerLinQ rapid health learning system. With CancerLinQ, ASCO seeks to: 1) capture, aggregate, and use complete longitudinal patient records from any source; 2) provide real-time, guideline-based clinical decision support; 3) measure clinical performance of eQOPI performance measures; and, 4) explore hypotheses from clinical data sets. Following a successful 2012 prototype, ASCO is implementing CancerLinQ system wide.^{46,47}
<p>American College of Surgeons National Surgical Quality Improvement Program</p> <ul style="list-style-type: none"> • Background: The National Surgical Quality Improvement Program (NSQIP) is a voluntary outcomes-focused program that started in the Veterans Administration (VA) system.⁴⁸ Since 2005, NSQIP has been available to non-VA hospitals through the American College of Surgeons (ACoS). Independent, trained reviewers prospectively collect NSQIP data via manual chart review and real-time patient follow-up. Participants receive semi-annual reports with risk-adjusted surgical outcomes; non-adjusted data are available via a web-based portal. • Benefits: Through standardized collection of pre-operative risk factors and 30-day post-operative outcomes, NSQIP supports robust, data-driven quality improvement and benchmarking. Extensive peer-reviewed, published literature demonstrates that participation is associated with fewer deaths and complications and with lower costs.⁴⁸⁻⁵¹ • Limitations: Currently, NSQIP does not collect cancer-specific risk factors, such as cancer stage, or longer-term outcomes (beyond 30 days after surgery). There is a significant time delay between data collection and receipt of reports containing risk-adjusted outcomes. Data abstraction and submission are time-consuming, and program costs are absorbed by participating practices. NSQIP's voluntary nature limits widespread penetration. • Recent Developments: NSQIP is piloting an oncology-focused module for use in solid tumor patients. Researchers are utilizing NSQIP to study risk factors associated with morbidity and mortality for certain cancer treatments. This research may guide treatment planning and patient counseling in the future.⁵²⁻⁵⁶
<p>National Radiation Oncology Registry</p> <ul style="list-style-type: none"> • Background: In 2012, the Radiation Oncology Institute (ROI) and the American Society for Radiation Oncology (ASTRO) began collaborating on the National Radiation Oncology Registry (NROR), the nation's first radiation oncology-specific national registry. The developers' goals include creating a system with automated data collection and near real-time benchmarking of structural, treatment delivery, and short- and long-term outcomes. NROR began information technology (IT) infrastructure testing for prostate cancer in December 2012.⁵⁷ • Benefits: The beta system has strong foundational elements, including: <ul style="list-style-type: none"> • A standardized prostate data dictionary, consisting of facility, physician, patient, disease, treatment, and outcome data elements; • An electronic infrastructure that automates abstraction and aggregation of treatment and outcomes data from various data systems (i.e., electronic medical records, patient portals, oncology information systems, and radiation therapy treatment planning systems); and, • Ten radiation practice metrics, including physician characteristics, staging, treatment planning and delivery, use of systemic therapies, and survivorship care. • Limitations: Due to its pilot status, it is unclear how successful NROR will be at automating data collection and reporting of the proposed measures. Additionally, it will take several years to assess NROR's impact on health care delivery and treatment outcomes. • Recent Developments: Patient enrollment and site expansions are planned for 2013 and 2014, respectively. Expansion to additional disease sites is planned for 2015.

Table 2
Recommendations for a Learning Health Care System—Relevant Meaningful Use Stage 2 Objectives, Cancer-Specific Gaps, and Potential Management Strategies

Table 2 represents the authors’ view of relevant Meaningful Use Stage 2 objectives (for eligible hospitals and critical access hospitals, together “EH”, and for eligible providers, or “EP”) associated with the IOM’s ten recommendations to accelerate progress toward a learning health care system, cancer-specific gaps, and potential management strategies.^{40,58}

Foundational Elements
Recommendation 1: The Digital Infrastructure Improve the capacity to capture clinical, care delivery process, and financial data for better care, system improvement, and the generation of new knowledge.
<i>Relevant Meaningful Use Stage 2 Objectives</i> <ul style="list-style-type: none"> • Automatically track medications with an electronic medication administration record (EH) • Imaging results accessible through Certified Electronic Health Record (EHR) Technology (EP/EH) • Incorporate clinical lab-test results into Certified EHR Technology (EP/EH) • Protect electronic health information created or maintained by the Certified EHR Technology (EP/EH) • Record and chart changes in vital signs (EP/EH) • Record demographic information (EP/EH) • Record electronic notes in patient records (EP/EH) • Record patient family health history (EP/EH) • Record smoking status for patients 13 years old or older (EP/EH) • Record whether a patient 65 years old or older has an advance directive (EH) • Use computerized provider order entry (CPOE) for medication, laboratory and radiology orders (EP/EH)⁵⁸
<i>Cancer-Specific Gaps</i> <ul style="list-style-type: none"> • EHRs do not routinely capture oncology-specific data elements, such as tumor type and stage • There is a shortage of trained health data scientists with experience in managing and analyzing large datasets and the associated infrastructure⁵⁹
<i>Potential Management Strategies</i> <ul style="list-style-type: none"> • The Office of the National Coordinator for Health Information Technology (ONC) should incorporate cancer-specific objectives (e.g., capturing essential oncology data elements) in future stages of its Meaningful Use program • The ONC should fund career development awards aimed at training information technology (IT) professionals in managing large health datasets
Recommendation 2: The Data Utility Streamline and revise research regulations to improve care, promote the capture of clinical data, and generate knowledge.
<i>Relevant Meaningful Use Stage 2 Objectives</i> <ul style="list-style-type: none"> • None
<i>Cancer-Specific Gaps</i> <ul style="list-style-type: none"> • Existing regulations (e.g., the Health Insurance Portability and Accountability Act, or HIPAA, and the Common Rule) may create unnecessary barriers to activities that advance clinical science and performance improvement, but are not research or clinical practice^{1,40}
<i>Potential Management Strategies</i>

<ul style="list-style-type: none"> The Department of Health & Human Services (HHS) should review existing regulations that govern patient privacy and human subjects research to ensure that the prescribed level of oversight corresponds to the level of patient risk ¹
Care Improvement Targets
Recommendation 3: Clinical Decision Support Accelerate integration of the best clinical knowledge into care decisions.
<i>Relevant Meaningful Use Stage 2 Objectives</i> <ul style="list-style-type: none"> Use clinical decision support (CDS) to improve performance on high-priority health conditions (EP/EH) ⁵⁸
<i>Cancer-Specific Gaps</i> <ul style="list-style-type: none"> CDS tools exist for oncology, but are not widely used and lack non-clinical factors that influence treatment options (e.g., genomics and patient preferences) New knowledge is not rapidly disseminated into the evidence base or clinical practice
<i>Potential Management Strategies</i> <ul style="list-style-type: none"> The ONC should incorporate cancer-specific CDS objectives in future stages of its Meaningful Use program The National Cancer Institute (NCI) and standard-setting organizations, such as the National Comprehensive Cancer Network (NCCN), should develop strategies and standards to promote faster translation of clinical trials and comparative effectiveness research into the evidence base and clinical practice, such as through a CDS public library ¹
Recommendation 4: Patient-Centered Care Involve patients and families in decisions regarding health and health care, tailored to fit their preferences.
<i>Relevant Meaningful Use Stage 2 Objectives</i> <ul style="list-style-type: none"> Provide patients the ability to view online, download and transmit their health information (EP) Provide patients the ability to view online, download and transmit their health information within 36 hours after discharge (EH) Use certified EHR technology to identify patient-specific education resources (EP) Use certified EHR technology to identify patient-specific education resources and provide those resources to the patient if appropriate (EH) Use secure electronic messaging to communicate with patients on relevant health information (EP) ⁵⁸
<i>Cancer-Specific Gaps</i> <ul style="list-style-type: none"> Many patients (and their families) lack timely access to their medical records and to patient education resources Existing data systems and payment models give insufficient consideration to shared decision-making, patient engagement, and personalized medicine
<i>Potential Management Strategies</i> <ul style="list-style-type: none"> The Agency for Healthcare Research and Quality (AHRQ) and the Patient-Centered Outcomes Research Institute (PCORI) should fund development of oncology-specific tools for shared decision-making The Center for Medicare & Medicaid Innovation (CMMI) and private payers should fund development of payment models that encourage shared decision-making ⁶⁰
Recommendation 5: Community Links Promote community-clinical partnerships and services aimed at managing and improving health at the community level.
<i>Relevant Meaningful Use Stage 2 Objectives</i> <ul style="list-style-type: none"> Identify and report cancer cases to a State cancer registry (EP) Identify and report specific cases to a specialized registry (other than a cancer registry) (EP) Submit electronic data on reportable lab results to public health agencies (EH) Submit electronic data to immunization registries (EP/EH) Submit electronic syndromic surveillance data to public health agencies (EP/EH) ⁵⁸
<i>Cancer-Specific Gaps</i>

<ul style="list-style-type: none"> • Clinical and public health practices are poorly integrated • Many community providers (particularly providers that serve vulnerable and underserved populations) lack the resources and manpower to adopt the advanced IT available to other providers
<p><i>Potential Management Strategies</i></p> <ul style="list-style-type: none"> • The Centers for Medicare & Medicaid Services (CMS) and private payers should incorporate population health measures into their payment models;⁴⁰ the NQF “measure incubator” could accelerate measure development • The ONC should fund grants to increase EHR implementation among providers that serve vulnerable and underserved populations
<p>Recommendation 6: Care Continuity Improve coordination and communication within and across organizations.</p>
<p><i>Relevant Meaningful Use Stage 2 Objectives</i></p> <ul style="list-style-type: none"> • Generate and transmit permissible prescriptions electronically (eRx) (EP) • Generate and transmit permissible discharge prescriptions electronically (eRx) (EH) • Perform medication reconciliation (EP/EH) • Provide clinical summaries for patients for each office visit (EP) • Provide structured electronic lab results to ambulatory providers (EH) • Provide summary of care record for each transition of care or referral (EP/EH) • Use clinically relevant information to identify patients who should receive reminders for preventive/follow-up care (EP)⁵⁸
<p><i>Cancer-Specific Gaps</i></p> <ul style="list-style-type: none"> • Current data systems lack interoperability and do not facilitate care coordination and inter-provider communication • Current payment models do not award care coordination and inter-provider communication
<p><i>Potential Management Strategies</i></p> <ul style="list-style-type: none"> • AHRQ should partner with professional organizations and patient advocates to fund development of cancer-specific care transition tools • CMS and private payers should incorporate oncology-specific care coordination measures in their payment models; the NQF “measure incubator” could accelerate measure development • CMMI and private payers should fund development of payment models that encourage effective care coordination and transitions
<p>Recommendation 7: Optimized Operations Continuously improve health care operations to reduce waste, streamline care delivery, and focus on activities that improve patient health.</p>
<p><i>Relevant Meaningful Use Stage 2 Objectives</i></p> <ul style="list-style-type: none"> • Generate lists of patients by specific conditions to use for quality improvement, reduction of disparities, research, or outreach (EP/EH)⁵⁸
<p><i>Cancer-Specific Gaps</i></p> <ul style="list-style-type: none"> • Few provider systems have executed system-level initiatives to reduce waste and variation in cancer care • There is no clear mechanism to disseminate operational improvements within the cancer care community, particularly to providers that treat vulnerable and underserved populations • Provider access to and experience with systems engineering tools and process improvement methods varies
<p><i>Potential Management Strategies</i></p> <ul style="list-style-type: none"> • CMMI and NCI should sponsor oncology-specific projects to eliminate inefficiencies and improve patient health through operational improvements; specific funding should be directed to providers that treat vulnerable and underserved populations • Professional organizations should co-develop strategies and standards to promote faster dissemination of operational improvements within the cancer care community, such as through a publicly-available best practice database or a learning consortium⁴⁰ • Credentialing organizations should strengthen re-certification requirements to include demonstration of systems thinking and projects to reduce wasteful care

<p>Supportive Policy Environment</p>
<p><u>Recommendation 8: Financial Incentives</u> Structure payment to reward continuous learning and improvement in the provision of best care at lower cost.</p>
<p><i>Relevant Meaningful Use Stage 2 Objectives</i></p> <ul style="list-style-type: none"> • None
<p><i>Cancer-Specific Gaps</i></p> <ul style="list-style-type: none"> • Fee-for-service reimbursement does not incentivize high-quality, lower-cost care • Existing alternative payment models (e.g., value-based purchasing) are insufficient to incentivize sustainable improvements in care • Existing payment models do not incorporate long-term outcomes and patient-reported outcomes (e.g., survival and functional status)
<p><i>Potential Management Strategies</i></p> <ul style="list-style-type: none"> • Public and private insurer payment models should incentivize high-quality, team-based care focused on patient goals, needs, and preferences ⁴⁰ • CMMI and private payers should sponsor demonstration projects for oncology-focused alternative payment models that incorporate outcomes that are important to patients; the NQF “measure incubator” could accelerate outcome measure development • Provider organizations and health care systems should reward continuous improvement and professional development through financial incentives ⁴⁰
<p><u>Recommendation 9: Performance Transparency</u> Increase transparency on health care system performance.</p>
<p><i>Relevant Meaningful Use Stage 2 Objectives</i></p> <ul style="list-style-type: none"> • None
<p><i>Cancer-Specific Gaps</i></p> <ul style="list-style-type: none"> • There are significant gaps in outcome, safety, cost, and other quality data to guide patient decision-making and to guide performances improvements; timeliness is also an issue
<p><i>Potential Management Strategies</i></p> <ul style="list-style-type: none"> • PCORI should fund research regarding which cancer quality data are most important to patients and when and in what format these data should be pushed to patients to aid in their decision-making • HHS, private payers, professional organizations, and patient representatives should collaborate to implement a coordinated, transparent reporting infrastructure that meets the information needs of all stakeholders (in particular, patients and their families) and presents information on a real-time basis and in a way that is understandable to patients • Public and private payers should promote transparency in outcomes, safety, cost, and other quality data through alternative payment models
<p><u>Recommendation 10: Broad Leadership</u> Expand commitment to the goals of a continuously learning health care system.</p>
<p><i>Relevant Meaningful Use Stage 2 Objectives</i></p> <ul style="list-style-type: none"> • None
<p><i>Cancer-Specific Gaps</i></p> <ul style="list-style-type: none"> • Fragmented measure development and reporting efforts inhibit progress toward a learning health care system
<p><i>Potential Management Strategies</i></p> <ul style="list-style-type: none"> • Professional societies, credentialing organizations, and accreditation organizations should incorporate continuous learning and improvement into educational, certification, and accreditation requirements • Professional societies should collaborate with experts in organizational development to establish standards and strategies that promote organizational cultures that support continuous improvements and transparency • Health care organizations and public and private payers should align financial incentives accordingly