National Quality Forum

Comments on Gaps Report: National Voluntary Consensus Standards for Patient Outcomes (Phases I and II)

October 22, 2010

Member Council/ Public	Organization Contact	Topic	Comment
P	Janet Dauman, Colorado State and Veterans Nursing Homes	General Comments	The Gaps report is spot on for the missing measurements in all the areas listed. Every healthcare setting should be more patient-focused and therefore the questions asked, the outcomes of care, and the person's experience of healthcare need to be relevant to the patient.
M, Purchaser	Christine Chen, Pacific Business Group on Health	General Comments	The Pacific Business Group on Health appreciates the opportunity to provide comments on the "A Gaps in NQF-Endorsed Outcomes Measures Report". We greatly applaud the Steering Committee's work to acknowledge current deficiencies and speed the rate at which outcome measures become available to assess care. We believe that this work is central to refocusing the measure development and endorsement processes to aid consumers who are seeking providers of cost-effective health care and redirecting resources to emphasize a set of parsimonious but high-value measures. Also, efforts to close gaps in available measures, for example for outcome measures, should seek to address the areas that will generate the greatest value rather than attempt to fill all gaps in all areas. We provide a few recommendations on how the Steering Committee can strengthen the report, as well as words of support. We feel very strongly, however, that the current report begs more questions than it answers about NQF's role in filling these critical gaps. NQF needs to say explicitly how it sees this report being used, and by whom, to achieve the outcome we are all looking for – fast-track development of better outcomes measures for NQF endorsement? These questions should be answered in the introduction of the report to signal NQF's intent.
M, Purchaser	Christine Chen, Pacific Business Group on Health	General Comments	Patient-reported outcomes: We strongly support the emphasis on the need for measures of patient-reported outcomes and the recognition that "the beneficiary of healthcare services is often in the best position to evaluate the effectiveness of those services" (page 6). In line with the Steering Committee point that the "current portfolio emphasizes condition-specific measures rather than cross-cutting measures" (page 3), we encourage the Steering Committee to include a discussion on the ability of generic patient-reported outcome tools, such as SF-36, to assess pain, anxiety, depression, sleep, and physical and social functioning across conditions. Appropriateness of care and longitudinal outcomes: We are encouraged that the report underscores the need to link outcomes to appropriateness of care and shared-decision making, and to track patient outcomes over a longer time frame to better understand the impact that care had on a patient (pages 7-8).
M, Purchaser	Christine Chen, Pacific Business Group on Health	General Comments	Introduction: The introduction should articulate the urgency of having outcome measures to support provisions of the Affordable Care Act that are geared towards health care delivery reform. For example, measures of outcomes are foundational to: a) Providing needed information for consumers to use in choosing their providers; b) Helping the Patient Centered-Outcomes Research Institute determine which treatments work best for which patients; and c) Assessing which of the new models of care and payment (e.g., ACOs, medical homes, bundled payment) produce the best results for patients.

M, Purchaser	Christine Chen, Pacific Business Group on Health	General Comments	Public reporting: We would emphasize that what will move the public is reporting on the outcomes of care, which is one of their chief concerns, along with their portion of the cost. We applaud the statement that "data collected or supported by any public funds should be available for use in performance measurement" (page 12). Where the public finances data collection on provider performance, the public has the right to have access to the resulting provider performance information. Equally important will be making sure that the data from government-sponsored programs are made available at a granular level to allow for aggregation with private sector data to provide a more comprehensive picture of individual provider performance.
M, Purchaser	Christine Chen, Pacific Business Group on Health	General Comments	Risk adjustment: The document states, "risk adjustment is an essential component of useful outcome measures" (page 11). We do not agree with this blanket statement. While risk adjustment is generally important for outcome measures, there is research suggesting that risk adjustment may be of limited value for outcome measures in particular circumstances. For example, patients undergoing the same surgical procedure tend to be a homogenous group and lack systemic variation in patient severity of illness (see Justin B. Dimick et al. Composite Measures For Predicting Surgical Mortality In The Hospital, vol. 28, no. 4 (2009): 1189-1198, http://content.healthaffairs.org/cgi/content/abstract/28/4/1189; J.B. Dimick and J.D. Birkmeyer, "Ranking Hospitals on Surgical Quality: Does Risk-Adjustment Always Matter?, Journal of the American College of Surgeons Vol. 207, No. 3 (2008): 347–351, http://www.journalacs.org/article/S1072-7515(08)00389-X/abstract.) We recommend that the sentence be rephrased to read, "risk adjustment is an important component of outcome measures where necessary".
M, Purchaser	Christine Chen, Pacific Business Group on Health	General Comments	Condition-specific recommendations: The deficiencies in the measures submitted for review in this NQF outcomes project are nowhere more evident than in the area of cancer care. Five-year disease-free survival is the gold standard outcome measure for any life-threatening form of cancer. It has been widely used in scientific publications and is the most important outcome to cancer patients. NQF should find a way to endorse these measures as quickly as possible so that they can be used for reporting at the cancer treatment center and, where appropriate, physician-specific levels.
M, Purchaser	Rabia Khan, Centers for Medicare and Medicaid Services	General Comments	The term "appropriateness" should be removed from the document. The term "appropriate" is challenging to define and measure. Moreover, "appropriate" is difficult to apply to segments of the population that are complex. If the point is to determine whether testing/treatment/intervention is congruent with patient preferences, we suggest that this be re-framed as "patient preferences." Mental Health should stand alone as a measure gap category. This category should include cognitive impairment, psychological health and caregiver burden to mention a few.
M, Consumer	Debra Ness, National Partnership for Women & Families	General Comments	The National Partnership for Women & Families thanks the National Quality Forum for the opportunity to comment ont his report, and we salute the Steering Commttee's work on both the evaluation of the patient outcome measures, as well as the assessment of where we still have deficiencies and gaps. We believe that efforts to close gaps in the measurement portfolio, particularly in the realm of outcome measures, should be guided by a focus on what measures will generate the greatest value. There is much to support in this report, but our main concern is that it raises more questions than it answers, particularly regarding NQF's role in filling these gaps. We understand that NQF is not a measure developer, but we feel the report would be strengthened by explicitly stating the ways in which NQF thinks it should be used, and by what audience.

M, Consumer	Debra Ness, National Partnership for Women & Families	General Comments	We believe that the introduction would be strengthened by clearly articulating the significant need for outcome measures to support the health care quality and delivery system provisions of the Affordable Care Act. For example, outcome measures are integral not only to helping consumers best choose providers, but also to help determine which new payment models (e.g. ACOs, medical homes, and bundled payments) are improving outcomes while reducing costs. Outcome measures are also integral to the hospital and physician value-based purchasing programs outlined in ACA. Outcome measures, stratified by race, ethnicity, gender and language will also be needed if we are to identify and address disparities in care. All of these should be more clearly delineated in the introduction.
M, Consumer	Debra Ness, National Partnership for Women & Families	General Comments	Regarding patient-reported outcomes, we support putting a strong emphasis on the need for these types of measures, and are pleased to see language in the report that reflects this on page 6: "the beneficiary of healthcare services is often in the best position to evaluate the effectiveness of those services." Patient-reported outcomes provide all stakeholders with a view of the patient's perspective of care, and are critical to establishing a patient-centered health care system. Toward that end, we agree with the Steering Committee's contention that the "current portfolio emphasizes condition-specific measures rather than cross-cutting measures" (page 3), and we strongly encourage inclusion in the report of the need for more patient-reported outcome tools, such as SF-36, to assess pain, anxiety, depression, sleep, and physical and social functioning across conditions.
M, Consumer	Debra Ness, National Partnership for Women & Families	General Comments	We fully support the report's discussion of the linkage between outcomes and appropriateness of care/shared decision-making. By tracking patients over time and understanding their health status longitudinally, we can best understand the effects that the system is having on the patient. Viewing care longitudinally is an important concept for consumers as well, particularly when it comes to self-management. Regarding the public reporting section, we again emphasize the need for public reporting and transparency on outcomes, as well as costs. We are pleased to read in the report the statement that "data collected or supported by any public funds should be available for use in performance measurement" (page 12). The public should undoubtedly have access to data that is collected using public resources, particularly when it relates to provider performance. Furthermore, making public sector data available to the private sector will allow us to achieve the goal of aligning public and private sector efforts to improve quality and reduce costs.
M, Consumer	Debra Ness, National Partnership for Women & Families	General Comments	Regarding the report's statement on risk adjustment, we suggest some clarifying language. While we agree that risk adjustment is generally important for outcome measures, there is research suggesting that risk adjustment may be of limited value for outcome measures in particular circumstances. One example is patients undergoing the same surgical procedure. The evidence indicates that this population can tend to be a homogenous group and lack systemic variation in patient severity of illness. We recommend that the sentence be rephrased to read, "risk adjustment is an important component of outcome measures where necessary."
M, Health Plan	Jenna Williams-Bader, WellPoint, Inc.	General Comments	WellPoint is excited to see this report, especially the gap analysis that identifies where endorsed measures currently exist or don't exist for various conditions. However, we wonder how this report will be used. We urge NQF to be transparent about how it thinks this report will be implemented to drive measure development. One way in which we think this gap report could inform the national measurement agenda is to ensure it aligns with the National Quality Strategy. Condition-Specific Gaps: We agree with the gaps identified, although we would like to suggest an additional three topics: depression, low back pain, and maternity care.

M, Health Plan	Rebecca Zimmermann, America's Health Insurance Plans	General Comments	Thank you for the opportunity to provide comments on the NQF Outcomes Measures - Gap Analysis. We have reviewed the report with our member plans and offer the following comments. The report clearly identifies gap areas for outcomes measures in the NQF endorsed set. AHIP supports the general recommendations on types of outcomes measures (e.g., patient-reported outcomes, functional status) and those that address specific challenges (e.g., disparities, population health). We also agree with the challenges noted in the report regarding outcomes measures (e.g., risk adjustment, data availability). We found the appendix, which maps specific measures to targeted areas, useful in identifying specific measures that should be developed. NQF should also consider mapping the measures to the NPP priority areas. The report was unclear in determining how the specific conditions were selected for measurement gap analysis (e.g., cardiovascular, cancer, metabolic conditions, and infectious disease). NQF should consider expanding this list of conditions as the outcomes measure project progresses. Based on analysis from health plan data, AHIP recommends adding the following conditions in the gap analysis: Depression, Low Back Pain, Maternity Care including Pregnancy and Delivery, and Hospital-acquired Conditions (including venous thromboembolism).
M, Purchaser	Gaye Fortner, HealthCare 21 Business Coalition	General Comments	The current report begs more questions than it answers about NQF's role in filling these critical gaps. NQF needs to say explicitly how it sees this report being used, and by whom, to achieve the outcome we are all looking for. These questions should be answered in the introduction of the report to signal NQF's intent.
P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	General Comments	This draft report highlights important areas for further work and offers some valuable guidance on how to strengthen performance measurement of patient outcomes. BIPI would like to comment specifically on several of the general project recommendations suggested by NQF. BIPI believes an episode-of-care approach to performance measures may be better able to holistically assess quality for multiple elements of a patient's care, and is appropriate for certain conditions. There are clearly disease areas for which an episode-of-care approach is not yet possible or necessarily suitable. An episode-of-care approach is most valuable for conditions in which there is agreement among stakeholders on a discrete set of processes and outcomes that should be asssessed for that patient population. We emphasize that for conditions in which this is not the case, stakeholders such as NQF consider whether the episode-of-care model should be either adjusted appropriately or not applied.
P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	General Comments	Functional status performance measurement is an effective approach to capturing patient experience with his or her disease. Outcome measures assessing functional status provide insight into whether a patient is receiving appropriate therapy to control their symptoms. As such, BIPI supports the continued development and endorsement of this type of measure. BIPI agrees that measures should be applied to the broadest possible *appropriate* populations. The discussion in the report on "broader measures" and "cross-cutting measures" seem consistent with this approach. However, the report could better describe the differences between these concepts; broader measures and cross-cutting measures are both positioned as approaches to addressing care for more (and more diverse) patient populations. We encourage NQF to provide more specific information on these measures types so that measure developers can consider how to fill these gaps.

P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	General Comments	A clear focus on the individuals for whom the measure is most relevant will ensure the greatest effect. Similarly, cross-cutting measures will be important to develop because patients with multiple chronic conditions represent a vulnerable population. It will be important for new measures to be created that address clinical topics which are not limited to only specific disease states. BIPI supports the development of performance measures that can assess outcomes for such individuals. Finally, BIPI agrees that performance measures should take advantage of electronic health record (EHR) data and be re-tooled for compatibility. Additionally, registry data - which is expected to provide more robust clinical information - may be a promising source for measure reporting. We encourage NQF and measure developers to consider these data structures as measures are developed and new concepts for measures are discussed.
M, Health Professionals	Karen Fitzner, American Association of Diabetes Educators	General Comments	As an organization dedicated to improving the health of people with diabetes, AADE applauds the NQF for its efforts to foster effective strategies to advance outcomes measurement. We believe that action arising from this document will help advance self-management for people with diabetes and help the diabetes educators who treat them. It is essential to fill critical gaps in the area of outcomes measurement. among who require health care interventions. Overall, we very much support: the intent of the report and its content; the 'episode of care' approach, which is an all-inclusive of care as opposed to the traditional look at an event. It will likely be long-term and cover all aspects of care from beginning to end. The intent of the appropriateness of measurement for procedures/interventions for a particular patient is aligned with authoritative documents relating to diabetes self-management education/training (DSME/T). (1); the approach to addressing evidence-based data and informed input from other patients; and the holistic approach to measurement of care that can only be beneficial to the patients. References 1. Mulcahy K, Maruyniuk M, Peeples M, et al. Diabetes Self-Management Education Core Outcomes Measures. The Diabetes Educator. 2003. 29(5):768-803. 2. American Association of Diabetes Educators. Position Statement - Standards for Outcomes Measurement of Diabetes Self-Management Education. The Diabetes Educator. 2003. 29(5). 804-816.
M, Health Professionals	Rita Munley Gallagher, American Nurses Association	Cardiovascular Disease	The American Nurses Association (ANA) supports the Steering Committee in noting that information on surgical outcomes for younger patients is also important and recommending that the measure be expanded to include all ages and be stratified by age bands. In addition, for patients with COPD, ANA concurs that additional measures for pulmonary rehabilitation (PR) would be useful, such as appropriateness or selection of referral for PR, evaluation of quality of life for patients not receiving PR, adherence/completion rates for PR, and patient assessment of PR services.

P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Cardiovascular Disease	BIPI echoes the finding that there is a need for additional outcomes performance measures for cardiovascular disease measures. We agree that new measures should address the effectiveness of treatment in controlling symptoms, maintaining function, and determining health status or quality of life. New measures should also evaluate appropriate use and effectiveness of medication management, procedures, and cardiac rehabilitation services. BIPI agrees that measures to evaluate the care for patients with atrial fibrillation (AF) are needed, and we have previously emphasized this in our comment submissions. In particular, measures of effective stroke prevention treatment for AF patients would be valuable to the patient and provider communities. AF not associated with clinically signficant valvular heart disease increases the risk of stroke five-hold. Strokes associated with AF are also disabling and fatal more often than strokes not associated with AF. As such, additional performance measures to assess stroke prevention in AF can target a high-burden aspect of this condition. We recognize that this will also address the gap in outcomes measures for cerebral vascular disease.
P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Cardiovascular Disease	Measures to assess the quality of care transitions for AF patients - who are often hospitalized for acute events such as stroke or another co-morbid condition - may also be an important area of focus in order to reduce readmissions and improve overall care coordination. Specifically, more effectibe patient-provider communication, discharge planning, and follow-up may help to ensure that a patient receives appropriate care when moving through various treatment settings. Further, we recognize that care transitions measures can support the NQF recommendation that patients be assessed for their conditions within an episode; an episode-of-care should capture all processes, procedures, and outcomes across various settings and providers.
P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Cardiovascular Disease	Medication adherence is another crucial element in patient management of chronic conditions; NQF highlights existing diabetes measures of medication possession ratio (MPR), for example, in this report. We emphasize that adherence is also an area in which additional measures are needed for AF patients. Evidence suggests that there is a signficant amount of under-treatment in this category, relative to the proportion of patients that are eligible according to current clinical guidelines. Give this evidence, we underscore the important role that adherence measures may play in improving these rates and, subsequently, patient outcomes. Finally, there are compelling reasons as to why NQF should foster development of (and endorse) composite outcome measures for AF. For example, there is significant level of interaction between acute myocardial infarction (AMI), heart failure (HF), and AF; AF is a common complication of AMI or HF. As a result, AF is prevalent in 20 to 30 percent of patients with HF. A composite measure could address outcomes common to these disease areas.
P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Metabolic Conditiions, Including Diabetes and Chronic Kidney Disease (CKD)	BIPI agrees that more diabetes outcomes measures that assess symptom management, functional status, and lifestyle/behavioral improvement strategies are needed. Measures that encourage patient involvement through shared decision-making and self management would be particularly beneficial. In addition, measures of care coordination have potential to greatly improve outcomes. Further, given that clinical guidelines emphasize weight loss as a key intervention in controlling diabetes, we agree that performance measures of such an outcome would be a significant indicator of successful patient management. BIPI also concurs that more robust outcome measures are needed for CKD. Functional status, preserving kidney function, quality of life, and intermediate outcomes are crucial areas of focus for which measures should be developed. Similar to diabetes, measures that encourage care coordination and shared decision-making are needed to facilitate improved outcomes for CKD patients. Importantly, poor glycemic contron can also have an impact on co-morbidities such as CKD, as diabetes is the leading cause of kidney failure. Given this, we also encourage the consideration of performance measures that focus on the high-risk diabetes-CKD co-morbid population.

P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Metabolic Conditiions, Including Diabetes and Chronic Kidney Disease (CKD)	Additionally, we acknowledge NQF findings that current measures do not include estimated glomerular filtration rate (eGFR) testing in nephropathy assessment measure specifications. This is the case despite the inclusion of eGFR monitoring in the assessment of nephropathy in widely-accepted clinical guidelines. We support incorporating this test into measure specifications to ensure providers utilize it consistently. Finally, BIPI supports the appropriate development and endorsement of new diabetes composite measures and refinement of existing measures. We recognize the benefits of this measure type, which considers each outcome as crucial in diabetes care, and shows how measures can more holistically quantify best practices with respect to a disease. We encourage NQF to carefully consider the complex issues associated with composite measurement (e.g., attribution and "all-or-none" scoring) in its deliberations.
M, Provider	Dana Jenkins, Roswell Park Cancer Institute	Cancer	Roswell Park Cancer Institute joined NQF in 2006 in order to be a part of developing measures related to the care of those with cancer. We agree that oncology has proven to be more complex than other disease groups and strongly endorse NQF as the group charged with making progress on this. While legislation calls for measures in six domains, we support an emphasis on outcomes measures. We believe a cancer-specific risk adjustment model, coding that reflects this model , and use of analytic cases only will be promote valid comparison and improvement. While we believe that outcomes measures represent a good beginning point we also hope the NQF will facilitate research in other domains- such as patient-centered care, quality of life, and efficiency. National measures for some of these exist (FACT for quality of life) and NQF endorsed measures for falls, and infection rates for which more work needs to be done. Finally, we feel that the measures suggested marginalize a substantial part of the population we serve. Endometrial cancer represents a relatively small population compared to the hematological cancers and chemotherapy, not represented in these measurs, is not only used for many cancer patients but represents a huge cost. Finally, we believe end-of-life indicators will be important to measure care across numerous domains. We hope you will call upon us to work with you this important initiative.
M, Provider	Thomas Ross, H. Lee Moffitt Cancer Center and Research Institute Hospital, Inc.	Cancer	The H. Lee Moffitt Cancer Center and Research Institute is looking forward to the opportunity to work with NQF and others in identifying and endorsing oncology outcome indicators. The need for this is apparent from recent articles as well as legislation mandating oncology metrics. While challenging for any population the emphasis on long-term episodes of care, the need for cancer-reflective risk adjustment, and coding methodology that represents the acuity of cancer patients makes this population even more challenging. Ultimately improved results (outcomes) are the end goal of quality care. For cancer patients this is oftentimes more reflected in survival than mortality. We believe the gold standard is 5 year survival for specific disease/stage. Additionally, we suggest that there are current NQF-endorsed outcome metrics worthy of inclusion in oncology including those addressing CLABSI, UTI, VAP, VTE, falls, and pressure ulcers. Future opportunites for development include metrics for patient-centered care, diversity, quality of life, those specific to cancer care modalities (radiation and chemotherapy), and management of cancer-therapy complications. If disease specific categories are continued they currently are not representative of the patient population and we suggest the addition of skin and hematology. We look forward to the opportunity to work with you in this endeavor.

M, Provider	Ron Walters, MD Anderson Cancer Center	Cancer	We appreciate the opportunity to comment on the Patient Outcomes Gaps Report and are glad to see the NQF focusing its efforts on identifying and prioritizing the gaps in its portfolio of currently-endorsed cancer measures. We support the approach taken by the Project Steering Committee to stratify these measure gaps across outcome tiers (Table 3 in the report). We would like to work with the NQF to complete the chart, but would like to see some changes made to its structure first. We agree with the Steering Committee's focus on defining cancer-specific outcome measures for the top five cancers (i.e., breast, colon, lung, prostate and endometrial). If the intent is to focus on the top five cancers, please understand that in 2010 bladder cancer is the number five in frequency and causes far more deaths than endometrial cancer (NCI 2010). We would like to see the Steering Committee expand its focus to include other cancers (especially hematologic malignancies and the lymphomas) in this review. We also note that several outcome measures (e.g., fatigue management) apply to multiple cancers and should be included in this type of review.
M, Provider	Ron Walters, MD Anderson Cancer Center	Cancer	Additionally, some of the measure tiers used in the report will not be intuitive to the average clinician (e.g., "Healthcare service utilization as a proxy for patient outcome (e.g., change in condition) or potential indicator of efficiency"). As an alternative, we would suggest you consider developing or using some existing terminology, which is easier to understand, such as the Michael Porter “Outcomes Measure Hierarchy” outlined in his book Redefining Health Care: Creating Value-Based Competition on Results: Tier 1: Health Status Achieved Survival Degree of health/recovery Tier 2: Process of Recovery Time to recovery or return to normal activities Disutility of care or treatment process (e.g., discomfort, complications, adverse effects, errors, and their consequences) Tier 3: Sustainability of Health Sustainability of health or recovery and nature of recurrences Long-term consequences of therapy (e.g., care induced illnesses)

M, Provider	Ron Walters, MD Anderson Cancer Center	Cancer	Integral to the success of this work is the development of robust risk-adjustment methodologies for the cancer population. Volume and experience may be the most important factors in developing these methodologies for some cancers. For all cancers, significant IT and resource allocation is needed to move beyond the standard approaches. Overall, we would like to see a greater emphasis placed on obtaining outcome measures that contain severity adjustments, such as stage of disease and even co-morbidities, since these are critical factors in developing meaningful metrics for comparative purposes. While this project focuses on outcome measures, little attention has been given to the other types of measures identified in the Patient Protection and Affordable Care Act (i.e., Structure, Process, Cost of Care, Efficiency and Patient Perception of Care) that the PPS exempt centers will be publically reporting in 2014. The NQF has endorsed very few cancer-related measures in these areas, though there is a strong correlation in many instances to patient outcome. For example, the correlation between Structure (e.g., nurse staffing ratio) and Efficiency measures (e.g., return to the OR within 48 hours due to incomplete margins of resection) and patient outcome is well-documented. We would like to see the NQF apply a similarly tiered approach to address the gaps in Structure, Process, Cost of Care, Efficiency and Patient Perception of Care measures.
M, Provider	Ron Walters, MD Anderson Cancer Center	Cancer	The End of Life measures included in Table 3 (NQF measures 0212 - 0215) are not outcome measures. We suggest reclassifying these measures as Efficiency measures as they address treatment of terminally ill cancer patients in an acute care setting (i.e., ICU or emergency center). Similarly, we recommend addressing the "Patient and/or caregiver experience with care; knowledge, understanding, motivation; health-risk status/ behavior (including adherence)"category with other types of Patient Perception of Care measures since this is such an important and often overlooked area of measure development. Currently, the NQF has endorsed the HCAHPS survey as a Patient Perception of Care measure. The HCAHPS survey applies to inpatients only and is not cancer-specific; therefore, its use with respect to cancer patients is limited. We would like to see the NQF focus significant effort in expanding this area of cancer-related measures.
M, Provider	Jeremy Miransky, Memorial Sloan-Kettering Cancer Center	Cancer	As long time NQF members and participants in the Cancer TAP, we welcome the opportunity to comment on the document on "Gap Areas in NQF-Endorsed and Candidate Outcomes Measures for Cancer-Related Conditions." We believe the lack of measures reflects the complexity of cancer-specific metrics rather than lack of attention. While we share your concern in the ability to define, extract and analyze oncology patient and treatment specific measures, we do have some disagreement about the nature of the gap analysis you present on pages 22 - 26 of the document. Following are our general comments: First, the development of oncology-specific metrics requires a sound foundation for the most effective use of such information. We feel that the development of an oncology-specific risk adjusted model is of paramount importance. Equally critical in the understanding of outcomes is the development of coding which accurately reflects the acuity level of cancer patients. Types of cases included in the metrics should be uniform. Finally, the ability to retrieve data efficiently while not sacrificing accuracy must be considered.

M, Provider	Jeremy Miransky, Memorial Sloan-Kettering Cancer Center	Cancer	Second, we believe that under the "Type of Outcomes Measure" column, several categories need additional clarification. For example, if a patient developed anthracycline-induced cardiomyopathy, would it be captured under "non-mortality clinical morbidity related to disease control and treatment" category; or under "healthcare-acquired adverse event or complication (non-mortality)" category? We also note that some of the "general cancer measures" may reflect process rather than outcomes measures (e.g. 0213). Third, some measures cross all cancer types and should not be classified by disease (e.g. fatigue). In addition, there are diseases prevalent in the population, which are not reflected in the disease categories. We would lose disease specific outcomes if all other subtypes are included in "Other Cancers." We believe, for example, that Non-Hodgkin lymphoma (the fifth highest incidence) would merit inclusion as a specific disease category. The rationale for choosing endometrial cancer as a target tumor is unclear, given the need for prioritizing efforts and focusing on cancers with high incidence. In this line, we also recommend that the intermediate metric category be removed since it is a lower priority at this stage than other measures mentioned.
M, Provider	Jeremy Miransky, Memorial Sloan-Kettering Cancer Center	Cancer	Fourth, we would propose survival as an end point metric, in addition to mortality. To the extent possible, quality of life metrics should be cancer specific (e.g. the FACT and EORTC-Q subscales). Also, treatment modalities central to cancer care (e.g. chemotherapy, biotherapy, radiation therapy) are a gap which has not been identified in the current document. Finally, there are numerous NQF endorsed non-cancer specific metrics which are applicable to the cancer population, and which have not been taken into account for this gap analysis (e.g. falls, central line catheter-associated blood stream infection rate for ICU, surgical site infection, etc.). Again, thank you for opportunity to respond to this gap analysis and we look forward to our continuing collaboration with NQF.
M, Provider	Jeremy Miransky, Memorial Sloan-Kettering Cancer Center	Cancer	The development of an oncology-specific risk adjusted model is of paramount importance. Equally critical in the understanding of outcomes is the development of coding which accurately reflects the acuity level of cancer patients. Types of cases included in the metrics should be uniform. Several categories need additional clarification. There are diseases prevalent in the population, which are not reflected in the disease categories. Non-Hodgkin lymphoma (the fifth highest incidence) would merit inclusion as a specific disease category. The rationale for choosing endometrial cancer as a target tumor is unclear. In this line, we also recommend that the intermediate metric category be removed. Survival as an endpoint should be considered, in addition to mortality. Quality of life metrics should be cancer specific. Treatment modalities central to cancer care are a gap which has not been identified in the current document. There are numerous NQF endorsed non-cancer specific metrics which are applicable to the cancer population, and which have not been taken into account for this gap analysis.
M, Provider	Barbara Jagels, Seattle Cancer Care Alliance	Cancer	As a Comprehensive Cancer Center, the Seattle Cancer Care Alliance supports your efforts to determine cancer metrics, and we agree with your disappointment at the lack of progress toward defining acceptable measurements of patient outcomes. We support the current NQF cancer metrics, and will continue to identify opportunitites for improvements. Specifically, we remain concerned that current coding methodology does not accurately reflect acuity levels of cancer patients, and in order to address this deficit we need to develop a methodology that incorporates the use of a cancer-specific risk adjusted model. As an example, cancer patients experience fatigue across treatment modalities (chemotherapy, radiation, surgery), but treatment of fatigue cannot be captured in the current data definitions, and fatigue is not represented in proposed outcomes measures. We strongly support the development of patient-centered quality of life metrics, and we recommend developing the data collection systems to address the feasibility of this endeavor.

M, Provider	Tricia Kassab, City of Hope	Cancer	Thank you very much for the opportunity to participate in the work and the realization of the goals of the National Quality Forum (NQF). At the City of Hope we believe that the NQF provides us with a unique forum for the development of relevant and innovative metrics that can allow us to improve patient safety and outcomes in the United States. As such we read the gap analysis regarding existing quality metrics with great care. The gap analysis identified a number of important areas in healthcare where metrics were either limited or entirely lacking. As such, we concur with the disappointment of the committee that performed the gap analysis, but we believe that the lack metrics are reflective of the difficulty and complexity of developing appropriate, cancer-specific metrics. We support currently endorsed oncology NQF measures and we are pleased that the NQF has placed such a strong focus upon patient care outcomes.
M, Provider	Tricia Kassab, City of Hope	Cancer	We also believe that any metrics should be appropriately risk-adjusted so that they retain their meaning across the breadth of cancer-care center. The selected measures also need to accommodate the different modalities of treatment (i.e., surgery, chemotherapy, radiation) and measures should include treatment outcomes, associated adverse events and post-therapeutic complications. In addition, we would urge the in the development of future metrics that the NQF consider the ease of data acquisition and recognize that the current methods of diagnostic coding does not accurately reflect the severity of illness in the cancer patient.
M, Provider	Tricia Kassab, City of Hope	Cancer	We also believe, however, that it is essential that the new metrics are sufficiently robust so that they can have an impact upon the lives of our patients and their families. We also believe that they need to adequate reflect the complexity of the diverse patient populations and the diverse nature of health care organizations. It is also essential that we select outcome measures that will assist us in improving the quality of care that we provide. Our concern with the realization of this is that if the goal is to develop measures that can be applied broadly to community hospitals, centers of excellence and comprehensive cancer centers, then the selected measures need to be general enough so as not to be influenced by unknowns associated with either clinical research or the high-risk nature of patients referred to centers of excellence and comprehensive cancer centers.
M, Provider	Tricia Kassab, City of Hope	Cancer	A cancer specific non-propriety risk adjustment tool must first be developed in order to adequately risk adjust various populations. Many patients treated at a referral center are extremely complex, hence the referral. Besides the usual co-morbid conditions and the diagnosis of cancer, thingssuch as a previous history of chemotherapy and radiation therapy or history ofprior surgical procedures all place our patients at higher risk than the general population and are often not included in risk adjustment models. Identification of appropriate metrics must be done in a multidisciplinary manner across the continuum within each disease category. These metrics should ideally include process as well as pure outcome measures. The metrics must have clearly defined definitions as well as established guidelines for how to collect the data for each metric. Currently,much of this data is collected manually or collected from billing and coding data sources. The billing and coding data is not designed to be used to measure quality and therefore may not be an appropriate source for quality data metric collection. With the onset of CIS technology, we can now access clinical data electronically, but again without a common language, these comparisons of metrics will not be possible.

M, Provider	Tricia Kassab, City of Hope	Cancer	Once these basic issues have been dealt with, then individual metrics should be identified and then piloted on a subset of patients and facilities. In addition to our caution regarding the generalizability of evolving metrics, we are also concerned that the types of cancer identified within the gap analysis as having the highest priority do not seem accurately reflect the types of cancer seen in the modern cancer center. We recommend that the following cancer types should be targeted for further metric development: Lung, Breast, Prostate, Colorectal, Non-Hodgkin's lymphoma, Multiple myeloma, Head and neck cancers and Gynecological cancers. We believe that it is essential to draw both upon the peer-reviewed literature and to look upon data derived from the experience of comprehensive cancer centers and centers of excellence in the development of cancer-specific metrics. The National Comprehensive Cancer Network (NCCN) has done considerable evidence-based work in developing process and outcome measures. Their practice guidelines in oncology are viewed national as a key tool in the management of cancer patients.
M, Provider	Tricia Kassab, City of Hope	Cancer	Regulatory and accrediting bodies, such as Federation for the Accreditation of Cellular Therapies (FACT), have helped their members develop quality metrics related to hematopoietic cell transplantation. Many of these metrics are published and provide reasonable initial benchmarks. We should leverage this body of data to help the NQF enhance its body of relevant metrics. Additional examples of potential metrics for consideration should include the those metrics related to end-of-life care; this might include the percentage compliance with offering advanced directives to patients. In addition we should look toward the development of patient-centered quality of life metrics. Given the enormity of this challenge, we are very concerned with the adequacy of a four week timeline to solicit key clinician stakeholder input. Given the complex nature of our patients, the need to ensure the relevance of the proposed metrics and the diversity of care-settings, we respectfully request a 6-month timeline to carefully evaluate and recommend comprehensive cancer outcome metrics.
M, Provider	Tricia Kassab, City of Hope	Cancer	We are enthusiastic about the efforts of the NQF. We believe that they are essential to ensure that all of our patients and their families receive the best and most innovative care possible. We thank you for your consideration in reviewing our response and we look forward to our continuing discussion with both the NQF and our colleagues in the national oncology community.
M, Consumer	Debra Ness, National Partnership for Women & Families	Cancer	Finally, regarding condition-specific recommendations, we would like to see more emphasis on the deficiencies in cancer outcomes measures. We know that "five-years disease-free survival" is the gold standard outcome measure for any life-threatening form of cancer, and is the most important outcome measure communicated to cancer patients. We strongly suggest that NQF develop a strategy to evaluate and endorse cancer outcome measures as rapidly as possible for use in reporting at the ambulatory and inpatient/outpatient hospital levels, as appropriate.

P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Cancer	BIPI agrees with NQF findings that more robust outcomes measures for most cancer types are needed. This is particularly salient as stakeholders begin to implement multi-payer delivery models and episodes-of-care evaluations that require assessment of care across settings. An oncology patient who switches between numerous providers and care settings is all the more candidate for performance measures that drive accountability. Quality of life and functional assessment measures are excellent areas of focus for oncology measurement. Outcome measures assessing quality of life demonstrates whether a patient is receiving appropriate therapy to control and manage his or her symptoms. Functional assessments such as these can potentially be a proxy metric for determining whether a patient has convenient dosing, reduced toxicity, and/or manageable tolerability. BIPI recognizes that a number of well-developed functional status tools and quality of life scales exist; however, they have largely been untested outside of clinical trials. BIPI encourages NQF to performance measures for public reporting. Specifically, measure developers could test these existing tools at the clinician and practice level to determine if they may be able to meet the need for such outcomes measures.
P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Pulmonary/ ICU Conditions	BIPI acknowledges that NQF has not endorsed any pulmonary outcomes measures to date and supports further measure development in this therapeutic area. BIPI agrees that more chronic obstructive pulmonary disease (COPD) measures that assess pulmonary rehabilitation are needed. BIPI stresses that measures that address appropriate and timely diagnosis through patient screening using questionnaires for at risk populations and spirometric evaluation to confirm diagnosis are also needed, as they are key to ensuring early diagnosis, intervention, and management. Published literature has also shown that a significant number of COPD patients are non-adherent to their prescribed therapies. Further, physicians often do not widely follow clinical guidelines. This underscores a clear need for performance measures that can help improve adherence to protocols that support improved quality of life, functional capacity, medication possession ratio, and pulmonary rehabilitation completion rates.
P	Christopher Corsico, Boehringer Ingelheim Pharmaceuticals, Inc.	Pulmonary/ ICU Conditions	BIPI would also like to emphasize the importance of developing COPD measures around hospital readmissions for exacerbations. COPD accounts for one of the top five medical conditions associated with the largest number of readmission rates. BIPI supports the development of COPD care transitions measures to reduce these readmissions and improve the overall care for COPD patients across an episode. As noted earlier, evidence shows that improved patient-provider communication, discharge planning, and follow-up may foster improved transitions through care settings. If provider groups adhere to the recommendations put forth in evidence-based clinical guidelines for care of the condition, then they greatly decrease the chances of recurring exacerbations and hospital readmission. As with other chronic conditions, we finally urge NQF to consider whether appropriate composite measures can be developed and endorsed for COPD. Such composite measures could include important processes (e.g., influenza and pneumonia vaccination, smoking cessation, appropriate use of maintenance therapies and pulmonary rehabilitation) alongside significant outcomes (patient physical functional capacity, rates of exacerbation, ER visits and hospitalization).

M, Health Professionals	Jinoos Yazdany, American College of Rheumatology	Bone and Joint Conditions	The Quality Measures Subcommittee leadership at the American College of Rheumatology (ACR) has carefully reviewed the measure gaps for Bone and Joint conditions identified in the National Voluntary Consensus Standards For Patient Outcomes: Phase I and II. As we move forward with our measure development and testing efforts at the ACR, we will consider these gaps and attempt to address them when possible. We hope that the NQF will continue to collaborate with the ACR in the development and endorsement of measures in the area of Bone and Joint Conditions in the future. In addition, in thinking about measure gaps for outcomes pertinent to rheumatic conditions, one area not mentioned in the NQF document in which the ACR is actively developing measures is gout. There is substantial evidence of a quality gap for those with gout, and outcome measures are feasible in this condition. Gout may also be an important area given the condition's link to other NQF priority conditions, such as cardiovascular disease, diabetes, renal failure, and obesity.