Measure Registry Needs Assessment

Summary of Stakeholder Discussions

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Measure Registry Needs Assessment

Summary of Stakeholder Discussions

Executive Summary

The Measure Registry Needs Assessment project, funded by HHS, is intended to gather feedback on needs and key considerations for a standardized approach for identifying and tracking measure information. This summary offers details about a variety of organizations' and agencies' current systems and approaches used to gather, store, and/or access measure information, including:

- The formats and measure naming and versioning conventions for current systems in use;
- Details of these systems, grouped by stakeholder perspective;
- Major challenges in gathering and/or maintaining measure information; and
- Ideas from stakeholders to make a potential standardized system or approach valuable.

NQF spoke with measure developers, accreditation entities, and large healthcare delivery systems that have their own systems in place to manage measure information and at times link that information to performance. Some measure developers also provide tools and resources for implementers to access information about measures. But no single system or approach exists today to meet all the needs of the diverse stakeholders involved in healthcare quality measurement and reporting. Furthermore, when organizations both develop measures and implement measures, those two perspectives within the same organization do not necessarily rely on the same internal processes to manage information.

Across the board, those who implement measures have to "beg, borrow, and steal" from a handful of sources to collect the most up-to-date measure information. Most organizations look to the Agency for Healthcare Research and Quality, the National Quality Forum, the Centers for Medicare & Medicaid Services, and measure developers and accreditation bodies for the measure information they need. Because the information from these sources varies, Google searches and other attempts to gather information are also used to collect the full suite of information needed to use a measure.

Significant challenges exist with respect to accessing and maintaining information over time, both for organizations that develop measures and organizations that implement measures, including:

- Sustainability of resources to maintain measure information over time;
- Lack of standardization of measure information;
- Insufficient and inconsistent information across available sources;
- Inconsistent or unclear approaches to measure versioning;
- Unique information needs associated with eMeasures and their implementation; and
- The dynamic nature of the quality measurement field.

Finally, there is mixed opinion on whether a single, standardized approach will meet the 'one-stop shop' needs of developers and implementers alike. Because all of the organizations who participated in the discussions have some form of a system or approach in place, they must balance their information needs with their current resources and business models. But what is currently available falls short of providing what measure implementers need. Full, up-to-date measure specifications and a consistent approach to identifying and versioning measures is needed. To the extent that a single system or approach can go beyond that basic information to also include eMeasures, measure results, feedback loops, details on measure use, implementation guidance, and more, most stakeholders would see great value in such a system or approach.

Background

The Department of Health and Human Services (HHS) and other stakeholders have expressed interest in being able to consistently identify and track measures and their related versions along the measure development, endorsement, and use pipeline. As a result, HHS has contracted with the National Quality Forum (NQF) to conduct a needs assessment to explore key issues and considerations for a single system or standardized approach to gathering, storing, and accessing measure information.

The Measure Registry Needs Assessment project (www.qualityforum.org/RNA) will gather information and seek perspectives from across the quality measurement enterprise to assess the need for and related key considerations regarding the development of a standardized system or approach for tracking measure information. This document summarizes information gathered from stakeholders who developed and use their own systems for maintaining measure information and/or who seek information about measures from external sources.

Summary of Stakeholder Discussions

From June 25, 2012, through July 11, 2012, NQF conducted discussions with public- and private-sector organizations¹ involved in gathering, storing, and/or accessing measure information (Appendix A). NQF sought input on the degree of interest in and the potential value of having a standardized approach to tracking measures and their related information. The stakeholder discussions were tailored to two audiences: (1) stakeholders who develop measures and/or maintain information about those measures; and (2) stakeholders who use or implement measures and seek information about measures (Appendix B – Stakeholder Discussion Guide).

This document summarizes what was shared by stakeholders regarding:

- current systems and approaches in use for maintaining or accessing measure information;
- challenges in maintaining or accessing complete and reliable measure information; and
- potential value in and key considerations for a standardized system for or approach to gathering, storing, and accessing measure information.

Information collected through these discussions is organized by system in Table 1 for quick and easy comparison, and then described by stakeholder perspective in the narrative that follows. Challenges the organizations and agencies face are offered and are supported by suggestions for what would make a single, standardized system or approach most valuable to all stakeholders in healthcare quality.

¹ NQF recognizes the role it plays in supporting measure information needs of stakeholders. While NQF was not included as one of the organizations that were interviewed, information about NQF's system and approach for gathering, storing, and displaying measure information is included throughout this document.

Table 1. Formats, Measure Versioning, and Measure Naming Conventions for Current Systems and Approaches for Measure Information Management

The following table describes current formats for systems and approaches for measure information management, including associated measure versioning process and measure naming convention(s). Some organizations may be listed twice as they offered multiple perspectives from which they manage measure information.

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
Agency for Healthcare Research and Quality (AHRQ) Approach for managing measure information associated with AHRQ's measures (called 'Quality Indicators' (QIs)).	Track measure information in Word documents received from the AHRQ QI subcontractor.	AHRQ provides users the QI specifications as well as software for implementation so version changes can depend on changes to the QI specifications or software.	AHRQ QIs are grouped into four categories— Prevention Quality Indicators, Inpatient Quality Indicators, Patient Safety Indicators, and Pediatric Safety Indicators—and are assigned a three-letter acronym based on the category they belong to, followed by a sequentially-assigned number. For instance, an Inpatient Quality Indicator may be referred to as 'IQI 13'. Because this identifier will always remain with the measure, the numbering for the active indicators will not continue sequentially, as some indicators are retired over time. Significant changes to the measure or the software result in the number increasing by one whole number (e.g., 1 to 2) while smaller changes result in a decimal point increase (e.g., 1.1 to 1.2). Important, off-cycle specification or software updates may require mid-course corrections; those updates are labeled with letters (e.g., version 1.1a) and will include new supporting documentation.

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
Agency for Healthcare Research and Quality (AHRQ) Approach for managing measure information for the National Quality Measures Clearinghouse (NQMC).	Track measure information in several internal systems, including content management systems and SharePoint sites.	NQMC displays the most recent version of a measure that has been provided to AHRQ. The NQMC Measures Archive displays information about measures that are either withdrawn from NQMC or are historic versions of current measures in NQMC. An archived measure is identifiable by its title and date for its version and not by a consistent data or code linking the current measure with earlier version(s).	Each measure entered into the content management system is designated a unique NQMC ID. The NQMC ID changes when information from the measure developer or regarding the evidence that supports a measure is updated. Measure titles in NQMC are renamed according to a measure title naming convention that AHRQ employs.
American College of Cardiology (ACC) Approach for managing measure information for their measure development efforts.	Track measure information in Excel spreadsheets.	ACC captures the most recent and historic versions of its measure. ACC does not yet have a formal versioning process in place.	

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
American College of Cardiology (ACC) Approach for managing measure information in their quality improvement registries.	Track measure information in Excel spreadsheets.	Changes to the measures in ACC's registries do not have to coincide with a version change to the registry. Monthly meetings occur to consider the priority and level of effort for measure changes.	ACC does not have a consistent naming convention. They generally refer to the registry that the measure is in and then reference an ID number that each registry designates. For the reports derived from the registry, each measure's executive summary has a unique identifier and the details section of the report references the measure by another identifier.
Beacon Communities in Greater Cincinnati, Pennsylvania (Keystone), and Rhode Island Approach for managing measure information for implementation purposes.	Track measure information in Word documents and/or Excel spreadsheets.	Because of the brevity of the Beacon program and to examine trends over time, Beacon communities do not update measure specifications even when the measure developer changes the specifications.	
California Office of the Patient Advocate (OPA) Approach for managing measure information for their Quality of Care Report Card.	Rely on measure developer/accreditation entities for tracking measure information.	OPA evaluates the significance of changes to a measure and determines whether those changes are significant enough to explain in the report card.	

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
Centers for Medicare and & Medicaid Services (CMS)/Health Services Advisory Group (HSAG) Approach for managing measure information for CMS' measure development efforts.	Track measure information in an internal Access database, entitled the CMS Measures Inventory.	HSAG captures the most recent version of the measure. They indicate the version of the measure in a "Notes" field.	A unique ID is sequentially assigned to each measure in the CMS Measures Inventory. The measure ID does not change throughout the measure's lifecycle. If there are multiple CMS programs that use the same measure and the specifications are the same for that measure across the various programs, HSAG will assign that measure one ID. However, if the measure is used in several programs and the specifications for that measure vary depending on the program's needs, different IDs will be assigned to the measure. All versions of a measure can be cross-referenced by the NQF measure number if the measure is endorsed. If the measure is not NQF-endorsed, it is referred to by its measure name.
Health Resources and Services Administration (HRSA) HIV/AIDS Bureau Approach for managing measure information for their measure development efforts.	Track measure information in Word documents.		The HRSA HIV/AIDS Bureau does not assign unique IDs to the measures that they develop but instead refers internally to those measures based on the major category, such as clinical care or medical case management, to which a measure is assigned.

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
The Joint Commission Approach for managing measure information for their measure development efforts.	Track measure information differently for measures co-managed by CMS and measures solely managed by The Joint Commission. These distinct processes involve Word, Excel, web-based tracking applications, and Wikis.	The Joint Commission captures the most recent and historic versions of a measure. They identify versions based on patient discharge dates that apply to the specifications manual. One manual is for discharges from January to June and the second manual is for discharges from July through December.	An acronym is assigned to a measure based on the topic area of the measure set to which up to nine measures may be assigned (e.g., the measure set for prenatal care is labeled 'PC'). For internal purposes, all measures used in their accreditation programs are assigned a measure ID once the measure is entered into the system. The database also assigns an alpha ID to the data elements to clearly identify relationships between the data elements, the measures, and measure sets within which the measures are included.
Kaiser Permanente Approach for managing measure information for implementation purposes.	Track measure information in an Access database, entitled the Quality Measures Navigator.	While the Quality Measures Navigator does not use an established process for capturing measure changes over time, Kaiser Permanente is considering using a "Notes" field to identify measure versions or having different entries in its system for each measure version.	A unique ID is assigned to each measure in the Quality Measures Navigator, and those IDs remain constant regardless of how many or the extent of changes occurs to a measure over time. The unique identifiers do not change throughout the measure's lifecycle.
Leapfrog Group Approach for managing measure information for the Leapfrog Hospital Survey.	Track measure information in Word documents and Excel spreadsheets.		

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
Minnesota Community Measurement (MNCM) Approach for managing measure information for their measure development efforts.	Track measure information in Excel spreadsheets.	MNCM tracks measure versions by date.	MNCM's annual guides reference new versions of measures by date.
National Business Coalition on Health (NBCH) Approach for managing measure information for their eValue8 program.	Track measure information in Word documents.		
National Center for Health Statistics, Centers for Disease Control and Prevention (CDC) Approach for managing health indicator ² information in the Health Indicators Warehouse (HIW).	Track indicator information in a back-end system. This system includes a separate database for managing the data sources used for the various indicators.	When an indicator's methodology or data source changes, it is considered a different indicator.	Each health indicator is assigned an ID number sequentially. The ID number will always be unique to that indicator and is used in the back-end to create dynamic URLs for the indicators. Identifiers stay constant even if changes occur to an indicator's definitions, codes, or other information.
National Committee for Quality Assurance (NCQA) Approach for managing measure information for their measure development efforts.	Track measure information in a database.	NCQA captures the most recent and historic versions of a measure.	NCQA uses three-letter acronyms based on the "parent" measure to label the "child" measures that have the same intent as the 'parent' measure, regardless of the care setting.

² According to the HIW website (<u>www.healthindicators.gov/Resources/Glossary</u>), 'health indicators' are measurable characteristics that describe the health of a population; determinants of health; and health care access, cost, quality, and use.

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
National Library of Medicine (NLM) Approach for managing source vocabularies in the UMLS Metathesaurus.	Track source vocabularies within relational files stored in the back-end database.	NLM captures changes to the concepts as well as specific changes to linkages between sources and concepts.	Each concept is assigned a Concept Unique Identifier, or CUI. CUIs do not change over time as long as the definition for the concept remains the same; if the definition of a concept changes, the CUI is retired and new CUI created.
National Quality Forum (NQF) Approach for managing measure information for NQF's measure endorsement and maintenance processes.	Track measure information in a webbased database, which supports information that is displayed in the Quality Positioning System (QPS).	NQF captures the most recent and historic versions of a measure. All changes to a measure are captured as well as all actions that are taken during the endorsement and maintenance processes.	NQF assigns a number to each measure that is submitted for endorsement. If the measure is endorsed, its numeric identifier will remain constant throughout its endorsement lifecycle.
Office of the National Coordinator for Health Information Technology (ONC) Approach for managing eMeasures and their value sets.	Track measure information in Excel spreadsheets.	ONC captures the most recent version of the measure. They distinguish a new version of a measure if its intent changes.	A measure is referenced by the NQF measure number, if it is endorsed. If the measure is not endorsed, they apply an internal numbering system so that the measure has "ONC" as a prefix and then four numeric characters (i.e., a non-endorsed measure may be referenced as 'ONC2345').
Pacific Business Group on Health (PBGH) Approach for the managing measure information for the Consumer Purchaser Disclosure Project.	Track measure information in Excel spreadsheets.		

Organization/Agency & Perspective	Format of System or Approach	Measure Versioning Process	Measure Naming Convention(s)
U.S. Department of Veterans Affairs (VA) Approach for managing	Track measure information in a multi- purpose database, the Performance Integrated	PITA considers significant measure specification changes to warrant the entry of a new measure (with a new unique identifier) in its database.	Measures are designated a three-letter acronym based on the measure's condition or topic area (e.g., major depressive disorder is 'MDD') and then a number (two to four numbers long), assigned in
measure information for implementation purposes.	Tracking Application (PITA).	PITA tracks parent and child measures.	sequential order.

Current Systems and Approaches for Maintaining and Accessing Measure Information

Measure Information Management by Measure Developers

The following organizations and agencies shared information about their systems and approaches for maintaining and/or accessing measure information to support their measure development initiatives:

- American College of Cardiology
- Agency for Healthcare Research and Quality
- Centers for Medicare & Medicaid Services/ Health Services Advisory Group
- Health Resources and Services
 Administration

- The Joint Commission
- Minnesota Community Measurement
- National Committee for Quality Assurance
- Office of the National Coordinator for Health Information Technology

Structure or Format of Systems and Approaches

Many stakeholders rely on Microsoft Word documents, Microsoft Excel spreadsheets, various databases, or a combination thereof for managing measure information. Each of these documents has different internal structures and data elements, and within organizations there can be differences in what elements are tracked.

- The American College of Cardiology (ACC) and Minnesota Community Measurement (MNCM) use Excel spreadsheets for tracking their measures and changes to specifications over time.
- The Health Resources and Services Administration (HRSA) HIV/AIDS Bureau tracks the measures they develop in Word documents.
- For the Office of the National Coordinator for Health Information Technology's (ONC's) work with eMeasures and their corresponding value sets, staff and contractors primarily house information in an Excel spreadsheet, with one workbook documenting the measure narratives (which are maintained in Word documents), another workbook documenting the measure logic and referencing the value set, and a third workbook containing the actual value set. Through its joint work with the National Library of Medicine (NLM) on value sets, ONC has been introduced to a sophisticated, collaborative tool—TeamForge—which NLM uses for maintaining information and managing collaborative discussions and ONC is considering using in the future.

Several measure developers utilize various types of databases for maintaining measure information.

- The National Committee for Quality Assurance (NCQA) has a team that manages its measure specification manuals (called 'volumes') and publications and maintains a historic database, which tracks all measure information, including code lists.
- The Health Services Advisory Group (HSAG), a contractor to the Centers for Medicare & Medicaid Services (CMS), manages a Microsoft Access database, called the CMS Measures Inventory, which tracks measures that CMS is using, developing, or planning to implement.
- The Joint Commission has two distinct processes and databases for managing measures: one for those that are co-managed with CMS and another for measures solely managed by The Joint Commission. The former are maintained in Word documents that are housed on a Microsoft SharePoint site that is accessible to both Joint Commission and CMS staff. The latter is maintained in Excel spreadsheets that are uploaded to a Wiki, which uses XML files to produce Wiki exports. The Joint Commission also maintains another application that assigns a measure

identifier (ID). That application also establishes relationships between measures, the measure set to which those measures belong, and the measures' data elements.

Inclusion of Measure Information

Generally, these organizations focus most on those measures which they themselves develop. Some organizations capture full specifications for a measure, while others capture only high-level information about a measure.

- NCQA's database encompasses all measure information, including the technical specifications.
- The CMS Measures Inventory includes the measure title, description, numerator, denominator, exclusions, and risk adjustment methodology.

For a majority of these organizations, measure information is entered manually into documents or databases. The ACC, MNCM, and HSAG (on behalf of CMS) all have manual processes for updating information in their various systems.

Measure developers also vary regarding the information they gather about the *use* of their measures.

- ACC tracks which specific measures are used in their registries or included in specific CMS programs.
- MNCM tracks measure use via the general inquiries they receive about their measures, requests to use specific MNCM tools, and word-of-mouth.

Most measure developers also access external measure information systems or sources to inform their measure development efforts.

- ACC only tracks others' measures if they are developing or updating measures and want to conduct an environmental scan to know what measures currently exist.
- HSAG relies heavily on NQF's Quality Positioning System (QPS) as well as CMS' QualityNet for specification manuals.

Different practices are in place for identifying measure gaps, and most organizations must visit multiple sources to collect the information they need.

- CMS relies on information from NQF, including consensus development projects' reports, Measure Applications Partnership's reports, and NQF's Annual Report to Congress.
- NCQA uses the National Quality Measures Clearinghouse (NQMC).
- MNCM relies on NQF's search tools, NQMC, and NCQA HEDIS specification manuals.
- ONC uses QPS, Google searches, the Agency for Healthcare Research and Quality (AHRQ) U.S. Health Information Knowledgebase site, and also contacts measure developers directly to "beg, borrow, and steal" the full information needed to support implementation of a measure.

Versioning Processes

Most of the organizations involved in measure development have some type of process in place to track different versions of the same measure. Some capture only the most recent version of the measure while other systems catalogue all versions, both current and historic.

• MNCM tracks measure versions in Excel spreadsheets and new versions of measures are referenced by date annually in MNCM's measure manuals (or 'guides').

- HSAG maintains the latest version of a measure in the CMS Measures Inventory and inserts a comment in a "Notes" field indicating the measure version.
- The Joint Commission, ACC, and NCQA have processes in place for capturing the most current version of a measure as well as historic versions, with documentation of the specific changes over time.
- ONC's approach for tracking eMeasures and their value sets involves capturing only the latest version of the measure.

The majority of developers make changes to measures on an annual or bi-annual basis, but a wide range of approaches exist for distinguishing between versions of measures. Furthermore, there is no consistent approach across organizations for what determines a new version of a measure.

- ONC classifies a new version of a measure when that measure's intent changes.
- The Joint Commission identifies measure versions based on dates of patient discharge that apply
 to a particular specifications manual—one manual is for discharges from January to June and a
 second manual is for discharges from July through December.
- As a measure developer, AHRQ provides users the specifications for their measures (called 'Quality Indicators') as well as software to implement them. Given this, version changes can depend on the changes to the measures or changes to the software. The measure specifications and their changes over time are tracked internally by AHRQ using Word documents.
- NQF tracks the version of a measure in its back-end database using a numbering system. Digits are assigned to reflect three types of changes to a measure in the following order: major, minor, and patch changes (e.g., a measure with version number '1.2.20' would indicate that one major, two minor, and 20 patch changes have been applied over time). Changes to endorsement status are considered 'major' changes; changes to a measure that do not impact the measure specifications are considered 'minor' changes; and 'patch' changes reflect administrative edits to a measure. The number is refreshed when a measure goes through endorsement maintenance and its endorsement is renewed (in this example, the measure version would be updated from '1.2.20' to '2.0.0').

Naming Conventions

Each organization or agency has its own way of uniquely identifying measures within its system. These variances exist to: meet the practical needs of the specific organization; conform to the automated naming conventions that exist within database systems that are employed; and/or allow for a consistent way to reference measures and their versions within the organization.

- In ONC's spreadsheet, a measure is referenced by the NQF measure number if the measure is endorsed. If the measure is not endorsed, ONC applies an internal numbering system so that the measure has an ONC prefix and then four numbers that follow (i.e., a non-endorsed measure may be referenced as 'ONC2345').
- The Joint Commission assigns an acronym to a measure set based on the topic area, to which up to nine measures may be assigned (e.g., the measure set for prenatal care is labeled 'PC'; children's asthma care is 'CAC'). For internal purposes, all measures used in Joint Commission accreditation programs are assigned a measure ID once the measure is entered into the system. This database also assigns an ID to the data elements of the measure to clearly identify relationships between the data elements, the measures, and measure sets in which the measure is included.
- NCQA uses three-letter acronyms based on the "parent" measure to label the "child" measures that have the same intent as the 'parent' measure, regardless of the care setting.

- A unique measure ID is assigned sequentially to each measure in the CMS Measures Inventory and will not change throughout the measure's lifecycle. If there are multiple CMS programs that use the same measure and the specifications are the same for that measure across the various programs, HSAG will assign that measure one ID. However, if the measure is used in several programs and the specifications for that measure vary depending on the program's needs, different IDs will be assigned to the measure. All versions of a measure, however, are able to be cross-referenced by the NQF measure number if the measure is endorsed. If the measure is not NQF-endorsed, it is referred to by its measure name.
- AHRQ measures are grouped into four categories—Prevention Quality Indicators, Inpatient Quality Indicators, Patient Safety Indicators, and Pediatric Safety Indicators—and are assigned a three-letter acronym based on the category to which they belong, followed by a sequentially-assigned number. For instance, an Inpatient Quality Indicator may be referred to as 'IQI 13'. Because this identifier will always remain with the measure, the numbering for the active indicators will not continue sequentially, as some indicators are retired over time (and their numbers may retire with them). Significant changes to the measure or the software result in the number increasing by one whole number (e.g., 1 to 2), while smaller changes result in a decimal point increase (e.g., 1.1 to 1.2). Important, off-cycle specification or software updates may require mid-course corrections; those updates are labeled with letters (i.e., version 1.1a) and will include new supporting documentation.
- HRSA's HIV/AIDS Bureau, because of the small set of measures it develops, does not assign
 unique identifiers to its measures but instead refers internally to those measures based on the
 major category, such as clinical care or medical case management, to which a measure is
 assigned.

Communicating Measure Changes

Various methods are used by measure developers to communicate to external stakeholders the changes made to measure information. A majority of measure developers communicate measure changes via their publications or specifications manuals that are updated when measure information changes on a regular schedule.

- NCQA communicates changes to their HEDIS measures in their annual HEDIS measure specification manual.
- MNCM also shares any measure changes in their annual publication.
- Twice a year, The Joint Commission releases two specification manuals: one for measures maintained with CMS and another for those managed solely by The Joint Commission. In each manual, the release notes outline the changes made to measures and include corrections and clarifications. The manual includes the date the measure was last updated and the version of the manual in which the update is included any time a measure is mentioned. In addition, the manual for the measures maintained with CMS highlights in yellow where specific changes have occurred. For measures managed solely by The Joint Commission, the Wiki that is used to track and maintain these measures allows users to view a side-by-side comparison of measure versions to allow for clear understanding of specific changes made to a measure.
- In the past, the ACC did not release documents detailing the technical specifications of measures. However, it is testing a new approach of releasing implementation notes in their journals and posting those updates online.
- In addition to the annual publication that AHRQ produces documenting the latest versions of their measures, they also manage a listserv that people can subscribe to in order to receive updates or announcements of updates to measures.

Measure Information Management by Those Who Advance Measure Implementation and Use

NQF spoke to organizations and agencies that provide information, resources, and tools to those implementing measures, reporting results, and using results to make decisions. Discussion was targeted to specific tools or processes the organizations use (Table 2).

Table 2. Targeted Discussion Topics

Organization/Agency	Focus of Discussion
Agency for Healthcare Research and Quality	National Quality Measures Clearinghouse and HHS
Agency for fleatificate Research and Quality	Measure Inventory
American College of Cardiology	Hospital- and practice-based registries
California Office of the Patient Advocate	Annual Quality of Care Report Card
The Leapfrog Group	Leapfrog Hospital Survey
National Business Coalition on Health	eValue8 program
National Center for Health Statistics, Centers for Disease Control and Prevention	Health Indicators Warehouse
National Library of Medicine	Unified Medical Language System's Metathesaurus
Pacific Business Group on Health	Calculating measures and reporting results on behalf of members

Structure or Format of Systems and Approaches

There is great diversity in the systems and approaches used for maintaining measure information to support quality measurement and reporting initiatives. Organizations that maintain web-based resources with public-facing components also maintain internal, back-end databases for managing the measure information.

- AHRQ's National Quality Measures Clearinghouse has several internal systems, including
 content management systems and SharePoint sites for managing information, that support the
 information displayed on the public-facing front-end. The HHS Measure Inventory is a separate
 database of measures that are currently being used by Divisions in HHS for quality
 measurement, improvement, and reporting. It is accessible via the NQMC website. Measures in
 the HHS Measure Inventory are not subject to the same information management processes as
 are measures within the NQMC.
- The CDC's National Center for Health Statistics maintains the Health Indicators Warehouse (HIW), which has a back-end database that supports the public-facing website and houses the indicator information.³ The back-end includes a database dedicated to managing and maintaining the approximately 150 data sources, or data collection tools, used for the various indicators.

³ According to the HIW website (<u>www.healthindicators.gov/Resources/Glossary</u>), health indicators are measurable characteristics that describe the health of a population; determinants of health; and health care access, cost, quality, and use.

- The National Quality Forum maintains an internal, web-based database for managing and
 maintaining measure information to support their measure endorsement and maintenance
 processes. This database serves as the back-end system for where NQF's measure search tool,
 the Quality Positioning System, pulls its information. The back-end system includes detailed
 information on the measures submitted to NQF for consideration for endorsement, while QPS
 displays the information NQF is allowed to represent publicly according to its agreements with
 measure developers.
- ACC uses two approaches to manage the measure and other technical information that drives its
 web-based registries. ACC staff compiles an extensive spreadsheet that stores specifications and
 algorithms for all their measures, which is loaded into a SQL server and then used to dictate how
 the data is aggregated and reported. Additionally, for purposes of tracking measure changes to
 be documented in reports derived from the registries, ACC also has a spreadsheet to track
 measures and any changes to those measures.
- The National Library of Medicine's Unified Medical Language System® Metathesaurus® is a large database of vocabularies, classifications, and code sets that are linked at the concept level and derived from over 150 source vocabularies (electronic versions of classifications, code sets, thesauri, and lists of controlled terms in the biomedical domain). The Metathesaurus is available through a web-based platform that is structured around a set of relational files organized by concept. These relational files house alternative names and views of the same concept from different source vocabularies and note useful relationships between different concepts.

Microsoft Word and Excel documents provide some organizations with simple, practical, and user-friendly exchange of information to support internal working and sharing of measure information with external stakeholders.

- The Pacific Business Group on Health (PBGH) is heavily involved in the Consumer-Purchaser
 Disclosure Project, which recently developed a spreadsheet for storing measures relevant to
 their work around the latest CMS proposals on incentive payments.
- The National Business Coalition on Health (NBCH) houses measure information in Word documents for its eValue8 program.
- The Leapfrog Group maintains measure information each year for its Leapfrog Hospital Survey
 using Word documents, which include hyperlinks to the original online source for the
 specifications. This information is kept in Word documents because hospitals need to be able to
 easily cut and paste the measure information. The Leapfrog Group also uses an Excel
 spreadsheet to track measure changes over time.

Processes for Inclusion of Measure Information

The degree of measure information captured by organizations depends on the information needed for their systems or approaches. Some systems, such as the NQMC and HIW, have inclusion criteria that are used to decide which measures are included in a system and displayed for public use.

Much of the measure information included in NQMC is retrieved directly from measure
developers by clearinghouse staff, and this process is the same for measures developed by
AHRQ; AHRQ does not have a standardized approach for transferring measure information
about AHRQ measures into the NQMC. And as measures included in the HHS Measure Inventory
are self-reported by various Divisions in HHS, these measures may or may not also be included

⁴ According to the NLM website (<u>www.nlm.nih.gov/mesh/trackingmeaning.html</u>), terms from different constituent vocabularies with the same meaning are gathered into a 'concept'. This is different from a 'measure concept' (defined on page 27).

in NQMC. This may be due to a number of factors including: the measures not meeting the NQMC inclusion criteria; a different version of the HHS Measure Inventory measure being represented in NQMC; or the specifications for the measures not being submitted to AHRQ.

Besides the measure specifications that are housed within the NQMC or HIW, both AHRQ and CDC include or are exploring inclusion of other types of measure information.

- AHRQ is exploring inclusion of eMeasures in the NQMC. While AHRQ often receives user requests for benchmarking and displaying results of measures, AHRQ views NQMC first and foremost as an information repository.
- CDC's HIW provides links from indicators to evidence-based interventions that support
 communities in improving performance on those indicators. As the HIW matures, CDC plans to
 conduct data validation of the indicator data they receive to more display reliable results on
 those indicators.

NQF and NLM have similar approaches for representing information.

- NQF's back-end database for measure information is automatically populated by the full specification information that measure developers submit to NQF via a web-based form. Additional fields in the database are populated and used by staff to document and track a measure's progress through the endorsement and measure maintenance processes. The back-end database also allows staff to generate reports to support the review of measures when they are being considered for initial or renewed endorsement. Once a measure is endorsed, per NQF's agreements with measure developers, only the measure title, NQF measure number, numerator, denominator, exclusions, and whether risk adjustment is applied are publicly displayed.
- The NLM has a process in place for obtaining, maintaining, and displaying the 150 source vocabularies within the Metathesaurus. NLM retrieves data from a source provider's website if published publicly or otherwise relies on the source provider to submit updates. NLM creates 'recipes' or codes for ensuring the fields for data coming from source providers are accurately matched to the display fields for the Metathesaurus, and these recipes are provided on the Metathesaurus site.

In order to access or maintain measure information to support their resources or tools, purchaser and consumer organizations seek measure information from multiple sources.

- The Leapfrog Group's Hospital Survey team gathers measure information from the NQF website annually and then hyperlinks to original online sources for measure specifications.
- The California Office of the Patient Advocate, for its Quality of Care Report Card, accesses measure information from NQF and from NCQA's QualityCompass and HEDIS specification manuals.

Versioning Processes

Most organizations and agencies have a process in place for capturing or tracking historic versions or changes to measure information over time, but those processes vary significantly across organizations. Organizations that produce annual or regularly scheduled reports or deliverables generally track historic versions via their specification manuals.

 NLM captures in history files and displays publicly all changes to concepts as well as specific changes to the linkages between sources and concepts.

- NQMC publicly displays the most up-to-date version of a measure that has been provided to AHRQ. While the history of a measure is captured in the back-end database, that historical information is not fully displayed in NQMC. The NQMC Measures Archive shows information about measures that are either withdrawn from NQMC or that have previous versions, but the older versions are not accessible directly from the current version of a measure. An archived measure is identifiable by its title and date for its version. There is no consistent data or code linking the current measure with earlier version(s).
- NQF houses all historic versions of a measure in its internal database and publicly displays only
 the most current version of the measure. All material changes to a measure are captured in the
 internal database, as are actions that are taken during the endorsement and measure
 maintenance processes.

Organizations and agencies have unique ways of deciding when a measure should be considered as having a new version. For most, the significance of the change to the measure is what determines a new version, and the assessment of what is 'significant' is subjective.

- The California Office of the Patient Advocate evaluates changes to a measure and determines whether those changes are significant enough to explain in their Quality of Care Report Card.
- For the ACC, in the past, measure versions in registries coincided with the version of the registry (usually every three years), as measures were not often changed. Now, ACC makes smaller changes to the measures in their registries without implementing registry version changes.
 When deciding on changes to the measures, ACC has monthly prioritization meetings where they identify changes as high, medium, or low, and consider the level of effort needed to make that change.

While processes are in place for updating information in NQMC and HIW, definitive rules as to what distinguishes a version change do not exist. Updates are largely driven by the extent to which information is available from the sources for measures.

- While the NQMC team regularly searches various sources for updates to measure information (e.g., websites, citation tools) and annually asks measure developers to verify that NQMC has the most current version of their measures, AHRQ may withdraw measures from NQMC when a developer no longer wishes to maintain what is represented about the measure in NQMC or when the developer does not provide updates to the evidence for a measure or indicate that a review of the latest evidence base was conducted.
- Indicators in the HIW are updated as data becomes available. For most federal sources of the
 indicators, data is released on an annual basis. When an indicator's methodology or data source
 changes, it is considered a different indicator. The CDC is working on an approach to classifying
 indicators when they change and how and when to designate a new identifier for an indicator.
 One idea being considered is that when the change to the indicator is substantial, both versions
 of the indicator will be posted online.

Naming Conventions

Organizations have diverse approaches to how measures are referred to in their systems or approaches.

ACC does not have a consistent way of identifying measures within their registries; it refers to
the registry within which the measure is used and then references an ID number that each
registry designates.

- The back-end system for NLM's Metathesaurus assigns a Concept Unique Identifier, or CUI, to each concept. CUIs do not change over time as long as the definition for the concept remains the same; if the definition of a concept changes, the CUI is retired and new CUI is created.
- CDC's HIW sequentially assigns each indicator an ID number. The ID number is always unique to
 an indicator and is used in the back-end to create dynamic URLs for the indicators. IDs stay
 constant even if changes occur to an indicator's definitions, codes, or other information. CDC
 encounters challenges in understanding and capturing when changes have been made to
 indicators and continues to work to address this challenge.
- NQF assigns a number to each measure that is submitted for endorsement. If the measure is endorsed, its numeric identifier will remain constant throughout its endorsement lifecycle.
- AHRQ uses a different approach for the NQMC. Similar to HIW and NQF's database, each measure receives a unique ID; however, that unique ID changes when information from the measure developer or regarding the evidence that supports a measure is updated. An important distinction of NQMC from other systems is that the measure titles in NQMC are renamed according to a naming convention developed by AHRQ. Therefore, to track changes over time to a measure in the NQMC, users must know the title of the measure as it appears in NQMC. While AHRQ recognizes that this may cause confusion, it finds value in renaming measure titles to best communicate the intent of the measure.

Communicating Measure Changes

Most changes to measures are communicated through standardized manuals or websites that are the primary information sources for users of these systems.

- The ACC provides quarterly reports to participants in their registries. Participants can view a report's release notes or the report's companion guide for specific changes. These reports capture changes for the latest version only, so a user must track through historical reports to see measure changes over time, though ACC may implement a new numbering system to allow for historical information to be shared. Significant changes are also communicated via webinars, announcements on a registry's web page, and weekly newsletters.
- NQF notifies users that subscribe to updates on a project or measure of a measure's progress through the endorsement process as well as when a measure has lost its endorsement.
- The California Office of the Patient Advocate makes a clear statement in their report card when the measure specifications have been changed to alert users not to compare current results to previous years' results.
- The CDC posts release notes on the HIW site and uses an RSS feed so users can receive notifications of data updates and related news.

Measure Information Management by Implementers

The following organizations and agencies shared information about their systems and approaches for maintaining and/or accessing measure information to support their measure implementation efforts:

- Beacon Communities in Greater Cincinnati, Pennsylvania (Keystone), and Rhode Island
- Kaiser Permanente
- U.S. Department of Veterans Affairs

Structure or Format of Systems and Approaches

Similar to other organizations that have not developed systems to manage measure information, Beacon communities use approaches that are most practical for those they work with in the field. For example, when the Rhode Island Beacon Community needed to harmonize the set of measures to use across its providers, it used Excel spreadsheets to determine the best measures to use and currently uses Word documents to manage measure specifications.

Alternatively, as large healthcare systems, both Kaiser Permanente and the U.S Department of Veterans Affairs (VA) found the need over time to develop customized databases for maintaining and tracking measure information.

- Kaiser Permanente originally tracked changes to measure specifications using Word documents
 and later moved to tracking this information in Excel spreadsheets. Later they developed a
 Microsoft Access database—the Quality Measures Navigator—to better meet their information
 needs. The information about measures in this database is linked directly to the performance
 dashboard Kaiser Permanente uses for its providers.
- The VA also increasingly found it difficult to gather meaningful information from their various internal sources. They developed a multi-purpose system, the Performance Integrated Tracking Application (PITA), with one of its functions being a database to house and track technical measure specifications for measures used throughout the VA network for quality improvement and accountability. PITA also stores data for the measures, produces reports on performance on those measures, and provides a reporting interface for network providers.

Inclusion of Measure Information

Those involved in measure implementation collect and maintain detailed information about the measures they use *and* the measure results they calculate and/or report.

- PITA captures the measures for which the VA holds network providers accountable from a national perspective. There are currently 471 active measures in PITA, which includes a combination of measures developed by The Joint Commission, NCQA, AHRQ, and the VA. They rely on measure developers' websites for information about non-VA measures. PITA includes both the technical attributes (definitions, numerator, denominator, scoring, etc.) and administrative attributes (level of data available, refresh and report frequency, and data delivery method) of measures. Although the measures in PITA are limited to measures from the national level to hold all network providers accountable, sometimes innovation at the local level can spur the development of measures that the national office will consider using across its network. And while PITA does not yet capture eMeasures, the VA is working to bridge measurement and information technology across its network to link PITA to the Veterans Health Information Systems and Technology Architecture—VA's electronic health record.
- Kaiser Permanente tracks eMeasure value sets and views them as part of the information that is captured and stored within a measure's specifications.

The need to evaluate improvement over time also drives the approach to monitoring changes to measure specifications.

 Specifically, due to the short duration of the Beacon program grants and the need to demonstrate improvement, the Keystone Beacon Community continues to use the original specifications adopted for use at the start of the grant period, even when measure specifications change. The Rhode Island and Greater Cincinnati Beacon communities use the same approach as Keystone, updating measure specifications or altering how the measure is calculated only if a significant change is made to a measure in use.

Versioning Processes

Kaiser Permanente and the VA use or are considering different approaches for tracking measure versions over time.

- While Kaiser Permanente's Quality Measures Navigator does not use an established process for capturing measure changes over time, Kaiser Permanente is considering using a "Notes" field to identify measure versions or having different entries in its system for each measure version.
- PITA, alternatively, considers significant measure specification changes to warrant the entry of a
 new measure (with a new unique identifier) in PITA. The VA tracks parent and child measures
 and notes which measures contribute to which provider performance reports.

Naming Conventions

Naming conventions for measures vary across organizations.

- In the VA's PITA, measures are given a three-letter acronym based on the measure's condition or topic area (e.g., major depressive disorder is 'MDD' in the system) followed by a number (two to four numbers long), assigned in sequential order.
- Kaiser Permanente assigns unique identifiers to each of the measures in the Quality Measures
 Navigator, and the measure ID remains the same regardless of how many or the extent of
 changes occurs to a measure over time.

Communicating Measure Changes

How changes to measures are communicated with stakeholders also varies.

- The Rhode Island Beacon Community posts the Word documents that house their measure information on their collaborative portal where Beacon partners can access them at any time for review.
- The VA's PITA system includes a reporting interface in which customized reports can be produced to view measure changes and trends for measure results over time.

Challenges with Accessing and/or Maintaining Measure Information

In addition to capturing detailed information about the approaches used to gather and/or maintain measure information, stakeholders shared the challenges they face in meeting their own information needs. While some acknowledge that their systems or approaches can only go so far due to scope or limitations in resources to expand systems, a handful of organizations find that their systems meet their needs. The majority of organizations share common views about the biggest challenges to using measures and their results to inform improvement and accountability over time. The most significant challenges that these organizations and agencies face, regardless of perspective, include:

- Sustainability of resources to maintain measure information over time;
- Lack of standardization of measure information;
- Insufficient and inconsistent information across available sources;
- Inconsistent or unclear approaches to measure versioning;

- Unique information needs associated with eMeasures and their implementation; and
- The dynamic nature of the quality measurement field.

Sustainability of Resources to Maintain Measure Information over Time

The extent to which systems have (or have not) been developed by stakeholders is indicative of the resources different organizations are able to allocate to managing measure information. For the most part, large and established measure developers have systems that meet the internal needs of maintaining measure specifications and changes over time, and their processes work for them. Multiple teams and several staff are devoted to measure information management. Smaller measure developers have similarly devoted the staff time and resources they need to manage their measures. They use simpler approaches, such as tracking changes within Word or Excel documents, to meet the basic needs of and to keep processes practical for the management of measure information. However, regardless of size, all measure developers acknowledge that they devote as many resources as they can to maintain measure information over time, and that they do the best that they can with available resources and tools.

In essence, all organizations must work to sustain their current level of resource allocation for information management, and most admit that their systems do not fully meet their measure information needs or desires. For many, the trade-off is made to rely on simpler, practical tools over more sophisticated or advanced ones; while a complex system may automate certain parts of the process and eventually minimize staff time devoted to manual entry and tracking of measure information, the resources required to build more robust systems simply are not available. Most "make it work" and use multiple information gathering approaches to fill the deficiencies in their current systems.

Funding is what drives the ability for organizations to continue to enhance or improve their systems to meet organizational priorities or demand from external users.

- While the creation of the HIW was a direct result of the CDC needing to more efficiently manage
 the numerous data analysis requests from external stakeholders—and now the warehouse is
 viewed as a primary resource for community indicators of health and related interventions—
 CDC continues to struggle with how to sustain the HIW long term.
- AHRQ recognizes that it if it had access to more resources, it would be able to better meet measure developers' and implementers' measure information needs.

Lack of Standardization of Measure Information

Another challenge is the lack of standardization that exists at multiple points in the measure development and use pipeline. From a measure implementer perspective, many organizations are unsure of the consistency with which data is collected and reported out; variations in the measure specifications used make 'apples to apples' comparisons of results of measures difficult, even when it appears the same measure is in use.

Organizations would value standardized definitions and elements for the information that is collected about a measure, particularly measure specifications. The variation in titles for the same measure across multiple systems presents significant challenges to ensuring that the measure referred to in one system is the same as what appears to be the same measure in another system. To date, no one system or approach accurately links information between systems using common or consistently derived measure identifiers.

Even within one organization or agency, consistent approaches to managing measure information may not exist or may fall short of meeting the needs of those who use or are held accountable for performance on certain measures.

- AHRQ does not have an internal system in place for NQMC to easily update the specifications for the measures that AHRQ develops.
- The ACC is working to find a solution for not having simple, unique identifiers for their measures and to improve users' ability to easily refer to ACC measures.

Insufficient and Inconsistent Information across Available Sources

Most organizations that seek information about measures must access multiple sources to piece together all of the information they require. Despite organizations' approaches being largely similar on the primary sources they use for measure information—AHRQ, NQF, measure developers, and Google searches—no one system provides the full set of information needed to use a measure, nor do the pieces of information from multiple sources give organizations confidence that the information they gather is consistently accurate. Measure information fields that are common to multiple sources may contain conflicting information about the same measure. Some stakeholders, such as purchasers, have to take the measure information they piece together and then determine and communicate the *intent*, or purpose, of a measure.

Even some measure developers do not have centralized systems for collecting and maintaining across all of its programs the full specifications for the measures they develop.

- The ACC recognizes the tedious nature of looking for information about current measures for the purpose of identifying and potentially filling measure gaps.
- Some organizations, such as NLM, recognize that the correct or aligned incentives would better support the collection of information from sources so that their systems can accurately represent that information.
- AHRQ recognizes that it encounters great challenges in accurately representing measure information in NQMC because it lacks clear incentives for measure developers to submit updates to measure information.
- The incentive for measures to gain and maintain endorsement over time supports NQF's ability to collect measure information from measure developers.

The lack of standardization of the information collected and represented about measures between systems further lends to the challenges in accurately representing the most up-to-date information about a measure. Related, CMS is aware of the burden that currently exists for measure developers to submit measure information to multiple parties for multiple purposes and wishes not to add to that burden by requiring more beyond what is currently asked. Many suggest that updates to measures be conducted at times according to a set schedule, rather than using arbitrary timing for updating measure information.

Inconsistent or Unclear Approaches to Measure Versioning

Each organization and agency describes unique approaches to understanding changes to measures or attempting to reflect measure versions. There is no single definition for what determines a new version of a measure; most organizations use their own judgment regarding the significance of changes to determine when a measure update should be considered a 'new' version. Some organizations maintain a measure's unique identifier over time, regardless of the number or extent of updates to a measure, while others create a new identifier for each new version of a measure. Most organizations recognize

that their own approach may have limitations, and would like greater clarity on what ought to determine when a change to a measure constitutes a 'new' version.

Stakeholders expressed the need to have access to measure information even after measures are retired, lose their endorsement, or otherwise "disappear" from the current primary sources of measure information. Those who implement measures, in particular, require access to historical information about a measure, with details on specific changes that were made to the measure, as well as the reason(s) why a measure changed, was retired, was never endorsed, or lost its endorsement. Implementers would like access to all information on a measure at any time, regardless of its stage within the development and use pipeline.

Unique Information Needs Associated with eMeasures and Their Implementation

Several organizations and agencies recognize the complex nature of eMeasures and the challenges associated with capturing eMeasure information at a sufficient level for implementation. All eMeasures have globally unique identifiers, or GUIDs, but these identifiers are not universally used as the way to refer to eMeasures. Specifications for an eMeasure can change when that measure is implemented to conform to the requirements of the electronic health record in which it is used. This limits the ability to compare performance across healthcare systems or providers that use different electronic health records to collect data and report results on performance and patient outcomes. To ensure it maintains the relationship between measures and eMeasures, Kaiser Permanente captures eMeasure value sets with the information that is captured and stored about a measure. Other measure information systems, such as NQMC, do not currently display eMeasure specifications, but may incorporate eMeasures in the future. In all, any resource that attempts to coherently capture and share information about eMeasures will need to do so with great attention to detail.

eMeasures also add a layer of complexity when attempting to track measure versions. Because an eMeasure is an iteration of a measure, it needs to have its own specifications tracked over time. Also, because an eMeasure may be created based on a version of a measure that is not the most current version, updates to the eMeasure may be out-of-sync with updates to the measure on which it is based. Keeping an eMeasure in sync with the original measure and aligning changes to both the eMeasure and the original measure across different systems has proven to be complex.

Dynamic Nature of the Quality Measurement Field

As the quality measurement field continues to evolve and advance, the sources for measure information must also evolve and improve to meet measurement needs. Developers and implementers alike need access to more information, including full specifications of a measure. Many would like to link measures with benchmarks, reference points, or other performance results to provide users insight on assessing performance on a measure or comparing results across settings.

For measure implementers, staying current on the status of measure development and endorsement is difficult. Implementers would like to know about measures that may be in development to inform their own implementation planning efforts.

Potential Value of a Single System or Approach

All organizations and agencies were asked whether a single, standardized system or approach for gathering and maintaining measure information would provide value. Nearly all organizations recognized that the current approaches they use or the sources they access fall short of meeting the full

range of their needs. Some measure developers and accreditation bodies are generally satisfied with their internal systems and approaches and do not see value in, or have resources to contribute to, a process outside of their organizations to maintain measure information beyond what they already submit to external entities.

Where measure developers and accreditation bodies see benefit from a singular approach is if that system or approach helped to standardize across organizations or agencies the information requested regarding measures. Developers recognize that they play an important role in sharing measure information with others, particularly as it relates to maintaining endorsement of a measure over time or assisting implementers in the correct application and analysis of a measure. However, given current workflow and workload to maintain internal systems, simply creating another place for measure information to be submitted and maintained is not perceived as offering value to the field. For some measure developers, access to complete and current measure specifications is only available when an entity participates in a certification or accreditation program managed by that developer; payment for information about measures is key to the organization's business model. Measure developers recognize that they need to maintain their internal systems regardless of whether a single, standardized system is put into place in the future.

Other stakeholder groups view a single system or approach as offering great value to the field. Implementers in particular appreciate that a 'one-stop shop' approach for measure information would significantly reduce the resources currently devoted to finding measure information. It could simultaneously offer the kind of information needed about a measure that may not be systematically captured today (i.e., measures being developed, measure gaps, measure use, results and benchmarks, feedback loops).

All organizations recognize the complex nature of quality measurement and are interested in a collaborative space for shared learning and guidance on what measures need development and how best to implement measures. They also recognize that a governance structure would need to be put into place to successfully manage the different inputs and outputs of such a system, to ensure that the measure information is accurately displayed and reliably managed over time.

Evaluating Opportunities within Current Systems and Approaches

Many groups offered caveats about the value a new system might offer, as current information sources do provide value despite falling short in some ways. HRSA, for example, shares that AHRQ's NQMC is a strong resource and may require less adaptation to meet all the information needs of users. Similarly, if NQF displayed full measure specifications and expanded to include information about measure use, it could better meet information needs regarding endorsed measures. Others recognize that certain systems provide information about different aspects of measures specific to where the measure may be along the development and use pipeline. They suggest that an improved system might simply pool and validate the information from current sources into a central location. Economies could be realized for those seeking information, as having one place to access up-to-date and historical information about measures would lower the burden on organizations that already commit staff time to tracking down measure information.

Establishing Expectations—Primary Audiences and Intentions

There is great diversity in the kind of information stakeholder groups would expect from a single system or approach. Some stakeholders suggest that focusing efforts on having a single place to access updated measure specifications will be enough to support quality measurement. Most other organizations and agencies hope that a single system or approach brings in more information than is currently available

across all information sources. Many suggest that in order to understand what information the potential system or approach should include, clarity is needed first on the primary audiences and the primary purpose. Organizations warn that if something is constructed in an attempt to meet the wide range of information needs—from developers' to implementers' needs—it may fail to fully satisfy any single stakeholder group's needs.

Balancing Governance of Information Management with Incentives for Maintenance

Several organizations suggest that the federal government should be the entity to establish and maintain a governance structure for curating and assuring the accuracy of measure information. Stakeholders realize that any system would depend on information from measure developers and from implementers if the system captured measure use *and* results. Incentives for maintaining measure information currently exist, such as maintenance of endorsement via NQF and reporting results for performance-based payment programs. Incentives may need to expand to motivate groups to share information regarding measures, such as specifications from measure developers and measure results or benchmarks from measure implementers. A standard schedule of updates across all involved entities may also be needed to keep current all information collected.

Expanding Current Information Collection and Feedback

Organizations and agencies note that the following information would be helpful to have access to in any system or approach:

- A consistent way to uniquely identify measures along the lifecycle
- Measure concepts⁵
- All measures and eMeasures (whether tested or endorsed) and their versions
- Clear indications of current versions and documentation of changes to measures over time
- Full measure specifications
- Implementation guidance
- Information about similar and/or related measures
- Feedback mechanisms between measure developers and implementers
- Reporting and incentive programs within which the measure is included
- Measure use experience information from implementers
- Measure results and benchmarks

It is clear that no single system or approach in use today meets the full needs of any organization. So, regardless of how expansive or comprehensive a single system or approach may or may not be, there is a shared need for a source of full measure specification information and measure implementation guidance. Many implementers have to find their way through the measure information maze, and have little confidence that congruency exists between the top three or four information sources they access. Many implementers also are not confident that a single, standardized system would be successful.

If nothing else, implementers would like for AHRQ, NQF, CMS, and measure developers to work more closely together to: (1) reliably collect and display full measure specifications; and (2) allow for feedback loops for measure developers to share implementation guidance and those in the field to share their implementation experience.

⁵ 'Measure concepts' are the preliminary considerations for a measure. A measure concept has not been fully tested and the technical specifications are not fully defined. It includes the following elements: numerator, denominator, exclusions, preliminary specifications, proposed levels of analysis, data source, and settings of care; and description of proposed risk adjustment/stratification methodology and risk factors.

Exploring Functionality to Support Information Needs

Several organizations and agencies suggest that a single system or approach may benefit from creative thinking to make the system more valuable to users. For example, building a system around a unifying framework—such as the National Quality Strategy—may help organize measures within relevant areas. The system or approach could also be designed so that the front-end offers options relevant to the unique needs of specific stakeholders, so long as all of the information is connected. The system or approach will need to allow for easy input and output of measure information. Regardless of the technical platform used, the search functionality must meet the needs of users from basic to advanced, and provide logical filters for finding measures and related information.

Certain organizations recognized that a "dream system" would likely require a significant amount of resources to build and maintain. So, beyond ensuring that a certain set of information be available to all users, a tiered, subscription-based approach for users to obtain more details about a measure and its use may be an option for sustaining the system over time. At least half of the organizations that participated in the discussions (primarily those involved in implementation) indicate they might be willing to pay for such a system as long as it meets their needs. This system cannot, however, add burden to staff or require significant re-working of their current workflow processes.

Next Steps

The diversity of stakeholders involved in healthcare quality measurement and reporting and their respective needs suggests that further discussion is necessary to gather the input required to assess the value of a single, standardized system or approach being created to meet these needs. Over the course of the next several months, NQF will continue to gather feedback and share that feedback publicly through the HHS-sponsored Measure Registry Needs Assessment project.

On July 26, 2012, NQF will host a public webinar to highlight some of the measure information systems and approaches currently in use and to provide an open discussion forum for participants. NQF will then host an in-person meeting on September 5, 2012, at which participants will explore needs, related trade-offs, and potential recommendations for a defined system or approach to gathering, storing, and accessing measure information. A final report summarizing the findings will be submitted to HHS and shared via the NQF website by the end of 2012. More information on this project is available at www.qualityforum.org/RNA. Questions should be directed to Anisha Dharshi at rna@qualityforum.org/RNA.

Appendix A—Organizations Involved in Stakeholder Discussions

Stakeholder Organization	Website for Organization/System*
Agency for Healthcare Research and Quality (AHRQ)	www.ahrq.gov www.qualitymeasures.ahrq.gov
American College of Cardiology (ACC)	www.cardiosource.org
Beacon Communities	www.healthit.hhs.gov/portal/server.pt?open=512 &objID=1805&parentname=CommunityPage∥ entid=2&mode=2&cached=true
California Office of the Patient Advocate (OPA)	www.opa.ca.gov
Centers for Medicare & Medicaid Services (CMS)/Health Services Advisory Group (HSAG)	www.cms.gov www.hsag.com
Health Resources and Services Administration (HRSA)	www.hrsa.gov
The Joint Commission	www.jointcommission.org
Kaiser Permanente	www.kaiserpermanente.org
Leapfrog Group	www.leapfroggroup.org
Minnesota Community Measurement (MNCM)	www.mncm.org
National Business Coalition on Health (NBCH)	www.nbch.org
National Center for Health Statistics (NCHS), Centers for Disease Control and Prevention	www.cdc.gov/nchs www.healthindicators.gov
National Committee for Quality Assurance (NCQA)	www.ncqa.org
National Library of Medicine (NLM)	www.nlm.nih.gov/research/umls/knowledge_sou rces/metathesaurus/index.html
National Quality Forum (NQF)	www.qualityforum.org/QPS
Office of the National Coordinator for Health Information Technology (ONC)	www.healthit.hhs.gov
Pacific Business Group on Health (PBGH)	www.pbgh.org
U.S. Department of Veterans Affairs (VA)	www.va.gov

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^{*} For those organizations that have a public-facing resource for measure information, the website for that resource has been included.

Appendix B—Stakeholder Discussion Guide

Registry Needs Assessment Stakeholder Discussion Guide

Note: The following is a set of questions to guide discussions with specific stakeholder groups for the Registry Needs Assessment effort. The exact questions asked will depend on the stakeholder and the conversation as it progresses. It is not expected that all stakeholders will answer all of the questions within the allotted time for the discussions.

FOR STAKEHOLDERS WHO DEVELOP MEASURES AND/OR MAINTAIN INFORMATION ABOUT THOSE MEASURES:

- 1) In your current role, please briefly describe your measure and eMeasure information needs.
- 2) How does your organization track and store indicator information? Please describe:
 - o Purpose of the system or approach
 - o Structure or format (electronic, paper, web-based, etc.) of system or approach
 - Types of information about measures (including versions, at any point along the measure development, endorsement, and use pipeline) included in your system or approach
 - Processes for maintaining and managing the infrastructure of your system or approach and keeping the measure information current
 - O Who uses the system (e.g., internal staff, individuals outside your organization), how often is it used, what the different access permissions are, and what it costs for others to use your system or approach
 - o Why users access your system (what value do they see in your system or approach)
 - o What value you find in maintaining your own system or approach
- 3) Do you have any unmet needs from the systems or approaches you currently use? If so, what are they?
- 4) Would it be helpful to have a consistent way to identify and track versions of the same measure, including eMeasures, regardless of measure developer, endorsement status, level of analysis, etc.?
- 5) What are your thoughts or reactions to the following issues that could arise through the process of identifying a consistent approach to measure information:
 - o Agreeing on a standard versioning convention
 - Cost of managing the system or approach
 - Incentives for organizations to adopt the system or approach
 - o Intellectual property constraints
 - o Issues unique to eMeasures
 - o Potential impacts on your workflow for your system or approach
 - a) Which of these issues is the most important to address?
 - b) Are any primary issues missing from the list above?
- 6) Do you have any other comments about this?

FOR STAKEHOLDERS WHO USE OR IMPLEMENT MEASURES AND SEEK INFORMATION ABOUT MEASURES:

- 1) In your current role, please briefly describe your measure and eMeasure information needs.
- 2) Do you use information systems (or approaches) that are external to your organization? If so, please describe:
 - o Organization that owns or produces the system or approach
 - o Types of information you pull from that system
 - Why you use that system
 - o How often you use the system
 - Most useful attributes, functions, or content of the system
 - Cost of using the system, if any
- 3) Do you have any unmet needs from those external systems or approaches you currently use? If so, what are they?
- 4) Would it be helpful to have a consistent way to identify and track versions of the same measure, including eMeasures, regardless of measure developer, endorsement status, level of analysis, etc.?
- 5) Describe an ideal system or approach to address your needs:
 - o How would the system or approach work?
 - O Who would have access and how would that happen?
 - o What information about measures would be included?
 - o How would measure information be maintained or kept current?
 - o What would motivate people to use the system or approach?
 - O What would it cost, if anything, to use this system or approach?
 - o What might be a barrier to achieving this system or approach?
- 6) What are your thoughts or reactions to the following issues that could arise through this process:
 - Agreeing on a standard versioning convention
 - Cost of managing the system or approach
 - o Incentives for organizations to adopt the system or approach
 - o Intellectual property constraints
 - o Issues unique to eMeasures
 - a) Which of these issues is the most important to address?
 - b) Are any primary issues missing from the list above?
- 7) Do you have any other comments about this?