

REPORT FROM THE
NATIONAL QUALITY FORUM

HHS-Sponsored Measure Registry Needs Assessment

FINAL REPORT
DECEMBER 21, 2012



NATIONAL
QUALITY FORUM

CONTENTS

EXECUTIVE SUMMARY	2
BACKGROUND	3
MAJOR FINDINGS	4
Challenges to Address	4
Participating Organizations' Primary Measure Information Needs	6
Value in a Standard Approach to Meeting Needs	7
Opportunities to Consider	10
Suggested Next Steps	11
Conclusion	14
ENDNOTES	16
APPENDIX A Organizations that Provided Input into the HHS-Sponsored Measure Registry Needs Assessment Project	17
APPENDIX B Activities and Corresponding Reports of the HHS-Sponsored Measure Registry Needs Assessment Project	18

EXECUTIVE SUMMARY

As healthcare quality measurement evolves and reporting on quality measures becomes more common, an increasing number of organizations need to maintain and/or access measure information. The process is challenging. Lack of standardized measure information and varied approaches to identifying and tracking changes to measures over time make finding information about measures difficult and resource-intensive. Without a uniform system to catalogue measure information, measures that seem the same may differ in their specifications and their applications, complicating organizations' ability to measure and compare performance.

Recognizing these critical issues, the Department of Health and Human Services (HHS) asked the National Quality Forum (NQF) to convene measure developers and others who have a need for information about measures to help HHS: 1) assess measure information needs across the measure lifecycle; 2) identify systems or approaches currently in use to access and/or maintain measure information; and 3) explore the potential value in a standard approach for tracking measure information. This report summarizes the key findings from the resulting [Measure Registry Needs Assessment project](#) and details next steps suggested by participants to support meeting the measure information needs of organizations that develop, select, and/or use measures. This report can inform HHS' near-term decisions on where and how to invest in managing measure information. The report can also help HHS determine the role that the federal government can play to help meet measure information needs, both through coordination across HHS agencies and within the context of aligned public- and private-sector efforts.

The findings of this assessment confirm that measure developers, implementers, and others involved in quality measurement require access to complete, up-to-date measure specifications that are appropriate for how the measure is to be used. They also need clear ways to identify measures and

related versions across the lifecycle of a measure—from conceptualization to the development, testing, endorsement, use, and retirement of a measure. Participants in this process also want to know how a measure is used, understand performance on measures, and access benchmark information to compare quality across settings and regions over time. No one system available today provides all of this information, but the participants indicated support for specific actions that can be taken to better meet measure information needs. These key near-term actions include:

- Building the foundation for shared definitions of measure information elements and consistent processes for identifying and tracking changes to measures over time;
- Defining a clear vision for measure information management by first clarifying target audiences and the business cases that support their active participation in and use of any potential approach;
- Taking an incremental approach to meeting measure information needs, examining first whether existing systems can contribute to the solution;
- Supporting the market forces that drive engagement and innovation in measure development and implementation, including connecting measure developers and implementers for shared learning; and
- Furthering measure information management activities across HHS agencies, in collaboration with private-sector efforts.

The participating organizations indicated a shared view that the time is now for establishing a consistent approach to measure information management. Opportunities exist to capitalize on the readiness of the field to achieve alignment and streamline efforts to accessing and maintaining measure information.

BACKGROUND

As healthcare quality measurement evolves, many organizations need to maintain and/or access measure information and find that task challenging. While there have been various attempts to address these challenges, no single system exists today that meets the needs of all those involved in quality measurement and reporting. HHS and others have expressed interest in being able to consistently identify and track measures and their related versions within the measure conceptualization, development, testing, endorsement, use, and retirement lifecycle. As a result, HHS contracted with NQF¹ to convene organizations involved in measure development, selection, and/or use to conduct a needs assessment that explores key issues and considerations for a standard approach to gathering, storing, and accessing measure information.

The resulting **Measure Registry Needs Assessment project** involved NQF gathering information from and convening a wide range of organizations involved in quality measurement (**Appendix A**) to: 1) assess measure information needs across the measure lifecycle; 2) identify systems or approaches currently in use to access and/or maintain measure information; and 3) explore the potential value in a standard approach for tracking measure information. This project is not an evaluation of current measure information management systems. Therefore, the report does not include a history or complete description of measure information management systems or an analysis of efforts currently underway to improve those systems.

This report can inform HHS' near-term decisions on where and how to invest in managing measure information. The report can also help HHS determine the role that the federal government can play to help meet measure information needs, both through coordination across HHS agencies and within the context of aligned public- and private-sector efforts.

This report includes findings from the following information-gathering and convening activities (see **Appendix B** for further information on each activity):

- An open call for information about current systems and approaches to measure information management;
- A public webinar to share information about selected systems;
- Targeted discussions with public- and private-sector organizations involved in measure development and implementation; and
- A multi-stakeholder workshop to explore measure information needs, requirements, and potential approaches to measure information management.

This report provides an analysis of the information gathered during these project activities, and reflects suggestions developed during the multi-stakeholder workshop regarding next steps to support meeting the measure information needs of those who develop, select, and/or use measures.²

MAJOR FINDINGS

The findings summarized in this report are based on information and perspectives shared by the broad range of organizations who participated in this project.³ For example, measure developers and implementers alike use a variety of methods to maintain measure information. Some organizations use Microsoft Word documents or Excel spreadsheets to manage specifications for a measure or track a federal reporting or incentive program in which a measure is used. Others have developed and maintain custom databases. Some organizations rely on one or two individuals to design and manage these custom databases, while others devote more staff resources to maintaining such tools.

Despite this diversity and regardless of perspective, participants share major challenges to accessing and maintaining measure information. Most gather measure information from more than one source, citing key organizations (e.g., Agency for Healthcare Research and Quality (AHRQ), Centers for Medicare & Medicaid Services (CMS), National Library of Medicine (NLM), National Quality Forum) and measure developers as primary sources. Sometimes multiple downloads are required to get all of the needed information from one source, so the multitude of sources exponentially increases complexity and time needed to access measure information. Because information available from these sources varies, internet searches are often used to complete the full information needed. As quality measurement and improvement continue to evolve, along with a growing interest in achieving greater alignment across measurement approaches, a consistent approach is needed regarding measure information itself.

Challenges to Address

Limited Resources for Maintaining Measure Information

Securing and sustaining resources to support measure information management is an ever-present challenge for most organizations. For all, funding (or lack thereof) drives the process as well as the extent of and enhancements to their systems or approaches. Many make the trade-off to rely on simple, practical tools because the resources required to build and maintain a database or more robust measure information system are not available. Even measure developers, who devote significant resources to develop and maintain their measure information, report that limited resources hamper their ability to fully support their business models and workflow processes. Measure developers often are not aware of potential overlap in measure development areas until they have specified and tested a measure, straining already limited resources and/or funding streams to develop and maintain measures.

Lack of Standardized Measure Information

Participating organizations noted that they would find value in a standardized set of elements, with standardized definitions, for measure metadata—the specific information elements that are important to capture *about* a measure, such as the measure's unit of analysis and type of result (e.g., percentage or rate) it generates. Currently, because measure specifications and related information can vary between sources and across those who use measures, and because there are no standard definitions for the various measure

elements, it is challenging to ascertain specific differences across sources and users regarding what may appear to be the same measure.

Lack of Standard Measure Identification Practices

Across the many existing measure information systems, there is no single or common approach or numbering system to identify measures, making it impossible to link information from different sources about the same measure. Even within one organization or agency, there may be different approaches used to identify the same measure. Some organizations use specific combinations of letters and numbers to identify measures they develop or track, while others use their databases to automatically generate an identifier for a measure. Some organizations change the titles of measures to match their internal convention, adding further complexity to this challenge. For endorsed measures, many use the NQF measure number to track those measures over time and across specific internal quality improvement efforts and/or reporting and payment incentive programs. Accurately tracking changes to a measure is extremely difficult without a unique identifier consistently used for each measure regardless of setting or source. To some, this high priority need cannot be overstated.

Insufficient and/or Inconsistent Information across Available Sources

No system provides the full set of information participants need about a measure, nor can organizations that gather information from multiple sources have confidence in the consistency or accuracy of that information. Some large measure developers do not have centralized systems for collecting and maintaining the complete specifications for the measures included in their measurement, reporting, and/or incentive programs. In addition, participants noted that measures might “disappear” from information sources when they are retired or are no longer endorsed by NQF.

Inconsistent or Unclear Approaches to Measure Versioning

There is no shared or common definition across existing measure information systems regarding what determines when changes to a measure are significant enough to consider it a “new” version of that measure. Most organizations use their own judgment regarding the significance of changes to a measure. How such organizations track changes to a measure over time is also inconsistent; some organizations maintain a unique identifier for a measure over time—regardless of the number or extent of updates to that measure—while others create a new identifier each time a “significant” update is made to a measure.

Unique Information Needs Associated with eMeasures

Organizations recognize the complex nature of eMeasures and the challenges associated with identifying, using, and capturing eMeasure specifications within their systems. Because an eMeasure may be created based on an older version of a measure, updates to the eMeasure may be out-of-sync with updates to the measure on which it is based. Furthermore, specifications for an eMeasure may need to change to conform to the requirements of the electronic health record in which it is used.

Dynamic Nature of the Quality Measurement Field

As quality measurement continues to evolve, a growing number of organizations are using measurement to improve outcomes. But no one organization has the responsibility for ensuring the reliability and accuracy of measure information. The sources for measure information must also evolve and improve to meet measurement needs. Those who develop and/or implement measures need access to more information, including complete measure specifications. Many would like to link measures with benchmarks or measure results to assess performance or compare results across settings and geographic areas over time.

Participating Organizations' Primary Measure Information Needs

Through this project's activities, participants engaged in measure development and/or use helped to clarify and prioritize the major measure information needs that a standard approach could help satisfy (Table 1). First and foremost, nearly all of the participants noted that they need access to complete, up-to-date measure specifications. Participants also need clear ways to identify measures and related versions across the measure lifecycle—from conceptualization to the development, testing, endorsement, use, and retirement of a measure. Those who implement

measures in particular want to know how a measure is used, understand others' performance on measures, and access benchmark data to compare quality across settings and regions over time. This includes feedback loops to help inform measure developers regarding whether their measure development focus is on-target. Such feedback loops can also enable organizations to gain access to potential resources or partners to meet market needs. This is especially needed given the increasing collection and use of electronic data sources for measurement and reporting, which is spreading due to advances in technology and incentives through public- and private-sector initiatives.

TABLE 1. PARTICIPANTS' PRIMARY MEASURE INFORMATION NEEDS

Priority	Measure Information Needs
1	Complete, up-to-date measure specifications , including associated codes, logic, and related information
2	Consistent approaches to definitions for elements of measure information, or metadata , as well as measure identification and versioning processes to help organizations track a measure and changes to it throughout the development and use pipeline (including measure concepts and measures no longer maintained by the measure developer)
3	Measure use information (including use in national reporting and incentive programs and use at the local, state, and regional levels) with systematic, structured feedback loops between measure developers and measure end-users to support collaboration and implementation
4	Measure results and benchmark data , including information that can support comparisons across settings and regions over time, and that can inform action to close performance gaps
5	Other information to support use of a measure including: <ul style="list-style-type: none"> • Measure abstracts (concise summaries of the most essential information about a measure, including the context for why the measure is important and/or the intent of the measure) • Harmonization among and relationships between measures • Measure gaps • Reliability and validity testing information

Value in a Standard Approach to Meeting Needs

All organizations participating in the project agree that the current varied approaches to tracking measures and their changes are too disjointed. At the same time, many believe that existing systems and processes can be leveraged effectively to some degree. Most participants support a consistent approach to measure information management, seeing value if the approach helps to standardize measure information across organizations or agencies. Those who implement measures, in particular, would greatly value an approach that reduces the level of effort and resources required to find measure information and stay abreast of changes to measures over time. These participants will need to work together to determine the optimal approach for moving forward.

Potential Approaches to Measure Information Management

At the workshop convened for this project, participants considered four potential approaches to frame their input on key functions and actions that could be taken to meet primary measure information needs. The approaches represent new thinking on how to meet measure information needs, building on existing systems. Potential approaches are described below and in [Table 2](#), with key benefits, challenges, and trade-offs highlighted. These approaches are not exhaustive, nor are they mutually exclusive; components of one approach may be combined with another's to ensure flexibility and to be inclusive of multiple organizations' needs. Regardless of the ideal approach, participants agree that creating a standard approach should be done in phases. A smaller-scale or simpler approach could provide the foundation for a future, larger-scale effort.

Alignment of Information in Existing Systems

Participants agree that the first—and more easily achievable—step toward meeting measure information needs is to enable the alignment

of information in current measure information systems that store measure information for public and/or private use. Examples of current systems include AHRQ's National Quality Measures Clearinghouse, CMS' Measures Inventory, NQF's Quality Positioning System, Kaiser Permanente's Quality Measures Navigator, and The Joint Commission's Performance Measurement Network Q&A Forum. This step includes defining a set of data elements with commonly agreed-upon formats and definitions. Examples of this approach range from long-standing efforts like Electronic Data Interchange sponsored by the Data Interchange Standards Association (www.disa.org) to newer alignment efforts like the Legal Electronic Data Exchange Standard (www.ledes.org), both of which support or maintain standards for business-to-business data exchange.

A benefit of aligning information in existing systems is the ability to take an incremental approach—widely preferred by participants—with the potential to connect data systems (manually or systematically) based on common, standardized data elements. Additionally, eMeasure implementation may provide guidance at the data element and structure level on how and what to standardize. However, lack of an existing standard-setting body to manage this process, and the unique data needs of individual systems and organizations, pose challenges for such a design.

Ultimately, assuming sufficient incentives for participation are in place, aligning information in existing systems could set the stage for improved communication among organizations at a comparatively low cost. However, it does not ensure the measure information will be any more accessible, consistent, or accurate.

Independent Systems and Information Repositories Accessible via One Access Point

Making data within multiple measure information systems accessible via a single access point is another potential approach to meeting participants' needs. In this approach, content is “scraped” from other sites or information

TABLE 2. POTENTIAL APPROACHES TO MEETING MEASURE INFORMATION NEEDS AND CORRESPONDING BENEFITS, CHALLENGES, AND TRADE-OFFS

Potential Approach	Benefits	Challenges	Trade-Offs
Alignment of Information in Existing Systems	<ul style="list-style-type: none"> • Ability to take an incremental approach • Potential to connect data systems (manually or systematically) based on common, standardized data elements 	<ul style="list-style-type: none"> • Lack of an existing standard-setting body or organization to manage the approach • Unique data needs of individual systems and organizations 	With the right incentives, this approach could set the stage for improved communication among organizations at a comparatively low cost, but it does not ensure the measure information is any more accessible, consistent, or accurate.
Independent Systems and Information Repositories Accessible via One Access Point	<ul style="list-style-type: none"> • Ability to create single access point relatively quickly by using commercially-available products • Flexibility in indexing of systems • Could support better understanding of existing information sources and where opportunities for alignment of information exist 	<ul style="list-style-type: none"> • Manual assessment of the indexed information would be needed to assure relevancy of the information returned from systems • Potential for duplicative information about measures 	Moving forward with this approach would force organizations to balance the rapid time to market and lower development costs and data entry requirements with concerns over the accuracy, completeness, and relevance of the information.
Multiple Systems Connected into One System	<ul style="list-style-type: none"> • Ability to take an incremental approach • Cost of information and system maintenance can be distributed across several entities • Could provide a deeper and wider set of information to users than other approaches 	<ul style="list-style-type: none"> • With loose alignment of multiple systems, issues of authority and control over input and maintenance of data can occur • Potential for duplicative information about measures 	This approach distributes the burden of input of data and allows some autonomy for participants, but it does not assure the accuracy, completeness, or relevance of information to the user without considerable governance and strict alignment across participating systems.
One Registry for Measures	<ul style="list-style-type: none"> • Greater assurance of the accuracy, completeness, and relevancy of the information within the system • Could be achieved by expanding an existing system • Would necessitate alignment across organizations' measure information 	<ul style="list-style-type: none"> • Least suited for the desired incremental approach • Would require significant resources and strict governance to build, maintain, and enhance over time • May unequally burden segments of the measure development community 	This approach could help meet the primary needs identified if sufficient resources are allocated, and the governance structure and business case for participation and use are widely accepted and not unduly burdensome, particularly for measure developers.

sources and a variety of techniques used to allow users to find the information they are looking for with greater speed and precision than an internet search or by visiting multiple systems/sites individually. This model would be similar to employment search sites such as [simplyhired.com](https://www.simplyhired.com) or [indeed.com](https://www.indeed.com) that “crawl” the variably-structured content of thousands of employers’ sites and unify it into a single interface that allows for easier searching by individuals.

A key benefit of making data within multiple measure information systems accessible via a single access point is the ability to create it relatively quickly by using a number of commercially-available products. This approach would be flexible in which systems it indexes and how it indexes those systems, and also could pave the way for a better understanding of the existing information sources and where the opportunities for alignment of information exist. Conversely, it would be difficult to assure relevance of the information returned from multiple systems without resorting to manual assessment of the indexed information. Furthermore, information on the same measures would be returned from different sources, leaving the end-user to sort and determine the applicability or relevance of individual information sources.

Moving forward with making data within multiple measure information systems accessible via a single access point would require organizations to balance the rapid time to market and lower development costs and data entry requirements with concerns over the accuracy, completeness, and relevance of the information to the user.

Multiple Systems Connected into One System

Federated models enable the display of information from multiple independent information systems while allowing those systems to maintain their independence to evolve and meet their own

users’ needs. Similar to the previous approaches, a federated model brings information from multiple systems into one location; however, it is different from the previous approaches in that it is dependent, in part, on some level of information alignment among systems. This alignment could be strict (e.g., use of a common identifier) or loose (e.g., map two fields in System A to one field in System B). This is a common feature of financial sites like [mint.com](https://www.mint.com) or airfare sites like [kayak.com](https://www.kayak.com). These sites pull in data from a variety of other organizations. Sometimes they must pay for access to this information and use a variety of data standards, interchange formats, and data transportation methods that conform to those of the organizations from which they are pulling information.

Benefits of a federated model include enabling incremental implementation; systems can be added as they are ready. Also, the cost of information and system maintenance can be distributed across several entities (i.e., current system owners). Since this approach may not require strict alignment of information fields, it could provide a deeper and wider set of information to users than other approaches. However, with multiple systems loosely aligned, issues of authority and control over input and maintenance of data could occur. Also, similar to the previous approach, there is potential for duplicative information about measures, as the same measure could be visible from multiple systems and each system may have a different version of the measure and its related information.

Overall, a federated model distributes the burden of data input and allows some autonomy for participants, but it does not assure the accuracy, completeness, or relevance of information to the user without considerable governance and strict alignment across participating systems.

One Registry for Measures

Several participants were supportive of a “one-stop shop” to meet their primary information need: complete and up-to-date measure specifications. The most direct approach to achieve this goal is to create a single, authoritative system. A first step toward this model would be to examine current systems and their potential to meet the major needs identified. Most participants suggest pursuing the creation of one measure registry only after first determining that the above approaches do not provide the needed value. The International Standard Book Number system (www.isbn.org) is an example of a single, authoritative system that assigns and requires maintenance of related information according to standardized protocol, including conventions for designating new editions of published books.

Benefits of one registry for measures include a level of assurance of the accuracy, completeness, and relevancy of the information within the system and, over time, a resource that meets the primary needs of all organizations. This model could be achieved by expanding an existing system and would necessitate alignment across organizations’ measure information. The model, however, is least suited for the desired incremental approach to aligning information across sources. Significant resources would be required to build, maintain, and enhance the system to meet growing needs, as would strict governance and corresponding incentives to ensure widespread participation and use. It may also unequally burden segments of the measure development community.

If alternative approaches or existing measure information systems are not successful, one registry for measures could help meet the primary needs identified. Sufficient resources would need to be allocated and the governance structure and business case for participation and use widely accepted. To be successful, participation in and use of this approach cannot be unduly burdensome, particularly to measure developers.

Opportunities to Consider

Existing systems for measure development and dissemination inform much of the understanding of opportunities surrounding potential approaches. Since most of the desired measure information exists, participants noted several ways to improve the accessibility and reliability of information across sources.

Alignment of Measure Information Would Benefit All, Regardless of Approach

Many measure information management systems have been designed based on an organization’s needs and not on a consistent or shared approach to collecting and maintaining information about measures. Consequently, system structures are often specific to an organization’s internal business processes or program objectives. There is tremendous opportunity—if progress is made on consistency across measure information management approaches—to align information across multiple systems. Taking an iterative approach, perhaps first with a core set of measure information, opens up additional opportunities for bringing together data from these disparate sources. Alignment of measure metadata and incentives for participation and use can offer even greater assurance and relevance of the information to users. Participants mentioned that future efforts could build upon a 2009 collaborative effort by AHRQ, CMS, NQF, The Joint Commission, the National Committee for Quality Assurance, and the American Medical Association-convened Physician Consortium for Performance Improvement (AMA-PCPI) to identify common data fields for measures. While this alignment presents a significant challenge, each commonly agreed upon data element, including a common approach or numbering system to identify measures, presents significant new opportunities for collaboration and shared benefit.

The Technical Elements of All Approaches are Achievable

Although some systems are closed or apply inclusion criteria, technical work can be done to bring measure information together. Sharing information across systems could reduce the data entry and tracking burden for many organizations, as long as resources, intellectual property, and security challenges can be overcome. Participants recognize that technology is not the barrier to achieving a vision for meeting measure information needs.

Greater Collaboration Can Spur Uptake While Protecting Competition

Measure development is a competitive space that requires organizations to make significant investments to produce a usable measure. Measure developers regard measures as their intellectual property and wish to protect the integrity of their measures. As a result, some organizations control how, when, and with whom measure information, such as specifications, is shared. Given these restrictions, organizations like AHRQ and NQF that create tools to share information about measures are limited in their ability to display measure information so that it is readily available to potential users. These limitations hamper free sharing of measure information as a “public good.” Making measure information readily available and protecting the intellectual property of developers are not mutually exclusive, but these opportunities have not yet been explored or tested. There is opportunity to find middle ground on sharing specifications with users for the sake of supporting greater uptake and use of measures, creating space for developers and implementers to work collaboratively to improve measures over time.

Results Would Drive Increased Understanding and Improvement

Those who use or implement measures want the ability to share and review measure results from

other implementers, for use in benchmarking and to better understand performance within and across regions. Certainly, trade-offs exist; in systems which allow multiple users to enter data on behalf of multiple organizations, it may be difficult to judge who has the authority to submit data for the organization. The stronger the need for authority and authenticity, the greater the need for innovative incentives to encourage participation. However, with standard measure identifiers, consistent approaches to versioning, and definitions for key measure information elements, it could be feasible to accurately tie measure results to the correct version of a measure and ensure results available for benchmarking are truly comparable.

Suggested Next Steps

Based on the needs and perspectives shared by participating organizations, the time is now for establishing a consistent approach to measure information management. While foundational work has been completed or is underway in a variety of areas, a more coordinated and concerted effort is needed. Some examples of these foundational efforts include:

- Public efforts to align measure specifications using purpose-based common metadata by CMS, The Joint Commission, and AMA-PCPI;
- AHRQ’s development and maintenance of tools and resources, including the National Quality Measures Clearinghouse and the National Guidelines Clearinghouse;
- Registry design that has been done by AHRQ on the Registry of Patient Registries and the Outcome Measures Framework to support the process of collecting and displaying information on outcome measures currently used in patient registries;
- NQF’s development and maintenance of tools and resources, including the Quality Positioning System, which enables public access to

current information about endorsed measures based on NQF's measure endorsement and maintenance processes;

- Efforts to further electronic data collection and measurement initiatives, including Meaningful Use and the NLM's Value Set Authority Center, and their impact on formalizing the infrastructure for standardized specification of measures.

In considering the multitude of steps organizations take to research and secure information about a measure, coupled with the desire to improve and compare results about the quality of healthcare, the field is ready for a consistent approach.

Regardless of the approach taken, building the foundation will take time, energy, and funding. Shorter-term actions can begin to help better meet measure information needs. Based on these observations, participating organizations suggest HHS consider the following to guide its next steps.

Build the Foundation

Specific areas require agreement across a wide range of organizations involved in measure development, selection, and/or use to support progress on meeting primary measure information needs. First, as participants need clear and consistent information about a measure from the concept stage through retirement, clarity is needed on the specific components of the lifecycle of a measure's development and use. This clarity can help drive increased understanding and the development of definitions for the specific information elements that are important to capture about a measure.

Because organizations use different approaches for identifying measures within their systems, a consistent approach to measure identifiers is also needed across all systems. Users of any potential approach would benefit from standardized measure identifiers to ensure information from multiple systems is connected and to reduce the time it takes to piece together measure

information that does not share a common measure identifier.

Finally, as no standard approach exists to document and share specifics on changes made to measures over time, a consistent method of measure versioning is needed. Those who develop and use measures need to know the most current version of a measure, the specific changes to a measure over time, why those changes were made, and what implications may exist for performance results on prior versions. Taken together, these elements provide the foundation for any approach to measure information management and likely provide the greatest benefit to the field if no other steps are taken.

Providing solid ground for meeting measure information needs includes:

- Defining a measure's development and use lifecycle;
- Determining the key information about a measure throughout its lifecycle that is important to capture and defining those information elements (metadata);
- Creating a consistent approach to measure identification; and
- Defining a consistent approach to measure versioning.

Create a Road Map

Any approach to managing measure information requires a vision to guide its progress and priorities. Defining key audiences and the business cases to support their participation in and use of a potential approach allows for clarity on the purpose and scope of the work, and informs decisions about the specific content and functions. Next efforts can capitalize on areas for improving access to and quality of measure information where there is a shared vision, related efforts to build upon, and/or public- and private-sector resources that can be leveraged to meet the needs of the broad range of participants.

Overwhelmingly, participants agree that defining the primary audiences for any standard approach will help ensure that the approach taken will meet the measure information needs of those target audiences. Participants warn that if a system or approach is constructed at its start to meet *all* measure information needs, it will likely fail to fully satisfy any one organization or perspective. In other words, a “one size fits all” attempt may result in a “one size fits none” outcome. Participants recognize the central role measure developers play in contributing measure information to a system; therefore, if a single system is created and it disrupts workflow for measure development, endorsement, or maintenance, the approach could exacerbate the challenges that already exist.

Actions for defining the vision for the approach include:

- Clarifying the primary audiences;
- Defining the value to each audience of participating in and using the potential approach; and
- Determining the impact the approach may have on organizations’ resources and workflow.

Take an Incremental Approach

Considering the universe of options for meeting measure information needs, a phased approach to any option is essential. Clarity on the intended purpose of the approach—derived from its vision and target audiences—can provide guidance on how best to phase the approach’s design and development. The technology exists to meet needs, and most participants do not favor starting from scratch; rather, participants suggest that current systems and approaches be evaluated for their strengths and potential for contributing to a solution. Working through the specific design components of a potential approach could logically follow. Furthermore, a step-wise approach in the near-term may be able to better support a larger, long-term vision of a more robust system

for meeting high-priority measure information needs.

Based on the vision, actions for a phased approach include:

- Evaluating current systems for their effectiveness and potential to contribute to a solution;
- Seeking multi-stakeholder input on the potential design and functionality of the system; and
- Creating a development plan that first caters to an initial set of organizations’ needs with the intention of more comprehensively meeting all primary needs in the longer term.

Support Competition and Collaboration

Any potential approach must be able to balance the measure information needs of organizations with the market forces that drive engagement and innovation in measure development and implementation. For example, intellectual property constraints must be addressed when considering ways to meet the need for complete and up-to-date measure specifications. Also, the extent to which measure developers and system owners align with defined measure metadata fields may be driven by incentives to contribute measure information and possibly maintain that information over time. Finally, enabling measure developers and measure implementers to connect and learn from each other is desirable in any approach and has the potential to help close gaps in available measures and in the use of measures.

Actions to ensure participation and use include:

- Examining opportunities to share measure specifications widely while respecting business models of measure developers;
- Developing creative approaches to encourage alignment with defined measure metadata fields; and

- Creating structured approaches that enable measure developers and implementers to learn from each other and support continued innovation and expansion of effective performance measurement.

Coordinate on the Plan

Work is already underway within and across HHS agencies to better manage measures and related information over time. Some agencies are also aligning efforts with private sector initiatives to support measurement and improvement efforts across the country. There is a clear role for the federal government to take these and other steps to coordinate efforts across federal agencies and work in partnership with the private sector to improve and expand measure information management and access.

Regardless of the approach taken to meet primary measure information needs, participants recognized that there must be a solid plan for maintaining the approach and keeping it viable in the long-term. This plan must support the business case and the broader vision for keeping the approach relevant and flexible enough to meet ongoing and evolving needs. Leadership and investment of time and resources from both public- and private-sector entities will help ensure the approach is sustainable and valuable to the field for years to come.

Actions to work together include:

- Furthering the alignment activities across HHS agencies, including identifying and implementing transparent processes for consistently tracking measures used in HHS programs;
- Capitalizing on current and potential opportunities for the public and private sectors to coordinate on ensuring the accuracy and data integrity of measure information used in quality improvement and public reporting initiatives;
- Allocating resources to the development and ongoing maintenance of a standard approach to measure information management; and
- Creating incentives that motivate active participation in and use of the consistent approach to measure information management across organizations.

Conclusion

The participating organizations involved in measure development, selection, and/or use recognize the great opportunity to begin to meet the high-priority measure information needs to support healthcare quality improvement. These needs include: access to complete and up-to-date measure specifications; clear ways to identify measures and related versions across the measure lifecycle—from conceptualization to development, testing, endorsement, use, and retirement; information about how measures are used; and feedback loops to inform all organizations involved in healthcare measure development and/or use.

The suggestions presented in this report—to build the foundation for shared definitions of measure information elements and consistent processes to identify and track changes to measures over time; define a clear vision for measure information management; determine the best technical approach to meet measure information needs; support market forces that drive engagement and innovation in measure development and use; and collaborate across the public- and private-sector—are required actions, regardless of the long-term approach. Participating organizations agree that these need to be done by the end of 2013, and other actions must be taken in the next several years. Participants urge HHS to start by building on efforts completed and underway by various federal agencies (AHRQ, CMS, NLM) and private organizations (NQF, organizations that develop and use measures) to track measures over time,

from conception through retirement, to avoid reinventing the wheel.

Widespread participation in and use of any approach will be needed to satisfy the primary needs of measure developers and implementers alike. Immediate next steps, involving coordinating efforts across HHS agencies and defining the vision and target audiences, can capitalize on the readiness of the field to achieve alignment and can streamline efforts to accessing and maintaining measure information over time.

ENDNOTES

1 This report was produced in response to Task 6.5, Registry Needs Assessment.

2 Participants represented a broad range of organizations, some which develop measures, others which select and/or use measures, and several who do all three. As a result, and recognizing that measure information needs vary depending on the activity, the suggestions for next steps, as described in this assessment, reflect an

expanded view of measure information needs as noted by the participants (e.g., use of measures in federal, state or local programs; measure results for use in benchmarking).

3 Detailed findings from each of the project's activities can be found at www.qualityforum.org/RNA. Additional information on and links to each activity's report is included in [Appendix B](#).

APPENDIX A

Organizations that Provided Input into the HHS-Sponsored Measure Registry Needs Assessment Project

ActiveHealth Management	The Joint Commission
Aetna	Kaiser Permanente
Agency for Healthcare Research and Quality	Keystone Beacon Community
Aligning Forces for Quality National Program Office	Lantana Group
Allscripts	Leapfrog Group
America's Health Insurance Plans	Mathematica
American College of Cardiology	McKesson
American College of Physicians	Minnesota Community Measurement
American College of Surgeons	National Business Coalition on Health
American Institutes for Research	National Committee for Quality Assurance
American Nurses Association	National Database of Nursing Quality Indicators
Architelos	National Hospice and Palliative Care Organization
Brookings Institution	National Institute of Standards Technology
California Office of the Patient Advocate	National Library of Medicine
Centers for Disease Control and Prevention	National Partnership for Women & Families
Centers for Medicare & Medicaid Services	National Quality Forum
Cincinnati Beacon Community	Office of the National Coordinator for Health Information Technology
Colorado Beacon Community	OptumInsight
Consumer Purchaser Disclosure Project	Pacific Business Group on Health
Department of Veterans Affairs	Quality Insights of Pennsylvania
ECRI Institute	Rhode Island Beacon Community
Geisinger Health System	Society for Thoracic Surgeons
Health Care Incentives Improvement Institute	Substance Abuse and Mental Health Services Administration
the Health Collaborative of Greater Cincinnati	SunCoast Regional Health Information Organization
Health Resources and Services Administration	Truven Health
Health Services Advisory Group	United Healthcare
Humana	Wyoming Department of Health
Indian Health Service	

APPENDIX B

Activities and Corresponding Reports of the HHS-Sponsored Measure Registry Needs Assessment Project

Activity	Brief Description	Date(s)	Corresponding Report(s)
Open Call	An open call for information about current systems and approaches to measure information management.	May 16 – June 6, 2012	Summary of Responses
Stakeholder Discussions	Targeted discussions with public- and private-sector organizations involved in measure development, selection, and/or use.	June 11 – July 11, 2012	Summary of Stakeholder Discussions
Webinar: Current Systems	A public webinar to share information about selected measure information management systems.	July 26, 2012	Webinar Summary Webinar Recording Slide Presentations
Workshop	A multi-stakeholder workshop to explore measure information needs, requirements, and potential approaches to measure information management.	Sept. 5, 2012	Workshop Summary: Part I , Part II Meeting Recordings: Morning , Afternoon Slide Presentations
Webinar: Major Findings	A public webinar to share major findings from the above information-gathering activities.	Oct. 26, 2012	Webinar Summary Webinar Recording Slide Presentations
Public Comment Period	A 4-week period for members of the public to review and provide feedback on the Draft Report summarizing major findings.	Oct. 26 – Nov. 28, 2012	Summary of Feedback on the Draft Report
Final Report	The final report to HHS on the major findings on the project, including edits based on public feedback.	Late Dec. 2012	Final Report

NATIONAL QUALITY FORUM
1030 15TH STREET, NW, SUITE 800
WASHINGTON, DC 20005

www.qualityforum.org

ISBN 978-1-933875-38-5