Report from the National Quality Forum: HHS-Sponsored Measure Registry Needs Assessment

DRAFT REPORT FOR PUBLIC COMMENT

October 26, 2012
Executive Summary

As healthcare quality measurement evolves and reporting on quality measures becomes more common, an increasing number of stakeholders 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 stakeholders’ 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 assess: 1) measure information needs across the measure lifecycle; 2) systems or approaches currently in use to access and/or maintain measure information; and 3) the potential value in a standardized approach for tracking measure information. This report summarizes the key findings from the resulting Measure Registry Needs Assessment project and details specific next steps to support meeting the measure information needs of measure developers and implementers alike.

Stakeholders in quality measurement require access to complete, up-to-date measure specifications. 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. Stakeholders 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 specific actions can be taken to better meet measure information needs. Key near-term actions include:

- Building the foundation for consistent definitions of measure information elements and 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 time is now for establishing a consistent approach to measure information management, and 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 stakeholders 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 other stakeholders 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 NQF to conduct a needs assessment to explore key issues and considerations for a standardized approach to gathering, storing, and accessing measure information.

The resulting Measure Registry Needs Assessment project is intended to gather information and perspectives from the wide range of stakeholders involved in quality measurement (Appendix A) to assess: 1) measure information needs across the measure lifecycle; 2) systems or approaches currently in use to access and/or maintain measure information; and 3) the potential value in a standardized approach for tracking measure information.¹ This needs assessment includes findings from the following information-gathering 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 includes recommendations for specific next steps to support meeting the measure information needs of measure developers and implementers alike.

Major Findings

Stakeholders use a variety of methods to maintain measure information. For example, to manage specifications for a measure or track a federal reporting or incentive program in which a measure is used, some organizations use Microsoft Word documents or Excel spreadsheets. 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 resources to maintaining such tools.

Despite this diversity and regardless of perspective, stakeholders share major challenges to accessing and maintaining measure information. Most access 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 Quality Forum) and measure developers as primary sources. Because information available from these sources varies, internet searches are often used to piece together the full information needed. As quality measurement and improvement continue to evolve,

¹ By including measure end-users in project activities, the original scope of this assessment expanded to consider additional measure information needs, such as use of measures (i.e., in federal programs; at local, state, and regional levels) and results information for comparison over time and across settings.
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 and 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 system are not available. Even measure developers, who devote significant resources to maintenance of 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.

*Lack of Standardized Measure Information*

Organizations would find value in a standardized set of elements, with standardized definitions, for the information that is collected about a measure (metadata). Currently, because measure specifications and related information can vary between sources and across those who use the measures, and because there are no standardized definitions for the various elements of measures, it is challenging to ascertain the specific differences between sources and users on what may appear to be the same measure.

*Lack of Standard Measure Identification Practices*

There is no single or common approach or numbering system to identify measures, making it impossible to link information about the same measure across systems. Even within one organization or agency, consistent approaches to identify measures may not exist. Some organizations change the titles of measures to match their own convention or preference, adding further complexity to this challenge. Accurately tracking changes to a measure is extremely difficult without a unique identifier consistently used for each measure across all settings.

*Insufficient and/or Inconsistent Information across Available Sources*

No system provides the full set of information stakeholders 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. Finally, 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 for 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. Tracking such changes 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 stakeholders are using measurement to improve outcomes. But no one stakeholder 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. Developers and implementers alike need access to more information, including full 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.

**Stakeholders’ Primary Measure Information Needs**

Through this project’s activities, stakeholders helped to clarify and prioritize the major measure information needs that a standardized approach could help satisfy (Table 1). First and foremost, stakeholders need access to complete, up-to-date measure specifications. Stakeholders 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. Implementers in particular 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. This includes feedback loops to support measure developers knowing whether their measure development focus is on-target and gaining access to potential resources or partners to better meet market needs. These elements are especially needed within the context of increasing electronic measurement and reporting, which are spreading due to advances in technology and incentives through public- and private-sector initiatives.

**Table 1. Stakeholders’ Primary Measure Information Needs**

<table>
<thead>
<tr>
<th>Priority</th>
<th>Measure Information Needs</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Complete, up-to-date <strong>measure specifications</strong>, including eMeasures and related information</td>
</tr>
<tr>
<td>2</td>
<td>Consistent approaches to definitions for elements of <strong>measure information</strong>, or metadata, as well as <strong>measure identification and versioning processes</strong> to help stakeholders 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)</td>
</tr>
<tr>
<td>3</td>
<td><strong>Measure use information</strong> (including use in national reporting and incentive programs and use at the local, state, and regional levels) with systematic, structured <strong>feedback loops</strong> between measure developers and measure end-users to support collaboration and implementation</td>
</tr>
<tr>
<td>4</td>
<td><strong>Measure results and benchmark data</strong>, including information that can support comparisons across settings and regions over time, and that can inform action to close performance gaps</td>
</tr>
</tbody>
</table>
| 5        | Other **information to support use of a measure** including:  
  - 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 Standardized Approach to Meeting Needs

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

Potential Approaches to Measure Information Management

At the workshop convened for this assessment, participants considered several 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. Regardless of the ideal approach, stakeholders agree that building a standardized 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

Generally, stakeholders 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. 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 (EDI) sponsored by the Data Interchange Standards association (www.disa.org) and the Dublin Core (dublincore.org) to newer alignment efforts like the Legal Electronic Data Exchange Standard (www.ledes.org).

A benefit of this approach is the ability to take an incremental approach—widely preferred by stakeholders—with the potential to connect data systems (manually or systematically) based on common, standardized data elements. Additionally, this approach can be informed by eMeasure implementation. 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, this approach 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 from One Access Point

Making data within multiple measure information systems accessible via a single access point is another potential approach to meeting stakeholders’ needs. In this approach, content is “scraped” from other sites or information 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 or 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.
Table 2. Approaches to Meeting Measure Information Needs and Corresponding Benefits, Challenges, and Trade-Offs

<table>
<thead>
<tr>
<th>Potential Approach</th>
<th>Benefits</th>
<th>Challenges</th>
<th>Trade-Offs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alignment of Information in Existing Systems</td>
<td>▪ Ability to take an incremental approach&lt;br&gt;▪ Potential to connect data systems (manually or systematically) based on common, standardized data elements</td>
<td>▪ Lack of an existing standard-setting body or organization to manage the approach&lt;br&gt;▪ Unique data needs of individual systems and organizations</td>
<td>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.</td>
</tr>
<tr>
<td>Independent Systems and Information Repositories Accessible from One Access Point</td>
<td>▪ Ability to create single access point relatively quickly by using commercially-available products&lt;br&gt;▪ Flexibility in indexing of systems&lt;br&gt;▪ Could support better understanding of existing information sources and where opportunities for alignment of information exist</td>
<td>▪ Manual assessment of the indexed information would be needed to assure relevancy of the information returned from systems&lt;br&gt;▪ Potential for duplicative information about measures</td>
<td>Moving forward with this approach would force stakeholders 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.</td>
</tr>
<tr>
<td>Multiple Systems Connected into One System</td>
<td>▪ Ability to take an incremental approach&lt;br&gt;▪ Cost of information and system maintenance can be distributed across several entities&lt;br&gt;▪ Could provide a deeper and wider set of information to users than other approaches</td>
<td>▪ With loose alignment of multiple systems, issues of authority and control over input and maintenance of data can occur&lt;br&gt;▪ Potential for duplicative information about measures</td>
<td>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.</td>
</tr>
<tr>
<td>One Registry for Measures</td>
<td>▪ Greater assurance of the accuracy, completeness, and relevancy of the information within the system&lt;br&gt;▪ Could be achieved by expanding an existing system&lt;br&gt;▪ Would necessitate alignment across organizations’ measure information</td>
<td>▪ Least suited for the desired incremental approach&lt;br&gt;▪ Would require significant resources and strict governance to build, maintain, and enhance over time&lt;br&gt;▪ May unequally burden segments of the measure development community</td>
<td>This approach could help meet the primary needs of stakeholders 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.</td>
</tr>
</tbody>
</table>
A key benefit of this approach is the ability to create it relatively quickly by using a number of commercially-available products. It is 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 this approach would require stakeholders 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. A federated model 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 or airfare sites like 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 this approach 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, this approach 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 stakeholders 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 of stakeholders. Most stakeholders suggest pursuing the creation of one measure registry only after first testing and 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 this approach 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 stakeholders. 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, this approach could help meet the primary needs of stakeholders. Sufficient resources would need to be allocated and the governance structure and business case for participation and use widely accepted. Participation in and use of this approach cannot be perceived as unduly burdensome, particularly by 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, there are ways to improve the accessibility and reliability of information across sources.

Alignment of Measure Information Would Benefit All, Regardless of Approach

Most approaches 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. Stakeholders 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 to identify common data fields for measures. While this alignment presents a significant challenge, each commonly agreed upon data element 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. Stakeholders 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**

The opportunity to share and review measure results could significantly support implementers in benchmarking and better understanding 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.

**Next Steps**

The time is now for establishing a consistent approach to measure information management. 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 stakeholders’ needs.

**Build the Foundation**

Specific areas require agreement across a wide range of stakeholders to support progress on meeting primary measure information needs. First, as stakeholders 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, consistent and unique measure identifiers are 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);
- Devising 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. Overwhelmingly, stakeholders agree that defining the primary audiences for any standardized approach will help ensure that the approach taken will meet the measure information needs of those target audiences. Stakeholders 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 stakeholder group. In other words, a "one size fits all" attempt may result in a "one size fits none" outcome. Stakeholders 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 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 stakeholders’ 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 stakeholders do not favor starting from scratch; rather, stakeholders 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
- Devising a development plan that first caters to an initial set of stakeholders’ 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 stakeholders 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;
- Devising 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 several 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, 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 public- and private-sector entities alike 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 standardized 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

There is great opportunity to begin to meet the high-priority measure information needs of stakeholders in healthcare quality. The ideas presented here are actions that are required regardless of the approach taken. Organizations throughout the quality measurement field are aware that some actions need to be taken in the short-term (by the end of 2013), and others will be important to achieve over the next several years. In all, start by looking first to existing systems 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.
Appendix A—Organizations that Provided Input into the HHS-Sponsored Measure Registry Needs Assessment Project

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

<table>
<thead>
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<th>Activity</th>
<th>Brief Description</th>
<th>Date(s)</th>
<th>Corresponding Report(s)</th>
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<tr>
<td>Open Call</td>
<td>An open call for information about current systems and approaches to measure information management.</td>
<td>May 16 – June 6, 2012</td>
<td>Summary of Responses</td>
</tr>
<tr>
<td>Webinar: Current Systems</td>
<td>A public webinar to share information about selected measure information management systems.</td>
<td>July 26, 2012</td>
<td>Webinar Summary, Webinar Recording, Slide Presentations</td>
</tr>
<tr>
<td>Workshop</td>
<td>A multi-stakeholder workshop to explore measure information needs, requirements, and potential approaches to measure information management.</td>
<td>Sept. 5, 2012</td>
<td>Workshop Summary: Part I, Part II, Meeting Recordings: Morning, Afternoon Slide Presentations</td>
</tr>
<tr>
<td>Webinar: Major Findings</td>
<td>A public webinar to share major findings from the above information-gathering activities.</td>
<td>Oct. 26, 2012</td>
<td>Note: Webinar Recording and Summary to be posted online by Nov. 19, 2012, at <a href="http://www.qualityforum.org/RNA">www.qualityforum.org/RNA</a></td>
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<tr>
<td>Public Comment Period</td>
<td>A 4-week period for members of the public to review and provide feedback on the Draft Report summarizing major findings.</td>
<td>Oct. 26 – Nov. 28, 2012</td>
<td>Submit Feedback on the Draft Report</td>
</tr>
<tr>
<td>Final Report</td>
<td>The final report to HHS on the major findings on the project, including edits based on public feedback.</td>
<td>Late Dec. 2012</td>
<td>Note: Final report to be posted online at <a href="http://www.qualityforum.org/RNA">www.qualityforum.org/RNA</a></td>
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