Measure Registry Needs Assessment

Workshop Summary

Background

The Measure Registry Needs Assessment project (www.qualityforum.org/RNA), funded by the Department of Health and Human Services (HHS), is intended to gather perspectives and ideas from a range of stakeholders regarding needs and key considerations for a standardized system or approach to gathering, storing, and accessing measure information. The National Quality Forum (NQF) hosted a workshop on September 5, 2012, at which participants explored measure information needs, requirements, and potential approaches for systematically identifying and tracking measures along the measure development, endorsement, and use pipeline.

The results of this workshop are summarized below, divided into two parts: Part I provides an overview of the workshop proceedings and the major themes that emerged during the day; Part II is in a Microsoft Excel workbook listing the full details of the workshop's break-out group discussions.[1]

The objectives of the workshop were to:

- Identify top-priority measure information needs;
- Identify top-priority technical and non-technical requirements to meet those needs; and
- Discuss potential system-based approaches and related trade-offs to address needs and requirements. (See Appendix A for workshop agenda.)

Workshop participants represented a wide range of stakeholder perspectives, encompassing both the public and private sectors (Appendix B). To set the context for the day, Mary Nix (Agency for Healthcare Research and Quality) discussed what a 'registry' may entail (e.g., formal processes and governance for measure information input and maintenance, mandatory versus voluntary participation) and informed the group of HHS' interest in stakeholder input. Diane Stollenwerk (NQF) summarized the major findings gathered thus far from previous project activities, including interviews with individuals from more than 20 organizations and a webinar to discuss insights from the interviews and to learn about existing measure information systems. These findings covered current approaches stakeholders use and the challenges they encounter in accessing and/or maintaining measure information.[2]

Defining Primary Measure Information Needs

Workshop participants were asked to review the measure information needs identified from the project's previous activities, add any that are missing, and identify their top priorities. Participants suggested modifications to pre-identified needs (e.g., adding "unique identifiers" as part of the need for consistent measure metadata fields) as well as additions (e.g., access to reliability and validity testing information, identification of relationships between measures). Based on the discussion, 15 measure information needs were identified and prioritized (Table 1). These needs served as the foundation for

[1] A recording of the plenary sessions of the workshop can be found at www.qualityforum.org/RNA.
[2] A summary of the findings from discussions with stakeholders engaged in measure development and implementation on their measure information access and maintenance practices, processes, and tools is available at www.qualityforum.org/RNA.

remaining discussion at the workshop, covering the key requirements, potential approaches, and actions steps for meeting the identified measure information needs. It was acknowledged that several needs overlap and in some cases may be combined to better describe stakeholders' interests in measure information.

Table 1. Identified Measure Information Needs in Order of Priority

Priority	Measure Information Need
1	Complete and up-to-date measure specifications
2	Measure use information, including use in national reporting and incentive programs
3	Consistent measure metadata fields including unique identifiers for measures
4	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)
5	eMeasure specifications and related information
6	Measure results and benchmark data
7	Systemic, structured feedback loops involving measure developers and implementers
8	Information about a measure or measure results that can inform action or change, and potentially impact revenue
9	Reliability and validity testing information about measures
10	Measures in the development and use pipeline (including measure concepts and measures no longer maintained by the measure developer)
11	Specific changes made to a measure when updates are released
12	A warehouse of data sources that can be used for testing or calculating measures
13	Historical information about a measure (from concept through retirement)
14	Measure gaps
15	Harmonization and relationships between measures

Identifying Top-Priority Technical and Non-Technical Requirements

In multi-stakeholder break-out groups, workshop participants used the prioritized measure information needs to identify what it would take to meet those needs. They discussed technical requirements (e.g., capturing how measures have changed over time, accessing benchmarking data) and other non-technical requirements (e.g., creating incentives to support sharing of measure information, securing sustainable resources to maintain system). Each break-out group was also asked to specify barriers associated with the requirements, particularly within the context of potential approaches for managing measure information. They were provided three different approaches to consider, and asked to suggest other approaches if desired (Table 2).

Table 2. Potential System-Based Approaches for Meeting Measure Information Needs

Potential Approach	Definition
Align Current Measure Information Systems	Establish standardized measure information fields and definitions for those fields across existing measure information systems. Access to the information would continue to occur through individual systems.
Connect Several Existing Measure Information Systems into One	Establish a single access point for all measure information maintained within multiple participating measure information systems.

Create One Measure Registry	Establish a comprehensive measure registry to log all information about all measures. Information would be added, organized, and accessed through a single system.
Other Approach(es)	Other approach(es) as identified by participants.

Technical and Non-Technical Requirements Identified

Each break-out group presented its top-priority technical and non-technical requirements for meeting measure information needs. Those requirements are summarized below. A complete list of the requirements identified by workshop participants can be found in Part II of this summary.

General Themes: Technical Requirements for Meeting Measure Information Needs

- **Capture measure changes** – Allow users to easily identify the 'root', or original measure, and how a measure has changed over time.
- **Track the measure through its lifecycle** – Define the various stages in the measure lifecycle and allow users to identify measures at any point along the continuum: in development, endorsed, in use, or retired.
- **Standardize metadata fields** – Include commonly-identified measure information fields, or metadata, that are standardized based on clear and consistent definitions.
- **Capture measure use information** – Allow those who provide input to the system to identify how and where a measure is in use, including reporting and incentive programs, as well as specify when they are no longer using a measure.
- **Incorporate search and browse functionality –** Allow for basic and more advanced measure search and filter capabilities.

General Themes: Non-Technical Requirements for Meeting Measure Information Needs

- **Ensure 'value-add'** – Align with the business drivers and workflow of the target users of the system to avoid creating extra or unexpected burden for them.
- **Address intellectual property issues** – Address intellectual property issues to ensure that when information is shared organizations have the ability to protect their work and interests.
- **Encourage widespread participation** – Investigate business models to encourage participation across all major stakeholder groups.
- **Allow for flexibility** – Structure the approach so that it can evolve over time to accommodate the wide-range of stakeholders who may find value in using the system or approach.
- **Ensure data quality** – Ensure that the measure information (e.g., specifications, information about use, results) entered and maintained is reliable, up-to-date, and accurate.
- **Enable learning and collaboration** – Include methods or functions that support for direct interaction and feedback loops among measure developers and implementers.

Identifying Short- and Long-Term Actions

Workshop participants returned to their break-out groups to discuss short-term actions (e.g., defining the target audience[s] and the business case for each) and long-term actions (e.g., addressing intellectual property issues). Each group was asked to consider these issues within the framework of the potential approaches (Table 2 above) to meet the top-priority technical and non-technical requirements identified from the earlier session. Participants were also asked to consider associated pros and cons for each potential approach.

Short- and Long-Term Actions Identified

Each break-out group presented their short- and long-term actions as well as any pros and cons identified for each potential approach. Those actions are summarized below. A complete list of the short- and long-term actions identified by workshop participants can be found in Part II of this summary.

General Themes: Short-Term Actions (to be completed by the end of 2013)

- **Define the vision and target audiences** – Identify the intended audiences and related vision for this system, along with a clear and compelling value-driven business case for creating this system.
- **Assess existing measure metadata** – Conduct a thorough environmental scan to assess the variation in measure metadata fields and their definitions, to begin to identify how these fields could be aligned.
- **Build consensus around standardization** – Convene stakeholders from across the healthcare quality field to explore methods for standardizing measure information capture and management.
- **Improve existing systems** – Enhance current measure information management systems to better meet the identified measure information needs.
- **Understand measure inclusion within federal programs** – Coordinate across HHS agencies and with key private sector organizations to assess and better understand which measures are used in national-level public and private sector reporting and payment incentive programs.
- **Track eMeasures and related activities** – Monitor activity pertaining to electronic measurement to determine how eMeasures would best fit into a standardized system or approach.

General Themes: Long-Term Actions (to be completed within the next five years)

- **Build on what already exists** – Assess how current measure information management systems or approaches could be improved or optimized to avoid duplicative work yet meet the identified needs.
- **Identify funding sources** – Explore potential funding streams to support the development and maintenance of a standardized system or approach.
- **Create sufficient incentives and increase participation** – Determine the most effective methods for motivating stakeholder use of the system, including input, updating and use of measure information over time.
- **Address intellectual property issues** – Evaluate intellectual property issues to accommodate the needs of key stakeholders while encouraging sharing of needed measure information (e.g., specifications, use, results).

Pros, Cons, and Trade-offs for Potential Approaches

Participants identified a number of pros, cons, and trade-offs associated with potential approaches during the final break-out session. Themes from the discussion are summarized below. A complete list of the pros, cons, and trade-offs identified by workshop participants can be found in Part II of this summary.

A key theme reiterated throughout the day was that building a standardized system or approach would need to be conducted in phases, regardless of the ideal approach. Many thought that building such a system or approach required establishing trust among stakeholders, and recommended starting with areas in which there is the greatest agreement (i.e., 'low-hanging fruit'). All potential approaches involve human and financial resources to develop and maintain over time, which must be considered in identifying immediate next steps.

Potential Approach 1: Align Current Measure Information Systems

Generally, most participants agreed that the first—and more easily achievable—step toward meeting measure information needs would be to align current measure information systems. However, questions were raised about whether the owners of the existing systems would adopt the standardized approach (e.g., measure information fields and definitions).

Potential Approach 2: Connect Several Existing Measure Information Systems into One

Many participants agreed it would be necessary to standardize the measure information fields and definitions in order to connect several existing measure information systems through a single portal. The benefit of this approach includes centralized information and a potential spread of the cost with a minimal amount of maintenance across several entities. Conversely, centralizing the information may create concerns about the control and maintenance of the information over time. Potential for duplicative or conflicting information is also a risk of this approach (e.g., the same measure going into the system from multiple sources).

Potential Approach 3: Create One Measure Registry

Several participants were inclined to pursue the creation of one measure registry only after trying and determining that the above approaches do not provide the necessary value to the field. Some advised that while a one-stop shop may be ideal, 'one size fits all' may turn into 'one size fits no one.' A few questioned the feasibility of this approach, asking who would own the registry or be the "czar", and what the potential costs may be to develop and maintain such a system.

Other Potential Approaches Proposed at the Workshop

As referenced above, some attendees proposed an alternate approach based on the idea of indexing key measure information systems and websites and establishing one access point for aggregated measure information (similar to potential approach #2 above). Examples of websites such as Kayak.com for flight information were noted as potential models to consider. Participants noted that an advantage to such an approach may be that the cost of this kind of system is spread across parties. Also noted was the disadvantage that there would likely be no assurance of the consistency or reliability of the measure information derived from each system.

Other suggestions included shorter-term and smaller steps to begin to bring measure information to users. For example, one break-out group suggested that measure developers could potentially agree on a limited set of measure information to share in a standard format and have available for export. This export would exclude information that measure developers do not want to release. In considering the growth and implementation of eMeasures in the field, another break-out group suggested looking to Meaningful Use Stages 2 and 3 for guidance on eMeasures inclusion within a potential measure registry.

Next Steps

Overall, participants supported the idea of more deliberately working together to meet measure information needs. Participants suggested potential immediate next steps for HHS, such as developing a vision for meeting measure information needs, including identification of the primary target stakeholders and the business case for each. It was suggested that HHS convene follow-up meetings to specify possible design elements of a potential measure registry, as well as propose methods and definitions for standardizing metadata and measure versioning. Participants also suggested that HHS agencies work closely together to align their approaches to measure information management and engage the private sector in those efforts.

NQF's final report due to HHS by the end of 2012 will reflect a more detailed analysis of all information gathered during the Measure Registry Needs Assessment project activities. Input gathered from this project is expected to be used by HHS to: 1) inform near-term decisions regarding where and how HHS might invest in measures and measurement; and 2) help determine whether there is a unique role for the federal government to help meet the identified measure information needs.

More information about this project is available at www.qualityforum.org/RNA. Questions should be directed to Anisha Dharshi at rna@qualityforum.org.□

Appendix A—Workshop Agenda

Measure Registry Needs Assessment

Workshop
Wednesday, September 5, 2012
8:00 am – 5:30 pm Eastern

National Quality Forum
1030 15th Street, NW, Suite 950 West
Ninth Floor Conference Center
Washington, DC 20005

Important Notes for Participants:

- Participants will be actively engaged in working sessions and will be asked to provide their perspective throughout the day. (Breaks have been scheduled to allow participants to attend to personal or work matters.)
- Previews of the day's exercises are referenced throughout this agenda. No pre-work is required.
- Please check in with the guard in the lobby of the building. He/she will provide access for you to the workshop location.
- If you would like to learn more about this project and its previous activities, visit www.qualityforum.org/RNA.

AGENDA

Objectives:
Provide an interactive setting for participants to:

- Identify top-priority measure information needs;
- Identify top-priority technical and non-technical requirements to meet those needs; and
- Discuss potential system-based approaches and related trade-offs to address needs and requirements.

8:00 am Registration and Networking

8:15 am **What We've Learned Thus Far and Expectations for the Day**
Mary Nix (AHRQ), Diane Stollenwerk (NQF)

- Impetus for this effort
- Overview of the project and what HHS plans to do with today's input
- What a measure registry may be

- Major learnings thus far, including examples of what others currently use to manage measure information
- Format and expectations for the day
- Q&A with participants to clarify expected outcomes for meeting

8:45 am **Defining Primary Measure Information Needs**
Moderator: Diane Stollenwerk

Via a structured discussion involving all attendees, measure information needs identified through previous information gathering efforts for the project will be presented and discussed. Participants will add any missing needs to the list.

Participants will vote on their top three choices and the final list will be used throughout the day to support discussion and ensure that potential approaches, key requirements, and short- and long-term action steps discussed correspond with the prioritized needs.

10:00 am **Preparing for the Day: Format and Expectations**
Anisha Dharshi (NQF)

Participants will be briefed on the format and expectations for the break-out and report back sessions through the morning and afternoon.

10:15 am Transition to Break-outs

10:30 am **Multistakeholder Break-out Session, Part I – Identifying Technical and Non-Technical Requirements**
Break-out Group Moderators: Jeffrey Hill (Rhode Island Quality Institute Beacon Program); Joseph Jentzsch (Kaiser Permanente); Kevin Larsen (Office of the National Coordinator for HIT); Ann Watt (The Joint Commission); Marcia Wilson (Aligning Forces for Quality National Program Office)

Participants will be assigned to multistakeholder break-out groups to identify top-priority technical and non-technical requirements to meet the needs identified in the morning session.

During discussion, each break-out group will use the worksheets to:

- Specify technical requirements and identify corresponding barriers to meeting those requirements (i.e., identifying how measures have changed over time, accessing benchmarking data).
- Specify non-technical requirements and identify corresponding barriers to meeting those requirements (i.e., creating incentives or buy-in to support sharing of measure information, securing sustainable resources for upkeep of system(s) over time).
- Prepare a report out to the full group of participants on the top-priority technical and non-technical requirements that apply across all potential approaches and that

may be unique to one or more approaches. [Template slides will be provided to assist with the report out.]

Note: Participants will be provided lists of potential technical and non-technical requirements as well as barriers – identified during information gathering sessions that took place prior to the in-person meeting – to consider when completing this exercise.

The requirements discussion will be framed according to potential approaches to maintaining and accessing measure information. These potential approaches will be used to help participants discuss *how* measure information needs can be met:

- **Align Current Measure Information Systems**: Establish standardized measure information fields and definitions for those fields across existing measure information systems. Access to the information would continue to occur through individual systems.
- **Connect Several Existing Measure Information Systems into One:** Establish a single access point for all measure information maintained within multiple participating measure information systems.
- **Create One Measure Registry**: Establish a comprehensive measure registry to log all information about all measure. Information would be added, organized, and accessed through a single system.
- **Other Approach(es)**: Other approach(es) as identified by participants.

12:00 pm **Lunch Break**, Networking Session

12:45 pm **Sharing Identified Top-Priority Technical and Non-Technical Requirements**
Moderator: Diane Stollenwerk

Each break-out group will report back to all participants the top-priority technical and non-technical requirements identified. Commonalities and novel ideas across break-out groups will be summarized at the end of the discussion by the moderator.

2:00 pm **Networking Break**; Transition Back to Break-out Groups

2:15 pm **Multistakeholder Break-out Session, Part II – Identifying Short- and Long-Term Actions**
Break-out Group Moderators: Jeffrey Hill; Joseph Jentzsch; Kevin Larsen; Ann Watt; Marcia Wilson

Participants will return to their break-out groups to discuss specific short- and long-term actions – within the framework of the potential approaches – to meet the top-priority technical and non-technical requirements identified from the earlier session. For each potential approach, related pros and cons will also be discussed and prepared for reporting back to all participants. [Template slides will be provided to assist with the report out.]

3:30 pm **Sharing Short- and Long-Term Actions**
Moderator: Diane Stollenwerk

Each break-out group will report back to all participants the identified short- and long-term actions to meet the requirements, including associated pros and cons. A question and answer session will be conducted after each report and at the end of the session. Identified actions will be themed real-time by the moderator. The trade-offs associated with each potential approach and for one approach over another will then be discussed as a large group.

4:30 pm **Bringing it All Together**
Moderators: Mary Nix, Diane Stollenwerk

In this final session, major themes, actions, and pros and cons that emerged throughout the day's discussion will be presented. Participants will discuss the preliminary commonalities and identify potential immediate next steps to suggest to HHS based on the day's discussion. Participants will also have the opportunity to clarify specific points and offer final input.

5:15 pm **Wrap Up and Next Steps**
Moderators: Mary Nix, Diane Stollenwerk

The day's moderators will close the meeting with a review of the next steps for the project.

- Summarizing input from today's meeting into a report to HHS
- Opportunities for additional input and feedback before the report is finalized
- Reminder of how input will be used by HHS moving forward

5:30 pm **Adjourn**

Appendix B—Workshop Participants

Aneel Advani
Indian Health Service

Tanya Alteras
National Partnership for Women & Families

Andy Amster
Kaiser Permanente

Fred Bloom
Geisinger Health System

Edna Boone
Office of the National Coordinator for Health Information Technology

James Bush
Wyoming Department of Health

Coretté Byrd
American College of Physicians

Chengjian Che
Lantana Group

Ann Clancy
Health Services Advisory Group

Vivian Coates
ECRI Institute

Monique Cohen
Agency for Healthcare Research and Quality

Ian Corbridge
Health Resources and Services Administration

Jim Craver
Centers for Disease Control and Prevention

Christine Dang-Vu
QASC/Brookings Institution

François de Brantes
Health Care Incentives Improvement Institute

Jessica DiLorenzo
Health Care Incentives Improvement Institute

TJ Dube
The Health Collaborative of Greater Cincinnati

Nancy Dunton
University of Kansas / National Database of Nursing Quality Indicators

Mary Fermazin
Health Services Advisory Group

Susan Fitzgerald
American College of Cardiology

Beth Franklin
National Quality Forum

Barbara Gage
QASC/Brookings Institution

Louis Galterio
SunCoast RHIO

Daniel Green
Centers for Medicare & Medicaid Services

Jane Han
The Society of Thoracic Surgeons

Matthew Haskins
National Hospice and Palliative Care Organization

Sharon Hibay
Quality Insights of Pennsylvania

Jeffrey Hill
Rhode Island Quality Institute Beacon Program

Joseph Jentzsch
Kaiser Permanente

Rabia Khan
Centers for Medicare & Medicaid Services

Deborah Krauss
Centers for Medicare & Medicaid Services

Lisa Lang
National Library of Medicine

Kevin Larsen
Office of the National Coordinator for Health Information Technology

Laurie MacCallum
Truven Health Analytics

Sarah Mahmood
American College of Physicians

Martin Makary
Johns Hopkins University

Myles Maxfield
Mathematica

Patricia McDermott
Aetna

Lauren McKown
America's Health Insurance Plans

Ginny Meadows
McKesson Corporation

Rhonda Medows
UnitedHealthcare

Barbara Mendenhall
California Office of the Patient Advocate

Steven Merahn
ActiveHealth Management

Ashley Morsell
National Quality Forum

Michael Moses
Health Care Incentives Improvement Institute

Elisa Munthali
National Quality Forum

Dennis Nalty
American Institutes for Research

Quyen Ngo-Metzger
Health Resources and Services Administration

Mary Nix
Agency for Healthcare Quality and Research

Mamatha Pancholi
Agency for Healthcare Research and Quality

Lisa Patton
Substance Abuse and Mental Health Services Administration

Darryl Roberts
American Nurses Association

Ann Sheely
OptumInsight

Foong-Khwan Siew
National Business Coalition on Health

Lara Slattery
American College of Cardiology

Mark Smith
Truven Health Analytics

Carol Sniegoski
Agency for Healthcare Research and Quality

Sharon Sprenger
The Joint Commission

Lori Stephenson
Rocky Mountain Health Plans

Diane Stollenwerk
National Quality Forum

Melanie Swan
ECRI Institute

Wendy Vernon
National Quality Forum

Bani Vir
ActiveHealth Mangagement

Marcia Wilson
The George Washington University / AF4Q Measure Alignment Affinity Group

Ann Watt
The Joint Commission

Steven Wright
Department of Veterans Affairs