

PUBLIC COMMENTS:

Data Needed for Systematically Improving Healthcare

QUESTION ABBREVIATION KEY

Abbreviated Question	Full Question
<i>General Comments</i>	General Comments
<i>Promising ways to expand capabilities for using data?</i>	The report found that data are often underutilized because of limited capabilities to analyze and apply the data. What are the most promising ways to expand capabilities for using data to improve care and health outcomes?
<i>Agree with potential recommendations? Strategies you could implement?</i>	The white paper identifies opportunities for stakeholder action. Do you agree with these potential recommendations, or are there additional recommendations that should be added? Are there strategies for moving forward that you could implement?
<i>Challenges and solutions you identified? Does report capture?</i>	What challenges and solutions have you identified for creating meaningful and actionable data that informs improvement efforts? Are these challenges accurately and comprehensively captured in the report?

Aligning Forces for Quality

Aliza Norcross

General Comments

Aligning Forces for Quality (AF4Q) appreciates the opportunity to comment on this report, and supports the proposed strategies for improving healthcare data usability and transparency. The experiences of the 16 AF4Q grantees support the finding that providing timely and clinically relevant data can result in improvement. Additionally, we would like to underscore the importance of combined data sets – those able to use multiple distinct data sets can provide a more comprehensive view of a community’s health and better identify areas needing improvement. As mentioned in the report, often issues of political will are greater barriers than technological constraints – this should be top of mind when developing strategies for improving healthcare data. More information on AF4Q’s experience can be found on our website at forces4quality.org. Two resources in particular that outline AF4Q lessons on effectively using data to impact quality care and outcomes are *The Promise of Regional Data Aggregation* and *Data: Foundation of Improving Quality and Value*.

AMA

Koryn Rubin

General Comments

- It would be helpful to garner support in the physician community to have a vignette highlighting a physician practice that is successful in using data for performance improvement. The report only highlights activities related to large health systems. Their resources and needs are much different than a medium to small physician practice.

Promising ways to expand capabilities for using data?

- The AMA-Rand Study found that new payment models are being implemented across diverse markets and in physician practices of differing sizes and specialties with surprisingly similar across the board effects. Physicians in all communities we studied have seen some positive effects from some of the model’s they’ve implemented, but the study findings also highlight the challenges that must be addressed in order to achieve more widespread adoption and sustainable improvements. The key challenges relevant to date and highlighted in Chapter 7, “The Importance of Data and Data Analysis”, include:

- More needs to be done to streamline and harmonize quality metrics. There is far too much variability in the large array of quality metrics being promoted by multiple payers, both commercial and public. There is also a lack of accuracy in the data being reported back to physicians. Managing metric variability for each health plan requires significant resources that could be better spent on the investments practices need to succeed in alternative payment models.
- We also face the paradox of too much data being directed to physicians but yet there is a dearth of accurate, actionable and timely information. Lack of interoperable and usable EHRs hamper this effort, as physicians have become typists entering data to meet measurement requirements, while at the same time it is difficult to extract the information physicians need for patient care from their current EHRs.

***Agree with potential recommendations?
Strategies you could implement?***

- We also urge NQF to include a recommendation on requiring payers and third-parties to provide physicians the opportunity to review and correct data before any public release of data. The AMA has a guide highlighting the challenges with releasing raw claims: <http://www.ama-assn.org/ama/pub/news/news/2015/2015-06-01-ama-guide-media-reporting-cms-medicare-data.page>
- Under “Strategies for Moving Forward”, we suggest a bullet highlighting the need for states to work with the federal government to streamline the heterogeneous patchwork of state privacy laws that impede information exchange. At the state level the following must occur:
 - Build analytic platforms for Medicaid;
 - Use the levers at a governor’s disposal to access the different sources of healthcare data across the state and use it to improve data; and
 - Work with the federal government to streamline and align state privacy laws which can impede information exchange.

***Challenges and solutions you identified?
Does report capture?***

- Data provenance will become even more of an issue as data collection systems start accepting patient

generated data, device data, and crowd-sourced socioeconomic data for public health. For data to be useful there is a need for metadata tagging to occur to identify such things as source and author, as well as for an industry effort to coalesce around common definitions.

- Missing from the report is a discussion on trust in data by physicians and the potential mismatch between practice data and payer data, and the need for physicians to receive actionable data in an understandable format. The statement is based on findings from the 2nd joint AMA-Rand report entitled, ‘The Effects of Health Care Payment Models on Physician Practice in the US.’

American Nurses Association

Maureen Dailey

General Comments

Comments supported by the American Nurses Association (ANA) provided by nursing leaders at the Nursing Knowledge: Big Data Science third annual conference June 4-5, 2015, Minneapolis, MN.

“Healthcare Organizations - Develop culture, mindset, skills, and tools to effectively use data” theme:

The organizational will need to prioritize QI activities that are tightly aligned to reimbursement and other financial incentives. It may be useful to look at the existing incentive programs and adjust them to be more outcome and interprofessional focused. Another place to leverage is the accreditation bodies, both the broad agencies such as Joint commission but also the “specialty accreditation” agencies (i.e. Stroke). Holding the local Boards accountable to real changes in patient outcomes is also an important lever to use. This organizational attributes are so important for change to happen including key strategies related to leadership, accountability, incentives etc.

Promising ways to expand capabilities for using data?

Comments supported by the American Nurses Association (ANA) provided by nursing leaders at the Nursing Knowledge: Big Data Science third annual conference June 4-5, 2015, Minneapolis, MN.

p.3 - The need for data in addition to EHR data.

There are timely discussions occurring regarding the

pros and cons of entering all the data into the EHR rather than integrating all the data into a clinical data warehouse. It is important to understand what data and the various ways in which data can be integrated for just in time analytics and decision support. There are evolving methods for having timely data in a data warehouse and running analytics from it rather than putting everything into the EHR i.e. streamlining HL7 feeds.

p. 3 Scaling up and spreading improvements. From the Nursing Knowledge: Big Data Science conference, there are recommendations for sharing a variety of best practices - but a method of making these available through open sourcing is needed. Examples are creating a basic set of flow sheet data elements and standardized code sets that everything vendor and health system should implement for sharable and comparable data to support eMeasures, quality improvement and research.

p. 4 There are emerging methods of evaluating data quality in a quantified manner- electronically rather than manual data collection. For instance Michael Kahn works with the PCORI data quality group to develop repeatable process to compare data quality. Steve Johnson, a PhD student of mine is involved with this group and is building the next generation of comparative metrics for data quality that relies on extraction of data from EHRs or data warehouses.

***Agree with potential recommendations?
Strategies you could implement?***

Comments supported by the American Nurses Association (ANA) provided by nursing leaders at the Nursing Knowledge: Big Data Science third annual conference June 4-5, 2015, Minneapolis, MN.

p.4 Untapped potential from learning from people- in addition to suggestions made - there should be serious consideration of the "open notes" movement (<http://www.myopennotes.org/>). Patients have a right to see their EHR data, not just the portal. Previous research has shown that providing open access to the patient's entire EHR did not increase provider's time and improved patient satisfaction

p. 5 - Focus on common metrics and improve the efficiency of measurement- this should include common metrics for data quality derived from electronic health data.

***Challenges and solutions you identified?
Does report capture?***

Comments supported by the American Nurses Association (ANA) provided by nursing leaders at the Nursing Knowledge: Big Data Science third annual conference June 4-5, 2015, Minneapolis, MN.

Noted on bottom of p. 1 - a systems approach is needed that emphasizes multiple disciplines and cross continuum evaluation for improvement in health and health care. The focus is often focus on physician care so the expansion across disciplines is applauded. There many quality measures to be improved (not just the numerator and denominator reported). This requires change in behavior and documentation practices of all team members.

P. 2 - systems improvement tools to achieve their potential, they require multiple types of data, - An important issue in addition to EHR data from all team members is the integration of device data that can save time if someone doesn't have to retype the data and provide timely data for clinical decision support.

p.2 - also noted was compliance with care bundles -In current NSF research, predictions regarding adherence with the surviving sepsis campaign is being investigated. There is a major quality problem. The suspicion of sepsis date/ time and therefore timely application of this guideline cannot be easily determined from documentation. The diagnosis of suspicion of sepsis is in a note and not in a discrete field. Our most accurate way of determining the likelihood of sepsis is from vital sign data. There is a need to determine which data elements must be in discreet fields to evaluate the effectiveness of guidelines and prevent adverse events.

Association for Professionals in Infection Control and Epidemiology

Nancy Hailpern

General Comments

The Association for Professionals in Infection Prevention and Epidemiology (APIC) welcomes the opportunity to comment on the National Quality Forum (NQF) draft white paper on Data for Systematic Improvement.

- APIC endorses the need for a robust data infrastructure that will serve to provide a systems approach to improving and sustaining healthcare.
- APIC underscores the importance of identifying appropriate, meaningful and actionable data, with emphasis on streamlining the number of measures collected, thereby targeting improvement efforts.
- APIC agrees with the challenges of interoperability and the inability to link disparate data sources and recognizes the need to overcome this issue as paramount in order to develop a robust data infrastructure.
- The challenge of “trust in data” is an ever present barrier in the healthcare environment. Standardized definitions, risk adjustment, and collection methodology, as well as input from stakeholders can serve to help resolve these trust issues over time.
- Accessibility to shared, evidenced- based prevention strategy data is a key to sustained improvement activities.
- Although the electronic health record (EHR) is often seen as the solution to all data needs and accessibility, this is not necessarily the case. Methods need to be found to maximize access to data contained in the EHR and to minimize the cost associated with that access.
- APIC conveys that although access to digital information may appear to be improving in some arenas, there are still many organizations with disparate data systems that will take years to align.
- We recommend an additional “Strategy to Move Forward” for Healthcare Organizations: “Strengthen and align information technology prioritization methods to include databases related to quality and improvement activities in order to provide relevant, timely data.” This must be done before data can be used effectively.

- Finally, APIC agrees that patient, consumers and the public are important partners in the effort to continually improve and sustain improvements in healthcare.

Health Action Council

Lisa Kaiser

Agree with potential recommendations? Strategies you could implement?

Strategies for Moving Forward

The project identified several opportunities to improve data and make it more useful for systematic improvement. The following list outlines several opportunities for specific stakeholder action.

Medicare

- Make data more broadly available in a timely manner

States

- Build analytic platform for Medicaid
- Use the levers at Governor’s disposal to access the different sources of healthcare data across the state and use if to improve data.

Private Payers

- Open data and facilitate public reporting

EHR vendors and Health IT policy makers

- Promote true interoperability between different electronic clinical data systems
- Serve as collaborative catalyst for how data are used to manage populations
- Improve healthcare delivery system’s ability to retrieve and act on data, such as by preventing high, recurring fees for data access

Healthcare Organizations

- Develop culture, mindset, skills, and tools to effectively use data

All stakeholders

- Focus on common metrics and improve the efficiency of measurement
- For open data, provide analyzed data sets (not just raw data)
- Broaden technical agreements on standards, data use, and data practices
- Promote greater linkage of EHR data to claims data and patient-derived data

- Establish standards on common data elements to collect, exchange, and report; alternatively, standardize the core set of data points for interoperability

Mallinckrodt Institute of Radiology

James Duncan

General Comments

1. It was a pleasure to review the NQF document and learn about the widespread interest in this topic. Appreciate the opportunity to comment on this initiative.
2. The NQF should strive to create an infrastructure which supports a balanced portfolio of improvement efforts. Ideally, the portfolio will include all aspects of healthcare. The portfolio should also include a balanced array of both process and outcome measures. The current NQF process for measure evaluation favors outcome measures even though topics like radiation exposure from medical imaging are better served by process measures.
3. This NQF effort on data for systematic improvement might use radiation exposure from medical imaging as test case. Industry wide standardized formats such as DICOM-SR are already being used for data collection. Multiple vendors have developed platforms for aggregation and analysis of this data. The available evidence demonstrates widespread and unnecessary variation in radiation exposure at multiple levels (dose/image, images/study, studies/illness). The linkage between radiation exposure and population risk of future cancers is well studied. That data indicates a linear increase in risk with increasing levels of exposure. In addition, the overuse of medical imaging strains financial resources and generates harm through incidental findings. Given its rich informatics infrastructure, medical imaging is well suited to data-driven improvement.

Promising ways to expand capabilities for using data?

Promising ways to expand capabilities include:

1. Development of analysis and visualization algorithms that help transform raw data into useful information. While improvement experts commonly use control charts and other tools from statistical process control to identify special causes within

large datasets, these tools are not routinely used to analyze clinical data. Suggest that these tools could easily be embedded into EHRs and medical devices to help clinical teams detect nonrandom deviation from predicted trend lines.

2. Recognize the importance of analyzing sequences of events. In the same way that text communications require arranging symbols into particular sequences, care processes require arranging tasks into specific sequences. In *A Mathematical Theory of Communication*, Claude Shannon created the field of information theory and illustrated how prior events provide context. Too often the information embedded in these sequences is discarded prior to analysis. Improving the processes used to diagnose and treat patients will almost certainly require aggregating and synchronizing data from multiple channels. Stated another way, rarely do we rely on a single metric to assess if a patient is getting better or worse. Rather we look for patterns in time series that encompass multiple metrics.

Agree with potential recommendations? Strategies you could implement?

Engage manufacturers of medical equipment in efforts to promote standardization and interoperability. Medical imaging provides an example with its standardized data format (DICOM). Such standardization allows medical images acquired anywhere in the world to be shared and analyzed on a wide variety of devices. New DICOM standards for reporting radiation data (DICOM-RDSRs) are a key element in efforts to improve the quality and safety of imaging.

Challenges and solutions you identified? Does report capture?

Challenges we have faced in our improvement efforts

1. Lack of access to data embedded within the EHR and other information systems (radiology information system, lab information system, surgical information system, billing system, etc). Considerable effort is required because these systems are typically configured to support financial transactions rather than process improvement.
2. Using humans for routine data collection. Other industries use electronic sensors to collect the process data needed to drive and sustain

improvement efforts. While humans are highly capable observers, there are numerous opportunities to use technology for data capture. Such investments would free up personnel to perform roles that leverage their capacity to provide pattern recognition and human comfort.

3. Lack of integration between information systems. The data from patient monitors, imaging equipment, IV pumps, etc is treated as individual data points rather than a holistic set of sequential signals that contain diagnostic and therapeutic information. The resulting low level data is often discounted as unsuitable for further analysis. However, other industries have shown how integrated streams of basic data can provide considerable insight into the subtle nuances of human behavior and system performance.

4. While gigabytes of data flow through a hospital's walls on any given day, few resources are allocated to use those mountains of data and metadata to systematically improve patient care. Robust algorithms and tools like statistical process control are needed to visualize and transform raw data into information. Only then can we begin to using information to build knowledge.

5. Lack of uniform data coverage. For example, CMS data on imaging efficiency is available via Hospital Compare but it does not include pediatric patients, imaging centers, and inpatient exams.

The NQF report nicely captures how data promises to improve healthcare. The report's Strategies for Moving Forward section rightfully emphasizes:

1. Expanded availability of Medicare, Medicaid and private payer data
2. Improving the efficiency of measurement
3. Standards for data collection, sharing data and reporting results

University of Colorado College of Nursing

John Welton

General Comments

Following is a brief example of the concepts addressed above

Consider pain management and control in an acute care environment. Physicians prescribe interventions

and pharmacologic therapies which nurses carry out around the clock. Optimum pain management strategies would minimize discomfort to promote healing and well-being and avoid adverse effects of the therapies. Nurses assess and provide PRN (pro ra nata or as needed) medications such as narcotic analgesics for pain control. Too few assessments or opioids could let the patient suffer with acute pain which could delay healing and increase stress, too much opioids could have serious side effects such as respiratory depression, hypotension, and fecal impaction. Current data systems have the ability to extract nurse assessments of pain, frequency, time/place, identify the nurse making the assessment, etc. as well as the dose, time, and follow up observations of PRN opioids used in a particular setting and patient population. The value of this large dataset is to identify practice patterns, effectiveness of pain management, differences in use of narcotics among different types of nurses (do inexperienced nurses give more/less PRN narcotics) or differences between shifts and time of day (does night shift give more/less drug and are there large differences in PRN narcotic use across nurses and how does that affect patient well-being, outcomes of care, costs of care, and patient satisfaction?). This is just one small example of the power of current data systems to extract key real-time clinical and operational performance metrics at different units of analysis such as the individual patient, individual nurse, and setting (e.g. surgical floor). My recommendation to consider new expert panels should focus on key clinical and operational data that can examine patient care at a level and timeliness that has not been possible until recently.

References

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Promising ways to expand capabilities for using data?

Expanding on my comments above, NQF should facilitate development and deployment of common data models that can be added to any EHR environment to extract key data into a common repository then apply basic statistical analysis, graphics and other easily understood summaries as well as more sophisticated statistical analysis that can be reported back to clinicians and healthcare leaders in a timely and actionable way (Welton, 2014). I was co-leader for a national expert panel of nurses to develop and conceptualize nursing value, produce core metrics and nursing business intelligence analytics and tools and develop a common data model to extra key nursing sensitive data from any EHR. This work was recently presented at the Big Data and Nursing Knowledge Development Conference sponsored by the University of Minnesota School of Nursing. The purpose of this model is to extract key data such as patient level nursing costs, nursing interventions and outcomes of care, as well as metrics related to performance, efficiency, and effectiveness of nursing systems and individual

nurses. For example, the model allows direct linkage of each nurse caring for a patient and can identify nurse, patient, and unit level factors that are associated with outcomes and costs of care such as experience, workload, and patient acuity (Welton & Harper, 2015).

Agree with potential recommendations? Strategies you could implement?

The recommendations are a good start but as stated, are too general and abstract to be actionable at this point. Some additional recommendations for NQF to consider:

1. Seek ways to identify and link every provider of care to each patient within the EHR (defined as any information system that collects patient identifiable data in any setting). For example, every nurse assigned to care for a patient in a hospital should be identified and linked to each patient during the course of hospitalization.
2. Break down system silos to allow seamless data collection, integration, and access across all setting in which patient care occurs to identify all “touch points” of providers across the broad spectrum of healthcare (Kaplan & Porter, 2011; Porter, 2008, 2010)
3. Move towards a “value orientation” in the data we collect and use for health services and quality & safety research. Value in this case includes both the costs and quality of care related to outcomes – these should be considered together not separate entities in our ongoing work to optimize the healthcare system (Pappas, 2013).
4. NQF should consider developing expert panels of clinicians, informaticists and health system researchers to identify actionable data from the EHR, then develop common data models to extract relevant data to use in repositories that can better inform clinicians, leaders, payer, and policy makers in more timely ways.
5. NQF should also consider facilitating the development and use of healthcare centric business intelligence and analytic approaches using real-time data in varied healthcare settings including developing benchmark patient, provider, and facility performance and cost metrics that can be used across many settings (Welton, 2014).

***Challenges and solutions you identified?
Does report capture?***

First, the broad implications for using “big data” for health systems research is how to leverage increasingly large, high volume, high velocity, real-time healthcare (and nursing) data to improve overall healthcare quality, decrease costs and achieve high value outcomes of care (Clancy et al., 2014). One potential strategy is to change how we view quality metrics and analytics from mostly a retrospective and reactive endeavor to a forward looking approach that uses real-time data to identify potential problems or precursors to low quality and safety. The second problem is how to define and build common data models to extract similar healthcare data from these systems to identify efficiency, effectiveness, productivity, performance, and costs of care within and across all healthcare settings and do so in a vendor agnostic way (Welton, 2013). Common data models are intermediate products that create small to intermediate data repositories that focus on a particular problem or set of clinical or operational metrics that are based on data extracted from electronic health records (EHR) and provide a pool of easy to access data that otherwise would be difficult to analyze directly from the EHR. See the medication administration example below.

Van Buren County Hospital

Jim Carle

***Promising ways to expand capabilities
for using data?***

The incredible amount of data gathered does, indeed, take a measure of expertise to properly analyze and draw appropriate conclusions. Education in the areas of data analysis is a must. As a practitioner in Six Sigma, we are taught very simply that $y = \text{a function of } x$. If we know the desired outcome, and we understand the major influencing inputs, we can better understand the capabilities of our systems and implement appropriate changes. Too often we try to include more variables than are necessary to make improvements and therefore attempt to implement too many changes at once. This process is doomed to failure. Appropriate scoping of process improvement opportunities, appropriate data analysis and incremental, sustainable changes are the recipe for success.

***Challenges and solutions you identified?
Does report capture?***

In healthcare we gather millions and millions of points of data every year. I would argue that we suffer from analysis paralysis. Between regulatory bodies, voluntary data submissions and internal improvement efforts, we get lost in a sea of data. Part of the problem is that we try to apply all the data system-wide rather than scoping down the data to reflect areas of highest importance to each health system. We don't live in a “one size fits all” world but I believe there are common threads that are problematic throughout healthcare. Identify the 20% of the issues that are causing 80% of our problems and we have a fighting chance.