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TO: Decision Aids Expert Panel
FROM: NQF Decision Aids Project Team
RE: Environmental Scan of Measures of Shared Decision-making Quality
DATE: June 15, 2016

The Moore Foundation: National Standards and Measurement to Support Informed Patient Decisions project aims to build consensus around national standards, criteria, and the process for national certification of decision aids. In addition, the project will aim to identify approaches to measure the quality of decision making and provide guidance to support the development of measures that can assess the impact of shared decision making (SDM). Toward this goal, the National Quality Forum (NQF) conducted an environmental scan of measures related to SDM. The term "measures" was used broadly and included both the instruments/tools to assess SDM and performance measures used to assess if SDM is occurring. These measures are organized by the constructs of: decision antecedents, decision making processes and decision outcomes. The scan included procedure and condition specific measures that apply to patients, providers and surrogate decision-makers. NQF identified 13 performance measures and 64 instruments using a strict set of inclusion and exclusion criteria. The identified performance measures and instruments are included in a compendium and briefly summarized within this memo. The instruments and performance measures captured in the scan provide a snapshot of measurement in SDM and may not be fully representative of all efforts. The results of the scan point to the need to develop performance measures in order to incentivize widespread use and close gaps in measurement as well as the need to expand empirical testing of existing instruments to establish reliability and validity. It also highlights the need to move toward performance measurement and identify the best measures for use to improve quality in shared decision making. This memo provides a description of the purpose of the environmental scan, methodology, results, and the challenges to measurement the expert panel will consider during the June 22-23 in-person meeting. The panel will also be asked for feedback on potential opportunities and challenges in promoting the use of performance measures in SDM.

Background

The current healthcare paradigm focuses on disease-specific interventions and outcomes, despite widespread acknowledgement that patient goals, values, and preferences should play a key role in care planning and decision making. The focus on disease states and clinical indicators is important, but not always the most meaningful for patients with multiple chronic conditions, severe disability, or advanced illness, or for persons approaching end-of-life.[31] As people increasingly take a more active role in making decisions about their care, many turn to decision aids, or educational tools such as videos, pamphlets, and other online and print resources, to guide conversations with their clinicians about care options. There is an enormous amount of information available via the Internet, and an increasing amount of tools being labeled as "decision aids." However, there are no national standards about the

best resources for patients and their families to use to ensure that these tools best support important conversations and choices that reflect their personal health goals. Through developing standards for decision aids and identifying measures of decision quality and of SDM, NQF seeks to bring together stakeholders to advance goal-based care (i.e., care that focuses on a patient's health goals across physical, social, functional, and other dimensions). [31]

Goal-based care has the potential to support personalized, individualized care for patients. Meaningfully incorporating individuals' goals, values, and preferences into care planning requires respectful and compassionate conversations between clinicians and patients. These discussions should adequately elicit patients' goals and values as well as encourage patients and caregivers to be partners in SDM. To transform healthcare, the nation needs to move toward routine assessment of patient goals, patient engagement in SDM, and measurement of resultant outcomes. Currently, clinical practice and electronic health records rarely assess and capture patient goals. Strong evidence demonstrates that decision aids have improved patients' knowledge about options and their outcomes, increased accurate risk perception, resulted in a better match between values and choices, reduced decisional conflict, and decreased the number of people who remain undecided about treatment. [42] A study reviewing the use of decision aids in hip and knee surgery rates found that patient decision aids were associated with 26 percent fewer hip replacement surgeries, 38 percent fewer knee replacements, and 12-21 percent reduction in costs. [1]

Multiple barriers hinder implementation of strategies to incorporate decision aids into shared decision making. These barriers include the lack of national standards for decision aids, which has limited the identification of evidence-based and reliable decision aids, and the fact that SDM through the use of decision aids not yet been prioritized and meaningfully incorporated into national accountability and payment programs.

The International Patient Decision Aids Standards (IPDAS) Collaboration has conducted work around specifying minimum standards for patient decision support interventions; however, IPDAS has not yet applied this work through the lens of national standards and criteria. There are also efforts in place in the state of Washington to develop and implement a process to certify patient decision aids. Washington's Health Care Authority is adapting a streamlined subset of criteria developed by IPDAS to review and certify decision aids. The state envisions that the spread and use of certified decision aids by providers and delivery systems will improve healthcare quality and reduce avoidable costs by actively engaging patients in their care decisions. The certification of evidence-based products represents a first step towards this vision. NQF seeks to build upon the work of IPDAS and Washington State.

Methodology

NQF conducted a search for information sources using the inclusion and exclusion criteria highlighted in Appendix A. During the search, NQF examined the grey literature (e.g. technical reports and white papers), peer-reviewed research publications, measure repositories, and relevant environmental scans. Databases for the literature review included: Academic Search Premier, PubMed/Medline, Google Scholar and the Cochrane Collaboration. NQF utilized a "snowballing method" to search the literature and focused on identifying systematic reviews. Databases were searched using variations of the keywords in Appendix B. These terms were combined with terms such as "measure", "survey", "scale", etc.

In addition, NQF requested input from experts in the field of SDM by conducting four key informant interviews with representatives from the National Institutes for Health, The Health Decision Sciences Center at Massachusetts General Hospital, the Washington State Health Authority, and the Informed Medical Decisions Foundation. Participants were asked to describe the current landscape of

measures that assess decision quality; the most appropriate search terms and places to look for measures; and the seminal works in the field of SDM that are relevant to this effort.

NQF collected and reviewed over 50 information sources. These sources were used to identify and extract measures (e.g. performance measures and instruments etc.). The primary sources for the environmental scan were the National Cancer Institute (NCI) Grid-Enabled Measures Database, the Ottawa Hospital Research Institute website, the Health and Human Services (HHS) Measures Inventory, the AHRQ Quality Measures Clearinghouse, and the Massachusetts General Hospital Health Decision Science Center website. These repositories contain many of the measures found in the literature. Performance measures were only collected if the information source contained the data elements listed in Appendix A (e.g. title, description, and measure type). NQF did not extract knowledge-based measures developed for a specific study procedure that were not developed for use outside of the study. However, these measures have been compiled and summarized in several systematic reviews[15,30,34,36,42,43,44,51].

Results

There is a large body of work that has demonstrated the effectiveness of SDM. The Cochrane Collaboration published in 2009, 2011 and 2014 systematic reviews of key constructs and measures/instruments that establish the effectiveness of decision aids. These reviews included studies that have used measures that are in various stages of development, from psychometrically validated measures that have been tested in multiple populations and settings to measures without evidence of any testing. The most recent Cochrane review contained 115 studies that involved 34,444 participants which built on the previous reviews. The investigators (Stacey et al.) sought to identify measures that mapped onto at least one of the IPDAS effectiveness criteria. They found the majority of studies include measures that assess knowledge, accurate risk perceptions, informed value-based choice, decision-making process attributes, and patient's perception of being informed and clear about values. [41]Another systematic review, by Scholl et al in 2011, focused on identifying psychometrically tested instruments that measure shared decision making process. The investigators examined 27 studies and found 9 instruments that have demonstrated strong validity and 11 instruments that have been proposed for testing or are undergoing testing. The study concluded that there are not many widely used instruments, although new instruments are constantly being developed. The authors concluded that there is a need to standardize instruments to allow for cross study comparisons. More recently, Winn et al. conducted a systematic review of measures that assess the concordance between patients' preferences and medical treatments. They identified 61 studies and found 72 measures of concordance between preferences and treatment. Out of the 61 studies, 26 involved a patient decision aid and 30 of them reported an assessment of decision outcomes. [41]The investigators concluded that there is a great deal of variability in the way constructs are defined and calculated.

The field of SDM and specifically efforts to assess the quality of SDM has been developing rapidly. Moving the performance measurement industry toward measures that matter most in assessing the quality of SDM presents both challenges and opportunities. Performance measures must be predicated on instruments/measures that are already proven to be reliable and valid. Out of the SDM instruments identified, only a small number have been psychometrically tested and are in current widespread use. Researchers have attempted to organize the concepts commonly used to assess the quality of SDM in a framework of three categories. These categories include:

- decision antecedents which describe the features (e.g. preferences, health literacy, attitudes, and skills) of the patient, provider, or organization that can influence the decision-making process,

- decisionmaking processes focus on features of behaviors (e.g. level of patient engagement, topics included in SDM process, and tools used) and the amount and type of deliberation between providers and patients; and
- decision outcomes, like decision quality, that include knowledge based measures and the extent to which treatment is aligned with an individual's preferences and goals. [37-34]

NQF used this framework to organize the performance measures and instruments found in the environmental scan.

SDM Performance Measures

NQF defined a performance measure as a numeric quantification of an aspect of shared decisionmaking quality that can be generated using data from many types of sources. Performance measures aggregate data collected from sources like instruments, administrative claims, electronic health records, etc. An example of a performance measure description is: the percentage of parents who reported their experiences with shared decision-making for their children with chronic conditions uses data generated from the Consumer Assessment of Health Providers and Systems (CAHPS) 4.0 Health Plan Survey (Child Questionnaire). NQF identified 13 {7 process and 6 outcome, of which 3 can be classified as patient-reported outcomes Ms)} performance measures, a majority of which were condition-specific and at the individual level of analysis (8 clinician, 4 health plan, and 1 facility level).

SDM Instruments

NQF defined an instrument (e.g. survey, scale and single-item measure) as a tool used to assess an aspect of shared decisionmaking obtained from a patient, provider or observer by directly asking them to self-report (e.g. Decision Regret Scale). NQF identified 64 decisionmaking or decision aid instruments, which are displayed in the compendium of measures. Many instruments include items that assess constructs in all three categories. The majority of instruments assess decision antecedents (n=33), but there are many that assess decision outcomes (n=29) and the decisionmaking processes (n=14). There was limited evidence of psychometric testing for many of these measures. The most commonly measured constructs are listed in Table 1.

Table 1: Commonly Measured Constructs

Decision Antecedents	Decisionmaking Process	Decision Outcomes
• Control preferences • Communication preferences • Decision support • Decision values • Self-efficacy • Health numeracy • Health literacy • Preferences for autonomy	• Consideration of future consequences • Decisional conflict • Effective communication • Level of engagement • Risk communication	• Decision quality • Decisional regret • Health outcomes • Patient experience • Patient satisfaction • Vigilance and decision avoidance • Patient activation • Discordance

Commonly Used Instruments

One of the cornerstones of performance measurement is to ensure the data elements required for reporting are valid, reliable, feasible, and responsive their target population. Many elements of SDM quality that can be used to generate performance measures are collected through instruments. Although there are many instruments, only a few have been tested and are in use outside of research. These instruments share similar characteristics. They are relatively short, simple in style, and easy to implement in routine care. For example, the Control Preference Scale is a psychometrically tested instrument that assesses decision antecedents. The scale was originally specified for assessing how treatment decisions are made among people with life threatening diseases and developed using a set of cards. It is now a 5-item instrument that asks for the participant's level of agreement with a set of statements ranging from "I prefer to make the final treatment decision" to "I prefer to leave all treatment decisions to my doctor". [34] The scale has now been validated in a variety of populations, from those with advanced illness to the general population.

There are also several commonly used measures of decision process. The Decision Conflict Scale assesses a patient's perception of their level of uncertainty when choosing between different options. [31]It includes questions like "are you clear about which benefits matter most to you". [31]The results are used to understand how much support the patient needs in making a decision. Another commonly used instrument is the OPTION scale, which assesses the extent to which providers engage patients in their care. It is 12-item scale and is broadly applicable to a variety of settings. The items focus on the existence of communication behaviors such as the approach to delivering information. In addition, there are a set of items included in CAHPS that assess the decision making process. These items include questions like "did you and a doctor or other health provider talk about the reasons you might want to take a medicine".[31]

A commonly used instrument that measures decision outcomes is the Decision Regret Scale. It is also a 5-item instrument and it assesses how comfortable patients are with the decision they have made. Participants respond using a Likert scale that asks them to rate their predisposition to regret. For example, once they have made a choice, how often they wonder what would have happened if they chose differently. Other commonly used measures of decision outcomes are the 14 Decision Quality Instruments developed by the Health Decision Sciences Center at Massachusetts General Hospital.[15] These instruments are specified for a variety of health conditions, and ask decision-specific questions about knowledge, goals and the extent to which patients have been meaningfully involved in their care decisions.

Opportunities and Challenges in Performance Measurement

Interest and appreciation of the value of using performance measures to assess the quality of SDM as part of the broader accountability and performance improvement landscape are mounting. To accelerate the adoption of performance measures that can be used for these purposes several underlying issues must be addressed, which will require collaborative and collective effort across multiple stakeholder groups including providers, consumers, purchasers, measure developers, researchers, and others. First, SDM performance measures have not been widely adopted for clinical use outside research settings in the United States; for that reason, they may be unfamiliar to many health professionals, payers, and provider institutions. Therefore, steps need to be taken to raise awareness among these stakeholders of the benefits of using decision aids to engage patients in their care improve outcomes. Second, there are several method-related challenges such as aggregating patient data on

decision aids to measure performance at multiple levels of analysis (e.g., individual, group practice, organization) and use of proxy respondents.[53]

Measurement of SDM outcomes through the use of decision aids will require a strategic approach. Once there are national standards and a certification process has been identified, the healthcare system can begin incentivizing the use of certified decision aids. After they are used more often in routine care, the system will need to measure their impact (measurement can also incentivize the use of decision aids). At that point, there will also need to be incentives to catalyze measurement. The findings of the environmental scan suggest that there are many existing instruments, just not being used widely or outside of research. There are also few tested instruments in use and even fewer existing performance measures that assess SDM. Performance measures are critical to comparing entities and understanding variability across settings where SDM is in use and driving improvements in quality of care.

There are a few promising performance measures that have recently been submitted to NQF for endorsement. For example, *Measure 2962: Informed, Patient Centered (IPC) Hip and Knee Replacement Surgery* is a patient-reported outcome measure that assesses adequate knowledge and preference for surgery. This measure is based on use of the respective Decision Quality Instrument developed by Massachusetts General Hospital. *Measure 2962: Shared Decision Making Process* is another patient-reported outcome measure that assesses the extent to which providers involve patients in the decision making process. There are also promising measures related to SDM that are already endorsed. *Measure 2483: Gains in Patient Activation Score at 12 months* assesses an individual's knowledge, skill, and confidence for managing his or her health and health care.

Beyond these examples, there are many other measures that can be implemented and/or be translated for broader use. However, there is no gold standard for measurement or consensus on a set of measures that should be used to access the impact of SDM. In addition, the evidence available for existing measures varies widely. And, although there has been a lot of research to establish the effectiveness of SDM in improving decisions, there is less research that demonstrates improvements in health outcomes.[37] The expert panel has been tasked with considering the opportunities and challenges in performance measurement. In addition, the panel will discuss recommendations on how to promote the use of measures.

Endnotes:

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Appendix A:

Table 1: Inclusion and Exclusion Criteria for Information Sources

Included	Excluded
• Developed or published after 2000 OR originally published prior to 2000 and still current • Measures that include specifications that meet the operational definition of the shared decision making, patient decision aids and/or decision quality • Instruments, scales, survey tools, and surveys	• Published before 2000 and not current • Not available in English • Does not include data required data elements (Table 2) • Study specific measures that were intended for use in other contexts

Table 2: Data Elements Captured in the Environmental Scan

Data Element	Description
Title	Name of measure
Description	Measure description, if available
Numerator (optional)	Numerator statement
Denominator (optional)	Denominator statement
Measure Type	Measure type based on NQF taxonomy
Focus	General, procedure specific or condition specific
Level of Analysis	Entity being held accountable by the measure (e.g. state, individual provider, agency, consumer)
Data Source (optional)	Data source for measure information (i.e. inventory, database, repository)

Appendix B: Keywords for Literature Search

Search Terms: NQF utilized a "snowballing method" to search the literature but focus on identifying systematic reviews. Databases were searched using combinations and variations of the search terms below. These terms were combined with terms like "measure", "survey", "scale", etc.

- Decision
- Decision-making
- Decision trees
- Risk communication
- Health communication
- Patient decision making
- Shared-decision making
- Decision aid/tool/support/guide/technique
- Patient provider communication
- Comprehension
- Participation
- Choice

- Options
- Adherence to chosen option
- Risk information
- Commuter assisted decision
- Informed choice
- Informed decision