MEETING SUMMARY

NATIONAL QUALITY FORUM
Driving measurable health improvements together

Advancing Measurement of Diagnostic Excellence for Better Healthcare

IN-PERSON MEETING SUMMARY
SEPTEMBER 2024

ABOUT THE NATIONAL QUALITY FORUM

The National Quality Forum (NQF) is a not-for-profit, nonpartisan, membership-based organization that works to improve healthcare outcomes, safety, equity, and affordability. Our unique role is to bring all voices to our table to forge multistakeholder consensus on quality measurement and improvement standards and practices that achieve measurable health improvements for all. NQF is a proud affiliate of The Joint Commission. Learn more at www.qualityforum.org.

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OUR MISSION

To be the trusted voice driving measurable health improvements

OUR VISION

Every person experiences high value care and optimal health outcomes

OUR VALUES

Collaboration • Excellence
Integrity • Leadership
Passion

Impact Statement

Purpose
NQF held this meeting of the Diagnostic Excellence Committee to discuss challenges to the development and use of accountability measures for diagnostic excellence identified by NQF in an environmental scan and to prioritize and recommend challenges and potential solutions on which the Diagnostic Excellence Committee will focus for the remainder of the initiative, which concludes in winter 2025.

Key Findings
The Diagnostic Excellence Committee discussed opportunities for NQF work in four areas:

1. Data specificity and data standards, including challenges related to electronic health records such as the difficulty of abstracting laboratory and imaging reports and the lack of documentation regarding diagnostic uncertainty and medical decision making
2. System fragmentation, including the lack of linkage between informatics and quality teams and the lack of patient participation in data validation
3. Patient-reported measurement, including mismatches between patient and clinician mental models regarding what constitutes diagnostic excellence
4. Diagnostic equity, including challenges with measuring bias and discrimination in the diagnostic process

Informed by Committee prioritization and feedback from the initiative's Advisory Group, NQF has focused the project's work on patient-reported measurement and diagnostic equity, specifically, mismatches between patients' and clinicians' mental models regarding what constitutes diagnostic excellence, disadvantaged groups being inadvertently omitted from measurement, and measurement of bias and discrimination in the diagnostic process.

Applications
This report is designed to keep NQF stakeholders informed about the Diagnostic Excellence Committee's discussions about challenges and potential solutions related to diagnostic excellence measurement.

Table of Contents

Executive Summary

Timely, accurate diagnosis is a crucial step in the healthcare process that can set patients on the path to needed care, treatment, or services. The National Quality Forum (NQF) is currently engaged in a three-year project, the Advancing Measurement of Diagnostic Excellence for Better Healthcare initiative (Diagnostic Excellence initiative), to break through barriers to measuring diagnostic excellence in ways that improve patient care.

On November 16, 2023, NQF's Diagnostic Excellence Committee convened for its second meeting. The Committee heard from a patient panel regarding their challenges on their own diagnostic journeys. These panelists highlighted several significant problems, including communication challenges, clinician bias and the assumptions clinicians make about patients, sources of information viewed by clinicians as factual, the fragmentation of care across providers and institutions, and insurance coverage challenges. The Committee also heard the results of an environmental scan conducted by NQF.

The Committee divided into four breakout groups to discuss four challenge areas in depth, identifying the following opportunities for NQF work in each area:

Data Specificity and Data Standards

- The difficulty of abstracting laboratory and imaging reports from electronic health records (EHRs)
- Measures requiring data that are not always fully captured in EHRs
- The difficulty of distinguishing among differential, working, and final diagnoses in the EHR

System Fragmentation

- The lack of linkage between informatics and quality teams in healthcare organizations
- The lack of patient participation in data validation
- The difficulty of distinguishing among differential, working, and final diagnoses in the EHR (echoing this concern from Data Specificity and Data Standards above)

Patient-Reported Measures

- Mismatches between patients' and clinicians' mental models regarding what is diagnostic excellence
- The collection of data at multiple times in a diagnostic journey to provide a complete picture of diagnostic excellence. (The Committee noted that doing so prospectively is challenging, particularly for performance attribution when a patient receives care in multiple settings.)
- Incorrect information in EHRs

Diagnostic Equity

- Disadvantaged groups inadvertently omitted from measurement
- Measurement of bias and discrimination in the diagnostic process
- Small sample sizes that limit evaluating care for subpopulations

After the meeting concluded, NQF presented Committee members with challenges prioritized by the breakout groups. The voting results helped NQF understand the Committee's priorities. NQF discussed the voting results with the project's Advisory Group, composed of experts in the field, to further consider where the Committee's deliberations could have the greatest impact. Based on the voting results and the Advisory Group discussion, NQF has focused the project's work on three subtopics:

1. Patient-Reported Measures: Mismatches in mental models
2. Diagnostic Equity: Historically disadvantaged groups being omitted from measurement
3. Diagnostic Equity: Measuring bias and discrimination in the diagnostic process

This report summarizes the meeting discussion. Additional findings and recommendations will be forthcoming in the Diagnostic Excellence Committee's technical report, to be issued spring 2025, and a call to action, to be issued winter 2025.

Introduction

Timely, accurate diagnosis is a crucial step in the healthcare process that can set patients on the path to needed care, treatment, or services. In an iterative process, clinicians gather information through a clinical history and interview, physical exam, diagnostic testing, referral, and consultation; integrate and interpret the information; and develop a working diagnosis and ultimately communicate the diagnosis to the patient.[1]

Diagnosis is a complex process, and diagnostic errors are a concern throughout the healthcare system. As in many other areas of healthcare, measurement can be a powerful tool to improve patient care and reduce harm throughout the diagnostic process. Yet despite the importance of measuring diagnostic excellence, it remains difficult to measure.

Diagnostic excellence has been defined as "an optimal process to attain an accurate and precise explanation about a patient's condition. An optimal process would be timely, cost-effective, convenient, and understandable to the patient."[2]

The National Quality Forum (NQF) is currently engaged in a three-year project, the Advancing Measurement of Diagnostic Excellence for Better Healthcare initiative (Diagnostic Excellence initiative), to break through barriers to measuring diagnostic excellence in ways that improve patient care.

With funding from the Gordon and Betty Moore Foundation, NQF's work takes an end-to-end look across all the steps in the measurement process to address these barriers, enhance patient voices, and improve equity. NQF's work includes examining data capture and aggregation, defining measurement approaches, and addressing barriers to implementing measures at scale.

The Diagnostic Excellence initiative builds on other national efforts to define a framework for measuring diagnostic excellence and to identify and address barriers to developing, testing, and implementing them.[1,3-5] NQF's work consists of five related efforts:

1. Identifying the diagnostic excellence-related data standards needed to speed interoperability
2. Developing recommended data and methods solutions that address existing diagnostic measurement challenges
3. Building a framework and criteria for assessing artificial intelligence (AI) in clinical quality measures
4. Developing a call to action to foster adoption of diagnostic excellence measurement
5. Creating a virtual repository for diagnostic excellence measurement resources

NQF has several expert groups guiding this work. A five-member Advisory Group provides strategic insight and guidance to NQF across the entire project based on their extensive experience in diagnostic excellence quality measurement. The group provides feedback on the direction and content of the work and background on the larger diagnostic excellence landscape.

In addition, the Diagnostic Excellence Committee contributes expertise, feedback, and recommendations related to diagnostic excellence quality measurement. They inform the data standards work, data and methods solutions, and call to action. Appendix B contains a roster of the project staff, and Appendix C lists the Committee members and Advisory Group members.

On November 16, 2023, the Diagnostic Excellence Committee convened for its second meeting. The agenda is in Appendix D. Focused on the data and methods solutions space, the meeting objectives included the following:

- Share the key themes identified in an environmental scan conducted by the project team
- Discuss challenges to developing and using accountability measures for diagnostic excellence
- Prioritize and recommend challenges that the Diagnostic Excellence Committee will focus on for the remainder of the initiative, which concludes in December 2025

Context

For the purposes of this project, when we refer to "diagnostic excellence quality measures," we mean **quality measures for accountability purposes that can be used for fair comparisons of entities across different health systems.** These measures can be used to improve care in specific and impactful ways, and stakeholders agree that measure results can be used for practical purposes such as payment adjustment or public reporting.

To set the context for discussion of diagnostic excellence measurement challenges and solutions, the Committee heard from a patient panel and subsequently about the results of an environmental scan conducted by NQF.

PATIENT PANEL

The panel included four individuals who have personal, lived experience with diagnostic errors as patients and/or care partners who shared their experiences. All are also members of the Diagnostic Excellence Committee.

Patients highlighted **communication problems** as a major barrier to receiving an accurate, timely diagnosis. This includes clinicians:

- not listening to patients and their caregivers;
- not taking patients and their caregivers seriously, including not acknowledging their concerns as real problems;
- speaking to patients and caregivers in a condescending manner; and
- not providing clear instructions about what to do if the patient's condition worsens while waiting for a diagnosis.

Some examples shared by panelists include the following:

> *"They only amputated my leg and my hip, and most of my pelvis. They didn't amputate my brain. I mean, people don't talk to me the same way, people talk down to me, or they don't [talk to me]. Many times, they would talk to my husband and … my husband would say, 'Don't talk to me, talk to her because she's going to be very upset if you don't,' but yet they would talk down to me."*

> *"… often nobody listens, especially to the caregivers. And in pediatrics, parents can sometimes be seen as the troublemaker. If you bring something up or you're a really strong advocate, you're seen … as causing more of a problem within the healthcare system, and not being listened to."*

Further, **clinician bias and the assumptions clinicians make about patients** pose significant challenges to the diagnostic process. Panelists named bias based on race, age, gender, and disease or condition as key concerns among others.

One panelist who has sickle cell disease, a notably painful condition, described their encounters:

> *"I was that patient that went in all the time with my [medicine] list … and as soon as I start naming narcotics that I take to control my pain, I get pegged as a drug seeker and so that works against me. … That has played a role in my delayed diagnosis and my treatment multiple times."*

Another panelist described the assumptions that clinicians often make about patients who use wheelchairs and have had an amputation:

> *"I was never a diabetic, had no signs of diabetes, but…I have been questioned up and down and tested up and down for diabetes … assumptions are made for people that are in wheelchairs and are amputees [that they have diabetes] that aren't truthful."*

Related to communication and bias, panelists discussed the **sources of information viewed by clinicians as factual**, and the problems this can pose. Panelists highlighted multiple instances of clinicians not treating patients and care partners as knowledgeable sources of truth during the diagnostic process. In addition, multiple panelists discussed problems caused by inaccuracies in medical records, which despite patients and caregivers knowing the information is incorrect will "follow us from place to place to place and perpetuate errors and mistakes and perpetuate biases."

Another source of challenge comes from the **proliferation of clinicians and institutions** involved in the diagnostic process and their skills:

> *"My daughter's care spanned, at one point, five hospitals … now we're down to four … but having physicians listen and work together … it's difficult even within one healthcare system, let alone across multiple healthcare systems."*

Another panelist also described their experience with a proliferation of clinicians during a hospital stay:

> *"So, one day I was in the hospital for a 24-hour period, [and] I counted how many people came in my daughter's room: 44. How do we measure? How do we make sure that everyone's [has] the same situational awareness [and is] sharing the same information?"*

Insurance coverage poses challenges throughout the diagnostic process. This is notably true for individuals who lack health insurance. At the same time, insurance requirements and processes can pose barriers during complex diagnostic processes:

> *"… as genetic testing and genomic testing gets better, you get re-evaluations and that leads to other pieces that they find. But then they sometimes have to get verification [from a specialist] before they can give you the results. And then you're back in the prior authorization process with the insurance [company] … before you can hand on this piece of information to a specialist who might be able to figure out something that's happening. Insurance is holding that up before anyone can even look at it."*

Beyond the challenges described here to receiving an accurate, timely diagnosis, patient panelists encouraged consideration of two more factors:

1. Panelists encouraged a focus on **measuring what matters to patients**. One example highlighted that when they are treated in more than one hospital, patients are not concerned with which hospital gets the "credit" or "blame" for problems in their diagnostic process—something that is of great importance to the hospitals involved.
2. Patients emphasized **the importance of transparency, feedback, and learning**, so that patients are made aware of what may go wrong during diagnostic processes and so that clinicians and health systems can use information to improve over time.

ENVIRONMENTAL SCAN

NQF presented the results of an environmental scan conducted by the project team. The goals of the scan were to capture and synthesize the field of diagnostic excellence quality measurement used for accountability purposes and to identify challenges and solutions to the development, testing, and implementation of diagnostic excellence quality measures. The environmental scan was designed to support the Diagnostic Excellence Committee in its discussions of challenges and solutions to measure development and use.

The environmental scan found some progress over time in measurement capabilities. Early measures focused on process measures and screening rates, with more recent measures focusing on intermediate clinical outcomes and outcomes, capturing quality of care across the diagnostic process as well as

timeliness and clarity of communication with patients. These changes align with attempts to measure what is meaningful to patients and to capture the full concept of diagnostic excellence.

NQF identified multiple existing measure gaps through the scan, and work being done by grantees funded by the Gordon and Betty Moore Foundation is integral to filling these gaps. Among the challenges to developing and implementing diagnostic excellence measures are the following:

- Lack of specificity in data standards needed for quality measurement
- Lack of standardized documentation guidelines to ensure uniformity and required detail
- The specification of patient-reported measures (e.g., outcomes, experience)
- A limited number of measures that assess equity in the diagnostic process

In addition, NQF categorized measures identified during the environmental scan according to the steps in the diagnostic process (as described by the National Academy of Medicine in their 2015 report[1]). NQF found no measures that corresponded to the first two steps in the process: "patient experiences a health problem" and "patient engages with the healthcare system."

We have included a fuller description of the environmental scan and its results in the project's environmental scan.

Challenges and Solutions

Committee members spent time in four breakout sessions to engage in deeper discussions of challenges and potential solutions in four areas of diagnostic excellence quality measures. NQF divided the Committee into breakout groups based on four categories of challenges that NQF staff identified during the environmental scan:

- Lack of data specificity and data standards
- System fragmentation
- Limited work to date on patient-reported outcome and experience measures specific to the diagnostic process
- Diagnostic inequities

NQF tasked each breakout group with:

- discussing challenges and potential solutions to the development of diagnostic excellence quality measures in their discussion category;
- discussing the actionability (activities for which the NQF Committee work and call to action could drive progress in the field) and impact of solving each challenge; and
- prioritizing their top three challenges to bring forward for full Committee voting.

DATA SPECIFICITY AND DATA STANDARDS

Developing quality measures requires:

- extracting specific, detailed data from insurance claims, clinical records, and other sources;
- ensuring that such data are comparable to one another (e.g., data on a patient's condition, tests, or procedures is represented in structured data fields that have the same meaning in one EHR as another); and
- determining that these data meet standards for accuracy and completeness.

Building measures of diagnostic excellence requires accessing data from multiple systems such as the EHR for each provider seen by a patient, laboratory records, imaging systems, and claims from each insurer through which the patient has coverage. These systems may have discrepancies in documentation style and terminology.

In addition, commonly used terminologies such as International Classification of Diseases (ICD), Current Procedural Terminology (CPT), and Systematized Medical Nomenclature for Medicine (SNOMED) are often not specific enough to reflect the clinical subtleties of diagnostic decision-making or to reflect what is currently captured in unstructured data such as images and free text. There is a lack of standardized interoperable data for certain critical data elements, such as the timing of events and of symptoms, that the Diagnostic Excellence initiative is addressing through related activities to advance Fast Healthcare Interoperability Resources (FHIR) standards.

Committee members participating in this breakout group built on NQF's environmental scan to identify challenges associated with data specificity and data standards such as the following:

- Codes in available terminologies do not have the level of specificity needed for measure specification.
- Problem lists in medical records are not well maintained, with old diagnoses remaining on many problem lists.
- Dates, such as dates of screening tests and dates of diagnoses, are not routinely captured in consistent ways.
- Results of screening tests are difficult to abstract from EHRs, and there is no clear documentation regarding whether a test was done for screening or for diagnostic purposes.
- Radiology reports vary in how they are structured.
- Working diagnoses and differential diagnoses are not distinguishable from final diagnoses in the medical record.

The top three challenges from this breakout discussion, along with the solution(s) prioritized by the breakout group for discussion and anticipated impact/actionability, are shown in Table 1. As noted below, not all groups had time to address impact and actionability for every challenge.

Table 1: Challenges and Associated Solutions for Data Specificity and Data Standards

Challenges and Associated Solutions for Data Specificity and Data Standards
Data Standards Challenge 1: Laboratory and imaging information Anticipated impact: Not discussed Anticipated actionability: Not discussed ***Challenge Description*** It is difficult to abstract EHR information for laboratory and imaging reports, such as radiology, pathology, and microbiology. This information is needed for diagnostic excellence quality measures, yet core challenges to working with these data include that (1) some data elements (e.g., results) do not exist as discrete EHR items; (2) not all reports are structured; and (3) there are differences in the structure and content of reports across healthcare systems. ***Potential Solutions*** • Link EHR data with disease registry data to supply needed information from a source outside the EHR. • Use natural language processing and machine learning to extract information from unstructured text. • Advocate for guidelines that support uniformity of clinical notetaking and reporting, including the use of synoptic reporting[6] with standardized language as well as language to address degree of certainty. Alternatively, standardize reports for radiology, pathology, and microbiology.
Data Standards Challenge 2: Needed data not fully captured in EHRs Anticipated impact: High Anticipated actionability: Low ***Challenge Description*** EHRs were originally designed for billing rather than for extracting the data needed for quality measurement. As a result, the data in EHRs may not capture all the clinical data needed for quality measurement, may present an incomplete clinical picture, and may not be in a standardized format that supports data extraction for quality measurement. ***Potential Solutions*** • Create a single, national EHR system or standard. • Redesign EHR data fields for quality measures. • Implement penalties/financial incentives for data accuracy in EHRs. • Standardize reports (radiology, pathology, microbiology).

Challenges and Associated Solutions for Data Specificity and Data Standards

Data Standards Challenge 3: Differential, working, and final diagnoses

Anticipated impact: Medium
Anticipated actionability: Medium

Note: This challenge was also listed among the top challenges by the System Fragmentation breakout group.

Challenge Description

The diagnostic process is subject to uncertainty and evolution, and it does not always lend itself to identifying a single point in time at which the diagnosis is final. Further, there is no structured, standardized way to capture uncertainty, diagnostic reasoning, or medical decision making in the EHR. As a result, it can be difficult to distinguish among a differential, working, and final diagnosis in the EHR. In contrast, quality measures do not account for the uncertainty of the diagnostic process, as measures are specified in a binary manner (either the diagnosis is present or not present).

Potential Solutions

- Facilitate EHR capture of the status of diagnosis as differential, working, or final in a way that does not inadvertently affect billing.
- Differentiate between certain and uncertain diagnoses in the EHR.
- Create an EHR data field with a time stamp associated with these different types of diagnoses.
- Refine the way we develop measures to allow for differing levels of uncertainty during the iterative diagnostic process to accommodate working diagnoses and ongoing evaluations.

SYSTEM FRAGMENTATION

The U.S. healthcare system is notoriously fragmented, with patients receiving care from multiple clinicians associated with multiple organizations that lack established mechanisms for coordinating care or sharing data. For patients, this can result in lack of continuity of care, duplication of services, increased costs, and poor health outcomes.

During the diagnostic process, patients may need care from multiple different medical specialties, with clinicians from each specialty bringing their own perspectives, expertise, and battery of diagnostic tests. A lack of interoperability among health information technology systems—and missing data within those systems—limits the availability of full information to all clinicians involved in a patient's diagnostic journey. Additional barriers are posed by variation in documentation, data linkage issues, and limited provider communication and coordination.

One Committee member described a potential example of this:

> *"If we wanted to say this patient was diagnosed, a part of diagnosis is communication and communication across settings. So, if the urologist knows about the diagnosis, but the primary care doctor doesn't, [is that diagnostic excellence]?"*

NQF's environmental scan and the breakout discussion raised several concerns including the following:

- Measures to identify missed diagnostic opportunities are longitudinal and retrospective and require comprehensive data from multiple sources across the patient's diagnostic journey.
- Certain measures, such as those that assess follow-up within certain time frames or the completion of referral care, require linking patient data from multiple providers, which is hindered by a lack of interoperable, standardized data between EHRs.
- EHRs do not consistently capture diagnoses in structured fields that are comparable across systems.
- Patient registries do not always contain needed information.

The top three challenges from this breakout discussion, along with the solution(s) the breakout group prioritized for discussion and anticipated impact/actionability, are shown in Table 2.

Table 2: Challenges and Associated Solutions for System Fragmentation

Challenges and Associated Solutions for System Fragmentation
System Fragmentation Challenge 1: Linking informatics and quality teams Anticipated impact: High Anticipated actionability: Medium ***Challenge Description*** System fragmentation can exist in a single healthcare system when different clinical specialties may not communicate or coordinate the care they provide. There are limited workflows in place to link informatics teams with quality teams in the same healthcare system, resulting in fragmented information flow. ***Potential Solutions*** • Build comprehensive data across the patient's journey, including all sources of their healthcare data, informed by collaboration between informatics and patient safety design experts and leaders. • Build a structure or process measure focused on measuring whether informatics and patient safety teams/systems are working together.

Challenges and Associated Solutions for System Fragmentation
System Fragmentation Challenge 2: Patient participation in data validation Anticipated impact: High Anticipated actionability: Medium ***Challenge Description*** Patients do not participate in validating and tracking data across different healthcare systems and within single healthcare systems. Conversations around system fragmentation do not often include the patients' willingness or desire to participate in their own data validation. ***Potential Solutions*** • Give patients an opportunity to validate or correct their own data to give them more agency/voice. • Enable patients to track their own journey across healthcare systems by creating simplified or standardized patient portals.
System Fragmentation Challenge 3: Differential, working, and final diagnoses Anticipated impact: Medium Anticipated actionability: Medium **Note**: This challenge was listed among the top challenges by the Data Specificity and Data Standards breakout group, and details are shown on page 14.

PATIENT-REPORTED MEASURES

Patient-reported measures are gaining attention in the quality measurement space. As reliable, valid measures of performance, they (1) are based on information collected directly from patients; and (2) can be used for holding healthcare entities accountable for their performance.

Patient-reported measures take advantage of patients' unique point of view to capture information that is meaningful to patients and that that only they can supply, such as health-related quality of life, functional status, symptoms and symptom burden, and experience. Because patients are an integral part of the diagnostic process and their experience is viewed as the gold standard for assessing excellence throughout that process, there is a strong interest in building patient-reported measures in this area.

NQF's environmental scan identified gaps in developing patient-reported measures as a specific area of unique interest in measuring diagnostic excellence, with significant challenges in determining what to measure, when to measure, and how to measure.

Committee members and NQF staff identified several potential challenges in more detail, including the following:

- A disconnect between the ways patients and care partners think compared to how clinicians think about the diagnostic process and diagnostic errors
- The difficulties associated with collecting data on how and how well diagnoses are communicated to patients
- The need to collect data at multiple times during a patient's diagnostic journey

- Challenges associated with patients who need to correct their medical record to address inaccurate diagnoses

One Committee member relayed an anecdote about:

> *"A patient who described … how emotionally exhausting the diagnostic process was, and that by the time they got to the diagnosis, they felt like that journey of exhaustion and despair was not documented anywhere in their medical record, and yet it affected their trust in [the] organization, their likelihood of following up, [and] how they interacted with their clinicians."*

The top three challenges from this breakout discussion, along with the solution(s) prioritized by the breakout group for discussion and anticipated impact/actionability, are shown in Table 3.

Table 3: Challenges and Associated Solutions for Patient-Reported Measures

Challenges and Associated Solutions for Patient-Reported Measures
Patient-Reported Measures Challenge 1: Mismatches in mental models Anticipated impact: High Anticipated actionability: High ***Challenge Description*** Mismatches between patients' and clinicians' mental models regarding what is diagnostic excellence make it challenging to agree on what to ask patients or their care partners to assess health system performance. Mismatches include differences in prioritization of what domains to measure (e.g., trust, diagnostic accuracy, communication of uncertainty); why one would ask patients/care partners about a given domain (e.g., because it would matter to patients/care partners and so that health systems will understand how to act on the result); and how to ask patients/care partners for their experiences and outcomes (e.g., timing and format of data collection). ***Potential Solutions*** • Create guidance for measure developers based on early learnings in patient-reported measure development for diagnostic excellence. • Determine ways to coordinate with other efforts underway in the emerging diagnostic excellence patient-reported measure community (e.g., Committee members shared their awareness of researchers and patient communities working on developing patient-reported measures; early stage testing of some patient-reported measures that is underway; and samples of roadmaps for patient-reported measures with specified goals that have been created and can be elaborated further for performance measures).

Challenges and Associated Solutions for Patient-Reported Measures
Patient-Reported Measures Challenge 2: Multiple contacts with patients Anticipated impact: Medium Anticipated actionability: Medium ***Challenge Description*** While the diagnostic process may involve many points of contact between patients and the healthcare system over an extended time, it is difficult to determine when best to gather information directly from patients about diagnostic failures and successes. Such information could include whether, when, and how diagnostic test results are communicated to patients and other members of their care team as well as when and how patients receive communication about which clinician(s) are responsible for their diagnostic process as it evolves. ***Potential Solution*** • Identify measurement workflows related to the diagnostic process that are feasible to implement for patients/care partners and health systems.
Patient-Reported Measures Challenge 3: Incorrect information in EHRs Anticipated impact: High Anticipated actionability: Medium ***Challenge Description*** Information in the EHR is incorrect but patients cannot change it, nor can they require clinicians to stop using it in their diagnostic workups. ***Potential Solution*** • Amplify the issue, work on solutions, and determine measurement opportunities to monitor improvements/actions.

DIAGNOSTIC EQUITY

Inequities have been documented across the U.S. healthcare system, affecting individuals based on their health insurance coverage status, race/ethnicity, socioeconomic status, age, sex, LGBTQIA+ status, disability, presence of a stigmatized health condition (such as obesity), rural residence, and other characteristics. These inequities profoundly affect access to care, receipt of treatment, quality of care, and health outcomes.

Research has also documented inequities in opportunities for diagnosis, and such inequities are an important contributor to unequal health outcomes. Because the diagnostic process begins even before a patient seeks care, diagnostic equity is influenced by factors such as patients knowing when and where to seek care, being able to access that care in a timely way, and having trust in the healthcare system.

Committee members participating in this breakout group built on NQF's environmental scan to identify challenges to developing measures of diagnostic equity, such as the following:

- There is limited information on which populations are affected by diagnostic inequities, because there are few measures of diagnostic equity and measures of diagnostic excellence are rarely stratified by subgroup.
- Some groups most at risk of diagnostic delays have limited encounters with healthcare providers and are therefore often missing from diagnostic measures because their information is not included in providers' data.
- Including people with limited access to care in diagnostic excellence measures requires deciding what entities to hold accountable for those patients.

The top three challenges from this breakout discussion, along with the solution(s) prioritized by the breakout group for discussion and anticipated impact/actionability, are shown in Table 4.

Table 4. Challenges and Associated Solutions for Diagnostic Equity

Challenges and Associated Solutions for Diagnostic Equity
Diagnostic Equity Challenge 1: Disadvantaged groups are inadvertently omitted from measurement Anticipated impact: High Anticipated actionability: High ***Challenge Description*** Current diagnostic excellence measures fail to assess all patients and disproportionately omit historically disadvantaged groups. These patients are often not included in the healthcare visit data used for measurement because they may not have access to care due to insurance gaps, lack of transportation, provider shortages, or language barriers; because they may not seek care due to discouragement or lack of trust in the healthcare system; or due to other barriers. ***Potential Solutions*** • Define target organizations for measurement (such as health plans, states, public health systems) that are responsible for the whole at-risk population, rather than only for those who seek care. • Develop methods and strategies for identifying the full population at risk when the performance of hospitals or clinicians is measured. Do so by using health plan enrollment data and/or surveying those who are at risk but do not seek care regularly. • Consider symptom registries (rather than disease registries) to identify and measure the full scope of patients at risk for missed, delayed, or wrong diagnoses.

Challenges and Associated Solutions for Diagnostic Equity

Diagnostic Equity Challenge 2: Measurement of bias and discrimination

Anticipated impact: High
Anticipated actionability: Medium

Challenge Description

There are no direct measures of diagnostic equity, including discrimination, in the experience of the diagnostic process. There are multiple sources of bias in the diagnostic system known to affect historically disadvantaged groups disproportionately, including assumptions made about people with certain conditions, who take certain medication regimens, who do not have a clear diagnosis yet, or who are from certain racial, ethnic, or social groups. Certain groups also face barriers to navigating the diagnostic process, such as transportation and language, which affects equity in the diagnostic process.

Potential Solutions

- Support efforts to stratify diagnostic excellence measures by risk factors for diagnostic inequity. For example, define priority groups and identify standard code sets already defined and those that need development.
- Consider methods for assessing how and when trust and/or discrimination may impair diagnostic excellence.
- Improve the standardization and collection of data on social determinants of health, and define an approach to integrating these data into diagnostic excellence measurement.

Diagnostic Equity Challenge 3: Small sample sizes

Anticipated impact: High
Anticipated actionability: Low

Challenge Description

Small numbers of patients per measured provider limit the ability to make inferences about quality. This is a particular challenge for stratifying measures by factors such as social risk or personal characteristics.

Potential Solution

- There was consensus in the breakout group that statistical considerations limit the ability to assess quality for groups with small sample sizes. The group, however, did not identify any specific strategies to address this challenge.

Moving Forward

COMMITTEE PRIORITIZATION

After the meeting concluded, NQF presented Committee members with the top challenges identified by the breakout groups. NQF asked the committee members to vote and thereby establish priorities to govern the work of the Committee moving forward, with each Committee member able to cast three votes. The voting results are shown in Table 5.

Table 5: Prioritization Voting Results

Challenge	Breakout Topic	Percent of Total Votes
Differential, working, and final diagnoses	Data Standards and System Fragmentation	19%
Laboratory and imaging information	Data Standards	18%
Mismatches in mental models	Patient-Reported Measures	13%
Disadvantaged groups inadvertently omitted from measurement	Diagnostic Equity	11%
Measurement of bias and discrimination	Diagnostic Equity	11%
Linking informatics and quality teams	System Fragmentation	8%
Patient participation in data validation	System Fragmentation	7%
Multiple contacts with patients	Patient-Reported Measures	4%
Incorrect information in EHRs	Patient-Reported Measures	4%
Needed data not fully captured in EHRs	Data Standards	4%
Small sample sizes	Diagnostic Equity	1%
Total	*	**100%**

*cell intentionally left blank

NEXT STEPS

The voting results further clarified the Committee's priorities. NQF discussed the voting results with the project's Advisory Group, composed of experts in the field. Together, NQF and the Advisory Group had a deeper discussion regarding the potential impact and actionability of the options and identified those where further committee work and NQF's leadership could make the greatest difference; and where NQF could best leverage the ongoing involvement and leadership of NQF's members and collaborators and of other organizations working to advance diagnostic excellence measurement. Following this discussion, NQF has focused the project's work in three areas: 1) mismatches between patients' and clinicians' mental models regarding what constitutes diagnostic excellence; 2) disadvantaged groups inadvertently omitted from measurement; and 3) measurement of bias and discrimination in the diagnostic process.

Following the meeting, NQF examined these three challenges in more detail and developed initial approaches to address them. Subcommittees (composed of Diagnostic Excellence Committee members) met to discuss the challenges in more detail and provide feedback on potential solutions. NQF will next summarize their insights for the full Committee for discussion. NQF will include the Committee's findings and recommendations in the two major products this initiative will produce: a technical report that reflects the Committee's discussions and recommendations, and a call to action.

NQF staff are also addressing one of the additional challenges identified, gaps in data standards, as part of this initiative. NQF prepared a memo for the Office of the National Coordinator of Health Information Technology (ONC)[7] to advance interoperability of key data elements needed for diagnostic excellence. Finally, in partnership with the American Medical Association, NQF is also advancing data standards for symptoms[8] under a separate Gordon and Betty Moore Foundation grant.

Appendix A: References

1. National Academies of Sciences, Engineering, and Medicine. *Improving Diagnosis in Health Care.* The National Academies Press; 2015. https://doi.org/10.17226/21794.
2. Yang D, Fineberg HV, Cosby K. Diagnostic Excellence. *JAMA*. 2021;326(19):1905-1906.
3. The National Quality Forum. *Improving Diagnostic Quality and Safety*; 2017. https://www.qualityforum.org/Publications/2017/09/Improving_Diagnostic_Quality_and_Safety_Final_Report.aspx.
4. The National Quality Forum. *Improving Diagnostic Quality and Safety/Reducing Diagnostic Error: Measurement Considerations – Final Report*; 2020. https://www.qualityforum.org/Publications/2020/10/Reducing_Diagnostic_Error__Measurement_Considerations_-_Final_Report.aspx.
5. Battelle. *Diagnostic Excellence Initiative: Measure Implementation Challenge-to-Action Brief*; 2022. https://www.battelle.org/insights/white-papers/diagnostic-excellence-initiative-measure-implementation-challenge-to-action-brief.
6. Linda Zheng, Amanda Francescatti, MS, Susan Deming, et al. *Synoptic Reporting for Cancer Surgery: Current Requirements and Future State*; 2021. Accessed May 2024. https://www.facs.org/for-medical-professionals/news-publications/news-and-articles/bulletin/2021/12/synoptic-reporting-for-cancer-surgery-current-requirements-and-future-state/.
7. The National Quality Forum. *Memo to the Office of the National Coordinator of Health Information Technology (ONC): Priority Data Element Recommendations to Measure and Improve Diagnosis Quality*; 2024. https://www.qualityforum.org/WorkArea/linkit.aspx?LinkIdentifier=id&ItemID=98503.
8. The National Quality Forum. Advancing Collection of Standardized Symptoms Data. Accessed September 19, 2024. https://www.qualityforum.org/Advancing_Collection_of_Standardized_Symptoms_Data_.aspx

Appendix B: Acknowledgements

NQF's Advancing Measurement of Diagnostic Excellence for Better Healthcare Initiative and the work of the Diagnostic Excellence Committee are made possible by funding from the Gordon and Betty Moore Foundation.

This report was prepared by Robin M. Weinick, PhD, Principal, Resonant LLC, with input and feedback from Elizabeth Drye, Jenna Williams-Bader, and Hannah Ingber.

Project Staff

Elizabeth Drye, MD, SM
Chief Scientific Officer

Kathryn McDonald, PhD
Bloomberg Distinguished Professor of Health Systems, Quality and Safety and project co-principal investigator

Jenna Williams-Bader, MPH
Managing Director

Chuck Amos, MBA

Managing Director

Deidra Smith-Fisher, MBA, PMP
Director

Claudia Hall, DNP, RN
Director

Hannah Ingber, MPH
Senior Manager

Carolee Lantigua, MPA
Senior Manager

Chanel Lee, MPH
Analyst

Isabella Rivero
Analyst

Appendix C: Committee, Federal Liaison, and Advisory Group Rosters

Diagnostic Excellence Committee Members

Matt Austin, PhD
Associate Professor, Johns Hopkins Armstrong Institute for Patient Safety and Quality
Baltimore, MD

Rosemary "Rosie" Bartel, MA
Patient Advisor, Institute for Patient- and Family-Centered Care
Chilton, WI

Sigall Bell, MD
Associate Professor of Medicine, Harvard Medical School
Boston, MA

Joseph Cerimele, MD, MPH
Professor, University of Cinncinati School of Medicine
Cincinnati, OH

Melissa "Missy" Danforth, BA
Vice President of Health Care Ratings, Leapfrog Group
Washington, DC

Christina Davidson, MD
Vice Chair of Quality, Patient Safety & Health Equity, Baylor College of Medicine
Houston, TX

William Brendle Glomb, MD, FCCP, FAAP
Subject Matter Expert
String Prairie, TX

Joseph A. Grubenhoff, MD, MSCS
Medical Director, Diagnostic Safety Program at Children's Hospital Colorado
Denver, CO

Carole Hemmelgarn, MS
Senior Director of Education, MedStar Institute for Quality and Safety
Denver, CO

Barbara Jones, MD, MSCI
Associate Professor, University of Utah
Salt Lake City, UT

Michael Kanter, MD
Professor and Chair, Kaiser Permanente Bernard J. Tyson School of Medicine
Pasadena, CA

Joseph Kunisch, PhD, RN-BC, CPHQ
Vice President of Quality Programs, Harris Health System
Houston, TX

Prashant Mahajan, MD, MPH, MBA
Professor of Emergency Medicine and Pediatrics, Chief of Pediatric EM at University of Michigan
Ann Arbor, MI

Raquel Mayne, MPH, MSN, RN, CPHQ
Vice President of Quality Management, Phelps Hospital Northwell Health
Sleepy Hollow, NY

Nicholas Meo, MD
Associate Medical Director of Quality and Patient Safety, UW Medicine – Harborview Medical Center
Seattle, WA

Matthew Nielsen, MD, MS, FACS
Chair, Science and Quality Council at American Urological Society
Durham, NC

Irit R. Rasooly, MD, MSCE
Assistant Professor, Children's Hospital of Philadelphia, University of Pennsylvania
Philadelphia, PA

Kimberly R. Rodgers
Certified Patient Advocate
Chicago, IL

John Sather, MD
Director of Patient Safety and Quality, Department of Emergency Medicine, Yale School of Medicine
New Haven, CT

David Seidenwurm, MD, FACR
Physicians Alliance Chief Medical Officer, Sutter Health
Sacramento, CA

Hardeep Singh, MD, MPH
Co-Chief, Health Policy, Quality & Informatics, VA Center of Innovation and Baylor College of Medicine
Houston, TX

Julia Skapik, MD, MPH, FAMIA
Chief Medical Information Officer, National Association of Community Health Centers (NACHC)
Bethesda, MD

Alexis Snyder, BA
Patient and Stakeholder Engagement Specialist
Brookline, MA

Leslie Tucker, BA
Senior Policy Advisory, Society to Improve Diagnosis in Medicine
Alexandria, VA

Divvy Uphadyay, MD, MPH
Program Lead on Committee to Improve Clinical Diagnosis, Geisinger Health System
Danville, PA

Valerie Vaughn, MD, MSc
Director of Hospital Medicine Research, University of Utah
Salt Lake City, UT

Emily Volk, MD, MBA, FCAP
President, College of American Pathologists
Louisville, KY

Kevin P. Wake, MS, SCDAA, CMR
President, Uriel E. Owens Sickle Cell Disease Association of the Midwest
Kansas City, KS

Scott Woller, MD, FACP, FCCP
Chair of Medicine, Intermountain Medical Center
Salt Lake City, UT

Jennifer Woodward, MD, MPH
Medical Director, Quality & Performance Measurement, American Academy of Family Physicians
Kansas City, KS

Ronald Wyatt, MD, MHA
Chief Science Officer and Chief Medical Officer, Society to Improve Diagnosis in Medicine
Orange Beach, AL

Diagnostic Excellence Committee (Federal Liaisons)

Andrea Benin, MD
Division of Healthcare Quality Promotion, Centers for Disease Control and Prevention
Atlanta, GA

Stephanie Clark, MD, MPH, MSHP
Medical Officer, Centers for Medicare & Medicaid Services
Philadelphia, PA

Romsai Tony Boonyasai, MD, MPH
Division of Quality Measurement and Improvement, Agency for Healthcare Research and Quality
Baltimore, MD

Helen Burstin, MD, MPH, MACP
Washington, DC

Karen Cosby, MD, FACEP, CPPS
Rockville, MD

Patricia Dykes, PhD, MA, RN
Boston, MA

Helen Haskell, MA
Columbia, SC

Catherine H. MacLean, MD, PhD
New York, NY

Appendix D. Meeting Agenda

November 16, 2023
Washington, DC

9:00 AM	Welcome and Opening Remarks *Elizabeth Drye, Chief Scientific Officer, NQF*
9:15 AM	Committee Member Introductions
9:30 AM	Overview of Initiative, Agenda, and Meeting Objectives *Jenna Williams-Bader, Managing Director, NQF*
9:45 AM	Patient Panel *Moderator: Kathy McDonald, Bloomberg Distinguished Professor, Johns Hopkins University* *Panelists: Alexis Snyder, Carole Hemmelgarn, Kevin Wake, and Rosie Bartel*
10:45 AM	Break
11:05 AM	Environmental Scan Findings *Hannah Ingber, Manager, NQF*
11:30 AM	Lunch
12:30 PM	Measurement Challenges Overview *Jenna Williams-Bader, Managing Director, NQF*
12:40 PM	Breakout Group Sessions

- Data Specificity and Data Standards
- Diagnostic Equity
- Patient-Reported Outcome-based Performance Measures (PRO-PMs)
- System Fragmentation

2:20 PM	Break
2:35 PM	Breakout Group Report Outs and Large Group Session
3:55 PM	Closing Remarks *Jenna Williams-Bader, Managing Director, NQF*
4:00 PM	Adjourn