REPORT

NATIONAL QUALITY FORUM
Driving measurable health improvements together

Diagnostic Excellence Measurement Challenges and Recommended Solutions

REPORT
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ABOUT THE NATIONAL QUALITY FORUM

The National Quality Forum (NQF) works with members of the healthcare community to drive measurable health improvements together. NQF is a not-for-profit, membership-based organization that gives all healthcare stakeholders a voice in advancing quality measures and improvement strategies that lead to better outcomes and greater value. Learn more at www.qualityforum.org.

ABOUT THE GORDON AND BETTY MOORE FOUNDATION

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Impact Statement

Purpose

Diagnostic errors, including missed, delayed, or incorrect diagnoses, are prevalent in healthcare and can lead to significant patient harm. Avoiding diagnostic errors and improving the diagnostic process relies on measuring diagnostic excellence. This report identifies and addresses key challenges in measuring diagnostic excellence, proposing actionable solutions that focus on improving diagnosis for every patient and from the patient's perspective.

Key Takeaways

- Diagnostic Excellence for All: The report highlights the need for measures that improve diagnosis for all people. It proposes strategies such as measuring late-stage diagnoses and using data that do not rely on healthcare interactions to account for all patients.

- Patient-Reported Measurement: Emphasizing the importance of the patient's perspective, the report discusses the development and use of patient-reported measures (PRMs) to assess diagnostic excellence. It explores key domains for PRMs, such as access, care coordination, communication, and transparency, and suggests approaches to integrating these measures into healthcare systems.

- Timeliness and Access: The report highlights how measures of timeliness of and access to diagnostic care can incorporate the patient voice and assess the diagnostic journey for all people.

- Actionability and Accountability: The report underscores the need for actionable measures that can drive diagnostic quality improvement and accountability. It recommends developing measures (PRMs and others) that are feasible to collect, actionable for clinicians, and attributable to healthcare entities for performance assessment.

Applications

This report is intended for policymakers, measure developers, healthcare organizations, and the public. It identifies impactful next steps for overcoming challenges related to developing and implementing diagnostic excellence measures that can be used for accountability and quality improvement.

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Executive Summary

Accurate and timely diagnoses are critical to delivering high-quality, safe, and effective patient care and minimizing patient harm. Yet diagnostic errors, which include missed, delayed, or incorrect diagnoses, are prevalent in healthcare and may lead to significant patient harm, including permanent disability and death. The annual rate of outpatient diagnostic errors is estimated to be 5 percent nationally, affecting approximately 12 million U.S. adults every year. In hospitalized patients, diagnostic errors are also significant, with an estimated 18 percent of misdiagnosed hospitalized patients experiencing harm or death. It has been estimated that 250,000 diagnostic errors occur in the hospital setting every year in the U.S.[1-4] Measuring diagnostic performance could help to identify variations in diagnostic processes and outcomes, assess the impact of quality improvement interventions, and motivate changes in processes and structures, thereby leading to improved patient outcomes and enhanced healthcare delivery for all people. However, despite increased attention to the issue in recent years, there have been only modest advances in the measurement of diagnostic performance, with significant challenges and barriers impeding the use of such measures for accountability.

Funded by the Gordon and Betty Moore Foundation, NQF convened a national Committee of experts and interest holders with a variety of perspectives related to diagnostic quality measurement to identify potential solutions to the challenges of measuring diagnostic excellence. Committee members included:

- Diagnostic excellence measurement experts
- Diagnostic excellence measure developers
- Health information technology (HIT) professionals
- Patient-reported measurement experts
- Patients, care partners, and patient advocates
- Representatives of health systems
- Other subject matter experts

Considering the urgency and critical significance of diagnostic excellence to health and healthcare, and guided by the Committee's preferences, NQF asked Committee members to systematically identify challenges in diagnostic excellence measurement, prioritizing those with actionable solutions that are applicable to the unique aspects of diagnostic excellence accountability. The Committee considered a range of issues as part of this process, including inadequate data specificity and standardization; unnecessary variations in diagnostic care across populations; a lack of patient-reported measures; and healthcare system fragmentation.[a] To further optimize the work's impact, the Committee focused on challenges and solutions for measures suitable for use in accountability programs that incentivize improvement.

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[a] In addition to the challenges described in this report, NQF is operationalizing solutions to two challenges identified at the outset of the project based on prior work: identifying data standards for diagnostic excellence measurement needed to speed data interoperability, and better leveraging the use of artificial intelligence (AI) in measurement, including for diagnostic excellence. These issues are being addressed through separate but related NQF projects.

The Committee prioritized and considered solutions for three specific challenges:

Challenge A: Most existing diagnostic excellence measures use healthcare visit data—either claims or electronic—to evaluate performance, leaving out data on individuals who do not interact or have limited interaction with the traditional healthcare system. Thus, experiences and outcomes of these individuals are not captured adequately for diagnostic excellence measurement, improvement, and accountability.

Challenge B: There are known differences in outcomes and experience of the diagnostic process across different populations, yet existing measures and methods fail to capture information on a multitude of factors associated with variations in receipt (or not) of the highest quality diagnostic care.

Challenge C: There is a lack of consensus and strategic direction on how to define and assess diagnostic excellence in a way that meets the needs and expectations of patients, their care partners, clinicians, and health systems. This hinders decision making on the path forward for patient-reported measures of diagnostic excellence. Currently, the perspectives of patients, their families, and other care partners are not yet assessed in the context of diagnostic excellence accountability programs.

For each of these challenges, this report presents the evidence of the need for measurement, barriers to measurement, and the Committee's discussion and recommended solutions for overcoming impediments. For each challenge, the report provides approaches to measurement, accompanied by principles in how measure developers and programs should apply the solutions. The major findings are summarized below.

CHALLENGE A: MEASURING DIAGNOSTIC EXCELLENCE FOR ALL PATIENTS

To address the challenge of measuring diagnostic excellence for individuals who have limited or no contact with the healthcare system, the Committee recommended two approaches: (1) assessing by measuring late-stage diagnosis, and (2) using data that do not rely on individuals interacting with the healthcare system.

Assess by Measuring Late-Stage Diagnosis

The Committee supported prioritizing development, testing, and implementation of measures of late-stage diagnosis as a way to assess the quality of diagnostic care for individuals who are not included in other types of diagnostic excellence measures. While groups of patients may be missing from measures of diagnostic excellence due to limited interaction with the healthcare system early in the diagnostic process, some of these patients may receive care once their conditions have significantly progressed. Establishing diagnosis in such circumstances can be referred to as late-stage diagnosis. Some late-stage diagnoses are detected at "emergency presentation," reflecting progression of disease due to a lack of timely access to diagnostic care, or a failure of the diagnostic process to identify the disease at an earlier stage. Therefore, developing measures that assess rates of late-stage diagnosis may help to estimate diagnostic outcomes for a broader group, including those who do not interact or interact only partly with the healthcare system during the diagnostic process. The Committee recommended exploring accountability for late-stage diagnosis and emergency presentation measures as applied to entities with defined populations (e.g., health plans, integrated health systems, public health agencies), while acknowledging some of the complexities of these types of measures.

The Committee discussed potential approaches and considerations for measurement of late-stage diagnosis, including how to prioritize diagnoses and populations for measure development, how to define the time of diagnosis for measurement purposes, and additional methods that could be used to measure delayed diagnosis (e.g., using prevalence data to estimate "expected" rates of diagnosis in order to identify gaps in diagnostic excellence for all patients).

Use of Data That Do Not Rely on Individuals Interacting With the Healthcare System

While acknowledging the exclusion of those who are uninsured, the Committee proposed focusing measurement on health plans, because these entities accept responsibility for making certain that their insured members have access to necessary care, and can readily identify plan enrollees regardless of whether they interact with the healthcare system. This strategy provides a starting point from which to identify individuals who are at risk for lack of access to the diagnostic process and individuals who could be included in diagnostic excellence measures that do not rely on healthcare visit data.

To address limitations of health plan data, Committee members suggested alternative sources of data outside the healthcare system. These include community-based organizations (CBOs), school- and university-based clinics, and departments of public health. Committee members also suggested additional sources of data and methods for identifying individuals at risk of having *limited* access to diagnostic care. Potential data sources could include health information exchanges (HIEs), emergency departments, urgent care facilities, and federally qualified health centers (FQHCs).

CHALLENGE B: LACK OF MEASURES ASSESSING WHETHER ALL PEOPLE RECEIVE THE HIGHEST QUALITY OF DIAGNOSTIC CARE

To address the lack of measures and methods assessing factors associated with differences in the quality of diagnostic care across populations, the Committee proposed two potential approaches: (1) stratifying measures using data that identify populations that may be impacted by variations in diagnostic care, and (2) measuring perceived variation and bias in experiences of the diagnostic process.

Stratification of Measures Using Data That Identify Variations in Diagnostic Quality Across Populations

Even though diagnostic quality varies for different populations, there is a lack of measures and methods assessing differences across populations in diagnostic processes, outcomes, and experiences. Stratifying measures of diagnostic excellence using variables that may be associated with differential diagnostic quality, such as geographic location (including rurality), income, education, age, gender, and other patient characteristics, may provide insights into these differences. Among the main challenges to stratification are the availability and quality of relevant data and the selection of measures to stratify. Committee members noted high missing rates of data used for stratification and discussed trends and strategies for advancing data collection. Among other approaches, the Committee recommended developing guidance, criteria, or a framework for evaluating acceptable levels of missingness, data adequacy, and data quality. In addition, the Committee noted that establishing reference groups against which diagnostic excellence analyses can be conducted would facilitate development of diagnostic performance benchmarks. The Committee emphasized that there will be a need for a variety of approaches to prioritizing measures for stratification, including targeting measures for diagnoses with

known large differences in diagnostic quality by group, because a single approach cannot be identified. The Committee also suggested prioritizing a small number of diagnoses around which to develop measures that can identify differences across groups in diagnostic processes, outcomes, and experiences, and to demonstrate methods for stratifying those measures.

Measurement of Perceived Bias and Variations in Experiences of the Diagnostic Process

One potential impediment to individuals receiving the highest quality diagnostic processes and outcomes is patients' experiences of bias or variations in care during the diagnostic journey. Individuals from some populations are more likely to experience bias or variations in care. These individuals may be more susceptible to diagnostic error because of factors such as language barriers, reduced self-advocacy, lower health literacy, or lower levels of trust in providers, which can hinder communication between patients and clinicians about symptoms, disease presentation, and other information supporting timely and accurate diagnosis. The Committee's recommendations included supporting the addition of questions to the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys to assess patients' experiences of perceived variation and bias during the diagnostic journey, including whether patients feel that factors such as language barriers or lower levels of trust in providers may have impacted this journey. The Committee also acknowledged and emphasized the potential of artificial intelligence (AI) to assess explicit and implicit bias in diagnostic encounters by analyzing both in-person interactions and written communications.

Measuring Access to and Timeliness of Diagnostic Care

The Committee highlighted measuring access and timeliness of diagnostic care in discussions about measuring delayed diagnosis and understanding underlying differences across populations in diagnostic processes, outcomes, and experiences. Either of these two measurement domains (access to care, timeliness) may uncover differences in diagnostic care and outcomes associated with factors that contribute to variations in receipt (or not) of the highest quality diagnostic care. At the same time, measurement related to these two domains would benefit from data collection directly from patients or their care partners. For example, the Committee recommended developing measures of timeliness that take into account patient preferences for defining when the diagnostic process starts for them. The Committee also emphasized that access should be defined broadly to include access to diagnostic care and personal health information, access to an understandable diagnosis, and, especially in the setting of a highly uncertain diagnosis, access to contingency plans in case the course of illness is not as expected. Measurement of access should address whether patients have access to clear, timely, and understandable communication related to the diagnostic process, including diagnostic information in a language they understand and access to digital tools, interpretive services, and other resources.

CHALLENGE C: ADVANCING PATIENT-REPORTED MEASUREMENT

To address the need to represent the perspectives of patients, their families, and care partners in diagnostic excellence accountability measures, the Committee prioritized solving the challenges related to employing patient-reported measures (PRMs). The Committee identified five key themes for solutions that build upon each other to address the core challenges:

1. Setting the stage for the use of PRMs in accountability programs and for action on diagnostic excellence
2. Identifying patient-reported domains that matter to patients and ways to measure those domains
3. Creating a pipeline of PRMs for actionability to inform meaningful PRMs for accountability
4. Supporting immediate progress on a small number of promising diagnostic excellence PRM concepts
5. Moving from a small number of PRM concepts to PRMs for diagnostic excellence accountability

The Committee elaborated on the challenges associated with determining and operationalizing what to measure, when to measure, and how to measure diagnostic excellence from the patient and care-partner standpoints for accountability. Particularly, the Committee focused on hypothesized potential differences in expectations and beliefs about diagnostic excellence between patients, their care partners, clinicians, and health systems. This challenge is amplified by limited progress with accountability measures of diagnostic excellence overall and lack of existing diagnostic excellence accountability PRMs. Finally, Committee discussions on whether patients can truly reflect on all aspects of diagnostic excellence included some views that contested this possibility.

The Committee noted that the full scope of patient-reported outcomes and experiences relevant to diagnostic excellence is currently unknown and that there is a multitude of experience and outcome domains that overlap—and some domains are not specific to diagnosis only, such as access, coordination, and communication and transparency. The Committee indicated the need for a process that prioritizes patient-reported domains for diagnostic excellence accountability and prevents biases in such prioritization. The Committee noted a potential need for many diagnostic excellence accountability PRMs to cover different settings, timing, and patient populations, and discussed challenges related to different timing and setting junctures for patient-reported assessment that are actionable.

The Committee highlighted unique challenges with defining the “accountability unit” for patient-reported diagnostic excellence and with confirming that response actions are within the control of that accountable unit, for example, while assessing diagnostic access and care coordination. This identified a need for forming unique accountability units for action and for mediated efforts to create accountability partnerships between interested parties. The Committee noted that as potential differences in expectations and beliefs about diagnostic excellence are not currently assessed, the introduction of PRMs for diagnostic excellence accountability might inadvertently reinforce or mask these potential differences, increasing the risk of unintended consequences that might be difficult to identify and that could persist unnoticed over time. This underlines the many unknowns that proposed solutions face.

The Committee highlighted that first-of-their-kind diagnostic excellence accountability PRMs will not only make diagnostic excellence patient-centered, but these types of measures are required to establish whether diagnostic excellence occurred. The Committee noted that these measures are needed to help define diagnostic excellence and supported work to update the scope of patient-reported experience and outcome domains for diagnostic excellence. In addition, the Committee noted that support is also required for enhancing collection methods of diagnostic excellence PRMs and establishing an evidence base for actions that can be taken in response to diagnostic excellence accountability PRMs. The Committee indicated that response actions might also be undertaken by patients if these measures are

publicly reported, and by institutions that promote patient safety and diagnostic excellence for the healthcare system as a whole. The Committee highlighted that, as patient-reported diagnostic excellence touches upon experiences and outcomes across the healthcare system, diagnostic excellence accountability PRMs might support less compartmentalization of healthcare quality to institutions and greater cultivation of shared accountability. The Committee emphasized that diagnostic excellence accountability PRMs also enable looking into earlier stages of diagnostic journeys from the onset of symptoms, integrating the healthcare and public health systems and drawing attention to earlier stages of diagnostic journeys. The Committee suggested that diagnostic excellence accountability PRMs are likely to lead to patient engagement in patient safety and learning health systems, which eventually might support patients in leading healthcare system redesign. This plethora of opportunities provided by diagnostic excellence accountability PRMs led to identifying several directions for associated solutions.

The Committee endorsed supporting work on diagnostic excellence PRMs for accountability that measure areas:

- Where concordance between patients, their care partners, clinicians, and health systems is anticipated
- Representing divergences between patients, their care partners, clinicians, and health systems
- Responsive to capturing as many patient-reported experiences and outcomes of diagnostic excellence that matter to patients as possible

The Committee emphasized supporting better definitional development of what diagnostic excellence looks like, from all points of view, to inform such work.

The Committee also identified three supports for this work that together form an ecosystem to address measurement challenges in this area:

- A forum for accountability for diagnostic excellence accountability PRMs
- Coordinating activities, leadership, and change management for diagnostic excellence accountability PRMs
- Purposeful funding of development and implementation of diagnostic excellence PRMs

The Committee noted that diagnostic excellence PRMs can be introduced gradually, starting with pay for reporting, public reporting, and then only based on this experience, used for paying for performance. Another gradual pathway for incorporation of diagnostic excellence PRMs into pay-for-performance accountability programs is to pair them with diagnostic excellence accountability measures that are not based on patient reporting.

The Committee noted the benefits of creating an ecosystem encompassing all diagnostic excellence accountability PRMs and needed support. The ecosystem approach is ultimately integrative, addressing diagnostic quality for all persons and the need for PRMs to illuminate variations in the quality of diagnostic processes, outcomes, and experiences by hearing from all patients. Given the limited development of diagnostic excellence accountability PRMs, an ecosystem approach will monitor the gradual evolution through the various stages from PRM use in pay for reporting to the final stage of PRM integration into payment incentives for diagnostic excellence.

CONCLUSION

These recommendations aim to establish a more patient-centered and effective framework for diagnostic excellence measurement within the U.S. healthcare system to improve diagnostic care for all people. This Committee focused on advancing diagnostic excellence measurement that encompasses the fullest possible population and is supported by actionable, concrete solutions. Twenty-nine potential solutions to key challenges and 24 guiding principles for their execution are discussed in this report (see Appendix D for a list of recommendations and principles). Other key issues related to diagnostic excellence, such as data standardization and harnessing the potential of artificial intelligence to facilitate more effective and less burdensome collection of information from medical records and notes, are being addressed as part of separate NQF workstreams. The Committee recognized that incorporating and reflecting patient perspectives will be critical to effective measurement of diagnostic excellence and emphasized the importance of defining a systematic approach to the conceptualization and development of patient-reported diagnostic excellence measures. The Committee also recognized as critical the use of new sources of data and late-stage diagnosis measures, measure stratification by groups vulnerable to variations in care, and measurement of patients' perceptions of bias and variation. Measurement of timeliness and access to diagnostic care emerged as a solution theme that cuts across other diagnostic quality challenges. Acting upon these recommendations will help to build accountability for diagnostic performance and produce measurement-based incentives for diagnostic excellence. Success will require coordinated effort across healthcare entities and careful consideration of the needs of all patients. Inspired to contribute to coordinating these efforts, NQF seeks to improve patient outcomes of diagnostic care, reduce diagnostic errors, and promote high-quality diagnostic care for all through measures suitable for accountability programs.

Introduction

FOCUS OF THIS REPORT

Accurate and timely diagnoses are critical to delivering high-quality, safe, and effective patient care and minimizing patient harm. Diagnostic errors, which include missed, delayed, or incorrect diagnoses, are prevalent in healthcare and may lead to significant patient harm, including permanent disability and death.[1-4] Measuring diagnostic performance could help to identify variations in diagnostic processes and outcomes, assess the impact of quality improvement interventions, and motivate changes in processes and structures, thereby leading to improved patient outcomes, enhanced healthcare delivery, and reduced disparities in care. However, there are challenges to developing and implementing quality measures related to diagnostic performance that have impeded their use.[5]

To support progress on measurement of diagnostic excellence, the National Quality Forum (NQF) convened a national committee representing a variety of perspectives, the Diagnostic Excellence Committee, to better identify and inform solutions to diagnostic excellence measurement challenges. NQF is a consensus-based entity that convenes interest holders[b] from all sectors of the healthcare system to move the healthcare quality community beyond intractable real-world measurement challenges. By finding solutions to measurement challenges and fostering their use in accountability programs, the project seeks to improve patient care and outcomes, reduce diagnostic error, and promote diagnostic excellence for all patients.

This report presents NQF's in-depth work with the Diagnostic Excellence Committee to systematically identify priority challenges and actionable solutions to diagnostic excellence measurement for accountability. The report provides background on the impact of diagnostic errors; defines the project's methods for identifying, prioritizing, and evaluating challenges and solutions; and presents key findings and recommendations from the Committee. The methodology used by NQF is described in detail in the Methodology section of this report. In brief, NQF convened the Diagnostic Excellence Committee through a formal nominations process. Then, through a structured process informed by NQF's information gathering and synthesis, the Committee narrowed its focus to challenges associated with two related areas of diagnostic excellence measurement: measuring diagnostic equity, meaning the achievement of diagnostic excellence for every patient in every situation, and measuring the patient's perspective of diagnostic quality. This report presents the Committee's consideration of challenges, selection of two priority areas, and the Committee's discussion, conclusions, and recommendations for each of these areas.

This report is part of a broader body of NQF diagnostic excellence measurement work supported by the Gordon and Betty Moore Foundation (the Moore Foundation), NQF's Advancing Measurement of Diagnostic Excellence for Better Healthcare initiative (Diagnostic Excellence initiative). In addition to the

[b] The term *interest holder* is similar to *stakeholder*. The Diagnostic Excellence Committee expressed a preference for the term interest holder. Committee members representing the patient perspective raised the concern that stakeholder may not include patients. This alternative term is also considered to be more inclusive and does not bear the same negative connotations that the term stakeholder may for certain groups.[6]

challenges described in this report, NQF is operationalizing solutions to two challenges identified at the outset of the project based on prior work[5]: identifying data standards for diagnostic excellence measurement needed to speed data interoperability, and better leveraging the use of artificial intelligence (AI) in measurement, including for diagnostic excellence. To support the former, NQF analyzed the measures funded by Moore Foundation grants to identify key data elements that could improve diagnostic quality and enhance measurement of the diagnostic process. NQF used these findings as the basis for a memo to the Office of the National Coordinator for Health Information Technology (ONC, now the Assistant Secretary for Technology Policy) providing comments and feedback on data elements for inclusion in United States Core Data for Interoperability (USCDI). To support the use of AI, with a separate technical panel, NQF is developing strategies to advance trustworthy AI-enabled measures and recommendations for developing, selecting, and implementing AI-enabled quality measures in accountability programs. NQF will publish this guidance in 2026.

Further, through a separate grant from the Moore Foundation, NQF is working with the American Medical Association (AMA) to develop and advance consensus-based data standards for symptoms data, defined in Fast Healthcare Interoperable Resources (FHIR), through HL7's international standard setting process. This approach will build consensus on the key terms, attributes, and characteristics that support sharing of symptoms data across care settings, which over time will both better enable measurement of diagnostic excellence and better support provider access to the clinical data needed to optimize diagnosis in a fragmented system. More standardized, electronically available symptoms data will improve the availability and consistent meaning of symptoms data needed for both AI-enabled and traditional digital quality measures.

BACKGROUND

Impact of Diagnostic Errors

Diagnostic errors have a profound impact on patient safety and healthcare outcomes. Virtually every adult American who has had a healthcare encounter has experienced at least one diagnostic error.[4] The rate of outpatient diagnostic errors is estimated to be 5 percent nationally, affecting approximately 12 million U.S. adults every year.[2] In hospitalized patients, diagnostic errors are also significant. In one study, approximately 23 percent of hospitalized patients transferred to the intensive care unit, patients who died, or both, experienced a diagnostic error, with an estimated 18 percent of misdiagnosed hospitalized patients experiencing harm or death.[3] The National Academy of Medicine (NAM) estimated that 250,000 diagnostic errors occur in the hospital setting every year in the U.S.[4]

The consequences of these errors are dire. Each year, an estimated 795,000 Americans become permanently disabled or die across care settings because dangerous diseases (e.g., stroke, sepsis, and pneumonia) are misdiagnosed.[1] Approximately 64,000 preventable deaths annually in the U.S. are due to diagnostic errors.[4] Preventable deaths from diagnostic errors account for approximately 25 percent of all medical error-related deaths,[4] making diagnostic error likely the single largest source of deaths linked to medical errors across all care settings.[1] Diagnostic errors also have an impact on the patient-clinician relationship. One study, in which 13.4 percent of patients reported their physician had made a wrong diagnosis, also found that 14.1 percent of the study's patients changed physicians because of a mistake.[7]

Furthermore, diagnostic errors disproportionately affect historically disadvantaged populations,[8] meaning groups that have historically faced systemic discrimination and persistent disadvantage due to factors like race, ethnicity, language preference, English proficiency, health literacy, sexual orientation, gender identity, digital literacy, rurality, or disability. For example, in a study of individuals presenting to the emergency department (ED) with chest pain, or other symptoms indicating acute cardiac ischemia, women under 55 years old or non-White patients were less likely to be hospitalized, facing higher risks of missed diagnoses of myocardial infarction.[9] In another study, individuals who identified as Asian, Black, or Hispanic were less likely to receive a timely diagnosis of dementia than those who identified as White; in addition, those who identified as Asian received a less comprehensive dementia evaluation when compared to other groups.[10] Diagnostic disparities are also documented in children; for example, in a study analyzing rates of delayed diagnosis of appendicitis, non-Hispanic Black children with symptoms of appendicitis were less likely to undergo imaging, and more likely to have appendiceal perforation or a delayed diagnosis of appendicitis than non-Hispanic White children.[10]

Historically disadvantaged populations are also more likely to be diagnosed in acute care settings rather than ambulatory settings. In a recent study, new-onset heart failure diagnosis was more likely to occur in acute care settings (ED or inpatient hospitalization) than outpatient settings, particularly among those with female sex, American Indian race, and dual eligibility for Medicare and Medicaid (a proxy indicator for low income), indicating that inequities within outpatient clinician practices may contribute to delayed diagnoses and interventions, potentially exacerbating health disparities and impacting patient outcomes.[11] In another study analyzing cancer patients who visited the ED between 0 to 30 days before their cancer diagnosis, several patient characteristics were associated with an ED visit, including older age, female sex, non-Hispanic Black and Native Hawaiian or Other Pacific Islander race, and poverty. Such ED visits are associated with lower cancer survival rates and greater healthcare disparities.[12] These studies highlight some of the disparities that exist in diagnostic care, demonstrating how historically disadvantaged populations often face delayed diagnoses and worse outcomes.

In addition, diagnostic errors contribute to inflated healthcare spending. NAM estimates that inefficiencies, including diagnostic errors and related unnecessary services, account for 30 percent of all annual healthcare spending.[13] Direct costs to patients accrue from failure to treat the true condition, inappropriate testing and treatments for the incorrectly diagnosed condition, and any medical or legal costs or payments.[14] The patient safety consequences, disparate impact, and cost of diagnostic errors demonstrate the need for urgent action to improve the quality of the diagnostic process.

Diagnostic Excellence and Quality Measurement

The importance of improving diagnostic processes and outcomes received nationwide attention in 2015 when the Institute of Medicine (IOM, now NAM) released a landmark report highlighting the problem of diagnostic error and recommending goals to reduce diagnostic error and improve diagnosis. In that report, NAM's committee defined diagnostic error as the "the failure to (a) establish an accurate and timely explanation of the patient's health problem(s) or (b) communicate that explanation to the patient."[4] Since 2015, thinking about diagnosis has evolved, with increased focus on when diagnosis succeeds, not only when it fails. The term *diagnostic excellence* emerged, which the Moore Foundation described as an "optimal process to attain an accurate and precise explanation about a patient's condition"— one that is timely, cost-effective, convenient, and understandable to the patient.[15] This

definition acknowledges that improving the diagnostic process is not just about avoiding errors, and prompts consideration of whether diagnostic performance is high quality across the full range of well-established quality domains of safe, effective, patient-centered, timely, efficient, and equitable care.[15] Quality measurement is a potentially powerful way to facilitate better support for patients and care teams to improve the diagnostic process and achieve diagnostic excellence.[16] Diagnostic excellence measurement has evolved in the past decade, although few measures are currently in use. A decade ago, there was a clear need for leadership and research to move the field forward. In 2015, NAM's committee concluded that, "it would be premature either to adopt an accountability framework [related to quality measurement] or to assume that the traditional accountability frameworks for public reporting and payment will be effective in reducing diagnostic error."[15] Further, the work of this NAM committee indicated that, given the complexity of the diagnostic process, no single data source, method, setting, or circumstance will enable complete understanding of the causes and risks of diagnostic error; measuring diagnostic errors will require a comprehensive, or "all in," approach.[17]

To advance measurement in this space and move toward greater accountability for diagnostic performance, both NQF and the Moore Foundation subsequently started initiatives designed to spur diagnostic excellence measure development for use in public reporting and accountability programs. In 2017, supported by the U.S. Department of Health and Human Services (HHS), NQF convened a committee to develop a conceptual framework for measuring diagnostic quality and safety, identifying measure gaps and providing guidance for future measure development.[18] NQF continued this effort in 2019 when it convened a committee to develop specific use cases to address diagnostic errors in real-world scenarios.[18,19] Similarly, the Moore Foundation started its Diagnostic Excellence initiative in 2019. The primary strategy of the initiative was to "strengthen accountability for diagnostic excellence by helping to develop and validate new measures for diagnostic performance."[20] The Moore Foundation strove to catalyze development of diagnostic excellence measures by funding four cohorts of measure developers between 2019 and 2023 to develop and test measures of diagnostic excellence for use in accountability programs. The experience of those four cohorts identified common and systemic challenges, especially as they moved from research toward quality assessment for accountability purposes.

Measures used for accountability purposes present unique challenges. The measure results must be comparable across measured entities and allow for fair comparisons across varied patient populations (e.g., through risk adjustment). The measures must be implemented thoughtfully, as there may be unintended consequences if the accountability measures are implemented without considering artifacts of patient characteristics or data quality and variability in measure results. Measures used for accountability purposes must also be feasible for a variety of entities with different data infrastructures and clinical workflows.

Despite these challenges, developing measures suitable for use in accountability programs is an important mechanism for improving diagnosis. To date, the use of diagnostic excellence measures for accountability has been limited.[21] Solving barriers to the development and use of these types of measures is critical to ensuring healthcare entities are evaluated fairly and are motivated to improve their diagnostic processes and outcomes. Measures suitable for use in accountability programs can be leveraged to motivate quality improvement through payment adjustments and public reporting, driving

systemic improvements in the care provided to patients. This report, and the work described within, focuses on diagnostic excellence quality measures that may be suitable for use in accountability programs.

TERMS TO KNOW

This report references several terms. The definitions of these terms (see below) were established at the outset of the project and refined with Committee's input and are subject to change as the diagnostic excellence field evolves.

- ***Quality measure:*** A quality measure is a standardized tool used to assess the performance of healthcare providers in delivering care. These measures help gauge various aspects of healthcare quality (safe, effective, timely, patient-centered, equitable, efficient) and guide improvements.
- ***Accountability measure:*** An accountability measure is a type of quality measure specifically used to hold healthcare providers or organizations accountable for their performance. These measures are often tied to public reporting, payment adjustments, or accreditation requirements, motivating clinicians and organizations to meet specific standards of care. These measures must fairly compare specific types of "accountable entities"—such as clinicians, health delivery sites such as hospitals or clinics, health plans or other organizations in the health system—to similar entities.
- ***Diagnostic excellence:*** The Moore Foundation describes diagnostic excellence as an "optimal process to attain an accurate and precise explanation about a patient's condition"—one that is timely, cost-effective, convenient, and understandable to the patient.[14] However, as discussed by the Diagnostic Excellence Committee and referenced in the Patient-Reported Measurement section of this report, this definition may need to be redefined, incorporating patients and care partners in that process.

METHODOLOGY

NQF generated Committee findings and recommendations on solutions to challenges to diagnostic excellence measurement for accountability through a structured process. In brief, NQF convened a national committee representing a variety of different perspectives, and conducted an environmental scan to inform its work. NQF presented challenges related to diagnostic excellence measurement to the Diagnostic Excellence Committee (Appendix A) at an in-person meeting in November 2023 and asked them to prioritize the most important and actionable challenges. The Committee prioritized two challenge areas and ideated specific, actionable solutions to the prioritized challenges, formulated as recommendations and principles. Throughout, NQF supported the Committee's deliberations through information gathering, analysis, and synthesis. These steps are presented in greater detail below. In addition, NQF consulted with a five-person Diagnostic Excellence Advisory Group (Appendix A), composed of national leaders with different perspectives that NQF convened to guide the project.

Steps NQF implemented to generate Committee recommendations:

1. Convened the Diagnostic Excellence Committee through outreach to NQF membership and a broad public call for nominations. NQF sought to include members who represent diverse areas of interest and expertise. NQF seated 31 Committee members comprising diagnostic excellence measurement experts; diagnostic excellence measure developers; health equity experts; health information technology (HIT) professionals; patient-reported measurement experts; patients, care partners, and patient advocates; and representatives of health systems. NQF also seated liaisons from several federal agencies to listen to Committee discussions and provide input on agency activities relevant to diagnostic excellence quality measurement.
2. Conducted an environmental scan (consisting of a measures scan, literature review, and review of Moore Foundation measure developer grantee reports) to identify diagnostic excellence accountability measures and gaps in these measures, as well as challenges to developing and implementing these measures, and potential priority areas for further work.
3. Defined potential "challenge categories"—each with several challenges—for Committee review and prioritization.
4. At an in-person meeting (described briefly below and in a separate report) solicited Committee input on the challenge categories and additional challenges that may have been missed, and workshopped the challenges and challenge categories with the Committee to sharpen priorities. This led to 12 revised priority challenges.
5. Through a Committee vote, and in consultation with the Advisory Group, selected two final priority challenge topics (diagnostic equity and patient-reported measures [PRMs]) for concentrated work based on their actionability (areas where the Committee's work could drive progress in the field) and the potential impact of solving each challenge.
6. Divided the Committee into two subcommittees to ideate specific, actionable solutions to the prioritized challenges.
    a. The Diagnostic Equity Subcommittee focused on addressing the lack of inclusivity in diagnostic excellence measures, including of historically disadvantaged groups, and the absence of metrics to assess equity, bias, and discrimination in the diagnostic process and diagnostic outcomes (see the Diagnostic Equity section).
    b. The Patient-Reported Measurement Subcommittee focused on the potential divergence between expectations of patients, care partners, clinicians, and health systems on what constitutes diagnostic excellence for the purposes of the assessment of health system performance (since perspectives of patients, their families, and care partners currently are not part of that assessment, these potential divergences should be addressed) (see the Patient-Reported Measurement section).
7. Conducted additional research to inform further Committee work, including a targeted environmental scan of measures, literature reviews, and key informant interviews.
    a. For diagnostic equity, NQF identified four potential approaches for discussion and refinement.
    b. For patient-reported measurement, NQF identified five key themes for discussion and refinement.
    c. Measurement of access to and timeliness of diagnostic care emerged as a cross-cutting theme.
8. Through discussion and refinement of the potential approaches and key themes in two meetings with each Subcommittee, developed recommendations and principles (Appendix D).
9. Synthesized the recommendations and principles for full Committee review in a draft report.
10. Elicited and consolidated Committee feedback and reviewed this report in a final meeting with the Committee.

Environmental Scan Findings

To support the Committee's deliberations, NQF conducted an environmental scan. The goals of the scan were to capture and synthesize the field of diagnostic excellence quality measurement used for accountability purposes as of spring 2023 and to identify challenges and solutions to the development, testing, and implementation of diagnostic excellence quality measures. NQF consulted with the Diagnostic Excellence Committee early in the scan process to review inclusion and exclusion criteria for the scan. The scan used three sources of data: (1) diagnostic excellence measures submitted for endorsement review by consensus-based entities (CBEs) or used in accountability programs; (2) peer-reviewed literature about the use of diagnostic excellence measurement for accountability purposes, the development of measures in this field, and the challenges and potential solutions related to measurement; and, (3) information from measure developers funded by the Moore Foundation that related their experiences with developing new diagnostic excellence measures. This last portion of the environmental scan focused on measures produced through Moore Foundation–funded projects to ensure that findings reflected concrete challenges that are directly relevant to measure development efforts in this area.

Key findings from the environmental scan, as of spring 2023, included the following:

- **There is a lack of progress in creating quality measures that incorporate patient-reported information,** which would meaningfully contribute to understanding whether diagnostic excellence has occurred.[16] The measures scan and literature review identified no diagnostic quality measures that use patient-reported information. NQF found that two of the Moore Foundation measure development grants funded the development of these types of measures, but these measures are still in development and not yet ready for use in accountability programs.
- **There has been little advancement in developing measures that address equity in the diagnostic process, outcomes, and experience (i.e., "diagnostic equity" measures).** The measures scan and literature review identified no measures of diagnostic equity. Few measure developers funded by the Moore Foundation were able to investigate diagnostic equity by stratifying measures (e.g., by sociodemographic factors), as they had insufficient data to compare and assess differences in measure calculation across groups. None of the developed measures were specifically designed to measure diagnostic equity.
- **Measures do not assess the early part of the diagnostic journey when the individual has had little or no interaction with the healthcare system.** The measures scan and literature review found no measures that address the first two steps of the diagnostic process, as described by NAM.[4] These steps are "patient experiences a health problem" and "patient engages with health care system."
- **There are few diagnostic outcome measures.** The measures scan and literature review found only three measures that assess outcomes related to diagnostic performance; these measures are limited to certain conditions (community-acquired pneumonia and urinary tract infection) and settings (ED, hospital).
- **Measure developers are investigating AI methods for diagnostic excellence measures under development.** The measures scan and literature review identified no measures utilizing AI methods. However, several measure development grantees funded by the Moore Foundation

were able to use AI methods (e.g., Brigham and Women's Hospital developed the Diagnostic Delay of Venous Thromboembolism in Primary Care [DOVE] measure using natural language processing [NLP]) in the development and testing of their measures. Several of the grantees found NLP useful to query unstructured fields and narrative reports, such as clinical notes, and radiology and pathology reports, while other developers used machine learning to identify patients meeting certain characteristics related to their diagnosis. However, AI methods for identifying data for diagnostic excellence measures were in their infancy and were not yet used in accountability programs as of the time of the environmental scan.

- **Measure developers are challenged by their ability to access needed data; challenges include a lack of data specificity and system fragmentation.** This lack of data specificity and system fragmentation is especially problematic for the diagnostic process, because the process may unfold over several healthcare visits or care sites. Measure developers funded by the Moore Foundation experienced these challenges often, manifesting as a lack of interoperable data elements, lack of specificity in coding languages, a lack of specificity in data standards and clinical documentation requirements, and significant differences in coding practices across different health systems. Measure developers also encountered challenges related to a lack of granularity in existing binomial or structured data that excludes important contextual components (e.g., capturing patient symptoms, differential diagnosis, diagnostic reasoning, time of diagnosis, change in diagnostic labels over time).

Prioritization of Diagnostic Excellence Measurement Challenges

PRIORITIZATION OF CHALLENGES: DETAILED METHODS

Prior to the November 2023 in-person meeting, NQF conducted an environmental scan and identified challenge categories and example challenges to inform the Committee's focus and prepare the Committee for prioritizing challenges (Methodology, steps 3 and 4; Appendix B). In identifying and narrowing challenges for discussion, NQF analyzed each challenge by assessing whether it

- could apply to other measures beyond the one mentioned in the literature or by the developer,
- was a measure development challenge specific/integral to diagnostic excellence measurement (as opposed to quality measurement in general),
- was unique or if it could be combined with other challenges,
- required novel solutions or if it already had known and existing solutions, or
- could be solved through Subcommittee discussion as part of the Diagnostic Excellence initiative.

Through this analysis, NQF curated four challenge categories for discussion by the Diagnostic Excellence Committee (see Table 1).

Table 1. Initial Challenge Categories Identified for Diagnostic Excellence Committee Discussion

Challenge Category	Definition
Data specificity and data standards	There is variation in the completeness and integrity of information available in clinical records as well as discrepancies in documentation style and terminology used due to clinician, system, and patient-level factors. Available terminologies (ICD, SNOMED, CPT) are often not specific enough to reflect the subtleties of clinical decision making, nor are they specific enough to reflect what is currently captured in unstructured data (e.g., images, clinical notes, diagnostic test reports).
System fragmentation	There are interoperability and missing data implications that limit data availability across the care continuum to capture and measure the complete diagnostic journey. Measures that are constructed to identify missed diagnostic opportunities are often structured for longitudinal, retrospective analysis, requiring comprehensive data across the patient's diagnostic journey and across data sources. There is also variation in documentation, electronic health record (EHR) variability, data linkage issues, and limited provider-to-provider communication and multi-center coordination. For example, diagnoses are not routinely captured in the same structured fields in the EHR and the way they are documented varies across both health systems and providers within health systems, which makes it challenging to develop measures that work across different systems.
Patient-reported measurement	There are difficulties with determining and operationalizing what to measure, when to measure, and how to measure diagnostic excellence from the patient perspective, in spite of the patient's central role in the diagnostic process and the importance and uniqueness of their lived experience for establishing diagnostic excellence.

Challenge Category	Definition
Diagnostic equity	Research has identified inequities in diagnostic opportunities and subsequent treatment. Identifying the characteristics of patients who face inequity in diagnosis and targeting these groups for measurement may help reduce disparities. However, there are a limited number of measures that capture whether diagnostic inequities are happening, and uncertainty exists regarding what to measure. In addition, the data needed for identifying these disparities (e.g., data needed for measure stratification) is sometimes not captured or documented.

To inform the Committee's discussion, NQF developed summary sheets for each challenge category with relevant potential solutions identified in the literature, by measure developers, or ideated by NQF (Appendix B).

At the in-person meeting, NQF divided Committee members into four breakout groups (one for each challenge category). NQF tasked each breakout group with:

1. Discussing challenges and potential solutions to the development of diagnostic excellence quality measures in their challenge category
2. Discussing the actionability (activities for which the Committee work could drive progress in the field) and impact of solving each challenge
3. Prioritizing no more than three challenges to bring forward for full Committee voting

Each breakout group summarized their discussions and presented their prioritized challenges to the entire Committee. A meeting summary, published separately, provides details about the Committee discussions and challenges prioritized by each breakout group.

After the meeting concluded, Committee members voted via an online platform for the three challenges they viewed as the highest priority (i.e., challenges that have significant impact on the field of diagnostic excellence measurement) for concentrated work by the Subcommittees. Appendix C contains details of the additional challenges Committee members voted on during this prioritization exercise, and the results of that exercise.

PRIORITIZATION OF CHALLENGES: RESULTS

The results of this prioritization exercise informed the later activities of the Diagnostic Excellence initiative. Table 2 summarizes the three challenges prioritized by the Committee and NQF (Methodology, step 5), 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.

Table 2. Prioritized Challenges Assigned to Subcommittees

Brief Description of Challenge	Further Definition of Challenge
Challenge A (Diagnostic Equity Subcommittee): Most existing diagnostic excellence measures use healthcare visit data to identify patients for inclusion in measures, leaving out of the measures individuals who do not interact or partly interact with the healthcare system, which disproportionately leaves out individuals from historically disadvantaged groups.	Individuals who do not interact or partly interact with the healthcare system are often not in the healthcare visit data used for measurement. Individuals may not interact with healthcare for multiple reasons, including that they may stop seeking care due to discouragement, bias, discrimination, and lack of trust; they may not feel heard; they may have experienced harm; and they may not have access to care because of insurance gaps, lack of transportation, provider shortages, language barriers, or other barriers.
Challenge B (Diagnostic Equity Subcommittee): There are few measures that illuminate differences across populations in diagnostic processes, outcomes, or experience (i.e., measures of diagnostic equity).	There are multiple sources of bias in the diagnostic system that are known to affect historically disadvantaged groups disproportionately, including assumptions made about people with certain conditions, who are on certain medication regimens, or who do not have a clear diagnosis. Disadvantaged groups include individuals vulnerable to diagnostic errors due to their age, race, ethnicity, sex, sexual orientation, gender identity and expression, income, insurance status, immigration status, language, cultural identity, health literacy, geographic location, and other characteristics. These biases might lead to discrimination and inequity in how people experience the diagnostic process, in the quality of diagnostic care they receive, and in outcomes. Measures related to bias or discrimination in the diagnostic process currently do not exist.
Challenge C (Patient-Reported Measurement Subcommittee): There may be differences in expectations and beliefs about diagnostic excellence between patients, their care partners, clinicians, and health systems.	Divergences might exist between patients, care partners, clinicians, and health systems regarding what constitutes diagnostic excellence for the purposes of the assessment of health system performance. Perspectives of patients and their families and care partners currently are not part of that assessment. Incorporating these perspectives into the diagnostic excellence accountability assessment requires understanding and navigating these potential divergences.

The remainder of this report will focus on the challenges prioritized in Table 2 and summarize the Committee's and Advisory Group's discussions, conclusions, and recommendations for solving these challenges (for a full list of recommendations and principles, see Appendix D). The first section presents the focus area of diagnostic equity and the second of patient-reported measurement.

Diagnostic Excellence Measurement Challenges and Potential Solutions

MEASURING DIAGNOSTIC EXCELLENCE FOR ALL PATIENTS

As noted above, the Diagnostic Equity Subcommittee focused on two measurement challenges:

- Challenge A: Most existing diagnostic excellence measures use readily accessible healthcare visit data to identify patients for inclusion in measures, leaving out of measures individuals—disproportionately from historically disadvantaged groups—who do not interact or only partly interact with the healthcare system. While quality measures are constrained by the availability of data, this is an instance where the denominators in existing measures are particularly limited, obstructing the field's ability to fully understand the nature and scope of diagnostic challenges across populations.
- Challenge B: There are few measures that illuminate differences across populations in diagnostic processes, outcomes, or experiences (i.e., measures of diagnostic equity).

NQF reviewed and researched potential approaches to solving or mitigating these challenges to support the Diagnostic Equity Subcommittee's discussions (Methodology, step 7). Based on this information gathering, NQF identified and briefed the Diagnostic Equity Subcommittee on two potentially feasible approaches for advancing diagnostic excellence measures for individuals who do not interact or partly interact with the healthcare system and two potentially feasible approaches for advancing measures that identify diagnostic disparities and may contribute insights about diagnostic equity (see Table 3).

Table 3. Approaches to Addressing Diagnostic Equity Measurement Challenges

Challenge	Potential Approaches for Addressing Challenge
Challenge A: Most existing diagnostic excellence measures use readily accessible healthcare visit data to identify patients for inclusion in measures, leaving out of measures individuals who do not interact or only partly interact with the healthcare system.	1. Assess by measuring late-stage diagnosis 2. Use data that do not rely on individuals interacting with the healthcare system
Challenge B: There are few measures that illuminate differences across populations in diagnostic processes, outcomes, or experiences (i.e., measures of diagnostic equity).	3. Stratify measures using data that identify historically disadvantaged groups 4. Measure bias and discrimination in experiences of the diagnostic process

As the two Subcommittees worked independently initially, measuring access to and the timeliness of diagnostic care were suggested by both Subcommittees as potential approaches addressing both challenge A and B, as well as challenge C, concerning patient-reported measurement. Specifically, the

Committee considered measuring access and timeliness as important for understanding how certain population groups are excluded from most existing diagnostic excellence measures. The Committee also considered measuring access and timeliness as essential for understanding differences across populations in diagnostic processes, outcomes, or experiences. Finally, the Committee considered access and timeliness as important domains for patient reporting that are currently not incorporated into diagnostic excellence accountability assessment. Defining, measuring, and incorporating access and timeliness, as reported by patients and their care partners, might explicate potential divergences in expectations and beliefs about diagnostic excellence between patients, their care partners, clinicians, and health systems (challenge C).

Approach 1: Assess by Measuring Late-Stage Diagnosis

Measuring late-stage diagnosis is a promising strategy for identifying potential failures in access to a high quality, timely diagnostic process, even for individuals who are missing from other diagnostic excellence measures. While groups of patients may be missing from measures of diagnostic excellence due to a lack of interaction with the healthcare system early in the diagnostic process, some of these patients may receive care once their conditions have significantly progressed. Establishing a diagnosis in such circumstances can be referred to as late-stage diagnosis. Developing measures of late-stage diagnosis may help to assess diagnostic outcomes for a broader group of individuals, including those who do not interact or interact only partly with the healthcare system during the diagnostic process. In addition, the standardized capture of demographic data, including on social determinants of health (SDOH), of those who present with late-stage diagnoses might help inform identification of that broader group.

One type of measure that assesses late-stage diagnosis is measurement of diagnosis following emergency presentation (e.g., cancer diagnosis within a certain time frame after ED or inpatient visit). Emergency presentation may reflect progression of disease due to a lack of access to diagnostic ambulatory care or a failure of the ambulatory diagnostic process to identify the disease at an earlier stage. Committee members added that emergency presentations might occur in different settings, for example, in urgent care settings, in addition to emergency care or inpatient settings. Through information gathering described in Methodology, step 7, NQF found five measures of late-stage diagnosis or emergency presentation of conditions (Table 4), including measures developed by Moore Foundation grantees, which NQF shared with the Diagnostic Equity Subcommittee for feedback about whether these types of measures could address the challenge of individuals missing from diagnostic excellence measures.

Table 4. Measures of Late-Stage Diagnosis

Measure Title (Measure Steward)	Description	Level of Accountability and (Planned) Use
Ambulatory Care Sensitive Emergency Department Visits for Dental Caries in Children (American Dental Association)	Number of emergency department visits for caries-related reasons per 100,000 member months for all Medicaid-enrolled children	Medicaid and CHIP plans that provide both medical and dental benefits; in use in Texas Health and Human Services Dental Pay-for-Quality Program

Measure Title (Measure Steward)	Description	Level of Accountability and (Planned) Use
Late HIV Diagnosis (Centers for Disease Control and Prevention)	Percentage of persons 13 years and older diagnosed with Stage 3 HIV infection (AIDS) within three months of HIV diagnosis	Population-level (regional and state) measure for public health, disease surveillance, and public reporting with data from National HIV Surveillance System for public reporting/disease surveillance
Percent of New Cancer Diagnoses Made in the Emergency Room Setting (Baylor College of Medicine)[22]	1. Proportion of new lung cancer diagnoses made within 30 days after emergency department or inpatient visit 2. Proportion of new colorectal cancer diagnoses made within 30 days after emergency department or inpatient visit	Health system where the patient receives most ambulatory and primary care; not currently in use
Percent of Newly Diagnosed Cancers at a Late Stage (Stage III-IV) (Baylor College of Medicine)	1. Proportion of late-stage lung cancer diagnoses (stage 3 or 4) at time of initial diagnosis 2. Proportion of late-stage colorectal cancer diagnoses (stage 3 or 4) at time of initial diagnosis	Health system where the patient receives most ambulatory and primary care; not currently in use
Percentage of Incident Heart Failure Diagnosed in the Outpatient Setting (Stanford University)	Percentage of patients aged 18 years or older (who are Medicare fee-for-service beneficiaries) with a first heart failure diagnosis documented in the outpatient setting	Clinician group measure; not currently in use

Rationale and Considerations for Measuring Late-Stage Diagnosis

The Committee supported prioritizing development and implementation of measures of late-stage diagnosis as a way to assess the quality of diagnostic care for individuals who are not included in other types of diagnostic excellence measures. One Committee member noted that the United Kingdom already uses emergency presentation of cancer at a hospital as a metric of regional accountability[23,24] and that the U.S. hospital where this member works uses a similar metric. Another Committee member affirmed that emergency presentation of cancer is an important measure and suggested that NQF specifically call out measures of late-stage diagnosis and emergency presentation of cancer as targets for future development. Advisory Group members also supported prioritizing development and implementation of measures of late-stage diagnosis, particularly for late-stage diagnosis of cancer.

Committee and Advisory Group members discussed how measures of late-stage diagnosis and disease prevalence could identify differences in diagnostic care. Committee members noted that emergency presentation of cancer may be indicative of health disparities.[12] Several Advisory Group members suggested developing measures of cancer prevalence among entities managing populations of patients (e.g., clinician groups or health plans) and then stratifying those measures by cancer stage at diagnosis and also by race, ethnicity, and SDOH. Committee members additionally suggested that EHR data could be used to identify potential biases in diagnosis by stratifying diagnoses and treatment by race, ethnicity, and language. Committee and Advisory Group members raised some considerations related to

selecting diagnoses for measures of late-stage diagnosis and defining "late stage." A Committee member cautioned that what is considered "late-stage" diagnosis will vary between diseases. An Advisory Group member noted that there are differing levels of evidence that earlier diagnoses lead to better outcomes and lower costs for different cancers, making generalization of this strategy difficult. Both Advisory Group and Committee members suggested targeting diagnoses for measurement for which there is evidence of potential clinical improvement and lower costs with earlier diagnosis (e.g., colorectal or breast cancer) and suggested measuring conditions with well-defined stages and end-organ disease (e.g., heart disease, heart failure, diabetes).

Committee members noted that failure to screen may be a common cause of late-stage diagnosis for conditions such as breast, cervical, colorectal, and lung cancer. They cautioned that measures of late-stage diagnosis may incidentally measure screening rates, which existing quality measures already address. They stated that a limitation of measuring late-stage diagnosis would be the ability to adjust for health systems' screening rates. Other members did not share this concern and suggested these types of quality measures could identify opportunities to improve the screening process, access to screening, and care coordination, noting that failure in the use of effective screening is a type of diagnostic error, one of omission. In addition, a Committee member disagreed that incidental measurement of screening rates would be a concern, citing research that has shown most problems that lead to a delayed diagnosis relate to symptoms or clinical findings, not screening. This research indicates that many cancers are diagnosed by their symptoms and may not even have a screening test available; diagnostic delays occur when symptoms are not recognized or appropriately addressed.[25] Consequently, avoiding diagnostic delays in symptomatic cancers could potentially decrease rates of late-stage diagnosis.

Advisory Group members also discussed the challenge of extracting staging data for measures of late-stage cancer diagnosis. For example, one cautioned that it may be difficult to extract cancer stage data from EHRs, although they noted that natural language processing (NLP) may help to extract this data in the future. To address this challenge, another Advisory Group member suggested investigating whether claims data about treatments for diagnoses could be used to determine if a diagnosis was late (e.g., an individual who just received their first diagnosis of breast cancer and is receiving a mastectomy and chemotherapy as treatment may indicate a late-stage diagnosis). An Advisory Group member acknowledged that late-stage diagnosis may be a difficult concept to operationalize. However, a Committee member noted that measures of late-stage diagnosis might align with the Centers for Medicare & Medicaid Services (CMS) goal of implementing digital quality measures, as the data needed for this type of measure is structured (e.g., data coming from EHRs and cancer registries). Similarly, another Committee member suggested using data from tumor registries as it would have accurate, or at least accessible, staging data.

Diagnoses and Populations to Target for Measurement of Delayed Diagnosis

In addition to the diagnoses assessed by existing diagnostic excellence measures and measures under development of late-stage diagnosis (Table 4), Committee members suggested additional diagnoses that could be the focus of diagnostic delay measurement more broadly (not focused on late-stage diagnosis specifically). Examples of the diagnoses mentioned but not discussed in detail by the Committee were stroke, sepsis, chronic kidney disease, type 2 diabetes, auto-immune conditions, endometriosis, and behavioral health conditions. Members noted that this list is incomplete and merely illustrative.

Several Committee members noted that appropriate diagnoses to measure for delayed and late-stage diagnosis may differ between pediatric and adult patients (e.g., agreeing that cancer would likely not be the ideal condition to measure for pediatric patients). One Committee member noted that there may be additional complexity when diagnosing pediatric conditions. Committee members suggested several other diagnoses with known diagnostic delays in children, including, for example, appendicitis, iron deficiency anemia, cystic fibrosis, sickle cell disease, and intracranial tumors.

In addition, Committee members suggested populations at risk for delayed diagnoses and data sources that could inform measurement of delayed diagnoses. One member recommended measuring delayed diagnosis in the incarcerated or previously incarcerated population and using data managed in occupational/employee clinics to measure workplace injuries. Another member recommended that rather than focusing on particular diagnoses, to focus on high-risk individuals (e.g., patients who have not received primary care or recommended screenings for years), as has been done by health centers. This information may be available in health plan data.

Additional Methods for Measuring Delayed Diagnosis

In addition to discussing measures of late-stage diagnosis, the Committee also discussed methods for measuring delayed diagnosis. Although some of these methods would rely on encounter data from early in the patient's diagnostic journey and, therefore, may miss individuals not interacting with the healthcare system, the Committee had a productive discussion about these strategies as part of its discussion of Approach 1, as summarized here. As difficulties accessing care may create delays in diagnosis, there was some overlap in the Committee's discussion about measuring delayed diagnosis and measuring timeliness of and access to diagnostic care. Their comments about measuring access and timeliness are summarized in the section titled Measuring Access to and Timeliness of Diagnostic Care. Similarly, there was an overlap in the Committee's discussion about measuring diagnostic delays, timeliness, and access by using patient reports. Thus, some of the comments that relate to patient-reported measurement are summarized under the section titled Identifying Patient-Reported Domains that Matter to Patients and Ways to Measure Those Domains.

Committee member recommendations about measuring delayed diagnosis included assessing patients with repeat visits for the same complaint, the number and variety of providers a patient sees before receiving a diagnosis (e.g., consultants/specialists), and the time taken for patients to secure an appointment, particularly for populations lost to follow-up (e.g., patients who seek care multiple times for the same complaint but stop seeking care before there is a final diagnosis). One member noted that existing measures of diagnostic excellence currently start with patients who have a diagnosis (i.e., with a diagnosis appearing in their chart or on claims). This comment raised questions about how to define a delay in diagnosis, with one Committee member suggesting that using a statistical threshold, such as two standard deviations from the mean time to diagnosis, could suffice as a definition of "delay." Another member noted that defining the time of diagnosis itself may be a challenge, as there are several ways to define this. For example, it could be when there is definitive evidence, such as labs or imaging, available, when the clinician enters a diagnosis into a patient's record, or when the diagnosis is communicated to the patient or family.

Several Committee members discussed using prevalence data to assess diagnostic delay. A Committee member recommended developing a measure to compare rates of diagnosis for a given condition in a

certain population to known prevalence rates for that condition (i.e., an observed to expected ratio for stroke, cancer, or diabetes). The Committee member suggested this approach could serve as a preliminary step toward developing quality measures of delayed diagnosis by prioritizing areas for further measure development (i.e., diagnoses where there are large variations in observed to expected ratios). Another Committee member cited research that indicates variation in rates of disease prevalence where variation is not expected may also indicate diagnostic delays that may be mitigated.[26] In response, another Committee member noted artificial intelligence (AI) may be able to assist in estimating the observed to expected rates of diagnosis, although they cautioned this would rely on accurate rates of expected diagnoses (e.g., through the use of registries). A Committee member noted that differences in rates of diagnosis or condition-specific causes of death between demographic groups could identify potential disparities in diagnostic care, although another member noted that without an autopsy, the listed cause of death may not be reliable. An Advisory Group member cautioned that it may be too difficult to determine the expected rate of diagnosis in all populations for measuring observed to expected ratios of diagnoses to be feasible. Instead, they suggested measuring avoidable hospitalizations or avoidable ED diagnoses to determine missed diagnoses.

Accountability for Measures of Late-Stage Diagnosis

The Committee discussed how to leverage late-stage diagnosis accountability measures to motivate better diagnostic care for individuals who have not yet interacted with the healthcare system. Because accountability measures require attributing accountability to particular providers or payer types, the Committee discussed attribution of accountability for measures of late-stage diagnosis and associated challenges. An Advisory Group member noted that since the point at which the diagnosis is made is typically downstream from a point where an entity could have intervened at an earlier stage, it complicates the use of late-stage diagnosis measures for accountability purposes outside integrated healthcare systems where one system assumes care and is accountable for all care. However, Committee members noted that patients living in rural areas may not be close to integrated health systems.

Several Committee members supported holding health plans or health systems accountable for diagnostic excellence in their populations through late-stage diagnosis accountability measures. One member suggested that health plans could assist in understanding late-stage diagnosis from a population health perspective. They noted payers have access to comprehensive data and could use these types of measures to compare outpatient and inpatient diagnoses, and early- versus late-stage diagnosis rates. Another member cautioned that, when applying measures in programs, it is important to consider differences among the health plan types being measured and their populations (for example, commercial plan, primarily Medicaid-enrolled plan, safety net system or health department). One Committee member commented on the challenge of attributing patients to specific providers within such measures, noting that individuals may seek care in several different health systems before receiving a diagnosis. They suggested that measures of late-stage diagnosis only include patients who are seen within the same health system over two years. On the contrary, another Committee member suggested keeping health plans accountable for their full covered populations and recommended pairing a health plan retention rate measure with measures of late-stage diagnosis and emergency presentation, as this would provide an understanding of the plan's potential impact on these diagnostic outcomes, which may unfold over a period of time. A Committee member cautioned that restricting

late-stage diagnosis measures to individuals who have been a beneficiary within a plan for a certain amount of time may miss individuals who change health plans frequently. Another Committee member raised concerns about making health plans or health systems accountable for all patients who do not seek care early as it happens for a variety of reasons. Overall, Committee and Advisory Group members acknowledged both the complexity and critical importance of attribution for accountability of late-stage diagnosis measures.

Committee Recommendations and Principles

- The Committee recommended:
    - Prioritizing development, testing, and implementation of quality measures of late-stage diagnosis and emergency presentation as a method for assessing diagnostic outcomes for individuals who may not be included in other measures of diagnostic excellence
    - Focusing accountability for late-stage and emergency presentation on entities with defined populations, such as health plans, integrated health systems, or public health agencies, acknowledging the complexity and importance of attribution for accountability
    - Targeting for measurement those specific diagnoses with known diagnostic delays, defined stages, and known outcome improvements and cost savings from timely diagnosis, noting that diagnoses with these features may differ for pediatric patients versus adult patients
    - Considering other non-disease-specific analytic approaches to identify variations in diagnostic timeliness and/or assess diagnostic delays with attention to their limitations
- The Committee emphasized the following principles for measures of late-stage and delayed diagnosis and emergency presentation:
    - Taking into account how screening rates might impact late-stage diagnosis; for example, improving screening rates may decrease late-stage diagnosis rates but may not address some of the equity issues with missed diagnosis
    - Emphasizing that improving screening practices relates not only to increasing screening rates, but also to the optimal use of appropriate screening tests based on risk and successful follow-up of abnormal tests
    - Acknowledging that attribution of accountability should consider the accountable entity's ability to impact late-stage diagnosis rates

Approach 2: Use Data that Do Not Rely on Individuals Interacting With the Healthcare System

Most existing diagnostic excellence measures use healthcare visit data to identify patients for inclusion, since there are currently no formal methods for collecting healthcare data before patients enter the healthcare system. Through their reliance on healthcare visit data, these measures often overlook individuals who do not interact or partially interact with the healthcare system and inadvertently leave them out of measures (which disproportionately affects individuals from historically disadvantaged populations). Individuals from historically disadvantaged populations may experience difficulties when seeking care, in receiving timely care, obtaining health insurance, and may not have a usual source of care.[27] These factors may impact the amount of healthcare visit data available for measures assessing the diagnostic journey. These individuals may also have lower health literacy, as well as language and cultural barriers, impeding their ability to access care which deepens the challenge of assessing the

diagnostic process for these populations.[28] Individuals from these populations also frequently experience a lack of care coordination, a challenge that is often exacerbated by poor interoperability and resource limitations affecting the healthcare providers within underserved communities.[29] Including individuals who do not interact with the healthcare system in diagnostic excellence measures involves identifying potential data sources and entities with data about these individuals before they seek care. This could include examining the use of home testing and home health monitoring, alternative or non-traditional health-related resources, genetic testing, or other approaches.

Considerations for Using Health Plan Data to Measure Individuals With a Potential Lack of Diagnostic Care Access

NQF proposed focusing measurement on health plans because these entities accept responsibility for ensuring their members receive care and can readily identify plan enrollees regardless of whether they interact with the healthcare system, while acknowledging that using health plan data to measure individuals with a potential lack of diagnostic-care access excludes those who are uninsured. This strategy provides a starting point from which to identify individuals who are at risk for lack of access to the diagnostic process, and to identify individuals who could be included in diagnostic excellence measures that do not rely on healthcare visit data (for example, by identifying individuals who might be at risk for poor or no access to diagnostic care). Key informant interviews (Methodology, step 7) indicated that health plans could conduct advanced analytics to identify which enrollees are not receiving care, although the informants noted that this may be limited to identifying patients needing routine preventive services (e.g., population health screenings). The informants also disclosed that plans could use data from health needs assessments and health-related social needs (HSRN) screenings conducted when individuals enroll in the health plan to identify individuals who are potentially at risk for poor diagnostic access (based on SDOH risk factors). However, the informants noted many individuals do not provide this information at enrollment. The informants also noted that health plans will have limited to no data on why individuals are not accessing care and will not know whether they need diagnostic care.

Health plans may be able to identify individuals from historically disadvantaged populations who might be at risk for poor or no access to diagnostic care using race, ethnicity, and SDOH data. However, Committee members cautioned that a significant challenge to using health plan data to measure diagnostic excellence for individuals who are not interacting with the healthcare system (but who are insured) is that enrollee data is often missing race, ethnicity, and SDOH data. This concern underscores feedback NQF received during the key informant interviews. A Committee member shared their experience, for example, that some of the most frequently unanswered questions asked of Medicaid enrollees relate to SDOH. A Committee member also raised a concern that health plan enrollees who do not regularly access health services may not be willing to respond to outreach from the plan, and that plans may not have correct contact information for these individuals. The Committee member also voiced concerns about the feasibility of using health plan data to identify individuals not interacting with the healthcare system, suggesting that the amount and quality of data currently available to health plans may be too limited to allow meaningful measurement in this area. Several Committee members and an Advisory Group member noted other concerns, primarily that this approach would ignore people without insurance or those with unstable insurance status and therefore, miss some individuals who lack access to diagnostic care. However, another Committee member noted that while the health plan

data is imperfect, this might be the best available data source. The Committee member suggested that accountable care organizations in the Medicare Shared Savings Program may also be appropriate entities to hold accountable for diagnostic care of an entire population as participants in this program accept responsibility for an assigned Medicare fee-for-service population.

Another Committee member and several Advisory Group members cautioned that having a health plan does not guarantee access to healthcare, as there are many other barriers to seeking and accessing care (e.g., high deductibles, co-insurance, language barriers, trust, culture). Committee members elaborated on how to better understand these barriers, including gathering patient input on why they do not interact with the healthcare system; acknowledging patient distrust, provider biases, and the lack of diversity in the medical workforce; and engaging patient advocacy groups. Committee members and an Advisory Group member emphasized the importance of developing measurement methods in partnership with the communities that lack access to diagnostic care.

Acknowledging that plans may be missing race, ethnicity, and SDOH data for all enrollees and will need to use other methods for identifying patients at risk for lack of access to diagnostic care, an Advisory Group member recommended that health plans could survey enrollees who have not accessed health services about their health status and potential reasons why they may not be accessing care. They suggested that plans could ask enrollees questions to confirm their own perceptions of their health status or if they have used any health services. The Advisory Group member suggested that plans could use branching logic to identify access issues if their enrollees do signal health problems but are not accessing care. A Committee member made a similar suggestion, stating that health plans could determine which enrollees are underutilizing the healthcare system with measures such as the number of enrollees who have not had a primary care visit in the last five years or the number of enrollees who only receive care from EDs.

Alternative Sources of Data and Methods to Identify Individuals Not Accessing Diagnostic Care

Given the Committee's uncertainty on how to use data from health plans to capture diagnostic excellence in individuals who are not interacting with the healthcare system, members made suggestions for alternative sources of data outside the healthcare system. Members listed community-based organizations (CBOs), health services at public schools and universities, and departments of public health as additional sources of data. An Advisory Group member suggested social media as a data source, cautioning potential concerns for such use, yet recalling successful experience using social media data during the COVID-19 pandemic (e.g., number of searches about symptoms in search engines). One Committee member noted that programs like the Supplemental Nutrition Assistance Program (SNAP) collect data on disability and health insurance status, and that school and higher education systems may have health data related to the children in a family. Other Committee members supported utilizing data from household or census surveys, recognizing that these types of surveys have their own bias but also noting they may cast a "bigger net" than those that rely on the healthcare system for capture. One Committee member suggested that patient advocacy groups or programs that deliver cancer screening programs to communities (e.g., the College of American Pathologists' See, Test, and Treat Program) could have useful data about individuals who are not interacting with the healthcare system. An Advisory Group member noted that it will be difficult to learn from informal networks of health information exchange that exist outside the healthcare system. However, they supported these

suggestions for alternative sources of data and added that religious and social communities may also serve as alternative sources of information for measurement. Overall, the Committee acknowledged the novelty and unknown feasibility of using these alternative data sources for diagnostic excellence measurement.

Committee members also suggested additional sources of data and methods for identifying individuals at risk of having limited access to diagnostic care (rather than individuals who are not interacting with the healthcare system). Committee members listed health information exchanges (HIEs), EDs, urgent care, federally qualified health centers (FQHCs), and institutions similar to FQHCs as potential sources of data. To identify individuals at risk for having limited access to diagnostic care, an Advisory Group member recommended using data from encounters with emergency medical services. A Committee member suggested targeting for inclusion in measurement individuals who have a certain number of health-related social needs (HRSNs) or who have accessed a certain service (e.g., the ED) and then combining diagnostic data using an HIE or EHRs to complete the data for the measure. This member cited an FQHC that developed a stratification approach defining people with seven or more HSRNs as "high risk" as an example. Committee members also recommended identifying individuals who are potentially underserved by diagnostic care by determining those individuals who are accessing the ED and urgent care, rather than primary care, and measuring diagnostic excellence for these individuals. However, other Committee members raised concerns with this approach to assessing access to diagnostic care through primary care providers. One member noted that there may be underlying HRSNs affecting an individual's use of the ED or urgent care. Another member noted that access to primary care providers can be limited in some geographic areas.

Committee Recommendations and Principles

- The Committee recommended:
    - Developing and applying measures of diagnostic excellence accountability to health plans so that measures include individuals regardless of whether or when they seek care
    - Using several sources of data outside of the healthcare system that potentially could effectively identify individuals who are not interacting with the healthcare system
- For developing measurement approaches to capture diagnostic excellence among individuals who are not interacting with the healthcare system, the Committee emphasized the following principles:
    - Acknowledging important limitations of health plan data to identify individuals who are not interacting with the healthcare system
    - Understanding the reasons individuals are not interacting with the healthcare system and diagnostic process, including HRSNs and other factors
    - Including the communities that are not interacting or only partly interacting with the healthcare system in developing diagnostic excellence accountability measures

Approach 3: Stratify Measures Using Data That Identify Historically Disadvantaged Groups

The Committee agreed that stratifying diagnostic excellence measure results using data on patient characteristics can provide important insights into inequities in diagnostic processes and outcomes. To achieve further progress on stratification, the Committee discussed:

- Setting priorities for stratification
- Addressing the practical challenges presented by inaccuracy and missingness of patient characteristics data
- Establishing benchmarks for equitable care
- The need to consider how intersecting social risk factors affect diagnostic quality

Prior NQF-convened consensus panels have addressed how to identify the most important measures to stratify[30,31] (for measures broadly and not specific to diagnostic excellence measures) and the social risk factors that can be used for stratification that are both feasible and important to address.[32] NQF asked the Committee to consider prioritizing diagnostic excellence measures for stratification and identifying target populations for stratification based on patient characteristics such as race, ethnicity, and other factors (such as SDOH) as a strategy to advance diagnostic equity with the ultimate goal of accountability.

Accuracy and Missingness of Data to Define Strata

The Committee was aware that to date there has been limited work to stratify current measures of diagnostic excellence. For example, although the Moore Foundation measure developer grantees were encouraged to evaluate racial and ethnic differences in measure scores, most were unable to due to limited race and ethnicity data.[21] The Committee discussed barriers and solutions to data availability challenges. Several Committee members noted that limited confidence in the accuracy of recorded race, ethnicity, and SDOH data makes it difficult to stratify diagnostic excellence measures by these variables. In contrast, a Committee member shared work they had done with another Committee member to examine state-level disparities using Healthcare Cost and Utilization Project (HCUP) claims data that showed statistically significant differences in the rates of harm between Black, White, and Hispanic patients.[33] They acknowledged the limitations of stratifying measures using claims data yet recommended this type of claims-based analysis as a feasible step for identifying targets for more detailed measurement of diagnostic inequities.

Committee members also noted the high missing rates of data used for stratification and discussed trends and strategies for advancing data collection. A Committee member noted that having race/ethnicity marked as "unknown" is a particularly large obstacle to stratification, while another noted this data may become better documented over time, stating that SDOH capture at their organization has improved since CMS started requiring both screening for SDOH and reporting of positive screening results in the fiscal year 2023 Hospital Inpatient Prospective Payment Systems for Acute Care Hospitals and the Long-Term Care Hospital Prospective Payment System (IPPS/LTCH PPS) final rule.[34] They expressed optimism that SDOH data quality will continue to improve given a CMS change in reimbursement, which promotes the use of Z codes (ICD-10 codes from claims that define and report patients' social, economic, and environmental determinants directly affecting their health), to document SDOH in the EHR. Two other Committee members mentioned their investigations and development of best practices for collecting and using SDOH data. One noted that the Children's Hospitals' Solutions for Patient Safety Network has outlined best practices for comparing rates of harm between racial/ethnic groups, including guidance on collecting and reporting infection data stratified by patient race and ethnicity. The other reported that, in their health system, sharing the rationale for collecting SDOH data with staff and providing staff with a script to use to assist hesitant patients with sharing SDOH

information improved data collection. Another Committee member emphasized the importance of sharing the rationale for SDOH data collection with patients.[35]

Reference Groups for Benchmarking Inequities

The Committee discussed the need to develop methods for and consensus around how to set benchmarks for disparate quality measure results across patients with social risk factors. The Committee suggested creating guidance that organizations could use when choosing reference groups for diagnostic equity analyses specifically. Some Committee members suggested that organizations should use the "healthiest" group as the reference group, but others noted that there are challenges in defining and agreeing on what the "healthiest" group truly is as it varies between settings and measures, and one Committee member suggested avoiding the "healthiest" term altogether. A Committee member also noted that the terms "disparity" and "inequity" are not synonymous. A Committee member cautioned that using the average as a comparator may not reveal disparities and recommended using the group with the best performance on the measure as the reference. An Advisory Group member noted that performance can be poor for all groups, in which case alternative approaches to benchmarking may be needed.

Prioritizing Diagnostic Excellence Measures for Stratification

Several Committee members were in favor of stratifying diagnostic excellence measures, but they expressed different perspectives about which measures to prioritize for stratification. Committee members recommended stratifying diagnostic excellence measures for diagnoses where there are known inequities in care as demonstrated by the medical literature (e.g., appendicitis, end-stage kidney disease, preeclampsia), measures that focus on areas where harm is most likely to occur (e.g., measures of timeliness, accuracy, and closed-loop communication, particularly for cancer diagnoses), or measures of access. Another Committee member acknowledged that all areas of measurement are susceptible to inequities so it may be worthwhile to stratify all measures of diagnostic excellence. Other Committee members questioned the ability to stratify measures at this time given that the science is evolving in diagnostic excellence measurement. One Committee recommended that local healthcare organizations stratify and track their measures first to build evidence and groundwork for more robust stratification of accountability measures.

The Committee considered strategies for ensuring that equity of diagnosis is measured comprehensively. Members noted there may be different equity issues at play with each of the steps in the diagnostic process (e.g., patient engagement in the diagnostic process, clinician making the diagnosis, clinician communicating back to the patient) and recommended that the Committee take a diagnostic equity lens to the entire diagnostic process. In turn, measure developers could design measures to assess these inequities more specifically or choose stratification approaches for different measures depending on the equity issues that might be relevant. One Committee member also suggested picking specific diagnoses and mapping the full diagnostic process to elucidate and specify where the inequities stem from in the diagnostic process.

Assessing Intersecting Risks

Some Committee members emphasized the importance of understanding how intersecting risks impact patients, recognizing there are compounding effects of multiple risk factors (e.g., a patient whose first

language is not English, who does not have U.S. citizenship, lacks transportation) that might affect risk in a nonlinear way. A Committee member questioned how to determine whether to stratify measures by factors that identify individuals whose risk is amplified by multiple vulnerabilities with regards to inequities in diagnostic care. Another Committee member suggested assessing measure results across multiple axes to understand how inequities intersect across groups.

Committee Recommendations and Principles

- The Committee recommended:
    - Stratifying measures of diagnostic excellence and called for further consensus and technical guidance on two challenges:
        - The variable accuracy and high levels of missing data that could be used to identify subpopulations for stratification
        - Approaches for setting benchmarks across stratified groups
    - Developing a framework, guidance, or criteria on acceptable levels of missingness, data adequacy, and data quality that measure developers and implementers could apply to data and variables used for stratification of diagnostic excellence measures
    - Reviewing NAM's diagnostic process with an equity lens at each step to further identify diagnostic excellence measures for stratification and potential stratification variables applicable to each step
    - Prioritizing a small number of diagnoses around which to develop diagnostic equity measures and demonstrate methods for stratifying those measures
- The Committee emphasized the following principle:
    - Using several approaches to prioritizing measures for stratification, including targeting measures for diagnoses with known large disparities

Approach 4: Measure Bias and Discrimination in Experiences of the Diagnostic Process

One potential impediment to individuals receiving equitable diagnostic care and achieving equitable diagnostic outcomes is bias and discrimination during their diagnostic journey. Individuals from historically disadvantaged populations are more likely to experience bias or discrimination.[36] These individuals may be more susceptible to diagnostic error because of language barriers, reduced self-advocacy, lower health literacy,[28,37] or lower levels of trust in providers,[38] which can hinder communication between patients and clinicians about symptoms, disease presentation, and other information supporting timely and accurate diagnosis.

NQF gathered information related to quality measures and tools that assess bias and discrimination in the diagnostic process specifically, and bias and discrimination in healthcare more broadly (Methodology, step 7). NQF found no such measures specific to the diagnostic journey. However, Patients for Patient Safety US is leading an initiative, Project PIVOT, that will make recommendations on patient-prioritized PRMs that could be used in the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys and research to assess bias and discrimination (as well as patient safety, diagnostic accuracy, and transparency) in healthcare. NQF asked the Committee for their feedback on potential tools or methods that measure bias or discrimination in the diagnostic process, as well as additional dimensions of experiences of the diagnosis process that should be considered in the development of diagnostic equity measures. The Committee discussions that relate to measuring bias, discrimination, and additional experience domains using patient reporting are described later in this

report in the section Identifying Patient-Reported Domains That Matter to Patients and Ways to Measure Those Domains. Below are summarized discussions related to measuring bias, discrimination, and additional experience domains using other methods.

The Committee discussed several potential methods of gaining insight into the effects of bias or discrimination on diagnostic care. Members considered how AI could be utilized to measure bias (specifically explicit and implicit bias) and discrimination. One Committee member noted that AI could identify whether specific topics, like preventive care recommendations, were addressed during a clinical interaction. Other Committee members suggested that AI could be applied to analyze clinical documentation and patient portal interactions, specifically to detect biases in language, communication patterns, and disparities in patient engagement. One Committee member flagged that grievance data can reveal systemic or structural problems even among correct diagnoses. They cautioned, however, that grievance data is likely biased, underrepresenting those with limited English proficiency, low health literacy, and those who fear retribution for raising concerns. In addition, a Committee member mentioned collaboratives in which episodes of bias, discrimination, racism, and ageism are entered into safety event reporting systems to identify opportunities for improvement in diagnostic timeliness and other diagnostic outcomes.

Committee Recommendations and Principles

- The Committee recommended:
    - Supporting the addition of questions to CAHPS surveys to assess the patient experience of bias and discrimination during the diagnostic journey, including supporting the current work of Project PIVOT to add questions about diagnostic safety and bias/discrimination to CAHPS surveys
- The Committee emphasized the following principle:
    - Acknowledging the potential that AI can bring to assessing explicit and implicit bias and discrimination in diagnostic encounters by analyzing both in-person interactions and written communications

MEASURING ACCESS TO AND THE TIMELINESS OF DIAGNOSTIC CARE

The Committee highlighted measuring access and timeliness of diagnostic care in discussions about measuring delayed diagnosis and understanding underlying differences across populations in diagnostic processes, outcomes, or experiences. Either of these two types of measures may uncover inequitable diagnostic care and outcomes. The Committee discussed how inequities in access to the healthcare system may lead to delayed diagnostic care and, therefore, worse outcomes. Timeliness of care is interwoven with the Committee's discussions of access because accessibility issues often lead to delayed care. However, delays in care are common among all patients, including those who have "access" (e.g., among the insured) due to, for example, appointment wait times or cost sharing that prohibit the patient from pursuing care. Therefore, measuring timeliness of diagnosis may help raise quality for all patients and identify patients at greater risk for inequitable diagnostic outcomes.

Potential Measurement Approaches to Assess Timeliness of Diagnostic Care

Committee members recommended the development of several different categories of measures to address timeliness of diagnostic care. Several Committee members recommended measure concepts that could assess the timeliness of appointments using administrative data. The Committee discussed the opportunities and challenges around using the patient's first contact with the healthcare system as a point from which to assess timeliness of diagnostic care. Committee members suggested that starting measures when a patient first experiences a symptom or contacts the healthcare system will help to address the gap in measures assessing the first two steps of the diagnosis process: "patient experiences a health problem" and "patient engages with healthcare system."[4] Committee members noted, however, that the first contact would need to be defined, and that this data may be difficult to capture depending on which entity within the healthcare system the patient contacts. For example, patients may contact a hospital or an insurance company asking for guidance about their symptoms, and Committee members were unsure if this would count as first contact. Two Committee members noted that the point of first contact, especially for acute conditions, may be an ED or urgent care where capturing and sharing data across healthcare systems has its own challenges. Members highlighted that starting with the patient's first contact is important because patients often feel frustrated with delays in getting care (for example, getting appointments with specialists). The Committee also noted a patient's diagnostic experience starts when they first feel symptoms, not when they have their first healthcare visit. When the patient first experiences a symptom, however, can only be captured using patient report.

Committee members suggested other timeliness concepts based on administrative data. One member suggested measuring the time between when a diagnosis is made and when it is conveyed to the patient. Another Committee member suggested measuring the number and cost of tests ordered before a specific diagnosis is made, which could highlight inequities in testing strategies. There is some research suggesting that non-English primary language speakers receive fewer diagnostic tests than primary English speakers, although preferred language was not associated with a higher risk of diagnostic error.[39] A Committee member cautioned that differing perspectives between patients and clinicians on what constitutes a diagnosis could complicate efforts to assess diagnostic timeliness using administrative data. This is described in more detail in the Patient-Reported Measurement section. Another Committee member cautioned that untimely diagnosis might be a result of patient preferences (e.g., patient was offered screening but declined or did not schedule screening).

Potential Measurement Approaches Using Varying Definitions of "Access"

The Committee's discussion about access revealed variation in ways to think about access as it contributes to the diagnostic process. Some Committee members focused on access to diagnostic care, while others considered access more broadly to include access to health information, including a diagnosis; how to manage without a diagnosis (e.g., contingency plans and how to monitor and respond to symptoms), as well as the clarity of that information; and digital tools for communicating with health systems during their diagnostic journey. Committee members agreed that access is an important component of achieving diagnostic quality and should be measured. Several Committee members cautioned, however, that having good access to diagnostic care does not always equate with better diagnostic outcomes. For example, there may be patients who have frequent encounters with the healthcare system but are still not able to get a diagnosis. Committee members described that even if a patient seeks care, they may not get a diagnosis due to biases the clinician has about the patient if the

clinician does not take a history, give an exam, or provide follow-up. A Committee member noted that one challenge to measurement of access is that health systems, measure developers, and researchers do not understand the reasons why patients do not or cannot access care earlier (e.g., patients may not make appointments until their Medicaid is approved). Another Committee member agreed and suggested that patients be asked about their barriers getting to and making an appointment (e.g., transportation, childcare, financial, prior authorization, etc.).

Committee members emphasized that a lack of access to clear, timely, and understandable communication contributes to worsened diagnostic care and outcomes. One member highlighted that the diagnostic process begins with a patient engaging with the healthcare system, but this can be delayed by access issues that are difficult to measure. This discussion then led to recommendations for measuring a patient's access to next steps in the diagnostic process. One Committee member suggested measuring both timely and accurate communication by asking patients through patient portal prompts if they understood their visit outcome, and by stratifying the results using self-reported variables. However, other Committee members cautioned that patient difficulties with using portals and inadequate monitoring by providers of those portals may limit their usefulness as a data source. Another Committee member noted closing the loop on patient communication could improve access, and that improving infrastructural supports would facilitate loop closure and care coordination. Other members noted that it is important for patients to understand not only the diagnosis (i.e., to have access to an understandable diagnosis), but next steps as well, especially if they do not yet have a diagnosis. They recommended assessing how well the patient understands the diagnosis, and if they do not have a diagnosis, if they understand next steps or how to manage their condition until they have a diagnosis. Another Committee member recommended assessing whether a patient has control over, or access to, next steps (e.g., if patient lost insurance, they were unable to find a specialist, they moved because of lost housing).

Committee members also recommended assessing if diagnostic information meets the needs of a patient (i.e., is accessible to the patient), is communicated in a language that the patient can understand and is delivered via technology that the patient can use. Specifically, one Committee member recommended developing and stratifying measures that assess whether patients:

- Are served in their primary language
- Have an accessibility need and if it is appropriately addressed
- Have equitable broadband access
- Have access to electronic devices that allow them to access their own data in a patient portal
- Have the skills to sign up for the patient portal
- Are receiving communication consistent with their level of education

Committee members flagged that patient needs will differ according to digital and health literacy levels and patient language preferences, and therefore, they recommended that care should be tailored to each patient.

Some noted that, in the context of diagnostic equity measurement, differential access to digital tools may deepen inequities in access and diagnosis. Committee members cautioned that as digital capabilities improve and data from these tools are used in measurement, there is a risk that the

diagnostic journey of more patients will not be captured due to their limited access to those digital tools. In addition, one member recommended assessing whether patients are accessing the tools available to them (e.g., the patient portal, information translation) but cautioned that those who do not access the healthcare system at all will not be included in the assessment.

The Committee discussed communication barriers, measurement strategies, and consequences. Two Advisory Group members and a Committee member suggested assessing the availability of interpreter services, a structural measure, as a potential measure of diagnostic equity given the evidence that non-English speakers are more likely to be misdiagnosed. An Advisory Group member also suggested assessing time to access deaf and hard-of-hearing services. These recommendations align with a Committee member's research that found patients who prefer a language other than English were five times more likely to report that they did not feel heard in the diagnostic process.[28] This Committee member also cited results from an Institute for Healthcare Improvement (IHI) study indicating that there were "significant differences of contributing factors by 'LEP [limited English proficiency]' or 'low SES [socioeconomic status]'" among patients who self-reported a diagnostic error, which included having many doctors but no specific doctor in charge, not being able to afford care, not being able to make follow-up appointments, having no translator provided, and lack of understanding, as well as other factors.[40] These studies demonstrate how structural factors (that can be measured) impact patient diagnostic journeys, which, in turn, impact patients' diagnostic experience and outcomes and may lead to diagnostic inequities.

Committee Recommendations and Principles

- The Committee recommended developing measures of:
    - Timeliness while taking into account patient preferences for defining when the diagnostic process starts for them
    - Whether patients have access to clear, timely, and understandable communication related to the diagnostic process
    - Patients' access to diagnostic information that assess whether patients can access diagnostic information in a language they understand, the availability of interpretive services, and the use of digital tools they can understand and can access (e.g., broadband access, access to community health workers, healthcare navigation specialists)
- The Committee emphasized applying the following principles to the development of measures of diagnostic timeliness and access:
    - Defining access broadly to include access to diagnostic care and personal health information, an understandable diagnosis, and, especially in the setting of a highly uncertain diagnosis, access to contingency plans in case the course of illness is not as expected
    - Measuring timeliness starting with either the patient's first contact with the healthcare system or, where feasible, when the patient first experiences symptoms and could potentially benefit from a diagnosis

PATIENT-REPORTED MEASUREMENT

As introduced earlier, the Patient-Reported Measurement (PRM) Subcommittee focused on the following challenge hypothesized and prioritized by the Diagnostic Excellence Committee:

- Challenge C: There may be differences in expectations and beliefs about diagnostic excellence between patients, their care partners, clinicians, and health systems. In other words, divergences might exist regarding what constitutes diagnostic excellence for the purposes of the assessment of health system performance. Perspectives of patients, their families, and care partners currently are not part of that assessment. Incorporating these perspectives into the diagnostic excellence accountability assessment requires understanding and navigating these potential divergences.

As noted in Methodology, step 7, to support the PRM Subcommittee's discussions, NQF conducted a comprehensive review of potential strategies to address challenges that such potential divergences in perspective might pose for the development and use of PRMs for diagnostic excellence measurement. NQF presented the PRM Subcommittee with a memo summarizing the review's findings. NQF identified five key themes through discussions with the PRM Subcommittee that build upon each other and represent promising avenues for advancing the role of PRMs in diagnostic excellence (see Box 1), which NQF then discussed with the full Committee. Each of the sections below provides detailed insights and recommendations from the Committee and the Advisory Group aimed at overcoming barriers to the effective use of PRMs in diagnostic excellence, especially in the context of PRMs for use in accountability programs.

Box 1. Five Key Themes Identified Through Discussion With PRM Subcommittee for Advancing the Role of PRMs in Diagnostic Excellence Measurement

1. Setting the stage for PRMs to drive accountability and action on diagnostic excellence
2. Identifying patient-reported domains that matter to patients and ways to measure those domains
3. Creating a pipeline of PRMs for actionability to inform meaningful PRMs for accountability
4. Supporting immediate progress on a small number of promising diagnostic excellence PRM concepts
5. Moving from a small number of PRM concepts to PRMs for diagnostic excellence accountability

Setting the Stage for PRMs to Drive Accountability and Action on Diagnostic Excellence

As mentioned in the Background, diagnostic excellence is the optimal process—timely, cost-effective, convenient, and understandable to the patient—to attain an accurate and precise explanation about a patient's condition.[15] Diagnostic excellence involves making a correct and timely diagnosis using the fewest resources while maximizing patient experience and managing uncertainty.[41,42] Inclusion of the patient's perspective within the definition remains essential.[43,44] Healthcare is increasingly moving from a technocratic, professionally dominated framing of "excellence" to one that seeks and incorporates the values, knowledge, context, actions, and power of patients and their care partners.[8,36] For the pursuit of

diagnostic excellence, these perspectives of co-production, patient-centeredness, and sharing of power between clinicians and patients have deep implications.[45,46]

Using patient reports for assessing diagnostic processes and outcomes is an embodiment of patient-centered care. Patients (or their care partners as proxies) are the only source of information for understanding their experiences throughout their diagnostic journeys. Patients also have unique insights about the ramifications of diagnostic errors and inequities that they face. The scope of patient-reported outcomes and experiences relevant to diagnostic excellence is unknown, yet gaining that knowledge could help refine, measure, and achieve such excellence.[47,48]

PRMs have potential to enrich the field's understanding of diagnostic excellence, as patient reporting brings the values, knowledge, context, actions, and power of patients and their care partners to the foreground.[46,48,49] Many interest holders, including CMS, are committed to using patient-reported measures to assess health system performance (e.g., patient-reported measure-based performance measures [PRM-PMs]), including in the areas of interest—diagnostic quality and safety. However, NQF's review established that no PRM-PMs of diagnostic excellence currently exist.[21] At present, no PRMs of diagnostic excellence are being developed specifically for use in accountability programs. Instead, they are primarily intended to inform organizational learning, quality improvement, or research. Even for these purposes, very few PRMs of diagnostic excellence are in development.

Divergences Regarding Diagnostic Excellence

At its November 2023 meeting, the Committee prioritized the challenge of what was referred to as "misalignment" between those who would be the source of information for PRMs of diagnostic excellence (the patient along with care partners such as family and friends) and those whose performance is being assessed and relayed to the public for system-level accountability (the clinician along with other professionals in the health system). To illustrate, an accurate and timely diagnosis might be incorporated into health system performance assessment irrespective of suboptimal patient experience of establishing that diagnosis and communication failures during the diagnostic process. Performance assessments in areas where patients and clinicians misalign the most, taking into account the importance of those areas to patients and to clinicians, might impact patient-clinician relationships and diagnostic care. If diagnostic excellence PRMs for accountability are introduced in ways that reinforce the misalignment, this path might lead to more adversarial rather than collaborative patient-clinician relationships, confusion, dissatisfaction, and compromised outcomes for patients and their care partners during the diagnostic process. Thus, the misalignment might result in "divergences" regarding diagnostic excellence.

The Committee held diverse views on how to approach divergences between patients and clinicians in how diagnostic quality should be defined. Two Committee members noted that divergences should not be seen as negative but viewed instead as a rich source of learning. For example, when a diagnostic error occurs, clinicians might consider whether a competent clinician could make this mistake or whether the diagnostic care was below the standard. A patient might reflect whether an outstanding clinician in an outstanding health system could have made the diagnosis correctly. Two other Committee members added that learning from divergences highlights the uniqueness of patient perspectives and that those perspectives make such learning holistic. Another Committee member suggested that while recognizing divergences is critical, reducing those divergences is not the goal. Another Committee

member suggested describing the divergences surfaced between patients and clinicians as differences of perspectives and experiences. They also noted that all interested parties of diagnostic excellence should be aligned in their desire to address this challenge. Another Committee member, reflecting on the aim of making diagnostic excellence patient-centered, further underscored that where the diagnosis may be the endpoint in diagnostic excellence for clinicians, it might be just the beginning for patients who ultimately seek relief from their symptoms, from the uncertainty of not knowing, and sometimes, from the exhausting, disrespectful, or even gaslighting experience of ultimately receiving a diagnosis.[46] They added that those differences in perspectives might also contribute to divergences in how the diagnostic process is experienced, yet suggested that every participating party should care about these differences for delivering good care.

Several Committee members and an Advisory Group member suggested avoiding the terminology of *divergences*. A Committee member suggested framing divergences as *unique patient insights*, arguing that it avoids confusion or potential negative connotations and highlights the important value added by patient perspectives and the challenge of eliciting them. Another Committee member supported this framing as using positive language that might counter a negative language tone that they believe is currently associated with patients and families. An Advisory Group member noted that while patients and clinicians may have differing perspectives, neither perspective should be dismissed. They added that the thoughtful use of language in presenting PRMs might avoid the suggestion that clinicians' medical expertise is wrong or that patient reports substitute for clinicians' judgment, proactively anticipating the potential defensive nature of some medical practices.

These hypothesized divergences may span across the entire continuum of measure development, starting with (1) selecting which experiences and outcomes during and after diagnosis that patients would prioritize for reporting, and (2) choosing methods to collect those reports. The selection of particular experiences and outcomes, referred to as "domains," includes outlining the process and rationale for their selection and prioritization. The choice of methods to collect PRMs also includes outlining the process and rationale for such decision-making.

Divergences in the Context of Accountability

As mentioned previously, the Diagnostic Excellence initiative focuses on measures for accountability purposes. The development and use of PRMs involves many other decision points related to how to use the measures that are developed and what happens as a result of the development and use of the PRMs. For example, measures for quality improvement purposes require enough granularity about quality deficiencies to direct actions at the practice level. In contrast, measure sets designed to hold entities accountable for their performance ideally assess all aspects of providing diagnostic excellence in order to correctly classify entities' diagnostic performance as strong or needing improvement. Moving from quality improvement to accountability uses for measures might magnify the tensions and friction points that emanate from divergences in opinions between different interest holders of the healthcare system, regardless of the measurement data source. For example, with diagnostic excellence PRMs, one Committee member noted that there are varying viewpoints from clinical experts about the preventability of delays in diagnosing pediatric sepsis, even without factoring in how care partners (e.g., families) would characterize the outcome and their experiences during the diagnostic process. However, when the data source adds burden to patients or their care partners (as PRMs have the potential to do),

a focus on divergences in what would be valued for measurement becomes appropriately more pronounced. Another Committee member added that in addition to the burden, PRMs, like any other quality measures, pose a risk of unintended consequences, making consideration of divergences even more important.

Prior work provides a starting point for approaching PRMs for diagnostic excellence. NQF's 2022 report on patient-reported outcome performance measures (PRO-PMs) defined the attributes of high-quality patient-reported outcome measures (PROMs) that are appropriate for use in a digital PRO-PM.[50] The term *PROM* can be broadened to a more inclusive *PRM*, which includes both outcomes and experiences and more aspects of patient reporting. The terms PRM and PRM-PM will be used in this report. The term *attributes* refers to traits of a PRM that make it suitable for use in a PRM-PM. According to the report, they include but are not limited to the following:

- PRM covers domains important to patients
- PRM is actionable for clinicians at the point of care
- PRM is feasible to collect
- PRM can be attributed to a measured entity for accountability

These attributes, while specific to PRM-PMs, appear generic to any clinical context (described in terms of patient populations and clinical priorities), yet they have not been formulated explicitly for the diagnostic excellence context.

In the context of diagnosis, which might span various settings and providers over time, it is especially important to confirm that clinicians can take actions in response to diagnostic excellence PRM-PMs and that any response actions are within the control of an accountable unit whose performance will be measured. In this regard, diagnostic excellence PRM-PMs do not differ from any other diagnostic excellence accountability measures. However, the introduction of diagnostic excellence PRMs might require redefining the concept of accountable unit to reflect patient diagnostic journeys. Those journeys, for example a delayed cancer or multiple sclerosis diagnosis, might span multiple providers whose accountability might need to be bundled in novel ways.

The Committee and Advisory Group member discussions highlighted and exemplified specifics of actionability and accountability for potential future diagnostic excellence PRM-PMs. Some Committee members emphasized the necessity of tailoring patient-reported diagnostic measures specifically to the contexts they are meant to assess. For example, a member shared a concern that an ED-specific measure may be capturing problems occurring elsewhere in the healthcare system. However, another member recommended making a measure as widely applicable as possible, not limiting it to a specific setting unless necessary for attributing accountability. One Committee member discussed the importance of actionable measures at the point of care. They noted that asking questions in a process-oriented way might help PRMs to inform and improve specific processes that are being assessed. They also noted that it might also be easier and more informative for patients to report on the process (for example, their understanding) rather than the outcome (for example, inaccurate diagnosis requires patients' classifying their situation as such). An Advisory Group member added that diagnostic excellence process PRMs versus outcome PRMs might also be perceived as less threatening to clinicians. Discussions of potential domains for diagnostic excellence PRM-PMs, such as access and care

coordination across the diagnostic continuum, also highlighted specifics for making PRM-PMs that measure those domains actionable and attributable for accountability.

The Committee and Advisory Group members highlighted the importance of understanding and improving alignment between clinicians and patients in their diagnostic care and cautioned about impacts, including unintended consequences, on that care with the introduction of diagnostic excellence PRMs for use in accountability programs. An Advisory Group member suggested considering where patients can make meaningful contributions to diagnostic care (for example, reporting on what matters to patients; experiences going through the diagnostic care process that patients can report on with reliability and validity) and where patients' contributions might be viewed as less meaningful for measure development (for example, providing input on diagnostic processes to include in measures, detailing measure specifications, or engaging with measurement science). A Committee member provided a hypothetical scenario where a patient might request more diagnostic testing, being unaware that diagnostic excellence encompasses cost-effectiveness and use of the fewest resources. Another Committee member argued that such a scenario is an illustration of an opportunity for patient education after which the patient might make a different informed decision. Another Committee member interpreted this hypothetical scenario as a situation where the patient might be aware of the costs yet might have a different valuation of the diagnostic testing importance. They added that only PRMs might elicit such differences in valuation exemplifying divergences between patients and clinicians. Another Committee member cautioned that focusing on the application of patient reporting to the use in accountability programs might interfere with both opportunities for clinicians to learn more about what matters for patients and for patients and their care partners to learn more from clinicians on the diagnostic process, thus thwarting progress toward diagnostic co-production.

Paths to Address Divergences

The Committee and Advisory Group members coalesced around three potential paths forward, informed by discussions about maneuvering the selection of domains for measurement, reasoning for these selections, deciding where and how to collect patient reports, and the need for diagnostic excellence PRM-PMs to drive accountability and action on diagnostic excellence. These three paths forward are represented by **three goal statements** for addressing hypothesized divergences between patient and professional communities about what constitutes diagnostic excellence:

- Diagnostic excellence PRMs for accountability may be more acceptable if they measure only areas where patients and their care partners, clinicians, and health systems share similar beliefs and expectations about diagnostic excellence
- Diagnostic excellence PRMs for accountability should capture all aspects that patients and their care partners consider to be diagnostic excellence from their perspective
- A precondition for diagnostic excellence PRMs for accountability is better definitional development of what diagnostic excellence is from all points of view

To illustrate the Committee and Advisory Group members' thinking along these three paths, an Advisory Group member suggested that the first path (a) prevents addressing any divergences, but under the second path (b) a health system might be incentivized to choose, for example, one diagnostic excellence patient-reported domain to improve each year that patients and their care partners prioritize. A Committee member suggested that neither of those paths can be achieved without the final path (c)

being completed. The report's four key themes clarify the origin and basis of these and many more insights from the Committee and Advisory Group around these goal statements.

Identifying Patient-Reported Domains That Matter to Patients and Ways to Measure Those Domains

To prepare the PRM Subcommittee for discussion about the divergence challenge, NQF presented examples of patient-reported experience and outcome domains taken from a publication that reviewed the literature from 2015 to 2020.[48] The review identified 41 diagnostically relevant patient-reported outcome and experience domains. Examples of domains are as follows: listening and taking concerns seriously, provider checked patient understanding, and untimely diagnosis. The authors commented that the large number of domains presents a challenge for measurement and prioritization. Out of those 41 domains, 17 were communication-focused domains. The review classified 10 of 41 domains as patient-reported outcomes, 28 as patient-reported experiences, and three as mixed outcome and experiences. According to the review, 19 of 41 domains were captured in existing instruments, and 20 were captured only in qualitative studies, while two domains were only conceptualized. In terms of measurement timing conditions, for 27 domains patients and care partners report on a specific encounter, while for 14 domains reporting relates to an entire diagnostic journey over time. The review highlighted that these two distinct measurement timing conditions are the minimum possible and presented both measurement opportunities and challenges related to different timing and setting junctures for assessment.

The Committee discussion further illustrated challenges with selecting particular domains for measurement, revealing a variety of perspectives and illustrating hypothesized divergences. In particular, the discussion focused on the multi-faceted patient-reported domains of access, care coordination, and communication and transparency.

Access

When discussing access as it relates to patient-reported measurement, the Committee raised several themes that also emerged during Committee discussion of diagnostic equity measurement. For example, several Committee members discussed how access, broadly understood, impacts patients' understanding of the diagnostic process and achieving diagnostic excellence. Advisory Group members also provided a range of comments on how access impacts the diagnostic process and fits into a patient-reported measurement approach of diagnostic excellence. An Advisory Group member discussed how the "access issue" is more complicated than just health insurance or insurance coverage limitations, noting it is also related to culture and trust. A Committee member stated the importance of viewing access broadly, including access to care, health information, and recognizing alarm symptoms (e.g., learning what they are and when to act on them and how). For example, the issue of access to and co-payments for specialists and medical tests can be more or less generous even with health insurance. Another Committee member further elaborated that access is not just about getting to a physician, but rather it is about a multitude of factors, such as transportation, cultural understanding, interpreter services, and others interrelating together when assessing access. Several Committee members noted the importance of capturing the reasons why patients might not engage in the diagnostic process or follow through on recommended steps in the process. Another member cautioned that clinicians and health systems might not always consider access to be a diagnostic issue, which might undermine

accountability for this domain and exacerbate the lack of diagnostic excellence measures in the time frame between onset of symptoms and interacting with the healthcare system. Another Committee member noted that access might be attributable to the organizational or health system level, beyond any individual clinician.

An Advisory Group member noted the importance of considering measures of diagnostic excellence in the context of access. They suggested using access as an exclusion criterion for some measures, as a risk adjustor for some measures, or as a factor that drives performance on other measures. For example, a measure related to timely diagnoses made through specialty care is dependent on adequate access to that specialty care. They finally noted that the accountable unit matters and might differ from one diagnosis to another when operationalizing any measurement of access in the diagnostic context.

Care Coordination

Several Committee members discussed gaps and limitations in care coordination and how they may impact diagnostic excellence, echoing long-established challenges of care coordination measurement and emphasizing the role of patient and care partner reporting for such measurement. Multiple Committee members emphasized the need for better coordination across the diagnostic continuum and improved care transitions. These Committee members noted that effective care coordination can prevent issues arising from both the absence of necessary encounters and the events that occur between visits.

As was also mentioned in the Potential Measurement Approaches Using Varying Definitions of "Access" section, the Committee discussed differences in how patients might view the start of the diagnostic process compared to clinicians and the healthcare system. One member noted that for patients, the diagnostic process might start when symptoms start, whereas for clinicians and health systems, it starts when the patient accesses care with that clinician or health system. Another member noted that the starting point may also be viewed differently from a public health perspective, where waiting until symptoms develop leaves out the diagnostic opportunity to screen for risks of chronic disease. However, an Advisory Group member suggested centering on the diagnostic process and noted that it does not begin until an individual takes action to start the diagnostic process, be it the patient, their care partner, or someone in the healthcare system. This would impact how care coordination is viewed by patients and care partners versus clinicians and health systems, or even population management and public health professionals. Recognizing the different starting points of the diagnostic process for patients and clinicians, Committee members and an Advisory Group member highlighted the importance of acknowledging these discrepancies to better align the diagnostic process and engagement with the health system and to identify opportunities to intervene. They highlighted the importance for the care team members to clarify their roles and responsibilities to the patient and each other during the diagnostic journey to ensure effective coordination among multiple parties.

Taking a broader view of care coordination, a Committee member noted that patient reporting on care coordination might produce additional benefits, such as attention to diagnostic process facilitators within community education and community-based health programs, especially in underserved communities; use of telehealth and mobile health technologies; and policies supporting universal access to preventative care. An Advisory Group member noted the importance of considering (and potentially measuring via patient reporting) the availability of interpreter services to strengthen diagnostic

coordination, as strong evidence suggests higher degrees of misdiagnosis when patients are not easily understood. This recommendation also applies to the diagnostic equity discussion, underscoring how patient-reported measurement may contribute to measuring diagnostic equity. Another Advisory Group member endorsed care coordination as an important domain for patient-reported measurement as only the patient knows when their care "falls between the cracks" on the diagnostic journey across settings, providers, and encounters; however, the member also noted a challenge with assigning accountability for care coordination failures.

Communication and Transparency

Several Committee and Advisory Group members emphasized the importance of effective communication and transparency throughout the diagnostic process, highlighting those as key domains that are essential for development of effective PRMs. They underscored the need for effective communication and transparency to ensure patients feel heard, respected, and fully informed about their diagnostic journey. One Committee member recommended that diagnostic excellence should include asking specific questions about communication and making system-level changes to support "clinician listening," as patients not feeling heard can signal potential diagnostic breakdowns. A Committee member noted that diagnosis requires a high level of communication between the patient and the clinician, which can be impacted by cultural, language, or other factors. The Committee stressed the need for clear, timely, and respectful communication, with a focus on understanding the patient's perspective and ensuring they feel heard and respected throughout their diagnostic journey. A Committee member cautioned that, due to medical appointments being short, the diagnostic process does not lend itself to building trust with patients and their families and to having meaningful conversations. Another Committee member shared findings from a survey where patients frequently reported not feeling listened to as a significant contributing factor to diagnostic errors.[40]

Another Committee member noted that measuring and improving communication might support clinicians in shared decision making with the patient, diagnostic co-production, and understanding instances when a patient seeks a second opinion.[51,52] The member explained that patients may experience negative outcomes if their clinicians do not communicate or if the clinicians disagree when the patient seeks a second opinion. Another member noted that patients may experience a negative diagnostic interaction even if the diagnosis itself is correct, and this negative experience may influence whether they continue to seek care.

With respect to transparency in communication, a Committee member stressed the necessity of clear dialogue between clinicians and patients, questioning whether clinicians can make their thinking about the diagnostic process clearer to patients. Another Committee member advocated for an environment where feedback is not only exchanged openly but also incorporates often overlooked aspects of the patients' diagnostic journeys, such as feelings of being unheard, disregarded, or disrespected. One Committee member further highlighted the need for healthcare providers to interpret unspoken patient concerns, requiring a high degree of openness and attentiveness. They noted there are sometimes disconnects between what patients understand from a clinician and what the clinician means, providing personal examples of both poor and clear communication outcomes.

An Advisory Group member discussed how the communication of new diagnoses, particularly cancer, is often problematic when communicated through patient portals without adequate explanation, leading

to confusion and anxiety for patients. A Committee member argued that recent studies report that patients may prefer to have access to a cancer diagnosis through the portal so they can learn the results as quickly as possible, take it in when they want to, and do so in a comfortable setting. Overall, these discussions emphasized the multiplicity of patient-reported domains related to communication and their overlap with patient satisfaction, respect, trust, rapport, and others.

Other Domains for Patient-Reported Measurement

Along with the domains that sparked intensive conversations between Committee members, members mentioned more than a dozen domains without further discussions. Among those were:

- Experience of bias
- Open conversations about diagnostic uncertainty
- Cross-clinician communication
- Resolution or relief of the patient problem
- Pain
- Emotional exhaustion
- Timeliness of the resolution
- Financial burden of the diagnostic process to the patient
- Harms during any diagnostic experience
- Broader impacts of the diagnosis on the patient's life
- Patient's understanding of the diagnostic process
- Congruence with patient's preferred mode of communication and other adaptations to patient's preferences and patient health, literacy, and language needs while communicating the diagnosis
- Equitable information-sharing such as medical notes access, readability, and patient portal functionalities
- Ability for patients to correct their medical records when they detect incorrect information
- Honesty
- Patient experience of not receiving a sincere apology after their experience of a diagnostic error

A Committee member elaborated on the last domain above highlighting the importance of conflict resolution and ability of patients to report on their experience with the conflict resolution in the context of the diagnostic process. They added that patient reporting on conflict resolution is especially important in the context of diagnostic equity as addressing these conflicts between patients and clinicians motivates healthcare organizations to make meaningful changes to reduce disparities in diagnostic excellence and build trust. Most of these 16 domains are described in the review of the diagnostically relevant patient-reported domains; however, some domains were not included in that review. Another Committee member noted additional literature sources on potential patient-reported diagnostic excellence domains.[46,53]

Process and Outcome PRMs

Several Committee members favored process-oriented PRMs over outcome-based ones, with several members emphasizing the importance of capturing the patient's lived experience. Two Committee members expressed concerns about the ability of patients to accurately report diagnostic outcomes such as timeliness and accuracy, while others challenged this view. A Committee member suggested

classifying PRMs as (1) outcome (e.g., "Was the diagnosis delayed? Incorrect?") and (2) process (e.g., "Was the patient's perception of the diagnostic journey that it was efficient, effective, good, bad?"). Several Committee members raised a concern that, in the context of diagnostic excellence accountability PRMs, patients may not be able to report on the accuracy of their diagnoses, and one Committee member mentioned a similar concern about the viability of patient-reported timeliness of diagnosis measures. Several Committee members emphasized that diagnostic excellence PRMs should measure patients' lived experience instead.

In contrast to favoring diagnostic excellence process PRMs over outcome PRMs, several Committee members emphasized the importance of measuring outcomes of care and quality of life via PRMs. Another Committee member elaborated that a patient's perception of the accuracy of a diagnosis and its timeliness is worthwhile to measure in order to understand diagnostic excellence patterns of the health system and subsequently provide systems with information that would contribute to improvements. Another Committee member mentioned that timeliness or delay in diagnosis is the most common issue when reviewing patient safety events regarding the diagnosis, with failure to close the loop as second to timeliness. Several Committee members suggested careful consideration when reviewing and using patterns of diagnostic outcome PRMs for reimbursement as different care delivery institutions have different resources and patients of varying complexity and needs. Another Committee member added that diagnostic excellence outcome PRMs might be a source of feedback on diagnostic performance for which clinicians do not currently receive any other feedback due to the fragmentation of health systems.

There were also comments about the intersection between process and outcome PRMs. An Advisory Group member noted that in terms of diagnostic outcomes, there is a difference between how well patients think the diagnostic process unfolds versus clinicians' perspectives, giving the example of a provider thinking the diagnosis is correct while the patient thinks it is incorrect. A Committee member noted benefits of measuring process indicators that inform outcomes and that PRMs should inform both. For example, PRMs that track patient-reported delays in receiving test results can highlight inefficiencies in the diagnostic process. By analyzing these reports, healthcare systems might identify bottlenecks and implement process changes, such as improving coordination between laboratory testing and clinicians.

Committee members spoke to the wording choices describing measurement. Several Committee members suggested describing diagnosis in PRMs as both *process* and *outcomes* that patients might report on, by ensuring that wording of PRM items is appropriately implemented. Another Committee member elaborated on wording choices for diagnostic excellence, potentially using *diagnostic safety* as a choice in terminology that patients might prefer. A Committee member and an Advisory Group member suggested that the choice of the term and its definition should ultimately be determined with patients, families, and care partners.

Measurement Considerations for Patient-Reported Diagnostic Excellence Domains

A Committee member reflected that there may be a divergence between clinicians and patients about what is part of the diagnostic process and what is not. Two Committee members expressed uncertainty about how to develop PRMs that are specific to the diagnostic process and questioned how diagnostic excellence measures might overlap with existing patient experience measures. Another Committee

member questioned how PRMs of diagnostic excellence relate to existing, general PRMs from other settings (e.g., CAHPS and patient satisfaction measures) that already assess access or clinician communication. Another Committee member noted that CAHPS surveys include questions related to whether the patient feels their provider listened to their concerns and whether the patient is satisfied. An Advisory Group member also noted that there is an existing supplement to the Surveys on Patient Safety Culture® (SOPS®) Medical Office Survey[54] intended to assess diagnostic quality in the ambulatory setting. However, the SOPS supplement is completed by medical offices and, therefore, does not assess the patient experience. One Committee member said that the domains discussed by the Committee are similar to their experience in reviewing patient complaints. An Advisory Group member argued that drawing similarities between patient complaints and diagnostic excellence PRMs might not always be appropriate. The Committee and Advisory Group members recognized that CAHPS surveys do not necessarily reflect all patients, so this method would likely miss important representation of those who experience inequities.

In addition, the Committee noted that the current CAHPS surveys lack specificity regarding bias and discrimination in the diagnostic process. An Advisory Group member supported modifying CAHPS to assess bias and discrimination, which could in turn indicate potential inequities in diagnostic excellence. A Committee member suggested that stratifying CAHPS survey questions by gender, race, or ethnicity would allow for comparisons across entities at a macro level and support the identification of variation and opportunities for improvement. An Advisory Group member suggested asking patients with common conditions that should be diagnosed quickly about difficulties faced during the diagnostic process and stratifying the results by SDOH to uncover inequities in care. A Committee member suggested stratifying a measure of patient experience (e.g., whether a patient does or does not feel heard) by patient characteristics such as race, gender, income, education, or zip code.

Another Committee member questioned how to prioritize the domains correctly and ensure that the elements of diagnostic excellence being captured are the most meaningful to patients. An Advisory Group member recommended that measures should reflect the patient's journey, including the time and effort required to achieve a diagnosis. Another Advisory Group member mentioned the importance of capturing patient experiences with delays in diagnosis and the frustration patients feel when they cannot get timely appointments. These discussions underscored the need for prioritizing domains for patient reporting of diagnostic excellence, delineating the process and rationale for this prioritization, as well as resolving the issue that identified domains are often not specific to the diagnostic process but reflect healthcare broadly.

Committee members discussed the optimal time for collecting patient-reported data for measures. One Committee member discussed how current measures often focus on discrete healthcare events like visits, despite the fact that issues can arise for the patient between these encounters, and these issues often remain invisible to the healthcare system. Another Committee member expressed concern that anchoring on events between encounters may be too restrictive, as many problems stem from the absence of necessary encounters. Multiple Committee members agreed on the need to consider the initial step when a patient first seeks care and to ensure measures capture the entire diagnostic continuum, not just isolated events. As described previously, measures as currently designed will not capture patient experiences for patients who have not yet entered the healthcare system. One member

noted the challenge of incorporating information about what happens with a patient between visits without causing clinician burnout or information overload, underscoring the need for better mechanisms to effectively integrate patient experiences into the diagnostic process. Overall, several Committee members supported an approach to anchoring patient-reported measurement not just on visits.

Multiple Committee members emphasized the need for and challenges of broader inclusion of patient and care partner perspectives. One Committee member stressed the importance of collecting the source of feedback, whether from the patient or family, and considering the degrees of separation from the patient. Another Committee member raised concerns about who is usually surveyed and the potential bias in current response demographics, suggesting a need for broader representation. Another Committee member warned that patients were not historically included in measurement and many established measure development processes and definitions need to be reviewed and revised. For example, several Committee members suggested that, since diagnostic excellence PRMs might report on experience and outcomes for which patients are the only legitimate source of information, traditional validation (for example, against medical records or claims) might not be applicable and should be reevaluated. Another Committee member added that errors of omission, by definition, will be absent in medical records and only reporting by patients and care partners makes identification of such errors possible.

Finally, the Committee acknowledged that at the stage of selecting domains for patient reporting, there is no full understanding of what domains matter to patients in certain diagnostic contexts and timing, while diagnostic excellence from patient perspectives has been under-investigated and not prioritized. The Committee emphasized the importance of having a definition of diagnostic excellence from the perspectives of both patients and their families or care partners. Multiple Committee members noted that understanding the patient definition of diagnostic excellence is critical to developing meaningful measures that matter to patients, which is especially important for PRMs. They discussed the necessity of defining what constitutes diagnostic excellence more clearly and whether the focus should be on errors or broader excellence metrics. Others elaborated that embedding patient engagement and co-design with patients and care partners in diagnostic excellence PRM development should include defining both diagnostic excellence and markers of success.

Committee Recommendations and Principles

- The Committee recommended:
    - Supporting regular, comprehensive reviewing and updating of the scope of patient-reported experience and outcome domains for diagnostic excellence, mapping existing measures onto those domains and assessing the rigor of those measures
    - Flagging patient-reported domains that lack rigorous measurement as targets for measure development, including multi-faceted domains of access, care coordination, and communication and transparency
    - Funding research and implementation initiatives to deepen the reservoir of rigorously developed PRMs on a variety of diagnostic excellence domains, including access, care coordination, and communication and transparency

    - Outlining process and rationale for selecting and prioritizing patient-reported domains that matter to patients specifically for measurement of diagnostic excellence accountability
- The Committee emphasized the following principles for diagnostic excellence PRMs and PRM-PMs:
    - Formulating language used in diagnostic excellence accountability PRMs through substantial input from patients, families, and care partners
    - Ensuring that work on defining diagnostic excellence from the patient perspective is informed by a multitude of patient voices (diverse, equitable, and inclusive)
    - Highlighting how bias and discrimination impact the patient's diagnostic journey given how integral patient-clinician interactions are to the diagnostic process
    - Anchoring patient-reported measurement not only on post-encounter measurement but capturing patient experiences and outcomes along patient diagnostic journeys through the entire diagnostic continuum
    - Striving for broader patient inclusion and representation in domain selection and measure development supported by equitable and comprehensive patient reporting collection

Creating a Pipeline of PRMs for Actionability to Inform Meaningful PRMs for Accountability

As the measure reservoir has deepened in diagnostic excellence, the dearth of PRMs is notable. PRMs have potential for supporting many goals besides accountability, such as individual patient care decisions, quality improvement, population health, research for new evidence to inform clinical practices and guidelines, and real-time monitoring of patient-reported data to allow rapid referral. A recent publication, *Achieving Diagnostic Excellence: Roadmaps to Develop and Use Patient-Reported Measures With an Equity Lens*,[45] established that the use of PRMs can achieve multiple goals for diagnostic excellence. Those goals include but are not limited to:

- PRMs for diagnostic continuity
- Diagnostic PRM alerts
- PRM-based quality improvement
- PRMs for research
- PRMs for routine screening
- PRM-based diagnostic excellence population-level patterns
- PRMs supporting patient storytelling

This work considered diagnostic equity as a cross-cutting goal that the use of PRMs can and should support.

Actionability is a recurring theme in measure development.[50] It is established that patients do not want to be burdened with surveys that collect PRMs unless the results are used for a purpose that improves care for themselves and others. Likewise, clinicians, clinical teams, and other entities reporting quality measures do not want to use measures showing gaps in their diagnostic care based on PRMs unless there are potential actions they can take. However, several Committee members noted that potential actions may be taken by patients and care partners to change their provider or health plan in response

to diagnostic excellence accountability PRMs in the context of public reporting. This raises questions of actionability for whom, accountability for whom, and their interplay.

Before becoming accountability measures, PRMs require testing about how they can fit into workflows and enhance diagnostic care performance and reduce preventable harms. Additional consideration should be given to actionability because diagnostic excellence PRMs will also align to Safety II approaches in contrast to diagnostic error measures using solely Safety I approaches.[55] Safety I is a state in which as few things as possible go wrong and the operational focus is on minimizing adverse outcomes. The goal is to understand the causes of errors to prevent the future occurrence of a similar event. Safety II seeks to understand what is going well, as opposed to what went wrong. The underlying premise is that safety occurs when as many things as possible go right. Safety II focuses on understanding why most healthcare delivery processes are successful and how they are performed correctly in high-performing units rather than why they fail. A Committee member noted that diagnostic excellence accountability PRMs, by assessing both Safety I and Safety II, might support healthcare organizations in creating a more resilient and effective safety culture and culture of equity that prioritizes learning from successes and failures alike to continuously improve patient care.

Actionability relies on integrating collection of PRMs, their analysis, and presentation to interest holders in diagnostic care. Without more efforts to incorporate PRMs into workflows for data collection and response, the proof of the specific value proposition of diagnostic excellence PRMs has yet to be securely established. The hypothesized divergences are expected to influence the operational aspects of collecting data from patients. Testing out various approaches to collecting and responding to PRMs is necessary given the variability of patient diagnostic journeys. The previously mentioned publication on roadmaps[45] relied on the taxonomy of diagnostic journeys to identify goals for the use of PRMs for diagnostic excellence. The taxonomy grouped patient journeys into six pairs of diagnostic error and counterfactual diagnostic excellence scenarios, as well as separately highlighting those who are "invisible" to the health system. The grouping of the journeys into the taxonomy was based on their timing, setting, and diagnostic care utilization. This work illustrates the need for multiple PRMs with various collection methods so that these PRMs can be actionable for a given time and setting.

Divergences in the Context of Actionability

The Committee members discussed many of the decision points for PRM collection and use. One Committee member emphasized the importance of real-time measurement efforts on learning about diagnostic harm from patients and suggested that a structural measure from the patient perspective of diagnostic safety may capture whether patients know where to go and how to report a safety problem. An Advisory Group member suggested using direct patient observation and AI to capture patient-reported data during diagnosis, noting the challenges of subjectivity in patient-reported experiences. A Committee member suggested that reliable, evidence-based, patient-facing AI tools can help with translation and language simplification in the future.

When reacting to information about one of the Project PIVOT[c] goals on incorporating diagnostic safety questions into CAHPS surveys, multiple Committee members raised several issues with this source for data collection and PRM actionability in this context. One Committee member noted that not all patients who had either a negative or positive experience will complete a CAHPS survey. A Committee member recommended it would be useful to "plug into" existing questionnaires from various healthcare settings to create a cross-cutting measure rather than trying to create a separate diagnostic excellence patient survey. Overall contributions from Committee members centered on the need for a balanced approach in patient questioning, avoiding survey fatigue while still gathering essential data. An Advisory Group member noted that while measures like CAHPS are useful, they often do not capture diagnostic challenges accurately and suggested exploring additional methods to gather patient-reported diagnostic errors. A Committee member also encouraged seeking new accessible data collection methods for diagnostic excellence PRMs.

Interplay Between Actionability and Accountability

The Committee discussed learnings from the Narrative Elicitation Project[56,57] that emphasized the need for understanding the broader scope of patient-defined adverse experiences and harms and the ways that these experiences shape subsequent trust and care-seeking behaviors. In the Agency for Healthcare Research and Quality (AHRQ) issue brief, the narrative elicitation project team stated, "Experiences that have short-term actionability are best elicited by incorporating questions about diagnostic experiences into existing patient experience surveys fielded by health plans, hospitals, long-term care facilities, and other clinicians. Identifying practices that affect the persistence of adverse effects long after a perceived diagnostic mishap or that cross organizational boundaries require population-based surveys designed for retrospective inquiry about past diagnostic events." In addition, they stated, "Responsibility for eliciting patient experiences should be divided in a strategic manner between (a) Healthcare providers responsible for rectifying diagnostic shortfalls related to clinician-patient interactions, and (b) Agencies responsible for promoting structural reforms to promote safety for the healthcare system as a whole." Under this division, patient experiences that are immediately actionable and centered on single organizations are most effectively collected by incorporating elicitation questions into existing patient experience surveys. These include actions from both providers and individual healthcare organizations. However, patient experiences that involve diagnostic problems crossing clinical settings and organizational boundaries, as well as assessing long-term sequelae of diagnostic shortfalls, need to draw on population-based surveys designed for this purpose. The Committee voiced support for these shared learnings. This strategic vision emphasized a different understanding of response actions and actionability for different interest holders of the healthcare system.

A Committee member suggested that the introduction of diagnostic excellence PRMs for use in accountability programs might both precede and stimulate the work on testing various approaches to collecting and responding to these PRMs. They elaborated that understanding the patterns of excellence

[c] Led by Sue Sheridan, Martin Hatlie, Suz Schrandt. Background available on Patients for Patient Safety US website: Patients For Patient Safety US | Project PIVOT

on measured patient-reported domains might identify already existing best practices and performance assessments on those domains and might expedite the diffusion of those practices. An Advisory Group member agreed that adding the prerequisite of actionability for a diagnostic excellence accountability measure is not necessary. A Committee member suggested that diagnostic excellence PRMs might play an educational and patient engagement role by reducing the gap in health literacy and educating patients about their health condition. Another Committee member elaborated that collecting diagnostic excellence PRMs could be accompanied by novel decision support systems developed specifically for patients that are similar to clinical decision support systems. These patient support systems might rectify gaps in patient understanding identified via PRMs that focus on information exchange with patients and advise patients when to contact their care teams. Several Committee members supported that idea and offered further ideas for incorporating such patient diagnostic decision support systems. A Committee member noted that some challenges that diagnostic excellence accountability PRMs face are not unique to PRMs and thus learning from other sources is possible, although PRMs bring an additional set of challenges and modify others.

A Committee member noted a major challenge to actionability for most traditional measures is the lag between the clinical action, the measurement, the feedback to the clinician or health system, and the ultimate behavior change. They added that this lag could be even longer for PRMs. They suggested differentiating between the actionability of quality measures and actionability in the context of measures that provide more real-time feedback that could be especially important for patient communication. Another Committee member suggested that diagnostic excellence PRMs should be prospective, a part of workflows, and incorporated into dashboards that healthcare delivery organizations use. Two Committee members noted that PRMs will be more actionable if they are created via a collaborative design approach (involving patients, care partners, and frontline providers) and if there is the capability for rapid-cycle improvement. Another two Committee members added that it is important to elicit from patients what was done in response to their reporting via the PRMs reaffirming the loop between reporting, response actions, and informing patients that their reporting is valuable and was acted upon. They also suggested that it is as important to learn from diagnostic excellence PRMs as it would be to use those PRMs for accountability purposes.

Finally, the Committee acknowledged that given the paucity of diagnostic excellence PRMs, there is no full understanding of opportunities and barriers to PRM collection and acting upon those PRMs; however, it is evident that there is no ubiquitous solution for many diagnostic care contexts.

Committee Recommendations and Principles

- The Committee recommended:
    - Supporting funding for the development and implementation of diagnostic excellence PRMs that inform diagnostic excellence PRMs collection and actions
    - Creating mechanisms for shared learning of both successes and failures across the implementation of diagnostic excellence PRMs
    - Nominating diagnostic excellence PRMs with strong actionability as accountability measure candidates and supporting the adaptation and testing of these PRMs for accountability purposes
- The Committee emphasized the following principles for diagnostic excellence PRMs and PRM-PMs:

- Burdens associated with diagnostic excellence accountability PRMs collection and analysis should be outweighed by benefits these PRMs bring to the diagnostic process through their actionability
- Importance of actionability of diagnostic excellence PRMs for their further use for accountability
- Importance of diagnostic excellence PRMs that do not aim to become accountability measures but inform learning
- Support of and learning from multiple PRMs as collection and actions upon PRMs will differ by setting and timing

Supporting Immediate Progress on a Small Number of Promising Diagnostic Excellence PRM Concepts

In preparation for the PRM Subcommittee meetings, NQF presented to the Subcommittee the following diagnostic excellence patient-reported measurement concepts, including concepts for accountability measures, patient-reported survey tools, and PRM frameworks, that were informed by key informant interviews.

PRM Concept A. PRIME-ED: Patient-Report to Improve Diagnostic Excellence in Emergency Department Settings.[58] PRIME-ED consists of 17 statements about diagnostic excellence covering 13 domains that were selected from 41 diagnostically relevant domains. The selection of domains for measurement prioritized what can be reported by patients and their care partners within 30 days of ED discharge and that can give a flag for further follow-up. The measurement domain choices were informed by both patients and clinicians based on the goal of using PRIME-ED for quality improvement. PRIME-ED is integrated into a health system's ED performance dashboard for internal monitoring, with four domains viewable to clinicians and administrative leaders.

PRM Concept B. Patient Experience Measures for Timeliness of Cancer Diagnosis.[59] These measures were derived from a 28-question survey completed by patients with a cancer diagnosis in the last 12 months. Patients reported on factors that might have contributed to delays in their cancer diagnosis, such as barriers to usual and specialty care, ease and timeliness of receiving tests and test results, and communication with healthcare professionals. In addition, patients reported approximate date of first visit or test related to their cancer diagnosis and the date of diagnosis (diagnostic interval) and their perception of the timeliness of their diagnosis. The survey was designed to uncover care experiences that are associated with diagnostic delays that are important to patients and families, that patients can report on, and that health systems can potentially act upon. In some instances, the survey uncovered problems with access to care that occurred before a patient was attributed to a health system, including long wait times for appointments. The research team explored various quality measures that can be built from items in the survey to assess communication in usual and specialty care, timely usual and specialty care, and timely receipt of tests and test results.

PRM Concept C. OurDX and PRDBs: Patient-Reported Diagnostic Process-Related Breakdowns. [28,60-63] The OpenNotes team developed a framework that identified and categorized PRDBs to inform organizational learning in ambulatory care. The framework described 7 patient-reported breakdown categories (with 40 subcategories), 19 patient-identified contributing factors, and 11 potential patient-reported impacts. Patients identified breakdowns in each step of the diagnostic process, and the

framework highlighted instances that only patients can report on and instances that patients describe differently than clinicians. One aim of developing the framework was to create a patient-centered taxonomy reflecting how patients view diagnostic breakdowns. The language of patients could then be used for understandable and meaningful patient-reported process and outcome measures related to patients' lived experience of diagnosis. Because patients and families have a unique vantage point as the single connecting thread between different visits, providers, and even healthcare systems, their perspective can identify diagnostic process safety concerns that may not otherwise be observed by providers or improved by the health system (i.e., "blindspots"). Based on the framework, the OpenNotes team co-created with patients the OurDX online tool that invites patients to contribute unique information to co-create diagnostic safety and report experiences of potential breakdowns in the diagnostic process before they lead to diagnostic delay, error, or harm.

PRM Concept D. DExPRM+: Center for Patient-Reported Measures of Diagnostic Excellence.[45] The Center, located at Johns Hopkins University, grounds its work in a vision of diagnostic excellence that is co-driven by patients and care partners along with professional teams, includes diagnostic workflows across healthcare settings and beyond, and seeks to optimize patient experience and outcomes for all patients equitably within a broad paradigm of diagnosis. The Center has developed building blocks as a learning platform for the community of developers, evaluators, users, and beneficiaries of all PRM activity for diagnostic excellence (DExPRM+). The Center conducted the scoping review[38] of patient-reported outcome and experience domains for diagnostic excellence, introduced the taxonomy of diagnostic journeys, and published roadmaps[8] to develop and use PRMs with an equity lens, all of which were described earlier in this report. Collectively, the Center's work informs a number of potential PRM-PMs of diagnostic excellence and the benefit of coordinating work on sets of measures.

PRM Concept E. Narrative Elicitation Project.[57] This AHRQ-funded project takes a rigorous approach to learning systematically from patient experience to address diagnostic problems. At this stage, the project has identified and reported several key insights: (1) Representative accounts of patients' diagnostic experiences require asking questions about diagnostic issues using broad language, rather than using the term *diagnostic error*; (2) The broader scope of patient-defined adverse experiences is valuable in understanding the ways that these experiences shape subsequent trust and care-seeking behaviors; (3) The survey recently fielded in a national sample elicits experiences involving both the mishap itself and its aftermath; (4) Feedback from patient experiences is feasible and can be useful for addressing diagnostic failures by providing two data sources: a) verbatim narratives that identify concrete, actionable changes and b) quantifiable metrics associated with the narrative elicitation; and (5) The extent of actionable feedback derived from narrative accounts requires careful attention to elicitation techniques (e.g., question wording and sequencing).

PRM Concept F. Project PIVOT.[64] This recent initiative is tasked with identifying questions that tackle patient safety, diagnostic excellence, and patient discrimination that can be added to the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. The initiative plans to engage broad and diverse patient and caregiver communities to hear their lived experience of diagnostic error, discrimination, and the impact that it had on them. Strategic partnerships (in progress) include patient advocacy organizations, government agencies, measure developers, purchaser organizations, healthcare systems, and others in order to expedite the implementation of the patient-identified

questions into standard measures of the quality of healthcare (e.g., HCAHPS), patient-centered outcomes research (PCOR), and other relevant processes.

Committee discussion of these PRM concepts spurred suggestions regarding target domains for patient-reported measurement of diagnostic excellence, ways to capture patient reporting, and needs to understand unique learnings on PRM collection and response actions. In addition, several Committee members provided feedback regarding these novel diagnostic excellence PRM concepts. A Committee member found the PRIME-ED example helpful, stating that it provides real-world experience that permits refining the value of diagnostic excellence PRMs and further improving the granularity of the questions. Another Committee member found the PRIME-ED example relatable and highlighted the challenges in implementing patient-reported measurement, particularly the need to balance "capturing the domains that need to be captured" against the many other patient-reported experience measures and patient-reported outcome measures that organizations must collect, track, and report. While discussing Patient Experience Measures for Timeliness of Cancer Diagnosis, one Committee member supported the approach but advocated for stratification by type of cancer, acknowledging significant variation in patient experiences and delays across different cancer types. Another Committee member noted that while the level of specificity of these measures might be useful for a service line or disease-specific registry, they would likely be significantly shortened once implemented. Another Committee member suggested it would be helpful to know the consequences related to the timeliness (or not) of the diagnosis, noting that not all delays negatively impact outcomes. While discussing OurDX and PRDBs, the feedback highlighted the complex interplay between measuring diagnostic safety versus diagnostic excellence and capturing the patient's experience and safety perceptions.

NQF described the state of actionability for these diagnostic excellence PRM concepts. This spurred additional discussions. The Committee concluded that none of the provided examples have adequate evidence for their broad actionability at this time. A Committee member suggested developing a better understanding of how well the presented diagnostic excellence PRM concepts are prepared for implementation in healthcare delivery organizations beyond those where they were initially conceptualized.

Committee Recommendations and Principles

- The Committee recommended:
    - Supporting further development of the presented diagnostic excellence PRM concepts into actionable and widely implementable PRMs
    - Promoting coordinated shared learning for patients, clinicians, and the health system across these examples
- The Committee emphasized the following principle for diagnostic excellence PRMs and PRM-PMs:
    - Encouraging implementation of the diagnostic excellence PRMs in a manner that informs PRM data collection and actionability

Moving From a Small Number of PRM Concepts to PRMs for Diagnostic Excellence Accountability

As mentioned previously, the Committee coalesced around three potential paths forward for addressing the hypothesized divergences between patients and clinicians on what constitutes diagnostic excellence

for the purposes of the assessment of health system performance. These three paths forward are represented by **three goal statements**:

- Diagnostic excellence PRMs for accountability may be more acceptable if they measure only areas where patients and their care partners, clinicians, and health systems share similar beliefs and expectations about diagnostic excellence
- Diagnostic excellence PRMs for accountability should capture all aspects that patients and their care partners consider to be diagnostic excellence from their perspective
- A precondition for diagnostic excellence PRMs for accountability is better definitional development of what diagnostic excellence is from all points of view

Committee discussions about these goal statements are presented below. In further discussions, the Committee emphasized the importance of finding the "middle ground" between these three paths, which will require engagement of all interested parties, including many different patient groups.

Measuring Only Areas with Convergence Among Patients, Care Partners, Clinicians, and Health Systems

Several Committee and Advisory Group members favored measuring only areas where patients and their care partners, clinicians, and health systems align in terms of sharing beliefs and expectations about what constitutes diagnostic excellence and what to prioritize for measurement. They argued that an accountability measure that avoids areas of misalignment would have better uptake and indicate success for diagnostic excellence PRMs. A Committee member noted that focusing on a specific set of measures might help with identifying more concrete, attainable, and time-bound recommendations. Another Committee member suggested that because diagnostic safety is a shared responsibility, the accountability for diagnostic safety should be shared as well. They elaborated that to achieve shared accountability, all interested parties should agree and, thus, measure development for accountability should focus on the area with the most convergence of views.

A Committee member warned that achieving the perfect alignment might not be possible. An Advisory Group member suggested scanning for candidate PRMs among existing measures, including those used by the World Health Organization (WHO), that can be supported by multiple interest holders and become nationally used. However, the member also suggested that a diagnostic excellence PRM should be capturing the area of discordance. Committee discussions that focused on the domains where patient reporting is a sole source of measurement—patients' experiences of feeling unheard, disrespected, disregarded, or discriminated against; patients' understanding of communication of diagnosis; or patients' perceptions of access or care coordination—indirectly supported interest in capturing the area of discordance (where patients' perspectives exist and clinicians' perspectives do not). A Committee member suggested the health system should be responsible for learning and understanding areas of discordance.

When discussing how to select one diagnostic excellence PRM that targets the area of most accordance, Committee members suggested alternative approaches. Several Committee members recommended selecting a measure, "even if not perfect," and advocating for its implementation to start the process for such a PRM to become an accountability measure. One Committee member referred to this approach as simulated pressure testing of candidate measures. The member clarified that selection of the PRM

would imply assessing it against principles and criteria that should be developed and agreed upon by multiple interest holders. Another Committee member noted that while one measure might not be comprehensive, it may achieve some impact by being an accountability measure tied to reimbursement. Another Committee member cautioned that it is necessary to acknowledge that patients are not homogenous and that for each group of patients (adults, children, linguistically diverse, minority populations, etc.) one PRM may not capture enough different domains to be relevant to all patient populations. Also related to the challenge of selecting a single PRM, one Committee member suggested that there should be one diagnostic excellence PRM *process* measure, one diagnostic excellence PRM *outcome* measure, and one diagnostic excellence PRM *structure* measure. Another Committee member suggested focusing on process and structural measures for accountability while outcome PRMs are developed. They elaborated that the CMS Patient Safety Structural Measure[65] provides substantial opportunities to include PRMs that can be further mapped to diagnostic excellence aspects of patient safety in general and diagnostic excellence PRMs in particular.

Capturing All Patient-Reported Aspects Important to Patients

The Committee and Advisory Group member discussions affirmed the importance of incorporating patient and family perspectives into the definition of diagnostic excellence. One method of incorporation is through PRMs, although an Advisory Group member noted that selection of PRMs for accountability needs to center on what patients and their care partners wish to prioritize. This member further noted that even if PRMs are prioritized by patients, the healthcare system would need to respond to these diagnostic excellence PRMs effectively. Another Advisory Group member noted that it is important to consider the setting and timing that would make patient-reported measurement actionable for improving care.

A Committee member reflected that moving toward an ecosystem of PRMs – reflecting all aspects that patients want included —is necessary for the critical challenge of no one "owning the problem" when diagnosis occurs over time and across settings, as it often does. An Advisory Group member suggested to stop compartmentalizing quality to institutions but to embrace the patient perspective on the diagnostic process. The member elaborated that the current piecemealing of quality of care due to payment and performance assessment of specific settings and models prevents embracing the patient perspective. Conceptualizing an ecosystem approach to PRMs would allow different types of measures that are patient-centered, and not institution-centered. Another Advisory Group member emphasized the need for a holistic approach to measuring patient experiences and outcomes throughout the diagnostic journey, from symptom onset to diagnosis. In addition, as highlighted by key informants, under the ecosystem of PRMs, patient reporting is more likely to lead to patient engagement in patient safety and learning health systems and eventually to patients leading healthcare system redesign.

Several Committee members noted that while incorporating patient and family perspectives into the definition of diagnostic excellence is important, this definition should be developed via consensus of all involved parties and that some aspects that matter to patients might be subsequently decided not to be a part of diagnostic excellence. Several Committee members noted that patients should be included to the degree they want to be engaged. They also clarified that currently it is not possible to know *all* patient-reported aspects that matter to patients. One Committee member indicated that including all

domains of diagnostic excellence could reduce the focus on measuring and eliminating preventable patient harm due to diagnostic errors if these domains are not prioritized over the rest of the domains.

Defining Diagnostic Excellence *First*

Several Committee members expressed concern that development of diagnostic excellence PRMs for accountability cannot proceed without a comprehensive and better understanding of what diagnostic excellence is from the patient perspective. They also expressed doubt about whether the hypothesized divergences are discoverable as factually true and, thus, questioned whether the selection of one measure for accountability based on the area of the most concordance between patients and clinicians is even possible. An Advisory Group member suggested that work on defining diagnostic excellence might be done in parallel with the other two approaches. Another Advisory Group member suggested that additional defining of diagnostic excellence would make it possible to sort between what is aligned and what is not and that it is important to know where there are divergences. Several Committee members reinforced the need to elicit a patient-generated definition of diagnostic excellence. Another Committee member suggested defining diagnostic excellence first as a potential approach for advancing overall diagnostic excellence measurement, more broadly than PRMs and diagnostic excellence measures for accountability.

Supporting the Goals

Regardless of the chosen path forward, the activities to achieve these goal statements require support and vision. To facilitate Committee discussion of what is needed for diagnostic excellence accountability PRMs and to inform potential Committee recommendations, NQF provided the examples of potential supports described in Table 5. NQF created the examples by synthesizing inputs from key informant interviews with leaders of the diagnostic excellence PRM concepts presented earlier and other PRM interest holders.

Table 5. Examples of Potential Supports for Diagnostic Excellence PRMs

Forum for Accountability	Measure Development Funding	Coordinating Activities and Leadership
A forum (or fora) that convenes to stimulate interest holders to create new accountability partnerships for diagnostic excellence and equity, supports accountability commitments and multi-party arrangements especially for vulnerable populations, and promotes public reporting for accountability that uses diverse collection methods and payment for reporting of diagnostic excellence PRM-PMs with an equity and inclusivity in measurement lens.	A call for action to support PRM developers in diagnostic excellence and those who develop novel methods and modes of collection of patient reports for diagnostic excellence and equity, to support learning more about what patients view as diagnostic excellence, and to support securing streams of funding that are needed for full measure development and implementation cycles of PRM-PMs that reach out to all populations.	Coordinating activities needed include active monitoring and ensuring that domains important to patients for diagnostic excellence move into PRM-PMs or are advanced elsewhere, synergizing and streamlining work of measure developers and those working on enhancing methods and outreach of collecting patient reports with focus on inclusive population definitions and PRM challenges, supporting learning about challenges particularly those that block the ability of patients and families to co-create diagnostic safety with providers, cultivating collaborations to solve raised problems, and identifying coordinating leadership for these types of coordinating activities.

Other support examples rely on the first three supports for their further operationalization and implementation. Those include offering shared stewardship of diagnostic excellence PRM-PMs and pairing diagnostic excellence PRM-PMs with other measures for shared accountability.

The Committee engaged in discussion about suggested supports for diagnostic excellence PRMs refining and expanding the original ideas proposed by NQF.

Forum for Accountability

Committee members discussed motivation for, functioning, interest holders' roles, and concerns that might inform a proposed forum. Committee members reaffirmed the forum's mandate on co-creating diagnostic measures with patients, clinicians, payers, and regulators to ensure that patient perspectives are reflected in diagnostic excellence PRM-PMs. One member highlighted that it is typically the payer or regulator that can hold a health system or hospital accountable on behalf of a patient. Another member recommended that this type of forum could try to solve problems around attribution and accountability for measures of diagnostic excellence, citing challenges related to multiple clinicians and teams being involved in the diagnostic process. An Advisory Group member suggested that employers could play a role in pushing for diagnostic excellence PRMs from payers, as delayed or incorrect diagnoses can impact employee productivity. Similarly, a Committee member recommended encouraging employers to push for diagnostic accountability from payers to drive culture change in healthcare settings. Several Committee members cautioned that clinicians and hospitals may push back as they are the ones who would be evaluated by these measures. A Committee member warned that diagnostic excellence PRMs will be questioned for their scientific validity, reliability, and feasibility as they become part of the

reimbursement process. The Committee member further suggested designating an objective third party to arbitrate possible disputes. A Committee member questioned how the forum for accountability would participate in securing funding for diagnostic excellence PRM development and how the forum would get PRMs in the field and implemented. Another Advisory Group member suggested that the forum or fora for accountability could also strive for buy-in for diagnostic excellence PRM implementation and use.

Coordinating Leadership

Committee members discussed motivation for and functioning of a potential coordinating leadership entity. A Committee member suggested that coordinating leadership should imply advocating for normalizing feedback on diagnostic excellence, combatting a culture of fear or blame toward individual clinicians for errors, and embracing transparent conversations on diagnostic uncertainty between clinicians and patients. Moreover, coordinating leadership requires fostering leaders among interest holders of the healthcare system that would endorse and champion patient reporting and demonstrate commitment to having PRMs. Committee members emphasized the importance of having a patient-driven approach for coordinating leadership. It was noted by a Committee member that Patients for Patient Safety US, a patient advocacy organization that leads Project PIVOT, has demonstrated its capacity for coordination and leadership in aspects such as advocacy for culture change and for the role of patients in the Patient Safety Structural Measure recently proposed by CMS. An Advisory Group member questioned whether the new University of California, San Francisco (UCSF) Coordinating Center for Diagnostic Excellence (CODEX) has a role in coordinating patient-reported measurement for diagnostic excellence, and how that might fit with the Center for Patient-Reported Measures of Diagnostic Excellence (DExPRM+) at Johns Hopkins University and ways to coordinate leadership for elevating patient reporting more broadly.[66]

CODEX was funded by the Moore Foundation to serve as a national coordinating entity, engaging the diagnostic excellence community to promote novel findings, catalyze action, and advance the field. To accomplish this, CODEX established three interrelated programs that will connect and expand the diagnostic community, support new and ongoing work to improve diagnosis, and drive advancements across the healthcare system. Those programs are (1) *The Learning Hub* to synthesize and disseminate major advancements in diagnostic excellence research and clinical practice; (2) *The Engagement Hub* to convene and continue network building for the field among researchers, clinicians, fellows, grantees, and others; and (3) *The Action Incubator* to develop several "action roundtables" to advance progress toward diagnostic excellence and drive measurable outcome improvements for patients.

The DExPRM+ Center at Johns Hopkins University, also funded by the Moore Foundation as described in the earlier section (Supporting Immediate Progress), aims to support connectivity and coordination within the emerging international community of PRM developers (including patients/care partners), PRM implementers, and others interested in progress on PRMs and PRM-PMs for diagnostic excellence and equity.

Measure Development Funding

Committee members discussed challenges and approaches to securing funding for the development of diagnostic excellence PRMs. The Committee noted the need for research and funding in the area of

diagnostic excellence PRMs that are currently lacking, adding that this is a complex scientific area that needs multidisciplinary input. A Committee member expressed concerns that there would not be a "scientific push" on developing diagnostic excellence PRMs, jeopardizing this emerging field. Another Committee member emphasized the importance of engaging entities responsible for implementing measures into the process. The Committee reaffirmed the importance of including patients early in the process. An Advisory Group member advocated for federal funding to support needs of the PRM ecosystem, infrastructure, and measure development.

An Accountability Ecosystem for Diagnostic Excellence PRMs

These three supports—forum, coordinating leadership, and funding—together form an ecosystem directed to multiple goals. This ecosystem approach enables attention on diagnostic equity while scaling, coordinating, and supporting the multitude of diagnostic excellence accountability PRMs that continuously improve and move through the development pipeline. The ecosystem both supports measuring diagnostic excellence of those currently not interacting with the health system and measuring inequities in diagnostic process, outcomes, and experience. Given often times staged deployment of accountability PRMs from pay for reporting to pay for performance, the ecosystem raises visibility throughout these stages for diagnostic excellence PRMs measurement to become sustainably integrated into payment incentives. In order to get to this point, the ecosystem likely includes the introduction of PRM development for high alignment areas between patients, care partners, clinicians, and health systems. At the same time, the ecosystem enables continued development of a wider range of diagnostic excellence accountability PRMs. The ecosystem brings together interested parties in further definition development of diagnostic excellence, while coordinating findings with efforts in measure development and improvement. The ecosystem approach also supports scalability, standardization of measure development and interpretation, and harmonization within diagnostic excellence accountability PRMs and with other accountability measures.

Committee Recommendations and Principles

- The Committee recommended:
    - Supporting work on better definitional development of what diagnostic excellence is and determining the continuum of alignment (accordance-discordance) that informs and affects PRM development and implementation
    - Establishing a process to identify whether a proposed diagnostic excellence PRM assesses a measure domain with strong accordance or discordance between those reporting and those accountable for measure performance
    - Supporting work on diagnostic excellence PRMs for accountability that measure areas where *alignment* between patients, their care partners, clinicians, and health systems is anticipated
    - Supporting work on diagnostic excellence PRMs for accountability that measure areas where *misalignment* between patients, their care partners, clinicians, and health systems is anticipated
    - Supporting work on PRMs for accountability responsive to capturing *as many as possible* patient-reported experiences and outcomes of diagnostic excellence that matter to patients
    - Considering as supports for this work: (1) creating a forum for accountability for diagnostic excellence PRMs; (2) advocating for purposeful funding of development and

implementation of diagnostic excellence PRMs; and (3) coordinating leadership activities and structures

- The Committee emphasized the following principles for diagnostic excellence PRMs and PRM-PMs:
    - Ensuring that no domain that is important to patients is "left behind" in definitional development of diagnostic excellence
    - The final set of domains prioritized for diagnostic excellence PRM-PMs should be decided via consensus of interested parties
    - As PRMs are developed, monitoring reactions from all healthcare system interest holders to learn how the hypothesized divergences might inhibit diagnostic excellence PRMs
    - Diagnostic excellence PRMs should be informing actions regarding diagnostic outcomes, process, and structure

Conclusion

Given the urgency, uniqueness, and critical significance of diagnostic excellence to health and healthcare, NQF under its Advancing Measurement of Diagnostic Excellence for Better Healthcare initiative convened the Committee whose work is summarized in this report. The Committee prioritized diagnostic excellence measurement challenges for in-depth exploration. The prioritization aimed to set a path for potential solutions that are actionable, novel, and applicable to the unique aspects of developing and implementing diagnostic excellence accountability measures. Three challenges were prioritized:

Challenge A: Most existing diagnostic excellence measures use healthcare visit data to identify included patients, thus leaving out of the measures individuals—disproportionately from historically disadvantaged groups—who do not interact or have limited interaction with the healthcare system.

Challenge B: There is a lack of measures assessing equity in diagnostic processes, outcomes, and experience.

Challenge C: There may be differences in expectations and beliefs about diagnostic excellence between patients, their care partners, clinicians, and health systems; at the same time, perspectives of patients, their families, and care partners currently are not represented in diagnostic excellence accountability measures.

The Committee produced a total of 29 recommendations informing solutions to these challenges supplemented by 24 principles guiding the execution of these recommendations. In addition, recommendations for measurement of timeliness of and access to diagnostic care emerged as cross-cutting domains for the three challenges.

Acting upon these recommendations will enable effective measurement of diagnostic excellence, inclusive of patient-centeredness and equity, build accountability for diagnostic excellence, and produce measurement-based incentives for diagnostic excellence in the U.S. healthcare system. Taking advantage of recommendation synergies and working with interdependent sets of recommendations will accelerate the path forward.

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Appendices

APPENDIX A: DIAGNOSTIC EXCELLENCE COMMITTEE MEMBERS, ADVISORY GROUP MEMBERS, AND NQF STAFF

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APPENDIX B: CHALLENGE SUMMARY SHEETS

Data Specificity and Data Standardization

This challenge category focuses on the variation in the completeness of information available in clinical records as well as discrepancies in documentation style and terminology used due to clinician, system, and patient-level factors. Available terminologies (ICD, SNOMED, CPT) are often not specific enough to reflect the clinical subtleties of diagnostic decision-making, nor are they specific enough to reflect what is currently captured in unstructured data (images, free text). The challenges below exemplify these issues across diagnostic excellence quality measurement.

Key: **bolded** solutions have been implemented by measure developers; *italicized* solutions are potential solutions identified during the environmental scan and have not yet been implemented

Challenge	Potential Solution(s)
1. **Codes in the available terminologies do not have the level of specificity required for measure specification (e.g., codes do not differentiate between somatic or germline biomarker testing, or in ICD-10 there are no specific codes for fetal congenital heart disease).**	• *Advocate for introduction of needed codes in existing coding systems.*
2. **The problem list is not well-maintained (e.g., old diagnoses remain as current on problem lists and there is no standard process for maintaining this list).**	• *Advocate for guidelines that support uniformity of clinical notetaking and reporting, including the use of synoptic reports with standardized language and language to address degree of certainty.* • *Consider novel uses of electronic health record (EHR) and other system metadata that may provide information about early disease manifestations or diagnostic activity.* • *Engage patients to ensure their problem list is up to date.*
3. **Dates important to measures of diagnostic excellence, such as diagnosis date or date of screening test, are not routinely captured in the same way or accurately. For dates of diagnoses, it could be the date on which a diagnosis was entered or on which a diagnosis was made (e.g., there are often places to insert the date of diagnosis, but no hard stops requiring that this be completed or guidance on how).**	• *Same as first two bullets in box above* • *Short-term solution: Linkage with registry data could supply needed information from another source, as long as registries contain needed information.*

Challenge	Potential Solution(s)
4. **Results of screening tests are difficult to abstract from the EHR because they do not exist as discrete items (e.g., radiologists compose written reports to share results and recommendations, or test results are scanned in as images).**	• *Linkage with cancer registry data could supply needed information from another source.* • **Use natural language processing (NLP) to extract language from unstructured text.**
5. **Some sites use structured radiology reports, but others do not (e.g., recommendations for surveillance are unstructured or are not written in a patient-centered manner).**	• *Advocate for guidelines that support uniformity of clinical notetaking and reporting, including the use of synoptic reports with standardized language and language to address degree of certainty.* • **Use NLP to extract language from unstructured text.**

Diagnostic Equity

Challenges with health equity are integral to diagnostic excellence quality measurement because research has identified inequities in diagnostic opportunities and subsequent treatment. Identifying the characteristics of patients who face inequity in diagnosis and targeting these groups for measurement will help reduce disparities. The factors defining these groups might include both individual characteristics and factors outside the health care system.[d] Examples of risk factors for diagnosis inequity include a person's insurance coverage status, continuity of coverage, race and ethnicity, socioeconomic status, rural residence, age, sex, and LGTBQ+ status. A person's physical status, including disability or presence of a stigmatized condition, such as obesity, may also overshadow the correct diagnosis. The challenges below exemplify these issues across diagnostic excellence quality measurement.

Key: **bolded** solutions have been implemented by measure developers; *italicized* solutions are potential solutions identified during the environmental scan and have not yet been implemented

Challenge	Potential Solution(s)
1. **There is limited information on which populations face diagnostic inequities. First, there is a lack of measures of diagnostic equity. Second, few diagnostic excellence measures are stratified (scored by subgroups to illuminate differences across groups) to reveal inequities.**	• *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. Develop data sources and code sets to fill gaps.*

[d] McDonald KM. Achieving equity in diagnostic excellence. *JAMA*. 2022;327(20):1955–1956. doi:10.1001/jama.2022.7252

Challenge	Potential Solution(s)

2. **Some groups most at risk of diagnostic delays or misses have limited encounters with providers due to inadequate insurance coverage, transportation, availability of providers in their community, language barriers, or other risk factors. Therefore, they are often missing from diagnostic measures because their data is not part of the data collected for measurement. Including people who have limited access to care in diagnostic excellence measures is challenging. For example, it requires obtaining and linking their data on signs and symptoms, but such data may not be accessible if they are not "in the system."**	• *Create guidelines to inform choices about including populations with limited health care access—especially historically disadvantaged populations—in measures of missed or delayed diagnoses.*
	  ○ *The guidelines would inform measure development and consensus-based measure endorsement/review.*
	• *Leverage patient experience and patient input to enrich understanding of early diagnostic signals, and definitions of measure denominators (who is included) to inform measure design and make measures more acceptable to those most impacted by diagnostic misses and delays.*
	  ○ *Inform patient engagement with focused literature review of drivers of reduced access to primary care.*

3. **Including people who have limited access to care in diagnostic excellence measures requires deciding who (which providers) or what (e.g., health plans) to hold accountable for patients who are affiliated with a practice or plan but experience difficulties accessing providers.**	• *Create guidelines to inform choices about which providers and level(s) of the healthcare system to hold accountable for measures of diagnostic excellence that would reflect the whole, at-risk population.* • *Encourage development of measures at the health plan, accountable care organization, state, or other levels in order to bring forward the full population at risk into measures of diagnostic excellence.*

Challenge	Potential Solution(s)
4. **We may be less likely to develop measures of diagnostic excellence for conditions that are relatively low prevalence in the general population but more common in socially and historically disadvantaged populations (e.g., lead poisoning in poor urban areas or sickle cell disease among Black persons), even if the risk of missed diagnosis is high. Causes for missed/misdiagnoses may include lack of historically disadvantaged persons' access to high-continuity, high-quality care and language barriers that make diagnostic misses more likely.** **The lack of measure development in this area may also reflect limited engagement of patients and diagnostic excellence researchers from Historically disadvantaged groups.**	• *Target diagnostic excellence measures at conditions or treatments that are concentrated in historically disadvantaged populations and that exhibit evidence of inequitable diagnosis in these populations.* • *Engage patients and researchers in defining the areas for greatest focus.*

Patient-Reported Outcome Performance Measures (PRO-PMs)

There is a strong need and interest in creating patient-reported outcome performance measures (PRO-PMs) to capture diagnostic excellence performance. This is primarily because the patient is viewed as an integral part of the diagnostic process, and their experience is viewed as the gold standard for assessing whether excellence has happened. However, there are difficulties with determining what to measure, when to measure it, and how to measure it. Although this challenge was not among the six identified by Battelle, NQF's environmental scan identified gaps in the development of PRO-PMs as a specific challenge area with unique issues regarding diagnostic excellence measurement. Some common terms and definitions that arise when discussing PRO-PMs[e] are listed in the table below.

Table 1. Distinctions Among PROs, PROMs, and PRO-PMs

Concept	Definition
Patient-reported outcome (PRO)	The concept of any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else.

[e] The National Quality Forum. Patient Reported Outcomes (PROs) in Performance Measurement. 2013.

Concept	Definition
Patient-reported outcome measure (PROM)	Instrument, scale, or single-item measure used to assess the PRO concept perceived by the patient, obtained by directly asking the patient to self-report.
Patient-reported outcome performance measure (PRO-PM)	A performance measure that is based on PROM data aggregated for an accountable healthcare entity.

Key: **bolded** solutions have been implemented by measure developers; *italicized* solutions are potential solutions identified during the environmental scan and have not yet been implemented

Challenge	Potential Solution(s)
1. For a PRO-PM, there is a disconnect between the concept of/typical understanding of an error as it is most often medically defined, versus a patient's conception of a patient-reported error.	• **The measure developer used careful language to describe the results of patient-reported feedback and actions for providers to take in response to the feedback. Whenever they shared results, the developer explained that these may not be errors as typically defined by the medical world, but they are still significant as they led the patient to not believe their diagnosis, and thus not take the necessary follow-up steps to manage their new condition.**
2. Collecting data on communication related to the explanation of the health condition (working diagnosis) to patients is currently difficult.	• **Measures of communication for diagnostic excellence have been developed from manual review of records.** • *Measures could be developed to reduce patient response burden (e.g., short-form surveys).* • *Other methods are under development, such as narrative elicitation that, while more cumbersome, may be necessary for effective response from health systems.*
3. Collecting data at multiple time points in a diagnostic journey is needed for a complete picture of diagnostic excellence, yet doing so prospectively is structurally challenging (what, where, when, and how all vary in ways that cannot be assumed given diagnostic uncertainty as the diagnostic process unfolds). It is also challenging for performance attribution when patients receive care in multiple settings and from different health systems.	• *Develop a new measurement architecture for summary measures based on patient reporting at multiple time points in the diagnostic process.*

System Fragmentation

The fragmentation of the U.S. healthcare system raises many challenges. There are subsequent interoperability and missing data implications that limit data availability across the care continuum to capture the complete diagnostic journey. Within this concern, barriers included variation in documentation, electronic health record (EHR) variability, data linkage issues, and limited provider communication and multi-center coordination. The challenges below exemplify these issues across diagnostic excellence quality measurement.

Key: **bolded** solutions have been implemented by measure developers; *italicized* solutions are potential solutions identified during the environmental scan and have not yet been implemented

Challenge	Potential Solution(s)
1. **Measures that are constructed to identify missed opportunities are often structured for longitudinal, retrospective analysis, requiring comprehensive data across the patient's diagnostic journey and across data sources.**	• *Health information exchanges and clinical disease registries may have more complete data (consolidated across patient providers) and greater data specificity (e.g., tumor staging) than EHRs. Linking patient data across sources can address data gaps and deficiencies inherent to each source.*
2. **Measures of follow-up within certain time frames or about closing referral loops require linking relevant patient data from all providers and lab/procedure sites. Lack of access to full patient data due to poor interoperability and data exchange could lead to measures misclassifying care as poor quality.**	• *Same as above.*
3. **Diagnoses are not routinely captured in the same structured fields in the EHR. History, problem list, and encounter diagnoses are variably used in different health systems (e.g., some providers put a new cancer diagnosis in the problem list, some put a diagnosis in history, some use both). This varies across both health systems and providers within health systems, which makes it challenging to develop measures that work across different systems.**	• *Build measures that prioritize use of interoperable data elements that are required to be accessible by a Fast Healthcare Interoperability Resources (FHIR) application programming interface (API).*
4. **Registries do not always contain information that is needed (e.g., information upon which to link EHR and cancer data for each patient is unavailable).**	• *Create mechanisms and governance structures for more easily linking data across EHRs and other sources and registries.*

APPENDIX C: CHALLENGES PRESENTED DURING COMMITTEE PRIORITIZATION EXERCISE AND VOTING RESULTS

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[f] 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).

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[f] Zheng L, Francescatti A, Deming S, et al. Synoptic Reporting for Cancer Surgery: Current Requirements and Future State. 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/. Accessed May 5, 2024.

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.

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.

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

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).

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) is 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.

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.

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.

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%**

APPENDIX D: SUMMARY OF COMMITTEE RECOMMENDATIONS AND PRINCIPLES

Measuring Diagnostic Excellence for All Patients

Approach 1: Assess by Measuring Late-Stage Diagnosis

- The Committee recommended:
    - Prioritizing development, testing, and implementation of quality measures of late-stage diagnosis and emergency presentation as a method for assessing diagnostic outcomes for individuals who may not be included in other measures of diagnostic excellence
    - Focusing accountability for late-stage and emergency presentation on entities with defined populations, such as health plans, integrated health systems, or public health agencies, acknowledging the complexity and importance of attribution for accountability
    - Targeting for measurement those specific diagnoses with known diagnostic delays, defined stages, and known outcome improvements and cost savings from timely diagnosis, noting that diagnoses with these features may differ for pediatric patients versus adult patients
    - Considering other non-disease-specific analytic approaches to identify variations in diagnostic timeliness and/or assess diagnostic delays with attention to their limitations
- The Committee emphasized the following principles for measures of late-stage and delayed diagnosis and emergency presentation:
    - Taking into account how screening rates might impact late-stage diagnosis; for example, improving screening rates may decrease late-stage diagnosis rates but may not address some of the equity issues with missed diagnosis
    - Emphasizing that improving screening practices relates not only to increasing screening rates, but also to the optimal use of appropriate screening tests based on risk and successful follow-up of abnormal tests
    - Acknowledging that attribution of accountability should consider the accountable entity's ability to impact late-stage diagnosis rates

Approach 2: Use Data that Do Not Rely on Individuals Interacting With the Healthcare System

- The Committee recommended:
    - Developing and applying measures of diagnostic excellence accountability to health plans so that measures include individuals regardless of whether or when they seek care
    - Using several sources of data outside of the healthcare system that potentially could effectively identify individuals who are not interacting with the healthcare system
- For developing measurement approaches to capture diagnostic excellence among individuals who are not interacting with the healthcare system, the Committee emphasized the following principles:
    - Acknowledging important limitations of health plan data to identify individuals who are not interacting with the healthcare system
    - Understanding the reasons individuals are not interacting with the healthcare system and diagnostic process, including HRSNs and other factors
    - Including the communities that are not interacting or only partly interacting with the healthcare system in developing diagnostic excellence accountability measures

Approach 3: Stratify Measures Using Data that Identify Historically Disadvantaged Groups

- The Committee recommended:
    - Stratifying measures of diagnostic excellence and called for further consensus and technical guidance on two challenges:
        - The variable accuracy and high levels of missing data that could be used to identify subpopulations for stratification
        - Approaches for setting benchmarks across stratified groups
    - Developing a framework, guidance, or criteria on acceptable levels of missingness, data adequacy, and data quality that measure developers and implementers could apply to data and variables used for stratification of diagnostic excellence measures
    - Reviewing NAM's diagnostic process with an equity lens at each step to further identify diagnostic excellence measures for stratification and potential stratification variables applicable to each step
    - Prioritizing a small number of diagnoses around which to develop diagnostic equity measures and demonstrate methods for stratifying those measures
- The Committee emphasized the following principle:
    - Using several approaches to prioritizing measures for stratification, including targeting measures for diagnoses with known large disparities

Approach 4: Measure Bias and Discrimination in Experiences of the Diagnostic Process

- The Committee recommended:
    - Supporting the addition of questions to CAHPS surveys to assess the patient experience of bias and discrimination during the diagnostic journey, including supporting the current work of Project PIVOT to add questions about diagnostic safety and bias/discrimination to CAHPS surveys
- The Committee emphasized the following principle:
    - Acknowledging the potential that AI can bring to assessing explicit and implicit bias and discrimination in diagnostic encounters by analyzing both in-person interactions and written communications

Measuring Access to and the Timeliness of Diagnostic Care

- The Committee recommended developing measures of:
    - Timeliness while taking into account patient preferences for defining when the diagnostic process starts for them
    - Whether patients have access to clear, timely, and understandable communication related to the diagnostic process
    - Patients' access to diagnostic information that assess whether patients can access diagnostic information in a language they understand, the availability of interpretive services, and the use of digital tools they can understand and can access (e.g., broadband access, access to community health workers, healthcare navigation specialists)
- The Committee emphasized applying the following principles to the development of measures of diagnostic timeliness and access:

- Defining access broadly to include access to diagnostic care and personal health information, an understandable diagnosis, and, especially in the setting of a highly uncertain diagnosis, access to contingency plans in case the course of illness is not as expected
- Measuring timeliness starting with either the patient's first contact with the healthcare system or, where feasible, when the patient first experiences symptoms and could potentially benefit from a diagnosis

Patient-Reported Measurement

Identifying Patient-Reported Domains That Matter to Patients and Ways to Measure Those Domains

- The Committee recommended:
  - Supporting regular, comprehensive reviewing and updating of the scope of patient-reported experience and outcome domains for diagnostic excellence, mapping existing measures onto those domains and assessing the rigor of those measures
  - Flagging patient-reported domains that lack rigorous measurement as targets for measure development, including multi-faceted domains of access, care coordination, and communication and transparency
  - Funding research and implementation initiatives to deepen the reservoir of rigorously developed PRMs on a variety of diagnostic excellence domains, including access, care coordination, and communication and transparency
  - Outlining process and rationale for selecting and prioritizing patient-reported domains that matter to patients specifically for measurement of diagnostic excellence accountability
- The Committee emphasized the following principles for diagnostic excellence PRMs and PRM-PMs:
  - Formulating language used in diagnostic excellence accountability PRMs through substantial input from patients, families, and care partners
  - Ensuring that work on defining diagnostic excellence from the patient perspective is informed by a multitude of patient voices (diverse, equitable, and inclusive)
  - Highlighting how bias and discrimination impact the patient's diagnostic journey given how integral patient-clinician interactions are to the diagnostic process
  - Anchoring patient-reported measurement not only on post-encounter measurement but capturing patient experiences and outcomes along patient diagnostic journeys through the entire diagnostic continuum
  - Striving for broader patient inclusion and representation in domain selection and measure development supported by equitable and comprehensive patient reporting collection

Creating a Pipeline of PRMs for Actionability to Inform Meaningful PRMs for Accountability

- The Committee recommended:
  - Supporting funding for the development and implementation of diagnostic excellence PRMs that inform diagnostic excellence PRMs collection and actions
  - Creating mechanisms for shared learning of both successes and failures across the implementation of diagnostic excellence PRMs

  - Nominating diagnostic excellence PRMs with strong actionability as accountability measure candidates and supporting the adaptation and testing of these PRMs for accountability purposes
- The Committee emphasized the following principles for diagnostic excellence PRMs and PRM-PMs:
  - Burdens associated with diagnostic excellence accountability PRMs collection and analysis should be outweighed by benefits these PRMs bring to the diagnostic process through their actionability
  - Importance of actionability of diagnostic excellence PRMs for their further use for accountability
  - Importance of diagnostic excellence PRMs that do not aim to become accountability measures but inform learning
  - Support of and learning from multiple PRMs as collection and actions upon PRMs will differ by setting and timing

Supporting Immediate Progress on a Small Number of Promising Diagnostic Excellence PRM Concepts

- The Committee recommended:
  - Supporting further development of the presented diagnostic excellence PRM concepts into actionable and widely implementable PRMs
  - Promoting coordinated shared learning for patients, clinicians, and the health system across these examples
- The Committee emphasized the following principle for diagnostic excellence PRMs and PRM-PMs:
  - Encouraging implementation of the diagnostic excellence PRMs in a manner that informs PRM data collection and actionability

Moving From a Small Number of PRM Concepts to PRMs for Diagnostic Excellence Accountability

- The Committee recommended:
  - Supporting work on better definitional development of what diagnostic excellence is and determining the continuum of alignment (accordance-discordance) that informs and affects PRM development and implementation
  - Establishing a process to identify whether a proposed diagnostic excellence PRM assesses a measure domain with strong accordance or discordance between those reporting and those accountable for measure performance
  - Supporting work on diagnostic excellence PRMs for accountability that measure areas where *alignment* between patients, their care partners, clinicians, and health systems is anticipated
  - Supporting work on diagnostic excellence PRMs for accountability that measure areas where *misalignment* between patients, their care partners, clinicians, and health systems is anticipated
  - Supporting work on PRMs for accountability responsive to capturing *as many as possible* patient-reported experiences and outcomes of diagnostic excellence that matter to patients
  - Considering as supports for this work: (1) creating a forum for accountability for diagnostic excellence PRMs, (2) advocating for purposeful funding of development and implementation of diagnostic excellence PRMs, and (3) coordinating leadership activities and structures
- The Committee emphasized the following principles for diagnostic excellence PRMs and PRM-PMs:
  - Ensuring that no domain that is important to patients is “left behind” in definitional development of diagnostic excellence

- The final set of domains prioritized for diagnostic excellence PRM-PMs should be decided via consensus of interested parties
- As PRMs are developed, monitoring reactions from all healthcare system interest holders to learn how the hypothesized divergences might inhibit diagnostic excellence PRMs
- Diagnostic excellence PRMs should be informing actions regarding diagnostic outcomes, process, and structure