

Issue Brief 12

**Patient Experience as a Source for
Understanding the Origins, Impact,
and Remediation of Diagnostic Errors
Volume 1: Why Patient Narratives Matter**



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Patient Experience as a Source for Understanding the Origins, Impact, and Remediation of Diagnostic Errors

Volume 1: Why Patient Narratives Matter

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Executive Summary

Patient perspectives offer unique information about how diagnosis-related events alter patients' trajectories through the healthcare system and their expectations for clinicians. This brief, the first of two on learning from patient experiences, explores:

- How patient-reported experiences can augment other methods of identifying diagnostic failures,
- How patient feedback about the diagnostic process and its outcomes can enrich clinicians' understanding of patient and family experience and reduce the harms that follow adverse diagnostic events, and
- What questions about learning from patients' diagnostic experience remain in need of future research.

Key insights about learning from patient experience to address diagnostic problems include:

1. To obtain representative accounts of patients' diagnostic experiences, it is important to ask questions about diagnostic issues using broad language, rather than trying to give patients and families more precise definitions of "medical errors" or "mistakes."
2. Although patient and family conceptions of adverse events do not always conform to clinical definitions of diagnostic errors, it is important to identify and understand the broader scope of patient-defined adverse experiences, in part because these shape subsequent trust and care-seeking behaviors.
3. To assess the full implications of diagnostic mishaps for patients and families, it is essential to elicit their experiences involving both the mishap itself and its aftermath.
4. Feedback from patient experiences can be useful for addressing diagnostic failures in two distinct ways: first, as verbatim narratives that identify concrete, actionable changes and second, based on quantifiable metrics that can be extracted from those narratives.
5. Learning from patient and family experiences can potentially improve diagnosis through both changes in clinician-patient interactions and system-level responses that address the harms that persist in the aftermath of a diagnostic mishap.

Introduction

Policymakers and clinician-leaders are increasingly looking to patient experience to improve health system performance.^{1,2} Quantifiable scores derived from closed-ended survey questions have been linked to financial incentives for clinicians in the United States and other countries.³ Narrative accounts have emerged as a valued source of actionable feedback for quality improvement in a variety of treatment settings.^{4,5,6}

Despite improvements in some metrics of patient safety over the past decade,⁷ learning from patient reports about safety threats has lagged behind.⁸ This lag reflects, in part, some legitimate concerns that patients and their families:

- Might be unaware of certain types of errors⁹;
- Might vary in their willingness to speak up about medical mishaps, inducing disparities in error reporting¹⁰; or
- Might erroneously presume errors occurred if treatment outcomes fell short of their expectations.¹¹

Therefore, systematic elicitation of patients' experiences related to safety events remains limited in scope and largely untested for reliability, despite some promising one-off innovations in recent years.^{12,13,14,15,16,17}

Investment in learning from patients' experiences about diagnostic errors is even more limited.¹⁸ As one paper about diagnostic problems characterized matters:

...while patients' and families' experiences are gradually being recognized as sources of valuable information that can help improve safety and quality, there are no current policy or practice initiatives to supplement patient safety data using patient reported experience and patient information and feedback.¹⁹

A 2020 review of measurement methods for diagnostic errors characterized "solicited reports from patients" as still in the exploratory stage methodologically, with limited availability of patient-reported information about diagnostic issues.²⁰ The National Quality Forum (NQF) identified no newly published measures based on patient experiences with diagnostic errors between 2017 and 2020, a time when several dozen new measures from other sources emerged in the literature.^{21,22}

Patients and families offer a unique source for understanding a variety of diagnostic problems, such as communication breakdowns between clinicians and patients, a common aspect of diagnostic errors.^{23,24} The patient/family perspective is equally crucial for:

- Identifying diagnostic breakdowns during transitions among clinical settings^{19,25};
- Assessing the impact of adverse events on the health and well-being of patients²⁶; and
- Understanding the impact of diagnostic problems on the subsequent attitudes and behaviors of patients and families.^{23,27}

Failing to assess patient and family perspectives undercounts diagnostic harms and makes it harder to constructively address a substantial portion of diagnostic shortfalls.²⁸

To learn most effectively from patient experiences with the diagnostic process requires sensitivity to how diagnostic mishaps feel to those who experience them and to how *they themselves* describe their experiences, cast in terms familiar to those recounting them. Learning from patient experience also calls for a lasting commitment to parlay insights into action that can mitigate future resulting harms, since remediation efforts in response to patient feedback will induce more subsequent reporting of problems by patients and families.

Throughout this brief, we refer to adverse diagnostic events as "diagnostic mishaps," "diagnostic errors," "diagnostic problems," "diagnostic concerns," and "diagnostic shortfalls." The variety of terms might seem like a source of imprecision, especially when contrasted with approaches identifying diagnostic errors from clinical records or incidence reports based on precise clinical terms. But patients and families do not describe adverse diagnostic events with such uniformity. The lexicon in this brief mirrors the variability embodied in narratives themselves, emphasizing that learning from reported experience requires addressing survey respondents on their own terms, using their own words.

In the sections that follow, we first synthesize what is known about patient/family reporting of safety events generally and diagnostic errors specifically. We next identify alternative strategies for measuring patient experience, strategies that can be categorized (in accordance with a recent NQF report) as "measure concepts." We conclude by identifying questions and research opportunities related to how best to implement these new approaches to learning from and responding to patient and family perspectives on the diagnostic process.

Past Research on Patient Perceptions of Safety and Diagnostic Mishaps

The small body of research on patient-reported experiences involving safety only sporadically touches on diagnostic concerns but nonetheless offers insights that can guide more concerted attention to diagnostic issues in the future.

Perceptions of Safety and Medical Errors from Patients' Perspectives

Four past findings have relevance for future research in diagnostic safety:

- **Patient Experiences Must Sometimes Be Reported by Others:** Accounts of patient experience related to safety are often (40%-60% of cases) reported by family and friends.¹ This finding holds whether accounts are collected through complaint/grievance systems,^{5,14,29} population-based surveys,^{22,30} or other means.^{19,31} Accounts from family and other caregivers are vital when patients are deceased or too debilitated or discouraged by their experiences to report. Moreover, caregiver accounts offer distinct perspectives on factors influencing safety.³²
- **Patient Perspectives on Safety Differ From Clinicians' Assessments:** Based on the broader literature on patient safety, clinicians typically focus on errors, that is, what they would perceive as preventable and harmful events. By contrast, the perceived mishaps patients and families report are more consistent with notions of adverse events, since they often cannot observe or reliably assess all aspects of the likelihood of preventability.^{9,11,33,34} For example, in a large-scale study of patient safety experiences during hospitalizations in the United Kingdom, about one-third of the “incidents” that triggered patients' concerns about safety were judged by clinical reviewers as preventable.¹⁶
- **Patient Accounts Augment Other Forms of Safety Reporting:** Reports from patients and families are vital complements to other methods of detecting adverse events.³⁵ A study of pediatric hospitalizations in the United States documented that family reports identified five times as many errors and three times as many other adverse events as incident reports clinicians filed.¹³ The study of adult hospitalizations in the United Kingdom cited above found that two-thirds of the errors identified from patient narratives were not captured by the hospital's other safety reporting systems.¹⁶
- **Patient Perspectives Reveal Actionable Information:** Narrative accounts from patients and families often have sufficient concreteness to identify actionable steps that might have prevented the adverse event or mitigated its harm.^{5,12} Although patient accounts do not always convey a complete picture of the sources of heightened safety risk, they can provide new clues into events that gave rise to the adverse event or mediated its impact.^{16,26,36}

¹We will henceforth use the term “family” as a shorthand for these other actors. Our own (unpublished) data suggest that 79% of survey respondents who are not reporting on their own experiences as patients are describing experiences they identified as a family member of the patient.

Perceived Promise of Reported Patient Experience for Addressing Diagnostic Shortfalls

Prior findings make clear the potential for learning about safety concerns from patients and families. That promise holds similar appeal for addressing diagnostic failures.³⁷ As one paper concluded, “Insights from patients can be valuable in gaining a comprehensive understanding of diagnostic errors and informing strategies for mitigation.”¹⁹

This potential is greatest when patients and families have a unique perspective or capacity to interpret events that induced the mishap or exacerbated its harms. The NQF’s recent report on diagnostic quality and safety provided examples of such circumstances:

Gathering information directly from a patient, family or caregiver may be the most optimal way to measure communication quality and avoid possible diagnostic errors in a fragmented system ... when only the patient is aware of miscommunication across clinicians and settings.²¹

Healthcare organizations and clinicians should engage patients who have undergone diagnostic odysseys to evaluate their experiences with the diagnostic process. Currently, there is a paucity of measures that exist to capture the extent or effect of diagnostic odysseys on patients.²¹

The domains of experience identified in the NQF report are aspirational, aspects of care for which patient experiences might be expected to provide crucial insights. But it offered no evidence that patients and families would actually report on these matters. Our own (as yet unpublished) research collecting diagnostic narratives suggests that carefully elicited patient experience will indeed generate insights in each of these areas. In Exhibit 1, we offer examples relevant to the first of NQF’s priorities: insights regarding communication and care coordination. (The examples are verbatim and have not been edited.)

Exhibit 1. Excerpts from elicited patient narratives related to diagnostic communication and coordination

Diagnostic Mishaps Related to Patient-Clinician Communication

[I wish the care team had] acknowledged my daughter-in-law's pain as well as her confusion and fear. The doctors should have listened better. They shouldn't have suggested that that kind of pain could be from stress. My daughter-in-law felt that they weren't understanding or believing of her when she was truly in pain. Her fears should have been acknowledged. She went home still feeling worried that she didn't really know what was wrong. She just felt unjustified and that the doctors were treating her like she was wasting their time.

My son has extremely low platelet counts. Nobody knows the root of the problem. If someone would have immediately taken a thorough look at his medical history and not treated him like a number it would have been helpful. Treat people like people, not numbers. Start by communicating more than medical jargon. There's zero compassion!

The focus of most of the specialists I saw was in their particular sub specialties. The cardiologist insisted that the symptoms I had following open heart surgery could not be related to my heart. They were, in fact, directly related to the hole in my new valve...No one spoke to me about the errors they made. I never saw the surgeon again after I left the hospital the first time. If someone had sat and talked with me, or even said they were sorry for the delay in diagnosis, I would have felt better about everything, but no one did. They did not acknowledge that I had really been sick due to their error in diagnosis and never had to go through any of it.

Diagnostic Mishaps Related to Coordination Among Clinicians

[The patient] complained about pain in her abdomen. Her tests all came back normal. Her doctor said it was just a part of aging. She kept complaining and was eventually referred to a specialist where she was diagnosed with cancer. [Following the diagnostic mistake or problem I wish the care team had] followed up with [the patient] about what the specialist had uncovered - shared info with her new doctor - they don't seem to share or trust each other's notes.

[Person] was having issues with depression and also with supposed epileptic episodes. She moved several times and each time her medications were changed, dosages increased and additional medications given. I think she was alone in a way off state and taken advantage of because she had Medicaid and believed every doctor she spoke to. By the time she moved back home she had seen probably 10 different doctors, all adding to the confusion. Each having a different diagnosis and she ended up being treated for every ailment under the sun. A person going from state to state may have much information the new doctor never becomes aware of. And nobody probably knows if any one person is to blame.

My wife was struggling with digestive issues... got allergy testing as well as scoping... still unclear what was wrong... but not heartburn or allergies as originally diagnosed. Too many doctors that are too busy and don't communicate with each other even though they are in the same group [might have led up to the issue]. It's all lack of communication. All the symptoms tie together but specialists only work on one area. Think holistically! How hard is it to pick up the phone for a quick phone conversation. There needs to be a "quarterback" who runs it all... but the primary care doc is pretty uninvested.

What Research Reveals About Patient/Family Reporting of Diagnostic Experiences

Past research shows that patients and their families can identify diagnostic shortfalls and at least some factors that might have caused the perceived mishap or mediated its consequences. A handful of population-based surveys of Americans’ experiences with medical errors document cases that respondents believed involved diagnostic problems.^{24,29,38} About half of reported medical errors identified by patients or their families were seen to have some connection to a perceived diagnostic shortcoming.

Several additional studies that collected narrative accounts clarified the nature of perceived diagnostic shortfalls (Exhibit 2).^{19,24} These clustered in three broad (somewhat overlapping) categories: delays in diagnosis, missed or misdiagnosis, and failures or flawed interpretation of tests.

Exhibit 2. Types and prevalence of patient/family-reported diagnostic errors

Type of Diagnostic Error	Frequency of Reported Concerns by Aspects of Diagnosis	
	Empowered Patient Coalition Survey ¹⁹ (n=184)	Medical Error Recontact Survey ²⁴ (n=94)
Delay in diagnosis or treatment	76.1%	56.4%
Misdiagnosis	65.2%	68.1%
Proper tests not ordered	48.4%	18.1%
Results misplaced or disregarded	17.9%	18.0%
Lab or pathology lab mistake	7.1%	11.7%

Key: n = sample size.

Note: For each source, the percentages in the columns total more than 100 percent because narratives often identify multiple forms of diagnostic error. The Medical Error Recontact Survey percentages were calculated by the authors from unpublished data.

Although a promising first step, these findings fall short of what ought to be expected when carefully and thoroughly assessing patient experience, in three ways.

First, existing research shows that patients and families will report diagnostic experiences when asked if an “error” has occurred. However, as noted earlier, patients’ understanding and description of diagnostic shortfalls often differ from the definitions of errors in medical research.²⁸ Therefore, problems may go unreported because they do not accord with clinician-derived notions of what constitutes a medical error, thereby missing important opportunities for promoting diagnostic excellence. For example, patients may experience problems that undermine their confidence in the diagnostic process, communications about diagnoses, or meaningful understanding of the diagnosis, without perceiving any of these as representing “errors.”³⁹

Second, the literature on patient reporting of diagnostic problems focuses on factors that lead to mishaps, not what patients experience in their aftermath. A substantial body of literature addresses patient interactions with clinicians after adverse events,^{21,27,31,40,41,42} including studies examining how best to ask patients and families about interactions after an adverse event.⁴³ But these studies are largely limited to treatment-related errors. Because diagnostic problems more frequently involve multiple clinicians across multiple settings, the after-effects may be more difficult to constructively manage than for treatment errors.

Third, it becomes more challenging for patients and families to attribute responsibility among multiple clinicians,^{11,44} making it more difficult for them to respond in ways they think will reduce their risk of future diagnostic errors. Multiple clinicians also make it more challenging for clinicians to discuss diagnostic mishaps openly. Such conversations would call for them to assess and discuss with patients the actions of other clinicians, which they may be reluctant to do.⁴⁵ For all these reasons, patients or families may fail to report some diagnostic problems because they see less potential in mitigating the induced harms.^{46,47}

Although past research collecting patient narratives shows that patients and families can describe in some detail aspects of their diagnostic experience,^{19,43} to date no research has assessed how reliably different aspects of these experiences are reported. Awareness of a problem does not always result in a willingness or readiness to fully describe all aspects of the event, even for patient experiences that involve quite egregious harms.^{46,47}

The harder it is for patients to attribute responsibility for a problem, the less likely they are to report that the event occurred at all.^{39,47} That may lead to systematic underreporting of more complex diagnostic failures. It also may bias who reports on diagnostic problems, if less educated or less experienced patients find it harder to make sense of their diagnostic experiences.

Other biases may also emerge from differences in propensity to report diagnostic concerns, including previously documented forms of underreporting, such as among patients and families who have less trust that clinicians will respond to their concerns.^{39,46} Since experiencing adverse diagnostic events in the past erodes trust in ways that persist over time,^{24,48} those who have experienced repeated adverse events may be particularly reticent to report those experiences.

Thus, it is not sufficient to document that some patients (or their families) are willing to report on some aspects of their diagnostic experiences. If underreporting of certain aspects of care or the experiences of particular subsets of patients consistently occurs, partial or uneven feedback could actually worsen existing disparities in diagnostic quality.^{49,50,51,52,53}

For example, clinicians and quality improvement teams may learn from patient feedback primarily about diagnostic shortfalls that emerge from interactions with a regular source of primary care, since patients and family can usually identify the clinician in this context. In this situation, diagnostic experiences of economically disadvantaged patients will be less frequently accounted for, because they are less likely to have a regular source of primary care.

To mitigate the risk of uneven or biased reporting, it is essential to carefully identify which diagnostic mishaps induce the most reliable and complete patient accounts and to identify subgroups of patients who convey their accounts more or less reliably. Based on the source of uneven reporting, methods of eliciting diagnostic experiences can be adapted to ensure greater consistency in how and how much can be learned from patient experience.

Directions for Future Research

Past research on eliciting patient experience shows the capacity of patients and families to convey accounts about many aspects of their healthcare encounters.⁶ But achieving more consistent reporting of these accounts requires attention to rigor in the design, testing, and implementation of data collection about diagnostic experiences.

For each of these aspects of rigor, additional research could clarify the limits of existing elicitation techniques for diagnostic experiences, while also identifying ways to enhance fidelity in the future. We explore these opportunities further in the second volume of this issue brief, identifying some of the most pressing needs for additional research.

Additional studies could also help map out an agenda for implementing multiple channels of feedback about patients' diagnostic experiences, embedding those channels within learning health systems used to drawing on diverse patient experiences. We identify below several promising opportunities for future research in each of these domains.

Inviting Participation: Two key issues related to participation merit additional study. First, it is essential to move away from previous practices of asking respondents if they experienced medical or diagnostic “error.” One can frame alternative invitations in many ways, and it remains unclear which approaches encourage the broadest participation and most representative set of reported experiences.

Second, it is also clearly essential to gather accounts from family members (or other close acquaintances) to learn about the care of patients unwilling or unable to recount their own experiences. But not all secondary observers are equally prepared to convey a balanced and complete account of the diagnostic process. It may be useful to clarify criteria for when family respondents are more or less likely to provide thorough accounts. Criteria may include the closeness of caregivers' relationships with patients or the extent to which they participated in clinical encounters during diagnosis. Research on these criteria could enrich future elicitation efforts.

Drawing on Narrative Accounts To Address Diagnostic Inequities: Past research has documented multiple ethnic and racial disparities in diagnostic performance.⁴⁹ These quantitative studies reveal the magnitude of diagnostic differences but can rarely identify causes. The availability of actionable detail in narrative accounts, by contrast, can illuminate sources of disparities. More compellingly, such details can also facilitate a transformative shift in discourse: from a focus on disparities that is inherently about counting and comparison to one that offers an enriched exploration of diagnostic *inequities*.

Future research could leverage accounts of patients' experience toward this end in two ways. The first would use narratives to identify healthcare experiences respondents perceive to be unfair or unjust. The challenge here is to identify how best to encourage patients and family members to report situations in which they have felt unfairly treated, without predetermining specific sorts of “unfairness.” Open-ended narrative inquiries, if carefully worded, have virtues in exploring these matters, because they can allow respondents to define what constitutes evidence of unfairness from their own perspective.

A second approach would look beyond respondents' own views about fairness, by looking for patterns in the types of diagnostic shortfalls described by different subgroups of patients and families and mapping these into existing conceptual frameworks of healthcare inequities. Both approaches can enrich our understanding of the origins of diagnostic inequities and the points of leverage through which diagnostic experiences can be made more just.

Enhancing the Legitimacy and Future Use of Elicited Patient Feedback: Two key questions need to be explored to more effectively use information in elicited patient accounts to change diagnostic practices. The first question involves identifying the agencies (government or nonprofit) Americans would most trust to field population-based surveys of diagnostic experiences. Thorough narrative responses are predicated on a modicum of trust. But we need research to better understand how responses vary across states, practice settings, and sociodemographics of respondents.

Additional research is also needed about effective feedback techniques when diagnostic episodes extend across multiple settings, as is frequently the case.ⁱⁱ Feedback methods that have been tested to date have been applied to single clinical settings. When multiple settings and multiple clinicians are involved, appropriately assigning responsibility and analyzing improvement possibilities are crucial first steps in assessing appropriate remedial action. To be sure, when settings are not all under the auspices of a single health system, the process of doing so may become quite complicated and may even prove counterproductive. Identifying the most appropriate and effective techniques calls for careful study.

Thus, a variety of promising opportunities are available for future research. Some are more immediately feasible, while others might benefit from findings generated by other studies on the list. To provide a simplified roadmap, we have summarized these options in Exhibit 3.

Exhibit 3. Research priorities related to patient experiences with diagnosis

Questions Meriting Future Research

1. Whose Accounts Should be Elicited?
 - Describing diagnostic shortfalls so respondents know what to report
 - Determining when family/friends know enough to be surrogate respondents regarding diagnosis
2. How Might Information Derived From Narrative Accounts Enhance Diagnostic Equity?
 - Explaining the origins of disparities identified through quantitative metrics
 - Documenting how equity and disparity frames can diverge when applied to diagnoses
 - Identifying actionable points of leverage for enhancing diagnostic equity
3. How Can Elicited Patient Experiences Be Most Effectively Fed Back To Promote Change?
 - Matching feedback mechanisms to diagnostic settings
 - Illuminating practices that allow some learning health systems to become more patient centric; adapting to promote consistent attention to patients' diagnostic experiences
 - Identifying trusted sponsors for population-based surveys of diagnostic experiences
 - Refining feedback methods to address diagnostic shortfalls that cross clinical settings

ⁱⁱOur own unpublished data suggest that about half of the perceived diagnostic shortfalls reported on population-based surveys involve multiple settings, and 30 percent involve three or more settings.

Conclusions

Despite the importance of learning from patients and families about diagnostic mishaps—their origins, impact, and longer term consequences—to date investment supporting this sort of feedback has been limited. As new initiatives emerge to promote diagnostic safety, it is essential to expand investment and to enhance capacity to rigorously elicit patients’ diagnostic experiences.

The number of extant questions requiring future research might initially seem daunting. But it is important to recognize that many of these questions can remain unanswered while efforts continue to improve diagnostic experiences. Even if it remains unclear how best to feed back patient experience when diagnostic mishaps cross multiple clinical settings, half of the diagnostic problems patients report occur in a single setting. Thus, substantial gains could be achieved by starting with that simpler context.

These challenges are perhaps most pronounced when assessing the persistent impact of perceived diagnostic problems on the subsequent actions and attitudes of patients and their families. Whether or not clinicians or healthcare experts would define diagnostic issues as “errors,” the events patients and families perceived as adverse will nonetheless do damage, undermining the public’s faith in healthcare and medical professionals.

Because we so infrequently elicit information about perceived diagnostic mishaps from the public, the magnitude of these detrimental effects is obscured. But that hidden impact does not diminish its corrosive effect on patient-clinician relationships, confidence in healthcare facilities, and trust in healthcare generally.^{54,55} We need to better understand these broad effects in order to respond to them in a more systematic and effective manner.

To pursue this goal, we must aspire to more effectively learn from patient experiences. One crucial prerequisite for this effort is creating the capacity to track patient experience in the aftermath of diagnostic problems across multiple subsequent treatment settings. This step is essential toward building a collective understanding of the long-persisting impact of diagnostic breakdowns. That, in turn, seems an essential first step in mustering the collective wherewithal to more effectively assist patients and families in the aftermath of these diagnostic mishaps.

We have the methods to learn more about the impact of diagnostic errors on patients and families. We must now commit to the actions that can deploy these methods to best promote learning and, in the longer run, improve diagnostic safety.

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