Issue Brief 23

The Patient's Role in Diagnostic Safety and Excellence: From Passive Reception Toward Co-Design

Agency for Healthcare Research and Quality

PATIENT SAFETY

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Introduction

Patients are the ultimate arbiters of diagnostic excellence. They are the only ones present and focused on getting results through the full diagnostic process beginning when they initiate it. Only they know for certain if the medical process, systems, teamwork, and professional expertise have resulted in an accurate, timely, and effectively communicated diagnosis. And they are the ones who must live with the results of diagnostic errors.

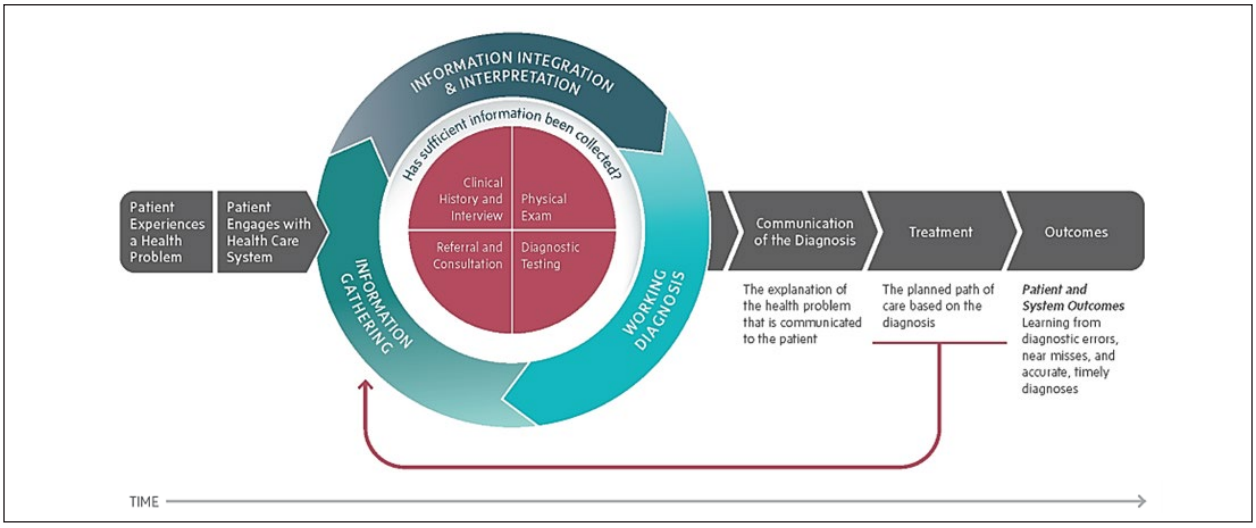
Patients and caregivers who have experienced a diagnostic error can provide a unique perspective. Because they interact with different healthcare providers from different medical specialties in different healthcare settings across the entire healthcare continuum, they can have both a broader and a more specific point of view on what is needed to reduce diagnostic errors.[1,2] Yet their input, preferences, goals, and concerns are too often the last to be considered.[3,4]

The issues surrounding diagnostic error, quality, safety, and excellence came into national prominence in 2015. That year, the Institute of Medicine (IOM) issued the seminal report Improving Diagnosis in Healthcare[5] (the Institute of Medicine is now the National Academy of Medicine, part of the National Academies of Science, Engineering, and Medicine [NASEM]). The IOM report noted the size of the problem and the level of patients' desire to be properly diagnosed and established that most patients will experience at least one diagnostic error in their lifetime.[5]

Patients are concerned about the quality of their diagnoses[6] and many have experienced diagnostic error personally. Almost one-quarter of Americans have been affected by a diagnostic error experienced personally or by close friends and family.[7] Approximately 800,000 patients experience significant harm from diagnostic errors every year in the United States.[8]

The diagnostic process (Figure 1) has been a helpful framework for healthcare systems and patients[4] in identifying gaps in the process that indicate potential diagnostic missteps. It is incomplete because it excludes patients' work product of evaluating their own health problems and analyzing the when, where, and how to engage with the healthcare system.

Figure 1. Diagnostic process.



Source: Committee on Diagnostic Error in Health Care; Board on Health Care Services; Institute of Medicine; National Academies of Sciences, Engineering, and Medicine; Balogh EP J, Miller BT, Ball JR, eds. Improving Diagnosis in Health Care. Washington, DC: National Academies Press; December 2015; Figure S-1, "The diagnostic process." https://www.ncbi.nlm.nih.gov/books/NBK338596/. Used with permission of the National Academies Press.

The committee report concluded with eight recommended goals to improve diagnosis and reduce diagnostic error. Only two of those goals explicitly mention patients and their family members (Figure 2, highlighted) as part of the team. But it is reasonable to assert that each goal would be enriched through meaningful engagement of patients and family members as valued members of the diagnostic team.

Figure 2. Goals for Improving Diagnosis and Reducing Diagnostic Error

- Facilitate more effective teamwork in the diagnostic process among health care professionals, patients, and their families
- Enhance health care professional education and training in the diagnostic process
- Ensure that health information technologies support patients and health care professionals in the diagnostic process
- Develop and deploy approaches to identify, learn from, and reduce diagnostic errors and near misses in clinical practice
- Establish a work system and culture that supports the diagnostic process and improvements in diagnostic performance
- Develop a reporting environment and medical liability system that facilitates improved diagnosis by learning from diagnostic errors and near misses
- Design a payment and care delivery environment that supports the diagnostic process
- Provide dedicated funding for research on the diagnostic process and diagnostic errors

Source: Committee on Diagnostic Error in Health Care; Board on Health Care Services; Institute of Medicine; National Academies of Sciences, Engineering, and Medicine; Balogh EP J, Miller BT, Ball JR, eds. Improving Diagnosis in Health Care. Washington, DC: National Academies Press; December 2015; Chapter 9, page 358. https://www.ncbi.nlm.nih.gov/books/NBK338596/. Used with permission of the National Academies Press.

Limited attention to the patient's role in diagnostic safety is perpetuated in how we identify diagnostic errors. Identification and characterization of diagnostic errors have predominantly used a variety of sources, including:

- Retrospective reviews of medical records (including clinical outcomes such as diagnostic delay and returns to the emergency department),
- Claims data,
- Autopsy studies,
- Hospital staff voluntary reporting systems,
- Patient satisfaction surveys, and
- Emerging techniques. to identify and mitigate diagnostic errors using triggers in the medical record.

To date, few approaches to diagnostic error measurement or research have made the patient's experiences, knowledge, and input a priority, weighing their expertise as equal to that of the doctor or the health system.

Diagnosis is a complex and multifaceted process that relies on clarity of communication from the patient and family and an actively listening clinical team to get it right. As noted in a recent AHRQ report, studies show that diagnostic errors result from a confluence of factors, including:

- Communication challenges,
- Inadequate history taking and physical examinations, and
- Issues of clinical cognition and implicit biases.

All these factors occur within a fragmented and difficult to navigate healthcare system.[9]

Importantly, many of these contributing factors stem from the same problem, not fully listening to the patient's (or family members') input, goals, and concerns. Sir William Osler, 19th-century physician and a cofounder of Johns Hopkins Hospital, said it first: "Listen to your patient; he is telling you the diagnosis."[10]

Sadly, health system pressures have truncated the time available for a primary care visit. This lack of time has reduced the opportunity for a thorough examination and complete patient history. In addition, it has led to amplified reliance on expensive diagnostic tests and deprioritized engagement with the patient and family, including communication of the working diagnosis, diagnostic uncertainty, and opportunities for shared decision making.[11] The production pressures faced by clinicians and patients have slowed the progress of patient involvement in their own healthcare decisions greatly. It is difficult to partner with your medical team if they neither listen nor consult with you.

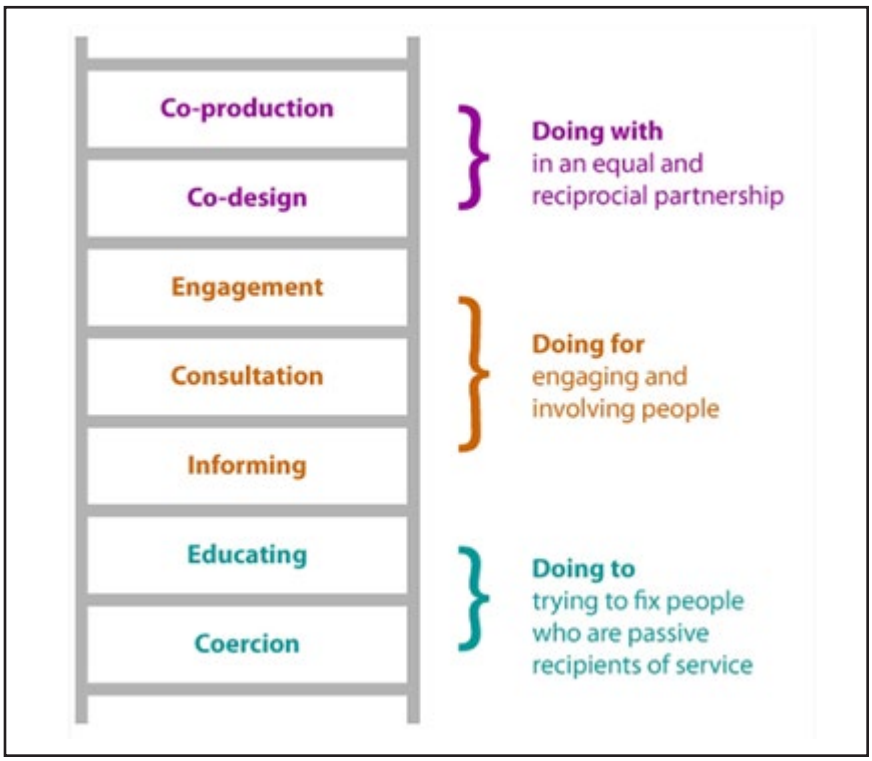
In our experience, patients of all levels of experience and education are eager to partner with their medical teams. Perhaps counterintuitively, those who have experienced diagnostic limbo, had long or difficult diagnostic journeys, and even those who may have felt as if some providers were dismissive of their symptoms or concerns, are often activated to get involved at a deeper level. This feeling is seen especially in patients with conditions that are difficult to diagnose or rare.

The History of Patient Roles

The synergy and trust created when the patient and clinician have a good working relationship is key to any successful diagnostic process. Over the past century, patients have seen the evolution of their potential role grow from passive recipient to co-producer. Co-production of health is defined as "the interdependent work of users [patients] and professionals [clinicians] who are creating, designing, producing, delivering, assessing, and evaluating the relationships and actions that contribute to the health of individuals and populations."[12]

The National Co-Production Advisory Group based out of the United Kingdom, drawing inspiration from the original ladder of citizen participation[13] and from the teachings of Cormac Russell's Four Modes of Change,[14] created the Ladder of Co-Production (Figure 3). This ladder shows a series of steps toward full co-production in health and social care.[15] It supports great understanding of the various steps such as access, inclusion, and consultation.

Figure 3. Ladder of co-production



Source: Developed by Think Local Act Personal and the United Kingdom National Co-production Advisory Group. https://www.thinklocalactpersonal.org.uk/.

In the authors' mutual observations, we have learned that experienced patients agree that the heart of diagnostic excellence requires co-production of a diagnosis with the co-design of a treatment plan in partnership with a clinician with whom they share power. Yet this goal is seldom achieved, due in part to the historical relationships, power gradients, biases, and inequities between the patient and the members of the team caring for them.

Transforming the diagnostic experience to one of co-production, where power is shared among team members, leads to a transition in the diagnostic journey from doing things to or for a patient toward doing things with and ultimately by a patient, enabling diagnostic excellence. When we think of diagnosis as a journey that starts when the patient experiences a health problem, it is easy to recognize the critical and complex nature of a patient's work toward achieving an accurate, timely, and communicated diagnosis.

Historically, patients have been the passive recipients of care experiences, akin to the "To" and "For" modes of change.[16] In transforming care toward achieving diagnostic excellence, the ultimate aim is coproduction of the diagnosis with the patient and their family and design of the treatment plan by the patient in accordance with their goals, values, and preferences. Similar to rethinking the role of community members in healthcare transformation promoted by Russell,[16] this change is a radical paradigm shift toward diagnostic excellence. It moves away from well-meaning "expert" clinicians assigning a diagnosis or determining a treatment plan toward one of patient self-empowerment, where patients drive their own healthcare.

The modes of change model highlights lessons learned from the past and strategies for the future to enable the paradigm shift, while emphasizing the new role of patients in diagnostic safety.

TO the Patients

Since the beginning of medicine, healthcare has been applied to the patient. Healers, physicians, and surgeons used their skills to fix what was deemed wrong with the patient's body or mind. Their "health" was a product of the expert's knowledge and the patient had no access to that knowledge.

This mode of top-down power is still experienced by certain vulnerable patients in disparate, low-resourced communities and may be still preferred by a subset of patients frightened by or uncomfortable with unfamiliar complex concepts. This dynamic can foster a sense of disempowerment and mistrust, particularly among patients who have experienced diagnostic or medical errors. For them, medicine can feel like something that is done to them rather than a collaborative process in which they are active participants.

Due to this top-down dynamic, although these patients are highly compliant,[17] following medical advice and treatment plans strictly, they may still view medical interventions as unwelcome due to past negative experiences or a lack of understanding and involvement in their own care.[18,19,20] This compliance might stem from a fear of negative consequences if they do not follow instructions, rather than from trust or belief in the treatment's benefits.

FOR the Patients

The past half century of medical advances has seen a gradual evolution from healthcare that was applied to the patient to healthcare approaches that attempted to educate patients and caregivers and provide them a greater measure of control over their care and bodies. The proliferation of options in both treatment and diagnostic testing has meant that more decisions could be seen as depending on the values and wishes of the patient, a state of affairs reinforced by court decisions on informed consent reaching back to the 1950s.[21]

While this brief primarily focuses on the diagnostic process, the effort to create a federal law allowing patients to control their end-of-life treatment decisions—even if they were noncommunicative due to coma, for example—formalized the FOR the patient mode of care.

The Patient Self Determination Act of 1990[22] is a federal law that was initially written to support patients' right to create advance healthcare directives and have healthcare institutions follow their decisions. Today, every hospital asks a patient or family member if they have an advance healthcare directive before surgery or inpatient treatment. The decision to include a Do Not Resuscitate order is one element of an advance healthcare directive.

However, the act was written in such a way that it mandated a sea change in how healthcare institutions were to respect patient wishes and how patients engaged with healthcare. Three elements of the Patient Self Determination Act of 1990 required hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations to:

- Inform patients of their rights under state law to make decisions concerning their medical care;
- Ensure that legally valid advance directives and documented medical care wishes are implemented to the extent permitted by state law; and
- Provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and advance directives.

Ideally in this model, the evolved medical professional's role is to inform the patient and discuss the patient's medical circumstances:

- Starting with taking the patient's history,
- Reviewing symptoms,
- Examining the patient,
- Discussing the tests the professional is ordering,
- Communicating the results, and
- Discussing and consulting with the patient about next steps until a diagnosis is identified and treatment agreed on.

This model considers patient engagement and communication as primarily one way. One example is the proliferation of educational pamphlets and standardized instructions in discharge papers handed to patients after diagnosis containing essential but basic information. Pamphlets such as Do You Need Lung Cancer Screening? or Get Off the Blood Glucose Roller Coaster are informative but generalized unidirectional communications. Most major healthcare systems and medical research groups still use this model today, providing optional patient information they assume exemplifies patient engagement and patient-centered care.

WITH the Patients

The next stage of the patient's role in healthcare exists when the medical professional, their institution, and the patient/caregiver work together in an equal and reciprocal relationship. It is what is meant by the phrase "patient-centered care."[23] True patient-centered care affects every part of healthcare by being respectful of and responsive to the patient's preferences, needs, and values and ensuring that the patient's "values guide all clinical decisions."[23] Patient engagement, communication, shared decision making, medical and clinical research, goal setting, and true patient-centered medicine are all bidirectional and shared. Diagnosis is a team sport and without everyone working together in partnership, it will not succeed.

Nearly 30 years ago, the Institute of Medicine Committee on the Future of Primary Care called for a "sustained partnership" between clinicians and patients "predicated on the development of mutual trust, respect, and responsibility."[24] Yet we still have far to go.

"Nothing about us without us" is a slogan used by South African disability rights groups in the 1990s.[25] It expresses the concept that no decisions should be made about healthcare, in the public policy world, or for an individual patient without the patient or their representative in the room and part of the conversation. It has since spread to many other patient advocacy organizations.

Despite the evolution of healthcare toward a co-produced model, patients often have to identify ways to fill the gaps between the diagnostic information they want and the diagnostic information they get. Applying just one metric—that insufficient time is available to effectively care for all of a patient's needs in the current healthcare setting[26,27]—means patients feel they have to ensure complete communications with their healthcare provider.

Somewhere between being interrupted by their clinician after 11 seconds[28] and the 30-plus-minute appointment slot for concierge doctors[29] and other physicians who do not take health insurance lies a happy medium. It gives every patient the time needed to share all characteristics of their symptoms and for clinicians to fully consider the diagnostic differential.

Another aspect of 21st century medicine is the rapid proliferation of disease identification. Almost 23,000 distinct disorders have been identified,[30] including rare diseases, new named diseases, and medical conditions no one knew existed 20 years ago. The list is growing. It is hard to diagnose a disease that has no name or known etiology.

What is particularly relevant today is that information about novel and rare diseases is publicly accessible, allowing patients to become more informed about their health. Patients are becoming more engaged and empowered, using digital tools to navigate the complexities of modern healthcare. More than three-quarters use Google search,[31] and social media groups,[32,33] and about 15 million leverage free symptom checkers online monthly.[34] All are important parts of the diagnostic process patients use in determining whether, when, and how to seek care.

Real patient-centered care and patient representation in research has been the goal of many patient advocates and advocacy groups. This goal is especially important to those who represent medical conditions that are frequently misdiagnosed because their symptoms are unrecognizable to their physicians or are rarely considered by physicians, including:

- Patients with rare or yet unnamed diseases,
- Women with heart disease or endometriosis,
- Family members of patients who have died from sepsis,
- Survivors of kidney cancer, and
- People with long COVID.

This lack of knowledge places patients in the untenable position of having to advocate for care, band together to fund research, or suffer alone.

The role of co-production and co-Design in medicine WITH the Patients

The established reasons for the patient's expanding role in care decisions are closely tied to reasons many patients want to play a larger role in related medical research. To reflect the importance of this paradigm shift, the Affordable Care Act of 2010 established the Patient-Centered Outcomes Research Institute (PCORI). PCORI is a research agency focused on advancing research that patients and people with lived and living experiences of care prioritized as unmet needs.

Just as the patient's voice is essential in their own medical decisions, it is essential in planning and designing research projects. Different levels of co-design are possible, including:

- Co-producing care (e.g., making sure we all agree on a birth plan or postsurgical care plan),
- Co-designing research (e.g., having expert patient voices on the study design expert panel of a diagnostic error study for pediatric emergency departments), and
- Co-designing interventions (e.g., co-creating a home blood pressure monitoring program the healthcare system will roll out).

Closing the gap between research production and implementation is a key challenge for healthcare delivery researchers. Engagement of individuals representing broad sectors of healthcare delivery, including the patient, is increasingly promoted as an important pathway to achieving impact and as a move toward sustainable and equitable healthcare systems.

Despite this discourse, researchers often assign patients a passive role (e.g., patient is a data point) rather than fully engaging with patients as experts with unique experiences and knowledge as a result of living with illness and navigating the healthcare system. Stakeholder engagement is critical to participatory methodologies and in our experience, essential to designing solutions that are practical and tactical for improving patient care.[35,36]

Co-design involves learning from and with end users but also testing and creating with them.[37] The meaningful involvement of end users in research ensures clinical utility, increased adoption, and reduction of research waste (research that fails to create meaningful benefit for patients).[38] In particular, the co-design approach focuses on research pertaining to patient, clinician, and other end-user engagement in healthcare delivery research during the research planning or design and development phase. During this phase, research agendas are set, research questions are designed, study materials are developed and finalized, and solutions are conceptualized. A human-centered approach to design ensures that solutions developed and tested are meaningful to the end user and uniquely patient centered.[39]

Co-design workshops are designed to match expert clinicians (who have deep knowledge of disease pathology, diagnosis, and treatment) with expert patients (who understand what it is like to live with a disease) to co-produce solutions for healthcare settings. The co-design approach actively involves all knowledge users (people who have or will have to use the intervention or solution) in the design process to help ensure that the results meet their needs and are usable. Goals include:

- Engaging people,
- Capturing their experiences and ideas,
- Organizing the learning that they bring,
- Creating new understanding and insight from the perspective of the care journey, and
- Continuing together in partnership to review learning and ideas, plan and implement improvements, and review outcomes of the changes.[40]

Human-centered co-design workshops have also been applied to develop solutions for mitigating diagnostic disparities.[41]

The future of medicine WITH the patients

Moving innovations in care from research to practice remains a challenge, but hope is around the corner. A key example is the evolution of Patient Reported Outcome Measures (PROMs).[42] Initially, PROMs were developed by researchers and clinicians without patient input, focusing mainly on research.[43] The patient's voice was not always central to the development process, which sometimes led to measures that did not fully capture the patient experience or priorities. However, there has been a shift toward co-designing PROMs with patients, making them integral to coproducing health and care plans.

This approach recognizes that the patients are the best judges of the success of their care. The new approach has involved actively involving patients in the co-design process, ensuring that the measures reflect what is truly important to them. This shift recognizes the value of patient input in creating tools that are not only clinically useful but also resonate with patients' lived experiences.

While historically PROMS were not co-designed with patients for research, their translation into routine care is one key part of a revolution toward co-production that is happening in healthcare, patient engagement, education, empowerment, and leadership. PROMs are increasingly valuable in enhancing diagnostic safety

by providing detailed insights into each patient's unique diagnostic journey. As PROMs contribute to a more comprehensive patient narrative, new applications are emerging that leverage these data to improve diagnostic accuracy and patient outcomes.[44,45]

BY the Patients: The Future of Diagnostic Safety

The last element of Cormac Russell's Four Modes of Change[46] is BY. The future of innovative and patient-centered healthcare delivery and healthcare research involves patient-initiated, patient-run, and patient-controlled healthcare innovations, interventions, and research.

Patients' possible range of responsibilities has proliferated "from having a seat in the back of the room, to sitting at the table, being heard, and now shaping the patient safety landscape."[47] While their involvement is still growing, researchers are bringing patients in to design and lead research projects while some patient-led organizations are initiating, designing, and funding research on their own, hiring researchers to focus on their agendas.

There are practical and moral reasons to give patients a voice in setting the research agenda. Patient involvement can greatly influence research priorities, from a focus on technical developments to one that is more relevant to existing patient needs.[1] Examples of the patient's role in innovations are plentiful. More than 10 years ago, one paper noted that patients are being "encouraged to take a more proactive role in their own care and safety," recognizing the existence of opportunity to develop patient-oriented strategies to reduce diagnostic errors.[48]

The patient-created, patient-led organization LymeDisease.org began with patient education about the disease. They also participated in research to expand the Centers for Disease Control and Prevention criteria for proper diagnosis and raised funds to conduct research into diagnostic testing, explore treatment options, and produce support for patients. The LymeDisease.org patient research project MyLymeData is the biggest study of Lyme disease diagnosis and treatment conducted to date, with more than 16,000 patients enrolled.[49] It has been a model for many on how to educate and engage patients in collaboration with researchers.

Another organization created and run by patients has broken significant research barriers. The Patient-Led Research Collaborative[50] is a group of patients with long COVID who designed, funded, and conducted the first research on long COVID in April 2020. They have published papers on long COVID and created a $5 million patient-guided fund for biomedical research.

When cofounder Lisa McCorkell presented to the NASEM's June 30, 2023, panel on patient-driven research initiatives,[51] she succinctly summed up what is at stake: "It's not enough just to have a patient in a room. Their voice needs to matter in that room, their expertise needs to be valued, their insights need to be incorporated."

Organizations such as the Pulse Center for Patient Safety Education and Advocacy[52] and their TakeCHARGE Campaign[53] represents an initiative that encourages patients to become informed and active participants on their own healthcare team. Its unique approach directly engages patients and their families to take charge of their healthcare decisions with the 5 Steps to Safer Health Care. These are things patients can do on their own that can positively affect their care (e.g., keep a record handy of their medical history and current medications and prepare for doctor visits in advance and make a list of questions). Campaigns such as TakeCHARGE convey the value of patients taking charge of their own care, which directly affects diagnostic safety.

Impact of Disparities and Lack of Equity on Patient Engagement

Diagnostic excellence is challenging—if not impossible—to achieve without true equity. This level of work BY Patients can leave some patients behind. The way current healthcare systems are built and current practices of patient engagement are designed makes it difficult for patients who have been historically marginalized and underserved to feel welcome and to be truly involved if they want to do so.

Despite ongoing efforts, gaps in healthcare continue to widen, particularly affecting vulnerable populations. The gap is ever widening. The patient's level of medical literacy, general education, current health status, and resources already create barriers to simple access to medical care and therefore thicken layers of exclusion for many of these patients.

These inequities will need to be addressed to further level the playing field and enable patients of all backgrounds to lead research and care in the future. The Centers for Medicare & Medicaid Services has increasingly prioritized the measurement of social determinants of health, recognizing their critical role in health outcomes.[54,55] Concurrently, healthcare systems are intensifying their focus on equity, with a growing body of work dedicated to addressing the needs of priority populations. Federal agencies, including AHRQ, have initiated comprehensive strategies aimed at reducing healthcare disparities and advancing health equity.[56]

The barriers to getting involved with co-design and co-production come from all directions. While some healthcare systems and research organizations are inviting trained patient advocates with established backgrounds to sit on planning and advisory panels, the majority do not. People with full-time jobs may not be allowed or able to afford time off work. Caregivers or parents may not be able to leave their family members.

Patients who are significantly ill may simply lack the mental and physical energy to engage, especially those in survival mode. Circumstances may affect a patient's ability to evaluate complex decisions and their consequences. Such circumstances include limited English proficiency, lack of housing or adequate employment, addiction or significant mental illness, and dementia or memory loss.

People who live in communities with limited access to medical resources are hamstrung by a lack of choice in their care. For example, many living in rural communities have lost all access to local care. Many hospitals have been shuttered or sites with care that is less financially rewarding have been closed, including pediatrics and labor and maternity. Many willing and able patients report the unwillingness or inability of medical professionals to equally engage, especially in resource-limited environments.

A recent series of workshops identified 21 various typologies of potential diagnostic disparities solutions.[57] A few simple steps that have been studied to help reduce disparities include:

- Concordance of race and culture among patients and doctors, which improves the communication of symptoms and the resulting quality and timeliness of an accurate diagnosis.[58,59,60]
- One-on-one in-person explanations of next steps in the diagnostic process, including checking for comprehension; clarifying tests, their goals, how to prepare, when to expect results, and what those results mean; and providing aid in scheduling and followup of specialists, including helping to arrange transportation.[61,62]
- Presence of a family member or friend at all appointments to help with memory, comprehension, adherence, and other issues.[63,64]

Next Steps

Achieving diagnostic excellence is more than a noble act; it is a mandate of our healthcare system. The NASEM report Improving Diagnosis in Health Care concluded that "improving the diagnostic process is not only possible, but also represents a moral, professional, and public health imperative."[65] It is not a "one and done" but a continual pursuit to deliver care in a way that is truly patient centered if not patient partnered.

Poor communication between medical professionals and patients is a key factor in all diagnostic error, up to 78 percent in primary care settings. Thus, enhancing communication between patients and their healthcare team is central to improving diagnostic quality in this new era of healthcare delivery.[66]

Improving patient-clinician communication is an intervention ripe with possibilities to reduce diagnostic errors.[47] New communication strategies focus on healthcare providers and patients and families. Medical specialty groups[67] and general practitioner groups68 are testing and launching their own programs while patient-led organizations are teaching their membership how to speak up and ask questions.

An environmental scan of Patient and Family Engagement Resource Research Questions identified more than 300 versions of "questions to ask your doctor" tools, organized by medical condition and specialty, including patient toolkits.[69] AHRQ's Toolkit for Engaging Patients in Diagnostic Safety[70] provides "deceptively simple" strategies to help patients and clinicians bridge the diagnostic communication divide to co-produce an accurate and timely explanation of their health problem.

The ideal form of communication is bidirectional, collaborative, relational, and closed looped.[71] The bidirectional form is a respectful back and forth between sender and receiver and a continual exchange of information to determine the diagnosis and build trust. The closed loop is coming full circle on the agreement of that diagnosis. A person has not communicated until they've checked for comprehension. If all else fails, just listen to the patient; they are telling you the diagnosis.[10]

Work remains in the efforts for patients to become partners and coleaders of research.[72] As we navigate this transition, it becomes evident that while we may "talk the talk" of equality in partnership and decision making, the infrastructure to support deep collaborations that allows us to "walk the talk" is lacking. A lack of commitment and supportive infrastructure creates a gap between aspiration and reality. This gap sets researchers and involved patients or community members up for failure.

The active involvement of patients represents a paradigm shift essential to achieving the goal of diagnostic excellence. Moving up the ladder of co-production—from being passive recipients of care to becoming active partners and leaders of their own care—has profound implications for enhancing diagnostic accuracy and safety.

The journey toward co-production in diagnostic safety involves creating and sustaining structures that support patient leadership and partnership, bringing valuable insights and lived experiences into the diagnostic process. It requires healthcare systems to embrace transparency, trust, and mutual respect, acknowledging that patients are experts in their own right. This evolution not only enhances diagnostic accuracy but also builds a healthcare system that is more responsive, patient centered, and, ultimately, safer for all.

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