

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



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

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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.

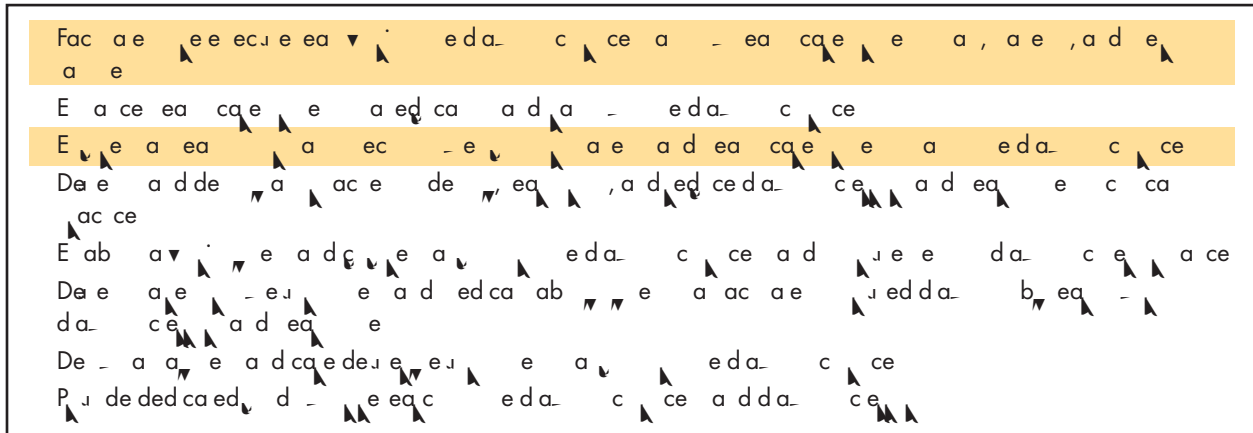
Patients and caregivers who have experienced a diagnostic error can provide a unique perspective. Because they interact with different healthcare providers from different medical specialties in different healthcare settings across the entire healthcare continuum, they can have both a broader and a more 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 [NAEM]). 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 diagnoses⁶ 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.

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



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:

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.

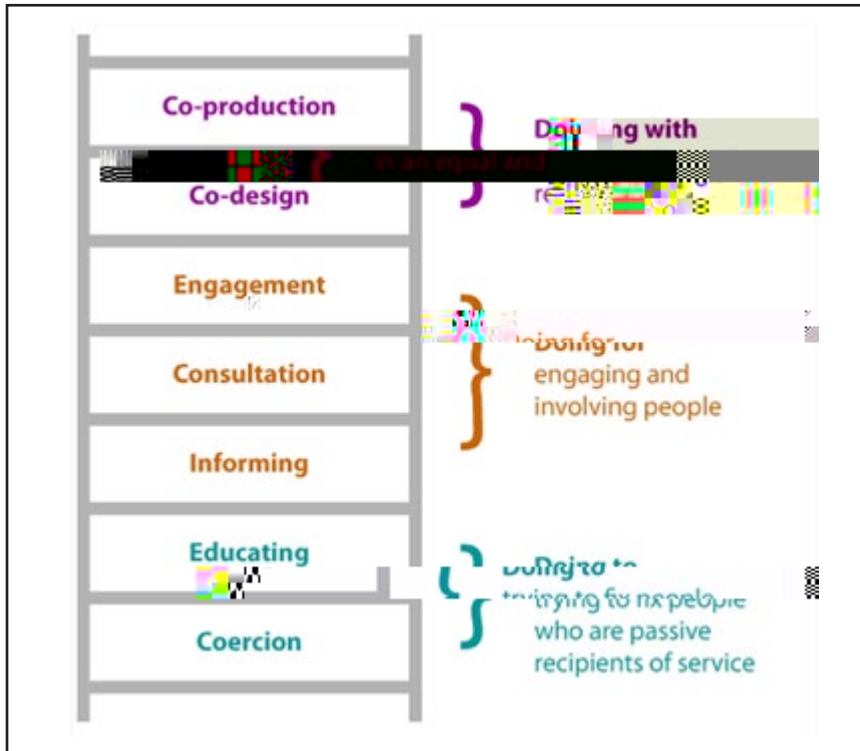
In our experience, patients of all levels of experience and education are eager to partner with their medical teams. Perhaps counterintuitively, those who have experienced diagnostic limbo, had long or difficult diagnostic journeys, and even those who may have felt as if some providers were dismissive 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 participation¹³ 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

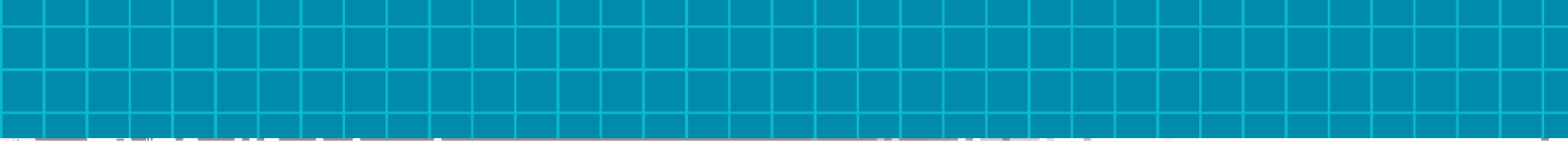


Source: Developed by Think Local Act Personal and the United Kingdom National Co-production Advisory Group. <https://www.thinklocalactpersonal.org.uk/>.

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.





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

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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 Change⁴⁶ 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-



Impact of Disparities and Lack of Equity on Patient Engagement

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 groups⁶⁷ 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 Safety⁷⁰ 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.

References

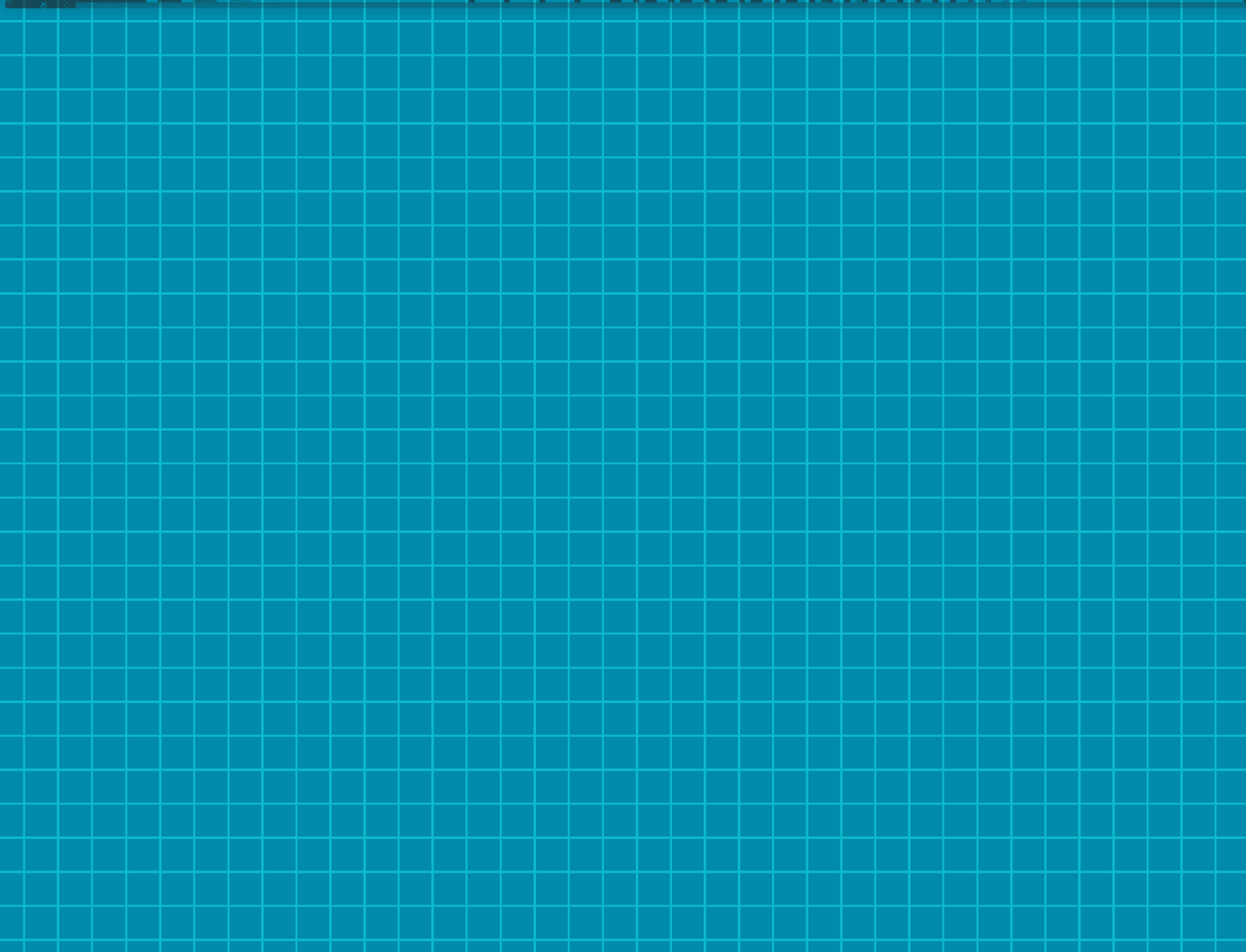
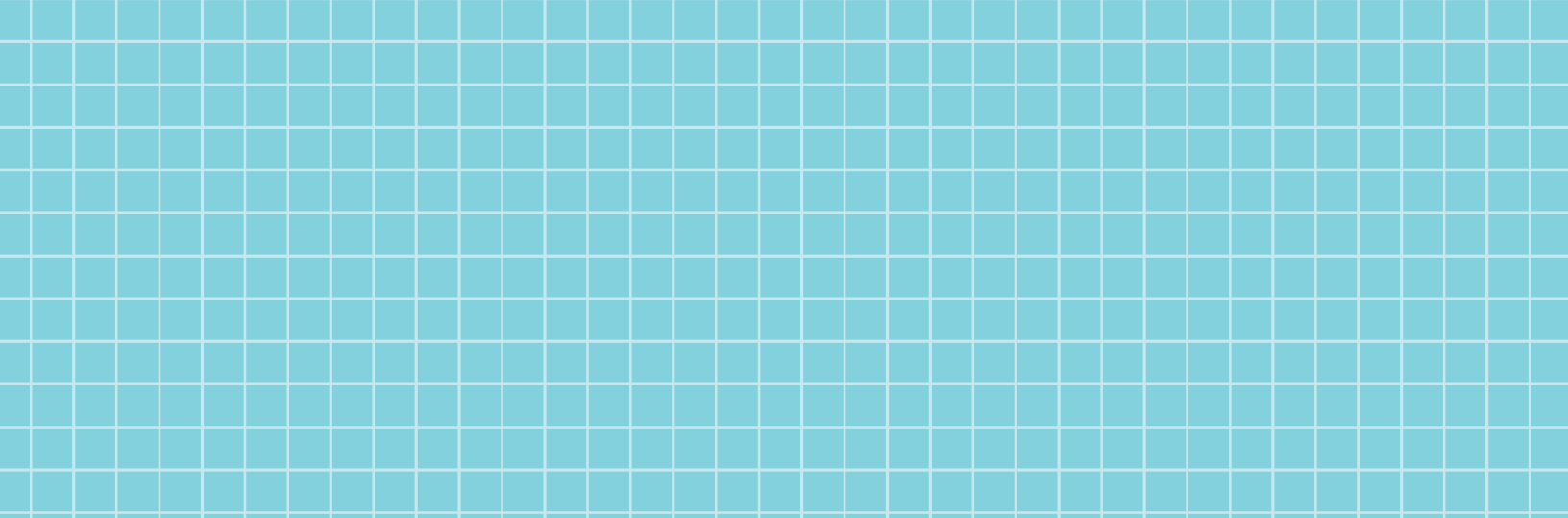
1. Zwaan L, Smith KM, Giardina TD, Hooftman J, Singh H. Patient generated research priorities to improve diagnostic safety: a systematic prioritization exercise. *Patient Educ Couns*. 2023 Jan;107650. DOI: [10.1016/j.pec.2023.107650](https://doi.org/10.1016/j.pec.2023.107650).
2. Giardina TD, Haskell H, Menon S, Hallisy J, Southwick FS, Sarkar U, Royse KE, Singh H. Learning from patients' experiences related to diagnostic errors is essential for progress in patient safety. *Health Aff (Millwood)*. 2018;37:1821-1827. <https://www.healthaffairs.org/doi/10.1377/hlthaff.2018.0698>.
3. Kelly MP, Heath I, Howick J, Greenhalgh T. The importance of values in evidence-based medicine. *BMC Med Ethics*. 2015 Oct 12;16(69). <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4603687/>.
4. Sheridan S, Merryweather P, Rusz D, Schiff G. What if? Transforming diagnostic research by leveraging a diagnostic process map to Engage Patients in Learning from Errors. *NAM Perspectives*. 2020 Feb 18; 2020:10.31478/202002a. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8406596/>.
5. Committee on Diagnostic Error in Health Care; Board on Health Care Services; InstitutjEM.OIC

15. Think Local Act Personal (TLAP) and the National Co-Production Advisory Group (NCAG). Ladder of Co-Production. <https://www.thinklocalactpersonal.org.uk/>.
- 16.

31. The Digitalis Blog: Cutting Edge Healthcare Marketing. All the Healthcare Marketing Statistics To Pay Close Attention to in 2023. <https://digitalismedical.com/blog/healthcare-marketing-statistics/#:~:text=Google%20is%20a%20popular%20search>.
32. Gaddy A, Topf J. Facebook groups can provide support for patients with rare diseases and reveal truths about the secret lives of patients. *Kidney International Reports*. 2021 May;6(5):1205-1207. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8116909/>.
33. Al Mamun M, Ibrahim HM, Turin TC. Social media in communicating health information: an analysis of Facebook groups related to hypertension. *Prev Chronic Dis*. 2015 Jan 29;12:E11. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4310711/>.
34. Hammoud M, Douglas S, Darmach M, Alawneh S, Sanyal S, Kanbour Y. Evaluating the diagnostic performance of symptom checkers: clinical vignette study. *JMIR AI [Internet]*. 2024 Apr 29;3:e46875. <https://ai.jmir.org/2024/1/e46875>.
35. Hatlie MJ, Nahum A, Leonard R, Jones L, Nahum V, Krevat SA, Mayer DB, Smith KM. Lessons learned from a systems approach to engaging patients and families in patient safety transformation. *Jt Comm J Qual Patient Saf*. 2020 Mar 1;46(3):158-166. DOI: [10.1016/j.jcjq.2019.12.001](https://doi.org/10.1016/j.jcjq.2019.12.001).
36. Mazor KM, Smith KM, Fisher KA, Gallagher TH. Speak up! Addressing the paradox plaguing patient-centered care. *Ann Internal Med*. 2016 May 3;164(9):618-619.
37. Steen M, Manschot M, De Koning N. Benefits of co-design in service design projects. *Int J Design*. 2011 Aug 15;5(2). <https://www.ijdesign.org/index.php/IJDesign/article/view/890/346>.
38. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview. *CoDec*.

46. Russell C. Getting to authentic co-production: an asset-based community development perspective on co-production. In: Loeffler E, T, eds. *The Palgrave Handbook of Co-Production of Public Services and Outcomes*. Cham, Switzerland: Palgrave Macmillan; November 2020. pp. 173-192. https://doi.org/10.1007/978-3-030-53705-0_9.
47. Hemmelgarn C. Future of Personal Health: The Patient Evolution and Revolution. <https://www.futureofpersonalhealth.com/patient-safety/the-patient-evolution-and-revolution/>.
48. McDonald KM, Bryce CL, Graber ML. The patient is in: patient involvement strategies for diagnostic error mitigation. *BMJ Qual Saf*. 2013 Oct;22(Suppl 2):ii33-ii39. <https://doi.org/10.1136/bmjqs-2012-001623>.
49. LymeDisease.org. Largest study ever conducted of Lyme disease finds both early diagnosis and better treatment essential for patients to get well. www.prnewswire.com. 2016 Dec 21. <https://www.prnewswire.com/news-releases/largest-study-ever-conducted-of-lyme-disease-finds-both-early-diagnosis-and-better-treatment-essential-for-patients-to-get-well-300381529.html>.
50. About the Patient Led Research Collaborative. <https://patientresearchcovid19.com>.
51. Forum on Microbial Threats and Forum on Neuroscience and Nervous System Disorders. *Toward a Common Research Agenda in Infection-Associated Chronic Illnesses: Proceedings of a Workshop*. Washington, DC: National Academies Press; 2024. <https://nap.nationalacademies.org/catalog/27462/toward-a-common-research-agenda-in-infection-associated-chronic-illnesses>.
52. Pulse Center for Patient Safety, Education & Advocacy. <https://www.pulsecenterforpatientsafety.org>.
53. Pulse Center for Patient Safety, Education & Advocacy. *TakeCHARGE: 5 Steps to Safer Health Care*. <https://www.pulsecenterforpatientsafety.org/takecharge>.
54. Seshamani M, Jacobs DB. Leveraging Medicare to advance health equity. *JAMA*. 2022 May 10;327(18):1757-1758. DOI: [10.1001/jama.2022.6613](https://doi.org/10.1001/jama.2022.6613).
55. Centers for Medicare & Medicaid Services. *CMS Framework for Health Equity*. Page last modified May 2024. <https://www.cms.gov/priorities/health-equity/minority-health/equity-programs/framework>.
56. Valdez R, Chesley FD, Mistry KB. *AHRQ Views: Vanquishing Healthcare Disparities by Advancing Healthcare Equity*. Rockville, MD: Agency for Healthcare Research and Quality; November 28, 2023. <https://www.ahrq.gov/news/blog/ahrqviews/vanquishing-healthcare-disparities.html>.
57. Dukhanin V, Wiegand AA, Sheikh T, Anushka Jajodia, McDonald KM. Typology of solutions addressing diagnostic disparities: gaps and opportunities. *Diagnosis (Berl)*. 2024 Jul 3. <https://pubmed.ncbi.nlm.nih.gov/38954499/>.
58. Shen MJ, Peterson EB, Costas-Muñiz R, Hernandez MH, Jewell ST, Matsoukas K, Bylund CL. The effects of race and racial concordance on patient-physician communication: a systematic review of the literature. *J Racial Ethn Health Disparities*. 2018 Feb;5(1):117-140. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5591056/>.
59. Takeshita J, Wang S, Loren AW, Mitra N, Shults J, Shin DB, et al. Association of Racial/Ethnic and Gender Concordance Between Patients and Physicians With Patient Experience Ratings. *JAMA Network Open*. 2020 Nov 9;3(11):e2024583.

60. Alsan M, Garrick O, Graziani GC. Does Diversity Matter for Health? Experimental Evidence from Oakland. NBER Working Papers 24787. Cambridge, MA: National Bureau of Economic Research; June 2018.



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