

At the Intersection of Diagnosis and Health Equity: A Primer for Health Services and Policy Research

Summary

The concept of diagnostic equity melds diagnosis, or “identifying a disease, condition, or injury from its signs and symptoms,”¹ with the principle of health equity—defined by the World Health Organization as the ability of everyone to “attain their full potential for health and well-being.”²

“The diagnostic process is iterative, and as information gathering continues, the goal is to reduce diagnostic uncertainty, narrow down the diagnostic possibilities, and develop a more precise and complete understanding of a patient’s health problem,” according to a 2015 National Academy of Medicine report.³ In essence, the diagnostic process is a journey—linking what patients experience in the community—their initial symptoms and personal and social determinants of health⁴—with what happens and doesn’t happen with clinicians in health care settings.⁵ As such, the diagnostic process can both worsen or lessen health inequities, defined by the American Medical Association and Association of American Medical Colleges as “gaps that are unjust, avoidable, unnecessary and unfair.”⁶ Similarly, one proposed definition of diagnostic inequity describes “the presence of preventable unwarranted variations in diagnostic processes among population groups that are socially, economically, demographically, or geographically disadvantaged.”⁷ Additionally, the United Kingdom’s National Health Service assesses diagnostic equity across the domains of patient access, experience, and outcomes.⁸

AcademyHealth, supported by the Gordon and Betty Moore Foundation, seeks to engage health services and policy researchers in building evidence to identify, measure, intervene, and reduce diagnostic inequities.⁹ Building on work examining pre-hospital

diagnostic delays,¹⁰ AcademyHealth interviewed 21 clinicians, researchers, funders, and patient advocates in 2023 to develop a more nuanced understanding of diagnostic equity reflecting both the complexities of the U.S. health care system and patients’ lived experience. This brief identifies and synthesizes key themes identified through the interviews, including definitions of diagnostic equity; barriers and challenges to diagnostic equity; needed research and data; designing more equitable research solicitations; and potential solutions.

Defining Diagnostic Equity

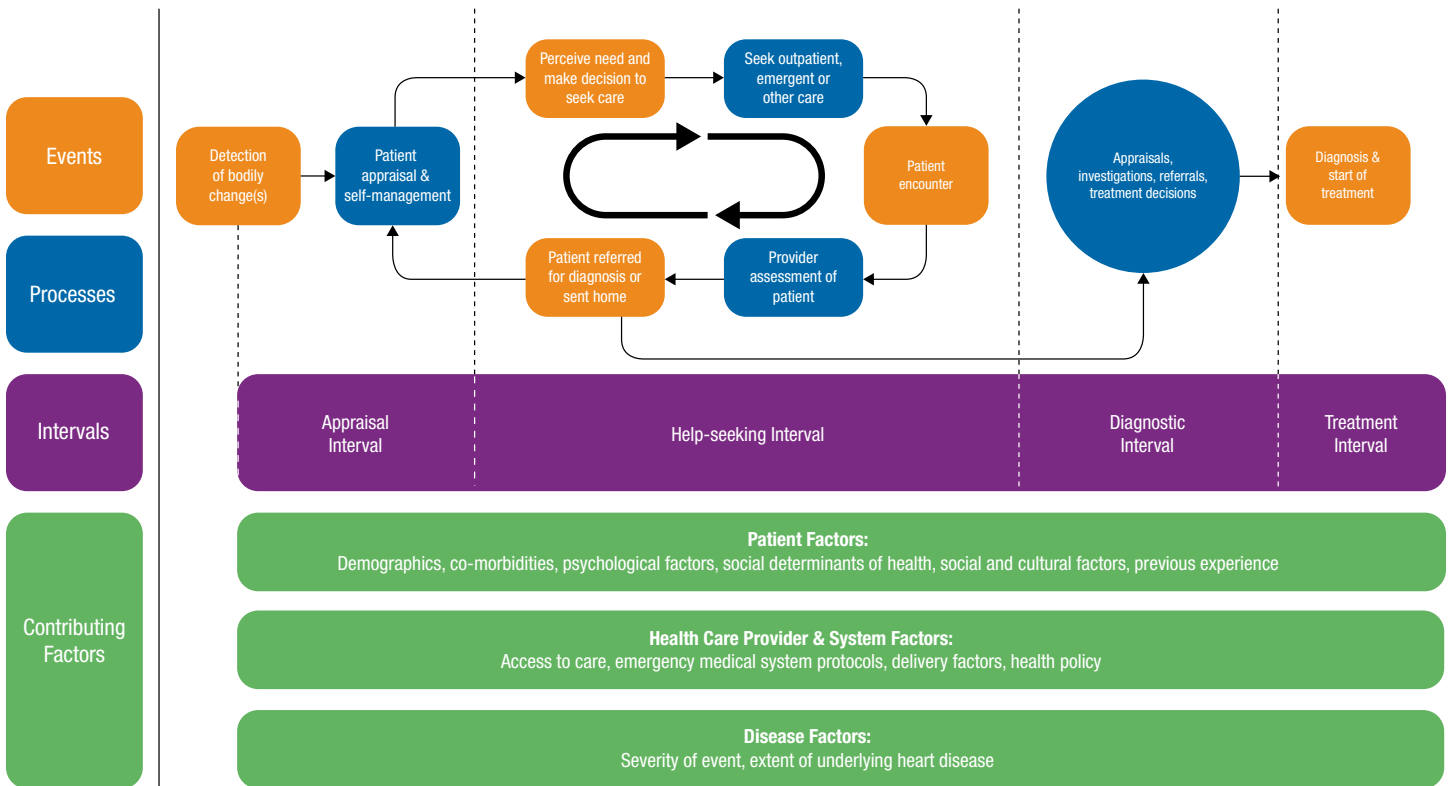
Across respondents, there was variation in people’s familiarity with and understanding of the term diagnostic equity. As a nascent field, diagnostic equity lacks a common nomenclature to bridge the worlds of researchers focused on health disparities and equity and those focused on advancing diagnostic excellence. Often, those working in the diagnostic sphere use a lens of diagnostic error or misdiagnosis. Similarly, the term diagnostic disparities is sometimes used interchangeably with the term diagnostic equity.¹¹

Regardless of terminology, there is little question that harm from diagnostic errors, compounded by health inequities for underserved populations, are a major quality and safety problem in American health care and worldwide.¹² For example, a recent study estimated that nearly 800,000 people annually die or face permanent disability from misdiagnosis across U.S. care settings.¹³ Just 15 diseases account for about half of the harms, and five diseases—stroke, sepsis, pneumonia, venous thromboembolism, and lung cancer—accounted for almost 40 percent, or roughly 300,000 serious harms annually, according to the study. At the same time, women and people of color—whether characterized by race or

About this Brief

This brief is a part of a project undertaken by AcademyHealth, with support by the Gordon and Betty Moore Foundation, to build evidence that will enable researchers to identify, measure, intervene, and reduce diagnostic inequities. AcademyHealth interviewed 21 clinicians, researchers, funders, and patient advocates in 2023 to develop a more nuanced understanding of diagnostic equity reflecting both the complexities of the U.S. health care system and patients’ lived experience. This brief identifies and synthesizes key themes identified through the interviews, including definitions of diagnostic equity; barriers and challenges to diagnostic equity; needed research and data; designing more equitable research solicitations; and potential solutions.

Figure 1. Pathways to Diagnosis and Treatment: Adaptation of Walter, 2012



Adapted from Walter F et al. The Andersen Model of Total Patient Delay: a systematic review of its application in cancer diagnosis. *J Health Serv Res Policy*. April 2012. 17 (2): 110-8.

ethnicity—have an estimated 20 percent to 30 percent higher likelihood of being misdiagnosed when facing life-threatening diseases like strokes or heart attacks.¹⁴

One interview respondent defined diagnostic equity as “a state where a person, regardless of their background or characteristics, has an equal probability of getting an accurate [timely] diagnosis of whatever they are presenting with. That accurate diagnosis then supports appropriate interventions. So, that to me is diagnostic equity.” Another respondent associated diagnostic equity with diagnostic accuracy, saying diagnosis and equity intersect “when the personal characteristics of a person inappropriately lead to a pathway of diagnosis that could potentially lead to an error.” Additionally, one respondent identified a need to “socialize” the concept of diagnostic equity to increase understanding among patient, clinical, research, policy, and other stakeholder communities.

“Barriers related to race, ethnicity, ability, language, geography, sexual orientation, and gender identity might be distinct factors, but often they’re either operating in tandem with each other or people are living at the intersections of multiple marginalized communities, and then those barriers are not additive, they’re multiplicative,” said a researcher who focuses on improving care for LGBTQ+ people.

Barriers and Challenges to Diagnostic Equity

Mapping the diagnostic process and related components can help capture the complexity and many factors that affect whether a patient receives a timely, equitable, and accurate diagnosis (Figure 1).

Moreover, while people often view health and health care disparities through the lens of race and ethnicity, disparities occur across many other dimensions, including gender, socioeconomic status, age, geographic location, disability status, citizenship status, and sexual identity and orientation.¹⁵ In January 2021, the federal government, via a Biden administration executive order, defined equity to mean “the consistent and systematic fair, just, and impartial treatment of all individuals, including individuals who belong to underserved communities that have been denied such treatment, such as Black, Latino, and Indigenous and Native American persons, Asian Americans and Pacific Islanders and other persons of color; members of religious minorities; lesbian, gay, bisexual, transgender, and queer (LGBTQ+) persons; persons with disabilities; persons who live in rural areas; and persons otherwise adversely affected by persistent poverty or inequality.”¹⁶

Intersectionality. Moreover, population subgroups at highest risk for inequities “are not mutually exclusive and often intersect in meaningful ways.”¹⁷ In the context of diagnostic equity, “barriers related to race, ethnicity, ability, language, geography, sexual orientation, and gender identity might be distinct factors, but often

they're either operating in tandem with each other or people are living at the intersections of multiple marginalized communities, and then those barriers are not additive, they're multiplicative," said a researcher who focuses on improving care for LGBTQ+ people.

Trust and Engagement. Across multiple interviews, respondents cited trust, distrust, and mistrust of the health care system and clinicians as barriers to diagnostic equity, especially for marginalized communities that historically have experienced mistreatment or people who have had "untoward" health care encounters. Several respondents also mentioned that most researchers study trust as a patient characteristic rather than examining the trustworthiness of the health system and clinicians, especially given the U.S. profit-driven system and fee-for-service payment incentives that generally reward higher volume of care rather than patient outcomes. "If we are talking about how can we solve this big issue of diagnostic inequity, and part of that matrix of solutions is more trust, the only way you can develop trust is by creating situations in which you can be trusted," a respondent said.

A clinician respondent noted that trust is necessary but insufficient, and that patient engagement is the next step, saying, "I think of both as the responsibility of the health care system. So, one, we need to earn trust.... The presumption of trust should never be innate, and so, I had to actively earn their trust. I need to listen. I need to make sure they understand that I'm prioritizing their care.... So, they may trust me, but if I am not proactively engaging them in the participation of their care or proactively working with communities to actually seek out care, their willingness to trust me is still not sufficient. So, I think of trust as more of a personal relationship characteristic, where engagement is the action that I actually have to take."

Costs, Health-Related Social Needs, and Other Patient Access Barriers. It is difficult to disentangle more universal barriers to accessing care from barriers specific to diagnostic equity given the overlap between the two. For example, symptomatic people who never seek care because of access barriers—ranging from uninsurance and other cost worries to health-related social needs like transportation, housing, food, and childcare—never have a chance at diagnostic equity. "I'll bet you that the health disparities piece of the puzzle is huge before the person activates the health care system. I wouldn't be surprised if—and I'm not talking about 20 percent to 30 percent—you're talking about 200 percent or 300 percent or 20-fold or 50-fold kind of numbers compared to people with better access, better means, higher socioeconomic status, whatever all the social determinants of health are—every one of them probably has a massive impact on people activating the health care system," a physician researcher said.

"Starting at the very, very beginning, when a patient experiences symptoms, the likelihood of them seeking care is, I would say, very often determined by their life circumstances...they may present after several weeks of symptoms as opposed to several days of symptoms simply because they couldn't get time off from work, or they're

worried that if they took time off, that they would lose their job," said a physician researcher who cares for patients at a large urban safety-net hospital. "Or they had caregiving responsibilities, or they were worried that they would get hit with a big bill... or they might be undocumented and afraid that if they sought care, that somehow that would lead to them getting entangled with the legal system."

People who live in rural areas, especially remote frontier areas like Alaska, face additional access barriers, with one respondent reporting that people in remote areas may "wait for symptoms to be a lot more severe before they seek care, because it's such a trek to get to places." Moreover, in small rural communities where everyone knows one another, people may not seek care because of stigma related, for example, to behavioral health. "Whether it's mental or behavioral health or a substance use disorder, it comes with so much stigma. In an urban or suburban area, you can seek care and remain fairly anonymous. In a rural community, if you're at a clinic, or you're seeing a certain practitioner, or you're doing something, everyone in the community knows about it.... They know that's your pickup truck," a respondent said.

Clinician shortages, especially access to primary care and behavioral health providers, also contribute to access barriers, especially for members of racial and ethnic minority groups. A psychiatrist respondent pointed to limited availability of outpatient mental health services as part of the explanation for why African-American and Hispanic people are more likely to receive psychiatric care in a crisis rather than earlier when their conditions might have been more easily treated. Similarly, older people, especially those living in long-term care settings like nursing homes, face access barriers. "In long-term care settings, it's really dismal—it's horrible. You have an undertrained workforce of mostly certified nursing aides. You have very little access to mental health services in most places.... So, folks struggle. The rates of depression in nursing facilities and long-term care, many studies show, is between 30 and 50 percent," the psychiatrist said.

Listening to Patients and Eliciting Information. Across interviews, multiple respondents cited the importance of clinicians not only listening to patients but also eliciting information vital to an accurate and timely diagnosis. "Health care is designed for this fictional person in the middle of the bell curve.... One of the many problems with health care is that it doesn't build in as routinely as it should, as intuitively as it should, the flexibility to look for the ends of the bell curve. Because if you do that, then lo and behold, you have captured everyone in the bell curve. You are now prepared to receive, interpret the signs and symptoms and complaints and whatever other challenges for everyone in the bell curve because you universally designed the diagnostic approach that way," a physician respondent said.

Moreover, growth of medical knowledge, combined with time demands, makes it almost impossible for clinicians to keep up to date on the evidence in their specialties without decision support

tools. To help manage information overload, as well as concerns about wide practice variation, many specialties and other entities have developed practice guidelines for various conditions. While practice guidelines can help improve quality and patient outcomes, two major challenges are the inadequacy of the evidence base supporting guidelines and tailoring guidelines to individual patients.¹⁸ The same physician respondent suggested that how guidelines are developed matters in the context of diagnostic equity, saying, “The practice standards, what populations were they derived from? What cultural lenses were they guided by and written for?”

Another respondent encouraged clinicians to use the concept of diagnostic equity as a cue to self-monitor for biases that we all have in one form or another, saying, “What are the things you do mentally to ensure that you’re not subject to that bias?”

Continuing, the physician respondent indicated that clinicians, as diagnosticians, need an “almost forced constant intellectual curiosity...to ask how many other ways can I be thinking about this, given this person’s context, and being humble and maybe asking the person, or asking the people around them, ‘Is this what you mean? Tell me more.’ Give me more texture so that I can filter it through my cultural understanding and vocabulary and then I, as the professional, can translate that and remap it back to my practice standards. Because that’s not your job, as a first-generation immigrant, or as a person who may be non-speaking, to figure out how to map your symptoms to the practice standards.... The clinician, I think, has abdicated that responsibility. They will often say, well, the patient didn’t complain about a headache. Yes, but the patient told you that they laid down in a dark room for three hours or they couldn’t listen to music that day. That’s on you to figure out, right?”

Another physician respondent who leads a large community health center noted that for patients who have experienced racism or sexism, “It’s a traumatic event, and so they’re very sensitized to that already. So, even a doctor who is well intentioned and trying to be careful, if they don’t understand trauma, then they perpetuate a lot of the same inequities. So, from an equity standpoint, I think some of the models in trauma-informed care, kind of put the onus back on us to reflect and then to be able to rethink the way we communicate, not just from a language perspective, but just what words we use, what examples we use to describe things so that we don’t retraumatize our patients, or not even traumatize, maybe push them away from us.”

Health Literacy/Fluency. Across interviews, respondents noted that people’s level of health literacy is key to recognizing when symptoms are serious enough to seek care and the importance of preventive care. “One of the biggest questions would be, how does health literacy affect diagnostic equity? I think that—and that’s not necessarily putting things on the patient, right? So, I think that

there’s a tendency to say, ‘Oh, health literacy, health education is about the patient.’ No. It’s really about the health care system,” a health services researcher said.

Respondents also pointed to the complexity and fragmentation of the U.S. health care system, which in some cases can turn a patient’s diagnostic journey into a “diagnostic odyssey” of medical misadventures. “I think that people who have had significant contact with the health care system in the past may, if they have had poor experiences, delay care, and it’s not because of health literacy, it’s not because of financial resources, it’s not because of having negative experiences based on race, ethnicity, or other types of identity, but just because the system doesn’t work,” the researcher continued.

Bias. Among the many factors contributing to health and health care disparities are explicit and implicit biases—the former are the attitudes and assumptions that we acknowledge as part of our personal belief systems, while the latter are attitudes and beliefs about race, ethnicity, gender, age, ability, or other characteristics that operate outside conscious awareness and “surreptitiously influence judgment and can, without intent, contribute to discriminatory behavior.”¹⁹ In the context of diagnostic equity, bias is likely as old as the practice of medicine itself, with several respondents citing the age-old stereotype of labeling women with hysteria or as psychiatric cases when an obvious diagnosis is elusive. Another respondent encouraged clinicians to use the concept of diagnostic equity as a cue to self-monitor for biases that we all have in one form or another, saying, “What are the things you do mentally to ensure that you’re not subject to that bias?”

A researcher described how clinicians use heuristics, or mental shortcuts, that reduce cognitive load to assess a patient, citing the example of a person presenting in the emergency department and “they’re lower income, they may not be dressed as well, they’re a person of color, and they’re in pain—those all add up to drug seeker.” Similarly, stereotyping patients based on their sexual orientation or gender identity can lead to errors and inequities. As one respondent said, “How do we not slide from the appropriate use of heuristics to kind of help guide us generally...and not slide into a whole bunch of assumptions about who someone is, what that means about their health, such that we ascribe things to them that aren’t true. Not every gay bisexual [sic] man is at high risk for HIV, but from the way providers act toward them, you’d think they were.

“There’s a famous case study in the New England Journal that talks about a transgender man who goes to the emergency department with abdominal pain... but looking at him, he’s a dude, nobody thinks that he might be pregnant, which in fact he is, and he almost dies, and the fetus is lost because of this delay—the misdiagnosis of ‘well, you couldn’t possibly be pregnant.’”

Then how do we not miss things? If you're a cisgender heterosexual Black woman, and your provider's not even thinking about HIV, and what if that gets missed...because your provider looks at you, profiles you, says, well, you're not a gay man, so forget about that HIV stuff. That's a huge diagnostic error."

Similarly, transgender people can face diagnostic inequities because clinicians may assume "everyone is straight, everyone is cisgender," said a researcher specializing in sexual and gender minority populations, who stressed the importance of "not making assumptions, for example, that transgender men don't exist and can't get pregnant. There's a famous case study in the *New England Journal* that talks about a transgender man who goes to the emergency department with abdominal pain... but looking at him, he's a dude, nobody thinks that he might be pregnant, which in fact he is, and he almost dies, and the fetus is lost because of this delay—the misdiagnosis of well, you couldn't possibly be pregnant."²⁰

"But when the presentations are atypical, when they're subtle, when they're nonspecific, and people are making judgment calls about what it is or it isn't, that's where you start to see these little pieces—little, small decisions getting made—that add up to this 20 percent to 30 percent difference between women and minorities and their white male counterparts."

A patient's age also can trigger bias, with a physician respondent sharing an example of elderly patients living in nursing homes who are experiencing a new symptom. In such cases, a nurse typically calls a physician, and the physician's first question often is whether the person has a do not resuscitate/do not intubate (DNR/DNI) order. "We had a case where it was an older gentleman with heart issues, and the nurse called because he was having chest pain. The physician that they called said, 'Are they DNR/DNI?' The nurse answered honestly, 'Yes, they're DNR/DNI.' Oh, okay. Well, give him blah, blah, blah. The pain didn't go away. They called back. Well, give him some more blah, blah, blah. The pain didn't go away.... The nurse wrung her hands all night, and he died," said the respondent who serves as medical director for several nursing homes. "That's not what he wanted...but it was just a terrible example of what happens when you introduce explicit bias into clinical decision-making."

A physician researcher posited that bias "creeps in" when clinicians face atypical or vague symptoms, saying, "The bias lives in the crevices where there's uncertainty. If somebody comes in and they're clutching their chest and their electrocardiogram and there are giant abnormalities consistent with a heart attack, and they've got a history of high blood pressure, diabetes, high cholesterol and smoking and they're 65, it doesn't matter whether they're white, Black, blue, male, female, or anything else, they're all going to get

the right diagnosis. But when the presentations are atypical, when they're subtle, when they're nonspecific, and people are making judgment calls about what it is or it isn't, that's where you start to see these little pieces—little, small decisions getting made—that add up to this 20 percent to 30 percent difference between women and minorities and their white male counterparts."

Overshadowing. Several respondents cited a phenomenon known as diagnostic overshadowing, when clinicians ascribe some sign or symptom to a patient's underlying condition—for example, schizophrenia, an intellectual and/or developmental disability (IDD), obesity, or age—rather than looking for other explanations. "Because everyone walks around thinking about Occam's razor, right? That's what we're ruled by, that's how we're trained," said a physician respondent knowledgeable about the care of people with IDD's. "So, this person goes with an undiagnosed rupturing esophageal ulcer for several weeks until a GI doc says, 'I believe you,' to the mom and bothers to do an endoscopy. So, the person couldn't speak—not their problem. It's your problem as a clinician. You had help. The mother was there telling you that something different is going on. You had the tools. You've got CAT scans, you've got endoscopes, you've got esophageal pH meters, probes. There are all kinds of things you could do. You have to balance how invasive you want to be and how hard you want to work at it, but until there is resolution of the problem, it's actually your task to solve it as a clinician."

Lack of Secondary Diagnostic Review. Several physician respondents noted that secondary or peer review/discussion of diagnostic decisions is the exception rather than the rule. Given the fragmented nature of the delivery system, clinicians in many cases may not even know if their diagnoses were accurate. Within the specialties of pathology and radiology, however, secondary review is common, a pathologist respondent said, characterizing pathologists and radiologists as "visual specialists" focused on the mechanistic aspects of diagnosis because they usually examine images rather than actual patients. In contrast, direct-care clinicians focus on manifestation of patient symptoms, such as pain or a cough, opening the door to biases. Using diagnostic equity as a frame helps to differentiate the nature of a diagnostic error. "It's an equity error versus I forgot something," the physician said, adding that secondary review is a way to check if the clinician is "thinking in a systematic way that isn't biased." At the heart of secondary review is measuring accuracy, the physician said, and research needs to focus on "why did the clinician make that diagnosis" even though that will generate "huge pushback" from clinicians. Therefore, using an approach that helps clinicians "rather than puts them in trouble" is critical.

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Prioritizing Diagnostic Equity Research

Data—quantitative, qualitative, or a mix—are the lifeblood of health services researchers whether studying health equity or diagnostic errors. Unfortunately, both fields of study lack ready access to high-quality data, compounding the challenges of collecting the right information at the right time to study diagnostic equity. “We don’t have any well-oiled natural mechanisms for tracking diagnostic errors in our current health care system, which is one of the big problems that is an impediment even to measuring disparities or equity issues in health care if you can’t measure diagnostic errors and you can’t measure equity issues in diagnostic areas. So, there’s a gap that’s important to fill,” a physician researcher said.

Similarly, the historical but outdated gold standard for research has been to reference “normal” based on the average white male, as one respondent said. Moreover, according to multiple respondents, researchers need to move beyond quantitative data collection and use multiple approaches and methods, including more qualitative and mixed-method study designs. For example, narrative elicitation is a way to study patients’ diagnostic journey consistently, and community-based participatory research can help make sure research is relevant and meaningful to patients.

Poor quality race, ethnicity, and other sociodemographic data hinder research and identifying the magnitude of diagnostic inequities. “We simply don’t have great data to quantify some really basic questions, like, ‘What are the diagnoses that are commonly missed or delayed, and how do those vary across race, ethnicity, gender, language, all the usual factors?’ I think the biggest barrier, honestly, is just that we don’t, at this point, have great metrics of diagnostic accuracy, and even where we do, I’m not aware of really accurate data that can help us quantify and help us break down by demographics and other factors to help us identify what the inequities are. I think we’re very much at the early stages of even understanding what the problem is,” a physician researcher said.

While increased emphasis on health equity has highlighted the dearth of high-quality race and ethnicity data, for example, one researcher cautioned that simply collecting better data is insufficient without a plan to use the information in a meaningful way. “Don’t disentangle the data from the actions. So, you’re busy collecting measures and data. Well, what do they produce?” the researcher said, adding, “It’s such a disservice to the people who are most marginalized by the current systems to gather information and then not figure out how to use it.”

Using SPADE to Identify Diagnostic Inequities. Instead of costly and labor-intensive medical record reviews to identify diagnostic errors, several respondents cited the potential of using large administrative datasets to reach the scale needed to conduct case-control studies and subgroup analyses to detect diagnostic inequities. Researchers already are using an approach known as SPADE—Symptom-Disease Pair Analysis of Diagnostic Error—to do such

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research for major diseases like stroke.²¹ “With the acute diseases, there’s a short-term serious adverse event likely if we miss it—so if you miss a heart attack, or an aortic dissection, or a pulmonary embolism—there’s some period of time during which, not everybody, but some percentage of the patients who are misdiagnosed are going to get hospitalized, and worse, they’re going to die.... We can actually track those events, and we can measure the number of times somebody gets sent home from, say, the emergency department or a primary care clinic and told that they don’t have anything serious, and then they come back, and they’re re-admitted with a serious disease,” a physician researcher said.

For example, the SPADE (case-control) approach would examine all stroke cases and look back to see if the patients had presented earlier in a specified timeframe with a symptom of dizziness but were discharged with benign dizziness. “Using those techniques and symptom-disease pair approach to diagnostic error enables us to look at large data sets, and from that, we can look at demographic differences. You can’t find a 20 percent to 30 percent difference between groups if you’ve got a small single hospital study of 100 patients—you can’t get a statistically significant result. You have to look at thousands of records to see that that pattern exists,” the physician researcher said.

“The key concept here is that there’s a natural history of disease, and we’re leveraging that natural history of disease to either look back from the disease to the initial symptoms at an earlier visit or to look forward from the initial symptoms to a subsequent disease,” the physician researcher continued. “They tell us slightly different things. In the disease lookback, what it tells us is given people are at risk for that dangerous disease, what are the risk factors, and that’s how you get to the demographics part of the analysis. The look-forward question tells us more about rates. It tells us how often this is happening and becomes kind of a needle that we can move conceptually.”

Embracing More Qualitative and Mixed-Methods Research. Multiple respondents suggested developing and integrating patient-reported outcome measures (PROMs) into the diagnostic process to better elicit the patient voice. “What are they reporting about their own quality of life and wellbeing or lack of wellbeing, and how could that be used in the diagnostic process.... Nobody is using those patient-reported measures to try to sort out what you have when there’s no explanation for your problem yet,” a researcher said.

“If you are not learning from key partners and patients and caregivers what is infeasible, what is unacceptable, what is irrelevant to their interest, you can do all kinds of research in a vacuum that is going to be meaningless and not able to be implemented. Certainly, you can disseminate it into the ether.... We’re all sitting here funding studies to look at the rate at which paint dries on the wall when the house is absolutely on fire.”

While acceptance of qualitative and mixed-methods research has grown, clinicians may still dismiss the value of the patient voice as an important perspective in learning about diagnostic errors, according to multiple respondents. One researcher recounted the frustration of submitting papers to clinical journals related to incorporating patient perspectives into diagnostic errors, saying, “We get back responses from reviewers who are clinical and who are immediately, with all due respect, diminishing the belief that there could be a ground truth from the patients—that the ground truth is from clinical expertise. Until you’ve matched up what the patient says to what the clinician said, you don’t know whether the patients experienced their own experience. Then you’ll hear, ‘Oh, this is patient satisfaction. This is more than patient satisfaction...it’s not about one’s right, one’s wrong. It’s more about what do we synthetically learn that we didn’t know.... How do we coproduce with patients?’”

Echoing that view, a physician respondent cited the need to develop meaningful measures that focus on patient outcomes rather than process-oriented practice guidelines, which the respondent generally viewed as a failure and part of the problem of diagnostic inequities. “I think that there’s proactive work by researchers and measure developers to come up with better ways of measuring the disconnects, the gaps between guideline-based constructs for diagnosis versus what patients experience and how patients express them in different personal and cultural contexts.... We have enough guideline-based metrics. Let’s focus on something more meaningful, and that could be around pain...appetite, I think, would be a huge area where cultural differences make a great deal of impact. You can talk to anthropologists and get a list of the constructs that they think would be most likely to vary. Then, do that psychometric work to figure out what are the words, what are the more universal, generally applicable ways of asking these questions—of prompting patients—to elicit from them what you need such that you can then map it back to the guidelines.”

A technique known as narrative elicitation²² lays out a systematic way to collect patient perspectives, according to a researcher familiar with the approach, “It’s in that nice middle space between the qualitative and the quantitative. If the health services research world and the policy world invest more in that, I feel quite confident it will help us with the equity challenge in the diagnostic space in a much more effective way because the effort is around what’s the action-

able information that’s coming out of these methods of acquiring a representative sample of people’s experience with problems and mistakes in the diagnostic journey...it’s a series of measurement development steps to end up with a huge, rich data of the narratives but also a more structured quantification of problems and where there are problems,” the researcher said.

Focusing on the Entire Diagnostic Journey Not Individual Care Settings. Most diagnostic error research focuses on individual encounters in specific care settings, such as the emergency department or other hospital settings. “If you zoom out a little bit, I think that the field needs to start thinking about the diagnostic journey across health care settings because that’s really what the patient experiences, first of all, and each of those encounters in different settings play a role in diagnosis.... right now, most diagnostic error research focuses on the individual encounters within that journey and not the entire journey. So, as a field, I think if we want to take a more patient-centered view of diagnostic error, we need to start thinking more about the diagnostic journey from the patient’s viewpoint,” a physician researcher said.

Designing an Equitable Process for Diagnostic Equity Research Solicitations

Multiple respondents cited the need to design a more equitable process for soliciting, reviewing, and awarding research grants to build the evidence around diagnostic equity. They stressed the importance of engaging with patients and advocates, communities, and community leaders who know the local context when designing and awarding research grants. “Do we continue to fund and re-fund and re-fund the same groups studying something at arm’s length as opposed to letting newcomers in who are from and in the community?” a respondent asked. Similarly, a funder said, “If you are not learning from key partners and patients and caregivers what is infeasible, what is unacceptable, what is irrelevant to their interest, you can do all kinds of research in a vacuum that is going to be meaningless and not able to be implemented. Certainly, you can disseminate it into the ether.... We’re all sitting here funding studies to look at the rate at which paint dries on the wall when the house is absolutely on fire.”

Including people with lived experience on grant review committees is necessary but insufficient—they must be empowered as well. “It’s great if you have a diverse panel, but at the end of the day, if the person who gets the final vote is the same set of old white guys...” a physician researcher said.

Other suggestions for making grant awards more equitable included requiring interdisciplinary teams and getting the word out about funding opportunities to researchers in atypical disciplines like urban planning and demographics, for example, who may not be as familiar with health services research. “We also made it clear that researchers had to have interdisciplinary teams. We were not going to accept anybody who was coming in with a team full of M.D.s or a team who’s a bunch of health economists,” another funder said.

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Several respondents recommended explicitly requiring researchers to show how they will engage community members and people with lived experience in the research, with one saying, “I would require that every research team include community members and a community advisory board and that they actually tell you as an applicant what their process will be for authentic engagement. That means something very particular in my head. I don’t think the vast majority of research teams really know how to do that.”

Diagnostic Equity as a Focus for System Improvement

Despite a reputation for cutting-edge biomedical research and high-tech hospitals and specialty care, by almost any measure—access, quality, patient and clinician experience, equity, or costs—the U.S. health care system underperforms relative to other high-income nations.²³ Given the investments and available resources—both human and otherwise—the U.S. health care system arguably delivers less than the sum of its parts and essentially isn’t really a system at all. The result is fragmented, siloed, disconnected care encouraged by payment incentives that favor doing things to patients rather than talking with them. As W. Edwards Deming said, “A bad system will beat a good person every time.”²⁴

Across the interviews with clinicians, researchers, funders, and patient advocates, many respondents noted that the concept of diagnostic equity is a useful way to frame and focus on the myriad system issues that impede accurate and timely diagnosis and equity. Many also suggested borrowing a page from the patient-safety playbook and taking a systems approach to building the evidence base for diagnostic equity. Medicine historically has treated errors as failures of individual clinicians, reflecting inadequate skill or knowledge. In contrast, a systems approach holds that “most errors reflect predictable human failings in the context of poorly designed systems.”²⁵

Changing Hearts and Minds. Given the multi-level barriers to diagnostic equity—individual, interpersonal, organizational, and societal ranging from health literacy to bias to access to care to structural racism—one respondent posited that a first step is to consider: “When do we have to change hearts, and when do we have to change minds? If we’ve changed a heart or a mind, what supports do they need to act?”

Changing hearts means recognizing that everyone has biases and then proactively working to avoid acting on those biases, the respondent said, adding, “I think diagnostic equity is an opportu-

nity to remind clinicians: ‘You have to work through all kinds of intellectual bias all the time—stop taking this so personally.’” To change minds requires building the evidence base, showing clinicians the evidence and why it matters to patient care, and then building a pathway to accomplish diagnostic equity—the tools, resources, guidance, training—all while engaging patients and learning from them.

Reinvesting in Primary Care. Along with fee-for-service payment incentivizing piecemeal, procedure-driven specialty care, payers’ disinvestment in primary care in recent decades likely plays a nontrivial role in diagnostic inequities, according to several respondents. “I think the single best thing payers can do to improve diagnostic equity is to pay primary care in at least a hybrid, if not a voluntarily fully capitated fashion, at a rate that is at least 50 percent to 75 percent higher than where we are today, and then, walk out of the room,” said a physician respondent and former health plan executive.

“That is premised on them deciding that the diagnosticians they want to be most active are the PCPs [primary care physicians], which is what I would want unless I know which organ system is affected,” the physician said. “Even then, you go to a specialist, you’re going to end up going to a series of specialists because they all have their hammer, and they’re all looking for their nail. There’s nothing they can do about it. It’s who they are. It’s how they were raised and incentivized. Your options as a payer are limited. Either you take money away from them and reinvest it in primary care or you just reinvest in primary care, eat those costs, and do your best to keep as much of the service and diagnostic work within the primary care world and let as little leak out to specialists as possible.”

Another physician respondent familiar with federally qualified health centers (FQHCs), recommended examining how many FQHCs do a lot with limited resources and applying effective practices across the broader health care system.

Multiple respondents stressed the importance of communication as an integral aspect of the diagnostic journey, both in patients telling their stories and clinicians eliciting and interpreting patient information accurately and without bias. Related themes emerging across the interviews included team-based, interdisciplinary care that supports informed shared decision making with patients and families and development of meaningful and actionable patient-reported outcomes related to diagnostic equity.

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Involving Communities, Building Trust, Supporting Prevention and Health Literacy. Across respondents, many cited community engagement and participation as foundational to helping people in communities most likely to experience diagnostic inequities increase symptom awareness and embrace regular preventive care.

“I think a lot of it is really going to start with community-based work—helping people trust the system and going into the communities and saying, ‘Hey, we want to help.... and this is how we’re going to help,’” a researcher said. “We’re going to teach you how to recognize symptoms for these common illnesses happening in your community. We have data about this, and we know that XYZ is really common in the lower resource communities.... We’re going to teach you what those symptoms are like. We’re doctors who treat them. We care about you.”

People also need a reliable onramp to a trustworthy health care system, and several respondents suggested deploying community health workers who know the community, know the people, and know how to communicate effectively to help people navigate the system and learn self-care strategies. One respondent suggested flipping the usual focus on a community’s problems to what works in a community—in other words, taking an asset-based rather than a deficit-based approach—when engaging and partnering with communities.

Clinician Training. Underscoring that diagnostic equity is a useful framework to illustrate the intersection of equity with the diagnostic process, several respondents suggested clinician training to raise awareness and emphasize the importance of communication and listening skills in reaching an accurate and timely diagnosis. “I often think about clinical education when it comes to this stuff,” a researcher said. “So, I think that the concept of diagnostic inequity should be introduced as soon as possible whether it’s medical education, nursing education, other health care providers—just the concept that there is inequity in diagnosis because you learn a lot... about diagnosis but the diagnosis is always assuming someone has the resources and the access and the literacy to present. So, I think as we learn more about diagnostic inequity, that needs to be introduced.”

Artificial Intelligence. Several respondents cited both the potential pitfalls and the promise of artificial intelligence related to diagnostic equity. For instance, artificial intelligence and machine learning could increase diagnostic disparities if the underlying algorithms rely on non-diverse datasets or inappropriate variables. On the other hand, artificial intelligence might be a useful tool to help streamline the diagnostic process and increase patient access. Regardless, multiple respondents pointed to artificial intelligence as a fertile area for research related to diagnostic equity.

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Conclusion and Implications

Moving forward, AcademyHealth’s goal is to leverage diagnostic equity as a framework to help prioritize the diagnostic process among health disparities and equity researchers while bringing equity to the forefront among researchers seeking to advance diagnostic excellence. By generating synergies among researchers, the hope is that the resulting evidence base will help identify “modifiable actions” along the diagnostic journey to quantify, intervene, measure progress, and eliminate diagnostic inequities.

About the Author

This issue brief is by Alwyn Cassil, an independent writer in Washington, DC. She was assisted in conducting the interviews upon which the brief is based by Katherine Froeb, an independent analyst in Arlington, VA.

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