DIAGNOSTIC EXCELLENCE

Achieving Equity in Diagnostic Excellence

Inequities in health and healthcare are common. Worldwide, metrics track infant mortality, life expectancy, patient safety, and quality of care. Countries with better health outcomes are acknowledged for success, whereas those with lower-ranked health outcomes seek to close the gap on their deficits. In the US and elsewhere, inequity gaps in health have been widely recognized. 

The research enterprise has yet to accumulate much knowledge about inequitable diagnosis. For instance, the percentage of life-years that could be saved from more equitable diagnostic excellence has not been estimated. The contribution of suboptimal diagnostic approaches to the morbidity and mortality experienced by those with inequitable outcomes has not been analyzed. These data gaps limit current understanding of the determinants and consequences of diagnostic inequities.

Achieving equity in diagnostic excellence needs to consider multiple perspectives. Systems thinking can set the stage for areas of potential improvement, for actionable knowledge about diagnostic inequities that originate within or outside the medical system, and for actionable knowledge about coordination across system boundaries.

The Promise of Equitable Diagnostic Excellence

Diagnostic excellence could be considered to occupy a multidimensional space; when full, the space represents the sum of all health benefits that could accrue from achieving diagnostic excellence for every person in every situation. Diagnostic inequity represents the lack of a fair and just chance to have these diagnostic excellence benefits. Multiple equity gaps exist and involve what has not materialized for marginalized or otherwise at-risk populations for diagnostic inequity.

Examples of some of these populations and risk factors for possible diagnostic inequities include the following: racial and ethnic groups (eg, Black/African American, Asian American, Native/Indigenous American, Hispanic/Latino populations); residence location (eg, rural, inner urban); income (eg, low-income, middle-income); insurance status (eg, public, uninsured, underinsured); age-related (eg, children, youth, older adults); disability communities (eg, physical, hearing, visual, developmental, psychiatric); linguistic communities (eg, non-English speakers, low literacy, low numeracy); and sex, sexual orientation, and gender identity (eg, female/women, lesbian, gay, bisexual, transgender, nonbinary).

Ideally, measurement systems under development for diagnostic excellence could analyze inequity risk groups to reveal and quantify these gaps, especially for those related to missed opportunities to receive a life-saving diagnosis (such as melanoma in Black individuals or vestibular stroke in young individuals). Patient-reported measures for diagnostic experiences and outcomes could be particularly valuable as long as they are developed carefully to enhance learning in communities that could be overlooked (thereby exacerbating inequities). From there, diagnostic excellence equity dashboards to drive action could be incorporated into broader health equity data-driven efforts. Such dashboards could focus on the at-risk population categories that are derived from the US National Healthcare Quality and Disparities Report, a Telehealth Equity Dashboard project, and other equity frameworks based on hypothesized or known diagnostic vulnerabilities. Further subcategories and intersectionality among multiple categories will also be important for revealing diagnostic inequities.

Systems Thinking for Action Toward the Promise of Diagnostic Excellence Equity

While improved measurement systems quantify diagnostic inequities, they cannot represent the complexity of many diagnostic activities that take place within and outside the medical system. Systems thinking helps protect against oversimplification of such complexity and brings together useful tools for explicating mental models of complex problems. For example, if problem-solving related to diagnostic inequity centers only on the clinician’s office, a diagnostic test, or any other parts of the medically guided diagnostic process, then the population-level risks for suboptimal diagnostic experiences for any disempowered or historically disadvantaged people have already gone unnoticed and will persist.

The Diagnostic Framework Within the Medical System

The National Academy of Medicine (NAM) Improving Diagnosis Conceptual Framework is a systems model with 3 key parts relevant to exploring inequity risk: the work system, the diagnostic process, and outcomes that provide feedback for learning. Potential pitfalls and risks related to specific inequity risk populations could be connected to components of the framework. For example, at a 2021 Society to Improve Diagnosis in Medicine Patient Summit, care partners of people with a disability (eg, physical, intellectual) or a stigmatized condition (eg, obesity, schizophrenia) pointed out the phenomena of overshadowing from the condition’s presence (ie, limiting evaluation for other conditions) leading to an unsatisfactory diagnostic process with potentially serious outcomes (eg, missed cancer). While use of prior probabilities is a necessary and appropriate part of clinical reasoning, the actual prior probability assumptions are prone to embedding biases linked to racism, sexism, ableism, and other related types of prejudice (from individual to structural) that contribute to diagnostic inequities. Adding these types of inequity-producing phenomena to the NAM framework is best done in close
partnership with communities at risk of diagnostic inequities. At times, the overreliance on medical expertise may have inhibited more comprehensive explanations for inequities.

With matters of equity, learning about the problems that diverse patients encounter during the diagnostic process is paramount for evolving patient engagement components of the NAM framework. Many patients frequently have limited knowledge of what to expect or what questions they may be asked when they seek medical care and may find the entire experience uncomfortable and anxiety-provoking. Given how much patient reporting matters for diagnosis, how might equity-informed, human-centered design expertise be routinely undertaken with diverse populations to create solutions to advance equitable diagnostic excellence?

The Diagnostic Process Often Starts Outside the Medical System

Systems thinking for fully understanding the inequities present in the diagnostic process requires expanding outside the medical system’s typical purview. If the process begins in the health system, a large part that happens before a person officially becomes a patient could be missed, including prior symptoms or concerns and the influence of family members and friends on a person’s health decision-making. Also missed may be the insights that members of historically marginalized communities contribute to a vision of diagnostic excellence that includes learning from their lived experiences and activating their social networks over the course of an unfolding diagnostic process. Diagnostic excellence could be enhanced when the system of diagnostic practice is not restricted to a medical lens but also viewed through a complementary sociological lens that heightens attention on how the social world shapes diagnosis (eg, trust in health care, stigmatized conditions, familiarity and comfort with digital health).8,9

Diagnostic Care Coordination With an Equity Lens

Systems thinking prioritizes attention to connections between interacting parts. For the goal of equitable diagnostic excellence, what are the connections between what happens inside the medical system and what happens outside that matter most for addressing diagnostic disparities and contributing to health equity? Ever-present changes to models of care and payment systems strongly influence the diagnostic process for healthcare professionals, patients, and patients’ care partners, but the equity consequences of such instability that are related to the many dimensions of diagnosis receive minimal attention. For example, a change in insurance coverage can set off a cascade of challenges (eg, new physician, inconvenient location, difficulty getting an appointment, medical record discontinuities) that could heighten the likelihood of delays in diagnosis for some groups more than others. A patient-centered focus on disconnections in diagnostic processes would be helpful, especially to address the extra challenges among people from communities with greater risks for diagnostic inequity.

The Path to Diagnostic Equity

The path to health equity in diagnostic excellence is simultaneously simple and difficult to envision. The simple side involves the concept of identifying and implementing the most effective equity-enhancing actions while also monitoring in real time for equity gaps using diagnostically salient measures. On the difficult side, each part of the concept requires designing solutions based on a thorough participatory process with people at risk of diagnostic inequities and medical system professionals who have barely started to join together on the broad issue of diagnostic excellence, much less on that which would embed equity and safety in all aspects of such design work, followed by equity-informed implementation. In tandem with other contributors (eg, pharmacoequity10), progress on health equity depends on fair and just access to working to achieve diagnostic equity.

Key Points for Diagnostic Excellence

1. Inequitable health outcomes can originate from diagnostic inequities
2. A spectrum of group attributes, such as age, race and ethnicity, disability, income, and gender identity, can increase the risk of diagnostic inequity
3. Countering diagnostic inequity requires beginning outside the health system and attending to factors that shape how diagnostic care is accessed and experienced
4. Progress toward equity in diagnosis should involve systems thinking to incorporate many relevant parts and a participatory approach to system redesign with those at risk of diagnostic inequity

ARTICLE INFORMATION

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1. Nundy S, Cooper LA, Mate KS. The quintuple aim with other contributors (eg, pharmacoequity10), progress on health equity depends on fair and just access to working to achieve diagnostic equity.