



## Optimizing the Patients' Voice in Diagnostic Equity

Prepared by staff at the National Health Council  
Silke Schoch, MA and Omar A. Esconrias, DrPH, MPH

### I. Executive Summary

Achieving the diagnostic process for patients is a public health imperative. The realities and disparities that prevail today for many patients in the health care system can often be linked to a diagnostic error. According to a formative report authored by the National Academy of Medicine, *Improving Diagnosis in Health Care*, diagnostic errors occur in approximately 60% of patients, accounting for 40,000-80,000 deaths per year.<sup>1</sup> These gross statistics confirm the necessity to improve health care quality, safety, and diagnostic performance. In partnership with AcademyHealth, the National Health Council (NHC) conducted a series of listening sessions to understand the lived experiences of patients through the diagnostic process. From January-February 2024, three listening sessions were facilitated with large and medium sized patient advocacy organizations and patients/caregivers. A structured questionnaire was developed by using the NHC's Patient Experience Mapping Toolbox and data from key informant interviews conducted by AcademyHealth in diagnostic equity. Through qualitative analysis, several themes emerged in regard to the diagnostic process: Medical Education; Disbelief or Refusal to Conduct an Exam or Test (Clinician); Reluctance to Enter or Continue Care in the Healthcare System (Patient); Discrimination and Bias Based on Race, Gender, Language, or Perceived Social Status During Diagnosis; Economic Realities; Patient-provider Concordance; and Availability of New Delineated Data. Though these themes may explain some barriers and challenges for patients when receiving a diagnosis, they also provide opportunities to shift the paradigm in diagnostic performance to drive innovation and mitigate diagnostic errors by centering the patient and communities. This summary provides a comprehensive overview of this project.

### II. Background

#### A. Purpose of Study

The purpose of this study was to conduct a series of listening sessions with patient and patient advocate experts to understand the range of factors that influence diagnostic equity across the domains of patient access, experience, and outcomes and explore patient-, clinician-, system-, and policy-related challenges that contribute to diagnostic inequities and delays. The National Academy of Medicine has noted that "diagnostic errors account for almost 60% of all medical errors and an estimated 40,000-80,000 deaths per year."<sup>1,2</sup> The majority of deaths due to these errors can be attributed to diseases and conditions such as infections and sepsis, cancer, and cardiovascular events like heart attacks and strokes. There are three parts in a high-quality diagnostic

process—the **diagnosis should be accurate, timely, and communicated** in a way that the patient/family and caregivers understand what it is and what the next clinical steps are.<sup>3</sup> A diagnostic delay or error is a breakdown in any, or all, of those three components. Inequities in the diagnostic process can lead to further errors or delays. These can be exacerbated by the social determinants of health.<sup>4</sup>

## **B. Role of Project Team**

Funding for this study was provided by the Gordon and Betty Moore Foundation. The concept and foundational research for this study originated with AcademyHealth, a research organization that works to improve health and the performance of the health system by supporting the production and use of evidence to inform policy and practice. The listening sessions were conducted by patient engagement experts at the NHC, a nonprofit that was founded over 100 years ago and whose mission is to provide a united voice for the 160 million people living with chronic diseases and disabilities and their family caregivers.

### **Project Team**

- Michael E. Gluck, PhD, MPP, Vice President, AcademyHealth
- Allison Isaacson, MPH, Senior Manager, AcademyHealth
- Lydia Babcock, MA, MPH, Senior Research Associate, AcademyHealth
- Omar A. Escontrías, DrPH, MPH, Senior Vice President, Equity, Research and Programs, National Health Council
- Silke Schoch, MA, Director, Research and Programs, National Health Council

## **C. Previous Findings**

In 2023, AcademyHealth conducted 21 expert interviews with clinicians, researchers, and patient advocates. During this research they found that inequities occurred through race and ethnicity, gender, socioeconomic status, age, geographic location, disability status, citizenship status, and sexual identity and orientation.<sup>5</sup> The interviews revealed the importance of issues such as intersectionality, trust and engagement, health care costs, social needs, health literacy and fluency, bias, and diagnostic overshadowing. Participants emphasized the need for clinicians to actively listen to patients and caregivers and utilize better methods to probe for information. Suggested future research and solutions included having better sociodemographic data available to researchers, using mixed-methods research approaches in studies, researching diagnostic inequity from the patient's viewpoint rather than the clinicians or hospitals, and having an inclusive and diverse study populations.

## **III. Methods**

### **A. Role of Patient Moderator**

To center the patient voice in this work, and equalize power dynamics between participants, the NHC recruited a patient moderator for this study. Suzanne Schrandt, JD, Founder of ExPPect, and the patient moderator for these sessions has 20 years of experience as a patient instructor in clinical training initiatives aimed at increasing early diagnosis and appropriate, patient-centered management of chronic disease.

## **B. Recruitment & Virtual Listening Sessions**

Patient advocate attendees for the listening sessions were recruited from the NHC's membership. Made up of more than 160 national health-related organizations and businesses, the NHC's core membership includes the nation's leading patient organizations. Patients and caregivers were recruited by the patient moderator through their general advocacy work and projects with the Society to Improve Diagnosis in Medicine. The virtual listening sessions were divided into main three categories:

- I. Listening Session #1: Large patient advocacy groups focusing on conditions such as cancer, infections, and heart conditions,
- II. Listening Session #2: Medium-sized patient advocacy groups that focus on different levels of disease incidence and prevalence, acuity, and characteristics of patients, including rare and autoimmune disease patients, and
- III. Listening Session #3: Patient representatives and or caregivers from organizations or other institutions representing a variety of conditions including cardiovascular, cancer, and rare disease.

Recruitment began in December 2023 and the sessions were conducted in January and February 2024 over Zoom. Twenty-seven (n=27) experts were invited to participate and eighteen (n=18) accepted. Listening session attendees were offered compensation in the form of an honorarium of \$350 each. This is in line with the NHC's patient engagement Fair-Market Value Calculator.<sup>6</sup>

## **C. Listening Session Guide Development**

The listening session guide was developed by the NHC utilizing *AcademyHealth's Guide for Semi-structured Key Informant Interviews to Better Understand Diagnostic Equity* as a framework in conjunction with the National Health Council's validated qualitative interview research guide, from the Patient Experience Mapping Toolbox.<sup>7</sup> The patient moderator for the listening sessions reviewed the listening session guide to assess its application to patients and caregivers with lived experiences. Questions in the listening session guide were centered on diagnostic inequity encountered in both participant's personal spheres and advocacy work. Questions also explored how different populations experience the diagnostic process, life factors and social determinants of health that may affect diagnostic equity, culturally responsive care, policy and societal perspectives, methodology and innovations in diagnostic equity, and community engagement in diagnostic equity.

## **IV. Analysis/Results**

### **Demographics**

There were six (n=6) participants in each of the three listening sessions. Participants included executive level staff of patient advocacy organizations, and some participants had overlapping roles as patients themselves or were patients who had worked for a patient advocacy group (Table 1). Several of the patients involved in the listening sessions were multi-generational caregivers as well as patients (some with the same

condition as a family member). Patients were categorized below by their primary affiliation during the recruitment stage. There were a variety of diseases and conditions represented by participants including autoimmune, cancer, blood disorders, heart disease, mental health, and neurological diseases. Some of the patient advocacy group representatives also represented subgroups within each disease such as female patients or LGBTQ+ patients, and many of the participants specialized in health equity. Participants were from a variety of racial and ethnic, gender, sexual orientation, disease group, and geographical backgrounds. However, that data was not collected from each participant as part of this work, so it is not formally recorded in a demographics table.

### A. Position Titles, Job Roles, and Primary Condition Represented by Participants (Table 1)

Title/Job Role	(n)	Disease/Condition	(n)
Patient	5	Autoimmune	4
Caregiver	1	Bleeding Disorders	1
CEO/President	4	Cardiovascular	5
Chief Officer	2	Cancer	3
Executive Vice President/ Vice President	3	Infectious Disease	1
Senior Director/Director	3	Neurological	1
		Mental Health	1
		Rare Disease	2
<b>Total</b>	<b>18</b>	<b>Total</b>	<b>18</b>

Data source: Diagnostic Equity Listening Sessions, National Health Council, 2024.

### B. Thematic Analysis

*“[It] is just fatigue and not fatigue from chronic or acute illness that we're all aware of, but the fatigue of fighting against the system at every phase.”*

– Moderator in response to attendee comments

An analysis of the listening sessions demonstrated that diagnosis problems can stem from a lack of provider education and training, provider refusal to conduct an exam or test, a reluctance on behalf of the patient to enter the healthcare system, discrimination during diagnosis, and economic and financial issues related to access. These issues are intertwined with bias. In rare disease spaces, the cost of testing multiple times, finding a specialist for diagnosis, and the availability of screenings for newborns was an important issue. Patients living in rural areas of the United States where there may be a dearth of specialists or providers with up-to-date medical information was also noted as a barrier to receive accurate and timely diagnoses. Lastly, patient advocacy organizations are concerned with the lack of current delineated data on their constituency. It is difficult for them to conduct research and educational awareness campaigns without useful data.

Some patients and patient advocates described positive experiences when receiving a diagnosis. This was due to several factors: significant health literacy (often years of

being an advocate), higher social status (i.e., career or working in a healthcare adjacent field), or because of patient-provider concordance (i.e., an African American provider). Some patients went through multiple providers until they found one who listened to their concerns.

A total of seven themes emerged through this analysis:

1. Medical Education
2. Disbelief or Refusal to Conduct an Exam or Test (Clinician)
3. Reluctance to Enter or Continue Care in the Healthcare System (Patient)
4. Discrimination and Bias Based on Race, Gender, Language, or Perceived Social Status During Diagnosis
5. Economic Realities
6. Patient-provider Concordance
7. Availability of New Delineated Data

Below are illustrative quotes (Table 2) that elucidate these points in accordance with the emerged themes.

### Common and Overarching Themes of Patient/Caregiver/Patient Advocate Listening Sessions (Table 2)

Theme	Illustrative Quote
<b>Medical Education</b>	<p>“One of the big challenges is [that in] diagnostics there is no cataloging specifically for people of color. If you present with a disease, an autoimmune disease...that results in a longer journey to diagnosis simply because <b>there is not a catalogue, in effect a diagram book of what these diseases look like when they are on people with darker skin or skin tones that are not considered white.</b>” –Listening Session #2 Patient Advocacy Organization Leader</p> <p>“[Bleeding disorders in females] cannot be explained by the way we explain bleeding in males, and part of that is lack of education. Part of that is that they’re not believed. <b>When a male walks in, he says, I have an internal bleed in my knee. Everybody says, okay, when a woman says I’m having a horrible period, we ask them to measure it. How many cc’s do you bleed a month?</b>” –Listening Session #1 Patient Advocacy Organization Leader</p> <p>“There’s bias in the dementia care system, and we’ve got to also think about it from the provider perspective. <b>Enhancing opportunities for cultural competence, humility, standards, and training.</b>” –Listening Session #1 Patient Advocacy Organization Leader</p>
<b>Disbelief or Refusal to Conduct an Exam or Test (Clinician)</b>	<p>“[The] scariest thing at this point is cardiology issues and major family history of it. <b>It’s probably taken me over 4 to 5 years of fighting with my primary care and my rheumatologists to actually get a cardiac counsel.</b>” –Listening Session #3, Patient</p> <p>“...what we hear day in, and day out is that the journey inevitably passes through months, if not years, of believing that [heart disease in women] is a mental health issue. And the gaslighting that person is experiencing in the health care system becomes internalized, so they go, ‘yeah it must</p>

	<p>be.' It must be anxiety. It must be depression because I'm still having these symptoms, but they say, the clinicians say it isn't a heart condition." <b>So, I think that to me that's probably one of the most infuriating things about the process, the drawn-out process of getting a diagnosis not believing your instinct, or having to forego your instinct because everyone is telling you, "Nope you're wrong."</b> –Listening Session #2, Patient Advocacy Organization Leader</p> <p>"Around 5 days postpartum is when I started having a shift in mental state. I just [knew]... something was wrong. I was really confused, and I <b>remember having to urge and plead with the nurse manager like, "please come and check on me. Something is wrong. I don't feel right."</b> And sure enough, it was actually a subarachnoid brain hemorrhage, which is a type of stroke..." –Listening Session #3, Patient</p> <p>"I was in the middle of doing laundry when I had started having the first signs of something's wrong, cause I couldn't figure out the buttons on the washing machine. So I was like, uh oh, and then, I don't sweat. I started sweating profusely. But my doctor, previously to this, kept saying that my job was stressing me out... So my doctor recommended [that] I quit my job. So my doctor started recommending holistic approaches to things. <b>Throughout that whole time, her knowing that my father had a stroke, all these different things in my family's history, she never gave me a physical [exam]. I never had a physical.</b>" –Listening Session #3, Patient</p> <p>"But one of the common threads that we continue to see is that [women's] symptoms were not taken seriously. <b>They're being told they're overdramatic. Told their stressed or even themselves not having confidence in their own symptoms to go see a doctor.</b>" –Listening Session #1, Patient Advocacy Group Leader</p>
<p><b>Reluctance to Enter or Continue Care in the Healthcare System (Patient)</b></p>	<p>"We're dealing with the situation where you've got some state attorney generals trying to subpoena records about how many people are going for medical transition. <b>Whether or not those documents are safe and preserved, and HIPAA being respected, is another major concern for LGBTQ folks these days that keeps us out of doctors' offices.</b>" –Listening Session #2, Patient Advocacy Group Leader</p> <p>"<b>We see a lot of undocumented women who are afraid to seek care because they don't know what that's going to mean in terms of alerting authorities [about] their situation.</b>" –Listening Session #2, Patient Advocacy Group Leader</p> <p>"<b>The number one reason that those that individuals from the LGBT+ community don't seek care is because of discrimination. Right? So they won't.</b> They maybe think they have a family history. But they're not going to go seek that full diagnosis right? Because of that discrimination from healthcare providers. So they're gonna delay diagnosis, and then when they do, they know that they're going to have to endure sometimes health professionals in the health and healthcare setting that can be, you know, discriminatory, right and can be not too, not helpful in the system." –Listening Session #1, Patient Advocacy Group Leader</p>

<p><b>Discrimination and Bias Based on Race, Gender, Language, or Perceived Social Status During Diagnosis</b></p>	<p>“And so, looking back so the reflectiveness of it, <b>I can look back and say, yeah, I think the way I dressed play a huge part in me being taken serious.</b>” –Listening Session #3, Caregiver</p> <p>“So there's this other type of caste or hierarchy system that's in play as well, so there's a multitude of things that really play part in why, we had a delay and a misdiagnosis, one being race and gender [and rank bias]. <b>I came back the next day, they understood that I was an officer [in the Armed Forces]...and I tended to get a little more attention to the things that were, the problems, or the concerns that I had.</b>” –Listening Session #3, Caregiver</p> <p>“I do think the color of my skin had a great impact on my care, and I've seen this in our community as a patient advocate. You know so many patients with sickle cell feel like they have to get dressed up and do their hair and present themselves in a different way when they go to the ER in pain. So they're taken serious, and I myself have done that. In fact, <b>when I had my third stroke, I felt like I needed to change my shirt, comb my hair and take a shower.</b> That has been ingrained in my thought process when I go to the hospital, I need to present myself in a different way to be taken serious.” –Listening Session #3, Patient</p> <p>“So I think once someone gets into a doctor's office or clinics office. The other barriers that they may encounter, whether it comes through comes through their gender comes, through their race. <b>And then language, we're finding language is really can really be that barrier right? Just to be able to communicate with your healthcare team to even clearly understand.</b> You know what are the symptoms? What are the other factors outside of clinic space? So those other social determinative health factors?” –Listening Session #1, Patient Advocacy Group Leader</p>
<p><b>Economic Realities</b></p>	<p>“<b>There's monetary issues that come with having to see a specialist across the country [for children with rare diseases not diagnosed at birth].</b> We did a follow up study on a comparison on 7 different rare diseases, what would happen in a family who receive a timely diagnosis [compared to a] family who does not receive a timely diagnosis. We found that on average families who did not receive a timely diagnosis spent roughly \$220,000 a year trying to find a diagnosis for their child.” – Listening Session #2, Patient Advocacy Group Leader</p> <p>“<b>The thing that just comes to mind for me [is] economic. LGBTQ folks [are] more likely to be unemployed, [and] more likely to have lower income jobs.</b> And folks with less income can't take the time off work to do 5 rounds of different tests to make absolutely sure you've got the right diagnosis.” –Listening Session #2, Patient Advocacy Group Leader</p> <p>“And [diagnosis] often can require multiple trips to a healthcare professional. <b>And so there's an economic inequity built in there, too. If you have a job where it's not easy for you to take time off work or get to that doctor's appointment during those core 9 to 5 hrs of the day.</b>” –Listening Session #1, Patient Advocacy Group Leader</p>

<p><b>Patient-provider Concordance</b></p>	<p>“I think, of the lack of medical professionals that are representative of the communities they serve. We know the rates for physicians. And then when we look at more specialized physicians, right, those numbers get even lower when it comes to whether it's women, whether it's about race or ethnicity or sexual orientation. <b>And so that is why I think it's so important we also look at the representation of professionals that are represented of the community because that's part of the diagnosis. If you don't have that same lived experience, or you can't see yourself [as] a particular patient, that contribute[s] to the diagnostic process, and how we can overcome diagnostic inequity.</b>” –Listening Session #1, Patient Advocacy Group Leader</p> <p>“I've heard many stories from our African American [women with heart disease patients] who say I didn't really get the care that I knew I deserved until I started to see an African American female cardiologist. So, to me, that's a really important social determinant. If you are not able to connect with a provider that just gets you because they've had similar lived experience because of culture, etc. I think that's a real issue.” –Listening Session #2, Patient Advocacy Group Leader</p> <p>“We switched doctors and to a private care [at the] VA. <b>I found an African American doctor, and what a difference in care! What a difference!</b> And I think that helped me when I had my stroke.” –Listening Session #3, Patient</p>
<p><b>Availability of New Delineated Data</b></p>	<p>“I think a couple of things in our line of work in the [health care associated infections where] research around race/ethnicity, sexual orientation [is needed]. <b>You know, the data that we have is old. It's incomplete. Certainly there's ways that we could use health services research to really advance that.</b>” –Listening Session #1, Partner of a Patient Advocacy Group Leader</p> <p>“<b>The disease numbers that we have now are 20 years old, and they are extrapolated from data that was Danish.</b> And you know Denmark doesn't look anything like we do. Now some of those have been updated...those numbers as an aggregate reflect 29 [autoimmune] diseases, and we reflect over 150 of that data.” –Listening Session #2, Patient Advocacy Group Leader</p> <p>“I can tell folks that we know that LGBTQ folks are 4 times as likely to attempt suicide. <b>I also have to tell you that I have no idea how many LGBTQ people die by suicide every year, because we do not have that data.</b> So many of the major government data sets simply do not speak to sexual orientation or gender identity. We are finally getting to the place where HHS is rolling out a data plan[s] to include [certain] questions.” –Listening Session #2, Patient Advocacy Group Leader</p>

Data source: Diagnostic Equity Listening Sessions, National Health Council, 2024.



### **C. Barriers to Diagnosis**

As noted above there were several themes that illuminated problems in the patient's experience when:

- 1. Entering the healthcare system**
- 2. Receiving a diagnosis during emergency care**
- 3. Struggling for multiple years to receive a diagnosis**

Patients reported having to go through numerous hurdles to receive a diagnostic test, even if they had a family history of having the disease or had a chronic condition that causes multi-system disorders (i.e., arthritis can cause cardiovascular disorders, but the patient was unable to get a cardiac exam for years). Patient advocacy organizations noted that their female constituents reported frequent gender bias, especially in the cardiovascular space where patients were met with the suggestion that their condition was a mental health-related issue. African American patients and caregivers reported needing to dress or speak a certain way so that they would be taken seriously at the ER with one patient reporting that they delayed care for a stroke so that they could change their clothes. LGBTQ+ patients and patient advocates reported that some patients would not enter the health care system at all due to anticipation and the fear of bias or even violence from healthcare providers and staff. LGBTQ+ patients may also attend appointments with "chosen family" rather than a spouse or a parent and want their support network to feel included in care. Language and health literacy was frequently noted to be a potential barrier to high-quality care, with some patients also being reluctant to disagree with providers due to their cultural background and perceptions of hierarchy. Patients also had concerns about being seen as "drug-seeking" when they went to the ER, so would forego or delay care. Rare disease patients, caregivers, and patient advocates had unique challenges due to the often strict and high-cost diagnostic testing needs that are sometimes only available in a small amount of academic centers. This was intertwined with considerations around rural care, where research on prevalence of conditions and outcomes is lacking.

Health system problems such as time spent with each patient and provider shortages were noted to be frequent problems. Patients and patient advocates wished they could spend more time with their providers or have their providers involved in holistic parts of their care. Some noted that they felt that providers work too many hours due to incentives from the health care system and that nurses were not paid fairly, and that this can lead to poor quality care and access issues. Patient advocates also felt that academic medicine does not focus enough on diversity in disease presentations. For example, autoimmune conditions in people with darker skin tones are not represented frequently in medical textbooks. Cultural humility and competency were also barriers that advocates felt could be improved upon in medical education. Although one participant noted that they are receiving pushback from providers on anything providers perceive as "diversity, equity, or inclusion (DEI)-related."

#### **D. Health Services Research**

***“So we believe that the answers are in the community. That’s why we’re doing a lot more of local impact investing in local communities. We really want to get on the ground... Yes, patients, communities, and understanding what was that barrier to that first access right to a diagnosis. Whether it was stigma, whether it was actual economics, whether it’s, location, geography, and a number of other factors.”***

–Listening Session #3

Many participants cited the need for researchers to look into the community to prioritize research needs and solutions. Patient advocacy organizations are increasing efforts in local communities, especially to address social determinants of health and other disparities. Ultimately patients and patient advocates emphasized the following themes and questions they think are important for health services researchers to delve into:

- Diagnostic tests/guidelines that are inclusive of everyone (i.e., gender differences in diagnostic tests)
- Availability of healthcare facilities and diagnostic outcomes
- Including social determinants of health, behavioral, and environmental factors into research (i.e., how does transportation affect people seeking care? Insurance? Health literacy? Rural vs. Urban?)
- Artificial intelligence and equity and diversity
- Pay-for-performance incentives and outcomes in diagnosis
- Utilizing mixed-methods research approaches
- Community-based research

Some of the other topics that were raised include collecting data on race, ethnicity, and sexual orientation specifically in healthcare associated infections; food and nutrition being studied as an important aspect of preventive care, considerations in genome sequencing and genomic testing of children, and diagnostic stewardship. Patients and patient advocates report that it is difficult to prioritize which research questions should be answered first because the needs of communities are overwhelming. They shared that even small steps forward and addressing those easy issues first is a way to make a foothold into the issue.

#### **E. Societal and Policy Needs**

The patient advocate leaders, patients, and caregivers identified the following societal and policy needs that would help them in their work or improve the lives of patients like them:

- Access to up-to-date, delineated data
- Bias training at every level of care and health system interaction
- Increased Patient and Family Advisory Councils (PFACs) in hospital systems
- Better measurement of care provided to patients (i.e., tracking diagnosis issues/discrimination)
- Pay-for-performance incentives in care/outcomes-based care.

The patients and caregivers in these listening sessions were very interested in participating in research, advisory boards, and leadership positions where they could improve diagnosis and outcomes for other patients. Patients were also invested in opportunities to give recommendations in the “C-suite” to provide their point of view at the top of the power hierarchy. While comments about the diagnosis and the attitude of providers was an overarching theme, patients and patient advocates also noted that there should be changes to the way data is collected and coded. One participant shared that when they told their provider they were a lesbian in response to a question about pregnancy status, they had “high-risk homosexual behavior” added in their notes. The provider in this case responded that their coding system was old, and they did not have another place to list the patient’s sexual orientation. Another participant cited common patient fears about the repercussions of the qualitative comments section of provider notes leading to later bias in diagnoses. Overarching societal problems like systemic racism were acknowledged, and participants felt that chipping away at any equity issues, no matter how small, could help correct the trajectory of these problems.

## **V. Conclusion & Recommendations**

Researchers addressing diagnostic equity and inequity must go to patients, caregivers, patient advocacy organizations, and the community to identify and prioritize needs. Patient advocacy organizations have often done research in this space and have made strides in addressing diagnostic inequities in their populations. However, the problem requires changes to the entire system. Researchers need to capture information on patients who not only go into the healthcare system and whose symptoms are dismissed, but also patients who never enter the healthcare system when they are experiencing symptoms because there are concerns they will face discrimination and even worse outcomes to their health and safety. Researchers must also account how biases beyond race and gender may affect diagnosis such as the perceived social status of the patient and their health literacy. The advent and rise of artificial intelligence, which has been cited as a solution to some of these issues, has concerned patient advocacy leaders due to ethical and equity problems and whether it will help mitigate disparities or widen them. Given the complexities in diagnostic inequities, coalesced efforts are warranted to improve the staggering disparities that prevail today.

## **VI. Acknowledgements and About the Authors**

The NHC would like to thank AcademyHealth for their incredible trailblazing work in diagnostic performance and excellence and for entrusting us to conduct these listening sessions. The NHC is grateful to the countless patients, patient advocates, and patient advocacy organizations for their participation in the listening sessions and for their ongoing advocacy work to improve health equity. Our gratitude is also extended to the Gordon and Betty Moore Foundation for funding this important work. This summary report was prepared by Ms. Silke Schoch, the NHC Director of Research and Programs and Dr. Omar A. Escontrías, the NHC Senior Vice President, Equity, Research & Programs.

## VII. Suggested Citation

Schoch S & Escontrías O. Optimizing the Patients' Voice in Diagnostic Equity. National Health Council. February 2024.

## VIII. References

1. Committee on Diagnostic Error in Health Care, Board on Health Care Services, Institute of Medicine, The National Academies of Sciences, Engineering, and Medicine. *Improving Diagnosis in Health Care*. (Balogh EP, Miller BT, Ball JR, eds.). National Academies Press (US); 2015. Accessed February 10, 2024. <http://www.ncbi.nlm.nih.gov/books/NBK338596/>
2. Research on Pre-Hospital Diagnostic Delay | AcademyHealth. AcademyHealth. Accessed February 9, 2024. <https://academyhealth.org/about/programs/research-pre-hospital-diagnostic-delay>
3. Balogh EP, Miller BT, Ball JR, et al. The Diagnostic Process. In: *Improving Diagnosis in Health Care*. National Academies Press (US); 2015. Accessed February 15, 2024. <https://www.ncbi.nlm.nih.gov/books/NBK338593/>
4. Social Determinants of Health - Healthy People 2030 | health.gov. Healthy People 2030. Accessed February 9, 2024. <https://health.gov/healthypeople/priority-areas/social-determinants-health>
5. Ndugga N, Published SA. Disparities in Health and Health Care: 5 Key Questions and Answers. KFF. Published April 21, 2023. Accessed February 12, 2024. <https://www.kff.org/racial-equity-and-health-policy/issue-brief/disparities-in-health-and-health-care-5-key-question-and-answers/>
6. National Health Council Patient Engagement Fair-Market Value Calculator. Published online June 2020. Accessed December 15, 2023. <https://nationalhealthcouncil.org/fair-market-value-calculator/>
7. Oehrlein EM, Schoch S, Majercak K, et al. Development and Testing of a Chronic-Disease Patient Experience Mapping Toolbox. *The Patient*. Published online January 3, 2024. doi:10.1007/s40271-023-00658-3