

Proceedings of a Workshop Series Highlights

# Advancing Diagnostic Excellence

# **A Workshop Series**

To examine opportunities for improving diagnosis within the U.S. health care system, the National Academies of Sciences, Engineering, and Medicine hosted a series of six workshops. The series, which was requested by the Gordon and Betty Moore Foundation, focused on conditions and populations associated with a disproportionate share of diagnostic error and patient harm. Workshop participants highlighted unique challenges faced in achieving diagnostic excellence, opportunities and obstacles to improving diagnosis, and strategies and interventions to promoting diagnostic excellence across the care continuum. Topics included:

- Diagnosis of sepsis (Workshop 1, August 2020)
- Diagnosis of acute cardiovascular events (Workshop 2, April 2021)
- Cancer diagnosis (Workshop 3, October 2021)
- Diagnostic lessons learned from the COVID-19 pandemic (Workshop 4, January 2022)
- Diagnostic excellence for older adults (Workshop 5, July 2022)
- Diagnostic excellence for maternal health care (Workshop 6, July 2023)

## EMPHASIZING PATIENT-CENTERED CARE

The workshops highlighted strengthening patient-centered care to improve the diagnostic process and achieve optimal health outcomes.

Tamika Felder, Cervivor, described empowering patients to be proactive and communicate their thoughts and questions to clinicians. The importance of listening to patients to improve diagnosis was also emphasized throughout the workshops. Although studies have shown that 80 percent of diagnoses can be made by listening to what a patient says, the average clinician interrupts a patient's story within approximately 18 seconds, said Beverly Canin, SCOREboard Patient Advocate Board. Similarly, Ann Borders of the Illinois Perinatal Quality Collaborative described patients as experts of their own experience and advocated for allowing them to make choices through accessible and nonjudgmental communication.

Rick Bright, The Rockefeller Foundation, described the shifting of diagnostics into patients' homes and how that move has empowered patients to play a larger role in their own health care. However, Steven Schachter, Harvard Medical School, also cautioned that as these tests move closer to the patient, support should be available to help patients accurately interpret and act on the results they receive.

## STRENGTHENING CLINICIAN AND PATIENT EDUCATION

Education for clinicians and patients emerged as a need across conditions and populations in workshop discussions. Sharon K. Inouye, Harvard Medical School, called for education and training across health professions to include assessment of atypical presentation and the impacts of declining cognition and mobility in older adults. Kathleen Kerrigan, University of Massachusetts Chan Medical School, highlighted the importance of enhancing the obstetric curriculum and encouraging simulations and drills in education for emergency care providers.

Increased patient education can also help to improve accurate and timely diagnoses. Christine Goeschel, MedStar Health, suggested more education campaigns for patients and families on the signs and symptoms of sepsis to promote earlier identification and diagnosis. Opeolu Adeoye, Washington University, emphasized the lack of awareness of stroke symptoms in underserved communities, and said that even emergency medical service providers are often limited in their recognition of symptoms, which makes it difficult to ascertain fast and effective triage and can delay treatment. Adeoye and Jeffrey Kline, Indiana University School of Medicine, called for more training and education campaigns to improve public awareness of the signs and symptoms of both stroke and pulmonary embolism to facilitate prompt diagnosis and treatment.

# DEVELOPING INNOVATIONS IN TECHNOLOGY AND CARE DELIVERY

Harnessing data and technologies to improve diagnosis was a consistent theme across the workshops. Eric Topol, Scripps Research Translational Institute, noted that machine learning (ML) and artificial intelligence (AI) technologies have the potential to improve the quality of diagnosis for acute cardiovascular events, but accomplishing those goals will require large, high-quality clinical datasets and data sharing among health systems. Workshop speakers highlighted the ongoing work and potential benefits of harnessing data through AI and ML to identify biomarkers for improving diagnosis, but they also said successful use of these technologies will require a user-centered design and effective integration into the clinical workflow. Caroline Thompson, University of North Carolina at Chapel Hill, highlighted the need to create more data linkages between Medicaid and cancer registries to better understand patterns of patient navigation in the health care system. Similarly, Bright suggested linking diagnostic test results to the delivery of appropriate and timely treatment to achieve better health outcomes.

Across the workshops, the value of virtually connecting patients and clinicians was also discussed. Sindhu Srinivas, University of Pennsylvania, highlighted a successful program for remote blood pressure monitoring whose clinical trial participants saw reduced postpartum hypertension readmission and even 6 months later had lower levels of adverse outcomes. Moreover, when discussing new technologies, Maryellen Giger, University of Chicago, and Raj Ratwani, MedStar Health, mentioned the importance of intentionally creating unbiased systems and algorithms and including patients in the development process.

#### IMPROVING THE HEALTH CARE SYSTEM FOR DIAGNOSIS

Workshop speakers called attention to the fragmented systems of care delivery that continue to challenge diagnostic excellence and described health care system-level efforts to improve the diagnostic process. Jasmin Tiro, University of Texas Southwestern Medical Center, emphasized improving care coordination and diagnostic pathways for cancers, but also noted that such improvements would require shared clinical information systems and more structured results to optimize workflows. Pascale Carayon, University of Wisconsin–Madison, highlighted that diagnosis is an iterative process embedded in multiple work systems, not a single event, with opportunities for continuous quality improvement. Thus, Goeschel said, diagnostic improvement requires engagement and accountability from the entire health team, as well as engagement and feedback from patients, families, and caregivers.

System-level efforts include collecting high-quality data to drive practice change and improve patient care (Kathy Tossas, Virginia Commonwealth University, and Gary Weissman, University of Pennsylvania), developing novel biomarkers and predictive analytics to identify high-risk patients (Vincent Liu, Kaiser Permanente), and using policy levers for quality improvement (Jeremy Kahn, University of Pittsburgh, and Jennifer Moore, Institute for Medicaid Innovation). Zsakeba Henderson, National Institute for Children's Health Quality, said that statewide perinatal quality collaboratives have improved maternal outcomes, but she called for continued investment. Christina Davidson, Texas Children's Hospital, suggested stratifying quality measures by demographics and implementing a disparities dashboard to achieve health equity in maternal health care. Arlene Bierman, Agency for Healthcare Research and Quality, and Inouye called for fundamentally shifting the health care system and culture to be age-friendly and personcentered by aligning with the goals of patients.

#### IMPROVING EQUITY AND REDUCING DISPARITIES

Improving equity in access to high-quality diagnosis was an overarching theme across the workshops in which disparities in patients' access to care and health outcomes were discussed. Adriann Begay, HEAL Initiative, suggested strategies to mitigate disparities, such as reducing barriers to access, increasing clinician cultural competence and awareness, and enhancing data collection from historically underrepresented and marginalized populations. Urmimala Sarkar, University of California, San Francisco, emphasized the importance of evidence-based communication practices such as teach-back and literacyappropriate communication to improve patient-clinician communication and reduce disparities in diagnosis. To improve equity in cancer screening and diagnosis, Felder and Tossas suggested leveraging patient navigation and implementation science. Chyke Doubeni, Mayo Clinic, discussed examining social determinants of health (SDOH) to address disparities in cancer screening and diagnosis. Charlie P. Hoy-Ellis, University of Utah, highlighted examining structural and individual levels of discrimination and considering the entire context of a person's life during health assessments to promote health equity. Henderson offered approaches to reduce disparities, including addressing implicit bias, structural racism, and SDOH.

Each workshop also discussed the importance of community engagement to mitigate disparities: by improving community education on stroke detection to reduce time between diagnosis and treatment (Ava Liberman, Weill Cornell Medicine); leveraging local community health workers to educate women about the need for screenings (Electra Paskett, The Ohio State University); partnering with community health clinics to increase access to underserved populations (Chau Trinh–Shevrin, NYU Langone Health); and strengthening community, patient, and clinician collaboration to reduce disparities in health outcomes (Jennie Joseph, Commonsense Childbirth Inc.).

## **IDENTIFYING RESEARCH PRIORITIES**

The workshops also highlighted opportunities for research to advance diagnostic excellence. Inouye and Kerrigan called for expanding the inclusion of underrepresented populations in clinical trials and research studies (e.g., older adults, pregnant patients). Strategies were discussed to enhance data quality. Trinh–Shevrin called for disaggregating data to reduce misclassification errors and better understand the nature and prevalence of COVID–19 disparities. Both Herman Taylor, Morehouse School of Medicine, and Henderson discussed the role of social factors, including SDOH and demographic data, in contributing to diagnostic disparities such as delayed diagnosis of acute cardiovascular events and maternal health conditions.

Elizabeth Sarma, National Cancer Institute, highlighted the importance of collecting data to describe prediagnosis care and diagnostic pathways in the U.S. health system. Liu discussed using diverse data sources to develop ML and AI tools for diagnosis. He suggested leveraging embedded research approaches within health systems and ensuring data interoperability for a learning health system to improve diagnosis. He also noted millions of data elements are being collected each day but remain in silos and are not contributing to building a better picture of understanding.

Laura Evans, University of Washington, emphasized that progress in advancing diagnostic excellence

requires moving beyond discipline silos to integrate novel strategies and collaborate across fields. Hallie Prescott, University of Michigan, highlighted the need to acknowledge diagnostic uncertainty in clinician decision making, which could increase care coordination and enable clinicians to tailor treatments to each patient.

Finally, the importance of effective communication to achieve diagnostic excellence was emphasized throughout the workshops. Canin said effective clinician-patient communication includes informing patients at each step of the diagnostic process and involving family members or caregivers in the communication process to ensure patients understand their diagnoses. She also highlighted fostering communication among all clinicians to support a team approach and improve care coordination.

Potential actions to advance diagnostic excellence suggested by workshop speakers throughout the series are presented in the box below.

# BOX

# Potential Actions to Advance Diagnostic Excellence Suggested by Workshop Speakers Throughout the Series

#### **Emphasizing Patient-Centered Care**

- Encourage active communication and participation of patients in their health care decisions to achieve optimal outcomes (Borders, Canin, Felder).
- Consider the whole person by listening to patients and their personal stories (Canin).
- Inform patients at each step of the diagnostic process and include family members and caregivers to ensure patients understand their diagnoses (Canin).
- Shift diagnostics closer to patients to empower their role in health care (Bright).

## **Strengthening Clinician and Patient Education**

- Expand clinician education and training on factors such as atypical presentation to improve accurate and timely diagnosis (Inouye, Kerrigan).
- Increase patient, family, and community education on signs and symptoms of conditions to promote earlier identification and diagnosis (Adeoye, Goeschel, Kline).

continued

# **BOX CONTINUED**

#### Developing Innovations in Technology and Care Delivery

- Support data infrastructure and connect health systems to more effectively share data and communicate with clinicians in real time (Thompson, Topol).
- Expand remote monitoring to improve timely and accurate diagnosis and encourage patient engagement (Srinivas).
- Link diagnostic test results to the delivery of appropriate and timely treatment (Bright).
- Create unbiased systems and algorithms and engage patients in the development of new technologies (Giger, Ratwani).

#### Improving the Health Care System for Diagnosis

- Encourage the engagement and accountability of the care team and engagement and feedback from patients, families, and caregivers through continuous quality improvement (Goeschel).
- Collect high-quality data to drive practice change and improve patient care (Sarma, Topol, Tossas, Weissman).
- Develop novel biomarkers and predictive analytics to identify high-risk patients (Liu).
- Use policy levers for quality improvement (Henderson, Kahn, Moore).

## Improving Equity and Reducing Disparities

- Increase clinician cultural competence and employ evidence-based communication practices to improve patient-clinician communication and reduce diagnostic disparities (Begay, Sarkar).
- Leverage patient navigation and implementation science to improve equity in screening and diagnosis (Felder, Tossas).
- To eliminate disparities, consider complex factors that contribute to health outcomes, including social determinants of health, inadequate access to health care, and structural and individual levels of discrimination (Doubeni, Henderson, Hoy–Ellis, Taylor).
- Strengthen community, patient, and clinician collaboration to reduce disparities (Joseph).

continued

# **BOX CONTINUED**

#### **Identifying Research Priorities**

- Expand inclusion of underrepresented and marginalized individuals in clinical trials and research studies (Inouye, Kerrigan).
- Collect disaggregated data to reduce misclassification errors (Trinh-Shevrin).
- Leverage embedded research approaches within health systems and ensure data interoperability for a learning health system to improve diagnosis (Liu).
- Foster cross-disciplinary collaboration and support a team approach (Canin).

#### FOR MORE INFORMATION

This Workshop Highlights was prepared by Jennifer Lalitha Flaubert, Sharyl Nass, and Megan Snair as a factual summary of what occurred at the workshops. The statements made are those of the rapporteurs and do not necessarily represent the views of all workshop participants, the planning committee, or the National Academies of Sciences, Engineering, and Medicine.

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For additional information regarding the workshop series, visit https:// www.nationalacademies.org/our-work/advancing-diagnosticexcellence-a-workshop-series.

The publications from this workshop series are available from the National Academies Press at (800) 624-6242 | http://www.nap.edu | http://www.nationalacademies.org

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