Improving Diagnosis in Health Care—Institute of Medicine Issues New Report

By Susan Carr  
Newsletter Editor

During a strategic planning retreat in the spring of 2013, leaders of the Society to Improve Diagnosis in Medicine (SIDM) asked themselves, "What can we do that would have the most impact on improving diagnosis?" (ML Graber, email communication, November 2015). *To Err Is Human,* the Institute of Medicine (IOM) report about medical error, attracted national attention when it was released in 1999 and spawned the current patient safety movement. Might an IOM report about diagnostic error—mentioned in *To Err Is Human* but largely ignored until recently—create similar momentum? At the retreat, board member Hardeep Singh, MD, called the IOM to ask what a report of that sort would cost to develop and produce ($1.5 million), a generous member stepped forward with a donation that made the impossible possible, and two-and-a-half years later, the report was released just prior to Diagnosis in Medicine (DEM), SIDM’s annual conference.

Between the idea’s conception and completion, with the support of other stakeholders interested in diagnostic safety, SIDM petitioned the IOM and raised the rest of the needed funding. The IOM (now part of the National Academies of Sciences, Engineering, and Medicine) convened a committee of experts, including SIDM leaders, with the broad range of expertise and knowledge necessary for developing the report.

The Cautious Patient Foundation provided more than half of the funding for the 2015 report, with additional contributions from a wide range of supporters:

- Agency for Healthcare Research and Quality
- American College of Radiology
- American Society for Clinical Pathology
- Centers for Disease Control and Prevention
- College of American Pathologists
- The Doctors Company Foundation
- Janet and Barry Lang
- Kaiser Permanente National Community Benefit Fund at the East Bay Community Foundation
- Robert Wood Johnson Foundation

The report, *Improving Diagnosis in Health Care,* consolidates existing research about diagnostic error and recommends actions designed to improve the process and outcome of diagnosis. Specifically, the report identifies eight goals for improving diagnosis and reducing diagnostic error:

1. Facilitate more effective teamwork in the diagnostic process among health care professionals, patients, and their families.
2. Enhance health care professional education and training in the diagnostic process.
3. Ensure health information technologies that support patients and health care professionals in the diagnostic process.
4. Develop and deploy approaches to identify, learn from, and reduce diagnostic errors and near misses in clinical practice.

Also in This Issue…
SIDM Supporters............................................3  
Patient Engagement Community and Committee...........................................4

Better Outcomes Through Better Diagnosis
Defining Diagnostic Error

A common adage says that a process or action must be measurable before it can be managed or improved, and anything that’s going to be measured must first be defined. Physicians and researchers—including SIDM President Mark L. Graber, MD, and members Gordy Schiff, MD, and Hardeep Singh, MD—had developed different definitions of diagnostic error; those definitions and others have been the subject of a perennial debate at the annual DEM conference. Which one would the IOM adopt?

The IOM Committee reviewed three established definitions of diagnostic error (Figure 1, page 3) and chose to create a new definition of its own, based on the principle that diagnosis has to be for and about the patient:

- The failure to (a) establish an accurate and timely explanation of the patient’s health problem(s) or (b) communicate that explanation to the patient.3(p3-4)

Some people find the new definition refreshing and accessible, while others are puzzled. Reactions, heard in discussions at DEM, include disappointment that the word diagnosis doesn’t appear in the definition, replaced by “explanation of the patient’s health problems.” The IOM’s definition is also notable in that reaching an accurate and timely diagnosis is no longer sufficient: if the diagnosis is correct but not communicated effectively to the patient, it is still considered a diagnostic error.

In a summary of the report, the IOM explains, “The definition frames diagnostic error from the patient’s perspective.” The definition is also designed to reflect “the complex nature of the diagnostic process, as well as the need to convey more than simply a label of a disease.”4(p3) The definition is the cornerstone of a patient-engagement theme that runs throughout the report.

Reframing Diagnosis as a Process

The need to reframe diagnosis as a collaborative process involving a dynamic team of professionals, as well as the patient and his or her family members, is a fundamental message of the report. Citing the increasing complexity of medical care, the rise of precision medicine, and growing numbers of patients with multiple chronic conditions, the report states that the traditional model of diagnosis as a solitary activity is ineffective.1

Training in teamwork and communication is a staple of efforts to improve patient safety. In diagnosis, the professional team may change rapidly and frequently depending on the setting and the kinds of expertise the patient’s problems require. The team should also include the patient whenever possible. The report describes diagnostic teams as “fluid” and “unstable,”3(p4-4) requiring specialized training for collaboration and teamwork. Health information technology and organizational culture can also be used to promote and support effective teamwork. The report includes chapters on each of those topics, as well as payment and care delivery model reform, which can also have a profound effect on diagnostic safety.

Clinicians are expected to be sensitive to patients’ needs and skillful at eliciting information from them that will help indicate the correct diagnosis. Through its recommendation that clinicians help patients learn about the diagnostic process, the report expects patients, according to their preferences and abilities, to engage with professionals and the system to help improve diagnosis. Diagnostic safety will improve through the actions of patients who are able to share feedback, ask questions, discuss discrepancies, and use electronic health records to access visit notes and test results.6(p1)

The working title of the report was Diagnostic Error in Medicine. At its first meeting, the committee decided to call it Diagnostic Error in Health Care because that “better reflected the patient-centered and teamwork-oriented aspects of the diagnostic process.”3(4-2)

Future Efforts

Although successful completion of the report is a significant achievement for the society, SIDM leaders are aware that it is only the beginning. To Err Is Human1 is a benchmark for patient safety
because of the work and improvement that its publication triggered. Time and effort will tell whether the diagnostic error report will have similar impact.

To galvanize these efforts, SIDM is enlisting medical societies and organizations in a new organization, the Coalition to Improve Diagnosis. Each member organization has pledged to take measurable action—at least one project—to improve diagnosis and to work together on one joint initiative.

Asked what else SIDM is doing to build momentum, Graber says that SIDM supports all the recommendations in the IOM report and will explore every opportunity to see them translated into action. SIDM will leverage the growing power of the organizations in the Coalition to help raise awareness and drive change. “The ability to work with both patients and Coalition members gives us the opportunity to advance diagnosis and diagnostic safety on many fronts,” says Graber. (personal communication, November 2015).

SIDM also advocates development of a national research agenda on diagnosis and diagnostic error, research funding awarded in proportion to the harm caused by diagnostic error, and for each federal agency to consider steps it could take to promote reliable diagnosis. Graber says, “We would also like to see all federal agencies step up to the plate.”

Figure 1. Definitions of Diagnostic Error
Patient Engagement Community and Committee Wraps Up 2015

By Kathryn McDonald, MM
Helen Haskell, MA
Co-chairs
Patient Engagement Community and Committee

The SIDM Patient Engagement Community and Committee have been busy on many fronts in 2015. On September 26, the committee sponsored the second annual Patient Summit held just prior to the Diagnostic Error Meeting (DEM) in Alexandria, Virginia. The summit featured two keynote speakers, Dr. Leana Wen, author of *When Doctors Don’t Listen: How to Avoid Misdiagnoses and Unnecessary Tests*, and Dr. Roger Leonard, who discussed optimizing patient-centered teams to improve diagnostic error. At DEM, patient advocate Peggy Zuckerman led a multidisciplinary panel entitled “Diagnosis and Dialog: Patient Access to Patient Data.”

Other accomplishments of the Patient Engagement Community and Committee this year include:

- Involvement in the Agency for Healthcare Research and Quality project on using public deliberation as a means to inform and learn from patients on the topic of diagnostic error. Patient engagement committee members observed and spoke at community deliberations in Syracuse, New York, and the deliberation group’s recommendations were reviewed at the Patient Summit.
- Developed a patient-oriented area on the SIDM website.
- Further dissemination of the Patient Toolkit for Diagnosis.
- At the Patient Summit in September, the committee launched the Expert HealthSearch program to connect patients with librarians and their ability to search the literature and supply information to help people get the right diagnosis.
- Appointment of patient representative and Patient Engagement Committee member Sue Sheridan to the SIDM Board of Directors.
- Patient involvement in developing the IOM report, *Improving Diagnosis in Health Care.* Committee chair Kathy McDonald was a member of the committee that produced the report, and two committee members were reviewers. The patient engagement committee helped publicize the report; several committee members contributed commentary to print and video materials.

Currently, the committee is developing a strategy to respond to the IOM report. Many of the report’s recommendations relate directly to patient partnership, but how exactly will those partnerships be fostered? The committee believes it is crucial for SIDM to facilitate projects for three levels of partnership:

1. Encounters among patients and healthcare professionals (patient needs and opportunities for making their diagnostic journey as safe as possible, including tools and educational strategies)
2. Organizational partnerships (hospitals, primary care setting, clinics, etc.)
3. Public policy (patient and family participation in discussions about changes needed in regulatory, payment, legal, and research funding arenas)

The Patient Engagement Community welcomes new members. Through email, we announce projects, seek feedback on potential plans, and make requests for help on a regular basis. To join, please contact Kathy McDonald (kathy.mcdonald@stanford.edu) or Helen Haskell (haskell.helen@gmail.com).

---

**ImproveDx** is a bimonthly publication of the not-for-profit Society to Improve Diagnosis in Medicine. The opinions expressed in this publication are not necessarily those of the Society to Improve Diagnosis in Medicine or its Board of Directors.

Editorial Board
Mark L. Graber, MD
Michael Grossman, MD
Jeannine Cyr Gluck, MLS

Managing Editor
Lorri Zipperer
Zipperer Project Management
Albuquerque, NM

Editor
Susan Carr
Concord, MA

© 2015 Society to Improve Diagnosis in Medicine

Permission to reprint portions of this publication for educational and not-for-profit purposes is granted subject to accompaniment by appropriate credit to SIDM and ImproveDX. Commercial reproduction requires preapproval. Some fees may apply.