

Improving Communication of Test Results in a Changing World

Susan Carr
Newsletter Editor

Despite years of improvement efforts, reliable communication of test results continues to be a patient safety problem.¹ In 2005, the Joint Commission on Accreditation of Healthcare Organizations (now The Joint Commission) included “reporting critical test results and lab values...to the appropriate licensed caregiver” on its list of National Patient Safety Goals for hospitals.² Ten years later, “Get important test results to the right staff person on time” is still on the list³ and remains the only patient safety goal that directly addresses diagnostic error.

When critical test results are lost or delayed by delivery and communication problems, diagnosis may be compromised or missed entirely. Whether the results relate to a known, suspected, or potential condition, or reveal an incidental finding, they warrant prompt action.

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The challenge of creating and sustaining reliable processes for test results has increased as the healthcare environment has become more fast-paced and complex. Since the 1990s, many hospitals have been able to receive and transmit test results electronically, which offers advantages as well as new perils.⁴ Awareness is growing that technology is a tool, not a panacea, and that the complex environment—often referred to as the socio-technical system⁵—within which health information technologies are used determines whether they improve or threaten patient safety.

Physicians may receive hundreds of test results to review each day, contributing to information overload and alert fatigue, yet these alerts provide a safety net that can help ensure that critical results aren't missed.⁶

Ensuring that crucial information travels with patients during transitions from one care setting or provider to another is notoriously difficult even with electronic systems. A vexing set of

problems is posed by test results that are still pending at discharge from an inpatient stay or from the emergency department.

Regulations and Culture Adjust to Digital Records

Traditionally, test results have been delivered to the ordering physician. In a new and growing trend, patients may now see direct reports of test results through online access to their medical records, without a physician's consultation. While this new development heightens patient engagement—a hallmark of healthcare reform and the patient safety movement—it is too early to know how many patients will be willing and able to participate, how physicians will react, and whether or not this development will improve diagnosis.

In 1996, when most medical records were still stored on paper, the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule gave patients the right to receive a copy of their own records.⁷

In his 2004 State of the Union address, President George W. Bush endorsed early efforts to

Also in This Issue ...

| | |
|--|---|
| MESSAGE FROM SIDM LEADERSHIP: SIDM Convenes Coalition to Improve Diagnosis | 4 |
|--|---|



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computerize medical records and pledged that the country would complete the transition by 2014.⁸ The Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009—part of a federal plan to stimulate the economy following the recession that started in 2008—provided an extraordinary boost, with \$20 to \$30 billion dollars of incentive payments made available to physicians and hospitals for acquiring and implementing electronic medical record systems.^{4,9}

Having access to medical records, usually through an online “portal” connected to an electronic medical record system, was central to a growing movement to empower patients as full partners in their healthcare. Dave deBronkart, known as e-Patient Dave, gave the patient data movement its rallying cry, “Gimme my DaM Data,” in 2009.¹⁰

Providing patients with electronic access to medical records is included in Meaningful Use, the requirements used by the Office of the National Coordinator (ONC) to ensure that physicians and hospitals use their new systems to improve care. Among other required actions, physicians must show that their patients actively “view, download or transmit” their personal health information, including lab and test results.¹¹ When ONC proposed in March 2015 to decrease the required participation from 5% of patients to just one patient, advocates protested and issued a call for a grassroots “day of action” to demonstrate the importance of data access.¹²

In 2014, the Clinical Laboratory Improvement Amendments of 1988 (CLIA) and the HIPAA Privacy Rule were amended to require laboratories to provide patients direct access to their test results, “...empowering them to take a more active role in managing their health and health care.”^{13(p7290)}

Modifications made to the Mammography Quality Standards Act in 2006 have had the most dramatic impact on direct reporting to patients. The Act requires mammography results to be sent directly to the patient with 30 days of the test.¹⁴ That emphasis on establishing reliable communication is one of the major factors contributing to the improving quality of breast cancer care in the US.

While the use of patient portals is increasing, it is not known how many patients in the US routinely use them to access their records or how that access affects outcomes. Beth Israel Deaconess Medical Center launched one of the first

online portals, PatientSite, in 2000. In a study of its use by patients, published in 2006, researchers reported, “Radiology reports, laboratory results, and email messaging were the features most often accessed.”^{15(p94)} A systematic literature review published in 2015 found indications that patient portals contribute to increased patient satisfaction and customer retention but do not improve medical outcomes.¹⁶

Fundamental Changes

Giving patients direct access to test results offers another channel and safety check in the communication process. When a provider or the system drops the ball, who better than the patient to catch it? Although early data showed that the use of patient portals did not cause problems for physicians;¹⁵ some worry that access to results of diagnostic testing, screening data and, in some cases, visit notes, causes harmful anxiety for select patients.

Beyond those cases where a patient speaks up about a test result that warrants follow up and that his or her physician missed, direct access to test results can stimulate fundamental changes in the physician-patient relationship.

A thread on the listserv of the Society to Improve Diagnosis in Medicine offers examples of the positive effect of direct access to test results:

Of course, a patient who can compare lab results over a period of time may note trends that are missed by the doctor's review, or note something else that was not initially of concern during the previous appointment.

—Peggy Zuckerman, March 8, 2015

We know that patient engagement is key to improving diagnosis. What is less clear in our complex system is exactly how to achieve maximum engagement. Rather than telling patients that a portal “is available” for their “convenience,” maybe we should be strongly encouraging use as part of their engagement in care.

I know that for myself and my family, the portal has allowed far more active monitoring and dialogue. It was always frustrating simply hearing “it's within normal range.” That doesn't tell me anything. However, being able to watch trends over a few years, I've been able to have meaningful dialogue with my primary care [provider]. It also feels like her “respect” and “listening” has grown as my ability to provide her with data has grown. Data I gathered from my own record.

—Geri Amori, March 10, 2015

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Also in that listserv thread, Michael Bruno, MD, provides a reminder that, as a group, “engaged patients” may not represent the general population. Bruno’s radiology department devised a rigorous process for notifying patients seen in the ED about unexpected findings, results not related to the patient’s original problem and available only after discharge. Counter to recent hope for improved patient engagement, Bruno’s department found that many patients are difficult to reach and unlikely to respond even when contacted directly by mail and telephone about a potential health problem.

On the other hand, Bruno sees how access to information, including radiology reports, is beginning to change healthcare. Bruno et al¹⁷ refer to the radiologist’s report as an “Open Letter,” written by the radiologist to referring physicians and now readily available to a wider readership, including patients. In a world of easy electronic access, radiologists, through their primary work product, are newly accountable to patients and patient safety efforts:

... these disruptive changes now situate radiology reports squarely at the crossroads of quality and safety initiatives, norms regarding patient-centered care, and risk management and malpractice procedures, just as they become more readily accessible to patients via web-based portals.^{17(p864)}

Timely, accurate transmission of test results has always been challenging; when that process is unreliable, it may cause harm through delayed or missed diagnoses.¹⁸ Electronic medical records used as communication tools between physicians and made directly available to patients through online portals can help, but they also add new opportunities for error and may not reach those patients who are most in need of healthcare services. Access to comprehensive medical records, however, can help engaged patients work together with physicians more effectively to improve diagnosis and care in general.

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SIDM Convenes Coalition to Improve Diagnosis

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Anticipating the fall 2015 release of the Institute of Medicine’s landmark report on diagnostic error in healthcare, the Society to Improve Diagnosis in Medicine (SIDM) has invited a number of leading healthcare organizations to join together in a coalition. The coalition will represent clinicians and other healthcare professionals, patients and families, employers, consumer advocates, insurers, researchers, policymakers, and educators.

The coalition is intended to bring much needed attention, action, and awareness to this issue as an essential step in improving the quality of care patients receive and reducing harm to patients that can result from diagnoses. Coalition members will be asked to support shared principles, work to increase attention to this issue, and commit to taking measureable action to improve

diagnosis and raise awareness among their organization’s leadership and members.

The inaugural meeting of organizations interested in becoming a member of the coalition was held in April 2015 in Washington DC. Senior level executives or board members of thirteen major organizations attended. Everyone in the room showed enthusiasm for the initiative and understanding for the magnitude of the problem. They will now go back to their governance structures to get formal approval to join with SIDM in the coalition.

In a forthcoming issue of *ImproveDX*, more details, including the names of the organizations who have formally joined the coalition, will be shared. In the meantime, inquiries should be addressed to info@improvediagnosis.net.

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Keynote Presenters



Sunday, 27 September
Tejal K. Gandhi, MD, MPH, CPPS,
is President and Chief Executive Officer of the National Patient Safety Foundation. She is also a board certified internist, Associate Professor of Medicine at Harvard Medical School, and a certified professional in patient safety.



Monday, 28 September
Richard Kronick, PhD,
is the director of AHRQ; his work, and that of the Office of Health Policy under his leadership, was integral to the implementation of the Affordable Care Act.



Tuesday, 29 September
Francis 'Jay' Crosson, MD,
is a member of the Medicare Payment Advisory Commission. Previously, he was group vice president, American Medical Association, and prior to that, a physician and physician executive at Kaiser Permanente as well as senior fellow at the Kaiser Permanente Institute for Health Policy.

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