

The Portal Is Always Open

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The gastroenterologist decided to order an abdominal-pelvic CT “for completeness” in the 89-year-old man after performing a normal colonoscopy and upper endoscopy to evaluate anemia. The imaging result, however, was a big surprise. The preweekend, online MyChart report delivered with a ping to the patient’s phone, and read:

Significant increase in size of abdominal aortic aneurysm, likely with an endoleak. Retroperitoneal: 11.9 cm abdominal aortic aneurysm, previously 6.4 cm. There is heterogeneous increased density within the aneurysmal sac. Associated common iliac artery stents. Indeterminate, numerous splenic hypodensities may be benign or metastatic.

The patient’s 85-year-old wife, married to him for 65 years, texted her physician son, “Please call me on this phone. Dad’s CT shows likely endoleak and increase in AAA. And lesions in his spleen.”

The gastroenterologist had not called yet. The family’s decision was to contact the patient’s vascular surgeon, who had done an open repair of his abdominal aortic aneurysm (AAA) several years earlier, on Monday during business hours.

The man worried that the open surgical procedure (after two endovascular procedures could not repair his AAA) several years earlier had apparently failed, and he therefore had a ticking time bomb in his abdomen. This was particularly demoralizing as the surgery and postoperative rehab were grueling but he had persevered believing (as the surgeon stated) that this would fix the problem once and for all. The entire family spent a weekend worried that an AAA of that size could rupture at any moment. Google was not reassuring; it informed family members of the rupture rate for aneurysms based on size—his was off the tables’ scales. His wife worried perhaps the most.

The hematologist following her for hemochromatosis had done routine bloodwork; she had worsening anemia and the calcium returned elevated at 12.4. A chest/abdomen/pelvic CT was ordered. The radiologist’s report posted on MyChart showed

Irregular neoplastic inhomogeneously enhancing mass within the lateral left upper lobe measures 4.1 cm in anterior posterior dimension by 3.2 cm in transverse dimension by 3.8 cm in superior to inferior extent. Neoplastic lesion obstructs posterior upper lobe bronchi. Pathologic left prevascular inhomogeneously enhancing lymphadenopathy is identified. Multifocal hepatic neoplastic disease the largest lesions within the right lobe of liver either a single confluent lesion or 2 adjacent lesions maximally 7.2 cm. Multiple additional lesions with the largest within the right lobe and smaller within the left lobe.

A registered nurse with three prior episodes of different cancers, she knew what neoplasia meant without looking it up. It was a Friday evening. The ordering physician hadn’t yet called; she called her son to look at the online report. Accompanying the portal report was a link to RadiologyInfo.org with a patient education page on “How to Read Your Radiology Report.” A liver biopsy was ordered the following week and was scheduled for the first available time in 2 weeks. She had had a false alarm in the past when her liver’s iron deposits from her hemochromatosis were misdiagnosed as metastasis; she was hopeful this was the case this time as well.

Less than 24 hours later, after the enlarging AAA report, the son received another text from his mother about her liver biopsy. “Please read my latest report on MyChart. What!”

The MyChart test result showed

Liver, core biopsy: Moderately to poorly differentiated CK7+/GATA3+/p63+, favoring from urothelial origin. It shows no expression of TTF1 or CK20, effectively excluding primaries of lung and colon.

A call was placed to her oncologist, who had not read it yet, for his interpretation.

Besides her right upper quadrant pain, she soon developed severe back pain, and reluctantly was driven to the local community hospital emergency department. An X-ray was done; it was MyChart that revealed a pathologic fracture in a lumbar vertebra.

The man's vascular surgeon called early in the next week and stated he had reviewed the CT and believed that what the radiologist was seeing was a postsurgical artifact and did not actually represent a newly enlarging problematic aneurysm, as the wall of the aneurysm was left in place at surgery and the earlier repair inside this appeared intact. A follow-up CT result on MyChart showed no definite endoleak; it still showed the aneurysm but the surgeon was able to explain that all was ok. His reassurance was a source of great relief for the man, the man's wife, and his family.

These are two instances in one family this past summer of online results delivered prior to a clinician's communication—one a serious false-alarm imaging report that caused significant anxiety in a whole family over a weekend. The other was a case of learning of a diagnosis of metastatic cancer from a health system's web platform rather than from a physician or other health care professional.

That family was mine.

The 21st Century Cures Act was designed to make health care information more accessible and transparent to patients and has largely succeeded. It has most likely improved the accuracy and safety of health care, served to increase patient engagement and adherence to prescribed medications and treatment plans, and led to more prompt treatment. Portals allow patients to help reconcile medication lists, allergies, immunizations, preventive screening, and problem lists outside of office visits. Over 96% of patients in a survey study of 8,139 respondents at four US academic medical centers preferred receiving immediately-released test results online even if their clinician had not yet reviewed the result. A subset of respondents experienced increased worry after receiving abnormal results.¹ However, some patients reported feeling more anxious or angry regarding the immediate release of more sensitive tests such as cancer-related tests.² Patients also preferred in-person visits (but not virtual visits) for results of a PET scan for Alzheimer disease, fetus miscarriage, and cancer tests; and preferred portal availability for strep tests, cholesterol tests, and to a lesser degree genetic tests for cancer. Notably, a phone call was the only mode of notification that was not rated negatively by patients for communicating the results of any of the tests, simple or serious.² Another study found that complex documents such as radiology or pathology notes caused patients more discomfort compared to laboratory test

results.³

Originally coined to describe injury inflicted on someone or something other than the intended target in military operations, the term "collateral damage" is now commonly used in nonmilitary contexts to signify unintended negative consequences or injuries. Patient portals, which provide some great intended benefits, are inadvertently also delivering unintended collateral damage every day to patients and their physicians, who are being put in the position of contacting patients with bad news in too short a time window to beat the portal's delivery speed.

Every medical school and family medicine residency has either a formal or informal curriculum on delivering bad news to patients. Sending a text message or email would not be considered adequate or appropriate, yet patients are now often receiving bad news electronically. Technology typically moves faster than policy to ensure safe use. A competitive profit motive often supersedes concerns about safety. Recent examples include ubiquitous online gambling, smartphones in schools and when driving, social media, and electronic nicotine delivery systems. For patient portals, it is not primarily a technology issue; it is a failure to have adequate policy in place concerning their use. Efficient data delivery often supplants compassionate, person-centered care delivery.

Family physicians provide context to data and turn it into usable information for patients. Reporting medical results data without proper context causes risks to both patients and physicians. Without context, data can quickly become misinformation. Misinterpretation leads to significant worry in patients and their families, causing anxiety and emotional trauma that is never fully eliminated. Misinterpretation may also cause a loss of trust in the physician or the system, especially if there is a lack of underlying trust in the first place. Misunderstanding or miscommunication due to lack of context certainly led to reduced trust in future radiological reports in the AAA example mentioned previously, as the surgeon had to override the radiologist's online interpretation. Going from the portal to Google, patients may make an inaccurate self-diagnosis or have resulting unnecessary medical concerns. The binary nature of lab results,⁴ normal or abnormal, with very minor values out of normal range can lead to excessive future testing.

Anyone who has been on the receiving end of bad news can relate in great detail, years later, how the news was delivered. As family medicine educators, we need to catch up to the technology and be intentional in addressing these new challenges in our training environments. This includes teaching how to better communicate with patients when we order a test about pretest probabilities, and what a positive or negative test means—and doesn't mean. We need to teach learners how to thoughtfully plan follow-up communication with each patient, and to know the importance of going the extra mile and using the phone or virtual call if an office visit isn't possible or practical. Squeezing in the patient, in person or through telehealth, to provide rapid access for serious results

should be part of the training culture, even if the office's regular operations do not support it particularly well. Being a member of a care team does not eliminate this personal responsibility.

We need to ensure our learners help set appropriate expectations for patients regarding personal communication of test results, be informed about the release timing of results, and know the importance of follow-up visits to review and discuss information. There must be explicit curriculum on topics such as the optimal use of portals to manage increased inbox burden, how to mitigate a digital divide with increased inequity, managing fragmented care if utilizing different portals that don't communicate, and preventing and managing privacy breaches.

Teaching intraorganizational advocacy also has a large role. Especially with the growing opportunities and potential pitfalls of the artificial intelligence revolution, it is up to us generalists to offer a broad and informed perspective into new policy decisions needed. These should not be left to narrow, sometimes conflicted perspectives. Offering "consumers" faster information service for commercial advantage may have not been well thought out. There are currently no national guidelines to inform optimal patient portal use. Decisions are being made locally without clear consensus on industry-wide requirements for safe and effective use that take unintended consequences into account.

Nearly every health care institution has a committee that develops local policy for medical result release. Do you know who is on that committee at your own institution? Is there a family medicine voice? Do your faculty know who your chief medical information officer (CMIO) or medical informatics leader is, and what the governance structure is? Is your practice's patient safety system utilized when potentially devastating medical information is released to the portal without physicians having the opportunity to contact the patient first? Some institutions auto-release lab values, but pathology and imaging showing unanticipated findings are not released until the treating physician is first notified to give time to contact the patient directly. Strategic delays in posting to patient portals are needed to ensure that physicians have sufficient time to contact patients with important medical results.⁵

Invite your CMIO to a future meeting or educational conference to discuss portal use and educate learners in thinking through these issues, perhaps using a case-based approach from the practice. Make sure your institution's result release policy is known to all. Explicitly assessing as part of the precepting encounter the learner's use of anticipatory guidance for lab or imaging results is more important than ever, as is how to best communicate indeterminate, worrisome, or benign abnormal results outside the context of a visit. Utilizing previsit labs more often may be another strategy, although this may involve two on-site trips for the patient rather than one.

This may be another opportunity to personalize care by asking patients their preferences about obtaining report results, not only in the abstract but also on a case-by-case basis

prior to ordering tests. Patient preference can change over time based on the stage of a disease. Electronic health records should evolve to enable this personalized approach. In the event of bad news, patients deserve the presence of a doctor supporting them with "I am here for you and here's the plan." Portals do not and cannot do this.

We are now swimming in a data-rich but often information-poor clinical teaching environment. A cold, dispassionate imaging study or life-changing test result without a human touch is not appropriate and even more than a little inhumane. For our patients, our learners, and ourselves, we need to insist on better.

REFERENCES

1. Steitz BD, Turer RW, Lin CT. Perspectives of patients about immediate access to test results through an online patient portal. *JAMA Netw Open*. 2023;6(3):233572.
2. Bruno B, Steele S, Carbone J, Schneider K, Posk L, Rose SL. Informed or anxious: patient preferences for release of test results of increasing sensitivity on electronic patient portals. *Health Technol (Berl)*. 2022;12(1):59–67.
3. Leonard LD, Himelhoch B, Huynh V. Patient and clinician perceptions of the immediate release of electronic health information. *Am J Surg*. 2022;224(1):27–34.
4. Whyte MB, Kelly P. The normal range: it is not normal and it is not a range. *Postgrad Med J*. 117;94:613–616.
5. Davis KA, Smith LB. Ethical considerations about EHR-mediated results disclosure and pathology information presented via patient portals. *AMA J Ethics*. 2016;18(8):826–832.