

DEBATE: PART II

Patient Access to Electronic Records: Not Now

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I remember the first day of my third-year medicine clerkship well. I remember the patient at the Washington, DC, VA hospital. I remember meeting him and knowing that my face, flushed red with anxiety, was probably a stark contrast to my starched and bleached lab coat. I remember my [attempt at a] physical exam, checking for neck vein distention in a gentleman who had been admitted two weeks prior with a congestive heart failure exacerbation. And I remember looking at his medical record and seeing what seemed like every laboratory and imaging result listed as “abnormal.” And I thought, “Wow, do I have a lot to learn.” Graduating from high school, graduating from college, and finishing two-and-a-half years of medical school left me less than prepared to interpret his results with anything but trepidation. One by one, I made sense of them—and then came back the next day to do it all over again.

So should patients, most of whom are not medical students, have full access to their labs and study results? Very few will argue that giving patients access to their information is the *wrong* thing to do. Some have even argued that the patient “owns” the result since it was their blood,¹ and that clinicians have long been behind the curve in terms of sharing information with patients. Quest, with its smartphone app Gazelle, has routinely released results to patients that sign up since 2009. After notifying the physician, it gives a 48-hour window until patients can access results directly—though it does not release HIV results, cancer diagnoses, or genetics results.¹

Health and Human Services Secretary Kathleen Sebelius, when announcing an HHS initiative to provide laboratory results directly to patients, stated that “when it comes to health

care, information is power.”¹ One of the first lessons I learned in my medicine clerkship, though, was that *knowledge* is power. Information is not. There does not seem to be a public outcry to get access to the information [yet]. So why is there a push to do this right away?

Two studies are often cited to say that patients should have access to their labs. The first is a 2009 study from the *Archives of Internal Medicine* that showed in people age 50 to 69, physicians failed to inform (or failed to document that they informed) patients of abnormal labs results 7.1% of the time.² The second is a study in *JGIM* in 2010 where Martin Were and colleagues showed that of patients discharged from the inpatient setting with pending results, only 16% of discharge summaries contained this information and concluded that “discharge summaries are grossly inadequate at documenting...tests with pending results.”³ Yes, things definitely do fall through the cracks. Physicians, like the patients we care for, are humans, prone to mistakes.

The argument based on these two studies is that patients having access to lab results, or even full chart access, will help to improve safety and make patients more involved and participatory in their health care while also improving communication.

I think patients, some day, should be given access to their entire chart—just not now. Why? Let me explain.

1. Charts are primarily written for physician-physician communication. I include my thought process and future plans in many of the charts I write. I will often cite advice I gave a patient and their reaction. It helps me remember how to

provide advice in the future and “personalizes” that patient’s care. I do not necessarily want patients to see certain pieces of information. Yet if I omit it from my note, chances are, seeing 100 patients a week, I will forget it in six weeks when I see that particular patient again. I have not been “trained” to write charts for patients to read. I can do it, but presently I write chart notes so that I and other physicians can read them. If patients can access charts, shouldn’t the documentation be in language that patients can understand? Many physicians barely have time to write notes with abbreviations and notes that colleagues can understand.

2. 95% of my patients read and write Spanish. My notes are in English. For those who speak and write other languages, I would argue the charts should be translated for them. Additionally, if patients are given full access, thus changing the function of medical records and charts, this should also change simultaneously at the level of undergraduate medical education (i.e. in medical school) so that we teach students how to do this from day one. Has this been considered and implemented yet at any medical school?

3. There are no data from Quest or other companies/organizations showing that patient access improves safety or quality, which are necessary before taking this to the national level as HHS proposes. (Groups including Walker, Delbanco, et al. are presently working on related projects.) We have the cart before the horse on this presently if we use patient access for this

reason. We do not have quality, safety, or outcomes data from even a single controlled research environment regarding patient access. This is needed before developing national policy.

- Secretary Sabelius argues that information is power. Unless labs are delivered with hyperlinks to patient-level information and advice, information is not power. Patients need the knowledge to interpret tests results, which they get from their providers. Wouldn't it be interesting to see if patients could be notified of actual results, or just notified that "all your results are back, please contact your doctor if you have not heard from him/her," and see what is better for patients? Although potentially a good study, this has not been done. Patients need *knowledge* to make decisions. Bestowing that knowledge and being a *teacher* is one of the tenets of good doctor-patient communication and informed consent. Simply providing results does not make patients' decisions better ones.
- I recently got a radiology report stating "the differential includes infection, malignancy or possible immunodeficiency. Sarcoid could also be a possibility." If patients have questions about radiology and other reports, will they contact the radiologist or the primary care physician? We all know the answer to this: They'll call the primary care physician, who already spends a quarter of the day doing paperwork and other unreimbursed activities. Has this been considered and discussed with specialties other

than general medicine? Has it been thought of in terms of an already existing national primary care shortage?

- The Healthy People 2010 report was released in October of 2011 (http://www.cdc.gov/nchs/data/hpdata2010/hpdata2010_final_review.pdf) and showed that "overall, disparities remained unchanged for about 80% of the objectives.⁴ Drawing correlates from prior data on electronic patient portal use published in the October 2011 *JGIM*, "The odds of repeat portal use...increased with white race, English language, and private insurance or Medicaid compared to no insurance. Racial disparities were small but persisted in models that controlled for language, insurance, and health status."⁵ I would argue that electronic access to labs, charts, and other medical information will potentially strengthen racial, linguistic, and economic disparities in health care even more as an unintended secondary consequence. The people who might benefit most will end up benefitting least.
- Will chart and lab access be only for outpatients? Why not inpatients, too? When will this occur? Will house staff training need to be altered as a result (rounding in internal medicine twice a day)? Will turnaround time need to be different for labs? Will computers and access be provided to all inpatients, not just those who can bring computers in from their homes? If not, will this further exacerbate disparities?

Despite my points mentioned above, I do (believe it or not!) think patients should have access to their information or data. But I think that doing so now, without systemic changes and thoughtful consideration, will potentially worsen the bedrock of medicine—that is, the patient-physician relationship. I also think it will affect "the system" in ways that have not been fully considered. Given the data on health care disparities, I also feel they could become more entrenched rather than decreased.

Let's do this thoughtfully. Let's do this correctly. Let's do this well.

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