

## POLICY FORUM

### Ethical Considerations about EHR-Mediated Results Disclosure and Pathology Information Presented via Patient Portals

Kristina A. Davis, MD, and Lauren B. Smith, MD

#### Abstract

Electronic health records (EHR) now include patient portals where patients can obtain clinical reports, including notes, radiology reports, and laboratory/anatomic pathology results. Although portals increase patient access to information, no guidelines have been developed for hospitals about appropriate delays in posting different types of pathology reports to the EHR. Delays exist as a matter of policy to allow physicians time to answer questions and provide emotional support when discussing sensitive results with patients. Some types of results are more sensitive than others, however, including results of cancer, genetic, and HIV testing. Ethical questions about patient access to test results online are discussed.

#### Introduction

The nationally mandated use of [electronic health records](#) (EHR) has resulted in both new opportunities and challenges regarding patients' access to their clinical information. In this era of online patient portals, not only can patients look up their upcoming appointments or request medication refills, they can also see results of clinical laboratory and anatomic pathology testing. While patients have a right to know the contents of their health record, ethical and clinical concerns arise about the timing of results' availability and potential harms stemming from early access to results without a clinician to help interpret and contextualize those results. Currently, access to results and the timeframe in which they become available vary among institutions [1]. Benefits of access must be weighed against the risks of patients' possible misinterpretation of results and the emotional sequelae and stress that could occur when patients learn of abnormal results without adequate clinical guidance.

#### Timing of Access to Results

There are no mandates regarding whether hospitals should delay [patients' electronic access](#) to test results for a certain period of time to ensure that clinicians are able to discuss results with patients prior to posting them in a patient's portal. Opinions vary, and little research has been done regarding patient preferences or possible harm to patients in receiving results without a clinician being available for discussion and

consultation. One study reported that a small number of patients (up to 8 percent) found the information in the patient portals anxiety-provoking or confusing [2]. In our experience, the time before the results are released to a patient portal differs depending on whether the patient is an inpatient or an outpatient and on the category of report. For example, inpatient results are posted to the portal 24-28 hours after they are completed. Outpatient results are held for variable periods of time depending on the type of result. Point-of-care testing results (e.g., pregnancy tests, glucose) are released on the same day they are performed. Routine laboratory results are released in 3-4 days. Outpatient diagnostic reports such as anatomic pathology, cytology, flow cytometry, and radiology are held for 14 days. HIV testing results are held for 28-31 days and genetic testing results are held for 90 days to allow time for follow-up appointments. The only tests that are not reported to the patient portal at our institution are human leukocyte antigen (HLA) results, because these contain not only patient but also donor information; the primary clinical purpose of these tests is to assess transplant compatibility. Attempts have been made to formulate automated delays in result availability based on the type of report; however, these are not foolproof. Some items that might seem like routine laboratory results can be similar to anatomic pathology reports and contain sensitive and potentially upsetting information.

### **The Value of Access to Routine Laboratory Results**

Patients can benefit from access to routine laboratory results, such as complete blood counts (CBC), [cholesterol results](#), and standard chemistries (e.g., sodium and potassium). Some of this information could be helpful, especially hemoglobin A1c (used in diagnosing and monitoring control of diabetes) and cholesterol values, if patients wish to have these results available for future reference or in tracking any improvement over time. For example, a patient taking a statin to lower cholesterol could benefit from easy access to prior test results. Liver enzymes would also be relevant when taking a statin since liver and muscle damage can be serious side effects. Of course, physicians should also be monitoring these results closely and discussing them with their patients, but some patients might have more peace of mind knowing of abnormal results more quickly or having easy access to the actual values.

Access to EHR can also improve patients' self-reliance and their relationships with clinicians. Studies have found that portals can lead to shared patient and physician responsibility if patients feel empowered to access their own results [3] and might lead to improved outcomes for [diabetes management](#) and other chronic conditions [4]. Access to records can also increase patient-physician trust [3]. Other authors, however, have questioned the ideal of "patient empowerment;" patients could end up feeling that they are to blame for their own poor outcomes since patient vigilance might not change the ultimate outcome in many cases [5].

An important goal of EHR is to have a record that is easily accessed at any medical center for any patient. Access to laboratory values could allow patients to get second opinions

more easily. Having results available to other physicians might minimize unnecessary test duplication [6]. It has also been postulated that patients' access to the electronic records could decrease errors if patients see incorrect information and alert their physicians, although this benefit has not been borne out in practice in some studies [2].

### **Ethically and Clinically Relevant Problems that Can Arise in Access to Routine Laboratory Results**

Although access to CBC and other routine laboratory results might seem reasonably harmless and even beneficial to some, situations do occur in which these results can be upsetting to patients. One example would be the diagnosis of leukemia, which could be made in conjunction with a routine CBC held for pathologist review. Some patients present with unexplained symptoms and their diagnosis of leukemia is a surprise to both patients and clinicians. In our experience, 14-day delays do not exist for these types of results when they are considered part of the routine CBC order. A pathologist's review of peripheral blood smears automatically happens when specific abnormalities exist on a CBC. Other diseases such as chronic lymphoproliferative disorders, myeloproliferative neoplasms, and myelodysplastic syndromes—which vary in their severity and prognosis—can also be diagnosed or strongly suspected with a CBC and morphologic review. All of these disorders can be confusing, and myeloproliferative and myelodysplastic neoplasms tend to be beyond the scope of expertise of a primary care physician; nonetheless, a patient can receive these results at home with access only to the Internet. Preferably, these results would be provided to patients by their primary care physician with the promise of expedited referral to a hematologist or oncologist. In the era of patient portals and physician time constraints, however, the practice of physicians trying to provide their patients with emotional support by verbally explaining abnormal results in person might be over.

Another serious risk of EHR test result disclosure that's not mediated by a physician is that [patients can misinterpret their results](#). For example, a patient could notice that his or her hemoglobin or hematocrit is low and decide to self-treat with iron supplements. This self-treatment could be harmful in patients with anemia of chronic disease, sideroblastic anemia, or thalassemia, as iron can cause gastric upset and iron overload. Patients might also access the Internet if they're trying to understand an abnormal result and don't have access to a clinician's expertise, and information that patients obtain on the Internet can be inaccurate, lead to inappropriate self-treatment, and generate anxiety.

### **Access to Anatomic and Cytopathology Pathology Reports**

Anatomic pathology and cytopathology reports are generated when patients undergo a tissue biopsy, resection, or fine needle aspiration. These are the types of reports that are used when cancer is diagnosed or staged (i.e., when the extent of a cancer's location in the body is determined). Anatomic pathology reports contain technical clinical terminology and are written for physicians' levels of health literacy. In some cases, the

information can be beyond the scope of understanding for even a primary care physician and might require access to a specific specialty literature or a conversation with a pathologist or oncologist to be adequately integrated and understood. Ideally, a patient would receive such results from a clinician, via phone or in person, when emotional support and additional information can be provided in real time. Receiving diagnoses via an electronic portal could become the new norm if physicians fail to personally connect with patients about results. Electronic disclosures can be ethically and clinically problematic, as patients can have many questions and fears. One of the primary duties of a physician, therefore, is not only to alert patients to abnormal results, but also to educate them on their conditions and apprise them of follow-up that will be needed for treatment.

### **Access to Genetic Testing and HIV Testing Results**

*Genetic testing.* Genetic test results are considered particularly sensitive, especially from a [privacy](#) standpoint [7]. Genetic testing results can be upsetting or life changing, as in the case of Huntington's disease, breast cancer, or a serious congenital condition. [Results of genetic testing](#) can also carry implications for people besides the patient, such as his or her children. Given these concerns about privacy, genetic testing is an area of medicine in which there has typically been a strong commitment to pre- and posttest counseling, which is often performed by a genetic counselor rather than a physician. Genetic testing is unique in that patients can receive information about conditions that might only develop later in life and conditions that might not develop at all. Interpretation of these results should be personalized, as they often depend on close scrutiny of [family trees](#) (pedigrees) in order to tailor the results to a given patient. Given this complexity, genetic results are particularly difficult for patients to understand without the availability of a genetic counselor, who could provide explanations.

Times have changed from the early days of genetic testing in the mid-1990s, however. Mail-order genetic testing companies often bypass any type of one-on-one genetic counseling. As this industry has only recently been regulated, patients could receive results of tests that are not routinely performed in medical practice. Such information could be upsetting if people consent to testing without being well informed about potential risks of learning new information about their genetic makeup. These risks include emotional distress or concerns about privacy. Although health insurance discrimination based on genetic testing results is now illegal [8], patients who have known genetic conditions still do not have equal access to some services, such as affordable long-term care insurance to cover the costs of managing their illness, which is not included under the Genetic Information Nondiscrimination Act of 2008 [8]. Genetic counseling can help patients understand these risks prior to undergoing testing. Due to the complexity of the information and social and familial implications, additional delay in releasing results to an electronic portal could be justified based on the time it takes for physicians and genetic counselors to coordinate appropriate follow-up appointments. As

there is a shortage of genetic counselors nationwide, some have suggested that genomic medicine tools be developed for the patient portals to allow patients to better understand their results without long waits for appointments with genetic counselors [7].

*HIV testing.* [HIV tests](#), like genetic tests, have typically been considered sensitive information. This judgment is based not only on the seriousness of an HIV diagnosis but also on historical concerns related to stigma and discrimination. Although the life expectancy for HIV/AIDS patients has improved dramatically over the last few decades, social stigma still exists. Extra time for counseling by a physician might be important for an individual patient's well-being. However, it could also be argued from ethical and clinical perspectives that results of HIV tests should be communicated as soon as they are available, since partners of patients would be at risk and could be told.

### **Optimizing Patient Portal Experiences**

The practice of medicine is changing, and patient access to results can be both beneficial and problematic. In order for patients to maximize the benefits and minimize the harms of changes to clinical record maintenance and access, additional research is needed to elicit patients' preferences about electronic access to their test results. Patients might very well differ in their preferences about results reporting. In one study, 40.5 percent of patients wanted results to be communicated differently for malignant and benign diagnoses [9]. While the majority of patients in the same study (51.7 percent) valued rapid results [9], some want information as soon as it's available and others prefer to hear about new information from their physicians. Patient preferences can also change over time based on the stage of disease [10]. It would be desirable if patients could choose which option they prefer in the future. It would be ideal if patient preferences could be built into an electronic health record system. Moreover, patients have been found to have concerns about how their privacy is protected, which will also need to be addressed for increasing patient satisfaction [2, 11, 12]. Of course, a subset of patients—perhaps elders or members of disadvantaged populations—might not be computer literate or have access to a computer [13, 14]; in these cases, other solutions will be necessary [15].

It is important to remember that electronic portal access to laboratory and biopsy results does not abrogate a physician's responsibility to adequately support and educate patients about critical clinical information. Strategic delays in posting to patient portals will be needed to ensure that physicians have sufficient time to contact patients with important medical results. Integrating patient preferences for communicating results into the portals would be ideal. Also, finding alternative ways to emotionally support, educate, and counsel patients could be helpful if physicians will not always be conveying the results of laboratory testing in the Internet era.

### **Conclusion**

The era of electronic health records and patients' access to online, portal-mediated results is not a future challenge; it's a current one. Access to electronically based health data provides patients with opportunities to be more actively engaged in their care. On the other hand, deciding the nature and timing of this access must take into consideration potential harms to patients that can arise from unexpected or potentially confusing results. Finally, in debating what is best for patients, it is incumbent on pathologists and all physicians to remember that patients are individuals with unique preferences that should be addressed as carefully and compassionately as possible.

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**Kristina A. Davis, MD**, completed her residency in anatomic and clinical pathology at the University of Michigan in Ann Arbor. She has a strong interest in patient-centered care and will be pursuing fellowship training in transfusion medicine and histocompatibility.

**Lauren B. Smith, MD**, is an associate professor of pathology, section head of hematopathology, and director of the Ethics Path of Excellence (a co-curricular program) at the University of Michigan Medical School in Ann Arbor. She also serves as a hospital ethicist, performing ethics consultations at the University of Michigan Medical Center.

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### **Related in the *AMA Journal of Ethics***

[Confusion over Cholesterol Testing](#), December 2004

[Controlling Diabetes](#), November 2005

[Ethical Dimensions of Meaningful Use Requirements for Electronic Health Records](#), March 2011

[Genetic Diseases and the Duty to Disclose](#), August 2012

[Shedding Privacy Along with our Genetic Material: What Constitutes Adequate Legal Protection against Surreptitious Genetic Testing?](#), March 2016

[Will the Potential of Personal Health Records Be Realized?](#), November 2013

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