

# Research finds patients and providers differ in opinions about immediate access to medical records

January 21 2022

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While both patients and clinicians prioritize information transparency, a 21st Century Cures Act requirement for the immediate release of test

and lab results is proving more controversial, according to recently published survey results of clinicians and patients.

The study, published recently in *The American Journal of Surgery*, found that of the clinicians surveyed, nearly 63% agreed that immediately released results would be more confusing than helpful for patients, whereas about 16% of patients surveyed agreed with that statement.

"I think for clinicians, the concern has been that it's going to cause stress to patients getting these really complex reports that are not written at a level that's easy for non-[medical professionals](#) to understand," says Laura Leonard, MD, the study's primary author and chief resident of quality and safety for the University of Colorado Department of Surgery.

"I've called patients back within 20 minutes of receiving their results and they're already down in the fine print," adds Sarah Tevis, MD, a study co-author and an assistant professor of surgical oncology. "As clinicians, we may have just received the results ourselves, so we're not only going through them for the first time, but trying to help patients know where to focus and to know what these results mean for them."

## **Studying the impact in real time**

The 21st Century Cures Act, which became law in 2016, includes a requirement that went into effect in 2021 requiring health care institutions to release all electronic health information (EHI) to patients immediately.

"We recognized at the time that we had a unique opportunity to study the impact of something as it was happening," Leonard says, adding that UCHHealth, whose patients and clinicians were surveyed, was proactive in working with and preparing clinicians for the change beginning in 2020.

Leonard, Tevis, and the research team designed a voluntary cross-sectional survey to administer via e-mail to clinicians at UCHealth in October 2020. Clinicians who regularly work with oncology patients were invited to participate. A corresponding survey was administered to patients recruited from breast cancer and pancreatic cancer multidisciplinary clinics and breast radiology patient lists. These participants were specifically selected to represent patients who have had significant experience with testing as well as reviewing test results.

Survey results showed that of those surveyed, about 90% of patients and 81% of clinicians agreed that providing patients with access to their health information is necessary in delivering high-quality care. However, providers were more likely to disagree that patients are comfortable reviewing blood work results, radiology results, and pathology reports on their own.

The survey results also showed that about 75% of patients felt their provider should contact them within 24 hours of the release of abnormal results, whereas 9% of clinicians agreed with that timeframe.

## **Balancing transparency and patient benefit**

"For a lot of providers, the concern is that these results can come back at 6 o'clock on a Friday night, at 9 o'clock on Saturday morning," Tevis explains. "I've had patients whose results came in on Thanksgiving Day. So, as providers, one of the concerns is how to provide the best care to patients while also managing time.

"With my patient whose results came in on Thanksgiving, I was going back and forth with, 'Do I call my patient? Do I not call my patient?' I tend to send a message through the electronic medical records system saying, 'This looks good for these reasons and I'll call you tomorrow' or 'I'll call you at an appropriate time'."

When the transition to immediate release of EHI was announced, Leonard says, many providers expressed concern about the impact it would have on their patients, as well as how they could adjust their workflows so they could call or message their patients right away.

UCHealth has been at the forefront of connecting patients with access to their EHI, led in particular by CT Lin, MD, a professor of internal medicine in the CU School of Medicine. The access and transparency benefits and empowers patients in their health care, Leonard says, but an area of concern for providers is how to help patients navigate the complex medical terminology and data generally found in lab and test results.

The survey included a section asking patients to define certain medical terms to get a baseline of their understanding, Leonard says, as well as sections asking for their opinions about receiving results and their experience with online portals for medical records.

## **Understanding patient comfort level**

Results from the survey offer significant insights into areas of differing expectations between patients and providers, Leonard says. They also can inform institutions and providers in creating resources to support patients in receiving and understanding their EHI.

"One of the things that was interesting in the survey is how patients view their comfort with interpreting results compared with how providers view patients' comfort," Leonard says. "In general, patients reported they felt more comfortable interpreting lab results, pathology results, and radiology results than providers felt patients were. So how do we address that disconnect between what providers think patients can do and what patients think patients can do?"

Other areas for further research and resource development include addressing the digital divide and supporting patients with less or no access to devices to view their electronic records, as well as supporting patient populations with lower health literacy, Tevis says.

"Even before the 21st Century Cures Act, it's been a challenge in health care to support patients who might want to immediately turn to Google," Tevis says. "It's really hard for anybody—patients, providers, anybody in health care—to determine what's good information and not good information on the internet. It can be hard to make your way to reliable resources, especially if you're now trying to understand complex [lab results](#)."

## Creating resources for patients

Leonard recently received a quality improvement grant provided through the CU School of Medicine's Clinical Effectiveness and Patient Safety (CEPS) program to create and pilot educational tools that patients can use while viewing their EHI in the online portal. The goal, Tevis says, is to involve patients in the process of creating these tools.

The survey results also are significant in guiding conversations with providers, Leonard says, who are looking to give patients the best quality of care while also working with them to manage their expectations about when providers contact them about results.

"Based on the [survey results](#), I don't think provider concerns were coming from a place of not wanting patients to have access to data or not wanting to communicate with patients in a timely way," Leonard says.

"We saw in the comments we received that people who were concerned about this were worried about patient distress and causing undue harm".

"Nobody felt that [patients](#) shouldn't have the information, they were just

concerned about the immediacy aspect. They wanted to be able to speak with the patient first or at least have a plan in place for when they would speak to the patient and how they would go through the results together."

**More information:** Laura D. Leonard et al, Patient and clinician perceptions of the immediate release of electronic health information, *The American Journal of Surgery* (2021). [DOI: 10.1016/j.amjsurg.2021.12.002](https://doi.org/10.1016/j.amjsurg.2021.12.002)

Provided by CU Anschutz Medical Campus

Citation: Research finds patients and providers differ in opinions about immediate access to medical records (2022, January 21) retrieved 23 June 2024 from <https://medicalxpress.com/news/2022-01-patients-differ-opinions-access-medical.html>

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