

# Q&A: Physician discusses unintended consequences of patients having immediate access to test results

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In a fast-paced digital age where patients can open their test results as soon as they are available, what happens when a patient reads through

complicated results without a physician there to help them understand what it all means? And what happens when a patient misinterprets bad news as good news, or vice versa?

It's a scenario Benjamin Vipler, MD, confronted after his mom received her colonoscopy results on her health system's patient portal. Like many patients, she opened up her results before meeting with her clinician, and tried to decipher the medical jargon.

Thinking the results showed she was cancer-free, she shared the good news with her son, who is an assistant professor in the Division of Hospital Medicine at the University of Colorado Department of Medicine. But when she subsequently asked him what lymphoma meant, Vipler discovered she had misinterpreted results that actually indicated she had cancer.

The experience prompted Vipler to contemplate the impact of the 21st Century Cures Act, a [federal law](#) that requires the immediate electronic release of all patient results and documents without delay. The law is intended to empower patients with their [health information](#), but as Vipler has witnessed, it can also have unintentional consequences for patients and clinicians alike.

Hoping to encourage further studies on the law's impact and promote discussion on how the current system can improve, Vipler wrote a Perspective article titled "'What's Lymphoma?'—Risks Posed by Immediate Release of Test Results to Patients," which the *New England Journal of Medicine* has [published](#).

In this interview, Dr. Vipler discusses his concerns, suggestions for improving [patient care](#), and the need for further research.

**What prompted you to write this Perspective article?**

This actually was not my mom's first experience with a [cancer diagnosis](#), but the first happened before the Cures Act. The experience that she had then, compared to after the law was enacted, was night and day. That was one of my reasons for writing this article. Seeing a potentially empowering piece of legislation have a negative outcome was really disheartening, and I hope that we can find fixes.

On the primary care side, I've had experiences where patients got their results before I had the chance to review them, and they essentially did their own Google searches on whatever their new diagnosis was.

So, I've always been interested in this because it's definitely a shift in how we practice medicine. The fact that it hit so close to home made me want to share it even more.

**In the article, you said the Cures Act was designed, in part, 'to foster patient-centeredness' and 'increase timeliness of result notification.' In practice, what do you think are the main risks of immediately releasing test results to patients?**

There are a lot of upsides to the Cures Act, but a downside is that it assumes patients have a certain degree of medical understanding and health literacy. This assumption has the potential to make the immediate release of lab results an inequitable process. It also assumes that if someone doesn't understand something, they'll go to their clinician as opposed to going to other resources that are not well-vetted—which may not always be the case.

**You cited research that suggested a majority of patients prefer to receive test results immediately over**

## **a patient portal. Why do you think most patients prefer the immediate test results?**

Knowledge can be power. I think giving patients their results and putting some of the ownership of their health care on them can be very impactful and very powerful, if used correctly.

Regarding the Cures Act, I'm not necessarily saying there should be a repeal or policy change. When you have large numbers of patients who prefer to have their results immediately released, maybe that is the best thing for patients and health care. But we shouldn't forget the minority of patients who don't just because they are in the minority.

## **In the article, you wrote, 'Many clinicians now feel they must race to convey results before their patients read them.' How does the immediate release of test results impact clinicians?**

I think one of the complications that can arise is if the patients' research on an abnormality in their results leads them to thinking they have a prognosis or a diagnosis that is worse than what the abnormality actually means.

Also, having to provide reassurance to patients when the "cat is already out of the bag" can be a big challenge. There is a way that we are trained to convey bad news and it's a multi-step process. This new process of delivery sort of circumvents that tried-and-true method. And I think there may be some moral injury or personal distress if a patient receives bad news in a way other than the way we were trained to give bad news.

## **Throughout your article, you mentioned ways the**

## **current system of delivering test results can improve. What are some of those suggestions?**

Many of the lab results patients receive that we're most unprepared for are either incidental findings or things that we weren't necessarily expecting when we ordered a test. And those can be the most challenging because it may not come up in the clinic visit before you order the test. If you're ordering a test that will either have one outcome or another, you can walk the patient through those potential outcomes ahead of time. But if you're getting a scan of the patient's belly, there is a lot that you could find in there. In those cases, I think being very transparent with patients that there are these potential "unknown unknowns" is really important.

Another thing that we can do is give plain language statements in our lab reports, radiology reports, or pathology reports that patients can read when they get immediate access to them.

Finally, we can counsel about whether or not patients should be checking or should be getting alerts as soon as their results drop. If patients do not want to receive their results immediately, they should probably turn off the notifications.

## **You said it is too soon to understand the full implications of the Cures Act. What additional research do you think needs to be done?**

There is a lot of ongoing, good research on the Cures Act, and some of that was [done out of our own university](#). Much of the research right now is on patient experience. I think that if the act had goals of empowerment and improvement in health outcomes, we also need to study that.

Unfortunately, some of the literature says that we are not very good at following up on incidental, abnormal findings, given the fragmentation in health care. I think if we can show that giving patients their results in real time leads to fewer missed follow-up appointments and results, having that data could really support the potential benefits of the Cures Act.

**More information:** Benjamin Vipler, "What's Lymphoma?"—Risks Posed by Immediate Release of Test Results to Patients, *New England Journal of Medicine* (2024). [DOI: 10.1056/NEJMp2312953](https://doi.org/10.1056/NEJMp2312953)

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